

# TOWARD A FAMILY-ORIENTED TREATMENT APPROACH FOR CONSUMERS AND CARERS OF MENTAL ILLNESS

**Pooja Sawrikar and Kristy Muir**

**Corresponding author** Dr Pooja Sawrikar, School of Human Services and Social Work (HSV), Griffith University (GU), Gold Coast campus, Parklands Drive, Southport, Queensland, 4222, Australia,  
[p.sawrikar@griffith.edu.au](mailto:p.sawrikar@griffith.edu.au)

**Co-author** Professor Kristy Muir, Centre for Social Impact (CSI), University of New South Wales (UNSW),  
[k.muir@unsw.edu.au](mailto:k.muir@unsw.edu.au)

**Disclaimer** This manuscript has not been published elsewhere, and is not under consideration by any other journal. However, this article draws on findings from a report written for *beyondblue* in 2010–11, so some content overlaps. It is overall different from the original report in that it summarises its key findings to address one specific issue (differing consumer and carer needs), and has updated the literature since the study was conducted.

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## **Abstract**

In 2010–11, a qualitative focus group study was commissioned by Australia's *beyondblue* to explore the needs and experiences of consumers and carers of mental illness. Overall, it was found that their 'stories' are substantially different from one another, leading to high stigma within families. The aim of this paper is to discuss these phenomena more deeply. In summary, the pervasive stigma associated with mental illness in society affects: people from gaining in-depth knowledge about it and therefore capacity to recognise symptoms early and provide the necessary empathy required; the capacity of health professionals to provide holistic treatment and not simply rely on a 'medical model'; and the provision of adequate funding to ensure the formal mental health system has appropriate infrastructure to meet consumers' needs. Stigma essentially hides mental illness from the community, placing pressure on families to provide support instead, but who lack the expert knowledge that clinical consumers require. The ongoing and stressful nature of caring can cause carers to develop stigmatic attitudes and behaviours. These are intensified with misperceptions about consumers' control over their mental illness, unequal distributions of attention within the household, and low consumer insight into the carer experience. It can also lead to the development of their own trauma that requires formal help. To address these complex issues, stigma is the foremost issue in need of redress. It can help reduce barriers to help-seeking in both consumers and carers, and ensure the provision of an informed and well-resourced 'mental health response' for families.

**Keywords** Consumers, carers, mental illness, stigma, focus group, qualitative research

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## Introduction

### **Background: Why was this study conducted, what is the aim of this article, and why is it significant?**

In 2010–11, a qualitative focus group study was commissioned by *beyondblue* to identify the needs and experiences of consumers and carers of mental illness in relation to four key themes: (a) community awareness, (b) stigma, (c) social and economic impacts, and (d) treatment needs. Consumers are defined as people with personal experience of depression, anxiety, and related substance use disorders, and carers are defined as family members and friends who care for consumers (*beyondblue*, 2010). *beyondblue* is a leading not-for-profit organisation in Australia, established in 2000, whose overarching aims are to “increase awareness and improve treatment of depression, anxiety, and related substance use disorders and reduce the associated stigma” (*beyondblue*, 2010).

One of the main findings of the study was that the needs and experiences of consumers were substantially at odds with those of their family carers, leading to high stigma of mental illness within the family.<sup>1</sup> The aim of this article is to comprehensively identify these differences and discuss stigma by family carers, as the basis for promoting a more sophisticated knowledge base to policy makers and health care service providers, and thus ensure that appropriate and tailored service delivery is being offered to families. The results are analysed in relation to what is currently known about the differing needs of consumers and carers, and recommendations for practice are made.

This is a significant contribution to the literature because stigma within families as a result of their differing needs has only recently garnered some momentum, so this article adds to the growing body of knowledge. It is also significant because the voices of consumers and carers are being captured and represented as the basis for informing principles of good practice.

### **Literature review: What do we know so far about the differing needs of consumers and carers?**

Mental illness is highly prevalent; for example, 1 in 5 Australians experience depression at some point in their life and there are more than 200 depression-related suicides per month (*beyondblue*, 2005). Reflecting this, much research is devoted to understanding, treating, and preventing mental illness. However, consumers do not

live in a vacuum. They are “enmeshed in a family context” (Cowling, Edan, Cuff, Armitage, & Herszberg, 2006, p. 416), so mental illness also affects those closest to them. Given this, the literature on family carers of people with a mental illness is also “the subject of reasonably extensive research” (McAuliffe, Andriske, Moller, O’Brien, Breslin, & Hickey, 2009, p. 2).

The current literature on carers indicates that a key and common part of their experience is dissatisfaction with professional service providers (e.g. Bradley, 2015; Goodwin & Happell, 2007; Gunasekara, Pentland, Rodgers, & Patterson, 2014; Hodgson, King, & Leggatt, 2002; Lakeman, 2008; McAuliffe et al., 2009; Wainwright, Glentworth, Haddock, Bentley, & Lobban, 2015). This is often because of “superior attitudes” (Hodgson et al., 2002, p. 3) that cause professionals to dismiss carer knowledge.

Coker, Williams, Hayes, Hamann, and Harvey (2016) report in their focus group study that carers feel uncertain about their role in treatment and the nature of the consumer’s illness; they want to feel included and acknowledged in the treatment process, and they want more information on mental illness, including symptomatology, prevention, treatment, medication, causes, warning signs, recovery, and prognosis. Consumers and carers also reported wanting to improve their communication so they can understand each other better and reduce conflict. Carers additionally want to know how to better support and encourage their family member. Finally, carers noted a need for life balance, as well as financial difficulties due to helping their family member become independent with money.

McAuliffe et al. (2009) note that even though recent government policies accept the necessity of including consumers and carers in the treatment process and are moving toward a consumer-focused service, consumer and carer needs and issues have also incorrectly been seen as essentially synonymous by policymakers. In their focus group study, carers talked about relief, frustration, fear, confusion, grief, loss, sadness, love, anger, respect, exhaustion, hopelessness, and hope. All participants reported that living with mental illness impacted significantly on the entire family and dramatically altered their lives (e.g. “[like] living in a nightmare”).

Bradley (2015) reports that as a result of caregiver burden, carers are at greater risk of psychiatric morbidity, lower health-related quality of life, and stress-related illness than either the general population or those caring for people with somatic illness only. This is especially the case for carers of partner or children consumers.

Overall, there is research interest in carers, and organisations like *beyondblue* have lobbied governments to ensure that carer needs are ‘on the agenda’ (McNair, Highet, Hickie, & Davenport, 2002). However, more still

needs to be done to ensure that the needs of consumers are met through a holistic approach toward recovery, and this means looking at their wider family circle. Family members have a critical capacity to contribute to consumer's support informally, but do not always do so and therefore can add burden to consumers already significantly distressed and subject to victimisation and discrimination (Cleary, Freeman, Hunt, & Walter, 2006; Hight, McNair, Davenport, & Hickie, 2004). Thus, some in-depth knowledge is beginning to take shape about carers, but it is not specifically about *why* they do not always provide support to consumers. This article further contributes toward that goal.

