

Relatives' perspectives on quality of life and psychiatric care in severe and persistent mental illness in Germany

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Abstract

Background

Relatives provide essential long-term support for people living with severe and persistent mental illness (SPMI), yet their perspectives remain insufficiently represented in psychiatric research and service development. As key partners in daily care, relatives offer unique insights into how living conditions, family relationships, and mental health service structures shape quality of life (QoL). Understanding these perspectives is important for developing more person-centred and quality-of-life-oriented psychiatric care. This study explored how relatives conceptualise QoL for their affected family members, which life domains they consider most important, and how they perceive the responsiveness of current psychiatric care.

Methods

A qualitative study design was employed using semi-structured interviews with eight relatives of people living with schizophrenia, bipolar disorder, or chronic depression recruited through self-help organisations in Germany. Interviews were audio-recorded, transcribed verbatim, and analysed using qualitative content analysis according to Mayring, supported by MAXQDA 24. In addition, a proxy-adapted version of the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW) was administered digitally to identify and prioritise QoL domains. SEIQoL-DW index scores and nominated domains were analysed descriptively and interpreted alongside the results of the interviews.

Results

Relatives described QoL as multidimensional, with health and well-being, social relationships, freedom and self-determination, and meaningful daily activities emerging as particularly relevant aspects. Organisational and structural challenges, including fragmented care pathways, communication and information deficits, unclear responsibilities, and limited family involvement, were repeatedly described as barriers to continuity and support in daily life. Despite considerable caregiving demands, relatives described various coping strategies, including setting personal boundaries, seeking information, and engaging in self-help and peer-support formats.

The SEIQoL-DW findings complemented the interview data by identifying family and partnership, friendships and social contacts, work or daily structure, or both, and hobbies and leisure activities as the most frequently nominated QoL domains.

Conclusion

Relatives conceptualised QoL in SPMI as extending beyond symptom-related aspects and as shaped by both personally meaningful life domains and the relational and service-related conditions surrounding daily life. Social relationships, meaningful activities, autonomy, and health and well-being were

particularly relevant, while communication deficits, discontinuities in care, and limited family involvement were perceived as barriers to supporting QoL. These findings highlight the importance of continuity, transparent communication, coordinated care, and meaningful family involvement in developing person-centred psychiatric services that respond to individual priorities and daily circumstances.

Background

Relatives play a central and enduring role in supporting individuals living with severe and persistent mental illness (SPMI). As well as providing emotional support, they often take on practical and organisational tasks, such as arranging appointments, managing daily routines and helping to access mental health services.

In doing so, they often compensate for structural limitations within psychiatric care, such as fragmented care pathways, insufficient continuity between inpatient and outpatient services, and limited community-based support (Stoll et al., 2022). Despite their substantial contribution, relatives' perspectives remain insufficiently represented in psychiatric research and service development.

Although a large body of research has documented caregiver burden and psychological distress among relatives of people living with SPMI, considerably less attention has been paid to how relatives conceptualise quality of life (QoL) for their affected family members and how they perceive the relational and structural conditions that influence it. Focusing predominantly on caregiver burden risks overlooking the experiential knowledge that relatives have about the factors that promote or hinder daily stability, participation, and well-being over the course of long-term mental illness.

This perspective has become increasingly relevant as contemporary psychiatric care focuses more on person-centred, recovery-oriented, and palliative-informed approaches. Recovery-oriented care emphasises the pursuit of a meaningful and satisfying life despite persistent symptoms or vulnerabilities, with autonomy, personal goals, and participation representing central elements of recovery (Roberts & Wolfson, 2004). Person-centred approaches similarly place individual needs, preferences, values, and lived experiences at the centre of care. Palliative-informed approaches complement these perspectives by explicitly addressing persistent suffering and QoL when symptom remission or functional recovery remain limited (Roberts & Wolfson, 2004; Trachsel et al., 2021). Across these perspectives, QoL extends beyond symptom reduction to encompass social connectedness, autonomy, emotional stability, meaningful participation in family and social life, and opportunities to live a life consistent with personal values (Trachsel et al., 2021; Westermair et al., 2023). This understanding is also consistent with the Capability Approach, which conceptualises QoL in terms of the real opportunities individuals have to pursue ways of living they personally value. From this perspective, QoL is shaped not only by individual health or functioning but also by relational, social, and institutional conditions that enable or restrict autonomy, participation, social connectedness, and control over daily life (Nussbaum, 2011; Hopper, 2007). The Capability Approach therefore provides a useful interpretative framework for examining how relatives describe both personally relevant QoL domains and the

conditions within psychiatric care that influence their enactment. Because relatives are closely involved in daily care and frequently experience the consequences of fragmented services, communication difficulties between patients and relatives and medical services, and restrictive confidentiality practices, they possess unique experiential knowledge of how these factors shape QoL in daily life (Stoll et al., 2022; Westermair et al., 2023). Integrating relatives' perspectives may therefore contribute to a more comprehensive understanding of QoL and inform the implementation of psychiatric care that is better aligned with the long-term needs of people living with SPMI and their families.

To address this gap, the present study explored how relatives of people living with SPMI conceptualise QoL for their affected family members, which life domains they consider most important, and how they perceive the responsiveness of current psychiatric care in Germany. Individualised approaches to QoL assessment are particularly relevant in this context because they allow personally meaningful life domains to be identified rather than defining relevant dimensions a priori. The SEIQoL-DW was developed for this purpose, enabling respondents to nominate, rate, and weight the life domains they consider most important to QoL (Hickey et al., 1996). Previous applications have demonstrated its value in identifying individually relevant QoL domains across chronic and severe illness contexts, including the relevance of family and social relationships (Nijboer et al., 2010; Prince & Gerber, 2001). To capture both narrative experiences and explicit QoL priorities, qualitative interviews were combined with a proxy-adapted version of the Schedule for the Evaluation of Individual Quality of Life – Direct Weighting (SEIQoL-DW) (Hickey et al., 1996). Integrating qualitative interview data with structured proxy assessments provides complementary insights into relatives' perspectives and enables comparison with corresponding studies involving people living with mental illness and mental health professionals. By combining these approaches, the study contributes to a more comprehensive understanding of QoL in patients with SPMI from a family perspective and supports the further development of person-centred and QoL-oriented psychiatric care. The Capability Approach is used as an interpretative framework to relate personally relevant QoL domains to the relational and service-related conditions identified in relatives' accounts (Nussbaum, 2011; Hopper, 2007).

