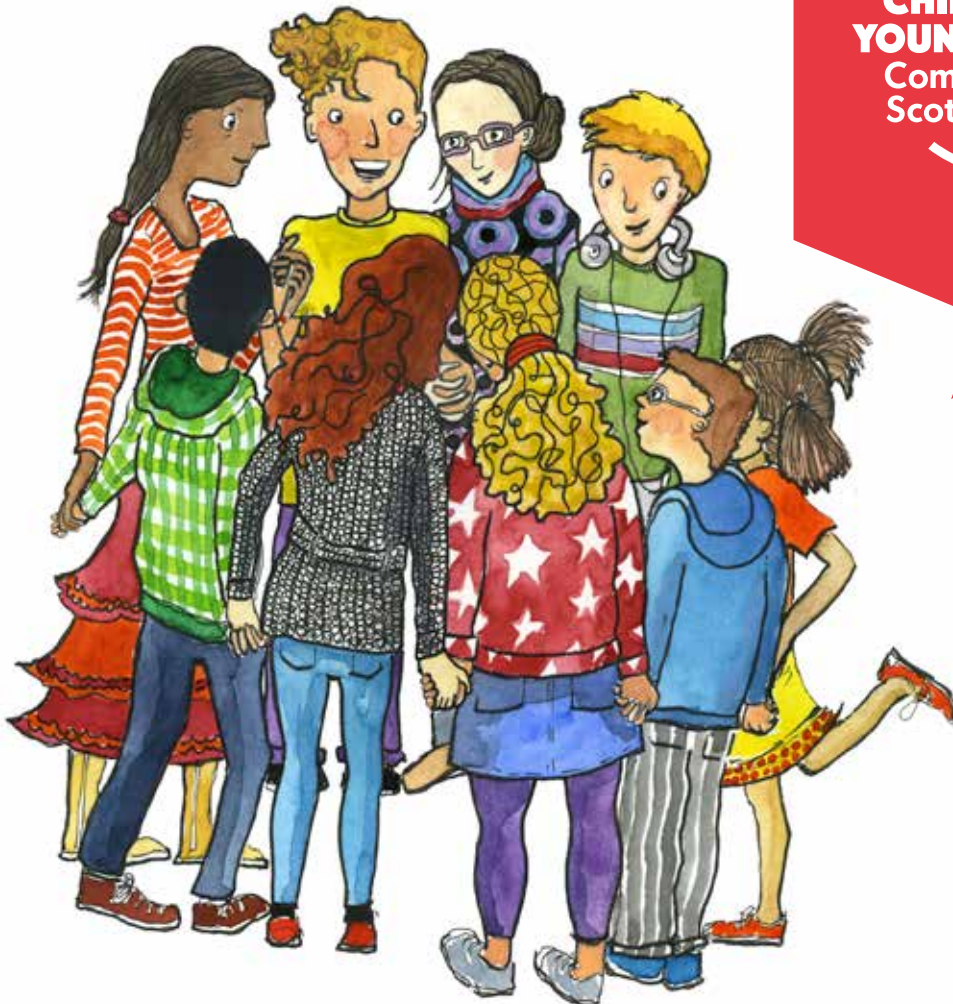


“Coping is difficult, but I feel proud”

Perspectives on mental health and wellbeing of young carers

Children and Young People's
Commissioner Scotland, Carers
Trust Scotland and Scottish
Young Carers Services Alliance

**CHILDREN &
YOUNG PEOPLE'S**
Commissioner
Scotland



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“Coping is difficult, but I feel proud”
Perspectives on mental health and wellbeing of young carers

February 2017

Authors: Glenys Watt, Onyema Ibe and Ella Edginton (Blake Stevenson), and Dr Ross Whitehead (HBSC Research Fellow, University of St Andrews)

Illustrator: Jenny Capon

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Foreword

Since becoming Commissioner one of the events which has always inspired me is the annual Scottish Young Carers Festival. This residential festival gives young carers from across the country the space to chill, meet friends and have fun, but it also allows time for more serious reflection on issues and the opportunity to share experiences with others in similar circumstances. This year, the festival saw the beginning of our research into the impact that caring can have on young carers' mental health and wellbeing, an issue we do not know enough about.

This research is the first in the UK to match young carers and their perceptions of their health and wellbeing against a comparable sample of young people. By matching the young people in this way, it allows us to draw out the findings that relate specifically to their caring responsibilities so that we can see what impact this can have. It was commissioned in partnership with Carers Trust, Scotland with the support of Scottish Young Carers Services Alliance. A team from Blake Stevenson and the Child and Adolescent Health Research Unit (CAHRU) at the University of St Andrews carried out the research.

We know that national surveys do not uncover the full extent of young caring as it can be a real challenge to identify young carers, not least because many do not see themselves in such terms, whilst others are fearful of intrusion or unwelcome intervention into family life.

A key finding of this report is that the positive aspects of caring are often overlooked. We found that the young carers who completed the survey are in a lower socio-economic group compared with the main young population, for a variety of factors, but that despite their socio-economic circumstances they have greater feelings of self-worth than their counterparts who are not caring for someone at home.

However, what is evident is that those with the greatest caring responsibilities (between one quarter and one third of respondents – suggesting this is not a small group), are more likely to feel the negative aspects of caring. There are more negative results across a range of factors: they are less happy, they sleep less and they are more likely to report more stress-related factors and more negative health symptoms than those with lower levels of responsibility. In short, they are not coping as well with everyday life compared to the whole young carers' population.

It is no surprise to hear from young carers that being able to talk to someone who really listens and understands helps them cope better, as does having enough time away from caring to do fun things. We need to know who has caring responsibilities, create safe spaces for them and through positive relationships ensure that young carers are not left to manage the stress and responsibility alone.

I would like to thank all the young carers who took the time to share their experiences with us, and in particular the group of young carers at the festival who took part in the pilot in August 2016.

Tam Baillie
Children & Young People's Commission Scotland

1. Introduction

- 1.1 There are at least 29,000 young carers in Scotland who are taking on “practical and / or emotional caring responsibilities that would normally be expected of an adult”¹. Young carers can be any child or young person below the age of 18 who take on these responsibilities. It is likely this figure is an underestimate.
- 1.2 The Children and Young People’s Commissioner Scotland, in partnership with Carers Trust and the Scottish Young Carers Services Alliance, commissioned Blake Stevenson Ltd to undertake research about the impact of caring responsibilities on the mental health and wellbeing of young carers. The research was conducted between August and October 2016.
- 1.3 A team from Blake Stevenson undertook the research along with two associates from the University of St Andrews’ Health Behaviour in School Aged Children (HBSC) study, whose expertise provided a means for comparison between this young carers’ survey with the Scottish cohort of young people involved in the HBSC survey.
- 1.4 The HBSC study is an international survey of adolescents aged 11, 13 and 15 that is conducted every four years in 44 countries in Europe and North America, of which Scotland is one. The most recent Scottish survey was in 2014 with a nationally-representative sample of 10,839 school pupils.

The research questions

- 1.5 The key research questions as given in the research brief were as follows:
 - What are the main concerns of young carers?
 - How do young carers perceive their levels of anxiety, stress, unhappiness or levels of worry?
 - How do their caring responsibilities affect the mental health and wellbeing of young carers?

1 <http://www.gov.scot/Resource/0047/00473691.pdf>

Methods

- 1.6 The methods included a short literature review to examine the research relating to the mental health and wellbeing of young carers and a paper-based survey containing a total of 40 questions which was distributed with the help of the Scottish Young Carers Services Alliance through the young carers' support groups across the country.
- 1.7 The survey questions were obtained from a number of sources. These sources included using some questions from the 2014 HBSC Scottish survey. Using the HBSC survey questions allowed the data on young carers to be compared to the wider population. It also included drawing on two research tools developed by the University of Nottingham in association with the Princess Royal Trust for Carers² to allow a focus on the level of caring activities and responsibility each young carer was undertaking. The first of these is the multidimensional assessment of caring activities (MACA-YC18), an 18-item self-reported questionnaire, which provides an index of the total amount of caring activity the young carer undertakes. We have used this scale as a starting point for developing our own measure of caring responsibility, which contains many of the same items, as well as others suggested by the client and young carers themselves when the survey was piloted at the 2016 Scottish Young Carers Festival. The differences between the MACA-YC18 and the items in this study's caring responsibility index are detailed in Appendix 2. The second tool provides questions around the positive and negative outcomes of caring (PANOC-Y20), a 20-item self-report measure used to provide two separate indexes of positive and negative impacts of the caring role. Finally the survey adapted one question from the Scottish Youth Parliament's Campaign Research Survey³ about accessing a variety of services to support mental wellbeing.
- 1.8 We piloted the survey with three groups of young carers at the Scottish Young Carers Festival in August 2016. Following this event we made amendments to the survey questions but retained the HBSC- related questions to allow for robust comparison. Appendix 4 contains the final survey: we have added the source for all questions so that it is clear which are related directly to the HBSC comparison against this nationally representative dataset. We also met with workers from young carers groups at the festival to take them through the survey so that they could support young people as they filled it in if any questions arose.

2 Joseph, S. Becker, F. and Becker, S. (2009) Manual for Measures of Caring Activities and Outcomes for Children and Young People. London: The Princess Trust for Carers.

3 Scottish Youth Parliament: Our Generation's Epidemic http://www.syp.org.uk/our_generation_s_epidemic

- 1.9 We distributed approximately 500 copies of the survey to young carers' groups. We received 237 completed surveys. We have used a statistical technique, "propensity score matching", to select an appropriate comparison group from the HBSC Scottish sample that is matched to the group of young carers as closely as possible on a range of demographic and contextual variables including: age, gender and socio-economic status.
- 1.10 This approach has allowed us to distil the unique impact that caring responsibilities have on young carers' mental health in isolation from other factors. The matched sample applies to 153 from the young carers' respondents: some of the respondents could not be matched due to missing responses on match criteria (predominantly ages or postcodes were missing). Appendix 1 contains a more detailed explanation of the matching procedures and statistical methods used. We report in Chapter 3 on the results of this comparison and also on the results of the overall young carers' survey so that the views of those who were not able to be matched against the HBSC cohort are also included.

Report layout

- 1.11 This report provides the findings from this research and is set out as follows:
- Chapter 2 contains the literature review and national context setting;
 - Chapter 3 provides the main findings from the survey analysis; and,
 - Chapter 4 sets out the conclusions of the research.

2. Literature review and national context

Introduction

- 2.1 There is a variety of different definitions applied to the term “young carers”, varying by both the age range covered and the level of caring responsibility. Additionally, much of the existing research carried out with young carers is limited in how far it can be generalised due to:
- relatively small sample sizes;
 - a propensity for qualitative methods; and,
 - where quantitative data is used, it is often not compared to the general population, or is compared without controlling for other influencers such as socio-economic factors.
- 2.2 This makes comparisons across the literature, and their application to this project, imperfect. Despite this, it is informative to consider the general themes that emerge from the literature. Consequently, this chapter considers the following five areas:
- recognising, identifying and involving young carers, and the impact this can have on their wellbeing;
 - recognising the positive aspects of young caring;
 - the impact young caring can have on mental wellbeing;
 - experiences of school and bullying for young carers; and,
 - gender dynamics and the different emotional burdens experienced by girls and boys in caring roles.

Recognising, Identifying and Involving Young Carers

Going unrecognised

- 2.3 It is widely acknowledged that national surveys do not uncover the full extent of young caring, and that there are major challenges in identifying young carers. Research points to a number of reasons for this. Chief amongst them is that many young people who provide support and help to family members who need it often do not recognise this as a “caring” role (Morrow 2005, Moore and McArthur 2007, Cass et al. 2009), instead viewing the tasks they carry out as being ordinary chores or just “being helpful”, and not recognising that the things they are doing go beyond what would be expected in most families. Both Australian and UK studies have suggested that this is especially common among some minority cultural and ethnic communities (Misisic 1996, EDAC 2003, Hill and colleagues. 2009).
- 2.4 Many young people who provide care do not disclose this to teachers, doctors, social workers or other adults because they fear separation. Six studies found that young

carers were reluctant to tell others about their situation for fear of intrusion into family life or “being taken into care”. Moore and McArthur (2007) reported that this makes young carers reluctant to seek help of any sort, in case this revealed their family circumstances, or gave others the perception that the family was not coping, thus causing them to be taken into care. This appeared to contribute to their feelings of isolation even further.

- 2.5 A variety of other negative emotions such as shame or stigma, uncertainty about who to talk to, or difficulty opening up about and articulating their feelings are also cited in the literature as impediments to identifying young carers.
- 2.6 A consequence of this is that there is a large hidden population of young carers, whose emotional needs are likely going unmet since they are not engaged with the social services that might support them. Warren’s (2005, 2007) research in the UK found, unexpectedly, that around a tenth of her randomly selected group of children (intended as a comparator to a group of known young carers) also had considerable caring responsibilities, sometimes as substantial and significant as the known young carers in the same study. This shows that there is both a hidden group of young carers within the general population, and also that this group can be located at the heavier end of caring responsibilities. This is consistent with findings from Cass and colleagues. (2009), Hill and colleagues. (2009), Hounsell (2013) and Smyth and colleagues. (2011), all of whom found that often young people do not identify themselves as “carers”, and some adults do not report young people in the household who are providing care when responding to surveys.

Excluded from decision-making

- 2.7 Research carried out by McAndrew, Warne, Fallon and Moran (2012) found that often the importance of young carers’ roles is not acknowledged by health professionals, shutting them out of decision-making and making them feel undermined and unimportant. In their research, the young people told stories of being excluded from decisions relating both to themselves and those they were caring for (despite being the main caregiver in the family), being dismissed by professionals, and indirectly excluded through the use of technical or adult language. The young carers described themselves as “the forgotten”, and felt that these experiences undermined them as people.

