What can the experiences of young adult carers tell us about what can make services more helpful for them and their families?

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Published online: 25 Jun 2021.

Routledge
Taylor & Francis Group

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ABSTRACT

Young adults who provide unpaid care for older relatives have poorer outcomes than their peers in education, employment, health and wellbeing. Services that can potentially have a positive impact on their lives include services provided to the person they care for. However, survey research in England has indicated that receipt of such services is not necessarily linked to fewer negative consequences for young adult carers. We conducted in-depth interviews with fourteen young adult carers who had responded to the original survey. We explored their experiences with services for the care recipient and what factors limit or enhance the usefulness of those services. We found three interrelated themes. First, difficulties accessing services can add to stress, and make problems harder to address when services are implemented; second, lack of continuity of services, and practitioners, undermines relationships and future trust in services, whereas consistent relationships are beneficial. Third, young adult carers described the benefits that resulted from their being involved in discussions and decisions about services, and the problems when this does not happen. The wellbeing of the young adult carer and the person receiving care are shown to be inextricably interrelated; we draw out implications for efforts to improve services.

Introduction

There has been growing research and policy concern about children and young people who provide unpaid care over the past few years. Whilst this has been seen in a number of countries worldwide, some countries have focused more on this topic than others (Leu and Becker 2017). In the UK, research on young carers was largely initiated by the pioneering work of Becker and of Aldridge (Aldridge and Becker 1993; Becker and Becker 2008) and has expanded greatly since then, although much less so in terms of research about young adults who provide care (Joseph et al. 2020). Growing research and policy interest has been boosted by campaigning work by young carers and young

carer organisations, informed and motivated by growing evidence on the extent of young caring and the wide-ranging negative impacts on young people (Olsen 2006; Aldridge 2018). There has been an accompanying generally high level of media interest. Whilst relatively new, some commentators have sought to draw parallels with other, historical, transformations of childhood (Olsen 2006). As some researchers, support organisations and young carers themselves have pointed out, there can be downsides to this increased attention on young carers, such as the promotion of the needs of one group of vulnerable children over other groups who may have equal or greater need of support (Aldridge 2018) and/or taking attention away from the failures of the state to provide adequate care to disabled people with disabilities. Adequate services for the person with care needs have been seen as a possible solution (Olsen 2006).

Young adult carers, generally defined in the literature as aged 16–25, have poorer outcomes than their peers in terms of their education, employment, mental health and wellbeing (Office for National Statistics 2013; National Union of Students 2014; Brimblecombe, Knapp, et al. 2020). Our previous survey research, for example, found 41% of young adult carers had symptoms of anxiety and depression (Brimblecombe, Stevens, et al. 2020). Young adult carers struggle to cope in higher education (Carers Trust 2014). They are also less likely to continue into further or higher education than other young people (Yeandle and Buckner 2007). If they do, they are four times more likely to drop out of higher education than others and are recognised as an under-represented and disadvantaged group in the National Strategy for Access and Student Success in Higher Education in the UK (Sempik and Becker 2014).

The services which can potentially impact on the lives and wellbeing of young adult carers include services directed at the young person themselves, but also services for the person they care for, the main focus of the study described in this paper. In the absence of adequate formal care provision, young adult carers undertake tasks which are usually associated with trained professionals; often to an extent which contributes to negative impacts on the young person (Joseph et al. 2020). The Care Act (2014) in England not only stipulates that the impact of caring by young people on their wellbeing and personal development (including health, education and employment) be considered, but also that assessments must consider whether young people's needs can best be met through provision of services *for the person they care for*. This is often termed 'replacement care'. Purcal and colleagues' framework of how young carers can be supported sets out three main groupings of aims of support services (Purcal et al. 2012). First, to assist the young people in their caring role; second, to mitigate the care-giving responsibility; third to prevent the commencement or entrenchment of a young person's care-giving role. The provision of services to the cared-for person can particularly contribute to addressing the latter two aims.

Our previous survey research, however, found that young adult carers continued to be negatively affected by their caring role (in terms of their education, employment and wellbeing) in cases where formal services were being received (Brimblecombe, Stevens, et al. 2020). This finding seemed to contrast with research with older carers, where receipt of services for the person with care needs is associated with better employment and wellbeing outcomes for the carer (Rand and Malley 2014; Geyer and Korfhage 2015; Haberkern, Schmid, and Szydlik 2015; Pickard et al. 2015; Van den Broek and Grundy 2018). We decided to interview a subsample of respondents to our survey up to one year

later, to explore their experiences of the usefulness of services involved with their families, how services help, and what prevents support from services having more impact.

