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ORIGINAL PAPER

Helping Carers Care: An Exploratory Study of Factors Impacting Informal Family Carers and Their Use of Aged Care Services

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Abstract This exploratory study considered the role of informal carers and their decision-making regarding various aged care services that supposedly support their ageing relatives. Consideration was given to the stressors and overall well-being of informal carers and the support services they did or did not receive during their time of caregiving. A questionnaire was utilised to gain exploratory quantitative and qualitative data plus basic demographic information from informal carers who connected with a single caregiver association based in Victoria, Australia. Several themes emerged from the analysis of data regarding carer well-being, carer decision-making and carer relationships—particularly with respect to the various authorities and organisations ostensibly responsible for supporting carers. While the majority of participants indicated a religious association, nevertheless spiritual considerations were not stress factors paramount in their decision-making or their criticism of carer support services. Other concerns dominated such as the need of having appropriate practical support, better case management, organisational transparency and greater recognition of the role of informal carers. Although this research was isolated to a particular locality, carers in similar situations globally have indicated comparable stresses and challenges further indicating that greater accountability and improved organisation are required for the support of carers internationally. Recommendations are suggested for how service providers can support carers—most importantly, the need for ongoing government assessment and government service improvement in order to help carers care into the future.

Keywords Aged care · Carers · Caregiving · Caregivers · Palliative care

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Introduction

Informal carers—those people caring for others significant to them and who are not professionally employed for that function—regularly make healthcare decisions for a person for whom they have assumed responsibility. According to the Australian Bureau of Statistics (2012), approximately 13.6%[1] of the population in the State of Victoria (Australia) identified as being a 'carer' (ABS 2012). Not-for-profit support agency 'Carers Victoria' (Australia) stated that of this cohort, almost 28.1%[2] (n = 217,800) are operating in a primary caring role (ABS 2012). It can be argued, however, that this number could in fact be much larger as some carers do not always formally indicate that they are actually performing a carer role or engage with services (Schulz and Sherwood 2008). It can also be argued that the contribution of these informal carers reduces pressure on healthcare systems by these voluntary individuals providing their physical labour and resources at no cost to either government, non-profit or commercial organisations (ABS 2012).

Prior research investigating the role of informal carers spans several decades and originates from many countries across the world—all indicating that carers experience stress and difficulty accessing adequate support (e.g. Rani 2012; Ineichen 1998). Tasks involved with being a carer are complex for many reasons; however, various worldwide researches have consistently identified problematic areas, namely personal inexperience, limited resources and a lack of support which fails to specifically address carers' particular needs. The burden the care relationship demands is often reported to leave carers feeling as if they were constantly under pressure and under-resourced (e.g. Alrashed 2016; Penrod et al. 1998; Miller 1997).

To discover the challenges faced by carers and identify what type of support services they perceive as being helpful or futile has previously been considered by Ottmann et al. (2013), who focussed on the notion of consumer-directed care and what this means for carers. Carer's perspectives about consumer-directed care and how clients can become the centre of care planning are beneficial, as this assists in greater improvements for carers. Ottmann et al. (2013) compared USA, UK and New Zealand carers research with the Australian carer perspective, which allows agencies to utilise international data to discern more clearly where and how they can be most useful to carers, and thus help to target existing resources to achieve greater efficiency and effectiveness (Ottmann et al. 2013; Fetherstonhaugh et al. 2013). Indeed, the issue of what levels and types of support to offer is one that continually challenges various organisations that provide support to carers. Internationally, this is reported as a consistent theme, with carers in countries across the world reporting difficulties in accessing services to help alleviate carer burden (e.g. Willemse et al. 2016; Abu Bakar et al. 2014).

As the carer's role can constantly alter, with varying levels and types of support required at different times, consumer-directed care is something that has proven difficult for carers and agencies alike to proactively manage (Bigby et al. 2011; Cantor 1991). Carer stress may also be due to the lack of understanding around the ecological and environmental influences which affect carer and consumer choice in aged care—something which Ottmann et al. (2013) noted needs to be fully investigated. Given the many stresses that carers can experience, it is necessary that further investigation into helping carers

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[1] ABS (2012) Population data for the State of Victoria based on the Census of 2011—total estimate population as of December 2012: 5 million 679,600 (13.6%: n = 773,400/5, 679,600).

[2] Carers Victoria estimate: State of Victoria population fulfilling the role of informal 'primary carer' (n = 217,800/773,400: 28.1%).

strengthen their resources and coping be undertaken—something which will benefit the entire community (Schultz and Schultz 1998). Based on previous research findings and recommendations, it would seem advantageous to specifically identify service usage according to carers, as well as the experiences carers have of those services. Despite the findings of some research in this area, little progress seems to have been made to improve the outcomes of, and appreciation for, the carer. In order to achieve such understanding, this research attempted to explore (a) the challenges that carers face in maintaining their role as informal carers of aged relatives, (b) gain knowledge from their personal experiences of the services utilised and (c) propose realistic and manageable changes for an aged care service provider in response to carer feedback.

Background Literature

In 2012, the State Government of Victoria (Australia) legislated the *Carers Recognition Act* (hereafter '*CRA')*, which formally recognised and acknowledged the role of carers. This specifically outlined the efforts, dedication and contribution in easing stress on the healthcare system that carers contribute, as well as appreciate the social and economic contribution carers make to the community (CRA 2012). The *CRA* defined 'Carers' as '…a person—including a person under the age of 18 years—who provides care to another person with whom he or she is in a care relationship because one of the persons in the relationship, (a) has a disability, or (b) is older, or (c) had a mental illness, or (d) has an ongoing medical condition (including a terminal or chronic illness or dementia, or (e) holds a relationship where an individual has custody and guardianship of a child or youth' (CRA 2012).

While this current study focused upon carers of older people, nevertheless, the demands upon the carer are noted to be considerable irrespective of the age of the care recipient. Schultz and Schultz's (1998) model based upon years of experience working with families who had carer responsibilities is a paradigm that reflects the contemporary understanding of the impact upon carer's health and well-being from a bio-psychosocial–spiritual perspective—a holistic model for understanding the complete carer perspective (refer Fig. 1). Their 'carer well-being model' has become a cornerstone paradigm for carer research, as it indicates a number of key dimensions (i.e. physical, psychological, social, emotional and spiritual) and associated aspects that can affect the carer. This model also helps carers (and researchers) to visualise and consider how numerous aspects can interact with each other, and with outside influences, giving a more complete picture of the potential elements that can cause stress for the carer.

