

TITLE PAGE

THE NEEDS OF YOUNG CARERS AND THE ROLE OF THE SCHOOL NURSE: A REVIEW OF THE LITERATURE

AUTHORS

Helen Lovell, Specialist Community Public health Nurse, School Nursing.

Kent Community Health NHS Foundation Trust.

The Oast Unit,

Hermitage Court

Hermitage Lane

Barming

Maidstone Kent ME16 9NT

Dr Karen Cleaver* Head of Department, Family Care & Mental Health

Faculty of Education & Health

University of Greenwich

London SE9 2UG

k.p.cleaver@greenwich.ac.uk

Tel: 020 8331-8075. Fax: 020 8331-9160

* Corresponding author.

Abstract

Young Carers provide a significant contribution to society in their caring role, which is in line with the UK Government's Big Society agenda. In contrast with their contribution to society, young carers have huge associated costs related to poor outcomes and the numbers that end up not in employment, education or training (NEET). Missing school due to caring responsibilities is likely to have an effect on future education and job prospects. Understanding the impact of the caring role on the school experience of young carers will enable school nurses to provide appropriate support for Young Carers, improving their school experience and subsequent outcomes.

Keywords: Young Carers; School Nurse; psychological and emotional wellbeing; school experience; social isolation

Introduction

The number of Young Carers is increasing and their caring role significantly contributes to society. However, there is a high personal cost to be paid as a consequence of undertaking this role. Young Carers experience poor educational outcomes and high numbers fail to progress into employment, education or training. The Government has pledged support for carers aiming to improve outcomes for both Young Carers and those they support (HM Government 2010). Several definitions of the term ‘Young Carer’ exist; the definition adopted for the purpose of this paper is:

Children and young people under 18 who provide regular and on-going care and emotional support to a family member who is physically or mentally ill, disabled or abuses substances.

The Children’s Society (2012 p.6)

Background

There has been a rise of 24.2% in the number of Young Carers (Office of National Statistics 2013); indeed, one BBC survey suggested that the real number could be four times greater than census figures indicate (BBC 2010). A report from The Children’s society (2013) revealed that there are 166,363 young carers in England compared to around 139,000 in 2001, with around 8% caring for more than 15 hours/week, 5% for between fifteen and thirty hours and 3% for thirty hours or more. As a consequence, one in 20 Young Carers miss school because of their caring responsibilities and ultimately young carers are more than likely than the national average to be not in education, employment or training (NEET) between the ages of 16 – 19 (The Children’s Society 2013:5)

Dearden and Becker’s (2004) study found that 10% of Young Carers care for more than one person and further research has identified that one third of Young Carers

provide care for a parent and just over half care for a sibling; other care recipients include grandparents, other relatives and non-relatives (Children's Society 2013).

The nature of the illness or disability suffered by people requiring care impacts on the type of care required. Intimate care is required most commonly by those with physical health problems and more often carried out by girls (Dearden and Becker 2004). The need for emotional support is high across all groups of physical, mental, learning and sensory illness or disability but more so in those with mental health problems. A consequence of providing care for family members with mental illness or substance dependency may result in Young Carers becoming deliberately invisible but this invisibility means they cannot be supported in their role to health and social care personnel (Children's Society 2013).

Review of the Literature

A literature review was undertaken to examine the experiences of Young Carers and how their role impacts on their school experience. A search of the following databases was conducted: Academic Search Premier, Medline, CINAHL, Psychology and Behavioural Science Collection and Psych INFO. In order to identify an appropriate range of literature, papers were included that had been published between 2003-2013. The final search was completed in September 2013. Search terms used were “Young car*” OR “Young people who care” OR “Young people caring” OR “Child caring” OR “Children who care”. The search included literature from North America, Canada, Scandinavia, Europe, Australia and New Zealand. These countries were considered to be similar to the United Kingdom both economically and culturally. The initial search yielded 56 papers, whose abstracts were reviewed and assessed for relevance. A total of 8 papers met the study inclusion criteria (See Table 1). A further study (Warren 2007) was identified as meeting the inclusion criteria, from a reference list, making a total of 9 papers. Each paper was appraised using a format from the Critical Appraisal Skills Programme (CASP) (2013). At this stage a further 4 papers were discarded. The findings of the remaining 5 papers (Lloyd 2013, Moore et al 2011, Warren 2007, Thomas et al 2003 and Cree 2003) were considered. A process of thematic analysis as advocated by Braun and Clarke (2006) was undertaken, resulting in three themes: psychological and emotional wellbeing, school experience and social isolation.

