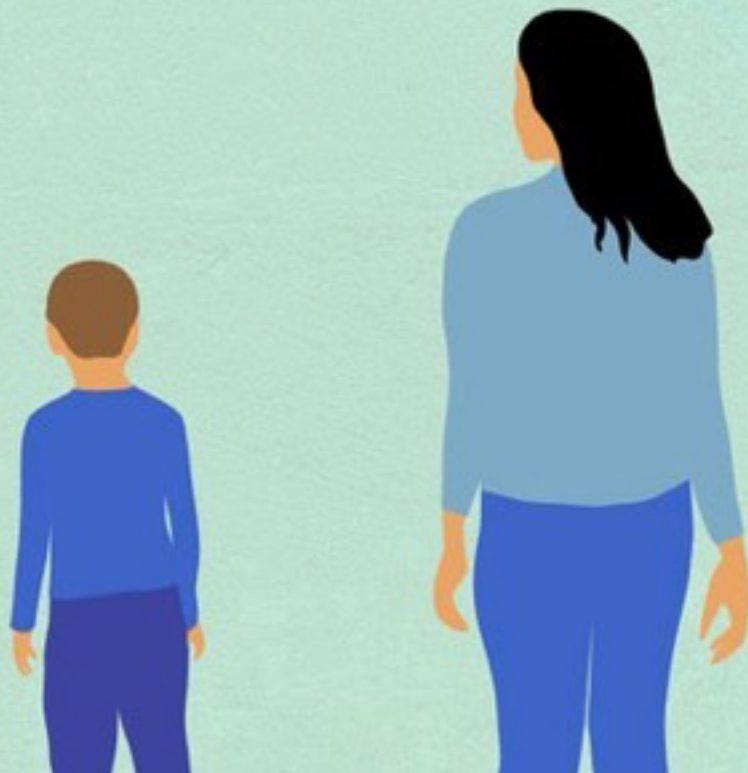




University of East Anglia

UNDERSTANDING THE NEEDS OF YOUNG CARERS IN THE CONTEXT OF THE COVID-19 GLOBAL PANDEMIC

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CHILDREN AND FAMILIES**

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 **Caring
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so that carers have choices

UNDERSTANDING THE NEEDS OF YOUNG CARERS IN THE CONTEXT OF THE COVID-19 GLOBAL PANDEMIC

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WHY IS THIS STUDY IMPORTANT?

Young carers are often marginalised, their voices unheard, and their needs unrecognised. It is therefore vital to raise awareness of these concerns in the context of the COVID-19 pandemic.

There are an estimated 800,000 young carers in the UK under the age of 18. Within this cohort some children as young as five years of age are recognised as young carers under the Care Act 2014 and Children and Families Act 2014 definition of providing excessive and/or inappropriate care. In the 2011 Census 41% of identified young carers were aged 10 – 14. Among older young carers, there are a significant number of adolescents aged 16-25 who have their own specific needs in relation to their transition to adulthood and their aspirations for the future. These are children and young people who provide essential care for their families, often 24 hours a day and over the course of their whole childhood. The nature and intensity of the care provided can have a detrimental impact on their own social, economic and educational wellbeing as well as their physical and mental health, which may carry forward into adulthood. Despite this, research consistently shows that young carers are a vulnerable and often hidden group, falling through the gaps of both public policy and health and social care services.

The global pandemic of the COVID-19 virus will undoubtedly have far reaching implications for young carers. While it would seem that children and young people are less likely to experience significant physiological effects from the virus itself, the indirect impact of attempts to counter the spread of the virus are highly likely to have a major impact on their psychological well-being. Alongside this, the support systems in place are struggling under increased pressure, potentially drawing the focus away from the needs of these marginalised young carers. This is one likely outcome of the potential Care Act easements, created under the Coronavirus Act 2020, which allow local authorities to suspend their duty to assess and meet eligible support needs of carers.

AIMS OF THE STUDY

The study aims to benefit young carers during the COVID-19 pandemic in the following ways:

- Increase the recognition of young people providing care – promoting an awareness across services of the impact that changes in service provision will have on young carers.
- Capture the views of young carers about their current experiences in order to inform the provision of effective support and identify urgent support needs.
- Consider whether any child living with a parent with long-term physical health condition, disability or mental ill health is considered as a young carer throughout this pandemic.

