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'The sooner you can change their life course the better': The time-framing of risks in relationship to being a young carer

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Short title: The time-framing of risks in relationship to being a young carer

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#### **Abstract**

In this article, we compare accounts given by young carers and specialist support workers about the riskiness of becoming a carer relatively early in life. We argue that since the mid-1990s the policy response has problematised the comparatively early adoption of a caring role as a risk factor for future personal development. This temporal issue has become societally organised around concern about NEETs (young adults not in education, employment or training). Such concern is predicated on cultural assumptions, now being undermined in response to economic crisis, about the existence of a critical age for transition to adulthood, successful navigation of which requires a time-limited period of personal freedom. Our findings suggest that, whereas support workers mostly see young caring in terms of risks to future prospects, young carers themselves identify not only current stresses, but also personal gains, from their experiences. Instead of categorising the timing of their caring as a source of risk, young carer respondents questioned service

shortcomings which they felt made it harder for them to cope in the present, particularly inadequate social service support for relatives with disabilities and insensitivities in the education system. They did not see service providers as helping them to manage their futures. We locate this tension in risk social science debates about individualisation (Beck and Beck-Gernsheim, 2002; Beck, 1992; Giddens, 1991); transition to adulthood in late modern society (Roberts, 2012; Roberts, 2007; Wyn and Woodman, 2007); and risk management for those deemed vulnerable (Alaszewski, 2013; Spencer, 2013; Thing and Ottesen, 2013.

King Harry: We are glad the Dauphin is so pleasant with us.

... And we understand him well,

How he comes o'er us with our wilder days,

Not measuring what use we made of them. (Shakespeare, Henry V, Act 1, Scene 2)

Professionals need to understand that a person in their 20s, or a 5 year old, or a person who is disabled themselves, can still be a carer. The sooner you can change their life course the better. The younger the person, the more solid the dreams and ambitions. (Interview with Tina, young carers service manager).

#### Introduction

As illustrated by these quotations, the first from Shakespeare's Henry V, and the second from a service manager interviewed for the research discussed in the present article, the 'proper' use of youth as preparation for adulthood has long been contested. In the latemodern era, such debates tend to be couched in terms of risk, here to the longer-term future of young adults who do not undergo certain assumedly essential life experiences at supposedly critical times in the developmental process. The article explores the perspectives of young adults and young carers workers<sup>i</sup> about the impact on young people of looking after a family member who has disabilities.

We draw on data from a research project undertaken by the first author, Anna Heyman, to contrast the problematisation of the young adult carer role as a source of developmental risk by most support workers with the more nuanced and variable accounts offered by young adults themselves. The article should contribute to a small existing research

literature concerned with young carers' life experiences (Rose and Cohen, 2010). With respect to the theme of this special issue, we will critically analyse the culturally derived belief that taking on caring responsibilities 'too early' in life creates risks for personal development. Challenging the developmental psychology of fixed stages can provide a stimulus for reappraising social policies towards young carers. Our analysis can also shed light on the societal organisation of risk management.

We will start by briefly sketching the ambivalence present in current wider societal attitudes towards young adulthood. We will then outline the UK social policy context governing services for young carers. We draw on this material to highlight issues relating to culturally-situated thinking about the short and long-term consequences of adopting a caring role earlier in life than peers, the starting-point for data analysis.

# Young adult hood, risks and caring

Cultural Templates of Young Adulthood

A media-fuelled cult of youth has directed intense, often sexualised, selective attention onto young adulthood, viewed both as a peak life state, and as a critical foundation stage for future prospects (Willis, 1977; Henderson *et al.*, 2007), and therefore a source of risk. As with most culturally constructed time-frames, the boundaries of young adulthood have not been clearly specified. They have expanded during the period of post-1945 Western economic growth to encompass an age-range from late childhood to the early thirties. The notion of 'sowing one's wild oats', a sexually discriminatory metaphor for experiencing a temporary period of wild enjoyment as a precursor to settling down to adult responsibilities, well evokes this conception<sup>ii</sup>, now somewhat dated.

The experiential template of young adulthood has always been counterbalanced by the imperative placed on young people to build the educational, occupational, relational and personal foundations required for a productive middle age. These two aims do not inherently contradict each other since a timely and temporary loosening of goal-directed discipline may open up experiences and possibilities which contribute to the maturing process<sup>iii</sup>. But it is easy to see how this process can malfunction. It asks young people to fulfil themselves, learning from a time-limited burst of temporary anarchy, as Shakespeare's Henry V claimed to have done, whilst at the same time working hard to prepare for their future. At best, from this perspective, the transition to full adult status is fraught with risks. At worst, it may never happen, leaving the older adult trapped in a deviant, age-inappropriate life.

Although not abandoned, this template has been significantly challenged by the economic crisis which has afflicted most developed countries in the early twenty-first century (Mizen, 2003). As the decline in demand for unskilled workers accelerated from the 1980s, formal qualifications became an increasingly necessary prerequisite for entering the labour market. In response, from the 1990s onwards, policy-makers started to give greater emphasis to reducing school absenteeism (Fox 1995). Young people who fail to make timely work or career moves are now classified as NEETs (aged 16-24 and not in education, employment or training), and seen as at risk of being permanently excluded from employment. Research suggests that young people have adapted to these changes by placing greater value on 'getting on' through obtaining formal qualifications (Henderson et al., 2007). A darker image of youth may now be developing, in which this age is coming to be classified as a period dominated by risks, with the young person both a source and an object of unwanted contingencies (Macdonald 1997). Since 2010, in the UK, the

Conservative-led Government has attempted with some success to overlay the Blairite model of family alienation transmitted over generations with a moralistic rhetoric of the unemployed, many of whom are young adults, as 'shirkers'.

