

## Research Article

# Understanding primary carers' occupational adaptation and engagement

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**Background/aim:** Primary carers for people with intellectual disability living in remote rural areas experience high demand care commitments that may require them to be available twenty-four hours seven days a week and reduce their access to formal or respite support leaving them little time to engage in other occupations. The aim of this study was to explore the impact of caring for a person with an intellectual disability living in remote rural farming location on primary carers' occupational engagement.

**Method:** A thematic analysis, using an interpretive phenomenological analysis approach, was conducted on seven in-depth semi-structured interviews of primary carers.

**Results:** Occupational adaptation and engagement, emerging as a primary theme, indicated that primary carers' occupations were affected by: limiting opportunity to develop occupations; developing new occupations; adapting occupations; and ceasing occupations. A number of influencing themes, affecting the primary carers' occupational engagement also emerged, including: lifestyle and occupational roles; wellness and health; engaging quality supports; societal and community context; and vision for the future.

**Conclusion:** The results provided an initial understanding of the impact of caring on the primary carers' occupational adaptation and engagement, and a suggestion that clinicians consider using a family-centred approach as an effective and meaningful intervention.

**KEY WORDS** family, intellectual disability, occupation, rural and remote.

## Introduction

Engagement in meaningful occupations is associated with health and wellbeing (Stadnyk, Townsend & Wilcock, 2010; Wilcock, 1998, 2005), and a good quality of life (Molineux, 2009). In 2009, 2.6 million Australians were engaging in carer occupations, assisting a person with disability or an elderly person, with approximately a third being primary carers (Australian Bureau of Statistics (ABS), 2009). Many primary carers are family members (La Trobe University, 2013) who are mostly women and who provide informal assistance (ABS). In 2009, over 3 million Australians reported a disability with core-activity limitations, including communication, mobility or self-care difficulties and schooling or employment restrictions (ABS). As caring may be a twenty-four hour seven day a week job, a primary carer's occupational engagement opportunities may be limited (Chaffey & Fossey, 2004). Occupational engagement refers to the performing or doing of occupations, with a view to achieve (Wilcock, 2006). To understand occupation, and occupational engagement, it is necessary to understand the context within which occupation occurs (Molineux).

Primary carers may experience little relief and consider their caring as a lifelong responsibility (Chou, Pu, Lee, Lin & Kröger, 2009). Such an ongoing responsibility is physically and mentally exhausting (Chambers, Ryan & Connor, 2001), and may prevent primary carers from fully engaging in other occupations, including self-care, leisure and social participation (Hwang, Rivas, Fremming, Rivas & Crane, 2009). Many primary carers may change their lifestyle by adapting to accommodate the carer occupation and limiting their opportunity to engage other occupations (Schkade & Schultz, 1992; Schultz & Schkade, 1992). In addition, some primary carers may organise their other occupations around the care recipients' occupations and needs (Chaffey & Fossey, 2004).

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Engagement of primary carer occupations has physical, emotional and relational impacts on carers and families, including effects on finances and engagement in paid employment (Edwards, Higgins, Gray, Zmijewski & Kingston, 2008). Impacts on primary carers' lives may be positive or negative and affect their occupational engagement. Positive impacts on primary carers' lives may include gaining a sense of pride (Kellett & Mannion, 1999; McGarry & Arthur, 2001), self-worth and fulfilment (Sanders, 2005) and competence in their role from providing a high standard of care (Kellett & Mannion; McGarry & Arthur). Primary carers may also gain a sense of personal growth (Sanders), purpose (Lane, McKenna, Ryan & Fleming, 2003) and meaning (Kellett & Mannion). Such positive impacts may enhance primary carers' health and wellbeing and their engagement in occupation (Abrahams, 2008).

Negative impacts on primary carers' lives may include experiencing stress (Pinquart & Sorensen, 2003), financial hardship (Edwards *et al.*, 2008), social isolation (Chambers *et al.*, 2001), mental illness (Edwards *et al.*), concern and worry for the future (Bowey & McGlaughlin, 2007), prioritisation of care recipients' needs (McGarry & Arthur, 2001), poorer quality of life (Chou, Chiao & Fu, 2011) and higher morbidity (Bedard, Koivuranta & Stuckey, 2004).