Other literature also supports such a holistic perspective, arguing that any service planning requires the input of the individual, namely (in this case) the carers themselves, to explain their real-world narrative and experience—after all, it can be argued that carers are the real experts in caring (Pearlin et al. 1990). This is evident from the Australian Bureau of Statistics census data (ABS 2012), which indicated that the most common reason of primary carers in Victoria (n = 217,800) for becoming caregivers was a sense of family responsibility (66.8%: n = 145,708/217,800). This, coupled with the next most common reason, 'feeling they could provide better care than anybody else' (49.3%: n = 107,375.4/217,800), indicates the carer and family experience (ABS 2012).

By taking into account the informal carer's 'full story' experience, the stresses of providing quality care from a carer's perspective will hopefully be clearer and potentially

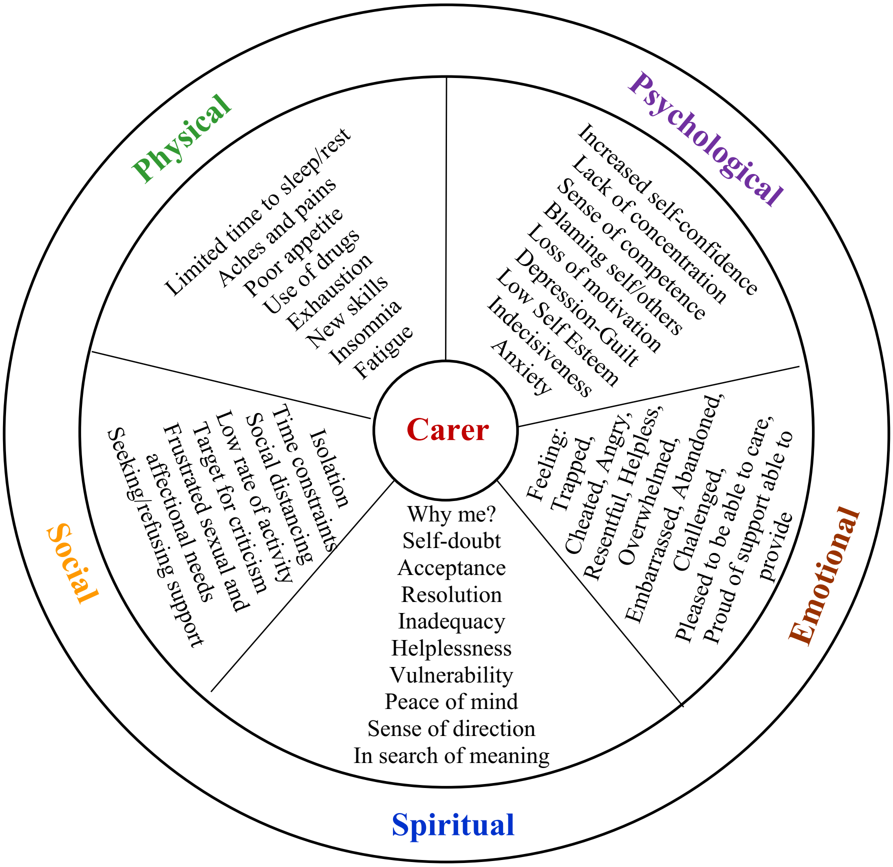

Fig. 1 Carer well-being model—impact of caregiving on the carer (Reproduced with permission from Schultz and Schultz 1998)

identify the strengths and weaknesses of care support structures and thus add to professional knowledge (Nathenson 2012). According to ABS data, another reason that almost one fifth of informal family carers in Victoria became a caregiver was simply because they 'had no choice' (19.7%: $n = 42{,}906.6/217{,}800$; ABS 2012). The notion of 'consumer-directed care' and 'ultimate choice' is often discussed as being key to supporting carers; however, with no consensus within policy or guidance for service providers, these issues are still inconsistent on the front line of caring (Ottmann et al. 2013).

Carer Stress-Related Literature

Table 1 provides an example of the key literature that reports research results based around reported carer stress in their role—primarily indicating that the greatest stress to carers occurred at the time of actual decision-making occurs. Much of this research is qualitative research and aims to understand the carer's position. Overall, in addition to identifying

Table 1 Carer well-being literature relating to stress

References	Origin	Model	Main theme: stress
Abel et al. (2013)	Australia	Patient centred model of care	Promotes social care model, community decision-making
Ducharme et al. (2012)	Canada	Grounded theory, symbolic interactionism	Human action, psychosocial effect Carer stress; placement predictors
Hoefman et al. (2010)	Netherlands	Quantitative test of questionnaire tool validity	Carer well-being, decision-making stress Carer Qol-VAS test (measures carer effects)
Tamiya et al. (2009)	Japan	Stress model, critical theory	Carer stress Decision-making processes
Schulz and Sherwood (2008)	US	Stress-coping models (several references)	Caregiver stress and burden Caregivers as a critical health resource
Boston and Mount (2006)	Canada	Lived experience, focus groups	Carer spirituality (well-being in distress); existential suffering
Kellett (1999)	Australia	Hermeneutic, phenomenology	Burden and stress on carer; identifying coping strategies
Kellett and Mannion (1999)	Australia	Phenomenology	Nursing and family care relationships
Penrod et al. (1998)	US	Grounded theory, thematic analysis	Conflicts within decision-making Institutionalisation as a stress 'last resort'
Pearlin and Aneshensel (1994)	US	Goffman's moral career theory	Stress, episodial versus chronic of the carer Carer burden
Aneshensel et al. (1993)	US	Role captivity, stress-buffering model	Stress caused by decision-making causes caregiving difficulties; in home care versus institutionalisation
Schultz et al. (1993)	Australia	Psychoeducational support model, mixed methodology	Development of a carer model of support to educate and assist, with psychological focus

carer stress, the research also argued that the carer is playing a crucial healthcare role, which helps alleviate the burden on the healthcare system as a whole.