# UK Social Policy Towards Young Carers

The analysis we present in this article must be understood in a UK social policy context, but should have some relevance to conditions in other developed countries<sup>iv</sup>. In the UK, moves towards viewing young carers as an at-risk group derived from a well-intentioned wider shift of policy-making attention towards family caring in the New Labour decade prior to the financial crash of 2007. Family carers became marked out for their underappreciated but invaluable contribution to sustaining the life quality of people with disabilities. Improving help for family carers came to be viewed both as a form of social justice, and as a cost-effective way of delivering societal support for the large population of people with disabilities. Young carers aged under 18 became doubly entitled to statutory assessment, as children and as carers, through the Children's Act (1989) and Carers Acts (1995), respectively.

The UK National Strategy for Carers (DoH 1999) identified a major role for the voluntary sector in supporting young carers. The sector is expected to provide support in partnership with statutory agencies to young carers in order to reduce risks perceived to arise from their taking on care responsibilities so early in life (DoH 1999). An important organisational vehicle for delivering such support has been Carers Centres (Roulstone *et al.* 2006). These centres often offer teams of specialist young carers workers dedicated to providing opportunities for young carers to take part in extra-curricular activities, access services such as counselling and careers advice, and share experiences with others. Local

authorities were initially required to protect money for these projects, although, in some areas, the money was allocated to children's charities rather than Carers Centres. The present Conservative-led Government has continued to ring-fence this funding. But the total allocation has been reduced substantially as part of its wider austerity programme. A recent survey (Action for Children, 2011) found that almost a third of young carers service providers expected to close entirely, or considered themselves at serious risk of having to do so, and that almost all anticipated being forced to offer significantly reduced provision. The data discussed below were collected in the period 2008-2010 before austerity measures had been implemented.

The Definition of 'Young Carer'

Reviewing definitional issues is a necessary precursor to analysis of depictions of risks. One of the first references to 'young carers' came in a ground-breaking report (Aldridge and Becker, 1993) from a group which established the visibility of young carers as a risk category (Thomas *et al.* 2003). However, it should not be assumed that the presence of a culturally recognised category necessarily indicates the existence of a single entity (Power, 2007, p.3). Application of the label 'young carer' is underpinned by complex, often unarticulated, assumptions involving both the age-range considered 'young', and the criteria for being counted as a carer.

The temporal boundaries specified for young caring have varied considerably (Rose and Cohen, 2010). Cree (2003) included those aged 5-25 years, whereas the UK Department of Health (DoH, 1999) considered only those aged under 18 as young carers. Young adult carers may be differentiated from young carers in general, a broader category which includes children and adolescents. The only major UK report on young adult carers

(Becker and Becker 2008) specified an age range of 16-25 which overlaps with that for children and adolescents. Regardless of the ages covered, the notion that carers are 'young' implicitly problematises them as being at risk. As with any temporal or other form of risk categorisation, this cutting-up of biographical ages homogenises substantial differences, at the extreme between 5-year old and 25-year old carers, and also imposes an arbitrary differentiation from 'the rest' (Heyman *et al.*, 2010, pp. 39-43) who fall outside whatever risk boundaries are delineated.

The differentiation of carers from non-carers raises more difficult definitional issues. This categorisation intersects with that of age boundaries because the specification of 'carer' has a bearing on analysis of the age range which might be considered 'too young' for the adoption of a caring role. The definition must not be so broad that it includes every young person who lives in a household which contains members with disabilities, around three million children in the UK (Bibby and Becker, 2000). Its scope can be narrowed by only counting as young carers those who carry significant caring responsibilities over-andabove those normal for their age group (Walker, 1996). This delineation, in turn, raises the question of what is to count as 'significant', and how the boundary with 'non-significant' is to be set, an issue which may partly explain the wide range of published prevalence estimates (Banks et al., 2002). The UK population of young carers was estimated as 20-50,000 by the Department of Health (DoH, 1999), 165,000 in the 2011 census (The Children's Society, 2013) and 750,000 in a survey of secondary schoolchildren (BBC, 2010). Such a huge variation results partly from the methodology employed, with children more likely than their parents, who would complete census forms, to classify themselves as carers. Moreover, it artificially differentiates young carers from other young people who carry substantial home responsibilities for reasons other than disability in the family by, for example, looking after younger siblings (Fox, 1995). The contrast between systematic

problematisation of young carers supporting a relative who has disabilities as a risk factor and its relative absence in relation to caring for non-disabled siblings perhaps reflects tacit stereotypes about the former. Implicitly, helping a person with disabilities is viewed as a 'burden' whilst acting in a similar role for younger, non-disabled siblings is not.

In the social work literature, definitions of young carers often highlight impact on the young person. One widely quoted definition only includes those whose lives 'are affected by the illness or disability of someone in his or her family' (Cree, 2003, p. 301, present authors' emphasis) as young carers. A more explicitly negative framing is given to the definition most widely cited by UK local authorities of a young carer as young person 'whose life is in some way restricted' by caring responsibilities (Carers National Association [now Carers UK], 1998, NPN, present authors' emphasis). Moreover, the methodology of studies which explore young carer experiences usually directs attention towards those who are most easily accessible accessible to researchers through receiving formal support (Newman, 2002). This orientation towards risk factors reflects the organisational culture of social work (Early and Glenmaye, 2000) in its wider socio-political environment. Although many analyses of young caring as a risk factor have been put forward, Newman (2002) concluded that studies involving control groups have indicated little aggregate impact, with slightly higher average anxiety levels balanced by gains in maturity (McHale and Harris, 1992).

