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This is the Published version of the following publication

Cameron, Sarah LA, Laletas, Stella, Gallo Cordoba, Beatriz and McLean, Louise (2024) Who Cares? Service Users' Opinions and Opportunities for Family Involvement in Mental Health Care. *International Journal of Mental Health Nursing*, 33 (6). pp. 2203-2214. ISSN 1445-8330

The publisher's official version can be found at
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ORIGINAL ARTICLE OPEN ACCESS

Who Cares? Service Users' Opinions and Opportunities for Family Involvement in Mental Health Care

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ABSTRACT

Involving families in mental health care can provide benefits to service users, their families and clinicians. However, family involvement is neither uniform nor routine. Understanding the complexities of this involvement is critical to improving application. This study sought to increase current knowledge about service users' opinions and opportunities for family involvement in mental health care. Data were collected from a total of 10 adult participants through 10 individual semi-structured interviews of approximately 30 min each. Findings are reported in accordance with COREQ and EQUATOR guidelines. Thematic analysis identified several consistent themes: respect for service user opinions of family involvement; opportunities for family involvement; negative and positive service user opinions of family involvement. Our findings support previous appeals for routine family involvement in care but extend this charge with the assertion that as important is a customary discussion with service users to ask their opinions about this involvement. Establishing this dialogue prior to treatment commencement has the potential to alleviate or resolve service user concerns and potentially improve and/or increase how families are engaged.

1 | Introduction

Involving families in mental health care can provide benefits to service users, (Banerjee et al. 2021; Huang et al. 2020; Waller et al. 2019) families (Ong, Fernandez, and Lim 2021; van Grieken et al. 2014; Weimand et al. 2011) and clinicians (Peters et al. 2011; Wonders, Honey, and Hancock 2019; Wood et al. 2019). These benefits can be short and long-term (Ong, Fernandez, and Lim 2021). Despite this, service user and family involvement are often perceived as separate components of care with little effort to integrate the two (Hamann and Heres 2019). To date, there is substantially greater research pertaining to the viewpoints of families (see systematic review Maybery et al. 2021) and clinicians (Kim and Salyers 2008; Skundberg-Kletthagen et al. 2020; Sunde, Vatne, and Ytnehus 2022) and a gap in the current knowledge of service

users' opinions and opportunities for family involvement in their care.

For the purposes of this study, in referring to *families* we concur with the concept described by Osher and Osher (2002) who assert that a family defines itself and thus is most accurately described by its members. In this paper therefore, references to family are not limited to a family of origin but may include partners, friends or other carers. Involvement is best understood as existing on a 'spectrum' (Eassom et al. 2014, 2) and can refer to aspects of care such as decision-making and/or participation in treatment and care planning (Fisher et al. 2018; Tambuyzer and Van Audenhove 2013), information retention and disclosure (Clements et al. 2019; Waller et al. 2019) emotional support and comfort (Aldersey and Whitley 2015; Giacco et al. 2017; Wells et al. 2018) as well

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as practical aspects of care including symptom monitoring, medication adherence and transport (Hinton et al. 2015; Hyde, Bowles, and Pawar 2015; Milton and Mullan 2015; van Grieken et al. 2014).

A recent large-scale analysis of survey data collected by mental health services in Australia via the *Your Experience of Service* questionnaire (The Secretary to the Department of Health (Vic) 2013; $n = 9147$) indicated the importance of family involvement from the service user perspective. This study reported an association between family involvement and key outcomes related to recovery, in areas including hopefulness, managing day-to-day life, overall well-being and experience of care, reinforcing previous findings in this area (Hamann and Heres 2019). Cameron, Gallo Cordoba, and Maybery (2023, under review) reported that the majority of service users described both a positive experience of care and feeling that they had opportunities for family involvement and that their opinions were usually or always respected, an outcome previously reported in reviews of service users (Cameron, Tchernegovski, and Maybery 2022) and families (Maybery et al. 2021). These findings support previous calls for routine inclusion of families in care (Svensen et al. 2021); however, there are varied opinions among service users and less information about specific circumstances for the nature of this involvement (Cameron, Gallo Cordoba, and Maybery 2023; Cameron, Tchernegovski, and Maybery 2022; Eassom et al. 2014; Maybery et al. 2021).

