narra j

Original Article

Assessing health-related quality of life in schizophrenia patients using EQ-5D-5L index: Insights from patients and caregivers

Nugraha A. Prasetiyo[1], Elly Wahyudin[1], Iman Setiawan[2], Mayamariska Sanusi[3], Fredrick D. Purba[4], Sylmina D. Alkaff[5] and Bustanul Arifin[1,6]*

[1]Department of Pharmacy, Faculty of Pharmacy, Universitas Hasanuddin, Makassar, Indonesia; [2]Department of Statistics, Faculty of Mathematics and Natural Sciences, Universitas Tadulako, Palu, Indonesia; [3]Department of Psychiatry, Dadi Regional Specialized Hospital, Makassar, Indonesia; [4]Faculty of Psychology, Universitas Padjadjaran, Jatinangor, Indonesia; [5]Robotics and Artificial Intelligence, Faculty of Advanced Technology and Multidiscipline, Universitas Airlangga, Surabaya, Indonesia; [6]Department of Health Sciences, University Medical Center Groningen (UMCG), University of Groningen, Groningen, the Netherlands.

*Corresponding author: bustanul.arifin.ury@unhas.ac.id

Abstract

Schizophrenia is a prevalent mental health disorder often marked by relapses, significantly affecting the health-related quality of life (HRQoL) of both patients and their families. The aim of this study was to compare the EuroQol 5-Dimension 5-level (EQ-5D-5L) responses of schizophrenia patients and their caregivers. Using an observational cross-sectional design, HRQoL was assessed among schizophrenia patients and their family caregivers recruited from a provincial referral hospital. Sociodemographic (age, sex, education, marital status, income) and clinical variables (diagnosis, treatment duration, comorbidities) were analyzed alongside HRQoL using structured interviews, medical record reviews, and the EQ-5D-5L instrument (self-report by patients and proxy-reported by family caregivers). Statistical analyses included chi-square tests for associations, Wilcoxon tests for patient-family caregiver comparisons, and multivariate modeling of HRQoL determinants. A total of 526 participants (263 patients and 263 accompanying family caregivers) were included. Significant differences were observed between patients and family caregivers in two domains: pain/discomfort and anxiety/depression. Also, the agreement between patients' and family caregivers' reports showed good results. A substantial agreement was observed between patient-reported and family caregiver-assessed HRQoL, as indicated by a Cohen's Kappa value of 0.8. This result suggests a strong level of consistency between the two assessments, supporting the potential use of family caregivers as reliable proxies for evaluating patient HRQoL when self-reports are unavailable or unreliable. In the self-care domain, mobility, and daily activities, patient and caregiver assessments show high agreement. In conclusion, the closeness between patients and caregivers significantly influences patients' HRQoL, providing critical insights for evaluating treatment effectiveness in schizophrenia cases. While discrepancies exist between patient and caregiver assessments, these interactions are particularly impactful in subjective domains like pain/discomfort and anxiety/depression, but not for other domains that are visible.

Keywords: EQ-5D-5L, health-related quality of life, index score, Indonesia, Schizophrenia.

https://narraj.org/

Introduction

Schizophrenia significantly impacts the health-related quality of life (HRQoL) of patients, impacting their emotional, social, and economic aspects. Symptoms such as delusions,

Received: August 11, 2024 - Accepted: March 27, 2025 - Published online: April 28, 2025

hallucinations, and difficulty thinking clearly often make it difficult for patients with schizophrenia to maintain employment, relationships, and daily activities [1]. Those with schizophrenia also have to face stigma from the surrounding community. This condition often exacerbates their existing mental health issues [1]. Furthermore, the social stigma can also impact family support, leading to the isolation of individuals with schizophrenia from their living environment. However, proper care, family support, and rehabilitation therapy can improve their HRQoL, enabling them to lead a more stable and meaningful life [1]. The World Health Organization (WHO) reported that in 2022, an estimated 24 million people were living with schizophrenia, equivalent to approximately one in every 300 individuals [2]. In line with the WHO report, a study in 2018 showed an increase in the number of cases in almost the last three decades [3]. In 1990, there were 13.1 million people with schizophrenia, and by 2016, this number had increased to 20.9 million [3]. Indonesian Basic Health Research (*Riset Kesehatan Dasar*/RISKESDAS) 2018 shows that the prevalence of schizophrenia was at 6.7%, or around 282,000 people, with a distribution of 6.4% in urban areas and 7.0% in rural areas, while treatment coverage for schizophrenia patients was 85% [4]. The highest prevalence of schizophrenia/psychosis was observed in Bali and Yogyakarta provinces, with rates of 11.1 and 10.4 per 1,000 households, respectively. In South Sulawesi, a province in Sulawesi Island known for its ethnic diversity and healthcare challenges, 13,356 households reported cases of schizophrenia/psychosis in 2018, including 2,427 cases in Makassar City. The prevalence rates were 13.4 and 12.1 per 1,000 households in South Sulawesi and Makassar City, respectively [5].

Relapse in schizophrenia patients is often triggered by non-compliance with treatment, stress or depression, and substance abuse. Non-compliance, caused by drug side effects or stigma, makes symptoms more likely to relapse because treatment is not continued as recommended. Stress and depression, especially those arising from conflict or life pressures, also worsen the condition, considering that schizophrenia patients tend to be more vulnerable to psychosocial factors. Therefore, ongoing support, stress management, and rehabilitation programs are essential to reduce the risk of relapse and improve the HRQoL of schizophrenia patients [6]. The manifestation of schizophrenia primarily appears as positive symptoms, including hallucinations, delusions, and thought disorders, which directly impact cognitive functioning and daily activities. These symptoms often lead to negative symptoms such as emotional problems, lack of motivation, diminished interest in social interactions, self-neglect, and reduced communication desire [7]. The combination and interaction of positive and negative symptoms significantly deteriorate patients' overall functioning and social relationships, ultimately resulting in a substantial decline in their HRQoL [8].

Measuring HRQoL as a way to evaluate treatment and care for patients with schizophrenia is important [9,10]. In addition, it has crucial relevance for doctors in designing effective treatment and focusing on health aspects that influence treatment [11], as well as providing an understanding of the patient's HRQoL [12]. Comprehensive health evaluations carried out by doctors are based on information provided by the patient [13].

