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Young carers: Review of research and data

HEALTH AND SOCIAL CARE

social
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Executive Summary

Review of data and evidence on young carers

Young carers are those who provide help or support to family members, friends, neighbours or others because of either long term physical or mental ill health, disability or problems related to old age. This paper discusses the data and evidence on young carers and young adult carers. In this report, the term 'young adult carers' refers to people aged 16–24 years, and the term 'young carers' to people aged 4–15 years. This is primarily due to the way in which the statistical data is organised and it is recognised that young carers are usually considered as those aged under 18[1].

The purpose of this paper is to:

- Investigate the profile, characteristics and impacts of caring for young carers and young adult carers
- Provide an increased understanding of the existing evidence on the prevalence and impacts of young caring and the available support, in advance of the implementation of the Carers (Scotland) Act which is due to be commenced on 1 April 2018

It combines an analysis of data on young carers from Scotland's Census 2011 with the findings of a review of the evidence on young carers focused on the period 2005-2015.

Who are young carers in Scotland?

The most accurate estimate (from the Scottish Health Survey) suggests that around 7% of young people in Scotland (93, 000) have caring responsibilities. It is likely that this is an under estimate[2] as not all young carers will identify as a young carer, either because they do not see themselves in that role or because they are concerned about revealing their caring responsibilities.

Young carers are a diverse group of all ages and backgrounds and live in all areas of Scotland. However, the Census shows that caring is more common in some groups of young people than others. The data suggests that as children become older more of them regularly provide a few hours of caring per week. The majority of young carers and young adult carers are female. A higher proportion of young people in the most deprived areas report providing care and they provide the most

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[1] The Carers (Scotland) Act defines young carers as those aged under 18 or who are aged 18 and a pupil at school.

[2] For example, surveys conducted by the Carers Trust have found larger percentages.

hours of care. Young carers in rural areas may face additional challenges due to the more dispersed nature of services and facilities.

Young carers' health and well-being

The data shows that being a young carer tends to be associated with poorer health and well-being. This is true for self-reported health, long term conditions or disabilities and mental health conditions. This is likely to have implications for other areas of young carers' lives, such as education and employment.

Although those providing more hours of care appear to have worse self-reported health, it is not possible to say the extent to which this is directly related to caring responsibilities. Other factors such as deprivation, gender and support networks are also likely to have an impact.

Research suggests that young carers may face challenges in participating in social or leisure activities and may feel isolated as a result. However, it is also important to note that young carers can be positive about their caring role and feel that it brings benefits.

Young carers' education and employment

Caring may adversely affect a young person's education but there is inconsistent evidence on the extent of the impact. The issues most commonly found to affect a young carer's education were school attendance, tiredness and bullying. Schools therefore have an important role in helping to support young carers. Young carers can face challenges in balancing their caring responsibilities and education and employment requirements and opportunities.

Caring responsibilities may influence education and employment choices and flexibility is an important factor in enabling young carers to balance different commitments. The negative impact of combining caring and education may have potentially significant enduring consequences for workforce participation, and geographic and social mobility, with the risk of compounding deprivation and inequalities.

The number of students in further and higher education who say that they are carers declines with each year of age. Caring roles may impact on the choice of university and on the choice of course and research has also highlighted young adult carers' financial concerns in education.

Support for young carers

The evidence is stronger on the challenges facing young carers than it is on effective support and interventions. However, it does highlight the importance of recognition and an assessment of need and that effective support can be either or both for the young carer or for the cared person.

Evidence suggests that children and young people engaged in young carer support projects feel recognised, supported and valued. Although schools are also seen as a potentially valuable avenue for support the evidence on effective support and interventions in schools is underdeveloped. Older young carers have specific needs as they transition into adulthood but there may be limited services available to support them.

Conclusions

Research on young carers continues to be a developing area. This paper summarises a mixed range of survey data (both general population and specifically of young carers) and a range of small-scale qualitative studies, from which it is difficult to generalise. Research and analysis of Census data identify a number of important challenges facing young carers and young adult carers. There is considerable evidence that young carers often experience poorer mental and physical health than peers without caring responsibilities. This is likely to have implications for other aspects of their life such as education and employment. It may also be that young carers need support to ensure that their own health needs are not overlooked. Research suggests that young carers may face challenges in participating in social or leisure activities and may feel isolated as a result.

Young carers can face challenges in balancing their caring responsibilities with education and employment requirements and opportunities. This has potentially profound long-term effects on socio-economic and health outcomes and on inequality. It is possible that young carers may be more likely to experience problems at school and have lower attainment although this will not apply to all young carers. Schools therefore have an important role in being aware of and helping to support young carers.

Young carers can be positive about their caring role and feel that it brings benefits. However, given the potential impact of caring on young people, access to an assessment of their needs and support is critically important. Improving access to assessments and support requires awareness of young caring amongst professionals and service providers, and ensuring that assessments and support are provided in a way that is sensitive to young people’s concerns about being identified as a carer or about requiring help.

The evidence is limited on the effectiveness of different interventions to support young people but does identify some of the needs that support can help to address.

As caring can be associated with poorer mental health (particularly for female young carers) it is important they are able to access services and supported to be able to participate in non-caring activities to reduce the risk of isolation. Given the potential impacts on young carers' education, support in schools is also crucial. Although existing evidence is limited (and this is an important gap) it does suggest a range of potential ways to support young carers including through the provision of support to the cared-for person and by helping young people participate in other activities (for example by providing transport) in order to balance caring with other aspects of their lives. Whatever form of support is provided it is important that it is based on the needs of the young person and that young carers' voices are heard.

The findings from this review sit within a context of on-going policy and service development with the Carers Scotland Act to be commenced in April 2018. As policy and practice continue to develop it will be important to understand the factors that enable young carers to seek and access support and to strengthen the evidence base on effective intervention and support options for young carers.

1. Introduction

This is a report on the profile of young carers and young adult carers in Scotland. Young carers are those who provide help or support to family members, friends, neighbours or others because of either long term physical or mental ill health, disability or problems related to old age. This paper discusses the data and evidence on young carers and young adult carers. In this report, the term 'young adult carers' refers to people aged 16–24 years, and the term 'young carers' to people aged 4–15 years. This is primarily due to the way in which the statistical data is organised and it is recognised that young carers are usually considered as those aged under 18[3]. The report provides insight into who young carers are, and the amount and type of care they provide. It considers their health and well-being and the impact of caring on them and their education and employment. Finally, the evidence on young carers' needs and the support offered to them is discussed.

The purpose of this paper is to:

- Investigate the profile, characteristics and impacts of caring for young carers and young adult carers
- Provide an increased understanding of the existing evidence on the prevalence and impacts of young caring and the available support, in advance of the implementation of the Carers (Scotland) Act which is due to be commenced on 1 April 2018

It is recognised that young carers and young adult carers can have differing experiences and needs (Hamilton & Adamson, 2013, p. 102) from older carers. In this report, the term 'young adult carers' refers to people aged 16–24 years, and the term 'young carers' to people aged 4–15 years. This is primarily due to the way in which the statistical data is organised. The term 'young carers and young adult carers' is used for children and young people aged 4-24 years who are carers. Indeed, the analysis revealed many similarities between the two groups and where this is the case the findings are reported for young carers and young adult carers.

The literature used in this report covers a broad timeframe in order to ensure comprehensive coverage of the existing evidence which includes surveys, research reports and policy documents. The review was undertaken in 2015 and searched for publications in the previous 10 years. While the search covered international evidence, the paper is focused primarily on UK based evidence. The literature search approach is described in more detail in the Annex. The more recent research, along with the Census analysis, suggests that many of the issues identified in the earlier literature remain valid. However, it is recognised that policy and practice continue to evolve in order to address the challenges facing young carers and the evidence discussed here may not include all recent developments.

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[3] The Carers (Scotland) Act (2016) defines young carers as those aged under 18 or who are aged 18 and a pupil at school.

1. 1 Legislative and Policy Context

The Carers (Scotland) Act (2016), to be commenced on 1 April 2018, is a central component of Scottish Government carers' policy. It aims to "ensure better and more consistent support for carers and young carers so that they can continue to care, if they so wish, in better health and to have a life alongside caring." (Scottish Parliament, 2015, p. 11).

The Act builds on existing legislation, strategies and guidance and recognises the work done by a range of national and local organisations to promote the important contribution made by carers in Scotland and to ensure that more is done to support carers. This has included the Care 21 Report (Scottish Executive, 2006), the Scottish Government and COSLA strategy 'Getting it Right for Young Carers' (2010) and the Social Care (Self-directed Support) (Scotland) Act 2013 which contains a discretionary power to support carers, including young carers.

There are other wider legislative frameworks and policy initiatives that are related to young carers in Scotland. Under the Social Work (Scotland) Act 1968 and the Children (Scotland) Act 1995, carers have the right to request an assessment of their ability to care. The Act states there is a duty for local authorities to identify and provide services for children affected by the disability of another family member, who may be a sibling, parent or other relative. The Social Care (Self-directed Support) (Scotland) Act 2013 came into force on 1 April 2014 and places a duty on local authority social work departments to offer people who are eligible for social care a range of choices over how they receive their support. Self-directed Support allows people, their carers and their families to make informed choices on what their support looks like and how it is delivered, making it possible to meet agreed personal outcomes. Potentially this could reduce the level and type of care that young carers need to provide.

1.2. Who is a young carer in Scotland?

There are a number of interacting factors in the concept of being a "young carer" and a "young adult carer" that impact on support for, and research on, young carers. This report draws on a variety of data and evidence sources, therefore the definitions are not entirely consistent.

In the literature there is no minimum time threshold of care that marks out a young carer (Graham, 2011, p. 11) as distinct from a young person who helps out, although the terms 'substantial' and 'significant' are often used to illustrate caregiving duties that mark out a young carer (Becker, 2000, p. 378). The nature of care activities are often elements in defining a young carer. These can be activities not usually expected of young people, such as intimate care or 'emotional labour' (Moore, et al., 2011, p. 166). The latter and its impact can be outside the direct caring: "A child who worries a great deal about their parent's illness or addiction may be regarded as a young carer on the grounds of undertaking emotional labour, even if they are not undertaking additional caring tasks" (Banks et al. 2002, p.15). Therefore whilst time and caring activities are ways of identifying young carers, the complexity of the caring should be borne in mind.

The Carers (Scotland) Act defines carers as those who provide or intend to provide care for another individual (the "cared-for person"). A young carer is aged under 18 years or aged 18 and a pupil at school. In addition, consideration will be given to the nature and extent of the care provided by the young carer being "appropriate". The young person will have the opportunity to discuss if the care they are providing is appropriate to their age and circumstances.

Young carers and young adult carers are in large part identified by their age and the meaning of this for their life stage, although there is no fixed definition for a young adult carer. The Carers Act Scotland will provide a Young Carers Statement that will continue until that carer is provided with an Adult Carer Support Plan easing the transition between young carer and adult services.

It is acknowledged that many young carers are hidden or not known about, primarily for four reasons:

- Many young people who care for others do not identify themselves as being a 'young carer' (Christie, 2006, p. 244). They may see their role as not particularly exceptional or unusual (Smyth, et al., 2011, p. 147) because caring responsibilities are situated within a normative framework of familial obligation (O'Connor, 2007, p. 168).
- Young carers can actively seek to conceal their caring role. This can be due to fear of stigma (Smyth, et al., 2011, p. 154). This is the case when the caring involves substance misuse or mental health problems (ACMD, 2011, p. 50); (Christie, 2006, p. 191). It can be to avoid the label due to fear of unwanted intervention and worry about being separated from their parents (Moore, et al., 2011, p. 174), which may be based on seeing the experience of others. (In 2000 the Department of Health stated that parental ill health was the third most common reason for being admitted to care (Dearden & Becker 2005, cited in (Barry, 2011, p. 1)).
- Public services have previously been challenged for not effectively and consistently identifying and reaching out to support young carers (Barnardos, 2006, p. 6). This is particularly the case for young carers in travelling communities (MECOPP, 2012, p. 12) and those who are home-schooled (Smyth, et al., 2011, p. 157).
- Societal norms can contribute towards the invisibility of young carers; the term 'young carer' may seem inappropriate due to the societal expectation for children and young people to be cared for rather than to care for others (Smyth, et al., 2011, p. 156).

These difficulties in defining and identifying young carers impact on the provision of support for and research on young carers.

The detailed analysis in this report is based on Scotland's 2011 Census. This is a reliable, robust source, although its limitations are discussed next. The data is supplemented with a discussion of the research evidence to provide further information and understanding of the experiences and impacts of young caregiving, and how to meet the needs of young carers.

