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

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 (Magana, Ramirez Garcia, Hernandez, & Cortez, 2007). Other demographic characteristics that effect burden include lower levels of caregiver education and younger carer age, both of which have been associated with higher levels of depression (Finch, Kolody, & Vega, 2000; Gonzalez, Haan, & Hinton, 2001; Papastavrou, Charalambous, Tsangari, & Karayiannis, 2010; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). Also, supporting consumers who display heightened positive or negative symptoms exacerbates the detrimental impact on carers' quality of life, work efficiency, and lost days of work (Rabinowitz, Berardo, Bugarski-Kirola, & Marder, 2013).

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

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

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

Methods

Study Design

We undertook a cross-sectional survey of Australian mental health caregivers. The Murdoch University Human Research Ethics Committee granted ethical approval for this study (Approval Number 2016/215).

Survey Instrument

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

Recruitment

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

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 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

Date 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 of the carers' experience, are derived from a partitioning of the graph into regions or neighbourhoods. Moreover the open ended data collected in the survey may be used to assist with the development and confirmation of any structures or themes in the analysis.

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

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%).

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 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. 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.

The subsequent section details the items contained in each region. Interpretation of the items reported below may be aided by bearing in mind that the following values are assigned to each category: 0=never; 1=sometimes; 2= regularly; 3=often; and 4= always. In addition, the delineation of these regions is further supported by the presentation of the qualitative open-ended responses.

Region 1: Promoting the Safety of Mental Health Consumers

The region captures some of the concerns of carers which led them to adopt a more protective stance as a way of promoting the safety of consumers for whom they cared. Table 3 displays the seven items encapsulated in the promoting safety region. The overall mean value for the promoting safety region was 1.7. As can be seen from the mean values for the individual items, the respondents were 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 promoting safety region reflected concern about the healthcare their relative/friend was receiving. The qualitative material showed that respondents were worried about several aspects of the delivery of mental healthcare. Many respondents stated that it is was 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"

In some cases the lack in continuity of care was the primary concern, which undermined the relationship between carers and health professionals, and left carers' feeling isolated and concerned: "… the mental health system is that it is so disjointed and I find it hard who to trust with our information and finding someone that cares enough to follow up and support me".

Inadequate government support was often thought to detrimentally impact on the quality of mental healthcare. The paucity of support meant that the onus for care fell on the respondents: "governments have let us down immeasurably and as a result the burden has been immense". Some respondents were left feeling hopeless, but others were eventually able to obtain adequate mental healthcare:

> "Getting help for my son and guidance for me to help him has been an arduous and very lengthy process. If I wasn't as steadfast and committed I may have given up several times after being told 'NO'. I have had to struggle to find the few people that are now

> involved in my son's care, and they are brilliant most of the time. But they didn't all come to help us, I had to research hard to find them over years.”

The item that enquired about carers’ worry in regard to their friend/relatives safety also recorded a relatively high mean score. However, the phrasing used for this item meant that it was difficult to identify explicit safety issues. Finally, the mean scores for the items that captured details about concern over self-harm, alcohol, and illegal substances were relatively low. But these issues were nonetheless a source of substantial concern for some respondents, as the following excerpt demonstrates:

> “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming burden to have a child of any age, want to destroy themselves this way. So in answer to the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?" the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only encourage, support and guide him to the best of my ability”

Region 2: Impact of Caring on Caregivers’ Personal Lives

The second neighbourhood of items illustrated on the 2D plot emphasises the personal impact of caring on carers’ lives (see Table 4). The overall mean value for this region was 1.8. The mean values for the individual items in this region indicate that the respondents were most troubled by the carer burden that resulted from their relative/friend’s mental health problems. Some respondents noted that caring for mental health consumers was accompanied by a sense of loss that had both physical and mental health consequences:

> "It would be useful to look at the issue of ambiguous loss for family carers, particularly for those who are long term family carers. This is something that is under-identified in the area of impact on carers and mental health and yet, anecdotally I know from my peers that it has a very real and very significant impact on people's physical (autoimmune disorders) and mental (grief and depression) health".

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

> "You feel very alone. You just wish you could have time to yourself. You don't want to walk on eggshells any more. You want to celebrate your other kids and spend time with them but your attention is always diverted towards this one. When I'm not with them I worry are they ok. I would just like to be by myself without having to worry."

This sense of isolation in some instances was compounded by a lack of support from family members:

> "I do find I isolate and insulate myself as my family won't discuss it, they don't want to know as it's too stressful. My son's father abandoned him three years ago as he cannot cope with his mental illness."

In addition to the physical and mental health consequences, respondents also often drew attention to the financial burden associated with caregiving. Time spent on caring meant that respondents were unable to participate fully in the workforce. This had a direct material impact on the respondents' "own future", which was another of the items in the personal impact region that had a relatively high mean value. Other concerns that carers had about their future involved the effect on career prospects and lifestyle, as can be seen from the following excerpts:

> "I was extremely depressed when I was a full-time carer. I deferred university, failed subjects and lost touch with my own aspirations."

> "It's hard to express the impact it has on my life. It's the day-to-day impact, the need to be there or in contact at anytime. The need to consider her needs in all my decisions. The impact on my future plans - I would dearly love to go live overseas, but my mother is still relatively young, and as much as it feels wrong to say this, she may live a long time and make my dreams impossible."

The remaining items in the personal impact region captured details about interpersonal tension between carers and mental health consumers. Relatively high mean values were reported for the items that enquired about the strained atmosphere, quarrels, and annoyance at the relative/friend's behaviour. These issues could be especially distressing, as one respondent noted: "It's more than hard- dealing with this is something one can't explain and the emotional verbal assaults we get from him is soul destroying."

Given the often substantial nature of the ongoing interpersonal tension, especially for those carers undertaking this work on a long-term basis, it would be understandable if carers discontinued their support of mental health consumers. Yet some carers demonstrated extraordinary levels of empathy and resilience, as was the case with this respondent:

> "Caring for my husband is a tremendous burden. His episodes are full of emotional abuse, anger coupled with destruction of property and then feelings of the very deepest self-loathing. For me though, it's given me a greater capacity to improve myself and to experience empathy when it's not the natural response in this situation. No matter how much he hurts me, and believe me he really does, it's nothing compared to how much he is hurting and hates himself. My heart breaks for him. He suffers from a biological illness that affects every part of him. His relationships, his day-to-day life. Underneath the imbalance is the reason I married him."

Region 3: Enabling the Recovery of Mental Health Consumers

The third area clearly identified in the space emphasises the carers' role in the recovery journey for consumers. Table 5 displays the 12 items encapsulated in the enabling recovery region. The overall mean value for the enabling recovery region was 2.4. Many of the items in this region enquire about aspects of caring that could be conceptualised as supporting social and functional components of mental health recovery. In terms of functional recovery, encouraging and helping mental health consumers with self-care and normal tasks, and concerns about consumers' ability to manage financially, were the items with highest mean values. Assisting with self-care and normal tasks could be onerous and was an area in which professional support would be beneficial, as the following excerpts demonstrate:

> "I feel it's a battle I am fighting but losing. I struggle with him to look after himself personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking at groups online to seek help not only him but myself"

> “Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving me with any time… her inability to accept help in her personal washing and getting into her clothing makes for a lot of time lost in a day. I am about to seek help from the professionals”

Financial concerns were one of the most frequently raised issues in the open-ended responses. A key element of these concerns was the inadequate level of government financial assistance:

> “He is on the disability support, and after rent, has only less then $200 a fortnight to feed himself, buy petrol and food, feed dogs… so guess who pays for the necessities? It is quite a strain and the National Disability Insurance Scheme has not been able to assist in the way he would like”.

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

Finally, in the enabling recovery region, the second highest mean value was recorded for the item that asked the respondents if they were worried about their relative/friends future. It is unsurprising that carers were often concerned about the mental health consumers’ prospects. As the above material has shown, it was not uncommon for mental health consumers to experience social isolation and struggle with daily activities and finances. The journey towards recovering pieces of consumers' lives clearly requires time and can be difficult, but could nonetheless be a gratifying for carers: "It is tough at times, but you get some little rewards along the way when they achieve things on their own".

Discussion

The regions identified through the SSA provide a basis to understand the manner in which carers' prioritise issues that arise in supporting mental health consumers. 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.

Psychiatric disability services are available in the community throughout Australia to assist mental health consumers with issues like activities of daily living, housing, recreational and social activities, and employment opportunities (Edwards, Fisher, Tannous, & Robinson, 2009). Despite the availability of such services, the respondents in this study were highly concerned about helping with self-care and promoting consumer participation in activities. Our findings suggest either that Australian mental health carers are unable to access adequate levels of support from psychiatric disability services or were unaware of the availability of these services. Recent data from the Australian Institute of Health and Wellbeing indicates that the proportion of mental health consumers who use disability services varies considerably between jurisdictions, which may suggest that access to disability services is of particular concern in some Australian states and territories (AIHW, 2018). It also seems likely that carers' knowledge about the availability of disability services could be improved through educational campaigns, but further studies are warranted to examine this issue.

