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Research Article

Young Adult Carers Services in England: Facilitating Choice over Future Caring?

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This paper reports findings from a national, qualitative study in England that investigated if young adult carers services are facilitating young people's transitions to adulthood, including considering a future beyond caring. Semi-structured, online interviews were conducted in 2022 with a purposive sample of managers or lead workers of eleven young adult carers services in England. We discuss the consideration given in assessments to young people's caring preferences and the availability of support to facilitate them to relinquish their role, if they so wished. The majority of young adult carers services gave young people the opportunity to express their views on this issue. Although the Care Act 2014 aimed to provide choice over caring in adulthood to young adult carers, this was not matched by the necessary service provision to facilitate their preferences. A new national carers strategy is urgently required to ensure that young people, particularly women, have a credible choice over their future lives.

1. Introduction

Young people aged 16 to 24 years who provide regular care and emotional support to a family member who is physically or mentally ill or disabled are referred to as young adult carers [1, 2]. There are approximately 376,000 young adult carers in the UK (16 to 25 years [3]). The 2011 census showed that almost 28% of 16 to 24 year olds in England and Wales were providing unpaid care for twenty or more hours per week [4]. Their caring responsibilities include undertaking domestic and personal care tasks and providing emotional and financial support [5, 6]. A quarter of young adult carers are from ethnically diverse backgrounds [7]. As most young adult carers are female, caring is a gendered issue even in young adulthood [8]. Socio-cultural norms, including family values, religious beliefs and gendered role expectations, underpin a perceived obligation to care, particularly among women from ethnic communities. In turn, transgressing such norms can lead to a greater sense of guilt for women [5, 9].

While young people may see moral value in the caring role, it is usually acquired rather than negotiated [5]. Previous research in the UK found they had little or no choice over taking on the carer role [5, 10]. Consequently, young people can feel obligated to act as carers for their loved ones [11]. A study of young and young adult carers in New Zealand showed some actively chose to care while others had no choice in the matter. Additionally, the requirement and desire to care co-existed, although ultimately this morphed into a sense of obligation [12]. As the UK is more reliant on informal care than many other countries [13], this has led to a greater dependence on young people taking on caring roles. However, research into the lives of young carers in England found many parents were keen to reduce the caring demands they experienced [14]. While the academic literature has examined whether young people have a choice over taking on this role, whether they choose to continue caring into adulthood has not been systematically investigated.

UK social care policy recognises the importance of supporting adult and young carers, but the needs of young adult carers have received less attention [2, 15]. These young people occupy a liminal space between young carers who require protection due to their vulnerability as children, and adults who are the main providers of social care [16]. In particular, the Carers Action Plan emphasised the need to provide better support to adult carers [2]. The policy priority given to adult carers within the UK and internationally has been driven by “a highly organised and politically active carers movement” [17], but young adult carers lack this critical strength and political voice. However, a new Young Carers Alliance in England [18] aims to ensure that young and young adult carers’ views are heard. Indeed, there has been growing recognition of young carers—and, to a lesser extent, young adult carers—within global policy [19]. The Care Act 2014 [20] recognised carers’ right to an assessment of their needs, although there was less of an emphasis on young adult carers. Given young adult carers’ developmental stage, their needs differ from those of young carers, for example, preparing for employment and independent living [1]. The Carers Action Plan highlighted the importance of supporting carers to ensure they “provide the best care they can” [2]. However, there is a risk that young adult carers will become “locked” into caring as they become adults [6], with little regard paid to the wishes and aspirations of young people themselves.

