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Abstracts

Critical Review of the Literature Abstract

Background: Parents of children and young people with Obsessive Compulsive Disorder (OCD) often "accommodate" (adapt their behaviour), attempting to help alleviate their child's distress. However, the varying types and function of accommodation that can be exhibited are poorly understood. **Aims:** This systematic review aimed to evaluate the types of parental accommodation. It also aimed to evaluate how these types of accommodation relate to the cognitive behavioural understanding of OCD, and the implications for treatment. **Method:** The databases searched in this systematic review were Scopus, Web of Science, CINAHL, PsycINFO, Ovid SP, ProQuest Dissertations & Theses Global, ProQuest ASSIA Applied Social Sciences Index and Abstracts, and Proquest Sociology Collection. Publication dates ranged from January 2008 to May 2021. Studies were included if they were peer reviewed, quantitative articles or review papers, used cognitive-behavioural theory, used a sample of children and young people with OCD, and accommodation was explored descriptively or categorically. **Results:** The search returned 1124 papers; 68 papers were selected for detailed screening. One additional paper was included from citation and hand searches. A final 11 papers were identified for the review. All papers demonstrated the presence of five theoretically derived categories of accommodation behaviours. However, some categories identified in papers overlapped as accommodation is mainly measured and operationalised by topography rather than function. **Conclusions:** The findings suggest accommodation is frequently observed in young people with OCD. Further research should examine how distinct these categories are in terms of function as present measures of accommodation overlook the function of and motivation for such behaviour

Service Improvement Project Abstract

Background: Across the UK, autistic young people receive very little post-diagnostic support despite the importance highlighted in policies and best practice guidelines. This study reported on a service improvement project exploring the needs of young people post-diagnosis and delivering a service user informed post-diagnostic support package. **Method**: A sample of twenty-two (n = 22) young people aged 13-18, and their parents, who were diagnosed within the last year were recruited using purposive sampling within a CAMHS service in Oxfordshire, UK. The research was in two phases. Phase one gathered feedback from young people and parents on what support they had and what support they would like post-diagnosis. Phase two was a tailor-made post-diagnostic support package in line with their feedback. **Results**: The results of phase one indicated a need for young people to meet and hear from others diagnosed with autism , as well as speak to a clinician. The results from phase two found young people enjoyed a live space to meet other autistic young people and found the chance to speak to a clinician and have their views heard valuable. **Conclusions**: Further improvement and provision of post-diagnostic support for young people is needed. Post-diagnostic support is recommended to be routinely offered to young people in services.

Theoretically Driven (Main) Research Paper Abstract

Background: Current research suggests that foster carers experience higher carer stress than biological parents and face more behaviours that challenge from the children they care for. Reflective functioning (the ability to view one's own mental state separately to the child's; viewing them as a separate, independent entity) may facilitate foster carers to persevere when highly stressed and faced with behaviours that challenge. Wellbeing

factors may also play such a role. **Aims:** This study aimed to explore whether foster carers who are highly stressed also report their foster child to have higher levels of behaviours that challenge. It also aimed to explore whether higher stress impacted upon a carer's ability to use reflective functioning and their wellbeing. Finally, it explored whether wellbeing moderated the impact of behaviours that challenge. **Method:** Seventy-eight (n = 78) foster carers took part by completing online questionnaires. The highest and lowest scoring forty-six (n = 46) foster carers on a measure of carer stress were compared. The total sample was used to explore whether wellbeing was a moderator in a regression model. **Results:** The results showed that carers with high parental stress reported higher levels of behaviours that challenge and had lower levels of wellbeing. Reflective functioning abilities did not differ between the high and low stress groups. Wellbeing did not moderate the impact behaviours that challenge had on carer stress. **Conclusions:** Further research is required to explore variability in reflective functioning abilities in foster carers, and factors that help moderate the impact of factors that increase carer stress.

Critical Review of the Literature

"It ain't what you do but the way that you do it": A Systematic Review Exploring Parental Accommodation towards a Young Person's OCD.

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Conflict of interest: Professor Paul Salkovskis is editor of the proposed journal.

The data that support the findings of this study are available from the corresponding author, AH, upon reasonable request. Relevant papers can be found in the appendices.

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Journal structure: Behavioural and Cognitive Psychotherapy.

Rationale: This journal is dedicated to the advancement of the theory and evidence-base for Cognitive Behavioural Theory. It welcomes a broad range of design, and has an impact factor of 1.657. It is 76th out of 130 journals related to clinical psychology.

Abstract

Background: Parents of children and young people with Obsessive Compulsive Disorder (OCD)often "accommodate" (adapt their behaviour), attempting to help alleviate their child's distress. However, the varying types and function of accommodation that can be exhibited are poorly understood. **Aims:** This systematic review aimed to evaluate the types of parental accommodation. It also aimed to evaluate how these types of accommodation relate to the cognitive behavioural understanding of OCD, and the implications for treatment. **Method:** The databases searched in this systematic review were Scopus, Web of Science, CINAHL, PsycINFO, Ovid SP, ProQuest Dissertations & Theses Global, ProQuest ASSIA Applied Social Sciences Index and Abstracts, and Proquest Sociology Collection. Publication date ranged from January 2008 to May 2021. Studies were included if they were peer reviewed, quantitative articles or review papers, used cognitive-behavioural theory, used a sample of children and young people with OCD, and accommodation was explored descriptively or categorically. **Results:** The search returned 1124 papers; 68 papers were selected for detailed screening. One additional paper was included from citation and hand searches. A final 11 papers were identified for the review. All papers demonstrated the presence of five theoretically derived categories of accommodation behaviours. However, some categories identified in papers overlapped as accommodation is mainly measured and operationalised by topography rather than function. **Conclusions:** The findings suggest accommodation is frequently observed in young people with OCD. Further research should examine how distinct these categories are in terms of function as present measures of accommodation overlook the function of and motivation for such behaviour.
Keywords: obsessive compulsive disorder; accommodation; cognitive behavioural theory

Introduction

Obsessive Compulsive Disorder (OCD) is characterised by the presence of recurrent intrusions that are followed by distress (e.g. anxiety, guilt) and compulsions which attempt to manage the distress and reduce perceived dangerousness linked to the intrusions (Turner, 2006, American Psychiatric Association, 2013). OCD presents similarly in children and young people (CYP) as in adults, yet with some differences in symptomology, insight, or content of intrusions (Kalra & Swedo, 2009, Krebs & Heyman, 2015). Cognitive-behavioural theory (CBT) of OCD consolidates traditional behavioural theories and interventions for OCD with cognitive theory (Beck, 1976, Rachman, 1993, 1998, Salkovskis, 1985, 1989). The theory emphasises the importance of the meaning attached to the intrusions, particularly responsibility appraisals, whereby an inflated sense of responsibility and accountability for harm is held in relation to the intrusions (Salkovskis & Freeston, 2001). As such, safety-seeking behaviours are motivated primarily to reduce both harm and responsibility for it, to thus increase safety, and usually therefore to reduce the distress. Overt behavioural responses (safety seeking) include avoidance, reassurance seeking, or rituals, and covert responses include mental rituals, neutralisation, and thought suppression or replacement (Salkovskis, 1999). There are at least three *intrapersonal* categories of safety seeking behaviours seen within OCD as outlined by CBT and phenomenology (Cougle, Lee & Salkovskis, 2007):

1) *Avoidance:* of certain feared situations, of thoughts, or of others
2) *Restitution:* this is future oriented and is the need to 'put something right'. Restitution often corresponds to washing behaviours
3) *Verification:* this is past oriented, and is the uncertainty and therefore need to verify based on "I'm unsure if I have or haven't done something, so I need to make sure"

Interpersonal strategies are also important. The National Institute for Health and Care Excellence (NICE) guidelines recommend involving family or carers in treatment, and the consideration of psychosocial and family factors in relation to a CYP's OCD (NICE, 2005). This is of importance as a bi-directional relationship of OCD within families has been identified, suggesting that "families influence and are affected by OCD" (Flessner et al., 2011, p. 716). Cognitive-behavioural family treatment (CBFT) considers parental influences and requires one or more parents to attend the majority of treatment sessions (Freeman et al., 2014, Iniesta-Sepúlveda et al., 2017). CBFT has been found to be effective in the treatment of childhood OCD in reducing symptom severity, with improvements maintained at 6 month follow up (POTS, 2004, Barrett, Healy-Farrell & March, 2004, Iniesta-Sepúlveda et al., 2017). The role of family and parents in relation to the maintenance of a CYP's OCD must therefore be considered.

Research in OCD has examined how parents alter their behaviours in response to their child's symptoms and rituals. One such response is parental "accommodation", whereby a parent engages in certain behaviours or responses in ways directly related to their child's obsessional experience in an attempt to manage, reduce or prevent the distress their child's experiences (Flessner et al., 2011, Shimshoni et al., 2019). Accommodation is usually due to parents wanting to respond helpfully to the OCD or to minimise its impact (Futh, Simonds & Micali, 2012). This involvement has predominantly been reported as having an unhelpful role because it is believed to be involved in the maintenance of the OCD because it may encourage the child to avoid and/or ritualise. However, it is also important to consider the developmental needs of children, and nuanced differences and normative ways parents respond dependant on their age and stage. The most widely reported manifestations include avoidance, reassurance giving, complying or participating in the child's rules or rituals, and adapting

family norms or routines (Storch et al., 2010, Thompson-Hollands et al., 2014, Wu et al., 2019, Zavrou et al., 2019). By doing so, the parents can appear to be involved in worsening the OCD process (Shimshoni et al., 2019).

Although parental accommodation has been found in a wide range of mental health problems, it is noted to be particularly prominent in OCD (Shimshoni et al., 2019). Findings suggesting that as many as 99% of parents report accommodating their child's OCD in some way (Flessner et al., 2011a). Higher levels of family accommodation are associated with symptom severity and poorer treatment outcomes (Stewart et al., 2008, Flessner et al., 2011a, Lebowitz et al., 2012, Strauss, Hale & Stobie, 2015, Lebowitz, Panza & Bloch, 2016, Wu et al., 2016). More overt forms of OCD are found to be accommodated more frequently, notably contamination intrusions (Wu et al., 2014). Treatment trials have therefore included parental accommodation reduction as a component within cognitive-behavioural therapy , and interventions are increasingly targeting accommodation directly (Lebowitz, Omer, Hermes & Scahill, 2014, Lebowitz, Panza & Block, 2016, Shimshoni et al., 2019). Using CBFT, a moderate effect size was found in relation to reduction of parental accommodation (Iniesta-Sepúlveda et al., 2017). However, such interventions have not been disaggregated from the broader CBT package.

One account of why parental accommodation may occur so frequently in OCD lies in the importance given to responsibility for harm to self or others. The Salkovkis OCD model places emphasis on responsibility appraisals, whereby intrusions lead to heightened fear and a sense of responsibility (1999). The inflated responsibility model suggests that intrusive thoughts are misinterpreted, and the individual believes they have personal responsibility to prevent harm from occurring (Mitchell, Hanna & Dyer, 2020). Reassurance seeking and safety seeking behaviours are thus used to protect and discharge

some of the responsibility from the self, thereby lessening the amount of responsibility held and lessening distress (Kobori & Salkovskis, 2012). As such, a ritual that involves other people does not only deal with threat, but also with responsibility for other people.

Parental accommodation has therefore been found to be prominent within CYP OCD using a range of measurement strategies. Frequently used parental accommodation measurements are based on the original Family Accommodation Scale (FAS) (Calvocoressi et al., 1999, Flessner et al., 2011a). Other commonly used measures of accommodation are the FAS-Parent Report (FAS-PR) and the FAS-Anxiety (FASA) (Flessner et al., 2011b, Lebowitz et al., 2013). Although these measures are generic and not developmentally or age-specific, they are the primary available measures of accommodation that are widely used. Current literature has not systemically examined or synthesised the types of accommodation found in current research going beyond the purely descriptive. Based on the three intrapersonal safety-seeking behaviours outlined above, theory and phenomenology would suggest the following as functionally equivalent broad *interpersonal* categories for accommodation:

1) *Avoidance:* asking other people for and being given avoidance strategies, or avoidance of responsibility. For example, asking family not to use particular words, not going into certain areas due to contamination fears
2) *Reassurance seeking and giving:* seeking and receiving reassurance in a way that leads to the interpersonal transfer or sharing of responsibility in order to amplify the extent of the checking. Examples include asking another person to do the ritual for them as a proxy, such as checking a door (Halldorsson, 2015, Halldorsson et al., 2016, Halldorsson & Salkovskis, 2017)

3) *Enabling the ritual/modification:* enabling the rituals to continue so as to not disrupt the process, such as changing family norms and rituals, and allowing the shift of responsibility
4) *Doing the ritual for the child:* this includes checking, buying new clothes, washing clothes, and typically involves responsibility transfer
5) *Prevention:* this is a form of avoidance but can be used before the feared event even happens e.g. preventing contamination occurring. This is intended to prevent responsibility for harm occurring.

Previous reviews have explored types of accommodation within OCD, looking at correlates of family accommodation, factors that increase levels of accommodation, and its relation to treatment outcomes (Lebowitz et al., 2012, Lebowitz et al., 2016, Shimshoni et al., 2019). However, they have included both child and adult samples given the prevalence of accommodation in adult OCD. The accommodation themes identified as consistent forms of accommodation in the three prior reviews were avoidance of triggers, participation, enabling/modification, and reassurance. Shimshoni et al.'s review explored family accommodation more generally (i.e. any family member accommodating the disorder of any other family member) in relation to a number of disorders including OCD (2019). They identified similar types of accommodation across various anxiety disorders. We aim to add to the existing literature by synthesising the types of parental accommodation in CYP OCD with reference to psychological theory. The present review will examine the ways that accommodation is exhibited by identifying different subtypes of accommodation. It will aim to answer the following questions:

- What are the types of parental accommodation exhibited in relation to a child or young person's OCD?

- How do these types of accommodation relate to the CBT theoretical framework, and what are the implications for treatment?

One possible clinical application from this review may be that certain types of accommodation are identified with varying functions, motives and style. Differing categories of accommodation will therefore require different approaches and management strategies, and have differing implications for support and interventions.

Methods

Eligibility criteria

An integrative review was conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). The inclusion criteria were (1) peer reviewed quantitative articles or review papers, (2) cognitive-behavioural theory used as a framework to ensure specificity for clinical recommendations, (3) a sample of children and young people with OCD (maximum age 18), and (4) themes of accommodation being explored descriptively or categorically. Studies were excluded if they (1) were qualitative, mixed methods or a case study (2) used a non-Western sample (in consideration of wider systemic factors), (3) used a sample of non-biological relatives, foster, or adoptive families (4) used a non-OCD sample or an adult sample, (5) did not evaluate accommodation, or it was explored as a broad category without subtypes.

Search strategy

The full review protocol can be found on Prospero. The databases searched were Scopus, Web of Science, CINAHL, PsycINFO, Ovid SP, ProQuest Dissertations & Theses Global, ProQuest ASSIA Applied Social Sciences Index and Abstracts, and Proquest Sociology Collection. To account for more recent publications, publication date was filtered from 2008 to the date of the search, with the initial search being conducted in

March 2020 then repeated in May 2021 to include emerging literature. The search was limited to 2008 onwards as earlier literature on accommodation was emerging, and previous reviews had explored the earlier literature. Parental accommodation was defined as a parent altering their behaviours and family norms to accommodate and adjust to OCD symptoms. The search terms were (accommodation) and ("obsessive compulsive disorder" or rituals or OCD) and (parental or family) and (Child or Adolescen* or Young Per* or Young Peo*) and (CBT or Cognitive Behav* The*). Endnote was used to import references from each database, and duplicates were removed.

Selection of articles and synthesis

Titles and abstracts were reviewed as a minimum, and the most relevant papers were read in full and quality assessed. Papers which met inclusion criteria from abstract screening were then read in full text and checked for oversight or bias by a peer-reviewer (JM). Citation searches and hand search were then conducted on all papers included in the review.

Quality assessment

As there are no suitable quality assessment tools for cross-sectional studies, an adapted tool was developed (Appendix A). The questions were developed from the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies tool and from the Critical Appraisal Skills Programme (CASP) checklist (CASP, 2019, NHLBI, 2020). A points system with an overall quality score was used. All papers were also reviewed by a peer reviewer (JM) who independently completed a quality check using the adapted quality assessment tool for reliability checks to minimise bias. Differences in scoring were then discussed and reconciled.

Results

The database search returned 1280 papers, which reduced to 956 after duplicates were removed. Following the initial screen of titles and abstracts, 47 papers were selected based on the inclusion/exclusion criteria. All papers were read in full text and considered against the inclusion and exclusion criteria, then checked for oversight or bias by a peer-reviewer (JM) (see Appendix B for excluded papers). No disputes were raised during the peer-review process for papers included and excluded. Of the 47 papers read in full and compared against the inclusion/exclusion criteria, 9 were eligible to be included in this review. Citation and hand searches were then conducted on all 9 papers on Scopus and Web of Science. 7 additional papers were identified through citation and hand searching and also read in full; only 1 additional paper met inclusion criteria and was included in the review (Monzani et al., 2020). Following the re-run in 2021, an additional 168 papers were identified, and subjected to the review process. One additional paper was identified and included in this review. In total, there were 11 papers from initial search and secondary citation or hand searches which met the inclusion criteria. All 11 were quality assessed using the adapted quality assessment tool (Appendix A.). All were also quality assessed by a second reviewer (JM). Inter-rater review showed near perfect agreement bar one exception. This was on question 7 for Peris et al. (2008a) (Table 2). An agreement was reached as the measure is not widely used but was developed only for that paper. Figure 1. outlines the process selection.

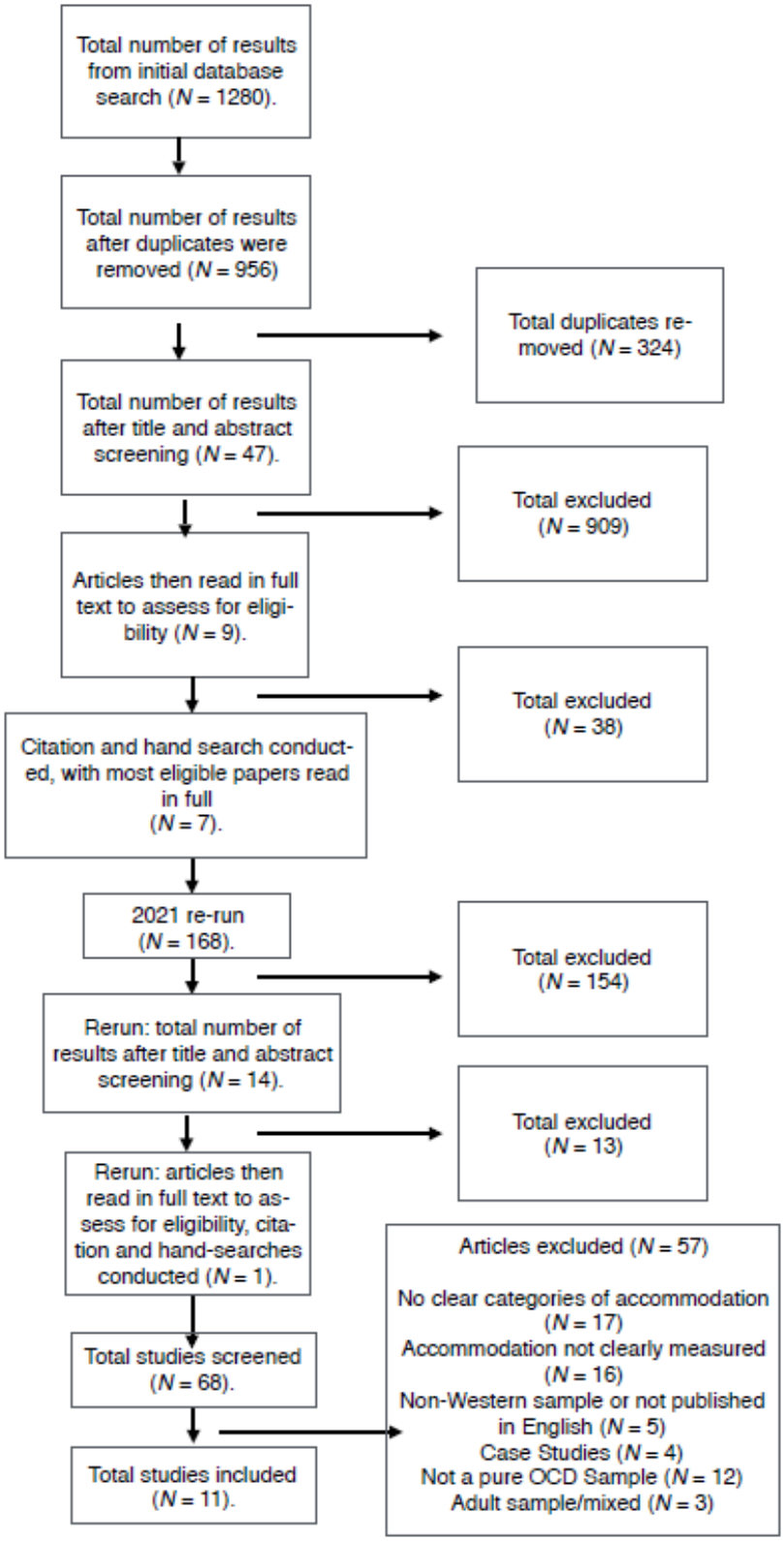


Figure 1. Flow chart depicting the process of paper selection.

