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Entering into a system of care: A qualitative study of carers of older community-dwelling Australians

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Abstract

Informal carers provide the majority of care to older Australians and play an essential role in assisting older people with complex care needs to remain living in their own homes. As such, carers are increasingly faced with systemic responsibilities, including coordinating services across multifaceted health and aged care systems and negotiating treatment and supports. The aim of this study was to explore how systemic complexity and associated work is experienced by carers of older adults and what personal capacities carers draw on in managing the systemic work. A descriptive phenomenological approach guided the research. Semi-structured interviews were conducted with 16 carers of community-dwelling older adults with complex care needs recruited through a local health service. Giorgi's phenomenological data analysis methods (1997) was utilised for the data analysis. Two main themes were derived from the analysis: Becoming part of the caring system, and Mastering the caring system. The findings indicate that the majority of carers perceived the work of interacting with multiple systems and services as a burden and an onerous obligation. Furthermore, change in the health or social circumstances of the older adult amplified differences in the nature of the systemic work and concomitantly, revealed differences in carers' capacities. This paper reveals that the caring system is in some sense disposed to create disparities, as carers' specific capacities were integral to mastering the systemic work. An understanding of informal care work that supports older people to live in the community can assist health care professionals and service providers to better identify carer requirements and assess carer capacity to manage the work.

What is known about this topic

- Older people with complex health and aged care requirements are living longer and rely on support from informal carers to remain at home.
- The work of informal carers is systemic in nature which involves dealing with multiple sectors, institutions and providers to access, manage and coordinate the care and supports.
- The work of supporting an older person is exacerbated by system complexity.

What this paper adds

- Carers of older adults experience the systemic work involved in interacting with multiple providers as onerous and burdensome.
- Carers demonstrate varying capacities to take on systemic work which impacts their ability to master the health and aged care systems.
- An awareness of systemic work and carers capacity to manage this work may usefully inform policy and practice to reduce the burden on informal carers.

Key words

Carers, informal care, caregiving, phenomenology, systemic work, qualitative research

1 INTRODUCTION

Informal carers provide the majority of care to older Australians. Unpaid personal care, support and assistance from family or friends is crucial in assisting older people to remain at home (Parliament of Australia, 2010). It is estimated that by 2050, the global population aged over 80 years will be more than 125 million (World Health Organisation, 2019). Within Australia, government policy and consumer preferences emphasise that community dwelling with support services is appropriate for managing the needs of older people wherever possible (Australian Government, 2012; Cash et al., 2013; Faulkner, 2016). This shift away from institutionalised care, alongside increasing longevity because of advances in medical technology and healthcare provision, means that support from informal carers to remain at home is increasing in importance (Collins & Swartz, 2011; Vreugdenhil, 2014), in terms of both sustainability of the health system (Essue et al., 2010) and cost savings (Deloitte Access Economics, 2015). A 2015 estimation suggests that informal carers provide 1.9 billion hours of care each year, which if substituted for purchased services from formal providers, would equate to a cost of care in excess of \$60.3 billion per annum (Deloitte Access Economics, 2015). Moreover, their contribution is expected to increase with future demographic and social trends, adding to an already reported burden (Deloitte Access Economics, 2015). Understandably, the consequences of ignoring the workload placed on carers are significant for carers, care recipients, and the health and aged care systems.

There is extensive literature that examines both positive and negative aspects of caring. Positive outcomes include being valued, a sense of worth and accomplishment, the fostering of closer relationships, enabling reciprocity, and providing opportunities for personal growth (Kim et al., 2020; Mason & Hodgkin, 2018; Roth et al, 2015; Sarris et al., 2019). However, as the work of informal carers is becoming increasingly complex