Primary carers of people with an intellectual disability experience additional demands as care recipients may have complex social and psychological functioning care needs (Emerson, 2003) requiring substantial support (McGarry & Arthur, 2001). Hence, primary carers of people with an intellectual disability and complex needs have less time to attend to their own needs (Acton, 2002). Limited research also suggests that the responsibilities for primary carers of care recipients with intellectual disability living in remote rural areas are magnified when their access to formal support and/or respite services is restricted (Bedard *et al.*, 2004). Here, primary carers may spend more time in care activities such as travelling longer distances to access formal services (Eley, Boyes, Young & Hegney, 2009) and/or having shorter or no breaks away from caring due to little or no access to respite services (ABS, 2009; Commonwealth of Australia, 2009).

As noted, engagement in meaningful occupation is associated with health and wellbeing (Stadnyk *et al.*, 2010; Wilcock, 1998, 2005) and quality of life (Molineux, 2009). Although research suggests primary carers of people with intellectual disability living in remote rural areas encounter complex care responsibilities and associated positive and/or negative experiences, little is known about the impact of caring on their occupational engagement. This study aimed to explore the impact of undertaking a carer occupation on primary carers of care recipients with intellectual disability living in a remote rural community occupational engagement.

## Methods

### Design

Using a multiple case-study design, this study explored the impact of caring for a person with intellectual disability living in a remote rural area on a primary carers' occupational engagement.

### Ethics

Ethics approval was gained from Curtin University Human Research Ethics Committee (OTSW-19-2010).

### Participants

Sixty-four primary carers of a person with an intellectual disability, living in a remote rural farming area in Western Australia were approached using purposive sampling. They were provided an information and consent form by a local disability service provider. Only primary carers aged 40 years or over, caring for recipients with an intellectual disability and living in the same rural remote community were accepted into the study. Although nine primary carers consented and were contacted, due to changing circumstances only eight were interviewed. Seven of the primary carers interviewed were women. On average, primary carers were 58 years of age (Table 1) and had been caring of their children (average age 26 years – Table 2) for an average of 25 years (Table 1).

### Data collection

In-depth semi-structured interviews were developed using an interpretive phenomenological analysis (IPA) approach (Smith & Osborn, 2003). Questions were designed, using relevant literature, to capture primary carers' experiences of caring and occupational engagement (Smith & Osborn) as illustrated:

What are your experiences of caring?  
What activities do you do now?

The interview was piloted with a primary carer over 40 years of age, caring for a person with intellectual disability living in the Perth metropolitan area. Once piloted, recorded interviews (30–120 minutes) were completed with primary carers at a location and time of their choosing, transcribed (verbatim) and analysed.

### Data analysis

Interviews were analysed using thematic analysis, embedded within an IPA approach (Smith & Osborn, 2003). The interview text was reviewed for meaning of primary carers' personal and social world lived experiences, and simultaneously used to validate the researchers' interpretations (Smith & Osborn). Firstly, the transcripts were read and analysed independent of each other to annotate meaning of and/or comments around the textual information (Smith & Osborn). Initially, three transcripts were reviewed and moderated

**TABLE 1:** *Socio-demographic and caring information of eight primary carers*

Participant's name*	Age	Gender	Work status	Family composition	Primary carer	No. of years caring
Kelsie	42	F	Not working	2 adults, 3 children	Y	17
Susan	63	F	Retired	2 adults, 1 child	Y	34
Kylie	55	F	Full-time	2 adults, 6 children	Y	25
Jo	49	F	Part-time	2 adults, 2 children	Y	10.5
Natalie	70	F	Retired	2 adults, 3 children	Y	44
Anne	47	F	Not working	2 adults, 2 children	Y	13
Marion & Alastair	66	F	Retired	2 adults, 2 children	Previously Y	30
	71	M	Retired		Previously not primary carer	30

\*Pseudo-names used to maintain participant anonymity; F, Female; M, Male; Y, Yes.