Governments worldwide extend support for family involvement in care (e.g., Council of Australian Governments Health Council 2017; Dixon et al. 2010; The Norwegian Directorate of Health. [Helsedirektoratet] 2017). However, despite the extensive literature describing the positive aspects to this involvement and the financial benefits of informal care (Council of Australian Governments Health Council 2017) there are barriers to mental health services routinely engaging families in care (Cameron, Tchernegovski, and Maybery 2022; Cree et al. 2015; Dixon et al. 2001; Foster, O'Brien, and Korhonen 2012; Goodwin and Happell 2006; Kim and Salyers 2008; Lucksted et al. 2012; Maybery et al. 2021; Murray-Swank et al. 2007; Reupert et al. 2018).

Research suggests that service users' opinions may not always be aligned with that of their families (Cohen et al. 2013) or clinicians (Nurjannah et al. 2014). Furthermore, views about involving families can vary within stakeholder groups (Banerjee et al. 2021; Chatzidamianos, Lobban, and Jones 2015; Clements et al. 2019; Giacco et al. 2017; Hinton et al. 2015; Waller et al. 2019) reinforcing the existing knowledge that a standard approach cannot meet the needs of all service users (Waller et al. 2019). A more precise understanding of service users' opinions and preferences for family involvement is necessary for better service and create more positive experiences for all stakeholders (Cameron, Tchernegovski, and Maybery 2022).

Multiple barriers to family engagement and varied views among service users were identified in a recent review of qualitative literature (Cameron, Tchernegovski, and Maybery 2022). One of four primary themes that emerged was that family involvement can be positive and negative. Service users describe feeling appreciative of the role families played

in sharing information with practitioners (Wonders, Honey, and Hancock 2019) and acknowledge their part in recovery (Aldersey and Whitley 2015) however also cite feeling excluded (Banerjee et al. 2021) and sidelined in decision-making regarding hospitalisation (Huang et al. 2020). Barriers to including families in treatment and care range from negative attitudes and/or relationships (Hinton et al. 2015) and fears relating to burden or stigma (Chatzidamianos, Lobban, and Jones 2015; Wonders, Honey, and Hancock 2019) as well as more practical obstacles such as family work commitments and other responsibilities (Giacco et al. 2017). Quantitative research also reports heterogeneity among service users' opinions about involving family in mental health care (Batten et al. 2009; Bolkan et al. 2013; Hershenberg et al. 2014; Murray-Swank et al. 2007). Individual studies provide wide-ranging indications of what may impact service users' opinions, including factors such as age (Jones et al. 2021), perceived benefit, preferred mode of involvement, impact on self/family (Cohen et al. 2013), privacy, relationships, time/travel limitations (Cohen et al. 2019) and invitations from professionals (Bolkan et al. 2013).

There is an important and valuable role for families in mental health care and understanding the complexities of this involvement is critical to improving implementation. Distinguishing the differences among stakeholders' viewpoints has been identified as an important juncture from which to extend current knowledge (Landeweer et al. 2017), however less is known about service users' perspectives when compared to families and clinicians. This study aims to add depth to the current knowledge of service users' experiences and further understand these perspectives through semi-structured interviews exploring who, what, when and where this group want their families involved in their care. This study seeks to answer the following research questions:

1. What are mental health service users' opinions about family involvement in their care (and are these opinions respected)?
2. What are mental health service users' experiences of having opportunities for family involvement in their care?

Large-scale quantitative studies have provided valuable data supporting the important role of families in mental health care and links with positive outcomes (Cameron, Gallo Cordoba, and Maybery 2023). Qualitative research often looks to explore the *why* of observed patterns (Busetto, Wick, and Gumbinger 2020) and was chosen for this study to investigate service users' perspectives of family involvement in their care in greater detail.

2 | Methods

2.1 | Design

The semi-structured interview model utilised in this study both encourages participant dialogue and provides sufficient consistency to enable comparison between individual experiences (Williams et al. 2023). Drawing on data from interviews allows a richer understanding of individual viewpoints, as

well as the opportunity to explore developing themes within a cohort. This approach allowed the researchers to investigate previously identified touchpoints for mental health service users as well as offering flexibility and a springboard for new perspectives to emerge. Findings are reported in accordance with COREQ and EQUATOR guidelines (Tong, Sainsbury, and Craig 2007).