Methods

Design and Setting

A qualitative interview design was employed to explore how relatives of people living with SPMI conceptualise QoL and perceive current psychiatric care structures. Semi-structured interviews were chosen to facilitate the systematic exploration of predefined topics while allowing participants to introduce issues they considered relevant based on their own caregiving experiences.

Data were collected in Germany between June and August 2025. Qualitative content analysis following Mayring combined deductive and inductive category development (Mayring, 2015). Deductive main categories were defined a priori based on the study aims and the literature on QoL, family caregiving, and psychiatric care.

To complement the interviews, a proxy-adapted version of the SEIQoL-DW was used as a structured elicitation tool (Hickey et al., 1996). Relatives nominated, weighted, and rated the life domains they considered most relevant to the QoL of their affected family member. The SEIQoL-DW was not used for quantitative evaluation or hypothesis testing but rather to make participants' individual priorities explicit and to inform interpretation of the qualitative findings.

Combining qualitative interviews with a structured proxy-based assessment provided complementary information on contextualised caregiving experiences and explicit prioritisation of QoL domains. This approach facilitated comparison with corresponding studies involving mental health professionals using a qualitative approach and people living with mental illness using a quantitative approach (Martorana et al., manuscript in preparation; Martorana et al., manuscript under review).

Participants and Recruitment

Relatives were eligible for participation if they were at least 18 years of age and were currently or had previously been involved in caring for a family member living with schizophrenia, bipolar disorder, or chronic recurrent depression.

Participants were recruited through the German Federal Association of Relatives of People with Mental Illness (Bundesverband der Angehörigen psychisch erkrankter Menschen; BApK). Interested relatives received via e-mail detailed information about the study aims, study procedures, voluntary participation, and data protection. Written informed consent was obtained from all participants prior to participation.

Eight relatives participated in the study, including six mothers, one mother–father dyad, and one adult daughter. Participant characteristics, caregiving roles, and interview durations are presented in Table 1.

Table 1
Characteristics of participating relatives

Code	Duration	Role	Mode of data collection
INT_A01	75'	Mother	Telephone
INT_A02	37'	Mother	Telephone
INT_A03	83'	Mother	Videoconference
INT_A04	57'	Mother	Telephone
INT_A05	36'	Mother	Telephone
INT_A06	57'	Mother and Father	Telephone
INT_A07	22'	Daughter	Telephone
INT_A08	60'	Mother	Telephone

Note. Age of participants was not collected, as the study focused on qualitative exploration of caregiving experiences rather than sociodemographic description.

Data Collection

Semi-structured interviews were conducted by telephone or video call, according to participants' preferences. Interviews lasted between 22 and 83 minutes (see Table 1) and were audio-recorded with the informed consent of the participants.

The interview guide was developed based on the study aims, findings from preceding work within the broader research project, including a preliminary study and a qualitative study involving mental health professionals, as well as the literature on QoL, family caregiving in severe and persistent mental illness, and structural aspects of psychiatric care (Martorana et al., manuscript in preparation; Martorana et al., manuscript under review; Martorana & Kübler, manuscript under review). It combined open-ended exploratory questions with more focused prompts, enabling participants to introduce issues they considered important while ensuring that all pre-defined key topics were addressed.

Interviews began with an open introductory question designed to elicit participants' own understanding of QoL: *"What does quality of life mean to you in relation to your affected family member?"* This was followed by questions exploring important life domains, daily caregiving experiences, and perceived challenges within psychiatric care, including: *"Which aspects of daily life are particularly important for your relative's well-being?"* and *"Where do you experience gaps or difficulties in current care structures?"*

The proxy-adapted SEIQoL-DW was subsequently administered as a structured elicitation tool. Participants nominated five life domains they considered most important for the QoL of their affected family member, assigned relative importance weights summing to 100%, and rated, from a proxy perspective, their affected family member's perceived satisfaction within each domain on a scale ranging from 0 to 100 (Hickey et al., 1996). The digital assessment was implemented using the "SoSci Survey" platform while preserving the original SEIQoL-DW administration and scoring principles.

The SEIQoL-DW was completed step by step together with each participant to ensure comprehension, completeness, and plausibility of responses. Immediately afterwards, responses were reviewed jointly to identify and resolve potential misunderstandings, inconsistencies, or data-entry errors. Individual SEIQoL-DW index scores were calculated according to the original scoring procedure by multiplying satisfaction ratings by their corresponding importance weights and summing up the resulting values. The calculation can be expressed as the sum of the five domain-specific products of satisfaction and relative importance (SEIQoL-DW index = $\sum$ satisfaction $\times$ relative importance weight) (Hickey et al., 1996).

An illustrative example of the SEIQoL-DW proxy scoring procedure is provided in Table 2.

Table 2

Illustrative example of SEIQoL-DW proxy scoring showing nominated QoL domains, satisfaction ratings, importance weights, and resulting index score.

Domain	Level (0-100)	Weight (%)	Weight (decimal)	Product (Level x Weight)
Housing	1	21	0.21	0.21
Financial security	1	21	0.21	0.21
Partnership	1	27	0.27	0.27
Friends	1	21	0.21	0.21
Family	1	10	0.10	0.10
Sum				1
Note. Table 2 provides an illustrative example of the calculation of a proxy-adapted SEIQoL-DW index score. The index is obtained by multiplying each satisfaction rating (0–100) by its corresponding importance weight and summing the weighted values. The example is presented for illustrative purposes only.				

