Culturally and linguistically diverse carers' perceptions of the cultural appropriateness of carer support services: An exploratory study

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Culturally and Linguistically Diverse Carers’ Perceptions of the Cultural Appropriateness of Carer Support Services: An Exploratory Study

Andrea Creado

A report submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Arts/Science (Psychology) Honours, Faculty of Computing, Health and Science, Edith Cowan University. Submitted (June, 2010)

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7/6/2011
Culturally and Linguistically Diverse Carers' Perceptions of the Cultural Appropriateness of Carer Support Services

Abstract

Research on service utilisation by primary family carers has highlighted that carers from culturally and linguistically diverse (CALD) backgrounds face specific barriers in accessing services, such as lack of culturally appropriate services, communication issues, prejudice, feelings of failure and misunderstanding of mental illness. However, little is known about how to best overcome these factors from the carers' perspective. The aim of this study was to investigate the perceptions CALD carers had of the cultural appropriateness of carers' support services available in Perth. Ten primary family carers from CALD backgrounds participated in a semi-structured interview to explore their perceptions of existing services. Their responses were analysed using qualitative methodology and four significant themes emerged: emotional impact of caring, service usage (respite, emotional, social and financial support services), barriers in accessing services and suggestions for making services culturally appropriate. Findings indicated that the biggest challenge carers faced was managing the behaviour of their care recipient and expressed an acute need for education programs that could help them cope better. Carers expressed the need for information about disabilities, support services and financial benefits, to be given to them by service providers as soon as they assumed the caring role and suggested culturally appropriate ways of disseminating information. Carers preferred culturally diverse service providers for respite and counselling services but not necessarily for education and social support programs. However they preferred to participate in multicultural social support groups and would like to choose the language in which they received information about services and disabilities. Encouragement from service providers to use services, ability to discuss their needs with service providers, having information on disabilities and services widely available in various languages, frequent personal contact from service providers, help with dealing with paper work related to financial benefits, consistent and low cost respite services delivered by professional ethno specific staff, were some of the suggestions given to make services culturally appropriate.

Andrea Creado

Dr. Justine Dandy

June, 2010
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Dated 31/6/2011
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With the shift in government policies to move health care from institutions and hospitals to home and community care settings, research on home-based carers has increased in momentum (Higginson & Sengupta, 2000; Nolan, 1997). Carers have been studied according to gender, age, ethnicity, type of illness or disability of the care recipient and duration of care, type of services received and usefulness of services. The impact of caring on the physical and mental health of the carers, as well as the social and financial impact of caring and perceptions of the caring role have also been explored (Andren & Elmstahl, 2008; Chipchase & Lincoln, 2001; Connell & Janevic, 2009; Hancock, Jarvis, & L’Veena, 2007; Hepworth 2007; Hoare, Harris, Jackson, & Kerley, 1998; Kosloski, Montogmery & Karner, 1999; McKeown, Porter-Armstrong, & Baxter, 2003; Sansoni, Vellone, & Piras, 2004; Zodikoff, 2007). However, little research attention has been devoted to understanding the perceptions of carers about the cultural appropriateness of services. Therefore the aim of the present study was to examine the perceptions culturally and linguistically diverse (CALD) carers had of the cultural appropriateness of services (whether social, emotional, respite or financial) provided for them in Western Australia.

Definition of ‘Carer’ and Scope of this Review

In everyday discourse, the term ‘carer’ is used in many ways, including to describe a foster carer, or a grandparent who is the primary carer of a healthy grandchild, a child care worker, an aged care worker or a formal paid carer who provides care to an individual who is ill, disabled or frail aged either in the home or
hospital. However, for the purpose of this study the definition of a primary carer is “A carer is a person who provides care or assistance to another person who is frail, has a disability, a chronic illness or a mental illness, without payment apart from a pension, benefit or allowance” (Carers’ Recognition Act, 2004).

Whilst there is a body of literature related to services for main stream carers and young carers, the focus of this research is on adult CALD carers and therefore the literature reviewed relates to services provided for adult carers from a CALD background.

**Background Of Caring In Australia**

According to a report published by the Australian Bureau of Statistics (2004) it is estimated that 2.6 million Australians provide care to individuals who are ill, disabled or frail aged. Of these, approximately 19% are primary carers, that is, they are the main source of unpaid and informal care, and annually these primary carers save the Australian economy $30.5 billion (Access Economics, 2005). The Australian Bureau of Statistics in 2006 recorded approximately 400,000 carers who were born outside Australia, of which about 277,400 spoke a language other than English at home (ABS, 2008).

On average, carers spend approximately 40 hours per week providing care (ABS, 2004). Caring duties including feeding, bathing, dressing, toileting, administering medication, visits to the medical practitioners, providing emotional support, managing finances and sometimes transporting care recipients (Carers Australia, 2007). The Australian government recognizes the enormous economic and social contribution carers make to the community and in 2010 passed the Carers Recognition Bill in Parliament that recognizes the rights of carers. This bill states that carers have the same rights and choices as other Australians, should have access
to services that are timely and appropriate, should be treated with dignity and respect and should be supported in their caring role so that they can maintain their own health and wellbeing (Carers Recognition Bill, 2010).

A survey carried out by Carers Australia (2007) on carers’ health and wellbeing found that caring could be one of the leading causes of depression in Australia, with carers not receiving treatment due to lack of time and financial resources. Caring also reduces carers’ wellbeing and makes them twice as likely to experience chronic pain, with almost a third of carers experiencing extreme stress. Without support, caring can have a negative impact on the physical, mental and emotional health of carers (Carers Australia, 2007). A report by Access Economics (2005) found that the productivity loss due to carers not being able to engage in the workforce because of their caring responsibilities is about $4.9 billion. In addition to an economic loss to the nation, caring causes financial strain to carers in both the long and short term (Carers Australia, 2007; Dow, Haralambous, Giummarra, & Vrantsidi, 2004) which means that carers have to cope with financial strain in addition to the physical, mental and emotional burden of caring.

Given that approximately 50% of carers in Australia who are born overseas speak a language other than English with about 15% of these reporting they did not speak English at all (ABS, 2006), and the impact the caring role has on the wellbeing of carers, it is important to understand the impact the caring role has on CALD carers and how services can enhance their wellbeing.

**CALD Carers’ Perceptions Of The Caring Role**

Research has shown that not all members from ethnic minority communities identify themselves as ‘carers’ based on the formal definition of carers (EDAC,
The term 'carer' has different cultural conceptualizations and can conflict with a range of cultural understandings in relation to family dynamics, filial relationships and responsibility towards the care recipient (EDAC, 2003; Markovic & Manderson, 2007). Often carers from ethnic minority groups living in culturally diverse societies such as Australia identify themselves more in terms of the filial relationship to the care recipient, like parent, sibling or child, rather than as a 'carer'. They view 'caring' as a duty or responsibility rather than a label that describes them (Cardona, Chalmers, & Neilson, 2006). In Australia, a majority of CALD carers do not identify themselves as 'carers' and some find it difficult to accept they have assumed the caring role (Bittman, Fisher, Hill, Thomson, & Thomson, 2004). One possible reason for not accepting the term 'carer' could be that the term implies an emotional detachment between the carer and the care recipient, focusing only on the physical tasks of caring (Parker, 2000). Identifying oneself as a carer gives an individual certain rights and responsibilities (Shaver & Fine, 1995). However, as noted above, identifying oneself as a carer is not always apparent in CALD communities. In addition, the term is associated with the role being a burden rather than the role being one of mutual support. This relationship with caring being a burden can be demeaning to both carer and care recipient and often leads to the rejection of the title and subsequently renders some services invisible to carers and vice versa (Wilson, 1998).

Acceptance of services by CALD carers is dependent on the various perceptions carers have of their caring role. If the tasks to be carried out by the carer were perceived to be culturally appropriate, accepting external help to carry out those tasks would not be acceptable. For example, in Botswana whilst examining the perceptions family carers had of accepting help in looking after an ageing relative,
the authors Shaibu and Wallhagen (2002) found that it was considered unacceptable for a daughter to engage services from an external agency to help with the intimate tasks (like bathing and washing of underwear) of caring for an ageing parent, but acceptable for a son to accept similar help if he was caring for an ageing parent. This was further illustrated in an Australian study where the perceptions of eight Russian women about their caregiving role was explored by Markovic and Manderson (2007). Through in-depth interviews with women and service providers the authors concluded that because women thought of their caring role as their duty and not as a social construct, they did not think of accessing any social support. Similar findings were found in a Canadian study on migrant female carers, by Neufeld, Harrison, Stewart, Hughes and Spitzer (2002). The authors of both the Canadian and Australian studies concluded that changes to social policy are required in order to make welfare support more accessible to carers from CALD backgrounds.