Patients with cognitive disorders cannot provide a valid description of their HRQoL [14]. This affects the trustworthiness and accuracy of the information they provide as informants [15]. However, several other studies argue that patients with low to moderate cognitive impairment can provide good assessments of their HRQoL [16,17]. In order to evaluate how clearly patients with schizophrenia who experience cognitive impairment can explain their HRQoL, it is necessary to provide assessment support by proxy. Assessment of patients' HRQoL often relies on proxies as the main source of information [18].

Several previous studies have evaluated the extent of consistency between direct patient-reported and proxy assessments of the HRQoL of patients with schizophrenia [19,18,20]. In general, proxies are people who have a relationship with the patient or function between the patient and their family caregiver as someone who provides support and assistance in their lives and as a companion to the patient [21,22]. Closeness to the patient can increase the validity of the assessment of the patient's HRQoL [23]. Several studies have previously evaluated the extent of consistency between direct patient-reported and proxy-reported assessments of HRQoL in patients with schizophrenia [18,19,20]. Another study conducted in Indonesia revealed significant differences between the reports provided by inpatients with schizophrenia and those provided by psychiatrists' nurses using the EQ-5D utility score [20]. Building upon this foundation, our research shifts the focus to outpatients with schizophrenia. It examines the patients and their family caregivers—individuals who offer daily support and accompany them during therapy sessions at Dadi Regional Specialized Hospital, a provincial referral hospital in Makasar, South Sulawesi, Indonesia. This study compared assessment results between patients and their family caregivers, examining the relationship between caregiver observations and patient self-evaluations. This comparison is very useful in future cost-utility analyses (CUAs) of schizophrenia patients. The aim of this study was to investigate and analyze the differences between patient and family caregiver reports regarding the EuroQol 5-Dimension 5-level (EQ-5D-5L) responses in schizophrenia patients.

Methods

Participants

This was a cross-sectional study that involved two main participant groups, namely patients and family caregivers. Family caregivers were those who accompanied the patients when they took medication every month (periodic routine check-ups). Apart from that, the patients' family caregivers were those who claimed to have the closest emotional contact with the patient (helping with the patient's daily activities). Participants were at least 18 years old, willing to participate in the study and had good communication skills. In addition, patient participants were required to undergo routine follow-up examinations and receive approval from the doctor in charge as confirmation of their eligibility to participate in this study.

Based on the average visit data from the past nine months of 2023, Dadi Regional Specialized Hospital served an average of 840 patients per month. To determine the minimum number of statistically representative participants for this study, a sample size calculation method based on the table from Isaac and Michael was used [24]**.** The minimum required number of participants was 263. The number of caregivers was the same as the number of patients.

Instrument

This study used the Indonesian version of the EQ-5D-5L instrument registered under ID 55559 [25]. The EQ-5D-5L consisted of two sections: the first section included five dimensions that describe the patient's health (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression). Each dimension had five levels of severity: no problem, mild problem, moderate problem, severe problem, and unable/extreme problem. The EQ-5D-5L utility score is a single index value derived from this five-dimensional descriptive system. A unique five-digit code represents the health state, which is then converted into a utility score using a value set developed from population-based preferences. The value on the EQ-5D index score ranges from 0 (poor quality health) to 1 (good quality health). The index value is calculated using the formula: index value = 1-(Σ dimension penalties+constant penalty), where the severity level beyond 'no problems' is assigned a weight, and an additional penalty is applied for extreme health conditions. If multiple responses are selected within a dimension, the most severe level is used in the calculation. For example, if a patient selected level 3 for mobility ("*Saya cukup kesulitan dalam berjalan* / I have moderate problems in walking"), level 1 for self-care ("*Saya tidak kesulitan dalam merawat diri*/ I have no problems washing or dressing myself "), level 2 for usual activities ("*Saya sedikit kesulitan dalam melakukan aktivitas sehari-hari* / I have slight problems doing my usual activities"), level 4 for pain/discomfort ("*Saya sangat kesulitan karena nyeri atau tidak nyaman* / I have severe pain or discomfort"), and level 5 for anxiety/depression ("*Saya merasa sangat cemas atau depresi (sedih)* / I am severely anxious or depressed (sad)"), this results in a health profile of 3–1–2–4–5. Using the Indonesian EQ-5D-5L value set, the corresponding penalties for each level are -0.120 for mobility, 0 for self-care, -0.045 for usual activities, -0.200 for pain/discomfort, and -0.350 for anxiety/depression, with an additional penalty of -0.100 for extreme health states. The final calculation is: EQ-5D-5L index value = 1-(0.120+0+0.045+0.200 +0.350+0.100)=1-0.815=0.185 [25].

The second section of the EQ-5D-5L used a visual analog scale (EQ-VAS), which measures the patient's general health status on a scale from 0 (worst health) to 100 (best health) [26,27].

This score is not summed with the index value, as they serve distinct purposes. The EQ-5D-5L index score is derived from societal health preferences, while the EQ-VAS score reflects an individual's subjective perception of their health status, ensuring a comprehensive evaluation of HRQoL. In this study, the instruments used by family caregivers were the same instruments used by patients. However, family caregivers were instructed to assess the condition of patients with schizophrenia, rather than themselves, during the use of this instrument. This explanation was also conveyed during the data collection procedures.

Before filling out the main instrument, participants (both patients and family caregivers) were asked to complete their sociodemographic data separately. For patients, the collected data included personal information such as age, education level, occupation, marital status, and place of residence. For family caregivers, in addition to the number of family members, education level, occupation, income, marital status, and relationship to the patient, they were also asked other sociodemographic details such as age, sex, and the duration of care provided to the patient. This separation ensured clarity and accuracy in the sociodemographic information gathered from each group.

Procedures

The research was conducted from July to September 2023 at Dadi Regional Specialized Hospital in Makassar, Indonesia. This hospital is a referral psychiatric hospital in South Sulawesi Province. Data collection procedures were carried out in the outpatient wards. Verbal consent was initially obtained from both patients and their family caregivers to confirm their willingness to participate in the study. The attending nurse facilitated this process by providing verbal informed consent to potential participants, including patients and their accompanying family caregivers. This step was implemented to ensure immediate acknowledgment of participation, particularly for patients with schizophrenia who might require additional support from their caregivers to understand the study requirements. Subsequently, written informed consent was formally obtained from all participants (patients and their family caregivers) before they proceeded to complete the research instrument. Family caregivers not only consented on their own behalf but also assisted in confirming the participation of the patients they accompanied. In summary, this two-step consent procedure—beginning with verbal consent facilitated by the nurse and followed by written consent—was designed to uphold research ethical standards while addressing the specific needs of the study population.

