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Variation in family, specialist project and mainstream service support improves, mitigates and exacerbates the impacts of young carer responsibilities.

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Abstract

Support can moderate the impacts of caring for family members during childhood but, while specialist projects have been found to be beneficial for those with substantial responsibilities, there is limited evidence on how mainstream services can identify and support the larger population. This phenomenological study of the wider spectrum investigated experiences of accessing support over a year-long period. The findings highlight the diversity of the spectrum in terms of family support, care receiver relationships, and motivations for privacy or disclosure. Participants also contrasted the individualised support offered by projects with the lack of engagement and identification by mainstream services.

Keywords: young carers; phenomenology; family; services

Word count: 7902

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Introduction

Three decades of research has explored children's experiences of providing care for family members with illnesses or disabilities. This includes their perceptions of being supported by family, friends, community and services, but also the barriers to recognition and the accessing of assistance. While the traditional research focus, influenced by the challenges of identifying an often hidden and stigmatised population, has been on those who access specialist projects designed primarily for those with substantial responsibilities, a recent narrative review (Joseph et al, 2020) on future directions in research argued for the need to recognise the larger population with diverse responsibilities and lives.

This larger population is the focus of this paper with a young carer defined as any child under the age of 18 who provides some level of regular care to a family member, because of an illness or disability including substance misuse or mental health issues. Recruitment was conducted through schools and specialist projects to ensure representation of the spectrum. This paper reports on the varying levels of privacy, identification and self-disclosure across the sample, and explores their differing experiences of accessing support from multiple sources.

Evaluations of young carer projects

Support for young carers, whether within the family, from friends or neighbours, or from formal services is key, and policy and legislation has sought to improve societal recognition and valuing of the group. The recent Strategy for Unpaid Carers (Welsh Government, 2021) reiterated this, partly in the context of the coronavirus pandemic that resulted in young carers

having increasing responsibility but also the closure of support services, and partly due to an expected increase in future prevalence as people live longer but need more familial support.

The strategy also highlighted a lack of evaluations of services, reinforcing the argument that young carer projects and interventions have increased in number despite little evidence of effectiveness (Purcal et al, 2012). Most evaluations have been of individual settings with Schlarmann et al (2011) finding benefits of opportunities to play, socialise and find out about the caring role. Programmes pairing young carers with a 'buddy' outside the family home have been found to reduce loneliness (Wind and Jorgensen, 2020; Nissen et al, 2022), while evaluations of intensive and immersive activities outside the project setting identified improved emotional literacy from meeting new people and being in nature (Acton and Carter, 2016), social benefits and the development of new coping skills (Cunningham et al, 2017). Evaluations that compare multiple services to better understand why some interventions work better than others are rare, though Phelps (2021) conducted interviews with young carers, family members and project staff from ten projects in the same geographical area. Knowledgeable staff and long-term individualised support were key to the provision of social opportunities and emotional support.

Mainstream support and professional awareness

Awareness of young carers is low among mainstream health, social care and education professionals (Leu et al, 2018, 2020). This includes evidence of healthcare professionals encountering but not formally identifying young carers due to high workload and lack of time (Justin et al, 2022), while a systematic review of young carer access to mental health support (Dharampal and Ani, 2020) found that many are overlooked due to professionals not checking whether patients had children, and that young carer support can be discontinued upon care receiver discharge. Barriers were similar in education with a need for training on identification and the use of better communication to build trust with young carer families (Untas et al, 2022; Warhurst et al, 2022).

Some young carers and young adult carers, particularly those caring for people with Multiple Sclerosis and Huntington's Disease, have significant medical responsibilities including administering medication and using assistive devices (Kavanaugh et al, 2019). These carers

have clear additional needs but, despite the responsibilities being widely recognised as inappropriate, few are trained by medical professionals (Raj et al, 2022). They are instead shown by the care receiver or another family member or friend (Kavanaugh et al, 2015), or self-taught through observation.

Informal support from friends and within the family

A recent realist review of how the impacts of caring vary with individual caring and family circumstances (Janes et al, 2021) highlighted how support from friends can reduce the impact of the caring role (Sharer, 2015), while community recognition can reduce isolation (Andersen, 2012). Family appreciation is particularly key to reducing depression (Kavanaugh, 2014), though a scoping review of young carer's education (Moloney et al, 2023) found that feelings of being held back and guilt from wanting to move on can affect these relationships.

While research has investigated children caring due to family members having other commitments or being unwilling to provide care (Lane et al, 2015; Assaf et al, 2016), knowledge of caring dynamics at a family level is limited (Nagl-Cupal and Hauprich, 2018). Their research with young carers and parents found the presence of an inherent family logic that balances family member contributions towards a central caregiving routine with the needs of the individuals. While maintained in most families, this balance can be upset if the needs of the care-receiver are too high.

This study aims to investigate variation in privacy, self-disclosure and identification amongst a diverse sample of young carers, before exploring how their access of differing support sources influences the impacts of their caring responsibilities. In particular, the research was conducted through schools to recruit young carers who are unknown to services and rarely involved in research, contrasting their experiences of accessing informal support from family and friends with those who access specialist services. The article aims to complement a previous paper on the same sample (Janes, 2022) which explored how the negative and positive impacts of caregiving responsibilities varied across the spectrum.

Materials and methods

The qualitative study used phenomenological methods to understand young carer experiences of accessing support and, more specifically, utilised a Gadamerian methodology for two reasons. First, Gadamer (2004) recognised that the ability of researchers to understand a person's experiences is limited by their own experiences, and instead highlighted the potential for genuine conversation to enable a shared understanding. Second, he was interested in how a person's perception of their experiences evolves over time in the light of changing circumstances. The decision to use a Gadamerian approach informed the methods used, as detailed in this section.