## **Method**

### **Approach and timeline**

Qualitative research is an important empirical tool because unlike quantitative research, which explores the *extent* to which people's lives are affected by mental health issues ('how much'), qualitative research explores the *nature* of how people's lives are affected by mental health issues ('what, how, and why'). This is particularly important for being able to identify the full range of themes relevant to complex phenomena; it captures nuanced and individualised experiences in ways that quantitative research is not able to.

Thus, qualitative research takes a holistic approach to people and gives a direct voice to the group of interest, to identify what group members themselves consider relevant and important to their well-being. It values the 'insider's' perspective rather than imposing an outsider's 'expert' view during the processes of data collection and analysis. In this way, it also takes responsibility for power differentials between researchers and the people they wish to understand more deeply by 'putting the power' in the hands of the participants and using their life experiences and personal contributions to research to inform how best to meet their needs.

Given the prevalence of mental illness – with some calling it an epidemic<sup>2</sup> – designing treatment that has the capacity to be effective because it has been informed by those who need it is of utmost importance. To this end, qualitative focus groups were conducted and they have provided a rich set of data generated from inclusive and participatory research methods to help inform practice. (Note: The names of all participants have been replaced with codes to protect their confidentiality and anonymity). These voices have also been captured here to honour their sharing, and ensure consumers and carers feel that the outcomes of research are fed back to them, consistent with ethical practice (Callander, Ning, Crowley, Childs, Brisbane, & Salter, 2011; Cleary, Walter, & Luscombe, 2007; Horsfall, Cleary, Walter, & Malins, 2007; Gee, McGarty, & Banfield, 2015).

Focus groups were selected over one-on-one semi-structured interviews for two reasons. The first is that within the short time constraints of the project (six months) a larger sample was able to be recruited, which assists with representativeness. The second was that discussion between participants on similarities and differences in their experiences was also being sought; by including 6–8 people in each focus group, diversity could be explored. Unfortunately, focus groups also risk having some voices dominate others. This risk was managed as best as possible with skilled facilitation, but is a limitation inherent to this data collection process.

The project was conducted between September 2010 and February 2011. It involved: (a) obtaining ethics approval, (b) conducting a literature and *beyondblue* document review, (c) designing three semi-structured schedules for the ‘consumers only’, ‘carers only’, and ‘mixed groups of consumers and/or carers’ informed by the literature, (d) recruiting participants through *beyondblue*’s national consumer and carer e-based reference group ‘blueVoices’, (e) conducting focus groups in four urban (Melbourne, Hobart, Sydney, and Adelaide) and four regional (Bendigo, Burnie, Tamworth, and Mount Gambier) sites (f) transcribing the recorded focus groups (permission to record was first sought), (g) thematically analysing the discussions, and (h) writing up results in a Final Report to *beyondblue*. Only the findings relating to the differing needs of consumers and carers have been reported and expanded on here. The relevant literature has also been updated here since the study was conducted. (More details on the study’s methodology can be found in the original report; a summary has only been provided here for brevity).

### **Sample description**

Of the total sample (n=61), 32 (52.5%) were ‘consumers only’ [Cons\_], 24 (39.3%) were ‘carers only’ [Carer\_], and five (8.2%) were ‘consumers and carers’ [ConsCar\_]; 31 (50.8%) were from urban sites and 30 (49.2%) from regional sites; the age range was 17–78 years, with an average of 43.1 years (n=60 completed responses on age); there were 23 (37.8%) males and 38 females; and three participants (5.1%) identified as Aboriginal and/or Torres Strait Islander, 10 (16.9%) identified as non-English speaking background (NESB), and the remaining 46 (78.0%) identified as Anglo (two participants did not respond to the question on ethnicity on a short Demographic Survey that followed the focus groups but appeared Anglo; total n=48).

Thus, the sample is nationally representative of urban/regional residence and age, but not of consumer/carer status, sex, or cultural background. However, it is known in the literature that carers (Langlands, Jorm, Kelly, & Kitchener, 2008), males (Eerola, Huurre, & Aro, 2005; Littman et al., 2010), and non-mainstream groups

(Isaacs, Sutton, Hearn, Wanganeen, & Dudgeon, 2016; Nesci, 2006) are less likely to seek help, so their lower representation in the study is on par with broader trends.

Depression and anxiety were the two most common mental illnesses reported by the ‘consumers only’; 29 of 32 (90.6%) were diagnosed with depression and 26 of 32 (81.3%) with anxiety. The ‘carers only’ were most commonly caring for a person affected by depression (16 of 24; 66.7%), anxiety (10 of 24; 41.7%), and/or bipolar disorder (11 of 24; 45.8%). Finally, the ‘consumers and carers’ reported that they were most affected by depression and anxiety (4 of 5 reported that they themselves have depression and/or anxiety, and 4 of 5 reported that they were caring for a person with depression).

Although depression, anxiety, and bipolar disorder were the most common mental illnesses affecting the participants, a range of mental health and other problems were also reported. These included: substance abuse, obsessive compulsive disorder (OCD), post traumatic stress disorder (PTSD), post natal depression (PND), agoraphobia, social phobia, and eating disorders. (Note: potential participants with co-morbid psychotic illnesses such as schizophrenia, schizoaffective disorder, and schizotypal personality disorder were excluded to ensure the sample was more representative of people without this co-morbidity. However, this was not always disclosed during the recruitment phase, so a small number of participants reported these).

## **Results**

This article has pooled results from across the four key themes explored in the study – community awareness, stigma, social and economic impacts, and treatment needs – to create brief ‘stories’ about what it is typically like to be a consumer and carer, while acknowledging that really there is no such thing as each individual is unique. Thus, they are more attempting to capture the ‘essence’ of these experiences. These have been presented separately to identify their unique needs first. Following this is a discussion on why stigma is high in families, as this appears to be the cornerstone issue in their varying experiences.

### **‘The consumer experience’**

#### *Awareness, acceptance, and stigma*

Awareness of mental illness in the community has increased over the last 20 years, especially of depression (compared to “post natal depression” [Cons\_10]), and among “the younger generation” [ConsCar\_1], so “people do talk about it more” [Cons\_7]. However, the association between awareness of mental illness and acceptance

of it is not direct. Thus, overall it “is still something people are reluctant to talk about” [Carer\_15], (and more so among males). The mediating variable is stigma.

