The Moral Resilience of Young People Who Care

How to cite:

For guidance on citations see FAQs.

© 2020 Geraldine Boyle

https://creativecommons.org/licenses/by/4.0/

Version: Version of Record

Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.1080/17496535.2020.1771606

oro.open.ac.uk
The Moral Resilience of Young People Who Care

Geraldine Boyle

To cite this article: Geraldine Boyle (2020) The Moral Resilience of Young People Who Care, Ethics and Social Welfare, 14:3, 266-281, DOI: 10.1080/17496535.2020.1771606

To link to this article: https://doi.org/10.1080/17496535.2020.1771606
The Moral Resilience of Young People Who Care
Geraldine Boyle

School of Health, Wellbeing and Social Care, The Open University, Milton Keynes, UK

ABSTRACT
This paper draws on findings from a qualitative study of the social wellbeing of young people caring for a close family member. The research makes a novel contribution to the international literature by examining the moral resilience of young adult carers. Focus groups or individual, semi-structured interviews were undertaken with fifteen young people in South-East England during 2018–2019. The paper explores whether young people with a seriously ill or disabled family member define and conduct themselves in moral terms and how they respond to the moral challenges of a caring life. It was found that the participants saw moral value in their caring role and their actions reflected a desire to provide compassionate care. Previous research into young adult carers had indicated that the caring role stimulated their political consciousness, but this study suggests that the role also strengthens their moral consciousness. However, designating girls as carers in early life shifts the moral responsibility to females and compounds gender inequity in caring. Hence, there is a need to address social and gender inequalities in care. In addition, healthcare professionals should recognise when statutory input is necessary to facilitate young people’s broader lifeplans.

KEYWORDS
Young adult carers; wellbeing; moral resilience; care inequities; gender

Introduction
Children and young people under the age of 18 who provide regular care and emotional support to a family member who is physically or mentally ill or disabled are referred to as ‘young carers’ (Clay et al. 2016). However, the Care Act 2014 (England) acknowledged that young people often continue caring after the age of 18. There has been increasing recognition of these ‘young adult carers’, as they tend to have greater caring responsibilities. It is estimated that there are 290,000 carers aged 16–24 years in the UK. Although they are often on the cusp of major life transitions – to university, employment and couple relationships – there had been little research undertaken into their caring experiences until quite recently (Becker and Becker 2008).

Concerns have been expressed about the possible impact of caring on young people’s physical and psychosocial wellbeing. A qualitative study in England showed that young carers (aged 5–17 years) experienced family strain, stress, restrictions in social activities...
and relationships and under-engagement in education (Clay et al. 2016). The Longitudinal Survey of Young People in England examined the hidden lives of young carers via a questionnaire administered to year 9 pupils (usually aged 13–14), followed up annually from 2004 to 2010. It was found that they missed out on leisure, friendship and learning opportunities, which negatively affected their educational and occupational outcomes (Hounsell 2013). Similarly, a meta-synthesis of qualitative studies internationally identified that young carers struggled to balance caring with schoolwork and a social life (Rose and Cohen 2010). They also experienced tensions in the transition to adulthood, related to their need to start studying, leave home and seek employment (McDougall, O’Connor, and Howell 2018). Being a young carer can, therefore, limit opportunities for exploring alternative futures (Rose and Cohen 2010). Caring also impacts on young people’s emerging identities, as they experience tensions between the need to enjoy childhood or adolescence and take on adult caring responsibilities; between adopting a caring identity and identifying with one’s peers and in terms of their overall sense of belonging. Socio-demographic factors such as gender influence their self-image, particularly as young men may feel that a caring role threatens their masculine identity (Rose and Cohen 2010). Additionally, their physical and mental health may be affected. An online survey of young adult carers in the UK found that 45 per cent reported mental health problems, particularly young women and often in combination with physical ill-health (Becker and Sempik 2019). Yet, the Carers Strategy and the subsequent Carers Action Plan (England) stated that young people need to be able to enjoy their childhood or adolescence and have opportunities ‘to learn, develop and thrive’ (Dept. of Health and Social Care [DHSC 2010], 37, 2018). The latter emphasised that support for young adult carers should be improved to help them make positive life transitions.

It is important to acknowledge that young people generally value their caring role. Previous research showed that, despite the challenges they faced, most young carers viewed the role positively (Wayman, Raws, and Leadbitter 2016). Studies in England and Australia identified that young carers (aged 14 or 16–25) had contributed to the happiness of family members they cared for, developed maturity and acquired practical and interpersonal skills (Heyman 2018; McDougall, O’Connor, and Howell 2018). Rose and Cohen (2010) concluded that young people gained competency, self-esteem and a sense of identity from their role and felt it better prepared them for the challenges of adulthood. In contrast to a ‘burden’ lens applied in much research, applying an affirmation model to young carers helps to recognise when the caring role provides them with a positive self-concept and promotes their maturity (Heyman 2018).

