Enablers and barriers experienced by grandparents who become primary caregivers of grandchildren: An occupational perspective

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ENABLERS AND BARRIERS EXPERIENCED BY GRANDPARENTS WHO BECOME PRIMARY CAREGIVERS OF GRANDCHILDREN: AN OCCUPATIONAL PERSPECTIVE

Janice du Preez

A report submitted in Partial Fulfilment of the Requirements for the Award of Bachelor of Occupational Therapy Honours, Faculty of Health, Engineering and Science Edith Cowan University September 2014

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ACKNOWLEDGEMENTS

I would like to express my gratitude to my supervisors Professor Ruth Marquis and Dr Janet Richmond for their support and guidance throughout the research process. Thank you for your tireless support and for the investment you have made in my career as a researcher and as an occupational therapist. Furthermore, I would like to thank the participants of this study who generously shared their hearts and their time. Finally, I would like to thank my family and friends for their unending support and sacrifice throughout this entire process.

I dedicate this research project to my husband. Thank you for your unwavering belief in me.
ISSUES AFFECTING AUSTRALIAN GRANDPARENTS WHO ARE PRIMARY CAREGIVERS OF GRANDCHILDREN: A REVIEW

ABSTRACT

Aim:
The aim of this review was to identify current issues affecting grandparents who are raising their grandchildren in Australia.

Method:
The study systematically reviewed twelve studies that evaluated supports for grandparents. The Checklist Analysis of Research for Systematic Review and the Quantitative and Qualitative Checklist were used to evaluate the studies.

Findings:
Five support issues affecting grandparent-headed families were evidenced in the literature as being of priority. These include stress, intergenerational conflict, community support, legal and financial aspects, policies and service frameworks.

Conclusions:
The paucity of research implies that further funding for large-scale research is required. Implications for informal primary carers of grandchildren are that the lack of legal status and the sustained burden of care will continue to negatively impact upon the grandparents’ well-being.

Recommendation:
Further research to identify priorities and develop intervention strategies supported by policy development is required to enhance the health and well-being of grandparent carers and their grandchildren.

KEY WORDS:

* Grandparental caregiver, Grandparent-headed, informal primary care-givers
INTRODUCTION

Over the past twenty-five years there has been a significant increase in the number of children in Australia being raised by grandparents (Backhouse & Graham, 2009a). This group represents almost half of the 41000 young people placed in in-house care by child protection authorities with relatives or kin in Australia (Australian Institute of Health and Welfare, 2012). Grandparents, who have become the informal primary carers of their grandchildren, find their new role and its characteristics challenging and difficult to comprehend (Valentine, Jenkins, Brennan, & Cass, 2013). This situation is compounded by the fact that Australian policies addressing this issue are less developed compared to other countries, such as the United States of America and the United Kingdom, preventing proper identification of this new parenting role and determining how support services should be prioritised and delivered.

While there is a growing awareness about this issue through anecdotal evidence provided by community service organisations, there is a paucity of research literature on the issues facing this group and the effectiveness of intervention strategies that are currently in place to support them. The purpose, therefore, of this review is to examine research, policy and practice related to caregiving grandparents in the Australian context.

BACKGROUND

There are several ways in which a grandparent becomes the primary carer of their grandchildren. These include being made the custodians of their grandchildren by the Family Court or Federal Court Circuit, grandparents themselves making application to the Children’s Court for a court order that orders that the children live with them, State
or Territory Child Protection interventions or, by informal arrangement which may or may not have the approval of the parents and may involve the State Child Protection Authorities (Brennan et al., 2013).

An informal grandparent-headed family is characterised as one where grandchildren are cared for solely by their grandparent/s without any input from their biological parents (Council on Ageing in each State and Territory (COTA) & National Seniors Productive Ageing Centre (NSPAC), 2003). The number of grandparents informally raising grandchildren is rising in Australia (COTA National Seniors, 2003; Dunne & Kettler, 2008; O'Neill, 2011). In 2011, the Australian Bureau of Statistics reported that there were 46,680 grandparent-headed families in Australia.

**Table 1: Defines the percentage breakdown of the figures reported**

<table>
<thead>
<tr>
<th>Couples with non-dependant grandchildren aged 24 years and older.</th>
<th>Couples with dependant grandchildren under 24 years of age.</th>
<th>Single grandparents with non-dependant grandchildren 24 years and older.</th>
<th>Single grandparents (mostly grandmothers) with dependant grandchildren under 24 years of age.</th>
</tr>
</thead>
<tbody>
<tr>
<td>21%</td>
<td>30.7%</td>
<td>21%</td>
<td>27.3%</td>
</tr>
</tbody>
</table>


There are a number of characteristics that set this group apart from other primary carers of children. Grandparents raising grandchildren are generally older than parental carers and the children in their care tend to be older (COTA National Seniors, 2003). Based on their study of 499 participants in 2003, COTA reported that 42% of grandparents raising grandchildren were non-employed grandmothers who rely on the age pension as their main source of income (COTA National Seniors, 2003). Many of these informal grandmother carers reported having already used all of their savings and voiced their concerns about how they and their grandchildren will survive (COTA National Seniors, 2003).
Research indicates that grandparents in Australia are increasingly being driven to become primary care-givers informally because of factors such as unemployment, parental death and mental illness of the biological parent (Horner, Downie, Hay, & Wichman, 2007). Family factors such as divorce, child abuse, family violence or dysfunction, incarceration or increased parental substance abuse have been identified as being major contributing factors (COTA National Seniors, 2003; Horner et al., 2007).