1.3 Measuring the number of young carers

Based on the 2012/13 Scottish Health Survey (SHeS) there are an estimated 93,000 young carers and young adult carers in Scotland. This is the best estimate for the total number of young people and young adults caring in Scotland. However, the sample is too small for detailed analysis. Scotland's Census 2011 also provides an indication of the number of young carers in Scotland and as a whole population survey has sufficient numbers to look at the profile of young carers in more detail. Both sets of data are based on self-identification as someone who undertakes caring duties (not necessarily as a 'carer').

There were 37,393 young people aged 4-24 (2.85%) identified as young carers in Scotland's Census 2011:

- 10,002 (1.47%) of young people aged under 4-15 identified themselves as carers. (There were a very few carers younger than this identified, but the numbers are so small that they are not reported here.)
- 27,391 (4.33%) aged between 16 and 24 identified themselves as carers.

Annex 1 provides a more detailed explanation for the differing numbers in these two surveys. This includes the method of survey completion although the key issue is that SHeS uses a category for providing care up to 4 hours a week, whereas the lowest category in the Census is up to 19 hours. Scotland's Census 2011, while underestimating what we understand to be the true level of young caring (by not capturing those doing a small number of hours of caring), allows for more detailed analysis of young carers.

1.4 Structure of the report

The report discusses the available data and evidence on:

- Who are young carers in Scotland?
- Young carers' health and well-being
- Young carers' education and employment
- Support for young carers

2. Who are the young carers in Scotland?

Introduction

This chapter contains demographic analysis of young carers including: age; gender; ethnicity; deprivation; geographical location; and also discusses the nature of care-giving duties. In general the data on young carers and young adult carers is a very similar picture so they are reported as one group.

Key points:

- The majority of young carers are older young people.
- Data suggests, as they get older, more children and young people provide a few hours caring per week.
- A larger proportion of girls and young women are carers and a majority of young carers and young adult carers are female.
- Evidence suggests that female young carers are more likely than male young carers to carry out domestic tasks and to provide intimate care.
- There are more young carers in the most deprived areas and they undertake more hours of care.
- Research suggests that young carers in rural areas carry out similar caring tasks but may face additional challenges such as more dispersed facilities and services.
- Nearly one quarter (22%; 8328) of young carers aged 4-24 (who are more likely to be young adult carers) provided 35 hours or more care per week.
- The nature of caregiving tasks varies significantly according to the health condition(s) experienced by the cared-for person.

2.1 Age

Census and SHeS data suggests that as children become older, more of them regularly provide a few hours caring[4]. Scotland's Census 2011 shows that the number of young people providing care increases with age: from 157 (0.28%) at age 5, to 2,996 at age 18 (4.4% of 18 year olds). The percentage decreases slightly at 19/20 and there is then a slight increase in the proportion of young carers in their early 20s (4.6% of 23 years olds).

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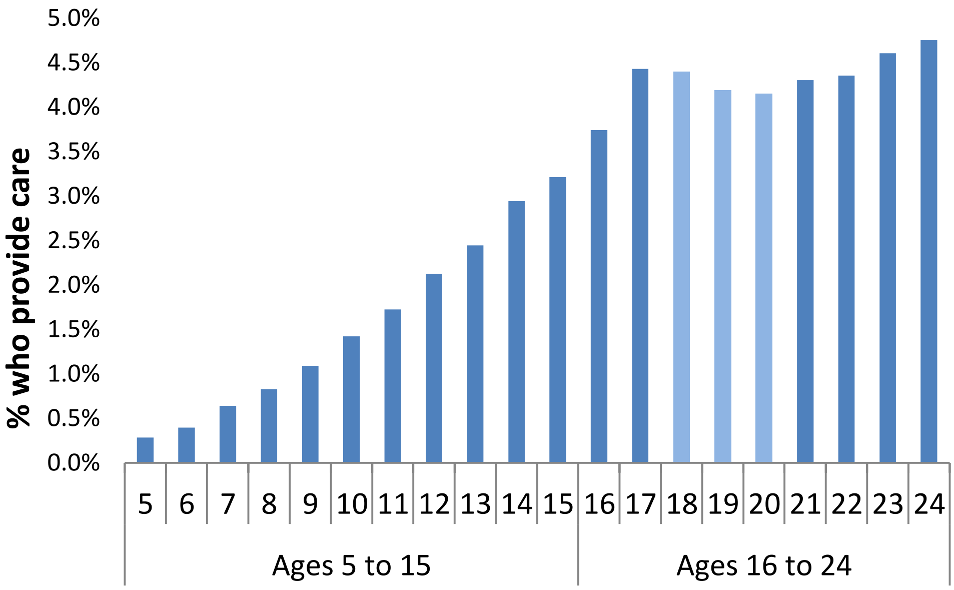
[4] A comparison of the SHeS and census data is available in the Annex.

Figure 1: % of population providing care, by single year of age



The majority of young carers are older young people;

- 53% are aged 13-15
- 30% are aged 10-12
- 14% are aged 7-9
- 4% are aged 4-6.

The reason for the fall in the number of young carers after the age of 18 is due in part to completion of universal schooling and moving to employment, further or higher education. Research indicates that some young carers move away from home and reduce their caring, whilst others retain their caring role. At the other end of the age range, a small group of children under five are known to provide care.[5]

2.2 Gender

Both young women and men are carers but a majority of young carers and young adult carers are female:

- 55% of young carers are female and 45% are male
- 3.2% of young women are carers and 2.5% of males

Research has also found that found that girls are more involved in caring tasks – particularly as they get older (Dearden & Becker, 2004, p. 3).

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[5] One study found an example of a young girl who had translated in sign language for her deaf mother since she was three years old (Baker, 2002).

There is limited evidence which focuses on differential experiences of caring due to gender, but we know that gender differences impact upon the type of care work undertaken by young people. A survey of young carers in contact with support services in the UK (Dearden & Becker, 2004) found that 85% of female young carers carried out domestic tasks, compared to 69% of boys. Furthermore, they established that almost twice as many female young carers in the sample carried out intimate care compared to male young carers.

Table 1: Caring tasks by age and gender

Caring Task	Gender	Age 5-10	Age 11-15	Age 16-18
Domestic	Boys	52%	67%	69%
	Girls	60%	77%	85%
	% difference	+8%	+10%	+26%
Intimate	Boys	11%	15%	17%
	Girls	13%	22%	32%
	% difference	+2%	+7%	+15%

Table adapted from Dearden and Becker (2004, p. 9)

Eley’s small qualitative study (2004, p. 68) found that boys had different pressures in their caring roles compared to girls. One boy in her study explains: “I'd be shouting my head off [to my brother/sister] saying get ready, get your school bag ready and get your breakfast.” In this instance, the boy was expected to adopt a disciplinary role as part of his caring duties.

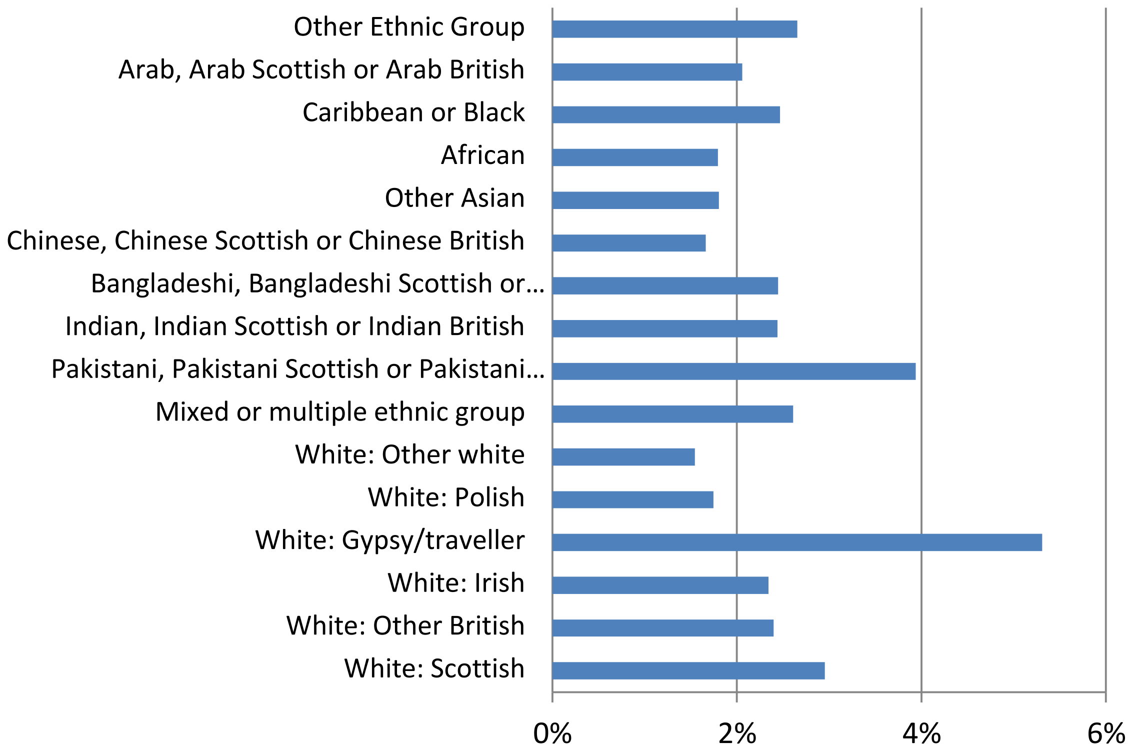
From the Census data and in various research studies, it is apparent that female young carers report that they have poorer wellbeing compared to young male carers. In the Census data, the difference is particularly pronounced in relation to the 16-24 year old age group. Research has found that young female carers were more likely to report problems and worries compared to young male carers (Cree, 2003, p. 306). A further small-scale study (Hamilton & Adamson, 2013, p. 112) found that young men reported higher levels of satisfaction with their mental health compared to young women. They note that half of the females in the study rated their mental health as 4 or below out of 10 (female total in sample n=14, age 7-17). Young carer’s wellbeing is discussed further in Chapter 4.

2.3 Ethnicity

According to Scotland’s 2011 Census, of all 4-24 year olds; 84% are white Scottish; 6% are white other British and 10% are from other ethnic groups. The proportion that are young carers and young adult carers is similar; 3% white Scottish and 2% others.

Although the numbers are small, there is a variation according to individual ethnic groups. The highest prevalence is 5% of white gypsy/traveller young people, followed by 4% of Pakistani, Scottish Pakistani or British Pakistani young people.

Figure 2: % of young people in different ethnic groups providing care



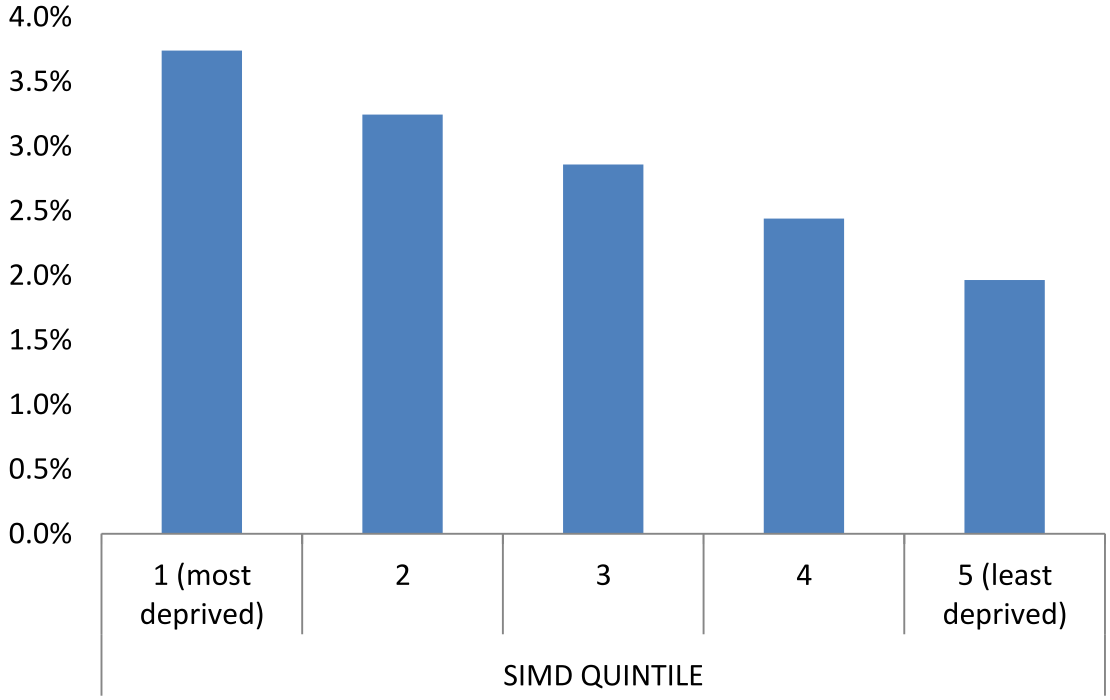
The small numbers do not allow for further analysis by ethnicity in Scotland. There is also a lack of research in relation to the specific experiences of young carers from black and minority ethnic (BME) communities. Jones et al (2004, p. 11) argue that young carer research has focussed on the experiences of white young carers, and thus there are many assumptions and unfounded statements about the needs and experiences of BME young carers. Their small-scale study investigated the circumstances, experiences and needs of black young carers and their families in Manchester. They found that the families in the study were largely hidden to agencies, many of the disabled parents did not receive any services and many of the young carers in the study did not relate well to the term ‘young carer.’ However, it is difficult to know how far such findings can be generalised to Scotland.

