**HOW DID THE COVID-19 RESTRICTIONS IMPACT PEOPLE LIVING WITH DEMENTIA AND THEIR INFORMAL CARERS WITHIN COMMUNITY AND RESIDENTIAL AGED CARE SETTINGS IN AUSTRALIA? A QUALITATIVE STUDY**

**AUTHORS**

**Dr Katarzyna Małgorzata Lion**

<https://orcid.org/0000-0002-3699-6896>

Research Fellow, Menzies Health Institute Queensland, Griffith University

176 Messines Ridge Rd, Mount Gravatt QLD 4122

T +61 7 373 58440 | email k.lion@griffith.edu.au

**Professor Wendy Moyle**

<https://orcid.org/0000-0003-3004-9019>

Program Director, Menzies Health Institute Queensland and Professor of Nursing School of Nursing and Midwifery,

170 Kessels Road, Nathan, Brisbane, QLD 4111, Australia

T +61 7 373 5526 | email w.moyle@griffith.edu.au

**Dr Monica Cations**

<https://orcid.org/0000-0002-9262-0463>

Senior Research Fellow, College of Education, Psychology and Social Work, Flinders University

GPO Box 2100 Adelaide SA 5001

T +61 8 8201 3058 Email: monica.cations@flinders.edu.au

**Ms Sally Day**

<https://orcid.org/0000-0002-1194-4360>

Flinders University, College of Education, Social Work and Psychology

GPO Box 2100, ADELAIDE, SA, 5001, Australia

T +61 8 82013058 | email sally.day@sydney.edu.au

**Dr Lihui Pu**

<https://orcid.org/0000-0003-0136-0940>

Research Fellow, Menzies Health Institute Queensland, Griffith University

170 Kessels Road, Nathan Queensland 4111

T +61 7 3735 7212 | Email l.pu@griffith.edu.au

**Ms Jenny Murfield**

<https://orcid.org/0000-0001-9595-4242>

Research Fellow, Food & Mood Centre, Institute for Mental and Physical Health and Clinical Translation (IMPACT), School of Medicine, Deakin University

285 Ryrie Street, Geelong, VIC, 3220

T +61 3 522 73842 | Email jenny.murfield@deakin.edu.au

**Professor Mark Gabbay**

<https://orcid.org/0000-0002-0126-8485>

Professor of General Practice University of Liverpool and Director National Institute of Health Research Applied Research Collaboration North West Coast, GP Brownlow Health, Liverpool.

Dept of Primary Care and Mental Health, University of Liverpool, 1st floor, Waterhouse Block B, 1-5 Brownlow St, Liverpool, L69 3GL.

m.b.gabbay@liverpool.ac.uk

**Dr Clarissa Giebel**

<http://orcid.org/0000-0002-0746-0566>

Senior Research Fellow

National Institute of Health Research Applied Research Collaboration North West Coast, Department of Primary Care and Mental Health

Waterhouse Building Block B, 2nd Floor, The University of Liverpool

Liverpool L69 3GL, Tel.: 0151 794 9966

clarissa.giebel@liverpool.ac.uk

**CORRESPONDENCE**

Dr Katarzyna Lion

Menzies Health Institute Queensland, Griffith University, Health Sciences (N48),

170 Kessels Road, Nathan, Brisbane, Queensland, 4111, Australia

Email: k.lion@griffith.edu.au; Tel: +61(0)7 373 58440

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**ABSTRACT (149/150 words)**

This study aimed to explore how formal social support changed after implementation of the COVID-19 public health measures and how these restrictions impacted people living with dementia and their informal carers in Australia. Sixteen informal carers and two people living with dementia were interviewed between August and November 2020. Participants were asked about their experiences of the pandemic and the impact that the restrictions had on their lives and care. Thematic analysis identified four over-arching themes describing 1) pre-pandemic limitations of the aged care system; 2) the aged care system’s response to the COVID-19 restrictions; 3) changes impacting informal carers and 4) the challenges faced by people living with dementia. The findings highlighted the challenges faced by the Australian aged care system before the pandemic, as well as the additional burden placed on informal carers who supported people living with dementia across residential and home settings during the pandemic.

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**CONFLICT OF INTEREST**

None

**AUTHORS' CONTRIBUTIONS**

CG and MG contributed to the conception and design of the original study that took place in the UK. KL and WM arranged the study in Australia. KL, JM, LP, and SD recruited participants, conducted, and transcribed the interviews. KL and WM analysed and interpreted the data. KL wrote the first draft of the manuscript. WM, MC, CG, MG, LP, SD, JM revised the draft. All authors read and approved the final manuscript.

**INTRODUCTION**

In Australia, the first case of the novel coronavirus disease (COVID-19) was reported on January 25, 2020 (Minister for Health, 2020). Strict social restrictions, recommendations, and measures were implemented nationally to control the spread of the virus on March 23, 2020 (Minister for Health, 2020). These measures included physical distancing, recommendations to stay at home, avoidance of non-essential travel, and reduced physical contact with people. In addition, older Australians, who are particularly vulnerable to risk of serious illness from COVID-19, were advised to self-isolate at home and limit their outside activities to essential activities, such as grocery shopping (Prime Minister of Australia, 2020a). As a result, many organisations, including social services and health and aged care services, stopped providing or significantly limited/modified their client services. For example, residential aged care facilities (RACFs) restricted visiting for families and friends of residents. From May 2020, these restrictions began to ease, with the various states and territories across Australia navigating a COVID-safe re-opening based on health advice (Prime Minister of Australia, 2020b). However, individual jurisdictions also imposed local lockdowns and other measures based on their state/territory situation to control the spread of the coronavirus.

