Community Mental Health Journal (2019) 55:318–330
https://doi.org/10.1007/s10597-018-0292-2

ORIGINAL PAPER

Family Inclusion in Mental Health Service Planning and Delivery: Consumers' Perspectives

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Received: 21 March 2017 / Accepted: 6 June 2018 / Published online: 7 July 2018

Abstract

Family inclusion in treatment planning and delivery for people living with mental illness is advocated in government policy but is yet to be widely translated into practice. While external barriers have been identified, including concerns about consumers' best interests, little is known about consumers' own views. This study explores consumers' experiences and perspectives of including family in treatment. Semi-structured interviews were conducted with 13 adult consumers who could identify supportive family members. Data were analysed using constant comparative analysis. The findings indicated that the outcomes reported from family inclusion depended on who, how, how much and when family were included, and the degree of choice consumers had regarding these features For consumers to have real choice around these features, family inclusion needed to be accessible, families needed to be willing, and all parties needed to agree upon a consumer-centred purpose. Findings can aid health professionals to facilitate consumer choice.

Keywords Mental illness · Adult · Family inclusion · Recovery

Background

Family inclusion or collaboration in mental health treatment is endorsed in mental health policies and practice standards internationally (Standing Council on Health 2012; Commonwealth Department of Health and Ageing 2008; Crombie et al. 2007; Department of Health 2010, 2013; Office of Adolescent Health 2018; Substance Abuse and Mental Health Services Administration (SAMHSA) 2009). The increasing emphasis on family inclusion represents a growing acknowledgement that families can be a vital recovery support for people living with mental illness (referred to hereafter as consumers). The importance of families to consumer outcomes has long been recognised. For example, a large body of research has found that a wide variety of psycho educational and therapeutic interventions with families can improve consumer outcomes such as relapse rates, medication compliance, duration of hospital stays and quality of life (Glick et al. 2011; Lucksted et al. 2012; McFarlane et al. 2003; Pitschel-Walz et al. 2001). The vital role of family support is also highlighted in more recent, recovery based literature. Recovery in mental health does not refer to an absence of symptoms, but rather to a deeply personal process in which the person develops new meaning and is able to live a satisfying life beyond the effects of their illness (Anthony 1993; Commonwealth Department of Health and Ageing 2008). Research evidence suggests that the support provided by families can have a positive influence on recovery overall (Aldersey and Whitley 2015; Pernice-Duca 2010). More specifically, family support can help to reduce consumers' stress, increase motivation for recovery, and contribute to rekindling hope (Aldersey and Whitley 2015; Ellis 2003; Tooth et al. 2003).

Family inclusion can be distinguished from both family interventions, which are specific programs aimed at educating families and improving the family environment, and family support more generally, which refers to the emotional, practical, and material support provided by family members (Aldersey and Whitley 2015; Eassom et al. 2014). Family inclusion in treatment expands the role of families to collaborating with consumers and professionals in consumers' overall mental health plans, treatment, and recovery (Eassom et al. 2014). This collaboration is congruent with a recovery-based approach in which practitioners are no longer seen as

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the only "experts" in the team. Rather, the consumer and family are experts through their own lived experience (Shepherd et al. 2008). This approach sees social support networks as essential to promoting recovery and focuses on strengthening non-mental health resources in consumers' lives, particularly those that already exist (Anthony 1993; Farkas et al. 2005; Shepherd et al. 2008). The literature about family inclusion, however, is relatively sparse. The few, mostly qualitative, studies that have evaluated family inclusion have reported a number of benefits. Families who are successfully included in treatment have reported improved relationships with the consumer and decreased feelings of frustration and helplessness (Boye et al. 2001; Cleary et al. 2006; Greenberg et al. 1997; Lakeman 2008; Piippo and Aaltonen 2008), which are likely to have flow-on effects in terms of improving family support. Practitioners have also reported that families can provide experiential information and contribute to a better understanding of the consumer, enabling more informed decision making (Bee et al. 2015; Cleary et al. 2006; Crombie et al. 2007; Oyebode 2005; Piippo and Aaltonen 2008). Consumers have also indicated that family inclusion is valuable, and while few studies have reported on their views, those that have, show many consumers felt more satisfied with services when family inclusion was encouraged (Marshall and Solomon 2000; Rapaport et al. 2006).

While the small amount of literature available suggests that family inclusion is helpful and it is advocated in government policies (Cleary et al. 2006), expert commentary, advocacy groups and qualitative research suggest that widespread translation into practice is lacking (Cleary et al. 2006; Crombie et al. 2007; Leggatt 2011; Marshall and Solomon 2000; McMahon et al. 2010; Sane Australia 2016). Families have reported routinely being excluded from service planning and delivery, having their input discredited, and experiencing poor communication with practitioners. This has resulted in them feeling ill equipped to support loved ones (Eassom et al. 2014; Goodwin and Happell 2007; Lakeman 2008; Ridley et al. 2010).