The Care Act guidance [21] states that transition assessments should be undertaken with young people in caring roles to facilitate their preparation for adulthood, including identifying if they wish to continue caring after the age of 18. It has been suggested that the assessment process could help to lift them out of their caring roles [22], but research has not previously examined if this is the case. A survey of local authorities in England showed they were not monitoring the outcomes of assessments undertaken with young adult carers [23]. In turn, the local authorities did not know what impact any support provided made to their lives, including whether the caring roles were reduced or avoided. However, a mixed-methods study in England into the impact of services for people with care needs on young adult carers found that even when these services were provided, they were insufficient to lessen young people’s caring responsibilities [24]. Similarly, consultation events with young adult carers in England showed they often had to choose between caring for their family member and their future aspirations [23]. Consequently, the Children’s Commissioner [25] recommended that research is needed on the impact of any support provided on young people’s caring roles.

This paper reports key findings from a qualitative study in England that explored if young adult carers services are facilitating young people’s transitions to adulthood, including giving them an opportunity to consider a future beyond caring. Our paper discusses the attention given in assessment processes (especially transition assessments) to young people’s preferences for continuing caring in adulthood. Additionally, we identify any barriers to relinquishing the caring role if young people wished to do so, especially the availability of formal or informal support.

2. Methods

2.1. Choice of Methods. Individual, semistructured interviews were conducted in 2022 with the lead worker or manager for each young adult carers service. This type of interview facilitates in-depth exploration of social phenomena from the perspectives of key informants [26]. Online interviews were undertaken using video-conferencing software (MS Teams), as these provide accessibility when participants are geographically dispersed [27]. A brief survey was used to record participants’ socio-demographic characteristics, notably gender, ethnicity (self-defined), and age range. Documentary analysis was also undertaken of any policies applied by the young adult carers services, but only the interview data is reported here. Ethical approval for the study was obtained from the Open University Human Research Ethics Committee: Reference: 4274/Boyle.

2.2. Sampling and Recruitment. Purposive sampling was used to recruit the organisations and key informants [28]. A sampling frame of young adult carers services in England was devised via a mapping process using the Google search engine. Rather than creating an exhaustive list, we identified a sufficiently varied and geographical spread of carers centres or other voluntary organisations, including those in urban and rural locations and with different types of local authorities. Organisations located in areas of high deprivation and/or with ethnically diverse populations were distinguished using the English Indices of Deprivation 2019 [29]. A list of thirty organisations was produced. Additionally, a national network of organisations providing services to young or young adult carers emailed brief study information to their members, requesting they contact the lead researcher if they were interested in taking part.

A study invitation was emailed to the chief executive or manager of the relevant organisations, requesting their organisation’s involvement. However, two organisations were no longer delivering young adult carers services, and a third service was being decommissioned by the local authority. Otherwise, when a senior staff member agreed to an organisation taking part, they were asked to forward the participant documentation to the lead worker or manager for the young adult carers service. The information sheet explained that we wanted to hear about their assessment and support processes and the key factors that influenced the organisation’s ability to provide transitional support to young adult carers. We assured them that their participation was voluntary and that their personal details and the names of their organisations would be kept confidential. Each employee who agreed to take part completed a consent form, whereupon an interview was arranged.

2.3. Data Collection and Analysis. The interviews were digitally recorded, transcribed, and anonymised. Participants’ names were replaced by pseudonyms. The interview length varied from 39 to 71 minutes. Thematic data analysis was undertaken [30]. An inductive, interpretative approach

ascertained the attention given in assessments to young people's caring preferences, the availability of support, and any subsequent lessening or discontinuation of caring roles. Coding was undertaken iteratively by both authors as fieldwork was being conducted. Preliminary coding by the lead author was reviewed and developed by the second author; final codes were then agreed. The codes derived from all the transcripts were aggregated into themes.

2.4. Sample. Eleven voluntary organisations took part in the study, namely carers centres and charities supporting children and young people. Each organisation provided a young adult carers service, often via a carers centre supporting carers of all ages and/or in combination with a young carers service. The organisations were geographically dispersed across England, including cities and more rural areas. The sample incorporated organisations located within areas of high deprivation. Half of the participants (6 out of 11) indicated that their local populations were mainly White British; the remainder highlighted significant ethnic diversity within their areas. Most of the participants were female (8 out of 11), White British, and had worked in young adult carers services for up to 18 years. The young adult carers were usually assessed at the outset, although the assessment may have been completed over more than one meeting, partly to allow trust to be established. Only one service undertook transition assessments with the young adult carers. Ten services completed adult carers assessments instead or referred the young people to an adult carers service or the local authority to have this assessment. Where the latter occurred, the young adult carers services also conducted their own in-house assessments of the young people's needs.