Although the COVID-19 pandemic in Australia presented differently to most other countries internationally, with strict closure of international borders limiting the numbers of locally acquired cases in Australia, it has still increased concerns for older people, including people living with dementia and their informal carers (Pachana et al., 2020; Wang et al., 2020). The pandemic has impacted them directly by increasing morbidity and mortality, and indirectly through restrictions in healthcare and social support usually available to residents and their families (Migliaccio & Bouzigues, 2020). In compliance with federal, state, and territory government rules and similar to changes across the globe (Giebel, Cannon, Hanna, Butchard, et al., 2021; Thyrian et al., 2020; Verbeek et al., 2020), the COVID-19 pandemic has left many Australians living with dementia and their informal carers without care support because of temporary closures of daycare/respite centres and restrictions to face-to-face home support and RACF visits. The pandemic has also highlighted the need for a better model of health and aged care services for older people, people living with dementia, and their carers (Low et al., 2021; Pachana et al., 2020).

Informal carers provide a vital role in care delivery for people living with dementia in Australia. As dementia progresses, informal care is supported by the formal care services via Commonwealth home and respite care packages, and then through admission into residential care. However, with the formal care system unable to cope with the increasing demand for formal care services, the need for informal care provided by family members, friends or neighbours is rising (Mohanty & Niyonsenga, 2019; Vickland et al., 2011). In addition, studies from other countries suggest that the pandemic restrictions have impacted informal carers and people living with dementia, including increasing levels of burden, distress, anxiety, and depression (Giebel, Lord, Cooper, Shenton, et al., 2021; Hanna et al., 2021; Suárez-González et al., 2021). There is also evidence that social isolation and lack of activities may contribute to the progression of dementia symptoms (Cagnin et al., 2020; Carpinelli Mazzi et al., 2020; Suárez-González et al., 2021).

In Australia, there is limited knowledge describing the impact of the pandemic on people living with dementia, with published studies focusing on either people living with young onset dementia or the positive aspects of providing informal care to people living with dementia (Cations et al., 2021; Tulloch et al., 2021). Therefore, our study aimed to explore how the implemented changes in formal social support, due to the COVID‐19 public health measures, impacted people living with dementia and their informal carers in Australia. This information can help us prepare for future health emergencies and know where to direct appropriate support and resources to help address the issues the COVID-19 pandemic has caused.

**MATERIALS AND METHODS**

**Study design**

A qualitative, exploratory design was used to investigate the impact of the COVID-19 pandemic and associated restrictions of people living with dementia and their informal carers in Australia, especially their experiences in care reception and their wellbeing. The study obtained ethical clearance from the Human Research Ethics Committee at Griffith University (Australia) [GU Ref No: 2020/488]. The project used the methodology developed in the parallel UK study (Giebel et al., 2020). The study was conducted between July 2020 and November 2020.

**Participants and recruitment**

We recruited 18 participants aged over 18 years living in Australia. In addition to 16 informal carers (current and former), we interviewed two people living with dementia (with the capacity to make informed consent and participate in the study assessed by experienced researchers conducting the interviews). As per the inclusion criteria, all our participants with dementia and their carers could speak and understand English as well as accessed some form of social care/support, including daycare/respite care, support groups, home care, or long-term residential care, before the coronavirus restrictions were implemented. There were no specific exclusion criteria. Participants were recruited using convenience sampling via Step Up for Dementia Research (a research participation and engagement service funded by the Australian Government Department of Health and implemented by a dedicated team at the University of Sydney), social media accounts and groups, and third sector and social support service organisations, using their mailing lists and newsletters.

**Data collection**

Participants volunteering to participate in the study were contacted via email or telephone by a member of the authorship team to inform them about the study’s purpose, risks,

benefits, and informed consent. Consent was obtained verbally at the time of the interview and recorded in the interviewer’s notes. The interviews were conducted by trained researchers (KL, LP, SD) between July and November 2020, either by telephone or via videoconferencing according to the participant’s preferences. At the time of data collection, the restrictions in Australia were easing except for the state of Victoria. In this state, the strict restrictions were re-implemented due to the second outbreak that began on July 7, 2020 and lasted for almost four months.

Semi-structured interview topic guides (Supplementary Material 1) were prepared based on the parallel UK study conducted by Giebel et al. (2020). The original UK study protocol was developed in cooperation with three unpaid carers and one person living with dementia, and several third sector organisations and support providers for dementia.

The interview explored participants’ experiences of using social services in Australia before and after restrictions were implemented, changes in service access, and individual experiences. Initial questions focused on participants’ background characteristics, including age, gender, living situation, and relationship with the person living with dementia/informal carer. Interview duration ranged from between 15 to 63 minutes (*M* = 34.39 minutes; *SD* = 13.6).