Lack of widespread inclusion may be partially explained by a number of potential barriers identified in the literature. First, barriers in the service context may include lack of funding, staffing, structural support, such as training opportunities, lack of time, and a crisis management focus (Eassom et al. 2014; Jakobsen and Severinsson 2006; Rose et al. 2004; Wright 1997). Second, barriers may exist within families themselves, such as resistance, not living locally, other commitments, family health issues, and having English as a second language (Lakeman 2008; Rose et al. 2004).

A third set of barriers exists around practitioners' views and assumptions about consumers' best interests. Practitioners may not believe that family inclusion would be helpful if they have negative attitudes towards families, such as views that they cause or exacerbate consumers' problems (Rose et al. 2004). The traditional idea of practitioners as experts who can best judge consumers' needs also works against a valuing of families' input (Eassom et al. 2014; Mental Health Council of Australia 2000; Rose et al. 2004). Consumers' right to confidentiality is a perennial concern. Health professionals often express confusion about how to comply with confidentiality requirements when facing differing stakeholder needs (Cleary et al. 2005; McMahon et al. 2010; Piippo and Aaltonen 2008; Rose et al. 2004). While, in some cases, practitioners who truly want to include family may be prevented by determined refusal from a consumer, some family members believe that health professionals have used confidentiality as an excuse to deny inclusion (Cleary et al. 2006; Goodwin and Happell 2007; Hungerford and Richardson 2013; Jakobsen and Severinsson 2006; Lakeman 2008; Marshall and Solomon 2000). Consumers themselves have sometimes reported families being denied information on the grounds of confidentiality, despite the consumers perceiving the provision of information as necessary and their consent not having been sought (Lakeman 2008; Marshall and Solomon 2000).

Consumers' own perspectives on family inclusion have rarely been investigated. Most research about family inclusion reports the perspectives of health professionals and families (Eassom et al. 2014). Research reporting consumers' perspectives have focused on specific related issues such as the release of information to families (Marshall and Solomon 2000) or family support more generally (Aldersey and Whitley 2015; Pernice-Duca 2010). Only two studies were found that focused on family inclusion in mental health care planning and treatment, and included consumers' voices. Both reported consumers' perspectives in conjunction with that of other stakeholders (Lakeman 2008; Piippo and Aaltonen 2008). The first, Lakeman's (2008) survey study, included 127 consumers and 86 carers in hospital and community settings. Participants were asked three open-ended questions about barriers, benefits, and ways to improve family inclusion. Responses, which were "typically short and unambiguous" (Lakeman 2008, p. 204), were analysed using summative content analysis with numbers of consumers and carers reporting each theme being compared. The study revealed that consumers saw families as helping them to access services and facilitating professional treatment. However, there was no opportunity to explore responses further given the survey format and responses often related to family support more generally rather than family inclusion.

In the second study, researchers Piippo and Aaltonen (2008) conducted group interviews with consumers, their family members and their practitioners together. Consumers and families reported that successful inclusion often led to more open communication and increased understandings of each other. While more detailed exploration of consumers' perspectives was possible through the interviews, consumers may not have felt comfortable sharing certain thoughts in these mixed group interviews. Furthermore, all participants had been involved in a specific family inclusion program in Finland, limiting applicability.

An in-depth understanding of consumers' views and experiences of family inclusion is needed (Eassom et al. 2014). To gain such an understanding, methods are required that neither compromise consumers' openness by involving other stakeholders simultaneously in data collection, nor dilute their specific experiences by analyzing their data together with other groups. Understanding consumers' perspectives will enable health professionals to facilitate family inclusion that is valued and of most benefit to consumers.

The aim of this study was to develop an in-depth understanding of how consumers experience inclusion of family members in their treatment.

Methods

Study Design

This study used a grounded theory approach. Grounded theory aims to understand and explain people's experiences by developing theory directly from data and is appropriate for this topic given that significant gaps exist in the literature and there is a need to understand consumers' experiences on a conceptual level (Bryant and Charmaz 2007; Charmaz 2014). While development of a full grounded theory was beyond the scope of this small-scale, exploratory study, key techniques of grounded theory were used to develop a preliminary conceptual framework that makes sense of consumers' experiences (Bryant and Charmaz 2007; Charmaz 2014). The techniques used were simultaneous data collection and analysis, detailed coding of data, constant comparative analysis and memo writing (Charmaz 2014).

