# Does the Carer Support Needs Assessment Tool (CSNAT) cover the support needs of young carers? A systematic literature search and narrative review


1. Yuen Ki Fung[1] 0009-0004-3285-8340
2. Dr A Carole Gardener[2] 0000-0002-8064-3780
3. Professor Morag Farquhar[2] 0000-0001-7991-7679

1. Former postgraduate student at the University of East Anglia
2. School of Health Sciences, University of East Anglia

Corresponding Author
Morag Farquhar, School of Health Sciences, University of East Anglia, Edith Cavell Building, Norwich Research Park, Norwich NR4 7TJ, UK. Email: M.Farquhar@uea.ac.uk

## Abstract

Background: Young carers support family members with a range of health issues but with known detrimental impacts on young carers themselves suggesting they require support. The Carer Support Needs Assessment Tool (v3.0) is a well-established tool enabling unpaid/family carers to identify and express their support needs to healthcare professionals. However its comprehensiveness for young carers is unknown.

Aim: To explore whether the Carer Support Needs Assessment Tool (v3.0) covers the support needs of young carers identified within published literature.

Design: Systematic literature search and narrative review. English language studies were identified against predetermined inclusion/exclusion criteria through searching databases and reference lists of included papers. Papers were critically appraised, and data extracted and synthesised by three reviewers. Identified needs were mapped to the Carer Support Needs Assessment Tool (v3.0) questions.

Data sources: CINAHL (EBSCO), EMBASE (Ovid), Applied Social Science Index and Abstract, Medline (EBSCO), American Psychological Association, PsycINFO and the Cochrane Database of Systematic Reviews (Jan 2010-Dec 2024).

Result: Thirty-four papers were included. Synthesis of findings confirmed that young carers have (often unmet) support needs relating to information, emotional distress, relationships (including parent-child relationships), accessing services and education. Mapping these to the Carer Support Needs Assessment Tool (v3.0) questions suggested it requires adapting to ensure coverage of education and parent-child relationships.

Conclusion: Young carers can require support across many areas, suggesting they would benefit from identifying and expressing their needs to healthcare professionals. The Carer Support Needs Assessment Tool Intervention could enable this but requires identified adaptations to the v3.0 tool.

## KEY STATEMENTS

### What is already known about this topic?

- Young carers play a vital role in supporting family members with a disability, physical illness, mental health condition, or drug or alcohol problem.
- Young carers may have unidentified support needs that could be a target for intervention.
- The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based, person-centred tool to enable identification and expression of adult carer support needs, however its comprehensiveness for young carers is unknown.

### What this paper adds?

- Synthesis of knowledge relating to young carer support needs from published literature, including needs carers felt were met or unmet, and inputs carers considered helpful.
- Mapping these support needs to the CSNAT (v3.0) identified that young carers' educational needs and parent-child relationships were not adequately covered by the tool, suggesting that adaptions could be made to enhance its comprehensiveness for young carers.

### Implications for practice, theory or policy

- Many of the support needs of young carers are unmet; particular areas of concern relate to information needs, emotional distress, relationship issues, access to services and education needs.
- Young carers would benefit from identification, and from a comprehensive, holistic, person-centred assessment of their needs and appropriate response to these needs.
- The CSNAT holds promise for identification of unmet young carer support needs although it would benefit from amendment to ensure it encompasses the full range of potential needs of this group.

## KEY WORDS

- caregivers, child, systematic review

## Introduction

Young carers have been defined as those under 18 years who help look after a relative with a disability, illness, mental health condition, or drug or alcohol problem.[1] It is currently estimated that around 7-8% of children in the UK and Europe are young carers[2] and that there are similar numbers in the USA, Canada and Australia.[3,4] The Commonwealth Charter for Young Carers has also highlighted the presence of young carers worldwide.[5] However, inconsistencies in definitions used, the lack of up-to-date statistics in many countries, combined with the reluctance of some young people to identify as a carer suggests that the total global number of young carers remains unknown.[2,3,6]

Existing evidence has shown that young carers carry out household tasks, provide emotional and physical support, look after younger siblings, administer medication, manage and support household finances, provide mobility assistance and act as a communication facilitator for the carer recipient.[2-4,7] However, it is also well documented that being a young carer can result in highly detrimental impacts on mental health, physical health and well-being.[4,8-15] Studies have shown that the role is associated with high levels of stress, anxiety, and depression.[12] There is evidence that young carers are more likely to report physical health problems than their peers, and that being a young carer is linked to higher mortality rates.[8,12,16,17] There are also known detrimental impacts on education, employment opportunities and financial security.[15,18,19] Young carers themselves describe having little time to follow their own interests,[20] and feel they are often seen primarily as a carer rather than a child with a full life ahead of them.[5] Young carers, and organisations who represent them, have highlighted the need for greater support to mitigate these impacts.[5,19,21]

In the UK, statutory authorities have a responsibility to assess the support needs of young carers and consider preventative strategies in relation to their caring role,[6] but young carers can be reluctant to participate in assessments for fear of being brought to the attention of social services. Healthcare professionals have a role to play in assessing and responding to the impact of being a young carer (alongside colleagues in social care, education and the voluntary sector)[6] by opening up vital, but less intimidating, conversations with young carers about support they may need. Existing tools and interventions to facilitate this currently focus on young carer identification and understanding the context and impact of the role on a young carer's life.[22] There is also a growing awareness of the need to consider a whole family approach.[4,6] However there remains a lack of evidence-based interventions that are purposively designed to pro-actively involve young carers in conversations with healthcare professionals about their support needs and the actions required to address them.

The Carer Support Needs Assessment Tool Intervention (CSNAT-I) is a well-established evidence-based means to enable unpaid/family carers to identify and express their support needs to healthcare professionals and enable tailored support.[23-26] CSNAT-I is a comprehensive, person-centred intervention facilitating holistic support to unpaid/family carers, and has been adopted internationally for adult carers: https://csnat.org.[27-29] It comprises two components: (1) a carer-completed evidence-based, 15 question tool that comprehensively encompasses carers' holistic support needs (CSNAT v3.0), which is integrated into (2) a five-stage person-centred process that facilitates assessment, response and review of carers' support needs[29]. However, the CSNAT[27,28] – the tool itself – was origionally developed and validated only with adult carers and so the relevance of its questions to young carers, and therefore its potential utility for young carers, is unknown. In conducting a narrative review to establish the comprehensiveness of an earlier version of the CSNAT (CSNAT v2.0) for adult carers of patients with chronic obstructve pulmonary disease (COPD), Micklewright and Farquhar[30] noted that the needs of young carers were likely to vary significantly from adult carers and recommended that a dedicated review was required to inform a specialist support needs assessment tailored for this age group (see supplemental material Appendix B Inclusion Criteria)[31].

This review therefore aims to systematically identify the support needs of young carers from the published literature and use the findings to examine the comprehensiveness of CSNAT v3.0 for young carers through question mapping.

## Methods

### Review question

Does the CSNAT (v3.0) comprehensively cover the published support needs of young carers?

### Study design

A systematic search of peer-reviewed English language research literature published between 2010 to 2020, and subsequently updated to 2024, was conducted by three reviewers, informed by scoping searches. The data extracted were synthesised and mapped to the CSNAT v3.0 questions, then narratively described. This pragmatic approach was considered the most appropriate for the review question and was methodologically guided by Micklewright and Farquhar's[30] previous CSNAT-related review and mapping exercise for adult COPD carers. The initial young carers' review protocol (2010-2020) was registered (Prospero database: CRD42021238883, available at https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021238883); no other post-registration changes were made to the protocol beyond extending the search to 2024. The PRISMA

checklist and flowchart was used to ensure clarity in reporting of activity at the various stages of the review.[32] The required licence granting use of the CSNAT v3.0 for this review was obtained.

## Study identification

A scoping search identified that young carers had a range of support needs across physical, mental, and social domains, emphasising the need to incorporate a multi-disciplinary perspective into the literature search. Relevant papers were therefore sought by searching a range of electronic databases including CINAHL (EBSCO), EMBASE (Ovid), Applied Social Science Index and Abstract, Medline (EBSCO), American Psychological Association, PsycINFO and the Cochrane Database of Systematic Reviews. Grey literature was not included, however reference searching of included studies supplemented the search strategy.

The search terms are outlined in Table 1. These were informed by the previous CSNAT-related review for COPD carers[30] in which search terms were chosen to reflect variation in how unpaid/family carers are referred to, both by themselves and by others. Where appropriate potential search terms were adapted for young carers.[30]

*[TABLE 1 ABOUT HERE]*

The inclusion and exclusion criteria are outlined in Table 2. Eligible studies had to include participants who were children (aged 18 years or under), who provided unpaid care for people with any type of health condition (physical/mental). Again informed by the previous CSNAT-related review for COPD carers,[30] and by CSNAT development work,[27] relevant papers also had to include information about the young carers' support needs and/or 'helpful inputs' i.e., inputs they considered a helpful response to their needs. Editorials, opinion pieces, case studies and non-empirical studies were excluded.