Other perceptions held by CALD carers like stigma towards mental illness and dementia also prevented carers from using services, as was highlighted in the UK based study by Mackenzie (2006). In this study the author found that cultural understanding of dementia influenced South Asian and Eastern European carers decisions’ to engage with services, with those carers that felt high levels of stigma, not engaging with services. Furthermore, while comparing the support needs of South Asian, Black Caribbean and White British carers of people with dementia in another UK based study, authors Lawrence, Murray, Samsi and Banerjee (2008) found that that those carers who held a traditional view of their caring role as being a ‘virtuous’ state, found it easier to accept formal services if they perceived the service to be beneficial to the care recipient. The study also found that South Asian carers with traditional views did not ask for professional help because they viewed it as a
failure to fulfil their responsibilities. This finding was also reported in the study by Shaibu and Wallhagen (2002) where registering the elderly for help with a government agency meant that the family had failed in its duty to provide for their ageing relative. In their discussion Lawrence and colleagues (2008) state that services may be perceived to be more appropriate if they could communicate “their commitment to respecting individual preferences for care, and to supporting, rather than substituting, family members in the care giving role” (Lawrence et al., 2008, p. 244). These studies have highlighted that the perceptions held by carers clearly influenced their decision to engage with services.

Impact Of Services On Carers

The caring role, whether the person identifies with the term carer or not, has an impact on the carer’s wellbeing (Dow et al., 2004; EDAC, 2003) and it has been suggested that CALD carers should have access to culturally appropriate services that meet the specific cultural needs of carers and their families (Cardona et al., 2006). Much of the research related to service utilization has focussed on the use of respite services and educational programs. There is a lack of research on other support services like social, psychological and financial support, therefore in examining the the impact of services on CALD carers there is more emphasis on respite and educational support.

Respite and psychosocial support.

Studies exploring the impact of respite service on carers have shown that if carers are not satisfied with services they are less likely to engage with services. For example, in a Finland based study, Raivio and colleagues (2007) sent out postal questionnaires to determine carer satisfaction with respite services. Their sample consisted of 1943 carers, of which only 39% reported being satisfied with respite
services and 69% stated that they felt they had no influence on the services offered. As these results were obtained by analysing responses to a postal survey it eliminated the opportunity to explore the reasons for dissatisfaction and led the authors to conclude that official services poorly met the expectations of carers. A study of this magnitude would have added valuable insights on how services could be improved if the researchers had given the participants an opportunity to suggest areas of improvement.

Similar findings of dissatisfaction were reported in an Australian based study of CALD carers where only 30% of the sample of 21 carers interviewed reported being satisfied with the services (Yun-Hee, Brodaty, O'Neill, & Chesterson, 2006). As this research was conducted by interviewing carers the authors could explore the reasons for dissatisfaction and found that carers attributed dissatisfaction to inadequate and poor quality services. They also found that only 43% of their sample had used services and the reasons for not using services were that carers did not have any expectations of or trust in services and often needed to be reminded by service providers of the respite opportunities available. Those carers that did not use respite at all reported living under constant strain.

However in another Taiwan based study of family carers (n=116) using respite services, all carers reported being satisfied with services and having better social support, higher levels of life satisfaction, and experienced relief from the burden and the psychological stress of caring (Chou, Tzou, Pu, Kroger, and Lee, 2008). These results, the authors acknowledge, may be due to a biased sample as only those carers who used the respite service were interviewed (no data were available for those carers who did not access respite services). The researchers recommend that comparison studies between users and non user would shed light on
the reasons for non-use of respite services by carers and would help deliver more appropriate services (Chou et al., 2008). This study also showed that middle class and better educated carers who had more access to information used respite more frequently than the lower income groups and those with lower educational levels.

In contrast another Taiwan based study found that, those carers with more respite help had more depressive symptoms compared to those with less respite help (Huang, Muslin, Zauszniewski, & Wykle, 2006). Carers (n = 148) participated in a structured interview and completed standardized tests to ascertain their depressive symptoms, coping mechanisms and social support. This study did not observe the perceptions of the caring role held by the carers themselves and perhaps if it had, this result may have not been unexpected. In a study with South Asian carers, Lawrence et al., (2008) found that carers who asked for help thought they were failing in their responsibilities. Perhaps this may have been true for the Taiwanese carers in Huang et al.'s (2006) study. In addition, use of open-ended questions, rather than structured interviews and use of standardized tests, or a combination of both open ended questions and standardized tests, may have offered more explanations for these results.

This study by Huang et al., (2006) also showed that those carers with high levels of information support and lower emotional support had more depressive symptoms, thereby suggesting that emotional support was more important in reducing carer burden than information about the illness on its own. Consistent with this interpretation, Choo, Low, Karina, Poi, Ebenezer and Prince (2003), found that carers of people with dementia in Malaysia who received more emotional support reported less carer burden that those with less emotional support. Additionally this
study showed, those who received more physical support reported more depressive symptoms than those receiving less help.

A meta-analysis conducted by Cowley and Orbell (1999) with research published between 1974-1997, reiterates the same issues raised in the studies mentioned above where service providers thought carers would not use services if they were not useful or if using services was an indication of their own incompetence in providing care. Given the historical repetition of these issues in recent research, as discussed above, it further emphasizes the need of the present study which is to explore the perceptions held by carers themselves about the appropriateness of services.

The benefits of short breaks, another form of respite where carers get the opportunity to relax away from their caring responsibilities for a weekend, have also been explored with carers reporting that these brief breaks were beneficial in several ways as it offered them a break from the routine demands of caring; chance to spend time with other family members; an opportunity to have a rest; helped to alleviate their sense of loneliness and refreshed them. The most common suggestion was to increase the availability of the service and the duration of the break (Dow et al., 2004; McConkey, Truesdale, & Conliffe, 2004; Winslow, 2003).

Accessing psychosocial support groups has been reported as being beneficial to carers with CALD carers stating that social support groups helped them make friends, increased their knowledge about services and offered them an opportunity to share experiences with other carers (Dow et al 2004; Momose, Asahara, & Murashima, 2003; Winslow 2003). Research has also shown that early intervention in the form of psychosocial support like counselling and increased interaction with health care professionals, results in improved capacity to cope with the caring role
and maintain well being (Dobrof, Ebenstein, Dodd, & Epstein, 2006; Sorensen, Waldroff, & Waldemar, 2008). Encouragement from health professionals to use support groups by inviting carers to the group, helping them interact with other carers and encouraging carers to access other community services have been reported to be useful in alleviating some of the stigma and hesitancy experienced by some CALD carers in using support groups (Momose et al., 2003).

However as some CALD carers may associate stigma with accessing services (Dow et al., 2004; Cardona et al., 2006; EDAC 2003; Rooney, Wright & O’Neil, 2006) psychosocial interventions may be more acceptable if they are offered in a manner where the carers could remain anonymous. Use of technology can help to meet this need, and in Australia an innovative psychosocial intervention in the form of a telephone support groups was trialled with four language groups of CALD carers: Greek, Cantonese, Korean and Italian with an Arabic group declining to participate as they were not yet ready for this form of support (Shanley, Roddy, Cruysmans & Eisenberg, 2004). Carers found this medium of support to be acceptable and appropriate because it allowed a certain level of anonymity and as it was home based, allowed to them to get emotional support without having to leave home. Some of the difficulties that arose were in recruiting carers to participate in the eight week trial, with recruitment being undertaken via extensive promotion in ethno-specific media, by word of mouth and personal networks. The second challenge was in resolving the difficulties participants faced when using the telephone if there was a bad connection. When contacted by telecommunications provider staff, carers were sometimes not able to follow what needed to be done. This difficulty in use of technology was also reported in an American study where comparisons between White and African American carers showed that, carers’
education and race were directly related to the perceived ease of use of computer based support groups with higher levels of education associated with more positive expectations of ease of use, and African-Americans reporting fewer positive experiences in using the computer support groups than White Americans. Lack of access to technology was the biggest barrier in using these support groups (Smyth, Rose, McClendon, & Lambrix, 2007). This sample consisted of only 15% African American carers and 85% White American carers however, so any racial difference noted should be regarded with caution as the sample size was too small and disproportionate.

**Educational and information support services.**

Research has shown that the need for education programs among CALD carers is very high as it helps reduce stigma about the illness and helps carers cope better with their caring role (Azar & Dadvar, 2008; Choo et al 2003; Dobson, Upadhyaya, McNeil, Venkateswaran, & Gilderdale, 2001; EDAC 2003; Huang et al., 2006; Pearce, McGovern, & Barrowclough, 2006) and in providing educational programs whether in the form of an educational pack (Dobson et al., 2001) or in the form of an educational program (Azar & Dadvar, 2008), or a hospital based program (Mackenzie & Mhl, 2007; Lee, Lui & McKenzie 2005) four factors influenced carer satisfaction: use of appropriate language; use of culturally appropriate examples, emotional support and encouragement by service providers to use services (Azar & Dadvar, 2008; Dobson et al., 2001; Lee et al., 2005; Mackenzie & Mhl, 2007; Pearce, et al, 2006; Yun-Hee et al., 2006).

