

# ESSS Outline Experiences of young carers in university and transitioning to work

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## Introduction

This evidence summary addresses the following question relating to young carers: What are the experiences of people with caring responsibilities at university college and transitioning to work?

We searched for academic research and grey literature using terms like: young carers, education, children carers.

The evidence below comes largely from the UK, specifically from the Carers Trust. This source favours large-scale quantitative studies that survey young carers across England, Scotland or Wales. These reports highlight a) how young carers find themselves in disadvantaged positions because of their caring role (Dearden and Becker, 2003; Becker and Becker, 2009) and b) make recommendations on how education institutions can accommodate the needs of young carers (Carers Trust, 2017; 2018) Several studies (Cluver and colleagues, 2012; Moore and colleagues, 2006; Skovdal and colleagues, 2009) explore young carers' qualitative experiences in more depth, which includes their involvement with education at various levels.

## Background

Aldridge and Becker (1993) argue that all children have a fundamental right to access education, but many young carers are denied this right because of their caring duties. Dearden and Becker (2002) reviewed UK studies of young carers and found high levels of school absence, tiredness, anxiety, poor attainment and behavioural problems. Young carers and carers in higher education are at a disadvantage as their caring role is often not considered by higher education institutions. Transitioning to work is not mentioned by many articles. Below outlines the main findings of how caring roles affect the experiences of young people.

#### Social life:

Many children and young people feel socially isolated from their peers due to their caring responsibilities within the home. Young carers are also reluctant to have visitors for fear of adverse reactions (Moore, 2005; Morgan, 2006). Many young carers, however, feel that connecting with children and young people with similar experiences allows them to form strong and long-lasting relationships (Morgan, 2006).

#### **Employment:**

A majority of young carers do not work (Carers Australia, 2002). Many believe that they have many qualities and skills that would make them employable, but that their caring is a full-time job in itself. Some young carers were also studying for caring professions like social work or childcare (Sempik and Becker, 2014).

#### Transitions into adulthood:

Through their caring, young carers develop skills and gain independence that can aid them in the future (Carers Australia, 2002; Skovdal and colleagues, 2009). As a result of the restrictions on their education and their capacity to connect with the community around them, transitions to adulthood can be difficult (Halpenny and Gilligan, 2004).

#### **Outlook:**

Many young carers feel hopeful and optimistic about the future. They believe that having dealt with adversity that they are more equipped and capable of dealing with future difficulties and challenges (Skodval and colleagues, 2009; Halpenny and Gilligan, 2004; Moore, 2005).

#### Caring into the future:

Many young carers are resigned to their long-term caring role (Halpenny and Gilligan, 2004). They believe their caring role will affect the work they can do, their relationships, and the way they will be able to take part in the wider community. Many young carers are aware that their care responsibilities will end eventually– either following their cared for relative's death, or through transitioning into other care arrangements (Frank and colleagues, 1999, cited in Moore, 2006, p.14).

#### Their own health and well-being:

Many young carers are aware of the long-term impacts that caring can have on their lives. Others are concerned about their own susceptibility to illnesses and conditions and that of their future children (Moore, 2005). Below I have provided a summary of a key report that highlights the cumulative experiences of young carers in higher education. I also present the findings of three key studies that took a qualitative approach:

## Surveys on cumulative data

#### Report

## Sempik J and Becker S (2014) Young adult carers at college and university. Retrieved from <u>www.carershub.org</u>

Sempik and Becker (2014) surveyed 295 young carers in the UK. The 101 young adult carers who were in further or higher education, on average, provided a 'Very high' level of care.

- 39% rated their physical health as either 'Just OK' or 'Poor'; and 45% reported having mental health problems.
- Most respondents (79%) enjoyed college or university but over half of them (56%) were experiencing difficulties because of their caring role. 16% were concerned that they might have to drop out of college or university.
- Those who reported that they found college or university difficult had significantly higher caring responsibilities.
- 75% of respondents informed college or university staff of their caring role. Despite this, 45% said there was no one who recognised them as a carer and helped them. Young carers who chose not to inform college or university staff felt there was 'no point'.
- Most respondents (62%) had not been formally assessed by a social worker or other health/social care professional. Almost a third (30%) believed they had not received good services as a young carer or adequate support for their families (31%).

- 56% of respondents received a bursary to help with their studies, including 12 of the 17 at university. Only four respondents (4.6%, n=87) received Carer's Allowance, and 13 (21%, n=62) were in receipt of some other form of benefit.
- 60 of the respondents were attending young carers or young adult carers service. Of these, almost all (95%) felt that their confidence had improved as a result and that they had more friends (87%).

This survey and other studies like it do not consider in depth the experiences of young carers. Several studies focused on personal experiences of young carers and their education experience, but most included the perspectives of younger participants.

## Young carers personal experiences

#### **Academic article**

Skovdal M, Ogutu VO, Aoro C et al (2009) Young carers as social actors: coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social Science and Medicine*, 69, 4, 587–595. <u>https://doi.org/10.1016/j.socscimed.2009.06.016</u>

Skovdal and colleagues (2009, p594) see young carers as competent social actors rather than passive victims of detrimental circumstances. Their study looks at the coping strategies of children carers in Western Kenya. The study selected twenty-four children aged between 11 and 17 and 10 adults (including eight lay people and two social development professionals). This research describes itself as an action research project that involved children in the research and data collection process. Researchers gave the children participants disposable cameras as tools for eliciting their perceptions and experiences of their life circumstances and how they coped with daily problems and challenges. Photovoice is a method through which marginalised groups can communicate, identify and represent their community and circumstances (Wang, 2006). The photovoice data collection process involved four stages.