If being a young carer is specified in terms of adverse effects, it becomes a risk factor through a process of circular reasoning. This issue is not merely scholastic since the established risk categorisation is likely to be applied to all carers in the problematised age group. Such broad-brush policy prescriptions can be contrasted with the personal experiences of those sucked into a risk category.

Young carers may struggle to follow the currently prescribed educational/vocational pathway because of the other demands on their time and energy. Recent research has indicated that about 20 per cent of young carers aged 16-18 had been NEET for at least six months, compared with about 10 per cent for the overall age-group (Audit Commission, 2010). Young people who look after a relative or other person achieve significantly lower General Certificate of Education (GCSE) grades than their peers (The Children's Society, 2013). However, the construction of young caring entirely in terms of risk excludes consideration of alternative routes to employment, and of personal development other than through the formal education system. As documented in the data analysis section, many young carers reject this view.

Professionals, drawing on the prevailing cultural template of youth may consider that the 'untimely' adoption of a caring function places the young person's developmental progress at additional risk. From this interpretive starting-point, a young adult who is also a carer may be seen as facing a high probability of losing their time-limited opportunities for enjoyment, self-development, education and career-building. Such presumed self-sacrifice has been depicted as a role-reversal which disrupts the 'normal' process of maturing into adulthood (Aldridge and Becker, 1993). This view has spawned the psychoanalytic notion of the 'parentification' of young carers, now criticised for its personally rigid and culturally unreflective assumptions about the presumed 'nature' of childhood (Earley and Cushway, 2002). Fox (1995) found that teachers, welfare officers and children's counsellors framed being a young carer predominantly as a cause of truancy. In contrast, young carers may identify positive developmental gains from playing this role (Thomas *et al.*, 2003).

The risk-oriented view of being a young carer underestimates the ability of families to negotiate adaptive versions of child/parent roles (Aldridge and Becker, 2003, pp. 86-88). It implicitly treats supporting a family member as unpaid, burdensome labour. This risk framing is predicated on a folk developmental psychology predicated on normative assumptions which young carers themselves often do not share (O'Dell *et al.*, 2010).

The data which we present below explores young carers' perceptions of their prospects, and compares their accounts with those of practitioners offering support services. Our analysis will contrast service-provider depictions of caring 'too young' as a risk factor for future development with the mostly here-and-now perspectives of young people themselves.

# Methodology

This article draws on Anna Heyman's fieldwork, carried out in North East England between 2008 and 2010. The aim of the study was to explore the perspectives of young carers and specialist young carers workers about the lives and young carers' prospects. Including both groups facilitated qualitative comparisons. Another distinctive feature of the study was the effort made to include young carers who were not in receipt of services. To this effect, five additional respondents were recruited via presentation events to youth work professionals and students who were interested in the research. Following ethical approval from the Faculty of Natural and Social Sciences, University of Sunderland in 2008, Anna Heyman carried out individual interviews with 13 young adult carers (average length, 45 minutes), and 10 staff (average length, 60 minutes) from the emerging profession of young carers workers (Heyman, in press). Young carers were recruited

through local authority projects aimed at this group (N=3), two regional higher education institutions (N=5), and public seminars put on by the first author (N=5). The researcher asked staff working at centres catering for young carers and social work lecturers known to have students with care responsibilities on their programmes to approach regular attendees and students who undertook caring responsibilities, respectively. Five of the 13 young carer research participants were aged 16-19, seven 20-25 and one 29, slightly outside the usual delineation of the young adult age range. Their families represented a range of socioeconomic backgrounds, and of locations in urban and quasi-rural areas such as former mining villages. They had received various mixes of service support, five from specialist young carer workers, and three from a generic youth worker. Five respondents had not received any formal assistance. Young carers were interviewed individually at a location of their choice, close to their place of work/study or home, or at their young carer project. Ten practitioners were also interviewed individually (N=4) or in pairs (N=6) as they preferred. The practitioners included three managers and seven young carers workers drawn from the same four locations as the young carers.

The design of the interview schedule for young carers was based on a realist biographical approach (Henderson *et al.*, 2007; Bertaux, 1981). This approach assumes that categories and causal assumptions drawn upon by respondents are social constructs that nevertheless relate to real events, referencing life histories rather than merely life stories. A lightly structured, open interviewing style organised around a set of topics was adopted. Questioning covered: family structure; the needs of the person(s) with disabilities, and how those needs were met; the adequacy of any service support; wider public attitudes; and expectations about the future with respect to work, living arrangements and relationships. The latter questions provided the most directly relevant material for the analysis offered in this paper, but issues about risks and benefits for future prospects came up throughout the

interviews. Talking about their relationships with professionals prompted young carers to think about advice they had been given about future careers and personal development. Practitioner interviews with three managers and seven young carers workers covered their views about the service context of young carers projects, education, careers advice and social services support in relation to the needs and prospects of young carers.

## **Findings**

We focus our data analysis on perceptions of risks and benefits resulting from taking on caring responsibilities relatively early in life. We present the findings in two main sections which explore the perspectives of service-providers and young carers respectively, allowing us to draw qualitative comparisons. Brief clarifying comments on verbatim quotes, including rewordings of NE English dialect, are given in square brackets

## Service-provider perspectives

In the wider social context of high levels of unemployment for young people, and policy concern about NEETs, discussed above, the predominant service-provider interpretive framing was one of risk, particularly in relation to young carers suffering long-term harm through missing out at a critical time in their development. The second of the opening quotations given at the beginning of this article vividly conveys a sense of urgency about the need to intervene before young carers get locked into sub-optimal trajectories. As Jim, a young carers project manager, put it, youth is a time 'to be free and go off and fly'. This telling metaphor of youths as fledglings whose first flights must occur at the right time in their development can be readily applied to the risk narrative outlined below. Kate, a young carers worker, discussed the value of setting up mutual support groups of young carers.

