Thesis submitted in partial fulfilment of the degree of

Doctor of Clinical Psychology (DClinPsy)



Ruxandra Vasile

Doctorate in Clinical Psychology

Green Templeton College

University of Oxford

July 2024

Word count by component

Systematic Review of the Literature:	6,872 (after corrections)
Service Improvement Project:	4,252 (after corrections)
Theory-Driven Research Project:	3,976 (after corrections)
Executive Summary:	894 (after corrections)
Connecting/Reflective Narrative:	881
Total:	**16,875**

Note. Tables and figures are capped at 100 words. References and appendices are not included in the word count.

Table of contents

Word count by component…….……1

Table of contents……...…….……..2

Abstracts…….……..5

Systematic Review of the Literature…….…….5

Service Improvement Project…….……6

Theory-Driven Research Project……..…….…….8

Understanding the psychosocial impact of a child's cleft lip and/or palate on family members and familial relationships: a systematic review…….……...9

Abstract……10

Introduction……..11

Methods……15

Results……...…17

Discussion……40

References……46

Young People's Supported Accommodation (YPSA) Service: Understanding the experiences of young people in need of support for managing interpersonal relationships…….…….51

Abstract……...…52

Introduction…….…… 54

Methods……56

Results……..59

Discussion……79

References……85

Exploring the impact of cognitive appraisals, anxiety, and falls concern in spinal cord injury rehabilitation……..86

Abstract……..87

Introduction……88

Methods……..92

Results……...…….97

Discussion……...…..100

References…….104

Executive Summary for Theory-Driven Research Project…….…….106

Connecting/Reflective Narrative……109

Acknowledgements…….…….112

Appendices…….……...…..……...113

Appendix A: SRL Journal Submission Guide……113

Appendix B: SRL Specific Search Terms……..116

Appendix C: SRL QualSyst Appraisal Tool……...…117

Appendix D: SIP Journal Submission Guide…….118

Appendix E: SIP Information Sheet for Young People…….123

Appendix F: SIP Information Sheet for Staff……...…….126

Appendix G: SIP Consent Form for Young People…….……..129

Appendix H: SIP Consent Form for Staff…….....130

Appendix I: SIP Interview Schedule for Young People……131

Appendix J: SIP Focus Group Schedule for Staff…….……132

Appendix K: SIP Additional Supporting Quotations from Phase 1……...133

Appendix L: SIP Additional Supporting Quotations from Phase 2……..…..…135

Appendix M: SIP Dissemination Poster……137

Appendix N: TDRP Journal Submission Guide……138

Appendix O: TDRP Appraisals of Disability - Primary and Secondary Scale (ADAPSS)..144

Appendix P: TDRP Generalized Anxiety Disorder-7 (GAD-7) Questionnaire…….148

Appendix Q: TDRP Spinal Cord Injury – Falls Concern Scale (SCI-FCS) ……..149

Appendix R: TDRP The Hopkins Rehabilitation Engagement Rating Scale (HRERS)……150

Appendix S: TDRP Information Sheet for Participants ……...……..…151

Appendix T: TDRP Consent Form for Participants……...……....155

Appendix U: TDRP Sample Email for Physiotherapists……..…….156

Appendix V: TDRP Histograms of dependent variables……...157

Appendix W: TDRP Results from original data analysis plan……..160

Appendix X: TDRP University of Oxford Research Governance, Ethics & Assurance Approval……162

Appendix Y: TDRP Letter of NHS HRA REC approval……..163

Appendix Z: TDRP Letter of Support from Buckinghamshire Healthcare NHS Trust……165

Abstracts

Systematic Review of the Literature

Understanding the psychosocial impact of a child's cleft lip and/or palate on family members and familial relationships: a systematic review

A child's cleft lip and/or palate (CL/P) may have psychosocial effects on them, but also their family. This review examines the psychosocial impact of a CL/P on children's families and familial relationships compared to having a child born without CL/P. We systematically reviewed 21 quantitative studies. Studies measured outcomes that broadly fit into five areas: parental mental health, parenting stress, quality of life, family functioning, and parent-child relationships. Findings were mixed, with some evidence indicating that having a child born with a CL/P is linked to negative psychosocial outcomes, and some suggesting no significant differences in those outcomes between parents of children born without a CL/P and parents of children born with a CL/P. This could be because studies were highly heterogenous in the outcome measures used and variables that were measured and controlled for. We conclude with a discussion of limitations of included studies and of this review, and suggestions for further research, such as studying what factors separate families of children born with CL/P who are impacted psychosocially more than others.

Service Improvement Project

Young People's Supported Accommodation (YPSA) Service: Understanding the experiences of young people in need of support for managing interpersonal relationships

Background: Existing literature highlights the additional needs that young people (YP) in supported accommodation have with regards to understanding and forming healthy relationships. This project aimed to investigate the relationship support needs of YP in the Oxfordshire Young People's Supported Accommodation (YPSA) service from staff and YP perspectives, and to consider what type of interventions and materials might be most suitable for addressing those needs.

Methods: Semi-structured interviews and a focus group were held with 10 YPSA residents aged 18-24 and 4 staff members. Thematic analysis was conducted separately for YP and staff data.

Results: Three main themes emerged from YP: 1) mixed experiences of interpersonal relationships, 2) mixed experiences of previous support, and 3) needs within future support. Three main themes emerged from staff: 1) relationship difficulties and their impact, 2) support to be offered gently and thoughtfully, and 3) staff needs related to delivering this support.

Discussion: YP struggle with a range of difficulties in families, friendships, and romantic relationships. The need for additional support to develop and maintain healthy relationships was corroborated by both staff and YP's accounts. Support should be delivered in an individualised and sensitive manner according to each YP's needs and preferences. Content of such support should include a focus on a range of topics related to relationships, including dependency, exploitation, abuse, online safety, and online relationships. The delivery of such support should make use of multimedia and a clearly defined content structure to promote engagement. An adaptation of a pre-existing relationships program, titled 'Real Love Rocks'

(Barnardo's, 2022) has been suggested as potentially meeting these needs. Staff require appropriate training opportunities to better equip them to deliver healthy relationship support to the YP within the YPSA.

Keywords: interpersonal relationships, adolescent, social care, qualitative, childhood trauma

Theory-Driven Research Project

Exploring the impact of cognitive appraisals, anxiety, and falls concern in spinal cord injury rehabilitation.

Study design. Cross-sectional, between-groups, questionnaire.

Objectives. To investigate the impact of falls concern, anxiety, and cognitive appraisals on engagement in spinal cord injury rehabilitation.

Setting. The National Spinal Injuries Centre (NSIC), Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, United Kingdom.

Methods. Participants were inpatients at the NSIC. They completed a questionnaire comprising three measures. The Generalized Anxiety Disorder-7 (GAD-7) measured symptoms of anxiety, the Spinal Cord Injury-Falls Concern Scale (SCI-FCS) measured falls concern, and the Appraisals of DisAbility: Primary and Secondary Scale (ADAPSS) assessed cognitive appraisals. Engagement in rehabilitation was measured using the Hopkins Rehabilitation Engagement Rating Scale (HRERS), completed by participants' physiotherapists. Correlational analyses and a hierarchical multiple regression were conducted.

Results. Engagement in rehabilitation was not significantly correlated with cognitive appraisals of disability, falls concern, or generalised anxiety. The overall multiple regression model was not statistically significant.

Conclusions. Cognitive appraisals of disability, falls concern, and generalised anxiety are not significantly correlated with or predictive of engagement in SCI/D rehabilitation. Engagement in rehabilitation was rated generally high. There was a high prevalence of falls concern and generalised anxiety. Suggestions for future research include considering other psychological factors which may predict engagement, conducting this research in settings

with more varied engagement levels, and further exploring falls concern and its link with actual falls.

Systematic Review of the Literature

Understanding the psychosocial impact of a child's cleft lip and/or palate on family members and familial relationships: a systematic review

Trainee: Ruxandra Vasile (ruxandra.vasile@gtc.ox.ac.uk)

Internal supervisor: Dr Matthew Hotton (matthew.hotton@hmc.ox.ac.uk)

External supervisor: Dr Nicola Stock (nicola2.stock@uwe.ac.uk)

Date: February 2024

Word count: 6872

Proposed journal: The Cleft Palate-Craniofacial Journal. This journal is the premier interdisciplinary international journal dedicated to cutting-edge research related to cleft and craniofacial conditions. See *Appendix A* for author guidelines.

Conflicts of interest: None.

Abstract

A child's cleft lip and/or palate (CL/P) may have psychosocial effects on them, but also their family[2]. This review examines the psychosocial impact of a CL/P on children's families and familial relationships compared to having a child born without CL/P. We systematically reviewed 21 quantitative studies. Studies measured outcomes that broadly fit into five areas; parental mental health, parenting stress, quality of life, family functioning, and parent-child relationships. Findings were mixed, with some evidence indicating that having a child born with a CL/P is linked to negative psychosocial outcomes, and some suggesting no significant differences in those outcomes between parents of children born without a CL/P and parents of children born with a CL/P. This could be because studies were highly heterogenous in the outcome measures used and variables that were measured and controlled for. We conclude with a discussion of limitations of included studies and of this review, and suggestions for further research, such as studying what factors separate families of children born with CL/P who are impacted psychosocially more than others.

Introduction

A cleft lip and/or palate (CL/P) is a congenital condition occurring in approximately one in 700 births worldwide[3]. Cleft lip (CLs) directly affect the appearance of one's face, whilst cleft palates (CPs) are more closely associated with speech and functional difficulties (e.g. feeding)[4,5]. Some may be born with both a cleft lip and palate (CLP). The distribution of cleft types in the UK is approximately 42% CP, 30% CLP, and 25% CL with 3% unspecified or 'other' (CRANE, 2023). Individuals with a CL/P frequently engage with numerous healthcare professionals throughout childhood[4]. Many interactions with services occur early in childhood, and typically decrease over time[6]. After diagnosis, parents receive support and information related to CL/P and assistance with feeding when there is palatal involvement. This is followed by CL/P surgeries, typically between three months and one year of age. Additionally, individuals born with CL/P and their families meet with speech and language therapists, dentists, orthodontists, and clinical psychologists.

The burden and stress related to the many interventions affect the individual in question, but also their family. Qualitative research has been a useful starting point in understanding some of the effects on family. A child's diagnosis of CL/P may produce negative parental appraisals and prompt parents to feel shame, guilt and worry about the future[7]. Mothers of children with CL/P score higher on measures of depression and anxiety, and parents of these children report more stress compared to parents of children born without a CL/P[2]. Parental anxiety is also related to fear of social exclusion and stigmatization, and worry about the child's future[8]. Parental worries that their child might not be 'beautiful' and that their appearance will cause them difficulties are higher in parents whose children have a CL rather than a CP[5], with visible differences typically being more present in children with CL. Contrastingly, worries that a child will not be able to speak well are higher in parents of children with CPs[5].

As CL/Ps are sometimes genetic, many parents who have CL/Ps themselves experience feelings of sadness, because they know the challenges that lie ahead for their child[9] and may blame themselves for their child's CL/P, leading to increased stress and anxiety[10]. A further stressor is that parents must make difficult decisions about their child's treatment and manage seeing their child undergo surgery[11]. However, other studies show family resilience, quality of family relationships, empathy for others, and personal growth to be higher in parents of children with CL/P compared to parents of children without a CL/P[2].

Qualitative research examining the impact of a child's CL/P on their (anatomically) unaffected siblings shows that these siblings might benefit from an intensified bond compared to other siblings[12]. Although this could be seen as positive, because it can act as a protective factor against harmful social experiences in children with a CL/P, it may also have negative effects on unaffected siblings, who assume great responsibility for their affected sibling[12]. Qualitative research on the impact on grandparents showed that these individuals experienced difficult emotions and concerns for the future around the time of diagnosis yet received little support and information[13].

The 'ABC-X Model of Family Stress and Coping' suggests that the way a family deals with a stressful situation, such as their child receiving a CL/P diagnosis, is determined by their appraisal of (A) the stressor event, (B) the resources available to a family, (C) the family's perceptions of the stressor, and (X) the likelihood of crisis or negative outcomes[14]. An event is perceived as stressful if the demands of it outweigh the resources the family has to cope with the event. Resources may include skills and coping mechanisms but also external resources such as social support. This suggests that a wider familial approach for psychological care in CL/P can be beneficial. This idea is further supported by the support-buffering hypothesis, which suggests that in the presence of health difficulties, social support is linked to better adjustment to a health condition[15]. In some CL/P research, social support

has even been linked to more post-traumatic growth for parents with children born with CL/P[16].

Qualitative research investigating the impact of a child's CL/P on family members presents a mixture of positive and negative outcomes, both of which are vital to consider when developing psychological interventions, so that strengths can be recognized and optimized, and difficulties can be addressed. Furthermore, understanding how CL/Ps affect the wider family system may reveal needs that are currently unsupported as well as untapped sources of support[9]. Two reviews to date have investigated this[8,17]. Nelson et al. (2012) found a gap in the literature for the impact on parents once their child was out of infancy, as well as varied results with regards to the extent to which having a child born with a CL/P impacts families' psychosocial outcomes[18]. Namdar et al. (2022) looked specifically at anxiety, depression, and quality of life of mothers of children born with CL/P and found that the majority of included studies showed increased levels of anxiety and depression in the exposure group[17]. However, neither review has compared this population to parents of children born without CL/P, meaning that it is challenging to determine the extent to which these outcomes might be specifically due to their child being born with CL/P.

Given the lack of systematic reviews about the psychosocial outcomes of having a child born with a CL/P compared to a child born without one, as well as the age of the review by Nelson et al. (2012)[18] and the limited range of outcomes examined by Namdar et al. (2022)[17], our first review question was: What is the psychosocial impact of having a child born with a CL/P on that child's family members and the familial relationships within that family, compared to having a child born without a CL/P?

Given the differences in difficulties faced by children with different types of cleft (e.g. appearance in CL versus feeding in CP) identified in qualitative research[5], our second

review question was: Within included studies, are there differences in psychosocial outcomes between parents of children with different types of cleft?

Methods

Search strategy

The protocol was registered through PROSPERO (ID: CRD42022338615) and PRISMA guidelines[1] were followed in the review process. Searches were conducted on PsycINFO, PubMed, Embase, and Medline. The PICO (population, interventions, comparators, outcomes) acronym was used to guide selection of search terms. 'Interventions' was not used as we wanted to include all relevant designs irrespective of whether interventional or not. Whilst inclusion of a 'comparator' group was necessary for inclusion in the review, this was not included in search terms to ensure all relevant papers were captured. Search terms were based around concepts of 'CL/P', 'psychological outcomes', and 'family' (see *Appendix B* for full search terms).

Inclusion/Exclusion criteria

Inclusion criteria comprised any quantitative studies investigating the psychosocial impact of a child's CL/P on their family and familial relationships. Studies had to be published in peer-reviewed journals and include a control group of families of children born without a CL/P.

Non-English language publications, purely qualitative papers, case studies, case series, and reviews were excluded. Publications were excluded if they looked at the impact of CL/P alongside other health conditions, without measuring the specific impact of CL/P.

Study selection

The initial search was run on 26th July 2023. Screening was conducted using titles/abstracts, followed by full-texts. The lead author and second author discussed the screening procedure to ensure inclusion/exclusion criteria and practiced applying the criteria together. Afterwards, separately, the lead author screened all papers, whilst the second screened 20% and 25% of titles/abstracts and full-texts, respectively. Inter-rater reliabilities were good: titles/abstracts: Cohen's kappa=.80; full-text: Cohen's kappa=.85[19]. When

disagreements arose, these were discussed and resolved. If disagreement was not resolvable, the lead author's decision was adhered to.

The search was re-run on 16th February 2024 and 262 more papers were found. None met inclusion criteria.

Data synthesis

Study information was extracted for country of origin, setting, design, sample size, participant demographic data, type of psychosocial outcome studied, and outcome measure used. Study results were extracted and divided into outcomes which compared participants with CL/P with unaffected controls, and those which looked at outcomes for different types of CL/P.

Study quality was appraised using the QualSyst tool[20] (see *Appendix C* for tool). This tool contains 14 criteria for scoring whether research adheres to recommended guidelines. Scoring options and scores are 'Yes' (2), 'Partial' (1), and 'No' (0), with total scores being transformed into percentages. 3/14 criteria (#5, #6, #7) did not apply to this review's studies as they referred to interventional studies. These criteria were excluded, and included studies were marked as percentages of a total possible score of 22 rather than 28, as set out in the original tool. Inter-rater reliabilities between the first and second rater for a proportion of these (47%) achieved good agreement: Cohen's kappa=.82;[19].

A narrative synthesis was conducted due to the range of psychosocial outcomes that were measured. A meta-analysis was not possible due to notable heterogeneity in outcomes measures between studies.

Results

Study characteristics and quality appraisal of the included studies are reported in *Table 1.1* and *Table 1.2*, respectively. *Table 1.3* reports results by study.

Study characteristics

Overall, 21 studies met inclusion/exclusion criteria (*Figure 1.1*).

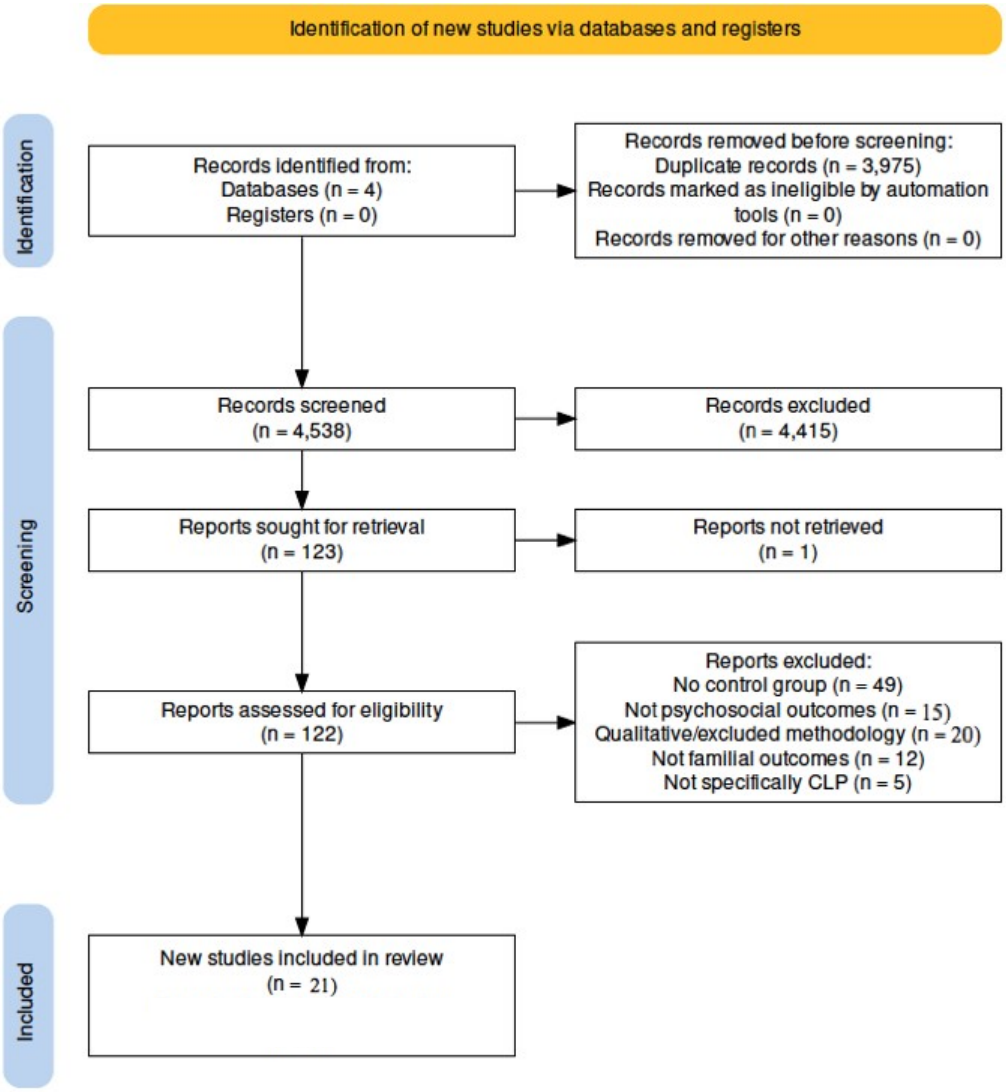


Figure 1.1. PRISMA diagram of included studies[1].

Sample sizes varied from 44 participants[21] to 99432[22]. Three studies (14%) were population-wide studies of over 79,000 participants[22-24]. Six studies (29%) collected data at multiple time points whilst the majority used a cross-sectional design. In line with inclusion criteria, all studies only included children under the age of 18 and had a control group of

children born without a CL/P. Nine studies (43%) included only one-year-olds or younger. One study did not specify child age beyond confirmation that participants were under 18[22]. Recruitment of participants happened across a range of sites, including outpatient hospitals, CL/P services, community, outpatient dental services, and maternity wards. Aside from having a control group of children born without CL/P, three studies also had additional groups of children born with Down's Syndrome[22], children born with coronary heart disease (CHD)[25], and children suffering from migraines[26]. Eight studies (38%) were from Europe, eight from Asia, three (14%) from North America, and two (10%) from South America. Six studies (29%) did not report the gender ratios of both children and parents. Studies which reported gender did this in binary female/male categories, with no option of 'non-binary'/'other' categories. Gender proportions ranged from 16%-62% female in children, and 18%-100% female in parents. 12 studies (57%) focused exclusively on mothers. Only three studies (14%) reported participants' ethnicities[26-28]. Therefore, ethnicity was not a variable included in *Table 1.1*. Gassling et al. (2014) included 100% White participants[26], Collett et al. (2012) over 88% White participants[29], and Wyszynski et al. (2005) mostly Latino participants[28]. Fifteen studies reported on cleft type (71%). Three of these included participants with only one type of cleft (CLP).

Table 1.1. Study characteristics of included studies.

Authors (year)	Country of origin	Setting	Design	Total sample size	Cleft group - Children			Non-cleft group - Children			Cleft group - Parents		Non-cleft group - Parents		Domains measured (Specific outcome measure/s used)
					Cleft type. (%)	Age (mean, SD)	Gender (F%)	Participant characteristics	Age (mean, SD)	Gender (F %)	Age (mean, SD)	Gender (F%)	Age (mean, SD)	Gender (F %)	
Antunes et al. (2014)	Brazil	Outpatient dental patients	Cross-sectional question-naire	100 (cleft n = 50, non-cleft n = 50)	CL: 8 CP: 30 CLP: 62	9.52 years (4.02)	40	Unaffected controls	8.76 years (2.60)	40	NR	NR	NR	NR	**QoL** (Brazilian Family Impact Scale [B-FIS])
Aslan et al. (2018)	Turkey	Outpatient dental patient	Cross-sectional question-naire	292 (cleft n = 148, non-cleft n = 144)	NR	Age 0-6: 2.62 years (1.65) Age 7-12: 9.27 years (2.63) Age 13-18: 15.11 years (1.57)	41	Unaffected controls	Age 0-6: 2.74 years (1.90) Age 7-12: 9.41 years (1.57) Age 13-18: 14.51 years (1.75)	43	Mothers: Age 0-6: 26.15 (3.14) Age 7-12: 33.45 (4.12) Age 13-18: 42.08 (5.06) Fathers: Age 0-6: 29.23 (4.35) Age 7-12: 37.76 (3.98) Age 13-18: 47.86 (4.53)	50	Mothers: Age 0-6: 27.29 (4.21) Age 7-12: 35.76 (4.52) Age 13-18: 43.16 (4.56) Fathers: Age 0-6: 32.32 (3.95) Age 7-12: 38.36 (4.08) Age 13-18: 48.83 (3.64)	50	**QoL** (Short form of the Turkish version World Health Organization QoL [WHOQOL-BREF-TR]) **Family functioning** (Family Assessment Scale [FAS])
Boztepe, Yildiz & Cinar (2016)	Turkey	Outpatient hospital patients	Cross-sectional question-naire	200 (cleft n = 50, non-cleft n = 150)	NR	Range: 1-12 months Mean/SD NR	58	Unaffected controls (n = 100) & infants with coronary heart disease (n = 50)	Range: 1-12 months Mean/SD NR	51	Lower range: 19 Mean/ SD NR	100	Lower range: 19 Mean/SD NR	100	**Parent-child relationships** (Maternal-infant attachment levels using the Maternal Attachment Inventory [MAI])
Boztepe, Cinar & Ozgur (2020)	Turkey	Outpatient hospital patients	Cross-sectional question-naire	180 (cleft n = 90, non-cleft n = 90)	CL: 33 CP: 33 CLP: 33	5.9 months (3.4)	44	Unaffected controls	5.9 months (3.4)	44	29.6 (5.2)	100	28.5 (5.4)	100	**Parenting stress** (The Parenting Stress Index - Short Form [PSI-SF] & Multi-dimensional Scale of Perceived Social Support)
Collett et al. (2012)	USA	Community sample	Cross-sectional question-naire	217 (cleft n = 93, non-cleft n = 124)	CL: 26 CP: 38 CLP: 35	6.9 years (1.0)	51	Unaffected controls	6.7 years (1.1)	53	NR	100	NR	100	**Parenting stress** (Parenting Stress Inventory [PSI])
Despars et al. (2011)	Switzerland	Maternity ward patients	Longitudinal	58 (cleft n = 22, non-cleft n =	CL: 45 CLP: 55	Timepoint 1: 2 months (SD NR) Timepoint	23	Unaffected controls	Timepoint 1: 2 months (SD NR) Timepoint	58	Mothers: 31.1 (3.8) Fathers:	100	Mothers: 32.6 (4.51) Fathers: 35 (5.22)	100	**Parent-child relationships** (Working Model of the Child Interview)

Authors (year)	Country of origin	Setting	Design	Total sample size	Cleft group - Children			Non-cleft group - Children			Cleft group - Parents		Non-cleft group - Parents		Domains measured (Specific outcome measure/s used)
				36)		2: 12 months (SD NR)			2: 12 months (SD NR)		33.2 (4.6)				**Parental mental health** (Maternal post-traumatic stress using the Impact of Events Scale)
Gassling et al. (2014)	Germany	Outpatient CL/P patients	Cross-sectional observational study	55 (cleft n = 15, non-cleft n = 40)	CLP: 100	9 years (1.25)	53	Unaffected controls (n = 20) & children suffering from migraines (n = 20)	Unaffected controls: 10.6 years (2.6) Migraine group: 10.55 years (1.5)	Unaffected controls: 60 Migraine group: 40	Mothers: 37.9 (6.7) Fathers: 40.4 (8.4)	50	Unaffected controls: Mothers: 40.6 (5.4) Fathers: 41.4 (4.2) Migraine group: Mothers: 39.3 (4.1) Fathers: 43.7 (7.1)	Unaffected controls: 50 Migraine group: 50	**Parent-child relationships** (Intra-familial interaction task)
Habersaat et al. (2013)	Switzerland	Maternity ward patients	Longitudinal	85 (cleft n = 40, non-cleft n = 45)	CL: 28 CP: 10 CLP: 62 (72 unilateral)	Timepoint 1: 2 months (SD NR) Timepoint 2: 12 months (SD NR)	23	Unaffected controls (2 groups collected from 2 different hospitals)	Group 1: 1: 2 months (SD NR) Timepoint 2: 12 months (SD NR) Group 2: 1: 4 months (SD NR) Timepoint 2: 12 months (SD NR)	Group 1: 55 Group 2: 40	30.7 (4.2)	100	Group 1: 34.2 (9.4) Group 2: 31.2 (5.1)	100	**Parent-child relationships** (The Care Index & The Strange Situation Procedure) **Parental mental health** (Perinatal Posttraumatic Stress Questionnaire)
Habersaat et al. (2018)	Switzerland	Maternity ward patients	Longitudinal	44 (cleft n = 30, non-cleft n = 14)	NR	Timepoint 1: 2 months (SD NR) Timepoint 2: 12 months (SD NR) Timepoint 2: 5 years (SD NR)	23	Unaffected controls	Timepoint 1: 2 months (SD NR) Timepoint 2: 12 months (SD NR) Timepoint 2: 5 years (SD NR)	50	Age at childbirth: 30.90 (4.44)	100	Age at childbirth: 30.90 (36.91)	100	**Parent-child relationships** (Working Model of the Child Interview, Parental Development Interview & Parenting Style and Dimensions Questionnaire)
Kumar et al. (2020)	India	Outpatient CL/P & paediatric patients	Cross-sectional question-naire	240 (cleft n = 142, non-cleft n = 98)	Age <10: CL: 44 CP: 24 CLP: 32 Age> 10: CL: 70 CP: 13 CLP: 17	Age <10: 3.4 years (SD NR) Age> 10: 16.14 years (SD NR)	NR	Unaffected controls	NR	NR	*Age <10:* Mothers: 29.76 (SD NR) Fathers: 34.56 (SD NR) *Age> 10:* Mothers:	Age <10: 46 Age> 10: 23	Mothers: 41.27 (SD NR) Fathers: 44.30 (SD NR)	18	**Parental mental health** (Parental depression, anxiety & stress using General Health Questionnaire-12 & Depression, Anxiety, Stress Scale [DASS])

Authors (year)	Country of origin	Setting	Design	Total sample size	Cleft group - Children			Non-cleft group - Children			Cleft group - Parents		Non-cleft group - Parents		Domains measured (Specific outcome measure/s used)
											45.24 (SD NR) Fathers: 50.25 (SD NR)				
Lentge et al. (2022)	Germany	Outpatient CL/P patients	Cross-sectional questionnaire	571 (cleft n = 33, non-cleft n = 538)	NR	Under 4 years (M & SD NR)	NR	Unaffected controls (taken from two previous studies)	Under 6 years (M & SD NR)	NR	34.7 (5.5)	79	34.9 (6.1)	NR	**Parenting stress** (The Parenting Stress Index)
Losier, Cyr & Dubois-Comtois (2020)	Canada	Outpatient CL/P patients & adoption agencies	Cross-sectional questionnaire	84 (cleft n = 29, non-cleft n = 55)	CLP: 100 (66 unilateral)	3.85 years (1.47)	48	Unaffected controls	2.54 years (1.16)	62	42.2 (5.3)	NR	41.2 (2.5)	NR	**Parent-child relationships** (The Strange Situation Procedure & mini-Maternal Behaviour Q-Sort)
Madhoun et al. (2021)	USA	Outpatient CL/P patients & community	Cross-sectional question-naire	60 (cleft n = 30, non-cleft n = 30)	CL: 17 (100 unilateral) CP: 47 CLP: 37 (73 unilateral)	43 days (22.1)	47	Unaffected controls	48 days (24.5)	43	27 (5.8)	100	29 (4.4)	100	**Parental mental health** (Edinburgh Postnatal Depression Scale) **Parenting stress** (Parenting Stress Index – SF) **QoL** (Feeding/Swallowing Impact Survey)
Montirosso et al. (2012)	Italy	Outpatient CL/P & paediatric patients	Cross-sectional question-naire	50 (cleft n = 25, non-cleft n = 25)	NR	64.16 days (6.14)	16	Unaffected controls	64.36 days (4.85)	16	34.43 (2.96)	100	34.18 (4.99)	100	**Parental mental health** (Beck Depression Inventory & Italian version of Infant Behavior Questionnaire-Revised) **Parent-child relationships** (Global Rating Scales of Mother–Infant Interaction)
Murray et al. (2008)	UK	Outpatient CL/P & maternity ward patients	Longitudinal	190 (cleft n = 94, non-cleft n = 96)	Early lip repair group: CLP: 57 CL: 43 Late lip repair group: CLP: 64 CL: 36	Timepoint 1, 2, 3, 4 respectively: 2, 6, 12, 18 months (M & SD NR)	Early lip repair group: 35 Late lip repair group: 36	Unaffected controls	Timepoint 1, 2, 3, 4 respectively: 2, 6, 12, 18 months (M & SD NR)	35	Early lip repair group: 28.83 (4.84) Late lip repair group: 29.22 (5.21)	100	28.93 (5.36)	100	**Parent-child relationships** (Measures of maternal sensitivity, maternal positive involvement, and infant distress & The Strange Situation Procedure)
Nes et al. (2014)	Norway	Community	Longi-tudinal	99432 (cleft n = 179, non-cleft n =	NR	NR	NR	Unaffected controls (n = 99139) & infants with Downs syndrome (n =	NR	NR	NR	100	NR	100	**Parental mental health** (25-item Hopkins Symptom Checklist & Satisfaction With Life Scale)

Authors (year)	Country of origin	Setting	Design	Total sample size	Cleft group - Children			Non-cleft group - Children			Cleft group - Parents		Non-cleft group - Parents		Domains measured (Specific outcome measure/s used)
				99253)				114)							
Sato et al. (2021)	Japan	Community	Longi-tudinal	84750 (cleft n = 148, non-cleft n = 84602)	CL: 31 CP: 20 CLP: 49	Timepoint 1: 1 month (SD NR) Timepoint 2: 6 months (SD NR) Timepoint 3: 12 months (SD NR)	CLP: 33 CL: 41 CP: 57	Unaffected controls	Timepoint 1: 1 month (SD NR) Timepoint 2: 6 months (SD NR) Timepoint 3: 12 months (SD NR)	49	31.2 (5.0) (across CL/P & non-CL/P groups)	100	31.2 (5.0) (across CL/P & non-CL/P groups)	100	**Parental mental health** (Kessler Psychological Distress Scale (K6) & Japanese version of the 10-item Edinburgh Postnatal Depression Scale [EPDS])
Sunal Akturk et al. (2023)	Turkey	Outpatient hospital patients	Cross-sectional question-naire	128 (cleft n = 82, non-cleft n = 46)	CLP: 47 (40 unilateral) CP: 53	CLP: 9 days (6.0) CP: 8.9 days (5.9)	CLP: 30 CP: 43	Unaffected controls	7.3 days (6.1)	52	*CLP:* Mothers: 28.5 (5.6) Fathers: 32.2 (5.5) *CP:* Mothers: 27.7 (6.1) Fathers: 31.4 (4.9)	50	Mothers: 27.9 (4.8) Fathers: 32.2 (5.1)	50	**Parental mental health** (State-Trait Anxiety Inventory [STAI])
Tsuchiya et al. (2019)	Japan	Community	Cross-sectional question-naire	79140 (cleft n = 211, non-cleft n = 78929)	CLP: 30 CL: 43 CP: 27	1 year (M & SD NR)	<35 primiparae: 47 <35 multiparae: 44 >35 primiparae: 39 >35 multiparae: 46	Unaffected controls	1 year (M & SD NR)	<35 primiparae: 49 <35 multiparae: 49 >35 primiparae: 49 >35 multiparae: 48	M & SD NR Median & IQR reported	100	M & SD NR Median & IQR reported	100	**Parent-child relationships** (Mother-to-Infant Bonding Scale)
Wysznski et al. (2005)	Argentina	Outpatient CL/P & paediatric patients	Cross-sectional question-naire	345 (cleft n = 165, non-cleft n = 180)	UCLP: 48 BCLP: 42 CP: 10	UCLP: 6 years (4.2) BCLP: 6.9 years (4.3) CP: 5.5 years (3.8)	NR	Unaffected controls	NR	NR	UCLP: 34.1 (7.7) BCLP: 38.8 (10.9) CP: 35.7 (7.3)	UCLP: 69 BCLP: 65 CP: 80	29.4 (9.2)	89	**Family functioning** (Moos Family Environment Scale)
Zeraatkar et al. (2018)	Iran	Outpatient CL/P & dental patients	Cross-sectional question-naire	102 (cleft n = 55, non-cleft n = 47)	CLP: 100 (61 unilateral)	Range: 2-5 years Mean/SD NR	43	Unaffected controls	Range: 2-5 years Mean/SD NR	49	NR	NR	NR	NR	**Family functioning** (Early Childhood Oral Health Impact Scale [ECOHIS])

Note. CL/P = cleft lip and/or palate; CLP = cleft lip and palate; CL = cleft lip; CP = cleft palate; F = female; IQR = interquartile range; M = mean; N = number; NR = not reported; SD = standard deviation; QoL = quality of life.

