Archived at the Flinders Academic Commons:

http://dspace.flinders.edu.au/dspace/

'This is the peer reviewed version of the following article: Suzanne Dawson, Adam Gerace, Eimear Muir-Cochrane, Deb O'Kane, Julie Henderson, Sharon Lawn & Jeffrey Fuller (2015): Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia, Aging & Mental Health, DOI: 10.1080/13607863.2015.1078283

which has been published in final form at

DOI:

http://dx.doi.org/10.1080/13607863.2015.1078283

Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia

Corresponding author:
Ms Suzanne Dawson: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: + 61 8 82013337; email: suzanne.dawson@flinders.edu.au

Co-authors:
Dr Adam Gerace: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: +61 8 82017640; email: adam.gerace@flinders.edu.au

Professor Eimear Muir-Cochrane: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001 Australia; tel: +61 82015907; email: eimear.muircochrane@flinders.edu.au

Ms Deb O'Kane: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: +61 8 82017962; email: debra.okane@flinders.edu.au

Dr Julie Henderson: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: +61 8 82017638; email: julie.henderson@flinders.edu.au

Associate Professor Sharon Lawn: School of Medicine, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: +61 8 84042321; email: sharon.lawn@flinders.edu.au

Professor Jeffrey Fuller: School of Nursing & Midwifery, Flinders University; GPO Box 2100 Adelaide 5001, Australia; tel: +61 8 82017641; email: jeffrey.fuller@flinders.edu.au

Word length: **5304** (Main text) plus **250** (Abstract)

Journal: Aging & Mental Health

Acknowledgements

Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia

Ageing & Mental Health

Abstract (250)

Objectives

Mental health care for older people is primarily delivered in the community and is largely dependent on informal carers. Mental health policy encourages partnerships between carers and service providers to facilitate service access, coordination and positive experience of care. However, carers often lack information and support from services, with the potential for carer burden, and negative impacts on their own health and capacity to fulfil caring tasks. This paper explores rural carers' experiences of accessing care from a range of services for older people with mental health problems.

Methods

The Pathways Interview Schedule was used to facilitate nine in-depth care journey interviews with eleven carers of older people with a mental health problem. Interviews explored their journeys to and through mental health, aged care, primary care and social care services. Framework analysis was used to explore carers' experiences and perceptions of care with a focus on access enablers and barriers.

Results

Carers had a significant role in navigating services and operationalising care for their relative. Enablers to accessing care included carer knowledge and workers actively involving carers in planning. Barriers included carer mental health literacy, consumer and carer readiness for services, and worker misinterpretation of confidentiality and privacy laws.

Conclusion

Carers should be considered key partners in mental health care planning that crosses service sectors. For this to occur changes are required at the worker level, including increased communication between mental health workers and carers, and the service level, involving training for staff in interpreting confidentiality and privacy policy.

Introduction (5304)

Mental health care for older people is primarily delivered in the community (WHO, 2013, Commonwealth of Australia, 2009), with significant input from informal carers (Pirkis et al., 2010). In Australia it is estimated that there are 2.7 million informal carers (12% of the population), who provide unpaid care to family members or friends with a disability, mental illness or chronic conditions (ABS 2012). Informal carers are particularly important to older people, who may have mental health and other chronic health conditions, as they are the main providers of care for this group (Productivity Commission, 2011). The ageing population trend means that this care need will continue to increase, with many people caring into later life (Carers UK, 2015).

Policies supporting carer partnerships with services are prominent in Australia and overseas (Department of Human Services, 2006, UK Care Act, 2014, Mental Health Commission of Canada, 2009, Ministry of Health, 2012). Australian mental health policy encourages partnerships between consumers, carers and service providers in order to facilitate service access, coordination and positive experience of care (Commonwealth of Australia, 2009). The strategic plan of Carers Australia (2015-2018) aims to 'ensure that caring is a shared responsibility of family, community and Government' and calls for active partnerships between service providers and carers (Carers Australia, 2015).

In Australian and international literature high levels of unmet need for mental health care for older people have been identified with longer delays to first seeking treatment, as well as reduced use of mental health services amongst older people compared to other age groups (Haralambous et al., 2009; Royal Australian and New Zealand College of Psychiatrists, 2010; Slade, 2009; Crabb & Hunsley, 2006; Thompson, Issakidis, & Hunt, 2008). Unmet need for primary mental health care can be significant for both older people and carers. Consequences identified for older people include poorer physical and mental health, increased hospitalisation and earlier admission to residential care (Draper & Low, 2004; Ryan, McCann, & McKenna, 2009). Poorer consumer health has the potential to increase carer stress and impact upon their ability to provide required care (Buhr, Kuchibhatla, & Clipp, 2006).

The complexity of older people's mental and physical health needs means that a range of health professionals and services can be involved in the provision of care, with the potential for fragmentation, lack of co-ordination and duplication of services (Reed, Cook, Childs, & McCormack, 2005). In Australia, the service landscape is complex, with funding and governance split between three levels of government (federal, state and local) and the private sector (Australian Commission on Safety and Quality in Health Care, 2014).

