

An examination of the experiences of young people who care for a family member experiencing physical or mental health problems in Australia

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A substantial and increasing number of children and young people provide primary care to family members experiencing physical and mental health problems. Much past research on young carers has been dominated by a focus on negative outcomes and based on adult-centred interpretations and agendas. This paper describes qualitative research which aimed to give young carers a voice to tell their own stories about their experiences in order to develop a more complex and young person centred account. The research involved in-depth semi structured interviews with six young people from Australia who identify as primary carers. Although the young carers described significant difficulties, the findings of this study challenge the dominant 'negative' paradigm of young carer research. Most of the young people were positive about their experience, which they reported stems from a strong sense of family connectedness and reciprocal support provided by parents. Significantly, additional difficulties emerged, imposed on young carers through the impact of problematic social constructions of 'normal' young person, carer, and disability, which are manifested in negative attitudes and treatment of young carers and their families.

Over recent decades, governments in Australia have progressively withdrawn from providing care facilities for people with physical and mental health problems, with care now increasingly provided in the home. This change was initially driven by the paradigm-breaking Richmond report, commissioned by the NSW Government, which advocated a refocus on community care (Richmond, 1983). While there is no reliable historical information on numbers of carers, it is estimated that since this process of de-institutionalisation began, there has been a very substantial increase in both adults and young people providing care in the home (House of Representatives, 2009).

Young carers may provide care for a parent or sibling who has physical or mental illness, a disability, or has a substance abuse problem. Carers Australia (2002) estimates that there are more than 18,800 young people providing primary care in Australia, and 388,800 young people providing supporting care. Even these significant numbers are reported to be an underestimation, as many young people do not identify as carers or are 'hidden' due to factors such as privacy, shame, or cultural influences where family concerns are kept within the confines of the family

(Aldridge & Becker, 1994; Banks et al., 2002).

The number of young people caring is likely to increase in coming decades. The trend by governments worldwide as well as in Australia to withdraw social support, together with changes in family and demographics is likely to have a significant impact. Australia, like many Western countries, is experiencing increases in life expectancy and in the size of older populations (ABS, 2004), and parents having children at an older age (Laws, Li, & Sullivan, 2010). Research also suggests a move towards more complex family structures (single parents; blended families) and reduced roles of extended family, which will have an effect on the part children play in supporting immediate family members (ABS, 2003; Lackey & Gates, 2001).

Current Body of Research

The experiences and well-being of young carers is thus an issue of increasing importance and in recent decades, as the term 'young carer' has emerged, research has simultaneously increased. While not dismissing valuable contributions of existing research into young carers, overall it can be characterised as overwhelmingly UK-based,

predisposed to negative outcomes, and overly reliant on reports by parents and other adults. What is striking about the body of existing research is the relative absence of qualitative research that engages young carers.

Early UK research largely focused on negative effects of caring and comparing young carers with an idealised 'normal childhood' free from family disability or serious illness. Caring is thus portrayed almost wholly as negative, most particularly by Aldridge and Becker, the most prominent and prolific researchers in the field (e.g., Aldridge & Becker, 1993, 1994). The negative impacts reported include restricted opportunities for social activities, sport, and leisure (Thomas et al., 2003), poor educational outcomes (Aldridge & Becker, 1993; Cree, 2003; Warren, 2007), and mental health difficulties such as depression, anger, anxiety, and emotional exhaustion (Aldridge & Becker, 1993; Thomas et al., 2003).

There is also a body of research focusing on the phenomenon of 'parentification' of young carers and damaged transition to adulthood (Earley & Cushway, 2002). Parentification generally refers to a functional or emotional role reversal between parent and child wherein the parent surrenders their role as a parent and transfers that responsibility to their child. It is characterised by Chase (1999) as having a destructive and life-long affect on the child. Such studies raise questions about the extent to which reports on the negative aspects of caring are grounded in problematic constructions of children and young people. Young carers present a challenge to the traditional way in which children and young people are positioned as requiring, and being subject to, adult protection. The concern about the impact on these young people of assuming responsibilities usually considered to be 'adult' sets the tone for research implicitly based on a social action agenda to protect young carers. Questionnaires and surveys comprising lists of adverse affects on young carers, such as friendships, school, appearance, and bullying can be argued to be superficial but also reflect very limited assumptions of what young people 'should' be experiencing (e.g. Cree, 2003). Problematic assumptions

involve a 'known' and 'normal' level of age appropriate domestic chores and caring, departure from which results in social, physical, or psychological problems for young carers (Olsen, 1996).