Recruitment

The research set out to identify a sample of young carers representative of the wider spectrum through schools, and is the first qualitative research known to the author to do this. With the sensitive nature of the research and significant stigma and privacy in the population, maintaining confidentiality was key, and a detailed procedure was developed and approved by Cardiff University's School of Social Sciences Research Ethics Committee.

The procedure included a three-stage approach to recruit and interview young carers in the school setting. First, information was disseminated to 20 schools in August 2018, and expanded to an additional 30 in April 2019. Eight schools were recruited, and individual procedures were developed for each in line with their policies and processes to ensure confidentiality. These procedures detailed how a point of contact would liaise with potential participant families while maintaining confidentiality from the wider school, information dissemination, the seeking of parental consent, and the hosting of confidential interviews. Second, school-wide information dissemination, usually through researcher-led assemblies and reinforced with paper information, was used to engage with pupils. Third, seven interested pupils approached their point of contact to request a parent information sheet and consent form. Consent for the opt-in study was received for five children.

The protracted and time-intensive nature of the recruitment resulted in the expansion to include specialist projects. The recruitment process was similar with recruitment of projects

followed by engaging with young carers and seeking consent from families. An additional five participants were recruited.

Participant Information

The participants are summarised in Table 1 with all ten interviewed in the setting they were recruited from. Ages varied from 11 to 16, and duration of caring role ranged from 9 months to 11 years at the time of the first interview. The participants included six females and four males, and three were siblings from the same family. Seven were providing support for their mother at the time of their interviews, and two were supporting a disabled sibling. One participant had been a young carer until their mother's death. All names are pseudonyms.

[Table 1 here]

[Table 2 here]

Table 2 summarises involvement with different support sources. This includes whether the young carer and their family had disclosed their status, been identified, or remained unknown to each source, and there was significant variation in identification beyond the immediate family. In particular, those accessing projects had more likely informed their schools and sought informal support from friends and neighbours. In contrast, those recruited through school were often reliant on informal assistance alone.

Interviews were conducted between March 2019 and August 2020, with six young carers participating in all three interviews. Lyra and Lucy only completed the first interview because of changing family circumstances. The closure of services due to the coronavirus pandemic presented challenges for four interviews; the final interviews with Harry and Patrick were held online, but this was not possible for Thea and Richard.

Phenomenological interviews

Semi-structured interviews up to a maximum of 60 minutes long were held in the respective setting, ensuring a familiar environment. The interviews began with considering assent, and the researcher reintroduced the aims of the project, how the interview would work and the

topics that would be covered. Respondents then signed an informed consent form with them agreeing that they had been told about the research, were happy to be recorded, and knew they could refuse to answer a particular question or stop the whole interview.

The development of topic guides was informed by evidence gaps from a realist review of young carers' mental health and psychosocial wellbeing (Janes et al, 2021). Their first interview sought to gather contextual information relating to the circumstances of the young carer, care receiver and the caring role at the first timepoint. This also included questions relating to self-disclosure of status, identification by services, the accessing of informal and formal support, and how this support helped them manage the caring role. The use of creative methods included a paper template of the young carer and the care receiver, addition space for them to write and draw, and rating scales for support sources. These methods enabled the development of rapport that put participants at ease, and the drawings informed more detailed conversation that improved the researcher's understanding of their experiences.

Transcription of the initial interviews informed planning of subsequent meetings with each participant, enabling increasingly individualised interviews. Second interviews began with a recap of the previous interview and clarity-seeking, and the creative outputs from the previous interview were vital as both memory aids and for discussing change in circumstances. These interviews then focused on health and wellbeing, with participants initially sharing words for how they felt caring affected them, before selecting additional impacts from pre-produced opposing pairs. Next, participants were given an impact triangle (Figure 1) that reflected the three domains of the realist review of young carer health and wellbeing. Chosen impacts were numbered, and participants placed each within the triangle to reflect the extent to which the impact was due to caregiving responsibilities, support, and the young carer identity, with the method again informing further conversation to reach a shared understanding.

[Figure 1 here]

Transcriptions of the second interviews then informed the final interviews which again began with a recap and clarity-seeking. There was then an increased focus on changing health and

wellbeing in the light of evolving caring responsibilities, family circumstances and accessing of support.

Analysis

All first interview transcripts were initially analysed at a whole-text level to identify the fundamental meaning. Nvivo 11 was then used to identify specific themes, code the transcript in detail, and identify sections that demonstrated shared understanding between participants and the researcher. The previous section considers how the interviews utilised drawings, rating scales and impact triangles to inform subsequent conversation, and the analysis included triangulating the different data sources to increase the trustworthiness of the findings.

This was repeated for the second set of interviews, and then the final set. This longitudinal approach ensured that analysis of each participant's later transcripts were informed by their earlier interviews, particularly concerning how change in their outcomes related to their evolving circumstances.

Results

The results section considers how different support sources can influence the positive and negative impacts of caring, beginning with the immediate household. This is followed by a focus on the varying levels of privacy that can influence the decision to inform the wider family, friends and community members and, for those known to specialist projects and mainstream services, their experiences of accessing formal support.

Support and relationships within the family

Eight participants were caring for parents, and there were clear dual dynamics between the carer and the care receiver, and between the parent and child. First, concerning the carer-care receiver relationship, most reported positive relationships and appreciation expressed

through affection, joint activities where 'We always talk, we always do things together, stuff like that' (Sophie, I1) and gratitude.