HOW WAS THE STUDY DONE?

In order to gain a rapid and holistic understanding of the issues facing young carers in the COVID-19 crisis, views were sought from a range of perspectives. Twenty participants were recruited through young carer organisations and across the social media platform Twitter.

Semi structured interviews were conducted with eight young carers, five young adult carers, three parents of young carers and four youth workers. Interviews were held using video conferencing and telephone. Detailed notes were taken throughout the interviews and key sections were transcribed verbatim.

Ethical approval was granted by the University of East Anglia, and each participant received information about the project and signed a consent

“People don’t realise the entirety of my life is me being a mini adult, but it’s not a pick and choose the time sort of thing.”
Izzy 12

form via email. The age of the young carers/young adult carers ranged from twelve to twenty-two years of age. Participants under the age of 16 also provided acknowledgement of consent from their parents. The youngest participant (12) chose to be interviewed with her older brother (19). Given the potential adversity and anxiety associated with the current crisis, each of the young carers were recruited by their young carers organisations Caring Together and West Berkshire Targeted Intervention Services who agreed to offer support during and after the interview process. Caring Together also agreed to offer support and signposting for any young adult carer following their interview if they did not have existing support.

The data was analysed from each sub group of participants and combined together to inform key emerging themes. These themes have been refined and presented in the key findings. Pseudonyms are given for all the participants I spoke to.

KEY FINDINGS

COMPLEXITY OF CARE

No two young carers are alike, nor is the complexity of the care they provide or the context within which they provide that care. Several of the young people within this study cared for 2/3 members of their household with a wide range of both physical and mental health needs. This included caring for both a parent and siblings each with competing care needs. The range of care tasks that the participants faced were equally varied - from cooking, cleaning, organising bills and managing medication, to tasks that were less easily quantifiable such as emotional support described as 'keeping him happy and calm', 'looking out for crisis points' and 'making sure mum doesn't hurt herself'.

Young carers from a single parent household appeared to carry a greater level of responsibility. Those with siblings (that they were not caring for) felt that they could at times share the load and distract one another during the lockdown period. Bianca (14) commented that it can be easier for a young carer when there is more than one

adult in the household. This was echoed by other participants such as Elizabeth (19) who felt that the roles were reversed for her and her father, leaving her with responsibility for him rather than him for her. Olivia's (17) care role included keeping her mother's mental health needs hidden from the rest of the family. Olivia explained that her mother found her mental ill health 'humiliating' and did not like to refer to Olivia as a young carer as she felt it made her sound 'less of a parent' and as such, in the past Olivia had been preventing from reaching out for support and often felt isolated in her role. The potentially interlocked nature of the caring relationship was also highlighted by a parent who recalled her marriage breaking down when her son was 11-years-old. From that point she described her son as 'becoming my everything' her only source of care and support and upon whom she was entirely dependent.

“Being a young carer has its ups and downs but there’s so much we can learn that other kids will never understand... in the long run it is going to do me a lot of good.”

Bianca 14

INCREASE IN CARING ROLE

Each of the youth workers that took part in the study said that the caring responsibilities for older carers had increased exponentially. This included greater responsibilities both for the person they were caring for and their younger siblings. This was expressed in terms of generally looking after younger siblings and providing additional support for siblings with specific needs, which for two young carers meant a significant increase in dealing with their challenging behaviour. Ethan (17) described how his brother missed his school and its associated routines which meant his behaviour had got worse, 'we can't tell him off because it's not his fault but it is hard being bit and hit all day'. Often participants

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explained that their younger siblings did not understand about the virus or the reason for the lockdown which led to frustration and conflict.

The loss of school and established routine was also said to have an impact on the physical and mental health of parents which in turn has increased the caring burden on the young carer. One parent with complex health needs, Louise, described her usual routine as sleeping for 3 hours each day while her children were at school. However, since lockdown both she and her children have lost this routine. While Louise explained that she had tried to 'push through' in the initial weeks this had left her exhausted and in so much pain that she was unable to get out of bed for three days during which time her 15-year-old daughter had to care for her and her siblings alone.