Following completion of the SEIQoL-DW, interviews continued with an in-depth discussion of the nominated life domains and their relevance, as well as broader topics including collaboration with mental health professionals, communication and confidentiality practices, coping strategies, and expectations regarding psychiatric and palliative-informed care. Interviews concluded with a closing question inviting additional reflections if so wished: *"Is there anything else you would like to add that we have not yet discussed?"*

The interview guide was developed and administered in German and is available from the corresponding author upon reasonable request.

Data Analysis

All interviews were audio-recorded, transcribed verbatim, and anonymised. Data were analysed using qualitative content analysis according to Mayring (Mayring, 2015), combining deductive and inductive category development.

Deductive main categories were defined *a priori* based on the study aims and the literature on QoL in SPMI, family caregiving, and structural aspects of psychiatric care. The initial coding framework comprised four main categories: quality of life domains, caregiving experiences and coping strategies, perceived challenges and barriers within psychiatric care, and developmental and action-oriented perspectives.

These categories provided an initial analytical framework to ensure that conceptually relevant dimensions of relatives' perspectives were systematically addressed.

Within this framework, subcategories were developed inductively from the interview material to capture themes and meanings emerging directly from participants' narratives. Coding followed an iterative process in which the category system was continuously refined. Text segments could be assigned to multiple categories where appropriate, reflecting thematic overlap and the complexity of participants' accounts.

Coding frequencies refer to the number of coded text segments rather than the number of participants. Because individual interviews could contribute multiple segments to a given category, frequencies may exceed the total number of interviews ($N = 8$). Categories and subcategories are presented in descending order of coding frequency to indicate their relative prominence within the dataset. An overview of coding frequencies across the main categories is presented in Fig. 1, while the complete coding framework, including all main categories and subcategories, is provided in Supplementary Table S1.

Proxy SEIQoL-DW data were analysed descriptively. Frequencies of nominated QoL domains and individual index scores were used to illustrate how relatives prioritised and weighted different aspects of QoL for their affected family members. These data were not analysed inferentially but rather were used to supplement the qualitative findings by making participants' explicit QoL priorities visible.

Qualitative interview findings and SEIQoL-DW results were examined alongside one another to identify areas of convergence and divergence between narrative accounts and structured domain prioritisation.

Qualitative data management and coding were supported by MAXQDA 24. Relational and matrix-based functions were used descriptively to explore co-occurrences between selected categories, such as QoL domains and perceived structural barriers, and to support the interpretation of the qualitative findings.

All interviews were conducted in German. Quotations presented in the Results section were translated into English by the first author. An AI-based language tool was used to support the translation process. Final wording and interpretation remained the responsibility of the first author and was supervised by the senior author.

Results

The results are organised according to the four predefined deductive themes of the coding framework. Within each theme, additional subthemes were developed inductively from the interview material. Coding frequencies refer to coded text segments rather than individual participants and may therefore exceed the number of interviews due to multiple coding.

Theme 1: Quality of life factors

Relatives conceptualised QoL as embedded within a shared family context and linked to multiple areas of daily life, including health and well-being, social relationships, autonomy, daily structure, housing, and

economic security. Rather than referring solely to the affected family member, participants frequently described QoL as influencing the well-being of the entire family system.

Within the qualitative interview data, health and well-being emerged as the most frequently coded QoL domain (61 coded segments). Participants emphasised physical and psychological stability, emotional well-being, and the ability to cope with daily demands as fundamental components of QoL. One relative explicitly emphasised the importance of improving the affected person's health:

It would of course be important, first, to treat his illness and to restore his health to some extent.

(INT_A04, author's translation)

"Health is very important to me. Being physically and mentally well means being able to manage my life and accomplish what I want."

(INT_A01, author's translation)

Social relationships represented the second most frequently coded domain (41 coded segments). Family relationships, friendships, and partnerships were viewed as essential sources of support, although they were often challenged by social withdrawal and the chronic course of illness. Family was described as providing emotional support, a sense of belonging, and a first point of contact when help was needed. Friendships were similarly considered important, but several relatives described how previously established social networks had diminished or been lost over the course of the illness, sometimes resulting in considerable social isolation. Partnerships were described as another potential source of security and stability, although maintaining intimate relationships could also be difficult in the context of persistent mental illness.

"For me, quality of life is about relationships."

(INT_A08, author's translation)

Freedom and self-determination were described as inherently ambivalent (27 coded segments). Participants emphasised the importance of autonomy while simultaneously expressing concerns about relapse, excessive demands, and safety, illustrating the ongoing tension between independence and protection in daily caregiving. For example, relatives described self-determination as being able to pursue personally meaningful goals and to live as independently as possible. At the same time, one relative mentioned how the affected family member wanted to regain independence and avoid dependence on the family, while repeatedly requiring their support in daily life. Other accounts highlighted situations in which relatives perceived a need for greater protection or intervention while the affected person rejected treatment or support, illustrating the difficulty of balancing autonomy with perceived care and safety needs.

He wants to be independent again and not have to depend on us, but he repeatedly has to rely on our help.

(INT_A04, author's translation)

Housing and the living environment were closely associated with stability (22 coded segments). Secure and predictable living conditions were linked to reduced stress and greater continuity in daily life, whereas housing insecurity and repeated relocations were perceived as contributing to destabilisation and crisis escalation. Examples included having a permanent home that provided a place of retreat and a sense of security, access to supported accommodation with regular contact with social workers, and financial support that enabled housing to be maintained. At the same time, relatives described repeated periods of homelessness, temporary stays in shelters, the loss of accommodation during periods of crisis, and situations in which affected family members were left without a safe place to sleep.

Daily structure also emerged as an important QoL domain (20 coded segments). Participants highlighted the value of meaningful daytime activities, including employment, structured routines, and regular responsibilities. Examples included maintaining regular sleeping and eating patterns, attending day programmes, pursuing education or employment, and having regular activities that provided structure throughout the day. Within this domain, hobbies and leisure activities formed an inductively derived subcategory. Sports and other personally meaningful activities, including cycling, surfing, climbing, inline skating, and badminton, were described as providing enjoyment, social connection, and a sense of purpose. At the same time, opportunities to engage in these activities were often limited by fluctuating functioning, reduced motivation, and insufficient external support.