Access to support

- 2.8 There exists some debate in the literature about the relationship between recognition of young carers, access to support, and the impact on wellbeing. While most argue that giving formal recognition to young carers helps to ensure they access all the

support services possible, lessening the emotional burden on them and thus improving their wellbeing, there are those who disagree. Some have argued that support services for young carers might have the unintentional impact of “rewarding” them, and thus, reinforce their caring role. It is suggested that because providing high levels of care could be harmful to the young carer’s own health, education, and life opportunities, some organizations take the view that it is better to reduce levels of support in an attempt not to re-enforce young people in the caring role (McAndrew, Warne, Fallon and Moran, 2012).

Positive Aspects of Young Caring

- 2.9 In both Aldridge (2006) and Aldridge & Becker (2003) it is pointed out that young people should not be considered unwilling partners in providing care to their parent/s, as to do so implicitly undermines the deep familial love that motivates most young carers.
- 2.10 While the negative effects of caring on young people are well documented, much of the literature also emphasises that there is also a positive side, which should not be overlooked. Sahoo and Suar (2010), found that the insecurity, distrust and worry young carers experienced was in part counterbalanced by the fact that caring also taught children positive values such as nurturing, endurance and sympathy. Becker (2007) linked caring with enhanced coping mechanisms, developing life, social and other skills, maturity, a sense of purpose and closer attachment (although they did not think these benefits outweighed the fact that “many children who take on regular or substantial caring responsibilities experience “significant restrictions in their development, participation and opportunities, and educational attainment”). Aldridge and Becker (2003) and Noble-Carr (2002) similarly found closer relationships and greater maturity, as well as increased self-esteem.
- 2.11 Several studies found that young carers actively sought to derive a sense of pride and self-esteem from their “caring” identity in order to offset the negativity that can be associated with it. Bolas and colleagues (2007) found that young carers reported a sense of pride that was “reinforced by idealised images of carers as being ‘brave’ and ‘noble’”. Other research has found that young people particularly valued the skills they were learning (Bilsborrow 1993, Earley and colleagues 2007). However, the “positive narrative” of caring can itself have some drawbacks; Moore and MacArthur (2007) found that some young carers did not like being labelled “angels” or “heroes”, as it left them with no room for failure or to ask for support.

Mental wellbeing

2.12 The literature on the impact of caring on young people's mental wellbeing suggests that, while many young carers are resilient and manage well, others experience increased levels of stress and other negative emotions. These can have health and behavioural consequences, and can also feed into a cycle of social isolation. Each of these areas is outlined below.

Emotional consequences

2.13 In Cree's 2003 survey of Edinburgh-based young carers, respondents pointed to a range of worries, some of which are common to most adolescents (for example, 55% of young carers worried about their appearance), while others could be wholly explained in terms of their lives as young carers:

- 81% worried about the health of the person they care for;
- 67% worried about their own health;
- 58% worried about the behaviour of the person they care for, and
- 53% worried about who will look after them in the future.

2.14 Similarly, Lloyd's (2013) study of young carers in Northern Ireland found that children who were carers reported less happiness with their lives than their peers who were not carers (although this study does not control for other potential influencers such as socio-economic status or extent of caring responsibility). Frank's survey (1995) also showed that some young carers reported feelings of resentment, anger, emotional exhaustion and a sense of isolation.

2.15 These findings are in line with the large body of literature relating specifically to young carers of parents with mental illnesses, which show substantial increases in stress levels amongst this group (Ali, Krevers, Sjoström & Skarsater, 2014). Children with a mentally ill parent may experience more frequent negative emotions, including anger, fear and sadness, placing them at a higher risk of problems such as depression and anxiety (Beidel and Turner, 1997; Weissman and colleagues, 2006; Van Loon and colleagues, 2013).

Health and behavioural consequences

- 2.16 The impact on mental wellbeing described above can manifest in flow-on effects for young people's physical health and their behaviour. The 2015 Scottish Adolescent Lifestyle and Substance Use Survey found that having caring responsibilities was a risk factor for smoking, drinking and using drugs, and research with Northern Irish young carers showed they had poorer health outcomes (Lloyd, 2013).
- 2.17 Similarly, in Cree's study of Edinburgh-based young carers, respondents reported a range of problems in relation to their wellbeing, including those typical to adolescents (such as problems with friends), but also difficulties that may be associated with mental health problems, including difficulty in sleeping (reported by 60% of young carers) eating (30%), and, most notably, over one-third said that they had self-harmed (34%) and had thoughts of suicide (36%), although it is important to note that these rates were not compared to the general population of young people.
- 2.18 Vitaliano, Zhang & Scanlan's (2003) review of 23 studies showed many studies have found that being in a caring role worsens an individual's own health. Another project, synthesising the findings of 11 qualitative studies completed with young carers, also found that they reported mental health problems of their own as well as stress-related physical disorders such as asthma and hair loss (Rose & Cohen, 2010).

Social isolation

- 2.19 Aldridge and Becker argued in 2003 that one consequence of taking on caring responsibility was that young people could become isolated from their peers, due to the time their responsibilities take up preventing them from typical activities like spending time with friends or playing sport. This is consistent with earlier findings from Dearden and Becker's general review of the literature on young carers (1999), which found consistent evidence that young carers feel isolated and "different" from their peers.
- 2.20 These issues can be compounded when a young carer does not have adults to turn to for support (L. Ali, B. Hedman Ahlström, B. Krevers, I. Skärsäter 2012 and A. Johansson, E. Brunnberg, C. Eriksson 2007). Given the challenge of trying to emotionally support others in the household, while social barriers make it difficult for one's own emotional needs to be met, it is not surprising that young carers are vulnerable to their mental health being compromised.

School and bullying

School work and teachers

- 2.21 A 2011 study using data from the Kids' Life and Times online survey in Northern Ireland found that young carers were more likely than the general population of children to be bullied at school, and had poorer educational aspirations and outcomes than their peers, however this study did not control for other potential influencers here such as socio-economic status.
- 2.22 Previous research examining young carers' educational experiences suggested that many worried about their schoolwork, for example Dearden and Becker (2000), and Cree (2003), which notes that 68% of the study's sample reported worrying about school work, and that although this concern is typical for many young people, being a young carer brought an added dimension to the issue.
- 2.23 Worries about school may be compounded by the fact that, when caring takes a toll on their school work, young carers may find it difficult to explain the reasons to their teachers. A study of several qualitative papers on young carers found that one common theme was that young carers often felt they had to conceal their role from teachers because they considered it a "story" or "excuse" (Rose & Cohen, 2010).

Bullying

- 2.24 Much of the literature also makes reference to high rates of bullying reported by young carers, particularly in the school environment. Lloyd (2011) found that P7-aged children who had caring responsibilities were more likely than their peers who did not to say they had been bullied at school, while Becker and Becker (2008), Early and colleagues (2007) and Warren (2007) all found that at least some of the bullying reported was "specifically for being a young carer". Retrospective data gathered from adults who had been young carers suggests that as many as 71% had been bullied physically, verbally or emotionally at school (Bibby and Becker 2000).

School as respite

- 2.25 Despite these negative narratives about experiences at school, it is also important to note that several studies have reported that young carers feel positively about school because it provides "relief" or "respite", and the expectations placed on them are more age appropriate and less emotionally taxing than those they face at home (Gates and Lackey 1998; Bilsborrow 1993; Cree 2003; Martin, 2006; Rose & Cohen, 2010).

Gender dynamics

2.26 The literature also reveals gender differences, both in the distribution of the caring responsibility, and in the experiences and mental wellbeing of boys and girls who provide care. In general, some studies have found that girls are more likely to be young carers than boys, while others have found that boys and girls provide care at similar rates.

Caring Responsibility

2.27 As far back as 1981 Brody argued that socio-cultural expectations perpetuate the idea that young women “naturally” have the skills and knowledge required for caring, as well as the desire to carry it out. Young carers in a study carried out by Eley (2004) described a ‘hierarchy of care’ whereby age and gender determined who cares. There was an expectation that older, female children would care and that male children would care only if necessary (Martin 2006). Australian data explored by Hamilton and Cass showed that young women and men had similar rates of caring overall, but that young women were more likely to be primary carers (Hamilton & Cass 2011).

2.28 While it is likely that the social forces Brody describes cause young women to engage in more caring work than young men, Smyth, Braxland and Cass (2010) also point out that young men may be less likely to admit to taking on a caring role because to do so “contravened social expectations of masculinity.”

Gender differences in impact on mental wellbeing

2.29 Cree (2003) found that, amongst a sample of young carers in Edinburgh, girls were much more likely to describe both problems and worries than boys. The paper points out that this may be explained in terms of girls’ greater willingness to share their feelings and express emotions, but that there also may be additional gender issues in caring that make the experience more troublesome for girls than for boys, such as greater expectation that they take on the role regardless of whether they want to, or that caring should come easily to them (Tucker & Liddiard 1998).

2.30 Conversely, a number of studies found that care-giving could be uncomfortable for young male carers in unique ways as well, particularly when they view it as inconsistent with a masculine identity (Bolas and colleagues. 2007, Earley and colleagues. 2007). This can add to the negative emotions they feel about their role, and also make them less likely to disclose it to others, reducing the support they can access.

Conclusion

- 2.31 This review shows that, although there can be highly negative assumptions made about the impact of young caring, the picture is often more nuanced and it is important to remember its positive aspects as well. Young carers can develop skills, relationships and emotional maturity that hold them in good stead, although it is also true that some can become socially isolated, preoccupied with worry, or engage in detrimental behaviours such as substance abuse or self-harm. Some young carers struggle to keep up with school work and feel misunderstood by teachers, but school can also be seen as an enjoyable respite for some. Caring may be an especially negative experience for girls, due to a stronger social expectation that they take on this responsibility and that it will be easy for them, but boys may also feel particularly negative about it for the converse reason - taking on a traditionally “feminine” role may be seen as embarrassing or challenging their masculinity.
- 2.32 This diversity reflects both the complexity of individual lives, and the diversity of experiences within the category of young carers - that different degrees of responsibility, economic security, and family circumstances mean young carers are not a homogenous group. To help tease out these nuances it is important that this research is methodologically robust. Therefore the survey was designed so that the effects that different degrees of caring responsibility have on wellbeing could be examined and so that comparisons could be made between young carers and similar groups of young people.

3. Survey findings

Introduction

- 3.1 The survey was designed so that the findings could be analysed on several levels. In this chapter we present the findings in three different ways. First we cover the whole young carers' survey respondents to look at the overall picture from all those who responded to the survey; second we have undertaken a matched comparison with the HBSC Scottish sample and thirdly we have analysed the results according to the level of caring responsibility each young carer has.
- 3.2 To help make this three-tier analysis clearer we have colour-coded the charts that illustrate the text:
- all data from the young carers survey is presented in blue: ■
 - the demographically matched group drawn from the HBSC survey is presented in green: ■
 - the overall, unmatched HBSC group is presented in pink: ■

Overview of respondents

Age

- 3.3 The ages of those who took part in the young carers' survey ranged from 9 years to 20, with an average age of 14.8 years. Figure 1 illustrates the age distribution. The Scottish HBSC study, which we used for comparison in this research, focuses on those aged 11, 13 and 15.

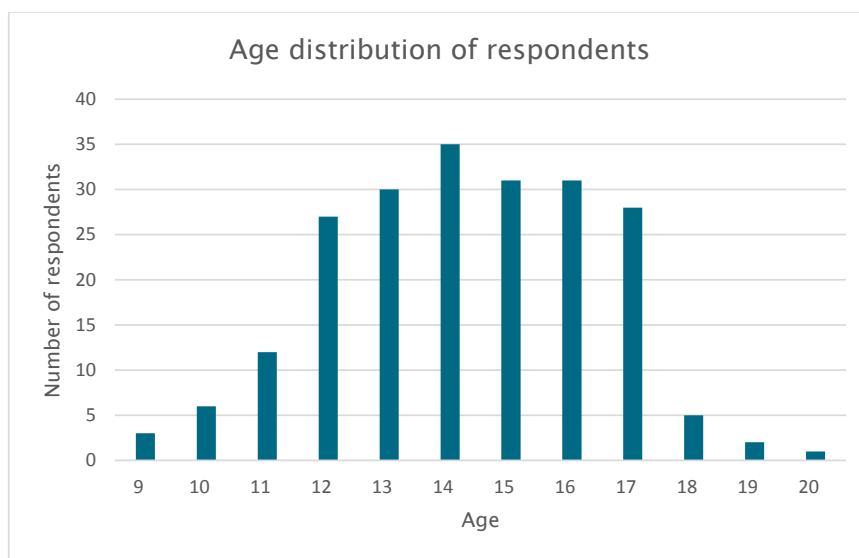


Figure 1: Age distribution of respondents

Gender

3.4 Just over 65% of those who responded were girls and just under 35% were boys. The national gender balance in Scotland between girls and boys aged 9-18 is 49%-51%, indicating that girls are significantly over-represented in the respondents to the survey. Insights from the literature review suggest two possible reasons for this, both of which likely play a role – that girls are more likely to take on caring responsibilities and also that boys who do have caring responsibilities are less likely to self-identify as carers and to fill in surveys.

Ethnicity

3.5 Ninety-three per cent of the young carers who responded to the survey were white and 6.5% were from visible ethnic minorities. Scottish population statistics for this age group suggest that our sample has a slightly higher representation from visible ethnic minorities (nationally around 4.5% are from this latter group whilst over 95% of this age group are white).

Disability

3.6 Nearly 20% of the survey respondents classified themselves as having a disability, long-term sickness or learning disability. 76% said they had no disability and 4% preferred not to answer the question. There are no directly comparable figures for the national population but the long term conditions question from the Scottish Health Survey⁴, tells us that about 8% of households reported having someone aged 10-19 with a long term condition.