Fragmented service systems havebeen found to have a negative impact on rural carers who seek to access and navigate services for people with dementia (Orpin, Stirling, Hetherington & Robinson, 2014; Peel & Harding, 2014; Morgan et al., 2014; Di Gregorio, Ferguson & Wiersma, 2015). Barriers to accessing services include health professionals and carers' lack of awareness of services (Di Gregorio et al., 2015; Hansen, Robinson, Mudge & Crack, 2005) and lack of communication between professionals and with carers (Hansen et al., 2005). Facilitators include informal professional networks (Hansen et al., 2005) and close personal relationships that are a feature of small communities (Blackstock, Innes, Cox, Smith & Mason, 2006). In a systematic review on informal caregiving for dementia in rural settings, recommendations included increasing use of case management and greater integration of services (Innes, Morgan & Kostineuk 2011).

In an earlier study we explored the views of health and social care providers regarding the barriers to effective mental health care for rural older people in a regional area in Australia (Muir-Cochrane, O'Kane, Barkway, Oster & Fuller, 2014). Barriers identified included service provider and service user difficulties in recognising mental health problems, and poor service access due to lack of services, as well as lack of use of available services. Lack of effective collaboration between services was considered to contribute to these access barriers. Given the central role that carers have in supporting older people, an exploration of carer experiences in accessing and navigating the broad range of services needed by older people with mental health problems in the rural context was considered important. The purpose of this study was to explore carers' experiences of seeking and navigating mental health care for older people in this same region. More specifically, we were interested in identifying the barriers and enablers in the access to and transition between care services.

Method

Participants

The study was part of a larger project testing a network model to plan and manage integrated primary mental health care for rural older people (Fuller et al., 2014). The study location was a rural region in South Australia. Health professionals (from health, social and aged care services) were asked to identify potential carer participants, provide them with an information sheet and seek their voluntary consent. Purposive sampling was used to recruit participants at different service contact points (e.g. primary care, community services or mental health) in order to maximise variability of experience. A broad definition of mental health problems was taken that was inclusive of those that attract a psychiatric diagnosis; dementia with behavioural and psychological symptoms; and psychological distress that does not attract a psychiatric diagnosis (Anderson et al., 2013; Sane Australia, 2014; Fuller, Edwards, Procter, & Moss, 2000). Consenting carers were invited to participate in an interview at a time and location convenient to them.

Eleven carers of older people (67-94 years) with mental health problems participated in the study. The majority of carers were women (n = 7), and ranged in age from 55-91 years. Carers were most often family members, including marital partners (n = 5) and children (n = 2) or in-laws (n = 2). Two were friends. Those being cared for were mainly male and diagnosed with a form of dementia with four having an additional mental health disorder pre-dating the onset of dementia. The service contact point for carers were mental health services (n = 7), a residential facility (n = 1), and primary care services (n = 1).

Data Collection

The Pathways Interview Schedule was used as the framework to collect information about the routes and sources of care used by participants (Sartorius & Janca, 1996). This schedule records sources of care, the interval between first experiencing symptoms and seeking care, and then between first seeking care and being referred to a specialist service. While the schedule can be used to quantitatively measure intervals between care points, we used it as a qualitative heuristic device to help participants think back through key critical junctures in their care seeking experiences (Hannigan & Evans, 2013). The interview also included broader questions about experiences of access to and transitions through care, focusing on barriers, gaps and enablers in the transition between mental health, aged care, primary care and social care services; how these transitions impacted on the help seeking experience and

journey; and caregivers' views on how mental health services for older people could be improved. Interviews lasted approximately 60 minutes, and were recorded and then transcribed verbatim.

Analysis

Framework Analysis (Strivastava & Thomson, 2009) was used to explore participants' journeys to care including gaps, barriers and enablers in care transition points. This qualitative research method provides a clear analytic format using five stages (Ward et al. 2013). Stage one is familiarisation with the data through reading and re-reading and making early codes from the transcripts. Stage two involves the development of early themes in collaboration between the researchers. In Stage three a draft thematic framework is established using both a priori and new themes arising from the data. Stage four involves summarising data in an analytical framework, where researchers reduce material into understandable but brief summaries of what was said by participants. Stage five is the final stage where synthesis of data and refining of themes takes place.

Ethical approval

Approval was obtained from human research ethics committees of the South Australian Health Department (HREC/13/SAH/126) and Flinders University (notification 10/2014).

Results

Six themes were identified that describe rural carers' perspectives of seeking and utilising mental health care for the older person. Enablers and barriers to accessing appropriate support and care are presented throughout each of the following themes: challenges in using services; carer as service navigator; the informed and confident carer; familiarity in small communities; approach of the worker; and carer health and stress. Participant interviews are denoted by number in parentheses after quotes.

Challenges in utilising services

Challenges in using services were common for many participants. This occurred at both the individual and service level. At the individual level, the use of a service was not sought when carers misinterpreted symptoms and decline in function for normal ageing or grief "…. *I noticed, I've been noticing it for a couple of years...there was a bit of memory stuff but you don't know whether that's just age*" (3). During such time some carers had sought advice

from the older person's general practitioner (GP), with one describing how this occurred intermittently over a period of six years as the older person's symptoms fluctuated:

> *It was hard for us to know what was wrong with her because she'd fluctuate...she'd come good and then she'd go back again...but there were just a few odd things that she'd say, the people next door were spying on her, it was really quite bizarre* (6).