As English local authorities struggle with continuing demands on limited budgets (Lloyd et al. 2019), this paper seeks to look beyond the issues of insufficient services being received, and carers not contacting services, to consider factors which limit the usefulness of the services which *are* being received, or where young people *have* sought help. The hope is to inform efforts to improve the benefit received from available resources. Drawing on the experiences of young adult carers, the aim of the paper is to consider what can get in the way of services being helpful.

Methods

We conducted qualitative in-depth interviews with a sample of young adult carers to investigate their experiences with services being received by the person with care needs. The sample was drawn from a survey conducted previously and described elsewhere (Brimblecombe, Stevens, et al. 2020). The qualitative interview study explored questions raised by the survey findings about why receipt of services was not always linked to improved outcomes for the young adult carer. Following up survey results up to one year later contributed a rare longitudinal element to the data, enhancing the capacity of the interviews to capture experiences over time.

Sample

The survey of young carers carried out in 2017 was aimed at young people living in England age 16–25 who responded yes to the following question:

> 'Do you look after, or give any help or support to family members, friends, neighbours or others because of long-term physical or mental ill health/disability; problems with drugs or alcohol; problems related to old age? Do not count anything you do as part of your paid employment'.

A final question in the survey asked respondents whether they would be interested in taking part in further research and to provide contact details if so. Of those, we invited individuals who met the following criteria to take part in an interview: Young people who were providing care for at least ten hours per week, and where some kind of service was being received or was perceived as needed. To represent a mix of situations, we approached potential interviewees by randomly choosing from within three sub-groups of those who had said they would be interested in future research. The number of interviewees contacted was in proportion to the size of each sub-group: (i) those saying the amount of services received was too much or about right (sub-group $n = 27$) (ii) those saying some services were received but more were needed (sub-group $n = 34$) (iii) those saying they needed services but none were received (sub-group $n = 7$). Although potential interviewees had indicated they were willing to be contacted recruitment was difficult because of the time which had elapsed since the original survey and because most people had provided only an email address and were contacted from an email address they did not recognise. Fourteen young people agreed to be interviewed. Although 27% of the survey sample were male, all but one of the fourteen interviewees

were female. Ten out of the fourteen interviewees (71%) were caring for someone with a mental health condition (in many cases coexisting with a physical health condition), compared to 56% of those in the survey sample. Ten care recipients had a physical health condition; other co-occurring conditions included learning disability. Most participants were caring for a mother, while a small number were caring for siblings. Three participants were aged 16–17, five were 18–21 and six were 22–24.

Data collection

Participants chose whether to be interviewed in person or by phone; all except one chose by phone. Interviews were loosely structured around a topic guide, which began by asking about respondents' current caring situation. This information was asked previously, in the survey, along with summary measures of thoughts and feelings about the impact of participants' caring role. Revisiting the same questions up to one year later, with the original responses to hand, facilitated a rich discussion of changing circumstances and changing feelings over time. The interview then explored in depth the involvement of services in families' lives, and perceived impacts on the carer's life. The interviewer prompted where necessary to ask about impacts (both positive and negative) on employment, education, health, wellbeing and any other aspects of their lives, and the reasons for participants' views. Helpful and unhelpful aspects of services were explored. Respondents were asked specifically about whether their own needs appeared to be taken into account by services aimed primarily at supporting the person they cared for. A final question asked participants: 'Is there any particular message you'd like to give to policy-makers, the government, service providers or anyone like that'. The interviews lasted between 30 and 60 minutes.

Data analysis

All interviews were transcribed verbatim and entered into Nvivo (QSR 2015). Transcripts were analysed using a structured thematic analysis approach (Braun and Clarke 2006). Coding was both deductive, with key themes based on the interview topic guide, and inductive, allowing the development of unanticipated themes. Each transcript was initially coded individually based on the questions informing the topic guide, such as: How do young adult carers perceive the effect of social care services or lack of services received by the person with care needs on their employment, education, health, wellbeing and social participation? How do young adult carers perceive the effect of their employment, education, health, wellbeing and social participation needs and situation on access to, and receipt of, social care services for the person with care needs? What are young carers' experiences of the facilitators and barriers to accessing/receiving social care services for the person with care needs? However, codes were also developed in response to the data, so that an additional set of themes emerged. When new codes were added, previously coded transcripts were revisited to consider the relevance of the new code. Codes were adjusted as the analysis proceeded, with some codes gathered together while others were divided or had sub-codes added.