For example in a pilot study by Azar and Dadvar (2008), in Northern Carolina, 14, Farsi speaking Iranian carers were interviewed to explore the efficacy of a psycho-educational intervention program which was tailored to suit their needs.
The most beneficial change reported was translating all the material into Farsi and having Farsi translators at all the sessions. Another important change was adapting the English material on ‘coping with caregiving’ to be more useful for the carers by expanding the information about dementia and its causes, modifying the vignettes in the manual to be more consistent with the Iranian culture and streamlining the sessions so that the carers were not overwhelmed by the written material. These changes were welcomed by the participants as was evidenced by their feedback which rated the programs as being excellent and the carers stating that they would recommend it to other family and friends (Azar & Dadvar, 2008).

The question of whether to have information in the various dialects and languages was raised in the study by Dobson et al., (2001) and the authors concluded that having one self explanatory audio-visual aid accompanied by written material in various languages, would be useful for carers and should be made publicly available through common places like General Practice surgeries, day care centres and community centres. The study also emphasized the need for this pack to be of the same standard and quality as that available to the white majority community (Dobson et al., 2001).

Research has also identified that providing education programs can be beneficial to carers provided they were delivered in conjunction with emotional support (Choo et al 2003; Huang et al., 2006; Lee et al., 2005). For example, an evaluation of an education program aimed at Chinese family carers of stroke survivors in Hong Kong, found that a multidisciplinary education program that included information on nutrition, causes of stroke, management of incontinence and other daily living activities( like feeding, walking, standing) were beneficial to the carers, and increased their knowledge(Lee, et al., 2005). Carers were satisfied with
the education program but also expressed a need to discuss family and relationship problems and it was recommended that individual support could be targeted at this area (Lee et al. 2005). This is consistent with earlier findings where carers in the Huang et al., (2006) and Choo et al., (2003) studies reported emotional support as more important in reducing carers' burden than information about illness alone.

Contrary to the results of satisfaction found in the studies described above, when Mant, Carter, Wade and Winner (1998) trialled the effects of an information pack on stroke patients and their carers in the UK they found that there was no significant difference in levels of satisfaction between the intervention group that received the information pack and the control group (did not receive the information pack). However, the researchers stated that the members in the intervention group reported better mental health outcomes but could not test if this was due to the age of the care recipients being younger in the intervention group or due to the information pack which had information about support groups being run locally. Carers who had received this information may have accessed these groups which may have contributed to their better mental health. The use of the information pack was not explored with the participants and the outcomes of this study could have been better evaluated using interviews and assessment tools, to get a better understanding of the impact of the information packs.

The review so far has focussed on studies conducted globally and in most studies ethnicity has been associated with dissatisfaction with services. However this was not reported in one Canadian study which did not find any association between carer’s cultural backgrounds and satisfaction (Savard, Leduc, Lebel, Beland, & Bergman, 2006). The authors examined satisfaction with support services using a standardised test with a sample of 291 carers. Though 30% of their sample reported
being multilingual they did not find any association between ethnicity and dissatisfaction. These results could be attributed to two factors, firstly the criterion for inclusion was fluency in English or French (as French is the major language spoken in Canada), therefore those who were not fluent in either of these languages were automatically excluded, and secondly the sample consisted of participants who, on average, had higher education levels than those reported in the general population. These two factors could mean that those carers who were multilingual were better educated and fluent in English or French, therefore were more confident in engaging with support services. Therefore their ethnicity did not show any correlation with satisfaction.

**Under-utilization of services by CALD carers.**

The review so far has discussed the benefits and barriers of service utilization by CALD carers in range of studies. In the past two decades there has been some research on the influence values, perceptions and beliefs of carers have on service utilization (Pedlar & Smyth, 1999). However, most of this literature has focussed on exploring the perceptions of usefulness of community services of carers of people with Alzheimer’s disease (Collins, Stommel, Given & King, 1991; Miller & Mukherjee, 1999; Noelkar, Bass & McCarthy, 1999) with only a few studies exploring the perceptions held by CALD carers (Kosloski et al., 1999). The studies exploring perceptions among CALD carers have looked at the perceptions of the caring role (Hepworth, 2005; Kosloski et al., 1999) and how those influence service use. In none of these studies were participants explicitly asked to state what cultural appropriateness meant to them in terms of services.
Though research has highlighted the benefits of accessing various forms of support services to CALD carers, several studies have revealed an under-utilization of services by CALD carers. The reasons for underutilization have been explored in two ways. Firstly through specific studies whose primary aim was to understand underutilization by applying the Anderson Behavioural Model and secondly by identifying the barriers faced by carers in accessing services.

The Anderson Behavioural Model has linked CALD carers service utilization to predisposing, enabling and need factors (Herrera, Lee, Palos, & Torres-Vigil, 2008; Kosloski et al., 1999; Sacharlach, Giunta, Chun-Chung Chow, & Lehning, 2008). These studies have found that service usage depended on predisposing factors like age, gender, ethnicity, relationship to care recipient, carers’ employment status and education. Carers with higher levels of education, older carers, employed carers and those with family support were more likely to use respite and social support services. Male carers were more likely than female carers to use respite services and services that provided meals. The enabling factors associated with service usage were emotional support, family contribution and care recipient service use. Those carers who had supportive family members and care recipients who themselves used services, were more likely to use carer support services. These studies found that low service use among immigrant groups was associated partly with lack of education, social isolation and lack of involvement of care recipient in support services. The authors suggest that some ways of making service accessible would be to hire staff from the same cultural background, involve elders in the service planning and tailoring the content of programs to suit the norms and expectations of ethnic groups (Herrera et al., 2008; Kosloski et al., 1999; Sacharlach et al 2008).
The factors that have been identified as barriers to accessing services have also been reported by carers and service providers as reasons for under utilization of services. Lack of English fluency, lack of family support, refugee experiences, lack of information about services, unfamiliarity and confusion about services, limited availability of services, lack of culturally appropriate services, stigma attached to counselling, values and attitudes attached to the caring role and conflicts with the care recipient have all been found to be barriers in accessing services causing underutilization of services (Bittman et al., 2004; Cardona et al., 2006; Dow et al., 2004; EDAC, 2003; Kokanovic, Petersen, Mitchell & Hansen, 2001; Misic, 1996; Payne & Ehrilch, 1998; Rooney et al., 2006).

Furthermore, the study by Bittman and colleagues (2004), highlighted other cultural issues that acted as barriers to accessing services by CALD carers, including failure to identify as carers, feelings of failure in accepting help and perceived prejudice faced by carers from service providers. The cultural implications of expressing the need for services and fear that service providers may not be able to provide the same level of culturally appropriate care as that of the primary carer have been additional factors that have been identified as factors that prevented carers from utilizing services (Cardona et al., 2006).

Findings in Western countries where carer support services are provided, like the UK, Canada and the USA, have shown that service utilization is affected by factors like migration policies that prevent migrants from accessing some community based services, lack of language appropriate resources, inadequate information about services, inadequate resources like transport and finance to access some services, resistance from care recipient, stigma or guilt felt by carers, concerns over costs and quality of home care and hassles in negotiating the paperwork and information in order
to access appropriate help (Delgado & Tennstedt 1997; Dobrof et al., 2006; Herrera et al., 2008; Lawrence et al., 2008; McKenzie, 2006; Neufeld et al. 2002).

In addition, lack of awareness of welfare support, dependency on professional referrals to access support and poor referrals by professionals that led to a low uptake in accessing welfare support have also been reported as factors that led to under-utilization of carer support services by CALD carers (Hepworth 2005; Merrel, Kinsella, Murphy, Philpin & Ali, 2005; Neufeld et al., 2002; Winslow, 2003). More recent research has shown that stigma, lack of information about services, lack of culturally appropriate services and traditional values of family obligations in providing care continue to be barriers in services utilization for CALD carers (Han, Choi, T. Kim, Lee, & Kim, 2008). The authors of these studies have concluded that there was a need to identify and develop culturally appropriate support services and focused outreach programs. These results further justify the need to explore the perceptions of cultural appropriateness of carer support services.

Summary

This review has examined studies conducted internationally with carers and issues related to service utilization. The most common methodology used in all the studies reviewed was in-depth interviews because these are oft regarded as the best method of exploring experiences. The common aspects explored were the benefits of and barriers to accessing services and reasons for underutilization of services by CALD carers. Several researchers recommend that in order to be culturally appropriate, services must include the services of bilingual workers, disseminate information at various levels in appropriate languages, be non-judgemental and have cultural competency training for all service providers (Cardona et al., 2006; Cole &
Gucciardo-Masci 2003; Dow et al., 2004; Herrera et al., 2008; Karner & Hall 2002; Kosloski et al., 1999; Sacharlach et al., 2008). These recommendations, however, are mainly given by the researchers based on their interpretations of what carers have identified as barriers and few studies have examined the carers' perceptions of what would make service culturally more appropriate, thereby increasing service utilization.

