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# Young People with Caring Responsibilities: Time for Action.

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**Research Findings, Policy & Practice Recommendations**  
**Extended Appendices**

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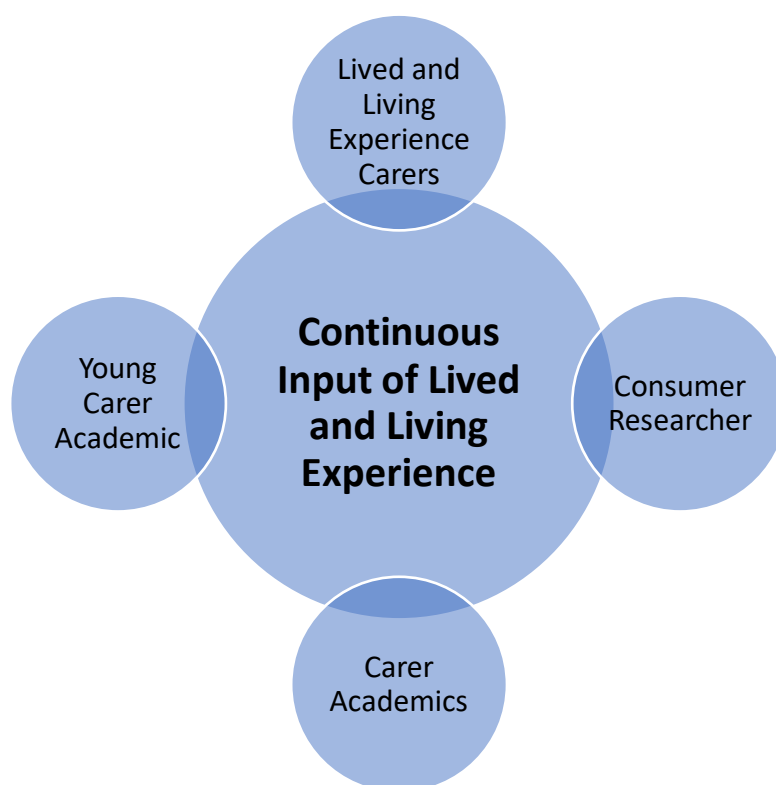
Department  
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## Appendix A:

# Continuous Input of Lived and Living Experience



**Fig.1.** Input of lived and living experience throughout project conceptualisation, data collection methods, data analysis and reporting.

Engaging young people in caring roles in research and/or consultations is sensitive and potentially confronting (e.g., discussing sensitive and complex concerns such as mental health and resilience). Therefore, it was essential that the consultations were undertaken in safe, ethical ways to ensure the wellbeing of participants. Consequently, all phases of consultation required ethical review and approvals by the La Trobe University Human Ethics Committee (Ethics Approval Number HEC23347). Engagement approaches for young people were informed by best practice guidelines, child safe standards, and child's voice principles. This included considering age-appropriate methods to engage young people and families safely and inclusively, such as peer support and the use of trained lived/living experience youth facilitators (e.g., youth facilitators from the Satellite Foundation).

Central to this project was the engagement and voice of a diverse range of young people in caring roles, family members, non-government organisations (NGOs) and government stakeholder perspectives. Their perspectives are represented in the findings of the field studies. Moreover, the design and execution of the research studies was continuously informed by the Bouverie Centre's three Lived and Living Experience (LLE) Carer and Consumer Researchers and a partner Carer

Academic from La Trobe University. The rapid review was led by a lived experience consumer academic (JO) and a carer academic (HK), and supported by the Centre's full research team.

Most importantly, the project integrated the work and views of a Young Carer Academic (SD). The Bouverie Centre's research team worked with the Satellite Foundation to engage a young person with current caring responsibilities (SD), who worked with the team at the Centre over three months and helped shape the design, analysis data and recommendations. This mentoring experience was a unique knowledge exchange, both an opportunity for our team to learn from and with this young person and for the young person to be mentored by a range of researchers in study design, data searching, synthesis and reporting.

In a knowledge exchange exercise, the Young Carer Academic was taught many of the academic methods involved in systematic reviewing, and in turn contributed to the interpretation of findings and to the design and execution of the field studies. Ongoing collaboration was enabled through weekly meetings with our LLE advisors and stakeholders, including the Department's Lived Experience Branch, ensuring input into design, field work, analysis to write up and the finalisation of recommendations.

## Appendix B: Rapid Systematic Literature Review

This rapid review was conducted in accordance with the Joanna Briggs Institute methodology framework (Aromataris & Munn, 2020). The reporting for the review followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) statement to guide methods and results reporting. The review protocol was registered with the PROSPERO repository:

[https://www.crd.york.ac.uk/prospERO/display\\_record.php?ID=CRD42023446988](https://www.crd.york.ac.uk/prospERO/display_record.php?ID=CRD42023446988) (Page et al., 2018) prior to conducting initial searches.

### Search strategy

The eligibility criteria for this review were developed following the Population, Intervention, Comparator, Outcome, and Study design (PICOS) framework (McKenzie et al., 2019). Only literature written in English language and published in the last 10 years was included. In the searched literature, terms such as young carer and young person with caring responsibilities are used to refer to children and young people (up to 25 years of age) whose home life include caring responsibilities. In this review, these terms are used interchangeably.

### Inclusion criteria

The search was completed based on the criteria in the concepts and detailed descriptions, as reported in Table 1.

**Table 1. PICOS inclusion and exclusion criteria.**

Element	Inclusion criteria	Exclusion criteria
<b>Population (P)</b>	<ul style="list-style-type: none"> <li>Young people with caring responsibilities</li> <li>Young Carer</li> <li>Young people mean age ≤25 years (inclusive)</li> <li>Adults (&gt;25 years) retrospectively reporting on YC supports throughout their caregiving youth (&lt;25 years).</li> <li>YC supporting a family or friend with a mental illness (inc. ASD) or AOD concern.</li> <li>Care recipient can have any co-occurring condition</li> </ul>	<ul style="list-style-type: none"> <li>Young carer mean age &gt;25 years (exclusive).</li> <li>Not caring for family member or friend with mental illness and/or AOD concern.</li> <li>Caring for someone with physical or neurological condition only</li> </ul>
<b>Intervention (I)</b>	<ul style="list-style-type: none"> <li>Provision of any young carer-specific support</li> <li>Report on a young-carer specific support</li> </ul>	
<b>Comparison (C)</b>	<ul style="list-style-type: none"> <li>Optional comparison group</li> </ul>	
<b>Outcome (O)</b>	<ul style="list-style-type: none"> <li>Optional outcome data on support service engagement, identification, and referral experience and efficacy</li> </ul>	<ul style="list-style-type: none"> <li>No support in the education, AOD and mental health service systems.</li> </ul>
<b>Study design (S)</b>	<ul style="list-style-type: none"> <li>Published in English from 2013-2023</li> <li>Quantitative, qualitative, or mixed-methods studies.</li> </ul>	<ul style="list-style-type: none"> <li>Unpublished literature</li> <li>Non-human studies, protocols, commentaries, editorials, newspaper articles, conference abstracts, book chapters, secondary studies</li> </ul>

Note. AoD=Alcohol and Other Drug use; ASD=Autism Spectrum Disorder; YC=Young Carer.

## Search strategy

On July 14, 2023, a systematic search of electronic databases PsycINFO , MEDLINE , Embase and CINAHL . Only studies published in English from 2013 - July 14, 2023, were searched. Table 2 details the search strategy. Following a rapid review methodology, grey literature was excluded from the present review (Moons et al., 2021; Tricco et al., 2015).

**Table 2. Search strategy for each database.**

PICO Elements	Concept	Search Strategy
Patient/ population	Informal or formal child or youth carer	(young ADJ3 (caregiv* OR carer OR care-giver)) OR (teen* ADJ3 (caregiv* OR carer OR care-giver)) OR (adolescen* ADJ3 (caregiv* OR carer OR care-giver)) OR (youth ADJ3 (caregiv* OR carer OR care-giver)) OR (child* ADJ3 (caregiv* OR carer OR care-giver)) OR student* ADJ3 (caregiv* OR carer OR care-giver) OR children of impaired parent [MeSH] OR children as caregivers [MeSH]
Patient/ population	Parents/family members with the mental health or AOD concern	family OR parent OR sibling OR relatives OR grandparents OR guardian OR friend ADJ4 "mental health" OR "mental disorder" OR depression OR anxiety OR "psychological distress" OR "mental illness" OR "substance use" OR addiction OR stress OR "post-traumatic stress disorder" OR "severe mental illness" OR "serious mental illness" OR "schizophrenia" OR "psychosis" OR "schizoffective" OR "schizo-affective" OR "bipolar disorder*" OR mania OR manic OR bipolar OR "major depressive disorder" OR "mental wellbeing" OR "emotional health" OR "emotional wellbeing" OR "well-being" OR psychosocial OR socioemotional OR externali#ing OR internali#ing OR "child behav*" OR "peer relations" OR "peer interactions" OR "social skill*" OR attachment OR conduct OR oppositional OR aggressive OR impulsiv* OR hyperactive OR antisocial OR AOD OR "alcohol and drug" OR "substance use" OR alcohol OR autistic OR autism OR asperger* OR ASD OR neurodivergent OR mental disorder [MeSH] OR mental health [MeSH] OR depression [MeSH] OR anxiety [MeSH] OR substance related disorder [MeSH] OR Autistic disorder [MeSH] OR Autism Spectrum Disorder [MeSH]
Intervention		This will not be included in the search strategy due to the breadth of possible supports (e.g., mental health, financial, educational, employment)
Comparison		This will not be included in the search strategy as inclusion of a comparison group was optional



<b>Outcome</b>	<b>Support for type/context</b>	Provider OR treatment OR agenc* OR program* OR rehab* OR detox* OR service OR "AOD service system" OR "alcohol and drug service" OR "mental health care" OR "social care" OR "legal service" OR "primary care" OR "early childhood" OR "early learning" OR kindergarten OR educat* OR school or universit* OR college OR academ* OR "child protection" OR "child service" OR work OR organi#ation* OR workplace OR workforce OR career OR corporate OR management OR workplace [MeSH] OR education [MeSH] OR school [MeSH] OR universities [MeSH] OR child protective service [MeSH]
<b>Outcome</b>	<b>Support user experience outcomes</b>	This will not be included in the search strategy due to the breadth of possible search terms (e.g., engagement, user experience, accessibility)

**Notes** The use of the wildcard sign (\*) at the end of a word enables databases to find words with alternative spelling and/or word variations, while the use of quotation marks ensures that multiple words are searched as a complete phrase and not as the individual words that comprise it. The use of the hash sign (#) replaces one letter for another. MeSH terms are medical subject headings, used for article referencing. All search concepts, search terms, and databases will be selected and developed with the assistance of a specialist health-science librarian. ADJ3= Proximity search which finds two terms next to each other in any order. Using ADJ3 will find any terms in any order within 3 words (or fewer).

## Study selection

All records were subsequently imported to EndNote (2013) and Covidence systematic review software (Veritas Health Innovation, 2020; <https://www.covidence.org>), with duplicates removed. Once all records were identified, duplicates were removed in Endnote ( $n=1707$ ) (Kisely & Siskind, 2020) and Covidence ( $n=221$ ) (McKeown & Mir, 2021). Following duplicate removal, 5403 records remained for initial screening.

## Study screening

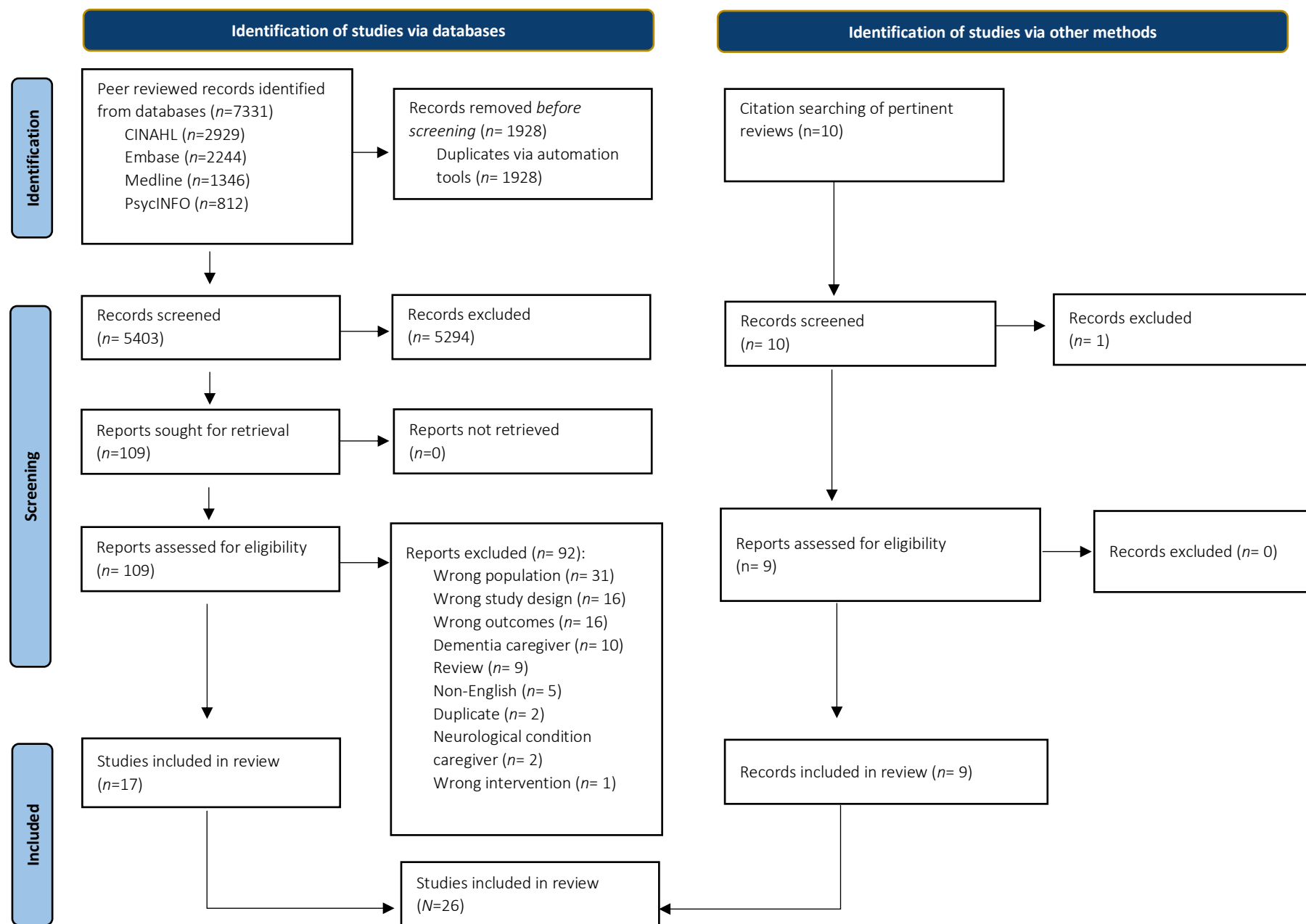
Identified studies were screened for eligibility via: (1) title, keyword, and abstract screening; and (2) full-text article screening. Studies were screened against the aforementioned eligibility criteria. After all studies were screened those that met eligibility criteria were included and had pertinent data extracted. See Fig. 1. for an example of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram (Page et al., 2021).