Psychological and emotional wellbeing

The studies highlighted that Young Carers experience psychological and emotional effects as a result of their caring role (Cree 2003, Thomas et al 2003, Warren 2007, Moore et al 2011 and Lloyd 2013), which impacts on health, wellbeing, school experiences and educational attainment, meaning that Young Carers are less likely to say they are very happy with their life. A link between psychological wellbeing and the caring role was evident (Lloyd 2013). Caring for a parent with a drug or alcohol issue can lead to Young Carers suffering from a lack confidence, low self-esteem and limited hopes for the future (Moore et al 2011), resulting in barriers for fulfilling their future ambitions (Warren 2007).

There is also evidence to suggest that Young Carers suffer mental health problems as a consequence of their role. Cree (2003) found that Young Carers worry about finances, bullying, schoolwork and being friendless; in addition, the mental health problems they experienced included poor sleep, eating problems, self-harm, anger, aggression and suicide. Moore et al's (2009) study found that 52% of Young Carers felt angry and upset, which often led to them punishing school colleagues or acting out in class. Thomas et al (2003) describes the sense of responsibility that Young Carers feel towards fulfilling their caring role; it identified that Young Carers often have to act in an adult like way when they do not feel like adults. These findings are apparent in other studies; Bolas et al (2007) highlighted the powerful negative emotions experienced by Young Carers, and describe the role as relentless, overwhelming and inescapable. O'Dell et al (2010) state that such role confusion is psychologically challenging for Young Carers and may impact on their mental wellbeing and school experiences. This is particularly pertinent during adolescence, a critical period for identity formation (Chalmers and Lucyk 2012).

School Experience

Their caring role has an important impact upon the school experience of Young Carers (Moore et al 2011, Cree 2003, Thomas et al 2003, Lloyd 2013 and Warren 2007). Whilst most Young Carers do not miss school, they are more likely to miss

school than their peers, additionally, while most Young Carers are not late for school, they are more likely to be late than their peers (Warren 2007). Fifty percent of Young Carers have difficulties at school because of the conflicting priorities between their caring role and meeting the needs of course/home work (Thomas et al 2003); they also find themselves unable to concentrate, feel tired and fall asleep in class, 68% of Young Carers worry about their school-work (Cree 2003). Schools fail to identify Young Carers and do not recognise the impact of the role, as a result Young Carers experience pressures from teachers whilst they struggle to meet the demands of both their caring role and the school environment (Cree 2003, Thomas et al 2003).

These findings are supported in the wider literature. Young Carers are frustrated by a lack of flexibility in the school system (Morgan 2006, Hamilton and Adamson 2013) with 42% of Young Carers feeling that teachers do not take an interest in their home circumstances (Barnardos 2006). Young Carers may experience increased anxiety if they cannot contact home during the school day due to schools' strict mobile telephone rules and worry and anxiety in the classroom is likely to result in lack of concentration and impact on their academic performance and also result in punishment (Family Action 2012). Seventy-five percent of Young Carers are aware of discriminatory talk at school with regard to illness, disability, alcohol, drug and mental health issues which makes them uncomfortable and adds to their stress at school. Teachers are noted to be implicit in these discussions either through contributing or failing to respond appropriately (Moore and McArthur 2009), although some Young Carers report that, some teachers try too hard to help and become over- intrusive (Cree 2003).

Bullying also impacts on Young Carers' school experience (Warren 2007, Cree 2003 and Lloyd 2013). Cree (2003) found over one third of Young Carers worry about bullying and Lloyd (2013) found that one third of Young Carers has been physically bullied in the last two months and almost half bullied in other ways. Young Carers are bullied for various reasons including the bullies' knowledge of the Young Carers' caring role, the parent's illness or disability or because the Young Carer is perceived by peers as being different and therefore unacceptable (Warren 2007). However, some Young Carers find school a place of refuge (Cree 2003).