Quality appraisal of studies

Quality was appraised using the QualSyst tool[20] and scores are shown in *Table 1.2*. Eight (38%) studies scored 95%-91%, 11 (52%) scored 68%-86%, and two (10%) scored below 68%. All but one study[30] reported some estimate of variance in their results, and most used appropriate, well-described analytic methods and reported their results in enough detail.

Common issues which decreased quality of papers included failures to explain how control participants were recruited, omission of participant characteristics (e.g. cleft types), and no explanations for why sample sizes were chosen. Furthermore, outcome measures were not always fully described, and psychometric properties of these were often not reported. Lastly, although all studies included a control group, it was not always clear whether confounding variables had been controlled for (e.g. matching based on age/gender and conducting statistical analyses to test whether groups significantly differed on potentially confounding variables).

Table 1.2. Quality appraisal of included studies.

Authors (year)	Question/ objective clear?	Design evident/ appropriate?	Subject selection described/ appropriate?	Subject characteristics described?	Outcome well-defined/ robust?	Sample size appropriate?	Analytic methods described/ appropriate?	Estimate of variance?	Confounding?	Results reported in detail?	Conclusion supports?	Score (%)
Antunes et al. (2014)	2	1	1	1	2	1	2	2	2	2	2	82
Aslan et al. (2018)	1	2	1	1	2	1	2	2	2	2	1	77
Boztepe, Yildiz & Cinar (2016)	1	2	0	1	2	1	2	2	1	2	2	73
Boztepe, Cinar & Ozgur (2020)	1	1	0	1	2	1	2	2	1	2	2	68
Collett et al. (2012)	2	2	2	1	1	2	2	2	2	2	2	91
Despars et al. (2011)	2	2	2	2	1	1	1	2	1	2	2	82
Gassling et al. (2014)	2	2	2	2	1	1	2	2	2	2	2	91
Habersaat et al. (2013)	1	2	2	2	2	1	2	0	2	2	2	82
Habersaat et al. (2018)	1	2	2	1	2	1	2	2	1	2	2	82
Kumar et al. (2020)	2	1	1	1	1	1	2	2	1	1	1	64
Lentge et al. (2022)	1	2	1	1	2	1	2	2	2	2	2	82
Losier, Cyr & Dubois-Comtois (2020)	2	2	2	2	2	1	2	2	2	2	2	95
Madhoun et al. (2021)	2	2	1	2	2	1	2	2	2	2	2	91
Montirosso et al. (2012)	2	2	2	1	2	1	2	2	2	2	2	91
Murray et al. (2008)	2	2	2	2	1	1	2	2	2	2	2	91

Nes et al. (2014)	2	2	2	1	1	2	2	2	2	2	1	86
Sato et al. (2021)	1	2	2	2	1	2	2	2	2	2	2	91
Sunal Akturk et al. (2023)	2	2	1	2	1	1	2	2	2	2	2	86
Tsuchiya et al. (2019)	1	2	2	2	2	2	2	2	2	2	2	95
Wysznski et al. (2005)	1	2	2	1	2	1	2	2	1	2	2	82
Zeraatkar et al. (2018)	1	1	1	1	1	1	1	2	1	1	2	59

Table 1.3. Findings of included studies.

Authors (year)	Comparison between CL/P group & control group	Factors associated with outcomes in CL/P group
Antunes et al. (2014)	▪ The CL/P group was associated with greater negative impact on quality of life of families in the following areas: parental emotions, parent/family activity, and financial burden.	▪ CL and CLP groups demonstrated greater negative impact on familial quality of life than the CP group.
Aslan et al. (2018)	▪ Parents of children born with CL/P aged 0-6 scored in the 'problematic' range on subtests of behavioural control, required attention and role dimensions. Parents of unaffected controls aged 0-18 also scored within the 'problematic' range in the aforementioned areas. ▪ Parents of children born with CL/P aged 7-18 only struggled with required attention. ▪ Parents of unaffected children aged 13-18 scored significantly higher on measures of physical, psychological, and social quality of life than the age group-matched parents of children born with CL/P.	
Boztepe, Yildiz & Cinar (2016)	▪ Mothers of infants born with CL/P scored lower on measures of secure attachment to their infant than mothers of unaffected controls and mothers of infants with coronary heart disease.	▪ Mothers of infants born with CL/P who did not experience psychological difficulties during pregnancy scored significantly higher on measures of secure attachment to their infant than mothers of infants born with CL/P with perinatal psychological difficulties.
Boztepe, Cinar & Ozgur (2020)	▪ Mothers of children born with CL/P reported significantly more stress and significantly less social support than mothers of unaffected infants. ▪ A significant correlation was found between the social support score and the parenting stress score for mothers of children born with CL/P, but not for mothers of unaffected infants.	▪ There were significant differences in stress scores of mothers with different cleft types, with mothers of children born with CL/P scoring the highest, followed by mothers of children born with CP, followed by mothers of children born with CL. ▪ There were significant differences in social support scores between cleft types. Mothers of children born with CL reported higher social support. ▪ For all cleft types, higher stress occurred when diagnosis was after birth, the child was not breastfeeding and having difficulties with feeding, the child was perceived to have a difficult temperament, and mothers reported self-blame, blame of others, anger, and concern for the future. ▪ Mothers whose infants had not yet undergone CL/P surgery reported higher stress.
Collett et al. (2012)	▪ No significant differences were found on the 'child characteristics' or the 'parent characteristics' domains of the Parenting Stress Index between parents of children with CL/P and those of unaffected children.	
Despars et al. (2011)	▪ Mothers of children born with CL/P presented with significantly fewer secure and significantly more disengaged attachment representations compared to mothers of health infants. ▪ Mothers of children born with CL/P scored significantly higher on posttraumatic stress outcomes than mothers of unaffected infants. ▪ Mothers of children born with CL/P with relatively low PTSD symptom scores were more likely to be categorised as having disengaged attachment patters compared to mothers of unaffected infants and mothers of children born with CL/P with relatively high PTSD symptom scores.	▪ Different cleft types did not significantly affect the quality of mothers' attachment representations or maternal post-traumatic stress.
Gassling et al. (2014)	▪ Mothers of children born with CLP tried to support their children more often than mothers of children born without CLP. ▪ Fathers of children born with a CLP used help strategies less frequently towards their child compared to fathers of unaffected children.	

	▪ Children born with CLP displayed more autonomous behaviours towards their mothers and fathers compared to children experiencing migraines and unaffected children. ▪ Children born with a CLP displayed less reliance on their fathers and asked them less questions than children in the other two groups.	
Habersaat et al. (2013)	▪ There was a trend showing more sensitive maternal behaviours, such as increased attentiveness and reactiveness to child behaviours in mothers of unaffected children compared to mothers of children born with a CL/P. ▪ In mother-infant interactions, children born with a CL/P cooperated less than unaffected children. ▪ There was no significant difference between mothers of children born with CL/P and mothers of unaffected children on posttraumatic stress symptoms as measured by the Perinatal Posttraumatic Stress Questionnaire. Posttraumatic stress symptom scores were exceptionally low in both groups. ▪ There was no influence of posttraumatic stress symptoms on mother-infant interaction styles.	
Habersaat et al. (2018)	▪ There were no significant differences in maternal representations of the mother-child relationships between mothers in the cleft and mothers in the non-cleft group at 2 months, 12 months, or 5 years. ▪ Parents of children born with a CL/P were significantly more authoritarian and used significantly more punitive strategies than parents of children without a cleft when their child was aged 5.	▪ Mothers of children born with a cleft showed significantly more caregiving sensitivity, fear for the infant's safety, involvement with their child, and pride about their child when the child was 12 months old than when the child was 2 months old. They also showed significantly less indifference.
Kumar et al. (2020)	▪ Statistically significant differences were found in parental depression, anxiety, and stress scores between parents of under 10 year olds with CL/P, parents of over 10 year olds with CL/P, and parents of unaffected infants. Parents of over 10 year olds with CL/P scored the highest on all three domains.	▪ For parents of under 10 year olds with CL/P, cleft type did not affect depression, anxiety, or stress scores. ▪ For parents of over 10 year olds with CL/P, there was a significant difference in depression and anxiety scores between parents of children born with CP and parents of children born with CL/P, with parents of children born with CL/P scoring higher.
Lentge et al. (2022)	▪ Parenting stress, as measured by the Parenting Stress Index, was significantly higher in parents of children born with a CL/P compared to parents of unaffected children. ▪ The most significantly different subscales on the measure between the two groups were 'Parental depression' and 'child-related requirements'.	
Losier, Cyr & Dubois-Comtois (2020)	▪ Mothers of adopted children born with a CLP presented as less sensitive compared to mothers of adopted children born without a CLP as rated by the mini-Maternal Behaviour Q-Sort. ▪ Children presenting with both a CLP and an insecure attachment style were more likely to have less sensitive mothers.	
Madhoun et al. (2021)	▪ Having an infant with a CL/P compared to an unaffected infant led to significantly reduced maternal health-related quality of life due to infant feeding problems. ▪ There were significant differences on the 'worry' subscale of the Feeding/Swallowing Impact Survey between mothers of children born with CL/P and mothers of unaffected infants, with mothers of children born with CL/P worrying more about their child's general health and whether they are doing enough to help with their child's feeding difficulties. Mothers of unaffected infants worried more about whether their child was getting enough to drink or eat. Both groups of mothers worried about whether their child will choke. ▪ Mothers of children born with CL/P ranked their biggest concern to be leaving their child due to fear of others having to take care of them and feed them. Mothers of unaffected infants ranked their biggest concern to be being too tired to carry out their activities of daily living. ▪ Mothers of children born with CL/P reported significantly greater overall stress compared to mothers of unaffected infants, but both groups scored within the 'normal' range of the Parenting Stress Index.	▪ Infants with CP only scored highest on the 'feeding difficulties' subscale. ▪ Total stress scores differed between cleft type to an almost significant level (p=.06), with mothers of children born with CP scoring the highest, followed by CL/P.
Montirosso et al. (2012)	▪ Scores of depressive symptoms as judged by the Beck Depression Inventory did not significantly differ between mothers of children born with CL/P and mothers of unaffected infants.	

	▪ In an infant-mother interaction task, mothers of children born with CL/P showed significantly fewer communicative signals, a lower level of engagement, and more depressive signs as judged by their facial expression, tone of voice, and demeanour. Mothers of unaffected infants showed more reciprocal and satisfying engagement with their infants compared to mothers of children born with CL/P. In mothers of children born with CL/P, there was a significant association between more positive infant temperament (as rated by mothers) and less maternal negative affect (depressive-like behaviour) as judged by facial expression, tone of voice, and demeanour.	
Murray et al. (2008)	▪ Compared to controls, mothers of infants having late CL repair were less sensitive and positively involved with their infants. These mothers and their infants looked at each other less compared to those in the control group. ▪ Compared to controls, mothers of infants having early CL repair were less sensitive.	▪ Mothers of infants having late CL repair were less positively involved with their infants than mothers of infants having early CL repair. ▪ Infants having late CL repair spent less time looking at their mothers than infants having early CL repair. ▪ Mothers of infants with a higher level of 'disfigurement' were less positively involved with their infant in both early and late repair groups. ▪ 'Severely disfigured' infants having late CL repair looked at their mothers significantly less than infants with milder 'disfigurement' having late CL repair. ▪ Infants with CLP in both early and late repair groups looked at their mothers less than infants with just CL.
Nes et al. (2014)	• There were no significant differences in psychological distress scores between mothers of unaffected infants, infants born with CL/P, and infants born with Down's during pregnancy. At all post-partum timepoints, mothers of infants born with Down's scored significantly higher on psychological distress than and unaffected controls' mothers and mothers of children born with CL/P. At 6 months post-partum only, mothers of children born with CL/P scored significantly higher than unaffected controls' mothers on psychological distress. • Satisfaction with life scores were relatively high for all mothers throughout the study, but decreased over time, reaching their lowest point at 3 years post-partum. • Higher educational level and being a first-time mother were significantly associated with higher life satisfaction and lower psychological distress in both case and control groups.	
Sato et al. (2021)	• At 27 weeks pregnancy, mothers of CL/P or CP infants had a greater risk of psychological distress than the mothers of unaffected controls. • At 6 months post-partum, mothers of CP infants had a greater risk of psychological distress than mothers of unaffected infants. • At 1 year post-partum, there were no significant associations between being the mother of an infant with any cleft type and having higher risk of psychological distress. • At 1 month post-partum, CLP mothers (but not CP or CL) had a greater risk of post-partum depression than mothers of unaffected controls.	• There were significant associations at 27 weeks of pregnancy between being the mother of a CLP or CP infant (but not CL) and having psychological distress. • At 1 month post-partum, CLP mothers (but not CP or CL) had a significantly greater risk of post-partum depression.
Sunal Akturk et al. (2023)	• Parents of CP and CLP newborns had moderate levels of state and trait anxiety. Parents of unaffected newborns had low state anxiety and moderate train anxiety. • Mothers of unaffected newborns had significantly lower levels of both anxiety types than mothers of CP and CLP infants. • Fathers of CLP infants had higher state anxiety scores than fathers of unaffected infants. • Mothers of CLP newborns had significantly higher trait anxiety scores than their father counterparts.	• There were no significant differences in state or trait anxiety scores between CP and CLP mothers. • Both CLP and CP mothers were most concerned about their child's speech and feeding. CLP mothers reported significantly more anxiety about their child's facial appearance than CP mothers.
Tsuchiya et al. (2019)	• There was no increased risk of bonding disorders in mothers of infants born with a CL/P compared to mothers of unaffected infants when not separating by age or parity. • Amongst advance-aged (over 35) multi-parae, there was a significant association between having	

	a child born with a CL/P and experiencing a bonding disorder. This association was weakened after adjusting for maternal depression.	
Wysznski et al. (2005)	• Families of children born with CL/P scored better on subdimensions of family relationships, level of independence, and structure and organisation than families of unaffected children. • Families of children born with CL/P reported participating in fewer recreational activities than families of unaffected children.	
Zeraatkar et al. (2018)	• Parents of CLP children scored significantly higher on measures of parental stress, and these families had significantly more negative family functioning scores than parents of unaffected children. Financial impact had the highest score amongst sub-categories of 'difficulties faced by families' in CLP families.	• The impact on families appeared to be more severe in families of children with bilateral CLP compared to unilateral CLP. • There were no significant differences in scores of CLP mothers and fathers.

Findings

Study findings are summarised according to different domains of psychosocial functioning.

Parental mental health

Seven studies looked at parental mental health, with three focusing on depression[23,31,32], two on anxiety[31,33], two on general psychological distress[22,23], and two on posttraumatic stress symptoms[30,34].

Depression

Two studies investigated depression up until the first year postpartum[23,32] and found mixed evidence of depressive symptoms in mothers of infants born with CL/P. At one-month post-partum, mothers of babies born with CLP had a significantly greater risk of post-partum depression compared to mothers of controls. This was not found in mothers of babies born with just CL or CP[36]. This difference in depressive symptoms between exposure group and control group mothers was also observed in an infant-mother interaction task – mothers of infants born with CL/P showed significantly more depressive signs as judged by facial expression, tone of voice, and demeanour[32]. However, as this study did not break down participants by cleft type, it is difficult to say whether the differences noted in Sato et al. (2021) between mothers of infants born with CLP and CP/CL are also identifiable through an infant-mother interaction task[32].

One additional study looked at parental depression beyond the first year of life, where differences in parental depression were also noted between parents of children born with CL/P and parents of controls[31]. Specifically, parents of over 10-year-olds with CL/P scored higher than parents of under 10-year-olds with CLP and parents of children born without CL/P. Within this highest-scoring group, parents of children with CLP scored significantly higher than parents of children with CP-only, and higher (but not significantly) than parents of

children with CL-only[31]. Given that primary surgical treatment for CL/P typically occurs below the age of 10[6], reasons behind this finding appear less related to the stressors associated with primary surgery and early adjustment to a child's CL/P. However, this could be linked to the burden of ongoing CLP treatment as well as adolescence in general coming with changes in a child's behaviour and self-concept[59], which can affect how their family copes[60].

Some evidence indicates that there is no significant difference in depression between parents of children born with CL/P and those of children born without CL/P[32]. Although Montirosso et al. (2012) found differences in depressive symptoms as judged by the mother-infant interaction task[32], self-reported scores on the Beck Depression Inventory[38] did not significantly differ between mothers of infants born with CL/P and mothers of infants born without CL/P[32]. One possible explanation for this was highlighted through the quality appraisal of the outcome measured - infants were only 2 months old, and the measure used to study depression was not specific to post-partum depression and hence may not have captured symptoms accurately.

Anxiety

Two studies investigated parental anxiety, with one focusing on parents of newborns[33], and one focusing on parents of 0–18-year-olds[31].

Overall, parents of newborns with CP and CLP had 'moderate' levels of state and trait anxiety, whilst parents of newborns without CL/P had 'low' state and 'moderate' trait anxiety, as measured by thresholds of the State-Trait Anxiety Inventory[33,39]. Mothers of infants born with CL/P had significantly higher levels of both anxiety types compared to mothers of infants born without, whilst fathers of infants born with CL/P had significantly higher state anxiety compared to fathers of infants born without[33]. Mothers of newborns with CLP were significantly more anxious on state and trait measures than their male counterparts.

Cleft type did not lead to significant differences in maternal anxiety scores, but mothers of newborns with CLP reported significantly more anxiety about children's facial appearance compared to mothers of newborns with CP, and mothers of newborns with both cleft types noted speech and feeding to be their top concerns.

Differences in parental anxiety were also found in parents of older children; parental anxiety was reported to be significantly different between parents of under 10-year-olds born with CL/P, parents of over 10-year-olds born with CL/P, and parents of children born without CL/P, with parents of over 10-year-olds born with CL/P scoring the highest[31]. Furthermore, parents of over 10-year-olds born with CLP scored higher than parents of over 10-year-olds born with CP only. Within the group of parents of under 10-year-olds, cleft type did not affect parental anxiety.

Psychological distress

Two studies measured general psychological distress: one using the Hopkins Symptom Checklist[22,40], and one using the Kessler Psychological Distress Scale[23,41]. While one study focused on infants up until the age of one[36], the other did not specify child age beyond confirmation that children were under 18[22].

General psychological distress was found to be higher in mothers of babies born with CL/P compared to mothers of children born without CL/P from pregnancy up until one-year post-partum[22,23]. One possible explanation for increased psychological distress in the perinatal period is that it occurs because of the shock of receiving this diagnosis once mothers have already started imagining a life with their baby, and the fear associated with the unexpected future[11]. After birth, on top of expected difficulties that come with newfound parenthood, parents of babies with CL/P also face additional difficulties of cleft surgeries which understandably could impact upon psychological distress, due to additional 'stressor events' and higher likelihood of 'negative' outcomes from surgeries, as noted in the ABC-X model.

Sato et al. (2021) identified that having a child with CL/P can affect maternal psychological distress prior to birth (but after diagnosis)[36]. For example, at 27 weeks pregnancy, mothers of foetuses with CLP or CP experienced significantly greater risk of psychological distress than mothers of foetuses without CL/P. However, being pregnant with a foetus with CL was not significantly associated with psychological distress compared to being pregnant with a foetus without a CL/P. This was opposed in Nes et al. (2014), who indicated that there were no significant differences in psychological distress between mothers of foetuses without CL/P, foetuses with CL/P, and foetuses with Down's Syndrome during pregnancy[22]. Although differences in overall quality of these two studies are unlikely to explain this contrasting finding as both studies were rated highly, Nes et al. (2014) failed to report cleft type. It is important to consider that differences in psychological distress may have been prevalent for mothers of children with some cleft types only (such as in Sato et al., 2021).

Nes et al. (2014) indicated that at 6-, 18-, and 36-months post-partum, mothers of babies with Down's syndrome scored significantly higher on psychological distress than mothers of babies with CL/P and mothers of babies without CL/P[22]. At six months post-partum only, mothers of children born with CL/P scored significantly higher than mothers of controls on psychological distress. Similarly, in Sato et al. (2021), mothers of children born with CP (but not CL and CLP) had a greater risk of psychological distress than mothers of infants without CL/P aged six months[36].

At one-year post-partum, there were no significant associations between having an infant with any cleft type and having higher risk of psychological distress[23]. In both groups, higher educational level and being a first-time mother were significantly associated with higher life satisfaction and lower psychological distress[22].

Post-traumatic stress

Two studies looked at post-traumatic stress (PTS); Despars et al. (2011) using the Impact of Event Scale[42], with one-year-olds[34] and Habersaat et al. (2013) using the Perinatal Posttraumatic stress Questionnaire[43] with 2-month-olds[30]. Despars et al. (2011) found that mothers of children born with CL/P scored significantly higher on PTS outcomes than mothers of infants born without CL/P[34]. Cleft complexity (with CLP defined as more 'complex' than CL alone) did not significantly impact this[34]. Of note, mothers of children born with CL/P with relatively low PTS symptom scores were more likely to be categorised as having disengaged attachment patterns, compared to mothers of infants born without CL/P and mothers of children born with CL/P with relatively high PTS symptom scores[34]. Contrastingly, Habersaat et al. (2013) did not find any significant difference in PTS symptoms between mothers of babies born with CL/P and those without; in fact, compared to normative data, mean scores were low in both groups[30].

In one study, mothers of babies born with CL/P scored significantly higher on posttraumatic stress outcomes than mothers of control-group infants[34]. However, mothers of babies born with CL/P with relatively low PTSD symptom scores were more likely to be categorised as having disengaged attachment patters, compared to mothers of infants born without CL/P and mothers of infants born with CL/P with relatively high PTSD symptom scores. This finding was suggested to be due to disengagement with the infant leading to less emotional involvement, and hence less stress, highlighting the need for clinicians to be particularly sensitive to the coping of parents in the early years.

Interestingly, the two studies were rated as equal quality (82%) and originate from the same country yet have contrasting results. However, Habersaat et al. (2013) better controlled for confounding variables, which may explain why no significant differences were found between exposure and control group parents. Another explanation may be that this sample

was overall particularly well-adjusted, given both groups scored low on PTS symptoms compared to normative data.

Parenting stress

Five studies looked at parenting stress using various measures, in parents of children aged up to 12 weeks[45], up to one year[44], up to four years[47], between 2-5[46], and 5-9[27]. The four studies looking at children aged five and under all found that parenting stress was significantly higher in parents of children born with CL/P than parents of controls[44-47]. Factors which may explain the higher parenting stress in parents of children born with CL/P included greater caring concerns for these babies[45]. One study found that across cleft types, higher parenting stress occurred when diagnosis was after birth, the child was not breastfeeding and having feeding difficulties, the child was perceived to have a difficult temperament, and mothers reported self-blame, blame of others, anger, and concern for the future[44]. Mothers whose infants had not yet undergone corrective CL/P surgery reported higher stress[44]. Collett et al. (2012) found no significant differences in parenting stress between parents of children aged 5-9 in the exposure and control groups[27]. This could be because by the time some children are five, such as those born with CP in isolation, their cleft will likely have been operated on and, for the majority of children, speech difficulties improved through speech and language therapy and/or secondary surgery[6]. This is especially likely to be the case in a country with a developed healthcare system such as the USA, where this study was conducted[27].

There were significant differences in stress scores of mothers with different cleft types, with mothers of babies born with CL/P scoring the highest, followed by CP and lastly CL. There were also significant differences in social support scores between mothers of children with different cleft types, with mothers of babies born with CL reporting higher social support. Furthermore, a significant correlation was found between social support

scores and parenting stress scores for mothers of babies born with CL/P, but not for mothers of infants born without CL/P. Across cleft types, higher parenting stress occurred when diagnosis was after birth, the child was not breastfeeding and having feeding difficulties, the child was perceived to have a difficult temperament, and mothers reported self-blame, blame of others, anger, and concern for the future. Mothers whose infants had not yet undergone corrective CL/P surgery reported higher stress.

Quality of life

Three studies investigated quality of life[45,49,50]. All found some reduction in quality of life of families of children born with CL/P compared to families of children born without CL/P.

In one study looking specifically at mothers, significantly reduced maternal health-related quality of life was found in mothers of infants born with CL/P compared to mothers of infants born without CL/P[45]. Reduced quality of life was also seen in mothers and fathers of older children, with parents of children aged 13-18 born with clefts scoring significantly lower on measures of physical, psychological, and social quality of life than the age group-matched parents of children born without CL/P[50]. Similar areas of quality of life were also negatively affected by having a child born with a CL/P in a study looking at mothers and fathers of 4–17-year-olds[49]. Specifically, parents of children born with CL/P scored significantly lower in the quality-of-life areas of parental emotions ($p<.01$), parent/family activity ($p<.01$), and financial burden ($p=.03$)[49]. Furthermore, being the parent of a child born with CL or CLP of this age was associated with a greater reduction in familial quality of life compared to being the parent of a child with CP[49].

Family functioning

Family functioning was measured in three studies[28,46,50], focusing on families of children aged 0-18[50], 2-5[46] and approximately 5-7[28]. Zeraatkar et al. (2018) focused only on

children born with CLP (unilateral and bilateral)[46], whilst Wyszynski et al. (2005) also included children with CP[28] and Aslan et al. (2018) failed to specify cleft type[50].

There were mixed findings on family functioning outcomes, though the three studies measured family functioning very differently[28,46,50]. One study, conducted in Iran (where cleft care is not free), found that family functioning was significantly poorer in families of children born with CL/P. They defined family functioning as 'missing work' and 'financial impact'[46] – it is understandable then, that the financial impact and time commitment of surgeries would lead to poorer family functioning in parents of children born with CL/P. This was more marked in parents of children born with a bilateral rather than unilateral CLP[46] – possibly due to the increased costs and complexity of surgeries for these children, resulting in a larger financial impact and recovery time leading to parents staying off work longer.

Aslan et al. (2018)[50] failed to specify cleft type, which prevents us from hypothesising about whether this factor affected family functioning. However, they measured family functioning in a very different way to the aforementioned study[46], choosing to look at 'behavioural control', 'role dimensions', and 'required attention'. Although families of children born with CL/P struggled in these areas, families of children born without CL/P also did – indicating that raising a child in general can lead to changes in how families function based on the child's different ages. Wyszynski et al. (2005) found improved familial functioning in families affected by CL/P on levels of cohesion, expressiveness, and conflict[28], suggesting that facing a challenging situation together could bring a family closer. However, families of children born with CL/P reported participating in fewer recreational activities than families of children born without CL/P. Ten percent of relatives of children born with CL/P reported avoiding taking their child to social events, and 20% of children born with CL/P reported being called names related to their cleft. This suggests that although internal family

functioning may be improved, external pressures can still lead to difficulties related to social participation for families affected by CL/P.

Lastly, it is important to consider that Aslan et al. and Wyszynski et al.'s studies scored significantly higher in quality than Zeraatkar et al.'s – particularly important is that Zeraatkar did not define their outcomes as well as the other two studies, potentially leading to the inclusion of a study defined as measuring family functioning when this was in fact more focused on practical aspects such as finances and impact on work.

Parent-child relationships

Nine studies looked at parent-child relationships. Seven looked at infants aged one and under, one studied 1-6 year-olds[51] and one 9-year-olds[26]. Two studies[21,34] used The Working Model of the Child Interview (WMCI)[52], which is a semi-structured interview allowing a mother's perceptions of her child's individual characteristics to be quantitively classified. Five studies involved researchers observing and rating parent-child interactions based on various constructs[26,30,32,51,53]. Two studies used self-report measures of attachment and relationships; Boztepe et al. (2016) used the Maternal Attachment Inventory[25,54], whilst Tsuchiya et al. (2019) used the Mother-To-Infant Bonding Scale[55,56].

All nine studies found that relationships were in some way affected by having a child born with a CL/P. They found that mothers of infants with CL/P presented with significantly more disengaged attachment representations compared to mothers of control-group infants[34], scored lower on self-report measures of healthy attachment[25], and showed significantly fewer communicative signals, attentiveness, responsiveness, sensitivity, a lower level of engagement, and more depressive signs[30,32,51,53].

Mothers of infants born with CL/P who did not experience perinatal psychological difficulties scored significantly higher on measures of secure attachment to their infant than mothers of infants with CL/P with perinatal psychological difficulties[25]. Similarly, older

mothers of babies born with CL/P with other children were more likely to struggle to bond with their affected baby (though this association was weakened when adjusting for maternal depression)[56].

Discussion

The literature on the psychosocial impact on families of having a child born with a CL/P compared to a child born without one is varied. Whilst some studies indicated that having a child born with CL/P negatively affects parental mental health, parenting stress, parental quality of life, family functioning, and parent-child relationships, others found no significant differences in these outcomes when compared to parents of children born without a CL/P. One study noted better outcomes regarding family functioning in families affected by CL/P compared to unaffected families[28]. Studies also present mixed findings related to whether cleft type has an impact on psychosocial outcomes. Below, we break down our discussion by research question.

