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## PUBLIC HEALTH | RESEARCH ARTICLE

# The physical health dilemmas facing custodial grandparent caregivers: Policy considerations

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**Abstract:** *Objective:* This study sought to determine what impact the task of raising grandchildren is having on custodial grandparents' physical health. *Design and Methods:* Thematic analysis was conducted on interview data collected from 49 custodial grandparents. *Results:* The task of raising grandchildren on a fixed-income is difficult for grandparents with limited respite-care options. Hence, they periodically face the dilemma of deciding whether to defer or not defer their own health needs so they can continue to care for their grandchildren. Grandparents are also wary of asking for health-related respite-care assistance: (i) in case their asking is perceived as an admission they are not coping; (ii) that some harm might befall their grandchildren while they are in respite-care; and (iii) that a respite-care placement will cause their grandchildren's underlying abandonment insecurities to resurface. *Policy considerations:* To help overcome custodial grandparents' respite-care access barriers greater consideration needs to be given to delivering health promotion information within the non-judgemental and receptive confines of grandparent support groups.

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### PUBLIC INTEREST STATEMENT

A growing number of grandparents are becoming the fulltime carers of their grandchildren due to parental illness, death, substance-misuse, or child-neglect. This study investigated the impact that raising grandchildren has on custodial grandparents' physical health. This was achieved by interviewing 49 custodial grandparents and analysing their experiences. We determined that a critical issue for many custodial grandparents is that they are operating on a fixed superannuation/retirement income, one which was not designed to accommodate one or more grandchildren. Hence, when funds are short grandparents tend to defer their health needs rather than scrimp on their grandchildren's everyday requirements. Grandparents also reveal that they are often wary of seeking respite-care assistance in case their asking is perceived as an admission they are not coping. To address these issues consideration needs to be given to delivering health promotional and financial assistance information to grandparents within the non-judgemental confines of grandparent support groups.

**Subjects: Development Studies, Environment, Social Work, Urban Studies; Social Sciences; Behavioral Sciences; Health and Social Care; Health & Society; Public Health Policy and Practice; Social Work and Social Policy**

**Keywords: physical health; custodial grandparents; respite care barriers; caregiver role strain; policy considerations**

## 1. Introduction

Assuming the custodial care responsibility for a vulnerable grandchild is an act of love which grandparents unstintingly do in instances where their grandchildren's parents are incapable of parenting them due to their immaturity, substance addiction, ill-health, incarceration, distance employment, relationship breakdown, or death (Hadfield, 2014; Strom & Strom, 2011; Taylor, Coall, Marquis, & Batten, 2016; Trail Ross, Kang, & Cron, 2015). It is estimated that 46,680 Australian, 200,000 British and 2.4–2.8 million American grandparents (20% of whom are below/at the poverty line) are fulltime caregivers. It is also estimated (Vasel, 2017) that it presently costs between US \$12,350 and 14,000 a year (approximately 12,350 and 14,000 Australian dollars—10,225 and 11,600 British pounds) to raise a child. Hence, when operating on a fixed retirement income or a state pension the task of providing for the daily needs of one or more grandchildren places a considerable financial strain on custodial grandparents (Taylor, Marquis, Batten, & Coall, 2015). When this caregiving financial strain is coupled with the emotional distress associated with coming to terms with their own offspring's inability to adequately parent their grandchild/ren as well as the ongoing daily challenge of raising grandchildren, caregiving exacts a toll on grandparents' mental health (Taylor, Marquis, Batten, & Coall, 2016). Indeed, a growing number of researchers have determined that custodial grandparents experience significantly higher levels of stress, depression, anxiety, sadness, and social isolation than non-custodial grandparents. However, the impact that impoverished mental health has on custodial grandparents' ongoing physical health and longer-term ability to continue caring for their custodial grandchild/ren has yet to be determined (Commonwealth of Australia, 2014; Cox & Miner, 2014; Grant, 2014; Hank & Buber, 2011; Honea et al., 2008; Kelley, Whitley, & Campos, 2012; Kirby & Sanders, 2014; Marken & Howard, 2014; Rodakowski, Skidmore, Rogers, & Schulz, 2012; Sprang, Choi, Eslinger, & Whitt-Woosley, 2015; Taylor, Marquis, et al., 2016).