Grandparents are typically devoted to their grandchildren and have peace of mind when their grandchildren are thriving in a welcoming, stable and safe environment (Backhouse & Graham, 2009b). However, parenting grandchildren can bring stressors that may negatively impact upon grandparents’ quality of life and well-being (Backhouse & Graham, 2009a; COTA National Seniors, 2003; Horner et al., 2007).

When children at risk are moved into informal out-of-home care situations, including informal grandparent care, they fall outside the sphere of influence of State welfare and other support services (Parliament of Tasmania Joint Standing Committee on Community Development, 2003). These findings and the minimal access to support services result in out-of-home care of their grandchildren being provided at great cost to grandparents. Costs reported impact upon finances (Dunne & Kettler, 2008), relationships, psychosocial health, quality of life and well-being (Orb & Davey, 2005). In addition, the limited resources and increasing privatisation of Child Protection Services, long waiting lists for support services and the expense of private support services also has potential to shift the cost of out of home care privately to grandparents (Department of Human Services, 2014).

With insufficient evidence as a result of the lack of robust research and inaccurate prevalence data, planning of service frameworks by policy makers has frequently been ineffectual, sparse and inaccurate (Horner et al., 2007). While some policy makers and
support agencies have made positive changes to meet these increasing policy concerns, there appears to be a gap between the services provided and the services being accessed (Valentine et al., 2013). The purpose of this review is to identify and discuss research evidence that currently informs and develops policies that address the issues of informal primary care-giving grandparents.

METHODS OF REVIEW

Search and Information sources

A search of the literature was systematically conducted using combinations of keywords, phrases and related words to capture identifying studies relating to the research question. (Table 2) Key words such as: grandparents, kinship care, grandparent-headed, informal grandparental carers, community support for grandparents raising grandchildren and primary care-giving grandparents initiated the search. Online databases included: CINAHL, PsychBooks, PsycINFO, Cochrane Library, SCOPUS, PEDro, OTseeker, Library Information Science and Technology, Web of Science, PubMed, Cambridge Journal Online, University of New South Wales and the Australian Government Department of Human Services. An online search on the Google scholar search engine using the statements, “support for grandparents raising grandchildren in Australia” and “services for grandparents raising grandchildren” was also conducted. A search within full text articles and of reference lists from articles that matched the inclusion criteria completed the search.

Eligibility Criteria

For inclusion in the review, articles needed to be within the Australian context, having been published within the years 2003 – 2014 to ensure the literature is current and discussed research and community supports for grandparents who are the primary
carers of their grandchildren. Eight studies and four government reports met these criteria and were included. Refer to Table 2 to view additional eligibility criteria.

[Place Table 2 here]

**Exclusion Criteria**

Articles were excluded if an abstract was not available; the article was not available in English, did not include clinical queries and did not include all journal subsets. Articles that were not evidence-based i.e. scientifically-based and peer-reviewed, fell outside of the 2003-2014 time period and were not exclusively Australian were also excluded.

**Data Extraction**

The critical appraisal instrument Checklist Analysis of Research for Systematic Review (Tong, Sainsbury, & Craig, 2007) (Table 3) and the Quantitative and Qualitative Checklist (Kmet, Lee, & Cook, 2004) were used to evaluate the studies. The Checklist Analysis of Research for Systematic Review (Tong et al., 2007) is a summary of the results of each study that met the initial inclusion criteria. The summary includes the reference, sampling procedures including the number of participants, how participants were selected and recruited, study design, data collection methodology, outcome measures, the results of each study and comments. Seven of the studies were independently assessed by two reviewers using the Standard Quality Assessment Criteria for evaluating primary research papers (Kmet, et al., 2004). This assessment contains a 14-item quantitative and a 10-item qualitative checklist with instructions to assist reviewers when assessing quality of research and calculating a rating. Due to the consistency of the ratings, and a correlation on the extent of the agreement between the two reviewers, the remaining studies were rated by the primary researcher. The use of the Standard Quality Assessment Criteria for Evaluating Primary
Research (Kmet, et al., 2004) ensured that the assessment of methodological rigour was thorough. The researchers discussed the scores and reached consensus as to which studies qualified for inclusion.

RESULTS

Study selection

The Search methodology for Review (Table 2) and the Flow Diagram (Moher, Liberati, Tetzlaff, & Altman, 2009) (Fig.1.), demonstrate that the search was conducted over a period of days in which 1341 000 results were found. A total of 1130 000 studies were excluded as irrelevant based on duplication, the title, if it was not published between the years 2003 – 2014, did not relate to informal primary carers of grandchildren or the needs of grandparents who care for their grandchildren. Full text screening of the remaining 211 studies resulted in a further 199 of those studies being excluded because they were written for the American context and did not reflect the Australian context.

FINDINGS

The findings discuss the quality of the research, participants, data collection, outcome measures, results and the design limitations and strengths of each study. This is followed by identifying the conclusions and themes found in the various studies.

