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Young carers in England: Findings from the 2018 BBC survey on the prevalence and nature of caring among young people

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Abstract

Background. Many young people are involved in caring for parents, siblings, or other relatives who have an illness or disability. The aim of this study was to estimate the prevalence of caring by young people in England.

Method. A national survey of 925 English young people was conducted using the 18-item survey version of the Multidimensional Assessment of Caring Activities Checklist for Young Carers (MACA-YC18).

Results. Around 7% of young people were identified as doing a high amount of caring activity, and 3% a very high amount. Most frequently, caring by a young person is for a mother or a sibling, with a physical disability. Caring activity consisted mostly of domestic activities, household management, and emotional care.

Conclusion. This study provides the most up to date and methodologically sophisticated survey data on the prevalence of young caring in England, with implications for policy and practice.

Keywords: Young carers, Multidimensional Assessment of Caring Activities, MACA-YC18, BBC, England.

1. Introduction

Over the last decade it has become increasingly recognised that many young people take on an unpaid and informal caring role for family members who suffer from an illness or disability. Referred to as a 'hidden army' (Stamatopoulos, 2015), it has been estimated that 2-8% of all children in advanced industrialized capitalist societies are carers (Becker 2007; Day 2015). The aim is to investigate the prevalence of caring among young people in England.

The UK is seen as the most advanced society in terms of its recognition of young carers (Leu & Becker, 2016). One of the first sources of information on prevalence in the UK was from the Census in 2001 which estimated that 2% of children between 5 and 17 years had a caring role (Becker & Becker 2008). But as the census required parents to disclose the caring role of their children, these figures were most likely an underestimate. Also, it can't be assumed that the prevalence is consistent across all parts of the UK. A survey in 2001 of 378 children aged between 9 and 18 years living in England reported a much higher figure of 9% who self-identified as looking after a disabled or ill relative (Warren & Ruskin, 2008). However, as the survey was with a relatively small sample, and now after a decade of the government austerity programme, there is a need for new research on the current prevalence of caring among young people in England.

Although increasingly many young people are beginning to recognize themselves as carers and to identify with the term 'young carer', it is important that research into the prevalence of young caring does not rely on self-identification. Research with these young people is challenging because they often do not recognise themselves as carers (Cass *et al.* 2009, 2011; Noble-Carr & Woodman 2016). One advance has been the development of the Multidimensional Assessment of Caring Activities (MACA-YC18: Joseph, Becker, Becker, & Regal, 2009). This is an 18-item checklist of caring activities that has been adopted across the UK by local authorities, carers organisations, researchers, and professionals. Many

English local authorities and the services they commission now routinely use the MACA-YC18 in their young carers' assessment procedures to help them identify levels of caring.

2. Method

2.1. Procedure

The project was initiated by the UK Affairs Producer for BBC News. In order to recruit a sample of young people in England an analysis of the population in relation to geographical spread was carried out based on Office for National Statistics (ONS) data. It was concluded that we needed a ratio of 15% of schools from low population density areas (rural) (or have a catchment area that is predominantly low population density); 20% in medium density areas (town); and the remaining 65% in high-density areas (city).¹ Schools were then highlighted by population density area and selected schools approached to request their involvement. Schools were selected from a list of schools across England that were already engaged with the BBC via its School Report initiative. This is an initiative in which schools register to take part in a national educational scheme organized by the BBC to help students produce their own journalism. The target was to recruit approximately 1000 young people into the survey. Based on Organisation for Economic Cooperation and Development Statistics², the average class size is 25.9. As such, it was estimated that 21 schools each returning 2 classes were needed to take part.

Twenty one schools (3 from rural areas, 4 from towns, and 14 from cities) took part in the research. We asked each school to choose two classes: one Year 7 class (11 and 12 year olds) and one Year 10 class (14 and 15 year olds). These were non-streamed classes. The year 10 classes didn't need parental consent but each child under the age of 13 (Year 7

¹ The ONS data on population density by local authority was used to calculate which areas could be classed as being within three geographical categories: city (more than 15 people per hectare), suburbs/town (between 3 and 15 people per hectare), and rural (less than 3 people per hectare).

² https://stats.oecd.org/Index.aspx?DataSetCode=EDU_CLASS

children) had to return parental consent before completing the questionnaire. In line with Data Protection legislation each questionnaire was anonymous. The only details about the child were their year group and gender. No details of the school were to be given.