## Data extraction and synthesis

Data extraction was limited to a minimal set of required data items. Data extraction was recorded on a *a priori* standardised data extraction forms, consistent with Tables 2, 3, and 4. Outcomes of examination were data-driven, wherein we privileged frequently reported outcomes.

## Risk of bias assessment

Following data extraction, study quality was assessed. We used the Mixed Methods Appraisal Tool (MMAT; Hong, 2018), which is a validated risk of bias tool. Upon appraisal completion, studies were be labelled as 'weak', 'moderate', or 'high' in terms of their methodological quality. An *a priori* decision was made not to exclude any record based on study quality.



**Fig. 1. PRISMA diagram of the phases of the review process and record selection.**



## Study selection

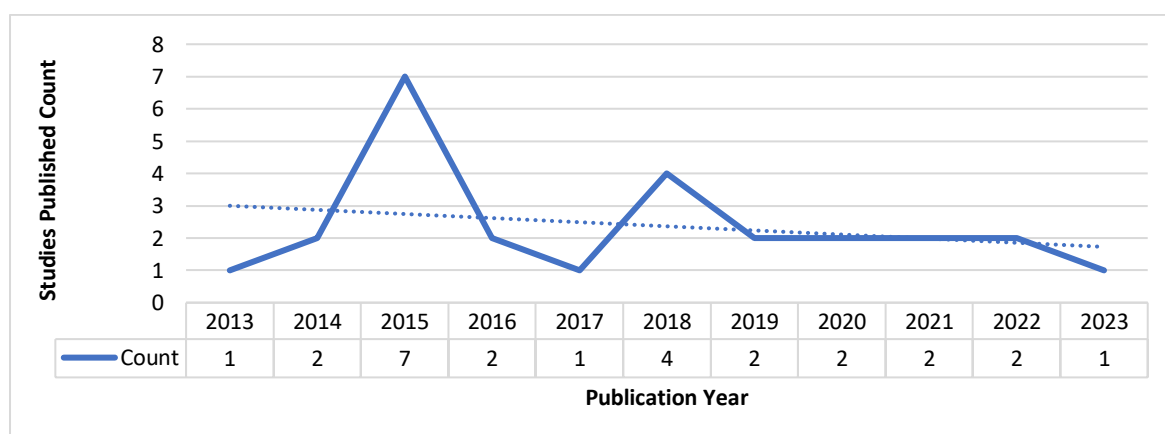
The search was completed on July 14, 2023, yielding 7340 published records. Following the removal of duplicates, 5403 records remained, of which 5387 records were excluded at title/abstract ( $n=5295$ ) and full-text ( $n=92$ ) screening levels. An additional ten studies were identified by searching for citations of pertinent reviews. The reviews were then screened for eligibility. A total of 26 published primary studies met all inclusion criteria and were included in the present review. Figure 1 (PRISMA) details the results at each level and reasons for exclusion.

## Study quality

Overall, the quality of included studies was high. The majority of studies were of low risk of bias ( $n=14$ ), followed by moderate risk of bias ( $n=10$ ), and high risk of bias ( $n=2$ ). Most studies of poor quality (with a moderate to high risk of bias) utilised mixed-methods designs ( $n=6$ ). In these studies, the quantitative data was not effectively integrated with the qualitative data. See Figure 1 for a visual presentation of study quality.

## Study characteristics

Among the 26 included studies, 14 were qualitative, six were quantitative and the remaining six were mixed methods in design. All participant data was collected through self-report measures. In the group of qualitative studies, varied study designs and methodologies were employed. Specifically, five studies used thematic analysis (Hagström & Forinder, 2019; McDougall et al., 2018; Phelps, 2021; Tabak et al., 2016; Wolpert et al., 2015), two employed manifest content analysis (Dam et al., 2018; Nilsson et al., 2015), two utilised phenomenological approaches (Cudjoe et al., 2023, Kettell, 2018) and two adopted inductive analysis methods (Trondsen & Tjora, 2014; Van der Werf et al., 2020). Additionally, one study was a retrospective observational design (Tanonaka & Endo, 2021), one used grounded theory (VanParys, 2015) and one followed an exploratory approach (Stamatopoulos, 2015). Study publication year ranged from 2013 to 2023, with a decrease in the number of studies published per year, as shown in Figure 2. See Table 2 for a description of the included studies' characteristics.



**Fig. 3.** Association between publication year and the number of identified published studies.



**Fig. 2.** Visual presentation of study quality.

Note: Question 1-2: Asked for all study designs. Q3-7: Mixed methods designs; Q8-12: Qualitative designs, Q13-17: Quantitative designs.

**Table 3. Characteristics of included studies.**

Study (year), Country	Study design	Respondent	Study aim	Pre N (AR%)
<i>Recruitment</i>	<b>Details</b>			
Acton (2016), UK, <i>School</i>	MM	YC, parent, teacher	Examine effects of immersive outdoors activities in woodlands on YC emotional literacy & well-being	8 (NR)
Ali (2013), Sweden <i>Community^</i>	MM <b>Quan: Cross-sectional; Qual: Inductive content analysis</b>	YC	Explore how YCs of a person with a MI use & experience support	Quan: 241 (0), Qual: 12 (0)
Ali (2014), Sweden <i>Community^</i>	Quan <b>RCT (2-arm)</b>	YC	Compare two interventions (1. web-based support [received access to website with resources, forum]; 2. folder support [received a folder with information on support services]), for YCs caring for someone with MI	241 (22.5 web group; 28.1 folder group)
Ali (2015), Sweden <i>Community^</i>	Quan <b>Cross-sectional (2-arm)</b>	YC	Compare caring situation, health, self-efficacy, & stress of young informal carers supporting a friend (i.e., friend group) with MI to a family member (caring for parent, sibling, partner, or others they lived with (i.e., family group) with MIs	225 (2)
Cudjoe (2023), Ghana <i>Out-patient mental health units</i>	Qual <b>Phenomenological approach</b>	YC	Explore experiences of YCs living with parental MI	21 (NR)
Dam (2018), Faroe Islands <i>Community^</i>	Qual <b>Retrospective observational, manifest content analysis</b>	YC	Explore experience of retro YCs who grew up with MI parents	11 (NR)
DeRoos (2017), Netherlands <i>Community^</i>	Quan <b>Longitudinal (2-arm)</b>	YC	Assess differences in well-being, need for help, & support use between youth with & without a chronically ill or disabled family member; & the role played by illness type, relationship to family member & nature of caring responsibilities	Total: 1581 (3) (Non YC: 1439 (NR), YCs: 142 (NR))
Drost (2015), Netherlands <i>Mental health service</i>	MM <b>Case study; Quan: Observational analysis; Qual: Content analysis</b>	YC	Understand YCs support seeking & support participation ( <i>SurvivalKid</i> )	1 (NR)
Gettings (2015), UK <i>Mental health service</i>	MM <b>Longitudinal (Quan: explorative, 1-arm; Qual: semi/structured interviews, thematic analysis)</b>	YC, parent	Explore the feasibility of sibling support groups through use of audio-conferencing	6 (17)
Gough (2020), UK <i>YC service</i>	MM <b>Exploratory sequential design (Qual: focus group, thematic coding; Quan: Correlation analysis)</b>	YC	Explore the factors associated with young carer's adjustment, protective factors, coping strategies and any benefit-finding	Qual: 4 (NR); Quan: 46 (NR)
Hagström (2019), Sweden <i>YC service</i>	Qual <b>Longitudinal, narrative thematic analysis</b>	YC	Understand what it means for children living with parents who misuse alcohol as well as what their support needs & coping strategies were	19 (NR)
Kettell (2018), UK <i>University</i>	Qual <b>Interpretative phenomenological analysis</b>	YC	Explore motivations, barriers, & challenges when considering higher education	3 (NR)
Landi (2022), Italy <i>Community^</i>	Quan <b>Longitudinal (3-arm)</b>	YC	To investigate YC responsibilities & mental health outcomes during COVID-19	Total: 1048 (79) (YCs: 235 (74), Non-carers: 813 (73))
McDougall (2018), Australia <i>Community^</i>	Qual <b>Thematic analysis</b>	YC	Explore the lived experiences of YCs, including the benefits & challenges of the role	13 (NR)
Nilsson (2015), Sweden <i>Mental health service</i>	Qual <b>Retrospective observational, descriptive, content analysis</b>	YC	Explore young adults' childhood experiences of support groups when living with a MI parent	7 (NR)
Phelps (2021), UK <i>YC services</i>	Qual <b>Thematic analysis</b>	YC, unwell parent, professional	Determine changes that YC services made to YCs & their families & what fosters changes	8 (NR)
Spratt (2018), Ireland <i>YC services</i>	Quan <b>Cross-sectional explorative analysis.</b>	YC	Explore YC protective & risk factors. Generate knowledge regarding such factors to inform policies & practices designed to promote YC resilience	22 (NR)
Stamatopoulos (2015), Canada <i>YC service</i>	Qual <b>Exploratory qualitative research</b>	Professional	Assess range of YC services & identify barriers to improving scope & reach	5 (NR)

Tabak (2016), Multiple countries* <i>Community</i> <sup>^</sup>	Qual <b>Observational, thematic analysis</b>	YC, healthy & unwell parent, professional	Analyse needs, expectations & consequences for YCs living with a parent with MI from the perspective of professionals & family members	96 (15 adult retro YCs; 31 MI parents; 50 professionals) ( <b>NR</b> )
Tanonaka (2021), Japan <i>Mental health service</i>	Qual <b>Retrospective observational, descriptive design (semi-structured interview)</b>	YC	Identify helpful resources for YC to cope	10 ( <b>NR</b> )
Trondsen (2014), Norway <i>Community</i> <sup>^</sup>	Qual <b>Inductive, issue-focused approach</b>	YC	Identify roles of online self-help group in supporting YCs in managing life with a MI parent	16 ( <b>19</b> )
Van der Werf (2020), Netherlands <i>University</i>	Qual <b>Retrospective observational, inductive analysis</b>	YC	Understand 'expectations & prospects' YCs have regarding support from professionals	25 ( <b>NR</b> )
VanParys (2015), Belgium <i>Community</i> <sup>^</sup>	Qual <b>Retrospective observational, grounded theory</b>	YC	Examine how YCs retrospectively experienced parental depression & parentification	21 ( <b>NR</b> )
Waters (2019), UK <i>YC service</i>	MM <b>Qual: focus groups, semi-structured interviews; Quan: cross-sectional</b>	YC, parent, professional	Explore how YCs were identified, assessed, & supported in <i>Royal Borough of Kingston upon Thames</i> .	Total: 78 ( <b>NR</b> ): YC Focus groups: 33 (NR); YC Surveys: 23 (NR); YC parents: 5 (NR); Professionals: 17 (NR)
Wepf (2022), Switzerland <i>Educational institutions</i>	Quan <b>Cross-sectional (3-arm)</b>	YC	Examine impact of a caring youth mental health & assess YCs needs	2525 ( <b>84</b> )
Wolpert (2015), UK <i>YC service</i>	Qual <b>Thematic analysis</b>	YC, unwell parent	Explore YC and parent experience of <i>Kidstime</i> and identify improvement needs	20 (6 current YCs attending support; 5 current parents attending support; 2 former service users who finished support; 7 former brief support attendees) ( <b>NR</b> )

Note. <sup>^</sup>Community=Includes recruitment via national surveys, social media, flyers in community settings; \*England, Finland, Germany, Italy, Norway, Poland, Scotland MI=Mental illness; MM=Mixed methods; NR=Not reported; Qual=Qualitative; Quan=Quantitative; RCT=Randomized controlled trial; Retro=Retrospective; UK=United Kingdom; YC=Young carer.

Among the quantitative studies, three were cross-sectional studies (Ali et al., 2015; Spratt et al., 2018; Wepf & Leu, 2022), two were longitudinal (DeRoos, 2017; Landi, 2022) and one was a randomized controlled trial (pre-post design; Ali, 2014). Three of these studies included two comparison groups (two-arm; DeRoos et al., 2017; Ali et al., 2014; Ali et al., 2015), while a further two included three comparison groups (three-arm; Landi et al., 2022; Wepf & Leu, 2022). In the mixed methods designs various approaches were used for both quantitative and qualitative analyses. For the quantitative portion, three studies used cross-sectional analyses (Ali et al., 2013; Gough & Gillford, 2020; Waters, 2019;), one used a longitudinal design (Gettings et al., 2015), one used a pre-post design (Acton, 2016) and one conducted an observational case study (Drost & Schippers, 2015). For the qualitative portion, thematic analysis was employed in three studies (Acton & Bernie, 2016; Gough & Gillford, 2020; Gettings et al., 2015), content analysis was used in another two (Drost & Schippers, 2015, Ali et al., 2013) and one study used interviews but did not specify their analytical approach (Waters, 2019).

Included studies were geographically diverse but concentrated on European countries ( $n=22$ , 85%). All studies except one (4%; Cudjoe et al., 2023) were conducted in Western Anglophone countries. The United Kingdom had the highest concentration with seven studies (27%), followed by Sweden with five studies (19%) and the Netherlands with three studies (12%). One study included multiple European countries including England, Finland, Germany, Italy, Norway, Poland and Scotland (Tabak et al., 2016). Of note, only one study (4%; McDougall et al., 2018) was conducted in Australia, indicating a lack of Australian-based research. Participants were frequently recruited from the community ( $n=11$ ; 42%; e.g., national surveys, social media), followed by mental health services ( $n=5$ ; 19%), young carer specific services ( $n=6$ ; 23%), universities ( $n=3$ ; 12%) and schools ( $n=1$ ; 4%).