*[TABLE 2 ABOUT HERE]*

Titles and abstracts of potentially relevant papers were screened by a first reviewer (initial search YKF; updated search CG) against the eligibility criteria. If eligibility remained unclear a full text reading was undertaken. In cases of on-going uncertainty, the text was discussed with the second reviewer (MF) to ensure a consensus for both searches. The second reviewer (MF) also reviewed 10% of all identified papers independently to establish reproducibility of screening for both searches (agreement was high).

## Quality assessment

An assessment of all included papers was carried out to establish methodological quality. As per the inclusion criteria, all identified papers reported on qualitative studies therefore quality assessment was undertaken using the Critical Appraisal Skills Programme (CASP) Checklist for qualitative papers.[33] The quality assessment was completed by a first reviewer (initial search YKF; updated search CG), and four studies (11%: two from each search) were randomly selected for independent appraisal by the second reviewer (MF); the assessments were then compared to establish accuracy (agreement was high) and ensure the consistency in quality assessment.

## Data Extraction

In line with the previous CSNAT-related review for COPD carers' methods,[30] data on young carers' support needs were identified from the included papers then extracted and grouped using Ewing and Grande's[27] framework of three types of carer support need data: their (1) unmet needs, (2) met needs, and (3) helpful inputs. In the context of young carers, 'unmet needs' were support needs that young carers considered unresolved or unsuported, whereas 'met needs' were support needs that young carers considered to be resolved, potentially via intervention from health, social or other services. 'Helpful inputs' referred to the support or responses that young carers identified as helpful in addressing, reducing or resolving their support needs. The concept of 'support needs' was based on Bradshaw's concept of 'expressed need':[34] this is in keeping with the role of the CSNAT as a tool used to identify the needs of a unique individual through self-report.

Using this framework two reviewers initially, but independently, extracted data from five eligible papers (15%: three from initial search; two from updated search). Following comparison of the reviewers' findings (agreement was high), a consistent approach to the extraction and grouping of data was established. The first reviewer (initial search YKF; updated search MF) subsequently extracted the relevant data from the remaining papers.

## Data Analysis

The different types of support needs extracted from included papers (unmet needs, met needs and helpful inputs) were then mapped to the 15 CSNAT v3.0 questions. To do this two reviewers examined each support need identified from the young carers' literature and, in turn, considered them in relation to each of the 15 CSNAT v3.0 questions to identify whether, and to which question(s), the

need could be mapped. In line with the principles established by the original developers of the CSNAT, this process allowed for several different support needs to be mapped to the same CSNAT v3.0 questions (reflecting the domain-based nature of the CSNAT questions),[27] and for some individual support needs to be mapped to more than one CSNAT v3.0 question. This is in keeping with how the tool functions in practice.

Identified support needs that could not be mapped onto the tool's existing questions suggested areas where amendements to the tool might be necessary to ensure comprehensiveness for young carers. These unmapped support needs were reviewed to establish whether they could be incorporated into existing questions on the tool (i.e., through modification of question wording) or, following the approach of the previous CSNAT-related review for COPD carers,[30] synthesised to represent one or more additional broad areas of support need or new 'domains of need' (i.e., new questions on the tool). This process was achieved through discussion within the research team (which included one of the developers of CSNAT v3.0: MF), followed by consultation with one of the two original CSNAT developers.

Once agreement was reached about amendements required to improve comprehensiveness for young carers, a narrative description of the findings was produced. As noted by the previous CSNAT-related review for COPD carers,[30] this analytic approach was congruent with the paradigm of pragmatism in providing the best methodological approach to answer the very applied review question.[35]

## Results

### Study selection

The searches yielded 34 eligible papers (see Figure 1): all were qualitative and their characteristics are reported in Appendix 1 (supplementary material). Included papers reported findings from the UK,[36-39,63-65,68-70,75,76,78] Canada/USA,[40-42,49,79] Australia,[43,44,61,73] Norway,[45,46] Italy,[67,77] Slovenia,[77] Germany,[71] Austria,[72] Switzerland,[47] Belgium,[48] Tiawan,[80] South Africa,[66] and West Kenya.[62] Study participants were recruited via community advertising and a range of health, community and educational organisations. The age of young carers range across all included studies was between six and 18 years. Nine studies also included data relating to young adult carers, however data were only extracted for the carers aged 18 years or younger.[43,47, 61,63,65,66,73,75,78] Five studies reported data from adults looking back on their time as young carers.[40,41,64,79,80]

*[FIGURE 1 – PRISMA FLOW CHART ABOUT HERE*]

## Quality appraisal

The quality appraisal findings reported in Appendix 2 (supplementary material) highlighted a number of issues that may have impacted the validity of the findings reported in the papers. Some studies chose an indirect approach to exploring young carers' experiences such as (as noted) conducting retrospective interviews with adults about their experiences of being a young carer,[40,41,64,79,80] or by using using vignettes.[38] One study collected data from young carers in the presence of their care recipients which may have censored how young carers spoke about their caregiving experiences.[48] Some studies provided limited explanations as to how relevant data were retrieved from interviews and the themes developed.[40,42,43]

## Overview of findings relating to identified young carers' needs

The literature reviewed identified that young carers have a range of support needs, many of which are unmet. In particular, young carers require support in relation to information needs, emotional distress, relationship issues, access to the support services and education. These five key areas of need are outlined below, before the mapping of young carers' support needs to the CSNAT v3.0 questions is presented.

### Information needs

Having information and knowledge about the person being cared for was seen as important for young carers, but was an area where they frequently failed to receive the support needed. Many of the included papers noted young carers lacked access to information about the cared-for person's illness and their care (for example:[37,45,46, 47,48,49,64,67,74,76-78]). As a result, young carers often obtained information indirectly, such as by overhearing household conversations, leading them to interpret these on their own.[37]

Even when information was discussed directly with them, young carers reported receiving inconsistent and vague information which could cause confusion.[37,48] Similarly, some stated that clinicians failed to provide disease-related information, did not update them on their parents' condition, or used professional language rendering communication ineffective.[36,37,49] In response

young carers highlighted the need for an individualised approach, including use of age-appropriate methods for information delivery.[37,45,49]

Emotional distress

Many of the young carers described unmet needs in relation to their fears and worries. For some this arose from feelings of uncertainty in relation to the cared for person's illness.[37,46,48,80] Here young carers described worrying about symptom management, changes in the cared-for person's health status and uncertainty about the future. Young carers also described the distress experienced in response to perceived stigma from their peers associated with both with their role[39,44] and with the presence and nature of illness in their family.[37,41,42,45,71] Finally, the dual roles of being a child (with school work) and a carer (with responsibilites at home) could result in exhaustion and feeling overwhelmed.[36,42,43,46,47,70] Family members and healthcare profesisonals were identified as key sources of support for this (for example:[39,41,46,49]). Where young people didn't have access to someone with whom they could discuss these feelings their distress was often compounded by a percieved need to disguise and self-manage their emotions, and focus instead on the needs of the person they supported.[45]

Relationship issues

Young carers also identified unmet needs in relation to interperonal relationships, including challenges in relationships with peers, healthcare professionals and family. Many of the included papers mentioned the time cost of caregiving that led to frequent absence of young carers from social activities, and subsequent feelings of social isolation (for example:[36,38-40,42-45,47]). Difficulties establishing supportive relationships with healthcare professionals were similarly highlighted.[36,37,41,46,49]

Famiy relationships were also affected. Young carers felt dissatisfied with the lack of recognition from parents in relation to their caregiving contribution[39,45] and the unequal division of caring responsibilities within the family.[42] Family dynamics could also be impacted by deterioration in a sick parent's behaviour or personality, leading in some cases to family breakdown.[37,42,44] Young carers also described having to take on additional roles caring for siblings[44] and the need for practical support to assist with this e.g. help with school pickups.[36] Some studies noted the financial stress on the whole family, for example from loss of income when the parent was not working, or in response to funding

addictions, and the subsequent need for more financial stability.[36,44,45,62,65,67,76-78] A key finding was that being a young carer to a parent could lead to loss of the parent-child relationship:[36-42,44-46,49,53,64-68] this particular area of need is discussed further below, under 'Mapping needs to CSNAT questions'.

