



**For love
for faith
for duty
for deed**

*beliefs and values about caring in the
Anglo-Celtic, Greek, Italian, Polish, Turkish
and Vietnamese communities in Victoria*

A report prepared for
CARERS VICTORIA
by Rebecca Cole and
Tonina Gucciardo-Masci

2003

Acknowledgements

This research was made possible by a grant from the Department of Human Services through the Home and Community Care funding round of 2001-2002. The authors would like to thank Carers Victoria for the opportunity to work on this project. We are grateful to all staff at Carers Victoria and Carer Links West for their support of, and interest in, this project. We particularly thank Maria Bohan, Nilgun Yucel and Joyce Rebeiro for their unending enthusiasm, commitment to the project and practical and moral support. We would also like to specifically thank other Carers Victoria staff, Trish Waters, Marg Carty, Chris Porter and Helen Franks, for their administrative support, research assistance and assistance with briefing researchers. Thanks also to Peter Cruttenden for editing and proof reading. We also thank the reference group members for their input, guidance, positive feedback and suggestions (see Appendix A for member details). The research would have been impossible without the linguistic abilities, cultural awareness, research skills and tenacity of our fellow researchers, Merih Cherkez (Turkish), Eva Hussain (Polish), Betty Kafanelis (Greek) and Kim Nguyen (Vietnamese).

Finally, and most importantly, we would like to thank the carers who participated in this research project. While we cannot name them for confidentiality reasons, we were truly touched by the extent to which they were prepared to share with us and the other researchers the details of their lives and their experience of providing care to their elderly family members. We hope that the best thanks they are given is for service providers and policy makers to gain a greater understanding of the values and beliefs informing carers' approach to family caregiving. Such understanding will inform the continued development of culturally appropriate services to support carers in their roles.

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First published in 2003 by
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ISBN: 0 9750037 7 1

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Executive Summary

Introduction

This report presents the findings from a study conducted by Carers Victoria (CVic) into the beliefs and values of carers from six ethnic groups residing in Melbourne. This six-month research project was made possible by a grant from the Department of Human Services through the Home and Community Care funding round of 2001-2002. The project arose out of a consultation with carers in 1999 jointly conducted by *Carers Victoria* and the Carer Respite Centre Southern Region. The research was limited to carers of the aged in the first instance, with the intention of follow-up research in the areas of disability and mental health at a later stage.

The primary purpose of the research was to collect qualitative data to assist service providers and policy makers in their efforts to encourage carers to access support services and maintain their own health and wellbeing. Specifically the research aimed to:

- enable CVic to facilitate better understanding of care issues in ethnic communities;
- be incorporated into CVic's education program for service providers and carers;
- be a resource to relevant services for carers in Victoria and nationally in the provision of support services for CALD carers;
- inform policy development on carer issues.

Research Themes

This research was based on the premises that:

- beliefs and values directly impact on the way that carers do or do not seek assistance for themselves
- culture (including for example ethnicity, birthplace, language, religion) is a key determinant in the development of beliefs and values
- migration and settlement experience has an impact on beliefs and values

The research sought to explore the following main themes among carers:

- experience of providing care
- values and expectations about caring
- attitudes to self-care
- attitudes to support networks and services

Methodology

Qualitative data gathering methods were chosen for conducting this research. It was recognised that values and beliefs are often deeply held and are not always easy for respondents to identify or disclose. As such, a discursive method of information collection was deemed most suitable to meet the projects' objectives. A mixture of individual interviews and focus groups was used to allow for in-depth information collection and the inclusion of respondents who would not be comfortable about sharing their experiences of caregiving in a group setting. The focus group discussion also allowed the opportunity to test findings from the individual interviews.

Bi-lingual/bi-cultural co-researchers were employed to recruit respondents and conduct the interviews and focus group discussions. A Reference Group was established to provide advice and support to the project.

Target Groups

The project targeted carers from the Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese communities in Australia. These groups were chosen for the following reasons:

- resources allowed for the inclusion of six target groups, with one focus group discussion and eight individual interviews per group
- the Anglo-Celtic group should be included so that 'mainstream' beliefs and values also be recognised as being culturally driven
- the target groups should reflect significantly ageing/aged ethnic communities
- the target groups should represent various lengths of settlement in Australia
- various settlement experiences, including migration and refugee experiences, should be included
- a variety of religious influences should be included

Respondents

A total of 91 respondents were involved in the research. As this study focussed on aged care, all respondents were caring for a care recipient over the age of 65. All respondents were also:

- current carers
- caring on a full-time basis (self assessed)
- from one of the targeted ethnic groups
- a first generation migrant caring for another first generation migrant from the same cultural background (with the exception of Anglo-Celtic carers and care recipients who did not need to be first generation migrants)
- not currently using carer support services to any great extent (this criteria did not apply to focus group discussion participants)

Key Findings

The following were the main findings to emerge from this study:

- As anticipated by the study's original hypothesis, beliefs and values had a direct bearing on:
 - the way carers perceived and carried out their roles
 - what carers were prepared to tolerate and take responsibility for
 - the priority that carers placed on self care, and
 - the point at which, if at all, carers sought professional support services
- Carers across all the ethnic groups targeted in this study were cognisant of family and community expectations regarding their role and were influenced by these to more or lesser degrees
- A number of universal notions and issues emerged as affecting carers across all ethnic backgrounds. These included:
 - the view that care is predominantly a family-based responsibility
 - the fact that caring has both emotional and physical impacts on carers, as well as impacts on their relationships and their lifestyles

- the fact that all carers seek to fulfil their care responsibilities to the best of their abilities, within the mental and physical resources available to them, for as long as they deem it possible for them to do so
- the fact that carers define themselves primarily by their filial relationships within the family (eg as 'wife', 'son', or 'daughter') and not as 'carers'.
- Despite there being a number of similarities in the beliefs and values of respondents from the same ethnic group, there were also many differences between them based on the nature of their:
 - personal attributes
 - individual and family circumstances, and
 - past and present relationship with their care-recipient
- Carers across all the target groups viewed their caring role in terms of fulfilling a 'duty', however this concept held different nuances for the different groups of respondents.
- Although carers from some of the target groups expressed more homogenous views than others, all groups revealed salient beliefs and values particular to them.
- Attitudes toward self care varied markedly between carers from the different ethnic groups.
- There were notable differences in attitudes toward and uptake of the use of professional carers support services between carers from the six target groups.

Introduction

Project Background

This research project emerged from a consultation conducted by Carers Victoria (CVic) with carers of culturally and linguistically diverse (CALD) backgrounds in 1999, as part of a larger consultation about access, availability and quality of services (Nankervis and Rebeiro, 2000). The consultation provided some insight into the diversity of beliefs and values among various cultures about family caregiving and indicated that these could be influenced by length of residence and pre-migration experience.

To further explore these beliefs and values, CVic applied for, and received, HACC funding for a six-month research project aimed at understanding how the influences of beliefs and values about caring impact on CALD families. The findings from this research are presented in this report. The purpose of the research was to collect data to assist service providers and policy makers in their efforts to encourage carers to access support services and maintain their own health and wellbeing.

The project targeted the Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese¹ communities by way of individual interviews and focus groups. A Reference Group was established to provide advice and support to the project.

The main issues explored in the research were:

- experience of providing care
- values and expectations about caring
- attitudes to self care
- attitudes to support networks and services

Consideration of migration experience, length of residence, English language ability and education levels was also included.

It is hoped that the findings from the research will:

- enable CVic to facilitate better understanding of care issues in ethnic communities
- be incorporated into CVic's education program for service providers and carers
- be a resource to relevant services for carers in Victoria and nationally in the provision of support services for CALD carers
- inform policy development on carer issues.

¹ The terms 'Anglo-Celtic', 'Greek', 'Italian', 'Polish', 'Turkish' and 'Vietnamese' have been used throughout the report to refer to members of the Australian community who were born either in Australia or overseas but who identify themselves as having the relevant cultural background to the term used. The terms should be read as interchangeable with 'Anglo-Australian', 'Greek-Australian' etc.

Literature Review

Introduction

This literature review concentrates on material published in the last 15 years that explores general and elder-care related issues in Australia for the target groups selected for this study (Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese). Literature on carers of people with mental illness or a disability has generally been excluded, although it should be noted that there are many commonalities in carer experiences, values and attitudes regardless of the condition of the care recipient. One of the significant differences between care of the elderly and care of people with a mental illness or disability is the issue of stigmatisation often attached to the last two conditions, which does not manifest in relation to the frail aged (see for example Bartolini, 1993; Georgopoulos, 2002; Kapsalis, 1996).

While Barnett and Cricelli (1990) note that by 1990 there had been little research undertaken in Australia to identify the needs of unofficial caregivers, there is a significant amount of recent literature dealing with family caregivers and access to carer support services. However, the authors have not identified any study specifically examining the values and beliefs informing caregiving and the use of services. In terms of texts dealing with ethno-specific issues, there has been an increase in this material in the last decade, with the studies tending to focus on exploring barriers to service use from an access and equity point of view (for example, linguistic barriers).

A number of qualitative research projects or consultations specifically targeting carers from diverse cultural and linguistic backgrounds have been identified and are discussed below under the relevant target group.

Carers from Diverse Cultural and Linguistic Backgrounds

It is clear from the literature that, statistically, across all cultures in Australia, families are the most significant source of care for the elderly, with women in particular providing care (Weston, Qu and Soriano, 2001, p5, ABS Disability, Ageing and Carers 1998, Table 25, p 40). In terms of care relationships, spouses predominate as principal carers of the frail aged (Ibid, Table 32, p 47), however, the current study included a diverse range of care relationships. The majority of such family carers (51%) do not receive assistance from either family or formal services in their caregiving role (Ibid, Table 35, p50). In a consultation with carers speaking Arabic, Cambodian, Greek, Mandarin, Polish and Russian, CVic focussed on issues of access to services. They found that 40% of participants had never used a community service to assist them in their caregiving role (Nankervis and Rebeiro, 2000, p45).

It has been suggested that this is due to strong cultural expectations of family care that regard the accessing of formal services as inappropriate. This was the case for the carers of Greek, Italian and Polish background in Barnett and Cricelli's study, most of whom could not contemplate any option but providing in-home care to their disabled family member. Most respondents perceived such care as a 'duty', denial of which would have seen them incapacitated by guilt (Barnett and Cricelli, 1990, p42). Similarly, Misic found on the basis of focus groups with carers from Chinese, Croatian, Greek and Spanish backgrounds that most respondents felt it was their responsibility to provide all care and therefore most did not receive support services (Misic, 1996, p7). Plunkett and Quine also made similar findings based on interviews with women from CALD backgrounds (Plunkett

and Quine, 1996, p43). According to Papanicolaou and Fitch there is a strong expectation of family-based care in all cultures, however, different cultures make different distinctions as to what level of care is considered reasonable, with incontinence and wandering often considered too difficult to manage (Papanicolaou and Fitch, 1996, p21).

Many texts report common experiences of caregiving regardless of ethnic background, such as sublimation of carer needs, social isolation and physical and mental stress (eg Campbell, Small and Moore, 1997; Moodie, 1993; Papanicolaou and Fitch, 1996; Schofield, 1998 et al; Legge and Westbrook, 1993; Nankervis and Rebeiro, 2000). In addition to these more negative aspects of the carer experience, the Victorian Carers Program study found that a high proportion of carers across cultural groups also report feelings of satisfaction deriving from their carer role (Schofield et al, 1998, p46).

Despite similarities across cultures in the experience of caregiving, and cultural expectations regarding the appropriateness of service access, NESB carers have been found to face additional stressors in accessing services. These are largely due to language and communication difficulties, lack of familiarity with the Australian health care system, culturally inappropriate professional care options and racism (Campbell, Small and Moore, 1997, p85).

There also seem to be differences in care experiences in terms of gender. While across cultures women are over-represented in the number of carers in comparison with their proportion in the population, Alcorso and Schofield (1991) reported that women from NESB assume a higher burden of unpaid care than do women from English speaking background. As a result, they found NESB women experienced greater degrees of isolation and loneliness in the carer roles. Fischer also found that women from NESB are constrained by cultural barriers from seeking help outside the family (Fischer, 1995a, p155). Interestingly, the Victorian Carers Program population study found that there were proportionately more male carers in the NESB respondents than in those from English speaking background (Schofield et al, 1998, p47).

The idea that within NESB groups elderly care is provided in the context of a cosy, mutually supportive extended family has been challenged by many authors. For example, Evert and Kukulska (1993) quote the Ethnic Affairs Commission of NSW report, Ageing People of Non-English Speaking Backgrounds: A Policy Perspective, which stated that aged people are often forced onto relatives due to the inaccessibility of services when they would in fact prefer to remain independent. Kratiuk and colleagues also state that lack of service use by carers from NESB is due to lack of service awareness rather than other reasons such as a lack of need due to extended family support (Ibid, p17). They note that the terms 'community' and 'family' care are misleading as in-home care is usually performed by one person, usually a woman, with little family or community assistance (Ibid, p18). Based on their focus groups conducted with female carers from Italian, Greek, Croatian, Jewish, Turkish, Arabic-speaking Christian, Vietnamese and Hong Kong Chinese backgrounds, McCallum and Gelfand also found an over-romanticisation of extended family support in these communities and that, in fact, respondents were in considerable distress as a result of the lack of support for their caring role (McCallum and Gelfand, 1990, pii).

Many authors have discussed why carers are prevented from using formal services for assistance in their carer role. The most commonly cited reasons include the cultural barriers discussed above as well as:

- lack of awareness of or information about services - often related to language barriers (Fischer, 1995a; Georgopoulos, 2002; Kratiuk et al, 1992; Legge and

- Westbrook, 1991; Moodie, 1993; Morse and Messimeri-Kiandis, 1997; Nankervis and Rebeiro, 2000; Plunkett and Quine, 1996, Schofield et al, 1998)
- `care recipients do not like or want to use services (Georgopoulos, 2002; Legge and Westbrook, 1991, Schofield et al, 1998)
 - `lack of availability of adequate services (Fischer 1995a; Moodie, 1993; Morse and Messimeri-Kiandis, 1997)
 - `fear of interference from professional service providers (Georgopoulos, 2002; Moodie, 1993)
 - `difficulty in applying for services (Fischer, 1995a; Moodie, 1993; Plunkett and Quine, 1996)
 - `financial barriers (Fischer 1995a; Moodie, 1993, Morse and Messimeri-Kiandis, 1997)
 - dissatisfaction with previous use (Schofield et al, 1998, Nankervis and Rebeiro, 2000)

Fischer concluded that attitudinal shifts by both carers and the community in general were required before service uptake would occur (Fischer, 1995a, p156). He recommended that services form partnerships with NESB carers and community, promote services and conduct community education using ethnic radio, and provide flexible policy and program responses (Fischer, 1995a, p156-7). McCallum and Gelfand recommended that to relieve the burdens on NESB women of elder caregiving, men and care recipients themselves need to change and be educated about effective caring relationships (McCallum and Gelfand, 1990, p41). Bilingual and bicultural workers were also seen in many studies as crucial to making a service more usable (eg Nankervis and Rebeiro, 2000, p48).

Rebeiro argues that beliefs, as socially constructed guiding principles for living, are subject to change and can be barriers for carers in accessing support services. Therefore, "enabling carers to evaluate their beliefs and values from a range of perspectives leading to a more balanced assessment will give them freedom to give themselves permission to accept either family or external support, thereby taking care of their own legitimate needs for wellbeing and quality of life" (Rebeiro, 2002, p17).

Carers from Anglo-Celtic Background

McDonald suggests that, despite the myth that extended family is not important to Anglo-Australians, in fact such support is prevalent and important in the lives of most Australians. The Anglo-Australian "ideal seems to be for family members of different generations to live separately but relatively close to each other" (McDonald, 1995, p45, ABS Disability, Ageing and Carers: Summary of findings, Table 36, p.51). This is consistent with findings from the Victorian Carers Program study which found that more care recipients of Anglo-Celtic background lived separately from their carers than did their NESB counterparts (Schofield, 1998).

In a study of the influence of cultural values on beliefs as to who is responsible for the care of the frail aged, a survey of people from Chinese, German, Greek, Italian, Arabic-speaking and Anglo-Australian communities found that all groups attributed a major responsibility to government (Legge and Westbrook, 1993, p287). However, there were significant differences in perceptions as to the role of community, ethnic and religious organisations, and the family in providing care. There were also marked differences in perceptions of which family members have the major responsibility to provide care. For example, all NESB groups thought sons had more responsibility than did the Anglo-Australian group (Legge and Westbrook, 1993, p294). Italian and Greek respondents considered the family had greater responsibility for aged care than the Anglo-Australian group (Legge and Westbrook, 1993, p294). However, the Anglo-Australians considered that more distant relatives such as sisters, grand-daughters and nieces had a

responsibility to provide care (Legge and Westbrook, 1993, p8). In terms of the target groups of the current study, Greeks attributed greater responsibility to religious groups than did the Anglo-Australian group.