**TABLE 2:** *Socio-demographic, disability and living information of care recipients*

Participant's name*	Care recipients			Diagnosis	Living arrangement
	Name*	Age	Gender		
Kelsie	Darcy	17	M	Cerebral palsy & intellectual disability	Family home
Susan	Rowan	34	M	Intellectual disability	Family home
Kylie	Frazer	25	M	Intellectual disability	Own home
Jo	Henry	13	M	Mild intellectual disability	Family home
Natalie	Peter	44	M	Mild/moderate intellectual disability	Family home
Anne	Michelle	18	F	Acquired brain injury	Family home
Marion & Alastair	Justin	33	M	Intellectual disability	Permanent supported living

\*Pseudo-names used to maintain participant anonymity; F, Female; M, Male.

by the coding researcher and an independent researcher (90% inter-rater agreement). The remaining transcripts were then reviewed by the coding researcher. The transcripts, once reviewed and annotated for meaning and/or comment were re-read to define initial emerging themes. The initial emerging themes were then collaboratively reviewed and clustered by researchers to refine final (primary, superordinate and sub) themes (Smith & Osborn). Table 3 illustrates the final themes and the number of text statements and primary carers' experiences that contributed to each theme. Member checks completed by five primary carers revealed 100% agreement of the final themes.

## Results

Primary carers' occupational adaptation and engagement, emerging as a primary theme, related to five possible influencing themes, including the following: (i) lifestyle and occupational roles; (ii) wellness and health; (iii) engaging quality supports; (iv) societal and community context; and (v) vision for the future.

### Primary theme: Occupational adaptation and engagement

Primary carers' occupational engagement in their own occupations was influenced when undertaking a caregiving role. Four emerging subthemes that influenced

primary carers' occupational engagement included the following: (i) limiting opportunity to develop occupations; (ii) developing new occupations; (iii) adapting occupations; and (iv) ceasing occupations. The 'caregiving lifestyle' limited primary carers' engagement in their own (e.g. developing their careers, socialising and holiday travelling) and/or their other children's occupations. In this caregiving lifestyle, primary carers gave consistent consideration to the potential impact of engaging any occupation beyond the carer occupation, on the care recipient, which Susan and Marion, respectively, describe as follows:

Probably you've got to think of Rowan with anything you do instead of being spontaneous. You've got to make sure that he can fit in with it too.

I suppose you're more tied down and you think more about- before you go and do something you think a lot more about it.

Some primary carers experienced positive opportunity to develop new occupations, which Kylie describes as follows:

Even my job, even working at the school came about through caring... I didn't apply for the job, I was rung up and asked if I'd be interested because of my background.

**TABLE 3:** Descriptive information about themes from data provided by primary carers

Primary, superordinate and sub themes	Total no. of text statements	Primary carers who shared an experience related to the theme
Primary theme		
Occupational adaptation and engagement	99	7
Limiting opportunity to develop occupations	21	5
Developing new occupations	12	3
Adapting occupations	44	7
Ceasing occupations	21	6
Influencing themes		
Lifestyle and occupational roles	169	7
Assuming the role of carer	85	7
Unconditional responsibility	59	7
Putting others first	11	5
Lifelong role	14	6
Wellness and health	106	7
Caring, health and self-management	24	7
Emotional wellbeing	15	4
Coping	38	7
Resilience	31	6
Engaging quality supports	61	7
Availability and access	18	7
Formal supports	14	6
Informal supports	29	7
Societal and community context	34	7
'Cultural experience'	13	6
Networks and relationships	11	5
Acceptance and inclusion	10	5
Vision for the future	40	6
Ageing and the ability to care	15	6
Expectations of the future	12	5
Securing the future	12	3

Commonly, primary carers reported adapting their own occupations to ensure that care recipients received a high standard of care. In making adaptations, primary carers continually considered how their occupational decisions were likely to affect the care recipient and responsively structured their own occupational choices around the care recipients' needs, which Jo and Alastair, respectively, describe as follows:

I guess it's just being more aware of where would be suitable for me to take Henry and where wouldn't be.