It was unsurprising to find that financial concerns figured prominently in the open-ended responses and also had a high mean item rating. Many mental health carers forgo employment or reduce their working hours while supporting consumers (ABS, 2014; Diminic et al., 2016). In Australia, modest income support payments are available to mental health carers who do not work, but these payments are only accessible to a small proportion of carers (Diminic et al., 2016; RANZCP., 2015). The hardship that results from the lack of adequate financial assistance is further compounded by the often substantial level of financial support that carers provide to mental health consumers (Diminic et al., 2016). These difficulties draw attention to the need to increase the level of financial assistance that the Australian government offers to mental health carers.

The respondents in this study clearly experienced substantial distress about numerous issues, but areas of notable concern involved the quality of mental healthcare and personal impact of the caregiving role. In addition there is a very significant cost of caring that effects informal carers in a multitude of ways, often to the detriment of their own health and wellbeing as individuals. Understanding and acknowledging fully this impact could assist professional carers in supporting them which could in turn promote recovery for consumers. The findings have several implications that health professionals could take into account when working with the families of mental health consumers. To some extent, the concern that carers experience in regard to the provision of services may be lessened through exploring and incorporating their views in planning and delivering mental healthcare (McFarlane 2016) (McFarlane, 2016). In terms of reducing caregiver burden, it would initially be beneficial for health professionals to evaluate carers' strengths and limitations in supporting mental health consumers (Dirik et al., 2017; Mottaghipour & Bickerton, 2005). Such information could inform the development of personalised interventions that would enable health professionals to address the particular requirements of each family (Dirik et al., 2017; Mottaghipour & Bickerton, 2005).

Limitations

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

Conclusion

Our findings demonstrated that carers' prioritised roles that promoted the recovery of mental health consumers. However, such 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. 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 Morrisoncontributed 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

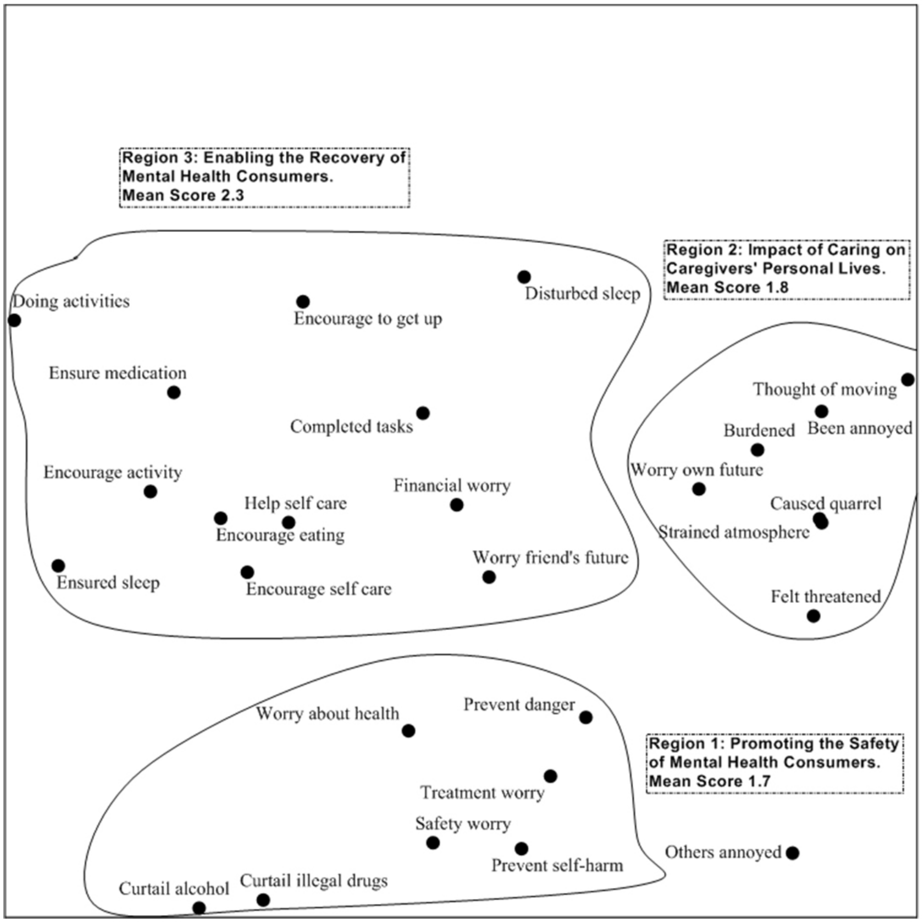
Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal 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)



99x97mm (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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy6-7	
		(*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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.

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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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

levels of depression. [16-19] Also, supporting consumers who display heightened positive or negative symptoms exacerbates the detrimental impact on carers' quality of life, work efficiency and lost days of work. [20]

Although much of the available literature focuses on adverse consequences, caregiving for mental health consumers also results in beneficial outcomes for carers. Some mental health carers' note that supporting consumers has sensitised them to the needs of people with disabilities, enabled them to clarify their priorities in life and enhanced their resilience. [21] The sense of satisfaction and meaning that carers find in helping consumers has been associated with higher levels of quality of life. [22-24]

Research has demonstrated that carers contribute importantly to the recovery of mental health consumers. In particular, the involvement of family members in the provision of mental health services has been found to decrease consumer relapse and rehospitalisation rates by 20-50%. [4] Other mental health consumer benefits that may be attributed to supportive family relationships include improved participation in vocational rehabilitation, higher employment rates, enhanced social functioning and reductions in psychiatric symptoms. [4]

To our knowledge no prior qualitative studies have explored Australian mental health caregiver burden. However, a few quantitative studies have examined issues involved with caring for mental health consumers in an Australian context. [13,25,26] The Australian quantitative studies[13,25,26] on mental health caregiver burden have reflected the results of research conducted in other countries,[7,15,27], in that they have shown that carers experience social isolation and impaired physical and mental health. To our knowledge, no prior studies in an Australian setting have quantified aspects of mental health caregiving. This information is

important since it provides an understanding of the extent to which individual factors influence mental health caregiver burden, and may enable health services to develop interventions that target the factors that contribute most substantially to such burden. Hence, the purpose of this study is to explore Australian mental health carers' experiences through rating the importance of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Methods

Study Design

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

Survey Instrument

The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer burden. [27] The decision to use the IEQ in this study was based on the findings of a systematic review, which recommended the IEQ as one of the two most superior instruments to assess mental health caregiver burden.[28] The questionnaire comprises four scales: 1) tension (nine items), which assesses interpersonal difficulties between consumers and carers; 2) supervision (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and dangerous behaviour; 3) worrying (six items), which captures details regarding troubling interpersonal like concern about the consumer's future and safety, overall health, and quality of health care; and 4) urging (eight items), which assesses the extent to which carers' encourage consumers to undertake general activities and self-care. [27] Each item is scored on a five point Likert scale (never, sometimes, regularly, often, always). The following values were assigned to each scale category: never=0; sometimes=1; regularly=2; often=3; always=4. [27] To facilitate comparison between the scales, which contained differing numbers of items, a total scale score was produced by summing the items, that was then divided by the number of items within the scale, after which a mean scale score was derived. Finally, a single open-ended question allows carers to make comments about their experiences.

The structure of the IEQ was originally established through subjecting data from a Dutch mental health caregiver population to principal components analysis, which yielded the aforementioned four scales. [27] The IEQ has subsequently been translated into English and undergone psychometric testing, which consisted of an examination of its internal consistency and test-test reliability. The results demonstrated that the IEQ scales exhibited adequate levels of test-retest reliability. [27] But the IEQ's supervision and urging scales had less than satisfactory Cronbach alpha values, which cast some doubt over the adequacy of the IEQ's scale structure.[28] To our knowledge, no further psychometric testing of the IEQ has been conducted in English language populations.

Recruitment

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

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 carers[30], 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 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 approach[36] 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.

The subsequent section details the items contained in each region. Interpretation of the items reported below may be aided by bearing in mind that the following values are assigned to each category: 0=never; 1=sometimes; 2= regularly; 3= often; and 4= always. In addition, the delineation of these regions is further supported by the presentation of the qualitative open-ended responses.

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”

In some cases, the lack in continuity of care is the primary concern, which undermined the relationship between carers and health professionals, and left carers’ feeling isolated and concerned: “… the mental health system is that it is so disjointed and I find it hard who to trust with our information and finding someone that cares enough to follow up and support me”.