2.4 Geographical location and deprivation

There are young carers and young adult carers across Scotland. Higher proportions of young people have caring responsibilities in areas of higher deprivation and lower income. Living with a disability or long-term health condition is often associated with living in poverty, being unemployed or living in relative income poverty.

Higher rates of caring by young people are found in areas of greater deprivation and amongst groups with lower incomes. The Census data shows that young people in the most deprived areas provide more care than in wealthier areas.[6] In the most deprived areas close to 4% of young people provide unpaid care and this gradually drops to just 2% in the least deprived.

Figure 3: % of people aged 4 to 24 providing care, by SIMD Quintile



The Census data also shows that young carers living in the most deprived areas are the most likely to be providing more than 35 hours of care per week. This trend is also the same for adult carers (Scottish Government, 2015, p. 23).

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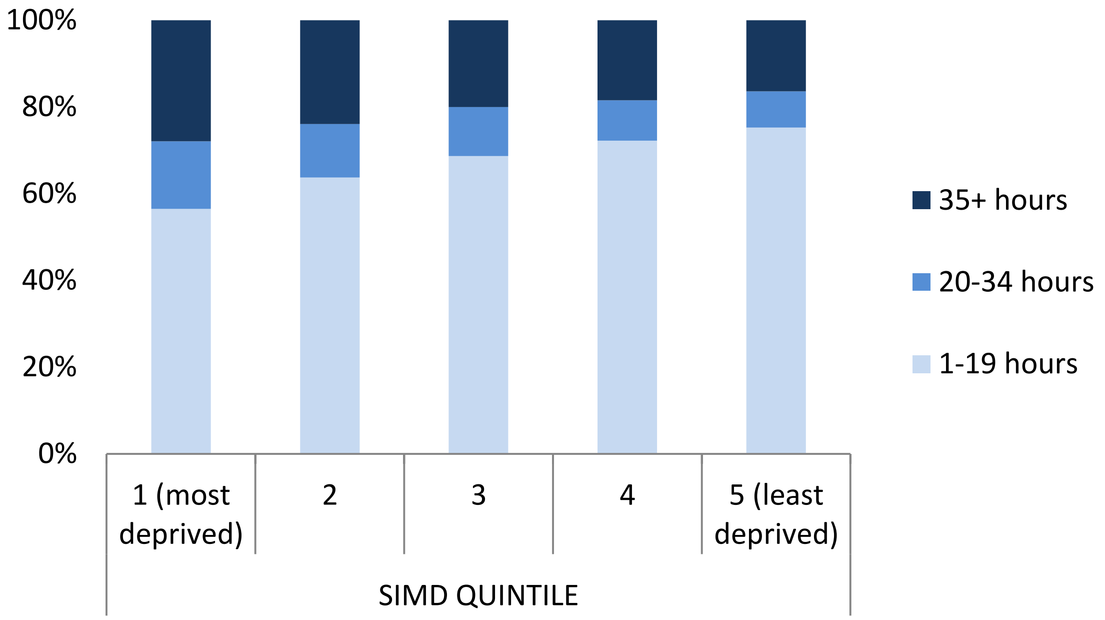
[6] Scotland's 2011 Census data was analysed according to the Scottish Index of Multiple Deprivation (SIMD) that ranks the 6,505 datazones that cover Scotland from the most deprived (ranked 1) to the least deprived (ranked 6,505). For the analysis here the datazones were divided into five quintiles with SIMD1 the 20% that are the most deprived to SIMD5 which is the 20% of datazones that are least deprived. Both the proportion of young carers and young adult carers and the intensity of caring rises as levels of deprivation increase.

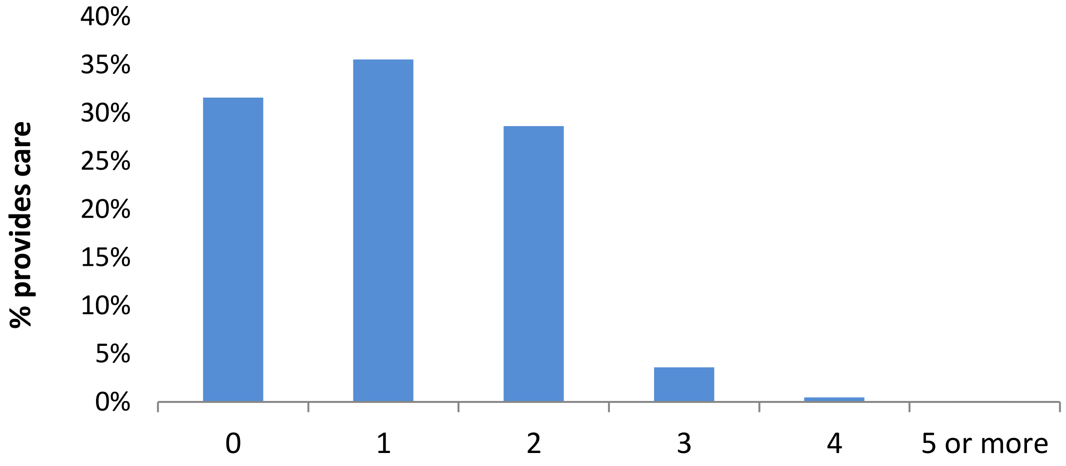
Figure 4: Hours of care per week provided by carers aged 4 to 24 by SIMD Quintile



Whilst almost 30% of young carers care for over 35 hours in the most deprived areas, this is less than 20% in the least deprived areas. The pattern is the same for both the young carers group and young adult carers.

There is a consensus within the literature that young carers are more likely to live in a deprived area, have a low socio-economic status and be affected by poverty (Banks, et al., 2002, p. 807) (Barry, 2011, p. 524) (SCIE, 2005). The Children's Society (2013, p. 5) found that the average annual income for families with a young carer is £5000 less than families who do not have a young carer. Children in families living with at least one disabled member are more likely to be living in poverty (21%); compared to children in families with no disabled member (16%) (Department for Work and Pensions, 2014). Research tells us that young carers are more common in families with unemployed parents or low incomes (SCIE, 2005, p. 3) and this is also shown in the census data.

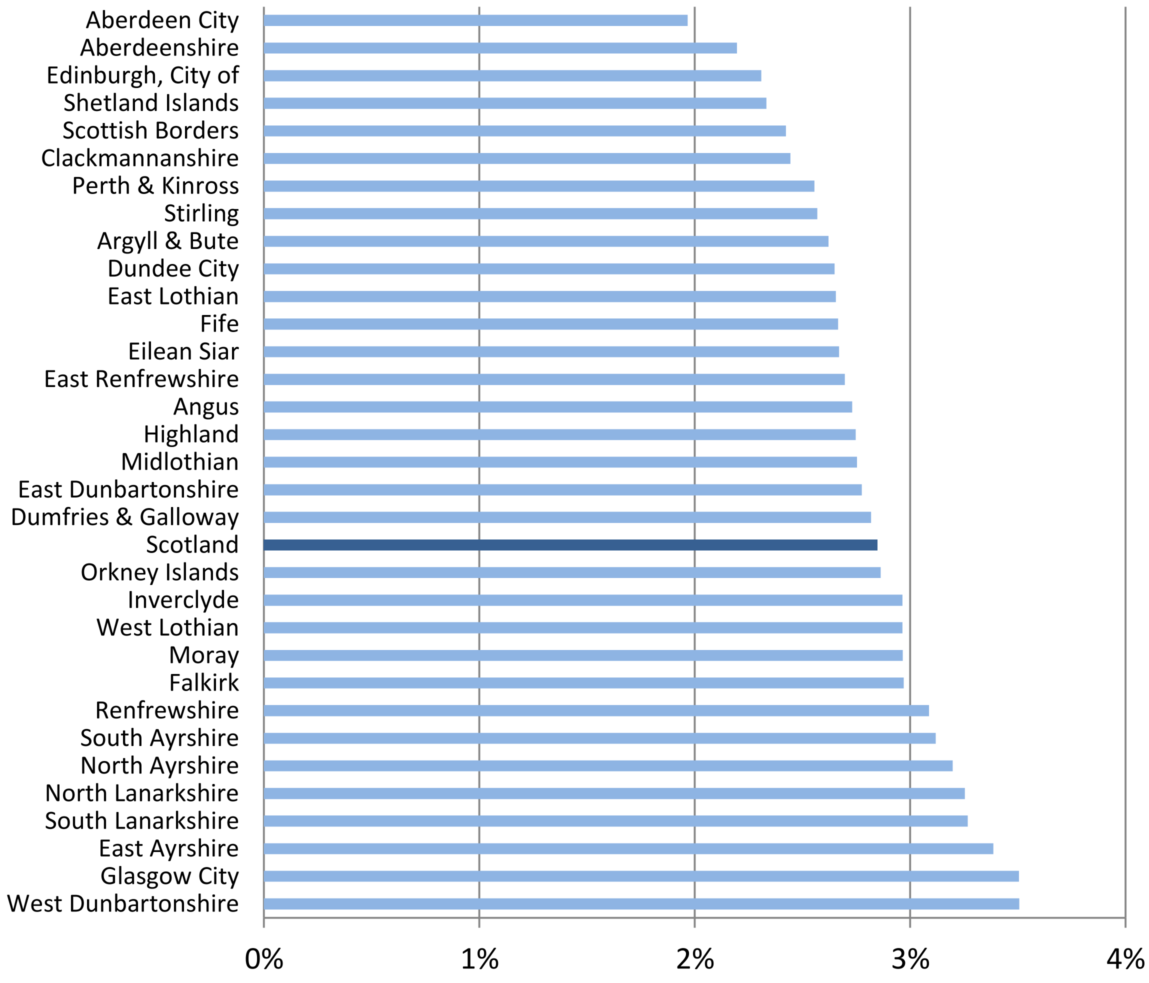
Figure 5: 4-15 year olds who provide unpaid care, by how many adults in their household are in employment



It is very difficult to separate the impact of caring from the impacts of unemployment, poverty, poor housing and low socio-economic status. This is a persistent problem which features in the young carer literature, shared by a number of researchers (e.g. (Newman, 2002); (Cree, 2003, p. 305). Studies which do not have control groups have been criticised by the likes of Olsen & Parker (1997, p. 125) on this basis. A small number of studies comparing carers and non-carers provide important findings (Warren, 2007) (Lloyd, 2013).

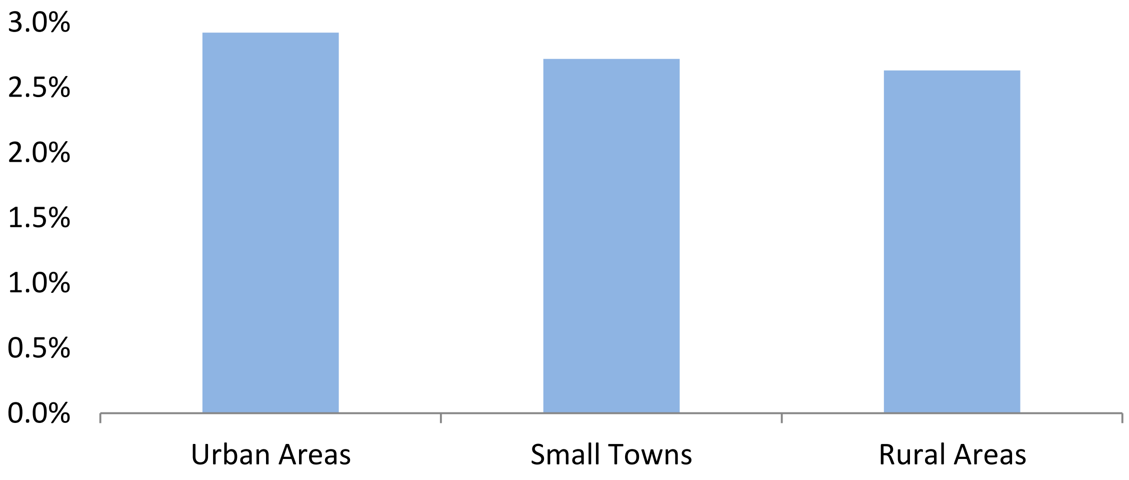
Glasgow and West Dunbartonshire have the highest proportion of young carers by local authority area.