Once the coding scheme reached a point that seemed that it could be logically and consistently applied, a second coder tested the scheme by applying it to a number of

transcripts. Analysis continued across cases, by examining material related to the same code across transcripts; codes were reorganised as needed and developed into themes; counter examples were sought and considered. Candidate themes were discussed between the two coders (the co-authors). Themes were examined and revisited to consider their contribution to the emerging narrative (Braun and Clarke 2006). The key themes highlighted in this paper emerged from the analysis as the most significant factors relating to experiences of services received in the families of these young adult carers.

All participant names in the following account are pseudonyms.

Findings

This section draws out implications of the interview accounts for the role of 'replacement care' services in supporting young adult carers. While the focus of the study was to investigate impacts on carers, these impacts were closely interwoven with impacts on the people they cared for. Positive impacts on the person with care needs were to a large extent shared; the same was true for negative impacts.

Erra noted how the activities she'd been able to access for herself from being a young carer had been good for both her and her mum:

'It made mum happy cos mum says when I'm happy, she's happy … . and she liked how things that she couldn't do with me, I did with them, so I still got to experience that.'

Activities or support that made the care recipient happy had a similar knock-on effect. Lucy's mother saw a counsellor every six weeks and felt that the benefit her mum received from this impacted on her also:

'it has a positive effect [on me] – it makes me happy to see her happy'.

All respondents described examples of stress caused by their caring role, as well as stress caused by worries over money and housing. Where reliable services were provided to the person with care needs (as was reported in the accounts of five young people: Ashley, Erra, Hannah, Maanya and Ruth) they were described as improving carers' own wellbeing by reducing stress levels. Any services that improved care recipients' wellbeing or took care of them with activities, company or therapy that the care recipient was happy to be involved with, appeared to be beneficial to the wellbeing of the young carers.

In the remainder of this findings section, we bring out other key themes related to the role of services in preventing negative impacts on carers' employment, education and health. We focus on themes with implications for how the efficiency and effectiveness of services could be improved, to help make best use of existing, limited, resources.

Accessing services for the care recipient

Interviewees were directly asked about indications that their own needs were being considered in decisions taken by local authorities over levels of formal care needed for the care recipient (as mandated in the 2014 Care Act) and almost none felt this to have been the case. Ashley was eventually an exception, but it took a while for services to

realise she would otherwise be caring for her mother alone, aged 16 at the time. She told us:

> 'I don't feel like social services liaises with mental health or liaise with Young Carers … so when my mum was in hospital I feel like they should have had a multi-agency meeting but instead they kind of dealt with things individually which left gaps in the system … I think they really need to look into who was at home, what they do, what their responsibilities are, and how they can go forward.'

Six interviewees said difficulty accessing services for the care recipient had created additional stress. Processes for accessing services could be lengthy, time-consuming and distressing. Respondents believed delays in getting appropriate services meant that the family's situation worsened, and that earlier support could have been preventative. Sometimes support was not available at the time it was needed and when it became available was no longer needed, but damage to the young carer had sometimes occurred in the meantime (for example, to education or employment prospects). Natasha said:

> 'After going to the doctor's and initiating it, that was fine, but then I found the two years following that horrific, trying to get the diagnosis.'

Natasha took time out of her university education to dedicate time to documenting her mother's condition so that she would have the necessary evidence to access support.

Lack of funding for services was mentioned by eight respondents and sometimes delays in service provision were put down to funding issues, as Freya described:

> 'We tried [to get more services] and they said, sorry – this was about June – we've run out of funding for the year, try again in April … ..in April it will then go to a panel and if he's selected we'll let you know within three months.'

Often young people and those they care for are not aware of available services; but hearing about possible support which is then not provided can be worse, as Freya described:

> 'I think the biggest problem that you have, is you become aware of these services, and then they take it away from you for funding reasons, or that you don't fit into the right box, you're not the right type of disabled – we've had that one … So you know about the services that are not helping you, whereas if you were only in contact with one or two and those one or two are brilliant, you seem supported … Being turned away, for whatever reason, going 'I need help' and being turned away, can really knock a carer back.'