Emotive titles like "Punishing children for caring..." (Aldridge & Becker, 1993) position young carers as exploited victims. Newman (2002) notes that research which identifies positive outcomes for young people in a caring situation is uncommon, despite accounts that caring can enhance relationships with cared for parents, develop life skills and promote independence and maturity (Banks et al., 2001; Thomas et al., 2003). Newman (2002) further argues that this focus on portraying negative outcomes causes parents to feel demeaned, disempowered, and guilty. The focus on negative aspects has been extended in recent research to quantitative studies of the mental health of young people living in families with disabilities (e.g. Mayberry, Reupert, Goodyear, Ritchie & Brann, 2009). The conclusion that young people should find caring situations difficult and stressful is expected but research focuses on coping problems and children's mental health which serves to individualise and pathologise young carers and mask the contexts of a stressful environment and a lack of services. Finally, much research on the experiences of young carers fails to include young carers at all.

Parents' accounts of children's caring experiences (Aldridge & Becker, 1994), recollections by adults of their experiences as young carers (Lackey & Gates, 2001; Shifren & Kachorek, 2003), and the perspectives of professionals from health and social care sectors of young carers (Gray, Robinson, & Seddon, 2008; McClure, 2001) are all researched widely. While these are no doubt important accounts, they suggest young carers are not able to articulate their own experience.

Clearly there will be negative aspects to caring for at least some young carers, but the dominant 'negative' paradigm has been problematic in generating a narrow range of research that has not properly explored the experience of young carers. It is significant

that Aldridge (2008), one of the most prolific of the early researchers, argues that it is time to move away from the simplistic portrayal of young carers as exploited victims.

Giving Young People a Voice through Qualitative Research

Walker, Crawford, and Taylor (2008) have noted the importance of young people having a voice in processes that affect them, both from a children's rights standpoint and to improve policy making. Cogently argued by Grover (2004), 'authentic' research gives power and voice to children to provide insight into their subjective world – to allow them to be 'subject' in the research rather than just 'object'.

Given the limitations in the body of research described above, it is not surprising that agreement has emerged that what is missing is deeper insight that can be gained through qualitative research that engages with the experience of young carers (Aldridge, 2006; Doran, Drever & Whitehead, 2003; Earley, Cushway & Cassidy, 2007; Gray et al., 2008). While qualitative methods and in-depth examinations are not the only step needed to give power to young people in research, they are an important step. The need for such qualitative research in the Australian context is compelling. Australian research to date has been limited, comprising mostly of Government-sponsored reports with a policy-making agenda focussed on services (Carers Australia, 2002; FaHCSIA, 2009; Moore & McArthur, 2007).

Description of the Research

The present study employed a qualitative approach to examine the beliefs and perceptions of young carers in Australia about their experiences of providing care to family members. The research question was framed as: "How do young people perceive their experience of providing care to family members with physical and mental health problems".

Methodology

As discussed, much past research has been dominated by adult-centred perspectives, interpretations and agendas, which carries with it the implication that children and teenagers

are not capable of 'knowing' or describing their experiences. This research epistemologically assumes that young carers have the capability to reflect on and articulate their own experiences. Moreover, this standpoint acknowledges that they are the experts of their subjective experiences. It assumes that authentic research must empower and give a voice to young carers. While the research aimed to provide space for young carers to communicate their experiences, it was not able to involve them throughout the research process. On the one hand more extensive collaboration with young people is desirable (Fox, 2013). On the other hand it was felt for this study that deeper involvement might have been too intrusive in the already busy lives of the young carers.

Methodologically this study includes the assumption that the young carers' subjective accounts are socially constructed, informed by the subjectivity of the researcher, and the situated discursive context the young people live within (Banister, Burman, Parker, Taylor & Tindall, 1994; Willig, 2001). This approach is concerned with how people make sense of their world and experience events in their lives (Willig, 2001).

Method

The definition of 'young carer' adopted for this research is that generally used in the literature: A person under the age of 18 years who provides substantial care and support to another family member, assuming a level of responsibility usually associated with an adult (Banks et al., 2002; Newman, 2002).

Young carers were invited to take part in the study through a government funded centre which provides respite and related support services to both adult and young carers. Six young carers responded and telephone discussions were conducted in the first instance with the young person or their parent/guardian to outline the research project and interview process. An information sheet was provided to enable informed consent and consent contracts were signed by researcher, young carer and an adult parent/guardian (where carers were under the age of 16).

The carers ranged in age from 14 to 17 years and comprised three girls and three boys. They were from a diverse range of caring situations and geographically spread over 300 kilometres. Each participant was asked to nominate a location and time for the interview to minimise inconvenience to them and provide an environment for the interview where they feel most comfortable: All chose their own home.

Interviews were semi-structured, using an interview guide to facilitate discussion. Questions were open-ended and neutral and sought to encourage the young people to talk freely and, as far as possible, allow them to direct the conversation and talk about the matters that were important and meaningful to them.

Data Analysis

Interview transcripts were analysed drawing upon Interpretive Phenomenological Analysis (IPA), following the procedures for IPA set down in Smith and Osborn (2003). IPA was chosen because it is an approach developed specifically to explore idiographic subjective experiences and how participants make sense of their worlds (Smith & Osborn, 2003). Appropriately for the young carers, as noted by Smith, Flowers and Larkin (2009, p. 206), IPA provides “insights into the lives of people whose voices might not otherwise have been heard, or whose experiences were ignored, or else constructed quite differently”.

