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Abstracts

Critical Review of the Literature Abstract

Background: Chronic Fatigue Syndrome (CFS) is a complex disorder characterised by extreme exhaustion not improved with rest (NICE, 2021). Cognitive behavioural models for understanding CFS adopt a Biopsychosocial framework which asserts that cognitive, behavioural, and affective factors perpetuate CFS symptoms and effect treatment outcomes. **Purpose:** The present review adopted a narrative synthesis approach to explore the relationship between self-efficacy and causal attributions on therapeutic outcomes (fatigue & functional impairment), as detailed in Vercoulen et al.'s (1998) model.

Method: A systematic review of databases (Psychinfo, Medline, CINAHL & PubMed) was carried out. Studies were included if psychological intervention was delivered to participants, 16 years of age and above, with a diagnosis of CFS and if scores of self-efficacy and causal attributions were reported. **Results:** Fifteen studies were included in this review. Only one study demonstrated a relationship between attributions on outcomes whereas several studies indicated a relationship between self-efficacy on outcomes, however, this relationship was reported to be small in several studies. **Conclusions:** The findings of this review do not conclusively provide support for Vercoulen et al.'s model. Clinicians should take caution when applying this model to clinical practice. Further research should focus on what works well for whom and when, possibly using network analysis.

Service Improvement Project Abstract

Background: The process of an organ recipient writing to a donor/donor family is supported by NHS Blood and Transplant (NHSBT, n.d). **Objectives:** This service improvement project aimed to understand the barriers and facilitators faced by professionals when supporting recipients to think about writing this letter, at the Oxford Transplant Centre (OTC). **Method:** Eight post-transplant professionals (five nurses & three consultants) attended individual interviews and four pre-transplant nurses attended a focus group. Two Likert-scale questions were asked which explored importance and confidence in supporting recipients with letter writing. **Results:** Reflexive Thematic Analysis was employed to analyse the data. Five themes were identified in the focus group, with six sub-themes, and six themes were identified in the interviews, with 10 sub-themes. These themes shed light on some of the barriers (information overload) and facilitators (empathetic understanding) to talking with recipients about letter writing. **Conclusions:** Recommendations were drawn from these themes, which included increasing recipient awareness of the possibility of letter writing (e.g., by displaying a poster in the waiting room/ward).

Theory Driven Research Project Abstract

Background: Caregiver resources could mediate against the development of Secondary Traumatic Stress (STS) in foster carers, according to a conceptual model (Whitt-Woosley et al., 2020). The relationship between coping styles (emotion-focused, problem-focused, and avoidant; Carver et al., 1997) and STS has yet to be researched in UK foster carers.

Aims: To explore the relationship between STS and coping styles whilst controlling for anxiety and depression and to explore group differences in the use of the individual facets on the Brief COPE. **Design:** A cross-sectional, between subjects design. **Method:** Data was collected from 132 foster carers at one time point using online self-report questionnaires. Two groups were formed, 'high' and 'low' STS based on the clinical cut-off score of '38' on the Secondary Traumatic Stress Scale (Bride et al., 2004). **Results:** Analysis of Covariance (ANCOVA) found that foster carers who reported high STS also reported significantly greater use of problem-focused and avoidant coping styles, with the greatest effect size in problem-focused coping. Exploratory analysis identified 'behavioural disengagement', 'substance use', and 'denial' were significantly different between the two groups. **Discussion:** The majority of the sample reported high STS. The greater use of the coping facets in the high STS group suggest that STS could be impacting on the effectiveness of coping responses. Greater awareness and screening for STS could allow for early intervention focused on secondary trauma which could support the effectiveness of the coping strategies employed. Future research should explore this relationship further and the efficacy of a trauma-based intervention.

Critical Review of the Literature

The Role of Causal Attributions and Sense of Control on Outcomes of Psychological Therapy in Chronic Fatigue Syndrome.

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Rationale: A British journal which publishes psychological research in the field of clinical health psychology (Appendix A).

Abstract

Background: Chronic Fatigue Syndrome (CFS) is a complex disorder characterised by extreme exhaustion not improved with rest (NICE, 2021). Cognitive behavioural models for understanding CFS adopt a Biopsychosocial framework which asserts that cognitive, behavioural, and affective factors perpetuate CFS symptoms and effect treatment outcomes. **Purpose:** The present review adopted a narrative synthesis approach to explore the relationship between self-efficacy and causal attributions on therapeutic outcomes (fatigue & functional impairment), as detailed in Vercoulen et al.'s (1998) model. **Method:** A systematic review of databases (Psychinfo, Medline, CINAHL & PubMed) was carried out. Studies were included if psychological intervention was delivered to participants, 16 years of age and above, with a diagnosis of CFS and if scores of self-efficacy and causal attributions were reported. **Results:** Fifteen studies were included in this review. Only one study demonstrated a relationship between attributions on outcomes whereas several studies indicated a relationship between self-efficacy on outcomes, however, this relationship was reported to be small in several studies. **Conclusions:** The findings of this review do not conclusively provide support for Vercoulen et al.'s model. Clinicians should take caution when applying this model to clinical practice. Further research should focus on what works well for whom and when, possibly using network analysis.

Key words: Chronic Fatigue Syndrome, Causal Attributions, Self-Efficacy, Outcomes.

Introduction

Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME) (hereafter referred to using the acronym 'CFS') is a complex and debilitating chronic condition with significant fluctuations in both the qualitative nature and severity of symptoms amongst sufferers (NICE, 2021). Symptoms include fatigue, post-exertional malaise after activity, non-refreshing sleep, and cognitive difficulties (NICE, 2021). The unpredictable nature of these symptoms has a profound impact on functioning and quality of life (Rimes et al., 2016), indeed one study reported that 25% of patients are housebound (Pendergrast et al., 2016). NICE reported that over 250,000 individuals in England and Wales have a diagnosis of CFS, with 2.4 more females affected than males.

Due to the uncertainty that surrounds the pathophysiology and management of CFS, it has been considered a 'medically unexplained syndrome', a name which has led to stigma and the view that it is not a 'real' condition from physicians and the patient's social network (Dickson et al., 2007). It was not until 2002 that CFS was considered a genuine medical condition (Speight, 2013).

Cognitive Behavioural Models of CFS

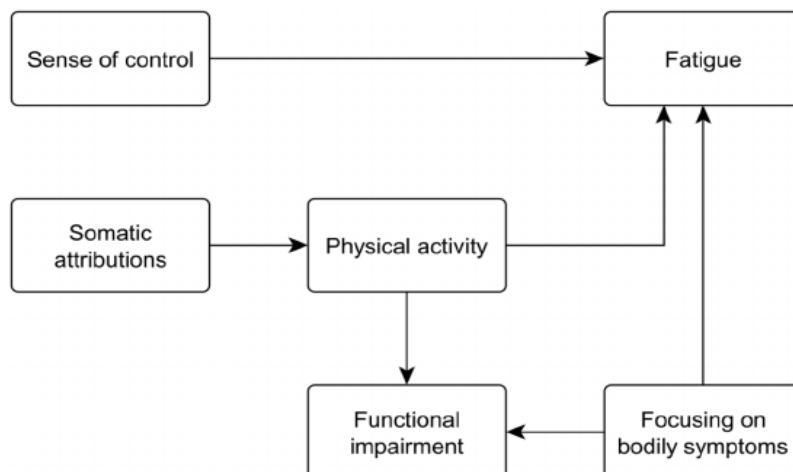
Psychiatrists in the 1990's in the United Kingdom, proposed that CFS could be understood using Beck's Cognitive Behavioural Theory (Beck, 1964). Cognitive Behavioural Models of CFS were cyclical and centred around 'precipitating', 'predisposing' and 'perpetuating' factors and were embedded in the Biopsychosocial model. For example, CFS was viewed as an illness perpetuated by cognitions that reduced patients' activities, whereby fatigue

and pain reinforce unwanted cognitions and avoidance behaviours. A theoretical model was proposed by Surawy et al. (1995) and this was built upon to create a cognitive behavioural model of CFS (Vercoulen et al., 1998).

Vercoulen et al.'s (1998) cognitive behavioural model explored six perpetuating factors of CFS from a cognitive, behavioural, and affective framework (see Figure 1). Of these six factors, two cognitive factors, causal attributions (i.e., somatic versus psychological) and sense of control over symptoms will be explored further in this review. The model stipulates that the symptomatology of CFS is perpetuated by attributing the symptoms to a somatic cause, a low level of perceived control over fatigue and a focus on symptoms (Vercoulen et al., 1998). However, this model was critiqued by Song and Jason (2005) who reported that it was not clear if the sample the model was derived from met CDC criteria for CFS and therefore, may be useful in understanding psychiatric conditions but not CFS.

Figure 1.

Vercoulen et al.'s (1998) Cognitive Behavioural Model of CFS.



Vercoulen et al.'s. (1998) model enabled for the identification of perpetuating factors which led the way for the development of interventions, such as Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) (Van Houdenhove & Luyten, 2008). These treatments focused on an increase in physical activity and cognitive restructuring, particularly of fatigue related beliefs (Heins et al., 2013). Research demonstrated support for the efficacy of CBT in the treatment of CFS (White et al., 2006), therefore, CBT and GET were recommended therapeutic interventions for CFS in NICE (2006) guidelines. Although there is limited understanding on the specific factors that impact on therapeutic outcomes in this sample (Luyten et al., 2008), research has found that causal attributions were central tenants to motivation in psychotherapy, linked to withdrawal and disengagement in therapy (Timmer et al., 2006).

However, criticism surrounds the recommendation for CBT/GET as treatments for CFS due to methodological flaws and limited sample sizes in the research studies the guidelines were based upon (Vink & Vink-Niese, 2019). This led to the review of the NICE guidelines for CFS which were subsequently changed in October 2021 (NICE, 2021). The new guidelines advocate that CBT should not be considered a treatment for CFS but rather, support the management of symptoms and associated distress. Therefore, it was considered important to explore in more detail the role of cognitive factors on symptoms and outcomes (fatigue & functional impairment) in CFS.

Summary

The aetiology of CFS remains unknown, debate and controversy surround the understanding and treatment of this condition. The Biopsychosocial Model was considered

a helpful framework to support the development of cognitive behavioural models of CFS. Research reported cognitive, behavioural, and affective factors could perpetuate the experience of CFS symptomology. Vercoulen et al.'s (1998) model supported the development of interventions that target the wide and varying symptoms of CFS. This systematic review aimed to explore the impact of two of the cognitive factors, (causal attributions & sense of control), on outcomes (fatigue & functional impairment) following psychological therapy.

Review questions

This paper aimed to systematically review the literature on associations between causal attributions (psychological vs somatic) and sense of control on therapeutic outcomes (fatigue & functional impairment) following psychological intervention for CFS (e.g., CBT). The review will also explore if the research supports Vercoulen et al.'s (1998) Cognitive Behavioural Model. The review questions are:

- 1) Is there a relationship between causal attributions of CFS and treatment outcomes (fatigue & functional impairment) following psychological therapy for CFS?
- 2) Is there a relationship between reported sense of control and treatment outcomes (fatigue & functional impairment) following psychological therapy for CFS?
- 3) Do attributions change over the course of psychological therapy?
- 4) Does sense of control change over the course of psychological therapy?

Method

A protocol for this review was assessed for feasibility, a priori, by three qualified clinical psychologists at the University of Oxford and it was registered on PROSPERO (registration number: CRD 42021290203). The Preferred Reporting Items for Systematic Reviews and Meta Analyses (PRISMA; Page et al., 2020) guidance was followed to improve rigour of data extraction and reporting.

Search strategy

Systematic searches of four electronic databases (PubMed, CINAHL, PsychINFO & Medline) were conducted by the first author in March 2022 and updated in March 2023. No limits or restrictions were enforced during the search (e.g., year of publication). Three sets of search terms pertaining to words relating to ‘Chronic Fatigue Syndrome,’ ‘psychological therapy’ and ‘causal attributions’/ ‘locus of control’ was split by “OR” linked with “AND” (see Appendix B for full search terms). Reference management software allowed for all the results to be pooled together as well as the disposal of duplicates.

Inclusion/Exclusion criteria

The inclusion/exclusion criteria were considered using the PICOS (participants, interventions, comparators, outcomes & Study design) approach recommended in PRISMA (Page et al., 2020). Studies were deemed appropriate if the participants were 16 years of age and older, because cognitive capacity at the age of 16 years was found to have reached adult levels (Icenogle et al., 2019). Participants were required to have a diagnosis of CFS using clearly stated diagnostic criteria e.g., US Centers for Disease Control and

Prevention (CDC-94; Fukuda et al., 1994) or Oxford research criteria (Sharpe et al., 1991) as well as CFS being the primary diagnosis. The abstract sections were screened to ensure that studies had (a) employed a psychological intervention, such as CBT (b) included outcome measures relating to causal attributions and/or sense of control and (c) reported on therapeutic outcomes e.g., fatigue and functional impairment.

Sense of control in this review is defined as an individual's perception that they can manage and have control over CFS symptomology, e.g., a sense of control over fatigue despite its impact. For a paper to be included it would require a measurement of sense of control. Causal attributions in this review are defined as the beliefs an individual holds about the cause and/or maintenance of CFS symptomology. For a paper to be included it would require a measurement of causal attributions.

A comparator was not a requirement for this review; however, comparators could include treatment as usual, waitlist, or an alternative intervention. This review only included quantitative studies; grey material, secondary analysis and single case designs were excluded due to a risk of bias. Papers were required to be written in, or translated to, English language.

Study Selection and data extraction

A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al. 2020) flow diagram (Figure 2) documents the systematic review process. A total of 1109 articles were retrieved and 906 remained following the removal of duplicates. The first author reviewed all papers, and the second reviewer (BM) independently assessed the

title and abstracts of 221 of these articles, agreement between the researchers was good (Kappa = 0.82). Papers did not advance to the next stage if there was agreement that it did not meet the criteria according to the title and abstract. If there was a difference in opinion at this stage, the paper still advanced for full text screening. A total of 876 papers were discarded at the title and abstract screening stage due to violations of the inclusion criteria and 30 papers went through to full text review. The first author reviewed all papers and conducted a manual search of the reference lists of all articles passed through to full text screening. The second rater (BM) independently assessed eight papers, perfect agreement between the raters (Kappa = 1) was reported. Fifteen papers were excluded for reasons such as participants not having a formal diagnosis and no reported measure of attributions or sense of control. Therefore, a total of 15 papers, based on 14 studies made the final review. One study (Huibers et al., 2004a) conducted a prospective study 12 months after the original study, therefore there were 15 papers based on 14 studies. The figures include the updated search, which yielded 29 more unique entries, but none were relevant to the current review.

A spreadsheet for data extraction was developed to promote reliability and accuracy of data collection. The first author completed data extractions on items of interest for the research question which included: sample size; basic demographics such as age and gender as well as information on outcome measures, diagnostic criteria, type of psychological therapy and study design. The second rater checked the accuracy of this reporting by independently completing the data extraction spreadsheet for 50% of the papers, a perfect agreement between raters was observed.

Quality assessment

The methodological quality of the included studies was assessed using the Kmet Quality Assessment Tool (Kmet et al., 2004) (see Appendix C). This tool provides a systematic reproducible and quantitative means of appraising quantitative studies and has the flexibility to be applied for use with a variety of different study designs. Information on the sample, study design, intervention, and outcome measures etc., were rated on a 4-point scale (N/A, 0 = no, 1 = partial, 2 = yes) with 28 being the maximum score. Both the first and second rater assessed the quality of each included study independently.

Methodological quality was classified as follows: a score of > 90% was considered 'very high quality', 80% 'strong quality', a score of 70–79%, 'good quality', 50–69%, 'fair quality' and < 50% was considered 'poor' quality (Kmet et al.). Any difference in opinions were discussed and consensus was agreed. Agreement between the researchers was good (Kappa = .82). For commentary on the quality assessment (see Appendix D).

Data Synthesis

Due to the heterogeneity of studies (i.e., methodology & measures), a meta-analysis was not appropriate for this review, therefore, a narrative synthesis was conducted. The narrative synthesis was guided and structured in accordance with the research questions and aims of the review. Patterns within and between studies will be commented on to help further understand what works well and for whom.

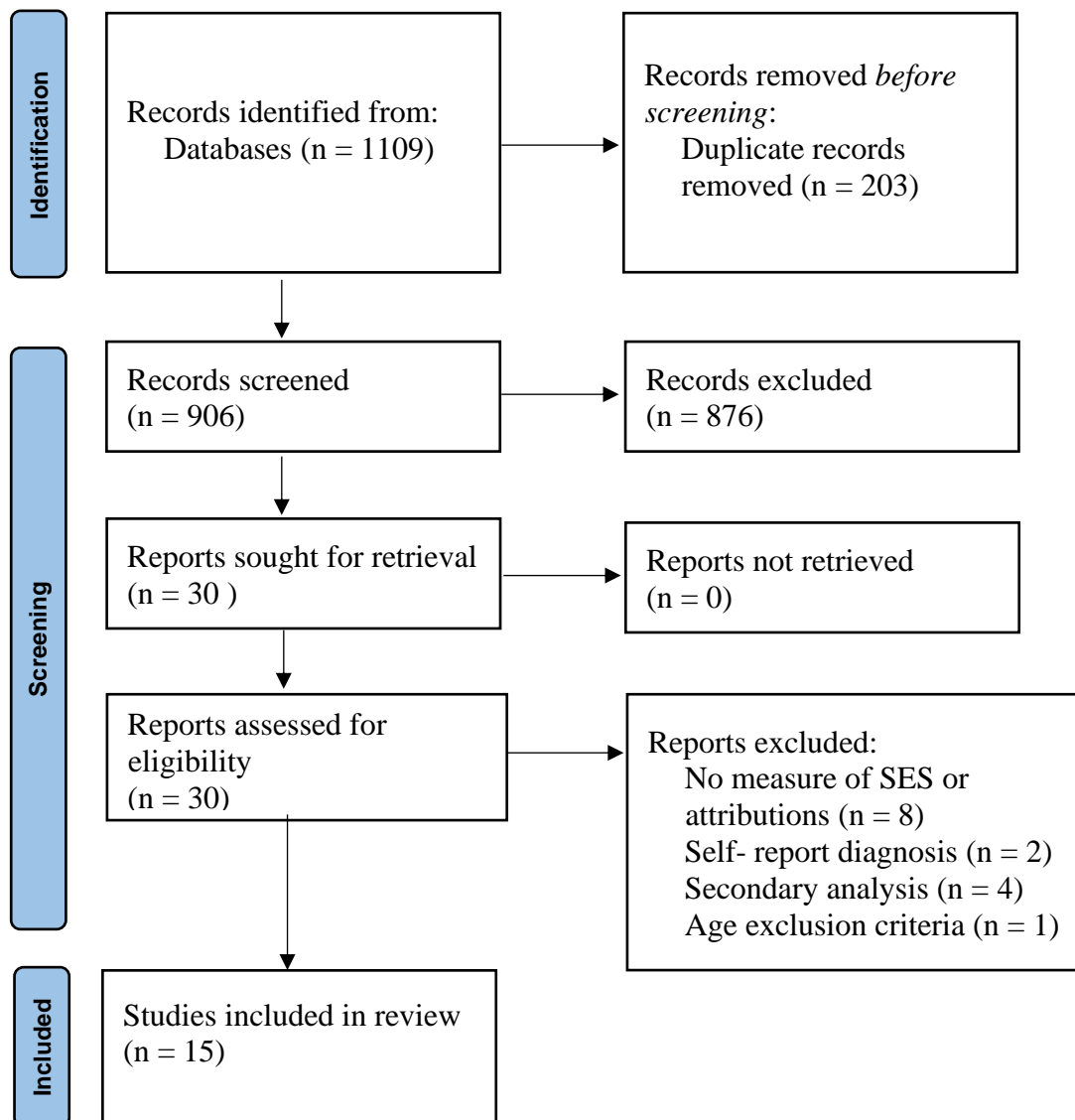
Results

The results section will initially provide an overview of the main study characteristics and quality appraisal (Table 1). Followed by an overview of the systematic search of the

literature on the role of attribution and sense of control on outcomes (fatigue & functional impairment) following psychological therapy.

Figure 2.

PRISMA Flow Diagram of Study Inclusion.



The Kmet et al. (2004) quality rating checklist rated all of the included studies as ‘Strong’ ‘fair’ or ‘good’ in their methodological quality. However, variability relating to sampling, sample size, and therapeutic input, made drawing conclusions on the relationships between attributions and self-efficacy on therapeutic outcomes, challenging. Four studies were conducted in primary care, nine studies used CDC diagnostic criteria as an inclusion criterion and three studies only included a proportion of the sample who met CDC criteria. Sample size varied, ranging from 44 (Goudsmit et al., 2009) to 278 (Prins et al., 2001). Notably, five studies (Bazelmans et al., 2005; Goudsmit et al., 2009; Deale et al., 1997; Jason et al., 2007; Prins et al., 2001) lacked a sufficient sample size and therefore, these studies could be underpowered and may result in a Type II error. Three studies did not include a control group which impacts on validity of interaction between therapeutic outcomes and sense of control/attribution.

In addition, the means of measuring the outcome variable fatigue varied, with some studies using and reporting on subjective measures of fatigue rather objective measures (Vos-Vromans et al. (2015).

All papers reported outcome measures, that were clearly defined, valid, reliable, and implemented consistently across study participants.

Overall, three papers were rated as ‘fair’ five papers were rated as ‘good’ and six as ‘Strong’.

Description of Included Studies / Study Characteristics

The studies were published between 1996 and 2017. Ten of the studies measured attributions and 10 measured 'sense of control'. Six of the included studies were Randomised Controlled Trials (RCTs).

Table 1*Summary of Included Studies.*

Citation	Design	Sample size & Age	% Female	Psychological intervention (Comparator)	Diagnostic criteria	Measure	Format & setting	Quality rating
Bazelmans et al. (2005) Netherlands	NRS	<i>N</i> =67 CBT <i>M</i> = 37.4 (<i>SD</i> = 8.6) Waitlist <i>M</i> =35.8 (<i>SD</i> = 9.0)	73%	CBT (Waitlist)	CDC	CAL & SES	Group 24 hours Hospital outpatients	Fair
Chalder et al. (2003) UK	Randomised trial	<i>N</i> =160 Completers <i>M</i> =40.0 (<i>SD</i> = 13.6) non-completers <i>M</i> =37.2 (<i>SD</i> = 13.5)	73%	CBT (Counselling)	Chalder's case criteria for fatigue (28% CDC)	Illness Attributions	Individual 6 hours Primary care	Strong
Deale et al. (1997) UK	RCT	<i>N</i> =60 CBT <i>M</i> =31 (<i>SD</i> =9) Relaxation <i>M</i> =38 (<i>SD</i> =11)	68%	CBT (Relaxation)	CDC	Open-ended questions	Individual 15 hours Hospital outpatients	Good
Goudsmit et al. (2009) UK	NRS	<i>N</i> = 44 treatment <i>M</i> =39.6 (<i>SD</i> = 13.4) Waitlist <i>M</i> =37.7 (<i>SD</i> = 14.4)	66%	Multi- component programme (Waitlist)	Oxford research criteria	Self- Efficacy Other Symptoms subscale	Individual Hospital outpatients	Fair
Heins et al. (2013) Netherlands	Cohort study	<i>N</i> = 183 <i>M</i> =38.2, (<i>SD</i> = 11.5)	75%	CBT	CDC	SES	Individual 12.9 sessions Specialist care	Good

Huibers et al. (2004) Netherlands	RCT	<i>N</i> = 151, CBT <i>M</i> =43.6 (<i>SD</i> =8.9) usual care <i>M</i> = 43.3 (<i>SD</i> = 7.7)	55%	CBT (Usual care)	35+ on the Dutch Checklist Individual Strength (44% CDC)	SES & CAL	Individual 3.5 hours Primary care	Strong
Jason et al. (2007) USA	Randomised trial	<i>N</i> = 178 <i>M</i> = 40.37 (<i>S.D</i> = 9.57)	83%	CBT (CT, ACT, Relaxation)	CDC	SES	Individual 9.75 hours Primary care	Strong
Kempke et al. (2010) Belgium	Experimental design	<i>N</i> = 114 <i>M</i> = 43.8	85%	Rehabilitation programme	CDC	SES & CAL	Group Monthly- 21 sessions, Weekly-52 sessions Tertiary care	Fair
Pinxsterhuis et al. (2017) Norway	RCT	<i>n</i> = 137 intervention-44.0 (11.8) control – 43.8 (11.6)	88%	Self-management programme (Usual care)	CDC	SES	Group 20 hours Hospital outpatients	Strong
Prins et al. (2001) Netherlands	RCT	<i>N</i> = 278 CBT <i>M</i> = 36.2 <i>SD</i> = 9.4 Guided support <i>M</i> = 37.1 <i>SD</i> = 10.6 Natural course <i>M</i> = 36.7 <i>SD</i> = (10.3)	76%	CBT (Guided support & natural support)	CDC	SES & CAL	Individual 16 hours Hospital outpatients	Good
Ridsale et al. (2004) UK	RCT	<i>N</i> = 163 CBT <i>M</i> = 40 <i>SD</i> = 12.3) GET <i>M</i> =40 <i>SD</i> = 10.8	68%	CBT (GET)	Chalder's case criteria for fatigue (29% CDC)	Illness Attributions	Individual 4.5 hours Primary care	Strong

Schreurs et al. (2011) Netherlands	Experimental design	<i>N</i> = 160 34.0 <i>M</i> =10.4	88%	Rehabilitation program	CDC	SES & CAL	Group 75 sessions Inpatient & Outpatient	Good
Sharpe et al. (1996) UK	RCT	<i>N</i> = 60 CBT <i>M</i> = 34 Medical treatment <i>M</i> = 38	68%	CBT (Medical care)	Oxford research criteria	Illness attributions	Individual 16 hours Secondary care	Good
Vos-Vromans et al. (2015) Netherlands	RCT	<i>N</i> = 122 MRT <i>M</i> = 40.0 <i>SD</i> = 10.2 CBT <i>M</i> = 40.6 <i>SD</i> = 12.0	80%	CBT (MRT)	CDC	SES & CAL	Individual 16 hours Rehab Centre	Strong

Note: Abbreviations. Non-randomised study (NRS), Randomised controlled trial (RCT), Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET), Multidisciplinary Rehabilitation Team (MRT), Cognitive Therapy (CT), Anaerobic activity (ACT), Centre for disease control (CDC) (Fukuda et al., 1994), Self-Efficacy Scale (SES) (Vercoulen et al., 1994)., Causal attribution list (CAL; Vercoulen et al., 1994). Chalder's case criteria for fatigue (Chalder et al., 1993), Oxford research criteria (Sharpe et al., 1996), Self-Efficacy Other Symptoms subscale (Lorig et al., 1989), Illness attributions (Wessely & Powell, 1989).