## Participant characteristics

Participants were frequently recruited from the community ( $n=11$ ; 42%; e.g., national surveys, social media), followed by mental health services ( $n=5$ ; 19%; e.g., specialist child and adolescent mental health Service (CAMHS), outpatient mental health units), young carer specific services ( $n=6$ ; 23%), universities ( $n=3$ ; 12%) and schools ( $n=1$ ; 4%). Participants included young carers ( $n=19$ ), both young carers *and* parents ( $n=2$ ; Gettings et al., 2015; Wolpert et al., 2015), professionals ( $n=1$ ; Stamatopoulos, 2015), or multiple study participants comprising of young carers, parents and health professionals or teachers ( $n=4$ ; Acton & Bernie, 2016; Phelps, 2021; Tabak et al., 2016; Waters, 2019). The age of young carers varied from 4-49 ( $n=22$ ), with a mean young carer age of 19.65 ( $n=13$ ). No age data could be collected on other participant respondents (e.g., parent, professional) due to missing data. The sample size of included studies varied widely (range=1–2525;  $M=257.54$ ). Study participants (i.e., young carers *and* non-young carers) were predominantly female ( $n=21$ ;  $M=68.11\%$ ); similarly, when only looking at the young carers, 68.87% ( $n=21$ ) of the participants were female. There were few parent respondents ( $n=6$ ) and most of them were female ( $n=2$ ; 91.67%). Only one study (DeRoos et al. 2017), conducted in the Netherlands, reported on young carer race/ethnicity, with 88.1% of participants of Dutch descent. For detailed information regarding participant characteristics, consult Table 4.

**Table 4. Characteristics of young people with caring responsibilities**

Study (year), Country <i>Recruitment</i>	M age (range), F%	YC account	Education, vocation etc. status	Care recipient relationship to YC	# caring for	Condition requiring care	Youth health status	Degree/amount/type of carer support provided (FT/PT etc.)
Acton (2016), UK <i>School</i>	NR (9-13), <b>37.5</b>	Current	Students: 8	Parent: 8	1	MI, drug addiction, learning difficulties, very limited mobility	1 female had learning difficulties, 3 male ADHD & behavioral issues	Daily care (incl. emotional support, housework, cooking, sibling care, medication management)
Ali (2013), Sweden <i>Community</i>	Quan: 20.1 (16-25), <b>71</b> Qual: 21.3 (16-25), <b>75</b>	Current	Quan: other education:79; employed: 50; university: 47; unemployed: 25. Qual: other education: 1; elementary school: 4; upper secondary school: 7	Family member (parent, sibling, other relative)	1	MI (depression: 178, bipolar: 27, anxiety: 113, self-harm: 55, ADHD/ASD: 15, ED: 46)	81% good general health; 63% good general quality of life; 47% completed wkly leisure activities; 62% exercise wkly	Quan: M care duration in mo. =108; Qual M care duration=44.6mo.
Ali (2014), Sweden <i>Community</i>	Web support: 20.5 (16-25), <b>73</b> ; Folder support: 20.5 (16-25), <b>69</b> ; Total sample: NR (16-25), <b>70.54</b>	Current	Web support: employee: 26; university: 24; other education: 42; unemployed: 10. Folder support: employee: 24; university: 23; other education: 37; unemployed: 15	Family member (parent, sibling, other relative) or friend.	1	MI	NR	Inclusion criteria required participants to provide care over an extended period of time (time undefined)
Ali (2015), Sweden <i>Community</i>	Family group: 20.8 (16-25), <b>73</b> ; Friend group: 19.4 (16-25), <b>70</b> ; Total sample: NR (16-25), <b>72</b>	Current	Family group: employee: 33; university: 26; other education: 28; unemployed: 9; Friend group: employee: 27; university: 23; other education: 59; unemployed: 18	Family member (parent, sibling, or other relative): 97 Friend: 128	1	MI ( <b>Family group:</b> (depression: 71, bipolar: 15, anxiety: 42, self-harm: 18, ED: 14, ADHD/aspergers: 9) <b>Friend group:</b> (depression: 107, bipolar: 12, anxiety: 71, self-harm: 37, ED:32, ADHD/aspergers: 6))	48% of total sample feel alone. 47% participate in wkly leisure activities	Family group provided support (to parent, sibling, partner or others they lived with) for a longer period (M=65mo.) vs. the friend group (M=29mo.)
Cudjoe (2023), Ghana <i>Out-patient mental health units</i>	13.29 (10-17), <b>61.9</b>	Current	NR	Parent (mothers: 17, fathers: 3)	1	MI (depression: 9, schizophrenia: 5, psychosis: 5, anxiety disorder: 2)	NR	NR
Dam (2018), Faroe Islands <i>Community</i>	34 (18-49), <b>72.3</b>	Retro	NR	Parent (mothers: 10, father: 1)	1	MI (bipolar: 5, schizophrenia: 6)	NR	Some YC's had no relatives to help them & so they had to take care of practical matters on their own;
DeRoos (2017), Netherlands <i>Community</i>	Total: 14.6 (13-17), Non-YCs: 14.6 (NR), YCs: 15.0 (NR) <b>Total: 55.47%, Non-YCs: 55.1%, YCs: 59%</b>	Current	Students	Family member (parent, sibling, grandparent)	1	MI: 30%, physical illness: 53%, MI & physical illness: 17%	YCs reported more psychosocial problems, but more pro-social behavior than non-YC	65% provided care for a M= 5.7hrs per wk (range 1-24); 24% provided only domestic &/or administrative help; 43% provided only care &/or company; 33% provided both care & company.
Drost (2015), Netherlands <i>Mental health service</i>	24 (24), <b>100</b>	Retro	Employed: 1	Parents & younger siblings: 1	>1	MI: 1	Retro YCs reported poor health when younger & sought subsequent treatment. Past YC role still had health impacts.	Sibling care, household chores
Gettings (2015), UK <i>Mental health service</i>	NR (8-13), <b>YC: NR, Parent: 83.33</b>	Current	NR	Sibling: 6	1	Complex neurodevelopmental disorders involving 2> co-morbid conditions (incl. ASD: 6, ADHD: 4, OCD: 2, ODD: 1, multiple anxiety	NR	NR

Gough (2020), UK <i>YC service</i>	Qual: NR (16-20), <b>100</b> Quan: 15.28 (12-17), <b>63</b>	Current	Qual: YCs achieved a General certificate of secondary education: 4. Quan: secondary education: 46	Qual: NR; quan: mother: 29, father: 11, brother: 13, sister: 10, grandparent: 1, other relative: 1	37% were caring for >1	disorders: 1, mood disorder: 4, harmful use of cannabis: 1. Qual: NR; Qual: Physical: 29, Mental: 21, Substance: 1, Learning: 14, Sensory: 3, Other (brain injury/ neurological): 4	NR	Qual: Time providing care ranged from 8-13 years ( <i>M</i> = 9.25 years), indicating a significant amount of time spent caregiving during childhood. Quan: Type of care provided: General care: 39, household: 24, sibling care: 23, Emotional support: 20, Personal/intimate: 3, Finance: 2. Weekly hrs of care: 6–10hrs: 14; 11–15hrs: 4; 16–20hrs: 3, 21–30 hrs: 5; 31–40hrs: 6; 41–50hrs: 1, >50hrs: 5. Care length: <2yrs: 13, 3–5yrs: 28, 6–9yrs: 35, ≥10yrs: 24.
Hagström (2019), Sweden <i>YC service</i>	7.89 (6-11), <b>41</b>	Current	Employed: 7; students: 10; unemployed: 2	Family member (father: 10; mother: 4; both parents: 5; sibling: 4)	Some cases >1	Alcohol dependent	NR	Cared for alcoholic parent (e.g., dressing, bedtime assistance, medication reminding, phoning for help, household support, cleaning up vomit)
Kettell (2018), UK <i>University</i>	21.67 (20-23), <b>100</b>	Current	Higher education: 3	Family member (sister: 1; mother: 1; brother & father: 1)	1 >1	Mental health: 1, autism & bipolar disorder: 1, MS: 1	NR	NR
Landi (2022), Italy <i>Community</i>	Total: 24.5 (18-29), <b>74.3</b> YC: 22.79 (NR), <b>75.74</b> Non-carer: 24.57 (NR), <b>73.92</b>	Current	Student: 597; employed: 355; not in education or employment: 103	Family member: (parent: 162, sibling: 50, grandparent: 72, uncle/aunt/cousin: 113)	1	Parent carer (46.3% MI, 66.1% physical illness) or non-parent carer (45.2% MI, 56.2% physical illness)	Physical health condition in YCs who care for: parent carer (11.1%); non-parent carer (16.4%); Physical health condition in non-carers** (8.9%)	Mean scores moderate levels of caregiving responsibilities via YCPI-R: 1. parent carer: 2.16; 2. non-parent carer: 2.11; non-carer: 1.89
McDougall (2018), Australia <i>Community</i>	18 (14-25), <b>53.8</b>	Current (12) Retro (1)	Students: 6; employed: 6; tertiary education: 6	Parent/grandparent: 7; siblings: 7; cousin: 1; non-family: 1	4 >1	MI, physical disabilities, chronic, life limiting, terminal illness	NR	NR
Nilsson (2015), Sweden <i>Mental health service</i>	NR (19-26), <b>100</b>	Retro	NR	Parent: 7	NR	MI: 7	NR	NR
Phelps (2021), UK <i>YC services</i>	NR (9-17), <b>YCs: NR, Parents: 100</b>	Current	Students	Parent (3/5 mothers)	NR	Disability & other conditions not described	NR	NR
Spratt (2018), Ireland <i>YC services</i>	NR (8-18), <b>81.8</b>	Current	Students	Parent	NR	MI: 16, physical disability/illness: 6	1 attempted suicide; 2 self-harmed	NR
Stamatopoulos (2015), Canada <i>YC service</i>	NR	Current	NR	NR	NR	NR	NR	NR
Tabak (2016) Multiple countries* <i>Community</i>	NR	Retro	NR	Parent: 31	NR	MI: 31	NR	NR
Tanonaka (2021), Japan <i>Mental health service</i>	NR (NR) - 20s (40%), 30s (20%), 40s (30%), 50s (10%), <b>70</b>	Retro	NR	Parent: 11	1	MI: Schizophrenia: 10; panic disorder: 1	NR	60% of YCs completed <i>all</i> household chores on top of other duties (10% money management). 20% <i>some</i> household chores on top of other roles (20% accompanying parent on hospital visits; 10% medication help; 10% chat/advice)
Trondsen (2014), Norway <i>Community</i>	NR (15-18), <b>100</b>	Current	Students	Parent	1	Severe MI (incl. bipolar, psychotic episodes, suicide attempts)	NR	NR



Van der Werf (2020), Netherlands <i>University</i>	21.4 (NR), <b>96</b>	Retro	Current education: bachelor of applied sciences: 14; secondary vocational: 11	Family (mother: 5; father: 5; sibling: 4; other relative: 4; multiple family members: 7	7 >1	Physical disorder: 8; mental disorders & addiction related problems: 8; multiple health concerns: 9	NR	NR
VanParys (2015), Belgium <i>Community</i>	23 (18-29, <b>85.7</b>	Retro	Students: 13; employed: 8	Parent (mothers: 15, fathers: 6)	1	MI (depression): 21	NR	Participants recounted that their childhood consisted mainly of actions in the service of family well-being
Waters (2019), UK <i>YC service</i>	Quan: NR (9-18), <b>NR</b> ; Qual: NR (7-18), <b>51.5</b>	Current	NR	Family member (parent: 12; brother: 10, sister: <b>NR</b> )	5 >1	MI or learning disability: 35% physical disability: 43% ADHD/ASD: 35%	43% had additional needs (incl. diabetes, asthma). 77% sometimes/always felt stress/anxious/isolated/lonely/tired/upset/down/sad/angry due to YC role	96% of YCs had support with caring tasks, most commonly mothers (65%) & sisters (43%). All YCs lived with care recipient. Care roles incl. cooking, shopping, pet care, transport, driving (61%); emotional support (61%); personal caring (24%).
Wepf (2022), Switzerland <i>Educational institutions</i>	Total: 17.73 (15–21), <b>59.6</b> ; YCs: 17.91, <b>70.40</b> ; Non carer (health problems): 17.76, <b>63.9</b> ; Non carer (healthy): 17.65, <b>53.8</b>	Current	General education: 110; vocational education: 2161; transitional options: 73; other: 81	Family (parent: 31.9%; sibling: 12.4%; grandparent: 19.8%; aunt/uncle: 7.2%), friend: 27.1% (incl. partner: 7.7%), NR: 1.5%	1	Mental/cognitive difficulty: 46.4%; physical difficulty: 31.4%; mental/cognitive & physical difficulties: 22.2%	Well-being moderate on WEMW Scale, <i>M (SD)</i> : Total: 50.89 (8.76), Young adult carer: 49.14 (8.51). Perceived stress moderate on PSS, <i>M (SD)</i> : Total: 20.32 (6.24), Young adult carer: 22.95 (5.93)	Responsibility <i>M (SD)</i> =25.12 (6.58) on the 7-item scale of the YCOPI, on 5-point scale, demonstrating moderate levels of caring responsibilities
Wolpert (2015), UK <i>YC service</i>	NR (4-16), <b>NR</b>	Current (6) Retro (9)	NR	Parent	1	MI (psychotic disorders (incl. schizophrenia, bipolar, personality disorder, chronic depression, anxiety disorder)	NR	NR

Note. ADHD= Attention-deficit/hyperactivity disorder; ASD=Autism spectrum disorder; ED=Eating disorder; Hr=Hour; MI=Mental illness; mo.=months; MS=Multiple sclerosis; NR=Not reported; OCD=Obsessive-compulsive disorder; PSS=Perceived stress scale; Qual=Qualitative; Quan=Quantitative; Retro=Retrospective; UK=United Kingdom; WEMWS=Warwick-Edinburgh Mental Well-being Scale; YC=Young carer; YCPI-R =Young Carers of Parents Inventory-Revised; YCOPI=Young Caregiver of Parents Inventory; Yr=Year; \*England, Finland, Germany, Italy, Norway, Poland, and Scotland. \*\*=This study compared the physical health of young carers to non-carers (those who were not young carers).