**Thematic analysis**

The interviews were digitally audio-recorded and transcribed verbatim by an independent transcription service and imported into NVivo (QSR International Pty Ltd). The transcripts were anonymised, checked for accuracy, and read several times by the lead author (KL) to get an overall understanding of the content. Data were analysed by two research members (KL, WM) using a thematic approach that was both deductive and inductive (Braun & Clarke, 2012). First, we identified codes reflecting the content of the interview questions deductively, then adopted an inductive approach to categorise the other relevant codes. Throughout this process, KL met regularly with WM to review the analysis and discuss the developing codebooks, working together to compare, contrast, and consolidate the codes generated. Similar codes were grouped to generate themes and subthemes that represented the main issues within the data. An iterative approach was taken to uphold trustworthiness of the analysis where the data were repeatedly reread to confirm the overall representativeness of the categories and to check for overlap and uniqueness. The data were continuously reviewed and discussed until final themes and subthemes were agreed upon.

**RESULTS**

**Participant characteristics**

A total of 18 participants were interviewed for this study: two people with dementia living in the community and 16 people providing informal care to a person with dementia living in residential (*n* = 10) and community (*n* = 6) settings. Participant demographics are summarised in Table 1. In brief, most participants lived in New South Wales, Australia (two people with dementia and nine carers). The mean age of people living with dementia was 68.5 years (*SD* = 3.5); one was male and one female, both had a tertiary level of education, one lived alone, and the other lived with their spouse. Most informal carers were female (*n* = 12). Nine adult children and five spouses were among those carers who lived in one household with people living with dementia. Among carers, two formal carers actively advocated and provided support to other carers and people living with dementia. The mean age of carers was 63.25 years (*SD* = 12.26).

[Table 1]

**Themes**

Thematic analysis generated four over-arching themes with several sub-themes related to how coronavirus restrictions in Australia impacted people living with dementia and their informal carers in community and residential settings, and the character of restrictions/adaptations within the aged care sector. These themes are visually presented in Figure 1. One to two exemplar quotations are provided for each subtheme. Although all quotations have been reproduced verbatim, we have applied standard punctuation to enhance their readability.

[Figure 1]

**Theme 1: Existing limitations of the aged care system in Australia prior to COVID-19**

***Insufficient formal care availability within home and residential care settings***

Informal carers reported they have an important role in providing care for people living with dementia. Formal aged care system services in Australia experienced many challenges even before the COVID-19 pandemic, across both home and residential care services delivery. This impacted on carers being able to access home care services via the Australian government-provided packages. These usually required a long waiting period after assessment of the client and decisions about the support package level are made. Those home care packages are assigned based on the level of care needs (1 – basic to 4 – high care) and the government pays the chosen provider a subsidy to arrange those services. The packages cover a range of services, including bathing, meal preparation, home and garden maintenance, transport. Additionally, service providers coordinate and manage these packages, and they require a management fee, significantly reducing the available support hours within the available package as indicated in the following statement:

You hardly get any hours because half of the money goes into fees or management fees. So, even with a level 4 package, which is the highest you can get, you only end up with about 12 hours of care a week… I couldn't have a life with 12 hrs of care a week, so really, in my mind, aged care packages are pretty useless. (Informal carer 11[[1]](#footnote-2), female, 55 years old, residential setting, New South Wales)

Within residential care, informal carers reported the need for providing additional care and support to people living in RACFs before the COVID-19 pandemic. Most of them regularly visited the RACF to provide some form of support – washing clothes and feeding before the pandemic, as stated by one of the carers:

I was surprised at how much time it took… When I put her into care, I thought that I would have a lot more time, but I actually didn't because I would cook. The food was so bad that I would cook food for her and take it to her… So, the cooking, the shopping of the food, cooking it, taking it, and then at least three times a week I would take her out for a couple of hours, so we go out for lunch, coffee, walk, whatever. All the things that they didn't provide. (Informal carer 11, female, 55 years old, residential setting, New South Wales)

 However, several carers noticed that some places provided better care to people living with dementia than other facilities. For example, one informal carer changed RACFs during the peak of the COVID-19 pandemic to help her with the care for her family member. This carer noted that, in the new facility, they could visit their parent without worrying about washing their clothes or bringing in fresh food.

***Difficulties in reaching services and information***

Rural and remote settings were reported as facing additional challenges in accessing services and information about them as the majority of aged care providers are based in larger cities. Additionally, some people do not have internet access, or their technology literacy is limited, making it difficult to identify information about services or specialised knowledge, as shown by this quotation:

Can’t get information because they’re not on the net. Everything is on the net. You know? Yeah, they can’t even do the Dementia Australia Dementia Training, dementia essentials. Any of those courses because they haven’t got the Internet. (Former informal carer 14, female, 91 years old, New South Wales)

**Theme 2: Aged care system response to COVID-19**

***Changes in formal care provision across home and residential care and individual decisions***

As the pandemic restrictions were implemented across the various states and territories in Australia, it was reported that home and residential care services adjusted their care provision based on the local health advice and regulations in place. As a result, day services, such as respite care, were reported to be cancelled.

However, home care services in most jurisdictions were not cancelled but rather provided in a modified way. Individual providers set their own rules, resulting in different levels of care and services offered across the same region. For example, paid carers from one company were not allowed to take someone living with dementia for a walk outside the house, but this was possible for carers employed through another company. In some cases, the care provision regulations were stricter than the general health advice of local governments. This is illustrated by the following carer referring to home based services during the pandemic:

The Dementia Support Programme only allowed carers to be in the home. They wouldn't allow her to go out, which was quite difficult because she wanted to go out. She couldn't understand why she couldn’t go out. They wouldn’t allow her to go for a walk in the local, outdoor walk, which I was a bit… I mean, they were the rules that have been set in place, but it was a bit frustrating because you know you're allowed. You were allowed to go out and exercise, but they weren't allowed to do that. (Informal carer 9, female, 47 years old, community setting, New South Wales)

On the other hand, many interviewees cancelled home care services themselves as they were afraid of the virus being spread by people coming into their homes.