A summary of the findings can be found in Table 3. Of the 12 studies included in this review one was a cross-sectional mixed-methods study between a group who completed a postal open-ended questionnaire survey and the in-depth interviews of grandparents conducted in a support group (Dunne & Kettler, 2008). The study used a self-styled Demographics questionnaire, the Depression, Anxiety and Stress Scale
(DASS21) (Lovibond & Lovibond, 1995) and the Caregiver form of the Strengths and Difficulties Questionnaire (SDA) (Goodman & Scot, 1999). This study was of a high standard because it used standardised measures between groups and the mixed method strengthened reliability of results, however the researchers were unable to determine onset, prevalence and duration of stress due to confounding variables.

Another strong mixed-methods study utilised a convenience sample of grandparent caregivers (n=335) recruited through national media, support groups and peak service provider bodies (Brennan et al., 2013). The limitations of this study include: not reporting the details of the survey design, the number of focus group participants were not included and the sample may not be representative, possibly involving people already registered with agencies. However, the size of the sample provided significant data for statistical analysis, it was culturally inclusive with qualitative interviews being conducted with twenty Aboriginal grandparents as a special focus and data were also collected from service providers and policy makers.

Four of the studies were qualitative studies, (Backhouse & Graham, 2009b; O'Neill, 2011; Orb & Davey, 2005; Valentine et al., 2013) all of which had design strengths that enhance trustworthiness by including: richness of data, multiple researchers involved in data analysis, involvement of Government, non-government and peak body organisations, and interview data being checked by participants for accuracy. The design limitations lie in the studies being limited to New South Wales, the Northern Territory and South Australia therefore not inclusive of the whole of Australia, meaning that different policies governing other states may not be fairly represented.

Two studies were narrative reviews with one study reviewing 49 refereed papers and making a comparison between Australian and International literature, while the second review commented on two group case studies, one being of young carers up to
24 years of age and the other of grandparents caring for grandchildren (Horner et al., 2007). This review was Australian specific addressing current policy issues and services gaps however, a limited theoretical framework of social care drove the analysis of this study thus limiting its design (Cass, 2007). The remaining four studies were government reports or independent inquiry reports from peak body organisations.

Quality of studies

Table 4a: Percentages scored for each study

<table>
<thead>
<tr>
<th>AUTHORS</th>
<th>RATER 1 SCORE %</th>
<th>RATER 2 SCORE %</th>
<th>INCL.</th>
<th>EXCL.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantitative</td>
<td>Qualitative</td>
<td>Quantitative</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Dunne and Kettler, 2008</td>
<td>0.90</td>
<td>0.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Orb &amp; Davey 2005.</td>
<td>0.95</td>
<td>0.95</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Horner, Downie, Hay &amp; Wichmann, 2007</td>
<td>0.55</td>
<td>0.60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Valentine, Jenkins, Brennan &amp; Cass, 2013</td>
<td>0.90</td>
<td>0.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Cass, 2007</td>
<td>0.65</td>
<td>0.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. O'Neill, 2011</td>
<td>1</td>
<td>0.85</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Brennan, et al., 2013</td>
<td>1</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Backhouse &amp; Graham, 2009</td>
<td>1</td>
<td>Not rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Joint Standing Committee, 2003</td>
<td>Not rated</td>
<td>Not rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Families Australia, 2007</td>
<td>Not rated</td>
<td>Not rated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. COTA National Seniors, 2003</td>
<td>1</td>
<td>Not rated</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Kmet et al., 2004)

Table 4b: Strength categories of the methodological quality of the 12 studies reviewed

<table>
<thead>
<tr>
<th>Categories of Strength</th>
<th>Percentage scored</th>
<th>No. of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited</td>
<td>scored &gt;49%</td>
<td>0</td>
</tr>
<tr>
<td>Adequate</td>
<td>scored between 50-69%</td>
<td>1</td>
</tr>
<tr>
<td>Good</td>
<td>scored between 70-79%</td>
<td>2</td>
</tr>
<tr>
<td>Strong</td>
<td>Scored &lt; 80%</td>
<td>9</td>
</tr>
</tbody>
</table>

The methodological quality of the 12 studies reviewed is presented in Table 2. Studies employing quantitative methods were appraised using 14 items on the checklist.
for quantitative studies and studies employing qualitative methods were appraised using 10 items on the checklist for qualitative studies (Kmet et al., 2004). Items were scored depending on the degree to which the special criteria were met (“yes” = 2, “partial” = 1, “no” = 1). A summary score was calculated for each paper by summing the total score obtained across relevant items divided by the total possible score (Kmet et al., 2004). The studies were allocated to categories of strength according to the percentage scored.

The methodological quality ranged from adequate to strong. Of the 12 studies reviewed, one study was adequate and scored between 50-69%, two of the studies were good, scoring between 70-79% with the remaining nine studies meeting more than 80% of the criteria on the Quantitative and Qualitative Checklist (Kmet et al., 2004). These nine studies described the objectives of the study sufficiently, the study design was evident and appropriate, the context of the study was clear, sampling strategies were described, relevant and justified, data collection methods and data analysis was clearly described and systematic, verification procedures established credibility and the conclusion was supported by the results (Kmet et al., 2004).