1) What is the psychosocial impact of having a child born with a CL/P on that child's family members and the familial relationships within that family, compared to having a child born without a CL/P?

With regards to parental mental health, it seems the post-diagnosis pregnancy period and the first year of life is more likely to bring difficulties for parents of children born with CL/P than for parents of children born without CL/P. However, this was not the case in all studies. Many studies were unable to identify risk or protective factors for psychological distress in parents of children with CL/P, but the wider literature suggests that healthcare satisfaction, relationship satisfaction, and positive life orientation are protective factors and

pre-natal maternal mental health difficulties, stressful events during pregnancy, and older paternal age are risk factors[2].

Furthermore, it seems the psychological impact has been more studied in mothers, but even in studies that looked at both parents, mothers appeared to be impacted more negatively. Sunal Akturk et al. (2023) found anxiety and depression to be higher in mothers of children born with CL/P than their father counterparts[33] – a finding which may be explained by mothers often being the primary caregivers[61], and so having to deal with more of the day-to-day stressors, as well as being responsible for breastfeeding the baby – a process which is disrupted when the baby has a CP[45]. Higher anxiety and depression in mothers compared to fathers has also been observed in cohort studies of parents with babies born with CL/P[2] and in the general population[62].

With regards to parenting stress, the four studies looking at children aged five and under all found that parenting stress was significantly higher in parents of children born with CL/P than parents of children born without CL/P[44-47]. This highlights the need for early support for affected families and suggests that stressors of being parents to a child born with a CL/P decrease over time.

Quality of life of parents of children born with CL/P appeared poorer than that of parents of children born without CL/P across studies[45,49,50]. One study found this in infants[45]; explanations from qualitative research suggest this may be because infants born with CL/P have more feeding difficulties and there are more likely to be parent-infant interaction problems due to this[11].

There were mixed findings on family functioning outcomes, though the three studies looking at this measured family functioning very differently[28,46,50]. Although one study reported family functioning to be reduced in families of children born with CL/P, this was in relation to financial and occupational aspects. One of the remaining two studies found that

the psychosocial impact of having a child born with a CL/P on family functioning is a positive one compared to unaffected families. This positive finding is echoed by two of the largest cohort studies looking at family functioning in families of children born with CL/P[2,63].

Overall, parent-child relationships were negatively affected by having a child born with a CL/P in all nine studies that measured this. Older maternal age and perinatal mental health difficulties were identified as risk factor for compromised mother-infant attachment. This is perhaps to be expected given poor perinatal mental health affects mother-infant attachment in the general population as well[64].

An important clinical implication of this is that impaired mother-infant attachment can have detrimental consequences for both mother and child outcomes; for example, a higher risk of abusive parenting[65], intimate partner violence[66], child behavioural problems[67], lower infant social engagement[68], and higher infant cortisol and negative emotional reactivity[68]. This highlights the importance of early psychological support for families forming part of multi-disciplinary cleft care, as is the case in countries such as the UK[69].

2) Within included studies, are there differences in psychosocial outcomes between parents of children with different types of cleft?

Some included studies showed differences in psychosocial outcomes with regards to cleft type – in particular, in infancy, when CL and CP co-existed, creating a wider host of difficulties. For example, Sato et al. (2021) found post-natal depressive levels to be higher in mothers of babies with CLP rather than CL and CP alone[36] – this could be explained by the greater range of issues in CLP (both speech, feeding, and hearing which are related to CP and appearance concerns which are related to CL), indicating multiple 'stressor events' causing greater demand on resources, as noted in the ABC-X model[14]. However, another study looking at maternal post-traumatic stress showed that cleft complexity (with CLP defined as

more ‘complex’ than CL alone) did not significantly impact this[34], perhaps indicating that type of cleft only impacts some mental health difficulties.

With regards to later childhood, Antunes et al. (2014) found that being the parent of a child aged 4-17 born with CL or CLP was associated with a greater reduction in familial quality of life compared to being the parent of a child with CP[49]. This suggests that the CL aspect may be playing a role – perhaps due to a permanent visible difference associated with a CL, as opposed to speech differences in CP which are mostly resolved by this age[6]. These permanent differences may be altering families’ perceptions of the stressors, as noted in the ABC-X model, due to them being longer-lasting. Kumar et al. (2020) highlighted a similar difference in parents of over 10-year-olds as well, indicating that parents of over 10-year-olds with CLP scored higher in anxiety than parents of over 10-year-olds with CP only.

Limitations of included studies

The heterogeneity in findings from included studies could be for several reasons, including that studies used different measures to investigate the same phenomena, focused on children of different ages, and included participants with different cleft types. The studies were conducted in different countries with different healthcare systems, so families likely received different levels of post-diagnostic support and cleft care which differed in quality, which may have impacted on psychosocial outcomes.

Some studies did not include participant characteristics such as child age and cleft type, hence preventing us from drawing conclusions about whether all children with CL/P are affected in the same way. The studies that did break down outcomes by age and cleft type showed differences in outcomes, highlighting the issue that some studies did not consider this. Furthermore, all studies except three[26-28] failed to report participants’ ethnicities. Therefore, we are not able to identify whether families of children with CL/P of different

ethnicities might need to be supported in different ways. We know that people from minority ethnic backgrounds face more stigma[70], so considering the intersectionality of being from an ethnic minority background and being born with a CL/P is paramount. In fact, Crerand et al., (2015) noted poorer family functioning for families of children born with CL/P from ethnic minority backgrounds and linked this to potential disparities in healthcare access.

Included studies were also biased to investigating mothers over fathers and other family members. It is understandable that studies choose to focus on mothers, who are typically primary caregivers[61], but paternal mental health, which is often neglected[71], fails to be fully addressed yet again. Furthermore, as qualitative evidence has identified, unaffected siblings[12] and grandparents[13] can also be affected by a child's CL/P, yet the lack of quantitative research on these members meant this review did not capture such information.

Limitations of the current review

This review focused only on studies which included a control group of children born without CL/P. This was necessary for understanding similarities and differences between parents of children born with CL/P and the general population but means that studies which would have added valuable information were excluded.

Heterogeneity in outcome measures studied meant there were insufficient papers to conduct a meta-analysis, which would have added more information on magnitude of the effect of having a child born with a CL/P (versus not born with a CL/P) on parental outcomes.

Conclusions

There is mixed evidence for whether having a child born with a CL/P does negatively impact psychosocial outcomes of family members and familial relationships – some families are negatively affected by this compared to control groups, and some are not. Factors which

impact this include experiencing perinatal psychological difficulties[25], the type of cleft[23], and age of the child[27].

However, it is clear that even though some families of children born with CL/P do not score worse than controls on psychosocial outcomes, these families still experience stressors such as feeding difficulties[45], numerous surgeries and medical appointments[6], difficulties with community integration[28] financial difficulties, and disrupted work[46]. For some families, these stressors, coupled with fewer perceived resources available to them and a higher perceived likelihood of negative outcomes, can lead to increased psychosocial difficulties. Therefore, continued support for these families remains of high importance.

Future research should aim to further disentangle what factors separate those families of children born with CL/P who are impacted psychosocially more than others. This will allow for early identification of families that are more likely to be impacted, and hence early intervention.

References

1. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *Rev Esp Cardiol (Engl Ed)*. Sep 2021;74(9):790-799. Declaracion PRISMA 2020: una guia actualizada para la publicacion de revisiones sistematicas. doi:10.1016/j.rec.2021.07.010
2. Stock NM, Costa B, White P, Rumsey N. Risk and Protective Factors for Psychological Distress in Families Following a Diagnosis of Cleft Lip and/or Palate. *Cleft Palate Craniofac J*. Jan 2020;57(1):88-98. doi:10.1177/1055665619862457
3. Jorge PK, Ambrosio ECP, Mello-Peixoto YCT, et al. Current Perspectives on Cleft Lip and Palate and Children's Health. *Children (Basel)*. May 11 2023;10(5)doi:10.3390/children10050857
4. Stock NM, Feragen KB. Psychological adjustment to cleft lip and/or palate: A narrative review of the literature. *Psychol Health*. Jul 2016;31(7):777-813. doi:10.1080/08870446.2016.1143944
5. Niinomi K, Ueki S, Fujita Y, et al. Differences in specific concerns perceived by parents of children with cleft lip and/or palate based on the types of cleft. *Int J Paediatr Dent*. May 2022;32(3):304-313. doi:10.1111/ipd.12886
6. Dudding T, Martin S, Popat S. An introduction to the UK care pathway for children born with a cleft of the lip and/or palate. *Br Dent J*. Jun 2023;234(12):943-946. doi:10.1038/s41415-023-5998-z
7. Nelson PA, Kirk SA, Caress AL, Glenny AM. Parents' emotional and social experiences of caring for a child through cleft treatment. *Qual Health Res*. Mar 2012;22(3):346-59. doi:10.1177/1049732311421178
8. Nelson PA, Glenny AM, Kirk S, Caress AL. Parents' experiences of caring for a child with a cleft lip and/or palate: a review of the literature. *Child Care Health Dev*. Jan 2012;38(1):6-20. doi:10.1111/j.1365-2214.2011.01244.x
9. Stock NM, Rumsey N. Parenting a child with a cleft: the father's perspective. *Cleft Palate Craniofac J*. Jan 2015;52(1):31-43. doi:10.1597/13-035
10. Nelson J, O'Leary C, Weinman J. Causal attributions in parents of babies with a cleft lip and/or palate and their association with psychological well-being. *Cleft Palate Craniofac J*. Jul 2009;46(4):425-34. doi:10.1597/07-194.1
11. Stock NM, Zucchelli F, Hudson N, Kiff JD, Hammond V. Promoting Psychosocial Adjustment in Individuals Born With Cleft Lip and/or Palate and Their Families: Current Clinical Practice in the United Kingdom. *Cleft Palate-Craniofacial Journal*. 01 Feb 2020;57(2):186-197. doi:https://dx.doi.org/10.1177/1055665619868331
12. Stock NM, Stoneman K, Cunniffe C, Rumsey N. The Psychosocial Impact of Cleft Lip and/or Palate on Unaffected Siblings. *Cleft Palate Craniofac J*. Nov 2016;53(6):670-682. doi:10.1597/15-148
13. Guest E, Costa B, McCarthy G, Cunniffe C, Stock NM. The Experiences and Support Needs of Grandparents of Children Born With Cleft Lip and/or Palate. *The Cleft palate-craniofacial journal : official publication of the American Cleft Palate-Craniofacial Association*. 29 May 2019:1055665619850709. doi:https://dx.doi.org/10.1177/1055665619850709
14. Rosino M. ABC-X Model of Family Stress and Coping. *Encyclopedia of Family Studies*. 2016:1-6.
15. Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychol Bull*. Sep 1985;98(2):310-57.

16. He M, Shi B, Zheng Q, Gong C, Huang H. Posttraumatic Growth and its Correlates Among Parents of Children With Cleft Lip and/or Palate. *Cleft Palate Craniofac J*. 2024;61(1):110-118.
17. Namdar P, Pourasghar M, Alizadeh FL, Shiva A. Anxiety, Depression, and Quality of Life in Caregivers of Children with Cleft Lip and Palate: A Systematic Review. Review. *Iranian Journal of Psychiatry and Behavioral Sciences*. 2022;16(2) (no pagination)e113591. doi:https://dx.doi.org/10.5812/IJPBS-113591
18. Nelson P, Glenny A, Kirk S, Caress A. Parents' experiences of caring for a child with a cleft lip and/or palate: A review of the literature. Literature Review. *Child: Care, Health and Development*. Jan 2012;38(1):6-20. doi:https://dx.doi.org/10.1111/j.1365-2214.2011.01244.x
19. Altman DG. *Practical Statistics for Medical Research.* Chapman and Hall.; 1991.
20. Kmet LM, Lee RC, Cook LS. *Standard quality assessment criteria for evaluating primary research papers from a variety of fields.* 2004.
21. Habersaat S, Turpin H, Moller C, et al. Maternal representations and parenting style in children born with and without an orofacial cleft. *Cleft Palate-Craniofacial Journal*. January 2018;55(1):88-97. doi:https://dx.doi.org/10.1177/1055665617718840
22. Nes RB, Roysamb E, Hauge LJ, et al. Adaptation to the birth of a child with a congenital anomaly: a prospective longitudinal study of maternal well-being and psychological distress. *Developmental psychology*. 01 Jun 2014;50(6):1827-1839. doi:https://dx.doi.org/10.1037/a0035996
23. Sato Y, Yoshioka E, Saijo Y, et al. Trajectories of the Psychological Status of Mothers of Infants With Nonsyndromic Orofacial Clefts: A Prospective Cohort Study From the Japan Environment and Children's Study. Research Support, Non-U.S. Gov't. *Cleft Palate-Craniofacial Journal*. 03 2021;58(3):369-377. doi:https://dx.doi.org/10.1177/1055665620951399
24. Tsuchiya S, Tsuchiya M, Momma H, et al. Association of cleft lip and palate on mother-to-infant bonding: a cross-sectional study in the Japan Environment and Children's Study (JECS). *BMC Pediatrics*. 2019;19(1):1-8. doi:10.1186/s12887-019-1877-9
25. Boztepe H, Ay A, Kerimoglu Yildiz G, Cinar S. Does the visibility of a congenital anomaly affect maternal-infant attachment levels? *Journal for specialists in pediatric nursing : JSPN*. 01 Oct 2016;21(4):200-211. doi:https://dx.doi.org/10.1111/jspn.12157
26. Gassling V, Christoph C, Wahle K, et al. Children with a cleft lip and palate: An exploratory study of the role of the parent-child interaction. *Journal of Cranio-Maxillofacial Surgery*. September 2014;42(6):953-958. doi:https://dx.doi.org/10.1016/j.jcms.2014.01.016
27. Collett BR, Cloonan YK, Speltz ML, Anderka M, Werler MM. Psychosocial functioning in children with and without orofacial clefts and their parents. *Cleft Palate-Craniofacial Journal*. July 2012;49(4):397-405. doi:https://dx.doi.org/10.1597/10-007
28. Wyszynski DF, Perandones C, Yannibelli P, Bennun RD. Family environment of individuals with oral clefts in Argentina. *Cleft Palate-Craniofacial Journal*. March 2005;42(2):185-191. doi:https://dx.doi.org/10.1597/03-118.1
29. Collett BR, Cloonan Y, Speltz ML, Anderka M, Werler MM. Psychosocial functioning in children with and without orofacial clefts and their parents. Research Support, U.S. Gov't, P.H.S. *Cleft Palate-Craniofacial Journal*. Jul 2012;49(4):397-405. doi:https://dx.doi.org/10.1597/10-007
30. Habersaat S, Monnier M, Peter C, et al. Early mother-child interaction and later quality of attachment in infants with an orofacial cleft compared to infants without cleft. *Cleft Palate-Craniofacial Journal*. November 2013;50(6):704-712. doi:https://dx.doi.org/10.1597/12-094.1

31. Kumar K, Kumar S, Mehrotra D, Gupta S, Khandpur S, Mishra RK. A Psychologic Assessment of the Parents of Patients With Cleft Lip and Palate. *The Journal of craniofacial surgery*. 01 Jan 2020;31(1):58-61. doi:https://dx.doi.org/10.1097/SCS.0000000000005835
32. Montirosso R, Fedeli C, Murray L, et al. The role of negative maternal affective states and infant temperament in early interactions between infants with cleft lip and their mothers. *Journal of pediatric psychology*. Mar 2012;37(2):241-250. doi:https://dx.doi.org/10.1093/jpepsy/jsr089
33. Sunal Akturk E, Seker ED, Capkin D, Kutuk MS. Evaluation of Anxiety in Turkish Parents of Newborns with Cleft Palate with or Without Cleft Lip. *Cleft Palate Craniofacial Journal*. 2023;doi:https://dx.doi.org/10.1177/10556656221148903
34. Despars J, Peter C, Borghini A, et al. Impact of a Cleft Lip and/or Palate on Maternal Stress and Attachment Representations. *Cleft Palate-Craniofacial Journal*. 2011;48(4):419-424. doi:10.1597/08-190
35. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression. Development of the 10-item Edinburgh Postnatal Depression Scale. *Br J Psychiatry*. Jun 1987;150:782-6. doi:10.1192/bjp.150.6.782
36. Sato Y, Yoshioka E, Saijo Y, et al. Trajectories of the Psychological Status of Mothers of Infants With Nonsyndromic Orofacial Clefts: A Prospective Cohort Study From the Japan Environment and Children's Study. *Cleft Palate Craniofac J*. Mar 2021;58(3):369-377. doi:10.1177/1055665620951399
37. Kumar K, Kumar S, Mehrotra D, Tiwari SC, Kumar V, Dwivedi RC. Reliability and psychometric validity of Hindi version of Depression, Anxiety and Stress Scale-21 (DASS-21) for Hindi speaking Head Neck Cancer and Oral Potentially Malignant Disorders Patients. *J Cancer Res Ther*. Jul-Sep 2019;15(3):653-658. doi:10.4103/jcrt.JCRT_281_17
38. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Arch Gen Psychiatry*. Jun 1961;4:561-71. doi:10.1001/archpsyc.1961.01710120031004
39. Spielberger CD, Gorsuch RL, Lushene RE. *Manual for State–Trait Anxiety Inventory (Self Evaluation Questionnare)*. Consulting Psychologist Press; 1970.
40. Hesbacher PT, Rickels K, Morris RJ, Newman H, Rosenfeld H. Psychiatric illness in family practice. *J Clin Psychiatry*. Jan 1980;41(1):6-10.
41. Kessler RC, Andrews G, Colpe LJ, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med*. Aug 2002;32(6):959-76. doi:10.1017/s0033291702006074
42. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med*. May 1979;41(3):209-18. doi:10.1097/00006842-197905000-00004
43. Quinnell FA, Hynan MT. Convergent and discriminant validity of the perinatal PTSD questionnaire (PPQ): a preliminary study. *J Trauma Stress*. Jan 1999;12(1):193-9. doi:10.1023/A:1024714903950
44. Boztepe H, Cinar S, Ozgur Md FF. Parenting Stress in Turkish Mothers of Infants With Cleft Lip and/or Palate. *Cleft Palate-Craniofacial Journal*. 06 2020;57(6):753-761. doi:https://dx.doi.org/10.1177/1055665619898592
45. Madhoun LL, Crerand CE, O'Brien M, Baylis AL. Feeding and Growth in Infants With Cleft Lip and/or Palate: Relationships With Maternal Distress. Research Support, Non-U.S. Gov't. *Cleft Palate-Craniofacial Journal*. 04 2021;58(4):470-478. doi:https://dx.doi.org/10.1177/1055665620956873
46. Zeraatkar M, Ajami S, Nadjmi N, Golkari A. Impact of oral clefts on the oral health-related quality of life of preschool children and their parents. *Nigerian journal of clinical practice*. 01 Sep 2018;21(9):1158-1163. doi:https://dx.doi.org/10.4103/njcp.njcp_426_17

47. Lentge K, Lentge F, Zeller AN, et al. Cleft lip and palate: the psychological burden of affected parents during the first three years of their children's lives. *Int J Oral Maxillofac Surg*. Nov 2022;51(11):1462-1468. doi:https://dx.doi.org/10.1016/j.ijom.2022.04.003
48. Abidin RR. *Parenting Stress Index Professional Manual.* 4th ed. Psychological Assessment Resources; 2012.
49. Antunes LS, Maues CP, Nadaes MR, Costa MC, Kuchler EC, Antunes LA. The impact of nonsyndromic oral clefts on family quality of life. *Special care in dentistry : official publication of the American Association of Hospital Dentists, the Academy of Dentistry for the Handicapped, and the American Society for Geriatric Dentistry*. 01 May 2014;34(3):138-143. doi:https://dx.doi.org/10.1111/scd.12046
50. Aslan BI, Gülşen A, Tirank Ş B, et al. Family Functions and Life Quality of Parents of Children With Cleft Lip and Palate. *J Craniofac Surg*. Sep 2018;29(6):1614-1618. doi:10.1097/scs.0000000000004611
51. Losier V, Cyr C, Dubois-Comtois K. International adoption of cleft lip and palate children: Attachment, behavior problems, and parental sensitivity. Empirical Study; Interview; Quantitative Study. *Journal of Applied Developmental Psychology Vol 68 2020, ArtID 101138*. May-Jun 2020;68doi:https://dx.doi.org/10.1016/j.appdev.2020.101138
52. Zeanah CH, Benoit D. Clinical applications of a parent perception interview in infant mental health. *Child Adolesc Psychiatr Clin N Am*. 1995;4:539–554.
53. Murray L, Hentges F, Hill J, et al. The effect of cleft lip and palate, and the timing of lip repair on mother-infant interactions and infant development. Empirical Study; Followup Study; Longitudinal Study; Quantitative Study. *Journal of Child Psychology and Psychiatry*. Feb 2008;49(2):115-123.
54. Muller ME. A questionnaire to measure mother-to-infant attachment. *J Nurs Meas*. Winter 1994;2(2):129-41.
55. Yoshida K, Yamashita H, Conroy S, Marks M, Kumar C. A Japanese version of Mother-to-Infant Bonding Scale: factor structure, longitudinal changes and links with maternal mood during the early postnatal period in Japanese mothers. *Arch Womens Ment Health*. Oct 2012;15(5):343-52. doi:10.1007/s00737-012-0291-1
56. Tsuchiya S, Tsuchiya M, Momma H, et al. Association of cleft lip and palate on mother-to-infant bonding: a cross-sectional study in the Japan Environment and Children's Study (JECS). *BMC Pediatr*. Dec 20 2019;19(1):505. doi:10.1186/s12887-019-1877-9
57. Crittenden PM. Care-Index: Coding Manual. 1988
58. Moran G, Pederson DR, Bento S. Maternal behavior Q-Sort (MBQS)-overview, available materials and support. http://works.bepress.com/gregmoran/48
59. Kaye DK. Negotiating the transition from adolescence to motherhood: coping with prenatal and parenting stress in teenage mothers in Mulago hospital, Uganda. *BMC Public Health*. Mar 4 2008;8:83. doi:10.1186/1471-2458-8-83
60. Valizadeh L, Zamanzadeh V, Rassouli M, Rahkar Farshi M. Concerns of Parents with or Raising Adolescent Children: a Qualitative Study of Iranian Families. *J Caring Sci*. Mar 2018;7(1):27-33. doi:10.15171/jcs.2018.005
61. Bornstein MH, Putnick DL. Mothers' and Fathers' Parenting Practices with their Daughters and Sons in Low- and Middle-Income Countries. *Monogr Soc Res Child Dev*. 2016;81(1):60-77.
62. Vismara L, Rolle L, Agostini F, et al. Perinatal Parenting Stress, Anxiety, and Depression Outcomes in First-Time Mothers and Fathers: A 3- to 6-Months Postpartum Follow-Up Study. *Front Psychol*. 2016;7:938. doi:10.3389/fpsyg.2016.00938
63. Crerand CE, Rosenberg J, Magee L, Stein MB, Wilson-Genderson M, Broder HL. Parent-reported family functioning among children with cleft lip/palate. *Cleft Palate-Craniofacial Journal*. November 2015;52(6):651-659. doi:https://dx.doi.org/10.1597/14-050

64. Meuti V, Aceti F, Giacchetti N, et al. Perinatal Depression and Patterns of Attachment: A Critical Risk Factor? *Depress Res Treat*. 2015;2015:105012. doi:10.1155/2015/105012
65. Kitamura T, Ohashi Y, Kita S, Haruna M, Kubo R. Depressive mood, bonding failure, and abusive parenting among mothers with three-month-old babies in a Japanese community. *Open J Psychiatry*. 2013;3(3):1-7.
66. Kita S, Haruna M, Matsuzaki M, Kamibeppu K. Associations between intimate partner violence (IPV) during pregnancy, mother-to-infant bonding failure, and postnatal depressive symptoms. *Arch Womens Ment Health*. 2016;19(4):623–34.
67. Hairston IS, Waxler E, Seng JS, Fezzey AG, Rosenblum KL, Muzik M. The role of infant sleep in intergenerational transmission of trauma. *Sleep*. Oct 1 2011;34(10):1373-83. doi:10.5665/SLEEP.1282
68. Sliwerski A, Kossakowska K, Jarecka K, Switalska J, Bielawska-Batorowicz E. The Effect of Maternal Depression on Infant Attachment: A Systematic Review. *Int J Environ Res Public Health*. Apr 14 2020;17(8)doi:10.3390/ijerph17082675
69. Hotton M, Cropper J, Rundle J, Crawford R. The role of the clinical psychologist within a cleft service. *Br Dent J*. Jun 2023;234(12):887-891. doi:10.1038/s41415-023-5952-0
70. Kapadia D. Stigma, mental illness & ethnicity: Time to centre racism and structural stigma. *Sociol Health Illn*. May 2023;45(4):855-871. doi:10.1111/1467-9566.13615
71. Fisher SD. Paternal Mental Health: Why Is It Relevant? *Am J Lifestyle Med*. May-Jun 2017;11(3):200-211. doi:10.1177/1559827616629895

Service Improvement Project

Young People's Supported Accommodation (YPSA) Service: Understanding the experiences of young people in need of support for managing interpersonal relationships

Trainee: Ruxandra Vasile (ruxandra.vasile@gtc.ox.ac.uk)

Internal supervisor: Dr Ciorsdan Anderson (ciorsdan.anderson@hmc.ox.ac.uk)

External supervisor: Dr Kim Jackson-Blott (kim.jackson-blott@oxfordshire.gov.uk)

Date: June 2023

Word count: 4,252

Proposed journal: Child and Adolescent Social Work Journal. This journal was chosen because it is a leading journal focusing on current research relevant to young people in the social care system. See *Appendix D* for author guidelines.

Conflicts of interest: None.

Abstract

Background: Existing literature highlights the additional needs that young people (YP) in supported accommodation have with regards to understanding and forming healthy relationships. This project aimed to investigate the relationship support needs of YP in the Oxfordshire Young People's Supported Accommodation (YPSA) service from staff and YP perspectives, and to consider what type of interventions and materials might be most suitable for addressing those needs.

Methods: Semi-structured interviews and a focus group were held with 10 YPSA residents aged 18-24 and 4 staff members. Thematic analysis was conducted separately for YP and staff data.

Results: Three main themes emerged from YP: 1) mixed experiences of interpersonal relationships, 2) mixed experiences of previous support, and 3) needs within future support. Three main themes emerged from staff: 1) relationship difficulties and their impact, 2) support to be offered gently and thoughtfully, and 3) staff needs related to delivering this support.

Discussion: YP struggle with a range of difficulties in families, friendships, and romantic relationships. The need for additional support to develop and maintain healthy relationships was corroborated by both staff and YP's accounts. Support should be delivered in an individualised and sensitive manner according to each YP's needs and preferences. Content of such support should include a focus on a range of topics related to relationships, including dependency, exploitation, abuse, online safety, and online relationships. The delivery of such support should make use of multimedia and a clearly defined content structure to promote engagement. An adaptation of a pre-existing relationships program, titled 'Real Love Rocks' (Barnardo's, 2022) has been suggested as potentially meeting these needs. Staff require

appropriate training opportunities to better equip them to deliver healthy relationship support to the YP within the YPSA.

Keywords: interpersonal relationships, adolescent, social care, qualitative, childhood trauma

Introduction

Young people (YP) in care and supported accommodation have often had negative early life experiences such as parental abuse, neglect, out-of-home placements, and exposure to the negative effects of poverty (Sellers et al., 2020). These experiences can lead to problems with regulating emotions, difficulties with forming supportive relationships, and a heightened threat alert system (Bath, 2015; McCrory et al., 2010). Furthermore, adolescents who have experienced childhood abuse are more likely to perpetrate and/or experience adolescent dating violence (ADV) (Foshee et al., 2001). This may be because children whose attachment style is adapted to abusive and neglectful parenting have difficulties with regulating emotions and knowing what healthy relationships are, alongside lacking the socio-emotional skills to develop and maintain healthy relationships (Farina et al., 2020; Perry, 2009).

The intergenerational transmission of trauma theory suggests that when these YP then get into romantic relationships, they are more likely to perpetrate or experience domestic violence (Buck, 2012). Furthermore, when they become parents, their children are more likely to form insecure attachments (Du, 2020; Yehuda & Lehrner, 2018). People's abilities to form healthy attachments and relationships with their own children are therefore likely to be diminished, perpetuating the cycle (Perry, 2009). Interventions aimed at breaking this cycle are of paramount importance.

A meta-analysis of RCTs measuring the impact of prevention programmes in reducing ADV found these programmes successful in decreasing the risk of emotional, physical & sexual violence (Russell et al., 2021). Most interventions trialled school- and community-based activities; for example, the programme *Safe Dates* aimed to help YP gain anger management and conflict resolution skills, learn about resources and places for support, and support them to challenge gender norms and dating violence norms (Foshee et al., 2014;

Russell et al., 2021). However, only one intervention focused on at-risk youth with histories of child maltreatment (Wolfe et al., 2003). This 18-session intervention focused on teaching "positive alternatives to aggression-based interpersonal problem-solving and gender-based role expectations" through educational sessions, skills development, and social action. The intervention was successful in reducing perpetration of emotional and physical abuse, and emotional distress, but was assessed as posing a moderate risk of bias (Russell et al., 2021).

The current project aims to investigate the relationship support needs of YP in a Young People's Supported Accommodation (YPSA) service, who may be at increased risk of struggling to form and maintain healthy relationships due to their early life experiences. The project aims to consider what types of interventions and materials might be most suitable for addressing those needs. It aims to understand what facilitates and hinders engagement with services to better adapt any intervention to meet the specific needs of the YPSA population.

Service context

The YPSA helps YP aged 16-24 in Oxfordshire with managing their accommodation and finding employment, apprenticeship, or educational opportunities. The service offers YP support to manage mental health difficulties and sustain healthy relationships. YP within the YPSA comprise a demographic of vulnerable young adults – care leavers, unaccompanied asylum-seekers, and young parents in mother and baby units (MBUs). They have typically experienced relational traumas, and many have witnessed, experienced or perpetrated relational violence. Several psychology consultations have been requested regarding the support needs of YP who have difficulties within the context of their relationships. Whist the service has been able to signpost staff and YP to helpful websites, there is currently a lack of evidence-based preventative support on offer.

The YPSA staff have identified that YP accessing their service experience high levels of interpersonal instability, risk and violence and want to support YP with their relationships.

Staff have suggested running a group. The YPSA clinical psychology team have bought rights to use the 'Real Love Rocks' program (Barnardo's, 2022) which is a trauma-informed, educational program co-developed with YP aimed at raising awareness about healthy and consensual relationships in the 21st century. It includes topics which are not conventionally covered in older relationships programmes, like criminal and sexual exploitation, and cyberbullying (Barnardo's, 2022). For this reason, the YPSA clinical psychology team felt that it would be suited to the relationship difficulties that YP within the YPSA are presented with.

However, it needs to be clarified what content and indeed if a group format would best meet the needs of the YPSA population. It is unclear whether YP in this setting also believe they need support in this area, and if so, what the best format is to provide this support given their unique and complex needs. Recommendations for improving support will be based on information from the current study. The feedback will be shared with the service to ensure that they are working in a YP-focused way and tailoring the support they offer to the needs identified.

Method

Ethics

This project received ethical approval from Oxfordshire County Council (OCC) after a meeting with their research panel. Informed written consent was gathered from all participants (see *Appendices E-H* for information & consent sheets).

Phase 1: YP

Participants

The inclusion criteria were English-speaking YP aged 16-24 who were resident in a YPSA home at the time of interviewing. Convenience sampling was used to recruit participants. A clinical psychologist working within the YPSA contacted staff members

working at different YPSA homes to ask them to inform residents about the project and feed back to the researcher if any of them were interested in taking part. Ten participants (eight females, two males) aged 18-23 (M = 19.5) living across three different homes were recruited. Three were living in a shared accommodation home for 18–24-year-olds, whilst seven lived in shared accommodation homes for young parents. All were White British and had been living at their respective homes for between two months and four years (M = 14.1 months). YP were reimbursed for their time with a £10 voucher.