In the residential settings, informal carers reported decreasing personnel number and limitations in available activities to people living with dementia. Additionally, some of the carers mentioned that these changes could be related to sustaining the financial benefit of RACF rather than protecting their residents. They were also concerned that the lack of visits could contribute to lowered care standards, as the informal carers could not monitor the situation in RACFs and react when something worried them. This is how one of the carers described the management policies of the RACF:

Management shouldn't be as authoritarian as it is. Being able to prohibit people visiting just because they think it would be easier and maybe save money. (Informal carer 1, male, 86 years old, residential setting, New South Wales)

***Importance of aged care service providers communication***

Informal carers and people living with dementia raised the importance of communication and receiving information from community and RACF providers. Many noted that there were problems with timely communication about local lockdowns in RACFs and home service delivery (stopping, restoring, cancellation, modifications), as presented by this quotation:

We received an email from the facility saying they're in complete lockdown, and we were only given a few hours’ notice. (Informal carer 13, female, 50 years old, residential setting, New South Wales)

The poor communication led to confusion, frustration, or lack of control among informal carers. Carers did not have enough time to prepare for the rapidly implemented restrictions in visiting and they were unsure how long they would last. Similarly, restrictions in day care services led to informal carers feeling unsure about how long the service cancellation would last, when the respite care would be available again, or if they would need to qualify again.

***RACF personnel’s vital role in facilitating communication***

The carers highlighted the vital role of RACF personnel in getting in touch with people living in RACFs. They appreciated their engagement in helping people living with dementia stay in touch despite restrictions in visiting by facilitating online videoconferencing. The availability of engaged and supportive staff was crucial in connecting with people living with dementia by providing verbal clues to them, as explained by this example:

While we're on these FaceTime calls and things like that, and these two wonderful therapists’ sort of giving her guidance: ‘That's your daughter’, ‘look here’ and all this kind of stuff. (Informal carer 12, female, 50, residential setting, New South Wales)

Some carers only scheduled the calls when they knew the staff member would be present and could assist their loved ones.

***Challenges in restoring formal care***

 Some RACFs had restored their visiting access at the time of conducting this study. However, each facility had different rules for visitors and specified hours. Some carers expressed being content with the rules, as presented by the informal carer 11:

It's very structured, and it's very much adhering to all the social distancing. I think they've done it very well. Provide access to outside so you can actually take your loved ones outside for a walk in the sunshine. (Informal carer 11, female, 55 years old, residential setting, New South Wales)

Similarly, in some places, the day and home services had been gradually restored during the time of this study. However, in other instances, carers were informed that the restoration of services would take another few months or until the following year creating uncertainty. Several carers also expressed their concerns about people living with dementia progressing during this time and not using those services in the future, as explained by this quotation:

If he then is to go back, he's also got to go to the bottom of the list. In case someone with greater urgency has come up and taken his place in what was an existing programme. And if your family drops down to the bottom of the list, go to the hassle of getting back money that we paid months and months ago. So, it's not a simple, easy process to say: OK, will just pick up where we left off. (Informal Carer 10, female, 71 years old, home setting, Victoria)

**Theme 3: Changes impacting informal carers**

***Increased burden of informal care***

The informal carers reported the increased hours of providing care at home during the implemented restrictions. Additionally, some people reported increased workload due to COVID-19, related to providing informal care to people living with dementia and other responsibilities (i.e., home-learning, working from home, and implementing COVID safe policies in workplaces), as described here:

I had a lot going on… I had two children home-schooling. I was still working, and I was working from home. And, of course, with the COVID, my workload actually increased dramatically because we had to put in place COVID plans. So, quite a lot was happening both at work and at home with Mum and Dad. (Informal carer 9, female, 47 years old, home care setting, New South Wales)

Providing care also impacted several of the informal carers financially. Due to changes and limitations in obtaining formal care due to implemented restrictions, carers were forced to modify their working hours (i.e., take annual and/or unpaid leave) or ask other family members for help in providing informal care. These issues are represented by the following statement:

I have my daughter. I mean that was a cost too because she had to go without work. She's a casual. So, I said to her, ‘I'll pay you’ … It was costly, too. (Informal carer 11, female, 55 years old, residential setting, New South Wales)

***Limited availability of support for informal carers***

The informal carers and other family members did not receive much-needed breaks because of limited services for people living with dementia. At the same time, the available support for informal carers was reduced similarly for formal services for people living with dementia. Some support group meetings were also cancelled, with uncertainty about when they would be reactivated or moved online, as explained here:

They didn't do anything. I had proposed an online forum, but they didn’t follow through…so I don’t know... Nothing’s happened with that. (Informal carer 9, female, 47 years old, home care setting, New South Wales (about lack of online groups))

However, informal carers who could participate in online support groups also faced additional challenges in using these services, such as being in the presence of the person living with dementia. This made them feel restricted in how much they could share during the online meetings. They were also worried about what their care recipient was doing, i.e., in another room while they were occupied with the meeting as explained by one of the participants:

Not too much for him, but for me, the Dementia Australia meetings went to go online. But there is a set time, and the bottom line is that - Is something else happening?... while online, you've got to make certain that the person you're caring for, if they are not actively engaged, what are they actually up to? (Informal Carer 10, female, 71 years old, home setting, New South Wales)

Informal carers mentioned the role of informal Facebook groups for people caring for people living with dementia in supporting each other and providing ongoing advice and support, as explained in more detail by the following statement:

I'm in the Dementia Support Australia Facebook group, and it's a group of 3000 individuals who have a family member with dementia. There are a few people who have early-onset dementia, but it's mostly people who care for a parent. They are from everywhere, and so we all get on there, we enjoy it. (Informal carer 12, female, 53 years old, residential setting, New South Wales)

The pandemic did not impact these groups. Carers were also content about newsletters provided by organisations like Dementia Australia (registered non-profit charity).

