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Abstract

This qualitative study, undertaken in England, explored young carers' perspectives on the nature of their caring responsibilities. The findings are significant, particularly in the context of England's Care Act 2014 which seeks to prevent children engaging in 'excessive' or 'inappropriate' caring. Our research placed children at the heart of the debate on what constitutes appropriate care. The findings raise key questions regarding effective implementation of contemporary child policy, duties of care towards children in caring roles, and priorities for child protection and family support policy and practices, with the potential to inform thinking around child well-being in wider contexts.

Introduction

In England, in 2014, the Care Act and Children and Families Act were passed placing new statutory responsibilities on local authorities to identify, assess and support young carers and their families. The Care Act sought to ensure that 'inappropriate and excessive caring' is not being undertaken [DoH 2014, Subsection 2.50]. However, inappropriate and excessive care are ambiguous concepts and to date no corresponding guidance has been developed to support families and services in identifying and addressing what constitutes inappropriate and excessive caring.

Judgements about whether a particular task or caring role are appropriate are subjective and hence it seems pertinent to consider whose subjectivities are taken into account when deciding whether care provided by children is appropriate or not. There may be legal frameworks to consider, as well as social norms and practices but, ultimately, we argue that the views of the young carers themselves must carry significant weight. As articulated elsewhere (Hart and Brando 2018), the interests of the child should remain paramount and they should be involved in decision-making insofar as their maturity and competence allows. The research reported on here aimed to support young carers in expressing their views about the nature of caring from their unique perspectives in order to generate insights into how the concepts of inappropriate and excessive care can be understood.

The paper firstly reviews existing literature in this field, exploring research on young carers' roles and the impact of those roles, alongside evidence of how legislation has been interpreted to date. Key search criteria included: young carers; ethics of caring; appropriate and inappropriate care; young carers' services; Care Act; young carers' assessments; Children and Families Act. The next section of the paper considers the landscape of young carers in England and is followed by a discussion of the prevalence of young carers, the impact of caring on their everyday lives, and an assessment of their needs. The research methods used in the empirical study are detailed, followed by an exploration of the findings, in particular the categorisation of inappropriate caring responsibilities, followed by a discussion of the implications of the findings for policy and practice.

Landscape of Young Carers in England

The term 'young carers' has been used by service providers, researchers and policy makers to describe children in England who undertake caring responsibilities. Young carers were legally acknowledged for the first time in the Carers' (Recognition and Services) Act 1995, as 'children and young people (under the age of 18) who provide or intend to provide a substantial amount of care on a regular basis' *(*DoH 1996, p.10-11)*.* This definition has been revised a number of times. The current definition used by the Department of Health in the Care Act 2014 (subsection (7)) and Children and Families Act 2014 (section 96(1)) defines a young carer as:

> A person aged under 18 years, 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.

Legislation in England has limited the age range up to 18, with young adult carers (age 18+) being considered as adult carers.

For our research we used a wider age range than the government in England's definition, thus our working definition of a young carer is 'a child/young person under the age of 25 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol'. This enabled us to include young adult carers representing the age range covered by the young carers service (ages 8-25) which was used to recruit research participants. Thus, while our study offers a springboard for developing thinking in relation to those aged 18 to 25, our initial concern is effective implementation of the current legislation.

All of these definitions include reference to providing care for another person that, within this paper, we refer to as 'caring responsibilities'. However, neither the legislation nor the statutory guidance (DoH, 2014) provide indicators for professionals on how to determine the level and scope of responsibilities a child takes which may push them from providing appropriate levels of care to providing inappropriate care. Distinguishing between culturally and legally acceptable familial care (where children help out in their families on an ad hoc informal basis) and caring responsibilities, (where children are responsible for taking on more substantial caring) is challenging and by extension the definitions of inappropriate and excessive boundaries are, therefore, difficult to pinpoint.

Some scholars have introduced the term 'care work' to describe more substantial caring responsibilities with Becker (2001), for example, asking about when care is viewed as familial caring and when is it care work?

> It would be inconceivable to employ children as Community Care Assistants or other care workers - there would be a public outcry as well as all the other ramifications. However, within the 'private' domain of the family children do provide unpaid care work - but their labour is not defined as work. (Becker, 2001, p.73)

Becker raised a critical point about the nature of caring responsibilities and whether or not a child should undertake such tasks. By defining it as work, Becker explicitly challenged society's tacit acceptance of children providing substantial care for others. Although we carefully considered using the term 'care work' in our research we decided against this to avoid bias in evoking moral objections to child labour and to focus more practically on shedding light on the nature of inappropriate care.

The Children Act 2004 and Carers (Equality of Opportunity) Act 2004 placed responsibility on local authorities to be proactive in identifying young carers in their area and adopting a family approach to assessments of need across adult and children's services. Previous legislation and policy had given local authorities the statutory duty for assessment of need only.