Patients with schizophrenia who participated in the study received approval from their psychiatrist, ensuring they met the positive and negative syndrome scale-excited component (PANSS EC) score criteria above 7. The PANSS is a standardized instrument used to evaluate patients with aggressive or agitated behavior [28]. PANSS items consist of five questions, and items are rated on a 7-point scale (1=absent, 2=minimal, 3=mild, 4=moderate, 5=moderate severe, 6=severe, and 7=extreme); because the absence of symptoms is equal to 1 point, the lowest possible total score on both PANSS scales is 7 [28]. Patients and their family caregivers were placed separately, and researchers accompanied each patient and family caregiver during the signing of informed consent, provided instructions on how to fill out the instrument, and offered an opportunity to ask questions. For caregivers, the researchers emphasized that their entries were based on their personal assessment of the patient.

Socioeconomic data were collected through structured interviews, including patients' employment status and family caregivers' monthly income. Among the participants, one male patient has resided in an orphanage since childhood, with care provided by the orphanage staff. For the remaining participants, income levels were categorized using the official regional minimum wage (RMW) of Makassar, South Sulawesi, Indonesia, as the threshold [29]. As established by the local government, this minimum wage was set at IDR 3,643,321 (equivalent to 231 USD at an exchange rate of IDR 15,770 per USD) for 2024. Family caregivers' incomes were classified as below or above this threshold to assess their economic status. The data collected from patients and family caregivers includes: sex, age, number of family members, level of education, occupation, monthly income, marital status, and residence ownership status.

Data analysis

Descriptive analysis was used to describe the socio-demographic profile of participants (both patients and family caregivers), chi-square tests, as well as modelling (multiple ordinal regression) to investigate the socio-demographic and clinical variables that significantly influence the EQ-5D index score. Next, comparison health status assessments of each dimension reported by patients and proxies using the Wilcoxon paired rank test, as data were not normally distributed. The evaluation of agreement on each dimension of the EQ-5D-5L was carried out by calculating the correlation percentage and kappa coefficient. The intraclass correlation coefficient (ICC) was used to look at the inter-rater agreement of utility scores between patients and proxies. Interpretation of the agreement coefficient refers to published criteria, where a value <0.2 indicates a low level of agreement, a value between 0.21 and 0.40 indicates a moderate level of agreement, and a value between 0.41 and 0.60 indicates a fairly high level of agreement, values between 0.61 and 0.80 indicate a substantial level of agreement, and values >0.80 indicate a very high or perfect level of agreement [27]. All research data were analyzed using IBM's SPSS version 25 software (IBM, New York, USA) and R software (R foundation for statistical computing, Vienna, Austria).

Results

Characteristics of participants

Of the 297 initially recruited patients with schizophrenia, 263 participated in the study, with males comprising 73% of the patients. Thirty-four patients were excluded due to not meeting the inclusion criteria, incomplete instruments, or voluntary withdrawal. Each participant had a family caregiver, predominantly female (61.6%), including sisters, biological mothers, and wives. The majority of patients (97%) were young and middle-aged adults in their productive years. Despite being of productive age, 67.4% of the patients were unemployed, and 44.5% of their family caregivers reported monthly incomes below the regional minimum wage (**Table 1**).

Table 1. Sociodemographic characteristics of patients and family caregivers (n=526)

Characteristics	Patient (n=263)		Family caregiver (n=263)	
	n	%	n	%
Sex				
Male	192	73	101	38.4
Female	71	27	162	61.6
Age				
Young adults (19–44 years)	190	72.3	124	47.1
Middle-aged adults (45–59 years)	65	24.7	124	47.1
Elderly (>60 years)	8	3	15	5.8
Number of family members				
≤4 (small family)	127	48.2	121	46
5–6 (medium family)	104	39.6	113	43
>7 (large family)	32	12.2	29	11
Level of education				
Never attended school	2	0.7	2	0.7
Elementary school	20	7.7	12	5.1
Junior high school	43	16.3	21	7.6
Senior high school	171	65.1	203	77.6
Bachelor degree	27	10.2	25	9.0
Occupation				
Jobless	177	67.3	15	5.7
Active employment	72	27.4	163	61.9
Homemakers	14	5.3	85	32.4
Monthly income				
Equal to or above regional minimum wage	20	7.6	64	24.3
Below the regional minimum wage	59	22.4	117	44.5
No income	184	70	82	31.2
Marital status				
Married	45	17.1	209	79.5
Unmarried	210	79.8	44	16.7
Divorced	8	3.1	10	3.8
Residence ownership status				

Characteristics	Patient (n=263)		Family caregiver (n=263)	
	n	%	n	%
Private house	242	92	252	95.8
Rented house	8	3	6	2.2
Staying at a relative's home	12	4.6	4	1.6
Orphanage	1	0.4	1	0.4

Assessment reports from participants

Analysis of EQ-5D-5L assessments revealed significant differences ($p<0.005$) between patient self-reports and family caregiver evaluations in two dimensions. For the fourth dimension (pain/discomfort), 83.6% of caregivers reported 'no problems' compared to 75.5% of patients. In the fifth dimension (anxiety/depression), 71.4% of caregivers versus 68.0% of patients reported 'no problems.' These findings suggest that caregivers perceived fewer health-related problems than patients reported experiencing in these dimensions. The overall EQ-5D-5L utility scores reflected this trend, with caregiver assessments scoring 0.018 points higher than patient self-assessments (0.94 vs 0.92). Complete comparative data across all dimensions are presented in (**Table 2**).

The assessments given by family caregivers to patients showed a significant level of similarity, with 57% reported by patient family caregivers, compared to assessments that had at least one or more dimensions differing from the patient's self-reported assessment, as presented in (**Table 3**). However, a small number of assessments (0.3%) reported by family caregivers showed overall differences in all dimensions.