Data collection involved using paper questionnaires that were completed during regular classes within the classroom setting. Each questionnaire included a flier, which could be taken away and read. It offered a number of options, should anything in the questionnaire raise any issues: speaking to a member of the pastoral team at school; contacting Barnardo's (who agreed to put any child in touch with one of their young carer groups, or signpost if it's outside an area they cover); Childline's number (the NSPCC agreed to have the number included).

Questionnaires were not taken away from the classrooms but completed during dedicated time that was set aside. All pupils who were present on the day were asked to take part except those with no parent consent. As such take up was lower for year 7's than year 10. For year 10's the mean return per class was 21 from city schools, 17 from town schools, and 25 from schools in rural areas. For year 7's, the mean returns were 17, 18, and 22, respectively. In total, we received back 925 completed questionnaires. The exact figures of how many were supposed to be in each class were not available to us but assuming the national mean of 25.9 students per class, this is an overall 85% return.

The survey adhered to the BBC's ethical guidelines for conducting such research. Editorial Policy highlighted the duty of care the BBC has to each child who filled in a questionnaire. The BBC data protection lawyer included an explanation paragraph which would describe to each child how the data will be used and treated. Details were included in the covering letter to each school. All raw data were safely stored and encrypted.

2.2. Measures

A short survey (see Appendix) was designed to identify young carers, who they care for, the amount of caring they undertake, and to find out whether caring is related to gender, age group, and well-being. Question 1 asked: ‘Is there is someone in your house with an illness or disability?’. Question 2 asked: ‘If there is someone with an illness or disability, do you ever help to look after this person and do things to help them around the home?’. These two questions were designed such that an affirmative response to both provided our operational definition of being a young carer. Question 3 asked: ‘If you do provide help, who is it you provide help to?’ Participants were asked to check from the list: mum; dad; bother/sisters; grandparents; other relatives; and I don’t provide help. Question 4 asked ‘If you do provide help, why do you need to look after them?’ Participants were asked to check from the list of illness and disability categories: i.e., they have a physical disability (e.g., problems getting around, or lifting things); they have a learning disability; they have mental health problems (e.g. depression, anxiety, schizophrenia); they drink too much alcohol; and I don’t look after anybody.

2.2.1. Multidimensional Assessment of Caring Activities (MACA-YC18)

Following the four opening questions, participants were asked to complete the MACA-YC18 (Joseph *et al.* 2009; 2012), a widely used and validated 18-item inventory of caring activities undertaken by children and young people. Used to assess the amount of caring that is carried out by young people, the MACA-YC18 provides a total sum score ranging from 0 (indicating that no caring is carried out) to 36 (indicating the highest amount of caring).

The Manual states that scores of 14-17 a high amount of caring activity, and a score of 18 and above is used to indicate a very high amount of caring. In addition, the MACA-YC18 also consists of subscales measuring the amount of caring in six domains: (1) domestic activity such as cleaning and cooking, (2) household management such as shopping, (3) financial and practical management such as helping to pay bills, (4) personal care such as

helping to dress, (5) emotional care such as keeping company, and (6) sibling care. On each of the six subscales, scores have a possible range of 0 to 6.

The MACA-YC18 was originally developed as an assessment tool to be completed by young people who have already been identified as young carers. As such, seven items (i.e., 9, 10, 11, 12, 13, 14 and 15) were modified for use in the present and similar studies to be used as a general survey instrument with all young people regardless of whether they undertook caring activities (e.g., item 11 ‘Help the person you care for to have a wash’ was reworded as ‘Help someone in the house to have a wash’). As such, the survey version of the MACA-YC18 can be used with all young people as a screening tool to identify young carers and to understand the differences between the activities of those who care from the normal helping activities of young people around the home.

3. Results

In total, 925 young people (407 boys, 467 girls, 6 transgender, 27 preferred not to say, 18 missing) completed the survey (424 in Year 7, 499 in Year 10, 2 missing) in different locations in England (606 city, 179 town, 140 rural). Two-hundred of these young people (22% - 200/925) answered that there was someone in their house who suffered from an illness or a disability and who they helped to look after and do things to help them around the home. These young people were classed as ‘young carers’ by our method. Results for these showed that care was most frequently provided for their mother (n = 91, 46%), followed by siblings (n = 79, 40%), father (n = 46, 23%), grandparents (n = 45, 23%), and other (n = 32, 16%). Almost a third (n = 63, 32%) responded to more than one of these categories indicating that they were providing help to more than one person. The most frequent problems of the person being cared for were physical disability (n = 70, 35%), followed by long term illness (n = 48, 24%), mental health problem (n = 47, 24%), being ill in another way (n = 31, 16%),

learning disability (n = 26, 13%), drug use (n = 7, 4%), and alcohol problems (n = 3, 2%).