2.2 | Recruitment

Participants were recruited via social media platforms (e.g., Facebook and Instagram), posters displayed in public and community spaces (e.g., universities, libraries, recreation centres) and through *snowballing* by *word-of-mouth*. Effort was made to include disparate settings in varying geographical locations to encourage participation from a diverse population. Inclusion criteria for participants comprised being aged over-18 years and a current or previous mental health service user in Australia. To assess their interest and eligibility potential participants were provided with an expression of interest form, explanatory statement and informed consent form, as well as the Kessler Psychological Distress Scale (Kessler et al., 2002) to determine their emotional capacity to be part of the study. None of the eligible, invited participants declined to participate. Participants were awarded a \$50 supermarket voucher as compensation for their time.

2.3 | Data Collection

Data were collected from a total of 10 participants through 10 individual interviews of approximately 30 min each. Data saturation was achieved prior to full analysis and transcripts were returned to participants for comment. No changes or corrections to the transcripts were requested. See Table 1 for participant demographics.

Interviews were conducted in September 2023 by the lead author, a psychologist and researcher, via the Zoom platform. Cameras were not switched on for the duration of the interviews to ensure participant comfort and privacy. All sessions were recorded via Zoom to allow accurate transcription and analysis of the data. Interviews were transcribed by a researcher or professional transcription service. All participants were de-identified and assigned pseudonyms to protect their privacy, in keeping with good ethical practice for reporting qualitative data (Blignault and Ritchie 2009). Interview questions were guided by the authors' previous recent research in the area and associated research questions as well as a review of the relevant literature.

2.4 | Data Analysis

Interview data were analysed in accordance with the thematic analysis framework described by Braun and Clarke (2006), a common method for illustrating participants' lived experiences (Braun et al. 2019). Analysis commenced with thorough familiarisation with the data through review of the transcribed interviews. Two researchers reviewed and discussed transcript data to identify initial codes which were then assigned to

initial coding groups. These groups were then further reviewed to articulate patterns and then themes relevant to the research questions. These themes were further refined through iterative discussions and consultation among the researchers until final agreement was reached. Where relevant, themes were organised into sub-themes. To illustrate how themes were devised based upon multiple participant perspectives; participant and number of excerpts assigned are indicated with representative quotes. The data and described coding process are illustrated in Tables 2 and 3 in Appendix S1.

3 | Results

Several consistent themes were identified from coding and categorising of participant data. These were: respect for service user opinions of family involvement; opportunities for family involvement; negative and positive service user opinions of family involvement. The interrelationship of these themes is further illustrated in Figure 1 below.

3.1 | Respect for Service User Opinions of Family Involvement

The majority of participants felt that their opinions regarding family involvement were respected. For example:

In the psychology and the psychiatry ... they said whatever makes you feel comfortable (regarding family involvement)

(Charlotte)

In some cases, opinions were considered, if not followed, and in others participants conceded that they might at times be too unwell to give their opinions or know what is in their best interests. Service users might also misunderstand what their family's involvement might mean:

Yeah I'm laughing because at the time I thought she'd take me home; I kept trying to get her to take me home... in my state of un-wellness I was convinced that if I said the right things to her she might take me home again

(Elizabeth)

Other service users felt that their opinions were not always respected and that clinicians prioritised the family's opinion over the service user's which could have a negative and lasting impact on relationships. Several participants referred to mental health care during their adolescence and acknowledged that family involvement might have been necessary due to age. Despite this, they felt the family presence had an impact on treatment and more consideration for their opinions was warranted:

I think overall that was a negative experience... I felt like the sessions weren't productive because... I didn't feel comfortable saying a lot of things in front of my mum

(Anne)

TABLE 1 | Participant demographics.

| Participant ID | Pseudonym | Gender | Age | Diagnosis ^a | Admission type ^b | Involved family member |
|----------------|-----------|------------------|-----|--|-----------------------------|----------------------------|
| P1 | Charlotte | Female | 22 | ADHD ARFID Anxiety | Voluntary | Partner Mother |
| P2 | Georgiana | Female | 57 | Psychosis Postnatal depression Anorexia nervosa Bulimia PTSD | Involuntary | Mother Father Sister |
| P3 | Elizabeth | Female | 40 | Anorexia nervosa PTSD | Voluntary Involuntary | Mother |
| P4 | Anne | Female | 21 | Anorexia nervosa Depression | Voluntary Involuntary | Mother |
| P5 | Harriet | Female | 48 | None | Voluntary | None |
| P6 | Mary | Female | 31 | None | Voluntary | None |
| P7 | Jane | Female | 24 | Anxiety Depression | Voluntary | Mother |
| P8 | Lydia | Female | 52 | Anxiety PTSD | Voluntary | None |
| P9 | Charles | Transgender male | 20 | ADHD Anxiety | Voluntary | Mother |
| P10 | Darcy | Male | 38 | Clinical depression Anxiety disorder Bipolar disorder | Voluntary | Partner |

^aAbbreviations: ADHD, attention-deficit hyperactivity disorder; ARFID, avoidant restrictive food intake disorder; PTSD, post-traumatic stress disorder.