### 1.1. Background literature

Grandparent-headed families are often “skipped generation” family units (i.e. households where the parent generation is absent) or multi-generational family units (i.e. three generation households where grandparents, parents and grandchildren are permanently/intermittently co-resident). Regardless of the household's generational composition custodial grandparents are at greater morbidity and declining health-risk than are non-custodial grandparents (Boetto, 2010; Hadfield, 2014). It is posited that this elevated risk is a facet of custodial grandparents assuming care of their grandchildren at an age (50 + years) when their pre-existing health complaints (e.g. diabetes, hypertension, heart disease, hearing problems, insomnia) are exacerbated by the financial, legal, and role strain stressors which arise from raising a second generation of children (Boetto, 2010; Carr, Hayslip, & Gray, 2012; Chen & Liu, 2012; Kelley et al., 2012; Neely-Barnes, Carolyn Graff, & Washington, 2010; Yardley, Mason, & Watson, 2009). Custodial grandparents' health declines are also a facet of intergenerational tensions, parental conflict, and disruptive family processes (Yorgason et al., 2014). Typically, caregiving strain places a higher morbidity risk on single, female, poorly supported/educated grandparents residing in low socioeconomic status areas (Bachman & Chase-Lansdale, 2005; Coall, Hilbrand, & Hertwig, 2014; Conway, Jones, & Speakes-Lewis, 2011; Hadfield, 2014; Kelley et al., 2012).

A second area of custodial grandparent health which has attracted some research interest is their levels of physical activity. While, some custodial grandparents report higher levels of physical activity than do non-custodial grandparents (Jun, Cho, Park, Han, & Wassel, 2013), other studies reveal that even after controlling for race, educational attainment, socioeconomic and marital status, custodial grandparents are less likely to be physically able to complete menial tasks (e.g. walk six blocks), engage in preventative health initiatives (e.g. pap smears, cholesterol screening, influenza vaccinations)

than are non-custodial grandparents (Baker & Silverstein, 2008; Jun, 2015; Sprang et al., 2015). Also, custodial grandparents have been found to be at an increased risk for obesity (Hadfield, 2014; Hayslip, Blumenthal, & Garner, 2014a; Kelley et al., 2012; Roberto, Dolbin-McNab, & Finney, 2008).

### **1.2. Grandparents' caregiving burden**

Caregiving is the mental and physical effort required to support, respond to, or look after someone who is in need of care in order to survive and perform their daily functions (Grant, 2014). Even though custodial caregiving is stressful, grandparents rarely describe caregiving in terms of it being a burden (Greenwood, Mackenzie, Cloud, & Wilson, 2009), particularly, in cultures where caregiving is considered a familial/filial obligation (Bastawrous, 2013). Invariably, though, caregiving exacts a cost on the caregiver, which is termed, "caregiver burden". Although, achieving a categorical definition of caregiving burden remains elusive (Chou, Chu, Tseng, & Lu, 2003; Lingler, Martire, & Schulz, 2005) it is characteristically delineated by type. The first type being subjective burden, which relates to the perceived burden that caregiving has on a caregiver's financial resources and social identity, as well as the emotional distress (anxiety) that arises out of assuming the responsibilities which accompany the caregiving occupational role (Bastawrous, 2013; Grant, 2014). The second type, objective caregiving burden, relates to the physical aspects of caregiving (i.e. the number of hours involved, the degree of care needed) and the socio-structural constraints (e.g. work, family, social life, finances) that impinge upon, the caregiver's capacity to care (Bastawrous, 2013; Grant, 2014).

The impact of caregiver burden on caregiver health is relational to the context in which the caregiving is undertaken, the gender of the caregiver (Chen & Liu, 2012), and the availability of community, emotional and financial support (Taylor et al., 2015). Conversely, when such supports are absent then role overload/conflict commonly occurs (Bastawrous, 2013). According to role strain theory, when individuals are faced with multiple conflictual roles the role strain they experience imposes a cost impost on their physical health (e.g. weight gain/loss, disturbed sleep, personal neglect) and mental wellbeing (Chen & Liu, 2012; Murphy, Christian, Caplin, & Young, 2006). Some role burden assistance is provided to Australian custodial grandparents in the form of respite care. In this regard, custodial grandchildren are sometimes admitted into foster short-term care. However, the provision of respite care varies, and is typically not available to informal grandparents or grandparents residing in rural/remote communities (Commonwealth of Australia, 2014).

Given the fragmented nature of the existing body of custodial grandparent literature (Hadfield, 2014), this study aimed to provide some connective context in relation to understanding the role-related impacts that custodial caregiving has on grandparent physical health. In pursuance of this aim the study was guided by the following research questions: What are the daily occupational role experiences of custodial grandparents? How do custodial grandparents perceive these experiences impact on their physical health? What are the health policy implications of custodial grandparent role experiences?

## **2. Design and methods**

To address these questions a qualitative research design located within the symbolic interactionist tradition was employed. Symbolic interactionism is built upon Social Theory's premise that people assign meanings to their role activities based on their social interactions with others.

