



BISHOP
GROSSETESTE
UNIVERSITY

[BG Research Online](#)

Efstratopoulou, M. (2019) *Working with unhappy children who are young carers*. In: *Bring My Smile Back: Working with Unhappy Children in Education. Psychology of Emotions, Motivations and Actions*. Nova Sciences, New York. ISBN 9781536172775

This is an Accepted Manuscript published by Associação de Psiquiatria do Rio Grande do Sul in its final form on 12th March 2020.

This version may differ slightly from the final published version.

Copyright is retained by the author/s and/or other copyright holders.

End users generally may reproduce, display or distribute single copies of content held within BG Research Online, in any format or medium, for personal research & study or for educational or other not-for-profit purposes provided that:

- The full bibliographic details and a hyperlink to (or the URL of) the item's record in BG Research Online are clearly displayed;
- No part of the content or metadata is further copied, reproduced, distributed, displayed or published, in any format or medium;
- The content and/or metadata is not used for commercial purposes;
- The content is not altered or adapted without written permission from the rights owner/s, unless expressly permitted by licence.

For enquiries about BG Research Online email bgro@bishopg.ac.uk.

Chapter

WORKING WITH UNHAPPY CHILDREN WHO ARE YOUNG CARERS

Maria A. Efstratopoulou, PhD

Bishop Grosseteste University, Lincoln LN, UK

INTRODUCTON

Nearly a quarter of a million children in England and Wales are caring for a relative. Figures from the ONS (Office for National Statistics) suggest 244,000 people under 19 are carers - about 23,000 are under nine years of age. This is likely to be “the tip of the iceberg” and an underrepresentation of the true picture. Young people across the country grow up caring for family members or adults who are ill, disabled or involved with drink or drugs. However, the work that these young carers do can often go unnoticed. This chapter aims to raise awareness of young carers, to help identify these young people, the responsibilities they take on, and how we can do our best to support them, help them to have bright futures, and smile again!

BEING A YOUNG CARER: ANNA'S STORY

Anna was only 11 when she had to look after her brothers and sisters because her mum was drunk a lot. She had a difficult time at home and did not feel like a child. She hopes her story will let others know that you can get support. She explains:

I thought my life was normal and everyone lived the way I did. An average day for me would be getting up in the morning where my mum would normally be drunk. I would get my brothers and sisters ready, either for school or for spending the day at home with mum. After that, I'd go to school. What would happen when I got home from school would depend on what mood my mum's boyfriend was in. If he was angry, he would beat my mum up and the police would get involved. Then he would apologise and come back home and the same thing would happen again the next day. The violence was not daily, but it had happened often. There was never any violence towards me and my siblings but we saw violent things happen to mum.

I did not feel like I was a child, I felt like I was growing up too quickly. I did not speak to anyone about what was going on at home because I did not realise it was wrong. That was just my life and I thought it was normal.

My mum used to drink every day as far back as I can remember. Her drinking meant that I had to be the mum to my siblings and I did not really have a life. I was responsible for making sure my siblings all were fed, were dressed and bathed and in school. I cooked and cleaned around the house too.

I didn't really see friends outside of school; I was at home all of the time looking after my siblings. I was able to separate school and home and continue to concentrate in class and work really hard because I knew education would be my only escape from home and my mum. I always made sure that whatever was going on at home it would not affect my education and future chances. I do not think people at school were aware of what was going on. I gave a good impression of a happy child.

Things changed when I managed to talk to people who I could trust. It took me a while to trust and talk about my real worries but after I did, I felt better and I got support. If I did not get support, I do not think I would have been able to go to college and would have ended up looking after my brothers and sister full time. I would have had no life.

I am planning on going to university and I know I previously would not have been able to. After being the mum to my brothers and sister for so long, I could not see any end to it. My future is looking bright now and I can smile again!

YOUNG CARERS CAN BE HIDDEN

A “young carer” is defined in section 96 of the Children and Families Act 2014 as: ‘a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).’ For the purposes of this document, this relates to care for any family member who is physically or mentally ill, frail elderly, disabled or misuses alcohol or substances. The key principle is that: ‘Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.’