The difficulties caused when services are not provided in a timely manner are highlighted by the positive reports of those who did receive services quickly when needed and described how helpful this had been.

Continuity of services and practitioners

Six respondents referred to problems with turnover of staff in cases where care was or had previously been, provided:

> Erra: 'they rebrand or they get bought out by another company, or they make the cuts, they always change their staff and sometimes it's like you're talking to one person … about everything – you've got to re-explain it.'

Erra's sister added: ' … and then you've got to find somebody new, and you don't want that – the whole world in and out your house. You don't want the whole world knowing all your feelings.'

However, Ashley did not find the range of caring staff who might be visiting her mother a problem. Carers came four times per day and could be any of about ten individuals. Ashley had previously been left without any support for a period and now felt the service was reliable.

Six respondents referred to services for the person they cared for ending while still wanted; some specifically related these problems to their own wellbeing. Jane described how her mother's psychology contacts were stopped, and the resultant deterioration in her mother's health, and the impact on her from trying to provide the support instead. As well as the potential harm done by taking away good services, unreliable or inappropriate services could also cause harm. In Jane's case the regular psychology appointments had been replaced with someone who would come to the house every few weeks:

> Jane: If anything it stresses my mum out more because she'll just turn up at the house when my mum's like only just woken up.
>
> Interviewer: So she comes without an appointment?
>
> Jane. Yeah, she just comes – she just turns up.

Lack of continuity and reliability of services was described as affecting the quality of relationship with the practitioner, and this could have negative impacts on carers' wellbeing, as well as sometimes discouraging care recipients from accepting external care services at all. In some cases, effective support required a lot of attention to relationship-building particularly in cases of severe mental illness. Care recipients' resistance to services, or to particular services, created additional stress and burden for the young person.

Although Jane wanted help from care services, she described how it could be more trouble than it was worth:

> 'Sometimes just for the benefit of my mum it's easier to not have them involved, cos it would just cause too many issues'

Where trust had not developed, a practitioner's visits could be experienced as harmful. Hannah reported:

> 'She really didn't like him. So that would make her worse. Funnily enough though, when he had left, she was alright, because obviously all that stress had gone, but it would have been nicer not to have had all the stress.'

Hannah had had a contrasting experience with a person both she and her mother loved, who they felt had made a real difference to them.
And Isabel noted about her mother:

> 'Every time we get so much support in place, these voices in her head, that the people who are there to help her are trying to kill her. And it's just an absolute nightmare trying to get anything in place where she will cooperate.'

Evidently, not only continuity but also the characteristics, skills, sensitivity and behaviours of practitioners, including reliability and punctuality, were seen as important in creating beneficial relationships. Good relationships reduced stress:

> Maanya: 'It's been really, really good. Well, one of them is a lovely woman … who we know quite well, and she is absolutely wonderful and she's so good at her job, and she's so kind to him, and she's so kind to us.'

This close relationship had been important when the practitioner supported the family in finding the right person to be a befriender for her brother. Maanya said that other people often felt they did not have a choice and that they had to take the befriender offered or get none.

Involving the young adult carer in service provision

A common, and complicated, theme was the degree to which service providers involved the young adult carer interviewees in decisions and discussions about care provision and the young people's feelings about this. The theme speaks to both the previous themes, as the young people on occasion struggled to be taken seriously when seeking support for the care recipient (accessing services) and could also be excluded from information, and from having their views sought, about what services were getting involved/stopping involvement. Conversely, interviewees valued practitioners who included them and appreciated and acknowledged their role. Interviewees wanted to be listened to and included in decisions about the care recipient's care and where this did not happen it added to stress, partly because carers can be in possession of facts which services are not acting on. Where care recipients are themselves resistant to service use, excluding the view of the young person creates additional difficulties.

Cleo was a carer for both her mother and sister and all three had therapeutic input from the same team. Although confidentiality was respected, she felt it was important the service was aware of the extent of her caring and understood her need to be involved, and to attend care planning appointments with her family members:

> 'I'm the one who understands it all, I needed to be there or it would be pointless having an appointment'.

Several interviewees expressed a desire to be included in discussions around service provision, diagnoses and prognosis. Young adult carers may be experts on their relative's condition, so not involving them or taking their views into account can undermine service effectiveness. Natasha's message for policy and practice was:

> 'You need to consider more people and more opinions, and the people that are close to them, because it might be that one person is unaware of what they're looking for with someone with [that condition], or what symptoms to look for.'