The Young People Interviewed

Brief profiles of the six young people participating in this research, including details of their caring situations, are provided below: **Rebecca** is 17 years old and cares for her elderly grandmother who, in addition to being frail, has a serious heart condition and can only be left alone for short periods. Rebecca runs the household, including all domestic chores, managing accounts, medical matters and transport. Rebecca became responsible for caring for her grandmother at age 15 years. **Carly** is 15 years old and is a carer for her younger brother. Her brother was diagnosed with Asperger’s Syndrome and Oppositional Defiance Disorder. Carly is involved with household chores, cooking and cleaning, and administration of medication.

David is 14 years old and cares for his mother who has cerebral palsy and his father who has physical disabilities and aphasia. He has been fully involved in providing care to his parents since he was 10 years old. His caring role includes cooking, cleaning, managing medication for his parents and, at times, assisting with dressing and toileting.

Ben is 15 years old and cares for his elderly and frail grandmother who is in ill health. Ben was raised by his grandparents and when his grandfather died just over three years ago, he largely began his caring responsibilities. His caring involves housework, cooking, taking his grandmother to medical appointments, and most particularly being at home with her because of her frailty.

Kate is 15 years old and cares to varying degrees for her father, mother, and three year old sibling. Her father is badly debilitated by cancer and a heart condition. Her mother has a chronic back condition sustained in an accident. Kate is involved with cooking, cleaning, and generally running the house, tending to her sibling, administering medication for her parents, and, at times, showering and toileting.

Travis is 16 years old and is the primary carer for his mother and secondary carer for his two younger brothers. One brother has a number of severe congenital conditions and his other brother has autism. Travis’ mother has multiple sclerosis. Travis’ caring role includes cooking, preparing lunches, cleaning, washing, bathing, dressing, and administration of medication. He has been a carer since he was eight years old.

Findings

The six young participants encompass a diversity of caring situations in terms of the family member or members being cared for and the type and severity of their illness or disability. Accordingly, the participants have a wide range of caring tasks and levels of responsibility which generate many common but some diverse experiences. The young people did give an account of the difficulties involved in caring, and these are described in the theme *It is hard: Stressors described by*

young carers. The second theme describes in detail some of the positives the young people reported on in the theme *I love what I'm doing: Finding meaning in being a carer*, which builds upon largely overlooked areas of young carer's lives. Finally, the tensions between the social constructions of 'child' and 'adult' which mediate the experiences of these young carers are explored in the theme *The shifting positions of a young carer*.

"It is Hard": Stressors Described by Young Carers

A dominant and very explicit outcome that the young people reported on is that they face many difficulties in caring for family members. This area is well reported in existing research and may not be surprising, but is important for two reasons. Firstly the particular stressors reported by these young carers provide context and background against which further insights can be interpreted. Secondly the young carers detailed a wide range of stressors from both within the family and from outside it which build upon the often reported more superficial areas of increased chores and less time for homework and social activity.

Stressors from 'within' the family. The young carers described stressors that arose within the family which are an unavoidable consequence of family illness and disability. Most significant was an overwhelming level of responsibility that these young people feel for the wellbeing of their families. This was associated with ongoing vigilance, worry about the present, and anticipatory worry for the future. David described caring being relentless, inescapable, and needing ongoing vigilance:

It's on an ongoing basis. I wake up in the morning, I am helping, I go to school and when I come home, and I immediately start helping again. All my weekends I am helping [...] it's almost like being on guard, it's a constant watch (David).

For those young people who are the sole carer and only other family member in the household, the sense of responsibility is extended to needing to be present at all times. For these carers, there is concern about 'going

out', demonstrated in Ben's account:

I feel that I can't go anywhere [...] and I feel like if I go anywhere too long, like, maybe she may have fallen over and that one minute too late, she might have done something, or if I was there a minute earlier (Ben).

These insights expand ideas of particular activities which might increase for young carers, to a more complex sense of responsibility and vigilance. Additionally however, most of the young carers conveyed that their main difficulty is not the tasks and responsibilities of caring as such: While clearly very onerous, they were downplayed and largely dismissed as an issue. The worst aspect of their situation was most often seen in terms of the distress involved in witnessing the suffering and treatment of family members with illnesses and disabilities. In Kate's interview, she portrays 'witnessing' family members struggle with their illnesses as being the hardest thing:

You know, probably seeing what they are going through, that's probably the hardest thing [...] other than that, nothing else really is difficult or bothers me (Kate).

Stressors from 'outside' the family.