More recent legislation, the Care Act 2014 and Children and Families Act 2014, strengthened young carers' rights through new statutory duties on local authorities to adopt a `whole system, whole council, and whole family approach` to coordinating services around the needs of the young carer within the context of their family and support network. The legislation requires local authorities to consider if the young carer is a child in need as identified in the Children Act 1989 and consider the impact of caring on their education, development and well-being (DoH, 2014).

Prevalence of young carers

Young carers are a group of largely hidden children who provide vital care for their families, often overnight and over prolonged periods of time. The exact number of young carers in the UK is unknown, however the most recent Census (Office of National Statistics 2013) identified 177,918 young carers aged 5-17 in England. The data is limited because the census relies on self-identification by families, with adults in the family asked to identify young carers and the amount of time they spend caring. Some, or indeed many adults, may not have identified or recognised their children's caring roles. A BBC study with the University of Nottingham (Joseph et al 2019) found levels closer to one in 12 children providing mid to high-level care for a family member which is equivalent to 700,000 young carers. The lack of reliable and consistent statistics highlights the need for better methods of identifying and registering young carers.

Research on Black, Asian and Minority Ethnic (BAME) young carers concluded they were one and a half times more likely to be a young carer and less likely to self-identify than White British young carers, and may be less likely to know where to go to get help. This results in BAME children being underrepresented in statistics, less likely to access appropriate services and face barriers and exclusion from services (Wayman et al 2016).

The lack of clarity and guidance about how to identify a young carer, and what constitutes in/appropriate care, makes it difficult for families to get the support they need to prevent children becoming young carers in the first instance. There are children who are caring for family members who need support in their own right as children and as young carers. Evidence suggests they need access to a range of health, social care and educational support [Local Government Association 2018). However, like carers generally, some children may not identify as a young carer and can remain hidden from professionals and services.

Impact of Caring on Young Carers

Young carers have reported some positive outcomes of caring including feeling mature and prepared for life, having close attachment to family members, feeling positive about caring for a loved one, and learning new life skills. However, the nature and intensity of children's caring responsibilities often severely impacts on their own health, social, economic and educational well-being. As Becker noted, 'young carers are involved in adult-like tasks which require maturity, responsibility and often a high degree of expertise (and which would often attract a fee or salary if undertaken by adults from outside the family)' (Becker et al 2001, p.83).

The Care and Support Statutory Guidance (DoH, 2014) issued under the Care Act 2014 stated 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 well-being and their prospects in education and life. (DoH 2014, Subsection 2.50)

The guidance alludes to the short, medium and long-term impacts of caring roles on children, including their education, mental and physical health and employment prospects and these are now explored in turn.

Education

The education of young carers is often adversely affected by caring. For example, a Barnardo's report stated that, '27% of young carers aged 11-16 experience educational difficulties or miss school because of their caring responsibilities, rising to 40% for young carers with parental mental ill health/substance misuse' (2017, p.32). Similarly, Dearden and Becker (1998) reported that 33% of young carers in 1998 and 28% in 1995 were missing school due to their caring responsibilities. A more recent study identified that one in 20 young carers were missing school due to caring responsibilities and had lower educational attainment at GCSE level than their peers (Children's Society, 2013). Young carers aged 16-19 were also more likely than the national average, to not be in education, employment or training (Children's Society op cit.).

Mental health

'Young carers are one and a half times more likely than their peers to have a special educational need or a disability' (The Children's Society 2013, p.5). While some children develop coping strategies, children who have been caring for longer periods may not cope as well. Moreover, prolonged caring, for longer than two years, has been shown to have an adverse impact on children's health and wellbeing with children reporting lower self-esteem and feeling less optimistic about their future (Abraham & Aldridge, 2010). Becker and Sempik (2019) addressed the link between physical and mental health for young adult carers (aged 14-25): There was a highly significant association between the reporting of physical poor health and mental health problems. (2019, Vol.33, p383)

Physical Health

There is less research evidence around physical health impacts on young carers. Research by the Royal College of General Practitioners in 2011 highlighted how young carers can sustain physical injuries while caring, for example back strain from lifting carers, diets can be limited due to a lack of cooking skills and low income in families, and physical exercise and leisure activities can be limited due to time devoted to caring responsibilities (Simon 2011).

Impact of COVID-19 pandemic

Whilst our research was conducted prior to the pandemic, more recent research has illustrated the impact on young carers. The Carers Trust (2020) highlighted the impact on young carers' mental health with 40% of young carers and 59% of young adult carers saying their mental health was worse; and 67% of young carers and 78% of young adult carers are more worried about the future since Coronavirus. Blake-Holmes (2020) research highlighted the increase in caring responsibilities, reduction in support, including in education, and the increase in pressure and stress for young carers, with a key recommendation;

> 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. (p.8)

Agency and Choice

The concepts of agency and choice are also relevant when considering the impact on young carers. Studies have found adults are more likely to perceive that children are freely choosing to care, whilst children themselves are more likely to feel compelled to care (Banks 2002; Aldridge & Becker 1994). In terms of social justice, it is important to consider the degree to which caring responsibilities are perceived by stakeholders to be inappropriate. A study by Hamilton (2013) drew on the concept of bounded agency to understand the way in which young carers interpret and inhabit the constraints associated with their caring situations. The study found that, 'aspirations change rather than the environment; young carers lower their aspirations because they don't think their caring responsibilities will change/can change' (Hamilton, 2013, p109).