Aims and Objectives of the Present Study

There is clearly a need for increasing service utilization among CALD carers and more research on understanding, from the carers' viewpoint, what makes services culturally appropriate. Therefore, the aims of the present study were to understand, from the CALD carers' perspective, what is meant by culturally appropriate services and their perceptions of the cultural appropriateness of existing carer support services in Perth, WA. Because there is little known about these perceptions and the associated lack of culturally-appropriate research instruments in this area, the research was a qualitative, exploratory study. Using the phenomenological approach which yields descriptive data was considered to be the ideal research process to understand these perceptions through semi structured interviews with CALD carers. It is expected that the results from this study will help inform policy and may be instrumental in developing culturally appropriate services for CALD carers.
Method

Paradigm and Assumptions

This study was informed by the phenomenological approach which is defined as a study that "describes the meaning for several individuals of their lived experiences of a concept or phenomenon." (Creswell, 2007, p.57).

Through this approach the researcher describes the commonalties of the individual experiences and develops a comprehensive description of the main features of the experience. This description consists of the ‘what’ and ‘how’ of the experience, Moustakas (as cited in Creswell, 2007). The phenomenological approach is best suited to research where it is important to understand several individuals’ common experiences of an event in order to develop a comprehensive understanding of the occurrence. This can then be translated into a change in policies and practices which influence the experiences of the phenomenon. For this research the phenomenological approach was best suited because the main objective of this research was to determine carers’ perceptions of culturally appropriate services, therefore their individual lived experiences had to be explored and analyzed for common themes which were then used to suggest changes to existing policies and models of service delivery.

There were several philosophical assumptions underpinning the choice of phenomenology for this study. As this was an exploratory study there were no theories, assumptions or hypothesis to base the study. The participants’ responses would guide the enquiry and determine the questions to be asked or changes to be made as the interview progressed. In Creswell (2007) this process of using inductive
logic to develop an emerging design is termed the methodological philosophical assumption.

The researcher believed that the participants, who are typically underrepresented in research, would get an opportunity to express their opinions with the expectation that the outcomes of this research may help inform government policies and facilitate better services delivery for them. The research paradigm chosen was therefore participatory in nature as it allowed the participants who were marginalized an opportunity to engage in the process of enquiry and to voice their opinions in a safe, non judgmental environment (Creswell, 2007).

In phenomenology the researcher must ignore past knowledge and experience in order to get a fresh perspective and a deeper understanding of the experience being studied Marleau Ponty, (as cited in Creswell, 2007). In order to adhere to the phenomenological research design, the researcher used the process of bracketing which has been defined as isolating one’s own emotions, past experiences, values, beliefs and thoughts from the experience being observed (Creswell, 2007). As the researcher was the Service Manager for the Ishar Multicultural Carer Support Service in the past and is currently the Director of the Ishar Multicultural Women’s Health Centre where the service is delivered, it was imperative for the researcher to bracket past experiences during the research process.

Participants

Criterion sampling was used as it works well when using the phenomenological approach as all the participants would represent people who have experienced the same phenomenon (Creswell, 2007) and it also ensured that the data collected would not be diluted by too many variations (Miles and Huberman, 1994). Multiple purposive case sampling allows the researcher to make claims about a
larger group of people (Miles and Huberman, 1994); keeping this in mind, the sample size of 10 was determined as it would allow the researcher to sufficiently explore the issues at hand in the given time frame, without diluting the focus or compromising the generalizability of the findings. As sampling also involved decisions about the settings, at the onset it was decided that participants would be offered the choice of two settings; their home or the researcher’s office to maximise the carers’ comfort level and minimise costs to participants in terms of time, money or childcare arrangements.

In order to be eligible all participants had to be above the age of 24 years, so they would not qualify as young carers, and be first generation migrants or refugees with English as their second language, providing informal care to a family member or friend with no financial remuneration. Participants had to be fluent enough in English to understand and respond to the questions if they did not want to use an interpreter.

Once the carers met these criteria the process of selection was semi-random. Letters (see Appendix A) were sent to all adult primary carers on the databases of four organizations that provide carer support services: Carers WA, ARAFMI, Mental Health Access Service and Ishar Multicultural Carers Support Program. The first 10 carers who responded with an interest to participate in study and were available for the interview were recruited.

Through this process the final sample consisted of 10 primary carers who were all female, first generation Australians who entered Australia as adult migrants or refugees with English as their second language. The age group of the participants ranged between 34-67 years.
Table 1
Ethnicities Of Participants

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Number of participants (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Burma</td>
<td>1</td>
</tr>
<tr>
<td>Iran</td>
<td>3</td>
</tr>
<tr>
<td>Italy</td>
<td>3</td>
</tr>
<tr>
<td>Romania</td>
<td>1</td>
</tr>
<tr>
<td>Spain</td>
<td>1</td>
</tr>
<tr>
<td>Turkey</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2
Relationship To Care Recipient

<table>
<thead>
<tr>
<th>Relationship between carer and care recipient</th>
<th>Number of participants(n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child (daughter looking after an ageing mother)</td>
<td>1</td>
</tr>
<tr>
<td>Ex-spouse (ex wife looking after her ex-husband)</td>
<td>1</td>
</tr>
<tr>
<td>Parent to a young child (mother looking after her son)</td>
<td>1</td>
</tr>
<tr>
<td>Parent to an adult child (mothers looking after adult children)</td>
<td>3</td>
</tr>
<tr>
<td>Sibling (sister looking after her adult brother)</td>
<td>1</td>
</tr>
<tr>
<td>Spouse/Partner (wives/partner looking after their husband/partner)</td>
<td>3</td>
</tr>
</tbody>
</table>
Procedures

Materials.

The interview questions were open ended, evolving and non-directional in order to allow the carers to express their opinions. The questions were framed to allow participants to expand on their experiences as carers, explore their understanding of what cultural appropriateness meant and to get an understanding of how current services could be modified to be more culturally appropriate. The schedule consisted of approximately seven open ended questions and mostly began with the words ‘what’ and ‘how’ as these characteristics are stated as being typical of the central research questions in qualitative research (Creswell, 2007; see Appendix B for interview schedule). Background information was obtained and written on the interview schedule by the researcher to get a demographic picture of the participants.

Data collection.

After approval from the Faculty of Computing, Health and Science, Human Research Ethics Sub Committee, carers who met the inclusion criteria and were willing to participate were interviewed. All the participants were assured that the contents of the interview would be kept confidential and used only for the purpose of the study. The interview schedule was sent to them prior to the interview so that they had the opportunity to think about the questions and if they had any doubts about participating in the study they could still opt out of the process.

Before commencing the interview the researcher once again refreshed the participant about the purpose of the study and the sort of questions that would be asked and checked if the participant had any questions or doubts. Once these were clarified, the participant was then asked to sign the consent form (see Appendix C).
During the interview the researcher asked prompting questions and allowed the participant to talk at length with little interruptions from the researcher. The interviews, which lasted between 45-70 minutes, were tape recorded and transcribed verbatim. The transcripts were offered back to the participants to check for any discrepancies or changes that needed to be made. The data were then analyzed.

**Analysis**

In order to organise the interview data into meaningful units it had to first be reduced. This was done through the process of coding and making marginal remarks consistent with the procedures described in Miles and Huberman (1984, 1994). The data were coded with phrases that were derived from the main theme: length of time as a carer, most challenging aspect of the caring role, social support, respite support, emotional support, financial support, lack of information about services, suggestions for changes to be made to current services and other issues. Data displays were developed for a conceptually clustered matrix (see Appendix D) and this was subjected to one level of analysis using methods detailed in Miles and Huberman (1984).

**Rigour**

Methodological rigour was attained through verification by reviewing the literature, adhering to the phenomenological methods, bracketing past experiences, using an adequate sample and interviewing until a saturation point in the data was achieved (Creswell, 2007). Validation was achieved through member checking by participants and coding by only one researcher.
Findings and Interpretations

In order to build rapport and to determine the context in which care was being provided, all participants were asked to describe their caring role, the length of time as a carer, the condition of the care recipient and the most challenging aspects of their caring role. All participants described their caring role in terms of the daily tasks they performed for the care recipient like bathing, cooking, cleaning, visits to health professionals and organizing other daily activities. The length of time they had been carers ranged between six to twenty years, with eight carers having been in the role for an average of ten years. Six participants reported looking after a family member with schizophrenia, one with Down’s syndrome, one with general global delay, one with stroke and one with multiple sclerosis. All participants reported the most challenging aspect of their caring role was dealing with the emotional behaviour of their care recipient. The length of time as a carer or the nature of the care recipients condition were not analysed with respect to any of the themes that emerged in relation to service usage.

From the data four major themes emerged: the emotional impact of caring, perceptions of the cultural appropriateness of services, perceived barriers in accessing services, and suggestions for culturally appropriate changes to services. The theme on cultural appropriateness of services was further subdivided into service type: respite, social, emotional and financial.