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

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

The item that enquired about carers' worry in regard to their friend/relatives safety also recorded a relatively high mean score. However, the phrasing used for this item meant that it is difficult to identify explicit safety issues. Finally, the mean scores for the items that captured details about concern over self-harm, alcohol, and illegal substances are relatively low. But these issues are nonetheless a source of substantial concern for some respondents, as the following excerpt demonstrates:

> "Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming burden to have a child of any age, want to destroy themselves this way. So in answer to the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?" the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only encourage, support and guide him to the best of my ability"

Region 2: Impact of Caring on Caregivers' Personal Lives

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

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

> peers that it has a very real and very significant impact on people's physical (autoimmune disorders) and mental (grief and depression) health".

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

> "You feel very alone. You just wish you could have time to yourself. You don't want to walk on eggshells any more. You want to celebrate your other kids and spend time with them but your attention is always diverted towards this one. When I'm not with them I worry are they ok. I would just like to be by myself without having to worry."

This sense of isolation in some instances was compounded by a lack of support from family members:

> "I do find I isolate and insulate myself as my family won't discuss it, they don't want to know as it's too stressful. My son's father abandoned him three years ago as he cannot cope with his mental illness."

In addition to the physical and mental health consequences, respondents also often drew attention to the financial burden associated with caregiving. Time spent on caring meant that respondents are unable to participate fully in the workforce. This directly impacts materially on the respondents' "own future", which is another of the items in the personal impact region that has a relatively high mean value. Other concerns that carers hold about their future involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:

> "I was extremely depressed when I was a full-time carer. I deferred university, failed subjects and lost touch with my own aspirations."

> "It's hard to express the impact it has on my life. It's the day-to-day impact, the need to be there or in contact at anytime. The need to consider her needs in all my decisions. The impact on my future plans - I would dearly love to go live overseas, but my mother is still relatively young, and as much as it feels wrong to say this, she may live a long time and make my dreams impossible."

The remaining items in the personal impact region captured details about interpersonal tension between carers and mental health consumers. Relatively high mean values were reported for the items that enquired about the strained atmosphere, quarrels and annoyance at the relative/friend's behaviour. These issues could be especially distressing, as one respondent noted: "It's more than hard- dealing with this is something one can't explain and the emotional verbal assaults we get from him is soul destroying."

Given the often substantial nature of the ongoing interpersonal tension, especially for those carers undertaking this work on a long-term basis, it would be understandable if carers discontinued their support of mental health consumers. Yet some carers demonstrate extraordinary levels of empathy and resilience, as was the case with this respondent:

> "Caring for my husband is a tremendous burden. His episodes are full of emotional abuse, anger coupled with destruction of property and then feelings of the very deepest self-loathing. For me though, it's given me a greater capacity to improve myself

> and to experience empathy when it's not the natural response in this situation. No matter how much he hurts me, and believe me he really does, it's nothing compared to how much he is hurting and hates himself. My heart breaks for him. He suffers from a biological illness that affects every part of him. His relationships, his day-to-day life. Underneath the imbalance is the reason I married him."

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

The third area clearly identified in the space emphasises the carers' role in the recovery journey for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional recovery region. The overall mean value for this region was 2.4. Many of the items in this region enquire about aspects of caring that can be conceptualised as supporting social and functional components of mental health recovery. In terms of functional recovery, encouraging and helping mental health consumers with self-care and normal tasks, and concerns about consumers' ability to manage financially, are the items with highest mean values. Assisting with self-care and normal tasks could be onerous and is an area in which professional support would be beneficial, as the following excerpts demonstrate:

> "I feel it's a battle I am fighting but losing. I struggle with him to look after himself personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking at groups online to seek help not only him but myself"

> "Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving me with any time... her inability to accept help in her personal washing and getting into her clothing makes for a lot of time lost in a day. I am about to seek help from the professionals"

Financial concerns are one of the most frequently raised issues in the open-ended responses. A key element of these concerns is the inadequate level of government financial assistance:

> “He is on the disability support, and after rent, has only less then $200 a fortnight to feed himself, buy petrol and food, feed dogs… so guess who pays for the necessities? It is quite a strain and the National Disability Insurance Scheme has not been able to assist in the way he would like”.

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

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

Discussion

The regions identified through the SSA provide a basis to understand the manner in which carers prioritise issues that arise in supporting mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value is considerably higher than the personal impact and promoting safety 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.

The high level of concern that respondents report about daily living functional recovery suggests that the provision of services that assist with these issues may contribute to the reduction of caregiver burden. Psychiatric disability services are available in the community throughout Australia to help carers and mental health consumers with tasks like activities of daily living, housing, recreational and social activities and employment opportunities. [37] However, the extent to which Australian carers and mental health consumers access these services is presently unknown. Further studies might be beneficial in identifying whether the provision of psychiatric disability support services adequately address the needs of mental health caregivers in regards to assistance with consumers daily living functional recovery.

It was unsurprising to find that financial concerns figure prominently in the open-ended responses and also have a high mean item rating. Many mental health carers forgo employment or reduce their working hours while supporting consumers. [38,39] In Australia, modest income support payments are available to mental health carers who do not work, but these payments are only accessible to a small proportion of carers. [38,40] The hardship that results from the lack of adequate financial assistance is further compounded by the often substantial level of financial support that carers provide to mental health consumers. [38]

Our findings show that health professionals also have an important role to play in alleviating mental health caregiver burden. Concerns over the provision of metal health care are highlighted in this study, especially in regard to being isolated from the care that consumers were receiving. Such issues reflect the results of other mental health carer studies that have been conducted in Australia and within the United Kingdom.[6,41] To some extent, the concern that carers experience in regard to the provision of services might be lessened through exploring and incorporating their views in planning and delivering mental healthcare. [4]

Limitations

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

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)

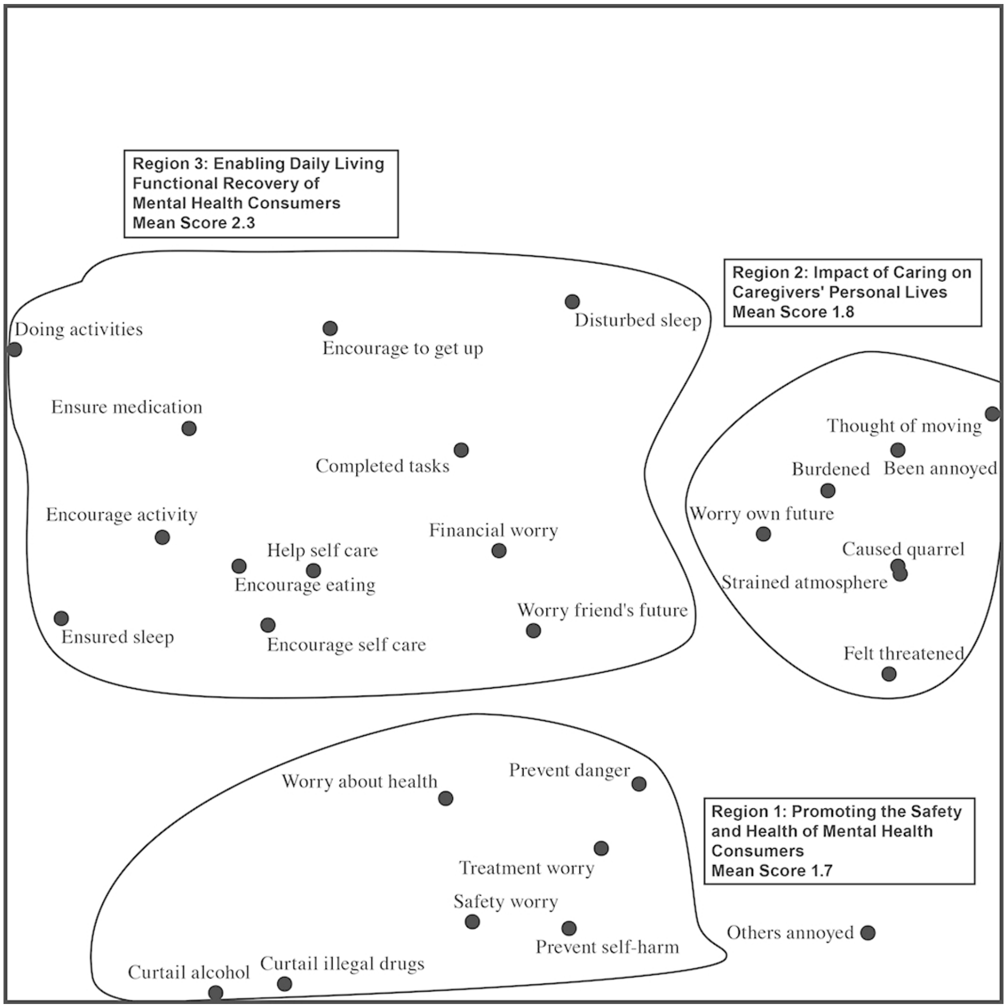
Table 4. Personal Impact

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)



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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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy6-7	
		(*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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.