Socio-economic status

3.7 Nearly 27% of the young carers who responded to the survey are from the 15% most deprived areas of Scotland (based on 2016 SIMD⁵ data). This is higher than the national percentage for young people of this age range of around 15% and compares to the whole HBSC sample of 11.5%. This suggests that young carers are more likely to live in more deprived circumstances than the average young population. Figure 2 illustrates this difference between the young carers and the overall HBSC sample.

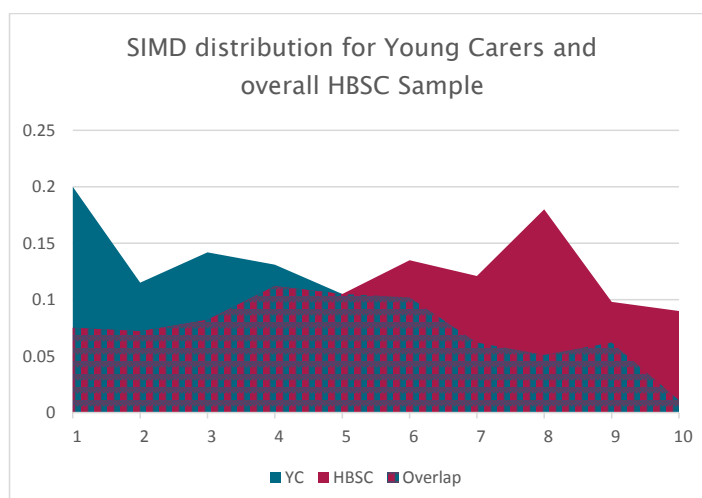


Figure 2: Comparison of the SIMD distribution for young carers compared to the overall HBSC sample

4 Scotland's People Annual Report: Results from 2013 Scottish Household Survey: Revised October 2015

5 SIMD: Scottish Index of Multiple Deprivation

Caring responsibilities

3.8 Figure 3 illustrates the number of people the young carers are caring for and the number of people, if any, with whom they share their caring responsibilities. Seventy-two per cent of the young carer respondents provide care for just one person, with most of the remainder providing care for two people. Almost 6% provided care for three or more people. Although it was most common for young carers to share their responsibilities with one (30%) or two (31%) other people, just over a quarter of respondents (27%) reported not having anyone else living at home with whom they shared the caring responsibilities. Clearly this last group together with those who are caring for two or more people (26%) are likely to have the greatest responsibility.

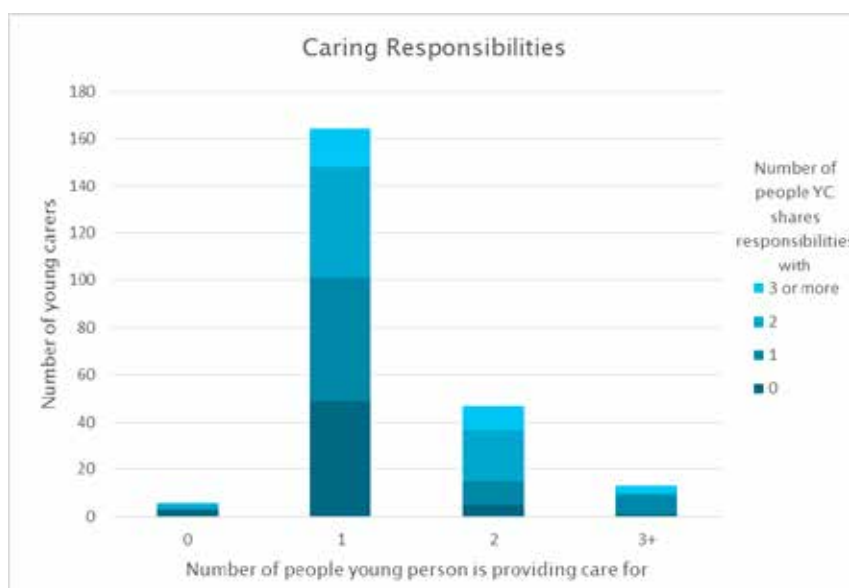


Figure 3: The number of people the young carers are caring for and the number of people they share their caring responsibilities with

3.9 We asked young carers about the tasks they had done to help over the past month (see Figure 4). The most common tasks falling on young carers were mostly general tasks related to spending time with the person, such as taking them out, keeping an eye on their wellbeing and keeping them company. Household tasks such as cleaning, cooking and shopping for groceries were also near the top of the list. Helping financially and intimate tasks such as helping to bathe or wash were relatively uncommon, although almost 40% of the respondents had to help the person they cared for dress or undress at least some of the time.

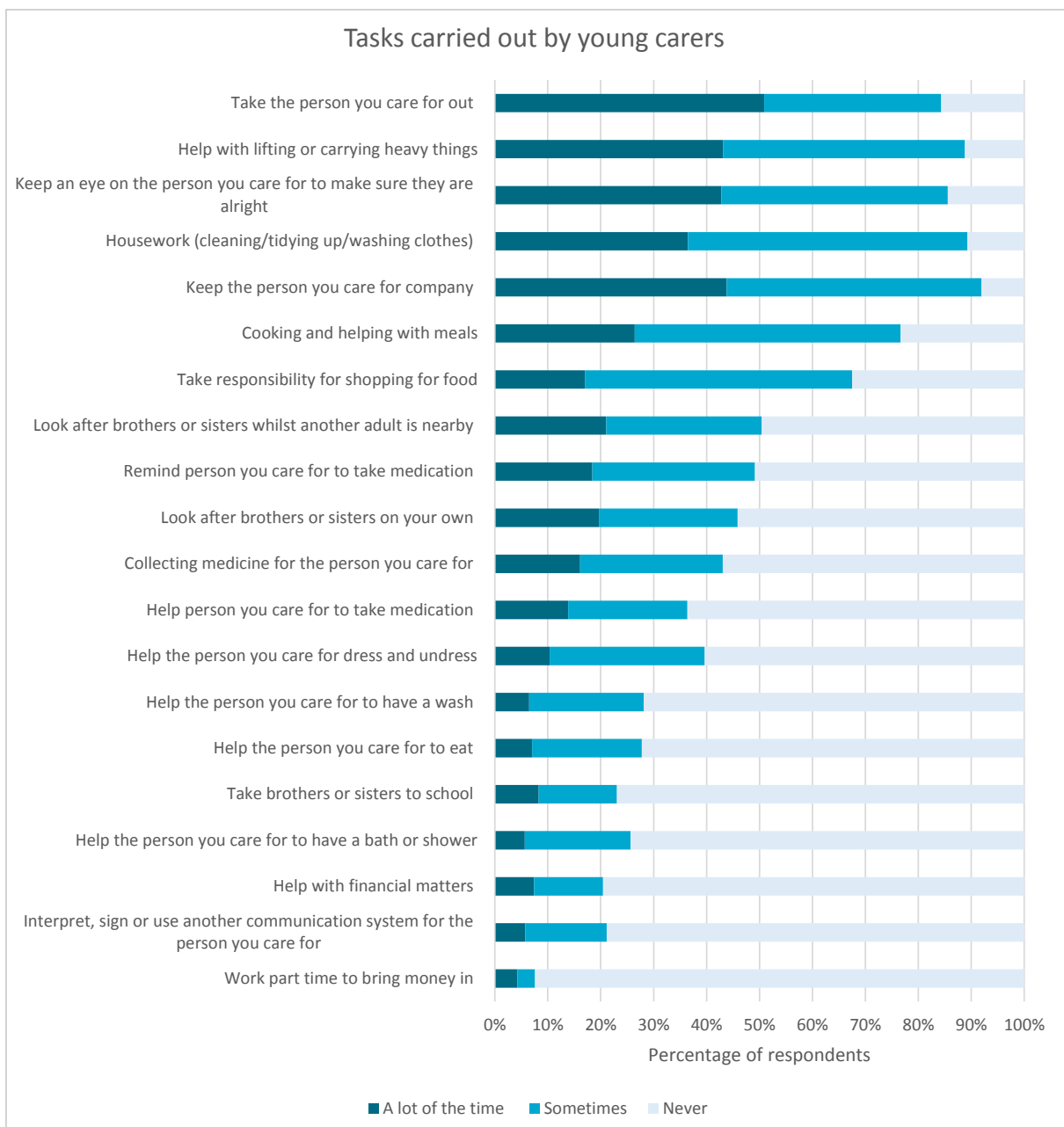


Figure 4: The types and frequency of tasks undertaken by young carers

3.10 We asked about how frequently the young carer has to help during the night (see Figure 5). Interestingly just over half, 51%, have to help at some point during the night although for most of these (43%) this is an occasional occurrence. Just over 1% (6 respondents) said they have to help every night.

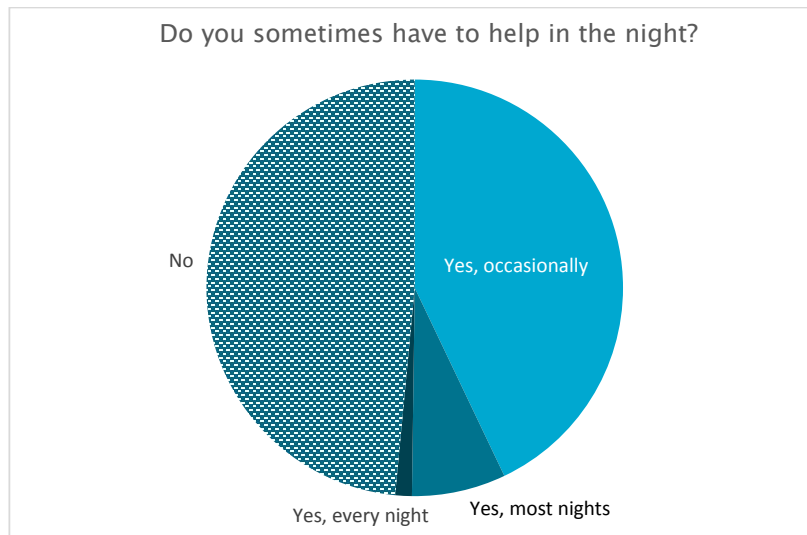


Figure 5: Frequency of young carers helping during the night

3.11 Based on the results reported in section 3.8 about the tasks undertaken by young carers we have developed a measurement for the level of responsibility carried by young carers which was used to generate three groups: low, medium and high levels of caring responsibility. We have used this measurement of caring responsibility throughout the rest of the analysis to investigate the impact of caring responsibility on various outcomes. This forms a central element of the findings of this research and, as will be seen, leads to some interesting findings.

How I feel about my caring responsibilities

3.12 Using one of the scales developed by Nottingham University⁶ we asked young carers about how they feel about their caring responsibilities. In the survey questions the positive and negative were mixed in with each other but for ease of illustrating the analysis we have grouped them in Figure 6 with the positive all together at the upper end of the chart and the negative aspects at the lower end. In general this shows that our sample of young carers felt more positively about their caring responsibilities than negatively about them and illustrates that caring can provide young people with a sense of worth and resilience.

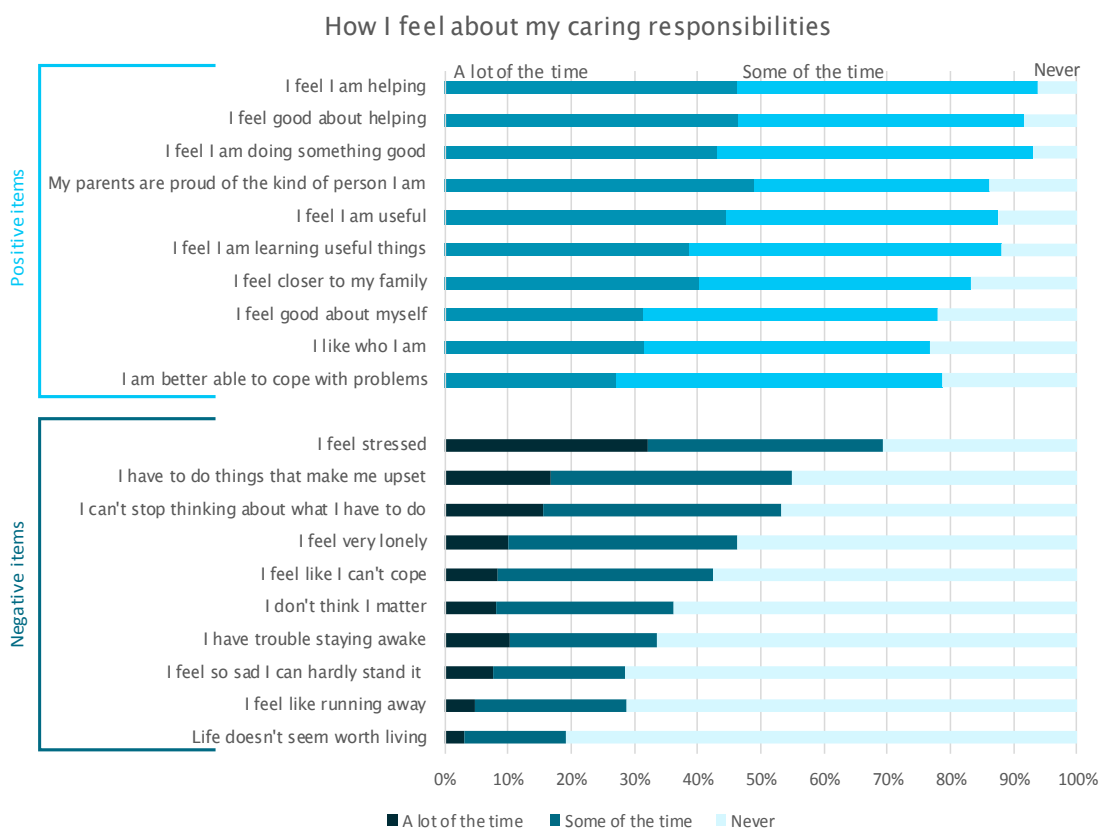


Figure 6: How young carers feel about their caring responsibilities

3.13 As described earlier, we developed a measure of the level of caring responsibility based on the tasks (as shown in figure 4) a young carer undertakes. We now examine the impact that the level of caring has on young carers. When we compare the results for the *level* of caring responsibility with how young carers *feel* (Figure 6) about their caring responsibilities we find a significant relationship between the level of caring responsibility and negative attitudes towards caring.