and systemic in nature, it is argued that this work creates an additional burden in addition to more extensively examined work of direct care tasks (Funk et al., 2019). Systemic work refers to the system-wide work that arises when seeking to meet the needs of the older person across both health care and aged care systems. It is a consequence of dealing with multiple sectors, institutions and providers in an effort to access, manage and coordinate the care and supports required to address unpredictable and complex needs (Funk et al., 2019). Previous research on carers of older people has shown the prominence of increasing system-related challenges such as navigating systems (Funk et al., 2019; Bookman & Harrington, 2007) and accessing services (Singh et al., 2014; Wiles, 2003). Other challenges include obtaining relevant information pertaining to availability, eligibility and location of services and supports (Ballantyne et al., 2015; Funk et al., 2019), coordinating multiple services (Kuluski et al., 2018, Lopez-Hartman et al., 2016;) and advocacy on behalf of the older person to ensure their needs are met within the system (Bookman & Harrington, 2007; Jeffs et al., 2017; Hainstock et al., 2017). Understanding carers' experiences of complex systemic work is important to ensure they are supported and do not face undue burden.

A shift in policy towards community dwelling and away from institutionalised care means carers are now supporting older adults that require access to both health and aged care systems (Parliament of Australia, 2009). For carers in Australia this can mean dealing with complicated institutional arrangements and demarcation of funding and services, which impedes coordinated provision. The health care system operates through a complex mix of public and private funding with responsibilities divided across federal and state and territory governments, and public and private providers (Duckett & Willcox, 2015). Primary Health Care, which includes General Practitioners, is funded by the Commonwealth Government through Medicare, a universal public insurance scheme

providing free or subsidised treatment (Australian Institute of Health and Welfare, 2016) and although the Commonwealth Government is the major funder of public hospitals, these are managed by the various state and territory governments (Duckett & Willcox, 2015). Community aged care services are funded by the Commonwealth Government, via funding non-government organisations to provide services locally. These arrangements perpetuate the challenges for informal carers when seeking to access and manage supports across health and aged care systems (Parliament of Australia, 2009). The My Aged Care platform, introduced in 2016 by the Australian Government, added further complexity for informal carers (<https://www.health.gov.au/initiatives-and-programs/my-aged-care>). This platform was designed to be the main entry point to the aged care system, enabling older people and their informal networks of support to access information and locate the services they need. However, reviews of the system highlighted areas of concern specifically regarding accessibility for those with complex care needs (Tune, 2017).

Systemic work is arguably challenging for informal carers as needs increase and intensify or change rapidly. This occurs typically because of exacerbation of comorbidities, frailty, functional decline or cognitive impairment, or other sudden deterioration, which directly impact a person's ability to function and maintain independence (Strivens et al., 2015). Consequently, the number of sectors, services and providers involved, and the frequency and duration of contacts can alter rapidly (Araujo de Carvalho et al., 2017; Hudson et al., 2019; Wodchis et al., 2015). For the informal carer, this can add significantly to the work of coordinating appointments, assessments and services, all of which incur time and resources (Funk et al., 2019). Unfortunately, the capacities and abilities of informal carers to navigate and manage these systemic tasks vary. Personal attributes such as resilience, skills such as problem-solving and

organisational skills, physical and cognitive abilities, support networks, financial status, life workload, and the environment are all known influences (Gallacher et al., 2018). As such, systemic work may be perceived as burdensome by some carers but not others depending on personal and external resources.

This paper reports on a qualitative study about lived experiences of the systemic work of caring undertaken by carers of community-dwelling older adults. The aims are to explore 1) how systemic complexity and associated work is experienced by carers of older adults and 2) what personal capacities carers draw on in managing systemic work. In doing so, the intention was to expand the understanding of informal care work that supports older people to live in the community and to highlight how some informal carers might be overwhelmed and better supported.

