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Consumer and carer perspectives in the development of a mental health research, treatment, and teaching facility: A thematic analysis

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Short title: Consumer and carer perspectives

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## Abstract

**Introduction:** Recovery-oriented mental health policies recognise consumer and carer participation in service decision-making as essential, but little is known about the views of these individuals in the earliest stages of service development. **Aim:** This study sought consumer and carer perspectives addressing the establishment of a mental health research, treatment, and teaching facility in their region. **Methods:** Two 2 hr focus groups were conducted, with separate groups held for mental health consumers ( $n = 9$ ) and carers ( $n = 9$ ) respectively. Discussions pertained to mental health literacy, gaps in current services, desires for an ideal facility (in terms of physical design and services offered), and what would help in recovery. **Results:** Inductive thematic analysis was used to generate three themes: care outside of consultations, carer involvement in recovery, and holistic approaches to mental healthcare. Consumers desired a facility that could cater to individual needs. Carers felt excluded in recovery and unable to provide effective support. Both groups preferred holistic approaches to mental health, expressing ambivalence towards medication and hospitalisation. **Discussion:** Consumers and carers have many needs that conventional practices may not meet. **Implications for practice:** They have clear desires for equal partnership in recovery and for transformation of conventional treatment methods.

## Key words

Carers, consumers, consumer and carer participation, mental health, recovery, thematic analysis

## Relevance Statement

This paper explores consumer and carer perspectives in the development of a mental health research, treatment, and teaching facility. Although the study commenced with the premise of informing the development of new services, the themes identified also have relevance to broader issues in practice across both hospital and community settings. The consumers and carers who contributed to the qualitative analysis are individuals with whom mental nurses would interact in their day-to-day work. Thus, we believe the paper is relevant to mental health nursing practice.

## Accessible Summary

### What is known on the subject

- Around the world, recovery has become a focus in mental health policy. The participation of people accessing mental health services (consumers) and carers of such individuals in decision-making related to services forms part of this recovery-orientation and studies suggest positive outcomes following such participation.
- However, little is known about consumer and carer desires at the earliest stages of development of new services.

### **What this paper adds to existing knowledge**

- Consumers and carers desire changes to how mental health services are provided.
- Many factors affect consumer and carer experiences, including language use, physical design of spaces, accessibility, consideration of individual needs, practical help, and how well care is continued from hospital to community settings.
- Carers may feel sidelined in treatment and be distressed as a result. They wish to be respected and involved in recovery.
- Consumers and carers wish for focus on broader health, with care taken to address physical health, psychological needs, social needs, and treatment of the whole person rather than just an illness.

### **What are the implications for practice**

- Consumers and carers desire partnership with professionals in recovery. Tokenistic participation should be avoided.
- Flexibility in how services are provided and less formality may help engage consumers and carers. Specifically, professionals may help by linking consumers and carers to services that address practical needs.
- Professionals should communicate with carers to draw on their expertise about the individual accessing the mental health service and help carers understand how they can assist the individual's recovery.

### **Introduction**

Several countries, including the USA, UK, Canada, and Australia, have adopted a recovery-oriented basis for mental health policy (Gaffey *et al.* 2016; Wallcraft *et al.* 2011). The recovery-orientation model emphasises respect for people experiencing mental illness and recognises their rights for dignity and autonomy (Wallcraft *et al.* 2011). As part of this international movement, the participation of consumers and carers in decision-making has been acknowledged as essential for improving service delivery (Australian Government Department of Health 2014; Wallcraft *et al.* 2011). Consumer and carer participation refers to partnership between mental health professionals, people who access or have accessed services, and carers of such individuals, who are often family members.

Consumer and carer participation relates to an individual's involvement in both service provision in being a partner with the clinician/s in the therapeutic process, but also extends this to include a collaboration on discussion and implementation of greater structural processes, influencing the broader context of how services operate (Lloyd & King 2003). Professionals have expert knowledge of mental health but may not have knowledge of consumer and carer experiences of negotiating the mental health care pathways to obtaining services. This may contribute to some insensitivity to the effects that those structural and systemic processes have on the consumer and/or carer outside of the therapeutic relationship. Consumers and carers may experience particular difficulty when required to obtain services from multiple healthcare professionals.