Semi-structured interviews

The semi-structured interview schedule was co-developed with a clinical psychologist working within the YPSA. The questions focused on YP's previous experiences with relationship support, examples of relationship support materials from the 'Real Love Rocks' program (Barnardo's, 2022), and facilitators and barriers for potential future support (see *Appendix I* for schedule). Two YP with lived experience of residing in the YPSA were consulted on the interview schedule to ensure it was appropriate to the aims of the study and sensitive in nature.

Interviews occurred in March and April 2023. Interviews were face-to-face and 1:1 at participants' homes. Each interview lasted approximately 30 minutes.

Phase 2: Staff

Participants

The inclusion criteria were English-speaking members of staff working at any YPSA home. Convenience sampling was used to recruit. A clinical psychologist working within the YPSA contacted staff members working at different YPSA homes to ascertain their interest in taking part. Four staff members (three females, one male) aged 29-60 (M = 40.5) working across four different homes were recruited. Two worked in shared accommodation homes for 18–24-year-olds, whilst two worked in shared accommodation homes for young parents. One

each of these two types of homes had YP resident who took part in Phase 1 of this study. All staff were White British and had been working at their respective homes for between two and 60 months (M = 26.25 months).

Focus group

The focus group schedule was co-developed with a clinical psychologist working within the YPSA. The questions focused on staff's perceptions of YP's relationship support needs and how (or whether) these are currently being met, examples of relationship support materials from the 'Real Love Rocks' program (Barnardo's, 2022), facilitators and barriers for potential future support, and any training requirements staff felt would help them deliver this support (see *Appendix J* for schedule). As in Phase 1, two YP with lived experience were consulted on the schedule.

Two data collection points occurred in April and May 2023 over Microsoft Teams. One was a 1:1 interview and one was a focus group with three members of staff (this was due to one member of staff being unable to attend at the time of the focus group). The interview lasted 30 minutes whilst the focus group lasted 80 minutes.

Data analysis

Thematic analysis was chosen as it is the recommended methodology for analysing qualitative data in applied health-related research (Braun & Clarke, 2014). An inductive approach was taken due to little previous research in this area having occurred within the service. Interviews and the focus group were transcribed and then analysed in the software programme NVivo using the six-step thematic analysis process (Clarke & Braun, 2017). Specifically, after data familiarisation, initial codes were formed. Themes were formed according to the codes, and these were reviewed, defined, and named.

Reflexivity

Data collection and analysis was undertaken by RV, a female trainee clinical psychologist in her mid-20s. Themes were reviewed with CA, a consultant clinical psychologist with experience in thematic analysis and working with looked after children. The results of the analysis were discussed with KJB, a clinical psychologist working within the YPSA. The researchers considered and reflected on their stance whilst analysing this data. For example, the primary researcher, RV, noted that she had not spent any time in care or had significant negative relationship experiences, so although tried to understand YP's experiences, might not have been able to do this as fully as someone with lived experience of such events. Furthermore, RV noted a desire to make the themes and findings useful and understandable to the YPSA service, such that recommendation were clear and achievable, which may have subconsciously guided analysis.

Results

Phase 1: YP

Three main themes emerged: 1) mixed experiences of interpersonal relationships, 2) mixed experiences of previous support, and 3) needs within future support. Theme 1 describes the range of positive and challenging experiences that YP within the YPSA have had in relation to romantic, family, and peer relationships. Two subthemes emerged: positive relationships and challenging relationships. Theme 2 describes the range of experiences YP have had with previous relationship support, as well as the extent to which they've been able to use this support to improve relationships. Three subthemes emerged: 1) lack of previous support, 2) positive experiences of support and 3) difficulty of putting learning into action. Theme 3 encapsulates the YP's thoughts around what good relationship support should include. Five subthemes emerged: 1) taking an individualised approach, 2) acknowledging the sensitive nature of topics, 3) creating engaging content, 4) taking a personable approach, and 5) considering practicalities and convenience.

Figure 2.1 depicts the map of themes and sub-themes. These themes and subthemes are presented alongside explanations and supporting quotes in *Table 2.1* below. Each YP was assigned a unique participant number (P). See *Appendix L* for further supporting quotes.

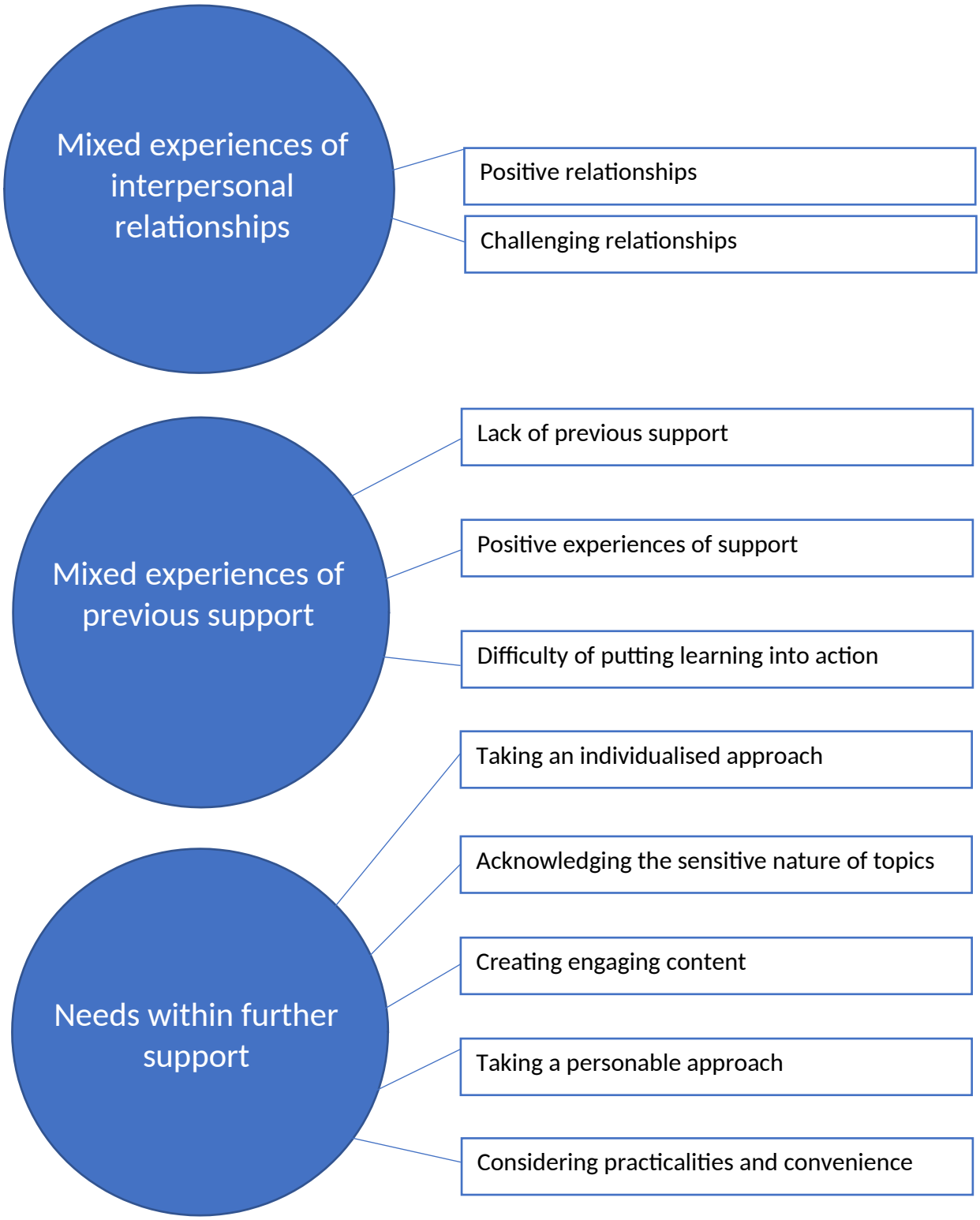


Figure 2.1. Map of themes and sub-themes from Phase 1 (YP).

Table 2.1. Themes, sub-themes, explanations, and supporting quotes from interviews with ten YP.

Theme 1. Mixed experiences of interpersonal relationships.		
Sub-theme	**Explanation**	**Example quotes**
Positive relationships	When asked to describe their relationships in three words, some participants identified positive interpersonal relationships in which they felt happy, supported, and cared for.	"'Loving' is because I have a really good bond with my family, and my partner, 'caring' is the same, like we get on well, we have a good relationship, if we ever need each other then we're kind of there for each other" (P10). "I would say loving, happiness and just it's nice to be around" (P4).
Challenging relationships	Although some participants noted positive experiences of relationships, the overwhelming majority of participants reported relationships to be challenging - romantically, with fellow YPSA residents, and with family.	"I'd say quite challenging most of the time, a lot of my relationships have been toxic or just not very well managed (P7)". "Sometimes bitchiness can occur and you know people can be horrible and singling people out and it's not very nice" (P7). "Obviously with family it's always been chaotic, with mum and siblings,

		there's a lot of them, it's tense" (P6).
	Some YP explained that previous challenging romantic relationships made them averse to getting into new ones. Participants reported feeling very dependent on their romantic partners, sometimes to a point where they wanted to only spend time with them.	"Relationships right now for me are just a no-go. I haven't gone near anyone for about 8 months now" (P4). "If I have a girlfriend, I like to cut out everyone else" (P3).
Theme 2. Mixed experiences of support.		
Lack of previous support	Many YP highlighted the lack of support around relationships. Some of these YP felt that it was their job to	"I spoke to CAMHS about like first relationships and relationship problems and that, but not really, I kind of had to figure it out all on my own through trial and error" (P3). "Just kinda gotta deal with it if I'm honest, and being a big man, don't

	deal with any difficulties on their own. Some YP reported they couldn't get the support they needed because it felt difficult to ask for it. Participants also recognised that comorbid substance use and/or mental health difficulties made it more difficult to get support around relationships.	know…" (P3). "Obviously no one judges but…sometimes it just feel a bit awkward speaking to them because we see them all day everyday" (P2). "I will openly admit it now, every single person in this place has a drug, alcohol, some sort of problem along those lines" (P2). "I find it quite hard to open up to people because I've got social anxiety so like, I'd say that was probably the most difficult thing" (P5).
Positive experiences of support	Most YP that received support describe this as helpful. Many of the young mothers who took part had engaged in a programme to learn about abusive	"I haven't had the best luck with relationships and I've been in quite a few abusive relationships, so, it's nice to be able to speak to someone" (P5). "That made me understand a lot more about the toxic side of relationships as well as the good" (P6).

	relationships and reported learning a lot from it.	"I think the home have been good in the fact that they always…they offer it to most of the women here, if they know you've had a previous history of domestic abuse" (P7).
Difficulty of putting learning into action	Though experiences of support were generally positive, YP recognised that taking the learning from conversations they had and programmes they attended and applying it to their own relationships is very difficult.	"It's more difficult to actually bring some of it into the relationship than to learn about something" (P6).
	YP reported that they could use their learnings to help others, but that helping oneself is much trickier.	"I'd say quite a lot to my friends if they had an abusive partner I'd be like, no you need to get away from that person like they're not going to be any good for you, but then I would stay in the relationship because obviously I wouldn't see the signs" (P7). "If I see someone getting all narcissistic to their partner, I'd be able to

		recognise that, but if I was in that situation it'd be very difficult to see how a narcissist would be" (P6).
Theme 3. Needs within future support.		
Taking an individualised approach	YP acknowledged that what might seem like 'the same problem' could actually be very differently experienced by two different people. For this reason, the most mentioned sub-theme was around preferences for content and mode of delivery of healthy relationships support having to be individualised due to different people's past experiences, needs, and wants. This was in relation to having group or 1-to-1 support, delivering support face-to-face or online, and whether support should be offered from an external or familiar person.	"There could be two people that are going through the same thing that are on completely different boats, so again it's all about the right support, not just normal support" (P6). "It depends on the person really because everyone's different and everyone opens up differently" (P10). "Depends on what people prefer, because for me, I don't like being in a room with lots of other people, it really frustrates me and I get anxious because of my autism and ADHD, and some people may want to do it in a group because they might want to hear other people's stories" (P9). "Having like various ways of doing it, like some people may not want to

		do it in person so then you could do it online if they feel like that's what they want you to do" (P10). "Sometimes if you've been through something traumatic it's better to speak to someone you're close with but then in other ways like I find it easier to speak to people I don't know because I feel like I'm judged more or it won't stay between us two if it's someone I know" (P5).
Acknowledging the sensitive nature of topics	All participants acknowledged that this is an important area to talk about, but also recognised that is it a very sensitive area. Some participants identified that a way to help with this is to let people taking part in a healthy relationships programme know beforehand what the content entails (and in which session).	"I think there's a lot of people in the houses that could do with knowing what a healthy relationship looks like" (P3). "To some people it could possibly be a bit triggering because it's speaking about like things that like some people have experienced" (P5). "Knowing what might be in…you know like with a book, you have on the back, it tells you basically a short little version of what it's about… it's basically the plot and you get to actually get the chance to know

		what this lengthy book is going to be about" (P6).
Creating engaging content	YP made it clear that support should be delivered in an engaging way rather than purely didactically. As a solution, participants suggested more video- and scenario-based activities than purely written content. A further idea was to incorporate fun, team-building activities.	"I can't be sitting there at a desk just like everyone heads down, someone talking at me, like I want to be able to like move around and like get up and speak to other people and not just be being spoken to" (P2). "Maybe like videos and things like that…it's alright like seeing it in writing, but maybe like videos of the scenario would be more helpful" (P10). "Say if this is going to be a 2 hour long thing, we're going to do the first thing you showed me, and then we're going to do say the cyberbullying bit after, and then we go off for half an hour and do a little dodgeball or whatever, and then we come back and do whatever the last thing was, I think that would be good" (P2).
Taking a	With this being such a difficult subject to talk	"A big one is the person who is delivering them. If you don't have trust

personable approach	about, YP highlighted the importance of the person delivering the support being trusting, gentle, personable, and approachable. YP reported that a key part of this was taking it at the pace of the person receiving the support.	and you don't have faith in that person there's no point, or if you don't like the person, there's no point working with them cause you're going to get nowhere" (P4). "It's how you deliver it, it's being open minded and mindful about how they're going to be feeling, like I don't know, not jumping into it I guess, like taking things quite slow, you never know how people are going to react to things and just being kind" (P7).
Considering practicalities and convenience	YP identified that practical aspects like time of day/week and location should be organised in such a way that they cause the least inconvenience to participants. Young parents brought up the additional practicalities they'd have to consider in order	"People in here, if it requires effort, they probably won't go, so if it's brought to them then they'll be more open to go to it, but say if they had to travel they probably wouldn't" (P7). "It's just about being flexible" (P4). "I would have to try find childcare and I think that's another reason why it's hard for young parents to speak about things" (P5).

	to attend a program like this.	

Phase 2: Staff

Three main themes emerged: 1) relationship difficulties and their impact, 2) support to be offered gently and thoughtfully, and 3) staff needs related to delivering this support. Theme 1 describes the range of relationship difficulties that staff have noticed YP to have as well as their perceived impact of these difficulties on the YP's lives. Three subthemes emerged: early relationships, romantic relationships, and friendships. Theme 2 relates to the gentle and thoughtful nature in which staff identified it is important to approach YP to support them with this difficult area of life. Four sub-themes emerged: trust, stealth, flexibility, and accessibility. Theme 3 relates to what staff identified as needing in order to be able to support YP in their relationships. Two sub-themes emerged: same approach used and training needs.

Figure 2.2 depicts the map of themes and sub-themes. These themes and subthemes are presented alongside explanations and supporting quotes in *Table 2.2* below. Each staff member was assigned a unique participant number (S). See *Appendix N* for further supporting quotes.



Figure 2.2. Map of themes and sub-themes from Phase 2 (staff).

Table 2.2. Themes, sub-themes, explanations, and supporting quotes from a focus group with four staff members.

Theme 1. Relationship difficulties and their impact.		
Sub-theme	**Explanation**	**Example quotes**
Early relationships	Staff noted that most YP have had difficult relationships with family and have experienced abuse, which has led them to having skewed ideas of what healthy relationships are and to staying in unhealthy relationships in their adult life.	"Most of the YP you speak to that are in unhealthy relationships, they tell you about the domestic abuse in their childhood, and that's really hard because it's like an inbuilt thing in them to follow those patterns" (S2).
	Staff reported that these early life experiences can lead to low self-esteem and a feeling of being unloved that YP try to rectify in future relationships.	"It can fill a need with the attention and that's a need that a lot of our YP have, they want to be loved, so you've got that whole issue of how do you work with YP to feel worthy or feel loved" (S3).
Romantic relationships	Similarly to the YP, staff were able to identify that YP struggle with depending too much on	"So quite often for them, the people that they're with, that's like their be-all and end-all, if anything happens with those relationships,

	their partners and making romantic relationships their everything. This dependency reportedly leads to YP avoiding being on their own. Staff identified that unhealthy romantic relationships can have impacts in the near and far future.	they're absolutely devastated" (S1). "An unhealthy relationship is better than no relationship at all and so better to be with someone than be on your own" (S2). "If you're in a healthy relationship it may mean that you don't smoke so much cannabis or you don't drink so much alcohol, it's a knock-on effect isn't it" (S2). "…the impact of an unhealthy relationship on their mental health and on perhaps in the future their children's mental health" (S2).
Friendships	Staff commented that YP can find it difficult to understand what healthy friendships look like.	"They've been shipped around different foster homes or they've been in different children's homes, quite often by themselves, they've missed out on learning how to interact appropriately and what will jeopardise a friendship" (S1).

	Staff also noted that social media negatively impacts YP and their friendships. They noted that these friendship difficulties can arise within YPSA residences as well.	"We've had it with YP where someone's turned their entire friendship group against them and they've been really horrible to them online" (S2). "Just from the way the YPSA is set up, they kind of feel pressure to be friends with everyone that's there… it might not necessarily be their kind of group of people" (S1).
Theme 2. Support to be offered gently and thoughtfully.		
Trust	Staff noted it is vital to build a trusting relationship with YP before discussing relationships with them. They noted that this trust is built up by offering a safe space.	"It's about building that relationship and that level of trust to begin with, it's about spending time with that YP and really listening to how the world is for them and understanding that" (S3). "Maybe it could be a little bit triggering to some of them, so being able to have a safe space and they can leave the room if they want" (S2).
Stealth	Staff noted that a stealthy approach to discussing	"If I said 'oh could I meet you tomorrow and we're going to talk

	relationships might be more welcome by the YP. They also noted that support needs to be offered gently and cautiously.	about healthy relationships', they ain't going to turn up, it's much more when you're with them, going to the shop, having a general chat…" (S2). "YP choose to be in relationships that are really quite unhealthy and we're trying to work with those YP without them thinking that you're trying to split them up from their partner because that isn't really going to help at all" (S2).
Flexibility	Similarly to YP, staff noted that practicalities such as group versus 1-to-1 delivery heavily depend on each person's preference and staff need to be flexible with this. Similarly, the content of the support needs to be tailored to individuals' needs.	"It would depend on the YP…as a group, they have a lot of good discussions and things, however with other YP that aren't quite on the same level, and might be quite learning disabled, they might not understand it, it might feel a bit out of their depth and they might glaze over and not quite concentrate on what's happening, and they're the YP that are more vulnerable to having these exploitations happen to them, so 1:1 key-working sessions would be really useful" (S1).

		"Having resources that are flexible is really useful because we're going off the residents needs and so staff can be flexible in how they're delivering things or talking about things" (S3).
Accessibility	Staff noted the importance of making content accessible due to some YP's additional learning needs. Staff also noted the benefit of having non-English materials.	"I know that more than one of them has dyslexia and I know that they've often left school quite early so they probably have a reasonably low reading age" (S4). "And different languages as well" (S4).
Theme 3. Staff needs related to delivering this support.		
Same approach used	Staff noted that it is vital for there to be a shared approach to working with YP in unhealthy relationships, because staff can get mixed messages about how to help YP, which can result in more harm than good.	"The most important thing is to agree what approach we are taking with our YP" (S2). "Sometimes you feel so much pressure that you've got to try to split them up sort of thing, and if the approach is more positive that we

		work with the YP, they are in this relationship and it's the relationship they want to be in, so we need to work with them on it to develop it into a healthy relationship" (S3).
Training needs	Staff felt that they receive more training in other areas, and recognised that whilst that is important, more emphasis should be placed on training related to relationships. Staff identified they would like trauma-informed care training and noted that this would facilitate a gentler approach to talking about this difficult subject.	"We did the training about drugs and alcohol, but relationships to me is the core of everyone's happiness, it should be a priority for the training of our organisations that we work for, above nearly everything else to be honest" (S2). "Training on working in a trauma-informed way around how you talk about relationships" (S2). "Continually putting little seeds into their heads really and just about what's right from wrong in a basic way, and what's healthy and what's not" (S1).

Discussion

The project aimed to investigate the relationship support needs of YP in the YPSA, who may be at increased risk of struggling to form and maintain healthy relationships due to their early life experiences. In addition, the project aimed to consider what types of interventions and materials might be most suitable for addressing those needs. Furthermore, it aimed to understand what facilitates and hinders engagement with services to better adapt interventions to meet the specific needs of the YPSA population.

YP and staff described a range of relationship difficulties for YP, and all noted that relationship support is important in this population. This is in line with previous findings on YP in care having experienced difficult early life relationships which affect emotional regulation and later-life relationships (Bath, 2015; McCrory et al., 2010; Sellers et al., 2020). The current study adds to existing literature because it gathered data on the wants and needs related to relationship support of an under-studied population. YP had mixed experiences of previous support. YP and staff were able to identify that future support should be individualised, engaging, conveniently timed and located, and delivered gently and sensitively. Staff identified they require additional training to feel comfortable delivering this support.

The example resources from the ‘Real Love Rocks’ program (Barnardo’s, 2022) met some of the requirements identified by participants as being important when delivering relationships support. In particular, they liked that the scenarios related to YP’s relationship experiences and felt that the range of topics covered (romantic relationships, exploitation, abuse, cyberbullying) were important. However, participants acknowledged that simply working your way through some worksheets feels an unnatural way to discuss this difficult topic and that putting the learning into practice is the most difficult aspect.

Recommendations for clinical practice

The below recommendations have been developed based on participants' experiences and comments and are directly linked to the aims of this project.

- Both YP and staff identified that additional relationship support is required and we therefore recommend that this be delivered within the YPSA.
- We recommend that an individualised approach to offering support needs to be maintained. This is because of the range of preferences participants reported related to 1:1 or group support delivery. A range of offers should be provided – one option to be a 'healthy relationships' group, but for those who do not feel able to take part in a group, staff should be supported to feel competent to draw on various aspects of the group materials as and when deemed relevant to the YP on their caseload so these discussions can form part of 1:1 support sessions. Alongside a YP, it would be helpful for the care team to consider what the YP's individual needs related to relationships are when they enter the YPSA, and note these in their care plan.
- We recommend that this support focuses on a range of different relationships – early life and family relationships, romantic relationships, and friendships.
- We recommend that this support covers a range of topics related to healthy relationships, including dependency, exploitation, abuse, online safety, and online relationships. This is in line with the large range of topics covered by the 'Real Love Rocks' resources being well-received by both YP and staff.
- To facilitate engagement, the delivery of support should be through a range of activities including conversations, videos, scenarios, and games. It would further facilitate engagement to include fun activities unrelated to relationships during breaktimes (e.g. outdoor, creative, sporty, or team-building activities).

- Engagement will further be improved if content is presented in an accessible way – simple language, lots of visuals and videos rather than too many words, and translations made available into other languages when needed.
- Engagement will also be maximised if the person delivering the support has a personable, trustworthy approach, and takes time to get to know YP and their needs.
- The 'Real Love Rocks' resources generated useful discussions and were generally well-received and deemed to be useful for discussing relationships issues. We recommend that the 'Real Love Rocks' program forms the basis of the support offered to YP, but that those specific resources are chosen which make more use of multimedia (photos, videos) and include activities rather than those that are purely wordy informational leaflets.
- We recommend that care staff members receive additional training in order to better support YP with relationship needs. We believe the below recommendations will maximise engagement with this area of support for YP.
    - Care staff would benefit from having the knowledge, information, and resources related to healthy relationships that they can bring into conversations with YP as and when they see appropriate. One way this may be achieved is by care staff members co-facilitating the 'healthy relationships' groups with YPSA clinical psychologist, using the 'Real Love Rocks' resources. In turn, these co-facilitators can then take ownership of sharing the resources and knowledge they acquire with more care staff.
    - Care staff could also benefit from training on trauma-informed care. This is because care staff reported that they know YP have had difficult upbringings which have impacted how they form and maintain relationships, but that they

do not understand the mechanisms by which this happens, and that training on this would make it easier to know how to approach this topic with YP.

- Lastly, it was acknowledged that a shared approach to working with YP in unhealthy relationships is needed. Staff currently report a mismatch, with some staff members being firm with YP about having to leave unhealthy relationships, and some staff supporting YP to stay in those relationships whilst trying to help them understand and change the unhealthy patterns within. From the project's findings, it seems that staff should not be quick to dismiss relationships even if there are some unhealthy patterns, as this can lead YP to lose trust in staff and continue the relationships outside of the home, where there is less supervision and therefore less safety. However, we recognise the complexities of achieving this shared approach within the context of potential safeguarding concerns, so seeking additional psychology consultations on this matter may be helpful.

Service response to findings

The YPSA clinical psychology team held a meeting to consider the findings and recommendations of this Service Improvement Project. The following feedback was received:

"Thanks Ruxandra. Having discussed your recommendations, we plan to pilot a 'Healthy Relationships' group within the YPSA based on the content of the 'Real Love Rocks' program, making use of its multimedia materials. We plan to design this group as a series of workshops, with each workshop having a clear remit that is shared with participants beforehand. Should YP have any concerns about a particular topic, they will be encouraged to speak to their YPSA support worker and/or the group facilitators, who will allocate an additional 30 minutes of time for check-ins post-workshop. Your suggestion of co-facilitating

this group with care staff members working across the YPSA is particularly helpful, as we agree that this will enable upskilling of care staff that can be cascaded across teams, enabling healthy relationship support to be included as part on individual support sessions when deemed relevant. There are already plans in motion for the YPSA Clinical Team to deliver care staff training in 'trauma-informed working', so we are glad to hear that this is deemed necessary and desirable. We plan to meet with our Clinical Director to further discuss these plans in the context of our capacity and service development objectives. We are very grateful for all your hard work on this project."

The poster summarising the findings and recommendations of this project (see *Appendix O*) will be emailed to staff and managers across the YPSA as part of the quarterly email sent out by the YPSA clinical psychology team.

Limitations

Firstly, it is important to note that the data was analysed and themes formed in the context of the primary researcher's stance and aims (discussed in 'Reflexivity' section). Different researchers may have made sense of the data and integrated subthemes in different ways based on their own stance and aims.

The staff focus group had to be separated into a smaller group and a 1:1 interview due to staff availability. This means the 1:1 staff member didn't have anyone to share their ideas with and the group may have come up with less rich data than otherwise. However, similar themes still emerged between the 1:1 interview and the focus group, and this flexible set-up meant that overall more staff members could participate in the research.

Convenience sampling was used for both YP and staff. For YP, it may mean that those YP with the most difficult of interpersonal relationships didn't participate because the topic feels too difficult or embarrassing to discuss, and these may be the YP most in need of relationship support. Furthermore, all YP were White British, making it difficult to generalise

the findings to YP from different ethnic groups. None of the YP were asylum-seekers, meaning the findings will not fully apply to asylum-seeking YP within the YPSA. For staff, it may be that only those most interested and motivated in supporting YP with relationships came forward, meaning that other staff might not feel it is as important or be as interested in receiving training for offering this support.

Future research could aim to understand the additional relationship support needs of asylum-seeking YP within the YPSA, as well as YP from different ethnic backgrounds. As focus groups are difficult to attend with staff's busy schedule, a briefer questionnaire could be administered so that a wider range of staff can comment on this topic.

Conclusions

YP within the YPSA experience relationship difficulties in their families, friendships, and romantic relationships which impact their wellbeing. It is recognised by YP and staff that relationship support is important, but that this must be delivered in an individualised, sensitive, and engaging manner. We recommend a 'healthy relationships' group based on the 'Real Love Rocks' program (Barnardo's, 2022) to be run. This should cover a range of topics related to relationships. However, 1:1 support should also be available for those YP who feel unable to attend the group. Care staff should receive appropriate training in order to be able to deliver this support. The recommendations of this project were well received and were deemed achievable by the YPSA service.

References

Barnardo's. (2022). *Real Love Rocks: Healthy Relationships & Exploitation Education Resources*. https://www.barnardosrealloverocks.org.uk/

Bath, H. (2015). The three pillars of traumawise care: Healing in the other 23 hours. *Reclaiming Children and Youth*, *23*(4).

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *Int J Qual Stud Health Well-being*, *9*(1), 26152-26152.

Buck, N. M. L., Leenaars, E. P. E. M., Emmelkamp, P. M. G., & Van Marle, H. J. C. (2012). Explaining the Relationship Between Insecure Attachment and Partner Abuse: The Role of Personality Characteristics. *Journal of Interpersonal Violence*, *27*(16). https://doi.org/https://doi.org/10.1177/0886260512441258

Clarke, V., & Braun, V. (2017). Thematic analysis. *The Journal Of Positive Psychology*, *12*(3), 297-298.

Du, Y. (2020). Analysis on Predictors of Attachment Style. *Advances in Social Science, Education and Humanities Research*, *496*.

Farina, A. S. J., Kremer, K., Maynard, B., Mancini, M., Hershberger, L., & Boyd-Ramirez, A. (2020). Intergenerational Trauma among Families in El Salvador: an Exploratory Study. *J Child Adolesc Trauma*, *13*(4), 515-525. https://doi.org/10.1007/s40653-020-00310-4

Foshee, V. A., Linder, F., MacDougall, J. E., & Bangdiwala, S. (2001). Gender differences in the longitudinal predictors of adolescent dating violence. *Prev Med*, *32*(2), 128-141. https://doi.org/10.1006/pmed.2000.0793

Foshee, V. A., Reyes, L. M., Agnew-Brune, C. B., Simon, T. R., Vagi, K. J., Lee, R. D., & Suchindran, C. (2014). The effects of the evidence-based Safe Dates dating abuse prevention program on other youth violence outcomes. *Prev Sci*, *15*(6), 907-916. https://doi.org/10.1007/s11121-014-0472-4

McCrory, E., De Brito, S. A., & Viding, E. (2010). Research review: the neurobiology and genetics of maltreatment and adversity. *J Child Psychol Psychiatry*, *51*(10), 1079-1095. https://doi.org/10.1111/j.1469-7610.2010.02271.x

Perry, B. D. (2009). Examining Child Maltreatment Through a Neurodevelopmental Lens: Clinical Applications of the Neurosequential Model of Therapeutics. *Journal of Loss & Trauma*, *14*(4), 240-255.

Russell, K. N., Voith, L. A., & Lee, H. (2021). Randomized controlled trials evaluating adolescent dating violence prevention programs with an outcome of reduced perpetration and/or victimization: A meta-analysis. *J Adolesc*, *87*, 6-14. https://doi.org/10.1016/j.adolescence.2020.12.009

Sellers, D. E., Smith, E. G., Izzo, C. V., McCabe, L. A., & Nunno, M. A. (2020). Child Feelings of Safety in Residential Care: The Supporting Role of Adult-Child Relationships. *Residential Treatment for Children & Youth*, *37*(2), 136-155.

Wolfe, D. A., Wekerle, C., Scott, K., Straatman, A. L., Grasley, C., & Reitzel-Jaffe, D. (2003). Dating violence prevention with at-risk youth: a controlled outcome evaluation. *J Consult Clin Psychol*, *71*(2), 279-291. https://doi.org/10.1037/0022-006x.71.2.279

Yehuda, R., & Lehrner, A. (2018). Intergenerational transmission of trauma effects: putative role of epigenetic mechanisms. *World Psychiatry*, *17*(3), 243-257. https://doi.org/10.1002/wps.20568

Theory-Driven Research Project

Exploring the impact of cognitive appraisals, anxiety, and falls concern in spinal cord injury rehabilitation.

Trainee: Ruxandra Vasile (ruxandra.vasile@gtc.ox.ac.uk)

Internal supervisor: Neil Carrigan (neil.carrigan@hmc.ox.ac.uk)

External supervisor: Jane Duff (janeduff@nhs.net)

Date: May 2024

Word count: 3,976

Proposed journal: Spinal Cord. This is the official journal of the International Spinal Cord Society and includes publications on all aspects of spinal cord injury and disease. See *Appendix P* for author guidelines.