The primary data extracted from the studies were the participant numbers, the clinical group (OCD only, or OCD as compared with other anxiety disorders or a control group), and the themes of accommodation reported. Table 1. depicts the characteristics of all the final studies included in the review. All studies identified were carried out in the USA and UK and published between 2008 and 2020. Six studies took place in a university clinic, three in OCD specialist clinics, two in outpatient settings, two in the community, and one in an inpatient setting. Eight papers were cross-sectional, and three were longitudinal studies. Sample sizes ranged between 23 and 209, and the total participant number included in this review was 1076 (910 OCD sample).

A total of five different measures of accommodation were used. Measures of family accommodation are based on the original Family Accommodation Scale (FAS), a 12-item clinician-administered scale which shows good internal consistency, reliability, and validity (Calvocoressi et al., 1999, Flessner et al., 2011b). The scale has been found to explore the wider categories of accommodation: participation, modification, and distress/consequences of accommodation (Albert et al., 2010). Four papers used the original FAS or the similar FAS-Interviewer Rated (FAS-IR) measure. An adapted version of the FAS is the FAS-Parent Report (FAS-PR), a 13-item measure which was developed as a parent-report version for childhood OCD (Flessner et al., 2011b). Three papers in this review used the FAS-PR. Another version of the FAS is the FAS-Anxiety (FASA), which is a modified version of the FAS to measure accommodation more broadly in childhood anxiety (Lebowitz et al., 2013). Three studies in the review used the FASA. Finally, one paper used the Parent-Report of Family Accommodation (PRFA), a 9-item measure derived from the FAS as the FAS-PR had not been developed at the time of the research (Peris et al., 2008a).

Table 1.
Study details and accommodation categories.

Quality Rating	17	18	20
Authors	Francazio et al., 2016	Zavrou et al., 2019	La Buissonniere-Ariza et al., 2018	Lebowitz et al., 2014a
Setting	Outpatient OCD clinic, inpatient.	OCD specialty Clinic	University clinic	Outpatient, health centre/hospital, or community treatment.	OCD specialty Clinic, medical centres, and community.
Type of Research	Longitudinal	Cross-sectional	Longitudinal	Longitudinal	Cross- Sectional
Sample Size	30	209	23 (5 OCD)	138 (51 OCD)	87 (26 OCD)
Comparison Group	NA	N/A	N/A	Other disorders	Other anxiety disorder, non-anxious sample
Accommodation Measure	FAS	FAS-PR	FASA	FASA	FAS, FASA
Themes	Avoidance Participation Modification Reassurance	Avoidance Participation Modification Reassurance	Avoidance Participation Modification Reassurance	Avoidance Participation Modification Reassurance	Avoidance Participation Modification Reassurance

14	14	15	16	16	17
Flessner et al., 2011a	Peris et al., 2008a	Flessner et al., 2011b	Wu et al., 2019	Wu et al., 2014	Peris et al., 2008b
University medical centre clinic	University clinic	University medical centre clinic	University clinic	OCD specialty clinic	University medical centre clinic
Cross- Sectional	Cross- Sectional	Cross- Sectional	Cross- Sectional	Cross- Sectional	Cross- Sectional
96	123	96	150	59	65
N/A	N/A	N/A	N/A	N/A	N/A
FAS-PR	PRFA	FAS-PR	FAS-IR	FAS	FAS-PR
Avoidance Participation Modification Reassurance	Avoidance Participation Modification Prevention	Avoidance Participation Modification Reassurance	Avoidance Participation Modification Prevention Reassurance	Avoidance Participation Modification Prevention Reassurance	Avoidance Participation Modification Reassurance

Table 2. outlines the final quality assessment ratings following peer-review. All papers had a clear research question, an aim to explore parental accommodation in the context of a CYP with OCD and used a sample representative of CYP with OCD. Only one study reported the number of participants who participated out of an eligible pool, having more than 50% of eligible participants take part (Peris et al., 2008b). No other studies reported this. All studies recruited from similar populations and uniformly used inclusion/exclusion criteria. Only two studies used control groups of other anxiety disorders and healthy controls (Lebowitz et al., 2014a, La Buissonniere-Ariza et al., 2018). One paper used a diverse sample of anxiety disorders but did not clearly state its use as a comparison group (Zavrou et al., 2019). One paper clearly reported adequate power and sample size justification in the methods section (Lebowitz et al., 2014a). Three papers discussed power or effect size either retrospectively or to outline the study not being adequately powered (Francazio et al., 2016, Zavrou et al., 2019, Monzani et al., 2020). All papers except one used measures which are valid, reliable and are widely used. The paper which did not use a widely used, standardised measure (the PRFA) due to the need to develop a modified version of the FAS was based on the FAS and found to have good internal consistency (Peris et al., 2008b). All papers reported means, standardised deviations and significance levels. Eight papers directly considered and controled for confounding variables or bias. Two papers did not directly explore this (Peris et al., 2008b, Flessner et al., 2011b). One paper discussed confounding variables as a factor (Flessner et al., 2011a). All papers showed results consistent with previous research and outlined the clinical implications of their findings.

Table 2.

Quality Assessment Ratings.

	Wu et al., 2019	Wu et al., 2014	Peris et al., 2008b	Francazio et al., 2016	Monzani et al., 2020	Zavrou et al., 2019	La Buissonniere-Ariza et al., 2018	Lebowitz et al., 2014a
	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2
	0	0	2	0	0	0	0	0
	2	2	2	2	2	2	2	2
	0	0	0	0	0	1	2	2
	1	2	0	1	1	1	0	2
	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2
	2	2	1	2	2	2	2	2
	2	2	2	2	2	2	2	2
	2	2	2	2	2	2	2	2
	16	16	17	17	17	18	18	20

Authors	Flessner et al., 2011a	Peris et al., 2008a	Flessner et al.,
Q1: Clear Question/Objective	2	2	2
Q2: Representative Sample	2	2	2
Q3: Participation Rate 50%	0	0	0
Q4: Uniform recruitment and inclusion/exclusion	2	2	2
Q5: Control Group	0	0	0
Q6: Power/Effect Size	1	1	1
Q7: Valid/Reliable Measures	2	0	2
Q8: Means/Standard Deviation/Significance Reported	2	2	2
Q9: Confounding Variables/Bias Considered	0	2	1
Q10: Fit Evidence	2	2	2
Q11: Clinical Implications	2	2	2
Q12: Quality Rating	14	14	15
Peer Review Agreement		Q7 – yes valid (2)	

Synthesis of Accommodation Themes

The accommodation themes identified in these papers are synthesised for the purposes of this review. All five theory-based categories specified above were identified, although not all were present in all papers (Table 1.). In the study with the highest rated quality, Lebowitz et al. explored accommodation in a child OCD sample, non-OCD anxious sample, and non-anxious community sample (2014a). They found that rates of participation and modification were highest in the OCD sample, followed by the non-OCD anxious sample, and lowest in the non-anxious sample. Closer analysis of themes mapped on to the four categories of avoidance, participation, modification, and reassurance giving. The study with the second highest quality rating identified the same four themes of accommodation using the FASA on a sample of youth with

anxiety, including OCD (La Buissonniere-Ariza et al., 2018). Zavrou et al. conducted a longitudinal study, although without a control group or sample size justification, exploring frequency and types of accommodation in a sample of children with OCD and measuring changes pre and post CBT (2019). They identified the same four categories.

Monzani et al. scored similarly highly in quality rating (2020). They explored potential differences between mothers and fathers in accommodation approaches in an OCD sample, finding that both accommodate symptoms with high frequency, although mothers accommodate to a greater extent. This study identified the same four categories. Other studies exploring accommodation types and factors leading to increased levels of accommodation also identified these four categories (Peris et al., 2008b, Francazio et al., 2016). However, these three studies were problematic due to not using a control group and either having no recorded statistical power or an inadequately powered sample. Wu et al. explored family accommodation typologies and factors that predict higher levels of family accommodation in CYP OCD (2014). They identified categories of accommodation in line with all five theoretically driven categories. A later study by Wu et al. explored the phenomenology and typology of accommodation and factors that increase rates of accommodation in a sample of CYP with OCD (2019). They also identified accommodation in line with all five categories. However, both studies did not use a control group or report a sample size justification. Flessner et al., conducted a study with no control group, sample size justification, and without broader exploration of confounding factors, however used a homogenous, representative sample and valid measures (2011b). They identified the four categories of avoidance, participation, modification, and reassurance.

In one of the studies that scored lowest on quality ratings due to no control

group, sample size justification or power analysis, and the use of an adapted accommodation measure, Peris et al. developed the Parental Attitudes and Behaviors Scale which measures behaviours, attitudes and beliefs of parents of CYP with OCD (2008a). Within its development, parental accommodation was examined, and avoidance, participation, modification, and prevention were identified as accommodation themes. They did however have a representative, homogenous group of CYP with OCD, with good consideration for confounding variables and findings consistent with previous research. Finally, Flessner et al. also scored lowest on quality due to no control group, no report of power analysis, and no clear exploration of confounding factors (2011a). They did use a representative, homogenous sample, a widely used and validated measure of accommodation, and had findings consistent with previous literature. It must be noted that Flessner et al's 2011a and 2011b papers used the same sample. Their paper explored predictors of family accommodation, identifying avoidance, participation, enabling, and reassurance as accommodation themes (2011a). Overall, similar themes of accommodation were consistently found in line with the five superordinate categories hypothesised for the purposes of this review.

In summary, regardless of quality, there was consistent identification of the five theoretically driven categories, although only two papers referred to all five. All papers identified avoidance, participation, and modification as themes. All but one also identified reassurance, and the one that did not instead identified prevention. As all studies used either the FAS or an adapted or developed version of the FAS, the types of accommodation measured often overlapped. This indicates that there is some homogeneity in the literature when exploring themes of accommodation. However, there is a need for better standardisation and consistency of accommodation types so it can be measured uniformly.

Discussion

The purpose of this review was to synthesise the literature on family accommodation in childhood OCD and determine if themes of accommodation identified in current research evidence map on to five distinct forms of accommodation based on cognitive-behavioural theory and phenomenology. The two research questions were to identify the various types of parental accommodation, and to examine how these relate to the CBT theoretical framework and consider implications for treatment. Eleven papers were identified which clearly identified and categorised types of parental accommodation. In line with previous reviews, four out of five categories were found in ten papers (avoidance, participation, modification/enabling, and reassurance), demonstrating general consistency in the presence of these four types of accommodation (Lebowitz et al., 2012, Lebowitz et al., 2016, Shimshoni et al., 2019).

The fifth accommodation category, prevention, was found least commonly, and had not been explicitly highlighted in the previous review papers. This may be due to it being very similar to avoidance or modification. Additionally, as the essence of prevention is to stop things from happening in the first instance, it is possible that these instances are reported less as people do not tend to recall things that never occurred. The recent paper by Monzani et al. suggests that although both parents accommodate OCD symptoms, mothers tend to do this more (2020). When measuring accommodation, it may therefore be of greater benefit to assess intentionality or motivation behind accommodating behaviours as opposed to topography. It may also be useful to explore the approach and frequency of accommodation by different caregivers.

In measuring and operationalising accommodation by topography, there may be a risk that accommodation is seen in a superficial way. The current literature may

demonstrate this due to all papers either using the FAS or an adapted version of the FAS to measure accommodation (Calvocoressi et al., 1999). The FAS is designed to measure accommodation by identifying observable behaviours rather than the function or underlying motive of the behaviour. In line with CBT, measuring accommodation in this way overlooks the function and motivation of behaviour, a vital part of understanding behaviour. As such, a behaviour may appear topographically similar but serve a different underlying function. An example of this is a child fearing their parent will come into harm by going near sharp objects, therefore remains close to them and holds their hand. The parent's behavioural response may be to stay close to their child and hold their hand tightly, which can be viewed as avoidance, prevention, or participation. Through exploring the motivation and the function underlying accommodation, clearer and more differentiated types of measurement and assessment can be used.

Although function has not been explicitly explored for accommodation types, research on reassurance-seeking has explored this. Recent research found that, as an inter-personal response, reassurance has a key function of providing support to a loved one's distress (Halldorsson, 2015, Halldorsson & Salkovskis, 2017). As such, removing reassurance led to greater distress and negative affect. Within CBT, Theory A/Theory B is often used to demonstrate that the intrusions being true may not be the problem, but rather the problem is the fear that the intrusions are true (Salkovskis, 1999). As such, reassurance or accommodation is inadvertently reinforcing that Theory A is in fact true. However, providing support in response to feelings of anxiety by soothing, using inter-personal strategies, or emotion regulation strategies may be more helpful, and would support Theory B.

A further consideration is the absence of measuring alternative responses to the

child requesting accommodation. Another study demonstrated that caregivers often feel unsure of alternative ways of responding; as such, reassurance is used with the awareness that it provides short-term relief, but with the frustration at its negative impacts (Halldorsson, Salkovskis, Kobori & Pagdin, 2016). This has similarly been found in accommodation, with many parents, despite engaging in accommodation, feeling that it does not improve symptoms (Calvocoressi et al., 1999). Alongside this, individuals with anxiety often seek reassurance as it provides immediate, short-term relief, yet inadvertently maintains the problem as the easing of anxiety is temporary (Salkovskis & Kobori, 2015). The function and motivation underlying behaviours is therefore crucial to explore when considering accommodation and reassurance-giving behaviours. Without alternative responses, it is difficult to stop accommodating. Future research is encouraged to explore alternative ways parents interact with their child in the context of OCD.

Furthermore, it is important to consider the differences between helpful levels of accommodation and unhelpful levels. Similarly to reassurance-giving, strategies of accommodation are normative and expected from parents, and to a degree may be developmentally appropriate to support with coping. This should be with particular consideration of developmental stage and needs of the child. For example, accommodation through the use of modification may enable a child to have a structure or environment that challenges them just enough within their proximal zone of development. Understanding the function and role of accommodation is therefore important in disentangle whether accommodation strategies are helpful and functional, or part of safety-seeking and safety-giving. Future studies are encouraged to consider this. Measures of accommodation that account for different ages and developmental stages are also needed. Currently, the FAS and its derivatives are not age-specific. This

may overlook the specific differences and nuances of developmental needs.

There are some limitations to this review. Firstly, the review did not include any qualitative studies. However, such papers often do not explore the underlying mechanisms, rather they look at the phenomenology. Additionally, all papers that were included used the FAS or one of its derivatives, therefore there is a risk of bias to the accommodation themes identified. However, as they are the dominant measures of accommodation, and no other paper has explored accommodation categories previously, it is a useful starting point to explore the themes more broadly. Future studies could explore qualitative literature or case reports. Secondly, the search was set for papers from 2008 onwards. It is possible to have included broader date brackets; however earlier literature on accommodation was emerging. Ideally, the search would have been conducted from 2013 to coincide with the release of the Diagnostic and Statistical Manual of Mental Disorders (DSM–5). However, many relevant papers could have been missed. Broader inclusion of disorders could have been made. For example, dual diagnoses of OCD and Autism Spectrum Condition. However, research has shown that accommodation can present differently depending on the difficulties and even within OCD depending on the type of intrusion (Wu et al., 2014, Shimshoni et al., 2019). In order to control for confounding variables, disorder-specific accommodation responses should be considered. A final limitation is the inclusion of only Western studies, which could have created ethnocentric bias. There is a small amount of literature emerging from South America, Asia, and European countries which have found similar themes of accommodation, however better understanding of cultural contexts and variations would be imperative as accommodation is a relational and systemic phenomenon (Bipeta et al., 2013, Gomes et al., 2014, Gorenstein, 2015, Shimshoni, Shrinivasa, Cherian, Lebowitz, 2019).

Overall, the findings broadly support the presence of five theoretically driven categories of accommodation. As such, the clinical implications show that although many papers use accommodation scales, such as the FAS, they often look at high or low levels of accommodation. Looking at distinct forms of accommodation can ensure clinical intervention is more focused and directed towards the specific accommodating behaviour. It may also be of interest to explore how different forms of accommodation may relate to different clinical outcomes. This would be further enhanced by future research exploring the function underlying types of accommodation, assessing times where accommodation has worked or been helpful, and assessing times when alternative responses were used, such as support.

The theoretical implications of this review suggest the relevance of the existing themes of accommodation as mapped onto the five theoretically driven categories of accommodation. Within the current literature, various categories of accommodation are identified. A factor analysis conducted on the FAS-PR found modification and involvement/participation in compulsions to be categories of accommodation (Peris et al., 2008b, Flessner et al., 2011b). However, Lebowitz et al. report avoidance as a key overarching category (2012). They also identify that the FAS was found to have a three-factor structure of modification, distress, and participation, whereas report the FAS-PR has avoidance of stimuli and participation (2012). The literature therefore indicates inconsistencies in the theoretical definitions and categories of accommodation.

Overall, this review was able to map the types of parental accommodation in the context of CYP OCD to five, theoretically driven superordinate categories of accommodation. The papers included in the review support the prevalence of accommodation within this population as outlined in previous reviews with a child and adult OCD sample. Greater consistency of defining types of accommodation is needed

to ensure the phenomena is defined and measured uniformly in research, with greater emphasis needed on exploring the function underlying the accommodating behaviours. This will further assist clinically in delineating the presentation of specific types of accommodation, and whether certain types of accommodation impact upon treatment outcomes.

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Appendix A

Adapted quality assessment tool

1. Was there a clear research question, and were the aims of the paper focused at looking at parental accommodation in the context of OCD?
2. Is the sample representative of children and young people with OCD?
3. Was the participation rate of eligible persons at least 50%?
4. Were all the subjects selected or recruited from the same or similar populations (including the same time period)? Were inclusion and exclusion criteria for being in the study pre-specified and applied uniformly to all participants?
5. Was a control group exploring accommodation in another anxiety disorder or a non-anxious group used to differentiate between types of accommodation unique to OCD?
6. Was a sample size justification, power description, or variance and effect estimates provided? If reported, was it adequately powered?
7. Were the measures used valid, reliable, and implemented consistently across all study participants? Have they had their psychometric properties assessed and reliability checks (e.g. a factor analysis)?
8. Are the means, standard deviations, and significance levels reported?
9. Could the results be affected by confounding variables or bias? Were these considered?
10. Do the results fit with the evidence on parental accommodation in OCD, or extend the other available evidence?
11. Do the findings show that assessing accommodation in this way has implications for clinical practice?