Social isolation

The caring role results in social isolation for many Young Carers (Thomas et al 2003, Warren 2007, Moore et al 2011). In spite of being a group with the greatest need to socialise and see friends, this group may have the fewest opportunities (Thomas et al 2003). This is supported in the wider literature which indicates that Young Carers often find it difficult to bring friends home due to stigma and their desire to conceal their home circumstances (Banks et al 2002, Moore and McArthur 2009, Smyth et al 2011, Barry 2011 and Chalmers and Lucyk 2012).

Financial restrictions are identified as an important factor in limiting social and leisure activities and these restrictions limit social activity and associated travel (Warren 2007, Moore et al and Thomas et al 2003). The extracurricular activities in which Young Carers do participate are school-based or in community groups. In contrast, their peers are involved in a wider range of interests e.g. sports, music, Brownies, Guides; needing to be at home means that Young Carers miss out on social activities (Warren 2007).

High numbers of Young Carers report problems with friendships; the caring role can set Young Carers apart from their peers who do not understand the caring role (Thomas et al 2003). Young Carers find it more difficult to make and maintain friendships and consequently, their social development may be restricted. As a consequence, Young Carers with restricted opportunities for peer interaction may possess limited social skills and thus experience increased difficulty making friends. It is suggested by McAndrew et al (2011) that the anger and frustration felt by Young Carers is likely to hinder them communicating with potential allies and supporters.

Implications for the School Nurse

The papers reviewed demonstrated that the caring role undertaken by children and young people has an impact on education and schooling and psychological and emotional wellbeing. Social isolation was a feature of all but one paper (Lloyd 2013) although Lloyd (2013) does identify bullying as an issue for Young Carers, which

was found to impact on their social isolation in other studies (Warren 2007 and Cree 2003).

The School Nurse has an understanding of public health and social care provision, school infrastructure, family relationships and child and adolescent development. This knowledge means that the School Nurse is in a prime position to advocate for and provide proactive support to Young Carers and their families with the specific aim of improving the school experience and subsequent outcomes for Young Carers. In addition, School Nurses are able to establish and coordinate effective partnerships with the professional groups who have a remit to support Young Carers e.g. Child and Adolescent Mental Health services, counsellors, teachers, social workers and General Practitioners. School Nurses need to work with school staff to identify Young Carers to then establish sensitive and discrete forms of practical and emotional support which is specific to the age and circumstances of the Young Carer. Ensuring that a universal approach to anti-discriminatory and anti-bullying messages is effectively taken and then delivered in schools is also an area in which the School Nurse can collaborate with school staff. The Department of Health has recognised the high importance of addressing these needs (2014) with the development of its strategy 'Supporting the health and wellbeing of Young Carers'. This evidence-based strategy endorses new training for School Nurses in order to further develop their understanding of the needs of Young Carers.

There are no conflicts of interest.

References

- Barnardo's (2006) *Hidden lives: unidentified Young Carers in the UK*. London:
- Barry, M. (2011). 'I realised that I wasn't alone': the views and experiences of young carers from a social capital perspective. *Journal of Youth Studies*, 14 (5), 523-539.
- Bolas, H., Wersch, A. V., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology and health*, 22(7), 829-850.
- Braun, V. Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77-101
- BBC (2010) *Young Carers are 'four times' the official UK number*. Available at: <http://www.bbc.co.uk/newsbeat/11758368> (last accessed: 4/11/2013)
- Chalmers, H., & Lucyk, L. (2012). The Impact of Caregiving: Is it who I am or what I do?. *Relational Child & Youth Care Practice*, 25(2).
- Cree, V. E. (2003). Worries and problems of young carers: issues for mental health. *Child & Family Social Work*, 8(4), 301-309.
- Dearden, C. and Becker, S. (2004) *Young Carers in the UK: the 2004 report*. London: Carers UK
- Family Action (2012) *Be Bothered! Making Education Count for Young Carers*
- Hamilton, M. G., & Adamson, E. (2013). Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies*, 16(1), 101-117.
- HM Government (2010). *Recognised, valued and supported. Next steps for the Carers Strategy*. Crown copyright.
- Lloyd, K. (2013). Happiness and well-being of young carers: extent, nature and correlates of caring among 10 and 11 year old school children. *Journal of Happiness Studies*, 14 (1), 67-80.
- McAndrew, O. S., Warne, T., Fallon, D., Moran, P. (2011). Young, gifted and caring: A project narrative of Young Carers, their mental health, and getting them involved in education, research and practice. *International Journal of Mental Health Nursing* 21,12-19.
- Moore, T., McArthur, M., Noble-Carr, D. (2011). Different but the same? Exploring the experiences of young people caring for a parent with alcohol or other drug issue. *Journal of Youth Studies* 14(2), 161-177

