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Connecting Narrative **993 words**

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Abstracts

Systematic Review of the Literature (SRL) Abstract

Acceptance and Commitment Therapy for Psychosocial Outcomes in Children and Young People with Long-Term Physical Health Conditions: A Systematic Review of Intervention Studies

Background: Children and young people (CYP) with long-term physical health conditions (LTCs) are at greater risk of psychosocial difficulties. Systematic reviews on adults with LTCs have supported acceptance and commitment therapy (ACT) in improving several psychosocial outcomes.

Aims: This systematic review aimed to investigate the effectiveness of ACT on CYP-reported psychosocial outcomes among CYP with LTCs. It also examined the factors associated with the effects and the quantitative acceptability of the included ACT interventions.

Methods: Eligible studies used a quantitative experimental design to evaluate ACT for CYP-reported psychosocial outcomes in CYP (≤18 years old) with LTCs. Only studies published in English in peer-reviewed journals, from any year, were included. CINAHL (EBSCO), Cochrane Library, Embase (Ovid), MEDLINE (Ovid) and PsycInfo (Ovid) were systematically searched. Google Scholar and Web of Science were also searched and forward and backward citation searching were completed for

included papers. Research quality was appraised using Cochrane risk of bias tools. Results were narratively synthesised.

Results: Sixteen studies (nine randomised controlled trials [RCTs], seven non-RCTs) from 19 reports met inclusion criteria, with 777 participants and five LTCs (chronic pain, diabetes, cancer, obesity, visual impairment). Findings provided preliminary support for the effectiveness of ACT on most CYP-reported psychosocial outcomes studied. Seven studies considered factors associated with intervention effects, with mixed findings. Acceptability was supported in the three studies that assessed it quantitatively. However, almost all studies had overall high/serious risk of bias ratings.

Conclusion: There is preliminary evidence supporting the effectiveness of ACT in improving CYP-reported psychosocial outcomes in CYP with LTCs, with limited but supportive findings for its acceptability. However, findings are constrained by high/serious risk of bias and small sample sizes. Larger, high-quality trials with active controls and longer follow-ups are needed to inform future care pathways.

Registration: This systematic review was pre-registered (PROSPERO registration number: CRD42023425918).

Keywords: acceptance and commitment therapy, child and adolescent, long-term physical health conditions, paediatrics, psychosocial outcomes

Service Improvement Project (SIP) Abstract

"We Are Here Too": Experiences and Perceived Support Needs of Adolescent Siblings of Paediatric Oncology Ward Inpatients at Oxford Children's Hospital

Background: Adolescent siblings of children and young people (CYP) with cancer are at increased risk of experiencing psychosocial difficulties. Kamran's Ward, a paediatric oncology ward at Oxford Children's Hospital, recognised the need for improving sibling support. This project aimed to explore the experiences and perceived needs of adolescent siblings of CYP on Kamran's Ward to inform service improvement recommendations for sibling support.

Methods: Semi-structured interviews were conducted with 10 adolescent siblings of CYP who had recently stayed on Kamran's Ward. Interviews were transcribed verbatim and analysed using reflexive thematic analysis. The findings were reviewed in consultation with staff and used to identify feasible recommendations for improving sibling support.

Results: An overarching narrative of siblings wanting to feel part of the cancer journey, including their family's experience on Kamran's Ward, was found, with three key themes: (i) "what about me?": overlooked and unseen, (ii) "always changing, never knowing": the challenge of uncertainty and (iii) "let me be part of it all": togetherness, communication and connection. These findings informed sibling support recommendations, organised by level of need. Recommendations included: psychosocial screening, staff training, opportunities for family time and

communication and developmentally appropriate information for all siblings (universal support), monitoring psychosocial difficulties, providing someone to talk to and fostering family and peer connection for siblings requiring additional support (targeted support) and one-to-one psychological support and family therapy for persistent and/or escalating distress (clinical/treatment support).

Conclusion: Based on the experiences of adolescent siblings, a range of sibling support recommendations have been identified. Implementation and evaluation of these recommendations are warranted.

Keywords: siblings, cancer, oncology, hospital, adolescence, psychosocial support, paediatrics

Theory Driven Research Project (TDRP) Abstract

Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

Background: People with temporal lobe epilepsy (TLE) are at increased risk of mental health difficulties. Self-compassion, comprised of self-kindness, common humanity and mindfulness, has been associated with better mental health in wider epilepsy populations. Previous research suggests that self-compassion may be protective by fostering better emotion regulation. However, this has not been studied in TLE.

Aims: To (1) compare adults with TLE, other types of epilepsy (non-TLE) and non-epilepsy controls on measures of self-compassion, anxiety and depression, and (2) investigate the relationships between self-compassion, mental health and emotion regulation difficulties in adults with TLE.

Methods: A cross-sectional, online survey was completed by 180 adults with TLE, 149 with non-TLE and 127 non-epilepsy controls. The survey measured sociodemographic and epilepsy-related factors, self-compassion, anxiety, depression and emotion regulation difficulties.

Results: Anxiety and depression were highest in adults with TLE, followed by non-TLE and then non-epilepsy controls. Overall self-compassion, and components self-kindness and common humanity, were lowest in adults with TLE, followed by non-

TLE and then non-epilepsy controls. Mindfulness was lower among epilepsy groups than non-epilepsy controls but did not significantly differ between epilepsy groups. In TLE, higher self-compassion predicted lower anxiety and depression, after controlling for significant sociodemographic and epilepsy-related factors. Emotion regulation difficulties partially mediated such relationships.

Clinical implications: These findings contribute to understanding risk factors for poor mental health among adults with TLE. Future research evaluating interventions to target such factors is needed, to inform psychological support and care pathways.

Keywords: epilepsy, temporal lobe epilepsy, anxiety, depression, self-compassion, emotion regulation

Systematic Review of the Literature (SRL)

Acceptance and Commitment Therapy for Psychosocial Outcomes in Children and Young People with Long-Term Physical Health Conditions: A Systematic Review of Intervention Studies

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Proposed Journal

This SRL has been submitted to BMC Pediatrics. This peer-reviewed journal publishes papers on all aspects of healthcare in children and adolescents. BMC Pediatrics has published systematic reviews evaluating psychological interventions among paediatric populations. Therefore, this journal was considered relevant, and it is anticipated that this systematic review will reach a wide audience. Appendix A outlines the author submission guidelines.

Abstract

Background: Children and young people (CYP) with long-term physical health conditions (LTCs) are at greater risk of psychosocial difficulties. Systematic reviews on adults with LTCs have supported acceptance and commitment therapy (ACT) in improving several psychosocial outcomes.

Aims: This systematic review aimed to investigate the effectiveness of ACT on CYP-reported psychosocial outcomes among CYP with LTCs. It also examined the factors associated with the effects and the quantitative acceptability of the included ACT interventions.

Methods: Eligible studies used a quantitative experimental design to evaluate ACT for CYP-reported psychosocial outcomes in CYP (≤18 years old) with LTCs. Only studies published in English in peer-reviewed journals, from any year, were included. CINAHL (EBSCO), Cochrane Library, Embase (Ovid), MEDLINE (Ovid) and PsycInfo (Ovid) were systematically searched. Google Scholar and Web of Science were also searched and forward and backward citation searching were completed for included papers. Research quality was appraised using Cochrane risk of bias tools. Results were narratively synthesised.

Results: Sixteen studies (nine randomised controlled trials [RCTs], seven non-RCTs) from 19 reports met inclusion criteria, with 777 participants and five LTCs (chronic pain, diabetes, cancer, obesity, visual impairment). Findings provided preliminary support for the effectiveness of ACT on most CYP-reported psychosocial outcomes studied. Seven studies considered factors associated with intervention effects, with

mixed findings. Acceptability was supported in the three studies that assessed it quantitatively. However, almost all studies had overall high/serious risk of bias ratings.

Conclusion: There is preliminary evidence supporting the effectiveness of ACT in improving CYP-reported psychosocial outcomes in CYP with LTCs, with limited but supportive findings for its acceptability. However, findings are constrained by high/serious risk of bias and small sample sizes. Larger, high-quality trials with active controls and longer follow-ups are needed to inform future care pathways.

Registration: This systematic review was pre-registered (PROSPERO registration number: CRD42023425918).

Keywords: acceptance and commitment therapy, child and adolescent, long-term physical health conditions, paediatrics, psychosocial outcomes

Introduction

Approximately 1.7 million children and young people (CYP) have long-term physical health conditions (LTCs) in the UK (1). CYP with LTCs are at greater risk of psychosocial difficulties, such as anxiety and depression (2,3). Multiple factors may contribute, including illness symptoms, uncertainty and reduced independence (4).

Psychosocial difficulties in CYP with LTCs have been associated with adverse outcomes, including lower educational attainment, increased suicide risk and poorer illness management (5–8). Consequently, health agencies have emphasised the need for psychological care in LTC populations (9,10).

Psychological Interventions

Psychological intervention research in CYP with LTCs has primarily focused on cognitive behavioural therapy (CBT) (11,12). However, systematic reviews have reported mixed findings, with moderate-high risk of bias and limited evidence for outcomes such as quality of life and depression (11–14).

Given some LTC-related cognitions (e.g. unpredictability, limited independence) may reflect real experiences, traditional CBT techniques such as thought challenging may be less suitable for some (15,16). Thus, exploring alternative psychological interventions without this key focus may be useful.

Acceptance and Commitment Therapy

One such intervention is acceptance and commitment therapy (ACT) (17). Based on relational frame theory, which describes how we construct meaning and understand the world by forming relationships between concepts (18), ACT uses a transdiagnostic approach that focuses on enhancing psychological flexibility. Psychological flexibility has been described as accepting thoughts, emotions and sensations without judgement, maintaining present-moment awareness and taking meaningful values-based action, even during difficult experiences (19). To target psychological flexibility, ACT incorporates six core processes (acceptance, cognitive defusion, committed action, present moment, self as context, values).

Psychological flexibility may be particularly relevant to LTC populations, as LTCs are persistent, making it important to maximise one's fit with the situation rather than challenging it (20). Systematic reviews in adults with LTCs have shown preliminary support for ACT on several psychosocial outcomes (15,21–24), and clinical guidelines for chronic pain management in adults recommend ACT (25).

For CYP, ACT may provide a developmentally sensitive, adaptable treatment approach (26). Developmentally, CYP typically become more exploratory and seek independence (27,28), which ACT could facilitate through psychological flexibility. A recent meta-analysis of 14 randomised controlled trials (RCTs) showed ACT significantly improved anxiety and depression in clinical and non-clinical CYP (29). Another meta-analysis of four RCTs comparing ACT and CBT for adolescents with

anxiety found no significant differences in outcomes, despite CBT being the recommended intervention (30,31).

Although ACT has shown promising findings in adults with LTCs and CYP more broadly, a systematic review evaluating its effectiveness on psychosocial outcomes and acceptability among CYP with LTCs has not yet been undertaken. Focusing on CYP-reported psychosocial outcomes may be especially important, as discrepancies have been found between self-reports and proxy (e.g. parent) reports (32–34). Given ACT's transdiagnostic nature, understanding factors associated with its effects, such as the processes or mechanisms of change through which ACT exerts its effects, is also important for improving its application (35).

Aims and Research Questions

This systematic review aims to evaluate the effectiveness of ACT on CYP-reported psychosocial outcomes among CYP with LTCs. It also aims to examine the factors associated with the effects and quantitative acceptability of the included ACT interventions.

Primary Research Question

1) What is the effectiveness of ACT interventions on CYP-reported psychosocial outcomes in CYP with LTCs?

Secondary Research Questions

2) What factors are associated with the intervention effects of the evaluated ACT interventions in CYP with LTCs?
3) What is the quantitatively rated acceptability of the evaluated ACT interventions in CYP with LTCs?

Methods

Protocol

The protocol for this systematic review was pre-registered on the international database of Prospective Register of Systematic Reviews (PROSPERO) in May 2023 (registration number: CRD42023425918). The Preferred Reporting Items for Systematic review and Meta-Analysis (PRISMA) 2020 guidelines (36) were followed (see Appendix B for checklist).

Search Strategy

A systematic search of databases from inception was conducted on August 20th 2024, and updated on February 3rd 2025. The following databases were searched: CINAHL (EBSCO), Cochrane Library, Embase (Ovid), MEDLINE (Ovid), and PsycInfo (Ovid). Google Scholar and Web of Science were also searched for additional papers. Lastly, forward and backward citation searching were completed for included papers.

Search Terms

The search strategy captured two main concepts: (i) CYP and (ii) ACT. A decision was made to not have LTCs as a third concept to ensure the search was non-exclusive regarding LTCs.

The search strategy comprised the following terms: (Child* OR Adolescen* OR Teen* OR youth* OR young* OR juvenile* OR paediatric* OR pediatric* OR Boy* OR Girl* OR Schoolchild* OR Minor* OR "Under 18") AND ("acceptance and commitment therapy" OR "DNA-V" OR "Discoverer Noticer Advisor?Values" OR "psychological flexibility"). See Appendix C for details of full, line by line search strategy for each database.

Inclusion and Exclusion Criteria

The Patient, Intervention, Comparison and Outcome (PICO) framework (37) was used to define inclusion criteria (Table 1).

Table 1

Inclusion Criteria Using Patient, Intervention, Comparison and Outcome (PICO) Framework (37)

Component	Inclusion criteria
General	Quantitative experimental design (randomised and non-randomised designs, given the limited evidence base) including mixed methods studies with such a quantitative component. Published in a peer-reviewed journal (i.e. not a dissertation or non-peer reviewed conference abstract or pre-print). Published in English. Any publication year.
Population	All participants aged ≤18-years-old (or sub-analyses for ≤18-year-olds). All participants diagnosed with LTC(s). LTCs were defined as physical health conditions that typically persist for at least three months, require medical care and are associated with functional limitations (38).
Intervention	Any ACT-based intervention delivered to CYP. This may be with or without parent(s)/carer(s) involvement. ACT-based intervention only (or sub-analyses for ACT-based component if used in conjunction with other psychological/psychosocial interventions).
Comparator	Reports comparisons in outcomes at pre-intervention and post-intervention. RCTs should additionally report comparisons between an intervention and control/comparator group.
Outcome	Reports CYP-reported measure of any psychosocial outcome (e.g. anxiety, depression, psychological distress, coping).

Note. ACT = acceptance and commitment therapy. CYP = children and young people. LTC = long-term physical health condition. RCT = randomised controlled trial.

Studies were excluded if they were not in English, not peer-reviewed, qualitative only or case studies.

Study Selection

All citations identified through the search were imported into Excel. After removing duplicates, one researcher (RB) screened all titles and abstracts. A second researcher (NC) independently screened a random 20%. The two reviewers had almost perfect agreement for title/abstract screening (κ = .88). RB then completed full-text screening for all remaining reports to determine eligibility, and NC conducted an independent screen of a random 25%. The two reviewers had almost perfect agreement for included/excluded studies for full-text screening (κ = .91). At each stage, disagreements were discussed within the review team until consensus was reached.

Data Extraction and Synthesis

Data were extracted using Cochrane's data collection form for intervention reviews (39), modified for the current systematic review (see Appendix D). RB extracted data from all included reports, with NC independently extracting a random 50% to ensure accuracy and reliability. The two reviewers had almost perfect agreement for data extraction (κ = .94). Discrepancies were discussed and resolved within the review team. Additional information was sought by contacting study authors.

Given the clinical and methodological heterogeneity across studies (e.g. study designs, LTCs, ACT interventions, outcomes), data were not sufficiently homogenous for quantitative pooling (i.e. meta-analysis). Therefore,

results were narratively synthesised, following the Synthesis Without Meta-analysis (SWiM) (40) guideline (see Appendix B for checklist). Study characteristics (design and participants), intervention characteristics and CYP-reported psychosocial outcomes were reported in tabular form and narratively. Where available, factors associated with the effects of ACT and quantitative acceptability were also reported. Although the pre-registration specified examining mediators of ACT effects, the scope was broadened to include any analyses of factors associated with CYP-reported psychosocial outcomes, due to the limited number of studies reporting mediators.

To enhance LTC-specific interpretability for research and practice, study outcome syntheses were organised by LTC (from most to least number of studies). All time points and analyses were reported. In the absence of meta-analyses, potential reporting biases were described qualitatively. Regarding standardised metrics, where available, *p*-values and effect sizes for within-group and between-group analyses were extracted. Originally reported effect sizes were used due to the heterogeneity between studies in reported effect sizes. Effect size interpretations followed Cohen's guidelines (41). If not reported, appropriate effect sizes were calculated if data allowed. Inconsistent findings were qualitatively discussed regarding potential sources of heterogeneity.

Quality Appraisal Strategy

The Cochrane Risk of Bias 2 (RoB 2) (42) tool was used to assess the quality of RCTs. The Cochrane Risk Of Bias In Non-randomised Studies - of Interventions

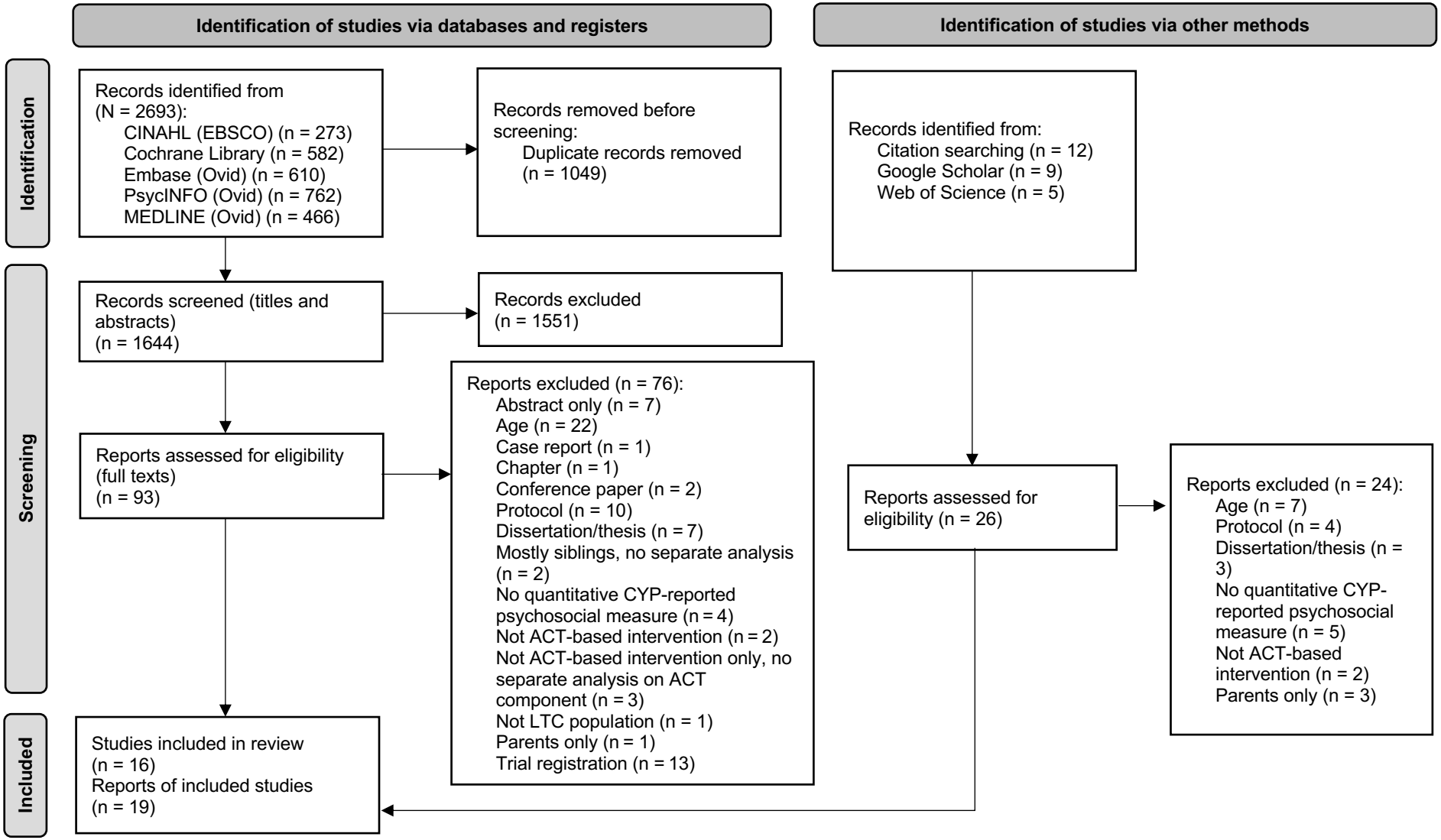
(ROBINS-I) (43) tool was used to evaluate non-RCTs. RoB 2 and ROBINS-I assess five and seven domains respectively, with each study's overall risk of bias reflecting its highest domain rating (42,43). Studies were not excluded from the synthesis based on risk of bias, to retain the full scope of relevant evidence, following Cochrane guidance (44). RB assessed the quality of all included studies, with NC independently appraising a random 30%. The two reviewers had perfect agreement ($\kappa = 1$) for overall risk of bias and almost perfect agreement ($\kappa = .82$) at the domain level. Discrepancies were discussed within the review team until consensus was reached.

Results

Overall, the database searches yielded 2693 citations. Duplicate screening removed 1049 reports. Titles and abstracts of the remaining 1644 articles were screened and 1551 were excluded. The full texts of the remaining 93 articles were read and assessed for eligibility; 76 were excluded (see Figure 1 for reasons) and 17 were included. An additional 26 reports were identified through hand searching Google Scholar and Web of Science and forward and backward citation searching of included report; 24 were excluded and two were included. Overall, 16 studies from 19 reports were included. A PRISMA flow diagram of this process is provided in Figure 1.

Figure 1

Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Flow Diagram of Selection Process



Study Designs and Participant Characteristics

Study designs and participant characteristics are presented in Table 2. Nine studies were RCTs (45–53). Two RCTs (46,47) had secondary analyses in additional reports (54,55). Three RCTs used active controls (50,52,53), three used treatment-as-usual (TAU) (47,51) and two offered no intervention (NI) (48,49). One RCT compared group ACT and individual ACT (45). The remaining seven studies were non-RCTs, one with a control group (NI) (56) and six without a control group (57–62). One non-RCT (60) had one additional report on secondary analyses (63).

Six studies were conducted in Iran (48–50,52,53,56), four in Sweden (45–47,60), two in Finland (47,59) and one in England (58), Italy (51), Romania (61) and the USA (62). Five LTCs were included: chronic pain (six studies) (45,46,57–60), diabetes (four) (47–49,61), obesity (three) (50,51,62), cancer (two) (52,56) and visual impairment (one) (53).

Overall, 777 CYP were included, with samples of seven to 187. Ages ranged from 7-18 years old. Across the 14 studies that reported gender, all but two (48,49), had all or mostly females (45–47,50,51,53,57–62). Only one study reported ethnicity, although not for all CYP (62).

Table 2

Study Designs and Participant Characteristics of Included Studies

Study	Design	Control/ comparator	Country	LTC	Participants					
					ACT			Control/comparator		
					Number	Age in years	Gender	Number	Age in years	Gender
Chronic pain										
Kanstrup et al. (2016) (45)	RCT (pilot).	Compared two delivery formats of ACT intervention (group and individual), with neither framed as the control/comparator.	Sweden.	Chronic pain (for more than six months).	N = 24 (randomised). ^ *n* = 12 (post-intervention).	*M* (*SD*): 16.3 (1.5). Range: 14-18 (overall).	11 (91.7%) females (91.7%), one (8.3%) male.	N = 24 (randomised). ^ *n* = 18 (post-intervention).	*M* (*SD*): 15.8 (1.6). Range: 14-18 (overall).	13 (72.2%) females, five (27.7%) males.
Wicksell et al. (2009) (46)	RCT.	TAU (multidisciplinary treatment and amitriptyline. Approach guided by biobehavioural model of longstanding pain, with input from physician, physiotherapist, psychiatrist and psychologist).	Sweden.	Chronic pain (idiopathic, more than three months).	N = 16 (randomised). *n* = 15 (post-intervention), n = 14 (one-month follow-up) and n = 13 (two-month follow-up). ^	*M* (*SD*): 14.8 (2.4) (overall) Range: 10.8-18.1 (overall).	25 (78.1%) females, seven (21.9%) males (overall).	N = 16 (randomised). *n* = 14 (post-intervention), n = 11 (one- and two-month follow-ups). ^	*M* (*SD*): 14.8 (2.4) (overall) Range: 10.8-18.1 (overall).	25 (78.1%) females, seven (21.9%) males (overall).
Secondary analysis reported in Wicksell et al. (2011) (54)					*n* = 15 (post-intervention).	*M* (*SD*): 14.8 (2.4). Range: 10.8-18.1.	23 (76.7%) females, seven (23.3%) males.	Not included in secondary analysis.		
Balter et al. (2021) (57)	Non-RCT without control group.	None.	Sweden.	Chronic pain (for more than six months).	N = 47 (recruited, no dropout, although some missing outcome data).	*M* (*SD*):14.8 (2.2). Range: 9.5-17.9.	33 (70%) females.	None.		

Study	Design	Control/ comparator	Country	LTC	Participants					
					ACT			Control/comparator		
					Number	Age in years	Gender	Number	Age in years	Gender
Kemani et al. (2018) (58)	Non-RCT without control group.	None.	England/ UK.	Chronic pain.	N = 187 (recruited). ^ *n* = 164 (pre-intervention). *n* = 164 (post-intervention). ^ *n* = 107 (three-month follow-up). ^	*M* (*SD*): 15.5 (1.8). Range: 11.3-18.9.	127 (77.4%) females.	None.		
Vuorimaa et al. (2019) (59)	Non-RCT without control group (feasibility study).	None.	Finland.	Chronic pain (idiopathic recurrent musculoskeletal pain, persistent pain over three months).	N = 32 (recruited). *n* = 24 (six- and 12-month follow-ups from pre-intervention). ^	*M* (*SD*): 14.4 (1.3). Range: 13-17.	26 (81%) females.	None.		
Zetterqvist et al. (2020) (60)	Non-RCT without control group (pilot).	None.	Sweden.	Chronic pain (duration ≥ three months).	N = 28 (recruited). *n* = 23 (post-intervention). ^ *n* = 20 (four-month follow-up, completed at 17-25 weeks). ^	*M* (*SD*): 15.43 (.26). Range: 13-17.	100% females.	None.		
Secondary analysis reported in Gentili et al. (2024) (63)					No separate demographic information for participants in secondary analyses.			None.		

Study	Design	Control/ comparator	Country	LTC	Participants					
					ACT			Control/comparator		
					Number	Age in years	Gender	Number	Age in years	Gender
Diabetes										
Alho et al. (2022) (47)	RCT (pilot).	TAU (included paediatric clinic visits once every three months and meeting with healthcare professionals, including a nurse and a doctor). Offered the same intervention after the post-measurements (final time point).	Finland.	Diabetes (type 1, with HbA1c levels above 7.5%).	N = 36 (randomised).	*M* (*SD*): 13.44 (13.44). Range: 12-16 (overall).	24 (67%) females, 12 (33%) males.	N = 36 (randomised).	*M* (*SD*): 13.36 (1.22). Range: 12-16 (overall).	21 (58%) females, 15 (42%) males.
					n = 31 (pre-intervention).	*M* (SD): 13.39 (1.12). Range: 12-16 (overall).	22 (71%) females, nine (29%) males.	*n* = 29 (pre-intervention).	*M* (*SD*): 13.48 (1.30). Range: 12-16 (overall).	16 (55%) females, 13 (45% males).
					n = 28 (post-intervention). ^			*n* = 27 (post-intervention). ^		
Secondary analysis reported in Alho et al. (2024) (55)					*n* = 28 (post-intervention).	Range: 12-16 (overall). States 15 participants were 12-13 and 13 participants were 14-16.	Not reported.	None.		
Ataie Moghanloo et al. (2015) (49)	RCT.	NI.	Iran.	Diabetes (type 1 or type 2, for at least one year).	N = 20 (randomised). ^			N = 20 (randomised). ^		
					n = 17 (post-intervention).	*M* (*SD*): 10.35 (2.91). Range: 7-15 (overall).	Eight (47.1%) males, nine (52.9%) female.	*n* = 17 (post-intervention).	*M* (*SD*): 10.59 (3.16). Range: 7-15 (overall).	Nine (52.9%) males, eight (47.1%) females.
Moazzezi et al. (2015) (48)	RCT.	NI.	Iran.	Diabetes (type 1 or type 2, for at least one year).	N = 20 (randomised). ^			N = 20 (randomised). ^		
					n = 18 (post-intervention).	*M* (*SD*): 11.44 (2.59). Range: 7-15 (overall).	12 (66.7%) males, four females (22.2%), two (11.1%) not reported.	*n* = 18 (post-intervention).	*M* (*SD*): 9.72 (2.37). Range: 7-15 (overall).	Nine (50%) males, seven (38.9%) females, two (11.1%) not reported.

Study	Design	Control/ comparator	Country	LTC	Participants					
					ACT			Control/comparator		
					Number	Age in years	Gender	Number	Age in years	Gender
Stefanescu et al. (2024) (61)	Non-RCT without control group.	None.	Romania.	Diabetes (type 1, for at least one year).	N = 57 (recruited). ^ *n* = 55 (post-intervention).	*M* (*SD*): 14.14 (2.26) Range: 10-18.	67% females.	None.		
Obesity										
Davoudi (2021) (50)	RCT.	Psychoeducation individual advice (12 weekly 90-minute sessions, delivered by person with clinical psychology masters and training in individual and group counselling for adolescent disorders).	Iran.	Obesity (BMI ≥ 95th percentile for age and gender).	N = 25 (randomised). *n* = 22 (post-intervention and 12-week follow-up). ^	*M* (*SD*): 15.22 (1.74). Range: 12-18 (overall).	100% females.	N = 25 (randomised). *n* = 24 (post-intervention) and *n* = 23 (12-week follow-up). ^	*M* (*SD*): 15.1 (2.22). Range: 12-18 (overall).	Gender: 100% females.
Guerrini Usubini et al. (2022) (51)	RCT.	TAU (received standard three-week in-hospital multidisciplinary rehabilitation program for weight loss and the standard psychological assessment and support for hospitalisation. This included dietary input, nutritional counselling, physical activity program with training and psychological counselling provided by clinical psychologist).	Italy.	Obesity (BMI > 97th percentile for age and gender).	N = 25 (randomised). ^ *n* = 17 (post-intervention).	*M* (*SD*): 15.5 (1.37). Range: 13-17 (overall).	13 (76.5%) females, four (23.5%) males.	N = 24 (randomised). ^ *n* = 17 (post-intervention).	*M* (*SD*): 15.6 (1.06). Range: 13-17 (overall).	14 (82.4%) females, three (17.6%) males.
Tronieri et al. (2019) (62)	Non-RCT without control group (feasibility study).	None.	USA.	Obesity (BMI ≥ 95th percentile for age and gender).	N = 7 (recruited). *n* = 6 (post-intervention).	*M* (*SD*): 13.7 (1.7). Range: 12 - 16. *M* (*SD*): 13.7 (1.9). range: 13.7 (1.9), 12 - 16.	Six (85.7%) females. Five (83.3%) females.	None.		

Study	Design	Control/ comparator	Country	LTC	Participants					
					ACT			Control/comparator		
					Number	Age in years	Gender	Number	Age in years	Gender
Cancer										
Asadi et al. (2016) (52)	RCT.	A meeting without offering a solution.	Iran.	Cancer.	N = 15 (randomised, no dropout).	*M* (*SD*): not reported. Range: 9-14 (overall).	Not reported.	N = 15 (randomised, no dropout).	*M* (*SD*): not reported. Range: 9-14 (overall).	Not reported.
Ebrahimi et al. (2022) (56)	Non-RCT with control group.	NI.	Iran.	Leukaemia (with at least a one-year history of the illness).	N = 15 (recruited, no dropout).	*M* (*SD*): not reported. Range, 8-14 (overall).	Not reported.	N = 15 (recruited, no dropout).	*M* (*SD*): not reported. Range, 8-14 (overall).	Not reported.
Visual impairment										
Mirmohammadi and Pourmohamadreza-Tajrishi (2024) (53)	RCT.	Make-up empowering sessions in the complex. The content of the ACT intervention was briefly held for the control group in three sessions after the end of the research process and follow-up period.	Iran.	Visual impairment (from low vision to total blindness).	N = 14 (randomised). *n* = 12 (post-intervention and eight-week follow-up). ^	*M* (*SD*): 16.17 (not reported). Range: 14-18 (overall).	100% females.	N = 14 (randomised). *n* = 14 (post-intervention). ^	*M* (*SD*): 16.22 (not stated). Range: 14-18 (overall).	100% females.

Note. ACT = acceptance and commitment therapy. LTC = long-term physical health condition. NI = no intervention. RCT = randomised controlled trial. TAU = treatment-as-usual.
Studies ordered by (i) LTC (most to least number of studies) and (ii) design (RCTs, non-RCTs with control group, non-RCTs without control group).
Participant numbers reported only at time points for which studies provided this information.
^ = no separate demographic data reported.

Acceptance and Commitment Therapy Intervention Characteristics

ACT intervention characteristics are summarised in Table 3. Fourteen studies reported intervention contents (45,47–51,53,54,57–62), all covering at least four core psychological flexibility processes. While not explicitly mentioned, some processes could be inferred from the material described. However, levels of detail on intervention content varied across studies, and some processes may not have been reported and therefore missed during extraction. Given limited reporting, the core psychological flexibility processes could not be identified for the cancer studies (52,56).

Nine studies reported parental involvement (45–47,50,57–60,62), including all six chronic pain studies. Four studies involved parallel or separate parent sessions/modules only (46,59,60,62), three studies involved a combination of joint and separate CYP and parent sessions (45,57,58), one study involved initial joint sessions for CYP and parents (50) and in one study parents only joined some of the first and last session (47).

Nine studies reported the delivery settings, with eight in medical settings (45,47,51,56,58,59,61,62) and one in an educational setting (62). Fourteen studies reported ACT facilitator(s): eight by psychologists (47–51,57,60,61), three by a multidisciplinary team (45,58,59), one by a psychologist and dietician (62), one by a psychologist and physician (46) and one by a counsellor (52).

Interventions mostly included weekly sessions, totalling between three and 90 hours of ACT-based support. Ten studies delivered ACT in groups (2-7 CYP) (47–50,52,53,56,57,59,62), four individually (46,51,60,61), one used a combined both group and individual format (i.e. participants received both) (58) and one compared group and individual delivery (45). Fourteen studies delivered ACT face-to-face (45–53,56–59,62), one online (60) and one a mix (61).

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Table 3

Acceptance and Commitment Therapy Intervention Characteristics of Included Studies

	ACT intervention contents (core processes of psychological flexibility in CYP sessions reported)	Parental involvement	Setting	Profession of facilitator	Delivery		
					Structure and dose	Format	Method
Chronic pain							
Kanstrup et al. (2016) (45)	Acceptance, cognitive defusion, committed action, values. ^ Note: same intervention as Balter et al. (2021).	Combination of joint and parallel parent sessions. Parent program aimed to enhance parents' ability in supporting their child to improve their functioning. Included pain education, values clarification and acceptance skills to manage personal distress in relation to their child's pain.	Tertiary pain specialist clinic.	Team of psychologists, pain physicians and physiotherapist. Most sessions conducted by a psychologist.	14 sessions for CYP. Session 12 was a joint session for CYP and parents. Three parent sessions held in parallel to CYP (for sessions three, six, 11). Group sessions were two hours and individual sessions were 45 minutes.	12 group (four groups, two-four participants per group) and 18 individual sessions. Short summary individually provided for each missed session.	Face-to-face.
Wicksell et al. (2009, 2011) (46,54)	Acceptance, cognitive defusion, committed action, self as context, values. Present moment inferred.	Separate parent sessions. Parent work emphasised the shift from symptom alleviation to valued life and operant mechanisms and exposure principles. Parental difficulties were addressed using the same psychological flexibility processes as in CYP sessions.	Not stated. Recruited from hospital.	Psychologists and physician.	Approximately 10 sessions (one hour, once a week) for CYP. One or two parent sessions (90 minutes).	Individual.	Face-to-face.
Balter et al. (2021) (57)	Acceptance, cognitive defusion, committed action, values. ^ Note: same intervention as Kanstrup et al. (2016).	Combination of joint and parallel parent sessions. Parent program aimed to enhance parents' ability in supporting their child to improve their functioning. Included pain education, values clarification and acceptance skills to manage personal distress in relation to their child's pain.	Not stated. Recruited via a tertiary pain clinic.	Psychologists.	14 sessions for CYP and one joint session for CYP and parents. Three parent sessions held in parallel to CYP. All sessions were two hours each.	Group.	Face-to-face.