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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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

levels of depression. [16-19] Also, supporting consumers who display heightened positive or negative symptoms exacerbates the detrimental impact on carers' quality of life, work efficiency and lost days of work. [20]

Although much of the available literature focuses on adverse consequences, caregiving for mental health consumers also results in beneficial outcomes for carers. Some mental health carers' note that supporting consumers has sensitised them to the needs of people with disabilities, enabled them to clarify their priorities in life and enhanced their resilience. [21] The sense of satisfaction and meaning that carers find in helping consumers has been associated with higher levels of quality of life. [22-24]

Research has demonstrated that carers contribute importantly to the recovery of mental health consumers. In particular, the involvement of family members in the provision of mental health services has been found to decrease consumer relapse and rehospitalisation rates by 20-50%. [4] Other mental health consumer benefits that may be attributed to supportive family relationships include improved participation in vocational rehabilitation, higher employment rates, enhanced social functioning and reductions in psychiatric symptoms. [4]

To our knowledge no prior qualitative studies have explored Australian mental health caregiver burden. However, a few quantitative studies have examined issues involved with caring for mental health consumers in an Australian context. [13,25,26] The Australian quantitative studies[13,25,26] on mental health caregiver burden have reflected the results of research conducted in other countries,[7,15,27], in that they have shown that carers experience social isolation and impaired physical and mental health. To our knowledge, no prior studies in an Australian setting have quantified aspects of mental health caregiving. This information is

important since it provides an understanding of the extent to which individual factors influence mental health caregiver burden, and may enable health services to develop interventions that target the factors that contribute most substantially to such burden. Hence, the purpose of this study is to explore Australian mental health carers' experiences through rating the importance of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Methods

Study Design

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

Survey Instrument

The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer burden. [27] The decision to use the IEQ in this study was based on the findings of a systematic review, which recommended the IEQ as one of the two most superior instruments to assess mental health caregiver burden.[28] The questionnaire comprises four scales: 1) tension (nine items), which assesses interpersonal difficulties between consumers and carers; 2) supervision (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and dangerous behaviour; 3) worrying (six items), which captures details regarding troubling interpersonal like concern about the consumer's future and safety, overall health, and quality of health care; and 4) urging (eight items), which assesses the extent to which carers' encourage consumers to undertake general activities and self-care. [27] Each item is scored on a five point Likert scale (never = 0, sometimes = 1, regularly= 2, often = 3, always = 4). [27] Finally, a single open-ended question allows carers to make comments about their experiences.

The structure of the IEQ was originally established through subjecting data from a Dutch mental health caregiver population to principal components analysis, which yielded the aforementioned four scales. [27] The IEQ has subsequently been translated into English and undergone psychometric testing, which consisted of an examination of its internal consistency and test-test reliability. The results demonstrated that the IEQ scales exhibited adequate levels of test-retest reliability, which was evidenced by the intra-class correlation coefficient values ranging from 0.83 to 0.90. [27] But the IEQ's supervision and urging scales had less than satisfactory Cronbach alpha values, which cast some doubt over the adequacy of the IEQ's scale structure.[28]

Recruitment

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

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 carers[30], 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 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. [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]

To facilitate comparison between the SSA scales, which contained differing numbers of items, a total scale score was produced by summing the items, that was then divided by the number of items within the scale, after which a mean scale score was derived.

The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis methods.[36] In this study, a theoretical, deductive approach 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.

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.

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"

In some cases, the lack in continuity of care is the primary concern, which undermined the relationship between carers and health professionals, and left carers' feeling isolated and concerned: "… the mental health system is that it is so disjointed and I find it hard who to trust with our information and finding someone that cares enough to follow up and support me".

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

> "Getting help for my son and guidance for me to help him has been an arduous and very lengthy process. If I wasn't as steadfast and committed I may have given up several times after being told 'NO'. I have had to struggle to find the few people that are now involved in my son's care, and they are brilliant most of the time. But they didn't all come to help us, I had to research hard to find them over years."

The item that enquired about carers' worry in regard to their friend/relatives safety also recorded a relatively high mean score. However, the phrasing used for this item meant that it is difficult to identify explicit safety issues. Finally, the mean scores for the items that captured details about concern over self-harm, alcohol, and illegal substances are relatively low. But these issues are nonetheless a source of substantial concern for some respondents, as the following excerpt demonstrates:

> "Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming burden to have a child of any age, want to destroy themselves this way. So in answer to the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?" the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only encourage, support and guide him to the best of my ability"

Region 2: Impact of Caring on Caregivers' Personal Lives

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

> "It would be useful to look at the issue of ambiguous loss for family carers, particularly for those who are long term family carers. This is something that is under-identified in the area of impact on carers and mental health and yet, anecdotally I know from my peers that it has a very real and very significant impact on people's physical (autoimmune disorders) and mental (grief and depression) health".

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

> "You feel very alone. You just wish you could have time to yourself. You don't want to walk on eggshells any more. You want to celebrate your other kids and spend time with them but your attention is always diverted towards this one. When I'm not with them I worry are they ok. I would just like to be by myself without having to worry."

This sense of isolation in some instances was compounded by a lack of support from family members:

> "I do find I isolate and insulate myself as my family won't discuss it, they don't want to know as it's too stressful. My son's father abandoned him three years ago as he cannot cope with his mental illness."

In addition to the physical and mental health consequences, respondents also often drew attention to the financial burden associated with caregiving. Time spent on caring meant that respondents are unable to participate fully in the workforce. This directly impacts materially on the respondents' "own future", which is another of the items in the personal impact region that has a relatively high mean value. Other concerns that carers hold about their future involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:

> "I was extremely depressed when I was a full-time carer. I deferred university, failed subjects and lost touch with my own aspirations."

> "It's hard to express the impact it has on my life. It's the day-to-day impact, the need to be there or in contact at anytime. The need to consider her needs in all my decisions. The impact on my future plans - I would dearly love to go live overseas, but my mother

> is still relatively young, and as much as it feels wrong to say this, she may live a long time and make my dreams impossible."

The remaining items in the personal impact region captured details about interpersonal tension between carers and mental health consumers. Relatively high mean values were reported for the items that enquired about the strained atmosphere, quarrels and annoyance at the relative/friend's behaviour. These issues could be especially distressing, as one respondent noted: "It's more than hard- dealing with this is something one can't explain and the emotional verbal assaults we get from him is soul destroying."

Given the often substantial nature of the ongoing interpersonal tension, especially for those carers undertaking this work on a long-term basis, it would be understandable if carers discontinued their support of mental health consumers. Yet some carers demonstrate extraordinary levels of empathy and resilience, as was the case with this respondent:

> "Caring for my husband is a tremendous burden. His episodes are full of emotional abuse, anger coupled with destruction of property and then feelings of the very deepest self-loathing. For me though, it's given me a greater capacity to improve myself and to experience empathy when it's not the natural response in this situation. No matter how much he hurts me, and believe me he really does, it's nothing compared to how much he is hurting and hates himself. My heart breaks for him. He suffers from a biological illness that affects every part of him. His relationships, his day-to-day life. Underneath the imbalance is the reason I married him."

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

The third area clearly identified in the space emphasises the carers' role in the recovery journey for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional recovery region. The overall mean value for this region was 2.4. Many of the items in this region enquire about aspects of caring that can be conceptualised as supporting social and functional components of mental health recovery. In terms of functional recovery, encouraging and helping mental health consumers with self-care and normal tasks, and concerns about consumers' ability to manage financially, are the items with highest mean values. Assisting with self-care and normal tasks could be onerous and is an area in which professional support would be beneficial, as the following excerpts demonstrate:

> "I feel it's a battle I am fighting but losing. I struggle with him to look after himself personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking at groups online to seek help not only him but myself"

> "Ironing, vacuum cleaning, cleaning floors, and all other household duties is not leaving me with any time... her inability to accept help in her personal washing and getting into her clothing makes for a lot of time lost in a day. I am about to seek help from the professionals"

Financial concerns are one of the most frequently raised issues in the open-ended responses. A key element of these concerns is the inadequate level of government financial assistance:

> "He is on the disability support, and after rent, has only less then $200 a fortnight to feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It

> is quite a strain and the National Disability Insurance Scheme has not been able to assist in the way he would like".

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

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

Discussion

The regions identified through the SSA provide a basis to understand the manner in which carers prioritise issues that arise in supporting mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value is considerably higher than the personal impact and promoting safety 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.

The high level of concern that respondents report about daily living functional recovery suggests that the provision of services that assist with these issues may contribute to the reduction of caregiver burden. Psychiatric disability services are available in the community throughout Australia to help carers and mental health consumers with tasks like activities of daily living, housing, recreational and social activities and employment opportunities. [37] However, the extent to which Australian carers and mental health consumers access these services is presently unknown. Further studies might be beneficial in identifying whether the provision of psychiatric disability support services adequately address the needs of mental health caregivers in regards to assistance with consumers daily living functional recovery.