Smyth (2011) argued that the acceptance of familial obligation means children do not identify as young carers and that familial care-giving is integral to their sense of identity, leading to a reluctance to access services as they are not seen as necessary or required. Furthermore, Rose (2010) argued that caring becomes part of a child's identity and questions the damage it could cause if this was denied or caring responsibilities were taken away from them.

Assessment of Young Carers' Needs

A young carer can be referred for a young carer's assessment as a `child in need` under the Children and Families Act or the Care Act 2014. The Children and Families Act 2014 Section 17ZA (12) stipulates that local authorities, 'must take reasonable steps to identify young carers in their area and assess their support needs' and that 'all young carers under the age of 18 have the right to an independent assessment regardless of who they care for or what type of care they provide and how often they provide this care'. In addition, under this Act, a young carer should no longer have to request an assessment, as they previously had to.

The Care Act 2014 lists a range of caring responsibilities that are deemed inappropriate for children to undertake and these are shown in Table 1. This is the only reference to inappropriate caring responsibilities within the legislation.

Warren (2007) argued to progress our understanding we need to establish a range of normal expectations of children but that evidence from the Social Services Inspectorate indicated 'no baseline exists for establishing normal expectations' (p.137). Determining what is inappropriate and excessive care by children is a complex, subjective and culturally-contextualised process. In the first instance, it requires an understanding of what are perceived to be acceptable levels of care by children who are not identified as young carers in the contemporary context of England. As a consequence, this would help define what kind of care is acceptable for children to undertake. There are differences of opinion on the subject, not least due to multiple cultural influences within the national landscape and, what children and families are able to say about acceptable levels of care within the current assessment process. As there is no defined threshold of acceptability for children undertaking domestic and caring responsibilities, this makes it harder to recognise the point at which children transition into becoming young carers.

The way in which the legislation is implemented and resourced locally determines the extent to which young carers are identified and supported. A survey of 152 English local authorities found that they were not fulfilling their legal requirements under the Children and Families Act 2014 and Care Act 2014 to identify, assess and provide support for young carers (Children's Commissioner Report 2016). The survey revealed that 67% of local authorities were meeting the need for assessment rather than providing support to young carers. Voluntary agencies commissioned by local authorities stated that the level of funding provided meant that assessments were prioritised, leaving minimal funding for meeting support needs.

In light of our review of literature and policy, we argue that in order to develop effective guidelines to implement the 2014 legislation, it is necessary to operationalise the ethical and legal boundaries of what is understood by 'inappropriate' and 'excessive' caring. We recognise that this is a subjective matter and different stakeholders have different opinions on what constitutes inappropriate and excessive. Therefore, our research aimed to give voice to young carers to shed light on this emotive and complex issue and place children at the heart of the debate.

Methodology

This paper reports on a small-scale exploratory study designed to operationalise the concepts of 'inappropriate' and 'excessive' care by children in England. We aimed to inform understanding of children's entitlements, societal obligations towards them and implementation of the legislation in terms of ethical and legal boundaries of children's caring responsibilities. Our initial literature review led to the question: What is the level of inappropriate or excessive care within the Care Act 2014 and Children and Families Act 2014? However, this broad question raised issues about who decides. We therefore focussed on young carers' voices within this, to ask: How can children and young people's perspectives on caring inform guidelines to identify young carers' needs?

Our approach was interpretive, focussed on 'empathic understanding of human action' and interpretation, recognising that different stakeholders may construct caring in different ways and with varied boundaries of tolerance in terms of appropriateness and excessiveness (Bryman, 2016:26). We sought to develop insights into the nature of children's caring activities, the circumstances in which they are carried out and the characteristics and lived experiences of those undertaking these responsibilities. We aimed to understand children's social constructions of their realities on the premise that this must be central in any assessment of what constitutes inappropriate or excessive caring by children.

Ethics

We developed our research approach for working with children on this sensitive topic drawing on work by Farrell (2005), Alderson and Morrow (2011) and Kellett (2010), taking account of multiple ethical considerations. We tried to mitigate the power relations at play and the fact that the lead researcher was a lead figure in a young carers' project from which the research participants were recruited. Young carers in our study were invited to become active participants as opposed to passive subjects of research and their agency was acknowledged throughout the research process.