While difficult issues to face, the illnesses and disabilities themselves were not the only source of difficulties conveyed by the young people: Rather these difficulties were often compounded by factors outside the family. In the following extract Travis describes the most negative aspect of being a carer as extending beyond his family:

The worst parts of a carer is going to Sydney hospital, witnessing what your eight year old brother has to go through, witnessing doctors in front of you saying *this kid's profoundly DUMB, he's behind his peers*. And then, on top of that, witnessing treatment of him, in schools and that, people treating my brother like he was a moronic idiot [...] and that's one thing that gets under me, and really hurts me (Travis).

Here, Travis focuses on the treatment his

brother receives from others, and the negative assumptions others make, which he suggests is more frustrating and hurtful than the conditions from which his brother is suffering.

Difficulties with school were described as a major stressor for all six young people themselves. This results from caring duties limiting time available for school work, disruptions to attendance, distractions caused by a difficult home environment, or difficulties in concentrating at school because of concerns for the cared for person at home. Again this is not an unexpected outcome and schooling has been the focus of much research on young carers (e.g., Cree, 2003; Warren, 2007). However, the young people elaborated additional difficulties experienced by a number of them through negative attitudes of schools to caring. In her account Rebecca speaks of being verbally abused by a teacher about a caring-related issue:

I have to have my phone on if something happens, in case she [grandmother] needs me to ring her or an emergency happens. And [the teacher] will just go ballistic at me and tells me my phone must be off. And I say I am a carer and I need my phone on and they just say they don't care (Rebecca).

Rebecca's experience, while potentially a unique one, highlights that while some disruption to schooling is an unavoidable aspect of caring, negative attitudes to caring in the school community can constitute an unnecessary additional stressor.

A sense that young carers are unrecognised and unappreciated emerged, through examples in school like the extract above, but additionally from experiences with other service providers. While only Travis and Rebecca have significant dealings with service providers and agencies (as there were adults in the other households who could undertake this role), both had similar experiences. From their perspective, a significant and unnecessary hindrance to being a carer is that they have no status, either as (adult) decision maker or as carer. The extract below reveals Travis' frustration:

I had a problem, Mum was in hospital and so on and so forth, and I was trying to pay bills and stuff, and one of the companies said no, you need the authorised person to be her. I've gone 'the authorised person is in a hospital bed, sick, unable to talk'. I said 'what the fuck am I supposed to do then' and the guy just looked at me and gone 'sorry I can't do that' (Travis).

David and Rebecca additionally conveyed a very heartfelt perception of a manifest lack of support from 'society'. This is poignantly captured in an extract from David's interview:

In today's society, when you are in trouble, you ask for help. And it's very annoying and frustrating, and it gets me down that when Mum and Dad need help, I am the help. There's no other help [...] and in the last holidays we all had a meltdown, and the one time we needed assistance, no-one could help, there was no-one there to do anything. We just sort-of had to pick ourselves up, you know and drag ourselves out of the mud (David).

David goes further in the following extract to argue that this lack of support as total indifference by the community to young carers:

Nobody seems to care. I really don't think at the moment that it would make a difference if, to the general community, if we were dead or alive, because they just don't care. They don't understand at all (David).

Rebecca perceives a negative attitude to carers more generally in her rural community: "they've [rural people] got this weird conception that, the way they think is different to city people, so we get, so we get a bit of stigma around caring too" (Rebecca).

While there are largely unavoidable stressors experienced by young carers that relate to family circumstances, the significant finding of this theme is that many other stressors are imposed on these young carers from outside the family which should be

largely avoidable. The difficulties faced by young carers and their families are compounded by, or may originate from, negative attitudes and stigmatisation, bad treatment of family members, lack of status with schools and service providers, and lack of support.

“I Love What I’m Doing”: Finding Meaning in Being a Carer

The struggle to understand. Finding meaning in a situation impacts crucially on how that situation is experienced. The young people interviewed all conveyed being acutely conscious that their caring situations had been imposed upon them with no choice and little control over what is a significant part of their lives. There are many references to caring being ‘thrown’ or ‘thrust’ upon them, not it should be noted, with negative reference to cared for family members themselves, but to the difficulties which have occurred.

Rebecca describes being forced into a caring role after being abandoned by other family members: “[my mother has] just moved out, and gone, my family don’t have much to do with me, so I feel quite isolated” (Rebecca). For Ben too there is anger and a sense of abandonment about why he is alone caring for his grandmother following the death of his grandfather: “no, it’s [the anger] sort of how the family has treated the situation. How they have just deserted me and Mum” (Ben).

For Travis, Kate and David who care for multiple family members with severe illness and disability, there is an underlying struggle to understand why these things happened to them and their family. The following comment from Travis suggests he finds the struggle for meaning both difficult and ongoing, not least of all because he feels ill-equipped for the situation in which he finds himself:

I have had my meltdowns. Yeah, I have said plenty of times, ‘why the hell did this get picked into my family. Why the hell did my life get thrown on the frigging head and why the hell did I get picked to deal with this’. Because I’m not the strongest person in the world (Travis).