**OUTCOMES**

Five support issues affecting grandparent-headed families were evidenced in the literature as being of priority; these were stress, intergenerational conflict, the importance of community support, legal and financial implications and policies and service frameworks.

**Stress**

Stress was a major health issue across both qualitative and quantitative research. From five of the qualitative studies it seems clear that grandparents, who are the informal primary carers of their grandchildren, experience stress, depression which is compounded when their grandchildren manifest difficult behaviour (COTA National
Seniors, 2003; Dunne & Kettler, 2008; Horner et al., 2007; O’Neill, 2011; Orb & Davey, 2005) and anxiety. These studies also report increased stress from intergenerational conflict, financial stress, the consuming nature of the caring role and concerns about the future (COTA National Seniors, 2003; Dunne & Kettler, 2008; Horner et al., 2007; O’Neill, 2011; Orb & Davey, 2005). Caring for grandchildren who have physical health and psychological issues is especially difficult for aging grandparents who may have their own chronic health issues (COTA National Seniors, 2003). The accumulated stress over time, without respite, may leave grandparents with a diminished sense of self-worth. Additionally, the extra financial burden of caring for their grandchildren on a meagre income from an aged pension or carefully budgeted retirement savings contributes to their stress (COTA National Seniors, 2003; Dunne & Kettler, 2008; Orb & Davey, 2005).

**Intergenerational conflict**

Another theme to emerge from the studies is the intergenerational conflict that arises between the grandparents and the biological parent/s of the child or between the grandchildren and the grandparents (Brennan et al., 2013; COTA National Seniors, 2003; Dunne & Kettler, 2008). An agency designed intervention program was evaluated using standardized methods (Horner et al., 2007). The program provided psychosocial support for 19 grandparent-headed families. Researchers confirmed that grandparents experienced severe emotional reactions at both pre-test and post-test to their family situation. However, qualitative data collected from this group revealed that many grandchildren and grandparents found the program to be valuable (Horner et al., 2007). There were contrasting findings on the issue around relationships between grandchildren and their biological parents (Horner et al., 2007). Research suggests that biological parents often cause instability in the household by spontaneously removing
the children and placing them in high risk environments (Backhouse & Graham, 2009b). Key to ensuring the psychosocial health of both the grandchildren and the grandparents is ensuring that the children maintain their relationship with their biological parents and other family members (Backhouse & Graham, 2009b). However, doing so is not without its conflicts. In addition to caring for their grandchildren, grandparents have to deal with the “baggage” that their adult children’s dysfunctional lives bring leaving the grandparents angry, frustrated and resentful as they now feel it their “moral” duty to care for the grandchildren while acknowledging that they cannot afford to do so (Backhouse & Graham, 2009b; Dunne & Kettler, 2008). It must be acknowledged however, that there are no perfect solutions and that stress will be evident in every outcome.

**Importance of community support**

There is limited published research that supports community support and professional services that negate the overwhelming challenges that grandparental carers face (Families Australia, 2007b; Horner et al., 2007; Orb & Davey, 2005; Valentine et al., 2013). Based upon their research findings of data collected from 499 participants, the report by the Council on the Ageing in each State and Territory (COTA) and National Seniors Productive Ageing Centre (NSPAC) (2003) asserts that support groups, counselling, legal aid, financial aid, respite and access to health services are supported by grandparents. However, services are also frequently declined and many grandparents refuse to utilize the services that are made available to them (COTA National Seniors, 2003; O’Neill, 2011; Orb & Davey, 2005). This may be as a result of their own prejudice towards professionals or their perception of being treated with disrespect by support staff or due to a lack of relevant information that meets the special needs of this subset (COTA National Seniors, 2003; Families Australia, 2007a; O’Neill,
In contrast, researchers argue that grandparents have trouble gaining access to information and support though little has been done to understand the barriers that cause this inaccessibility (Brennan et al., 2013; Valentine et al., 2013). Findings from a survey of 355 participants conducted by Brennan, Cass, Flaxman, Hill, Jenkins, McHugh, Purcal & Valentine (2013) found that support groups were the most widely used by the grandparents with services only being available to around 30-40% of the families surveyed and these services include: child care, respite and caseworker support (Brennan et al., 2013).

**Funding**

Financial challenges due to escalating costs of raising their grandchildren have negative personal, intergenerational and economic consequences on informal grandparental carers (Orb & Davey, 2005). Funding is not routinely accessible to grandparent-headed homes with a perception by grandparents that they do not have access to the same resources that parental carers have (Orb & Davey, 2005). There is some funding available to grandparents who rely on a government pension but any allowance that is received for child care is added to the total family income, which then results in Centrelink ([http://www.humanservices.gov.au](http://www.humanservices.gov.au)) reducing the grandparent’s personal assistance, with further reductions should the family be living in subsidised state housing.

Researchers report that the State is under no obligation to offer support except in cases where the grandparents are recognised by the State Children’s Court as being foster parents or have been awarded legal custody of their grandchildren (Dunne & Kettler, 2008). Results of a study conducted by Dunne and Kettler (2008), in which 52 grandparent carer participants completed a postal survey, revealed that financial stress was higher in middle class grandparent-headed homes because they do not qualify for
the subsidy from Centrelink that lower economic groups receive nor do they have a high enough income to support themselves and their grandchildren (Dunne & Kettler, 2008).