Carers from Greek Background

The Greek-Australian community is noted for its strong culture and language maintenance (Georgopoulos, 2002, p25). The elderly are traditionally cared for by female family members at home, with nursing home care seen as family rejection with expectations of community backlash should it occur (Georgopoulos, 2002, p25; McCallum and Gelfand, 1990, p15; Tsolidis, 1995). However, a cultural shift has occurred with Greek Australians no longer expecting future generations of Greek background in Australia to provide family care (Georgopoulos, 2002, p26; McCallum and Gelfand, 1990, p16; Morse and Messimeri-Kiandis, 1998; Tsolidis, 1995). Self-sacrifice is also identified as an inherent part of the carer experience (Georgopoulos, 2002, p27).

In their survey of 74 Greek, Chinese and Anglo-Australian carers of frail aged people, Legge and Westbrook found that the Greek carers used the fewest services and were least likely to have considered nursing home placement (Legge and Westbrook, 1991, p3). The area of most significant difference found between cultural groups was the frequency with which the respondents would advise others of their responsibility to care for the aged: 46% of Greeks and 13% of Anglo-Australians said they would do this (Ibid, p7). It was noteworthy that many of the services mentioned by Greek carers as ones that would enable their care recipient to remain in the home were, in fact, already available; the authors concluded that this indicated a reluctance to investigate and use such services (Ibid, p8). While it was predicted that Anglo-Australian and NESB carers would give different reasons for not accessing services, this proved to be inaccurate. However, differences in cultural values did seem to influence the use of services and "Greek values seemed to make it difficult for carers to use services" (Ibid, p9).

Greek women carers in McCallum and Gelfand's study reported that they had a continuous role in the care of the elderly (that is, it was not seen as something starting with illness and stopping with nursing home placement (McCallum and Gelfand, 1990, p12). Caring was understood as an expected wifely role and they experienced little acknowledgement from their care recipients (McCallum and Gelfand, 1990, pp12-13).

The most wide-ranging study of Greek background carers was undertaken by Morse and Messimeri-Kiandis (1997) involving comparison of interviews with 150 carers and 150 non-carers. They examined the health and social experiences of caregivers with co-resident care recipients with physical, psychiatric, intellectual, developmental or frail aged disabilities. The authors identified the belief among respondents that caregiving is a female, marital duty. The physical health of carers was reported as no worse than that of non-carers, however, their psychological and emotional health was reported as considerably worse due to the unrelieved stress and strain of caring (Morse and Messimeri-Kiandis, 1997, pi). Carers perceived their caregiving duties as keeping them housebound. The majority were using some form of assistance, but few were using a full range of carer support services (Morse and Messimeri-Kiandis, 1997, pii). In a follow-up journal article to their research report, the authors also stated that the respondents were not receiving practical support from extended family members, and they spoke of not wanting to burden their own children with the carer role (Morse and Messimeri-Kiandis, 1998). The authors concluded that "the notion of reduced burden through support and caring from a close-knit community and extended family was generally found to be a myth" (p212).

Based on feedback from a focus group with carers of Greek background, Misic had similar findings to those already reported. He also found that while respondents from other ethnic backgrounds were generally positive about the idea of a carer support group, respondents from Greek backgrounds were not in favour of them (Misic, 1996, p7).

Moodie reports that carers from Italian background were generally accepting of services while Greek-background carers were more reluctant to accept services (Moodie, 1993, p52).

Carers from Italian Background

In a study comparing the caregiving experience of 461 Anglo-Celtic and 48 Italian carers of elderly family members, it was surprisingly found (given previous literature) that the Italian respondents experienced significantly less trait anxiety than their Anglo-Celtic counterparts. Similarly surprising was that more of the Italian respondents in the study had used community supports than had Anglo-Celtic background carers (Carrafa, Shultz and Smyrnios, 1997, p699).

Italian female carers in McCallum and Gelfand's study (1990) gave parental love and feeling responsible for the hardships caused by migration as reasons for accepting the care burden of their elderly family members. They received limited support from their husbands in doing so, with caring seen as a gendered role specific to women (McCallum and Gelfand, 1990, p9). They also expressed reticence about nursing home care (McCallum and Gelfand, 1990, p11).

According to Vasta (1995), traditionally Italians expect children to care for parents, with reciprocal grandchild care provided by grandparents. She notes that older parents resist nursing home placement, but for some second-generation families there is no perceived choice (Vasta, 1995, p160).

Carers from Polish Background

In 1993 Drozd noted that there was only scanty and untested evidence to support the suggestion that Polish elderly may be unwilling to use nursing home care. She went on to note that the same comments had been made about the Italian community, however, once ethno-specific services had been established they were well used (Drozd, 1993, p65).

Evert and Kukulska interviewed 30 Polish carers and found that while most were using some form of support service, they were generally unfamiliar with respite care (Evert and Kukulska, p182). The authors also noted that for some carers, asking for assistance was difficult due to their own commitment to providing care for their family member (Ibid, p183). When asked who they would turn to for help in an emergency, 63% of respondents nominated family, 13% nominated friend or neighbours, and only 10% said nursing home admission (Ibid, p184). The most common reasons nominated for not wanting to use nursing home care was a belief that it would place additional stress on care recipients or fear that their care recipient would not receive proper care (Ibid, p184). The respondents were mainly female looking after their spouses with little help from their offspring. Many felt their children were not obliged to help them in the caring role as they had work commitments and families of their own.

In a study based on interviews with 30 house-bound Polish carers, Niedzwiecki identified the following themes impacting on family caregiving: cultural attitudes towards care made relinquishing carer ties difficult; there was a community expectation of family care; war experiences impacted on the caring role; carers relied on informal supports for assistance

and were reluctant to accept professional support; family conflict meant that family was a stressor rather than buffer for some carers; carers were socially isolated; demanding care recipients increased stress for carers; there was a social stigma associated with welfare services; and Catholic faith provided a strong coping mechanism for many carers (Niedzwiecki, 2000, p4-5).

Carers from Turkish Background

Based on a survey of 226 Turkish background elderly and disabled people and carers, Cuvegen found that carers experience social isolation, have insufficient time for themselves, and felt restricted and without choice in their caring role (Cuvegen, 1997, pvii). Respite care was not used due to guilt caused by perceived abandonment of the care recipient. There was also a lack of awareness of carer support services. Respondents were noted to have strong traditional family values (Cuvegen, 1997, pviii). Many respondents asked for companionship services such as home visiting, social activities and support groups (Cuvegen, 1997, pix).

In McCallum and Gelfand's study, Turkish women carers reported experiencing intergenerational conflict as a result of their co-residential carer role (McCallum and Gelfand, 1990, p25). They described caring as a woman's role, however, there was minimal opposition to services based on cultural norms (McCallum and Gelfand, p26).

Carers from Vietnamese Background

According to Nguyen and Ho, traditionally in Vietnamese society, "the parent-child relationship is based on the principle that pious children must obey their parents and look after them unconditionally in their old age" (Nguyen and Ho, 1995, p221). However, they also note that in Australia such unconditional care of parents by second generation Vietnamese migrants is diminishing (Nguyen and Ho, 1995, p238). Interestingly, the elderly Vietnamese people interviewed in a study by the Australian Vietnamese Women's Welfare Association said they felt they were a burden to their children (Australian Vietnamese Women's Welfare Association, 1997, p7).

According to Truc, the care burden in Vietnamese families rests with women, who are expected to look after their husband and children as well as their in-law relatives. Traditionally, such families are also living in intergenerational, extended family households [Truc, 1994, np]. This was confirmed by the Australian Vietnamese Women's Welfare Association study that found 66% of their respondents lived in extended family (three generation) households (Australian Vietnamese Women's Welfare Association, 1997, p24).

Caring in the Vietnamese community is described as an 'act of love' by Vu, who goes on to describe the Vietnamese expectation of family care as a way of expressing gratitude to parents and grandparents (Vu, 2002, p21). She notes that community criticism would be likely if a family did not care for their elderly family members at home (Vu, 2002, p21, Thomas, T, 1999).

Based on responses from 100 elderly Vietnamese service users (including carers) Campbell found that the traditional Vietnamese beliefs about filial piety and duty were a factor in preventing service access (Campbell, 1998, p23). However, the elderly respondent care recipients recognised a role for professional aged care services in providing respite for carers, especially those without family support or those looking after care recipients with very high care needs (Campbell, 1998, p3). Nursing home care was seen as a very last resort option for elderly care (Campbell, 1998, p3) and there was a

general lack of awareness in the research sample of formal aged care services (Campbell, 1998, p25). As such, principal barriers to use of services were English language difficulties and anxieties about cultural appropriateness.

McCallum and Gelfand found that women carers from Vietnamese background had little concern for their own leisure time (or the lack thereof) as a result of their carer duties (McCallum and Gelfand, 1990, p31).

Conclusion

It can be seen from the above review that the literature on carers from CALD backgrounds is burgeoning. Most of the studies quoted, like the current one, were qualitative in nature and dealt with relatively small sample sizes (with some notable exceptions of the studies by the Victorian Carers Program, and Morse and Messimeri-Kiandis).

Clearly carers from all cultural backgrounds have an expectation of family care for elderly members, although the extent to which formal services are used as an adjunct to this varies between groups for a variety of reasons. For those from NESB lack of information in appropriate formats and languages is often cited as a reason for lack of awareness of services leading to a lack of service usage. However, it is also evident that values and beliefs about who should be providing care is a significant factor in formal service investigation and uptake.

Methodology and Research Design

Qualitative Methods

This was a qualitative research project using individual interviews and focus group discussions to gather data from carers of elderly people from six targeted cultural backgrounds: Anglo-Celtic; Greek, Italian, Polish, Turkish and Vietnamese. A total of 91 respondents were involved in the project.

The individual interviews and focus group discussion were conducted using a semi-structured interview schedule and discussion guide respectively (see Appendix D and E) that included both closed and open questions. Quantitative demographic data was also collected about respondents' ethnicity, place of birth, preferred language, English language proficiency, length of Australian residency, age at migration, age, gender, education levels, marital status, relationship to care recipient, duration of care, living arrangements, care recipients' main condition requiring care, and age of care recipients. The individual interviews took from one to two hours and the focus group discussions lasted between 1 1/2 and two hours. Interviews took place in a venue of the respondents' choosing (nearly always their own home) and the focus group discussions were conducted in meeting rooms at public venues.

Qualitative data gathering methods were chosen to allow respondents to reflect on their own experiences as carers and to elicit a rich narrative reflecting the carers' perspective. It was recognised that values and beliefs are often deeply held and are not always easy for respondents to identify or disclose. As such, a discursive method of information collection was deemed most suitable to meet the project's objectives. A mixture of individual interview and focus groups were used to allow for in-depth information collection and the inclusion of respondents who would not be comfortable about sharing their experiences of caregiving in a group setting. The focus group discussion also allowed the opportunity to test findings from the individual interviews.

Reference Group

A reference group was established at the beginning of the research project to act as a resource to the researchers. Members were invited on the basis of their experience working with the relevant target groups, their knowledge and experience of carer issues, and their expertise in social research. The reference group met three times throughout the course of the project and individual members were consulted as required outside of formal meetings. A full list of reference group members is found at Appendix A.

Co-researchers

Bilingual/bicultural co-researchers were employed to recruit respondents and conduct the interviews/discussions. At the outset of the project consideration was given to the authors conducting all interviews using interpreters where necessary. Instead, co-researchers were chosen as this approach has the advantage of overcoming potential crosscultural communication barriers between researcher and respondent. It also takes advantage of the researchers' personal and professional networks in the relevant ethnic communities. Given the relatively short timeframe for this project and the expected difficulty of recruiting respondents (see 'Recruitment Challenges' in the Research Findings section) such access was deemed imperative.

In terms of cost there was little difference between using co-researchers or interpreters; indeed, the approach chosen was slightly cheaper. There are also potential disadvantages in using bilingual/bicultural co-researchers. The main ones of concern to this project were the potential for different interviewing techniques and skills leading to inconsistent information collection and reductive reporting of data gathered. Protection against these possible disadvantages was provided by an extensive briefing session for all co-researchers, the provision of written material to support their data collection and reporting, and ongoing support throughout the project from the authors.

Rationale for Choosing Target Groups

Assumptions

Some of the assumptions underpinning this research project were that:

- beliefs and values directly impact on the way that carers do or do not seek assistance for themselves
- culture (including ethnicity, birthplace, language, religion) is a key determinant in the development of beliefs and values
- migration and settlement experience has an impact on beliefs and values

Scope

To explore these assumptions it was decided that carers from a range of cultural and migration backgrounds should be included in the study. In deciding which groups to target, the following decisions were made:

- resources allowed for the inclusion of six target groups, with one focus group discussion and eight individual interviews per group
- the Anglo-Celtic group should be included so that 'mainstream' beliefs and values also be recognised as being culturally driven
- the target groups should reflect significantly ageing/aged ethnic communities
- the target groups should represent various lengths of settlement in Australia
- various settlement experiences, including migration and refugee experiences, should be included
- a variety of religious influences should be included

Based on these decisions, the groups chosen for the study were Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese. In addition to having a significant proportion of people over 50 years of age in their populations, these groups represented long (Anglo-Celtic), medium (Greek, Italian, Polish) and relatively recent (Turkish and Vietnamese) settlement. They also reflected Christian (Anglo-Celtic, Greek, Italian and Vietnamese), Buddhist (Vietnamese) and Muslim (Turkish) religious influences.

Selection Criteria for Respondents

To be eligible to be included in this research project as individual interviewees respondents had to meet the following criteria:

- they must be a current carer
- they must be a full-time carer (self-assessed)
- they must be caring for an elderly person (over the age of 65)
- they must be from the relevant ethnic background
- they must be a first generation migrant caring for another first generation migrant from the same cultural background (NB. Anglo-Celtic carers and care recipients did not need to be first generation migrants)
- they must not currently be using carer support services to any great extent

The same criteria applied to participants in the focus group discussion, with the exception that it was acceptable for them to be using carer support services. This was to allow for the focus group discussions to be conducted using existing carer support groups. By using existing groups, where available, it was hoped that respondents would be more comfortable discussing with others their values and beliefs about providing care.

Recruitment Methods

Researchers used a variety of techniques to identify and recruit potential respondents. These included using personal and professional networks, and contacting service providers (including HACC services and Carer Services) to seek referrals. Personal networks were the most useful source of potential participants. Snowball recruitment was also tried, with respondents being asked to refer further potential participants. However, this was largely unsuccessful as most respondents did not know other carers of the elderly.

Consent and Payment

Consistent with standard social research practice, all respondents signed a written consent form that documented their agreement to be interviewed, the confidential nature of the data collected and their rights as a respondent (for example to stop the interview at any time or to give feedback to CVic on the interviewer). The consent form was professionally translated and each researcher worked through its contents orally with the respondent.

All respondents were given the opportunity to be informed of the outcomes of the research project and all requested such follow up contact.

Again consistent with contemporary research practice, all respondents were paid a nominal sum of \$30. To prevent withholding of tax, all respondents completed an Australian Tax Office Statement by a Supplier form.

Data Collection and Analysis

All interviews and focus group discussions were conducted in the language of choice of the participants and, where permission was given, were taped. In addition, notes were taken by the researcher (or a scribe for the focus group discussions). Reports were then written in English and provided to the authors for collation and analysis. The authors of this report also conducted the field research for the Anglo-Celtic and Italian communities.

Analysis took the form of both authors identifying the key themes presented by the data and cross checking their analyses. Where necessary, further clarification of data was sought from the relevant co-researcher or independent community member. The preliminary findings were presented to CVic staff and the project reference group to check consistency with field workers' and researchers' past experiences of working with the target groups.

Target Group Profiles²

Anglo-Celtic³

Snapshot

Population	70% of Australian population is of Anglo-Celtic background*
Language	Nearly all speak English at home+ Nearly all speak English well or better+
Age	Largest Age group 25-44 (18%) 11% over 65
Main religion	Western Catholic (27%) Anglican (25%)

*In 1999, based on data calculated by Price, quoted in Hugo, 2002, no figures available for Victoria
+This is an estimate only

The United Kingdom has traditionally been the largest source of settlers arriving in Australia since European settlement began in 1788. Between then and 1852, 100,000 Anglo-Celtic convicts were transported to Australia. Further surges of Anglo-Celtic migration occurred during World War I and in the 1920s.

People from Anglo-Celtic background continue to represent the majority of the Australian community (70%). Compared with some of the other groups included in this study, the Australia-born community, although ageing, is relatively young with only 11% aged over 65.

² Unless otherwise stated, all information is based on 1996 Census data information provided online by the Department of Immigration, Multicultural and Indigenous Affairs (www.immi.gov.au). Unless otherwise state, figures quoted are national.

³ It is difficult to provide demographic data for people in Australia from Anglo-Celtic background. While 'what is your ancestry?' was asked in the 1986 and 2001 Cenus, respondents were able to choose more than one answer. This means, for example, that someone born in Australia to Italian-born parents could have identified themselves as both of Italian and Australian ancestry. In terms of other Census data, statistics for the 'Australia-born' would include people who would not be of Anglo-Celtic cultural background and the same applies to statistics for the total Australian population. Despite these inadequacies, statistics quoted here are, unless otherwise noted, based on figures for the Australia-born population.