Emotional Impact of Caring

In describing the nature of their caring role every carer described the emotional impact of caring on themselves. Every participant reported feeling depressed and at some point having been treated for depression. Carers attributed their depression to their loss of freedom to pursue relationships or careers, inability to take a holiday
due to caring responsibilities and lack of finances, lack of family support, lack of social networks and the desperation they felt when thinking about the life-long commitment they needed to give to their caring roles. Carers also reported being anxious about the future if they were to die before the care recipient. For example an Iranian carer said “I don’t how they can help the people more than that but I think is you know is [Tom] could go by himself then okay I can do by my life but, couldn’t do that, that is why I quit but I quit my life anyway for him”. The same carer also said she cannot pursue a job because of her caring role at home, “I think Government has to think about that, I am carer but is like I am working, if I go outside and work as a carer I am making absolutely good money”. In describing the impact of the caring role she said “I am down (depressed) person, honestly maybe everybody looking out I am okay but inside no body understand nobody understand what I did and my life is not mine.” She also described her sense of loss in developing a relationship, “Who will marry me if there is someone then they have to accept two persons they have to accept two persons I spent my life for them.”

A Romanian carer described the emotional impact of caring, “If I do not see anything for myself to escape then I get depressed within the house. I mean it disempowers me to just be in the house with him.” In addition, she stated that if services did something for carers to make them feel a sense of achievement it would help, “Coming back to the services something that would be acknowledging something that like a badge like you have passed six years or something. Here there is nothing you don’t achieve anything. You just wipe up shit and nothing nothing what do you achieve?”

A Burmese carer reported feeling a sense of relief when she was able to get some help for her care recipient to gain skills in life in the event of the carer passing
away, “that is the big problem I got she cannot go into the world like that after I pass away that is what I tell [Doctor] so that’s what I arrange for her that is why she got the unit....for me that is one support it makes me a bit less desperate.”

All participants felt their most acute need was to be able to get permanent relief from their caring roles by either the care recipient getting well and being able to manage on their own. Three carers said having family living overseas coming to live with them would help them with their caring responsibilities, which is illustrated by this quote from a Turkish carer, “someone from Turkey to come here and help when I really need help and I want immigration to support me when I want my family to come from Turkey to support me.”

These responses highlight the burden carers feel and have been reported in several studies (Blake, Lincoln, & Clarke, 2003; Cardona et al., 2006; EDAC, 2003; Nomura et al., 2005; Rooney et al., 2006; Wong, 2000). These studies have also reported that carers thought services were not appropriate to meet their needs. In relating to the various types of services, carers reported that services only offered short term and sometimes inadequate relief and to be truly effective and useful for them they needed services that would help them learn how to cope better with the caring situation as the most challenging aspect of their role was managing the behaviour of their care recipients. These findings are discussed in the following sections.

Service Usage

Participants were asked to describe their experience of using various carer support services and their perceptions are described according to service type.

Perceptions of the cultural appropriateness of respite services.
Respite services are mainly aimed at providing carers with a break from their caring role. There are three types of respite services offered in Australia; in home care, out of home respite for care recipient, and short breaks for carers. Home care is when a service provider comes into the care recipient’s home for a few hours a week and performs some tasks in looking after the care recipient so that the family carer can have a break. Out of home respite is when the care recipient goes away for a few days like a weekend camp so that the family gets a break and the care recipient can interact with other people with a similar health condition. Short breaks for carers provide carers with the opportunity to go away for a weekend with other carers while some other family member or a respite care worker looks after the care recipient in the home.

Eight carers reported having used respite services with two stating they did not need respite at this stage of their caring role. The respite services described were mainly short breaks and in-home respite.

**Short break for carers.**

Carers who had used short breaks as a form of respite for themselves found these to be useful, as is illustrated with the following response from a Burmese carer looking after a family member with a mental illness for six years “The mind forgot about everything for awhile and that was just very nice, just cut off like that so when I come back it was very fresh, like, relaxed, so it was very important for us and we did not know we could have all this and now for the first time it was that both me and my husband went on the short break.” Similarly, a Spanish carer who had been looking after a family member with mental illness for ten years said, “For me I say thankyou thankyou for the government to give support to me and for the associations
that give call to me to make a social for me….and all the support I get when I go for the short break for two nights and two days.”

These beneficial effects of a short break have been reported in other studies as well (Dow et al., 2004; McConkey et al., 2004; Winslow, 2003). Similar to the findings in those studies, these participants also did not have any suggestions on how to make short breaks culturally more appropriate but did express the need to have the break more often.

_Respite for the care recipient._

Carers reported that while the respite services offered for care recipients were useful, there was a need for the services to be consistent and offered over a period of time with few changes in the service providers. Carers also stated that having respite services delivered by staff who spoke their own language was more acceptable to the care recipient and an important factor in deciding whether to use the service or not. Use of respite was beneficial to both the carer and care recipient, as most CALD carers did not have many family members or friends to help them with their caring roles. For example, one carer said that the free products given by a respite provider helped her with the toileting tasks of her role, “Yes yes [name of service provider] this is good because after I spend a lot of money on the pampers you know [service provider] gives some for free and this is good” and the same carer also reported that while she was very happy with the respite service the care recipient was not “Another thing is that my husband does not like strangers he is very suspicious” which is why she found it hard to use respite services. However, on one occasion the worker spoke the same language and the care recipient was able to trust the worker, “If someone could come to my house and talk to my husband in the same language that would be good. Before there was social worker she come and she speak all
French, Spanish... she fix everything for the people she find the bus everything but the government cut these people, she come to visit my husband, my husband feel very close to her, he trusted her, my husband he feeling good after with her.”

This need for workers with the same language background and the care recipient and the need for consistency in workers was illustrated by another (Iranian) carer “Those few hours [Jack] was really looking forward to it and suddenly after a few months no more than a few months about 6-7 months she came and suddenly she said that’s it sorry about that, maybe they will send someone else. [Jack] was so upset as soon as he got used to somebody they will leave and then someone new came and then it takes a few weeks for you know, until you get used to them and then they leave again. I don’t know how it works but if they can have some permanent employees or carers who are not leaving that would be good.”

Another Iranian carer echoed the same need “But if people could go to sit with people who are sick, to sit and talk to them if they spoke the same language like my mum she would be happy. Like older people need help yes there is family but sometimes the family gets very drained and can’t do much so if there is some respite where sometimes you can take the older people and leave them there for a few hours just on a few days like a day care you know that would be good. It is very hard for older people to go specially for same speaking language like a Iranian and Afghanistan who speak the same language it would be good, like if there is one day only for Afghani and Iranian people it would be good.”

Previous research has also shown that carers are sometimes hesitant to use respite services because it may be perceived as a failure to fulfil their responsibilities (Cowley & Orbell, 1999; Lawrence et al., 2008). However this was not reported by any of the participants in this study as a reason for non use of services. Consistent
with previous findings these carers said that if the respite care was beneficial to the care recipient they were more likely to engage with it (Lawrence et al., 2008). Also similar to the findings in this study, other studies have reported that respite service are more likely to be used if they were more frequent, affordable, consistent and delivered by ethno specific staff (Cardona et al., 2006, Dow et al., 2004, Lawrence et al., 2008; Yun-Hee et al., 2006). While these findings have been reported in studies conducted in Australia and elsewhere for over a decade, there do not seem to be many significant changes in service delivery in spite of recent research showing that accessing respite services results in better health outcomes for the carer and increase carer well being (Chou et al., 2008).

**Perceptions of the cultural appropriateness of support groups.**

In Australia carers are offered social support in the form of support groups where carers meet generally once a week and participate in various leisure activities like bowling, movie mornings, lunches, picnics and some educational workshops. All participants had used support groups and had both positive and negative experiences to share. For example, a Romanian carer said she did not use mainstream support groups because, "I mean there is [a main stream organization delivering support groups] but you almost feel guilty to go there because they talk in such a way like how much they do for you. I mean it is weird. That is why I do not go to register there because I saw a few episodes of their presentations."

And another carer described her experience of using both a multicultural and main stream group, "These services which I was attending most of them were, err (sic), Australians, in that group I was the only migrant. I could mix with other cultures and I could you know speak with them and but you know they couldn’t understand. I was okay with it but I was just one odd among them, you know they
were all talking and I was just new to this country and I was just sitting and listening as I did not have any experience to share with them. But the other groups I joined later on which was more multicultural I felt easier and more comfortable and what I was feeling was they are all in the same situation as me they are all far from our family, far from our culture and we didn’t have much support, family support in here."

This was also echoed by a Burmese carer who narrated her experience of using both mainstream and multicultural groups “I can go to a White Australian group now but for me I like [multicultural service provider] better because it is multicultural and I learn new things from them, their ideas and all are different from everyone, not only one background. I went last two weeks to a group where most of them were white Australian group and it was different and I am not going back to that because I cannot have much say there they are only talking talking for themselves and you have to listen them only and don’t have a chance to speak for myself and what is happening in my family and they don’t listen to me also but in the multicultural group when they ask me how is your daughter that feels good.” The same carer also stated that she found the group useful because she was taken there by the social worker and would have never gone there on her own if she had not been taken by the service provider “the social worker she showed me a big list of multicultural [groups] she said by your own you have to contact them but I don’t contact them. Because I don’t know what’s it all about and I don’t think I could be able to afford I think it all costs money. But she said I take you to this one multicultural one and one day she make appointment and she take me and my husband to [support group] that’s how we come to know.” However, some carers
found support groups ineffective as was illustrated by one carer “To see the people you know to talk you know but sometime I am here but my mind is there.”