Inconsistent dimension describes the number of differences in views between patients and their families in assessing a number of items in a dimension. A score of 0 indicates no differences of opinion on all questions, reflecting perfect alignment of views. Conversely, scores of 1 to 5 represent the number of questions that have different assessments, ranging from one difference (score 1) to five differences (score 5), indicating a greater gap in perception. This parameter is an important indicator for understanding the extent to which the views of patients and families are aligned or different, which can reflect the quality of communication and shared understanding of the services received. Based on assessments reported by patients and proxies, there is a relatively large percentage of results that are almost equal between the two versions in each dimension. In assessment reports between patients and their family caregivers, the utility score was 0.8, and the agreement between the reports of patients and their family caregivers was much higher (**Table 4**). Assessing the quality of life of outpatients with schizophrenia can yield varying results depending on whether the evaluation is self-reported by the patient or assessed by a family caregiver. To quantify the level of agreement between these two sources, the agreement percentage and weighted kappa were used for the categorical dimensions of EQ-5D-5L, while the ICC was applied to the utility score, which is a continuous variable [30]. The level of agreement between patients and family caregivers across the five dimensions of EQ-5D-5L and the overall utility score is presented in (**Table 4**). The agreement percentage indicates the proportion of identical responses between patients and caregivers, while weighted Kappa accounts for agreement beyond chance. As the utility score is a continuous measure, ICC was used to assess consistency, with higher values indicating stronger agreement [30].

The results indicate variability in agreement across different dimensions of EQ-5D-5L (**Table 4**). Mobility and self-care show the highest agreement (>94%), yet self-care has an unusually low Weighted Kappa (0.1), suggesting a skewed response distribution that reduces the reliability of Kappa as an agreement measure. Conversely, anxiety/depression has the lowest agreement (74.1%), highlighting potential discrepancies in how patients and caregivers perceive the patient's psychological condition. For the utility score, an ICC of 0.8 suggests strong agreement between patients and family caregivers in assessing overall HRQoL. This finding implies that while individual dimension ratings may vary, caregivers generally provide a reliable estimation of the patient's condition when evaluated through the utility score.

The 95% LoA ranged from -0.190982 to 0.155742, with 95.3% of data points falling within this range and only 4.7% lying outside. This indicates a relatively high level of consistency between the two assessments, with most discrepancies remaining within an acceptable range. The small proportion of outliers suggests that, while caregiver-reported scores generally serve as reliable proxies, certain cases warrant further investigation to identify the sources of disagreement. Additionally, the analysis demonstrated that differences between patient and family caregiver utility scores were randomly distributed across all score levels, with no evidence of proportional bias. This indicates that discrepancies do not systematically increase or decrease with the magnitude of the reported utility scores.

The absence of a systematic trend reinforces the stability of agreement across the full range of scores. These findings suggest that EQ-5D-5L utility scores reported by family caregivers can generally be considered interchangeable with patient-reported scores, with minor adjustments. However, caution is warranted in cases where outliers are observed, as these may reflect situations where caregivers either overestimate or underestimate a patient's health status. These results support the reliability of family caregiver-reported utility scores as a valuable proxy in EQ-5D-5L-based health assessments while highlighting the need for careful interpretation in specific cases.

Discussion

The present study analyzed the differences between patient- and family caregiver-reported health status using the EQ-5D-5L instrument in outpatients with schizophrenia. The findings revealed that the majority of patients (92%) and family caregivers (94.3%) reported no mobility issues, while a small proportion (7.2% of patients and 5.7% of caregivers) reported slight mobility problems (**Table 2**). These results suggest that mobility impairments are not a major concern for most outpatients with schizophrenia in this study. Similarly, a previous study conducted in Indonesia among inpatients with schizophrenia reported 96.6% of patients and 95.6% of caregivers indicating no mobility issues, with only 1.94% of patients experiencing slight difficulties [20]. Moreover, following hospital discharge, 98.54% of inpatients reported no mobility issues, suggesting that mobility concerns may improve over time with appropriate treatment and recovery [20]. While mobility was not a significant issue, pain/discomfort (75.6%) and anxiety/depression (68%) were the most frequently reported problems among patients, whereas caregivers perceived fewer issues in these dimensions (**Table 2**). Furthermore, 57% of patient-caregiver pairs reported identical assessments across all dimensions, while 27.3% differed in one dimension, and 10.2% differed in two dimensions (**Table 3**), indicating a generally high level of agreement. However, agreement was notably higher in physical dimensions like self-care (95.8%) and mobility (94.3%), while the lowest agreement was observed in anxiety/depression (74.1%) (**Table 4**). Additionally, the Bland-Altman analysis (**Figure 1**) confirmed that 95.3% of the data points fell within the limits of agreement, with a bias line close to zero, indicating no significant systematic difference between patient- and caregiver-reported utility scores.

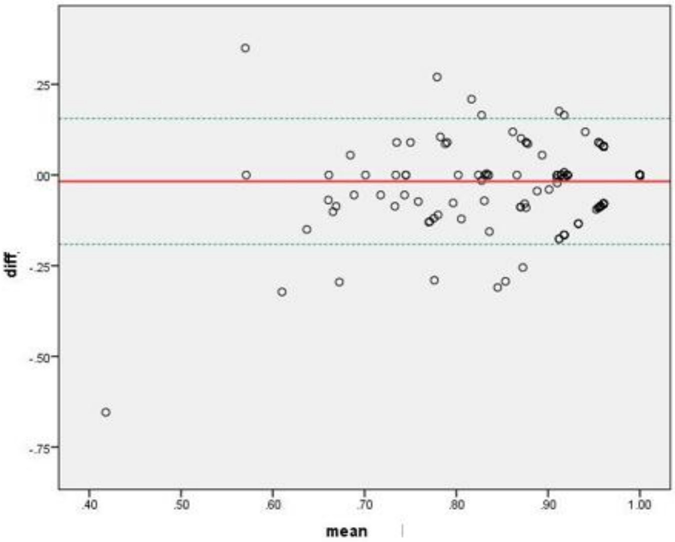

Figure 1. Bland-Altman plot of patient-reported and family caregiver-reported utility scores.