Appendix B

Excluded papers and rationale for exclusion

	Full Reference	Reason for Exclusion
1	Merlo, L. J., Lehmkuhl, H. D., Geffken, G. R., & Storch, E. A. (2009). Decreased family accommodation associated with improved therapy outcome in pediatric obsessive–compulsive disorder. *Journal of consulting and clinical psychology*, *77*(2), 355.	No clear categories of accommodation
2	Storch, E. A., Lehmkuhl, H., Pence, S. L., Geffken, G. R., Ricketts, E., Storch, J. F., & Murphy, T. K. (2009). Parental experiences of having a child with obsessive-compulsive disorder: Associations with clinical characteristics and caregiver adjustment. *Journal of Child and Family Studies*, *18*(3), 249-258.	No clear categories of accommodation
3	Canavera, K. E., Ollendick, T. H., May, J. T. E., & Pincus, D. B. (2010). Clinical correlates of comorbid obsessive–compulsive disorder and depression in youth. *Child Psychiatry & Human Development*, *41*(6), 583-594.	Accommodation not clearly measured
4	Smorti, Martina. (2010). The role of family in the development and treatment of obsessive compulsive disorders: The cognitive behavioral perspective. *Eta Evolutiva*, *96*, 107-117. Retrieved from http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc7&NEWS=N&AN=2010-19864-008.	Non-Western sample or not published in English
5	Storch, E. A., Björgvinsson, T., Riemann, B., Lewin, A. B., Morales, M. J., & Murphy, T. K. (2010). Factors associated with poor response in cognitive-behavioral therapy for pediatric obsessive-compulsive disorder. *Bulletin of the Menninger Clinic*, *74*(2), 167-185.	Accommodation not clearly measured
6	Storch, E. A., Larson, M. J., Muroff, J., Caporino, N., Geller, D., Reid, J. M., ... & Murphy, T. K. (2010). Predictors of functional impairment in pediatric obsessive-compulsive disorder. *Journal of anxiety disorders*, *24*(2), 275-283.	No clear categories of accommodation
7	Ginsburg, G. S., Burstein, M., Becker, K. D., & Drake, K. L. (2011). Treatment of obsessive compulsive disorder in young children: An intervention model and case series. *Child & family behavior therapy*, *33*(2), 97-122.	Case study

8	Piacentini, J., Bergman, R. L., Chang, S., Langley, A., Peris, T., Wood, J. J., & McCracken, J. (2011). Controlled comparison of family cognitive behavioral therapy and psychoeducation/relaxation training for child obsessive-compulsive disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *50*(11), 1149-1161.	No clear categories of accommodation
9	Caporino, N. E., Morgan, J., Beckstead, J., Phares, V., Murphy, T. K., & Storch, E. A. (2012). A structural equation analysis of family accommodation in pediatric obsessive-compulsive disorder. *Journal of abnormal child psychology*, *40*(1), 133-143.	No clear categories of accommodation
10	Lebowitz, E. R., Panza, K. E., Su, J., & Bloch, M. H. (2012). Family accommodation in obsessive–compulsive disorder. *Expert Review of Neurotherapeutics*, *12*(2), 229-238.	Accommodation not clearly measured
11	Peris, T. S., Sugar, C. A., Bergman, R. L., Chang, S., Langley, A., & Piacentini, J. (2012). Family factors predict treatment outcome for pediatric obsessive-compulsive disorder. *Journal of Consulting and Clinical Psychology*, *80*(2), 255.	Accommodation not clearly measured
12	Bipeta, R., Yerramilli, S. S., Pingali, S., Karredla, A. R., & Ali, M. O. (2013). A cross-sectional study of insight and family accommodation in pediatric obsessive-compulsive disorder. *Child and adolescent psychiatry and mental health*, *7*(1), 20.	Non-Western sample
13	Franz, A. P., Paim, M., Araújo, R. M. D., Rosa, V. D. O., Barbosa, Í. M., Blaya, C., & Ferrão, Y. A. (2013). Treating refractory obsessive-compulsive disorder: what to do when conventional treatment fails?. *Trends in psychiatry and psychotherapy*, *35*(1), 24-35.	Accommodation not clearly measured
14	Lebowitz, E. R., Woolston, J., Bar-Haim, Y., Calvocoressi, L., Dauser, C., Warnick, E., ... & Vitulano, L. A. (2013). Family accommodation in pediatric anxiety disorders. *Depression and anxiety*, *30*(1), 47-54.	Non-OCD Sample
15	Lebowitz, E. R. (2013). Parent-based treatment for childhood and adolescent OCD. *Journal of Obsessive-Compulsive and Related Disorders*, *2*(4), 425-431.	Accommodation not clearly measured
16	Pinto, A., Van Noppen, B., & Calvocoressi, L. (2013). Development and preliminary psychometric evaluation of a self-rated version of the Family Accommodation Scale for Obsessive-Compulsive Disorder. *Journal of Obsessive-Compulsive and Related Disorders*, *2*(4), 457-465.	Adult sample

17	Freeman, J., Garcia, A., Benito, K., Conelea, C., Sapyta, J., Khanna, M., ... & Franklin, M. (2012). The pediatric obsessive compulsive disorder treatment study for young children (POTS Jr): Developmental considerations in the rationale, design, and methods. *Journal of obsessive-compulsive and related disorders*, *1*(4), 294-300.	Accommodation not clearly measured
18	Gomes, J. B., Van Noppen, B., Pato, M., Braga, D. T., Meyer, E., Bortoncello, C. F., & Cordioli, A. V. (2014). Patient and family factors associated with family accommodation in obsessive–compulsive disorder. *Psychiatry and Clinical Neurosciences*, *68*(8), 621-630.	Non-Western sample
19	Labouliere, C. D., Arnold, E. B., Storch, E. A., & Lewin, A. B. (2014). Family-based cognitive-behavioral treatment for a preschooler with obsessive-compulsive disorder. *Clinical Case Studies*, *13*(1), 37-51.	Case study
20	Lewin, A. B., Park, J. M., Jones, A. M., Crawford, E. A., De Nadai, A. S., Menzel, J., ... & Storch, E. A. (2014). Family-based exposure and response prevention therapy for preschool-aged children with obsessive-compulsive disorder: a pilot randomized controlled trial. *Behaviour Research and Therapy*, *56*, 30-38.	No clear categories of accommodation
21	Thompson-Hollands, J., Kerns, C. E., Pincus, D. B., & Comer, J. S. (2014). Parental accommodation of child anxiety and related symptoms: Range, impact, and correlates. *Journal of anxiety disorders*, *28*(8), 765-773.	Non-OCD Sample
22	Manassis, K., Lee, T. C., Bennett, K., Zhao, X. Y., Mendlowitz, S., Duda, S., ... & Bodden, D. (2014). Types of parental involvement in CBT with anxious youth: a preliminary meta-analysis. *Journal of consulting and clinical psychology*, *82*(6), 1163.	Accommodation not clearly measured
23	Benito, K. G., Caporino, N. E., Frank, H. E., Ramanujam, K., Garcia, A., Freeman, J., ... & Storch, E. A. (2015). Development of the pediatric accommodation scale: Reliability and validity of clinician-and parent-report measures. *Journal of Anxiety Disorders*, *29*, 14-24.	Non-OCD Sample
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Service Improvement Project

Improving Post-Diagnostic Support for
Young People with Autism within a Neurodevelopmental Conditions Service.

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Journal: Research in Autism Spectrum Disorders. Brief report.

Rationale: This journal is dedicated to advance understanding for all things related to Autism Spectrum Disorders (ASD). As well as research articles, it welcomes papers that provide practical guidance on supporting autistic people and their system. The journal's impact factor is 1.688.

Abstract

Background: Across the UK, autistic young people receive very little post-diagnostic support despite the importance highlighted in policies and best practice guidelines. This study reported on a service improvement project exploring the needs of young people post-diagnosis and delivering a service user informed post-diagnostic support package. **Method**: A sample of twenty-two (n = 22) young people aged 13-18, and their parents, who were diagnosed within the last year were recruited using purposive sampling within a CAMHS service in Oxfordshire, UK. The research was in two phases. Phase one gathered feedback from young people and parents on what support they had and what support they would like post-diagnosis. Phase two was a tailor-made post-diagnostic support package in line with their feedback. **Results**: The results of phase one indicated a need for young people to meet and hear from others diagnosed with autism , as well as speak to a clinician. The results from phase two found young people enjoyed a live space to meet other autistic young people and found the chance to speak to a clinician and have their views heard valuable. **Conclusions**: Further improvement and provision of post-diagnostic support for young people is needed. Post-diagnostic support is recommended to be routinely offered to young people in services.

Key Words: Autistic, post-diagnosis, support, young people, adolescents.

Introduction

Autism, or Autism Spectrum Disorder (ASD) as it is referred to in DSM-V, is a lifelong neurodevelopmental condition characterised by social communication difficulties and restricted and repetitive behaviours that emerge during early development (American Psychiatric Association, 2013). Research indicates that those with autism express a preference for the terms "autism" or "autistic", which will be used in this paper (Kenny et al., 2015). In the UK, about 1 in 100 children are diagnosed with autism (BMA, 2019). Government policy and strategy places emphasis on providing post-diagnostic support and improving outcomes for autistic people (National Autistic Society, 2018b; Think Autism., 2014). One priority action point outlined in "Think Autism" is "providing relevant information and support throughout the diagnostic process" (House of Commons, 2016, p.10). The Children and Families Act outlines the importance of providing "advice and information about matters relating to the disabilities" to young people (Children and Families Act, 2014, p.28). The National Institute of Clinical and Health Excellence (NICE) guidelines recommend providing information on the meaning of the diagnosis to young people (NICE, 2017). It is therefore important to provide relevant post-diagnostic care to young people and their families.

Social Identity Theory emphasises the importance of belonging and its impacts upon identity and self-esteem (Tajfel et al., 1979). A positive identity is a protective factor against low self-esteem and mental health difficulties in autistic people (Cooper et al., 2017). Not receiving relevant support can impact a young person's identity formation, relationships, and create feelings of social difference (BMA, 2019; Mogensen & Mason, 2015). For some, receiving a label of autism or autism diminishes their sense of identity, and evidence has highlighted the importance of learning about

the diagnosis in order to navigate the social world and understand oneself (Mogensen & Mason, 2015). This is particularly important to consider in the context of a developmental framework, particularly during formative adolescent years where identity formation and exploration are occurring (Erikson, 1968). Interviews with autistic young people indicate that many do not want to be associated with the diagnostic label 'ASD' and its related stigmas, as well as reporting they have been offered little post-diagnostic support (Calzada et al., 2012).

Post-diagnostic support for parents of autistic children is well established and widely available (Dawson-Squibb et al., 2020). Within the UK, parental programmes include Barnardo's Cygnet programme; the National Autistic Society's EarlyBird programmes; and the ASCEND programme (Derguy, et al., 2018; National Autistic Society, 2018a; Stuttard et al., 2016; Wright & Williams, 2007). These have been found to improve parents' confidence and knowledge of auism, increase parents' abilities to manage behaviours, and improve their child's wellbeing (Ayyash et al., 2019; Bates, 2018; Stuttard et al., 2016). However, there is limited direct support offered to young people (Mogensen & Mason, 2015). Great Ormond Street Hospital developed a manualised psychoeducation group, PEGASUS, which has been found to aid young people's understanding of autism (Gordon et al., 2015). A feasibility study conducted in Stockholm of an internet-delivered psychoeducation group also found an increase in understanding of self and diagnosis in participants (Backman et al., 2018). Such post-diagnostic support therefore appears to be valuable for young people.

Yet as vital as such post-diagnostic interventions are, they are not consistently offered, and support varies by locality. A review of Autism Services in Hampshire reported service users desired better post-diagnostic support (Dittrich & Burgess, 2012). Additionally, qualitative research has shown that young people require further guidance

in developing independence as they become adults, and clarity around the support available (Jonsson et al., 2019). Despite this need, little research has been carried out on the needs of young people following their diagnosis, as well as how they would like this need to be met. As such, co-production is crucial in keeping young people's needs central to the provision of necessary post-diagnostic support (Backman et al., 2018).

The current study used a service-improvement model to scope the need of post-diagnostic support for young people seen within the Oxfordshire Child and Adolescent Mental Health Service (CAMHS) Neurodevelopmental (NDC) Pathway. Their feedback was used to develop a post-diagnostic intervention, which was then evaluated accordingly. The NDC Pathway is a specialist diagnostic and treatment service within the local CAMHS service for people aged 5-18 with possible autism and/or other neurodevelopmental conditions. Feedback following diagnosis is currently given to parents and young people, and post-diagnostic support groups are available for parents to attend. There is no routine post-diagnostic support available directly to the young people, although the service provides focused psychological interventions if this is needed.

This research aims to address the following questions:

- What support is currently being offered to or accessed by young people following their diagnosis?
- What needs do young people have following diagnosis?
- How would they like to have these needs met?
- How effective is the intervention that was selected based on the findings from the above questions in meeting their needs?
- How can the service feasibly continue to meet these needs?

Methods

Participants

Participants were twenty-two (n = 22) young people aged 13-18 and their parents who accessed the NDC service in Oxfordshire. The sample constituted 6% of young people who were diagnosed in the service over the period of a year. Due to this being a small, focused project, purposive sampling was used to select a proportion of young people within the service in order to improve homogeneity and control for differences. This was of importance due to the project making clinical recommendations on how to support a cross-section of the autistic population. Given the unique developmental needs experienced during adolescent years, in particular identity formation, the age range was set to 13-18 to account for this. Inclusion criteria were to have received a diagnosis of autism/ASD within the last year. Participants were not excluded based on their intellectual functioning or co-morbidities. In line with NICE guidelines, all had a neurodevelopmental history taken, and a direct observation (ADOS-2, school observation, or online assessment) (2017). Given this study's small-scale nature, a power analysis was not conducted.

Materials and Designs

The study was granted ethical approval by Oxford Health NHS Foundation Trust as an audit project. The study was conducted in line with ethical standards of the responsible committee on human experimentation (institutional and national) and with the Declaration of Helsinki (2000). Participant and guardian informed consent was obtained from all participants. The study design was in two phases. A quantitative design was used in phase one, and a mixed methods quantitative and qualitative design was used in phase two to ensure both standardised and more in-depth feedback was captured.

Procedures

Phase one gathered feedback from parents and, where possible, young people using a Qualtrics electronic questionnaire and telephone interviews (Appendix A, Appendix B). The feedback was analysed, and common themes identified which shaped a post-diagnostic intervention. Phase two was the implementation of the intervention to the young people who chose to take part in the study. Finally, phase two was evaluated using Qualtrics electronic questionnaires (Appendix C, Appendix D), and recommendations were made to the service on how to carry forward post-diagnostic support for young people.

Analysis

The data was analysed using descriptive statistics for phase one and phase two, with phase two also exploring participant satisfaction.

Results

Phase One

Of the twenty-two families contacted, seventeen provided feedback, four could not be contacted by telephone, and one declined to take part. A total of twenty-four responses were therefore collected from parents (*n*= 17) and young people (YP) (*n*=7). Young people who took part ranged in age from 13 to 18 years (M = 16.2, SD = 1.4), 65% males (*n*=11) and 35% females (*n*=6). Not all participants provided feedback as they either were not present or declined to speak on the phone, a challenge commonly reported for autistic people (Müller et al., 2008). Some were reported to dislike speaking about their diagnosis, with parents reporting that they are finding adjusting to the diagnosis challenging. Finally, the collection of data coincided with the start of a new school year following prolonged absences due to COVID-19 lockdown. Several parents reported that their child was preoccupied with adjusting to a new routine and distracted by school pressures.

The responses from YP and their parents indicated that they are currently not receiving professional post-diagnostic support around autism. Three young people and four parents reported that they do not require support. Figure 1 reflects the steps young people took in learning more about autism, including speaking to a member of their family (YP report *n*=5, parent report *n*=15), reading a book or leaflet (YP report *n*=4, parent report *n*=5), watching videos online (YP report *n*=4, parent report *n*=11), and watching TV shows or documentaries (YP report *n*=3, parent report *n*=2). Other steps taken were speaking to a therapist (*n*=1), speaking to a friend with autism (*n*=1), or speaking to a staff member at school (*n*=3).

Figure 1

A Graph Showing What Autistic Young People Have Done to Find Out More about Their Diagnosis as Reported by Young People and their Parents

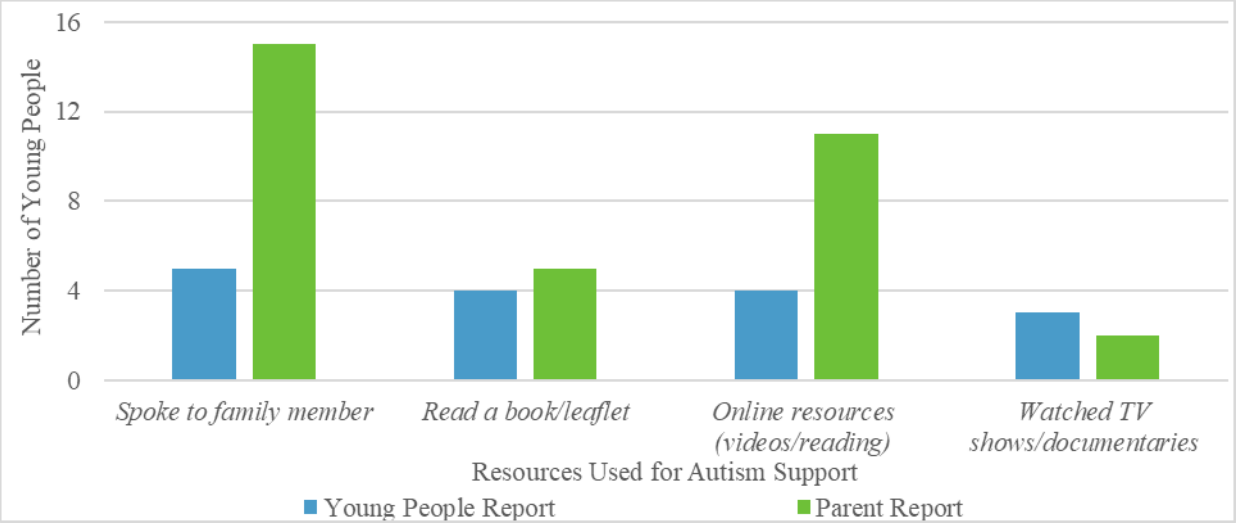


Figure 2 shows what support young people would like, including hearing what other autistic people have to say (YP report n=5, parent report n=11), speaking to another autistic person (YP report n=4, parent report n=11), meeting other autistic young people (YP report n=3, parent report n=11), talking to a clinician about autism (YP report n=3, parent report n=8), and learning more about autism (YP report n=2, parent report n=7). One parent requested support around navigating the social world and managing behavioural difficulties (n=1).

Figure 2

A Graph Showing What Support Autistic Young People Would Like as Reported by Young People and their Parents

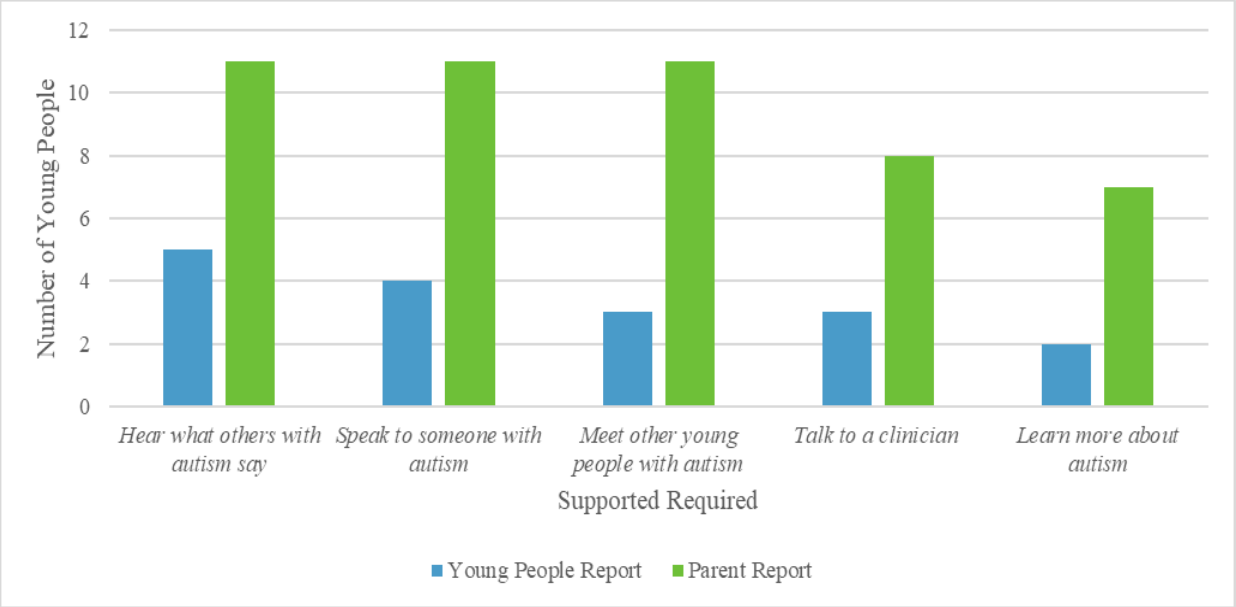
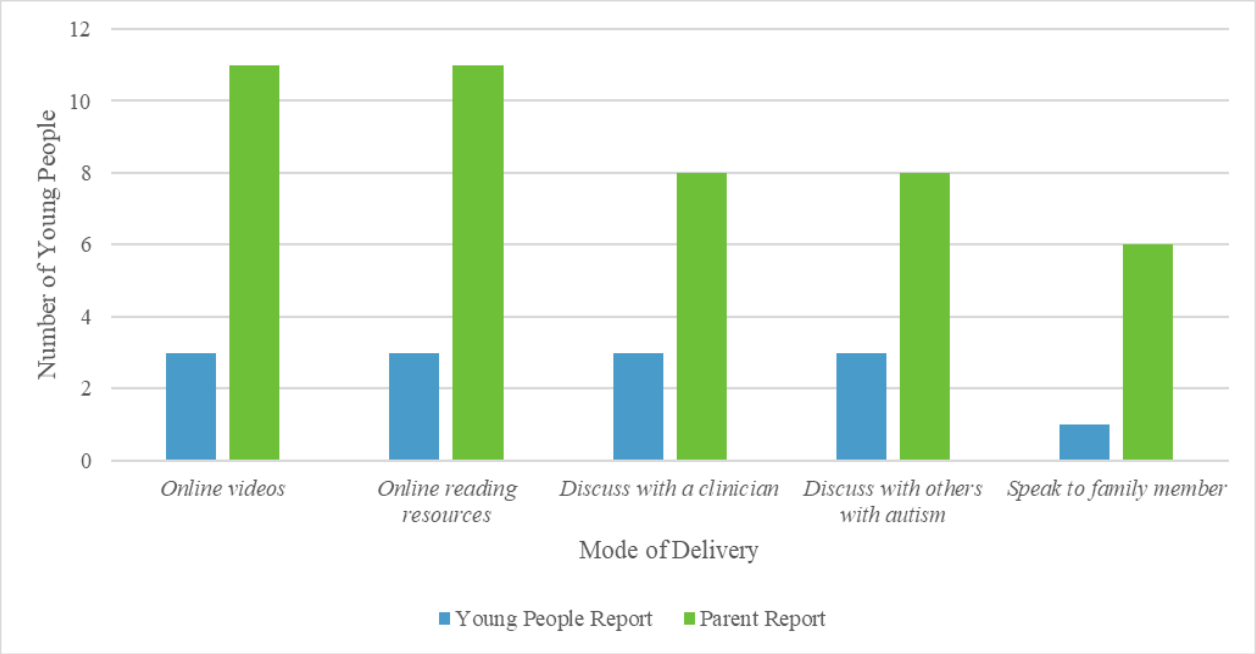


Figure 3 reflects how young people would like this information delivered. Responses requested were watching a video (YP report n=3, parent report n=11), reading about autism online (YP report n=3, parent report n=11), speaking to a clinician (YP report n=3, parent report n=8), meeting other autistic young people (YP report n=3, parent report n=8), and speaking to a member of their family (YP report n=1, parent report n=6). Parents additionally requested physical reading materials (n=2) and an online forum to meet other autistic young people (n=2).