Participants

Participants were over the age of 18, identified as having a lived experience of mental illness, were using or had used mental health services and were able to identify at least one family member who was supportive for them and their recovery. While discussion was not restricted to these supportive family members, this criterion was designed to enable discussion of issues and considerations around family inclusion beyond general supportiveness of family members. Family was defined broadly as people in the consumer's life with whom they shared a strong connection, regardless of whether there was a biological relationship (Family Mental Health Alliance 2006). Criterion sampling, where all available volunteers who met criteria were selected (Patton 2002), was used to maximise the number of participants and ensure an information rich sample. Participants were recruited through advertisements in consumer newsletters distributed electronically by three mental health advocacy organisations based in New South Wales, Australia. Additionally, the primary researcher explained the study to a group of potential participants at a non-treatment group run by one of the organisations and left advertisements at reception. These methods of recruitment ensured that the study was publicised to a large number of consumers and that participation was not limited to clients of specific treatment services. The advertisements invited anyone fitting criteria to contact the researcher (Patton 2002; Polgar and Thomas 2008). For those who did so, the researcher explained the study in detail, answered questions, ensured the consumer met inclusion criteria and obtained informed consent. Ethical approval was obtained from the Human Research Ethics Committee at the University [blinded] prior to recruitment.

Data collection

Data collection was undertaken through in-depth, semi-structured interviews exploring consumers' thoughts and experiences (Tracey 2013). Participants had the option of being interviewed face-to-face (n = 11) or by telephone (n = 2). Face-to-face interviews took place in private areas at community venues, such as libraries, quiet cafés, and community services depending on participants' preferences. Interviews, lasting between 45 and 90 min, began with a brief demographic questionnaire (Maxwell 2005). The researcher then used an interview guide with open-ended questions about participants' experiences and perspectives of family inclusion to trigger discussion and ensure essential topics were covered. The semi-structured style allowed for the guide to be used flexibly and in a conversational manner to permit exploration of participants' complex and unique experiences through follow up questions (Fontana and Frey 2003; Kvale and Brinkmann 2009; Polgar and Thomas 2008; Tracey 2013). Consumers were asked to think about people who supported them in their recovery, and describe their experiences and thoughts about how these people and other family members had and should or should not have been included in their treatment. Concurrent data collection and analysis enabled two revisions to be made to the guide following the emergence of new ideas (Thornberg and Charmaz 2014). For example, as it became evident that desired family inclusion changed over time, more specific questions were added, such as: "What would prompt you to include family in the future?" All interviews were audio recorded with consent from participants and transcribed verbatim for detailed coding.

Data Analysis

Analysis of the data occurred simultaneously with data collection, using grounded theory techniques (Charmaz 2003, 2014; Thornberg and Charmaz 2014). Initial analysis began with open, line-by-line coding, where short names were given to each small segment of data that embodied a particular idea. New data were compared to previously coded data and existing codes in order to continuously refine and clarify codes. This process is a key technique of grounded theory known as constant comparative analysis. It ensured that emerging concepts were derived from the data rather than from preconceived ideas and that findings represented participants' responses. Constant comparison revealed patterns and enabled codes to be grouped into broader categories. For example, the codes "Building a clearer picture for the health professional" and "Wanting family to understand" were identified as examples of the same broader category "Outcomes sought". As categories emerged, connections between them were examined to establish the relationships between concepts and develop a conceptual framework. For example, "Outcomes sought" and "Family relationships and roles" were both identified as factors affecting consumers' preferences about "Features of family inclusion". The researchers used QSR International's (2014) NVivo10 Software to assist with organising and managing data.

Several strategies were used to enhance analytic rigour. Two researchers coded the first interview separately then discussed their analysis in detail to ensure codes were consistent and representative of the data (Charmaz 2014). Following this, the researchers regularly discussed emerging codes as the analysis progressed. Notes were kept documenting emerging ideas in a process known as "memo writing" (Thornberg and Charmaz 2014). Tracking thought processes in this way allowed them to be better remembered and understood, assisted in decision making regarding emerging analysis, and helped the researcher to reflect on how her own views and ideas impacted the analytic process (Polgar and Thomas 2008). To ensure the data analysis reflected participants' voices (Charmaz 2014) they were sent, with their permission, both a copy of their interview transcript and, later, a two-page summary of the findings. While they were invited to provide feedback, no participants had corrections or additional suggestions.

Recruitment, data collection and analysis lasted approximately 7 months, concluding at the point of data saturation, when the researchers agreed that new data was no longer producing new concepts and existing concepts were clear and understood (Charmaz 2014).

Results

Participants

Interviews were conducted with 13 participants in total. All names in this paper have been replaced with pseudonyms in order to maintain confidentiality. Table 1 provides an overview of participants' characteristics. While all consumers could identify at least one supportive family member, not all supportive family members were included in treatment and not all those included were perceived as supportive. Only one consumer reported no inclusion of family in treatment.

Table 1 Participants

Characteristic	Participants *N = 13*
Gender	
Male	5
Female	8
Age (years)	
Range	24–67
Mean	49
Country of birth	
Australia	13
Living situation	
Alone	6
With family of origin	5
With family of procreation	1
With friends	1
Diagnosis[a]	
Depression	8
Anxiety	5
Psychosis	9
Other	4
Years since first diagnosis	
Range	5–41
Mean	18
Mode	16
Type of services currently used	
Community health service	7
Private health service	4
Mixed	2
Overall experience of family inclusion[b]	
Positive	8
Negative	1
Mixed	2
Neutral or ambivalent	2

[a] Participants could identify more than one diagnosis

[b] Researcher assessment based on interview data

The level of family inclusion for other participants varied. While many consumers had, at one point, included family in order for the practitioner to provide them with specific information (n = 9), more collaborative types of inclusion, such as collectively reviewing progress and setting goals, was experienced by only a few (n = 3).