Ethical approval for the research was granted by the researchers' academic institution and voluntary informed consent was sought from participants. Our research approach involved a commitment to respect the competence of children, both to "make decisions about whether to participate in research" and also "to provide valid sociological data" (Morrow and Richards, 1996: 98). Whilst it was the choice of the children to participate, we also sought parental consent from all participants under the age of 18. We adopted a participatory approach to research which respects a child's right to express their views in all matters affecting them as provided in Article 12 of the UN Convention on the Rights of the Child (UN CRC). Ongoing support was offered to study participants through the young carers' project in relation to issues raised through the research process.

Methods

Each young carer in our sample participated in one of four focus groups, each lasted three hours with breaks. They were held at a venue which was not the usual meeting space for the young carers in order to create as neutral an environment as possible. They were facilitated by the lead researcher, supported by a PhD student from the University of Sheffield and the Young Carers Project staff were on hand to support participation. Each focus group undertook the same set of activities outlined below.

Informed by Litoselliti's (2003) work on focus groups we aimed to provide a supported and non-judgemental space for reflection and discussion. The focus groups aimed to draw out the intensity and number of caring tasks participants undertake; the range and patterns of activities and tasks undertaken during a typical 24-hour period; how young carers feel about carrying out these tasks and the types of care young carers see as appropriate and manageable. We were not concerned with asking young carers about the impact of being a young carer, a topic which has been discussed elsewhere (see previous section p4).

To allow multiple opportunities for new ideas and views to emerge the focus groups incorporated oral discussion alongside creative participatory activities. For example, participants were asked to describe the role of a young carer using images and colours, and to describe the tasks and skills needed for this. They were also invited to draw their care tasks on a 24-hour clock and to place activities on a continuum from those that made them most happy to those that made them most sad (using smiley/sad faces).

On completion of the three initial focus groups, recordings and hand-written notes were transcribed, and data were analysed using thematic analysis techniques drawing on Braun & Clarke (2006). After transcribing the three focus groups and initial data analysis, we presented the findings to a final focus group of young carers who had participated in the third focus group. We asked about: their views of the findings and about the appropriateness of the tasks at the sad end of the continuum; any gaps in the research and additional information needed; how guidelines could be developed and what it would mean for them as young carers. Analysis of data from all the focus groups identified seven areas of inappropriate care, discussed below.

Sample

As previously mentioned, young carers are often a hidden population and therefore representative sampling was hard to achieve. Other researchers have discussed the issue of gatekeepers, the stigma of recognising a young carer in a family and parental concern about statutory involvement in their family. Our sample was drawn from service users of a young carers project, the base of our lead researcher in the north of England. In total, 21 self-selecting young carers, aged between 9 and 18 years, participated in the research (See Table 2). The sample was limited as all these young people had been identified, referred to and engaged in the young carers support services, unlike unidentified peers. However, we argue that this sample characteristic offers valuable insight into a potentially vulnerable target group whilst offering a safe and ethical environment for participants to access ongoing support beyond the research study. One participant was aged 18 and was therefore outside of the 'under 18' age limit to which the 2014 legislation applies. However, for ethical reasons the individual was permitted to participate in research activity as they formed part of an established peer group within the young carer project.

Research findings

Our findings highlighted a number of inappropriate caring activities carried out on a regular basis by the young people, which include five responsibilities identified by the Care Act 2014, as well as an additional two. The evidence showed that the young people had started to normalise these caring tasks and that the time required, nature of the caring tasks, and impact on their wellbeing and everyday lives were all important when assessing the appropriateness of caring responsibilities. Based on these findings we developed seven dimensions to help assess inappropriate care. The appropriateness of the caring responsibilities and the dimensions of care required to assess if care is inappropriate for young people are now discussed.

Indicators of inappropriate caring responsibilities

The focus group findings highlighted seven indicators of inappropriate caring identified by young carers. The first five: personal care; physical/strenuous activities; medication; financial; emotional were already identified in the Care Act 2014 (see Table One) and as part of a Continuum of children's caregiving (Becker 2009). Our findings identified two additional responsibilities: 'global parenting responsibilities' - showing that young carers were often carrying comprehensive parenting responsibilities not captured by identification of individual tasks; and 'global self-care' which reflects the responsibility young carers take for their own well-being and self-management of emotions and mental distress arising from the care gap in their homes and the demands on them to fill this gap. The term 'global' is used here to mean the scale and scope of responsibilities, rather than being world-wide. Our findings also suggested also that the term 'global' be applied to the first five categories (as defined in the Care Act) in future.