2 METHOD

2.1 Approach

Systemic work as burden

The approach to the study of carers' experiences in this paper is based on the idea that treatment and support can sometimes be burdensome. This idea was introduced by May et al., (2014) to help understand the experiences of individuals with health care complexities as they manage complex regimes involving health and social support systems. Describing the Burden of Treatment (BoT) Theory, May et al., (2014) argued that the expectation of self-care and the work of managing chronic and complex care had shifted to individual patients and their support networks thereby creating additional burdens of arranging and coordinating multiple services and supports. Treatment burden differs from illness burden because the emphasis is on the workload associated with treatment rather than the burden of the illness or disease itself, and the personal and

structural factors that potentially exacerbate this burden (May et al., 2014). Importantly, this approach focuses on the work generated by the system and considers the capacity of individuals and their networks to deal with those work demands. Although the original concept of BoT and much of the empirical work has focused on the patient perspective, and specifically patients dealing with chronic disease, it is highly relevant to informal carers who increasingly assume systemic work but of which little is known.

2.2 Design and setting

This study employed Giorgi's (1997) descriptive phenomenological approach to understand the essential structures of the experience of systemic work. Descriptive phenomenology was considered the most appropriate methodology of this qualitative enquiry as the aim of this study was to describe and not interpret the experiences of carers. This approach allows for the generation of new knowledge around a particular phenomenon without pre-supposing knowledge of those experiences (Converse, 2012; Usher & Jackson, 2014), is valuable when there is no previous research knowledge (Giorgi, 1997) and is especially suited for clinicians who highly value understanding patient experiences (Usher & Jackson, 2014). The study was conducted in one health service in a regional area of Far North Queensland, Australia. The health service has a high population of those with advancing age. In 2015, 20% of the health service's population were over the age of 60 with a projected growth of 24% by 2026. Compounding this is the high level of chronic disease and socio-economic disadvantage (Queensland Government, 2018). The health service provides geriatric services in acute, sub-acute and primary care settings.

2.3 Sampling and recruitment

A purposive sampling method was used to ensure diversity of experience (Creswell, 2013). This considered diversity across gender, ethnicity, duration of caring role, and relationship to and living arrangements with the older person. Participants were eligible if they were: (a) aged 18 years and over; (b) proficient in English; (c) an unpaid family member or friend providing informal care for a community dwelling older person (≥ 70 years for non-Indigenous and ≥ 50 years for Indigenous older adults) with complex care needs (complex needs were defined as a person whose underlying co-morbidities and individual circumstances had a direct impact on their ability to function and maintain independence on a daily basis (Agency for Clinical Innovation, 2014) and who had recent interactions with both the health care system and aged care system); and if they (d) had capacity to provide informed consent. Clinicians from across three community-based geriatric services within the health service assisted with recruitment. Clinicians from each organisation were asked to identify eligible participants through their routine daily clinical contact and provide them with Participant Information Sheet. Where potential participants were identified, clinicians were asked to gain verbal consent to be contacted by the researcher. All participants who ‘consented to contact’ were contacted by RQ via telephone who provided further information and answered participants’ questions. Carers willing to participate were asked for verbal consent, with written consent completed prior to the interview. No carers who had expressed an interest to participate were excluded. In order to explore diverse caring experiences, it was estimated that a sample of 15-20 participants would be required (Creswell, 2013) The data were analysed sequentially as recruitment occurred and recruitment ceased after 16 participants as it was deemed that further recruitment would not add significantly new information. Demographics of the 16 recruited carers are outlined in Table 1.

2.4 Ethics

Ethics approval was obtained from the Far North Queensland Human Research Ethics Committee (HREC/17/QCH/72-1155) and Griffith University Human Research Ethics Committee (GU:2017/698).

2.5 Data collection

A single face-to-face semi-structured interview was conducted by RQ at a mutually agreed time and place, between November 2017 and September 2018. The interview guide was based on the literature and Burden of Treatment concept and organised in four topic areas: (a) context of caring; (b) interactions with services and providers; (c) navigation and coordination; and (d) resources and capacity. Interviews ranged from 16 to 100 minutes (average 51 minutes) and were audio-recorded. One participant was unable to complete the interview in full, due to the unanticipated needs of the care recipient, and the interview was ceased after 16 minutes.