David similarly struggles to understand his situation and his parents’ disabilities. In his

interview David explicitly discusses his anger about ‘why’:

I tend to get quite angry at times. Just the situation I’m in and I suppose a bit of anger, that, why did it have to happen to me, why did it have to happen to them [parents] (David).

Appraisal and family connectedness.

Despite this struggle to come to terms with these situations, it was made very clear that all the young carers wanted to help their families. This included appraisals that they are repaying family, that there is a special relationship with siblings, or that their family is special.

In the following account Rebecca portrays her pleasure at being able to care for and repay her grandmother:

You know, I am happy to do, it’s a wonderful thing to do, being a carer, it really is. It’s good, it’s rewarding, I love it. I wouldn’t change it. My grandmother she raised me, she has a big influence on my growing up, so, for me to be able to care for her now feels like I am able to give back to her what she gave to me (Rebecca).

Ben suggests the additional benefit of enhancing a relationship:

I LOVE what I’m doing, I love looking after my Mum. I love the fact that I am repaying her. The good thing is that we’ve grown a lot closer (Ben).

For Travis, caring is appraised positively in terms of his special relationship with his brothers for whom he provides care. It is clear from the following passage that he derives great meaning from his brothers’ future awareness:

I am pretty happy that I’ve been here every step of the way. I know what my brothers have been through and I can relate to my brothers. And I know when they get older they will realise how much I’ve been there for them and they will realise how much I’ve done for them, and that’s the thing (Travis).

In the following extract, there is a strong sense that Kate sees her family as special – different from, but better than, ‘normal’

families:

Family comes first to me, it always has and always will. We love our family for who it is, but the best thing about it is, you know, it has made us stronger. We aren't like other families that don't respect each other, because they don't have that relationship with their parents, and that's where I'm lucky, I have that relationship where I can talk to them about anything, whereas these girls and boys, they don't (Kate).

For Kate, there is a sense that her view of the family is pivotal in her perception of her experience. She appears to see her caring situation, and indeed her life generally, through the prism of her relationship with her family which she values greatly.

The young people appear to view their caring responsibilities from a perspective strongly embedded in family connectedness. They reveal a view of family relationships that goes well beyond the portrayal of caring in terms of domestic chores and constraints on schooling and leisure activities, and reflects complex experiences that contradict the portrayal of young carers as exploited children. This connectedness to the family was also seen in the previous theme where the young carers described the negative experiences of their cared for family members as being more important than any chores and difficult activities they might face. These aspects of caring highlight a further issue with much young carer research, which positions young carers discretely from family and individualises their experience into negative activities. The young people in this study communicated a connectedness to family that suggested that the negative aspects of caring are compensated for by close family relationships.

Reciprocal family support. While not always explicitly articulated, a powerful factor for the young people in feeling good about caring appeared to be the reciprocal support they received from within the family. All of the young carers spoke proudly of receiving reciprocal support from parents which ranged from the practical to the more symbolic. The

following account from Kate gives an example of the emotional, social and, within limits, the physical support provided by parents and, importantly, how that support is very positively perceived by their children:

The thing is we all pitch in with each other, so it's a team effort, that's what we always say to each other, it's a team effort to do everything. Dad still goes down to the shop and buys some groceries just to make him feel normal, and things like that, and Mum likes to do some things, like she will cook sometimes, but they are only able to do little things. It's like what you give is what you get in return, that has always been like, our kind of motto thing (Kate).

Such reciprocal support and behaviours may be significant in acting as mediating factors against any disruption to the parent-child relationship arising from the caring situation. In the following extract it is clear that David is very conscious of, and fiercely supportive of, his parents' efforts to 'be parents':

Even though I care for my parents I still see them as busting their guts every day to do the best they can. I might cook the dinner, sometimes up to six days a week but they still do those things that parents do, they still do do them whenever they can (David).

These accounts contradict pathologising assumptions that disabled or ill parents provide inadequate parenting and further emphasises the collective family above discrete individuals. The experiences of these young people suggest that their parents and guardians often continue to provide emotional, social and other forms of support, heightening the sense of reciprocity of providing and receiving care, and enhancing the sense of family connectedness.

Finding benefit. An important aspect of the participants giving positive meaning to being a carer appeared to be the perceived benefits that emerge. Many of the young carers drew on a construction of 'normal' age-related development through childhood and teenage years against which they reported

themselves as having an advanced level of maturity. All six of the young carers conveyed that their experience has accelerated their maturity and made them more responsible, competent and, in one case, more employable.

Rebecca's account suggests that she sees caring as a life-changing experience and implies in the following passage that it might have saved her from bad life choices as a 'normal' teenager:

I was a normal teenager, and I was a bit run off the rails, a little bit, you know, caring really has given me responsibilities, it has made me grow up overnight, you know people say that when they have babies they feel like they have grown up overnight, and it is kind of the same thing, you become a carer, and you feel like, you know, you are put in an adult role, and you grow up and start to realise what's important in life. I have changed a lot (Rebecca).