Although limited quantitative studies have been conducted, a report by the Council on the Ageing in each State and Territory and National Seniors Productive Ageing Centre (COTA National Seniors, 2003) revealed that grandparents found that there was a lack of collaboration between the State and Commonwealth Government resulting in policies that were too complicated to understand. Informal grand-parental caregivers expressed a need for all government agencies, health professionals and community support services to work together to provide them with the recognition and special status they deserve. Grandparents who are the informal primary carers of their grandchildren see themselves as more of an economic asset than financial burden to the Government in that they are saving the government money by providing out-of-home-care to children that would otherwise be a monetary drain on the social welfare system (Backhouse & Graham, 2009a; COTA National Seniors, 2003).

Grandparents who have the responsibility of informally caring for their grandchildren in the practical sense but do not have legal authority, which is retained by the parents, feel that the lack of legal recognition exacerbates the situation as they have no legitimate authority to make decisions about their grandchildren’s education or medication without first consulting with the biological parents who are often unavailable (Backhouse & Graham, 2009b; COTA National Seniors, 2003). Grandparents belonging to this subset argue for recognition comparable to that which foster carers experience (Brennan et al., 2013). Findings from a qualitative study of the experiences of 34 grandparents raising their grandchildren, conducted by Backhouse and Graham (2009), suggest that foster carers are perceived by grandparents as being
more highly esteemed with privileges and access to funding, whereas the role of the primary caring grandparent is seen to be “expected” (Backhouse & Graham, 2009a).

**Policies and service frameworks**

Findings by the Parliament of Tasmania Joint Standing Committee on Community Development (2003) suggest that grandparents should be collaboratively included in the decision and policy making process as they are the experts on what is in the best interest of their grandchildren’s safety and quality of life. These findings were supported by other research conducted with grandparents who informally care for their grandchildren (Brennan et al., 2013). In addition, clinicians of the Australian Psychological Society have stated that priority should be given to adopting placement regulations for Aboriginal childcare placements as well as for migrants who have been thrust into this informal parental role (Australian Psychological Society, 2014).

**DISCUSSION**

Due to the limited research conducted in Australia, this review showed little evidence that adequate support is available to grandparent caregivers in Australia. The needs of this group, however, have been the focus of a Senate inquiry, the National Seniors Productive Ageing Centre, Families Australia and the Australian Psychological Society. Through consultation with grandparent caregivers themselves and service providers, it is clear that this population is at high risk of stress and financial disadvantage, which negatively impacts on well-being. This suggests that accumulated stress will inevitably result in grandparents’ diminishing capacity for social engagement and participation and cannot be ignored (Dunne & Kettler, 2008; O’Neill, 2011; Orb & Davey, 2005). These implications clearly demonstrate the need for increased provision of psychological support for grandparents and grandchildren (COTA National Seniors, 2003; Dunne & Kettler, 2008). However, Backhouse and Graham (2009) suggest that
these ‘care arrangements take place in a complex space marked by paradox and ambiguity’ (Backhouse & Graham, 2009a) and that existing policies fail to recognise the experiences of grandparents raising their grandchildren.

The lack of lawful recognition of informal grandparent-headed households impacts upon and limits the establishment of grandparents’ role identity, rights and responsibilities, access to financial support and the power to make decisions that are in the best interest of their grandchildren has been supported by robust research. Thus, legalisation of their “special” status, equal to that of foster carers, is required so that they can receive benefits equal to their responsibilities.

Orb and Davey (2005) state that grandparents who have unexpectedly become primary carers of their grandchildren without having time to make adequate provision financially for their retirement, should receive the immediate attention of policy makers. Failing to develop policies and adequate support will result in the state having the added burden of caring for the grandchildren and the grandparents once grandparents’ funds have been exhausted (Orb & Davey, 2005). Yet, the relationship between this group of carers and the Commonwealth government agencies and community support services is consistently complicated and fraught with misunderstanding (Valentine et al., 2013).

Grandparents require information about their rights and responsibilities, parenting skills and managing their relationships with biological parents and their grandchildren (Valentine et al., 2013). It is also important to consider how services are being provided and accessed, as an over reliance on advancing technologies may be difficult for older grandparent caregivers to access. Older carers may prefer information that is tailored to their specific needs and available in their local community to address limited mobility issues (Valentine et al., 2013). It is recommended that information be made available in various formats including brochures at the Libraries and Centrelink branches, through
the radio, television, telephone help-lines, newsletters, support groups and face-to-face consultations where grandparents feel accepted and respected (Brennan et al., 2013; Valentine et al., 2013).

In addition, support services should respond to the identified need for training programs for grandparents raising their grandchildren that will equip and empower them to fulfil their role with confidence (Valentine et al., 2013). Further needs identified are education relating to parenting, discipline, computer literacy, ways to access resources and information, stress management techniques, recreation and leisure activity ideas and respite care (Valentine et al., 2013). Training for the support workers and health professionals who have dealings with this subset is also essential to maximise benefits to the informal grandparent carers.