Young carers have been described as ‘kind, caring and responsible young people’ who deal with challenging life circumstances (Cassidy and Giles 2012, 652). However, it is important to avoid narrowly portraying them as ‘little angels’ or as victims of their parents’ illnesses (Aldridge 2008). Nonetheless, since their caring obligations may include providing personal care and emotional and financial support this can lead to stress, social isolation and mental ill-health (Cunningham et al. 2017). On the other hand, achieving social recognition of their caring role fosters their resilience (Skovdal and Andreouli 2011). Resilience has been defined as a process that promotes positive adaptation, despite adversity (Luthar, Cicchetti, and Becker 2000). Previous research showed that young carers who had good social support and positive coping strategies demonstrated better psychological adjustment than their counterparts (Cunningham...
et al. 2017). Although carers under 18 who were supporting a parent with young-onset dementia experienced a high degree of ‘burden’, most of them also demonstrated moderate resilience (Svanberg, Stott, and Spector 2010). Helping young carers to develop psychological resilience can also promote their good mental health (Svanberg, Stott, and Spector 2010). Yet, whilst the research to date has focused on their psychological resilience there has been little attention paid to their moral resilience.

Caring as a social practice requires demonstrating knowledge and competency, but also moral agency (Liaschenko and Peter 2016). Moral resilience is the individual’s capacity to maintain her/his integrity in response to moral complexity (Rushton 2016). The construct involves seeking meaning in difficult life circumstances, being clear about one’s values, responding ethically and being courageous in the face of obstacles (Rushton 2016). This requires the development of skills, attitudes and behaviours such as communication, honesty, responsibility and ethical decision-making (Monteverde 2016). It entails being realistic about situational constraints and recognising when circumstances are beyond individual control (Rushton 2016). Whilst moral resilience is essentially a character trait, it involves connecting to others and learning from moral challenges (De Filippis, Curtis, and Gallagher 2019; Rushton 2016).

Consideration of moral resilience is in line with the re-emergence of ‘virtue ethics’ in a recent debate, including within professional care (Clifford 2014). It is a necessary virtue for achieving nursing goals, notably comfort, dignity and quality of life (De Filippis, Curtis, and Gallagher 2019). Monteverde (2016) suggested that health trainees’ moral resilience can be enhanced by ethics education. They assessed the impact of a lecture on moral stressors on nursing students’ reactions to vignettes relating to morally stressful situations. Their intervention led to a statistically significant reduction in the students’ levels of distress. With regards to family care, a narrative study which examined older carers’ (over 60 years) moral choices related to caring highlighted that they defined themselves as ‘good carers’ (Pickard 2010). Their explanations centred on responsibility and duty but also femininity, indicating that gender plays a role in the construction of caring among young and old carers (see also Rose and Cohen 2010). Thus, moral resilience is a valuable concept for examining the ethical dimensions of young people’s care.

This paper draws on findings from a small-scale study of the social participation and wellbeing of young people caring for a close family member with an illness or disability. This is the first study internationally to examine the moral resilience of young adult carers. The paper explores whether young people with a seriously ill or disabled family member define and conduct themselves in moral terms and how they respond to the moral challenges of a caring life.

**Methods**

An exploratory, qualitative study was undertaken between 2018 and 2019. A focus group methodology facilitated collective dialogue and informed on the young people’s personal experiences (Bagnoli and Clark 2010). Individual, semi-structured interviews (face-to-face or phone) were conducted in two cases where the participants were unable to take part in focus groups. The fieldwork took place in London and two metropolitan counties in England. Ethical approval was obtained from the University Research Ethics Committee.
The participants were recruited via local carers organisations and a national voluntary organisation which supports young people growing up with a family member with a life-limiting illness. The voluntary sector staff provided study information at group meetings or contacted individuals directly. The recruitment was not limited to ‘young carers’ per se, because many young people in this situation do not perceive themselves as such (Wayman, Raws, and Leadbitter 2016). The recruitment was broadly aimed at young people who had a close family member with a serious illness or disability. Purposive sampling was used to recruit a varied group, for example, in relation to gender, ethnicity and relationship to the family member, but also to ensure a range of health conditions was represented. The young people were eligible to take part if they were aged from 16 to 23 years. Written consent was obtained in advance. Two focus groups and one interview took place in a carers centre or a community centre. One academic facilitated the focus group discussions and the other recorded notes. The focus groups and interviews were digitally recorded and transcribed verbatim.

