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Title

Service users' experiences and perceptions of carer support and involvement in care and treatment in adult mental health inpatient settings: A qualitative evidence synthesis.

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Abstract

Over the past decade, research has increasingly addressed the support needs of carers in mental health settings and their involvement in care and treatment. However, service users' perspectives have received comparatively limited attention, despite the importance of their preferences as a key starting point for carer involvement. Furthermore, existing evidence remains scattered across smaller qualitative studies. The aim of this qualitative evidence synthesis of adult mental health inpatient service users' experiences and perceptions of carer support and involvement in care and treatment. Systematic searches were conducted in CINAHL, PubMed, APA PsycINFO and Scopus for literature published between January 1, 2000, and January 3, 2025. Grey literature was identified through OpenGrey, GreyGuide, ProQuest Dissertations & Theses Global, Google, Google Scholar and relevant websites. Eligible studies underwent quality appraisal and were analysed using a thematic approach.

14 studies were included, encompassing findings from 632 service users. Five themes were developed: (1) eagerness versus hesitations towards involvement of carers in care planning, care and treatment; (2) the significance of receiving support from carers in coping with mental illness; (3) the necessity of supporting carers—recognising needs and burdens and (4) institutional barriers to carer support and involvement. These four themes are interrelated with an overarching theme five: (5) relationship between service users and carers. The overarching theme reveals that service users' perceptions of whether carer involvement and support were meaningful depended on the significance and quality of the relationship, which in turn was shaped by carers' knowledge and understanding of mental illness.

Keywords

Family relations; Mental health; Systematic review; Qualitative research.

Introduction

Internationally, practice views and clinical guidelines advocate for active involvement of carers in the care and treatment of service users in mental health settings, while also emphasizing the need to support carers in their caregiving roles (Javed & Herrman, 2017; National Institute for Health and Care Excellence, 2014, 2020). Evidence demonstrates that engaging carers in the care and recovery process of service users with mental illness is associated with better treatment outcomes, including improved compliance with treatment, relapse prevention and shortened admissions (Ashcroft et al., 2018). Thereby, involvement can help mitigate the substantial personal and socio-economic costs associated with mental illness (Javed & Herrman, 2017). Despite these apparent advantages, studies exploring carers' experiences consistently report a perceived exclusion from care and treatment planning (Cleary et al., 2020; Doody et al., 2017; Vestphal et al., 2023). From the perspective of healthcare professionals, studies have identified various obstacles to supporting and involving the carers of service users. These include both organisational factors and family-related constraints (Giacco et al., 2017; Skundberg-Kletthagen et al., 2020).

While considerable attention has been given to exploring the experiences of carers and healthcare professionals regarding carers' participation in care planning, e.g., relapse planning and shared decision-making processes, surprisingly less emphasis has been placed on service users' perspectives on this matter (Shimange & Shilubane, 2023). One previous study sought to synthesise qualitative research that examined how service users view the involvement of family members in their engagement with services and care (Cameron et al., 2023). However, this review had significant methodological limitations, including the absence of a comprehensive and transparent documented systematic literature search strategy and no grey literature searches. Furthermore, the scope of the review was narrow, focusing solely on service users' experiences of family involvement, while omitting their views on the need to support carers in managing the burdens associated with their caregiving role. Finally, the review was limited to immediate family members of service users, excluding support and involvement from the broader carer support network (e.g., other family relations and friends). Consequently, the aim of this qualitative evidence synthesis is to provide a systematic examination of service users' experiences and perceptions of carer support and involvement in care and treatment in adult mental health inpatient settings. Developing our understanding in this area will help to provide a solid foundation for improving the ways in carers are supported and involved in care and treatment in adult mental health inpatient settings.

Methods

The qualitative evidence synthesis incorporates the framework by Flemming and Noyes (2021) to ensure the study's methodological quality. To enhance transparency and completeness of reporting, we followed the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) guideline (Tong et al., 2012) and the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guideline (Page et al., 2021). A protocol is registered via PROSPERO in September 2023 and revised in February 2024 (CRD42023461807).

Focused review question

The qualitative conceptualizing model PICo (Population, phenomenon of Interest and Context) (Lockwood et al., 2015) was chosen to guide the development of the review question: what characterises service users (P) experiences and perspectives of carer involvement and support (I) in adult mental health inpatient settings (Co). The PICo elements are defined in Table 1.

Insert Table 1

Search strategy

Based on the review question, a pre-planned three-step literature search strategy was developed in collaboration with an informatics specialist to identify relevant studies. Firstly, systematic searches were conducted in CINAHL (EBSCOhost), PubMed (NCBI), APA PsycINFO (Ovid) and Scopus (Elsevier) for studies published in English between January 1, 2000, and January 3, 2025. The rationale for covering the past 25 years is that, since the turn of the millennium, healthcare has undergone significant shift towards patient-centred care, with an increasing emphasis on the involvement of families and carers in treatment planning and decision-making, as exemplified by the National Service Framework for Mental Health in the UK (NHS, 1999).