Table 2. Assessment reports from the patient and family caregiver using EQ-5D-5L and utility scores with significance

Level/Dimensions (%)	Mobility		Self-care		Usual activities		Pain/discomfort		Anxiety/depression		Mean Score	
	Caregiver	Patients	Caregiver	Patients	Caregiver	Patients	Caregiver	Patients	Caregiver	Patients	Caregiver	Patients
No problems	94.3	92	96.9	96.5	88.5	87.8	83.6*	75.6*	71.4	68*	0.94*	0.92*
Slight problems	5.7	7.2	2.6	2.6	11	11	15.2*	20.5*	23.9	25.8*		
Moderate problems	0	0.7	0.3	0.3	0.3	1.1	1.1*	3.4*	4.5	5.3*		
Severe problem	0	0	0	0.3	0	0	0*	0*	0	0.3*		
Extreme problem	0	0	0	0	0	0	0*	0.3*	0	0.3*		

**p*-value <0.05 was analyzed using the Wilcoxon test to see the comparison of the similarity of assessments between patients and family caregivers

Table 3. Inconsistencies in assessment reports between patients and family caregivers

Inconsistent dimension	Patient and family caregiver	
	Frequency	%
0	150	57
1	72	27.3
2	27	10.2
3	12	4.5
4	1	0.3
5	1	0.3

A score of 0 indicates perfect agreement between patient and family caregiver assessments across all dimensions of EQ-5D-5L. Scores 1 through 5 represent the number of dimensions where they disagree, with 5 indicating differences in all dimensions

Table 4. Percentage of agreement in assessment reports for patients with schizophrenia using the EQ-5D 5L descriptive system and utility scores

EQ-5D-5L Dimension/ utility score	Patient and family caregiver		
	Agreement (%)	Weighted kappa	Intraclass correlation coefficient (ICC)
Mobility	94.3	0.5	
Self-care	95.8	0.1	
Usual activities	88.5	0.4	
Pain/Discomfort	82.1	0.5	
Anxiety/Depression	74.1	0.5	
Utility Score	-	-	0.8

Cognitive impairments in schizophrenia have been widely recognized as a critical factor affecting the validity of self-reported health assessments, particularly in evaluating personal health status, social interactions, and environmental awareness [31]. Deficits in memory, attention, and logical reasoning may contribute to inaccurate perceptions, potentially leading to misinterpretations of health status [30,31]. Consequently, patient-reported outcomes may not always accurately reflect their actual health condition, particularly in subjective dimensions such as anxiety and pain. Therefore, physician confirmation has been recommended before involving patients in self-reported assessments to enhance the accuracy of evaluations and minimize the risk of misinterpretation that could impact research outcomes [31].

Instead of being directly caused by schizophrenia, mobility limitations in these patients are more likely to stem from medication side effects [8,32]. Our findings indicate that most patients in the outpatient settings do not perceive mobility as a significant issue. This suggests that schizophrenia alone does not inherently impair walking ability, but potential adverse effects of antipsychotic treatments should still be considered as contributing factors [8,32]. The high agreement between patient- and caregiver-reported mobility indicates that mobility impairments are not a primary concern for most individuals with schizophrenia, particularly in outpatient settings. However, further research is required to determine whether mobility limitations are predominantly influenced by clinical treatment regimens or the natural progression of the disorder over time. Additionally, considering the role of cognitive impairments in self-assessment accuracy, physician confirmation before patient participation in research remains essential to ensure reliable data collection and minimize potential biases in patient-reported outcomes [31].

The self-care dimension, which encompasses patients' ability to perform activities such as bathing, handwashing, and dressing, was reported. These activities, indicative of independent self-care, were either conducted under the supervision of family caregivers or initiated autonomously by the patients themselves. Moreover, this observation was further validated by family caregivers, who exhibited an almost perfect agreement in their evaluations of patients' self-care capabilities. In line with this, previous research has highlighted that self-care activities among individuals with mental disorders are influenced by a multitude of factors, including their physical health [33]. For instance, studies by Bowie et al [34] and Harvey et al [35] have demonstrated that outpatients with schizophrenia can sustain independence in daily activities when provided with appropriate support and interventions. Specifically, Bowie et al (2006) identified cognitive ability, functional capacity, and symptom management as critical factors enhancing patients' daily functioning [34]. Similarly, this finding aligns with the findings of Harvey *et al*. (2007), who noted that despite functional impairments associated with schizophrenia, many individuals retain the ability to perform daily activities independently, especially when supported by adequate social networks and therapeutic interventions [35]. Overall, both studies underscore the importance of a holistic approach in enabling individuals with schizophrenia to achieve greater independence in their daily lives [35]. A high level of agreement between patients and family caregivers was also observed in the activity dimension.

Similar findings have been reported in another study, despite differences in patient populations [36]. Objective assessments have demonstrated that patients and caregivers often share similar perspectives, primarily due to the emotional and physical proximity of family members to the patient. This proximity enables family caregivers to conduct more intensive observations and monitor patient’s condition, leading to a consistent evaluation. Additionally, it has been documented that patients with severe mental disorders are capable of performing daily activities effectively [33]. Furthermore, several studies have indicated that schizophrenia patients who engage in routine activities tend to exhibit better functionality, experience fewer depressive symptoms, and maintain stronger social relationships [37,38,39]. The involvement of family caregivers in patients’ daily activities was reflected in their assessment of the patient's health status, particularly in the dimensions of self-care and usual activities. This close relationship between patients and caregivers has been identified as a key factor in their understanding of the patient’s HRQoL, as evidenced by the EQ-5D utility scores obtained from both groups. The concordance observed in these assessments indicates that family caregivers play a crucial role in observing and comprehensively understanding the patient’s condition. Through active participation in supporting the patient’s needs, such as assisting with personal hygiene, dressing, and household activities, family caregivers are able to provide a more objective evaluation of the patient's functional limitations. Additionally, a strong patient-caregiver relationship has been associated with improved decision-making in medical care and intervention strategies. The similarity of EQ-5D utility scores between patients and caregivers further suggests that caregivers possess an accurate perception of the patient's condition, which can serve as a solid foundation for designing more targeted care strategies, both in clinical practice and in health policies aimed at enhancing the patient's HRQoL [40].