^bParticipants admitted in more than one capacity are noted multiple times, that is once for each type of admission.

3.2 | Opportunities for Family Involvement

Service users described varied opportunities for family involvement with many influencing factors.

3.2.1 | Who?

Participants described opportunities for family involvement that were impacted by the choice or availability of a family member. Service users reported a desire for autonomy in choosing who would be involved in their care, for example:

■ I wanted my mum involved, but not my dad
(Elizabeth)

Similarly, some participants acknowledged that although there were opportunities for family involvement, this was not necessarily their preference or conducive to a positive outcome:

■ Sometimes the family members are not the best people to look after another member... (a) carer... a friend or someone from the community ... might be a bit more beneficial, better... with the family

■ members, we're involved with so much emotion and distress

(Harriet)

Service staff also played a role in creating opportunities for family involvement.

Some, but not all clinicians invited family involvement, with those in a sessional setting, for example private psychology practice, more commonly making the suggestion than in a hospital environment:

■ My psychologist she's like, you can bring a dog I if you want, you can bring anybody in if you want... anything that makes you more comfortable

(Charlotte)

3.2.2 | What?

Opportunities for family involvement were also influenced by the type of care the service user was engaged with (e.g., assessment, intervention or counselling). For example, Charlotte commented that she did not see an opportunity for her mother to

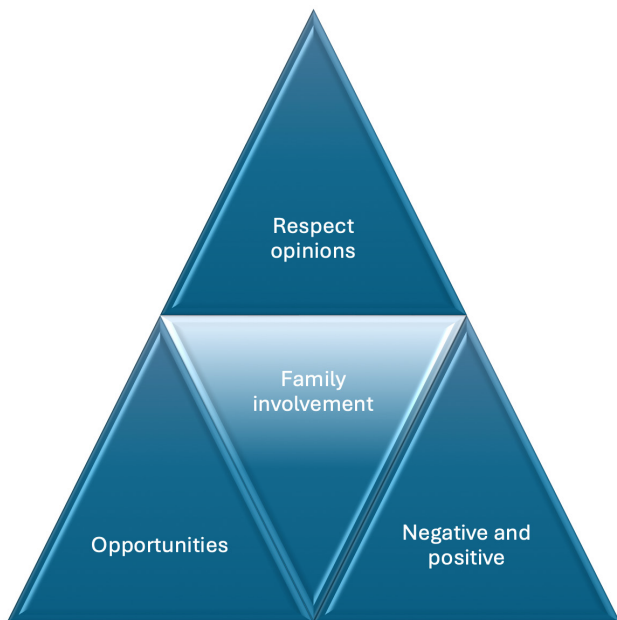


FIGURE 1 | Visual representation of identified themes.

participate in her ongoing treatment with a psychologist, however acknowledged the important contribution the presence of a parent had made during the assessment process:

I did my ADHD assessment ... and I had my mum there for that because that was a good way to have those extra stories and those extra observations from her side... having that external perspective ... really helped
(Charlotte)

Another participant, Charles, saw written communication as an acceptable means of involving his family, for example to email his parents with an overview of his diagnoses and medication ‘because I want them to know what’s going on’ but could not see any benefit to having them present in person. This sentiment was echoed by Mary, who commented that she was happy for her family to be communicated with, but only once her treatment was complete.

Some participants wished for staff to be more proactive and flexible with inviting their family’s involvement, such as options to involve family members via telehealth when they could not visit in person. Where families were involved, opportunities included attending appointments, information-sharing and driving the service user. One participant had not considered opportunities for family involvement in their care at any time (until the point of interview). Another participant wanted mainly financial involvement from his family:

My family involvement has been a very positive experience, mostly because my mum’s paying for my psychology sessions
(Charles)

3.2.3 | When?