### Access to services

Challenges in access to support services were raised in some of the included papers.[39,67,77,78] The difficulties experienced by some young carers in obtaining access to training and support and the infrequency of that support was noted.[39] Some had no knowledge of the available services for young carers:[36] poor advertising of support services and the different definitions of 'young carers' in agencies were noted.[41] Some young carers welcomed the idea of distant support using technology, although in-person support was preferred.[49] There was a particular unmet need around knowing what financial support was available, and how to access it.[65,67.77,78] The lack of available family support for immigrant families was highlighted, resulting in feelings of isolation for these particular young carers.[40]

### Education needs

Support needs related to education were commonly discussed in the papers. Given the age range of young carers, education had an important place in their daily lives but caring responsibilities led to negative impacts on education such as absenteeism, attention loss in class, and reduced learning ability.[37,39,42,46,47,61,62,66,70,78-80] Future education plans were also impacted by caring responsibilities. Two studies noted that young carers were particularly knowledgeable about universities' locations and course workloads, such that they could maintain a balance between studies and caring duties[42,43]. Studying abroad became a difficult decision for young carers to make.[45] In some extreme cases, young carers chose to postpone their further education to fulfill the young carer role.[42] Again, this particular key area of need is discussed further below, under 'Mapping needs to CSNAT questions'.

## Mapping needs to CSNAT questions

CSNAT v3.0 was found to cover most of the young carers' support needs identified from the review, and no CSNAT questions appeared to be redundant for young carers. However, support needs related to education issues and parent-child relationships were two areas in particular that some young carers required support with but which were not, or not adequately (given their particular importance

to the young carers' age group), covered by CSNAT v3.0. Data informing the mapping exercise is reported in Appendix 3 (supplementary material).

First, the educational needs of young carers requires attention. As noted, the included papers documented how the caregiving role affected young carers' ability to fulfill their student obligations and plan for their future education. Constructive suggestions for addressing these issues included partnering young carers with school teachers and nurses to develop a 'checklist' on the needs of young carers and flexible handling of young carers' attendance and schoolwork submission dates. [36] Enhancing teacher awareness of young carers and their needs was also noted.[61,63,65,71,78] The reported positive effect that accessing education could have as a source of support and information[36,37,41,47,48,61-63,65,66,71,78] and distraction from the caring role[66,72,79] is also worthy of note.

Second, the loss of the parent-child relationship was identified as an area of support need for young carers not adequately covered by the CSNAT v3.0. Missing out on a 'normal' parent-child relationship due to the health condition of the sick parent and the caring role was discussed in many of the reviewed papers. For example, for young carers of parents with dementia, the quality of interactions was diminished, leading to frustration with the parent-child relationship.[49] Further, a young carer with their own chronic condition could not count on their dependent parent to provide care for her, which led to feelings of loss of love in the filial relationship.[41] Some young carers shared the experiences of being bullied in school but not being able to rely on sick parents to manage this, making them feel helpless.[36]

Young carers also compared their parent-child relationships with those of their peers: some were jealous of their peers who had non-dysfunctional relationships with their parents and felt frustrated with their own poor parent-child relationship.[41,46] This parent-child relationship loss led to low self-esteem, despondency, poor academic performance, and poor peer relationships.[36,39,44] The reviewed papers reported that some young carers' parents were not capable of performing expected parenting responsibilities, such as providing 'emotional warmth', 'stability', and 'guidance' to meet young carers' developmental needs.[36,38,40,41,44-46] Thus, these parents were seen as unreliable, leading to the feeling of powerlessness in some young carers.[39] Some young carers sought 'pseudo parental support' from friends[42] and one young carer reported learning to be self-sufficient to deal with the challenges that she had in life instead of relying on her parents.[38]

## Discussion

## Main findings/results of the study

This review aimed to investigate the comprehensiveness of CSNAT v3.0 for identifying the support needs of young unpaid/family carers. The review process first identified young carers' support needs (areas where young carers experience a range of challenges due to their caring role and perceived shortfalls in support available), before using the findings to explore CSNAT v3.0's comprehensiveness for young carers. The very young age of some of the carers (some as young as six years old) was notable but in line with national reports.[7]

Unmet needs experienced by young carers

Unmet needs experienced by young carers included accessing information, support with emotional distress, managing relationships (including parent-child relationships), access to services and educational support.

The review highlighted the need to increase information sharing with young carers, and to consider ways to deliver this information effectively. Young carers noted that they lacked information about the nature of their parent's illnesss and how to manage symptoms and care. Furthermore they described how, even when they were included in information sharing processes, the information was often presented in a way that wasn't accessible to them. Young carers also expressed how this lack of information left them vulnerable to speculation, mis-information and feelings of concern. There is therefore a need for healthcare professionals to ensure that young people are included in the information transfer process and to adopt an individualised approach in terms of how the information is presented; this supports findings in the wider literature.[13,50]

Professionals can also make a difference supporting young carers' emotional well-being. Studies within the review found that young carers can feel emotional strain in response to worries about the cared-for person, the direct demands of their caring role, and the resulting strain that the role puts on other aspects of their lives. These findings are in line with quantitative studies that suggest young carers have poorer mental health than their non-caregiving peers.[12] In response, young carers described how they valued the opportunity to discuss their feelings and worries with family members, healthcare professionals and counsellors. Healthcare professionals can therefore play a role either in directly providing emotional support or enabling access to well-being services.

Young carers also described needing support to maintain and develop relationships with peers, healthcare professionals and within their families. In particular, the review found that young carers often need support to manage family relationships where they can require help to negotiate the nature of their caring role, maintain the parent-child role and address the strain experienced by the whole family. Equally, enabling young carers to spend time with peers and participate in activities outside the home may help them in developing their identity outside of being a carer. This further supports calls across Europe for a greater emphasis on understanding the young carer as a child first and foremost, and a focus on considering the needs of the care recipient within the context of the wider family and social care system.[6,81]

Healthcare professionals may also be able to support young carers with accessing wider services. Young carers described often being unaware of services and the lack of signposting from professionals with whom they were in contact. Healthcare professionals help improve this signposting by ensuring that they are comprehensive in their assessment of young carers' needs (through evidence-based interventions such as CSNAT-I), providing appropriate information about services to young carers, making referrals on their behalf and supporting them to engage with the services they require. The review highlighted a particular need to support young carers within minority ethnic communities in accessing services.

Finally schools play a key role in identifying young carers, enabling them to manage the dual respsonsibilities of academic work and their caring role, and encouraging and promoting participation in a range of social opportunities and activities. The review identified, however, that being a young carer can result in absenteeism and poor academic performance. Future education plans were also impacted by caring responsibilities. The review's findings reflect wider understanding of the need to promote and enable young carers' learning and educational opportunities, together with supporting their school engagement and attendance.[51] Healthcare professionals who work in schools can help young carers to consider the full range of their physical, emotional and social needs, as well as liaise with educational staff about how young carers might balance being able to fully participate in their education, and the other opportunities offered via school, with being a carer.[52,53]

In summary, a major finding of the review is the range of unmet support needs among young carers. This is supported by wider research and a number of reports produced by organizations that seek to advocate for, and support, young carers.[1,2,10,14,15,19-21,54] Further, the United Nations Convention on the Rights of the Child sets out the civil, political, economic, social and cultural rights of every child

(regardless of race, religion or abilities), requiring governments to meet children's basic needs, help them reach their full potential and have a right to a family life.[82] It is therefore likely that young carers would benefit from on-going conversations to identify their unmet support needs enabling appropriate and tailored support from health and social care professionals. Using the CSNAT Intervention to identify support needs and develop an action plan to meet these needs may be one way of accomplishing this although, as we now discuss, the review also indicates that the CSNAT itself (the tool underpinning CSNAT-I) would benefit from adaptation for young carers.

Comprehensiveness of the CSNAT v3.0 for young carers

The questions on CSNAT v3.0 covered most of the young carers' support needs identified by the review, and no question was redundant. However, based on the findings of this review, adaptations could be made to enhance the comprehensiveness of CSNAT v3.0 for young carers in relation to their educational needs and parent-child relationships. This is unsurprising given that previous CSNAT work (in both its development and testing) related only to the support needs of adult carers.

The explicit inclusion of need for support with 'education' on the CSNAT could help open conversations with young carers about their individual support needs related to this and ways to address them. Discussion with one of the two original CSNAT developers concluded that, for young carers, the adaption of question 4 on CSNAT v3.0 ('Do you need more support with your financial, legal, or work issues?') to include 'educational issues' might address this i.e., 'Do you need more suport with your educational, financial, legal, or work issues?'.

Although CSNAT v3.0 includes a question on 'managing relationships' (question 7), the centrality, complexity and range of impacts of the parent-child relationship for/on young carers suggests it warrants a new, separate, dedicated CSNAT question of its own for young carers. However, the addition of a new parent-child relationship question would require changes to the existing 'managing relationships' question (question 7) in two ways: (1) the addition of the word 'other' to its current wording i.e., 'managing other relationships', and (2) re-locating this question to follow the new parent-child relationship question (so that the inclusion of 'other' is logical). Consultation with one of the two original CSNAT developers confirmed this.