Such an exacerbation of difficulties was also a clear factor for parents with mental ill health. Olivia (17) described how the fear and insecurity inherent within the crisis has made her mother increasingly anxious 'it affects her sleep and then of course mine because she keeps waking me up so she is not alone'. This type of deterioration of mental health was an area of considerable concern for a youth worker, Melanie, who arranged a school placement for a young carer whose father suffers from acute mental ill-health. Melanie feared that with the reduction in his mental health support and with the loss of a break that the school day ordinarily provided, he would not be able to shield his child from the more distressing aspects of his mental ill health such as self-harm and suicidal ideation.

Several participants spoke about the amplified difficulties in managing the practicalities of supporting their families during the restrictions of lockdown. This included not being allowed into shops, or for Aiden (16) having to go to the shops several times a week as he is required to shop for a large family and has no access to transport. This was because his father, who is the only driver in the house, was on the Government's extremely vulnerable list.

EXTERNAL SUPPORT

Many of the participants spoke about an uneasy relationship with health and social care services, with poor communication and a lack of awareness of the needs of young carers. This has been further compounded by the restrictions in place through social distancing. Hannah (20), a young adult carer, spoke about returning home from university once the weekly contact her mother had with the community mental health team was being withdrawn, stating that this placed her back into a full-time care role and feeling overwhelmed.

Young carers also spoke about assessments both for the people they are caring for and themselves having been cancelled. While they understood the rationale for this, the uncertainty about when these would be re-arranged has left them feeling uneasy.

“Young carers groups are amazing, have made such a difference to my life but there are many more young carers who just don't even know about the groups I have been in young carers and it has let me know how to express myself and talk about what I am doing and how I am feeling.”

Aiden 16

Informal support had also been withdrawn, this included individual arrangements families relied upon such as shopping delivery, child care and cleaning services. Again, while the lockdown restrictions are in place preventing these services, the additional practical tasks are taken on in many cases by the young carers. The lack of support from friends and wider family was keenly felt by the young carers and their families. Katie (18) observed that the speed of the lockdown restrictions gave young carers and their families' limited time to adapt to the changes they were faced with.

EDUCATION

A strong desire for the routine and respite of school was prominent throughout the young carer interviews. Olivia (17) described attending 6th form as a release for her, elaborating that 'school has always been a place away that I can feel safe'. This resonated across the young carers who repeatedly described school as a respite, a break away from home and their caring role and a place within which they felt they could focus on themselves. For Grace (15) this safe space was also attributed to her teachers who she felt knew her well enough to 'pick up on when things were bad at home'. This, alongside their willingness to listen, made her feel that 'someone noticed and someone cared'

However, the contact and support that was being offered by school to the young carers within the study was extremely variable, ranging from weekly telephone contact being made by the pastoral team, to form teachers taking ten days to reply to an email. This lack of response was felt by many participants as illustrative of a lack of wider awareness of the needs of young carers. William (17) went on to link this to the lack of policy, regulation or statutory duty for schools to identify and respond to the needs of young carers, a specific expectation that was removed from the latest Ofsted inspection framework.

Some of the young carers were struggling to manage the requirements of home learning and felt that this was disproportionate to that of their peers who did not have caring responsibilities. Some participants described the practical barriers to learning such as having to care for younger siblings or not having a quiet space to be able to study. For others the additional pressure of their care role prevented them from focusing on themselves and their studies. This loss of focus can also be indicative of the stress that the young carers are under, 'I am struggling to focus on my college work or anything, even the smallest task makes me really tired, I have no motivation at all' Jessica (19)

A youth worker, Tony, also raised the concern that not only would there be an educational impact on

young carers as result of the restrictions but also a social developmental impact. 'Many young carers are more socially isolated and/or disadvantaged to begin with and the lockdown has compounded that'. Young carers may not have established friendship groups that they can reach out to outside of the school environment and when they return to school if they are significantly behind their classmates this could set them further apart.