Stress was chosen as a focus in the literature search and analysis due to the overall direct link it has to carer well-being, as well as the necessity of understanding that some stresses in aged care settings occur within a partnership and collaboration between professionals and carers. Carer stress is an issue well documented and supported by researchers such as Kellett (1999), Aneshensel et al. (1993), all of whom identified 'role captivity' and the considerable burden on carers undertaking the carer role as being key sources of stress. Abel et al. (2013), Hoefman et al. (2010), Tamiya et al. (2009), Penrod et al. (1998) and Aneshensel et al. (1993) all attempt to better understand these sources of carer stress, by investigating aspects of carer's lives such as difficulties involved in times of decision-making and the support carers identified as being necessary.

Carer and Family-Related Literature

Table 2 provides examples of carer well-being literature relating to families indicates that decision-making is a critical factor, especially when the carer is a family member—a factor that has been shown to create or reduce stress in the caring role. The social aspect of caring—namely that we support our own family members and then we become burdened by this support—is where many carers struggle and find the role incongruous to their original understanding of the demands involved.

Perception, or perhaps lack of perception meeting reality, is the key aspect of the literature with regard to carer role identity, as well as with support service provision, quality and availability. For many years, family dynamics have proven to be a critical predictor in carer role assumption (Stockwell-Smith et al. 2010; Walker et al. 1991). In identifying support structures of caring relationships that occur in informal settings, the literature which spans several decades depicted an understanding that these varying and complex maps may help to identify areas of difficulty for individuals, and describe how to include the carer within the healthcare system for more positive outcomes (Miller 1997; Minichiello 1987; Rani 2012). This is a continuing theme which is yet to be resolved to reduce carer stress

Aim/Purpose

Two key questions were identified as being relevant to this exploratory study:

Table 2 Examples of the carer well-being literature relating to families

References	Country of origin	Model	Main theme/s: families
Bigby et al. (2011)	Australia	Grounded, dimensional analysis	Decision-making, now and in the future Pathways to care (the pathway to a family member becoming a carer)
Stockwell-Smith et al. (2010)	Australia	Social theory	Role identification of the family member Limiting and motivating factors of respite use
Wylie and Brank (2009)	US	Critical theory, exploratory analysis	Kapp's family preference and Brody's caregiver burden models; motivations to care
Firbank and Johnson-Lafleur (2007)	Canada	Phenomenological, interpretive description	Transition, stages of relocation Family support networks as a source of support and information
Burns et al. (2003)	Australia	Stress-process model	Decision-making; Perceptions of illness by caregivers
Miller (1997)	US	QOL conceptual model	Client inclusion in decision-making Care is personal, so ask the people involved, i.e. the family
Walker et al. (1991)	US	Independence in adulthood model	Perceptions of aid and actual aid Family involvement in care
Cantor (1991)	US	Hierarchical theory, Social care model	Social care is most important Caregiver well-being, informal support
Minichiello (1987)	Australia	Lived experience	Family role in care, decision-making 'Last resort'

- What stresses and challenges do families encounter as informal carers making decisions regarding their elderly relatives?
- Which family members with elderly relatives are active and influential decision-making informal carers?

Further, three sub-questions around service utilisation became critical to establish the helpful and limiting factors affecting informal family carers:

- Are family members (as informal carers of elderly relatives) utilising community resources to address the stresses and challenges encountered?
- If so, what community resources are families aware of and utilising? Why or why not?
- What recommendations can be derived from this research to ‘help carers care’?

Method

A cross-sectional study was implemented primarily collecting exploratory quantitative and qualitative data from informal carers. Both sets of data were gathered via a single questionnaire comprising closed- and open-ended questions designed to illicit information from carers about their role—most specifically in relation to (i) stress factors experienced by carers, (ii) the utilisation or lack of utilisation of community resources, (iii) the types of resources used or not used by carers, (iv) the reasons why community resources are accessed or not utilised, and (v) basic demographic details about the care recipients for whom carers provided care.

The questionnaire also sought to collect participant carer’s demographic details to (vi) determine which family members were influential carers and (vii) various aged care service utility information, with (viii) additional requests relating to key stakeholders and sponsoring organisations. A single anonymous questionnaire was selected primarily to ensure confidentiality and encourage respondents to answer questions honestly and without repercussions which may have affected their situational factors or entitlements. This method was also preferable given time constraints, plus it was possible to access a larger cohort over a considerable geographical area.

Potential participants were identified using a database obtained from Carers Victoria (hereafter CV), a leading carer support organisations in the state of Victoria (Australia) which had as its aim ‘to ensure that caring is a shared responsibility of family, community and government’ (Carers Victoria 2016). The organisation also seeks as one of its primary functions to support carers to improve the quality of their life, while they are caring for loved ones. The CV database identified individuals who were listed as ‘carers’ of an aged person, either in their own home or in the home of the care recipient. Only those carer ‘clients’ who had pre-approved their willingness to participate in research according to CV’s membership conditions and those who were fluent in English were contacted directly by CV to participate in this research. Other participant inclusion criteria required participants to be caring for someone whom could no longer live independently, and for whom they considered themselves the primary carer. The research also specifically targeted carers over the age of 18 (for legal reasons) and limited the participation of care recipients to only those aged over 55 years to ensure this research focussed specifically on the care of Victoria’s ageing population (refer Table 3). There were no restrictions with regard to religious/spiritual association or cultural background.

Table 3 Inclusion/exclusion criteria for selecting research participants

Carer		Care recipient	
Age	> 18 years	Age	> 55 years
Residence	Carers' home or care recipient's home	Residence	Care recipient's home or carer's home
Nationality	Any	Nationality	Any
Language	English	Language	Any
Gender	Any	Gender	Any
Religious affiliation	Any	Religious affiliation	Any
Research consent	Yes	Research consent	Not required[b]
CV registered[a]	Yes	CV registered[a]	Not required[c]

[a] *CV* Carers Victoria

[b,c] Care recipients were not participants in this research—only their carer

Following ethics approval, all questionnaires and participant consent forms were distributed by Carers Victoria to the carer participant's home address and therefore were blinded to the researchers. Each questionnaire had a prepaid self-addressed envelope so that anonymous surveys could be returned directly to the researchers. The scrutiny of data had two steps; quantitative demographic data were entered and analysed using an excel spreadsheet to provide basic descriptive statistics, and then secondly, qualitative responses from short answer questions were transcribed and analysed using open and axial coding techniques (Bryman 2012).