Stigma refers to negative connotations, so it usually produces feelings of shame in members of the stigmatised group. It can manifest either as negative attitudes to people with mental health issues (i.e. prejudice), or negative behaviours toward them (i.e. discrimination) (Angermeyer & Matschinger, 2003). *beyondblue* recognises that stigma and the associated prejudice and discrimination are difficult to overturn, saying in their Strategic Framework (2005–10) after their first term, “it cannot be asserted that Australian society now understands and responds to the personal and social impact of depression, without stigma and discrimination. It is clear and certain that there is important work to be continued” (p. 8).

#### *Delays in recognising symptoms and seeking formal help early*

Stigma is problematic for several reasons. One is that it impedes potential carers (i.e. family and friends) from being able to develop an in-depth, rather than cursory, understanding of what depression is; an “illness that is prolonged, serious” [Cons\_2] and episodic. This kind of knowledge is particularly important to develop because the lack of first-hand experience makes it difficult to relate to; “depression is all experiential” [Cons\_21]. “If you don’t have it, you don’t understand how debilitating it is” [Cons\_9]. Stigma can therefore capitalise on a person’s “ignorance” [Carer\_11] or “fear” [Cons\_18] of mental illness.

Family and friends are important sources of informal support, and their being able to recognise the symptoms of mental illness is critical for seeking help early, including when consumers “drive away the people who are close to [them]” [Cons\_21] and “withdraw” [Cons\_1] and “isolate” [Cons\_32] themselves. Indeed, if consumers have ‘self-stigma’ – internalising the shame associated with mental illness and labelling themselves as “weak” [Cons\_3], “lazy” [Cons\_2], or a “burden or disappointment” [Cons\_3] to their family and the “family name” [Cons\_9] by “airing dirty laundry in public” [Cons\_11]) – then there is a risk that the severity of symptoms will escalate due to personal barriers. Consumers may go to great lengths to “look normal” [Carer\_20] and help manage any guilt in the family (e.g. “my parents feel they’re a failure” [Cons\_25]), but this can lead to a situation where “the effort it takes to cover up is almost worse than being depressed” [Cons\_10]. Sophisticated knowledge and understanding in the general community about the complex and lived experience of mental illness can help mitigate delayed recognition of symptoms and formal help-seeking.



This is especially important because “most people, when they’re severely depressed, won’t seek out help. When we’re really ill, we don’t” [Cons\_16]. This, in turn, may be related to feelings of: (a) *worthlessness* (e.g. “I didn’t feel I deserved help, that it was a waste of government resources, they should allocate it to people who deserve it, were worth it, were more valuable than I” [Cons\_21]); (b) *denial* (e.g. “denial was holding me back from getting help” [Cons\_27]); (c) *pride* (e.g. “I didn’t open up to anybody, I just struggled on like a warrior. ‘Warrior’ may be a glorious word, but there’s nothing glorious about depression. You should reach out to somebody. There’s nothing praiseworthy about being too proud to tell” [Cons\_15]); (d) *avoidance* (e.g. “I left to try and commit suicide because I thought, ‘I’m never going to get better and I’m a burden to my family’. Then I thought, ‘if I’m considering suicide, maybe there’s something wrong with me’. I waited until it got so bad that I was almost incapacitated before I got help” [ConsCar\_2]); (e) *resistance* (e.g. “he refuses to go to a doctor or counsellor” [ConsCar\_1]); and (f) *minimisation* (e.g. “you could see [my wife] was depressed, but I didn’t realise exactly how depressed until she tried to OD on some Valium. That was a wakeup call” [ConsCar\_5]). All these thoughts and feelings reflect the bigger issue of stigma (e.g. “the guilt and shame of being officially classified a basket case stopped me getting formal help” [Cons\_21]; and “because of the stigma, I just couldn’t face the idea that I needed to see a psychologist” [ConsCar\_2]).

As it is, “a lot of people [with] a mental illness [can be] victimised by society” [Carer\_15]; specifically, by their families, friends, and at work. For example, participants said: “some of my family are very patronising” [Cons\_11]; “families are so utterly cruel about it” [ConsCar\_3]; “the phrase ‘attention seeker’ – because you don’t want to do something – is still the most common put-down” [Cons\_7]; “my husband said if he’d known I had depression earlier in my life he would never have had anything to do with me” [Cons\_17]; “I lost a few friends once the word got around. On the other hand, it flushed out all the fickle friends” [Cons\_21]; “you get made to feel lazy, like I just couldn’t be bothered turning up to work. I ended up having to resign” [Cons\_9]; and “you can’t say, ‘I’ll be better in six months or a year’ because you don’t know. We were in dire problems financially [with] no or very little income” [Cons\_17].

Thus, mental illness has a global impact on consumers’ lives, and mere exposure to advertisements and the idea that mental health issues are a common experience, are not sufficient for decreasing stigma; this is something that will need to be broken down and challenged at the individual level, where a *person* takes responsibility for their stigmatic attitudes and behaviours. Sources of informal support that are truly informed can help carry some

of this load in the form of empathy and non-judgmental attitudes and behaviours, as well as encouragement of formal treatment.

### *Engagement with health professionals*

Stigma also affects the way health professionals engage with consumers. For example, general practitioners (GPs) were not seen “to have a lot of knowledge” [Cons\_31]. This is problematic because consumers and carers understandably have a higher expectation of this sector of the community in regards to awareness levels. They are also often the first point of call for consumers and carers seeking formal help, so informed, caring, empathic, passionate, compassionate, hopeful, encouraging, and positive experiences here act as a signal for the possible effectiveness of longer-term treatment (e.g. “mental illness needs to be recognised by health professions, who have the capacity to help acceptance of treatment and prevention in the community” [Cons\_18]).

It may be that “depression is not seen as an illness in the way we view physical illness” [Cons\_2] even among GPs, where “six weeks off for glandular fever is [seen] a lot different than six weeks off for depression” [Cons\_9]. Perhaps the litmus test for the eradication of stigma is when mental illness is treated in the same way that a physical illness is; “if anyone regarded somebody who has depressive anxiety as if they have a broken leg, then I would say the stigma had gone. That would sort a lot of problems out” [Carer\_24].

However, health professionals – general and specialist – also need to take care not to medicalise mental health problems rather than engaging with consumers holistically (through the provision of not just empathy but constructive practical strategies as well). Several participants indicated that medication was necessary for them (e.g. “I’d be dead if my GP hadn’t said ‘take these’” [Cons\_8]; and “I don’t care if I’ve got to take medication for the rest of my life. Something in my brain[’s] not working properly chemically. I need this to function. It doesn’t make me happy, but it stops me feeling like crap” [Cons\_27]). However, several others expressed resistance to the ‘medical model’ (e.g. “I had post-natal depression after all my children. Every doctor instantly would try to put me on anti-depressants” [Cons\_31]; and “if you have good counselling set up, more people will be inclined to do that than be stuffed full of medication, which is the medical model. People have feelings” [Carer\_15]).