Figure 3

A Graph Showing the Mode of Delivery Autistic Young People Would Like Support as Reported by Young People and their Parents.



Phase Two

Phase two was developed based on the feedback from phase one showing that young people wished to meet and hear from other autistic young people, with some wanting to also hear from a clinician. As the preferred mode of delivery was through the use of online videos and resources, a resource pack including PowerPoint slides with an embedded video of a clinician talking through the slides was emailed to all parents to share with their children (Appendix E). In order to meet the need of meeting other young, autistic people and a clinician, online Q&A drop-ins were scheduled after the resource packs were sent out.

When asked to rate how satisfied they were with the resource packs, a total of three rated it “average” (YP report n=1, parent report n=2) and one rated it “good” (parent report n=1). Qualitative feedback reflected that “the information made me think”,

however that “some of the information was quite basic, I already knew a lot of it. The video could have said more than what was on the slides to make it more interesting”.

Three separate Q&A drop-in sessions were offered via Microsoft Teams to allow flexibility of attendance. A total of four young people attended the sessions accompanied by a parent. Two young people attended the first session. Although there were differences in terms of the difficulties they experienced, they both shared a common difficulty of finding school and social situations challenging. Feedback from them indicated that hearing about each other’s similar experiences was validating. The second group coincided with mock examinations and changes in national lockdown guidance, therefore no young people attended. Two young people attended the third group, and found common ground in both their experiences and their identities. They shared how powerful and useful it was to connect with someone so similar to them, sharing that they had never met anyone similar to themselves. This was particularly useful due to efforts of seeking out online information about autism, and coming across stigmatising or negative information. Feedback was shared that they remained in contact and are exploring ways to start a support group for other autistic young people locally. A key theme to be considered from this feedback is around social connection and social identity.

Two young people and three parents provided feedback on the sessions, which were rated “good” (YP report n=2, parent report n=2), and one parent rating it “average” (parent report n=1).When asked if it was helpful for the young person to speak to someone from CAMHS about autism, two people responded “certainly true” (parent report n=2), two responded “partly true” (YP report n=2), and one responded “not true” (parent report n=1). When asked if their views and worries were taken seriously, all answered “certainly true” (YP report n=2, parent report n=3). When asked if it was

helpful to hear from other autistic young people, all responded “certainly true” (YP report n=2, parent report n=3). When asked if overall the help offered was “good”, four people responded “yes” (YP report n=2, parent report n=2) and one responded “no” (parent report n=1). Qualitative feedback was that “meeting more people with autism would be helpful to normalise” and “needed to know more about the steps to help me to talk more easily and how to make friendships, more social skills training. Being on camera was difficult. My child didn’t feel [they] got anything out of it and would have preferred talking about it 1-1. Breaks would have been helpful as concentration lapses, and chunks of information that is more specifically relevant to their needs.”

Discussion

The aim of this service improvement project was firstly to explore what support young people are currently offered following their autism diagnosis, what their needs are, and how they would like these needs to be met. Secondly, it explored how helpful the intervention was, and ways the service can continue to meet the needs of young people. In line with previous research, findings showed that young people do not receive any post-diagnostic support (Dittrich, R., & Burgess, 2012; Mogensen & Mason, 2015). Feedback from both the young people and their parents highlighted a need to know more about autism, particularly by meeting and speaking to other autistic young people and speaking to a clinician. The steps many young people have taken alone to learn more about their diagnosis, including reading about it online, watching documentaries about autism, or speaking to family members or school staff indicates a real need to provide routine post-diagnostic support.

Findings from the second phase of the study indicated that participants valued the space to meet other autistic young people. The ability to connect with young people with similar experiences to them was reported to be a normalising experience. Feedback from the young people who attended the Q&A groups highlighted the significance of connecting with others you feel similar to. This is consistent with Social Identity Theory and previous research emphasizing the importance of social inclusion and the value of connecting with others like oneself (Cooper et al., 2017; Mogensen & Mason, 2015; Tajfel, et al., 1979). It also highlights the developmental needs of adolescents, and the importance of identity formation at this developmental stage in like with Erikson's theory (1968). For some, speaking to a clinician and having a space to be heard was also important. Overall, the findings indicate that those who accessed the support found it helpful. In line with government policies and best practice guidance, it

is important for young people to receive such post-diagnostic support (Children and Families Act, 2014; House of Commons, 2016; National Autistic Society, 2018b; National Institute of Clinical and Health Excellence., 2017; Think Autism., 2014).

One limitation of the study was the delay from diagnosis to intervention (up to 12 months). Many had already sought out their own information. Young people reported a reduced need for post-diagnostic support, and some shared that the online information they accessed was unreliable and sometimes stigmatising. As such, service-delivered post-diagnostic support would ensure young people had access to more reliable evidence-based information. Additionally, the small uptake, particularly in phase two, may have been due to the timing this was offered. This coincided with mock examinations at school, as well as changes in lockdown rules due to the COVID-19 pandemic. It may be also due to the delay in offering support. Research indicates that long waiting times can create pre-treatment attrition and a greater likelihood of dropout (Carter et al., 2012). Better uptake may therefore have occurred if the waiting times were shorter. More focused outcome measures could have also been used, for example exploring whether the intervention helped increase their understanding of autism (Backman et al., 2018; Gordon et al., 2015). It must also be considered that all who took part in the study received a later diagnosis in their adolescent years given the 13-18 age range and requirement to have been diagnosed no more than one year prior. The sample of young people who took part may therefore have a unique set of needs due to the delay in diagnosis. This is of significance as those who are diagnosed at a younger age may have had longer to adjust to the diagnosis, integrate it into their identity, hear a consistent narrative about autism from those around them, and even have had more tailored support (e.g. in school) for a longer period of time. Future studies are

encouraged to explore the needs of autistic young people with consideration of such variations in developmental needs.

Further considerations of the differing needs of young people across genders, developmental levels, and learning needs could have additionally been considered. For example, as females can experience delayed diagnosis and "camouflaging", it would be important to offer tailored support for autistic girls (Green et al., 2019). It may have been helpful to gather descriptive statistics of parental demographics to explore differences in engagement. Finally, this study was conducted during the COVID-19 pandemic (World Health Organization, 2020). Greater involvement of autistic young people in the design and implementation of this project was hoped for. However, due to national lockdown, access to community support groups through charities to gain such feedback was unavailable. Additionally, interventions had to be delivered virtually as in-person groups were not possible. The feedback received indicated that video sessions were difficult, and in-person groups may have been preferable.

This study highlighted a need for effective post-diagnostic support for autistic young people, and a further refinement of ways the service can feasibly deliver this in the context of COVID-19. Recommendations to the service are to involve young autistic people in the development and design of future service reviews, with an aim towards co-production or service user involvement. It is also recommended to offer the intervention in a timely fashion to increase uptake and ensure young people access accurate information early on. To improve participation and uptake of the support, careful consideration should be paid to the timing of the group. Avoiding periods of change (e.g. school transitions) or exam times may improve engagement. If virtual sessions are necessary, it is recommended that strategies to help reduce anxiety are crucial (e.g. sending out photographs and biographies of clinicians beforehand, the use

of “breakout rooms”, or session warming exercises). In order to better tailor the support offered, separate groups focusing on specific topics, e.g. autism and anxiety, could be offered. This would allow young people the choice to attend more focused sessions on areas of difficulty, and to meet others with similar experiences. It is also important to tailor the support offered to the specific developmental needs of the young people, with consideration of developmental stage and social identity theory. For example, the needs of a younger child would be different to an adolescent, and therefore post-diagnostic support should be tailored accordingly. In line with feedback, it may also be relevant to offer social skills training within the “social relationships” module. As the PowerPoint slides were reported to be information-dense, shorter video clips about a topic accompanied by a handout sheet summarising information and available online resources may be preferable. It is hoped that through continually evolving this support in collaboration with young people, the post-diagnostic needs of young people can be better met. Initial feedback from the service prior to feedback in a team meeting is included in Appendix F, and a lay summary for dissemination purposes is outlined in Appendix G. Overall, this research was a modest yet important start in keeping the needs of autistic young people at the heart of post-diagnostic service provision and highlighting the value of post-diagnostic support.

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Conflict of Interest

There are no conflicts of interest.

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Appendix A

Parent Questionnaire, Phase One

Support from CAMHS Questionnaire – Parents

Thank you for taking time to tell us about how you would like to be supported in CAMHS. We're working hard to make this service the best it can be for your child, so we're asking for your ideas on how we can better support young people with autism.

How old is your child? [_____]
What gender is your child? Male / Female / Non-Binary

Please think about the support your child received after they were diagnosed with autism.

1) Did they do any of these things to find out more about autism?
Please tick any that are relevant.
• Watched a video or a TV programme
• Read about it online
• Read about it in a book, magazine, or leaflet
• Spoke to a family member about it
• Attended a group
• Other:
_____
_____

2) What support does your child currently have for their autism?
_____
_____
_____

3) What kind of support might they need?
• To learn more about what autism is
• To find out what other people with autism say
• To meet other young people with autism
• To talk about it with a clinician in CAMHS
• To talk about it with someone else who has autism
• They don't want anything
• Other:
_____
_____

4) How can CAMHS support them with those things?
• Through online videos
• Through online material on a website
• Through reading materials (e.g. leaflet or booklet)
• To speak to someone in the family about it
• To learn about it from a clinician
• To meet other young people with autism
• Other:
_____
_____

Appendix B

Young Person's Questionnaire, Phase One

Support from CAMHS Questionnaire – Young People

Thank you for taking time to tell us about how you'd like to be supported in CAMHS. We're working really hard to make this service the best it can be for you, so we're asking for your ideas on how we can support you and other young people with autism.

How old are you? [_____]
What's your gender? Male / Female / Non-Binary

Think about when you found out you had autism. We'd like to know…

1) Have you done any of these things to find out more about autism?
Put a tick or 'X' next to any you've done
• Watched a video or a TV programme
• Read about it online
• Read about it in a book, magazine, or leaflet
• Someone in my family talks to me about it
• Went to a group
• Other:
_____
_____

2) What support do you have at the moment for your autism?
_____
_____
_____

3) What do you need?
• I want to learn more about what autism is
• I want to see what other people with autism say
• I want to meet other young people with autism
• I want to talk about it with a clinician in CAMHS
• I want to talk about it with someone else who has autism
• I don't want anything

4) How can CAMHS support you with those things?
• I want to watch a video about it
• I want to read about it online
• I want to read about it in a leaflet or booklet
• I want someone in my family to talk to me about it
• I want to learn about it more at CAMHS with a clinician
• I want to meet other young people with autism
• Other:
_____
_____

Appendix C

Young People's Feedback: Phase Two

1. Please share your thoughts on how you found the following:

	Poor	Average	Good
The PowerPoint Slides			
The Q&A Session			

2. What did you find helpful or useful from the PowerPoint and resources?

   _____

   _____

3. Was there anything you didn't like or that needs improving about the PowerPoint and the resources?

   _____

   _____

4. We'd like to know how you found the Q&A session. Please select the box that best describes how you think or feel:

	Don't Know	Not True	Partly True	Certainly True
It was helpful speaking to someone from CAMHS about my Autism				
My views and worries were taken seriously				
It was helpful hearing from other young people with Autism				

5. Was there anything you didn't like or that needs improving about the Q&A drop ins?

_____

_____

_____

6. Overall, do you feel the help you got was good?

Yes ☐

No ☐

Appendix D

Parents' Feedback: Phase Two

1) Please share your thoughts on how you found the following:

	Poor	Average	Good
The PowerPoint Slides			
The Q&A Session			

2) What did you find helpful or useful from the PowerPoint and resources?

_____

_____

3) Was there anything you didn't like or that needs improving about the PowerPoint and the resources?

_____

_____

4) We'd like to know how you found the Q&A session. Please select the box that best describes how you think or feel:

	Don't Know	Not True	Partly True	Certainly True
It was helpful for my child to speak to someone from CAMHS about their Autism				
Their views and worries were taken seriously				
It was helpful for my child to hear from other young people with Autism				

5) Was there anything you didn't like or that needs improving about the Q&A drop ins?

_____

_____

_____

6) Overall, do you feel the help offered to your child was good?

Yes ☐

No ☐

Appendix E

Summary of the resource pack sent out.

- **PowerPoint Slides 1: What is Autism?**
  - Explanation of what Autism is
  - Explanation of what Autism is not
  - Different names given to Autism
  - Video by “Ambitious about Autism” on YouTube about people’s experiences of Autism
  - Strengths of people with Autism
  - Where to find out more about Autism (websites including NAS, Autistica, local charities)
- **PowerPoint Slides 2: Anxiety and Autism**
  - What is anxiety? Basic CBT ABC maintenance cycle, physiological features, behavioural responses to anxiety (escape, avoidance), thoughts/images experienced when anxious
  - Autism and anxiety, iceberg formulation
  - “Emotional Toolbox” strategies including graded exposure, the FEAR approach
  - Recommended resources:

    Websites

    - Young Minds https://youngminds.org.uk/find-help/conditions/anxiety/#treating-anxiety
    - Anxiety UK https://www.anxietyuk.org.uk/get-help/support-for-children-young-people/
    - Mood Juice https://www.moodjuice.scot.nhs.uk/Anxiety.asp

    Apps

    - Calm - Guided meditation app for young people and adults.
    - DreamyKid – This app offers meditation, guided visualisation and affirmations
    - Headspace – guided medication to manage stress and anxiety.

- Thought Diary and Catch It - app to record thoughts and emotions.

Books

- Exploring Feelings: Cognitive Behavioural Therapy to Manage Anxiety by Tony Attwood.

- **PowerPoint Slides 3: Friendships, Relationships, and Autism**
  - Why are friendships and relationships challenging for some autistic people?
    - Video from “Ambitious about Autism” on YouTube on young people with autism talking about communication
    - Things that can help autistic people with friendships and relationships
    - Recommended resources (NAS and Ambitious about Autism sections on friendships), Starving the Anxiety Gremlin: A Cognitive Behavioural Therapy Workbook on Anxiety Management for Young People: 1 (Gremlin and Thief CBT Workbooks) by Kate Collins-Donnelly, Making Friends: A Guide to Getting Along with People by Andrew Matthews, Reading People: How to Understand People and Predict Their Behaviour Anytime, Anyplace by Jo-Ellan Dimitrius.
- **PowerPoint Slides 4: Support and information for autistic people and their families**
  - Mental health support for children and young people (people aged between 0 and 18 years)
  - Mental health support for adults (people aged 18 years to 65 years)
  - Support with education
  - General Support (local and national).

Appendix F

Preliminary feedback from the service

- I think the prompt response is important and could be met by the service if something is developed that rolls over every 2/3 months and picks up all adolescents with a diagnosis in that time frame.
- The information about virtual sessions is also important for face-to-face sessions I think, concerning photographs in advance and warm-up sessions. You could also think about the physical environment (e.g. lights, noise, stim toys available), and having clear group ground rules developed for each group to help with social expectations and anxiety.
- Specific groups may be tricky, but I think specific videos and more general Q&A sessions might be easier (like we have for the parent groups currently).
- Short clips are a great idea - ideally delivered by young people themselves perhaps?
- You could make a point about co-producing all materials / support with autistic YP.
- Future work could look at the means of feedback and information - i.e. through written communication (e.g. texting) for autistic individuals who are less comfortable on screen, or nonverbal. See this paper on adults' preferences for example: Autistic adults' views of their communication skills and needs - Cummins - 2020 - International Journal of Language & Communication Disorders - Wiley Online Library
- For focus groups, it would be helpful to have some focused upon strengths too e.g. it would be amazing to have a session where young people can share their passions / special interests with each other and see how talented they all are / reflect on their own talents.
- Social skills training is a very contentious topic among the autistic community (cf. double empathy problem) so I would be wary of trying to encourage this unless explicitly asked for. Also see this recent paper: Self-reported social skills importance ratings, not social skills themselves, predict sociometric status among youth with autism spectrum disorder - ScienceDirect
- Your data would seem to suggest that the young people want to hear from other autistic young people - facilitating this may be a recommendation from your project perhaps?

Appendix G

Lay summary

After a young person gets a diagnosis of autism, it is usually the parents or guardians who are offered support and information about the diagnosis. Some support is available if the autistic person themselves has specific difficulties (e.g. anxiety support or family therapy). However, no support is available for the young people after they're diagnosed to help them understand the diagnosis and adjust to it.

This project first gathered information from 7 autistic young people and 17 parents using an online survey about what kind of support the young person is accessing after their diagnosis. The feedback showed that young people are not receiving any professional post-diagnostic support around their autism. Three young people and four parents reported that the young person does not want any support. All participants shared that they sought out their own information, including:

- Speaking to a member of their family, staff at school, a therapist, or an autistic friend about it
- Looking it up online or watching TV shows/documentaries
- Reading about it in books or leaflets .

We asked young people and their parents what support they as young people would like. Some of the things they told us they would like were to:

- Speak to or meet another autistic person and hear what they have to say
- Speak to a clinician about it
- Learn more about autism.

We then developed a resource pack based on this feedback. This included PowerPoint slides with a video of a clinician talking through the slides. Satisfaction ratings of the resource pack showed that most people felt it was "average" and one person thought it was "good". After this, we offered a Q&A drop-in session online for young people to join, have the chance to meet other autistic people, and ask questions. Four young people came to the session with a parent. Most people rated the session as "good" and one person rated it "average". Overall, young people felt it was helpful to hear from other autistic people, and they felt their views and worries were taken seriously. So that the local service can continue to provide post-diagnostic support for autistic young people, recommendations were made, including making drop-in groups more topic-specific (e.g. one on understanding the diagnosis, one on social skills, one on anxiety), and for the resource pack to be shorter video clips with a handout summarising the information.

Theoretically Driven (Main) Research Paper

Title: Stay close to me: An exploration of foster carers' strengths, reflective functioning, and abilities to maintain closeness when faced with carer stress and challenging child behaviour.

Short Title: Foster carer stress, strengths, and challenging child behaviour.

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Word Count: 4964

Date of Report: 25/05/2021

Journal: Journal of Adoption and Fostering.

Rationale: This is the only UK journal focused on adoption and fostering. It publishes articles across disciplines (e.g. psychology, law, social work). It is run by CoramBAAF Adoption & Fostering Academy, a leading charity for adoption and fostering.

Abstract

Background: Current research suggests that foster carers experience higher carer stress than biological parents and face more behaviours that challenge from the children they care for. Reflective functioning (the ability to view one's own mental state separately to the child's; viewing them as a separate, independent entity) may facilitate foster carers to persevere when highly stressed and faced with behaviours that challenge. Wellbeing factors may also play such a role. **Aims:** This study aimed to explore whether foster carers who are highly stressed also report their foster child to have higher levels of behaviours that challenge. It also aimed to explore whether higher stress impacted upon a carer's ability to use reflective functioning and their wellbeing. Finally, it explored whether wellbeing moderated the impact of behaviours that challenge. **Method:** Seventy-eight (n = 78) foster carers took part by completing online questionnaires. The highest and lowest scoring forty-six (n = 46) foster carers on a measure of carer stress were compared. The total sample was used to explore whether wellbeing was a moderator in a regression model. **Results:** The results showed that carers with high parental stress reported higher levels of behaviours that challenge and had lower levels of wellbeing. Reflective functioning abilities did not differ between the high and low stress groups. Wellbeing did not moderate the impact behaviours that challenge had on carer stress. **Conclusions:** Further research is required to explore variability in reflective functioning abilities in foster carers, and factors that help moderate the impact of factors that increase carer stress.

Key words: Foster carer, attachment, behaviours that challenge, reflective functioning, wellbeing.

Introduction

Within the UK, the number of children who are looked after by local authorities is increasing (Adams, Hassett and Lumsden, 2018). Government reports indicate 1 in 10 children in care experience multiple placement moves within a year (The Children's Commissioner, 2017). This can significantly impact upon normative development, disrupt attachments, and affect the child's psychosocial wellbeing (Konijn *et al.*, 2019). Government policy emphasises the importance of placement stability for all children (Department for Education, 2013). Stability is underpinned by consistent and sensitive caregiving. A recent meta-analysis suggests that some of the greatest contributors to instability are behaviours that challenge and foster carers who are not well-trained in therapeutic parenting (Morgan and Baron, 2011; Konijn *et al.*, 2019).

Foster carers play a key role in supporting children who are cared for. Attachment theory highlights the importance of emotional and relational bonds created from birth (Bowlby, 1969, 1982; Ainsworth, Bell and Stayton, 1974; Bretherton, 1992; Ainsworth *et al.*, 2015). The formation of secure attachments provides many benefits including positive mental health, socialisation, and emotion regulation, whilst the experience of developmental trauma (e.g. abuse, neglect) can have deleterious impacts on attachment development (Bowlby, 1969; Crittenden, 1983; Crittenden and Ainsworth, 1989; Schore, 2001; Thompson, 2008). Rates of attachment difficulties are higher in children who are in foster care compared to children who live with biological parents (Scheper *et al.*, 2016). However, children in foster care with insecure attachment styles who receive attuned, consistent, therapeutic care can develop adaptive, secure attachments (Bunday *et al.*, 2015). Foster carers play a pivotal role in supporting this, giving rise to therapeutic parenting approaches which encourage secure

attachments (Tarren-Sweeney, 2008; Zeanah, Shauffer and Dozier, 2011; Dozier, Zeanah and Bernard, 2013).