Results

Of the total population of carer's listed by CV ($N = 6000$), 100 participants who matched the criteria were chosen randomly by CV. A total of 44 participants ($n = 44/100$: 44%) completed and returned the survey. In overall terms, the majority of carer respondents (hereafter CR) completing a survey were female ($n = 38/44$: 86.3%), over the age of 45 years ($n = 37/44$: 84.1%), Australian and spoke English ($n = 37/44$: 85%) and were of Catholic faith ($n = 24/44$: 55%). Likewise, in overall terms, the majority of carer recipients whom the carer respondents looked after were also female ($n = 38/44$: 86.3%), over the age of 76 years of age ($n = 37/44$: 84.1%), Australian ($n = 30/44$: 68.1%), spoke English ($n = 29/44$: 65.9%) and were of Catholic faith ($n = 25/44$: 56.8%). Half of the care recipients lived with their carer ($n = 22/44$: 50%) either in their own home or in the home of a family member (refer Table 4).

Predominantly, daughters were overrepresented when it came to the gender and familial position of the carers in this research, with 38 of 44 respondents (86.4%) identifying as the daughter of the care recipient (refer Table 4). When investigating the situational aspects of caring relationships, Fig. 2 indicates the choice carers had in assuming the caring role. Just over half of respondents indicated that they believed they had no choice or minimal choice in becoming a carer ($n = 23/44$: 52.3%; nil choice: 27%; minimal choice: 25%).

Table 4 Carer and care recipient demographic data

Carer	*n*	%	Care recipient	*n*	%
Gender			Gender		
Female	38	86	Female	38	86
Male	5	12	Male	5	12
Not specified	1	2	Not specified	1	2
Age			Age		
18–25	0	–	55	1	2
26–35	1	2	56–65	1	2
36–45	6	14	66–75	5	11
46–55	10	23	76–85	14	32
56–65	17	38	86–95	21	48
66 +	10	23	95 +	2	5
Nationality			Nationality		
Australian	38	86	Australian	30	68
Italian	1	2	Italian	5	12
British	1	2	British	2	5
Croatian	1	2	Croatian	1	2
Maltese	1	2	Maltese	1	2
Not specified	2	6	Malay	1	2
			German	1	2
			Greek	1	2
			Not specified	2	5
Language			Language		
English	37	84	English	29	66
Italian	4	9	Italian	7	16
Maltese	1	2	Maltese	2	5
Not specified	2	5	Hokkien	1	2
			Polish	2	5
			German	1	2
			Greek	1	2
			Not specified	1	2
Religion			Religion		
Catholic	24	55	Catholic	25	57
None	16	36	None	13	29
Protestant	3	7	Protestant	4	9
Other	1	2	Other	2	5
Residence			Residence		
Lives with care recipient	20	45	Lives with carer	20	45
Lives alone	12	27	Lives alone	12	27
Lives in institution	6	14	Lives in institution	6	14
Other arrangement	4	9	Other arrangement	4	9
Lives with a relative	2	5	Lives with relative	2	5

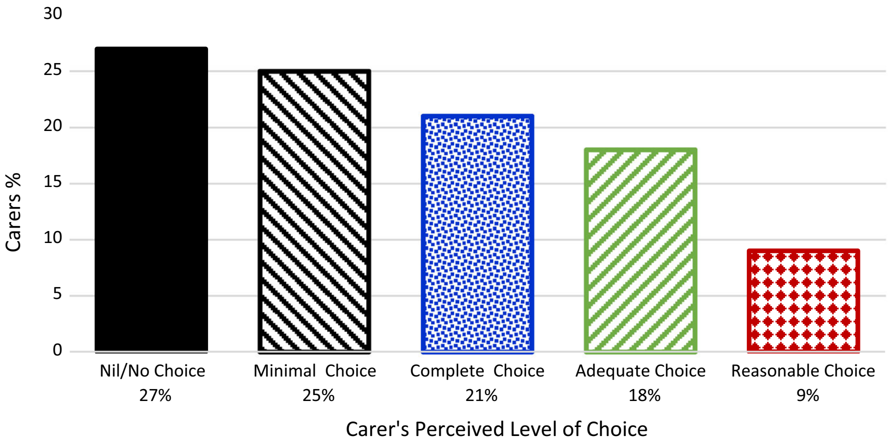

Fig. 2 Carer’s perceived level of choice in undertaking carer role ($n = 44$). *Note*: percentages rounded to the nearest whole number

Approximately 48% (n-21/44: 47.7%) believed they had complete (21%), adequate (18%), or reasonable choice (9%) in taking on this role.

Themes

Collectively, when considering both the quantitative and qualitative data that arose from respondents [R], three key areas in relation to the difficulties experienced by carers were identified:

- Guilt and responsibility
- Personal support structures
- Carer support through services

Guilt and Responsibility

An overwhelming factor that contributed to the stress that carers felt came from their sense of responsibility in *‘taking care of someone who took care of me’* [R15]. Greater than 75% ($n = 34/44$: 77.2%) of respondents indicated an attempt to keep their ageing relative within a familial environment—in either their own home or the home of another family member (refer Table 4: residence). The remaining 22.8% ($n = 10/44$) of carers, who indicated that the care recipient lived in an institution or under some other living arrangement, still indicated (via written answers) the substantial guilt carers felt about making a placement decision for their relatives, and the overwhelming responsibility to maintain as much contact and involvement in decision-making as possible to compensate for their guilt.

Carer issues in succeeding to achieve a positive outcome with service providers generally came about when the professionals involved in providing them did not meet consumer expectations. This left the carer feeling useless and powerless unable to negotiate residential care in whatever setting was desired. Subsequent to an inability in being able to reciprocate care, a number of carers indicated it was ‘too much to bear’ [R46] to be left out of the care relationship. This particular sentiment appeared in almost half of the written survey responses and seemed to be the basis of most decisions to become a carer, instead of choosing institutionalisation, even if circumstances in the carer's life made caring very difficult and added to existing stress: 'I couldn't just leave him to fend for himself' [R1]; 'Because she is my mother and she looked after me my whole life' [R15].