Greek

Snapshot

Population	1.4% of Victorian population (61,890) is born in Greece 0.7% of Australian population (126,520) is born in Greece
Language	89% speak Greek at home 67% speak English well or better 32% speak English not well/not at all
Age	Largest age group 45-64 (57%) 19% over 65
Main religion	Greek Orthodox (92%)
Top 3 LGAs in Victoria	Darebin, Monash, Moreland

It is thought that the first Greece-born people to arrive in Australia did so in 1829, although the first significant wave of Greek migrants did not arrive until the gold rush in the 1850s. A second wave of Greek migration occurred between the two World Wars. However, the largest numbers arrived after the Second World War with the establishment of an assisted-passage scheme. At the 1961 Census there were 77,333 Greece-born people in Australia. This number expanded rapidly, rising to 160,200 in 1971. Most of these arrived as young adults and worked in blue-collar occupations.

The education levels of the Greece-born in Australia are notably very low, with 62% of Greece-born women either never having attended school or leaving school before the age of 15 (compared with 15% of all Australians). However, this is reversed in the second generation with 23% having higher qualifications (compared with 17% of all Australians).

By 1996 the total number of Greece-born living in Australia had fallen to 126,571, slightly outnumbered by the second generation (153,876). The vast majority of all the Greece-born in Australia live in Melbourne, with most in the northern suburbs.

The Greek community has a very high degree of first language maintenance, with 89% of the Greece-born and 68% of the second generation reporting speaking Greek at home. Sixty-seven percent of Greece-born people report speaking English well or better, however, 56% of Greece-born people over the age of 65 report low English language proficiency.

Italian

Snapshot

Population	2.3% of Victorian population (99,123) is born in Italy 1.3% of Australian population (238,216) is born in Italy
Language	84% speak Italian at home 75% speak English well or better 23% speak English not well/not at all
Age	Largest age group 45-64 years (50%) 31% over 65
Main religion	Western Catholic (93%)
Top 3 LGAs in Victoria	Moreland, Darebin, Moonee Valley

People have been migrating from Italy to Australia since very early in the history of European settlement; however, it was post-World War II that saw the first large-scale Italian migration. By 1971 the Italy-born population had risen to 289,500 from 33,600 in 1947. Most of these people arrived in Australia in the 1950s and '60s as young adults and worked in blue-colour occupations.

By 1996 the total number of Italy-born in Australia had fallen to 238,300, however, they are significantly outnumbered by the second generation. Together with their children, they form the largest origin group in Australia after those of Anglo-Celtic origin. Victoria has the largest number of Italy-born residents with 41% of the national total living here.

The Italy-born population in Australia is distinctly aging with 31% over the age of 65.

The Italian community has a very high degree of first language maintenance, with 84% of the Italy-born speaking Italian at home. Seventy-five percent of Italy-born people report speaking English well or better, however, 42% of Italy-born women over the age of 65 report low English language proficiency.

Polish

Snapshot

Population	0.5 % of Victorian population (23,061) is born in Poland 0.4% of Australian population (68,496) is born in Poland
Language	70% speak Polish at home 85% speak English well or better 14% speak English not well/not at all
Age	Largest age group 65+ (39%)
Main religion	Western Catholic (79%)
Top 3 LGAs in Victoria	Brimbank, Glen Eira, Moreland

There have been three main waves of immigrants arriving in Australia from Poland. Although the first Polish settler arrived in 1803, the first and largest wave occurred immediately after World War II, when Australia's Poland-born population rose from 6573 to 56,594. Most of these people were refugees or displaced persons and 4,000 were Polish ex-servicemen from the British army. The second wave occurred between 1957 and 1966 with about 15,000 Poles arriving as migrants during this period. The most recent wave of Polish migrants came in the 1980s. During this decade more than 25,000 Poland-born people arrived in Australia, many as refugees. The typical Poland-born settler of the 1980s was between 25 and 37 years of age, married with a young family, from an urban area and well educated.

The 1996 census recorded 68,496 Poland-born people living in Australia (0.4% of the total population). Victoria has the highest number of Poland-born residents, with 35% of the national total living here.

The Poland-born population in Australia is distinctly ageing with nearly 40% over the age of 65. In Victoria, the Polish community has one of the largest numbers of older persons.

The Polish community has a high degree of first language maintenance, with 70% of the Poland-born and 19% of the second generation reporting speaking Polish at home. However, English language proficiency is also high with 85% of the Poland-born population reporting that they speak English well or better.

Turkish

Snapshot

Population	0.3% of Victorian population (14,818) is born in Turkey 0.2% of Australian population (28,866) is born in Turkey
Language	82% speak Turkish at home 63% speak English well or better 35% speak English not well/not at all
Age	Largest age group 25-44 (52%) 6% over 65
Main religion	Islam (77%)
Top 3 LGAs in Victoria	Hume, Moreland, Greater Dandenong

People from Turkey have been living in Australia since the late-19th century. However, the introduction of the White Australia Policy in 1901 excluded Turks from migrating to Australia and their numbers in the population consequently diminished. The largest wave of Turkish migration occurred after Australia and Turkey signed a bilateral agreement in 1967 on assisted migration. This resulted in about 10,000 Turks entering Australia during the 1960s. While the agreement sought to encourage skilled workers to come to Australia to fill labour shortages, most arrivals during the early part of the program were unskilled and were employed in blue-collar jobs. The Turkey-born represent the first large Muslim population to settle in Australia.

The 1996 census recorded 28,866 Turkey-born people living in Australia (0.2% of the total population). Victoria has the highest number of Turkey-born residents, with 51% of the national total living here.

The Turkey-born population in Australia is generally younger than other migrant groups and only slightly older than the total Australian population. The Turkey-born in Australia are heavily weighted towards the working-age groups with only 6% over the age of 65.

The Turkish community has a high degree of first language maintenance, with 82% of the Turkey-born reporting speaking Turkish at home. However, English language proficiency is also relatively high with 63% of the Turkey-born population reporting that they speak English well or better.

Vietnamese

Snapshot

Population	1.3% of Victorian population (55,217) is born in Vietnam 0.8% of Australian population (151,085) is born in Vietnam
Language	74% speak Vietnamese at home 55% speak English well or better 43% speak English not well/not at all
Age	Largest age group 25-44 (52%) 5% over 65
Main religion	Buddhist (41%) Western Catholic (23%)
Top 3 LGAs in Victoria	Greater Dandenong, Brimbank, Maribyrnong

The Vietnam-born population in Australia is a relatively recently arrived group with the first significant migration beginning after the end of the Vietnam War in 1975. There have been two distinct phases of Vietnamese migration: refugee arrivals from 1975 to 1985; and family reunion arrivals since 1985. In 1975 there were approximately 1000 Vietnamese-born in Australia; in two decades this figure rose to approximately 150,000. Ethnic Chinese people are also a significant component of the Vietnam-born community in Australia with 17% speaking Chinese at home.

The 1996 census recorded 151,058 Vietnam-born people living in Australia (0.8% of the total population). Victoria has the second highest number of Vietnam-born residents (NSW the highest), with 36% of the national total living here.

The age distribution of the Vietnam-born population in Australia is heavily weighted to the working-age groups, with only 5% over the age of 65.

The Vietnamese community has a high degree of first language maintenance, with 74% of the Vietnam-born speaking Vietnamese at home. English language proficiency is generally low, with 43% reporting they speak English not well or not at all.

Research Findings

Recruitment challenges

Several challenges were faced in recruiting respondents for this research. The main challenge was finding respondents who met the selection criteria, although some researchers also encountered challenges in encouraging potential respondents to participate.

From the outset, the researchers felt that recruitment would be potentially difficult due to the responsibilities of carers and their possible reluctance, or inability, to be focussed on something other than their care recipient for the one to two hours required for interviews or focus group discussion. We also felt there may be reluctance by carers to divulge personal information to a researcher and in a group (hence the research design of both individual interviews and focus groups). In the event, it was not these issues that posed the most significant challenges.

Instead, the main barrier to recruitment was the requirement that respondents not be already linked with carer support services. This was particularly problematic for the Anglo-Celtic community. In the event, nearly all respondents, except those from Greek background, were using some form of carer support service (mainly HACC services). Given more time, it may have been possible to locate more respondents who were completely unconnected with services using other recruitment methods (such as advertising in ethnic media, but this has not been a particularly successful method in the past).

Additional challenges were faced by the Turkish and Vietnamese researchers who had trouble locating carers of the elderly at all, and then, once located, found that respondents did not want to participate in a focus group discussion for privacy reasons. This resulted in smaller focus group discussions than anticipated.

For most researchers, once a suitable respondent had been identified (mostly through personal networks, as service providers could generally not suggest carers who were not using services) it was a relatively simple matter to contact the carer, explain the project, seek consent (generally readily given) and arrange a suitable interview time. The Greek researcher faced a more complex task, as potential respondents were very concerned about privacy and confidentiality. Repeat phone contact was required to first build rapport and establish trust before participants would agree to participate.

Carers from Anglo-Celtic Background

Profile of Respondents

There were 14 respondents from Anglo-Celtic background; eight participated in individual interviews and six participated in the English-speaking focus group discussion⁴. The majority of respondents were female (10). All of the respondents were aged 40 years and over; four were between the ages of 40 and 59, three were between the ages of 60 and 74, and the remaining seven were aged 75 years and over. The majority were married, two were single and one divorced.

With the exception of one person who was born in the United Kingdom, all the respondents were born in Victoria, Australia. They all cited English as their preferred language. All but one person had attained secondary school education, and five of these had also completed tertiary studies.

Experiences of Caring

“Caring has its rewards, but there are the downsides of your family suffering and of not getting any appreciation for what you're doing.” (daughter carer)

“I'd have to say that sometimes I don't feel very good [about caring], sometimes I think I could throw a brick through the window, especially when the wife gets up, she just sits in the chair with her eyes closed, she's not asleep, but you've got nobody here bar the wireless or the television, say, to talk to ... It drives me a bit silly at times, I just feel like I want to get out, I get out in the garden quite a bit, I take it out on the weeds.” (spouse carer)

“Every grey hair has my mother's name on it!” (daughter carer)

The respondents from Anglo-Celtic background found themselves in a variety of care situations. Five were caring for a parent, seven were caring for partners, one cared for his brother and one for her brother-in-law. Four of the respondents had been in their carer role for two years or less, six had been caring between three and nine years, and five had been caring for 10 years or more. The majority (12) were living with their care recipient. The remaining two care recipients lived alone, one in a granny flat on the same property as her carer. The care recipients suffered from a diverse (sometimes multiple) range of illness and conditions. The age of care recipients ranged from 70 to 92, with the mean being 84.

The experiences of caring among the respondents from Anglo-Celtic background ranged from assistance with personal care and mobility to help with daily living and domestic duties. For some respondents, caring involved things such as constant monitoring throughout the day and night, and heavy lifting work. For others, caring was more about being 'available' and 'on stand-by' for their care recipient. A number of respondents described the experience of caregiving as 'rewarding', others viewed it as 'rewarding but difficult', yet others spoke of caring as 'a difficult unrewarding job'. Many spoke of feeling 'worried', 'isolated', 'frustrated', 'restricted' and 'both physically and emotionally stressed' by their caring experience. A number of respondents also made reference to negative effects on their own health. However, the most salient characteristic for this group of respondents was in fact their diversity of experience in providing care.

⁴ The English speaking focus group was conducted with an existing carer support group and included a total of 10 participants. Four participants were from non-English speaking background. As they were not from the target groups of this study only the responses of the Anglo-Celtic background respondents has been included in the research findings reported here.

Values and Expectations about Caring

"I don't really expect anything [from caring]. It's my duty ... I don't consider it a hardship. I'd just like to think that I can look after Mum and keep her independent. ... I guess it's the belief that I'm the eldest daughter and I should look after her." (daughter carer)

"A carer should be compassionate, level-headed when it comes to any crises, tolerant, understanding, caring, loving and competent." (daughter carer)

"We've been married over 51 years, so it's a long time in life to have shared, and, I think what she's done for me with giving me three children and I think that I owe that to her for the rest of my life." (spouse carer)

A sense of duty, obligation and 'doing the right thing' were among the values to emerge from the Anglo-Celtic respondents. The majority held a generally positive, albeit resigned, attitude toward their role as a carer, making comments such as 'I just do it!' and 'It's a job that has to be done, isn't it?'. Many of the spousal carers referred to fulfilling their marriage vows of 'for better for worse'. Many spoke of the need for compassion, kindness, patience and the love they have for their care recipients.

For most, religion and faith played a part in their role as carer; even many of those who did not see themselves as 'practicing', or feeling alienated from religious institutions, referred to faith giving them strength, to the power of prayer in their lives and to living by Christian values.

Attitudes to Self Care

"... I know I must really [look after myself] and take things fairly steadily, because if I'm not here to look after myself, I'm not here to look after my husband and he needs me looking after him." (spouse carer)

"As soon as he's out of the house I'm lost. On days when he's in respite I think 'well, what do I do now?'" (spouse carer)

"I play golf twice a week and I'm quite thrilled, it's a saving grace. Everyone needs an outlet, you can't be consumed by things or resentment comes in." (daughter carer)

All the respondents from Anglo-Celtic background recognised the importance of self care in fulfilling their caring role. Nearly all the respondents identified a range of activities that they undertook to meet their own needs. These included activities such as working part-time, gardening, going to the movies, singing in a choir, yoga classes, playing bowls, going out with their care recipient, lunching with friends, bingo, knitting and crochet. Many respondents acknowledged, however, that it was not always easy to make time for themselves and that this required a conscious effort. Opportunities for self-care activities were made easier for some either because their care recipients still had a level of independence and/or their care recipients were encouraging them to take time out for themselves.

Attitudes to Support Networks and Services

"I couldn't imagine going for a holiday if my wife was in a nursing home or respite care, ... people have suggested it for us, but I don't want to do it ... If we were going to use it, we'd need it local so that I could go every day to visit her." (spouse carer)

"I think that if it comes to the stage where she's got to have it [residential care], I'm not going to be saying no, I'll have to agree to it. If she's got that bad that I can't look after her I think we've both got to agree to it." (spouse carer)

"People say 'you should put him in a home because he's too hard for you'. And I agree, it is too hard for me, but I don't really want to see my man walk out of his home. I was in the nursing home where he was in respite and I looked around the room and thought, 'what a sad, pathetic life that must be for these people.'" (spouse carer)

All the respondents from Anglo-Celtic background had some level of personal support networks and/or professional services assisting them in their carer roles. Some referred to receiving help from their immediate families and/or siblings, and others identified friends and neighbours as a source of support.

The majority of respondents were using home help services, while some were also receiving assistance with showering. Unhappy with Meals on Wheels, a couple of respondents had organised their own catering options, such as using a local caterer or ordering 'Lite and Easy' meals. Many of the respondents were familiar with respite services and used them with varying degrees of success. Some of those who had not used respite services were unsure about how their care recipient might respond to being left in the care of strangers and/or were unwilling to be separated from their loved ones for any length of time.

There were also varying experiences of, and attitudes towards, carer support groups. These included those who attended on a regular basis, those who did not feel they had reached a point in their caring role that they required this level of support, and those who did not perceive any benefits from attending such a group. Participants in the English-speaking focus group discussion, all of whom were members of a carer support group, were very positive about the benefits of attending the group, particularly in terms of learning from and sharing with other carers.

When asked about the use of residential care for their loved ones, all agreed that it would not be their preferred choice, but nevertheless acknowledged that it may be inevitable in the future. A number felt that they would be forced to use residential care if they themselves were no longer able to provide an appropriate level of care, or if their care recipient was no longer able to take responsibility for their own personal hygiene (such as bathing or toileting).

Overall, this group showed a level of readiness to use services if and when it became necessary to do so.

Carers from Greek Background

Profile of Respondents

There were 16 respondents from Greek background; eight participated in individual interviews and eight in the Greek-speaking focus group discussion. The Greek respondents were in many ways the most homogeneous of all groups; all of them were females between the ages of 60 and 74 years, and all were married.

All of the respondents were born in Greece and had migrated to Australia over 20 years ago. All the respondents had migrated as teenagers or young married women. The majority (10) migrated between the ages of 11 and 20; the rest (six) were between 21 and 30 when they arrived in Australia.

All respondents cited Greek as their preferred language; while half the group (eight) reported some proficiency in English, equally half (eight) rated themselves as minimally proficient in the English language. The respondents had either no schooling (10) or primary school education (six), making them the least-educated of all the groups of respondents.