Description of participants

The total sample size for the included studies was 1877, the sample sizes ranged between 44-183 participants for non-RCTs and 60-278 participants for RCTs. A total of 1429 females were included in the papers, the percentage of female participants ranged between 55%-88% across studies. This is consistent with research showing more females are diagnosed with CFS than males (NICE, 2021). The studies were all conducted in high-income countries, including the Netherlands (6), United Kingdom (5), Belgium (1), Norway (1) and USA (1). Nine studies reported that all participants fulfilled the Centers for Disease Control and Prevention (CDC; Fukuda et al., 1994) diagnostic criteria for CFS. Two studies (Goudsmit et al., 2009; Sharpe et al., 1996) used the Oxford Research Criteria for CFS. Two studies (Ridsale et al., 2004; Chalder et al., 2003) used Chalder's Case Criteria for Fatigue (Chalder et al., 1993), with 29% and 28% of participants respectively, meeting CDC criteria. One RCT (Huibers et al., 2004) used a cut-off score of 35 or more on the Dutch Checklist Individual Strength (CIS; Vercoulen et al., 1999) with 44% of the participants meeting CDC criteria.

The smallest mean age reported in the studies was 31 years, the largest mean age was 44 years and the grand mean age of all participants in the studies was 39 years.

Description of Interventions

Twelve studies used CBT as an intervention, which involved exploring perpetuating cognitive factors and increasing activity. One RCT combined CBT with GET (Ridsale et al., 2004) and another study used a multi-rehabilitation approach which included CBT (Goudsmit et al., 2009). Of the two studies that did not use CBT, one RCT (Pinxsterhuis et al., 2017), used a self-management programme. A peer counsellor with a personal experience of CFS

facilitated this therapy with an occupational therapist. The therapy involved education, peer support, self-management skills and was based on a self-efficacy theory. Furthermore, Goudsmit et al. (2009) used a multi-component programme devised by Ho-Yen (1993).

Ten papers delivered individual and four delivered group psychological intervention. Ten papers mentioned the explicit use of a manualised approach to guide intervention. The total therapy time was not clearly stated for one paper where weekly multi-component intervention was compared to monthly; a total of 39 weekly sessions and a total of 21 monthly sessions were offered (Kempke et al., 2010). In another paper, CBT was delivered partly in a rehabilitation setting, whereby patients alternated between five days inpatient and nine days at home. The treatment took place over 25 weeks and included 75 therapy sessions; however, the duration of the sessions was unclear (Schreurs et al., 2011). There was an average of 12.9 sessions in the study by Heins et al. (2013). The average hours of therapy were not reported in the paper by Goudsmit et al. (2009). Of the papers which included average therapy hours, the average ranged from 2.5 hours – 24 hours.

Description of the comparative condition

Three studies did not include a comparator group. A variety of comparative conditions were used in the other 11 included papers, (e.g., relaxation, counselling, GET, usual care, waitlist, & medical care alone). One study (Jason et al., 2007) compared CBT to three intervention groups (Anaerobic activity [ACT], Relaxation & Cognitive therapy), another study compared a Multi-Rehabilitation Team approach with CBT against CBT alone. One paper split the participants into groups dependent upon the frequency of the multi-component treatment program, weekly or monthly (Kempke et al., 2010) and another study compared CBT to

guided- and natural support (Prins et al., 2001). Guided support involved non-directive, client centred mutual peer support and participants were free to have other examinations or treatments as were the participants in the control group.

Two studies (Goudsmit et al., 2009; Pinxsterhuis et al., 2017) made no comment on the conditions placed on the control group. The control groups in two studies (Bazelmans et al., 2005; Huibers et al., 2004) were free to access any support and in one study the medical care alone group received medical care, reassurance that they did not have a physical illness and guidance on their activity levels (Sharpe et al., 1996).

Description of outcome measures

All sense of control and attribution scores were obtained with the use of self-report measures. A range of different measures were used to determine attributions, six studies used the Causal Attribution List (CAL; Vercoulen et al., 1994). This questionnaire consisted of two subscales, somatic and psychological attributions, it had good reliability and validity (Vercoulen et al., 1996). Three studies measured ‘illness attributions’ using a scale created by Wessely and Powell (1989) whereby participants were asked to tick a statement related to whether their illness was either psychological, physical or a combination. One study (Chalder et al., 2003) asked participants an open-ended question “*what do you think caused your illness?*”. The responses were categorised as physical, psychological, or multifactorial.

Of the 10 papers that measured sense of control, nine used the Self-Efficacy Scale (SES) (Vercoulen et al., 1994). The SES consists of five items (e.g., “Whatever I do, I cannot change my complaints”). The SES has demonstrated good reliability and validity (Leganger

et al., 2000). One study, Goudsmit et al. (2009) used the modified version Self-Efficacy Other Symptoms Subscale (Lorig et al., 1989) where participants were asked to rate their confidence regarding their ability to control their illness on a scale ranging from 10 ('very uncertain') to 100 ('very certain').

Attributions pre/post psychological interventions

Ten of the 14 studies included in this review explored the impact of attributions, six made a comparison of pre- and post-attribution scores following psychological intervention.

Four studies reported a reduction of physical attributions following psychological intervention. Bazelmans et al. (2005) found that physical attributions reduced after group CBT but increased for participants in the waitlist group. There were no restrictions on participants in the waitlist group, they could independently access support. Sharpe et al. (1996) reported a significantly greater reduction of illness beliefs following individual CBT compared to participants in the medical care alone group, 33% in the CBT group and 7% of the medical care alone group experienced a reduction of physical attributions. Ridsale et al. (2004) reported that participants in primary care experienced a shift towards psychological attributions, following individual CBT, which focused on psychological perpetuating factors but participants who received GET, which focused on physical perpetuating factors did not. Vos-Vromans et al. (2015) compared MRT with CBT and found no significant changes in attributions pre- or post-intervention for either group and no significant between group differences. Psychological attributions increased in both conditions between baseline and 26 weeks, but this reduced at 52-week follow-up and was lower than at baseline for the CBT group. All four studies used different study designs and settings, however, they all used a manualised CBT approach tailored to CFS. The quality of the studies was 'fair', 'good' and

‘strong’, all studies did not appropriately control for confounds and Bazelmans et al. (2005) had an underpowered study.

Two RCTs reported no change in causal attributions following CBT intervention, relaxation (Deale et al., 1997) or treatment as usual (Huibers et al., 2004). Deale et al's. (1997) research was rated as ‘good’ quality and Huibers et al's. (2004) research was rated as ‘strong’ quality. The sample size in Deale et al's. (1997) was deemed inappropriate and the study was underpowered.

Therapy outcomes and causal attributions

Four papers (Deale et al., 1997, Prins et al., 2001, Vos-Vromans et al., 2015; Ridsale et al., 2004) found that attributions were not associated with therapeutic outcome.

Both Schreurs et al. (2011) and Kempke et al. (2010) reported that all cognitive-behavioural variables measured, except attributions, significantly related with individual strength at post-treatment. Kempke et al. (2010) research was rated as ‘fair’ quality and Schreurs et al. (2011) was rated as ‘good’ quality.

Bazelmans et al. (2005) found that for participants in tertiary care, physical attributions were diminished after group CBT but not in the waitlist condition, yet participants in the waitlist group reported a significant improvement in functional impairments and participants in the CBT group reported improvement in fatigue. Sharpe et al., (1996) found that for participants in secondary care, psychological attributions increased in the CBT group, and they reported reduced disability, post-therapy. This finding was maintained after the completion of therapy.

Chalder et al. (2003) found that holding psychological attributions at baseline led to reduced fatigue, depression, and GP visits, following psychological treatment, irrespective of whether psychological therapy received was CBT or counselling. This study was conducted in primary care whereby 28% of the sample met CDC criteria for CFS. In a univariate analysis holding physical illness attributions was associated with fatigue. In a multivariate analysis, holding illness attributions at baseline were associated with poor outcome and poor social adjustment at follow-up. Holding psychological attributions at the start of therapy led to better outcomes, although GP visits aren't an outcome detailed in Vercoulen's (1998) model, it could be that attending the GP less frequently is indirectly linked with an increase in functioning. In addition, the wider literature on depression (Beck & Lester, 1973) indicates a relationship with both fatigue and functional impairment, therefore, a reduction in depression scores could indirectly indicate a reduction in fatigue and functional impairment. This is contrary to Ridsale et al. (2004) who reported that holding psychological attributions did not lead to positive therapeutic outcomes for fatigue or functioning, the authors concluded that fatigue and functioning outcomes occur independently of cognitive change. Although they reported conflicting results, both Chalder et al. (2003) and Ridsale et al. (2004) were rated 'strong' quality, both studies performed and described random allocation, used a comparison group, and did not use blinding.

In a prospective study, 12 months after intervention, Huibers et al. (2004a) found higher psychological attributions and low somatisation at baseline were predictive of recovery from fatigue. However, this was only found for the participants who did not meet CFS caseness. This research was rated as 'strong' quality, the finding was in contrast to Ridsale et al. (2004) and in support of Chalder et al. (2003). However, Huiber et al. (2004) was the only study to use a control group, whereby one group received usual care.

Sense of control pre/post psychological intervention

Ten of the included studies explored the impact of sense of control following psychological intervention. Four studies (Heins et al., 2013, Kempke et al., 2010, Schreurs et al., 2011; Prins et al., 2001) did not report a pre/post measure of sense of control following psychological intervention.

Two papers (Bazelmans et al., 2005; Huibers et al., 2004) noted an increase in self-efficacy scores following CBT intervention but this was not significantly different when compared to the waitlist or treatment as usual groups. These studies had different methodological designs, were hosted in different settings, and involved different treatment durations. On the other hand Pinxsterhuis et al., (2017) found a significant difference in sense of control scores, in favour of the intervention group (self-management programme), at six-months, but this was not sustained at the one-year follow-up. However, the authors reported that this result primarily reflected a decline in self-efficacy in the usual care, control group. Both Huibers et al. (2004) and Pinxsterhuis et al., (2017) were rated strong quality, they both used randomisation and a control group.

Three studies all noted improvements in self-efficacy in both the intervention conditions (CBT, multi-component treatment & multidisciplinary rehab team) and comparator conditions (treatment as usual, waitlist, cognitive therapy, relaxation, ACT & MRT).

Goudsmit et al. (2009) noted significant differences in sense of control scores approximately six months after the start of CBT when compared to the waitlist group. However, any additional gains were minimal at six months follow-up. Vos-Vromans et al. (2015) found an

increase in sense of control scores at 12-month follow-up in both MRT and CBT but more so in the MRT condition. Jason et al. (2007) reported an increase in sense of control scores across all conditions (Cognitive therapy, CBT, Relaxation & ACT) with the greatest improvement observed in the relaxation group, which was maintained at the 12-month follow-up. However, the CBT and ACT groups had significantly higher scores on self-efficacy at baseline compared to the relaxation group.

Therapy outcomes and sense of control

Three studies did not find a relationship between sense of control scores and therapeutic outcomes. Pinxsterhuis et al. (2017) reported that although a sense of control increased following intervention this did not lead to a positive impact on functioning outcomes and fatigue scores reduced in the control group who received usual care. Huibers et al. (2004) did not find a difference in sense of control or in therapeutic outcomes (fatigue, clinical recovery & absences from work) between the groups. However, Huibers et al. (2004a) prospective study at 12-month follow-up, found a high self-efficacy and lower pain at baseline was associated with better fatigue outcomes, however this was only for individuals who met CFS-like caseness. Although absence from work was not an outcome detailed in Vercoulen et al.'s (1998) model, it could be that a reduced absence from work could indirectly indicate an increase in functional impairment. Bazelmans et al. (2005) also did not find a difference in sense of control scores and functional impairment but reported a moderate effect of fatigue following group CBT, however, this was independent of sense of control scores.

Jason et al. (2007) reported that participants with a significantly higher sense of control at baseline did not experience the greatest improvement in sense of control scores or the greatest therapeutic outcomes (physical functioning, fatigue, pain, anxiety & depression).

Participants who were in the relaxation group had significantly lower self-efficacy scores at baseline and experienced the highest increase in self-efficacy score. However, the participants in the relaxation group only experienced significant change in 12% of the therapeutic variables compared to 28% for participants in the cognitive therapy group. Although Huibers et al. (2004a) found a sense of control at baseline was associated with better fatigue outcomes Jason et al. (2007) did not, both studies were rated 'strong' quality, although Jason et al's. (2007) sample size was deemed inappropriate.

Two studies found that the group who experienced an increase in sense of control also experienced favourable therapeutic outcomes following psychological intervention. Goudsmit et al. (2009) found that the multi-component treatment group experienced significant improvement in fatigue and self-efficacy compared to a waitlist control. Vos-Vromans et al. (2015) reported that sense of control significantly increased following MRT compared with CBT intervention and the MRT group had significantly improved fatigue outcomes scores but there was no difference between group difference in quality-of-life scores. Although quality of life is not an outcome directly predicted by the model, it may be indirectly linked with the model as an improvement in functional impairment could lead to an improvement in quality of life. There was a difference in the quality of these studies with Goudsmit et al. (2009) rated as 'good' and Vos-Vromans et al. (2015) rated as 'strong' quality.

Four studies found an interaction effect between sense of control and therapeutic outcomes following psychological intervention. Prins et al. (2001) reported that an improvement in fatigue severity at eight months was predicted by interactions of CBT with sense of control and by a passive activity pattern, rather than by CBT alone. In the CBT group, patients with a

greater sense of control at baseline had a larger decrease in fatigue severity at eight months, immediately after CBT, than patients with lower sense of control. In addition, Heins et al. (2013) found an increase in sense of control over fatigue, perceived activity, self-reported physical functioning, and decreases in focusing on symptoms explained 20% to 46% of the variance in fatigue.

Furthermore, Schreurs et al. (2011) found that individual strength at post-treatment was predicted by sense of control over symptoms at follow-up and a clinically significant improvement in subjective fatigue was predicted by a higher sense of control over symptoms.

Both Schreurs et al. (2011) and Kempke et al. (2010) reported that all cognitive-behavioural variables measured (sense of control, depression, somatic focus, physical activity & physical impairment) apart from attributions, significantly related with individual strength at post-treatment. However, correlations were small, Kempke et al. reported that these factors explained approximately 5% of variance in post-treatment fatigue and depression was the only factor uniquely associated with post-treatment fatigue. These studies were rated as 'fair' and 'good' quality.

Discussion

The literature pertaining to the impact of sense of control and attributions on therapeutic outcomes following psychological interventions for individuals (aged 16 years & over) with CFS was reviewed. This discussion will consider the key findings, theoretical implications, clinical implications, and methodological issues to support understanding. The review aimed to explore whether cognitive factors (attributions and sense of control) in Vercoulen et al.'s

(1998) model were associated with therapeutic outcomes following psychological intervention.

Impact on attributions

A reduction of illness beliefs (Sharpe et al., 1996) occurred in the medical care alone group. These participants received reassurance and advice on activity levels and therefore, psychological intervention tailored towards cognitive/behavioural factors may not be required to impact on illness beliefs.

In one study physical attributions increased in the waitlist group, despite no restriction on accessing support. This could suggest that being placed on the waitlist and independently searching/navigating support systems could increase physical attributions which could impact on therapeutic outcomes (Bazelmans et al., 2005).

Contradictory findings were reported as to whether the focus of therapy (psychological or behavioural) impacted on attributions and whether attributions held at baseline were important for therapeutic outcomes (Ridsale et al., 2004; Chalder et al., 2003). It could be that causal attributions could become part of a wider illness narrative and that when the intervention is broadly psychological the narrative includes more psychological attributions compared to when there might be no intervention.

Significant differences in attributions were not observed between CBT (16 hours) and MRT (44.5 hours) (Vos-Vromans et al., 2015) therefore, this does not provide support for the need

for intensive multi-disciplinary treatment. In addition, neither therapy led to long-term change in attributions.

Two RCTs reported no change in causal attributions following CBT intervention, or the comparator, relaxation (Deale et al., 1997), treatment as usual (Huibers et al., 2004). Both studies used a manualised approach with therapy. Deale et al. focused on attempting to increase activity and reduce rest time as part of the CBT intervention and Huibers et al. focused on adapting rest and activity in line with the impact of fatigue.

Causal attributions impact on outcomes

Causal attributions were associated with therapeutic outcomes for help-seeking participants who accessed support in primary care with less severity (Chalder et al., 2003). However, this was not a conclusive finding as Ridsale et al. (2004), reported that therapeutic outcome occurred independent of cognitive changes. Both Ridsale et al. and Chalder et al., (2003) conducted research in primary care using the same diagnostic criteria with a similar number of participants meeting CDC criteria and short-term individual CBT as an intervention.

Both Schreurs et al. (2011) and Kempke et al. (2010) reported that attributions were the only cognitive-behavioural variable not related to therapeutic outcomes. Therefore, this could suggest that attributions are not a principal factor in outcomes for participants in tertiary care, where there is a higher severity of symptomology. Both studies were conducted in tertiary care and used a high number of sessions in a group format.

Impact on sense of control

Inexperienced therapist delivered CBT in two studies (Huibers et al., 2004; Bazelmans et al., 2005) that did not find a significant difference in sense of control between CBT and treatment as usual. Therefore, it could be that experienced therapists are required to deliver CBT to improve self-efficacy scores, or the interaction with a caring clinician alone, in the treatment as usual group could have impacted on this score. In addition, this finding could have been confounded by participants in the control groups being able to access any support they wished. Thirty-one percent of the control group in Huibers et al. received psychosocial co-intervention (treatment by a psychiatrist, a psychologist &/or medication).

It could be that psychological therapy does not need to explicitly target perpetuating factors such as sense of control as Jason et al. (2007) found improvements in self-efficacy across all interventions. The relaxation group had significantly lower self-efficacy at baseline which could explain the greatest increase in self-efficacy scores. This study did not lend support to the idea that high self-efficacy at baseline leads to better therapeutic outcomes and nor did it lend support for the idea that an increase in self-efficacy scores leads to better therapeutic outcomes.

Interestingly, the significant difference in self-efficacy scores between the self-management group and treatment as usual group was found to primarily reflect the reduction of self-efficacy in the treatment as usual group (Pinxsterhuis et al., 2017). This could suggest that ‘treatment as usual’ is detrimental to a patients’ self-efficacy and could negatively impact on treatment outcomes. It could be that a self-management programme for patients attending hospital outpatients may not be effective in increasing self-efficacy scores.

Sense of control impact on outcomes

Huibers et al. (2004) and Bazelmans et al. (2001) found a high self-efficacy at baseline was associated with improved fatigue outcomes, only for participants who met CFS-like casesness. This could suggest that individuals with more severe CFS symptoms and a higher self-efficacy at baseline could experience better therapeutic outcomes than those who have lower self-efficacy at baseline or who do not meet CFS diagnostic criteria. Both studies had inexperienced therapists deliver the CBT intervention, therefore, it could be that levels of self-efficacy at baseline are more important for therapeutic outcomes than the experience of the therapists delivering the treatment.

Heins et al. (2013) concluded that levels of fatigue over the course of CBT intervention were related to a change in cognitive factors such as the sense of control over fatigue. The included sample met CDC criteria for CFS and received treatment in an hospital outpatient setting. The authors reported three quarters of participants experienced fatigue severely after 18 weeks of therapy, with fatigue normalising after this point. Therefore, highlighting the need for long-term therapy for CFS. The authors suggested that a decrease in fatigue could have allowed participants to increase their activity levels which in turn could have increased their sense of control over fatigue. However, a causal relationship could not be observed in this correlational study and the authors considered the relationship between sense of control and therapeutic outcomes as more complex than a cause-and-effect relationship. Rather it was suggested that this relationship could be reciprocal and form a complex feedback process.

Kempke et al. (2010) and Schreurs et al. (2011) used a multidisciplinary rehabilitation programme approach, which included CBT, for participants who met CDC criteria, and used

the same measures. However, inconclusive results were found for depression, it was the most important cognitive behavioural factor for therapeutic outcomes in Kempke et al. (2010) but not, Schreurs et al. (2011). Although, the authors suggested that the time in which the depression measure was completed could have confounded this as participants may have been concerned that reporting depression could exclude them from participating.

Therapeutic outcomes, sense of control and attributions

Of the six papers that measured both attributions and sense of control, three (Prins et al., 2001; Kempke et al., 2010; Schreurs et al., 2011) found that sense of control was associated with therapeutic outcomes, but attributions were not. All three studies were conducted in tertiary care, used the same measures, the same diagnostic criteria, CDC (Fukuda et al., 1994) diagnostic criteria for CFS and provided long-term treatment.

Commentary on the model

The studies included in this review did not provide consistent evidence supportive of Vercoulen. Et al.'s (1998) model that attributions and sense of control impact on therapeutic outcome. Several studies concluded that cognitive behavioural factors may be less important at determining therapeutic outcomes than previously thought. A relationship between psychological therapy and self-efficacy was primarily demonstrated in tertiary care, however, one study found that depression was the most important factor (Kempke et al., 2010). Song and Jason's (2005) research advocated that Vercoulen et al.'s (1998) model applies to participants with psychiatric conditions but not for participants with CFS or participants with medical causes of CFS. Therefore, the authors concluded that CFS could not be explained purely by psychogenic factors. In addition, Vercoulen et al. (1998) did not reference whether

the sample the model was based on met CDC criteria (Fukuda et al., 1994) criteria, therefore how well this model could be applied to our understanding of CFS is questionable.

Measurement of attributions

One standardised measure for causal attributions was not used across all papers included in this review. It could be that the open-ended question Chalder et al. (2003) asked was accessing the cause of CFS rather than the perpetuation, this could have confounded the results and could explain why Chalder et al. found a relationship with therapeutic outcomes and other studies did not. Most studies used a measure created by Vercoulen to assess Vercoulen et al.'s model and therefore, it can be assumed that these tools were able to measure the constructs reported in the model.

Clinical implications

Caution should be adopted when applying Vercoulen et al.'s (1998) model to clinical practice. Instead of choosing a therapy based on cognitive or behavioural perpetuating factors such as attribution/sense of control, it may be more important to choose a therapy based on the individual formulation. It could be that depression impacts on CFS symptomology however, this was not conclusively reported, therefore, more research is required to understand this further.