[Alastair assisted his wife in caring for their son, particularly when Justin became distressed] ... Especially if I had to leave the farm, because I had to more or less be on call, just in case.

Caring responsibilities often acted as a barrier to primary carers' occupational engagement where, in prioritising care recipient's needs, their engagement in their own occupation was reduced. Primary carers gave up their careers, leisure activities and/or time for self-care. Some primary carers ceased their occupations to

accommodate care recipients' supervision requirements in difficult situations (e.g. not able take care recipients with them to the work occupation, find others to share caring responsibilities and/or leave care recipients alone) or because care recipients had an occupation at the same time as their occupation. Anne and Kelsie, respectively, describe ceasing meaningful occupations:

Obviously the horses had to go... because I can't be away from her for that amount of time.

My husband would like to go overseas on a trip and it's just not an option at this point in time sort of thing.

Similarly, Marion describes occupational engagement limitations:

I suppose you're more tied down and you think more about - before you go and do something you think a lot more about it.

Engagement in carer occupation acted as an enabler to primary carers, providing them opportunity to engage in new occupations. However, it also acted as a barrier, limiting their opportunity to develop other occupations or requiring them to adapt or cease current occupations. These barriers restricted their engagement in their own occupations to accommodate carer occupational commitments.

### **Influencing theme one: Lifestyle and occupational roles**

Influencing theme one describes primary carers' experiences of a 'caregiving lifestyle'. Primary carers caregiving lifestyle was influenced by (i) assuming the role of carer; (ii) unconditional responsibility; (iii) putting others first; and (iv) making a commitment to a carer occupation as a lifelong role.

Primary carers' undertaking the role of a carer was underpinned by their belief 'it is just what parents do' and the caring activities were influenced by gender-specific expectations that Alastair and Susan, respectively, describe as follows:

As a man I don't really care much for caring. It's a tie; it's not what blokes do. Give your son a shower and that's not what most blokes have to do.

Because women are generally more caring, they see more of what needs to be done...Guys expect it, I guess. They've always been the breadwinner and they expect the women to do the caring.

Furthermore, primary carers' experience of the caregiving lifestyle was associated with the unconditional responsibility shown by them towards care recipients. Regardless of the care recipients' level of independence, primary carers performed additional tasks based on

their belief that they know care recipients the best, and as such are best placed to provide high standard of care. Unconditional responsibility was also based on their belief that others should not be burdened with caring role responsibilities that Natalie and Anne, respectively, illustrate as follows:

You don't feel like putting it on neighbours too much. I know they're really willing and they're really happy and they enjoy Peter's company, which is great. But you don't feel like putting it on them too often, you know?

But you get to the point where everyone has their own life.

Unconditional responsibility and a caregiving lifestyle were also supported by the belief, and consequent action, to 'put others first'. In this, primary carers acknowledged and prioritised the care recipients' lives, needs and occupations, followed by other family members over and above their own health, time, occupations and commitments, which Anne and Kelsie, respectively, describe as follows:

Putting someone else first. Just, yes, their total wellbeing, their quality of life, their health- yes, basically you think of everyone else first and you last.

I think it probably involves putting someone else first which is probably the wrong thing to say about caring because you're supposed to care for yourself, and then- if you can't care for yourself then you're not going to be helping others but there are so many things that just if I didn't do them Darcy couldn't do them and it's sort of critical.

The caregiving lifestyle, supported by engaging unconditional responsibility and putting others first, was considered to be a lifelong responsibility that would last for the duration of care recipients' life regardless of whether care recipients were or were not in the primary carers' direct care. Primary carers acknowledged that they were likely to provide caring in some capacity as a lifelong role, which Susan and Anne, respectively, describe as follows:

Having the responsibility, lifetime responsibility.

Yes [in reference to seeing the carer role as a lifelong role] in this situation, yes...because her care is so high...I think I've just got so used to it now...it becomes a mother/child intuitive thing, I just know, I know the signs. So that limits me to who can and is willing to care for her...