It was unsurprising to find that financial concerns figure prominently in the open-ended responses and also have a high mean item rating. Many mental health carers forgo employment or reduce their working hours while supporting consumers. [38,39] In Australia, modest income support payments are available to mental health carers who do not work, but these payments are only accessible to a small proportion of carers. [38,40] The hardship that results from the lack of adequate financial assistance is further compounded by the often substantial level of financial support that carers provide to mental health consumers. [38]

Our findings show that health professionals also have an important role to play in alleviating mental health caregiver burden. Concerns over the provision of metal health care are highlighted in this study, especially in regard to being isolated from the care that consumers were receiving. Such issues reflect the results of other mental health carer studies that have been conducted in Australia and within the United Kingdom.[6,41] To some extent, the concern that carers experience in regard to the provision of services might be lessened through exploring and incorporating their views in planning and delivering mental healthcare. [4]

Limitations

The demographic details of Australian mental health carers vary considerably between studies. It is therefore difficult to develop a standardised profile of Australian mental health caregivers. However, the demographic characteristics of the carers in this study are highly consistent with the details reported in the most recent study of Australian mental health caregivers, which to some extent supports the generalisability of our findings. [38] Finally, our value for the coefficient of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is considered to represent a good fit.[35] That said, the coefficient of alienation should be interpreted in light of the SSA visual structure, which in the case of our study clearly delineated distinct regions.[35]

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)

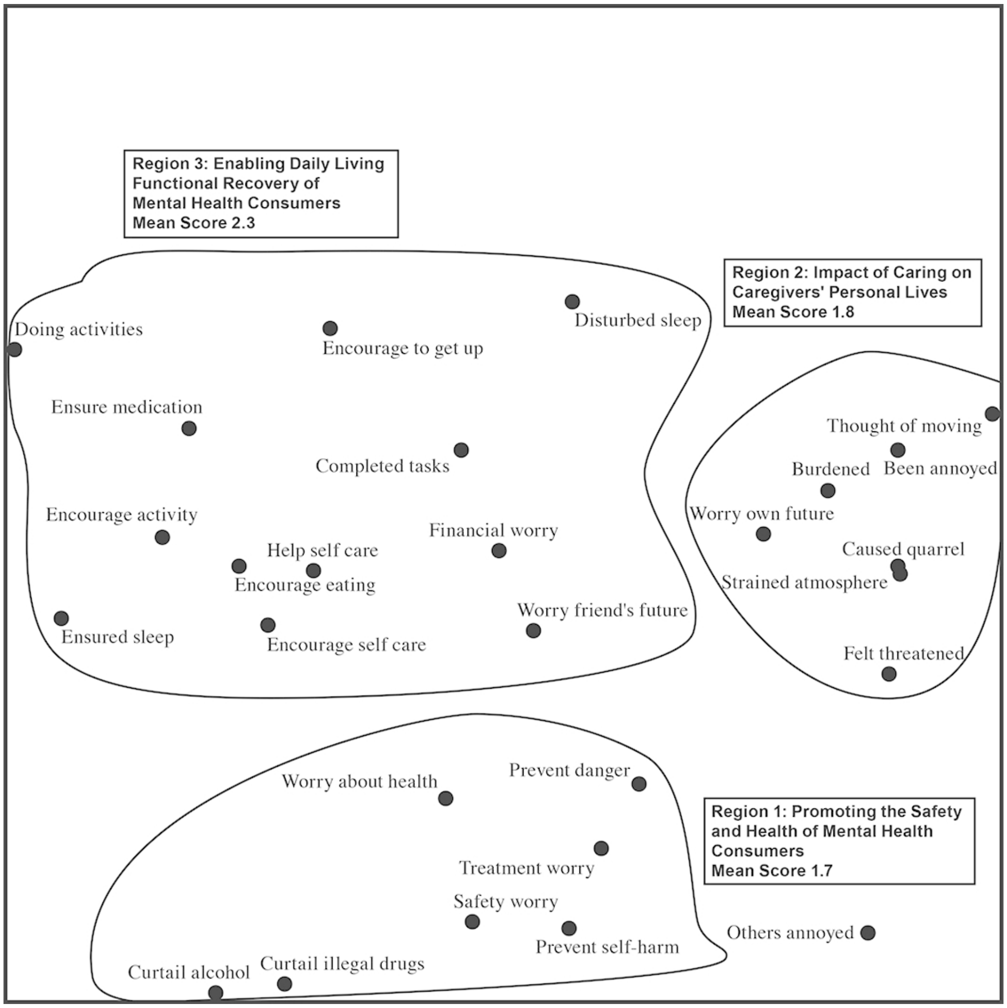
Table 4. Personal Impact

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)

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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy6-7	
		(*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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.

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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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

levels of depression. [16-19] Also, supporting consumers who display heightened positive or negative symptoms exacerbates the detrimental impact on carers' quality of life, work efficiency and lost days of work. [20]

Although much of the available literature focuses on adverse consequences, caregiving for mental health consumers also results in beneficial outcomes for carers. Some mental health carers' note that supporting consumers has sensitised them to the needs of people with disabilities, enabled them to clarify their priorities in life and enhanced their resilience. [21] The sense of satisfaction and meaning that carers find in helping consumers has been associated with higher levels of quality of life. [22-24]

Research has demonstrated that carers contribute importantly to the recovery of mental health consumers. In particular, the involvement of family members in the provision of mental health services has been found to decrease consumer relapse and rehospitalisation rates by 20-50%. [4] Other mental health consumer benefits that may be attributed to supportive family relationships include improved participation in vocational rehabilitation, higher employment rates, enhanced social functioning and reductions in psychiatric symptoms. [4]

To our knowledge no prior qualitative studies have explored Australian mental health caregiver burden. However, a few quantitative studies have examined issues involved with caring for mental health consumers in an Australian context. [13,25,26] The Australian quantitative studies[13,25,26] on mental health caregiver burden have reflected the results of research conducted in other countries,[7,15,27], in that they have shown that carers experience social isolation and impaired physical and mental health. To our knowledge, no prior studies in an Australian setting have quantified aspects of mental health caregiving. This information is

important since it provides an understanding of the extent to which individual factors influence mental health caregiver burden, and may enable health services to develop interventions that target the factors that contribute most substantially to such burden. Hence, the purpose of this study is to explore Australian mental health carers' experiences through rating the importance of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Methods

Study Design

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

Survey Instrument

The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer burden. [27] The decision to use the IEQ in this study was based on the findings of a systematic review, which recommended the IEQ as one of the two most superior instruments to assess mental health caregiver burden.[28] The questionnaire comprises four scales: 1) tension (nine items), which assesses interpersonal difficulties between consumers and carers; 2) supervision (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and dangerous behaviour; 3) worrying (six items), which captures details regarding troubling interpersonal like concern about the consumer's future and safety, overall health, and quality of health care; and 4) urging (eight items), which assesses the extent to which carers' encourage consumers to undertake general activities and self-care. [27] Each item is scored on a five point Likert scale (never = 0, sometimes = 1, regularly= 2, often = 3, always = 4). [27] Finally, a single open-ended question allows carers to make comments about their experiences. This question was phrased as follows: “Multiple choice questions cannot possibly cover all that you have experienced with the person you care for. Please feel free to add any comments you may wish to make in the space below.”

The structure of the IEQ was originally established through subjecting data from a Dutch mental health caregiver population to principal components analysis, which yielded the aforementioned four scales. [27] The IEQ has subsequently been translated into English and undergone psychometric testing, which consisted of an examination of its internal consistency and test-test reliability. The results demonstrated that the IEQ scales exhibited adequate levels of test-retest reliability, which was evidenced by the intra-class correlation coefficient values ranging from 0.83 to 0.90. [27] But the IEQ’s supervision and urging scales both had inadequate Cronbach alpha values 0.68 at two sites (London and Santander) that cast some doubt over the adequacy of the IEQ’s scale structure.[28]

Recruitment

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

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 carers[30], 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 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. [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] To facilitate comparison between the SSA scales, which contained differing numbers of items, a total scale score was produced by summing the items, that was then divided by the number of items within the scale, after which a mean scale score was derived.

The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis methods.[36] In this study, a theoretical, deductive approach 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. Both authors initially reviewed the full set of open-ended responses. One of the authors then mapped the responses into an excel spreadsheet that contained the coding framework. The other author reviewed the conceptual fit of the mapped responses. The authors then met in-person to clarify and further elaborate the themes and sub-themes through a consensus driven discussion.

Results

The total number of returned questionnaires was 231, of which 122 contained responses to the open-ended question. 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.

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" [Participant 120]

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" [Participant 42]

In some cases, the lack in continuity of care is the primary concern, which undermined the relationship between carers and health professionals, and left carers' feeling isolated and concerned: "…the mental health system is that it is so disjointed and I find it hard who to trust with our information and finding someone that cares enough to follow up and support me" [Participant 57].