Additionally, there were many accounts of negative feelings indicated by respondents towards nursing homes and respite care; mainly that it was seen as the 'last resort' [R27] or comparative to a 'jail' [R40]. These sentiments may be due to personal experience, or possibly just a combination of hearing other's carer stories, or that high-level care within institutions drew visions of vitamised food and bedridden and bedsore persons. Such stories influence the desire carers have to maintain a family environment for the care recipient rather than the relative being institutionalised. Several respondents noted their concerns around this as a necessary step, rather than as a choice: 'She has Alzheimer's. If I wasn't here, she'd be locked up' [R40], '[I care for her] …to prevent my mother ending her days in an institute treated by strangers as a lesser human being…' [R47]; 'I was not prepared to put her in a home. She would not survive without her family around her' [R19].

Carers often indicated they were completely aware that alternate forms of care might be required at some point in the future and that maintaining their role for an extended period required skills and time they often did not possess. This knowledge of limitations to their caring ability caused emotional stress for a number of carers admitting, 'it has always concerned me… that I was not readily available should a crisis arise' [R30], 'I do not want her to go into aged care permanently, I promised her I would care for her as long as humanely possible. I love her' [R44].

Carers consistently mentioned the time- and energy-consuming roles they undertook. Tasks that participants indicated to perform as part of their carer's role are listed at Table 5. Notably, those tasks which involved the basic human needs of eating and medical care (i.e. shopping and attending medical appointments) were tasks that almost all carers (between 98 and 100%) indicated they undertook. In fact, all tasks listed in the particular

Table 5 Tasks which carers perform within their role

Carer tasks	*n*[a]	%
Regular tasks for the care recipient (e.g. shopping, banking, appointment keeping)	44	100
Driving/transport of the care recipient for any reason	43	98
Attendance at appointments of a medical nature with or for the care recipient	43	98
Recreational, social time with the care receiver	41	93
Correspondence of any kind on the care recipient's behalf	41	93
Regular conversations with the care receiver regarding their care preferences	40	91
Contact with community resources to provide any form of support to both you and the care recipient	38	86
Designated power of attorney for the care recipient	35	80
Daily personal care for the care recipient (e.g. showering, dressing, personal hygiene)	20	45
Other[b]	14	32

[a] Participants were encouraged to indicate more than one response if applicable

[b] 'Other' responses were: 'cleaning, laundry', 'cooking', 'patching up family feuds', 'keeping care recipient in contact with social circles and involved in events', 'social secretary/organiser', 'advocating', 'volunteering', 'reading', 'keeping track of medications'

survey question which produced these results were commonly performed by at least 80% of carers (except for 'daily personal care', 45%; and 'other', 32%; see Table 5). These numerous, demanding responsibilities could be a reason why many carers expressed fears that their own health would deteriorate over time, that the stress of caring exacerbated their present health status and that these factors were not conducive to maintaining good health.

The worry that burdened many carers was their concern about what would happen to the person they cared for if they themselves (as carers) become unwell, or developed a stress-related illness. As noted, for example, by several carers: 'I am the age where my health is declining—I will [have to] leave my caring role for my mother, [I'll] then be elderly myself. It never ends' [R9]; 'I fear for my own health. The toll it will take on me, physically and mentally' [R1]; 'I had my own health scare recently (life-threatening). It was sudden, (so I) needed to think how to leave financial affairs to provide for and protect my ageing mother' [R18].

Personal Support Structures

The carers themselves had many of their own ideas regarding how the support they receive could be improved, and generally, these suggestions seemed to be focused towards the 'little things' that could make a substantial difference. Carers were adamant that it was not about having the role taken away, but to be better informed and able to make the best decisions for their particular situation.

Several suggested that additional support through home visits would help: 'It would be nice if a community person could contact registered carers to visit and discuss new care needs as they arise' [R32]; 'I wish my mum had someone who could visit her once a week, have a chat in Italian and a cup of tea. The companionship would be really good for her… When I come home from work she talks non-stop because she has had no one to speak to all day' [R10]; 'I think it would be good to have a list of psychologists who understand the carer role who would be willing to support people… And bulk bill (the Government for) the consultations' [R18].

Notably, those tasks which were not ones that carers regularly performed (e.g. daily personal care for care recipient; $n = 20/44$: 45.5%) may have been excluded from some carer's role due to the private and personal nature of these tasks, with some carers indicating that professional assistance was required. As well as this, it is important to note that these tasks are often done by only one person: 'As the only unmarried sibling' [R27]; or 'I am the only single child' [R24]; or 'because I'm the girl' [R16]. These reasons for becoming a carer added to the pressure from family members about the expectations of care and how the role should be fulfilled, which certainly seemed to pose an additional strain on the physical, mental and emotional well-being of carers.

When considering participants' explanation about their response to the question, '*How much choice do you feel you had in taking on your role as a carer?'* (Fig. 2), it was clear that the various responses had a common theme. Despite participants answering the question differently, it seemed that no matter the level of control perceived in becoming a carer, the individual could always find a justifiable reason for undertaking the role (e.g. 'No choice in a way. It was something I was always going to do if needed. A pleasure, an honour, a privilege' [R18]; 'Had little choice but I am happy being able to help' [R38]; 'It's expected in our culture to care for your parents when they get old. Because they cared for us kids when we were young, it's expected that we will return the favour' [R51]).

When it came to explaining why these carers had taken on the role, words such as 'duty' and 'responsibility' were prominent in written responses and, therefore, a much clearer picture of carer responsibility was evident. It was also indicative that this sense of responsibility caused pressure for carers in an almost expected way: ‘I know that if the role was reversed, that he would do it for me’ [R25]; ‘Whilst I was unwell, my father passed away and his last request was for me to look after mum. I guess we can look after each other as best we can’ [R32].

Predominantly, females were overrepresented when it came to the gender and familial position of carers, with the majority of respondents identifying as the daughter of the care recipient (86.3%; refer Table 4). What could be considered most interesting though, was that daughters of care recipients seemed to believe that simply being a daughter, or female alone, was reason enough to become primary carer to their elderly parent: ‘As the only unmarried sibling of 6 (I) was able to move back “home”’ [R27]; ‘Being the eldest daughter the role is automatic for me’ [R8]; ‘I have more time than my brother, I am the eldest (so) I took it on’ [R34]. For some however, it appeared that this role assumption took on a feel of martyrdom at times; ‘[I am] … feeling alone and know that family members just wish my dad would get on with dying’ [R20]; or ‘there is no other family—cousins/sister/brother/wife to look after him, it was me or no one’ [R1].