***Impact on physical health and well-being of informal carers***

The increased informal care load resulted in emotional and physical health problems. The carers were worried about their family members whom they provided care for, either because of becoming infected with the virus or the consequences of implemented restrictions (i.e., possible cognitive or physical decline because of less stimulating activities). The complex situation of informal carers and their concerns is illustrated by this statement:

I guess the worst was during that stage three lockdown. We didn't know how severe this [coronavirus infection] was, and we knew it was all kind of new for everybody. I limited my contact with him coz I still had children going to school at that point, and I was very worried about my Dad. My Mum, while she's got the dementia, she's physically quite healthy. Whereas my dad has other physical ailments … He would be high risk if he got COVID. (Informal carer 9, female, 47 years old, home care setting, New South Wales)

Additionally, the frustration of people living with dementia due to a lack of understanding of the restrictions and new regulations was exhausting for carers.

 For informal carers whose relatives lived in residential care, the restrictions and inability to visit increased their anxiety and stress levels. They also felt frustrated and emotionally exhausted when they were unable to visit, reach out, or assist their family members to provide company and care. One of the carers summarised her emotional state in such a way:

It was extremely distressing for me, and to be honest with you, I act as an educated woman. You've made me realise I'm stupid because I should have called some kind of a counsellor or someone to speak to from Dementia Australia... I should have even been recommended that by the nursing home, but I wasn't recommended that either. But to be honest, it was extremely distressing for me because I'm very close to him and I was used to seeing him twice a day, and I was very, I was sickeningly worried about him. So, I didn't sleep very much. (Informal carer 13, female, 50 years old, residential setting, New South Wales)

***Role of support network, self-care, and coping strategies***

 Informal carers highlighted the significant role of maintaining their routine and self-care to help them cope with the increased burden and stress due to the implemented restrictions. They also highlighted the support obtained from family and friends, usually delivered by telephone due to the restrictions. However, for some informal carers, the increased level of care and stress impacted their everyday life, changing their daily routine and limiting their ability to take care of themselves (i.e., stopping exercises due to being physically too tired or because of closure of the facilities, such as the swimming pool or gym). For some carers, the additional restrictions limited their ability to access help for themselves, as illustrated by this carer:

I can't get any exercise which I find really hard. I have very bad arthritis. I used to attend the community hydrotherapy pool. I can't do that now, so I'm struggling with that myself. (Informal carer 4, female, 62 years old, home care setting, New South Wales)

As a result, some people used unhealthy coping strategies like drinking alcohol, as explained by this quotation:

There was a period when I was probably drinking a glass of wine every night, which I don't normally do. I don’t drink during the week. I drink socially like we're out and about. And then, probably about a month, I said to my husband that we have got to stop this. (Informal carer 9, female, 47 years old, residential setting, New South Wales)

**Theme 4: Challenges faced by people living with dementia**

***Difficulties in following the implemented restrictions***

The implemented changes and restrictions created several challenges, reported by informal carers and people living with dementia. For example, mandatory masks in some states and territories limited the possibility of seeing visual prompts during conversations and reduced the ability to understand people by those living with dementia. In addition, some of the restrictions, such as limiting the number of people being in the shops, simultaneously made it difficult for people living with dementia to bring a family carer to assist them. Informal carers also reported that people living with dementia struggled to understand and follow the implemented restrictions and rules, as explained by the informal carer 13:

So, every now and then, he asked me why are you wearing a mask? I said that you know I have a virus, but sometimes he wants to touch my face or hold my hand, you know? So, I find that that's been the hardest thing not to be able to kiss or touch him. (Informal carer 13, female, 50 years old, residential setting, New South Wales)

***Facilitating technology use by people living with dementia***

Using technology by people living with dementia varied depending on their technology literacy, cognitive abilities, and motivation to use it. For example, two people with dementia participating in this research actively used technology before the COVID-19 restrictions, and they continued using it throughout the pandemic period. However, they also mentioned that not all people living with dementia are the same, as explained by this participant living with dementia:

I’ve used a lot of technology in my time, and I’m comfortable with technology, so it’s been a lot easier for me than it has been for many. (Person with dementia 2, female, 71 years old, home setting, New South Wales)

The participants also mentioned many difficulties and challenges in using digital technology, including user-friendly websites for people with different needs, and difficulties with following up technology modifications and updates. Informal carers highlighted the need to assist people living with dementia for most technology-based activities due to their cognitive or other health-related challenges, as explained by this statement:

But with hearing difficulties, she [Mum with dementia] doesn't hear clearly and connect the words, you know. So, I've gotta translate everything. You can't do online stuff with her. (Informal carer 4, female, 62 years old, home care setting, New South Wales)