Some carers were reluctant to accept the use of services because of guilt, and felt that by accepting services they were abandoning their responsibility**, as one carer said,** *"I feel terrible about it, I feel as though once he's in [Residential Facility] that's his life, he's going to die in there and I just feel so guilty"*(7).

At the service level, carers reported that after noticing problems and instigating contact with services, delays were often experienced, as diagnosis typically took a long time and involved different specialist services. When treatment was obtained, carers were not always kept informed by services about what was going on. One carer described being left feeling *"quite bewildered"* when they were not given details of decisions made about care**,** and another carer talked about being unsure about how active they should be in asking health professionals for information:

> *It seemed to us that somebody came and took him away [to hospital]. We understood that because of the silly things that he'd done [that] they would do that, but we didn't know who had [arranged the admission]* (1).

> *I don't know whether the onus is on me to ask [for feedback]....whether they [Allied Health practitioners] know that they should be, because there isn't any guardianship yet, [so] it might be that they don't see that [as] something I need* (3).

While carers understood that services may not provide them with information because of the priority to maintain patient confidentiality, this was viewed to be at odds with what was needed by the family:

> *At what time do you say to somebody 'I am really concerned about your husband...are you considering that there's some things that are happening that probably aren't just normal ageing'...there really is a fine line between the rights of the patient to confidentiality and then to my right to know if it's something that's going to affect either his safety or my wellbeing and the rest of my family's wellbeing* (3).

Carer as service navigator

Some carers were clearly the main navigator in the help-seeking process, with prior experience in using services and personal connections assisting this. Others without this experience or connections had no clear starting point with one carer asking: "*Where does that [information about services] come from? Where would that come from?*"(8). These carers were reliant on service providers to give information and refer them to additional services. Such reliance led to carers subsequently describing missed opportunities for referral of their relative at various service contact points including the GP, Geriatrician and Accident and Emergency Department.

In addition to being the primary navigators in the help-seeking process, carers were typically required to operationalise the care as directed by health professionals: "*…with the case conference with different services we probably picked up from there what was available and then followed these things up…*"(1). Carers followed up practical tasks such as contacting services, arranging appointments and providing transport for their relative to appointments, in addition to doing most of the daily activities at home, viewing this as an expected part of their role. When formal care crossed health and social care sectors caring became more complicated as there was no over-arching coordination that bridged the sectors, as the following carer described:

> *I really wonder what would happen if we weren't there to help...I mean he couldn't do it himself, he just could not do it...I feel you need to have a coordinator ... who's been recommended by the doctor or the [hospital]...to stand by them to fuddle all these points through* (1).

Informed and confident carer

Carers had varying levels of mental health literacy and knowledge about services that impacted both positively and negatively upon accessing care. Some carers had prior knowledge of services from working in related areas or from contact for other family members (e.g. parents). In addition to knowing what services existed and what they could provide, prior experience helped mitigate frustration, as described by the following carer, "*...we went through all this situation with mum so we're sort of half aware that things don't all fall into place instantly*" (1).Carers' awareness of what they wanted enabled them to advocate for the person they were caring for, with prior knowledge of services further enhancing their ability to get a response:

> *What I think to myself is: What do I want as a response? Do I want to have something done? So if I want to have something done I've got to make this sound like it needs attention* (6).

This carer was confident to request help, though for others being expected to know what was needed was a cause of stress if health professionals left it to them to assess changes and request help: "*It's hard because I actually work [in Aged Care] and I think they're relying on me to pick up if there are changes*" (4). Another carer spoke of having to advocate on several occasions for services to engage as she was considered capable of caring independently due to her nursing background.

Familiarity in small communities

Those carers living in smaller remote communities experienced the personal benefits of people knowing each other, as one carer stated:

> *I think it's been pretty easy [to get help], everybody's been so supportive…part of that is …because I have personal friendships and I think that that's true for most people in the community ... That community feeling of 'we see you down the street, we know who you are, let us know how we can help'* (3).

This familiarity in small locations meant that any point of service contact resulted in the required referral, even to the point of blending professional and personal boundaries. This involved one carer telephoning the District Nurse at home to ask for help. Across the interviews, carers highlighted the value of meaningful social contact for their relative that was provided by workers, as the following carer described:

> *[The mental health worker] has actually taken him out a couple of times, her husband's a mechanic and that's what my husband was for years and years, so a couple of times she's taken him there just to hang around in the workshop...so that's been nice...it's almost a social occasion for him to get out which has been very, very good.*(3)

The impact of this familiarity seemed to provide a sense of inclusion and security which the following carer thought would not likely be found in larger communities:

> *I would've liked to have moved but now it's sort of a bit restrictive and I know that the care pattern here will be more personalised is a good way to put it than it would be if*

she went somewhere in [the city]. It's like a family whereas [in the city] it's like a job and you can see that when you go there (5).