Thus, psychosocial rehabilitation should be encouraged because it is holistic and empowering (e.g. “medication and counselling go hand in hand. They can fix the symptoms in the short term, but you also need to work on the stuff that’s in your head” [Cons\_4]; “they wasted so much money on medications and hospitalisations. Who

would have thought it would be as cheap as a dog and a community choir?!” [Cons\_11]; “talking to people who have similar experiences [in support groups] is the most critical thing, and it’s what you can do early on” [Cons\_16]; “[it is important to have] a GP who’ll look at you holistically and be responsive” [Cons\_30]; and “in an ideal world, I would love if they focus[ed] on total health care; realising that mental illness has a flow-on effect over the total body. [That] it’s not just brain chemistry that’s the problem” [Carer\_17]).

A psychosocial approach also helps ensure that responsibility for power differentials between professionals and consumers is taken. For example, participants said: “my best experiences have been through counsellors. Basically, the more casual their title, the better [they are] to relate [to and] form a proper relationship” [Cons\_3]; and “there needs to be more focus with psychiatrists on developing empathy, and not just looking at identifying a symptom and treating that. Because I was treated like that, I didn’t want to talk about it, I didn’t feel comfortable. You’re just touching the surface. ‘Well, I enjoyed the seat – \$200 later!’” [Cons\_2]. In one discussion, participants said:

“Sometimes people going through issues won’t hear it from a psychologist. If they hear it from somebody who’s been there, they take it on board more; an ‘expert by experience’” [Cons\_11].

“You’re not such a victim [then]. When you’re talking to a doctor, it’s more professional. You’re the victim and they’re the doctor” [Cons\_9].

“The big powerful doctor” [Cons\_11].

#### *A well-resourced treatment response*

Finally, stigma affects structural factors. Adequate funding for a system that is easy to navigate, cost-effective/affordable, and continually available is another indication that mental illness is being addressed in a way that does not further perpetuate the many forms of discrimination consumers already face. For example, participants said: “I’m lucky because I’m a registered nurse. I know the ins and outs of the public hospital system. But I worry about the person next to me who doesn’t have any idea how to contact anyone, what to do, or what to ask” [Cons\_18]; “people can barely afford the prescription let alone the [psychiatrists’] sessions” [Cons\_7]; “the more you try to find a service that fits, the more you get referred on to other services. It’s a big roundabout, and turmoil in itself” [Carer\_9]; and “you need someone round the clock. These places are nine to five. What do you do after that?” [ConsCar\_4].

A well-resourced ‘mental health response’ by “the federal government” [Carer\_14] would also ensure that services: (a) *were adequate in “regional areas”* [Carer\_13], (b) *addressed co-morbid substance abuse* (e.g. “they’re not dealing with the two issues together. ‘Oh sorry, you have drug problems. That’s not our problem. That’s somebody else’s problem’” [Carer\_24]; see also Tobin, Matters, Chen, Smith, & Stuhlmiller, 2001), (c) *avoided lack of consistency in professionals* (e.g. “[my husband] saw six psychiatrists [while in hospital]. If you’ve got a sore knee, imagine telling the story six times?” [Carer\_21]), (d) *avoided long-term misdiagnosis* (e.g. “my son has a diagnosis of schizophrenia, but that’s been up and down like a yoyo for about 20 years. Now they say he’s bipolar. I don’t know, because I’m dealing with experts” [Carer\_15]; and “I was glad when she said ‘you’ve got depression’ because I didn’t know what was wrong with me. It was a relief to find out” [Cons\_26]), (e) *were sensitive to the recurring nature of mental health issues with centralised health information systems* (e.g. “it’s an illness. It’s recurring. It’s not going away. So why can’t we, as a society, have a structure that is elastic enough to go with the ebbs and flows. If you keep having to go back all the time, it keeps you stuck in the pain of the past. It’s counterintuitive” [Cons\_8]), (f) *had capacity to acknowledge the effort consumers are making* (e.g. “we’ve been married 39 years. He’s [husband] been really well for the last two and a half. It’s just dawning on me about how much hard work he’s putting in to maintain his good health” [Carer\_21]), (g) *monitor the implementation of policies* (e.g. “it’s one thing to have a policy, but if [the papers] sit on the wrong person’s desk, it doesn’t get implemented” [Carer\_13]), (h) *are not “top-heavy [with] hierarchy [and] administrative duplication”* [Cons\_30], and (i) *are funded more than just “twelve sessions a year [which] aren’t enough”* [Cons\_11] (e.g. “I heard on the radio the other day that mental health services are 13 per cent of all services, yet it only gets six per cent of the budget, so they don’t even get a one-on-one percentage wise” [ConsCar\_5]; and “people put more in research on coronary artery disease than mental health” [Carer\_15]).

### *Summary*

In summary, stigma: (a) impedes the effectiveness and full potential of awareness-raising campaigns including the development of in-depth knowledge, (b) impedes early recognition of symptoms and formal help-seeking especially when it is internalised (‘self-stigma’), (c) impedes health professionals from offering a holistic treatment approach (e.g. providing empathy, encouraging psychosocial rehabilitation, and taking responsibility for professional power differences), (d) impedes funding towards a well-resourced system that reflects mental health as a prioritised response by health care service providers and government, and (d) is difficult to overturn

(e.g. “it’s very difficult to change an attitude in society” [Carer\_17]). It is probably *the* fundamental issue in the consumer’s social experience of mental illness, with a net effect of stigma in both individuals and society feeding each other, and perpetuating and entrenching its potency.

### **‘The carer experience’**

#### *Carer identity and nature of caring*

Part of the experience of being a carer is identifying as a carer, which not all do – both from the carers themselves and others: “I have an issue saying I’m a carer because I don’t do physical things – wipe their bottom, pick them off a bed to put them in a wheelchair – but that’s my own problem. I hated saying I’m a carer because then it feels I’m supposed to be wiping his [husband] backside every day, when in fact all I’m doing is making sure he gets out of bed, eats, and if there’s any stress in our life, I’m trying to sort it out. We’re not seen as true carers in that respect” [Carer\_20].

The nature of caring for a person with mental illness is such that it is: (a) *time-consuming* (e.g. “I look after my wife [with] bipolar. The plan is that I’m part time looking after her, but often it becomes extended like the whole week. Fill[ing] up the car or dropping a video off is a major event” [ConsCar\_5]), (b) *unpredictable* (e.g. “as a carer, we all know it’s a roller coaster, isn’t it? It’s good, good, good and then the bad comes” [Carer\_14]), (c) *tiring* (e.g. “when my reserves are low, I’m impatient. I get angry, fed up. Because I’m involved virtually in a one-sided discussion and I can’t win it. It’s very wearying” [Carer\_15]), (d) *all-encompassing* (e.g. “I don’t want my son’s illness to define me. I have had to work very hard to not let this consume me” [Carer\_19]), and (e) *ongoing* (e.g. “the difficulty is that because your family and your friends are the people closest to you, for them it doesn’t end quickly. It goes on and on, and they need to support you for an extended period of time. That takes a huge toll” [Cons\_16]).