Service users’ preferences for family involvement were often dynamic, with multiple participants reporting that their opinions changed due to influences such as the state of their mental health or the stage of treatment. One participant commented:

When treatment got really, really challenging I’d really just want my mum to kind of come in and rescue me. Whereas when I was doing better or I was kind of making good progress I was ... more autonomous
(Elizabeth)

This need for family involvement during crisis was endorsed by other participants, for example when a community treatment order was in place or when the user was unable to care for themselves:

I’ve discussed with my psychologist... (if I am suicidal) they would be able to breach confidentiality for that purpose... to call in my partner to have an appointment with me instead of just like calling the cops or whatever... to reach out to people in my life
(Charles)

Families were also described as a necessary presence during admission and/or discharge, at times on the advice of clinicians:

I was seeing a psychologist beforehand and she recommended that my mum take me to emergency at (hospital) to be admitted as an inpatient. So my mum was with me during admission
(Anne)

3.2.4 | Where?

Service users reported that the setting could influence opportunities and preference for involvement. For example, one service user did not want their family involved when an inpatient in hospital, however, was more open to involvement as an outpatient. Another felt that her sessional appointments were less conducive to family involvement:

That (private setting) is more of a private thing for me ... but I have never really wanted my family involved in those sorts of things ... I don’t really tell my family exactly how I’m feeling... it’s a bit more of private thing for me and the psychiatrist
(Charlotte)

Multiple service users acknowledged that, in the hospital setting, they might not be consulted about family involvement due to their mental health:

At that time I really didn't have any choice in the matter (about having family involved)

(Elizabeth)

Some participants reported there were no opportunities for family involvement and wished for more opportunities in areas including improved advocacy and involving younger family members, for example psychoeducation for their children. Others reported that there were opportunities, but the service users did not want their family involved. Extraneous factors such as the COVID-19 pandemic and the resulting impact on hospital visitation also affected opportunities for family involvement for one participant.

3.3 | Service Users Have Positive Opinions of Family Involvement

The majority of participants described a positive experience of family involvement.

A next of kin... they can play a valuable part in the process of helping the person get well again

(Elizabeth)

Psychoeducation, information-sharing (providing and receiving), medication advice and/or support were listed as valuable areas for involvement. One participant thought it was beneficial for clinicians to observe relationship dynamics and that this could in turn aid treatment. Another participant believed the lack of family involvement in their care was an important factor in a positive experience of care. In other cases, family members were described as an important part of the recovery process.

I wanted them (family) to be part of the healing journey

(Jane)

These benefits could also extend to the family themselves, to enhance their understanding:

I want her (wife) to get involved so that she can get to learn from my experience that I'm passing through

(Darcy)

3.3.1 | Facilitators

Service users had strong ideas about what did or could have facilitated a positive experience of family involvement. Almost half of the participants credited staff invitation and encouragement of including families as important. Trust between the clinician and service user was also cited as a vital aid to this involvement.

The counsellor's ability to always encourage the parents to be there and them being there for me (facilitated family involvement)

(Jane)

Other facilitators were more unique to participants' individual experience. For example, one service user's parent was an allied health professional and her 'health literacy' was viewed as a useful component of her involvement in her family member's care. Other facilitators were more practical in nature such as having family members provide transport to appointments or where appointment times were convenient for all those attending. One participant believed that a strong family relationship could positively influence their service outcome.

3.4 | Service Users Have Negative Opinions of Family Involvement

Although most participants described positive aspects of family involvement, others cited examples where this involvement was negative, and in some cases participants believed there were both positive and negative aspects to family involvement. Negative experiences related to feeling family members were judgemental, lacking objectivity, impeding recovery and given too much power, for example through impacting the direction of treatment. Service users felt family relationships could be harmed through this involvement.

At times I think my mum's involvement in treatment and care has made things harder for my recovery... which just really later on strained the relationship even further

(Elizabeth)

Some participants wanted less family involvement, whereas others believe greater family involvement would have improved their experience.

I tried to involve my ex-husband... but he was not really interested in being with me on this journey

(Harriet)

3.4.1 | Barriers

Participants were quick to describe a range of barriers that contributed to a negative experience of family involvement in care. Privacy was a common concern, either that family members would be in receipt of private information about the service user or that their presence had the potential to limit the service user's willingness to be open and transparent with the clinician which could hinder treatment.

I would limit the information (if family were involved)... I just want ... the information only (to) be shared between me and the psychologist

(Mary)

In several cases, this was considered a *double-edged sword* whereby service users recognised the valuable contribution their family members could make but this could compromise the important confidentiality of their treatment.