### **2.1. Participants**

Forty-nine predominantly Caucasian custodial grandparents (4 maternal grandfathers, 26 maternal grandmothers, 2 non-biological grandmothers, 5 paternal grandfathers, and 12 paternal grandmothers) were interviewed. The sample was almost equally split between single-headed grandparent families and those that were two-person-headed. However, many of the latter two-headed families were comprised of a biological grandparent and a non-biological partner who had assumed a grandparenting role of their partner's grandchild/ren. Three quarters of the grandparents were retired and living off a fixed (superannuation/pension) income and the remaining quarter were engaged in part-time work.

The total sample ranged in age at the time of interview from 49 to 83 years (Median = 66 years). The age at which participants assumed the fulltime custodial care of their grandchildren ranged from 41 to 69 years (Median = 57 years). Fifty-five percent ( $n = 27$ ) of grandparents had formal custody of their grandchild/ren, 39% ( $n = 19$ ) had an informal custody arrangement, and the remaining 6% ( $n = 3$ ) were subject to an interim custody order. In total, 49 grandparents were caring for 71 grandchildren (34 females and 37 males) who ranged in age from 4 to 33 years (Median = 13 years). The number of grandchildren being cared for varied between one and five.

## 2.2. Procedure

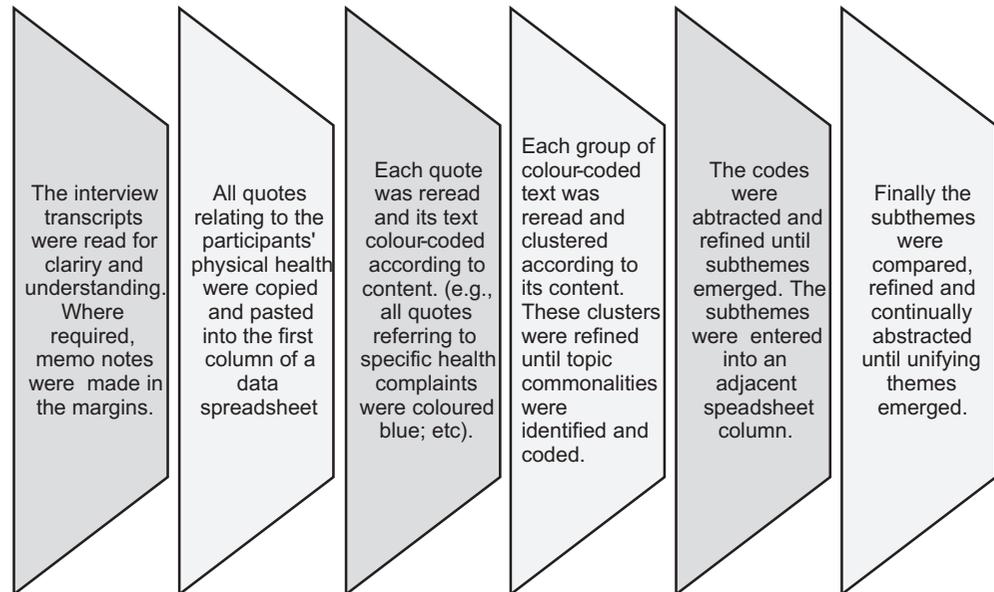
Following approval from the Human Research Ethics Committee of the administrating institution, a local grandparent support group were canvased regarding the general health related hardships facing custodial grandparents. From these anecdotal accounts a semi-structured interview schedule was developed and piloted. This piloting process resulted in the refinement of the initial interview schedule (see Table 1).

Participants were recruited through the auspices of three NGO's (Community Vision, Grandparents Raising Grandchildren WA Inc., and Wanslea) who distributed information letters about the study to their respective membership. The 49 responding grandparents who met the single selection criteria (i.e. being a custodial grandparent) were offered the choice of a face-to-face, telephone or a self-complete email interview. Of these, 17 completed face-to-face interviews, 17 completed telephone interviews and 15 completed email interviews. Issues of confidentiality and participatory rights were explained. The average length of the interview was 60 min. All of the face-to-face and phone interviews were audio-recorded and professionally transcribed verbatim and 10% of the transcriptions were checked against the audiotapes to ensure their accuracy. In the days following the interview, a gift-voucher was sent to participants as a surprise thank you present.