In terms of the traditional parent – child dynamic, participants recognised that parts of the usual parental role could be limited by illness or disability, but this was not a full reversal with other aspects clearly fulfilled. For example, Kirsty's mother had spina bifida but regularly made dinner and 'my lunch if I was having a packed lunch to school, brush my hair, make sure I was dressed, teeth cleaned, etc' (I2). Her mother's emotional support was also key, as it was for Martin who had recently become a carer due to the onset of his mother's aplastic anaemia. While he had found the responsibilities initially frustrating, open communication and the ability to discuss his difficulties helped to make his role easier:

She's definitely there for emotional support. The first time I went to visit her in hospital we both just sat there and cried, it was when we hadn't seen each other for a week. And she was in hospital, and she said, ever since I was born she's told me that I can talk to her about everything anything... so any time I need to say anything to her, we just have quite an open [conversation].

Martin (I1)

However, the relationship with the care receiver could be affected by their illness or disability, and their subsequent treatment. This was most obvious for Lyra, Thea and Lucy whose mother had bipolar disorder that affected her personality. Her needs were also affected by periods of institutionalisation that resulted in increased support needs following discharge. This had recently happened at the time of Lyra's first interview, and she felt that her medication was affecting her emotions and ability to provide care:

When she was taking the medication I just knew something still wasn't right, she wasn't like how she was... I feel like she still can't look after me how I need to be looked after if that makes sense.

Lyra (I1)

In contrast, Thea's first interview was held several months later, and their mother was making progress including 'getting back into cooking now. She's finally started making her own cup of teas, she's trying to, she's doing little washing, trying to do it on herself' (I1).

Two participants had significant caring responsibilities for a disabled sibling but their relationships were very different. Harry cared for his autistic brother Sean before and after school and felt that 'when I'm at home most of the time I've got to look after him' (Harry, I1). While Sean's verbal communication was limited, he expressed happiness through hugs and kisses and Harry felt appreciated. This was not the case for Patrick who cared for his sister Charlie due to her cerebral palsy. His responsibilities were also managed around the school day, including monitoring her for hours after she went to bed. At the time of his first interview he felt underappreciated due to Charlie being 'quite nasty to me because I didn't do something quick enough... she can be quite loud and aggressive' (I1) but, despite the pandemic indirectly improving the balance between caring, education and social time, their relationship deteriorated further. This was partly due to Charlie's shielding and resulting isolation, though Patrick also became increasingly impatient and angry during lockdown:

She's definitely problematic, because she's obviously not getting the social time from her friends... she thinks she can get away with more with me, because obviously I'm her brother. But that does not happen, because she cannot win.

Patrick (I3)

Family caring units

Support within the wider household was also important, especially in larger families. Family caring units refer to if and how caring responsibilities were organised, proportioned and carried out by different people, and Harry, Patrick and Angela, plus Kirsty at the time that she was a young carer, had two parents in the household. The caring units were clearest in Harry and Patrick's families where constant supervision was needed, and family-level routines were developed that required them having significant responsibilities during the week when their parents had work commitments, but more time at weekends when their parents were at home.

Thea, Lyra and Lucy formed their own family caring unit that had changed over time. This was initially due to Lucy's younger age and her not being 'able to kind of do a lot of the stuff' (Lucy, I1), resulting in responsibilities being shared between Thea and Lyra until Lucy was nine. Age continued to be a factor in who took on which roles:

[Thea] will do... the most responsible... the ironing, so we don't burn ourselves. I'll do the cleaning, washing and the clothes. Lyra will tidy up a lot more, and bring it out onto the line, make sure it's all dry and bring it back, fold it. Then Thea will take it up to the rooms, put it on our beds, then we put it in the drawers.

Lucy (I1)

The caring unit changed again as the research continued and, at the time of Thea's second interview, she was more focused on her GCSE exams than her caring role. While this was partly due to their mother's decreasing needs, Lyra and Lucy were taking 'over the part of me doing, because I'm trying to get the best GCSEs, so I get a nice job when I can' (Thea, I2).

Relatives outside of the home were more important in smaller households. For example, Martin's mother and grandmother had had a difficult relationship but worked to resolve this after realising that he needed support. Both Martin and Richard also benefitted from their mothers having partners who would stay on weekends, and 'I guess that's showing appreciation for what I do because he always helps my mum and gives me a break... I still do have to help her but nowhere as much' (I1).

Sophie's mother had a hearing impairment and diabetes. Her substantial responsibilities included managing her blood sugar levels during the night when they were prone to spiking, but her grandparents would help during emergencies and when Sophie was in school. She had reported how her responsibilities led to increased friendliness, maturity and domestic skills, but also highlighted how the family support and appreciation increased her confidence and boosted the initial benefits of caring further:

If you have to care for someone then you are gonna be quite skilled in how you care for them... I also feel like it's support as well, because if you're not supported by people

you might get really down about it and think that you're really bad at it if something goes wrong, you might think it's your fault even though it isn't.

Sophie (I2)

While most participants were part of successful caring units, the unit in Angela's family was deteriorating. Despite having Multiple Sclerosis, her mother's continuing independence and management of her illness lessened the family caring responsibilities. Angela was able to balance caring with school and social opportunities but was increasingly aware of becoming her mother's main carer. This was partly due to her older brother's increasing independence, but also because her father did not 'do a lot to be honest. He's a bit lazy and he gets frustrated. He doesn't like to do it so I usually end up doing it' (I1). She felt taken 'for granted to be honest...if I wasn't there they'd have to do a way lot more' (I1) and, in these circumstances, support from outside the household became increasingly key to Angela having a break from her responsibilities.