2.6 Data analysis

Giorgi's (1997), approach involving bracketing assumptions and preconceived beliefs, immersion in the data, and presenting participants experiences as themes was utilised. Bracketing strategies included documenting researcher knowledge and reflexivity in a field journal and discussion during analysis (Patton, 2020; Penner & Clement 2008). Giorgi argues a scientific approach to analysis is required providing a detailed and precise description of the specific experiences from an everyday attitude of others with a minimum number of generalities or abstractions (Giorgi, 1997). His methodology allows for variations within the procedure and the interpretation of each step of the process is neither exclusive nor exhaustive (Giorgi, 1997). Giorgi's method consists of firstly dividing the original descriptions into units; secondly, transforming the units into meanings as expressed by the researcher; and thirdly, combining the

descriptions to form a general description of the experience (Dowling, 2007). Table 2 outlines the analytical procedure utilised in this study.

FINDINGS

The meaning that participants gave to the experience of systematic work are expressed through two themes: *'Becoming part of the caring system'* and *'Mastering the caring system'*. Representative extracts are included to illustrate key findings.

Theme 1: Becoming part of the caring system

The first theme reflects the general experience of most participants who took on the systemic work of caring for an older person. Participants described changes in their social role and talked about expectations placed on them as they became part of a system of care for an older person. The personal characteristics and capacity of carers to make these changes and meet the demands of systemic work are highlighted.

For most participants, the transition from being a caring family member to an informal care provider was a gradual experience as they assumed more supportive tasks for the older person. As this participant reveals, this transition often happened without conscious awareness as she found herself moving from the mother/daughter relationship and into a more defined caring role:

Through a process of gradual creep, as she became less able to do things for herself or advocate for herself or she became a little bit less understanding and a bit more confused, it's just a general creep, that you... don't realise you're a carer until you're halfway in it and then this is the real deal, this is full on (P11).

Participants perceived the work differently. Some participants experienced the role with dread, describing arduous and demanding work: "I'm doing it [the work] and God forgive me, I hope it doesn't last for too much longer" (P10). Others described being motivated

for success, and experienced becoming part of this caring system positively, as a readily accepted challenge that they could cope with such as this participant who reflected that her accrued life skills enabled her to take on those challenges: “I have the skills and capability [to do the work]” (P11).

Differences in the participants’ approach to the work is related to their capacity in some respects. Some participants who set out to rise to the challenge of taking on the work, determined to succeed, reflected a form of stoic resilience. This participant who described his employment in a high pressured job, reflects how this influenced his attitude:

I don’t get into that “poor sorry me” thing, this is what’s happening and just get on and do it, sort it. It’s...you’ve got to be mentally and physically there and capable to keep going and if you start ... feeling sorry for yourself, you’ll end up in a heap (P8).

In contrast, other participants expressed a sense of feeling overwhelmed at times with the systemic work:

It [the work] was very, very difficult and it still is.....you know there are some days when I say to my doctor “I feel like going up to the top of the mountain and screaming my head off” (P6).

A common feature of many experiences was a sense of responsibility and duty. For these participants, the onus of work was seen to be theirs alone, an obligation to manage independently, and as such, they were hesitant to accept help. Relying on the system and depending on formal support was perceived as a weakness by some participants such as this participant whose belief to care for family independently was embedded in her cultural background: “I try not to depend on the system...I certainly don’t like to be a user or depend on anything” (P6). This participant who had achieved attainment in his professional career, described a sense of achievement when successfully doing the work without help:

I haven't had to ask for any extra help ... if I wasn't as capable [of doing the work] I mean there would be all sorts of problems. I can imagine it [caring] would be a nightmare certainly for [other] carers (P2).