It could be that treatment as usual or being placed on a waiting list is not good enough support and support offered in a timely manner could help therapeutic outcomes. Levels of fatigue did not normalise until after 18 weeks of therapy for individual's meeting CDC criteria in an hospital outpatient setting (Heins et al., 2013), therefore, long term treatment may be beneficial for individuals with a diagnosis of CFS. One study Pinxsterhuis et al.,

(2017) used a self-management programme whereby patients have access to a peer with similar experiences, although favourable outcomes were reported this was concluded to be a reflection of a deterioration of scores for individuals on the waitlist, therefore, it may be beneficial to have further research exploring the effectiveness of this therapy.

It could be that newly qualified therapists could deliver CBT intervention for clients who have a high self-efficacy score at baseline.

Finally, the relationship between causal attributions, sense of control and therapeutic outcomes may not be a simple cause-and-effect relationship. Instead, it could be part of a complex reciprocal feedback process. For example, changes in cognitions could lead to a reduction in fatigue which in turn could lead to further changes in cognitions.

Limitations

A meta-analysis was not considered appropriate because initial scoping searches revealed the heterogeneity in study methodology. A narrative synthesis approach was instead used, however, because of the heterogeneity of the studies, strong conclusions were not able to be drawn based on this synthesis. In addition, how far this review can go in guiding clinical implications is limited and a new theory/model has not been identified.

The included studies made use of different outcome measures, different methodological designs, different diagnostic tools, reported only subjective measures and some studies did not include a control group whereas others did. Therefore, patterns and trends were hard to comment on. In addition, three studies were rated as 'fair' quality, with five studies deemed to not have an adequate sample size. Therefore, this highlights the need for a higher quality

of research to be conducted in this area. Any conclusions reported in these studies should be critically evaluated before being used to shape clinical practice.

Conclusions and future research

This review did not find conclusive evidence of a relationship between the cognitive factors, sense of control and causal attributions and outcomes following psychological therapy for CFS. However, owing to the variation in both the methodologies and quality of the included studies, it is difficult to draw firm conclusions. There was more support for sense of control on therapeutic outcomes, however, sense of control as well as other cognitive/behavioural factors. In addition, the nature/presentation of CFS is so heterogenous amongst sufferers that it may be more beneficial to consider individualised models for CFS. Therefore, future research may need to consider a personalised network model to help define symptom presentation of CFS considering the full range of biopsychosocial factors that could be perpetuating CFS in the person, to help identify suitable interventions.

References

- Bazelmans, E., Prins, J., Lulofs, R., Van der Meer, J., & Bleijenberg, G. (2005). Cognitive Behaviour Group Therapy for Chronic Fatigue Syndrome: A Non-Randomised Waiting List Controlled Study. *Psychotherapy and Psychosomatics*, 74(4), 218–224.
- Beck, A. T. (1964). Thinking and Depression. *Archives of General Psychiatry*, 10(6), 561–571.
- Beck, A. T., & Lester, D. (1973). Components of depression in attempted suicides. *The Journal of Psychology*, 85(2), 257-260.
- Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D., & Wallace, E. P. (1993). Development of a fatigue scale. *Journal of Psychosomatic Research*, 37(2), 147–153.
- Chalder, T., Godfrey, E., Ridsdale, L., King, M., & Wessely, S. (2003). Predictors of outcome in a fatigued population in primary care following a randomized controlled trial. *Psychological Medicine*, 33(2), 283–287.
- Deale, A., Chalder, T., & Wessely, S. (1998). Illness beliefs and treatment outcome in chronic fatigue syndrome. *Journal of Psychosomatic Research*, 45(1), 77-83.
- Dickson, A., Knussen, C., & Flowers, P. (2007). Stigma and the delegitimation experience: An interpretative phenomenological analysis of people living with chronic fatigue syndrome. *Psychology & Health*, 22(7), 851–867.
- Fukuda, K. (1994). The Chronic Fatigue Syndrome: A Comprehensive Approach to Its Definition and Study. *Annals of Internal Medicine*, 121(12), 953.
- Goudsmit, E. M., Ho-Yen, D. O., & Dancy, C. P. (2009). Learning to cope with chronic illness. Efficacy of a multi-component treatment for people with chronic fatigue syndrome. *Patient Education and Counseling*, 77(2), 231–236.
- Heins, M. J., Knoop, H., Burk, W. J., & Bleijenberg, G. (2013). The process of cognitive behaviour therapy for chronic fatigue syndrome: Which changes in perpetuating cognitions and behaviour are related to a reduction in fatigue? *Journal of Psychosomatic Research*, 75(3), 235–241.
- Ho-Yen, D. O. (1993). *Better Recovery from Viral Illnesses*.
- Huibers, M. J. H., Bleijenberg, G., Van Amelsvoort, L. G. P. M., Beurskens, A. J. H. M., van Schayck, C. P., Bazelmans, E., & Knottnerus, J. A. (2004a). Predictors of outcome in fatigued employees on sick leave. *Journal of Psychosomatic Research*, 57(5), 443–449.

- Huibers, M. J. H., Beurskens, A. J. H. M., Van Schayck, C. P., Bazelmans, E., Metsemakers, J. F. M., Knottnerus, J. A., & Bleijenberg, G. (2004). Efficacy of cognitive-behavioural therapy by general practitioners for unexplained fatigue among employees. *British Journal of Psychiatry*, *184*(3), 240–246.
- Icenogle, G., Steinberg, L., Duell, N., Chein, J., Chang, L., Chaudhary, N., Di Giunta, L., Dodge, K. A., Fanti, K. A., Lansford, J. E., Oburu, P., Pastorelli, C., Skinner, A. T., Sorbring, E., Tapanya, S., Uribe Tirado, L. M., Alampay, L. P., Al-Hassan, S. M., Takash, H. M. S., & Bacchini, D. (2019). Adolescents’ cognitive capacity reaches adult levels prior to their psychosocial maturity: Evidence for a “maturity gap” in a multinational, cross-sectional sample. *Law and Human Behavior*, *43*(1), 69–85.
- Jason, L. A., Torres-Harding, S., Friedberg, F., Corradi, K., Njoku, M. G., Donalek, J., Reynolds, N., Brown, M., Weitner, B. B., Rademaker, A., & Papernik, M. (2007). Non-pharmacologic Interventions for CFS: A Randomized Trial. *Journal of Clinical Psychology in Medical Settings*, *14*(4), 275–296.
- Kempke, S., Goossens, L., Luyten, P., Bekaert, P., Van Houdenhove, B., & Van Wambeke, P. (2010). Predictors of outcome in a multi-component treatment program for chronic fatigue syndrome. *Journal of Affective Disorders*, *126*(1-2), 174–179.
- Kmet, L. M., Cook, L. S., & Lee, R. C. (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields.
- Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. *Arthritis & Rheumatism*, *32*(1), 37–44.
- Luyten, P., Van Houdenhove, B., Pae, C.U., Kempke, S., & Van Wambeke, P. (2008). Treatment of Chronic Fatigue Syndrome: Findings, Principles and Strategies. *Psychiatry Investigation*, *5*(4), 209.
- National Institute for Health and Care Excellence. (2006). NICE guideline (CG53). Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management Clinical guideline Published: 22 August 2007.
- National Institute for Health and Care Excellence. (2021). NICE guideline [NG206]. Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management. Published: 29 October 2021. Available online at: <https://www.nice.org.uk/guidance/ng206>

- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *International journal of surgery*, 88, 105906.
- Prins, J. B., Bleijenberg, G., Bazelmans, E., Elving, L. D., de Boo, T. M., Severens, J. L., van der Wilt, G. J., Spinhoven, P., & Van der Meer, J. W. (2001). Cognitive behaviour therapy for chronic fatigue syndrome: a multicentre randomised controlled trial. *The Lancet*, 357(9259), 841–847.
- Pinxsterhuis, I., Sandvik, L., Strand, E. B., Bautz-Holter, E., & Sveen, U. (2016). Effectiveness of a group-based self-management program for people with chronic fatigue syndrome: a randomized controlled trial. *Clinical Rehabilitation*, 31(1), 93–103.
- Pendergrast, T., Brown, A., Sunnquist, M., Jantke, R., Newton, J. L., Strand, E. B., & Jason, L. A. (2016). Housebound versus nonhousebound patients with myalgic encephalomyelitis and chronic fatigue syndrome. *Chronic Illness*, 12(4), 292–307.
- Ridsdale, L., Darbishire, L., & Seed, P. T. (2004). Is graded exercise better than cognitive behaviour therapy for fatigue? A UK randomized trial in primary care. *Psychological Medicine*, 34(1), 37–49.
- Rimes, K. A., Ashcroft, J., Bryan, L., & Chalder, T. (2016). Emotional suppression in chronic fatigue syndrome: Experimental study. *Health Psychology*, 35(9), 979–986.
- Schreurs, K. M. G., Veehof, M. M., Passade, L., & Vollenbroek-Hutten, M. M. R. (2011). Cognitive behavioural treatment for chronic fatigue syndrome in a rehabilitation setting: Effectiveness and predictors of outcome. *Behaviour Research and Therapy*, 49(12), 908–913.
- Sharpe, M., Hawton, K., Simkin, S., Surawy, C., Hackmann, A., Klimes, I., Peto, T., Warrell, D., & Seagroatt, V. (1996). Cognitive behaviour therapy for the chronic fatigue syndrome: a randomised controlled trial. *BMJ*, 312(7022),
- Song, S., & Jason, L. A. (2005). A population-based study of chronic fatigue syndrome (CFS) experienced in differing patient groups: An effort to replicate Vercoulen et al's model of CFS. *Journal of Mental Health*, 14(3), 277–289.
- Speight, N. (2013). Myalgic encephalomyelitis/chronic fatigue syndrome: Review of history, clinical features, and controversies. *Saudi Journal of Medicine and Medical Sciences*, 1(1), 11.

- Surawy, C., Hackmann, A., Hawton, K., et al. (1995). Chronic fatigue syndrome: A cognitive approach. *Behaviour Research and Therapy* 33: 535–544.
- Timmer, B., Bleichhardt, G., & Rief, W. (2006). Importance of Psychotherapy motivation in patients with somatization syndrome. *Psychotherapy Research*, 16(3), 348–356.
- Van Houdenhove, B. van, & Luyten, P. (2008). Customizing Treatment of Chronic Fatigue Syndrome and Fibromyalgia: The Role of Perpetuating Factors. *Psychosomatics*, 49(6), 470–477.
- Vercoulen, J. H. M. M., Swanink, C. M. A., Fennis, J. F. M., Galama, J. M. D., Van der Meer, J. W. M., & Bleijenberg, G. (1994). Dimensional assessment of chronic fatigue syndrome. *Journal of Psychosomatic Research*, 38(5), 383–392.
- Vercoulen, J. H. M. M. (1996). The Measurement of Fatigue in Patients With Multiple Sclerosis. *Archives of Neurology*, 53(7), 642.
- Vercoulen, J. H. M. M., Swanink, C. M. A., Galama, J. M. D., Fennis, J. F. M., Jongen, P. J. H., Hommes, O. R., Van der Meer, J. W. M., & Bleijenberg, G. (1998). The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis. *Journal of Psychosomatic Research*, 45(6), 507–517.
- Vercoulen, JHMM, Alberts, M., & Bleijenberg, G. (1999). The Individual Tension Checklist (CIS). *Behavioral Therapy*, 32 (131), 6.
- Vink, M., & Vink-Niese, A. (2019). Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective. Re-analysis of a Cochrane review. *Health psychology open*, 6(1).
- Wessely, S., & Powell, R. (1989). Fatigue syndromes: a comparison of chronic “postviral” fatigue with neuromuscular and affective disorders. *Journal of Neurology, Neurosurgery & Psychiatry*, 52(8), 940–948.
- Vos-Vromans, D. C. W. M., Smeets, R. J. E. M., Huijnen, I. P. J., Köke, A. J. A., Hitters, W. M. G. C., Rijnders, L. J. M., Pont, M., Winkens, B., & Knottnerus, J. A. (2015). Multidisciplinary rehabilitation treatment versus cognitive behavioural therapy for patients with chronic fatigue syndrome: a randomized controlled trial. *Journal of Internal Medicine*, 279(3), 268–282.
- White, K., Lehman, D. R., Hemphill, K. J., Mandel, D. R., & Lehman, A. M. (2006). Causal Attributions, Perceived Control, and Psychological Adjustment: A Study of Chronic Fatigue Syndrome¹. *Journal of Applied Social Psychology*, 36(1), 75–99.

Service Improvement Project

Improving support for donor recipients on communicating with donors and/or donor families.

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(See Appendix A).

Abstract

Background: The process of an organ recipient writing to a donor/donor family is supported by NHS Blood and Transplant (NHSBT, n.d). **Objectives:** This service improvement project aimed to understand the barriers and facilitators faced by professionals when supporting recipients to think about writing this letter, at the Oxford Transplant Centre (OTC). **Method:** Eight post-transplant professionals (five nurses & three consultants) attended individual interviews and four pre-transplant nurses attended a focus group. Two Likert-scale questions were asked which explored importance and confidence in supporting recipients with letter writing. **Results:** Reflexive Thematic Analysis was employed to analyse the data. Five themes were identified in the focus group, with six sub-themes, and six themes were identified in the interviews, with 10 sub-themes. These themes shed light on some of the barriers (information overload) and facilitators (empathetic understanding) to talking with recipients about letter writing. **Conclusions:** Recommendations were drawn from these themes, which included increasing recipient awareness of the possibility of letter writing (e.g., by displaying a poster in the waiting room/ward).

Key words: Transplantation, Writing Letters, 'Thank you', Donor, Recipient,

Correspondence.

Introduction

Between 1st April 2021- 31st March 2022, 3415 organ transplant surgeries took place in the UK (NHSBT, 2022). Following surgery, transplant recipients (hereafter referred to as ‘recipients’) are informed about contacting the living ‘unknown’ donor and/or family of deceased organ donors (hereafter referred to as ‘donor/donor family’, respectively), through an anonymous letter (The World Health Organisation [WHO], 2010). It was found that 90% of donor families wished to receive correspondence from a recipient (National Health Service Blood & Transfusion; NHSBT, 2015) and some recipients reported a desire to express gratitude post-transplant (Orr et al., 2007).

Benefits of letter writing for recipients and donor/donor families

Some evidence exists of the benefits for recipients and donor/donor families when contact is made. For example, donor families can feel stress and frustration due to not knowing the fate of the transplanted organs and experience disrespect and anger towards the recipient (Holtkamp, 2002). It was thought that if a donor/donor family have a positive experience of organ donation in the face of a highly distressing situation, they may vocalise their positive experience to others, which could lead others to consider organ donation (Stamp, 2019).

Writing to a donor/ donor family was noted for some recipients to support the process of accepting the donated organ (Siminoff & Chillag, 1999), reduced feelings of unworthiness and guilt, and lead to the empowerment of recipients (Colarusso, 2006; Coolican et al., 1997; Fox & Swazey, 1992; Azuri, 2012). Additionally, Scheel et al. (2019) found that recipients who reported less guilt had higher quality of life scores. Hence, it could be hypothesised that

writing to a donor/donor family could lead to better psychological wellbeing (reduced feelings of guilt and increased worthiness).

Current NHS practice

There are no local or national policies or guidelines in place for healthcare professionals in supporting recipients with writing to a donor/donor family. This could partly be explained by the emotional nature of writing this letter, as some recipients, reported that it was the hardest letter to write (Selves, 2011). Stamp (2019) found that recipients were being advised to wait 6-12 months after transplant to write to their donor/donor family, despite this not being informed by evidence and despite some recipients expressing a wish to write within the first three months post-transplant. This could reflect the need for research and guidelines to inform best practice. However, recipients should not feel pressured to write to the donor/donor family, instead the clinician's role is to support the recipient in-line with their choice (Azuri, 2012).

Initiatives such as 'how to' videos, information leaflets and changes to processes (e.g., a dedicated inbox for correspondence) have been produced by NHSBT to promote and support letter writing (NHSBT, 2015). The current project is an improvement initiative within a particular service, exploring the process of supporting recipients to think about letter writing.

Decision Making Theory

The Dual Processing Model (Mukherjee, 2010) postulates that there are two cognitive processes (System 1 and System 2) that impact on decision making. System 1 processes allow for decision making that is fast, intuitive, and experiential and system 2 processes allow for decision making that is slow, logical, and analytical. However, Sloman (1996)

reported that these two systems interact and can occur simultaneously. Therefore, the decision to talk to a recipient about writing to the donor/donor family could be based on experience, affect, or logic and a clinician may alternate between and draw upon all these factors when making this decision.

The Oxford Transplant Centre (OTC)

The OTC is a national centre, performing transplant surgeries, including kidney and pancreas. Pre-transplant clinicians provide care and information in an initial appointment and in an annual review prior to the transplantation and the post-transplant clinicians provide care and information immediately after surgery and in regular reviews.

Clinicians in both the pre-and post-transplant teams experience being part of the process of matching organs. They sometimes see the donor and hear circumstances of the donor's death. Clinicians also call recipients to let them know that an organ is available for them.

Clinicians in the two teams, pre-transplant and post-transplant have different roles and levels of involvement when speaking to transplant recipients about writing to their donor/donor family. The post-transplant clinicians currently speak to recipients and share NHSBT literature with recipients, however, pre-transplant clinicians do not.

Anecdotally, it is reported that low numbers of letters are sent both nationally and within the OTC. Currently recipients are handed a booklet on letter writing after their transplant. There is no consistent practice or guideline in place, with regards to when and how conversations with recipients about letter writing should take place. There is a strong sense within the clinical team that letters are a good thing, and they want to develop a service where all

recipients are provided with the information and opportunity to decide whether they want to write or not and support if they wish to do so. Thus, an exploration of current practice and barriers to supporting letter writing could be used to develop recommendations and thus help clinicians to support recipients with this process.

Summary

Writing to a donor/donor family can be psychologically and emotionally challenging. No local or national policies exist on how, when or where clinicians can support recipients with letter writing. Considering the potential psychological benefits of letter writing for patients outlined above, it was thought useful to explore the current processes, professional's confidence, and the clinician's role in information giving/facilitating conversations about letter writing. It is hoped that the information obtained can inform the development of a local policy and support clinician confidence.

Aim

This service improvement project aimed to explore the current practice of supporting patients with the letter writing process and to gain an understanding of facilitators and barriers with regards to this.

Methods

Oxford University Hospital Trust Research and Development Department categorised this project as a service evaluation and Oxford University Hospital, Renal and Transplant Clinical Governance Committee approval was obtained (Appendix E).

Participants

Clinicians within the pre-and post-transplant teams at the OTC were recruited using purposive sampling. Participants were initially informed about the project by the third author (LH). They were then contacted by the first author (RB), who provided further study information (Appendix F), took informed consent (Appendix G), and arranged an online interview, or an in-person focus group. The first author had no prior relationship with the participants.

Eight clinicians working within the post-transplant teams (three consultants & five nurses) and four pre-transplant nurses participated in this study. See Table 1 for mean years of experience in their current role and within transplant altogether.

Procedure

Transplant nurses and consultants in both the pre-and post-transplant teams were invited to take part in this study through email correspondence whereby the study poster was disseminated. Post-transplant clinicians were invited to attend 1:1 interviews and pre-transplant clinicians were invited to attend a focus group. All participants were provided with an information sheet and clinicians taking part in the interviews gave written informed consent. Participants were verbally asked the same four quantitative questions prior to the qualitative questions, and participants in the focus group wrote down their answers. One question explored the number of years' experience in their current role, and another explored total number of years' experience in transplant altogether. In addition, two Likert-scale questions were asked, relating to confidence and whether talking to a recipient formed an important part of their job role. With '1' being not at all important/ confident and '5' being

extremely important/ confident. It is planned for the clinicians to re-rate the Likert questions three months after the recommendations are implemented, to facilitate a comparison.

Interview schedule

The semi-structured interview schedule (Appendix H), including the order and content of the questions were discussed in two online meetings with an expert by experience. The final schedule was co-created with the first author (RB) and the expert by experience, with support and guidance from the co-authors. Both the focus group and interviews had the same nine questions and interview schedule, which focused on the current practice of speaking with recipients about writing to donors, the barriers, and the processes in place to support this.

A 40 minute, in-person, focus group was conducted in May 2022, with pre-transplant clinicians and eight individual online interviews were conducted with post-transplant clinicians. All interviews were audio-recorded and transcribed verbatim. Interviews ranged from 18 to 28 minutes ($M = 22.5$, $SD = 3.21$). Focus groups were conducted with the pre-transplant team as they currently are not involved in the process of talking to recipients about writing a letter. Therefore, a focus group would allow for a rich discussion to develop.

Data analysis

Data analysis began once the last interview had taken place. The qualitative data were analysed using the Braun and Clarke method of Thematic Analysis (Braun & Clarke, 2006). An essentialist/realist epistemological orientation was employed when analysing the data because the author wanted the experiences and meanings to be accessed and reflected upon. The frequency in which a theme was noted will not be documented in the report, in line with

Braun and Clarke (2019) who advocated that values do not equate to importance. During transcription, all identifiable information was removed, and participants were assigned numbers. The author ensured familiarity with the transcripts by listening to them or reading them a minimum of three times each. The author engaged in line-by-line coding; these codes were either semantic or inductive and they were drawn together to create preliminary themes. Coding was done systematically in an iterative and cyclical way. Data was managed and stored securely using Microsoft Word and Excel.

Results

Quantitative results

Table 1.

Mean and Range of Duration of Employment in Current Role and Within the Transplant Field Altogether.

	Pre-transplant (Range)	Post-transplant (Range)
Time in current role	5 years (9 months-- 11 years)	11 Ears (1-- 30 years)
Time in transplant	5 years (9 months-- 11 years)	18 years (4-- 30 years)

Results of the Likert scale prior to the dissemination of the recommendations are detailed in Table 2.

Table 2.

Mean Confidence and Importance Scores Prior to the Dissemination of Recommendations.

	Confidence	Importance
<i>Post- transplant</i>	4	3
<i>Pre-transplant</i>	3	4

The mean scores on the view that holding the conversation is an important part of the job role was three in the post-transplant team and four for the pre-transplant team. In the post-transplant team, there were two scores of ‘one’; both clinicians stated that this would be a ‘five’ if a recipient raised the conversation first.

Qualitative results

There were six themes from the interview data that described barriers/facilitators to decision making/holding these conversations: (1) The need for an individualised approach, (2) Multidisciplinary team roles and responses (3) Emotional heaviness (4) Structure and processes (5) Marked time points and, (6) Resources. Five themes from the focus group were identified (1) The need for an individualised approach (2) Pre-transplant team views on their roles and responsibilities (3) Empathetic understanding guides decision making (4) Information overload (5) Resources. See table 3 for this overview. Themes and sub-themes, together with exemplary quotes, are outlined in Table 4 and 5.

Table 3.*Summary of the Themes and Sub-Themes.*

Post-transplant		Pre transplant	
Theme	Sub-theme	Theme	Sub-theme
1)The need for an individualised approach.	1) Individual choice and motivation to write. 2) Difference and demographics. 3) Health status 4) Professional's approach to individuality	1)The need for an individualised approach.	1)Individual choice and motivation to write. 2)Individual ways of coping with the high emotion.
2)Multidisciplinary team roles and responsibilities.		2)Pre-transplant team views on their roles and responsibilities.	3)Facilitating the conversation did not feel part of the job role. 4)Reactive approach to raising the conversation. 5)Consideration of the timing of their involvement on the recipient's transplant timeline.
3) Emotional heaviness.	5) Empathetic understanding guides decision making. 6) Emotional impact on recipients. 7) Emotional impact on staff.	3) Empathetic understanding.	
4) Structure and processes. 5) Marked time points.		4) Information overload. 5) Resources.	6)What is already done in place to facilitate the conversation.
6) Resources.	8) Time constraints and information overload. 9) What is already done in place to facilitate the conversation. 10) Support that would help to facilitate the conversation.		