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

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

The item that enquired about carers' worry in regard to their friend/relatives safety also recorded a relatively high mean score. However, the phrasing used for this item meant that it is difficult to identify explicit safety issues. Finally, the mean scores for the items that captured details about concern over self-harm, alcohol, and illegal substances are relatively low. But these issues are nonetheless a source of substantial concern for some respondents, as the following excerpt demonstrates:

> "Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming burden to have a child of any age, want to destroy themselves this way. So in answer to the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?" the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only encourage, support and guide him to the best of my ability" [Participant 84]

Region 2: Impact of Caring on Caregivers' Personal Lives

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

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

> peers that it has a very real and very significant impact on people's physical (autoimmune disorders) and mental (grief and depression) health" [Participant 7]

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

> "You feel very alone. You just wish you could have time to yourself. You don't want to walk on eggshells any more. You want to celebrate your other kids and spend time with them but your attention is always diverted towards this one. When I'm not with them I worry are they ok. I would just like to be by myself without having to worry." [Participant 74]

This sense of isolation in some instances was compounded by a lack of support from family members:

> "I do find I isolate and insulate myself as my family won't discuss it, they don't want to know as it's too stressful. My son's father abandoned him three years ago as he cannot cope with his mental illness." [Participant 17]

In addition to the physical and mental health consequences, respondents also often drew attention to the financial burden associated with caregiving. Time spent on caring meant that respondents are unable to participate fully in the workforce. This directly impacts materially on the respondents' "own future", which is another of the items in the personal impact region that has a relatively high mean value. Other concerns that carers hold about their future involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:

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

> “It's hard to express the impact it has on my life. It's the day-to-day impact, the need to be there or in contact at anytime. The need to consider her needs in all my decisions. The impact on my future plans - I would dearly love to go live overseas, but my mother is still relatively young, and as much as it feels wrong to say this, she may live a long time and make my dreams impossible.” [Participant 67]

The remaining items in the personal impact region captured details about interpersonal tension between carers and mental health consumers. Relatively high mean values were reported for the items that enquired about the strained atmosphere, quarrels and annoyance at the relative/friend’s behaviour. These issues could be especially distressing, as one respondent noted: “It's more than hard- dealing with this is something one can't explain and the emotional verbal assaults we get from him is soul destroying.” [Participant 16]

Given the often substantial nature of the ongoing interpersonal tension, especially for those carers undertaking this work on a long-term basis, it would be understandable if carers discontinued their support of mental health consumers. Yet some carers demonstrate extraordinary levels of empathy and resilience, as was the case with this respondent:

> “Caring for my husband is a tremendous burden. His episodes are full of emotional abuse, anger coupled with destruction of property and then feelings of the very deepest self-loathing. For me though, it's given me a greater capacity to improve myself and to experience empathy when it's not the natural response in this situation. No matter how much he hurts me, and believe me he really does, it's nothing compared to how much he is hurting and hates himself. My heart breaks for him. He suffers from a biological illness that affects every part of him. His relationships, his day-to-day life. Underneath the imbalance is the reason I married him.” [Participant 24]

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

The third area clearly identified in the space emphasises the carers’ role in the recovery journey for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional recovery region. The overall mean value for this region was 2.4. Many of the items in this region enquire about aspects of caring that can be conceptualised as supporting social and functional components of mental health recovery. In terms of functional recovery, encouraging and helping mental health consumers with self-care and normal tasks, and concerns about consumers’ ability to manage financially, are the items with highest mean values. Assisting with self-care and normal tasks could be onerous and is an area in which professional support would be beneficial, as the following excerpts demonstrate:

> “I feel it's a battle I am fighting but losing. I struggle with him to look after himself personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking at groups online to seek help not only him but myself” [Participant 16]

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

Financial concerns are one of the most frequently raised issues in the open-ended responses. A key element of these concerns is the inadequate level of government financial assistance:

> “He is on the disability support, and after rent, has only less then $200 a fortnight to feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It is quite a strain and the National Disability Insurance Scheme has not been able to assist in the way he would like” [Participant 85]

The items that captured information about aspects of social recovery generally had lower mean values than the functional recovery items. And while the importance of facilitating social inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put it: “Exhaustion is constant as my partner relies on me totally for his social support and talks non-stop” [Participant 8].

Finally, in the enabling daily living functional recovery region, the second highest mean value was recorded for the item that asked the respondents if they are worried about their relative/friends future. It is unsurprising that carers are often concerned about the mental health consumers’ prospects. As the above material has shown, it is not uncommon for mental health consumers to experience social isolation and struggle with daily activities and finances. The journey towards recovering pieces of consumers’ lives clearly requires time and is difficult, but could nonetheless be gratifying for carers: “It is tough at times, but you get some little rewards along the way when they achieve things on their own” [Participant 78].

Discussion

The regions identified through the SSA provide a basis to understand the manner in which carers prioritise issues that arise in supporting mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value is considerably higher than the personal impact and promoting safety 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.

The high level of concern that respondents report about daily living functional recovery suggests that the provision of services that assist with these issues may contribute to the reduction of caregiver burden. Psychiatric disability services are available in the community throughout Australia to help carers and mental health consumers with tasks like activities of daily living, housing, recreational and social activities and employment opportunities. [37] However, the extent to which Australian carers and mental health consumers access these services is presently unknown. Further studies might be beneficial in identifying whether the provision of psychiatric disability support services adequately address the needs of mental health caregivers in regards to assistance with consumers daily living functional recovery.

It was unsurprising to find that financial concerns figure prominently in the open-ended responses and also have a high mean item rating. Many mental health carers forgo employment or reduce their working hours while supporting consumers. [38,39] In Australia, modest income support payments are available to mental health carers who do not work, but these payments are only accessible to a small proportion of carers. [38,40] The hardship that results from the lack of adequate financial assistance is further compounded by the often substantial level of financial support that carers provide to mental health consumers. [38]

Our findings show that health professionals also have an important role to play in alleviating mental health caregiver burden. Concerns over the provision of metal health care are highlighted in this study, especially in regard to being isolated from the care that consumers were receiving. Such issues reflect the results of other mental health carer studies that have been conducted in Australia and within the United Kingdom.[6,41] To some extent, the concern that carers experience in regard to the provision of services might be lessened through exploring and incorporating their views in planning and delivering mental healthcare. [4]

Limitations

The demographic details of Australian mental health carers vary considerably between studies. It is therefore difficult to develop a standardised profile of Australian mental health caregivers. However, the demographic characteristics of the carers in this study are highly consistent with the details reported in the most recent study of Australian mental health caregivers, which to some extent supports the generalisability of our findings. [38] Finally, our value for the coefficient of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is considered to represent a good fit.[35] That said, the coefficient of alienation should be interpreted in light of the SSA visual structure, which in the case of our study clearly delineated distinct regions.[35]

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

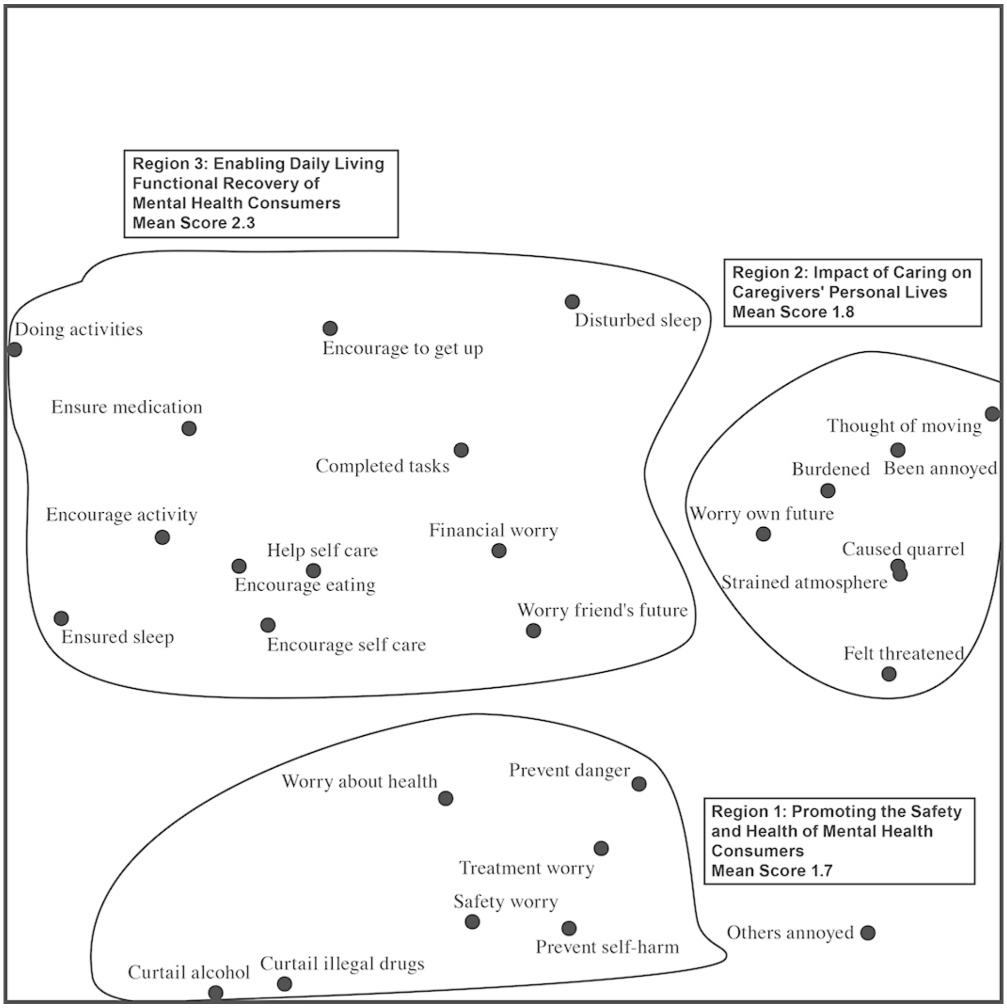
Item	Mean (SD)
Have you guarded your relative/friend from self-inflicted harm	1.1 (1.0)
Have you guarded your relative/friend from committing dangerous acts	1.3 (1.0)
Have you guarded your friend/relative from drinking too much alcohol	1.0 (1.2)
Have you guarded your friend/relative from taking illegal 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)