Of the 26 studies analysed, eight (31%) detailed participant attrition, revealing an average attrition of 28.71%. Attrition appeared to be influenced by the method of support delivery. For example, a guided website support program delivered asynchronously had an attrition rate of 22.5%, whilst an unguided program using printed materials exhibited a slightly higher rate at 28.1% (Ali et al., 2014). Further, Trondsen & Tjora (2014) reported a similar attrition rate of 19% for an online, combined synchronous and asynchronous self-help group. Notably, a blended support approach, which combined synchronous online and face-to-face sessions, maintained a low attrition rate, with 93% consistently attending (Gettings et al., 2015).

## Professionals

Among the included studies, 19% ( $n=5$ ; Acton & Bernie, 2016; Phelps, 2021; Tabak et al., 2016; Stamatopoulos, 2015; Waters, 2019) included professional qualitative insights. These insights encompassed various support aspects, young carer support needs, support impact, and support mechanisms. Most studies sought information from mental health professionals (Phelps, 2021; Stamatopoulos, 2015; Tabak et al., 2016; Waters, 2019). However, included were accounts from professionals within the education service system (e.g., teachers; Acton & Bernie, 2016; Tabak et al., 2016; Waters, 2019). Two studies provided insights from professionals in general healthcare, predominantly nurses (Tabak et al., 2016; Waters, 2019). Additionally, these studies included perspectives from other professionals such as psychologists, psychiatrists, and social workers (Tabak et al., 2016), as well as professionals from various sectors, including healthcare, schools, children's social care, adults' social care, and voluntary organisations (Waters, 2019).

## Young People with Caring Responsibilities

Out of the 26 included studies, 17 (65%) focused on *current* young carers, six (23%) examined *retrospective* young caregivers sharing their past caring accounts. The remaining three studies (12%; McDougall et al., 2018; Tabak et al., 2016; Wolpert et al., 2015) included perspectives from both current *and* retrospective young caregivers. Excluding studies that did not report sample age range ( $n=4$ ; Stamatopoulos, 2015; Tabak et al., 2016; Tanonaka & Endo, 2021; Van der Werf et al., 2020), young carer age ranged from 4 to 49 ( $n=22$ ), with a mean young carer age of 19.65 ( $n=13$ ). More specifically, for current young carers, age ranged from 6 to 29 years ( $M=16.88$ ). For retrospective accounts, age ranged from 18 to 49 years ( $M=25.60$ ). For studies including both current *and* retrospective young carers ( $n=2$ ; McDougall et al., 2018; Wolpert et al., 2015), age ranged from 4 to 25 years ( $M=18$ ).

The educational and employment status of young carers varied across included studies. Specifically, 13 studies revealed that the percentage of young carers engaged as students ranged from a low of 20% (Ali et al., 2013) to a full 100% (Acton & Bernie, 2016; Gough & Gillford, 2020; Kettell, 2018; Phelps, 2021; Spratt et al., 2018; Van der Werf et al., 2020) ( $M=82.35$ ). Regarding young carer employment ( $n=5$ ), employment rates ranged from 21% (Ali et al., 2013) to 46.15% (McDougall et al., 2018;  $M=35.21$ ). Three studies (Ali et al., 2013; Hagström & Forinder, 2019; Landi et al., 2022) reported young carer unemployment rates, with proportions consistent across these studies, ranging from 9.8% and 11% ( $M=10.27$ ).

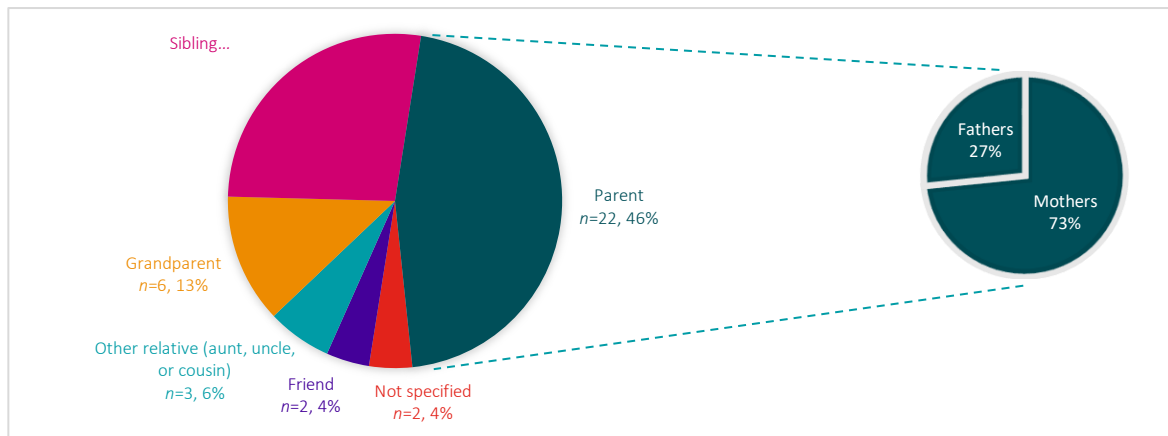
Of the studies reviewed, several did not provide specific details about the health status of their young carer participants ( $n=18$ ; 69%). Yet, from those that did, a diverse health profile of young carers emerged. One study (Ali et al., 2013) found that a majority of young carers perceived their general health positively, with 81% rating it as 'good'. Furthermore, 63% felt optimistic about their quality of life, and many were actively engaged in weekly leisure (47%) and exercise (62%) activities (Ali et al., 2013). On a concerning note, of the nine studies that did delve into the health status of young carers, more than half (56%) identified mental health challenges among these individuals. Issues raised included poor health overall, psychosocial difficulties, stress and a reduced sense of well-being, all of which were linked to their caregiving roles (DeeRoos et al., 2017; Drost & Schippers, 2015; Waters, 2019; Wepf & Leu, 2022). As for physical health, young carers had slightly higher reports of health issues compared to non-carers. More specifically, 11.1% of those caring for a parent and 16.4% of those caring for other relatives reported health concerns, relative to 8.9% for non-carers (Landi et al., 2022).

Emotionally, nearly half (48%;  $n=108$ ) of young carers admitted to feelings of loneliness (Ali et al., 2015). Meanwhile, Spratt et al. (2018) identified that 13.64% ( $n=3$ ) of the young carers in their sample had either made suicide attempts or engaged in self-harming behaviours. Further, young carers had higher levels of perceived stress and lower levels of well-being compared to their peers (Wepf & Leu, 2022). Three separate studies highlighted various health and behavioral concerns among young carers (DeRoos et al., 2017; Landi et al., 2022; Waters, 2019). Acton and Bernie (2016) reported that half of the young carers exhibited learning difficulties, attention deficit hyperactivity disorder, or behavioral issues.

## Care Recipient

Young carers most frequently provided care for parents ( $n=22$ ; 46%; see Fig 3). Among the seven studies that provided a breakdown of parent gender, mothers made up most parental care recipients (73%). Care recipients also included siblings ( $n=13$ , 27%), grandparents ( $n=6$ , 13%), other relatives (i.e., aunt, uncle, cousin;  $n=3$ ; 6%), or friend ( $n=2$ ; 5%). Among young carers, the majority ( $n=15$ , 58%) primarily provided support to a single family member or friend. However, approximately a quarter of studies ( $n=7$ ; 27%) found that young carers were responsible for supporting two or more family members or friends. In these instances, some cared for both parents who had a mental illness (Hagström & Forinder, 2019), while others cared for a parent *and* a sibling (Drost & Schippers, 2015; Kettell, 2018). In three additional studies, young carers were found to care for multiple family members, though specific details were not provided (McDougall et al., 2018; Van der Werf et al., 2020; Waters, 2019)."

Most young carers supported someone with a mental illness ( $n=13$ ; 52%). The remaining supported a family member or friend with a mental illness *or* neurodevelopmental disorder ( $n=4$ ; 16%), mental illness *and/or* drug addiction ( $n=2$ , 8%; Acton & Bernie, 2016; Van der Werf et al., 2020), mental illness *and/or* physical illness ( $n=2$ , 8%; DeRoos et al., 2017; Wepf & Leu, 2022), neurodevelopmental disorders ( $n=1$ ; 4%; Gettings et al., 2015) or AOD concern ( $n=1$ ; 4%; Hagström & Forinder, 2019). In one study, young carers supported someone with a physical illness, mental illness, substance use condition, *and/or* neurodevelopmental condition (Gough & Gillford, 2020). Two studies did not specify the care recipients' condition (8%; Phelps, 2021; Stamatopoulos, 2015).



**Fig. 4.** Care recipient relationship to young carer.

### Description of care responsibilities provided by the young carer

Fourteen (54%) included studies provided specified details of the young carers' tasks and responsibilities. Young carers provided a wide range of support, varying in responsibilities, duration, type and intensity. These included household management tasks such as purchasing groceries, cooking, laundry and cleaning (Acton & Bernie, 2016; Drost & Schippers, 2015; Gough & Gillford, 2020; Hagström & Forinder, 2019; Tanonaka & Endo, 2021; Waters, 2019). Some were also involved in healthcare support, such as assisting with parents' medication (Acton & Bernie, 2016; Hagström & Forinder, 2019) or accompanying them to medical consultations (Tanonaka & Endo, 2021). Furthermore, they completed miscellaneous tasks, which included driving responsibilities and pet care (Waters, 2019). When young carers supported another with AOD concerns, these young individuals faced particularly adult-oriented responsibilities, such as cleaning up vomit or helping them to bed (Hagström & Forinder, 2019). Many young carers supported siblings (Acton & Bernie, 2016; Drost & Schippers, 2015; Gough & Gillford, 2020; Hagström & Forinder, 2019), managed household finances (Gough & Gillford, 2020; Tanonaka & Endo, 2021) and performed administrative tasks (DeRoos et al., 2017). Beyond tangible duties, they played a role in providing emotional support (Gough & Gillford, 2020; Tanonaka & Endo, 2021; Waters, 2019).

Their roles highlighted adaptability, with roughly one-third providing a versatile range of assistance, spanning both domestic/administrative tasks and direct caregiving. The degree of responsibility they shouldered varied widely. In some cases, the absence of other assisting relatives placed *all* practical responsibilities on a single young carer (Dam et al., 2018). Many, however, managed moderate caregiving responsibilities (Landi et al., 2022; Wepf & Leu, 2022), with the extent of their role shifting based on the severity of the parent's illness and the presence or absence of another healthy parent or caregiver (Dam et al., 2018; Tanonaka & Endo, 2021). Young carers consistently demonstrated a long-term commitment to caregiving (3–5 years=13%, 6–9 years=16%, ≥10 years=11%; Gough & Gillford, 2020), with families typically benefiting from their support for extended durations averaging 65 months (Ali et al., 2015). In contrast, friends received care for an average of 29 months (Ali et al., 2015). On a weekly basis, 65% of young carers dedicated an average of 5.7 hours to their duties (DeRoos et al., 2017), while 30.4% devoted 6 to 10 hours a week to caregiving (Gough & Gillford, 2020).

## Support characteristics

The included studies aimed to comprehensively investigate the experiences and needs of young carers while they engaged in support programs. Support was provided through both formal and informal channels. The primary aim of formal support is to provide support through trained professionals (who are typically paid such as mental health professionals, school workers) and structured resources, policies and practices (Shiba et al., 2016). On the other hand, informal support is to provide unpaid emotional, practical and companionship support to young carers, helping them manage their responsibilities and maintain a sense of well-being (i.e., family, friends, young carer peers; Shiba et al., 2016). Formal young carer supports were reported in 11 studies (42%), while informal supports were mentioned in three studies (12%). Additionally, nine studies (35%) included both formal and informal young carer supports. In three studies (12%), the type of young carer support was not reported. Table 5 provides a description of included young carer supports.

**Table 5. Characteristics of young ‘carer’ supports.**

Study (year) YC type	Named support program (if no, explain)	Type of support context	Referral pathway into present support	Criteria for accessing present support	Support duration	Support program provider	Support delivery method	In person vs. online	Support location	In/formal support	Support content <i>A/synchronous delivery</i>	Engagement techniques	Referral pathway for <i>additional</i> support	YC co-design
Mixed methods														
Acton (2016) <b>Current</b>	<i>Good from the Wood</i>	Education , mental health	Self-selected via contact with a local charity for YCs	Self-selected	24 hours over 5 days	Natural workshops staff, researcher ethnobotanist, forest school session leader, bushcraft expert, assistant session leaders	Individual Pairs Group	In person	Outdoor woodlands	Formal Informal	Outdoor activities in local woodlands to provide respite: 1. practical skills: fire making, cooking, using tools; 2. reflection; 3. games; 4. ecology focus time <b>Sync</b>	NR	NR	NR
Ali (2013) <b>Current</b>	No - YCs report whether they received the following prior support: Web-support, counseling, group counseling, psychoeducation	Mental health	Swedish national population register & Recruitment company screened for eligibility.	NR	NR	NR	NR	Online	Mental health service	Formal	Web-support, counseling, group counseling, psychoeducation <b>NR</b>	NR	NR	NR
Drost (2015) <b>Retro</b>	<i>SurvivalKid</i>	Mental health	Therapist informed YC of program.	NR	NR	Counsellor, peer	Individual Group	Online	Home	Formal Informal	Website includes psychoeducation in coping (through short blocks of text, real-life stories, games, quizzes), opportunities for peer support (via message boards & moderated chat) & opportunities to contact professional counsellor via chat or email. <b>Sync &amp; async</b>	Website participation anonymous. Inappropriate posts deleted & visitors who do not comply with rules excluded by moderator.	NR	NR
Gettings (2015) <b>Current</b>	Unnamed support program	Mental health, education	NR	Support group participants were siblings of patients being treated at a national specialist CAMHS	8 wkly 1-hour sessions	Clinicians	Group	In person, Online	Home (Web-based) Hospital clinic	Formal	Session 1. Explanations, questionnaires & introductions; 2. Getting to know each-other; 3. Understanding your brother’s or sister’s illness; 4. School matters; 5. Sharing stories about recreation time; 6. Sharing concerns & solutions; 7. Talking about opportunities & thinking about the future; 8. De-briefing & farewells & evaluation. <b>Sync</b>	Arrangements for privacy & confidentiality to be maintained during audio-conferencing sessions.	Some YCs referred to GP for further support due to symptoms identified during group meetings indicating possibility of depression, PTSD symptoms or ADHD.	NR
Gough (2020) <b>Current</b>	No – YCs received support from parent, sibling, extended family, a YC Project, YC peers, carer support service within community, & teachers.	NR	YCs recruited through Young Carer Project & self-enrolled	YCs self-enrolled to the study	NR	NR	NR	NR	NR	Formal Informal	NR	NR	NR	NR
Waters (2019) <b>Current</b>	<i>Kingston YCs’ Project (YCP)</i>	Mental health	Participants were recruited from Kingston YCP, which is part of Kingston Carers' Network.	NR	NR	Healthcare professional	Individual, group	In person	YCs’ Project venue	Formal Informal	Provides information & advice, 1:1 support, opportunities to meet other YCs, fun activities, respite activities, drop-ins, YC awareness raising, advocacy efforts, whole family support. <b>Sync</b>	NR	NR	NR