	ACT intervention contents (core processes of psychological flexibility in CYP sessions reported)	Parental involvement	Setting	Profession of facilitator	Delivery		
					Structure and dose	Format	Method
Kemani et al. (2018) (58)	Acceptance, cognitive defusion, committed action, present moment, self as context, values.	Parents participated in most CYP sessions and modelled intervention skills. Parent-only group input focused on applying the skills learned in the previous session to manage challenging parenting situations. Parents also had some keyworker sessions, either with or without the adolescent.	Tertiary national specialist centre.	Interdisciplinary (medics, psychologists, physiotherapists, occupational therapists and nurses). ACT framework consistently applied throughout.	Approximately 90 hours during a three-week period for CYP: 34 hours of physical conditioning, 22 hours of psychology, 15 hours of activity management and 15 hours of mixed sessions. Parents participated in sessions, except for a four-day period mid-intervention when adolescents worked independently, and parents had a three hours of a parent-only group. Structure/dose of parent keyworker sessions, with or without adolescent, not specified.	Mix of individual and group. CYP received, on average, three hours of individual input (i.e. majority was group-based, six per group).	Face-to-face.
Vuorimaa et al. (2019) (59)	Acceptance, committed action, present moment, values. Cognitive defusion and self as context inferred.	Parallel parent sessions. Parent sessions focused on developing pain-related problem-solving skills in the context of their child's pain and managing health-related anxiety. Parents supported CYP with active and flexible strategies for coping with pain.	Paediatric rheumatology outpatient clinic.	Multidisciplinary team (psychologist, physiotherapist, paediatric rheumatologist and nurse).	10 days of sessions at the outpatient clinic for CYP. Intervention modules one and two occurred one and two months after the pre-intervention assessment. Parent group sessions were held in parallel.	Group (five-six per group).	Face-to-face.
Zetterqvist et al. (2020) (60), secondary analysis (Gentili et al., 2024) (63)	Acceptance, cognitive defusion, committed action, present moment, values. ^	Parents had access to seven parent modules (parent program), including acceptance, cognitive defusion, commitment action and values. Exercises related to content in CYP modules. Parents also received feedback from therapist via platform and in the second intake (of two) parents had a scheduled phone call (contents of feedback and phone calls not specified).	Internet-delivered. Conducted at a tertiary pain clinic in an urban setting and self-recruited from community via newspaper adverts and social media.	Psychologists.	Eight weeks of access to four CYP modules. CYP received feedback a minimum of every other weekday from therapist, via platform. In the second intake (of two) phone call scheduled at week two/three. Parents had eight weeks of access to seven modules, received feedback at least once a week and in the second intake (of two) a phone call was scheduled at week two/three.	Individual.	Internet-delivered.
Diabetes							
Alho et al. (2022) (47), secondary	Acceptance, cognitive defusion, committed action,	Parents joined start of first and last session to receive information regarding the intervention procedures.	Hospital.	Psychologist.	Five sessions (1.5-hours, once a fortnight).	Group (five-seven per group).	Face-to-face.

	ACT intervention contents (core processes of psychological flexibility in CYP sessions reported)	Parental involvement	Setting	Profession of facilitator	Delivery		
					Structure and dose	Format	Method
analysis (Alho et al., 2024) (55)	present moment, self as context, values.						
Ataie Moghanloo et al. (2015) (49)	Acceptance, cognitive defusion, committed action, self as context, values. ^ Note: same intervention as Moazzezi et al. (2015).	None reported.	Not stated. Recruited from the Diabetes Association.	Psychologist.	10 sessions (90 minutes, once a week).	Group.	Face-to-face.
Moazzezi et al. (2015) (48)	Acceptance, cognitive defusion, committed action, self as context, values. ^ Note: same intervention as Ataie Moghanloo et al. (2015).	None reported.	Not stated. Recruited from the Diabetes Association.	Not reported.	10 sessions (90 minutes, once a week).	Group.	Face-to-face.
Stefanescu et al. (2024) (61)	Cognitive defusion, committed action, present moment, values. Committed action interred. ^	None reported.	Hospital (for face-to-face sessions).	Clinical psychologist.	Four sessions (50 minutes each, once per week).	Individual.	33% face-to-face, 67% online via Zoom.
Obesity							
Davoudi (2021) (50)	Acceptance, cognitive defusion, committed action, present moment, self as context, values.	Parents participated in first two sessions. Included work on creative helplessness and parental control strategies.	Not stated. Recruited via nutrition clinics and medical offices.	Clinical psychology masters.	12 sessions (90 minutes, once a week). First two sessions were joint sessions for CYP and parents.	Group.	Face-to-face.
Guerrini Usubini et al. (2022) (51)	Acceptance, cognitive defusion, committed action, present moment, self as context, values.	None reported.	Hospital (specialist clinical centre).	Clinical psychologist.	Three sessions (one hour, once a week).	Individual.	Face-to-face.
Tronieri et al. (2019) (62)	Acceptance, cognitive defusion, present moment, values. Committed action inferred. ^	Parallel parent sessions. Included supporting their child with healthy changes (e.g. modelling behaviours), praising choices and learning strategies through exercises (e.g.	Urban university medical centre.	Psychologist and registered dietician led simultaneous group sessions.	16 sessions (60-90 minutes, once a week). CYP and their parents/guardians attended separate groups.	Group. Make-up visit individually	Face-to-face.

	ACT intervention contents (core processes of psychological flexibility in CYP sessions reported)	Parental involvement	Setting	Profession of facilitator	Delivery		
					Structure and dose	Format	Method
		parenting values, accepting emotional experiences, defusing from thoughts, willingness).				provided for each missed session.	
Cancer							
Asadi et al. (2016) (52)	Medical consulting based on ACT. No details on content.	None reported.	Not stated. Recruited from hospital.	Counsellor.	Three sessions (two hours each). Between the final session and the follow-up, a weekly phone call with counsellor was provided to maintain contact and taper the intervention.	Group (five per group).	Face-to-face.
Ebrahimi et al. (2022) (56)	Contents/core processes not reported in English (translation deemed unsuitable, as psychological flexibility processes may not translate accurately due to lack of direct linguistic equivalents and reliance on culturally embedded metaphors).	None reported.	Hospital.	Not reported.	Six sessions (one-hour each).	Group.	Face-to-face.
Visual impairment							
Mirmohammadi and Pourmohamadreza-Tajrishi (2024) (53)	Acceptance, cognitive defusion, committed action, present moment, self as context, values.	None reported.	Specialist educational complex.	Not reported.	10 sessions (one hour, once a week).	Group (seven per group).	Face-to-face.

Note. ACT = acceptance and commitment therapy. CYP = children and young people.
Studies ordered by (i) LTC (most to least number of studies) and (ii) design (randomised controlled trials [RCTs], non-RCTs with control group, non-RCTs without control group),
^ = the report did not explicitly mention the remaining core psychological flexibility process(es).

Quality Appraisal

Results from the quality assessment are presented in Figure 2, created using the robvis app (64). Following RoB-2 and ROBINS-I guidelines (42,43), quality was assessed for each CYP-reported psychosocial outcome. As outcome ratings were identical within each study, a single combined rating is presented per study. The effect of interest was assignment to intervention. The quality appraisal is summarised below (see Appendix E for more detailed appraisal per domain).

RCTs

Overall risk of bias was rated 'high' for eight RCTs (45–51,53) and 'some concerns' for one RCT (52). However, the latter rating should be viewed with caution, as it reflects insufficient reporting in several domains, which per tool guidelines should be rated as 'some concerns' rather than 'no information' (42).

A strength of several RCTs was randomisation, with appropriate sequence generation and no substantial baseline imbalance (45–47,51). Five RCTs reported insufficient information regarding randomisation (48–50,52,53). In terms of missing outcome data, apart from one RCT with no dropouts (52), dropout rates varied between 7.14% and 37.5% from randomisation to final time point. Five RCTs reported dropout reasons: two reported non-health-related reasons (50,53), two reported ≤5% health-related dropouts (48,49) and one reported >20% health-related dropouts, with rates differing between groups (45). In RCTs lacking reasons, dropout rates were similar across groups (46,47,51).

While all RCTs had appropriate outcome measurements, comparable between groups, all outcomes were self-reported (as required for inclusion eligibility). As participants were the outcome assessors and most RCTs used TAU or NI as controls (46–49,51), outcomes may have been influenced by awareness of the intervention received.

Across RCTs, no deviations from intended interventions were indicated, although one provided no intervention content details (52). However, all but two RCTs, one with no dropouts (52) and one which used intention-to-treat analyses (46), did not include all randomised participants in analyses. Although three RCTs were pre-registered (47,50,51), none included pre-specified analysis plans. Therefore, all RCTs lacked sufficient evidence to assess selective reporting.

Non-RCTs

Overall risk of bias was rated as 'serious' for non-RCTs, indicating 'important problems' (43). However, without the 'measurement of outcome' domain, which was rated as serious for all non-RCTs due to self-reported psychosocial measures being required for inclusion eligibility, two would be rated as 'moderate' (57,58), indicating sound evidence for non-RCTs, though not comparable to well-performed RCTs (43).

A strength across non-RCTs was participant selection. Participant selection occurred before the intervention had begun and time points coincided for most participants, although in one non-RCT four-month follow-ups were completed by

participants between 17-25 weeks post-ACT (60). For most non-RCTs, intervention groups were also well-defined, with no deviations from intended interventions indicated.

Considering weaknesses, all outcome measures were self-reported and subjective, with assessors (participants) unblinded to the intervention received. Another common area of weakness was potential confounding. Although all non-RCTs excluded the risks of some confounders through eligibility criteria, only two controlled for potential confounders in analyses (57,58).

Missing data varied across non-RCTs. Two reported no or <5% dropouts or missing outcome data (56,61). In the remaining non-RCTs, rates of dropout and missing data ranged from 14.3% to 42.8%. No attrition reasons were reported, so potential bias could not be ruled out. Regarding selection of the reported results, one non-RCT's pre-registration specified follow-ups at four months and one year but collected four-month data inconsistently (at 17-25 weeks) and omitted the one-year data (60), indicating potential selective reporting. The remaining non-RCTs lacked pre-registration/a-priori analysis plans, limiting assessment of reporting bias.

Figure 2

Quality Appraisal Summaries



Note. Traffic-light plot and summary plot for randomised controlled trials, assessed using the Cochrane Risk of Bias 2 (RoB 2) (39) on the left. Traffic-light plot and summary plot for non-randomised controlled trials, assessed using the Cochrane Risk Of Bias In Non-randomised Studies - of Interventions (ROBINS-I) (40) on the right (study with a control group listed first, followed by studies without a control group).

Study Outcomes

Each study reported the effects of ACT on between one and thirteen CYP-reported psychosocial outcomes. Seven studies reported findings on factors associated with ACT effects (47,51,54,57–59,63) and three studies reported quantitative acceptability data (53,55,62). Three studies also reported qualitative acceptability data, beyond the scope of this systematic review (55,60,61).

Eight studies assessed outcomes at two time points (pre-intervention and post-intervention) (47–49,51,56,57,61,62), with another study adding an additional mid-intervention time point (45). Seven studies included follow-ups; six had three time points (50,52,53,58–60) and one had four time points (two follow-ups) (46). Follow-ups ranged from one to 12 months post-intervention.

Study outcome data is narratively synthesised for each LTC below regarding (i) ACT intervention effectiveness, (ii) factors associated with the effects of ACT and (iii) acceptability of ACT. Notably, all included studies were rated as high/serious risk of bias, except one cancer study (52), rated as some concerns due to insufficient methodological reporting. Across studies, only one in chronic pain indicated potential selective reporting (60); however, the absence of a-priori analysis plans for the remaining studies limited assessments of selective reporting, as detailed in the quality appraisal.

Chronic Pain

Effectiveness on CYP-Reported Psychosocial Outcomes

Outcome data from the chronic pain studies are presented in Table 4. Pain-related outcomes were assessed across studies. In two RCTs (45,46) and two non-RCTs (57,58,60) per outcome, significant improvements in pain intensity and pain interference were observed over time for CYP receiving ACT. Wicksell et al.'s (46) RCT also found significantly greater improvements in ACT than TAU. In Kanstrup et al.'s (45) RCT, no significant between-group (group ACT and individual ACT) differences were found.

The remaining pain-related outcomes were assessed by one study each. Wicksell et al.'s (46) RCT reported significant improvements in pain impairment beliefs and pain-related discomfort over time (to two-month follow-up) in ACT, with large effect sizes. Significant between-group differences were also in support of ACT (large effect sizes). In Kanstrup et al.'s (45) RCT, significant pre-post improvements in pain reactivity were found for both formats combined, with medium effect sizes, and no between-group (group ACT and individual ACT) differences were found. Kemani et al.'s (58) non-RCT found pain-specific anxiety significantly improved pre-post ACT.

Five studies assessed depression (45,46,57,58,60). Non-RCTs (57,58,60) consistently found significant improvements in depression over time among CYP receiving ACT, with medium effect sizes reported by two studies (58,60). Similarly, Kanstrup et al.'s (45) RCT found significant pre-post improvements in depression for

both formats combined (medium effect size), with no significant between-group differences. However, Wicksell et al.'s (46) RCT found no significant within-group or between-group effects of ACT on depression. Notably, only Wicksell et al. (46) compared ACT to a non-ACT control.

Two studies assessed insomnia: Zetterqvist et al. (60) found significant improvements pre-ACT to follow-up (medium effect size), whereas Balter et al. (57) found no significant changes pre-post ACT. Although both non-RCTs had overall ratings of serious risk of bias, methodological differences, such as Zetterqvist et al.'s (60) inclusion of a follow-up and potential selective reporting and Balter et al.'s (57) controlling for potential confounders, may, at least partly, account for such differences.

Three studies consistently supported the effects of ACT on psychological flexibility (45,57,60), with two studies reporting large effect sizes (45,60). In Kanstrup et al.'s (45) RCT, no significant between-group (group ACT and individual ACT) differences were found. Acceptance also significantly improved pre-post ACT in one study (58), with a medium effect size.

Mixed findings were reported for outcomes of functioning. Wicksell et al.'s (46) RCT, found significant improvements in functional disability over time in ACT (large effect size), but no between-group differences. Two non-RCTs found significant pre-post ACT improvements for social functioning and physical functioning (57,58), with small effect sizes reported in one (58). Significant improvements over time (to three-month follow-up) in family functioning were reported in one non-RCT (58) (medium

effect size) and significant pre-post improvements in emotional functioning were reported in another (57). However, two non-RCTs found no effects on school functioning (57,60).

Of the remaining outcomes, assessed by one study each, Wicksell et al.'s (46) RCT found kinesiophobia, mental quality of life and physical quality of life significantly improved over time in ACT, with large effect sizes. Between-group differences were also significant for kinesiophobia and mental quality of life at post-intervention in support of ACT, with large effect sizes, but not for physical quality of life. No significant within or between-group effects were found for internalising/catastrophising. Kemani et al.'s (58) non-RCT found no significant effects of ACT on development.

Factors Associated with CYP-Reported Psychosocial Outcomes

Regarding pain-related factors, in Wicksell et al.'s RCT (46,54), post-ACT pain impairment beliefs mediated changes in depression at both the one- and two-month follow-ups and in pain interference at the one-month follow-up only, while pain reactivity mediated changes in both depression and pain interference at both follow-ups. Furthermore in Vuorimaa et al.'s (59) non-RCT, higher pain risk profiles moderated the effectiveness of ACT, with the high-risk group reporting significant improvements over time (to 12 months from pre-intervention) in depression, pain frequency and pain catastrophising, but the medium-risk group reporting no significant changes. Other post-ACT outcomes (internalising/catastrophising, kinesiophobia, pain intensity or self-efficacy) were not significant mediators.

Changes in parent psychological flexibility were significantly positively associated with changes in adolescent pain acceptance in Kemani et al.'s non-RCT (58). In Zetterqvist et al.'s non-RCT (60,63), higher acceptance in the early treatment phase was significantly related to larger decreases in pain interference (medium effect size), whereas defusion, values formation and committed action shown no significant effects.

Regarding neurodevelopment, Balter et al. (57) found CYP with higher autistic traits or clinically significant autism/ADHD symptoms showed significantly greater pre-post improvements in insomnia and emotional functioning, but not in other outcomes (depression, pain intensity, pain interference, psychological inflexibility or physical, school or social functioning).

Acceptability of Interventions

Not quantitatively studied.

Table 4

Summary of Findings for Chronic Pain

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
Kanstrup et al. (2016) (45) (RCT)	Pre-intervention Mid-intervention Post-intervention	Depression, CES-DC	Depression significantly decreased pre-post intervention for both groups combined (p = .004, r = .37), with 39% of adolescents showing a clinically significant reduction. Pre-mid intervention changes were not significant (p = .213) but mid-post intervention changes were (p < .001).	Not studied.
		Pain intensity (rated 0-6)	Pain intensity did not significantly change pre-post intervention for both groups combined (p = .346, r = -.13). 15% of adolescents showed a clinically significant reduction. Both pre-mid intervention (p = .697) and mid-post intervention changes (p = .255) were not significant.	
		Pain interference, PII	Pain interference significantly decreased pre-post intervention for both groups combined (p < .001, r = .51), with 47% of adolescents showing a clinically significant reduction. Pre-mid intervention changes were not significant (p = .026) but mid-post intervention changes were (p = .002).	
		Pain reactivity, PRS	Pain reactivity significantly decreased pre-post intervention for both groups combined (p < .001, r = .49), with 48% of adolescents showing a clinically significant reduction. Pre-mid intervention changes were not significant (p = .362) but mid-post intervention changes were (p < .001).	
		Psychological inflexibility, PIPS	Psychological inflexibility significantly decreased pre-post intervention for both groups combined (p < .001, r = .59), with 63% of adolescents showing a clinically significant reduction. Pre-mid intervention changes were not significant (p = .027) but mid-post intervention changes were (p < .001). Between-group analyses: There were no significant differences between the conditions (individual ACT and group ACT) in any of the outcome variables at any of the time points (p = .109 to 1.00). There were no significant differences between group ACT and individual ACT in the number of adolescents with clinically significant pre- to post-intervention improvements for any of the variables (p = .083 to 1.00). A trend towards a significant difference was indicated for depression (p = .028), with more adolescents in the individual condition reporting clinically significant reductions in depression. Note: a conservative significance level of p < 0.01 had been set to take into account multiple comparisons.	

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
Wicksell et al. (2009, 2011) (46,54) (RCT)	Pre-intervention Post-intervention One-month follow-up Two-month follow-up	Depression, CES-DC	Depression did not significantly change over time in ACT (p = .063, ηp^2 = .18) or TAU (p = .568, ηp^2 = .03). Between-group differences were not significant post-intervention (p = .055, ηp^2 = .12) or when including follow-ups (p = .088, ηp^2 = .10).	Post-ACT pain impairment beliefs mediated changes in pre-ACT measures of depression to both follow-up one (95% CI = 1.75 to 14.59) and two (95% CI = 2.46 to 26.55). Post-ACT pain impairment beliefs mediated changes in pre-ACT pain interference to follow-up one (90% CI = .00 to 2.40) but not two (95% CI = -.41 to 3.18). Post-ACT pain reactivity mediated changes in pre-ACT measures of pain interference and depression to both follow-up one (pain interference, 95% CI = .08 to 3.01; depression, 95% CI = .01 to 14.77) and two (pain interference, 95% CI = .17 to 4.32; depression, 90% CI = 3.52 to 31.96). No significant mediation effects were found for post-ACT measures of internalising/catastrophising, kinesiophobia, pain intensity or self-efficacy measured using SES. Significant mediating effects were analysed further. Post-ACT pain-impairment beliefs were not significantly related to depression change scores from pre to follow-up one when controlling for depression post-ACT (p = .107). However, pain-impairment beliefs did significantly predict change to follow-up two (p = .028), with pain impairment beliefs at post-ACT explaining 33% of the variance when controlling for post-ACT depression. Post-ACT pain reactivity significantly predicted changes in pain interference at both follow-up one (56% variance, p = .002) and follow-up one (54% variance, p = .003), after controlling for post-ACT pain interference. For depression, pain reactivity explained 21.1% of the variance in change to follow-up one (p = .090), but not at follow-up two (p = .111).
		Kinesiophobia, TSK	Kinesiophobia significantly decreased over time in ACT (p < .001, ηp^2 = .56) and TAU (p < .001, ηp^2 = .42). Between-group differences were significant post-intervention, with significantly greater reductions in ACT (p = .010, ηp^2 = .21), but not when including follow-ups (p = .052, ηp^2 = .12).	
		Functional disability, FDI	Functional disability significantly decreased over time in ACT (p = .002, ηp^2 = .38) and TAU (p = .049, ηp^2 = .21). Between-group differences were not significant post-intervention (p = .944, ηp^2 = .00) or when including follow-ups (p = .474, ηp^2 = .02).	
		Internalising/ catastrophising, subscale of PCQ	Internalising/catastrophising did not significantly change over time in ACT (p = .051, ηp^2 = .19) or TAU (p = .106, ηp^2 = .14). Between-group differences were not significant post-intervention (p = .622, ηp^2 = .01) or when including follow-ups (p = .916, ηp^2 = .00).	
		Mental quality of life, subscale of SF-36	Mental quality of life significantly increased over time in ACT (p = .027, ηp^2 = .22) but not TAU (p = .993, ηp^2 = .00). Between-group differences were significant post-intervention, with significantly greater increases in ACT (p = .033, ηp^2 = .15), but not when including follow-ups (p = .067, ηp^2 = .11).	
		Pain impairment beliefs, PAIRS	Pain impairment beliefs significantly decreased over time in ACT (p = < .001, ηp^2 = .47) and TAU (p = < .001, ηp^2 = .33). Between-group differences were significant post-intervention, with significantly greater reductions in ACT (p = .002, ηp^2 = .29), and when follow-ups were included (p = .007, ηp^2 = .23).	
		Pain intensity (rated 0-10)	Pain intensity significantly decreased over time in ACT (p = .004, ηp^2 = .35) but not TAU (p = .251, ηp^2 = .09). Between-group differences were significant post-intervention, with significantly greater reductions in ACT (p = .046, ηp^2 = .13), and when follow-ups were included (p = .048, ηp^2 = .13).	
		Pain interference, PII, based on interference subscale of MPI and pain interference items of BPI	Pain interference significantly decreased over time in ACT (p = .016, ηp^2 = .28) and TAU (p = 001, ηp^2 = .29). Between-group differences were significant post-intervention, with significantly greater reductions in ACT (p = .024, ηp^2 = .16), but not when including follow-ups (p = .107, ηp^2 = .09).	
		Pain-related discomfort, five questions (each rated 0-10).	Pain-related discomfort significantly decreased over time in ACT (p = .003, ηp^2 = .42) and TAU (p = .006, ηp^2 = .32). Between-group differences were significant post-intervention, with significantly greater reductions in ACT (p = .001, ηp^2 = .34), and when follow-ups were included (p = .031, ηp^2 = .15).	

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
		Physical quality of life, subscale of SF-36	Physical quality of life significantly increased over time in ACT (p = .010, ηp^2 = .31) and TAU (p = .004, ηp^2 = .32). Between-group differences were not significant post-intervention (p = .367, ηp^2 = .03) or when including follow-up (p = .224, ηp^2 = .05). Note: the groups were not fully comparable at follow-up, as TAU received a substantially greater amount of treatment after post-intervention assessments.	
Balter et al. (2021) (57) (Non-RCT without control group)	Pre-intervention Post-intervention	Depression, CES-DC	Depression significantly decreased pre-post intervention (p < .001).	CYP higher in autistics traits showed significantly greater improvements in insomnia (p < .05) and emotional functioning (p < .05), but not pain interference (p < .07). The significant time-autism interactions for insomnia (p = .004) and emotional functioning (p = .007) remained significant when adjusting for age and gender. The non-significant time-pain interference (p = .057) interaction remained unchanged when adjusting for age and gender. No significant time-autism interactions were found for other outcomes (depression, pain intensity, physical functioning, psychological inflexibility, school functioning or social functioning), and no significant time-ADHD interactions were found. When CYP were split into above and below clinically significant autism or ADHD scores, between-group analyses showed that those with clinically significant levels of autistic traits and/or ADHD symptoms improved more for insomnia (p = .016) and emotional functioning p = .007). relative to those without clinically significant levels. Improvements in pain interference did not significantly differ by group (p = .293). Note: autistic traits were measured using SRS and ADHD symptoms were measured using Conners-3 ADHD Index [i.e. Conners Hyperactivity Index], Conners-3-P).
		Emotional functioning, subscale of PedsQL	Emotional functioning significantly increased pre-post intervention (p = .010).	
		Insomnia, ISI	Insomnia did not significantly change pre-post intervention. *	
		Pain intensity, item of the LPQ	Pain intensity significantly decreased pre-post intervention (p = 0.016).	
		Pain interference, PII	Pain interference significantly decreased pre-post intervention (p < .001)	
		Physical functioning, subscale of PedsQL	Physical functioning significantly increased pre-post intervention (p = .001).	
		Psychological inflexibility, PIPS	Psychological inflexibility significantly decreased pre-post intervention (p < .001)	
		School functioning, subscale of PedsQL	School functioning did not significantly change pre-post intervention. *	
		Social functioning, subscale of PedsQL	Social functioning significantly increased pre-post intervention (p = .019).	

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
Kemani et al. (2018) (58) (Non-RCT without control group)	Pre-intervention Post-intervention Three-month follow-up	Acceptance of pain, CPAQ-A	Acceptance significantly increased from pre-intervention to three-month follow-up (p < .001, d = .73).	Changes in parent psychological flexibility over time (pre, post, and follow-up), measured using the PPFQ, were significantly (positively) associated with greater changes in adolescent pain acceptance while controlling for changes in all domains of functioning (p ≤ .01).
		Depression, subscale of BAPQ	Depression significantly decreased from pre-intervention to three-month follow-up (p < .001, d = -.26).	
		Development, subscale of BAPQ	Development showed no significant main linear effect of time (p > .05, d = .10).	
		Family functioning, subscale of BAPQ	Family functioning scores significantly decreased (indicating higher levels) from pre-intervention to three-month follow-up) (p < .001, d = -.64).	
		General anxiety, subscale of BAPQ	General anxiety significantly decreased from pre-intervention to three-month follow-up (p < .001, d = -.68).	
		Pain intensity (rated 0-10)	Pain intensity significantly decreased from pre-intervention to three-month follow-up (p = .020, d = -.68).	
		Pain-specific anxiety, subscale of BAPQ	Pain-specific anxiety significantly decreased from pre-intervention to three-month follow-up (p = .020, d = -.24).	
		Physical functioning, subscale of BAPQ	Physical functioning scores significantly decreased (indicating higher levels) from pre-intervention to three-month follow-up (p < .001, d = -.42).	
		Social functioning, subscale of BAPQ	Social functioning scores significantly decreased (indicating higher levels) from pre-intervention to three-month follow-up (p < .001, d = -.40).	
Vuorimaa et al. (2019) (59) (Non-RCT without control group)	Pre-intervention Six-month follow-up (from, pre-intervention) 12-month follow-up (from pre-intervention)	Pain catastrophising, subscale of PCQ	Note: no overall comparisons across time were conducted for the full sample, as participants were divided into two groups (based on pain risk profiles) for analyses. Nineteen adolescents were high-risk (total PPST score ≥3; psychosocial subscale score ≥3), and 13 adolescents were medium-risk (total PPST score ≥ 3; psychosocial subscale score 0 to 2). The potential moderating effects of PSST on outcomes were assessed (see right column).	For pain catastrophising, the time-group interaction was significant (p < .001). The high-risk group significantly decreased by 19% (p =.008). There was no significant change in the medium risk group *. For depression symptoms, there was a significant time-group interaction (p = .020). The high-risk group significantly decreased by 36% (p = .005). There was no significant change in the medium risk group *. For pain frequency, the significant time-group interaction was significant (p = .019). The high-risk group significantly improved by 25% (p =
		Depression, CDI		
		Pain frequency, SPQ		

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
				.005). There was no significant change in the medium risk group *. At one-year follow-up of the 24 adolescents who remained, seven (37.5%, p = .008) initially in the high-risk group were reclassified as medium risk. No medium-risk adolescents were reclassified.
Zetterqvist et al. (2020), secondary analysis (Gentili et al., 2024) (60,63) (Non-RCT without control group)	Pre-intervention Post-intervention Four-month follow-up (completed at 17-25 weeks)	Depression, CEDS-DC Insomnia, ISI Pain interference, PII Psychological inflexibility, PIPS School functioning, subscale of PedsQL	Depression significantly decreased from pre-intervention to follow-up (p < .001, d = -.78). Insomnia significantly decreased from pre-intervention to follow-up (p = .007, d = -.54). Pain interference significantly decreased from pre-intervention to follow-up (p < .001, d = -1.09). Psychological inflexibility significantly decreased from pre-intervention to follow-up (p < .001, d = -1.13). School functioning from pre-intervention to follow-up did not significantly change (p = .885, d = -.03).	Higher mean acceptance in the early treatment phase was related to a larger decrease in pain interference over the course of treatment (p = .049, ρ = -.45), explaining 20% of the variance in outcome. Defusion (p = .795), values formulation (p = .607) and committed action (p = .541) showed no significant influence on pain interference. Note: ADPM, revised for the current study, was used to measure acceptance, defusion, values formation and committed action.

Note. ACT = acceptance and commitment therapy. CYP = children and young people. NI = no intervention. RCT = randomised controlled trial. TAU = treatment-as-usual.
Measures used: ADPM = Acceptance and Defusion Process Measure (65); BAPQ = Bath Adolescent Pain Questionnaire (66); BPI = Brief Pain Inventory (67); CDI = Children Depression Inventory, Finnish version (68); CEDS-DC = Center for Epidemiological Studies Depression Scale for Children (69,70); CHAQ = Childhood Health Assessment Questionnaire, Finnish version (71); Conners-3-P = Conners 3rd Edition-Parent (72); CPAQ-A = Chronic Pain Acceptance Questionnaire Adolescent (73); FDI = Functional Disability Inventory - child form (74); ISI = Insomnia Severity Index (75,76); LPQ = Lubeck Pain-Screening Questionnaire (77); MPI = Multidisciplinary Pain Inventory (78); PAIRS = Pain and Impairment Relationship Scale (79); PCQ = Pain Coping Questionnaire (80); PedsQL = Pediatric Quality of Life Inventory (81,82); PII = Pain Interference Index (46); PIPS = Psychological Inflexibility in Pain Scale (83); PPST = Pediatric Pain Screening Tool (84); PRS = Pain Reactivity Scale (46); SES = Self-Efficacy Scale (85); SF-36 = Short Form-36 Health Survey (86); SPQ = Structured Pain Questionnaire (87); SRS = Social Responsiveness Scale (88); TSK = Tampa Scale of Kinesiophobia (89).
Studies ordered by design (RCT, non-RCT without a control group).
* = no p-value reported.

Diabetes

Effectiveness on CYP-Reported Psychosocial Outcomes

Outcome data from the diabetes studies are presented in Table 5. Three outcomes, depression, psychological flexibility and stress, were assessed by two studies each. The effectiveness of ACT on stress outcomes was supported by both Moazzezi et al.'s (48) RCT, which found perceived stress (and its subscales) significantly improved pre-post ACT compared with NI, and Stefanescu et al.'s (61) non-RCT without a control group, which found significant pre-post ACT improvements in stress, all with large effect sizes. The effectiveness of ACT on psychological flexibility was also consistently supported, with Alho et al.'s (47) RCT supporting the effectiveness of ACT on diabetes-related psychological flexibility pre-post ACT compared with TAU (47) (small effect size) and Stefanescu et al.'s (61) non-RCT reporting pre-post ACT improvements in psychological flexibility (large effect size).

Although pre-post improvements in depression were supported in Ataie Moghanloo et al.'s (49) RCT compared with NI, Alho et al.'s (47) RCT found no significant between-group differences. However, the RCTs differed methodologically. Alho et al. (47) utilised a TAU control, while Ataie Moghanloo et al. (49) used NI. Unlike Alho et al. (47), Ataie Moghanloo et al. (49) also reported insufficient information on randomisation and lacked pre-registration.

The remaining outcomes were assessed by one study each. In Alho et al.'s (47) RCT, between-group analyses supported ACT for improving anxiety compared with TAU (small effect size). However, no significant between-group differences were found for diabetes-related quality of life and general quality of life. Between-group analyses in the RCTs comparing ACT and NI (48,49) supported the effectiveness of ACT on depression, feeling of guilt, psychological wellbeing and special health self-efficacy, all with large effect sizes. Significant improvements pre-post ACT in patient-doctor relationship with a large effect were also found in Stefanescu et al.'s (61) non-RCT.

Notably, no ACT studies for CYP with diabetes included follow-ups, meaning long-term effectiveness could not be considered.

Factors Associated with CYP-Reported Psychosocial Outcomes

Diabetes-related psychological flexibility did not mediate the effects of ACT on anxiety in Alho et al.'s (47) RCT.

Acceptability of Interventions

In Alho et al.'s (47,55) RCT, most adolescents reported satisfaction with the ACT intervention including its length. All adolescents perceived benefits and all but one reported that they would recommend the intervention to other adolescents.

Table 5

Summary of Findings for Diabetes

Study (Design)	Time-points	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
Alho et al. (2022) (47), secondary analysis (Alho et al., 2024) (55) (RCT)	Pre-intervention Post-intervention	Acceptance and mindfulness, CAMM	Acceptance and mindfulness change pre-post intervention was not significantly different between groups (p = .218, d = .25).	Changes in diabetes-related psychological flexibility did not mediate the effect of ACT on anxiety (95% CI = -.01 to .02).
		Anxiety, RBDI	Anxiety change pre-post intervention was significantly different between groups (p = .012, d = .48). Change over time was significantly greater in ACT than TAU, with those in ACT showing a decrease in anxiety (d = .25).	
		Depression, RBDI	Depression change pre-post intervention was not significantly different between groups (p = .814, d = .04).	
		Diabetes-Related Psychological flexibility, DAAS	Diabetes-related psychological flexibility change pre-post intervention was significantly different between groups (p = .040, d = .29). Change over time was significantly greater in ACT than TAU, with those in ACT showing an increase in diabetes-related psychological flexibility (d = -.26).	
		Quality of life – diabetes, KINDL^R	Diabetes-related quality of life change pre-post intervention was not significantly different between groups (p = .733, d = .05).	
		Quality of life – general, KINDL^R	Diabetes-related general quality of life change pre-post intervention was not significantly different between groups (p = .107, d = .29).	
Ataie Moghanlo et al. (2015) (49) (RCT)	Pre-intervention Post-intervention	Depression, RCDS	Depression was significantly lower in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .86^), with the means indicating depression decreased only in ACT.	Not studied.
		Feeling of guilt, EFGS	Feeling of guilt was significantly lower in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .85^), with the means indicating a greater decrease in ACT than NI.	
		Psychological wellbeing, SWLS	Psychological wellbeing was significantly higher in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .78^), with the means indicating a greater decrease in ACT than NI.	
Moazzezi et al. (2015) (48) (RCT)	Pre-intervention Post-intervention	Negative perceived stress, subscale of PSS	Negative perceived stress was significantly lower in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .92), with the means indicating a greater decrease in ACT than NI.	Not studied.
		Positive perceived stress, subscale of PSS	Positive perceived stress was significantly higher in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .85), with the means indicating a greater increase in ACT than NI.	