That was important to her; we organised our lives, our leisure time, everything around her competitions and her passion for sport.

(INT_A06, author's translation)

Finally, economic security was identified as an important component of QoL (14 coded segments), particularly in relation to long-term uncertainty, dependence on social benefits, and concerns about future financial stability. Examples included reliance on social benefits to cover basic living and housing costs, difficulties managing available income, recurring financial shortfalls, and accumulated debt. Relatives described financial security as a basic condition for maintaining other areas of life, including housing and social relationships.

Relationships are the most important aspect of quality of life, but without a basic [financial] foundation, they cannot work either.

(INT_A08, author's translation; clarification added by the author)

Theme 2: Challenges and barriers

Challenges and barriers represented a dominant theme across the interviews. Participants described a range of organisational and structural constraints that undermined stability, continuity of care, and their capacity to manage ongoing caregiving responsibilities.

Gaps within the mental health care system emerged as the most frequently coded barrier (116 coded segments), followed by communication and information deficits (72 coded segments) and feelings of helplessness and frustration (70 coded segments). Examples of perceived gaps included long waiting times for psychotherapy, premature or insufficiently coordinated hospital discharge, limited follow-up care, difficulties accessing supported housing, and a lack of clearly identifiable contact points for relatives. Participants also described having to organise psychiatric or neurological follow-up and access to medication themselves after discharge. In some cases, relatives perceived affected family members as falling between existing services, for example when their support needs were considered too extensive for independent living but insufficient for access to more intensive supported accommodation.

Communication and information deficits were described across different stages of care. Relatives reported receiving limited information about the illness, treatment options, available support services, and how to respond in daily or crisis situations. Some described having to develop an understanding of the illness themselves over time, while others reported that information was provided only sporadically rather than as part of continuous guidance. Restrictive interpretations of confidentiality were perceived as a particular barrier to family involvement after affected family members reached adulthood. Relatives described situations in which they could provide information to professionals but received little or no information in return, including during periods of acute illness.

These experiences were closely linked to feelings of helplessness and frustration. Relatives described uncertainty about whom to contact, what they could do when treatment or support was declined, and how to respond when an affected family member deteriorated. Some accounts also illustrated consequences for relatives' own lives, including emotional distress and difficulties maintaining employment or other responsibilities.

I was once told by a physician that my son could remain in care if I paid €400 per day. These are the kinds of experiences relatives encounter.

(INT_A08, author's translation)

And the waiting lists for psychologists are just endlessly long. And if you have a mental illness and are supposed to wait three quarters of a year for an appointment, well, then the damage is already done.

(INT_A05, author's translation)

Among the more specific organisational barriers, unclear responsibilities between services (34 coded segments) were most frequently described, followed by housing shortages (26 coded segments), inadequate discharge and transition management (25 coded segments), and rigid service requirements

(25 coded segments). Housing-related barriers included long waiting lists for supported accommodation and a lack of suitable options between independent living and more intensive residential support. Inadequate transitions were illustrated by experiences of discharge without sufficient follow-up or appropriate housing, while rigid service requirements were perceived as particularly problematic when affected individuals were unable to initiate or maintain contact with services independently.

If the affected person refuses any psychiatric help, then the rest of the family is simply forced to endure the delusions. That creates a constant state of tension.

(INT_A03, shortened, author's translation)

Finally, stigmatisation (27 coded segments) and lack of trust in institutions (13 coded segments) were reported across both healthcare and broader social contexts. Examples of stigmatisation included feeling excluded from society, being perceived as less capable because of mental illness, and encountering barriers to employment and social participation. Relatives also described how stigma and shame could contribute to social withdrawal and the loss of friendships. Lack of trust was associated with previous negative experiences with mental health services, feeling that concerns were not taken seriously, and disappointment when promised or expected support was not provided.

There is a lack of empathy for people with mental illness. There is simply a lack of trust that they are capable of something.

(INT_A05, author's translation)

Theme 3: Coping strategies

Despite substantial and ongoing caregiving demands, relatives described a range of coping strategies aimed at maintaining their own well-being while continuing to support their affected family member (45 coded segments).

Frequently reported strategies included physical activity, spending time outdoors, maintaining friendships and social contacts, and deliberately creating time for themselves. Some relatives described sport as an important way of regaining energy, while others emphasised the importance of supportive friendships, professional therapeutic support, or contact with nature. Self-help groups and dialogue formats provided opportunities for exchange with other relatives and people with lived experience and helped participants gain a better understanding of mental illness and available forms of support.

Establishing personal boundaries and protecting one's own life emerged as another important strategy. Examples included limiting availability, maintaining separate living arrangements, reconsidering the extent of responsibility for an adult family member, and consciously preserving time for work, relationships, and personal recovery. One participant described maintaining regular contact with her daughter while deciding not to live together because doing so would jeopardise her own well-being.

Relatives also actively sought knowledge and support to navigate situations in which formal guidance was perceived as insufficient. Examples included reading about mental illness, attending seminars and trialogue meetings, learning about legal and social support options, contacting health insurers, and seeking information about benefits and available services. For some participants, advocacy, professional reorientation, or engagement in relatives' organisations also provided a sense of agency in situations otherwise characterised by limited influence.

I decided that I wanted to work with animals professionally, and the animals gave me a lot of strength. I think that was my biggest coping strategy, finding my own path.

(INT_A07, author's translation)

Theme 4: Developmental and action-oriented perspectives

Relatives articulated a broad range of development- and action-oriented perspectives aimed at improving QoL and the organisation of psychiatric care (112 coded segments). Central to these accounts was the desire for support that responds more closely to individual circumstances and the needs of daily life rather than primarily to institutional requirements. Examples included continuous support by trusted professionals, home visits, closer support during transitions between inpatient and community care, and services that take individual living circumstances, interests, and daily needs into account. Participants particularly emphasised continuity of relationships, arguing that contact with professionals should be maintained during periods of stability rather than being re-established only during crises.