Thematic data analysis was undertaken. Initially, an inductive, interpretative approach was used to identify what the participants understood by caring, if they viewed themselves as carers, whether there were challenges or rewards associated with a caring role and any perceived impact on their wellbeing. The transcripts were read and re-read line-by-line until initial codes were generated. The codes derived from all the transcripts were then compared and aggregated into themes. Further refining produced a set of key themes and sub-themes, whereupon a thematic map was developed (Braun and Clarke 2006). Forwarding the summary analysis to the participants gave them an opportunity to comment on the academic interpretations, enhancing credibility (Barbour 2001). As the focus groups and interviews did not adopt an explicitly moral framework, for the purpose of this paper, further data analysis explored whether the participants perceived and represented themselves and their caring role in moral terms and if their personal qualities, actions and choices – elicited in response to key challenges faced – were indicative of moral resilience.

The sample consisted of fifteen young people, including two siblings. There were ten females and five males, aged 16–23 years. The majority were White British; one was British-Pakistani (Muslim), two were Irish or British–Irish and one was East Asian (ethnicity was self-defined). Most of the participants were still in school or at college or university. Some of them had part-time or full-time jobs, often in conjunction with studying. The ill or disabled family members consisted of one or both parents, a sibling or another combination (for example, a mother and sister). One participant was bereaved – his father had died a couple of months before the interview. He was included in the study as he particularly wanted to be involved. Although efforts were made to recruit young people who did not necessarily view themselves as carers (via youth and ethnic minority organisations), this had limited success.

Findings

Key themes identified were ‘becoming a young carer – a moral identity’; ‘acting morally – what young carers do’, ‘acting relationally’ and ‘the moral value of being a young carer’. More broadly, these themes pointed to an over-arching theme – moral identity and agency. To avoid imposing a carer label a priori, the participants are frequently referred
to as young people. Otherwise, they are primarily described as young carers. The pseudonyms were chosen by the participants (FG indicates a focus group or I an interview).

**Becoming a young carer – a moral identity**

The participants’ accounts of their journey to becoming young carers suggested that this role provided them with a sense of moral worth and a moral identity. A young person’s significant involvement in caring was at times prompted by the ill-health of a parent and/or the main carer. Suzanne took on a lot of the responsibility for caring for her disabled brother when her mother became ill: ‘I became more involved in a caring role at 16 when my mum had a stroke’ (I). In contrast, two brothers said they cared for their mother together. In other instances, it was a sibling who needed support or, alternatively, there was more than one family member who received care. When there were other family carers and/or homecare services in place the young person was part of a broader network of care, which influenced the extent of their caring role.

Occasionally a young participant emerged as the sole carer even when there was a well parent or mature siblings. Findlay cared alone for her father who had a memory condition, even though she had other siblings: ‘it’s just me’ (FG2). Factors such as distance (if they lived away from home) and/or job or university commitments influenced whether siblings could contribute to care. However, the young person’s key caring role could also have been prompted by a lack of support from a significant adult. Although Suzanne provided support to her brother (who had a neurological condition), she was quite clear that her father ‘doesn’t care’ for him. She pointed to his lack of practical involvement (albeit he provided financial support), but also inferred that there was an absence of moral care or even love: ‘he’s never really cared for his children’. As she also revealed that her father had been psychologically abusive towards her mother, it appeared that this disregard was not limited to her brother (I). Hence, care was not always shared equitably within families and the caring role was occasionally avoided by those with ostensibly the greatest moral responsibility for same, markedly a father’s responsibility to a disabled son.

It was noteworthy that nearly all the young people viewed themselves as carers. Bailly stated quite proudly: ‘yeah, I’m a young adult carer’ (FG1). Her declaration was illustrative of how these young people usually owned the term ‘carer’ and a carer identity. Space had been relieved to discover there was a label for what he did and for who he had become: ‘I do now have a name or title that I can put to it … (before) it was quite tough for me’. This title made it easier for him to overcome other’s lack of understanding about his caring role: ‘now that there is a name that I can put on to it they tend to better understand’ (FG1). In contrast, Chris did not refer to himself as a carer, partly because his father had been admitted to a care home due to dementia when he started secondary school (and subsequently died there): ‘that sort of title almost comes from young people who have been caring for their parents all the way through … I feel like I have, but obviously because he went into a care home when I was still quite young’ (I, 17-year old). Nonetheless, he acknowledged that he had previously been involved in caring for his father: ‘I helped to look after him on weekends and stuff like that’. Both he and his sister rejected the carer label, partly perhaps because of the stigma associated with caring and dementia: ‘We didn’t want that to be the thing that we were viewed as, like we were “the two kids whose dad was not very well”’. Indeed, the participants had often felt growing up that their
situation was odd and that being a carer was perceived to be abnormal. As Chloe said, ‘you’re not normal’ (FG1). Conversely, their carer identity was validated when they joined a young carers group.