Study (year) <b>YC type</b>	Named support program (if no, explain)	Type of support context	Referral pathway into present support	Criteria for accessing present support	Support duration	Support program provider	Support delivery method	In person vs. online	Support location	In/formal support	Support content <i>A/synchronous delivery</i>	Engagement techniques	Referral pathway for additional support	YC co-design
Qualitative														
Cudjoe (2023) <b>Current</b>	No - YCs reported receiving support from their siblings.	Mental health, physical*	Families recruited from out-patient mental health units	NR	NR	Sibling	Individual	In person	Home	Informal	Siblings generally provide comfort to each other by offering supports ranging from emotional, physical & informational. <i>NR</i>	NR	NR	NR
Dam (2018) <b>Retro</b>	No - YCs reported receiving support from healthy parent, grandparent, aunts, uncles	Practical support	NR	Recruited through emails, mental healthcare system contacts, voluntary sectors, mass media	NR	Healthy parent, grandparent, aunts, uncles	NR	In person	Home	Informal	Family offered YCs support by taking care of chores. Some took care of children/siblings. NR	NR	NR	NR
Hagström (2019) <b>Current</b>	<i>Children are People Too (CAP)</i>	AOD	YCs mothers initiated participation CAP, regardless of whether they were the parent with AOD concerns.	NR	15 group meetings	NR	Group	In person	School, mental health service	Formal	Topics include self-care/coping; AOD psychoeducation. <b>Sync</b>	NR	Some referred to psychiatric care, social services, mental illness, AOD.	NR
Kettell (2018) <b>Current</b>	No- YCs received support from Peers, teachers	Education	NR	NR	NR	Peers, teachers	NR	NR	School	Formal Informal	NR	NR	NR	NR
McDougall (2018) <b>Current &amp; Retro</b>	No - YCs received support from family, friends, peer YCs	NR	NR	NR	NR	Family members, friends, YCs	Group	NR	NR	Informal	NR	NR	NR	NR
Nilsson (2015) <b>Retro</b>	Unnamed support program	Mental health, education, AOD	NR	NR	NR	Group leader	Group (separated by YC age)	In person	Mental health service	Formal	Group activity themes: Emotions, values, mental illness, alcohol, addiction, family roles, communication. <b>Sync</b>	NR	Several YCs required later life support (e.g., therapy; employment; education).	NR
Phelps (2021) <b>Current</b>	<i>Hampshire Young Carers Alliance (HYCA)</i>	Mental health, education	YCs from The Hampshire YCs Alliance (HYCA), a network of ten YC services in the UK	HYCA commissioned the University of Winchester to undertake an independent evaluation of the work of the Alliance.	NR	HYCA YC service project managers	Individual, group	In person, Online	School, home	Formal	Support offering respite, family support, school support. Whole family approach through home-visits, family activities, referring & signposting to other services (to help families with rent, or changing accommodation), & providing direct support to parents on parenting & family relational issues. Projects have helped families with finances by informing them of entitled benefits & practically with financial documentation. Projects run both trips & groups; group & activity days (e.g., cooking, sports, crafts); an online forum to share experiences. YC school support (drop-in sessions, 1:1 support). <b>Sync &amp; async</b>	Projects had guidelines to ensure confidentiality & no bullying.	Families provided additional supports where needed—directly from projects (e.g., phone support), from other services (e.g., an accommodation agency) facilitated by the projects, or indirectly (e.g., referred to Early Help Hub)	NR



Stamatopoulos (2015) <b>Current</b>	YCs Initiative: Powerhouse Project; Cowichan YC Program; Hospice Toronto's YC Program	Mental health, education, vocation	Teachers	Parental consent was required for those aged under 18 to access program	Bi-wkly, wkly, monthly program/meeting	NR	Individual, group	In person	Home (home visits), school, community	Formal	Programs assisted YC in caregiving roles (via counselling, support service information, self-help techniques, peer support groups) or mitigating negative consequences (via respite services, educational, training, employment support). <b>Sync</b>	NR	NR	NR
Tabak (2016) <b>Retro</b>	No – This is about future support needs. Findings of this study were used to develop the CAMILLE training.	NR	Recruited from health service centers, university-based education centers, social welfare centers, & non-statutory organizations.	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Tanonaka (2021) <b>Retro</b>	No - YCs received support from teachers, healthy parent, relatives, YC peers	Mental health, education	NR	Participant s identified through organizations that hosted Kodomo no tsudoi (meetups for COPMI)	NR	Teachers, healthy parent, relatives, YC peers	NR	NR	School, home	Formal Informal	1. Academic support (teachers & healthy parents helped with homework & child's studies); 2. Financial security & support by an adult (healthy parent, aunt or grandparent); 3. Mental support from healthy parent, sibling, relative, & mental health professional; 4. Emotional support from teacher/school nurse, girlfriends, or boyfriends, teachers, or YC peers; 5. Socialising or time for relaxation, fun, & hobbies away from parent including interacting with others online <b>Sync</b>	NR	A teacher recommended a YC to consult a mental health specialist at a clinic	NR
Trondsen (2014) <b>Current</b>	Unnamed support program	Mental health, practical support	Self-recruited through invitations on Web sites for youth, mass media announcements, posters at schools, & health personnel	Participant s had to sign a written consent form before they were allowed to enter the study. Those < 16 years of age had to provide signed permission from one parent	NR	Self-help peer-support discussion forum moderated by clinician & researcher	Group	Online	Home	Formal	Website included: information pages, open-access forum, Q&A service where health professionals responded to questions submitted by users. <b>Sync &amp; async</b>	Forum designed as a password protected, user-directed list server (news group), in which participants were anonymous through use of nicknames. A moderator monitored forum discussions & communicated to how the service could represent a safe & supportive space	Discussions in online self-help group encouraged several participants to more actively seek help & support from health professionals	NR
Van der Werf (2020) <b>Retro</b>	No- YCs received support from GPs, nurses, social workers, school psychologists, teachers	Mental health, education	Self-identified & recruited through Bachelor's program or secondary vocational courses.	NR	NR	GP, nurses, social workers, school psychologists, teachers	NR	NR	NR	Formal	N	NR	NR	NR

VanParys (2015) <b>Retro</b>	N- YCs received support from grandparent, friend, teacher, mental health workers	Mental health	NR	NR	NR	Grandparent, friend, teacher, mental health workers	NR	NR	NR	Formal Informal	NR	NR	NR	NR
Wolpert (2015) <b>Current &amp; Retro</b>	<i>Kidstime</i>	Mental health	Referrals from mental health workers, social workers, GPs, volunteers, psychiatrists, family therapists, psychologists, attending families	NR	After school monthly meetings each 2.5 hours	Mental health professionals, social care professionals, drama practitioner, volunteers	Group	In person	After-school workshop	Formal	1. Seminar for children & parents together (psychoeducation, questions, discussions); 2. Separate parent & child groups (child groups: games, warm-up exercises, sharing stories, dramatisations, play); 3. Parents & children come together at end of workshop (pizza, group discussion) <b>Sync</b>	NR	NR	NR

Study (year) <b>YC type</b>	Named support program (if no, explain)	Type of support context	Referral pathway into present support	Criteria for accessing present support	Support duration	Support program provider	Support delivery method	In person vs. online	Support location	In/formal support	Support content <i>A/synchronous delivery</i>	Engagement techniques	Referral pathway for additional support	YC co-design
Quantitative														
Ali (2014) <b>Current</b>	<i>www.psyoungsupport.se</i>	Mental health, education	Self-identified from the Swedish national population register	Self-identified as in a close relationship with MI & supporting them	8 months	Researchers, Ph.D. students	Web support:: 1:1; group  Folder support: Self-help YCs can independently contact listed supports	Web support: : Online  Folder support: : Offline	Web support: Home  Folder support: Home	Formal	Web support: Async information, advice, self-care tips, where/how/when to find help, mental illness information via website; blogs; forum with discussions about optional topics & Q&A. Folder support: A folder with information on 24 different community supports <b><i>Sync &amp; async</i></b>	Web group could choose & personalise username to stay anonymous	NR	YCs co-designed website
Ali (2015) <b>Current</b>	No –YCs received support from friends, family, health services, social services	Mental health	Self-identified from Swedish national population register	Recruitment company assessed eligibility.	NR	Friends, family, health & social services	NR	NR	NR	Formal Informal	NR	NR	NR	NR
DeRoos (2017) <b>Current</b>	No – YCs specified if they needed extra support, and whether use of supports differed according to demographics	Mental health, education	NR	Self-identified through survey^	NR	Social worker, guardian, educational worker, youth welfare service, psychologist, psychiatrist mental health service	NR	NR	School, mental health service	Formal Informal	NR	NR	NR	NR
Landi (2022) <b>Current</b>	No –Provided recommendations to support YCs in the context of COVID-19	Mental health	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR
Spratt (2018) <b>Current</b>	N - two research partners facilitating the study were Barnardo's YC and Action for Children YCs projects	Mental health, practical support*	YC referred by parents, social workers, general practitioners & schools on the basis that they required additional help & support in coping with the caring role	YC identified as requiring additional support in managing	NR	NR	Individual, group	NR	YCs organisation	Formal	Personalised: Based on YC's needs, supports include counselling, group activities, advocacy, offering both practical & emotional support. <b><i>Sync</i></b>	NR	NR	NR
Wepf (2022) <b>Current</b>	No – YCs specified the level of support they received for caring	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR	NR

*Note.* ^=Dutch Health Behavior in School-aged Children survey; ADHD=Attention deficiency or hyperactivity disorder; Async support= delayed delivery of support; e.g., text message, email)CAMHS=Children and adult mental health services; GP=General practitioner; HYCA=Hampshire Young Carers Alliance; MI=Mental illness; N=No; NR=Not reported; OT= occupational therapy; Synchronous support=live delivery of support (e.g., audio/video conference); Y=Yes; YC=Young carer; wkly=Weekly; \*Practical support=Could range from cooking, cleaning, and housework, to managing finances and attending appointments. \*\*Physical support=Could range from getting help with getting washed to dressed.

## Formal support programs

Across eight studies, we identified ten unique formal supports. One study (Stamatopoulos, 2015) reported on three unique programs (Hospice Toronto's Young Carers, Young Carers Initiative: Powerhouse Project, Young Carers Initiative: Powerhouse Project). Seven specific support programs were named (1. Children are People Too; 2. Cowichan Young Carers; 3. Hospice Toronto's Young Carers; 4. Kidstime; 5. Hampshire Young Carers Alliance; (6. Young Carers Initiative: Powerhouse Project; 7. [www.psyyoungsupport.se](http://www.psyyoungsupport.se)). Three programs were unnamed (Gettings et al., 2015; Nilsson et al., 2015; Trondsen & Tjora, 2014). Among the studies that did not report on a specific support program, solely formal support ( $n=1$ ; Van der Werf et al., 2020) were provided by a mix of general practitioners, community nurses, social workers, school, psychologists, and teachers. Other studies did not specify the formal support provider ( $n=2$ ) but indicated that such support was provided at a mental health service (Ali et al., 2013) or young carer organisation (Spratt et al., 2018).

## Informal supports

Three studies did not report on a specific support program and indicated that young carers received support from informal networks. Solely informal support included friends, extended family members (Cudjoe et al., 2023; Dam et al., 2018), and other young carers (McDougall et al., 2018). This informal support primarily revolved around building and nurturing relationships, emotional support, and information sharing (Cudjoe et al., 2023). Informal support also related to providing practical and physical support, such as support with household chores and childcare (Dam et al., 2018). In addition to family and friends providing support, peer support, especially from fellow young carers, allowed for the exchange of mental health knowledge and coping strategies (Drost & Schippers, 2015). Moreover, peer support, particularly from fellow young carers, facilitated the exchange of mental health knowledge and coping strategies (Drost & Schippers, 2015). These peer interactions also created a supportive environment where young carers could openly discuss and validate their experiences, ultimately reducing feelings of isolation (Acton & Bernie, 2016; Tanonaka & Endo, 2021).

## Formal support programs and informal support

Nine studies included both formal *and* informal program support elements. Of these combination supports, three reported on specific programs (1. Good from the Wood; 2. SurvivalKid; 3. Kingston Young Carers' Project).

## Prior or current engagement with other supports

Among the 26 studies reviewed, only four (15%) mentioned that young carers had been or were currently involved with additional support services beyond the one under examination. Acton and Bernie (2016) reported that all eight young carers in their study had previously engaged with a local charity tailored for their needs. Meanwhile, Gettings et al. (2015) noted that only one of their six participants (17%) was actively affiliated with a young carer organization, although the specific organization wasn't mentioned. Trondsen & Tjora (2014) highlighted that some young carers in their study had sought assistance from healthcare professionals and had attended in-person support groups alongside their current support. Furthermore, Waters (2019) stated that every young carer in their study regularly attended the Kingston Young Carers' Project, part of the Kingston Carers' Network, which offers services such as personal support, group activities, advocacy, and raising awareness.

## Context and types of young carer support services

While we intended to include support programs from varied support service systems (i.e., mental health, AOD, education, vocation, financial) young carer supports were only identified in the mental health context and education context; however, some these studies did report on outcomes that were related to other support service systems (e.g., financial).

## Support program target age range

Thirteen (46.43%) formal support programs for young carers were tailored to distinct age groups. One intervention (Ali et al., 2014) focused on older young carers (ages 16-25). Six programs were designed specifically for primary school-aged children between 6-13 years, as detailed in four studies (Acton & Bernie, 2016, Good from the Wood; Hagström & Forinder, 2019, Children are People Too; Gettings et al., 2015: Unnamed; Stamatopoulos, 2015: Young Carers Initiative: Powerhouse Project, Cowichan Young Carers Program, Hospice Toronto's Young Carers Program). Three other supports addressed a broader age span, covering 9-17 years (Phelps, 2021; Hampshire Young Carers Alliance (HYCA), 9-18 years (Waters, 2019; Kingston Young Carers' Project), and 15-18 years (Trondsen & Tjora, 2014; unnamed). Drost and Schippers (2015) reported on a program for youth aged 12-24 years (SurvivalKid), and Wolpert et al. (2015) offered support for a wider age range of 4-16 years (Kidstime). One intervention (unnamed support program) divided their groups into four distinct age groups, but details were not specified (Nilsson et al., 2015).