Problems with internet uptake and limited access for some people to receive online support were noted, particularly in rural areas, due to several reasons including geographical barriers and technological literacy. This is summarised by the following statement: “The assumption that most services have is that you have good Internet access to use them.” (Person living with dementia 1, male 66 years old, home setting, New South Wales)

***Ability to commute and visit relatives***

The pandemic restrictions have also impacted travelling and commuting. For example, participants living with dementia reported changes impacting their ability to travel due to the fear of contracting coronavirus. They were no longer able to visit someone, as they used to travel by public transport. Long-distance travel for things like medical appointments was also difficult, as people were reluctant to drive for a few hours when they wanted to avoid using public transport like trains. One of the participants living with dementia provided an illustrative example:

He's living about four hours away, his older brothers, about an hour and a half away, and the ability for them to be able to travel is much more restricted. So physically, being able to see them on a semi-regular basis is much harder. (Person living with dementia 1, male 66 years old, home setting, New South Wales)

Although for some participants moving online was an advantage and reduced problems related to commuting, it also limited using public transport, especially from rural places.

Additional challenges were related to the restricted possibility of travelling to visit their family due to the restrictions imposed by lockdown or border closures (state, territory, and international), as explained by one of the informal carers:

 She can't come to visit me, and that was what she always used to do every few months. Can't fly down to Sydney to visit me …she hasn't been able to come here, and she's quite desperate to see me. To be honest, I would really like to see her, but it'll be another six months, I imagine, so I think she feels quite cut off from lots of things. (Informal carer 5, female, 53 years old, community setting, Victoria)

***Physical, emotional, and cognitive changes in people with dementia***

Carers reported that the changes implemented during the COVID-19 pandemic reduced the physical and social activities of people living with dementia across residential and community settings. The implemented modifications in care provision resulted in changes in daily routine, reduced social connectivity, with consequences visible in changes to their mental and physical health. People living with dementia and their carers reported difficulties in coping with the isolation, as mentioned by one of the participants: “It's very difficult to cope with.” (Person living with dementia 1, male 66 years old, home setting, New South Wales)

Some carers noted changes in people living with dementia’s physical abilities across the few months since the pandemic began (i.e., not being able to walk again). These consequences were reported by carers providing care at home and with limited access to the activities (i.e., day care centres, formal carers were not allowed to take people with dementia for a walk). In residential care, the activities were also reduced, and people living with dementia did not receive as much care/services as before the pandemic, reducing their physical activities. Carers also noticed a decline in the cognitive functioning of people living with dementia after a period of restrictions. These experiences are aptly summarised by the following statement:

We were so ripped off, and you know, my mother spent hours and hours and hours in her room. She lost all her muscle mass because there’s no outdoor access, no exercise. She’s now got a back problem because of the muscle wastage. She’s now got permanent back pain. (Informal carer 11, female, 55 years old, residential setting, New South Wales)

 The important role of visiting people in residential care was highlighted by several carers, who noted some positive changes in their family members after the easing of restrictions enabled them to visit again. One of the carers described it as follows: “Ever since I've been returning to the nursing home every day, he's starting to talk more again.” (Informal carer 13, female, 50 years old, residential setting, New South Wales)

**DISCUSSION**

Our study provides an early insight into the complex impact of the COVID-19 pandemic and associated subsequent restrictions on people living with dementia and their carers’ lives in the context of the Australian aged care system. Specifically, our findings highlight the challenges faced by the system before the pandemic, which were also described in the Royal Commission into Aged Care Quality and Safety report (2021), including difficulties with accessing services, the gaps/barriers in delivering services to people living with dementia and their informal carers, the quality of care received by older people, and need for systemic changes. Further, our study also points out the vital role of unpaid, informal carers in Australia in providing care for people living with dementia across community and residential settings and, ultimately, in supporting the existing formal aged care system.

The already insufficient aged care system within Australia (Royal Commission into Aged Care Quality and Safety, 2021) had to respond to the changing situation and pandemic restrictions (i.e., restricting visits to RACFs, and modifying or stopping home services), and this caused additional burden on the system itself and impacted the people relying on it – older adults, people living with dementia and their informal carers. The RACFs faced an extremely difficult situation trying to prevent the outbreaks and to protect the health and lives of residents. The necessary changes and adjustments were made, but they resulted in consequences for the wellbeing of residents, their families, and personnel. Despite receiving much-needed governmental financial support at the beginning of COVID-19 pandemic (to improve infection control, prioritise personal protective equipment (PPE) access, and introduce some changes to home care) (Low, 2020), the lack of a systemic solution, communication, and readiness for health emergencies like the COVID-19 pandemic increased the care burden of informal care for families and impacted people in various aspects of physical and mental health, and their social and financial situation.

As indicated in our results, informal carers reported higher care responsibilities, even if some home services were still provided. The increased burden of care was quite often caused by additional changes related to the pandemic, such as home-learning and working from home. This increased burden of care was observed internationally in countries like the UK, Canada, and Poland (Giebel et al., 2020; Losada et al., 2021; Maćkowiak et al., 2021), and especially among women (Eurocarers/IRCCS-INRCA, 2021; Power, 2020).