The young participants’ caring involvement may have arisen due to necessity or a sense of duty. Accordingly, they had a realistic view of what this role required practically and emotionally. A comment by Space – one of two brothers who supported their mother – suggested that he viewed caring as a type of labour in itself: ‘We’ve sort of worked as a team’ (FG1). Nonetheless, love was also a motivation for caring for a family member. As Ash explained: ‘caring for someone that you love – you want to be able to give them as much support and as much care as you can’ (FG1). Similarly, Findlay mentioned her love for her father: ‘like I love him’ (FG 2). Their comments suggested that it was taken for granted that loving meant not just caring about someone but also caring for them (Graham 1983). Thus, caring had a moral basis and the carer role was therefore perceived to carry moral worth.

As regards what distinguished the young carers from their peers, particularly as they got older, it was felt that the latter could make plans without having to consider a family member’s welfare. In contrast, their life choices were constrained by the carer role. Harvey (whose father previously had a vascular injury) said other young people can readily socialise or take a holiday, but these freedoms are restricted for young carers. ‘The difference is to be a son and a daughter and you go out and you go on holiday, you can forget about them’ (FG2). Similarly, as Suzanne was needed at home to help care for her brother, this prevented her from living away while at university or even taking part in campus events. She said: ‘straight after uni I’ll have to go home’ (I). A few participants mentioned that disabled people (or those with mental ill-health) are frequently perceived as abnormal or even inhuman and they experienced this stigma by association. Chloe’s teenage sister often became aggressive in public, but Chloe learned to ‘ignore the people around you who are staring at her and you’ (FG1). Whilst it was apparent that the young carers perceived their role to have moral worth, they incurred a penalty in the stigma experienced. This was made more difficult if they were also coping with a marginalised sexual identity (see also Carers Trust Scotland 2016). Yet, their willingness to find meaning in the caring identity, adjust their lives to meet the needs of loved ones and have the courage to withstand societal disregard reflected ethical values indicative of moral resilience. The young carers demonstrated practical competencies (discussed in the next section), but it also appeared that they were morally competent (Rushton 2016).

**Acting morally – what young carers do**

In describing their duties and responsibilities, the young carers conveyed their attentiveness and compassion, indicating that they sought to act morally. Their responsibilities varied in kind, including household tasks, facilitating communication and chaperoning. They also assisted with mobility, personal care and medication; provided social and emotional support; supervised and liaised with healthcare staff. The complexity of care depended on the condition of the family member and if they had high dependency needs. Where a parent required support, particularly if s/he had been a breadwinner, some young people were also involved in managing family finances or even contributing
financially via employment. If the young carer was not the primary carer, sometimes they also provided support to the latter.

With regards to domestic care, the participants had not necessarily distinguished when they were younger between the chores undertaken by their peers and the caring responsibilities they assumed. Ash said: ‘you don’t think you’re a carer … you’re just doing your chores’ (FG1 – male). Findlay currently did all the housework for her father who had a memory condition, including cooking, laundry and ironing.

The young carers’ communication role often involved maintaining and facilitating communication, particularly if the family member had limited verbal ability. As Chris’s father had impaired speech, he had sustained their conversations by doing most of the talking, particularly about school and hobbies: ‘I’d talk about the plays that I was being in, or the work I had at school, sort of more normal stuff to make the situation feel as normal as possible really’ (I). Suzanne actively interpreted her brother’s idiosyncratic sounds to discern their meaning: ‘now it’s just … “ah-ah” … because we’re family we understand what he’s saying’.

Caring frequently involved supervising the ill family member. As Findlay’s father had a memory condition, she guided him to ensure his dietary and personal care needs were addressed: ‘like even brush his teeth, even eat, drink … he’ll forget, and then it’s like “oh I’m kind of hungry I’ll have cereal” (but she advised him): “No dad, let’s have a proper meal”’ (FG2). Suzanne (aged 21) supervised her older brother when he ate or used the toilet: ‘we need to feed him, we need to watch him drink or he chokes … and stuff’ (I). In addition to family care, he received homecare services during the week. As he was highly dependent, albeit in his 30s, she felt that caring for him was ‘like taking care of your own child’. At times, young carers protected the person from causing harm to themselves or others. As Findlay’s father had visuo-perceptual difficulties, he misconstrued television action as reality and reacted by using kitchen utensils as weapons, whereupon Findlay took evasive action: ‘I’ve had to lock knives away … he’d find the knives in the house and he’d start like trying to stab the TV with it’. In attending to the basic and critical needs of a family member, young carers maintained their dignity and wellbeing, demonstrating moral commitment.