Study (Design)	Time-points	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
		Total perceived stress, PSS	Total perceived stress was significantly lower in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .20^), with the means indicating total perceived stress decreased only in ACT.	
		Special health self-efficacy, SHSES	Special health self-efficacy was significantly higher in ACT than NI at post-intervention, after controlling the pre-test (p = < .001, ηp^2 = .85), with the means indicating special health self-efficacy increased only in ACT.	
Stefanescu et al. (2024) (61) (Non-RCT without a control group)	Pre-intervention Post-intervention	Acceptance, AADQ	Diabetes acceptance scores significantly decreased (indicating higher levels) pre-post intervention (p < .001, r = .98).	Not studied.
		Patient-Doctor Relationship, PDRQ-9	Patient-doctor relationship significantly increased pre-post intervention (p < .001, r = -.86).	
		Psychological flexibility, CPFQ	Psychological flexibility significantly increased pre-post intervention (p < .001, d = -.54).	
		Stress, PSS-C	Stress significantly decreased pre-post intervention (p < .001, d = 1.18).	

Note. ACT = acceptance and commitment therapy. CYP = children and young people. NI = no intervention. RCT = randomised controlled trial. TAU = treatment-as-usual.
Measures used: AADQ = Acceptance and Action Diabetes (90); CAMM = Child and Adolescent Mindfulness Measure (91); CPFQ = Children's Psychological Flexibility Questionnaire (92); DAAS = Diabetes Acceptance and Action Scale (93); EFGS = Eysenck Feeling of Guilt Scale, Iranian version (94); KINDL^R Revised Children's Quality of Life Questionnaire (91); PDRQ-9 = Patient-Doctor Relationship Questionnaire (95); PSS-14 = Perceived Stress Scale (96); PSS-C = Perceived Stress Scale for Children (97); RBDI = Revised Beck Depression Inventory (98); RCDS = Reynolds Child Depression Scale (99); SES = Self-Efficacy Scale (85); SHSES = Special Health Self-Efficacy Scale (100); SWLS = Satisfaction With Life Scale (101).
Studies ordered by design (RCT, non-RCT without a control group).
^ = effect size calculated.

Obesity

Effectiveness on CYP-Reported Psychosocial Outcomes

Outcome data from obesity studies are presented in Table 6. Three outcomes, depression, avoidance and fusion and stress, were assessed by two studies. Results for stress outcomes were consistent, with two studies finding no significant effects (51,62). However, findings for depression and experiential avoidance and fusion were inconsistent. In Guerrini et al.'s (51) RCT comparing ACT+TAU and TAU, no significant effects for depression or experiential avoidance and fusion were found, yet in Tronieri et al.'s (62) non-RCT, depression decreased (large effect size) and experiential avoidance increased (small effect size) pre-post ACT. However, Tronieri et al.'s (62) study lacked a control group and, as a feasibility study, had a considerably smaller sample size and no tests of statistical significance. Different outcomes measures for depression were also used. Such methodological differences may account for the inconsistent findings.

The remaining outcomes were measured by one study each. The effectiveness of ACT on food addiction over time (to 12-week follow-up) was supported in between-group analyses of an RCT comparing ACT and psychoeducation on individual advice by Davoudi (50), although effect sizes could not be calculated.

In Guerrini et al.'s (51) RCT, the remaining findings were mixed. Emotional eating significantly improved pre-post intervention in both ACT+TAU and TAU,

although no significant between-group differences were found. However, anxiety levels increased in both groups, with a significantly greater increase in ACT+TAU over time (small effect size). No significant effects for emotion dysregulation and psychological wellbeing were found. In Tronieri et al.'s (62) non-RCT, pre-post ACT scores improved for cognitive restraint and quality of life rating for social life (medium effect sizes) and hunger, overall quality of life and quality of life ratings for body esteem and family relations (small effect sizes). However, body dissatisfaction showed a mean increase pre-post ACT, with a small effect size. Disinhibition and physical comfort showed no change pre-post ACT.

Factors Associated with CYP-Reported Psychosocial Outcomes

In Guerrini et al.'s (51) RCT, pre-ACT psychosocial outcomes (anxiety, depression, emotion dysregulation, experiential avoidance and fusion, stress) were not significantly associated with emotional eating post-ACT.

Acceptability of Interventions

Tronieri et al.'s (62) non-RCT assessed acceptability. Adolescents, including the one who dropped out, reported high acceptability on an adapted version of the Treatment Evaluation Inventory Short Form (102). They also gave high ratings for likelihood of enrolling in a similar programme in the future, if they wanted to lose more or maintain their weight, and reported frequent use of ACT skills.

Table 6

Summary of Findings for Obesity

Study (Design)	Timepoints	CYP-reported psycho social outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
Davoudi (2021) (50) (RCT)	Pre-intervention Post-intervention 12-week follow-up	Food addiction, YFAS	Food addiction showed significantly greater changes over time (pre-post-follow-up) in those receiving ACT than psychoeducation on individual advice ($p < .001$), with means being lower in ACT at both post-intervention and follow-up.	Not studied.
Guerrini Usubini et al. (2022) (51) (RCT)	Pre-intervention Post-intervention	Anxiety, subscale of DASS-21	For anxiety, a significant time-group interaction effect was reported ($p = .031$, $\eta^2 = .02$). Levels of anxiety significantly increased in both groups, with a higher increase in ACT+TAU than in TAU over time.	The groups (ACT+TAU vs. TAU only) did not significantly moderate the effect of pre-intervention anxiety ($p = .543$, $\eta^2 = .01$) or emotion dysregulation ($p = .785$, $\eta^2 = .00$) on post-intervention emotional eating. In the ACT+TAU group, pre-intervention depression, experiential avoidance and fusion and stress were not significantly associated with emotional eating at post-intervention.
		Depression, subscale of DASS-21	For depression, the time-group interaction effect ($p = .784$, $\eta^2 = .000$) was not significant.	
		Emotion dysregulation, DERS	For emotion dysregulation, the time-group interaction effect ($p = .332$, $\eta^2 = .00$) was not significant.	
		Emotional eating, subscale of DEBQ-EE	For emotional eating, the time-group interaction effect was not significant ($p = .896$, $\eta^2 = .00$), although a significant main effect of time ($p = .010$, $\eta^2 = .01$) was reported. This indicates emotional eating decreased pre-post intervention in both ACT+TAU and TAU.	
		Experiential avoidance and fusion, AFQ-Y	For experiential avoidance and fusion, the time-group interaction effect ($p = .299$, $\eta^2 = .00$) was not significant.	
		Psychological wellbeing, PWB	For psychological wellbeing, the time-group interaction effect ($p = .990$, $\eta^2 = .00$) was not significant.	
		Stress, subscale of DASS-21	For stress, the time-group interaction effect ($p = .844$, $\eta^2 = .00$) was not significant.	
Tronieri et al. (2019) (62) (RCT without a control group)	Pre-intervention Post-intervention	Body dissatisfaction, subscale of the EDI-3	Body dissatisfaction showed a mean increase pre-post intervention ($d = .31$). *	Not studied.
		Cognitive restraint, subscale of EI	Cognitive restraint showed a mean increase pre-post intervention ($d = .76$) *	
		Disinhibition, subscale of EI	Disinhibition shown no change pre-post intervention ($d = -.06$). *	

Study (Design)	Timepoints	CYP-reported psycho social outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes	Factors associated with ACT intervention effects on CYP-reported psychosocial outcomes
		Depression, PHQ-A	Depression showed a mean reduction pre-post intervention (*d* = -1.20). *	
		Experiential avoidance, AFQ-Y	Experiential avoidance showed a mean increase pre-post intervention (*d* = .43). *	
		Hunger, subscale of EI	Hunger showed a mean reduction pre-post intervention (*d* = -.42). *	
		Mindfulness, CAMM	Mindfulness showed no change pre-post intervention (*d* = .04). *	
		Perceived stress, PSS-14	Perceived stress showed no change pre-post intervention (*d* = -.17). *	
		Quality of life (total), IWQOL-Kids	Overall quality of life rating showed a mean increase pre-post intervention (*d* = .38). *	
		Quality of life physical comfort, subscale of IWQOL-Kids	Quality of life for physical comfort showed no change pre-post intervention (*d* = -.19). *	
		Quality of life body esteem, subscale of IWQOL-Kids	Quality of life rating for body esteem showed a mean improvement pre-post intervention (*d* = .44). *	
		Quality of life social life, subscale of IWQOL-Kids	Quality of life rating for social life showed a mean increase pre-post intervention (*d* = .82). *	
		Quality of life family relations, subscale of IWQOL-Kids	Quality of life rating for family relations showed a mean improvement (*d* = .26). *	
			Note: the study states that because this was a feasibility study, it was not powered to detect statistical significance. Therefore, tests of statistical significance were not conducted and instead the focus was on effect sizes.	

Note. ACT = acceptance and commitment therapy. CYP = children and young people. RCT = randomised controlled trial. TAU = treatment-as-usual. Measures used: AFQ-Y = Avoidance and Fusion Questionnaire for Youths (103) Italian version (104); CAMM = Child and Adolescent Mindfulness Measure (91); DASS-21 = Depression Anxiety Stress Scales, Italian version (105); DEBQ = Dutch Eating Behavior Questionnaire, Italian version (106); DERS = Difficulties in Emotion Regulation Scale, Italian version (107); EDI-3 = Eating Disorder Inventory 3 (108); EI = Eating Inventory (109); IWQOL-Kids = Impact of Weight on Quality of Life-Kids scale (110); PHQ-A = Patient Health Questionnaire for Adolescents (111); PSS-14 = Perceived Stress Scale (96); PWB = Psychological Well-Being Scales, Italian version (112); YFAS = Yale Food Addiction Scale (113).
Studies ordered by design (RCT, non-RCT without control group).
* = no *p*-value reported.

Cancer

Effectiveness on CYP-Reported Psychosocial Outcomes

Outcome data from cancer studies are presented in Table 7. For anger, between-group analyses supported the effectiveness of ACT (to one-month follow-up) compared with a meeting offering a solution in one RCT by Asadi et al. (52). For resilience and self-concept, the effects of ACT were also supported compared with NI in one non-RCT by Ebrahimi et al. (56). Of note, all outcomes had large effect sizes and no dropouts were reported for both studies. However, both studies provided insufficient reporting of their methodology.

Factors Associated with CYP-Reported Psychosocial Outcomes and Acceptability of Interventions

Not studied.

Table 7

Summary of Findings for Cancer

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes
Asadi et al. (2016) (52) (RCT)	Pre-intervention Post-intervention One-month follow-up	Anger, ChIA	For anger, a significant time-group interaction effect was reported ($p < .001$, $\eta^2 = .87$^). Change over time was significantly greater in ACT than meeting without offering a solution, with means indicating anger decreased in ACT.
Ebrahimi et al. (2022) (56) (Non-RCT with control group)	Pre-intervention Post-intervention	Resilience, CD-RISC	Resilience was significantly higher in ACT than NI post-intervention after removing the interaction effect ($p = .002$, $\eta p^2 = .48$^).
		Self-concept, PHCSCS	Self-concept was significantly higher in ACT than NI post-intervention after removing the interaction effect ($p = .001$, $\eta p^2 = .31$^).

Note. ACT = acceptance and commitment therapy. CYP = children and young people. NI = no intervention. RCT = randomised controlled trial.
Measures used: CD-RISC = Connor-Davidson resilience scale (114); ChIA = Children's Inventory of Anger (115); PHCSCS = Piers-Harris Children's Self-Concept Scale (116).
Studies are ordered by design (RCT, non-RCT).
^ = effect size calculated.

Visual Impairment

Effectiveness on CYP-Reported Psychosocial Outcomes

Outcome data from the visual impairment study are presented in Table 8. For emotional maturity, and its components, between-group analyses supported the effectiveness of ACT compared with empowering make-up sessions in one RCT by Mirmohammadi and Pourmohamadreza-Tajrishi (53), with large effect sizes. The effects of ACT were maintained at eight-week follow up. Although this RCT included an active control, details on the randomisation process were not reported.

Factors Associated with CYP-Reported Psychosocial Outcomes

Not studied.

Acceptability of Interventions

Mirmohammadi and Pourmohamadreza-Tajrishi's (53) RCT assessed acceptability using the Intervention Rating Profile Questionnaire (IPR-15) (117). The social validity rating of ACT indicated it was acceptable to adolescents.

Table 8

Summary of Findings for Visual Impairment

Study (Design)	Timepoints	CYP-reported psychosocial outcomes	Findings on intervention effects on CYP-reported psychosocial outcomes
Mirmohammadi and Pourmohamadreza-Tajrishi (2024) (53) RCT	Pre-intervention Post-intervention Eight-week follow-up	Emotional maturity (overall), EMS	Emotional maturity scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .90), with the means indicating emotional maturity decreased only in ACT.
		Emotional progression, subscale of EMS	Emotional progression scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .59), with the means indicating emotional maturity decreased only in ACT.
		Emotional stability, subscale of EMS	Emotional stability scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .69), with the means indicating emotional maturity decreased only in ACT.
		Independence, subscale of EMS	Independence scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .68), with the means indicating emotional maturity decreased only in ACT.
		Personality integration, subscale of EMS	Personality integration scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .92), with the means indicating emotional maturity decreased only in ACT.
		Social adaptation, subscale of EMS	Social adaption scores were significantly lower (indicating higher levels) in ACT than make-up empowering sessions post-intervention, after controlling for pre-test scores (p = .001, ηp^2 = .55), with the means indicating emotional maturity decreased only in ACT.
			In the ACT group, there were no significant differences between post-intervention and follow-up for emotional maturity (p = .660), emotional progression (p = .210), emotional stability (p = .240), independence (p = .749), personality integration (p = .504) and (p = .489).

Note. ACT = acceptance and commitment therapy. CYP = children and young people. RCT = randomised controlled trial.
Measure used: EMS = Emotional Maturity Scale (118).

Discussion

This systemic review evaluated the effectiveness of ACT on CYP-reported psychosocial outcomes among CYP with LTCs. The factors associated with the effects and the quantitative acceptability of the included ACT interventions were also examined. Following a systematic literature search, 16 studies from 19 reports were included.

Effectiveness of ACT on CYP-Reported Psychosocial Outcomes

Many CYP-reported psychosocial outcomes were evaluated, encompassing mental health, emotional wellbeing, cognitive processes, interpersonal relationships, functioning and quality of life. All 15 studies that assessed statistical significance reported significant improvements in at least one CYP-reported psychosocial outcome (small-large effect sizes) (45,47–54,56–61). Notably, eight studies found significant improvements in all CYP-reported psychosocial outcomes studied (48–50,52,53,56,59,61). This provides preliminary transdiagnostic support for the effectiveness of ACT in CYP with LTCs.

It is noteworthy that significant effects on all investigated CYP-reported psychosocial outcomes were found only in the cancer and visual impairment studies, though fewer outcomes were assessed in these LTC groups. Although most CYP-reported psychosocial outcomes demonstrated significant effects of ACT in the chronic pain, diabetes and obesity studies, a minority did not. In most cases, these non-significant results were limited to one or two outcomes per study.

Mixed findings within LTC groups were reported for a small number of CYP-reported psychosocial outcomes, namely depression in chronic pain, diabetes and obesity (45–47,49,51,57–60,62), insomnia in chronic pain (57,60) and experiential avoidance in obesity (51,62). While notable methodological heterogeneity between studies may have contributed to such inconsistencies, all studies were limited by high/serious risk of bias ratings. Only two outcomes worsened pre-post ACT, each in one obesity study: anxiety (51) and body dissatisfaction (62), although the latter was not tested for statistical significance.

A variety of ACT intervention delivery structures, doses, formats, methods and contents showed significant effects. Such findings are promising, as some are less resource-intensive and therefore more feasible to implement. This may fit with stepped-care approaches, whereby intervention intensity provided is based on need (e.g. the Pediatric Psychosocial Preventative Health Model for paediatric care) (119). However, further research comparing varying intensities of ACT interventions on different subgroups of CYP with LTCs is needed to draw such conclusions.

Factors Associated with CYP-Reported Psychosocial Outcomes

Seven studies considered the factors associated with the effects of ACT (five chronic pain, one diabetes, one obesity) (47,51,54,57–59,63). One study found no mediating effect of adolescent diabetes-related psychological flexibility on anxiety (47), differing from findings in other clinical samples including adult LTC populations (120–122). However, another study found that changes in parent psychological flexibility were significantly positively associated with changes in adolescent pain

acceptance (59). One study assessed different psychological flexibility processes, finding that higher acceptance in CYP statements early in ACT treatment were significantly associated with greater decreases in pain interference, while cognitive defusion, values and committed action were not (63).

Significant mediators, namely pain reactivity on pain interference and depression and pain impairment beliefs on depression (54) and moderators, namely pain risk on improvements in pain catastrophising, depression and pain frequency (59), were also found. Other factors associated with the effects of ACT were autistic traits and ADHD (57). However, these factors were only assessed in one study each, with several other factors also showing non-significant associations.

Acceptability of ACT Interventions

Three studies provided quantitative acceptability data for ACT (in diabetes, obesity and visual impairment) (47,53,55,62). Scales (including two standardised measures) were utilised, with high acceptability/satisfaction reported by CYP across studies.

One study considered satisfaction with intervention length, with most participants being satisfied (47,55). Of other acceptability questions asked, ratings were high for recommending the intervention to others (47,55) and for the likelihood of signing up to a similar programme in the future if warranted (62), and all participants reported perceived benefits (55).

Limitations

The findings of this systematic review should be viewed in the context of several limitations. Overall, the studies had a small, combined sample size, of predominantly females, with limited or no reporting of participant ethnicity. Additionally, only five LTCs were included. Such sample limitations make it difficult to generalise the findings to wider populations of CYP with LTCs.

Most RCTs were small-scale or pilots, and only one non-RCT had a control group. Few studies used active controls, making it difficult to ascertain whether effects were due to ACT or non-intervention-specific factors (e.g. therapeutic alliance) (123). Most studies also had no or short follow-ups, limiting assessment regarding sustained effects. The synthesis was limited by the high heterogeneity of included studies, rendering meta-analysis inappropriate. Moreover, most CYP-reported psychosocial outcomes were examined in only one study each and effect sizes for several outcomes were not reported and could not be calculated from the available data. Thus, conclusions surrounding the effects of ACT remain tentative. Conclusions on factors associated with these effects and acceptability are also limited given the small number of studies reporting such data.

Almost all studies had high/serious risk of bias, along with poor methodological reporting, which may inflate effect sizes and undermine the reliability and validity of the findings. However, these ratings may partly reflect the quality assessment tools used. Although Cochrane recommends RoB 2 and ROBINS-I for systematic reviews evaluating interventions (42,43), some criteria (e.g. blinding) are

difficult to meet in psychological interventions requiring active participation (124). Some criteria also misaligned with the current systematic review; for example, outcome measurement domains received poorer ratings due to its inclusion criteria (i.e. CYP-reported psychosocial outcomes). Despite these limitations, the promising initial findings highlight the need for higher-quality research on ACT in CYP with LTCs.

Clinical Implications and Future Directions

This systematic review provides preliminary support for the effectiveness and acceptability of a variety of ACT interventions in CYP with LTCs. Encouragingly, research on ACT studies in CYP with LTCs are increasing, with half of the included studies published in the past five years. To broaden the evidence base, is important for future research to evaluate ACT among CYP with other LTCs, seeking more diverse samples. Consistency in studies should be sought, to enable meta-analyses to be performed.

To better understand ACT treatment processes, assessments of psychological flexibility and other potential mediators and moderators should be included in future trials. Acceptability should also be considered to help support intervention engagement and satisfaction. This could include qualitative findings to offer a richer understanding of acceptability. To widen applicability, such qualitative findings, and the inclusion of parent-reported CYP outcomes and LTC-related outcomes (e.g. physical symptoms), should also be considered in future reviews.

Taken together, the findings on ACT among CYP with LTCs remain limited. To build upon the current evidence base, large-scale, methodologically rigorous and well-reported RCTs with active control conditions and long-term follow-ups are warranted. Such research could inform the development of care pathways and clinical guidelines for CYP with LTCs.

Conclusion

This systematic review of 16 eligible studies across 19 reports provides preliminary evidence supporting the effectiveness of ACT interventions on CYP-reported psychosocial outcomes among CYP with LTCs. Seven studies considered factors associated with intervention effects, with mixed findings. Acceptability was also supported by the three studies that quantitatively assessed it. However, almost all studies were rated as high/serious risk of bias. Investment is needed in methodologically rigorous evaluations of ACT interventions in more diverse samples to inform psychosocial care pathways for CYP with LTCs.

Declarations

Availability of Data and Materials

The data supporting the findings are reported within systematic review.

Competing Interests

The authors declare no competing interests.

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Service Improvement Project (SIP)

"We Are Here Too": Experiences and Perceived Support Needs of Adolescent Siblings of Paediatric Oncology Ward Inpatients at Oxford Children's Hospital

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Proposed Journal

This SIP has been published in the British Journal of Health Psychology. This is a peer-reviewed journal focusing on health-related psychology, including childhood cancer and sibling coping in paediatric settings, making it highly relevant to readers. The published article is presented in Appendix F, with the author submission guidelines outlined in Appendix G. The journal requested inclusion of a statement of contribution, as shown in the published article. A lay summary of the project is also provided in Appendix H.

Abstract

Background: Adolescent siblings of children and young people (CYP) with cancer are at increased risk of experiencing psychosocial difficulties. Kamran's Ward, a paediatric oncology ward at Oxford Children's Hospital, recognised the need for improving sibling support. This project aimed to explore the experiences and perceived needs of adolescent siblings of CYP on Kamran's Ward to inform service improvement recommendations for sibling support.

Methods: Semi-structured interviews were conducted with 10 adolescent siblings of CYP who had recently stayed on Kamran's Ward. Interviews were transcribed verbatim and analysed using reflexive thematic analysis. The findings were reviewed in consultation with staff and used to identify feasible sibling support recommendations, organised by level of need using the three-tier Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006).

Results: An overarching narrative of siblings wanting to feel part of the cancer journey, including their family's experience on Kamran's Ward, was found, with three key themes: (i) "what about me?": overlooked and unseen, (ii) "always changing, never knowing": the challenge of uncertainty and (iii) "let me be part of it all": togetherness, communication and connection. These findings informed sibling support recommendations, including: psychosocial screening, staff training, opportunities for family time and communication and developmentally appropriate information for all siblings (universal support), monitoring psychosocial difficulties, providing someone to talk to and fostering family and peer connection for siblings requiring additional support (targeted support) and one-to-one psychological support

and family therapy for persistent and/or escalating distress (clinical/treatment support).

Conclusion: Based on the experiences of adolescent siblings, a range of sibling support recommendations have been identified. Implementation and evaluation of these recommendations are warranted.

Keywords: adolescents, cancer, hospital, oncology, paediatrics, psychosocial support, siblings

Introduction

Approximately 1,800 children and young people (CYP) aged 0-14-year-olds are diagnosed with cancer in the UK each year (Cancer Research UK, 2021b). While survival rates are improving, a growing evidence base has drawn attention to the adverse short- and long-term psychosocial impacts experienced by CYP with cancer (Duran et al., 2020; Osmani et al., 2023). Such impacts extend beyond the unwell child, affecting the daily routines and emotional balance of the wider family (Mu et al., 2015).

Clinical guidelines acknowledge the importance of assessing and supporting the psychosocial needs of family members of CYP with cancer (National Institute for Health and Care Excellence [NICE], 2014). An evidence-based sibling psychosocial standard of care further recommends psychosocial input for siblings (Gerhardt et al., 2015). However, sibling have remained largely overlooked, with inconsistent support and often unmet needs (Davis et al., 2023).

Sibling Impacts and Needs

Sibling relationships are characteristically distinct, commonly sharing unique histories and potentially greater longevity than parental, spousal and peer relationships (Cicirelli, 2013). Siblings of CYP with cancer have been found to face increased risks of psychosocial difficulties, including anxiety, depression and loneliness (Alderfer et al., 2010; Weiner & Woodley, 2018). Hospitalisation can bring additional challenges, including routine disruptions, family separation and role adjustments (Niinomi & Fukui, 2022). Indeed, psychosocial difficulties among

siblings have been found to intensify during hospitalisations (Nabors & Liddle, 2017).

Adolescent siblings of CYP with cancer have been shown to experience greater distress than younger siblings (Cordaro et al., 2012). Additionally, childhood cancer studies often combine siblings of different ages in samples, without consideration of how the experience may affect particular developmental stages (Long et al., 2018). Many studies have also utilised proxy informants, predominantly parents, despite discrepancies between self- and proxy-reports being recognised (Pariseau et al., 2020). This underscores the importance of gathering the perspectives of adolescent siblings directly.

Within family contexts, one theoretical model for understanding stress and coping is Hill's (1958) ABC-X model. The model encompasses the elements of (A) stressor(s), (B) resources to cope with the stressor(s), (C) perceptions of the stressor(s) and (X) the resulting level or likelihood of stress/crisis. The ABC-X model posits that B and C determine if stressors in category A result in stress/crisis (poor psychological adjustment). For siblings of CYP with cancer, previous research indicates that common stressors (A) may include diagnosis, bereavement and hospitalisation, helpful resources (B) may include developmentally appropriate information, family support and peer support and important perceptions (C) may include those surrounding the cancer, prognosis, family cohesion and their roles (Long et al., 2018; Zegaczewski et al., 2016).

This suggests supporting adolescent siblings of hospitalised CYP with cancer (i.e. the stressor) with their resources and perceptions may be important, although their experiences have not yet been specifically investigated.

Service Context: Kamran's Ward

Kamran's Ward, the oncology ward at Oxford Children's Hospital, Oxford University Hospitals NHS Foundation Trust (OUH), has 13 beds for 0-16-year-olds. Ward staff described sibling support as limited; activity days were infrequently accessed, especially by adolescent siblings, and siblings only accessed individual psychological support when they had already reached crisis.

Understanding the experiences and perspectives of adolescent siblings could inform recommendations to support their resources and perceptions. With input from Kamran's Ward staff and the wider paediatric oncology team, such recommendations could then be organised using the Pediatric Psychosocial Preventative Health Model (PPPHM; Kazak, 2006). Used across Oxford Children's Hospital, the PPPHM proposes screening all families for indicators of higher psychosocial risks and then uses three tiers to guide support dependent on levels of need: 'universal' support available to all, 'targeted' additional support for specific needs and 'clinical/support' support for persistent and/or escalating distress. With feasibility in mind, offering universal low-intensity support may reduce demand for higher-intensity support, helping to meet the psychosocial needs of more siblings.

Aims and Key Questions

This project aimed to improve support for adolescent siblings of CYP with cancer on Kamran's Ward. The following improvement questions were considered:

1. What are the experiences and needs of adolescent siblings of CYP on Kamran's Ward?
2. What changes could be made on Kamran's Ward to better support adolescent siblings?

Methods

Participants

Siblings were recruited through word-of-mouth by oncology staff, posters and letters/emails. Screened by OUH staff, eligibility criteria were CYP who were (i) aged 11-16 years old and (ii) had a sibling who had stayed on Kamran's Ward for at least one week in the previous six months. This ensured a substantial inpatient stay had occurred since siblings were permitted back on Kamran's Ward following the easing of COVID-19 regulations in May 2023. To reduce the risk of causing distress, interviews were conducted only when their sibling with cancer was between admissions or had been discharged. Bereaved siblings were also excluded, as their support needs may differ (Ridley & Frache, 2020). No siblings dropped out following recruitment.

Ten siblings, all from different families, took part (Table 1). Most were white British, full siblings from nuclear families. Siblings were equally split in gender and position (i.e. older, younger) compared to their sibling with cancer.

Table 1

Demographic and Family-Related Information of Sibling Participants

Characteristic	**Siblings without cancer (N = 10)**
Age, mean (standard deviation; range)	14.10 (1.79; 11-16)
Age when sibling was first diagnosed with cancer, mean (standard deviation; range)	11.80 (1.99; 9-14)
Gender, *n*	
Female	5
Male	5
Ethnicity, *n*	
White British	6
White Irish	1
White, Other	1
Black British	1
Chinese	1
Position in family (compared to sibling with cancer), *n*	
Older	5
Younger	5
Number of siblings, *n*	
One	5
Two	4
Three	1
Relationship (to sibling with cancer), *n*	
Full sibling	8
Half-sibling	1
Stepsibling	1
Family composition, *n*	
Nuclear family	7
Single-parent family	2
Stepfamily	1

Demographic and cancer-related characteristics of their sibling with cancer were also gathered (Table 2). Most were white British and 60% were male. They

covered a range of current ages, ages at diagnosis and types of common childhood/teenage cancer (Cancer Research UK, 2021a).

Table 2

Demographic and Cancer-Related Information of the Siblings with Cancer

Characteristic	**Siblings with cancer (N = 10)**
Age, mean (standard deviation; range)	11.90 (3.03; 6-16)
Age at cancer diagnosis, mean (standard deviation; range)	9.40 (2.99; 4-14)
Gender, *n*	
Male	6
Female	4
Ethnicity, *n*	
White British	6
White Irish	1
White, Other	1
Black British	1
Chinese	1
Type of cancer, *n*	
Acute lymphocytic leukaemia (ALL)	2
Acute myeloid leukaemia (AML)	2
Osteosarcoma	2
Glioblastoma	1
Melanoma	1
Neuroblastoma	1
Wilms tumour (nephroblastoma)	1

Lived/Living Experience Involvement

Three siblings (two females, one male; aged 11, 14 and 16 years-old) of CYP on Kamran's Ward were involved in developing the project's aims, interview schedule and materials. Their feedback helped ensure the materials and questions were clear, representative and relevant to a diverse range of siblings (e.g. through

representative graphics). Payment was offered consistent with the NHS Trust policy where the lead author was employed.

Procedure

According to the Health Research Authority decision tool, ethical approval was not required (Appendix I). OUH service evaluation/audit approval was obtained (Appendix J) and OUH processes were adhered to. All siblings and their parent(s)/carer(s) were given a project information sheet (Appendix K) and provided written informed consent/assent according to their age (Appendix L).

Semi-structured one-to-one interviews were conducted by RB between December 2023 and March 2024. The interview schedule (see Appendix M) was informed by previous literature, elements of the ABC-X model (Hill, 1958) and the siblings with lived/living experience. In summary, siblings were asked some warm-up questions (hobbies, family), followed by questions about their experiences of Kamran's Ward and what could be improved. Post-interview, siblings were debriefed and signposted to relevant sibling and wellbeing support (Appendix N).

All interviews were conducted remotely; eight via videoconferencing and two via telephone calls. Interviews were 33-58 minutes long.

Data Analysis

Interviews were audio recorded, stored on an encrypted device and transcribed verbatim, with identifiable information removed pre-analysis. Inductive reflexive thematic analysis was utilised, due to its flexibility and common use for exploring themes and patterns in experiential data (Braun & Clarke, 2006, 2019). Inductive coding with an experiential approach was taken, allowing the meanings, realities and experiences of the siblings to be accessed and unanticipated themes rooted in the data to be explored.

The analysis phases described by Braun and Clarke (2006, 2019) were followed: (1) familiarising with data, (2) generating initial codes, (3) constructing themes, (4) reviewing potential themes, (5) defining and naming themes and (6) producing the report. RB identified potential themes and subthemes. These were then reviewed by a second coder (EH), who checked that they reflected the semantic content of the dataset. Potential themes and subthemes were discussed over multiple meetings with a project supervisor (ALD), who had read through and checked all the transcripts and codes. Following this process, themes and subthemes, and their interrelated links, were consolidated and defined. Data analysis was conducted using NVivo for Mac (Version 14.23.2; QSR International Pty Ltd., 2023).

After finalising the thematic framework, in May 2024 the findings were reviewed in consultation with staff on Kamran's Ward and the wider oncology team

(see Appendix O for the plan for this consultation), to identify feasible support recommendations, organised using the PPPHM (Kazak, 2006).

Author Positionality

The researchers had a mix of clinical and research experience supporting CYP with serious illnesses and their families. All researchers had previous experience of conducting research with reflexive thematic analysis and position themselves as passionate about equitable and accessible healthcare for CYP and their families.

To address potential researcher bias, including blind spots, preconceptions and positionality, bracketing exercises (e.g. reflective interviews with colleagues) (Tufford & Newman, 2012) and reflexive journaling (McGrath, 2021) were utilised. All authors paid careful attention and regularly reflected on how their perspectives, research interests and experiences might be influencing the process of analysis, interpretation and identification of the siblings' needs and service improvements.

Results

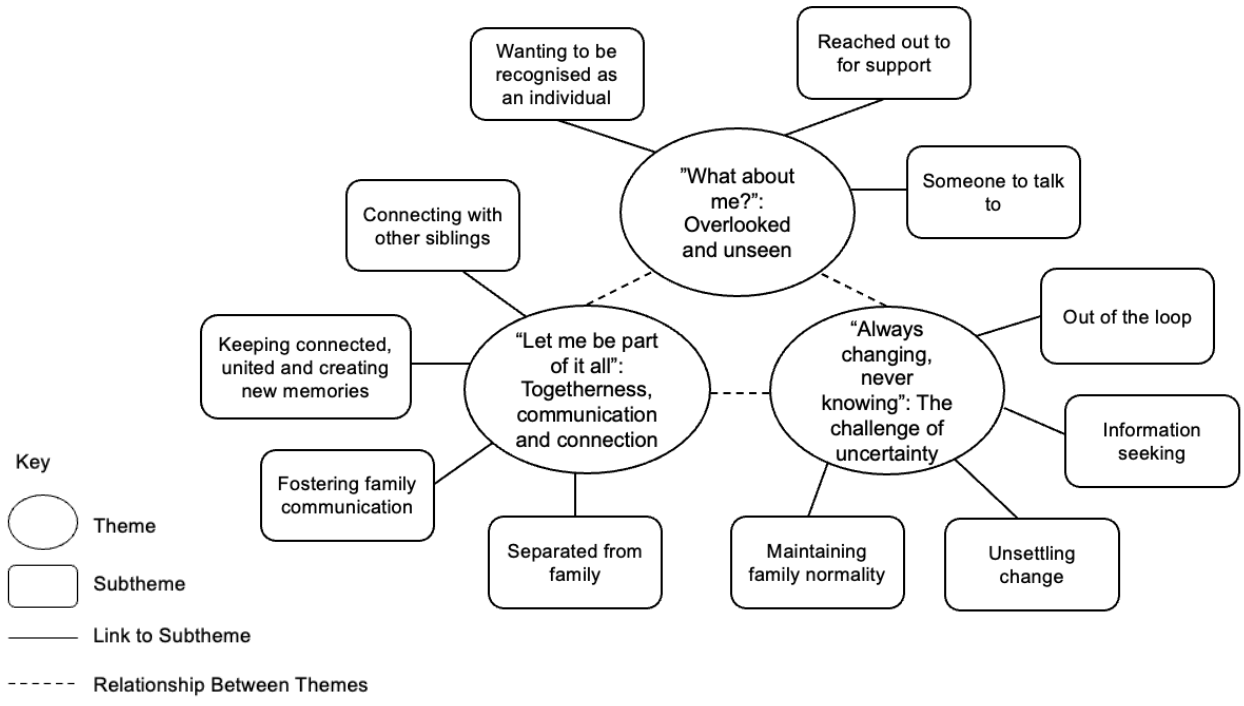
An overarching narrative was found of adolescent siblings wanting to feel part of the cancer journey, including their family's experience on Kamran's Ward. Ultimately, they sought a sense of belonging, pertaining to involvement and closeness. Such desires were woven throughout the main themes and their subthemes. Specifically, three main themes were developed describing the experiences and perceived needs of siblings: (i) "what about me?": overlooked and

unseen, (ii) “always changing, never knowing”: the challenge of uncertainty and (iii) “let me be part of it all”: togetherness, communication and connection.

Themes and subthemes and outlined in Figure 1 and summarised below with anonymised quotes. Consistent with reflexive thematic analysis guidance (Braun & Clarke, 2006, 2019), theme and subtheme frequencies were not reported; instead, guidelines for quantifying language were followed, with ‘all’ referring to all siblings (or all but one), ‘most’ referring to more than half and ‘some’ referring to fewer than half but more than two (Hill et al., 2005).

Figure 1

Overview of Themes and Subthemes



“What About Me?”: Overlooked and Unseen

This theme represents siblings feeling invisible and wanting to be reached out to for support. There was a sense of siblings wanting to be included and acknowledged in the context of their sibling’s care, while their identity outside of their sibling also being appreciated. This included having someone in the know outside of the family to talk to, just for them.