Table 4.*Barrier/Facilitator Themes and Sub-themes Identified from the Interviews.*

Theme	Sub-theme	Example
The need for an individualised approach	Individual choice and motivation to write	“...some people don’t want to write... some patients get great satisfaction from writing”. “...it’s very much their own personal choice”
	Difference and demographics	“...communication barrier you know erh some patients especially if they’re not English speaking I don’t think they understand it well”. “...some would be really worried about it and are not health literate enough to write themselves”. “...very middle-class thing to do to write a thank you letter”
	Health status	“...they are not recovering well post-transplant I don’t feel in myself I don’t feel right to add another you know to discuss something like that”. “Sometimes I hold back if they’re not done too well”. “If they’re really struggling and they’re quite unwell, that’s not appropriate to raise something like that”
Multidisciplinary team roles and responses	Professional’s approach to individuality	“...developed a connection with us so we are erm a big part of the process to be able to discuss it with them”. “When I get to speak to the recipient... I try to erm gauge their interest in it”. “...it’s not something that you need to rush whenever you feel ready...”
		“...it’s important part of anybody who sees transplant recipient post-transplant and who are involved in their care”. “Making the wider MDT aware would probably be quite a good thing”. “We should be better at it”

Theme	Sub-theme	Example
Emotional heaviness	Empathetic understanding guides decision making	<p>“Appreciating that it’s very difficult thing for them to talk about and also making sure that there’s enough time”.</p> <p>“There’s no immediate pressure but we do know that the donor families really appreciate it, and it helps them to have a sense of closure”.</p> <p>“Some people are uncomfortable with writing and because they think it’s going to be difficult for the donor families to read...”</p>
	Emotional impact on recipients	<p>“Some of them you know will cry and they feel really sorry for the... for the loved one... for the donors loved one”.</p> <p>“...just the thought of having somebody else’s body part inside you has got a lot of psychological effect”.</p> <p>“...they have this sort of a guilt feeling that somebody else has just died for them erm yeah so it’s not an easy conversation”</p>
	Emotional impact on staff	<p>“It feels uncomfortable it doesn’t feel morally right but if they express a wish themselves to write then I will encourage them”.</p> <p>“...scary feeling about anything that relates directly to death almost like a like its bad luck or something to talk about it like you might summon it if you talk about it too much”.</p> <p>“I guess there’s psychological emotional barriers from the clinician side of things”</p>
Structure and processes		<p>“We really need to have a conversation or maybe something in writing when to, when and how to approach a recipient about it”.</p> <p>“...staff on the ground who are working with the patient will be the best ones to decide”.</p> <p>“...for certain things guidelines are most unhelpful”</p>

Theme	Sub-theme	Example
Marked time points		<p>“...I want to plant the seed quite early so that if it’s mentioned later in clinic or something it doesn’t seem so odd”.</p> <p>“...not their year anniversary or ’m not doing the education on the ward...then sometimes I do forget”.</p> <p>“...transplant community generally don’t think that’s the sensible period of which to send it”</p>
	Resources	
	Time constraints and information overload	<p>“Making sure that there’s enough time when you start the conversation”.</p> <p>“Really pressured clinic and you’ve got you know 10 patients to see in 20 minutes slots you can’t spend 20 minutes talking to somebody about you know what they need to do about donor letter writing”.</p> <p>“You don’t want to tell people something that ’they’re going to forget immediately erm because it’s not their priority”</p>
	What is already in place to facilitate the conversation.	<p>“Patients have the leaflets to let them know what is and ‘isn’t suitable for writing about”</p> <p>“...NHSBT website they have some videos”.</p> <p>“...Facebook group for post- transplant patients”</p>
	Support that would help to facilitate the conversation.	<p>“Make staff more aware”.</p> <p>“Re-education for everyone involved”.</p> <p>“Maybe having up posters or something that catches the eye”</p>

Post-transplant Interview Themes

1. The need for an individualised approach (“Some people don’t want to write; some patients get great satisfaction from writing”)

Individual Choice and Motivation to Write

Variations in motivation to write were noted. Some recipients requested to write to the donor family and gained satisfaction from writing, but others did not. The importance of personal choice and being mindful of the assumption that everyone wants to write was highlighted.

Difference and Demographics

Recipients represent a heterogeneous group of people, the requirement for an organ transplant could happen to anybody regardless of age, gender, ethnicity, or socio-economic status. An individualised approach, considerate of demographic differences was deemed important. Demographic differences were thought to impact on a person’s motivation, ability to access and understand the conversation and their responses. Letter writing was considered a middle-class task which could alienate recipients of a lower socio-economic status. In addition, a certain degree of health literacy and reflection was thought necessary, this was a barrier to holding this conversation with recipients who had English as a second language or with low educational attainment.

Health status

The health status, medical history and transplant trajectory of recipients was noted to impact on whether the conversations were raised, and the responses given. Clinicians reflected that some recipients experience complexities following organ transplantation, e.g., a delayed graft

function, and some felt like life had not changed or expressed regret regarding their transplant decision. Clinicians stated that this acted as a barrier to holding the conversation as it felt like they were adding to the distress. This did not feel like a priority for the recipient at this point and did not seem right for the donor to receive a letter informing them of the difficulties experienced. However, it was noted that the correspondence to the donor/donor family could be a 'simple' 'thank-you' rather than a reflective letter. The purpose of holding the conversation appeared unclear for some clinicians, viewing it as a request to write. Finally, although clinicians felt more inclined to raise the conversation if the recipient was recovering well, they did not take for granted the emotionality of the conversation or that the recipient would engage with the conversation.

Professional's approach to individuality

An individualised person-centred approach in supporting recipients was described, clinical judgement and rapport was used to guide decision making on whether it was the appropriate time to raise the conversation. If the recipient posed a question about their donor or implied that they had been thinking about their donor, this was used as a way for clinicians to initiate the conversation about writing to a donor/donor family. Some clinicians reported a reactive approach to holding the conversation, choosing not to raise the conversation until the recipient did.

Although a good therapeutic rapport was felt to facilitate the conversation for several clinicians, a contrary opinion was expressed whereby a good therapeutic rapport did not encourage the clinician to initiate the conversation. It was felt that the conversation could be perceived as requesting the recipient shows and feels gratitude. Therefore, the purpose of the conversation was viewed as a request to write, rather than an opportunity to create awareness.

2. Multidisciplinary team roles and responses (“Making the wider MDT aware would probably be quite a good thing”)

Not all clinicians initiated the conversation of writing to a donor/donor family with a recipient, however, the view that all clinicians involved in the care of a recipient *should* raise this conversation was commonly reported. Transplant nurses reported initiating and facilitating these conversations more frequently as part of their job role, consultants less so. This was thought to reflect several factors including training backgrounds, time, views on their job role and perceived approachability for psychological support.

A role for psychology was reported in supporting clinicians to manage the emotional heaviness of facilitating the conversation and supporting the formation of best practice.

- 3) Emotional heaviness (“I just tell them that well it’s not something that you need to rush, whenever you feel ready”)

Empathetic understanding guides decision making

An empathetic understanding towards recipients and donors was perceived as helpful in facilitating the conversation of writing to a donor/donor family. Clinicians used several statements that communicated empathy and reflected upon their own personal circumstances and perspectives. Clinicians who had worked with donors/donor families reported using that experience to help facilitate the conversation. However, that experience could also be a

barrier to holding the conversation if recipients appeared to take their organ for granted (e.g., not following medical advice).

Several clinicians reflected on their positive feelings of hearing of correspondence being sent back and forth between the recipient and donor/donor family and seeing a relationship develop. Holding these in mind appeared to support some clinicians to facilitate this conversation.

However, this empathetic understanding made knowing more about the donor than they could share, feel unfair and unequal, as the clinician felt like they were asking for something from the recipient and were not able to provide the information requested.

Emotional impact on staff

Some clinicians noted that raising the conversation drew attention to the fact that someone had died and evoked a general uncomfortableness with talking about death. The emotional responses of the recipients were sometimes experienced as difficult by clinicians who also had other time pressures. Furthermore, one clinician questioned the ethics and morality as the conversation felt like a request for gratitude.

In addition, the reported current process whereby recipients do not receive confirmation that their letter has been received felt unsatisfactory to clinicians and was a barrier to facilitating these conversations. Clinicians reported that this was difficult, felt unfair and confirmation of receipt would help with facilitating the conversation.

Emotional impact on recipients

The emotional heaviness of engaging in the conversation about writing to a donor/donor family was reflected on by some clinicians. It was noted that the nature of the conversation drew attention to the death of the donor. Some recipients expressed sadness, guilt and felt conflicted that their best day arose from someone else's loss. The high emotional intensity and individual coping styles made raising the conversation difficult. For example, if a recipient coped by avoidance and denial, then raising the conversation was likely to lead to distress.

4) Structure and processes (“We really need to have a conversation or maybe something in writing...when to, when and how to approach a recipient about it”)

No current guidelines support clinicians to facilitate the conversation of writing to a donor/donor family. There were differing views on the usefulness of guidelines. The emotional complexity surrounding the conversation was thought by some to be helped by structure and guidelines. However, other clinicians felt that some form of structure would be beneficial, it was felt that rigid guidelines would not be, and any guidelines should be informed by the clinicians themselves. The importance of having the right structure was identified; it was felt that some structure could be helpful but when inflexibly applied or if applied from a top-down approach, it could feel unhelpful.

For some clinicians, talking with colleagues and using previous experience was thought to be useful in guiding decisions as to whether/when to raise the conversation. One clinician felt that the interview was helpful in providing a space for reflection on their current practice and decision making.

5) Marked time points (“...want to plant the seed quite early so that I’ it's mentioned later in clinic or something it doesn’t seem so odd”)

Clinicians emphasised the importance of raising the conversation as early as they possibly could. Marked time points (e.g., on the ward, during education prior to discharge, in the regular check-ins & at the year anniversary) were thought to help reduce the likelihood of forgetting and help to facilitate the conversation. It was noted that recipients tended to mark and remember their donor at the one-year anniversary. A few clinicians referred to a recommendation not to write straight after transplantation, however, this is contrary to NHSBT literature, which advocates that it is never too soon/late to write to the donor/donor family.

6) Resources

Time constraints and information overload

There was not always enough time to dedicate to holding the conversations. Some recipients, due to the emotional nature of the conversation and coping styles, require time to discuss the process and support the psychological wellbeing of the recipient. This was made difficult with the number of recipients attending clinics and the time constraints faced.

Reference was made to all the other priorities and information needed to be given to recipients in their reviews and prior to discharge. Some clinicians noted that they would sometimes forget to hold the conversation with recipients because of time constraints.

What is already in place to facilitate the conversation.

The NHSBT website was referenced frequently as a useful resource, where clinicians accessed research and videos. An NHSBT information leaflet on writing to a donor/donor family is given to recipients prior to discharge and was felt to be a helpful resource in facilitating a conversation. In addition, a current Facebook page for recipients was thought to be a good resource to share information and testimonies on writing to a donor/donor family.

Support that would help to facilitate the conversation.

Emphasis was placed on having a visual display in the waiting room and on the wards; this was felt to be a helpful visual prompt for the recipients but also for staff members. However, this required careful consideration on wording and accessibility. Seminars were thought to be a useful platform to discuss topics important for recipients and it was felt that this format would lend itself well to talking about writing to a donor/donor family.

Table 5.*Barrier/Facilitator Themes and Sub-themes Identified from the Focus Group.*

Theme	Sub-theme	Example
The need for an individualised approach	Individual choice and motivation to write.	<p>“...it depends on the patient”.</p> <p>“...some seem much more open to it in which case you...you feel instinctively you can broach it with them”.</p> <p>“...just when it happens it happens whereas you get others who researched and researched and researched and then they would love to look all the links and all the posts or whatever, but a lot of patients don’t in my experience”</p>
	Individual ways of coping with the high emotion.	<p>“People are terrified with everything you’re telling them”.</p> <p>“There’s probably a lot of fear, anxiety and erm awkwardness”.</p> <p>“...patients that we see are largely psychologically not ready to hear how to write a letter”</p>
Pre-transplant team views on their roles and responsibilities	Facilitating the conversation did not feel part of the job role.	<p>“It's not something I think about”.</p> <p>“...not a major part of job role”</p> <p>“I don’t think really as a tea’ we've ever thought that we need to up it”</p>
	Reactive approach to raising the conversation.	<p>“...not something we proactively raise”.</p> <p>“Certainly, if they ask about it, we can go absolutely about that and then we place great importance on it”.</p> <p>“I think if a patient mentions it then we look into it for them, but we don’t routinely talk about it”</p>
	Consideration of the timing of their involvement on the recipient’s transplant timeline	<p>“You could argue that it’s probably not the most appropriate time to raise it erm which is probably why we don’t instinctively in a way as well”.</p> <p>“We tend to thin’ it's better point in the timeline for them to have the basics explained to them”</p>

Empathetic understanding
guides decision making

“I think if it were me, it would mean a lot to me to know what would have happened”

“...what was the best day of your life turned out to be the worst day for them and they just don't know how to put that on paper”

“I think about the donor family quite often I feel like if the recipients are happy to do it then that would give the donor family a sense of what happened”

Information overload

“...they have two hours of information giving and receiving and so it's such an overload for them it is one of the things that sort of falls to the bottom of the list because it's not a present issue”.

“...it's such an overwhelming amount of information”.

“...we're overloading them with a lot of things that they have to be aware of when they have the transplant”

Resources

What is already in place to facilitate the conversation

“There's written information that we could give out, but it tends to be something that the post-transplant team do”.

“I think NHSBT have done like a video about this”.

“... humanised real-life perspective which I'm sure that's why people appreciate”.

“...that's something that we don't point people towards as such.... but we could I guess”

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Pre-transplant Focus Group Themes

1. The need for an individualised approach (“...it depends on the patient”)

Individual Choice and Motivation to Write.

The individualised ways of coping and responding to the preparation for transplant was reflected upon. Clinicians stated that some recipients appear avoidant whereas others appear motivated to read and learn as much as possible. Therefore, some recipients would be less likely to take information in than others, clinical judgement was used to consider what information would be helpful at what time and for whom.

Individual Ways of Coping with the High Emotion

Clinicians reflected on how some recipients seem more curious and open about thinking/talking about the donor than others. It was felt that some recipients were not psychologically ready to have these conversations, they experienced emotions like; terror, fear, anxiety, and awkwardness and raising the conversation draws their attention to the fact that a person would have died.

2. Pre-transplant team views on their roles and responsibilities (“...not a major part of job role”)

Facilitating the conversation did not feel part of the job role.

Holding the conversation with a recipient about writing to the donor/donor family was not viewed as part of the pre-transplant team job role. The different roles of the pre- and post-

transplant teams were highlighted, and the conversation was thought to be better placed with the post-transplant team.

Reactive approach to raising the conversation.

Clinicians felt able and confident to initiate the conversation and thought it was important, however, a reactive approach was reported. Therefore, this reactive approach did not appear to be associated with a difficulty with confidence in how to navigate the discussion nor a view that it's not important, rather that it was not common practice in pre-transplant.

Consideration of the timing of their involvement on the recipient's transplant timeline.

The clinician's involvement with the recipient at the time of their transplant trajectory was a barrier to holding these conversations. It felt like an inappropriate time to raise the conversation as there are a lot of other 'basics' that need to be covered, therefore, it could be that recipients forget information. The pre-transplant clinicians expressed an interest in learning from post-transplant clinicians on their processes/resources used when facilitating the conversations.

However, it was noted that some recipients spend several years under the care of the pre-transplant team and so it may be that this conversation could be held in their annual review rather than in their initial appointment.

Similarly to the clinicians in the post-transplant team, clinicians reported being informed that recipients should not be encouraged to write immediately after transplantation. It was felt that one year after the transplant was a more appropriate time as it was felt that this was when a recipient would be most likely to raise it.

3. Empathetic understanding guides decision making (“I think about the donor family quite often”)

Clinicians were aware of the research regarding the positive impact behind receiving a letter for the donor family and this awareness was considered helpful to facilitate a conversation with recipients about letter writing. Reflections were made on what the clinician would like if they were in the recipient’s or donor/donor family’s position. However, they reflected on the difficult task of writing to someone about something positive that had come from the death of their loved one. Therefore, empathetic understanding could impact on how and when this conversation is held.

4. Information overload (“...it’s such an overload for them... it is one of the things that sort of falls to the bottom of the list”)

A recipient meets with pre-transplant clinicians for two hours prior to transplantation. This time felt very precious and involved the recipient receiving important information that they would need to understand and remember in order to consent for the transplant. Recipients could feel overwhelmed by the amount of information given and letter writing did not fall within the ‘core’ information. In addition, because of the likelihood of information overload, a conversation with recipients further into their transplant journey, one year on, felt like a more suitable time as the recipient would have had time to take on board and process the information.

5. Resources

What is already in place to facilitate the conversation

The NHSBT website and leaflet was thought to be helpful to signpost recipients to. Although aware of these resources, pre-transplant clinicians reported their infrequent use. Seminars were reported as helpful spaces to hold these conversations and it was felt that recipients who had written to a donor/donor family could be invited to share their experiences.

Discussion

The views of eight post-transplant and four pre-transplant clinicians were captured using interviews and a focus group to gain an understanding of the barriers and facilitators to holding a conversation with recipients about writing to the donor/donor family.

Most of the post-transplant clinicians reported holding these conversations frequently. Pre-transplant clinicians reported an awareness but did not initiate these conversations. Some themes were similar across both pre-and post-transplant teams. Overall, most clinicians reported favourable attitudes to speaking to recipients about writing but stated that it should be acknowledged that this is a personal choice. Of key importance when making the decision to raise the conversation for the post-transplant team appeared to be individual factors such as the health status of the recipient. If a recipient was experiencing complications post-transplant it was felt that initiating the conversation would contribute to the distress. For both teams it was noted that the emotional heaviness of the conversation appeared an important factor especially if a recipient had an avoidant coping style. A key factor that was noted by the pre-transplant clinicians related to their involvement with the recipient at the initial stages of their transplant trajectory. Pre-transplant did not seem like the right time to raise the conversation given a recipient could wait for a transplant for several years.

It appeared that the purpose of the conversation may feel unclear to some clinicians, and this impacted on the clinicians' approach. Phrases used by some clinicians were recalled within the interviews and some appeared apologetic (e.g., "would you mind"). Therefore, it may be helpful for a reflective meeting, to explore this and reflect on the purpose of the conversation. A summary of recommendations is documented in Table 5.

We can understand the themes in relation to the Dual Processing Theory. System 1 processing, whereby decision making was impacted by previous clinical experience, was demonstrated when clinicians reported using time points to raise the conversation. However, sometimes these decisions were based on System 2 processing: using logic and reflection, for example, considering the patient's health status and current emotional coping as to whether to hold the conversation.

Like the findings of Stamp (2019), several clinicians in both teams reported hearing the recommendation apparently not grounded in research, for recipients not to write immediately after transplantation.

Mean confidence scores for the post-transplant team before the implementation of recommendations was 'four', compared to 'three' for the pre-transplant team. This could be reflective of the post-transplant team holding these conversations more frequently than colleagues in the pre-transplant team.

Clinical recommendations

The themes of this study have led to the identification of recommendations for service improvements that can support staff to feel more confident with speaking to recipients about writing to the donor/donor family.

Table 6*Clinical Recommendations.*

Category	Recommendation
Information and resources	<p data-bbox="450 451 2011 635">Visual displays directed at recipients would support awareness and may encourage the recipient to ask the clinician about letter writing. This could also act as a prompt to remind clinicians to hold the conversation. Hearing from other recipients and donors/donor families may support recipients who experience guilt/worry about writing to the donors/donor families.</p> <p data-bbox="450 675 2011 778">A bright, colourful poster on the wall of the waiting room and ward. This would be created by the team and provide information on writing to a donor/donor family and signpost to NHSBT. It could also include testimony of recipients and donors/donor families.</p> <p data-bbox="450 818 2011 922">Use Facebook to signpost/create awareness of the opportunity to write to a donor/donor family and to share the NHSBT information video on letter writing.</p> <p data-bbox="450 962 2011 986">Lay summary of this study to be disseminated with clinicians, which could be shared in discussions with recipients. (See Appendix I)</p> <p data-bbox="450 1026 2011 1129">Automatic message in the footer of clinic letters with information on writing to the donor/donor family, to create awareness, provide information and signpost to NHSBT.</p> <p data-bbox="450 1169 2011 1273">Post-transplant clinicians to continue to use the NHSBT leaflets to help facilitate the conversation and pre-transplant clinicians to use the NHSBT leaflet.</p>

Category	Recommendation
	<p>For those recipients wanting more information, a seminar on writing to a donor could be hosted, a recipient who has written a letter could be invited to share their experience.</p> <p>The use of webinars and social media would allow recipients to access the information outside of their clinic times.</p> <p>Recipients could hear from others and their experiences of the process of writing the letter.</p>
Structure and processes	<p>The development of local guidelines should be done in consultation with clinicians. Consultation processes are important to ensure the whole team is behind the approach. This would allow for roles and responsibilities of clinicians in initiating this conversation to be clear which is hoped to support with confidence. The guidelines will need to consider the themes identified in this study including: the emotional intensity, individuality, and information overload. Guidelines would refer to the aim of holding the conversation, when, where, how the conversation is raised and by whom as well as signposting to resources e.g., NHSBT.</p> <p>Suggestions for suitable time points for post-transplant recipients were prior to discharge, in regular reviews and in an annual review.</p> <p>However, ways of preventing patients being asked multiple times should be embedded in the service processes. This could be mitigated by recording on the patient record when the conversation has been held with the recipient and the outcome. This was suggested to ensure that the conversation is raised with everyone at least once, and to emphasise to the patient that it's their individual choice rather than feeling pressure to write by being asked by multiple clinicians.</p> <p>The team can identify a named 'champion', who will disseminate the latest resources to clinicians, ensure posters and leaflets are available, and to review how the recommendations are being implemented and how they are working.</p>

Category	Recommendation
<p>Managing emotional impact for staff and patients</p>	<p>An annual reflective group can be held, led by the team psychologist, which can be a space for clinicians to reflect on the possible challenges with the process of supporting patients to think about letter writing, including the emotional impact of this for staff and patients. It will be emphasised that the team ethos is to support patients to think about writing (not telling them they ‘should’) and creating opportunities for patients to writing this, if this is what they choose. This reflective space would help clinicians to talk about and think through some of the difficulties such as holding more information about the donor than they’re allowed to share.</p> <p>Training should form part of the reflective session, to include the dissemination of research.</p> <p>The clinicians who reported it felt unequal for recipients to write a letter but not receive confirmation of receipt stated this made it harder to have this conversation and it would be easier if recipients were informed of the outcome. This requires some thought with the wider system. At the OTC, therefore, clinicians could be supported to reflect on the feelings that arise within themselves and the recipients as a response to this process.</p>

Strengths and Limitations

This study has provided an insight into clinician confidence, their views on the importance of supporting recipients to write to their donors, and on current practice. In addition, this study has led to the identification of several barriers and facilitators of supporting patients and the identification of several recommendations derived directly from the clinician's experiences.

A good cross-section of the teams was included in this study, nearly all transplant nurses participated. This study provided a helpful space for reflection on an area that was clearly a need owing to such little guidance and research available.

The use of individual interviews and a focus group allowed for an in-depth and complex understanding on beliefs and experience, which would not have been possible with other methods such as surveys.

The development of this study was guided by an expert by experience. However, the voices of recipients and donors/donor families were not captured in this study. Therefore, this data could be further enriched by capturing these views. It would be useful to hear from recipients about what would be helpful in facilitating this process.

Conclusions

Holding an awareness of several barriers and facilitators for clinicians doing this type of work has helped with the development of clinical recommendations. It is hoped that these recommendations can support clinician's decision making and confidence when working with recipients.

References

- Azuri, P., & Tabak, N. (2012). The transplant team's role with regard to establishing contact between an organ recipient and the family of a cadaver organ donor. *Journal of clinical nursing*, 21(5-6), 888-896.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Braun, V., & Clarke, V. (2019). Answers to frequently asked questions about thematic analysis. The University of Auckland.
- Colarusso, C. (2006). Giving back to donor families: The "thank you letter" package insert project. *Progress in Transplantation*, 16(1), 82-86.
- Coolican, M., Politoski, G., & Casey, K. (1997). Programs for families of organ and tissue donors. *EDTNA-ERCA Journal* 32, 5–8.
- Fox, R. C., & Swazey, J. P. (1993). Spare Parts: Organ Replacement in American Society. *Contemporary Sociology*, 22(5), 749.
- Holtkamp, S. (2002). Trauma-driven grief and the organ donor family. Sue H. *Wrapped in mourning: the gift of life and organ donor family trauma*, 75-100.
- Mukherjee, K. (2010). A dual system model of preferences under risk. *Psychological Review*, 117(1), 243–255.
- NHS Blood and Transplant. (2015). Taking organ transplantation to 2020. A detailed strategy.
- NHS Blood and Transplant. (2022). Statistics about organ donation. <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/statistics-about-organ-donation>.