Key terms corresponding to each of the three PICo elements were used to generate both subject headings and relevant keywords for the literature search. The searches further included truncation and phrase searching. Secondly, we employed supplementary search strategies by conducting citation searches and utilising the 'find similar/related articles' function in the databases (Frandsen & Eriksen, 2023). Finally, searches for grey literature (Mahood et al., 2014) were made in grey literature databases (Open Grey, GreyGuide and ProQuest Dissertations & Theses Global), general search engines (Google and Google Scholar) and on four websites run by health authorities and relevant interest organisations: National Institute for Health and

Care Excellence (nice.org.uk), Danish Health Authority (sst.dk), Danish Association for Mental Health (sind.dk) and International Family Nursing Association (internationalfamilynursing.org).

A detailed description of the three-step literature search strategy is provided in the supplementary material table 1-3, except for the website searches. The websites searched do not support advanced search functionality, therefore it was not possible to report search strings and the number of records returned. The searches were conducted by the first author on September 9, 2023, and updated on January 3, 2025.

Study screening and selection

To be included in this qualitative evidence synthesis, studies identified through the searches based on the PICo elements (see Table 1) were required to meet the following criteria:

Inclusion criteria:

- Studies conducted within any adult mental health inpatient setting
- Peer-reviewed, qualitative and mixed-method studies
- Studies published in English

Exclusion criteria:

- Studies conducted within a community and learning disability setting
- Conference papers, thesis, book-chapters, reviews, protocols, editorials, comments on papers
- Studies investigating service users' experiences and perceptions of support and involvement of their children

The first and the last author independently screened the literature for inclusion. Title and abstract screening was conducted to assess relevance; retained studies were subject to full-text screening for thorough evaluation. Discrepancies arising during the screening process were resolved through discussion.

Of note, studies were included if they explored inpatient experiences, regardless of whether participants were admitted at the time of data collection. Furthermore, studies that included other informants in addition to service users were eligible for inclusion, provided that service users' experiences were reported separately.

Quality assessment

The included studies were systematically assessed for quality and bias using the JBI checklist for qualitative research for the qualitative studies (Lockwood et al., 2015) and the Quantitative Descriptive Checklist in the Mixed Methods Appraisal Tool for the survey studies (Hong et al., 2018). The first author initially conducted the quality assessment of the studies, which was subsequently critically reviewed by the last author. In cases of disagreement, the two authors discussed the evaluations to reach consensus.

Data extraction

Data from the included studies were extracted using the Matrix Method (Garrard, 2017). General information, i.e., author and year of publication; study methods, i.e., design, sample and demographical information (gender/age); and study context, i.e., clinical mental health care setting and country.

The first author initially performed data extraction, which was subsequently critically reviewed by the last author. In cases of disagreement, consensus was reached through discussion.

Synthesis methodology

The results from the studies were categorised and analysed using a thematic synthesis described by Thomas and Harden (2008) and guided by the following two analytical questions: (I) what characterises service users' experiences and perceptions of carer support? and (II) what characterises service users' experiences and perceptions of carer involvement in care and treatment? Firstly, the results from each included study were subjected to line-by-line coding by the first author, incorporating both the study authors' interpretations and quotations, ensuring that each text paragraph was assigned at least one code. Simultaneously, a list of codes was created inductively and their respective definitions was developed. Secondly, the codes and attached text paragraphs were categorised, and themes evolved that reflect results across the included studies. Thirdly, all authors iteratively reviewed and critically discussed these themes, exploring relationships between them and 'going beyond' the initial findings to generate an analytical level, reflecting a more interpretative and advanced understanding.

Results

Study inclusion

From the searches conducted on September 9, 2023, 2,378 studies were initially identified across the four databases (see PRISMA flow diagram in Figure 1). Following the removal of duplicates, 1,636 studies were screened for eligibility based on title/abstract using the screening tool Covidence. Of the 96 studies that were subjected to full-text review, 85 studies were excluded. Reasons for exclusion at full-text screening for each study are elaborated in the supplementary material page 7-10. Furthermore, as shown in Figure 1, 1,333 studies were identified through other methods (citation searches, alternative searches and grey literature searches), of which one study was included. An updated search conducted on January 3, 2025, identified two additional studies, resulting in a final sample of 14 included studies.