⁶ Known as MACA-YC18; Joseph, S. Becker, F. and Becker, S. (2009) Manual for Measures of Caring Activities and Outcomes for Children and Young People. London: The Princess Trust for Carers.

- 3.14 These results imply that those with a higher caring responsibility are more likely to perceive the negative aspects of being a young carer, for instance feeling stressed or lonely because of their responsibilities.
- 3.15 However, the equivalent relationship was weaker for an index of positive attitudes towards caring, as Figure 7 shows.

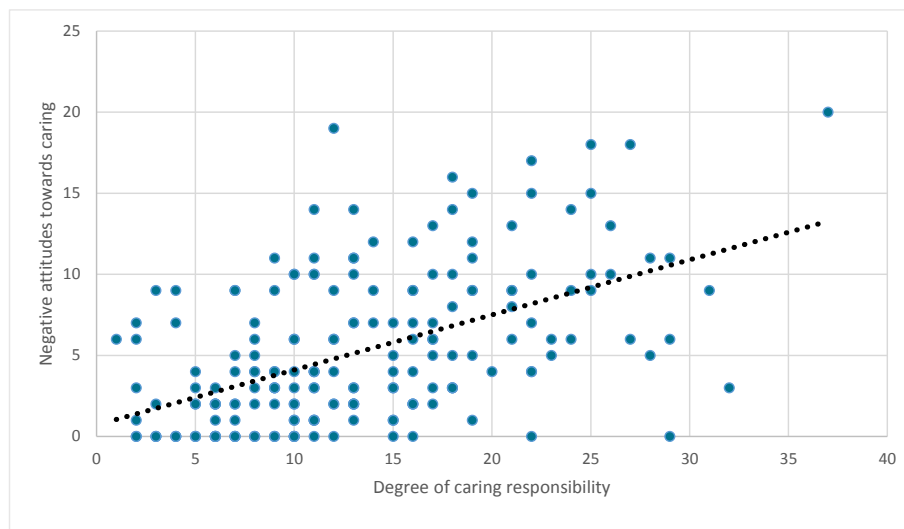


Figure 7: Attitudes towards caring linked to levels of caring responsibility

- 3.16 This suggests that the level of caring responsibility is less important in determining whether or not young people are able to reflect on the positive aspects of caring (for example, feeling that they are doing something good, and that their parents are proud of them).

My health and how I feel about myself

Quality of life

3.17 The survey asked young carers to mark on a ladder where they stand in terms of the best possible life (scoring 10) and the worst possible life (scoring 0). The average score given for all respondents was 6.6. Overall, 28% rated their lives in the bottom half of the ladder and 72% in the upper half of the ladder.

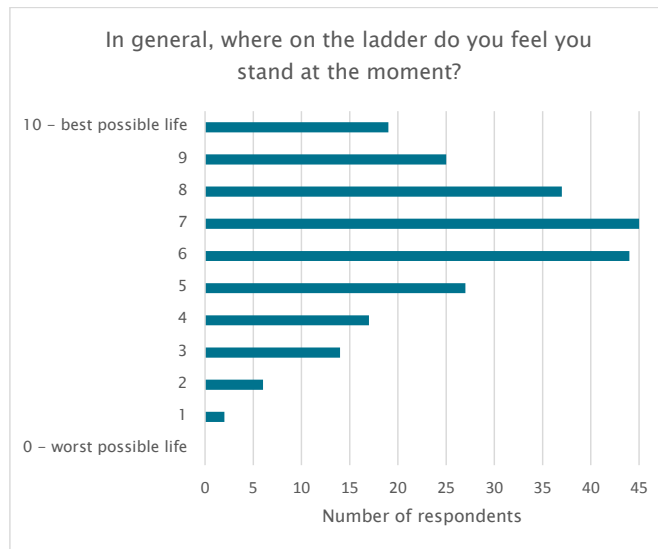


Figure 8: Rating of quality of life

3.18 We compared these survey results to those from the HBSC matched sample and the HBSC whole Scottish cohort (Figure 9). This shows a small but statistically significantly higher level of satisfaction for the young carers when compared to the matched HBSC sample. This bears out the assumption that there are positive elements of caring that give satisfaction and this effect may negate any impact of demographic factors that would otherwise reduce life satisfaction (including socio-economic status, age, gender).

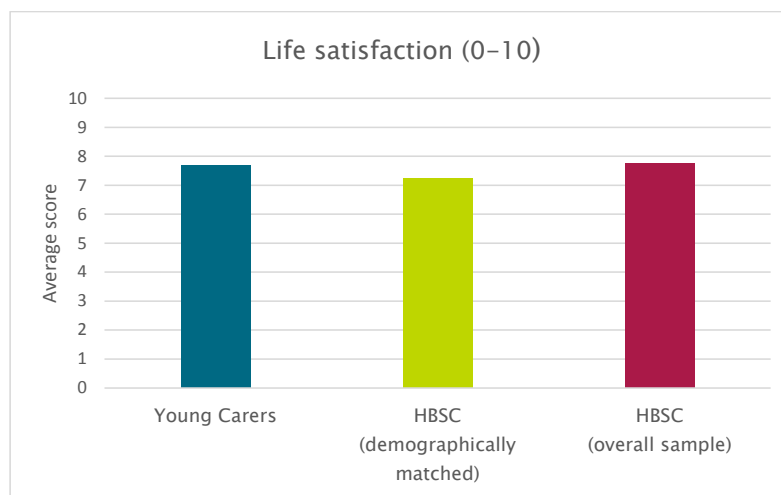


Figure 9: Rating of life satisfaction across the young carers, the matched HBSC sample and the overall HBSC sample

3.19 However when analysing the levels of life satisfaction in relation to the levels of caring responsibility we found the following results (Figure 10): the higher the degree of caring responsibility the less life satisfaction. So although overall the young carers reflect higher levels of life satisfaction than those who are comparable in terms of demography, life satisfaction reduces as caring responsibility increases. This makes sense intuitively and we will see this pattern in relation to those with a higher caring responsibility repeated many times in the rest of the analysis.



Figure 10: Life satisfaction relating to levels of caring responsibility

Happiness

3.20 We asked young carers about how they feel about their life at present: very happy, quite happy, not very happy and not at all happy, in order to give us an overall impression of their sense of their current life. The chart at Figure 11 illustrates how happy the young carers feel about their life at present. The majority (78%) feel either very happy or quite happy.

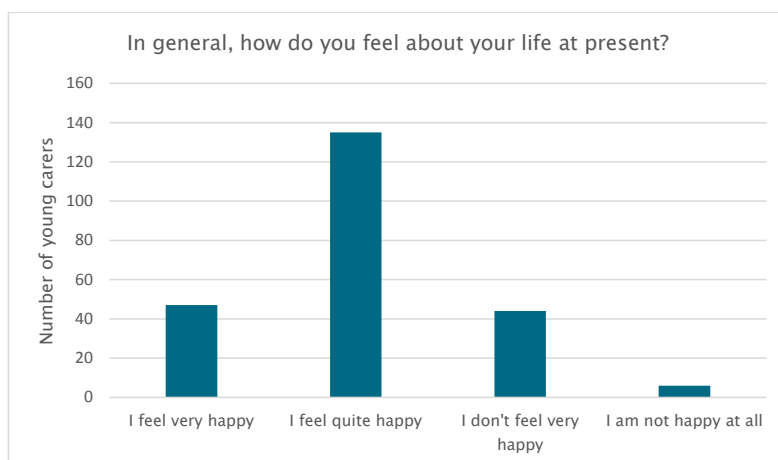


Figure 11: Levels of happiness with present life

3.21 However when we compare those who say they are “very happy” with the matched HBSC group and the overall HBSC group the young carers group comes out as having significantly lower levels of happiness than the matched HBSC group who in turn are lower than the overall HBSC group, as illustrated in Figure 12.

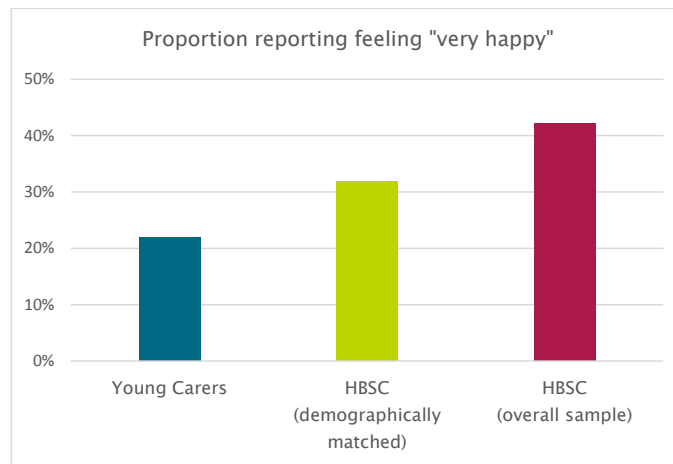


Figure 12: Comparison of feeling “very happy” with the HBSC matched sample and the overall HBSC sample

3.22 When we examine the level of caring responsibility with the stated levels of happiness we find a correlation between the happiness expressed by the young carers and their levels of caring responsibility, namely that the higher the level of caring the lower the level of happiness as shown in Figure 13.

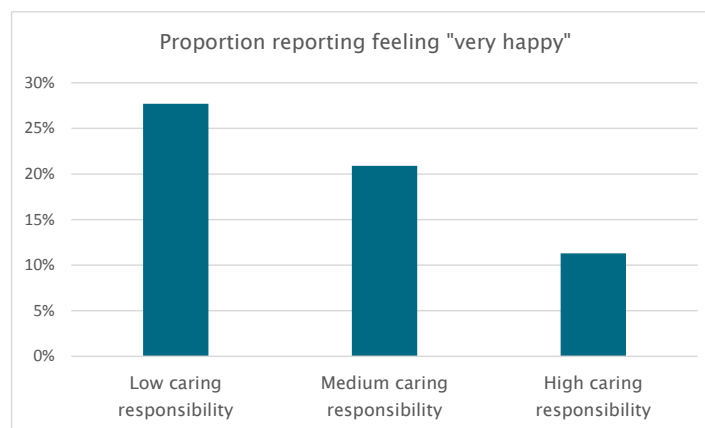


Figure 13: Comparison of feeling “very happy” across the different levels of caring responsibility

Health

3.23 We asked young carers to rate how often they had had certain physical and psychological symptoms in the last six months: rarely /never; about every month; about every week; more than once a week; about every day. Figure 14 shows the results. It appears that the health items relating to feelings and emotions such as difficulties getting to sleep, feeling nervous, irritability and feeling low are more frequent than those which are more physical such as being sick, dizziness, stomach ache and backache. Given that we have seen earlier that just over half our sample of young carers have to get up at least occasionally during the night, and so have disturbed sleep, this is perhaps not surprising.

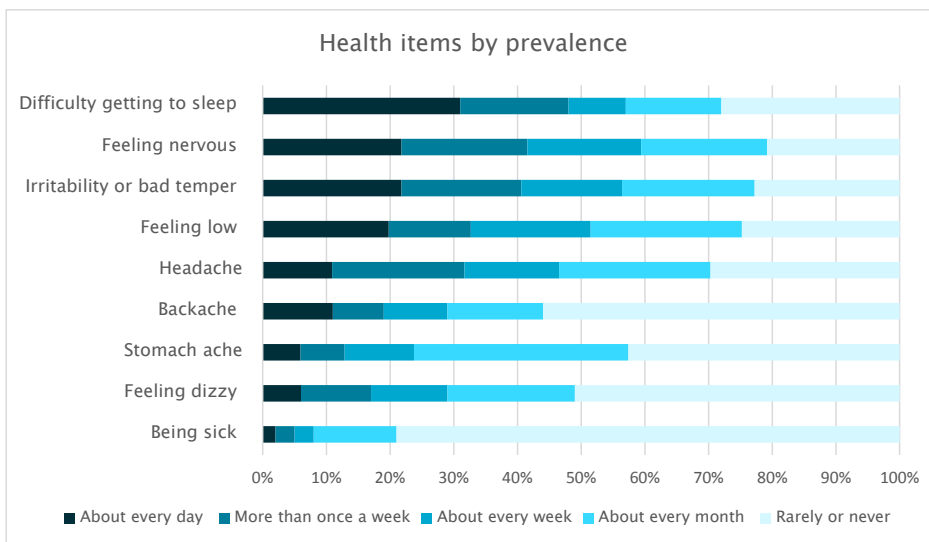


Figure 14: Prevalence of health symptoms in last 6 months

3.24 When we compare the health symptoms expressed by young carers to the HBSC matched⁷ and overall samples (see Figure 15) we find that the young carers have a significantly higher level of health symptoms than both the two HBSC groups. There is also a significant difference between the two HBSC samples showing that the more deprived group, the matched HBSC sample, has the greater frequency of health symptoms. In other words it bears out the old maxim that wealth is health. But being a young carer has an additional impact to the demographic impact.