Strengths and Limitations:

To our knowledge this is the first review to explore the comprehensiveness of the well-established internationally-adopted CSNAT for use with young carers. The review benefitted from the expertise and insight of one of the two original CSNAT developers. Included papers were exclusively qualitative: the use of qualitative methods in these studies yielded a wealth of information such that 'support needs' could be identified within their narratives.[37,39,44,46,48]

This review has some limitations resulting from limted resources. Excluding grey literature and papers not written in English language may have resulted in the loss of potentially useful information. Including grey literature can increase the quality of a review, as well as reduce publication bias.[55] Authors of papers included in the review were not contacted as field experts: such an approach might have identified additional literature not captured by the searches. Further, search terms were limited to title field only (due to the excessive hits resulting from full paper or abstract searches), however citation searching was used as a supplementary strategy.

The population subject of this review, young carers, are challenging to identify. Some of the reviewed papers commented that young carers are a 'hard to reach population'[41,44] and this is supported by the broader young carers' literature.[56,57,58] Moreover, young carers' concerns about the associated stigma of the 'young carer' label might limit the representativeness of study samples to the population. Likewise, some papers indicated young carers' worries related to privacy invasion and unwanted interventions for their families.[58,59] It is worth noting that the participants in some of the included studies were not labelled as 'young carers', instead being described as 'young people', 'children' or 'adolescents'.[37,39,44,46,48]

Finally, the process of mapping support needs to CSNAT v3.0 was, to a certain degree, subjective due to both the complexity and the nature of 'support needs'. It was also conducted by adult researchers. Young carers may have different interpretations of the CSNAT questions compared to adult researchers. The proposed adaptations to CSNAT v3.0 are an attempt to enhance the comprehensiveness of the tool for this group, to ensure it includes the full range of domains of support needs for young carers in order to prompt them to consider and identify their individual support needs. Young carers should be engaged in the actioning of the suggested CSNAT adaptions to ensure appropriate wording and relevance, then validation, but this was beyond the scope of this review.

Establishing the acceptability of a CSNAT which includes the proposed adaptations for young carers is also beyond the scope of this review, as is establishing the acceptability and feasibilty of CSNAT-I (the approach, as opposed to the tool itself) for young carers. Exploring both of these with young carers, alongside implementation work with health, social care and education professionals, are key next steps.

### What this review adds:

This review identifies and synthesises the support needs of young carers, as identified by young carers themselves. It explores the comprehensiveness of the well-established, internationally used, CSNAT for use with carers of a younger age than previously engaged with. The findings suggest that CSNAT-I, using the adapted CSNAT for young carers, could be a useful means for health, social care and education professionals to work with young carers in order to identify and address their support needs.

## Conclusion

The findings of this review highlight that young carers have a range of support needs arising from their caring role, but that many of these needs remain unmet. Delivery of the evidence-based CSNAT Intervention by appropriately trained and skilled professionals could address this, but this review identified that the CSNAT (the tool underpinning CSNAT-I) requires adaptation in order to include questions related to 'education' and the 'parent-child relationship', thereby enhancing its comprehensiveness for young carers.

## ACKNOWLEDGEMENTS

This study utilised the Carer Support Needs Assessment Tool (CSNAT) v3.0 which can be accessed via https://csnat.org. A licence was obtained granting permission to use the CSNAT for this review. The authors additionally thank Dr Gail Ewing (one of the two original developers) for advice and guidance.

## AUTHOR CONTRIBUTIONS

YKF and MF contributed towards designing the review, data analysis and synthesis. All three authors contributed to drafting and editing the manuscript and gave the final approval of the version to be published.

## DECLARATION OF CONFLICTING INTERESTS

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## FUNDING

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Morag Farquhar and Carole Gardener were supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridgeshire and Peterborough NHS Foundation Trust. The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care. Carole Gardener was addiitonally supported by RCF from the Norfolk and Waveney Integrated Care Board, administered by the Norfolk and Suffolk Primary and Community Care Research Office.

**FIGURE 1 – PRISMA FLOW CHART (Page et al.,2021[32])**

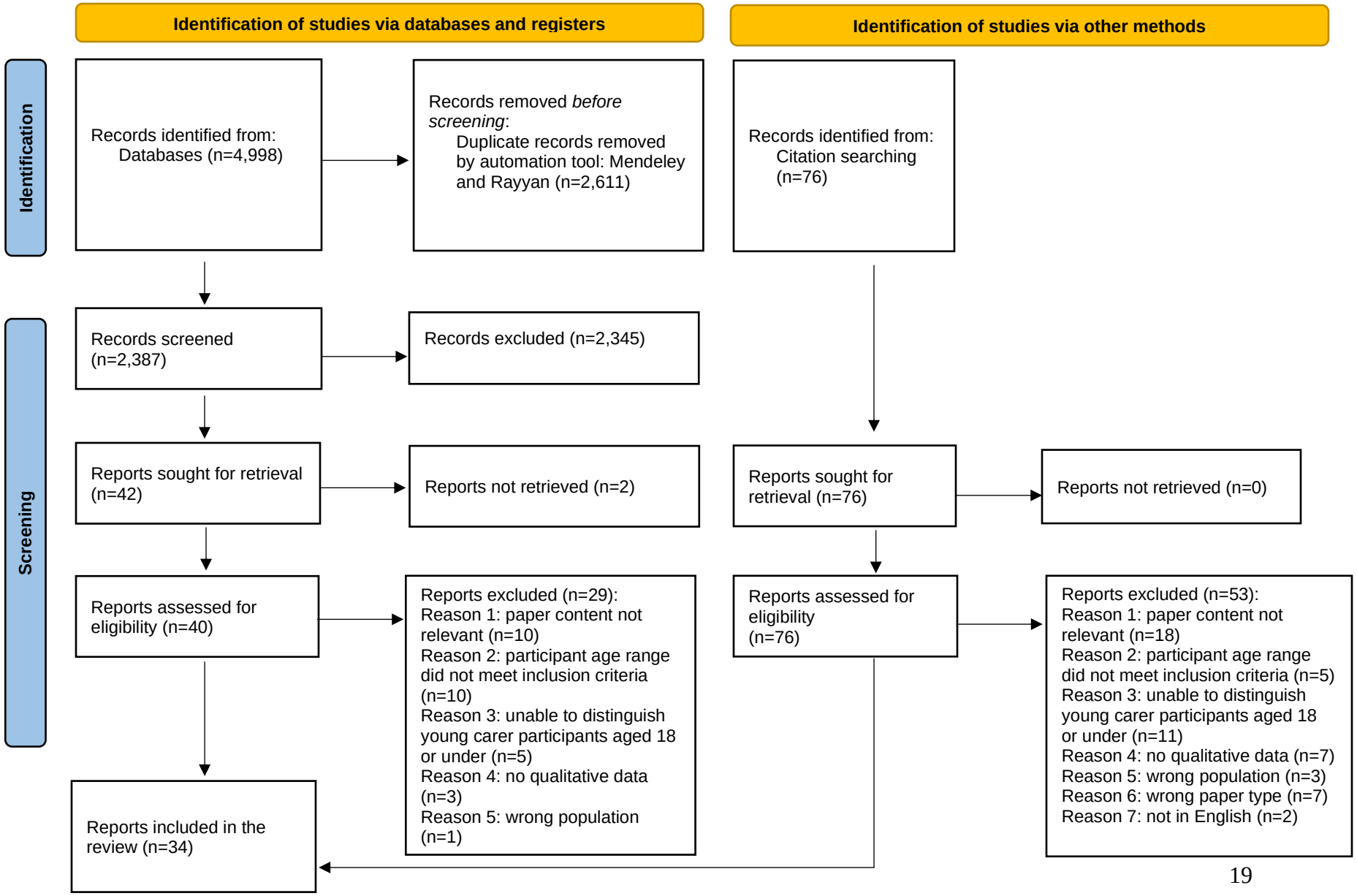

Table 1: Search terms

| Search terms: | | | | |
|---|---|---|---|---|
| Age group 'OR' between terms | | Population 'OR' between terms | | Interest 'OR' between terms |
| child* OR adolescent* OR youth* OR teenager* OR young* | AND | carer* OR caregiver* OR supporter* OR informal* OR famil* OR friend* OR relative* OR lay* | AND | support* OR need* |
| **Expanders:** similar terms * | | | | |
| **Limiters:** 2010-2024, English language, peer-reviewed, qualitative studies, young carers who are aged 18 or under | | | | |
| Search terms limited to titles only | | | | |

Table 2: Inclusion and exclusion criteria with key justifications

| Inclusion criteria | Justification |
|---|---|
| Papers that included information about the support needs of children who are unpaid/family carers of patients with any health condtion (physical/mental) | To ensure the included papers contained findings relating to the review question |
| Qualitative studies | To ensure extraction of support needs identified by young carers themselves |
| Unpaid/family carers who are aged 18 years or under | Some definitions of young carers include those aged 18 years, but some state under 18 years (e.g., NHS 2021), however the age of 18 is considered a transition year from child to adult Schraeder et. al (2020)[60] and so is included. |
| Peer-reviewed papers only | To increase confidence in the quality of the papers |
| Papers written in English | No translation resources available |
| Publishing period: January 2010 to December 2024 | To ensure data relating to the contemporary support needs of young carers |
| **Exclusion Criteria** | **Justification** |
| Paid/professional carer (those who have healthcare related qualification or providing paid care work) | Paid/professional carers are likley to have different support needs compared to (young) unpaid/family carers who are the focus of the review question |
| Editorials, expert opinions, and case studies | Lower quality evidence was excluded to increase the reliability and strength of the findings. |

References

1. NHS. Being a young carer: your rights, https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights/ (2024, accessed 04/06/2025).