**Table 1. Custodial grandparent interview questions**

Q. No.	Question
1	How old are you?
2	Are you the maternal or paternal grandparent of the grandchild you are raising?
3	How old is your grandchild?
4	Is your grandchild male or female?
5	Are the parents of your grandchild alive?
6	If the parents are alive how far (approximately) do they live from your house?
7	How old were you when you took on the responsibility of raising your grandchild?
8	Do you have legal custody of your grandchild?
9	How did you become the custodial carer of your grandchild?
10	What changes have you made to your lifestyle since becoming the carer of your grandchild?
11	How did you feel at the time you became the carer of your grandchild and how you have coped since?
12	What aspect of raising your grandchild have you found particularly challenging?
13	Have you been able to maintain your social and family relationships since taking on the care of your grandchild?
14	Have you made any new relationships through your grandchild? (e.g. through their playgroup, school or sporting activities)
15	Has the extra responsibility of caring for your grandchild affected your health either positively or negatively?
16	Do you have any concerns about your own health and how this might impact on your future ability to care for your grandchild?
17	Do you know of or use any community services or grandparent carer support services in your area?
18	What support services do you think grandparents need to help them raise their grandchild?

**Figure 1. Six stage analytic process.**



### 2.3. Data analysis

Thematic analysis was independently conducted to discern recurring patterns within the data (Braun & Clarke, 2006). Using the constant comparative analytic technique (see Figure 1) these recurring patterns were noted, coded, clustered, and reordered until they described a series of coherent sub-themes and themes (Liamputtong & Ezzy, 2006; Smith, Flowers, & Larkin, 2009). Where coding disagreement occurred a third author adopted an adjudicating role, thus ensuring the study's interpretive rigour (Liamputtong & Ezzy, 2006). Participant anonymity was maintained by not ascribing any tracking identifiers (e.g. pseudonyms, ID numerals, or initials) to the quotes noted in the Results section. Also, as an additional anonymity measure, where names were recorded in the transcripts they were removed and a non-identifiable generic replacement was inserted (e.g. my grandson, my granddaughter, he, she etc.). Participant quotes were amalgamated, shortened and temporally ordered (as indicated by a ... marker) so as to eliminate repetitive or off-subject statements.

## 3. Results

The three themes and seven subthemes that emerged from the analysis are displayed in Table 2 and detailed below.

### 3.1. Theme I: Age-related health issues

#### 3.1.1. Subtheme 1: It's a knee operation here and a prolapse there

While, a few grandparents described themselves in terms of being "physically fit", the majority related having at least one serious/chronic health complaint that was either age and/or care-related (see Table 3). Grandparents conceded that it was impossible to categorically prove that the manifestation/progression of their physical ailments (muscular /vision/weight/dietary/ cardiovascular) complaint was a direct consequence of their custodial caregiving responsibilities. Nevertheless, they assert that the fatigue and stress levels which accompany the task of raising grandchildren in older age invariably has a negative impact on the physical health and/or mental wellbeing of grandcarers. Moreover, grandparents maintained that these negative impacts had hampered their ability to physically engage with their grandchild/ren at the same level they had done in their younger years when they had parented their own children

At our age you're just tired and people don't realise it takes all your energy to raise a grandchild, not just emotionally, but physically. It sucks everything out of you ... You're tired ... because you're twenty years older this time round ... When you're older you just don't want to do the more active things, because if you did you'd fall down and probably break or tear something.

**Table 2. Themes and subthemes**

Themes		Subthemes	
Theme I	Age-related health issues	Subtheme 1	It's a knee operation here and a prolapse there
		Subtheme 2	Health is a big thing at our age so I've just got to make sure I look after myself
		Subtheme 3	Your health is a daily concern not only to yourself, but also to your grandchild
Theme II	Respite care needs and uptake dilemmas	Subtheme 4	Respite care gives us grandparents a break
		Subtheme 5	Respite, I probably wouldn't use it as much as I'd want to
Theme III	Government healthcare financial assistance	Subtheme 6	It's been a struggle right from the start to get anything from Centrelink
		Subtheme 7	I chase up all the help we need because nobody's going to come in and help!

It's your age and your physical capacity that affects you the most ... I was physically unprepared for running after a toddler and waking up during the night. I feel like any other mother of a 4–5 year old, but with not as much energy as a 20 something year old.

Other grandparents related that the physical health declines they experience are a consequence of coping with the combinational emotional stressors that arise out of dealing with: (i) their offspring's substance abuse or health issues which had precipitated their abandonment/relinquishment of their child/ren; (ii) the criticism they received from family/friends over their decision to assume the custodial care of their grandchild/ren; (iii) the pervasive social isolation that occurred as a direct result of their decision to parent their grandchild/ren; (iv) the problems they encountered in trying to obtain the necessary health, education, and legal documentation they required to care for their grandchild/ren (e.g. school enrolment immunization records, permissions for medical procedures, and school trips authorizations); (v) the financial hardships associated with raising grandchildren on a fixed pension income or self-funded retirement budget; and (vi) the simultaneous responsibilities of dealing with the care needs of an elderly parent, ailing partner, or maltreated grandchild:

My wife worries too much and when she worries she can't sleep so it does drag her down.