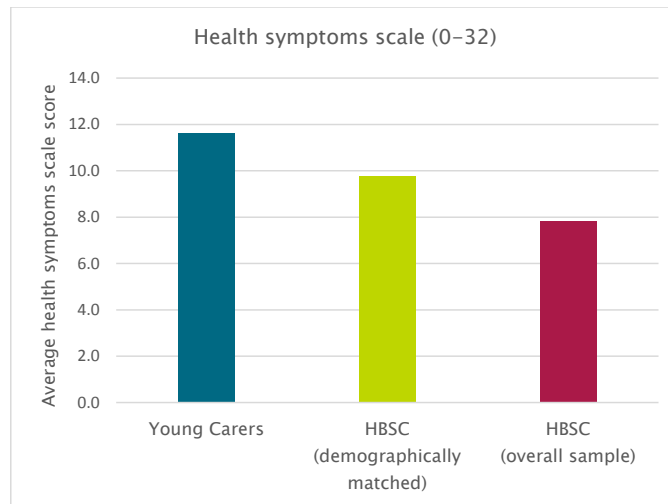


Figure 15: Health symptoms expressed by young carers compared to the matched and full HBSC sample

3.25 We also undertook a comparison within the young carers' sample (not illustrated here), which shows again that those with the greatest caring responsibility have higher levels of reported health symptoms.

⁷ We were only able to match eight of the nine health symptoms with the HBSC matched group as an additional item (being physically sick) had been added in by the young carers consulted at the festival.

3.26 We asked young carers to rate their health overall. When we compare the responses of those who said they have excellent health with those of the matched sample and the overall HBSC group (see Figure 16) we find that the overall HBSC group is significantly more likely to report excellent health than either the matched HBSC group or the young carers and there is no significant difference between the latter two groups.

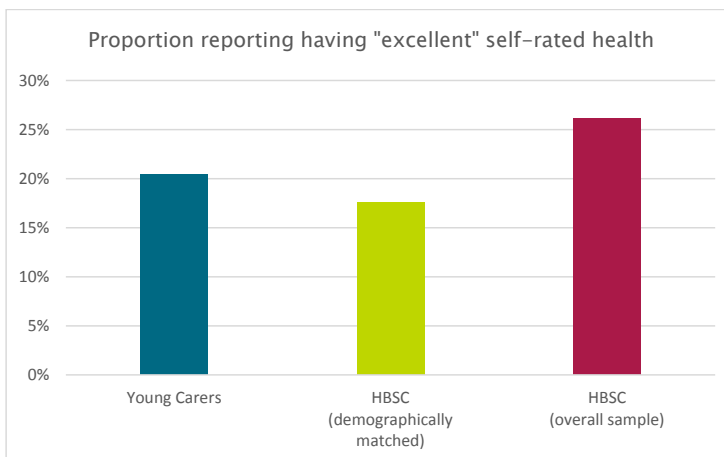


Figure 16: Young carers reporting "excellent" self-rated health compared to the HBSC matched and overall groups.

Confidence

3.27 We compared the young carers who stated they "always" feel confident with the matched and whole HBSC groups (see Figure 17). The HBSC whole group is significantly different to the matched HBSC sample indicating that there is only a demographic effect and that the young carers do not appear to have less confidence than those they are matched to demographically.

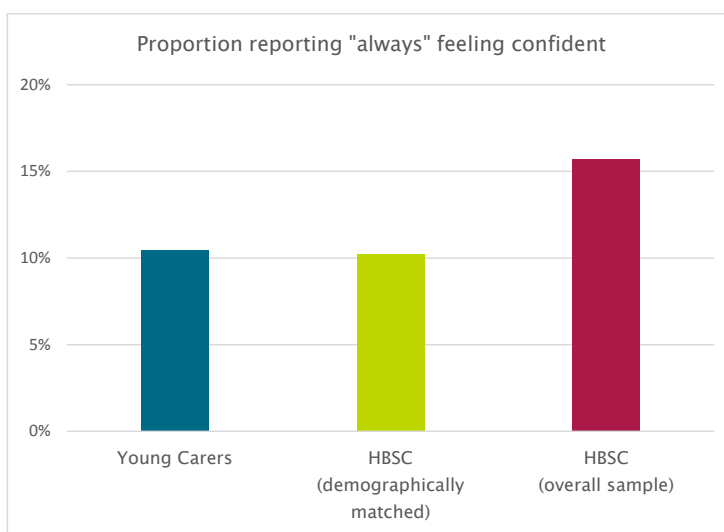


Figure 17: Young carers' level of confidence compared to the matched and whole HBSC groups

Stress

3.28 We asked the young carers to rate how often in the last month they had felt the following:

- unable to control the important things in their life;
- confident about their ability to handle their personal problems;
- that things were going their way; and,
- that difficulties were piling up so high that they could not overcome them.

3.29 The results from our overall respondent group of young carers (Figure 18) show that over half reported at least sometimes feeling that difficulties were piling up so high they could not overcome them, and an even greater proportion at least sometimes felt that they could not control the important things in their life. It could be useful to undertake further qualitative research around this aspect to explore in more depth the reasons for these feelings.

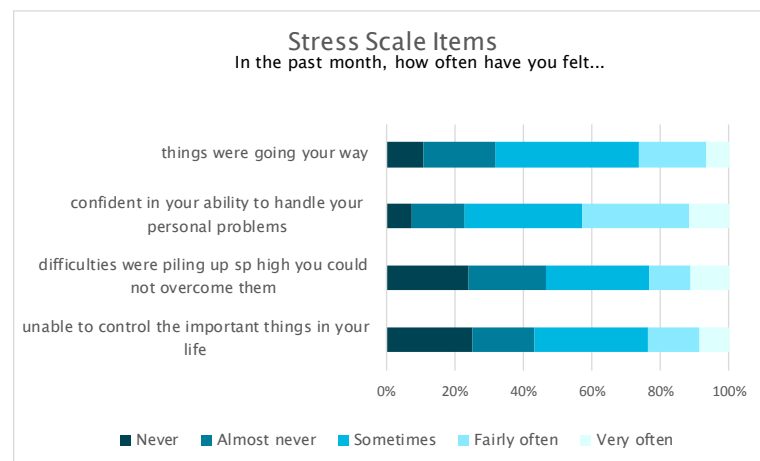


Figure 18: Stress levels expressed by the young carers

3.30 We amalgamated the four items above to provide a general stress level and compared the answers to those given in the HBSC matched sample and the overall HBSC group (not illustrated). The results show that there is no significant difference between the young carers group and the matched HBSC group but there is a significant difference between the matched HBSC and the overall HBSC groups which implies that there is only a demographic effect in this instance. As before we compared the stress levels of those with lower and higher degrees of caring responsibility and not surprisingly those with a higher caring responsibility have higher levels of stress as shown in Figure 19.

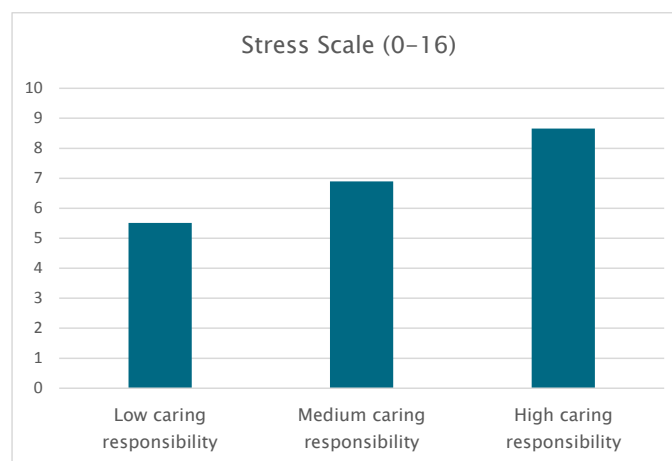


Figure 19: Levels of stress compared across different levels of caring responsibility

Sleep

3.31 We asked the young carers about the time they go to bed on school nights and get up in the morning, and about any difficulties they had in getting to sleep. The overall group of young carers who responded reported an average of 8.03 hours between when they go to bed and when they get up in the morning. This is not significantly different from their matched cohort, although there is a significant difference between the matched group and the HBSC overall, suggesting a demographic effect.

3.32 However, it is important to consider not just the hours spent in bed, but also the amount and quality of sleep. Young carers are significantly more likely than the other two groups to report having difficulty sleeping more than once a week (see Figure 20). Additionally, we already know that over half the young carers who responded reported having to help during the night at least occasionally.

3.33 There is also a significant difference between the matched HBSC and the overall HBSC group, suggesting that there is a demographic effect in sleep disturbance: that those who have lower socio-economic status are more likely to experience sleeping difficulties. However, the sleep disruption that young carers experience appears to go beyond this effect, suggesting that young carers are likely getting less, and lower quality, sleep above and beyond the demographic effect.

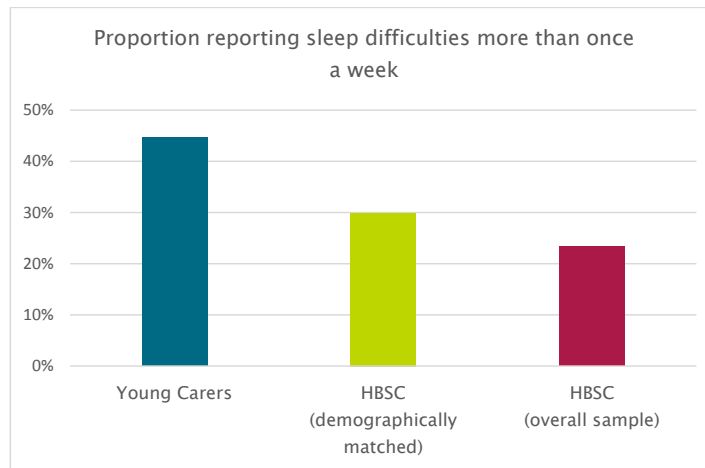


Figure 20: Young carers reporting having sleep difficulties compared to the HBSC matched and overall groups

3.34 Looking at the data on caring responsibility reinforces this point. Those with the lowest caring responsibility are about as likely as their demographically matched cohort to report having difficulty sleeping, but as caring responsibility increases, so does the reported sleep difficulty (see Figure 21).

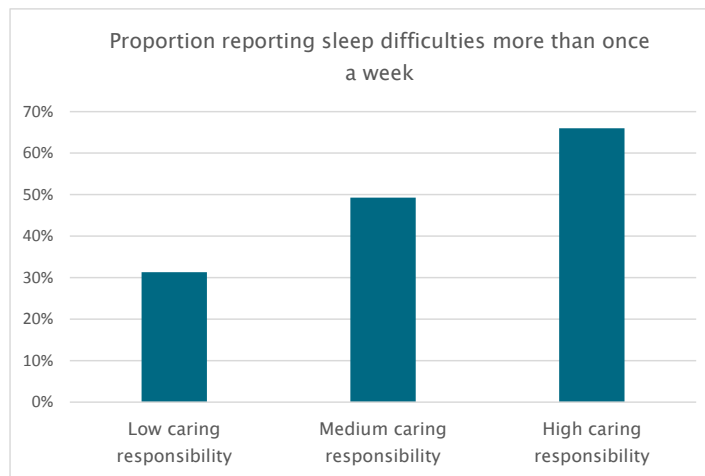


Figure 21: Young Carers reporting sleeping difficulties more than once a week

School

3.35 School life is important to any young person and so we wanted to find out about issues for young carers in relation to school. The results show that young carers are significantly more likely than the matched HBSC group to like school “a lot” (see Figure 22) but there is no significant difference between them and how the whole HBSC group like school. This is interesting and suggests that caring responsibilities in some way “negate” the impact of being in a lower demographic group in terms of liking school. This may be because school offers some welcome respite from caring responsibilities.

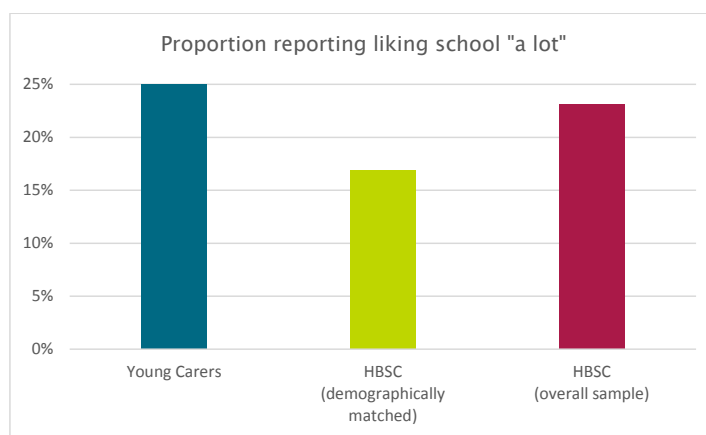


Figure 22: Comparison between young carers and the HBSC matched and overall groups of liking school “a lot”

3.36 We asked the young carers to rate five statements about how well their teachers support and accept them. The results show that the overall HBSC group feels most supported and accepted by their teachers and there is a significant difference between them and the matched HBSC group. However there is no significant difference between the young carers group and the matched HBSC group although there is a slight sense that the young carers come somewhere between the two. We might wonder whether this relates to the higher confidence levels in the overall HBSC group and therefore their sense that teachers are there to help and support them may come more readily than those from lower demographic backgrounds.

Friends and being included/left out

3.37 We asked the young carers about the number of friends they have. When we compare the results to those of the matched and whole HBSC groups (see Figure 23) we do not find any significant difference. This indicates that neither the caring responsibility nor demographic effects influence the number of friends one has. We should remember of course that the young carers we have surveyed were drawn from those who attend young carers groups and who may therefore be more inclined to make friends /be sociable than those who do not attend such groups. This latter point is

borne out when we analyse the results for the number of friends by the level of caring responsibility: this appears to make no difference to the number of friends one has.