## Individual vs. peer group vs. familial group program

Most supports were provided directly to the individual young carer ( $n=6$ , 23%) (Ali et al., 2014; Drost & Schippers, 2015; Phelps, 2021; Stamatopoulos, 2015; Spratt et al., 2018; Waters, 2019), while five provided only group-based supports (Gettings et al., 2015; Hagström & Forinder, 2019; Nilsson et al., 2015; Trondsen & Tjora, 2014; Wolpert et al., 2015). Of the five group-based supports, two were relational in nature, designed for multiple family members, accommodating two members (child and affected parent) (Nilsson et al., 2015; Wolpert et al., 2015), while the other four were designed for groups of peers with similar experiences (Gettings et al., 2015; Hagström & Forinder, 2019; Nilsson et al., 2015; Trondsen & Tjora, 2014). One support program was delivered individually, in pairs, and as a group (Acton & Bernie, 2016).

## Criteria for accessing young carer support

The support entry criteria were unspecified in most studies ( $n=20$ ; 77%). From the seven studies that reported on support eligibility criteria (27%) several criteria were evident. Firstly, young carers often needed to self-refer (i.e., self-identify, self-selection) as someone supporting a close individual with a mental illness to join the support program ( $n=3$ ; Acton & Bernie, 2016; Ali et al., 2014; Trondsen & Tjora, 2014). In specific instances, participants were affiliated with the Hampshire Young Carers Alliance (HYCA) program, which was a network of ten young carer services, under evaluation by the University of Winchester (Phelps, 2021). Other programs focused on individuals, like siblings of patients, who were associated with a national Child and Adolescent Mental Health Service (Gettings et al., 2015). Some studies mandated written participant consent (Stamatopoulos, 2015; Trondsen & Tjora, 2014), and for those <18 (Stamatopoulos, 2015) or <16 (Trondsen & Tjora, 2014), parental consent was required.

## Physical location of support

Out of 18 studies (formal=10; informal=2; formal *and* informal=6) detailing the location of young carer support, the most common physical support location was 'home' through remote online methods (Ali et al., 2014; Drost & Schippers, 2015; Trondsen & Tjora, 2014). Additionally, two studies highlighted the combination of schools and home as support locations (Phelps, 2021; Tanonaka & Endo, 2021), while two others mentioned schools in conjunction with mental health services (DeRoos et al., 2017; Hagström & Forinder, 2019). Mental health services (Ali et al., 2013; Nilsson et al., 2015), young carer services (Spratt et al., 2018; Waters, 2019) and in-person home support (Cudjoe et al., 2023; Dam et al., 2018) were each noted in two studies (8% for each). A single support was offered at the following venues: outdoor intervention sites (Acton & Bernie, 2016); hospital clinic and home (Gettings et al., 2015); after-school workshops (Wolpert et al., 2015); school (Kettell, 2018); and a variation of home (home-visits), schools, and community hubs (Stamatopoulos, 2015).

## Co-designed young carer supports

Only one study (4%; Ali et al., 2014) reported the involvement of young carers in shaping and designing the support program. Specifically, young carers collaborated with the project team to co-create a website. This was a formal support.

## Support delivery personnel

Many studies did not specify who facilitated the support programs ( $n=8$ ; 31%). For those that did, the facilitators varied widely. Some programs were run by mental health clinicians, either individually ( $n=2$ ; Gettings et al., 2015; Waters, 2019) or in collaboration with peers or researchers ( $n=2$ ; Drost & Schippers, 2015; Trondsen & Tjora, 2014). Other facilitators included researchers ( $n=1$ ; Ali et al., 2014), youth workers ( $n=1$ ; Phelps, 2021), healthcare workers individually ( $n=1$ ; Waters, 2019). Supports from multidisciplinary teams comprised of mental health professionals, drama practitioners, volunteers ( $n=1$ ; Wolpert et al., 2015), outdoor activity program experts and researchers ( $n=1$ ; Acton & Bernie, 2016), general practitioners, community nurses, social workers, school psychologists, and teachers ( $n=1$ ; Van der Werf et al., 2020). At the more nuanced level, solely informal support was provided by family members in two studies (Cudjoe et al., 2023, Dam et al., 2018).

## Standardised vs. personalised support

Of the 26 studies, 12 specified whether the support was standardised and/or personalised. Of these, most ( $n=8$ ; 67%) detailed a standardised support program, where the support was consistent for all participants and predefined. Three studies (25%; Acton & Bernie, 2016; Phelps, 2021; Spratt et al., 2016) adopted a personalised approach to support wherein program activities were selected and prepared specifically for the young carer based on their unique needs and experiences. One further study involved both standardised *and* personalised support (Wolpert et al., 2015). Personalised elements in three studies (Acton & Bernie, 2016; Phelps, 2021; Wolpert et al., 2015) involved dynamically curated activities based on participants' needs and modified session topics to align with their interests and concerns throughout program completion. A fourth study (Spratt et al., 2016) took an even more tailored approach, designing a program uniquely for each young carer. This entailed individual assessments to decide the suitability of counselling sessions and group activities for each participant prior to program commencement.

## Support program mode of delivery

Of the 26 included studies, 14 reported on the support's mode of delivery, which was variable. Eight support programs were delivered in-person, three were delivered solely online (Ali et al., 2013; Drost & Schippers, 2015; Trondsen & Tjora, 2014), two supports were blended (i.e., providing both in-person and online elements; Gettings et al., 2015; Phelps, 2021) and one study compared an online program to an offline in-person program with printed out materials (Ali et al., 2014). Most supports were delivered synchronously ( $n=9$ , 35%) (i.e., live delivery), with no support delivered solely asynchronously (delayed delivery of support; e.g., text message, email). A further four synchronous programs were supplemented with asynchronous interaction (15%; e.g., email support, forum posts, question and answer feature providing opportunities to get questions answered) (Ali et al., 2014; Phelps, 2021; Trondsen & Tjora, 2014; Drost & Schippers, 2015).

## Support program length and intensity

Six of the 26 included studies (23%) provided details about the length, frequency, or intensity of their support. Intervention length ranged from 5 days to 8 months ( $M=14.49$  weeks) as reported in three studies (Ali et al., 2014; Acton & Bernie, 2016; Gettings et al., 2015).

Programs varied in frequency, ranging from weekly to monthly sessions. For instance, Stamatopoulos (2015) mentioned bi-weekly sessions, while both Stamatopoulos (2015) and Wolpert et al. (2015) reported monthly support sessions. Information on the number of support sessions was reported infrequently; Hagström (2019) described a program consisting of 15 group meetings, while Gettings et al. (2015) reported a support program with eight sessions, with an average attendance of 5.63 sessions.

## Describing front-end support spectrum content and outcomes

Fourteen studies (54%) reported on specific support content. Supports took a multifaceted approach to assisting young carers, meeting informational, emotional, social, and practical needs; however, mental health support was privileged as it was reported upon most frequently.

Key supports for young carers encompassed a range of vital services and resources to address a diverse range of young carer needs. One primary element was *mental health support*, which focused extensively on young carers social and emotional well-being, delivered mainly by mental health professionals (Ali et al., 2014; Drost & Schippers, 2015; Stamatopoulos, 2015; Tanonaka & Endo, 2021). Another pivotal component of these supports was *psychoeducation*, which equipped young carers with the knowledge to navigate their unique position effectively. Such psychoeducation further highlighted the importance of prioritising the carer's health, imparting coping mechanisms, and emphasising self-care (Ali et al., 2014; Drost & Schippers, 2015; Hagström & Forinder, 2019) as well as self-help techniques (Stamatopoulos, 2015). This education also ensured they understood the care recipient's condition, making them more prepared and knowledgeable (Ali et al., 2013; Gettings et al., 2015; Hagström & Forinder, 2019; Wolpert et al., 2015). *Academic support* was infrequently reported; however, of the two studies that reported on this support element (Phelps, 2021; Tanonaka & Endo, 2021), tailored academic support took shape in the form of 'drop-in' sessions and dedicated one-on-one assistance (Phelps, 2021). While also infrequently reported ( $n=2$ ; 8%; Phelps, 2021; Tanonaka & Endo, 2021), many young carers also benefited from *financial support* structures, alongside training and employment programs tailored to their unique circumstances (Stamatopoulos, 2015). Finally, the



provision of *carer respite* in the form of social and recreational activities (e.g., outdoor activities, cooking, sports, crafts) granted them the much-needed breaks from their caregiving responsibilities (Acton & Bernie, 2016; Phelps, 2021; Stamatopoulos, 2015; Waters, 2019).

### **Online supports**

Three distinct studies (Ali et al., 2014; Drost & Schippers, 2015; Trondsen & Tjora, 2014) offered online support, while a further two studies (Gettings et al., 2015; Phelps, 2021) offered blended support (in-person and online). Support featured online content in various formats. The primary form of online support was through web support, which could be delivered by a peer (Drost & Schippers, 2015), practitioner (Drost & Schippers, 2015; Trondsen & Tjora, 2014), and researcher (Trondsen & Tjora, 2014). Online supports, such as 'SurvivalKid' and 'www.psyoungsupport.se,' provided a range of services including synchronous (real-time) and asynchronous (delayed, e.g., email, forums) support. These services encompassed psychoeducation (Drost & Schippers, 2015; Ali et al., 2014), advice (Ali et al., 2014), self-care tips (Ali et al., 2014), access to mental illness resources (Drost & Schippers, 2015; Ali et al., 2014), peer support posts (Drost & Schippers, 2015), moderated chat sessions (Drost & Schippers, 2015) and even the option for users to directly contact professional counsellors via email (Drost & Schippers, 2015). Some support programs utilised blogs to deliver updates and news (Ali et al., 2014). Forums were frequently used, serving as a space for discussions and Q&A sessions (Ali et al., 2014; Phelps, 2021; Trondsen & Tjora, 2014). Among these forums, there were open-access platforms that facilitated direct interactions with healthcare professionals (Trondsen & Tjora, 2014).

### **In-person supports**

Most informal support was provided in person (Dam et al., 2018; Cudjoe et al., 2023). In-person programs, much like their online counterparts, offered psychoeducational content, including self-care advice, coping, understanding alcohol and substance use (Hagström & Forinder, 2021; Nilsson et al., 2015) and mental illness (Nilsson et al., 2015; Wolpert et al., 2015). Notably, studies by Nilsson et al. (2015) and Wolpert et al. (2015) included support programs that fostered family involvement, incorporating both children and their parents. These sessions emphasised the dynamics of family roles and effective communication. Moreover, these face-to-face programs frequently incorporated recreational activities to provide young carers with a break or 'respite' from their caregiving responsibilities. Activities varied and ranged from, for example, cooking to crafts to sports (Acton & Bernie, 2016; Waters, 2019; Phelps, 2021; Stamatopoulos, 2015). Gettings et al. (2015) elaborated on the structure of these in-person sessions, reporting that there were informal moments, such as refreshment breaks, that enabled young carers to engage in casual conversations. Icebreakers, games, and warm-up exercises set a relaxed tone for the sessions (Gettings et al., 2015).

### **Young carer support needs**

Within the mental health service system, young carers have expressed specific support needs. They emphasised the importance of multidisciplinary and multi-agency care. Children of Parents with Mental Illness (COPMI) require assistance not only from mental health professionals trained to work with children but also from various community organisations. There is a highlighted need for more young carer and child-centric interventions (Tabak et al., 2016). Additionally, young carers have identified a need for both 'information and emotional support' from general practitioners, community nurses and social workers to help them navigate their family situations

(Van der Werf et al, 2020). In the education service system, young carers expressed several support needs. They highlighted the importance of school psychologists and teachers in assisting with their family situations (Van der Werf et al., 2020). Furthermore, they expressed the need for a comprehensive support system in schools, including a friendship network, teachers and particularly, a school counsellor who interacts daily with the young carer. As reported by children as well as parents, improved communication between schools and homes was also a significant need (Tabak et al., 2016). Additionally, there is a call for stronger guidance or signposting for young carers in higher education (Kettell, 2018).

Support programs for young carers have identified a wide range of needs within this community and the effectiveness of support varies in addressing these needs. In terms of psychoeducational support, young carers express a need for clear information about illnesses and coping strategies (Van der Werf et al., 2020; Tabak et al., 2016). For socioemotional support needs, young carers report various needs, including external emotional support, opportunities for relaxation, socialisation and friendship-building. They also emphasise the importance of feeling supported and understood within their caregiving roles, which encompass managing finances, balancing education, and acquiring life skills. Young carers express a strong desire to know they are not alone in their journey and seek someone who listens and offers stress management strategies (Phelps, 2021; Tabak et al., 2016). Furthermore, support needs vary based on factors such as young caregiver age, gender, education, family structure, and caregiving intensity, with more intensive caregiving correlating with a greater need for support, while the type of illness or family relationships does not appear to impact support needs (DeRoos et al., 2017). Professionals in the field also stress the importance of cohesive family relationships and understanding family roles in providing whole-family support (Phelps, 2021; Van der Werf et al., 2020).

## **Support across varied service systems**

While this review aimed to identify data from varied service systems, due to limited data, content within this section largely pertains to the mental health service system and the education service systems only.

## **Engagement**

### **Recruitment**

Of the 26 studies included in the review, only two studies (8%) specified their recruitment engagement methods. In Ali et al. (2014), participants who completed questionnaires at multiple time points received various incentives, such as lottery tickets and gift vouchers for cinema passes, to encourage their participation. They also used a competition with a chance to win a gift card valued at approximately 50 euros as a promotional strategy to motivate young carers to engage with the support.

In Stamatopoulous et al. (2015), recruitment through awareness raising and public presentations across local schools provided a steady stream of youth participants. Additionally, the development of a course credit allowance for participants not only enabled some young carers to graduate but also enhanced support participation. It further eased potential parental concerns related to their child's involvement in the support and facilitated a greater turnaround in the necessary parental consent forms required for student participation in the program while legitimising the support.