There are international calls for consumer and carer participation in all levels of mental health service development, delivery, and evaluation, and the evidence base is growing (Patel *et al.* 2008). Early evidence supported positive outcomes related to consumers and carers participating in training mental health workers (Simpson & House 2003), monitoring services (Srebnik *et al.* 1997), and planning services through committees (Crawford *et al.* 2003). Research supports the effectiveness of consumer led services, such as self-help groups (Chinman *et al.* 2014; Doughty & Tse 2011), and some have argued that consumer led services may serve as alternatives to conventional psychiatry (see Russo & Sweeney 2016). Recent studies have considered consumer perspectives on mental health services and recovery principles, with many consumers citing problems navigating back to a normal life (Davidson *et al.* 2010) and finding meaning beyond treatment (Kidd & McKinstry 2015). Likewise, studies have documented that informal carers experience many hardships in conventional practices (e.g., Ewertzon *et al.* 2011; Fulford & Farhall 2001; Wilkinson & McAndrew 2008).

An extensive literature has also been established regarding consumer led research projects (e.g., Barber *et al.* 2011; Davidson *et al.* 2010), which offers a parallel to consumer led services. Studies have suggested that consumer involvement can have numerous benefits, such as building of trust and commitment between consumers and researchers, mutual learning, and valuable inputs for the study design and interpretation (Barber *et al.* 2011; Savage *et al.* 2006). However, many have been critical of participation models, arguing that deeper structural problems are not addressed and superficial participation serves to reinforce traditional power relationships (Cooke & Kothari 2001; Hodge 2005). Difficulties have also been noted when consumers and other stakeholders differ in their level of understanding and in researchers' use of jargon (Boote *et al.* 2010).

The present study was conducted as plans were underway for the establishment of a mental health research, treatment, and teaching facility in the Sunshine Coast region of South-East Queensland. Queensland has the highest suicide rate for young people aged 15-24 in Australia, with regional Queensland having the highest number of youth suicides (ages 5-17; Australian Bureau of Statistics 2016). Adults in the Sunshine Coast region have also been identified as having elevated levels of mental, behavioural, and mood problems, with men and women ranking in the bottom 20% of the Australian population (Sunshine Coast Medicare Local 2015). To address this high prevalence, consumer and carer perspectives were sought on the development of the new facility. This study provided an opportunity to obtain consumer and carer input with the intention being to influence design and decision-making before the facility was operational. Research has established that services and research can benefit from consumer involvement and that consumers and carers experience difficulties in traditional mental health services, but less is known about consumer and carers' specific needs and desires at the earliest stages of development of new facilities. This study

intended to explore these perspectives in depth while also being an initial step towards involvement of consumers and carers in the local project, consistent with a recovery orientation.

The conceptual framework for this study was based on the Australian National Recovery Framework (Australian Government Department of Health 2014). The founding principles of the framework emphasise recognition of the value of lived experience and the insights available from consumers, carers, and families in supporting recovery. The framework supports a breakdown of traditional power structures in mental health, with increased emphasis on respect for all individuals involved in recovery based on the experience, expertise, and strengths they can contribute. Recovery-orientation through the framework also calls for a focus away from organisational priorities, shifting instead towards the needs of people who use the services, that is, consumers and carers. The conceptual framework was operationalised through allowing consumers and carers to articulate issues important to them.

## **Aim**

The aim of this study was to improve understanding of mental health needs and service delivery in the local region from consumer- and carer-driven perspectives to inform the planning, development, and eventual establishment of the facility.

## **Methods**

### **Theoretical framework**

Inductive thematic analysis was chosen to underpin the study.

### **Participant selection**

Adult consumers ( $n = 9$ ) and carers ( $n = 9$ ) were recruited through mental health organisations, professional networks, community centres, and community boards. A snowball sampling technique was used given that these individuals are from a hard-to-reach population, with many participants being recruited with the help of networks of a local community organisation. Participants were reimbursed with an AUD\$50 voucher for their time, following recommendations in the literature for consumer and carer participation (Trowse *et al.* 2012).