I'm developing aches and pains as I get older and I worry I'll not be able to keep up with my grandchild.

My mum has been very sick so I've had to deal with her too ... she's in her 80s.

You're more stressed and I think ... the stress might've brought on my heart condition.

### 3.1.2. Subtheme 2: Health is a big thing at our age so I've just got to make sure I look after myself

Some grandparents spoke of the importance of keeping as active as they possibly could in order to keep their muscles and joints supple and their energy levels elevated to prevent undue fatigue. By being proactive they hoped to be able to continue to care for their custodial grandchild/ren until they were of an age to graduate from high school. To help achieve this longevity goal physically active grandparents revealed they followed an exercise regime:

I'm very conscious of being healthy ... So, we walk to and from school. I do that because I want to live long enough to see my grandchild's life come to a meaningful fruition.

**Table 3. Example of grandparents' recounted age-related physical health issues**

Health issue	Examples
Muscular-skeletal	I'm now dealing with pretty sore hands from years of hard work
	I have osteoarthritis
	I have rheumatoid arthritis
	I suffer from severe arthritis ... My arthritis is shocking and I had to have cortisone
	I've got aches and pains all over
	My partner's had a shoulder operation ... and a knee replacement. These things you know, have stopped his mobility
	I've constant shoulder and back pain. I'm not sure if this is just the age or the lifting
	I've got an ongoing arthritis problem and I've got spurs on the vertebrae in my neck, had growing onto my neck and I'm having a lot of trouble with those at the moment because I can't move my head very well
Vision	I've got cataracts that are creating confusion
Weight gain/loss	I eat too much. I've put on weight, I'm now a type two diabetic
	I have put on weight. Whereas before if I wasn't hungry I could please myself but now I think it's important to sit down with my grandson at meal times
	I've put on approximately 20kgs in the 3 years I've looked after my grandson
	My wife's lost at least five kilograms ... and she'll never put it back on while she is in the situation she is in because she worries too much
Cardiovascular	I have high blood pressure, I'm medicated for it but it's still high at times
	I've got hypotension
	My partner had a stroke
	I've got a tachycardia problem with my heart, it just means that when it suits itself it beats too bloody fast and it just buckles my knees under me ... I've got to take tablets for my heart they don't do any good, it still bangs away when it wants to
	My wife she's got four stents in her heart and sees the cardiologist every year
Chronic conditions	I'm asthmatic
	I've had kidney stones
	My partner's has every complication of diabetes
	My husband's had a kidney transplant
	My husband's been a diabetic he had advanced kidney failure and he'd been on dialysis. He had a kidney transplant almost at the time we got the children
	Because I smoked I've had a cancer of the bladder removed
	I can add myself to the list of grandmothers having a prolapse operation
	My partner, he's had a bad back injury and emergency surgery and spent time in hospital and, when that happened, is when I got breast cancer
	He's got shingles. The worst case the doctor said he had ever seen
Stress and fatigue	I suffer from chronic fatigue
	I don't sleep you see, because I've got the worry
	I'm physically tired, whether that's actual or mental because of the extra workload I don't know
	I notice that my energy is fairly depleted at times
	I got cancer, had my bladder removed and about three months after I was out of hospital my wife's sitting in the chair and she said: I think I'm having a heart attack. It was all brought on by stress
	I've got a few guts-aches
	I've notice my energy levels are certainly different

A secondary advantage of establishing a regular exercise regime grandparents revealed was that by default their grandchild/ren's fitness levels also improved.

While, maintaining a level of personal fitness was important to some grandparents, other grandparents, particularly those in part/fulltime employment, spoke of how they had reached the realization that being a custodial grandparent was an activity that demanded all of their time. As such, grandparents explained they needed to prioritize their occupational roles and, in doing so, make some far-reaching and difficult decisions (e.g. reduce or completely give up their paid employment:

About three months ago I gave up work because my own health was starting to go down and I thought I can't let this happen. I've got to be careful about what I do health-wise.

However, the one aspect of their role that grandparents were adamant they would not scrimp upon was their day-to-day care of their grandchild/ren.