In our study, the level of agreement between patients and their family caregivers regarding HRQoL assessment reached Cohen's kappa value of 0.799, indicating substantial agreement, as classified by Landis and Koch. According to their classification of inter-observer agreement, a kappa value between 0.61 and 0.80 is considered substantial, while a value above 0.81 is categorized as almost perfect agreement (Landis and Koch, 1977) [30]. This finding aligns with previous studies on the level of agreement between patients and caregivers in assessing HRQoL in schizophrenia. For example, Aini *et al.* reported that caregivers tended to rate patients' HRQoL lower than the patients did, which may be attributed to caregivers' perception of the high burden of care [41]. Similarly, Santoso *et al.* found that caregivers with high levels of stress were more likely to provide lower HRQoL ratings for patients compared to the patients' self-assessment, highlighting the influence of caregivers' psychosocial factors on HRQoL evaluations [42]. However, Caqueo-Urízar *et al.* reported that in some cases, caregivers rated patients' HRQoL higher than the patients themselves, particularly in the social domain, which was associated with stronger social support within the family environment. Moreover, methodological differences across studies may contribute to variations in findings regarding patient-caregiver agreement [43]. Therefore, while our study demonstrates substantial agreement between patients and caregivers in assessing HRQoL in schizophrenia, it is crucial to consider external factors such as caregivers' psychosocial conditions and social support to comprehensively understand this dynamic.

Significant differences were observed in the agreement between patients and proxies regarding the pain/discomfort and anxiety/depression dimensions, indicating that these conditions are inherently subjective and challenging for others to assess. In these dimensions, patients tended to provide more emphatic self-assessments at each level, whereas caregivers were more likely to offer generalized assessments, often indicating that the patient had no issues. Perceptual discrepancies in these evaluations may be influenced by differing perspectives between patients and caregivers [36]. Similar findings have been reported in a study involving different patient populations [44]. Schizophrenia patients describe their illness experiences individually, using varying definitions, which makes it difficult to establish a consistent framework that fully captures their lived experiences [45]. The difference in perception between schizophrenia patients and their family members often creates a gap in understanding the patient's condition. Although they reside in the same household, family members frequently encounter difficulties in comprehending the patient's perspective due to a lack of in-depth interaction or communication. Meanwhile, patients experience various mental phenomena, such as hallucinations or feelings of isolation, that are inherently subjective and cannot be fully understood by others. These differences in perception often contribute to a sense of alienation among patients, who may feel misunderstood, while families tend to assess the patient's condition based solely on external observations without recognizing the internal experiences being endured. To bridge this gap, establishing an open dialogue and understanding the patient's experiences from their perspective has been recommended, as empathetic support has been shown to significantly aid the recovery process of schizophrenia patients [46].

The difference in agreement between patient and family caregiver assessment reports was also reflected in significantly different utility score values, with patients reporting an average index score of 0.92. Variations in the perception of the EQ-5D index score's influence among schizophrenia patients were observed based on the assessments provided by participants. Family caregivers, in particular, reported a significantly different score, with an average utility index of 0.94. In this context, patients tended to rate their own condition lower than the assessment provided by caregivers. The subjective nature of caregiver evaluations has been attributed to their reliance on emotional experiences and daily observations. These assessments are shaped by direct interactions, emotions, and personal perceptions of the patient's behavior. For instance, families may observe changes in the patient's sleep patterns, communication levels, or responses to specific social situations and subsequently draw conclusions regarding the patient's mental state based on these observations [47].

Our analysis revealed a low level of agreement between patients and family caregivers regarding pain/discomfort and anxiety/depression assessments, emphasizing potential limitations in proxy evaluations of subjective health conditions. Initial data indicated that 48.2% of patients resided in households with fewer than four family members. However, it has been acknowledged that the mere presence of family members does not necessarily equate to active caregiving roles. The dynamics of family caregiving are inherently complex, as caregiving responsibilities are often concentrated among a limited number of family members, regardless of the total household size. Therefore, distinguishing between the number of family members and actual caregiving involvement has been considered essential in understanding the quality of patient care and support.

Based on our findings regarding the discrepancies in perception between outpatients with schizophrenia and their family caregivers in assessing HRQoL and mental health conditions, a policy-driven, multi-tiered approach is essential within Indonesia's healthcare system. First, joint education programs for both patients and families should be systematically integrated across all levels of healthcare facilities (primary, secondary, and tertiary) [48]. These programs should involve medical professionals as facilitators to ensure that both parties receive evidence-based information, thereby fostering a more objective and shared understanding of schizophrenia. Primary healthcare centers could conduct regular educational workshops, while tertiary hospitals could integrate these programs into their outpatient and inpatient care protocols. A previous study demonstrated that structured interactions in a short-term cohousing initiative helped reduce stigma and improved shared understanding among patients, caregivers, and the broader community [48]. Thus, the Indonesian healthcare system should adopt similar models to enhance caregiver engagement and awareness. Second, Indonesia's mental health system should further integrate family-centered care services, ensuring that families are not merely passive companions but active participants in evidence-based treatment strategies. This approach aligns with family-centered care models, where structured family involvement has been shown to improve therapeutic outcomes by creating a more supportive treatment environment [48]. For instance, multi-family therapy has been identified as an effective intervention, as it allows both patients and caregivers to learn together and collaboratively develop coping strategies [49]. Incorporating such therapy programs into national mental health policies would enhance long-term caregiver engagement and improve treatment adherence. Third, healthcare policies should mandate structured education initiatives for families, emphasizing the significance of empathetic caregiving in patient recovery. Healthcare professionals should be actively involved in facilitating these sessions, ensuring that caregivers acquire practical skills to support patients effectively. Paganin (2024) highlighted that multi-family therapy offers a promising approach to managing difficult-to-treat psychiatric conditions by fostering collective learning and mutual support among families [49]. Similarly, dedicated family therapy sessions can enhance mutual understanding and communication, reducing misinterpretations in HRQoL assessments [49]. By implementing these recommendations at a policy level, the Indonesian healthcare system can improve the quality of mental health services, ensuring that caregivers are well-informed, actively engaged, and capable of providing meaningful support to schizophrenia patients.

Notably, professional involvement is equally essential in bridging the understanding between patients and their families regarding the patient's condition. In addition to delivering medical information in a comprehensible manner, healthcare providers must also consider the patient's subjective perspective. A patient's self-assessment of their HRQoL and overall well-being may differ significantly from the perceptions of their family or healthcare providers. A previous study highlighted the importance of subjective assessments in understanding the quality of life and well-being of schizophrenia patients, as well as their relationship with self-efficacy [43]. By implementing a multi-faceted approach that includes education, open communication, family involvement, and the active role of healthcare professionals, greater alignment between patient and family assessments can be achieved. Ultimately, fostering a more supportive environment and a deeper understanding of schizophrenia can facilitate a more optimal recovery process for patients [45,46].

