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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Abstract

Objectives: The objective was to explore Australian mental health carers' prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Design: Cross-sectional survey.

Setting: All Australian States and Territories.

Participants: Responses were received from 231 Australian mental health caregivers.

Main outcome measures: The Involvement Evaluation Questionnaire was used to assess caregiver burden.

Results: Smallest space analysis identified three distinct regions, which were conceptualised as:

1) promoting the safety of mental health consumers; 2) enabling the recovery of mental health consumers; and 3) impact of caring on caregivers' personal lives. The analysis demonstrated that carers were most concerned with enabling recovery, for which the mean value was considerably higher than the personal impact and promoting safety regions. In terms of the individual questionnaire items, the issues of most importance were assisting with self-care, worrying about consumers' future, finances and general health, encouraging consumer involvement in activities, and concerns over the treatment consumers were receiving.

Conclusion: Caregiving often came at significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support, and providing tailored psychosocial interventions that meet the needs of families.

Strengths and Limitations

- To our knowledge, this was the first Australian study to examine mental health carers prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden
- Qualitative data was used provide further insight into the quantitative findings
- Respondent bias may have influenced our results

Background

The deinstitutionalisation of services has seen informal carers becoming increasingly involved in the mental health system (Gutierrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005; Sales, 2003). Carers in adopting these roles face ongoing challenges, which may include advocating on behalf of mental health consumers, crisis management, helping with daily activities, and providing financial assistance (Kuipers, 2010; McFarlane, 2016; P. Morrison & N. J. Stomski, 2017). The burden associated with assuming these responsibilities, coupled with the impact of witnessing their relative experience mental illness, means that carers often report significant levels of distress (Kuipers, 2010; Magliano et al., 2000; McFarlane, 2016; Stomski & Morrison, 2018).

About one third of mental health consumers' family members experience emotional distress (Magliano 2000; moller-leimkuhler 2006) (Magliano et al., 2000; Moller-Leimkuhler & Wiesheu, 2012). Such distress may encompass feelings of loss, anxiety, and distress (Cormac & Tihanyi, 2006; Kuipers, Onwumere, & Bebbington, 2010; Oyebode, 2003). In addition, caregiving may lead to social isolation, reduced work productivity, financial loss, and disruption in family routines, which may substantially impair carers' quality of life (Cormac & Tihanyi, 2006; Hayes,

1 Hawthorne, Farhall, O'Hanlon, & Harvey, 2015; Kuipers et al., 2010; Magliano, Fiorillo, De Rosa,
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3
4 Malangone, & Maj, 2005; P. Morrison & N.J. Stomski, 2017).

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8 Several factors have been identified that influence mental health caregiver burden. Studies
9
10 have shown that caring for a male mental health consumer leads to significantly higher levels
11
12 of stress (Magana, Ramirez Garcia, Hernandez, & Cortez, 2007). Other demographic
13
14 characteristics that effect burden include lower levels of caregiver education and younger
15
16 carer age, both of which have been associated with higher levels of depression (Finch, Kolody,
17
18 & Vega, 2000; Gonzalez, Haan, & Hinton, 2001; Papastavrou, Charalambous, Tsangari, &
19
20 Karayiannis, 2010; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Also,
21
22 supporting consumers who display heightened positive or negative symptoms exacerbates the
23
24 detrimental impact on carers' quality of life, work efficiency, and lost days of work (Rabinowitz,
25
26 Berardo, Bugarski-Kirola, & Marder, 2013).

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33 Although much of the available literature focuses on adverse consequences, caregiving for
34
35 mental health consumers also results in beneficial outcomes for carers. Some mental health
36
37 carers' note that supporting consumers has sensitised them to the needs of people with
38
39 disabilities, enabled them to clarify their priorities in life, and enhanced their resilience (Gupta
40
41 2015) (Gupta, Solanki, Koolwal, & Gehlot, 2015). The sense of satisfaction and meaning that
42
43 carers find in helping consumers has been associated with higher levels of quality of life (Doval,
44
45 Sharma, Agarwal, Tripathi, & Nischal, 2016; Kate, Grover, Kulhara, & Nehra, 2013; Kulhara, Kate,
46
47 Grover, & Nehra, 2012).

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54 Research has demonstrated that carers contribute importantly to the recovery of mental
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56 health consumers. In particular, the involvement of family members in the provision of mental
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1 health services has been found to decrease consumer relapse and rehospitalisation rates by 20-
2 50% (McFarlane, 2016). Other mental health consumer benefits that may be attributed to
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4
5
6 supportive family relationships include improved participation in vocational rehabilitation,
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8
9 higher employment rates, enhanced social functioning, and reductions in psychiatric symptoms
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11 (McFarlane, 2016).
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13
14

15 Limited quantitative research has examined issues involved with caring for mental health
16
17 consumers in an Australian context. The findings of these studies have reflected the results of
18
19 research conducted in other countries, in that they have shown that carers experience social
20
21 isolation and impaired physical and mental health (Hayes et al., 2015; Kenny, King, & Hall, 2014;
22
23 Poon, Curtis, Ward, Loneragan, & Lappin, 2018). To our knowledge, no prior studies in an
24
25 Australian setting have quantified aspects of mental health caregiving. Hence, the purpose of
26
27 this study was to explore Australian mental health carers' experiences through rating the
28
29 importance of key elements of caregiving and establish the extent to which particular issues
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31 contribute to carer burden.
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38 **Methods**

39 *Study Design*

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41 We undertook a cross-sectional survey of Australian mental health caregivers. The Murdoch
42
43 University Human Research Ethics Committee granted ethical approval for this study (Approval
44
45 Number 2016/215).
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52 *Survey Instrument*

53
54 The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer
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56 burden. The questionnaire comprises four scales: 1) tension (nine items), which assesses
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1 interpersonal difficulties between consumers and carers; 2) supervision (6 items), which
2 enquires about carers' monitoring consumer sleep, medicine intake, and dangerous behaviour;
3
4 3) worrying (six items), which captures details regarding troubling interpersonal like concern
5
6 about the consumer's future and safety, overall health, and quality of health care; and 4)
7
8 urging (eight items), which assesses the extent to which carers' encourage consumers to
9
10 undertake general activities and self-care (Wijngaarden van B, Koeter, Vazquez-Barquero,
11
12 Knudsen, & Lasalvia, 2000). Each item is scored on a five point Likert scale (never, sometimes,
13
14 regularly, often, always). Also, a single open-ended question allows carers to make comments
15
16 about their experiences.
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25 *Recruitment*

26 All Australian caregivers for mental health consumers were eligible to participate in this study.
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28 Twenty-two carer, mental health carer, and mental health consumer organisations
29
30 disseminated study invitation notices on our behalf through Twitter, Facebook, e-newsletters,
31
32 and online sites. We also personally distributed invitation notices through Facebook pages of
33
34 mental health carer and consumer groups. The invitation notices outlined the study's purpose
35
36 and provided the link for the online survey questionnaire. A comprehensive information letter
37
38 was placed at the beginning of the survey, which the prospective participants were asked to
39
40 read before starting to answer the survey questions. All responses were anonymous and return
41
42 of the questionnaire was used to indicate consent. Data were collected from March 2017 to July
43
44 2017.
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52 *Participant Involvement*

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54 Mental health caregivers were not actively involved in the design of this study, but did
55
56 contribute extensively to the development of the instrument used in this study.
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Sample Size

Cochran's formula for continuous variables was used to establish the number of returned questionnaires required to generalise the study findings. Given that there were approximately 15,666 Australian mental health carers (Morgan et al., 2012), and incorporating a 5% level of acceptable risk and 3% margin of error, it was established that 133 completed questionnaires were needed to generalise the study findings.

Data Analysis

Data were entered and analysed in the Hebrew University Data Analysis Package v.8. All demographic variables were reported descriptively. Smallest space analysis (SSA) was used to examine the structure of the dataset. It is an especially robust method that can be used to analyse many different types of data (Borg, Groenen, & Mair, 2013; Guttman & Greenbaum, 1998). SSA is one of a host of non-metric multidimensional scaling (MDS) methods used to represent relationship measures between variables or items in a low dimensional space (Guttman & Greenbaum, 1998). The SSA program calculates associations between variables, where the association between any two variables is expressed as the distance between them on a graph such that the smaller the distance between two plotted variables, the stronger the association.

In this instance SSA was used in an exploratory manner to uncover any hidden structures in the dataset that could be easily identified and displayed visually (Borg et al., 2013). It provides a means for reducing data and in so doing produces a summary of complex data that can be examined and interpreted. Themes or patterns may arise from the visual depiction. A particular clusters of variables, each of which represents a construct or theme that captures something

1 of the carers' experience, are derived from a partitioning of the graph into regions or
2
3
4 neighbourhoods. Moreover the open ended data collected in the survey may be used to assist
5
6 with the development and confirmation of any structures or themes in the analysis.
7
8
9

10 SSA also produces a measure, the co-efficient of alienation, of how well the plotted graph
11
12 represents correlations between the questionnaire items. The coefficient of alienation can
13
14 range from 0 (best fit) to 1 (worst fit) while coefficients of less than 0.15 are considered
15
16 satisfactory (Kumar & Ryan, 2009). Others have suggested that a coefficient of .20 (Donald &
17
18 Canter, 1994) or more than this can also be useful (Katz, Haas, & Gurevitch, 1973).
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25 Results

26
27 The total number of returned questionnaires was 231. The respondents' demographic
28
29 characteristics are displayed in Tables 1 and 2. The average age of the respondents was 51.7
30
31 (SD=12.3) years. Almost all respondents were female (91.0%). Respondents tended to be in a
32
33 long-term relationship or married (59.2%), and generally lived with their spouse, partner, or
34
35 children (72.6%) in metropolitan locations (55.8%). During the past four weeks, most
36
37 respondents experienced a physical or mental health problem (75.0%), for which they most
38
39 commonly consulted a general practitioner (68.0%).
40
41
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43
44

45 *Smallest Space Analysis*

46
47 The coefficient of alienation for the SSA was .21. Figure 1 displays the 2-dimensional plot that
48
49 resulted from the SSA. An inspection of the plot shows that the items were clustered into three
50
51 distinct regions. These regions were conceptualised as: 1) promoting the safety of mental
52
53 health consumers; 2) enabling the recovery of mental health consumers; and 3) impact of
54
55 caring on caregivers' personal lives. Note that one of the items, "annoyed others", did not
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1 clearly fall into a distinct region, and hence was not included in the interpretation of the
2
3 findings.
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8 The subsequent section details the items contained in each region. Interpretation of the items
9
10 reported below may be aided by bearing in mind that the following values are assigned to each
11
12 category: 0=never; 1=sometimes; 2= regularly; 3=often; and 4= always. In addition, the
13
14 delineation of these regions is further supported by the presentation of the qualitative open-
15
16 ended responses.
17
18

19 20 21 22 **Region 1: Promoting the Safety of Mental Health Consumers**

23
24 The region captures some of the concerns of carers which led them to adopt a more protective
25
26 stance as a way of promoting the safety of consumers for whom they cared. Table 3 displays
27
28 the seven items encapsulated in the promoting safety region. The overall mean value for the
29
30 promoting safety region was 1.7. As can be seen from the mean values for the individual items,
31
32 the respondents were most concerned by their relative/friends general health. Such concern is
33
34 unsurprising as mental health consumers often experience multiple co-morbidities, which is
35
36 captured in the following respondent's statement:
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43 “Physical health problems are compounded by mental health. [My] partner also has
44
45 diabetes, sleep apnoea, irregular heartbeat, high blood pressure, high cholesterol,
46
47 arthritis, severe hearing loss, and more”
48
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50
51
52 The item with the next highest mean value in this promoting safety region reflected concern
53
54 about the healthcare their relative/friend was receiving. The qualitative material showed that
55
56 respondents were worried about several aspects of the delivery of mental healthcare. Many
57
58

1 respondents stated that it is was difficult to access services, especially in regional or rural areas
2
3
4 for example:

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6
7
8 “Help for mental illness is practically non-existent in rural areas. The nearest mental
9
10 health facility is a two hour trip away and it hasn't been helpful at all. Firstly, I have
11
12 found the person presenting is interviewed by an intake officer, and that intake officer
13
14 makes a decision based possibly upon the criteria for the day; if all the boxes aren't
15
16 checked, the person presenting gets no help. This has been my experience with my
17
18 family member, turned away because all the boxes weren't checked and terrible
19
20 consequences followed”
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27 In some cases the lack in continuity of care was the primary concern, which undermined the
28
29 relationship between carers and health professionals, and left carers' feeling isolated and
30
31 concerned: “... the mental health system is that it is so disjointed and I find it hard who to trust
32
33 with our information and finding someone that cares enough to follow up and support me”.

34
35
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37
38 Inadequate government support was often thought to detrimentally impact on the quality of
39
40 mental healthcare. The paucity of support meant that the onus for care fell on the
41
42 respondents: “governments have let us down immeasurably and as a result the burden has
43
44 been immense”. Some respondents were left feeling hopeless, but others were eventually able
45
46 to obtain adequate mental healthcare:
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52 “Getting help for my son and guidance for me to help him has been an arduous and very
53
54 lengthy process. If I wasn't as steadfast and committed I may have given up several
55
56 times after being told ‘NO’. I have had to struggle to find the few people that are now
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1 involved in my son's care, and they are brilliant most of the time. But they didn't all
2
3
4 come to help us, I had to research hard to find them over years.”
5
6
7

8 The item that enquired about carers' worry in regard to their friend/relatives safety also
9
10 recorded a relatively high mean score. However, the phrasing used for this item meant that it
11
12 was difficult to identify explicit safety issues. Finally, the mean scores for the items that
13
14 captured details about concern over self-harm, alcohol, and illegal substances were relatively
15
16 low. But these issues were nonetheless a source of substantial concern for some respondents,
17
18 as the following excerpt demonstrates:
19
20
21
22
23

24 “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming
25
26 burden to have a child of any age, want to destroy themselves this way. So in answer to
27
28 the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?"
29
30 the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only
31
32 encourage, support and guide him to the best of my ability”
33
34
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36
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38 **Region 2: Impact of Caring on Caregivers' Personal Lives**

39
40 The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact
41
42 of caring on carers' lives (see Table 4). The overall mean value for this region was 1.8. The mean
43
44 values for the individual items in this region indicate that the respondents were most troubled
45
46 by the carer burden that resulted from their relative/friend's mental health problems. Some
47
48 respondents noted that caring for mental health consumers was accompanied by a sense of
49
50 loss that had both physical and mental health consequences:
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1 “It would be useful to look at the issue of ambiguous loss for family carers, particularly
2 for those who are long term family carers. This is something that is under-identified in
3
4 the area of impact on carers and mental health and yet, anecdotally I know from my
5
6 peers that it has a very real and very significant impact on people's physical
7
8
9 (autoimmune disorders) and mental (grief and depression) health”.

10
11
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14
15 Another issue that several respondents noted had on impact physical and mental health was
16
17 the substantial amount of time devoted to caring, which resulted in social isolation, less time
18
19 given to other family members, and neglect of their own wellbeing. As one respondent put it:
20
21

22
23
24 “You feel very alone. You just wish you could have time to yourself. You don't want to
25
26 walk on eggshells any more. You want to celebrate your other kids and spend time with
27
28 them but your attention is always diverted towards this one. When I'm not with them I
29
30 worry are they ok. I would just like to be by myself without having to worry.”
31
32

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35
36 This sense of isolation in some instances was compounded by a lack of support from family
37
38 members:
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41
42
43 “I do find I isolate and insulate myself as my family won't discuss it, they don't want to
44
45 know as it's too stressful. My son's father abandoned him three years ago as he cannot
46
47 cope with his mental illness.”
48
49

50
51
52 In addition to the physical and mental health consequences, respondents also often drew
53
54 attention to the financial burden associated with caregiving. Time spent on caring meant that
55
56 respondents were unable to participate fully in the workforce. This had a direct material impact
57
58

1 on the respondents' "own future", which was another of the items in the personal impact
2 region that had a relatively high mean value. Other concerns that carers had about their future
3
4 involved the effect on career prospects and lifestyle, as can be seen from the following
5
6 excerpts:
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9

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11
12
13 "I was extremely depressed when I was a full-time carer. I deferred university, failed
14 subjects and lost touch with my own aspirations."
15
16

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18
19
20 "It's hard to express the impact it has on my life. It's the day-to-day impact, the need to
21 be there or in contact at anytime. The need to consider her needs in all my decisions.
22
23 The impact on my future plans - I would dearly love to go live overseas, but my mother
24 is still relatively young, and as much as it feels wrong to say this, she may live a long time
25 and make my dreams impossible."
26
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33
34 The remaining items in the personal impact region captured details about interpersonal tension
35 between carers and mental health consumers. Relatively high mean values were reported for
36 the items that enquired about the strained atmosphere, quarrels, and annoyance at the
37 relative/friend's behaviour. These issues could be especially distressing, as one respondent
38 noted: "It's more than hard- dealing with this is something one can't explain and the emotional
39 verbal assaults we get from him is soul destroying."
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50 Given the often substantial nature of the ongoing interpersonal tension, especially for those
51 carers undertaking this work on a long-term basis, it would be understandable if carers
52 discontinued their support of mental health consumers. Yet some carers demonstrated
53 extraordinary levels of empathy and resilience, as was the case with this respondent:
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4 “Caring for my husband is a tremendous burden. His episodes are full of emotional
5
6 abuse, anger coupled with destruction of property and then feelings of the very
7
8 deepest self-loathing. For me though, it's given me a greater capacity to improve myself
9
10 and to experience empathy when it's not the natural response in this situation. No
11
12 matter how much he hurts me, and believe me he really does, it's nothing compared to
13
14 how much he is hurting and hates himself. My heart breaks for him. He suffers from a
15
16 biological illness that affects every part of him. His relationships, his day-to-day life.
17
18 Underneath the imbalance is the reason I married him.”
19
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27 **Region 3: Enabling the Recovery of Mental Health Consumers**

28
29 The third area clearly identified in the space emphasises the carers' role in the recovery journey
30
31 for consumers. Table 5 displays the 12 items encapsulated in the enabling recovery region. The
32
33 overall mean value for the enabling recovery region was 2.4. Many of the items in this region
34
35 enquire about aspects of caring that could be conceptualised as supporting social and
36
37 functional components of mental health recovery. In terms of functional recovery, encouraging
38
39 and helping mental health consumers with self-care and normal tasks, and concerns about
40
41 consumers' ability to manage financially, were the items with highest mean values. Assisting
42
43 with self-care and normal tasks could be onerous and was an area in which professional
44
45 support would be beneficial, as the following excerpts demonstrate:
46
47
48
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52 “I feel it's a battle I am fighting but losing. I struggle with him to look after himself
53
54 personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking
55
56 at groups online to seek help not only him but myself”
57
58
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3
4 “Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving
5
6 me with any time... her inability to accept help in her personal washing and getting into
7
8 her clothing makes for a lot of time lost in a day. I am about to seek help from the
9
10 professionals”
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14

15 Financial concerns were one of the most frequently raised issues in the open-ended responses.

16 A key element of these concerns was the inadequate level of government financial assistance:
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18

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20
21
22 “He is on the disability support, and after rent, has only less than \$200 a fortnight to
23
24 feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It
25
26 is quite a strain and the National Disability Insurance Scheme has not been able to assist
27
28 in the way he would like”.
29
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34 The items that captured information about aspects of social recovery generally had lower
35
36 mean values than the functional recovery items. And while the importance of facilitating social
37
38 inclusion was noted, it appears to have been an issue that was difficult to resolve. As one
39
40 respondent put it: “Exhaustion is constant as my partner relies on me totally for his social
41
42 support and talks non-stop”.
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44
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48 Finally, in the enabling recovery region, the second highest mean value was recorded for the
49
50 item that asked the respondents if they were worried about their relative/friends future. It is
51
52 unsurprising that carers were often concerned about the mental health consumers’ prospects.
53
54 As the above material has shown, it was not uncommon for mental health consumers to
55
56 experience social isolation and struggle with daily activities and finances. The journey towards
57
58
59
60

1 recovering pieces of consumers' lives clearly requires time and can be difficult, but could
2
3 nonetheless be a gratifying for carers: "It is tough at times, but you get some little rewards
4
5 along the way when they achieve things on their own".
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9