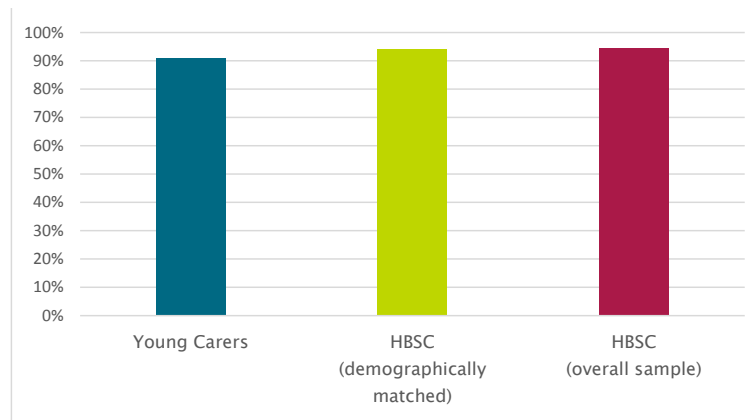


Figure 23: Young carers reporting having three or more friends compared to the HBSC matched and overall groups

3.38 Most young carers (90%) do have at least a friend who knows about their caring responsibilities: when asked whether their close friends know about their caring responsibilities, 29% said all of them did; 61% said some of them and 10% said none of them. The next question asked whether these friends are understanding about the young carer’s caring responsibilities. 44% said yes always; 37% said sometimes and 19% said not really or no. These results are illustrated in Figure 24. While it is positive that most young carers find their friends at least generally supportive, this does still leave almost one in five without friends who are understanding of their responsibilities.

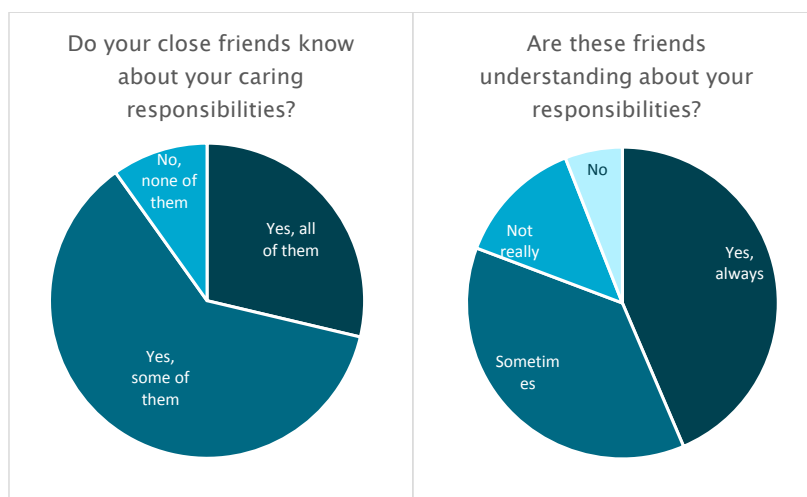


Figure 24: Illustration of whether friends know about caring responsibilities and whether they are understanding about them

3.39 We also asked the young carers to rate how often they felt “left out of things”. The overall young carers responses showed that two thirds feel left out at least some of the time (see Figure 25).

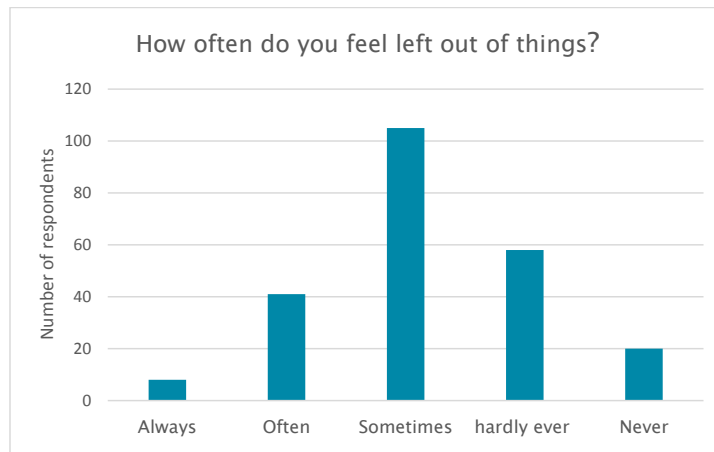


Figure 25: How often young carers feel left out of things

3.40 Figure 26 shows the comparison between the young carers reporting of feeling left out to the HBSC matched and overall groups. In comparison with the HBSC matched sample and the HBSC whole group, the latter is significantly more likely to never feel left out than the young carers group, but there is no significant difference between the two HBSC groups. This might indicate a summative effect: if one is both a young carer and in a certain demographic group they will be more likely to feel left out of things. Neither caring in itself nor belonging to a certain demographic group seem sufficient on their own to cause this effect.

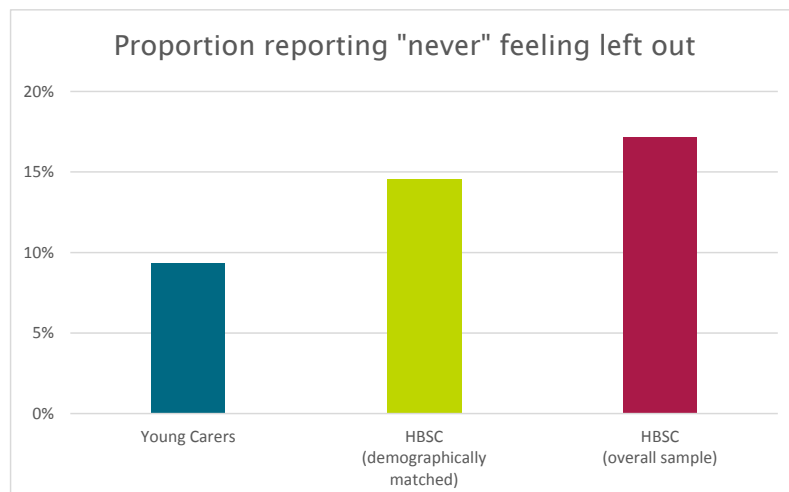


Figure 26: Young carers reporting feeling left out compared to the HBSC matched and overall groups

Use of support services

3.41 We wanted to find out about the kinds of external support that young carers are accessing. Table 1 shows the percentage of support services used by young carers in the past year. This shows that, as we would expect, there is a high usage of young carers' services (66%) followed by school guidance (47%) and then the doctor (37%). Just over a quarter of our sample (27%) have made use of counselling services and just under a quarter (23%) have used the Child and Adolescent Mental Health Services (CAMHS).

Table 1: Frequency of external support services accessed by young carers in the last year

Service	Proportion used in last year
Young Carers service	66.0%
School guidance	47.5%
Doctor	36.6%
Counselling	26.9%
CAMHS	22.7%
Website	20.6%
Smartphone app	18.9%
Helpline (Childline/Samaritans)	7.6%
Other	4.2%

"I get really tired a lot and really depressed a lot."

"It's because my mum passed away 5 months ago."

"Sleeping is the main problem."

"The worst thing about feeling really down is you don't know how to speak to people or tell them about your problems because you think they don't care or think your annoying."

What else would help with how you feel and how you are coping with everyday life?

3.45 There were 78 responses to this question. Of these 36 (almost half) said that either there was nothing else, they didn't know or they were fine. The remaining suggestions included many that focused on being able to talk to someone, either other family members, friends or services such as CAHMS or special befrienders:

"Someone to talk to who understands what it's like to care for someone."

"CAMHS and mental health services being better. Less waiting times."

"One-to-one chats."

"Meet with my support worker in school to slowly talk about how I got to feel how I am now."

3.46 Others talked about practical enjoyable things that would help such as young carer drop-ins and visits to the countryside or video games. The other practical things that young carers mention are more help from other people in their caring role:

"Someone to sit with my mum."

"More help from other family members."

"More regular support groups."

3.47 One respondent provided a helpful summary of all the things that would help them which mirrors all of the other comments:

"More awareness from people around me on how I'm coping/what I deal with. People just to listen and try to understand, be more patient with me and more flexible with deadlines/pressures. Someone specific who I can talk to who won't judge me and who will offer support and advice. More respite activities to get a break and to have fun, relax. Workshops to help me cope better-learn techniques, understand feelings and emotions in caring are normal and to not feel guilty."

3.48 The next chapter draws conclusions from these findings and sets out key issues which policy makers and those concerned with supporting young carers might consider.

4. Conclusions

Introduction

- 4.1 This survey has attempted, for the first time in Scotland, to match young carers and their perceptions of their health and wellbeing against a comparable sample of young people so that the findings that relate specifically to their caring responsibilities can be drawn out. This approach offers possibilities for repeating the exercise, segmenting other parts of the young population to compare with the overall and a matched HBSC group.

The make-up of the young carers' sample

- 4.2 Overall the results offer scope for interesting reflection in terms of the comparison with the matched group and in terms of the differentiation that has been possible within the young carers group between those who have a higher level of caring responsibility and those with medium and lower levels of caring responsibilities. It demonstrates clearly that "young carers" are not a homogeneous group.
- 4.3 Our sample of young carers includes two-thirds female and one-third male respondents: this is a higher female gender balance than the national young population gender balance. It also contains a higher balance of non-white young carers in comparison with the national young non-white population.
- 4.4 Over a quarter of the young carers' sample comes from the 15% most deprived areas of Scotland.

Highlights from the results

- 4.5 One of the clear results from this survey is that young carers are in a lower socio-economic group when compared with the main young population. This may be because there is generally poorer health and wellbeing in lower socio-economic groups or that in those instances where a parent is being cared for, the fact that one of the adults in the family is not working may have impacted on the family's socio-economic status.
- 4.6 Just over one quarter of the young carers have no-one else at home with whom they share their caring responsibilities and over a quarter provide care for two or more people.
- 4.7 In terms of the types of caring activities that young carers are fulfilling the most frequent ones relate to spending time with the person cared for, followed by undertaking household tasks. Forty per cent of young carers have to either dress or undress the person they care for at least occasionally. Young carers undertake financial and more intimate caring tasks less frequently.
- 4.8 Just over half the young carers' groups have to help at some point during the night at least occasionally.
- 4.9 Young carers expressed more positive feelings than negative ones about their caring role. This is important to reflect on as for some young carers the positive aspects of what they are doing clearly bring benefits to their own lives. This positive aspect can sometimes be overlooked. However those with a higher caring responsibility are more likely to perceive the negative aspects of caring.
- 4.10 A similar finding is seen in relation to life satisfaction: that while the overall group of young carers rate life satisfaction fairly positively, there is less satisfaction shown within those with a higher level of caring responsibilities.
- 4.11 The same pattern is found elsewhere in the results: around one quarter to a third of the young carers with the highest caring responsibilities have more negative results across a range of the aspects we looked at. For these young carers they:
- report more negative health effects than those with lower levels of caring.;
 - are generally less happy;
 - report more stress-related items; and,
 - get less sleep and are more likely to report sleep difficulties;
- 4.12 The quantitative data we have compiled appears to link to the qualitative data where again between a quarter and a third of the comments given about everyday coping showed signs of lack of coping and unhappiness.

4.13 Other points worth noting:

- Young carers show more self-worth than those in the matched sample, which indicates that despite lower socio-economic circumstances they have greater feelings of self-worth than their counterparts who are not caring for someone at home.
- Health problems relating to mental/emotional health are raised more frequently than physical health problems by the young carers.
- Young carers like school more than their counterparts who live in similar socio-economic circumstances. This might be because school offers respite from caring responsibilities. A by-product of this survey is that it illustrates the lower confidence levels generally of those in lower socio-economic groups and how this also translates into feelings of liking school less and feeling less supported by teachers.
- The number of friends you have does not appear to be affected either by caring or socio-economic status.
- Feeling left out of things seems to relate to both being a carer and belonging to a certain demographic group.

4.14 It appears from the survey that young carers are accessing services to support them and just over a quarter have accessed counselling support in the past year, with just under a quarter making use of the CAMHS service. However the survey did not explore issues to do with what young carers thought of the quality of these services and it could be useful to follow this up in any later research.

4.15 The survey asked young carers what would help them cope better. Being able to talk to someone who really listens and really understands is essential. Having enough time away from caring to do fun things such as attending the young carers' groups, which meet across Scotland or sports activities are clearly highly valued by those who take part in them. However we are conscious that our survey, which was distributed through young carers' groups, may not have reached the young carers who are more isolated and that this sample may in some respects contain more positive views than if we had been able to capture the views of all carers, both those who attend and those who do not attend young carers' groups.

Points for policy makers to consider

- 4.16 This survey has been undertaken at a time when there is increasing attention on the mental health and wellbeing needs of children and adolescents. The new mental health strategy which is due to be published in early 2017 will seek to ensure, among other things, that children and adolescents have access to appropriate mental health services.
- 4.17 This survey suggests that the young carers with the highest levels of caring amount to between one quarter and one third of the young carers population. This group have significantly lower levels of life satisfaction, feelings of happiness and general wellbeing than those with lower levels of caring. They are not coping as well with everyday living compared to the whole young carers' group. Their mental health and wellbeing is more at risk.
- 4.18 We suggest that for policy makers this is a key finding: how to divert the greatest levels of support to those young carers who are most in need of it. It is the young carers with the highest levels of caring responsibility who are most likely to suffer negative impact on their mental health and wellbeing.
- 4.19 In addition this research has suggested other work that it may be useful to consider:
- further qualitative research with those who have the greatest caring responsibilities to enable them to give more in-depth views about what would be most helpful in their situation;
 - qualitative research with "non-reached" young carers, that is those who do not necessarily attend the young carers' support groups who this survey has not reached;
 - repeating this survey work with other targeted groups of young people such as those with disabilities or travelling young people.

APPENDIX 1

Full explanation of Statistical and matching methods

A technique called “Propensity Score Matching” was used to generate a group against which the young carers sample can be compared on a range of mental health outcomes. The comparison group was selected from the 2014 Health Behaviour in School-aged Children (HBSC) study in Scotland. Up to five individuals from the HBSC sample were chosen as matches for each young carer (average of 4.7). After Propensity Score Matching, the young carers sample and the HBSC comparison group were statistically equivalent on five criteria pertaining to age, gender, socio-economic status ($\times 2$), and country of birth. We therefore make the assumption that the most important difference between the two resultant samples (in terms of likely mental health outcomes) is caring responsibility, however note that young carers are treated as a homogenous group for this analysis (i.e., differences in caring responsibility are not taken into account).