Additionally, informal carers in Australia experienced emotional, social, financial, and health-related implications similar to those in other countries (Liu et al., 2021). As many of the RACFs did not provide sufficient care quality before the pandemic (Royal Commission into Aged Care Quality and Safety, 2021), there was increased anxiety and concern for several carers. Not being able to visit their family member resulted in uncertainty in the quality of care provided during the visiting restrictions, especially when the actions of some management personnel concerned the financial situation instead of the health and wellbeing of residents (Ibrahim et al., 2021). The emotional aspects across family members within all settings, also covered being worried about the safety and health of people living with dementia, contracting the virus, as well as the increased level of distress, anxiety, and depressive symptoms. Such findings were also reported in many other countries worldwide (Suárez-González et al., 2021) and partially relate to reported higher levels of anxiety and depression among older Australians compared to pre-COVID-19 (Strutt et al., 2021). Our findings did not highlight positive aspects of providing informal care for people living with dementia, such as spending more time together, which were reported by carers in other countries and in an Australian study focusing on positive experiences and coping strategies (Maćkowiak et al., 2021; Tulloch et al., 2021). This aspect should be explored in further studies.

The pandemic-related changes have also impacted people living with dementia, restricting them from social and physical activities that are vital for maintaining their health and well-being. This was also confirmed by researchers investigating changes impacting people with young onset dementia living in Australia (Cations et al., 2021) and in other studies around the globe (Giebel, Cannon, Hanna, Butchard, et al., 2021; Hanna et al., 2021; Suárez-González et al., 2021). Moreover, people living with dementia across different care settings faced challenges in understanding and respecting the restrictions, including the need for mask wearing and social distancing. These challenges were also observed elsewhere (Giebel, Hanna, Rajagopal, et al., 2021; Liu et al., 2021). In Australia, these difficulties in understanding the restrictions could be even more confusing for people living with dementia in particular because of the quick implementation of lockdowns and subsequent modified restrictions in response to health advice compared to other places worldwide (Stobart & Duckett, 2021), and the importance of following the routine (Parker, 2016). There is also emerging evidence on the faster cognitive deterioration among people living with dementia over the months of the pandemic and increased isolation (Giebel, Cannon, Hanna, Butchard, et al., 2021; Suárez-González et al., 2021), which was also reported by our study participants.

Despite the limited number of restrictions in 2020 in Australia (compared to most countries worldwide), our participants spoke about being socially isolated due to the restrictions. This encouraged the increased use of technology, across both residential and home care settings, and aligns with the general trend of an increased use of technology and digital communication among older Australians during COVID-19 (Strutt et al., 2021). Despite this, participants noticed several challenges faced by informal carers needing to support people living with dementia to use technology or providing additional care to enable carers to participate in a meeting facilitated by technology. Our study has also highlighted the role and need for communication between service providers and consumers. Providing regular updates in the form of a newsletter and regular telephone calls/text messages providing updates about people living with dementia in RACF could reduce family members concerns about their family, and this was also reported in a UK study (Giebel, Hanna, Cannon, et al., 2021).

**Recommendations**

Our study findings can be used to guide several recommendations to improve the aged care system in Australia during the next phase of moving forward during this pandemic, as well as in preparation for the potential challenges of future pandemics. First, there is the need for improvement in formal care provision to ensure that the needs of people living with dementia and their carers are met across both settings. This should also take account of the additional responsibilities of informal carers (i.e., work or child care related) while making changes in formal care systems. It is necessary to develop good practice recommendations in cooperation with customers and personnel – to promote collaboration between formal and informal care providers. Some of these aspects were already communicated by the Royal Commission into Aged Care Quality and Safety (2021).These two parts of dementia care – formal and informal – are vital for this population and can improve life quality and life satisfaction and enable people to live well with dementia, during and after the COVID-19 pandemic. Second, there is a need to establish guidelines and protocols, as already reported elsewhere (Low et al., 2021), to allow safe visiting in RACFs to maintain the well-being of people living with dementia and their families. Alternatively, some form of digital communication (i.e., iPads or telepresence robots) for residents and families can be organised, ensuring the assistance of engaged staff members (Moyle et al., 2019). Finally, an improvement in communication between care providers and service recipients is needed to avoid the confusion and frustration related to the lack of information about modifications (or cancelling), restoring services, and changes in restrictions. The official government communication should also be clearly delivered in a way that does not cause confusion among people living with dementia and their informal carers.

**Limitations**

Our study has several limitations. First, the sample size was small. Despite our considerable efforts to interview at least five people with dementia, we were unable to recruit more than two people who were available to interview over the telephone or via videoconferencing at the time of conducting the study. Although we planned to describe the Australian experiences of coronavirus restrictions, we could not recruit interviewees from all states and territories, so our intentions in respect of purposive sampling were not entirely realised. Our study did not represent Tasmania, South Australia, or the Northern Territory. Within the recruited sample it was not feasible to analyse differences between the experiences of people representing different states and territories, rural or metropolitan areas or care settings. Second, the primary recruitment tool was online, which limited the recruitment of people who were not active users of the internet. Third, we did not specifically investigate people living with young onset dementia, who can access some form of social care services through the National Disability Insurance Scheme (available for people with disabilities under 65 years old, not just the aged care system packages in Australia). These people experience distinctive impacts in everyday life, therefore they faced different challenges during the pandemic restrictions, as presented elsewhere (Cations et al., 2021). Finally, although the interviews were conducted between July and November 2020, this period was dynamic, and restrictions and measures were changing variously, both within and between states and territories. Participants from different states and territories as well as from different local government areas (i.e., metropolitan vs rural vs remote) faced different restrictions and recommendations and available support varied. During that time, the state of Victoria has implemented restrictions while other states and territories imposed internal border closures, physical distancing rules and service providers adjusted their services based on health advice, especially access to RACFs. The restrictions differed between states, and this was based on time, location, as well as decisions of the responsible organisation (Australian Health Protection Principal Committee, 2020). Further studies are needed into how different states’ responses to COVID-19 in Australia impact people living with dementia and their informal carers.