Many participants' benevolence to their families created a barrier to involvement, whereby concerns for their welfare or the risk of burdening family members was a deterrent. Others were cognisant of judgement and the stigma associated with mental health difficulties, particularly in certain cultures, and the risk of embarrassment if families were aware of their problems. Two participants expressed themselves as follows:

I was a bit embarrassed ... because the way they (staff) treated you ... it doesn't make you feel human ... I didn't really want my family or friends to see me like that

(Anne)

The stigma from my family here in Australia, my in-laws, feeling that we can't talk about mental issues

(Harriet)

Culture could also present a more tangible barrier where families spoke a language other than English and translation services were not offered, or where families were located in another country. In other cases, either the family member was unwilling or unable to be involved due to mental health concerns or other reasons. One participant commented that the mode of treatment could discourage family involvement, for example when engaged with a text-based service. Another service user was concerned their family member might monopolise the session and detract from her opportunity to use the time productively.

4 | Discussion

This study sought to understand mental health service users' opinions about family involvement in their care and whether such opinions are respected. A further aim was to gain insight into opportunities for family involvement available to service users. The use of individual interviews with mental health service users allowed for the extraction of important detail and an enhanced understanding of user experience that, while unique to each participant, supported some common points-of-view. The results identified three themes: respect for service user opinions of family involvement; opportunities for family involvement; negative and positive service user opinions of family involvement. A key outcome of these findings was identifying the need for systematic but importantly individualised involvement of families in mental health care.

In line with previous research (Cameron, Gallo Cordoba, and Maybery 2023; Hamann and Heres 2019) this study found that family involvement in mental health care is important to service users and has the potential to influence service outcomes. The findings illustrated the benefits of family involvement and indicated that positive outcomes are invariably linked to service users' opinions of this involvement being respected. It was acknowledged that at times service users may be unable to make these decisions, however where possible, inviting and adhering to their preferences is critical. Service users have strong beliefs about who, what, when and where they want their families involved in their care and respecting these perspectives is key to a positive experience.

Participants provided varied and specific examples of how families brought knowledge and support that was beneficial to their care. As described in previous research (Aldersey and Whitley 2015; Wonders, Honey, and Hancock 2019), service users want their families to receive education to aid treatment and recovery and acknowledge their important function as information providers. Emphasising the triadic nature of mental health care, the results indicated that service users view clinicians as key to facilitating this role by inviting family involvement and providing a safe and trusting environment.

Clinicians and families also acknowledge the contribution the latter group can make to treatment and care planning (Maybery et al. 2021; Wood et al. 2019), yet this involvement so often does not occur (Eassom et al. 2014; Landeweer et al. 2017). Several participants commented that their clinician had not invited family involvement. One explanation might be that clinicians' lack of training or understanding of the value such contributions can have on service user outcomes discourages invitations for family involvement. Clinicians report insufficient knowledge, training and experience in family-focused practice (Biebel et al. 2014; Hestmark et al. 2021; Maybery and Reupert 2006) that can be compounded by a lack of communication between service providers and government agencies (Foster, O'Brien, and Korhonen 2012). The lack of capacity for services that are labour-intensive (e.g., family psychoeducation) may also lead to poor implementation of family involvement (Hestmark et al. 2021). Clinicians are more likely to hold positive attitudes and have greater confidence in working with clients' relatives when trained in this area (Kim and Salyers 2008). Employing service staff with specialised competence in family involvement as well as including information meetings and formalised routines (e.g., procedures, checklists, educational materials/letters) for family involvement and support may increase awareness and recognition of the importance of this tridirectional relationship. However, implementing these practices without training would require significant effort (Hestmark et al. 2021). Therefore, it might be that the likelihood of clinicians inviting family involvement would increase with greater education and support in the areas outlined above, as well as improving clinicians' understanding of the pivotal impact such invitations can have upon outcomes.

Reinforcing the findings of previous literature (Cameron, Gallo Cordoba, and Maybery 2023; Cameron, Tchernegovski, and Maybery 2022), this study found that the majority of participants reported a positive experience of family involvement; however, this perspective was not unanimous. This finding is important in two key respects; firstly to acknowledge that experiences of family involvement are not homogenous. Some participants wished for less family involvement whereas others would have preferred more, emphasising that an undifferentiated model cannot meet the needs of all service users. One explanation that may assist understanding those who wished for less family involvement may link to the trauma described by several participants, particularly when related to family members. One participant, a victim of intrafamily abuse, indicated her family's involvement was only at the insistence of the clinician. Her reluctance supports previous research of some abuse survivors who indicate increased distress associated with disclosure or seeking support

(Brand and Alexander 2003; Johnson and Kenkel 1991; Solberg et al. 2021), although this view is not universal (Easton 2013; Murthi and Espelage 2005). Other participants had negative experiences of family involvement in their care during childhood or adolescence and this discouraged inviting families to attend or participate in adulthood. Another explanation might link to the impact of a service user's mental health difficulties on their family member, who may experience emotions including anger and resentment in relation to their caring obligations (Hill and Broady 2019). Such behaviours might discourage service users from inviting or accepting family involvement for fear of negative repercussions or damage to relationships.