Conflicts of interest: None.

Abstract

Study design. Cross-sectional, between-groups, questionnaire.

Objectives. To investigate the impact of falls concern, anxiety, and cognitive appraisals on engagement in spinal cord injury rehabilitation.

Setting. The National Spinal Injuries Centre (NSIC), Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, United Kingdom.

Methods. Participants were inpatients at the NSIC. They completed a questionnaire comprising three measures. The Generalized Anxiety Disorder-7 (GAD-7) measured symptoms of anxiety, the Spinal Cord Injury-Falls Concern Scale (SCI-FCS) measured falls concern, and the Appraisals of DisAbility: Primary and Secondary Scale (ADAPSS) assessed cognitive appraisals. Engagement in rehabilitation was measured using the Hopkins Rehabilitation Engagement Rating Scale (HRERS), completed by participants' physiotherapists. Correlational analyses and a hierarchical multiple regression were conducted.

Results. Engagement in rehabilitation was not significantly correlated with cognitive appraisals of disability, falls concern, or generalised anxiety. The overall multiple regression model was not statistically significant.

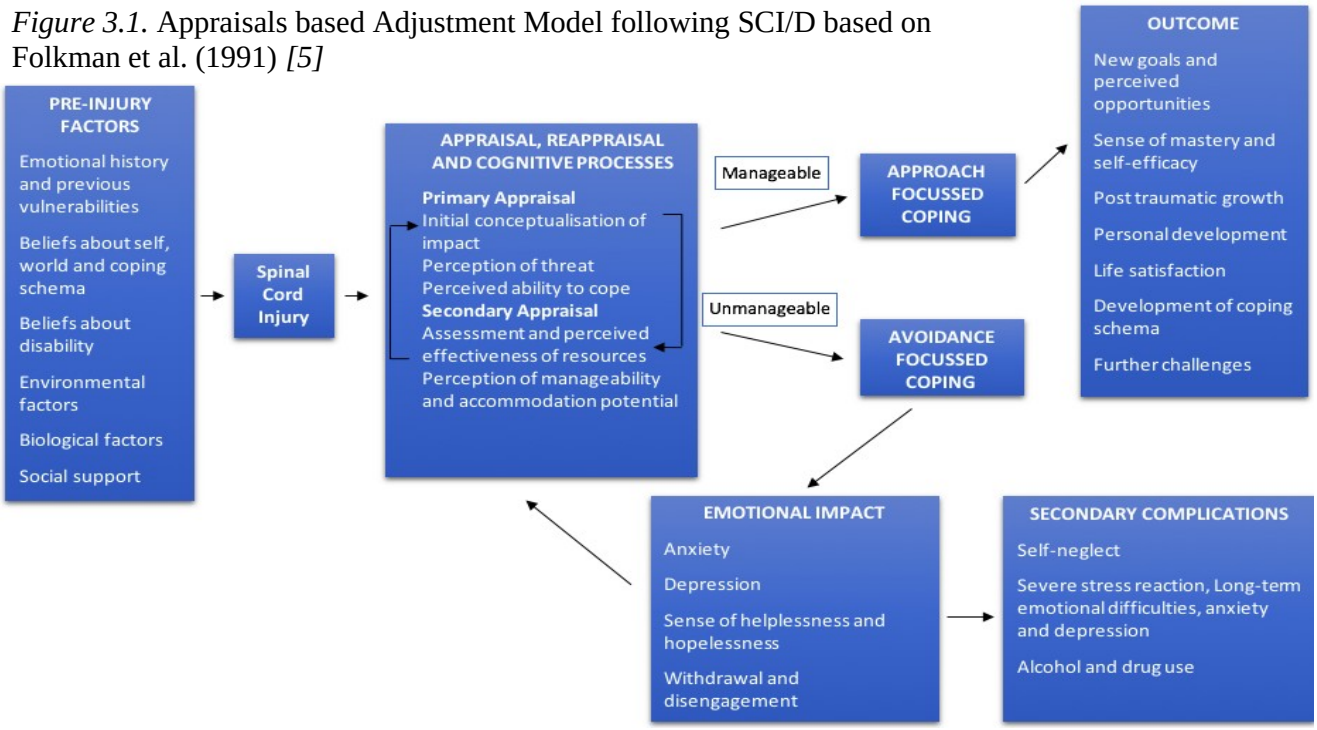
Conclusions. Cognitive appraisals of disability, falls concern, and generalised anxiety are not significantly correlated with or predictive of engagement in SCI/D rehabilitation. Engagement in rehabilitation was rated generally high. There was a high prevalence of falls concern and generalised anxiety. Suggestions for future research include considering other psychological factors which may predict engagement, conducting this research in settings with more varied engagement levels, and further exploring falls concern and its link with actual falls.

Introduction

Spinal cord injuries and disorders (SCI/Ds) are characterised by damage to the cells and/or nerves in the spinal cord, which are responsible for communication between the brain and the body [1]. SCI/Ds can occur due to externally-caused events, called 'traumatic injuries' (e.g. road traffic accidents or sports injuries), or internally-caused events, referred to as 'non-traumatic injuries' (e.g. strokes or infections) [2]. This damage can result in temporary or permanent impairments in movement, sensory, or autonomic functioning [1]. Individuals who are able to walk post-SCI/D are neurologically referred to as being 'ambulatory' [3].

A model which can explain how individuals cope with sustaining a SCI/D is the transactional model of stress and coping [4]. This model proposes that when individuals face a situation, they must first appraise whether it is likely to cause them stress or not. If appraised as stressful, situations are then categorised into whether they pose a challenge, a threat, a loss, or are benign. Secondly, individuals evaluate what strategies and mechanisms they possess to cope with the situation. The transactional model of stress and coping has been re-interpreted for SCI/D (see *Figure 3.1*) [5]. This SCI/D-specific model considers pre-injury

Figure 3.1. Appraisals based Adjustment Model following SCI/D based on Folkman et al. (1991) *[5]*



experiences and contextual factors and proposes that primary and secondary appraisals determine how a person copes with their injury. It proposes that individuals who appraise their SCI/D as a challenge are more likely to have positive beliefs about 'manageability', and so consider that they have the tools to cope with the injury. These individuals are more likely to use approach-focused coping, and therefore be more engaged in rehabilitation. Contrastingly, individuals who appraise their SCI/D as a loss or a threat, and unmanageable, are more likely to use avoidance-focused coping [5]. Approach-focused coping can result in new perceived opportunities, a sense of mastery and self-efficacy, post-traumatic growth, personal development, life satisfaction, and further enhancement of coping strategies [5]. Avoidance-focused coping does not ameliorate the stress reaction and requires the individual to either re-appraise their coping approach and situation or places the individual at risk of anxiety, depression, a sense of helplessness and hopelessness, and withdrawal, which may lead to secondary complications such as self-neglect, long-term stress, and alcohol/drug use [5]. Given this, it is unsurprising that anxiety, depression, and posttraumatic stress disorder are twice as prevalent in people with SCI/D (PwSCI/D), and suicide three times more common [6].

For inpatients with SCI/D to achieve the best possible outcomes post-injury, being fully engaged in the rehabilitation process is key [7]. It could therefore be said that approach-focused coping in the acute inpatient rehabilitation phase involves engagement with rehabilitation therapy. Lequerica and Kortte (2010) define engagement in rehabilitation as "a deliberate effort and commitment to working toward the goals of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers" (p. 416).

The Appraisals-based Adjustment Model (*Figure 3.1*) would suggest that engagement in rehabilitation is affected by a patient's cognitive appraisals. Cognitive appraisals have been

shown to play a role in psychological adjustment in early-stage SCI/D rehabilitation, more so than injury characteristics [8]. As seen in *Figure 3.1*, these appraisals include perception of threat, ability to cope, effectiveness of resources, and manageability to cope with the injury [1]. Cognitive appraisals that are formed early on in SCI/D rehabilitation have been shown to impact long-term physical and psychological outcomes [9]. One measure looking at cognitive appraisals during SCI/D rehabilitation is 'The Appraisals of DisAbility: Primary and Secondary Scale (ADAPSS)' [10]. This looks at six different appraisal domains of disability – three domains (fearful despondency, overwhelming disbelief, and negative perceptions of disability) load onto the factor 'catastrophic negativity/loss', whilst three domains (determined resolve, growth and resilience, and personal agency) load onto the factor 'determined resilience'. The measure and a breakdown of questions by domain is available in *Appendix Q*.

Individuals who have reduced 'determined resilience' appraisals and heightened 'catastrophic negativity/loss' appraisals are said to view their SCI/D as unmanageable, a threat, and a loss [8]. Therefore, according to the model, they present with more avoidant behaviour and greater dependence on others in relation to their own health needs [11]. This negatively impacts psychological and functional outcomes, adjustment, and engagement in rehabilitation [11] and impacts on long term health and mortality [12].

Further potential barriers to engagement in rehabilitation are experiences of falls or falls concern [7]. PwSCI/D are at increased risk of falls, and therefore, falls-related injuries [13], even when compared to other vulnerable populations [14]. A meta-analysis reports that 34-82% of ambulatory and 31-73% of wheelchair-using PwSCI/D experience falls [14]. Falls concern has been defined as "a lasting concern about falling that leads to an individual avoiding activities that he/she remains capable of performing" [15]. Falls concern has been found to significantly predict recurrent and injurious falls [16]. The mechanism underpinning

this relationship is unclear; it is possible that fear is caused by fall-related experiences, and fear leads to falls, or may be that factors which increase fall risk also stimulate fear (e.g. muscle weakness, impaired balance, and impaired sensation) [16]. Either way, as seen in *Figure 3.1*, 'perception of threat', which falls concern relates to, impacts whether someone views their SCI/D as manageable or unmanageable. Furthermore, research has shown that falls concern, rather than actual falls, has been found to negatively impact participation in daily life and community activities, autonomy, and life satisfaction [17]. Falls concern has been identified as a significant constraint for successful rehabilitation in older adults recovering from hip surgery, stroke, or other disabilities, and predicted rehabilitation outcomes at discharge and follow-up [18, 19].

Based on the above, engagement in rehabilitation may be an appropriate way to identify whether someone is using 'approach focused coping' or 'avoidant focused coping' during the inpatient SCI/D rehabilitation stage [5]. There has been limited research into factors that contribute to engagement in rehabilitation in SCI/D inpatients, including cognitive appraisals of disability. Furthermore, there is little research on the impact that falls concern has on SCI/D inpatients and their ability to engage with rehabilitation. It is also unclear whether falls concern exists independently or might be related to a larger generalised anxiety problem in PwSCI/D. PwSCI/D have reported a desire for better access to psychological interventions [20]. However, for effective interventions to be delivered, we must first understand what these interventions should focus on in order to maximise the outcomes of rehabilitation.

Given the aforementioned literature, the aim of this research is to understand if and how cognitive appraisals of disability, falls concern, and generalised anxiety differ between SCI/D inpatients with high engagement in rehabilitation and those with low engagement. The implications are that this research may indicate whether the aforementioned factors should be

specifically targeted in SCI/D rehabilitation to facilitate better physical and psychological outcomes. Our primary hypothesis is that inpatients who have high engagement in rehabilitation will have fewer threat/loss appraisals of their SCI/D (as measured by ADAPSS-Threat/Loss domain) and greater determined resilience appraisals (as measured by ADAPSS-Resilience domain) compared to individuals with low engagement in rehabilitation. Our secondary hypothesis is that inpatients who have high engagement in rehabilitation will be less likely to experience generalised anxiety and falls concern compared to individuals with low engagement in rehabilitation.

Methods

Ethics

Ethical approval was obtained from the University of Oxford Research Governance Committee, Hampshire HRA NHS Research Ethics Committee (23/SC/0298), and Buckinghamshire Healthcare NHS Trust (see *Appendices X-Z* for ethical approvals).

Experts-by-experience

An expert with lived experience of SCI/D working at the NSIC was consulted throughout the study design process on the study materials (e.g. information sheet and consent form) and the selected outcome measures.

Participants

Participants were recruited from the National Spinal Injuries Centre (NSIC), Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust. Recruitment took place through approaching suitable inpatients and through the NSIC Clinical Psychology Team referrals. Inclusion criteria included: being an inpatient undergoing first time rehabilitation, being ambulant or a wheelchair-user with a SCI/D and being aged 18 or older. Exclusion criteria included being non-English speaking, being admitted for medical complications such as urinary tract infections or pressure sores and having cognitive deficits which prevent

informed consent. Once inpatients completed their questionnaires, their physiotherapist was approached via email and asked to complete a questionnaire about that patient's engagement in rehabilitation.

No previous research used this study's engagement measure in a SCI/D population, or similar populations (e.g. people with multiple sclerosis or other inpatient populations undergoing rehabilitation). An a-priori power calculation conducted using G-Power, with effect size=.15 (medium), alpha level=.05, power=.8, calculated required sample size as 78. Due to difficulties with recruitment, a final sample size of 54 was achievable, and hence the study was underpowered.

Measures

Inpatient-rated measures

The Generalized Anxiety Disorder (GAD-7) questionnaire [21] (see *Appendix R*): This 7-item self-report measure uses a 4-point Likert-type scale ('not at all' to 'nearly every day') to screen for symptoms of anxiety [21]. Higher scores indicate more anxiety symptomatology. This measure has been found to have 89% sensitivity, 82% specificity, and good reliability (α=.88) [22, 23]. This measure is included to differentiate between generalised anxiety, and anxiety specifically related to falls ('falls concern' – see below). This study's sample achieved an internal consistency of α=.886.

Spinal Cord Injury-Falls Concern Scale (SCI-FCS) [24] (see *Appendix S*): This 16-item self-report measure uses a 4-point Likert-type scale ('not at all concerned' to 'very concerned') to assess concern related to falling during different tasks (e.g. washing self or reaching for high objects) in PwSCI/D. Higher scores indicate more

falls concern. The scale has high internal consistency (α=.82-.92) and test-retest reliability [24]. This measure is used for permanent wheelchair users and ambulatory PwSCI/D, as both use wheelchairs during the early rehabilitation stages and are at risk of falls. This study's sample achieved an internal consistency of α=.95.

The Appraisals of DisAbility: Primary and Secondary Scale (ADAPSS) [10]: This 33-item self-report measure uses a 6-point Likert-type scale ('strongly disagree' to 'strongly agree') to assess 6 different appraisal domains of disability. Three domains (fearful despondency, overwhelming disbelief, and negative perceptions of disability) map onto the factor 'catastrophic negativity/loss', whilst three domains (determined resolve, growth and resilience, and personal agency) map onto the factor 'determined resilience'. Some items are reverse coded, such that higher scores on both 'catastrophic negativity/loss' and 'determined resilience' domains add up to an overall higher score, which indicates that individuals appraise their injury more negatively. This measure has been validated for use within samples of PwSCI/Ds [25, 26] and shows sufficient sensitivity, reliability, validity, and internal consistency (α=.775) [8, 26]. This study's sample achieved an internal consistency of α=.931.

Physiotherapist-rated measure

The Hopkins Rehabilitation Engagement Rating Scale (HRERS) [27] (see *Appendix T*): This 5-item clinician-scored measure uses a 6-point Likert-type scale ('never' to 'always') to assess an inpatient's engagement in their physical rehabilitation with regards to: attendance, active participation, need for verbal or physical prompts to participate, attitude towards rehabilitation and acknowledgement of the need for rehabilitation. This is the first measure of engagement to capture the multiple

elements of engagement, rather than solely focusing on attendance or a singular overall rating of engagement as a whole concept [27]. The scores can range between 5 and 30, with a higher score representing better engagement with rehabilitation. This has been validated for use within samples of PwSCI/Ds [27]. The HRERS has good internal consistency (α=.91) and interrater reliability (intraclass correlation coefficient=.73) and represents a unidimensional construct [27]. This measure was completed by the PwSCI/D's physiotherapist. This study's sample achieved an internal consistency of α=.878.

Procedure

Inpatients were approached on the NSIC wards by the researcher or by other members of the psychology team if the researcher had previously had any clinical contact with the potential participant. Inpatients were given a verbal description of the study, the information sheet (see *Appendix U*), and the consent form (see *Appendix V*). If they provided informed consent to participate, a time was scheduled to complete the questionnaires, and participants chose whether to complete the questionnaires themselves or with a researcher based on preference and ability – for example, if preferred, for inpatients with tetraplegia the researcher administered the measures. Physiotherapists were emailed immediately after and asked to complete the HRERS via an online survey tool, Qualtrics, by entering the inpatients' unique identification number (rather than their name) (see *Appendix W* for sample email).

Statistical analyses

Patient's paper questionnaires were entered into Qualtrics by the researcher. Patient and physiotherapist questionnaires were linked through unique identification numbers. Data

was analysed using SPSS v17.0. Means (M), standard deviations (SDs), and proportions (%) were calculated for demographic data and SCI/D characteristics.

The original data analysis plan was to use a median split on the HRERS to create the 'high engagers' and 'low engagers' in rehabilitation groups. This split was chosen based on previous research using this measure [27] and conversations with the measure's authors, who also confirmed that the measure did not have set cut-off points for 'level' of engagement. Histograms were plotted (see *Appendix V*), assumptions for parametric tests were investigated and corresponding statistical tests conducted (see *Appendix W)* to assess differences in dependent measures between 'high' and 'low' engagers in rehabilitation. However, it became apparent that this data analysis plan was not the most appropriate as most participants scored very highly on the HRERS, making it difficult to differentiate the two groups. For research integrity purposes, the original data analysis plan was still carried out and is included in *Appendix W*.

Instead, correlations were conducted between engagement in rehabilitation scores (HRERS) and GAD-7, SCI-FCS, and ADAPSS scores to determine order of input into a hierarchical regression model to assess the main study hypotheses. Prior to this, tests of assumptions for a multiple regression were also conducted.

Results

Participant characteristics

Table 3.1 displays demographics and SCI/D-related characteristics of the 54 individuals who participated in the study. Most study participants were male (70.4%), White British (77.8%), and either not religious (46.3%) or Christian (40.7%). Study participants'

ages ranged from 18 to 85 (*M*=51.54, *SD*=19.01). Twenty-five (46.3%) participants had a cervical injury (C2-C8), 27 (50%) a thoracic injury (T1-12), and two (3.7%) a lumbar injury (L1-L5). Thirty-three participants (61.1%) had a complete injury and 21 (38.9%) an incomplete one. *Table 3.1* also includes a comparison column of the 177 newly-injured and admitted NSIC patients from the 2022/23 tax year. Study participants appear relatively representative of general admissions to the NSIC in 2022/23.

Table 3.1. Demographics and clinical characteristics of study sample and of NSIC patients from 2022/23 annual report.

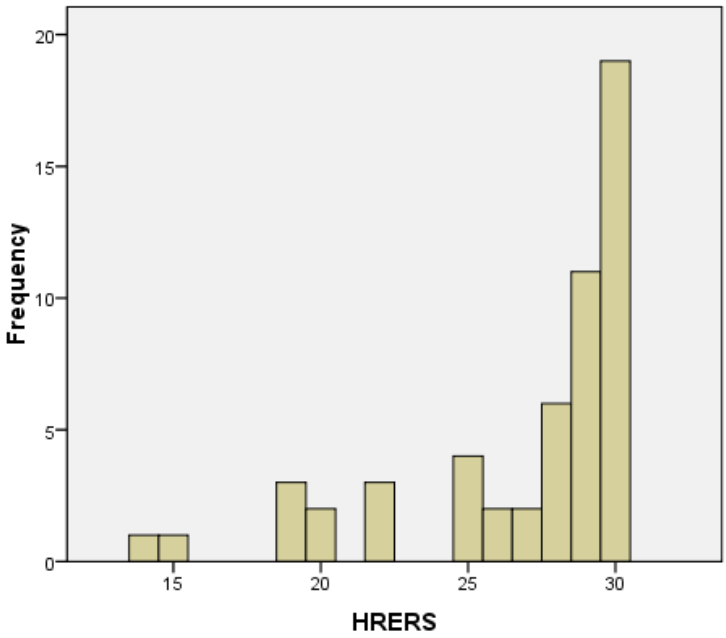
	Study sample		**Annual report 2022/23**
	M	**SD**	
Age	51.54	19.01	NR
	N	**%**	**%**
Gender			
Male	38	70.40	62.71
Female	16	29.60	37.29
Ethnicity			
White British	42	77.80	65.54
White Other	1	1.90	8.47
Black, Black British, Caribbean, or African	6	11.10	7.34
Asian or Asian British	5	9.30	11.86
Religion			
Christian	22	40.70	NR
Muslim	3	5.60	NR
Sikh	1	1.90	NR
Hindu	1	1.90	NR
No religion	25	46.30	NR
None of these	2	3.70	NR
Injury level			
Cervical (C)	25	46.30	48.59
Thoracic (T)	27	50.00	41.24
Lumbar (L)	2	3.70	10.17
Injury completeness			
Tetraplegia complete (ASIA ABC)	11	20.40	54.80*
Paraplegia complete (ASIA ABC)	22	40.70	
Incomplete (ASIA D)	21	38.90	37.23

Note: NR = not reported. M & SD provided for age, N & % for all other demographics. All participants defined their gender as male or female. Where % does not add up to 100 in annual report column, this is because the report included categories that the current study did not. *Annual report categorised tetraplegia and paraplegia complete into one category, so this figure covers both.

Descriptive statistics for 'engagement in rehabilitation' measure

Figure 3.2 shows that HRERS scores were negatively skewed, with many high scores (M=26.94, SD=4.16, Median=29), suggesting most participants were highly engaged in rehabilitation.

Figure 3.2. Histogram of HRERS scores for full sample.



Descriptive statistics for patient-responded measures

Means (M) and standard deviations (SDs) of GAD-7, SCI-FCS, and ADAPSS scores are presented in *Table 3.3*. Overall, 30% of participants scored above the GAD-7 clinical cut-off of 10 [21], and 58% of participants scored above the norm median score of the SCI-FCS [24].

Table 3.3. Means and standard deviations of GAD-7, SCI-FCS, and ADAPSS scores.

Measure		M	SD
	SCI-FCS	30.76	12.56
	GAD-7	7.02	5.87
	ADAPSS	108.74	31.32

Correlation analyses

Bivariate correlations were conducted between engagement in rehabilitation scores and GAD-7, SCI-FCS, and ADAPSS scores. *Table 3.4* displays the correlations.

Table 3.4. Pearson's correlation between engagement in rehabilitation and GAD-7, SCI-FCS, and ADAPSS scores.

		GAD-7	**FCS**	**ADAPSS**
HRERS	Pearson's correlation	-.080	-.138	-.192
	Sig. (2-tailed)	.321	.568	.165

The strongest negative correlation was between engagement in rehabilitation and cognitive appraisals of disability, $r(52)=-.192$, $p=.165$, followed by generalised anxiety, $r(52)=-.080$, $p=.321$ and then falls concern, $r(52)=-.138$, $p=.568$. Whilst this finding might suggest that as engagement in rehabilitation scores increase, GAD-7, FCS, and ADAPSS scores decrease, none of these correlations were statistically significant.

Multiple regression

The data met the assumptions of linearity, multivariate normality, and multicollinearity for multiple regression analysis. A hierarchical multiple regression was conducted to test if ADAPSS, FCS, and GAD-7 scores significantly predicted engagement in rehabilitation. The variables were entered into the model based on their level of correlation with HRERS as shown in *Table 3.4*. *Table 3.5* displays outputs of the regression analysis. The overall final model was not statistically significant, $F(3,50)=0.994$, $p=.404$, suggesting that ADAPSS, FCS, and GAD-7 scores did not collectively predict engagement in rehabilitation. The model did not account for a substantial proportion of the variance in engagement in rehabilitation scores, $R^2=.056$. None of the predictors showed statistically

significant relationships with engagement in rehabilitation scores in any of the models; ADAPSS: *t*=-1.408, *p*=.165; FCS: *t*=-.653, *p*=.517; GAD-7: *t*=.783, *p*=.437.

Table 3.5. Multiple regression of ADAPSS, FCS, and GAD-7 on engagement in rehabilitation.

Model	**Unstandardised β**	**Coefficients standard error**	***t***	***p***	**95% Confidence Interval for β**	
					Lower	Upper
Step 1						
Constant	29.711	2.044	14.537	<.001	25.610	33.812
ADAPSS	-.025	.018	-1.408	.165	-.062	.011
Step 2						
Constant	30.296	2.242	13.513	<.001	25.795	34.796
ADAPSS	-.022	.019	-1.173	.246	-.060	.016
FCS	-.031	.047	-.653	.517	-.125	.064
Step 3						
Constant	31.318	2.602	12.037	<.001	26.092	36.544
ADAPSS	-.033	.024	-1.405	.166	-.080	.014
FCS	-.051	.054	-.945	.349	-.159	.057
GAD-7	.111	.142	.783	.437	-.174	.397

Discussion

The findings from the current study indicate that falls concern, generalised anxiety, and cognitive appraisals of disability do not predict engagement in SCI/D rehabilitation when entered into a hierarchical multiple regression model. These results are not in line with the experimental hypotheses of the study or the appraisals-based adjustment model post SCI/D (*Figure 3.1)*. Based on the appraisals-based adjustment model post-SCI/D (*Figure 3.1*), the primary hypothesis was that cognitive appraisals of disability would be significantly different between high and low engagers in rehabilitation. We did not find this, or a predictive effect of cognitive appraisals of disability on engagement in rehabilitation. The secondary hypothesis was that falls concern and generalised anxiety would be significantly different between high and low engagers in rehabilitation. Similarly to our primary hypothesis, we did not find this. If we had found that cognitive appraisal of disability, anxiety, and/or falls concern were

predictive of engagement in rehabilitation, it would have provided important evidence for implementing interventions targeted at these, in order to also improve physical and functional outcomes post-SCI/D. However, as our original data analysis (see Appendix W) and the multiple regression presented above did not support this, it may be the case that engagement in rehabilitation is not a good indicator of whether someone is using approach- or avoidant-focused coping to manage their SCI/D. An alternative interpretation may be that engagement in rehabilitation is a good indicator of coping style, but that there are other psychological factors that were not measured which predict engagement.

Interestingly, HRERS scores were very high across the sample. This could be due to the nature of the setting; post-hoc discussions with physiotherapists at the NSIC confirmed that this setting has a very rigorous, intensive, and structured approach to rehabilitation. For example, inpatients have physiotherapy timetabled into their schedules as a priority and if they fail to appear to sessions, their physiotherapists look for them and support them to attend. Furthermore, by the time most inpatients arrive for rehabilitation at the NSIC, they have already been on the waiting list for months, having received non-specialist treatment for their SCI/D on a general trauma ward. Consequently, the NSIC is inpatients' first opportunity for a specialist spinal rehabilitation program, which may motivate inpatients to 'get the most' out of their stay. A further potential reason for overall high HRERS scores could be a self-selection bias – perhaps those inpatients that were more engaged in rehabilitation were also more likely to consent to taking part in research than those who were not as engaged in rehabilitation (eleven inpatients that were asked declined to take part). Nonetheless, it would be beneficial to understand if/what psychological factors facilitate such high engagement, so as to promote these factors in other, less specialist settings where SCI/D patients may be undergoing rehabilitation and struggling to engage with it.

Our findings also show that 30% of participants scored above the clinical cut-off of the GAD-7, which is in line with previous research on anxiety in PwSCI/D [6]. This is higher than the general population [6]. Furthermore, the findings show that 58% of participants scored above the norm median score of the falls concern measure. As falls concern has been understudied in the SCI/D population, this is an important finding as it sheds light on the increased prevalence of this issue in this population. Given the findings of elevated generalised anxiety and falls concern, there is rationale to consider interventions targeted at improving this in PwSCI/D.

A further area for development is to collect data on frequency and severity of falls experienced by each patient. This data could have been used to investigate the currently understudied relationship between falls concern and actual falls. Future research within the NSIC could seek ethical approval to access inpatients' clinical records, as these contain a clinician-rated 'falls risk screen', which assesses history and risk of actual falls.

Lastly, this study did not reach its recruitment target, so it is important to consider the findings in the context of this being an underpowered study. Future research in this field should aim to recruit more participants, be conducted in a range of settings where engagement in rehabilitation levels are likely to vary, and measure other factors which could impact engagement. This study demonstrates the need for further research in the currently under-researched areas of engagement in SCI rehabilitation and falls concern, as well as supporting previous findings on the increased prevalence of generalised anxiety in PwSCI/D.

Conclusions

This study did not find a significant effect of cognitive appraisals of disability, anxiety, or falls concern on engagement in SCI/D rehabilitation. This indicates that either (i) engagement in rehabilitation is not a good indicator of whether someone is using approach- or avoidant-focused coping post-SCI/D, or (ii) engagement is a good indicator of coping

style, but cognitive appraisals of disability, anxiety, and falls concern do not impact engagement, and there are other factors that may predict it. Despite the lack of significant findings related to our hypotheses, this study was able to demonstrate the high level of engagement that exists in rehabilitation at the NSIC, as well as a presence of falls concern and generalised anxiety in the inpatient SCI/D population. The study was able to make suggestions for expanding the currently limited evidence base on engagement and falls concern in SCI/D rehabilitation.

Funding

The project is part of a Doctorate in Clinical Psychology thesis and did not receive any funding.

References

1. Craig A, Duff J, Middleton J. Spinal cord injuries. Comprehensive Clinical Psychology. 8: Elsevier; 2022. p. 301-28.

2. Center NSCIS. Spinal cord injury facts and figures at a

glance: National Spinal Cord Injury Statistical Center; 2021 [Available from: https://www.nscisc.uab.edu/Public/Facts%20and%20Figures%20-%202021.pdf.

3. Menon N, Gupta A, Khanna M, Taly AB. Ambulation following spinal cord injury and its correlates. Ann Indian Acad Neurol. 2015;18(2):167-70.

4. Lazarus RS, Folkman S. Stress, appraisal, and coping. New York: Springer Publishing Company; 1984. 445 p.

5. Duff J, Kennedy P. Spinal Cord Injury. In: Llewelyn S, Kennedy P, editors. Handbook of Clinical Health Psychology: John Wiley & Sons, Ltd.; 2003. p. 251-78.

6. Bombardier CH, Azuero CB, Fann JR, Kautz DD, Richards JS, Sabharwal S. Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury: Clinical Practice Guideline for Healthcare Providers. Top Spinal Cord Inj Rehabil. 2021;27(2):152-224.

7. Lequerica AH, Kortte K. Therapeutic engagement: a proposed model of engagement in medical rehabilitation. Am J Phys Med Rehabil. 2010;89(5):415-22.

8. Eaton R, Jones K, Duff J. Cognitive appraisals and emotional status following a spinal cord injury in post-acute rehabilitation. Spinal Cord. 2018;56(12):1151-7.

9. Kennedy P, Evans M, Sandhu N. Psychological adjustment to spinal cord injury: the contribution of coping, hope and cognitive appraisals. Psychol Health Med. 2009;14(1):17-33.

10. Dean RE, Kennedy P. Measuring appraisals following acquired spinal cord injury: a preliminary psychometric analysis of the appraisals of disability. Rehabil Psychol. 2009;54(2):222-31.

11. Kennedy P, Smithson E, McClelland M, Short D, Royle J, Wilson C. Life satisfaction, appraisals and functional outcomes in spinal cord-injured people living in the community. Spinal Cord. 2010;48(2):144-8.

12. Kennedy P, Kilvert A, Hasson L. A 21-year longitudinal analysis of impact, coping, and appraisals following spinal cord injury. Rehabil Psychol. 2016;61(1):92-101.

13. Jorgensen V, Butler Forslund E, Franzen E, Opheim A, Seiger A, Stahle A, et al. Factors Associated With Recurrent Falls in Individuals With Traumatic Spinal Cord Injury: A Multicenter Study. Arch Phys Med Rehabil. 2016;97(11):1908-16.

14. Khan A, Pujol C, Laylor M, Unic N, Pakosh M, Dawe J, et al. Falls after spinal cord injury: a systematic review and meta-analysis of incidence proportion and contributing factors. Spinal Cord. 2019;57(7):526-39.

15. Tinetti ME, Powell L. Fear of falling and low self-efficacy: a case of dependence in elderly persons. J Gerontol. 1993;48 Spec No:35-8.

16. Jorgensen V, Butler Forslund E, Opheim A, Franzen E, Wahman K, Hultling C, et al. Falls and fear of falling predict future falls and related injuries in ambulatory individuals with spinal cord injury: a longitudinal observational study. J Physiother. 2017;63(2):108-13.