Although participants grappled with the immediacy of the older persons' needs, most also talked about planning for the future as the older persons' care needs escalated. However, the unpredictability of future need meant negotiating decisional and financial complexities across health and aged care systems. This work depended on personal capacity to adapt and work through challenges, and as these extracts from two retired professionals indicate, past experiences often helped:

I had quite well-developed research skills to be honest, I mean that came with my previous career, so ... I'm probably not your average Joe Blow in terms of resourcing [supports and services] (P11)

And

My background is that I'm an administrator anyway, mainly obviously on the finance side of it, that's what I'm qualified as, I'm used to having to do [administration work] a bit (P9).

Furthermore, participants perceived that their personal characteristics influenced their ability to tackle systemic work. Advantageous personal characteristics included persistence, flexibility, openness to change, and being able to take on a challenge. This successful businessman reflects:

I don't mind change and I get in there and get things done, and if I don't know how to do it I find out how to do it, that's how I'm made (P5).

Theme 2: Mastering the Caring System

Mastering the caring system encapsulated the learning and experiential work participants face to successfully and masterfully navigate multiple and complex organisational and administrative processes and information across the health and aged care systems, while locating, accessing and coordinating services for the older person. It highlights how participants strived to ensure successful outcomes for themselves and the

older person by manoeuvring within the caring system to make it responsive to their needs.

Participants talked about how they pieced together information to better understand various systems and their functions so they could access the care and support required to address the older person's needs. This often involved understanding components of different and unfamiliar systems and for this carer who had very little previous exposure to the aged care system, was problematic:

I'm trying to think what's going to happen and I'm trying to find out what NDIS [National Disability Insurance Scheme] is going to do, and aged care....what's under their umbrella, what services do they have... Age Care and NDIS are not together. They're two different companies [systems], which I didn't know (P13).

According to participants, mastering the caring system involved making sense of the various organisations and providers that operated within these systems, the scope of services and costs, and how to access what was required:

You try and work out how it [Commonwealth aged care services] would work cost wise, what you might get, when the services are going to be available, who the provider was going to be, and whether it was going to be something that mum wanted or not (P11).

Participants used different resources and had varying capacities for mastering the caring system. Some used personal connections, such as this participants with an extensive family network, to access the information and help they needed: "I've got a nephew and a good friend that works up there [hospital] ... he said, 'I'll send someone around, to help you out'" (P16). Others were able to mobilise 'inside experts' to access systems, such as enlisting the GP, community health staff or hospital staff:

[support worker] put me in touch with [community nurse], and then from there things started happening because [community nurse] just went and did everything for me, got all the forms,... if it wasn't for [community nurse], I'd be still here, scratching my head (P16).

However, not everyone knew where to locate the required information, “I have absolutely no idea where to go, what I’m to do or whom I’m to see with regards to what mum can get” (P3); while for others the process was time consuming, “You just haven’t got time to be wasting hours a day trying to get in touch with someone to get advice” (P8).

Multiple interactions and time-consuming scheduling work typified systemic work that needed to be mastered. Participants described arranging specialist appointments; obtaining tests; arranging and co-ordinating assessments; seeking diagnoses; facilitating appropriate health care; following up referrals, test results and assessment outcomes; managing appointments; liaising with health professionals; and negotiating with service providers to access and co-ordinate support and care services. This could be burdensome, particularly for carers in other paid employment (P14), and equally for those who had reduced personal capacity due to competing work commitments (P6):

If I did have a lunch break or take an extended lunch for another half an hour to speak with [service provider], and going through, say, Mum’s budget and, what we’ve got in place for Mum. Other times would be over the phone or I’d take a day off as well, just to try ... and sit down and go through stuff like that [service provision] with [service provider] (P14).

Last year I would say was one of the worst, worst years of my life because I spent practically all year going to the doctors, going to the hospitals, going to the GPs (P6).

Mastering the caring system included important advocacy work to ensure the most appropriate health care and supports were in place for the older person: “I have to answer the questions [that the GP asks]. He’ll [older person] give a rough sort of idea but he misses things out” (P12). To do this effectively, participants described needing to stay abreast of the older persons’ health conditions and current medications, relaying this to health staff: “I always used to write [medications] down on a list and what the latest was, and I took that up the hospital when she first got admitted and passed that round

everybody that was interested” (P1). Existing knowledge about health conditions and the ways that systems worked was an important resource that made a difference to some participants’ ability to master the caring system. This participant who works within a health setting reflects:

I can understand why other people find it really difficult as well too, if they didn’t have that health sort of background and know maybe where to look as well. It would be very difficult (P14).