10 **Discussion**

11
12 The regions identified through the SSA provide a basis to understand the manner in which
13
14 carers' prioritise issues that arise in supporting mental health consumers. The analysis
15
16 demonstrated that carers were most concerned with enabling recovery, for which the mean
17
18 value was considerably higher than the personal impact and promoting safety regions. In terms
19
20 of the individual questionnaire items, the issues of most importance were assisting with self-
21
22 care, worrying about consumers' future, finances and general health, encouraging consumer
23
24 involvement in activities, and concerns over the treatment consumers were receiving.
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31
32 Psychiatric disability services are available in the community throughout Australia to assist
33
34 mental health consumers with issues like activities of daily living, housing, recreational and
35
36 social activities, and employment opportunities (Edwards, Fisher, Tannous, & Robinson, 2009).
37
38 Despite the availability of such services, the respondents in this study were highly concerned
39
40 about helping with self-care and promoting consumer participation in activities. Our findings
41
42 suggest either that Australian mental health carers are unable to access adequate levels of
43
44 support from psychiatric disability services or were unaware of the availability of these
45
46 services. Recent data from the Australian Institute of Health and Wellbeing indicates that the
47
48 proportion of mental health consumers who use disability services varies considerably
49
50 between jurisdictions, which may suggest that access to disability services is of particular
51
52 concern in some Australian states and territories (AIHW, 2018). It also seems likely that carers'
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1 knowledge about the availability of disability services could be improved through educational
2 campaigns, but further studies are warranted to examine this issue.
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8 It was unsurprising to find that financial concerns figured prominently in the open-ended
9 responses and also had a high mean item rating. Many mental health carers forgo employment
10 or reduce their working hours while supporting consumers (ABS, 2014; Diminic et al., 2016). In
11 Australia, modest income support payments are available to mental health carers who do not
12 work, but these payments are only accessible to a small proportion of carers (Diminic et al.,
13 2016; RANZCP., 2015). The hardship that results from the lack of adequate financial assistance is
14 further compounded by the often substantial level of financial support that carers provide to
15 mental health consumers (Diminic et al., 2016). These difficulties draw attention to the need to
16 increase the level of financial assistance that the Australian government offers to mental
17 health carers.
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34 The respondents in this study clearly experienced substantial distress about numerous issues,
35 but areas of notable concern involved the quality of mental healthcare and personal impact of
36 the caregiving role. In addition there is a very significant cost of caring that effects informal
37 carers in a multitude of ways, often to the detriment of their own health and wellbeing as
38 individuals. Understanding and acknowledging fully this impact could assist professional carers
39 in supporting them which could in turn promote recovery for consumers. The findings have
40 several implications that health professionals could take into account when working with the
41 families of mental health consumers. To some extent, the concern that carers experience in
42 regard to the provision of services may be lessened through exploring and incorporating their
43 views in planning and delivering mental healthcare (McFarlane 2016) (McFarlane, 2016). In
44 terms of reducing caregiver burden, it would initially be beneficial for health professionals to
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1 evaluate carers' strengths and limitations in supporting mental health consumers (Dirik et al.,
2 2017; Mottaghipour & Bickerton, 2005). Such information could inform the development of
3
4 personalised interventions that would enable health professionals to address the particular
5
6 requirements of each family (Dirik et al., 2017; Mottaghipour & Bickerton, 2005).
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10 11 12 13 *Limitations*

14
15 The demographic details of Australian mental health carers vary considerably between studies.
16
17 It is therefore difficult to develop a standardised profile of Australian mental health caregivers.
18
19 However, the demographic characteristics of the carers in this study were highly consistent
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21 with the details reported in the most recent study of Australian mental health caregivers,
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23 which to some extent supports the generalisability of our findings (Diminic et al., 2016).
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29 **Conclusion**

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31 Our findings demonstrated that carers' prioritised roles that promoted the recovery of mental
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33 health consumers. However, such caregiving often came at significant personal cost. The
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35 burden that results from caring for mental health consumers could perhaps be alleviated
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37 through the expansion of psychiatric disability services, increasing government financial
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39 support, and providing tailored psychosocial interventions that meet the needs of families.
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41 Such assistance would not only improve the circumstances of caregivers, but would also
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43 probably enhance the recovery of mental health consumers.
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47 **Figure Legends**

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50 Figure 1. Regions Identified Through Smallest Space Analysis
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30

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32

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34

35 **Competing Interests**

36

37 The authors have no competing interests to declare

38

39 **Contributors**

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41 Paul Morrison contributed to the conceptualization, conduct, analysis, and reporting of this

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43 study. Norman Stomski contributed to the conceptualization, conduct, analysis, and reporting

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45 of this study

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49 **Ethics Approval**

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51 Murdoch University Human Research Ethics Committee

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53 **Data Sharing Agreement**

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55 No additional data are available

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Table 1. Demographics- Personal Characteristics

	Mean (SD)
Carer's Age (n=198)	51.7 (12.3)
Consumer's Age (n=199)	41.6 (19.1)
	Proportion
Gender	
Carer Female (n=201)	91.0%
Consumer Female (n=201)	41.8%
Carer Relationship Status (n=201)	
Married/Long Term Relationship	59.2%
Divorced	18.9%
Widowed	2.0%
Unmarried	13.4%
Other	6.5%
Carer's Relationship to Consumer (n=200)	
Mother/Father	43.0%
Daughter/Son	15.0%
Sister/Brother	6.5%
Other Relative	1.0%
Wife/Husband/Partner	28.5%
Friend	2.5%
Other	3.5%
Carers with Physical or Mental Health Problems in Last Four Weeks (n=200)	75%
Assistance Type for Physical or Mental Health Problems in Last Four Weeks (n=150)	
General Practitioner/Family Doctor	68.0%
Social Worker/Psychologist/Psychiatrist	45.9%
Medication	48.7%
Carer Support Groups	36.5%
Online Information	52.9%
Online Support	25.0%
Extra expenses over last four weeks incurred on behalf of person for whom they care (n=201)	
Professional Help for Consumer	36.4%
Large Expenditures Incurred by Consumer	14.3%
Damage Caused by Consumer	12.1%
Consumer's Travel Expenses	19.9%
Medicine for Consumer	38.5%
Paying Off Consumer Debt	19.9%
Other	20.8%

Table 2. Demographics- Living Arrangements

Residential Location (n=199)	Proportion
Metropolitan	55.8%
Regional	34.2%
Rural	10.0%
State/Territory (n=200)	
Australian Capital Territory	1.5%
New South Wales	24.5%
Northern Territory	4.0%
Queensland	21.0%
South Australia	5.5%
Tasmania	5.0%
Victoria	17.0%
Western Australia	21.5%
Carer Household Composition (n=201)	
Live Alone	8.0%
Live with Spouse/Partner/Children	72.6%
Live with Parents/Sisters/Brothers	4.0%
Live with Other Relatives	3.0%
Live with Friends	0.5%
Other	11.9%
Carer Time Spent Living with Consumer Last Four Weeks (n=189)	
Entire Four Weeks	67.2%
None	25.4%
Some	7.4%
(mean number of days = 8.3)	
Personal or Telephone Contact Per Week Between Consumer and Carer	
More than 32 hours	51.8%
17 to 32 hours	8.0%
9 to 16 hours	12.1%
5 to 8 hours	17.6%
Less than 5 Hours	10.6%

Table 3. Promoting Safety

Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal drugs	0.8 (1.2)
Have you worried about the type of help/treatment your friend/relative is receiving	2.5 (1.2)
Have you worried about your friend/relatives safety	2.3 (1.2)
Have you worried about your friend/relatives general health	2.8 (1.1)

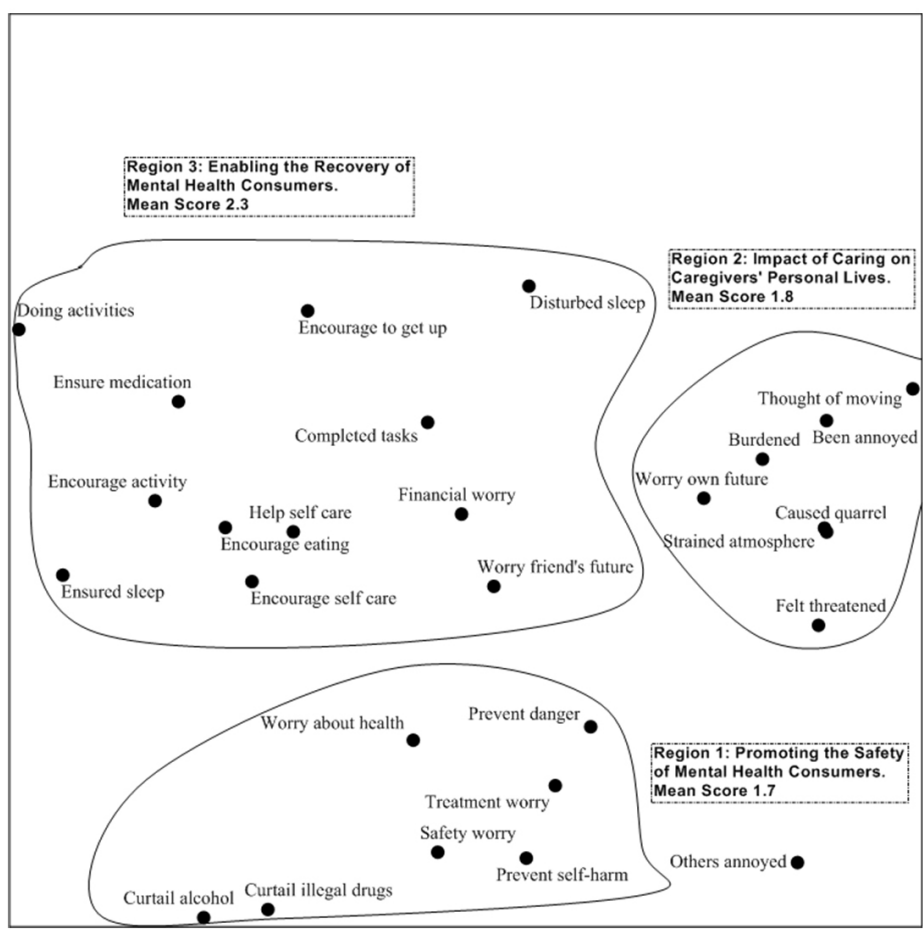
Table 4. Personal Impact

Item	Mean (SD)
Has the atmosphere been strained between you both, as a consequence of your friend/relatives behaviour	2.1 (1.1)
Has your friend/relative caused a quarrel	1.9 (1.0)
Have you been annoyed by your friend/relatives behaviour	2.1 (1.0)
Have you felt threatened by your friend/relatives behaviour	0.9 (0.9)
Have you thought of moving out as a result of your friend/relatives behaviour	1.2 (1.2)
Have you worried about your own future	1.9 (1.2)
Have your friend/relatives mental health problems been a burden to you	2.3 (1.2)

Table 5. Enabling Recovery

Item	Mean (SD)
Have you encouraged your friend/relative to get up in the morning	1.8 (1.2)
Have you ensured your friend/relative received sufficient sleep	2.0 (1.1)
Has your friend/relative disturbed your sleep	1.9 (1.0)
Have you worried about how your friend/relative would manage financially if you were no longer able to help	2.7 (1.3)
Have you worried about your friend/relatives future	3.0 (1.1)
Have you encouraged your friend/relative to take proper care of her/himself	3.1 (0.9)
Have you helped your friend/relative to take proper care of her/himself	2.7 (1.1)
Have you encouraged your friend/relative to eat enough	2.2 (1.3)
Have you encouraged your friend/relative to undertake some kind of activity	2.5 (1.1)
Have you accompanied your friend/relative on some sort of outside activity, because your friend/relative did not dare go out alone	2.0 (1.3)
Have you ensured your friend/relative has taken the required medicine	2.4 (1.3)
Have you carried out tasks normally done by your friend/relative	2.4 (1.1)

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	17
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6-7
		(b) Describe any methods used to examine subgroups and interactions	6-7
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy ⁶⁻⁷	
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA-cross sectional, data collected at single time point
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	7-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	In Tables located at end of manuscript
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

For peer review only

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Keywords

Mental Health; Carer; Caregiver; Burden; Smallest Space Analysis

Word Count

4148 words

Abstract

Objectives: To explore Australian mental health carers' prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Design: Cross-sectional survey.

Setting: All Australian States and Territories.

Participants: Responses were received from 231 Australian mental health caregivers.

Main outcome measures: The Involvement Evaluation Questionnaire was used to assess caregiver burden.

Results: Smallest space analysis identified three distinct regions, which we conceptualise as: 1) promoting the safety and health of mental health consumers; 2) impact of caring on caregivers' personal lives; and 3) enabling daily living functional recovery of mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value was considerably higher than the personal impact and promoting safety and health regions. In terms of the individual questionnaire items, the issues of most importance are assisting with self-care, worrying about consumers' future, finances and general health, encouraging consumer involvement in activities and concerns over the treatment consumers are receiving.

Conclusion: Caregiving often came at significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support and providing tailored psychosocial interventions that meet the needs of families.

Strengths and Limitations

- To our knowledge, this is the first Australian study to examine mental health carers prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden
- Qualitative data is used to provide further insight into the quantitative findings
- Respondent bias may influence our results

Background

The deinstitutionalisation of services has seen informal carers becoming increasingly involved in the mental health system.^{1,2} Carers in adopting these roles face ongoing challenges, which may include advocating on behalf of mental health consumers, crisis management, helping with daily activities and providing financial assistance.³⁻⁵ The burden associated with assuming these responsibilities, coupled with the impact of witnessing their relative experience mental illness, means that carers often report significant levels of distress.⁴⁻⁷

About one third of mental health consumers' family members experience emotional distress.^{7,8} Such distress may encompass feelings of loss, anxiety and distress.⁹⁻¹¹ In addition, caregiving may lead to social isolation, reduced work productivity, financial loss and disruption in family routines, which may substantially impair carers' quality of life.^{9,11-14}

Several factors have been identified that influence mental health caregiver burden. Studies have shown that caring for a male mental health consumer leads to significantly higher levels of stress.¹⁵ Other demographic characteristics that effect burden include lower levels of caregiver education and younger carer age, both of which have been associated with higher

1 levels of depression.¹⁶⁻¹⁹ Also, supporting consumers who display heightened positive or
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4 negative symptoms exacerbates the detrimental impact on carers' quality of life, work
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6 efficiency and lost days of work.²⁰
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10 Although much of the available literature focuses on adverse consequences, caregiving for
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12 mental health consumers also results in beneficial outcomes for carers. Some mental health
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14 carers' note that supporting consumers has sensitised them to the needs of people with
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16 disabilities, enabled them to clarify their priorities in life and enhanced their resilience.²¹ The
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18 sense of satisfaction and meaning that carers find in helping consumers has been associated
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20 with higher levels of quality of life.²²⁻²⁴
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27 Research has demonstrated that carers contribute importantly to the recovery of mental
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29 health consumers. In particular, the involvement of family members in the provision of mental
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31 health services has been found to decrease consumer relapse and rehospitalisation rates by 20-
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33 50%.⁴ Other mental health consumer benefits that may be attributed to supportive family
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35 relationships include improved participation in vocational rehabilitation, higher employment
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37 rates, enhanced social functioning and reductions in psychiatric symptoms.⁴
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43 To our knowledge no prior qualitative studies have explored Australian mental health caregiver
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45 burden. However, a few quantitative studies have examined issues involved with caring for
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47 mental health consumers in an Australian context.^{13,25,26} The Australian quantitative
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49 studies^{13,25,26} on mental health caregiver burden have reflected the results of research
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51 conducted in other countries,^{7,15,27} in that they have shown that carers experience social
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53 isolation and impaired physical and mental health. To our knowledge, no prior studies in an
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55 Australian setting have quantified aspects of mental health caregiving. This information is
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1 important since it provides an understanding of the extent to which individual factors influence
2 mental health caregiver burden, and may enable health services to develop interventions that
3 target the factors that contribute most substantially to such burden. Hence, the purpose of this
4 study is to explore Australian mental health carers' experiences through rating the importance
5 of key elements of caregiving and establish the extent to which particular issues contribute to
6 carer burden.
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18 **Methods**

19 *Study Design*

20 This study involves a cross-sectional survey of Australian mental health caregivers. The
21 Murdoch University Human Research Ethics Committee granted ethical approval for this study
22 (Approval Number 2016/215).
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31 *Survey Instrument*

32 The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer
33 burden.²⁷ The decision to use the IEQ in this study was based on the findings of a systematic
34 review, which recommended the IEQ as one of the two most superior instruments to assess
35 mental health caregiver burden.²⁸ The questionnaire comprises four scales: 1) tension (nine
36 items), which assesses interpersonal difficulties between consumers and carers; 2) supervision
37 (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and
38 dangerous behaviour; 3) worrying (six items), which captures details regarding troubling
39 interpersonal like concern about the consumer's future and safety, overall health, and quality
40 of health care; and 4) urging (eight items), which assesses the extent to which carers'
41 encourage consumers to undertake general activities and self-care.²⁷ Each item is scored on a
42 five point Likert scale (never, sometimes, regularly, often, always). The following values were
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1 assigned to each scale category: never=0; sometimes=1; regularly=2; often=3; always=4.²⁷ To
2 facilitate comparison between the scales, which contained differing numbers of items, a total
3 scale score was produced by summing the items, that was then divided by the number of items
4 within the scale, after which a mean scale score was derived. Finally, a single open-ended
5 question allows carers to make comments about their experiences.
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15 The structure of the IEQ was originally established through subjecting data from a Dutch
16 mental health caregiver population to principal components analysis, which yielded the
17 aforementioned four scales.²⁷ The IEQ has subsequently been translated into English and
18 undergone psychometric testing, which consisted of an examination of its internal consistency
19 and test-test reliability. The results demonstrated that the IEQ scales exhibited adequate levels
20 of test-retest reliability.²⁷ But the IEQ's supervision and urging scales had less than satisfactory
21 Cronbach alpha values, which cast some doubt over the adequacy of the IEQ's scale
22 structure.²⁸ To our knowledge, no further psychometric testing of the IEQ has been conducted
23 in English language populations.
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38 *Recruitment*

39 All Australian caregivers for mental health consumers were eligible to participate in this study.
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41 Twenty-two carer, mental health carer, and mental health consumer organisations
42 disseminated study invitation notices on our behalf through Twitter, Facebook, e-newsletters
43 and online sites. We also personally distributed invitation notices through Facebook pages of
44 mental health carer and consumer groups. The invitation notices outlined the study's purpose
45 and provided the link for the online survey questionnaire. A comprehensive information letter
46 was placed at the beginning of the survey, which the prospective participants were asked to
47 read before starting to answer the survey questions. All responses were anonymous and return
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1 of the questionnaire was used to indicate consent. Data were collected from March 2017 to July
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4 2017.
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8 *Participant Involvement*

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10 Mental health caregivers were not actively involved in the design of this study, but did
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12 contribute extensively to the development of the instrument used in this study.
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15 *Sample Size*

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17 Cochran's formula for continuous variables was used to establish the number of returned
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19 questionnaires required to generalise the study findings.²⁹ Given that there were
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21 approximately 15,666 Australian mental health carers³⁰, and incorporating a 5% level of
22
23 acceptable risk and 3% margin of error, it was established that 133 completed questionnaires
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25 were needed to generalise the study findings.
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32 *Data Analysis*

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34 The analysis combined quantitative and qualitative approaches. For the quantitative
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36 component, data were entered and analysed in the Hebrew University Data Analysis Package
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38 v.8. All demographic variables are reported descriptively. Given the lack of robust evidence for
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40 the dimensionality of IEQ, smallest space analysis (SSA) was used to examine the structure of
41
42 the dataset. SSA was used as it offers numerous advantages over statistical methods such as
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44 factor analysis.^{31,32} Such advantages include: provision of geometric output that is readily
45
46 comprehensible; derivation of the fewest number of dimensions; results remain invariant
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48 under rotation; and lack of need to select orthogonal or oblique rotations.^{31,32} It is an especially
49
50 robust method that can be used to analyse many different types of data.^{33,34} SSA is one of a
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52 host of non-metric multidimensional scaling (MDS) methods used to represent relationship
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measures between variables or items in a low dimensional space.³⁴ The SSA program calculates associations between variables, where the association between any two variables is expressed as the distance between them on a graph such that the smaller the distance between two plotted variables, the stronger the association.

In this instance SSA is used in an exploratory manner to uncover any hidden structures in the dataset that could be easily identified and displayed visually.³³ It provides a means for reducing data and in so doing produces a summary of complex data that can be examined and interpreted. Themes or patterns may arise from the visual depiction. A particular clusters of variables, each of which represents a construct or theme that captures something of the carers' experience, are derived from a partitioning of the graph into regions or neighbourhoods.