3. Findings

Three key themes were identified: facilitating voice; constraints on choice; and a lack of available support to facilitate choice. Additional subthemes are shown below.

3.1. Facilitating Voice. The participants were asked if they explored with young adult carers during the assessment processes if they wanted to continue caring after the age of 18. Most of the participants said they addressed this issue with young people, but not necessarily in a direct way.

3.1.1. Young People Encouraged to Be Open. P1 said it was important to establish a rapport with the young person before this question could be posed, given its sensitivity: "...you would frame it in those terms; it just would not be the first thing you ask; it can be clearly articulated when you've established a good rapport." P5's service gave young people the opportunity to articulate if they wanted to continue caring: "So part of our role is pretty much that is to sort of say...are you wanting to continue being a carer, you know, what can we do if you don't not want to continue caring...let's look at what support can be offered to the cared-for (person)." Similarly, P7 said they encouraged young adult carers to be vocal about their wishes, particularly to avoid a crisis. It was notable that the organisational response was

aimed at reducing the young person's caring role, rather than enabling them to relinquish it: "We encourage them to be open with us and say, look, if you feel that you can no longer do your caring role...please don't not let it get to crisis point...let us try and get help for you beforehand, put things in place, and make things easier for you."

3.1.2. Young People had to Raise the Issue. P4 said this topic was usually avoided unless the young people brought it up themselves. P4 explained that giving up the caring role, particularly for young people who wanted to study at university, often necessitated moving out of the family home. However, financial and accommodation barriers made this very difficult: "...I probably wait for them to ask for help with moving out. But even then, there isn't housing; they don't not have the finances; they are not in secure enough work. So I think I wouldn't plant things in their mind that they have not already suggested to me."

3.1.3. Young People Reluctant to Admit They Do Not Want to Continue Caring. A few participants pointed out that it was difficult for young people to admit they no longer wanted to care for their family members. P1 said some young people were reluctant to reveal their true feelings on this issue: "...because you're usually referring to their parent or their sibling. They couldn't in good conscience admit that they didn't want to care for them anymore, even if that was the case." Similarly, P5 said the young adult carers felt conflicted: "So it's not as easy for them to just say, "oh no, I'm not going to care, I'm not going to be a carer anymore" because it's their loved one and they want to be there for them; they want to support them. So I think for them it's a real conflict..." Indeed, P11 said some young adult carers require emotional support to overcome the sense of guilt that can result: "I'll do some soft touch counselling type thing about, you know, it's OK if you're feeling guilty about that...if you need to step away for two years, that is fine; you know, it's not a given that you're doing this for the rest of your life."

Hence, this was a very delicate and challenging issue for participants to explore, particularly when young people were unwilling to admit they did not want to continue caring. As the young adult carers often felt guilty about wanting to give up the role, making this choice clearly placed them in a moral bind [5]. The participants were anxious to avoid a crisis situation. Similarly, adult carers frequently seek support at a time of crisis, but a White Paper on planned reforms to adult social care in England has stressed the need for early intervention to prevent crises occurring [31]. It was noteworthy that organisational interventions in our study were primarily limited to reducing the young person's caring role, rather than replacing it.