Put them [young carers] into small groups, and help them to make friends and hopefully develop their confidence at the early stage, so that when they get to 15-18 it's not so ingrained in them that they're frightened to go out, frightened to have new things. It's easier to stay at home and be a carer for the foreseeable future ... Don't wait until they're 16, don't wait until they've been doing it for years and they're knackered. (Kate, young carers worker)

This instructive comment is implicitly predicated on three common assumptions about the time-framing of developmental risks. Firstly, Kate was concerned that the demands of caring at an early age could leave the young person permanently confined to a narrow home environment. This risk concern is predicated on the presupposition that capacity for venturing beyond the narrow home environment atrophies quickly if not developed during the assumedly critical period of young adulthood. Secondly, Kate suggested that looking after a relative can provide a more comfortable alternative to venturing into new environments which young carers may prefer in the short term. By selecting a less challenging option, unavailable to others in their age group, young carers can avoid the stresses associated with personal challenges, but only at the price of not moving on. In terms of the metaphor outlined above, a fledgling who finds it too easy to stay in the nest may never acquire the ability to fly. This temporal dynamic is accounted for in terms of two explanatory factors: missing the 'natural' prime-time for adventurous risk-taking even before the age of 16; and becoming too exhausted to catch-up later through being worn down by the demands of caring. The identification of the second explanatory factor depends on the presumption that caring for a relative with a disability is a personally debilitating burden, a view which does not necessarily correspond to those of carers themselves (Oulton and Heyman, 2009). Finally, Kate believed that service interventions

could at least partly compensate for the negative impact of caring on the young person acquiring social networking skills at the 'right' age.

Although recognising that it was possible to ground a career on young caring, Kate expressed concern about the narrowing of life experience which might result from taking this pathway. The following account concerned a young carer who had decided to go back into education with a view to obtaining a qualification in health and social care.

He decided he would go to college. His mam [mother] at first said he couldn't, he would have to get carer's allowance and whatever, and we sorted it out the funding ...

And he was convinced to do ... [a course in] health and social care. And we tried to talk to him about not having to put all his eggs in one basket, not having to be a carer, and maybe the beauty of leaving the house and doing something completely different, ... trying to instil a sense that this wasn't his lifetime role, that he wasn't there until he was 40, until his mam passed away and then, "Aw, I haven't got any life", which I've seen is what happens. And you didn't want that to happen to people. (Kate, young carers worker)

Again using a metaphor, of eggs and baskets, Kate suggested that she could adopt a longer time-frame than young carers because she had previously observed young carers feeling subsequently confined to an overly narrow life. This longer time-frame, Kate believed, enabled her to identify the risk of regret in later life which the young carer might only discover too late. The quotation articulates the culturally derived notion that discovering a sound direction of life-travel necessitates trying out a range of possible futures during the formative years of early adulthood.

Pam and Anthony, two jointly interviewed young carers workers, discussed a related risk, that a young person who was engaged in looking after a family member might adopt a less committed approach to their longer-term future.

We always say to them, "Where's your future aspiration? You're not going to stay at home forever surely? You're going to want a flat, you're going to want to move out?". [They say] "I can't do that. Who's going to look after them?". [We say] "Well, that's what we're saying. If it's pre-planned, it doesn't mean it's going to happen tomorrow. But if you look ahead, and start looking at that, and planning for that, and then you know it's going to happen". And if they can see that, they're more likely to stay at college and carry on, because they think, "Ah yeah I can - there is a future for me". But if they're going in [to college] half-heartedly, and think, "Ah [if it gets hard], I'll just walk away". (Pam and Anthony, young carers workers)

The quotation suggests, again, that acting as a carer makes young people more likely to become NEETs because their focus on immediate responsibilities not normally carried by young adults in developed societies causes them to lose sight of the longer-term risk of social exclusion. As also argued by Kate above, this analysis opens up a crucial role for young carers workers based on helping those at risk to keep in mind their future prospects. However, the young carers whose views are discussed below mostly rejected this risk assessment. Some, including Tom, Lauren, Pete and Ryan who are quoted below, identified potential learning and career opportunities arising from skills they had built-up in this role. Clem recognised this alternative route into maturity and occupation.

They're more likely to pursue, kind of, a practical-led, vocational-led route, which doesn't then prevent them from going back and doing an academic route. But they

are just going about it in a different way. I think they recognise that they have got a lot of practical skills. And maybe, in the years that they've missed out education, they feel different, or at a different level to, their peers. (Clem, young carers worker)

In contrast to the workers already quoted, Clem, whilst acknowledging that young carers might miss out educationally in the short term, identified alternative temporal routes to formal education as well as informal opportunities to acquire vocationally valuable practical skills. Crucially, he identified a personal maturing process which young carers might feel that they had gone through, a view which young carers themselves shared, as illustrated below. However, according to Jeanne, enabling young carers to progress educationally requires supporting organisations to adapt services to their circumstances.

Organisations have to be creative in order to accommodate for example by providing remote learning materials. These aren't hard to reach, 'stuff your course' [types].

(Jeanne, young carers project manager)

Jeanne switched the locus of risk problematisation from the 'lifestyle' choices made by young carers to the rigidities of the prevailing educational system.

In summary, the young carers workers whom we interviewed mostly constructed being a young carer in terms of risks to their personal and vocational future well-being, although one research participant identified positive occupational spin-offs, and another problematised service inflexibility rather than young carers. We will now consider young carer perspectives.