There are so many hidden carers, so many people hiding inside thinking there is no help or if I ask for help I will be discriminated against. I will be stigmatised. (Young carer)

However, there are many children that are taking care of their disabled parents. What do we mean by disabled parents? The Pathway uses the term ‘disabled’ with the meaning set out in section 6 of the Equality Act 2010. A

disabled person is an individual who has a physical and/or mental impairment, which the law states has ‘a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.’ Disability is treated as one of several protected characteristics. There is no need for a person to have a medically diagnosed cause for their impairment; what matters is the *effects* of the impairment on their ability to live a full life. It is recognised that not all parents included in this definition would self-define as disabled. Parents include prospective parents, biological parents, grandparents, same sex couples, kinship carers, those who raise, adopt or foster children and step-parents. Some disabled adults may have support needs related to their parenting roles or responsibilities and need support to access the same choices and opportunities as non-disabled people, for themselves and their children. People who provide social and health care services should not assume that family members will be able and willing to take on or continue caring for a disabled person. No one should be obliged to give up paid work or educational opportunities because of a lack of services to a disabled member of their family. No child should be forced to grow up too early. Some young people do not even realise they are carers but see themselves as “just looking after” a loved one. However, young carers should not have the same responsibilities as adult carers, nor should they be spending the majority of their time looking after someone.

Young carers are not easily identified; they do not look any different to other young people of their age, so their caring role is hidden away and kept separate. Most recent statistics put the number of young carers in England at just over 166,000 - but this is likely just the tip of the iceberg. The true figure is likely very much higher.

CHILDREN FROM BLACK, ASIAN AND MINORITY ETHNIC (BAME) COMMUNITIES

Studies have found that members of Black, Asian and Minority Ethnic communities may be more likely to experience ill health, are at greater risk of developing mental health problems, and are more likely to have a health need that is unrecognised and unsupported. In these circumstances, their care is likely to fall to other members of their close or extended family, including young people.

This assertion is supported by research that highlighted that young carers are 1.5 times more likely to be from BAME communities. Studies have also shown that BAME carers fail to access support because they are unaware that support services exist. It is clear that there is additional work to be done to ensure that support services are accessible to young carers and families from BAME backgrounds.

In addition, research has also shown that BAME parents with mental health problems are more likely to experience poverty, unemployment and homelessness, issues that further compound negative impacts for young carers in these communities.

WHO DO YOUNG CARERS CARE FOR?

The cared-for person may not necessarily live as a member of the young carer's household. Those cared for may include siblings, biological parents, grandparents, same sex couples, those who raise, adopt or foster children, and step-parents. In some circumstances, children may care for friends or other members of the community, particularly unaccompanied refugee children.

This care may be given to any one of these individuals having a physical disability, sensory disability, emotional or learning impairment, long-term illness, HIV and other blood-borne viruses, drug or alcohol dependence, mental health issues, or trauma caused by war and/or torture.

An individual who is seeking help from services should be given every assistance and opportunity to express their own point of view. Advocacy, support and interpretation services should be made available if needed.

Nearly a quarter of a million children in England and Wales are caring for a relative. Figures from the ONS (Office for National Statistics) suggest 244,000 people under 19 are carers - about 23,000 are under nine years of age. This is likely to be “the tip of the iceberg” and an underrepresentation of the true picture. A study for the BBC in 2010 suggested that there are likely to be at least 700,000 young carers in the UK. The report suggested that 1 in 12 young carers provide care to others for more than 15 hours per week, and around 1 in 20 miss school due their caring responsibilities. In addition, young carers are 1.5 times more likely than their peers to have a special educational need or a disability.

There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen. Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers. Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

“It’s just something I do. It has to be done and there is no one else to do it.” (Young carer)

The Home Office estimates that there are between 250,000 and 350,000 children of problem drug users in the UK. Up to 2.6 million children live with a parent who drinks hazardously, and 705,000 children live with a dependent drinker.