Self-disclosure and identification beyond the family

All participants were known as young carers within the household, though there was variation in awareness beyond this immediate family. Only one participant, Harry, felt that they were truly open about their caring role. Several of his friends were aware of his role and, while he did not receive 'advice from them, it's just so they can listen to like what's going on' (I1). His family had informed his school and he was particularly positive about his local young carer project as 'very supportive to me, because knowing about other people's problems makes me feel like we're all in the same boat' (I3).

Harry's openness and sense of community (Figure 2) contrasted with the privacy that was most extreme in Patrick's family. His family were keen to be self-reliant to the extent that they did not seek the support of relatives beyond the household, preferring to rely 'on ourselves to keep us going because they have their own lives that they should worry about rather than worrying about us' (I1). With the exception of some friends who knew but were

not confided in, he was completely unidentified as a young carer. He also chose not to discuss the challenges of his caring role or his relationship with Charlie with his parents:

[Figure 2 here]

R: Do you talk to your parents?

P: ... No, I don't actually, about her... I just don't feel like there's any need to talk to them about it. Like they know what's going on, so that's like enough.

Patrick (I3)

Patrick's substantial caring responsibilities, combined with the difficult relationship with Charlie and lack of support, resulted in a negative view of his caring as something that marked him as different to 'anyone else who lives the normal life' (I2).

Compared to these extremes, most families sought to balance the need for support with their wish for privacy. They were selective over who they told, with Thea's family needing to inform the school because they were living with their aunt, but choosing to inform a specific project. Thea was however protective of 'myself, mainly my family, my sisters come first... when Lucy first started school, she started getting bullied, so I sorted that straight out, and she hasn't been bullied since' (I2). Thea preferred to develop a relationship over a significant period of time before deciding to confide in the person, but this could give people the wrong impression about her:

I come across as very intimidating. I do have a big mouth... but then when people actually finally get to know me, I'm actually a really nice person, and I'm very open and I care about a lot of people. I was speaking to some girl before and she just joined my school and I scared her when she first joined, because of the way I am. She got to know me...we're good friends now.

Thea (I2)

Martin was also wary due to the previous spreading of false rumours in school about his mother but, over time, he developed a network of informal support. This included a close relationship with Joel, a friend who Martin felt able to be honest to. He was 'my best friend and when something goes wrong I always know that I can talk to him and stuff. Like when me and my mum have an argument ... he's very supportive' (I1). Martin had also developed a close relationship with some neighbours while his mother was in hospital, and they would regularly chat and check how he was doing. However, these informal relationships could be less stable, and Martin spoke of arranging to visit his neighbours and 'they didn't answer the door. I did that for a couple of days... I've seen them a couple of times but we haven't really mentioned it.' (I2). Similarly, his relationship with Joel went through periods of deterioration and improvement:

I've got a very guilty conscience. So when I do something wrong and then, we sort of have an argument... I'm just like I hope we talk again and stuff like that and I just overthink things... it just makes me really down when we're not talking, like me and Joel didn't speak for a week.

Martin (I3)

However, privacy was not the only factor in non-disclosure of status. Sophie reported that 'My mum doesn't want me getting like, a lot of attention for doing these things' (I2), but also highlighted her perceived normality of these daily activities. This was similar for Kirsty who 'didn't really look at it as being a young carer... it was my way of life. As a result it, the way I saw it, it wasn't anything special' (I2).

Access to specialist support

Five participants were attending specialist projects, with the families having disclosed their status in order to access support. Four were members of the same service, while Richard lived in a different area but also had a different motivation which affected his choice of project. In addition to caring for his mother he had autism, and his project offered a chance

to meet other children, with Richard feeling 'it would probably be best if I come here, talk to some more people who actually have few things in common with me, helping their parents out' (I2). The project was independent of the local authority, and the lack of a needs assessment also suited his family's preference for privacy.

The social opportunity was one reason for Harry, Thea, Lyra and Lucy to attend their project that was a partnership between the youth service and social services. Thea particularly appreciated that the project gave her the confidence to 'talk in front of people, to allow myself to actually find out who I am, to hear or talk to... people who have been in similar situations to me, people who have been completely different' (I2). However, the process for joining also included formal assessments of their caring role where:

Our social worker now came in and did an assessment on us, see if we were eligible... We fill out questions like how much do we help out at home, do we like pay for any bills, do we help our carer, the person we care for in the shower... we do it once or twice a year.

Thea (I1)

These assessments enabled additional benefits including individualised support to the child and their family. For example, Thea's mother was prone to accidents and 'had an accident with the kettle, she burnt all her hand. When we first became young carers, we asked could we get a kettle which is more suitable for her and her shakes which we got, thankfully' (I2).

Janes (2022) considers how young carers could benefit from the caring role, with positive impacts including usefulness and happiness from making a difference to a family member's life. Harry and Thea felt their project increased these effects further by increasing their confidence (Figure 3) and giving them a positive outlook on the caring role. They also highlighted the importance of project workers being actively engaged in giving 'the support I need... they actually ask you how's everything at home... they see the value of what we do as a young carer, because they actually talk to us' (Harry, I1). This increased their understanding as 'They know me on a personal level... speaking to me four or five years, so they know my

difficulties, they know me as well. They know me at my good times, they know me at my bad times (Thea, I1).