2. ME-WE consortium. Enabling young carers to pursue their goals in life and reach their full potential: converting research into policy actions. https://carers.org/resources/all-resources/107-enabling-young-carers-to-pursue-their-goals-in-life-and-reach-their-full-potential-converting-research-findings-into-policy-actions (2019, accessed 04/06/2025).

3. Hendricks BA, Kavanaugh MS and Bakitas MA. How far have we come? An updated scoping review of young carers in the U.S. *Child Adolesc Social Work J* 2021; 38: 491-504.

4. Joseph S, Sempik J, Leu A, et al. Young carers research, practice and policy: an overview and critical perspective on possible future directions. *Adolescent Res Rev* 2020; 5: 77-89.

5. Commonwealth Organisation for Social Work. The Commonwealth Charter for Young Carers. https://cosw.info/young-cares/ (2020, accessed 04/06/2025).

6. Aldridge J. Where are we now? Twenty-five years of research, policy and practice on young carers. *Critical Social Policy* 2018; 38: 155-165.

7. Aldridge J, Clay D, Connors C, et al. The lives of young carers in England. https://www.gov.uk/government/publications/the-lives-of-young-carers-in-england (2016, accessed 04/06/2025).

8. Nagl-Cupal M, Daniel M, Koller MM, et al. Prevalence and effects of caregiving on children. *J Adv Nurs* 2014; 70: 2314-2325.

9. Office for National Statistics. Providing unpaid care may have an adverse effect on young carers' general health. http://bit.ly/1uHR1PX (2013, accessed 04/06/2025).

10. Becker F and Becker S. *Young Adult Carers in the UK Experiences, Needs and Services for Carers aged 16-24.* 2008. London: The Princess Royal Trust for Carers.

11. Frank J, Tatum C and Tucker S. *On small shoulders. Learning from the experiences of former young carers.* 1999. London: The Children's Society.

12. Lacey RE, Xue B and McMunn A. The mental and physical health of young carers: a systematic review. *Lancet Public Health* 2022; 7: e787-e796.

13. Dharampal R and Ani C. The emotional and mental health needs of young carers: What psychiatry can do. *BJPsych Bulletin* 2020; 44: 112-120.

14. Carers Trust. My future, my feelings, my family. https://carers.org/downloads/what-we-do-section/my-future-my-feelings-my-family.pdf (2021, accessed 04/06/2025).

15. Department of Health. Recognised, valued and supported: Next steps for the Carers Strategy.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf (2010, accessed 04/06/2025).

16. Tseliou F, Rosato M, Maguire A, et al. Variation of caregiver health and mortality risks by age: a census-based record linkage study. *Am J Epidemiol* 2018; 187: 1401-1410.

17. Robison OMEF, Inglis G and Egan J. The health, well-being and future opportunities of young carers: a population approach. *Public Health* 2020; 185: 139-143.

18. Hounsell D. *Hidden from view: the experiences of young carers in England 2013.* 1May 2013. London: The Children's Society.

19. Carers Trust Scotland. *Scottish Young Carers Festival 2023 Report*
https://carers.org/resources/all-resources/147-scottish-young-carers-festival-2023-report (2023, accessed 04/06/2025).

20. Carers Trust. *Being a young carer is not a choice- it's just what we do: The voices and experiences of young carers and young adult carers from across the UK.* May 2023. Rugby: Carers Trust.

21. All-Party Parliamentary Group for Young Carers and Young Adult Carers Trust. *Inquiry into the life opportuities of young carers and young adult carers.* https://carers.org/all-party-parliamentary-group-appg-for-young-carers-and-young-adult-carers/appg-on-young-carers-and-young-adult-carers-inquiry-into-life-opportunities (2023, accessed 04/06/2025).

22. Joseph S, Becker S, Becker F, et al. Assessment of caring and its effects i n young people: development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child Care Health Dev* 2009; 35(4): 510-520.

23. Aoun SM, Grande G, Howting D, et al. The impact of the carer support needs assessment tool (CSNAT) in community palliative care using a stepped wedge cluster trial. *PLoS One* 2015; 10: e0123012. 20150407.

24. Grande GE, Austin L, Ewing G, et al. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ Support Palliat Care* 2017; 7: 326-334.

25. Lund L, Ross L, Petersen MA, et al. Effect of the Carer Support Needs Assessment Tool Intervention (CSNAT-I) in the Danish specialised palliative care setting: a stepped-wedge cluster randomised controlled trial. *BMJ Support Palliat Care* 2020 bmjspcare-2020-002467

26. Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners' perspectives of its impact and mechanisms of action. *Palliat Med* 2016; 30: 392-400.

27. Ewing G, Grande G and Home NAfHa. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013; 27: 244-256.

28. Ewing G, Brundle C, Payne S, et al. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013; 46: 395-405.

29. Ewing G, Austin L, Diffin J, et al. Developing a person-centred approach to carer assessment and support. *Br J Community Nurse* 2015; 20: 580-584.

30. Micklewright K and Farquhar M. Does the carer support needs assessment tool cover the established support needs of carers of patients with chronic obstructive pulmonary disease? A systematic literature search and narrative review. *Palliat Med 2*020; 34: 1305-1315.

31. Micklewright K and Farquhar M. Appendix B: Inclusion and exclusion criteria https://journals.sagepub.com/doi/10.1177/0269216320939243#supplementary-materials (2020, accessed 04/06/2025).

32. Page M J, McKenzie J E, Bossuyt P M, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021; 372: n71.

33. Critical Appraisal Skills Programme. CASP Qualitative Checklist. https://casp-uk.net/casp-tools-checklists/qualitative-studies-checklist/ (2018, accessed 04/06/2025).

34. Bradshaw J. The taxonomy of social need. In: McLachlan G (ed.) *Problems and progress in medical care.* Oxford: Oxford University Press, 1972, pp.69-82.

35. Tashakkori A and Teddlie C. *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA, US: Sage, 1998.

36. McAndrew S, Warne T, Fallon D, et al. Young, gifted, and caring: a project narrative of young carers, their mental health, and getting them involved in education, research and practice. *Int J Ment Health Nurs* 2012; 21: 12-19.

37. Mordoch E. How children understand parental mental illness: "you don't get life insurance. What's life insurance?". *J Can Acad Child Adolesc Psychiatry* 2010; 19: 19-25.

38. O'Dell L, Crafter S, De Abreu G, et al. Constructing 'normal childhoods': young people talk about young carers. *Disability & Society* 2010; 25: 643-655.

39. Svanberg E, Stott J and Spector A. 'Just helping': Children living with a parent with young onset dementia. *Aging Ment Health* 2010; 14: 740-751.

40. Charles G, Stainton T and Marshall S. Young carers in immigrant families: An ignored population. *Canadian Social Work* 2011; 12(1): 83-92.

41. Newman K, Bookey-Bassett S, Wang AH, et al. Carers need care too: recalling the experience of being a young female carer for a relative living with dementia. *Perspectives* 2019; 40: 6-16.

42. Stamatopoulos V. The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child & Youth Services* 2018; 39: 180-205.

43. Hamilton MG and Adamson E. Bounded agency in young carers' lifecourse-stage domains and transitions. *Journal of Youth Studies* 2013; 16: 101-117.

44. Moore T, McArthur M and Noble-Carr D. Different but the same? Exploring the experiences of young people caring for a parent with an alcohol or other drug issue. *Journal of Youth Studies* 2011; 14: 161-177.

45. Mauseth T and Hjälmhult E. Adolescents' experiences on coping with parental multiple sclerosis: a grounded theory study. *J Clin Nurs* 2016; 25: 856-865.

46. Trondsen MV. Living with a mentally ill parent: exploring adolescents' experiences and perspectives. *Qual Health Res* 2012; 22: 174-188.

47. Leu A, Frech M and Jung C. Young carers and young adult carers in Switzerland: Caring roles, ways into care and the meaning of communication. *Health Soc Care Community* 2018; 26: 925-934.

48. Van Parys H and Rober P. Trying to comfort the parent: a qualitative study of children dealing with parental depression. *J Marital Fam Ther* 2013; 39: 330-345.

49. Nichols KR, Fam D, Cook C, et al. When dementia is in the house: needs assessment survey for young caregivers. *Can J Neurol Sci* 2013; 40: 21-28.

50. Howatson-Jones L and Coren E. Scoping the assessment needs of young carers of adults with a long term condition. *J Nurs Care* 2013; 2:2.