[Insert Figure 1]

Evaluation of study quality

Table 2 presents the results of the quality appraisal. Generally, the methodological quality of the studies was rated as medium or above, except for two studies (Giacco et al., 2017; Lakeman, 2008) where many methodological issues were identified. The most frequent methodological weaknesses in the qualitative studies included uncertainty regarding the congruity between the authors stated philosophical perspective and the research methodology (item 1), the absence of statements disclosing the authors' cultural or theoretical beliefs and values (item 6) and unclear descriptions of how the authors may have influenced the research process (item 7). In the survey studies, the most frequent methodological weakness was related to item Q4.3, which considers the appropriateness of the measurements.

No studies were excluded based on the quality appraisal.

Insert table 2

Characteristics of included studies

The 14 included studies were published between 2008 and 2024. The studies were conducted in the United Kingdom (Day & Petalas, 2020; Dirik et al., 2020; Giacco et al., 2017; Giacco et al., 2018), Ireland (Walsh & Boyle, 2009), Germany (Schuster et al., 2021; Schuster et al., 2020), Australia (Cameron et al., 2024; Hyde et al., 2015; Isobel, 2019; Lakeman, 2008), China (Huang et al., 2020), India (Mahomed et al., 2019) and South Africa (Shimange & Shilubane, 2023). These studies included findings from 632 service user participants (two studies, based on the same sample, are only counted once) (Dirik et al., 2020; Giacco et al., 2017). Most studies had a relatively balanced distribution between genders; however, in four studies, gender was not reported (Hyde et al., 2015; Isobel, 2019; Lakeman, 2008; Walsh & Boyle, 2009). Regarding the specific care setting, one study was conducted in private rehabilitation (Day & Petalas, 2020), one in specialized mental health establishments or psychiatric hospitals (Shimange & Shilubane, 2023) and three in acute mental health settings (Isobel, 2019; Schuster et al., 2020; Walsh & Boyle, 2009), whilst the remaining eight studies related to inpatient settings not further defined. The majority of the studies reported interview-derived data (individual and focus groups), while three studies used surveys with open-ended questions included (Lakeman, 2008; Schuster et al., 2021; Schuster et al., 2020). A detailed overview of the study characteristics is displayed in Table 3.

Insert Table 3

Results

Analysis of the included studies revealed five themes: Theme one, *eagerness versus hesitations towards involvement of carers in care planning, care and treatment;* Theme two, *the significance of receiving support from carers in coping with mental* *illness; and Theme three, the necessity of supporting carers – recognising needs and burdens*. As shown in figure 2, Themes one, two and three are linked with Theme four: *institutional barriers.* Furthermore, these four themes are interrelated with an overarching theme five: *relationship between service users and carers*, representing a higher level of analytical abstraction. All five themes are elaborated below.

[Insert Figure 2]

Theme one: Eagerness versus hesitations towards involvement of carers in care planning, care and treatment

Service users often expressed an eagerness to engage their carers in assessment, care planning, and shared decision-making during hospitalisation. Service users believed that carers should be recognised as valuable resources, providing unique insights into the service users current mental state. Additionally, they considered carers to play a crucial role in supporting symptom monitoring and ensuring treatment adherence following discharge from hospital (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Schuster et al., 2021; Shimange & Shilubane, 2023).

However, some service users were more reluctant to engage their carers or completely avoided carer involvement both of which were linked to the nature of their relationship with their carers (Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Lakeman, 2008). Notably, in some studies, service users choose not to engage their carers, despite close relationships, as they considered that their carers were already overburdened by the service users' mental illness, or were mentally or physically unwell themselves, and service users wanted to avoid adding further distress or worry (Cameron et al., 2024; Giacco et al., 2017; Giacco et al., 2018; Lakeman, 2008; Schuster et al., 2020).

From the perspective of service users, carers' understanding of mental illness is a key prerequisite for their involvement and participation in care planning, care and treatment. Therefore, service users believed that healthcare professionals should provide information and education about mental illness to carers (Cameron et al., 2024; Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Lakeman, 2008; Walsh & Boyle, 2009). Furthermore, when carers lack this understanding, it can negatively impact the relationship between the service user and the carer, e.g., by conveying a lack of trust or by placing pressure on the service user for progress (Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Lakeman, 2008). Finally, service users described how carers being overinvolved could exacerbate distress in the service user (Dirik et al., 2020) and impede the recovery process (Cameron et al., 2024; Huang et al., 2020; Schuster et al., 2021; Shimange & Shilubane, 2023). In such cases, service users appreciated being 'protected' from carer over-involvement by healthcare professionals, such as through excluding the carer from participating in (Dirik et al., 2020; Huang et al., 2020; Schuster et al., 2020).

Service users emphasised that they should ultimately decide upon the level of carer involvement and information sharing. However, they acknowledged that their ability to provide consent for their carers' involvement may be influenced by their mental capacity and symptoms (Cameron et al., 2024; Dirik et al., 2020; Giacco et al., 2017).