Approach of the worker

The approach of the worker was mentioned by many carers as having a positive impact on the process of getting help. Health professionals who were flexible offered support when the person was ready,… *he said 'look if we get your mum on a good day bring her in'* (6). In this case the worker kept an open invite to contact for a year. Having a known worker to contact enabled nine of the eleven carers to identify a service or specific person from whom they could seek help. These workers were all within the health sector and included GPs, mental health workers and community health workers. For those not wanting services, even though the need was evident, it appeared that some workers kept regular contact that was non-intrusive and could be stepped up when required:

> *I haven't actually used any of the services at this stage because I'm basically looking after her and I'm probably one of those persons that would probably not go until I really needed to because I'm independent, but I know the services are there now. There is one person that comes around and sees her, it might not be a regular thing but maybe every couple of weeks...someone will come and talk to her and give some advice on what she need*s (5).

Benefits of being kept informed by workers were evident for those who were involved in case conferences, as this carer described: "*I think it's very good for everyone to see what page we're all on...she's sort of keeping us a step ahead...talking about the next step we need to take*" (1). Carers also spoke about the helpfulness of health professionals taking responsibility for those decisions that could have a negative impact upon their relationship with the person for whom they were caring. One carer who was struggling to recommend that her husband's driving licence be removed was helped when services facilitated this,... "*[The GP told me]…I'll be the bad person, you don't have to be the bad person*"(3).

Carer health and stress

Often carers were providing significant levels of support and their own health had an impact on their ability to provide this support. One carer**'s** own deteriorating health led to the move of his wife into residential care and another's health was compromised because of lack of treatment due to her caring responsibilities:

We both got bronchitis...that was the lead up to [her] going into the nursing home...I think [she] could've been home for twelve months longer...That's the thing, when you get sick and you're old there's nothing you can do (9).

There's no way I can go to hospital [as recommended]...because I would be worse worrying about the dogs...he's got to the point where he could possibly leave the gate open...he leaves all the lights on, the water going...doors open...(7).

Stress was experienced by carers due to the ongoing level of support that they needed to give, "*…you get tired, you don't just cook the dinner and wash the dishes...you're still there for the rest of the twenty-four hours...*"(9). The importance of respite as a break from this ongoing stress was evident, although some carers who used respite stated that this resulted in them feeling guilty. Stress was also experienced by carers who did not live with the person for whom they were they were caring, as they expressed concerns about the length of time the person was on their own and hence the potential risks,"*…there's still twenty-two hours in a day where he could fall over outside or he could do some silly things, that's he's just by himself* "(1).

When one partner in a couple was the carer, they were at risk of becoming socially isolated: "*If you go somewhere you've got to go somewhere that your partner can go...you finish up you've got no friends because you just can't visit half of them*"(9). Partners experienced significant limitations on their own activities: *"We used to go out a bit but [she] doesn't want to leave the house. Basically now [we] go shopping, usually on a Wednesday morning, and that's pretty much her outing"*(5). A carer, who was still working, expressed the inner conflict between her own needs outside of the home and the desire to keep her husband at home:

What do I do? Do I need to give up work?...I'll be very honest...I think we'd drive each other crazy if I was home all day…I get a lot of value in my work and that gives me a lot of pleasure and a lot of validation…so at what point do I say that I'm at home all day…[because]…I'd like him to be in this home as long as he can (3).

Family dynamics could affect help-seeking and engagement with services. Mental illness could lead to conflict between family members and the ill person: *"You couldn't help mum, ten years ago I tried to get help and she…didn't talk to me for six years"* (8). In this case, services were eventually accessed after the whole family made a joint decision to seek help:

"We had to have a round table discussion to actually get to a doctor, we had to have the whole family" If different views were held by family members this could lead to conflict and delay seeking help, as described by the following carer:

> *He thinks I dramatise, I'm making a mountain out of a molehill, but I know I wasn't…If there were family members that weren't open and someone had a mental health problem, how do they cope?* (2)

Discussion

The purpose of this study was to explore carers' experience of seeking and navigating mental health care for older people. This study is the first to use the Pathways Interview Schedule (Sartorius & Janca, 1996) as a heuristic to help elucidate reasons for unmet needs for older people with mental health problems. The Pathways Interview Schedule promoted a detailed interview that provided an in-depth understanding of the complexity that rural carers faced in accessing a broad range of services over time. The themes which emerged highlight the significant roles carers have in providing care for older people, including facilitating service access, navigating a complex service landscape and being required to take the role as overall coordinator of care. The impact of these roles on carers' own health was evident, although living in a rural location and the approach of workers ameliorated some of the difficulties carers experienced.

Overall, carers in the present study were the primary navigator and care provider. Carers liaised with workers across sectors and reported difficulties in identifying service options as well as communication with and between services. The complexity of health servicing is likely to have contributed to the challenges carers experienced when navigating access to help (Orpin et al., 2014; Innes et al., 2011; Innes, Szymczynska, & Stark, 2014). A recent study exploring access to health and social care services from the perspective of dementia carers in the UK recommended that support is provided to help carers navigate the complex service landscape (Peel & Harding, 2014). Our study adds to this by highlighting that this complexity still exists for carers, even when they are engaged with services providing case management. Interviews highlighted that there was no overarching professional care coordinator that bridged all sectors (health, aged and social care) and subsequently carers found they were often the primary navigator across services.