The seven areas of inappropriate care identified through our focus group discussions are now explored with specific examples identified through verbatim quotes from participants:

1. Global personal care of the cared for person e.g. bathing and toileting;

> *I help with bathing and it's really not okay. (young carer aged 18)*

2. Global strenuous and physical activities e.g. lifting, shopping (heavy bags), assisting cared for person, including moving and handling often coupled with emotional labour;

> *I help with shopping because they don't leave the house but it is heavy to carry. (young carer aged 9)*
> *I do all the housework, I don't like to do it but it stops her from hurting herself. (young carer aged 11)*

3. Global responsibility for medication – e.g. collecting and administering medication, including giving the medication when the cared for person does not want to take it, undertaking medical tasks;

> *I give medication to the person I care for* but *if they don't want it, I don't like forcing them. (young carer aged 13)*

4. Global household financial responsibility – e.g. maintaining the family budget, paying bills and worrying if there is enough money to pay them, using their own money to pay;

> *Yeah sometimes my mum tells me to bring my money 'cos she doesn't have enough money. (young carer aged 15)*

5. Global emotional support and responsibility for the cared for adult – e.g. cheering them up, checking on them in the night, listening and lifting their mood;

> *Having to worry all the time, that's just gets on your nerves to be fair. (young carer aged 15)*

One young carer (aged 12) who participated in a focus group describes what she thinks defines a young carer compared to those without caring responsibilities:

> *I think you can really identify a young carer cos most of the things that make people young carers is the emotional state. It isn't the physical. I feel like most young people do clean the house or do the dishes cos that's something their parents make them do anyway, like chores, cos that's how you grow up to be an adult, but the emotional part not everyone does.*

The following two indicators were in addition to those outlined in the Care Act 2014 guidance:

6. Global parenting responsibility e.g. child acting in a parenting role towards the cared for adult, siblings or other family members;

> *My mum sometimes feels scared or down about what my sister's doing, she normally asks me to stay in her bed with her for a night, so I do that sometimes. (young carer aged 12)*
> *I check in on my mum every night, I'll go into her room and be like 'I'll come and check on you in a bit but do you need anything for now? (young carer aged 11)*

7. Global self-care responsibility e.g. related to young carer's own well-being, keeping their emotions in check, staying calm, tolerating parent anger or aggression and/or excessive mental stress;

> *Young carers need to be reminded about their own emotions and physical well-being as well as caring. (young carer aged 13);*
> *This is hard because you have to be in control of them [emotions], you can't be angry or cry. (young carer aged 11)*

Dimensions of Caring

It is significant that some young people appeared to have normalised care work tasks as something they think everyone does with one participant commenting, '*when you think about it though, people think like, when someone's got used to it for so long you don't realise that you're a young carer, unless someone goes 'you're a young carer you know' (young carer, aged 15)*. This means that the caring responsibilities articulated through the research process were likely to represent a partial view of the full gamut of responsibilities undertaken by children.

Furthermore, we found that young carers often undertook caring responsibilities for their family members for much of the day and in some instances overnight, and this could be over short, intermittent or long periods. The young carers found night time caring particularly challenging, for example, constantly worrying, checking on the cared for person and making sure their home is safe and secured overnight. The disturbed nights impacted on sleep and on young carers' well-being and ability to function in their daily lives, especially on school days. We provide two examples (Tables 3 and 4) of a young carer's day.

The findings aligned with national research that indicated at least one in seven (14%) of all young carers were providing care for more than four hours a day on top of their studies (Cheesbrough 2017). The findings that night-time was challenging as well as impacting on the young person's well-being indicated that both time, task and impact are all factors to consider when defining (and assessing) inappropriate care.

Beyond identifying the types of care that young carers carry out it is crucial also to consider the manner in which that care takes place. Our findings indicated seven key dimensions that merit consideration in assessing the scale of care undertaken by a child and whether that care is inappropriate or not.

The seven key dimensions (with possible measures in brackets) are:

1. Frequency (hourly, daily, weekly, etc) non-stop 24hr carer;

> *And you forget a lot, when you've been put on the spot or like when you think about things, it's like you can't, your brain doesn't work the way you want it to work. Cos if you have a mum or a dad who's ill, you want to do so many things for them but you*

> *can't cos you have two hands, two feet and it takes more time than you think, if you were thinking to do it more quicker, you take more time cos you want to do everything that you want to do in the time. (young carer aged 15)*

2. Duration (over week, month, year) For many young carers, they have been caring for a family member for a long time, considering themselves as long term carers;

> *When you think about it though, people think like, when someone's got used to it for so long you don't really realise that you're a young carer, unless someone goes 'you're a young carer you know. (young carer aged 13)*

3. Range (combination of tasks);

> *Be an adult to not only the 'ill' person but the whole family*; *I have to multi-task between speaking to friends on the tablet and watching my little brother; time management skills; be mature and know how to handle things maturely. (young carer aged 15)*

4. Severity (intensity, time, effort, risk);

> *I don't sleep a lot but still keep moving. (young carer, aged 9).*

'I randomly wake up and panic if you hear someone snoring, thinking your sister is having a seizure and needs to go to hospital. I don't like this, it is hard. (young carer, aged 15)

5. Overnight (regular, intermittent, unpredictable) They can be an overnight carer;

> *I stay up but I get tired just like young carers stay up due to worry/care – it can be exhausting; mum wakes up at night because of the pain and this keeps me up when I worry. (young carer aged 12)*