Optimising communication and information processes emerged as the most frequently coded subtheme (60 coded segments). Participants emphasised the importance of timely, transparent, and inclusive communication, particularly regarding treatment decisions, care transitions, and family involvement. Concrete suggestions included providing relatives with information about the illness and available services, establishing clearly identifiable contact points, offering guidance on how to respond to crises and changes in functioning, and improving information exchange between professionals and services. Relatives also wished for greater continuity of information following discharge and more active guidance regarding available therapeutic, social, and financial support.

A recurrent concern was that healthcare professionals often lacked knowledge of the affected person's life history and identity prior to the onset of illness. Participants therefore emphasised that care should take into account previous abilities, interests, relationships, and personally meaningful activities rather than focusing predominantly on current symptoms and limitations.

The doctors were completely unprepared for who she had been before her illness. That left us quite speechless.

(INT_A06, author's translation)

Participants also highlighted the importance of integrating the social environment into care processes (29 coded segments). This included actively involving relatives in treatment where possible, providing them with opportunities to share observations and concerns, and recognising their own need for information and support. Participants suggested that relatives should be approached proactively rather than having to seek involvement themselves. Trialogue formats were described as particularly helpful for facilitating exchange between affected individuals, relatives, and professionals.

Beyond family involvement, participants described a need for supportive and non-clinical environments that facilitate meaningful participation in daily life. Examples included gardening, working with animals, workshops, sport and other activity-oriented settings, as well as supported living and home-based forms of care. Such approaches were valued because they could build on individual interests and abilities while providing structure, social contact, and support outside traditional clinical settings.

For my son, I would wish for something connected to nature. Gardening, working with animals.

(INT_A08, author's translation)

Additional suggestions included improving continuity across care transitions, strengthening collaboration between services and families, and expanding opportunities for participation beyond traditional clinical settings.

SEIQoL-DW proxy assessments

The proxy-adapted SEIQoL-DW was used to document how relatives prioritised QoL domains for their affected family members. Across all assessments, participants nominated nine distinct QoL domains. The most frequently nominated domains were family and partnership, friendships and social contacts, work and/or daily structure, and hobbies and leisure activities. Therapy and support services were also nominated by several participants, alongside housing security, financial security, health, and self-determination. An overview of all nominated domains and their frequencies is presented in Fig. 2.

The proxy-rated SEIQoL-DW scores varied considerably across participants (Table 3), reflecting relatives' evaluations of the overall QoL of their affected family members.

Table 3
SEIQoL-DW proxy index scores (relatives)

Participant ID	SEIQoL-DW index score
INT_A01	3.8
INT_A02	26.0
INT_A03	52.2
INT_A04	39.0
INT_A05	23.0
INT_A06	13.5
INT_A07	41.5
INT_A08	1.0
Note. Index scores range from 0 to 100 and reflect relatives' proxy evaluations of overall quality of life for their affected family members.	

The lowest index score (1.0) resulted from consistently low satisfaction ratings across all nominated domains in combination with their respective importance weights.

Integration of qualitative interview findings and SEIQoL-DW data

Several QoL domains were represented in both the qualitative interviews and the SEIQoL-DW proxy assessments, including social relationships, daily structure, housing, and health. Social relationships were frequently nominated in the SEIQoL-DW and were also identified in the qualitative interviews. In addition, the interviews identified relational, service-related, and structural aspects, including communication deficits, stigma, and gaps within the mental health care system, which were not represented as explicit QoL domains in the SEIQoL-DW assessments. Figure 3 provides an overview of findings across both data sources.

Discussion

The present study explored how relatives of people living with SPMI conceptualise QoL and perceive current psychiatric care structures. **Relatives' accounts reflected a multidimensional understanding of QoL that extended beyond symptom-related aspects. In the qualitative interviews, health and well-being and social relationships were the most frequently coded QoL domains, followed by freedom and self-determination, housing and the living environment, and daily structure. The SEIQoL-DW assessments similarly highlighted family and partnership, friendships and social contacts, work and/or**

daily structure, and hobbies and leisure activities. At the same time, the relative prominence of individual domains differed between the two approaches: health and well-being was particularly prominent in the qualitative interview coding, whereas social relationships featured more strongly among the explicitly prioritised SEIQoL-DW domains. **Across both approaches, social relationships and opportunities for meaningful daily participation emerged as particularly relevant aspects of QoL.** These findings are consistent with previous research emphasising the importance of **social relationships, participation, and meaningful daily activities** for QoL in people living with severe mental illness, particularly in long-term care contexts (Prince & Gerber, 2001; Dorvil et al., 2008; McGraw et al., 2014; Pinfold et al., 2004).

Participants also identified hobbies and leisure activities as important contributors to daily well-being. Within the qualitative interviews, these activities were closely connected to daily structure, social participation, enjoyment, and continuity in daily life, while hobbies and leisure activities also emerged as an explicitly nominated domain in the SEIQoL-DW assessments. This convergence across the two data sources highlights the relevance of ordinary, non-clinical aspects of daily life for QoL in the context of long-term mental illness (Prince & Gerber, 2001; McGraw et al., 2014; Pinfold et al., 2004).

A central finding was the prominence of organisational and structural challenges within relatives' accounts. Fragmented care pathways, insufficient continuity across care transitions, and limited access to timely information were consistently described as sources of strain and uncertainty. Communication difficulties and restrictive interpretations of confidentiality further limited relatives' involvement in care, particularly during psychiatric crises. Similar barriers have been reported in studies examining family involvement, continuity of care, and collaboration between relatives and mental health services (McCann et al., 2011; Eassom et al., 2014; Tham et al., 2024; Riebschleger et al., 2021). Previous research has also shown that families may be marginalised in care planning processes, receive insufficient information and experience difficulties relating to confidentiality. Successful family involvement requires organisational structures that actively facilitate collaboration (Eassom et al., 2014; Tham et al., 2024; Riebschleger et al., 2021). These findings suggest that organisational conditions can influence the daily circumstances in which QoL is experienced and supported.