[Figure 3 here]

Young carer provision in schools

The families of Harry, Thea, Lyra and Lucy had also informed their schools. The schools kept a young carer register but were largely unaware of the details as ‘they don’t really ask us too much... they don’t really know how we help out at home. So they don’t really give any support’ (Harry, I1). Opinions were mixed on whether this was a positive, with Lyra preferring them to have limited knowledge (Figure 4), and to seek support if needed, while Harry and Thea felt that greater knowledge of individual young carer was key to a proactive approach that would encourage engagement with school. Thea also highlighted a school policy for a staff member with responsibility for supporting young carers, but felt the policy was not active (Figure 5).

[Figure 4 here]

[Figure 5 here]

Many preferred instead to seek the support of individual trusted teachers, and Thea would ‘just go in... be like ‘Oh I’ve had a bad day, I’m just going to sit in here’. They never really ask me a question. They ask me how am I, how’s my mum, that’s about it’ (I1). Kirsty had not been known as a carer to her school, but also spoke retrospectively about having ‘a couple of past teachers who... would be rallying round me, giving me that support I needed’ (I1).

Service identification of undisclosed young carers

Many families remain private despite self-disclosure enabling the seeking of support, and mainstream services are increasingly expected to identify them, particularly those with substantial responsibilities who are likely to require assistance. Three participants had been identified by mainstream professionals, including Richard who had been identified by his school and health service as a result of his mother’s past substance misuse and accessing of

mental health support. However, he chose not to access mainstream young carer support, appearing guarded about services knowing further details and if there was 'any reason for them to know? I mean it's ok if they do, just, it won't change anything and I don't really need change, I'm doing well as it is' (I2). Martin had also been recognised while accompanying his mother to a medical appointment. He was offered the opportunity to meet the doctor about her illness but, when he could not attend the meeting on a school day, no further appointment was offered and the opportunity lost.

The third participant, Sophie, had been identified by her mother's diabetic nurse at the time of her first interview as having significant medical responsibilities that included night-time care, operating assisting devices and giving injections. This identification was despite her family's privacy, and the nurse involved her in conversations, demonstrated particular tasks and recognised when something was done well:

If I help her with carb counting... my mum's got this app on her phone that tells her her blood sugars and then I get it as well. She always goes 'Well done for doing that' and stuff, because I often have to, coach my mum in to doing things.

Sophie (I1)

This initial support was a precursor to more substantial family change. A new diabetic pump was installed prior to her second interview, and the nurse had trained them both with her mother getting 'a book as well on how to use it... I read it... then I went with my mum to the nurse's house and she was like explaining everything more' (I2). While there had been some initial equipment problems with poor-quality needles, these initial problems had been resolved by Sophie's final interview, and she reported increasing knowledge and confidence in using the machine (Figure 6).

[Figure 6 here]

The benefits for her mother were extensive with the pump stabilising her blood sugar levels and improving her sleep. This reduced Sophie's night-time responsibilities as, instead of monitoring her until after midnight every night and later if concerned, Sophie was in bed several hours earlier every night. There were also nights where Sophie had 'a full night sleep...

I wake up in the morning less tired' (I3). The pump also replaced the need for inappropriate responsibilities, particularly the administering of injections without medical training.

Gaps in health service support

The remaining participants were regularly accompanying the care receiver to medical appointments. While they had not disclosed their status, they felt that they should have been recognised as young carers and involved in appointments. Kirsty reported attempting to 'speak up, get a grip of what was going on but... for the sole reason that I was under 18 I was just overlooked' (I2), while Patrick felt able to discuss 'What it's like from the day to day... but then you just sit there because they don't ask you (I2).

Participants saw value in being better informed and knowing 'what's going on with him... if I know it I can make changes or... do different things with like what they tell me' (Harry, I1). In the absence of medical training or information, they learnt in alternative ways. Thea had learnt through experience the first time her mother was discharged from hospital, and then felt better prepared when she was hospitalised and discharged again. Others were taught by either the care receiver or another family member, including Kirsty who was shown how to treat absence seizures by her parents. This enabled her to remain calm when 'her eyes would sort of glaze over and the way of getting out of that was just like squeezing her earlobes really tightly... there wasn't pretty much else to it' (I3). This enabled Kirsty to remain 'quite cool about it... if I hadn't had that information, especially the first time that it happened, I would've just had like this great fear instilled in me and may not have been able to do much' (I3).

Richard preferred being informed by his mother who had 'a better way of phrasing things to me' (I2), but there were also risks of being informed by family members. Martin's mother had talked to him extensively about her treatment for aplastic anaemia but he also shared an example of her misunderstanding the limitations of a compromised immune system and what she was able to do. For that reason he preferred 'to see someone who is a professional and knows exactly what's going on than someone who's going through it and doesn't know everything about it' (I3).

Discussion

This phenomenological paper is a follow up to Janes (2022) that explored how the impacts of care vary depending on the circumstances of the individual and suggested a need to tier support to the different parts of the young carer spectrum. This paper, based on the same dataset, set out to report on the varying levels of privacy, identification and self-disclosure across the spectrum, and how this affects the accessing of support from different sources. This support, whether formal or informal, had the potential to mitigate the negative impacts and maximise the benefits of caring responsibilities alone, though poor quality support can also be detrimental.

Many young carers were found to benefit from close relationships with the care receiver, but a difficult relationship can exacerbate already negative impacts of caring. Similarly, while many were part of successful family caring units, there were examples of young carers having increasing responsibilities as a result of other family members reducing their role. While sometimes attributed to the breaking of the family logic as a result of care receiver needs becoming unmanageable (Nagl-Cupal and Hauprich, 2018), there was also evidence of this occurring in families where this need was low.