A few young people managed the family finances, either independently or with an older adult. Harvey oversaw the family’s monthly budget and paid the bills for his younger brothers’ extra tuition: ‘I do all our monthly finances, because I’ve done bookkeeping for a year’ (FG2).

Uncertainty about health trajectories meant that young carers were often concerned about what the future held for their loved ones. Space said: ‘a lot of the time I tend to worry about my mother who I care for’ (FG1). They experienced anxiety when they were apart, as they dwelt on their family members’ health status. Findlay fretted about her father whenever she left him alone for a night: ‘I’ll then worry about dad, so I’ll just ring my neighbour up and be like “can you please go check on him”’ (FG2). Thus, caring for someone also involved worrying about them, further indicative of moral responsibility. Indeed, attentiveness and responsiveness are core principles of an ethic of care (Barnes and Branelly 2008).

Where a parent or other person was the main carer, the young people regularly provided practical and emotional support to them and any younger siblings. Suzanne’s mother relied on her to translate to healthcare staff, as she spoke little English. As her
mother also shared her worries with her, including the impact of cutbacks to healthcare services and welfare benefits, Suzanne found this stressful: ‘She does tell me (if she’s worried) but then I get stressed’. The young carers therefore took on some emotional and moral responsibility for other family members, not just the care recipient, which at times had a negative impact on their own wellbeing.

As the above data illustrates, the young people were sensitive to their loved ones’ needs, responding practically and emotionally and collaborating with other family carers and staff or taking the lead as required. They developed problem-solving skills in order to deal with any challenges they faced. As well as demonstrating practical competencies, they showed attentiveness and commitment, such as when they continued to take responsibility even when away from home. It appears that they did not shirk from ensuring their loved ones’ needs were met. Of course, they expressed frustration when they did not fully understand their loved ones’ conditions. Whilst it might be argued that the young people undertook the caring role out of a sense of duty, it appeared that they were ethically motivated by compassion and love.

**Acting relationally**

The young people endeavoured to act relationally and ethically within the context of family ill-health or disability, demonstrating their recognition of the moral nature of relationships. Being a young carer had a clear impact on their family life and friendships. They often felt they had missed out on a ‘normal’ childhood, related to the caring role and the loss of family life and parental attention. When a family member was hospitalised, this disrupted personal and family routines, including education and holidays. Alternatively, family outings were curtailed when they needed to be at home. The effect on domestic life was lessened when a parent strove to maintain key rituals such as shared mealtimes. As Suzanne illustrated: ‘because my mum put so much of an effort to like having dinners together and things like that, it didn’t really feel so much (as if they missed out on family life)” (I). However, illness naturally had an impact on parenting ability. Chris’s father stopped going to school meetings when his condition became more advanced: ‘I don’t think he went to many parent-teacher meetings after that because I don’t know how much of it he would have been able to take in as such’ (I). In such instances, the young person felt an onus to maintain the parent–child relationship. As Chris kept his father informed about his schooling, this maintained some normality in their relationship. Young people additionally missed out on the attention of another parent or guardian as the needs of the person being cared for had to take priority. Chloe felt she had ‘lost’ her nana during her childhood: ‘growing up it’s been hard, because you kind of lose the person who also cares for them’ (FG1). Indeed, this sometimes led to a young carer feeling quite invisible within the family. June’s older sister was often hospitalised with multiple health conditions: ‘I always felt like I was put last. Like I was invisible, because she needed all the help with everything’ (FG2). This suggests that the moral load of a young adult carer involves accepting when another family member needs more care and making do with less attention themselves.

Growing up with family illness had made it harder for some young participants to make friends. Katie explained: ‘So in a class you might not make friends as easy, because mentally you have to deal with so much that you are mentally that much older than the person
sat next to you’ (FG1). Friendships were impinged upon when parents indicated that they were needed at home, heightening feelings of difference and isolation. Mona who helped care for her sister said: ‘because you see everyone going out … you kind of feel separated from everybody else your age’ (FG2). Nonetheless, the young people believed they had a duty to be there for the family member: ‘because your responsibility is on (to) the person you’re caring for’ (Ash – FG1). Whilst this was a practical requirement it could also be seen as a moral responsibility. Finding time to meet friends was even more of a challenge when the latter did not understand their care obligations: ‘because it’s just not something people understand’ (Mona – FG2). Thus, the moral regard which young carers gave to their family members was not always extended to them by others.