Conceptual Framework

Participants reported a range of outcomes from family inclusion. These outcomes depended on the features of family inclusion: who was included; how they were included; how much they were included; and when they were included. Consumers' preferences about these features were affected by their circumstances, the outcomes they wanted, and family relationships and roles. Central to achieving desired and positive outcomes was the consumer having choice about the features of family inclusion. While having choice ensured that the features were consistent with consumers' preferences, it also had its own effect on the outcomes.

For consumers to have choice, three facilitators needed to be in place. First, family inclusion needed to be accessible to consumers. That is, it needed to be available and encouraged within health services and, importantly, consumers needed to know about their family inclusion options. Second, family members needed to be willing to be included. Third, the purpose of including family needed to be centred around the consumer's wants and needs, and agreed on by all those involved. Figure 1 illustrates these critical concepts and how they relate to one another. Each of these is described in detail below.

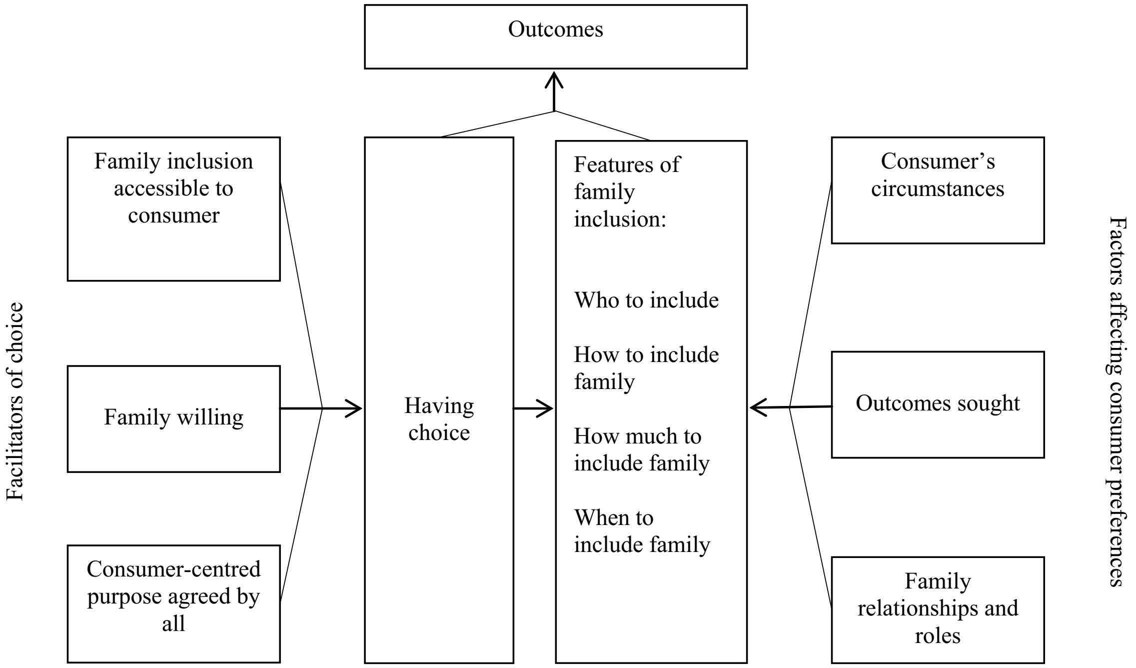

Fig. 1 Conceptual framework

Outcomes

Participants experienced a variety of outcomes as a result of family inclusion. The most common positive outcome, reported by 8 of the 13 participants, was that family members gained a better understanding of them and were, therefore, able to provide better support. This was often a result of clear and authoritative explanations and advice that practitioners were able to give:

> "With any of the questions that the other family members came up with [my health practitioner] was able to say to them, "Well look this is what Tim has difficulties with, with x, x and y, and…please be supportive in those kind of situations." And it has helped. It really has helped." [Tim]

> "What was good about it is that my psychiatrist was quite prepared to bring them in and be the scapegoat, to put the conversation out there and not make me have to stress about what he said. I knew he would be up front and honest with them. That made me feel a little bit at ease, that I had that support alongside of me to take them on, in a sense, and tell them what it needs to be." [Mona]

Family inclusion not only had the potential to improve family support, it could also improve professional support. For example, some participants described how hearing families' unique perspective helped the practitioner to gain a better understanding of their situation and consequently provide better care:

> "To make sure I got maximum benefit out of this, my wife, and separately my son, attended two of the sessions with [my psychiatrist] too and I went outside so they could both freely talk to her for a few minutes and tell her what they observed about my behaviour, to help her in her diagnosis because no one's objective about himself." [James]