### *3.1.3. Subtheme 3: Your health is a daily concern not only to yourself, but also to your grandchild*

The whole issue of remaining healthy was a worry to grandparents because of their advancing years and inevitable mortality. In this regard, they spoke of living with the constant worry of what would happen to their grandchild/ren if they were no longer around. While, some grandparents tried to make light of the situation, other grandparents (especially those who had become socially isolated from their offspring/extended family members/former friends) attempted to devise a Plan B care option for their grandchild/ren:

I had an asthma attack that nearly killed me ... because of that I watch my health ... I'm very frightened of getting sick ... because if I do, what'll happen to my grandson?

What was distressing to grandparents was when their Plan B concerns were echoed by their grandchild/ren (e.g. grandchildren asking: What will happen to me if you get sick or die?).

Two years ago I had a triple bypass and that really affected my granddaughter. Now on a regular basis she'll ask: Are you going to die Granddad? So that's a concern to us ...

Grandparents stated that their grandchildren's future-care concerns were so prominent in their mind that even when they experienced a relatively minor ailment (e.g. cold, stomach upset, headache, back/limb soreness) their grandchild/ren would again raise their "what-will-happen-to-me" concerns.

## **3.2. Theme II: Respite care needs and uptake dilemmas**

### *3.2.1. Subtheme 4: Respite care gives us grandparents a break*

Staying well and prioritizing their grandchild/ren's needs were particularly difficult aspirations for custodial grandparents with mobility issues. They confided that having a mobility issue was not only an ongoing impediment to their physical engagement in their grandchild/ren's daily activities, but it also engendered feelings of frustration, anger and resentment in their grandchild/ren:

Because I've got a disability and walk with sticks there's probably a lot more challenges ... Any activity that takes running or mobility I can't do with her. She gets annoyed ... like at the park she'll say: Come down the slide with me grandma!! Well, I can't do that ... I know she gets angry. It's hurtful, because you want to do things and you can't.

Both grandparents with and without mobility issues frequently reached the conclusion that at times they needed some form of respite care. While, kin-respite care was the ideal (i.e. grandchild/ren going periodically to stay with an aunt/uncle) this was not a viable option for grandparents who were socially isolated from their family. Isolated grandparents commonly stated that the type of respite

care they required was largely dependent on the age of the grandchild/ren they were raising. For example, grandparents of toddlers expressed their need for nursery/babysitting care; grandparents of primary school-aged grandchildren indicated their need was for after-school care/holiday/week-end care; and grandparents of teenaged grandchildren expressed that their requirement was for mentorship opportunities:

Having a babysitter ... Someone who would play with them, do other things with them.

Weekend respite care would be good because it would give them somebody else who cared about them and who'd do things with them.

Having a younger enthusiastic person ... who has a family of their own and who can take my kids out with them ... and do holiday stuff with them.

When respite care options were unavailable grandparents stated that they had no other option than to subjugate their own longer-term health in favour of their immediate need to care for their grandchild/ren. Although, grandparents were aware that by doing so they be putting their own health at-risk and, the risk was acute for some grandparents:

If I don't look after me I potentially get a secondary cancer ... My problem is with the cancer medication ... it makes me sick. I took myself off it ... because of looking after my grandkids ... I know that's silly because my meds are to help stop any secondary cancer coming back which would be incurable ... Then I'd be even less able to look after my grandkids than I'm now ... My dilemma is ... do I take the pills and get well ... or do I not take them and spend my energy looking after my grandkids? I don't feel I can do both!

### 3.2.2. *Subtheme 5: Respite, I probably wouldn't use it as much as I'd want to*

Even when respite care options were available, grandparents expressed reservations about utilising them. Many of these revolved around issues of trust. For instance, some grandparents were reluctant to apply for respite care fearing that if they did, then the act of asking would be seen as an admission that they were not coping with their custodial caregiving role. Moreover, if they were considered to be under coping stress, then their grandchild/ren's Department of Child Protection (DCP) case worker would interfere with their upbringing. Or, in a worst case scenario, permanently remove them from their custodial care:

DCP involvement is very difficult ... because there're policy rules they have to observe. I try not to step out-of-line, but ... sometimes there's interfering, and undermining.

A second reticence that grandparents had about utilizing non-kin respite care was their grandchild/ren would be placed in the care of strangers:

I know the kids wouldn't like it ... And, I wouldn't feel comfortable just putting them in a home where they don't know the people.

Their reticence was mitigated by the knowledge that all respite carers have to undergo a compulsory government "Working with Children" check, however, this did not negate a secondary gear that they had that any foster-care placement could reignite their grandchild/ren's underlying abandonment issues:

To leave him to have my problems fixed is like abandonment again in his eyes.