While the interviewed carers appeared to accept their caring responsibilities and roles, limited or no feedback from services was an issue, and is particularly pertinent given their central role in navigating service access. Inadequate information sharing between services and carers is recognised to be a major barrier impacting upon the caring role (National Mental Health Consumer & Carer Forum, 2011b; Gray, Robinson, Seddon, & Roberts, 2008; Hungerford & Richardson, 2013). While international and Australian policy places carers as central to care provision (UK, 2014, Mental Health Commission of Canada, 2009, Ministry of Health, 2012; Commonwealth of Australia, 2009), mental health workers interpretation of confidentiality provisions has been found to create 'confidentialitysmokescreens' that limits information sharing (Gray et al., 2008).

Health workers' interpretation of confidentiality and privacy in practice is complicated (Hansen, Robinson, Mudge, & Crack, 2005), resulting in a dichotomy between policy, service and carer expectation that carers should have a significant role, and the reality of practice, where carers face difficulties in getting information from services. This lack of information can result in carers feeling disempowered, angry, isolated, guilty and lonely (Gray et al., 2008), which subsequently impacts upon their ability to provide the required care. In the present study, even a few missed links in feedback left carers feeling 'bewildered'. The tension between client confidentiality and privacy and carer feedback needs to be addressed to enable information sharing between services and with carers. Our study demonstrates, that at a system level, current policy frameworks are too simplistic in guiding practice and carer involvement. The 2011 National Mental Health Consumer and Carer Forum paper concluded that changes needed to occur at the service level (training for staff and increased communication between all parties) and legislation level (advanced directives and carer legislation) (National Mental Health Consumer & Carer Forum, 2011).

Broader carer issues raised in our study concur with other research about carers' reluctance to accept services (Brodaty, Thomson, Thompson, & Fine, 2005; Hansen et al., 2005; Orpin et al., 2014), the negative impact of caring on carers' own health (Cuijpers, 2005), and the impact of leaving paid employment in reducing their social networks (Milligan, 2006; Winterton & Warburton, 2011). Our study supports the findings of Milligan (2006) which highlighted the inter-relationship of carers' own health to the health of the care-recipient and postulated that shared decision making between carers and workers could reduce stress experienced by the carer.

In many cases, carer issues and concerns were ameliorated by the worker. In this study, a variety of approaches were taken by workers to engage with older people and their carers that demonstrated a flexible and family-centred approach. This included taking responsibility for 'difficult' care decisions, shared decision making at care planning meetings attended by carers, flexible appointment times and contact by workers that was viewed to be non-intrusive. Psychosocial support provided by regular contact with workers who are known and trusted is highly valued (Ross, Curry, & Goodwin, 2011) and supports this 'low-key' but consistent approach to engagement. When mental health workers lack an understanding of carer experience this can impact upon their ability to effectively partner with caregivers (Jones 2004). At the service level, being more inclusive of carers and incorporating a more family-centred approach requires mental health workers to consider carers' needs specific to their particular context.

Our study found that carers were providing significant levels of practical and emotional support to the person for whom they were caring. Carers are recognised as adding to the quality of care for older people as they bring a holistic knowledge of the person (sometimes over a life time) that positively contributes to care planning and maintaining the person's well-being (Gray et al., 2008; Milligan, 2006). In our study, carers highlighted the value of the relationship with the worker and the older person as well as the importance of social contacts for the older person. This aligns with research exploring what consumers want from services from both the carer perspective (Innes et al., 2011; Innes et al., 2014; Orpin et al., 2014) and service user perspective (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007). In view of this value, as well as policy directives, carers should be active partners in the care planning process (Tambuyzer, Pieters, & Van Audenhove, 2011). As a component of this partnership, carers should also have access to an assessment of their own needs (Rapaport, Bellringer, Pinfold, & Huxley, 2006) to help address concerns specific to their context. Furthermore, as formal care planning is often episodic, on a needs basis, it is important that carers have a clear pathway (contact person or service) to facilitate access to further help, if required.

A finding less reported in the literature was the additional stress that may be experienced by the 'competent' carer. Good mental health literacy is considered an important enabler to seeking help when needed (Jorm et al., 2006). In our study, while good mental health literacy and knowledge of service options assisted carers to find and advocate for the required services, this knowledge also resulted in increased responsibility for care provision and

decisions about care, which some carers felt to be an additional stress. A study exploring the experience of caring for older people with dementia in a rural area reported a similar finding, identifying that carer competency could at times result in unrecognised carer needs and reduced access to respite (Wenger, Scott, & Seddon, 2002).