Family inclusion also allowed families to help ensure that services were working in consumers' best interests, for example, by discussing and evaluating treatment and treatment options:

> "[My sister] was very intelligent, so she would have given good questions to the doctor… [She] would have been considering the long-term effects the medication had on me, but then also the fact that I didn't have to worry about a tablet every day." [Tanya]

While primarily it was the consumers who felt better supported through family inclusion, participants additionally recognised that family members also felt better supported as a result:

> "I think them just being able to learn that even though it was a bit chaotic and a bit scary it was actually ok… and [that the hospital] was the best place for me at that time." (Haley)

Not all outcomes of family inclusion were positive. For example, some participants described how the support of their family was undermined and even lost, or talked of feeling traumatised and manipulated by negative family inclusion:

> "[That practitioner] so undermined the supportive relationship [with my family] that they would write things like: 'parental dependent'…And ultimately, that undermining of the relationship left me with no one I could turn to even in my own home…and I was so frightened of [that practitioner] and frightened of the stories that she as an 'expert' was putting into the minds of my family, which were not truth." [Amy]

> "I feel extremely damaged by the way that those initial encounters with psychiatrists failed to involve my family [the way I wanted]… And like, the thing about [telling Mum to lock] me up for punishment is just so disgraceful. A human rights abuse… really a part of me died then." [Lily]

Features of Family Inclusion

The outcomes that were achieved from family inclusion were thought to depend on the specific features of family inclusion, including who, how, how much and when family were included. In anticipation of outcomes, consumers had particular preferences about each of these aspects.

Who to Include

Participants often wanted some family members included in treatment but not others. Katie, for instance, chose to include only her mother, saying:

> "A lot of people in the family – there was a stigma with it and there was just lack of understanding. I didn't feel safe talking to certain people about it. [Katie]

How to Include Family

Participants described a wide range of ways that families were included in treatment. These are presented and exemplified in Table 2.

How Much to Include Families

Participants reported that the amount they wanted to include family members varied over time and in different situations:

> "I don't want [Mum] to be as involved these days either. Because it'll only get her upset." [Daniel]

When to Include Family

Different participants wanted inclusion in different situations and at different stages of their recovery. For example, some participants particularly wanted family included when they were unwell, as they sometimes did not feel up to interacting with services on their own. Many participants felt, however, that their family needed to be included at other times throughout the recovery journey so that they could understand recovery as a process and understand their role in that process. Haley, for example, felt that including families only in response to acute illness was inadequate:

> "[Recovery is] a whole different conversation and it's a whole different way of being involved and if they know that…that's where they can pick up the load and stuff like that then that's great….but if they aren't supported or don't understand how, then that's not going to happen." [Haley]

The features of family inclusion contributed to shaping the outcomes achieved. For example, if inclusion occurred only rarely and was restricted to provision of minimal

Table 2 How families were included

Type of inclusion	Example quote
Professionals provide families with general information and advice	"It's good for them to get informed and, you know, give them opportunities to learn about what's going on but also what's available and just things as well like how to decide when maybe it's a time to call the crises team or things like that." [Haley]
Professionals provide families with specific information and advice about the consumer	"You know, we got into the nitty gritty of my condition and at that stage it was following a routine while we're sort of getting me settled on medications and therapies." [Samuel]
Families provide health professionals with information about the consumer	"[My wife could tell them] things which I probably wouldn't reveal to him or her myself. Between the two of us it would've given the psychologist a more complete picture." [James]
Families help consumers to evaluate services	"So that's been helpful for me that they can actually sit down and go: 'Well here's what we see. You go in this way…and we don't see any change. If anything we see you come out worse than you went in.'"[Amy]
Families providing support and advocacy for consumers' interactions with services	"If I felt like I wasn't in a space to deal with things on my own… it was just good to have that extra support. And she would talk to the psych as well. It wasn't like she was just there, just as moral support. You know, she'd get involved in the conversation." [Katie]
Professionals mediating between consumers and families	"I felt I could air a few problems and the psychologist could mediate. Whereas otherwise we probably would've had a fight over it." [Alice]
Collaboratively reviewing consumer's progress and setting goals	"That's a big thing that [Mum] sits with me and my coordinator during my reviews and we work through what I've achieved in the last six months and where I'm at with that: whether it's been fully achieved, partially achieved or whether it really hasn't gone anywhere and what we want to achieve in the next six months, what our goals are..." [Amy]

general information, the benefits were likely to be limited compared to a situation where families were more frequently and deeply included. However, no one pattern of family inclusion was seen as optimal or preferable by all participants.

Factors Affecting Consumer Preferences

Participants' individual preferences regarding family inclusion varied greatly and changed over time. Consumers described a range of factors that affected what was wanted or needed.