MENTAL HEALTH/MANAGING THE STRESS

The increase of pressure and stress for young carers was palpable within many of the interviews. Participants described not being able to 'get space' to manage their stress, with Ethan (17) describing school as the only place where he could get 'breathing space'. The restriction of lockdown and the anxiety related to the risks associated with COVID-19 was central to their difficulties. The restrictions of lockdown increased the young carers caring load, preventing them from getting a break or from turning to their established coping strategies such as spending time with friends, engaging in a hobby or going for a long walk.

"Every young carer is different there is no standard, they all have different needs and desire for support, it has to be lead by the young carers themselves. They have to find the balance."
William 17

Several of the participants spoke about not feeling able to leave the house at all because of the level of physical vulnerability of the person they care for. While this was proportionate for some of the young carers considering the complex health care needs of their family member, for two young carers it was also rooted in traumatic experiences earlier in life where their parent had been critically ill. Debbie, a parent, spoke about her son's fear about

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her physical safety, explaining that while she was not included within the Government's 'clinically extremely vulnerable' list now, four years ago aged 11 her son had returned from school and found her collapsed unconscious on the floor. He called for an ambulance and she spent a period of time in intensive care. Debbie felt that it was the memory of this combined with the knowledge of the fragility of life and his parent's fallibility (which was beyond the experience of most of his peers) that led to him feeling so anxious and fearful of transmitting the virus to her. Youth worker, Melanie also talked about the young carers' awareness of the vulnerability of the health of the person they cared for. She suggested that this concern may 'become all consuming' as they no longer have any distraction or support in maintaining a healthy perspective.

Four young carers also described the impact on their own mental health as they tried to support their parents' deteriorating mental ill health. Olivia (17) described feeling that her mother's need for emotional support was relentless, 'I can't get a break, I can't even get 5 minutes, if I shut my door she is there and then verbally I just have to take it, there is nowhere for me to put it I just have to take it, she becomes anxious, then annoyed, then angry and neither of us can walk away now so I just have to take it'. Similarly, Elizabeth (19) said, 'being locked in together like this is a difficult thing, it's making his bad days into my bad days'

Despite these very difficult circumstances, many of the young carers felt unable to complain about their situation. They felt that to 'moan' about the pressures of their caring role would be 'selfish' as they reflected that there were 'people with much bigger problems than me' Izzy (12). They also felt that such a complaint would be insensitive towards the person they were caring for as they felt that the experience was much worse for them. As young carers there is often a sense of stoicism, since they feel there was little choice in the matter and it had become a normal part of their lives. Nor did they want to add to anyone else's burden as Grace (15) explained 'I look after myself, I have always tried

to be as independent as possible so no one has to look after me, my parents are busy enough with my sister'. This was echoed by one of the parents, Eva who felt that unwittingly she had always had to prioritise her child with complex needs over her daughter leaving her to 'bring herself up'.

MESSAGES FROM YOUNG CARERS

The young carers who took part in this study were very aware of the limited resources available to change things in the face of COVID-19 and its associated restrictions. Instead, they gave wider messages that they felt would be beneficial for young carers. All felt that awareness needs to be raised about what it means to be a young carer. This awareness raising was important for health, social care and educational services and staff, within the general public, and also, their own peer group.

"Zoom calls with [my young carers worker] really help, at first they feel a bit random then we are playing a game or chatting and everything feels a bit easier like I've had a break."

Chloe 16

They did not want assumptions to be made about their families, or indeed themselves, specifically Katie (18) who felt that people assumed she could not be a young carer because she was not able bodied herself. This need for consideration of the young carers own health needs are highlighted by the fact that young carers are 1.5 times more likely to have a disability or long-term illness.

All of the group greatly appreciated the support that they received from their young carers' organisation, but were acutely aware of the large percentage of young carers that are receiving no support at all. They reiterated that all young carers are different, the care that they give is different as is the context in which it is given. This meant that they should be able to define the service

they received, choosing when was best to engage with it and in what manner. Many had enjoyed the online support provided to them during the lockdown. A youth worker had observed they had little difficulties adapting to meeting virtually, particularly the younger carers who seemed 'fresh to new methods of communication'. While they appreciated the support offered during lockdown, the majority of young carers looked forward to being able to meet in groups and some spoke with fondness about times when they had been able to do day trips with other young carers, and about opportunities to feel normal in their recollection.