Figure 6: % of people aged 4-24 providing care, by Local Authority



There is a slightly higher proportion of young people caring in urban than rural areas, although the difference is minimal.

Figure 7: % of people aged 4 to 24 providing care, by urban/rural split



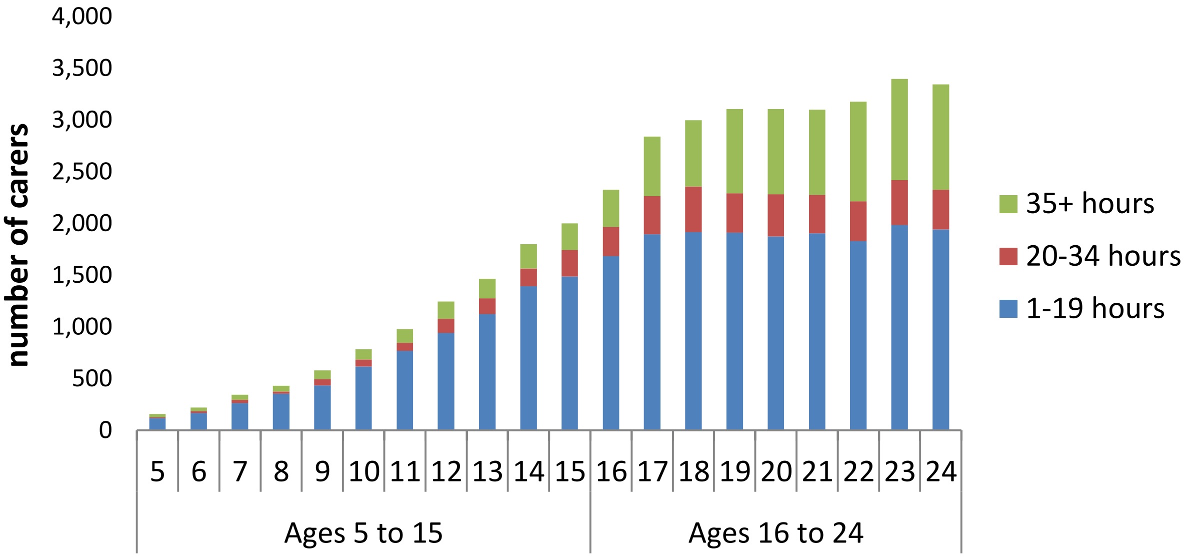
Evidence suggests that residing in a rural area brings additional challenges for young carers, and could serve to exacerbate the risk of social exclusion. Living in a rural area means that there are fewer facilities or services nearby for young people (Butler & Astbury, 2004, p. 297) (Commission for Rural Communities, 2010, p. 3). Due to the extra expense incurred in providing community care services in sparsely populated areas, there is not much flexibility or choice in the way in which services are delivered (Commission for Rural Communities, 2010, p. 10). In some circumstances, this may bring added duties for young carers. The Commission for Rural Communities (2010, p. 8) found that many of the young people in their study felt it was difficult to participate in the labour market, which had an impact on their economic wellbeing. However, the caring tasks carried out by children and young people are the same, whether in a rural or urban area (Frank, 1995).

2.5 The Nature of Caregiving Duties

Hours of Care Provided

The Census indicates whether the number of weekly hours of care provided was 1-19 hours; 20-34 hours and 35+ hours per week. Nearly one quarter (22%; 8328) of young carers aged 4-24 provided 35 hours or more care per week. Within this, 26% (7000) of young adult carers aged 16-24 and 13% (1328) young carers provide over 35 hours care. Around two thirds of young carers and young adult carers (66%) provide care for between one and 19 hours per week. This is a higher proportion than adult carers, 56% of adult carers provide this amount of care weekly.

Figure 8: Number of unpaid carers, by single year of age and hours of care



The majority of young carers provide care for 1-19 hours per week. This is a relatively large category, and it may not effectively capture lower levels of care (Scottish Government, 2015). It is notable that young adult carers are much more likely than child carers to provide over 35 hours of care per week. This is consistent with research findings which suggest that intensity of caring increases with age (Dearden & Becker, 2004, p. 3).

Caregiving tasks

The nature of caregiving tasks varies significantly according to the condition(s) experienced by the cared-for person (Lloyd, 2013, p. 68). For example, those caring for a person with a disability are much more likely to provide intimate care, and those caring for people with a mental health problem are much more likely to provide emotional care (Dearden & Becker, 2004, p. 8).

Historically there has been some debate about how much young carers actually differ in terms of their daily tasks compared to children from other households (Olsen, 1996, p. 44). This debate arose mainly due to a lack of evidence which compared the experiences of young carers and young non-carers of the same age (Olsen & Parker, 1997, p. 125). It is also the case that not all young people in households with people with care needs will be young carers.

Warren (2007) addressed this debate and gap in research by carrying out a study which compared the tasks that child carers and child non-carers undertook in the home. This was an extensive study involving structured interviews with 390 children from one local authority area. Warren (2007, p. 143) found that the ‘nature, frequency and time spent by young carers each week on domestic and caring tasks differs from that of other children and young people in the general population.’ It was also found, not surprisingly, that intimate care tasks most clearly distinguish young carers from peers who do not have a caring role (Warren, 2007, p. 140).

There have been consistent findings in the literature with regard to the types of tasks which are carried out by young carers. Dearden & Becker’s (2004, p. 7) repeated survey analysis established how caring tasks had changed over time in the UK:[7]

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[7] One limitation of this study was that it did not involve young people outwith the support of young carer groups. Furthermore, Dearden & Becker (2004, p. 4) do not indicate what proportion of the 6,178 young carers in the sample are Scottish, so we do not know to what extent this research is relevant to Scotland.

Table 2: Caring tasks over time

Caring Tasks	1995	1997	2003
Domestic	65%	72%	68%
General	61%	57%	48%
Emotional	25%	43%	82%
Intimate	23%	21%	18%
Child Care	11%	7%	11%
Other	10%	29%	7%

Note: Figures will not add up to 100% since most young carers perform several caring tasks (Dearden & Becker, 2004)

The table shows that there was an increase from 25% of young carers providing emotional support in 1995, to 82% in 2003. There was also a decrease in the proportion of children carrying out intimate caring tasks.

Many young people understandably find it difficult to quantify the care that they provide, particularly in relation to emotional support (Moore, et al., 2011, p. 167). Furthermore the nature of such care tends to be unpredictable and can fluctuate greatly over time. This may be more profound for those caring for others with substance misuse problems or mental health issues.

Length of Time Caring

Young carers often find it difficult to identify exactly when they started their caring role, which may be due to the gradual nature of their caring responsibilities developing over time (Hamilton & Adamson, 2013, p. 106). Young people have many different pathways into caring, and the intensity of the role can fluctuate greatly over time, and can be dependent on other factors such as family breakdown or when a sibling leaves home (Hamilton & Adamson, 2013, p. 106). Furthermore, it has been suggested by Christensen & James (2000, cited in (Cree, 2003, p. 304) that children gauge time in different ways than adults.

Cree (2003, p. 307) found differences in the extent of problems and worries shared by participants in her small, qualitative study, depending on how long it had been since they started caring. She found that none of the four young carers who said they had been caring ‘just recently’ had a high number of worries, as opposed to half of those who had been caring for ‘quite a long time’ with a high number of worries, but just over a third of those who had been caring for ‘as long as I can remember’. Cree (2003, p. 307) suggests that it is ‘possible that young people as carers may become less worried over time, as they understand more about the condition of the person they care for and they receive more help via agencies." However, generalisations cannot be drawn from such a small scale study.

It is important not to assume that the intensity of care is directly related to the level of need experienced by the person cared for. In studies, such as Moore et al. (2011, p. 168) that explored the experiences of children whose parents had substance misuse issues, the level of care provided by children was not necessarily related to the frequency and quantity of substance use or substance type.

2.6 Conclusion

The most accurate estimate suggests that around 7% of young people in Scotland have caring responsibilities[8]. The data shows the diversity of young carers' experiences with young people of all ages and backgrounds providing care for others.

However, the data also shows that young people become more involved in caring as they get older and that it is young people in the most deprived areas who provide the most care. The differences in gender are also more pronounced for older young carers with potential negative effects on well-being as young female carers are more likely to report poorer wellbeing. Young carers' health and well-being is discussed in more depth in chapter 3.

The differences in the intensity and type of care will have an impact on the extent to which caring affects young people's well-being and the implications for their education and employment. Understanding the profile of young carers has implications for ensuring that adequate and appropriate support is available for all young carers, and particularly for considering the needs of those living in deprived areas who may be providing larger amounts of care.

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[8] This is considered the most accurate estimate as it is based on large scale population sample with a robust sample. However, it is acknowledged that this is likely to be an underestimate.

3. Young carers' health and wellbeing

This chapter considers the physical and mental health and well-being of young carers drawing on the Census data on self-reported health and the wider research evidence. The data shows being a young carer tends to be associated with poorer health.

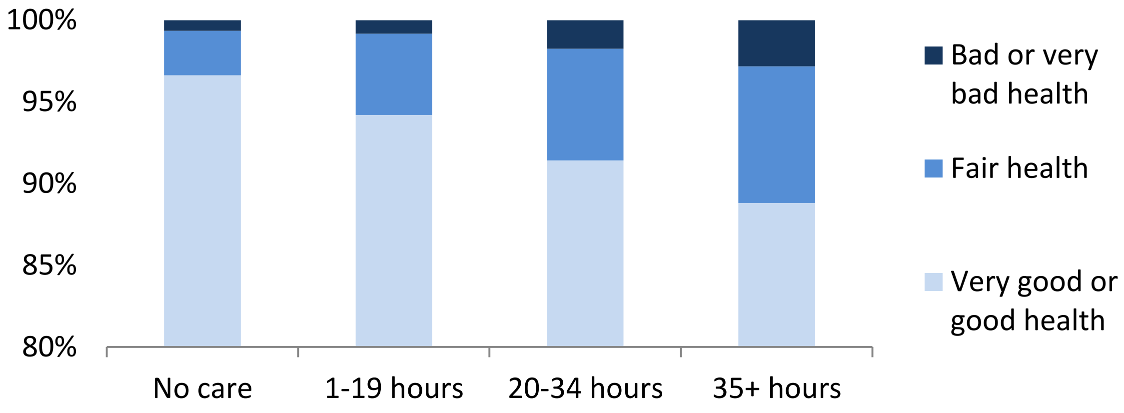
Key points:

- More young carers have worse self-reported health than non-carers and fewer have 'very good health'.
- A long term health condition or disability is more common amongst young carers and young adult carers. It is unknown if and how this may be related to their caring role.
- Tiredness and feeling 'run-down' is a physical impact that many young carers have reported in various studies.
- There is a high prevalence of young carers reporting physical disorders such as hair loss and asthma.
- Young carers and young adult carers are twice as likely as young people generally to report a mental health condition (2011 Census).
- There is considerable evidence to say that young carers are more likely to suffer from anxiety, stress and depression.
- Young carers who are female appear to have comparatively worse mental health compared to male young carers.
- Young carers may find it harder to participate in social activities which may contribute towards feelings of isolation.
- Studies have also shown that young people often find benefit in their care-giving experience.

3.1 Physical health

Overall, more young carers have worse self-reported health than non-carers and fewer have "very good" health. Figure 9 shows that health appears to get progressively worse depending on how much care a person provides. 97% of non-carers aged 4 to 24 were in "very good or good health", compared with 94% of those caring for 1-19 hours, 91% of those caring for 20-34 hours and 89% for those caring for 35+ hours per week.

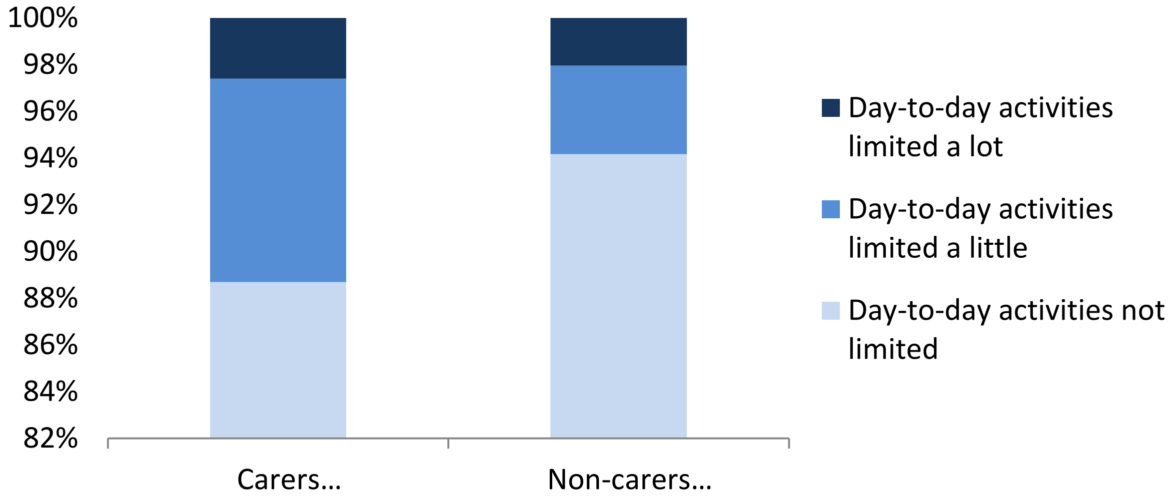
Figure 9: Self-reported Health Status of people aged 4 to 24, by hours of care provided



Deprivation is associated with both poorer health, and with increased likelihood of providing care. It is difficult to understand the extent to which these different factors separately or together contribute to poorer health outcomes for young carers.