SSA also produces a measure, the co-efficient of alienation, that demonstrates how well the distances between the points on the two- dimensional SSA plot reflect the correlations between the questionnaire items.³⁵ The coefficient of alienation can range from 0 (best fit) to 1 (worst fit), and should be ≤ 0.2 to be considered satisfactory.³⁵

The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis methods.³⁶ In this study, a theoretical, deductive approach³⁶ to coding was used as the main purpose of the analysis was to confirm and further illuminate the structures identified in the SSA analysis of the IEQ items. As such, a coding framework was developed wherein the SSA regions served as themes, and the items within each region acted as subthemes. All of the open-ended responses were then systematically analysed line by line and constant comparison was used to map extracts from these responses into the coding framework.³⁶

Results

The total number of returned questionnaires was 231. The respondents' demographic characteristics are displayed in Tables 1 and 2. The average age of the respondents was 51.7 (SD=12.3) years. Almost all respondents were female (91.0%). Respondents tended to be in a long-term relationship or married (59.2%), and generally lived with their spouse, partner, or children (72.6%) in metropolitan locations (55.8%). During the past four weeks, most respondents experienced a physical or mental health problem (75.0%), for which they most commonly consulted a general practitioner (68.0%). In terms of the psychiatric diagnoses for the consumers of whom the respondents supported, the most common were bipolar (19.9%) and schizophrenia/schizoaffective disorder (19.4%), followed by depression (10.4%), personality disorder (10.0%) and anxiety disorder (7.0%). In addition, about one-third (32.8%) of the respondents indicated "other" for the psychiatric diagnosis, of which two-thirds (66.6%) related to the co-occurrence of two or more psychiatric disorders.

Smallest Space Analysis

The coefficient of alienation for the SSA was .21. Figure 1 displays the 2-dimensional plot that resulted from the SSA. An inspection of the plot shows that the items were clustered into three distinct regions. These regions are conceptualised as: 1) promoting the safety and health of mental health consumers; 2) enabling the daily living functional recovery of mental health consumers; and 3) impact of caring on caregivers' personal lives. Note that one of the items, "annoyed others", did not clearly fall into a distinct region, and hence was not included in the interpretation of the findings.

1 The subsequent section details the items contained in each region. Interpretation of the items
2 reported below may be aided by bearing in mind that the following values are assigned to each
3 category: 0=never; 1=sometimes; 2= regularly; 3= often; and 4= always. In addition, the
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Region 1: Promoting the Safety and Health of Mental Health Consumers

The region captures some of the concerns of carers which lead them to adopt a more protective stance as a way of promoting the safety and health of consumers for whom they care. Table 3 displays the seven items encapsulated in the promoting safety and health region. The overall mean value for the promoting safety and health region was 1.7. As can be seen from the mean values for the individual items, the respondents are most concerned by their relative/friends general health. Such concern is unsurprising as mental health consumers often experience multiple co-morbidities, which is captured in the following respondent's statement:

“Physical health problems are compounded by mental health. [My] partner also has diabetes, sleep apnoea, irregular heartbeat, high blood pressure, high cholesterol, arthritis, severe hearing loss and more”

The item with the next highest mean value in this region reflected concern about the healthcare their relative/friend is receiving. The qualitative material showed that respondents are worried about several aspects of the delivery of mental healthcare. Many respondents stated that it is difficult to access services, especially in regional or rural areas for example:

1 “Help for mental illness is practically non-existent in rural areas. The nearest mental
2 health facility is a two hour trip away and it hasn't been helpful at all. Firstly, I have
3
4 found the person presenting is interviewed by an intake officer, and that intake officer
5
6 makes a decision based possibly upon the criteria for the day; if all the boxes aren't
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8 checked, the person presenting gets no help. This has been my experience with my
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10 family member, turned away because all the boxes weren't checked and terrible
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12 consequences followed”
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20 In some cases, the lack in continuity of care is the primary concern, which undermined the
21
22 relationship between carers and health professionals, and left carers' feeling isolated and
23
24 concerned: “... the mental health system is that it is so disjointed and I find it hard who to trust
25
26 with our information and finding someone that cares enough to follow up and support me”.
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30 Inadequate government support is often thought to detrimentally impact on the quality of
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32 mental healthcare. The paucity of support meant that the onus for care fell on the
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34 respondents: “governments have let us down immeasurably and as a result the burden has
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36 been immense”. Some respondents are left feeling hopeless, but others were eventually able
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38 to obtain adequate mental healthcare:
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45 “Getting help for my son and guidance for me to help him has been an arduous and very
46
47 lengthy process. If I wasn't as steadfast and committed I may have given up several
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49 times after being told ‘NO’. I have had to struggle to find the few people that are now
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51 involved in my son's care, and they are brilliant most of the time. But they didn't all
52
53 come to help us, I had to research hard to find them over years.”
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1 The item that enquired about carers' worry in regard to their friend/relatives safety also
2 recorded a relatively high mean score. However, the phrasing used for this item meant that it is
3
4 difficult to identify explicit safety issues. Finally, the mean scores for the items that captured
5
6 details about concern over self-harm, alcohol, and illegal substances are relatively low. But
7
8 these issues are nonetheless a source of substantial concern for some respondents, as the
9
10 following excerpt demonstrates:
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17 “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming
18
19 burden to have a child of any age, want to destroy themselves this way. So in answer to
20
21 the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?"
22
23 the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only
24
25 encourage, support and guide him to the best of my ability”
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31 **Region 2: Impact of Caring on Caregivers' Personal Lives**

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33 The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact
34
35 of caring on carers' lives (see Table 4). The overall mean value for this region was 1.8. The mean
36
37 values for the individual items in this region indicate that the respondents are most troubled by
38
39 the carer burden that resulted from their relative/friend's mental health problems. Some
40
41 respondents noted that caring for mental health consumers is accompanied by a sense of loss
42
43 that had both physical and mental health consequences:
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50 “It would be useful to look at the issue of ambiguous loss for family carers, particularly
51
52 for those who are long term family carers. This is something that is under-identified in
53
54 the area of impact on carers and mental health and yet, anecdotally I know from my
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1 peers that it has a very real and very significant impact on people's physical
2
3 (autoimmune disorders) and mental (grief and depression) health”.

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8 Another issue that several respondents noted has an impact physical and mental health is the
9
10 substantial amount of time devoted to caring, which results in social isolation, less time given
11
12 to other family members and neglect of their own wellbeing. As one respondent put it:
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16
17 “You feel very alone. You just wish you could have time to yourself. You don't want to
18
19 walk on eggshells any more. You want to celebrate your other kids and spend time with
20
21 them but your attention is always diverted towards this one. When I'm not with them I
22
23 worry are they ok. I would just like to be by myself without having to worry.”
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29 This sense of isolation in some instances was compounded by a lack of support from family
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31 members:
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37 “I do find I isolate and insulate myself as my family won't discuss it, they don't want to
38
39 know as it's too stressful. My son's father abandoned him three years ago as he cannot
40
41 cope with his mental illness.”
42
43
44

45 In addition to the physical and mental health consequences, respondents also often drew
46
47 attention to the financial burden associated with caregiving. Time spent on caring meant that
48
49 respondents are unable to participate fully in the workforce. This directly impacts materially on
50
51 the respondents' “own future”, which is another of the items in the personal impact region
52
53 that has a relatively high mean value. Other concerns that carers hold about their future
54
55 involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:
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4 “I was extremely depressed when I was a full-time carer. I deferred university, failed
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6 subjects and lost touch with my own aspirations.”
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11 “It's hard to express the impact it has on my life. It's the day-to-day impact, the need to
12
13 be there or in contact at anytime. The need to consider her needs in all my decisions.
14
15 The impact on my future plans - I would dearly love to go live overseas, but my mother
16
17 is still relatively young, and as much as it feels wrong to say this, she may live a long time
18
19 and make my dreams impossible.”
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24 The remaining items in the personal impact region captured details about interpersonal tension
25
26 between carers and mental health consumers. Relatively high mean values were reported for
27
28 the items that enquired about the strained atmosphere, quarrels and annoyance at the
29
30 relative/friend's behaviour. These issues could be especially distressing, as one respondent
31
32 noted: “It's more than hard- dealing with this is something one can't explain and the emotional
33
34 verbal assaults we get from him is soul destroying.”
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40 Given the often substantial nature of the ongoing interpersonal tension, especially for those
41
42 carers undertaking this work on a long-term basis, it would be understandable if carers
43
44 discontinued their support of mental health consumers. Yet some carers demonstrate
45
46 extraordinary levels of empathy and resilience, as was the case with this respondent:
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52 “Caring for my husband is a tremendous burden. His episodes are full of emotional
53
54 abuse, anger coupled with destruction of property and then feelings of the very
55
56 deepest self-loathing. For me though, it's given me a greater capacity to improve myself
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1 and to experience empathy when it's not the natural response in this situation. No
2
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4 matter how much he hurts me, and believe me he really does, it's nothing compared to
5
6 how much he is hurting and hates himself. My heart breaks for him. He suffers from a
7
8 biological illness that affects every part of him. His relationships, his day-to-day life.
9
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11 Underneath the imbalance is the reason I married him.”
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15 **Region 3: Enabling Daily Living Functional Recovery of Mental Health Consumers**

16
17 The third area clearly identified in the space emphasises the carers' role in the recovery journey
18
19 for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional
20
21 recovery region. The overall mean value for this region was 2.4. Many of the items in this region
22
23 enquire about aspects of caring that can be conceptualised as supporting social and functional
24
25 components of mental health recovery. In terms of functional recovery, encouraging and
26
27 helping mental health consumers with self-care and normal tasks, and concerns about
28
29 consumers' ability to manage financially, are the items with highest mean values. Assisting with
30
31 self-care and normal tasks could be onerous and is an area in which professional support would
32
33 be beneficial, as the following excerpts demonstrate:
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40 “I feel it's a battle I am fighting but losing. I struggle with him to look after himself
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42 personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking
43
44 at groups online to seek help not only him but myself”
45
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48 “Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving
49
50 me with any time... her inability to accept help in her personal washing and getting into
51
52 her clothing makes for a lot of time lost in a day. I am about to seek help from the
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54 professionals”
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4 Financial concerns are one of the most frequently raised issues in the open-ended responses. A
5
6 key element of these concerns is the inadequate level of government financial assistance:
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10 “He is on the disability support, and after rent, has only less than \$200 a fortnight to
11
12 feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It
13
14 is quite a strain and the National Disability Insurance Scheme has not been able to assist
15
16 in the way he would like”.
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22 The items that captured information about aspects of social recovery generally had lower
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24 mean values than the functional recovery items. And while the importance of facilitating social
25
26 inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put
27
28 it: “Exhaustion is constant as my partner relies on me totally for his social support and talks
29
30 non-stop”.
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36 Finally, in the enabling daily living functional recovery region, the second highest mean value
37
38 was recorded for the item that asked the respondents if they are worried about their
39
40 relative/friends future. It is unsurprising that carers are often concerned about the mental
41
42 health consumers’ prospects. As the above material has shown, it is not uncommon for mental
43
44 health consumers to experience social isolation and struggle with daily activities and finances.
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46 The journey towards recovering pieces of consumers’ lives clearly requires time and is difficult,
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48 but could nonetheless be gratifying for carers: “It is tough at times, but you get some little
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50 rewards along the way when they achieve things on their own”.
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56 Discussion

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1 The regions identified through the SSA provide a basis to understand the manner in which
2 carers prioritise issues that arise in supporting mental health consumers. The analysis
3 demonstrates that carers are most concerned with enabling daily living functional recovery, for
4 which the mean value is considerably higher than the personal impact and promoting safety
5 regions. In terms of the individual questionnaire items, the issues of most importance are
6 assisting with self-care, worrying about consumers' future, finances and general health,
7 encouraging consumer involvement in activities and concerns over the treatment consumers
8 are receiving.
9

10
11 The high level of concern that respondents report about daily living functional recovery
12 suggests that the provision of services that assist with these issues may contribute to the
13 reduction of caregiver burden. Psychiatric disability services are available in the community
14 throughout Australia to help carers and mental health consumers with tasks like activities of
15 daily living, housing, recreational and social activities and employment opportunities.³⁷
16

17 However, the extent to which Australian carers and mental health consumers access these
18 services is presently unknown. Further studies might be beneficial in identifying whether the
19 provision of psychiatric disability support services adequately address the needs of mental
20 health caregivers in regards to assistance with consumers daily living functional recovery.
21

22 It was unsurprising to find that financial concerns figure prominently in the open-ended
23 responses and also have a high mean item rating. Many mental health carers forgo
24 employment or reduce their working hours while supporting consumers.^{38,39} In Australia,
25 modest income support payments are available to mental health carers who do not work, but
26 these payments are only accessible to a small proportion of carers.^{38,40} The hardship that
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1 results from the lack of adequate financial assistance is further compounded by the often
2 substantial level of financial support that carers provide to mental health consumers.³⁸
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8 Our findings show that health professionals also have an important role to play in alleviating
9 mental health caregiver burden. Concerns over the provision of mental health care are
10 highlighted in this study, especially in regard to being isolated from the care that consumers
11 were receiving. Such issues reflect the results of other mental health carer studies that have
12 been conducted in Australia and within the United Kingdom.^{6,41} To some extent, the concern
13 that carers experience in regard to the provision of services might be lessened through
14 exploring and incorporating their views in planning and delivering mental healthcare.⁴
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26 *Limitations*

27 The demographic details of Australian mental health carers vary considerably between studies.
28 It is therefore difficult to develop a standardised profile of Australian mental health caregivers.
29 However, the demographic characteristics of the carers in this study are highly consistent with
30 the details reported in the most recent study of Australian mental health caregivers, which to
31 some extent supports the generalisability of our findings.³⁸
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43 **Conclusion**

44 Our findings demonstrate that carers' prioritise roles that promote the recovery of mental
45 health consumers. However, such caregiving often incurs significant personal cost. The burden
46 that results from caring for mental health consumers could perhaps be alleviated through the
47 expansion of psychiatric disability services, increasing government financial support and
48 involving families more closely in the planning and delivery of mental health services. Such
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1 assistance would not only improve the circumstances of caregivers, but would also probably
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 3
 4 enhance the recovery of mental health consumers.
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6 **Figure Legends**

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 8 Figure 1. Regions Identified Through Smallest Space Analysis
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Competing Interests

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The authors have no competing interests to declare

Contributors

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Paul Morrison contributed to the conceptualization, conduct, analysis, and reporting of this study. Norman Stomski contributed to the conceptualization, conduct, analysis, and reporting of this study

Ethics Approval

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Murdoch University Human Research Ethics Committee

Data Sharing Agreement

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No additional data are available

Table 1. Demographics- Personal Characteristics

	Mean (SD)
Carer's Age (n=198)	51.7 (12.3)
Consumer's Age (n=199)	41.6 (19.1)
	Proportion
Gender	
Carer Female (n=201)	91.0%
Consumer Female (n=201)	41.8%
Carer Relationship Status (n=201)	
Married/Long Term Relationship	59.2%
Divorced	18.9%
Widowed	2.0%
Unmarried	13.4%
Other	6.5%
Carer's Relationship to Consumer (n=200)	
Mother/Father	43.0%
Daughter/Son	15.0%
Sister/Brother	6.5%
Other Relative	1.0%
Wife/Husband/Partner	28.5%
Friend	2.5%
Other	3.5%
Carers with Physical or Mental Health Problems in Last Four Weeks (n=200)	75%
Assistance Type for Physical or Mental Health Problems in Last Four Weeks (n=150)	
General Practitioner/Family Doctor	68.0%
Social Worker/Psychologist/Psychiatrist	45.9%
Medication	48.7%
Carer Support Groups	36.5%
Online Information	52.9%
Online Support	25.0%
Extra expenses over last four weeks incurred on behalf of person for whom they care (n=201)	
Professional Help for Consumer	36.4%
Large Expenditures Incurred by Consumer	14.3%
Damage Caused by Consumer	12.1%
Consumer's Travel Expenses	19.9%
Medicine for Consumer	38.5%
Paying Off Consumer Debt	19.9%
Other	20.8%

Table 2. Demographics- Living Arrangements

Residential Location (n=199)	Proportion
Metropolitan	55.8%
Regional	34.2%
Rural	10.0%
State/Territory (n=200)	
Australian Capital Territory	1.5%
New South Wales	24.5%
Northern Territory	4.0%
Queensland	21.0%
South Australia	5.5%
Tasmania	5.0%
Victoria	17.0%
Western Australia	21.5%
Carer Household Composition (n=201)	
Live Alone	8.0%
Live with Spouse/Partner/Children	72.6%
Live with Parents/Sisters/Brothers	4.0%
Live with Other Relatives	3.0%
Live with Friends	0.5%
Other	11.9%
Carer Time Spent Living with Consumer Last Four Weeks (n=189)	
Entire Four Weeks	67.2%
None	25.4%
Some	7.4%
(mean number of days = 8.3)	
Personal or Telephone Contact Per Week Between Consumer and Carer	
More than 32 hours	51.8%
17 to 32 hours	8.0%
9 to 16 hours	12.1%
5 to 8 hours	17.6%
Less than 5 Hours	10.6%

Table 3. Promoting Safety and Health

Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal drugs	0.8 (1.2)
Have you worried about the type of help/treatment your friend/relative is receiving	2.5 (1.2)
Have you worried about your friend/relatives safety	2.3 (1.2)
Have you worried about your friend/relatives general health	2.8 (1.1)

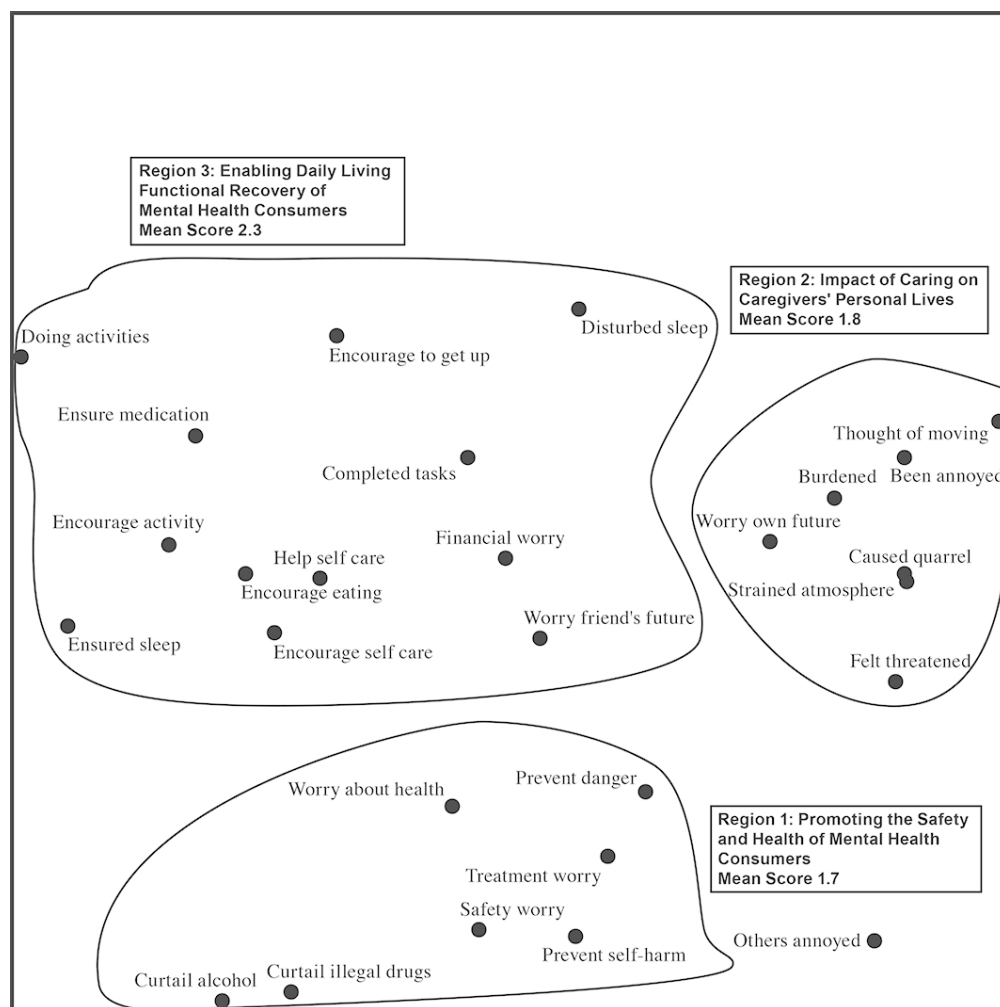
Table 4. Personal Impact

Item	Mean (SD)
Has the atmosphere been strained between you both, as a consequence of your friend/relatives behaviour	2.1 (1.1)
Has your friend/relative caused a quarrel	1.9 (1.0)

1	Have you been annoyed by your friend/relatives behaviour	2.1 (1.0)
2	Have you felt threatened by your friend/relatives behaviour	0.9 (0.9)
3	Have you thought of moving out as a result of your	1.2 (1.2)
4	friend/relatives behaviour	
5	Have you worried about your own future	1.9 (1.2)
6	Have your friend/relatives mental health problems been a	2.3 (1.2)
7	burden to you	
8		

Table 5. Enabling Daily Living Functional Recovery

	Item	Mean (SD)
11	Have you encouraged your friend/relative to get up in te	1.8 (1.2)
12	morning	
13	Have you ensured your friend relative received sufficient sleep	2.0 (1.1)
14	Has your friend/relative disturbed your sleep	1.9 (1.0)
15	Have you worried about how your friend/relative would	2.7 (1.3)
16	manage financially if you were no longer able to help	
17	Have you worried about your friend/relatives future	3.0 (1.1)
18	Have you encouraged your friend/relative to take proper care	3.1 (0.9)
19	of her/himself	
20	Have you helped your friend/relative to take proper care of	2.7 (1.1)
21	her/himself	
22	Have you encouraged your friend/relative to eat enough	2.2 (1.3)
23	Have you encouraged your friend/relative to undertake some	2.5 (1.1)
24	kind of activity	
25	Have you accompanied your friend/relative on some sort of	2.0 (1.3)
26	outside activity, because your friend/relative did not dare go	
27	out alone	
28	Have you ensured your friend/relative has taken the required	2.4 (1.3)
29	medicine	
30	Have you carried out tasks normally done by your	2.4 (1.1)
31	friend/relative	
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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	17
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6-7
		(b) Describe any methods used to examine subgroups and interactions	6-7
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy ⁶⁻⁷	
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA-cross sectional, data collected at single time point
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	7-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	In Tables located at end of manuscript
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Keywords

Mental Health; Carer; Caregiver; Burden; Smallest Space Analysis

Word Count

4148 words

Abstract

Objectives: To explore Australian mental health carers' prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Design: Cross-sectional survey.