**CONCLUSIONS**

This is the first known study highlighting the complex impact of the COVID-19 pandemic on the lives of people living with dementia and their informal carers in the context of using social services in Australia. Our findings contribute to the emerging evidence highlighting the importance of good quality social support and the need to sustain it during the pandemic (Giebel, Cannon, Hanna, Butchard, et al., 2021; Maćkowiak et al., 2021; Suárez-González et al., 2021). This study also highlights the need for procedures enabling people to receive social support despite pandemic-related restrictions in order to prevent emotional and physical consequences for people living with dementia and their informal carers.

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**Table 1 Background characteristics of participants**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **N (%)** | **People living with dementia** **(*n* = 2)** | **Carers community** **(*n* = 10)** | **Carers residential care (*n* = 6)** | **All carers** **(*n* = 16)** |
|  **Gender** |
|   | Female  | 1 (50%)  |  8 (80%) | 4 (66.7%) | 12 (75%) |
|   | Male  | 1 (50%)  |  2 (20%) | 2 (33.3%) |  4 (25%) |
| **Relationship with person living with dementia** **(carer, if person with dementia)**  |
|   | Partner/Spouse  | 1 (50%)  |  3 (30%) | 2 (33.3%) | 5 (31.25%) |
|   | Adult child/daughter/son-in-law | 1 (50%)  |  6 (60%) | 3 (50%) | 9 (56.25%) |
|  | Other (former carer)\* | - | 1 (10%) | 1 (16.7%) | 2 (12.5%) |
| **Living with a person with dementia/carer**  |
|   | Yes |  1 (50%) |  6 (60%) |  - | 6 (37.5%) |
|   | No |  1 (50%) |  4 (40%) |  6 (100%) | 10 (62.5%) |
| **Dementia type**  |
|  | AD | - | 1 (10%) | - | 1 (6.25%) |
|  | Mixed | - | 1 (10%) | 2 (33.3%) | 3 (18.75%) |
|  | Vascular | - | - | 1 (16.7%) | 1 (6.25%) |
|  | FTD |  1 (50%) | 2 (20%) | - | 2 (12.5%) |
|  | Unknown |  1 (50%) | 6 (60%) | 3 (50%) | 9 (56.25%) |
| **State in Australia**  |
|   | NSW | 2 (100%)  | 4 (40%)\*\* | 5 (83.3%)\*\*\* | 9 (56.25%) |
|  | QLD | - | 2 (20%) | 1 (16.7%) | 3 (18.75%) |
|  | VIC | - | 3 (30%) | - | 3 (18.75%) |
|  | WA | - | 1 (10%) | - | 1 (6.25%) |
| **Years of education**  |
|  | Over 15 | 2 (100%) | 4 (40%) | 4 (66.7%) | 8 (50%) |
|  | 15 and below | - | 6 (60%) | 2 (33.3%) | 8 (50%) |
| **Age** |
|  | Mean (SD), [Range]  |  68.5 (3.5) [66-71] | 63.4 (12.46)[47-91] | 63 (13.1)[50-85] | 63.25 (12.26) [47-91] |

*Note.* AD – Alzheimer’s disease; FTD – frontotemporal dementia; NSW – New South Wales, QLD - Queensland, VIC- Victoria, WA – Western Australia; \*despite the passing of their immediate relative with dementia, they have been actively supporting other person with dementia/other informal carers within the family/friends; \*\*one carer in rural NSW; \*\*\*one carer providing home care for three weeks during the restrictions while waiting for a new residential aged care facility

**Figure 1. Themes and Subthemes.**

**Supplementary material 1**

**Semi-structured interview questions in Australia**

1. We are interested in your experiences surrounding dementia /health care in general. What types of services\* have you (and/or the person you care for) been accessing since the dementia/medical diagnosis before COVID-19?
2. Are you aware of any services available: what are these, and how did you find out about them?
3. Do you have to pay to access these services, or how are they funded?
4. What are the effects of using these services? How do they make you and the person you care for feel?
5. Since the coronavirus outbreak, day care centres, support groups, and other social care services have been temporarily shut down. How did that make you feel when you first found out? How much does this affect you in your daily life as a carer (person living with dementia/older person)?
6. How do you feel about your relative (and you) having to self-isolate (if late-onset dementia or other chronic conditions and or >70)? In what ways does it affect you, and do you have to adapt the care you provide? What about more generally in terms of isolation and being confined to the home? What might help you (and the person you care for) during the period of isolation?
7. Do you access any digital support to help you care for your relative? Or to obtain support for yourself?
8. Is there anything else you would like to tell us about that which could help us to understand what this experience has been like for you and your relative?

*\*services – understood as any formal social form of support received before the pandemic and ruing, i.e. respite care for carers, formal care at home, day care as well as aspects of residential care.*

1. This person provided care for her parent at home during the COVID-19 strict restrictions for three weeks while waiting for a place in a new RACF. [↑](#footnote-ref-2)