Experiences of Caring

“I look at what I have to do for my husband day-in and day-out and I know that it's because I love him that I can go on... Your whole life is turned upside-down and inside-out and you feel all the negative emotions of anger, hate, resentment, bitterness, sadness and selfishness. At the end of the day and having felt all this you still keep doing it. Why? Only love, that's why.” (spouse carer)

“I am both angry and emotionally hurt by this [carer] situation that I find myself in ... I no longer have a life. I may appear self-absorbed and selfish, but that's the truth. I no longer feel alive or happy to wake up. My day is always organised and determined by my husband's situation and I don't have a say in it.” (spouse carer)

“The demands on me are like weights on my back. They weigh me down. I'm always running and working. The job of looking after someone never ends.” (spouse carer)

All the respondents from Greek background were caring for their husbands with whom they were co-resident. The majority (10) had been carers between three and nine years, while the remaining six had been caring for 10 years and over. Their care recipients suffered from a diverse range of illnesses, some with multiple conditions requiring care. The age of care recipients ranged from 68 to 95, with the mean being 71 years of age.

All the Greek respondents had care recipients that were highly dependent and required full-time care. All but one of the respondents described their experience as a carer with negative overtones emphasising physical and emotional stresses such as anxiety, exhaustion and social isolation. A number of them referred to caring as a burden that had had a significant impact on their own health and lifestyles. Some of the respondents referred to the carer's life as one of 'suffering'. This was particularly evident in the experiences of two respondents who were caring for husbands who had been physically and emotionally abusive to them in the past.

Both of these women spoke of their experience of caring in terms of a shift in the relationship dynamics between them and their husbands. With their husbands now both

physically and emotionally dependent on them, they characterised their carer role in terms of an opportunity for both emotional vengeance and spiritual righteousness. This is exemplified by their following comments:

"There is no greater revenge my dear than to do the right things by those who have hurt you and for them to see you happy. This torments them." (spouse carer)

"It's even more important in the eyes of God that I do the right thing by him and care for him to the best of my abilities because he is my enemy. The bible says to 'love your enemy.'" (spouse carer)

Values and Expectations about Caring

"I don't see myself as doing anything out of the ordinary. I am a simple woman with simple ideas. A carer is someone who looks after someone in the family. This is not something that only I do. There are many Greek women who look after someone all the time. ... You have a job to do as a wife or mother and that is all... You look after those family members, better than you would look after yourself." (spouse carer)

"For me there is no greater gift than to give to another. What I do by caring is give, give, give ... I am of service to the one I love. How can this be bad for me? ... So I lift sometimes and my back hurts me. It doesn't matter, it will pass. But the look in his eyes is forever ... I am so happy to be doing what I can. I am giving back what I have been given. I thank God every day for everything I have had and still have. What you might think is hard work, I think is wonderful work, and it's God's work." (spouse carer)

The most significant values to emerge from the Greek respondents were the importance of family cohesion, the clearly defined caregiving role of women, and the need to keep perceived family problems (including those arising from caring) private. All the respondents viewed their caring role as their wifely responsibility and did not separate their caring role from their duties as wives and mothers. Caring was seen as a natural part of the cycle of life that necessitated a level of self-sacrifice and self-denial. There was also overwhelming agreement among respondents that, for this generation in particular, women expected to be of service to their families and that caring was a gendered role reserved for women. These expectations were also placed upon them by their care recipient, their families and by the broader community. As one respondent explained:

"In our culture we don't live for ourselves. We don't use the word 'my', it's always 'ours' or 'theirs'. We live for our families. Therefore, I have not missed out on anything and don't feel that I am now. We were not taught to be self-absorbed. Perhaps women of my generation are able to cope with life because they never focused on themselves first and others later?" (spouse carer)

The Greek Orthodox religion was also a salient influence on values for many respondents within this group. Focus group members spoke of the Ten Commandments (embodied in values of love, family honour and respect) as a significant influence on their values about caring. For many their faith was also a source of great strength in fulfilling their roles as carers. Similarly, prayer was seen by some as a way of helping solve their problems and some viewed their caring as a way of 'pleasing God', of 'doing God's work' and of fulfilling a religious deed.

Attitudes to Self Care

"I go to church regularly, it's like a tablet for me. I walk in and I immediately feel different - more relaxed and stronger in myself." (spouse carer)

"Every day I am faced with the challenge of having to affirm that all the things I want to do for myself are not as important as what my husband needs. This is not easy. It is a job for a saint but for a human it is very, very, very hard." (spouse carer)

The concept of self care did not feature highly among the Greek respondents.

Not only did these carers state that they had little or no time to engage in self-care activities, they stressed that they had never been encouraged or, for some, been allowed, to have interests outside the family or home. At most, some found attending church as a way of meeting their personal needs.

Attitudes to Support Networks and Services

"I am a believer that we stay healthy and live better without a lot of interference from professional people and services. Several friends have accessed different services and have more problems. It's important for my husband to feel secure and comfortable in his home. To have people coming in and out or speaking to him or me about our life would cloud our thoughts and create problems. No thank you." (spouse carer)

"My husband could never allow someone to toilet him or do things for him. He gets too embarrassed and self-conscious. We want our problems to be kept among the family and ourselves. I don't like the idea of someone coming into my house." (spouse carer)

"I am probably one of many women who could never access services because her husband would not allow it. You see people that offer these services need to know when to let things be. The woman will work out her own way of getting help when it's right. I know that I would not be allowed the help." (spouse carer)

The respondents from Greek background were among the most isolated in their carer role of all the respondents in this study. Although many spoke of having emotional support from their children, it was also common for these carers to speak of the additional care responsibilities they had for their adult children. For the most part these carers did not have any practical support from their children in their role as carers. Indeed, there was a reluctance on their part to 'burden' their children about any difficulties they were experiencing in caring for their husbands.

There was an overwhelming sense within this group that it was important to maintain family privacy for fear of community judgement and gossip. In a few cases, however, respondents had turned to close friends or confidants such as a priest or doctor to seek emotional support.

With the exception of one respondent, who had had some modifications made to her home to assist in her husband's rehabilitation, none of the respondents from Greek background had accessed professional support services. With respect to the use of specific carer support services, such as respite and carer support groups, respondents had an overwhelmingly negative perspective. The main reasons stated against the use of such

services were: the perceived intrusion into the affairs of the family and the privacy of the family home; carers feeling that they would be seen as unable or unwilling to perform their carer duties; an unwillingness to be separated from their care recipient; and care recipients not allowing carers to seek such services.

The notion of carer support groups in particular elicited notions that it was disrespectful to air problems in a public forum, that they would be fertile ground for community gossip, and would potentially try to encourage changes (such as greater self-determination or self care) that were seen as essentially unattainable by these carers.

The use of residential care was universally unacceptable to this group of carers. For many it was viewed as the ultimate sign of disrespect toward their care recipient, an idea that could barely even be entertained and then only in the event that the carer passed away or was physically incapable of providing care. For others it was beyond the realm of possibility that their care recipient would allow it.

Carers from Italian Background

Profile of Respondents

There were 19 respondents from Italian background; eight participated in individual interviews and 11 participated in the Italian-speaking focus group discussion. All but four of the respondents were females; the majority (11) were aged between 60 and 74 years. Of the remaining eight, four were aged between 40 and 59, and four were aged 75 years and over. With the exception of one respondent who was widowed, all were married.

The respondents were all born in Italy and all of them had been in Australia over 20 years. Their ages at time of migration varied across the group with three respondents arriving at 10 years of age or less, four between the ages of 11 and 20, eight between the ages of 21 and 30, and three migrating between the ages of 31 and 40.

All the respondents cited Italian as their preferred language. The majority (12) reported some proficiency in English, while five said they were fluent and two had minimal English proficiency. Almost half (nine) of the respondents had attained primary school education. Of the remaining 10, eight had secondary schooling and two had completed tertiary studies in Italy.

Experiences of Caring

"Sometimes I feel like a prisoner in my own home. I used to have a very full life. I've always helped people who were sick, taken friends to the doctor, helped with their housework, but at least I was getting out." (spouse carer)

"Oh, it [being a carer] has been bad for me. I developed depression because of all of this, I burst into tears for no reason. He gets angry because he is unwell and can't understand things any more and takes it out on me." (spouse carer)

"It [being a carer] is not very easy, it has become a life of sacrifice." (spouse carer)

The majority (14) of respondents from Italian background were caring for partners, with the remaining five caring for a parent. A high proportion (14) of the respondents from Italian background were caring for people with dementia or a neurological condition. The remaining five cared for people with a diverse range of illnesses and conditions; however, almost all of them cared for people in high care need situations. Of the 19 respondents three had been caring for two years or less, seven had been caring between three and nine years, and nine had cared for 10 or more years. With the exception of three respondents whose care recipients lived alone, all lived with their care recipients. The age of care recipients ranged from 52 to 92, with the mean being 79 years of age.

Anxious, stressed, tired, depressed, trapped and isolated were among the most common terms used by respondents from Italian background to describe their experiences as carers. Many noted the significant degree of self-sacrifice required to fulfil their carer responsibilities; for some this was exacerbated by a decline in the status of their own health. The prevailing negativity, and sense of hopelessness, among this group about the impact of the caring role may have been due to the fact that the majority of respondents were caring for people with dementia or with neurological conditions caused by brain injury or strokes. Despite this, a number of respondents approached their responsibilities with a high degree of pragmatism and acceptance (for some fatalism) that this was 'their lot' which they had no choice but to bear.

Values and Expectations about Caring

"Believe me, for a man this life is very hard ... any other person would have put her [his wife] in a home or something. She's become very abusive in public now ... she calls me every name under the sun. But believe me, when someone spends a lifetime with their partner you can't get rid of them just like that. It's impossible! I'm Italian and I was raised in a family where we just would not do something like that. I could never do it!"
(spouse carer)

"[As a carer] I expect the maximum of myself. I have no time to myself, but my soul is at peace when I go to bed at night." **(spouse carer)**

"The idea of respect has been instilled in us since childhood. We grew up with our grandparents in our home and had to have respect for them especially." **(daughter carer)**

The most salient theme to emerge among the Italian respondents was an unquestioned expectation and desire to provide care to family members. Despite the fact that many found the task of caring demanding and difficult, no one questioned their sense of responsibility and duty to their loved one. This expectation was both self-imposed by carers and imposed on them by care recipients, family and the broader community. Respect and obedience toward elders, spouses and family members in general were the most common values to emerge among participants in the focus group discussion. A number of the individual interviewees (5) referred to the notion of self-sacrifice as a way of describing their commitment to caring. This notion was also raised in the focus group discussion.

What was also notable about the interviewees of Italian background was the fact that they found it difficult to identify any significant community expectations relating to their roles as carers. Most of the respondents either did not understand the gist of the question "What do you think people in the Italian community expect of carers?" or answered with comments such as 'I don't really know what other people think', 'I don't care what others think' and 'We don't have much to do with other Italians in the community'.

Five of the individual interviewees from Italian background cited their Catholic religion as being an important source of strength and support in their role as carers. This was also raised as a key value among participants in the focus group discussion. Many of these respondents labelled themselves as 'very religious' by way of praying frequently, and regularly attending church and prayer groups. Some also held strong beliefs in God's intervention and guidance, and cited examples of miracles they had experienced. This dependence on 'God's will' pointed to a certain degree of fatalism toward their roles as carers; that is, that whatever was to happen to them or their care recipient, God's will would prevail.

Attitudes to Self Care

"I don't do anything for myself any more. Any time that I do have time for myself, I spend it worrying if dad is alright and think about what I should be doing." **(daughter carer)**

"I've just put all my own interests on hold." **(spouse carer)**

"I do absolutely nothing for myself any more. Looking after my wife is my life now!"
(spouse carer)

There were very few instances of self care reported among the respondents of Italian background. One person worked one day per week in an aged care setting as a way of meeting her self-care needs. Three others mentioned 'going to church', 'attending a prayer group' or 'reading' as important outlets for them. Also, two of the respondents who had access to respite services made a point of noting that they rarely used the time for 'themselves', but rather used it to catch up with home duties and shopping.

Attitudes to Support Networks and Services

"I like to be self-sufficient, I don't like relying on anyone else for help. I have always been self-sufficient." (spouse carer)

"Just this morning my son said to me 'why don't you put Mum in a place so you can have a rest for a couple of weeks?'. But I said no, I just couldn't do it. I'm too proud of myself. Even having people in your home isn't nice. You lose all your privacy, it's terrible, and anyway my wife wouldn't want to go anywhere." (spouse carer)

"At first [when I put my father in a nursing home] I felt so guilty that I couldn't sleep at night, I would just shake and cry. Even now every time I think of him I feel like crying. Even though I know it was the best thing for him at the time, I still feel incredibly guilty for putting him in a home." (daughter carer)

The respondents from Italian background reported varying degrees of support from family and friends. Although some were able to give examples of emotional support from the latter, few were receiving support of a practical nature. Notably, of the participants in the focus group discussion, none said that they received support from family or friends. In fact, the majority felt despondent about the lack of family support, particularly from siblings. This sentiment was exemplified in the following statements:

"I don't have anyone in my family that takes any responsibility for my mother. My brothers come to visit and it's just more work for me. I have to make coffee, put out biscuits etcetera. Yes they all do their 'duty', but I would rather they take her off my hands for a while." (daughter carer)

"The lack of support is the worst part. If they come they just come to criticise, not to help. Especially my brothers and sisters, they never come to help. We always end up fighting when they come around." (daughter carer)

With regard to relying on adult children for assistance, most acknowledged that they were unwilling to burden their offspring with the responsibilities of caring because they understood them to be too busy with their own family and work commitments. In fact quite a number of the respondents indicated that they believed it was unreasonable for them to expect their children to care for them if and when they themselves require care.

The Italian respondents had varying degrees of access to, and preference for, professional support services. Only two of the respondents were accessing home help services; one other was considering it as an option on recommendation of her doctor, but expressed reservations about 'having a stranger in the home'. Others were decidedly not interested in home help either because they did not feel the need, or they preferred to be self-reliant in this respect.

Apart from the participants in the focus group discussion, all of whom were attending a carer support group, only one of the individual interviewees expressed an interest in

attending a carer support group. Others cited the following reasons for not wanting to attend such a group: 'can't see how it would help'; 'did not like the idea at all'; 'not a group person'; 'care recipient does not like to be left alone or with any other person'; 'don't like doing things without the care recipient'.

All of the focus group discussion participants and four of the individual interviewees were using weekly respite services. Of those who were not using respite, two did not feel they required the services at the stage of the interview, but maintained that they would consider it in the future; one was not willing to accept any assistance from professional services; and one maintained that her care recipient was unwilling to use any form of help outside of the family.

The majority of the individual interviewees viewed residential care as a last-resort option for their care recipients, only to be used if they could no longer fulfil their role as carers. Many of the focus group discussion participants also viewed residential care in this light and some who had used it in the past spoke of feeling guilty for having done so. Two of the respondents were adamant about not ever resorting to residential care despite their future circumstances, one person emphasising this by commenting: 'My husband would rather kill himself!' Only one respondent said that it would be 'OK' to consider the option of residential care for herself or her husband. Fear of community backlash as a result of using residential care was an issue raised in the focus group discussion - one man cited his experience when a close family friend accused him of 'having done a terrible thing' for placing his wife in a nursing home.

Carers from Polish Background

Profile of Respondents

There were 16 respondents from Polish background; eight participated in individual interviews and eight participated in the Polish-speaking focus group discussion. The majority of respondents were female (13). One of the respondents was aged between 25 and 39, five were aged between 40 and 59, seven were aged between 60 and 74, and three were aged 75 years and over. Marital status varied across the group to include six married respondents, three widowed, four divorced, two single and one separated person.

With the exception of one person who was born in Australia, all the respondents were born in Poland. Eight of the respondents had been in Australia for 20 years and over, five between 10 and 20 years, two people between six and 10 years, and one person between three and five years. Two of the respondents came to Australia as children under the age of 10, three were aged between 21 and 30, three were aged between 31 and 40, five were aged between 41 and 50, and two were 51 years and over.

Thirteen (13) of the respondents cited Polish as their preferred language, while the remaining three preferred English. The majority (six) reported being fluent in English or having some English language proficiency (seven). One respondent reported having minimal English and two had no English language skills. An equal number of respondents had completed secondary school education (six) and tertiary education (six); the remaining four had primary or no schooling.

Experiences of Caring

"I often compare my emotions to a roller-coaster ride, with many ups and downs. There are days when I feel suicidal. There are days when I feel happy that I am helping another human being." (FGD participant)

"I try to forget all the 'downs' in my caring role and concentrate on the 'ups'. I am very positive by nature, but tend not to bottle my feelings and verbalise them instead. When I reach a crisis point, I close the door of my bedroom and scream my lungs out. It helps." (daughter carer)

"I think that unless you find yourself in the caring role, you couldn't possibly understand what's involved in caring for someone else." (FGD participant)

The respondents from Polish background found themselves in a variety of care situations. Eight of the sixteen respondents cared for their parents, five cared for partners, two cared for sisters and one cared for a friend. Most (eight) had been caring for their care recipients for between three and nine years, five had been in their caring roles for 10 or more years, and two had been caring for two years or less (the remaining one was recorded as unknown). Twelve of the respondents were living with their care recipient, two care recipients lived alone, and two were in residential accommodation. The age of care recipients ranged from 63 to 95, with the mean being 82. Care recipients suffered from a diverse range of conditions, the majority requiring intensive levels of care.