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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy6-7	
		(*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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.

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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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

levels of depression. [16-19] Also, supporting consumers who display heightened positive or negative symptoms exacerbates the detrimental impact on carers' quality of life, work efficiency and lost days of work. [20]

Although much of the available literature focuses on adverse consequences, caregiving for mental health consumers also results in beneficial outcomes for carers. Some mental health carers' note that supporting consumers has sensitised them to the needs of people with disabilities, enabled them to clarify their priorities in life and enhanced their resilience. [21] The sense of satisfaction and meaning that carers find in helping consumers has been associated with higher levels of quality of life. [22-24]

Research has demonstrated that carers contribute importantly to the recovery of mental health consumers. In particular, the involvement of family members in the provision of mental health services has been found to decrease consumer relapse and rehospitalisation rates by 20-50%. [4] Other mental health consumer benefits that may be attributed to supportive family relationships include improved participation in vocational rehabilitation, higher employment rates, enhanced social functioning and reductions in psychiatric symptoms. [4]

To our knowledge no prior qualitative studies have explored Australian mental health caregiver burden. However, a few quantitative studies have examined issues involved with caring for mental health consumers in an Australian context. [13,25,26] The Australian quantitative studies[13,25,26] on mental health caregiver burden have reflected the results of research conducted in other countries,[7,15,27], in that they have shown that carers experience social isolation and impaired physical and mental health. To our knowledge, no prior studies in an Australian setting have quantified aspects of mental health caregiving. This information is

important since it provides an understanding of the extent to which individual factors influence mental health caregiver burden, and may enable health services to develop interventions that target the factors that contribute most substantially to such burden. Hence, the purpose of this study is to explore Australian mental health carers' experiences through rating the importance of key elements of caregiving and establish the extent to which particular issues contribute to carer burden.

Methods

Study Design

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

Survey Instrument

The Involvement Evaluation Questionnaire (IEQ) was used to measure mental health carer burden. [27] The decision to use the IEQ in this study was based on the findings of a systematic review, which recommended the IEQ as one of the two most superior instruments to assess mental health caregiver burden.[28] The questionnaire comprises four scales: 1) tension (nine items), which assesses interpersonal difficulties between consumers and carers; 2) supervision (6 items), which enquires about carers' monitoring consumer sleep, medicine intake, and dangerous behaviour; 3) worrying (six items), which captures details regarding troubling interpersonal like concern about the consumer's future and safety, overall health, and quality of health care; and 4) urging (eight items), which assesses the extent to which carers' encourage consumers to undertake general activities and self-care. [27] Each item is scored on a five point Likert scale (never = 0, sometimes = 1, regularly= 2, often = 3, always = 4). [27] Finally, a single open-ended question allows carers to make comments about their experiences. This question was phrased as follows: “Multiple choice questions cannot possibly cover all that you have experienced with the person you care for. Please feel free to add any comments you may wish to make in the space below.”

The structure of the IEQ was originally established through subjecting data from a Dutch mental health caregiver population to principal components analysis, which yielded the aforementioned four scales. [27] The IEQ has subsequently been translated into English and other languages and undergone psychometric testing, across five international sites, comprising an examination of its internal consistency and test-retest reliability. The results demonstrated that the IEQ scales exhibited adequate levels of test-retest reliability, which was evidenced by the intra-class correlation coefficient values ranging from 0.83 to 0.90. [27] But some of the Cronbach alpha values fell out of the ideal range of 0.70-0.80 proposed by Bland and Altman.[29] The Cronbach alpha values for IEQ scales ranged from 0.75-0.84 for the tension scale; 0.68-0.82 for the supervision scale; 0.77-0.86 for the worries scale; and 0.77-0.86 for the urging scale.[28] The range of these Cronbach alpha values suggested that it would be worthwhile to re-evaluate the structure of IEQ, using an exploratory method such as smallest space analysis (SSA).[30] In addition, guidelines for the international translation of health-related outcome measures recommend that exploratory techniques should be used to establish the structure of translated questionnaires.[31] This guidance further supported the use of SSA to reassess the structure of IEQ.

Recruitment

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

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. [32] Given that there were approximately 15,666 Australian mental health carers[33], 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 was used to examine the structure of the dataset. SSA was used as it offers numerous advantages over statistical methods such as factor analysis.[34,35] 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.[34,35] It is an especially robust method that can be used to analyse many different types of data. [30,36] 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. [30] 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. [36] 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. [37] The coefficient of alienation can range from 0 (best fit) to 1 (worst fit), and should be ≤ 0.2 to be considered satisfactory. [37] To facilitate comparison between the SSA scales, which contained differing numbers of items, a total scale score was produced by summing the items, that was then divided by the number of items within the scale, after which a mean scale score was derived.

The qualitative aspect of the analysis was based on Braun and Clarke's thematic analysis methods.[38] In this study, a theoretical, deductive approach 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. Both authors initially reviewed the full set of open-ended responses. One of the authors then mapped the responses into an excel spreadsheet that contained the coding framework. The other author reviewed the conceptual fit of the mapped responses. The authors then met in-person to clarify and further elaborate the themes and sub-themes through a consensus driven discussion.

Results

The total number of returned questionnaires was 231, of which 122 contained responses to the open-ended question. 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.

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” [Participant 120]

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” [Participant 42]

In some cases, the lack in continuity of care is the primary concern, which undermined the relationship between carers and health professionals, and left carers’ feeling isolated and concerned: “… the mental health system is that it is so disjointed and I find it hard who to trust with our information and finding someone that cares enough to follow up and support me” [Participant 57].

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

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

The item that enquired about carers’ worry in regard to their friend/relatives safety also recorded a relatively high mean score. However, the phrasing used for this item meant that it is difficult to identify explicit safety issues. Finally, the mean scores for the items that captured details about concern over self-harm, alcohol, and illegal substances are relatively low. But these issues are nonetheless a source of substantial concern for some respondents, as the following excerpt demonstrates:

> “Alcohol in the quantities that he consumes is totally destructive. It is an overwhelming burden to have a child of any age, want to destroy themselves this way. So in answer to the question "Do I guard him from self-harm, consuming drugs and excessive alcohol?" the answer is a huge yes, always! – but I cannot stop him, and I cannot control him, only encourage, support and guide him to the best of my ability” [Participant 84]

Region 2: Impact of Caring on Caregivers’ Personal Lives

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

> "It would be useful to look at the issue of ambiguous loss for family carers, particularly for those who are long term family carers. This is something that is under-identified in the area of impact on carers and mental health and yet, anecdotally I know from my peers that it has a very real and very significant impact on people's physical (autoimmune disorders) and mental (grief and depression) health" [Participant 7]

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

> "You feel very alone. You just wish you could have time to yourself. You don't want to walk on eggshells any more. You want to celebrate your other kids and spend time with them but your attention is always diverted towards this one. When I'm not with them I worry are they ok. I would just like to be by myself without having to worry." [Participant 74]

This sense of isolation in some instances was compounded by a lack of support from family members:

> "I do find I isolate and insulate myself as my family won't discuss it, they don't want to know as it's too stressful. My son's father abandoned him three years ago as he cannot cope with his mental illness." [Participant 17]

In addition to the physical and mental health consequences, respondents also often drew attention to the financial burden associated with caregiving. Time spent on caring meant that respondents are unable to participate fully in the workforce. This directly impacts materially on the respondents' "own future", which is another of the items in the personal impact region that has a relatively high mean value. Other concerns that carers hold about their future involve the effect on career prospects and lifestyle, as can be seen from the following excerpts:

> "I was extremely depressed when I was a full-time carer. I deferred university, failed subjects and lost touch with my own aspirations." [Participant 73]

> "It's hard to express the impact it has on my life. It's the day-to-day impact, the need to be there or in contact at anytime. The need to consider her needs in all my decisions. The impact on my future plans - I would dearly love to go live overseas, but my mother is still relatively young, and as much as it feels wrong to say this, she may live a long time and make my dreams impossible." [Participant 67]

The remaining items in the personal impact region captured details about interpersonal tension between carers and mental health consumers. Relatively high mean values were reported for the items that enquired about the strained atmosphere, quarrels and annoyance at the relative/friend's behaviour. These issues could be especially distressing, as one respondent noted: “It's more than hard- dealing with this is something one can't explain and the emotional verbal assaults we get from him is soul destroying.” [Participant 16]

Given the often substantial nature of the ongoing interpersonal tension, especially for those carers undertaking this work on a long-term basis, it would be understandable if carers discontinued their support of mental health consumers. Yet some carers demonstrate extraordinary levels of empathy and resilience, as was the case with this respondent:

> “Caring for my husband is a tremendous burden. His episodes are full of emotional abuse, anger coupled with destruction of property and then feelings of the very deepest self-loathing. For me though, it's given me a greater capacity to improve myself and to experience empathy when it's not the natural response in this situation. No matter how much he hurts me, and believe me he really does, it's nothing compared to how much he is hurting and hates himself. My heart breaks for him. He suffers from a biological illness that affects every part of him. His relationships, his day-to-day life. Underneath the imbalance is the reason I married him.” [Participant 24]

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

The third area clearly identified in the space emphasises the carers’ role in the recovery journey for consumers. Table 5 displays the 12 items encapsulated in the enabling daily living functional recovery region. The overall mean value for this region was 2.4. Many of the items in this region enquire about aspects of caring that can be conceptualised as supporting social and functional components of mental health recovery. In terms of functional recovery, encouraging and helping mental health consumers with self-care and normal tasks, and concerns about consumers’ ability to manage financially, are the items with highest mean values. Assisting with self-care and normal tasks could be onerous and is an area in which professional support would be beneficial, as the following excerpts demonstrate:

> “I feel it's a battle I am fighting but losing. I struggle with him to look after himself personally to do basic hygiene (shower, brush teeth, change clothes) I am now looking at groups online to seek help not only him but myself” [Participant 16]

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

Financial concerns are one of the most frequently raised issues in the open-ended responses. A key element of these concerns is the inadequate level of government financial assistance:

> “He is on the disability support, and after rent, has only less then $200 a fortnight to feed himself, buy petrol and food, feed dogs... so guess who pays for the necessities? It is quite a strain and the National Disability Insurance Scheme has not been able to assist in the way he would like” [Participant 85]

The items that captured information about aspects of social recovery generally had lower mean values than the functional recovery items. And while the importance of facilitating social inclusion was noted, it appears to be an issue that is difficult to resolve. As one respondent put it: “Exhaustion is constant as my partner relies on me totally for his social support and talks non-stop” [Participant 8].

Finally, in the enabling daily living functional recovery region, the second highest mean value was recorded for the item that asked the respondents if they are worried about their relative/friends future. It is unsurprising that carers are often concerned about the mental health consumers' prospects. As the above material has shown, it is not uncommon for mental health consumers to experience social isolation and struggle with daily activities and finances. The journey towards recovering pieces of consumers' lives clearly requires time and is difficult, but could nonetheless be gratifying for carers: "It is tough at times, but you get some little rewards along the way when they achieve things on their own" [Participant 78].

Discussion

The regions identified through the SSA provide a basis to understand the manner in which carers prioritise issues that arise in supporting mental health consumers. The analysis demonstrates that carers are most concerned with enabling daily living functional recovery, for which the mean value is considerably higher than the personal impact and promoting safety 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.

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

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

It was unsurprising to find that financial concerns figure prominently in the open-ended responses and also have a high mean item rating. Many mental health carers forgo employment or reduce their working hours while supporting consumers. [40,41] In Australia, modest income support payments are available to mental health carers who do not work, but these payments are only accessible to a small proportion of carers. [40,42] The hardship that results from the lack of adequate financial assistance is further compounded by the often substantial level of financial support that carers provide to mental health consumers. [40]

Our findings show that health professionals also have an important role to play in alleviating mental health caregiver burden. Concerns over the provision of metal health care are highlighted in this study, especially in regard to being isolated from the care that consumers were receiving. Such issues reflect the results of other mental health carer studies that have been conducted in Australia and within the United Kingdom.[6,43] To some extent, the concern that carers experience in regard to the provision of services might be lessened through exploring and incorporating their views in planning and delivering mental healthcare. [4]

Limitations

The demographic details of Australian mental health carers vary considerably between studies. It is therefore difficult to develop a standardised profile of Australian mental health caregivers. However, the demographic characteristics of the carers in this study are highly consistent with the details reported in the most recent study of Australian mental health caregivers, which to some extent supports the generalisability of our findings.[40] Finally, our value for the coefficient of alienation equalled 0.21, which was marginally outside of the range of 0.15 to 0.20 that is considered to represent a good fit.[37] That said, the coefficient of alienation should be interpreted in light of the SSA visual structure, which in the case of our study clearly delineated distinct regions.[37]

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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The authors have no competing interests to declare

Contributors

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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)

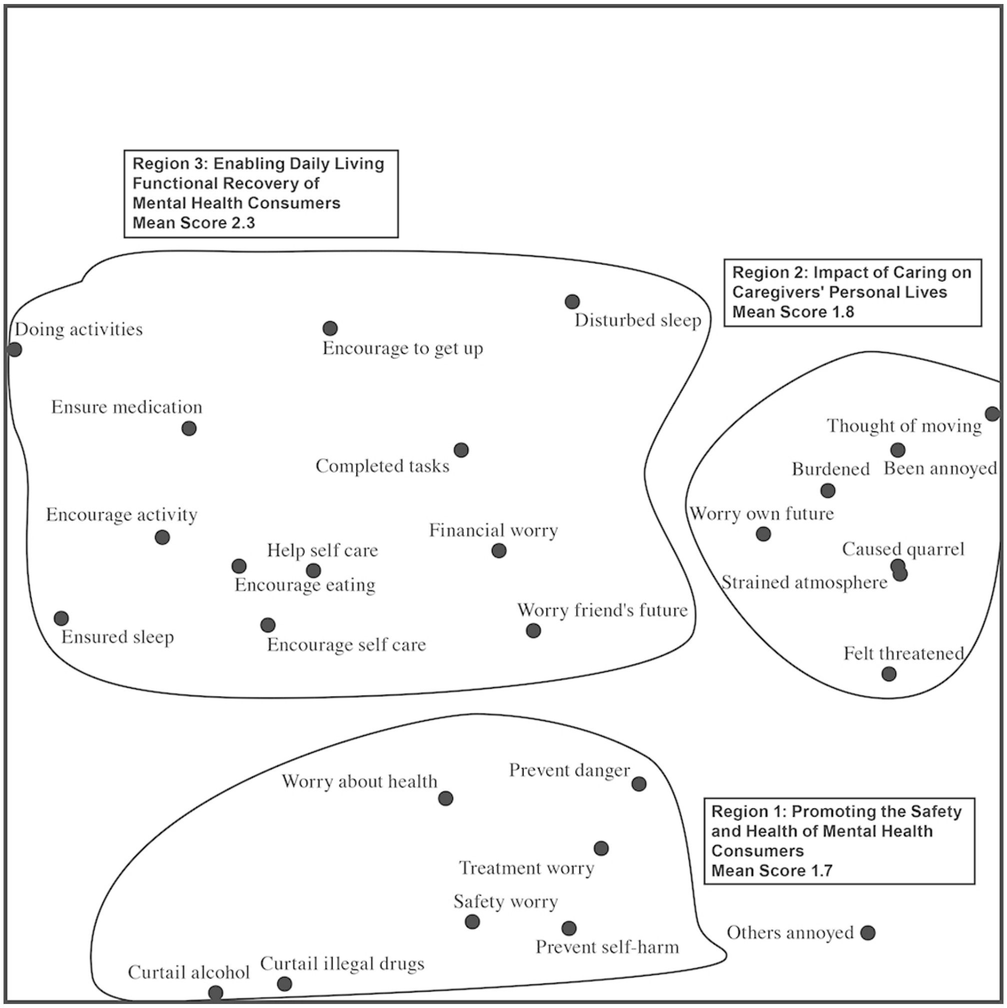
Table 4. Personal Impact

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)



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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*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—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 *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	5
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—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*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed	

		Cross-sectional study—If applicable, describe analytical methods taking account of sampling strategy6-7	
		(*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) *Cohort study*—Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	
		Cross-sectional study—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.

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.