Despite the young adult carers having so much involvement in the care recipients' care, services could sometimes be excluding. Jane, aged 18 at the time of interview, was asked whether crisis teams tried to involve her when they came to help her mother:

> 'No, it's always 'Get out of the way – we need to talk to your mum.'

She had similar experiences with regular services, and understood that they needed to focus on her mum's needs, but felt more could have been achieved if they had involved her:

'I get where they're coming from but it would be nice to sort of – you know, if there's anything that we need to know, rather than just focusing it all on my mum.'

Isabel, as a 16-year old carer in a family with an adult care recipient and young children [her siblings], felt that social services actively undermined family wellbeing through segregating them and not treating them as a mutually supportive unit:

'We had a family support worker as well, and it's like because I was over sixteen at the time, they went, no, we don't want you involved in any of it, you can go away. So, every time they came around I had to go and sit outside of my own house. I wasn't even allowed in the house because I could hear what they were talking about … I was left feeling like I was just the servant.'

Not being involved could impact negatively on carers' health and wellbeing as they struggled to know how best to support the care recipient and what to expect. Jane, when asked whether there was any other support she would like, wanted to be better informed about how she could help her mother:

'Even if I'm not able to go to an appointment – having leaflets or something for me to help me with any conditions that my mum has, or anything like that, because otherwise I'm literally in the dark.'

Jane's messages to policy and practice included:

'They need to be more aware that just because they're dealing with a direct patient, there's still a circle of people who are affected by every decision that's made by professionals … especially if medications change, cos they're going to have different symptoms or different outlooks on things, like mentally … . everyone needs to then be made aware of that, rather than people are going to assume that everything's still okay and suddenly something snaps.'

Interviewees valued being invited to be involved in consultations, and to ask questions. Daphne appreciated being able to:

'talk, and asking questions about services and what they offer and how she [her mother] could go about things'

They wanted to be taken seriously and recognised as a carer:

Isabel: 'They just say, ah no, we just have the one [identified carer]. And we're like, but that's not true because I'm just as much of a carer as my dad is.'

These young people often recognise themselves to be an expert on the care recipient's needs, sometimes perceiving themselves more so than the care recipient, particularly where there were mental health issues. Hannah finally uncovered that her mother, who had a mental health condition, did not like the carer who visited her, but felt frustrated that the service would not take action without hearing her mother's reasons, which her mother was not willing to speak about.

Difficulties over being involved, being heard or having their views taking seriously were particularly acute when the care recipient did not want the service or was reluctant.

This could be a very lonely situation for the young carer, especially if other family members also disagree about the need for external support. Of our sample of fourteen, eight carers perceived the person they cared for as being either in denial about their needs or resistant to services' involvement.

Natasha felt very strongly that help was not put in place until long after it was needed because she was not listened to, and that citing confidentiality enabled services not to respond to her requests for help:

> 'I put at the end of the letter to the psychologist, in the centre that I handed it into, that I – the line was, I'm begging you to do something to help me, because I don't know what else I can do … you're telling me it's confidential and my mum's got her own mindset and whatever, but I'm telling you though things are not right.'

Some practitioners did take into account the wider family's wellbeing in considering needs, and how they could best be met. Ashley, for example, reported that she now trusted that her mother's care workers would keep her informed and let her know if there were any problems, which gave her the peace of mind she needed to hold down a job. Maanya reported that her brother's social worker took account of the whole family's needs and signposted her to mental health services for her own needs. Lucy attended one in every four of her mother's counselling sessions and was included in the sessions, her own wellbeing was asked about as well as her views on how her mum was doing. Interestingly, Lucy had originally responded in the survey that her mum needed more support but at the interview she was happy with the support received. When questioned about this Lucy reported that they had all agreed an increase in the frequency of counselling sessions and that she and the therapist felt this change had been beneficial.

Freya reported that her GP issued a 'family prescription', which took into account the whole family's needs in relation to their responsibilities caring for Freya's adult brother. This had led to support for the brother's other unpaid carers: a sports camp break for Freya's sister and driving lessons for their mother so that she could drive him to appointments. Such an enlightened approach, listening to young carers' views about what was important to the family, could meet needs that might otherwise not be recognised. Isabel and her mother, conversely, lost transport and support that had provided her mother with some independence and enabled them both to attend a musical activity which had been important to them, with negative consequences for the family.