Census data shows young carers are more likely to have a long-term condition or disability. It is unknown from the Census data if and how this may be related to their caring role.

Figure 10: Young carers and non-carers, proportion whose activities are limited by a long-term health condition or disability



Evidence shows that young carers are at a higher risk of poor physical health. The Children's Society (2013, p. 5) found that young carers are 1.5 times more likely than their peers to have a disability or special educational need.

In a study that compared non-carers and carers aged 10 and 11 in Northern Ireland, Lloyd (2013, p. 74) found that the child carers had poorer health, when compared to their peers who were non-carers. Health was assessed using the 'KIDSCREEN-10' tool, where the children answered health related questions in a survey format. It was found that child carers were less likely to describe their general health as ‘excellent’ compared to their peers.

Tiredness and feeling ‘run-down’ is a physical impact that many young carers have reported in various studies (Banks, et al., 2001, p. 805) (Banks, et al., 2002, p. 239) (Hamilton & Adamson, 2013, p. 110) (Gates & Lackey, 1998, p. 13). This has consequences for many areas of a young person’s life, most notably health and wellbeing, school performance, and participation in leisure activities.

In the Dearden and Becker (1998) study, they found a high prevalence of young people reporting physical disorders such as hair loss and asthma. Similarly, Frank et al. (1999, p. 14) found that ‘psychological asthma’ and hair loss was experienced by participants in their sample. At the Scottish Young Carers Festival in 2012 around one in 5 of the young carers in attendance reported that they had asthma, which is much higher rates than in the general population in Scotland.[9] Studies show that asthma is a stress-related condition where distressing experiences in a child’s life can trigger asthma attacks (Sandberg, et al., 2000, p. 982).

Particularly in relation to young people caring for an adult with physical disabilities, it has been suggested that there is likely to be an increased risk of physical injury due to lifting and handling procedures (Sahoo & Suar, 2010, p. 142) (Frank, et al., 1999, p. 15). In relation to adults, it has been shown that the emotional stress associated with care giving may also increase the likelihood of physical illness (Brown, et al., 2009, p. 489).

3.2 Mental Well-being

According the 2011 Census, young carers and young adult carers are twice as likely as young people generally to report a mental health condition: 3.7% of young carers compared to 1.4% young people without caring responsibilities.

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[9] Data from an internal evaluation report from the Scottish Young Carers Festival (2012). Over 600 young carers attended the festival over three days. Information on asthma rates in the general population is available at http://www.scotpho.org.uk/health-wellbeing-and-disease/asthma/data/primary-care

Figure 11: % of young people with a mental health condition - carers v non-carers

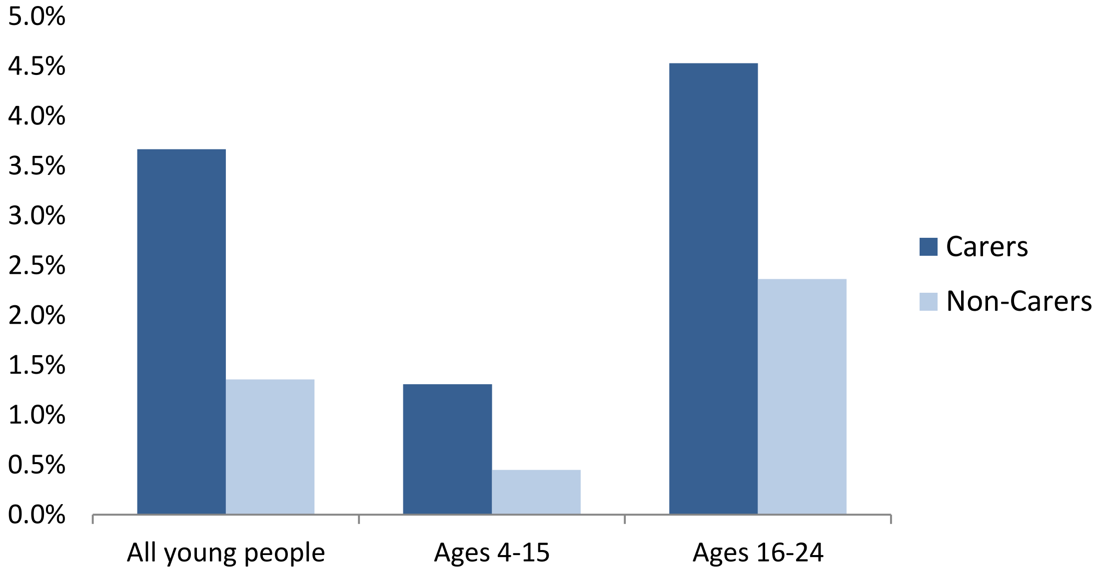
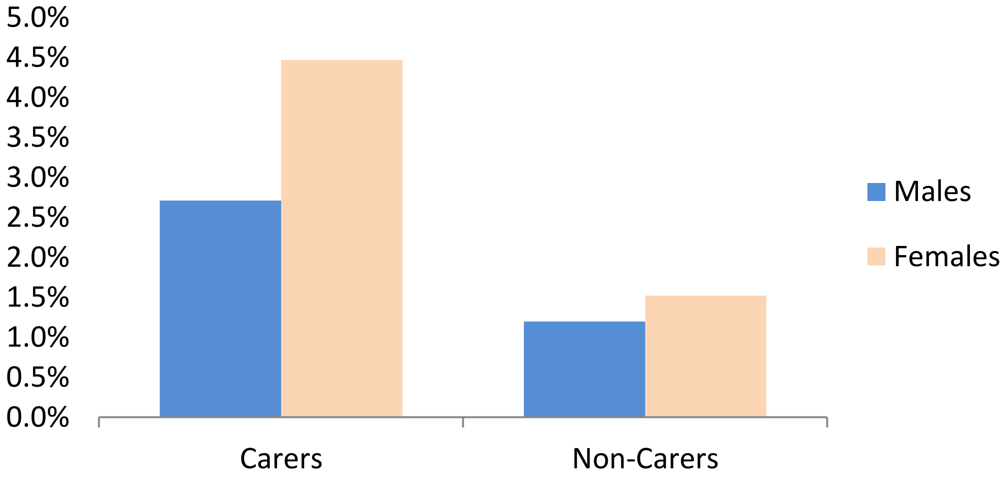


Figure 12: % of people aged 4-24 with a mental health condition - male and female carers v non-carers

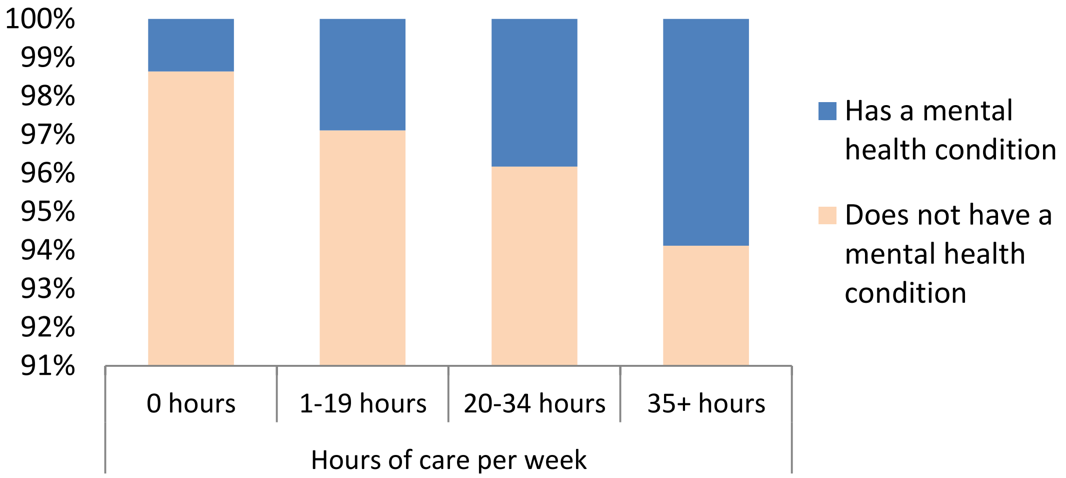


There is considerable evidence to say that young carers are more likely to suffer from anxiety, stress and depression (Cree, 2003, p. 301) (Lloyd, 2013, p. 67).

The study carried out by Lloyd (2013, p. 67) compared the mental wellbeing of child carers and child non-carers. Lloyd (2013, p. 77) found that children who are carers (aged 10 and 11) have poorer wellbeing and feel less happiness in their life overall when compared to children who are not carers. There is also a wealth of anecdotal qualitative evidence in relation to young carers and mental wellbeing. A selection of these studies reported that young carers in their samples had sleeping problems (Cree, 2003, p. 305), worry about 'being different' compared to other children (Roche & Tucker, 2003, p. 444), anxiety surrounding their parent's condition

(Thomas, et al., 2003, p. 41), depression (Broadbent, 1999, p. 2), self-harming behaviours (Cree, 2003, p. 305), and also confidence and self-esteem problems (Roche & Tucker, 2003, p. 445).

Figure 13: % of young people with a mental health condition - by hours of care provided



Research carried out in Scotland by Cree (2003) focused on the 'problems and worries' of young carers. The study involved a questionnaire completed by 61 children and young people, and an additional 11 interviews were carried out with children who had nominated themselves in the questionnaire to meet the researcher. Cree (2003, p. 305) found that around two thirds reported difficulties sleeping, as well as a third of participants saying that they had self-harmed and also contemplated suicide.

More female than male young people and young carers report mental ill health. Three possible explanations have been suggested as to why young female carers appear to have comparatively worse mental health compared to male young carers:

- Females tend to be more willing to share about their feelings and experiences (Cree, 2003, p. 306). It is possible that young women are more likely to report a mental health condition and the impact on young men is under represented.
- Young females are taking on more care than young males, due to gendered societal assumptions (Eley, 2004, p. 66)
- Due to psychological reasons i.e. adolescent females in the general population are more likely to suffer from mental health problems compared to adolescent males[10] (Abraham & Aldridge, 2010).

In the Cree study (2003, p. 306), it was found that female young carers were more likely to report problems and worries compared to male young carers, bringing Cree (2003, p. 306) to suppose that "there may be additional gender issues in caring which make it possible that the experience of being a young carer is more

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[10] The Scottish Health Survey 2015 found that the average wellbeing score for 13-15 year old boys was significantly higher than for girls of the same age.

troublesome for girls than for boys.” Girls were more likely to report problems and worries in all of the categories used by Cree (2003, p. 306) compared to boys, apart from ‘getting into trouble with the police.’ The most significant of these are:

- Falling out with friends (around three quarters of girls in the study compared to half of boys)
- Not having friends (nearly two-thirds of the girls compared to a fifth of the boys)
- Self-harming behaviour – past or present (half of the girls compared to a fifth of the boys)
- Think about suicide – past or present (half of the girls compared to a quarter of the boys)

3.3 Young caring and relationships

Studies have found that the nature of young people’s social and familial relationships can be affected by their caring role. Young people caring for siblings can have important differences in their experiences and needs, compared to, for example, young people caring for a parent (Hamilton & Adamson, 2013, p. 112). Evidence suggests that the majority of people with care needs looked after by children and young people are mothers (Dearden & Becker, 2004, p. 3) (Commission for Rural Communities, 2010) (Abraham & Aldridge, 2010). This is particularly the case in lone parent families, where in 70% of lone parent families where a child or young person had a caring role this was for their mother. In two parent families, nearly half of this group (46%) were caring for a sibling (Dearden & Becker, 2004, p. 3). Some young people also care for more than one person. In the Dearden and Becker (2004, p. 3) study, it was found that 1 in 10 care for more than one person.