Setting: All Australian States and Territories.

Participants: Responses were received from 231 Australian mental health caregivers.

Main outcome measures: The Involvement Evaluation Questionnaire was used to assess caregiver burden.

Results: Smallest space analysis identified three distinct regions, which we conceptualise as: 1) promoting the safety and health of mental health consumers; 2) impact of caring on caregivers' personal lives; and 3) enabling daily living functional recovery of mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value was considerably higher than the personal impact and promoting safety and health regions. In terms of the individual questionnaire items, the issues of most importance are assisting with self-care, worrying about consumers' future, finances and general health, encouraging consumer involvement in activities and concerns over the treatment consumers are receiving.

Conclusion: Caregiving often came at significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support and providing tailored psychosocial interventions that meet the needs of families.

Strengths and Limitations

- To our knowledge, this is the first Australian study to examine mental health carers prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden
- Qualitative data is used to provide further insight into the quantitative findings
- Respondent bias may influence our results

Background

The deinstitutionalisation of services has seen informal carers becoming increasingly involved in the mental health system.^{1,2} Carers in adopting these roles face ongoing challenges, which may include advocating on behalf of mental health consumers, crisis management, helping with daily activities and providing financial assistance.³⁻⁵ The burden associated with assuming these responsibilities, coupled with the impact of witnessing their relative experience mental illness, means that carers often report significant levels of distress.⁴⁻⁷

About one third of mental health consumers' family members experience emotional distress.^{7,8} Such distress may encompass feelings of loss, anxiety and distress.⁹⁻¹¹ In addition, caregiving may lead to social isolation, reduced work productivity, financial loss and disruption in family routines, which may substantially impair carers' quality of life.^{9,11-14}

Several factors have been identified that influence mental health caregiver burden. Studies have shown that caring for a male mental health consumer leads to significantly higher levels of stress.¹⁵ Other demographic characteristics that effect burden include lower levels of caregiver education and younger carer age, both of which have been associated with higher

1
2 levels of depression.¹⁶⁻¹⁹ Also, supporting consumers who display heightened positive or
3
4 negative symptoms exacerbates the detrimental impact on carers' quality of life, work
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6 efficiency and lost days of work.²⁰
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11 Although much of the available literature focuses on adverse consequences, caregiving for
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13 mental health consumers also results in beneficial outcomes for carers. Some mental health
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15 carers' note that supporting consumers has sensitised them to the needs of people with
16
17 disabilities, enabled them to clarify their priorities in life and enhanced their resilience.²¹ The
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19 sense of satisfaction and meaning that carers find in helping consumers has been associated
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21 with higher levels of quality of life.²²⁻²⁴
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29 Research has demonstrated that carers contribute importantly to the recovery of mental
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31 health consumers. In particular, the involvement of family members in the provision of mental
32
33 health services has been found to decrease consumer relapse and rehospitalisation rates by 20-
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35 50%.⁴ Other mental health consumer benefits that may be attributed to supportive family
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37 relationships include improved participation in vocational rehabilitation, higher employment
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39 rates, enhanced social functioning and reductions in psychiatric symptoms.⁴
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46 To our knowledge no prior qualitative studies have explored Australian mental health caregiver
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48 burden. However, a few quantitative studies have examined issues involved with caring for
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50 mental health consumers in an Australian context.^{13,25,26} The Australian quantitative
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52 studies^{13,25,26} on mental health caregiver burden have reflected the results of research
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54 conducted in other countries,^{7,15,27} in that they have shown that carers experience social
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56 isolation and impaired physical and mental health. To our knowledge, no prior studies in an
57
58 Australian setting have quantified aspects of mental health caregiving. This information is
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1
2 important since it provides an understanding of the extent to which individual factors influence
3
4 mental health caregiver burden, and may enable health services to develop interventions that
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6 target the factors that contribute most substantially to such burden. Hence, the purpose of this
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8 study is to explore Australian mental health carers' experiences through rating the importance
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10 of key elements of caregiving and establish the extent to which particular issues contribute to
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12 carer burden.
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19 **Methods**

20 *Study Design*

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22 This study involves a cross-sectional survey of Australian mental health caregivers. The
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24 Murdoch University Human Research Ethics Committee granted ethical approval for this study
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26 (Approval Number 2016/215).
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33 *Survey Instrument*

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35 The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer
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37 burden.²⁷ The decision to use the IEQ in this study was based on the findings of a systematic
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39 review, which recommended the IEQ as one of the two most superior instruments to assess
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41 mental health caregiver burden.²⁸ The questionnaire comprises four scales: 1) tension (nine
42
43 items), which assesses interpersonal difficulties between consumers and carers; 2) supervision
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45 (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and
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47 dangerous behaviour; 3) worrying (six items), which captures details regarding troubling
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49 interpersonal like concern about the consumer's future and safety, overall health, and quality
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51 of health care; and 4) urging (eight items), which assesses the extent to which carers'
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53 encourage consumers to undertake general activities and self-care.²⁷ Each item is scored on a
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2 five point Likert scale (never = 0, sometimes = 1, regularly = 2, often = 3, always = 4).²⁷ Finally, a
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4 single open-ended question allows carers to make comments about their experiences.
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9 The structure of the IEQ was originally established through subjecting data from a Dutch
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11 mental health caregiver population to principal components analysis, which yielded the
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13 aforementioned four scales.²⁷ The IEQ has subsequently been translated into English and
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15 undergone psychometric testing, which consisted of an examination of its internal consistency
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17 and test-retest reliability. The results demonstrated that the IEQ scales exhibited adequate levels
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19 of test-retest reliability, which was evidenced by the intra-class correlation coefficient values
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21 ranging from 0.83 to 0.90.²⁷ But the IEQ's supervision and urging scales had less than
22
23 satisfactory Cronbach alpha values, which cast some doubt over the adequacy of the IEQ's
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25 scale structure.²⁸
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33 *Recruitment*

34 All Australian caregivers for mental health consumers were eligible to participate in this study.
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36 Twenty-two carer, mental health carer, and mental health consumer organisations
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38 disseminated study invitation notices on our behalf through Twitter, Facebook, e-newsletters
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40 and online sites. We also personally distributed invitation notices through Facebook pages of
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42 mental health carer and consumer groups. The invitation notices outlined the purpose of the
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44 study and provided the link for the online survey questionnaire. A comprehensive information
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46 letter was placed at the beginning of the survey, which the prospective participants were
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48 asked to read before starting to answer the survey questions. All responses were anonymous
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50 and return of the questionnaire was used to indicate consent. Data were collected from March
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52 2017 to July 2017.
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Participant Involvement

Mental health caregivers were not actively involved in the design of this study, but did contribute extensively to the development of the instrument used in this study.

Sample Size

Cochran's formula for continuous variables was used to establish the number of returned questionnaires required to generalise the study findings.²⁹ Given that there were approximately 15,666 Australian mental health carers³⁰, and incorporating a 5% level of acceptable risk and 3% margin of error, it was established that 133 completed questionnaires were needed to generalise the study findings.

Data Analysis

The analysis combined quantitative and qualitative approaches. For the quantitative component, data were entered and analysed in the Hebrew University Data Analysis Package v.8. All demographic variables are reported descriptively. Given the lack of robust evidence for the dimensionality of IEQ, smallest space analysis (SSA) was used to examine the structure of the dataset. SSA was used as it offers numerous advantages over statistical methods such as factor analysis.^{31,32} Such advantages include: provision of geometric output that is readily comprehensible; derivation of the fewest number of dimensions; results remain invariant under rotation; and lack of need to select orthogonal or oblique rotations.^{31,32} It is an especially robust method that can be used to analyse many different types of data.^{33,34} SSA is one of a host of non-metric multidimensional scaling (MDS) methods used to represent relationship measures between variables or items in a low dimensional space.³⁴ The SSA program calculates associations between variables, where the association between any two variables is

1
2 expressed as the distance between them on a graph such that the smaller the distance
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4 between two plotted variables, the stronger the association.
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9 In this instance SSA was used in an exploratory manner to uncover any hidden structures in the
10 dataset that could be easily identified and displayed visually.³³ It provides a means for
11 reducing data and in so doing produces a summary of complex data that can be examined and
12 interpreted. Themes or patterns may arise from the visual depiction. A particular clusters of
13 variables, each of which represents a construct or theme that captures something of the
14 carers' experience, are derived from a partitioning of the graph into regions or
15 neighbourhoods.
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29 SSA also produces a measure, the co-efficient of alienation, that demonstrates how well the
30 distances between the points on the two- dimensional SSA plot reflect the correlations
31 between the questionnaire items.³⁵ The coefficient of alienation can range from 0 (best fit) to 1
32 (worst fit), and should be ≤ 0.2 to be considered satisfactory.³⁵
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41 To facilitate comparison between the SSA scales, which contained differing numbers of items,
42 a total scale score was produced by summing the items, that was then divided by the number
43 of items within the scale, after which a mean scale score was derived.
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51 The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis
52 methods.³⁶ In this study, a theoretical, deductive approach to coding was used as the main
53 purpose of the analysis was to confirm and further illuminate the structures identified in the
54 SSA analysis of the IEQ items. As such, a coding framework was developed wherein the SSA
55 regions served as themes, and the items within each region acted as subthemes. All of the
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1
2 open-ended responses were then systematically analysed line by line and constant comparison
3
4 was used to map extracts from these responses into the coding framework.
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8 **Results**

9
10 The total number of returned questionnaires was 231. The respondents' demographic
11 characteristics are displayed in Tables 1 and 2. The average age of the respondents was 51.7
12 (SD=12.3) years. Almost all respondents were female (91.0%). Respondents tended to be in a
13 long-term relationship or married (59.2%), and generally lived with their spouse, partner, or
14 children (72.6%) in metropolitan locations (55.8%). During the past four weeks, most
15 respondents experienced a physical or mental health problem (75.0%), for which they most
16 commonly consulted a general practitioner (68.0%). In terms of the psychiatric diagnoses for
17 the consumers of whom the respondents supported, the most common were bipolar (19.9%)
18 and schizophrenia/schizoaffective disorder (19.4%), followed by depression (10.4%), personality
19 disorder (10.0%) and anxiety disorder (7.0%). In addition, about one-third (32.8%) of the
20 respondents indicated "other" for the psychiatric diagnosis, of which two-thirds (66.6%)
21 related to the co-occurrence of two or more psychiatric disorders.
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42 *Smallest Space Analysis*

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44 The coefficient of alienation for the SSA was .21. Figure 1 displays the 2-dimensional plot that
45 resulted from the SSA. An inspection of the plot shows that the items were clustered into three
46 distinct regions. These regions are conceptualised as: 1) promoting the safety and health of
47 mental health consumers; 2) enabling the daily living functional recovery of mental health
48 consumers; and 3) impact of caring on caregivers' personal lives. Note that one of the items,
49 "annoyed others", did not clearly fall into a distinct region, and hence was not included in the
50 interpretation of the findings.
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Region 1: Promoting the Safety and Health of Mental Health Consumers

The region captures some of the concerns of carers which lead them to adopt a more protective stance as a way of promoting the safety and health of consumers for whom they care. Table 3 displays the seven items encapsulated in the promoting safety and health region. The overall mean value for the promoting safety and health region was 1.7. As can be seen from the mean values for the individual items, the respondents are most concerned by their relative/friends general health. Such concern is unsurprising as mental health consumers often experience multiple co-morbidities, which is captured in the following respondent's statement:

“Physical health problems are compounded by mental health. [My] partner also has diabetes, sleep apnoea, irregular heartbeat, high blood pressure, high cholesterol, arthritis, severe hearing loss and more”

The item with the next highest mean value in this region reflected concern about the healthcare their relative/friend is receiving. The qualitative material showed that respondents are worried about several aspects of the delivery of mental healthcare. Many respondents stated that it is difficult to access services, especially in regional or rural areas for example:

“Help for mental illness is practically non-existent in rural areas. The nearest mental health facility is a two hour trip away and it hasn't been helpful at all. Firstly, I have found the person presenting is interviewed by an intake officer, and that intake officer makes a decision based possibly upon the criteria for the day; if all the boxes aren't checked, the person presenting gets no help. This has been my experience with my family member, turned away because all the boxes weren't checked and terrible consequences followed”

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4 In some cases, the lack in continuity of care is the primary concern, which undermined the
5
6 relationship between carers and health professionals, and left carers' feeling isolated and
7
8 concerned: "... the mental health system is that it is so disjointed and I find it hard who to trust
9
10 with our information and finding someone that cares enough to follow up and support me".
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16 Inadequate government support is often thought to detrimentally impact on the quality of
17
18 mental healthcare. The paucity of support meant that the onus for care fell on the
19
20 respondents: "governments have let us down immeasurably and as a result the burden has
21
22 been immense". Some respondents are left feeling hopeless, but others were eventually able
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24 to obtain adequate mental healthcare:
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31 "Getting help for my son and guidance for me to help him has been an arduous and very
32
33 lengthy process. If I wasn't as steadfast and committed I may have given up several
34
35 times after being told 'NO'. I have had to struggle to find the few people that are now
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37 involved in my son's care, and they are brilliant most of the time. But they didn't all
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39 come to help us, I had to research hard to find them over years."
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46 The item that enquired about carers' worry in regard to their friend/relatives safety also
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48 recorded a relatively high mean score. However, the phrasing used for this item meant that it is
49
50 difficult to identify explicit safety issues. Finally, the mean scores for the items that captured
51
52 details about concern over self-harm, alcohol, and illegal substances are relatively low. But
53
54 these issues are nonetheless a source of substantial concern for some respondents, as the
55
56 following excerpt demonstrates:
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2 “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming
3
4 burden to have a child of any age, want to destroy themselves this way. So in answer to
5
6 the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?"
7
8 the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only
9
10 encourage, support and guide him to the best of my ability”
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16 ***Region 2: Impact of Caring on Caregivers' Personal Lives***

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18 The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact
19
20 of caring on carers' lives (see Table 4). The overall mean value for this region was 1.8. The mean
21
22 values for the individual items in this region indicate that the respondents are most troubled by
23
24 the carer burden that resulted from their relative/friend's mental health problems. Some
25
26 respondents noted that caring for mental health consumers is accompanied by a sense of loss
27
28 that had both physical and mental health consequences:
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36 “It would be useful to look at the issue of ambiguous loss for family carers, particularly
37
38 for those who are long term family carers. This is something that is under-identified in
39
40 the area of impact on carers and mental health and yet, anecdotally I know from my
41
42 peers that it has a very real and very significant impact on people's physical
43
44 (autoimmune disorders) and mental (grief and depression) health”.
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51 Another issue that several respondents noted has an impact physical and mental health is the
52
53 substantial amount of time devoted to caring, which results in social isolation, less time given
54
55 to other family members and neglect of their own wellbeing. As one respondent put it:
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1
2 “You feel very alone. You just wish you could have time to yourself. You don't want to
3
4 walk on eggshells any more. You want to celebrate your other kids and spend time with
5
6 them but your attention is always diverted towards this one. When I'm not with them I
7
8 worry are they ok. I would just like to be by myself without having to worry.”
9
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14 This sense of isolation in some instances was compounded by a lack of support from family
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16 members:
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21 “I do find I isolate and insulate myself as my family won't discuss it, they don't want to
22
23 know as it's too stressful. My son's father abandoned him three years ago as he cannot
24
25 cope with his mental illness.”
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31 In addition to the physical and mental health consequences, respondents also often drew
32
33 attention to the financial burden associated with caregiving. Time spent on caring meant that
34
35 respondents are unable to participate fully in the workforce. This directly impacts materially on
36
37 the respondents' “own future”, which is another of the items in the personal impact region
38
39 that has a relatively high mean value. Other concerns that carers hold about their future
40
41 involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:
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48 “I was extremely depressed when I was a full-time carer. I deferred university, failed
49
50 subjects and lost touch with my own aspirations.”
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55 “It's hard to express the impact it has on my life. It's the day-to-day impact, the need to
56
57 be there or in contact at anytime. The need to consider her needs in all my decisions.
58
59 The impact on my future plans - I would dearly love to go live overseas, but my mother
60

1
2 is still relatively young, and as much as it feels wrong to say this, she may live a long time
3
4 and make my dreams impossible.”
5
6
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9 The remaining items in the personal impact region captured details about interpersonal tension
10 between carers and mental health consumers. Relatively high mean values were reported for
11 the items that enquired about the strained atmosphere, quarrels and annoyance at the
12 relative/friend’s behaviour. These issues could be especially distressing, as one respondent
13
14 noted: “It's more than hard- dealing with this is something one can't explain and the emotional
15
16 verbal assaults we get from him is soul destroying.”
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26 Given the often substantial nature of the ongoing interpersonal tension, especially for those
27 carers undertaking this work on a long-term basis, it would be understandable if carers
28 discontinued their support of mental health consumers. Yet some carers demonstrate
29 extraordinary levels of empathy and resilience, as was the case with this respondent:
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39 “Caring for my husband is a tremendous burden. His episodes are full of emotional
40 abuse, anger coupled with destruction of property and then feelings of the very
41 deepest self-loathing. For me though, it's given me a greater capacity to improve myself
42 and to experience empathy when it's not the natural response in this situation. No
43 matter how much he hurts me, and believe me he really does, it's nothing compared to
44 how much he is hurting and hates himself. My heart breaks for him. He suffers from a
45 biological illness that affects every part of him. His relationships, his day-to-day life.
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47 Underneath the imbalance is the reason I married him.”
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Region 3: Enabling Daily Living Functional Recovery of Mental Health Consumers

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2 The third area clearly identified in the space emphasises the carers' role in the recovery journey
3
4 for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional
5
6 recovery region. The overall mean value for this region was 2.4. Many of the items in this region
7
8 enquire about aspects of caring that can be conceptualised as supporting social and functional
9
10 components of mental health recovery. In terms of functional recovery, encouraging and
11
12 helping mental health consumers with self-care and normal tasks, and concerns about
13
14 consumers' ability to manage financially, are the items with highest mean values. Assisting with
15
16 self-care and normal tasks could be onerous and is an area in which professional support would
17
18 be beneficial, as the following excerpts demonstrate:
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26 "I feel it's a battle I am fighting but losing. I struggle with him to look after himself
27
28 personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking
29
30 at groups online to seek help not only him but myself"
31
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36 "Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving
37
38 me with any time... her inability to accept help in her personal washing and getting into
39
40 her clothing makes for a lot of time lost in a day. I am about to seek help from the
41
42 professionals"
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48 Financial concerns are one of the most frequently raised issues in the open-ended responses. A
49
50 key element of these concerns is the inadequate level of government financial assistance:
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53
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55 "He is on the disability support, and after rent, has only less than \$200 a fortnight to
56
57 feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It
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1
2 is quite a strain and the National Disability Insurance Scheme has not been able to assist
3
4 in the way he would like”.