6. Sole carer (never, always, sometimes) Young carers were often the sole carer;

> *You want to do so many things to help but (you) only (have) two hands and it takes a lot of brain space. (young carer, aged 13).*

7. Choice by child (never, always, sometimes) though not necessarily from choice;

> *I don't know if this is bad, I don't know, anyway sometimes I think about having my own house and living by myself and being able to do stuff that I can't do at mum and dad's. I don't know if it's spiteful, ungrateful or anything. (young carer, aged 15).*

The above dimensions reflected the findings from the three focus groups, as one young carer said;

> *The thing is not every young carer's the same, just cos there's one young carer there's another, you can't say they're all the same young carers, cos some of their parents have battles with cancer and they're helping them recover and some have diabetes and there's lots of things. Cos some people have it easier, some people have it harder. (young carer aged 15)*

Linking the dimensions and the indicators from this research with the evidence of impact of caring on young lives, provide a clearer guide for defining and assessing inappropriate/appropriate care.

Discussion

The findings deepen our understanding of the nature of responsibilities young carers are taking on within the family. Our research has identified two important findings. Firstly, we have identified two key areas of caring responsibilities that are absent in the Care Act 2014. We have described the two newly identified areas as global parenting responsibility and global self-care responsibility. The term parenting role refers to those duties and responsibilities normatively held by parents in a household such as looking after children including boundary-setting, physical and emotional care, ensuring economic and food security and the safety of the home. Global parenting responsibilities can be viewed as when a child takes on multiple aspects of the parenting role. Global self-care refers to situations where a young carer, alongside caring for others, holds responsibility for their own emotional and physical well-being and often goes hand-in-hand with global parenting responsibilities. So, if a young person has parenting responsibilities it is likely they will have responsibility for meeting their own self-care needs as well. As the study incorporated only a small sample, further research is needed to establish how widespread these areas of caring responsibility are amongst young carers. Nonetheless the present study illuminated and extends current thinking on the typology of caring responsibilities undertaken albeit that this list may not be exhaustive.

A second key finding relates to the multi-dimensions of caring responsibilities children are undertaking. The time period over which a young carer is care-giving is significant in both the short and long term. That is to say an individual's range of caring may extend over the full 24-hour day and over a long period of duration, even years in some cases. Within this timeframe the range of activities, their frequency, duration and predictability also emerge as important factors to consider. Activities may occur concurrently or sequentially on a more or less predictable basis. Multiple examples were given by children of multi-tasking, having to remember to do certain things or to be responsive when unexpected events occurred, for example related to episodes of more severe illness or intoxication of the cared for adult. Night-time caring emerged as one of the more worrying times for young carers and was compounded where they perceived themselves as the principal or sole carer.

The findings delineate key indicators that could be taken into consideration in considering how children's caring responsibilities can be assessed in terms of levels of care and in identifying thresholds for judgements about appropriateness of care. However, in order to move forward England, as a society, as would be the case elsewhere, needs to have a set of criteria by which judgements can be made about whether the care undertaken by a child is viewed as appropriate and in the child's best interests.

If a young carer is undertaking any or all of the care tasks described by the seven indicators of inappropriate care and the dimensions of caring identified in this study, then this could constitute inappropriate caring responsibilities. The crux of any new assessment measure is developing agreed boundaries of acceptability of singular and combined care activities for a given child in a particular social and cultural context (including maturity, competence and aspirations). It may be that only partial agreement can be reached and that this is more feasible if working from the most extreme forms of care where consensus on inappropriate or excessive care may more easily be reached. For example, care by under five-year-olds may be deemed wholly inappropriate, and similarly with care by a sole child overnight.

The criteria for judgement are beyond the scope of this paper but we argue that the voices of children must feature strongly. This can particularly be argued to be the case if we are to avoid children undertaking tasks that they feel are inappropriate. Examples of assessments and criteria are available and would warrant further study to explore their potential in defining inappropriate caring responsibilities. We highlight one example, Hart (2016) which offers a set of criteria (initially used to judge aspirations) that can be applied to assessing the appropriateness and excessiveness of children's caring responsibilities. This should include consideration of whether that care is acceptable on i) legal, ii) moral and iii) feasibility grounds. It also entails considerations of iv) risks (to the child and others), v) sustainability (of care but also of child-wellbeing and well-being of related others), vi) length of care required and vii) priority of a child giving this care (what would happen if the care stopped, what alternatives exist). Judgements can also be influenced by a comparison of the extent to which a given child's life opportunities are expanded or contracted through their caring roles and, on the other hand, the extent to which their capabilities might be expanded or contracted if their care work was to cease (Hart, 2018).

These potential criteria require further research and analysis, with young carers voices playing a central role. We strongly reiterate that the criteria for judgement are critical and may only become tangible through ongoing reasoned debate among key stakeholders. This requires a commitment to meaningful engagement with children and families to understand their lived experiences and needs, as well as those of professionals.