One such approach stems from Peter Fonagy's work on mentalisation within an attachment context. Mentalisation is the ability to understand our own and others' behaviours by imagining the mental experiences and internal world of ourselves and others (Fonagy *et al.*, 1991; Sharp and Fonagy, 2008). Reflective functioning evolved from mentalisation principles and refers to a caregiver being able to reflect on their own mental states and experiences as well as the child's; critically, viewing the child as a separate, independent entity (Meins, 1999; Laranjo, Bernier and Meins, 2008; Sharp and Fonagy, 2008). Parental reflective functioning has been shown to be associated with secure attachment (Redfern *et al.*, 2018). Rather than responding to the child's overt behaviours, the carer is able to imagine a child's internal world and respond accordingly to attend to the child's underlying, unconscious needs (Slade, 2005; Luyten, Nijssens, *et al.*, 2017). This process of attunement enables the caregiver to consistently meet the needs of the child, increasing the probability of the child viewing them as a safe, secure base (Luyten, Nijssens, *et al.*, 2017).

Parental reflective functioning has also been shown to promote the child's own development of reflective functioning abilities, enabling them to regulate their emotions and have healthier psychosocial wellbeing (Luyten, Nijssens, *et al.*, 2017; Redfern *et al.*, 2018). In line with attachment theory, this allows the child to reconstruct their internal working models of themselves, others, and attachment relationships (Casswell *et al.*, 2014). Research indicates that low levels of parental reflective functioning is associated with both mother and child having insecure attachment styles in a biological parent sample (Kelly, Slade and Grienenberger, 2005; Slade, 2005; Slade *et al.*, 2005). This highlights the important role of reflective functioning in the formation of secure

attachment relationships. Furthermore, reflective functioning has been linked to attuned approaches in foster care. This includes affect regulation capabilities, and affective and behavioural responses being congruent to the child's needs (Kelly, Slade and Grienenberger, 2005; Bunday *et al.*, 2015). Programmes which support foster carers to use reflective functioning have a growing evidence-base (Bammens, Adkins and Badger, 2015; Bunday *et al.*, 2015; Midgley *et al.*, 2019; Staines, Golding and Selwyn, 2019; Adkins *et al.*, 2020; Lo and Wong, 2020). Parental reflective functioning is therefore vital in the context of attachment.

Due to limited research on reflective functioning, this literature review explored studies on mentalisation, reflective functioning, and mind-mindedness. Research indicates that the ability to mentalise is related to parental stress in a biological parent population (McMahon and Meins, 2012). In the study, mentalisation (measured using a mind-mindedness measure) was related to negative maternal behaviour (e.g. frightening or critical behaviours), which was indirectly mediated by maternal stress. A study exploring mind-mindedness in a sample of foster, adoptive, and biological parents found that when parents perceive child behaviours to be challenging, mind-mindedness was lower (Fishburn *et al.*, 2017). Longitudinal research found that mind-mindedness, maternal sensitivity, and attunement were related to the child having lower levels of internalising and externalising behaviours (Meins *et al.*, 2013). It is therefore important for similar explorations to be conducted in a non-biological sample.

In line with attachment theory, those with insecure attachments often experience relationships as threatening, and will utilise methods of self-preservation or behaviours that challenge, which may lead to relationship breakdown (Bowlby, 1969, 1982; Ainsworth, Bell and Stayton, 1974; Bretherton, 1992; Morgan and Baron, 2011; Ainsworth *et al.*, 2015). Providing sensitive, nurturing care for a child who appears not

to accept or want this care is difficult (Casswell *et al.*, 2014). It is therefore vital to explore the challenges and stresses foster carers face when supporting a child with an insecure attachment style.

Research suggests that foster carers experience more parental stress than biological parents, potentially experiencing higher levels of parental stress in the face of behaviours that challenge (Vanschoonlandt *et al.*, 2013; Harris-Waller, Granger and Gurney-Smith, 2016). Externalising behaviours have been found to be correlated with higher levels of foster carer stress, however, this was mediated by parental self-efficacy (Gabler *et al.*, 2018; Harding *et al.*, 2018; Bergsund, Wentzel-Larsen and Jacobsen, 2020). Foster carers have also been found to experience compassion fatigue and burnout, which can lead to blocked care, whereby the carer finds it difficult to continue offering attuned care (Ottaway and Selwyn, 2016). Research encourages further exploration around why such factors act as a buffer (Morgan and Baron, 2011). One possible mechanism is that the capacity to engage in reflective functioning not only leads to lower levels of parental stress, but may contribute to foster carers' abilities to maintain positive relationships with children who are displaying behaviours that challenge. This has been suggested in the literature, however, requires further exploration (Redfern *et al.*, 2018).

Considering factors which provide strength and perseverance to foster carers is important when thinking about maintaining parental reflective functioning and closeness with the child. Positive psychology is an approach which aims to recognise the strengths and positive qualities within people (Donaldson, Dollwet and Rao, 2015). Strengths-based practice, whereby an individual's resources and strengths are recognised and expanded upon, has been used with foster carers to promote feelings of reward and empowerment (Odell, 2008). Research exploring factors that lead to foster

carers continuing a placement include feelings of fulfilment and satisfaction, personal motivation to continue, and social support and connectedness (Geiger, Hayes and Lietz, 2013). Such research can support an understanding of how foster carers preserve crucial skills in the face of stressful and challenging situations.

One model within positive psychology theory is PERMA, which proposes five factors that capture elements of subjective wellbeing (Khaw and Kern, 2014; Goodman *et al.*, 2018; Seligman, 2018). These are: positive emotion (the ability to hold optimism and be constructive in the face of challenges); engagement (the ability to engage with activities that keep the person present and connected); relationships (feeling socially connected and valued, and holding meaningful interactions); meaning (gaining satisfaction and purpose from the work that they do); and accomplishment (gaining a sense of accomplishment through setting goals and pursuing ambitions).

The current study aims to explore whether there is an interaction between levels of parental stress in foster carers, parental reflective functioning and reported behaviours that challenge. Considering the current research, it is understood that carers who report higher levels of carer stress also report higher levels of behaviours that challenge. Although there is little literature present, it is difficult to conclusively assume directionality. However, the mechanisms at play may be that foster carers who report greater levels of behaviours that challenge experience greater stress or burnout due to the presence of more behaviours that challenge. Given the current evidence base suggesting that behaviours that challenge are a key contributor of placement breakdown, and that foster carers find it more difficult to provide attuned, nurturing care to a child who is displaying behaviours that challenge, it can be hypothesised that behaviours that challenge lead to greater carer stress. However, it may also be possible that carers who are more stressed perceive behaviours that challenge as more

challenging, distressing, or problematic, which may in turn contribute to greater stress levels. The relationship between wellbeing and carer stress and the presence of behaviours that challenge must also be considered. Little literature exists on the relationship between these constructs. It may be that behaviours that challenge lead to poorer wellbeing given the link with burnout and compassion fatigue, and that poorer wellbeing is closely linked to carer stress. These constructs are therefore difficult to disentangle, and more research is required to establish causality. The study will therefore also consider wellbeing factors and their interaction with parental stress.

The study aims to answer the following questions:

1) Do higher levels of behaviours that challenge relate to higher levels of parental stress in foster carers?
2) Do foster carers who experience higher levels of carer stress have lower levels of reflective functioning?
3) Do higher wellbeing scores relate to lower levels of carer stress?
4) Does wellbeing moderate the relationship between carer stress and behaviours that challenge and/or reflective functioning?

Based on the literature, the following hypotheses have been drawn:

1) Hypothesis 1: Foster carers with high parental stress will have children with significantly more behaviours that challenge.
2) Hypothesis 2: Foster carers with high parental stress will show significantly lower levels of reflective functioning.
3) Hypothesis 3: Higher wellbeing scores will result in lower levels of parental stress.
4) Hypothesis 4: Wellbeing will moderate the relationship between carer stress and any associated variables (behaviours that challenge and/or reflective functioning).

Methods

Participants

The sample consisted of UK foster carers aged 18+. Recruitment took place using social media, snowball and convenience sampling, and locally through Oxfordshire County Council. At least 64 (32 participants in each group) were needed to adequately power the study at a medium effect size with 0.05 probability. Carers were included if they were over 18, based in the UK, and were a foster carer who had a foster child placed with them at time of participation. The child had to be aged 1.5 years to 18 years, and the foster carer had to be their primary caregiver. Foster carers were not excluded based on any differences, however this information was gathered as demographic information. Carer status (long or short term), placement length, number of years of fostering experience, number of children fostered, age, gender, ethnicity, occupation, and whether they co-habited were recorded as demographic data.

Measures

Participants completed four questionnaires dependant on the age of the child:

1) Parental Stress:
    a. Parenting Stress Index, Fourth Edition (PSI-4) (Abidin, 2012) is a validated measure completed by parents/carers of children aged 0-12 exploring stressful aspects of the parent-child interactions and strains experienced by the parent/carer. The measure has parent domains, child domains, and life stress subscale. As items on the child domain conflicted with the CBCL measure, only the parent domains and the life stress subscale were administered. There are 54 questions on the parent domains and 19 questions on the life stress subtest (total 73). The measure has reliability coefficients of .75 to .87 on the parent domains, and good test-retest reliability.

b. Stress Index for Parents of Adolescents (SIPA) (Sheras, Konold and Abidin, 1998) is a validated measure completed by parents/carers exploring stressful impacts of the parent-child interactions and strains experienced by the parent/carer. This measure is designed for parents of children aged 11-19. There are 34 questions on the parent domains and 22 items on the life stress subscale (total 56). Internal consistency coefficients range from .80 to .90. Test-retest reliability coefficients for the subscales range from .74 to .91.

2) Challenging Child Behaviour:

a. Child Behavior Checklist Ages 6-18 (CBCL/6-18) (Achenbach and Edelbrock, 1991) is a validated measure completed by carers that identifies behavioural and emotional problems a child is experiencing. There are 113 items. It identifies internalising and externalising challenging behaviours. The scale has good internal consistency, and adequate test-retest reliability and inter-rater reliability (Albores-Gallo *et al.*, 2007; Ebesutani *et al.*, 2010).

b. Child Behavior Checklist Ages 1½-5 (CBCL/1½-5) (Achenbach and Rescorla, 2000) is a similar measure for younger ages which also identifies internalising and externalising challenging behaviours. There are 100 items, and the scale has been found to also have reliability and validity.

3) Reflective Functioning:

a. The Parental Reflective Functioning Questionnaire (PRFQ) is completed by the carer and explores their ability to reflect on their own internal states as well as the child's, viewing them as a separate entity in line with concepts of mentalisation (Luyten, Mayes, *et al.*, 2017; Luyten, Nijssens, *et al.*, 2017). This was initially validated for ages 0-5, but has been extended to age 12. There are a total of 18 questions. Internal consistency is shown to be 0.7 and

above, and emerging evidence shows good reliability and validity (Luyten, Mayes, *et al.*, 2017; Luyten, Nijssens, *et al.*, 2017; de Roo *et al.*, 2019). It measures three subscales: Pre-Mentalizing Modes (PRFQ-PM), Certainty about Mental States (PRFQ-CM), and Interest and Curiosity in Mental States (PRFQ-IC).

b. PRFQ-Adolescent Version is a similar measure for children aged 12-18. This has good reliability and validity, as well as factor structure (Luyten, Mayes, *et al.*, 2017). There are a total of 18 questions.

4) PERMA:

a. The PERMA Profiler is a 23-item self-report measure using the five PERMA factors to explore wellbeing (Butler and Kern, 2016). It has good reliability and good convergent and divergent validity, Cronbach's alpha was found to be 0.87 and above.

Design

To answer the first three research questions, a between-groups design was used (Figure 1). An extreme group analysis was used, comparing the highest and lowest scoring 30% of foster carers on the parent domains subscales on the PSI-4 and SIPA (Sheras, Konold and Abidin, 1998; Abidin, 2012). Based on the hypotheses, the relationship between carer stress, reflective functioning, challenging child behaviour, and wellbeing was tested.

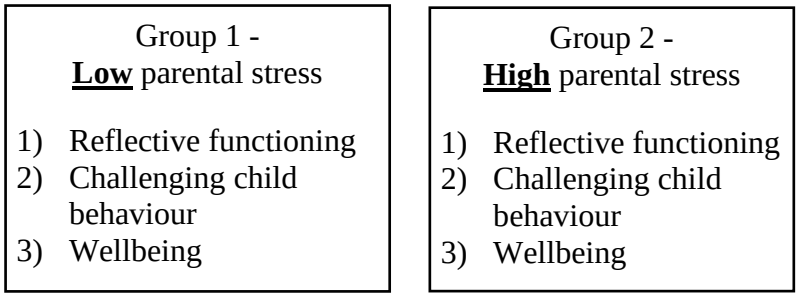


Figure 1. The between-groups design model used.

To answer the final research questions, a linear regression model was used on the overall sample to explore whether wellbeing moderated the relationship between carer stress and associated variables (Figure 2).

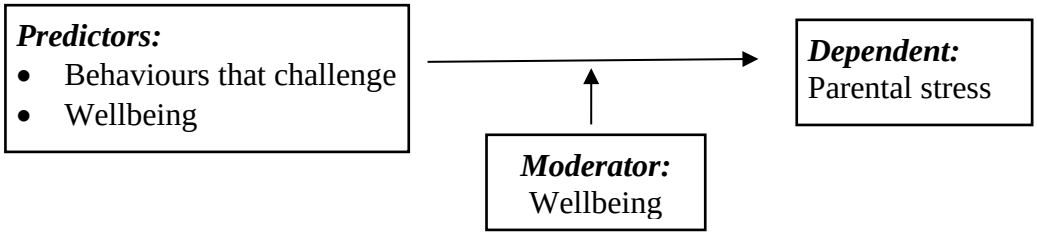


Figure 2. The regression model used with wellbeing as a moderator.

Procedure

Participants emailed to opt-in and were sent a Qualtrics link with the participant information form, consent form, and self-report measures. Participants completed demographic information, the CBCL, PRFQ, parental stress measure, and PERMA. Prior to the questionnaires appearing, participants had the following statement displayed: "for all questions, please think of one foster child who you find most challenging" to ensure that all answers were based on the same foster child. An end of survey page was then displayed with resources (Appendix A). Participant data was anonymised, and a spreadsheet was kept matching email addresses with unique

identifiers to allow participants to withdraw their data. Data was securely kept on an encrypted device.

Results

A total of 84 participants took part; 6 were omitted following data cleaning (*n*=4 child was above age limit, *n*=2 incomplete datasets). A total of 78 participants were selected for final analysis (female *n*=70; male *n*=8) (Appendix B.). Due to poor variance in the dataset, an extreme group analysis had to be used to compare participants by carer stress, using the highest and lowest 30% on the parent domains subscales on the PSI-4 and SIPA (*n*=46) (Sheras, Konold and Abidin, 1998; Abidin, 2012). Post-hoc power analysis showed an effect size of 0.38, indicating that, due to data loss, the final study sample was under-powered. Data was therefore analysed with caution.

The majority of participants were female, aged 40-60, White British, who fostered full time (Table 1.) The majority had previous fostering experience of more than five children for over five years. Most had biological children, and co-habited with a partner. Descriptive statistics of the foster children showed that 56.5% were male (*n*=26), 43.5% were female (*n*=20), with ages ranging from 1.5 years to 18 (*M* = 10.9 years, *SD* = 4.7).

Table 1

Participant Demographic Information

Participant demographics	*n*	*%*
Gender		
Female	40	87%
Male	6	13%
Age		
25-39	6	13%
40-60	30	65.2%
60+	10	21.7%
Ethnicity		
White British, Irish, or any other white background	43	93.5%
Mixed/multiple ethnic groups	2	4.3%
Black/African/Caribbean/Black British	1	2.2%
Full time carer?		
Full time foster carer	29	63%
I work alongside my fostering duties	17	37%
Previous fostering experiences		
Yes	40	87%
No	6	13%
Number of children fostered overall		
1-2	7	15.2%
3-5	7	15.2%
6-10	9	19.6%
11+	23	50%
Length of time fostering		
1-5 years	15	32.6%
6-10 years	10	21.7%
11-20 years	13	28.3%
21+ years	8	17.4%
Have their own biological children		
Yes	37	80%
No	9	20%
Single carer or co-habit		
Co-habit	39	85%
Single carer	7	15%

The data was checked for normal distributions and tested to see if it fulfilled normality assumptions (Appendix C). The life stress subscale was included as a

possible confounding variable to control for (Sheras, Konold and Abidin, 1998; Abidin, 2012). Life stress (positively skewed) and a subscale on the PRFQ measure (PRFQ-IC) (negatively skewed with a ceiling effect) did not fulfil normality assumptions. Transformation was used to normalise these datasets in line with (Tabachnick and Fidell, 2013). For life stress, an inverse transformation was used. For PRFQ-IC, a reflect and logarithm transformation was used (Appendix D).

The internal consistency of PRFQ was assessed due to calls to test the psychometric properties of the measure in varied samples (Luyten, Nijssens, *et al.*, 2017). Reliability analyses showed acceptable Cronbach alpha coefficients for the subscale PRFQ-CM in the low (α = 0.84) and high stress groups (α = 0.72). The PRFQ-IC subscale also showed acceptable internal consistency in the low (α = 0.76) and high stress group (α = 0.71). However, internal consistency was low for the PRFQ-PM subscale both in the low (α = -0.27) and high group (α = 0.28). Although removing items with low item-total correlations improved the alpha value, some items on the corrected item-correlations tab remained low (α = -0.14). Removing them would have left too few items remaining on the subscale, therefore this subscale was omitted from analysis.

To check for demographic differences between the high and low carer stress groups, a chi-squared test was conducted with Yates' continuity correction (Appendix E.). Due to small numbers in some groups, such as ethnicity, categories were collapsed for analysis purposes. The groups were not found to significantly differ by demographics.

<u>Hypothesis 1:</u> Foster carers with high parental stress will have children with significantly more behaviours that challenge.

An independent samples t-test was conducted comparing carer stress and behaviours that challenge. A statistically significant difference in CBCL scores between the high (M = 72, SD = 9.6) and the low stress group (M = 64.8, SD = 11.3; t (44) = -2.4, p = 0.02, two-tailed) was found. The magnitude of the difference found between the means was: mean difference = -7.4, 95% *CI*: -13.63 to -1.16. This supports hypothesis 1; carers with high parental stress rated their foster child as having more behaviours that challenge.

An independent samples t-test was conducted comparing carer stress and the transformed life stress variable. Equal variance was not assumed. There was a statistically significant difference in life stress scores between the high and low carer stress group (*mean difference* = 0.003, 95% *CI*: 0.0003 to 0.005). This suggests that foster carers who experience higher levels of carer stress experience higher levels of life stress.

<u>Hypothesis 2:</u> Foster carers with high parental stress will show significantly lower levels of reflective functioning.

Descriptive statistics exploring reflective functioning showed high levels of PRFQ-IC on average (M = 6.3, SD = 0.9), and average and more varied scores on the PRFQ-CM subscale (M = 4.2, SD = 1.1). This indicates that reflective functioning abilities of this sample were, on average, high.

A one-way between-groups multivariate analysis of variance (MANOVA) was used to assess the difference in high and low stress carers (independent variable (IV)) in reflective functioning abilities on the two PRFQ subscales (dependant variables (DV)).

Assumptions testing checked for univariate and multivariate outliers, linearity, normality, homogeneity of variance-covariance matrices, and multicollinearity, with no assumptions being violated. A significant difference in reflective functioning was not found between high and low stress carers, F (2, 43) = 0.46, p = 0.63; Wilks' Lambda = 0.98; partial eta squared = 0.021.

To explore whether a lack of a significant result between carer stress and reflective functioning was due to behaviours that challenge or life stress covarying the relationship, analyses of covariance were conducted. Assumptions of linearity, homogeneity of variances, normality, and homogeneity of regression slopes were checked. For life stress and PRFQ-CM, a violation of the assumption of homogeneity of regression slopes was found, therefore life stress was not covaried when assessing the relationship between carer stress and PRFQ-CM.

A one way between groups multivariate analysis of covariance (MANCOVA) was used to compare high and low carer stress group (IV), and PRFQ-IC (DV), with CBCL and life stress as covariates. No differences between the high stress and low stress group were found on PRFQ-IC, F (1, 42) = 0.54, partial eta squared = 0.009; nor for PRFQ-IC and CBCL (p = 0.28, partial eta squared = 0.27) and life stress (p = 0.74, partial eta squared = 0.003). This indicates that even after controlling for behaviours that challenge and life stress, there is no relationship between carer stress and the reflective functioning subscale, PRFQ-IC.

Following this, an analysis of covariance (ANCOVA) was conducted, with IV as carer stress group (low/high) and the DV as PRFQ-CM, covarying for CBCL. After adjusting for CBCL, no differences were found between carer stress group and PRFQ-CM, F (1, 43) = 0.96, p = 0.33, partial eta squared = 0.02); nor between PRFQ-CM and CBCL (p = 0.7, partial eta squared = 0.004). Overall, no relationship was demonstrated

between carer stress and reflective functioning on either subscale even after controlling for behaviours that challenge and life stress.

<u>Hypothesis 3:</u> Higher wellbeing scores will result in lower levels of parental stress.