Young carer perspectives

The views of young carer respondents about their situation and prospects varied considerably. We will discuss their comments about the positive learning opportunities arising from their role, after we have considered their views about downside risks. One young carer, John, quoted below, stood out because he had so narrowed his time-frame that, at least in terms of his surface narrative, the issue of future prospects did not arise for him. For the others, two related risk concerns will be explored: that their circumstances prevented young carers from 'being their age'; and that, in consequence, they became cut-off from peers. Their concerns differed in time-framing from those of care workers who feared for young carers' longer-term vocational and personal prospects. Young carers were more oriented to their immediate lives. They also identified support service shortcomings some of which will be briefly outlined at the end of the Findings section, with particular references to temporal issues.

Adverse consequences of being a young carer

As noted above, John, who appeared more stressed than other young carers, had responded by abandoning longer-term aspirations, however temporarily.

**Young carer:** I used to, at college like, go out during the day and come back on a night-time and look after her [grandmother] during the night.

**Interviewer:** And talking about plans for the future now, what do you see yourself doing at age 30 say?

Young carer: Ooh, I wouldn't like to think at the moment! I wouldn't really know. I'm just going to take each day as it comes ... Me nan [grandmother], if she's not too

well, I think that would put a hold on everything. She comes first basically. (John, 23, cares for physically disabled grandmother)

John depicted a previous double workload, subsequently abandoned, in which he had combined college attendance with caring for his grandmother at night. In response to the unpredictability of her health, he had shortened his time-frame to that of daily events, prioritising his grandmother's well-being. This narrowing of his temporal horizon excluded consideration of risks to his future prospects.

Looking back retrospectively, several young carers felt, like Pete, that adopting this role early in life had deprived them of part of their childhood.

I've only been just recently able to act meself [myself], and be me [my] age. (Pete, 21, cares for physically disabled sister and father)

Pete anticipated that he could belatedly catch up with the requirements of youthful enjoyment, a view which suggests some flexibility in the timing of life-stages.

Paradoxically, the allowances which responsible adults might make for a young carer's circumstances might themselves increase their sense of not being able to be their age.

Pete also commented on the way his transgressive behaviour was treated by college lecturers.

It could have been that I was out for a drink the night before that ... [My college work] didn't get done, and I'd have a hangover. And [college staff] could see it, and they'd say, "Aw, don't worry. Just get it handed in next time". When you've just told [my friend] that he's getting kicked off the unit because he hasn't brought it in, and we

were out drinking last night, it doesn't seem fair. (Pete, 21, cares for physically disabled sister and father)

Pete inferred from the difference between official responses to the same transgression by himself and his peers that he was receiving positive discrimination. In terms of the policy framework outlined in the Introduction, he was being kept out of the NEET category in recognition of his responsible adoption of a caring role. However, this indulgence further distanced him from participation in the local version of young adulthood. Lucy vividly described reversing the expected responsibilities of a parent.

I was in a ward [for ear surgery] with all these little kids. I was only little myself ... The day after [her surgery] they said to me mam [mother], "Oh, we'll have to take the bandage off to check her over" ... And [her mother] went, "I feel funny". I had a bandage half off me head. I said, "Mam lie down". I said [to the nurse], "Just give her some air, she'll be fine". They said, "We're going to have to send your mum to casualty". I said, "Oh just leave me!" (Lucy, 19, cares for physically disabled mother and sister)

In this account, Lucy contrasted her own responsibilities with those of other young children, and indicated that she had not been able to let-up even when recovering from childhood illness. The final comment, "Just leave me" conveys a weary, exasperated acceptance from early in life that the onus of caring always returned inexorably to her.

Young carers gave accounts of problems in their relationships with peers such as bullying and gaps in maturity which created barriers to them enjoying the normal, culturally

recognised fruits of youth. Lauren described having been bullied, but also indicated how this gap between herself and other schoolchildren had been overcome.

I had some problems ... when I was in like junior school ... There was another girl in my class who had a brother with cerebral palsy, and we did get bullied a little bit. And then they got a lady to come in and do some sign language in the school, just to like make people aware that some people are different and everything. And it got better after that. (Lauren, aged 24, cares for physically disabled brother)

In retrospect, at least, Lauren sought to explain why schoolmates had bullied her and another young carer, accounting for this behaviour as resulting from fear of anyone different. Being able to compare herself with another very young carer may have helped Lauren to avoid being personally wounded by bullying. She believed that the recognition which the school gave to disability had helped other children to learn to accept those living with such a condition.

The young carers who participated in our study also identified indirect barriers to their relationships with peers arising from their role as a young carer. Gemma felt that she had lost her entire informal social life when she was still in her early teens because the time-demands of caring made it difficult for her to meet peer expectations about participation in their joint activities.

I don't tend to go out much ... I do [like to], but, sort of, time's cut. Because me mam [mother] says I can go out with my mates, and have them here. But when they can come here, they're going out with their mates, they've plans sorted and stuff ... When I went to the seniors ... I didn't see my mates anymore. And when I did see them,

they had their mates, and they told us to, basically, nick-off [go away]. (Gemma, 16, cares for physically disabled mother)

In relation to the temporal theme of this special issue, the idea of time being 'cut' is of particular interest. The still prevailing notion of young adulthood requires high prioritisation of participation with peers in leisure activities during this culturally scripted stage of development. This tacit norm applies less strongly to roles undertaken in earlier and later life phases when home-work, parenthood and occupational career legitimate intermittent social availability. Gemma had been able to compensate somewhat for peer rejection by attending various formal activities including the young carers' project. She regretted losing friends, but valued the more formal activities, such as archery, which she was able to engage in.