### **Setting**

Consumer and carer participants joined separate focus groups held at a community mental health centre in June, 2015. A morning or afternoon tea was offered during each session. To begin, participants were provided with the project information sheet and a consent form. The facilitator explained the processes of the focus group, established ground rules for the discussions, and encouraged participants to ask questions. Following written consent, participants completed a brief demographic questionnaire.

The consumer group included six women and three men aged 25 to 62 years ( $M = 42.56$ ,  $SD = 13.40$ ) with a diagnosis of a mental illness and who were currently accessing mental health services. The carer group included nine women aged 43 to 71 years ( $M = 56.89$ ,  $SD = 9.36$ ) who identified as caring for a family member with a mental illness. Demographic characteristics are provided in Table 1.

## **Data collection**

The discussions were guided by semi-structured interview questions. The questions covered participant levels of mental health literacy, identified gaps in currently available services, explored what the ideal structure and function of the new facility would be, what would encourage or discourage use of the facility, what research was important to participants, and what would help in supporting the journey to recovery. Each focus group was audio-recorded and verbatim written transcripts were prepared from the recordings. The duration of each group was 2 hours.

## **Rigour and reflexivity**

Two of the authors were present during the focus groups: a facilitator and a note taker ([author details removed]). The facilitator was female, with extensive experience as a consumer and carer peer advocate and in focus group settings. These qualities allowed her to develop strong rapport with participants. The note taker was experienced in research more generally, supporting his capacity to monitor for bias introduced by the facilitator's familiarity with the issues under investigation.

To support the rigour of the analysis, two researchers coded the transcripts independently ([author details removed]) and then reviewed interpretations in discussion with a third researcher ([author details removed]) who was not involved in the analysis (Crowe *et al.* 2015). Due to anonymity of responses, transcripts were not returned to participants for comment or feedback.

## **Ethical approval**

Ethical approval was granted by the Human Research Ethics Committee of the home institution (approval code: A/14/641). A registered clinical psychologist was available during and after the focus group for any participant who experienced distress and participants were reminded that they were free to cease participation at any point.

## **Data analysis**

Participants were assigned pseudonyms and the transcripts were imported into NVivo (version 10, QSR International) for analysis. The inductive thematic analysis approach was used to generate codes, which were then collated into themes. Themes were then checked against the initial codes for consistency, before being defined explicitly with specific accounts chosen to illustrate each theme. Analysis followed a semantic rather than latent approach, describing what participants said and using this to arrive at interpretations, as opposed to seeking to identify participants' underlying ideas and conceptualisations (Braun & Clarke 2006). These decisions reflected the nature of the investigation, which sought to identify participants' explicit needs in order to inform practical action in mental health.

## **Results**

Three overarching themes were identified: care outside of consultations, carer involvement in recovery, and holistic approaches to health. These themes applied to multiple consumers or carers, unless otherwise stated.

## Care outside of consultations

Consumers and carers reported many experiences of difficulty outside the consultation room. Subthemes covered what an ideal facility would provide and the limitations in existing services.

### *Language use*

There was acknowledgement of the power of language in affecting individuals' perceptions of personal control in their mental health journey. Some participants felt uncomfortable with the power imbalance between consumers and service providers. More broadly, formality was discussed as a deterrent.

Any sense of formality, I mean, and- you know, without a sense of feeling that there was a, kind of Government stuff- anything to do with that, you know, then I'd just walk out.  
(Consumer FG, male participant)

### *Physical design*

The physical design of mental health facilities was also an avenue through which consumers reported that their experiences could be influenced, outside of consultations. There were desires for services to accommodate individual coping strategies even if they were inconsistent with health recommendations, such as tobacco use. Design was also discussed at length, with consensus reached for spaces that were nature-oriented and open.