The experiences of caring among the respondents from Polish background ranged from very positive to very negative. While some noted a sense of satisfaction and sense of fulfilment in being a carer, all acknowledged the physical, emotional and financial

demands of caring, and the fact that their lives had been totally re-gearred to meet the needs of their care recipients. Some also added that nothing could have prepared them for the difficulties they had encountered in their roles as carers and that no one could really understand what caring for another person involves until one experienced it for oneself.

For some respondents in this group, caring had had a significant negative impact on their relationships with, for example, spouses, children, siblings and friends. Some respondents also reported problematic, even hostile, relationships with their care recipients. These situations appeared to place extra strain on the caring role. For example, one woman talked openly about the fact that she had never had a good relationship with her mother, that she resented having to care for her and that she had only negative feelings about her mother and about her situation. Another respondent who visited her mother in a hostel on a daily basis reported feeling extremely stressed as a result of her mother's very demanding, domineering and negative attitude. Two other respondents, respectively caring for a sibling and father, cited examples of how their caring role had resulted in tensions within their marriages, even to the point of break-ups.

Many also expressed their frustration and dissatisfaction with the aged care system and saw it as a poor alternative to the care they can provide, and the fact that their financial struggles are neither recognised nor compensated by the Government.

Values and Expectations about Caring

"I am not a hero, I believe that caring for my husband is the only thing I can do in this situation. It is not a matter of choice. I know that no matter how unwell I feel or what else is happening in my life, I will always care for my husband." (spouse carer)

"I feel it is my duty to look after my mother, but do it only because I have no other choice. After so many years of caring for my mother, I just feel sick and tired of it. She has never been grateful for what I do for her." (daughter carer)

"My religion has taught me that one needs to look after one's mother and one's father. The family unit is sacred." (daughter carer)

Having a sense of duty and moral responsibility were among the main values to emerge from the respondents of Polish background. So too were notions of punctuality, obedience, honesty, hard work, stoicism and emotional strength. Respondents also spoke of being taught by their parents and families not to complain, to 'get on with things' and to develop a 'thick skin' approach to problems. Some felt that the outcome of these teachings was that family conflict was not discussed and remained unresolved. They believed that this also impacted on their ability to constructively discuss and negotiate their caring role with their care recipient.

Most participants in the focus group believed that they expected too much of themselves as carers but, paradoxically, did not perceive their efforts as good enough in their own eyes. All of them felt that they had no choice but care for their loved ones and believed that they were the best people to provide the care for that reason.

Many respondents had not considered how they were perceived by others in their caring role, nevertheless a number expressed the impression that the Polish community treated carers rather harshly in that carers were expected to remain in their role until the person

their care recipient dies, without really understanding what is involved in caring for another person. A number also raised the point they had been taught by their families 'not to wash their dirty laundry in public', some respondents adding that they were influenced by community perceptions of 'right' and 'wrong' and that many of their decisions were based on this.

Nine of the Polish-background respondents identified religion and/or spirituality as playing a large part in their lives. Most of these (seven) were practicing Catholics who attended church regularly where they sought inspiration and respite from daily tasks of caring. Two of the individual interviewees indicated that the Ten Commandments were played a part in their caring roles and in their lives in general.

Attitudes to Self Care

"I can't remember the last time I went to the movies or the opera. What I do for my mother consumes all my free time. When I did try to go out, I felt so guilty that I did not enjoy it at all." (daughter carer)

All the respondents from Polish background found it difficult to find the time to dedicate to self-care activities; in fact, many had had to give up interests they had prior to becoming carers. The majority did nevertheless acknowledge the importance of taking regular time out from carer duties, citing activities such as walking, swimming, yoga, meeting friends and going to church as ways of (time permitting) relieving their stress. Some, however, reported feeling a sense of guilt about doing things for themselves or did not take part in activities for fear of something happening to their care recipient in their absence.

Attitudes to Support Networks and Services

"My family doesn't help me in my caring duties. They are all busy with their families, work and their own problems. I have helped them for many years, but understand that they live their own lives and fight their own battles." (spouse carer)

"Respite services? I feel I would never use them because, while I am out, anything could happen to my husband. And if it did, I would feel guilty for the rest of my life". (spouse carer)

"I have a different view to that of my community in regards to residential care. I am neither for it nor against it. In most cases, people who make a decision to place their loved ones in a residential facility see it as a necessity after reaching a crisis point." (FGD participant)

The majority of the Polish respondents reported that they had little or no support from family members and friends. A number highlighted that asking for help had been a source of conflict within the family. In four instances, respondents acknowledged that their commitment to caring had caused tensions with spouses and other members of their immediate families. There was an overwhelming sense among respondents that nobody really understood or appreciated their circumstances.

Half (eight) of the respondents from Polish background received home help services, however, a number of these reported being dissatisfied with the service because of

frequent staff changes, lack of clarity about the role of home care workers, different workers having different approaches to their duties, and the limited nature of the service. Seven of the respondents had attended a Polish-speaking carer support group. Although all of them reported finding it helpful, several mentioned the fact that it had cheered them up initially, but at the end of the day they still went back to sometimes-depressing lives. One respondent also mentioned that he would probably no longer attend because his wife did not like to be left alone.

Only one of the respondents had used respite services on a single occasion, two were currently exploring options for respite care. The former had been unable to continue because her care-recipient spouse, who suffered from dementia, had believed that his respite worker was a second wife. The majority of respondents expressed that they were not likely to use respite services because they felt uncomfortable about leaving their loved one with a stranger and hence would not enjoy the free time. One respondent believed she would never use respite because she would look after her husband better than anyone else.

Two of the Polish respondents were already using residential care for their care recipients. Both were visiting their care recipients on a daily basis and providing a range of domestic duties such as cooking, washing and shopping. On a number of occasions throughout her interview, one of these respondents expressed her sense of guilt for placing her husband in residential care. Although she acknowledged that she had reached a point where she was no longer able to care for her husband, and had seen an improvement in her husband since he was in residential care, she admitted that was considering taking him home again because of her sense of guilt. Her situation had been exacerbated by a backlash from members of her community who had criticised her actions.

Several other respondents said that they had considered using residential care, however, most felt that they would use it only as a last resort and only if they could no longer cope with the demands of caring. One respondent indicated that she had reached this point in her caring role and was in the process of seeking appropriate residential care for her father. Quite a part from feeling very guilty at being unable to fulfil her commitment to looking after her father, she was feeling despondent at the lack of culturally appropriate residential care services available to him.

A number of the participants in the Polish-speaking focus group discussion also talked about their negative impressions after visiting aged care facilities.

Others also referred to language barriers preventing them from seeking professional services, and to feeling the additional stresses of dealing with an aged care system that is at times confusing and disorienting.

Carers from Turkish Background

Profile of Respondents

There were 10 respondents from Turkish background; seven participated in individual interviews and three in the Turkish-speaking focus group discussion. All the respondents were female, most of whom (six) were aged between 40 and 59 years. Of the remaining respondents, two were aged between 25 and 39, and two between 60 and 74. With the exception of one person who was divorced, all the respondents were married.

Eight of the respondents were born in Turkey, while the remaining two were born in Cyprus. All the respondents had been in Australia for 10 years and the majority (eight) migrated over 20 years ago. Most respondents (nine) were over the age of 16 when they migrated, with the youngest age at migration being 11 and the oldest being 28.

All the respondents cited Turkish as their preferred language, the majority having some (four) or minimal (five) English language proficiency. Only one person reported being fluent in English. Most of the respondents (six) had attended primary school; the remaining four had been to secondary school.

Experiences of Caring

"Sometimes my mother-in-law is like an angel when I care for her, I feel that I am rewarded by God ... but sometimes we have falling outs when she acts in a certain way towards my children. Then I have moments that I become angry, but this does not mean that I want to remove her from my life." (daughter-in-law carer)

"It's a good feeling. At least I feel comfortable, because I am with her every second, this makes me relaxed that I am providing care. However, it is difficult to care for her, I'm looking after my own house and her house, I am running in between the two houses all day ... because she is unwell I am worried ... My mental health is deteriorating." (daughter carer)

"My mental health can become affected and I can become nervous. I do not show this to him, but I eat myself up with worry. However, I am definitely not complaining about him ... he will always have his place with us ... when I get frustrated, my husband reminds me that he is an old man, he is my father and he is our ancestor." (daughter carer)

All the Turkish-background respondents were caring for people who had multiple illnesses or conditions, and who were in high care need situations. With the exception of one respondent who was caring for her spouse, all were caring for a parent (five) or mother-in-law (four). The majority (six) had been caring for 10 or more years, three had been caring between three and nine years, and only one had cared for two years or less. Nearly all the respondents (eight) were living with their care recipient, with one care recipient living in a granny flat and another living in her own home. The age of care recipients ranged from 66 to 86, with the mean being 78.

All the Turkish respondents spoke about the experience of providing care to their family members as being both positive and negative. They all mentioned negative impacts on their own mental and physical health as a result of anxiety about their care recipient's health, family conflict caused by their co-residential status, or the physical demands of providing personal care. However, they all also characterised being a carer as a rewarding experience and they spoke of 'feeling good' about providing care to their elderly family members.

Three respondents spoke about the impact of a co-residential parent or parent-in-law care recipient on their relationship with their own children. There was discussion of intergenerational value differences causing conflict (for example around disciplining children or appropriate social behaviour).

Values and Expectations about Caring

"I was expected to look after my mother-in-law. If you didn't, then you would not have a good relationship with your husband." (daughter-in-law carer)

"It doesn't matter if I am sick or even if it is very difficult to care for her. When you are God-fearing, not looking after your mother and father would be a very disrespectful thing to do. Looking after them is a form of prayer." (daughter carer)

"I do not think [being a carer] has anything to do with religion. I think it has more to do with humanity. Yes, I believe religion is very important for me, however, I value humanity. Religion comes after, it doesn't matter if I am a Muslim or a Christian." (daughter-in-law carer)

Respondents from Turkish background spoke about their own expectations of themselves as carers in terms of meeting both the physical and emotional needs of their care recipients. A number spoke about the importance of their care recipient not feeling like a 'burden' and the importance of concealing their own negative feelings about providing care. There were mixed feelings about whether or not families expected them to provide care, with the focus group agreeing with the comment, 'there is no push for us to provide care from our families', while six of the individual interviewees said they thought their families expected them to look after elderly family members.

Most participants (seven) felt that family care was expected by members of the Turkish community in Australia. They did not specify whether they perceived caring to be a gendered role, although the spouse carer did see providing care to her husband as part of her role as a wife and some of the women spoke about their husbands' and children's expectations that as women they would carry out domestic tasks such as cooking and cleaning. Members of the focus group commented that community members would be likely to comment negatively if they did not look after their parents and/or parents-in-law or if they placed them in nursing homes.

All respondents identified themselves as Muslims and saw religion as an important part of their lives, with some identifying it as a significant source of strength for them in carrying out their carer role. At least two respondents identified caring as a form of prayer. Several, however, made the point that they did not provide care because of their Muslim faith (despite its teachings to look after the sick and elderly), but rather because it was a 'natural' and 'humane' act based on 'commonsense'.

The majority of participants (eight) identified respect for the elderly and parents as values influencing their caring role. The focus group all agreed that this had been modelled by their own parents and one individual interviewee identified her caring for her mother as modelling for her own children.

There was a strong theme among the responses from Turkish-background carers that caring was part of their role within the family and that it was important to be compassionate and loving in the provision of care, even in the face of conflict and high demand from care recipients.

Attitudes to Self Care

"I am so overwhelmed that I do not have time for myself. I do not have anything that is just for me." (daughter-in-law carer)

"I actually go for walks everyday for 45 minutes with friends. It is a great feeling. We talk, we laugh on these walks." (daughter-in-law carer)

Nearly all respondents were able to identify activities that they undertook as acts of self care. These included reading the Qu'ran, prayer, visiting friends, exercising and watching TV. However half (five) said it was difficult to find time for themselves and one respondent said she felt guilty spending time on herself.

All focus group members thought self care was important for personal rejuvenation. However, no participant identified self-care activities without prompting.

Attitudes to Support Networks and Services

"If they can help me at home I would use services, but I would never leave her in a nursing home. ... I don't want to use a nursing home for myself, therefore how could I want this for my mother-in-law? My traditions, my upbringing does not accept this. I would lose respect for myself. If I leave my mother-in-law to a hostel or similar place then one day my children can do the same thing to me." (daughter-in-law carer)

"If I could I would not want to use these services [residential respite or permanent residential care]. However, if I become older and if I cannot care for him I would have to use them ... No one can provide the delicate care that I provide to him." (spouse carer)

"I think it [a Carer Support Group] is very good. People would provide support to each other. People would get advice from each other." (spouse carer)

Nearly all respondents reported that they received assistance in their carer roles from their children (both sons and daughters), husbands and/or brothers and sisters. This support took the form of moral and financial support, as well as practical help with cooking, cleaning, transport and personal care of their care recipients.

The respondents from Turkish background were generally comfortable with the idea of in-home assistance with domestic and nursing tasks. Four respondents reported using and being satisfied with HACC and district nursing services, while a further two respondents had used Meals on Wheels in the past, but had stopped it due to their care recipients' boredom/dissatisfaction with the meals. Those respondents currently not using these types of services did not do so either because they felt they did not yet need them (three) or because they did not have appropriate information about how to access them (three).

There were mixed attitudes about the use of respite care, with some respondents having refused offers of such care. Two respondents thought it was a good idea for both them and the care recipient. A further four respondents said they would use respite care in future if it was needed. Two respondents said that they would not use respite care because their care recipient would not like it and they, as carers, would feel guilty. Two respondents felt it was their role to provide care and one felt that respite care would not provide the same quality of care as available within the family.

With the exception of one person, respondents from Turkish background expressed very positive attitudes towards carer support groups. All spoke of the benefits of sharing the carer experience and receiving advice and information about their carer role. The respondent who reported that she would not want to attend a carer support group commented that she was already involved in Mosque-based activities and that she would talk to her husband and children if she needed to discuss carer issues.

Nursing home care was universally felt by respondents to be a last resort, only to be used if they were no longer physically able to provide care to their family members. A number of respondents commented that it was culturally inappropriate to place family members in a nursing home and expected negative community comment if they did so. This was summed up in the comment:

"My mother does not approve of families who have used [residential care services] because they are far away from the family ... I would not like to use them. When they have children who could care for them, it's not right to put them into nursing homes. She [my mother] might receive excellent care in these places; however, the services cannot provide the closeness that the children can give." (daughter carer)

Two respondents described using residential care (if there were family members healthy enough to provide care) as 'a sin'.

Carers from Vietnamese Background

Profile of Respondents

There were 16 respondents from Vietnamese background; 10 participated in individual interviews and six participated in the Vietnamese-speaking focus group discussion. The majority of respondents were female (14), with the two male participants part of the focus group discussion. The respondents varied in ages: two were aged between 25 and 39, eight were aged between 40 and 49, and the remaining six were aged between 60 and 74. The majority of respondents (nine) were married, three were single, two were widowed, one was divorced and one was separated.

All the respondents were born in Vietnam. Six had been in Australia between six and 10 years, nine between 10 and 20 years, and one had been in Australia over 20 years. It is notable that the Vietnamese respondents migrated to Australia at a later life stage than other groups in the study, with 13 arriving after the age of 31; of these, six arrived after the age of 50.

All the respondents cited Vietnamese as their preferred language, with four reporting some English language proficiency, five reporting minimal English language proficiency and five stating that they spoke no English. Two respondents reported being fluent in English. The majority of respondents had attended secondary (seven) or tertiary (four) education. Of the remaining five respondents, three reported having no schooling and two reported attending primary school.

"I feel sad, isolated sometimes, and physically very tired as I have to look after my husband almost 24 hours a day without any support. I cannot get enough sleep ... [however] I want to care for him because I know that he wants me to care for him and I also want to give him my love and support." (spouse carer)

"Caring for my parents has obviously impacted on my emotions, lifestyle and my relationships ... however, I don't see it as a big deal." (daughter carer)

"I feel really fulfilled because I have the opportunity to care for my mother when she is old and frail. I believe that looking after my mother is my duty, I don't feel I have been put at a disadvantage." (daughter carer)

Experiences of Caring

The majority (12) of Vietnamese respondents were caring for their parents or parents-in-law; the remaining four cared for their partners. The majority (13) had been caring for three or more years, and five of these had been caring for 10 years or more. All but two of the respondents were living with their care recipient; these two were reported to have care recipients living with others. The age of care recipients ranged from the 66 to 102, with the mean being 80 years of age.