This example points to health literacy being a requisite resource if carers are to master systemic work, specifically regarding effectively communicate with, and advocating for the older person as they navigated the caring system.

DISCUSSION

Increasingly, the work of providing informal care for older adults involves interacting with and navigating multiple systems, services and providers. This work is complicated by complex institutional and organisational arrangements and a lack of structure which enables coordination across systems. How carers experience working with multiple care systems and what personal attributes and supports they draw on is important to document, given their capacities to manage will differ. The qualitative study reported here aimed to shed light on these aspects of systemic work undertaken by informal carers in the Australian context.

Changes in the health or social circumstances of the older adult amplified differences in the nature of the systemic work and concomitantly, revealed differences in carers’ capacities. The findings show, not all carers had access to the necessary personal skills, knowledge and supports to proactively manage the intricacies of this systemic work. However, possessing skills and resources to navigate systems, especially knowledge about systems or networks of social and professional support, were key to

coping with systemic work. This finding is consistent with existing evidence that social or relational networks can help with the workload of negotiating systems for improved access to care, through transmission of advice and information about services (Funk et al., 2019; Hainstock et al., 2017; Shim, 2010) and reduce workload (McIntyre et al., 2018; Sav et al., 2016). Participants with prior system knowledge or career related knowledge were able to use this information to their advantage. Singh et al. (2014) found previous experience with the way support services operated provided carers with an advantage for negotiating future services. Wohlgemouth et al. (2015) described how obtaining health system knowledge by working in the health area provided a significant advantage because carers were able to speak the same language as care providers and use professional connections to access expert help.

The findings also suggest that systemic work is disposed to create disparities, primarily because carers' specific capacities and abilities were integral to mastering the caring system. The substantial workload involved in accessing services and dealing with providers was prohibitive for some participants in this study due to lack of personal resources and capacity such as, poor literacy, numeracy and language skills, thereby discouraging them from pursuing services, or hindering or delaying access. This raises some concern about whether or not the systems that are designed to address older people's needs and to support carers in their roles could amplify inequalities for those participants that do not have the capacity or resources to navigate complex systems. Previous studies have also highlighted how system organisation can lead to inequalities in access for older adults and their carers (Funk et al., 2019; Taylor & Quesnel-Vallee, 2017). Participants in this study, who had skills developed from previous life experiences, education, and professional careers seemingly reported some advantage, mostly because these skills gave a level of confidence to challenge barriers in the system and to utilise skills to navigate

the system. For participants who had prior experience of managerial tasks, research, or high-level negotiation, resourcefulness was derived from taking on the challenge themselves, setting out to problem-solve and actively seeking information and knowledge. This reflects existing studies that found system navigation was easier for those with more expertise and confidence (Funk et al., 2019; Wuest, 2000).

System complexity, a feature of the Australian context, further amplified the different capacities demonstrated by participants. Notably, for participants in this study, system complexity was compounded by lack of transparency about how organisations, services and providers across these systems were organised and functioned. This meant that carers needed sophisticated navigation, advocacy, negotiation and communication skills if they were going to master the caring system they had entered. This resonates with other research that describes system-induced or structural barriers to accessing care including: lack of process information, poor service co-ordination, organisational boundaries specifically between health and aged care, and the presence of numerous organisations with differing eligibility criteria and funding arrangements (Bookman & Harrington, 2007; Charles et al., 2017; Funk et al., 2019; Taylor & Quesnel-Vallee, 2017).