3.2. Constraints on Choice

3.2.1. No Real Choice over Caring. Some participants stressed that most young adult carers do not have the choice of giving up the caring role, suggesting this was a futile exercise. P1 said: "Sometimes questions like that can be,

they've got to be framed, because most of the time they do not have a choice and they're not going to have a choice." Similarly, P3 said young people themselves were aware they did not have a real choice when there was no-one else to take over the caring role and services were unavailable, placing them in a quandary: "...you want to talk about the right to say no, you want to talk about you have a right to have the opportunities like every young person does, but in reality they know—"but if I do not do that then nobody else will, and so what choice have I got, I don't have a choice." P9's comment indicated that asking the question led to young people revealing when they desperately wanted to be relieved of the caring role but also made evident when their choice could not be facilitated: "But in those instances where it's "no" and they're really desperate and they do not want to (continue caring) and they'll do anything to stop, it's tough because there's no choice anyway."

3.2.2. Families May Expect Young Adults to Continue Caring. The participants reported that the young adult carers were primarily female. P9 explained there was an expectation within families that caring was a young woman's duty: "...there is an expectation on them, particularly as females, to be kind of caregivers, and so they don't have an excuse." P4 said families from key ethnic communities expected young women to continue caring, creating another barrier to their freedom of choice: "...we've had conversations with young people about what if we were able to find somebody, and they've just gone, "Do you know what, it's just easier if I do it, because culturally I'm the daughter in this family." Similarly, P1 said there was a clear expectation in South Asian communities that young women—including daughters-in-law—should take on the caring responsibilities: "...when we get carers from, particularly the Bengali community, there is also a lot of family pressure...the expectation of the female member of that household to be doing all the care."

3.2.3. Caring Role Falls to Other Siblings. Two participants pointed out that giving up the caring role frequently meant this duty fell to siblings. Consequently, P3 said young adult carers felt torn about pursuing their own life goals, such as higher education: "...they leave maybe to go to university, but they know that that means their next sibling down is the one that's going to take on the responsibilities..." The youngest sibling in a family was therefore very constrained: "So often if you're the youngest sibling, that's when you get stuck because there's nobody to replace you once you move out" (P4).

3.2.4. Social Care System Expects Young Adult Carers to Continue Caring. P3 said the social care system assumes that young adult carers will continue caring, with the result that choice is just an ideal: "You're still operating within a system that is still expecting them to take on that caring and is still not necessarily going to provide something...They might still drop out of university because there's still not enough support in place for their family."

Therefore, the young adult carers services sought to promote young people's voices with regards to caring in adulthood. However, socio-cultural norms requiring women to be carers—especially in ethnically diverse communities—were a clear constraint on their personal agency. Similarly, a study of Bangladeshi adult carers in England found traditional gender role expectations were pervasive [32]. The government's planned reforms to adult social care in England emphasise that carers have to be given a choice over caring [31]. To date, however, this rhetoric has been unmatched by the necessary provisions to facilitate choice—discussed below (see also [24]).

3.3. Lack of Available Support to Facilitate Choice

3.3.1. Statutory Provision. Most of the participants said it was very difficult, if not impossible, to access services from local authorities that would reduce young people's caring responsibilities or enable them to give up the caring role. P2 said the statutory body only provided support when the young adult carer was in crisis: "...adult social care services, they're very stretched...And if we're saying this carer is at breaking point, there can be some intervention; if we're just saying this carer just wants to take a break, it doesn't get looked on as favourably." Similarly, P9 said their local authority lacked the funding to provide services, unless the young person no longer had the physical ability to care: "Like if a young person is physically able to care, then unless they have had a literal breakdown where they cannot get out of bed and they're completely screwed, then they will be required to carry on...because the local authority just doesn't have the funding to provide it." Two participants said the thresholds for accessing statutory support had significantly increased, reducing eligibility. Moreover, it was extremely challenging to obtain local authority support to replace full-time care. As P1 said: "...frustratingly, that's virtually impossible...because it's a 24-hour caring role that no local authority on earth is going to pay for." A few participants said that even when it was feasible to access care via the local authority, this was minimal. P11 said: "...you say right, we'll try and get a care package, and they're offered one visit a day."

3.3.2. Services within Voluntary Organisations. In some cases, the voluntary organisations provided a service that relieved the young adult carer of the caring role for a very short period. P10's organisation offered a sitting service for a couple of hours weekly: "The sitting service can then provide this amount of time per week where the carer then does not have to do that two hours a week..."