Most siblings emphasised **wanting to be recognised as an individual**. Siblings experienced a tension between understanding that their unwell sibling needed more attention and feeling “*a bit forgotten*” (Adolescent 5) when staff were having conversations with their family. Siblings wanted ward staff to know they existed and say *“hello…like I mattered too...*” (Adolescent 4). There was also a sense of wanting to feel appreciated as a “*person too*” (Adolescent 2) and be asked about other aspects of their lives, rather than just being known as ‘[name’s] sibling’.

Siblings described a preference of being **reached out to for support**. They appreciated being made aware of sibling support, as they valued siblings being “*thought of*” (Adolescent 7) during the admission. Most siblings hoped “*someone would notice that I was actually finding it sort of hard*” (Adolescent 5) and check in with them proactively, rather than needing to access help through their parents.

As such, most siblings found it helpful, or wanted, to have **someone to talk to** about their feelings and experiences. Among those who had someone to talk to, this included a school counsellor, a charity counsellor, Kamran’s Ward nurse and friends.

Most siblings stressed the importance of this person knowing the situation, while being "*separate from the family*" (Adolescent 6). Siblings emphasised that having this support, just for them, could help them develop coping strategies and foster self-compassion through feeling seen and validated.

"*Knowing that they were supporting me, as in specifically there for me, could help me to be less hard on myself and show me that my feelings matter too…*" (Adolescent 10)

"Always Changing, Never Knowing": The Challenge of Uncertainty

This theme describes the challenge of uncertainty faced by siblings, due to not knowing about their sibling's health and Kamran's Ward, and the varying changes in their lives. As such, siblings wished to have information shared with them and maintain some family normality.

Seeming **out of the loop** compared with the rest of their family, alluding to not being involved in cancer-related conversations, was highlighted as challenging by most siblings. There was a sense that "*parents would tell us less, but I think it made us worry more*" (Adolescent 5). Lacking information, some siblings assumed the worst outcomes, based on their limited experience and understanding of cancer and hospitals; for example and "*I just thought they would die even though that was*

actually not likely at all" (Adolescent 3) and *"I was worried she would die because when my grandad went to hospital, he then died…*" (Adolescent 4).

Consequently, most siblings described **information seeking**. This included wanting to "*know what was happening*" (Adolescent 3) *"about the cancer*" (Adolescent 6), including the treatment, hospitalisation and prognosis. Such information could help to reduce assumptions by helping "*me to stop imagining stuff or the worst outcomes*" (Adolescent 5). Some siblings reflected "*it got easier with time because of knowing what was happening a bit more"* (Adolescent 8). Most siblings also wanted more information about Kamran's Ward, such as what their room looked like, the staff caring for their sibling and who they could ask their questions. Suggestions included a video tour and "*pictures of the ward so we could imagine it before we went there, would have been comforting to know where they were*" (Adolescent 6). It was noted that information needed to be age-appropriate; "*it was hard to understand the words in the letter mum got…so it being written for kids or teenagers like me*" (Adolescent 5). Once they had seen Kamran's Ward, such benefits were identified, especially as it was often described as pleasant and friendly.

Experiencing **unsettling change** was described by most siblings. This included changes in routines, the atmosphere at home and seeing medical equipment and family members upset for the first time. For most siblings, responsibilities increased, including supporting other family members (e.g. younger siblings) and helping more at home. For most, changes also seemed ongoing; "*it was a bit over the place, I sometimes didn't know who was staying that night until the day*" (Adolescent 5) and had adverse impacts in other areas of life such as keeping

up with school expectations. Some siblings found new routines, helping them to adjust to a "*different normal*" (Adolescent 10) over time.

"*I remember most, vividly…when my dad came home and was crying because I don't think I had seen him cry until then…*" (Adolescent 6)

Among the uncertainty and change, **maintaining family normality** was described as helpful. Siblings appreciated their parents trying to keep things normal for them, such as engaging in usual family activities; for example, "*I think it [playing board games] made it feel normal…like it was OK…*" (Adolescent 2). Siblings appreciated when their unwell sibling's area on Kamran's Ward could be decorated with some "*things from their room*" (Adolescent 10) to help make the space feel more homely and familiar.

"Let Me Be Part of It All": Togetherness, Communication and Connection

This theme encompasses the narratives that focus on siblings desiring a sense of belonging within their family and peer group, the impacts of siblings being apart from their families and ways of being brought closer as a family and to other siblings.

All siblings recalled being physically and emotionally **separated from family**, often feeling "*quite distant from my parents and [unwell sibling's name] because I couldn't see them as much…*" (Adolescent 4). Siblings expressed sadness, loneliness and longing for their family; "*every day I did miss them*" (Adolescent 6). Some siblings stayed in other people's houses during the admission which

sometimes added to the physical distance from the hospital and meant seeing their family less.

"*I think mostly being away from them, it would bubble up inside of me, the sadness. Like grow but I didn't know what to do with that.*" (Adolescent 1)

Given such separation, **fostering family communication** was perceived as helpful, rather than all keeping quiet. Some siblings thought parental support could be beneficial to *"explain to us [siblings] what was happening"* (Adolescent 2). Some siblings reported wanting family support, to make sure everyone was included and for *"us all talk to each other…and…helping my family to see what we were doing well and to make us believe we could get through it*" (Adolescent 1).

Similarly, siblings perceived **keeping connected, united and creating new memories** as important and helpful. This often meant being together in different ways; for example, "…*sometimes we'd wait to know [the food on Kamran's Ward] and then we would try to have the same, so we felt together…"* (Adolescent 5). Some siblings described "*appreciating each other more*" and feeling more united. Some siblings spent more quality time with certain family members; for example, "*I saw my dad and then my aunt a bit more actually because they came to stay at the house…it was nice doing things with them*" (Adolescent 9). Still making family memories was also valued, such as "*I got a hot chocolate downstairs from the [hospital] café which was good…my dad said as a treat*…" (Adolescent 7).

Alongside keeping connected with their family, all siblings discussed a desire for **connecting with other siblings** on Kamran's Ward who *"get it*" (Adolescent 7) and could help them make sense of the experience. Siblings who had sibling(s) other than their unwell one found connecting with them beneficial; "*having my other brother was really helpful*" (Adolescent 6). Most siblings specified wanting to connect with other adolescent siblings, to feel they *"belonged, as younger children would not understand the challenges of being our age as much…"* (Adolescent 10). Suggested modalities included *"having things that siblings would say to other siblings, make them feel less alone*" (Adolescent 4) and "*doing activities while talking about hard things and learning ways of coping*" (Adolescent 10).

Service Improvement Recommendations for Sibling Support

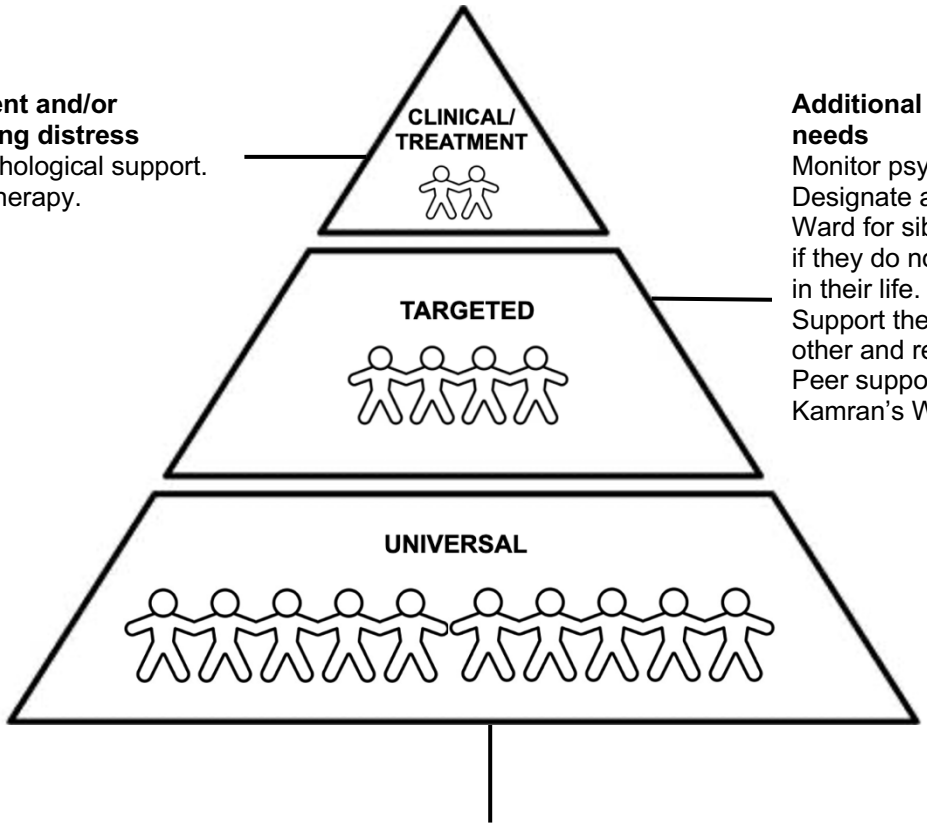
The findings were presented to staff on Kamran's Ward and the wider oncology team, who agreed that enhancing sibling support should be a priority. In consultation with the staff, the findings were used to identify feasible recommendations for improving sibling support for adolescents, mapped onto the PPPHM (Kazak, 2006).

The proposed recommendations for sibling support are displayed in Figure 2. In summary, these include psychosocial screening, staff training, opportunities for family time and communication and providing developmentally appropriate information about cancer and Kamran's Ward for all siblings (universal support),

monitoring psychosocial difficulties, providing someone to talk to and fostering family and peer connection for siblings requiring additional support (targeted support) and one-to-one psychological support and family therapy for persistent and/or escalating distress (clinical/treatment support).

Figure 2

Summary of Service Improvement Recommendations Organised Using the Pediatric Psychosocial Preventative Health Model (Kazak, 2006)



Persistent and/or escalating distress
1:1 psychological support.
Family therapy.

Additional support specific to needs
Monitor psychosocial distress.
Designate a person on Kamran's Ward for siblings to talk to, especially if they do not have someone separate in their life.
Support the family to talk with each other and recognise their strengths.
Peer support space for siblings on Kamran's Ward.

Available to all siblings
Psychosocial screening.
Staff to know the names of siblings and say hello to them on Kamran's Ward.
Staff to check in that siblings have someone outside of the family to talk to who knows what is happening.
Ask siblings about things in their life outside of their unwell sibling's cancer such as their hobbies.
Access to developmentally appropriate information/resources about cancer. Involve siblings in conversations when they are present, where appropriate.
Access to developmentally appropriate information about Kamran's Ward (e.g. photos, virtual tour and information booklets about the staff and food).
Staff training regarding the psychosocial needs of siblings.
Support for parents in terms of understanding ways of communicating with siblings about the cancer, with readily available resources.
Facilitate opportunities for families to do activities and spend quality time together.
Enable families to decorate room/space on Kamran's Ward so it feels more homely (e.g. bringing some items from home).
Develop a resource with notes and quotes from other adolescent siblings.

Discussion

This project sought to understand the experiences and perceived needs of adolescent siblings of CYP on Kamran's Ward to identify improvements for sibling support. Key themes were developed, interconnected by an overarching narrative of siblings wanting to feel part of the cancer journey, including their family's experience on Kamran's Ward. Such findings align with the family-centred approach to paediatric inpatient care, as recommended by NICE (2021) guidelines, whereby care is planned in partnership with and around the needs of the whole family.

Consistent with the evidence base, siblings described an array of emotions, including anxiety, sadness, shock and loneliness (Weiner & Woodley, 2018). While understanding that their unwell sibling required support, siblings perceived themselves as being overlooked, as previously noted (Van Schoors et al., 2019). Siblings wanted to be included in their family's care but also recognised as individuals, not just as their sibling's sibling. This balance of belonging and individual appreciation is perhaps particularly pertinent in adolescence, a time of developing autonomy and carving out personal identity while also consolidating social identity (Meeus, 2018).

Siblings desired proactive support, rather than needing to seek it themselves or go through parents. This is important, as reluctance to disclose and low parental awareness are known barriers to siblings accessing support (Brosnan et al., 2022; Weiner & Woodley, 2018). Being thought of by Kamran's Ward staff was also valued and may be beneficial, as having trusted relationships with relevant adults has been

shown to facilitate help-seeking among adolescents (Aguirre Velasco et al., 2020). To identify siblings experiencing psychosocial difficulties, families have supported regular psychosocial screening including via electronic questionnaires to support feasibility (Deatrick et al., 2022; Long et al., 2017). When experiencing difficulties, having someone to talk to outside of the family (e.g. one-to-one) was also reported as beneficial. This may include having a space to talk about the impact of the illness on their life and adjustment (Gerhardt et al., 2015).

As reported in the current study, lack of cancer-related information has been identified as a common unfulfilled need among adolescent siblings (Masoudifar et al., 2022) and linked to assumptions surrounding potential prognoses and therefore distress (Weiner & Woodley, 2018). Access to age-appropriate informational resources about cancer, both in general and specific to their sibling, could address such assumptions and reduce distress by fostering a more informed perception of the situation.

Previous research has indicated that most siblings prefer receiving information from sources within their network (Wawrzynski et al., 2023). Indeed, siblings in this study appreciated being informed by staff and their family. Accordingly, the sibling psychosocial standard of care recommends supporting parents and staff to communicate with siblings (Gerhardt et al., 2015). Family barriers to information acquisition were reported, including parents' reluctance to share information and siblings' hesitation to seek information or support from their family, often driven by a mutual desire to protect each other (Ilic et al., 2023). Such findings further support utilising a family-centred approach to involve siblings, for

example parental and family support for communication (e.g. information sharing, recognising strengths), to help foster perceptions of getting through it together. Previous research has also identified limited knowledge among staff regarding the issues faced by siblings (Gerhardt et al., 2015), indicating staff training may be beneficial.

In line with previous research, siblings described unsettling changes, including to their routines and responsibilities (Weiner & Woodley, 2018), making upholding expectations in areas such as school harder. Such changes may be compounded by the context of their psychosocial stage of development, whereby adolescents strive to create a continuous sense of identity as opposed to role confusion (Erikson, 1950). As such, maintaining some perception of normality (Yang et al., 2016), both within the family and their wider life as individuals, was desired and experienced as beneficial.

Consistent with the current evidence base, separation from family was difficult among siblings (Yang et al., 2016). During this time, perceived togetherness and connection with family was viewed as important. Indeed, family cohesion has been associated better psychosocial outcomes among siblings (Van Schoors et al., 2016, 2021). Siblings found benefits from spending quality time and making new memories with their families, something staff could help to facilitate.

Connecting with adolescent siblings who understand the experience of having a hospitalised sibling alongside typical adolescent stressors was desired. Seeking such connections may be especially pertinent during adolescence, a developmental

period when peer groups become increasingly important (Meeus, 2018). Thus far, benefits from group-based interventions for siblings of CYP with cancer have been identified, including improvements in psychosocial adjustment, cancer knowledge, sense of belonging and family relationships (Guan et al., 2021; Mooney-Doyle et al., 2021). Peer support spaces have also been sought as opportunities to connect, improve coping and learn information through activities (Ilic et al., 2023). As such, resources fostering peer support could also be helpful.

Clinical Implications

Informed by this project's findings, recommendations for improving sibling support were identified. These recommendations are intended to support siblings during the hospital admission (i.e. the stressor) by strengthening their resources (e.g. developmentally appropriate information, communication, family and peer support) and perceptions (e.g. being/feeling seen, reducing assumptions, maintaining normality, identifying family strengths) of being able to manage, therefore helping to reduce risks of poor psychological adjustment (Hill, 1958).

The proposed recommendations organised using the PPPHM (Kazak, 2006), complement existing standards and guidelines for the psychosocial care of siblings in paediatric oncology (Gerhardt et al., 2015; NICE, 2014). Furthermore, the recommendations align with the recently published ‘Sibling Services Blueprint’ for systematic psychosocial screening and support for siblings by Davis et al. (2024). Also organised using the PPPHM (Kazak, 2006), this blueprint includes routine use of psychosocial screening tools, universal-level support for all siblings (e.g.

educational materials) and a range of sibling psychosocial support options dependent on level of psychosocial need.

Limitations and Future Directions

Several limitations were identified. Although siblings varied in age (across the eligible age range), gender and the cancer type of their unwell sibling, most were white British and from nuclear families. Siblings seeking support and involvement may have also been more likely to take part. Therefore, it is difficult to ascertain whether such findings are generalisable to all siblings who met the project's inclusion criteria.

Given the eligibility criteria, which importantly enabled an in-depth understanding to be gathered for the group of interest, the findings may not apply to non-adolescent and bereaved siblings. Future projects focusing on other sibling groups could help to establish additional improvements for sibling. It is also important to evaluate the implementation and impact of the proposed recommendations through feedback (from siblings, families and staff), audits and further improvement projects.

Although this project was specifically for Kamran's Ward, exploring the experiences and needs of siblings on other paediatric oncology wards could be valuable, as the issue of unmet sibling support needs is widespread (Davis et al., 2023). This may include utilising longitudinal designs to investigate the trajectory of

experiences and understand the most optimal timepoints for providing sibling support.

Conclusion

Overall, this qualitative study captured the lived experiences and needs of adolescent siblings of CYP on Kamran's Ward. Interconnected by an overarching narrative of siblings wanting to feel part of the cancer journey, including their family's experience on Kamran's Ward, three key themes were developed. These findings informed sibling support recommendations, organised with Kamran's Ward and oncology staff using the PPPHM (Kazak, 2006). Based on their experiences, it is considered that such recommendations could support siblings with their resources and perceptions, therefore helping to reduce risks of poor psychological adjustment (Hill, 1958). Implementation and ongoing evaluation are needed, as well as exploring the experiences of all siblings, to ensure sibling support is continually improved and their needs are met.

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Theory Driven Research Project (TDRP)

Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

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Proposed Journal

This TDRP has been accepted for publication in *Epilepsy & Behavior*. This is a peer-reviewed journal, publishing papers on a variety of epilepsy-related topics including psychosocial aspects of epilepsy. It has published two recent studies on epilepsy and self-compassion, making up a substantial proportion of the limited evidence base in this area. As a result, this journal was deemed relevant, and it is hoped this project will reach a wide audience. Author submission guidelines are in Appendix P. The journal also requested highlights and a graphical abstract (see Appendix Q).

Abstract

Background: People with temporal lobe epilepsy (TLE) are at increased risk of mental health difficulties. Self-compassion, comprised of self-kindness, common humanity and mindfulness, has been associated with better mental health in wider epilepsy populations. Previous research suggests that self-compassion may be protective by fostering better emotion regulation. However, this has not been studied in TLE.

Aims: To (1) compare adults with TLE, other types of epilepsy (non-TLE) and non-epilepsy controls on measures of self-compassion, anxiety and depression, and (2) investigate the relationships between self-compassion, mental health and emotion regulation difficulties in adults with TLE.

Methods: A cross-sectional, online survey was completed by 180 adults with TLE, 149 with non-TLE and 127 non-epilepsy controls. The survey measured sociodemographic and epilepsy-related factors, self-compassion, anxiety, depression and emotion regulation difficulties.

Results: Anxiety and depression were highest in adults with TLE, followed by non-TLE and then non-epilepsy controls. Overall self-compassion, and components self-kindness and common humanity, were lowest in adults with TLE, followed by non-TLE and then non-epilepsy controls. Mindfulness was lower among epilepsy groups than non-epilepsy controls but did not significantly differ between epilepsy groups. In TLE, higher self-compassion predicted lower anxiety and depression, after

controlling for significant sociodemographic and epilepsy-related factors. Emotion regulation difficulties partially mediated such relationships.

Clinical implications: These findings contribute to understanding risk factors for poor mental health among adults with TLE. Future research evaluating interventions to target such factors is needed, to inform psychological support and care pathways.

Keywords: epilepsy, temporal lobe epilepsy, anxiety, depression, self-compassion, emotion regulation

1. Introduction

Epilepsy is among the most common neurological conditions worldwide, with an estimated prevalence of 633,000 people in the UK (1). People with epilepsy (PWE) are at increased risk of mental health difficulties (2,3), with several adverse outcomes (4). Thus, clinical guidelines recommend the assessment and provision of mental health support within routine epilepsy care (5).

1.1. Temporal Lobe Epilepsy and Mental Health

As the most common epilepsy type, temporal lobe epilepsy (TLE) accounts for approximately 60% of focal epilepsy cases (6,7). Among all epilepsies, TLE has been most frequently associated with mental health difficulties, including anxiety, depression and suicidality (2,8,9). However, mental health needs among PWE, including TLE, often remain unmet (10–13).

Alongside factors that may impact mental health across PWE (14), people with TLE can face additional challenges. TLE has been associated with structural and functional abnormalities in the temporal lobes, particularly medial regions, that impact cognition and emotion (8). Abnormalities can pre-date seizure onset, but ongoing seizure activity in the temporal lobes can also lead to cumulative damage. For example, hippocampal sclerosis from repeated seizures may impair memory (15), while amygdala damage may disrupt emotion recognition, processing and regulation (8,16,17). Although such neurological factors may partly explain elevated

mental health risks, less is known about the associations between psychological factors and mental health outcomes in TLE.

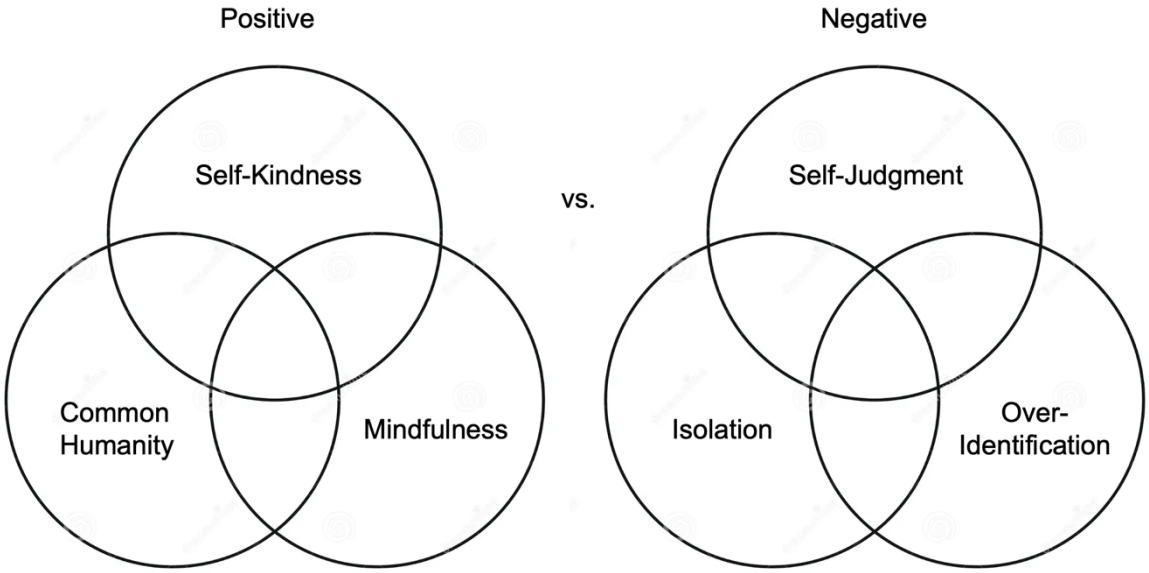
1.2. Self-Compassion

Self-compassion is a multifaceted concept, broadly defined as adopting an accepting, kind and non-judgemental stance toward oneself during challenging experiences (18). Self-compassion can be beneficial when difficulties are ongoing, unpredictable and cannot be effectively resolved, requiring adaptation, as is often the case with long-term physical health conditions (LTCs) (19).

A growing evidence-base has supported the associations between self-compassion and better mental health outcomes among LTC populations (19,20). Promisingly, self-compassion may be cultivated (21), making it a viable intervention target. In self-compassion literature, Neff's (18,22,23) theoretical model is most widely used, comprising three key positive components each with a negative counterpart (Figure 1).

Figure 1

Neff's Theoretical Model of Self-Compassion (18,22,23)



Self-kindness (versus self-judgment) involves taking a caring, non-evaluative approach towards oneself. This may help counter negative self-evaluations and shame from epilepsy-imposed restrictions such as driving limitations (24). Common humanity (versus isolation) frames one's experiences as part of a shared human experience, helping PWE connect with others with epilepsy (25). Mindfulness (versus overidentification) involves taking a non-judgemental view of present thoughts and emotional experiences, without attempting to alter, suppress or deny them. This may help with living with epilepsy-related symptoms, treatments and limitations (26).

PWE have been found to have lower self-compassion than people without epilepsy (27). Among PWE, higher self-compassion has also significantly predicted lower anxiety and depression, after controlling for sociodemographic and epilepsy-

related variables (28). However, self-compassion has not been studied specifically in TLE. In wider LTC populations, studies have begun exploring psychological mechanisms which may explain such relationships between self-compassion and mental health, including emotion regulation (29).

1.3. Emotion Regulation

Emotion regulation has been defined as an individual's ability to manage and respond to emotions through cognitive and automatic processes (30). Emotion regulation difficulties have consistently been associated with poorer mental health (30,31), including in PWE (32).

An emotion regulation model of self-compassion proposed by Finlay-Jones et al. (33) explains that self-compassion fosters greater psychological wellbeing by facilitating emotion regulation. Accordingly, a recent systematic review reported emotion regulation consistently mediated the relationship between self-compassion and mental health outcomes across clinical and non-clinical adult samples (34), with similar results being reported among people with LTCs (29). However, such relationships remain unexplored in epilepsy, including TLE, despite the increased risks of poor emotion regulation (17,35).

1.4. Aims

Although self-compassion has been associated with mental health difficulties in PWE, self-compassion has not been investigated specifically in TLE or compared

between epilepsy types. Research also suggests that self-compassion may be protective by fostering emotion regulation, yet this remains unexplored in TLE. Such understanding could inform psychological interventions.

This study aims to (1) compare adults with TLE, non-TLE and non-epilepsy controls on measures of self-compassion, anxiety and depression, and (2) investigate the relationships between self-compassion, mental health and emotion regulation difficulties in TLE.

1.5. Research Questions and Hypotheses

1) Do adults with TLE, non-TLE and non-epilepsy controls differ in levels of self-compassion (and its components), anxiety and depression?

   Hypothesis 1: Anxiety and depression will be significantly higher in adults with TLE, followed by non-TLE and then non-epilepsy controls. Therefore, based on Neff's (18,22,23) theory, self-compassion (and each component) will be significantly lower in both epilepsy groups than in non-epilepsy controls, with levels being lowest in TLE.

2) In TLE, does self-compassion significantly predict mental health outcomes (anxiety, depression) after controlling for significant sociodemographic and TLE characteristics?

Hypothesis 2: Higher self-compassion will significantly predict lower anxiety and depression once significant sociodemographic and TLE characteristics have been controlled for.

3) In TLE, do emotion regulation difficulties mediate the relationships between self-compassion and mental health outcomes (anxiety, depression)?

Hypothesis 3: Emotion regulation difficulties will mediate the relationships between self-compassion and mental health outcomes (anxiety, depression).

2. Methods

2.1. Study Design

This study used a cross-sectional survey design, using the online software 'Qualtrics' (www.qualtrics.com).

2.2. Patient and Public Involvement

Three PWE (two TLE, one non-TLE) were involved in developing the project. They provided feedback at multiple stages, including the proposal, forms, survey and advertisements, which informed amendments (e.g. language adjustments to ensure clarity and sensitivity). They supported the study's value and were compensated in line with the NHS Trust policy where the lead author was employed.

2.3. Ethical Approval

This study received approval from the Oxford University Central University Research Ethics Committee (CUREC; reference number R91618/RE001; Appendix R). All participants received full information about the study and gave informed consent through Qualtrics (Appendix S).

2.4. Participants

Participants were recruited through advertisements on epilepsy-related social media pages and 'Epilepsy Action' (UK-based epilepsy charity). Screening questions ensured eligibility (Appendix T). All participants were required to be ≥18 years old (no upper age limit) and a UK resident. Group categorisation, including epilepsy diagnosis, was based on self-report.

The following inclusion criteria determined group eligibility:

(i) TLE: current TLE diagnosis, with no current/previous diagnosis of a different epilepsy type.

(ii) Non-TLE: current diagnosis of any other type of epilepsy, with no current/previous diagnosis of TLE.

(iii) Non-epilepsy controls: no current/previous diagnosis of epilepsy.

Participants were excluded if they could not fit into one of the three groups. There were no further exclusion criteria.

Overall, 456 participants completed the survey (180 TLE, 149 non-TLE, 127 non-epilepsy controls). The non-TLE epilepsy types are listed in Table 1.

Table 1

Types of Epilepsy in Non-Temporal Lobe Epilepsy Group (n = 149)

Type of Epilepsy	Number (%)
Generalised epilepsy (unspecified)	28 (18.79%)
Generalised tonic-clonic seizures	27 (18.12%)
Mixed seizure types	19 (12.75%)
Focal epilepsy (unspecified)	16 (10.74%)
Frontal lobe epilepsy	12 (8.05%)
Absence seizures	11 (7.38%)
Catamenial epilepsy	6 (4.03%)
Occipital lobe epilepsy	2 (1.34%)
Parietal lobe epilepsy	2 (1.34%)
Unspecified/unknown	26 (17.45%)

Sociodemographic and epilepsy-related information were self-reported. For context, between-group differences in sociodemographic and epilepsy-related factors were assessed using chi-square tests, Fisher's exact tests, independent samples *t*-tests and one-way independent measures analysis of variance (ANOVAs) as appropriate.

Participants across all groups were mostly female and white British (Table 2). Significant between-group differences were indicated for education (p = .007) and occupation (p = .002). Notably, the two epilepsy groups had lower proportions of participants educated to postgraduate level and higher proportions of participants unable to work, compared with non-epilepsy controls. No other significant differences in sociodemographic factors were indicated.

Table 2

Sociodemographic Factors in Each Group

Variable	TLE *(n = 180)*	Non-TLE *(n = 149)*	Non-Epilepsy *(n = 127)*
Age in years, *M* (*SD*, range)	40.24 (11.66, 18-77)	37.45 (12.60, 18-72)	38.05 (13.51, 21-73)
Gender, *n* (%)			
Female	152 (84.4%)	121 (81.2%)	100 (78.7%)
Male	28 (15.6%)	25 (16.8%)	25 (19.7%)
Non-binary	0 (0%)	1 (.7%)	1 (.8%)
Trans man	0 (0%)	1 (.7%)	0 (0%)
Trans woman	0 (0%)	0 (0%)	1 (.8%)
Quoigender	0 (0%)	1 (.7%)	0 (0%)
Ethnicity, *n* (%)			
Asian, Asian British or Asian Welsh	4 (2.2%)	3 (2.1%)	8 (6.3%)
Black, Black British, Black Welsh, Caribbean or African	2 (1.1%)	2 (1.3%)	3 (2.4%)
Mixed or Multiple ethnic groups	2 (1.1%)	6 (4.0%)	2 (1.6%)
White British	161 (89.4%)	135 (90.6%)	105 (82.7%)
White other	11 (6.1%)	3 (2.0%)	9 (7.0%)
Marital status, *n* (%)			
Married	76 (42.2%)	51 (34.2%)	49 (38.6%)
Engaged	7 (3.9%)	10 (6.7%)	11 (8.7%)
Divorced	16 (8.9%)	8 (5.4%)	5 (3.9%)
Widowed	4 (2.2%)	0 (.0%)	1 (.8%)
Cohabiting	24 (13.3%)	23 (15.4%)	21 (16.5%)
Single (never legally married)	53 (29.4%)	57 (38.3%)	40 (31.5%)
Highest level of education, *n* (%)			
No qualification	4 (2.2%)	5 (3.4%)	1 (.8%)
Apprenticeship	5 (2.8%)	2 (1.3%)	2 (1.6%)
Secondary school or equivalent	34 (18.9%)	20 (13.4%)	13 (10.2%)
Advanced level(s)/BTEC qualifications or equivalent	43 (23.9%)	39 (26.2%)	22 (17.3%)
Undergraduate level degree	55 (30.6%)	54 (36.2%)	38 (29.9%)
Postgraduate level degree	39 (21.7%)	29 (19.5%)	51 (40.2%)
Current occupation (main), *n* (%)			
Full-time employment	72 (40.0%)	74 (49.7%)	72 (56.7%)
Part-time employment	38 (21.1%)	25 (16.8%)	18 (14.2%)
Unemployed	9 (5.0%)	9 (6.0%)	6 (4.7%)
Unable to work	35 (19.4%)	24 (16.1%)	3 (2.4%)
Retired	12 (6.7%)	3 (2.0%)	9 (7.0%)
Student	5 (2.8%)	6 (4.0%)	5 (3.9%)
Carer	2 (1.1%)	2 (1.3%)	2 (1.6%)
Other	7 (3.9%)	6 (4.0%)	12 (9.5%)

Note. BTEC = Business and Technology Education Council. TLE = temporal lobe epilepsy.

Epilepsy-related factors for the two epilepsy groups are displayed in Table 3. The TLE group had more years since seizure onset (p = .004), a higher seizure frequency (p = .002) and took longer to be diagnosed (p = .005) than the non-TLE group. Participants in the TLE group were also more likely to have experienced a seizure in the past 30 days (p < .001), be on multiple anti-seizure medications (ASMs) (p = .003) and have received additional epilepsy treatments (p = .001) than the non-TLE group. No other significant differences were indicated.

Table 3

Epilepsy-Related Factors in Each Epilepsy Group

Variable	TLE *(n = 180)*	Non-TLE *(n = 149)*
Age of seizure onset in years, *M* (*SD*, range)	15.60 (10.66, 1-52)	17.41 (11.31. 0-69)
Age of epilepsy diagnosis in years, *M* (*SD*, range)	19.03 (10.73, 1-58)	19.50 (11.32, 0-69)
Time since seizure onset in years, *M* (*SD*, range)	24.64 (14.91, 1-73)	20.04 (13.54, 0-60)
Aetiology, *n* (%)		
Unknown	103 (57.2%)	100 (67.1%)
Known (e.g. an acquired anatomic/pathogenic causation or genetics)	57 (31.7%)	36 (24.2%)
Seizure frequency (number of seizures in previous year), *M* (*SD*, range)	13.13 (30.31, 0-365)	4.54 (12.27, 0-100)
Time taken to diagnose in years, *M* (*SD*, range)	3.44 (4.39, 0-30)	2.09 (4.16, 0-29)
Time since most recent seizure, *n* (%)		
< 30 days	101 (56.1%)	49 (32.9%)
≥ 30 days	79 (43.9%)	100 (67.1%)
ASM treatment, *n* (%)		
Polytherapy (multiple ASMs)	115 (63.9%)	71 (47.7%)
Monotherapy (one ASM)	61 (33.9%)	75 (50.3%)
Additional epilepsy treatments (e.g. dietary therapy, surgery, VNS), *n* (%)		
No	142 (78.9%)	137 (92.0%)
Yes	38 (22.1%)	12 (8.5%)
Current ASM side-effects (if taking ASM), *n* (%)		
Present	127 (70.6%)	111 (74.5%)
Absent	48 (26.7%)	33 (22.2%)
Comorbid condition(s), *n* (%)		
No	89 (49.4%)	67 (45.0%)
Yes	91 (50.6%)	82 (55.0%)
History of non-epileptic/psychogenic seizures, *n* (%)		
No	129 (71.7%)	131 (87.9%)
Yes	31 (17.2%)	18 (12.0%)

Note. ASM = anti-seizure medication. TLE = temporal lobe epilepsy. VNS = vagus nerve stimulation.

2.5. Measures

2.5.1. Self-Compassion

The Self-Compassion Scale (SCS) (36) measured self-compassion. SCS has 26 items (scored 1-5), with six subscales that reflect Neff's (18,22,23) theoretical model's key components. Mean subscale scores (1-5) were calculated. Reverse-coded negative subscales (self-judgment, overidentification, isolation) were combined with their positive counterparts, to derive combined means for self-kindness, common humanity and mindfulness (1-5). An overall mean self-compassion score (1-5) was also calculated, with higher scores indicating higher self-compassion. SCS has been supported as reliable and valid (36), including in PWE (27,28). In the current sample, internal consistency was excellent for overall self-compassion in each group (α = .93 to .95) and between acceptable and excellent for each component in each group (α = .76 to .91).