Although some stress resulted from carers' good mental health literacy, poor mental health literacy was a significant barrier to service access in the first place, as it resulted in carers being entirely dependent on service providers to identify the need for referral to additional services. In the study, this resulted in missed opportunities at various service contacts (GP, Geriatrician and A & E assessment) and delays to treatment. A shared responsibility by all older people's services for facilitating further referral is needed, though this is also dependent on workers' own mental health literacy and knowledge of service options (Hansen et al., 2005; Muir-Cochrane et al., 2014). Recognising the need for shared responsibility some organisations are implementing system level interventions to facilitate service linkages to improve care (see the HARP initiative (Victoria, 2006)).

The context of this study was a rural location, where residents are considered to be at a disadvantage regarding service access and options (Royal Australian and New Zealand College of Psychiatrists, 2010). In our study, rural issues were not discussed in depth apart from the positive aspects of living in a small community. Carers in our study included people living in inner regional and remote settings. Those living in the remote locations had fewer service options but referred to the strong sense of familiarity as impacting positively upon the type of care received as well as on their ability to access available services. This finding was congruent with other studies conducted in rural locations that describe the benefits of social capital and personal relationships with providers in facilitating service access and enhancing personalised care (Blackstock, Innes, Cox, Smith, & Mason, 2006; Davis & Bartlett, 2008; Orpin et al., 2014).

Limitations

The small number of participants is a limitation of the study as well as the lack of a consumer perspective. Despite trying to recruit older people and their carers from a variety of service contact points, most of the participants were carers recruited from mental health teams. Three consumers were interviewed; however, it was decided not to incorporate these interviews due to the level of their cognitive impairment that became apparent during interviews. As there is limited research that explores accessing the broad range of services available for older

people, this study adds to the literature by investigating carers' experiences of accessing help across service sectors.

Conclusion

Given the central role carers have in older people's care, mental health care workers and services should acknowledge them as key partners. To facilitate a partnership approach, a family-inclusive service culture should focus on the identified barrier of lack of feedback from and between services, issues underpinning this (misinterpretation of confidentiality and privacy laws) and solutions (care planning inclusive of carers as partners). Policy and legislation related to confidentiality and privacy and partnering with carers needs to be interpreted and translated at the level of service provision.

References

Anderson, T. M., Sunderland, M., Andrews, G., Titov, N., Dear, B. F & Sachdev, P. S. (2013). The 10-item kessler psychological distress scale (K10) as a screening instrument in older individuals. *American Journal of Geriatric Psychiatry, 21*, 596-606. doi: 10.1016/j.jagp.2013.01.009

Australian Bureau of Statistics. (2012). 4436.0 - Caring in the Community. Canberra: Author. Retrieved from: http://www.abs.gov.au/ausstats/abs@.nsf/mf/4436.0

Australian Commission on Safety and Quality in Health Care. (2014). *Scoping Study on the Implementation of National Standards in Mental Health Services*, Sydney, ACSQHC.

Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V., & Baker, R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling, 68*(1), 33-42. doi: 10.1016/j.pec.2007.03.025

Blackstock, K. L., Innes, A., Cox, S., Smith, A., & Mason, A. (2006). Living with dementia in rural and remote Scotland: Diverse experiences of people with dementia and their carers. *Journal of Rural Studies, 22*(2), 161-176. doi: 10.1016/j.jrurstud.2005.08.007

Brodaty, H., Thomson, C., Thompson, C., & Fine, M. (2005). Why caregivers of people with dementia and memory loss don't use services. *International Journal of Geriatric Psychiatry, 20*(6), 537–546. doi: 10.1002/gps.1322

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist, 46*(1), 52-61.

Care Act. (2014). UK. Retrieved from: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm

Carers Australia. (2015). Strategic Plan 2015-18. Carers Australia. Retrieved from: http://www.carersaustralia.com.au/storage/2105-Carers-Australia-Strategic-Plan_2015-18_FA-Web.pdf

Carers UK, Aged Care UK. (2015). Caring into later life: The growing pressure on older carers. Carers UK. Retrieved from: http://www.carersuk.org/for-professionals/policy/policy-library/caring-into-later-life

Carers UK. (2014). Facts about carers. Who are carers? *Policy briefing*. Carers UK. Retrieved from: http://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014

Commonwealth of Australia. (2009). Fourth National Mental Health Plan: An agenda for collaborative government action in mental health 2009-2014. Retreived from: http://www.health.gov.au/internet/main/publishing.nsf/Content/9A5A0E8BDFC55D3 BCA257BF0001C1B1C/$File/plan09v2.pdf

Crabb, R., & Hunsley, J. (2006). Utilization of mental health care services among older adults with depression. *Journal of Clinical Psychology, 62*(3), 299-312. doi: 10.1002/jclp.20231

Cuijpers, P. (2005). Depressive disorders in caregivers of dementia patients: A systematic review. *Aging and Mental Health, 9*(4), 325-330. doi: 10.1080/13607860500090078

Davis, S., & Bartlett, H. (2008). Healthy ageing in rural Australia: Issues and challenges. *Australasian Journal on Ageing, 27*(2), 56-60. doi: 10.1111/j.1741-6612.2008.00296.x