Secondly, opinions about what should comprise family involvement are unique to individuals and can determine whether an experience is positive or otherwise. This was encapsulated succinctly by Mary who reported that *not* having her family involved had a positive impact on her experience of care and reiterates existing knowledge surrounding the difference of opinion that can exist within families (Cohen et al. 2013). Of interest, negative opinions of family involvement in care were framed both as potentially detrimental to the service user but also their family. Although some service users held concerns about how their family might impede their treatment and/or recovery, others were concerned for the family members themselves, and the negative impact upon them. Multiple participants were discouraged from involving their families for fear of burden, a concern previously acknowledged elsewhere by service users (Chatzidamianos, Lobban, and Jones 2015; Wonders, Honey, and Hancock 2019) and families also (Hill and Broady 2019; Jankovic et al. 2011; Maybery et al. 2021).

Although the notion of caregiver burden is well understood (The National Alliance for Caregiving and AARP Public Policy Institute 2015), appreciating the scope of this concept might be helpful to service users in their consideration of family involvement, in particular the cause of this burden. Although families may experience discomfort or difficulty through engaging in a family member's treatment or care and potentially poor support for their personal needs, their burden can also be impacted by whether they are included in collaborative treatment at all (Maybery et al. 2021; Okpokoro et al. 2014). Thus, perhaps by sharing their caregiving role with others, for example clinicians, families, they will in fact benefit rather than suffer from this inclusion in their relative's care. Moreover, this enables services to provide better care to service users who in turn require less from their caregivers thus further reducing this burden (Maybery et al. 2021). Once again, the education of all stakeholders as to the *how* of family involvement proves inextricably intertwined with the associated and far-reaching benefits and potential for positively influencing outcomes.

Another example of the value of open and deliberate communication among stakeholders pertains to privacy, a common consideration among service users. Participants of this study held concerns about both sharing personal information with their families or feeling apprehensive about disclosing personal details which might have a negative impact on their care. This is unsurprising. It was also noted that families provide an important role of information provision and therefore it is prudent to manage rather than remove this involvement, with service user

agency and autonomy a key priority. The described concerns surrounding confidentiality suggest that advance discussion at treatment outset regarding acceptable disclosure of information could be a useful aspect of dialogue between clinicians and service users. Such consultation could more appropriately investigate the needs of service users, tailor care to suit these needs, and in turn positively impact family members too, who frequently describe concerns about confidentiality and the need for more information and input (Førde et al. 2016; Jankovic et al. 2011; Katterl et al. 2023).

Having opportunities for family involvement was cited by most participants, with wide-ranging influences. The interview approach to data collection, afforded opportunity to uncover idiosyncratic detail of service user perspectives, and the specific factors that impact their experience, including a family member's connection to the service user, their professional training or ability to attend appointments. Service users place importance upon having agency regarding who, what, when and where this involvement occurs, and this in turn impacts overall experience. Furthermore, this involvement was cited as having lasting effects on relationships, a sentiment also previously reported by families and caregivers (Førde et al. 2016) and service users' attitude towards involving family in future. Understanding this granular detail of service user opinion has the potential to inform bespoke care in clinical practice but also highlights the often discrepant views among stakeholders. For example, the service user autonomy and discretion regarding family involvement described as essential by many participants of this study, has previously been reported as problematic or upsetting by families (Førde et al. 2016; Sugiura, Pertega, and Holmberg 2020). Such contrasts of opinion illustrate and reaffirm the disparate views existing not only within but between stakeholder groups, reiterating the necessity for personalised assessment of individual needs (Banerjee et al. 2021; Chatzidamianos, Lobban, and Jones 2015; Clements et al. 2019; Giacco et al. 2017; Hinton et al. 2015; Waller et al. 2019).