Conclusion

The research deepens insights into the way that young caring is manifested in complex family lives. In light of the study, we need to develop consensus on the criteria for judgements of inappropriate and excessive care within the parameters we have identified with young carers and other key stakeholders. Following this we recommend the development of a robust assessment tool to help professionals identify what is inappropriate or excessive for each individual young carer and to recognise the moments at which children transition into becoming young carers.

We recommend that young carers are provided with regular opportunities to discuss and reflect on their caring roles and to feel free to express their emotions without fear of judgement. This would include children being seen separately from family members, encouraging children's agency and active engagement in situations that directly affect them and their families. We also recommend that services work together to assess and monitor more accurately the type, range, frequency, intensity and duration of patterns of caring responsibilities undertaken by children and seek to incorporate those assessments in family-centred plans for support, not just of the cared for person but of the whole family.

Identifying where and when a young carer is undertaking inappropriate and excessive care, is just one part of a more complex response to a multifaceted issue. It has to remain the responsibility of professionals to safeguard children. Clearly, professionals and policy makers need to have systems in place to protect and support children. This begins with preventive measures that seek to flag potential care gaps early on when planning adult care. This would mean implementing a family-centred approach within both children's and adult health and social care services, alongside a person-centred approach, in order to provide appropriate care for the person being cared for as well as the child/ren in the family. The indicators and dimensions of caring responsibilities we have outlined can help to guide assessment of an individual's care needs and any potential care gap particularly where children are vulnerable to expectations, real or perceived, by self or others, to make up this shortfall. It will be necessary to consider the best timing for a caring responsibilities assessment to be undertaken (e.g. planned, reactive, one-off or repeated) and the training requirements to enable the health and social care workforce to undertake the assessment effectively.

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References

Abraham, K. & Aldridge, J. (2010). Who Cares About Me? Manchester. Manchester Carers' Forum.

Alderson, P., & Morrow, V. (2011). The Ethics of Research with Children and Young People: A Practical Handbook. London: SAGE Publications.

Aldridge, J. & Becker, S. (1994). Children Who Care: Inside the World of Young Carers. Journal of Social Policy. Vol.23, pp.128-129.

Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M. & Tisdall, K. (2002). Does the covert nature of caring prohibit the development of effective services for young carers. British Journal of Guidance and Counselling, Vol.30, Issue 3, pp229-246.

Barnardo's (2017) *Still Hidden, Still Ignored*. https://b.barnardos.org.uk/get_involved/campaign/stillhidden.htm Accessed 10.04.2021.

Becker, S. (2009). Global perspectives on children's unpaid caregiving in the family. Global Social Policy, Vol. 7, Issue 1, pp.23-50.

Becker, S., Dearden, C. & Aldridge, J. (2001). Children's labour of love? Young carers and care work, in Mizen, P., Pole, C. and Bolton, A. (eds) Hidden Hands: International Perspectives on Children's Work and Labour. Brighton. Falmer Press, pp. 70-87.

Becker, S. and Sempik, J. (2019). Young Adult Carers: The Impact of Caring on Health and Education. Children & Society, Vol 33, pp.377-386.

Bilsborrow, S. (1992). You Grow Up Fast, as Well: Young Carers on Merseyside. Ilford: Barnardo's.

Blake-Holmes, K. (2020). Understanding the needs of young carers in the context of the COVID-19 global pandemic. UEA-young-carer-CRCF-COVID-19-final-findings-v1.0.pdf (caringtogether.org) Accessed 12.01.2021

Bryman, A. (2016). Social Research Methods (5th ed.). London. Oxford University Press.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology. Vol.3, Issue 2, pp. 77-101.

Carers Trust (2020). My Future, My Feelings, My Family my-future-my-feelings-my-family.pdf (carers.org)

Cheesbrough, S., Harding, C., Webster, H. & Taylor, L. and Aldridge, J. (2017). The lives of young carers in England omnibus survey report. Department of Education.

Children's Commissioner Report (2016). Young Carers. The Support Provided to Young Carers in England. Children's Commissioner Office. London.

Children's Society (2013). Hidden from view: the experiences of young carers in England. London.

Dearden. C. and Becker, S. (1998). Young Carers in the United Kingdom: A Profile London: Carers National Association.

Department of Health (1996). Young Carers- something to think about. London, HMSO.

Department of Health (2010). Recognised, valued and supported: Next steps for the Carers Strategy. London, HMSO.

Department of Health (2014) 'Care and support statutory guidance: Issued under the Care Act 2014', paragraphs 16.67-68, London. HMSO.

Farrell, A., Abbott, L., Alderson, P., Allen, G., Anderson, C., Ball, J., Cuskelly, M., Danby, S., David, T. (2005) Ethical Research with Children. Maidenhead. Open University Press.