It is important to acknowledge that this study has several limitations. First, while a self-report version of the EQ-5D-5L was utilized to capture the patient's health status from the perspective of family caregivers, specific strategies were implemented to ensure the accuracy of data collection, despite the availability of a validated Indonesian proxy version. During data collection, family caregivers were explicitly instructed to assess the schizophrenia patients under their care rather than themselves. Multiple communication strategies were employed, including verbal instructions, supportive body language, and clear explanations, while also encouraging questions for clarification. All responses were confirmed with both patients and family caregivers to enhance data accuracy. Second, although this study was conducted at a single hospital, which may limit the generalizability of the findings to other regions in Indonesia, the hospital serves as one of the country's leading mental health referral centers, primarily catering to the Eastern Indonesia region. As a regional referral center specializing in the treatment of patients with cognitive disorders, this characteristic is considered to provide a more representative depiction of the cases examined.

Conclusion

The closeness between patients and caregivers plays a significant role in determining patients' HRQoL, serving as a critical factor in evaluating treatment effectiveness for schizophrenia patients in Indonesia. Although there are discrepancies between patient self-reports and caregiver assessments, these differences provide valuable insights into patients' health status. The most notable understanding occurs between patients and family caregivers, particularly in subjective dimensions such as pain/discomfort and anxiety/depression. In domains related to self-care and daily activities, interactions between patients and caregivers remain pivotal, whereas differences in subjective domains become more apparent.

Ethics approval

The research was approved by the Hospital Health Research Ethics Committee # 893.5/14327/RSKD-DADI, dated July 27, 2023.

Acknowledgments

We would like to express our deepest gratitude to all the participants for their invaluable contribution to this research. Their time and insights have been essential in advancing this study. We also extend our sincere thanks to the management of Rumah Sakit Khusus Dadi Makassar (Dadi Regional Specialized Hospital) for granting us permission to conduct this research. We also thank Dr. Syaharuddin Kasim, M.Si., Apt. and Abdul Rahim, S.Si., M.Si., Ph.D., Apt.

Competing interests

The author reports no conflicts of interest in this work.

Funding

This study did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors. The data collection costs were covered by the first author, while the Article Processing Charge (APC) was jointly contributed by all authors and supported by Hasanuddin University, Makassar, South Sulawesi, Indonesia.

Underlying data

Derived data supporting the findings of this study are available from the corresponding author on request. The research instrument we used can be accessed through this link dx.doi.org/10.6084/m9.figshare.28105964. Permission to use the Indonesian version of the EQ-5D-5L instrument can be submitted by applying to the website https://registration.euroqol.org/

Declaration of artificial intelligence use

This study utilized artificial intelligence (AI) tools and methods to support manuscript preparation in three main areas: language enhancement, content summarization, and technical writing assistance. AI language models, including ChatGPT, Claude, and QuillBot, were employed to improve grammar, sentence structure, and readability, summarize key findings and conclusions, and provide suggestions for structuring complex descriptions and crafting conclusions. The authors critically reviewed and revised all AI-generated outputs to ensure accuracy, coherence, and alignment with the study's objectives. The final decisions, interpretations, and manuscript content reflect the authors' independent judgment and intellectual contributions.

How to cite

Prasetiyo NA, Wahyudin E, Setiawan I, et al. Assessing health-related quality of life in schizophrenia patients using EQ-5D-5L index: Insight from patients and caregivers. Narra J 2025; 5 (2): e1314 - http://doi.org/10.52225/narra.v5i2.1314.

References

1. Moges S, Belete T, Mekonen T. Lifetime relapse and its associated factors among people with schizophrenia spectrum disorders who are on follow up at comprehensive specialized hospitals in amhara region, ethiopia: A cross-sectional study. Int J Ment Health Syst 2021;15(1):42.
2. WHO. Mental Health and COVID-19: Early evidence of the pandemic's impact 2022.
3. Charlson FJ, Ferrari AJ, Diminic DFS. Global epidemiology and burden of schizophrenia: findings from the global burden of disease study 2016. Schizophr Bull 2018;44(6):1195-1203.
4. Kementerian Kesehatan RI. Profil Kesehatan Indonesia 2019. Accessed: 2020.
5. Tim riskesdas. Laporan provinsi Sulawesi selatan riskesdas 2018. Accessed: 2018.
6. Rivelli A, Fitzpatrick V, Nelson M. Real-world predictors of relapse in patients with schizophrenia and schizoaffective disorder in a large health system. Schizophrenia 2024;10(1):1-11.
7. Picchioni MM, Murray RM. Schizophrenia. Br Med J 2007;335(7610):91-95.
8. Joshi, A, Joshy J, Mathew KA. Quality of life in Schizophrenia patients with and without adequate pharmaceutical care: A randomized controlled study. Clin Epidemiol Glob Health 2022;20:101208.
9. Hofer A, Baumgartner S, Bodner T. Patient outcomes in schizophrenia II: The impact of cognition. Eur Psychiatry 2005;20(5–6):395-402.
10. Hofer A, Baumgartner S, Edlinger M. Patient outcomes in schizophrenia I: Correlates with sociodemographic variables, psychopathology, and side effects. Eur Psychiatry 2005;20(5-6):386-394.
11. Lloyd M. Mental health policy and practice across Europe, edited by M. Knapp, D. McDaid, E. Mossialos and G. Thornicroft. Crit Public Health 2010,20(2),267-269.
12. Lim MWZ, Lee J. Determinants of health-related quality of life in schizophrenia: Beyond the medical model. Front Psychiatry 2018;9(12):1-9.
13. Susanti H, Brooks H, Keliat B anna. Stakeholder perspectives of family interventions for schizophrenia in Indonesia: A qualitative study. BMC Psychiatry 2024;24(1):1-15.
14. Nishiyama T, Ozaki N. Measurement limit of quality-of-life questionnaires in psychiatric settings. Qual Life Res 2010;19(1):25-30.
15. Boyer L, Baumstarck K, Boucekine M. Measuring quality of life in patients with schizophrenia: An overview. Expert Rev Pharmacoecon Outcomes Res 2013;13(3):343-349.
16. Marrie RA, Miller DM, Chelune GJ. Validity and reliability of the MSQ LI in cognitively impaired patients with multiple sclerosis. Mult Scler J 2003;9(6):621-626.
17. Baumstarck K, Pelletier J, Aghababian V. Is the concept of quality of life relevant for multiple sclerosis patients with cognitive impairment? Preliminary results of a cross-sectional study. PLoS ONE 2012;7(1):e30627.
18. Kim EJ, Song DH, Kim SJ. Proxy and patients ratings on quality of life in patients with schizophrenia and bipolar disorder in Korea. Qual Life Res 2010;19(4):521-529.
19. Becchi A, Rucci P, Placentino A. Quality of life in patients with schizophrenia-Comparison of self-report and proxy assessments. Soc Psychiatry Psychiatr Epidemiol 2004;39(5):397-401.