Theme two: The significance of receiving support from carers in coping with mental illness

In most of the included studies, the significance of carers' support during hospitalisation was emphasised and a deep sense of appreciation was expressed. Overall, maintaining a connection with carers throughout hospitalisation was considered to provide stability and encouragement during the recovery process (Day & Petalas, 2020; Giacco et al., 2018; Huang et al., 2020; Hyde et al., 2015; Lakeman, 2008; Mahomed et al., 2019; Shimange & Shilubane, 2023).

From the service users' perspective, support from carers could take various forms; however, emotional support was predominantly emphasised. Emotional support was characterised by carers' love and concern for the well-being of the service user, and expressed through encouragement to 'get better' and by adopting a compassionate and non-judgmental attitude (Day & Petalas, 2020; Dirik et al., 2020; Huang et al., 2020; Hyde et al., 2015; Lakeman, 2008; Mahomed et al., 2019; Schuster et al., 2021). Overall, emotional support from carers was considered crucial in coping with mental illness and as a significant motivating factor throughout the recovery process (Day & Petalas, 2020; Dirik et al., 2020; Hyde et al., 2015; Lakeman, 2008; Mahomed et al., 2019). Furthermore, emotional support could also support service users to abstain from substance abuse (Day & Petalas, 2020) and serve as a protective factor in preventing suicide attempts (Day & Petalas, 2020; Hyde et al., 2015).

From the perspective of the service users, carers' understanding and acceptance of the service users' mental health condition are essential prerequisites for carers to adopt a supportive role. Consequently, information provided to carers by healthcare professionals about mental illness was perceived as a key facilitating factor in enabling carers to adapt and fulfil this role (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Huang et al., 2020; Hyde et al., 2015; Lakeman, 2008; Mahomed et al., 2019). Such information was also seen to help prevent damage or strain on the relationships between service user and their carers (Giacco et al., 2017; Mahomed et al., 2019; Walsh & Boyle, 2009).

Alongside emotional support, carers could also play a role in supporting the service user's decision-making. For example, they could help the service user express their treatment preferences, thereby promoting shared decision-making (Dirik et al., 2020; Giacco et al., 2018; Huang et al., 2020). Furthermore, in the studies by Hyde et al. (2015) and Cameron et al. (2024), service users emphasised the importance of receiving support when deciding to be admitted to an inpatient facility, particularly as a means to prevent a suicide attempt. Finally, practical support from carers during hospitalisation (Cameron et al., 2024; Lakeman, 2008), and financial support were mentioned (Cameron et al., 2024). However, service users in two studies expressed a desire for self-sufficiency, viewing it as a means to promote recovery while also avoiding financial burdens on carers (Huang et al., 2020; Mahomed et al., 2019).

Theme three: The necessity of supporting carers - recognising needs and burdens

Service users acknowledged that their mental health could place severe burdens on carers and impact their everyday lives. Carers' burdens were primarily described in terms of emotional strains such as stress, frustrations, concerns and experiences of stigmatisation from the community (Cameron et al., 2024; Dirik et al., 2020; Giacco et al., 2017; Giacco et al., 2018; Huang et al., 2020; Mahomed et al., 2019). Additionally, physical consequences were noted (Giacco et al., 2017; Hyde et al., 2015). Service users described that hospitalisation adds further strain and burdens on carers (Giacco et al., 2018), often leading to feelings of guilt stemming from the perception that they are unable to manage their relatives' mental health difficulties on their own (Huang et al., 2020). In one study by Dirik et al. (2020), service users' hospitalisation was described as traumatising for relatives.

Concerned about the well-being of their carers, service users requested that emotional support be provided by healthcare professionals and carer organisations to help alleviate their carers' burdens (Dirik et al., 2020; Giacco et al., 2017; Hyde et al., 2015; Mahomed et al., 2019) and to promote hope and optimism (Hyde et al., 2015). Conversations with healthcare professionals, support groups for carers, and support for the whole family, such as family therapy to improve functioning, were mentioned across studies as potential ways to provide this necessary support (Giacco et al., 2017; Lakeman, 2008). Finally, information on mental illness, psychotropic medication, and adverse side effects was emphasised to alleviate carers' burdens and concerns (Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Mahomed et al., 2019).

Theme four: Institutional barriers

As shown in Figure 2, Themes one, two and three presented above are linked through several '*institutional barriers*', which constitute Theme four.