A further consideration for grandparents indicated was the costs associated with respite care:

I've had to think twice about the costs. It just all adds up. It's all extra costs.

The determining factor, for many grandparents is what is in the best interest of their grandchild/ren:

You put everything aside about you and you put the kid first.

### **3.3. Theme III: Government healthcare financial assistance**

#### *3.3.1. Subtheme 6: It's been a struggle right from the start to get anything from Centrelink*

The thing that the majority of grandparents on a fixed income wanted was financial relief from the medical/hospitalization costs associated with their and their grandchild/ren's ailments/illnesses. Grandparents asserted that while obtaining a government healthcare card for them self was a relatively straightforward process (providing they met the issuance criterion), obtaining a healthcare card for their grandchild/ren was more difficult:

It's diabolical the treatment that grandparents get. I found out I could get a healthcare card for my grandson so I went to Centrelink to get one and was told, yes I can have one, then no you can't have one, then yes I can ... It can be really demoralising when people are told the wrong things. You're treated like it's your fault and that's not good!

Even in instances where grandparents were able to obtain a healthcare card for their grandchild/ren, it did not provide the full financial relief they had anticipated, as there was often a co-payment:

My grandson needs braces. Even though he has a healthcare card they'll cost me \$3,500 which is payable up front.

Centrelink, the Australian Government's service that issues health-cards operates within strict statutory limits on how much a person can earn and yet retain their healthcare card. In this regard, grandparents with healthcare cards and who worked part-time to supplement their income, revealed they had to be "super careful" their employment hours did not exceed the allowed limit. For, if it did, they would then have to declare the overage and run the risk of losing their card.

#### *3.3.2. Subtheme 7: I chase up all the help we need because nobody's going to come in and help!*

Grandparents stated that another significant barrier to seeking help is that there is no central entity to which they can apply for advice/assistance. Therefore, the onus they contend falls on each individual grandparent to source the support resources they need:

It boils down to grandparents making it (help) happen. You've got to chase and chase ... That's hard ... if you're not the type of person that can get up and ask. I never used to be able to do it, but now I'll fight anybody to get what I need.

The objection some grandparents have with having to self-source support grandparents claim is that the process is inequitable. For, they explain, while some grandparents have the ability to source the help they require, many other grandparents who do not have the requisite skills. Hence, they claim a considerable disparity exists between the assistance that individual grandparents receive.

## **4. Discussion**

This research aimed to increase understanding of custodial grandparents' physical health issues and how these issues impact upon their capacity to "parent" their custodial grandchildren. Two of these physical health-related issues require urgent grandparent health policy consideration. For instance, the first issue financial role strain, that custodial grandparents live with is recognised as being detrimental to their health (see Hayslip et al., 2014a, 2014b; Marken & Howard, 2014). Partly because, as this study reveals, the assumption of the custodial grandparent caregiver role typically occurs in either the decade pre, or post retirement. Thus, the assumption of the role of custodial grandparent prior to their planned retirement age generally curtails their ability to amass a sufficient

superannuation nest egg to live off in their retirement years as grandparents typically give up work in order to care for their grandchildren. Or, if already retired at the time of assuming custody of their grandchild/ren have the financial strain of trying to live within a fixed income that is not designed to cover the needs of children. In addition, in both scenarios, age-related deteriorations in their physical health and the demands of caregiving reduce the ability of many grandparents to engage in part-time work that could supplementary their income.

Indeed, this study's cohort of custodial grandparents' accounts highlighted the relentless financial challenge most custodial grandparents face in trying to stretch their fixed income to incorporate one or more grandchildren. However, this study's findings reveal the extent that custodial grandparents will go to care for their grandchildren. For, they described situations where their budget was under strain and they were forced to economise. However, it was not their grandchild/ren's needs that were economised on, but rather it was their own health needs that were subjugated to free up budgetary capacity to pay for the needs of their grandchild. Such economies grandparents revealed increased their inner-doubts about their capacity to carry on fulfilling their caregiving role in the longer-term. Therefore, it is posited that the provision of a government healthcare card for all grandchildren and their custodial grandparents would help lessen grandparents' experiences of financial strain. Such a move is sound not only on compassionate grounds, but also from an economic standpoint. For, keeping grandparents healthy longer would lessen the cost impost of having to place grandchildren into foster care in instances when their grandparents are no longer able to care for them.