NHS Blood and Transplant. (n.d.). *Writing to a donor family or recipient*.

<https://www.nhsbt.nhs.uk/organ-transplantation/resources/writing-to-a-donor-family-or-recipient>.

Orr, A., Willis, S., Holmes, M., Britton, P., & Orr, D. (2007). Living with a kidney transplant: a qualitative investigation of quality of life. *Journal of health psychology*, 12(4), 653-662.

Scheel, J., Schieber, K., Reber, S., Jank, S., Eckardt, K. U., Grundmann, F., & Erim, Y. (2019). Psychological processing of a kidney transplantation, perceived quality of life, and immunosuppressant medication adherence. *Patient preference and adherence*, 13, 775.

Selves, L., & Burroughs, A. K. (2011). Letters from transplant recipients to the family of their donors are a positive experience for both and can help donation. *American Journal of Transplantation*, 11(9), 1994-1995.

Siminoff, L. A., & Chillag, K. (1999). The fallacy of the “gift of life”. *Hastings Center Report*, 29(6), 34-41.

Slovic, S. A. (1996). The empirical case for two systems of reasoning. *Psychological bulletin*, 119(1), 3.

Stamp, L. (2019). Encouraging organ transplant recipients to say thank you to their donor’s family. *Journal of Kidney Care*, 4(1), 32-33.

World Health Organisation. (2010). *Transplantation of human cells, tissues and organs*.
<https://www.who.int/transplantation/en>.

Theoretically Driven Research Paper

Title: Coping with trauma when caring -secondary traumatic stress in foster carers

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Journal: Journal of Adoption and Fostering (Appendix J).

Rationale: A UK journal focused on adoption and fostering. It publishes articles from psychologists, as well as social workers. It is run by a renowned fostering and adoption charity, CoramBAAF.

Abstract

Background: Caregiver resources could mediate against the development of Secondary Traumatic Stress (STS) in foster carers, according to a conceptual model (Whitt-Woosley et al., 2020). The relationship between coping styles (emotion-focused, problem-focused, and avoidant; Carver et al., 1997) and STS has yet to be researched in UK foster carers. **Aims:** To explore the relationship between STS and coping styles whilst controlling for anxiety and depression and to explore group differences in the use of the individual facets on the Brief COPE. **Design:** A cross-sectional, between subjects design. **Method:** Data was collected from 132 foster carers at one time point using online self-report questionnaires. Two groups were formed, 'high' and 'low' STS based on the clinical cut-off score of '38' on the Secondary Traumatic Stress Scale (Bride et al., 2004). **Results:** Analysis of Covariance (ANCOVA) found that foster carers who reported high STS also reported significantly greater use of problem-focused and avoidant coping styles, with the greatest effect size in problem-focused coping. Exploratory analysis identified 'behavioural disengagement', 'substance use', and 'denial' were significantly different between the two groups. **Discussion:** The majority of the sample reported high STS. The greater use of the coping facets in the high STS group suggest that STS could be impacting on the effectiveness of coping responses. Greater awareness and screening for STS could allow for early intervention focused on secondary trauma which could support the effectiveness of the coping strategies employed. Future research should explore this relationship further and the efficacy of a trauma-based intervention.

Key words: Secondary Traumatic Stress, Coping styles, Foster Carers.

Introduction

Social care context

In England, in 2022, 82,170 children were in care and 70% of these children resided in foster care. There's a requirement for 9,300 more foster homes in the UK, against a backdrop of an annual 13% attrition of foster carers (The Fostering Network, 2022).

Sixty-two percent of fostered children in the UK in 2016/2017 reported prior experience of neglect or abuse (Department for Education, 2017). Experiences of abuse (emotional, physical, sexual) and neglect, in infancy and early childhood could have detrimental consequences on child development and personality (Cicchetti, 2016) and could cause a condition of psychological vulnerability, known as developmental trauma. Developmental trauma could impact on affect regulation in stressful situations (Schimmenti & Caretti, 2010) and an ability to mentalise, which is used for emotion and behaviour regulation (Fonagy et al., 2002). Furthermore, developmental trauma impacts on an individual's sense of agency and self-esteem and therefore, increases the vulnerability for the development of mental health difficulties (Schimmenti, 2012). Children in care were found to be 12 times more likely to experience Post-Traumatic Stress Disorder (PTSD) than their peers (McGuire et al., 2022). High rates of mental health difficulties and behaviours that challenge, were reported factors which impact on placement stability (Hannah & Woolgar, 2018). Secondary Traumatic Stress is under researched in the foster carer population but prolonged exposure to primary/secondary trauma is thought to reduce a foster carers' ability to cope with life stressors and may lead to foster carers leaving the profession (Bridger et al., 2019).

Secondary Traumatic Stress in foster carers

Secondary traumatic stress is a stress response resulting from knowledge about a traumatic event experienced by a significant other (Figley, 1999). Exposure to the traumatising event experienced by another becomes the traumatising event, it is considered a syndrome of symptoms similar to PTSD (intrusion, avoidance & arousal) (Figley, 1999). Secondary Traumatic Stress refers to one of many possible adverse consequences following exposure to indirect trauma. Research has found that social workers exposed to the trauma details of the individuals under their care, present with symptoms of STS which could meet the threshold for PTSD (Bride, 2007). The term ‘compassion fatigue’ is used synonymously with STS in research and in one study, high compassion fatigue in foster carers was related to lower intent to continue fostering and lower job satisfaction (Hannah & Woolgar, 2018). In this study 25.2% of 131 participants were considered high risk for secondary trauma and 19.8% fell above the clinical cut-off. Models of STS could support understanding of both vulnerability and protective factors to developing STS in the foster carer population.

A Model of Secondary Traumatic Stress in Foster Carers

Carew (2016) reported that understanding the STS experiences of foster carers is important for recruitment, support, training, and retention. Whitt-Woosley et al. (2020) created a conceptual model to help explore factors that may serve to increase or reduce the likelihood of the development of STS in a foster carer population (Figure 1). The model considered; direct risks for the development of STS (e.g., dose of exposure); direct beneficial factors against the development of STS (e.g., caregiver support); and amplifiers of these risk and beneficial factors. It is important to explore and fully understand the nature of the beneficial and amplifying factors that mitigate against STS. Broader literature on managing adversity opens up the more extensively explored concept of coping styles. Although not explicitly

referenced in the STS model, these could be considered a possible direct beneficial factor/amplifier of STS. The model suggests resources (emotional/practical) protect against the development of STS; therefore, it is hypothesised that coping styles (emotion-focused/problem-focused/avoidance) could be associated with STS.

Figure 1.

Model of Secondary Traumatic Stress.

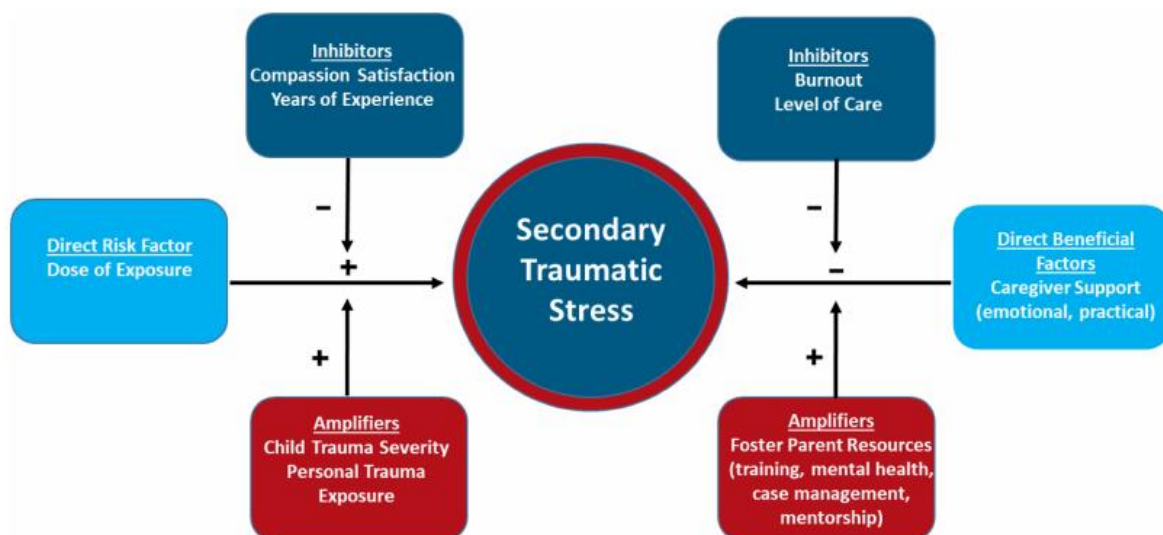


Fig. 1. Conceptual Model.

Psychological coping

Coping styles and resources can influence a person’s psychological and physical reactions to stressful situations and influence outcomes (Shikai et al., 2007). These could either be cognitive or behavioural attempts to modify the impact of the stressful event on an individual’s external and/or internal world (Carver & Connor-Smith, 2010).

Lazarus and Folkman's (1984) Transactional Stress Model, categorised coping as either problem-focused or emotion-focused, meaning that coping was either orientated toward the problem, or on emotional/physiological responses, respectively. A third coping style, 'avoidant', was later added to refer to an individual's attempt to ignore/ avoid the stressor and its emotional consequence (Carver et al., 1989).

The Brief COPE (Carver et al., 1989) has 3 coping subscales and 14 facets which fall under one of the subscales (Table 1). Mong et al. (2012) reported a negative correlation between active coping, (e.g., Positive reframing/ planning) and PTSD related symptoms. All items that fall under problem-focused coping are considered 'approach' strategies, whereas emotion-focused strategies are categorised as 'approach', or 'avoidant'. Problem-focused coping was found to be more effective than emotion-focused and avoidance in reducing the impact of everyday life stressors (Ben-Zur, 2009) and was negatively associated with PTSD symptoms (Vernon et al., 2009). Emotion-focused coping, particularly avoidant coping, (such as denial or self-distraction) was associated with the development of post-traumatic stress (Schnider et al., 2007) and worse overall mental health outcomes (Coyne & Racioppo, 2000). In addition, avoidant coping was found to increase the risk of PTSD (Gil & Caspi, 2006). Carver (1997) reported a relationship between the use of avoidant coping strategies and dysfunctional coping.

Table 1.
Active coping

Problem-focused		Emotion-focused		Avoidant
(Approach)'2) I've been concentrating my efforts on doing something about the situation I'm in.'7) I've been taking action to try to make the situation better	Emotional support (Approach)'5) I've been getting emotional support from others. '5) I've been getting comfort and understanding from someone.	Self-distraction (Avoidant'	1)I've been turning to work or other activities to take my mind off things. '9) I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	
Use of informational support (Approach)	10) I've been getting help and advice from other people. 23) I've been trying to get advice or help from other people about what to do.	Venting (Avoidant)'9) I've been saying things to let my unpleasant feelings escape. '1) I've been expressing my negative feelings.	Denial (Avoidant)'3) I've been saying to myself "this' isn't'real"'8) I've been refusing to believe that it has happened.	
Positive reframing (Approach)	'2) I've been trying to see it in a different light, to make it seem more positive. '7) I've been looking for something good in what is happening	Humour (*neither)	'8) I've been making jokes about it. '8) I've been making fun of the situation.	Substance use (Avoidant)'4) I've been using alcohol or other drugs to make myself feel better. '1) I've been using alcohol or other drugs to help me get through it.
Planning (Approach)	'4) I've been trying to come up with a strategy about what to do. '5) I've been thinking hard about what steps to take.	Acceptance (Approach)	'0) I've been accepting the reality of the fact that it has happened. '4) I've been learning to live with it.	Behavioural disengagement (Avoidant)'6) I've been giving up trying to deal with it. '6) I've been giving up the attempt to cope.
		Religion (*neither)	'2) I've been trying to find comfort in my religion or spiritual beliefs. 2') I've been praying or meditating.	
		Self- blame (Avoidant)	13) I've been criticizing myself. 26) I've been blaming myself for things that happened	

Facets of the Brief COPE

Secondary Traumatic Stress and coping styles

There's an absence of literature on the relationship between coping styles and STS in a foster carer population. A study conducted in America found problem-focused coping strategies significantly predicted levels of coping efficacy in foster carers (Coleman, 2019). In a sample of social workers, emotion-focused coping and avoidance coping were associated positively with higher reported rates of STS symptoms (Gil & Weinberg, 2015). This finding was replicated in another study which found emotion-based coping was correlated with STS symptoms in direct care staff working with individuals with PTSD (Stapleton et al., 2017). Furthermore, an avoidance of trauma related thoughts and memories was reported to be key to the development of secondary trauma (Figley, 1995).

Anxiety/depression

Research has found that STS exists alongside anxiety and depression. In research on emergency staff, rates of STS, anxiety and depression were found to be high, and they were related to low job satisfaction and low intent to continue in their role (İlhan, 2022). In another study on nurses, those who reported STS displayed more symptoms of anxiety, depression, and higher job strain (Bock, 2020). Given these findings it would be important to control for anxiety and depression when exploring the relationship between coping and STS.

Summary

There is an increased demand for foster carer placements each year, along with a high rate of attrition from the profession. High STS has been linked to high anxiety, depression, and poor job satisfaction. STS could impact on foster carer wellbeing which could have negative implications on placement stability (Hannah & Woolgar, 2018). Whitt-Woolsey's (2020) STS

model has identified factors that mitigate against the development of STS, such as caregiver support. This study will further explore the link between coping styles (emotion-focused, problem-focused, and avoidant) and STS. The facets that contribute towards these three coping styles will be explored to ascertain their relationship with levels of STS. Clinically, any findings could be used to inform tailored support and training to foster carers.

Research questions:

Question 1: Will there be group differences in the reported use of avoidant coping strategies when controlling for anxiety and depression?

Hypothesis 1: Foster carers who report high STS will use more avoidant coping strategies than foster carers who report low STS when anxiety and depression are controlled.

Question 2: Will there be group differences in the reported use of problem-focused coping strategies when controlling for anxiety and depression?

Hypothesis 2: Foster carers who report high STS will use less problem-focused coping strategies than foster carers who report low STS when anxiety and depression are controlled.

Question 3: Will there be group differences in the reported use of emotion-focused coping strategies when controlling for anxiety and depression?

Hypothesis 3: Foster carers who report high STS will use more emotion-focused coping strategies than foster carers who report low STS when anxiety and depression are controlled.

Exploratory analysis

Question 4: Are there significant group differences in each individual facet on the Brief-COPE?

Method

Design

This is a cross-sectional, between subjects design, to explore symptomology of STS and coping styles in foster carers. Demographic data was collected to assess the representativeness of the sample. To control for confounding factors such as anxiety and depression, the (GAD-7) and (PHQ-8) were completed by the respondents. Data was collected at one time point using online self-report questionnaires. An expert by experience, a current UK foster carer, reviewed all documents.

Ethical approval

Ethical approval was granted by the University of Oxford Central University Research Ethics Committee (Reference number: R84006/RE001) and Oxfordshire County Council (Appendix K).

Participants

One hundred and thirty-two participants were recruited from the UK foster carer population between January-May 2023. UK foster carers were invited to participate in this study if they were aged 18 years of age and older. Participants were excluded if they were a 'kinship carer', as a pre-existing relationship with the child who is cared for is assumed and this could impact on the participants relationship with any possible trauma.

Measures

The Secondary Traumatic Stress Scale (*STSS*) for DSM-4 (Bride et al., 2004)

The STSS was used to measure the symptoms consistent with PTSD as outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). These 17 questions rated on a 5-point Likert scale, were slightly modified to ensure that responses were directly related to the participants experiences of fostering e.g. “I wanted to avoid caring for some foster child(ren)” (Whitt-Woosley et al., 2020). The STSS has demonstrated good validity and reliability across studies of foster carers (Hannah & Woolgar, 2018). A split was performed on the scores on the STSS, with those in the high STS group scoring above clinical cut-off of ‘38’.

Brief Coping Orientation to Problems Experienced (*Brief COPE*, Carver, 1997).

The Brief COPE inventory is a self-report questionnaire exploring the frequency in which participants use a variety of different coping strategies. The questionnaire consists of 28 items on a 4-point Likert scale. Responses on this scale range between ‘1’ (“I haven’t been doing this at all”), 2 (“I’ve been doing this a little bit”), 3 (“I’ve been doing this a medium amount”) and 4 (“I’ve been doing this a lot”). Higher scores reflect greater use of a particular coping strategy. The Brief COPE has good internal reliability (Carver et al., 1997) and reported adequate predictive validity in a two-year study among caregivers of individuals with dementia (Cooper et al., 2008).

Generalised Anxiety Disorder Scale (*GAD-7*; Spitzer et al 2006)

The GAD-7 is a 7-item anxiety scale, for screening for anxiety disorders and assessing the severity of anxiety. The scale has demonstrated good reliability ($r = 0.83$) and validity (a =

0.92) (Spitzer et al., 2006). Items are scored on a 4-point scale (0-3), the higher the score, the higher the severity of symptoms. Scores up to 'four' indicate 'minimal anxiety', scores up to 'nine' indicate 'mild anxiety', up to '14' indicate 'moderate anxiety' and scores greater than '15' indicate 'severe anxiety'.

Patient Health Questionnaire (*PHQ-8*; Kroenke et al, 2009)

This is an 8- item scale used to measure depression, the ninth question in the DSM-IV was omitted as it assessed suicidal and self-harm cognitions and adequate intervention was not possible in the remit of this research. The PHQ-8 and PHQ-9 had similar psychometric properties demonstrating good construct and criterion validity (Kroenke & Spitzer, 2002). In a sample of individuals with heart failure the PHQ-8 internal consistency reliability was good with a Cronbach α of 0.82 (Pressler et al., 2010). Scores up to 'five' indicate 'mild depression', scores up to '10' indicate 'moderate depression', scores up to '15' indicate 'moderately severe depression' and scores up to '20' indicate 'severe depression'.

Demographic information

Demographic information was obtained via the use of an online survey, information was obtained on the age, gender, ethnicity, marital status, and education history of the participants as well as demographic information specific to fostering e.g. (how many foster children the respondents had fostered in total and at present).

Procedure

A study poster (Appendix L), information sheet and consent form (Appendix M) was shared with the ATTACH team (Oxfordshire County council), independent fostering organisations and on social media platforms. Participants accessed a Microsoft Forms link with the

participant information form, consent form, and self-report measures. Participants completed the STSS (Appendix N), Brief COPE (Appendix O), PHQ-8, GAD-7 (Appendix P) and demographic information (Appendix Q). Respondents were informed of the inclusion of potentially distressing questions and signposted to supportive services at the start, throughout and at the end of the survey (Appendix R). Data could not be withdrawn once submitted as all responses were anonymous.

Data Analysis

A Priori power analysis using G*Power Software (Faul et al., 2009) was used to calculate the sample size for an Analysis of Covariance (ANCOVA). This established a minimum of 128 individuals would be required to provide an 80% chance of detecting a medium effect size, based on $p < .05$. Based on previous research (Kellogg et al., 2018) a medium effect size of 0.25 was used. See Appendix S.

The Statistical Package for the Social Sciences (SPSS version 29) was used for data analysis. Descriptive statistics were calculated to describe demographic variables and the prevalence of STS symptoms in the study population.

Main Analysis

Three ANCOVA tests were performed, to address the relationships between STS and coping styles whilst controlling for anxiety and depression. Prior to the running of the one-way between groups analysis of covariance; preliminary checks were carried out to ensure there were no violations of assumptions of normality, linearity, homogeneity of variance, homogeneity of regression slopes and reliable measurement of the covariate. The covariates anxiety and depression were found to be highly correlated (.83). A t-test established that

depression accounted for the most variance, therefore, the analysis proceeded with just depression as the covariate.

Exploratory Analysis

The scoring on the Brief COPE is not mutually exclusive, meaning that an individual can report utilising all three coping styles simultaneously. Exploratory analysis was used to see if there were any significant group differences in the use of the individual facets on the Brief COPE. Data transformation was required on several facets when homogeneity of variance was violated. The coping facets that were significantly different between the high and low STS groups were explored by conducting a series of ANCOVA analyses on the individual facets of the Brief COPE. Three facets were not normally distributed (i.e., Denial, Substance use and Behavioural disengagement); for these, group differences were compared using Mann-Whitney *U* tests on the corresponding depression-regressed scores.

Results

One-hundred and thirty-two participants who met the inclusion criteria for participation, took part in this research study, 76 participants scored in the 'high' STS group and 56 scored in the 'low' STS group. Demographic information of this sample can be viewed in Table 2 and foster carer and clinical information can be viewed in table 3. Similarities in demographics was observed with the majority of respondents in both groups identifying as white, married, female, falling between the age range 55-64 and with the highest education level being university or college. The majority of foster carers in the high STS group were foster carers for the local authority whereas the majority of foster carers in the low STS group were foster carers with independent agencies. A similar number of total and current number of foster children cared for were reported, but the high STS group had more years' experience than the

low STS group. In addition, respondents in the high STS group scored higher for anxiety and depression.

Table 2.

Demographic Characteristics of Included Participants.

	High STS (<i>n</i> = 76)	Low STS (<i>n</i> = 56)
	N (%)	N (%)
Age		
25-34	27 (35.7)	2 (3.6)
35-44	23 (30.3)	5 (8.9)
45-54	32 (42.1)	19 (33.9)
55-64	6 (7.9)	23 (41.1)
65-74	1 (1.3)	7 (12.5)
75+		-
Sex		
Female	67 (88.1)	47 (83.9)
Male	9 (11.8)	9 (16.1)
Ethnicity		
White	72 (94.7)	51 (91.1)
Mixed/multiple ethnic groups	-	2 (3.6)
Asian/ Asian British	2 (2.6)	2 (3.6)
Black/African/Caribbean/ Black British	2 (2.6)	1 (1.8)
Marital status		
Single	5 (6.6)	6 (10.7)
Married/partnered	52 (68.4)	41 (73.2)
Divorced/widowed	9 (11.8)	8 (14.3)
Prefer not to say	2(2.6)	-
Other	8 (10.5)	1 (1.8)
Highest educational level		
Secondary school (>16 years)	8 (10.5)	11 (19.6)
High school (A-levels/BTEC)	9 (11.8)	9 (16.1)
University or College	39 (51.3)	28 (50)
Postgraduate degree	20 (26.3)	7 (12.5)
Prefer not to say	-	1 (1.8)

Table 3.*Foster Carer Information and Clinical Information of Participants.*

	High STS (n = 76)			Low STS (n =56)		
	<i>N (%)</i>	<i>M(SD)</i>	<i>Range</i>	<i>N (%)</i>	<i>M(SD)</i>	<i>Range</i>
Type of foster carer ^a						
Local Authority	41 (53.9)			17 (30.4)		
Independent Fostering Agency	35 (46.1)			38 (67.9)		
Other				1 (1.8)		
Number of people in the household		4.1 (1.7)	2-14		4.2 (1.8)	1-9
Number of foster children cared for (Total) ^b		18.5 (24.1)	1-104		18.9 (35.2)	1-200
Years of experience		10.6 (7)	2-29		8.3 (7.7)	1-30
Current number of foster children ^c		1.6 (.85)	0-3		1.7 (.92)	0-4
Psychometric data						
Anxiety (GAD-7)		8.2 (5.2)			2.6 (3.2)	
Depression (PHQ-8)		10.3 (6.0)			3 (2.7)	
Secondary Traumatic Stress (STSS)		50.7 (9.6)			27.6 (5.6)	

Note: ^a One foster carer indicated ‘other’ when answering the question on type of foster carer.

^b Some foster carers provided an estimate, with several reporting “over 100”, for the purposes of the analysis, this was counted as ‘100’. ^c Some fosterers reported being between placements/ offering respite fostering and so had no young people placed with them at the time of completing the survey.

There were no significant differences between the high STS and low STS groups when t-test and Chi-square analyses were performed on the demographic data, however, the analysis could not be run on ethnicity and marital status as this data violated Chi-Square assumptions.