The analysis revealed a significant institutional barrier in healthcare professionals refraining from engaging with carers. Service users mainly attributed this to healthcare professionals' lack of competencies in managing a trialogue involving the service user, carer and healthcare professional, as well as capacity constraints and the absence of consistent, structured approaches to carer engagement (Giacco et al., 2017; Giacco et al., 2018; Huang et al., 2020; Hyde et al., 2015; Lakeman, 2008; Schuster et al., 2020; Walsh & Boyle, 2009). Barriers related to culture and language in communicating with or engaging carers were also highlighted (Cameron et al., 2024; Giacco et al., 2017; Lakeman, 2008). Additionally, service users reported that hospital routines were inflexible, and carers' working hours often made it difficult for them to attend care planning discussions during ward rounds or care team meetings (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Giacco et al., 2017; Giacco et al., 2018; Lakeman, 2008). Consequently, carers lacked crucial information such as details about progress in the service users' expected trajectory and care plans, etc., which could limit their ability to be effectively involved and to make informed decisions (Dirik et al., 2020; Giacco et al., 2017; Hyde et al., 2015; Isobel, 2019; Lakeman, 2008; Schuster et al., 2020; Walsh & Boyle, 2009).

Another barrier reported by the service users was that some carers found the hospital environment frightening and unwelcoming due to the locked doors and limited visiting hours, whilst the geographic distance between carers' homes and the hospital was identified as a further challenge. Together, these barriers limited carers' contact with the service users and hindered their ability to provide support during hospitalisation and throughout the recovery process. Moreover, they also limited opportunities for carer support and information to help alleviate their burdens and concerns (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Lakeman, 2008; Mahomed et al., 2019).

Theme five: Relationship between service user and carers

Derived from the four themes presented above and supported by lines of argument from the included studies, an overall interpretive analysis identified an overarching theme: *relationship between service user and carer* (see figure 2).

This theme revealed that the meaning service users ascribe to carer support and involvement is closely linked to the significance and quality of their relationship with their carers (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Lakeman, 2008; Schuster et al., 2021; Shimange & Shilubane, 2023). Close relationships between service users and carers were associated with the perception that carers should be recognised as valuable resources in care planning, care and treatment. Furthermore, service users with close relationships viewed carers as offering significant support throughout their recovery process and expressed a need for support to be provided to carers to help them manage their burdens and concerns. Conversely, service users who lacked contact with, or had strained relationships with carers were more reluctant to engage them in care planning, care and treatment and did not emphasise the importance of support from or to their carers. The overall interpretive analysis further revealed that the service user-carer relationship quality is itself influenced by the carers' knowledge of mental illness and their understanding of the difficulties such experiences create for the service users in their daily lives (Cameron et al., 2024; Day & Petalas, 2020; Dirik et al., 2020; Giacco et al., 2017; Huang et al., 2020; Hyde et al., 2015; Lakeman, 2008; Mahomed et al., 2019; Schuster et al., 2021; Shimange & Shilubane, 2023; Walsh & Boyle, 2009).

Discussion

This qualitative evidence synthesis explored experiences and perceptions of service users regarding carer support and involvement in care and treatment in adult mental health inpatient settings. Based on a thematic synthesis of 14 studies, we found that service users held positive, though sometimes mixed, feelings towards involving carers in care planning, care and treatment, whilst highlighting the potential importance of carers' support on their coping with mental illness. The synthesis further highlighted the need to provide support to carers to address their own needs and alleviate their burdens.

Perceptions of whether carer involvement and support were meaningful and desirable were closely linked to the significance and quality of their relationship with their carers. This relationship was, in turn, shaped and informed by the carers' knowledge and understanding of mental illness. This clear connection was not found in the results of a systematic review (Cameron et al., 2023), which shares the same focal point as this present one. Thus, the findings of our study add significantly to existing research. It is important to note that service users' views on carer involvement and support may be fluid, changing over time or depending on circumstances such as the nature of the relationship with the carer (e.g., parent, sibling, friend), the service user's current mental state, age, or other relevant factors. However, based on the relatively limited evidence from 14 studies, no clear patterns or trends could be identified.

In light of the above, the results underscore the importance of healthcare professionals meaningfully engaging with carers, as well as the need for psycho-educational support and interventions. Qualitative studies exploring carers' perspectives similarly emphasize the value of providing them with knowledge and understanding of mental illness (Cleary et al., 2020; Maybery et al., 2021). Although psychoeducational interventions are delivered in various forms in clinical mental health settings, they are well-established and supported by strong evidence of effectiveness (Ewertzon & Hanson, 2019; McFarlane et al., 2003). Related to the results of our synthesis, service users perceived information on mental illness as an important factor in helping carers adopt a supportive and non-stigmatising attitude. This, in turn, enhances the service users' well-being and recovery process, while also fostering and maintaining meaningful relationships between service users and carers.