Roche and Tucker (2003, p. 444) found that young carers found it difficult to be spontaneous and participate in social activities with friends, because they had to attend to the needs of the cared-for person. Young carers can be reluctant to invite friends home and this can be a barrier to developing close relationships with peers (Banks, et al., 2001, p. 801). Young carers are also less able or willing to participate in social and leisure activities and report difficulties in attending activities such as youth clubs, sports participation, music groups, brownies, guides or other groups for many reasons including:

- Needing to help at home
- Financial problems
- Problems with transport
- Tiredness

This can contribute towards feelings of isolation, fewer social skills and means that young carers may find it more difficult to make and sustain peer relationships (Warren, 2007, p. 142).

3.4 Understanding young carers' experiences

Positive impacts from providing care are much less explored compared to negative impacts but studies have shown that children and young people often find benefit in their caregiving experience in terms of the experiences and skills developed, including interpersonal ones. Young carers often feel happy to perform their caregiving duties (Eley, 2004, p. 71), and feel that they are gaining practical life skills (Thomas, et al., 2003, p. 41). Others don't identify as being a 'young carer', feeling like there is nothing particularly exceptional or unusual about their role (Smyth, et al., 2011, p. 147).

Positive impacts include: a closer bond between the young carer and cared for person (Aldridge, 2006, p. 83); a sense of satisfaction (Banks, et al., 2002, p. 243); and the feeling that they have an important role within the family unit (Early, et al., 2006). There is also evidence which points towards resilience factors associated with the caring role. For example (Pakenham, et al., 2007, p. 709) found that young carers who reported high levels of social support reported positive impacts associated with their caregiving. Likewise, Cassidy et al (2014, p. 616) suggest that positive experiences of caregiving appear to be associated with availability of family support and recognition of the child or young person's caring role.

Some authors have called for a more nuanced approach in research in order to recognise the likelihood that children and young people are likely to feel ambivalent with regard to their caring roles, experiencing a mix of both positive and negative impacts over time (Heyman & Heyman, 2013, p. 561) (Cassidy, et al., 2014, p. 606).
The reality is that for many young people the problems they face and the impacts that they experience are multi-faceted. The majority of young carers live in supportive family units and receive the levels of support that any child would expect to receive from their parents; yet their lives and experiences are markedly different which can bring challenges. Banks et al (2001, p. 801) note that labelling children and young people as a 'young carer' can result in representing 'only one aspect of a child's identity, yet is often used as a total characterisation, obscuring other salient aspects such as social class, gender and ethnicity.' This highlights the importance of carrying out research which takes into account the many different variables at play in young people's lives. One study (Moore, et al., 2011, p. 171) highlighted that:

"The most stark finding for us on the nature and impact of the young people's caring role was that it was bound by the many intricacies and complexities of their family life that could only be understood when considered alongside a range of other significant and inter-related stressors affecting these young people and their families such as poverty, mental-health issues, conflict, violence and family separation."

Pakenham (2007, p. 722) and others have identified a need for evidence which would generate more nuanced understandings of young carers in different circumstances. This is important for ensuring that the required support is provided[11].

3.5 Conclusion

The key issue emerging from the research and data is that young carers tend to have worse health and well-being than young people who do not have caring responsibilities. This is true for self-reported health, long term health conditions or disabilities and mental health conditions. This is likely to have implications for other aspects of their life such as education and employment.

It is not possible to tell to what extent this is directly related to the caring role and it is not only those providing the most hours of care who have the worst reported physical and mental health. Other factors such as deprivation, gender, perceived stigma and lack of support may also have an influence. Whatever various factors are at play, young carers need support to ensure that their own health needs are not overlooked.

Research suggests that young carers face challenges in participating in social or leisure activities and may feel isolated as a result. However, it is also important to note that young carers can be positive about their caring role and feel that it brings benefits. As one Scottish young carer said:

"You get to feel proud and like you're really making a difference to someone in a good way. You learn skills about how to be independent and be able to function when I move out. We are more understanding and accepting of the problems faced by others." (Scottish Government and COSLA, 2010, p.7).

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[11] The Carers (Scotland) Act 2016, provides for a Young Carers Statement for all young carers. This should enable the responsible authority and the young carer to have a comprehensive view of any support needs and how these will be met. Young carers with a wellbeing need will also have a child's plan.

4. Young carers' education and employment

Introduction

This chapter considers the evidence and data on young carers' education and employment. It discusses school experiences and educational achievement; further and higher education; and employment.

Key points:

- Caring may adversely affect a young person's education but there is inconsistent evidence on the extent of the impact.
- This may be due to school attendance issues, or experiencing tiredness or bullying.
- The number of students in further and higher education who say that they are carers declines with each year of age. It is difficult to know whether this is due to changes in caring or educational status.
- Caring roles may impact on the choice of university and choice of course.
- Studying offers more flexibility but balancing commitments can be challenging.
- Around half of young adult carers are in full or part time employment.
- Financial considerations can be a concern for young carers in education and employment and when considering their work and study options.
- Flexible work arrangements and sympathetic employers are important for young adult carers seeking employment.

4.1 School Experiences and Educational Achievement

Research suggests that a young person's education can be adversely affected if they are a carer (Dearden & Becker, 2004, p. 3); (Barnardos, 2006, p. 8); (Children's Society, 2013, p. 3). Research in England by the Children's Society (2013, p. 5) found that the young carers in their sample had lower educational attainment compared to their non-caring peers, finding that the average young carers' attainment level was the equivalent of nine grades lower at GCSE (for example nine C's rather than nine B's) than young people without caring responsibilities. Research evidence in this area is quite inconsistent however, with varying numbers of young carers reporting that their caring roles have a negative impact on their education. Other factors such as deprivation are also likely to have an impact. For instance, 27% of young carers at secondary school reported that they had school-related problems (Dearden & Becker, 2004, p. 3) and in another study nearly half of the sample felt their school work was 'affected by their caring role' (Barnardos, 2006, p. 8). In a study which examined the lives of former young carers through retrospective interviews, Frank et al (1999, p. 16) found that 70% of respondents felt that their education had been affected by their caring roles. From the literature review, the three following issues appear to be the most common educational issues that may affect young carers:

- School attendance
- Tiredness
- Bullying

School attendance

Around one in 20 young carers miss school because of their caring responsibilities (Children's Society, 2013, p. 5). Based on three national studies there is some evidence to suggest that the numbers of children and young people missing school due to their caring roles have reduced over the years (Dearden & Becker, 1995) (Dearden & Becker, 1998) (Dearden & Becker, 2004). Newman (2002, p. 618) highlights that we do not know to what extent school absences are due to caring roles or, for example, poverty. Since we know that school absences are more common amongst young people who have a low socio-economic status, studies are required which control for this variable before claims can be made regarding the direct impact of caring on educational experiences. In a recent study of young carers by the Scottish Youth Parliament (2014) just over one in 10 of those surveyed said that they sometimes miss class due to their caring situation.

Tiredness

As already noted, experiencing tiredness due to the caring role has been found to have an educational impact. Nearly half of young carers in a Scottish survey (Scottish Youth Parliament, 2014) said that they are sometimes tired at school due to their caring situation. Young carers in a small scale, Scottish study by Eley (2004, p. 72) shared their experiences of how tiredness affected them. One participant reported getting into trouble with teachers for tiredness, (particularly yawning in class), another shared how they sometimes went into the school toilets to sleep if they had been caring during the night, and lastly another young person shared their general feeling of feeling ‘run down’ a lot of the time (Eley, 2004, p. 69). Likewise, in the qualitative research carried out by Roche and Tucker (2003, p. 445), one young carer illustrated their experience of arriving at school in a tired state due to her morning routine:

“My day starts at 5. I wash mum, make her comfortable and then get the breakfast ready for the rest of the family… sometimes when I get to school I’m knackered.” (Roche & Tucker, 2003, p. 445).

Bullying

Some studies have found that young carers are more likely to be bullied at school compared to their non-caring peers (Lloyd, 2013, p. 67) (Warren, 2007, p. 142).

There has been some concern over the methodological issue of establishing whether bullying is caused directly by the caring role, however some participants in these studies reported that they had been bullied ‘specifically for being a carer’ (Becker & Becker, 2008, p. 30). Interestingly, in the small study by Cree (2003, p. 306) young people reporting worries about bullying for their caring role was found to decrease with age. The proportion saying that they were concerned about being bullied fell from three quarters of those aged 5-9 years, to one third aged 10-15 years to one quarter of those 16 and over.

While these three issues recur across the literature, it is also important to note that some studies have found that young carers felt their caregiving duties had no effect on their schoolwork (Eley, 2004, p. 69) (Banks, et al., 2001, p. 809). A quarter of those surveyed by the Scottish Youth Parliament (2014) said that their caring situation does not affect their school work. Therefore it is important not to assume that all young carers will have educational problems. Some young people have actually reported that they feel school provides them with respite from the caring role (Gates & Lackey, 1998, p. 13). Young carers have also expressed mixed views on the impact of caring duties on their future opportunities (Scottish Youth Parliament, 2014). Around a third felt that it is more difficult to do well in school and a fifth felt that they had to consider caring responsibilities in decisions about work or further/higher education. Around a third felt that there is no effect. In focus groups, young carers noted they were not able to take advantage of internships, extracurricular activities and additional classes, and worried that this would be disadvantageous to future employment opportunities. It is possible that these mixed views are influenced by broader factors around family context and circumstances and the support available to young carers and their families.

4.2 Further & Higher Education

Data from Scotland’s 2011 Census shows that the number of students[12] who say that they are carers declines with each year of age. There were 1470 students at 18 years of age who identified themselves as carers in the Census, which is 4% of the student population. Students aged 21 were the least likely to provide care; just under 3% of this age group indicated that they provided care. It is difficult to ascertain whether this is due to student carers giving up their degree, or giving up their caring roles (Scottish Government, 2015, p. 21). It may be that it is harder for students nearing the end of their studies and planning toward employment to balance caring responsibilities.

We know that despite many young people having intensive caregiving duties, many young carers choose to study at college or university (Sempik & Becker, 2014, p. 2). Indeed, higher or further education may be an attractive option for many young carers because often colleges and universities offer a more flexible lifestyle compared to employment (NUS, 2013, p. 30). However, caring roles do impact

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[12] The Census analysis included young people aged 16-24. It therefore does not take into account mature students who may also have caring responsibilities.

upon young people's choice of university based on geography and proximity to their home (Hamilton & Adamson, 2013, p. 108). Particularly in rural areas, it seems likely that caring responsibilities will often constrain young people in terms of making the decision to go to university or not, and will also limit their options with regard to which course they could choose. location and mode of study. Existing support networks also influenced decisions about where to study.

The NUS (2013, p. 1) found that female carers are less likely to enter education compared to male carers of the same age group (age 16-24). This perhaps corresponds with the finding that girls are more involved in caring tasks, particularly as they grow older. Financial considerations are also important, young carers in Scottish focus groups expressed frustration that they lost their Carer's Allowance payments if they entered full time education (The Scottish Youth Parliament, 2014).

Studies suggest that the course that young carers choose is often influenced by their caregiving identities (Hamilton & Adamson, 2013, p. 108; NUS, 2013). Some have found that a large number of young carers went on to study nursing, due to their skills deriving from their caregiving background (Kirkton, et al., 2012, p. 645). The NUS (2013) found that students carers were interested in becoming better carers or in using their caring experiences to their advantage in the world of work.

Research shows that there are many challenges for young carers at college and university. Sempik and Becker (2014) looked at the experiences of young adult carers in school, further and higher education, and employment. They received 295 survey responses from young adult carers aged 14-25. In relation to young carers who were students in further and higher education, they received 101 responses, which gave considerable insight into their experiences and aspirations. Sempik and Becker's (2014, p. 3) found that 56% of young carers in the sample said that they were 'experiencing difficulties because of their caring role,' and 16% were thinking about dropping out of college or university.

In the study carried out by Hamilton & Adamson (2013, p. 107) they found that for the participants balancing further education with their care tasks was a challenge due to: increased workload, set timetables, the logistics of working out transport and also for some, finding the time to balance part-time work, caring and study.

Lack of time is a significant issue that impacts upon student carers' lives (Kirkton, et al., 2012, p. 643); and therefore can contribute towards associated difficulties such as tiredness, missed deadlines, time for studying, lateness and absence (NUS, 2013, p. 18). Indeed, the NUS (2013, p. 18) study found that only 36% of student carers in the sample felt able to balance their commitments, compared to 53% of students who did not have caring responsibilities. This could have very damaging consequences for students with caring responsibilities if they face penalties due to the difficulties experienced affecting academic performance (Kirkton, et al., 2012, p. 643). The Scottish Youth Parliament (2014, p. 21) survey found that 89% of young carers surveyed struggled to fit everything into their schedule. This was a much higher percentage than young carers in school (53%). In addition half of young carers in the Sempik & Becker (2014, p. 3) study reported having a mental health problem. In an NUS (2013, p. 29) study 15% reported mental health problems. Furthermore, 39% gave their physical health a rating of ‘just ok’ or ‘poor.