2.5.2. Anxiety and Depression

The Generalised Anxiety Disorder-7 (GAD-7) (37) measured current symptoms of anxiety. GAD-7 has seven items, each scored 0-3 (total summed score = 0-21). The Patient Health Questionnaire-8 (PHQ-8) (38) measured current symptoms of depression. PHQ-8 has eight items, each scored 0-3 (total summed score = 0-24). Higher scores indicate higher anxiety and depression. Both measures have been supported as reliable and valid measures among adults in general and

epilepsy populations (37–40). Each group of the current sample had good internal consistency for anxiety (α = .86 to .89) and depression (α = .82 to .89).

2.5.3. Emotion Regulation

The Difficulties in Emotion Regulation Scale (DERS) (41) measured emotion regulation difficulties. DERS has 36 items (scored 1-5), summed to derive a total score (36-180). Higher scores represent higher levels of emotion regulation difficulties. DERS has been supported as reliable and valid (41) and has been used in previous research with PWE (32,35). In the current sample, internal consistency was excellent in the TLE group (α = .95).

2.6. Procedure

The survey took approximately 20-25 minutes to complete. Following completion, participants were presented with a debrief sheet including signposts to epilepsy and mental health charities/organisations (Appendix U). Data collection occurred in April and May 2024.

2.7. Data Analysis

Data were analysed using SPSS (version 29.0.2.0). For statistical analyses, appropriate assumptions were checked for each group. This included normality of data (skew and kurtosis), which was met for each measure for each group. No missing data were observed.

For hypothesis 1, one-way independent ANOVAs were used to test between-group differences (TLE, non-TLE, non-epilepsy controls) in overall self-compassion, self-compassion components, anxiety and depression. Levene's test showed the groups had equal variance; therefore, the assumption of homogeneity of variance was met. Post-hoc Bonferroni corrected (α = .017) pairwise independent *t*-tests were conducted for each significant result. Effect sizes were calculated for ANOVAs (Eta Squared η^2) and pairwise comparisons (Cohen's *d*).

For hypothesis 2, two hierarchical linear regressions were conducted (one predicting anxiety, one predicting depression). Preliminary analyses assessed associations between the control variables (sociodemographic and TLE characteristics) and mental health outcomes (anxiety, depression). For categorical variables, independent samples *t*-tests and one-way independent measures ANOVAs were conducted. For continuous variables, Pearson's *r* correlations were conducted. Sociodemographic and TLE characteristics that showed significant associations with anxiety and depression were then entered in step one of a hierarchical regression model (for that outcome), followed by self-compassion components in step two (self-kindness, common humanity, mindfulness). Regression assumptions were satisfied: residuals were independent, normally distributed and demonstrated homoscedasticity, and multicollinearity was assessed as acceptable, with zero-order correlations between predictors within the range of -.9 to .9 and collinearity statistics (tolerance and variance inflation factor) within accepted limits. Adjusted R-squared was used to report explained variance, as it accounts for both

sample size and number of predictors, helping to reduce potential overestimation (42). Cohen's f^2 effect sizes were calculated for each model.

For hypothesis 3, two mediation analyses were conducted (one for anxiety, one for depression). Simple mediation models, using the PROCESS macro (version 4.3) add on for SPSS (43) were used, with self-compassion as the independent variable, anxiety and depression as the dependent variables and emotion regulation difficulties as the mediating variable. Assumptions for mediation analyses were met, including theoretical causal order, linearity, absence of multicollinearity and residuals that were independent, normally distributed and exhibited homoscedasticity. A four-step approach was followed, whereby several regression analyses were conducted, with significance determined at each step (44). The indirect effects were tested using a percentile bootstrap estimation approach with 10,000 samples (45). The proportions mediated by emotion regulation difficulties in the relationships between self-compassion and the mental health outcomes (anxiety, depression) were calculated.

2.8. Power Analysis

An a priori power analysis for ANOVAs, using G*Power (46), indicated a minimum of 252 participants (84 per group) were required for achieving 95% power for detecting a medium effect (f = .25), with .05 as the significance criterion.

For hierarchical regressions, using G*Power, a minimum of 109 participants were needed in the TLE group to have 80% power for detecting a medium effect (f^2

= .15), based on previous research on epilepsy and self-compassion (27,28), with an alpha level of .05 for up to eight predictors. For simple mediation analyses, a minimum of 118 participants were needed in the TLE group to have 80% power for detecting *a* and *b* pathways of medium effects and a *c*' path that is small (.14), within the Baron and Kenny method (44,47).

Therefore, all analyses were well-powered in this study.

3. Results

3.1. Between-Group Comparisons

Descriptive statistics for self-compassion (overall and each component), anxiety and depression are displayed in Table 4.

Table 4

Descriptive Statistics for Self-Compassion, Anxiety and Depression in Each Group

Variable	*M* (*SD*)		
	TLE (*n* = 180)	Non-TLE (*n* = 149)	Non-Epilepsy (*n* = 127)
Self-compassion	2.36 (.77)	2.65 (.86)	3.01 (.67)
Self-kindness	2.20 (.87)	2.55 (.96)	2.93 (.74)
Common humanity	2.51 (.80)	2.78 (.84)	3.11 (.69)
Mindfulness	2.41 (.86)	2.62 (.92)	3.13 (.72)
Anxiety	11.23 (5.60)	9.34 (5.76)	3.83 (3.60)
Depression	12.72 (6.56)	10.32 (6.61)	4.18 (4.14)

Note. TLE = temporal lobe epilepsy.

Significant between-group differences in self-compassion were indicated, $F(2, 453) = 29.69$, $p < .001$, with a large effect size ($\eta^2 = .17$). Post hoc Bonferroni

corrected (α = .017) comparisons indicated that self-compassion was significantly lower in adults with TLE than those with non-TLE (p = .003, d = .36) and non-epilepsy controls (p < .001, d = .90). Self-compassion was also significantly lower in the non-TLE group than non-epilepsy controls (p < .001, d = .47).

For self-compassion components, significant between-group differences with medium effect sizes were indicated for self-kindness, $F(2, 453) = 27.01$, $p < .001$, $\eta^2 = .11$, common humanity, $F(2, 453) = 22.13$, $p < .001$, $\eta^2 = .09$ and mindfulness, $F(2, 453) = 27.97$, $p < .001$, $\eta^2 = .11$. Post hoc Bonferroni corrected (α = .017) comparisons indicated that self-kindness and common humanity followed a similar pattern to overall self-compassion, with adults with TLE having significantly lower self-kindness and common humanity than those with non-TLE (p < .001, d = .38 and p = .007, d = .33 respectively) and non-epilepsy controls (p < .001, d = .90 and p < .001, d = .80 respectively). Self-kindness and common humanity were also significantly lower in the non-TLE group than non-epilepsy controls (self-kindness, p = .001, d = .44; common humanity, p = .001, d = .43). However, although mindfulness was significantly lower in adults with TLE (p < .001, d = .91) and non-TLE (p < .001, d = .62) than non-epilepsy controls, no significant differences were indicated between the epilepsy groups (p = .071, d = .24).

Significant between-group differences in both anxiety, $F(2, 453) = 78.50$, p < .001, and depression, $F(2, 453) = 77.19$, $p < .001$, were indicated, with large effect sizes (anxiety, $\eta^2 = .26$; depression, $\eta^2 = .25$). Post hoc Bonferroni corrected (α = .017) comparisons indicated that both anxiety and depression were significantly higher in adults with TLE than those with non-TLE (anxiety, p = .003, d = .33;

depression, $p = .001$, $d = .36$) and non-epilepsy controls (anxiety, $p < .001$, $d = 1.57$; depression, $p < .001$, $d = 1.56$). Anxiety and depression were also significantly higher in the non-TLE group than non-epilepsy controls (anxiety, $p < .001$, $d = 1.15$; depression, $p < .001$, $d = 1.11$).

3.2. Self-Compassion and Mental Health in Temporal Lobe Epilepsy

3.2.1. Preliminary Analyses

3.2.1.1. Sociodemographic and Epilepsy-Related Variables.

In adults with TLE, preliminary independent samples *t*-tests indicated scores for anxiety and depression were significantly higher in females than males and in those who had experienced a seizure in the previous month compared with those who had not. One-way ANOVAs indicated significant between-group differences in ethnicity for anxiety. Post-hoc Bonferroni corrected ($\alpha = .017$) comparisons indicated anxiety scores were significantly higher in non-white participants than white British and white other participants. Pearson's *r* correlation coefficients indicated that as age increased, anxiety significantly decreased and as time taken to diagnose increased, depression significantly increased. Additionally, as seizure frequency increased, both anxiety and depression significantly increased.

For both anxiety and depression, significant between-group differences or correlations were not indicated for all other sociodemographic and epilepsy-related factors (see Appendix V for all preliminary statistics and *p*-values).

3.2.1.2. Self-Compassion Variables.

Pearson's *r* correlation coefficients for self-compassion components and mental health outcomes (anxiety, depression) are shown in Table 5. All three components of self-compassion (self-kindness, common humanity, mindfulness) were significantly negatively correlated with anxiety and depression.

Table 5

Pearson's Correlation Coefficients (r) Between Self-Compassion Components and Anxiety and Depression in Adults with Temporal Lobe Epilepsy (n = 180)

Self-Compassion Component	Anxiety	Depression
Self-kindness	-.50***	-.54***
Common humanity	-.47***	-.44***
Mindfulness	-.49***	-.53***

Note. ***p < .001 (one-tailed).

3.2.2. Multiple Regression Analyses

For anxiety, the first model was significant and explained 9.8% of the variance in anxiety, $F(5, 174) = 4.91$, $p < .001$, adjusted R-squared = .098, with a small effect size ($f^2 = .14$) (Table 6). The final model, including the self-compassion components, explained significantly more variance than the first model, $F(3, 171) = 18.05$, $p < .001$ (medium effect size, $f^2 = .32$). Overall, the final model explained 30.3% of the variance in anxiety, $F(8, 171) = 10.74$, $p < .001$, adjusted R-squared = .303, with a large effect size ($f^2 = .50$).

For depression, the first model was significant and explained 8.8% of the variance in depression, $F(4, 175) = 5.29$, $p < .001$, adjusted R-squared = .088, with a

small effect size (f^2 = .12). (Table 6). The final model, including the self-compassion components, explained significantly more variance than the first model, $F(3, 172)$ = 21.16, p < .001 (large effect size, f^2 = .37). Overall, the final model explained 32.2% of the variance in depression, $F(7, 172)$ = 13.14, p < .001, adjusted R-squared = .322, with a large effect size (f^2 = .53).

In the final models, self-kindness was the only independent predictor to retain significance for anxiety (β = - .25, p = .023) and depression (β = - .28, p = .008), with higher self-kindness predicting lower anxiety and depression.

Table 6

Hierarchical Linear Regressions Predicting Anxiety and Depression from Sociodemographics, Epilepsy-Related Factors and Self-Compassion Components in Adults with Temporal Lobe Epilepsy (n = 180)

Variable	Anxiety						Depression					
	B	***SE B***	**β**	R^2 ΔR^2	Adj. R^2	***F*** **Δ*F***	***B***	***SE B***	**β**	R^2 ΔR^2	Adj. R^2	***F*** **Δ*F***
Step One				.124	.098	4.91***				.108	.088	5.29***
				.124		4.91***				.108		5.29***
Age	-.08	.04	-.17*				-	-	-			
Gender	2.16	1.15	.14				2.65	1.30	.15*			
Ethnicity	-1.49	1.19	-.09				-	-	-			
Time taken to diagnose	-	-	-				.20	.11	.13			
Seizure frequency	.03	.01	.16*				.03	.02	.16*			
Time since most recent seizure	-1.88	.82	-.17*				-2.11	.96	-.16*			
Step Two				.334	.303	10.74***				.348	.322	13.14***
				.221		18.05***				.240		21.16***
Age	-.06	.03	-.12				-	-	-			
Gender	.38	1.05	.02				.17	1.17	.01			
Ethnicity	-1.73	1.06	-.10				-	-	-			
Time taken to diagnose	-	-	-				.11	.10	-.07			
Seizure frequency	.02	.01	.09				.02	.01	.10			

Variable	Anxiety						Depression					
	B	***SE B***	**β**	R^2 ΔR^2	Adj. R^2	***F*** **Δ*F***	***B***	***SE B***	**β**	R^2 ΔR^2	Adj. R^2	***F*** **Δ*F***
Time since most recent seizure	-1.32	.73	-.12				-1.46	.83	-.11			
Self-kindness	-1.58	.68	-.25*				-2.10	.79	-.28**			
Common humanity	-1.17	.72	-.17				-.56	.83	-.07			
Mindfulness	-.81	.85	-.12				-1.63	.98	-.21			

Note. ***$p < .001$. **$p < .01$, *$p < .05$.

3.2.3. Mediation Analyses

In the TLE sample, the mean total for emotion regulation difficulties was 114.3 (*SD* = 28.5, range = 54-177).

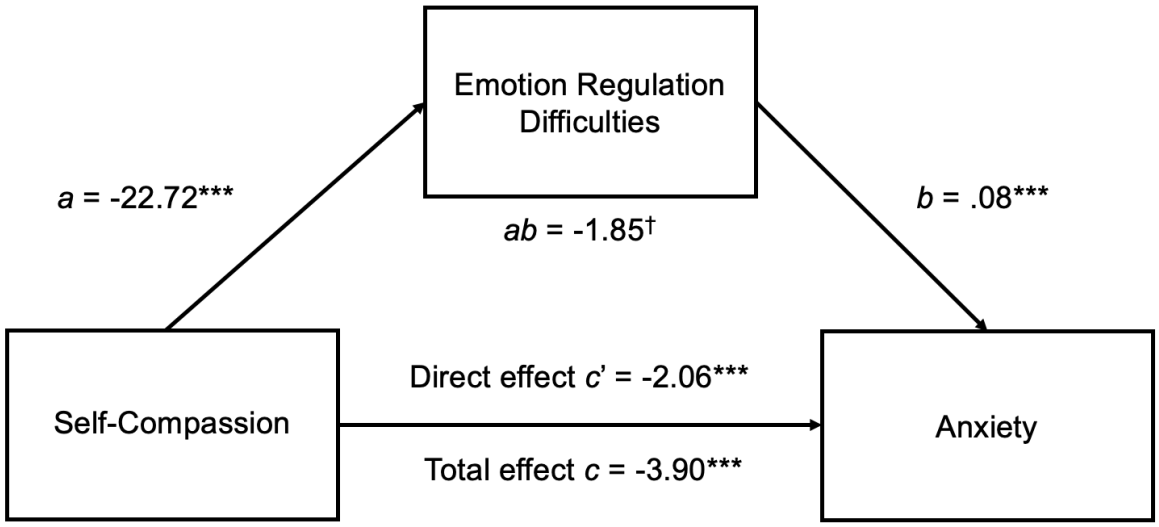
In step one, the total effects (pathway *c*) of self-compassion on anxiety, *b* = -3.90, *t*(178) = -8.51, p < .001, and depression, *b* = -4.72, *t*(178) = -8.91, p < .001, were significant. Therefore, higher self-compassion significantly predicted lower anxiety and depression. In step two, higher self-compassion significantly predicted lower emotion regulation difficulties, *b* = -22.72, *t*(178) = -10.42, *p* < .001 (pathway *a*). In step three, higher levels of emotion regulation difficulties significantly predicted higher anxiety, *b* = .08, *t*(177) = 5.58, *p* < .001, and depression, *b* = .12, *t*(177) = 7.71, *p* < .001, while controlling for self-compassion (pathway *b*).

In step four, the direct effect (unmediated relationship between self-compassion and anxiety and self-compassion and depression, while controlling for emotion regulation difficulties) was significant for both anxiety, *b* = -2.06, *t*(177) = -3.82, *p* < .001, and depression, *b* = -1.95, *t*(177) = -3.35, *p* = .001 (pathway *c*'). Higher self-compassion predicted lower anxiety and depression. Notably, significant negative indirect effects were found for anxiety (-1.85, 95% CI: -2.58 to -.95) and depression (-2.77, 95% CI: -3.76 to -1.91), with confidence intervals entirely below 0 (pathway *ab*). This indicates emotion regulation difficulties partially mediated the relationships between self-compassion and anxiety (Figure 2) and self-compassion and depression (Figure 3). Regarding the proportion mediated, emotion regulation

difficulties accounted for 47.4% of the relationship between self-compassion and anxiety and 58.7% of the relationship between self-compassion and depression.

Figure 2

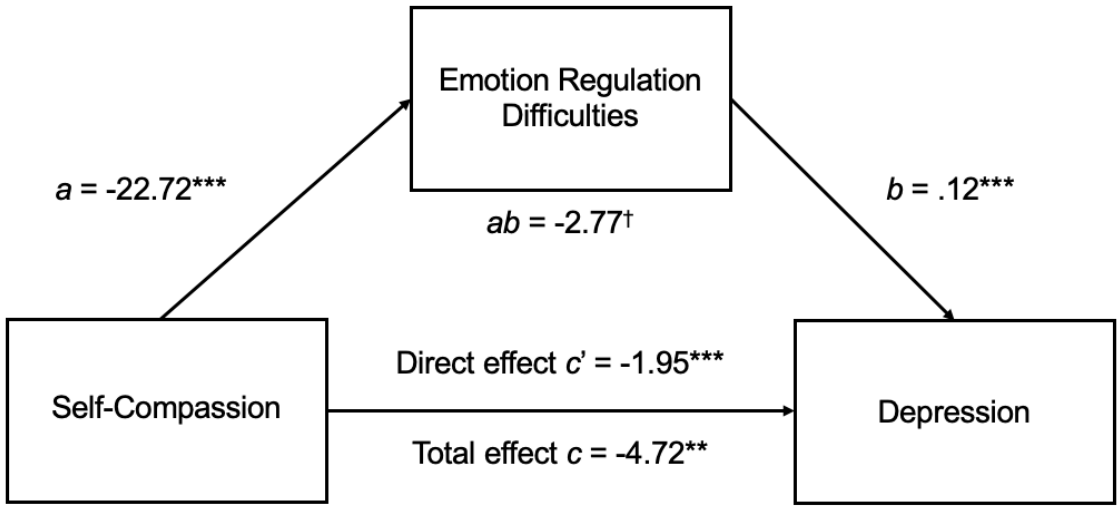
Mediation Model of Relationship Between Self-Compassion, Emotion Regulation Difficulties and Anxiety in Adults with Temporal Lobe Epilepsy (n = 180)



Note. ***p < .001, **p < .01, *p < .05, †significant indirect effect indicated as the 95% confidence intervals did not cross zero (-2.58 to -.95).

Figure 3

Mediation Model of Relationship Between Self-Compassion, Emotion Regulation Difficulties and Depression in Adults with Temporal Lobe Epilepsy (n = 180)



Note. ***p < .001, **p < .01, *p < .05, †significant indirect effect indicated as the 95% confidence intervals did not cross zero (-3.76 to -1.91).

4. Discussion

This study was the first to compare adults with TLE, non-TLE and non-epilepsy controls on self-compassion, anxiety and depression, and investigate the relationships between self-compassion, mental health and emotion regulation in TLE.

Supporting hypothesis 1, overall self-compassion, and components self-kindness and common humanity, were lowest in adults with TLE, followed by non-TLE and then non-epilepsy controls. However, although lower than non-epilepsy controls, mindfulness did not significantly differ between epilepsy groups. While

effect sizes between epilepsy groups were small, this suggests adults with TLE may face additional difficulties with self-kindness and common humanity. Further research exploring such differences is needed. This may include considering the role of other factors that adults with TLE have reported experiencing more than other epilepsy types, such as felt stigma, discrimination and social restrictions (48), and qualitative research exploring their experiences of each self-compassion component.

Consistent with previous research (2,8), anxiety and depression were significantly higher in both epilepsy groups than non-epilepsy controls, with large effect sizes. While effect sizes were small, adults with TLE also had higher anxiety and depression than adults with non-TLE. This may partly reflect neurological differences in adults with TLE (8); however, determining this was beyond the scope of the current study, as no formal neurological assessments were conducted. Additionally, no sociodemographic or epilepsy-related factors remained significant when entered with self-compassion in the hierarchical regression models. Aligned with conclusions from previous reviews (49), this indicates such factors alone are insufficient for explaining anxiety and depression outcomes in epilepsy populations.

Supporting hypothesis 2, and consistent with findings in wider epilepsy populations (28), self-compassion explained additional variance in both anxiety and depression, after controlling for sociodemographic and epilepsy-related factors, with medium to large effect sizes. Notably, self-kindness remained a significant independent predictor of anxiety and depression. Thus, interventions targeting self-compassion, especially self-kindness, may be beneficial.

Current epilepsy clinical guidelines (5) recommend following general population guidance for anxiety (50) and LTC guidance for depression (51). In both, the first-line psychological intervention is cognitive behavioural therapy (CBT). Building on the current findings, investigating the benefits of targeting factors (e.g. self-critical thoughts) which may be maintaining low self-compassion, especially self-kindness, in CBT may be helpful.

Regarding other psychological interventions, compassion-focused therapy (CFT) (52,53), which supports individuals experiencing self-criticism and shame, has shown promise in reducing anxiety and depression in adults with other neurological conditions such as acquired brain injury (54). In adults with LTCs, other compassion-related therapies have also significantly improved mental health outcomes and self-compassion (20), though few have explored effects on specific self-compassion components (e.g. self-kindness). Of these compassion-related therapies, only mindfulness-based interventions have been studied among PWE, finding significant reductions in anxiety and depression (55). Peer support has also been suggested to foster common humanity (56), with PWE reporting benefits such as mutual understanding (57). Therefore, investigating such interventions (e.g. CFT, mindfulness-based interventions, peer support) among adults with TLE could be beneficial.

Extending previous research on self-compassion in PWE and supporting the applicability of Finlay-Jones et al.'s (33) emotion regulation model of self-compassion to adults with TLE, the current findings indicate that self-compassion may foster better mental health by facilitating emotion regulation, with large mediation effects. Although further research into other potential mediators is warranted, particularly as

the mediation was partial, such findings are promising given the organic vulnerability to emotion regulation difficulties in TLE (8,16,17).

Thus far, one non-randomised intervention study in PWE has supported the effectiveness of mindfulness-based stress reduction in significantly improving cognitive emotion regulation strategies and depression compared with a waitlist control group (58). Future research could explore if such effects apply to other interventions for self-compassion in PWE, including TLE, and whether improvements in emotion regulation mediate reductions in anxiety and depression.

4.1. Clinical Implications

The current study highlights the need for mental health provision in PWE, especially TLE. Utilising well-validated mental health screening instruments has been shown to feasibly facilitate the timely identification of mental health needs among PWE (59). Screening levels of self-compassion (and its components) could also help to identify those at risk and, in combination with more formal assessments, determine treatment targets to optimise therapeutic outcomes.

However, the current evidence base for interventions targeting self-compassion and its components, in PWE, including those with TLE, remains limited, highlighting the need for future intervention research.

4.2. Limitations and Future Directions

Despite wide-scale online recruitment, most participants were female, white British and well-educated. Future research should seek more diverse samples to improve generalisability. Additionally, eligibility, including epilepsy diagnosis, was not formally verified, potentially impacting sample validity. To increase sampling rigor, epilepsy services could be involved in future research recruitment. Investigating the role of neurological and cognitive factors through neurological and cognitive testing may also build upon the current findings.

The cross-sectional design of the present study limited causal interpretation of the relationships. Given potential bidirectional links between self-compassion and mental health difficulties (60), future longitudinal studies are warranted to examine causality. Such research could help to refine mental health intervention targets.

5. Conclusion

This study suggests self-compassion is particularly low in adults with TLE and may be important for determining mental health outcomes, partially mediated by emotion regulation. Further investigation using longitudinal methods is needed. Future research evaluating the efficacy of interventions targeting such factors may help tailor psychological support for adults with TLE and inform care pathways.

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Executive Summary/Dissemination Document

Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

Why did we do this study?

Epilepsy is one of the most common neurological conditions worldwide, with temporal lobe epilepsy (TLE) being the most common type. Previous research has shown that people with epilepsy (PWE) are more likely to experience mental health difficulties and those with TLE are at even greater risk of mental health difficulties, such as anxiety and depression, in part due to the area of the brain that is affected. To support people with TLE, it is important to identify factors that can help to protect their mental health.

Self-compassion is often thought of as being made up three main components: self-kindness, common humanity and mindfulness. Self-compassion can be helpful when ongoing difficulties cannot be effectively resolved and therefore need to be adapted to such as long-term health conditions. In previous research, higher levels of self-compassion have been shown to predict lower levels of anxiety and depression in PWE. Previous research also suggests that self-compassion may be protective by fostering better emotion regulation.

Therefore, self-compassion may be a factor that supports mental health, but has not yet been studied in TLE, compared with non-TLE epilepsy types or considered in relation to mental health and emotion regulation.

What were our aims and research questions?

This study aimed to (1) compare adults with: TLE, other types of epilepsy (non-TLE) and no epilepsy (non-epilepsy controls) on measures of self-compassion, anxiety and depression and (2) investigate the relationships between self-compassion, mental health and emotion regulation in TLE.

Therefore, the following three research questions were asked:

1) Do adults with TLE, non-TLE and non-epilepsy differ in levels of self-compassion (and its component), anxiety and depression?
2) In TLE, does self-compassion significantly predict mental health outcomes (anxiety, depression) after controlling for (i.e. taking into account) significant sociodemographic and TLE characteristics?
3) In TLE, does emotion regulation explain the relationships between self-compassion and mental health outcomes (anxiety, depression)?

How was the study carried out?

Three PWE (two TLE, one non-TLE) helped to develop the project. They reviewed the project's plan, forms and the questions we asked. This helped to make sure the project was important and meaningful to the lives that it hopes to impact.

The study had a total of 456 participants, recruited online through epilepsy-related social media pages and 'Epilepsy Action' (UK-based epilepsy charity). All

participants needed to be at least 18 years old and living in the UK. Participants were split into three groups:

(i) 180 participants had a current diagnosis of TLE, forming the TLE group.

(ii) 149 participants had a current diagnosis of any other type of epilepsy, forming the non-TLE group.

(iii) 127 participants had no current or previous diagnosis of epilepsy, forming the non-epilepsy control group.

A cross-sectional (single point in time) design, based on self-reported data, was used. Participants completed an online survey which included questions on:

- A questionnaire gathering background information on sociodemographic factors, such as age, gender and ethnicity.
- A questionnaire gathering background information on epilepsy-related factors, such as seizure frequency and types of treatment.
- A questionnaire assessing symptoms of anxiety.
- A questionnaire assessing symptoms of depression.
- A questionnaire assessing overall self-compassion and its components (self-kindness, common humanity and mindfulness).
- A questionnaire assessing emotion regulation difficulties.

Before the survey, participants consented to take part. After the survey, participants were presented with a debrief sheet which included information about epilepsy and mental health charities where they could access support if needed. The

survey took approximately 20-25 minutes to complete. Participants took part in April and May 2024.

The data were analysed to answer the research questions.

What did the study find?

Between-group differences

We found that, as expected, anxiety and depression levels were highest in adults with TLE, followed by adults with non-TLE and then non-epilepsy-controls.

We also found that overall self-compassion, and components self-kindness and common humanity, were lowest in the TLE group, followed by the non-TLE epilepsy group and then non-epilepsy controls. Mindfulness was lower among epilepsy groups than non-epilepsy controls but did not differ between epilepsy groups.

In adults with TLE

In adults with TLE, higher self-compassion independently predicted lower anxiety and depression, after controlling for significant sociodemographic and epilepsy-related factors. This means those who are more self-compassionate tended to have less anxiety and depression, even after considering factors such as age, gender, ethnicity and information about their epilepsy. Within self-compassion, self-

kindness was found to be particularly important, with higher self-kindness independently predicting lower anxiety and depression.

Emotion regulation was found to partially explain the relationships between self-compassion and anxiety, and self-compassion and depression. This means self-compassion may help adults with TLE to regulate their emotions better, which in turn may reduce anxiety and depression. As emotion regulation only partially explained the relationships, other may also play a role.

How is this relevant for my work?

Clinicians

This study contributes to understanding risk factors for poor mental health among adults with TLE. The findings highlight the need for supporting people with TLE with their mental health. The high levels of anxiety and depression indicate that checking for symptoms of anxiety and depression in people with TLE may be helpful. Similarly, checking levels of self-compassion (and its components) could also help to identify those at risk.

The findings suggest that interventions targeting self-compassion, especially self-kindness, may be beneficial among adults with TLE. This may include compassion-focused therapy, which supports those experiencing shame and self-criticism, and which previous research has shown reduces anxiety and depression in adults with other neurological conditions such as acquired brain injury.

Researchers

Researchers in the field should carry out research to help understand the causal relationships between self-compassion, emotion regulation and mental health difficulties over time (e.g. through longitudinal methods). Investigating the efficacy of interventions which target self-compassion in people with TLE may be beneficial. Such research may help to tailor psychological support for adults with TLE and inform care pathways in the future.

Connecting Reflective Narrative

My three research projects shared a common theme: health, an area of interest I have had since a young age, shaped by my personal experiences with physical health conditions and an awareness of the connections between physical and mental health. My first NHS role was at Great Ormond Street Hospital, where one of my key roles involved supporting the development of a mental health drop-in service to support the psychological needs of patients and their families. Such experiences influenced my DClinPsy projects, with my research interests focusing on supporting people affected by physical health conditions, whether personally or through a loved one. Below, I reflect on each of my three projects.

SRL

I chose to focus my SRL on evaluating acceptance and commitment therapy (ACT) in paediatrics, as it is a widely used approach in clinical health services, an area I hope to continue working in post-training.

Although this was my first time as the primary researcher for a systematic review, I drew on my prior experience assisting with them. This helped me to develop the search strategy, extract the data and conduct the narrative synthesis. However, the Cochrane quality appraisal tools were new to me. Initially, I found their complexity challenging, yet came to appreciate their rigorous and intervention-specific design, recognising that they would ultimately strengthen the credibility of my SRL. I especially enjoyed the process of working together on aspects of the SRL with another trainee (the second coder) and supporting each other throughout.

While synthesising the findings, it struck me how little research there was, despite ACT being a widely used therapeutic approach in paediatric psychology services. This highlighted a gap between clinical practice and research, reinforcing the need for disseminating practice-based evidence, something I plan to do in my future roles.

Having my final-year placement in paediatrics, I have found this SRL particularly valuable in expanding my insight into the application of ACT for this population. I have also joined the ACT special interest group (SIG) on placement. The SIG meetings have been valuable for formulating different cases using ACT principles with experienced and passionate psychologists working within physical health settings. I also shared my SRL findings with the SIG and in paediatric psychology team meetings, further developing my presentation and leadership skills.

SIP

My interest in supporting siblings first developed during my roles in paediatric health settings, where I noticed that siblings were often overlooked compared to patients and parents. Reading the literature reinforced this observation, with inconsistent support for siblings being recognised as a wide-scale issue.

In shaping my SIP, I consulted several teams at Oxford Children's Hospital to better understand current sibling support practices. It was agreed with the Children's Psychological Medicine team that my SIP would be conducted on the paediatric

oncology ward, as the staff recognised sibling support as an unmet need. Focusing on adolescents was prioritised, as the existing support was aimed at younger children.

I was keen to conduct the project directly with siblings, as previous literature had found discrepancies between proxy reports (e.g. parents) and self-reports of sibling experiences. Collaborating with adolescent siblings throughout the development of the SIP was especially rewarding, as their insights helped ensure the project was meaningful to the lives it hopes to impact.

I enjoyed interviewing the siblings and learning about their experiences and perceived needs. Engaging in reflexivity exercises, such as considering positionality and bracketing, was invaluable, especially during reflexive thematic analysis. Balancing conciseness and depth within the word count was challenging, requiring careful selection of quotes to ensure each participant was represented. The longer word limit of the *British Journal of Health Psychology*, where the write-up was later published, allowed for additional quotes in the final article.

During my final-year placement in paediatrics, I have been able to support the service with implementing the recommendations. This process has felt rewarding, and I hope ongoing evaluations will drive further improvements.

TDRP

As a lived experience committee member for the most recent National Institute for Health and Care Excellence (NICE) epilepsy guidelines and a patient representative for the Royal College of Paediatrics and Child Health, I am acutely aware of the widespread recognition among professionals that mental health remains under supported in people with epilepsy (PWE). Among epilepsies, previous literature has shown that people with temporal lobe epilepsy (TLE) are particularly at risk of mental health difficulties, yet little research has focused on this population.

Understanding the roles of psychological factors is crucial for informing interventions. While self-compassion had been significantly associated with mental health outcomes among PWE in previous research, it had not been studied specifically in TLE. This gap shaped the focus of my TDRP. Exploring the role of emotion regulation in the self-compassion and mental health relationship further developed its theoretical underpinnings.

Involving PWE from different backgrounds in the process of developing my TDRP brought my attention to important perspectives. My personal experiences with epilepsy also made it especially valuable to keep a reflexive journal throughout. Both processes helped ensure the project remained relevant to the wider TLE community and not solely shaped through the lens of my own experiences and assumptions. This is a practice I plan to continue throughout my clinical and research career.

While further research using longitudinal methods and evaluating interventions targeting self-compassion in people with TLE is needed, my TDRP contributes to the current understanding of mental health difficulties in this population. I have since presented the findings to local adult neuropsychology teams and at a national neuropsychology conference and had a peer-reviewed paper accepted for publication in *Epilepsy & Behavior*.

Conclusion

Reflecting on training, I am deeply grateful for the research opportunities I have had and proud of the publications I have produced with the support of my supervisors. Looking ahead to my qualified roles, I hope to continue conducting research in collaboration with those with lived/living experience, striving to better understand and support the mental health of people affected by physical health conditions.

Acknowledgments

I would like to express my deepest gratitude to all the participants who gave their time to take part in my research project. I am also sincerely thankful to those with lived/living experience who shaped the direction of this work through their guidance, insights and feedback. Your contributions were invaluable and helped to make sure this research remained relevant and meaningful to the lives it hopes to impact.

Thank you to all of my research supervisors for their guidance and support throughout. Thank you especially to Dr Matt Hotton, for their encouragement, expertise and insightful feedback for all three of my projects. Special thanks to my course tutor, Dr Ciorsdan Anderson, for supporting me across my whole training journey. I will always remember the compassion and kindness you have shown me.

To Abi, Amber, Fran and Tasha, thank you for your support and friendship through every moment of training. I am very proud of us all for getting this far and it has been an honour to share this experience with you. I look forward to our annual weekend trips away together and to witnessing all the incredible things that await you all. Particular thanks to Tasha for your SRL support. I cherished our cosy study days together with Poppy, Casper and Lola.

To my friends, thank you for being my steady foundation. Your unwavering support, love and belief in me have meant so much. Thank you for helping me to maintain balance and keeping me grounded throughout this process. I am truly lucky to have each of you in my life.

Thank you to my tortoise, Fred, and cat, Poppy. Fred, your calm nature and unhurried pace have always reminded me to take life one moment at a time and, quite literally, slow down. Poppy, thank you for being my quiet companion during my final year of training. Your gentle affection, soothing purrs, sleepiness and warm cuddles have brought me so much peace when I have needed it most.

To my wonderful sister, Alice, and soon-to-be brother-in-law, Ivan, thank you for your constant encouragement. The weekends you spent visiting me are among my fondest memories of my time here in Oxford. Finally, thank you to my parents for your love, care and for always believing in me. I'm deeply grateful for everything you have done to help me reach this point. Your support has made this possible.

Appendices

Appendix A: SRL Journal Submission Guide - BMC Pediatrics

Aims and scope

BMC Pediatrics is an open access journal publishing peer-reviewed research articles in all aspects of health care in neonates, children and adolescents, as well as related molecular genetics, pathophysiology, and epidemiology.

The journal accepts the following article types:

- Research article
- Database article
- Software article
- Case report
- Study protocol
- Review
- Matters arising
- Comment
- Systematic review

Systematic review

Registration of systematic reviews

BMC Pediatrics strongly encourages that all datasets on which the conclusions of the paper rely should be available to readers. We encourage authors to ensure that their datasets are either deposited in publicly available repositories (where available and appropriate) or presented in the main manuscript or additional supporting files whenever possible.