Eleven percent (n = 22) preferred not to say what the problem was.

3.1. Amount of care

Of the 200 young carers, 177 had completed the MACA-YC18 in full. Their scores ranged from 3 to 36, 32% (56/177) scoring 14 and above indicating a high amount of caring activity, and 9% (16/177) scoring 18 or above indicating a very high amount. Extrapolating these figures to the total sample of 925 as a percentage, these data show that approximately 7% of all children are engaged in a high amount of caring and 3% in very high amounts.

3.2. Types of caring

Using a cutoff score of 3 or above to indicate a high amount of activity in the six domains of the MACA-YC18, 83% (162/194) indicated a high amount of domestic activity, 51% (96/190) of household management, 48% (92/191) of emotional care, 34% (63/188) sibling care, 10% (19/190) personal care, and 4% (7/191) financial and practical management.

3.3. Comparison with non carers

Many young people help around the home in a non-caring capacity, so it is important to determine to what extent the amount of caring faced by young carers is greater than more general helping around the home. In order to compare scores of young carers on the MACA-YC18, we identified 530 respondents who answered 'no' to question 1 and answered that 'nobody has an illness or disability' to question 2. These respondents were classified as young people with no caring role. The MACA-YC18 was completed in full by 488 of the non-carers. Scores ranged from 0 to 36, with 35% (171/488) scoring 10 or above, 13% (63/488) scoring 14 or above, and 3% (13/488) scoring 18 or above. Comparison of young carers and non-young carers are reported in Table 1. Young carers scored higher on the total MACA-YC18 and all six subscales than those not identified as young carers.

-insert Table 1 about here-

3.4. Gender and school year

Of the young carers, 198 answered the question about gender: 117 (59%) said that they were female, 74 (37%) that they were male, 2 identified as transgender (1%), and 5 preferred not to say (3%). Comparison of males and female young carers on the MACA-YC18 and the six subscales are reported in Table 2. There was no statistically significant difference between males and females on the total MACA-YC18 but there was a difference on the domestic activities subscale, with females scoring higher than males.

-insert Table 2 about here-

Of the non-carers group, 267 (51%) identified as females, 241 (46%) as males, 4 as transgender (1%), and 10 preferred not to say (2%). Comparing these figures with those above for young carers suggests that a disproportionate number of females are carers (i.e., 59% to 51%) than would be expected by chance. Comparing only females and males, it was found that those who identified as female were more likely be in caring roles than males (Chi square = 10.60, $df = 1$, $p < 0.01$).

Looking at the MACA-YC18 separately for school year, of the young carers, 95 (48%) were in year 7 and 104 (52%) were in year 10 (one person did not answer the question). There was no statistically significant difference between the year groups on the mean total MACA-YC18 scores, but we did observe a difference on two subscales, with the older group engaged in more domestic activities. We also found the younger age group to be engaged in more financial activities (see Table 3). However, as relatively few young people were engaged in financial caring we consider this is likely an outlier effect related to this particular sample.

-insert Table 3 about here-

Compared to young carers, 232 (44%) of those classified as non carers were in year 7 and 297 (56%) in year 10, suggesting the possibility that a disproportionate number of young

carers might be in the younger age group than would be expected by chance. However, there was no statistically significant difference in the likelihood of being a carer depending on year group (Chi square = 0.92, df= 1, $p > 0.10$).

4. Discussion

Using the adapted survey version of the MACA-YC18 we were able to provide the most detailed assessment to date of both the types and extent of caring activities in a sample of English young carers. It was found that 7% of young people provide a high amount of caring, and 3% a very high amount. Most frequently caring by a young person is for a mother or a sibling, with a physical disability. Caring activity consisted mostly of domestic activities, household management, and emotional care. Females are not only more likely to have caring roles but when they do, they also engage in more caring activity than males.