The stressful nature of caring is so great that some carers said: “it’s so ironic. You only get 10 years for murder” [Carer\_5]; “I had to put a court order on my mother for six months. It’s the hardest thing I ever did. She resented that but she hasn’t abused me again. Sometimes we’ve got to be cruel to be kind” [Carer\_6]; and “when [son] died, it was so desperately sad, but there was almost a relief. He was a beautiful human being, but his personality was just starting to disintegrate. There’s a hell of a lot of guilt over stuff you can’t control” [Carer\_21].

#### *Difficult behaviour*

Carers cope with difficult behaviour, which compounds the exhaustion associated with caring, and explains in part why stigma within the family is so high. For example, consumers perceive the label 'attention-seeker' as stigmatic and have no control over their illness, but this is difficult for carers to understand or have empathy for because they still perceive that attention is being taken away from others in the family. As one carer said, "as soon as I cuddle my three year old, my mother turns her back, because it's always about her. I feel bad when I cuddle my three year old. It's horrible. The feelings I have to feel, to please my mother, are horrible" [Carer\_6].

Carers may also feel that consumers have become so dependent on them that they are being taken for granted:

"I had to go away because [wife] wasn't getting any better. She was getting worse because she was relying on me so much. Going away meant she had to get out of bed [and] look after herself" [Carer\_4].

"It is very difficult when [they've] got no insight into their condition" [ConsCar\_1].

"The more you do for them, it's never enough anyway" [Carer\_6].

"They will take you for granted; they will let you do everything" [ConsCar\_1].

"My mum's over for tea every night but she'll leave the dishes for me. You think, 'oh, can you wash even just that one cup?' But she won't offer" [Carer\_6].

"I said to [wife], 'if anything happens to me, what are you going to do?' She said, 'well, when you die, I'll do something about it'" [Carer\_4].

"Did you say, 'I'm already dead. I'm already dead'?" [Carer\_6].

Finally, carers cope with "extremely objectionable, angry" [Carer\_7], and/or violent behaviour. For example, carers said: "my son [is] as nice as pie to a whole lot of people, yet I get taken apart" [Carer\_15]; "that's the other side of depression too, anger. People don't talk about that enough. Depressive people can get very, very, very angry at you" [ConsCar\_1]; "the verbal abuse is as bad as physical abuse" [Carer\_1]; and "when she [daughter] came back to my place, she was very violent, full of rage. Said she was going to kill me" [ConsCar\_1].

*Fear, worry, and grief and loss*

Carers also experience a range of emotions including fear, worry, and grief and loss. In regards to fear, some participants said: “we have the phone on all the time” [Carer\_24]; “my daughter hasn’t suicided for some time, but she’s threatened to. I can’t get over the fear that runs my life” [Carer\_17]; and “with my husband, who had three fairly significant suicide attempts, I got to the point where I was scared to go home because I never knew what I’d find. He was saying things like ‘we can’t be together because you might cop a bullet that’s meant for me’. I feared for my safety” [Carer\_11].

Fear in carers is not just of the unknown, but also of the consequences of taking action to protect oneself or seek help, e.g. “you’re scared of the ramifications. Like if someone got locked up because you rang the police on them, and then they get out, you feel like they’re going to come for you. That’s like battered women syndrome, where women feel safer to go back to the man that’s beaten on them” [Carer\_6]; and “a lot of times when he [husband] was having a bad episode, I’d say ‘I’ll ring the [mental health NGO] team’. ‘No, you don’t. Don’t you ring them. Or I’ll walk out and I won’t come back’” [Carer\_1].

Carers also worry about their consumer child “when the folks pass away” [Carer\_16]. One said, for example, “we’ve finally managed to sort out our will so that when we’re not around – which is a big worry for all of us – he [son] has some protection” [ConsCar\_5].

Finally, carers may feel a sense of grief and loss over ‘what could have been’ for both their family member and themselves. Participants said: “I want to break free from all of this. I’m 38. I’ve got a life to live and I haven’t got it yet” [Carer\_6]; “for those that have developed an issue later in life, you have to grieve the person you lost. I was told he would never, ever be the person he was when he first met me” [Carer\_20]; and “that’s one of the curses of being a carer. If you had the choice, you would be somewhere else. I have a life too ... And your family member would have the life that you thought they were going to have when you brought them into this world. A [carer] friend [of partner and children consumers] said, ‘you just need to let go of the story of how you thought your child’s life was going to be’” [Carer\_17].

### *Coping*

Carers may feel helpless, even if the consumer is receiving formal treatment (e.g. “as soon as he [son] was diagnosed [with depression], we did everything. I used to say to a psychiatrist, ‘what more can we do?’ He said, ‘you’re doing it’. But it’s that horrible feeling that you can’t make it better” [Carer\_21]). As a result, helplessness can cause carers to look for escape in other areas of life (e.g. “I used school as my safe haven,

somewhere I could go and forget about it [mother's bipolar]" [Carer\_8]; and "going to work was wonderful. You could get away for a while" [Carer\_5]).

Long standing feelings of helplessness and witnessing long term suffering of a family member can also cause carers to accept or prepare for their death, e.g. "this might sound hard, but we came to the conclusion that if it [suicide] did happen, we understood. 'If this is the life he is leading, it would be understandable he might do something'" [Carer\_15].

Carers can also develop their own mental health problems. For example, participants said: "have I been depressed since? Yeah, probably. But not to the stage that [it] becomes a real problem [and] you cannot exist in your daily routine. I think depression is something that follows us all like a shadow. I mean, grief is a form of depression" [Carer\_15]; and "I've started to feel depressed lately because I've never felt like I've had a life. Mental illness has made me depressed and my life a misery. Every year I want to burst out, live a real quality life, grab it with both hands [but] I haven't been able to have a job, a relationship, or anything without my mum being the centre of attention all the time" [Carer\_6].

When coping was effective, it involved: (a) *prioritising the self* (e.g. "if we crash, everything's going to crash. We realised we had to look after ourselves" [Carer\_24]); (b) *sharing the caring when possible* (e.g. "our daughter had this amazing ex-boyfriend. We worked like a tag team. I still think she would be dead if he didn't find her and bring her home ... I used to handle it most of the time. Then my husband would take the baton" [Carer\_14]), (c) *humour* (e.g. "we talk about it openly to people. [Husband] will say funny things like, 'I've got to take my crazy pills, just a minute!' We've been lucky we've been able to turn it into a humorous story. Humour [has] enabled us to cope, even though it's not funny at the time" [Carer\_11]), (d) *faith or hope* (e.g. "not necessarily being Christian, but having faith or hope in something, can help you take that higher perspective. I think that can help" [ConsCar\_1]), and (e) *respite* (e.g. "Commonwealth Respite Centre. I've had someone come out and clean my house for two hours a week, up to eight weeks at a time" [Carer\_20]).