At the minute I love going to cadets. I enjoy it, that's why I go. But when people get up my nose, I'm like, "I [don't] need this. I've got college to go to". And sometimes, I'm at college until 5 o'clock, sometimes on Thursday, and that's my commitment ... I've got enough with college, I've got enough with archery, and I've got enough to do, sort of like in here [the house] ... Sometimes I end up really tired. I don't sleep much on a night anyway ... My mam's worked all her life, basically worked herself to where she is now ... Doing things you enjoy [is important] ... Archery is my [way to] relax. (Gemma, 16, looks after physically disabled mother)

Gemma indicated that her father, who had introduced her to archery, had played a crucial role in enabling her to enjoy recreational activities. Her response vividly communicates the stress, over and above the demands of caring, which she managed by withdrawing from interpersonal conflict with peers. Gemma had concluded from her mother's life that she

needed to exist, to some extent at least, in the present, rather than allowing her life to slip away on a treadmill of duty. Although this concern corresponded to one expressed by workers, Gemma had synthesised living in the here-and-now with her caring responsibilities by pursuing organised activities. This mode of engaging with others for enjoyment perhaps required less personal engagement than the cultivation of close relationships, but gave her greater flexibility and control over her limited personal time resource.

Daniel had managed to sustain more personal ties with friends than had Gemma by compartmentalising his carer and young adult selves.

To be honest, I normally found most people [of own age] quite immature compared to me. I didn't really have anyone to confide in about [caring] ... What I got from my friends was just doing normal things, like we used to play computer games, maybe we'd hang out at the weekend we'd watch a film ... [Family] holidays are kind of out of the question really. And the difficulties of caring for someone on holiday as well ... If I want to get a holiday, like in university, I took the trip module in second and third year, so I got away both those years. And then, with my friends, I might go to gigs. We all like music so I normally go to a gig with them every couple of months. (Daniel, 23, cares for physically disabled mother)

Daniel valued being able to share activities with friends, particularly holidays which would not have otherwise been possible for him on account of his family circumstances.

However, he experienced a fissure between his emotional age and theirs which limited personal closeness. He coped with this gap by, in effect, compartmentalising himself into a self who could enjoy the pleasures of youth with friends and a more mature persona who

could not share the experience of caring with emotionally younger friends. He did, however, regret the distancing from peers which he felt arose from a gulf in experience.

I've got a very good friend who I've known since I started uni[versity], and we're still very good friends, but you mention things [about caring], and you end up giving up. You know they'll feel awkward, but you also know that they can't put themselves in your shoes. It kind of leaves you alone [feeling isolated] sometimes because, whereas you can understand that someone else feels uncomfortable about something, they can't understand [what you are feeling]. (Daniel, 23, cares for physically disabled mother)

## Gains from being a young carer

Young carers identified benefits which they believed that they had obtained from looking after a relative, including greater maturity, opportunities for developing a career related to their experience of caring, and heightened political awareness. These views stand in contrast to the future-oriented risk framework outlined above, that young carers are in danger of becoming NEET.

Meeting the demands of a caring role could be seen as a source of both enjoyment and personal development. Lauren, who looked after a brother with disabilities, spoke about how he appreciated her treating him similarly to her other siblings, saying that 'I wouldn't change him - he is hilarious'. She depicted young caring as a source of empathy with peers and a driver of personal maturity.

I went to an all-girls [secondary] school, and there was a couple of people in the year who had disabled parents. There was one girl whose mam had MS [multiple sclerosis], and there was another girl as well. When we were in second year her mam [mother] died ... Everyone was just really sad about it ... She'd get quite upset if anybody brought it up. So you tended not to. ... We were all girls as well, so, I think, ... more aware of people's emotions, I think. (Lauren, aged 24, cares for physically disabled brother)

Lauren identified particular circumstances which may have contributed to her positive experience of relationships with others, namely being at an all-girls school (and therefore also in a socially advantaged group), and not being the only young carer in her class. The account given suggests that relating to young carers may have helped other pupils to mature through becoming more aware of the feelings of fellows who had experienced distressing life-events.

Tom discussed personal learning which the saw as arising from this caring experiences.

I've just learned to get used to [distractions] because it happens. My brother is always in and out of me room, so I just get used to it. (Tom, 20, cares for learning disabled brother)

Participation in young carers projects could offer experiences which otherwise would not have been available.

With young carers [service], I've got my Duke of Edinburgh Award, I've done kayaking, skiing, I've been in Egypt, built the school house in [East European

country] for a small community, things like that. I wouldn't imagine it, a lot of people wouldn't imagine it. My friends come to me and say, 'You've done quite a lot. It's quite hard to believe'. And my history has allowed me to do this, and [young carers] services on offer have allowed me to do this. (Pete, 21, cares for physically disabled father and sister).

As confirmed by Pete's friends, his participation in young carers projects had enabled him to extend himself well beyond what was accessible to peers. Some respondents believed that they could use skills acquired through caring as a springboard for career development.

My final year [university] project, I'm doing for [the young carers project] ... I wouldn't mind working [in the future] with teenagers, but if I could then work with the young carers as well within this age group ..., I would use it maybe teaching youth about computers and the things I've done. It'd be a step forward using me degree to help them achieve something or at least give them a head start. (Tom, 20, cares for learning disabled brother).

Tom explained his relatively high level of motivation in terms of wanting to use his skills to contribute to the young carers' project that he had spent a number of years helping to develop. He was able to integrate the project with his degree work, and could identify career steps which would build on his activities as a carer. His account contains a reference to 'crossing the floor', switching from receiving a support service to providing a similar one, and therefore being able to draw on personal experience in order to help young people at risk of becoming NEET. Conversely, Ryan, who had also switched role

but in the opposite direction, had found that his work experience as a carer helped him to cope with looking after his nan (grandmother).