Hamilton, M. & Adamson, E. (2013). Bounded Agency in Young Carers' Life Course-stage Domains and Transitions. Journal of Youth Studies. Vol.16, Issue 1, pp.101–17.

Hart, C.S. (2016). How Do Aspirations Matter? Journal of Human Development and Capabilities. Vol.17, Issue 3, pp. 324-341.

Hart, C.S. (2018) Education, Capabilities and Sustainable Development in Comim, F., Fennell, S. & Anand, P.B. (eds.) New Frontiers of the Capability Approach. Cambridge. Cambridge University Press.

Hart, C.S., and Brando, N. (2018) 'A Capability Approach to Children's Well-being, Agency and Participatory Rights in Education'. European Journal of Education, August 2018.

Joseph, S., Kendall, C., Toher, D., Sempik, J., Holland, J. & Becker, S (2019). Young carers in England: Findings from the 2018 BBC survey on the prevalence and nature of caring among young people. Child Care Health Development. Vol.45, pp. 606–612.

Kellett, M. (2010). Small Shoes, Big Steps! Empowering children as active researchers. American Journal of Community Psychology, Vol.46, pp.195-203.

Litoselliti, L. (2003). Using focus groups in research. Continuum Research Methods. London. Bloomsbury.

Local Government Association and Bright Futures (2018). Meeting the health and wellbeing needs of young carers. Local Government Association.

Morrow, V. & Richards, M. (1996). The Ethics of Research with Children: An Overview. Children and Society. Vol.10, Issue 2, pp.90-105.

Office for National Statistics (2013) Census 2011: http://www.ons.gov.uk/ons/rel/census/2011-census/detailedcharacteristics-for-local-authorities-in-england-and-wales/index.html Accessed 10.04.2021.

Rose, H. (2010). The experiences of young carers: a meta-synthesis of qualitative findings, Journal of Youth Studies. Vol.13, Issue 4, pp.473-487.

Simon, C. & Slatcher, C. (2011). Young carers. Royal College of General Practitioners. Vol.4, Issue 8, pp.458-463.

Smyth, C., Cass, B. & Hill, T. (2011) ‘Children and young people as active agents in care-giving: Agency and constraint’, Children and Youth Services Review. Elsevier Ltd. Vol.33, Issue 4, pp. 509–514.

Warren, J (2007) Young Carers: Conventional or Exaggerated Levels of Involvement in Domestic and Caring Tasks? Children and Society. Vol.21, pp.136–146.

Wayman, S., Rals, P. & Leadbitter, H. (2016). There’s Nobody Is There - No One Who Can Help? The Challenges of Estimating the Number of Young Carers and Knowing How to Meet Their Needs. London. Children’s Society.

Tables

Table One: Caring responsibilities by children deemed inappropriate under the Care Act (2014).

Indicators of Inappropriate Caring Responsibilities identified in the 2014 Care Act
Personal care such as bathing and toileting
Strenuous physical activity such as lifting
Administering medication
Emotional support to the adult
Maintaining the family budget

Table Two: Composition of focus groups

Age of young carer	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**18**
Number	2	1	4	3	3	3	3	1	1

Gender identity	**Female**	**Male**
Number	15	6

Ethnic identity	**White British**	**British Asian**	**British Black**	**Arab/ Asian**
Number	16	3	1	1

Cared for person	**Mother**	**Sibling**	**Father**	**Grand parent**
Number	15	2	3	1

Reason for caring	**Fibromy algia**	**Anxiety and depres sion**	**Autism**	**Visual impair ment**	**Mental health diagnosis**	**Substance misuse**	**Learning disability**	**Physical disability**
Number	1	4	1	1	7	3	2	2

Table Three: example of a young carer's day

Young carer aged 12
6am: Wake up and worry
9am: School or at weekend – clean
12pm: If weekend - help make lunch, feed baby sister
4pm: Bus or tram home, clean, give meds to my mum, prepare food again
6pm: Give food to big bro when he comes home, change baby's nappy, play and talk with big sis
10pm: Med to sister and mum, change nappy, put baby to sleep
12am: Lie in bed and listen out to see if big sis is having a seizure. Worry. Careful to not wake the baby. Walk around to make sure doors are shut, windows are shut. Try to sleep, it's hard.

Table Four: example of a young carer's day

Young carer aged 14
6am: Get siblings up and ready for school
9am: Going into school late as had to take siblings to school
12pm: Hoping my dad isn't lonely and my mum isn't going crazy
2pm: Worrying about going home – having to go straight back to caring
4pm: At home doing care things – cooking for siblings
6pm: Settle the kids down ready for bed, shower and bathe them all
10pm: Make sure everything is okay, parents are okay and make sure the children are in bed asleep
Phone a friend, watch a movie, or read
12am: In bed or just waiting till my Mum shouts me as she gets lonely
2am: Awake or asleep because you are not sure
4am: Sleep.