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9 The items that captured information about aspects of social recovery generally had lower
10
11 mean values than the functional recovery items. And while the importance of facilitating social
12
13 inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put
14
15 it: “Exhaustion is constant as my partner relies on me totally for his social support and talks
16
17 non-stop”.

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23 Finally, in the enabling daily living functional recovery region, the second highest mean value
24
25 was recorded for the item that asked the respondents if they are worried about their
26
27 relative/friends future. It is unsurprising that carers are often concerned about the mental
28
29 health consumers’ prospects. As the above material has shown, it is not uncommon for mental
30
31 health consumers to experience social isolation and struggle with daily activities and finances.
32
33 The journey towards recovering pieces of consumers’ lives clearly requires time and is difficult,
34
35 but could nonetheless be gratifying for carers: “It is tough at times, but you get some little
36
37 rewards along the way when they achieve things on their own”.

38 39 40 41 42 43 44 45 **Discussion**

46
47
48 The regions identified through the SSA provide a basis to understand the manner in which
49
50 carers prioritise issues that arise in supporting mental health consumers. The analysis
51
52 demonstrates that carers are most concerned with enabling daily living functional recovery, for
53
54 which the mean value is considerably higher than the personal impact and promoting safety
55
56 regions. In terms of the individual questionnaire items, the issues of most importance are
57
58 assisting with self-care, worrying about consumers’ future, finances and general health,
59
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1
2 encouraging consumer involvement in activities and concerns over the treatment consumers
3
4 are receiving.
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9 The high level of concern that respondents report about daily living functional recovery
10 suggests that the provision of services that assist with these issues may contribute to the
11 reduction of caregiver burden. Psychiatric disability services are available in the community
12 throughout Australia to help carers and mental health consumers with tasks like activities of
13 daily living, housing, recreational and social activities and employment opportunities.³⁷
14 However, the extent to which Australian carers and mental health consumers access these
15 services is presently unknown. Further studies might be beneficial in identifying whether the
16 provision of psychiatric disability support services adequately address the needs of mental
17 health caregivers in regards to assistance with consumers daily living functional recovery.
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34 It was unsurprising to find that financial concerns figure prominently in the open-ended
35 responses and also have a high mean item rating. Many mental health carers forgo
36 employment or reduce their working hours while supporting consumers.^{38,39} In Australia,
37 modest income support payments are available to mental health carers who do not work, but
38 these payments are only accessible to a small proportion of carers.^{38,40} The hardship that
39 results from the lack of adequate financial assistance is further compounded by the often
40 substantial level of financial support that carers provide to mental health consumers.³⁸
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53 Our findings show that health professionals also have an important role to play in alleviating
54 mental health caregiver burden. Concerns over the provision of mental health care are
55 highlighted in this study, especially in regard to being isolated from the care that consumers
56 were receiving. Such issues reflect the results of other mental health carer studies that have
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1
2 been conducted in Australia and within the United Kingdom.^{6,41} To some extent, the concern
3
4 that carers experience in regard to the provision of services might be lessened through
5
6 exploring and incorporating their views in planning and delivering mental healthcare. ⁴
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10 11 *Limitations*

12
13 The demographic details of Australian mental health carers vary considerably between studies.
14
15 It is therefore difficult to develop a standardised profile of Australian mental health caregivers.
16
17 However, the demographic characteristics of the carers in this study are highly consistent with
18
19 the details reported in the most recent study of Australian mental health caregivers, which to
20
21 some extent supports the generalisability of our findings. ³⁸ Finally, our value for the coefficient
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23 of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is
24
25 considered to represent a good fit.³⁵ That said, the coefficient of alienation should be
26
27 interpreted in light of the SSA visual structure, which in the case of our study clearly delineated
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29 distinct regions.³⁵
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38 **Conclusion**

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40 Our findings demonstrate that carers' prioritise roles that promote the recovery of mental
41
42 health consumers. However, such caregiving often incurs significant personal cost. The burden
43
44 that results from caring for mental health consumers could perhaps be alleviated through the
45
46 expansion of psychiatric disability services, increasing government financial support and
47
48 involving families more closely in the planning and delivery of mental health services. Such
49
50 assistance would not only improve the circumstances of caregivers, but would also probably
51
52 enhance the recovery of mental health consumers.
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58 **Figure Legends**

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60 Figure 1. Regions Identified Through Smallest Space Analysis

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19 not-for-profit sectors.

22 Competing Interests

23
24
25 The authors have no competing interests to declare

27 Contributors

28
29 Paul Morrison contributed to the conceptualization, conduct, analysis, and reporting of this
30 study. Norman Stomski contributed to the conceptualization, conduct, analysis, and reporting
31 of this study
32
33
34
35

37 Ethics Approval

38
39 Murdoch University Human Research Ethics Committee

42 Data Sharing Agreement

43
44 No additional data are available
45
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48
49

50 **Table 1. Demographics- Personal Characteristics**

	Mean (SD)
Carer's Age (n=198)	51.7 (12.3)
Consumer's Age (n=199)	41.6 (19.1)
	Proportion
Gender	
Carer Female (n=201)	91.0%
Consumer Female (n=201)	41.8%
Carer Relationship Status (n=201)	
Married/Long Term Relationship	59.2%
Divorced	18.9%

1		
2	Widowed	2.0%
3	Unmarried	13.4%
4	Other	6.5%
5	Carer's Relationship to Consumer (n=200)	
6	Mother/Father	43.0%
7	Daughter/Son	15.0%
8	Sister/Brother	6.5%
9	Other Relative	1.0%
10	Wife/Husband/Partner	28.5%
11	Friend	2.5%
12	Other	3.5%
13	Carers with Physical or Mental Health Problems in Last Four Weeks (n=200)	
14	Assistance Type for Physical or Mental Health Problems in Last Four Weeks (n=150)	
15		
16	General Practitioner/Family Doctor	68.0%
17	Social Worker/Psychologist/Psychiatrist	45.9%
18	Medication	48.7%
19	Carer Support Groups	36.5%
20	Online Information	52.9%
21	Online Support	25.0%
22	Extra expenses over last four weeks incurred on behalf of person for whom they care (n=201)	
23		
24	Professional Help for Consumer	36.4%
25	Large Expenditures Incurred by Consumer	14.3%
26	Damage Caused by Consumer	12.1%
27	Consumer's Travel Expenses	19.9%
28	Medicine for Consumer	38.5%
29	Paying Off Consumer Debt	19.9%
30	Other	20.8%
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Table 2. Demographics- Living Arrangements

Residential Location (n=199)	Proportion
Metropolitan	55.8%
Regional	34.2%
Rural	10.0%
State/Territory (n=200)	
Australian Capital Territory	1.5%
New South Wales	24.5%
Northern Territory	4.0%
Queensland	21.0%
South Australia	5.5%
Tasmania	5.0%

Victoria	17.0%
Western Australia	21.5%
Carer Household Composition (n=201)	
Live Alone	8.0%
Live with Spouse/Partner/Children	72.6%
Live with Parents/Sisters/Brothers	4.0%
Live with Other Relatives	3.0%
Live with Friends	0.5%
Other	11.9%
Carer Time Spent Living with Consumer Last Four Weeks (n=189)	
Entire Four Weeks	67.2%
None	25.4%
Some	7.4%
(mean number of days = 8.3)	
Personal or Telephone Contact Per Week Between Consumer and Carer	
More than 32 hours	51.8%
17 to 32 hours	8.0%
9 to 16 hours	12.1%
5 to 8 hours	17.6%
Less than 5 Hours	10.6%

Table 3. Promoting Safety and Health

Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal drugs	0.8 (1.2)
Have you worried about the type of help/treatment your friend/relative is receiving	2.5 (1.2)
Have you worried about your friend/relatives safety	2.3 (1.2)
Have you worried about your friend/relatives general health	2.8 (1.1)

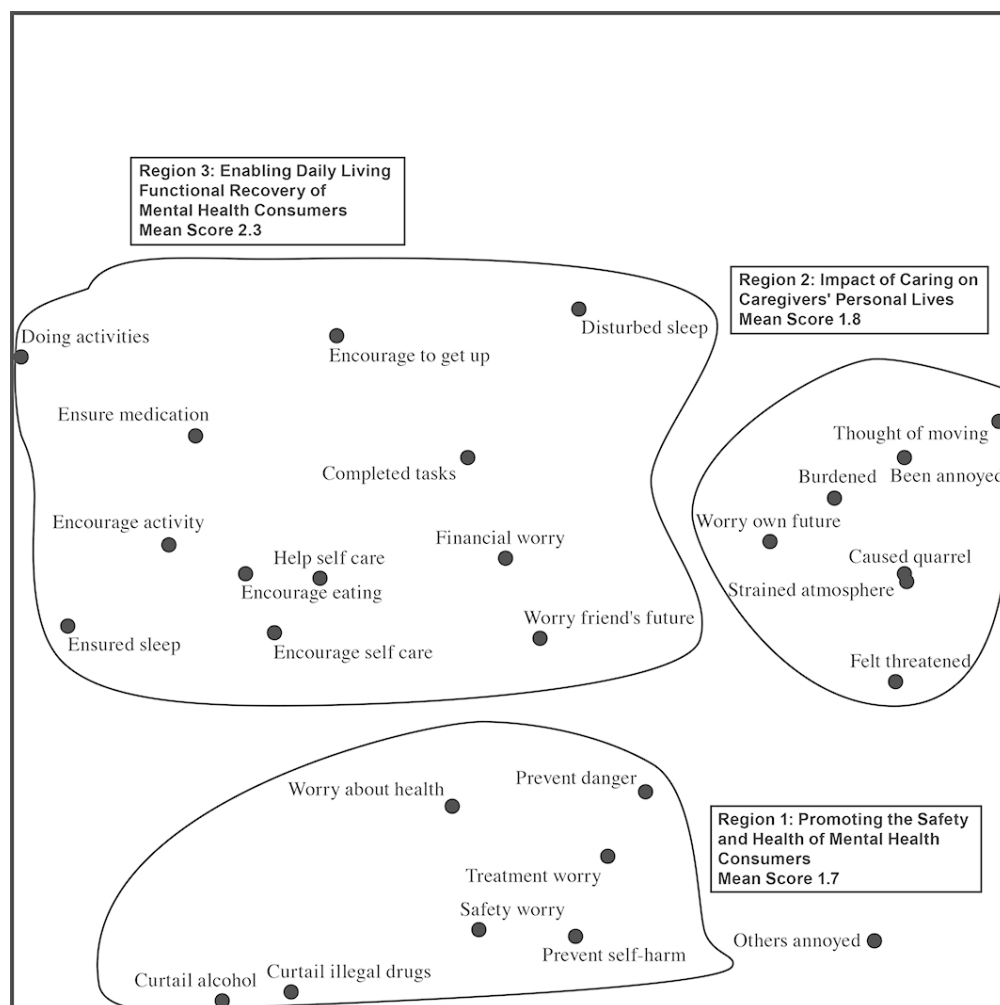
Table 4. Personal Impact

Item	Mean (SD)
Has the atmosphere been strained between you both, as a consequence of your friend/relatives behaviour	2.1 (1.1)
Has your friend/relative caused a quarrel	1.9 (1.0)
Have you been annoyed by your friend/relatives behaviour	2.1 (1.0)
Have you felt threatened by your friend/relatives behaviour	0.9 (0.9)
Have you thought of moving out as a result of your friend/relatives behaviour	1.2 (1.2)
Have you worried about your own future	1.9 (1.2)
Have your friend/relatives mental health problems been a burden to you	2.3 (1.2)

Table 5. Enabling Daily Living Functional Recovery

Item	Mean (SD)
Have you encouraged your friend/relative to get up in the morning	1.8 (1.2)

1		
2	Have you ensured your friend/relative received sufficient sleep	2.0 (1.1)
3	Has your friend/relative disturbed your sleep	1.9 (1.0)
4	Have you worried about how your friend/relative would	2.7 (1.3)
5	manage financially if you were no longer able to help	
6	Have you worried about your friend/relative's future	3.0 (1.1)
7	Have you encouraged your friend/relative to take proper care	3.1 (0.9)
8	of her/himself	
9	Have you helped your friend/relative to take proper care of	2.7 (1.1)
10	her/himself	
11	Have you encouraged your friend/relative to eat enough	2.2 (1.3)
12	Have you encouraged your friend/relative to undertake some	2.5 (1.1)
13	kind of activity	
14	Have you accompanied your friend/relative on some sort of	2.0 (1.3)
15	outside activity, because your friend/relative did not dare go	
16	out alone	
17	Have you ensured your friend/relative has taken the required	2.4 (1.3)
18	medicine	
19	Have you carried out tasks normally done by your	2.4 (1.1)
20	friend/relative	
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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	17
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6-7
		(b) Describe any methods used to examine subgroups and interactions	6-7
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy ⁶⁻⁷	
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA-cross sectional, data collected at single time point
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	7-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	In Tables located at end of manuscript
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

For peer review only

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Keywords

Mental Health; Carer; Caregiver; Burden; Smallest Space Analysis

Word Count

4148 words

Abstract

Objectives: To explore Australian mental health carers' prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Design: Cross-sectional survey.

Setting: All Australian States and Territories.

Participants: Responses were received from 231 Australian mental health caregivers.

Main outcome measures: The Involvement Evaluation Questionnaire was used to assess caregiver burden.

Results: Smallest space analysis identified three distinct regions, which we conceptualise as: 1) promoting the safety and health of mental health consumers; 2) impact of caring on caregivers' personal lives; and 3) enabling daily living functional recovery of mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value was considerably higher than the personal impact and promoting safety and health regions. In terms of the individual questionnaire items, the issues of most importance are assisting with self-care, worrying about consumers' future, finances and general health, encouraging consumer involvement in activities and concerns over the treatment consumers are receiving.

Conclusion: Caregiving often came at significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support and providing tailored psychosocial interventions that meet the needs of families.

Strengths and Limitations

- To our knowledge, this is the first Australian study to examine mental health carers prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden
- Qualitative data is used to provide further insight into the quantitative findings
- Respondent bias may influence our results

Background

The deinstitutionalisation of services has seen informal carers becoming increasingly involved in the mental health system.^{1,2} Carers in adopting these roles face ongoing challenges, which may include advocating on behalf of mental health consumers, crisis management, helping with daily activities and providing financial assistance.³⁻⁵ The burden associated with assuming these responsibilities, coupled with the impact of witnessing their relative experience mental illness, means that carers often report significant levels of distress.⁴⁻⁷

About one third of mental health consumers' family members experience emotional distress.^{7,8} Such distress may encompass feelings of loss, anxiety and distress.⁹⁻¹¹ In addition, caregiving may lead to social isolation, reduced work productivity, financial loss and disruption in family routines, which may substantially impair carers' quality of life.^{9,11-14}

Several factors have been identified that influence mental health caregiver burden. Studies have shown that caring for a male mental health consumer leads to significantly higher levels of stress.¹⁵ Other demographic characteristics that effect burden include lower levels of caregiver education and younger carer age, both of which have been associated with higher

1
2 levels of depression.¹⁶⁻¹⁹ Also, supporting consumers who display heightened positive or
3
4 negative symptoms exacerbates the detrimental impact on carers' quality of life, work
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6 efficiency and lost days of work.²⁰
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11 Although much of the available literature focuses on adverse consequences, caregiving for
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13 mental health consumers also results in beneficial outcomes for carers. Some mental health
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15 carers' note that supporting consumers has sensitised them to the needs of people with
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17 disabilities, enabled them to clarify their priorities in life and enhanced their resilience.²¹ The
18
19 sense of satisfaction and meaning that carers find in helping consumers has been associated
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21 with higher levels of quality of life.²²⁻²⁴
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29 Research has demonstrated that carers contribute importantly to the recovery of mental
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31 health consumers. In particular, the involvement of family members in the provision of mental
32
33 health services has been found to decrease consumer relapse and rehospitalisation rates by 20-
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35 50%.⁴ Other mental health consumer benefits that may be attributed to supportive family
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37 relationships include improved participation in vocational rehabilitation, higher employment
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39 rates, enhanced social functioning and reductions in psychiatric symptoms.⁴
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46 To our knowledge no prior qualitative studies have explored Australian mental health caregiver
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48 burden. However, a few quantitative studies have examined issues involved with caring for
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50 mental health consumers in an Australian context.^{13,25,26} The Australian quantitative
51
52 studies^{13,25,26} on mental health caregiver burden have reflected the results of research
53
54 conducted in other countries,^{7,15,27} in that they have shown that carers experience social
55
56 isolation and impaired physical and mental health. To our knowledge, no prior studies in an
57
58 Australian setting have quantified aspects of mental health caregiving. This information is
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60

1
2 important since it provides an understanding of the extent to which individual factors influence
3
4 mental health caregiver burden, and may enable health services to develop interventions that
5
6 target the factors that contribute most substantially to such burden. Hence, the purpose of this
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8 study is to explore Australian mental health carers' experiences through rating the importance
9
10 of key elements of caregiving and establish the extent to which particular issues contribute to
11
12 carer burden.
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19 **Methods**

20 *Study Design*

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22 This study involves a cross-sectional survey of Australian mental health caregivers. The
23
24 Murdoch University Human Research Ethics Committee granted ethical approval for this study
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26 (Approval Number 2016/215).
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33 *Survey Instrument*

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35 The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer
36
37 burden.²⁷ The decision to use the IEQ in this study was based on the findings of a systematic
38
39 review, which recommended the IEQ as one of the two most superior instruments to assess
40
41 mental health caregiver burden.²⁸ The questionnaire comprises four scales: 1) tension (nine
42
43 items), which assesses interpersonal difficulties between consumers and carers; 2) supervision
44
45 (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and
46
47 dangerous behaviour; 3) worrying (six items), which captures details regarding troubling
48
49 interpersonal like concern about the consumer's future and safety, overall health, and quality
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51 of health care; and 4) urging (eight items), which assesses the extent to which carers'
52
53 encourage consumers to undertake general activities and self-care.²⁷ Each item is scored on a
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55 five point Likert scale (never = 0, sometimes = 1, regularly = 2, often = 3, always = 4).²⁷ Finally, a
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1
2 single open-ended question allows carers to make comments about their experiences. This
3
4 question was phrased as follows: “Multiple choice questions cannot possibly cover all that you
5
6 have experienced with the person you care for. Please feel free to add any comments you may
7
8 wish to make in the space below.”
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13
14 The structure of the IEQ was originally established through subjecting data from a Dutch
15
16 mental health caregiver population to principal components analysis, which yielded the
17
18 aforementioned four scales.²⁷ The IEQ has subsequently been translated into English and
19
20 undergone psychometric testing, which consisted of an examination of its internal consistency
21
22 and test-test reliability. The results demonstrated that the IEQ scales exhibited adequate levels
23
24 of test-retest reliability, which was evidenced by the intra-class correlation coefficient values
25
26 ranging from 0.83 to 0.90.²⁷ But the IEQ’s supervision and urging scales both had inadequate
27
28 Cronbach alpha values 0.68 at two sites (London and Santander) that cast some doubt over
29
30 the adequacy of the IEQ’s scale structure.²⁸
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39 *Recruitment*

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41 All Australian caregivers for mental health consumers were eligible to participate in this study.
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43 Twenty-two carer, mental health carer, and mental health consumer organisations
44
45 disseminated study invitation notices on our behalf through Twitter, Facebook, e-newsletters
46
47 and online sites. We also personally distributed invitation notices through Facebook pages of
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49 mental health carer and consumer groups. The invitation notices outlined the purpose of the
50
51 study and provided the link for the online survey questionnaire. A comprehensive information
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53 letter was placed at the beginning of the survey, which the prospective participants were
54
55 asked to read before starting to answer the survey questions. All responses were anonymous
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1
2 and return of the questionnaire was used to indicate consent. Data were collected from March
3
4 2017 to July 2017.
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9 *Participant Involvement*