Grandparents raising their grandchildren often find themselves isolated from society. Some friendships are lost due to negative reactions to their new role as primary carers with the grandparents being blamed for “not raising their children properly” (Backhouse & Graham, 2009b) while other peer support is lost due to the time constraints minimizing participation in social events (Valentine et al., 2013). In addition, research that identified barriers that prevent grandparents from accessing appropriate supports and services recommends that support groups and respite care are possible solutions to this problem but there is a shortage of both within communities (Valentine et al., 2013). The research findings also support the development of a national framework for the delivery of support and services with the Government providing financial assistance, legal aid, education and psychological support for both the grandparents and the grandchildren (Australian Psychological Society, 2014; Backhouse & Graham, 2009b; Families Australia, 2007a). However, further research regarding effective strategies for informal grandparent carers is required.
Limitations

This review is limited by the dearth of research volume on grandparent carers which limited data extraction. Only journal articles and reports conducted in English during the time period 2003-2014 in Australia were included. All search terms and article searches were conducted by the sole researcher and the choice of databases and word combinations may have resulted in study bias.

CONCLUSIONS

The purpose of this review was to ascertain the quality and quantity of evidence that identify the challenges that grandparents who are raising their grandchildren in Australia. The reviewer concludes that limited research is available and most of the research is qualitative. This review identified a lack of policy development that addresses the needs of out-of-home care for grandchildren. In addition it was identified that programmes that support grandparental-carers health, access to information and social participation are not widely available. There is a need for support services to be designed and evaluated. While some research found that placing ‘children at risk’ in out-of-home care with their grandparents is the best solution for the grandchildren it is not always the desired outcome for grandparents with this new role often thrust upon them unexpectedly. Policy initiatives demonstrate a failure to acknowledge the complexity of informal parenting and what is really involved in raising grandchildren.

Implications for informal primary carers of grandchildren is that the lack of acknowledgment and the sustained burden of care will continue to negatively impact upon their occupational participation, health and well-being. With research indicating that the number of at-risk children is on the increase, this is an issue of growing concern and dependent on the health and willingness of grandparents to take on the responsibility of their care.
The implications for health professional practice is that health professionals require a deeper understanding of the unique needs of this group to inform evidence based practice and interventions. Health professionals need to invest time in research how informal grandparental caregiving impacts upon the occupational participation of grandparents. With a focus on education about stress management, parenting skills, dealing with child behavioural issues and in offering support through counselling and case management, health professionals can empower grandparents. Through the provision of evidence based, effective interventions, health professionals can be positioned as a buffer between the stressors influencing grandparental informal care-givers and their mental health thereby having a positive impact upon their quality of life and well-being.

The current paucity of research to provide evidence upon which policy makers can find solutions and build their service support frameworks needs to be addresses. Research into the financial stress on retirement savings, the needs of grandparents raising their grandchildren, the long term effects on the psychological, social and physical health of both the grandparents and the grandchildren is needed. Additionally, an in-depth review of the inequalities that exist between informal primary carers of grandchildren and foster carers of children and the identification of complex intergenerational issues that impact upon every family member involved is needed to ensure that effective interventions and policy reforms are legislated.
REFERENCES


APPENDICES

Table 2: Search methodology for Narrative Review

Fig. 1: Flow Diagram

Table 3: Checklist analysis for Review
Table 2: SEARCH METHODOLOGY FOR REVIEW:

<table>
<thead>
<tr>
<th><strong>Key words</strong> used in search:</th>
<th><strong>Expanders</strong> used in search: Boolean/Phrase</th>
</tr>
</thead>
<tbody>
<tr>
<td>grandparents”, “grandparenting”, *grandparent, grandparental caregiver, intergenerational, kinship care, informal carer, community support, family support services</td>
<td>Apply related words text of articles</td>
</tr>
<tr>
<td>Grandparents raising grandchildren, grandchildren in custodial care</td>
<td>Also search within full text of articles</td>
</tr>
<tr>
<td>Grandparents AND Australia, primary carers of children, services AND grand parents</td>
<td>Full text Month and Years: Jan 2003 – Dec 2014 – (to ensure the research found was current and relevant)</td>
</tr>
<tr>
<td>Grandparent headed families in Australia “out-of-home-care” grandparents in Australia</td>
<td>Peer Reviewed References Available</td>
</tr>
</tbody>
</table>

**SPECIAL LIMITATIONS:**
- Abstract available
- English language
- Evidence-based practice
- All clinical queries
- Research Articles
- Meta-synthesis
- All Journal subset

**PUBLICATION TYPE:**
- All
- PDF: Full text
- Sex: All

**DATABASES SEARCHED:**

<table>
<thead>
<tr>
<th>DATABASES SEARCHED:</th>
<th>DATES OF SEARCHES CONDUCTED:</th>
<th>TOTAL RESULTS:</th>
<th>NO. OF ARTICLES FULLY SCREENED</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL, PsycBooks, PsycINFO.</td>
<td>21/5/14</td>
<td>722 000</td>
<td>211</td>
</tr>
<tr>
<td>Cochrane Library</td>
<td>22/5/14</td>
<td>196 000</td>
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<tr>
<td>EBSCO</td>
<td>23/5/14</td>
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<td>SCOPUS</td>
<td>26/5/14</td>
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<tr>
<td>PEDro, OTseeker</td>
<td>5/06/14</td>
<td>423</td>
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<td>Library, Information Science and Technology</td>
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<td>Web of Science</td>
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<td>Cambridge Journals Online</td>
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<tr>
<td>University of New South Wales</td>
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<tr>
<td>Australian Government: Depart. of Human Services</td>
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<tr>
<td>Google search:</td>
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<td></td>
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<tr>
<td>Query 1: Support for grandparents raising Grandchildren in Australia</td>
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<td></td>
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<tr>
<td>Query2: Services for grandparents raising grandchildren</td>
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</table>
FLOW DIAGRAM (Fig. 1.)