We aimed to recruit a sample of young people by selecting schools representing different geographical categories. We estimated a response rate of 85% to our survey. This is the most methodologically sophisticated and reliable data to date on the prevalence of caring in young people in England. However, there are limitations. First, having to obtain parental consent for the younger age group will have lowered response rates. Some parents may have forgotten or not got around to replying. Research with young carers has also found that access may be refused by those in a gatekeeping role because of fears of a child protection intervention or invasion of privacy (Keenan, Fives, & Canavan, 2012). Second, it is known that young carers are more likely than non-carers to miss school (Warren, 2007). As a result it seems more likely that we have slightly underestimated rather than overestimated the prevalence of caring in young people.

The Government acknowledged in their recent Carers Action Plan (Department of Health and Social Care 2018) that young carers can suffer with poorer health and wellbeing

and often miss out on education and training opportunities. There is some evidence that caring is statistically associated with lower well-being (Lloyd, 2013), worry (Nagl-Cupal, Daniel, Koller, & Mayer, 2014), more frequent depressive states (Joseph, Becker, Becker, & Regel, 2009), and absence from education (Becker & Sempik, 2018). A prevalence of 7% would suggest that the effects of caring may have serious and widespread deleterious effects personally and socially. However, these are all cross-sectional investigations. Research now needs to understand the possible causal effects of caring over time and which young people are most at risk.

The Children and Families Act 2014 and the Care Act 2014 state that every local authority has a duty to assess whether a young person within their area has needs for support. This legislation means that young carers no longer have to request an assessment; it should be carried out when it appears that a child is involved in providing care. This assessment is compulsory regardless of who the young person cares for, what type of care they provide or how often they provide it. The MACA-YC18 provides a recognised national standard in assessment which allows a common understanding and point of reference across councils, facilitating more integrated working and consistency across services. The current study adds new information on the use of the MACA-YC18 that will be valuable to researchers, practitioners and policy makers concerned with the impact of caring.

Key messages

Describes the use of an 18-item survey version of the Multidimensional Assessment of Caring Activities Checklist for Young Carers, which can be used in research with all young people.

Around 7% of young people were identified as doing a high amount of caring activity, and 3% a very high amount

Most frequently caring by a young person is for a mother or a sibling, with a physical disability

Caring activity consisted mostly of domestic activities, household management, and emotional care.

Females are not only more likely to have caring roles but when they do, they also engage in more caring activity than males.

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Table 1: MACA domain scores for young carers and those without caring responsibilities

MACA Domain Scores	Young Carers			No Caring Responsibilities			Sig
	N	Mean	Std. Deviation	N	Mean	Std. Deviation	
Domestic	194	3.82	1.38	523	3.31	1.43	t = 4.31, p < 0.001
Emotional	191	2.56	1.49	511	1.53	1.49	t = 8.11, p < 0.001
Financial	191	0.51	0.95	520	0.23	0.61	t = 4.59, p < 0.001
Household	190	2.58	1.36	515	1.93	1.33	t = 5.69, p < 0.001
Personal	190	0.68	1.30	514	0.24	0.77	t = 5.57, p < 0.001
Sibling	188	1.80	1.67	517	1.18	1.45	t = 4.80, p < 0.001
MACA Total Score	177	11.82	5.24	488	8.41	4.55	t = 8.18, p < 0.001

Note that total numbers vary as not all respondents completed the MACA-YC18 in full.

Table 2: Young carers' MACA domain scores and gender

MACA Domain Scores	Male			Female			Sig
	N	Mean	Std. Deviation	N	Mean	Std. Deviation	
Domestic	73	3.44	1.43	112	4.05	1.27	t = -3.07, p < 0.002
Emotional	72	2.54	1.55	110	2.56	1.42	t = -0.10, p > 0.92
Financial	71	0.54	0.95	111	0.46	0.83	t = 0.56, p > 0.57
Household	72	2.69	1.37	109	2.51	1.32	t = 0.89, p > 0.38
Personal	70	0.53	1.15	111	0.72	1.23	t = -1.05, p > 0.30
Sibling	70	1.50	1.58	109	1.98	1.66	t = -1.94, P > 0.06
MACA Total Score	67	11.12	5.10	101	12.15	4.89	t = -1.31, P > 0.19

Note that total numbers vary as not all respondents completed the MACA-YC18 in full.