The demographic data pertaining to the type of foster carer (Local Authority/Independent Fostering Agency) and demographic factors were explored using t-test and Chi-Square. One significant difference was the number of foster children cared for altogether $t(72.48) = 2.80$,

$P = .006$, with Local Authority Foster carers looking after more foster children in total ($M = 27.22$; $SD = 38.77$) compared to independent fostering agency foster cares ($M = 12.01$; $SD = 1.88$). Highest level of education was also significantly different between the two groups $\chi^2(4,131) = 14.26$, $P = .007$ with Independent Fostering Agency foster carers reporting their highest level of education as A-Level/BTEC compared to local authority foster carers.

Main Analyses:

Hypothesis 1: Foster carers who report high STS will use more avoidant coping strategies than foster carers who report low STS when anxiety and depression are controlled.

Consistent with the hypothesis, there was a significant difference in avoidant coping, $F(1, 129) = 5.08$ $p = .03$, $\eta^2 = .04$, between the two groups. High STS ($M = 2.28$; $SD = 0.75$) used avoidant coping more frequently than low STS ($M = 1.96$; $SD = 0.61$).

Hypothesis 2: Foster carers who report high STS will use less problem-focused coping strategies than foster carers who report low STS when anxiety and depression are controlled.

There was a significant group difference in problem-focused coping $F(1, 129) = 6.22$, $p = .01$, $\eta^2 = .05$, between the two groups. High STS ($M = 2.88$; $SD = 0.61$) used problem-focused coping more frequently than low STS ($M = 2.50$; $SD = 0.79$). Therefore, the hypothesis was not confirmed.

Hypothesis 3: Foster carers who report high STS will use more emotion-focused coping strategies than foster carers who report low STS when anxiety and depression are controlled.

There was no significant group difference in emotion-focused coping $F(1, 129) = 1.59, p = .21, \eta^2 = .01$, between the two groups, high ($M = 3.17; SD = 0.80$) and low STS ($M = 2.94; SD = 0.88$). Therefore, the hypothesis was not confirmed.

Exploratory analysis

Question 4: Are there significant group differences in each individual facet on the Brief-COPE?

The coping facets that were significantly different between the high and low STS groups were explored by conducting a series of ANCOVA analyses on the individual facets of the Brief COPE. Three facets were not normally distributed (i.e., Denial, Substance use and Behavioural disengagement); for these, group differences were compared using Mann-Whitney U tests on the corresponding depression-regressed scores. A Bonferroni adjusted alpha level of .0035 per test (.05/14) was used. After applying Bonferroni correction, three of the avoidant facets, 'denial', 'substance use' and 'behavioural disengagement' remained significant. See table 4 for the descriptive statistics.

Table 4.

Descriptive Statistics of the Analysis.

Group	High STS			Low STS				
	Mean	Adjusted mean	<i>SD</i>	Median	Mean	Adjusted mean	<i>SD</i>	Median
Avoidant								
Denial	1.68			1.50	1.27			1.00
Behavioural	1.78			1.50	1.11			1.00
Disengagement								
Substance use	1.36			1.00	1.07			1.00
Self-distraction	2.85	2.74	0.69		2.13	2.8	0.78	
Emotion-focused								
Self-blame	2.58	0.33	0.98		1.67	0.25	0.96	
Venting	2.29	2.21	0.69		1.81	1.92	0.71	
Emotional support	2.78	2.84	0.87		2.46	2.34	0.83	
Acceptance	2.88	2.82	0.71		2.89	2.97	0.79	
Humour	2.05	1.99	0.94		1.71	1.79	0.96	
Religion	1.73	1.72	0.93		1.61	1.62	0.99	
Problem focused								
Active coping	2.95	0.28	0.77		2.66	0.33	0.86	
Use of informational support	2.76	2.81	0.86		2.39	2.33	0.88	
Planning	3.18	0.23	0.77		2.75	0.30	0.88	
Positive reframing	2.51	2.54	0.85		2.33	2.30	0.90	

Avoidant coping

After applying Bonferroni correction, a significant difference was found between the two groups on their use of Denial: $U = 774.00$ $z = 6.24$, $p < .001$, $r = 0.54$; Behavioural disengagement: $U = 1135.50$ $z = 4.58$, $p < .001$, $r = 0.40$ and Substance use: $U = 797.00$ $z = 6.14$, $p < .001$, $r = 0.53$. Self- distraction: was more frequently used in the high STS group $F(1, 129) = 8.50$, $p = .004$, $\eta^2 = .06$, but this was found not to be significant following the application of Bonferroni correction.

Emotion-focused coping

Self-blame: $F(1, 129) = 4.27, p = .04, \eta^2 = .03$; Venting: $F(1, 129) = 3.99, p = .05, \eta^2 = .03$; Emotional support: $F(1, 129) = 6.77, p = .01, \eta^2 = .05$; Humour: $F(1, 129) = 0.87, p = .35, \eta^2 = .01$ and Religion: $F(1, 129) = 2.32, p = .63, \eta^2 = .01$ were more frequently used in the high STS group than the low STS group, but were found not to be significant following the application of Bonferroni correction. Acceptance was used less frequently in the high STS group $F(1, 129) = 0.72, p = .40, \eta^2 = .01$ but this was not significant following the application of the Bonferroni correction.

Problem-focused coping

Active coping: $F(1, 129) = 4.52, p = .04, \eta^2 = .03$; Use of informational support: $F(1, 129) = 6.42, p = .01, \eta^2 = .05$; Planning: $F(1, 129) = 2.51, p = .12, \eta^2 = .02$ and Positive reframing: $F(1, 129) = 1.61, p = .21, \eta^2 = .01$ was found to be more frequently used in the high STS group than the low STS group, but were found not to be significant following the application of Bonferroni correction. See 'Appendix T' for analysis.

Discussion

This study aimed to explore whether there is a difference in the coping styles of foster carers who report high STS compared to those who report low STS when depression is controlled for. The second aim was to explore if there were any specific facets within the three coping styles (emotion-focused, problem-focused, and avoidant) that were significantly different in these two groups.

The findings support the first hypothesis, indicating that there are significant differences in the use of avoidant coping styles by foster carers when depression is controlled for. Foster carers who reported high STS made greater use of avoidant coping styles significantly more than those who reported low STS. This finding is supported by the literature which reported avoidance was associated with dysfunctional coping (Carver, 1997) and avoidant coping styles play a key role in the development of post-traumatic stress (Figley, 1995).

The findings contradicted the second hypothesis, that foster carers who report high STS will use less problem-focused coping strategies when depression is controlled for. The results indicate that those in the high STS group reported significantly more problem-focused coping than the low STS group. This was the strongest significant difference between the two groups, of all the coping styles. This goes against the previous literature that problem-focused coping reduces the impact of everyday life stressors (Ben-Zur, 2009) and the development of PTSD symptoms (Vernon et al., 2009).

The findings do not support the third hypothesis, that foster carers who report high STS will use more emotion-focused coping strategies when depression is controlled for. Although those in the high STS group used more emotion-focused coping, this was not found to be significant. This result does not lend support to the research which found emotion-focused coping was associated with the development of post-traumatic stress (Schnider, et al., 2007).

The results show that individuals with high STS made greater use of all coping styles. This group difference was significant for avoidant and problem-focused coping. As this is a cross-sectional study, commentary on causality can only be hypothesised. The finding could suggest that foster carers with high STS make use a full range of coping styles, yet they are

not effective, therefore, there could be a requirement for a more specific trauma treatment for STS. Problem-focused coping involves the adoption of strategies to manage and solve life stressors directly and avoidant coping involves ignoring or minimising the life stressor. Therefore, it could be that those with high STS adopt problem-focused coping but perhaps owing to STS these adaptive coping styles are less effective than in low STS and therefore, a contrary approach, avoidant coping is applied.

The exploratory analysis has highlighted that avoidant coping through substance use, behavioural disengagement and denial were significantly different between the two groups when depression was controlled. Therefore, it could be that foster carers may benefit from support focused on identifying and reducing these avoidant behaviours. It may be important for the professionals who support foster carers to have open conversations on coping and substance use. It could be that a psychological intervention that could support with behavioural disengagement and denial could be helpful.

Acceptance was the only facet that was more frequently used in the low STS group than the high STS group. Although this difference was non-significant, the coping facet denial was reported significantly more in the high STS group. Therefore, this could suggest that individuals in the high STS group make use of both adaptive and maladaptive coping strategies which could render them both unsatisfactory.

Individuals in the high STS group reported significantly greater use of problem-focused and emotion-focused strategies. The secondary traumatic model (Whitt-Woosley et al., 2020) purports that practical support is a direct beneficial factor to mitigate against STS. Therefore, the practical support that is currently being provided to foster carers may not be effective if

they have high STS. It could be that alternative support is required, for example a psychological based intervention rather than informational support.

Clinical implications

This study emphasised the importance of supporting UK foster carers to support their mental health, their effectiveness in caring for their children and preventing them from leaving the profession. It was found that the majority of foster carers have clinically significant STS and attempt to cope with this through utilising a variety of coping styles. They utilised significantly more problem-focused coping, a coping style linked to reduced likelihood of developing STS, this could suggest that this may not be adaptive for the nature of life stressor faced or STS has impacted upon the effectiveness of these coping skills. Therefore, creating awareness amongst social care professionals and foster carers, on STS and anxiety and depression is an important future direction. In addition, screening for STS and anxiety and depression. Supporting, a greater understanding and recognition of STS could support effectiveness of coping styles.

Interestingly, a greater proportion of the high STS group were foster carers for the local authority and the majority of the low STS group were foster carers for independent agencies. When comparing the two types of foster carers the only significantly different demographics were the number of total children cared for and highest level of education. Local Authority foster carers were had cared for a significantly higher number of foster carers in total compared to Independent foster carers. Therefore, it could that Local Authority foster carers have been party to a greater number of traumatic narratives than the Independent foster carers. The highest of levels of education was significantly different between the two groups with Independent foster carers reporting secondary level of education as their highest

educational attainment compared to the Local Authority Foster carers. Therefore, qualitative research could be useful to help us to better understand this difference between STS in Independent Fostering Agency and Local Authority foster carers.

Social care professionals should be aware and observant of the coping factors and their presentations to identify their use in foster carers. This could allow for conversations to be held on coping and psychoeducation/support to consider how the coping factors such as avoidant coping impact on STS.

Strengths and Limitations

To the authors knowledge, this is the only UK study to explore the relationships between coping styles and the specific factors within the coping styles with STS in foster carers. Therefore, this novel research adds to the sparse literature, enabling a better understanding of foster carer support needs. It reinforces the findings of other authors, that STS is prevalent in foster carers, and it also identifies areas for potential support, for example, creating awareness, screening for STS and a trauma intervention. More research is required to explore this further.

The recruitment method could be subject to bias. Although the volunteer sampling method allowed for a variety of carers to participate, volunteering may have meant carers who were more willing and readily able to engage and reflect took part in this study. However, this potential bias could have been reduced owing to the research design being an online survey, that could be accessed at any time. Additionally, the sample could have been biased by using the words 'secondary trauma' in the promotion of the study as it could be that foster carers

who did not identify with secondary trauma did not take part or those who attach stigma to experiences of STS may not have responded.

Experiences of primary trauma were not explored within this study, a key symptom of trauma is avoidance and therefore, it could have helped us to understand further whether the avoidant coping style was also more prominent in foster carers reporting primary trauma. Similarly, it could have been helpful to measure stress more generally because high levels of stress could increase the measures used for coping styles. Although dose of exposure to trauma material was not collected, individuals in the high STS group on average had more years' experience and fewer total foster children. Although firm conclusions cannot be drawn on this information, it could be that the high STS group have needed to provide more intensive support to the children they have had placed with them, therefore, fostering less children for a longer duration. In addition, it could be that having a greater number of years' experience has made this group more likely to hear traumatic details of their young person's history over time.

The ages of the participants were not able to be statistically verified to understand if both groups had equivalent ages as participants were asked to indicate which age bracket they fell within. In addition, it was unfortunate that the ethnicity and marital status data violated Chi-Square assumptions as it could be that these demographic factors influence STS.

In conclusion, this study highlights that foster carers who report high STS use a wide range of coping styles with the greatest significant difference in the use of problem-focused coping styles. It could be that enhancing awareness of STS amongst social care professionals and foster carers and screening could be beneficial and allow for early intervention. Early intervention could support the effectiveness of the coping strategies employed. It could be

that only providing additional information/advice or emotional support would not benefit foster carers with high STS. Future research must continue to ensure the support needs of foster carers are considered by exploring further the qualitative experiences of foster carers and the coping methods employed to manage.

References

- Ben-Zur, H. (2009). Coping styles and affect. *International Journal of Stress Management*, 16(2), pp.87–101.
- Bock, C., Heitland, I., Zimmermann, T., Winter, L. and Kahl, K.G. (2020). Secondary Traumatic Stress, Mental State, and Work Ability in Nurses—Results of a Psychological Risk Assessment at a University Hospital. *Frontiers in Psychiatry*, 11(298).
- Bride, B.E., Robinson, M.M., Yegidis, B. and Figley, C.R. (2004). Development and Validation of the Secondary Traumatic Stress Scale. *Research on Social Work Practice*, 14(1), pp.27–35.
- Bride, B.E. (2007). Prevalence of Secondary Traumatic Stress among Social Workers. *Social Work*, 52(1), pp.63–70.
- Bridger, K.M., Binder, J.F. and Kellezi, B. (2019). Secondary Traumatic Stress in Foster Carers: Risk Factors and Implications for Intervention. *Journal of Child and Family Studies*, 29(2), pp.482–492.
- Carew, N. M. (2016). Secondary traumatic stress and the foster parenting experience: Exploring factors associated with the prevalence of secondary traumatic stress in foster parents caring for children who have experienced trauma. *Michigan State University*.
- Carver, C.S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4(1), pp.92–100.
- Carver, C.S., Scheier, M.F. and Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology*, 56(2), pp.267–283.

- Carver, C.S. and Connor-Smith, J. (2010). Personality and Coping. *Annual Review of Psychology*, 61(1), pp.679–704.
- Cicchetti, D. and Handley, E.D. (2019). Child maltreatment and the development of substance use and disorder. *Neurobiology of Stress*, 10, p.100144.
- Coleman, J., (2019). Exploring relationships between parenting style, perceived stress, coping efficacy and coping strategies in foster parents. PCOM Psychology Dissertations, 512.
- Cooper, C., Katona, C. and Livingston, G. (2008). Validity and reliability of the brief COPE in carers of people with dementia: the LASER-AD Study. *The Journal of Nervous and Mental Disease*, 196(11), pp.838–843.
- Coyne, J.C. and Racioppo, M.W. (2000). Never the twain shall meet? Closing the gap between coping research and clinical intervention research. *American Psychologist*, 55(6), pp.655–664.
- Department for Education. (2017, September 28). *Children looked after in England including adoption: 2016 to 2017*. GOV.UK.
<https://www.gov.uk/government/statistics/children-looked-after-in-england-including-adoption-2016-to-2017>.
- Faul, F., Erdfelder, E., Buchner, A. and Lang, A.G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, 41(4), pp.1149–1160.
- Figley, C. R. (1995). *Compassion fatigue: coping with stress disorder in those who treat the traumatized*. Routledge, Cop.
- Figley, C. R. (1999). Compassion fatigue: Toward a new understanding of the costs of caring. In B. H. Stamm (Ed.), *Secondary traumatic stress: Self-care issues for clinicians, researchers, and educators*(2nd ed., pp. 3-28). Lutherville, MD: Sidran.

Fonagy, P. (2018). *Affect Regulation, Mentalization and the Development of the Self*. Milton: Routledge.

Fostering statistics / *The Fostering Network*. (2022). [Thefosteringnetwork.org.uk](https://www.thefosteringnetwork.org.uk).

<https://www.thefosteringnetwork.org.uk/advice-information/all-about-fostering/fostering>.

Gil, S. and Caspi, Y. (2006). Personality Traits, Coping Style, and Perceived Threat as Predictors of Posttraumatic Stress Disorder After Exposure to a Terrorist Attack: A Prospective Study. *Psychosomatic Medicine*, 68(6), pp.904–909.

Gil, S. and Weinberg, M. (2015). Secondary trauma among social workers treating trauma clients: The role of coping strategies and internal resources. *International Social Work*, 58(4), pp.551–561.

Hannah, B. and Woolgar, M. (2018). Secondary trauma and compassion fatigue in foster carers. *Clinical Child Psychology and Psychiatry*, 23(4), pp.629–643.

İlhan, B. and Küpeli, İ. (2022). Secondary traumatic stress, anxiety, and depression among emergency healthcare workers in the middle of the COVID-19 outbreak: A cross-sectional study. *The American Journal of Emergency Medicine*, 52, pp.99–104.

Kellogg, M.B., Knight, M., Dowling, J.S. and Crawford, S.L. (2018). Secondary Traumatic Stress in Pediatric Nurses. *Journal of Pediatric Nursing*, 43, pp.97–103.

Kroenke, K. and Spitzer, R.L. (2002). The PHQ-9: A New Depression Diagnostic and Severity Measure. *Psychiatric Annals*, 32(9), pp.509–515.

Kroenke, K., Strine, T.W., Spitzer, R.L., Williams, J.B.W., Berry, J.T. and Mokdad, A.H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of Affective Disorders*, 114(1-3), pp.163–173.

Lazarus, R.S. and Folkman, S. (1984). *Stress, appraisal, and Coping*. New York: Springer.

McGuire, R., Halligan, S.L., Meiser-Stedman, R., Durbin, L. and Hiller, R.M. (2022).

Differences in the diagnosis and treatment decisions for children in care compared to their peers: An experimental study on post-traumatic stress disorder. *British Journal of Clinical Psychology*.

Mong, M.D., Noguchi, K. and Ladner, B. (2012). Immediate Psychological Impact of the Deepwater Horizon Oil Spill: Symptoms of PTSD and Coping Skills. *Journal of Aggression, Maltreatment & Trauma*, 21(6), pp.691–704.

Pressler, S.J., Subramanian, U., Perkins, S.M., Gradus-Pizlo, I., Kareken, D., Kim, J., Ding, Y., Sauve, M.J. and Sloan, R. (2010). Measuring Depressive Symptoms in Heart Failure: Validity and Reliability of the Patient Health Questionnaire-8. *American Journal of Critical Care*, 20(2), pp.146–152.

Schimmenti, A. (2012). Unveiling the hidden self: Developmental trauma and pathological shame. *Psychodynamic Practice*, 18(2), pp.195–211.

Schimmenti, A. and Caretti, V. (2010). Psychic retreats or psychic pits?: Unbearable states of mind and technological addiction. *Psychoanalytic Psychology*, 27(2), pp.115–132.

Shikai, N., Uji, M., Chen, Z., Hiramura, H., Tanaka, N., Shono, M. and Kitamura, T. (2007). The Role of Coping Styles and Self-efficacy in the Development of Dysphoric Mood Among Nursing Students. *Journal of Psychopathology and Behavioral Assessment*, 29(4), pp.241–248.

- Spitzer, R.L., Kroenke, K., Williams, J.B.W. and Löwe, B. (2006). A Brief Measure for Assessing Generalized Anxiety Disorder. *Archives of Internal Medicine*, 166(10), pp.1092–1097.
- Stapleton, R., Young, A. and Senstock, T. (2016). Coping Styles and Secondary Traumatic Stress in Direct Care Staff Working in Residential Treatment Centers. *Journal of Therapeutic Schools and Programs*, 1(8), 71–80.
- Vernon, L.L., Dillon, J.M. and Steiner, A.R.W. (2009). Proactive coping, gratitude, and posttraumatic stress disorder in college women. *Anxiety, Stress & Coping*, 22(1), pp.117–127.
- Whitt-Woosley, A., Sprang, G. and Eslinger, J. (2020). Exploration of factors associated with secondary traumatic stress in foster parents. *Children and Youth Services Review*, 118, p.105361.

Executive Summary

Introduction to the study

Secondary Traumatic Stress (STS) is under-researched in the foster carer population. One study found that 19.8% of 131 participants fell above the clinical cut-off for STS and 25.2% were considered high risk for developing STS. Prolonged exposure to primary/secondary trauma was thought to reduce a foster carers' ability to cope, their job satisfaction and lead to foster carers leaving the profession.

Understanding the experiences of foster carers in relation to STS is important for recruitment, wellbeing, training, and retention. A model of STS in foster carers was developed to help guide understanding of factors that may support against or increase the risk of STS. Two beneficial factors were emotional and practical support.

Coping styles (avoidant, emotion-focused, problem-focused) and resources can influence a person's psychological and physical reactions to stressful situations and influence outcomes. This study aimed to explore the relationship between these coping styles and STS in foster carers.

Our research questions were:

Question 1: Will there be group differences in the reported use of avoidant coping strategies when controlling for anxiety and depression?

Question 2: Will there be group differences in the reported use of problem-focused coping strategies when controlling for anxiety and depression?

Question 3: Will there be group differences in the reported use of emotion-focused coping strategies when controlling for anxiety and depression?

Question 4: Are there significant group differences in each individual facets on the Brief- COPE?

How the study was carried out

This study recruited UK foster carers aged 18 years and over. Recruitment took place over social media and through liaison with Local Authorities as well as Independent Fostering Agencies. Demographic information as well as information on fostering experience was gathered using online surveys. Foster carers also completed four questionnaires looking at: Secondary Traumatic Stress, Coping Styles, Anxiety and Depression.

What we found

A total of 132 foster carers took part. We compared the 76 foster carers whose STS scores fell within the 'high' STS group with 56 foster carers who fell within the 'low' STS group. We found that foster carers who report higher levels of STS were significantly more likely to use avoidant and problem-focused coping. Individuals in the high STS group also made greater use of emotion-focused coping, but this was not a significant difference between the two groups. Three avoidant facets (substance use, behavioural disengagement, and denial); were used significantly more frequently by individuals with high STS. Acceptance was the only coping facet that was used slightly more frequently by the low STS group. The only

significant demographic difference between the high and low STS group was the total number of children fostered and type of foster carer, with more Local Authority foster carers falling in the high STS group compared to those with an Independent Fostering agency.

Clinical implications

These findings support the need for creating awareness of STS in foster carers, this could be done through psychoeducation and screening. Social care professionals should be aware and observant of the coping factors and their presentations to identify their use in foster carers. This could allow for conversations to be held on coping and psychoeducation/support to consider how the coping factors such as avoidant coping impact on STS.

Limitations and suggestions for future research

The title of this study could have prevented some foster carers from taking part if they did not identify with signs of secondary trauma. In addition, foster carer feedback highlighted the importance of primary trauma as well as secondary trauma, primary trauma was not measured. Future research must continue to ensure the support needs of foster carers are considered by exploring further the qualitative experiences of foster carers and the coping methods employed to manage.

Conclusions

Like other studies, we found that a high proportion of the sample were high STS and in addition high in anxiety and depression. This novel research was as far as the

author is aware the first research study in the UK to explore coping styles in foster carers and the relationship between coping styles and STS. This study emphasised

the importance of supporting UK foster carers to support their mental health, their effectiveness in caring for their children and preventing attrition of this valuable workforce.

Connecting Narrative

My personal and professional experiences led me to undertake research exploring psychological factors (e.g., cognitive and behavioural factors) that have an impact on psychological and physical health. The opportunity to undertake three research projects allowed me to explore these interests widely across a multitude of settings. My work as an assistant psychologist alongside my personal experience of mental health being impacted by physical health, led to a desire to contribute to the evidence-base in these fields.

A theme connecting all three projects was the focus on empowerment, and how cognitive and behavioural factors can have an impact on how empowered an individual feels when experiencing physical or mental health difficulties. I have developed my understanding of how cognitive (attributions/locus of control, self-blame) and behavioural (avoidance, behavioural disengagement) factors can impact on a person's psychological wellbeing following a physical and/or mental health concern. My service improvement project also explored how staff members could be aware of their clients' cognitive/behavioural factors, as well as their own, and use this knowledge to empower decision making. This matched my professional view that exploring both cognitive and behavioural factors of clients and professionals could support psychological wellbeing and empower the client to make a change that will improve their psychological wellbeing. I aspire to always hold in mind how clients and colleagues could be empowered through creating awareness of cognitive and behavioural factors.

Critical Review of the Literature Paper

My interest in exploring the role of cognitive/behavioural factors, such as attributions and behavioural disengagement on mental health following a physical health diagnosis led me to consider this topic for my review. Furthermore, the diagnosis of a dear friend motivated my interest in understanding Chronic Fatigue Syndrome.

I had never conducted a systematic review of the literature before and therefore, felt like this was a new skill I was developing. This was a steep learning curve, particularly after reading 5,000 titles and abstracts before realising I may need to re-look at my search criteria to make it more robust. Although this was time consuming, I tried to see it as a helpful lesson.