It has previously been argued that family involvement must be on the families' terms, rather than clinicians and that their role is not to compensate for existing gaps in service provision (Maybery et al. 2021). Although it is reasonable and fair to promote fulfilment of family wishes in their role in a service user's treatment, the results of this study suggest a strong argument for beginning with service users and their opinions in the first instance, as the key protagonists of this triumvirate. Service users welcome the opportunity and invitation to give their opinions about family involvement and the majority feel that these opinions were respected, if not always adhered to. Service users recognise the nuance to family involvement, such as where it may be more or less welcome, for example in assessment versus counselling or in private sessions versus in-hospital care. Some participants preferred to engage in treatment alone and only involve family when completed.

Also important to service users interviewed for this study was the ability to nominate which family member was involved in their care. For those who reported a lack of opportunities for family involvement, sentiments included a desire for greater advocacy as well as a lack of opportunity due to family member unwillingness or inability to engage in care. However, as

acknowledged previously by both service users and clinicians (Giacco et al. 2017; Hughes, Hayward, and Finlay 2009), service users might not always be best placed to provide sound judgement about family involvement or other aspects of their care, particularly when there is a risk of harm to either the service user or others. Elizabeth's reflections describe this sentiment and an understanding of situations in which a service user might not have capacity to decide: "It wasn't that they asked me and then didn't regard my wishes; it was more just because I was so unwell that they couldn't". Elizabeth spoke favourably about the advance care directive currently in place that allows for her family to intervene when she is too unwell to do so and expressed regret that such arrangements are not commonplace for others nor necessarily instated as soon as is desirable.

Once again, it is important to emphasise that within this population, there was variation among experience and some service users felt that their family's involvement was a significant detractor to treatment success, reiterating the heterogeneity of experience. Collectively, the results of this study support previous research suggesting that a single approach to involving families is unlikely to address the needs of all service users (Waller et al. 2019) and although routine discussion relating to how families are engaged is necessary, the nature of that involvement cannot also be routine. Despite consistent research findings emphasising the potential benefits of family involvement and calls for this to be clearly identified in legislation (Maybery et al. 2021), implementation is best described as "random and inadequate" (Hestmark et al. 2021, 8) and has been largely resisted, in both policy and practice. We propose that discussion surrounding the involvement of family becomes a customary component of care, and as common as conversations pertaining to informed consent and privacy. Rather than replicating existing methods that ask for families' (Drakenberg et al. 2023; Ewertzon et al. 2008) or clinicians' (Maybery, Goodyear, and Reupert 2012) opinions about family involvement, which are often implemented posttreatment, investigations should be dynamic, proactive and occur pretreatment where possible. Given the potential benefits to both service user outcomes and the experience of all stakeholders, training of clinicians to customarily invite this dialogue should be uniform in all mental health services.

5 | Strengths and Limitations

This study contributes new evidence about service users' experiences of family involvement in mental health care. Conducting semi-structured interviews allowed for the gathering of rich and idiosyncratic detail, as well as provision of a framework by which to explore patterns common to the population. The findings support previous suggestions that family involvement is generally positive, but importantly highlight the different permutations of experience among service users.

Reporting individuals' lived experience through interviews and thematic analysis (Braun et al. 2019) was a strength of this research. However, coupled with this approach is the inherent limitation of reduced generalisability of the findings. Future research in this important area of mental health care may consider combining a qualitative and quantitative design to investigate applicability of these findings to a wider population. Mixed

methodology research offers many benefits and in this instance would provide scope to investigate and explore both the breadth and depth of service user experience.

6 | Conclusions and Implications for Clinical Practice

Our findings support previous appeals for routine family involvement in care but extend this charge with the assertion that as important is a customary discussion with service users to ask their opinions about this involvement. Establishing this dialogue prior to treatment commencement has the potential to alleviate or resolve service user concerns and potentially improve and/or increase how families are involved. Our research suggests there is a need for both cultural and organisational change pertaining to family involvement. Without this consensus of approach, it appears unlikely that outcomes that are acceptable to each stakeholder group will be attained.

Author Contributions

The study was designed by all researchers. Interviews were conducted by S.C. Thematic analysis, discussion and review were conducted by S.C., S.L. First draft for publication was preferred by all authors.

Acknowledgements

The researchers would like to thank the interviewees for participating in this study. Open access publishing facilitated by Monash University, as part of the Wiley - Monash University agreement via the Council of Australian University Librarians.

Ethics Statement

Ethics approval was provided by the Monash University Human Research Ethics Committee (Project ID: 38791).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.