Being the age I am, and having other experiences as a support worker, I'd done so much of it that when it comes to my nan it wasn't a chore. it wasn't strenuous. It was handleable. It was easy. (Ryan, 25, cared for now deceased physically disabled grandmother)

However, Ryan had subsequently moved away from support work.

The support work [working with disabled students], that was long shifts. It was horrible, Everything went to pot [went wrong] really. You plan your time, get through this week. [The support worker job] did get very rutty [boring]. (Ryan, 25, cared for now deceased physically disabled grandmother)

This account resonates with the risk concern mentioned by support workers quoted in the first Findings' section. The modern cultural notion of young adulthood centres round the notion of experimenting with life choices before committing. From this perspective, the process of tentatively exploring choices may be restricted if a young person becomes locked into caring work too early in life. Ryan was glad to have come into family caring later in young adulthood, but might have had a different perspective had he actually experienced family caring at age 16.

Finally, some young carers believed that their experience had awakened them politically. Pete felt that he had had been enabled to engage with politicians at the highest level.

When I started going to Young Carers, I think it was 2000, there was no way that I could speak to somebody that I thought could make a difference. And since then, I've gone down to Downing Street every year and spoke to the Prime-Minister, spoke to politicians, about everything from transport, through to education and things like that. (Pete, 21, cares for physically disabled sister and father)

This political awakening had made him view his chosen career in accountancy from a wider societal perspective.

It's probably worked out for the best that I'm going with accounts because I'm very good at numbers as well ... I can see where the restrictions [on disability support] are coming from. It's not coming from the social workers. It's coming from the accounts department. I find that if I [go into accounting], maybe I can change something.

(Pete, 21, cares for physically disabled sister and father

Another young carer had successfully lobbied for funding to improve her young carers centre.

I secured 18 grand [£18,000] for Young Carers at [local town]. We had to go to the Centre and show these other young people what we wanted to do with the room, because we didn't have much. (Jenny, 19, cares for physically disabled mother and sister)

Such experiences could contribute to the personal maturity and self-esteem of young carers who found that they could bring about real societal change.

We identified a largely unappreciated discrepancy between the temporal orientations of specialist young carers workers and young carers themselves. The workers, as illustrated above, saw a major role for themselves in helping young carers to navigate the transition to adulthood. But young carers did not think about their circumstances in terms of risks to their personal futures, or realise that service providers viewed them as at risk. Instead, they judged the support they received in relation to its impact on their present lives. Within this interpretive framework, a divide could be identified between young carers' generally critical views about their treatment by generic social work and education, and their positive responses to specialist young carers services. Young carers also criticised the absence, as they saw it, of co-ordination between these two types of potential support. Both were needed since help for family members living with disability would also reduce the workload for young carers.

[Social services] *could offer some help, but they didn't, and that put more responsibility on me.* (Pete, 21, cares for physically disabled sister and father)

Perhaps the most critical temporal issue for young carers was lack of recognition for the length of time for which they had coped without service-support.

And she [young carers project worker] was, like, "You didn't tell a social worker to get out?" I said, "I did. If she's not going to do anything." I do everything me-self [myself]. I never ask for a cleaner, I've never asked for help. (Jenny, 19, cares for physically disabled mother and sister)

Jenny took pride in her independence, in effect viewing herself as a long-established, self-reliant carer who 'owned' responsibility for looking after two family members, rather than as a young person in transition to adulthood. Her comment suggested that she was thinking in terms of a trade-off in which any loss of self-esteem resulting from accepting support would have to be balanced by its benefits. Since she did not see any such gains, Jenny unhesitatingly rejected the social worker's intervention. By confiding in a young carers support worker, she, in effect, bracketed this service out of her criticism.

Another young carer felt that he had been fobbed off by other professionals onto young carers services.

The head of the Masters [degree programme] said to me, you know, "Do you have any support?" ... I said, "Not really. I just tend to get on with things". And he said, "Ah you might want to talk to, is it, Young Carers?" ... And I just found that offensive, because I'd been in this role for years, and I don't need that now! It's kind of rude isn't it, for someone to suggest that? Really insensitive, like, "I'm not going to help you, but someone else can, sort of thing". (Daniel, 23, cares for physically disabled mother).

Daniel's sense that the moral order had been violated was grounded in his perception of temporal inappropriateness. Although chronologically a young adult, his long history of looking after his mother led him to view himself as an old-hand whose track-record was being implicitly discounted. Also in an educational context, Pete felt that his tutors had failed to develop a realistic understanding of the role.

Having a bit of common sense – just because [a carer] gets a phone call doesn't mean they have to go home [to care for their family member] ... I think it's just the teachers, how they decide to treat [further education students]. There's the thing about voting, 'cause if you're old enough to go in the army, you're old enough to vote. If you're old enough to defend the country, why can't you be tret [treated] with the same respect? (Pete, 21, cares for physically disabled father and sister)

Pete considered that his need to combine caring and educational roles was not well-handled by teaching staff. He believed that this insensitivity derived from a wider age-inappropriateness of attitudes towards young adults who could vote or be killed in battle but were still treated as pupils in the further education system. Possibly, Pete's adoption of caring responsibilities so early in life made him more sensitive than others in transition between childhood and adulthood to inconsistencies in age-related societal expectations.