Rebecca's belief that caring has set her apart from her peers is reiterated by Kate, and in her interview she takes a pejorative view of the 'normal' teenager whom she sees as trivial and immature:

Everyone tells me that I am so mature for my age. Half my age group are already, you know, they're out drinking and getting pissed at parties every weekend, while I am at home getting tutoring or spending time with Mum and Dad. I am definitely different to the girls mature-wise and I'd look at things completely different to what they would (Kate).

Implicit in some of these comments is a view that young carers are more competent than a 'normal' teenager and doing something their peers 'couldn't handle'. Further to the benefits of caring, for some of the young carers a positive outcome was an increase in ambition, motivation and drive for the future. Kate identifies caring as a key driving force to do well:

I have pretty much always been a carer since I can remember, and I honestly don't think I would rather have it any other way. Because that's

made me the person I am, it has made me want to reach the goals I want and get to my full potential (Kate).

Rebecca has a similar perception and in the following passage attributes having the responsibility of her grandmother's care as the motivation to focus on her future:

I think it [the future] looks good for me, I am happy with the way I'm going in the future. It's a big thing being a carer, umm, it has benefited me in the way that it has made me really think about my life and my future. It drives me to finish my studies and to go places with my, you know, to get good results in exams. So it's really helped me, and the future, it looks good (Rebecca).

The portrayal of caring as impairing the future of young people is not how these young carers described their experience. Indeed, caring appears to have enhanced their view of the future. The sense of their position as young people who are not 'normal', but rather 'extraordinary', emerged as an important sub-theme. However, it also began to conflict somewhat and raise tensions in their accounts, between a desire to be 'normal', a desire to be 'extraordinary', and the occasionally negative descriptions of young people they viewed as 'normal'.

The Shifting Positions of a Young Carer

The ways in which socially constructed positions seemed to emerge for the young people in this study are both complex and conflicted and can be argued to have a significant impact on how they experience caring. This section considers the implications of the social constructions of 'child' and 'adult' which seemed often to mediate these young carer's experiences. Tensions appeared to be created by being positioned on the one hand as a child or 'normal teenager' who is assumed to be incapable, and on the other a carer with 'adult' responsibilities who is required to be supremely capable.

Just a kid. The term 'kid' was used by the young carers themselves several times. David for example, at times described

himself as a 'kid', and spoke of wanting to enjoy his childhood. He drew on this construction, with assumptions of incapability to demonstrate his bewilderment at getting little support from services: "one kid on my own with two disabled parents" (David). Ben recounted, and did not disagree with, the construction of him as a child by his grandmother when describing the difficulties he faces in caring: "I do [get overwhelmed] cause like she [grandmother] says I am still only a kid, still 15" (Ben).

The social construction of being 'just a kid' was sometimes employed to describe the stresses and difficulties of caring. In the following extract Travis asks for understanding that young carers are 'just kids', and hence expectations of them are too high:

And just basically people just need to open their eyes and realise that they need, like, they are kids, and not all the time will they be perfect, not all the time will they make the right decisions. They will make mistakes, like a lot of people and a lot of services don't realise that (Travis).

These accounts contrast with the earlier descriptions of greater maturity and competence and seem to involve a diminished sense of selves, both with the term itself of 'kid', and with terms like 'only', 'not perfect' and 'make mistakes'. These social constructions around the 'child' as incapable emerge in tension with other descriptions and cause potential dilemmas. The young carers often described a desire to be independent and respected autonomously, but what emerges at times, as in Travis' account above, was a role of 'child' as vulnerable and less capable which might be required in order to access services.

At the same time, the social construction of 'kid', child or teenager seemed to offer something productive for the young carers, most notably as an option to 'opt out' of caring. In the following extract Travis constructs quite a stark polarisation between being responsible and being a teenager, but infers usefulness for him when operating between these roles:

Well there is a switch in my brain. I'm pretty sure a little man controls that,

and, when I become like a responsible person and when I just lose my brain and I turn into a teenager (Travis).

The construct of teenager as lesser than adult, promoted culturally, emerges here in a quite stark form: As teenager without thought. In David's account this separation divided into self at home and at school. In his interview he talks about there being 'two Davids' – David the carer and David the 'regular kid':

I can get on that school bus in the morning and, the David that lives here can, it's almost as if he can stay here [...] I take this David to school and this David does, thought processes, all he does is his maths or his English (David).

This notion of leading separate lives, particularly between school and home was described by a number of the young people, and raises questions about schooling and the space in education for young people who do not fit into the 'normal' teenager role. Actively separating their selves seemed to be one way that some of the young carers managed the conflict between the societal construct of a teenager and that of a young carer associated with disability. While there are fundamental issues to be explored in the acceptance into school community of very different young individuals, this account additionally suggested a possibility for 'time out' which school can offer. With the exception of Kate, the other young people described keeping their caring role and home situation quite private from school and many friends and, in the case of Travis, actively seeking to keep it secret. This is suggested in the following extract from Travis where despite feeling conflicted about such choices, he does not wish to be treated in ways he perceives as negative:

I hide my fam- what goes on at home, I basically, umm, I know it's not the greatest thing to do but, I basically don't tell anybody what goes on at home, because basically I don't want to hear that whole I'm sorry to hear that Travis, I'll give you special treatment Travis, I'm sorry about that

I HATE that type of treatment
(Travis).