### **Influencing theme two: Wellness and health**

Wellness and health of primary carers influenced occupational engagement and related to: (i) caring, health

and self-management; (ii) emotional wellbeing; (iii) coping; and (iv) resilience. Primary carers require wellness and health to engage in a caregiving lifestyle and occupations beyond caring. Most reported that they were in good health, although some reported feeling tired and showed an awareness of the fragility of their own health that Kylie describes as follows:

I feel very conscious and I have in the last five, six years been conscious about my back, just because everyone says, well your back must be about to break.

Such awareness facilitated activity towards maintaining good health by engaging in fitness activities and a healthy diet (e.g. eating and supplement intake). Often primary carers' emotional rather than physical health seemed more challenged, manifesting in feelings of stress, guilt and tiredness. Guilt was a strong emotion, which Kelsie and Kylie, respectively, illustrate as follows:

...but the worst thing would be that you feel really torn that you're not spending enough time with [the two] other kids.

I literally feel like I am falling to pieces sometimes.

In managing their emotional wellbeing primary carers focussed on the positives of their situation, made use of support (discussed in next section), and sought to engage their own occupations. Positive thinking and perspective taking assisted, which Kylie describes as follows:

I think experience just teaches you that you've got to look at the positives...If you focus on the negative, you just go down and if you go down, you drag everybody else down.

I think it's made us better people. We're more compassionate, we're more understanding, we're a lot more tolerable...So I think overall, we've become better people.

Primary carers' engagement of carer occupation was supported by keeping physically healthy and using positive thinking and perspectives to manage emotional wellbeing. This assisted them to adapt to their situation providing them with resilience to maintain their caregiving lifestyle, but reduced their engagement in other occupations.

### **Influencing theme three: Engaging quality supports**

Engaging quality supports emerged as an influencing theme and related to (i) availability and access; (ii) formal supports; and (iii) informal supports. Not having access and availability to quality support was a barrier to primary carers' occupational engagement. Here, the

scarcity and availability of specialists in their remote rural community required them to travel longer times and distances to access formal services, and restricted their choices for quality support in alternative living options and/or respite. Such challenges are described by Kylie and Susan respectively:

When the kids were at school in Perth [major city], they had pretty much daily, weekly access to therapy. Here it's once every four weeks, every six weeks...It's pretty few and far between...A lot of it you still have to travel to.

But because you're in a rural area they don't employ them [professionals] so they weren't and he wasn't getting any of that because of being in a rural area.

Primary carers made use of the available limited formal support (e.g. employment support, funding, respite, education assistants and disability inclusion organisations) in their community, which Jo and Susan, respectively, describe as follows:

There's a lot of good people around...like the local area coordinator and AccessAbility. There's always someone that you can ring if you're struggling.

When Rowan was younger the service provider used to come down from Perth and I used to get cranky because there was a new team every time they came down.

However, primary carers used more accessible informal support more often (e.g. support from their spouse, mother/mother-in-law, other family members and the community) that Anne describes as follows:

We have wonderful support, if I ever have a problem...

Having access to quality support was very important for primary carers, and their occupational engagement, as knowing that care recipients were being well taken care of gave them a peace of mind and freedom to engage in other meaningful occupations.

#### **Influencing theme four: Societal and community context**

Primary carers' experience of living in a remote rural societal and community context seemed to influence their capacity to undertake a caregiving lifestyle. Societal and community context seemed influenced by: (i) 'cultural experience'; (ii) networks and relationships; and (iii) acceptance and inclusion. These experiences seemed to act as barriers and enablers, simultaneously, to primary carers' occupational engagement.

Primary carers' 'cultural experience' of living in a remote rural community reflected in their attitudes and beliefs, which indicated that living in a small rural com-

munity enabled them to experience the 'community spirit'. This allowed primary carers to gain a sense that the care recipient was cared for by their community. Primary carers and care recipients had established relationships and networks with everyone in the community and had become known by them. These connections fostered confidence that their community will 'look out' for care recipients and help as needed. Anne describes the value of relationships and networks:

It enhances it because you're known by everybody...So I know I only have to say help and they'll be here by the droves.