Department of Human Services, Mental Health Branch. (2006). *Caring together - An action plan for carer involvement in Victorian public mental health services.* Victoria: Commonwealth of Australia. Retrieved from: http://www.health.vic.gov.au/mentalhealth/carer/carer-involve.pdf

Di Gregorio, D., Ferguson, S., & Wiersma, E. (2015). From beginning to end: Perspectives of the dementia journey in Northern Ontario. *Canadian Journal on Aging, 34(1),* 100 – 112. doi: 10.1017/S0714980814000531

Draper, B., & Low, L. (2004). What is the effectiveness of old-age mental health services? *Copenhagen: WHO Regional Office for Europe (Health Evidence Network report).* Retreived from: http://www.euro.who.int/__data/assets/pdf_file/0008/74690/E83685.pdf

Fuller, J., Edwards, J., Procter, N., & Moss, J. (2000). How definition of mental health problems can influence help seeking in rural and remote communities. *The Australian journal of rural health, 8*(3), 148-153. doi: 10.1046/j.1440-1584.2000.00303.x

Fuller, J., Oster, C., Dawson, S., O'Kane, D., Lawn, S., Henderson, J., . . . Cochrane, E. M. (2014). Improving the network management of integrated primary mental healthcare for older people in a rural Australian region: Protocol for a mixed methods case study. *BMJ Open, 4*(9). doi: 10.1136/bmjopen-2014-006304

Gray, B., Robinson, C., Seddon, D., & Roberts, A. (2008). 'Confidentiality smokescreens' and carers for people with mental health problems: The perspectives of professionals. *Health and Social Care in the Community, 16*, 378-387. doi: 10.1111/j.1365-2524.2007.00748.x

Hannigan, B., & Evans, N. (2013). Critical junctures in health and social care: Service user experiences, work and system connections. *Social Theory & Health, 11*(4), 428-444.

Hansen, E., Robinson, A., Mudge, P., & Crack, G. (2005). Barriers to the provision of care for people with dementia and their carers in a rural community. *Australian Journal of Primary Health, 11*(1), 72-79. doi: 10.1071/PY05010

Haralambous, B., Lin, X., Dow, B., Jones, C., Tinney, J., & Bryant, C. (2009). Depression in older age: a scoping study. National Ageing Research Institute. *Australia*.

Hungerford, C., & Richardson, F. (2013). Operationalising Recovery-oriented services: The challenges for carers. *Advances in Mental Health, 12*(1), 11-21. doi: 10.1111/nhs.12088

Innes, A., Morgan, D., & Kostineuk, J. (2011). Dementia care in rural and remote settings: A systematic review of informal/family caregiving. *Maturitas, 68*(1), 34-46. doi: 10.1016/j.maturitas.2010.10.002

Innes, A., Szymczynska, P., & Stark, C. (2014). Dementia diagnosis and post-diagnostic support in Scottish rural communities: Experiences of people with dementia and their families. *Dementia, 13*(2), 233-247. doi: 10.1177/1471301212460608

Jones, D. W. (2004). Families and serious mental illness: Working with loss and ambivalence. *The British Journal of Social Work, 34*(7), 961-979. doi: 10.1093/bjsw/bch123

Jorm, A. F., Barney, L. J., Christensen, H., Highet, N. J., Kelly, C. M., & Kitchener, B. A. (2006). Research on mental health literacy: What we know and what we still need to know. *Australian and New Zealand Journal of Psychiatry, 40*(1), 3-5. doi: 10.1111/j.1440-1614.2006.01734.x

Mental Health Commission of Canada. (2009). *Toward recovery & well-being. A Framework for a Mental Health Strategy for Canada*. Retrieved from: http://www.mentalhealthcommission.ca/English/system/files/private/Seniors_Toward_Recovery_and_Well_Being_SUMMARY_ENG_0.pdf

Metropolitan Health and Aged Care Services Division. (2006). Improving care. Hospital Admission Risk Program (HARP) Public report. Victorian Government Department of Human Services, Melbourne, Victoria, Australia. Retrieved from: www.health.vic.gov.au/harp/downloads/improvingcare.pdf

Milligan, C. (2006). Caring for older people in the 21st century: 'Notes from a small island'. *Health and Place, 12*(3), 320-331. doi: 10.1016/j.healthplace.2004.12.002

Ministry of Health. (2012). *Rising to the Challenge. The Mental Health and Addiction Service Development Plan 2012–2017.* Wellington: Ministry of Health. Retrieved from: http://www.health.govt.nz/system/files/documents/publications/rising-to-the-challenge-mental-health-addiction-service-development-plan.pdf

Morgan, D.G., Walls-Ingram, S., Cammer, A., O'Connell, M.E., Crossley, M., Dal Bello-Haas, V., Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science & Medicine, 102*, 111-118. doi: 10.1016/j.socscimed.2013.11.023

Muir-Cochrane, E., O'Kane, D., Barkway, P., Oster, C., & Fuller, J. (2014). Service provision for older people with mental health problems in a rural area of Australia. *Aging & Mental Health, 18*(6), 759-766. doi: 10.1080/13607863.2013.878307