I found the library support invaluable, as well as working with my peer reviewer. I often became so immersed in the topic, having a second set of eyes to talk through my decision making proved incredibly valuable. This project helped me realise the value of conducting systematic reviews in my future role as a clinical psychologist.

Being aware of the impact that causal attributions and self-efficacy can have on treatment engagement and outcomes could empower an individual to reflect and cognitively restructure in order to support their mental health wellbeing.

I have developed a broad range of research skills and have taken an active role from conceptualisation through to analysis, and to the write-up. I have a strong appreciation of the value of research, and I am particularly interested in maintaining these skills post-qualifying to enhance and develop the clinical context that I am working in. However, practicalities such as time and resources may act a barrier to delivering clinically meaningful data, but I feel I now have a solid foundation of skills with which to try and overcome these constraints.

Service Improvement Project paper

My personal experience of having a severe physical health condition, whereby I required a blood transfusion, made me reflect on the psychological support available in these types of physical health services. Therefore, I knew I wanted to conduct at least one research study within clinical health psychology. I worked alongside Dr Louise Hankinson and Dr Susannah Jenner, both of whom have great experience in supporting the psychological wellbeing of individuals with physical health concerns. Initially I wanted to explore factors that impact on service user decision making regarding whether to write to a donor family, as well as exploring staff members' decision making. However, following the PAS panel, I was encouraged to pick one group, and after discussions and reflections on the ethical issues inherent in the initial plan, we decided to focus the project on staff members only.

Therefore, I hoped exploring the facilitators and barriers to decision making regarding letter writing will empower staff members to identify and implement recommendations which could lead to the empowerment of service users. I was

struck by the warmth, thoughtfulness, and dedication of professionals in their roles supporting transplant recipients. It was important to me to keep the voices of clients at the centre of the project and so I ensured that questions reflected on the client's experience.

Theoretically Driven Research Paper

I worked in children's social care prior to training, whereby I became aware of the need for more foster carers and their vital role in providing support to looked after children. The limited evidence base pertaining to foster carers surprised me.

Although I wanted to conduct novel research in this area, exploring a compassion focused therapy intervention, I learnt that there may be more value in building on the existing, albeit limited, evidence base first. Despite foster carers frequently being party to stories of neglect and abuse, they appear to be a population overlooked in the secondary trauma literature. I was supervised by experienced, knowledgeable, and passionate supervisors in this field; Dr Ciorsdan Anderson and Dr Claire Holdaway.

Recruitment was a heart-warming process. Using social media, connecting with charities and local authorities, allowed me to be party to a lot of inspirational resources. I noted how I felt a sense of motivation by connecting with both professionals and foster carers. Working alongside an expert by experience was a hugely rewarding task.

I knew data analysis was always going to be a challenge; but I enjoyed relearning statistical analysis, reminding me of my undergraduate with two friends, trying to

decipher what seemed like a whole new language, although this time there was some familiarity.

Having a greater awareness of coping styles and which coping styles may be more, or less, adaptive in relation to secondary trauma stress can empower individuals and services to use/provide more adaptive support.

Acknowledgments

This thesis is dedicated to my close friend, Michelle, a truly inspirational and compassionate friend, and a dedicated psychologist. Her support throughout our friendship was unwavering, she always shared in my successes and my frustrations and was with me every step of the way, you will always be with me!

To my dad, my mum, my sister, and my friends who have supported me throughout my career. You have given me the motivation and courage to continue to work towards achieving and realising this dream and you have provided me with the light relief I have needed to thrive throughout the course. I couldn't have got this far without my school friends: Sam, Aisha, Blaise, and James; my undergraduate friends: Ash and Emma; my work colleagues; Jeni and Nicole (the strings remain strong), and family friend, Pat.

To my two inspirational colleagues on the course, Jerica and Bertie, thank you for your friendship and moral support. Thanks also to Brad, whose support with my literature review was invaluable.

Finally, to my research supervisors who supported me throughout; the 'experts by experience' who collaborated on the creation of the studies and the participants who took the time to participate in the studies. Thank you.

Research Appendices

Appendix A.

Authors guidelines for British Journal of Health Psychology

4. PREPARING THE SUBMISSION

Open Research initiatives.

Recognizing the importance of research transparency and data sharing to cumulative research, *British Journal of Health Psychology* encourages the following Open Research practices.

Sharing of data, materials, research instruments and their accessibility. *British Journal of Health Psychology* encourages authors to share the data, materials, research instruments, and other artifacts supporting the results in their study by archiving them in an appropriate public repository. Qualifying public, open-access repositories are committed to preserving data, materials, and/or registered analysis plans and keeping them publicly accessible via the web into perpetuity. Examples include the Open Science Framework (OSF) and the various Dataverse networks. Hundreds of other qualifying data/materials repositories are listed at the Registry of Research Data Repositories (<http://www.re3data.org>). Personal websites and most departmental websites do not qualify as repositories.

Free Format Submission

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

Before you submit, you will need:

- Your manuscript: this can be a single file including text, figures, and tables, or separate files – whichever you prefer (if you do submit separate files, we encourage you to also include your figures within the main document to make it easier for editors and reviewers to read your manuscript, but this is not compulsory). All required sections should be contained in your manuscript, including abstract, introduction, methods, results, and conclusions. Figures and tables should have legends. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers. If your manuscript is difficult to read, the editorial office may send it back to you for revision.
- The title page of the manuscript, including a data availability statement and your co-author details with affiliations. (*Why is this important? We need to keep all co-authors informed of the outcome of the peer review process.*) You may like to use [this template](#) for your title page.
Important: the journal operates a double-anonymous peer review policy. Please anonymise your manuscript and prepare a separate title page containing author details. (*Why is this important? We need to uphold rigorous ethical standards for the research we consider for publication.*)
- An ORCID ID, freely available at <https://orcid.org>. (*Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.*)

To submit, login at <https://wiley.atyponrex.com/journal/BJHP> and create a new submission. Follow the submission steps as required and submit the manuscript. If you are invited to revise your manuscript after peer review, the journal will also request the revised manuscript to be formatted according to journal requirements as described below.

Revised Manuscript Submission

Contributions must be typed in double spacing. All sheets must be numbered. Cover letters are not mandatory; however, they may be supplied at the author's discretion. They should be pasted into the 'Comments' box in Editorial Manager.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; statement of contribution; main text file; figures/tables; supporting information.

Title Page

You may like to use [this template](#) for your title page. The title page should contain:

- A short informative title containing the major key words. The title should not contain abbreviations (see Wiley's [best practice SEO tips](#));
- A short running title of less than 40 characters;
- The full names of the authors;
- The author's institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Abstract;
- Keywords;
- Data availability statement (see [Data Sharing and Data Accessibility Policy](#));
- Acknowledgments.

Author Contributions

For all articles, the journal mandates the CRediT (Contribution Roles Taxonomy)—more information is available on our [Author Services](#) site.

Abstract

For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study. You can save words by writing short, direct sentences. Helpful hints about writing the conclusions to abstracts can be found [here](#).

Keywords

Please provide appropriate keywords.

Acknowledgements

Contributions from anyone who does not meet the criteria for authorship should be listed, with permission from the contributor, in an Acknowledgments section. Financial and material support should also be mentioned. Thanks to anonymous reviewers are not appropriate.

Statement of Contribution

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

Main Text File

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

Manuscripts can be uploaded either as a single document (containing the main text, tables and figures), or with figures and tables provided as separate files. Should your manuscript reach revision stage, figures and tables must be provided as separate files. The main manuscript file can be submitted in Microsoft Word (.doc or .docx) or LaTeX (.tex) format. If submitting your manuscript file in LaTeX format via Research Exchange, select the file designation “Main Document – LaTeX .tex File” on upload. When submitting a LaTeX Main Document, you must also provide a PDF version of the manuscript for Peer Review. Please upload this file as “Main Document - LaTeX PDF.” All supporting files that are referred to in the LaTeX Main Document should be uploaded as a “LaTeX Supplementary File.”

LaTeX Guidelines for Post-Acceptance:

Please check that you have supplied the following files for typesetting post-acceptance:

- PDF of the finalized source manuscript files compiled without any errors.
- The LaTeX source code files (text, figure captions, and tables, preferably in a single file), BibTeX files (if used), any associated packages/files along with all other files needed for compiling without any errors. This is particularly important if authors have used any LaTeX style or class files, bibliography files (.bbl, .bst, .blg) or packages apart from those used in the NJD LaTeX Template class file.
- Electronic graphics files for the illustrations in Encapsulated PostScript (EPS), PDF or TIFF format. Authors are requested not to create figures using LaTeX codes.

Your main document file should include:

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

Supporting information should be supplied as separate files. Tables and figures can be included at the end of the main document or attached as separate files but they must be mentioned in the text.

- The main text file should not include any information that might identify the authors. Please do not mention the authors’ names or affiliations and always refer to any previous work in the third person.

- The journal uses British spelling; however, authors may submit using either option, as spelling of accepted papers is converted during the production process.

References

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

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figures

Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted.

[Click here](#) for the basic figure requirements for figures submitted with manuscripts for initial peer review, as well as the more detailed post-acceptance figure requirements.

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Supporting Information

Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc.

[Click here](#) for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

General Style Points

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association. The following points provide general advice on formatting and style.

- **Language:** Authors must avoid the use of sexist or any other discriminatory language.
- **Abbreviations:** In general, terms should not be abbreviated unless they are used repeatedly and the abbreviation is helpful to the reader. Initially, use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation only.
- **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the [Bureau International des Poids et Mesures \(BIPM\) website](#) for more information about SI units.
- **Effect size:** In normal circumstances, effect size should be incorporated.
- **Numbers:** numbers under 10 are spelt out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).

Appendix B.

Search terms.

"Chronic Fatigue Syndrome" or "CFS" or "Myalgia Encephalomyelitis" or "Chronic Fatigue" or "M.E" or "immune Dysfunction syndrome" or "CFIDS" or "post viral fatigue syndrome" or "PVFS" or "post viral syndrome" or "PVS"

"Causal attribution" or "illness perception" or "attribution" or "somatic attribution" or

"Psychological attribution" or "Psychosocial attribution" or "Illness representation" or "self-efficacy" or "locus of control" or "Blame" or "Attitude" or "Belief" or "self-blame"

"Psychological Therap*" or "Cognitive Behavio* Therap*" or "CBT" or "mindfulness based therap*" or "Acceptance commitment therapy" or "therap*" or "intervention" or "Cognitive technique*" or "Psychotherap*"

Appendix C.

Quality assessment tool (Kmet et al.,2004).

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?				

Appendix E. Approval emails from Trust.

Re: Study classification
Dear Louise,

We have reviewed your study with the title (The Correspondence Between Organ Recipient and Donor Family in the Oxford Transplant Centre) in our classification meeting and we can confirm the project is an service improvement/evaluation .

You should ensure that your department leads are aware of the project and are happy for the activity to take place. You may also need to register the project with the clinical audit team. Details can be found here: <http://ouh.oxnet.nhs.uk/SafetyQualityRisk/Pages/Welcome.aspx>

All service review activity should comply with clinical governance requirements.

Please do get in touch if you have any further questions in the meantime.

With best wishes

Ronja

From: Ulysses@ouh.nhs.uk <Ulysses@ouh.nhs.uk>
Sent: 14 December 2021 13:20
To: Hankinson, Louise (RTH) OUH <Louise.Hankinson@ouh.nhs.uk>
Subject: **Clinical Improvement Module Notification - 7325**

You don't often get email from ulysses@ouh.nhs.uk. [Learn why this is important](#)

Clinical Improvement Module

Number: **7325**
Page: **03 - Approved QI**
Title: **The Correspondence Between Organ Recipient and Donor Family in the Oxford Transplant Centre: A service **Improvement** Project**
Request Date: **14/12/2021**
Target Date: **15/02/2022**
Start Date: **//**
Project Lead: **Louise Hankinson**
Project Supervisor: **Louise Hankinson**
Manager Feedback:

Click on the link below to view & action the record

[View & Action the record here](#)

Appendix F. Study flyer



Improving rates of letter writing between transplant recipients and donors/donor families.

What is this study about?

- NHS Blood and Transfusion (NHSBT) (2015) found that 90% of donor families wished to receive correspondence from transplant recipients.
- Writing to a donor/donor family was found to empower transplant recipients (Colarusso, 2006) and reduce feelings of guilt (Coolican et al., 2007).
- It is hoped that this project would lead to recommendations to help healthcare professionals support transplant recipients with the letter writing process.



Why participate?

- You will be helping us to understand the process of holding conversations with transplant recipients about writing letters to organ donors/donor families.

Who can participate?

- If you are a healthcare professional in the pre-transplant or post-transplant team.



What does participation involve?

To take part or ask a question, contact:

- Rebecca Bird
(Rebecca.Bird@oxfordhealth.nhs.uk)

Supervisors:

- Louise Hankinson
(Louise.Hankinson@ouh.nhs.uk)
- Susannah Jenner
(Susannah.Jenner@hmc.ox.ac.uk)

Pre-transplant professionals:

- You will be invited to attend a focus group.

Post-transplant professionals:

- You will be invited to attend an individual interview.

Which will last approximately 30-45minutes.

Appendix G.
Consent form.



Rebecca Bird, Trainee Clinical Psychologist
University of Oxford
Rebecca.Bird@hmc.ox.ac.uk

Participant identification number: A123B

CONSENT FORM

**Evaluating the rate of correspondence between transplant recipients and donors
/donor families in the Oxford Transplant Centre (OTC).**

Researcher:
Rebecca Bird (Trainee Clinical Psychologist): Rebecca.Bird@hmc.ox.ac.uk,

Supervised by:
Dr Susannah Jenner (Clinical Psychologist); Susannah.Jenner@hmc.ox.ac.uk
and Dr Louise Hankinson (Clinical Psychologist); Louise.Hankinson@ouh.nhs.uk

If you agree, please initial in the box next to the five statements:

1. I confirm that I have had the opportunity to consider the study information, ask questions and have had these answered satisfactorily.	<input type="checkbox"/>
2. I understand that my participation is voluntary and that I am free to withdraw my data up until the point of transcription without giving any reason, and without repercussion.	<input type="checkbox"/>
3. I understand and give consent for the interview to be audio recorded.	<input type="checkbox"/>
4. I am happy for the researcher to email me with a hyperlink three months after my initial participation. The purpose of this is to answer two questions via an online survey.	<input type="checkbox"/>
5. I agree to the use of anonymised quotes in the dissemination of the findings.	<input type="checkbox"/>
6. I agree to take part in this study.	<input type="checkbox"/>

Name of Participant

Date

Signature

Date:

Signature

Consent form	Version/Date: May 2022
Evaluation of the Correspondence Between Organ Recipient and Donors in the Oxford Transplant Centre Rebecca Bird (Rebecca.Bird@hmc.ox.ac.uk)	Version 1

1

Interview schedule

Closed questions:

Question 1: How long have you worked in this role?

Question 2: How long have you worked in transplant altogether?

Question 3: On a scale of 1-5 to what extent does talking to an organ recipient about writing to a donor/ donor family form an important part of your job role (1=not important at all, 5= Extremely important)?

Question 4: On a scale of 1-5 how confident do you feel in holding conversations with organ recipients about writing to a donor/donor family? (1=not at all confident, 5= Extremely confident)?

Open questions:

Question 5: Can you tell me what you do currently, if anything, to raise the idea of writing a letter to their donor family/donor?

Question 6: What has informed your current practice?

Question 7: What are your views on recipients writing a letter of thanks to donors/donor families?

Question 8: To what extent do you think talking to an organ recipient about writing to a donor family should form an important part of your job role?

Question 9: What are some of the things that get in the way of you talking to a transplant recipient about writing to their donor/donor family?

Question 10: What are some of the things that are currently in place that support you in talking to an organ recipient about writing to a donor family?

Question 11: What else do you think you or the wider service could do to encourage more transplant recipients to write letters to their donors/donor families.

Appendix I.

Lay summary.

Recipients of organ transplants are informed about writing to a donor/donor family, and this is supported by NHS Blood and Transplant (NHSBT, n.d).

Aims: This service improvement project aimed to explore the current practice of talking with recipients about writing to the donor/donor family and to gain an understanding of facilitators and barriers with regards to this.

Strategy: Pre-transplant clinicians participated in a focus group and post-transplant clinicians participated in individual interviews. Questions explored clinician confidence, current practice of speaking with recipients about writing to donors, barriers, and the processes in place to support this conversation.

Results: A reflective thematic analysis was conducted to identify the key themes. Overall, most clinicians reported favourable attitudes to speaking to recipients about writing to a donor/donor family but stated that it should be acknowledged that this is a personal choice. The emotional heaviness of the conversation appeared an important factor especially if a recipient had an avoidant coping style or were not recovering as they hoped, post-transplant. It was noted that the purpose of the conversation may feel unclear to some clinicians, and this impacted on the clinician emotionally and on their approach. The practicalities of holding this conversation pre-transplant were also considered.

Recommendations: Several recommendations were derived from the data. One recommendation was made for annual reflective meetings, facilitated by the team

psychologist. This would allow the teams to explore and reflect on the purpose of the conversation as well as the emotional impact of the conversation. Another recommendation related to increasing recipient awareness of the possibility of letter writing (e.g., by displaying a poster in the waiting room/ward).

Appendix J.

Authors guidelines for Journal of Adoption and Fostering

2. Editorial policies

2.1 Peer review policy

SAGE does not permit the use of author-suggested (recommended) reviewers at any stage of the submission process, be that through the web-based submission system or other communication.

Reviewers should be experts in their fields and should be able to provide an objective assessment of the manuscript. Our policy is that reviewers should not be assigned to a paper if:

- The reviewer is based at the same institution as any of the co-authors
- The reviewer is based at the funding body of the paper
- The author has recommended the reviewer
- The reviewer has provided a personal (e.g. Gmail/Yahoo/Hotmail) email account and an institutional email account cannot be found after performing a basic Google search (name, department and institution).

2.2 Authorship

All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

2.3 Acknowledgements

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.

Please supply any personal acknowledgements separately to the main text to facilitate anonymous peer review.

2.3.1 Third party submissions

Where 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 statements must:

- Disclose this type of editorial assistance – including the individual’s name, company and level of input
- Identify any entities that paid for this assistance
- 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.

2.4 Funding

Adoption & Fostering requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

2.5 Declaration of conflicting interests

Adoption & Fostering encourages authors to include a declaration of any conflicting interests and recommends you review the good practice guidelines on the [SAGE Journal Author Gateway](#).

For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

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3. Publishing Policies

3.1 Publication ethics

SAGE is committed to upholding the integrity of the academic record. We encourage authors to refer to the Committee on Publication Ethics’ [International Standards for Authors](#) and view the Publication Ethics page on the [SAGE Author Gateway](#).

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If material has been previously published it is not generally acceptable for publication in a SAGE journal. However, there are certain circumstances where previously published material can be considered for publication. Please refer to the guidance on the [SAGE Author Gateway](#) or if in doubt, contact the Editor at the address given below.

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4. Preparing your manuscript for submission

4.1 Formatting

The preferred format for your manuscript is Word. LaTeX files are also accepted. Word and (La)Tex templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

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For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

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4.5 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

Appendix K.

Ethical Approval for Theory Driven Research Paper CUREC 1

From: MSD Ethics <ethics@medsci.ox.ac.uk>
Sent: 07 December 2022 14:15
To: Rebecca Bird <rebecca.bird@hmc.ox.ac.uk>
Cc: Clordsan Anderson <clordsan.anderson@hmc.ox.ac.uk>
Subject: R84006/RE001: Coping with Trauma when Caring - Secondary traumatic stress in foster carers - Approval & Letter

Dear Rebecca,
Thank you for submitting the documentation for your proposed research study to MS IDREC for ethical review.

The study titled 'Coping with Trauma when Caring – Secondary traumatic stress in foster carers' has been granted ethical approval, under reference R84006/RE001, for a period of 18 months commencing today (7th December 2022).

Please find a formal letter of approval attached.

For our records, please send clean versions of all documents (comments removed and tracked-changes accepted), with the version numbers re-set to 1.0 for each, and with the ethics approval reference inserted. Please also find attached your CUREC form, where I made a slight revision to the recruitment text. When you clean up your documents, please can you send the recruitment material in its' own separate document – this helps with the filing of your documents on our database system, for future reference.

Best wishes
Leah

Appendix L.

Study poster



Invitation to take part in research for foster carers

Coping with Trauma when Caring – Secondary Traumatic Stress in Foster Carers



What is this study about?

- ◆ **Secondary traumatic stress (STS)** is the emotional state that is felt when someone hears about the trauma experiences of another person.
- ◆ **Coping** occurs in response to stress, there are **many** coping styles.
- ◆ By taking part you will help us to develop our understanding of the relationship between coping styles and STS in foster carers.

Who can participate?

- ◆ As a foster carer you will have been exposed to **written** reports, stories told by children and young people, social workers or fellow foster carers that have traumatic content. We want to learn more about how this has affected you and how you cope.
- ◆ Current local authority or independent foster carers (sorry not kinship care).
- ◆ Living in the UK.
- ◆ Aged 18 years old and over.



What will taking part involve?

- ◆ This is an online study; you will be asked to complete 5 electronic questionnaires.
- ◆ The questionnaires will ask about your experience as a foster carer, signs of Secondary Traumatic Stress, coping styles, symptoms of anxiety and depression.
- ◆ This will take you approximately 20-30 minutes to complete.
- ◆ Your participation is voluntary.

Scan the QR code to take part

How to participate

- ◆ If you wish to participate, click this link: <https://rb.gv/lashpk>

(Or copy and paste to your internet browser)



If you have any comments/questions or complaints, please contact the researcher directly: Rebecca Bird (Main Researcher) at: Rebecca.Bird@hmc.ox.ac.uk or a research supervisor: Ciorsdan Anderson (Ciorsdan.Anderson@hmc.ox.ac.uk); Claire Holdaway (Claire.Holdaway@oxfordshire.gov.uk).

This study was approved by the University of Oxford's, Central University Research Ethics Committee (Ref: R84006/RE001).

Appendix M. Patient information sheet and consent form

V 1.0 Information sheet

Rebecca Bird
University Direct Line: 01865 226431
University e-mail: Rebecca.Bird@hmc.ox.ac.uk



Coping with Trauma when Caring – Secondary Traumatic Stress in Foster Carers.

CUREC Approval Reference: R84006/RE001

General Information

This study aims to develop our understanding of Secondary Traumatic Stress (STS) in foster carers. It is hoped that this could inform the support provided to better serve foster carer needs.

We appreciate your interest in participating in this online survey. You are invited to participate if you are a UK foster carer, 18 years and over. Regrettably, if you are a Kinship carer you are not able to participate in this study, because of your pre-existing relationship with the young person you care for. Please read through this information before agreeing to participate (if you wish to) by ticking the 'yes' boxes below.

You may ask any questions before deciding to take part by contacting the researcher (details below).

The Principal Researcher is Rebecca Bird, who is attached to the Oxford Institute of Clinical Psychology Training and Research at the University of Oxford. This project is being completed under the supervision of Dr Clorsdan Anderson (Consultant Clinical Psychologist and Dr Claire Holdaway (Chartered Consultant Clinical Psychologist) in collaboration with Oxfordshire County Council.

You will complete 5 questionnaires focusing on; your demographic information; Secondary Traumatic Stress; Coping styles; symptoms of anxiety and depression. This should take 20-30 minutes to complete.

Do I have to take part?

No, your participation is voluntary. If you do decide to take part, you may withdraw at any point for any reason by closing your browser. Your responses are anonymous therefore, once you have pressed 'submit' your responses cannot be deleted.

How will my data be used?

We will not collect any data that could directly identify you. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

Your responses will be stored in a password-protected electronic file on University of Oxford secure servers and may be used in academic publications and reports for external organisations. All data will be retained for a minimum of 3 years after the public release of the project in line with Oxford University policy. All information will conform to the 2018 Data Protection Act with respect to data collection, storage, and destruction.

Are there any possible disadvantages from taking part?

If answering the questionnaires highlights to you that you are either struggling with coping or raises feelings about your role as a carer, we strongly encourage you to discuss this with your supervising social worker. If you do not feel able to do this, we would strongly encourage you to contact your GP, Mind (0300 123 3393) or Samaritans (116123) to think through what support you can access.

Who will have access to my data?

Only the research team will have access to your data. The results will be written up for a doctoral thesis. You will find a summary of the results on Twitter: https://mobile.twitter.com/carer_research 6 months after participating or by contacting the research team (details below).