17. Singh H, Chan K, Cheung L, Hitzig SL, Musselman KE. The impact of falls and fear of falling on participation, autonomy, and life satisfaction among individuals with spinal cord injury: A brief report. J Spinal Cord Med. 2021;44(sup1):S234-S9.

18. Visschedijk J, Achterberg W, Van Balen R, Hertogh C. Fear of falling after hip fracture: a systematic review of measurement instruments, prevalence, interventions, and related factors. J Am Geriatr Soc. 2010;58(9):1739-48.

19. Denkinger MD, Igl W, Lukas A, Bader A, Bailer S, Franke S, et al. Relationship between fear of falling and outcomes of an inpatient geriatric rehabilitation population--fear of the fear of falling. J Am Geriatr Soc. 2010;58(4):664-73.

20. Hearn JH, Cotter I, Fine P, K AF. Living with chronic neuropathic pain after spinal cord injury: an interpretative phenomenological analysis of community experience. Disabil Rehabil. 2015;37(23):2203-11.

21. Spitzer RL, Kroenke K, Williams JB, Lowe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med. 2006;166(10):1092-7.

22. Williams N. The GAD-7 questionnaire. Occupational Medicine. 2014;64:224.

23. Johnson SU, Ulvenes PG, Oktedalen T, Hoffart A. Psychometric Properties of the General Anxiety Disorder 7-Item (GAD-7) Scale in a Heterogeneous Psychiatric Sample. Front Psychol. 2019;10:1713.

24. Boswell-Ruys CL, Harvey LA, Delbaere K, Lord SR. A Falls Concern Scale for people with spinal cord injury (SCI-FCS). Spinal Cord. 2010;48(9):704-9.

25. Mignogna J, Christie AJ, Holmes SA, Ames H. Measuring disability-associated appraisals for veterans with spinal cord injury. Rehabil Psychol. 2015;60(1):99-104.

26. McDonald SD, Goldberg-Looney LD, Mickens MN, Ellwood MS, Mutchler BJ, Perrin PB. Appraisals of DisAbility Primary and Secondary Scale-Short Form (ADAPSS-sf): Psychometrics and association with mental health among U.S. military veterans with spinal cord injury. Rehabil Psychol. 2018;63(3):372-82.

27. Kortte KB, Falk LD, Castillo RC, Johnson-Greene D, Wegener ST. The Hopkins Rehabilitation Engagement Rating Scale: development and psychometric properties. Arch Phys Med Rehabil. 2007;88(7):877-84.

Executive Summary for Theory-Driven Research Project

Why the study was conducted

The way a person copes with and adjusts to sustaining a spinal cord injury or disorder (SCI/D) depends on a number of factors – a key one being how they think about their injury. This includes whether someone views their injury as a threat (e.g. having negative views of disability, being in disbelief that this has happened to them, and being fearful and hopeless about the future) or as a manageable challenge (e.g. feeling determined to take action to improve their future, feeling like they have control, and feeling like the experience is making them grow and develop). The exact reasons why someone might view their injury as a threat rather than a manageable challenge are still being investigated but include past experiences and social support.

Research has shown that those people who view their injury as a manageable challenge rather than a threat are more likely to have better physical and psychological outcomes. One proposed reason for this is because these people are not reluctant to 'face' the challenge, and hence will engage with physical rehabilitation that is offered to them. We wanted to understand whether this was true, and whether inpatients who engaged more in rehabilitation thought about their injury more positively than inpatients who engaged less in rehabilitation.

We also know that patients with SCI/Ds can be affected by falls (e.g. falling out of their wheelchair, whilst transferring, or whilst walking). Actual falls can lead to future fear about falling, but this fear may also exist without past experiences of falling. In similar populations, such as people recovering from hip surgeries and strokes, fear about falling has been shown to affect successful rehabilitation. Therefore, we were also interested in understanding whether those inpatients who engaged more in rehabilitation had less fear of falling than inpatients who engaged less in rehabilitation. We were also interested in finding

out whether fear about falling was different from general feelings of worry (generalised anxiety), and so wanted to understand whether those inpatients who engaged more in rehabilitation had less generalised anxiety than inpatients who engaged less in rehabilitation.

Understanding the above more fully is important as it allows psychologists to support people to think about their injury more positively and manage feelings of anxiety and fear of falling, in order to facilitate engagement in rehabilitation and improve functional outcomes and goal achievement.

What the study aimed to investigate

Given the above information, our aims were:

1) To investigate whether there is a relationship between engagement in rehabilitation and the way people think about their injury.
2) To investigate whether there is a relationship between engagement in rehabilitation and fear of falling.
3) To investigate whether there is a relationship between engagement in rehabilitation and anxiety.

How the study was conducted

The study took place at the National Spinal Injuries Centre (NSIC), Stoke Mandeville Hospital. It was co-developed with an individual with a SCI/D and received ethical approval from the NHS. Inpatients were invited to take part if they were over 18 years old, if it was their first time in SCI/D rehabilitation, and if they had no cognitive difficulties. Fifty-four inpatients consented to and filled out a questionnaire asking them about how they think of their injury, their levels of generalised anxiety, and how fearful about falling they are. Each inpatient's physiotherapist then filled out a questionnaire which rated how engaged that patient is in rehabilitation. The inpatients' and physiotherapists' questionnaires were matched up to analyse for relationships in the data.

What the study found

Findings from the questionnaires found that there was no relationship between engagement in rehabilitation and the way people think of their injury, fear of falling, or anxiety. We also found that those factors did not predict how well or not someone engaged in rehabilitation. Furthermore, we found that most inpatients were scored as engaging very well by their physiotherapists. Out of a total possible score of 30 (with higher scores indicating higher engagement), most people were scored 30, with the second most popular score being 29. This could be because the NSIC is a very intensive rehabilitation environment, making it hard for anyone to not engage in rehabilitation. It could also be because those people who were not as engaged in rehabilitation were also less engaged with research, and so did not agree to take part in the study. It is important to research what other psychological factors might be promoting such high engagement, so that these facilitators can be implemented in other settings where people might struggle to engage.

The study also found high rates of anxiety and fear of falling, indicating that this would be an important area for intervention. Further research should also further explore fear of falling and how/whether this is linked with actual falls.

Conclusions

The current study did not find relationships between the measured outcomes (how people thought of their injury, level of generalised anxiety, and amount of fear of falling) and how well people engaged with rehabilitation. We propose that future research should explore other factors that might impact engagement and be conducted in a variety of rehabilitation settings, where there may be a wider range of engagement levels. The current study was able to highlight the lack of norms around measuring engagement in this population, and the increased prevalence of anxiety and fear of falling in this population.

Connecting/Reflective Narrative

My main goal at the start of training was to have as varied an experience of placements and research as possible in order to allow me to decide where I might ultimately like to focus my career as a qualified clinical psychologist. With that in mind, my research projects spanned very different populations and services. However, a clear commonality is apparent – the focus of the projects on systemic factors, including how families of children born with a cleft lip and/or palate (CL/P) are affected, and how young people (YP) in residential settings and SCI/D inpatients can best be supported by their systems.

Critical Review of the Literature

Two keen interests of mine have always been working with YP and working in healthcare settings. Whilst each of my other two projects focused on one of those populations, I was also eager to have a project that looked at the interface of the two – paediatrics. A close friend of mine was born with a CL/P and had spoken about their experience with me, so when the opportunity arose to do this project, it felt very relevant.

Whilst a lot of research had been conducted into the effects on children of being born with a CL/P, children's systems were often overlooked. This made me think about how, across populations and services, more needs to be done to consider the needs of systems surrounding the primary client or patient.

I found the systematic nature of doing this project both reassuring and difficult at the same time – on one hand, the clear steps made me feel like I was being thorough and accurate with my work, but on the other hand, they were time-consuming and, at times, repetitive (e.g. the title/abstract screening process). However, seeing how all the little steps eventually fit into and created a coherent and rich piece of work felt incredibly rewarding. I also found that alongside enriching my understanding of the process of conducting reviews, this project

taught me a lot about a topic area that I knew little about from a psychological research point of view.

Service Improvement Project

Having worked as an Assistant Psychologist (AP) with YP in care and enjoyed this role, I jumped at the opportunity to have a project in this area. The thing that drew me to a project looking at healthy relationships in particular was that I had observed the lack of education around this when I was an AP. I was excited by the thought that I would have to work in a relational way (as in this case with this population) to explore a relational topic.

My Master's dissertation used qualitative methodology and thematic analysis, so I knew that I enjoyed this way of working and saw great value in it, especially given the sensitivity and richness of the topic of healthy relationships.

The most difficult aspect of this project was recruitment; I was not allowed to contact YP directly, so relied on residential staff that were very busy to refer YP to my study. Furthermore, some YP did not want to partake as they were (understandably) sceptical of meeting new professionals after previous negative experiences with adults. This meant that I travelled across the county to interview eligible participants. Therefore, it felt like a huge achievement when I reached my recruitment target and was able to provide the service with feedback they found valuable and were keen to implement. Ultimately, this was my favourite project and part of the reason that I decided to work towards a qualified career with Looked After Children.

Theory-Driven Research Project

Prior to training, I had the opportunity to work with a wonderful charity, called Horatio's Garden, who build accessible gardens in spinal injury centres around the country. This experience stayed with me and was a key reason why I chose a project with this population. I was excited by the prospect of investigating something that had not been studied

in this population before and was keen to work with a nationally renowned service. This project taught me a lot about designing and conducting research in NHS settings and the processes that need to be followed. Although it felt disappointing to not find any significant results, I learned a lot about understanding threats to validity of research and proposing ways in which such threats could be controlled for in the future.

However, I found this project the most challenging. When reflecting about why that was, I realised that this project had a lot of aspects that felt out of my control; for example, applying for NHS ethics was a tedious process and required me to wait for a response from the committee for weeks, without a clear indication of when this might be. A further source of uncontrollability was with regards to recruitment for this project – although I could control the amount of time I spent approaching inpatients, there came a point where I had approached all eligible inpatients and had to wait for new inpatients to be admitted. However, I could not ensure that all newly admitted inpatients were eligible for the study (e.g. if they were acutely unwell or had cognitive difficulties). Therefore, like with my Service Improvement Project, I felt a huge sense of achievement and relief when I reached a reasonable recruitment number.

Acknowledgements

I would like to extend my deepest gratitude to all participants that gave up their time to take part in my research – patients and physiotherapists of the National Spinal Injuries Centre, and residents and staff of the Oxfordshire Young People's Supported Accommodation Service.

A huge thank you to all my supervisors – Dr Jane Duff, Dr Neil Carrigan, Dr Kim Jackson-Blott, Dr Ciorsdan Anderson, Dr Matthew Hotton, and Dr Nicola Stock – their support, knowledge, time, and expertise have been pivotal to this thesis. A special thank you to my course tutor, Dr Myra Cooper, for always encouraging me and celebrating my achievements.

I am grateful to the wonderful cohort of Trainee Clinical Psychologists that I have been lucky enough to train alongside and learn from. Thank you in particular to my amazing housemates that have experienced the Doctorate with me and to the girls that got me through training through fun, laughter, and (mostly) respecting our 'no psychology talk outside of 9-5' rule.

Thank you to my parents who have always been role models for where hard work can get you, and to my brother and friends outside of psychology for keeping me grounded and always showing interest in my work.

Lastly, thank you to Reece for believing in me, supporting me through the ups and downs of training, and always having a rational solution.

Appendices

Appendix A: SRL Journal Submission Guide

Use of “Patient-First” Language

Please be sure you are using patient-first language in your entire manuscript (e.g., use "patients with CLP" instead of "CLP patients"; or "patients with 22q11.2 DS" instead of 22q11.2DS patients").

Avoiding Priority Claims

Manuscripts should avoid priority claims such as "this is the first study to...", "this is the largest study", etc. even when qualified by statements like "to our knowledge..."

Manuscript files to be uploaded

These include: Title Page (required); Manuscript (required); Tables (optional); Figures (optional); Supplemental Materials (optional).

Title Page

The Title Page (submitted separately from the manuscript) must include (in the following order):

- Title (maximum 20 words); should be informative, relevant, and concise
- Author names with *no more than* three highest attained degrees, in the order that they will appear in print
- Institutional affiliation for each author. The affiliation listed should be the institution where the research was conducted. If an author has moved to a new institution since completing the research, the new affiliation can be included in a manuscript note at the end of the paper.
- Name, address, telephone number, fax number, and email address of the corresponding author, who will receive all editorial communication and reprint requests
- Declaration of conflicting interest statement. Authors must disclose any relevant conflict of interest, including direct or indirect financial interests they may have in the materials or subject matter dealt with in the manuscript. If no conflict exists, please state that ‘*The Author(s) declare(s) that there is no conflict of interest*’.
- Any Acknowledgements to be included in the manuscript (see details below)
- If applicable, statement that manuscript was presented at a professional meeting, including the name, date, and location of the meeting
- Running title (less than 8 words)

Acknowledgments

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person

who provided purely technical help, or a department chair who provided only general support.

If professional writing assistance was provided (e.g., from a specialist communications company) this should be included in the Acknowledgements section. Authors must disclose any writing assistance – including the individual's name, company and level of input – and identify the entity that paid for this assistance.

When an individual who is not listed as an author submits a manuscript on behalf of the author(s), a statement must be included in the Acknowledgements section of the manuscript and in the accompanying cover letter. The statement must confirm that the listed authors have authorized the submission of their manuscript via third party and approved any statements or declarations, e.g., conflicting interests, funding, etc.

Where appropriate, Sage reserves the right to deny consideration to manuscripts submitted by a third party rather than by the authors themselves.

Do not include funding information in the Acknowledgements. Authors will be asked to disclose any sources of funding during submission.

To ensure that the article is anonymized, please do not include author names or affiliations, or any other identifying information in any portion of the manuscript other than this Title Page.

A formatted title page example can be found here for reference.

Manuscript

Word counts and specific formatting requirements for different article types are further described in Section 1.2. A formatted manuscript example can be found here for reference.

Page 1: Title The first page of the manuscript text file should include only the title used on the Title Page (above).

Page 2: Narrative reviews should include an unstructured abstract of no longer than 250 words.

A note about Key Words: *Please do not include a list of Key Words in the manuscript. During manuscript submission, authors will be asked to select Key Words from a list of curated terms. The minimum number of Key Words required is three*.

Page 3: Body of Manuscript. Where applicable, divide the body of the manuscript into the Introduction, Methods, Results, Conclusion, References, and Figure Legends (if figures are included).

Additional details on the References and Figure Legends are included below.

If accepted, a Declaration of Conflicting Interests statement and a Funding Disclosure statement will be added to the manuscript during production. If any Acknowledgments were

included on the title page, this text will also be added to the manuscript during production and will appear just before the references.

The *CPCJ* follows guidelines published in the *American Medical Association Manual of Style*.

- Manuscripts should be typed double-spaced with 1" margins, left justified, and use a standard 12-point font.
- Pages should be numbered consecutively in the upper right-hand corner.
- Do not print a running title.
- Turn off the word processing program's hyphenation feature and ''smart quotes'' feature before typing.
- Headings must be used to designate the major divisions of the manuscript. Up to three levels of headings may be used.

Units of Measure/ Abbreviations

The metric system is preferred for expressing units of measure. Abbreviations may be used for terms. The full term for each abbreviation should appear at its first use in the text, unless the abbreviation is a standard unit of measure. Abbreviations used in a table must be explained in a footnote below the table. For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814; http://www.councilscienceeditors.org) or other standard sources.

Citations/References

For citations and references, as of 2022 *CPCJ* uses the 11th Edition AMA Manual of Style. Note that in this style, in-text citations are represented by superscript numerals.

Tables

Tables should be numbered consecutively using Arabic numerals. Each table should have an appropriate title and explanation at its head. Abbreviations used in a table must be explained in a footnote below the table. Submit tables as separate files, with one table per file, in either .doc (text) or .xls (spreadsheet) format.

Appendix B: SRL Specific Search Terms

‘cleft lip and palate’ OR ‘cleft lip’ OR ‘cleft palate’ OR cleft OR CL/P OR ‘sub-mucous cleft palate’ OR ‘submucous cleft palate’

AND

‘psych* impact’ OR ‘psych* outcome*’ OR ‘psych* function*’ OR ‘quality of life’ OR QoL OR HRQoL OR ‘psych* adjustment*’ OR wellbeing OR ‘well-being’ OR attachment* OR bonding OR interaction* OR ‘interpersonal relationship*’ OR relationship* OR attitude* OR emotion* OR feeling* OR cope OR coping OR anxiety OR anxious OR depress* OR distress* OR mood OR emotion*

AND

‘family member*’ OR caregiver OR ‘care-giver’ OR ‘care giver’ OR famil* OR parent* OR mother* OR father* OR matern* OR patern* OR sibling* OR brother* OR sister* OR grandparent* OR grandmother* OR grandfather* OR aunt* OR uncle* OR cousin*

Appendix C: SRL QualSyst Appraisal Tool

Criteria		YES (2)	PARTIAL (1)	NO (0)	N/A
1	Question / objective sufficiently described?				
2	Study design evident and appropriate?				
3	Method of subject/comparison group selection *or* source of information/input variables described and appropriate?				
4	Subject (and comparison group, if applicable) characteristics sufficiently described?				
5	If interventional and random allocation was possible, was it described?				
6	If interventional and blinding of investigators was possible, was it reported?				
7	If interventional and blinding of subjects was possible, was it reported?				
8	Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?				
9	Sample size appropriate?				
10	Analytic methods described/justified and appropriate?				
11	Some estimate of variance is reported for the main results?				
12	Controlled for confounding?				
13	Results reported in sufficient detail?				
14	Conclusions supported by the results?				

Taken from Kmet, Lee, and Cook (2004).

Appendix D: SIP Journal Submission Guide

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references.

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- **Competing Interests:** Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication.

Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

General Manuscript Guidelines

All manuscripts should be in English. All manuscript pages (including figure-caption list, tables, and References list) should be double-spaced and use generous margins on all sides. Manuscripts should be checked for content and style (correct spelling, punctuation, and grammar; accuracy and consistency in the citation of figures, tables, and references; stylistic uniformity of entries in the References section; etc.). Empirical articles should include standard sections, such as Introduction, Methods, Results, and Discussion.

The Editors of Child and Adolescent Social Work Journal do not mandate a word or page count limit.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

ACKNOWLEDGMENTS

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

APA STYLE

The style and punctuation of the references should conform to strict APA style. In general, the journal follows the recommendations of the 2009 ***Publication Manual of the American Psychological Association*** (6th ed.), and it is suggested that contributors refer to this publication.

REFERENCES

CITATION

Cite references in the text by name and year in parentheses. Some examples:

- Negotiation research spans many disciplines (Thompson, 1990).
- This result was later contradicted by Becker and Seligman (1996).
- This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author's name). However, if authors shorten the author group by using et al., this will be retained.

REFERENCE LIST

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be ***italicized***.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

TABLES

- All tables are to be numbered using Arabic numerals.

- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

CONFLICT OF INTEREST

Also, a note about conflict of interest should be included in the manuscript in a separate section entitled Conflict-of-Interest Statement and placed on the separate title page prepared for double-blind peer review. If no conflict exists, this section should state: The author declares that the author has no conflict of interest. For manuscripts with more than one author, if no conflict exists, this section should state: The authors declare that they have no conflict of interest.

ETHICAL RESPONSIBILITIES OF AUTHORS

This journal is committed to upholding the integrity of the scientific record. As a member of the Committee on Publication Ethics (COPE) the journal will follow the COPE guidelines on how to deal with potential acts of misconduct.

Authors should refrain from misrepresenting research results which could damage the trust in the journal, the professionalism of scientific authorship, and ultimately the entire scientific endeavour. Maintaining integrity of the research and its presentation is helped by following the rules of good scientific practice, which include*:

- The manuscript should not be submitted to more than one journal for simultaneous consideration.
- The submitted work should be original and should not have been published elsewhere in any form or language (partially or in full), unless the new work concerns an expansion of previous work. (Please provide transparency on the re-use of material to avoid the concerns about text-recycling (‘self-plagiarism’).
- A single study should not be split up into several parts to increase the quantity of submissions and submitted to various journals or to one journal over time (i.e. ‘salami-slicing/publishing’).
- Concurrent or secondary publication is sometimes justifiable, provided certain conditions are met. Examples include: translations or a manuscript that is intended for a different group of readers.
- Results should be presented clearly, honestly, and without fabrication, falsification or inappropriate data manipulation (including image based manipulation). Authors should adhere to discipline-specific rules for acquiring, selecting and processing data.
- No data, text, or theories by others are presented as if they were the author’s own (‘plagiarism’). Proper acknowledgements to other works must be given (this includes material that is closely copied (near verbatim), summarized and/or paraphrased), quotation marks (to indicate words taken from another source) are used for verbatim copying of material, and permissions secured for material that is copyrighted.

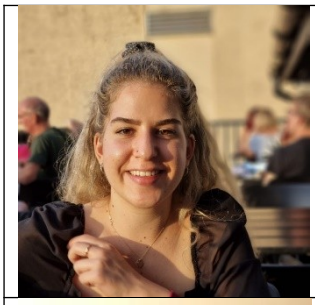
Important note: the journal may use software to screen for plagiarism.

- Authors should make sure they have permissions for the use of software, questionnaires/(web) surveys and scales in their studies (if appropriate).
- Research articles and non-research articles (e.g. Opinion, Review, and Commentary articles) must cite appropriate and relevant literature in support of the claims made. Excessive and inappropriate self-citation or coordinated efforts among several authors to collectively self-cite is strongly discouraged.
- Authors should avoid untrue statements about an entity (who can be an individual person or a company) or descriptions of their behavior or actions that could potentially be seen as personal attacks or allegations about that person.
- Research that may be misapplied to pose a threat to public health or national security should be clearly identified in the manuscript (e.g. dual use of research). Examples include creation of harmful consequences of biological agents or toxins, disruption of immunity of vaccines, unusual hazards in the use of chemicals, weaponization of research/technology (amongst others).
- Authors are strongly advised to ensure the author group, the Corresponding Author, and the order of authors are all correct at submission. Adding and/or deleting authors during the revision stages is generally not permitted, but in some cases may be warranted. Reasons for changes in authorship should be explained in detail. Please note that changes to authorship cannot be made after acceptance of a manuscript.

Appendix E: SIP Information Sheet for Young People

Invitation to take part in research:
Understanding the experiences and needs of young people in the Young People's Supported Accommodation (YPSA) service with regards to interpersonal relationships

The three of us are running this research study:

	Hi, my name is **Ruxi (pronounced "Ru-cksi", she/her)**. I'm a Trainee Clinical Psychologist at the University of Oxford. This piece of research is part of my work for university. Outside of psychology, I enjoy going to the gym, doing yoga, trying out new recipes, and going to live music events.
	Hi, my name is **Ciorsdan (pronounced "K-ears-den", she/her)**. I'm a Consultant Clinical Psychologist and Course Tutor at the University of Oxford. I am supervising this research project. Outside of psychology, I enjoy walking, dancing (and embarrassing my kids) and feeding my friends the things I like to cook and bake.
	Hi, my name is **Kim (pronounced "Kim", pronouns she/her).** I'm a Clinical Psychologist at the Young People's Supported Accommodation Service. I am also supervising this project. Outside of psychology, I enjoy walking my dog, spending time with friends, listening to music, and dancing.

Would you like to take part?
Before you decide if you would like to join in, please read and think about this information sheet carefully. It is important that you understand what the study is about. If you have any questions, please talk to staff, family, friends, or the researchers about them.

Background
We know that relationships are tricky to manage, and that experiencing difficulties in relationships is common. Some young people living within the Young People's Supported Accommodation (YPSA) service have reported experiencing such difficulties. However, there is currently no set support in place to help young people manage these difficulties. The staff want to know how best to support all of the young people they work with and their different needs related to forming and maintaining healthy and safe relationships.

Aims

This project has two parts to it. In the first part, we want to understand young people's opinions about support related to relationships. In the second part, we will be asking staff's opinions. You will be involved in the first part of the study, but if you want to find out more about the second part of the study, please just get in touch.
The aims for part one are:

1. To understand the experiences of young people living within the YPSA with regards to forming and maintaining interpersonal relationships.
2. To understand what support young people receive with regards to interpersonal relationships and anything that makes the support better or worse.
3. To understand young people's views about the type of support that would feel helpful.

Who is invited to take part?
Young people who are residents of the YPSA, which includes Oxfordshire Youth, Connection Support, A2 Dominion, Sanctuary, Stonewater or the YPSA 16-17 service.
What will it involve?
If you agree to take part, you will be asked to:

1. Sign a form to say you agree to take part, that you understand what the study is about, what it will involve and that you understand you can change your mind about taking part at any time up until the data is analysed.
2. You will then be asked to take part in an interview with the researcher (Ruxi), which will last up to 1 hour. The interview will be audio recorded. You will be asked questions about your experience of interpersonal relationships and how the staff at the YPSA have supported you with relationships. You will be asked about the type of support that would feel helpful and to provide feedback on some resources.
3. After the interview you will be given information about where to get support if needed and how to contact the researcher if you have any more questions. You will also be reimbursed for your time with a £10 voucher for a retailer of your choice out of a pre-selected range of retailers.

Do I have to take part?
No, it is completely your choice if you take part or not. If you decide to take part but then change your mind and no longer want to take part, you can stop your involvement at any time without having to give a reason for this. You can also ask for your data/information to be removed from the study up until the data gets analysed. After this point your information will be anonymised and no longer linked to any of your personal information. If you decide to withdraw, you will still receive your participation voucher.
What happens to my information/data?
Only the main researcher (Ruxi) will know who said what during the interviews. When the findings are written up, pretend names will be used to illustrate quotes. Ruxi does not work for the YPSA team, and all information about the team will be anonymised before it is shared, so whatever you say will not be linked back to you.
Any personal information (such as your name, age and audio recording) will be stored securely (password protected) on a computer for the shortest amount of time possible. Audio recordings will be deleted once they have been turned into text (known as a 'transcript') and only the external researchers (Ruxi & Ciorsdan) will have access to them before that.
The transcripts will be stored for 3 years after publication of the work. They will not include any of your personal or identifiable information.
What will happen with the findings of the study?

- They will be shared with the managers and staff across the YPSA and also across other services within Oxfordshire County Council. This is because we want as many young people as possible to benefit from your helpful insight and suggestions.
- None of the staff will know who said what during the study.
- The research will be written up as part of the researchers' work. We will aim to publish our findings in scientific journals, but this may be two to three years from the end of the study.
- You can have a copy if you would like one.

What are the pros and cons of taking part?

- The managers and staff across the YPSA will know what support is helpful and unhelpful for young people such as yourself that they support.
- You may play a part in improving the care and support of young people who stay within the YPSA and receive support from other services across Oxfordshire County Council.
- Although the research does not intend to cause upset, you might find some of the questions difficult. You do not have to answer, say, or share anything you do not want to.

Who has reviewed/approved this study?

This study has been reviewed and approved by a research panel at the University of Oxford and the research committee at Oxfordshire County Council.

What if there's a problem or I'm not happy with something?

If you are worried about any part of the study, please initially raise any concerns with your YPSA support worker/progression coach, who could contact Dr Kim Jackson-Blott (the YPSA Clinical Psychologist) on your behalf with any concerns or questions. If you prefer, you could contact Dr Kim Jackson-Blott directly using the email address provided below. Concerns can also be raised with Dr Ciorsdan Anderson, the research supervisor, who can escalate where required.

You can contact us on our email addresses.

Ruxandra Vasile: ruxandra.vasile@gtc.ox.ac.uk
Kim Jackson-Blott: kim.jackson-blott@oxfordshire.gov.uk
Ciorsdan Anderson: ciorsdan.anderson@hmc.ox.ac.uk

If further action is required, formal complaints can be made to Oxfordshire Country Council via the following contact methods:

Call: 01865 323589 Text: 07717 420419
Email: commentsandcomplaints@oxfordshire.gov.uk
Website: https://www.oxfordshire.gov.uk/council/about-your-council/have-your-say-about-council-services/complaints-about-oxfordshire-county-council/children-and-young-people

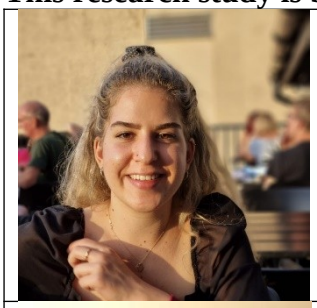
Thank you for reading this – please ask any questions if you need to.

Appendix F: SIP Information Sheet for Staff

Invitation to take part in research:

<u>Understanding the experiences and needs of young people in the Young People's Support Accommodation (YPSA) service with regards to interpersonal relationships</u>

This research study is being run by:

	Hi, my name is **Ruxi (pronounced "Ru-cksi", pronouns she/her)**. I'm a Trainee Clinical Psychologist at the University of Oxford. This piece of research is part of my work for university.
	Hi, my name is **Ciorsdan (pronounced "K-ears-den", she/her)**. I'm a Consultant Clinical Psychologist and Course Tutor at the University of Oxford. I am supervising this research project.
	Hi, my name is **Kim (pronounced "Kim", pronouns she/her).** I'm a Clinical Psychologist working across the Young People's Supported Accommodation Service. I am also supervising this project.

Would you like to take part?

Before you decide if you would like to take part, please read and think about this information sheet carefully. It is important that you understand what the study is about. If you have any questions, please talk to other staff or the researchers about them.

Background

We know that relationships are tricky to manage, and that experiencing difficulties in relationships is common, especially for vulnerable young people (YP). Some people living within the Young People's Supported Accommodation Service (YPSA) have reported experiencing difficulties in relationships. Several psychology consultations have been sought by staff to support young people who are struggling in relationships. However, there is currently no set support in place to help young people learn about and manage these difficulties.

Aims

This project has two parts to it. In the first part, we want to understand young people's opinions about support related to relationships. In the second part, we will be asking staff's opinions. You will be involved in the second part of the study, but if you want to find out more about the first part of the study, please just get in touch.

The aims for part two are:

4. To understand the experience of staff in the YPSA of supporting YP experiencing risk and violence in interpersonal relationships
5. To understand what support staff provide with regards to interpersonal relationships and anything that makes delivering the support easier or harder.
6. To understand staff's views about the type of support that would feel helpful.

Who is invited to take part?

Staff who are working within the YPSA service, which includes Oxfordshire Youth, Connection Support, A2 Dominion, Sanctuary, Stonewater or the YPSA 16-17 service.

What will it involve?

If you agree to take part, you will be asked to:

4. Sign a form to say you agree to take part, that you understand what the study is about, what it will involve and that you understand you can change your mind about taking part at any time before the data is analysed.
5. You will then be asked to take part in a focus group with other staff members and the researcher (Ruxi), which will last up to 1.5 hours. The focus group will be audio recorded. You will be asked questions about your experience of supporting young people to manage interpersonal relationships and the provisions that are in place within/across the YPSA to support young people with this.
6. You will be asked about the type of support that would feel helpful and to provide feedback on some resources.
7. After the interview you will be given information about where to get support from if needed and how to contact the researcher if you have any more questions.

Do I have to take part?

No, it is completely your choice if you take part or not and this decision will not affect your employment in any way. If you decide to take part but then change your mind and no longer want to take part in the focus group, you can stop your involvement at any time without having to give a reason for this. You can also ask for your data/information to be removed from the study up until the data gets analysed. After this point your information will be anonymised and no longer linked to any of your personal information.

What happens to my information/data?

Only the main researcher (Ruxi) will know who said what during the focus group. When the findings are written up, pseudonyms will be used to illustrate quotes. Ruxi does not work for the YPSA team, and all information from the focus groups will be anonymised before it is shared, so whatever you say will not be linked back to you.

Any personal information (such as your name, age and job title) will be stored securely (password protected) on a computer for the shortest amount of time possible. Audio recordings will be deleted once they have been turned into transcripts and only the external researchers (Ruxi & Ciorsdan) will have access to them before that.

The transcripts will be stored for 3 years after publication of the work. They will not include any of your personal or identifiable information.

What will happen with the findings of the study?

- They will be shared with the managers and staff across the YPSA and also across other services within Oxfordshire County Council. This is because we want as many young people as possible to benefit from your helpful insight and suggestions.
- No one outside of the focus group will know who said what during the study.
- The research will be written up as part of the researchers' work. We will aim to publish our findings in scientific journals, but this may be two to three years from the end of the study.
- You can have a copy if you would like one.