Policy in Wales and the wider UK has legislated for young carer assessments and specialist provision, while governments have also detailed their expectations of mainstream services to identify and support the population, albeit with little evidence of success. The results of this study highlight the differences between these services. Mainstream services have contact with almost all young carers but struggle to actively identify them within the larger population. In contrast, young carer projects, aimed primarily at those with significant roles, provide vital social opportunities, but service users particularly value the individualised support that some offer. Many participants highlighted the potential for similar individualised support for those with substantial responsibilities within mainstream services, but there remain questions over their capacity to support young carers alongside their core health and educational duties. The absence of research or good practice concerning successful mainstream provision is notable, and this is critical given the hidden nature of the population and the reluctance of families to seek support.

Strengths and limitations

This phenomenological study is the first qualitative research known to the researcher to recruit participants from across the young carer spectrum, enabling the inclusion of participants with more manageable responsibilities alongside those with more substantial roles. The school-based approach was key to this diversity but the challenge of identifying the often hidden group, and the resulting prolonged and time-intensive recruitment process, hampered the research. Despite expanding recruitment to include young carer projects, the sample size of ten was limited and further research with more participants is needed. A focus on developing methods for identifying and recruiting young carers from the general population would aid this research into the wider spectrum.

Participant diversity within the sample was reflected in the self-disclosure of status, with the sample including one young carer who was highly open about their role, one whose family were private to the point of not seeking support beyond the household, and several who were selective of who they confided in. Similarly, four of the young carers recruited through their school were unknown to all services, while all five accessing specialist support were known to social services and their school.

The longitudinal approach was beneficial as it enabled the following of participants as their relationships with the care receiver and support within the wider household and from services changed. In particular, this is the first study to follow a young carer as they went through the process of being identified by a health professional, having more suitable medical equipment for the care receiver installed, and receiving training. This resulted in substantial benefits, highlighting the potential difference that health service support can make, but also how improving the life of a care receiver can have indirect benefits on the young carer and wider family. Further research developed with the intention of following young carers as they access health support and other services would strengthen these findings.

Conclusion

This phenomenological study considers how support can influence the impacts of caring. Participant experiences varied with their differing motivations to seek formal assistance, or to maintain privacy and rely on support from family and possible friends and community members. For those known to services, there was also significant variation in experiences of accessing specialist young carer projects and seeking assistance from educational and health professionals.

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Conflict of interest statement

The Author(s) declare(s) that there is no conflict of interest.

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Table 1. Participant sample characteristics

Setting	Interviews completed	Name	Demographics		Care receiver	Care receiver details		Duration as young carer	Key responsibilities
			Sex	Age		Reason for need			
School	3	Sophie	F	13	Mother	Diabetes, hearing impairment		9 years	Force feeding, injections to stabilize blood sugar levels; operating diabetic pump
School	3	Angela	F	13	Mother	MS		2 years	Companionship; domestic responsibilities
School	3	Kirsty	F	14	Mother*	Spina bifida, hydrocephalus, epilepsy		5 years	Domestic responsibilities; companionship
School	3	Martin	M	13	Mother	Aplastic anaemia		9 months	Physical support; domestic responsibilities
Project	1	Lyra**	F	13	Mother	Bipolar disorder		4 years	Domestic responsibilities
Project	1	Lucy**	F	11	Mother	Bipolar disorder		2 years	Domestic responsibilities; nursing
Project	3	Harry***	M	16	Brother	Autism		11 years	Getting up in morning; physical support; taking to school; caring after school
School	3	Patrick***	M	14	Sister	Cerebral palsy; learning difficulties		9 years	Physical support; monitoring
					Grandfather*	Old age, dizziness, confusion			Domestic responsibilities
Project	2	Richard	M	16	Mother	Former substance misuse; mental health		11 years	Emotional support; domestic responsibilities
Project	2	Thea**	F	16	Mother	Bipolar disorder		4 years	Companionship; nursing; domestic responsibilities

* Care receiver deceased.
 ** Participants were siblings.
 ***Third interview was online

Table 2. Summary of participant disclosure, identification and support from different sources

Name	Family	Informal support			Formal intervention		
		Friends	Neighbours	School	Health authorities	Social services	Young carer
Sophie	I	SD	U	U	I	U	U
Angela	I	SD	U	U	U	U	U
Kirsty	I	I	U	U	U	U	U
Martin	I	SD	SD	U	I	U	U
Lyra	I	SD	SD	SD	U	SD	
Lucy	I	SD	SD	SD	U	SD	
Harry	I	SD	U	SD	U	SD	
Patrick	I	I	U	U	U	U	U
Richard	I	I	U	I	I	I	SD
Thea	I	SD	SD	SD	SD	SD	

U (Unidentified); SD (Self-disclosed); I (Identified)