Wellbeing scores on the PERMA measure were explored using descriptive statistics (Appendix F). For overall PERMA wellbeing scores, (measuring positive emotion, engagement, meaning, relationships, and accomplishment), 54% of foster carers rated themselves at 8 or 9 out of 10, with 10 indicating the highest levels of wellbeing (n = 25). When rating their health, 65% of foster carers rated their health at 8 or above out of 10 (n = 30). When asked about negative emotion, 50% of carers reported experiencing sadness, anger, or anxious at 3 or less, with a lower score indicating less frequent experience of negative emotions (n = 23). Finally, although 33% of carers rated not feeling lonely at all (n = 15), 24% rated feeling lonely at 7 out of 10, with 10 being very lonely (n = 11).

An independent samples t-test was conducted comparing carer stress and wellbeing scores. A statistically significant difference in PERMA scores between the high stress group (M = 6.3, SD = 1.9) and the low (M = 8.6, SD = 1.1; t (44) = 4.9, p = 0.00, two-tailed) was found. The magnitude of the difference found between the means was: mean difference = 2.26, 95% *CI*: 1.33 to 3.2. This suggests that foster carers with higher levels of carer stress also report lower wellbeing scores.

<u>Hypothesis 4:</u> Does wellbeing moderate the relationship between carer stress and any associated variables?

To explore whether wellbeing moderates the relationship between carer stress and behaviours that challenge, a linear regression was used, controlling for life stress.

Assumptions of normality, linearity, and homoscedasticity were not violated. The variance explained by the model was 38%, F (4, 70) = 10.75, p = <0.01, R^2 = 0.38. CBCL accounted for 24% of the variance in carer stress (b = 0.24, t(70) = 2.82, p = 0.006). PERMA accounted for the most of the variance in the model (b = -3.14, t(70) = -5.5, p = <0.001). The interaction between CBCL and PERMA was not significant (b = 0.02, t(70) = 0.27, p = 0.79). This indicates that higher scores of behaviours that challenge predict higher levels of carer stress, and higher levels of wellbeing predicted lower levels of carer stress. However, if behaviours that challenge are high, wellbeing does not moderate the relationship between behaviours that challenge and carer stress.

Discussion

This study aimed to explore whether foster carers with high levels of parental stress report their foster child has higher rates of behaviours that challenge. The second aim was to explore whether highly stressed carers had lower levels of reflective functioning. The final question was whether carers with higher wellbeing scores had lower levels of carer stress, and whether wellbeing moderated the relationship between factors that predict carer stress. Findings support the first hypothesis, indicating that foster carers with higher levels of parental stress also rate their child as having greater levels of behaviours that challenge. This is in line with previous research (Gabler *et al.*, 2018; Bergsund, Wentzel-Larsen and Jacobsen, 2020).

Hypothesis 2 predicted that foster carers with high carer stress would also have lower levels of reflective functioning. No difference was found in reflective functioning abilities between the high and low stress groups. Although carer stress has not been directly linked with reflective functioning, foster carers who experience higher levels of stress also report higher levels of behaviours that challenge. Current literature indicates that when behaviours that challenge are high, mind-mindedness is also reported to be lower (Meins *et al.*, 2013; Fishburn *et al.*, 2017). Research also indicates that carer stress mediates the relationship between mind-mindedness and negative maternal behaviours (McMahon and Meins, 2012). The sampling approach used in this study may have impacted the variability in reflective functioning scores. The mean scores on the PRFQ subscales indicate high levels of reflective functioning in the sample. There was also a lack of variance in carer stress within the sample. The majority of carers scored close to the mean, with few clinically significant scores. Although the sampling method allowed a variety of carers to participate, volunteering may have meant carers who were more willing to engage and reflect took part. This

may have excluded highly stressed carers without the capacity to participate. However, the current finding suggests that foster carers whose levels of stress are below clinical significance also have high levels of reflective functioning abilities.

The results support hypothesis 3, finding that foster carers with lower levels of carer stress also had higher wellbeing scores. This indicates that foster carers who feel a greater sense of engagement, meaning, accomplishment, positive emotion, or are supported in their relationships, also have lower levels of parental stress. This builds on previous research suggesting that feelings of social connectedness, fulfilment, and satisfaction is reported to be a reason that foster carers give to continue a placement (Geiger, Hayes and Lietz, 2013).

Finally, the findings did not support hypothesis 4. Although behaviours that challenge predicted higher levels of foster carer stress, wellbeing was not found to affect the relationship between behaviours that challenge and carer stress. This suggests that despite their wellbeing, foster carers experience stress when faced with behaviours that challenge. It is therefore important to support carers in addressing and managing behaviours that challenge. Future research is encouraged to explore factors that could moderate the impact of behaviours that challenge on carer stress.

One limitation of this study was the need to use an extremes analysis. Not using the data of carers who scored around the mean meant the study was underpowered, and that some variables required transformation to normalise the dataset. Future research is encouraged to use a comparison group, whereby carers scoring above clinical threshold and accessing specialist services are compared with general population foster carers. This might better capture variance in carer stress and any associated fluctuations in reflective functioning.

As the PRFQ is a self-report measure, it may not have captured detailed aspects of reflective functioning which interview-based measures would have (e.g. the Reflective Functioning Scale (RFS) within the Parent Development Interview or Adult Attachment Interview) (George, Kaplan and Main, 1996; Slade *et al.*, 2003). Reflective functioning abilities were also reported retrospectively, therefore not capturing it "live". Despite this, convergent validity between the PRFQ and the RFS has been found to be good (Anis *et al.*, 2020). In the current sample, reliability tests indicated that the PRFQ-PM subscale had low convergent validity, therefore was subsequently removed from analysis. Although the PRFQ had been used with foster carers and adoptive parents previously, it has not been used cross-sectionally or in a large-scale sample (Midgley *et al.*, 2019; Staines, Golding and Selwyn, 2019; Adkins *et al.*, 2020). Future studies are encouraged to use the PRFQ in a larger foster carer sample.

Similarly, the CBCL measures are also self-report, completed by the caregiver. As such, consideration to the perception of the caregiver must be made. The study asked foster carers to complete the questionnaires based on the foster child they find most challenging, however this may not be the child which displays the most behaviours that challenge. Behaviours that challenge are described as such as consideration has to be made to how they challenge those around them. Such a self-report measure does not capture the reasons why the specific behaviours are experienced as challenging by the caregiver, which is often a dynamic considered clinically. Factors include the caregiver's own attachment and life experiences, the caregiver's subjective ability to manage and tolerate stress and distress, or the caregiver's abilities to parent certain developmental ages, stages, or needs. The use of control groups, such as with biological or adoptive parents, may allow the relationship between behaviours that challenge and stress to be explored further. Future research

could also explore these constructs in a more experimental or objective way, rather than using self-report measures.

Finally, participant feedback highlighted a key contributor to their stress being the wider social care system. System stressors were not measured within this study. Additionally, due to an omission error, carers were not asked how many children they currently have at home, or if their children have additional needs. These may have potentially been confounding factors, as greater caring duties may mean greater pressures. Future research is encouraged to explore such stressors.

Despite these limitations, this study highlighted key factors related to foster carer stress. The study also allowed for concepts that are "assumed knowns" in clinical practice to be explored in a large sample of community foster carers. Current literature around foster carer stress, their wellbeing, and behaviours that challenge are sparse. Greater research is also needed to be carried out on reflective functioning given the focus on it in clinical practice (Bammens, Adkins and Badger, 2015; Bunday *et al.*, 2015; Midgley *et al.*, 2019; Staines, Golding and Selwyn, 2019; Adkins *et al.*, 2020; Lo and Wong, 2020). This includes more objective and experimental methods in assessing 'live' reflective functioning, and using compare groups to understand whether foster carer's abilities vary depending on clinical or community sample, and between biological or adoptive parents. The findings support previous literature on the impact of behaviours that challenge upon a carer's stress levels. It also provides evidence to suggest that higher levels of wellbeing factors, such as engagement and accomplishment, are related to lower levels of carer stress. Although directionality cannot be assumed in this analysis, this provides useful information on factors that relate to lower levels of foster carer stress. Wellbeing is therefore a useful factor to understand in the context of foster carer stress. More research is required to understand

how behaviours that challenge may relate to foster carer stress. The findings also provide useful information around behaviours that challenge predicting higher levels of carer stress. To better understand the interaction between these factors, longitudinal and experimental research is required. It is vital to continue adding to the evidence base around ways foster carers can be supported in providing attuned, nurturing care in the context of stressful environments and behaviours that challenge.

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Appendix A

Survey Layout

Page 1: Participant information sheet
Page 2: Participant consent form
Page 3: Demographic details:

Please write a unique identifier code for yourself. Be sure to keep a record of this for yourself so that if you wish to follow up on your data or have your data removed, we can identify your data using this code. Please keep this vague and do not use your name.

Please tell us a little about yourself. It's helpful for us to know demographic details to explore whether there are similarities or differences between groups of people.

Demographic questions.

Thank you for telling us a bit more about yourself.
Please click to the next page to begin the questionnaires.

Page 4: Details of foster child:

For all questions, please think of one foster child who you find most challenging.

How old is your foster child?
What is your child's gender?
Boy
Girl

Page 5: CBCL 1.5-5 or 6-18
Page 6: PRFQ or PRFQ-A
Page 7: Break

You're halfway through this survey!

The final two questionnaires will look at your strengths and any stresses you experience as a carer. There are 96 questions left.

Please do take a moment to stretch, get a drink and have a break if you need it!

Click through to the next page when you're ready.

Page 8: PSI-4 or SIPA
Page 9: PERMA

Thank you! You have completed all questions.
Please click to the last page for useful information.

Page 10: Survey termination page

Thank you!

You have completed all of the questionnaires for this study. We thank you so much for your time, and hope you found the questionnaires interesting and helpful.

We really value every person's contribution, and your responses can help us gain a better understanding of the strengths and difficulties foster carer's experience.

If you have any questions or queries, please don't hesitate to contact a member of the research team on:

- Sandy (Alexandra) Harper: alexandra.harper@oxfordhealth.nhs.uk
- Dr Claire Holdaway (supervisor): claire.holdaway@oxfordshire.gov.uk
- Dr Ciorsdan Anderson (supervisor): ciorsdan.anderson@hmc.ox.ac.uk

If you have a complaint about the research, please contact:

- Dr Claire Holdaway (supervisor): claire.holdaway@oxfordshire.gov.uk

If you feel that you have been impacted by this research in any way, please do speak to your supervising social worker, a trusted professional, or contact a member of the research team on the above contact details. There are also services which can offer support, so please do reach out if it's needed:

Support for Foster Carers

- Fosterline: a free helpline and website funded by the Department for Education offering advice, information and support on all issues related to fostering. Phone: 0800 040 7675. Website: https://www.fosterline.info/
- Foster Talk: Phone: 0121 758 5013. Provide independent support to foster carers for a range of issues. Website: https://www.fostertalk.org/
- The Fostering Network: the UK's largest fostering charity. Website: https://www.thefosteringnetwork.org.uk/

Mental Health Helplines

- Samaritans. To talk about anything that is upsetting you, you can contact Samaritans 24 hours a day, 365 days a year. You can call 116 123 (free from any phone)
- SANEline. If you're experiencing a mental health problem or supporting someone else, you can call SANEline on 0300 304 7000 (4.30pm–10.30pm every day)
- **Papyrus HOPELINEUK.** If you're **under 35** and struggling with suicidal feelings, or concerned about a young person who might be struggling, you can call Papyrus HOPELINEUK on 0800 068 4141 (weekdays 10am-10pm, weekends 2pm-10pm and bank holidays 2pm–10pm), email pat@papyrus-uk.org or text 07786 209 697.

Appendix B.

Table showing participant Demographic Information of Participants who originally took part.

Participant demographics	*n*	*%*
Gender		
Female	70	90%
Male	8	10%
Age		
25-39	10	12.8%
40-60	55	70.5%
60+	13	16.7%
Ethnicity		
White British, Irish, or any other white background	74	94.9%
Mixed/multiple ethnic groups	2	2.6%
Black/African/Caribbean/Black British	2	2.6%
Full time carer?		
Full time foster carer	50	64%
I work alongside my fostering duties	28	36%
Previous fostering experiences		
Yes	66	85%
No	12	15%
Number of children fostered overall		
1-2	14	17.9%
3-5	13	16.7%
6-10	18	23.1%
11+	33	42.3%
Length of time fostering		
>1 year	2	2.6%
1-5 years	27	34.6%
6-10 years	20	25.6%
11-20 years	19	24.4%
21+ years	10	12.8%
Have their own biological children		
Yes	59	76%
No	19	24%
Single carer or co-habit		
Co-habit	62	79%
Single carer	16	21%

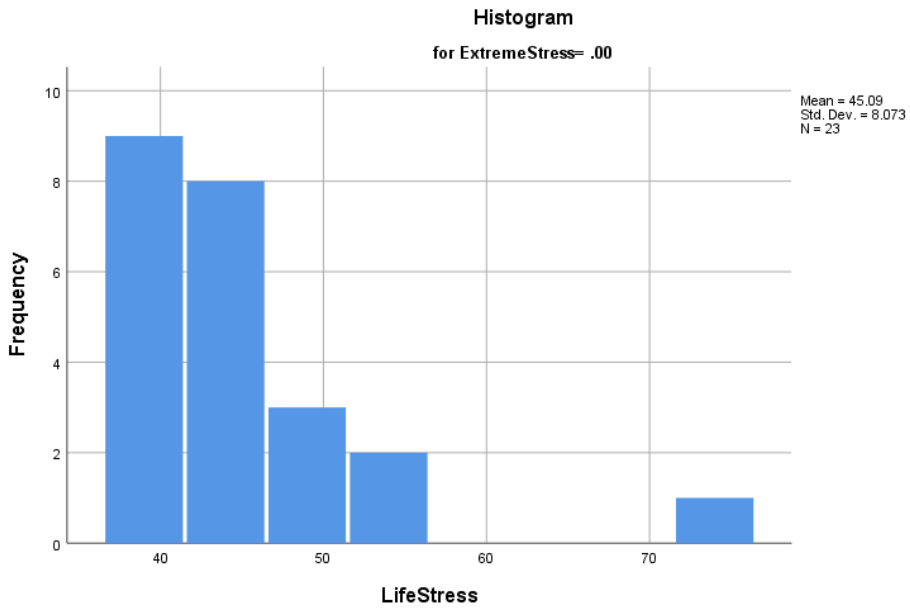
Appendix C.

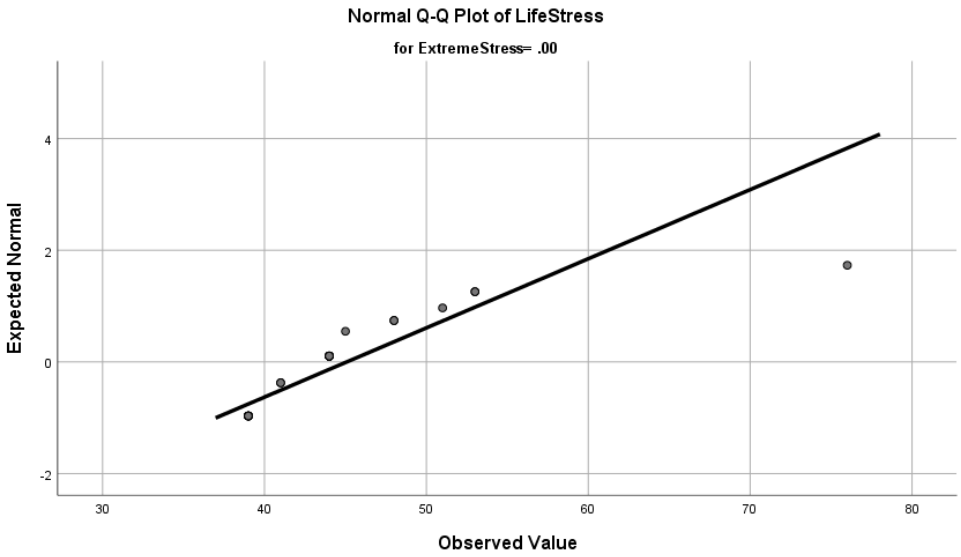
Normality distributions

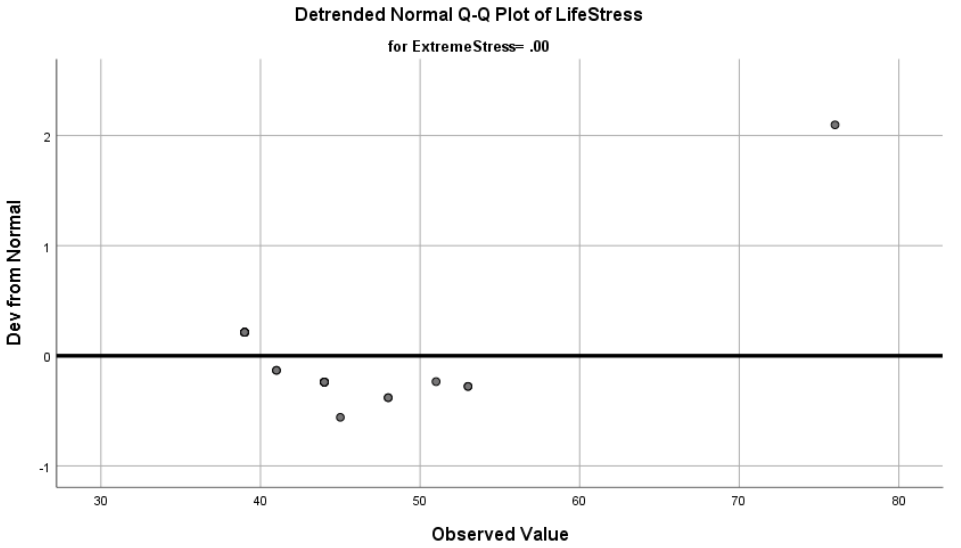
Table showing normal distribution data of all variables by stress group.

Variable	*M*	*SD*	*Skewness*	*Kurtosis*	*Shapiro-Wilks*
Life Stress					
High carer stress	52.48	13.36	0.85	-0.5	0.007
Low carer stress	45.09	8.07	2.8	9.7	0.000
CBCL					
High carer stress	72.2	9.6	-0.4	0.3	0.732
Low carer stress	64.8	11.3	-0.9	1.1	0.191
PRFQ-PM					
High carer stress	2.4	0.8	0.2	-0.1	0.004
Low carer stress	2	0.6	0.0	0.2	0.000
PRFQ-CM					
High carer stress	4	0.95	0.7	-0.3	0.002
Low carer stress	4.3	1.3	0.2	0.3	0.036
PRFQ-IC					
High carer stress	6.2	1	-1.1	0.1	0.000
Low carer stress	6.4	0.9	-1.2	0.7	0.000
PERMA					
High carer stress	6.3	1.9	-0.2	-0.5	0.213
Low carer stress	8.6	1.1	-1.6	4.5	0.000