What are the pros and cons of taking part?

- The managers, staff, and clinical team within the YPSA will know what support is helpful and unhelpful for the young people they support.
- You may play a part in improving the care and support of young people who stay within the YPSA and who receive support from other services across Oxfordshire County Council.
- Although the research does not intend to cause upset, you might find some of the questions difficult. You do not have to answer, say, or share anything you do not want to.

Who has reviewed/approved this study?

This study has been reviewed and approved by a research panel at the University of Oxford and the research committee at Oxfordshire County Council.

What if there's a problem or I'm not happy with something?

If you are worried about any part of the study, please initially raise any concerns with Dr Kim Jackson-Blott. Concerns can also be raised with Dr Ciorsdan Anderson, the research supervisor, who can escalate where required.

You can contact us on our email addresses.

Ruxandra Vasile: ruxandra.vasile@gtc.ox.ac.uk
Kim Jackson-Blott: kim.jackson-blott@oxfordshire.gov.uk
Ciorsdan Anderson: ciorsdan.anderson@hmc.ox.ac.uk

If further action is required, formal complaints can be made to Oxfordshire Country Council via the following contact methods:

Call: 01865 323589 Text: 07717 420419
Email: commentsandcomplaints@oxfordshire.gov.uk
Website: https://www.oxfordshire.gov.uk/council/about-your-council/have-your-say-about-council-services/complaints-about-oxfordshire-county-council/children-and-young-people

Thank you for reading this – please ask any questions if you need to.

Appendix G: SIP Consent Form for Young People

CONSENT FORM FOR YOUNG PEOPLE 16+

Understanding the experiences and needs of young people in the YPSA with regards to interpersonal relationships

Please tick the box next to the statement if you agree with what it says:

I have read and understand the information sheet and/or watched and understood the information video.	
I have had time to think about the information, ask questions and have them answered appropriately.	
I understand that I can stop taking part in the interview at any time, without giving any reason and without being affected in any other way. This will not affect whether I receive my participation voucher.	
I agree for my interview to be audio recorded.	
I understand how to make a complaint if I am unhappy with any part of the study.	
I agree to take part in the study.	

If you did not tick any of the statements or you don't want to take part, that's OK! It's your choice.

If you do want to take part, please write your name and sign below:

Your name _____

Your signature _____

Date _____

The researcher who explained this project to you needs to sign too:

Researcher's name _____

Researcher's signature _____

Date _____

Thank you!

Appendix H: SIP Consent Form for Staff

CONSENT FORM FOR STAFF

Understanding the experiences and needs of young people in the YPSA with regards to interpersonal relationships

Please tick the box next to the statement if you agree with what it says:

I have read and understand the information sheet.	
I have had time to think about the information, ask questions and have them answered appropriately.	
I understand that I can stop taking part in the interview at any time, without giving any reason and without being affected in any other way.	
I agree for the focus group to be audio recorded.	
I understand how to make a complaint if I am unhappy with any part of the study.	
I agree to take part in the study.	

If you do want to take part, please write your name and sign below:

Your name _____

Your signature _____

Date _____

The researcher who explained this project to you needs to sign too:

Researcher's name _____

Researcher's signature _____

Date _____

Thank you!

Appendix I: SIP Interview Schedule for Young People

1. If you could describe your relationships (with your peers/partner/s) in 3 words, what would these 3 words be?
2. Have you ever received support with managing your relationships?
    a. If yes: What did you think of this support? What was helpful? What wasn't?
    b. If no: Do you think this support would have been helpful? How come?
3. Can you think of any types of relationship support that are out there? If so, do you have any ideas about the type of relationship support that would be most helpful?
4. What do you think about the 'Real Love Rocks' programme as a way of accessing this support? *Present YP with various resources from the programme and ask for their feedback* Ask for each individual task "What do you make of it?", "On a scale of 1-10, how useful do you think this is and why?". 3 written resources and 1 video shown.

    Resource 1: 'Dilemma blog' – this resource contains some made up scenarios where YP have written into an online 'Agony Aunt' to seek advice on tricky romantic and friendship issues. Participants have to write a response to give advice.

    Resource 2: 'Match the meaning' – this resource defines different types of exploitation and abuse (e.g. child sexual abuse, financial exploitation, child sexual exploitation) and presents scenarios of YP experiencing those things. Participants have to match the meaning to the scenario.

    Resource 3: 'Cyberbullying' – this resource is an informative leaflet on the negative things that can happen online. It provides step-by-step advice for what to do if you experience cyberbullying.

    Video: 'Anna's story' – this video shows a made-up scenario of a young girl who is groomed and the warning signs of this.
5. If a programme covered all of these topics, what would you think of the programme? Would it be helpful? Unhelpful? Do you think anything about this programme would be difficult? Why?
6. If this programme were to be delivered, what do you think would be the best way to do that?
    - Where would this programme take place? Online? In-person? What location?
    - When do you think the programme should be delivered?
    - Would you like this to be delivered in an individual or group setting? Co-ed or separate?
    - Would you like your keyworker to be present?
7. What would make it easier to attend this programme?
8. What would make it harder to attend this programme?
9. Is there anything else you think I should know about offering support for healthy relationships?

Appendix J: SIP Focus Group Schedule for Staff

1. What do you believe the YP's needs are related to relationships with peers/partners?
2. Do you feel these needs are currently being supported? How? By who?
    a. In what ways does the YPSA try to support YP with healthy relationships? What is working well? What is not working well? Do you have any ideas about the type of support or changes that could be helpful?
3. In your experience, what has helped YP engage in previous support that has been offered to them? What has hindered engagement?
4. What do you think about the 'Real Love Rocks' programme as a way of accessing this support? *Present staff with various resources from the programme and ask for their feedback* Ask for each individual task "What do you make of it?", "On a scale of 1-10, how useful do you think this is and why?". 3 written resources and 1 video shown.

    Resource 1: 'Dilemma blog' – this resource contains some made up scenarios where YP have written into an online 'Agony Aunt' to seek advice on tricky romantic and friendship issues. Participants have to write a response to give advice.

    Resource 2: 'Match the meaning' – this resource defines different types of exploitation and abuse (e.g. child sexual abuse, financial exploitation, child sexual exploitation) and presents scenarios of YP experiencing those things. Participants have to match the meaning to the scenario.

    Resource 3: 'Cyberbullying' – this resource is an informative leaflet on the negative things that can happen online. It provides step-by-step advice for what to do if you experience cyberbullying.

    Video: 'Anna's story' – this video shows a made-up scenario of a young girl who is groomed and the warning signs of this.
5. What way of the service delivering support do you think would be most suitable?
    - Where should this support take place? Online? In-person? What location?
    - When?
    - How should this to be delivered? In a group setting? Co-ed or separate from young people who identify as the opposite gender?
    - Should key workers offer to attend with the YP?
6. What do you think would make it easier for the YP to access this support?
7. What do you think would make it harder for the YP to access this support?
8. What support or training do you feel might be beneficial for staff in order to better support YP with this area of need?
9. Is there anything else you think I should know?

Appendix K. SIP Additional Supporting Quotations from Phase 1 (YP)

Themes	Sub-themes	Supporting quotations
Mixed experiences of interpersonal relationships	Positive relationships	"Strong, loyal, eventful, so his dad's side are very close to me, so it's good, he's kept us together, but no like, it's very loyal" (P8).
	Challenging relationships	"If you're in care and stuff, like you very clearly haven't exactly had like the best support from like your parents and a lot of us have seen very unhealthy relationships but are normal to us and we think are fine because that's what our parents had, but it's not" (P1). "I'm like very like attached and quite dependent" (P1)
Mixed experiences of previous support	Lack of previous support	"You kinda get spoken to about some of it in school, but it's like not really" (P1). "Obviously I haven't really thought about anything like that before, and really learned about it, I think it would be important and good for me to learn it all" (P2). "No, I've had a social worker but not to manage relationships, I don't think" (P9).
	Positive experiences of support	"And I've come as far as what I've got so I'm happy with the results of the support I've received" (P4). "I think it's really helpful because a lot of people when they're younger or if they don't have like…if they haven't had a good family life I think or say they've grown up with narcissistic parents, you tend to like people-please and stuff like that, so when you get into a relationship where someone is gaslighting you and love-bombing you, I think you just have these rose-tinted glasses on, so like it kind of tells you all about that, and then you sort of think well that's definitely relatable" (P7).
	Difficulty of putting learning into action	"Not that I put my self-reflections into action but I think I'm quite self-reflective" (P3). "I could put it into a perspective of seeing someone else's relationship, and I could tell them like OK well, maybe work on these things, but with myself I'd probably be like oh no I don't need to do these things, when in reality I probably do" (P6).
Needs within future support	Taking an individualised approach	"I think it's just some people like to be prompted by other people and some people don't. It just depends on who you are" (P2).
	Acknowledging the sensitive nature of topics	"It's a very sensitive subject like, it's really bad, every single girl I've dated or gone out with or spoken to has had some sexual trauma or sexual assault" (P3). "I think it should be optional as to whether or not you watch it and to know what's involved before you watch it" (P5).

		"If you made a group that had different timings of different days with different categories, people can choose whether to go to them" (P4).
	Creating engaging content	"Say if you got all of us here together and did some sort of activities to build our relationships, do you know what I mean? That would be something good" (P2). "I prefer it to either be an activity that I do or a video like that, because I just find it easier to process the information" (P5).
	Taking a personable approach	"I think it's off energy like say like I walk to my keyworker and she's really low energy, that's like, okay well I'm not going to tell you this like, but if you're like happy and bubbly, things that make you more of a warm person, then I'll tell you" (P8). "I am going to bring up Shrek now OK…people are like onions, they have layers, once you get them comfortable, that will be easier to approach to them and actually talk to them about something like this and them feeling comfortable enough to carry it on" (P6).
	Considering practicalities and convenience	"If they've got kids, you've got to be more thoughtful about whether they could take them and it would be suitable for them as well" (P7).

Appendix L. SIP Additional Supporting Quotations from Phase 2 (staff)

Themes	Sub-themes	Supporting quotations
Relationship difficulties and their impact	Early relationships	"Quite often they've experienced quite a lot of rejection in their lives" (S3).
	Romantic relationships	"The YP that I work with in particular need help with being independent, because some of their relationships become quite dependent" (S4).
	Friendships	"They're having to kind of buy their friendships to show that they're a good friend, so giving tobacco, lending money…" (S2). "Sometimes we encourage them to block lots of people and that really limits their friendship group, so they can't bare that thought even if the people are being horrible to them" (S3).
Support to be offered gently and thoughtfully	Trust	"I feel it's a barrier to them being honest with us about what's really going on for them, and feeling safe to do so without some major knee jerk reaction where like I said the boyfriend is going to be banned, the boyfriend is going to be arrested, they're going to be arrested, they're going to get warnings from the landlord or whatever, so that's another really difficult one sometimes that when you know they're starting to tell you the truth, I can cringe thinking oh god because now this is going to happen and then you feel that your relationship with them is going to deteriorate, which you've spent a lot of time building up because their trust in you is going to go" (S3). "The only thing that I've been told is that the best thing for YP who have had a lot of trauma and stuff is that they have really trusting and healthy relationships with us and that's how things can change for them" (S2).
	Stealth	"When people are in relationships that are unhealthy, and it's like anything really, getting to them to look at stuff is the hardest part, getting them to really want to think about these things, because I always equate, because I smoke cigarettes, and I thought if I had to have a meeting once a week to talk about whether I still smoke three cigarettes a day, I wouldn't turn up. You know, you have to build things in in a way that they don't even know probably that you're even discussing things" (S2).
	Flexibility	"I think adapting our conversations to what they've identified as being their needs, because they've already identified that something is missing" (S2).
	Accessibility	"Although they may be like 16-19, actually cognitively they're usually quite a lot lower than that" (S1). "I would have thought that possibly Arabic would be useful or I think Urdu is one that I've come across a bit so far, but it's difficult to say which languages but from my experience those

		languages from the Indian subcontinent and Arabic would be most useful" (S4). "Especially for ones that are kind of autistic or the ones that…we have YP that were very close to being declared learning disabled, but they've just missed a point or two, so they've got big learning difficulties" (S1).
Staff needs related to delivering this support	Same approach used	"We've got these contradictory ways of support, so I think the whole approach and how we work in a therapeutic way is the most important thing" (S3).
	Training needs	"I think you've got to go right to the basics of part of induction training for staff and managers at all levels about how we're going to support YP in relationships, are we going to support them in the relationship they're in because we know splitting them won't work, and just talking to them in general all the time" (S2). "I think also perhaps just an idea that the relationship training as part of induction would also help relationships for us, with our peers and our managers, it's not just about YP in relationships it's about the whole shebang of our relationships with each other and our relationships with the YP, so yeah that would be really beneficial and I'm thinking it might be worth…we do have reflective practice but if it might be worth having some sort of training but you come back every 3 months to discuss how it's going" (S2).



Young People (YP) said they:

- *Have experienced a mixture of positive and challenging relationships.*
- *Have not received much support to manage relationships, but where support has been offered, it was generally good.*
- *Struggle to put learning from support into action in their relationships.*

- *Want to receive relationship support which is engaging, with lots of videos and scenario-based questions.*
- *Want this support to be individualised to each YP and delivered by someone kind and trusting, in a convenient location and with appropriate support (e.g. childcare).*
- *Need there to be trigger warnings because of how sensitive some topics are.*

Staff said they:

- *Have noticed YP struggle with a range of relationships (family, romantic, friendships).*
- *Think support needs to be delivered gently, flexibly, and accessibly, and sometimes drip-fed rather than in an intense sit-down conversation.*
- *Would like additional training to deliver this support, including trauma-informed care training.*



- *Need there to be a shared approach between staff members of how to support YP in unhealthy relationships (or how to encourage them to leave the relationships).*



We suggest that:

- *Additional support is offered to YP in the YPSA related to managing relationships, and that YP can choose between group-based and individual support.*
- *The 'Real Love Rocks' resource (Barnardo's, 2022) could form the bases of a 'healthy relationships' group, covering a range of topics and relationships (e.g. friendships, family, romantic) and topics (e.g. abuse, exploitation, cyberbullying).*

- *This group contains a range of activities (e.g. conversations, scenarios , games, and videos), and it would be helpful if fun team-building activities are also incorporated.*
- *Care staff members are trained to be able to use the materials from the group in 1:1 sessions with YP as and when needed, and they are trained in trauma-informed care.*
- *Psychology consultations are sought when it is unclear whether to support YP in unhealthy relationships to change patterns versus encourage them to leave relationships due to safeguarding concerns.*

Appendix N: TDRP Journal Submission Guide

Article (presenting primary data): ***Spinal Cord*** prioritises original research that contains prospectively collected data driven by clear a priori hypothesis. This includes but isn't limited to: randomised and non-randomised clinical trials; diagnostic studies; cohort studies; case-control studies; psychometric studies; basic cellular studies; animal studies; qualitative studies; explanatory or mechanistic studies; economic evaluation studies
The following studies are low publication priority: retrospective chart audits; studies of the demographics of patients of a single hospital presenting with new SCI; studies that are only of a regional interest; studies examining the reliability of outcome measures translated into a non-English language; surveys of small and non-representative samples. Exceptions will be made if the authors can demonstrate that the study is particularly novel and would be of wide interest to an international readership.
Specifications: S***tructured Abstract (Study Design; Objectives; Setting; Methods; Results; Conclusions; Sponsorship) max. 250 words***

Please note: all submissions should include a Title Page and a Conflict of Interest Statement. More information can be found below.

PREPARATION OF ARTICLES

House Style: Authors should adhere to the following formatting guidelines

- We accept UK English or American English, however authors should be consistent of their use of either within the manuscript.
- Text should be double spaced with margins of between 1cm and 3cm wide.
- All pages and lines are to be numbered continuously.
- Do not make rules thinner than 1pt (0.36mm).
- Use a coarse hatching pattern rather than shading for tints in graphs.
- Colour should be distinct when being used as an identifying tool.
- Commas, not spaces should be used to separate thousands. Decimal values should be proceeded by a dot, not a comma.
- At first mention of a manufacturer, the town (and state if USA) and country should be provided.
- Normally distributed data should be expressed as mean (SD). Skewed data should be expressed as median (25% and 75% percentiles).
- Sole reliance on statistically significance (and p values) is discouraged. Instead, we encourage reporting of effect sizes preferably in the units of the original scale.
- Units**:** Use metric units (SI units) as fully as possible. Preferably give measurements of energy in kiloJoules or megaJoules with kilocalories in parentheses (1 kcal = 4.186kJ). Use % throughout.
- Express all 95% confidence intervals in this format - "95% CI, xx to xx"
- Express all means and standard deviations in this format - "the mean (SD) was xx (xx)"
- Use person centred terminology throughout e.g. "people with tetraplegia" not "tetraplegics"
- Use the term "tetraplegia" (not quadripligea)
- Use the words "person/s", "people" or "individual/s" where ever possible (rather than patient/s) unless this distracts from the readability or meaning
- Use the word "participant/s" not "subject/s"

- Avoid spurious precision. As a general rule, report numbers between 0 and 1 to 2 decimal places, between 1 and 10 to 1 decimal place, and above 10 with no decimal place

Please note Articles must contain the below components.

Title Page: The title page should contain:

- Title of the paper - brief, informative, of 150 characters or less and should not make a statement or conclusion.
- Full first and last names of all authors along with initials for any middle names. Also provide the affiliations of all authors, as well as the e-mail address of the corresponding author (postal addresses are no longer required). If authors regard it as essential to indicate that two or more co-authors are equal in status, they may be identified by an asterisk symbol with the caption ‘These authors contributed equally to this work’ immediately under the address list.
- Consortia: Please refer to our consortia guidelines for consortia formatting guidelines, which should be adhered to prior to acceptance.

Large Language Models (LLMs), such as ChatGPT, do not currently satisfy our authorship criteria. Notably an attribution of authorship carries with it accountability for the work, which cannot be effectively applied to LLMs. Use of an LLM should be properly documented in the Methods section (and if a Methods section is not available, in a suitable alternative part) of the manuscript.

Structured Abstract: Articles must be prepared with a structured abstract designed to summarise the essential features of the paper in a logical and concise sequence under the following mandatory headings. Authors can also apply this layout to Review Articles if they wish to do so. (Structured abstracts must be used for systematic reviews but unstructured abstracts may be used for narrative reviews)

- **Study Design** e.g. Cohort Study; clinical trial; Narrative Review; Systematic Review - see "Article Description" for other examples
- **Objectives**
- **Setting** e.g. Hospital in Gothenburg, Sweden; University-based laboratory in Chicago, USA. (Narrative and systematice reviews do not need to include this heading)
- **Methods**
- **Results**
- **Conclusions:** Framed with respect to the objectives and primary results

Sponsorship (this is only relevant if a commercial company has sponsored the study)

Introduction: The Introduction should assume that the reader is knowledgeable in the field and should therefore be as brief as possible but, can include a short historical review where desirable. Please refrain from commencing with statements such as "Spinal cord injuries are devastating injuries" or similar

Methods: This section should contain sufficient detail, so that all experimental procedures can be reproduced by a knowledgeable scientist, and include references. Methods that have been published in detail elsewhere should not be described in detail. Authors should provide the name of the manufacturer and their location for any specifically named medical equipment and instruments, and all drugs should be identified by their pharmaceutical names, and by their trade name if relevant.

Results: The Results section should briefly present the experimental data in text, tables and/or figures. Tables and figures should not be described extensively in the text, but the text should refer to key findings/observations in Tables and Figures e.g. "As shown in Table 2, males are taller than females with a mean (SD) difference of 1.2 (0.3)cm". All results comparing groups should be presented as point estimates with measures of precision (eg. mean between-group differences, odds ratios or hazard ratios with 95% confidence intervals).

Discussion: The Discussion should focus on the interpretation and the significance of the findings with concise objective comments that describe their relation to other work in the area. It should not repeat information in the results. The final paragraph should highlight the main conclusion(s) and clinical implications, and provide some indication of the direction future research should take.

Data Availability Statement: Please include a statement at the end of your paper that tells readers where the data generated or analysed during this study can be found e.g. within the published article and its supplementary files, within a recognised repository, with a link to the data in said repository, or if additional data are available from the corresponding author on reasonable request.
Please see the Data Availability and Policy page for more information.

References: Only papers directly related to the article should be cited. Exhaustive lists should be avoided - see the limitations on number of references under Article Type Specifications above. References should follow the Vancouver format. In the text they should appear as numbers (starting at one) in square brackets before punctuations. Example "...the scale maintains adequate construct validity and measures the attributes it purports to measure [15,16]".
The full details of the References should appear at the end of the paper (double-spaced) in numerical order corresponding to the order of citation in the text. If you use a reference manager such as Endnote or RefWorks, make sure you check the results for completeness and proper capitalization of author names, Journal names, titles, and year/volume/issue/page information. The doi, PMCID and similar numbers should not be included unless the Reference is only available in electronic format. Please ensure the links to Endnote are removed prior to submission.

All authors should be listed for papers with up to six authors; for papers with more than six authors, the first six only should be listed, followed by ***et al.*** Abbreviations for titles of medical periodicals should conform to those used in the NCBI database. The first and last page numbers for each reference should be provided. Abstracts and letters must be identified as such. Papers in press may be included in the list of references.
Personal communications can be allocated a number and included in the list of references

in the usual way or simply referred to in the text e.g. "William Jones, personal communication, 2 June 2018". In either case authors must obtain permission from the individual concerned to quote his/her unpublished work.

Examples:

Journal article:
Neidlein, S, Wirth, R, Pourhassan, M. Iron deficiency, fatigue and muscle strength and function in older hospitalized patients. Eur J Clin Nutr. 2020; 75:456–463.
Journal article by DOI:
Kurotani K, Shinsugi C, Takimoto H. Diet quality and household income level among students: 2014 National Health and Nutrition Survey Japan. Eur J Clin Nutr. 2020; https://doi.org/10.1038/s41430-020-00794-1.
Journal article, in press:
Gallardo RL, Juneja HS, Gardner FH. Normal human marrow stromal cells induce clonal growth of human malignant T-lymphoblasts. Int. J Cell Cloning (in press).
Complete book:
Atkinson K, Champlin R, Ritz J, Fibbe W, Ljungman P, Brenner MK (eds). Clinical Bone Marrow and Blood Stem Cell Transplantation. 3rd ed. Cambridge University Press, Cambridge, 2004.
Chapter in book:
Coccia PF. Hematopoietic cell transplantation for osteopetrosis. In: Blume KG, Forman SJ, Appelbaum FR (eds). Thomas' Hematopoietic Cell Transplantation. 3rd ed. Blackwell Publishing Ltd, Malden, 2004. pp 1443–1454.
Abstract:
Abstracts from the 2020 Annual Scientific Meeting of the British and Irish Hypertension Society (BIHS). J Hum Hypertens 34; 2020; 1–20
Website:
Kassambara A. rstatix: pipe-friendly framework for basic statistical tests. 2020. https://rpkgs.datanovia.com/rstatix/.
Online Document:
Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. http://www.rsc.org/dose/title of subordinate document. Accessed 15 Jan 1999.

Acknowledgements: These should be brief, and should include sources of technical assistance, critical advice or other assistance, which contributed to the final manuscript.

Author Contributions: Authors must include a statement about the contribution of each author to the manuscript (see section on Authorship). The initials of each author may be used.

Funding: The funding section is mandatory. Authors must declare sources of study funding including sponsorship (e.g. university, charity, commercial organization) and sources of material (e.g. novel drugs) not available commercially. If no financial assistance was received in support of the study, please include a statement to this fact here.

Ethical Approval
Authors must provide a statement regarding ethical approval (see information on Human and Other Animal Experiments in the Editorial Policy section for further details). If ethical approval was not required, authors must provide an explanation of why it was not needed.

Competing Interests: Authors must declare whether or not there are any competing financial interests in relation to the work described. This information must be included at this stage and will be published as part of the paper. Please see the Competing Interests section under Editorial Policies for detailed information.

Patient consent for images or information used in a manuscript: If a patient or participant of a study can be identified in any way through images or information presented in a paper, the patient or participant provide written and signed consent for this identification. The consent needs to be emailed to the editorial office. Alternatively, please indicate where a photograph can be cropped to remove identifiable features. If consent has not been obtained, then any recognizable features must be masked so that the individual is 'officially unrecognizable'.

Figure Legends: These should appear on a separate manuscript page after the References section. Each Figure should have a brief title and may have a short footnote.

Tables: Tables should only be used to present essential data; they should not duplicate what is written in the text. Use lower case letters starting with 'a' to reference Table footnotes. Tables should consist of at least two columns; columns should always have headings. Ensure each Table is cited within the text and in the correct order, e.g. (Table 3). All measures of variability should be defined either within the table title or footnote. **It is imperative that tables are editable** and ideally submitted in Excel format although Word format is acceptable. **If uploading in Excel, each table must be uploaded as a separate workbook with a title or caption and be clearly labelled, sequentially**. Files for Tables need to be saved with one of the following extensions: .xls / .xlsx / .ods / or .doc or .docx. Please ensure that you provide a 'flat' file, with single values in each cell with no macros or links to other workbooks or worksheets and no calculations or functions.

Figures: Figures and images should be labelled sequentially and cited in the text (e.g. Fig1.). **Figures should not be embedded within the text but uploaded as separate files**. The use of three-dimensional histograms is strongly discouraged unless the addition of the third dimension is important for conveying the results. All parts of a figure should be grouped together. Where possible large figures and tables should be included as supplementary material.
Detailed guidelines for submitting artwork can be found by downloading our Artwork Guidelines. Using the guidelines, please submit production quality artwork with your initial online submission. If you have followed the guidelines, we will not require the artwork to be resubmitted following the peer-review process, if your paper is accepted for publication.

Standard Abbreviations: Abbreviations should be defined in full at their first usage in the Abstract, and again at their first usage in the body of the manuscript. So on first use of

an abbreviation, place it in parentheses after the full item. Do this separately for the abstract and the full texts). Note these abbreviations: gram **g**; litre **l**; milligram **mg**; kilogram **kg**; kilojoule **kj**; megajoule **mj**; weight **wt**; seconds **s**; minutes **m**; hours **h**. Do not add s for plural units. Terms used less than four times should not be abbreviated. It is not advised to use more than five abbreviations in total unless they are extremely common abbreviations.

Reporting of demographic and neurological details: Demographic data should be reported as mean and standard deviation, or median and interquartile range depending on whether the data are skewed or not. If data are to be grouped, authors are encouraged to follow the recommendations of Biering-Sørensen ***et al***.[1] Age should be grouped in 15 year increments: 0–15, 16–30, 31–45… to 76+. Reporting on the paediatric SCI population should use age groups 0–5, 6–12, 13–14, 15-17 and 18–21. When time since injury is grouped, 5 year increments should be used: <1 year, 1–5 years, 6–10 years, and 5-year increments thereafter. Calendar time (years during which the study is conducted) should be grouped by either 5 or 10 year increments with years ending in 4 or 9. The severity of injury should be grouped as C1-4 ASIA Impairment Scale grade (AIS) A, B, or C; C5-8 AIS A, B, or C; T1-S5 AIS A, B, or C; AIS D at any injury level; Ventilator-dependent at any injury level or AIS grade. If data are limited, the above groups can be collapsed. If data are limited, the above groups can be collapsed.

[1] Biering-Sorensen F, DeVivo MJ, Charlifue S, Chen Y, New PW, Noonan V. et al. International Spinal Cord Injury Core Data Set (version 2.0) including standardization of reporting. Spinal Cord 2017; 55: 759-764.

Appendix O: TDRP Appraisals of Disability - Primary and Secondary Scale (ADAPSS)

The **A**ppraisals of **D**is**A**bility: **P**rimary and **S**econdary **S**cale **(ADAPSS)**[1]

The ADAPSSsf is the short form / screening version of the scale and recommends a full sale ADAPSS is administered when people are at or above the cut off of 22. The scale was developed by Dr Rachel Dean and Professor Paul Kennedy. The Department of Clinical Psychology, National Spinal Injuries Centre, Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust is the main point of contact about the development for both the short and long form and welcomes connections with clinicians, researchers and users to broaden our understanding of the pivotal role of appraisals following spinal cord injury: bht.nsicpsychology@nhs.net. Please use the reference[1] for both scales in publications.

ADAPSSsf (short form)

*We are interested in the thoughts people have about their spinal cord injury. Using the following scale, rate the extent to which the following statements reflect your **current** perceptions of your injury by circling your responses.*

FD	Since my injury life is more frightening for me	STRONGLY DISAGREE 1	MODERATELY DISAGREE 2	MILDLY DISAGREE 3	MILDLY AGREE 4	MODERATELY AGREE 5	STRONGLY AGREE 6
OD	I cannot believe that this has happened to me	STRONGLY DISAGREE 1	MODERATELY DISAGREE 2	MILDLY DISAGREE 3	MILDLY AGREE 4	MODERATELY AGREE 5	STRONGLY AGREE 6
DR	I will continue to live my life to its full capacity	STRONGLY DISAGREE 6	MODERATELY DISAGREE 5	MILDLY DISAGREE 4	MILDLY AGREE 3	MODERATELY AGREE 2	STRONGLY AGREE 1
NPD	I am going to miss out on so many aspects of my life	STRONGLY DISAGREE 1	MODERATELY DISAGREE 2	MILDLY DISAGREE 3	MILDLY AGREE 4	MODERATELY AGREE 5	STRONGLY AGREE 6
GR	This experience has made me a stronger person	STRONGLY DISAGREE 6	MODERATELY DISAGREE 5	MILDLY DISAGREE 4	MILDLY AGREE 3	MODERATELY AGREE 2	STRONGLY AGREE 1
PA	There are many things that I can do to change my situation	STRONGLY DISAGREE 6	MODERATELY DISAGREE 5	MILDLY DISAGREE 4	MILDLY AGREE 3	MODERATELY AGREE 2	STRONGLY AGREE 1

[1] Dean RE and Kennedy P (2009). Measuring Appraisals following Spinal Cord Injury: A Preliminary Psychometric Analysis of the Appraisals of Disability. *Rehabilitation Psychology*, 54, 222-231

TOTAL =

SCORES 22 OR ABOVE: ADMINISTER ADAPSS LONG VERSION

The **A**ppraisal of **D**is**A**bility: **P**rimary and **S**econdary **S**cale – full scale (ADAPSS)

We are interested in the thoughts that people have about their spinal cord injury and how these thoughts may change over time. Using the following scale, please rate to what extent the statements below reflect ***your current perceptions of your spinal cord injury*** *by* ***clearly circling*** *the appropriate response. Please respond as quickly as possible as first responses are usually more accurate.*

1. **(NPD)**	This is something that will significantly change the rest of my life	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
2. **(PA)**	There are many things that I can do to change my situation	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
3. **(PA)**	I am the same person I have always been	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
4. **(NPD)**	I am going to miss out on many aspects of my life	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
5. **(PA)**	The more that I learn about this situation the better I am able to cope	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
6. **(OD)**	Since my injury I find it harder to control my emotions	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
7. **(OD)**	This is too much for anyone to deal with	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
8. **(PA)**	I am eager to manage my future	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
9. **(FD)**	The world is now a more hostile place	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
10. **(FD)**	Everyday is now a battle	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
11. **(GR)**	The ordinary things in life are now more valuable to me	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
12. **(NPD)**	This is negatively affecting everyone in my life	**Strongly Disagree** **1**	**Moderately Disagree** **2**	**Mildly Disagree** **3**	**Mildly Agree** **4**	**Moderately Agree** **5**	**Strongly Agree** **6**
13. **(PA)**	My past experiences help me to deal with this situation	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**
14. (GR)	This experience has made me a stronger person	**Strongly Disagree** **6**	**Moderately Disagree** **5**	**Mildly Disagree** **4**	**Mildly Agree** **3**	**Moderately Agree** **2**	**Strongly Agree** **1**

15. (FD)	I am frightened of what will happen to my physical health	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6

16. (NPD)	I can never forget that I am in a wheelchair	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
17. (GR)	I am more resilient	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
18. (FD)	It is hard for me to see what my future will be like	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
19. (DR)	I am not going to let this beat me	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
20. (FD)	Too much focus is on my physical and not my emotional needs	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
21. (DR)	I am independent	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
22. (GR)	We are now closer as a family	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
23. (OD)	I cannot accept my situation	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
24. (FD)	Everyday life is frustrating	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
25. (FD)	I have less choice over the things that matter to me	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
26. (OD)	I cannot believe that this has happened to me	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
27. (DR)	I will continue to live my life to its full capacity	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
28. (FD)	Other people see me as less of a person	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
29. (GR)	I now have a more positive view of disability	**Strongly Disagree** 6	**Moderately Disagree** 5	**Mildly Disagree** 4	**Mildly Agree** 3	**Moderately Agree** 2	**Strongly Agree** 1
30. (NPD)	The lack of movement totally dominates my life	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
31. (FD)	I feel more vulnerable	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
32. (OD)	I often think of the things that I am unable to do	**Strongly Disagree** 1	**Moderately Disagree** 2	**Mildly Disagree** 3	**Mildly Agree** 4	**Moderately Agree** 5	**Strongly Agree** 6
33.	I can overcome this	**Strongly**	**Moderately**	**Mildly**	**Mildly**	**Moderately**	**Strongly**

(DR)		Disagree 6	Disagree 5	Disagree 4	Agree 3	Agree 2	Agree 1

SCORING SHEET (LONG FORM)

To score answers on the ADAPSS, each subscale can be calculated by summing the scores for each item. Each item is coded according to the subscales below:

(FD) **FEARFUL DESPONDENCY (9 ITEMS - MAXIMUM SCORE 54)**

(OD) **OVERWHELMING DISBELIEF (5 ITEMS - MAXIMUM SCORE 30)**

(DR) **DETERMINED RESOLVE (4 ITEMS - MAXIMUM SCORE 24)**

(GR) **GROWTH AND RESILIENCE (5 ITEMS - MAXIMUM SCORE 30)**

(NPD) **NEGATIVE PERCEPTIONS OF DISABILITY (5 ITEMS - MAXIMUM SCORE 30)**

(PA) **PERSONAL AGENCY (5 ITEMS - MAXIMUM SCORE 30)**

Enter the total amounts into the table and see below for cut-off criteria.
Shaded boxes indicate scores that require attention.