Eight of the young carers described wanting quite 'low level' help for their relative, such as someone to provide company and/or enable their relative to participate in activities or just to get out of the house. When these were received (mentions included education, employment, voluntary work, classes and groups) the care recipient was happier, making things better for everyone:

> Tom said: I used to love the idea of, if we ever had the finances, to hire like a life coach to come in and encourage her to get up and to get ready and at least just go out and walk the dogs, you know, cos then she's done an activity and she's got up and committed to something rather than you know, just sitting around and sort of staying in her pyjamas and feeling depressed and low.'

Access to activities was valued, and Hannah felt that in the case of her mum's art therapy group it was the activity and social parts which were the most beneficial.

Services for the young person

While interviewees wanted to be involved and informed in care decisions for their relative, they often reported that their own needs were not considered in these conversations. Ruth did answer yes when asked whether services had taken her own needs into account, and was happy with the level of support for their family. She had been usefully referred to a young carers group. Other interviewees had on occasion been signposted to help for their own needs as shown above.

Isabel described how she'd been asked what help she could provide, but not whether she needed help herself:

> 'When we've had social services involved and whatever, I've not really spoke about me, I've spoke about what I can do to support my mum. So, it's not my needs, it's what I can do to help my mum and things like that, so it's like I've – and it's took a long time for me to realise, but I've just realised, even though everyone at work's always telling me, I don't actually put myself first.'

By the time of interview, all except one respondent had some connection with young carers organisations (reflecting the sources of our sample). However, many referred to having spent years as carers before being made aware, either that they were carers, or of the existence of these organisations. Other barriers to accessing such support existed: Hannah resisted becoming involved because of a desire to show they did not need help, while Tom had not joined when younger because of his mother's desire not to be identified as someone needing caring from her child for her mental health condition.

Despite such reservations, respondents had eventually received valued support via young carers and young adult carers organisations. Erra's message to policy-makers was to keep groups for carers running:

> 'There's loads of people that care for their parents and stuff, and they need that escapism. And when it's not there … there's nowhere to go cos when you leave the house you're sort of worried and things like that, and then there's like finances – some people can't afford to go out, go to the cinema or treat themselves sometimes. So it was nice that there was a carers group that could help people like me. It was good, while it lasted, but I don't know why it ended. Oh! It was pretty annoying. So hopefully one day it will be back.'

Many spoke about the value of the social opportunities and activities the young carers groups provided:

> 'It meant that you could pretend like that wasn't you and you could go somewhere else and you didn't have to think about it, cos it's alright talking about how difficult it is but sometimes you just want to – you know, forget it's a thing.'

Others noted the importance of knowing about, and meeting, others in similar situations.

Maanya wanted to highlight to policy and practice that not everyone was able to fight for services as her family had done (as had several other interviews including Ashley, Natasha and Cleo):

> 'People are dying here … it's death by services being missed or having to apply for help you don't really need to get help you need later, or … if you have to cut funding – and I know that funding must be cut – then at least be honest about it, at least say we're shutting this service down, don't say "we're turning it into a hub".'

Respondents reported the effects of services closing and we also heard about the closure of groups following the end of the data collection period. One interviewee's message for policy-makers was:

> 'Young carers are saving them billions of pounds a year. When are they going to wake up and realise that we need that support in place?.. there's money that can be used for social care a lot better and carers need a lot more support if they're going to be fit enough and not have to rely on the NHS when they're too ill to care for the people.'

Twelve interviewees mentioned financial difficulties and more funding was urged both for care recipients and to support carers, including fewer restrictions and more generosity in carers' allowances and grants.

Discussion

We have drawn on in-depth conversations with young adult carers to investigate their experiences with, or trying to get, services for the person for whom they are providing care. Our analyses of young people's accounts of both positive and more negative experiences can potentially inform service improvements. We have drawn out three interrelated themes in relation to services for the care recipient. One is difficulties with processes of accessing services, and how these can add to stress, meaning that problems can be harder to address when services are implemented. A second is continuity of services and practitioner turnover: continuity supports the development of relationships which can lead to more effective services. Third, there are perceived benefits of involving young adult carers in discussions and decisions about services, and problems when this does not happen.