All the respondents from Vietnamese background were caring for family members with a range of illnesses (mainly relating to being frail aged) requiring full-time care. Many were providing assistance with toileting and bathing, and all were responsible for the full range of domestic chores. They described the experience of providing care as being physically and emotionally stressful. They used terms such 'very tiring', 'depressing', 'isolating', 'hard work', 'emotionally and socially isolating', 'financially draining' and 'repetitive'. However, all these difficulties were tempered, for nearly all respondents, by positive feelings about the caring role as a way of fulfilling filial or spousal duties, and preserving

family values and traditions. Some made reference to having 'no regrets' about the sacrifices that caring entailed. Overall the individual interviewees were more positive about their experience of caring than the focus group discussion participants.

Many of the carers looking after very elderly parents commented that they felt fortunate to still have the opportunity to look after their parents.

Values and Expectations about Caring

"I feel happy about caring for my husband. I see it as a duty of a wife to look after her husband." (spouse carer)

"I believe that it is part of my role to fulfil my filial duty. Looking after my frail mother not only provides her with good loving care, but also sets a good example for my children. That reflects my family tradition and values." (daughter carer)

"I feel positive about caring for my mother-in-law because looking after her is the most valuable thing for me to do ... If I didn't need to look after my mother-in-law, I would do some voluntary work in nursing homes." (daughter-in-law carer)

There was universal acknowledgment among the respondents of Vietnamese background that they come from a Confucian tradition that places great emphasis on interdependence within the family, on respect for and duty toward elderly parents, and on the importance of filial piety. This was perhaps best summed up by the Vietnamese saying quoted by one respondent, 'rely on your parents when you are young - rely on your children when you are old.' This value of family reciprocity also extended to spouses who expected to care for one another in old age.

In terms of what they expected of themselves as carers, many respondents referred to not only giving practical assistance, but also providing 'love and support' to their care recipients. They spoke of 'pampering', being 'sensitive to their needs' and being 'gentle'. Offspring carers all agreed that their families expected them to provide care to their elderly parents. There was universal agreement that the Vietnamese community in Australia expects family care of the elderly and that this role was a source of pride.

All respondents cited religion as being an important feature of their lives, both in terms of teaching them the family values that influence their current caring role and in terms of providing support and strength to carry out their tasks. The majority of respondents were Catholic, with two stating they were Buddhist. Regardless of which faith they belonged to, there was also discussion of the cultural influences of Confucianism and ancestor-worship in terms of their values about caring for elderly family members.

Some respondents referred to learning their values from the example set by their own parents with their grandparents and hoped to provide a similar example to their own children. However, not all respondents expected to be cared for by their children, with two stating that they did not want to 'burden' their children and that they expected to enter residential care.

Attitudes to Self Care

"We don't really have time to think about ourselves much." (FGD participant)

"We feel very stressed sometimes. We forget to look after our health due to the fact that we are too busy looking after our family members." (FGD participant)

Individual interviewees did not mention self care at all per se, but referred to their religious beliefs and love for their family members as the source of their strength for maintaining their caring role. One respondent spoke about 'forgetting to look after' herself. Focus group discussion participants discussed the fact that they felt they had no time for themselves or for their children due to their carer role. However, they also stressed the importance of sacrificing their own needs and desires to meet the needs of their care recipient and the satisfaction they derived from this.

Attitudes to Support Networks and Services

"I will never use residential care for my mum because I will miss my mother, and she will miss me. ... If for any reason I am unable to look after my mother, then my children will look after her for me." (daughter carer)

"My parents always feel that if they ask someone to come to look after them, it would mean they bother other people too much." (daughter carer)

"I think respite services need to increase the time for people in my situation so that we can have more time to rest." (spouse carer)

There was a high dependence on family support (both practical and emotional) in this group, with the majority of respondents from Vietnamese background not using any carer support services. However, this did not necessarily reflect an opposition to use of these services. The participants in the focus group discussion noted that the extent to which family support could be relied upon would depend on how many family members were in Australia.

Only one respondent had used respite care (and was satisfied with the service and recommended it to others), but a further seven said they thought such a service was a good idea. Two of these respondents cited their care recipients' opposition as the reason for not using respite care. A further two said that if they did not have family members who could assist they would use respite care, and one respondent is currently in the process of organising in-home respite care.

Respondents were universally positive in their attitudes towards a carer support group, although three said they would not attend such a group. Many did add that the group would need to be conducted in Vietnamese and focus group participants also discussed the need for bilingual workers to inform them about support services available for carers.

Residential care was universally seen as a last resort and only to be used if no family members were available to provide care. There was an implicit suggestion that the Vietnamese community would be critical of someone who used residential care for a family member, with three respondents saying that if they had to use residential care they would not feel as if they had done their best to look after their loved one.

Discussion of Findings

Profile of Respondents

With the exception of all but one person in the Anglo-Celtic group, all respondents had come to Australia as migrants. All of the Greek and Italian respondents had resided in Australia for over 20 years, with the majority living in Australia for over 40 years. This closely reflects the largest waves of migration of these groups to Australia during the 1950s and 60s. Consistent with the general trend for these groups most had arrived as young adults.

The Polish group of respondents also reflected the different waves of Polish migration to this country. Half (8) of the respondents arrived over 20 years ago during the post-war migration period; the other eight had lived in Australia 20 years or less reflecting the most recent wave of Polish migration during the 1980's. What was notable about this group of respondents was the significant proportion (7) of people who migrated over the age of 40.

The Turkish and Vietnamese respondents also typically reflected the respective waves of migration to Australia of these groups. As with general migration trends of the Turkish community to Australia, the majority of respondents arrived during the 1960s and '70s. The Vietnamese target group was the only one in the sample that included people from refugee background. The majority of Vietnamese respondents had arrived in the post refugee family reunion phase beginning in 1985.

Of all of the groups of respondents, those from Greek background recorded the lowest level of English language proficiency. This is in keeping with the generally low levels of English proficiency among Greece-born people over the age of 65 in Australia. The other group of respondents to record low English language proficiency were the Vietnamese with over half (10) indicating that they had minimal or no English. This also reflects the trends in the broader Vietnamese community in Australia where 43% report that they do not speak English well or at all.

Although all the groups had typically more female than male respondents, the Greek and Turkish samples were all females. The Greeks were further homogenous by way of age with all the respondents falling between the ages of 60 and 74, while respondents in all other groups represented a broader range of age groups.

With respect to levels of education, the Greek respondents were once again notable with all having either no or very low levels of education. Once again this correlates closely with the overall education levels of Greece-born women in Australia, 62% of whom have either never attended school or left school before the age of 15. The Anglo-Celtic group of respondents had proportionally higher levels of education than any of the other groups with all but one of the fourteen respondents having completed either secondary or tertiary studies.

In comparing care recipients between groups, the Greeks stood out once again as more homogenous than other groups of respondents in that all were caring for their husbands, the majority of whom were aged 70 years and over. Although all the other groups reflected a wider range of care dyads, the Turkish and Vietnamese respondents were notable as the only groups to have daughters-in-law (and in the case of the Vietnamese, one son-in-law) caring for a parent.

In comparing the profile of care recipients, the Vietnamese also stood apart for the proportion of respondents who had care recipients over the age of ninety and indeed over the age of one hundred.

Experiences of Caring

While there were some themes about the experience of caring that emerged within specific target groups, and some themes that seemed to be universal (see discussion below), there was also overall a high degree of diversity and individuality in respondents' experience of caring both within and between target groups.

Personality and personal circumstances played a role in all groups, particularly in terms of carers' relationships with their care recipients. Across the groups there were care dyads characterised by the full spectrum of interpersonal relationships from mutual love and support through to hate and disrespect. It is therefore important to exercise caution in drawing generalisations about the experiences of caring in particular target groups based on the relatively small sample size of this research project. However, many of the issues raised below are consistent with the findings of other studies of carers from diverse cultural and linguistic backgrounds.

There were many aspects of the experience of caring that applied to respondents regardless of cultural background. For example, respondents in all groups spoke about both positive and negative aspects of caring for an elderly family member or friend. Many respondents expressed a tension between their dedication to their care recipient and carer duties on the one hand, and the difficulties caused by their caregiving role on the other.

All respondents identified experiencing emotional and physical stresses as a result of being a carer, however, some groups tended to have a more positive outlook overall than others. For example, respondents from Vietnamese background placed an emphasis on their carer role imparting a sense of satisfaction and fulfilment, and respondents from Turkish background commonly made reference to experiencing a 'good feeling' due to being a carer. Respondents from Vietnamese background were unique in referring to their good fortune in having their parents still alive at (in some cases) very old ages and for having the opportunity to provide care for them.

It is notable that not all carers identified their caring role as being grounded in positive values of familial duty or love or out of a desire to do the best for their care recipient. In such cases the nature of the relationship between the carer and care recipient prior to the need for care was notably negative and sometimes abusive. Some of these carers characterised the motivational factors in their provision of care in terms of new-found personal power and the ability to wreak revenge on the care recipient for past injustices. This was expressed emotionally rather than physically.

Values and Expectations about Caring

In analysing and comparing the different target groups' responses regarding values and expectations, it is worth considering that it can be difficult to both identify and articulate concepts that are often implicit in behaviour and not consciously acknowledged. A further complication is the potential differences in communication styles between cultures and the difficulty of translating particular words and concepts from one language to another. For example, some words may be more freely used in some languages and cultures than in others. In this research the concept of providing care as an expression of 'love' for their care recipient was more often mentioned by Vietnamese and Anglo-Celtic respondents than members of other target groups. However, it cannot be inferred from this that

respondents who did not articulate their care giving acts in this way do not have such feelings for their care recipients.

In terms of expectations about caring, respondents universally spoke of caring for the elderly as a family responsibility. Many respondents made the point that they think of themselves as 'daughters', 'partners' or 'siblings' rather than as 'carers'. In doing this they were acknowledging their carer role as part of their familial relationship, rather than as separate from it.

Expectations did vary, however, in terms of at what point it was appropriate, or possible, for a carer to relinquish any aspect of care. For some groups, there was generally a belief that all carer tasks needed to be carried out by the carer as long as they were physically capable (eg Greek respondents), while other groups were generally more willing to accept family or outside assistance in meeting their carer responsibilities (eg Anglo-Celtic respondents).

Statistically, it is known that most carers in the Australian community are women. This was reflected in this study (largely by chance rather than design) by the predominance of female respondents. Indeed, in target groups that included male respondents, this was by design, with an effort made to recruit at least one or two men. In terms of cultural values relating to the gender-specificity of the carer role, only participants of Greek backgrounds expressly identified caregiving as a woman's role and responsibility. It is also worth noting that the majority of male participants in this study were spouse carers, while there were a significant number of daughter carers represented by the female respondents.

Respondents were asked about their perceptions of community expectations of carers. In some target groups, respondents found it easier to articulate these community expectations than in others. For example, the respondents from Greek and Vietnamese backgrounds noted that other members of their ethnic communities expected family care of the elderly and would be critical of those who did not provide it. Conversely, many respondents from Italian background found it difficult to identify community expectations and some made the point of saying that, if such expectations existed, they were not relevant to them in their decision making as carers.

In terms of the values that informed respondents' behaviours as carers, the word 'duty' was commonly used across all target groups as a reason for caring for their family members. In further analysing the context of this remark, however, it became evident that the term 'duty' held nuanced meanings specific to different groups of respondents. For Vietnamese respondents, duty was generally understood in the sense of 'filial piety'; for the Anglo-Celtic respondents, it was more akin to 'doing the right thing'; for respondents of Greek background, duty could be interpreted as meaning having no choice but to provide care; for Polish respondents it was a moral responsibility; Turkish respondents understood duty in terms of religious teachings; and Italians spoke of duty in terms of respect and obedience to parents.

Some groups were more homogenous than others in terms of the values they identified or implied in discussing their carer role. It is notable, in the case of the Greek respondents, that the demographic features of this group were highly similar, perhaps explaining the homogeneity of their responses. For example, the Greek respondents consistently referred to the importance of keeping carer difficulties within the privacy of the family, the relevance of self-denial and the gendered nature of caring as a wifely responsibility. The most significant theme to emerge from the Italian respondents was that of self-sacrifice, while from the Turkish respondents it was the idea of caring as a humane act and the Vietnamese strongly emphasised filial piety as the main value influencing their attitudes

to caring. The Anglo-Celtic, Turkish and Vietnamese groups significantly spoke of the importance of treating their care recipients with kindness, love and compassion, as much as fulfilling their physical requirements. The Polish group were less homogenous in their responses, although there was some emphasis on valuing stoicism.

When asked about the influence of religion on their beliefs and values, some respondents across all target groups identified it as a relevant factor in their attitudes towards caring for their loved one. There were varying degrees of religious devotion and practice in each group, with participants identifying the expected dominant faiths (ie Greek Orthodox for Greeks; Catholic for Italians, Poles, Vietnamese and Anglo-Celts; Buddhist for Vietnamese; Muslim for Turks; and other Christian denominations for Anglo-Celts). Not all respondents who identified religion as important in their lives rated it as a relevant influence on their values and beliefs around caring.

Although all respondents, with the exception of those from the Anglo-Celtic background, were asked about their migration experience and subsequent life in Australia, it was not possible from the data gathered to draw any significant conclusions about the impact that this had had on their experiences as carers. One might have expected, for example, that respondents from the longer established communities (Greek, Italian and Polish) would exhibit higher levels of acculturation to mainstream Anglo-Celtic beliefs and values. This was not borne out by this research where high levels of cultural and language maintenance were exhibited. This was particularly the case with the Greek respondents who clearly held a set of views that seemed not to be influenced to any great degree by acculturation to Anglo-Celtic values. Conducting research with the second generation of these groups may well demonstrate higher levels of acculturation.

Although the Italian and Polish respondents showed more diversity in their responses, some of which more closely reflected the ideals of the Anglo-Celtic group, we can only infer that this may be because of acculturation as the research tool was not designed to specifically measure this.

Although some respondents identified the migration experience as fragmenting and diluting support networks of family and friends, it was notable that this recognition did not affect their expectations of themselves as family care givers. As such, while they suggested that it would be easier to provide care in their home country environments, their new environment did not seem to influence their values about caregiving or accessing support services.

It is possible that there is a link between the personal experiences of migration and the ability of participants to provide care in what were, in some cases, very challenging circumstances. Most respondents characterised their migration experience as painful and initially socially isolating. For some respondents there was also an expectation of a better life which they perceived as not being realised. Perhaps these life experiences of loss, grief and dashed hopes had a role in increasing the self-reliance and strength of respondents leading to higher expectations of themselves as caregivers.

Attitudes to Self Care

Attitudes towards self care varied significantly across target groups with Anglo-Celtic and Greek carers at polar extremes. Overall, Anglo-Celtic carers believed in the importance of self care, both for personal satisfaction and to maintain wellbeing so as to be able to continue providing care. All Anglo-Celtic participants were able to identify activities they undertook as acts of self care. At the opposite end of the spectrum, respondents from Greek backgrounds generally rated self care as unimportant and unattainable. They had

no expectation of looking after themselves and did not identify any acts of self care, although some did identify religious faith and counselling from priests as sources of strength for their caring role.

Of the other groups, respondents from Polish and Turkish backgrounds acknowledged the importance of self care to maintain physical and mental wellbeing, but not all were able to identify acts of self care. Some Polish respondents also referred to guilt experienced when undertaking activities to meet their own needs. Overall, respondents from Italian background said they did not have time for self care and that their needs appropriately came after those of their care recipient. Some Italian respondents did identify prayer and attending Mass services as a source of support and strength in carrying out their carer responsibilities. (It is worth noting that the focus group was conducted with members of a carer support group who, by their membership, were engaging in a self-care activity.) The Vietnamese group did not provide any examples of self care, and spoke of gaining satisfaction from the self-sacrificial act of caregiving.

Attitudes to Support Networks and Services

There were a variety of attitudes expressed between and among target groups regarding the use of carer support services that reflected universal, cultural and individual perspectives.

Across all groups, with the exception of those from Greek background, there were respondents that were already using, or had previously used, a range of HACC and home nursing services. Not all were satisfied with the services they had received, respondents from Polish background particularly noting their dissatisfaction with some aspects of HACC services. Respondents from Greek background, who were all spouses, were notable for refusing any services on the basis of their care recipients' unwillingness to accept professional help and because accepting services was perceived as tantamount to failing in their carer role.

All target groups perceived full-time residential care as a last resort for their care recipient; however, there did seem to be cultural differences as to the understanding of 'last resort'. For example, Anglo-Celtic respondents, while keen to keep their care recipients living independently in their own homes for as long as possible, were resigned to having to use residential care if their carer role became too physically demanding. In contrast, respondents from Vietnamese background saw residential care only as an option if there were no other family members available (there was a perception that other family members would take on the role if they could no longer manage). These values are reflected in the statistics on the use of nursing home care which show significantly lower levels of use by people from Vietnamese-speaking background compared to those from main English speaking countries. Greek respondents spoke of residential care only being an option if they themselves had passed away. This difference is consistent with earlier Victorian studies (Schofield et al 1998, p173).