I would prefer to be outside in the fresh air where I can feel the air on my face and I can breathe and walk around or something, so having that option in the inside room that feels not like a institution but more, you know, having nature in, being open but also having the flexibility of maybe a room that's breathable that's open to outside. (Consumer FG, female participant)

### *Accessibility*

In accessing the facility, several participants expressed interest in later opening hours. Reasons included wanting to avoid public gaze when attending the facility in times of personal distress, sleeping patterns in which morning attendance would be unfeasible, and being able to attend when family are available to assist (i.e., outside of typical work hours). Both consumers and carers expressed interest in having private space to allow time to process acute emotional experiences.

Late opening hours. You know, like lots of people trying to cope with their, you know, 9-5, whatever they're doing, and if they are suffering a- an issue, they're not gonna want- like, necessarily want that to be open. (Consumer FG, female participant)

### *Accommodating individual needs*

Regarding the function of the facility, some consumers reported being overwhelmed through challenges in identifying which services were appropriate or where they could begin looking for help. Some experienced difficulty gaining access to services that would accommodate multiple needs. Consumers suggested a solution for these problem would be a "one-stop shop".

You've heard it a million times, a one-stop shop, just simplify, and concentrate on every service that is available within the Sunshine Coast- wh- wh- whatever area we call it, um, so every person knows that, you know, you don't know who to ring sort of thing. (Consumer FG, female participant)

Consumers often used multiple services to compensate for service limitations, but reported a lack of consistency between these services. In attempting to gain consistency, one consumer reported that years of effort were needed to establish communication between multiple service providers. There was also discussion of lack of consistency being especially problematic for those who needed crisis support or experienced fluctuations in the severity of their concerns. Consumers with long-term concerns had difficulty with having to repeat their history to many professionals.

I want to stay with the one person and not have to share my story over and over and over. (Consumer FG, female participant)

#### *Practical assistance*

More broadly, outside the treatment context, consumers cited needs for practical assistance. Several consumers reported difficulty in arranging living necessities, such as accommodation and welfare payments, oftentimes feeling overwhelmed. For those with a history of hospitalisation, reintegration into community living was difficult to manage. Overall, there was a desire for services to help with these challenges.

Perhaps someone that you can sit [with], and go through what you're wanting, and they can translate that and help you by finding those resources for you. (Consumer FG, female participant)

#### *Continuity of care*

Continuity of care was raised as an issue, especially following release from hospital mental health units. For carers, it seemed there was no scope available for individual considerations in recovery.

There's no personal plans, really. They just have this set little plan they look at, and they write- wrote off that, and then if you don't fit the plan, too bad. (Carer FG, female participant)

In essence, these views might be summarised in terms of the consumers wanting a service able to respond to their changing needs as an individual and provide ongoing treatment, with crisis support available as required. The themes highlight the complexities consumers and carers face outside of consultation rooms.

#### **Carer involvement in recovery**

Carers frequently reported stress, lack of support, and an inability to contribute effectively to recovery.



### *Feeling ignored*

Many carers felt ignored and marginalised by professionals in the recovery of the person they cared for. This was met with frustration, as carers recognised their own expertise acquired through the lived experience with the person in question. These insights into subtle triggers were often considered to be the result of long-term experience.

One of the biggest things is that nobody will listen to- to us, you know, and we keep going over it and over it again, you know, this is what we want, we understand confidentiality and all that sort of thing, but- and I will personally always say to the professionals, it makes your jobs easier if you listen to what we have to say, you don't have to tell us what goes between you and- and the person that you [are] looking after, but listen to what we have to say, because- even if they're in hospital, mentally and physically, we're there 24/7, and we know much more than the professional people, and it would make their job a lot [easier]. (Carer FG, female participant)

For some carers, their desire to be involved in recovery was met with hostility.

I've even had like one of the social workers, um, from the [health centre] say to me "you- you don't know anything", you know, "you don't know anything about your son", you know, "we're the professionals, let us decide". (Carer FG, female participant)

In other cases, carers reported being sidelined, feeling a strong need for advocacy.

One of the psychiatrists put a mandatory treatment order on my son without consulting me, or his father, and- and um, I was just devastated, and- and it was because he was over 18, and I wasn't- no where, 100% aware- this is where I feel I need a bit more advocacy, I'm not sure of what the- the rules and regulations are, and- and so I was completely sidelined-. (Carer FG, female participant)

### *Limited in capacity to help*

Many carers felt frustrated and limited in their capacity to help, as professionals would often maintain strict confidentiality despite consumers often having an impaired ability to care for themselves. Several carers could sympathise with the experience of not being *invited* into the consultation room.