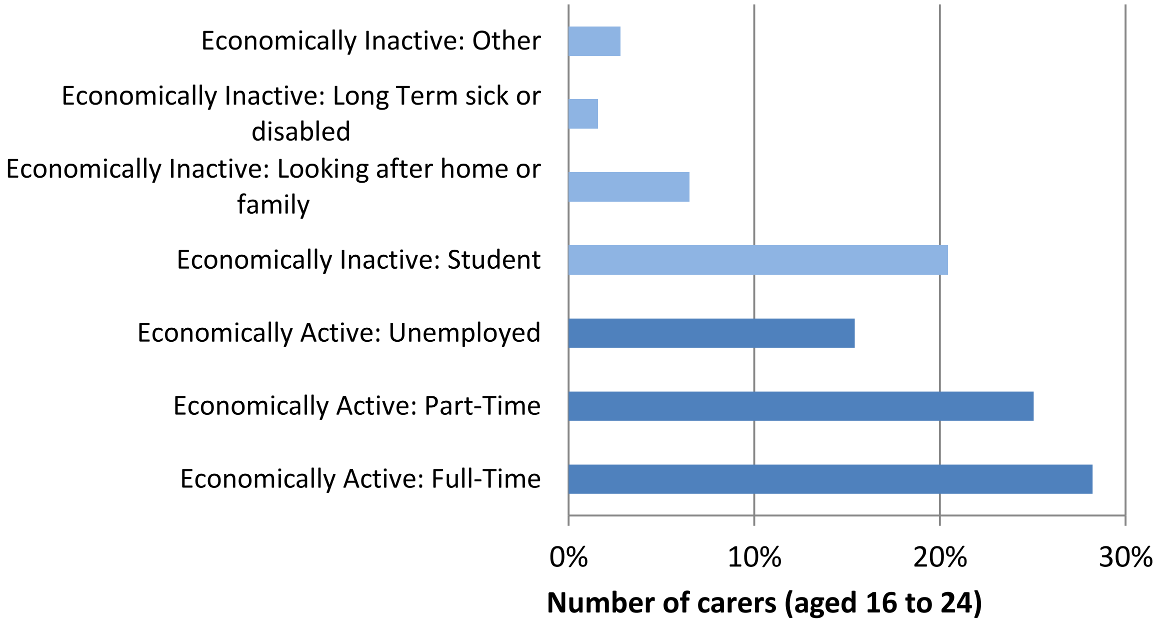
Financial concerns were also an issue. The NUS (2013) found that student carers were less likely to receive a student loans and twice as likely to have sought discretionary funding. Student carers were also more likely to receive state benefits (possible due to the prevalence of mature students in the sample). Full time students are the only group who cannot receive carers allowance even when they meet other conditions. However research has identified no reduction in the amount of caring undertaken by full time students. NUS also found that student carers were more likely to take on high risk debt and less likely to take on low risk debt. It is suggested that this could be partly explained by lack of access to accurate information about debt and finances. Many student carers are accessing both student support and state benefits and the complexity of managing these often requires specialist financial advice. For the majority of student carers combining work, studying and caring the most common reason for working was to cover basic household costs. They were less likely to work for extras for themselves. In Scotland young adult carers stated the difficulties in funding travel to college or university and back home (Scottish Youth Parliament, 2014). Some had found that the transport costs were greater than the cost of staying in student accommodation.

When the participants in the NUS study were asked about whether being a student brought positive or negative impacts for their caring, two thirds of those who felt their caring had been impacted reported that there had been a negative impact; whereas for one third of participants it was positive. This was due to having more flexibility to care and studying gave them a mental and physical break from their caring duties (NUS, 2013, p. 30).

4.3 Employment

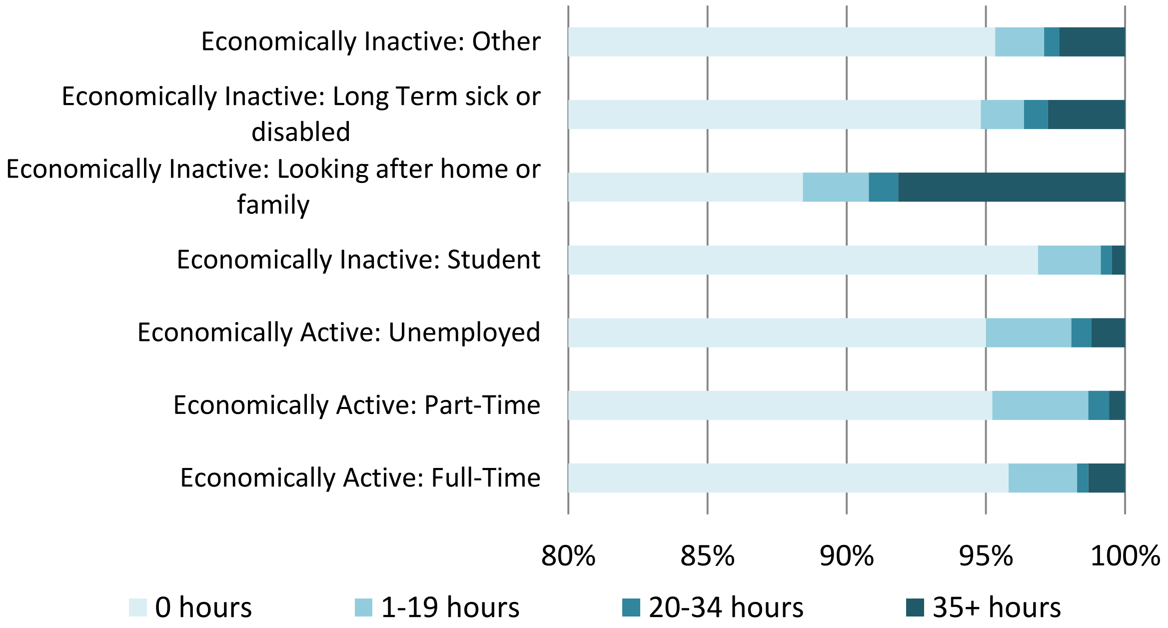
For young adult carers, the Census provides data on their employment and education status. Overall, just over half of young adult carers are in full or part time employment.

Figure 14: % of young adult carers, by employment status



As Figure 15 shows, employment status does vary by the hours of care provided. Those providing over 35 hours per week of care are more likely to be economically inactive and looking after the home or family.

Figure 15: Young adult carers (aged 16 to 24), by employment status and hours of care



As discussed above young carers may be more likely to experience problems at school and have lower educational attainment compared to their peers (Children's Society, 2013, p. 5). This will have a long term impact upon young carers' employment outcomes. Some young adult carers may feel constrained in their employment choices and aspirations due to their caring responsibilities. Becker and Becker (2008, p.43) found that young carers may be drawn to local jobs rather than necessarily the jobs which are best for them. One participant in the Hamilton and Adamson (2013, p.109) study commented that:

“I'll hopefully finish my degree this year but if I don't… full time work is not really possible, so I'm happy just to get something which is a really mediocre pushover easy job which just pays enough to cover the costs. That's what I'm aiming for the next few years.”

The Children's Society (2013, p. 5) found that young carers are more likely than the national average to be not in education, employment or training between the ages of 16 and 19. In the study by Hamilton and Adamson (2013:108), young adult carers discussed the difficulties of combining employment and their caring duties, mostly relating to the need for a ‘good employer’ and the necessity for work to be flexible to their needs. Flexible work arrangements, and empathy from employers were stated to be crucial.

Conclusions

Young carers can face challenges in balancing their caring responsibilities with education and employment requirements and opportunities. It is possible that young carers may be more likely to experience problems at school and have lower attainment although this will not apply to all young carers. Schools therefore have an important role in helping to support young carers. Caring responsibilities may influence education and employment choices and flexibility is an important factor in enabling young carers to balance different commitments. The negative impact of combining caring and education may have potentially significant enduring consequences for workforce participation, and geographic and social mobility, with the risk of compounding deprivation and inequalities.

5. Support for young carers

Introduction

This chapter discusses the evidence on support for young carers. It considers support provided in different settings and at different life stages. The evidence in this area is limited with a lack of research that explores the efficacy of particular interventions and strategies that aim to improve outcomes for young carers and their families (Banks, et al., 2002, p. vi). Apart from internal evaluations carried out by the likes of young carer groups, the literature search found only one study which tested the effectiveness of particular strategies for young carers (Ronicle & Kendall, 2011).

Key points:

- Young carers are formally recognised and entitled to a needs assessment but there is evidence to suggest that access to assessments could be improved.
- There may be a lack of awareness from professionals and young carers can feel unacknowledged or reluctant to seek help.
- Effective support can be either or both support for the cared-for person, and support to help young carers maintain a balance with other aspects of life.
- Evidence suggests that children and young people engaged in young carer support projects feel recognised, supported and valued.
- Although schools are also seen as a potentially valuable avenue for support the evidence on effective support and interventions in schools is underdeveloped.
- Older young carers have specific needs as they transition into adulthood but there may be limited services available to support them.

5.1 Understanding Young Carer’s Needs

Young carers are formally recognised in legislation and are entitled to a needs assessment. Under the Social Work (Scotland) Act 1968 and the Children (Scotland) Act 1995, carers have the right to request an assessment of their ability to care. This provision applies to children under the age of 16 (as enacted through the Community Care and Health (Scotland) Act in 2002). There are also other assessments that a young person may be offered, including a child’s plan.

The provision of a good quality assessment is essential in order to meet young carers’ needs. It is vital that young carers and their families have access to high quality information and advice about their entitlements to various supports, for example health and social care support, and welfare benefits (Sempik & Becker, 2013, p. 5). For example, as discussed in Chapter 4, many young carers have mental health needs. It has been argued that young carers should be a priority group in terms of being able to access counselling and mental health services (Sempik & Becker, 2013, p. 5).

Past research suggests considerable scope to increase the numbers of those receiving an assessment, although on-going developments in policy and practice in Scotland may be addressing some of these concerns. SCIE (2005, p. 11) suggest that young carers are not often assessed due to the following reasons:

- There is a lack of awareness amongst professionals and young people themselves about young carers' rights to be assessed.
- There also may be a potential reluctance to seek help from the young person or young person's family (see also Moore & McArthur (2007, p. 565).

A variety of writers have advocated an approach (Svanberg, et al., 2010, p. 740); (Moore, et al., 2011, p. 174) (Moore & McArthur, 2007, p. 561) that recognizes the importance of providing services to support the cared-for person, meeting the needs of the young carer and giving them a voice (Banks, et al., 2002, p. 70). There is huge potential for health professionals to help better identify young carers(they are well placed to do so) and to put them in touch with services (Thomas, et al., 2003, p. 45), (Sempik & Becker, 2013, p. 3)

Ronicle & Kendall (2011) carried out an evaluation of a pathfinder which reported on the efficacy of a whole family approach for young carers. Practitioners worked with 114 families across 18 English local authorities and provided support in various ways, including:

- Organising activities for the whole family
- Involving young carers in 'positive activities'
- Drawing upon support in the wider community
- Carrying out targeted work with key partners such as schools and adult services.

The evaluation found that the project was effective in reducing inappropriate caring tasks and reducing concerns about peer relationships and lack of engagement in positive activities. There were also some improvements in school attendance. Due to the likelihood of different causal factors at play in the lives of these families, the positive outcomes achieved for the young carers may not be directly related to the interventions being specifically based on a whole family approach.

5.2 What do Young Carers Want?

Young carers should be involved in designing and running all interventions, services and strategies. Given that young carers may be reluctant to identify themselves or seek help it is important to understand how they feel they could be effectively supported. The evidence suggests that this could be either or both support for the cared-for person, and support to help young carers maintain a balance with other aspects of life (Moore & McArthur, 2007, p. 563), (Hamilton & Adamson, 2013, p. 115).

In terms of support for the cared-for person this could include more respite opportunities (home or residential), particularly for example when the young carer is attending school, when they are sick, or when the family is experiencing conflict, or could include providing assistance with personal and intimate care tasks (Moore & McArthur, 2007, p. 563). Support to help young carers maintain a balance with other aspects of life included transport in order to participate more in community life and attend projects and leisure activities; support for siblings (Moore & McArthur, 2007, p. 563), and assistance and support at transition points in their lives (Hamilton & Adamson, 2013, p. 115).

Studies have also found that sometimes young carers do not want to disclose their caring roles to others which can exacerbate the ‘invisibility’ of this group (Christie, 2006, p. 198). Due to these disclosure issues, Banks et al (2002, p. 243) argue that where young carers are reluctant to identify themselves, support which singles out young carers may be of limited value. Possible options which may be seen as confidential and optional include the provision of a telephone hotline and online options including websites, therapy and counselling (Banks, et al., 2002, p. 234) (Ali, et al., 2012, p. 616).