Along with being a daughter, these carers also found other reasons to take on and maintain the caring role—none of which seemed to relate directly to the individual’s ability or resources to care: ‘My role as a carer was a natural progression as a wife and daughter’ [R35]; ‘Duty—culturally. (We are) of British descent so only ‘rejects’ go into nursing homes. Traditionally, elderly parents are looked after by the family’ [R2]; ‘In a close-knit Italian family it’s the done thing—there was no choice, it was my obligation to my mother’ [R10]. It is important to note at this point that none of these reasons for becoming a carer are ‘right’ or ‘wrong’, as these are individual choices and the outcome of a particular situation in which the families find themselves. They do so either by themselves or due to the unavailability of another—and therefore should not be judged by anyone for this decision.

‘Love’ was also a very telling factor in someone’s decision to become a carer. It was clear that when responses included the word love, it encouraged participants to reflect more deeply on why they were fulfilling this role in the first place, despite its challenges to both the individual and the familial relationships: ‘I love them, they are my family. I felt it was the right thing to do and have never regretted my choice/decision I made 11 years ago’ [R35]; ‘Because she is my mum and I love her… (I have) satisfaction that I am a caring person’ [R9]; ‘Return of love that has/was given to me (karma)’ [R26]. Although it could be argued that loving someone should not overtake practicality, nevertheless love was definitely an important reason as to why the first choice for many people was to keep their family close and become carers themselves.

Carer Support Through Services

Throughout the survey, questions were based around three key objectives: to find out if carers utilised formal and informal support, to find out which formal services were utilised, and finally to discover how useful this formal support was to them. Tables 6, 7, and 8 present results around these objectives separately, but all seemed to have definite themes which crossed over when coupled with comments made by participants.

Firstly, as indicated in Table 6, carers (and most likely the care recipients as well) maintain preferences to keep things ‘in house’, with most participants (n = 31/44: 70%) indicating they would turn to other family members for support before formal sources were investigated. Following this, referrals or information from professionals (e.g. G.P.’s) were

Table 6 Sources of support identified by carers

Sources of carer support	n[a]	%
Other family members	31	70
Formal care resources (professionally obtained contacts only)	25	57
Friends (of carer)	14	32
Community members (either gained through formal pathways—i.e. hospital)	11	25
Community members (either gained through formal pathways—i.e. church)	7	16
Friends (of the care recipient)	7	16
Other[b]	3	7

[a] Participants were encouraged to indicate more than one response if applicable

[b] 'Other' responses were: 'nursing home staff', 'retirement home owners', 'case manager', 'cleaner', 'podiatrist', 'nurses', 'nursing educators', 'general practitioner', 'police registrar', 'Mepacs alarms', 'Mecwacare', 'DoCare', 'Department of Veteran Affairs (DVA)', 'Eastern Access Community Health (EACH) home care packages', 'Doncare Community Services (Victoria, Australia) specialists', 'social worker', 'Legacy', 'respite centres', 'personal care assistants'

Table 7 Service use identified by carers

Formal services being utilised	n[b]	%
Carers Victoria[a]	38	86
Local council services	33	75
Government financial assistance (e.g. Centrelink)	30	68
Respite services	25	57
Community groups (for either yourself or the care recipient)	9	20
Other[c]	8	18
Religious/spiritual organisations	8	18

[a] Carer's Victoria rated highly as an identified support services as participants were registered with CV

[b] Participants were encouraged to indicate more than one response if applicable

[c] Other responses were: 'Royal District Nursing Service', 'Department of Veteran Affairs', 'Northern Hospital', 'Catholic Women's Group, care package', 'private physio/masseuse', 'Eastern Access Community Health (EACH)', 'Alzheimer's Australia', 'day respite centres', 'DO Care', 'Sandy Beach Music Respite', 'Villa Maria'

required for carers to seek out other forms of support. Although it was common for carers to follow this pathway ($n = 25/44$: 56.8%), it seems that generally, carers were not actively seeking further support from the community independently. As a result, this limited their information to what the G.P. knew or possibly wanted to tell carers.

When carers did utilise formal support, government ($n = 30/44$: 68.1%) and local council services ($n = 33/44$: 75%) rated highly in carer preference (shown in Table 7). However, when qualitative analysis of the participant comments with regard to their experiences of these services was conducted, the continuing frustrations carers felt became obvious. Some services were spoken about with positive regard, 'Services are certainly very appropriate and useful, otherwise I would be so stressed out and unable to perform my

Table 8 Experiences of services used by carers

Service use experience	*n*[a]	%
Attempted to use a service but it wasn't easy to access	22	50
Felt like my caring role was valued and I appreciated having some extra help	18	41
Tried a service and it did not meet our needs well enough to continue use	14	32
Did not feel like we were/are desperate or worthy enough to use services	7	16
Found a service was helpful, but felt left out of the care partnership	6	14
Other[b]	2	5

[a] Participants were encouraged to indicate more than one response if applicable

[b] Other responses were: 'not enough planning', 'individual planning required', 'requests got lost in bureaucracy', 'care recipient refused services', 'government agencies had too much red tape', 'requires the removal of the middle man', 'not enough places', 'no specialist training for staff', 'eligibility issues'

role as a primary carer with effectiveness' [R23], and many people were grateful for the little things; 'very useful—day respite (3 days) is a huge help' [R14]; 'I have a back problem and therefore really appreciate the cleaning, wish it was more often' [R24]; 'having someone come and cut mum's toenails' [R26]; 'Home care—council cleans to house for her (which) at least eliminates me (having to) look after two houses' [R6].

Nevertheless, it appeared that most of the difficulty reported in service access came from the unmet expectations carers had of the systems they believed were designed to support older people, possibly from the rising profile of carer issues in the media, etc.. One particular carer indicated this frustration by saying:

> "Our local medical centre I would have hoped could be of more assistance. I once enquired about the Veteran's CVC program and was told I could look for another centre that provided that. Community Health… offered respite, but when we rejected it they would not help any more. That was it" [R44].