I sympathise, I understand what that's like, not feeling- having control, and not being invited into the- con- consultation. (Carer FG, female participant)

In considering these views together, despite carers having expert knowledge from day-to-day experiences with consumers, carers felt they were being dismissed by mental health professionals. Their central role as a carer for the individual in question was often not acknowledged even though such consultation would likely have benefits in supporting recovery.

## Holistic approaches to health

Difficulties between service providers and consumers and carers became apparent in discussion about biological treatment of mental illness. There were desires for health to be addressed as a whole, with focus not just on mental ill-health. Carers especially expressed preferences for holistic healthcare, in some cases citing difficulties with health professionals in negotiating the evidence-base behind certain approaches.

### *Ambivalence towards medications*

Medications were treated with ambivalence. Some preferred alternatives, but recognised the role of medication, although reluctantly.

We prefer to go the holistic way and the alternative way, or the complementary way, or the integrative way, whatever you want to call it. . . [but] there's a process about- settling them down, and that may mean having some sort of medication that we don't particularly- shouldn't like them to have. (Carer FG, female participant)

Others reported experiencing challenges associated with medication side-effects. Some issues were relevant to specific conditions, such as weight gain in a consumer with an eating disorder. Concerns were also raised about perceptions of long-term health impacts from medication.

As most of us probably have experienced, being on medication that a lot of these people um have been on for years and years, they've put on heaps of weight, they've developed diabetes, um, they're insulin de-dependant- all sorts of things. (Carer FG, female participant)

Consumers' attitudes to antipsychotic medication in particular were negative, with hope for more holistic alternatives.

Medications are pretty horrific, and, uh, trying to introduce more holistic, you know, because there are certain things out there that apparently are working. (Consumer FG, female participant)

### *Dismissal of alternative approaches to health*

Despite consumer and carer concerns about medications, healthcare professionals often dismissed the alternative or complementary approaches to health that carers and consumers preferred.

When you go to hospital you have to take all your medication in- in the original packs and all the rest of it, and she's taken the Biobalance there um, and they've thrown it out, and it costs a lot of money, but it- it works for her. (Carer FG, female participant)

Part of this dismissal related to differences in opinion regarding what was considered evidence based.

But actually the label evidence based is- is- is- means nothing to doctors and things, because it's not scientifically based, and I don't say I agree with that, I believe in evidence based. (Carer FG, female participant)

### *General mental and physical healthcare*

More generally, consumers and carers expressed an interest in health and not just illness.

My son, we- like I said, he's not taking medication at the moment and he's doing all his own research on the internet, and I've had to do all my own research too, and he's very interested in, um, nutrition, you know, and the relationship between mental health at the moment, which is great, and exercise, you know, the importance of exercise. (Carer FG, female participant)

Carers also expressed feelings that the person they cared for was being treated with medication, but not taught to cope with their illness psychologically. The hospital mental health unit was identified as having an opportunity to work on general health. However, carers felt that these aspects were neglected and the units lacked being anything beyond a "jail" or "holding pen".

While somebody's in hospital, in the mental health ward, um, nobody is concerned about their general overall health, and um, we all feel that that- that's the time when that can be looked at. (Carer FG, female participant)

### *Psychotherapies viewed positively*

When mentioned, psychotherapies were discussed positively, including cognitive-behavioural therapy and dialectical behaviour therapy. Consumers also reported mindfulness and meditation training as helpful.

Mindfulness is- is the most important one, because ... when you're unwell, it's really hard to focus, so if- you know, to me, learning mindfulness before you even start any other group session is the most important because that gives you the tools to be able to be mindful and understand. (Consumer FG, female participant)

### *Treating the whole person*

Across the two focus groups, there was a desire for consumers to be considered as individuals, with identities separate from their mental illness. This desire included the ways in which staff responded to consumers and consumers' wants for services that had scope to accommodate individual needs. These ideas applied to the range of staff consumers interacted with, including those in hospital settings.