The main finding was that carers were more likely to use multicultural support groups rather than mainstream groups. The reasons cited for this was that in multicultural groups carers felt more welcomed and were easily able to identify with other carers. They also reported that the interactions helped them understand different methods of coping with the caring role across cultures. The personal contact by the service provider encouraging them to use the services was another factor that motivated carers to access a multicultural support group. The beneficial aspects of attending support groups has been identified in previous studies (Dow et al., 2004; Dobrof et al., 2006; Hepworth, 2005; Shanley et al., 2004; Smyth et al., 2007; Sorenson et al., 2008). Studies have also identified that CALD carers are more likely to use service if they are encouraged to do so by service providers (Azar & Dadavar, 2008; Dobson et al., 2001; Lee et al., 2005; Momose et al., 2006).

However, about half the carers interviewed said that while they did use support groups occasionally they did not find them useful because even though they were in the group their mind was at home with the care recipient. Some carers also stated that they were distracted because they had several other demands on their time which made it difficult to attend the groups. Non use of support groups due to stigma has been identified before (Cardona et al., 2006; EDAC, 2003; Rooney et al., 2006), but the ineffectiveness of support groups for multicultural carers has not been mentioned before indicating a need to explore this aspect of the effectiveness of support groups for CALD carers.

**Perceptions of the cultural appropriateness of emotional support.**
Emotional support is offered to carers in the form of individual counselling and in this sample only three of the ten participants reported having used a counselling service, though all carers expressed an acute need for emotional support. Lack of awareness of counselling services, perceptions of the ineffectiveness of counselling and preference for service providers who were from a similar cultural background or who spoke the same language were three reasons given for not using counselling services. For example one carer spoke about how she was not aware of counselling “I never had any counselling for myself, I never thought of myself, but I think I really needed it as at the time I was taking antidepressants for two years maybe maybe I really needed some help for myself, I don’t know maybe I didn’t know about it that I could get help for myself.”

An Iranain expressed her hesitancy in engaging with a services provider from a European background “I thought that with [name of multicultural service provider] maybe we are culturally close and I don’t know I mean I like [name of European service provider] and I respect her and she runs the carers’ group and all but I have never been close to her, I mean I am close but not close enough to talk to her about my problems.” The same carer also stated that “yes the main thing is that we are people who don’t speak English and we always need somebody to translate it when [name of Iranian service provider] was here it was nicer she could translate it and she could tell some of the things in Persian and some of the things in English.” However if carers could engage with someone from their own cultural background they were happy to engage with counselling services. For example one Spanish carer said she was very happy to be able to talk to a Spanish speaking counsellor “But sometime I get help because there is [name of multicultural service provider] who speak Spanish very well and help me.”
Research to date suggests CALD carers hesitate to use counselling services due to stigma, lack of information about services, family obligations, lack of information about the usefulness of counselling (Bittman et al., 2004; Cardona et al., 2006; Dow et al., 2004; EDAC, 2003; Kokanovic et al., 2001; Lawrence et al., 2008; Mackenzie 2006; Misic, 1996; Payne & Ehrlich, 1998; Pearce et al., 2006; Rooney, Wright & O'Neil, 2006). However, stigma or family obligations were not reported as reasons for non use by the participants in this group.

**Perceptions of the usefulness of financial support.**

In Australia carers can receive two forms of financial support; carers’ payment and carers’ allowance. Carers’ payment is a means-tested payment given to family members who live with the care recipient and, due to their caring responsibilities, cannot engage in any income earning activities. Carer allowance is given to carers who do not live with the care recipient but still need to perform various caring roles. These payments are a government social support payment and administered by Centrelink in Australia. Most care recipients also get a disability pension because they cannot work.

Carers’ responses on the usefulness of financial support were mixed, with some carers reporting the support as being useful yet causing interpersonal problems between themselves and the care recipient. For example on interpersonal issues one carer said “all the time he wants to borrow money and if I don’t give him he screams and I have to call somebody”. And she further states that Centrelink should not give her son the money because he does not give it to her for house hold expenses, “Not to my son because he don’t give it to me the Centrelink give it something for the house you know and he not give it to me.”
Most carers reported not being aware that they were eligible for such a payment because in their home countries looking after a aged or disabled family member was considered to be family obligation and not the government’s responsibility. All the carers in this sample reported becoming aware of this financial benefit only when a social worker or a friend told them about it and in some cases they started receiving the payment after several years of being a carer. As English was their second language, carers often found it hard to deal with all the paperwork and were often unaware of financial benefits, often requiring some help in getting information and accessing payments. For example a Burmese who has been a carer for six years said “Yes starting from this year only social worker applied for us but very little not much. Centrelink sent me some papers and they said only one or two dollars, so I do not apply, but I missed out my mistake I missed out on everything only this year I get the carers allowance and the bonus, yes, only this year I get.”

Another aspect which could be unique to CALD carers was the ability to be able to access these payments when they went to their home countries for longer than three months with the care recipient. Three carers reported going to their home country was a beneficial break for both themselves and the care recipient and they would like to be able to stay for longer than three months, but could not because if they did their payments would be stopped as one Spanish carer said “When I go to my country for three months that is very short and if Centrelink gave me six months or more time to be away from the country for six months or more that would be good if they gave the pension because in this country it is very lonely, in my country is it is very friendly everyone say hello [Harry], it is different, he[ care recipient] sleeps very well[in the home country]. If Centrelink give me more than six months I go and stay there but I can only get my pension [payment] for three months.”
Only three carers found the amount to be sufficient and the rest thought it to be inadequate as one Iranian carers said “Government just give me carers payment that’s it and the carer allowance, this one is not enough but I suffer and that’s it”.

Research on services to CALD carers has not focused on financial payments as a type of service, subsequently leading to scant information on the impact of this form of support to carers. These findings indicate that there is a need to investigate better means of communicating information about financial support to CALD carers. There is also a need to investigate if changes can be made to the rules regarding payments in order to accommodate the need for CALD carers to access their payments if they need to go to their home country for more than three months with their care recipient, as this would mean they were still carrying out their caring responsibilities.

**Perceptions of Existing Barriers in Accessing Services**

The main barrier reported in accessing services was the lack of information about services and disabilities. All the carers in this sample reported that when they first became carers they lacked information about the nature of the care recipients’ condition which made it hard for them to cope with the situation and then lack of information about services made services invisible to them. Unfamiliarity with government systems and lack of family and friends to guide them were some of the reasons carers gave as to why they needed information to help them cope with their caring roles. For example a Turkish carer, who has lived in Perth for two years, said “At the moment I do not know anyone in Perth, I do not have any friends, if they can help me in any area like, giving support to myself and helping me in any area or telling me what’s happening what services are available, any area, telling me what services are around, what is available for me and for the kids.”
Another extract from an Iranian carer illustrates the need for information specifically for CALD carers, "I think there are services available, there are a lot of services available but I think the problem is nobody knows. If you know what is available then you will get help from everything, like physically, emotionally, financially, anything, I think that’s good, we have lots of services in here, but how we can get those services out is the question, I don’t know." Furthermore, carers reported that the lack of information in their own languages prevented them from accessing services. For example, an Italian carer simply said “I like it in Italian as I can understand more.” In addition, an Iranian carer’s response was “…I think more information is the thing we have to have and in our own language and if the pamphlet is there nobody reads the pamphlets because it is in small writing and nobody reads it in those small packages.”

Lack of information about the condition of the carer recipient also made it difficult for carers to cope with the caring situation and more information often helped them deal with their situation better. For example, a Spanish carer said “It is very very difficult because these people with mental illness specially my husband with schizo because you know a lot of patience it is very hard you know because I have spent a lot of time to know him before I don’t know why he gets angry now I know what is happening in his mind sometimes he is fighting sometimes he says please cut my throat but I can’t, it is very hard until you [know] about these people and you know about the sickness.”

Another example from an Iranian carer further illustrates the usefulness of information about disabilities “First I did not understand what was happening to my mum, I thought she is home sick because she has come to a new country and her age as well, she was nearly 70 years old, I did not think anything was wrong with her and
that she was, making up stories, but slowly I realised she was talking about things that were not real and then I took her to the doctor and he said looks like she is having a mental illness, mental problems and they told me about mental problems, I was very upset and crying all the time and did not know what to do with her. I came [to multicultural service provider], the first time and talked about it, then I could cope with it.”

These findings reflect those in previous research (Azar & Dadvar, 2008; Dobson et al., 2001; Lee et al., 2005) where carers have found information to be very useful in coping with their caring role. This need for information and emotional support was also found to be more beneficial than respite in previous research (Choo et al., 2003; Huang et al., 2006). Several Australian studies have identified language and lack of information about disabilities and stigma as being barriers in accessing services (Cardona et al., 2006; Dow et al., 2004; EDAC., 2003; Rooney et al., 2006) and other studies have found that when carers receive information about the disability and about services in their own language it helps break down stigma about the disability and increases carers’ wellbeing (Azar & Dadvar, 2008; Dobson et al., 2001; EDAC ,2003; Huang et al., 2006; Lee et al., 2005; Pearce et al., 2006). Therefore, to make services culturally appropriate it would be beneficial to have more information programs in various languages. This and other suggestions given by participants in this study, are discussed below.