- The first stage was photo-taking. Researchers asked the young carers to take photographs over the course of two weeks guided by four questions: '(1) What is your life like?, (2) What is good about your life?, (3) What makes you strong? and (4) What needs to change?'.
- At the second stage, they encouraged children to choose their six favourite photographs. Children chose images guided by themes like 'how you get by, things that you lack and/or something that is important to you'.
- At the third stage, children were invited to reflect on their chosen photographs and write their thoughts. Their written reflections were guided by the following questions: '(1) I want to share this photo because, (2) What's the real story this photo tells?, and (3) How does this story relate to your life and/or the lives of people in your neighbourhood?'.
- At this stage, children were encouraged to draw the experiences they had not captured on camera (for ethical or practical reasons). This exercise generated 184 photos and 56 drawings, each with an accompanying written reflection.

Overall, the findings of this study show that children construct positive and empowered caring identities.

- Participants referred to their caring role as a source of skills and independence that would help them throughout their lives.
- Practical skills gained from caring included caring and nursing skills, income generation and personal qualities including empathy, commitment and being a hard worker.

- The study shows that the emotional cost of caregiving influenced children's own sense of well-being, leading some of them to construct a negative identity with their caring responsibilities.
- The study also found that the long-term impacts of the children's caring role had on their education and school attendance were their greatest concern.
- Some participants felt that the interrupted education caused all negative meanings they ascribed to their caring role.

#### Academic article:

Cluver L, Operario D, Lane T et al (2012) 'I can't go to school and leave her in so much pain': educational shortfalls among adolescent 'young carers' in the South African AIDS epidemic. *Journal of Adolescent Research*, 27, 5, 581–605. <u>https://doi.org/10.1177/0743558411417868</u>

Cluver and colleagues (2012) study combined qualitative and quantitative methods to study the relationship between being a carer and education. Six hundred and fifty nine adolescents were interviewed in South Africa. Three major themes were identified:

- Young people were missing school or dropping out of school to care for family members
- Young carers were experiencing hunger at school due to household-level poverty
- Young carers reported they were unable to concentrate due to worrying about their cared for person

Other themes that emerged in this study include:

- Young carers experience pride in regular school attendance or school achievement
- School was a refuge and a coping mechanism for young carers
- Young carers experienced complex dynamics between peer support and peer stigma at school

#### **Academic article**

Moore T and McArthur M (2007) We're all in it together: supporting young carers and their families in Australia. *Health and Social Care in the Community*, 15, 6, 561–568.

#### https://doi.org/10.1111/j.1365-2524.2007.00719.x

Moore and colleagues' (2006) study interviews 51 young carers between 12 and 21 years old. The project had an action research approach and trained a group of young carers as peer consultants. The young carers assisted the research team to shape how questions were constructed and the themes that the research should explore. In addition, the peer consultants influenced the language of the research, ensuring that it was appropriate and 'youth friendly' (Moore and colleagues, 2007). The young carers interviewed in this study felt that school:

- Offered them respite from their home lives
- Provided them opportunities to connect with other young people (particularly those in a similar situation to themselves) and to develop a sense of belonging
- Was a place where they could receive support and information from people who were understanding and caring

Young people in this study also suggested that their caring role affected their attendance at times as a result of:

- The level of care responsibility they assumed
- The lack of services available to support them and their relatives
- Family issues such as poverty and isolation
- Physical and emotional issues
- Not having time to complete homework and catch up with schooling

• Having a school system that was inflexible and unresponsive to their needs, skills and experiences

This study shows that young carers' social development was sometimes hampered by their care responsibilities and family dynamics. Issues arising from the research include:

- Lack of time to socialise with friends after school
- Difficulties in engaging with others who understand
- Losing friends because of home life
- Bullying and harassment
- Feeling uncomfortable and unsafe
- Expressing anger and other emotions negatively

These studies provide insight into the experiences of young carers in education, but there is little evidence on their experiences of transitions. Moreover, there are no qualitative studies on the experiences of young carers in higher education.

#### **Accessing resources**

We have provided links to the materials referenced in the summary. Some materials are paywalled, which means they are published in academic journals and are only available with a subscription. Some of these are available through the <u>The Knowledge Network</u> with an NHS Scotland OpenAthens username. The Knowledge Network offers accounts to everyone who helps provide health and social care in Scotland in conjunction with the NHS and Scottish Local Authorities, including many in the third and independent sectors. <u>You can register here</u>. Where resources are identified as 'available through document delivery', these have been provided to the original enquirer and may be requested through NHS Scotland's <u>fetch item service</u> (subject to eligibility).

Where possible we identify where evidence is published open access, which means the author has chosen to publish their work in a way that makes it freely available to the public. Some are identified as author repository copies, manuscripts, or other copies, which means the author has made a version of the otherwise paywalled publication available to the public. Other referenced sources are pdfs and websites that are available publicly.

#### **Further reading**

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