Staff have to learn that the patients are a w- are a whole person, and outside of that whole person there might be depression or there might be this, or they might be good at music or they might be good at something else, but the whole person is what they need to be looking at. (Carer FG, female participant)

### *Sense of community*

Further aligning with the social elements of holistic healthcare, there was also discussion related to sustainment of a mental health community. The consumers suggested one avenue through which this community could be built was through peer support and training opportunities. There was discussion of benefits from having opportunities to engage socially.

A drop in centre would be- be good. Or someplace where you can go just to be able to sit down and you know, you can have a chat with different people? I mean this is a- this is a great venue, because you sort of hear so many different points of a view, and- and uh, in a way, it- it helps to kind of distract- distract, I find these kind of situations distract me from my problems by getting more involved in the community. (Consumer FG, male participant)

Community engagement with consumers and carers could provide one means to furthering holistic healthcare and encouraging respect for them as individuals. Further to this building of community, many consumers and carers expressed interest in whether there would further opportunities to participate in discussion with the research team regarding the new facility. The consumers and carers were motivated to encourage change in the local mental health sphere.

## Discussion

This study sought consumer and carer perspectives in the development of a mental health research, treatment, and teaching facility in South-East Queensland. Consumers and carers envisaged the facility to be a place that is accessible, calming, and practical, where visitors can gain holistic, individualised support, be treated with respect, and feel part of a community. Traditionally, mental health services have followed a model whereby consumers attend a service and receive treatment in a discreet, contained manner. This model has been effective for many people and discretion in treatment and confidentiality remain paramount. However, the consultations with consumers and carers through this project showed divergence from this model. There was a strong desire for services able to extend beyond individual treatment, engage with consumer and carer perspectives, and provide a holistic experience for consumers. Past research has found that consumers and carers experience difficulties in traditional mental health services (Davidson *et al.* 2010; Ewertzon *et al.* 2011; Fulford & Farhall 2001; Kidd & McKinstry 2015; Wilkinson & McAndrew 2008) and consumer participation can have beneficial effects, such as building trust and facilitating learning (Barber *et al.* 2011; Savage *et al.* 2006). This study extends previous research by explicitly articulating consumer and carer desires at the beginning of development of a landmark project and the associated limitations in conventional practices. Together with past research, the present findings have implications in bringing awareness to the need for consumer and carer partnerships to extend beyond superficial involvement. In line with the long history of tokenistic participation (Cooke & Kothari 2001; Hodge 2005), the findings demonstrate a need for a paradigm shift in mental health. Consumers and carers are experts by experience and have skills to guide these changes (Jones *et al.* 2016).

The findings regarding holistic services and support align with the Australian Recovery Framework's emphasis on placing the person first and considering their life situation in its entirety (Australian Government Department of Health 2014). These findings also align with recent research expanding on the framework within which consumers highlighted the benefit of practical support, that is, actions taken to improve material circumstances (Bird *et al.* 2014). Specific help with processes associated with obtaining suitable housing, cleaning, and preparing meals may fall outside of current priorities for individual consultations, but the present evidence highlights that linkages with these services would likely have positive effects in facilitating other changes towards recovery.

Discussions with carers provided insight into the potential these individuals may also have in supporting recovery beyond superficial involvement. Despite carers recognising their own expertise and the Australian Recovery Framework emphasising responsiveness to family members and carers (Australian Government Department of Health 2014), many carers felt excluded. Navigating consumer confidentiality alongside high levels of carer involvement poses challenges that service providers may feel unprepared to manage (Bee *et al.* 2015). In contrast, however, dismissal of carers for these reasons suppresses the potential help these individuals have in recovery as part of holistic considerations of a consumer's life situation. Szmukler and Bloch (1997) argued that providers should seek consumer consent in the first instance, with consideration to the extent of risk for carers' wellbeing in cases where consent is not obtained.