## **Privacy and safety**

Five studies provided online support and all used anonymity as an engagement strategy. Offering anonymity helped to lower entry barriers and reduced the stigma often associated with being a young carer and support seeking, thereby encouraging participation and consistent involvement (Drost & Schippers, 2015; Gettings et al., 2015; Phelps, 2021; Trondsen & Tjora, 2014). Regarding in-person groups supports, one study had mechanisms in place to maintain participant privacy and confidentiality during group sessions (Phelps, 2021). To enhance safety and ensure a positive user experience, two of these programs employed moderators to oversee forum discussions (Drost & Schippers, 2015; Trondsen & Tjora, 2014). A further study reported that rule violators faced the possibility of being banned (Drost & Schippers, 2015).

## **Retention**

Transportation barriers affected young carer support engagement, leading to the provision of free taxis for some families in a particular support (Wolpert et al., 2015). Factors such as large group sizes dissuaded some parents of young carers from returning after an initial support session (Wolpert et al., 2015). In the education service sector, peers played a crucial role in supporting young carers in higher education by sharing notes and updates (Kettell, 2018). Within school-based young carer supports, establishing positive relationships between staff and young carers and their families was key to sustained engagement (Phelps, 2021).

## **Support usage**

Within varied research contexts, the utilisation of support programs among young carers showed diverse patterns. Ali et al. (2014) highlighted that, post-intervention at both 4 and 8 months, the web and folder support groups showed no significant differences in their engagement levels. Shifting to age and demographic factors, DeRoos et al. (2017) noted older adolescents accessed more support than their younger peers, and girls were more engaged than boys. Notably, those in advanced educational tracks used the support less, while adolescents from non-traditional or incomplete families sought out more support. Building on sources of support, Ali et al. (2013) emphasised that over a 4-month period, friends were the predominant source (over 45%), trailed by parents (over 35%) and siblings (over 25%). Conventional support systems like school personnel (<10%), professionals (<10%), or youth centers (<5%) lagged behind in usage, indicating a preference for informal or peer-based support avenues among young carers.

## **Support elements**

In one study (Wolpert et al., 2015), when attempts were made to engage young carers and their parents within the support context, it was observed that frequent attendees expressed frustration and anxiety regarding the need to repeatedly introduce themselves throughout the support sessions, suggesting this may in fact have a disengaging influence.

## **Identification**

Educational professionals' limited awareness and perceived lack of competence regarding young carers (Kettell, 2018; Waters, 2019) hindered the identification and support of young carers within school settings.

## Referrals pathways

### Referrals into the current support

Only two studies (8%; Stamatopoulos, 2015; Wolpert et al., 2015) reported on the referral pathways of young carers into the current support. Wolpert et al. (2015) reported that in the mental health service system, individuals were referred by a range of professionals, including mental health workers, social workers, volunteers, psychiatrists, family therapists, psychologists, and general practitioners. Recommendations from families previously engaged with the service also served as a referral pathway (Wolpert et al. 2015). Within the education service system, teachers selected students for participation in young carer programs based on their eligibility or specific needs (Stamatopoulos, 2015).

### Referrals from the present support on to future supports

Within the mental health service system, participants from the *Children are People Too* (CAP) program were occasionally directed to psychiatric care or social services because of their individual psychological challenges or substance misuse (Hagström & Forinder, 2019). Additionally, Gettings et al. (2015) highlighted that three siblings involved in their support program were recommended to consult with their General Practitioner after displaying symptoms that suggested possible depression, PTSD, or ADHD during group sessions. In the educational service system, families received additional support as needed. Phelps (2021) noted that this support was provided through initiatives such as phone consultations or external services, often with project staff involvement. Some families were also referred to or guided to other resources, such as the *Early Help Hub*. In a different case, a university teacher recommended a young carer to consult a mental health specialist at a clinic, where the carer continued to receive ongoing assistance (Tanonaka & Endo, 2021).

## Support attrition and adherence

Of the 26 studies analysed, eight (31%) reported on participant attrition details, revealing an average attrition rate of 28.71%. Within these eight studies, three reported on specific attrition and adherence details. Ali et al. (2014) focused on a guided website support program that was delivered asynchronously and found an attrition rate of 22.5%, indicating a drop-out of just over one-fifth of participants before completion. Contrastingly, a study by Gettings in 2015 examined a blended approach (i.e., online *and* face-to-face sessions). This method garnered significant adherence, with a 93% attendance rate, illustrating strong participant engagement. Trondsen and Tojora's (2014) examined an online self-help group, revealing an attrition rate of 19%, suggesting that nearly one in five participants did not persevere through the entire program.

## Intersection between existing supports

The intersection of existing support systems for young carers is an area marked by limited available data. Predominantly, the available information centers on the interactions within and between the mental health and education support systems. However, these support systems exhibit discernible gaps in collaboration and mutual understanding, leaving young carers and their families feeling inadequately supported (Tabak et al., 2016). This lack of intersection can be attributed to various factors. Firstly, professionals often lack awareness of how to effectively support young adult carers, perceiving it as beyond their competence and capacity (Waters, 2019; Kettell et al., 2018). Secondly, a clear disconnect exists between children's and adults' services, posing concerns about the continuity of care. Additionally, there is ambiguity regarding agency responsibilities and the tools used for family assessments, highlighting gaps in the development

of assessment protocols (Gettings et al., 2015; Waters, 2019). Furthermore, structured assessments for young carers are notably absent, suggesting a need for better connections between mental health services, school counsellors, and young carer support groups. Lastly, while current support services offer a range of interventions, there is a deficiency in preventative and systemic support for young carers, care recipients, siblings, and the broader family unit, as reported by Stamatopoulos (2015). Taken together, the available literature emphasises the importance of enhanced collaboration at various socioecological levels: from professionals to inter-agency collaboration, across the broad service systems and even down to greater teamwork and communication between family members.

### **Barriers to accessing support**

In the mental health service system, retrospective young carers expressed dissatisfaction with the mental health service system's ability to recognise and address their unique situations (VanParys et al., 2015). Access to mental health services was often perceived as challenging by these retrospective young carers. Many expressed a need for therapeutic assistance but found that therapists were frequently unavailable when needed (VanParys et al., 2015). Additionally, long waiting lists and difficulties in attending appointments or support sessions due to their caregiving responsibilities were also cited as significant obstacles to accessing services (McDougall et al., 2018). Program staff in these mental health supports, on the other hand, encountered their own set of challenges, particularly related to securing funding (Stamatopoulos, 2015). Furthermore, they faced obstacles in obtaining permission from local schools to run young carer programs on-site, whether during lunchtime or after school hours. These hurdles represented substantial barriers to providing easily accessible support for young carers (Stamatopoulos, 2015).

Within the education service system, there were challenges in recognising and supporting young carers. Specifically, schools faced difficulties in identifying young carers (Waters, 2019) and often missed students undergoing challenging family situations (VanParys et al., 2015). Moreover, support program providers found it hard to liaise with teachers to determine the suitability or need of students for certain programs. Added to this, obtaining parental consent for students under 18 years interested in participating posed another hurdle to support participation (Stamatopoulos, 2015). A further challenge to obtaining support in schools were mainly due to the cumbersome process involved, including students needing to submit written documentation to request formal assistance, with some students perceiving the effort required to seek help as excessive (Kettell, 2018).

### **User support expectations**

Support programs appear to influence user experience in various ways. According to Van der Werf et al. (2020), young adult caregivers underscore the importance of recognition, attention and active listening from professionals in supports. Young carers wished to discuss their family situations in an open, judgement-free environment, but often feel overshadowed when the focus shifts predominantly to their ill family members. Furthermore, they desire an open-minded approach from professionals to share without fear of judgment, though some still felt prejudice. Reliability is also crucial, as young carers appreciate professionals who uphold their word and maintain confidentiality. Emphasising the theme of autonomy, every participant highlighted the need for their independence to be respected. In a separate study, Ali et al. (2013) revealed that



young carers see a potential positive impact from certain supports. Specifically, 66% favored web-support, 70% individual counselling, 64% group counselling, and a significant 80% believed that having access to relevant information could ameliorate their situations.

### **User support experiences**

In the context of education, young carers' experiences accessing support have been diverse. Some young carers have encountered challenges, as their schools and colleges failed to adequately address their needs. They expressed frustration with the awareness of their caregiving responsibilities among school staff and college staff but were disappointed when the expected help was not provided (Gough & Gillford, 2020). Conversely, for others, school served as a valuable resource where they felt treated equally, often viewing it as an escape from their caregiving responsibilities. These individuals highlighted the positive influence of specific teachers who understood their situation and provided much-needed support (Gough & Gillford, 2020). However, despite the positive experiences some young carers had with certain teachers, access to psychosocial support within schools remains generally limited. Only a few young carers reported receiving assistance from counselors or psychologists (Hagström & Forinder, 2019). Importantly, the type and extent of support provided to young carers varied widely, leaving many of them perceiving the existing assistance as inadequate (Nilsson et al., 2015; Waters, 2019). While some young carers found teachers to be helpful, they also pointed out communication gaps and inconsistencies among program teams, which reduced the overall support efficiency (Kettell, 2018).

### **Measuring outcomes**

Validated quantitative and non-validated qualitative measures were used to assess young carers. Included studies (qualitative and mixed methods study design) primarily relied on qualitative methods such as semi-structured interviews, structured interviews, and focus groups to gather data ( $n=17$ ; 65%). Validated quantitative measures included the Emotional Literacy Checklist (ELC; Faupel, 2003), Perceived Stress Scale (PSS; Cohen et al., 1983); General Self-Efficacy 10-item scale (GSE; Schwarzer & Jerusalem, 1995); Well-being Index (WHO-5; Topp et al., 2015); Strengths and Difficulties Questionnaire (SDQ; Goodman, 2001); Paediatric Quality of Life Inventory Version 4.0 (PedsQL; Varni et al., 2002); The Benefit-Finding in Child Caregivers Scale (Cassidy & Giles, 2013); Adverse Childhood Experiences questionnaire (ACES-Q; Felitti et al., 1998); Warwick-Edinburgh Mental Well-being Scale (WEMWBS; Tennant et al., 2007)). Note that there was no young carer-specific validated measure employed in any of the 26 included studies; however, the *Carers of Older People in Europe Index* (COPE Index; McKee et al., 2003) was used in two studies (Ali et al., 2014; Ali et al., 2015).

### **Short-term vs long-term impact of young carer supports**

Two studies examined the immediate (short-term) and sustained (long-term) efficacy of support for young carers. Research on young carer support primarily centers on immediate, short-term support interventions without continuous post-intervention support, leading to benefits that diminish over time (Nilsson et al., 2015). One program called 'Children Are People Too,' which had 15 regular group meetings, showed lasting effects 9–13 years after its conclusion, despite not offering continuous support post-intervention (Hagström & Forinder 2019). In a separate study by Dam et al. (2016), participants were provided the option for a follow-up interview for emotional support, for ethical considerations, but none took advantage of this offer.

## Appendix C: Consultations

Phases of thematic analysis used to analyse the qualitative data (Braun and Clark, 2006)

Phase	Description of the process
Familiarising yourself with your data	Transcribing, reading and re-reading the data, noting down initial ideas
Generating initial codes	Systematically coding the data and collating data to generate codes
Generating themes	Collating codes into themes
Reviewing themes	Checking that the themes work in relation to the coded extracts and the entire data set
Defining and naming themes	Refining each theme and the overall story that the analysis tells; generating clear definitions and names for each theme
Producing the report	Selection of vivid, compelling extract examples; final analysis of selected extracts, relating back to the research question and literature review; producing a report of the analysis

### Qualitative analytic methods

The interviews were audio-recorded then transcribed verbatim. The transcripts of the interviews were read through several times. With the aid of the software package NVivo, the qualitative interview data were coded initially by the attachment of short phrases to sentences or short paragraphs that stayed close to the data and retained its meaning and action. The initial codes were then grouped together to form focused codes. Finally, the analytic codes, or themes, were generated by grouping the focused codes in response to the key research question of the project. The categorisation process largely involved two processes: (a) convergence, that is, deciding which bits of data fit together under a category, and (b) divergence, that is, fleshing out categories once they had been generated and labelled (Lutz & Hill, 2009). The researchers continued to categorise until they felt that most of the data had been included, that it had a sense of regularity and that there was likelihood of overextension in that additional information would yield little return (Braun & Clarke, 2006; Lutz & Hill, 2009).



## Identification and Recognition: We are not carers

responsible  
 mediator  
 peacemaker  
 experiencing a lot  
 alone  
 a people pleaser  
 the responsible one  
 youngest and the oldest  
 a thing to be used  
 a month to feed  
 a daughter  
 the glue  
 pathetic  
 the rock  
 a odd sheep  
 trying my best  
 the strength  
 not what they wanted  
 judged  
 not my own person  
 youngest but feel old  
 one who takes on too much  
 traumatised too  
 one keeping it together  
 the carer  
 a bit over it  
 a fixer  
 communicator  
 a little isolated  
 a sister  
 adulting  
 the baby  
 a mum  
 a son  
 codependent  
 caring  
 a helper  
 a mistake

The language of “young carer” seems to be policy based, and not something that appears in the naturally occurring narrative of the young people or the family members consulted.