Sustaining friendships continued to be challenging for young people currently, which contributed to a sense of loneliness. Jade (who cared for her brother) said: ‘you don’t get out and then you don’t get the support you need (so she felt), upset, lonely’ (FG2). Organising a short break was problematic, especially when the young person was the main carer and the family member struggled in their absence. Findlay’s father often rang her if she was away overnight, which enhanced her sense of responsibility for him (he received homecare during the week): ‘I stay over at my boyfriend’s house once a week just to get some bloody respite … And he called me twice … “I need to go home, I need to put him fi…”’ (FG2). Similarly, Suzanne felt ‘guilty that I’m doing something for myself’ (I). Hence, being a young carer involved a moral bind between prioritising the ill family member and addressing one’s own needs. However, moral resilience also necessitates being realistic about one’s own limitations (Rushton 2016). With regard to couple relationships, most of the participants felt that future partners would have to understand the caring commitment involved. In contrast, two young people who were currently in relationships did not experience this difficulty because their partners were also carers. As Ash explained: ‘my girlfriend, she is a carer herself … and she knows what it’s like’ (FG1).

The young people’s accounts indicated that they sought to act relationally and ethically in responding to their family members’ needs. As they naturally felt some resentment when their family or personal lives were disrupted, they viewed their caring situations honestly and realistically. Whilst it could be argued that their choice over taking on the carer role was limited, since there were other family members who were not involved in or even avoided caring, it appeared that these young people had made a moral choice to accept the caring role (see Pickard 2010). Yet, a loved one’s ill-health could lead to young people feeling overlooked within the family and their own social and emotional needs being given less priority. However, they did not neglect their duties, albeit this may have been difficult for them in such family contexts.

**The moral value of being a young carer**

In assuming the moral identity of a young carer and acting ethically and relationally within a caring context, the participants perceived their role to have moral value. Accordingly, they highlighted the affirmative aspects of their carer role and identity. It enhanced their ability to relate to others and to develop qualities such as patience, empathy and compassion. Suzanne said that caring for her brother had made her ‘more empathetic’ towards disabled people. Becoming young carers facilitated their maturity, as illustrated by Harvey: ‘you’ve had to grow up faster than everybody else. So you’re more mature than everybody else’
Being a carer enabled them to develop emotional intelligence: ‘like you’re able to understand people’s emotions a lot more’ (Chris, I). Where they had grown up with family ill-health and financial hardship, they could nonetheless be sanguine about their lives. Grace commented: ‘you learn to appreciate things that somebody who’s in a family where there’s no caring role and the mum and dad both work… doesn’t … not having to go to the hospital at eight o’clock in the morning or being able to get somewhere easily because they can afford to get a bus’ (FG1). They were determined to make the best of their own lives, as illustrated by Chris: ‘it’s kind of made me want to do a lot of things with my life’. Katie was quite emphatic that she would not choose a different path: ‘I wouldn’t want my life any other way’ (FG1). However, Findlay felt the rewarding aspects of being a young carer were eclipsed by the challenges, although she attributed this to her father’s progressive condition: ‘it’s heavily outweighed … because my caring role is only going to get worse, like it’s going to get more involved and eventually my dad probably won’t remember who I am, won’t eat on his own’ (FG2). Nonetheless, being a young carer appeared to enhance one’s emotional and moral development.

Discussion

The young people, in the main, found a sense of belonging in the carer identity. Their self-concept was especially validated when they joined a young carers group. They had often felt a lack of normality when growing up with an ill or disabled family member. In addition, they had experienced stigma when caring for others, particularly if the condition was associated with negative stereotypes (such as dementia or mental ill-health) or if the person’s behaviour attracted unwanted attention. Ironically, they could feel invisible within their own families when having unwell kin meant they received less attention. Therefore, being a young carer provided them with a positive social concept. Rose and Cohen (2010) had also identified that young carers integrate caring into their emerging identities, but similarly highlighted tensions between adopting a caring identity and more universal belonging. As the young people in this study showed courage in withstanding stigma and a determination to find meaning in their marginalised identity, this was indicative of moral resilience (Rushton 2016).