51. Association of Directors of Adult Social Services. *Young Carer Supporting Information: Young Carers' Needs Assessment*. https://www.local.gov.uk/sites/default/files/documents/Young%20Carers%20needs%20assessment.pdf (2015, accessed 04/06/2025).

52. Department of Health. *School Nurse Programme: Supporting implementation of the new service offer: Supporting the health and well-being of Young Carers*.

https://assets.publishing.service.gov.uk/media/5a7ce606e5274a2c9a484cad/Young_Carers_pathway_Interactive_FINAL.pdf (accessed 04/06/2025).

53. McClure L. School-age caregivers: perceptions of school nurses working in Central England. *J Sch Nurs* 2001; 17: 76-82.

54. Carers Trust. *It's Harder Than Anyone Understands -The Experiences and Thoughts of Young Carers and Young Adult Carers. A Carers Trust Report.* 2022. London: Carers Trust.

55. Paez A. Gray literature: An important resource in systematic reviews. *J Evid Based Med* 2017; 10: 233-240.

56. Fives A, Kennan D, Canavan J, et al. "If I can make their life a little easier, then I'm happy": Study of young carers in the Irish population. 2010. Dublin: The Stationary Office, Office of the Minister for Children and Youth Affairs, Department of Health and Children.

57. Fives A, Kennan D, Canavan J, et al. Why we still need the term 'young carer': Findings from an exploratory study of young carers in Ireland. *Critical Social Work* 2013; 14(1): 49.

58. Kennan D, Fives A and Canavan J. Accessing a hard to reach population: reflections on research with young carers in Ireland. *Child & Family Social Work* 2012; 17: 275-283.

59. Rose HD and Cohen K. The experiences of young carers: a meta-synthesis of qualitative findings. *Journal of Youth Studies* 2010; 13: 473-487.

60. Schraeder K, Dimitropoulos G, McBrien K, et al. Perspectives from primary health care providers on their roles for supporting adolescents and young adults transitioning from pediatric services. *BMC Fam Pract.* 2020 Jul 13;21(1):140.

61. Addo IY, Aguilar S, Judd-Lam S, et al. Young Carers in Australia: Understanding Experiences of Caring and Support-Seeking Behaviour. *Australian Social Work* 2024; 77:1, 60-73.

62. Andersen LB. Children's caregiving of HIV-infected parents accessing treatment in western Kenya: challenges and coping strategies. *Afr J AIDS Res* 2012; 11:3, 203-213.

63. Barry M. 'I realised that I wasn't alone': the views and experiences of young carers from a social capital perspective. *Journal of Youth Studies* 2011; 14:5, 523-539.

64. Blake-Holmes K and Cook L. Involved but not included: young carers' experiences of professional support while growing up with a parent with mental ill-health. *Journal of Social Work Practice* 2024; 38:3, 333-348.

65. Brimblecombe N, Stevens M, Gowen S, et al. Types and aspects of support that young carers need and value, and barriers and enablers to access: the REBIAS-YC qualitative study. *Health Soc Care Deliv Res* 2024;12(36).

66. Cluver L, Operario D, Lane T et al. “I can’t go to school and leave her in so much pain”: educational shortfalls among adolescent ‘Young Carers’ in the South African AIDS Epidemic. *Journal of Adolescent Research* 2012; 27(5) 581–605

67. D’Amen B, Socci M, Di Rosa M, et al. Italian adolescent young caregivers of grandparents: difficulties experienced and support needed in intergenerational caregiving - qualitative findings from a European Union Funded Project. *Int J Environ Res Public Health* 2022; 19, 103.

68. Doutre G, Green R and Knight-Elliott A. Listening to the voices of young carers using Interpretative Phenomenological Analysis and a strengths-based perspective. *Educational & Child Psychology* 2013; 30(4): 30-43.

69. Gowen SM, Hart CS, Sehmar P, et al. ‘..It takes a lot of brain space’: Understanding young carers’ lives in England and the implications for policy and practice to reduce inappropriate and excessive care work. *Children & Society* 2022; 36:118–136.

70. Janes, E. Young carer perception of control: results of a phenomenology with a mixed sample of young carers accessing support and unknown to services. *Int J Environ Res Public Health* 2022; 19, 6248.

71. Kaiser S, Siegemund-Johannsen S, Schulze GC, et al. Basic conditions for support of young carers in school: a secondary analysis of the perspectives of young carers, parents, teachers, and counselors. *Healthcare* 2024; 12: 1143.

72. Matzka M and Nagl-Cupal M. Psychosocial resources contributing to resilience in Austrian young carers – a study using photo novella. *Res Nurs Health* 2020; 43:629–639.

73. McDougall E, O’Connor M, and Howell J. “Something that happens at home and stays at home”: an exploration of the lived experience of young carers in Western Australia. *Health Soc Care Community* 2018; 26:572–580.

74. McGibbon M, Spratt T, and Davidson G. Young Carers in Northern Ireland: perceptions of and responses to illness and disability within the family. *British Journal of Social Work* 2019; 49(5), 1162-1179.

75. Nicholls W, Patterson P, McDonald FEJ, and Hulbert-Williams NJ. Unmet needs in young adults with a parent with a chronic condition: a mixed-method investigation and measure development study. *Scand J Caring Sci* 2017; 31; 191–200.

76. Phelps D. What changes for young carers? A qualitative evaluation of the impact of dedicated support provision for young carers. *Child and Adolesc Social Work J* 2021; 38:547–558.

77. Santini S, D’Amen B, Socci M, et al. Difficulties and needs of adolescent young caregivers of grandparents in Italy and Slovenia: a concurrent mixed-methods study. *Int J Environ Res Public Health* 2022;19, 2837.

78. Stevens M, Brimblecombe N, Gowen S, et al. Young carers' experiences of services and support: What is helpful and how can support be improved? *PLoS ONE* 2024; 19(3): e0300551.

79. Szafran O, Torti J, Waugh E et al. Former young carers reflect on their caregiving experience. *Canadian Journal of Family and Youth* 2016; 8(1):129-151

80. Yuan E H-W and Ku Y-W. The sacrificed children: listening to the voices of former young carers supporting parents with mental illness. *British Journal of Social Work* 2024; 54, 3243–3257

81. Goodger S and Kennedy A. *The situation of young carers in Europe.* 2024. Luxembourg: Policy Department for Economic, Scientific and Quality of Life Policies. European Union.

82. United Nations (1984) *Convention on the Rights of the Child (UNCRC)*. New York: United Nations.

**SUPPPLEMENTARY MATERIAL**

| Appendix 1: Characteristics of included studies | | | | | | |
|---|---|---|---|---|---|---|
| Study | Aim | Design & data collection | Recruitment | Analysis | Characteristics of young carers | Characteristics of those being cared for |
| Addo et al, 2021[61] (Australia) | To examine the effects of caring on the lives of young carers in New South Wales and their support-seeking behaviour | Qualitative: semi-structured interviews/focus groups | Fliers in schools and universities<br><br>Fliers/emails via young carers' organisations<br><br>Snowballing | Identification of codes/themes | N=28 young carers<br>Female (n=23)<br>Male (n=5)<br><br>Age 16–26 years (data only extracted for carers aged 18yrs or younger) | No information provided |
| Andersen, 2012[62] (Western Kenya) | To highlight the strategies that children adopt in order to cope with the hardship they face when becoming a primary caregiver to an HIV-infected parent on antiretroviral therapy in Western Kenya | Qualitative: ethnographic data collected through in-depth interviews, focus group discussions, drama, diaries and participant observation | Identified by local community health workers | Followed Emerson's (1995) five phases of analysis: reading, open coding, focused coding, initial memos, and integrative memo | N= 20 young carers<br><br>Age 6-16 years | HIV-infected parent on antiretroviral therapy |
| Barry, 2011[63] (UK: Scotland) | To explore the views and | Semi-structured interviews | Via young carers' projects | No information provided | N= 20 young carers<br>Female (n=10) | Mental or physical disabilities, mental |

| | | | | | | |
|---|---|---|---|---|---|---|
| | experiences of young carers in Scotland about their social networks and experiences of relationships with others, such as family, friends and teachers | | | | Male (n=10)<br><br>Age 12–23 years (data only extracted for the n=18 carers aged 18 years or younger) | health problems, ADHD, alcoholism and physical illnesses. Majority of the young carers were looking after their mother (although both parents ill or disabled in two cases); some were looking after siblings with disabilities or ADHD |
| Blake-Holmes & Cook, 2024[64] (UK) | To report young carers' retrospective accounts of professional support when caring for a parent with mental illness during childhood | Qualitative: biographical narrative interviews | Researcher speaking at public events, such as Mind, Young Carers' conferences and through social media | Thematic narrative method | N=20<br>Female (n=15)<br>Male (n=5)<br><br>Age 19-54 years (former young carers reflecting back on their childhood experiences of being a young carer) | Parents with mental ill health |
| Brimblecombe et al, 2024[65] (UK)<br>*Sits within the same study as* | To provide new knowledge and address prior research gaps regarding how best | In-depth qualitative methodology using focus groups, in-depth semi-structured | Young carers' organisations in four localities in England with contrasting | Thematic analysis | N=133<br>Age 9–25 years<br>Including:<br>N=41 aged 9-11<br>N=57 aged 12-15 | Where known, 25 cared for a sibling, 46 for a parent and 2 for another |