Predominantly though, carers did not speak in a positive way about the services: 'Council services were ad hoc and hard to access. Workers are disinterested in caring for the frail elderly. They do not appear to want to include the carer much' [R9]; 'My dad's support services always say that we are over budget… so it's always hard to get extra respite which I do for my own sanity. It's really hard' [R42].

Although it seemed that overall, carers had a solid grasp of what they were entitled to and what services were available for them to access, this pattern of unmet expectations repeated itself. Usually, this occurred with regard to issues of services not being useful or being difficult to access, compounded by the fact that care recipients in particular were not confidant in utilising them. This is indicative of the multiple impact this can have on any carer, especially when considering Schultz and Schultz's model mentioned previously (see Fig. 1), which highlights an understanding of how one issue or barrier to effective caring is interlinked with other complications and can create added pressure and difficulty to the carer role.

Several respondents indicated a variety of frustrations with regard to a particular barrier becoming problematic: '… they [local government] just send [elderly people] a whole lot of brochures and I have to sort through them myself' [R1]; 'Mum feels she cannot manage, going to the cinema or lunches as toileting is a major holdup—even though the carer's do not mind, mum hates being a nuisance' [R44]; '[Services were] not tailored to specific needs, I had to organise another assessment (as the) Commonwealth one done a month ago isn't enough' [R21]. Therefore, it was not surprising that a significant number of participants indicated a preference for family and internal knowledge to support and manage care instead.

Helping and Limiting Factors The experiences carers had when they did utilise services are depicted in Table 8. Half of all participants (n = 22/44: 50%) reported having had a negative service use experience, which may influence their uptake of, or any future attempts to gain support. Reinforcing this is that only 40.9% (n = 18/44) of participants felt supported by the service they used.

One factor that did support carer's positive service experience, however, was the availability of individually tailored services, particularly those (e.g. Alzheimer's Australia) which catered to specific illnesses or conditions that care recipient suffered. A number of respondents' comments affirmed such specialist organisations and described their skill in providing support: 'RDNS (Royal District Nursing Service) call weekly and provide reassurance that I am doing my best' [R20]; 'Alzheimer's Australia and the aged care advisor (are) subject matter experts' [R37]; 'The EACH (Eastern Access Community Health) program provides a Care Manager who is extremely helpful and provides support to me' [R35].

It is clear from the results that providing some situational management skills allowed the carer to feel in better control and was beneficial to their well-being: 'Mentally, Carer's Victoria have helped me immensely… when it was tough with mum at least I was shown how to not see things [to be] so overwhelming' [R36]. Another respondent also positively affirmed the specific care provided by non-government organisations:

> "Support groups … via Carers Vic [were] useful for cutting down isolation and [providing] spiritual support … 'Family Care Sisters' [Missionaries of Sacred Heart]… offered respite weeks for women up to age 70 years to assist with nourishment and/or focus weeks. This helps a lot" [R17].

The majority of respondents who reported difficulties concerned government organisations, particularly those providing monetary support to carers. It seemed to make the process of caring for loved ones at home an administrative nightmare—yet ironically the provision of home care by families has notably been an effective method for governments in terms of budgetary savings. Still, carers found that many tasks that should be simple are complicated by governmental ineptness: 'Centrelink people are really nice… but applications still require a lot of effort' [R18]; 'Trying to access financial support or find out what's available… [Federal Government] Centrelink had so much red tape and it was difficult to navigate their system' [R17].

Along with monetary support being difficult to access, carers also consistently described the lack of empathy they received from others, both in a personal sense and throughout the wider community with respect to the importance of the role carers contribute to the healthcare system. Several participants made suggestions as to how this could be rectified: 'Maybe some understanding regarding the time constraints and difficulties (of caring)' [R35]; 'More awareness from a government policy level to support carers in the workplace, community education (and) improve the long wait lists for help following aged care assessment' [R21].

Discussion

The primary aims and focus of this exploratory research were to consider the stresses and challenges encountered by informal carers, plus discern which family members were the most active and influential carers, and finally what community resources were carers actually using, and if not, why not?

Carers: Stresses and Challenges

In overall terms, this research confirmed that, similar to the carer well-being model of Schultz and Schultz (1998; refer Fig. 1), the carer role continues to be substantially challenging, which has considerable impact upon the carer, and that, generally, while carers have the best intentions when taking on the carer role, they were often ill-equipped and under-resourced. The results derived from this research raise a critical question, *'Why do the issues and stresses that carers experience, remain such an overwhelming burden to carers— particularly given the literature and research which confirms that informal carers are of considerable importance to society?'*

With government legislation and funding progressively being scrutinised within the health sector, plus the increasing numbers of people functioning in the informal carer role, another question arises; '*How can seemingly menial issues impacting the effectiveness of carers be such difficult tasks to resolve in the 21st Century?'* A factor which seems necessary to address such issues is that carers should have control to choose what they want and need, and determine how they want to manage the care of their loved one, with the complete support of professionals, who can provide advice (Bauer and Nay 2003; Pearlin and Aneshensel 1994). The opposite, which seems increasingly common in many healthcare settings, is that various professionals tend to 'dominate the process, not only excluding family members, but also failing to canvas ways of eliciting preferences (of the individual)' (Bigby et al. 2011).

When this occurs, the stresses that already exist for carers in their day-to-day existence are amplified, and the respect they should and need to have is diminished as any support is burdened with an overwhelming amount of administrative 'red tape'. Ottmann et al. (2013) suggest that if policy in any country aims to include the 'consumer' component of 'consumer-directed care', then 'a broad range of personalised options that allow service users to undertake the level of control and administrative responsibilities they feel comfortable with' needs to be a strategic priority (p. 579).

Carers: Active and Influential

Another aim of this research was to identify which family members with elderly relatives were active and influential informal carers. The results of this research indicated that the family members most active and therefore influential carers were usually daughters. The fact that women represented a large component of the cohort of informal carers is substantiated by other research, and interestingly, factors such as cultural diversity or geographical location do not seem to influence the prominence of females as carers (Walker et al. 1991). This is perhaps summed up perfectly by one participant who said, 'my role as a carer was a natural progression as a wife and daughter' [R20].

One consideration potentially being influential in carer decision-making is the possible link between traditional role expectations of being a carer and religious/spiritual beliefs.