Table 3: MACA domain scores by school year

MACA Domain Scores	Year 7			Year 10			Sig
	N	Mean	Std. Deviation	N	Mean	Std. Deviation	
Domestic	92	3.50	1.44	101	4.09	1.26	t = -3.03, p < 0.003
Emotional	89	2.62	1.56	101	2.47	1.49	t = 0.71, p > 0.47
Financial	90	0.63	1.04	100	0.34	0.64	t = 2.36, p < 0.02
Household	89	2.65	1.43	100	2.48	1.25	t = 0.88, p > 0.38
Personal	88	0.77	1.25	101	0.56	1.24	t = 1.21, p > 0.23
Sibling	87	1.71	1.61	100	1.83	1.67	t = -0.49, p > 0.63
MACA Total Score	82	11.70	4.91	94	11.66	4.97	t = 0.05, p > 0.96

Note that total numbers vary as not all respondents completed the MACA-YC18 in full.

Supplementary Material

Appendix

This is an anonymous questionnaire for BBC News, BBC School Report and Nottingham University.

About me and my family

Lots of young people help around the home because someone in the house suffers from an illness or disability. We would like to know about you and your family. Please read all parts of the questionnaire and answer everything as honestly as you can. There are no right or wrong answers.

1. Is there someone in your house who suffers from an illness or a disability
(please tick one box)

Yes []

Not sure []

No []

2. If there is someone with an illness or disability, do you ever help to look after this person and do things to help them around the home? (please tick one box)

Yes []

No []

Nobody has an illness or disability []

3. If you do provide help, who is it you provide help to? (Please tick as many boxes as apply to you)

Mum	<input type="checkbox"/>	Brother/s or sister/s	<input type="checkbox"/>
Dad	<input type="checkbox"/>	Grandparent/s	<input type="checkbox"/>

Other family members	<input type="checkbox"/>	I don't provide help	<input type="checkbox"/>
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4. If you do provide help, why do you need to look after them? (If you don't look after anybody please just tick the box that says you don't look after anybody. Otherwise, please tick as many boxes as apply to you).

They have a physical disability (e.g., problems getting around, or lifting things)	<input type="checkbox"/>	They use drugs	<input type="checkbox"/>
They have a learning disability	<input type="checkbox"/>	They have a long-term illness (e.g. cancer, epilepsy, heart problems)	<input type="checkbox"/>
They have mental health problems (e.g. depression, anxiety, schizophrenia)	<input type="checkbox"/>	They are ill in another way	<input type="checkbox"/>
They drink too much alcohol	<input type="checkbox"/>	I'd prefer not to say	<input type="checkbox"/>
I don't look after anybody	<input type="checkbox"/>		

5. Below are some jobs that young people do to help around the house and the people who live there. Please read each one and put a tick in the box to show how often you have done each of the jobs in the last month. If the job is not relevant to you please just tick never.

	Never	Some of the time	A lot of the time
Clean your own bedroom	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clean other rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Wash up dishes or put away dishes in a dishwasher	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Decorate rooms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Take responsibility for shopping for food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with lifting or carrying heavy things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Some of the time	A lot of the time
Help with financial matters such as dealing with bills, banking money or collecting benefits			
Work part time to bring money in			
Interpret, sign or use another communication system to help someone in the house.			
Help someone in the house to dress or undress			
Help someone in the house to have a wash			
Help someone in the house to have a bath or shower			
Keep someone in the house company e.g. sitting with them, reading to them, talking to them			
Keep an eye on someone in the house to make sure they are alright			
Take someone in the house out e.g. for a walk or to see friends or relatives			
Take brothers or sisters to school			
Look after brothers or sisters whilst another adult is nearby			
Look after brothers or sisters on your own			

6. Think about the last week. Please read every question carefully. What answer comes to your mind first? Tick the box that fits your answer best. Remember: This is not a test so there are no wrong answers.

In the last week	Not at all	Slightly	Moderately	Very	Extremely

1. Have you had fun with your friends or family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Have you had exercise by playing sports or games?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you found what you have been doing interesting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Have you learned new things at school or at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Have you done anything nice for other people, including your friends or family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. Which gender?

(Please tick)

Boy [] Girl [] Transgender [] Prefer not to say []

8. Which school year?

Year 7 [] Year 10 []

How this information will be used:

The anonymous information given in this questionnaire will be used solely by BBC News and Nottingham University. It will not be shared with any other agencies or companies. We will have no way of contacting you or identifying you once you have filled in the questionnaire.