In terms of their attitudes towards respite care, the majority of respondents in all target groups were keen to respect their care recipients' preferences, even if these differed from their own preferences. It was common to hear the comment that the care recipient 'would not like' to be left in the care of anyone else, even if the carer had identified that they would like a break from their carer role. Some respondents also spoke about guilt at leaving the care recipient with professional service providers (this was particularly notable in the Polish target group).

Attitudes towards carer support groups were largely individually determined. However, there was a notable degree of homogeneity in beliefs about such groups expressed by respondents from Greek and Vietnamese backgrounds respectively. Although support groups for carers of Greek speaking background do exist, these Greek respondents were universally opposed to such groups on the basis that public discussion of what was perceived to be family business was inappropriate and would lead to community gossip. In contrast, the Vietnamese participants were universally in favour of carer support groups, citing their benefits in terms of mutual carer support and information provision. This is an interesting finding given the recent attempt to establish a Vietnamese carer support group in the Western suburbs of Melbourne. The group disbanded once the pilot period was over.

While issues relating to access and equity - such as knowledge of services, the availability of information in languages other than English, and language-specific services - was a barrier for some people in accessing support (this was particularly raised by respondents from Polish, Turkish and Vietnamese backgrounds), for many their reluctance to use a seek or accept support had more to do with their cultural or personal belief and value systems.

Conclusion

This research project presented Carers Victoria with an opportunity to gain direct insight into the beliefs and values of carers from six different ethnic backgrounds living in Victoria.

The study reinforced the original hypothesis that beliefs and values have a direct bearing on:

- the way carers perceive and carry out their roles
- what carers are prepared to tolerate and take responsibility for
- the priority that carers place on self care, and
- the point at which, if at all, carers seek professional support services

The research findings also reinforced the notion that carers are, for the most part, cognisant of family and community expectations regarding their role and are influenced by these to more or lesser degrees.

Despite a great deal of diversity in caregiving situations both within and between the target groups, the study highlighted a number of themes and issues consistent with carers across the board (and previously highlighted by other studies as discussed in the literature review). These themes included:

- the view that care is predominantly a family-based responsibility
- the fact that caring has both emotional and physical impacts on carers, as well as impacts on their relationships and their lifestyles
- the fact that all carers seek to fulfil their care responsibilities to the best of their abilities, within the mental and physical resources available to them, for as long as they deem it possible for them to do so
- the fact that carers define themselves primarily by their familial relationships within the family (eg as 'wife', 'son', or 'daughter') and not as 'carers'

The study also highlighted the fact that despite there being a number of similarities in the beliefs and values of respondents from the same ethnic group, there were also many differences between them based on the nature of their:

- personal attributes
- individual and family circumstances, and
- past and present relationship with their care-recipient

The findings present a number of challenges and opportunities for those workers and services concerned with and committed to providing culturally sensitive and appropriate carer support services. Among these challenges are for individual service providers and their organisations:

- to be open to a diversity of attitudes and ideas about caring, some of which may not sit comfortably with their own values or may sit opposite to their views
- to be conscious of their own value base and the impact of this on the nature of services established [for example while some carers want a break from their carer duties, they do not want a break from their care recipient making residential respite care as it is currently structured an unattractive option]
- to treat the insights gained through this research as just that, insights, that need to be tested afresh which each new client from the ethnic groups represented in this study
- to recognise that the focus on caring as a family responsibility based on sometimes

complex family relationships requires working closely with carers not just as individuals but within the context of their families (this is particularly important for those carers who do not value individualism but rather a collectivist approach]

- to work for more open acknowledgment and discussion of carer responsibilities and experiences among all groups as part of a broader community discussion to promote more recognition of the role carers play and the issues that are affecting them
- to understand that the key to working effectively with carers from any cultural background is to seek out and uncover the meanings that carers themselves attach to their caring role and the factors that motivate them [eg the carer who sees caring as a way of pleasing God and is motivated by fulfilling the will of God or the carer who sees their caring as living up to family and community expectations and is motivated by wanting to set a good example for their children].

Facing these challenges will bring service providers that much closer to providing support that both respects carers' own perspective of their role and is meaningful and appropriate to the needs of individual carers.

Recommendations

It is recommended that:

1. Carers Victoria seek funding to implement a second stage of the current project, to be carried out in collaboration with ethnic organisations which will draw on the findings to explore better ways of supporting carers in addressing their own needs for health and wellbeing. This action research project will form the basis for improved carer support.
2. Carers Victoria develop for publication a series of composite case studies drawn from the data of the project to be used for community education, policy making and lobbying.
3. Carers Victoria develop education and training modules for mainstream and bilingual workers based on the data of the project, aimed at improving worker sensitivity to carers. Resources to underpin the modules to include handouts about culturally sensitive practice, workers' understanding of their own values and beliefs about culturally sensitive practice.
4. Carers Victoria promote the findings of the project through presentation of conference papers as opportunity presents.
5. Carers Victoria work with ethnic organisations in promoting awareness and understanding of carers and their needs.
6. Carers Victoria develop a pilot project with Carer Links West aimed at exploring flexible service (respite) responses to carers of culturally and linguistically diverse backgrounds: the findings of this project to be promoted to regional respite services in Victoria. Knowledge and experience of Carer Links West in working with CALD communities (eg. Carer retreats) to additionally inform the project's focus.

Service Providers

1. Service providers use the findings of this research to inform their own practice in culturally appropriate services to carers. In particular, service providers need to be aware of the key messages about avoiding stereotyping and recognising the impact of beliefs and values on carers' perceptions and approaches to caregiving, which influence responses to service access.
2. Service providers, mainstream and ethno-specific, ensure appropriate education and training for staff that acknowledges the influence of organisational and personal values of staff on their approach to carers.

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Appendix A: Reference Group Members

Emma Contessa, CO-AS-IT

Elizabeth Drozd, Australian Polish Community Services

Lucy Foley, Ethnic Communities Council of Victoria

Eugenia Georgopoulos, Australian Greek Welfare Society

Marek Grzelinski, Australian Polish Community Services

Nebahat Keceli, Turkish Community Representative

Huong Nguyen, Australian Vietnamese Women's Welfare Association

Ljubica Petrov, Partners in Culturally Appropriate Aged Care

Joyce Rebeiro, Carers Victoria

Yola Samplawski, Australian Polish Community Services

Ann Seitz, Swinburne University

Dimitra Xinarios, Australian Greek Welfare Society

Appendix B: Acronyms Used and Glossary

AGWS:	Australian Greek Welfare Society
CALD:	Culturally and Linguistically Diverse
CVic:	Carers Victoria
HACC:	Home and Community Care
NESB:	Non English Speaking Background
carer/caregiver:	a person who has the primary responsibility for supporting and providing the care needed by the care-recipient. They may live with the care recipient or in another household.
spouse carer:	a carer in a married, de facto or gay or lesbian relationship who provides care to their partner.
offspring carer:	a carer who provides assistance to a parent, including parents-in-law.
care-dyad:	the pair of carer and care-recipient.
care recipient:	a person who requires support and assistance due to disability, chronic illness or frailty in old age.
activities of daily living:	dressing, bathing, eating, toileting, getting in and out of bed/chair, etc.
domestic duties:	activities involved in maintaining the home such as cleaning, washing, cooking, gardening, etc.
self care:	the activities undertaken by a carer to maintain their own physical and mental wellbeing. These include a diverse range of activities such as, but not limited to, socialising, exercise, prayer, hobbies, personal grooming etc.
culture:	for the purposes of this study culture is defined as multifaceted, learned patterns of behaviour, values, attitudes, beliefs and social structures transmitted from one generation to the next by a society or population group
values:	one's judgement of what is valuable or important in life based on one's principles and standards
beliefs:	the acceptance of sets of things, facts, statements, etc. as true and existing
ethnic group:	A group of like-minded people in whose cultural practices one finds and ethnic identity. An ethnic group may be defined in terms of race, nationality, religion, language or combinations of these.

Appendix C: Respondent demographics

Anglo-Celtic Interviews

Ethnicity	Anglo-Celtic x 8
Place of Birth	Australia x 7 UK x 1
Preferred Language	English x 8
English Language Proficiency	Fluent x 8
Australian Residency	Over 20 years x 8
Age at Migration	N/A x 7 28 x 1
Age	40-59 x 1 60-74 x 1 75 & over x 4
Gender	Female x 6 Male x 2
Education Level	Secondary x 5 Tertiary x 3
Marital Status	Married x 6 Single x 1 Divorced x 1
Relationship to Care Recipient (CR)	Adult offspring x 4 Partner x 4
Duration of Care	2 years or less x 1 3-9 years x 5 10 years or more x 2
Living Arrangements	Co-resident x 6 CR lives alone x 1 Other x 1 (granny flat)
Main Condition of CR	<ul style="list-style-type: none">• Diabetes• Dementia, frail aged• Stroke, arthritis, cancer, limb mobility, frail aged• Arthritis, limb mobility, frail aged• Heart disease, limb mobility• Heart disease, hypertension, diabetes, limb mobility, kidney failure• Hypertension, diabetes, arthritis, limb mobility• Stroke, heart disease, frail aged
Age of CR	92 x 1 90 x 1 89 x 2 88 x 1 80 x 1 78 x 2

English-Speaking Focus Group

Ethnicity	Anglo-Celtic x 6
Place of Birth	Australia x 6 Preferred Language English x 6
English Language Proficiency	Fluent x 6 Australian Residency Over 20 years x 6
Age at Migration	N/A
Age	40-59 x 3 75 & over x 3
Gender	Female x 4 Male x 2
Education Level	Primary x 1 Secondary x 3 Tertiary x 2
Marital Status	Single x 1 Married x 5
Relationship to Care recipient (CR)	Adult offspring x 1 Partner x 3 Brother/brother-in-law x 2
Duration of care	2 yrs or less x 3 3-9 years x 1 10 years or more x 2
Living Arrangements	Co-resident x 6
Main condition of CR	<ul style="list-style-type: none">• Dementia x 3• Heart disease, arthritis, frail aged, kidney-failure• Dementia, deafness, chemical sensitivity syndrome
Age of CR	84 x 3 78 x 2 70 x 1

Greek Interviews

Ethnicity	Greek x 8
Place of Birth	Greece x 8
Preferred Language	Greek x 8
English Language Proficiency	Some x 3 Minimal x 5
Australian Residency	Over 20 years x 8
Age at Migration	15 x 1 17 x 1 18 x 2 19 x 1 21 x 1 22 x 1 24 x 1
Age	60-74 x 8
Gender	Female x 8
Education Level	No schooling x 6 Primary x 2
Marital Status	Married x 8
Relationship to Care recipient (CR)*	Partner x 8 Daughter in law x 1
Duration of care	3-9 years x 5 10 years or more x 3
Living Arrangements	Co-resident x 8
Main condition of CR*	<ul style="list-style-type: none"> • Stroke, arthritis • Diabetes, arthritis • Stroke, heart disease, mental illness • Cancer • Hypertension, limb mobility, arthritis • Frail aged • Quadriplegia, chronic asthma • Arthritis, emphysema • Heart disease, hypertension, amputation
Age of CR*	95 x 1 76 x 1 72 x 2 71 x 1 70 x 1 69 x 2 68 x 1

*One respondent cared for two family members

Greek-Speaking Focus Group

Ethnicity	Greek x 8
Place of Birth	Greece x 8
Preferred Language	Greek x 8
English Language Proficiency	Some x 5 Minimal x 5
Australian Residency	Over 20 years x 8
Age at Migration	15 x 1 17 x 2 18 x 1 20 x 1 21 x 2 25 x 1
Age	60-74 x 8
Gender	Female x 8
Education Level	No schooling x 4 Primary x 4
Marital Status	Married x 8
Relationship to Care recipient (CR)	Partner x 8
Duration of care	3-9 years x 5 10 years or more x 3
Living Arrangements	Co-resident x 8
Main condition of CR	<ul style="list-style-type: none"> • Diabetes, arthritis • Hypertension, diabetes, dementia • Stroke • Heart disease, diabetes, frail aged • Stroke, diabetes, sensory • Cancer • Arthritis, cancer • Arthritis, quadriplegia
Age of CR	75 x 2 72 x 2 71 69 x 3

Italian Interviews

Ethnicity	Italian x 8
Place of Birth	Italy x 8
Preferred Language	Italian x 8
English Language Proficiency	Fluent x 1 Some x 6 Minimal x 1
Australian Residency	Over 20 years x 8
Age at Migration	18 x 1 19 x 1 21 x 1 24 x 1 26 x 2 34 x 1 36 x 1
Age	60-74 x 6 75 & over x 2
Gender	Female x 6 Male x 2
Education Level	Primary x 4 Secondary x 3 Tertiary x 1
Marital Status	Married x 8
Relationship to Care recipient (CR)	Partner x 8
Duration of care	2 years or less x 2 3-9 years x 2 10 years or more x 4
Living Arrangements	Co-resident x 8
Main condition of CR	<ul style="list-style-type: none"> • Stroke, diabetes, sensory • Stroke, cancer • Dementia, blindness • Heart disease, diabetes, multiple hernias • Diabetes, blindness • Stroke, heart disease • Dementia • Arthritis, dementia
Age of CR	83 x 1 82 x 1 81 x 1 80 x 1 79 x 1 72 x 1 70 x 1 60 x 1

Italian-Speaking Focus Group

Ethnicity	Italian x 11
Place of Birth	Italy x 10 Australia x 1
Preferred Language	English x 1 English or Italian x 4 Italian x 6
English Language Proficiency	Fluent x 4 Some x 6 Minimal x 1
Australian Residency	More than 20 years x 11
Age at Migration	Less than 10 years x 3 11-20 years x 2 21-30 years x 4 31-40 years x 1
Age	NA x 1 40-59 x 4 60-74 x 5 75 & over x 2
Gender	Female x 9 Male x 2
Education Level	Primary x 5 Secondary x 5 Tertiary x 1
Marital Status	Married x 10 Widowed x 1
Relationship to Care recipient (CR)*	Adult offspring x 5 Parent x 1 Partner x 6
Duration of care	2 years or less x 1 3-9 years x 5 10 years or more x 5
Living Arrangements	Co-resident x 8 CR lives alone x 3
Main condition of CR	<ul style="list-style-type: none"> • Acquired brain injury • Dementia x 9 • Brain tumour
Age of CR	92 x 1 91 x 1 89 x 1 84 x 2 79 x 1 77 x 1 71 x 1 70 x 2 52 x 1

*One respondent cared for two family members

Polish Interviews

Ethnicity	Polish x 8
Place of Birth	Poland x 8
Preferred Language	Polish x 7 English x 1
English Language Proficiency	Fluent x 2 Some x 6
Australian Residency	3-5 years x 1 10-20 years x 3 Over 20 years x 4
Age at Migration	8 x 1 26 x 2 33 x 1 38 x 1 47 x 1 49 x 1 50 x 1
Age	40-59 x 3 60-74 x 4 75 & over x 1
Gender	Female x 6 Male x 2
Education Level	Primary x 2 Secondary x 2 Tertiary x 3
Post graduate x 1	Marital Status Married x 4 Defacto x 1 Divorced x 1 Separated x 1
Relationship to Care recipient (CR)	Adult offspring x 4 Partner x 3 Brother x 1
Duration of care	3-9 years x 4 10 years of more x 4
Living Arrangements	Co-resident x 6 Hostel x 2
Main condition of CR	<ul style="list-style-type: none"> • Hypertension, frail aged • Heart disease, frail aged • Cancer • Dementia • Frail aged, spinal injury • Blindness, liver failure • Dementia, limb mobility • Stroke, limb mobility, frail aged
Age of CR	95 x 1 85 x 3 81 x 1 80 x 1 74 x 1 65 x 1

Polish-Speaking Focus Group

Ethnicity	Polish x 8
Place of Birth	Poland x 7 Australia x 1
Preferred Language	Polish x 6 English x 2
English Language Proficiency	Fluent x 4 Some x 1 Minimal x 1 None x 2
Australian Residency	6-10 yrs x 2 10-20 x 2 Over 20 years x 2
Age at Migration	3 x 1 27 x 1 40 x 1 48 x 1 49 x 1 62 x 1 63 x 1 N/A x 1
Age	25-39 x 1 40-59 x 2 60-74 x 3 75 & over x 2
Gender	Female x 7 Male x 1
Education Level	No schooling x 1 Primary x 1 Secondary x 4 Tertiary x 2
Marital Status	Married x 2 Widowed x 2 Single x 2 Divorced x 2
Relationship to Care recipient (CR)	Adult offspring x 3 Parent x 1 Partner x 2 Brother x 1 Friend x 1
Duration of care	2 years or less x 2 3-9 years x 4 10 years or more x 1 unknown x 1
Living Arrangements	Co-resident x 6 CR lives alone x 2
Main condition of CR	<ul style="list-style-type: none"> • Stroke • Cancer • ABI, heart disease, hypertension, diabetes, frail aged • Dementia • Mental illness • Diabetes, arthritis, frail aged
Age of CR	89 x 1 87 x 2 82 x 2 79 x 1 78 x 1 63 x 1