3.3.3. Families May Refuse Services Offered. Even when it was feasible for a local authority to arrange support, the families sometimes refused the services offered, particularly if they were required to make a financial contribution. P10 said: "...that care package might have been put together but then declined because the cared-for person felt that their

contribution was too much.” It should be noted that poverty is higher among young carers (up to 19 years old) than their non-caring counterparts [33]. Additionally, the services were refused if the family did not want strangers providing care, leaving the young adult carer with no option but to continue caring. P10 explained: “for some families, even if they may be eligible for that and may be able to get fully funded for x amount of hours. . . they don’t maybe want someone else to be caring for them.” Similarly, previous research showed there can be a cultural preference for receiving care from young family members rather than strangers [12].

3.3.4. Family Members May Be Unavailable or Unwilling to Care. A few participants said there was often little or no support available from adult family members. P5 said family support was only available on an ad-hoc basis: “I think sometimes it is looking at family and those other support networks that are around them, you know, is there anyone else that might be able to help out a little bit more and identifying those people that could step in for them.” However, P1 pointed out that young adult carers were often isolated or had families who were unwilling to provide support: “I have worked with people where they have family living in the same block, the same residential block, who won’t come and visit, ask them how they are, lend support, because they just do not want to be involved with the caring in that way.” P6 said family members may assume that young adult carers will continue caring, perhaps to avoid having to take on this role themselves: “I think sometimes when the role has been something that these young adults have taken responsibility for, sometimes other people have let them continue in that role.”

Young adult carers services therefore struggled to access support via local authorities to enable young people to give up the caring role. The parliamentary Health and Social Care Committee reported that underfunding of local authorities in England has necessitated stringent cutbacks to social care services [34]. Although the government has pledged an additional 3.6 billion pounds per year between 2022 and 2025 to reform social care in England [31], it has been estimated that at least 7 billion pounds are required annually simply to meet current demand [34]. A consequence of the underinvestment in social care provision in England is that freedom of choice for young adult carers is illusory.

4. Discussion

The desire to give young adult carers a choice over the caring role reflects an ongoing shift towards empowering service users and carers, in order to improve their wellbeing [17]. By promoting their caring preferences, the Care Act has contributed to young people’s empowerment. Accordingly, the majority of the young adult carers services gave young people the opportunity to express their voice on this issue. Indeed, having a voice and engaging actively in decision-making are key dimensions of young people’s agency [35]. However, as there were a number of barriers to expressing

and facilitating choice, the participants were reluctant to address the issue directly or prematurely with the young people. Notably, they reported that young people were slow to admit their desire to give up the caring role. Women were especially reticent to express this wish, reflecting the prevailing societal norm regarding a feminine obligation to care [5]. Similarly, previous research into the lives of young adult carers in England found they experienced moral conflict between maintaining their caring involvement and pursuing their future aspirations [5]. As young adult carers are primarily women, they face a greater burden in such moral decision-making, but also with regards to the potential impact on their life chances [5, 36]. Although Larkin and Milne [17] suggested that “carers being able to choose to walk away from their caring role” is the key indicator of carer empowerment, even when young adult carers could give up the caring role (which was rare), the participants’ accounts showed they did not do so easily or unthinkingly. They frequently experienced guilt as a result, compounded when siblings acquired these responsibilities instead. Although previous research has highlighted young adult carers who are caring for siblings [12], there has been little attention given to when the latter have to take on the caring role, for example, when an older sibling attends university.