The value of psycho-educational interventions has also been shown to reduce caregiver burden (Ewertzon & Hanson, 2019; McFarlane et al., 2003). Caregiver burden is a well-documented multidimensional response associated with caring for individuals with mental illness (Gunawan et al., 2023). Some service users in the included studies expressed concern for their carers' well-being, leading them to withhold consent for carer involvement during hospitalisation to prevent overburdening them. Therefore, alongside the need for increased knowledge about mental illness, the results of this synthesis highlight the need for emotional support for carers. Studies show that caregiver burdens can be mitigated if carers receive proper support, enabling them to stay involved in the service users' care and provide the emotional support that they requests (Bademli & Duman, 2014; Ewertzon & Hanson, 2019; van Es et al., 2023). In mental health inpatient settings, emotional support to carers is typically performed through conversations with the healthcare professionals or support groups arranged by the hospital (Bademli & Duman, 2014; Ewertzon & Hanson, 2019; Rowaert et al., 2018). With reference to capacity constraints identified as an institutional barrier in the results of this present review, a study found that even a brief therapeutic conversation intervention can lead family members to perceive cognitive and emotional support (Sveinbjarnardottir et al., 2013). Moreover, in recent years, there has been an increased focus on the value of support from a family peer worker (Shalaby & Agyapong, 2020). Despite these examples, evidence shows that supportive practices for carers are still not 'standard care' (Cleary et al., 2020; Maybery et al., 2021; Vestphal et al., 2023).

Based on the findings of our synthesis and others (Cameron et al., 2023), the involvement of carers in assessment, care planning, and shared decision-making during hospitalisation is also not considered “standard care”. Several institutional barriers to this ‘triadic collaboration’ as well as supportive practices were identified, including inflexible hospital routines, absence of consistent, structured approaches to carer engagement and lack of competencies among healthcare professionals in working with families. These barriers largely echo other studies (Landeweer et al., 2017), concluding that a range of obstacles to supportive and involving practices, along with poor implementation, hinder success (Dirik et al., 2020). Although steps to a more family-oriented approach in mental health settings have been taken across mental health settings (see Rowaert et al. (2025) for an example within forensic mental health care in Belgium), family engagement requires a shift in culture in clinical settings (De Corte et al., 2023).

The findings of this synthesis also highlight the importance of connectedness between service user and their carers during hospitalisation. This was seen as offering stability and encouragement throughout the recovery process. However, the hospital environment in itself and the hospital procedures were identified as institutional barriers that prevent carers from providing the emotional support needed.

Limitations

The following limitations of this qualitative evidence synthesis must be considered. First, the search strategy only identified studies from 2008 onward, with none found in the first eight years of the search period. Second, only studies written in English were included. Third, some studies did not primarily focus on this review's aim, limiting the available data for synthesis. Fourth, the included studies were conducted in various countries. While this diversity can be seen as a strength, as it allows the results to reflect service users' perspectives across borders, it may conversely challenge the transferability of the findings. Different cultural norms, values and perceptions of mental illness are likely also to impact service users' perspectives regarding carer support and involvement (Bhugra et al., 2021)

Relevance to clinical practice

The findings of this qualitative evidence synthesis underscore the importance of healthcare professionals meaningfully engaging with carers and highlight the importance of fostering family engagement, particularly through psychoeducation and support for carers. Strengthening the connectedness between service users and their carers during hospitalisation, alongside promoting awareness of the importance of carers' knowledge of mental illness, plays a vital role in sustaining supportive relationships. Healthcare professionals must recognise their role in addressing carers' needs, challenge institutional barriers, and advocate for family-friendly routines. Ongoing education is essential to strengthen competencies in supporting carers and facilitating triadic collaboration. Such efforts are critical, as carer involvement is consistently associated with improved treatment outcomes for the service user.

Conclusions

Service users generally expressed positive, though sometimes mixed, feelings about involving carers in care planning, care and treatment while emphasising the value of carer support in coping with mental illness. The perceived meaningfulness of such involvement was closely tied to the quality of the relationship between service users and carers, shaped by carers' knowledge and understanding of mental illness.

This qualitative evidence synthesis highlights the need for additional evidence on service users’ experiences and perspectives regarding carer support and involvement across diverse mental health care settings. Eight of the included studies did not specify the type of inpatient unit (e.g., forensic, geriatric, addiction), limiting the contextual understanding. In addition to context-specific research, further studies should aim to develop knowledge on how service users’ views on the desirability of carers’ involvement in care and treatment may fluctuate over time or vary according to specific circumstances. Such knowledge would be highly valuable to guide the adaptation of interventions such as psychoeducation and supportive practices to the needs of both service users and carers and to the feasibility of specific care environments.

Supplementary material

Overview of systematic searches in bibliographic databases, supplementary searches, and searches for grey literature. Overview of studies excluded at the full-text screening stage.