Potential Impacts on Young Carers

Inappropriate caring responsibilities can affect the young carer’s own wellbeing and put them in need of support from health and social care

services. A whole family approach should be adopted in order to prevent these impacts and to protect their wellbeing. There may be problems at school, with completing homework, and getting qualifications. Young carers can be isolated from other children of the same age and from other family members, and they may lack time for play, leisure, or sport. There may be conflict between the needs of the person they are helping and their own needs, leading to feelings of guilt and resentment. Young children who are carers may feel that they are different from other children, that there is nobody there for them, and that professionals do not listen to them. In addition, there is a risk of developing their own physical or mental health problems as a result of their caring responsibilities.

There may be conflict between the needs of the person they are helping and their own needs, leading to feelings of guilt and resentment.

Other impacts on young carers are that they may feel that no one else understands their experiences, and they may have problems moving into adulthood, especially with finding work, living on their own, and establishing relationships. They may experience conflicting emotions, such as loving the cared-for person while resenting the burden of care; they may feel pride in what they do as carers, while resenting the restrictions placed on their young lives. This may lead to the young person feeling guilty or confused, and perhaps further isolated from their peer group.

“It’s not just the caring that affects you... what really gets you is the worry of it all. Having a parent who is ill and seeing them in such a state.”
(Young carer)

Many young carers have key skills and competencies that go unrecognised, and there is currently no way of accrediting such skills. While young carers who are unsupported might be unable to have the time to become accredited, such skills, if acknowledged would be an asset to many employers.

POSITIVE ASPECTS OF CARING

It is important to note that young carers do not necessarily dwell on the negative impacts of caring. They may welcome the sense of pride they feel about their caring role and achievements. They may also benefit from a close family environment that is supportive and caring of each other. The experience of being a young carer has some positive elements. Young carers can be highly self-motivated multi-taskers, coping with and achieving at school whilst also undertaking a caring role. However, it is important that recognition of the positive impacts of care does not inadvertently encourage the continuation of inappropriate care taking place or lead to the caring becoming a cause for celebration and not action. A young carer's ability to cope and achieve must not be used to mask their need for support.

“Young carers aren't born with extra abilities, we're no different from anybody else; we just learn to cope because we have to.” (Young carer)

Why are children and young people taking on caring responsibilities not identified and supported? When there is a person within the family needing care, a child may take on the role of sole or primary carer, or may help other adults or siblings with caring tasks. Some take on the role voluntarily, others are informally nominated as carer, while in some families it is expected or demanded of the young person. The majority, however, just grow into the role. There are many reasons why young carers may remain unidentified and unsupported, taking on levels of care that are inappropriate for their age. These include:

- the nature of the illness or disability including speed of onset or whether it is an episodic illness
- fear of the perceived stigma associated with the condition, particularly where there is a mental illness, substance dependency, HIV or AIDS
- lack of effective services from outside the family if the person does not meet eligibility criteria or the services are inflexible

- a gap in services, not sharing information or joint working and not recognising the need to support young carers until a crisis is reached

A whole family approach to assessments and service provision is key to identification and support of young carers.

WHAT TO DO IF YOU IDENTIFY A ‘CHILD IN NEED’

Where a young carer is a “child in need” needing protection and support, adult workers should discuss the case with the Children’s Services to decide if further action is needed. Further action might include a referral to an independent Young Carers’ service, accessing preventative support through the “Early Help Network,” a joint assessment where appropriate, and further investigation by Children’s Services about safeguarding concerns, if there is a likelihood of significant harm to the child. Where there are any aspects of a situation that indicates there are concerns about children’s and/or vulnerable adults’ safety, and either require protection from harm, these will be responded to swiftly and in line with local safeguarding procedures. Typically, children’s services will undertake the provision of services or support to children in need, and adult social services will undertake services and support to the adult. These may be directly provided or commissioned from other providers.