HBSC Matched Comparison Group

Throughout this report, statistical significance is evaluated at the 0.05 level. If a comparison has a p-value lower than this, then the difference between the two groups is likely to be a genuine effect (less than 5% likely to arise by chance alone).

Methods

In order to distil the unique impact that caring responsibilities have on young peoples’ mental health a comparison technique called “Propensity Score Matching” was used. In the context of the present study, this involves matching the sample of young carers against a comparator sample on a number of criteria that are known to affect the mental health outcomes of interest. Once a matched dataset is constructed, simple comparisons between these two groups can be conducted. These comparisons aim to reveal the impact of caring responsibilities, independently from potential confounds. If this matching technique was not applied, then any difference in mental health outcome between young carers and a comparison group might simply be due to differences in the cohorts sampled (e.g., one sample might be older, or include more of one gender).

In this study, a matched subset from the nationally-representative 2014 Health Behaviour in School-aged Children (HBSC) Scotland sample was selected as the comparator group. A detailed description of the 2014 HBSC Study is available elsewhere.⁸ Briefly, this study was conducted between January and June 2014 amongst 11, 13 and 15-year olds attending Scottish mainstream schools (N=10,839). Pupils self-completed a paper-based survey under classroom conditions, which included questions related to a broad range of health

8 http://www.cahru.org/content/03-publications/04-reports/hbhc_nr14_interactive_final.pdf

behaviours, mental health and social context. The questionnaire administered to young carers purposefully included a subset of questions from the 2014 HBSC Scotland study in order to allow comparison between this nationally-representative sample and those with caring responsibilities. In line with the national prevalence among the under 16 population, it is assumed that 4% of the 2014 HBSC Scotland sample have caring responsibilities,⁹ compared to 100% of those in the young carers' sample.

Five matching criteria are considered for the present analysis: age, gender, family affluence (measured via the family affluence scale,¹⁰ socio-economic status (assessed via the postcode-based Scottish Index of Multiple Deprivation - SIMD,¹¹) and country of birth. Whilst these criteria represent key factors associated with mental health¹² it is impossible for practical reasons to comprehensively survey all known determinants of mental health in a brief questionnaire. Therefore, when interpreting the comparative analysis in this report it should be borne in mind that there may exist un-measured differences between the group of young carers and the comparator group. However, mitigating the impact of this effect is the fact that the matching criteria that we were able to include are themselves known to be associated with a wide range of unmeasured determinants of mental health (e.g., age and gender are strong determinants of body image concerns, which were not measured in the young carer survey but represent a strong determinant of mental health problems).

Four of the five criteria showed significant differences between the two groups (there was no difference in country of birth). The five criteria were then used in the propensity score matching technique. Please note that 62 young carers (26.1%) were ineligible for matching because of one or more missing responses to questions relating to the matching criteria. Similarly, 4,070 pupils from the full HBSC sample (37.6%) were not available because of missing data on matching criteria.

The SPSS plugin "PSMATCHING3" (Thoemmes, 2012)¹³ was used to select from the 2014 HBSC Scotland sample a subset that was matched on age, family affluence, SIMD, gender and country of birth. Exact matches were sought on the latter two criteria, whereas for the former three, minor discrepancies between the young carer and matched control(s) were allowed (tolerance caliper = 0.1).

9 www.gov.scot/resource/0047/00473691.pdf

10 Hartley and colleagues., 2016 <http://link.springer.com/article/10.1007%2Fs12187-015-9325-3>

11 Scottish Government, 2016 <http://www.gov.scot/Topics/Statistics/SIMD>

12 Age Gender SES – Inchley and colleagues., 2016 <http://www.euro.who.int/en/health-topics/Life-stages/child-and-adolescent-health/health-behaviour-in-school-aged-children-hbsc>

Country of birth – Achenbach and colleagues., 2008 <https://www.ncbi.nlm.nih.gov/pubmed/18333930>

13 available at <http://sourceforge.net/projects/psmspss/files/>

We elected to match each young carer to a maximum of five individuals from the 2014 HBSC Scotland sample in order to maximise the precision of estimates from the HBSC subset. Matching at this ratio represents the optimal balance between precision and balance between groups (Ming & Rosenbaum, 2000). Nearest neighbour matching (without replacement) was used. This procedure generated a new dataset that contained 153 young carers¹⁴ and 714 individuals from the 2014 HBSC Scotland survey (reflecting a mean of 4.7 matches per young carer). This dataset is used for all comparisons between young carers and HBSC. For statistics not involving comparison with the HBSC sample all available data from the group of young carers are used.

After selecting the HBSC subset, a series of confirmatory statistics were conducted to verify that there was no significant difference between the group of young carers and the selected HBSC subset on the matching criteria. These results indicate that there were indeed no significant differences between these groups in terms of age, family affluence, SIMD, gender or country of birth. We therefore make the assumption that the most appreciable difference between these two groups (in terms of mental health determinants) is their caring responsibility, however note that matched comparisons do not take into account the extent of caring responsibility (young carers are treated as a homogenous group).

14 Of the 176 young carers providing information on each of the matching criteria, 23 were unable to be matched to any cases from the HBSC dataset (predominantly because of a large age discrepancy)

APPENDIX 2

Differences between Maca-yc13 and caring responsibility index used in this study

Identical in both versions
 Variation

	Original MACA-YC18 Items	Items in Caring Responsibility index for this study	
1	Clean your own bedroom	Housework (eg cleaning, tidying up, washing clothes etc)	1
2	Clean other rooms		
3	Wash up dishes or put dishes in a dishwasher		
4	Decorate rooms		
5	Take responsibility for shopping for food	Take responsibility for shopping for food	2
6	Help with lifting or carrying heavy things	Help with lifting or carrying heavy things	3
7	Help with financial matters such as dealing with bills, banking money, collecting benefits	Help with financial matters such as dealing with bills, banking money, collecting benefits	4
8	Work part time to bring money in	Work part time to bring money in	5
9	Interpret, sign or use another communication method for the person you care for	Interpret, sign or use another communication method for the person you care for	6
10	Help the person you care for to dress or undress	Help the person you care for to dress or undress	7
11	Help the person you care for to have a wash	Help the person you care for to have a wash	8
12	Help the person you care for to have a bath or shower	Help the person you care for to have a bath or shower	9
13	Keep the person you care for company eg. Sitting with them, reading to them, talking to them	Keep the person you care for company eg. Sitting with them, reading to them, talking to them	10
14	Keep an eye on the person you care for to make sure they are alright	Keep an eye on the person you care for to make sure they are alright	11
15	Tale the person you care for out, eg for a walk or to see friends or relatives	Tale the person you care for out, eg for a walk or to see friends or relatives	12
16	Take brothers or sisters to school	Take brothers or sisters to school	13
17	Look after brothers or sisters whilst another adult is nearby	Look after brothers or sisters whilst another adult is nearby	14
18	Look after brothers or sisters on your own	Look after brothers or sisters on your own	15
		Cooking and helping with meals	16
		Collect medication for the person you care for	17
		Remind the person you care for to take medication	18
		Help the person you care for to take medication	19
		Help the person you care for to eat	20

APPENDIX 3

References

- Aldridge, Jo. "The experiences of children living with and caring for parents with mental illness." *Child abuse review* 15.2 (2006): 79-88.
- Aldridge, Jo, and Saul Becker. *Children caring for parents with mental illness: Perspectives of young carers, parents and professionals*. MIT Press, 2003.
- Ali, Lilas, et al. "Daily life for young adults who care for a person with mental illness: a qualitative study." *Journal of psychiatric and mental health nursing* 19.7 (2012): 610-617.
- Ali, Krevers, Sjostrom & Skarsater, 2014
- Becker, Fiona, and Saul Becker. "Young Adult Carers in the UK." *Experiences, Needs and Services for Carers aged* (2008): 16-24.
- Becker, Saul. "Global perspectives on children's unpaid caregiving in the family research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa." *Global social policy* 7.1 (2007): 23-50.
- Beidel, Deborah C., and Samuel M. Turner. "At risk for anxiety: I. Psychopathology in the offspring of anxious parents." *Journal of the American Academy of Child & Adolescent Psychiatry* 36.7 (1997): 918-924.
- Bibby, Andrew, and Saul Becker, eds. *Young carers in their own words*. London: Calouste Gulbenkian Foundation, 2000.
- Bolas, Helen, Anna Van Wersch, and Darren Flynn. "The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis." *Psychology and health* 22.7 (2007): 829-850.
- Cass, Bettina, et al. "Young carers: Social policy impacts of the caring responsibilities of children and young adults." (2011).
- Cree, Vivienne E. "Worries and problems of young carers: issues for mental health." *Child & Family Social Work* 8.4 (2003): 301-309.
- Dearden, Christopher, and Saul Becker. "The experiences of young carers in the UK: The mental health issues." *Mental Health Care* 2 (1999): 273-276.
- Eley, Susan. "'If they don't recognize it, you've got to deal with it yourself': gender, young caring and educational support." *Gender and Education* 16.1 (2004): 65-75.
- Frank, Jenny. *Couldn't care more: A study of young carers and their needs*. London: Children's Society, 1995.
- Gates, Marie F., and Nancy R. Lackey. "Youngsters caring for adults with cancer." *Image: The Journal of Nursing Scholarship* 30.1 (1998): 11-15.
- Hill, Trish, et al. "Young Carers: Their characteristics and geographical distribution." Canberra, Australia: Social Policy Research Centre (2009).
- Hounsell, D. "Hidden from view: The experiences of young carers in England." (2013).

- Johansson A., Brunnberg E. & Eriksson C. (2007) Adolescent girls' and boys' perceptions of mental health. *Journal of Youth Studies* 2, 183–202. Lloyd's (2013) Lifestyle, Scottish Schools Adolescent. "Scottish Schools Adolescent Lifestyle and Substance Use Survey National Report 2015." (2016).
- Lloyd, Katrina. "Happiness and well-being of young carers: Extent, nature and correlates of caring among 10 and 11 year old school children." *Journal of Happiness Studies* 14.1 (2013): 67-80. Martin, 2006;
- McAndrew, Sue, et al. "Young, gifted, and caring: A project narrative of young carers, their mental health, and getting them involved in education, research and practice." *International journal of mental health nursing* 21.1 (2012): 12-19.
- Misic, Aleksander. *The Hidden Society: A Study of the Non-English Speaking Background Carer Issues*. Carers Association of NSW, 1996.
- Moore, Tim, and Morag McArthur. "We're all in it together: Supporting young carers and their families in Australia." *Health & social care in the community* 15.6 (2007): 561-568.
- Morrow, Ros. "A profile of known young carers and identification and snapshot of the ones who are hidden." (2005).
- Noble-Carr, Debbie. *Young carers research project: Final report*. Department of Family and Community Services, 2002.
- Olsen, Richard. "Young carers: challenging the facts and politics of research into children and caring." *Disability & society* 11.1 (1996): 41-54.
- Rose, Helena D., and Keren Cohen. "The experiences of young carers: A meta-synthesis of qualitative findings." *Journal of youth studies* 13.4 (2010): 473-487.
- Sahoo, Rojalini, and Damodar Suar. "Influence of social environment on young carers, assistance and consequences of caregiving." *Psychological Studies* 55.4 (2010): 323-329
- Smyth, Ciara, Megan Blaxland, and Bettina Cass. "'So that's how I found out I was a young carer and that I actually had been a carer most of my life'. Identifying and supporting hidden young carers." *Journal of Youth Studies* 14.2 (2011): 145-160.
- Tucker, Stan, and Penny Liddiard. "Young carers." *Care Matters: Concepts, Practice and Research in Health and Social Care* (1998): 54-65.
- Van Loon, Linda MA, et al. "The relation between parental mental illness and adolescent mental health: The role of family factors." *Journal of Child and Family Studies* 23.7 (2014): 1201-1214.
- Vitaliano, Peter P., Jianping Zhang, and James M. Scanlan. "Is caregiving hazardous to one's physical health? A meta-analysis." *Psychological bulletin* 129.6 (2003): 946.
- Warren, Janet. "Young Carers: Conventional or exaggerated levels of involvement in domestic and caring tasks?." *Children & Society* 21.2 (2007): 136-146.



Thoughts on your health and wellbeing

This is a chance to tell us how your important role as a young carer affects how you feel and how you cope with everyday life. It is important to know this so that support for young carers can be even better.

Please be completely honest with your answers, they will be anonymous because you don't have to put your name on it anywhere. If you fill in an answer incorrectly, just put a cross through it and then fill in the correct answer.

We hope you will complete this survey. To encourage as many people as possible to take part we are going to hold a **prize draw**.

Prize Draw



If you want your name to go into the prize draw please write it here with a contact number and which Young Carers' Group you attend. **Tear off** this sheet once you have answered the survey questions.

First prize - £100 voucher

Second prize - £75 voucher

Third prize - £50 voucher

Name _____

Telephone number: _____

Young Carers' Group _____



Firstly, some questions about your family (please circle your answers)

Q1 Do you have your own bedroom for yourself?

- ☆ Yes
- ☆ No

Q2 Does your family own a car, van or truck?

- ☆ No
- ☆ Yes, one
- ☆ Yes, two or more



Q3 How many computers does your family own (including PCs, Macs, laptops and tablets, **NOT** including game consoles and smartphones)?

- ☆ None
- ☆ One
- ☆ Two
- ☆ More than two

Q4 How many bathrooms (room with a bath/shower or both) are in your home?

- ☆ None
- ☆ One
- ☆ Two
- ☆ More than two

Q5 Does your family have a dishwasher at home?

- ☆ Yes
- ☆ No

Q6 How many times did you and your family travel out of Scotland for a holiday/vacation **last year**?