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Table 1. Definition of PICo elements

P = Population: ***Service users***	Service users is a general term used to describe individuals who utilise health and/or social care services provided by service providers. In mental health care, service users may also be referred to as clients, consumers, patients, and other similar terms.
I = Phenomenon of Interest: ***Carer involvement and support***	The concepts of support and involvement of carers in mental health care are often used interchangeably alongside other concepts like information, participation, partnership, cooperation, engagement and others. Consequently, there is no clear distinction between what constitutes supportive practices and involving practices, respectively. However, support for the service users carers typically refers to ways in which healthcare professionals support carers in their role and in relation to their own perceived burdens, whereas involvement of carers typically refers to ways in which carers are engaged as a resource in the service users care and treatment process, e.g., participation in shared decision-making.
Co = Context: ***Mental health inpatient settings***	Adult (typically 18 - 65 years) mental health inpatient services include acute and long-stay services, intensive psychiatric care units and forensic units (with different levels of security). These facilities can be privately owned or public (government-operated).

PICo = Population, phenomenon of Interest and Context

Table. 2. Critical appraisal of included studies

JBI Qualitative checklist	**Q1**	**Q2**	**Q3**	**Q4**	**Q5**	**Q6**	**Q7**	**Q8**	**Q9**	**Q10**
Cameron et al. 2024	U	U	U	U	U	U	U	Y	Y	Y
Day & Petalas 2020	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Dirik et al. 2020	U	Y	Y	Y	Y	N	Y	Y	Y	Y
Giacco et al. 2017	U	U	U	U	U	N	Y	Y	Y	Y
Giacco et al. 2018	U	Y	Y	Y	Y	Y	Y	Y	Y	U
Huang et al. 2020	U	Y	Y	Y	Y	Y	N	Y	Y	Y
Hyde, Bowles and Pawar 2015	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Isobel 2019	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Shimange & Shilubane 2023	Y	Y	Y	Y	Y	N	U	Y	Y	Y
Mahomed et al. 2019	U	Y	Y	Y	Y	N	U	Y	Y	Y
Walsh & Boyle 2009	U	Y	Y	Y	Y	Y	N	Y	Y	N
MMAT 4. Quantitative	**S1**	**S2**	**Q4.1**	**Q4.2**	**Q4.3**	**Q4.4**	**Q4.5**			

descriptive checklist										
Lakeman 2008	Y	Y	Y	C/T	C/T	C/T	Y			
Schuster et al. 2020	Y	Y	Y	Y	C/T	Y	Y			
Schuster et al. 2021	Y	Y	Y	Y	C/T	Y	Y			

Y= Yes. N= No. U= Unclear. C/T= Can’t tell

The 10 questions in the JBI Qualitative checklist:
Q1: Is there congruity between the stated philosophical perspective and the research methodology?
Q2: Is there congruity between the research methodology and the research question or objectives?
Q3: Is there congruity between the research methodology and the methods used to collect data?
Q4: Is there congruity between the research methodology and the representation and analysis of data?
Q5: Is there congruity between the research methodology and the interpretation of results?
Q6: Is there a statement locating the researcher culturally or theoretically?
Q7: Is the influence of the researcher on the research and vice-versa addressed?
Q8: Are the participants and their voices represented?
Q9: Is the research ethical according to current criteria for recent studies and is there evidence of approval by an appropriate body?
Q10: Do the conclusions drawn in the research report flow form the analysis or interpretation of the data?

The 7 questions in the MMAT 4. Quantitative descriptive checklist:
S1: Are there clear research questions?
S2: Do the collected data allow to address the research questions?
Q4.1: Is the sampling strategy relevant to address the research question?
Q4.2: Is the sample representative of the target population?
Q4.3: Are the measurements appropriate?
Q4.4: Is the risk of nonresponse bias low?
Q4.5: Is the statistical analysis appropriate to answer the research question?

Table 3. Data extraction

Authors(s)	Year	Aim	Study design	Sample	Demographical information (gender/age)	Care setting	Country
Cameron et al.	2024	To increase current knowledge about service users' opinions and opportunities for family involvement in mental health care.	Semi-structured interviews, thematic analysis	10 service users	80 % female/10 % male/10% transgender male Range: 20-57 years	Inpatient settings	Australia
Day & Petalas	2020	To add to our understanding of service users' views of their sibling relationships and empower people with severe and enduring mental health difficulties by offering them a voice	Semi-structured interviews, interpretative phenomenological analysis	11 service users	100 % Male Range: 18-55 years	Private Mental Health Rehabilitation Hospital	United Kingdom
Dirik et al.	2020	To explore patients', carers' and clinicians' perspectives on the role of carers in	Focus groups, inductive thematic analysis	31 patients (+ 22 carers and 33 clinicians)	48 % female/52 % male Mean: 43 years, SD: 12.3	Inpatient and out-patient mental	United Kingdom