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11 Mental health caregivers were not actively involved in the design of this study, but did
12
13 contribute extensively to the development of the instrument used in this study.
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18 *Sample Size*

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20 Cochran's formula for continuous variables was used to establish the number of returned
21
22 questionnaires required to generalise the study findings.²⁹ Given that there were
23
24 approximately 15,666 Australian mental health carers³⁰, and incorporating a 5% level of
25
26 acceptable risk and 3% margin of error, it was established that 133 completed questionnaires
27
28 were needed to generalise the study findings.
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36 *Data Analysis*

37
38 The analysis combined quantitative and qualitative approaches. For the quantitative
39
40 component, data were entered and analysed in the Hebrew University Data Analysis Package
41
42 v.8. All demographic variables are reported descriptively. Given the lack of robust evidence for
43
44 the dimensionality of IEQ, smallest space analysis (SSA) was used to examine the structure of
45
46 the dataset. SSA was used as it offers numerous advantages over statistical methods such as
47
48 factor analysis.^{31,32} Such advantages include: provision of geometric output that is readily
49
50 comprehensible; derivation of the fewest number of dimensions; results remain invariant
51
52 under rotation; and lack of need to select orthogonal or oblique rotations.^{33,34} It is an especially
53
54 robust method that can be used to analyse many different types of data.^{33,34} SSA is one of a
55
56 host of non-metric multidimensional scaling (MDS) methods used to represent relationship
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1
2 measures between variables or items in a low dimensional space.³⁴ The SSA program
3
4 calculates associations between variables, where the association between any two variables is
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6 expressed as the distance between them on a graph such that the smaller the distance
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8 between two plotted variables, the stronger the association.
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14 In this instance SSA was used in an exploratory manner to uncover any hidden structures in the
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16 dataset that could be easily identified and displayed visually.³³ It provides a means for
17
18 reducing data and in so doing produces a summary of complex data that can be examined and
19
20 interpreted. Themes or patterns may arise from the visual depiction. A particular clusters of
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22 variables, each of which represents a construct or theme that captures something of the
23
24 carers' experience, are derived from a partitioning of the graph into regions or
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26 neighbourhoods.
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33 SSA also produces a measure, the co-efficient of alienation, that demonstrates how well the
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35 distances between the points on the two- dimensional SSA plot reflect the correlations
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37 between the questionnaire items.³⁵ The coefficient of alienation can range from 0 (best fit) to 1
38
39 (worst fit), and should be ≤ 0.2 to be considered satisfactory.³⁵ To facilitate comparison
40
41 between the SSA scales, which contained differing numbers of items, a total scale score was
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43 produced by summing the items, that was then divided by the number of items within the
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45 scale, after which a mean scale score was derived.
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53 The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis
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55 methods.³⁶ In this study, a theoretical, deductive approach to coding was used as the main
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57 purpose of the analysis was to confirm and further illuminate the structures identified in the
58
59 SSA analysis of the IEQ items. As such, a coding framework was developed wherein the SSA
60

1 regions served as themes, and the items within each region acted as subthemes. All of the
2 open-ended responses were then systematically analysed line by line and constant comparison
3 was used to map extracts from these responses into the coding framework. Both authors
4 initially reviewed the full set of open-ended responses. One of the authors then mapped the
5 responses into an excel spreadsheet that contained the coding framework. The other author
6 reviewed the conceptual fit of the mapped responses. The authors then met in-person to
7 clarify and further elaborate the themes and sub-themes through a consensus driven
8 discussion.

22 **Results**

23 The total number of returned questionnaires was 231, of which 122 contained responses to the
24 open-ended question. The respondents' demographic characteristics are displayed in Tables 1
25 and 2. The average age of the respondents was 51.7 (SD=12.3) years. Almost all respondents
26 were female (91.0%). Respondents tended to be in a long-term relationship or married (59.2%),
27 and generally lived with their spouse, partner, or children (72.6%) in metropolitan locations
28 (55.8%). During the past four weeks, most respondents experienced a physical or mental health
29 problem (75.0%), for which they most commonly consulted a general practitioner (68.0%). In
30 terms of the psychiatric diagnoses for the consumers of whom the respondents supported, the
31 most common were bipolar (19.9%) and schizophrenia/schizoaffective disorder (19.4%),
32 followed by depression (10.4%), personality disorder (10.0%) and anxiety disorder (7.0%). In
33 addition, about one-third (32.8%) of the respondents indicated "other" for the psychiatric
34 diagnosis, of which two-thirds (66.6%) related to the co-occurrence of two or more psychiatric
35 disorders.

59 *Smallest Space Analysis*

1
2 The coefficient of alienation for the SSA was .21. Figure 1 displays the 2-dimensional plot that
3
4 resulted from the SSA. An inspection of the plot shows that the items were clustered into three
5
6 distinct regions. These regions are conceptualised as: 1) promoting the safety and health of
7
8 mental health consumers; 2) enabling the daily living functional recovery of mental health
9
10 consumers; and 3) impact of caring on caregivers' personal lives. Note that one of the items,
11
12 "annoyed others", did not clearly fall into a distinct region, and hence was not included in the
13
14 interpretation of the findings.
15
16
17

18 **Region 1: Promoting the Safety and Health of Mental Health Consumers**

19
20 The region captures some of the concerns of carers which lead them to adopt a more
21
22 protective stance as a way of promoting the safety and health of consumers for whom they
23
24 care. Table 3 displays the seven items encapsulated in the promoting safety and health region.
25
26 The overall mean value for the promoting safety and health region was 1.7. As can be seen from
27
28 the mean values for the individual items, the respondents are most concerned by their
29
30 relative/friends general health. Such concern is unsurprising as mental health consumers often
31
32 experience multiple co-morbidities, which is captured in the following respondent's statement:
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39
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41 "Physical health problems are compounded by mental health. [My] partner also has
42
43 diabetes, sleep apnoea, irregular heartbeat, high blood pressure, high cholesterol,
44
45 arthritis, severe hearing loss and more" [Participant 120]
46
47
48
49

50
51 The item with the next highest mean value in this region reflected concern about the
52
53 healthcare their relative/friend is receiving. The qualitative material showed that respondents
54
55 are worried about several aspects of the delivery of mental healthcare. Many respondents
56
57 stated that it is difficult to access services, especially in regional or rural areas for example:
58
59
60

1
2 “Help for mental illness is practically non-existent in rural areas. The nearest mental
3
4 health facility is a two hour trip away and it hasn't been helpful at all. Firstly, I have
5
6 found the person presenting is interviewed by an intake officer, and that intake officer
7
8 makes a decision based possibly upon the criteria for the day; if all the boxes aren't
9
10 checked, the person presenting gets no help. This has been my experience with my
11
12 family member, turned away because all the boxes weren't checked and terrible
13
14 consequences followed” [Participant 42]
15
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22 In some cases, the lack in continuity of care is the primary concern, which undermined the
23
24 relationship between carers and health professionals, and left carers' feeling isolated and
25
26 concerned: “... the mental health system is that it is so disjointed and I find it hard who to trust
27
28 with our information and finding someone that cares enough to follow up and support me”
29
30 [Participant 57].
31
32
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34
35

36 Inadequate government support is often thought to detrimentally impact on the quality of
37
38 mental healthcare. The paucity of support meant that the onus for care fell on the
39
40 respondents: “governments have let us down immeasurably and as a result the burden has
41
42 been immense”. Some respondents are left feeling hopeless, but others were eventually able
43
44 to obtain adequate mental healthcare:
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50

51 “Getting help for my son and guidance for me to help him has been an arduous and very
52
53 lengthy process. If I wasn't as steadfast and committed I may have given up several
54
55 times after being told ‘NO’. I have had to struggle to find the few people that are now
56
57 involved in my son's care, and they are brilliant most of the time. But they didn't all
58
59 come to help us, I had to research hard to find them over years.” [Participant 84]
60

1
2
3
4 The item that enquired about carers' worry in regard to their friend/relatives safety also
5
6 recorded a relatively high mean score. However, the phrasing used for this item meant that it is
7
8 difficult to identify explicit safety issues. Finally, the mean scores for the items that captured
9
10 details about concern over self-harm, alcohol, and illegal substances are relatively low. But
11
12 these issues are nonetheless a source of substantial concern for some respondents, as the
13
14 following excerpt demonstrates:
15
16
17

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19
20
21 "Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming
22
23 burden to have a child of any age, want to destroy themselves this way. So in answer to
24
25 the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?"
26
27 the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only
28
29 encourage, support and guide him to the best of my ability" [Participant 84]
30
31
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36 **Region 2: Impact of Caring on Caregivers' Personal Lives**

37
38 The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact
39
40 of caring on carers' lives (see Table 4). The overall mean value for this region was 1.8. The mean
41
42 values for the individual items in this region indicate that the respondents are most troubled by
43
44 the carer burden that resulted from their relative/friend's mental health problems. Some
45
46 respondents noted that caring for mental health consumers is accompanied by a sense of loss
47
48 that had both physical and mental health consequences:
49
50
51

52
53
54
55 "It would be useful to look at the issue of ambiguous loss for family carers, particularly
56
57 for those who are long term family carers. This is something that is under-identified in
58
59 the area of impact on carers and mental health and yet, anecdotally I know from my
60

1
2 peers that it has a very real and very significant impact on people's physical
3
4 (autoimmune disorders) and mental (grief and depression) health” [Participant 7]
5
6
7
8

9 Another issue that several respondents noted has an impact physical and mental health is the
10 substantial amount of time devoted to caring, which results in social isolation, less time given
11 to other family members and neglect of their own wellbeing. As one respondent put it:
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14

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18
19 “You feel very alone. You just wish you could have time to yourself. You don't want to
20 walk on eggshells any more. You want to celebrate your other kids and spend time with
21 them but your attention is always diverted towards this one. When I'm not with them I
22 worry are they ok. I would just like to be by myself without having to worry.”
23
24
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28 [Participant 74]
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34 This sense of isolation in some instances was compounded by a lack of support from family
35 members:
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39
40

41 “I do find I isolate and insulate myself as my family won't discuss it, they don't want to
42 know as it's too stressful. My son's father abandoned him three years ago as he cannot
43 cope with his mental illness.” [Participant 17]
44
45
46
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51 In addition to the physical and mental health consequences, respondents also often drew
52 attention to the financial burden associated with caregiving. Time spent on caring meant that
53 respondents are unable to participate fully in the workforce. This directly impacts materially on
54 the respondents' “own future”, which is another of the items in the personal impact region
55
56
57
58
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60

1
2 that has a relatively high mean value. Other concerns that carers hold about their future
3
4 involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:
5
6
7
8

9 “I was extremely depressed when I was a full-time carer. I deferred university, failed
10 subjects and lost touch with my own aspirations.” [Participant 73]
11
12
13
14

15
16 “It's hard to express the impact it has on my life. It's the day-to-day impact, the need to
17 be there or in contact at anytime. The need to consider her needs in all my decisions.
18
19 The impact on my future plans - I would dearly love to go live overseas, but my mother
20 is still relatively young, and as much as it feels wrong to say this, she may live a long time
21 and make my dreams impossible.” [Participant 67]
22
23
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31 The remaining items in the personal impact region captured details about interpersonal tension
32 between carers and mental health consumers. Relatively high mean values were reported for
33 the items that enquired about the strained atmosphere, quarrels and annoyance at the
34 relative/friend's behaviour. These issues could be especially distressing, as one respondent
35 noted: “It's more than hard- dealing with this is something one can't explain and the emotional
36 verbal assaults we get from him is soul destroying.” [Participant 16]
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48 Given the often substantial nature of the ongoing interpersonal tension, especially for those
49 carers undertaking this work on a long-term basis, it would be understandable if carers
50 discontinued their support of mental health consumers. Yet some carers demonstrate
51 extraordinary levels of empathy and resilience, as was the case with this respondent:
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1
2 “Caring for my husband is a tremendous burden. His episodes are full of emotional
3
4 abuse, anger coupled with destruction of property and then feelings of the very
5
6 deepest self-loathing. For me though, it's given me a greater capacity to improve myself
7
8 and to experience empathy when it's not the natural response in this situation. No
9
10 matter how much he hurts me, and believe me he really does, it's nothing compared to
11
12 how much he is hurting and hates himself. My heart breaks for him. He suffers from a
13
14 biological illness that affects every part of him. His relationships, his day-to-day life.
15
16 Underneath the imbalance is the reason I married him.” [Participant 24]
17
18
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23

Region 3: Enabling Daily Living Functional Recovery of Mental Health Consumers

24
25 The third area clearly identified in the space emphasises the carers' role in the recovery journey
26
27 for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional
28
29 recovery region. The overall mean value for this region was 2.4. Many of the items in this region
30
31 enquire about aspects of caring that can be conceptualised as supporting social and functional
32
33 components of mental health recovery. In terms of functional recovery, encouraging and
34
35 helping mental health consumers with self-care and normal tasks, and concerns about
36
37 consumers' ability to manage financially, are the items with highest mean values. Assisting with
38
39 self-care and normal tasks could be onerous and is an area in which professional support would
40
41 be beneficial, as the following excerpts demonstrate:
42
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51 “I feel it's a battle I am fighting but losing. I struggle with him to look after himself
52
53 personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking
54
55 at groups online to seek help not only him but myself” [Participant 16]
56
57
58
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60

1
2 “Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving
3
4 me with any time... her inability to accept help in her personal washing and getting into
5
6 her clothing makes for a lot of time lost in a day. I am about to seek help from the
7
8 professionals” [Participant 70]
9
10

11
12
13
14 Financial concerns are one of the most frequently raised issues in the open-ended responses. A
15
16 key element of these concerns is the inadequate level of government financial assistance:
17

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19
20
21 “He is on the disability support, and after rent, has only less than \$200 a fortnight to
22
23 feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It
24
25 is quite a strain and the National Disability Insurance Scheme has not been able to assist
26
27 in the way he would like” [Participant 85]
28
29
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34 The items that captured information about aspects of social recovery generally had lower
35
36 mean values than the functional recovery items. And while the importance of facilitating social
37
38 inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put
39
40 it: “Exhaustion is constant as my partner relies on me totally for his social support and talks
41
42 non-stop” [Participant 8].
43
44
45

46
47
48 Finally, in the enabling daily living functional recovery region, the second highest mean value
49
50 was recorded for the item that asked the respondents if they are worried about their
51
52 relative/friends future. It is unsurprising that carers are often concerned about the mental
53
54 health consumers' prospects. As the above material has shown, it is not uncommon for mental
55
56 health consumers to experience social isolation and struggle with daily activities and finances.
57
58
59 The journey towards recovering pieces of consumers' lives clearly requires time and is difficult,
60

1
2 but could nonetheless be gratifying for carers: “It is tough at times, but you get some little
3
4 rewards along the way when they achieve things on their own” [Participant 78].
5
6
7

8 9 **Discussion**

10
11 The regions identified through the SSA provide a basis to understand the manner in which
12
13 carers prioritise issues that arise in supporting mental health consumers. The analysis
14
15 demonstrates that carers are most concerned with enabling daily living functional recovery, for
16
17 which the mean value is considerably higher than the personal impact and promoting safety
18
19 regions. In terms of the individual questionnaire items, the issues of most importance are
20
21 assisting with self-care, worrying about consumers’ future, finances and general health,
22
23 encouraging consumer involvement in activities and concerns over the treatment consumers
24
25 are receiving.
26
27
28
29
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31

32
33 The high level of concern that respondents report about daily living functional recovery
34
35 suggests that the provision of services that assist with these issues may contribute to the
36
37 reduction of caregiver burden. Psychiatric disability services are available in the community
38
39 throughout Australia to help carers and mental health consumers with tasks like activities of
40
41 daily living, housing, recreational and social activities and employment opportunities.³⁷
42
43

44
45 However, the extent to which Australian carers and mental health consumers access these
46
47 services is presently unknown. Further studies might be beneficial in identifying whether the
48
49 provision of psychiatric disability support services adequately address the needs of mental
50
51 health caregivers in regards to assistance with consumers daily living functional recovery.
52
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58 It was unsurprising to find that financial concerns figure prominently in the open-ended
59
60 responses and also have a high mean item rating. Many mental health carers forgo

1
2 employment or reduce their working hours while supporting consumers.^{38,39} In Australia,
3
4 modest income support payments are available to mental health carers who do not work, but
5
6 these payments are only accessible to a small proportion of carers.^{38,40} The hardship that
7
8 results from the lack of adequate financial assistance is further compounded by the often
9
10 substantial level of financial support that carers provide to mental health consumers.³⁸
11
12
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14
15

16 Our findings show that health professionals also have an important role to play in alleviating
17
18 mental health caregiver burden. Concerns over the provision of mental health care are
19
20 highlighted in this study, especially in regard to being isolated from the care that consumers
21
22 were receiving. Such issues reflect the results of other mental health carer studies that have
23
24 been conducted in Australia and within the United Kingdom.^{6,41} To some extent, the concern
25
26 that carers experience in regard to the provision of services might be lessened through
27
28 exploring and incorporating their views in planning and delivering mental healthcare.⁴
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36 *Limitations*

37
38 The demographic details of Australian mental health carers vary considerably between studies.
39
40 It is therefore difficult to develop a standardised profile of Australian mental health caregivers.
41
42 However, the demographic characteristics of the carers in this study are highly consistent with
43
44 the details reported in the most recent study of Australian mental health caregivers, which to
45
46 some extent supports the generalisability of our findings.³⁸ Finally, our value for the coefficient
47
48 of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is
49
50 considered to represent a good fit.³⁵ That said, the coefficient of alienation should be
51
52 interpreted in light of the SSA visual structure, which in the case of our study clearly delineated
53
54 distinct regions.³⁵
55
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Conclusion

Our findings demonstrate that carers' prioritise roles that promote the recovery of mental health consumers. However, such caregiving often incurs significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support and involving families more closely in the planning and delivery of mental health services. Such assistance would not only improve the circumstances of caregivers, but would also probably enhance the recovery of mental health consumers.