The wellbeing of the young adult carer and the person receiving care are inextricably interrelated. While this seems obvious, framing of carer and cared-for relationships have sometimes been seen as going too far in separating the needs of each and the ways in which these might conflict; parents can feel they are portrayed as dependent or inadequate, and a threat to their children (Newman 2002), while Olsen called for greater sociological understanding of how the term young carer is a social construction which can problematise childhood (Olsen 2006; Joseph et al. 2020). The provision in the 2014 Care Act for replacement care specifically to support carers' needs goes some way towards at least recognising this interrelationship.

We saw that trying to discover available services was difficult, access to such services seemed sometimes arbitrary, and it was painful and damaging when requests for help were declined. The position of Joseph and colleagues, who have reviewed the international literature and policy on young and young adult carers, is that 'the first aim of policy towards this issue should always be to provide support for families such that young people do not have to take on roles that are disruptive to their own development, functioning, and education' (Joseph et al. 2020). While there are few studies of impact on young adult carers of formal care services, one qualitative study showed that where

families received good quality and reliable support and services this reduced young people's caring roles (Dearden and Becker 2000). Our study, however, showed examples, where the struggle to access services for the person being cared for, was itself so time-consuming and distressing that the young adult's education and wellbeing were directly affected.

Intervention was sometimes described as being more trouble than it was worth, particularly in relation to care recipients with mental health problems, causing distress rather than helping. High staff turnover played a role here, although it was also noted that *service* consistency could sometimes make up for visits coming from a variety of individuals. Research in Australia has pointed to the differential impact of mental health caring (Diminic et al. 2018), and the experiences of young carers of parents with mental health conditions have been explored qualitatively (Aldridge 2006), as well as the perceptions of professionals, which found that these young carers are a comparatively invisible group (Cornes et al. 2018). It has been suggested that greater shame and stigma is experienced by young carers of adults with mental health conditions than, for example, cancer patients (Rose and Cohen 2010) and that those parents are often perceived as a greater risk to their child (Aldridge 2006). Our findings suggest that inconsistency or inappropriateness of mental health services are exacerbating difficulties for young people providing care in these situations.

While the themes have relevance to all age groups of carers there are particular resonances for young adult carers; their youth can contribute to misunderstanding and even undermining of their role and their life stage can mean the effects are particularly harmful. Our participants wanted to both give and receive information. Sometimes they felt their insights were not taken advantage of, while at other times they wanted advice on how they themselves could provide better care for their relative. Joseph and colleagues point out the tensions around training (in care provision) for young adult carers (Joseph et al. 2020); this is rarely received and sometimes not welcomed by the young person, if there is a desire for secrecy, embarrassment, or fear of unwanted intervention (Moore and McArthur 2007). While Joseph and colleagues believe training for caring roles should be provided they also warn of possible 'normalisation' of high levels of caring: confidentiality, privacy and choice need to be considered in policy development and service provision (Joseph et al. 2020).

Addressing the two issues of taking account of the views of young adult carers, and offering training and advice where wanted could make services more effective and efficient. However, young adult carers also need to have their own needs addressed; respondents often downplayed their own needs or took time to realise their importance. Even then their own wellbeing was sometimes conceptualised in terms of the benefit to their families. Reluctance on the part of the care recipient to involve their child in services considerations, and social workers' concerns around confidentiality, dignity and respecting the views of the person with care needs, means this is a complicated and sensitive area.

The importance of relationships unites the themes and individual stories presented here. All the themes, and all the experiences described, show the importance, and challenges, for practitioners, of building constructive relationships with whole families, and the barriers faced by young adults trying to take their place in those relationships. Practitioners, from any service, need support and recognition for addressing these challenges.

While some of the issues can be addressed through greater awareness and sensitivity among service providers, others cannot be separated from resourcing issues. Staff turnover in the care sector is high (SCIE 2013; National Audit Office 2018). The impacts of staff turnover and lack of service connectedness leading to poor relationships and the need to be continually re-telling your story have been noted elsewhere in relation to other groups of vulnerable users, and potential users, of services (Stevens 2018). Careworkers' working conditions can have a direct impact on service quality, as well as on careworkers themselves (Colombo et al. 2011). Challenging work needs skilled, respected and properly remunerated workers.