## **Discussion**

In this article we have presented some findings about the ways in which young carers and young carers workers view the present lives of and future prospects for the young carers. We identified a qualitative contrast between two understandings of young carers' circumstances. Some, although not all, of the specialist workers who participated in this study believed that carrying out a caring role 'too early' in life poses risks for personal, relational and vocational preparation for adulthood. (However, two young carers workers problematised service inflexibility to varying circumstances rather than young carers themselves.) Their approach to risk management, fuelled by wider concern about the risks associated with being NEET, was predicated on the assumption that young carers could not themselves see the longer-term risks to their future life prospects which more

experienced adults could detect. A noticeable narrative feature of this risk construction was resort to metaphors, including sowing wild oats, fledglings learning to fly and eggs being spread between baskets. Such devices help to bring a sense of tangibility to the nebulousness of anticipated trajectories.

The young carers who participated in our study might not have responded kindly to attempts to nudge them into re-orienting themselves towards their longer term futures. However, they did not appear to realise that they were viewed in this way, living in a different risk universe to service-providers. Young carers valued the support which they received from specialist young carers services. They identified many difficulties relating to their role, including stress, loss of childhood and barriers to peer relationships. But they also perceived significant personal benefits in terms of maturation and work-relevant experience which the formal education system does not acknowledge, and which will not figure in UK school league tables.

The psychological template of fixed developmental stages generates a culturally unreflective narrative about the essential nature of childhood (O'Dell *et al.*, 2010) which is contradicted by belief systems prevalent in non-Western societies such as those of sub-Saharan Africa (Evans, 2010; Becker, 2007) where children and young people commonly take on caring and other roles. The prevailing cultural template of childhood in rich societies has generated a sense that caring at 'too early' an age puts young people at risk. This belief system is not shared by young carers themselves, and the framework from which it derives may itself be weakening, as faith that society can generate indefinite progress between generations has become eroded. Young carers viewed themselves as competent navigators of their own futures. They showed no awareness that they were regarded as vulnerable by agents of caring agencies. This finding is supported by recent

research into how members of social categories considered vulnerable may see themselves as competent risk managers (Alaszewski, 2013; Spencer, 2013; Thing and Ottesen, 2013).

As Roberts (2007) has argued, the concepts of biographical transition, for instance from adolescence to adulthood and historical transition, for example from Baby Boomers to the 'post-1970' generation (Wyn and Woodman, 2007), can be usefully juxtaposed, generating the view that understandings about the nature of human development themselves change over historical time. Both typologies can be viewed as cultural inventions rather than as descriptors, respectively, of freestanding psychological and historical phenomena. Debate on this issue has drawn on more or less critical readings of Beck's individualisation thesis (Beck and Beck-Gernsheim, 2002; Beck, 1992). Such work connects youth studies to risk social science (Roberts, 2012). A perhaps simplistic rendering of the individualisation thesis holds that the break-down of traditional community, social class and other solidarities leaves individuals with more choices, but also carrying greater responsibility. Brown *et al.* (2013) in this edition discuss a related analysis (Giddens, 1991), in which the strengthening imperative of the modernist societal clock is seen to collide with late-modern expectations about personal choice.

The individualisation thesis can be cast in terms of the critique of neo-liberal governmentality (Mitchell, Crawshaw, Bunton and Green, 2001). From this perspective, purveyance of a responsibility narrative provides legitimation for withdrawing state support from the poor and needy. However, it should not be assumed that young carers today receive less support than in the past. *Au contraire*, greater societal recognition during the early 21<sup>st</sup> century boom years of the contribution made by family carers may have simply heightened expectations which the state is no longer willing to fulfil.

#### Conclusion

Since the 1990s, the situation of young carers has been increasingly flagged up as a source of risk, in the UK and elsewhere. This risk concern arises from the culturally derived notion that youth should be a time of foundation-setting for adult life. This belief renders young caring as a risk requiring an organised management response. Although this view should not be dismissed, and is reflected in the stresses experienced by young adults quoted in the present paper and elsewhere, it can be contrasted with the normal expectations of the young in many other cultures. It also conflicts with the expectations placed on older adults in our own society, for instance in relation to the workloads facing parents of severely disabled children. Careful qualitative comparison of the perspectives of young carers and specialist service providers suggests that young carers oriented themselves primarily to present rather than future risks and benefits. Personal gains from their role need to be better acknowledged. Services directed at young carers need to be complemented by helping them indirectly through improving services for the relatives they are looking after, promoting family support and increasing the sensitivity of the educational system.

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However, young women have faced more restrictive cultural prescriptions than young men (MacRobbie 1984), a difference which has been somewhat mitigated in recent years through the strengthening movement towards sexual equality (Spence 1990).

<sup>&</sup>lt;sup>i</sup> The origins of the relatively new role of 'young carers worker' will be outlined below.

Arnold Bennett's play, *The History Boys* (2004) brilliantly evokes this paradox of young adulthood in contemporary culture since the only way in which the straight-laced headmaster of a secondary school can achieve his ambition to get as many boys as possible into a prestigious university is to rely on the eccentric, unreliable teacher who is able to develop his students' creative talents.

Little international comparative research into young caring has been undertaken. Becker (2007) noted that needs assessment surveys had been undertaken and followed-up with the establishment of dedicated services for young carers over roughly the same time period, from the mid-1990s through the mid-2000s in Australia and the UK. According to Becker, the first US survey was not published until 2005, and little specific support for young carers had been organised.

<sup>&#</sup>x27;However, cultural relativity should not be overdone since there may well be inherent limitations as to what children are capable of at various ages. Little is known about the plasticity of human development, and, in particular, the level of role demands, e.g. being exposed to war, which will permanently damage children through the 'loss' of childhood. Moreover, children everywhere are now exposed to Western, particularly American, models of childhood through the mass media.