		mental healthcare, particularly with regards to in-patient settings			- not disclosed from eight patients	health services NHS Foundation Trust and local service user and carer organisations	
Giacco et al.	2017	To assess the perspectives of patients, carers and mental health clinicians on how to improve carer involvement in inpatient settings.	Focus group study, thematic analysis	31 patients (+ 22 carers and 33 clinicians)	48 % female/52 % male Mean: 43 years, SD: 12.3 - not disclosed from eight patients	Inpatient wards and community NHS Foundation Trust and local carer or patient support groups	United Kingdom

Giacco et al.	2018	To explore the views of both patients and clinicians on barriers and facilitators to shared decision-making during involuntary hospital treatment	Focus groups and individual interviews, thematic analysis	24 patients - 18 participating in focus groups + 6 participating in individual interviews (+16 staff members)	Focus groups: 56,6 % female/43,4 % male Mean: 38,4 years, SD: 12.3 Individual interviews: 66,7 % female/33,3 male Mean: 37,7 years, SD: 12.6	Hospital and community NHS Foundation Trust	United Kingdom
Huang et al.	2020	To explore the perceptions of shared decision making from the perspective of people diagnosed with schizophrenia in China	Face-to-face and semi-structured interviews, inductive thematic analysis	12 inpatients	41,7 % female/ 58,3 % male Range: 19-49 years, Mean: 31,3, SD: 8.4	Psychiatry department of a tertiary hospital in Changsha, Hunan province.	China

Hyde, Bowles and Pawar	2015	To explore consumers' lived experience of inpatient care, with a special emphasis on implications for social work practice	In-depth semi-structured interviews, hermeneutic phenomenological analysis	8 consumers	N/A	Inpatient rural mental health facility	Au(Lakeman, 2008)(Lakeman, 2008)(Lakeman, 2008)stralia
Isobel	2019	To gather voluntary and involuntary service users' experiences of care during hospitalization in two acute adult mental health inpatient units, through the collaborative completion of a purpose designed tool	Structured interviews, content analysis using mixed inductive–deductive descriptive analytical approach	67 inpatients	N/A	Acute adult mental health inpatient units	Australia
Lakeman	2008	To explore the perceptions of service users and carers to carer participation in adult mental health services	Survey with three open-ended questions, summative	41 inpatient consumers (+ 53 carers to inpatients,	N/A	Hospital and community settings	Australia

			content analysis	86 consumers in community settings and 33 carers to consumers in community settings)			
Mahomed et al.	2019	To examine the experiences of mental health service users relating to stigma and support provided by family members and to consider ways in which family support can be improved	Semi-structured interviews using a protocol with 12 questions, 10 of which were open-ended, thematic content analysis	17 residential in-patient mental health service users	47 % female/53 % male Range: 22-64 years	In-patient mental health hospital	India
Schuster et al.	2020	To describe patterns of caregiver inclusion for a representative sample of	Cross-sectional survey with semi-structured	247 in-patients	56,3 % female/43,7 % male	Acute psychiatric state hospital wards	Germany

		psychiatric inpatients in upper Bavaria	interviews and standardised questionnaires, descriptive statistics and quantitative evaluation		Range: 17-84 years, SD: 15,6, Mean 43,9		
Schuster et al.	2021	To achieve better insight into the current shared decision making patterns of triads of service users, caregivers and clinicians in inpatient mental health care and the three parties' expectations towards the prospects of triadic shared decision making	Cross-sectional study with face-to-face structured interviews using closed, semi-open and open-ended questions, descriptive analysis	94 service users	60.6 % female/39.4 % male Range: 19-84 years, SD 17,0, Mean 43,8	Psychiatric inpatient treatment	Germany

Shimange & Shilubane	2023	To investigate the perspectives of hospitalized mental health care users on the involvement of family members in their care	Individual interviews, descriptive phenomenological analysis	15 mental health care users	40 % female/60 % male Range: 21-70 years, SD: 15,9, Mean 42,9	Specialized mental health establishments or psychiatric hospitals, Limpopo province	South Africa
Walsh & Boyle (2009)	2009	To explore psychiatric inpatients' strategies for coping with mental ill health and in what ways acute inpatient psychiatric hospital services are facilitative to the individual attempting recovery	Focus group interviews, systematic content analysis	55 service users	Gender: N/A Range: 16-68	Acute inpatient settings	Ireland

The content within the parentheses pertains to elements excluded from this review, in accordance with the exclusion criteria outlined.
N/A, not available. SD, standard deviation

Figure 2. Illustration of the five themes and their internal interconnectedness.