Figure Legends

Figure 1. Regions Identified Through Smallest Space Analysis

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Competing Interests

The authors have no competing interests to declare

Contributors

Paul Morrison contributed to the conceptualization, conduct, analysis, and reporting of this study. Norman Stomski contributed to the conceptualization, conduct, analysis, and reporting of this study

Ethics Approval

Murdoch University Human Research Ethics Committee

Data Sharing Agreement

No additional data are available

Table 1. Demographics- Personal Characteristics

	Mean (SD)
Carer's Age (n=198)	51.7 (12.3)
Consumer's Age (n=199)	41.6 (19.1)
	Proportion
Gender	
Carer Female (n=201)	91.0%
Consumer Female (n=201)	41.8%
Carer Relationship Status (n=201)	
Married/Long Term Relationship	59.2%
Divorced	18.9%
Widowed	2.0%
Unmarried	13.4%
Other	6.5%
Carer's Relationship to Consumer (n=200)	
Mother/Father	43.0%
Daughter/Son	15.0%
Sister/Brother	6.5%
Other Relative	1.0%
Wife/Husband/Partner	28.5%
Friend	2.5%
Other	3.5%
Carers with Physical or Mental Health Problems in Last Four Weeks (n=200)	75%
Assistance Type for Physical or Mental Health Problems in Last Four Weeks (n=150)	
General Practitioner/Family Doctor	68.0%
Social Worker/Psychologist/Psychiatrist	45.9%
Medication	48.7%
Carer Support Groups	36.5%
Online Information	52.9%
Online Support	25.0%
Extra expenses over last four weeks incurred on behalf of person for whom they care (n=201)	
Professional Help for Consumer	36.4%
Large Expenditures Incurred by Consumer	14.3%

Damage Caused by Consumer	12.1%
Consumer's Travel Expenses	19.9%
Medicine for Consumer	38.5%
Paying Off Consumer Debt	19.9%
Other	20.8%

Table 2. Demographics- Living Arrangements

Residential Location (n=199)	Proportion
Metropolitan	55.8%
Regional	34.2%
Rural	10.0%
State/Territory (n=200)	
Australian Capital Territory	1.5%
New South Wales	24.5%
Northern Territory	4.0%
Queensland	21.0%
South Australia	5.5%
Tasmania	5.0%
Victoria	17.0%
Western Australia	21.5%
Carer Household Composition (n=201)	
Live Alone	8.0%
Live with Spouse/Partner/Children	72.6%
Live with Parents/Sisters/Brothers	4.0%
Live with Other Relatives	3.0%
Live with Friends	0.5%
Other	11.9%
Carer Time Spent Living with Consumer Last Four Weeks (n=189)	
Entire Four Weeks	67.2%
None	25.4%
Some	7.4%
	(mean number of days = 8.3)
Personal or Telephone Contact Per Week Between Consumer and Carer	
More than 32 hours	51.8%
17 to 32 hours	8.0%
9 to 16 hours	12.1%
5 to 8 hours	17.6%
Less than 5 Hours	10.6%

Table 3. Promoting Safety and Health

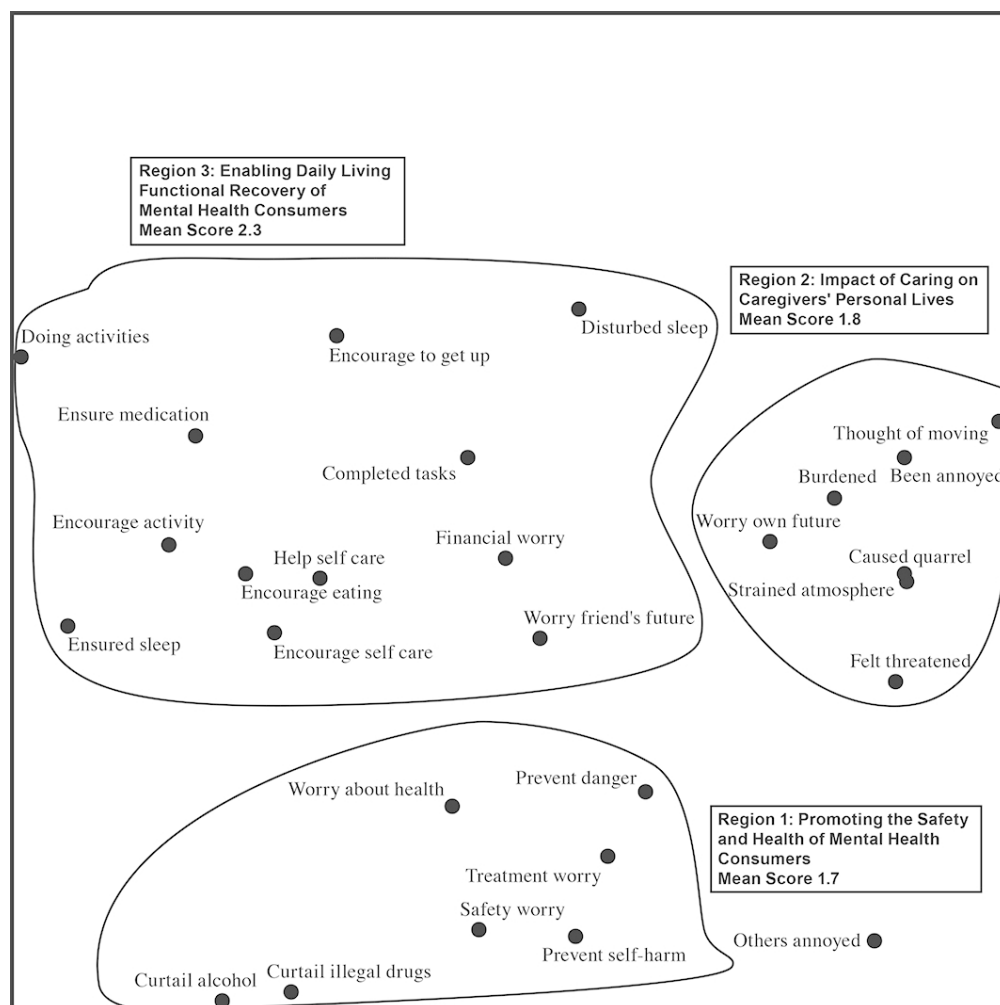
Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal drugs	0.8 (1.2)
Have you worried about the type of help/treatment your friend/relative is receiving	2.5 (1.2)
Have you worried about your friend/relatives safety	2.3 (1.2)
Have you worried about your friend/relatives general health	2.8 (1.1)

Table 4. Personal Impact

Item	Mean (SD)
Has the atmosphere been strained between you both, as a consequence of your friend/relatives behaviour	2.1 (1.1)
Has your friend/relative caused a quarrel	1.9 (1.0)
Have you been annoyed by your friend/relatives behaviour	2.1 (1.0)
Have you felt threatened by your friend/relatives behaviour	0.9 (0.9)
Have you thought of moving out as a result of your friend/relatives behaviour	1.2 (1.2)
Have you worried about your own future	1.9 (1.2)
Have your friend/relatives mental health problems been a burden to you	2.3 (1.2)

Table 5. Enabling Daily Living Functional Recovery

Item	Mean (SD)
Have you encouraged your friend/relative to get up in te morning	1.8 (1.2)
Have you ensured your friend relative received sufficient sleep	2.0 (1.1)
Has your friend/relative disturbed your sleep	1.9 (1.0)
Have you worried about how your friend/relative would manage financially if you were no longer able to help	2.7 (1.3)
Have you worried about your friend/relatives future	3.0 (1.1)
Have you encouraged your friend/relative to take proper care of her/himself	3.1 (0.9)
Have you helped your friend/relative to take proper care of her/himself	2.7 (1.1)
Have you encouraged your friend/relative to eat enough	2.2 (1.3)
Have you encouraged your friend/relative to undertake some kind of activity	2.5 (1.1)
Have you accompanied your friend/relative on some sort of outside activity, because your friend/relative did not dare go out alone	2.0 (1.3)
Have you ensured your friend/relative has taken the required medicine	2.4 (1.3)
Have you carried out tasks normally done by your friend/relative	2.4 (1.1)



90x90mm (300 x 300 DPI)

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STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	17
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6-7
		(b) Describe any methods used to examine subgroups and interactions	6-7
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy ⁶⁻⁷	
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA-cross sectional, data collected at single time point
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	7-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	In Tables located at end of manuscript
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Australian Mental Health Caregiver Burden: A Smallest Space Analysis

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Keywords

Mental Health; Carer; Caregiver; Burden; Smallest Space Analysis

Word Count

4148 words

Abstract

Objectives: To explore Australian mental health carers' prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Design: Cross-sectional survey.

Setting: All Australian States and Territories.

Participants: Responses were received from 231 Australian mental health caregivers.

Main outcome measures: The Involvement Evaluation Questionnaire was used to assess caregiver burden.

Results: Smallest space analysis identified three distinct regions, which we conceptualise as: 1) promoting the safety and health of mental health consumers; 2) impact of caring on caregivers' personal lives; and 3) enabling daily living functional recovery of mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value was considerably higher than the personal impact and promoting safety and health regions. In terms of the individual questionnaire items, the issues of most importance are assisting with self-care, worrying about consumers' future, finances and general health, encouraging consumer involvement in activities and concerns over the treatment consumers are receiving.

Conclusion: Caregiving often came at significant personal cost. The burden that results from caring for mental health consumers could perhaps be alleviated through the expansion of psychiatric disability services, increasing government financial support and providing tailored psychosocial interventions that meet the needs of families.

Strengths and Limitations

- To our knowledge, this is the first Australian study to examine mental health carers prioritisation of key elements of caregiving and establish the extent to which particular issues contribute to carer burden
- Qualitative data is used to provide further insight into the quantitative findings
- Respondent bias may influence our results

Background

The deinstitutionalisation of services has seen informal carers becoming increasingly involved in the mental health system.^{1,2} Carers in adopting these roles face ongoing challenges, which may include advocating on behalf of mental health consumers, crisis management, helping with daily activities and providing financial assistance.³⁻⁵ The burden associated with assuming these responsibilities, coupled with the impact of witnessing their relative experience mental illness, means that carers often report significant levels of distress.⁴⁻⁷

About one third of mental health consumers' family members experience emotional distress.^{7,8} Such distress may encompass feelings of loss, anxiety and distress.⁹⁻¹¹ In addition, caregiving may lead to social isolation, reduced work productivity, financial loss and disruption in family routines, which may substantially impair carers' quality of life.^{9,11-14}

Several factors have been identified that influence mental health caregiver burden. Studies have shown that caring for a male mental health consumer leads to significantly higher levels of stress.¹⁵ Other demographic characteristics that effect burden include lower levels of caregiver education and younger carer age, both of which have been associated with higher

1
2 levels of depression.¹⁶⁻¹⁹ Also, supporting consumers who display heightened positive or
3
4 negative symptoms exacerbates the detrimental impact on carers' quality of life, work
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6 efficiency and lost days of work.²⁰
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11 Although much of the available literature focuses on adverse consequences, caregiving for
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13 mental health consumers also results in beneficial outcomes for carers. Some mental health
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15 carers' note that supporting consumers has sensitised them to the needs of people with
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17 disabilities, enabled them to clarify their priorities in life and enhanced their resilience.²¹ The
18
19 sense of satisfaction and meaning that carers find in helping consumers has been associated
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21 with higher levels of quality of life.²²⁻²⁴
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29 Research has demonstrated that carers contribute importantly to the recovery of mental
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31 health consumers. In particular, the involvement of family members in the provision of mental
32
33 health services has been found to decrease consumer relapse and rehospitalisation rates by 20-
34
35 50%.⁴ Other mental health consumer benefits that may be attributed to supportive family
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37 relationships include improved participation in vocational rehabilitation, higher employment
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39 rates, enhanced social functioning and reductions in psychiatric symptoms.⁴
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46 To our knowledge no prior qualitative studies have explored Australian mental health caregiver
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48 burden. However, a few quantitative studies have examined issues involved with caring for
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50 mental health consumers in an Australian context.^{13,25,26} The Australian quantitative
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52 studies^{13,25,26} on mental health caregiver burden have reflected the results of research
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54 conducted in other countries,^{7,15,27} in that they have shown that carers experience social
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56 isolation and impaired physical and mental health. To our knowledge, no prior studies in an
57
58 Australian setting have quantified aspects of mental health caregiving. This information is
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1
2 important since it provides an understanding of the extent to which individual factors influence
3
4 mental health caregiver burden, and may enable health services to develop interventions that
5
6 target the factors that contribute most substantially to such burden. Hence, the purpose of this
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8 study is to explore Australian mental health carers' experiences through rating the importance
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10 of key elements of caregiving and establish the extent to which particular issues contribute to
11
12 carer burden.
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19 **Methods**

20 *Study Design*

21
22 This study involves a cross-sectional survey of Australian mental health caregivers. The
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24 Murdoch University Human Research Ethics Committee granted ethical approval for this study
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26 (Approval Number 2016/215).
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33 *Survey Instrument*

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35 The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer
36
37 burden.²⁷ The decision to use the IEQ in this study was based on the findings of a systematic
38
39 review, which recommended the IEQ as one of the two most superior instruments to assess
40
41 mental health caregiver burden.²⁸ The questionnaire comprises four scales: 1) tension (nine
42
43 items), which assesses interpersonal difficulties between consumers and carers; 2) supervision
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45 (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and
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47 dangerous behaviour; 3) worrying (six items), which captures details regarding troubling
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49 interpersonal like concern about the consumer's future and safety, overall health, and quality
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51 of health care; and 4) urging (eight items), which assesses the extent to which carers'
52
53 encourage consumers to undertake general activities and self-care.²⁷ Each item is scored on a
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55 five point Likert scale (never = 0, sometimes = 1, regularly = 2, often = 3, always = 4).²⁷ Finally, a
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1
2 single open-ended question allows carers to make comments about their experiences. This
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4 question was phrased as follows: “Multiple choice questions cannot possibly cover all that you
5
6 have experienced with the person you care for. Please feel free to add any comments you may
7
8 wish to make in the space below.”
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14 The structure of the IEQ was originally established through subjecting data from a Dutch
15
16 mental health caregiver population to principal components analysis, which yielded the
17
18 aforementioned four scales.²⁷ The IEQ has subsequently been translated into English and other
19
20 languages and undergone psychometric testing, across five international sites, comprising an
21
22 examination of its internal consistency and test-retest reliability. The results demonstrated that
23
24 the IEQ scales exhibited adequate levels of test-retest reliability, which was evidenced by the
25
26 intra-class correlation coefficient values ranging from 0.83 to 0.90.²⁷ But some of the Cronbach
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28 alpha values fell out of the ideal range of 0.70-0.80 proposed by Bland and Altman.²⁹ The
29
30 Cronbach alpha values for IEQ scales ranged from 0.75-0.84 for the tension scale; 0.68-0.82 for
31
32 the supervision scale; 0.77-0.86 for the worries scale; and 0.77-0.86 for the urging scale.²⁸ The
33
34 range of these Cronbach alpha values suggested that it would be worthwhile to re-evaluate the
35
36 structure of IEQ, using an exploratory method such as smallest space analysis (SSA).³⁰ In
37
38 addition, guidelines for the international translation of health-related outcome measures
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40 recommend that exploratory techniques should be used to establish the structure of
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42 translated questionnaires.³¹ This guidance further supported the use of SSA to reassess the
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44 structure of IEQ.
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55 *Recruitment*

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57 All Australian caregivers for mental health consumers were eligible to participate in this study.
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60 Twenty-two carer, mental health carer, and mental health consumer organisations

1
2 disseminated study invitation notices on our behalf through Twitter, Facebook, e-newsletters
3
4 and online sites. We also personally distributed invitation notices through Facebook pages of
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6 mental health carer and consumer groups. The invitation notices outlined the purpose of the
7
8 study and provided the link for the online survey questionnaire. A comprehensive information
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10 letter was placed at the beginning of the survey, which the prospective participants were
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12 asked to read before starting to answer the survey questions. All responses were anonymous
13
14 and return of the questionnaire was used to indicate consent. Data were collected from March
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19 2017 to July 2017.
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23 24 *Participant Involvement*

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26 Mental health caregivers were not actively involved in the design of this study, but did
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28 contribute extensively to the development of the instrument used in this study.
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32 33 *Sample Size*

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35 Cochran's formula for continuous variables was used to establish the number of returned
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37 questionnaires required to generalise the study findings.³² Given that there were
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39 approximately 15,666 Australian mental health carers³³, and incorporating a 5% level of
40
41 acceptable risk and 3% margin of error, it was established that 133 completed questionnaires
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43 were needed to generalise the study findings.
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50 51 *Data Analysis*

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53 The analysis combined quantitative and qualitative approaches. For the quantitative
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55 component, data were entered and analysed in the Hebrew University Data Analysis Package
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57 v.8. All demographic variables are reported descriptively. Given the lack of robust evidence for
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59 the dimensionality of IEQ, smallest space analysis was used to examine the structure of the
60

1
2 dataset. SSA was used as it offers numerous advantages over statistical methods such as factor
3
4 analysis.^{34,35} Such advantages include: provision of geometric output that is readily
5
6 comprehensible; derivation of the fewest number of dimensions; results remain invariant
7
8 under rotation; and lack of need to select orthogonal or oblique rotations.^{34,35} It is an especially
9
10 robust method that can be used to analyse many different types of data. ^{30,36} SSA is one of a
11
12 host of non-metric multidimensional scaling (MDS) methods used to represent relationship
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14 measures between variables or items in a low dimensional space. ³⁰ The SSA program
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16 calculates associations between variables, where the association between any two variables is
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18 expressed as the distance between them on a graph such that the smaller the distance
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24 between two plotted variables, the stronger the association.

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29 In this instance SSA was used in an exploratory manner to uncover any hidden structures in the
30
31 dataset that could be easily identified and displayed visually. ³⁶ It provides a means for
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33 reducing data and in so doing produces a summary of complex data that can be examined and
34
35 interpreted. Themes or patterns may arise from the visual depiction. A particular clusters of
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37 variables, each of which represents a construct or theme that captures something of the
38
39 carers' experience, are derived from a partitioning of the graph into regions or
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44 neighbourhoods.

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48 SSA also produces a measure, the co-efficient of alienation, that demonstrates how well the
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50 distances between the points on the two- dimensional SSA plot reflect the correlations
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52 between the questionnaire items. ³⁷ The coefficient of alienation can range from 0 (best fit) to 1
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54 (worst fit), and should be ≤ 0.2 to be considered satisfactory. ³⁷ To facilitate comparison
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58 between the SSA scales, which contained differing numbers of items, a total scale score was
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2 produced by summing the items, that was then divided by the number of items within the
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4 scale, after which a mean scale score was derived.
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9 The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis
10 methods.³⁸ In this study, a theoretical, deductive approach to coding was used as the main
11 purpose of the analysis was to confirm and further illuminate the structures identified in the
12 SSA analysis of the IEQ items. As such, a coding framework was developed wherein the SSA
13 regions served as themes, and the items within each region acted as subthemes. All of the
14 open-ended responses were then systematically analysed line by line and constant comparison
15 was used to map extracts from these responses into the coding framework. Both authors
16 initially reviewed the full set of open-ended responses. One of the authors then mapped the
17 responses into an excel spreadsheet that contained the coding framework. The other author
18 reviewed the conceptual fit of the mapped responses. The authors then met in-person to
19 clarify and further elaborate the themes and sub-themes through a consensus driven
20 discussion.
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40 **Results**

41 The total number of returned questionnaires was 231, of which 122 contained responses to the
42 open-ended question. The respondents' demographic characteristics are displayed in Tables 1
43 and 2. The average age of the respondents was 51.7 (SD=12.3) years. Almost all respondents
44 were female (91.0%). Respondents tended to be in a long-term relationship or married (59.2%),
45 and generally lived with their spouse, partner, or children (72.6%) in metropolitan locations
46 (55.8%). During the past four weeks, most respondents experienced a physical or mental health
47 problem (75.0%), for which they most commonly consulted a general practitioner (68.0%). In
48 terms of the psychiatric diagnoses for the consumers of whom the respondents supported, the
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2 most common were bipolar (19.9%) and schizophrenia/schizoaffective disorder (19.4%),
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4 followed by depression (10.4%), personality disorder (10.0%) and anxiety disorder (7.0%). In
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6 addition, about one-third (32.8%) of the respondents indicated “other” for the psychiatric
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8 diagnosis, of which two-thirds (66.6%) related to the co-occurrence of two or more psychiatric
9
10 disorders.
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12

13 14 15 16 *Smallest Space Analysis*

17
18 The coefficient of alienation for the SSA was .21. Figure 1 displays the 2-dimensional plot that
19
20 resulted from the SSA. An inspection of the plot shows that the items were clustered into three
21
22 distinct regions. These regions are conceptualised as: 1) promoting the safety and health of
23
24 mental health consumers; 2) enabling the daily living functional recovery of mental health
25
26 consumers; and 3) impact of caring on caregivers’ personal lives. Note that one of the items,
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28 “annoyed others”, did not clearly fall into a distinct region, and hence was not included in the
29
30 interpretation of the findings.
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35 36 **Region 1: Promoting the Safety and Health of Mental Health Consumers**

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38 The region captures some of the concerns of carers which lead them to adopt a more
39
40 protective stance as a way of promoting the safety and health of consumers for whom they
41
42 care. Table 3 displays the seven items encapsulated in the promoting safety and health region.
43
44 The overall mean value for the promoting safety and health region was 1.7. As can be seen from
45
46 the mean values for the individual items, the respondents are most concerned by their
47
48 relative/friends general health. Such concern is unsurprising as mental health consumers often
49
50 experience multiple co-morbidities, which is captured in the following respondent’s statement:
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2 “Physical health problems are compounded by mental health. [My] partner also has
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4 diabetes, sleep apnoea, irregular heartbeat, high blood pressure, high cholesterol,
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6 arthritis, severe hearing loss and more” [Participant 120]
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11 The item with the next highest mean value in this region reflected concern about the
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13 healthcare their relative/friend is receiving. The qualitative material showed that respondents
14
15 are worried about several aspects of the delivery of mental healthcare. Many respondents
16
17 stated that it is difficult to access services, especially in regional or rural areas for example:
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24 “Help for mental illness is practically non-existent in rural areas. The nearest mental
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26 health facility is a two hour trip away and it hasn't been helpful at all. Firstly, I have
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28 found the person presenting is interviewed by an intake officer, and that intake officer
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30 makes a decision based possibly upon the criteria for the day; if all the boxes aren't
31
32 checked, the person presenting gets no help. This has been my experience with my
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34 family member, turned away because all the boxes weren't checked and terrible
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36 consequences followed” [Participant 42]
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44 In some cases, the lack in continuity of care is the primary concern, which undermined the
45
46 relationship between carers and health professionals, and left carers' feeling isolated and
47
48 concerned: “... the mental health system is that it is so disjointed and I find it hard who to trust
49
50 with our information and finding someone that cares enough to follow up and support me”
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53 [Participant 57].
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59 Inadequate government support is often thought to detrimentally impact on the quality of
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61 mental healthcare. The paucity of support meant that the onus for care fell on the