Burden of Treatment was used as a conceptual approach in this study to consider the work placed on carers, as a direct result of entering and interacting with the systems that were designed to provide support and assistance. It is the imbalance between workload and capacity to manage that workload that creates the challenges for patients to manage health outcomes (May et al., 2014). The demand placed on carers in this study, challenged their capacity and for those where workload exceeded capacity the burden was overwhelming. This study contributes to the empirical evidence about the nature of systemic work and has helped to develop a conceptual understanding of these experiences as systemic burden.

There are several policy and practice implications that derive from the findings. Over the past decade in Australia, there have been numerous policies and initiatives designed to recognise and support informal carers. The National Carer Strategy implemented in 2011 (Australian Government 2011) set out broader reforms to incorporate recognition, education and training as well as health and well-being of carers. This was followed by the establishment of the Carer Gateway and further carer services and supports through the Integrated Plan for Carer Support Services which developed into a service model in 2015 (Australian Government, 2015). However, despite the widespread reforms and initiatives, gaps in the support provided to carers of older people persist, particularly in relation to the systemic work. The findings indicate that incentivising active steps to reduce the systemic burden on carers created by increased structures and bureaucratic systems would be advantageous.

Seamless funding arrangements are paramount in reducing system complexity. The pooling of funding across sectors to reduce fragmentation of health and social care within an integrated system has been implemented extensively within the UK (Goodwin & Smith, 2011) however is yet to be widely applied within Australia (Mann et al., 2019). Given the diversity of carers' capacities, it is also worthwhile to consider variations of navigation, care co-ordination or case management models to assist with system access and navigation for those who struggle. Nurse Navigation models within Australia, report success in the facilitation of access to information and services but advocate the requirement for connecting with patients early in the healthcare journey (Hudson et al, 2018).

From a practice perspective, provision of a more detailed assessment of carer's capacity to take on the work would be of value. A more comprehensive assessment of carer's capacity including their health, skills, resources, social supports, emotional needs, financial circumstances, competing caring or work obligations, relationship with the care recipient or other family dynamics, are all factors that could impact on their capacity to provide care. Within Australia, a carer assessment is offered through the Carers Gateway (<https://www.carergateway.gov.au>) which facilitates access to services and supports. This is usually in response to the carer initiating a search for services or supports. However, opportunities for additional assessment with a specific focus on the capacity to manage the work, lie with incorporating a carer assessment into the annual Over 75s' health check conducted in general practice (https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare_mbsitem_75andolder) or at touchpoints with interactions with health care systems such as hospital admissions. Strengthening how professionals can effectively acknowledge and build on the capacity and capabilities of carers will go some way to improving the support for carers to take on systemic work.

In this study, the experience of carers was explored at a single time point. The findings highlighted how experience with, and a working knowledge of systems influenced participants capacity to manage the systemic work. As such, further research could examine systemic workload over time and how this fluctuates with changes in carers' capacities. Furthermore, limited data was collected on each participants' socio-economic status, which as highlighted, has the potential to influence capacity and capabilities for systemic work. Exploring the relationship between those demographics and perceived burden is warranted. The study sample was from a very specific regional area of Australia, justifying further investigation of how structural factors such as

geography, race, gender and remoteness feature in the caring experience and the impact these have mastering the system.

CONCLUSION

The findings of this study provide a more nuanced understanding of how informal carers experience systemic work and the potential uneven distribution of burden given various personal capacities and gaps in policy support. This is a particularly grave omission given not only the substantial social and economic contribution of informal carers but more so, the likelihood that the burden will be worn unevenly across carers. In Australia, the work of carers with older adults could be better enabled and fairly sustained by integrating systems more effectively and attending more specifically to the needs and capacities of carers at the point of care. Both structural and practical mechanisms may help relieve the burden of becoming part of the caring system.