Preparing your manuscript

The information below details the section headings that you should include in your manuscript and what information should be within each section.

Please note that your manuscript must include a 'Declarations' section.

Title page

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract.

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

Introduction: the context and purpose of the study.
Methods: how the study was performed and statistical tests used.
Results: the main findings.
Conclusion: brief summary and potential implications.

Trial registration: If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

Introduction

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

Methods

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

Results

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

Discussion

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

Conclusion

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

References

Vancouver reference style.

Tables and Figures

Please include all Table and Figures in the main manuscript.

Quick points

- Use double line spacing
- Include line and page numbering
- Use SI units: Please ensure that all special characters used are embedded in the text, otherwise they will be lost during conversion to PDF
- Do not use page breaks in your manuscript

File formats

The following word processor file formats are acceptable for the main manuscript document:

- Microsoft word (DOC, DOCX)
- Rich text format (RTF)
- TeX/LaTeX

Please note: editable files are required for processing in production. If your manuscript contains any non-editable files (such as PDFs) you will be required to re-submit an editable file when you submit your revised manuscript, or after editorial acceptance in case no revision is necessary.

Appendix B: SRL Preferred Reporting Items for Systematic review and Meta-Analysis (PRISMA) 2020 (36) Checklist with Synthesis Without Meta-analysis (SWiM) 2019 (40) Reporting Items

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 11.
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Pages 12-13.
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Pages 14-16.
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Pages 16-17.
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Pages 18-19 including Table 1.
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 17.
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Page 18 and Appendix C.
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 20.
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Pages 20-21 and Appendix D.
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Pages 20-21 and Appendix D.
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Pages 20-21 and Appendix D.
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if	Pages 21-22.

Section and Topic	Item #	Checklist item	Location where item is reported
		applicable, details of automation tools used in the process.	
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Page 21.
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 21.
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Page 21.
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 21.
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Pages 20-21.
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Page 21.
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A - see item 15.
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Page 21.
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A - not formally conducted, due to substantial clinical and methodological heterogeneity and large number of outcomes across different long-term physical health conditions. Thus, certainty of evidence grading was unlikely to be meaningful, in line with SWiM guidance which recognises this assessment may not always be suitable/applicable.
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Pages 22-23 including Figure 1.
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1.
Study	17	Cite each included study and present its characteristics.	Pages 24-35 including Tables

Section and Topic	Item #	Checklist item	Location where item is reported
characteristics			2 and 3.
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Pages 36-39, including Figure 2, and Appendix E.
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Pages 40-60 including Tables 4, 5, 6, 7 and 8.
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Pages 40-60 including Tables 4, 5, 6, 7 and 8.
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Pages 40-60 including Tables 4, 5, 6, 7 and 8.
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Pages 40-60 including Tables 4, 5, 6, 7 and 8.
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A - see item 15.
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	Page 30.
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A - see item 15.
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Pages 61-63.
	23b	Discuss any limitations of the evidence included in the review.	Pages 64-65.
	23c	Discuss any limitations of the review processes used.	Pages 64-65.
	23d	Discuss implications of the results for practice, policy, and future research.	Pages 65-66.
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Pages 10-17.
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Pages 10-17.
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Page 21.
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 67.
Competing interests	26	Declare any competing interests of review authors.	Page 67.

Section and Topic	Item #	Checklist item	Location where item is reported
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Template data collection form(s). Data extracted from included studies presented in systematic review.

SWiM is intended to complement and be used as an extension to PRISMA		
SWiM reporting item	**Item description**	**Page in manuscript where item is reported**
1 Grouping studies for synthesis	1a) Provide a description of, and rationale for, the groups used in the synthesis (e.g., groupings of populations, interventions, outcomes, study design)	Page 21.
	1b) Detail and provide rationale for any changes made subsequent to the protocol in the groups used in the synthesis	N/A - no changes made to grouping(s).
2 Describe the standardised metric and transformation methods used	Describe the standardised metric for each outcome. Explain why the metric(s) was chosen, and describe any methods used to transform the intervention effects, as reported in the study, to the standardised metric, citing any methodological guidance consulted	Page 21.
3 Describe the synthesis methods	Describe and justify the methods used to synthesise the effects for each outcome when it was not possible to undertake a meta-analysis of effect estimates	Pages 20-21.
4 Criteria used to prioritise results for summary and synthesis	Where applicable, provide the criteria used, with supporting justification, to select the particular studies, or a particular study, for the main synthesis or to draw conclusions from the synthesis (e.g., based on study design, risk of bias assessments, directness in relation to the review question)	Pages 21-22.
5 Investigation of heterogeneity in reported effects	State the method(s) used to examine heterogeneity in reported effects when it was not possible to undertake a meta-analysis of effect estimates and its extensions to investigate heterogeneity	Page 21.
6 Certainty of evidence	Describe the methods used to assess certainty of the synthesis findings	N/A - not formally conducted, due to substantial clinical and methodological heterogeneity and large number of outcomes across different long-term physical health conditions. Thus, certainty of evidence

SWiM is intended to complement and be used as an extension to PRISMA		
SWiM reporting item	**Item description**	**Page in manuscript where item is reported**
		grading was unlikely to be meaningful, in line with SWiM guidance which recognises this assessment may not always be suitable/applicable.
7 Data presentation methods	Describe the graphical and tabular methods used to present the effects (e.g., tables, forest plots, harvest plots). Specify key study characteristics (e.g., study design, risk of bias) used to order the studies, in the text and any tables or graphs, clearly referencing the studies included	Page 21.
8 Reporting results	For each comparison and outcome, provide a description of the synthesised findings, and the certainty of the findings. Describe the result in language that is consistent with the question the synthesis addresses, and indicate which studies contribute to the synthesis	Pages 40-60 including Tables 4, 5, 6, 7 and 8.
Discussion		
9 Limitations of the synthesis	Report the limitations of the synthesis methods used and/or the groupings used in the synthesis, and how these affect the conclusions that can be drawn in relation to the original review question	Page 64-65.

Appendix C: SRL Search Strategy

CINAHL (EBSCO)

1	TI (Child* OR Adolescen* OR Teen* OR youth* OR young* OR juvenile* OR paediatric* OR pediatric* OR Boy* OR Girl* OR Schoolchild* OR Minor* OR "Under 18")
2	AB (Child* OR Adolescen* OR Teen* OR youth* OR young* OR juvenile* OR paediatric* OR pediatric* OR Boy* OR Girl* OR Schoolchild* OR Minor* OR "Under 18")
3	1 or 2
4	TI ("acceptance and commitment therapy" OR "DNA-V" OR "Discoverer Noticer Advisor?Values" OR "psychological flexibility")
5	AB ("acceptance and commitment therapy" OR "DNA-V" OR "Discoverer Noticer Advisor?Values" OR "psychological flexibility")
6	4 or 5
7	3 and 6

Cochrane Library

1	Title Abstract Keyword (Child* or Adolescen* or Teen* or youth* or young* or juvenile* or paediatric* or pediatric* or Boy* or Girl* or Schoolchild* or Minor* or "Under 18")
2	Title Abstract Keyword ("acceptance and commitment therapy" or "DNA-V" or "Discoverer Noticer Advisor?Values" or "psychological flexibility")
3	1 and 2

Embase (Ovid)

1	(Child* or Adolescen* or Teen* or youth* or young* or juvenile* or paediatric* or pediatric* or Boy* or Girl* or Schoolchild* or Minor* or "Under 18").ti,ab,kf.
2	("acceptance and commitment therapy" or "DNA-V" or "Discoverer Noticer Advisor?Values" or "psychological flexibility").ti,ab,kf.
3	1 and 2

MEDLINE (Ovid)

1	(Child* or Adolescen* or Teen* or youth* or young* or juvenile* or paediatric* or pediatric* or Boy* or Girl* or Schoolchild* or Minor* or "Under 18").ti,ab,kf.

2 ("acceptance and commitment therapy" or "DNA-V" or "Discoverer Noticer Advisor?Values" or "psychological flexibility").ti,ab,kf.
3 1 and 2

PsycInfo (Ovid)

1 (Child* or Adolescen* or Teen* or youth* or young* or juvenile* or paediatric* or pediatric* or Boy* or Girl* or Schoolchild* or Minor* or "Under 18").ti,ab,kf.
2 ("acceptance and commitment therapy" or "DNA-V" or "Discoverer Noticer Advisor?Values" or "psychological flexibility").ti,ab,kf.
3 1 and 2

Appendix D: SRL Data Extraction Form



Data collection form

Intervention review – RCTs and non-RCTs

This form can be used as a guide for developing your own data extraction form. Sections can be expanded and added, and irrelevant sections can be removed. It is difficult to design a single form that meets the needs of all reviews, so it is important to consider carefully the information you need to collect, and design your form accordingly. Information included on this form should be comprehensive, and may be used in the text of your review, 'Characteristics of included studies' table, risk of bias assessment, and statistical analysis.

Notes on using data extraction form:

- Be consistent in the order and style you use to describe the information for each report.
- Record any missing information as unclear or not described, to make it clear that the information was not found in the study report(s), not that you forgot to extract it.
- Include any instructions and decision rules on the data collection form, or in an accompanying document. It is important to practice using the form and give training to any other authors using the form.

Modified for use by Rachel Batchelor for *Acceptance and Commitment Therapy for Psychosocial Outcomes in Children and Young People with Long-Term Physical Health Conditions: A Systematic Review of Intervention Studies*.

1.General Information

Date form completed *(dd/mm/yyyy)*	
Name of person extracting data	
Reference citation	
Report title	
Report authors	
Report author contact details	
Publication type	
Study funding sources *(including role of funders)*	
Possible conflicts of interest *(for study authors)*	
Notes:	

2. Characteristics of included studies

2.1. Methods

	Descriptions as stated in report/paper		Location in text or source
Aim(s) of study *(primary and secondary)*			
Design *(e.g. RCT, non-RCT)*			
Follow-up time points *(yes – specify how many and when – or no)*			
Start date			
End date			
Duration of participation *(from recruitment to last follow-up)*			
Ethical approval needed/ obtained for study	☐ Yes ☐ No ☐ Unclear		
Notes:			

2.2. Participants (Characteristics of Children and Young People)

	Description *Include comparative information for each intervention or comparison group if available*	Location in text or source
Population description *(from which study participants are drawn)*		
Long-term physical health condition(s)		
Country		
Setting *(including location and social context)*		
Inclusion criteria		
Exclusion criteria		

Method of recruitment of participants *(e.g. phone, mail, clinic patients)*		
Informed consent obtained	☐ Yes ☐ No ☐ Unclear	
Total number randomised *(or total number at start for non-RCTs)*		
Clusters *(if applicable, number, type, number people per cluster)*		
Baseline imbalances *(e.g. age, gender, size of groups)*		
Withdrawals and exclusions *(if not provided below by outcome)*		
Age of children and young people *(mean, standard deviation, range)*		
Gender of children and young people		
Race/Ethnicity		
Other relevant sociodemographics		
Subgroups measure		
Subgroups reported		
Notes:		

2.3. Intervention groups

Intervention Group 1 copy and paste for other intervention groups if necessary

	Description as stated in report/paper	Location in text or source
Name of intervention		
Method of group allocation *(e.g. randomised, naturalistic)*		
Number of participants in group		
Theoretical basis of intervention *(include key references)*		
Description of contents *(e.g. core processes of psychological flexibility covered, parental involvement)*		
Delivery structure and dose *(e.g. duration of intervention, frequency of sessions, number of sessions, length of sessions)*		
Delivery format *(e.g. individual, group)*		
Delivery method *(e.g. face-to-face, online)*		
Providers/facilitators *(e.g. profession, training, ethnicity etc. if relevant)*		
Co-interventions		
Fidelity to intervention *(is each component of intervention being delivered in a comparable manner to all study participants over time?)*		
Compliance *(number of people who dropped out and at what stage)*		
Adverse events		

Notes:

Control Group 1 copy and paste for other control groups if necessary

	Description as stated in report/paper	Location in text or source
Type of control group *(e.g. active intervention [specify what], treatment-as-usual [specify what], no intervention, waiting list, other - specify)*		
Method of group allocation *(e.g. randomised, naturalistic)*		
Number of participants in group		
Theoretical basis of control intervention *(if relevant)*		
Description of control intervention *(if relevant, include sufficient detail for replication including contents, delivery structure and dose, delivery format, delivery method and provides/facilitators)*		
Notes:		

2.4. Outcomes

Note: Only extract psychosocial outcomes completed by children and young people (self-reported)

Copy and paste table for each outcome.

Psychosocial outcome

	Description as stated in report/paper		Location in text or source
Outcome name			
Time points measured *(specify whether from start or end of intervention)*			
Time points reported			
Outcome definition *(with diagnostic criteria if relevant)*			
Person measuring/ reporting			
Unit of measurement *(if relevant)*			
Scales: upper and lower limits *(indicate whether high or low score is good)*			
Is outcome/tool validated?	☐ Yes ☐ No ☐ Unclear		
Imputation of missing data *(e.g. assumptions made for ITT analysis)*			
Notes:			

3. Data and analysis

Copy and paste the appropriate table for each outcome, including additional tables for each time point and subgroup as required.

Psychosocial outcome

<table>
<tr><td></td><td colspan="6">Description as stated in report/paper</td><td>Location in text or source</td></tr>
<tr><td>Comparison (groups being compared)</td><td colspan="6"></td><td></td></tr>
<tr><td>Outcome</td><td colspan="6"></td><td></td></tr>
<tr><td>Subgroups (if any)</td><td colspan="6"></td><td></td></tr>
<tr><td>Time point
(specify from start or end of intervention)</td><td colspan="6"></td><td></td></tr>
<tr><td rowspan="2">Results
Mean, SD, number of participants</td><td colspan="3">Intervention (also list other timepoints if needed)</td><td colspan="3">Comparison (also list other timepoints if needed)</td><td rowspan="2"></td></tr>
<tr><td>Pre</td><td>Post</td><td>Follow-up(s)</td><td>Pre</td><td>Post</td><td>Follow-up(s)</td></tr>
<tr><td>Differences between timepoints
- Pre-post
- Post-FU
- Pre-FU</td><td colspan="6"></td><td></td></tr>
<tr><td>Any other results reported
- Odds ratio
- Assumed risk estimate
- Risk difference
- p-value
- CI
- Power and sample size calculations
- Level of power achieved</td><td colspan="6"></td><td></td></tr>
</table>

Effect size(s) *(reported or calculate, specify if calculated)*		
Missing data - *Number of missing participants and reason* - *How was missing data handled (intention to treat/imputation or exclusion?)*		
Statistical methods used and appropriateness of these *(e.g. adjustment for correlation)*		
Additional analysis *(on factors associated with effects on outcomes e.g. mediation, moderation, etc.)*		
Notes:		

Acceptability

	Description as stated in report/paper	Location in text or source
Measure of acceptability/satisfaction		
Results		
Notes:		

4. Other information

	Description as stated in report/paper	Location in text or source
Other outcomes included in the trial but not relevant for the review		
Economic information *(i.e. intervention cost, changes in other costs as result of intervention)*		
Key conclusions of study authors		
References to other relevant studies		
Correspondence required for further study information *(from whom, what and when)*		
Notes:		

.

Appendix E: SRL Quality Appraisal per Domain

Following RoB-2 and ROBINS-I guidelines (42,43), quality was assessed for each outcome of interest (i.e. CYP-reported psychosocial). As ratings were identical across outcomes within each study, a single set of combined outcome ratings have been presented per study. The effect of interest for the current systematic review was that of assignment to intervention. The quality appraisal for each domain has been summarised below.

RCTs

The overall risk of bias for most RCTs was rated as 'high' (45–51,53). One RCT was rated as having 'some concerns' overall (52). However, this rating should be interpreted with caution, as several domains had insufficient information and were therefore rated as 'some concerns' in accordance with the tool's guidance, which specifies that domain-level ratings cannot be 'no information' (42).

Randomisation

A strength for several RCTs was randomisation, as they reported appropriate methods of sequence generation (random and concealed allocation sequence) and did not indicate substantial baseline imbalance (45–47,51). Five RCTs did not report sufficient information about the randomisation process, rendering their rating as 'some concerns' (48–50,52,53).

Deviations from Interventions

An area of weakness for most RCTs was deviations from interventions. In all RCTs, participants and facilitators were aware of assigned interventions. No deviations from the intended intervention were indicated, although one RCT did not provide any information about the intervention content (52). All but two RCTs, one which indicated no dropouts (52) and one which used intention-to-treat analyses (46), did not include all randomised participants in the analyses; this meant they were rated as high for part two of, and consequently overall for, this domain.

Missing Outcome Data

Ratings for missing outcome data were mixed. Apart from one RCT which indicated no dropouts (52), dropout rates were high for most RCTs, varying between 7.14% and 37.5% from randomisation to final data collection point. Of the five RCTs that provided dropout reasons, two RCTs indicated non-health related reasons (50,53). Of the remaining three RCTs, two indicated 5% or less of dropouts were due to health-related reasons (48,49). The third indicated that over 20% of dropouts were due to health-related reasons and dropout rates differed between groups (45). In those that did not provide reasons, dropout rates were similar between groups (46,47,51).

Measurement of Outcome

Another area of weakness was measurement of outcome. While all RCTs had appropriate methods of outcome measurement, comparable between the groups, all outcomes were self-reported (as required for inclusion eligibility). This meant the outcome assessors were the participants and therefore were aware of the intervention received and were potentially influenced by this. The control groups were TAU or NI for all but four RCTs (45,50,52,53), making it more likely that the outcome may have been influenced by the intervention received.

Selection of Results

Three RCTs (47,50,51) were pre-registered, yet did not have pre-specified analysis plan in such registrations. Therefore, for all RCTs, there was no information on whether the result being assessed is likely to have been selected, based on the results, from multiple eligible outcome measurements (e.g. scales, definitions, time points) within the outcome domain and from multiple eligible analyses of the data, therefore fitting with the criteria for some concerns.

Non-RCTs

The overall risk of bias for non-RCTs were rated as ‘serious’, indicating ‘important problems’ (43). However, without the ‘measurement of outcome’ domain, which was rated as serious for all non-RCTs due to self-reported psychosocial measures being used (as required for inclusion eligibility), two non-RCTs would be

rated as ‘moderate’ (57,58), indicating they provide sound evidence for a non-RCT but cannot be considered comparable to a well performed randomised trial (43).

Confounding

One of the greatest areas of weakness of the included non-RCTs was the potential for confounding. Only two non-RCTs controlled for potential confounders in the analyses (57,58). The remaining non-RCTs were rated as serious rather than critical, as the exclusion criteria of all non-RCTs removed the risks of some confounders.

Selection of Participants

Considering strengths of the non-RCTs, selection of participants into all non-RCTs were not based on participant characteristics observed after the start of the intervention. It was indicated that the start of the intervention coincided for most participants and the follow-up(s) coincided for most participants in all but one non-RCT. In one non-RCT (60), the four-month follow-up was completed by participants between 17-25 weeks post intervention, with 64% not completed within the two-week timeframe.

Identification Classification

For most non-RCTs, intervention groups were well defined. One did not provide information about the intervention was not in English (56).

Deviations from Interventions

For most non-RCTs, no deviations from the intended intervention beyond what would be expected in usual practice were indicated. There was not sufficient information to assess this in one non-RCT, as information about the intervention was not in English (56).

Missing Outcome Data

Two non-RCTs (56,61) indicated no, or below 5%, dropouts or missing outcome data and were therefore rated as low for this domain. In the remaining non-RCTs, rates of dropout and missing data ranged from 14.3% to 42.8%. As none of these non-RCTs had control groups, determining the similarity of proportions of and reasons for missing data across groups was not relevant. However, no non-RCTs provided dropout reasons, meaning there was insufficient evidence to rule out bias from missing outcome data, resulting in moderate ratings.

Measurement of Outcome

Although methods of outcome assessment were comparable across groups and systematic measurement errors related to intervention status were not indicated, all non-RCTs were rated as serious, as outcome measures were self-reported, and therefore subjective, and assessors were aware of the intervention received by participants (i.e. not blinded).

Selection of Results

Regarding the selection of the reported results, only one non-RCT (60), specified in a pre-registered protocol that follow-up data would be gathered at four months and one-year post-intervention. However, the four-month data was gathered 17-25 weeks post-intervention and the one-year follow-up data was not mentioned at all in the reports, indicating potential selective reporting. Although most other non-RCTs were internally consistent across the methods and results, they did not have pre-registered protocol or a-prioi statistical analysis plan, meaning there was insufficient information to ascertain whether selective reporting may have occurred).

Appendix F: SIP Published Article in British Journal of Health Psychology

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ARTICLE

"We are here too": Experiences and perceived support needs of adolescent siblings of Paediatric oncology inpatients

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Abstract

Background: Adolescent siblings of children and young people (CYP) with cancer are at increased risk of psychosocial difficulties, yet many remain overlooked and unsupported. This project aimed to explore the experiences and perceived needs of adolescent siblings of paediatric oncology inpatients to inform service improvement recommendations for sibling support.

Methods: Semi-structured interviews were conducted with 10 siblings of CYP previously admitted to a paediatric oncology ward. Interviews were transcribed verbatim and analysed using reflexive thematic analysis. The findings were reviewed in consultation with staff and used to identify pragmatic/feasible recommendations for improving sibling support, organized using the three-tier 'Pediatric Psychosocial Preventative Health Model' (PPPHM; Families, Systems & Health, 2006, 24, 381).

Results: An overarching narrative of siblings wanting to feel part of the cancer journey was found, including their family's experience on the ward, with three key themes: (i) "what about me?": overlooked and unseen, (ii) "always changing, never knowing": the challenge of uncertainty and (iii) "let me be part of it all": togetherness, communication and connection. These findings informed sibling support recommendations. Such recommendations included providing psychosocial screening, resources and opportunities for family time/communication and developmentally appropriate information to all siblings (universal support), monitoring psychosocial difficulties, siblings having someone to talk to and fostering family and peer connection

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for siblings requiring additional support (targeted support) and offering one-to-one psychological support and family therapy for persistent and/or escalating distress (clinical/treatment support).
Conclusions: Based on the experiences of siblings, a range of sibling support recommendations have been identified. Implementation and evaluation of these recommendations are warranted.

KEYWORDS
adolescents, cancer, hospital, oncology, paediatrics, psychosocial support, siblings

Statement of Contribution

What Is Already Known on this Subject?

- Adolescent siblings of hospitalized children with cancer are at greater risk of psychosocial difficulties.
- The needs of siblings of children with cancer are often unmet, with support being inconsistent.
- Improving resources and perceptions can help families to manage stressors.

What Does this Study Add?

- This qualitative study explores the experiences and perceived support needs of adolescent siblings on a paediatric oncology ward to inform service improvement recommendations for sibling support.
- An overarching narrative was found of siblings wanting to feel part of their family's experience on the ward.
- Organized using the three-tier 'Pediatric Psychosocial Preventative Health Model' (PPPHM; Kazak, 2006), recommendations are made to improve support for adolescent siblings on paediatric oncology wards, including screening for psychosocial difficulties, providing developmentally appropriate information and fostering family and peer connection.

BACKGROUND

Approximately 1800 children and young people (CYP) aged 0–14 years old are diagnosed with cancer in the UK each year (Cancer Research UK, 2021b). Whilst survival rates are improving, a growing evidence base has drawn attention to adverse short- and long-term psychosocial impacts experienced by CYP with cancer (Duran et al., 2020; Osmani et al., 2023). Such impacts of childhood cancer extend beyond the unwell child, affecting the daily routines and emotional balance of the wider family (Bates et al., 2021; Mu et al., 2015). Clinical guidelines acknowledge the importance of assessing and supporting the psychosocial needs of family members (National Institute for Health and Care Excellence [NICE], 2014). Additionally, the standards for the psychosocial care of children with cancer and their families proposed by Wiener et al. (2015) include a sibling psychosocial standard of care which, based on evidence, strongly recommends psychosocial services for siblings of CYP with cancer (Gerhardt et al., 2015). However,

compared with CYP with cancer and their parents, siblings have remained largely overlooked, with support being inconsistent and needs often unmet (Davis, Alderfer, et al., 2023; Davis, Brosnan, et al., 2023).

Sibling relationships are characteristically distinct, often sharing a unique history and holding the potential for greater longevity than parental, spousal and peer relationships (Cicirelli, 2013; Noller, 2005). Siblings of CYP with cancer have been found to face increased risks of psychosocial difficulties, including anxiety, depression, posttraumatic stress symptoms and loneliness (Alderfer et al., 2010; Houtzager, 2004). Hospitalization can bring additional challenges to siblings, including routine disruptions, family separation and role adjustments (Niinomi & Fukui, 2022; Prchal & Landolt, 2012). Psychosocial difficulties have also been shown to intensify during hospitalizations, such as anxiety surrounding their unwell sibling's health (Nabors & Liddle, 2017).

Adolescent siblings of CYP with cancer have been found to experience more distress than younger siblings (Cordaro et al., 2012), yet little is known about their experiences of having a sibling in the hospital. Additionally, childhood cancer studies often combine siblings of diverse developmental stages (e.g. from young childhood to older adolescents) within the same sample, without specific consideration of the impact of the experience on each stage (Wilkins & Woodgate, 2005). Many have also used proxy informants, predominantly parents, despite known discrepancies between proxy and self-reports (Pariseau et al., 2020; Paul et al., 2023; Schulte et al., 2016), highlighting the need for gathering perspectives of siblings directly.

Within family contexts, one theoretical model for understanding stress and coping is Hill's (1958) ABC-X model. The model encompasses the elements of (A) stressor(s), (B) resources to cope with the stressor(s), (C) perceptions of the stressor(s), and (X) resulting level or likelihood of stress or crisis. The ABC-X model posits that B and C determine if stressor(s) in category A result in crisis (greater levels of stress than the individual/family feel able to manage). For siblings of CYP with cancer, common stressors (A) may include diagnosis, bereavement and hospitalization; resources (B) evaluated as helpful include developmentally appropriate information, family support and peer support; and perceptions (C) that may be important include those surrounding the cancer, prognosis, family cohesion and their role (Batchelor, 2019; Incledon et al., 2015; Long et al., 2018; Zegaczewski et al., 2016). Therefore, supporting adolescent siblings of CYP with cancer with their resources and perceptions is important. One specific stressor for adolescent siblings that has not been sufficiently investigated is hospitalization of the CYP with cancer.

Understanding the experiences and perspectives of adolescent siblings of paediatric oncology inpatients could inform the development of practical service improvement recommendations to support with resources and perceptions and consequently foster psychosocial adjustment. With input from ward and oncology staff, such recommendations could then be organized using the 'Pediatric Psychosocial Preventative Health Model' (PPPHM; Kazak, 2006). The PPPHM outlines screening all families for indicators of higher psychosocial risks and then uses three tiers to guide support dependent on their level of need; 'universal' support available to all; 'targeted' additional support specific to needs and 'clinical/support' support for persistent and/or escalating distress. Therefore, considering feasibility, by providing low-intensity resources (i.e. universally), fewer require more intensive support, as the psychosocial needs of more siblings can be met.

Aims and key questions

This project aimed to identify the experiences and support needs of adolescent siblings when the CYP with cancer is on a paediatric oncology ward. Such findings could then inform the development of service improvement recommendations. Our two main improvement questions were:

1. What are the experiences and perceived needs of adolescent siblings of CYP during an inpatient stay for cancer?
2. What changes could be made to better support adolescent siblings of CYP on a paediatric oncology ward?

METHODS

Participants

The purposive sampling method was used with emails/letters, recruitment posters, and word-of-mouth to recruit adolescent siblings of CYP who had been admitted to a paediatric oncology ward.

The paediatric oncology ward being studied is based in the United Kingdom and has 13 beds for 0-16-year-olds. Sibling support is currently limited. For example, activity days for siblings are infrequently accessed, especially by adolescents. Due to limited service provision, one-to-one psychological support is only offered in a minority of cases when families are extremely struggling (i.e. already reached crisis).

Eligibility criteria were (i) aged 11–16 years old and (ii) had a sibling who had stayed on the ward for at least 1 week in the previous 6 months. This ensured there had been a substantial inpatient stay since 17th May 2023, when siblings were allowed back on the ward following visiting restrictions imposed due to COVID-19.

To minimize risks of distress, siblings were excluded from taking part if their sibling with cancer, or any other immediate family member with cancer, was currently an inpatient in any ward/hospital or receiving palliative care. Siblings were also excluded if their sibling with cancer had died, as support needs may differ among bereaved siblings (Foster et al., 2012; Ridley & Frache, 2020). Hospital staff screened families for eligibility. No siblings dropped out of the study following recruitment.

Ten siblings, all from different families, took part. To contextualize the data, background information was gathered for participating siblings (Table 1). Most siblings were White British, full siblings (of their sibling with cancer) and from nuclear families. Siblings were equally split in gender and position in the family (i.e. older, younger) compared to their sibling with cancer. Eight of the participating siblings had visited their sibling with cancer on the ward; two had not due to the distance of the hospital from home.

Demographic and cancer-related characteristics of their sibling with cancer were also gathered (Table 2). Most were White British and 60% were male. They covered a range of current ages, ages at diagnosis and types of common childhood/teenage cancer (Cancer Research UK, 2021a).

Lived/living experience involvement

In line with participatory research methodologies (Montreuil et al., 2021; Vaughn & Jacquez, 2020), three siblings (2 females, 1 male; aged 11–16 years-old) were involved in developing the study. The study development period occurred prior to the recruitment period. Siblings were chosen who fit the eligibility criteria at the time of development (i.e. their sibling had been on the ward in the prior 6 months) but would likely not during the time of recruitment (as it would have been longer than 6 months since their sibling's latest ward admission). Therefore, the siblings who were involved in the development of the project were not the same siblings as those who participated.

The lived/living experience involvement included developing the main aims, interview schedule and project materials. Efforts were made (e.g. inclusive language, graphics representing different young people) to ensure the materials and questions were understandable, representative and applicable to a diverse range of siblings (e.g. age, gender, ethnicity, cancer type). They were offered payment in accordance with the service policy.

Procedure

Due to being focused on evaluating sibling experiences on a specific ward only, this project was registered as a service evaluation under the National Health Service Trust where it was conducted, with

TABLE 1 Demographic and family-related information of sibling participants.

Characteristic	Sibling without cancer ($N=10$)
Age, mean (standard deviation; range)	14.10 (1.79; 11–16)
Age when a sibling was first diagnosed with cancer, mean (standard deviation; range)	11.80 (1.99; 9–14)
Gender	
Female	5
Male	5
Ethnicity, *n*	
White British	6
White Irish	1
White, Other	1
Black British	1
Chinese	1
Position in family (compared to sibling with cancer)	
Older	5
Younger	5
Number of siblings	
One	5
Two	4
Three	1
Relationship (to sibling with cancer)	
Full sibling	8
Half-sibling	1
Stepsibling	1
Family composition	
Nuclear family	7
Single-parent family	2
Stepfamily	1

approval obtained. The relevant clinical governance committee was then informed of the project's completion.

All siblings and their parent(s)/carer(s) were given a project information sheet. Siblings aged 11–15 provided written informed assent, with their parent/carer providing written informed consent, and siblings who were 16 provided their own written informed consent. Consent was rechecked verbally at the start of the interviews.

Semi-structured one-to-one interviews were conducted by RB between December 2023 and March 2024. The interview schedule (see File S1) was informed by previous literature, the ABC-X model (i.e. stressors, resources, perceptions, crisis/coping; Hill, 1958), the clinical experiences of the researchers and the siblings with lived/living experience, as above. Siblings were initially asked some questions about their interests and mapped out their family tree to warm up; they were then asked questions about their experiences as a sibling; and finally, they were asked what might have been helpful/what could be improved about the ward's sibling support. At the end of the interview, siblings were debriefed and signposted to relevant sibling and well-being support.

All interviews were conducted remotely; eight via videoconferencing and two via telephone calls. Interviews were between 33 and 58 minutes in length (mean = 46.50, standard deviation = 7.71).

TABLE 2 Demographic and cancer-related information of the siblings with cancer.

Characteristic	Sibling with cancer (*N* = 10)
Age, mean (standard deviation; range)	11.90 (3.03; 6–16)
Age at cancer diagnosis, mean (standard deviation; range)	9.40 (2.99; 4–14)
Gender	
Male	6
Female	4
Ethnicity, *n*	
White British	6
White Irish	1
White, Other	1
Black British	1
Chinese	1
Type of cancer, *n*	
Acute lymphocytic leukaemia (ALL)	2
Acute myeloid leukaemia (AML)	2
Osteosarcoma	2
Glioblastoma	1
Melanoma	1
Neuroblastoma	1
Wilms tumour (nephroblastoma)	1

Data analysis

Interviews were audio-recorded and stored on an encrypted device and transcribed verbatim, with identifiable information removed prior to analysis. To address Aim 1, inductive reflexive thematic analysis was used, due to its flexibility and common use for exploring themes and patterns in experiential data (Braun & Clarke, 2006, 2019). Inductive coding with an experiential approach was taken. This enabled the experiences, meanings and the reality of siblings to be accessed and unanticipated themes rooted in the data to be explored.

The analysis phases described by Braun and Clarke (2006, 2019) were followed: (1) familiarization with the data by reading and re-reading the transcripts, (2) generating codes, (3) constructing themes, (4) reviewing potential themes, (5) defining and naming themes and (6) producing the report. RB identified initial potential themes and subthemes. These were then reviewed by a second coder (EH), who checked that they reflected the semantic content of the dataset. Any remaining inconsistencies were discussed with a project supervisor (ALD), who had also read through and checked all the transcripts and codes and was involved in discussions about the themes and subthemes over multiple meetings. Following this process, themes and subthemes, and their interrelated links, were then consolidated and defined. Data analysis was conducted using NVivo for Mac (Version 14.23.2; QSR International Pty Ltd., 2023). As data saturation is not an element of reflexive thematic analysis (Braun & Clarke, 2021), we were informed by information power (Malterud et al.,2016).

After finalizing the thematic framework, in May 2024 the findings were presented to staff on the ward and in the wider oncology team. To address Aim 2, the findings were reviewed in consultation with the staff and used to identify pragmatic/feasible support recommendations, organized using the PPPHM (Kazak, 2006) (see File S2 for staff consultation topic guide). Aligned with the wider hospital, the PPPHM is already being worked towards by psychologists within other paediatric specialities.

Author positionality

The researchers (authors) have a mix of clinical and research experience supporting CYP with serious physical illnesses and mental health difficulties and their families. All authors had no prior relationship with the participants. None of the authors have personal/lived experience of having a sibling with paediatric cancer. Professionally, all authors work within the field of psychology; one as an undergraduate psychology student, one as a trainee clinical psychologist and three as qualified clinical psychologists. All authors have previous experience of conducting research with reflexive thematic analysis and position themselves as being passionate about equitable and accessible healthcare for CYP and their families.

To address potential researcher bias, including blind spots, preconceptions and positionality, bracketing exercises (e.g. reflective interviews with colleagues) (Tufford & Newman, 2012) and reflexive journaling (McGrath, 2021; Orange, 2016) were utilized. All authors paid careful attention and regularly reflected on how their perspectives, research interests and experiences might be influencing the process of analysis, interpretation and identification of the siblings' needs and service improvements.

RESULTS

An overarching narrative was found of siblings wanting to feel part of the cancer journey including their family's experience on the ward. Ultimately, siblings sought a sense of belonging, pertaining to involvement and closeness. Such desires to be more involved were woven throughout the main themes and their subthemes. Specifically, three main themes were found describing the experiences and perceived needs of siblings: (i) "what about me?": overlooked and unseen, (ii) "always changing, never knowing": the challenge of uncertainty and (iii) "let me be part of it all": togetherness, communication and connection.

Themes and subthemes are outlined in Figure 1 and summarized below with quotes which have been anonymized to protect confidentiality. In line with thematic analysis guidelines, theme and subtheme frequencies are not reported; instead, guidelines for quantifying language were followed, with 'all' referring to all siblings (or all but one), 'most' referring to more than half and 'some' referring to fewer than half but more than two (Hill et al., 2005).