These relationships and networks supported primary carers' belief that care recipients were accepted and included by the community that Kylie describes as follows:

He loves being part of this community and being in a small community has been very helpful for him because everybody knows him and his problems and they accommodate it.

I think it's a big plus because most people know us, as a family, they know me personally and they know my son. Even though they don't overstep the boundaries of interfering and whatever, they're there and they know.

The value of the community support was seen in primary carers' reasoning for choosing to continue to live in a rural location that Anne describes as follows:

But we would forego the community, the community support and the family.

Alongside the positive 'cultural experience', primary carers encountered challenges of living in remote rural areas. Primary carers travelled large distances and times to access quality support services reducing their time to engage other occupations. Furthermore, living in a small remote rural community reduced some care recipients' opportunity to find a potential partner. Regardless, primary carers stated that living in the rural community enhanced their quality of life. For them, knowing that care recipients were accepted, respected and supported allowed them peace of mind and sense of freedom to not always accompany the care recipient to events. This allowed them more time to engage in other occupations and enhanced care recipients' opportunity to experience independence and community inclusion. Hence, primary carers living in remote rural areas encountered positive and challenging experiences that influenced their occupational engagement.

#### **Influencing theme five: Vision for the future**

Vision for the future, emerging as an influencing theme, reflected primary carers' hopes and fears, including the

following: (i) ageing and the ability to care; (ii) expectations of the future; and (iii) securing the future. Primary carers' vision and actions taken for the future acted as both barriers and enablers to their occupational engagement.

Primary carers found caregiving demands became harder as they aged, causing concern about their ability to continue to provide high standard care, which Kylie and Anne, respectively, describe as follows:

Because as I am getting older I'm starting to worry, not about my future, but about the future of the person that I care for when I'm not there.

...I am nervous about 10 years down the track. I find I'm still managing her now, but as she's gotten bigger and I've gotten older to get her up off the floor is harder than it used to be...But I can see it's going to get more difficult.

Some primary carers' expectations and concerns for the future included worry about the care recipients' circumstances changing, finding a spouse, attaining independence and safety that Natalie describes as follows:

...we sort of hope that he'll meet his dream princess but in reality, whereas we'd love it to happen it's probably not going to...

In addressing their concerns, some primary carers explored alternative living options for the care recipient, engaged family to discuss the care recipient's living arrangements, supported care recipients to develop and/or maintain independent living skills and/or maintained their own health as described by Kylie:

That's why we have started Frazer buying his own house and trying to be independent and all that sort of stuff.

These concerns and consequent actions had the potential to influence the primary carers' occupational engagement.

## Discussion

For primary carers in this study occupational adaptation was essential to engage in a carer occupation and carer lifestyle. Their occupational engagement was influenced by positive and negative adaptation (Wilcock, 1998, 2005, 2006). Positive adaptation occurred when these primary carers developed new or engaged in meaningful occupations that may have supported their health and wellbeing (Wilcock). Negative adaptation occurred when these primary carers restricted their opportunity to develop their current or new occupations and/or

ceased occupations to sustain their carer occupation, limiting their occupational engagement in other meaningful occupations and increasing their risk for poor health and wellbeing (Wilcock).

Occupational therapy interventions seek to enable care recipients' and carers' participation in meaningful occupations to foster health and wellbeing (Townsend & Polatajko, 2007; Wilcock, 1998, 2005, 2006). Engagement in a variety of productive, leisure and self-sustaining occupations is necessary for health and wellbeing (Zemke & Clark, 1996). Occupational engagement was challenged and limited for these primary carers, as they spent much time on caregiving. Often care recipients' occupations and needs were prioritised, leaving primary carers little or no opportunity to engage in their other meaningful occupations.