#### *Resistance to self help-seeking*

Carers may find it difficult to accept help because it is not part of their usual role or self-construal. For example, carers said: "I was determined I was not suffering from depression. 'I might get depressed about certain things, but I'm not suffering from depression'" [Carer\_19]; and "I got help. But I had to hit rock bottom ... 'Why did I let it get to that stage?' Because I was the one that needed to be handling things" [Carer\_13].



Given this resistance to seeking help, it may be helpful to boost *information* about mental health more to carers than mental health *services* or programs. This is an example of informal help and the study did find that the ‘carers only’ accessed more information than services. Unfortunately, it also found that male carers access less information than female carers.

Thus, resistance to seeking help appears heightened in male carers due to the processes of gender socialisation. Carers said: “the male ego has always been that you don’t show your emotions” [Carer\_6]; “women get things out, where men keep it bottled up” [Carer\_1]; “I went into the bathroom, away from my wife, and had a quiet sob, until I sorted it out. I came out, under control again. Because men are supposed to be in control” [Carer\_15]; and “there’s a problem with men. Men are the ‘Mr Fix-its’. We go through a stage of some years of trying to rectify the problem. ‘If you do this, if you do that, if you get out of bed, if you study, if you get a job, it’ll all be okay’. But it either drives the son or daughter away, or breaks the marriage up. Most men just say, ‘it’s too hard. I’ll bail out’” [Carer\_24].

Overall, not all carers need help themselves. However, resistance to seeking help may occur for a number of reasons such as not identifying as a carer, not acknowledging or prioritising their own mental health (‘self-care’; McAuliffe et al., 2009), and being aware of stigmatic attitudes in society for seeking help (Corrigan, Druss, & Perlick, 2014). Formal help for carers (despite their resistance) may actually be an important element of the healing process for both consumers and carers. The long term stress associated with caring for a family consumer may eventually ‘take its toll’ on carers, compromising their ability to provide the empathy consumers desperately need – for the mental illness as well as the life events that may have contributed to it.

#### *Impact on family relationships*

The way caring affects other family relationships depends on who the consumer is – partner, child, or parent. Carers with consumer partners are at high risk of divorce, but “it’s individual carers making the choice to either stay or go. I chose to stay. I’m traditional – ‘in sickness and in health’. A majority of people don’t stay” [Carer\_10].

Generally, carers with a consumer child felt that their “family have been incredibly supportive” [Carer\_7], but there was also a tendency for them to talk less about the effect of the mental illness on their relationship with their consumer child, and more about how their caring role affected the quality of their relationship with their partner (e.g. “[husband] said, ‘you’ve said it all before and nothing’s changed’, [so] we made a decision that she

[consumer daughter] would go, rather than one of us. A lot of people would say my child come[s] first, but in our case she had to be removed from our house for us to exist. She's happier, we're happier. That's what saved us" [Carer\_14]). Arguably, carers whose partner is not the consumer are at an advantage in terms of receiving social and emotional support from each other (e.g. "I feel shockingly for people who don't have someone supporting them. That would be so hard. Because no matter how much shit happens, you've got someone else there" [Carer\_21; consumer child]).

In the same way that carers with consumer children expressed concern to protect their marital relationship, carers with consumer parents also talked about the impact of caring on their own marital relationship (e.g. "we've had to spend a lot of time setting guidelines, but it doesn't make it any easier on our relationship. We're going to bed at 11 o'clock at night. That's where we're talking. Because we can't talk in front of Dad [consumer]" [Carer\_13]). (Unfortunately, the voices of young carers – referred to in the literature as 'COPMI' [Children of Parents with a Mental Illness; Alliston, Kluge, & Fudge, 2009] are not represented in this study; only one such participant took part).

Different family member attitudes can also increase friction and stress; "we separated [husband], because all his Dad wanted to do was belt it [depression] out of him [consumer child]. My eldest daughter, she's in denial – 'he's fine'. My mum said he just had to grow up. [Brother's] jealous because he was getting the attention. And they think he's a loser. Now I'm just that tired, I can't cope anymore" [Carer\_12]. Thus, the impact of mental health issues on family relationships and dynamics can be significant.

#### *Impact on friendships and work*

Caring affects ability to maintain previous friendships, but they also helped carers determine quality friendships. As examples: "friends we thought were very good friends fell off like flies. To restore your faith, a couple of people came out of the woodwork that we knew vaguely but then offered help" [Carer\_11]; and "with our friends, they have been absolutely fantastic and very aware and supportive. But then, we've been really open too" [Carer\_21].

Caring also affects families financially. Participants said: "I took some time off work because I realised I needed some time out" [Carer\_19]; "the financial impact is huge. We used to live the high life. Thank God we did, because we've got those memories" [Carer\_21]; "I'm the only person I know that uses up their carers' leave, annual leave, sick leave, their full entitlements for the year" [Carer\_20]; and "the work I do requires a lot of

concentration [but] my capacity to do my job [is] diminished. Then I get upset. I became resentful [of] the impact my family situation was having on my professionalism and what I wanted to achieve out of my job. I was always worried too that, if I was unable to do my job, what happened if I lost my job?" [Carer\_17].

#### *Lack of awareness and acknowledgement*

Finally, carers do not feel acknowledged for the informal work they do in supporting consumers, including by governments and professionals. Participants said: "it can be quite thankless" [Carer\_17]; "even government departments have a bias or stigma. 'Do you wipe their backsides? Do you feed them with a spoon?' That sort of stuff when you're filling out the carers' payment form, for instance. They don't give reports to such things as cleaning their house, cooking, gardening. Honestly, they would have been evicted from their houses long ago. Those things are not counted" [Carer\_24]; "it's important to get that professional network around you who do honour and support your role" [Carer\_17]; and "unbeknownst to us, he [son] was going to be discharged. They didn't consult with us. They don't respect your knowledge. They don't use the resources that are there. We are a resource. We're not part of the team" [Carer\_21].

#### *Summary*

The findings show that caring is a multi-faceted phenomena. As it is unrelenting, intense, stressful, difficult, and unpredictable, the experience of being carer makes it a trauma of its own; one that is often unacknowledged (Misrachi, 2012), could be marked by the same psychological battering and emotional abuse identified in the family violence literature (Phillips & Vandenbroek, 2014), and have lasting consequences on their mental well-being. There is a clear and substantial gap in current service provision for them. That the formal treatment system 'leans' on carers in the form of poor acknowledgment and awareness of the extensive and persistent informal support they provide, creates a new group of 'consumers' who may not necessarily be mentally ill but who are mentally 'unwell'.