There is some evidence that young carers have felt unacknowledged and unrecognised in a variety of settings (Bjorgvinsdottir & Halldorsdottir, 2013, p. 38) and that there is a lack of awareness amongst professionals about young carers (Thomas, et al., 2003, p. 44). Given the finding that resilience appears to be associated with recognition of the child or young person’s caring role (Cassidy, et al., 2014, p. 606), it is vital that young carers are recognized and feel valued for what they do.

5.3 Young Carer Services

Research has consistently found that young carers greatly value young carer projects. Children and young people in receipt of these services feel recognised, supported and valued (Thomas, et al., 2003, p. 41) (Barry, 2011, p. 535) (Banks, et al., 2002, p. 241) Young carers much prefer services that are accessible and provided by the third or voluntary sector as opposed to statutory services (SCIE, 2005, p. 10). However, such projects are often have only short-term funding and are vulnerable to closure. Furthermore, many young people do not have a young carer’s service near to them, which ‘results in a geographical inequity of access’ (Banks, et al., 2002, p. vi)[13].

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[13] According to the Carers Trust There is at least one dedicated young carers service in each local authority in Scotland, although the offer may be variable. Carers Trust offer support to young carers and young adult carers via https://babble.carers.org and https://matter.carers.org respectively

Young carers' projects should be given the resources to reach out to children and young people with caring responsibilities in a meaningful and regular capacity, with greater support and for longer periods of time (Barry, 2011, p. 16). Young carers' projects often do not have the resource or capacity to offer tailored or targeted services for certain sub-groups of young carers, which might be beneficial. Particularly for young adult carers, it has been recommended by Becker & Becker (2008, p. 78) that young carer services should plan for young carers leaving their service, empowering them to use other services after they leave.

5.4 Meeting Young Carers Needs at School

Many authors highlight the importance of provision in the school context and there is a range of suggestions for possible approaches to providing support. However, although there are suggestions on how best to meet young carers' needs in school (summarised below), more research and evaluation evidence is needed to understand how different approaches can benefit young carers.

Suggested approaches cover different ways of identifying and communicating with young carers and raising awareness of the nature of caring and its impacts for young people and school professionals. Local approaches may include having a carers lead or strategy, or including the concept of caring in classroom discussions to enable young people to feel that they can seek support. Other ways of supporting young carers could include taking account of their needs in existing services such as careers advice and school nurses.

5.5 Support for young adult carers

Young adult carers are a distinct group who have different needs as they transition into independent living, moving out of the family household, and may be participating in further and higher education and/or entering the labour force (Hamilton & Adamson, 2013, p. 102). They are an overlooked group, with limited services available which are specific to their needs, and little existing awareness about the specific challenges that they face (Sempik & Becker, 2014, p. 2). As previously noted, young people tend to take on more care as they grow older, but they are also less likely to be accessing a young carer service, depending on the age at which the service provision ends.

Transitions into adulthood can be particularly difficult for young adults with caregiving responsibilities (Dearden & Becker, 2000, p. 4) (Hamilton & Adamson, 2013, p. 101). Young adult carers often find it difficult to make decisions surrounding leaving the family home and making decisions about the future about whether to go into employment or higher/further education (Hamilton & Adamson, 2013, p. 115). Scottish Youth Parliament (2014) focus groups found that the transition from school to university or college is very difficult and extra support was needed during this time. Young adult carers also noted that it was particularly difficult to be classified as an "adult carer", but not have access to any young adult services. They expressed feeling out of place among older adult carers and missed the support of their peers and services tailored to young carers.

Colleges and universities tend to have general support and counselling services that young adult carers can access, however they tend not to have specific groups or support for young adult carers who are studying (Becker & Becker, 2008, p. 37).

Research has found that young adult carers require employers to be understanding and flexible regarding workplace arrangements (Hamilton & Adamson, 2013, p. 108). It has been argued that employers should understand the challenges young adult carers may be facing in their lives, and develop policies to clearly define the support and flexible working arrangements available for carers in the workplace (Sempik & Becker, 2014, p. 4).

Conclusion

Research on support for young carers identifies several important issues. Although assessment of young carers needs is a crucial part of accessing support, there is evidence that suggests only small numbers of young carers may be accessing an assessment. The reasons for this arise both from a potential reluctance on the part of young carers to identify as carers and also a potential lack of awareness on the part of service providers. However, as a result, young carers can feel unrecognised and unacknowledged in a range of settings and their needs can go unseen and unsupported.

When appropriate support has been accessed young carers can feel supported and valued and better able to balance caring with other aspects of their lives. There is limited research evidence on the efficacy of particular interventions and this is an important gap in the evidence base. Examples from practice are mostly base on a person centred approach to support.

It is important that support is provided in a way that is sensitive to concerns about identifying as carers and seeking help. Evidence from young carers themselves suggests that support can be either for the young carer directly or the cared for person.

However, the majority of existing studies only examine the experiences of those who are in touch with young carer projects. Knowledge is therefore biased towards these young carers who seek help and support. We know that many others are not in touch with young carer services. The experiences and needs of this hard-to-reach population are not well reflected in research studies.

6. Conclusions

There are an estimated 93,000 carers aged 4-24 in Scotland according to the most accurate estimate from the Scottish Health Survey (SHeS).

Young carers are a diverse group of different ages and backgrounds and live in all areas of Scotland. However, the Census data presented throughout this report shows that caring is more common in some groups than others:

- A larger proportion of young women are carers and a majority of young carers and young adult carers are female.
- There are more young carers in the most deprived areas and they provide more hours of care.
- Data suggests that as they become older, young people increasingly provide a few hours caring per week.
- Nearly one quarter (22%; 8328) of young carers aged 4-24 (who are more likely to be in the young adult age group) provided 35 hours or more care per week.

Research and analysis of Census data identify a number of important challenges facing young carers and young adult carers. There is considerable evidence that young carers often experience poorer mental and physical health than peers without caring responsibilities. This is true for self-reported health, long term health conditions or disabilities and mental health conditions. This is likely to have implications for other aspects of their life such as education and employment.

It is not possible to say the extent to which this is directly related to the caring role and those providing the most care do not always have the worst self-reported physical and mental health. Other factors such as deprivation and other inequalities will also have an influence. Young carers need support to ensure that their own health needs are not overlooked. Research suggests that young carers may face challenges in participating in social or leisure activities and may feel isolated as a result.

Young carers can face challenges in balancing their caring responsibilities with education and employment requirements and opportunities. This has potentially profound long-term effects on socio-economic and health outcomes and on inequality. It is possible that young carers may be more likely to experience problems at school and have lower attainment although this will not apply to all young carers. Schools therefore have an important role in being aware of and helping to support young carers. Caring responsibilities can influence education and employment choices and flexibility is an important factor in enabling young carers to balance different commitments.

Young carers can be positive about their role and feel that it brings benefits. However, given the potential impact of caring on young people, access to an assessment of their needs and to appropriate support is critically important. Improving access requires awareness of young caring amongst professionals and service providers, and ensuring that assessments and support are provided in a way that is sensitive to young people’s concerns about being identified as a carer or about requiring help.

The evidence is limited on the effectiveness of different interventions to support young people but does identify some of the needs that services can help to address. As caring can be associated with poorer mental health (particularly for female young carers) it is important they are able to access services and supported to participate in non-caring activities to reduce the risk of isolation. Although existing evidence is limited (and this is an important gap), the literature does suggest a range of potential ways to support young carers including through the provision of support to the cared-for person and by helping young people participate in other activities (for example by providing transport) in order to balance caring with other aspects of their lives. Whatever form of support is provided it is important that it is based on the needs of the young person and that young carers’ voices are heard.

This paper has reviewed the existing data and evidence on young carers focusing on the period 2005 – 2015 with the aim of providing an overview of the profile of young carers in Scotland and to explore the evidence base on the impacts of caring and support for young carers. The findings from this review sit within a context of on-going policy and service development with the Carers Scotland Act to be commenced in April 2018. As policy and practice continue to develop it will be important to understand the factors that enable young carers to seek and access support and to strengthen the evidence base on effective interventions and support options for young carers. There is a need for evidence that provides more nuanced understandings of young carers in different circumstances

Annex 1: Background Information

The overall estimate of young carers used in this report is from the Scottish Health Survey (SHeS) and detailed analysis is based on the Scotland's Census 2011. These are considered the most accurate data available for carers in 2012/13. The surveys include the same question that has been developed to help people identify that they are providing a caring role, even when they do not think of themselves as "carers". The question wording in both SHeS and the Census is: "looks after or gives any help or support to family members, friends, neighbours or others because of either long-term physical / mental ill-health /disability; or problems related to old age"

Table 3: Estimated number of young carers in Scotland – Census and SheS

Age Group	Census		SHeS	
	Carers	%	Carers	%
All people aged 0-24	37,393	2.8%	93,000	7.0%
Ages 4-15	10,002	1.5%	29,000	4.0%
Ages 16-24	27,391	4.3%	64,000	10.0%

For the first time in 2012/2013, the SHeS collated data on young carers. SHeS shows that 7% of people aged 4-24 provide unpaid care. This is the best overall estimate of young carers in Scotland.

There are an estimated 93,000 carers aged 4-24 (7%) in Scotland according to the SHeS. This comprises:

- 29,000 carers aged 4-15 (95% confidence limits: 22,000-36,000)
- 64,000 carers aged 16-24 (95% confidence limits: 46,000-81,000)

According to Scotland's 2011 Census, almost 3% of young people aged 0-24 provide unpaid care, however the Census is thought to underestimate caring, particularly the extent of low level caring. Both sources provide similar results when looking at carers who do substantial amounts of caring each week. However, because of the large numbers in Scotland's Census, it is the best source for detailed data on the profile of young and young adult carers and the care provided.

It is useful to understand why the figures from the SHeS and Scotland's Census differ. Scotland's 2011 Census and the 2012/2013 SHeS ask identical questions so it might be reasonable to expect a similar response.

There are a number of reasons why these differences may occur:

- In SHeS each young person aged 13-15 is personally asked the carers question as well as the adult in the household. They speak directly to the interviewer and say whether they provide care and how many hours a week.
- The SHeS has an additional category asking if people provide care for up to 4 hours each week whereas the first category in Scotland's 2011 Census is "up to 19 hours of care" a week. It may be that the large number of hours in the Census category deters people who only provide a small amount of care from answering.
- Because SHeS is an interview survey it allows the respondent to ask for clarification if they don't understand the question. There is not this opportunity with a postal survey.
- The SHeS question is asked as part of a detailed health survey and follows a block of questions about long-term conditions which means that people will be thinking more about health and care issues when they answer the question.

For all of these reasons, the Scottish Health Survey is considered to provide the best estimate of the overall number of carers in Scotland at present. However the numbers of young carers and young adult carers in the SHeS are too few for meaningful analysis of sub-groups. Scotland's Census 2011, as a survey of the whole population, allows for analysis of the profile of young carers and young adult carers and analysis at local authority level.

The data suggests that as children become older, more young people provide a few hours caring. This was concluded by comparing the findings from Scotland's Census and SHeS. Overall the profile of young carers in both is similar; the highest proportion of young carers are aged 13-15; those aged 4-6, comprise 4% of carers and those aged 7-9 are similar percentages as 14% (Scotland's 2011 Census) and 12% (SHeS).

There are larger differences at ages 10-12, 23% of young carers are this age according to the SHeS; compared to 30% in Scotland's 2011 Census. This reverses at ages 13-15 where the SHeS, that identifies more carers providing fewer hours, finds a higher proportion of young carers than the Census (63% compared to 53%).

Table 4: Age distribution of young carers – Census and SHeS

Age Group	Census		SHeS	
	Carers	%	Carers	%
Ages 4-6		4%		4%
Ages 7-9		14%		12%
Ages 10-12		30%		23%
Ages 13-15		53%		63%

The evidence base

The concept of young caring has only relatively recently been recognised and accepted as a social issue (Sahoo & Suar, 2010, p. 134). There was a development of interest during the 1990s (Olsen, 1996, p. 41) where the formation of the Young

Carers Research Group at Loughborough University was particularly influential in this movement. Young Carer research has broadened somewhat since the 1990s and is increasingly found in different pockets of literature.

A systematic approach was adopted to review the literature at the outset in order to generate a comprehensive account of the literature. To seek out studies relevant to the scope and purpose of the review, five databases were searched using keywords for material published between 1995 and 2015. Articles were scrutinised and narrowed down using inclusion/exclusion criteria mainly based on their relevance and quality. The articles located were used as the key sources of information to inform this literature review (see Bibliography for the articles identified through this process). After this point, reference lists of key articles were surveyed to obtain further literature relevant to the project.

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