National Mental Health Consumer & Carer Forum. (2011). Privacy, Confidentiality and Information Sharing – Consumers, Carers and Clinicians. Canberra: NMHCCF. Retrieved from: http://nmhccf.org.au/publication/position-statement-privacy-confidentiality-and-information-sharing-consumers-carers

Orpin, P., Stirling, C., Hetherington, S., & Robinson, A. (2014). Rural dementia carers: Formal and informal sources of support. *Ageing and Society, 34*(2), 185-208. doi: 10.1017/S0144686X12000827

Peel, E. & Harding, R. (2014). 'It's a huge maze, the system, it's a terrible maze': Dementia carers' constructions of navigating health and social care services. *Dementia, 13(5),* 642-661. Doi: 10.1177/1471301213480514

Pirkis, J., Burgess, P., Hardy, J., Harris, M., Slade, T., & Johnston, A. (2010). Who cares? A profile of people who care for relatives with a mental disorder. *Australian and New Zealand Journal of Psychiatry, 44*(10), 929-937. doi: 10.3109/00048674.2010.493858

Productivity Commission. (2011). *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra. Retrieved from: http://www.pc.gov.au/inquiries/completed/aged-care/report/aged-care-volume1.pdf

Rapaport, J., Bellringer, S., Pinfold, V., & Huxley, P. (2006). Carers and confidentiality in mental health care: Considering the role of the carer's assessment: A study of service users', carers' and practitioners' views. *Health and Social Care in the Community, 14*(4), 357-365. doi: 10.1111/j.1365-2524.2006.00631.x

Reed, J., Cook, G., Childs, S., & McCormack, B. (2005). A literature review to explore integrated care for older people. *International Journal of Integrated Care, 5*(14), e17. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1395528/

Ross, S., Curry, N., & Goodwin, N. (2011). Case management. What it is and how it can best be implemented. *The King's Fund.* Retrieved from: http://www.kingsfund.org.uk/sites/files/kf/Case-Management-paper-The-Kings-Fund-Paper-November-2011_0.pdf

Rowe, J. (2012). Great expectations: A systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing, 19*(1), 70-82. doi: 10.1111/j.1365-2850.2011.01756.x

Royal Australian and New Zealand College of Psychiatrists. (2010). Caring for older Australians: Submission to the Productivity Commission public inquiry into Australia's aged care system.

Ryan, A. A., McCann, S., & McKenna, H. (2009). Impact of community care in enabling older people with complex needs to remain at home. *International Journal of Older People Nursing, 4*, 22-32. doi: 10.1111/j.1748-3743.2008.00152.x

Sane Australia. (2014). Factsheets and Podcasts. (https://www.sane.org/).

Sartorius, N. & Janca, A. (1996). Psychiatric Assessment Instruments developed by the World Health Organisation. *Social Psychiatry and Psychiatric Epidemiology Journal* 31, 55-69.

Slade, T., Johnston, A., Teesson, M., Whiteford, H., Burgess, P., Pirkis, J. & Saw, S. (2009). The mental health of Australians: report on the 2007 National Survey of Mental Health and Wellbeing. *Department of Health and Ageing, Canberra.* Retrieved from: http://www.health.gov.au/internet/main/publishing.nsf/Content/mental-pubs-m-mhaust2

Strivastava, A., & Thomson, S. B. (2009). Framework analysis: a qualitative methodology for applied policy research. *Journal of Administration Governance, 4*(2), 72-79. Retrieved from: http://www.joaag.com/uploads/06_Research_Note_Srivastava_and_Thomson_4_2_.pdf

Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2011). Patient involvement in mental health care: one size does not fit all. *Health Expectations, 17*, 138-150. doi: 10.1111/j.1369-7625.2011.00743.x

The Health Foundation. (2014). Ideas into Action: Person-centred care in practice. London: The Health Foundation. Retrieved from: http://personcentredcare.health.org.uk/resources/ideas-action-person-centred-care-practice-learning-report.

Thompson, A., Issakidis, C. & Hunt, C. (2008). Delay to seek treatment for anxiety and mood disorders in an Australian clinical sample. *Behaviour Change, 25*(2), 71-84. doi: http://dx.doi.org/10.1375/bech.25.2.71

Ward, D. J., Furber, C.,Tierney, S. & Swallow, V. (2013). Using Framework Analysis in nursing research: a worked example. *Journal of Advanced Nursing, 69*, 2423–2431. doi: 10.1111/jan.12127

Wenger, G. C., Scott, A., & Seddon, D. (2002). The experience of caring for older people with dementia in a rural area: Using services. *Aging and Mental Health, 6*(1), 30-38. doi: 10.1080/13607860120101040

Winterton, R., & Warburton, J. (2011). Models of care for socially isolated older rural carers: Barriers and implications. *Rural and Remote Health, 11*(3). Retrieved from: http://www.rrh.org.au/articles/printviewnew.asp?ArticleID=1678

World Health Organisation. (2013). Mental Health Action Plan 2013-2020. WHO. Retrieved from: http://apps.who.int/iris/bitstream/10665/89966/1/9789241506021_eng.pdf