Participants’ Suggestions For Culturally Appropriate Changes To Services

Having reported on a range of factors that made service culturally inappropriate for CALD carers, participants were asked to give suggestions on how services could be made more suitable for them. Carers suggested that getting information was the most important aspect of accessing services and this could be
delivered in a number of ways. Firstly they suggested that when the diagnosis was first made health professionals should also think about the carers and give them more information about the condition of the family member so that they would be able to cope better with the situation. Secondly they also suggested that information about carer support services should be made available from the doctors, nurses and social workers in hospitals and from Centrelink staff.

This quote from an Iranian carer illustrates how Centrelink can be more than just a source of financial support to carers “I did not know about anything, having more information is needed, like when you go to Centrelink and ask and say there is a sick person I am looking after they need to have more information from Centrelink they need to help us more because they think we know, but they have to believe and they have to help us to help the person we are looking after, like they told me because you do not live with your mum we can only give you little money that is okay but I think in places like Centrelink they have to have more information like for four years I did not know anything about any places, that could help me, which if Centrelink asked me you have to go look for a job and I said who will give me a job, my age is not perfect and my mum is sick and can you help me get a job where I can do both together.”

Carers also suggested that disseminating information using ethnic media or by displaying information about carer support services in places that are frequented by minority ethnic groups like shopping centres, gourmet shops or social clubs would be useful for carers. This is illustrated by the following quote from an Iranian carer “A big celebration about 500 people and imagine that in those at least 10 families they were carers in there, the new arrivals, they come to that concert but they don’t go anywhere else because they have a bit of problem with communication
....if we get the information to those places they will find out what is available in here” The carer also suggested “They have shops I know there are shops like Chinese shops or Iranian shops or Arabic shops and if you put the flyers there, people go and do the shopping there and they can see in their own language, not in English.”

With regards to making service more appropriate for carers it is important for service providers to try to find out what the needs of carers are. For example, a Burmese carer said “What we need to ask is more support, more help, like that and they [service provider] don’t know what we need also if they do not come to us.” Another important aspect was that carers need to be encouraged to use services meant for them and the focus to be on them as well as the care recipient as this quotes from a Romanian carer illustrates, “It is good because you see he has disability so we have a house that is wheel chair accessible, it is close to the city and through work I would get a van that could accommodate his wheel chair. But you see it is all about him.”

Carers also suggested employing staff from a range of cultural backgrounds in organizations would help, for example an Iranian carer said, “I think that what makes migrants more comfortable is if at least we can have err(sic) like bilingual workers or anybody running those groups. If we can have anybody from those cultures in the groups that we can mix or mingle they can help each other, one can be the interpreter for the other one. Err (sic) employing more culturally diverse in those groups and organizations will help”. Research has shown that carers satisfaction with services is influenced by five factors; encouragement by service providers to use services; service delivery by culturally diverse staff; information about services and disabilities in appropriate languages; use of culturally relevant examples when
educating carers about disabilities and offering emotional support to carers (Azar & Dadavar, 2008; Choo et. al, 2003; Dobson et al., 2001; Herrera et al., 2008; Kosloski et al., 1999; Lee et al., 2005; Mckenzie & Mhl, 2007; Momose et al., 2003; Pearce et al., 2005; Sacharlach et al., 2008; Yun-Hee et al., 2006). Findings in this study have further emphasised that addressing these factors would help break down barriers in accessing services and would encourage carers to use support services.

**Summary and Conclusions**

Delivering culturally appropriate services appears to be a process begins with the promotion of the service and continues in the actual service delivery and follow up. The most common reason for not using services was the lack of information about services and the lack of encouragement by service providers to use services. Therefore to increase uptake by CALD carers it is important to disseminate information in culturally appropriate ways and equally important is the need for service providers to go beyond just supplying information and actually encourage CALD carers to engage with services.

Irrespective of the nature of the disability, relationship to the care recipient or the length of time as a carer the most challenging issue was managing the behaviour of the care recipient. Education programs on disabilities and treatments were perceived to be the most useful. Delivery of these education programs by health professionals as soon as the diagnosis was made would help carers cope better with the caring situation. The choice of receiving education programs in either English or another language should be given to the carers as not all CALD carers require programs to be in their own language.

In terms of making support groups culturally more appropriate, these findings highlight the fact that carers prefer multicultural groups because of the other
participants in the group, not because the service provider was themselves from an ethnic background. Recommendations given in previous research state that CALD carers would be more likely to attend a support group if it was delivered by bicultural staff. Clearly this does not seem to be the case in terms of support groups. In practical terms this means that if main stream organizations want to offer a support groups for CALD carers they need to have a separate group for CALD carers not integrate them into a mainstream group.

When it comes to using counselling and respite services these findings indicate that for counselling and respite services to be culturally appropriate and for carers to feel comfortable enough to use the service, it must be delivered by professionals who are from a CALD background and preferable the same ethnic background as the carer. Use of interpreters was not reported as being a useful method of overcoming the language barrier because sometimes meanings were lost in the translation process. Additionally care recipients were less likely to accept respite services from service providers who did not speak their language or if there were frequent changes of respite staff. Therefore employing service providers from a range of ethnic backgrounds with infrequent changes to staff, would make respite services more acceptable to CALD carers.

Financial support was generally perceived to be inadequate and presented CALD carers with unique challenges. Investigation into how these payments are spent by the care recipient, the interpersonal difficulties these payments cause and the adequacy of payments may also be beneficial to all carers not just CALD carers.

These findings show the most stressful part of the caring role was managing the behaviour of the care recipient and education, respite and counselling programs could help alleviate some of this stress. Yet these services are not being adequately
accessed by CALD carers as the services are either not available or not suitable. Therefore more effort needs to be directed towards making these services culturally appropriate using the suggestions given by carers.

The passing the Carers Bill in 2010 shows that the government is serious about acknowledging the role of carers and is committed to providing appropriate services for them. With the increasing number of CALD carers in our community it is important to take into consideration the findings of this and other similar studies when developing policies and services, so that services may be culturally appropriate and meet the needs of carers.

**Limitations.**

The small sample size of this group may not make it possible to generalize these findings to all CALD carers.

**Future Research.**

Future studies could be conducted involving larger groups of carers, carers from both genders and comparative studies based on the effects of acculturation and service use could be conducted. Based on the results of this study changes could be implemented in some existing services and service use could be tracked.
References


Appendices

Appendix A: Letter of Information

Dear potential participant,

I am a Psychology Honours student at Edith Cowan University working under the supervision of Dr Justine Dandy. As part of my degree requirements, I am completing a research study. The study is investigating what people who are from culturally diverse backgrounds think about the support service that are available when you are looking after someone who is ill, disabled or elderly. Specifically, I am interested in what people think about their role as carers, the challenges they encounter, and what their particular needs and experiences are.

The study will involve interviewing carers. You can help by consenting to participate in an interview. The interview will take about 60-90 minutes. The interview will be conducted at a venue of your choice, and only questions related to your caring role will be asked. However, if at any point in the interview you feel uncomfortable you have the choice to either stop the interview or choose not to answer the question. The interviews will be tape recorded and later transcribed. The information which you provide will only be used for the purpose of the project and will only be accessible to the student and supervisor involved. Any information that you give for this project will be kept confidential (private). You will not be identified in any written work or results from this project, even in the event that it was published. On completion of the study and writing of the report, I will send you a summary of what the findings of this study were.

This study has been approved by the Human Research Ethics Committee of the Faculty of Computing, Science and Health at Edith Cowan University. Your participation in the study is completely voluntary and if you choose not to participate it will not impact your access to any services or benefits you currently receive as a family carer. There is no payment involved for participating in this study, however if required I am happy to reimburse up to $10 for any travel cost you may incur in attending the interview.

Caring for family members who are ill, disabled or frail and elderly can be challenging. If you would like assistance with this, please feel free to contact the Commonwealth Carelink Centers on 1800 052 222, or Ishar Multicultural Carer Support Program Counsellor on 9345 5335, or Carers WA on 1800 242 636 (24 hours).

If you are willing to participate in this study, could you please complete the details below and sign the attached document.