Second, this study reveals that custodial grandparents are wary of asking for respite care assistance in case their asking is perceived to be (i) an admission that they are not coping with their grandparenting role; (ii) out of a fear that some harm might befall their grandchild/ren while in respite care; and (iii) that placement in respite could cause their grandchild/ren's underlying abandonment anxieties to resurface. Grandparents' concerns about the possible negative impacts of placing children in temporary foster respite care while grandparents address their own health needs is a vex one. For, research has shown that grandchildren who are placed into custodial grandparent care are vulnerable to manifestations of attachment strain and age-inappropriate internalizing/ externalizing behaviours (Bowlby, 1973; Liddle & Schwartz, 2002; Yorgason et al., 2014).

The addition that this study makes to the current understanding of the impact that respite care can have on vulnerable grandchildren's behaviours is that the catalyst for the manifestation of these age-inappropriate behaviours is not the actual placement in respite care, but is ever present within the children's thinking. As, even minor signs of grandparent ill-health can trigger inordinate concern in custodial grandchildren. Moreover, hearing and seeing their grandchildren's "what will happen to me" concern adds to custodial grandparents' lingering distress about their own long-term capacity to fulfil their grandcarer role. This distress in turn they maintain is detrimental to their mental well-being and aggravates their pre-existing (or developing) health conditions.

While, research into how best to ameliorate grandparent role strain is in its infancy, some encouraging results are beginning to emerge. For instance, exploratory clinical trials undertaken by Kelley, Whitley, and Campos (2010, 2011, 2013) into the efficacy of the integrated Project Healthy Grandparents (PHG) service program have demonstrated some significant mental health improvements (McLaughlin, Ryder, & Taylor, 2016). However, similar PHG gains have yet to be reported for physical functioning. Finally, based on the premise that empowering custodial grandparents to be proactive in terms of managing their day-to-day caregiving role will improve their health outcomes (Hayslip et al., 2014a, 2014b; Whitley, Kelly, & Campos, 2013), a need exists for future research to evaluate the potential of using allied health services, such as occupational therapy, as an interventional means of lessening grandparent role strain.

#### **4.1. Limitations and strengths**

An inherent limitation of qualitative research studies is that its findings are specific to the investigated cohort (e.g. Western Australian grandparents) and, therefore, cannot be generalised to a broader cohort (i.e. all custodial grandparents). Despite this limitation, the strength of qualitative research is that this methodology captures the breadth of participants' experiences. In doing so, qualitative studies add "context" to the wider understanding of the social phenomenon under investigation.

#### **4.2. Implications**

Six issues emerged from the study that are significant for grandparent health policy. Firstly, given the extent of the financial caregiver burden that grandparents operate under a need exists to increase their access to financial assistance and health intervention services. Especially, as research by Kelley et al. (2012) has demonstrated the provision of preventive healthcare to grandparents is cost-effective.

Second, this need appears well-founded given it is less costly to inform custodial grandparents of the benefits of addressing minor complaints in a timely manner, than it is to deal with the hospitalization costs of deferred chronic conditions. Third, educating grandparents about the importance of preventive health measures can have an intergenerational health promotion effect as grandparents are role models for the grandchild/ren they are raising.

Fourth, by helping grandparents to achieve their longevity goal of staying healthy long enough for their grandchild/ren to graduate from high school, governments could save on the considerable cost imposed they would otherwise incur, if they had to raise custodial grandchild/ren within the paid foster-care system.

A fifth health promotion consideration for governments is how to facilitate grandparents' willingness to access respite care and how to encourage them to engage with their grandchild/ren's case workers. For, what is needed is a mechanism for eradicating the fears that act as barriers to grandparents accessing respite care as well as a standardized policy framework that informs health promotion workers of grandparents' specific needs (Neely-Barnes et al., 2010). The need for grandparent tailored services is required given that grandparents' morbidity-risks and health maintenance needs are substantially different from those of first generation "parent"/"foster" carers.

Sixth, policy consideration needs to be given to delivering health promotional information to custodial grandparents in a non-threatening and supportive environment, such as a grandparent support group (see Antonucci, Birditt, & Akiyama, 2009; Antonucci, Fiori, Birditt, & Jackey, 2010; Hayslip et al., 2014a, 2014b). For, membership of a support group has been demonstrated to provide custodial grandparents with the types of objective and subjective social capital support resources (e.g. camaraderie, social recognition, confidence, trust and reciprocity) they need to best fulfil their custodial caregiving occupational role (McLaughlin et al., 2016).

#### **5. Conclusion**

In conclusion, if these health issues were addressed higher levels of social capital support would likely translate into lower morbidity rates (Chen & Liu, 2012). Therefore, it is hypothesized that in investing in grandparent support groups, governments may obtain substantial returns in terms of improved grandparent health and, by default, the health of the grandchildren they are raising. However, a comparative cost analysis study is required to test this hypothesis.

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### Competing Interest

The authors declare no competing interests.

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