Morgan, Dr. R. (2006) *Being a Young Carer: Views from a Young Carers Workshop*. Newcastle upon Tyne: Commission for Social Care Inspection:

O'Dell, L., Crafter, S., de Abreu, G., Cline, T. (2010). Constructing 'normal childhoods': young people talk about Young Carers. *Disability and Society* 25(6), 643-655

Office of National Statistics (2013) *Detailed Characteristics for England and Wales, March 2011* Available at: www.ons.gov.uk/ons/dcp171778_310514.pdf (last accessed 4/11/13)

Smyth, C., Blaxland, M., Cass, B. (2011). 'So that's how I found out I was a Young Carer and I actually had been a carer most of my life'. Identifying and supporting hidden Young Carers. *Journal of Youth Studies* 14(2), 145-160

The Children's Society (2012) *Working together to support Young Carers and their families*. London

The Children's Society (2013) *Hidden from view: The experiences of Young Carers in England*. London

Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire, S., Webb, A. (2003). "Your friends don't understand": Invisibility and unmet need in the lives of Young Carers'. *Child and Family Social Work* 8 (1), 35-46

Warren, J. (2007). Young Carers: conventional or exaggerated levels of involvement in domestic and caring tasks? *Children and Society* 21(2), 136-14

Table 1. Study Inclusion and Exclusion Criteria.

Inclusion criteria	Exclusion criteria
Primary research from peer reviewed journals	Reviews and commentary papers
Included participants up to 18 years of age;	Young Carers up to the age of 25 years but the over 18 age group was not considered relevant as not part of the school age population.
The focus was to explore first-person accounts of care-giving;	
Included children and young people who had caring responsibilities for at least one family member	

Table 2. Summary of Studies Reviewed.

Author /s & Date	Study Aims & Objectives	Sample	Methodology	Findings
Lloyd K (2013)	Examine the extent of caring among this age group and its relationship to health and wellbeing, school experiences and educational attainment	4192 children 53% girls 47% boys	Online survey	YC less likely to say they were very happy with their life, demonstrate lower wellbeing on KIDSCREEN score. More likely than peers to say they had been bullied at school; less likely to have sat entry test for grammar school, those who did sit test less likely to achieve highest grade.
Moore et al (2011)	Explore the experiences of young people caring for a parent with an alcohol or drug issue	15 participants 11-17 yrs 8 female 7 male	Focus group/ Interviews	YC felt they had little confidence; poor self esteem and limited hope for future. YP identified areas in which they were affected by their care for a family member: financial hardship, schooling, health and wellbeing, social isolation were evident
Warren (2007)	Examine how the lives of children and young people who are known to adopt caring roles might differ from that of other children and young people in the general population	390 children 9-18 yrs inc 12 YC	Survey – short questionnaire with face to face interview	YC more likely to miss or be late for school. More likely to report that other children make fun or bully them; prevented from participating in social and leisure activities; more likely to identify a range of barriers that may prevent them fulfilling their future ambitions.
Thomas et al (2003)	Determine the characteristics of YCs and their experiences of life and role	21 YCs *boys 3 girls 9 - 18 years	Focus groups and interviews	Conflict between child and school more common; 50% struggling at school. Caring sets YCs apart from friends and inhibits new relationships. Range of psychological symptoms evident. Worried about person being cared for and themselves.
Cree (2003)	Hear views about services for Young Carers find out whether the children and young people who were using EYCP had (broadly defined) mental health problems which would benefit from the support of a designated counsellor in the agency	61 children 34 girls 25 boys	Self completion questionnaire – closed and open questions	YC have a range of worries. Financial worries, worries about bullying. Pressure from school, tired at school, hard to concentrate, school a place of refuge, Mental health problems: 60% sleeping problems, 30% eating problems, 34% self harm, suicide 36%. Over one third YC reported problems with bullies.