Adapted from the PRISMA 2009 Flow Diagram (Moher, Liberati, Tetzlaff, & Altman, The Prisma Group, 2009).

Records identified through database searching (n=1317 000)

Records identified through other sources (n=24)

Records after duplicates removed (n=1341 000)

Records excluded (n=1130 000)

Records screened (n=1341 000)

Full-text articles assessed for eligibility (n=211)

Full-text articles excluded, with reasons (n=199)

Studies included in qualitative synthesis (n=12)

Studies included in quantitative synthesis (meta-analysis) (n=0)
### Table 3: QUALITATIVE RESEARCH CHECKLIST

**NOTE:** This checklist is based on the Consolidated Criteria for Reporting Qualitative studies (COREQ) 32-item checklist (Tong, Sainsbury & Craig, 2007). It was used in conjunction with the Standard Quality Assessment Criteria for Evaluating Primary Research Papers Qualitative Checklist (Kmet, Lee & Cook, 2004) (APPENDIX D) to ensure a rigorous systematic review of the literature.

<table>
<thead>
<tr>
<th>REFERENCES</th>
<th>SAMPLE</th>
<th>STUDY DESIGN</th>
<th>DATA COLLECTION METHOD</th>
<th>OUTCOME MEASURES</th>
<th>RESULTS</th>
<th>COMMENTS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Dunne &amp; Kettler, 2008.</td>
<td>AUSTRALIA: Convenience sample 52 participants raising their grandchildren (CAREGIVERS) and 45 grandparents who were not primary carer’s of their grandchildren (NON-CAREGIVERS)</td>
<td>A cross-sectional study mixed method between group postal survey -open ended -questionnaire Grandparent caregiver group</td>
<td>-Participants were voice-recorded during a semi-structured interview -Qualitative Analysis of interview content conducted describing <em>a priori</em> themes and emergent themes</td>
<td>-Depression, Anxiety and Stress Scale (DASS21) -The Caregiver form of the Strengths and Difficulties Questionnaire (SDQ)</td>
<td>-significantly higher levels of stress, anxiety and depression among caregiving grandparents -relationship between grandparent stress and grandchildren’s behaviour -higher stress in moderate economically advantaged than lower or higher, due to “hidden” financial stress -formal/informal care each present different set of problems -intergenerational conflict causing stress</td>
<td>Design limitation: - unable to determine on-set, prevalence and duration of stress Design strengths: - standardised measures between groups - Mixed method strengthened reliability of results</td>
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<td>REFERENCES</td>
<td>SAMPLE</td>
<td>STUDY DESIGN</td>
<td>DATA COLLECTION METHOD</td>
<td>OUTCOME MEASURES</td>
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<td>2. Orb &amp; Davey, 2005.</td>
<td>WESTERN AUSTRALIA: Purposive sample Sought from a local Private community organisation 17 participants 13 women and 4 men Age: (M=55) All Caucasian</td>
<td>Descriptive qualitative</td>
<td>Face-to face interviews</td>
<td>Australian grandparent caregivers experience stress and social isolation Lack of evidence for Australian policy makers to build policy or service frameworks Australian research needed</td>
<td>-Emergent themes found stress related to the consuming nature of caring, lifestyle changes, future concerns, difficulties in accessing support, financial concerns and dealing with welfare services.</td>
<td>Design limitation: small sample, snapshot view - all participants recruited from one support group and all Caucasian Design strengths: - Richness of data supplemented by field notes and journal notes - Multiple researchers involved in data analysis</td>
</tr>
<tr>
<td>3. Horner, Downie, Hay &amp; Wichmann, 2007</td>
<td>49 refereed papers reviewed</td>
<td>Narrative review of Australian and International literature</td>
<td>Multiple methods</td>
<td></td>
<td>-Australian grandparent caregivers experience stress and social isolation -Lack of evidence for Australian policy makers to build policy or service frameworks -Australian research needed</td>
<td>Design limitation: Narrative review Design strengths: - International research literature and Australian literature compared - Grey literature i.e. Government Reports included</td>
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<tr>
<td>REFERENCES</td>
<td>SAMPLE</td>
<td>STUDY DESIGN</td>
<td>DATA COLLECTION METHOD</td>
<td>OUTCOME MEASURES</td>
<td>RESULTS</td>
<td>COMMENTS:</td>
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</table>
| 4. Valentine, Jenkins, Brennan & Cass, 2013. | AUSTRALIA: Purposive sample of 29 service providers and 26 policy makers | Qualitative study | -semi-structured interviews and focus groups | Identified barriers exist preventing grandparents from accessing appropriate supports and services | | Design limitation:  
- Study limited to New South Wales, Northern Territory and South Australia  
Design strengths:  
- Government, non-government and peak organisations involved |
| 5. Cass, 2007 | AUSTRALIA: Young carers up to 24 years and grandparents caring for grandchildren | Narrative review: ABS, national, research literature, grey literature reviewed | 2 Group case studies | Policy development needs to address equitable distribution of costs of care in both cases | | Design limitation:  
- Limited theoretical framework of social care drives analysis  
Design strengths:  
- Australian specific addressing current policy issues and service gaps |
<table>
<thead>
<tr>
<th>REFERENCES</th>
<th>SAMPLE</th>
<th>STUDY DESIGN</th>
<th>DATA COLLECTION METHOD</th>
<th>OUTCOME MEASURES</th>
<th>RESULTS</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. O’Neill, 2011</td>
<td>Purposive sample 27 grandmothers and 7 grandfather caregivers</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Identified issues of financial hardship, stress, role loss, shame, strained family relationships and inadequate support</td>
<td>Design limitation: State focussed sample (Victoria) 1 Aboriginal participant Lack of information on ethnicity Design strengths: Interview data checked by participants for accuracy</td>
<td></td>
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<tr>
<td>7. Brennan, Cass, Flaxman, Hill, Jenkins, McHugh, Purcal &amp; Valentine, 2013</td>
<td>Purposive sample 27 grandmothers and 7 grandfather caregivers</td>
<td>Qualitative (survey) and qualitative (in-depth interviews and focus groups)</td>
<td>Postal survey and online survey -Focus groups across four states with policy makers and service providers -In-depth interviews with 20 Aboriginal grandparents</td>
<td>Significant disadvantages; Financial 70%, Employment 66% Inadequate housing 20% Physical and mental health deterioration (62%) Grandchildren’s physical problems 50% Grandchildren’s emotional problems 80%</td>
<td>Design limitation: Details of survey design not reported. Sample may not be representative, involving people already registered with agencies Numbers of focus group participants not included Design strengths: Sample size Aboriginal participants (5%) proportionate to population included Qualitative interviews with 20 Aboriginal grandparents as a special focus Data collected from service providers/policy makers</td>
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<tr>
<td>8. Backhouse &amp; Graham 2009</td>
<td>Purposive sample 27 grandmothers and 7 grandfather caregivers</td>
<td>Qualitative – narrative enquiry</td>
<td>In-depth interviews</td>
<td>Need for further research on emerging policy frameworks to address emotional, social, financial and pursuit of better outcomes for grandparents and grandchildren in their care.</td>
<td>Design limitation: Study confined to NSW</td>
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</table>
**GREY LITERATURE ANALYSIS: Government and peak body organisation reports**