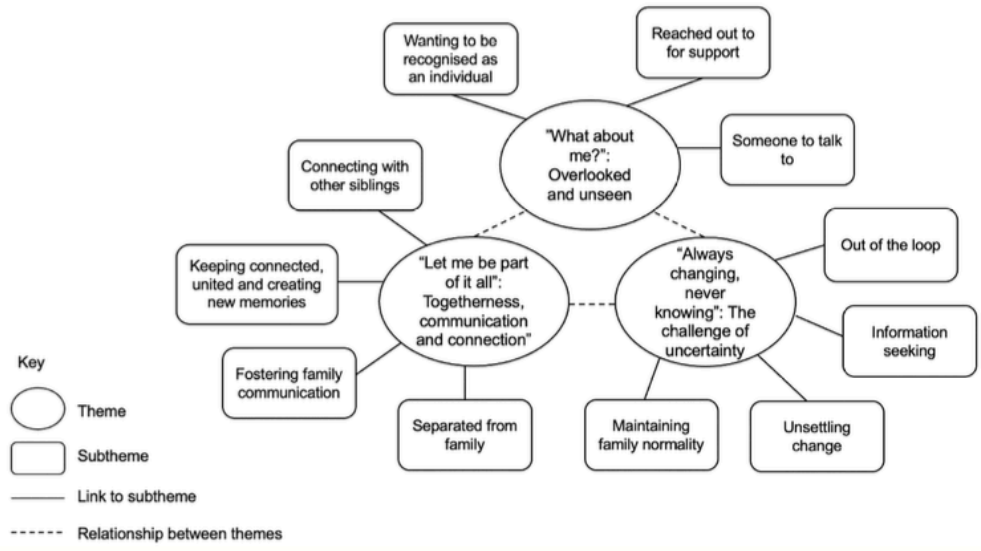

FIGURE 1 Overview of Themes and Subthemes.

Theme 1: "What about me?": Overlooked and unseen

This theme represents siblings feeling invisible and wanting to be reached out to for support. There was a sense of siblings wanting to be included and acknowledged in the context of their sibling's care, whilst also being seen and appreciated as themselves with an identity outside of their sibling's illness. This included having someone in the know outside of the family to talk to, just for them.

Most siblings emphasized wanting to be recognized as an individual. Siblings experienced a tension between understanding their unwell sibling needed more attention whilst also managing the challenges of feeling "*a bit forgotten*" (Adolescent 5) and "*spoken through rather than belonging*" (Adolescent 10) when staff were having conversations with their family. Siblings wanted ward staff to know they existed and notice them when they visited, "*maybe…said hello and stuff, might have made me feel like I mattered too…*" (Adolescent 4). Siblings wanted to feel appreciated as a "*person too*" (Adolescent 2), and be asked about other aspects of their life, by both ward staff and other people in their life, rather than just being known as '[name's] sibling'. Siblings valued areas of their life that did not change and experiences of not being treated differently, for example at school and within friendship groups, "*I liked that time with my friends was similar to before*" (Adolescent 4).

Siblings described a preference of being reached out to for support. They appreciated being made aware of support for siblings, as they valued siblings being "*thought of*" (Adolescent 7) during the hospital stay. Most siblings hoped "*someone would notice that I was actually finding it sort of hard*" (Adolescent 5) and check in with them proactively, rather than needing to go through their parents to access help.

> I never asked for help, but I think if someone had asked me how I was doing, like actually doing honestly, then maybe then I could have got help…rather than needing to ask my parents to see if that was a thing…
>
> (Adolescent 5).

As such, most siblings found it helpful to have, or wanted to have, someone to talk to about their feelings and experiences. Among those who had someone to talk to, this included a school counsellor, a charity counsellor, a nurse on the ward and friends. Most siblings stressed it was important that this person knew the situation, whilst being "*someone separate from the family*" (Adolescent 6). Siblings emphasized that having this support, just for them, could help them to develop coping strategies and foster feelings of kindness and compassion towards themselves through feeling seen and validated.

> Knowing that they were supporting me, as in specifically there for me, could help me to be less hard on myself and show me that my feelings matter too…siblings, we matter too.
>
> (Adolescent 10).

Theme 2: "Always changing, never knowing": The challenge of uncertainty

This theme describes the challenge of uncertainty faced by siblings, due to not knowing about their sibling's health and the ward and the varying changes in their lives. As such, siblings wished to have information shared with them and maintain some normality as a family.

Seeming out of the loop about cancer and treatment compared with the rest of their family, alluding to not being involved in cancer-related conversations, was highlighted as challenging by most siblings; "*no one told me they were going into that hospital…so was a shock and confusing*" (Adolescent 1). There was a sense that "*parents would tell us less, but I think it made us worry more*" (Adolescent 5). Lacking information, some siblings assumed the worst outcomes, based on their limited experience and understanding of cancer and hospitals; for example, "*I just thought they would die even though that was actually not likely at all*" (Adolescent 3); "*I was scared for the worst or that my family would feel a bit broken*

forever" (Adolescent 9); and *"I was worried she would die because when my grandad went to hospital, he then died…*" (Adolescent 4).

Consequently, most siblings described information seeking. This included wanting to "*know what was happening*" (Adolescent 3) *"about the cancer*" (Adolescent 6), including the treatment, hospitalization and prognosis. Such information could help to reduce assumptions by helping "*me to stop imagining stuff or the worst outcomes*" (Adolescent 5) and know "*what to say to others*" (Adolescent 9) when asked about their unwell sibling. One sibling found a book "*about having a brother or sister with cancer*" (Adolescent 7) helpful. Some siblings reflected "*it got easier with time because of knowing what was happening a bit more"* (Adolescent 8). Most siblings also wanted more information about the ward, such as what their room looked like, the staff caring for their sibling and who they could ask their questions to. Suggestions for providing this information included photos, a video such as a virtual tour to help visualize their family there, "*pictures of the ward so we could imagine it before we went there, would have been comforting to know where they were*" (Adolescent 6), and as such feel closer to them. It was noted that information needed to be developmentally appropriate; "*it was hard to understand the words in the letter mum got about it [the ward] so it being written for kids or teenagers like me*" (Adolescent 5). Once they had seen the ward, such benefits were identified, especially as the ward was often described as pleasant and the staff as friendly.

Experiencing unsettling change was described by most siblings. This included changes in routines, the atmosphere at home and seeing their sibling unwell with medical equipment and family members upset for the first time; for example, "*I remember most, vividly…when my dad came home and was crying because I don't think I had seen him cry until then…*" (Adolescent 6). For most siblings, responsibilities increased, including getting themselves ready for school, supporting other family members (e.g. younger siblings) and helping more at home. Some described building qualities such as independence and confidence from this, but also noted being "*too sad to be independent*" (Adolescent 4) and there being "*better ways to become more confident and independent than having a sibling be ill…*" (Adolescent 7). One sibling expressed a change in responsibility in relation to looking after their unwell siblings less; "*I helped to look after them a bit at home, so it was hard to lose that when they were in hospital…I couldn't be helpful in that way*" (Adolescent 4), demonstrating the complexities of role adjustment. For most, changes seemed ongoing; "*so it was a bit over the place, I sometimes didn't know who was staying that night until the day*" (Adolescent 5) and had adverse impacts in other areas of life such as keeping up with school expectations. Some siblings found new routines, helping them to adjust to a "*different normal*" (Adolescent 10) over time.

Among the uncertainty and change, maintaining family normality was described as helpful. Siblings appreciated their parents trying to keep things normal for them, such as engaging in usual family activities; for example, "*my mum and dad tried to keep things like normal sort of thing for me as much as they could because I told them the changes were kind of stressful*" (Adolescent 7) and "*I think it [playing board games] made it feel normal…yeah…and like it was OK and we were back in our home…even if we weren't…*" (Adolescent 2). Siblings appreciated when their unwell sibling's area on the ward could be decorated with some "*things from their room*" (Adolescent 10) to help make the space feel more homely and familiar.

Theme 3: "Let me be part of it all": Togetherness, communication and connection

This theme encompasses the narratives that focus on siblings desiring a sense of belonging within their family and peer group, the impacts of siblings being physically and emotionally apart from their families and ways of being brought closer as a family and to other siblings.

All siblings recalled being physically and emotionally separated from family, often feeling "*quite distant from my parents and [unwell sibling's name] because I couldn't see them as much…*" (Adolescent 4). Siblings expressed sadness, loneliness and longing for their family as a result; "*every day I did miss them*" (Adolescent 6). Some siblings stayed in other people's houses during their sibling's hospital stay which sometimes added to the physical distance from the hospital and meant seeing their family even less.

> I think mostly being away from them, it would bubble up inside of me, the sadness. Like grow but I didn't know what to do with that.
>
> (Adolescent 1).

Given such separation, fostering family communication was perceived as helpful, rather than all keeping quiet. Some siblings thought parental support could be beneficial to help their parents have their emotional needs met and *"to explain to us [siblings] what was happening"* (Adolescent 2). Some siblings reported wanting family support, to make sure everyone was included and for *"us all talk to each other… and…helping my family to see what we were doing well and to make us believe we could get through it"* (Adolescent 1).

Similarly, siblings perceived keeping connected, united and creating new memories as important and helpful. This often meant being together in different ways; for example, "*…sometimes we'd wait to know [the food on the ward] and then we would try to have the same, so we felt together…*" (Adolescent 5) and "*we wore the same bracelets to feel closer*" (Adolescent 10). Some siblings described "*appreciating each other more*" and feeling more united regarding "*us all against the cancer, together*" (Adolescent 7). There was a sense of feeling "*closer in my heart*" (Adolescent 7), even if in distance they were further apart. Some siblings spent more quality time with certain family members; for example, "*I saw my dad and then my aunt a bit more actually because they came to stay at the house…it was nice doing things with them*" (Adolescent 9). Still making family memories during this time was also valued, such as "*I got a hot chocolate downstairs from the [hospital] café which was good…my dad said as a treat…*" (Adolescent 7).

Alongside keeping connected with their family, all siblings discussed a desire to connect with other siblings on the ward who "*get it*" (Adolescent 7) and could help them make sense of the experience. As part of this, siblings who had sibling(s) other than their unwell one found connecting with them beneficial; "*…talking to other siblings too…because having my other brother was really helpful*" (Adolescent 6). Most siblings specified wanting to connect with other adolescent siblings, to feel they *"belonged, as younger children would not understand the challenges of being our age as much…"* (Adolescent 10). A variety of modalities were suggested, including *"having things that siblings would say to other siblings, make them feel less alone*" (Adolescent 4) and "*doing activities whilst talking about hard things and learning ways of coping*" (Adolescent 10).

Recommendations for improving sibling support

The findings within the themes/subthemes were reviewed in consultation with staff and used to identify pragmatic/feasible recommendations for improving sibling support, mapped onto the PPPHM (Kazak, 2006).

These recommendations are displayed in Figure 2, showing the universal support recommended for all siblings and then the more targeted and clinical/treatment support for siblings requiring more intensive support.

DISCUSSION

This project sought to understand the experiences and perceived needs of adolescent siblings of paediatric oncology inpatients to inform service improvement recommendations for sibling support. Key themes were found, all interconnected by an overarching narrative of wanting to feel part of the cancer journey including their family's experience on the ward. Such findings align with the family-centred approach to paediatric inpatient care, as recommended by NICE (2021) guidelines, whereby care is planned in partnership with and around the needs of the whole family.

Consistent with the evidence base, siblings described an array of emotions, including anxiety, sadness, shock and loneliness (Løkkeberg et al., 2020; Weiner & Woodley, 2018). Developing qualities, such as confidence and independence, were highlighted by some siblings, although siblings described desiring that they had built them in ways other than having an unwell sibling. Whilst understanding that

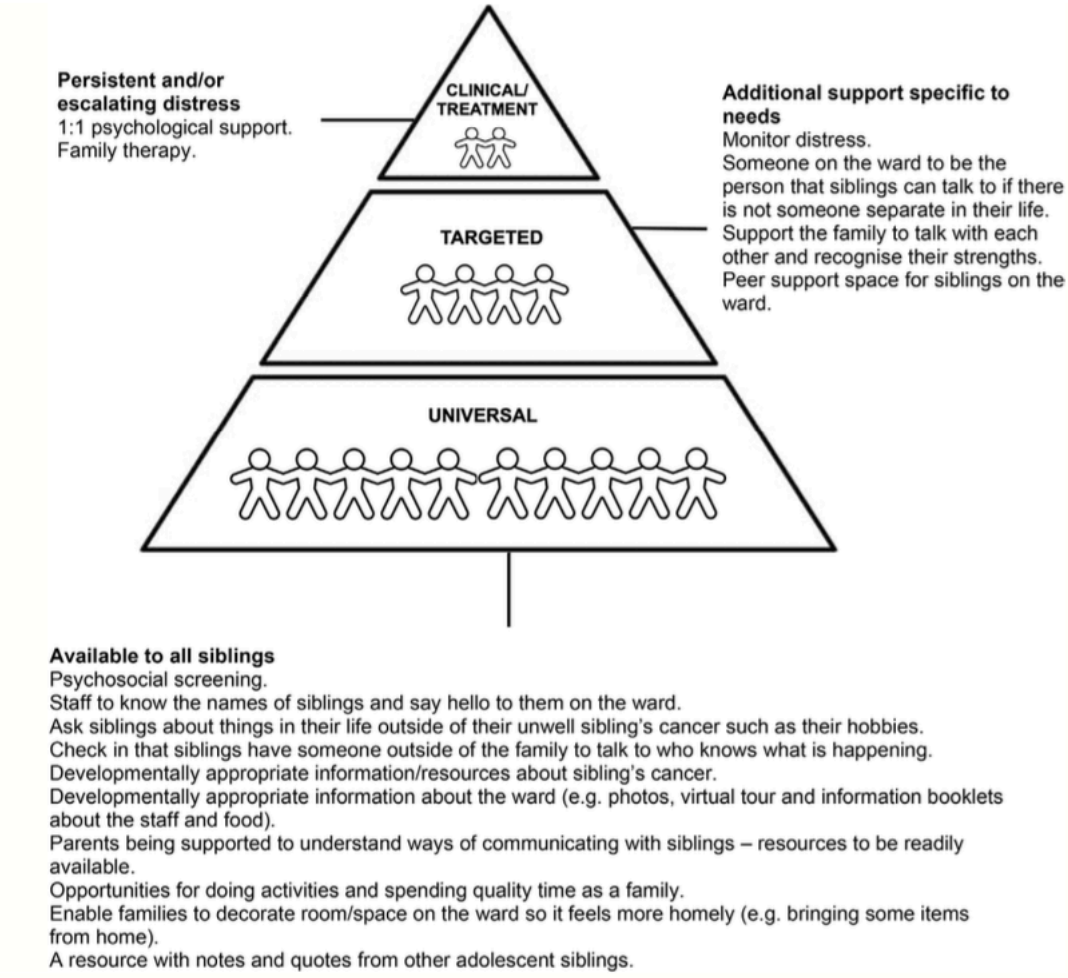

FIGURE 2 Summary of Service Improvement Recommendations Organized Using the Paediatric Psychosocial Preventative Health Model (Kazak, 2006).

their unwell sibling required support, siblings perceived themselves as being overlooked, as previously noted (Toft et al., 2019; van Schoors et al., 2019). As well as included in the care, siblings also wanted to be recognized as individuals, rather than just their sibling's sibling. The need for both belonging and individual appreciation is perhaps particularly pertinent for this age group, as adolescence is a time of seeking autonomy and independence to carve out personal identity whilst also consolidating social identity (Klimstra & van Doeselaar, 2017; Meeus, 2018).

A proactive approach for sibling support was desired, rather than needing to seek support themselves or go through parents. This is important, given that reluctance to disclose and low parental awareness have been recognized as barriers to siblings accessing support (Brosnan et al., 2022; Weiner & Woodley, 2018). Being thought of by ward staff was also valued and may be beneficial, as having trusted relationships with relevant adults has been shown to facilitate help-seeking among adolescents (Aguirre Velasco et al., 2020). To identify siblings experiencing psychosocial difficulties to then triage for support as appropriate, families have supported regular psychosocial screening including via electronic questionnaires to support feasibility (Deatrick et al., 2022; Long et al., 2017). This may include the 'Psychosocial Assessment Tool' (Kazak et al., 2018), a parent-reported screener based on the three-tier PPPHM (Kazak, 2006) or the newly developed 'PAT Sibling Modules' with validated diagnosis and follow-up versions which assess sibling risk factors and reactions respectively (Davis, Alderfer, et al., 2023; Davis, Brosnan, et al., 2023; Long et al., 2022). Utilizing the 'Sibling Cancer Needs Instrument' (SCNI) (Patterson et al., 2014), a sibling-report measure

which specifically assesses the unmet needs of adolescents and young adults with a sibling with cancer, may also be beneficial. When experiencing difficulties, having someone to talk to outside of the family (e.g. one-to-one) was also reported as beneficial. This may include having a space to talk about the impact of the illness on their life and adjustment (Gerhardt et al., 2015; Wiener et al., 2015).

As alluded to in the current study, lack of cancer-related information (including specific to their sibling) has been identified as a common unfulfilled need among adolescent siblings (Masoudifar et al., 2022) and linked to assumptions surrounding potential prognoses and therefore distress (Weiner & Woodley, 2018). Having access to developmentally appropriate informational resources about cancer in general and specific to their sibling could address such assumptions and reduce distress through having a more informed perception of the situation.

Previous research has indicated that most siblings do not seek information outside of their known network, preferring it to come from their parents or other trusted people (van Schoors et al., 2019; Wawrzynski et al., 2023). Indeed, siblings in the current study appreciated being informed by staff and their family. As such, the sibling psychosocial standard of care in the standards for the psychosocial care of children with cancer and their families proposed by Wiener et al. (2015) recommends that parents and staff should be supported to facilitate their communication with siblings. Family barriers to information acquisition were reported, including reluctance from parents to share information (out of protection) and siblings to seek information or ask for help from their family (to not take the focus away from their unwell sibling) (Brosnan et al., 2022; Ilic et al., 2023). Such findings further support utilizing a family-centred approach to involve siblings, for example, parental and family support for communication (e.g. information sharing, recognizing strengths), to help foster the perception that they could get through it together. Previous research has also identified a lack of knowledge of issues faced by siblings among staff as a barrier (Gerhardt et al., 2015), indicating staff training may also be beneficial.

In line with previous research, siblings described unsettling changes, including to their routines and responsibilities (Løkkeberg et al., 2020; van Schoors et al., 2019; Weiner & Woodley, 2018), making it harder to uphold expectations in other areas of their lives such as school (Tsimicalis et al., 2018). Such changes may be compounded by the context of their psychosocial stage of development, whereby adolescents strive to create a continuous sense of identity as opposed to role confusion (Erikson, 1950). As such, maintaining some perception of normality (Yang et al., 2016), both within the family and their wider life as individuals, was desired and experienced as helpful.

Consistent with the current evidence base, separation from family was difficult among siblings (Yang et al., 2016). During this time, perceived togetherness and connection with family was viewed as important. Better family functioning (e.g. cohesion) has been associated with lower levels of sibling loneliness and better psychosocial adjustment outcomes (van Schoors et al., 2016, 2021). Siblings found benefits from spending quality time and making new memories together with their families, something that ward staff could help to facilitate.

Connecting with other siblings was desired, particularly of similar age who could understand the experience of having a sibling with cancer in hospital in the context of other typical adolescent stressors. Seeking such connections may be especially pertinent during adolescence, a developmental period when peer groups become increasingly important (Meeus, 2018; Rageliené, 2016). Benefits from group-based interventions for siblings of CYP with cancer have been identified, including improvements in psychosocial adjustment, knowledge of cancer, sense of belonging, identity and family relationships (Guan et al., 2021; Mooney-Doyle et al., 2021). Such peer support spaces have also been desired as places to improve their coping skills and learn information through activities and workshops (Ilic et al., 2023). As such, resources fostering peer support could also be helpful for siblings of inpatients.

Clinical implications for sibling support

Informed by this project's findings, recommendations for improving sibling support were identified. Based on their experiences, such recommendations could support siblings during the hospital admission

(i.e. the stressor) with their coping resources (e.g. developmentally appropriate information, communication, family and peer support) and perceptions (e.g. being/feeling seen, reducing assumptions, maintaining normality, identifying family strengths) of being able to manage, therefore helping to reduce risks of poor psychosocial adjustment (Hill, 1958).

The recommendations proposed in the current study, organized using the PPPHM (Kazak, 2006), complement existing standards and guidelines for the psychosocial care of siblings in paediatric oncology (Gerhardt et al., 2015; NICE, 2014; Wiener et al., 2015). For example, the standards of care (Gerhardt et al., 2015; Wiener et al., 2015) for siblings specify the need for providing appropriate support to those who are psychosocially at risk. Furthermore, our recommendations align with the recently published 'Sibling Services Blueprint' for systematic psychosocial screening and support for siblings by (Davis et al., 2024). Also organized using the PPPHM (Kazak, 2006), this blueprint includes routine use of psychosocial screening tools, universal-level support for all siblings (e.g. educational materials), awareness of and commitment to addressing sibling needs (e.g. onwards) and a range of options for sibling psychosocial support matched to the level of psychosocial need.

Strengths and limitations

To our knowledge, this was the first study to investigate the experiences and perceived needs of adolescent siblings on a paediatric oncology ward in the UK. This study developed several service improvement recommendations for better-supporting siblings. However, siblings seeking support and involvement may have been more likely to take part, perhaps influencing some of the findings. Although most siblings had visited their sibling with cancer on the ward, data on the frequency and length of visits were not collected. Moreover, whilst the sample of siblings was diverse in some respects (e.g. gender), most were from nuclear families, most were White British and all were English speaking. Therefore, it is difficult to ascertain whether such findings are generalisable to all siblings who met the project's inclusion criteria.

Future directions

Given the eligibility criteria, which importantly enabled an in-depth understanding to be gathered for the group of interest, the findings may not apply to non-adolescent and bereaved siblings. Future projects focusing on other sibling groups could help to establish whether experiences and needs may vary for those siblings. The next critical steps are the implementation and evaluation of the recommendations to inform evidence-based care.

Although this project was specifically for the ward being studied, it is likely relevant to other similar contexts at least in the United Kingdom. Nevertheless, exploring the experiences and needs of siblings in other paediatric oncology wards may also be useful, given that unmet support needs among siblings are a wide-scale issue (Davis, Alderfer, et al., 2023; Davis, Brosnan, et al., 2023; Yang et al., 2016). This may include building collaborations with academic partners to harness innovative approaches, such as longitudinal designs to investigate the trajectory of experiences and understand the most optimal timepoints for providing sibling support.

CONCLUSION

This qualitative study captured the lived experiences and needs of adolescent siblings of CYP in a paediatric oncology ward. The overarching narrative found that siblings wanted to feel part of the cancer journey including their family's experience on the ward. Interconnected by such desires to be more involved, three key themes were found. These findings informed recommendations for sibling support, organized with ward and oncology staff using the PPPHM (Kazak, 2006). Based on sibling experiences,

it is considered that such recommendations could support their resources and perceptions for coping, therefore helping to reduce risks of poor psychosocial adjustment (Hill, 1958). Implementation and ongoing evaluation are needed, as well as exploring the experiences of all siblings, to help ensure sibling support is continually improved and their needs are met.

AUTHOR CONTRIBUTIONS

Rachel Batchelor: Conceptualization; formal analysis; investigation; methodology; project administration; resources; visualization; writing – review and editing; writing – original draft; data curation. **Matthew Hotton:** Conceptualization; methodology; project administration; resources; supervision; writing – review and editing; writing – original draft. **Eloise Harris:** Formal analysis; investigation; project administration; writing – original draft; writing – review and editing. **Alex Lau-Zhu:** Conceptualization; methodology; project administration; resources; writing – original draft; writing – review and editing; supervision. **Annabel L. David:** Conceptualization; methodology; project administration; supervision; resources; writing – original draft; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no competing interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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Appendix G: SIP Journal Submission Guide - British Journal of Health of Psychology

BJHP AUTHOR GUIDELINES

1. SUBMISSION

Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

2. AIMS AND SCOPE

The British Journal of Health Psychology publishes original research on all aspects of psychology related to health, health-related behaviour and illness across the lifespan including:

- experimental and clinical research on aetiology
- management of acute and chronic illness
- responses to ill-health
- health-related behaviour change and maintenance
- screening and medical procedures
- psychosocial mediators and moderators of health-related behaviours
- influence of emotion on health and health-related behaviours
- psychosocial processes relevant to disease outcomes
- psychological interventions in health and disease
- emotional and behavioural responses to ill health, screening and medical procedures
- psychological aspects of prevention

Papers must make a clear potential contribution to health psychology theory, knowledge and/or practice and employ rigorous research design and methodology.

3. MANUSCRIPT CATEGORIES

The types of paper invited are:

- papers reporting original empirical investigations, using quantitative, qualitative or mixed methods;
- theoretical papers which report analyses of theories in health psychology;
- review papers, which should provide systematic overviews, evaluations and interpretations of research in a given field of health psychology (narrative reviews will only be considered for editorials or important theoretical discourses);
- methodological papers dealing with methodological issues of particular relevance to health psychology;

- we particularly welcome papers reporting effectiveness (for example, Randomised Controlled Trials) and process evaluations of interventions in clinical and non-clinical populations.

4. PREPARING THE SUBMISSION

British Journal of Health Psychology now offers free format submission for a simplified and streamlined submission process.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered.

Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Statement of Contribution

All authors are required to provide a clear summary of 'what is already known on this subject?' and 'what does this study add?'. Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for 'what does this study add?' should be presented as bullet points of no more than 100 characters each.

Main Text File

As papers are double-anonymous peer reviewed, the main text file should not include any information that might identify the authors.

Your main document file should include:

- A short informative title containing the major key words. The title should not contain abbreviations;
- Abstract structured
- Up to seven keywords;
- Main body: formatted as introduction, materials & methods, results, discussion, conclusion;
- References;
- Tables (each table complete with title and footnotes);
- Figures should be uploaded as separate files;
- Statement of Contribution.

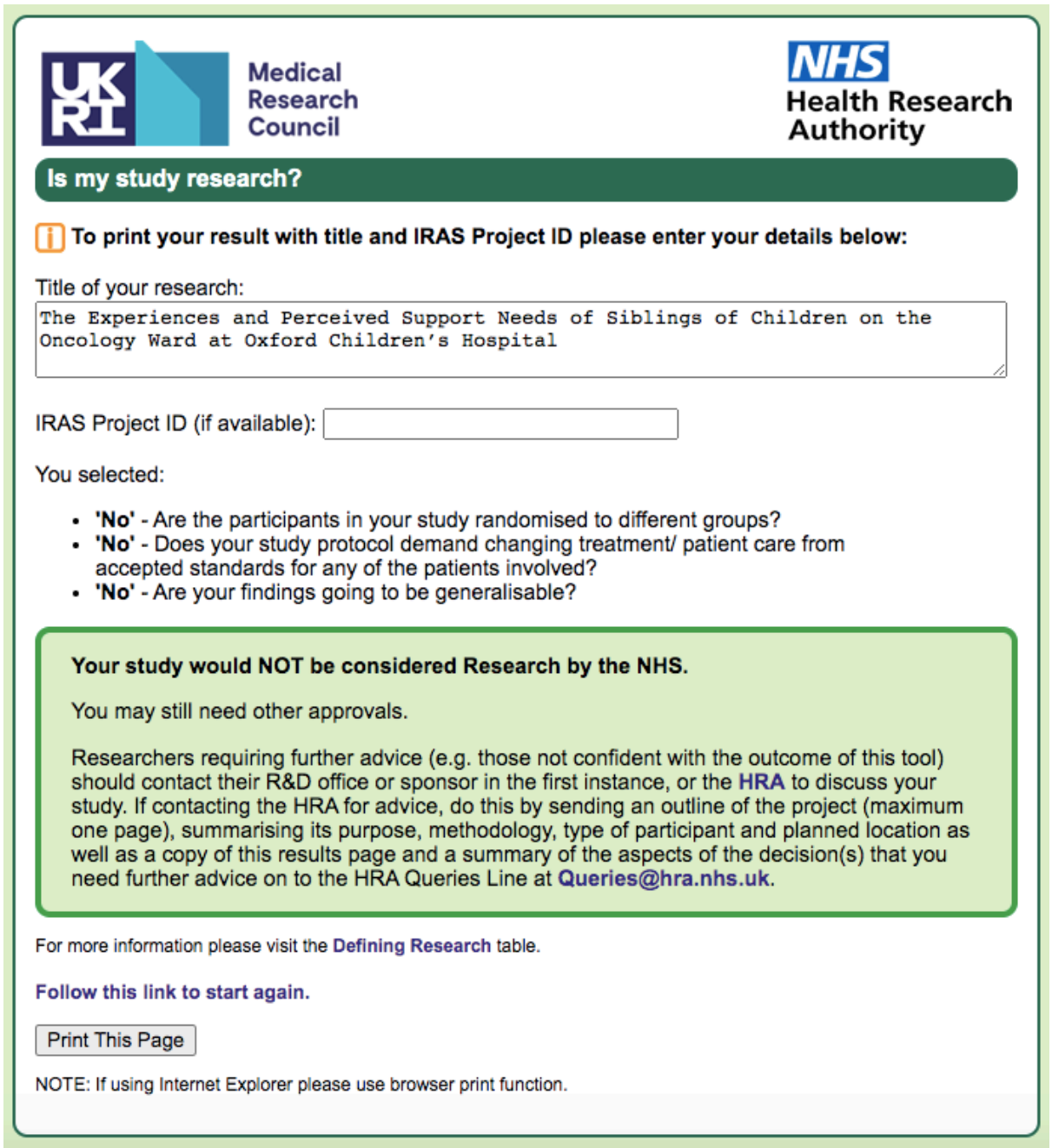
References

This journal uses APA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Appendix H: SIP Lay Summary

Adolescent siblings of children and young people (CYP) with cancer are at increased risk of experiencing difficulties such as loneliness, yet many do not receive adequate support. The children's cancer ward, 'Kamran's Ward', at Oxford Children's Hospital has recognised the need for improving sibling support. This project aimed to explore the experiences of adolescent siblings and develop recommendations for sibling support. Ten adolescent siblings of CYP who had recently stayed on Kamran's Ward were asked questions through one-to-one interviews about their experiences and perceived support needs. Siblings with lived experience helped to design these questions. Researchers analysed everything that the siblings talked about. It was found that siblings wanted to feel part of the cancer journey, including their family's experience on Kamran's Ward, with three main themes: (i) "what about me?": overlooked and unseen, (ii) "always changing, never knowing": the challenge of uncertainty and (iii) "let me be part of it all": togetherness, communication and connection. Such findings informed recommendations which were finalised with staff working on Kamran's Ward and the hospital's wider children's cancer services. The recommendations were organised using a three-tier framework to guide support dependent on level of need. Key recommendations included proactively screening siblings for psychosocial difficulties, recognising siblings as individuals, making sure they have someone to talk to, providing age-appropriate information, enabling siblings to connect with each other and fostering family normality, communication and connection. These recommendations should be evaluated to help ensure sibling support is continually improved.

Appendix I: SIP Health Research Authority Decision Tool Outcome



Medical Research Council

NHS Health Research Authority

Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

The Experiences and Perceived Support Needs of Siblings of Children on the Oncology Ward at Oxford Children's Hospital

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at Queries@hra.nhs.uk.

For more information please visit the Defining Research table.

Follow this link to start again.

Print This Page

NOTE: If using Internet Explorer please use browser print function.

Appendix J: SIP Oxford University Hospital NHS Foundation Trust Clinical Governance Approval

From: Ulysses@ouh.nhs.uk <Ulysses@ouh.nhs.uk>
Sent: Wednesday, May 10, 2023 4:26 PM
To: David, Annabel (RTH) OUH <Annabel.David@ouh.nhs.uk>
Subject: Audit Or QI Approved - 8345

Your Quality Improvement has now been approved

Number:	**8345**
Page:	**03 - Approved QI**
Title:	**A service improvement project to identify the psychosocial support needs of siblings of children and young people on Kamran's ward..**
Request Date:	**10/05/2023**
Target Date:	**01/12/2023**
Project Lead:	**Annabel David**
Project Supervisor:	**Annabel David**

Click on the link below to view & action the record

View & Action the record here

Appendix K: SIP Information Sheets

Oxford University Hospitals NHS
NHS Foundation Trust

Sibling Information Sheet (11-15-year-olds)

Project title: Improving Support for Siblings of Children and Young People on Kamran's Ward, Oxford Children's Hospital

Hello, my name is Rachel Batchelor. I am training to be a Clinical Psychologist. I am inviting you to take part in a project which aims to improve support for siblings on Kamran's Ward.
I would really appreciate your help! ☺



Before deciding if you would like to help, it is important that you understand what would be involved. Please read this information sheet and discuss it with your parent(s)/carer(s).

Why have I been invited?
You have been invited to take part, as you are aged 11-16 and have a sibling who has had an inpatient stay on Kamran's Ward for at least one week in the previous six months.

Do I have to take part?
No, it is up to you to decide. This will not affect your family's support from the hospital.

What will happen to me if I take part?
You will take part in a one-to-one interview over either Microsoft Teams or the telephone. Other siblings helped us to come up with these questions. This interview will last up to 30-60 minutes and cover:

- Your experiences of having a sibling on Kamran's Ward.
- What you think could have been helpful whilst your sibling was on Kamran's Ward.



What do I do next?
If you would like to take part, or have any questions, please ask your parents to contact Rachel Batchelor, rachel.batchelor@worc.ox.ac.uk, to arrange a time for the one-to-one interview.

Your parent/carer will need to sign a consent form and you will need to sign an assent form (if you are 16 you can sign the consent form yourself).

We can then arrange a time to talk online or over the telephone ☺ Thank you ☺

Sibling Information Sheet (16-year-olds)

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

We are inviting you to take part in a service improvement project. The aim of this project is to improve support for siblings of children and young people on Kamran's Ward. We are interested in learning about the experiences and perceived support needs of siblings. We are trying to find out about this in order to think about how siblings can be better supported in the future.

Why have I been invited?

You have been invited to take part, as you are aged 11-16 and have a sibling who has had an inpatient stay on Kamran's Ward for at least one week in the previous six months. We hope to interview 8-12 siblings to represent a range of experiences and perspectives.

Do I have to take part?

No, it is entirely up to you to decide. This decision will not affect your family's care from the hospital.

What will happen to me if I take part?

You will take part in a one-to-one interview over either Microsoft Teams or the telephone. Other siblings of children and young people on Kamran's Ward helped us to come up with these questions. This interview will last up to 30-60 minutes. The interview will cover:

- Your experiences of having a sibling on Kamran's Ward.
- What you think could have been helpful whilst your sibling was on Kamran's Ward.

The records of your sibling who has been on Kamran's ward may also be accessed to collect some background information about them (age, gender, ethnicity, position in the family) and their cancer (e.g. age of diagnosis, type and stage of cancer).

All data will be kept confidential and anonymised (your name would not be shown). We may publish anonymised quotes (i.e. things that you say) in a journal.

If you would like to take part, or have any questions, please contact Rachel Batchelor (see below), to arrange a time for the one-to-one interview. You will also be required to sign the consent form.

Thank you! ☺



Contact details:
Rachel Batchelor (photo to the right)
Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research, University of Oxford
Email: rachel.batchelor@oxfordhealth.nhs.uk

Supervised by:

Dr Alex Lau-Zhu, Research Tutor, University of Oxford
Dr Matthew Hotton, Research Tutor, University of Oxford
Dr Annabel David , Senior Clinical Psychologist, Oxford University Hospitals NHS Foundation Trust

Information Sheet for Parent/Carer

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

We are inviting your child to take part in a service improvement project. The aim of this project is to improve support for siblings of children and young people on Kamran's Ward. We are interested in learning about the experiences and perceived support needs of siblings. We are trying to find out about this in order to think about how siblings can be better supported in the future.

Why has my child been invited?

Your child has been invited to take part, as they are aged 11-16 and have a sibling who has had an inpatient stay on Kamran's Ward for at least one week in the previous six months. We hope to interview 8-12 siblings to represent a range of experiences and perspectives.

Does my child have to take part?

No, it is entirely up to you and your child to decide. This decision will not affect the care that your family receives from the hospital.

What will happen to my child if they take part?