If you have any questions about this project please feel free to contact either myself, Andrea Creado, on [REDACTED] or my supervisor, Dr. Justine Dandy, on 6304 5105, email: j.dandy@ecu.edu.au. If you would like to
speak to an independent person you can contact: Prof. Craig Speelman, Head, School of Psychology, Ph: 6304 5724 or email: c.speelman@ecu.edu.au

Sincerely,

Andrea Creado
Appendix B: Interview Schedule

Interview Schedule

Name:

Age:

Gender:

Address:

Phone number:

Relationship to caree (family member who needs care):

Disability of caree:

Interview questions:

1. How long have you been in Australia? How long have you lived in Perth?
2. Can you describe the nature of your caring role? (Prompts: responsibilities, the difficulties, the support available, the positive aspects of caring)
3. What is your experience of the support services available to carers? (Prompts: respite, home help, social support, financial help; Do you find them useful?)
4. Are there additional support services that you think are needed? (Prompts: what sort of services?)
5. How do you feel about the cultural appropriateness of existing services?
6. What are the challenges that you encounter in your caring role?
7. Is there any other information you would like to share with me?
Appendix C: Consent Form

Informed Consent Document

I ____________________________ have read the information above. Any questions I have asked have been answered to my satisfaction. I agree to take part in this study, however, I know that I may change my mind and stop at any time.

I understand that all information provided is treated as confidential and that my name will not be released by the investigator unless required to do so by law.

I agree for this interview to be recorded on tape.

I agree to be contacted to verify the transcripts of the interview.

I agree that research data gathered for this study may be published provided my name or other information which might identify me is not used.

Participant:

Date:

Investigator:

Date:

Investigator's Name:
Appendix D: Conceptually Clustered Matrix

Please turn to next page.
<table>
<thead>
<tr>
<th>No</th>
<th>Name/Age</th>
<th>Ethnicity</th>
<th>Time in AUS/Perb</th>
<th>Relationship to Caree</th>
<th>Length of Time as Caree</th>
<th>Conditions of Caree</th>
<th>Support Groups</th>
<th>Respite</th>
<th>Carer Payment</th>
<th>Centrelink</th>
<th>Lack of Information about Services</th>
<th>Emotional Support</th>
<th>Suggestions</th>
<th>Most Challenging Issue for Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>MC/51</td>
<td>Romani</td>
<td>Ex-Spouse</td>
<td>13 Years</td>
<td>M. Sclerosis</td>
<td>Pg 4 - 22 Mainstream groups are not culturally sensitive to the needs of CALD careers. Support groups or social support is of little use Pg 8 - 31 worries are still</td>
<td>Gets help from Umbrella, Respite and other help is good but only focused on the CR Pg 6 No 28</td>
<td>Payments - Pg 3 - No 20 an issue with carer receipt not contributing to household expenses Pg 7,30 - pension money is hit</td>
<td>C.R. 20</td>
<td>Services should honour carers with a badge. Pg 5, No 28</td>
<td>Some help from lehar</td>
<td>Services should be more comfortable in using groupsPg 9 - 36 advertising in the mediaPg 13 - More programs to help integration Pg 13 No 56 Pg 26 No 106 Emotional Support more a chat more community promotion required</td>
<td>Managing the daily behaviour is most challenging Pg 4 &amp; 5 No 24</td>
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</tr>
<tr>
<td>2</td>
<td>MT/47</td>
<td>Iranian</td>
<td>Mother</td>
<td>10 years</td>
<td>General Global Delay</td>
<td>Multicultural Groups - more comfortable Pg 4 No 14 and Pg 5 No 14 contd Social Support helps Pg 11 No 50 Pg 12 No 50</td>
<td>Lack of info about respite Services focused only on C.R. - Pg 11 No 46 More respite is required and consistency in respite Pg 21 - No 93 Pg 23 no 99 contd Page 20 No 85 culturally appropriate</td>
<td>Very good financial support Pg 5 No 14</td>
<td>Lack of information about services Pg 6 No 18 Pg 6 No 22 contd Page 19 - No 81 about promoting services</td>
<td>Page 5 No 14 Lack of emotional support Pg 10 No 40 No emotional support Pg 12 when emotional support was got after 6 years of being a carer It helped Pg 12 No 52</td>
<td>Emotional Support more a chat more community promotion required</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>VP/66</td>
<td>Italian</td>
<td>Mother</td>
<td>13 years</td>
<td>MI - Schizophrenia</td>
<td>Not much use. Lack of transport Pg 5 No 64 Speakers</td>
<td>No need for respite</td>
<td>Money is a big issue Pg 4 No 54 and Pg 6 No 74</td>
<td>Lack of information in Italian Pg 2 No 29</td>
<td>Nil - family and one friend</td>
<td>Carer pension should be given partly to carer</td>
<td>Dealing with emotions/behaviour</td>
<td></td>
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<tr>
<td>4</td>
<td>SB/82</td>
<td>Spanish</td>
<td>Wife</td>
<td>10 years/10 years</td>
<td>MI - Schizophrenia</td>
<td>Good Pg 2 No 10 Thankful for services given from the government - finds them useful</td>
<td>Good Pg 2 No 12 Useful Pg 3 No 18 Pg 5 - No 28 Respite for C.R should be consistent Pg 6 No 39</td>
<td>Good Pg 2 No 12</td>
<td>Pg 6 34 Culturally sensitive staff in hospitals</td>
<td>Someone to talk to C.R. in own language would be good Pg 5 no 28</td>
<td>Centrallink should give them pension even if out of the country for longer than 3 months Pg 4 No 24 and 26 Pg 6 No 26 continued</td>
<td>Dealing with emotions/Behaviour Pg 1 No 9</td>
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<tr>
<td>5</td>
<td>RC/87</td>
<td>Italian</td>
<td>Mother</td>
<td>14 years</td>
<td>MI - Schizophrenia</td>
<td>Not much use as it does not elivate worries about her son Pg 4 No 42 or Pg 7 No 60</td>
<td>Pg 5 No 56 Disability pension to the carer not care recipient Pg 5 NO 63 &amp;64</td>
<td>More information about drugs and medication in Italian Pg 3 No</td>
<td>Need emotional support Pg 3 No 36</td>
<td>More relevant Pg 8 &amp; 9 No 36</td>
<td>Dealing with violent behaviour Pg 1 No 4 Money Pg 5 No 56 or Pg 7 No 85 More relevant Pg 8 &amp; 9 No 93</td>
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## Appendix D - Conceptually Clustered Matrix

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<th>No</th>
<th>Name/Age</th>
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<th>Length of time as Carer</th>
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<th>Respite</th>
<th>Carer Payment</th>
<th>Centerlink</th>
<th>Lack of Information about Services</th>
<th>Emotional Support</th>
<th>Suggestions</th>
<th>Most Challenging Issue for Carer</th>
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<td>Sister</td>
<td>20 years</td>
<td>Down's syndrome</td>
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<td></td>
<td>Financial Support is not enough Pg 2 No 10 Pg 3 No 16 &amp; Pg 4 No 16 contd Pg 7 No 22</td>
<td>Pg 9/66 More info is needed Pg 5 - No 36 culturally close</td>
<td>Pg 7 - 58 culturally appropriate Pg 9 - 68 information via radio etc.</td>
<td>Managing the behaviour Pg 1/8</td>
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<tr>
<td>8</td>
<td>SK/50</td>
<td>Iranian</td>
<td>24 years</td>
<td>Mother</td>
<td>10 years</td>
<td>Schizophrenia</td>
<td>Pg 2 - 12 useful Pg 6 - 46 useful personal contact</td>
<td>Pg 2 - 14 &amp; 16 Respite is good but caree does not like it Pg 8/65 Respite for caree needs to be culturally appropriate Pg 10 - 76 More respite in language groups Pg 4 No 32</td>
<td>Pg 3 No 56/58 Respite is good Pg 4 - 73/78 Services are not used because care recipient does not want them Pg 2 No 30</td>
<td>Pg 5 - 89-92 Information would be useful</td>
<td>Managing the behaviour Pg 1/6 and 16</td>
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<tr>
<td>9</td>
<td>ED/65</td>
<td>Italian</td>
<td>50 years</td>
<td>Partner</td>
<td>8 Years</td>
<td>Stroke</td>
<td>Pg 4 - No 65 No 68 Information is good Pg 5 - 98 ---- is good Pg 3/4 No 65/58</td>
<td>Pg 2 - useful No 10 Pg 3 short break is very useful and good No 32 Pg 5 Culturally appropriate staff for caree No 70 Pg 6 - 92 staff that speak Burmese easier to understand the connotations Pg 7 No 109 more short</td>
<td>Pg 3 No 28 Information given but not enough. Services are used if the contact is more personal Pg 3 No 28 contd Pg 3 social worker applied for C payment No 34-36 Pg 48/5 No 52 Pg 7 No 100 useful Pg 3/4 - 44 Info about illness via counselling and from the doctor is useful Pg 4 No 48 No 52 Pg 7 No 100 useful</td>
<td>Managing the behaviour Pg 1/8</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>10</td>
<td>AR/62</td>
<td>Burmese</td>
<td>16 years</td>
<td>Mother</td>
<td>6 years</td>
<td>Schizophrenia</td>
<td>Pg 5 74-76 Multicultural groups are better</td>
<td>Pg 5 74-76 Did not know about it for six years. Paper work too much</td>
<td>Pg 4/5/5 No 61-62</td>
<td>Pg 3 &amp; 6 - 66-90</td>
<td>Pg 6 86-90</td>
<td>Managing the behaviour of caree</td>
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