Here there is suggestion that playing the ‘normal teenager’ role at school offers Travis a resistance to the position he views as negative which might be imposed by being labelled a young carer. The complex and contradictory manner in which this conflict is negotiated is shown by how Travis positions himself as a teenager and as a young carer. He describes teenagers as having “no brain” while striving to be seen as one, but conceals his role as a young carer while maintaining an idealised construction of them as being almost perfect and superhuman. Travis’ diverse positions are starkly illustrated by the juxtaposition of the following two extracts:

They [young carers] aren’t just normal people, but they are extraordinary people doing remarkable jobs. And these extraordinary jobs turn them into extraordinary people. People enter the group as kids and leave as adults. Not by choice, but what is thrust upon them, and it’s these words that I’ve lived by (Travis).

I just think I’m an everyday kid really
(Travis).

These contradictions reflect the power of the negative construction of a young carer and the powerful appeal of the construction of ‘normal’ teenager that operates culturally. These conflicting roles available to these young people potentially create difficulty for them *in addition* to their challenging experiences as carers. Travis desires to be positioned both as an extraordinary carer and as a ‘normal’ teenager, depending on the context: The former in terms of his self-image and feeling good about being a carer, the latter in terms of the abstract concept of not missing out on his teenager years.

A final aspect of the social constructions available to the young carers is a positive one: The way in which ‘carer’ and its assumptions of adult responsibility, give the young people some emancipatory space to transcend and resist the dominant position of teenager as incapable. Carly comments in her interview

that she is “totally different” from her peers because of her caring-related chores, albeit while reproducing the assumption that there is a known and ‘normal’ level of domestic tasks for teenagers:

I see my friends, they all have siblings who are normal, I guess you could say, and they don’t have the stresses of trying to look after, the housework, the cooking and cleaning, the administering medication, they don’t do that, and then there is me. Like I am totally different (Carly).

This resonates with Travis’ extract where he positions young carers as ‘extraordinary’, and the section earlier describing the ways the young people are ‘finding benefit’. Even when the competing roles of child and carer meet to make things difficult for the young people, they describe resistance and a refusal to conform to other’s expectations. At times for example, Travis refuses to accept being positioned as a child with no status in the ‘adult’ world and he responds with bold acts of resistance. This includes confrontations with service providers who expect an adult to interact with:

I was trying to put in an application form for Mum [and the guy said] ‘we need her signature’ so [I said] give me the paper and turn your back around, and he was like ‘what are you going to do’, and I’ve gone ‘it’s my mother’s signature’. Like if a person treats you like an idiot, just be up front and tell them where to go.
(Travis)

The problematic nature of these very different constructions appeared to result in competing tension young carers feel between caring and the proscribed life of a ‘normal’ teenager. While the young carers in this study are fiercely committed to their family, they are nonetheless conscious of, and react to, a duty to themselves and their development as a ‘normal’ teenager. Significantly, the assumption that young people should have few responsibilities potentially *adds* to their difficulties rather than reducing them. While these competing positions of child and of carer may create conflict, the young people

offer an account of the ways they resist these positions, and the ways they find to make them work for their own means.

Discussion

The aim of this study was to develop a more in depth account of caring with young people which methodologically allowed them to voice their experiences. Semi-structured interviews with the young people, in their homes went some way towards achieving this, but further collaborative methodologies need to be employed to explore more meaningfully and are discussed below.

With all research there is a potential selection bias between those people who choose to participate and those who do not. Young carers who volunteered to be interviewed may have very different experiences to those who did not. It is reasonable to surmise that those who chose to take part in this research felt more confident in talking to an adult and perhaps more positive about their experience as a carer. The recruitment of participants through a respite centre also means that they had been assigned the label of 'young carer'. As discussed in the literature review (Banks et al., 2002) a large number of young people who are caring are not in contact with any agencies. These young people may well not consider themselves 'young carers' and may not be exposed to constructions of loss and difference – and nor do they presumably have access to support outside of the family unit. Hence the experiences of these young people may be markedly different and would warrant further research.

Researcher constructing the research

In a study involving an adult researcher and young participants, there is a potential concern about the extent to which the young people feel able to openly discuss their experiences. Holding the interviews in the homes of the young carers was one way this research aimed to enable the young people to be more in control. It also appeared that the young people felt somewhat empowered by their experiences being recognised, conveyed for example by Ben: "like I love what you're doing, you're trying to get people to

understand what we're doing".