20. Purba FD, Anggriani Y, Murtini T. EQ-5D-5L in Schizophrenia: Differences between patients and nurses' reports. Health Qual Life Outcomes 2021;19(1):240.
21. Wilson KA, Dowling AJ, Abdolell M. Perception of quality of life by patients, partners and treating physicians. Qual Life Res 2000;9(9):1041-1052.
22. Tamizi Z, Khoshknab MF, Dalvandi A, *et al* Caregiving burden in family caregivers of patients with schizophrenia: A qualitative study. J Educ Health Promot 2020;9:12.
23. Lobana A, Mattoo SK, Basu D. Quality of life in schizophrenia in India: Comparison of three approaches. Acta Psychiatr Scand 2001;104(1):51-55.
24. Bell, Margaret E. "ISAAC, S. & M. Handbook in Research and Evaluation. Ed Publ 234 Pp 1981.
25. Purba FD, Hunfeld JAM, Iskandarsyah A, *et al.* The Indonesian eq-5d-5l value set. Pharmacoeconomics 2017;35(11):1153-1165.
26. Devlin NJ, Krabbe PFM. The development of new research methods for the valuation of EQ-5D-5L. Eur J Health Econ 2013;14(1):1-3.
27. EUROQoL-Group. EQ-5D-5L User Guide v3.0. Computer 2019(10):169-232.
28. Leucht S, Barabássy Á, Laszlovszky I, *et al.* Linking panss negative symptom scores with the clinical global impressions scale: Understanding negative symptom scores in schizophrenia. Neuropsychopharmacology 2019;44(9):1589-1596.
29. BPS. Badan pusat statistik provinsi Sulawesi selatan. 2021. Available from: https://sulsel.bps.go.id/id.
30. Landis JR, Koch GG. The measurement of observer agreement of categorical data. Biometrics 1977;33(1):159–174.
31. Harvey PD. Assessment of everyday functioning in schizophrenia. Innov Clin Neurosci 2011;8(5):21–24.
32. Guo J, Lv X, Liu Y. Influencing factors of medication adherence in schizophrenic patients: A meta-analysis. Schizophrenia 2023;9(1):31.
33. Chen C, Chen Y, Huang Q. Self-care ability of patients with severe mental disorders: Based on community patients investigation in Beijing, China. Front Public Health 2022;10(6).
34. Bowie CR, Reichenberg A, Patterson TL. Determinants of real-world functional performance in schizophrenia subjects: Correlations with cognition, functional capacity, and symptoms. Am J Psychiatry 2006;163(3):418-425.
35. Harvey PD, Heaton RK, Carpenter WT. Functional impairment in people with schizophrenia: Focus on employability and eligibility for disability compensation. Schizophr Res 2012;140(1-3):1-8.
36. Devine A, Taylor SJC, Spencer A. The agreement between proxy and self-completed EQ-5D for care home residents was better for index scores than individual domains. J Clin Epidemiol 2014;67(9):1035-1043.
37. Bryson G, Lysaker P, Bell M. Quality of life benefits of paid work activity in schizophrenia. Schizophr Bull 2002;28(2):249-257.
38. Chan S, Yu IuW. Quality of life of clients with schizophrenia. J Adv Nurs. 2004;45(1):72-83.
39. Martini LC, Barbosa Neto JB, Petreche B. Schizophrenia and work: Aspects related to job acquisition in a follow-up study. Rev Bras Psiquiatr 2018;40(1):35-40.
40. Caqueo-Urízar A, Rus-Calafell M, Urzúa A. The role of family therapy in the management of & amp;nbsp;schizophrenia: challenges and solutions. Neuropsychiatr Dis Treat 2015;11:145.
41. Aini R, Nugroho A, Sari DP. Differences in quality of life assessments between schizophrenia patients and caregivers in Indonesia. Malahayati Health Stud J 2022;5(1):45-56.
42. Santoso, B. Widodo, A. Suryani R. The impact of stress on caregivers and its relationship with schizophrenia patients' quality of life assessment. J Farm Klin Indones 2021;8(2):78-89.
43. Caqueo-Urízar A, Gutiérrez-Maldonado J, Miranda-Castillo C. Quality of life in caregivers of patients with schizophrenia: A literature review. Health Qual Life Outcomes 2009;7(1):84.
44. Takura T, Koike T, Matsuo Y. Proxy responses regarding quality of life of patients with terminal lung cancer: preliminary results from a prospective observational study. BMJ Open 2022;12(2):1-7.
45. Güner P. Illness perception in turkish schizophrenia patients: A qualitative explorative study. Arch Psychiatr Nurs 2014;28(6):405-412.
46. Harvey C. Family psychoeducation for people living with schizophrenia and their families. BJPsych Adv 2018;24(1):9-19.
47. Chino B, Nemoto T, Fujii C, *et al.* Subjective assessments of the quality of life, well-being and self-efficacy in patients with schizophrenia: Regular article. Psychiatry Clin Neurosci 2009;63(4):521-528.

48. Palacios-Ceña D, Martín-Tejedor EA, Elías-Elispuru A. The impact of a short-term cohousing initiative among schizophrenia patients, high school students, and their social context: A qualitative case study. PLoS ONE 2018;13(1):1-20.
49. Paganin W. Multifamily therapy in difficult-to-treat depression: An integrated and promising approach to rethinking clinical strategies. Front Psychiatry 2024;15(10):1-5.