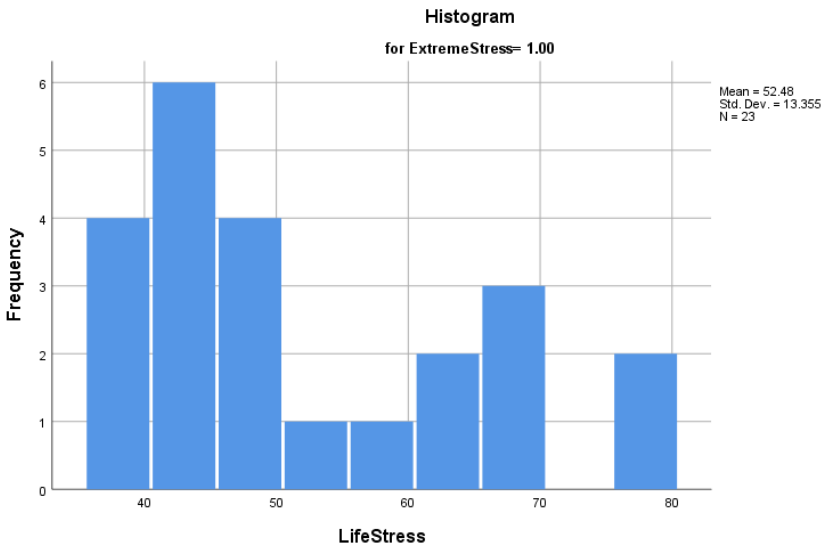
Life Stress – Low Carer Stress Group

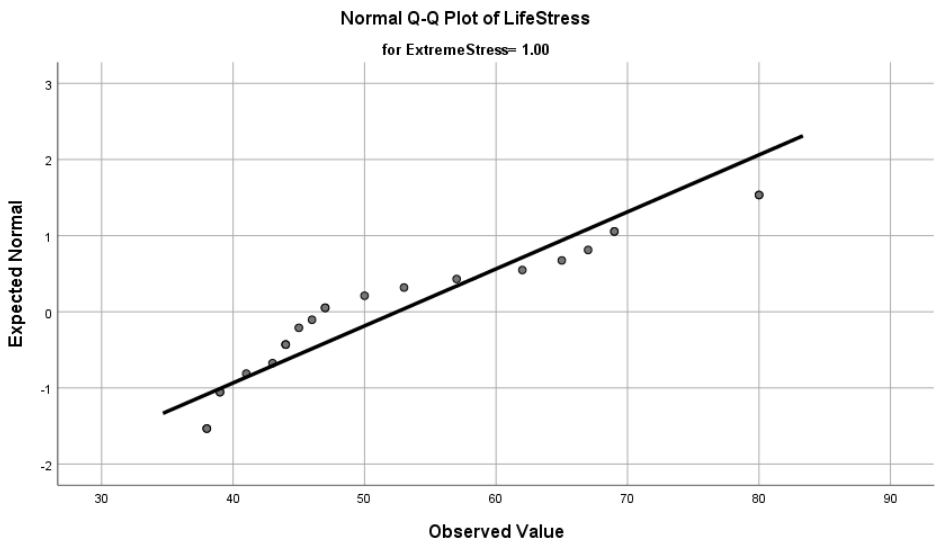


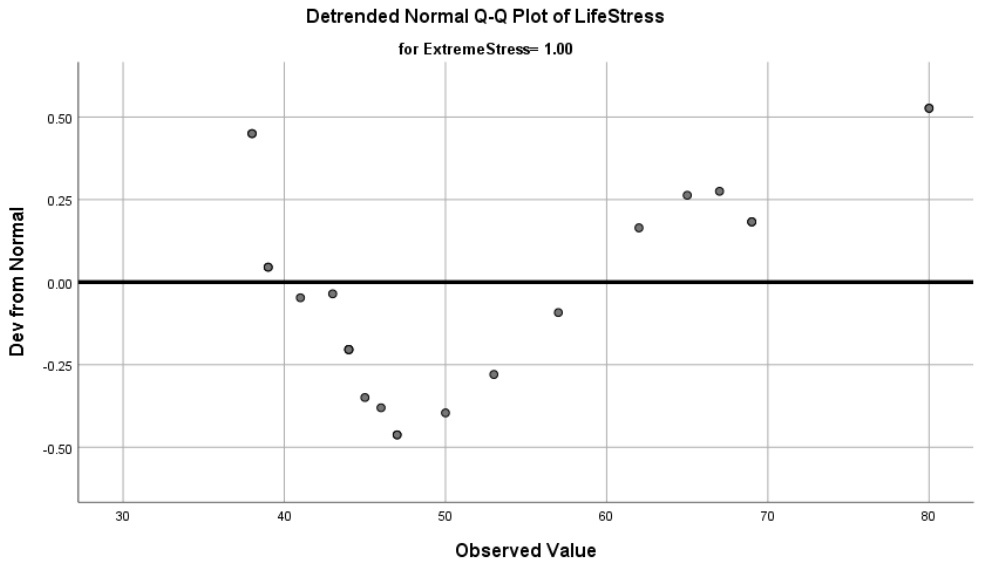


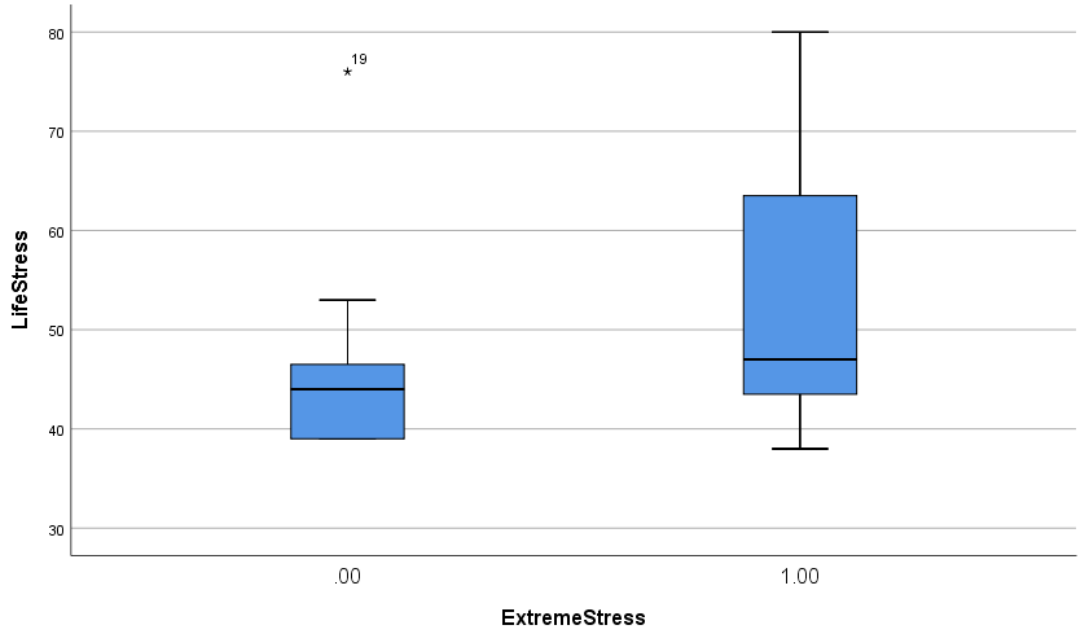


Life Stress – High Carer Stress Group

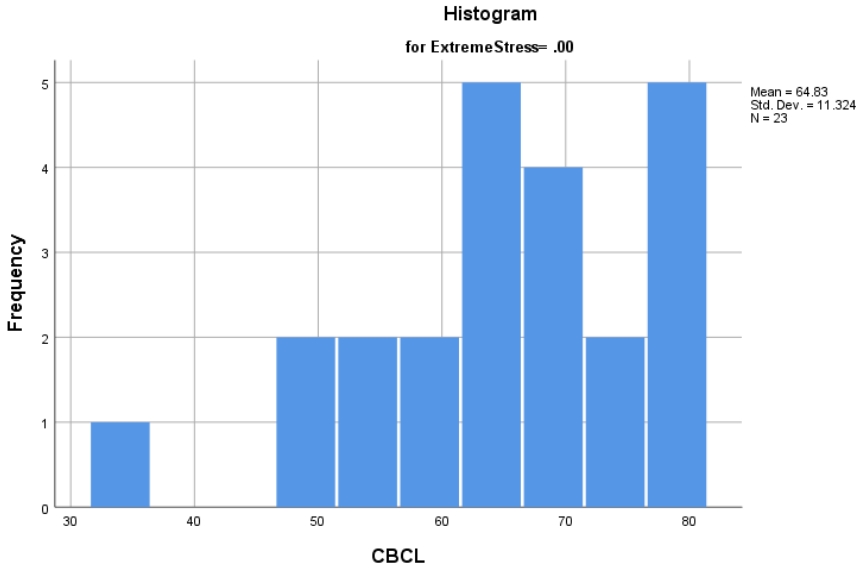


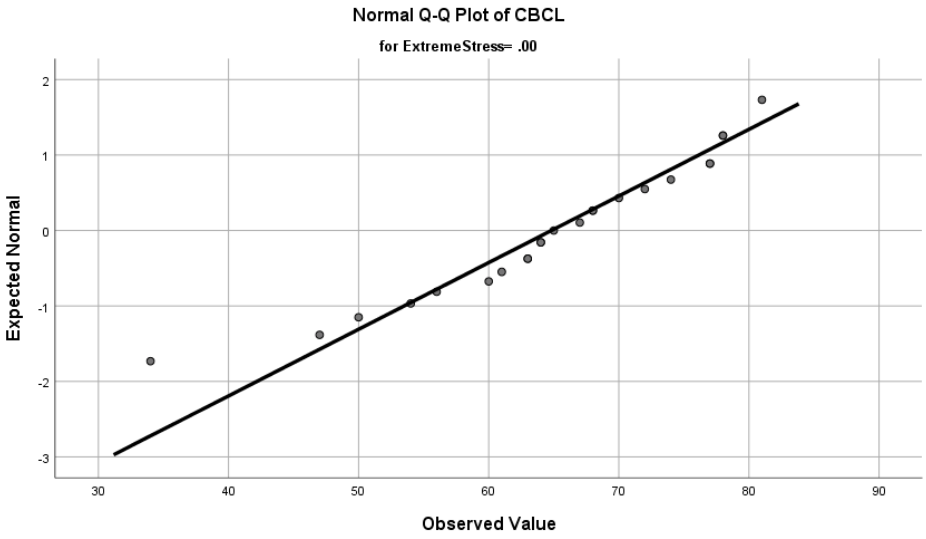

Normal Q-Q Plot of LifeStress
for ExtremeStress= 1.00
Expected Normal
Observed Value
3
2
1
0
-1
-2
30
40
50
60
70
80
90

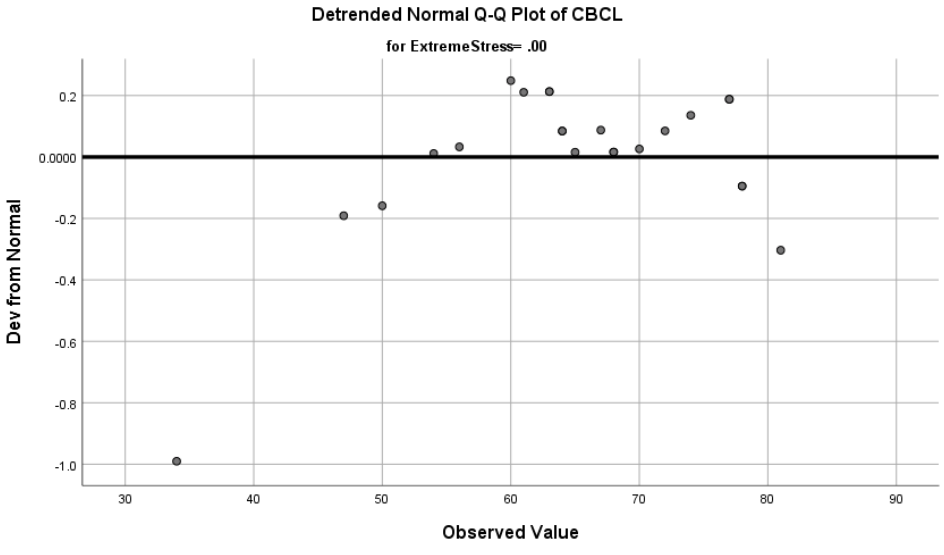

Detrended Normal Q-Q Plot of LifeStress
for ExtremeStress= 1.00
Dev from Normal
Observed Value
0.50
0.25
0.00
-0.25
-0.50
30
40
50
60
70
80