Figure 1. Young carer impact triangle

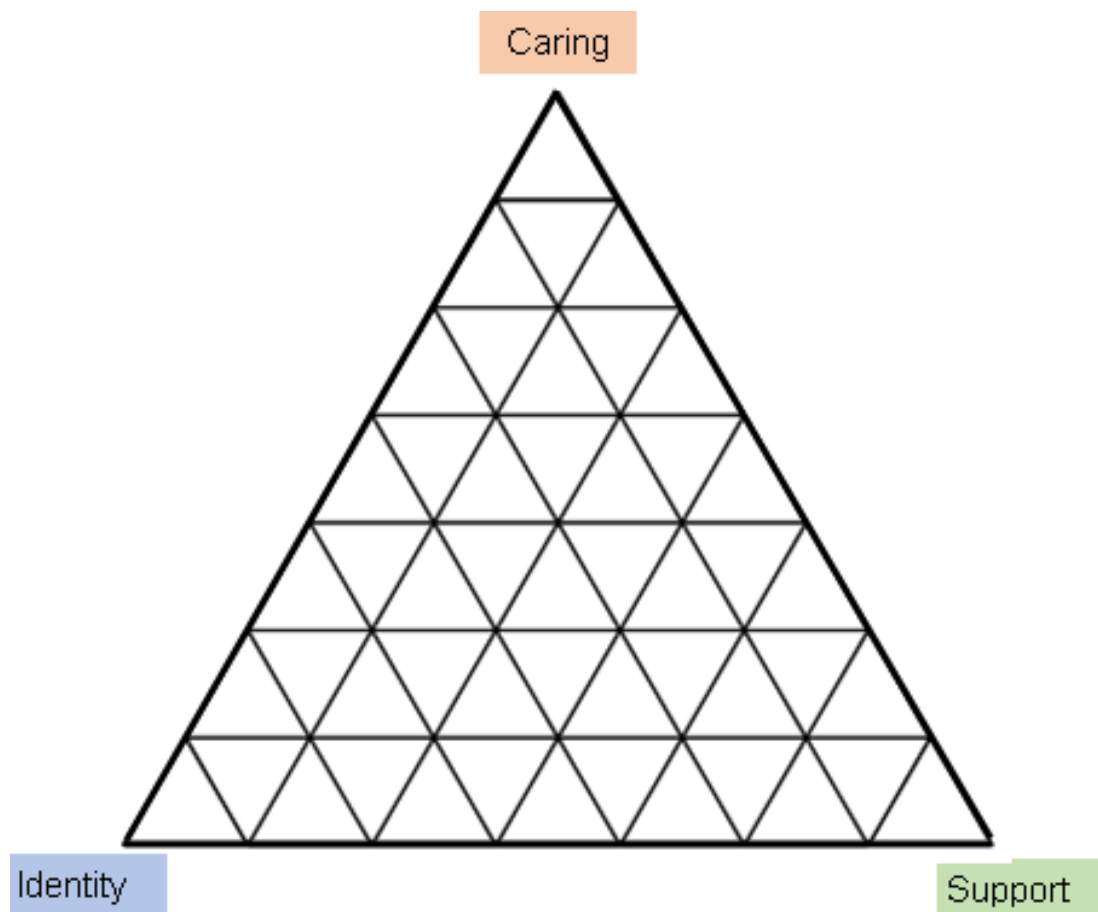
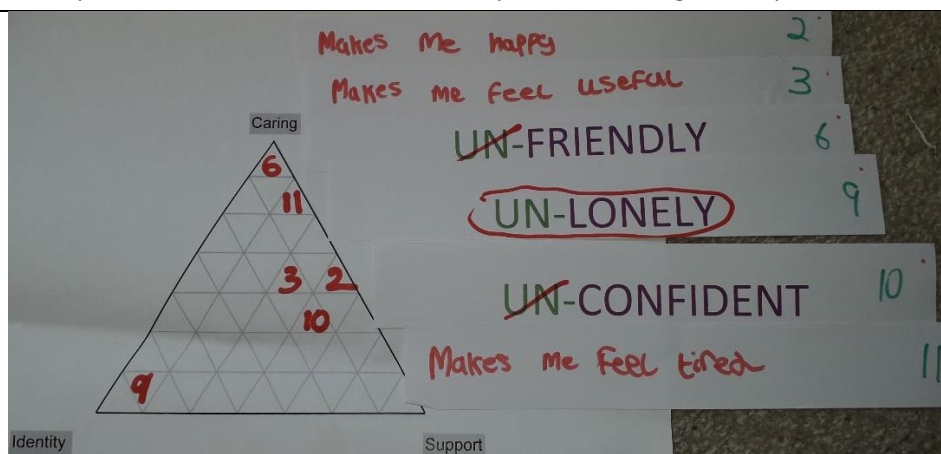


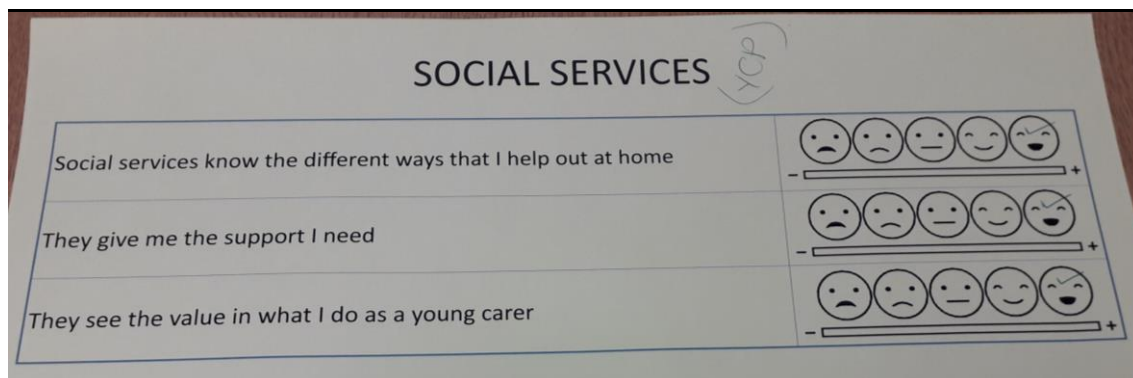
Figure 2. Harry associated his sense of community with his caring identity



The fact that I'm a young carer doesn't make me feel lonely. It makes me feel that I've got more people to be with if you get what I mean. Since knowing there's more young carers out there doesn't make me feel that I'm all alone.