**Fig. 2. Young peoples' description about their needs and what they want from support services**

Theme	In my words
<p><b>My lived experience of having caring responsibilities</b></p> <p>Lived experience interviews substantially confirmed the findings of the Royal Commission, namely the extent to which young people with caring responsibilities are burdened in the moment and developmentally. Their presence is overlooked in adult psychiatric settings, and their needs appear to go unrecognised, in particular within school settings.</p>	<ul style="list-style-type: none"> <li>• “Not being understood and supported by medical personnel”</li> <li>• “Having to struggle with their mental illness without support”</li> <li>• “Not knowing if you should ask for help from services”</li> <li>• “Despair after despair; stretching yourself to support everyone but yourself and forgetting to take care of your own needs”</li> </ul>
<p><b>Who I would like help and recognition from</b> (in order of importance to the young person)</p> <ul style="list-style-type: none"> <li>• Family members: most wished for more open communication and support within the family unit</li> <li>• Friends: only half reported that a friend knew about their circumstance. A wish for friends in similar circumstances</li> <li>• School and teachers: wish for their awareness for personal support, advocacy and special consideration</li> <li>• Healthcare professionals : involvement with caring responsibilities was often not recognised</li> <li>• Legal, court and child protection professionals: appear as threats rather than supports in the mix for young people</li> </ul>	<ul style="list-style-type: none"> <li>• “If only they could understand me and my challenges at home”</li> <li>• “I wish my friends knew how hard it was to juggle home life and my own mental health”</li> <li>• “At school I feel alone; and a little isolated”. “I think it would have been helpful for school to be aware of it....if I was running late for an assignment, I sometimes didn't feel comfortable to say why”</li> <li>• A wish for teachers who “listen to me and comfort me”</li> <li>• A wish to be asked “R U OK” by professionals, in a “less scary way...and making me feel reassured by listening to me and saying that how I feel is totally okay and its okay to be sad or whatever”</li> <li>• “only without calling child protection services, I just want empathy and support – it only makes things more difficult when you do that”.</li> </ul>

<p><b>What I needed support with:</b> The young people's responses in this category report the flow on effects of parental absence and the wish for a caregiving presence who could be focused on their needs, amidst the urgency of their parent's needs.</p> <p><b>Who provided the support?</b> Satellite Foundation; Headspace; Beyond Blue; teachers; school counsellors; general practitioner, counsellors, psychologist; family therapist; youth worker, online services.</p> <p><b>For those not connected to services... (n=6)</b> <b>What I wanted support with:</b> Themes of self-reliance dominated, lack of awareness that support services existed, and confusion about how to access them. The needs expressed were remarkably uniform across cultural backgrounds and across parent circumstance.</p>	<p><b>For those connected to services... (n=10)</b></p> <ul style="list-style-type: none"> <li>• "Knowing I'm allowed to exist outside of my family and having a space to do so"</li> <li>• "Figuring out how I want my relationship with my family to be"</li> <li>• "understanding myself"; "understanding and knowing how to take care of myself rather than just everyone around me"</li> <li>• "Needing time off school because of my caring roles"</li> <li>• "My parent's intervention order"</li> <li>• "Sexual health stuff"</li> </ul> <p><b>For those not connected to services... (n=6)</b></p> <ul style="list-style-type: none"> <li>• "I was my own greatest source of support"</li> <li>• "Everything. It was hard to even know and find out what types of assistance are available"</li> <li>• Understanding the "diagnosis".</li> </ul>
<p><b>What would good support look like?</b> The need for an easy way to navigate systems and services that meet their needs was evident throughout. Caring responsibilities for family members with a variety of conditions requires responsive, referral and access pathways to tailored services based on needs and circumstances.</p>	<ul style="list-style-type: none"> <li>• "support looks like someone who listens to me and tries to help when I need it"</li> <li>• "a less scary way to find help...by making it easier to go through the processes.... I get confused".</li> </ul>
<p><b>What young people need from support people and services</b> Amidst the crush of concern and care, the young people were nearly unanimous in the developmentally appropriate wish for growing autonomy from their parents and family. Some young people spoke about the loss of childhood.</p>	<ul style="list-style-type: none"> <li>• a "sense of independence and access to space for myself"</li> <li>• "money to enjoy life"; "financial freedom"</li> <li>• "rest"; "breaks"; "boundaries"; "mental health days"; I deserve "to be a kid"</li> </ul>

### Positive aspects of 'the caring experiences'

When asked about the 'good stuff' in their families, several young people spoke to a general sense of love, support, and connection within their families (e.g., *"loves me even when things are rough"*; *"cultural connection that the outside world can't give in the same way"*). Other young people commented on how love and time together as a family is shared through food (e.g., *"The dinners"*, *"How everyone come together and share their day"*).

Young people also commonly reflected on the bonds and relationships with siblings and other members of the family (e.g., *"The bond with my nanna and sister"*). Growth and maturity were mentioned both in a personal sense, *"the life skills I have developed"*; as well as in the context of other family members, *"being able to watch my family grow into good people"*.

Several young people also shared specific 'special moments' in the family. For example, *"the silly moments we have, where we can't stop laughing at each other and the moments at the beach together"*.

### Difficult aspects of 'the caring experiences'

In comparison to the good stuff (positive aspects) of their lived and living experience, when asked about the 'bad stuff' (difficult aspects), participants offered more responses, suggesting that there may be a dominance of more negative than positive aspects recognised within their family context.

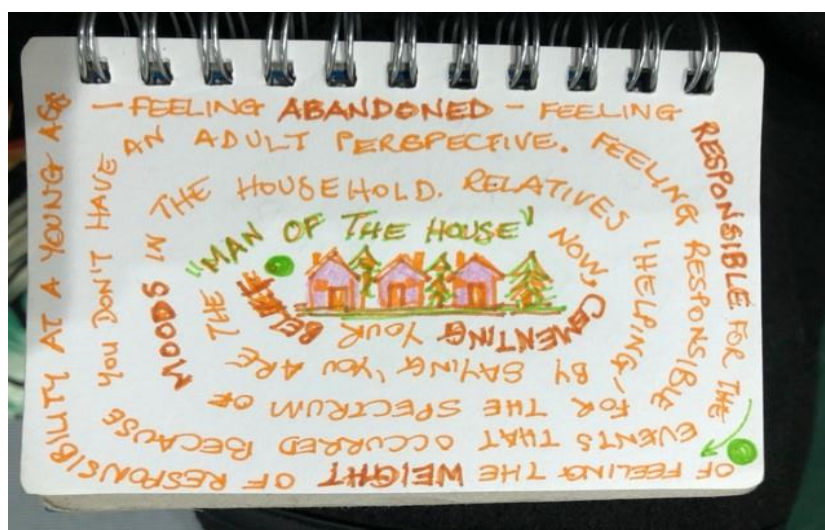
Many young people indicated that they felt sense of enormous responsibility and obligation to provide care and support (e.g., *"Being the emotional regular for everyone"*; *"The weight of it all"*; *"Feeling responsible for someone's life"*). In line with this, several participants noted *being angry for my parentification* and a *"loss of childhood"* associated with their caring responsibilities.

Some responses also reflected the difficulties in *not being able to express my feelings properly* and the need to 'pretend' things in their family were different to how they truly are. As part of this and in contrast to responses to the 'good stuff', some young carers indicated that communication was an issue. Impact on mental health was also dominant across responses, for example, someone shared *"having to struggle with mental illness without support"*. Another noted the struggle of having to deal with *body image issues and fat shaming*. A sense of helplessness was also evident in young people's responses – *"Not knowing what to do or how to help and feeling like things won't get better for my family"*.

## Consultations with Adult Family Members: Elaboration on Findings

Family members' views on their young person with caring responsibilities (n=6)

Key themes	In my words
<p><b>Language.</b> Family members were reluctant to use terms such as 'young carer'.</p>	<ul style="list-style-type: none"> <li>• "We don't really use carer... we generally use support person as a term. it feels kinder to us"; "that term is new to me, and I don't use the term, neither do my kids"; "they (young people) don't see themselves as doing anything differently"</li> </ul>
<p><b>Parent reflections on their young person as a 'carer'.</b></p> <p>While family members described family life on a spectrum from "<i>creative</i>" to "<i>struggling</i>", most participants expressed positive comments, pride and admiration for the young person caring for them, who contributed deeply to the sense of an ongoing family unit.</p> <p>All family members also expressed the difficult effects for their young person, as a result of caring during their mental health struggle, alcohol and other drugs concerns or addiction.</p>	<ul style="list-style-type: none"> <li>• "My daughter is incredible at holding space, she is deeply empathetic, she is also so strong and kind...whilst she has to support me at times, she does such an amazing job managing her own stuff. She is mature, has the most amazing sense of humour. She is learning to develop independence and has discovered she is an incredible cook"</li> <li>• "My son is often having to speak on my behalf, advocate for me in medical settings when I can't speak due to seizures or aphasia. He will at times have to co-regulate when I am overwhelmed in public settings"</li> <li>• "The isolation, all the things she misses out on. Sometimes the embarrassment if I am struggling with overwhelm or speech, the anxiety of my health issues, the confusions of the unpredictability" ; "sometimes when I have episodes of fatigue and exhaustion she misses out on a lot of things and has to assist with meals a lot".</li> <li>• "She gets overwhelmed, not feeling safe, withdrawn, having to see me struggle really upsets her"; "Doesn't go out with friends after school or sports things like that".</li> </ul>



**Fig. 3.** Adult family member's views on their young person with caring responsibilities

Key themes	In my words
<p><b>Use of supports</b></p> <p>For most family members, there was more reliance on informal support from the extended family network than on formal support. Often extended family members were unable to support when this was most needed. Three mentioned formal organisations : Little Dreamers, Satellite Foundation and TemCare.</p>	<ul style="list-style-type: none"> <li>• "She (the young person) does not have camps or support workers she debriefs with. Her older siblings help when they aren't busy. But I still feel people don't understand how hard it is on her own"</li> <li>• "Our friendship groups mainly through school connections have been amazing support, driving my kids to sport etc. Including them on holidays trips"</li> <li>• "Random agencies sometimes ask"; "High school does not ask, don't care"; "Agencies take information as a way to opt out sometimes" ; "I wish services and supports would understood....they did not see how hard it was for her (the young person)"</li> </ul>
<p><b>How could support and access be better?</b></p> <p>Family members emphasised having had adequate information and knowledge about services, together with de-stigmatising messages. Some family members highlighted the need for mental health and wellbeing related services for their young person, and others nominated the need for financial support.</p>	<ul style="list-style-type: none"> <li>• "Having knowledge on what she can access would help"; "I wish there had been a message that getting help is something that is okay and not a source of shame. We puddled along but it would have been so good him to be supported - perhaps I would have learned how to better support him"</li> <li>• "More support for her own mental health. The toll it takes on young people growing up in unpredictable situations, particularly health/mental health based is hard. The isolation is hard so more social support, social groups"</li> <li>• "More ability to have some financial independence and help learning the skills needed. For example, free first aide and mental health first aide training"</li> </ul>



## Consultations with Professionals and Practitioners: Elaboration on Findings

### Support rather than risk-based identification of young people

Consensus was clear, that shifting the focus of identification from “risk” to “support” provides a more promising approach to engage and support young people with caring responsibilities. A risk-oriented identification of young people leads to greater focus “in a negative sense” compared to “provision of actual support” and “enabling well-being”. In this light, one family practitioner working in adult mental health offered these steps:

1. “Always ask the question of the person being cared for, about the situation of their carers in their family,
2. Provide psychoeducation to the person being cared for (the patient/client) about the importance of their children and young people being supported in their caring role,
3. Gain parental consent to engage and work with their children and young people,
4. Approach the young person and provide support,
5. Adopt a relational practice - a whole family approach, also to the benefit of supporting the patient's recovery”.

### Barriers in identification and engagement of young people

Collectively, the consultations with practitioners identified a range of barriers at individual, family and service level that may hinder referral pathways and access to services for young people.

The core family themes, echoing many identified by family members and young people were:

**Young people’s lack of self-identification as “carer”.** Identity of family as normal and not needing or deserving of help.

*“Young people wrap around their family unit and say ‘this is my responsibility to care for this person. Well, I’ve grown up doing this. It’s part of how we operate as a family’”*

*“Many young people struggle with identifying as young carers as they feel it is simply their responsibility as a child or sibling to provide the carer supports to their family members. They are hesitant to reach out for support, especially because they do not identify as a young carer”*

- **Stigma and shame** for the young person, and/or their parent, associated with mental illness
- **Young carer guilt** about looking after themselves
- **Parents’ lack of trust in services**, and reluctance to share information (e.g., especially for First Nations families, due to fear of Child Protection involvement). In these regards, the need for these fears to be anticipated and fully seen was emphasised, alongside ‘normalising’ talks about cross-cultural family struggles with mental illness, substance use or addiction.
- **Lack of information about entitlements**, available services and how to navigate through services
- **Pragmatics:** time and transport



## The core services and systems themes were:

- **Risk Orientation:** Services adopting a risk oriented rather than support oriented identification to engagement with young people
- **Out of scope:** Service mandate and resourcing not inclusive of routine check-in on the well-being of each family member; minimal resourcing to be responsive when needs are detected beyond immediate care of the affected family member
- **No routine data collection** about the family's composition, needs and strengths. Most spoke about young people with caring responsibilities as the *"invisible members of the family"*.
- **Siloed approaches:** No or minimum inter-service or cross sector coordination, collaboration, and partnerships. Most participants pointed to a system that is not joined up. Adult mental health services, substance and/or addiction services were rarely connected to the young person's school.
- **Rules and regulations about consent.** If a parent is not in a stable mental state, they may not be in a headspace to be able to make decisions / give consent for services to support their young children 'carers'.

## Strengthening referral pathways:

*"...we need to break down some of those barriers for "young carers" (young people with caring responsibilities) so that they can connect with other young carers from a whole range of different support services and break down the barriers of understanding and support that young carers receive in environments like school settings, university settings, workplaces, normalising the need for flexibility, compassion and understanding across these sectors"*

From a service and system perspective, strong inter-service coordination, collaboration, and partnerships in meeting the specific needs of young people with caring responsibilities was called for.

## How are young people currently referred to services?

Participants reported a variety of ways in which young people are referred to support services. Some examples included Helpline via a Google search; word of mouth, brochure, GP, a mental health care plan, school, the family member's treating team. Some reported that despite identification, knowledge of referral processes or options was often inadequate.

*"if the parent's clinician is tuned in enough, they will identify the young person and their needs...but often they are not aware where to refer them" (FaPMI coordinator)*

## Strengthening referral pathways and access to services for young people

In terms of strengthening referral pathways, most participants spoke about “purposeful referrals” and “starting with the family”. For example, one of the child and youth workers stated that:

*“Starting where the family is at...the young child, the young person, and their families may already have formal and informal sort of networks that can be extended or built on, rather than the idea of, you know, sending them off to another thousands for referrals that actually might make their life much more complicated and might not actually relieve or provide any support”.*

In line with this “purposeful referral”, some of the participants emphasised the need to shift away from “clinical” perspectives to “opportunity” perspective, when engaging with young people with caring responsibilities. For example, one of the participants (FaPMI coordinators) stated that:

*“It's more about the opportunities for this young person, what this family needs to have happy, healthy relationships and develop and grow and have positive futures... the opportunities that parents might like for their children and young people”.*

In terms of type of services, the professionals and practitioners mentioned a great deal of variation in support and services for young people and their families. Examples of support include: Individual work and/or group activities with the young person (e.g., recreational, and fun activities), respite care; work with the whole family; practical and financial support (e.g., brokerage funds); mental health and social support; support with engagement in school and education; support with employment.

Collectively, the participants emphasised the need for a dual focus on individual provision of tailored support to the young person and support within a family context: “Family therapy services can offer whole of family mental health support”.

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