Participants also described psychiatric services as predominantly reactive, with support frequently becoming available only after crises had escalated. From relatives' perspectives, this crisis-oriented organisation of care limited opportunities to establish stable daily routines and maintain continuity over time. Similar concerns regarding fragmented care structures, insufficient continuity, and organisational barriers have also emerged in a corresponding study of mental health professionals' perspectives on QoL in people living with SPMI (Martorana et al., manuscript in preparation). Comparable observations have been reported in research examining family involvement and long-term support for people living with severe mental illness (Eassom et al., 2014; Tham et al., 2024; Riebschleger et al., 2021). The convergence between relatives' and professionals' perspectives suggests that discontinuity and delayed support may represent broader characteristics of current care structures rather than experiences confined to a single stakeholder group.

The proxy-adapted SEIQoL-DW findings additionally indicated that relatives perceived the QoL of their affected family members as substantially compromised. The mean index score of 25.0 was notably low when considered alongside SEIQoL-DW findings reported in other severe chronic conditions. For example, substantially higher individual SEIQoL-DW scores have been reported among people living with advanced amyotrophic lateral sclerosis (Nijboer et al., 2010). However, this comparison should be interpreted cautiously because the present assessments represent relatives' proxy evaluations rather than self-reported QoL. Previous research has shown that proxy evaluations of QoL in severe or terminal illness may be substantially lower than evaluations provided by affected individuals themselves (Lulé et al., 2013; Kübler et al., 2005).

Considering the qualitative interviews alongside the proxy-adapted SEIQoL-DW provided complementary perspectives on QoL. Social relationships were prominent across both data sources, while daily structure, housing, and health were also represented in both. The interviews additionally contextualised these QoL domains by identifying relational, service-related, and structural conditions that relatives perceived as supporting or constraining QoL in daily life. Communication deficits, stigmatisation, difficulties accessing appropriate services, and discontinuities in care were among the conditions described in this context.

Despite considerable caregiving demands, relatives described a range of coping strategies, including establishing personal boundaries, seeking information, participating in self-help groups, maintaining social contacts, and engaging in meaningful activities. These strategies have previously been identified as important resources for sustaining long-term caregiving and reducing psychological burden (Sin et al., 2022; Yao et al., 2024). The present findings further indicate that maintaining a life outside the caregiving role and establishing personal boundaries may be particularly important in long-term caregiving (Robinson et al., 2025), especially when relatives perceive limited possibilities to influence treatment or service provision. At the same time, the need for such strategies should not obscure the responsibility of professional services to provide accessible information, guidance, and support for relatives.

The development- and action-oriented perspectives expressed by participants provide further indication of how these findings could translate into care. Relatives particularly emphasised continuous professional relationships, proactive communication and information, coordinated transitions, greater involvement of families, and support that responds to individual circumstances and daily needs. These requirements show considerable overlap with principles of person-centred and recovery-oriented care, which emphasise individual priorities, participation, autonomy, and meaningful life beyond symptom reduction (Roberts & Wolfson, 2004). Family- and network-oriented approaches provide an additional point of reference, as they explicitly recognise collaboration between affected individuals, relatives, and professionals as part of psychiatric care (Eassom et al., 2014; Tham et al., 2024; Riebschleger et al., 2021; Clement et al., 2021). Evidence on family involvement further suggests that its implementation depends not only on individual professional practice but also on organisational commitment and coordinated routines within services (Eassom et al., 2014).

Over and above the aforementioned frameworks, the Capability Approach provides a broader, more integrative theoretical framework for these findings (Nussbaum, 2011; Hopper, 2007). Rather than conceptualising QoL solely in terms of health status or achieved functioning, it focuses on the real opportunities individuals have to pursue ways of living they personally value (Nussbaum, 2011). Applied to severe mental illness, this perspective draws attention to how individual agency interacts with social, relational, and institutional conditions that may enable or restrict such opportunities (Hopper, 2007). In the present study, relatives identified personally meaningful QoL domains, including social relationships, health and well-being, autonomy and self-determination, and meaningful activities, while also describing relational and service-related conditions that may affect their implementation. Communication and information, continuity and coordination of care, family and social support, and access to services were described as conditions relevant to these opportunities, whereas fragmented care, rigid service requirements, stigma, and unclear responsibilities were perceived as potential constraints.

Overall, the findings indicate that relatives conceptualise QoL as shaped by both personally meaningful life domains and the conditions under which daily life and psychiatric care are organised. Social relationships, meaningful activities, autonomy, and daily structure were particularly relevant, while communication deficits, discontinuities in care, and limited family involvement were perceived as barriers to supporting QoL. Viewed through the Capability Approach, these findings suggest that QoL is related not only to the presence of valued aspects of life but also to the opportunities individuals have to realise them within their relational and service environment (Nussbaum, 2011; Hopper, 2007).

Conclusion and Future Implications

The present study adds to the literature by showing that relatives conceptualise QoL in people living with SPMI as multidimensional and closely connected to both everyday life and the conditions under which psychiatric care is provided. Considering qualitative interviews alongside proxy-adapted SEIQoL-DW assessments provided complementary perspectives on personally relevant QoL domains and the contextual conditions perceived to support or constrain them.

The findings suggest that QoL-oriented psychiatric care should extend beyond symptom management and consider the relational and organisational conditions shaping everyday life. Strengthening continuity, communication, coordination, and appropriate involvement of relatives may contribute to care that is more responsive to the priorities and circumstances of people living with SPMI.

Future research should integrate the perspectives of people living with SPMI, relatives, and mental health professionals and examine how these perspectives converge or differ. Longitudinal and multi-perspective studies could further investigate how conditions supporting or constraining QoL change over time and how individual QoL assessment can inform person-centred service development without assuming that stakeholder perspectives necessarily coincide.