Harry (12)

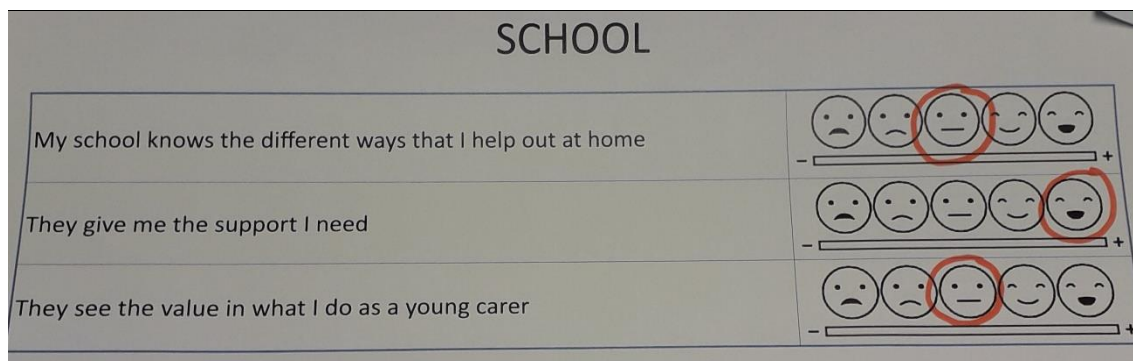
Figure 3. Thea's perception of support from her young carers project



They've taught me to be more confident in myself, they've taught me new skills. They've taught me ways of how I can cope with it... I shouldn't be embarrassed about caring, which I'm not. I, honestly I love caring, it gives me a great feeling.

Thea (11)

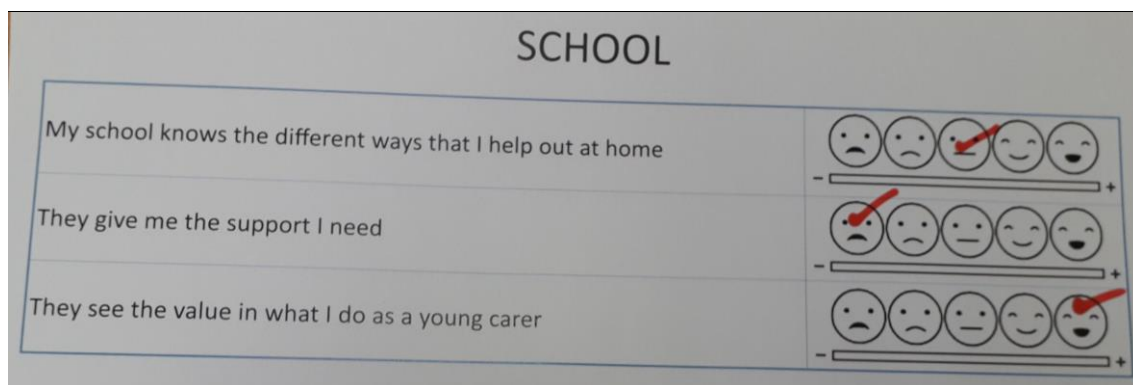
Figure 4. Lyra's experience of young carers support in her school



They know that I look after my mum, they know bits but they don't know 100%... personally I don't feel that they need to know 100% what I do.

Lyra (I1)

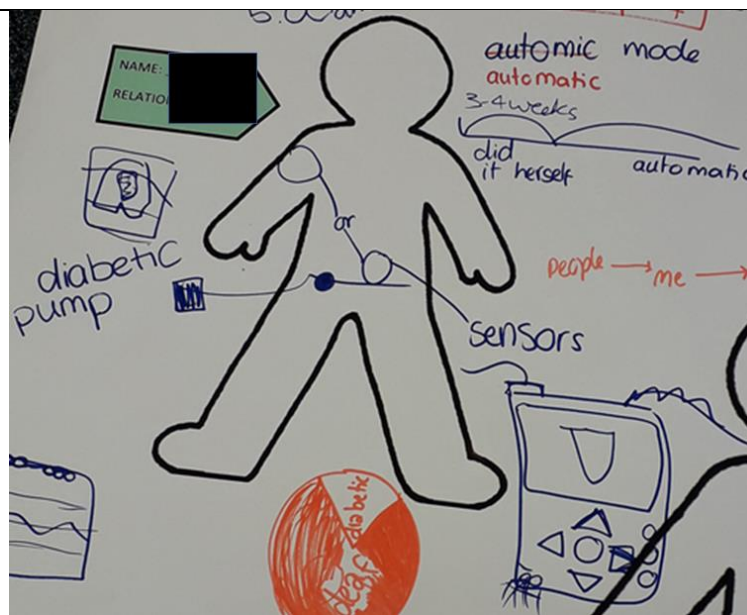
Figure 5. Thea's experience of young carer provision in her school



We're supposed to have a person who's supposed to be there for us, when we have caring problems, but I haven't seen her in about two years. We're supposed to have a meeting every term but she still hasn't done one... If you expect us to come to you, you should make an effort with us, because we don't know it, and she's supposed to be there, to be your own care supporter.

Thea (I2)

Figure 6. Sophie's knowledge of her mother's new diabetic pump



There's a little screen, and it will say where her blood sugars are... They are sensors so ... [If] her blood sugars go low, then it will... recommend an amount of Bolus to put in. The other day she had a hypo and it asked her if she wanted to insert like 1.1 units of Bolus.

Sophie (I2)