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Table 1: Demographics of participants

| Participant | Age | Gender | Living arrangements | Duration of carer role | Relationship to older person | Ethnicity | Employment status | Contextual information |
|-------------|-----|--------|---------------------|------------------------|------------------------------|------------------------|---|--|
| P1 | 70 | F | Co-resident | 6 years | Daughter | Caucasian | Retired, full-time carer | No other caring responsibilities, receives minimal support from wider family network |
| P2 | 76 | M | Co-resident | 4 months | Husband | Caucasian | Retired professional, full-time carer | No other caring responsibilities, no other family |
| P3 | 62 | F | Co-resident | 4 years | Daughter | Torres Strait Islander | Works full-time in a professional role | Extended family/ friends share some of the caring tasks |
| P4 | 89 | M | Co-resident | 5 years | Husband | Caucasian | Retired, full-time carer | Assistance provided by daughter living locally |
| P5 | 56 | M | Live apart | 2 years | Son | Caucasian | Works full-time in a professional role | Has own family commitments, some support from extended family |
| P6 | 57 | F | Co-resident | 3 years | Wife | Asian | Works part-time in a semi-skilled role | Some support from the extended family |
| P7 | 84 | F | Co-resident | 2 years | Wife | Caucasian | Retired professional, full time carer | Assistance provided by daughter living locally |
| P8 | 66 | F | Co-resident | 2 years | Husband | Caucasian | Works part-time in a semi-professional role | No other support locally |

| | | | | | | | | |
|-----|----|---|-------------|----------|----------|------------------------|---|---|
| P9 | 71 | M | Co-resident | 5 years | Husband | Caucasian | Retired professional, full time carer | No other support |
| P10 | 90 | M | Co-resident | 5 years | Husband | Caucasian | Retired, full-time carer | Assistance provided by daughter living locally |
| P11 | 59 | F | Live apart | 6 years | Daughter | Caucasian | Retired professional, part-time carer | Support from own spouse |
| P12 | 79 | F | Co-resident | 9 months | Wife | Caucasian | Retired, Semi-skilled professional, full time carer | Some support from extended family |
| P13 | 43 | F | Co-resident | 3 months | Sister | Torres Strait Islander | Full-time carer | Has other caring responsibilities within the family |
| P14 | 46 | F | Co-resident | 3 years | Daughter | Torres Strait Islander | Full-time employment | Has support from extended family |
| P15 | 48 | F | Co-resident | 2 years | Wife | Asian | Part-time employment | No additional support network |
| P16 | 53 | M | Co-resident | 2 months | Son | Aboriginal | Full-time carer | Limited support from extended family |

Table 2: Summary of the steps for Phenomenological analysis

| Steps of Phenomenological analysis (Giorgi, 1997) | Study Procedure |
|---|--|
| Collection of verbal data | 16 Semi-structured interviews conducted |
| Reading the data | RQ transcribed interviews verbatim and read them several times allowing for deep immersion into the data and providing a sense of the whole. |
| The dividing of the data into parts | Three transcripts were randomly selected and RQ divided the entire text into meaning units. Every stand-alone statement was identified and organised into manageable units. |
| Organisation and expression of raw data into disciplinary language. | <p>Each meaning unit was converted into statements of RQ's own language and reflections made on the meaning of statements through intuiting, describing and analysing each unit of data. This allowed the statements to move from what the participant said to what they meant whilst suspending RQ's own beliefs regarding the phenomenon (phenomenological reduction).</p> <p>MF, DH & CE reviewed the statements and discussions were held to explore the meaning of the statements. From these statements a coding framework was developed by RQ comprising 15 codes. This framework was reviewed and refined by MF, DH & CE. All 16 transcripts were then coded within the framework, by RQ with the assistance of NVivo© software, and rigorously checked by all team members to ensure that no significant statements were missed</p> |
| Expressing the structure of the phenomenon. | <p>Essential structures of the experience of the systemic work and the meaning participants gave to them were expressed in themes. These were developed by searching for connections between codes, looking for repetitions and patterns and crystallising codes into conceptual themes with reference to the study aims. Findings were clarified in discussion between all authors to ensure they reflected the data. These themes provided a description of the lived experiences of carers of older adults with complex care needs in the systematic work of caring.</p> |