The most significant impact that the researcher had on the research was an emotional reaction to the young people and their families' situations. Apart from the difficulties that these young people experience as carers, the circumstances of many of the families engendered great admiration and respect in the researcher for the manner in which these young carers and their families conduct themselves and meet their challenges.

This emotional connection to the young people and their families subjectively impacted upon the research process. This was drawn upon as a basis for analysis by both focusing in on the most surprising and emotionally eliciting aspects of the interviews and asking questions of the researcher's reactions as important subjective responses. Rather than being problematic for the analysis, this paper argues that the evoking of an emotional response by the data has potential to produce a better understanding of what it means to be a young carer (Grover, 2004).

Implications of Findings

The young carers who took part in this study did describe day to day difficulties such as household chores and managing homework which resonates with current literature (Aldridge & Becker, 1993; Cree, 2003). However they also reported on the more nuanced and complex difficulties of maintaining a strong sense of responsibility requiring vigilance and presence. These deeper stressors were described in greater depth and detail than the more superficial activities. In addition to these stressors however, the young people reported on difficulties which came from outside their family unit. The young people placed far greater emphasis on the negative impact of their loved ones experiencing physical or mental difficulties and disability. As well as the illness itself, the social constructions of disability and illness and therefore the treatment of their family by others, including services, were reported as being particularly problematic for the young carers and their families. The negative impacts of social

context are largely overlooked in previous research, and include the treatment of both the cared for family members and the treatment by outsiders and services such as education of the young carer.

While all of these difficulties were reported as being substantial, the young people were all keen to downplay and dismiss them. They gave far richer and more passionate descriptions of the benefits they perceived in being a young carer. These primarily included the levels of responsibility which they had reported as being difficult at times, and suggests some aspects of caring which can be framed as negative are not principally so.

The support from family and the increased cohesion of family relationships were also described in detail as positive outcomes of caring. The carers reported extensively on reciprocation and being part of a family effort which was very important to them feeling positive about their experiences. This challenges two aspects of existing research. The pathologising implication in some research literature of disabled and ill parents providing inadequate or selfish parenting (see Thomas et al., 2003) is questioned as is polarised assumptions that cared for parents become unable to parent and that young carers undergo parentification. For these young carers, having parents who require assistance from their children does not diminish the parental love, care, and guidance being provided. While there may well be a blending and shifting of roles, the young people voiced and took seriously the parenting support their families were able to provide. Secondly, this theme accords with the longstanding criticism made by Olsen (1996) that much of the research individualises the young carer as a discrete entity from family and studies them in isolation. The young people in this study conveyed the ways in which they were part of a whole that was blended and complex and which they valued greatly.

A significant outcome therefore of this study is that it highlights the nuanced nature of young carer's experiences, as being neither wholly positive nor negative, but rather complex. The young people identified and

articulated issues and difficulties in their lives, but still described the totality of their world and maintained an optimistic and enhanced view of their future. The view that caring endangers the future of young people, as discussed in the literature (e.g., Chase, 1999) is certainly not how these young people reported on their situation.

These blending of roles and the different responsibilities the young people took on in their families was described as being something they valued, but it did appear to raise tensions in the way they then experienced social constructions of 'child' and 'adult' which were at times useful and at other times difficult to manage, particularly in their dealings with others and with services. The social construction of 'child', as being incapable with assumed low levels of responsibility was at times useful for the young carers as a way to relinquish their selves at home. However, social expectations which the young carers were unable to fit into at other times became problematic and frustrating for them, particularly when dealing with services and needing to perform roles which might be assumed to be more 'adult'. Paradoxically, assumptions that these young carers should be doing less and should be afforded more 'normal' teenage lives may themselves be *compounding* the difficulties they face.

This research was able to promote young Australians voices in the research by undertaking in depth interviews in their homes. It has raised several issues which are worth exploring further. Methodologically, a more extensive collaborative, participatory approach which flexibly engages young people in research would allow for deeper and more sophisticated insight. This study has also raised various issues which would benefit being investigated further. The implications of these young people's negative experiences for service providers should be further examined. The experiences of young Australians, and the different context in which they are living, also merit further examination. Leading on from this initial study, a participatory project with a larger number of young carers, examining issues for

rural young people and from a service perspective is currently underway.

Conclusion

This paper provides a rich insight into the experiences of a small group of young people caring for family members in Australia. The findings challenge a number of assumptions underlying the dominant 'negative' paradigm of young carer research. Young carers do face significant difficulties, but they also report feeling good about caring and are optimistic about their future. Strong feelings of family connectedness are crucial to how they perceive caring, which in turn seems linked to reciprocal support between the young carer and the rest of the family. A significant and problematic finding is the unnecessary additional difficulties faced by young carers that stem from societal constructs of the 'normal' teenager, carers, and disability. This was reflected in stigmatising, negative attitudes and treatment of young carers and their families, and the difficulties they have in negotiating the various 'positions' imposed on them.

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