Some Important Things to Remember

- Where a young carer has been found to be a child in need the plan should be assessed at the same intervals as plans for other children in need in the authority.
- A whole family approach to reviews must offer the opportunity for everyone to have their say. It will be important to offer all involved,

and in particular children, the opportunity for private conversation, perhaps as part of preparing for a review meeting.

- The review should consider how best to maximise the wellbeing of the whole family, but it will be important that in responding to the needs of the adults concerned, sight is not lost of the child's needs.
- The review may need to identify issues where there are differences of opinion between the adults concerned and any young carer, or other children. The professional leading the review should aim to reach agreement as to how to resolve these, recognising children's distinct needs and vulnerability and the duty to prevent them from assuming an inappropriate or excessive care role.
- The review may conclude the plan needs to be revised, perhaps as a result of changes in individual circumstances. The lead professional would then be responsible for identifying the key issues to be re-evaluated, the services necessary to contribute to a revised assessment and an outline timescale for updating the plan

Mental ill-health Mental illness is often episodic. The situation at home can fluctuate from a normal secure home life to periods of instability, confusion and emotional upheaval. Changes in the behaviour of parents with mental ill health can be traumatic for the children, and all the more so if they are trying to take on some or all of the caring responsibilities. Children caring for a parent with mental ill health can feel a great sense of responsibility and loyalty to their parent, and some go to great lengths to conceal the illness and its effects, and to make up excuses for the adult's behaviour. Young carers may be responsible for administering medication to parents who have serious mental health problems. This has serious implications for the safety of both the young carer and the parent, and must be addressed as a matter of urgency. Some young carers may be supporting parents who are misusing drugs or dependent on alcohol in addition to having a mental illness.

“No-one ever sat down and explained to me and my brother what manic depression was. Mum might have done, but no professional person

... if someone had explained what it was it would have helped.” (Young carer)

SUPPORTING THE EMOTIONAL WELL-BEING OF YOUNG CARERS

Some recommendations to support the emotional well-being of young carers could include:

Information provision, peer and family support.

More specifically:

- Promote more open discussion and provide accessible ‘family friendly’ literature about mental ill health and how to access help.
- Inform children about family illness and changes to routine and circumstances at levels appropriate for child’s age and understanding regardless to whether they are caring or not.
- Offer training and support to young carers’ workers in listening skills so that they can continue to be a source of support, but also know when to refer a young person onto another agency.
- Consider monitoring and evaluating the peer support provided by groups to inform other models of support.
- Work with the family to support them in talking about and coming to terms with illness, if needed. Offering timely, well-structured and flexible support to the person in need of care could prevent a child undertaking inappropriate levels of care.

COPING STRATEGIES

Consider what coping strategies might help children and families deal with any stigma they feel or experience. Work with other social services and supporting agencies. Counselling and child psychiatric agencies, including CAMHS, could consider linking with young carers projects so their role is better known and understood by young carers therefore building elements of trust. Work with other professionals and with family members to promote understanding of the emotional needs of young carers, and with media, to identify ways to promote more understanding about mental illness in order to reduce stigma.

REFERENCES

- Action for Carers Surrey (2012). Carers Trust and The Children's Society. Making it real for young carers. Think Local Act Personal, UK.
- ADASS et al. (2015). No Wrong Doors: Working together to support young carers and their families. Carers Policy Network, London.
- Becker, F. & Becker, S. (2008). Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24. London: The Princess Royal Trust for Carers.
- Dearden, C. & Becker, S. (2014). Young Carers: Needs, rights and assessments. In: Horwath J. (ed.) *The Child's World: Assessing Children's Needs*. London: Jessica Kingsley Publishers. 2000.
- Department of Health. Care and Support Statutory Guidance - Issued under the Care Act 2014.
- Department of Health (2015). Improving Mental Health Services for Young People. London: Department of Health.
- Frank J. & McLarnon J. (2008). Young Carers, Parents and their Families: Key principles of practice. The Children's Society, London.

HM Government. (2015). Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children. London: Crown.

NG