Even when the young adult carers were able to express a wish to give up the caring role, the majority of them did not have an authentic choice. The services were rarely available from local authorities to enable them to set aside their caring responsibilities, particularly if this involved round-the-clock care. It was estimated that an annual increase of up to 12 billion pounds is needed in 2023 and 2024 to address the current funding gap in adult social care [37]. Previous research into the impact of service provision on young adult carers in England found the people they cared for did not receive any services in almost half of the cases. Even when services were received, they were insufficient to reduce young people’s caring roles [24]. Similarly, a study investigating the support given to adult carers following the Care Act showed that local authorities had to manage demand due to the financial pressures they faced, including by diverting people away from statutory services. Notably, services to substitute for the carers’ support were very limited [38]. While the Care Act strengthened adult carers’ rights, the same authors concluded that fiscal constraints within local authorities meant the legislation did not lead to any increase in support for carers [38]. Likewise, our findings suggest that the implementation of the Care Act has enhanced young adult carers’ rights to a voice and choice but not to the support that would make choice a reality.

Young adult carers also faced challenges within their families if they no longer wanted to continue caring. Since caring was primarily young women’s duty, even when families were offered services, these could be refused, leaving the former with no option but to continue caring. This was particularly evident in key ethnic groups, such as South Asians. Similarly, a survey of adult carers in Britain found that belief in familism—a familial obligation to provide care—was significantly higher among British South-Asian carers than their white British counterparts [39]. In addition,

research in Norway showed that older Pakistani people had strong beliefs about filial piety, whereby they expected younger female relatives to care for them, and the latter felt they had to conform [40]. Although the Care Act seeks to empower young adult carers, this empowerment is also constrained by socio-cultural norms. As young adult carers—predominantly women—are frequently obliged to continue caring as adults, the social reproduction of female care is perpetuated across the life course [41].

4.1. Limitations of Study. As this was a qualitative study consisting of eleven services, the sample is not representative of all young adult carers services in England. However, it should be noted that these services are patchy nationally and much less common than young carers services [23]. The research focused on key locations where young adult carers services were provided; support for this group is likely to be poorer in areas where such services are unavailable. As the experiences of young adult carers were reported indirectly by staff, future research should explore their experiences first hand.

5. Conclusions

The Care Act 2014 endorsed young adult carers' right to a choice over caring in adulthood, contributing to their empowerment. Accordingly, the majority of the young adult carers services gave young people the opportunity to express their voice on this issue. However, it appeared that young adult carers, particularly women, were reluctant to admit their desire to give up the caring role. Within the UK and internationally, women are more likely to be carers and to be caring intensively [42–44]. Yet, underfunding of social care in England has led to a further shift in responsibility for supporting ill and disabled people to carers, including young adult carers (see [45]). Since the legislative aim to provide choice to young adult carers was not matched by the necessary service provision to facilitate their preferences, they have ultimately been disempowered. However, a gender-blind legal and policy framework has rendered invisible the disproportionate impact on young women.

There had been plans to establish an All-Party Parliamentary Group for Young Carers and Young Adult Carers [45], which would have focused political attention on young people in caring roles, but this has not materialised. Such parliamentary scrutiny is necessary to examine the implementation of the Care Act 2014 and identify where this has failed, in part, due to insufficient funding and service provision. Leu et al. [46] suggested that the UK has a long tradition of promoting children's and carers' legal rights, compared to other European nations. However, the social care system in England too readily transitions young adult carers into adult caring roles, rather than enabling them to pursue alternative futures [47]. The state relies on carers and has ostensibly made a commitment to supporting them, yet the overarching objective of the Care Act was to reduce the use of formal care [31, 48, 49]. This recourse to statutory support has been reduced, but at a significant cost to carers.

Mobilising young adult carers into adult caring is likely to reduce their life chances, especially young women's opportunities. A new national carers strategy is urgently required in England to ensure that young people have a credible choice over their future lives.

Data Availability

The qualitative data used to support the findings of this study have not been made available because the participants have not given consent for data-sharing.

Additional Points

What is known about this topic: Many young adult carers provide high levels of care. Their caring role is acquired rather than negotiated. What this paper adds: Young adult carers services promote young people's voice and choice. Young people face barriers if they do not wish to continue caring as adults. There is a lack of statutory support to facilitate this preference.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

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