Consumer's Circumstance

Unique circumstances in each consumer's life affected their preferences about who, how, how much and when to include family in treatment. For example, participants described their age, the seriousness of the situation, the service itself and their relationship with that service as influencing the inclusion they saw as appropriate:

> "It's better if someone's there with you when you're having a psychosis…If I'm on my own there you don't know who to trust. You think they're all out to kill you or out to get you… You're fighting with everybody and everything. Lucky my sister was there because she can explain to [the doctors], you know, I told her and she told them." [Doug]

> "The only supports I had were my family so I wanted my family there and I wanted both of my parents there and…as that confidence [in the service] grew my father kind of was able to step out and now my mother comes in at different points in time as she feels the need." [Amy]

Outcomes Sought

Participants' preferences about the features of family inclusion were additionally influenced by what they wished to gain from the experience. For example, when consumers wanted their family members to understand them to provide better support, often they would include them in sessions so that practitioners could mediate discussions and facilitate understanding:

> "If a health professional is able to rationalise situations and explain things from your perspective that perhaps aren't getting through because you're emotional or distressed or trying to explain it – perhaps over talking it.

> 'Cause I can over talk it as I try to explain. They may be able to put it in a different way. So that's helpful." [Amy]

Family Relationships and Roles

Participants' perceptions about their relationships with family members and the roles that family members played in their recovery influenced the features of family inclusion desired. For example, when participants had a good and trusting relationship with a family member, felt that the family member understood them and their situation, and perceived the family member to be integral to their recovery, they typically wanted them included in treatment:

> "It all comes down to trust. You're only going to let in people that you trust. I had a bit of an issue with trust and [my mum] was the only one I trusted at the time." [Katie]

> "That's been really helpful to have that person standing outside who can see the forest when you can't 'cause you're in the forest and you can't see it through the trees." [Amy]

Conversely, when participants perceived that family members had negative attitudes towards mental illness, were untrustworthy or were difficult to communicate with they often chose to limit inclusion of those family members:

> "If it's something practical I talk to Mum. If it's something emotional or I'm going through one of my down phases, no I don't talk to Mum. It's kind of like the family dynamic…I'm so used to censoring myself around her. [If she was included] then I'd just be censoring myself in front of the professional as well." [Leonie]

Participants also reflected on family members' potential roles based on such things as their health, work, and other commitments. In fact, many participants chose not to include family members at times because they were concerned about their wellbeing:

> "[I wouldn't include them] at this point in time because they're going through a big emotional upheaval of such in their own lives." [Mona]

While the features of family inclusion that were desired varied between participants depending on the factors described above, it was clear that the critical element that determined whether family inclusion was perceived as positive was having choice.

Having Choice

For a positive experience of family inclusion, consumers needed to know that they were the person making the choices about its features. Amy reflected on how her recent positive experiences of family inclusion differed from past negative experiences. She described the reasons for this:

> "Because the power's put entirely in your hands – who you involve, how much you tell – that it's all about respecting you and respecting the fact that you do or do not disclose as you see fit and you do or don't involve who you want to as you see fit. Your world becomes bigger and bigger and…your level of safety and your comfort zone increases." [Amy]

Similarly, Mona summed up her opinion of what made family inclusion a positive experience:

> "I think that comes down to the actual consumer first…I think they need to dictate what can and can't be said to families…it comes down to the consumer setting those guides and those boundaries with their healthcare worker." [Mona]

When participants were not given choice, they often felt excluded from treatment decisions and isolated from both family and practitioners, as Haley described:

> "I didn't find it helpful that [my family] wanted to talk to the treating team but not with me involved…it was like I was excluded. Like I wasn't capable of making my own decisions and even though the hospital was very good, they would do things like that, that pissed me off." [Haley]

Facilitators of Choice

The data revealed that, in order to truly have choice about family inclusion, the following facilitators needed to be present.

Family Inclusion Accessible to Consumer

True choice about family inclusion was only possible for consumers if a range of options were accessible to them. In order for options to be accessible, consumers firstly had to be aware of them as possibilities. This was not always the case. If consumers did not have previous experience of family inclusion or were not thinking clearly, then having choice required professionals to actually suggest or offer to include family:

> "I don't think it was ever discussed. I think if someone had of brought up the point I probably would have done it. But I think I was kind of in survival mode or something and I wasn't really thinking that way." [Katie]

Some practitioners not only suggested family inclusion, but further facilitated choice by making options more available to the consumer, for example, by using online mediums, holding meetings in the consumer's family home to increase flexibility, and initiating contact with family members when wanted:

> "I have a younger sister who lives in America. [My psychiatrist] even went to the trouble of organising my sister to be online through Skype™ [software] and had a family conference in her office, which I thought was brilliant." [Tim]

> "I think [my psychiatrist has] attempted to try and keep [my parents] in the loop. Even though he wasn't able to treat me at the public [hospital], I still think he tried to keep Mum and Dad up to date with what was going on there." [Mona]

Family Willing

For consumers to be able to freely choose who, how, how much and when family were included, they needed to perceive family members as willing to be included. Daniel, for example, usually did not choose to include his family in treatment, but was confident that they would be willing whenever he wanted them to be included:

> "All I would have to whisper is to the nurse or the doctor or someone, "I want my brothers here with me. I want my parents to be advised." And they'd be there and I could rely on their good sense." [Daniel]

Participants generally saw their families as willing to be involved if they showed interest in the consumer's recovery and made efforts to understand them. When family members did not show interest in being involved, participants lacked choice about including family:

> "A big part of my mental health is that I hear voices. One day I wrote out what those voices do and say to explain it to them, and they wouldn't even read it. That's the sort of point where it stops at. They're not interested in participating in organizing my care…they don't come up and be a part of my discharge planning or anything." [Mona]

Consumer-Centred Purpose Agreed by All

To enable consumers to truly have choice about the features of family inclusion, others needed to recognise their right to make those choices. That is, all those involved needed to agree on the purpose of family inclusion and that purpose needed to be centred on the consumer and their needs.

> "It's very oriented around the person who's being served. It is not about the coordinator….It's not about what's good for the organisation in terms of getting funding." [Amy]

Sometimes, agreement on purposes and priorities was assumed, but at other times it was negotiated through discussion:

> "We'd talk about what was going to happen, is she going to stay outside, is she going to come in with me, is she going to talk, is she not going to talk – we negotiated all that before we went in. So it was a really nice arrangement and I was happy with that." [Katie]

In contrast, when those involved had conflicting reasons and agendas for engaging in family inclusion, participants were denied choice. For instance, both Lily and Amy described having been unable to make the decisions about family inclusion because health professionals and family members had followed their own interests and agendas:

> "I still had that idea that if she understood me better or anything about depression … that would be helpful. My mother, I realised afterwards, thought that she was there to tell my psychiatrist everything I'd ever done wrong in my life …I had a particular idea of how [the health professional] would manage things and she didn't do that at all… that particular day I really feel she let me down big time." [Lily]

> "They involved my family only so that they could create an alternative view of what was taking place… So they tried to get my family on side as a support to encourage and push me down an avenue that they wanted me to go." [Amy]

When family inclusion was made accessible by health professionals, family members were willing, and all agreed on a consumer-centred agenda, this allowed consumers maximum choice. Thus the features of family inclusion matched consumer preferences and consumers felt in control, resulting in a positive experience of family inclusion.

Discussion

This study aimed to understand and explain consumers' experiences of including families in treatment planning and delivery. Findings revealed that having choice about who, how, how much and when families were included was central to achieving positive outcomes for consumers and that this choice was possible when health professionals made family inclusion accessible, families were willing, and all parties agreed on a consumer-centred purpose for inclusion.

The importance of having choice is clearly consistent with current best practice in mental health, namely, recovery-oriented practice. The recovery literature has highlighted the role of consumer choice in treatment planning and delivery as crucial to recovery (Farkas et al. 2005). Family inclusion is one aspect of treatment, or a way of engaging in services, that consumers need to have choice about. Therefore, it is critical that practitioners are aware of a variety of family inclusion options and potential benefits, and that they are prepared to work towards enabling positive family inclusion wherever possible, by facilitating choice. Health professionals can do this by attending to the three facilitators of choice identified in this study.

First, for consumers to truly have choice about family inclusion, they needed opportunities for inclusion to be accessible. True choice can only exist if the options from which to choose are known. Many consumers in this study reported situations where, due to distress, lack of awareness or lack of experience with family inclusion, they had simply not thought about or considered including their families in treatment. If the option to include families was not raised by the consumer's health professional, then not including family members did not represent a choice but a lack of choice. Practitioners cannot assume that consumers know the possibilities for family inclusion or that they will raise the idea if they want it. Rather, practitioners should explicitly and actively inform consumers about their family inclusion options.

Health professionals can also help consumers to make informed choices about the features of family inclusion. For example, they can discuss, using the framework presented in this study, the possible outcomes of family inclusion, the different ways of including families, and the various factors that they might wish to consider in making their decisions. The potential benefits of family inclusion identified by consumers in this study are consistent with the literature reporting families' and health professionals' perspectives. These benefits include: both families and health professionals gaining a better understanding of the consumer and being able to provide better support; improved family relationships; and families feeling reassured (Cleary et al. 2006; Crombie et al. 2007; Lakeman 2008; Oyebode 2005; Piippo and Aaltonen 2008; Walker and Dewar 2001). However, benefits are not automatic or guaranteed and supporting consumers to choose features of family inclusion can mean helping them to consider factors such as their individual family circumstances. For example, issues of trust with particular family members and concerns about their wellbeing are relevant and have also been cited as barriers to family inclusion in previous literature (Lakeman 2008). Importantly, presenting options for family inclusion should not occur only during crisis. In this study, when consumers did want family included, many wanted them included throughout different stages of recovery. This reflects the concept of recovery as an ongoing journey requiring continuing support, and where needs and wants fluctuate (Leamy et al. 2011).