The welcome recognition in the UK Children and Families Act and the Care Act of 2014 of the needs and rights of young carers came at the same time as both a growing level of need for adult social care and government-imposed austerity. A move at the same time towards 'strengths-based approaches' in social care aimed to recognise and utilise the strengths in individuals, those around them, and their communities, to support people's independence, and focus services where most needed. This timing means that 'strengths-based' approaches have been interpreted by some as simply a means to cut local authority budgets by drawing further on the care that family members will provide 'for free' (Slasberg and Beresford 2017). Nevertheless, the themes revealed by our analysis chime with discussions about strengths-based social care and relational activism in social work. Central tenets of both are the importance of working in partnership with service users (or potential service users) and carers, and valuing community resources (Romeo 2018; Dove and Fisher 2019).

Our research concerns the UK context, where there are the policy aims of the Care Act to which we can compare experiences of practice. Research certainly exists from other countries that the level of practical support from healthcare and home-help services is not sufficient to meet the needs of young carers and the people they care for (Moore and McArthur 2007; Joseph et al. 2020), however, we are not aware of research from other countries investigating young adult carers' experiences with services for those they care for. Leu and Becker's assessment and categorisation of different countries' level of awareness of young carers and policy responses found a wide range of policy responses across countries and characterised the UK as relatively advanced (Leu and Becker 2017). If the problems reflected in our key themes exist in a relatively advanced policy context it seems likely that they will also be relevant to other country contexts, where there are lower levels of awareness about young carers, and even less adequate policies.

Taking whole families (and family/community resources) into account, shown to be important, and sometimes damagingly lacking, in our analysis, should help devise appropriate professional support, rather than no support. Support could be preventative and cost-effective by incorporating the 'softer' factors highlighted in participants' accounts, including activities, talking, and 'getting out'. The desire to facilitate activities which are part of normal life for so many was expressed by interviewees both in relation to the care recipient and themselves. Perhaps the effect of all services on the ability to carry out such activities should be considered. Listening to services users and those who care for them can identify, and help facilitate the types of activities which can support their mental health and wellbeing (Foot 2012).

Nearly all our interviewees had some connection with young carers organisations. This is not typical, as our interviewees confirmed, and reflects the fact that the survey was

advertised via these organisations (as well as elsewhere). Many young and young adult carers remain hidden, many of whom are not in touch with support services at all (Smyth, Blaxland, and Cass 2011; The Children's Society 2013). Respondents to the request for interview were often highly motivated individuals who not only wanted to do the best for their family, but also to contribute to improving the lot of other young carers. While the sample is not representative of young adult carers in general, respondents did provide a rich variety of accounts. Some were in regular contact with other young carers and drew on the examples of others in interviews. Some were engaged in trying to change systems. They provided a useful sample for an exploratory analysis aiming to understand impacts and shortcomings of services.

Our other research, has pointed to insufficiency and unavailability of services and the impacts this has on young adult carers (Brimblecombe, Stevens, et al. 2020). However, here we have taken a qualitative approach focussing on other aspects of young adult carers' experiences of the services received by the person they care for. The in-depth qualitative approach lets us explore the experiences behind survey responses, to gain insight into how different characteristics of individuals, or aspects of incidents and situations, are perceived as enhancing or damaging the usefulness of services. The interview format gave participants the opportunity to express their views in detail. The qualitative analysis allowed consideration of unanticipated themes deriving from the young people's key concerns, on the topic of services for the person they care for. Qualitative methods are well suited to allowing the voice of research participants to be heard, and our findings illustrate the importance of this voice in understanding the role of services in supporting young people.

Our findings contribute to evidence that the aims of the Care Act appear yet to be realised; there is more to be done in adjusting attitudes to young adult carers and providing services that meet their needs and enable them to have better life outcomes. Young adult carers described good experiences where they were listened to, their views were considered and practitioners took time to understand their situation. They described the value of consistency of individual practitioner, meaning less need to be re-explaining their story, and consistency of service provision across individuals. Interviewees referred to the loss of helpful services through funding cuts, and the value of support services for young carers, also now cut. As some of our interviewees pointed out, the long hours worked by many young and young adult carers are not paid and therefore represent a substantial saving, or resource, for health and social care services (Leu and Becker 2017; Joseph et al. 2020). Involving young adult carers in practitioners' understanding of family situations, explanations of service options and caring approaches, and decisions about appropriate services, could help both carers and care recipients in getting better value from available resources.

Acknowledgements

Disclosure statement

Funding

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