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<thead>
<tr>
<th>REFERENCES</th>
<th>SAMPLE</th>
<th>STUDY DESIGN</th>
<th>DATA COLLECTION METHOD</th>
<th>OUTCOME MEASURES</th>
<th>RESULTS</th>
<th>COMMENTS:</th>
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<tbody>
<tr>
<td>1. Australian Government Ministerial report Council on the Ageing in each State and Territory (COTA) &amp; National Seniors Productive Ageing Centre (NSPAC), 2003</td>
<td>AUSTRALIA: -wide COTA database Convenience sample: 499 respondents to invitation to participate</td>
<td>Qualitative - Senate Inquiry - forum discussion 110 written responses to questionnaire</td>
<td>22 Nation-wide forums Open-ended questionnaire available</td>
<td>-Significant reporting of stress and depression -Need for financial, legal, parenting, respite and information identified -Support groups identified as beneficial</td>
<td>Design limitation: - open-ended public enquiry approach to identify issues</td>
<td>Design strengths: - inclusive of Aboriginal and ESL participants - National focus - Large number of participants - Face-to-face and written data collected - Workshop facilitators received intensive training</td>
</tr>
<tr>
<td>2. Senate Community Affairs Reference Committee report by the Australian Psychological Society, 2014</td>
<td>AUSTRALIA: Ethnically diverse database No. of participants not stated</td>
<td>A REPORT</td>
<td>Qualitative results Evidence provided from psychology profession's clinical client base</td>
<td>-Psychological support for both grandparents and grandchildren needed -Development of inclusive service delivery and support needed</td>
<td>Report limitation: - No peer-reviewed evidence presented</td>
<td>Report strengths: - inclusive of Aboriginal and Torres Strait Islander participants - National focus - Face-to-face and written data collected</td>
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<td>3.</td>
<td>Parliament of Tasmania Joint Standing Committee on Community Development Report no. 2 on issues relating to Custodial Grandparents, 2003</td>
<td>TASMANIA: 14 written submission were received and 23 witnesses gave evidence before the Committee</td>
<td>Qualitative results The Committee advertised for public submissions in major newspapers -public hearing conducted</td>
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<td>Informal childcare by grandparents diverts the children from the formal child welfare system, giving grandparents access to limited funding. -grandparents are unable to access adequate assistance</td>
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<td></td>
<td>AUSTRALIA: 37 participants representing government, community and research organisations as well as grandparents</td>
<td>Focus groups and other qualitative results</td>
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|   |   |   |   |

**Report limitation:**
- Limited to Tasmania
- Small sample group

**Report strengths:**
- Inclusive discussion
- Results and recommendations similar to issues raised in other reports

**Report strengths:**
- Lived experiences shared
- Raised awareness

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