| | | | | | | |
|---|---|---|---|---|---|---|
| *Stevens et al 2024* | to support young carers from their perspective and that of the people they care for | interviews and workshops in four localities in England | ethnicity and rurality, and including areas of high deprivation | | N=36 aged 16-25 (data only extracted for carers aged 18 years or younger) | relative. Some cared for more than one person. Reasons for needing care, where known, were mental ill health (N=26), physical ill health (N=19), substance misuse (N=8) and other (N=5: e.g., dementia, neurodiversity and learning disability). Many had mental and physical ill health needs. |
| Charles et al, 2011[40] (Canada) | To explore caregiving experiences of young people from immigrant families and how the caring experience impacted their lives | Qualitative sub-study of young carers within British Columbia study: semi-structured interviews | Distributed posters in a broad range of locations | Thematic analysis | N=20 young carers<br>Female (n=17)<br>Male (n=3)<br>Age range: participants were adults who were young carers when 8-17 years old | No information provided |
| Cluver et al, 2011[66] (South Africa) | To determine educational impacts of household AIDS-sickness | Phenomenological qualitative approach: in-depth, open-ended qualitative | Door-to-door sampling in 20 rural communities or urban townships identified as the most deprived in | Thematic content analysis, followed by a phenomenological approach to analysis for the | N=659 young carers<br><br>Age range: 10-20yrs (data only extracted for carers | AIDS |

| | | | | | | |
|---|---|---|---|---|---|---|
| | and other sickness among adolescent young carers | interviews (including drawings) | the Western Cape, and through schools | experiences of young people caring for sick relatives | aged 18 years or younger) | |
| D'Amen et al, 2022[67] (Italy) *Sits within the same study as Santini et al 2022* | To describe the experiences of Italian adolescent young carers of grandparents, to explore difficulties encountered and support needed in the caring role | Qualitative data drawn from an online survey within EU Horizon 2020 Me–We project. Two open-ended questions focused on (1) help that would support the young carers and (2) main difficulties encountered as a young carer | Europe-wide convenience sample; Italian respondents mainly recruited among high school students from a region in the north and a region in centre of Italy | Open coding process, followed by grouping of codes referring to same phenomenon into sub-themes, and then higher-order themes, finally described in conceptual maps | N=87 young carers<br>Female (n=58)<br>Male (n=27)<br>Transgender/non-binary (n=2)<br><br>Age 15-17 years | Grandparents (older adults aged 65 years and over) with mainly from physical disabilities (62.1%) or cognitive impairments (35.6%) |
| Doutre et al, 2013[68] (UK) | To explore young carers' experiences to seek to better understand their lives through a strength-based perspective | Qualitative: Semi-structured interviews and photo elicitation techniques | Recruited through a Young Carers Project in a rural area of England | Interpretive Phenomenological Analysis | N=6 young carers<br><br>Age 11-13 years | Mental illness |
| Gowen et al, 2022[69] (UK) | To inform understanding of children's entitlements, societal obligations towards them and implementation of | Qualitative ("interpretive"): focus groups | Service users of a young carers project in the north of England | Thematic analysis | N=21 young carers<br><br>Age 9-18 years | Fibromyalgia, anxiety and depression, autism, visual impairment, mental health diagnosis, substance abuse, |

| | | | | | | |
|---|---|---|---|---|---|---|
| | the legislation in terms of ethical and legal boundaries of children's caring responsibilities | | | | | learning disability, physical disability |
| Hamilton & Adamson, 2013[43] (Australia) | To explore the caring responsibilities, impacts and needs of young carers | Qualitative: semi-structured interviews plus short online questionnaire post-interview | Via partner organisations displaying posters at educational institutions and health service providers | Thematic analysis | N=23 young carers<br>Female (n=8)<br>Male (n=14)<br>Age range: 8-17 years<br><br>N=13 young adult carers<br>Age range: 18-25 years (data only extracted for carers aged 18 years or younger) | Physical health (n=15)<br>Mental health (n=13)<br>Intellectual (n=10)<br>Long term condition (n=9)<br><br>Mother (n=9)<br>Father (n=6)<br>Siblings or other relatives (n=15) |
| Janes, 2022[70] (UK) | To identify the impacts of the caring role across young carers who access or chose not to access support | Qualitative | Via schools and young carers projects | Phenomenological approach | N=10<br>Female (n=6)<br>Male (n=4)<br><br>Age 11-16 years | Mother (n=8)<br>Sibling (n=2)<br>Grandfather and mother (n=1)<br><br>Bi-polar (n=3); diabetes and hearing loss (n=1); multiple sclerosis (n=1); spina bifida, hydrocephalus, and epilepsy (n=1); aplastic anaemia |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | | | | | (n=1); autism (n=1); cerebral palsy and learning difficulties (n=1); old age, dizziness, confusion (n=1); former substance misuse and mental health (n=1) |
| Kaiser et al, 2014[71] (Germany) | To explore how schools can develop comprehensive, sustainable<br><br>support systems for young carers | Secondary analysis of an existing data set | No information provided | Qualitative analysis involving coding and categorisation undertaken using MAXQDA | N=9<br>Age 13-16 years | No information provided |
| Leu et al, 2018[47] (Switzerland) | To explore the personal experiences and perceptions of young carers | Qualitative: semi-structured interviews and semi structured questionnaire with open questions | Healthcare services, schools and school based social workers, social services and NGOs working with specific illness types (including palliative care associations, home care nursing services and others) | Thematic analysis | N=15 young carers<br>Female (n=11)<br>Male (n=4)<br>Age under 18 years<br><br>N=14 young adult carers<br>Female (n=13)<br>Male (n=1)<br>Age range: 18–25 years (data only extracted for carers aged 18 years or younger) | Physical health (n=11)<br>Mental health (n=1)<br>Addiction (n=1)<br>No diagnosis (n=2)<br><br>Mother (n=6)<br>Father (n=1)<br>Siblings (n=8) |

| | | | | | | |
|---|---|---|---|---|---|---|
| Matzka & Nagl-Cupal, 2020[72] (Austria) | To identify psychosocial resources used by young carers in Austria | Qualitative descriptive study: photo elicitation interviews | Via private and state-funded healthcare and service providers operating throughout Austria that may have encounters with young carers | Directed qualitative content analysis and using the theoretical lens of resilience | N=10 young carers<br>Female (n=4)<br>Male (n=6)<br><br>Age range: 9-17 years | Chronically ill siblings or parents |
| Mauseth & Hjälmhult, 2016[45] (Norway) | To identify the main concerns and coping strategies of young carers who care for their parents with multiple sclerosis | Qualitative: semi-structured interviews | Local Multiple Sclerosis Society and the Norwegian Multiple Sclerosis Competence Centre | Thematic analysis | N=15 young carers<br>Female (n=8)<br>Male (n=7)<br><br>Age range: 12-18 years | Permanent wheelchair user (n=3)<br>Using walking aid (n=7)<br><br>Mother (n=8)<br>Father(n=7) |
| McAndrew et al, 2012[36] (UK) | To report on a participatory project which aimed to understand the needs of young carers | Participatory qualitative research involving participation in a young carer support group (VOCAL) presentation | Hosting of two World Café-based events to raise awareness of the mental well-being of young people, initially within the local community | Thematic analysis | N=6 young carers<br><br>Age range: 13-17 years | No information provided |
| McDougall et al, 2018[73] (Western Australia) | To explore the lived experiences of young carers | Qualitative descriptive design using a phenomenological framework through | Via online platforms and through posters in educational | Thematic analysis | N=13 young carers<br><br>Age range: 14-25 years (data only extracted for carers | Physical disabilities (e.g. cerebral palsy), a chronic life limiting or terminal illness (e.g. |

| | | | | | | |
|---|---|---|---|---|---|---|
| | | in-depth semi-structured interviews | institutions, health service providers, carer and youth support service offices, shopping centres, libraries and recreation centres | | aged 18yrs or younger) | dementia or advanced cancer), or mental health problems (e.g. schizophrenia) |
| McGibbon et al, 2019[74] (UK: Northern Ireland) | To identify the factors which contributed to, or challenged, the resilience of young carers | In-depth semi-structured interviews | Via Barnardo's Young Carers and Action for Children Young Carers Projects, along with the Health and Social Care Board | Thematic analysis | N=22 young carers<br>Female (n=18)<br>Male (n=4)<br><br>Age range: 8-18 years | Adult care recipients had a combination of mental and physical health problems. Care recipients under eighteen were living with conditions including cerebral palsy, ADHD and autism. N=11 cared for more than one person. A third reported childcare responsibilities whilst providing care and support for one or more care recipients. |