The participants also saw moral value in their caring role. By giving their time and effort and being adaptive and tenacious, they demonstrated responsibility, commitment and competency (Liaschenko and Peter 2016; Monteverde 2016). Bolas, Van Wersch, and Flynn (2007) had stated that young carers may feel they have no choice over taking on this role. In addition, carers with greater access to economic and social capital may be able to construct ‘a good life’ to reflect a chosen identity, whereas those with fewer resources may have less choice available (Pickard 2010). It was unclear whether the young people had a say over this role, given that it tends to be acquired rather than negotiated. Nonetheless, it appeared that they came to accept the caring role. Whilst young carers can sometimes be portrayed as exploited (Aldridge 2008), van Nistelrooij (2015) suggested that care does necessitate a degree of self-sacrifice. However, such commitment becomes problematic when limitations in statutory support, particularly linked to austerity, lead to the responsibility for social care being disproportionately placed on carers (Clifford 2014; Tarrant 2018). Yet, whilst caring may be constraining, it can also be
enriching (see also Hamington 2018). Notably, being young carers enhanced their emotional and moral development.

The young people sought to make moral judgements about what was ‘right and good’ for their family members (Jurchak and Pennington 2009, 78). Similar to caring professionals, their moral actions reflected a desire to provide compassionate care (Jurchak and Pennington 2009; Defilippis, Curtis, and Gallagher 2019). Their caring tasks included chaperoning their family members, monitoring personal care and intervening to protect them from harm. They demonstrated a willingness to act on behalf of their loved ones, for example, when they shielded them from negative public gaze; monitored their well-being from a distance or relayed concerns to healthcare professionals. Of course, being a young carer in itself can be viewed as a moral challenge. However, it was through these subtle actions that they addressed everyday ethical concerns, such as maintaining comfort, respect and dignity (Austin 2007). Thus, a moral approach to care is not about ‘adjudicating ethical dilemmas’ but involves acting ethically on behalf of others (Hamington 2018, 310). Engaging in a situated and relational approach to care may have helped to facilitate the young people’s moral resilience (Rushton 2016; Defilippis, Curtis, and Gallagher 2019). A previous study of young adult carers in England concluded that the caring role had stimulated their political consciousness (Heyman 2018). However, it is suggested that this role also strengthens their moral consciousness.

The participants felt some conflict between their desire for ordinary family life, friendships and couple relationships and their caring role. In their transition to adulthood, there were tensions emerging between maintaining their caring involvement and pursuing their own life projects. Their carer responsibilities somewhat constrained their personal aspirations, leading to a conflict between a commitment to care and their quest for self-fulfilment. Similarly, previous research showed that young carers experience challenges in the shift to adulthood, when their caring role is at odds with a need to leave home to study or seek employment (McDougall, O’Connor, and Howell 2018; Becker and Sempik 2019). Nonetheless, whereas Giddens (1991) had highlighted a shift to individualisation in society, the young people appeared to prioritise relationality, albeit via pragmatic means of compromise (for example, commencing university but continuing to live at home). Although their struggles mirrored societal tensions between self-actualisation and relational care ethics as underpinning values (Giddens 1991; Kittay 1999), they showed a predominant moral commitment to the latter.

The young carers’ accounts indicated that they were essentially concerned with doing good, as opposed to being noble. In contrast, previous research into the meaning that older carers (in their 60s and 70s) attached to their role found they presented themselves not just as carers but as ‘good carers’, asserting their moral status (Pickard 2010). It is likely that the current participants viewed care as inherently good. However, even when care is provided with the best of intentions, it can result in the person’s decision-making rights being disregarded or the attention given manifesting as control rather than care (see Boyle 2013; Morris 1993). Moreover, the Francis Report of the Mid-Staffordshire NHS Foundation Trust Public Inquiry (UK, 2013) showed that, at its extreme, institutional and professional care can fall below acceptable standards, resulting in neglect and suffering. Hence, care is not necessarily ‘good’ and serious failings can result from a lack of compassion and moral complacency (Francis 2013; Rushton 2016). Whereas empathy is the ability to relate to another’s pain, compassion additionally incorporates a desire for action aimed at relieving
suffering (Merriam-Webster 2019). As a result, the Francis Report recommended that admission procedures should ensure that aspiring nurses demonstrate a capacity for compassion prior to recruitment (2013, volume 3). Thus, compassion as a virtue has been identified as a pre-condition for good care, as illustrated by the young people in this study.

It is not clear whether young people with a caring and compassionate nature were more likely to emerge as carers in their families. A previous study of young adult carers in the UK found these were predominantly women, probably because they are seen as the ‘natural’ carers (Becker and Sempik 2019, 383; see also Aldridge, 2018). Likewise, most of the current sample were young women, mirroring a societal tendency to view caring as women’s work (England 2005; IDS 2016). Although there were a few male carers, they did not usually have female siblings, and this role is generally allocated to girls, unless there are no daughters available (Becker and Becker 2008). As it has traditionally been assumed that caring qualities are innately female, young men may perceive caring involvement as a threat to their masculine identity (Graham 1983; Rose and Cohen 2010). The male participants in this study did not explicitly convey concerns about the impact of caring on their masculinity, although it was notable that the only participant who rejected a carer identity was male. Young females and males explained how they dealt with the challenges of being a carer, including balancing duty and love with a desire for autonomy. They acknowledged the realities of their caring lives, but sought to use these to achieve personal growth (see Pickard 2010). However, it is probable that daughters were more likely to be designated as carers within these families.