	FEARFUL DESPONDENCY **(FD)**	OVERWHELMING DISBELIEF **(OD)**	DETERMINED RESOLVE **(DR)**	GROWTH & RESILIENCE **(GR)**	NEGATIVE PERCEPTIONS OF DISABILITY **(NPD)**	PERSONAL AGENCY **(PA)**
TOTALS						

Score	**FD**
51-54	**HIGH**
45-50	UPPER NORMAL
29-44	NORMAL RANGE
19-28	LOWER NORMAL
9-18	LOW

Score	**OD**
28-30	**HIGH**
25-27	UPPER NORMAL
13-24	NORMAL RANGE
9-12	LOWER NORMAL
5-8	LOW

Score	**DR**
4-8	HIGH
9-11	UPPER NORMAL
12-14	NORMAL RANGE
15-20	LOWER NORMAL
21-24	**LOW**

Score	**GR**
5-8	HIGH
9-11	UPPER NORMAL
12-18	NORMAL RANGE
19-24	LOWER NORMAL
25-30	**LOW**

Score	**NPD**
27-30	**HIGH**
24-26	UPPER NORMAL
19-23	NORMAL RANGE
12-18	LOWER NORMAL
5-11	LOW

Score	**PA**
5-8	HIGH
9-11	UPPER NORMAL
12-17	NORMAL RANGE
18-25	LOWER NORMAL
26-30	**LOW**

Appendix P: TDRP Generalized Anxiety Disorder-7 (GAD-7) Questionnaire

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Add the score for each column	+	+	+	

Total Score *(add your column scores)* =

Appendix Q: TDRP Spinal Cord Injury – Falls Concern Scale (SCI-FCS)

		Not at all concerned 1	*Somewhat concerned 2*	*Fairly concerned 3*	*Very concerned 4*
1	Getting dressed or undressed	*1*	*2*	*3*	*4*
2	Moving around the bed (including sitting up)	*1*	*2*	*3*	*4*
3	Inserting enema or toileting	*1*	*2*	*3*	*4*
4	Washing or showering self	*1*	*2*	*3*	*4*
5	Transferring on/off a commode or toilet	*1*	*2*	*3*	*4*
6	Transferring in/out of bed	*1*	*2*	*3*	*4*
7	Transferring in/out of a car	*1*	*2*	*3*	*4*
8	Reaching for high objects (e.g. pressing button on a lift, reaching to a high shelf)	*1*	*2*	*3*	*4*
9	Picking objects up from the floor (e.g. clothes, pet bowl, pen)	*1*	*2*	*3*	*4*
10	Cooking or food preparation (e.g. making a sandwich, stirring food on the stove)	*1*	*2*	*3*	*4*
11	Pushing wheelchair on flat ground	*1*	*2*	*3*	*4*
12	Pushing wheelchair on an uneven surface (e.g. rocky ground, irregular pavement)	*1*	*2*	*3*	*4*
13	Pushing wheelchair up/down gutters or curbs	*1*	*2*	*3*	*4*
14	Pushing wheelchair up/down a slope	*1*	*2*	*3*	*4*
15	Shopping	*1*	*2*	*3*	*4*
16	Lifting heavy objects across body (e.g. shopping bags, wheelchair into the car)	*1*	*2*	*3*	*4*

Appendix R: TDRP The Hopkins Rehabilitation Engagement Rating Scale (HRERS)

Please rate the patient's participation in your portion of his/her rehabilitation program on the following scales. This rating should be completed at the time of discharge and is a summary of his/her participation during the entire course of your interactions with the patient.

1. The patient regularly attended my therapy/ rehabilitation activity.

Never	Seldom	Some of the time	Most of the time	Nearly Always	Always

2. The patient required verbal or physical prompts to actively participate in my therapy/ rehabilitation activity.

Never	Seldom	Some of the time	Most of the time	Nearly Always	Always

3. The patient expressed a positive attitude towards my therapy/rehabilitation activity.

Never	Seldom	Some of the time	Most of the time	Nearly Always	Always

4. The patient acknowledged a need for rehabilitation services and the benefit of therapy exercises or rehabilitation activities.

Never	Seldom	Some of the time	Most of the time	Nearly Always	Always

5. The patient actively participated in his/her rehabilitation therapy/activity.

Never	Seldom	Some of the time	Most of the time	Nearly Always	Always

Appendix S: TDRP Information Sheet for Participants







National Spinal Injuries Centre (NSIC) Psychology Department
Stoke Mandeville Hospital
Buckinghamshire Healthcare NHS Trust
bht.nsicpsychology@nhs.net
01296 838394

Chief Investigator
Ruxandra Vasile
Oxford Institute of Clinical Psychology Training and Research
University of Oxford
ruxandra.vasile@gtc.ox.ac.uk
IRAS ID: 321646

PARTICIPANT INFORMATION SHEET

Exploring the impact of falls concern, anxiety and cognitive appraisals on engagement in spinal cord injury rehabilitation.

My name is Ruxandra Vasile and I am a researcher and Trainee Clinical Psychologist at the Oxford Institute of Clinical Psychology Training and Research within the University of Oxford. This research project is being completed under the supervision of Dr Jane Duff and Dr Neil Carrigan (Clinical Psychologists). Dr Jane Duff is a clinical psychologist working at the NSIC. Dr Neil Carrigan is a research tutor at the Oxford Institute of Clinical Psychology Training and Research and a clinical psychologist in the NHS.

This is an invitation to take part in a research study. Before you decide whether you wish to participate, it is important that you understand why the research is being done and what it will involve for you, as a potential participant. Please take time to read this information sheet. You can also discuss it with others if you wish. If you are unclear about anything stated within this information sheet, would like to discuss the study further, or have any questions, please email the researcher at ruxandra.vasile@gtc.ox.ac.uk.

What is the purpose of the study?

Individuals who have sustained a spinal cord injury and are in rehabilitation are being invited to take part in a research study looking at the role concern about falling, feelings of anxiety, and the way someone thinks about their injury may have on engagement in rehabilitation. We are hoping that this research may provide further understanding about how best to support spinal cord injury patients to engage with their rehabilitation.

What will happen to me if I decide to take part?

Your involvement in this study should take approximately 30 minutes. You will be asked to complete three questionnaires asking about your thoughts since sustaining your injury, your possible feelings of anxiety, and any concerns you might have about falling. Participant data will only be collected at one time point during the study.

Your consent will be sought for your physiotherapist to complete one questionnaire about your engagement in rehabilitation. This will have no impact on the

rehabilitation package that is offered to you – it is only used for the purpose of this research.
You are able to complete this study online, via a tablet, computer or smartphone. If you do not have access or are not comfortable with technology, you can also complete a paper version of this study. If you need a paper version, please ask one of the NSIC psychology team members for one, or, if you have access to an email account or a staff member can support, please contact ruxandra.vasile@gtc.ox.ac.uk or bht.nsicpsychology@nhs.net for this. This pack will contain a return envelope addressed to the researcher via the NSIC psychology department. Support will be provided by a member of your care team if you have difficulty writing and would like to participate – just let one of the NSIC psychology department staff members know, or email ruxandra.vasile@gtc.ox.ac.uk or bht.nsicpsychology@nhs.net and we will arrange support for you.

Why have I been invited?

You have been invited to participate in this research because you have a spinal cord injury. This research intends to involve 86 participants aged 18 and above from the NSIC.

Unfortunately, people who have sustained a head injury or have a cognitive deficit are unable to participate in this project. If you are unsure whether this applies to you, ask a member of your care team.

Do I have to take part?

No, taking part in this research is entirely voluntary. It is up to you whether you would like to participate or not, and you could choose not to continue at any time, without giving a reason. If you are completing this study online, you can do this by closing your web browser.

Are there any possible disadvantages or risks from taking part?

Taking part in this study will take approximately 30 minutes of your time in total.
It is possible that reading and thinking about the questions in the questionnaires may make you think more about your injury and perhaps be upsetting. If this is the case, the distress should not last very long., You can pause when doing the questionnaires for however long you need and return to the questionnaires later if you feel able. Alternatively, you are able to completely withdraw yourself at any point during the completion of the questionnaires by closing the web browser.
If the study leads you to feeling distress for a longer time, more than a day or few days after completing the questionnaires, we encourage you to speak to a member of the NSIC psychology team in the first instance, as they will be most familiar with the study. You can contact the Head of Psychology, Dr Jane Duff at janeduff@nhs.net. You can also speak to a trusted member of your care team, who can help put you in contact with the NSIC psychology team. We would also encourage you to contact the lead researcher by emailing ruxandra.vasile@gtc.ox.ac.uk.

What are the possible benefits of taking part? It is hoped that the findings from this study will further improve our understanding of how health care is delivered, and more specifically how best to support spinal cord injury patients to make the most out of their rehabilitation.

Will my taking part in the study be kept confidential?
All information collected about you during the research will be kept confidential and conform to the United Kingdom General Data Protection Regulation (GDPR) and Data Protection Act 2018. This applies to data collection, storage, and destruction. Access to this data will be restricted to study personnel. However, responsible members of the University of Oxford and Buckinghamshire Healthcare NHS Trust may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations. You will not be identifiable in any reports or publications arising from this research study.

Will I be reimbursed for taking part?
Unfortunately, there is no reimbursement provided for taking part in this research.

What will happen to my data?
Data protection regulation requires that we state the legal basis for processing information about you. In the case of research, this is 'a task in the public interest.' The University of Oxford, based in the United Kingdom, is the data controller and is responsible for looking after your information and using it properly. We will be using information from you and your hospital in order to undertake this study.
We will use the minimum personally-identifiable information possible (name and email address) about you in this study. We will keep identifiable information about you for 3 months after the study has finished. This excludes any research documents with personal information, such as consent forms, which will be held securely at the NSIC clinical psychology department for 5 years after the end of the study. Paper consent forms will be stored at the NSIC, in a securely locked room, until the end of the study. The Trust will use your patient records and admission records to contact you about the research study. A copy of the consent form from this study will be kept in your medical records for as long as those records are retained.
Your anonymised responses to the study questionnaires will be stored on a secure Cloud-based storage system at the University of Oxford. If you are completing this study in a paper format, your responses will be uploaded onto an encrypted Excel file and your original paper questionnaires stored in a locked cabinet in a locked room in the NSIC clinical psychology department. This anonymised research data will be kept for a duration of 5 years before then being permanently destroyed.
Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at
https://compliance.web.ox.ac.uk/individual-rights
You can find out more about how we use your information by contacting the lead researcher Ruxandra Vasile on ruxandra.vasile@gtc.ox.ac.uk

What will happen if I don't want to carry on with the study?
Participation in this research is totally voluntary and you are able to withdraw at any point whilst completing the study without reason. Withdrawal will not affect the clinical care you are receiving from the NSIC.

What happens at the end of the study?

The data from this study will contribute to a doctoral thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives. The data will also be used to generate research papers that will be distributed online and on paper in academic journals – some of these may be openly accessible. No data which can identify individuals will be published in the scientific report of the study. A lay summary of the report will be made freely available from the NSIC after the study. You will be able to contact the NSIC Psychology Department for the summary.

What if there is a problem?

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

If you wish to complain about any aspect of the way in which you have been approached or treated, or how your information is handled during the course of this study, you should contact Ruxandra Vasile on the email ruxandra.vasile@gtc.ox.ac.uk or you may contact the University of Oxford Research Governance, Ethics and Assurance (RGEA) office on 01865 616480, or the director of RGEA on rgea.complaints@admin.ox.ac.uk.

How have patients and the public been involved in this study?

People with lived experience of spinal cord injury have contributed to and reviewed study documents including the participant information sheets, and study materials such as the questionnaires.

Who is organising and funding the study?

The study is being completed as part of a Doctorate in Clinical Psychology, which is accredited by the University of Oxford. It will be led by Ruxandra Vasile who is being supervised by Dr Jane Duff and Dr Neil Carrigan. The University of Oxford are acting as sponsor for this project and funding is provided by the Oxford Institute of Clinical Psychology Training and Research.

Who has reviewed this study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given a favourable opinion by < _____> Research Ethics Committee.

For further information or questions:

If you are worried about any part of the study, please initially raise any concerns with Dr Jane Duff. Concerns can also be raised with Dr Neil Carrigan, the University research supervisor, who can escalate where required.

You can contact us on our email addresses for further information.

Ruxandra Vasile: ruxandra.vasile@gtc.ox.ac.uk

Dr Jane Duff: janeduff@nhs.net

Dr Neil Carrigan: neil.carrigan@hmc.ox.ac.uk

Thank you for reading this information and considering taking part.

Appendix T: TDRP Consent Form for Participants

National Spinal Injuries Centre (NSIC) Psychology Department
Stoke Mandeville Hospital
Buckinghamshire Healthcare NHS Trust
bht.nsicpsychology@nhs.net
01296 838394

Chief Investigator
Ruxandra Vasile
Oxford Institute of Clinical Psychology Training and Research
University of Oxford
ruxandra.vasile@gtc.ox.ac.uk
IRAS ID: 321646

CONSENT FORM

Exploring the impact of falls concern, anxiety, and cognitive appraisals on engagement in spinal cord injury rehabilitation.

Please initial box

1. I confirm that I have read the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to my physiotherapist completing a questionnaire about my rehabilitation. ☐
4. I understand that my data collected during the study may be looked at by individuals from University of Oxford and Buckinghamshire Healthcare NHS Trust Research & Innovation, from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my study data as required. ☐
5. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐
6. I agree to take part in the above study. ☐

_____ _____ _____

Name of Participant Date Signature

Appendix U: TDRP Sample Email for Physiotherapists

Dear ___,

Hope you are well.

As you may be aware, I am conducting a research study at the NSIC looking at the impact of anxiety, fear of falling, and how patients think about their injury on engagement in rehabilitation. As part of this, and with the patient's consent, I am kindly asking you to fill out the below survey about patient **NAME**. In the questionnaire, you will be asked for the participants unique identification code so as to keep their name anonymous. Please enter the code **CODE**.

The questionnaire will take no longer than 5 minutes to complete.

Many thanks for supporting this important research. If you have any questions at all, please just let me know.

Link:
https://psychiatryoxford.qualtrics.com/jfe/form/SV_9NSoi8WxZzekHJA

Best wishes,
Ruxandra

Appendix V: TDRP Histogram of dependent variables

Histograms were plotted for ADAPSS-Resilience, ADAPSS-Threat/Loss, GAD-7, and SCI-FCS scores (see *Figures 3.3*, *3.4*, *3.5*, and *3.6*, respectively. The ADAPSS-Resilience, GAD-7 and SCI-FCS histograms show a positive skew, suggesting that generally participants scored on the lower ends of the scales. The ADAPSS-Threat/Loss histogram does not show a particular trend, but rather indicates that participants had mixed levels of threat/loss appraisals of disability.

Figure 3.3. Histogram of ADAPSS-Resilience scores for full sample.

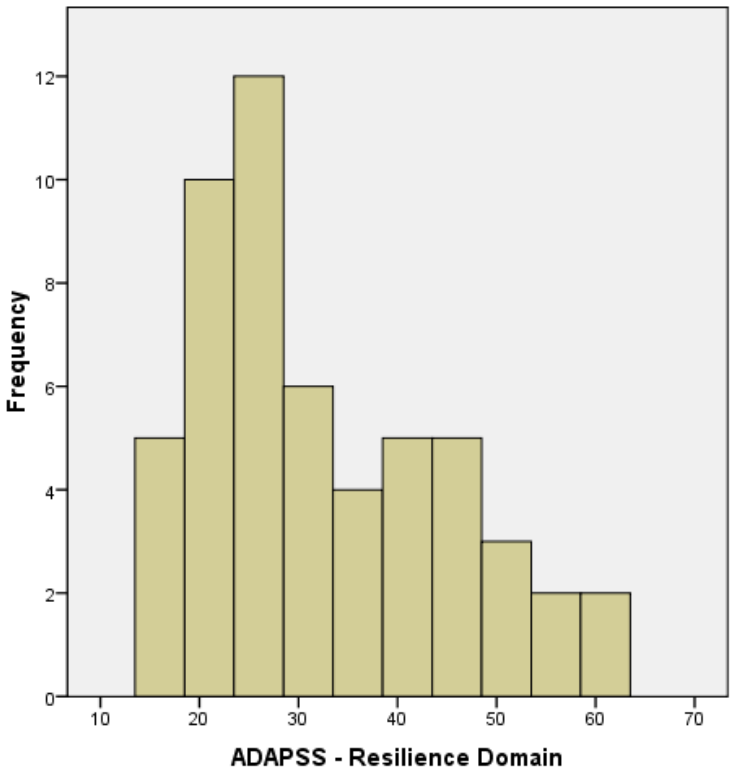


Figure 3.4. Histogram of ADAPSS-Threat/Loss scores for full sample.

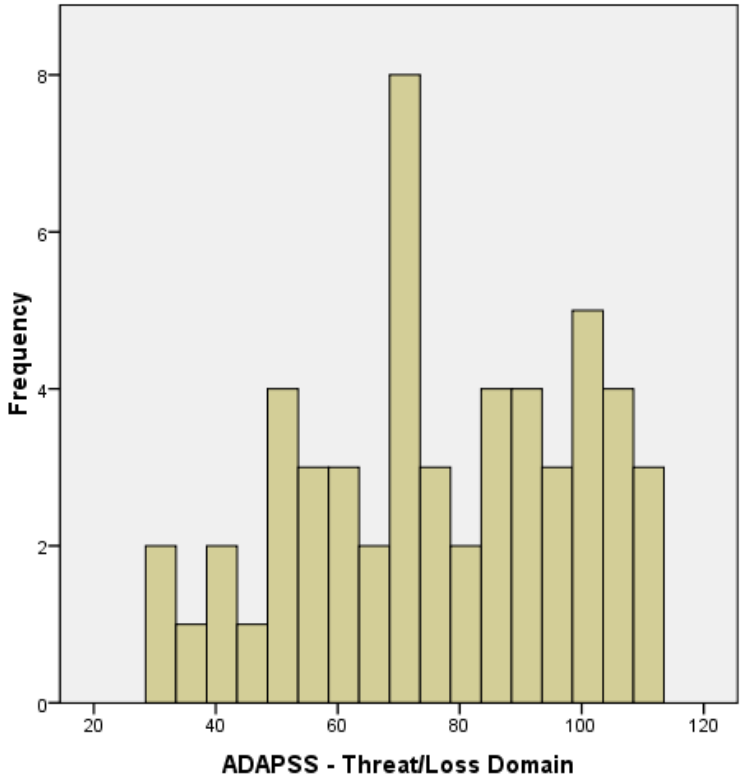


Figure 3.5. Histogram of GAD-7 scores for full sample.

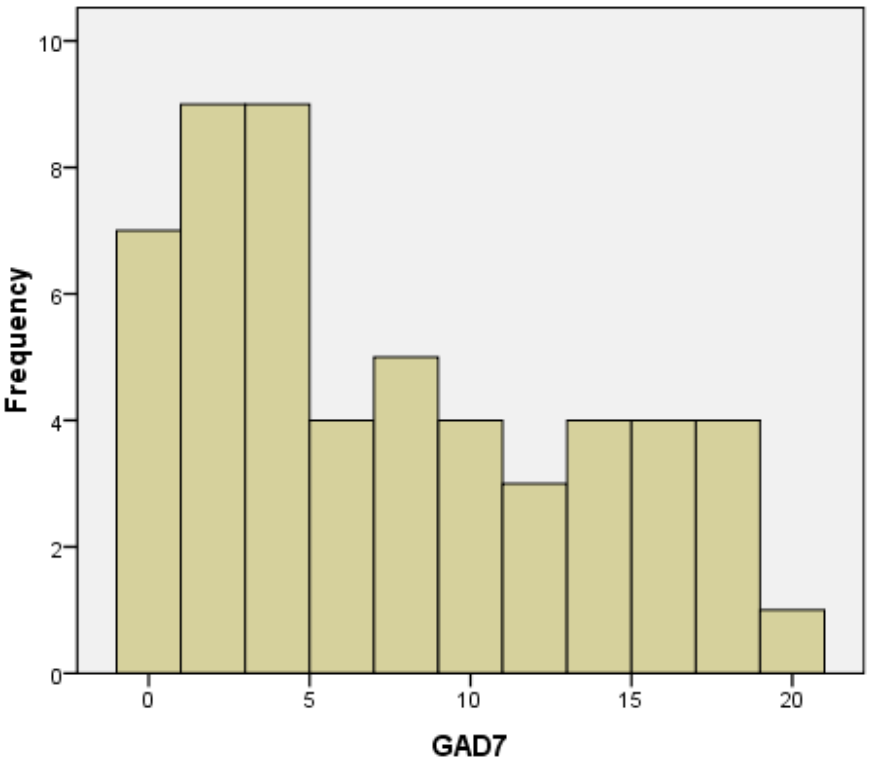
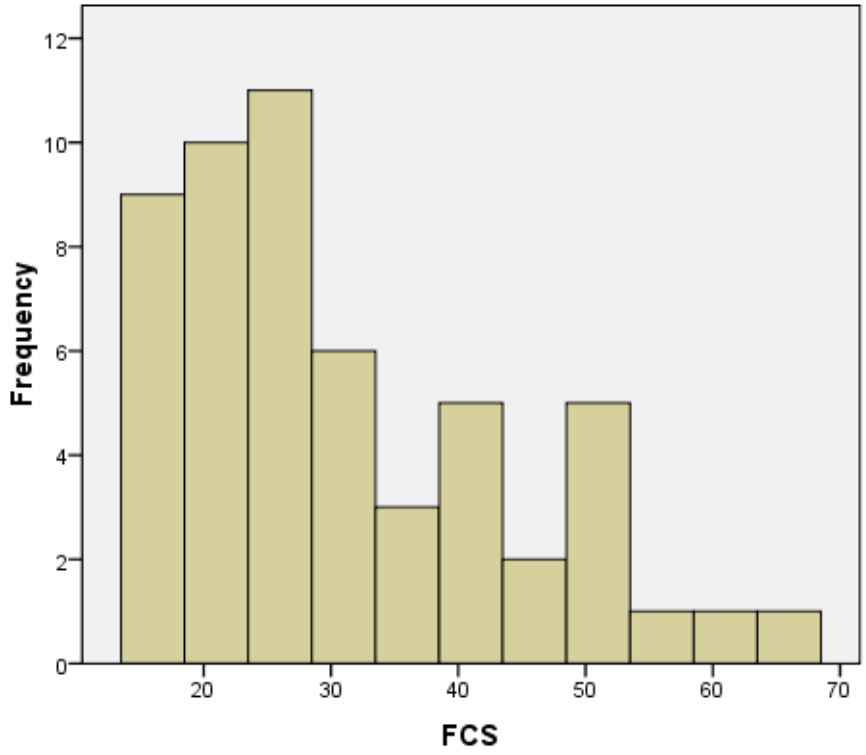


Figure 3.6. Histogram of SCI-FCS scores for full sample.



Appendix W: TDRP Results from original data analysis plan

Descriptive statistics for dependent measures

A median split of 29 on the HRERS was used to create two groups - 'high engagers' and 'low engagers'. *Table 3.2* illustrates means and SDs for SCI-FCS, GAD-7, and ADAPSS domains by engagement level and full sample. Low engagers scored only marginally higher on all measures, suggesting they were slightly more anxious and had a greater fear of falls. Both ADAPSS domains were also higher for the 'low engagers' suggesting that this group had marginally higher threat/loss-related appraisals of disability and less resilience-related appraisals of disability.

Table 3.2. Means and SDs for outcome measures by engagement level.

	Low engagers (N = 24)		**High engagers (N = 30)**		**Full sample (N = 54)**	
Measure	**M**	**SD**	**M**	**SD**	**M**	**SD**
SCI-FCS	31.71	13.01	30.00	12.36	30.76	12.56
GAD-7	7.71	5.53	6.47	6.17	7.02	5.87
ADAPSS – Resilience	33.62	10.65	30.93	13.58	32.13	12.33
ADAPSS – Threat/Loss	78.62	23.42	75.00	21.65	76.61	22.31

Note. ADAPSS-Resilience is reverse-coded, such that higher scores on this scale indicate lower resilience. Higher scores on ADAPSS-Threat/Loss indicate higher threat/loss appraisals of SCI.

Inferential statistics

Hypothesis 1: Differences in cognitive appraisals by engagement level

The histogram in *Figure 3.3* and the Shapiro-Wilk test for ADAPSS-Resilience scores indicated that this distribution differed significantly from normality; $W(54)=.926$, $p=.002$. Therefore, differences in ADAPSS-Resilience scores by engagement level were tested using a Mann-Whitney U test. There was no significant difference in resilience appraisals of SCI between high engagers and low engagers in rehabilitation; $U=285.00$, $z=-1.307$, $p=.191$, $r=-.178$.

The Shapiro-Wilk test for ADAPSS-Threat/Loss scores indicated that this distribution did not differ significantly from normality; $W(54)=.965$, $p=.116$. Therefore, differences in ADAPSS-Threat/Loss scores by engagement level were tested using an independent samples t-test. Levene's test indicated that the assumption of equal variances was met (p=.587). There was no significant difference in threat/loss appraisals of SCI between high engagers and low engagers in rehabilitation, t(52)=.590, p=.558.

Hypothesis 2: Differences in generalised anxiety and falls concern by engagement level

The histogram in *Figure 3.5* and the Shapiro-Wilk test indicated that GAD-7 scores differed significantly from normality; $W(54)=.906$, $p<.001$. Therefore, differences in GAD-7 scores by engagement level were tested for using a Mann-Whitney U. There was no significant difference in generalised anxiety between high engagers and low engagers in rehabilitation; $U=306.50$, $z=-.93$, $p=.350$, $r=-.13$.

The histogram in *Figure 3.6* and the Shapiro-Wilk test indicated that SCI-FCS scores differed significantly from normality; $W(54)=.910$, $p=.001$. Therefore, differences in SCI-FCS scores by engagement level were tested for using a Mann-Whitney U. There was no significant difference in falls concern between high engagers and low engagers in rehabilitation; $U=334.50$, $z=-.45$, $p=.657$, $r=-.06$.

Appendix X: TDRP University of Oxford Research Governance, Ethics & Assurance Approval

RESEARCH SERVICES
UNIVERSITY OF OXFORD

Research Governance, Ethics & Assurance
Boundary Brook House
Churchill Drive
Headington, Oxford
Oxon
OX3 7GB

To whom it may concern

Date: 02/08/2023

Title: Exploring the impact of falls concern, anxiety and cognitive appraisals on engagement in spinal cord injury rehabilitation.

PID: 17025

Protocol Date/Version: 02.08.2023 Version 1

The above study has been designed by Miss Ruxandra Vasile and colleagues at the University of Oxford and funded by the Departmental Resources (Internal Funding). I confirm that the University will accept the role of Research Sponsor of this Study and will comply with the requirements of the UK Policy Framework for Health and Social Care Research October 2017.

Insurance-provided indemnity arrangements are in place for the project with Newline Underwriting Management Ltd., at Lloyd's of London.

Sponsorship is confirmed subject to the condition that the following are sent to Research Governance, Ethics & Assurance for review prior to submission to the Research Ethics Committee. Failure to do so may compromise insurance cover for the project.

- Any minor or substantial amendments
- Any extension to the study end date
- Addition of any new research site or patient identification centre

In addition, annual progress reports, the end of study notification and final report must be copied to Research Governance, Ethics & Assurance.

Lastly, where they exist, University Core SOPs must be followed by default for all clinical research sponsored by the University. Further information can be found here: https://researchsupport.admin.ox.ac.uk/ctrg/resources

Any communications relating to Research Sponsorship should be directed to the undersigned.

Yours faithfully

DocuSigned by:
Carol Cornelius
259774BBA29F448...
02 August 2023

Carol Cornelius

Appendix Y: TDRP Letter of NHS HRA REC approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Miss Ruxandra Vasile
Trainee Clinical Psychologist
Oxford Health NHS Foundation Trust
Oxford Institute of Clinical Psychology Training and Research
OX3 7JXN/A

Email: approvals@hra.nhs.uk

10 September 2023

Dear Miss Vasile

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Exploring the impact of falls concern, anxiety and cognitive appraisals on engagement in spinal cord injury rehabilitation.**
IRAS project ID:	**321646**
Protocol number:	**0000000**
REC reference:	**23/SC/0298**
Sponsor	**University of Oxford / Research Governance Ethics and Assurance**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report

(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **321646**. Please quote this on all correspondence.

Yours sincerely,
Deanna Herron

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *University of Oxford - Research Governance, Ethics and Assurance*

Appendix Z: TDRP Letter of Support from Buckinghamshire Healthcare NHS Trust

Buckinghamshire Healthcare NHS Trust

Buckinghamshire Health Research & Innovation Centre

Research and Innovation Department
Buckinghamshire Health Research and Innovation Centre
Mandeville Road
Aylesbury
Bucks
HP21 8AL

Tel: 01296 831411
Email: bht.research@nhs.net
Web: www.bhtresearchandinnovation.org

Research Office

Date: 13th November 2023

Dear Ruxandra Vasile

Letter of access for research

As an existing NHS Employee, you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research project **'Engagement in Spinal Cord Injury Rehabilitation Study'** through Bucks Healthcare for the purpose and on the terms and conditions set out below. This right of access commences on **13th November 2023** and ends on **13th November 2024** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to Bucks Healthcare premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Bucks Healthcare, you will remain accountable to your employer **Oxfordshire Healthcare NHS Trust**, but you are required to follow the reasonable instructions of your nominated manager, **Jane Duff** in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating **Healthcare NHS Trust** prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 2018, further more you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The **Buckinghamshire Healthcare NHS Trust** will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 2018. Any breach of the Data Protection Act 2018 may result in legal action against you and/or your substantive employer.

You must act in accordance with Bucks Healthcare policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Bucks Healthcare in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Bucks Healthcare premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or you are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Where applicable, your substantive employer will initiate your Independent Safeguarding Authority (ISA) registration in-line with the phasing strategy adopted within the NHS and the applicable legislation. Once you are ISA-registered, your employer will continue to monitor your ISA registration status via the on-line ISA service. Should you cease to be ISA-registered, this letter of access is immediately terminated. Your substantive employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or ISA registration, or any other aspect that may impact on your suitability to conduct research, or your role in

research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



Nicola Higgins, RM&G Manager

cc: R&I office at Bucks Healthcare NHS Trust
HR department of the substantive employer (and provider of honorary clinical contract, where applicable)
HR department, Bucks Healthcare NHS Trust