Crisis management in acute hospital care settings places great demands on available resources, which are already likely to be limited (Lelliott & Quirk 2004). Consequently, consumers must sometimes be discharged whilst still symptomatic, placing additional responsibility on family carers and community. Continuity of care has been recognised as crucial for preventing complications in the transition from hospital to community care (Fortney *et al.* 2003). In supporting such care, past research has found family carers valued professionals' willingness to be open in providing information about the consumer and their listening to family members' perspectives and regarding such input as important (Cleary *et al.* 2005; Ewerzon *et al.* 2011). Consistent with carer views in the present study, past findings have indicated that a high proportion believe they did not experience such treatment from professionals (Ewerzon *et al.* 2011; Wilkinson & McAndrew, 2008). Services may have an impaired capacity to adequately inform and involve carers in recovery due to limited resources. However, professionals, consumers, and carers may all hold different expectations regarding discharge planning, creating issues for continuity of care (Fulford & Farhall 2001). Open communication with carers would likely be of great benefit in preventing hospital readmission whilst also respecting carers' integral role in supporting recovery. The present research contributes to the evidence by further highlighting the distress carers experience and their desires to be included in recovery.

Carers may pose challenges for mental health providers if they disagree with recommendations for treatment. Scepticism towards biomedical approaches and medications as treatments for mental illness was common within the focus group discussions. Such scepticism has a long history grounded in institutionalisation, power imbalances, and distrust of professionals (Gilbert *et al.* 2008). Studies have found that respondents often view psychiatric medications negatively or as a later preference treatment, despite their recommended use by clinical guidelines (Awad 2004; Jorm *et al.* 2005; Morrison *et al.* 2015; Riedel-Heller *et al.* 2005). Consistent with the present study's participants' preferences for alternative approaches to health, past research found respondents rated vitamin supplementation as helpful in treating depression in similar frequencies to antidepressant medications (Wang *et al.* 2007). Although some consumer and carer preferences may be problematic, professionals' use of coercion in forcing consumers to take medications, or in confiscating non-scientific complementary products, has been identified as a key barrier to formation of the therapeutic relationship (Gilbert *et al.* 2008). Similar issues might arise if professionals enforce well-intended regulations for cessation of smoking, which is highly prevalent in people with severe mental ill-health (Dickerson *et al.* 2013), without consumer consent.

Within the present study's discussions, another notable concern included the notion that consumers would be treated with medications without consideration for teaching them how to cope with their mental ill-health or for their overall physical health. Past research has also found consumers to express interest in physical activity in hospital settings (Fraser *et al.* 2015; McCloughen *et al.* 2016) and physical health gaps between people with mental illness and those in the general population are known to be large (Gray *et al.* 2016). The present study highlights that, to address concerns about holistic health, it may be necessary for service providers to emphasise where consumers can obtain additional help and, if possible, communicate with these external services to facilitate consistent approaches towards recovery. Consumers within this study reported great difficulties in attempting to gain such consistency and would likely benefit from services that can assist in these processes.

It is noteworthy that, although some concerns were raised regarding medications, little of the consumer discussions related to individual therapeutic sessions. Instead, the gaps consumers and carers identified focused largely on pragmatic issues outside of the consultation room. A strong evidence base has developed over time to support the use of psychotherapies and medications in treating mental ill-health (Malhi *et al.* 2015). Less attention is given towards the pathways consumers must navigate outside of the therapeutic context and the effects of such necessities. Community care emerged in deinstitutionalisation movements and was envisaged to provide a smooth recovery journey following hospitalisation (Pinfold, 2000). However, community care appears insufficiently resourced to address current needs. Given that community engagement has been identified as a means to minimising risk of relapse (Vine *et al.* 2016), the present research provides rationale for further exploration of these pathways.

### **Limitations**

A number of limitations are necessary to consider. Chiefly, considerations for service design were based on two focus groups. Although these analyses provide a starting point for consumer and carer participation, future research should consider avenues for longer and ongoing consultation. Participatory action research, particularly, would help ensure consumer and carer views are incorporated with authenticity and may have additional benefit through providing means for consumers to move beyond their service user identity (Hutchinson & Lovell 2013). The present consumers and carers expressed desire for continued involvement in the project, which suggests that such approaches would be welcomed.