Abbreviations

- **QoL**

Quality of life

- **SPMI**

Severe and persistent mental illness

- **SEIQoL-DW**

Schedule for the Evaluation of Individual Quality of Life – Direct Weighting

Declarations

Ethics approval and consent to participate

The study received a favourable ethical opinion from the Ethics Committee of the Institute of Psychology, Faculty of Human Sciences, Julius-Maximilians-Universität Würzburg, Germany, on 18 December 2024 (GZEK 2024-65). The study was conducted in accordance with the ethical guidelines of the aforementioned Ethics Committee and the Declaration of Helsinki. All participants provided informed consent prior to participation.

Consent for publication

Not applicable.

Availability of data and materials

The qualitative data generated and analysed during the current study are not publicly available due to the sensitive nature of the interview data and to protect participant confidentiality. Further information may be available from the corresponding author upon reasonable request.

Clinical trial number

Not applicable.

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Figures

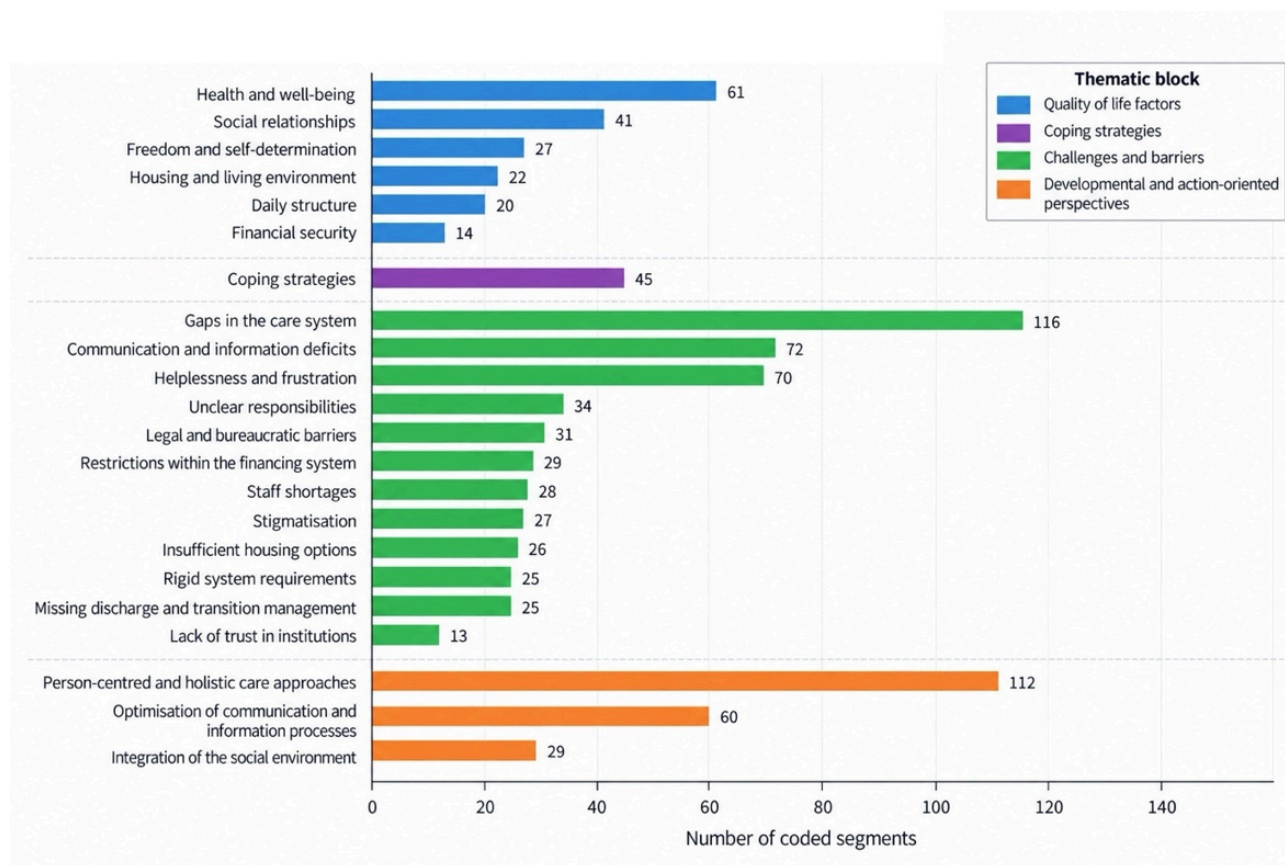


Figure 1

Overview of qualitative coding frequencies across the four main categories. Bars represent the number of coded text segments per category. Frequencies refer to coded segments and may exceed the number of interviews due to multiple coding

Note. Coding frequencies refer to coded text segments. Multiple coding was permitted where appropriate; therefore, frequencies may exceed the number of interviews ($N = 8$). Main categories and subcategories are presented in descending order of coding frequency within each main category.