Who has reviewed this study?

This study was reviewed by, and received ethics clearance through, Oxfordshire County Council and a subcommittee of the University of Oxford Central University Research Ethics Committee (R84006/RE001).

Who do I Contact if I have concern, or wish to complain?

If you have concern about any aspect of this study, please speak to Rebecca Bird, (Rebecca.Bird@hmc.ox.ac.uk) or their supervisors, Dr Clorsdan Anderson (Clorsdan.Anderson@hmc.ox.ac.uk) and Dr Claire Holdaway (Claire.Holdaway@Oxfordshire.gov.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB.

1. Please note that you may only participate in this survey if you are 18 years of age or over. *

I certify that I am 18 years of age or over

2. Please note that you may only participate in this survey if you live in the United Kingdom (UK) *

I certify that I am a UK resident

3. Please note that you may only participate in this survey if you are a current foster carer *

I certify that I am a current foster carer

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

Yes, I agree to take part

Appendix N.

The Secondary Traumatic Stress Scale (STSS) for DSM-4 (Bride et al., 2004)

SECONDARY TRAUMATIC STRESS SCALE

The following is a list of statements made by persons who have been impacted by their work with traumatized clients. Read each statement then indicate how frequently the statement was true for you in the past **seven (7) days** by circling the corresponding number next to the statement.

NOTE: "Client" is used to indicate persons with whom you have been engaged in a helping relationship. You may substitute another noun that better represents your work such as consumer, patient, recipient, etc.

	Never	Rarely	Occasionally	Often	Very Often
1. I felt emotionally numb.....	1	2	3	4	5
2. My heart started pounding when I thought about my work with clients.....	1	2	3	4	5
3. It seemed as if I was reliving the trauma(s) experienced by my client(s).....	1	2	3	4	5
4. I had trouble sleeping.....	1	2	3	4	5
5. I felt discouraged about the future.....	1	2	3	4	5
6. Reminders of my work with clients upset me.....	1	2	3	4	5
7. I had little interest in being around others.....	1	2	3	4	5
8. I felt jumpy.....	1	2	3	4	5
9. I was less active than usual.....	1	2	3	4	5
10. I thought about my work with clients when I didn't intend to.....	1	2	3	4	5
11. I had trouble concentrating.....	1	2	3	4	5
12. I avoided people, places, or things that reminded me of my work with clients.....	1	2	3	4	5
13. I had disturbing dreams about my work with clients.....	1	2	3	4	5
14. I wanted to avoid working with some clients.....	1	2	3	4	5
15. I was easily annoyed.....	1	2	3	4	5
16. I expected something bad to happen.....	1	2	3	4	5
17. I noticed gaps in my memory about client sessions.....	1	2	3	4	5

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Intrusion Subscale (add items 2, 3, 6, 10, 13)	Intrusion Score	_____
Avoidance Subscale (add items 1, 5, 7, 9, 12, 14, 17)	Avoidance Score	_____
Arousal Subscale (add items 4, 8, 11, 15, 16)	Arousal Score	_____
TOTAL (add Intrusion, Arousal, and Avoidance Scores)	Total Score	_____

Bride, B.E., Robinson, M.R., Yegidis, B., & Figley, C.R. (2004). Development and validation of the Secondary Traumatic Stress Scale. *Research on Social Work Practice, 14*, 27-35.

Appendix O.

Brief Coping Orientation to Problems Experienced (*Brief COPE, Carver, 1997*)

		I haven't been doing this at all	A little bit	A medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real".	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better	1	2	3	4
5	I've been getting emotional support from others.	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened.	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people.	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I've been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope.	1	2	3	4
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I've been trying to get advice or help from other people about what to do.	1	2	3	4
24	I've been learning to live with it.	1	2	3	4
25	I've been thinking hard about what steps to take.	1	2	3	4
26	I've been blaming myself for things that happened	1	2	3	4
27	I've been praying or meditating	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

Appendix P.
GAD-7 and PHQ-8

GAD-7 Anxiety

Over the <u>last two weeks</u> , how often have you been bothered by the following problems?	Not at all	Several days	More than 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 is 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

Patient Health Questionnaire –8 (PHQ-8)

Name: _____

Date of Birth: _____

Today's Date: _____

Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Feeling down, depressed, irritable or hopeless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Trouble falling or staying asleep, or sleeping too much	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling tired or having little energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Poor appetite or overeating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Feeling bad about yourself – or that you are a failure or have let yourself or your family down	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Trouble concentrating on things, such as school work, reading or watching television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix Q. Demographic questions

65. To which gender identity do you most identify? *

- Female
- Male
- Prefer to self-identify
- Prefer not to say

66. Please self-identify your gender in the box below *

Enter your answer

67. What is your ethnic group? *

This is a 2-part question, choose one option that best describes your ethnic group or background

- White
- Mixed/Multiple ethnic groups
- Asian/Asian British
- Black/ African/Caribbean/Black British
- Other ethnic group

68. What is your ethnicity? *

- White English/Welsh/Scottish/Northern Irish/British
- White Irish
- White Gypsy or Irish Traveller
- Any other White background

69. What is your ethnicity? *

- White and Black African
- White and Black Caribbean
- White and Asian
- Any other Mixed/Multiple ethnic background please describe

70. What is your ethnicity? *

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background please describe

71. What is your ethnicity? *

- African
- Caribbean
- Any other Black/African/Caribbean background, please describe

72. What is your ethnicity? *

- Arab
- Any other ethnic group, please describe

73. Please state your ethnic group *

Enter your answer

74. What is your marital status? *

- Single
- Married
- Divorced
- Widowed
- Prefer not to say
- Other

75. What is your age? *

- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

76. What is the highest level of education you have completed? *

- Primary school
- Secondary school (up to 16 years)
- Higher or secondary or further education (A levels, BTEC, etc.)
- College or university
- Post-graduate degree
- Prefer not to say

77. Which type of foster carer describes you best? *

- Local authority
- Independent fostering agency
- other

78. How many people live in your home? *



Enter your answer

79. How many foster children have you cared for over the years (provide total estimate)? *

Enter your answer

80. How many years of experience do you have as a foster carer? Please round up to a full year. *

Enter your answer

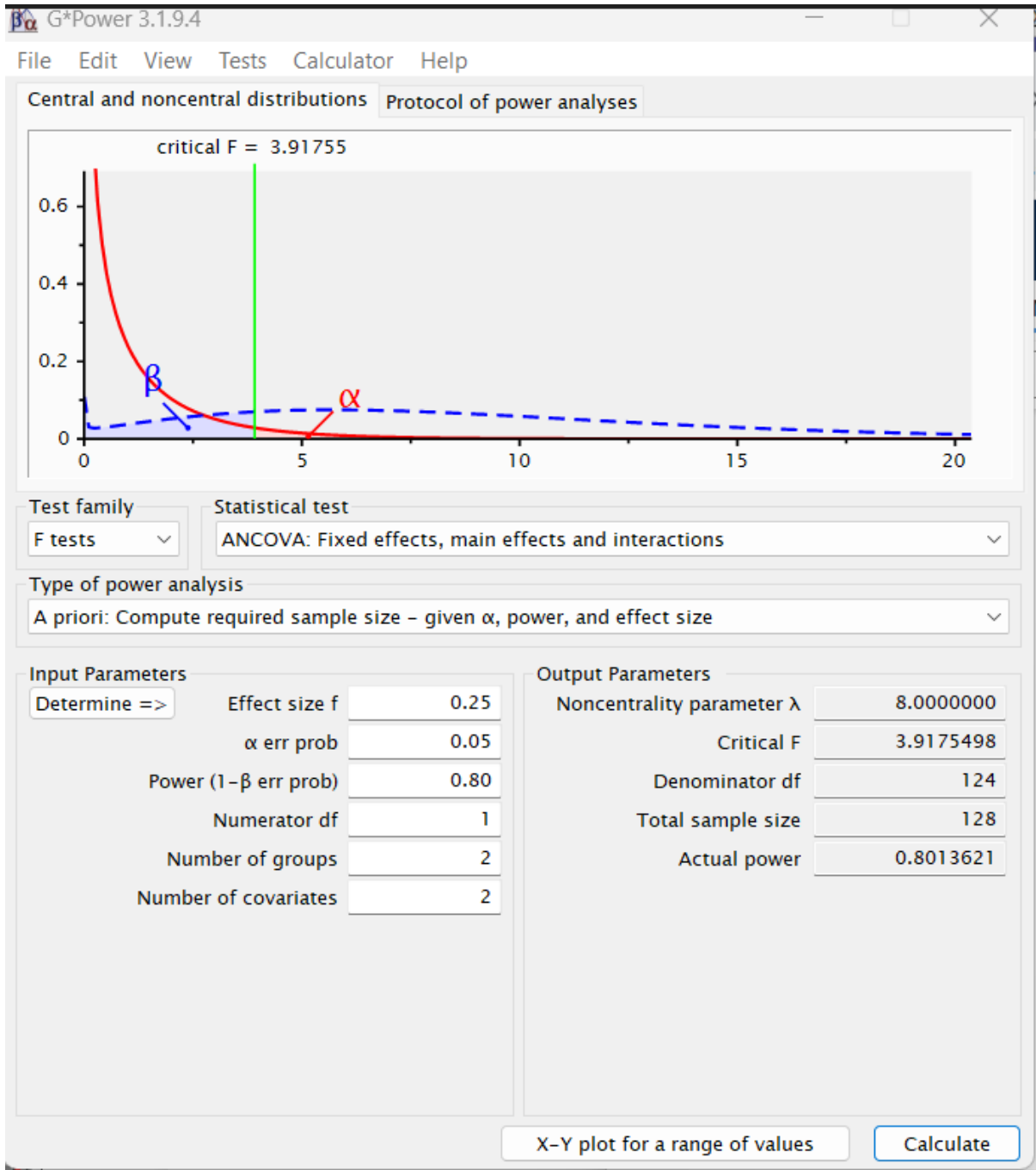
81. How many foster children do you currently care for? *

Enter your answer

Appendix R.
Signposting information

If answering the questionnaires highlights to you that you are either struggling with coping or raises feelings about your role as a carer, we strongly encourage you to discuss this with your supervising social worker. If you do not feel able to do this, we would strongly encourage you to contact your GP, Mind (0300 123 3393) or Samaritans (116123) to think through what support you can access.

Appendix S.
G*power calculation



Appendix T.
Analysis data

ANCOVA output for emotion-focused coping.

Tests of Between-Subjects Effects

Dependent Variable: E_12

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	8.232 ^a	2	4.116	6.024	.003	.085
Intercept	369.564	1	369.564	540.802	<.001	.807
phq_total	2.310	1	2.310	3.381	.068	.026
STS_total_1	1.084	1	1.084	1.586	.210	.012
Error	88.154	129	.683			
Total	1339.000	132				
Corrected Total	96.386	131				

a. R Squared = .085 (Adjusted R Squared = .071)

Estimates

Dependent Variable: E_12

STS_total_1	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
high	3.165 ^a	.105	2.957	3.374
low	2.936 ^a	.127	2.685	3.188

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

E_12			
STS_total_1	Mean	N	Std. Deviation
high	3.25000	76	.802081
low	2.82143	56	.876089
Total	3.06818	132	.857773

ANCOVA output for problem-focused coping.

Tests of Between-Subjects Effects

Dependent Variable: P_8

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	3.506 ^a	2	1.753	3.606	.030	.053
Intercept	343.292	1	343.292	706.200	<.001	.846
phq_total	.235	1	.235	.484	.488	.004
STS_total_1	3.026	1	3.026	6.224	.014	.046
Error	62.708	129	.486			
Total	1040.547	132				
Corrected Total	66.214	131				

a. R Squared = .053 (Adjusted R Squared = .038)

Estimates

Dependent Variable: P_8

STS_total_1	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
high	2.879 ^a	.089	2.703	3.055
low	2.497 ^a	.107	2.285	2.709

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

P_8

STS_total_1	Mean	N	Std. Deviation
high	2.8520	76	.61329
low	2.5335	56	.79469
Total	2.7169	132	.71095

ANCOVA output for Avoidant coping.

Tests of Between-Subjects Effects

Dependent Variable: A_8

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	22.540 ^a	2	11.270	26.089	<.001	.288
Intercept	141.490	1	141.490	327.541	<.001	.717
phq_total	7.446	1	7.446	17.237	<.001	.118
STS_total_1	2.194	1	2.194	5.080	.026	.038
Error	55.725	129	.432			
Total	685.000	132				
Corrected Total	78.265	131				

a. R Squared = .288 (Adjusted R Squared = .277)

Estimates

Dependent Variable: A_8

STS_total_1	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
high	2.282 ^a	.084	2.116	2.448
low	1.957 ^a	.101	1.757	2.156

Covariates appearing in the model are evaluated at the following values:

phq_total = 7.2197.

Report

A_8

STS_total_1	Mean	N	Std. Deviation
high	2.4342	76	.75429
low	1.7500	56	.61051
Total	2.1439	132	.77294

ANCOVA- Active coping facet

Tests of Between-Subjects Effects

Dependent Variable: neg_active

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.156 ^a	2	.078	2.279	.107	.034
Intercept	3.367	1	3.367	98.139	<.001	.432
phq_total	.070	1	.070	2.027	.157	.015
STS	.155	1	.155	4.522	.035	.034
Error	4.425	129	.034			
Total	16.461	132				
Corrected Total	4.582	131				

a. R Squared = .034 (Adjusted R Squared = .019)

STS

Dependent Variable: neg_active

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	.263 ^a	.024	.217	.310
Low	.350 ^a	.028	.294	.406

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Active_coping

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	2.9474	.76846
Low	56	2.7500	2.6607	.94440
Total	132	3.0000	2.8258	.85602

ANCOVA- Planning facet

Tests of Between-Subjects Effects

Dependent Variable: neg_planning

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.290 ^a	2	.145	3.924	.022	.057
Intercept	3.702	1	3.702	100.009	<.001	.437
phq_total	.030	1	.030	.820	.367	.006
STS	.093	1	.093	2.505	.116	.019
Error	4.775	129	.037			
Total	13.854	132				
Corrected Total	5.066	131				

a. R Squared = .057 (Adjusted R Squared = .043)

STS

Dependent Variable: neg_planning

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	.230 ^a	.025	.181	.278
Low	.297 ^a	.030	.238	.355

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Planning

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	3.1842	.76960
Low	56	3.0000	2.7500	.96295
Total	132	3.0000	3.0000	.88023

ANCOVA Self-blame facet

Tests of Between-Subjects Effects

Dependent Variable: pos_self_blame

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	1.781 ^a	2	.890	32.153	<.001	.333
Intercept	1.531	1	1.531	55.289	<.001	.300
phq_total	.685	1	.685	24.729	<.001	.161
STS	.118	1	.118	4.273	.041	.032
Error	3.572	129	.028			
Total	16.964	132				
Corrected Total	5.353	131				

a. R Squared = .333 (Adjusted R Squared = .322)

STS

Dependent Variable: pos_self_blame

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	.329 ^a	.021	.287	.371
Low	.253 ^a	.026	.202	.304

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

self_Blame

STS	N	Median	Mean	Std. Deviation
High	76	2.5000	2.5789	.97997
Low	56	1.5000	1.6696	.64157
Total	132	2.0000	2.1932	.96236

ANCOVA output for positive reframing

Tests of Between-Subjects Effects

Dependent Variable: Positive_Reframing

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	1.354 ^a	2	.677	.829	.439	.013
Intercept	280.089	1	280.089	342.971	<.001	.727
phq_total	.277	1	.277	.339	.562	.003
STS	1.314	1	1.314	1.609	.207	.012
Error	105.349	129	.817			
Total	889.750	132				
Corrected Total	106.703	131				

R Squared = .013 (Adjusted R Squared = -.003)

STS

Dependent Variable: Positive_Reframing

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.542 ^a	.115	2.314	2.771
Low	2.291 ^a	.139	2.016	2.565

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Positive_Reframing

STS	N	Median	Mean	Std. Deviation
High	76	2.5000	2.5132	.85234
Low	56	2.0000	2.3304	.96426
Total	132	2.5000	2.4356	.90251

ANCOVA output for Humour

Tests of Between-Subjects Effects

Dependent Variable: Humour

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	4.663 ^a	2	2.331	2.617	.077	.039
Intercept	139.585	1	139.585	156.709	<.001	.548
phq_total	1.114	1	1.114	1.251	.266	.010
STS	.772	1	.772	.866	.354	.007
Error	114.903	129	.891			
Total	598.750	132				
Corrected Total	119.566	131				

a. R Squared = .039 (Adjusted R Squared = .024)

Report

Humour

STS	N	Median	Mean	Std. Deviation
High	76	2.0000	2.0461	.93516
Low	56	1.2500	1.7143	.95754
Total	132	1.5000	1.9053	.95536

STS

Dependent Variable: Humour

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	1.987 ^a	.120	1.749	2.225
Low	1.794 ^a	.145	1.507	2.081

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

ANCOVA output for acceptance

Tests of Between-Subjects Effects

Dependent Variable: Acceptance

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	1.085 ^a	2	.542	.862	.425	.013
Intercept	346.356	1	346.356	550.173	<.001	.810
phq_total	1.081	1	1.081	1.717	.192	.013
STS	.453	1	.453	.720	.398	.006
Error	81.211	129	.630			
Total	1182.000	132				
Corrected Total	82.295	131				

a. R Squared = .013 (Adjusted R Squared = -.002)

STS

Dependent Variable: Acceptance

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.824 ^a	.101	2.623	3.024
Low	2.972 ^a	.122	2.730	3.213

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Acceptance

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	2.8816	.70649
Low	56	3.0000	2.8929	.90310
Total	132	3.0000	2.8864	.79260

ANCOVA output for religion

Tests of Between-Subjects Effects

Dependent Variable: Religion

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.425 ^a	2	.212	.215	.807	.003
Intercept	125.798	1	125.798	127.068	<.001	.496
phq_total	.005	1	.005	.005	.946	.000
STS	.230	1	.230	.232	.631	.002
Error	127.711	129	.990			
Total	501.500	132				
Corrected Total	128.136	131				

a. R Squared = .003 (Adjusted R Squared = -.012)

STS

Dependent Variable: Religion

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	1.727 ^a	.127	1.475	1.978
Low	1.621 ^a	.153	1.319	1.923

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Religion

STS	N	Median	Mean	Std. Deviation
High	76	1.2500	1.7303	.92535
Low	56	1.0000	1.6161	1.07446
Total	132	1.0000	1.6818	.98901

ANCOVA output for planning

Tests of Between-Subjects Effects

Dependent Variable: neg_planning

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	.290 ^a	2	.145	3.924	.022	.057
Intercept	3.702	1	3.702	100.009	<.001	.437
phq_total	.030	1	.030	.820	.367	.006
STS	.093	1	.093	2.505	.116	.019
Error	4.775	129	.037			
Total	13.854	132				
Corrected Total	5.066	131				

STS

Dependent Variable: neg_planning

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	.230 ^a	.025	.181	.278
Low	.297 ^a	.030	.238	.355

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Planning

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	3.1842	.76960
Low	56	3.0000	2.7500	.96295
Total	132	3.0000	3.0000	.88023

ANCOVA for self-distraction

Tests of Between-Subjects Effects

Dependent Variable: Self_distraction

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	20.278 ^a	2	10.139	19.833	<.001	.235
Intercept	231.345	1	231.345	452.525	<.001	.778
phq_total	3.807	1	3.807	7.446	.007	.055
STS	4.349	1	4.349	8.507	.004	.062
Error	65.949	129	.511			
Total	941.500	132				
Corrected Total	86.227	131				

a. R Squared = .235 (Adjusted R Squared = .223)

STS

Dependent Variable: Self_distraction

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.740 ^a	.091	2.559	2.920
Low	2.282 ^a	.110	2.064	2.499

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Self_distraction

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	2.8487	.69292
Low	56	2.0000	2.1339	.78330
Total	132	2.5000	2.5455	.81131

ANCOVA for emotional support

Tests of Between-Subjects Effects

Dependent Variable: Emotional_support

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	4.525 ^a	2	2.263	3.444	.035	.051
Intercept	341.257	1	341.257	519.496	<.001	.801
phq_total	1.066	1	1.066	1.623	.205	.012
STS	4.444	1	4.444	6.765	.010	.050
Error	84.740	129	.657			
Total	1012.000	132				
Corrected Total	89.265	131				

a. R Squared = .051 (Adjusted R Squared = .036)

STS

Dependent Variable: Emotional_support

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.840 ^a	.103	2.636	3.045
Low	2.377 ^a	.124	2.131	2.623

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Emotional_support

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	2.7829	.86539
Low	56	2.5000	2.4554	.73408
Total	132	2.5000	2.6439	.82548

ANCOVA for use of informational support

Tests of Between-Subjects Effects

Dependent Variable: Use_of_informational_support

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	5.149 ^a	2	2.575	3.429	.035	.050
Intercept	325.870	1	325.870	433.974	<.001	.771
phq_total	.728	1	.728	.970	.327	.007
STS	4.820	1	4.820	6.419	.012	.047
Error	96.866	129	.751			
Total	998.500	132				
Corrected Total	102.015	131				

a. R Squared = .050 (Adjusted R Squared = .036)

STS

Dependent Variable: Use_of_informational_support

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.811 ^a	.111	2.592	3.029
Low	2.328 ^a	.133	2.065	2.592

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Use_of_informational_support

STS	N	Median	Mean	Std. Deviation
High	76	3.0000	2.7632	.85819
Low	56	2.0000	2.3929	.87757
Total	132	2.5000	2.6061	.88246

ANCOVA for use of venting

Tests of Between-Subjects Effects

Dependent Variable: Venting

Source	Type III Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared
Corrected Model	9.382 ^a	2	4.691	10.832	<.001	.144
Intercept	160.356	1	160.356	370.276	<.001	.742
phq_total	2.047	1	2.047	4.726	.032	.035
STS	1.729	1	1.729	3.992	.048	.030
Error	55.866	129	.433			
Total	640.250	132				
Corrected Total	65.248	131				

a. R Squared = .144 (Adjusted R Squared = .131)

STS

Dependent Variable: Venting

STS	Mean	Std. Error	95% Confidence Interval	
			Lower Bound	Upper Bound
High	2.210 ^a	.084	2.044	2.376
Low	1.921 ^a	.101	1.721	2.121

a. Covariates appearing in the model are evaluated at the following values: phq_total = 7.2197.

Report

Venting

STS	N	Median	Mean	Std. Deviation
High	76	2.5000	2.2895	.68927
Low	56	2.0000	1.8125	.63649
Total	132	2.0000	2.0871	.70575

Mann-Whitney U output for substance use

Ranks

	STS	N	Mean Rank	Sum of Ranks
Unstandardized Residual	High	76	84.01	6385.00
	Low	56	42.73	2393.00
	Total	132		

Test Statistics^a

	Unstandardized Residual
Mann-Whitney U	797.000
Wilcoxon W	2393.000
Z	-6.143
Asymp. Sig. (2-tailed)	<.001

a. Grouping Variable: STS

Report

Substance_use

STS	N	Median	Mean
High	76	1.0000	1.3553
Low	56	1.0000	1.0714
Total	132	1.0000	1.2348

Mann-Whitney *U* output for behavioural disengagement

Test Statistics^a

	Unstandardized Residual
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Mann-Whitney U	1135.500
Wilcoxon W	2731.500
Z	-4.576
Asymp. Sig. (2-tailed)	<.001

a. Grouping Variable: STS

Ranks

	STS	N	Mean Rank	Sum of Ranks
Unstandardized Residual	High	76	79.56	6046.50
	Low	56	48.78	2731.50
	Total	132		

Report

Behavioural_disengagement

STS	N	Median	Mean
High	76	1.5000	1.7829
Low	56	1.0000	1.1161
Total	132	1.0000	1.5000

Mann-Whitney U output for denial

Ranks

	STS	N	Mean Rank	Sum of Ranks
Unstandardized Residual	High	76	84.32	6408.00
	Low	56	42.32	2370.00
	Total	132		

Test Statistics^a

Unstandardized
Residual

Mann-Whitney U	774.000
Wilcoxon W	2370.000
Z	-6.240
Asymp. Sig. (2-tailed)	<.001

a. Grouping Variable: STS

Report

Denial

STS	N	Median	Mean
High	76	1.5000	1.6842
Low	56	1.0000	1.2679
Total	132	1.0000	1.5076