Turkish Interviews

Ethnicity	Turkish x 7
Place of Birth	Turkey x 5 Cyprus x 2
Preferred Language	Turkish x 7
English Language Proficiency	Fluent x 1 Some x 3 Minimal x 3
Australian Residency	10-20 years x 2 Over 20 years x 5
Age at Migration	16 x 1 18 x 1 19 x 1 22 x 1 25 x 1 28 x 1 unknown x 1
Age	25-39 x 2 40-59 x 3 60-74 x 2
Gender	Female x 7
Education Level	Primary x 3 Secondary x 4
Marital Status	Married x 6 Divorced x 1
Relationship to Care recipient (CR)	Adult offspring x 4 Partner x 1 Daughter-in-law x 2
Duration of care	2 years or less x 1 3-9 years x 1 10 years of more x 5
Living Arrangements	Co-resident x 6 CR lives with others (children)
Main condition of CR	<ul style="list-style-type: none"> • Heart disease, hypertension, diabetes, cancer, limb mobility, frail aged • Stroke, heart disease, arthritis, mental illness, limb mobility, frail aged • ABI, stroke, heart disease, diabetes, dementia, frail aged • Heart disease, diabetes, arthritis, limb mobility, frail aged • Heart disease, hypertension, arthritis, limb mobility, Parkinson's • Hypertension, diabetes, arthritis, limb mobility, frail aged • Hypertension, diabetes
Age of CR	86 x 1 84 x 1 80 x 1 78 x 1 76 x 1 75 x 1 66 x 1

Turkish-Speaking Focus Group

Ethnicity	Turkish x 3
Place of Birth	Turkey x 3
Preferred Language	Turkish x 3
English Language Proficiency	Some x 2 Minimal x 1
Australian Residency	20 years and over x 3
Age at Migration	11-20 years x 2 21-30 years x 1
Age	40-59 x 3
Gender	Female x 3
Education Level	Primary x 3
Marital Status	Married x 3
Relationship to Care recipient (CR)	Daughter-in-law x 2 Daughter x 1
Duration of care	3-9 years x 2 10 years or more x 1
Living Arrangements	Co-resident x 2 Granny flat x 1
Main condition of CR	<ul style="list-style-type: none">• Hypertension, arthritis, frail aged, asthma• Hypertension, arthritis, frail aged• Acquired Brain Injury, dementia, frail aged
Age of CR	78 x 2 72 x 1

Vietnamese Interviews

Ethnicity	Vietnamese x 10
Place of Birth	Vietnam x 10
Preferred Language	Vietnamese x 10
English Language Proficiency	none x 5 minimal x 5 some x 4 fluent x 2
Australian Residency	6-10 years x 4 10-20 years x 6
Age at Migration	22 x 1 27 x 1 30 x 1 32 x 1 34 x 1 57 x 1 59 x 1 58 x 2 60 x 1
Age	25-39 x 2 40-59 x 3 60-74 x 5
Gender	Female x 10
Education Level	No schooling x 3 Primary x 2 Secondary x 3 Tertiary x 2
Marital Status	Married x 4 Widowed x 2 Single x 3 Separated x 1
Relationship to Care recipient (CR)	Adult offspring x 6 Partner x 3 Daughter-in-law x 1
Duration of care	2 years or less x 1 3-9 years x 5 10 years or more x 3 Unknown x 1
Living Arrangements	Co-resident x 10
Main condition of CR	<ul style="list-style-type: none"> • Frail aged • Mental illness, sensory, frail aged • Limb mobility, frail aged • Heart disease, hypertension, arthritis, dementia, frail aged • Hypertension, sensory, frail aged • Hypertension, diabetes, arthritis, dementia, limb mobility, frail aged, sensory • Dementia • Limb mobility, low blood pressure, paralysis • Limb mobility, asthma, spinal injury • Hypertension, dementia, frail aged
Age of CR*	102 x 1 100 x 1 97 x 1 92 x 1 87 x 1 83 x 1 80 x 1 78 x 1 75 x 1 72 x 1 71 x 1

*One respondent cared for two care recipients

Vietnamese-Speaking Focus Group

Ethnicity	Vietnamese x 6
Place of Birth	Vietnam x 6
Preferred Language	Vietnamese x 6
English Language Proficiency	Some x 4 Minimal x 2
Australian Residency	6-10 years x 2 10-20 years x 3 20 years and over x 1
Age at Migration	56 x 1 41 x 1 36 x 1 35 x 1 34 x 1 33 x 1
Age	40-59 x 5 60-74 x 1
Gender	Male x 2 Female x 4 Education Level Secondary x 4 Tertiary x 3
Marital Status	Married x 5 Divorced x 1
Relationship to Care recipient (CR)	Adult offspring x 3 Partner x 1 Daughter-in-law x 1 Son-in-law x 1
Duration of care	2 years or less x 3 3-9 years x 1 10 years or more x 2
Living Arrangements	Co-resident x 4 CR lives with others x 2
Main condition of CR	* Frail aged and severe intestinal disorder * Dementia * Hypertension, dementia, frail aged * Stroke * Heart disease, hypertension * Stroke
Age of CR	85 x 1 80 x 1 76 x 1 74 x 1 72 x 1 66 x 1

Appendix D: Individual Interview Schedule

Introduction

Thank you very much for agreeing to be interviewed. The aim of the interview is to talk about your experience as a carer, what you think about your caring role and the things that are important to you as a carer. Anything you say will be completely confidential.

This interview is part of a series of interviews that Carers Victoria is conducting with carers from six different ethnic communities. We hope that by finding out about these things we will be able to better assist service providers to support carers.

Administrative Matters

Before we begin the interview proper, there are a few administrative matters to take care of:

- **Participant Consent Form (Compulsory)**
(work through consent form with participant)
- **\$30 payment & Supplier Form (Compulsory)**
Explain that:
 - they need to sign the 'Supplier Form'
 - the form is to make sure that Carers Victoria is accountable for government funds
 - this form will be kept on file at Carers Victoria separately from the research results so confidentiality is maintained
- **Contact Information for Research Results (Voluntary)**
Finally, at the end of this research process we will be writing a report and we would like to give you the opportunity to be informed of the research results and how they will be used. If you would like to be informed, we will need your name and address - again, this information will be kept entirely separately from the research results, so confidentiality will be maintained.

Demographic Information

(Collect as per table)

Interview Questions

Background

The purpose of this series of questions is to find out about the person's background in terms of upbringing and the circumstances surrounding his/her migration to Australia.

The questions serve mostly as icebreakers and for building rapport, but also provide a backdrop for the participant's experience as a carer. The person's responses may also reveal information about beliefs and values about their role as carers. For example, the person may believe that care is a family responsibility. They may have grown up in a large extended family (in which carer duties were expected to be shared) but, after migrating to Australia, find themselves with fewer family and social networks. This may compound their isolation in their carer role given their belief that it is not appropriate to ask for extra-familial assistance.

Q1 How did you (your family) decide to come to Australia?

Prompts: What were the reasons for leaving?; what were the reasons for coming to Australia instead of another country; who made the decision?

Q2 Describe to me what your experience in Australia has been like

Probe for feelings of satisfaction/dissatisfaction/isolation/social integration.

Q3 Tell me a little about your life in (country of origin)...

Probe for type of upbringing, family circumstances, family values etc.

Experience of caregiving

Now I'd like to talk about your experience as a caregiver ...

The purpose of this series of questions is to find out as much as possible about the person's experience as a caregiver and their feelings about this role. We are interested in details about who they care for, how long they have been caring for them, the tasks they undertake as carers, the impact that caring has had on their lives. We are particularly interested in finding out how the caring role has affected things like health, emotions, lifestyle, finances and relationships.

Q4 Can you tell me about the sorts of things you do for _____?

Prompts: What types of tasks do you undertake? How long do they take?

Q5 You've been looking after _____ for _____ months/years now, can you tell me what is it like for you to care for _____?

Prompt: What impact has being a carer had on you personally?

Probe for impact on health, emotions, lifestyle, finances and relationships.

Expectations about the carer role

The aim of this series of questions is to find out the expectations the person has about their role as a carer and compare these expectations with those of others around them. There are often many unwritten rules in a family and community about who should take on the carer role. The carer may confront the challenge of trying to live up to other people's expectations as well as their own (which may conflict). Question 9 is also designed to give participants the opportunity to reflect on the expectations of the carer role without focusing on their own personal experience - it may be easier for them to articulate expectations in a less subjective fashion.

Q6 In looking after _____, what do you expect of yourself as a carer?

Q7 Do you think that _____ expects the same things of you?

Q8 What do you think your family expects of you as a carer?

Q9 What do you believe people in your community expect of carers?

Probe: If these expectations are different from what they have articulated in Q6, probe for how they feel about this difference.

Values influencing the carer role

The purpose of this series of questions is to find out the underlying values that inform participants' behaviours in their role as a carer. It is possible that participants will have difficulty articulating these values and will need assistance in 'getting at' their own beliefs and attitudes. The questions, prompts and probes are designed to assist with revealing beliefs and values. Participants may already have touched on these issues in responding to earlier questions, so you can build on these in asking the following questions.

Q10 We spoke at the beginning about your background and your upbringing, for many people part of that is religion, how important would you say religion is in your life.

Probe for particular religion?

Q11 Do you think religion has had any influence on your beliefs and values about your role as a carer?

Prompts: In what ways has your religion been an influence? Are there particular religious practices affecting your caring role?

Q12 What do you believe it means to be a carer?

Prompts: Can you complete the sentence ... "A carer should"

Q13 Can you now tell me a little about how do you feel about caring for _____?

Probe for positive and/or negatives feelings about their carer role.

Q14 Caring for someone can be hard work, what would you say sustains you or gives you the strength to care for _____?

Prompts: How do you feel about finding time to do things for yourself? What types of things do you do to look after your own needs? Are there things that you used to do that you can't do now? How important is this to you?

Networks and Support

The purpose of this series of questions is to find out what support the participant has in their role as carer. We are not so much interested in 'access and equity' issues (ie, what systemic barriers may exist to the participant accessing support), but rather what beliefs or values they may hold that prevent them from seeking assistance. We are also interested in to what extent participants have good support networks that preclude the need to seek help from 'official' service providers.

Q15 Do you receive any support from family and/or friends in your carer role?

Prompts: What, if any, sort of support have they offered? Who are the people who have been most helpful to you?

Q16 Have you tried to access support outside of family and friends? (If no go to next question. If yes, follow with question 18)

Q17 Can you tell me what reasons you have for not accessing outside support?

Prompt: What has stopped you from doing so? What would help you in accessing services? What do you think might make things easier?

Q18 What services have you accessed and how do you feel about them?

Probe for use of meals on wheels, home help/maintenance, home nursing.

Q19 One of the things some carers do is use respite services ...

(Respite services can supply a trained person to provide support at home or at facilities such as day care centres, hostels and nursing homes. Respite can be for a few hours, days or for longer periods.)

How do you feel about using respite care for _____?

Prompt: Have you used it? Would you contemplate using it in the future? Reasons for not wanting to use respite care?

Q20 Another thing that some carers do is attend Carer Support Groups ...

(People go to carer support groups to have a break, meet other carers and share ideas, information and concerns.)

How do you feel about such groups?

Prompt: Do you think you would ever attend?

Q21 Do you think that you would ever use Residential Care for _____?

(Residential care is when the person is cared for full time by professional carers in a nursing home, hostel or supported residential service.)

Prompt: Have you used it? Would you contemplate using it in the future? Reasons for not wanting to use residential care?

Q22 Do you know of any other carers in your community? Do you know if they receive any sort of help or services? What do you think makes it possible/different for them?

Closing

It is important in closing the interview to leave participants on a positive note. Other carers have reported that having the opportunity to speak about their experiences has validated their role, and often they see themselves as 'better off' than other carers. The last question is designed to leave the participant with an acknowledgement of the importance of the carer role.

Q23 That brings me to the end of the questions I had planned to ask you. Before we close, is there anything else you would like to add to what we have discussed?

Q24 Just before we finish, how has it felt to talk to someone about all these carer issues?

Now that we have finished the interview, I'd like to give you some information about Carers Victoria and services available to carers. There is also a tape you might like to listen to that includes a relaxation session. If you want to contact someone about carer support services, you can dial the freecall number 1800 242 636 [show them the Carer Resource Centre brochure].

Thank you very much for your time and insights today. The information you have given us will be very valuable in gaining a better understanding of carers' beliefs and values.

Note: Sometimes participants will provide you with a lot more information once the formal interview is over (eg as they farewell you at the front door or gate), be prepared for this and write down any additional valuable information as soon as you have left the participant.

Appendix E: Focus Group Discussion Guide

Introduction

Thank you very much for agreeing to participate in this focus group discussion. The aim of today's discussion is to talk about your experiences as a carer, what you think about your caring role and the things that are important to you as a carer.

While I have some specific questions I'd like to ask today, it's important that you feel free to discuss issues together. [Decide how you want to establish 'rules' for discussion.]

This focus group is part of a number of discussions that Carers Victoria is conducting with carers from six different ethnic communities. We hope that by finding out about these things we will be able to better assist service providers to support carers.

Administrative Matters

Before we begin the focus group, there are a few administrative matters to take care of:

- **Participant Consent Form** (Compulsory)
(work through consent form)
- **\$30 payment and supplier form** (Compulsory)

Explain that:

- they need to sign the 'Supplier Form'
- the form is to make sure that Carers Victoria is accountable for government funds
- this form will be kept on file at Carers Victoria separately from the research results so confidentiality is maintained)
- Contact Information for Research Results (Voluntary)

Finally, at the end of the research process we will be writing a report and we would like to give you the opportunity to be informed of the research results and how they will be used. If you would like to be informed, we will need your name and address - again, this information will be kept entirely separately from the research results so confidentiality will be maintained.

Demographic Information

(collect as per table)

- Q1 The aim of this research is to explore beliefs and values around caring. Our beliefs and values usually begin to be formed in childhood. So let's start with, what were the main values you were taught in childhood?**
- Q2 What is it like to be a carer?**
Prompt: What impact has being a carer had on you personally?
Probe for impact on health, emotions, lifestyle, finances and relationships.
Probe for positive and/or negatives feelings about their carer role.
- Q3 What do you believe your role is as a carer?**
Probe regarding expectations of themselves.
- Q4 Do you think that the person you care for expects the same things of you?**
- Q5 What do you think your family expects of you as a carer?**
- Q6 What do you believe people in your community expect of carers?**
Probe: If these expectations are different from what they have articulated in Q3, probe for how they feel about this difference.
Prompt: Complete the following sentence, "A carer should ..."
- Q7 Caring for someone can be hard work, what would you say sustains you or gives you the strength to care for _____?**

Prompt: How important would you say religion is in your life?

Probe: What religion?

Q8 How do you feel about looking after yourself?

Prompts: How do you feel about finding time to do things for yourself?

What types of things do you do to look after your own needs?

Are there things that you used to do that you can't do now? How important is this to you?

Q9 Do you receive any support from family and/or friends in your carer role?

Prompts: What, if any, sort of support have they offered?

Who are the people who have been most helpful to you?

Q10 What's your opinion/experience about seeking services outside family and friends?

Prompts: Have you tried to seek outside help? If yes, how do you feel about these services?

If no, what has prevented you from doing so? What would make it easier?

Q11 One of the things some carers do is use respite services.

(Respite services can supply a trained person to provide support at home or at facilities such as day care centres, hostels and nursing homes. Respite can be for a few hours, days or for longer periods.)

How do you feel about using respite care for _____?

Prompts: Have you used it?

Would you contemplate using it in the future?

Reasons for not wanting to use respite care?

Q12 Another thing that some carers do is attend Carer Support Groups.

(People go to carer support groups to have a break, meet other carers and share ideas, information and concerns.)

How do you feel about such groups?

Prompt: Do you think you would ever attend?

Q13 Do you think that you would ever use Residential Care for _____?

(Residential care is when the person is cared for full time by professional carers in a nursing home, hostel or supported residential service.)

Prompts: Have you used it?

Would you contemplate using it in the future?

Reasons for not wanting to use residential care?

Q14 Many carers we have spoken to have said they won't use outside services/support until they are incapable of caring and carrying out the task themselves, what do you think about that?

Closing

It is important in closing the focus group to leave participants on a positive note. Other carers have reported that having the opportunity to speak about their experiences has validated their role, and often they see themselves as 'better off' than other carers. The last question is designed to leave the participant with an acknowledgement of the importance of the carer role.

Q15 That brings me to the end of the questions I had planned to ask you. Before we close, is there anything else you would like to add to what we have discussed?

Q16 Just before we finish, how has it felt to talk to someone about all these carer issues?

Now that we have finished the interview, I'd like to give you some information about Carers Victoria and services available to carers. There is also a tape you might like to listen to that includes a relaxation session. If you want to contact someone about carer support services, you can dial the freecall number 1800 242 636 [show them the Carer Resource Centre brochure].

Thank you very much for your time and insights today. The information you have given us will be very valuable in gaining a better understanding of carers' beliefs and values.