Although many issues relating to carer occupation are universal, unique challenges may be faced when living in remote rural areas. Such challenges include having limited access to quality, timely, or quantity of formal services and increased travelling time and distance (Elliott-Schmidt & Strong, 1997) as experienced by these primary carers. However, similar to the results of Wiseman and Brasher (2008), these primary carers also had positive experiences, including having a sense of community and feeling supported, respected and accepted. They experienced a sense of belonging and unity with their community, which was important to their sense of wellbeing. Furthermore, supportive informal relationships and networks with the community were essential to their occupational wellbeing in reducing their isolation (Polatajko *et al.*, 2007a).

## Implications for practice

Occupational therapists, working with people with disabilities, come into contact with primary carers. Within these occurrences, a holistic intervention approach may be used to enhance the development and implementation of effective treatment and outcomes. Such an approach would need to recognise the experiences and impacts of caregiving on both the care recipient and primary carer.

Understanding primary carers' caregiving experiences and occupational engagement may assist to develop effective interventions for care recipients. Primary carers in this study were experiencing poor occupational outcomes, including occupational imbalance and deprivation from fully assuming and prioritising engagement of their carer occupation. Occupational imbalance (Christiansen & Townsend, 2010) was related to their beliefs and actions that supported caring as a lifelong role, put others needs first and avoided burdening others. Their self-assuming in full of the unconditional responsibilities of caregiving was supported by their perceptions and actions, and related to having limited access to quality, quantity or

timely support. Their occupational deprivation (Whiteford, 2000; Wilcock, 2006) associated with perceptions and actions that supported them to be dedicated to prioritising caregiving lifestyle commitments and care recipients' needs over their own, reducing their time to engage in occupations beyond caring. On an ongoing basis, such deprivation may erode the primary carers' health, wellbeing and resilience and manifest as poorer outcomes for care recipients.

It is potentially useful, when liaising with primary carers experiencing poor occupational engagement, for occupational therapists to engage relevant people involved in the care recipients' life (e.g. care recipient, primary carer/s and other family or service providers). This will enable a fuller understanding of the care situation and optimise the development of effective interventions. Effective interventions would enhance opportunity for primary carers and care recipients to engage in meaningful occupations and to achieve treatment outcomes that facilitate occupational justice by minimising imbalance (Polatajko *et al.*, 2007b).

The experiences reported by these primary carers suggest that families may benefit from services that meet the care recipient's and family's needs and wants (Dodd, Saggars & Wildy, 2009). A family-centred approach that encourages capacity building for individuals and the family unit (Dodd *et al.*) is a well-suited approach, as primary carers know their care recipients the best (Kellest & Mannion, 1999; Sanders, 2005). A family-centred approach that addresses family members' needs and wants, and seeks to implement adaptations to achieve occupational balance and justice for care recipients and primary carers, is beneficial (Wilcock, 1998, 2005, 2006).

The results of this study are specific to the sample of eight primary carers who participated, and are not generalisable to other carers, including non-primary carers or carers working across other types of disabilities and/or living in different rural or metropolitan areas. Despite these limitations the results provide insight into the occupational experiences of primary carers living in a remote rural area, which may be used to inform the development of effective occupational therapy interventions for care recipients with intellectual disabilities. Exploration of primary male carers, other type of carers and care recipients from different populations may expand this beginning insight.

## Conclusion

Primary carers' (of care recipients living with an intellectual disability in remote rural areas) occupational engagement was affected from limiting opportunity to develop occupations, developing new occupations and adapting and/or ceasing occupations when undertaking a caregiving lifestyle and carer occupation. Primary carers' occupational adaptation and engagement was influenced by lifestyle and occupational roles, health and wellness,

engaging quality supports, societal and community context, and a vision for the future. These influences were associated with their beliefs and actions that enabled their full engagement in caregiving lifestyle and carer occupation and impacted on their engagement of other occupations. These results suggest that occupational therapists consideration of primary carers' experiences, health and wellbeing within a family-centred intervention approach may provide for effective and meaningful intervention designed to meet care recipients' short- and long-term needs from enhancing occupational balance and justice for them, and their primary carers.

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