Your child will take part in a one-to-one interview over either Microsoft Teams or the telephone. Other siblings of children and young people on Kamran's Ward helped us to come up with these questions. This interview will last up to 30-60 minutes. The interview will cover:

- Their experiences of having a sibling on Kamran's Ward.
- What they think could have been helpful whilst their sibling was on Kamran's Ward.

The records of your child who has been on Kamran's Ward may also be accessed to collect some background information about them (age, gender, ethnicity, position in the family) and their cancer (age of diagnosis, type of cancer).

All data will be kept confidential and anonymised. We may publish anonymised quotes in a journal.

If your child would like to take part, or have any questions, please contact Rachel Batchelor using the email address below. You will also be required to sign the consent form (and your child who is taking part will be required to sign the assent form). We can then arrange a time for the one-to-one interview.

Many thanks for your consideration.

Contact details:

Rachel Batchelor
Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research, University of Oxford
Email: rachel.batchelor@oxfordhealth.nhs.uk

Supervised by:

Dr Alex Lau-Zhu, Research Tutor, University of Oxford
Dr Matthew Hotton, Research Tutor, University of Oxford
Dr Annabel David , Senior Clinical Psychologist, Oxford University Hospitals NHS Foundation Trust

Appendix L: SIP Consent and Assent Forms





Sibling Assent Form (11-15-year-olds)

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

Project lead: Rachel Batchelor, Trainee Clinical Psychologist

Before taking part in this project, you need to confirm that you are happy to take part. If you would like to take part, please complete the consent form below.

Please initial each box

1. I have read the information sheet Version 2.1 dated 12/11/2023 and understand what the project is about. ☐
2. I can stop the interview whenever I want. ☐
3. I understand that if my interview answers indicate that I am experiencing a high level of distress, my parent/carer will receive a letter inviting them to contact the research team to discuss this further. They may also need to tell another relevant professional. ☐
4. I understand that if the researcher is worried about me or someone else, they may need to tell my parent/carer or another professional. ☐
5. I am happy for my interview to be recorded. ☐
6. I agree to take part in this project. ☐

_____	_____	_____
Name	Signature	Date
_____	_____	_____
Researcher	Signature	Date

Sibling Consent Form (16-year-olds)

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

Project lead: Rachel Batchelor, Trainee Clinical Psychologist

Because your child is under the age of 16, you as the parent or legal guardian need to complete the consent form if you have discussed it with your child and are happy for them to take part.

Please initial each box

1. I confirm that I have read and understand the information sheet Version 2.1 dated 12/11/2023 for this project. I have had the opportunity to ask questions and have had these answered satisfactorily (if applicable). ☐
2. I understand that if my child says something that worries the researcher about risk of harm to them or someone else, I will receive a letter inviting them to contact the research team to discuss this further. The researcher may also need to tell another professional and if appropriate will also share this information with me. ☐
3. I agree to my child being interviewed online and for the interview to be audio recorded and transcribed. ☐
4. I consent to anonymised direct quotes from my child being used in the write-up of the research. ☐
5. I understand that data collected during the project may be looked at by authorised individuals from the research team, ethics committees and from Oxford University Hospitals NHS Foundation Trust. I give permission for these individuals to have access to my child's research data records. ☐
6. I understand that the records of my child who has been on Kamran's Ward may be accessed to collect some background information. I give permission for these records to be accessed. ☐
7. I agree to my child taking part in this project. ☐
8. I would like to receive a copy of the project results. YES/NO (please highlight)

Name of child	Name of Parent	Signature
		Date

Researcher	Signature	Date

Parent/Carer Consent Form

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

Project lead: Rachel Batchelor, Trainee Clinical Psychologist

Because your child is under the age of 16, you as the parent or legal guardian need to complete the consent form if you have discussed it with your child and are happy for them to take part.

Please initial each box

1. I confirm that I have read and understand the information sheet Version 2.1 dated 12/11/2023 for this project. I have had the opportunity to ask questions and have had these answered satisfactorily (if applicable). ☐
2. I understand that if my child says something that worries the researcher about risk of harm to them or someone else, I will receive a letter inviting them to contact the research team to discuss this further. The researcher may also need to tell another professional and if appropriate will also share this information with me. ☐
3. I agree to my child being interviewed online and for the interview to be audio recorded and transcribed. ☐
4. I consent to anonymised direct quotes from my child being used in the write-up of the research. ☐
5. I understand that data collected during the project may be looked at by authorised individuals from the research team, ethics committees and from Oxford University Hospitals NHS Foundation Trust. I give permission for these individuals to have access to my child's research data records. ☐
6. I understand that the records of my child who has been on Kamran's Ward may be accessed to collect some background information. I give permission for these records to be accessed. ☐
7. I agree to my child taking part in this project. ☐
8. I would like to receive a copy of the project results. YES/NO (please highlight)

_____	_____	_____
Name of child	Name of Parent	Signature
		_____
		Date
_____	_____	_____
Researcher	Signature	Date

Appendix M: SIP Semi-Structured Interview Schedule

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

Project lead: Rachel Batchelor, Trainee Clinical Psychologist

[Trainee to check that consent/assent forms have been returned prior to start of interview]

INTRODUCTION

[Parent/carer may be present for introduction – this is up to the sibling]

Hello, my name is Rachel Batchelor. I am a Trainee Clinical Psychologist. Thank you for meeting with me today, I am really grateful.

As a reminder, the project that we are meeting for today aims to improve support for siblings of children and young people on Kamran's Ward.

When you were first told about this project, you and your parent(s)/carer(s) will have been sent information sheets and consent forms. Do you have any questions?

You and your parent(s)/carer(s) will have also been sent a short questionnaire to gather more information about you and [name] such as your ages. This gives us helpful background information about your family and may help us to think about how the service could be improved for siblings who may have things in common with you, or who may be different to you. Thank you for completing this and sending it back to us.

[If they have not returned the short questionnaire, go through and complete it together- may need parent/carer to support with some questions]

I understand that when a child or young person is in hospital it can impact their siblings. I am going to start off by asking some questions about what it is like to have a sibling on Kamran's Ward. We will then talk about any ideas you have about what you might have found helpful whilst [name] was on Kamran's Ward.

In terms of **what to expect from our discussion**:

- I am not part of the team at Kamran's Ward; I am just doing this project with the service.
- I will not tell the staff on Kamran's Ward what you tell me, only a summary of all of the answers I get where they will not know who said what.
- All information from our discussion that could identify you such as names will be removed when I write up this project, to make sure your answers remain private.
- I understand that talking about these experiences may be hard, so please let me know if there are any questions that you do not want to answer.
- You can also take a break or stop the interview at any time.
- It is also OK if you are not sure about a question/answer.
- I am interested in both what the ward is doing well and what could be done differently for siblings. This information will hopefully help Kamran's Ward to make changes to improve the support for other siblings in the future.

Whilst I have some questions for you, this is also your opportunity to tell me anything else about having a sibling on Kamran's Ward that you think is important.

We will be talking for around 30 minutes to one hour.

Are you OK for your parent/carer to leave the room whilst we go through the questions together?

[Parent/carer to leave room]

Thank you. We are going to touch on some sensitive topics today, if that feels OK with you. Before we start, I **want to check in with how you are feeling today?**

Would it be helpful to do a **breathing/grounding exercise together**?

> Choice of either 54321 technique or breathing exercise

Check in again after breathing/grounding exercise.

Before I begin asking the questions I have for you, do you have any questions you want to ask me?

[Answer any questions the sibling may have]

Are you OK for me to now start recording and ask you my questions?

[Turn on recording]

<u>WARM UP AND BACKGROUND QUESTIONS</u>

I would like to start with a question to find out a more about you. What sorts of things do you enjoy doing?

> **Prompts:** What do you do in your free time? Do you have any particular hobbies or interests?

We are now going to think a bit about your family. To help us with this, I would like to draw out your family tree.

> Led partly by the sibling's answers, their family tree will be mapped out by discussing information such as their number of siblings, positions in family of interviewee and sibling with cancer, relationship to sibling (e.g. full sibling, half-sibling, stepsibling), who usually at home/in their household, etc.

[Questions regarding the relationships in the family will also be asked during this exercise, such as those below]

> Who do you feel closest to in the family?
> Who are you most like/similar to in the family?
> How might your family describe you?
> How would you describe [name]?
> Who do you spend the most time with?
> What do you enjoy doing with family members?
> Who do you talk to when you are upset or need help?

EXPERIENCES

Now I am going to ask a bit more about your experiences as a sibling. Could you tell me what it was like having a sibling stay on Kamran's Ward?

How did you feel when [name] was on Kamran's Ward?

> **Prompts:** *[prompt with emotions such as worry and sadness – and what these emotions were in relation to]*

What are your strongest memories from when [name] was on Kamran's Ward?

What was most difficult or challenging about [name] being on Kamran's Ward?

How was your homelife impacted when [name] was on Kamran's Ward?

Where did you stay whilst [name] was on Kamran's Ward?

How were other things impacted when [name] was on Kamran's Ward?

> **Prompts**: School life? Routines? Role/responsibilities? Anything else?

How about your relationships with your family, could you talk about how they may have changed or been affected when [name] was on Kamran's Ward?

> **Prompts:** *[make sure at least sibling and parent(s)/carer(s) are discussed, may consider time spent together, closeness, communication, missing them]*

Did you visit [name] whilst they were on Kamran's Ward?

If yes:

> What was your experience of visiting [name] whilst they were on Kamran's Ward?
>
> > **Prompts**: What was the ward environment like for you? What was helpful? What was unhelpful?
>
> What was it like seeing [name] on Kamran's Ward?

If no:

> Was there a reason why you did not visit [name] whilst they were on Kamran's Ward?
>
> > **Prompt**: *[if wanted to visit but barrier identified]* Is there anything that would have made it feel possible or easier to visit them?
>
> Interviewer: Is there anything that helped you or your family cope when [name] was on Kamran's Ward?
>
> > **Prompts:** *[this may include self-care, personal/family strengths, personal/family beliefs, particular support]*

Were you aware of any support you could access while [name] were on Kamran's Ward?

**Here the interview can progress in one of two ways. If yes, continue. <u>If no, skip to improvements</u>.*

What support was available?

Did you access any support?

If yes:

> What did you access and what was your experience of the support?
>
> > **Prompts**: What was helpful? What was unhelpful?

If no:

> Was there a reason why you did not access the support?
>
> **Prompt**: *[if barrier identified]* Is there anything that would have made it feel possible or easier to access the support?
>
> Is there anything that helped you or your family cope when [name] was on Kamran's Ward?
>
> **Prompts:** *[this may include self-care, personal/family strengths, personal/family beliefs, particular support]*

<u>IMPROVEMENTS</u>

Now I am going to ask about what could be improved about the support for siblings. What support would you have wanted whilst [name] was on Kamran's Ward?

> **Prompts**: *[explore a range of different support such as]* one-to-one support, peer support, family support, particular activities, resources, information booklet.

Is there anything you wish you had been told about [name] being on Kamran's Ward?

> **Prompts**: *[if sibling does not provide an answer]* About why they were on Kamran's Ward? About the ward itself? About their cancer or treatment?

What might it have been helpful for other people to have known or done?

> **Prompts**: *[if sibling does not provide an answer]* Perhaps about how you were feeling or your experiences? Can explore in terms of parents, staff, teachers, friends, extended family and other people in life or community.

Is there anything that could have helped you or your family to cope better with [name] being on Kamran's Ward?

Is there anything that could have helped you or your family to cope better when [name] first went onto Kamran's Ward or when they went back home?

Is there anything that you would want to tell another child or young person who has a sibling on Kamran's Ward?

ENDING

Before we end, is there anything that we have not talked about your experience of having a sibling on Kamran's Ward that you would like to share with me, or think is important?

Were you expecting we would talk about anything that we have not?

Are we OK to end there or is there anything else to do with Kamran's Ward that you would like to tell me?

Thank you very much for taking the time to talk to me today. We really appreciate you talking about your experiences so openly and you have been a great help to our project.

[Turn off recording]

[Provide sibling and parent/carer (for siblings age under 16-years-old) debrief sheet. Allow time for any questions about the project]

DEBRIEF

We have touched on some sensitive topics today – I wanted to check in with how you are feeling?

Option for another breathing/grounding exercise

Any questions?

Thank you again for taking part.

Appendix N: SIP Debrief Sheet

Debrief Sheet

Project title: Improving support for siblings of children and young people on Kamran's Ward, Oxford Children's Hospital

Project lead: Rachel Batchelor, Trainee Clinical Psychologist

A huge thank you for taking part in this project! Your participation is very much appreciated and will help us to understand how to better support siblings of children and young people on Kamran's Ward. We are hopeful that your answers could have a real impact.

We hope you found taking part interesting and have not been upset by the questions that we asked, or the information discussed. However, if you found any of it difficult and would like to get some support or talk to someone, please see the following potential sources of support:

- Your GP (for support with mental and physical health)
- NHS 111 (for urgent, but not emergency, medical or mental health support/advice)
- Young Lives vs Cancer charity: https://www.younglivesvscancer.org.uk/
- Sibs charity: https://www.sibs.org.uk

Thank you again for taking part. If you have any further questions about the project or would like to speak to the researcher or their supervisors, please see their contact information below.

Contact details:

Rachel Batchelor
Trainee Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research, University of Oxford
Email: rachel.batchelor@worc.ox.ac.uk

Supervised by:

Dr Alex Lau-Zhu
Research Tutor and Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research, University of Oxford
Email: alex.lauzhu@hmc.ox.ac.uk

Dr Matthew Hotton
Research Tutor and Clinical Psychologist
Oxford Institute of Clinical Psychology Training and Research, University of Oxford
Email: matthew.hotton@hmc.ox.ac.uk

Dr Annabel David
Senior Clinical Psychologist
Children's Psychological Medicine, Oxford Children's Hospital, Oxford University Hospitals NHS Foundation Trust
Email: annabel.david@ouh.nhs.uk

Appendix O: SIP Staff Consultation Guide

Section 1: Study Design and Findings

Brief presentation of service improvement project's methods and findings, including:

i) Rationale.
ii) Recruitment and background data, such as demographic, family and cancer-related information.
iii) Semi-structured interview schedule.
iv) Data analysis.
v) Thematic framework, with themes and sub-themes, derived from interviews (including example quotes).
vi) Proposed recommendations.

Section 2: Staff Views

Questions to staff members:

i) How could Kamran's Ward implement the proposed recommendations?
ii) What further considerations are there regarding what is feasible for service implementation?
iii) Are there any additional ideas for supporting siblings not mentioned in the thematic framework/recommendations?

Appendix P: TDRP Journal Submission Guide - Epilepsy & Behavior

Guide for authors

About the journal

Aims and scope

Epilepsy & Behavior is the fastest-growing international journal uniquely devoted to the rapid dissemination of the most current information available on the behavioral aspects of seizures and epilepsy.

Epilepsy & Behavior presents original peer-reviewed articles based on laboratory and clinical research. Topics are drawn from a variety of fields, including clinical neurology, neurosurgery, neuropsychiatry, neuropsychology, neurophysiology, neuropharmacology, and neuroimaging.

Epilepsy & Behavior publishes papers on the study of:

- Localization of ictal and postictal behaviors
- Neuroendocrine aspects of epilepsy
- Psychiatric and psychosocial aspects of epilepsy
- Behavioral aspects of epilepsy surgery
- Cognitive and affective effects of seizure treatment
- Functional imaging
- Animal models

Letters to the Editor will only be considered if they comment on articles that were previously published in *Epilepsy & Behavior.* The journal does not publish Case Reports. Authors who submit these to *Epilepsy & Behavior* will be offered a transfer or asked to resubmit their Case Reports to the journal?s companion title, *Epilepsy & Behavior Reports* .

Article types

Epilepsy & Behavior publishes the following types of articles:

- Original research articles (both clinical and laboratory research)
- Reviews
- Editorials
- Brief communications
- Letters
- Book reviews
- Calendar of events

Writing and formatting

File format

We ask you to provide editable source files for your entire submission (including figures, tables and text graphics).

Title page

Abstract

You are required to provide a concise and factual abstract which does not exceed 250 words. The abstract should briefly state the purpose of your research, principal results and major conclusions. Some guidelines:

- Abstracts must be able to stand alone as abstracts are often presented separately from the article.
- Avoid references. If any are essential to include, ensure that you cite the author(s) and year(s).
- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

Keywords

You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

We recommend that you only use abbreviations in keywords if they are firmly established in the field.

Highlights

You are encouraged to provide article highlights at submission.

Highlights are a short collection of bullet points that should capture the novel results of your research as well as any new methods used during your study. Highlights will help increase the discoverability of your article via search engines. Some guidelines:

- Submit highlights as a separate editable file in the online submission system with the word "highlights" included in the file name.
- Highlights should consist of 3 to 5 bullet points, each a maximum of 85 characters, including spaces.

Graphical abstract

You are required to provide a graphical abstract at submission.

The graphical abstract should summarize the contents of your article in a concise, pictorial form which is designed to capture the attention of a wide readership. A

graphical abstract will help draw more attention to your online article and support readers in digesting your research. Some guidelines:

- Submit your graphical abstract as a separate file in the online submission system.
- Ensure the image is a minimum of 531 x 1328 pixels (h x w) or proportionally more and is readable at a size of 5 x 13 cm using a regular screen resolution of 96 dpi.
- Our preferred file types for graphical abstracts are TIFF, EPS, PDF or MS Office files.

Tables

Tables must be submitted as editable text, not as images. Some guidelines:

- Place tables next to the relevant text or on a separate page(s) at the end of your article.
- Cite all tables in the manuscript text.
- Number tables consecutively according to their appearance in the text.
- Please provide captions along with the tables.
- Place any table notes below the table body.
- Avoid vertical rules and shading within table cells.

We recommend that you use tables sparingly, ensuring that any data presented in tables is not duplicating results described elsewhere in the article.

Figures, images and artwork

- Number images according to the sequence they appear within your article.
- Submit each image as a separate file using a logical naming convention for your files (for example, Figure_1, Figure_2 etc).
- Please provide captions along with the artwork.
- Text graphics may be embedded in the text at the appropriate position. If you are working with LaTeX, text graphics may also be embedded in the file.

Article structure

Article sections

- Divide your article into clearly defined and numbered sections. Number subsections 1.1 (then 1.1.1, 1.1.2, ...), then 1.2, etc.
- Use the numbering format when cross-referencing within your article. Do not just refer to "the text."
- You may give subsections a brief heading. Headings should appear on a separate line.
- Do not include the article abstract within section numbering.

Introduction

The introduction should clearly state the objectives of your work. We recommend that you provide an adequate background to your work but avoid writing a detailed literature overview or summary of your results.

Methods

The methods section should provide sufficient details about your materials and methods to allow your work to be reproduced by an independent researcher. Some guidelines:

- If the method you used has already been published, provide a summary and reference the originally published method.
- If you are quoting directly from a previously published method, use quotation marks and cite the source.
- Describe any modifications that you have made to existing methods.

Results

Results should be clear and concise. We advise you to read the sections in this guide on supplying tables, artwork, supplementary material and sharing research data.

Discussion

The discussion section should explore the significance of your results but not repeat them. You may combine your results and discussion sections into one section, if appropriate. We recommend that you avoid the use of extensive citations and discussion of published literature in the discussion section.

Conclusion

The conclusion section should present the main conclusions of your study. You may have a stand-alone conclusions section or include your conclusions in a subsection of your discussion or results and discussion section.

References

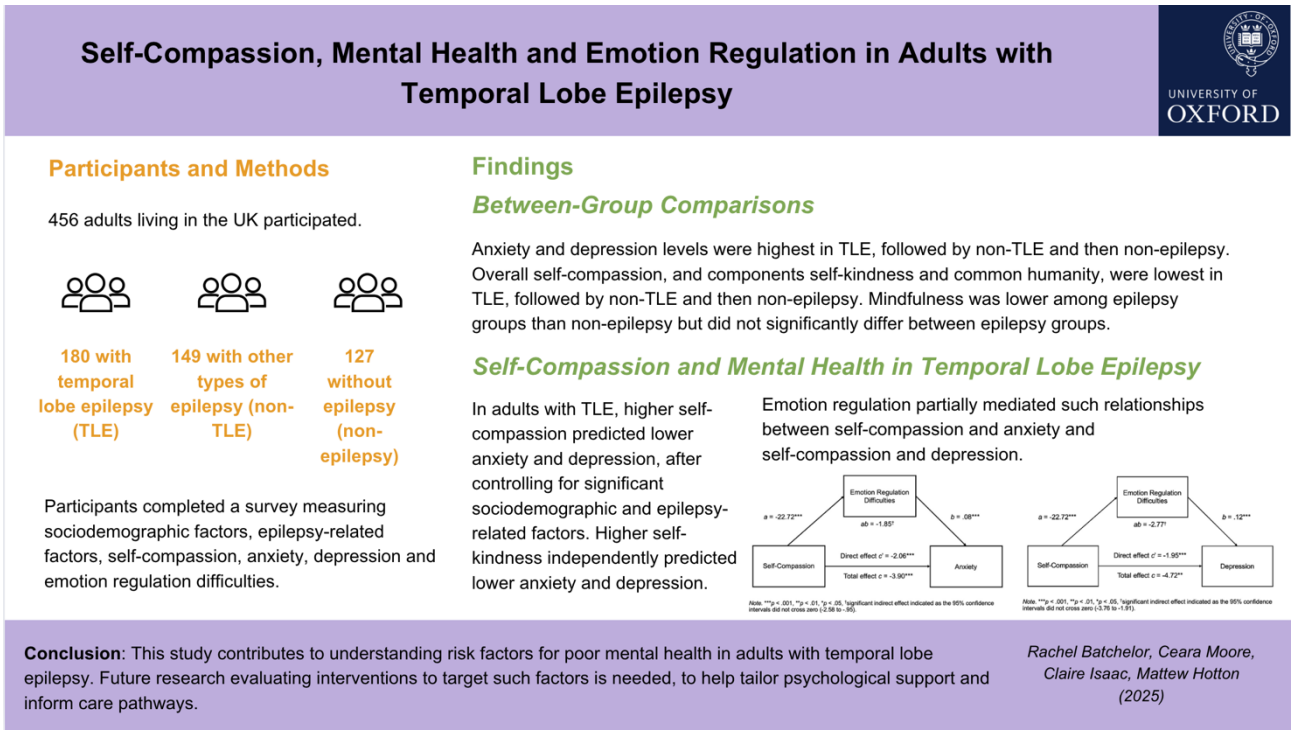
This journal uses Vancouver referencing style. Any references cited within your article should also be present in your reference list and vice versa.

Appendix Q: TDRP Highlights and Graphical Abstract for Journal

Highlights

- Self-compassion was lower in adults with TLE than other types and no epilepsy.
- In TLE, higher self-compassion predicted lower anxiety and depression.
- In TLE, higher self-kindness independently predicted lower anxiety and depression.
- In TLE, emotion regulation partially mediated such relationships.
- Research evaluating interventions targeting self-compassion is needed.

Graphical Abstract



Appendix R: TDRP Central University Research Ethics Committee (CUREC)

Ethical Approval

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, Boundary Brook House, Churchill Drive, Headington, Oxford, OX3 7GB
Tel: +44(0)1865 616575
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Dr Ceara Moore & Miss Rachel Batchelor
The Oxford Institute of Clinical Psychology Training & Research (OxCIPTR)
Isis Education Centre
Warneford Hospital
Oxford

20 March 2024

Dear Dr Moore and Rachel,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R91618/RE001

Study title: Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

Short title: Temporal Lobe Epilepsy: Self-Compassion and Mental Health

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (MS IDREC) in accordance with the University's procedures for ethical approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted from **20th March 2024** until **30th September 2025.**

Insurance-provided indemnity arrangements are in place for the duration of the approval stated above. It is your responsibility to ensure that you request an extension to the end date for indemnity to remain in place should you continue the research beyond the dates covered.

Amendments

Should there be any subsequent changes to the study, you should submit details to the MS IDREC for consideration and approval. Details of changes must be listed on an amendment form.

Yours Sincerely

DocuSigned by:
Leah Butts
9F14889D2BC549A...

Mrs Leah Butts
Research Ethics Administrator

for
Dr Helen Barnby-Porritt
Research Ethics Manager

Appendix S: TDRP Information Sheet Including Consent Questions

Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

CUREC Approval Reference: R91618/RE001

Information Sheet

General information

We are a group of Clinical and Trainee Psychologists at the University of Oxford. This is an invitation to take part in this online survey on Qualtrics.

Before you decide to take part, it is important you are aware of why this project is being conducted and what participation would involve. Please read this information sheet carefully.

If there is anything that is not clear or if you would like more information, please ask us by emailing the research team (Rachel Batchelor: rachel.batchelor@worc.ox.ac.uk or Dr Ceara Moore: ceara.moore@hmc.ox.ac.uk).

What is the purpose of this project?

People with epilepsy, especially temporal lobe epilepsy, are at increased risk of experiencing anxiety and depression. Self-compassion, defined as taking an accepting, kind and non-judgemental stance towards oneself during difficult experiences, can be helpful when ongoing difficulties cannot be effectively resolved and therefore need to be adapted to.

In people with epilepsy, self-compassion has been shown to predict anxiety and depression once sociodemographic (e.g. age) and epilepsy-related (e.g. seizure frequency) factors have been controlled for. Previous research also suggests that self-compassion may be protective by fostering better emotion regulation. However, self-compassion has not yet been studied in temporal lobe epilepsy, compared with other types of epilepsy or considered in relation to mental health and emotion regulation.

Therefore, the aim of this research is to compare self-compassion in adults with temporal lobe epilepsy, adults with other epilepsy types and adults without epilepsy. In adults with temporal lobe epilepsy, this study also aims to investigate if self-compassion predicts anxiety and depression once significant sociodemographic and epilepsy-related factors have been controlled for. Finally, the role of emotion regulation in explaining the associations between self-compassion and mental health outcomes will be explored.

We hope that understanding may help to inform psychological interventions, and therefore promote better mental health, for this patient group.

Who would we like to hear from?

We appreciate your interest in participating in this survey. You are able to participate if you are aged 18 years and over, a UK resident (you should be able to share your residency) and fit into one of the following three groups (you should be able to share your health details):

1. Have a diagnosis of **temporal lobe epilepsy**.

2. Have a diagnosis of **any other type of epilepsy** (i.e. not temporal lobe epilepsy).
3. **Do NOT have** a diagnosis of, or history of, epilepsy.

We are hoping to recruit as many people as possible, to help represent a range of people from different backgrounds.

What will taking part involve?

If you agree to participate, you will be asked to complete an online survey. This should take approximately 20-25 minutes. No background knowledge is required.

The survey will include questions related to self-compassion and emotion regulation and measure levels of anxiety and depression. At the start of the survey, you will be asked some questions about yourself, such as your age, gender and ethnicity, so that we can find out a little information about who you are. Those in the epilepsy groups will also be asked questions regarding the clinical characteristics of their epilepsy. Personally identifiable information such as your name or contact details will not be collected.

Do I have to take part?

No. Please note that participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by closing the browser. However, please note that it will not be possible to withdraw your responses after you have submitted them because the data are collected anonymously.

All questions are optional. If you miss any questions, you will be prompted to answer (although if there is a question you are not comfortable with answering, you will have the option to skip it). Answering as many questions as you are able to will aid the quality of the analysis by helping to reduce missing data.

How will my data be used?

We will not collect any data that could directly identify you.

Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The responses you provide will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications in peer-reviewed journal, conference presentations and reports for external organisations such as epilepsy charities. Research data will be stored for five years after publication or public release of the work of the research.

Who will have access to my data?

Data will be stored on Oxford University network files that are password-protected and solely accessible by the researchers: Rachel Batchelor (Trainee Clinical Psychologist, Oxford Institute of Clinical Psychology Training and Research, University of Oxford) and her

supervisors Dr Ceara Moore (Course Tutor and Clinical Psychologist, Oxford Institute of Clinical Psychology Training and Research, University of Oxford) and Dr Claire Isaac (Consultant Neuropsychologist, Oxford University Hospitals NHS Foundation Trust). The results will be written up for a Doctorate in Clinical Psychology Degree.

How have people with lived/living experience been involved in this study?

Individuals with different types of epilepsy have reviewed the research design and wording of the questionnaires, through the Epilepsy Action Volunteer network. Feedback on the relevance of the project was also provided to ensure it is meaningful to the lives of the people it hopes to impact.

Changes have been made to ensure that this survey is easy to follow, and the research process is as understandable as possible.

Who has reviewed this research?

This research has been reviewed by, and received ethics clearance through, a subcommittee of the University of Oxford Central University Research Ethics Committee [Ethics Approval Reference: R91618/RE001].

Who do I contact if I have a concern or I wish to complain?

If you have a concern about any aspect of this research, please speak to the project lead **Rachel Batchelor (**rachel.batchelor@worc.ox.ac.uk**),** or their primary supervisor Dr Ceara Moore (ceara.moore@hmc.ox.ac.uk), and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

Please note that you may only participate in this survey if you are 18 years of age or over and live in the UK

☐ I certify that I am 18 years of age.

If you have read the information above and agree to participate with the understanding that the data you submit will be processed accordingly, please select the box below to start.

☐ Yes, I agree to take part

Appendix T: TDRP Eligibility Screening Questions

Are you a UK resident aged 18 years or over?

- ○ Yes
- ○ No

Please select the group that you are in for this study

- ○ I have temporal lobe epilepsy (and no current or previous diagnosis of a different type of epilepsy)
- ○ I have any type of epilepsy apart from temporal lobe epilepsy (and no current or previous diagnosis of temporal lobe epilepsy). Please state the type of epilepsy you have
- ○ Non-epilepsy control (no current or previous diagnosis of epilepsy
- ○ I do not fit into any of the above groups

→

Appendix U: TDRP Debrief Sheet

Self-Compassion, Mental Health and Emotion Regulation in Adults with Temporal Lobe Epilepsy

CUREC Approval Reference: R91618/RE001

Debrief Sheet

Debrief sheet: Self-compassion, mental health and emotion regulation in adults with temporal lobe epilepsy

After reading this information, please click the arrow at the bottom of the page to submit your answers.

Thank you for taking part in our study on self-compassion, mental health and emotion regulation in adults with epilepsy. As mentioned in the information sheet at the start of the survey, we are investigating differences in self-compassion between adults with temporal lobe epilepsy, adults with other types of epilepsy and adults with no history of epilepsy (or any other neurological conditions). In people with temporal lobe epilepsy specifically, we are also investigating self-compassion as a predictor of anxiety and depression and exploring the role emotion regulation plays in the associations between self-compassion and mental health outcomes.

Little research has been caried out in this area and we hope this research will greatly enhance our understanding. We are also hopeful that your answers could have a real impact on developing resources and improving support for adults with temporal lobe epilepsy and epilepsy more broadly.

Your participation is therefore very much appreciated.

If you know anyone else who may like to participate, you are welcome to provide them with the survey link or our contact details (at the bottom of the page).

Your data

The data that you have provided for this study will be kept anonymous and confidential at all times.

Further support

Sometimes people find reading and answering questions about their physical and mental health difficult. If you feel that you have been affected in any way by the questionnaire or would like to seek further information about available epilepsy and mental health services, please visit the links provided below.

Epilepsy

- https://www.epilepsy.org.uk **(Helpline: 0808 800 5050)**
- https://www.youngepilepsy.org.uk **(Helpline: 01342 831342)**
- https://www.epilepsysociety.org.uk **(Helpline: 01494 601 400)**

Mental health

- https://www.samaritans.org **(Helpline: 116 123)**
- https://www.mind.org.uk/ (Helpline: 0300 123 3393)
- https://giveusashout.org/ **(Text 'SHOUT' to 85258)**

If you have further concerns about your mental health, please speak with your GP who can then refer you for further specialist help if needed.

Thank you for taking the time to read this information.

If you have any further questions about this study or the questionnaire you completed, please feel free to contact us using the details below.

Best wishes,
Rachel Batchelor

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Appendix V: TDRP Data for Preliminary Analyses

Table V1

Preliminary Associations Between Sociodemographic and Epilepsy-Related Variables and Mental Health in Temporal Lobe Epilepsy (n = 180)

Variable	Anxiety			Depression		
	M (*SD*)	*p*	*r*	*M* (*SD*)	*p*	*r*
Age (years)		.024 [a]	-.106		.092[a]	-.079
Gender		.004[b]			.039[b]	
Female	11.80 (5.44)			13.26 (6.51)		
Male	8.50 (6.00)			10.46 (6.65)		
Ethnicity		.048[c]			.560[c]	
Non-white	15.67 (4.18)			14.67 (7.31)		
White British	10.96 (5.38)			12.54 (6.35)		
White other	11.55 (8.20)			13.73 (8.97)		
Marital status		.163[c]			.116[c]	
Married	10.16 (5.16)			11.28 (5.65)		
Engaged	9.71 (5.50)			11.46 (6.55)		
Divorced	13.13 (5.90)			16.06 (7.06)		
Widowed	14.50 (8.50)			15.50 (8.96)		
Cohabiting	12.29 (5.54)			13.58 (6.65)		
Single (never legally married)	11.85 (5.93)			13.42 (6.24)		
Highest level of education		.463[c]			.112[c]	
No qualifications	12.25 (6.08)			17.25 (5.19)		
Apprenticeship	14.80 (6.18)			16.80 (7.89)		
Secondary school	11.26 (5.82)			13.53 (6.51)		
Advanced level(s)/BTEC qualifications or equivalent	11.56 (5.25)			13.12 (6.06)		
Undergraduate degree	11.65 (5.87)			13.09 (7.16)		
Postgraduate degree	9.92 (5.52)			10.54 (5.96)		
Current occupation (main)		.740[c]			.055[c]	
Full-time employment	11.07 (5.40)			12.00 (6.70)		
Part-time employment	11.21 (4.98)			11.50 (6.08)		
Unemployed	10.67 (8.09)			12.00 (7.14)		
Unable to work	12.80 (6.20)			16.37 (5.62)		
Retired	9.33 (5.74)			13.50 (7.55)		
Student	11.40 (7.92)			12.60 (8.02)		
Carer	11.50 (2.12)			11.50 (3.54)		
Others	10.29 (4.57)			11.14 (6.47)		

Variable	Anxiety			Depression		
	M (*SD*)	*p*	*r*	*M* (*SD*)	*p*	*r*
Age of seizure onset (years)		.236[a]	-.065		.370[a]	-.050
Age of epilepsy diagnosis (years)		.443 [a]	-.042		.928 [a]	-.005
Time since seizure onset (years)		.086[a]	-.129		.243[a]	-.087
Seizure frequency		.008[a]	.146		.002[a]	.171
Aetiology		.602[b]			.764[b]	
Known	11.61 (6.03)			13.00 (7.14)		
Unknown	11.12 (5.63)			12.66 (6.66)		
Time taken diagnose (years)		.458[a]	.056		.032[a]	.160
Time since most recent seizure		.017[b]			.007[b]	
< 30 days	12.08 (5.99)			13.88 (6.74)		
≥ 30 days	10.14 (4.88)			11.24 (6.04)		
ASM treatment		.663[b]			.115[b]	
Monotherapy (one ASM)	11.03 (5.87)			11.79 (6.86)		
Polytherapy (multiple ASMs)	11.43 (5.58)			13.44 (6.77)		
Additional epilepsy treatments (e.g. dietary therapy, surgery, VNS)		.284[b]			.788[b]	
Yes	12.16 (5.54)			13.08 (6.02)		
No	11.05 (5.67)			12.75 (6.75)		
Current ASM side-effects		.605[b]			.166[b]	
Present	11.41 (5.74)			13.32 (6.49)		
Absent	10.92 (11.75)			11.75 (7.02)		
History of non-epileptic/psychogenic seizures		.656[b]			.483[b]	
Yes	10.87 (5.26)			13.59 (7.73)		
No	11.37 (5.26)			12.66 (6.34)		
Comorbid condition(s)		.933[b]			.836[b]	
Yes	11.32 (5.80)			12.92 (6.64)		
No	11.25 (5.52)			12.71 (6.58)		

Note. ASM = anti-seizure medication. BTEC = Business and Technology Education Council. VNS = vagus nerve stimulation.

[a] Pearson's *r* correlation (two-tailed).

[b] Independent samples *t*-test (two-tailed).

[c] One-way independent measures analysis of variance.