Yet, even though the majority of participants involved in this study indicated a religious preference (as did the care recipients; refer Table 4), none of the carers specifically suggested that religious/spiritual factors were influential in their active caring. It seems likely, however (given the importance of spirituality to many elderly), that religious values and/or spiritual carers (e.g. clergy/chaplains) may have been integrally influential during carer decision-making (Doyle and Capon 2016; MacKinley 2012; Carey and Cohen 2009; Schultz and Schultz 1998). This assumption seems logical given that the majority of both carers and care recipients had identified as being either Catholic or Protestant (refer Table 4; total = 62%) and nearly a fifth of carers (18%) utilised religious/spiritual care organisations (refer Table 7). Thus, in general terms, the majority of carers and carer recipients may have been receiving or had adequate access to spiritual support in some way if needed—and thus not a high stress factor. Several respondents also positively affirmed the practical contribution provided by religious groups (e.g. Family Care Sisters, Villa Maria).

Irrespective of religious/spiritual factors, and as mentioned previously, the caring nature that many carers inherently possess can itself cause stress—something which was consistently noted by carers when their ability to make critical healthcare decisions were affected given their lack of knowledge and experience. These decisions were often required to be made at the very occurrence of an ill-health event, where it is assumed that stress levels were at their highest (Bigby et al. 2011; Wylie and Brank 2009; Walker et al. 1991). Bigby et al. go on to suggest that a major cause of this lack of knowledge falls on the shoulders of the health professionals and support organisations, who fail to provide families the relevant information and resources about the services available, which might make their decisions at the very least more informed, but fundamentally lead to lower levels of carer stress (Bigby et al. 2011).

Carers: Utilising Resources and Services

A final aim of this research was to consider whether informal carers of elderly relatives were actually utilising community resources to address the stresses and challenges that they as carers encountered. Subsequent to this, it was considered important to learn which community resources that carers were aware about and whether these were, or were not, being utilised and the reasons associated with this utilisation or lack of utilisation of resources/services. The results clearly indicated that carers use services that are available, but this does not directly have an impact on reducing stress in the caring role.

The results seems to suggest that many carers do not seem to necessarily mind that they have taken on a caring role, but they do not particularly want to perform this role single-handedly nor silently. This supports previous research by Wylie and Brank (2009) which indicated that it is a sense of 'personal autonomy' which an individual requires most in a caring role, and to be able to utilise services, as these are required, and do so without interference and direction from others (p. 920). If there is an interruption to services, this research suggests that carers would more than likely, turn their focus inward, looking towards family to compensate (if in fact this is an option for them, which is not always the case). This has the potential to begin a process of carers isolating themselves from the community, which in turn can have an adverse effect on the health and well-being of both carer and care recipient.

Table 9 Recommendations for service providers supporting carers

Theme	Recommendations
Guilt and responsibility	More information about nursing homes should be made available to the public to improve carer/family education and reduce anxiety Specialised training for staff is required, especially with regard to specific illnesses
Personal support structures	Knowledge/listing of care options is required—short, long term and for emergencies Practical informational and organisational skills for arranging finances, power of attorney, etc.—contact lists and support functions
Recognition and transparency	Official recognition/status needs to be provided by governing bodies for individuals who are carers Assessments of care recipients to occur with transparency and to be relevant to all services
Responsibility sharing and negotiation	Increased monetary support is needed for carers to work less or have more flexible employment arrangements Case managers in conjunction with families/carers to prepare/make alternate care plans if circumstances change
Carer thoughts about services	Clear and concise lists of services need to be available, with identified pathways for easy access Tailored, gender-based assistance is warranted where role identity is encouraged and confirmed
Helping/limiting factors	Easy access to basic assistance is required—cleaning, housekeeping—even if at a subsidised cost Healthcare professionals need to ensure that even if service uptake was not completed, the experience of attempting to do so is made positive for the carer and care recipient

Limitations

In relative terms, the sample size of this research involved only one carer organisation, therefore limiting the ability of the results to be generalised to carers associated with other organisations, or a broader population. Another limitations of this study was Carers Victoria possibly attracted a certain demographic of carer due to several factors such as language skills, willingness to accept support, religious affiliation and possibly only those carers who tended to be proactive. In addition, this research was primarily a cross-sectional study—a longitudinal study would have produced a wider range of results and is recommended for further research—particularly research which is inclusive of religious/spiritual factors, and hopefully a study that is deliberately multifaith (e.g. inclusive of Jewish, Islamic, Buddhist carers) so as to ensure culturally appropriate and holistically meaningful aged care services.

Even given the limitations of this research, the results of this exploratory study will hopefully contribute to redirecting and reshaping future service planning for carers, which in turn should help to 'facilitate participation and empowerment by increasing communication, bringing the key stake-holders together to negotiate and develop mutual understanding and consensus… (that may) assist in developing a genuine partnership between professional and informal carers, thereby improving structures that provide advice and support for carers' (Stockwell-Smith et al. 2010, p. 2063).

Conclusion and Recommendations

From this exploratory research, there was sufficient evidence to elicit recommendations and realistic manageable changes for any aged care service provider to consider. Six recommendations are made regarding (i) carer guilt and responsibility, (ii) personal support structures, (iii) recognition and transparency, (iv) responsibility sharing and negotiation, (v) carer thoughts about services (or lack of services) and (vi) various helping and/or limiting factors affecting carers (see Table 9). These recommendations relate to a necessity for agencies to be specific about the care services they offer and seek to provide the seemingly 'little things' which can have a substantial capacity for easing carer stress (see Table 9).

The core issue at stake arising from this research is whether aged care services, which are currently being provided, are of sufficient utility and accessibility to the very people who need these services the most, namely the carers. It seems superfluous to have services offered and available that fundamentally are not meeting the needs of carers and subsequently the aged. Services to support family carers may look impressive on paper and sound extraordinary when advertised or accolated by governments and their associated community organisations, but, in fact, maybe failing to provide real coverage where it is needed the most.

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Compliance with Ethical Standards

Conflict of interest The authors declare they have no conflict of interest.

Ethical Approval All applicable national and institutional guidelines for the care of humans were followed during this research in compliance with Australian 'National statement on ethical conduct in human research' (NHMRC, 2007), and thus, accordingly informed consent was obtained from all participants.

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