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2 respondents: “governments have let us down immeasurably and as a result the burden has
3
4 been immense”. Some respondents are left feeling hopeless, but others were eventually able
5
6 to obtain adequate mental healthcare:
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11 “Getting help for my son and guidance for me to help him has been an arduous and very
12
13 lengthy process. If I wasn't as steadfast and committed I may have given up several
14
15 times after being told ‘NO’. I have had to struggle to find the few people that are now
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17 involved in my son's care, and they are brilliant most of the time. But they didn't all
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19 come to help us, I had to research hard to find them over years.” [Participant 84]
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26 The item that enquired about carers' worry in regard to their friend/relatives safety also
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28 recorded a relatively high mean score. However, the phrasing used for this item meant that it is
29
30 difficult to identify explicit safety issues. Finally, the mean scores for the items that captured
31
32 details about concern over self-harm, alcohol, and illegal substances are relatively low. But
33
34 these issues are nonetheless a source of substantial concern for some respondents, as the
35
36 following excerpt demonstrates:
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43 “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming
44
45 burden to have a child of any age, want to destroy themselves this way. So in answer to
46
47 the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?"
48
49 the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only
50
51 encourage, support and guide him to the best of my ability” [Participant 84]
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58 ***Region 2: Impact of Caring on Caregivers' Personal Lives***

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1
2 The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact
3
4 of caring on carers' lives (see Table 4). The overall mean value for this region was 1.8. The mean
5
6 values for the individual items in this region indicate that the respondents are most troubled by
7
8 the carer burden that resulted from their relative/friend's mental health problems. Some
9
10 respondents noted that caring for mental health consumers is accompanied by a sense of loss
11
12 that had both physical and mental health consequences:
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19 "It would be useful to look at the issue of ambiguous loss for family carers, particularly
20
21 for those who are long term family carers. This is something that is under-identified in
22
23 the area of impact on carers and mental health and yet, anecdotally I know from my
24
25 peers that it has a very real and very significant impact on people's physical
26
27 (autoimmune disorders) and mental (grief and depression) health" [Participant 7]
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33
34 Another issue that several respondents noted has an impact physical and mental health is the
35
36 substantial amount of time devoted to caring, which results in social isolation, less time given
37
38 to other family members and neglect of their own wellbeing. As one respondent put it:
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42
43 "You feel very alone. You just wish you could have time to yourself. You don't want to
44
45 walk on eggshells any more. You want to celebrate your other kids and spend time with
46
47 them but your attention is always diverted towards this one. When I'm not with them I
48
49 worry are they ok. I would just like to be by myself without having to worry."
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53 [Participant 74]
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58 This sense of isolation in some instances was compounded by a lack of support from family
59
60 members:

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4 “I do find I isolate and insulate myself as my family won't discuss it, they don't want to
5 know as it's too stressful. My son's father abandoned him three years ago as he cannot
6 cope with his mental illness.” [Participant 17]
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14 In addition to the physical and mental health consequences, respondents also often drew
15 attention to the financial burden associated with caregiving. Time spent on caring meant that
16 respondents are unable to participate fully in the workforce. This directly impacts materially on
17 the respondents' “own future”, which is another of the items in the personal impact region
18 that has a relatively high mean value. Other concerns that carers hold about their future
19 involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:
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31 “I was extremely depressed when I was a full-time carer. I deferred university, failed
32 subjects and lost touch with my own aspirations.” [Participant 73]
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38 “It's hard to express the impact it has on my life. It's the day-to-day impact, the need to
39 be there or in contact at anytime. The need to consider her needs in all my decisions.
40 The impact on my future plans - I would dearly love to go live overseas, but my mother
41 is still relatively young, and as much as it feels wrong to say this, she may live a long time
42 and make my dreams impossible.” [Participant 67]
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52
53 The remaining items in the personal impact region captured details about interpersonal tension
54 between carers and mental health consumers. Relatively high mean values were reported for
55 the items that enquired about the strained atmosphere, quarrels and annoyance at the
56 relative/friend's behaviour. These issues could be especially distressing, as one respondent
57
58
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1
2 noted: "It's more than hard- dealing with this is something one can't explain and the emotional
3
4 verbal assaults we get from him is soul destroying." [Participant 16]
5
6
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8

9 Given the often substantial nature of the ongoing interpersonal tension, especially for those
10
11 carers undertaking this work on a long-term basis, it would be understandable if carers
12
13 discontinued their support of mental health consumers. Yet some carers demonstrate
14
15 extraordinary levels of empathy and resilience, as was the case with this respondent:
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21 "Caring for my husband is a tremendous burden. His episodes are full of emotional
22
23 abuse, anger coupled with destruction of property and then feelings of the very
24
25 deepest self-loathing. For me though, it's given me a greater capacity to improve myself
26
27 and to experience empathy when it's not the natural response in this situation. No
28
29 matter how much he hurts me, and believe me he really does, it's nothing compared to
30
31 how much he is hurting and hates himself. My heart breaks for him. He suffers from a
32
33 biological illness that affects every part of him. His relationships, his day-to-day life.
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35 Underneath the imbalance is the reason I married him." [Participant 24]
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45 ***Region 3: Enabling Daily Living Functional Recovery of Mental Health Consumers***

46 The third area clearly identified in the space emphasises the carers' role in the recovery journey
47
48 for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional
49
50 recovery region. The overall mean value for this region was 2.4. Many of the items in this region
51
52 enquire about aspects of caring that can be conceptualised as supporting social and functional
53
54 components of mental health recovery. In terms of functional recovery, encouraging and
55
56 helping mental health consumers with self-care and normal tasks, and concerns about
57
58 consumers' ability to manage financially, are the items with highest mean values. Assisting with
59
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1
2 self-care and normal tasks could be onerous and is an area in which professional support would
3
4 be beneficial, as the following excerpts demonstrate:
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9 “I feel it's a battle I am fighting but losing. I struggle with him to look after himself
10 personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking
11 at groups online to seek help not only him but myself” [Participant 16]
12
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18 “Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving
19 me with any time... her inability to accept help in her personal washing and getting into
20 her clothing makes for a lot of time lost in a day. I am about to seek help from the
21 professionals” [Participant 70]
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31 Financial concerns are one of the most frequently raised issues in the open-ended responses. A
32 key element of these concerns is the inadequate level of government financial assistance:
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39 “He is on the disability support, and after rent, has only less than \$200 a fortnight to
40 feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It
41 is quite a strain and the National Disability Insurance Scheme has not been able to assist
42 in the way he would like” [Participant 85]
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51 The items that captured information about aspects of social recovery generally had lower
52 mean values than the functional recovery items. And while the importance of facilitating social
53 inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put
54 it: “Exhaustion is constant as my partner relies on me totally for his social support and talks
55 non-stop” [Participant 8].
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4 Finally, in the enabling daily living functional recovery region, the second highest mean value
5
6 was recorded for the item that asked the respondents if they are worried about their
7
8 relative/friends future. It is unsurprising that carers are often concerned about the mental
9
10 health consumers' prospects. As the above material has shown, it is not uncommon for mental
11
12 health consumers to experience social isolation and struggle with daily activities and finances.
13
14 The journey towards recovering pieces of consumers' lives clearly requires time and is difficult,
15
16 but could nonetheless be gratifying for carers: "It is tough at times, but you get some little
17
18 rewards along the way when they achieve things on their own" [Participant 78].
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26 Discussion

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28 The regions identified through the SSA provide a basis to understand the manner in which
29
30 carers prioritise issues that arise in supporting mental health consumers. The analysis
31
32 demonstrates that carers are most concerned with enabling daily living functional recovery, for
33
34 which the mean value is considerably higher than the personal impact and promoting safety
35
36 regions. In terms of the individual questionnaire items, the issues of most importance are
37
38 assisting with self-care, worrying about consumers' future, finances and general health,
39
40 encouraging consumer involvement in activities and concerns over the treatment consumers
41
42 are receiving.
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51 The high level of concern that respondents report about daily living functional recovery
52
53 suggests that the provision of services that assist with these issues may contribute to the
54
55 reduction of caregiver burden. Psychiatric disability services are available in the community
56
57 throughout Australia to help carers and mental health consumers with tasks like activities of
58
59 daily living, housing, recreational and social activities and employment opportunities.³⁹
60

1
2 However, the extent to which Australian carers and mental health consumers access these
3
4 services is presently unknown. Further studies might be beneficial in identifying whether the
5
6 provision of psychiatric disability support services adequately address the needs of mental
7
8 health caregivers in regards to assistance with consumers daily living functional recovery.
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14 It was unsurprising to find that financial concerns figure prominently in the open-ended
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16 responses and also have a high mean item rating. Many mental health carers forgo
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18 employment or reduce their working hours while supporting consumers.^{40,41} In Australia,
19
20 modest income support payments are available to mental health carers who do not work, but
21
22 these payments are only accessible to a small proportion of carers.^{40,42} The hardship that
23
24 results from the lack of adequate financial assistance is further compounded by the often
25
26 substantial level of financial support that carers provide to mental health consumers.⁴⁰
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34 Our findings show that health professionals also have an important role to play in alleviating
35
36 mental health caregiver burden. Concerns over the provision of mental health care are
37
38 highlighted in this study, especially in regard to being isolated from the care that consumers
39
40 were receiving. Such issues reflect the results of other mental health carer studies that have
41
42 been conducted in Australia and within the United Kingdom.^{6,43} To some extent, the concern
43
44 that carers experience in regard to the provision of services might be lessened through
45
46 exploring and incorporating their views in planning and delivering mental healthcare.⁴
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53 *Limitations*

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55 The demographic details of Australian mental health carers vary considerably between studies.
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57 It is therefore difficult to develop a standardised profile of Australian mental health caregivers.
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59
60 However, the demographic characteristics of the carers in this study are highly consistent with

1
2 the details reported in the most recent study of Australian mental health caregivers, which to
3
4 some extent supports the generalisability of our findings.⁴⁰ Finally, our value for the coefficient
5
6 of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is
7
8 considered to represent a good fit.³⁷ That said, the coefficient of alienation should be
9
10 interpreted in light of the SSA visual structure, which in the case of our study clearly delineated
11
12 distinct regions.³⁷
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19 Conclusion

21 Our findings demonstrate that carers' prioritise roles that promote the recovery of mental
22
23 health consumers. However, such caregiving often incurs significant personal cost. The burden
24
25 that results from caring for mental health consumers could perhaps be alleviated through the
26
27 expansion of psychiatric disability services, increasing government financial support and
28
29 involving families more closely in the planning and delivery of mental health services. Such
30
31 assistance would not only improve the circumstances of caregivers, but would also probably
32
33 enhance the recovery of mental health consumers.
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38 Figure Legends

40 Figure 1. Regions Identified Through Smallest Space Analysis
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5

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10

11 **Competing Interests**

12
13 The authors have no competing interests to declare
14

15 **Contributors**

16
17 Paul Morrison contributed to the conceptualization, conduct, analysis, and reporting of this
18 study. Norman Stomski contributed to the conceptualization, conduct, analysis, and reporting
19 of this study
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27 **Ethics Approval**

28
29 Murdoch University Human Research Ethics Committee
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31 **Data Sharing Agreement**

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33 No additional data are available
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Table 1. Demographics- Personal Characteristics

	Mean (SD)
Carer's Age (n=198)	51.7 (12.3)
Consumer's Age (n=199)	41.6 (19.1)
	Proportion
Gender	
Carer Female (n=201)	91.0%
Consumer Female (n=201)	41.8%
Carer Relationship Status (n=201)	
Married/Long Term Relationship	59.2%
Divorced	18.9%
Widowed	2.0%
Unmarried	13.4%
Other	6.5%
Carer's Relationship to Consumer (n=200)	
Mother/Father	43.0%
Daughter/Son	15.0%
Sister/Brother	6.5%
Other Relative	1.0%
Wife/Husband/Partner	28.5%
Friend	2.5%
Other	3.5%
Carers with Physical or Mental Health Problems in Last Four Weeks (n=200)	75%
Assistance Type for Physical or Mental Health Problems in Last Four Weeks (n=150)	
General Practitioner/Family Doctor	68.0%
Social Worker/Psychologist/Psychiatrist	45.9%
Medication	48.7%
Carer Support Groups	36.5%
Online Information	52.9%
Online Support	25.0%
Extra expenses over last four weeks incurred on behalf of person for whom they care (n=201)	
Professional Help for Consumer	36.4%
Large Expenditures Incurred by Consumer	14.3%
Damage Caused by Consumer	12.1%
Consumer's Travel Expenses	19.9%
Medicine for Consumer	38.5%
Paying Off Consumer Debt	19.9%
Other	20.8%

Table 2. Demographics- Living Arrangements

Residential Location (n=199)	Proportion
Metropolitan	55.8%
Regional	34.2%
Rural	10.0%
State/Territory (n=200)	
Australian Capital Territory	1.5%
New South Wales	24.5%
Northern Territory	4.0%
Queensland	21.0%
South Australia	5.5%
Tasmania	5.0%
Victoria	17.0%
Western Australia	21.5%
Carer Household Composition (n=201)	
Live Alone	8.0%
Live with Spouse/Partner/Children	72.6%
Live with Parents/Sisters/Brothers	4.0%
Live with Other Relatives	3.0%
Live with Friends	0.5%
Other	11.9%
Carer Time Spent Living with Consumer Last Four Weeks (n=189)	
Entire Four Weeks	67.2%
None	25.4%
Some	7.4%
	(mean number of days = 8.3)
Personal or Telephone Contact Per Week Between Consumer and Carer	
More than 32 hours	51.8%
17 to 32 hours	8.0%
9 to 16 hours	12.1%
5 to 8 hours	17.6%
Less than 5 Hours	10.6%

Table 3. Promoting Safety and Health

Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal drugs	0.8 (1.2)
Have you worried about the type of help/treatment your friend/relative is receiving	2.5 (1.2)
Have you worried about your friend/relatives safety	2.3 (1.2)
Have you worried about your friend/relatives general health	2.8 (1.1)

Table 4. Personal Impact

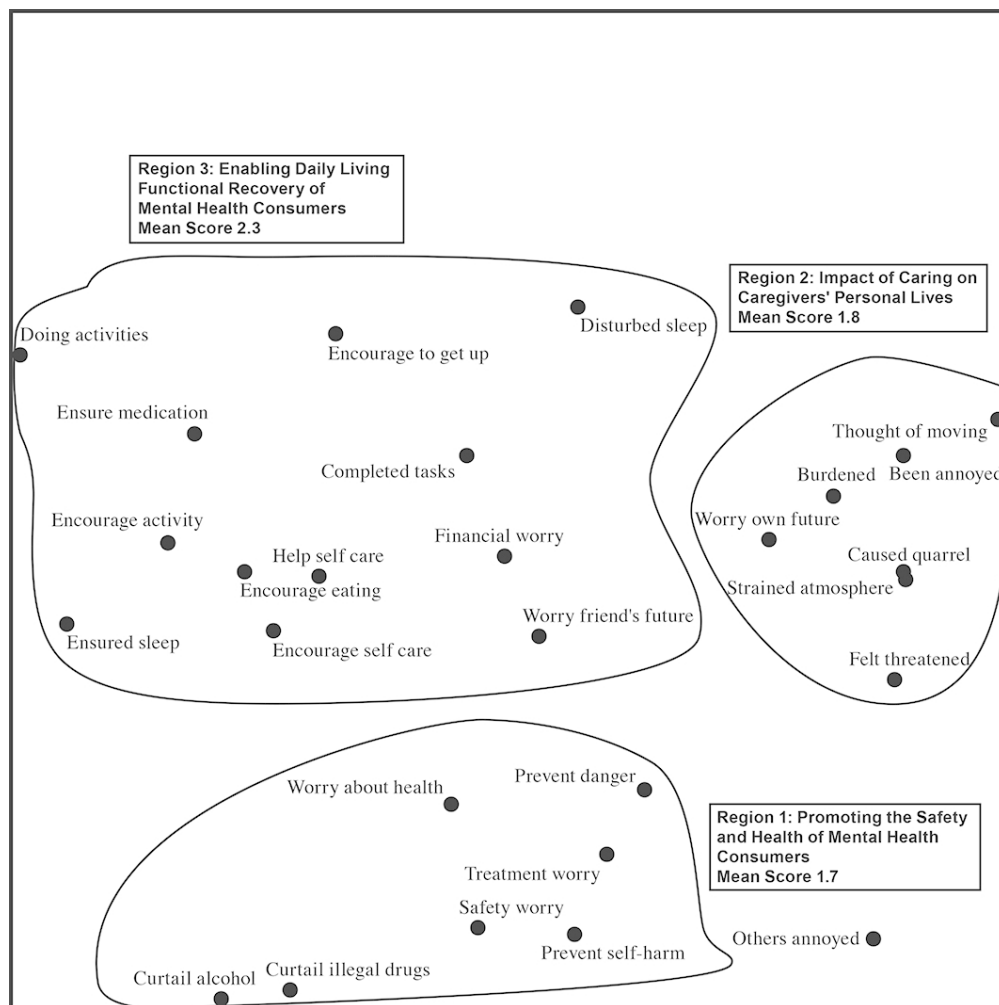
Item	Mean (SD)
Has the atmosphere been strained between you both, as a consequence of your friend/relatives behaviour	2.1 (1.1)
Has your friend/relative caused a quarrel	1.9 (1.0)

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Have you been annoyed by your friend/relatives behaviour	2.1 (1.0)
Have you felt threatened by your friend/relatives behaviour	0.9 (0.9)
Have you thought of moving out as a result of your friend/relatives behaviour	1.2 (1.2)
Have you worried about your own future	1.9 (1.2)
Have your friend/relatives mental health problems been a burden to you	2.3 (1.2)

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11**Table 5. Enabling Daily Living Functional Recovery**12
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Item	Mean (SD)
Have you encouraged your friend/relative to get up in te morning	1.8 (1.2)
Have you ensured your friend relative received sufficient sleep	2.0 (1.1)
Has your friend/relative disturbed your sleep	1.9 (1.0)
Have you worried about how your friend/relative would manage financially if you were no longer able to help	2.7 (1.3)
Have you worried about your friend/relatives future	3.0 (1.1)
Have you encouraged your friend/relative to take proper care of her/himself	3.1 (0.9)
Have you helped your friend/relative to take proper care of her/himself	2.7 (1.1)
Have you encouraged your friend/relative to eat enough	2.2 (1.3)
Have you encouraged your friend/relative to undertake some kind of activity	2.5 (1.1)
Have you accompanied your friend/relative on some sort of outside activity, because your friend/relative did not dare go out alone	2.0 (1.3)
Have you ensured your friend/relative has taken the required medicine	2.4 (1.3)
Have you carried out tasks normally done by your friend/relative	2.4 (1.1)



90x90mm (300 x 300 DPI)

STROBE 2007 (v4) checklist of items to be included in reports of observational studies in epidemiology*
Checklist for cohort, case-control, and cross-sectional studies (combined)

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2-4
Objectives	3	State specific objectives, including any pre-specified hypotheses	4
Methods			
Study design	4	Present key elements of study design early in the paper	4-5
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5
Participants	6	(a) <i>Cohort study</i> —Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants	5
		(b) <i>Cohort study</i> —For matched studies, give matching criteria and number of exposed and unexposed <i>Case-control study</i> —For matched studies, give matching criteria and the number of controls per case	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5
Bias	9	Describe any efforts to address potential sources of bias	17
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	6-7
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6-7
		(b) Describe any methods used to examine subgroups and interactions	6-7
		(c) Explain how missing data were addressed	NA
		(d) <i>Cohort study</i> —If applicable, explain how loss to follow-up was addressed <i>Case-control study</i> —If applicable, explain how matching of cases and controls was addressed	

		<i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of sampling strategy ⁶⁻⁷	
		(e) Describe any sensitivity analyses	NA
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA-cross sectional, data collected at single time point
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	<i>Cohort study</i> —Report numbers of outcome events or summary measures over time	
		<i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure	
		<i>Cross-sectional study</i> —Report numbers of outcome events or summary measures	7-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	In Tables located at end of manuscript
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	NA
Discussion			
Key results	18	Summarise key results with reference to study objectives	15
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	17
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	15-17
Generalisability	21	Discuss the generalisability (external validity) of the study results	17
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	NA

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

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Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

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