[Note: it is acknowledged that the recent consumer movement asks for change in language from 'mental illness' to 'mental unwellness'. As one participant said: "'mental wellness' is a better term because 'illness' is a medical construct. What you're trying to do is move these people from a degree of unwellness to a better degree of wellness. You might never get right back down here, but if you move from there to there, that's okay" [Carer\_15]. Ning (2010) also explains that 'recovery' and 'wellbeing' or 'wellness' are terms that are less pathologising and more holistic because they prefer a social model of care to a medical model and do not just

focus on the mental health problem. However, reconciling the needs of consumers, carers, and professionals about what constitutes appropriate and useful terminology is still being worked through. For the purposes of this paper, persons in need of clinical treatment are being differentiated from persons in need of non-clinical treatment].

### **Stigma in the family**

#### *Time and opportunity*

By first capturing the essence of the consumer and carer experience and honouring their individual needs without comparing them to each other, it becomes clear that they have different ‘stories’ to tell. It is also revealed that stigma within the family is high (Note: some families were supportive but this was not the general trend).

As consumers and carers spend most of their time with their family, and because caring is ongoing, family life becomes an environment that fosters strong stigmatic attitudes and behaviours; it is responding to the ‘hothouse’ of stress within it. However, in addition to family life being an environment that provides time and opportunity for stigma to develop, misperceptions of consumers’ control by carers, unequal division of attention within the household, and low insight into the carer experience by consumers, compound this.

#### *Misperceptions of control*

One consumer said, “a diagnosis like schizophrenia still has a lot of stigma attached, whereas depression is almost fashionable. People will go, ‘I’m so depressed’. It’s become much less stigmatised” [Cons\_11].

Contrarily, another consumer (with co-morbid schizophrenia) said, “maybe I’ve just been lucky, but I’ve never discovered a troublesome individual. I don’t tell everybody [about the schizophrenia], but when I do, it’s usually fine” [Cons\_15].

While schizophrenia was not a focus of this study, these findings are still informative for understanding the stigma associated with depression (and perhaps also anxiety, both of which were a focus of the study and the most common diagnoses in the sample). Specifically, it is possible that the general stigma associated with schizophrenia is comparatively higher than with depression, in part because it has more visible symptoms (Angermeyer & Matschinger, 2005), but when people interact with individuals that have schizophrenia they are less *judgmental* of them because schizophrenia is seen to be less within one’s control (Corrigan et al., 2001).

Indeed, common psychological treatments for depression and anxiety such as cognitive behavioural therapy (CBT) significantly centre on consumer's regaining (a sense of) control over their thoughts and lives, even if there is acknowledgement of their (sense of) lack of control. For example, participants said: "I am not my depression. I am me. And depression is something I suffer. I don't confuse that. It's not beneficial to me" [Cons\_8]; and "I did a bit of cognitive therapy. When I have certain thoughts, I [now] think to myself, 'no, that's your depression. You don't really feel that way when you're fine, you're only thinking that because you're having a bad time at the moment'. Just acknowledging that to yourself. You still feel like crap, but you just keep going" [Cons\_27]. In comparison, CBT is less commonly used for people with schizophrenia, and there has historically been greater emphasis on interventions that involve medication (Wykes, Steel, Everitt, & Tarrier, 2008).

Thus, the stigma associated with depression and anxiety may result in part from misperceptions of just how 'out-of-control' consumers feel, with the combined expectation that consumers are responsible for regaining it. Until they do, they (and not the mental illness) are perceived to be the cause of disruption to family's lives.

#### *Division of attention within the household*

Related to (mis)perceptions of control, a consumer may feel disempowered by family members when they are stigmatised for not meeting their expectations 'to do something' (e.g. "wash a cup" [Carer\_6]), when instead they are exercising their right to self-determination (or 'consumer autonomy' as Langlands et al. (2008) describe it). However, the capacity to exercise self-determination is seen by carers as indicative of a level of personal control. Thus, consumers who claim control over the right to behave in self-selected ways and at self-selected times (i.e. self-determination) – but who also claim feeling 'out of control' (e.g. "if we could 'get over it' we would. Like you choose to be here?!" [Cons\_11]; "if you could snap out of it, you would. Who would want to be in it? It's crazy" [ConsCar\_2]; and "it's like they're assuming you're enjoying being unhappy" [Cons\_2]) – confuse carers about the level of *actual* control they have over their mental illness.

This confusion or 'mixed message' creates the situation where carer's overestimate the level of (a sense of) control consumers have. In turn, this creates an expectation that consumers should take responsibility for their mental illness and thus reduce the impact it is having on family's lives. This can be heightened when carers see that great effort is being put into 'appearing normal' for others, but that the same effort is not being put in at home; where consumers finally feel they can be their true (depressed) selves, free from society's stigmatic pressure. Thus, when consumers are seen to hold on to their right to self-determination more than the extent to

which they are seen to be considering the impact their mental illness is having on family members, this can cause carers to become (more) judgmental of mental illness.

One of the most common ways this judgment manifests is in labelling consumers as ‘attention seekers’ (e.g. “when I attempted suicide for the first time, my mum and few of my siblings automatically called me an attention-seeker, and from that moment on that label stuck” [Cons\_4]). This stigmatic attitude develops because attention is a core human need (Fiske, 2004), and a limited resource that needs to be shared among family members. Self-focus is inherent to depression (Watkins & Teasdale, 2004), so it does inadvertently lead to skew in the distribution of attention within the ecological unit of a household, despite that it is not the consumer’s intention. Thus, the competing core need for attention among family members, the resulting disturbance in equilibrium due to the consumer’s mental illness, and that caring is an entrenched and long-standing stressor within the family, all cause overtly stigmatic attitudes to occur and be expressed.

#### *Consumer insight into the carer experience*

In the same way that carers find it difficult to relate to the consumer experience, consumers find it difficult to relate to the carer experience: “initially, it was tough because each didn’t know how to help the other. I didn’t know how [to] get my dad to come to my side and understand what I was going through, and he couldn’t get himself to come to my side. So there was that impasse that none of us could cross” [Cons\_21].

Bridging the gap between the consumer and carer experience requires depth of understanding, empathy, and insight from both parties, but given that mental health issues have such a substantial impact on (the quality of) family life, the question here is ‘do consumers have insight into the carer experience?’, and the answer is ‘few do’ (e.g. “people are often far more supportive than we give them credit for” [Cons\_8]; “with the whole depression and anxiety, I just got to be a mean person. I was arguing about everything. Whatever people did, it was just not right” [Cons\_13]; and “I was touchy and reactive” [Cons\_11]).