DISCUSSION

The strengths and skills of the young carers who spoke within this study were clear, and they described the support that they gave to their families as key to their relationships and identity. This can be a positive factor, building upon a young person's strengths and resilience, however, there is no doubt that being a young carer also comes with its own challenges and disadvantage. Without the right support young carers can feel isolated, overwhelmed and forgotten. If their caring role becomes too onerous this can have a significant detrimental bearing on their own health, well-being and development. The parents in this study did not want to feel that their child was being disadvantaged through their caring role, they were determined that the freedom to explore, develop and enjoy childhood should be available to their child as it should be to any other. But to ensure this is possible they needed to be able to talk about the care that their child provided without fear of judgement or discrimination. The commitment and drive to have the needs of young carers recognised and addressed resounded loudly from the youth workers that were supporting young carers through these difficult times. However, funding is key, and must be provided at a level which enables them able

to provide flexible and responsive support to young carers in all spheres of their lives.

This study had shown that the effect of COVID-19 is evident for young carers within the period of lockdown and restrictions. It is also highly likely that the impact will continue for years to come as the societal and economic repercussions become more apparent. It is expected that there will be long term changes for young carers, both to the services that support the family members that they care for and the organisations that support them in their role.

Young carers are a diverse heterogeneous group, while it was extremely positive to hear about the support many of the young carers in this study were receiving, it cannot be forgotten that many young carers remain hidden and subsequently unsupported. For some young carers the extraordinary functions they perform are so part of their daily life, they do not even consider themselves a young carer. This lack of awareness and recognition can be particularly difficult for children and young people caring for a parent with mental ill health, as the care they provide is often hidden, synonymous with their own mental well-being and therefore difficult to quantify.

In the years to come as we move through and recover from this health and economic crisis it is vital that a focus remains on supporting young carers and their families in a way that is personal and meaningful to them.

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KEY RECOMMENDATIONS/ IMPLICATIONS FOR POLICY & PRACTICE

1. Continue to raise awareness of young carers and young adult carers, particularly within educational settings which can act as a sanctuary and a safeguard for these vulnerable children and young people. As the schools reopen and students return, teachers in particular need to be mindful that some of their class may be young carers. They need to give careful consideration to the support they require to physically return to school and re-establish themselves within the curriculum, using the young person themselves as key to creating an individualised plan.
2. From a social care perspective, the stipulation of both the Care Act 2014 and the Children and Families Act 2014 that no child should undertake inappropriate and/or excessive care should be given additional weight within this health crisis. As such any child under the age of 18 years old living with a parent or a sibling with substantial disability, physical health needs or mental ill health should be automatically regarded as a young carer and supported accordingly
3. The work of young carers' organisations such as Caring Together are crucial for the health and wellbeing of carers. They are able to respond to young carers' needs in a flexible and proactive manner without the bureaucratic barriers and potential stigma of some statutory services. As such it is imperative that the value of their work is recognised and they are funded accordingly.
4. Young carers' voices are central to understanding the impact of caring on young carers' lives. They should be fully involved in all aspects of research, as well as policy and service development.

STRENGTHS AND LIMITATIONS

The strengths of this project lie in its ability to present a rapid response to the needs of young carers, this has been made possible by the collaboration and support of Caring Together. The commitment of this organisation and the Targeted Intervention Team of West Berkshire Council meant that a wide range of young carers from across England were able to participate in a safe and supported manner. The physical restriction of the research to comply with social distancing rules meant that no interviews were able to take place in person and the equipment was not available to record the interviews, thus complete verbatim transcription was not possible. Future research should also reach out to some of the many young carers not receiving support through young carers' organisations. The views of professionals from health, social care and education would also enrich subsequent research.

IMPACT

This project has already raised awareness of young carers needs in relation to COVID-19 through media coverage including BBC news, ITV news, LBC, Heart radio and Radio 4 Woman's Hour. It is hoped that this research continues to raise awareness and forms the basis of practice guidance.



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