| | | | | | | |
|---|---|---|---|---|---|---|
| Moore et al, 2011[44] (Australia) | To investigate the caring role and impacts of caring for a relative with alcohol or drug issues | Exploratory qualitative research project: open-end questions interview and prompts around themes developed from a literature review | Actively engaging agencies and services, and advertisements in newsletter articles and electronic bulletins | Thematic analysis | N=15 young carers<br>Female (n=8)<br>Male (n=7)<br><br>Age range: 11-17 years<br><br>N=12 participated in interviews<br>N=3 participated in focus group | Alcohol or drug issues (many were poly-drug users)<br><br>Mother (n=8)<br>Father (n=5)<br>Sibling (n=2) |
| Mordoch, 2010[37] (UK) | To explore how children understand parental mental illness and the message they want to tell other children | Qualitative: secondary analysis of a grounded theory study | Original study (Murdoch & Hall, 2008): mental health professionals working in acute care, community and consumer support groups distributed letters to parents explaining the study. Also, posters and adverts placed in newsletters and a community newspaper | Thematic analysis (secondary) | N=22 young carers<br>Female (n=8)<br>Male (n=14)<br><br>Age range: 6-12 years | Primary diagnosis of depression, bipolar disorder or schizophrenia and receiving treatment |
| Newman et al, 2019[41] (Canada) | To assess young carers' experiences and needs of caring | Qualitative (retrospective) descriptive study: semi-structured- | Youth organizations, social media and a youth dementia | Thematic analysis | N=5 young carers<br>Female (n=5) | Dementia (n=5)<br><br>Grandmother (n=2)<br>Grandfather (n=2) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | for a relative living with dementia | individual interviews conducted by telephone or Skype | awareness symposium held at the primary author's university | | Age range: adults who were young carers when 12–18 years old | Mother (n=1) |
| Nicholls et al, 2017[75] (UK) | Study 1 of two studies reported in the paper: To determine whether current knowledge from cancer literature regarding young carers is generalisable to chronic conditions and, therefore, whether an existing screening tool could be adapted for this population | Study 1 of two studies reported in the paper: qualitative interviews | Study 1 of two studies reported in the paper: opportunistic sampling from UK colleges | Study 1 of two studies reported in the paper: interpretive phenomenologcal analysis (Study 1 of two studies reported in the paper) | Study 1 of two studies reported in the paper:<br><br>N=7 young carers<br><br>Age range: 17-19 years (data only extracted for carers aged 18yrs or younger: n=6) | Study 1 of two studies reported in the paper: cared for parents lived with migraine, arthritis, epilepsy, renal failure/kidney disease, myalgic encephalopathy |
| Nichols et al, 2013[49] (USA & Canada) | To understand the needs and caring experiences of young carers who care for people with frontotemporal dementia (FTD) to create a relevant support website for young caregivers of dementia patients | Qualitative: semi-structured interviews | Young carers (from US and Canada) on a list of parents of young carers of people affected by FTD who were interested in voicing their opinions | Thematic analysis | N=14 young carers<br><br>Age range: 8-18 years<br><br>Focus group 1: (n=6)<br>Focus group 2: (n=8) | Frontotemporal dementia<br><br>Mother (n=2)<br>Father (n=10) (includes two stepfathers)<br>Grandfather (n=2) |

| | | | | | | |
|---|---|---|---|---|---|---|
| O'Dell et al, 2010[38] (UK) | To explore young peoples' thoughts on providing informal care for relatives | Qualitative: in-depth interviews using vignettes | Young carers from six schools and colleges in South East and south coast of England | Thematic analysis | N=46 young carers<br><br>Age range: 15-18 years | No information provided |
| Phelps, 2021[76] (UK) | In relation to Hampshire Young Carers Alliance to explore: (a) what are the most important changes that the young carer services made to young carers and their families? (b) what is it about the services that creates those changes? | Qualitative: Semi-structured interviews | Via young carer projects in the Hampshire Young Carers Alliance | Thematic analysis | N=8<br><br>Age 9-17 years | No information provided |
| Santini et al, 2022[77] (Italy and Slovenia)<br><br>*Sits within the same study as D'Amen et al 2022* | To shed a light on the needs and difficulties faced by a sample of adolescents aged 15-17, caring for grandparents living in Italy and Slovenia | Qualitative | Via secondary schools in Italy and Slovenia | Open coding process to identify concepts and their dimensions within the data with the support of MAXQDA | N= 162 living in Italy (n=87) and Slovenia (n=75)<br><br>Age 15–17 years | Grandparents<br><br>Physical Disabilities (n=102); cognitive Impairments (n=50); mental health (n=36); addiction (n=12); other (n=38) |
| Stamatopoulos, 2018[42] (Canada) | To explore the positive and negative impacts | Qualitative: two focus groups and one in-depth | Via formal young carers programs e.g., Young Carers | Thematic analysis | N=15 young carers | Conditions: substance (alcohol) abuse, terminal |

| | | | | | | |
|---|---|---|---|---|---|---|
| | for young carers delivering unpaid familial caregiving | interview, plus short survey post-discussion | Program (YCP) in Toronto and the Powerhouse Project's Young Carers Initiative (YCI) in the Niagara-Haldimand region | | Age range:15-18 years<br><br>Focus group 1: Toronto (n=10)<br>Focus group 2: Niagara region (n=4)<br><br>One interview with a young carer who had previously received program support | cancer, autism, and high likelihood of comorbidity<br><br>Relationship: >50% were siblings; next largest group parents; several provided care for multiple family members |
| Stevens et al, 2024[78]<br>(UK)<br>*Sits within the same study as Brimblecombe et al 2024* | To explore the experiences and views of young carers on aspects of services and support seen as helpful, valued, and acceptable, and what could be improved | Qualitative: focus groups or interviews | Young carers organisations in four localities in England with contrasting ethnicity and rurality, and including areas of high deprivation | Reflexive thematic analysis | N=133 young carers<br><br>Aged 9–25 years (data only extracted for carers aged 18 years or younger) | Parents, siblings or other relatives with mental ill health (n=26), physical ill health (n=19), substance misuse (n=8) or other (including dementia, neurodiversity, learning disability) n=5) |
| Svanberg et al, 2010[39]<br>(UK) | To discover children's experience and coping strategies, and how caring | Qualitative: semi-structured interviews, plus three quantitative measures | Via four UK dementia charities or an advertisement | Thematic analysis | N=12 young carers:<br>Female (n=6)<br>Male (n=6)<br><br>Age range: 11-17 years | Dementia<br><br>Female (n=2)<br>Male (n=7) |

| | | | | | | |
|---|---|---|---|---|---|---|
| | responsibilities impact their lives | | | | | |
| Szafran et al, 2016[79] (Canada) | To explore the experiences of young carers from the perspective of former young carers | Descriptive, exploratory study using focus groups | Purposefully recruited through community agencies using a recruitment notice, and snowballing | Descriptive perspective generating themes | N=5 former young carers<br><br>Age range: participants were adults who were young carers when under 18 years old | Parents or siblings living with schizophrenia, osteoarthritis, alcoholism, or autism, or abusive or neglectful parents |
| Trondsen, 2012[46] (Norway) | To explore the lived experience of young people living with mentally ill parents and potential role of online self-help groups for adolescents with mentally ill parents | Qualitative, action-oriented study: analysis of the conversation in an online self-help group for adolescents with mentally ill parents (about 600 messages) | Users from a Norwegian hospital website (comprising information pages and open access forum) for children and adolescents with mentally ill parents | Thematic analysis | N=16 young carers<br>Female (n=15)<br>Male (n=1)<br><br>Age range: 15-18 years | Conditions: bipolar disorder, some had had psychotic episodes or had attempted suicide |
| Van Parys & Rober, 2013[48] (Belgium) | To discover children's experience of parental depression and their caring roles in the family | Qualitative: semi-structured family interviews | Belgian university hospital psychiatric unit | Thematic analysis (one theme used as microanalysis in one family interview) | N=14 young carers<br>Female (n=9)<br>Male (n=5) | Depression<br><br>Mother (n=7)<br>Father (n=1) |
| Yuan & Ku, 2024[80] (Taiwan) | To listen to the voices of former young carers and explore their sense of responsibility, | Qualitative: interviews | Potential participants were recruited through advertisements in mental health and | Thematic analysis | N=19<br>Female (n=11)<br>Male (n=8)<br><br>Aged over 18 years | Parents<br><br>Schizophrenia and bipolar disorder (n=1); |

| | | | | | | |
|---|---|---|---|---|---|---|
| | their response to family and societal expectations and how these affected their lives | | social services of Taiwan, and through social media | | (Former young carers reflecting back on their childhood experiences of being a young carer) | schizophrenia (n=9); chronic mental illness (n=2); anxiety disorder (n=1); depression (n=1); bipolar disorder (n= 4); affective disorder (n=1) |