- ☆ None
- ☆ One
- ☆ Two
- ☆ More than two

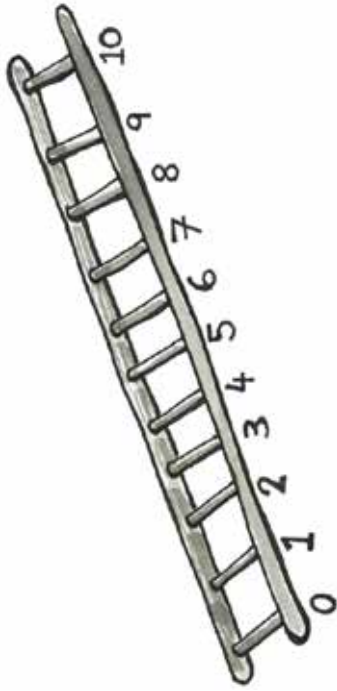


Q7 How well off do you think your family is?

- ☆ Very well off
- ☆ Quite well off
- ☆ Average
- ☆ Not very well off
- ☆ Not at all well off

Now, some questions about your health and how you feel

Q8 Here is a picture of a ladder. The top of the ladder '10' is the best possible life for you and the bottom '0' is the worst possible life for you. In general, where on the ladder do you feel you stand at the moment?



Draw a circle on the number that best describes where you stand.

Q9 Would you say your health is...? (please circle your answer)

☆ Excellent ☆ Good ☆ Fair ☆ Poor

Q10 In the last 6 months: how often have you had the following? (For each one, please circle your answer)

	About every day	More than once a week	About every week	About every month	Rarely or never
Headache	☆	☆	☆	☆	☆
Stomach-ache	☆	☆	☆	☆	☆
Backache	☆	☆	☆	☆	☆
Feeling low	☆	☆	☆	☆	☆
Irritability or bad temper	☆	☆	☆	☆	☆
Feeling nervous	☆	☆	☆	☆	☆



- Difficulties in getting to sleep ☆ ☆ ☆ ☆ ☆ ☆
- Feeling dizzy ☆ ☆ ☆ ☆ ☆ ☆
- Being sick ☆ ☆ ☆ ☆ ☆ ☆

Q11 How often do you feel left out of things? (Please circle your answer)

- ☆ Never
- ☆ Hardly ever
- ☆ Sometimes
- ☆ Often
- ☆ Always

Q12 How often do you feel confident in yourself? (Please circle your answer)

- ☆ Never
- ☆ Hardly ever
- ☆ Sometimes
- ☆ Often
- ☆ Always

Q13 In general, how do you feel about your life at present? (Please circle your answer)

- ☆ I feel very happy
- ☆ I feel quite happy
- ☆ I don't feel very happy
- ☆ I'm not happy at all



Now some questions about going to bed and sleeping... (Please circle your answer)

- Q14 When do you usually **go to bed** if you have to go to school the next morning?
- | | | | | | | | | | | |
|-------------------|--------|------|---------|------|---------|----------|---------|-----|--------|--------------|
| No later than 9pm | 9.30pm | 10pm | 10.30pm | 11pm | 11.30pm | Midnight | 12.30am | 1am | 1.30am | 2am or later |
| ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ |
- Q15 When do you usually **go to bed** at weekends or during holidays?
- | | | | | | | | | | | | | | | |
|-------------------|--------|------|---------|------|---------|----------|---------|-----|--------|-----|--------|-----|--------|--------------|
| No later than 9pm | 9.30pm | 10pm | 10.30pm | 11pm | 11.30pm | Midnight | 12.30am | 1am | 1.30am | 2am | 2.30am | 3am | 3.30am | 4am or later |
| ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ |
- Q16 When do you usually **wake up** on school mornings?
- | | | | | | | |
|-------------------|--------|-----|--------|-----|--------|--------------|
| No later than 5am | 5.30am | 6am | 6.30am | 7am | 7.30am | 8am or later |
| ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ |
- Q17 When do you usually **wake up** at weekends or during holidays?
- | | | | | | | | | | | | | | | | |
|-------------------|-----|--------|-----|--------|-----|--------|------|---------|------|---------|--------|---------|-----|--------|--------------|
| No later than 7am | 7am | 7.30am | 8am | 8.30am | 9am | 9.30am | 10am | 10.30am | 11am | 11.30am | Midday | 12.30pm | 1pm | 1.30pm | 2pm or later |
| ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ | ☆ |
- Q18 Do you sometimes have to help during the night?
- | | | | |
|-----------|-------------------|------------------|------------------|
| No, never | Yes, occasionally | Yes, most nights | Yes, every night |
| ☆ | ☆ | ☆ | ☆ |

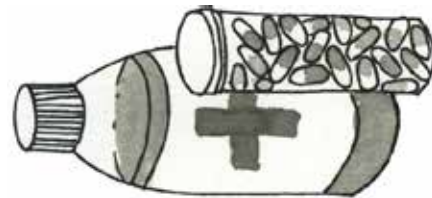
And now some questions about you as a carer...

Q.19

Below are some jobs that young carers do to help. Think about the help you have provided **over the last month.**

Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month.

	Never	Some of the time	A lot of the time
Take responsibility for shopping for food	☆	☆	☆
Housework (cleaning/tidying up/washing clothes)	☆	☆	☆
Help with lifting or carrying heavy things	☆	☆	☆
Cooking and helping with meals	☆	☆	☆
Help with financial matters such as dealing with bills, banking money, collecting benefits	☆	☆	☆
Work part time to bring money in	☆	☆	☆
Interpret, sign or use another communication system for the person you care for	☆	☆	☆
Help the person you care for to dress or undress	☆	☆	☆
Help the person you care for to have a wash	☆	☆	☆
Help the person you care for to have a bath or shower	☆	☆	☆
Help the person you care for to eat	☆	☆	☆
Keep the person you care for company e.g. sitting with them, reading to them, talking to them	☆	☆	☆
Keep an eye on the person you care for to make sure they are alright	☆	☆	☆
Take the person you care for out e.g. for a walk or to see friends or relatives	☆	☆	☆
Collecting medicine for person you care for	☆	☆	☆
Remind person you care for to take medication	☆	☆	☆
Help person you care for to take medication	☆	☆	☆
Take brothers or sisters to school	☆	☆	☆
Look after brothers or sisters whilst another adult is near by	☆	☆	☆
Look after brothers or sisters on your own	☆	☆	☆



Q20 How many **people** do you provide care for? (Please circle your answer)

- ☆ 0
- ☆ 1
- ☆ 2
- ☆ 3 or more

Q21 Do you **share** your caring responsibilities with anyone else living at home? (Please circle your answer)

- ☆ No-one else
- ☆ One other person
- ☆ Two other people
- ☆ Three or more other people

Q22 **Below are some things young carers like you have said about what it feels like to look after someone.**

Please read each statement and tick the box to show how often this is true for you.

	Never	Some of the time	A lot of the time
Because of caring I feel I am doing something good	☆	☆	☆
Because of caring I feel that I am helping	☆	☆	☆
Because of caring I feel closer to my family	☆	☆	☆
Because of caring I feel good about myself	☆	☆	☆
Because of caring I have to do things that make me upset	☆	☆	☆
Because of caring I feel stressed	☆	☆	☆
Because of caring I feel that I am learning useful things	☆	☆	☆

Because of caring my parents are proud of the kind of person I am	☆	☆	☆	☆	☆
Because of caring I feel like running away	☆	☆	☆	☆	☆
Because of caring I feel very lonely	☆	☆	☆	☆	☆
Because of caring I feel like I can't cope	☆	☆	☆	☆	☆
Because of caring I can't stop thinking about what I have to do	☆	☆	☆	☆	☆
Because of caring I feel so sad I can hardly stand it	☆	☆	☆	☆	☆
Because of caring I don't think I matter	☆	☆	☆	☆	☆
Because of caring I like who I am	☆	☆	☆	☆	☆
Because of caring life doesn't seem worth living	☆	☆	☆	☆	☆
Because of caring I have trouble staying awake	☆	☆	☆	☆	☆
Because of caring I feel I am better able to cope with problems	☆	☆	☆	☆	☆
I feel good about helping	☆	☆	☆	☆	☆
Because of caring I feel I am useful	☆	☆	☆	☆	☆

Q23 In the last month... (Please circle your answer)

	Never	Almost never	Sometimes	Fairly often	Very often
How often have you felt that you were unable to control the important things in your life?	☆	☆	☆	☆	☆
How often have you felt confident about your ability to handle your personal problems?	☆	☆	☆	☆	☆
How often have you felt that things were going your way?	☆	☆	☆	☆	☆
How often have you felt difficulties were piling up so high that you could not overcome them?	☆	☆	☆	☆	☆

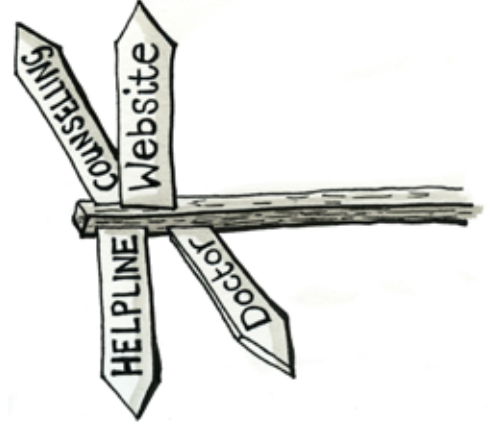
Q24 Is there anything else you would like to say about how you feel and how you are coping with everyday life?

Q25 Because of your caring responsibilities in the last year **have you used** any of the following services for help with how you've been feeling?

Because of your caring responsibilities **would you like to use** any of these services in the future?
 (Please circle your answers)

	Have used in the last year	Would like to use in future
--	-------------------------------	--------------------------------

Counselling	☆	☆
Website	☆	☆
Young carers service	☆	☆
Doctor	☆	☆
CAMHS (Child + Adolescent Mental Health Services)	☆	☆
Smartphone App	☆	☆
Helpline (Childline/Samaritans)	☆	☆
School guidance	☆	☆
Other _____	☆	☆



Q26 What else would help with how you feel and how you are coping with everyday life?

Here are some questions about school... (Please circle your answer)

- Q27 Do you go to school? (If no, skip to Q30)
 ☆ Yes ☆ No
- Q28 How do you feel about school at present?
 ☆ I like it a lot ☆ I like it a bit ☆ I don't like it very much ☆ I don't like it at all
- Q29 Here are some statements about the teachers in your class(es).
 Please circle your answers to show how much you agree or disagree with each one.
- | | Strongly agree | Agree | Neither agree nor disagree | Disagree | Strongly disagree |
|---|----------------|-------|----------------------------|----------|-------------------|
| I feel that my teachers provide me with choices and options | ☆ | ☆ | ☆ | ☆ | ☆ |
| My teachers listen to how I would like to do things | ☆ | ☆ | ☆ | ☆ | ☆ |
| I feel that my teachers accept me as I am | ☆ | ☆ | ☆ | ☆ | ☆ |
| I feel that my teachers care about me as a person | ☆ | ☆ | ☆ | ☆ | ☆ |
| I feel a lot of trust in my teachers | ☆ | ☆ | ☆ | ☆ | ☆ |



Now some questions about friends... (Please circle your answer)

Q30 At present, how many close male and female friends do you have? Please circle one answer in each column.

Males **Females**

- ☆ None ☆
- ☆ One ☆
- ☆ Two ☆
- ☆ Three or more ☆

Q31 How often do you meet your friends outside school time?

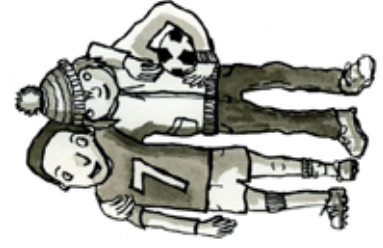
- | | | | | |
|-------------------|-------------------------|---------------------|--------|-------|
| | Hardly ever or
never | Less than
weekly | Weekly | Daily |
| Before 8pm | ☆ | ☆ | ☆ | ☆ |
| After 8pm | ☆ | ☆ | ☆ | ☆ |

Q32 Do your close friends know about your caring responsibilities?

- ☆ Yes, all of them ☆ Yes, some of them ☆ No, none of them

Q33 Are these friends understanding about your responsibilities?

- ☆ Yes, always ☆ Sometimes ☆ Not really ☆ No



Now some questions about you... (Please circle your answer)

- Q34 Are you a boy or a girl?
 Boy
 Girl
 Prefer not to say
- Q35 What is your date of birth? (Please write below, e.g. 7th August 1999 = 07 - 08 – 1999)

- Q36 Do you know the postcode for your home address?
 (This may be used, for example, to find out what type of place you live in (e.g. city, town or rural area).
 It will not be used to identify you).
 Yes, my postcode is: _____
 No
- Q37 In which country were you born?
 Scotland
 England
 Wales
 Northern Ireland
 Republic of Ireland
 Another country (please say where: _____)

- Q38 What language do you use most often at home?
☆ English, Scottish, and/or Gaelic
☆ Other (please say what: _____)
- Q39 Are you:
☆ Bangladeshi
☆ Black – African
☆ Black – Caribbean
☆ Black – Other
☆ Chinese
☆ Indian
☆ Pakistani
☆ White
☆ Other (please say what: _____)
- Q40 Do you have a disability, long-term sickness or learning disability?
☆ Yes
☆ No
☆ Prefer not to say

Thank you for filling in this survey!

Please now put it in the blank envelope provided and hand the envelope back to your Young Carers' Worker.

Remember to remove the front sheet with your prize draw details!



Rosebery House
Ground Floor,
9 Haymarket Terrace
Edinburgh EH12 5EZ

tel: 0131 345 5350
www.cypcs.org.uk
info@cypcs.org.uk

Freephone:
0800 019 1179

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