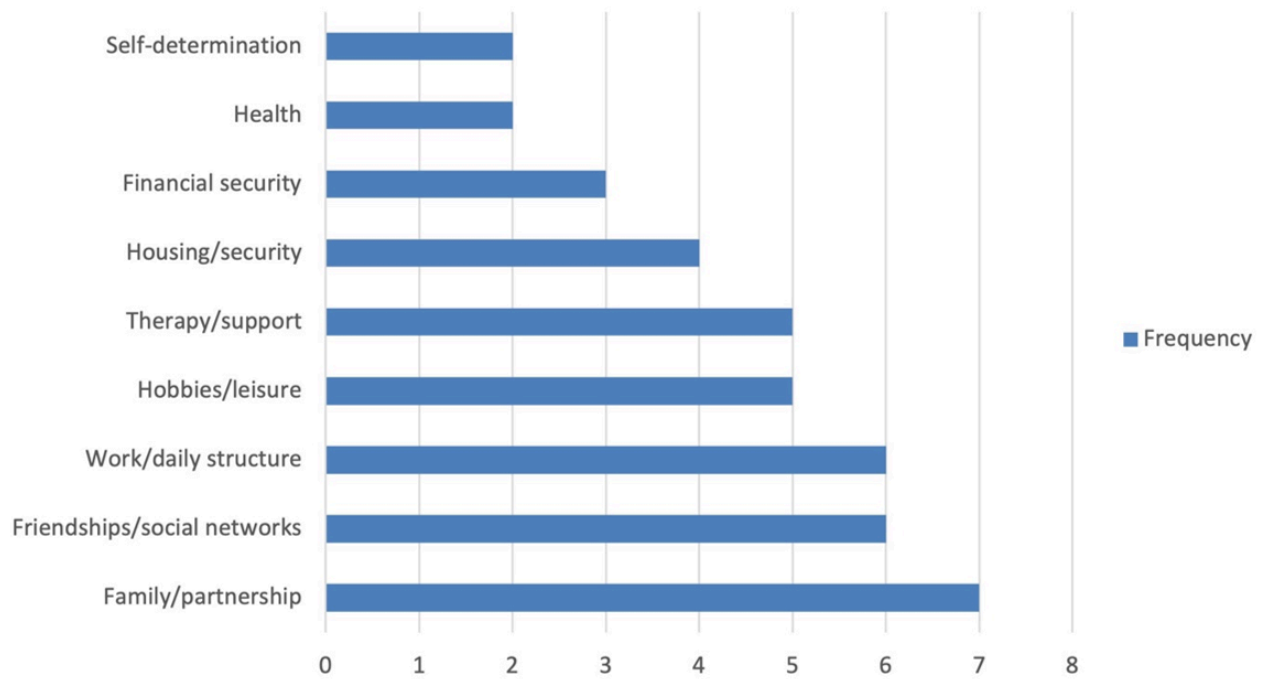


Figure 2

Frequency of SEIQoL-DW proxy domains nominated by relatives

Note. Frequencies indicate the number of times each QoL domain was nominated by relatives during the proxy-adapted SEIQoL-DW assessment. Because participants could nominate multiple domains, frequencies exceed the number of participants ($N = 8$).

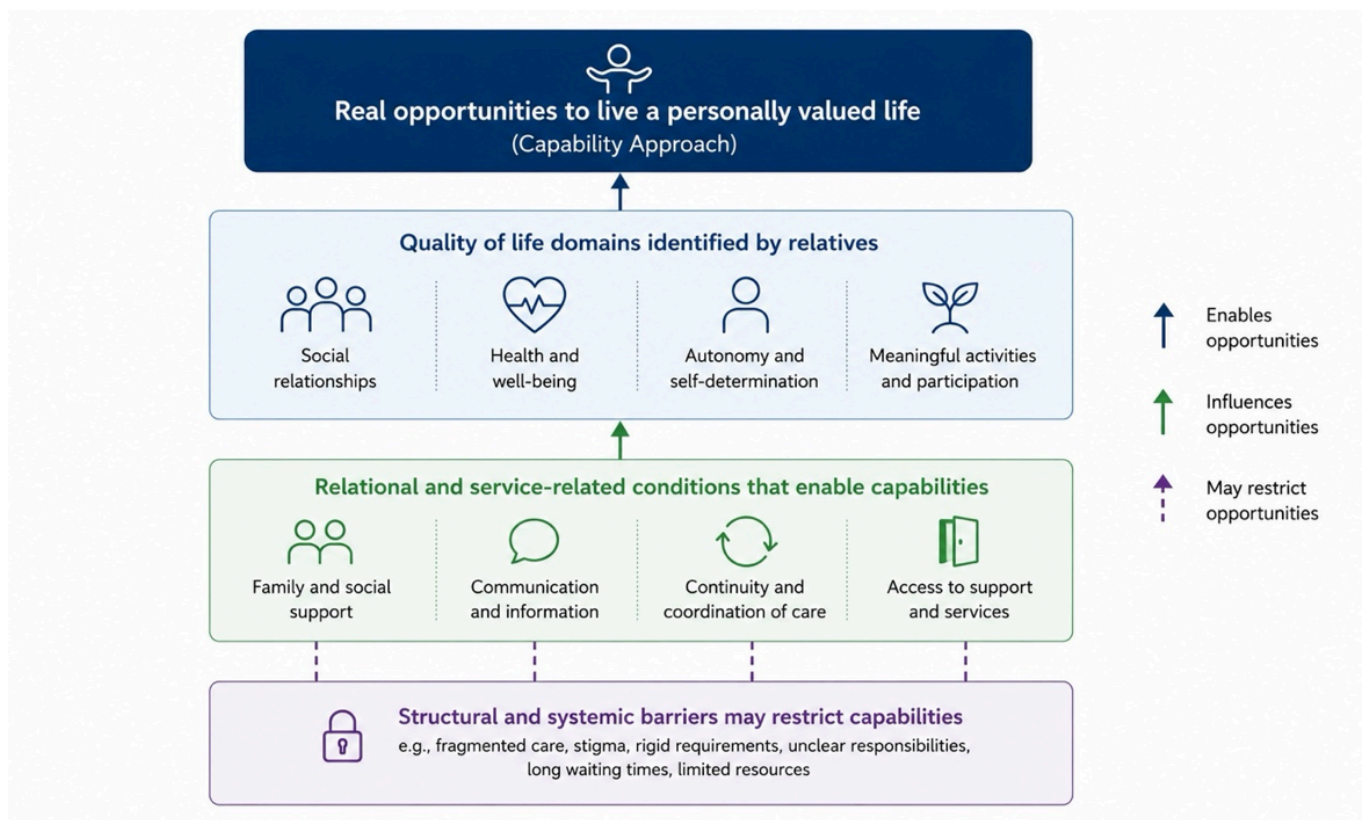


Figure 3

Capability-oriented interpretation of QoL from relatives' perspectives

Note. The figure illustrates how the empirical findings can be interpreted within the Capability Approach. Personally valued QoL domains are considered in relation to relational and service-related conditions that may enable or restrict opportunities to pursue a personally valued life. The figure represents an interpretative application of the Capability Approach rather than a newly developed model. The figure was created with the assistance of ChatGPT (OpenAI) for graphical visualisation; the conceptual content and interpretation were developed by the authors.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [SupplementaryTableS1.pdf](#)