Even when consumers were aware of the possibilities for family inclusion, it also needed to be encouraged and supported by practitioners. In this way, the data parallels families' experiences reported in Goodwin and Happell's (2007) article, in which they felt excluded from treatment when health professionals did not explicitly encourage their involvement. Making family inclusion accessible also meant helping to overcome some of the related barriers to family inclusion identified in the literature. For example, consumers in this study outlined how health professionals addressed barriers such as not living locally and lack of time or familiarity (Eassom et al. 2014; Rose et al. 2004) by having family members present through Skype™ video communication software, or by conducting some meetings in the consumer's family home.

The second facilitator needed for consumers to exercise choice over family inclusion features, was that consumers needed to perceive their family members as interested in or willing to be included, which was not always the case. Health professionals have similarly reported perceiving that some family members were resistant to inclusion and suggested that this may be due to them being resigned to the situation (Rose et al. 2004). Consumers' perceptions of family willingness may not necessarily be accurate, as families routinely misunderstand each other's perspectives (Gillespie et al. 2010). Where families do appear to lack interest, this may relate to a range of issues including concern for the consumer's privacy and autonomy (Lakeman 2008) or lack of awareness of their potential contributions. If family members are not given the opportunity to understand family inclusion and express their willingness or otherwise then both their choice and the consumers' choice is compromised. Health professionals can therefore facilitate choice by working with consumers to identify ways of potentially helping families to understand the role they can play through family inclusion.

The third facilitator of choice revealed in this study was the purpose of family inclusion being client-centred and agreed on by all involved. Consumers in this study identified tensions and negative impacts when family inclusion was driven by someone else's purpose. In recovery-oriented treatment, the agenda of the health professional or services should not dictate family inclusion as this represents a superseded medical approach (Slade et al. 2012). Rather, family inclusion should be driven by the consumer's priorities, an important component of recovery-oriented practice (Repper and Perkins 2003). Families have also reported feeling dissatisfied with inclusion when the process was dictated by the health professional's agenda (Walker and Dewar 2001). However, while the needs and wants of families and consumers can be similar, they are often not identical (Cleary et al. 2005; Noble and Douglas 2004; Pilgrim 2005) which may cause tensions when collaborating in treatment (Cleary et al. 2006). Consumers in Piippo and Aaltonen’s (2008) study reported negative experiences of family inclusion when they felt the relative’s influence was too strong. Though families’ needs are important and should be addressed, this should be done outside the context of consumers’ treatment when they diverge from consumers’ wants and needs.

As with any qualitative study the applicability to different population groups should be assessed with reference to the sample characteristics (Polgar and Thomas 2008). In particular, consumers included in this study lived in and around the city of Sydney and were all born in Australia. Views on family inclusion may well be different in other cultural groups and experiences are likely to be shaped by the New South Wales health system. All participants could identify supportive family members, presumably had some interest in family inclusion given they volunteered for the study, and nearly two-thirds reported primarily positive experiences of family inclusion. This would not be the case for all consumers. Additionally, participants were relatively experienced with the mental health system, averaging 18 years since first diagnosis, and were recruited through recovery-based mental health organisations, thereby representing a relatively well-informed group of consumers. This method of recruitment likely contributed to the homogeneity of the sample. For example, it is unlikely the call for volunteers reached consumers without easy access to the internet, or those not linked in with recovery-based services, such as less experienced or more isolated consumers. This limited the potential for variety. Further study about family inclusion should be done to gather perspectives on a wide variety of consumer populations and explore the potential contextual differences, such as experiences in different cultures, health systems, and treatment types. A larger sample and broader recruitment strategies would facilitate this. For example, advertising through a wide range of treatment and non-treatment based services in different health areas including rural communities, publicising the availability of interpreters, and using both hard-copy and electronic advertisements would expand recruitment. Larger samples would also allow subgroup comparisons to be made, providing insight into differences relating to such features as gender, age and diagnosis, Though this study suggested numerous positive outcomes from family inclusion, like other studies of family inclusion, it was a small-scale study of stakeholders’ subjective perspectives. Further research would be helpful to gain an understanding of the measurable impact of family inclusion on specific outcomes. These might include traditional outcome measures, for example, rehospitalisation rates, but could also utilize emerging measures of recovery (Hancock et al. 2015).

Conclusion

This study addressed a lack of in-depth exploration of consumers’ specific experiences and perspectives of including family members in mental health treatment. Notwithstanding the limitations, this study provides a framework for understanding these experiences that can help promote and guide family inclusive practice. Specifically, findings highlight the importance of informed consumer choice about family inclusion, to maximise the potential for positive outcomes. Practitioners can facilitate this by making options accessible, ensuring both families and consumers are aware of the features and potential outcomes of inclusion, and ensuring consumers’ needs and wants are driving family inclusion processes. The findings provide guidance for health professionals who seek to operate within government policy and recovery-oriented practice to ensure that consumers have true choice in family inclusion.

Compliance with Ethical Standards

Conflict of interest The authors declare no conflict of interest with respect to the authorship and/or publication of this article.

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