Being absolved from this role may enable young men to sustain their masculine identity. Although Hunter, Riggs, and Augoustinos (2017) had suggested that there has been a partial shift in society from hegemonic to ‘caring masculinity’, their study focused on routine childcare rather than the care of ill or disabled persons. Indeed, research into the experiences of male spouse-carers concluded that the concept of caring remains ‘intimately bound up with female identity’ (Gollins, no date, 7). Thus, when men are involved in caring, the role does not contribute to their sense of maleness. Although academic debate has highlighted gender inequalities in caregiving, little attention has been given to gendered care inequities among siblings. Nonetheless, a study in Finland which investigated how parental care responsibilities were shared among adult siblings found that daughters were usually the main carers, whereas sons were only a backup or were absent from the care scenario (Leinonen 2011). Within the UK, more informal care is provided by women [58 per cent are carers versus 42 per cent of men – England and Wales], although men contribute to end-of-life care and older men have a key role in caring for their frail spouses (Corden and Hirst 2011; ONS 2013; Hoff 2015; Milligan and Morbey 2016). Whether such men have had prior caring experiences is rarely examined in the literature.

Study limitations

As this was a small-scale study, research studies with larger samples are needed to further our understanding of young people’s gendered experiences of caring. Since the participants were predominantly recruited via carers organisations, it is likely that they more readily identified as carers. Future research should, therefore, aim to recruit young people from networks other than carers organisations and also recruit more young
carers from ethnic groups. The use of a focus group methodology limited the extent to which individual perspectives could be explored. Creative research methods might enable young men to express themselves more readily if they are reluctant to talk about their experiences.

Conclusions

A focus on moral resilience broadens debate about the lives of young adult carers beyond physical and psychological resilience. It is a valuable concept for nurturing the emotional and moral development of women and men, including via a caring role. The construct is helpful in promoting the development of reflective individuals, capable of responsibility and sound judgement (Clifford 2014). However, an interest in the moral actor should not lead to the neglect of societal obligations, notably the importance of addressing social and gender inequalities (Clifford 2014). Society places a greater expectation on women to demonstrate a virtuous character by being morally responsible, including via compassionate care. As a result, women are socialised into being ‘ideal carers’ (Clifford 2014, 11). Yet, designating girls as carers in early life compounds gender inequity in caring, but also shifts the moral responsibility to females. Thus, a political-ethical approach is required which acknowledges the ‘messy everyday realities of care’ (Klaver, van Elst, and Baart 2014; Barnes et al. 2015, 243). Gilligan (1982) had suggested that there are gendered differences in morality, whereby women adopt a relational ethics of care whereas men focus on individual rights. She concluded that a combination of care and justice orientations is needed for moral development. Since care is a matter of justice, not just compassion (Mullin 2011), a societal response is required which encourages a more balanced gender distribution in young people’s caring (see also van de Sand, Laxman, and Nolan 2018). Carers organisations should consider the particular support needs of young women and men, but also the expectations that are being placed on the former by their families. In addition, health and social care professionals should have regard for when other family and statutory input may be required to protect young people from inappropriate caring and to facilitate their broader lifeplans (DHSC, 2010, 2018). As current studies focus predominantly on psychological resilience, there is scope for further research into moral resilience within caring contexts, particularly how such resilience might be discerned and nurtured in young people.

Acknowledgements

Thanks to all the young people who took part in the study and the voluntary organisations that helped with recruitment.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This project was supported internally by the Open University.
Notes on contributor

Geraldine Boyle is a Senior Lecturer in the School of Health, Wellbeing and Social Care, at the Open University, UK. With a background in healthcare and social policy, her research interests focus on the personal lives of women and men living with challenging conditions and those who support them; social inequalities in health and care and gendered and ethical dimensions of care. She is a member of an NHS Research Ethics Committee and an academic advisor for BBC and Open University co-productions on dementia, notably Our Dementia Choir. Her previous research included studies on decision-making by people with dementia and decisions made by healthcare professionals on behalf of people lacking capacity, funded by the ESRC and the Dept. of Health.

ORCID

Geraldine Boyle  http://orcid.org/0000-0002-8185-1354

References