In one discussion, some consumers said: “when you get involved in a [support] group you think you’re in a safe place. But I’ve been burnt ... She offloaded all her problems onto me. It can smother you” [Cons\_25]; “in [my support] group, I didn’t need someone talking about mental health issues all the time and offloading it onto me. It drained me. It’s about boundaries and being safe” [Cons\_31]; and “I [saw] a lovely lady on the weekend [but] it was like four hours of offloading. I felt so exhausted that I ended up hiding in the room from her. It’s about recognising that this isn’t healthy for me” [Cons\_30]. In all these instances, consumers experienced the

exhaustion carers live with, but did not demonstrate self-awareness and insight about their own capacity to exhaust others.

Some consumers also reported feeling helpless when their carers came to them for assistance with their depression. For example, one consumer said, “she’s [mother] not been diagnosed, but recently she’d had real anxiety and depression issues. When she said, ‘what should I do?’ I was like, ‘oh, I don’t know, it’s not that bad, just keep going to work. Go to a GP, mental health plan, you’ll be right’. I didn’t know what to do. And I’ve been through it!” [Cons\_1]. Such experiences reinforce the need to educate the public (carers and consumers) on how to react to/talk with and support consumers.

### *Summary*

In short, consumers’ are less in control of their mental illness than carers may acknowledge or realise, but because the on-going nature of caring makes it exhausting, carers’ frustrations and stigmatic attitudes and behaviours may cause consumers to (further) withdraw from what they perceive to be unsupportive families. This exacerbates the loneliness and social isolation characteristic of depression, and entrenches their need for empathy. Arguably, the greater the consumers’ need for empathy, the less insight they have into the impact of their mental illness on the family, who also want their experiences to be understood. Thus, a vicious cycle begins to reinforce the disjunction between consumers and carers.

## **Discussion**

### **Summary of findings in relation to previous literature**

The findings of this study overlap with those identified in previous research: consumers and carers share some experiences such as impacts on family relationships, friendships, work and financial circumstances, and mental well-being, but their needs overall are substantially different from one another. This calls for a third party to act as a ‘broker’ and mediate their respective needs, specifically, the formal health care system. Formal treatment can meet the consumers’ ‘fight for life’ and the carers’ need for ‘quality of life’.

Families can play a critical role in the early stages of recognising symptoms and providing supportive, empathic, and encouraging responses to seeking help (which all in turn require awareness-raising campaigns that are in-depth rather than cursory in the knowledge they provide). However, families cannot really be expected by either

the health care system or consumers to provide expert and ongoing help, because when they are there is a risk that they too will need their own form of intervention, leading to an increased number of people in need of help.

Consistent with this, carers said: “the psychiatrist said, ‘just remember, you need to be his parent not his therapist’. That was really liberating for me. It’s my job to love this child [and] I can contribute to his recovery in many ways, [but] I can’t fix this. I am not the expert here” [Carer\_22]; “I got to the point where you say, ‘I can’t do any more than I’ve done. It’s his [husband] responsibility’” [Carer\_11]; and “the person they’re talking to needs to just listen without offering advice too soon. Sometimes it can be complicated by friends who think they know, so they start down a different direction to where the[y] actually need to go” [Carer\_9].

Additionally, consumers have every right to expect a health care system that is fully resourced to provide them the help they need, (often) to save their life (McNair et al., 2002; Ning, 2010). That is, a robust health care response should be the first point of call upon diagnosis, and to help ensure that barriers to help seeking are overcome, stigma needs to be addressed. Stigma seems to permeate and frame the entire experience; eradicating it would move consumers to access high-quality services that they need quickly and relieve family carers of providing thankless, ongoing, and stressful informal support that essentially hides mental illness from the community. In short, a whole-of-community approach is required – one that is aware, informed, and empathic to consumers’ and carers’ respective needs; when such systemic infrastructure is in place, suicide prevention and strategies for intervening early are likely to be more effective.

### **Recommendations for policy and practice**

A number of recommendations for policy and practice emerge from the findings, which have the potential to ease stigma within families. These include:

- Continuing campaigns that promote in-depth knowledge and awareness of mental illness and directly address issues of stigma
- Normalising help-seeking
- Educating health professionals (general and specialist) about an holistic treatment approach
- Adequately funding formal mental health systems
- Offering formal treatment, support, and information for carers, and
- Acknowledging and including carers in family-oriented treatment for consumers.

### **Conclusion**



While a number of strategies can and should be implemented, at a ‘bigger picture’ level it is argued that there are two important and necessary tiers for effective service delivery. The first is a ‘top-down’ approach that stresses the importance of structural or systemic efforts to increase community awareness, decrease stigma, promote awareness of its social and economic impacts, and improve treatment; these efforts help ensure that *all* individuals benefit from a system that is sensitive to and aware of mental health issues. The second is a ‘bottom-up’ approach and draws attention to the fact that the impact of depression, anxiety, and related disorders is unique to the individual consumer and carer, and thus it is also important that within a system that is sensitive and aware, treatment places the individual at its centre so that it can be tailored to meet individual needs (‘person-centredness’; Amering, 2010) and thereby take a flexible, local, and responsive stance. By sufficiently resourcing these two necessary tiers, there will be a better chance of nourishing a positive feedback loop between individuals and society and thus address what seems to be the fundamental issue: stigma.

### **Study limitations**

The focus groups varied in length from 2 to 2.5 hours, and thus were in-depth. They also recruited widely across four states (New South Wales, Victoria, South Australia, and Tasmania) to ensure national representativeness. However, the extent to which the findings transfer to international contexts requires caution; themes identified in an Australian sample of 61 may or may not generalise to other countries – both developed and developing – and needs rigorous investigation.

### **Future research**

While it may be slow or difficult to overturn such pervasive barriers as stigma, it is still crucial to monitor the extent to which it is perceived to affect the lives of consumers and carers. In doing so, any decreases in stigma can be acknowledged, and any increases can be more quickly addressed. Thus, ongoing research in relation to consumers’ and carers’ psychological well-being, sense of inclusion, and ability to participate fully in society and ‘a contributing life’ (National Mental Health Commission, 2012), is critical to monitor over time.

Overall, the study points to the doggedness of stigma and the need to fully appreciate the obstacle it presents to social and clinical functioning. But after establishing its firmness, the theoretical question still remains: why? Future research, perhaps using evolutionary psychology in a search for some root causes of stigma, may need to be explored. If nothing else, such a line of inquiry may help contribute to the development of realistic

expectations of how quickly stigma can be addressed. It would be consistent with the critical call of Maj (2016) to acknowledge the complexity associated with mental illness without being defeated by it.

<sup>1</sup> See original report for all findings (Sawrikar, Muir, & Craig, 2011).

<sup>2</sup> <http://www.mentalhealthcommission.gov.au/media-centre/news/can-we-talkabout-mental-illness-and-suicide.aspx>

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