In considering the limited number of focus groups, it is necessary to consider the contextual factors related to the sample that may influence the consumer and carer desires. Notably, consumer participants were in an outpatient setting, most having experiences with a long mental health journey. Individuals seeking mental health treatment with milder concerns likely have different experiences and needs. For instance, they would be less likely to require multiple services, thus avoiding many of the difficulties discussed in navigating services. Furthermore, the consumers were highly educated, with many having a university qualification. It is possible that this influenced their views.

Another quality of participants was that many accessed community-based mental health services. Consequently, views expressed on engagement with community may be especially strong within the sample and not representative of consumers in general. For others, private mental health consultations may remain a sufficient and preferable approach to treatment. It might also be

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assumed that as participants responded to advertisements for the study requesting input into a new mental health facility, many were likely to feel strongly about gaps in current services. Individuals who were satisfied with or did not hold strong views on the mental health system would perhaps not be inclined to participate. In addition, views were given by consumers and carers, but not mental health professionals. As mentioned earlier, these stakeholders are likely to have different expectations in treatment, such as in discharge planning (Fulford & Farhall 2001). The perspectives of these individuals may bring different interpretations to each situation and caution is thus necessary in interpreting the findings. Given these limitations, it is possible that data saturation was not reached and further themes might be identified with broader sampling. However, for the consumers and carers under investigation, the themes represented issues shared by multiple individuals, lending support to the relevance of these themes.

Although gaps in current services have been identified, these gaps may apply only to subgroups within the population. In considering the applicability of these findings to other regions in Australia, it is possible that some are generalisable. It might be reasonable to assume that similar issues are faced in dispersion of services, continuity of care, and carer involvement, given consistencies with past research discussed earlier.

### **Implications for practice**

The key implication of this research is that consumers and carers have clear desires for a paradigm shift in methods of service provision. Consumers and carers expressed a strong desire for ongoing consultation and involvement. This ongoing commitment entails efforts to avoid tokenistic participation in decision-making and instead to value consumer and carer expertise by experience. In mental health services within Australia and globally, there may be similar divergences between conventional services currently offered and consumer and carers perspectives on ideal approaches to treatment and recovery. Taking these opportunities to draw on expertise through lived experience may provide additional means to addressing the prevalence of mental ill-health currently faced in the local region and international contexts more broadly.

Professionals working in clinical settings would benefit consumers and carers by elevating them to an equal standing in decision-making. Service providers may also provide benefit through devoting additional resources to holistic and practical matters. Specifically, linking consumers and carers to external services would help in addressing practical concerns. Furthermore, respecting consumers' choices, such as by tolerating consumer or carer preferences for alternative or supplementary healthcare, would likely help in forming therapeutic relationships. Carers also have potential in supporting recovery. Their involvement in discharge planning may benefit both consumers and the carer's own sense of efficacy and help alleviate burden on professionals. Although the evidence presented here does not assess the effectiveness of acting on the consumer and carer desires, considering these perspectives upholds humanistic principles in line with recovery-orientation and may have potential in supporting recovery from hospital to community settings.

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Table 1. Demographic characteristics of consumer and carer participants.

	Consumers ( <i>n</i> = 9)	Carers ( <i>n</i> = 9)
<b>Gender</b>		
Male	3 (33%)	0
Female	6 (67%)	9 (100%)
<b>Marital status</b>		
Never married	4 (44%)	2 (22%)
Widowed	1 (11%)	0
Divorced	1 (11%)	2 (22%)
Separated but not divorced	2 (22%)	0
Married	1 (11%)	5 (56%)
<b>Birth country</b>		
Australia	7 (78%)	7 (78%)
Other	2 (22%)	2 (22%)
<b>Student</b>		
No	1 (11%)	7 (78%)
Yes, full-time	7 (78%)	1 (11%)
Yes, part-time	1 (11%)	1 (11%)
<b>Highest qualification</b>		
Secondary school Year 12	1 (11%)	2 (22%)
Trade certificate/ Apprenticeship	1 (11%)	1 (11%)
University degree	4 (44%)	2 (22%)

TAFE	3 (33%)	1 (11%)
Other	0	3 (33%)
Currently working	1 (11%)	5 (56%)

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