LifeStress
ExtremeStress
80
70
60
50
40
30
19
.00
1.00

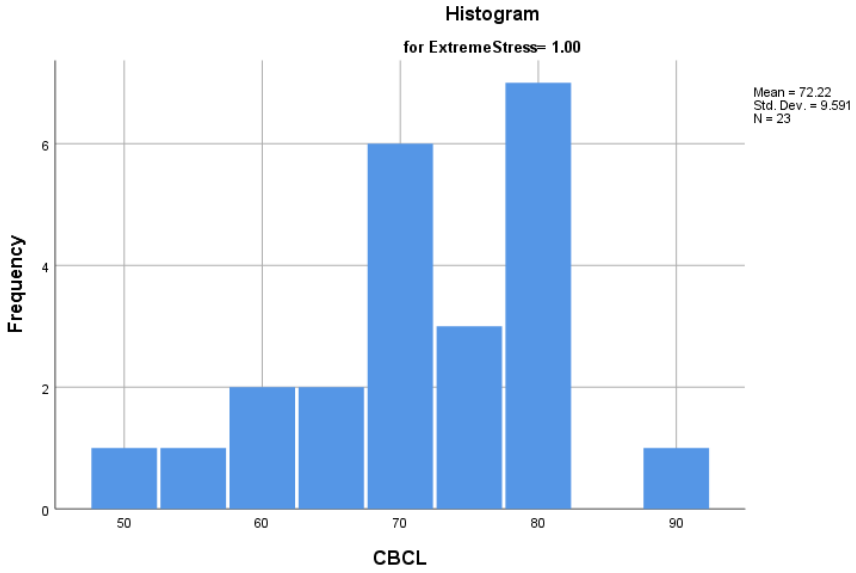
CBCL – Low Carer Stress Group

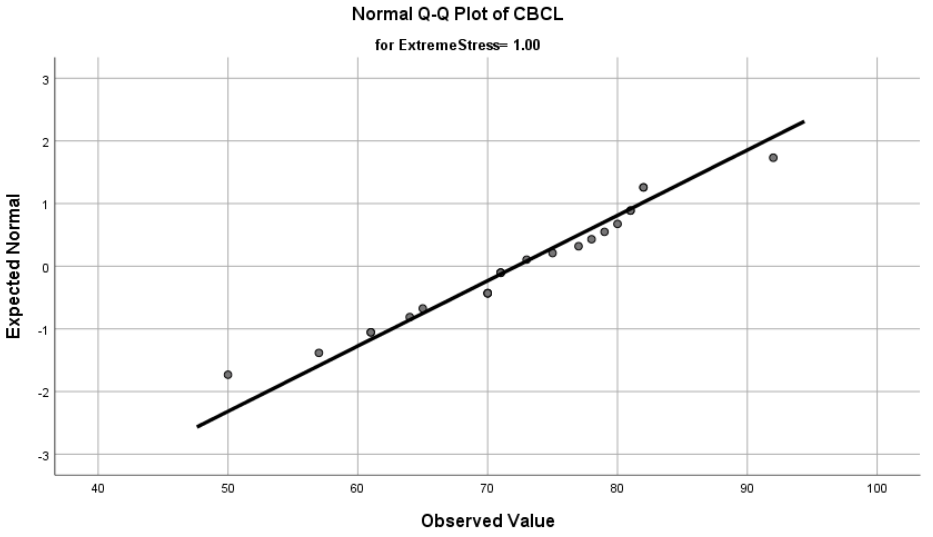


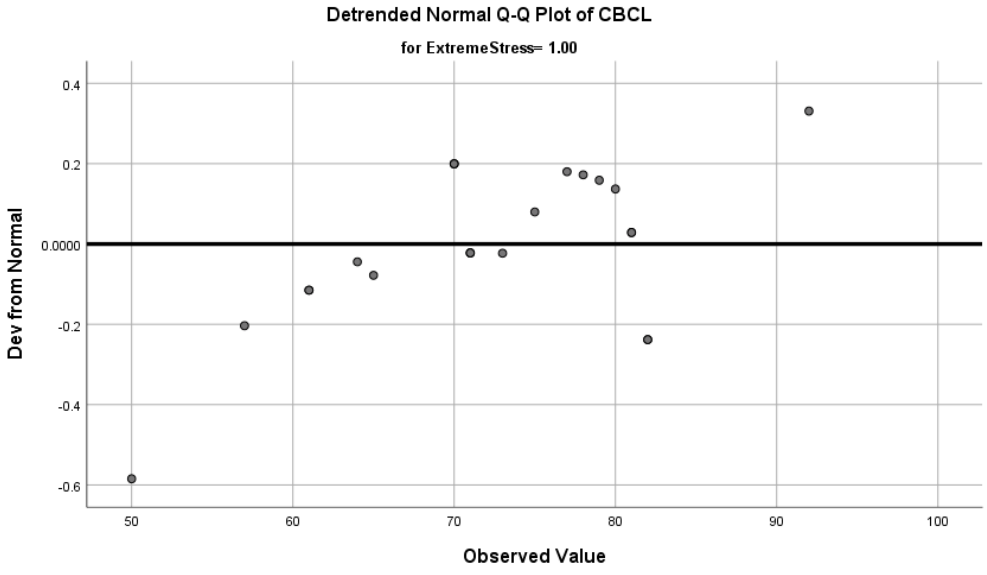


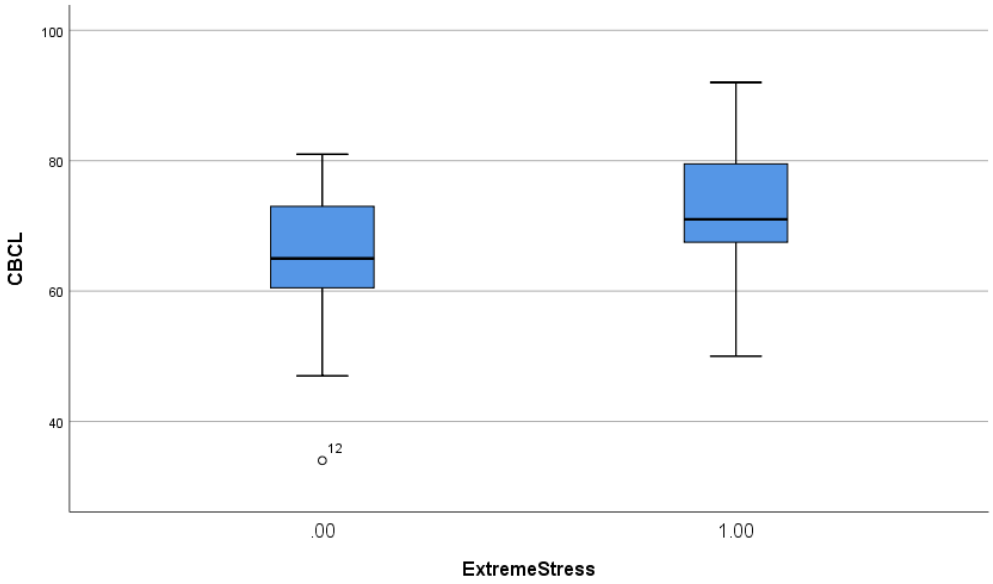


CBCL – High Carer Stress Group

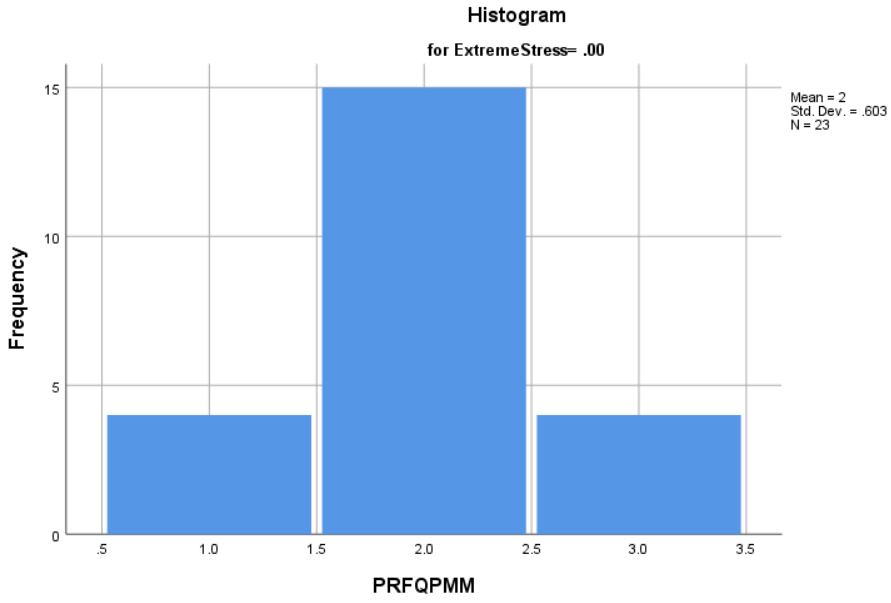


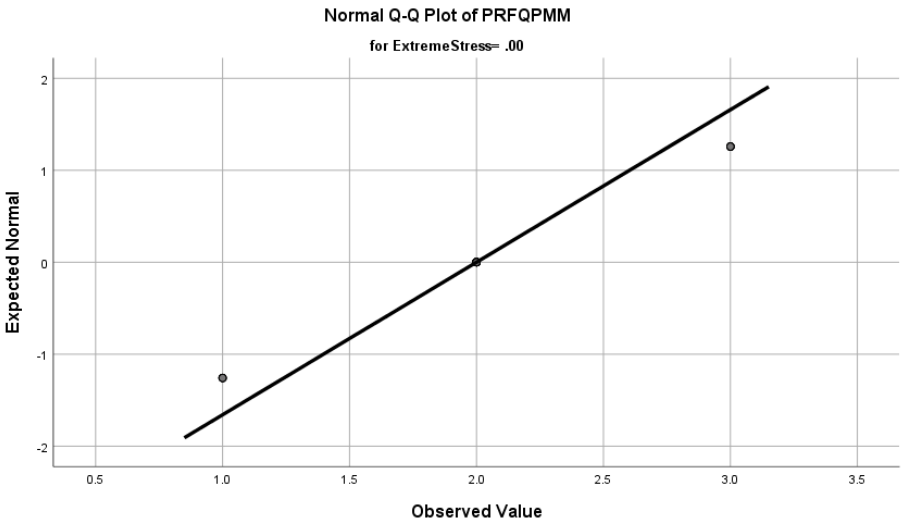


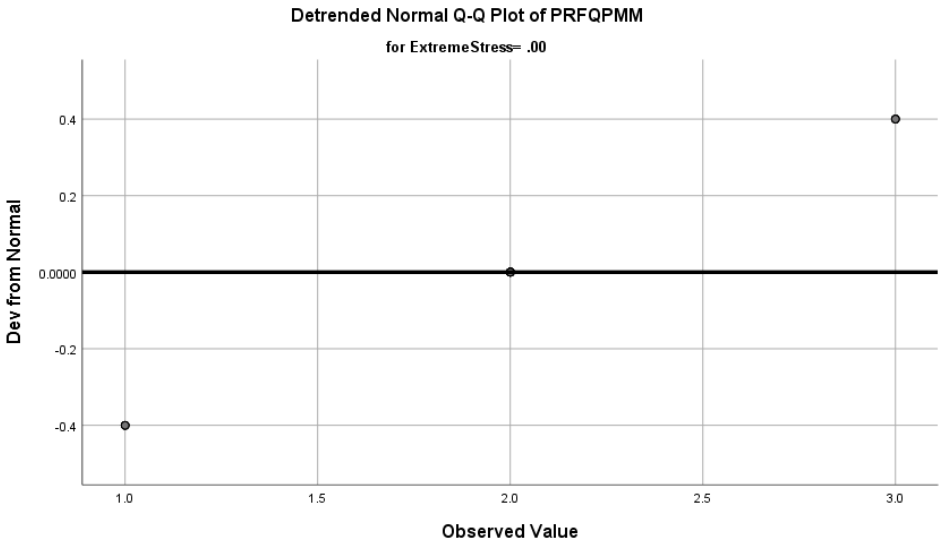




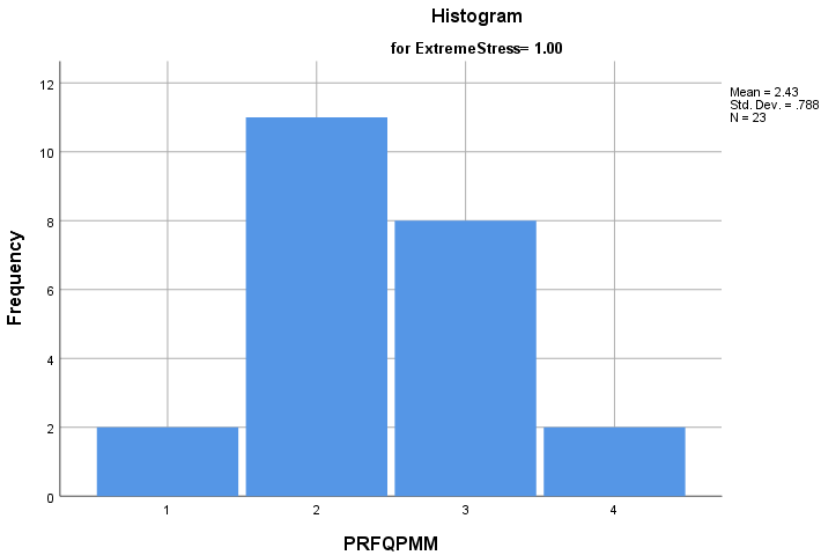
PRFQ-PM – Low Carer Stress Group

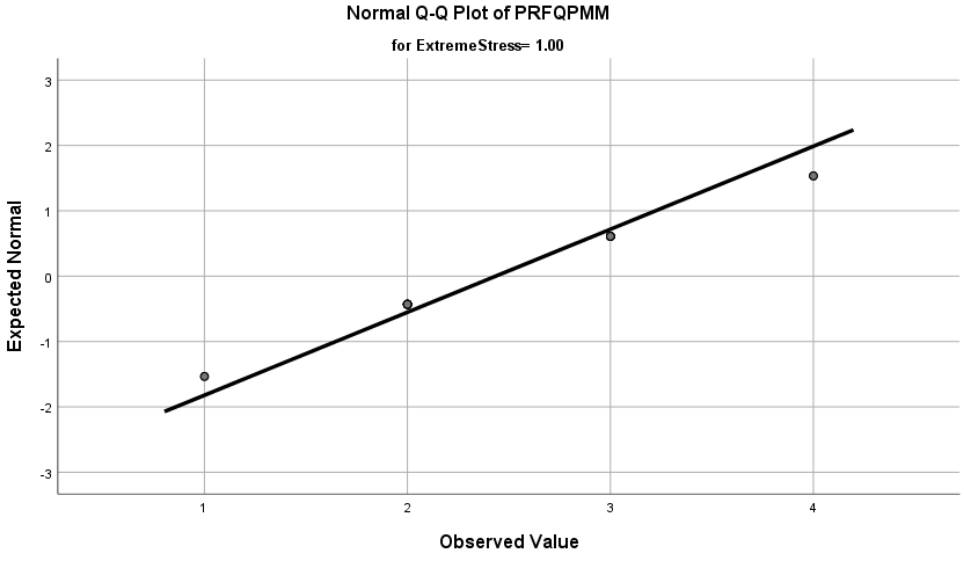


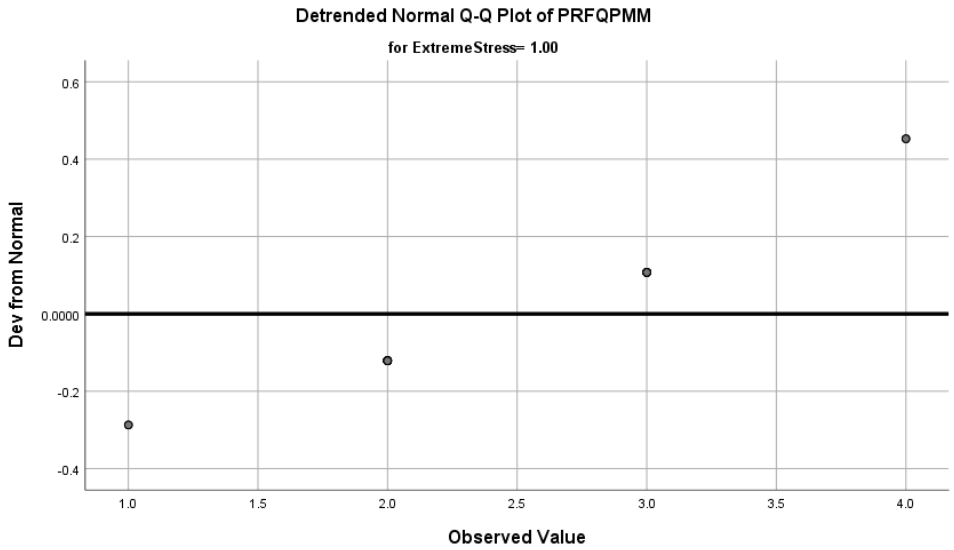


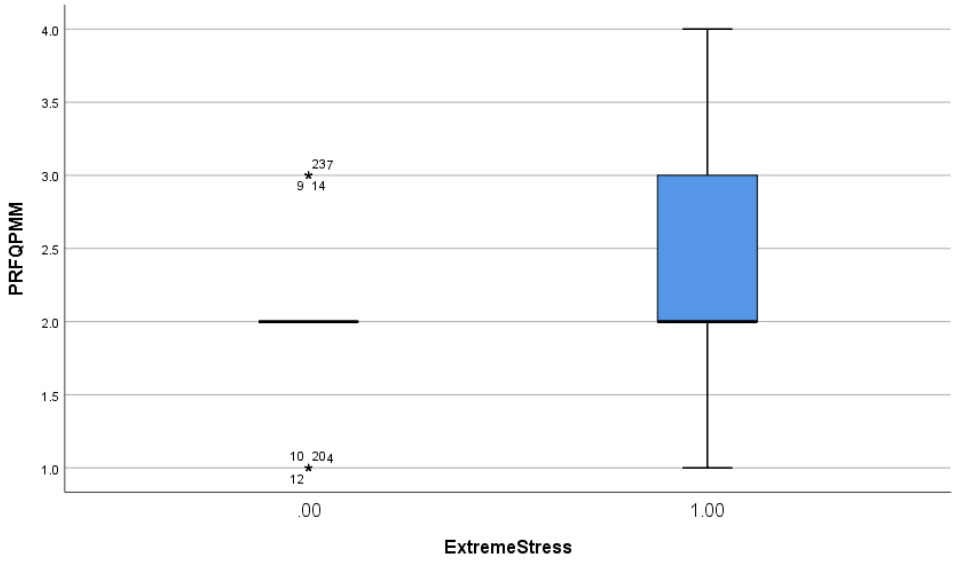


PRFQ-PM – High Carer Stress Group

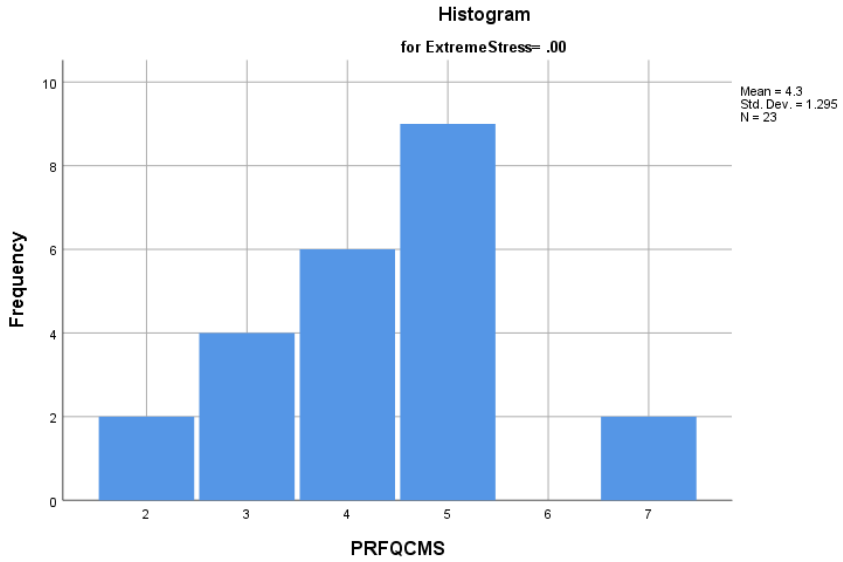


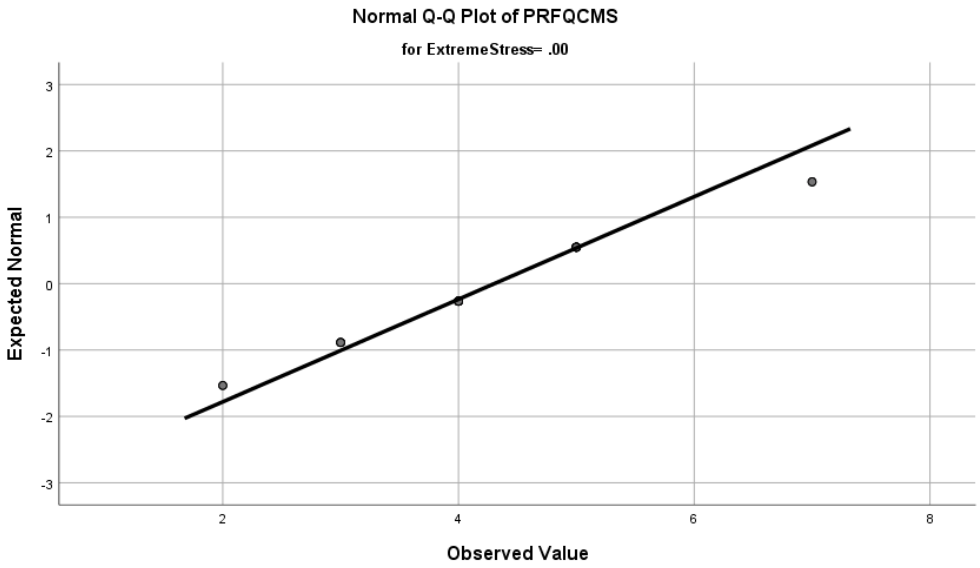


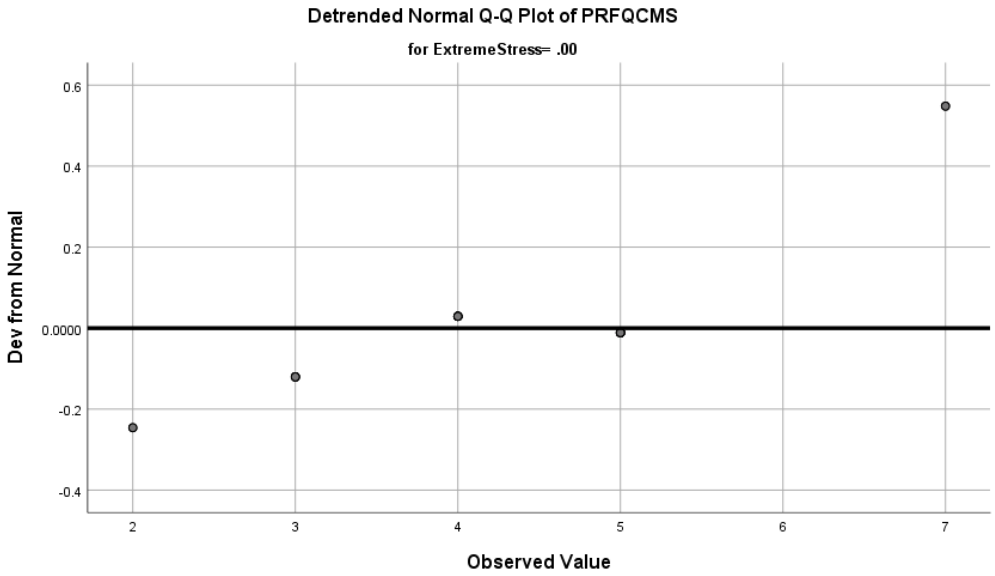




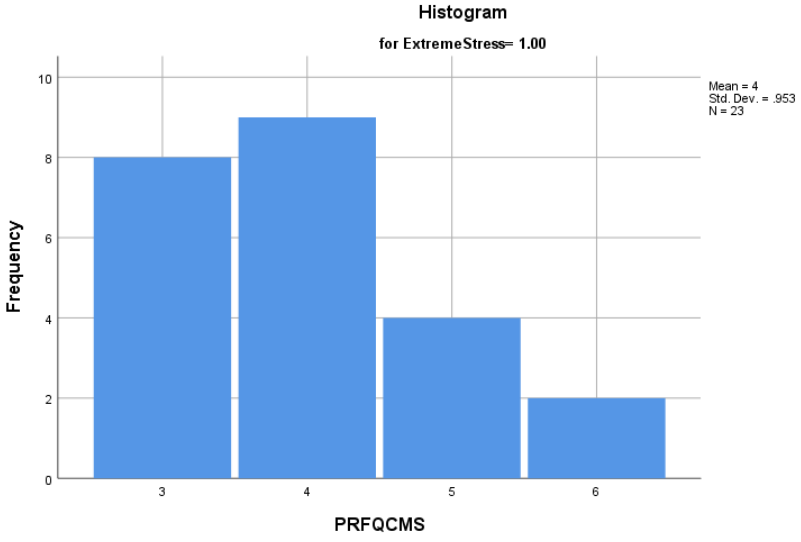
PRFQ-CM – Low Carer Stress Group

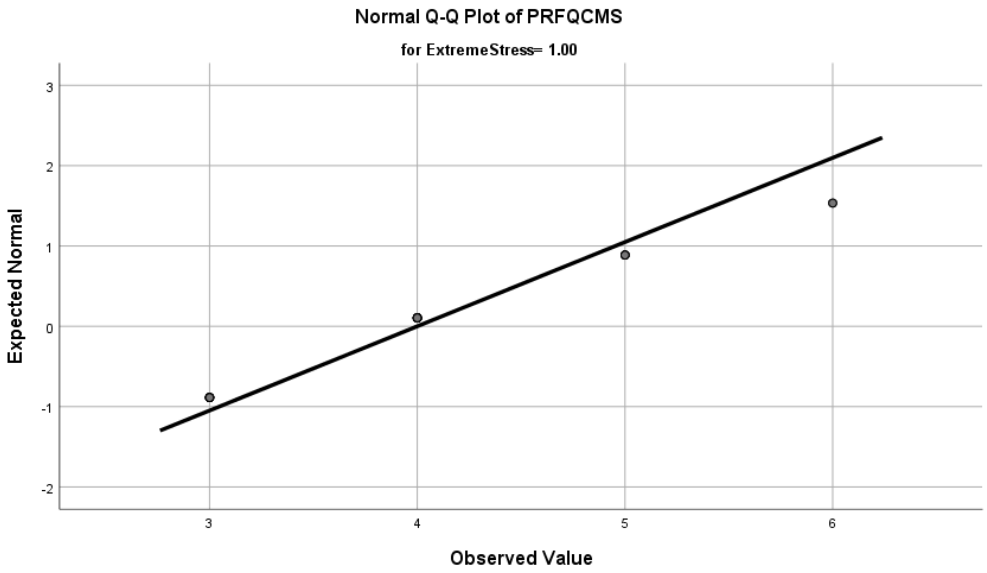


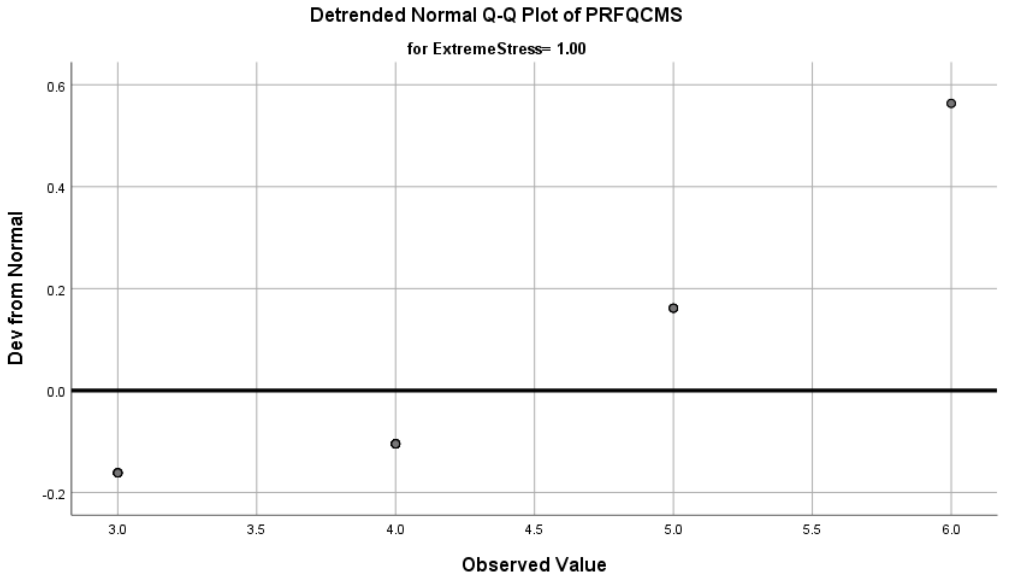


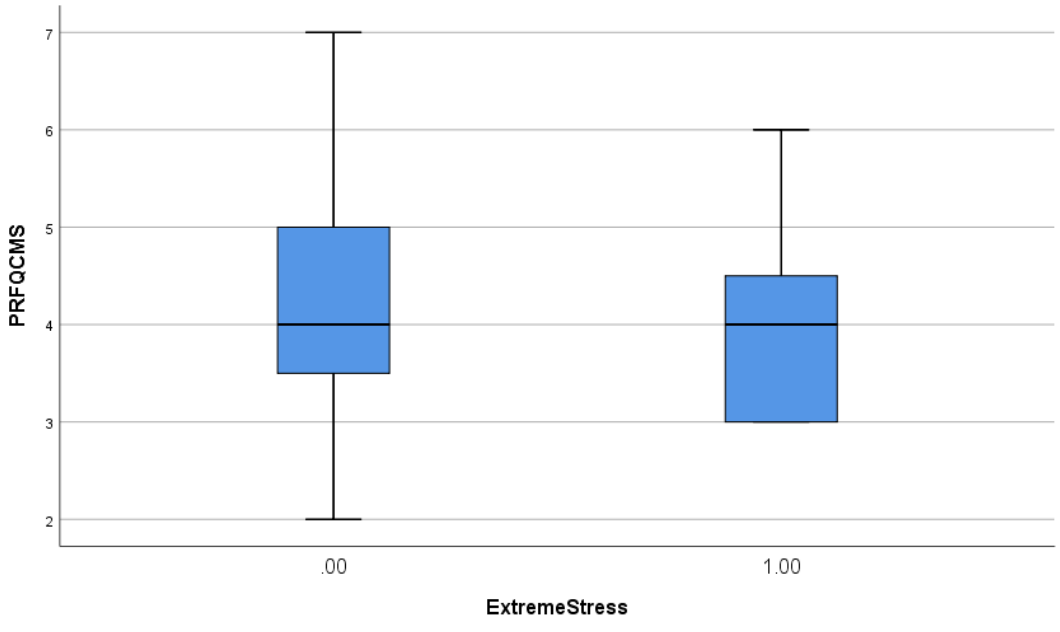


PRFQ-CM – High Carer Stress Group

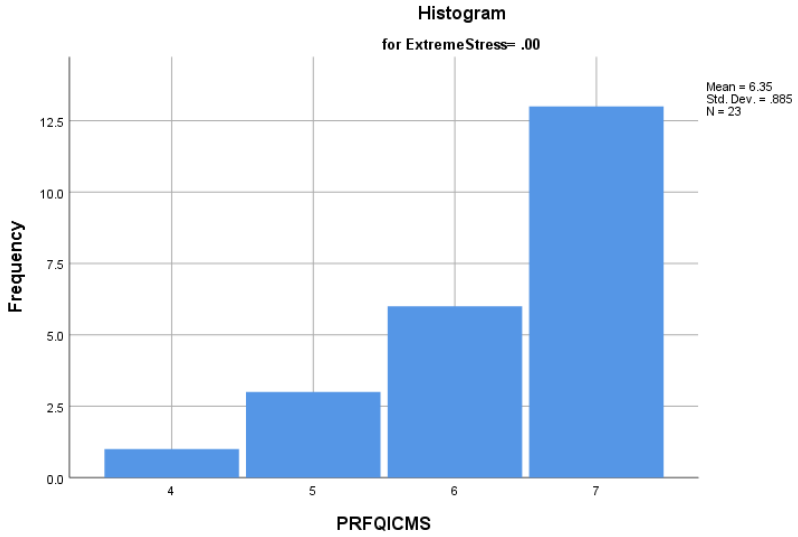


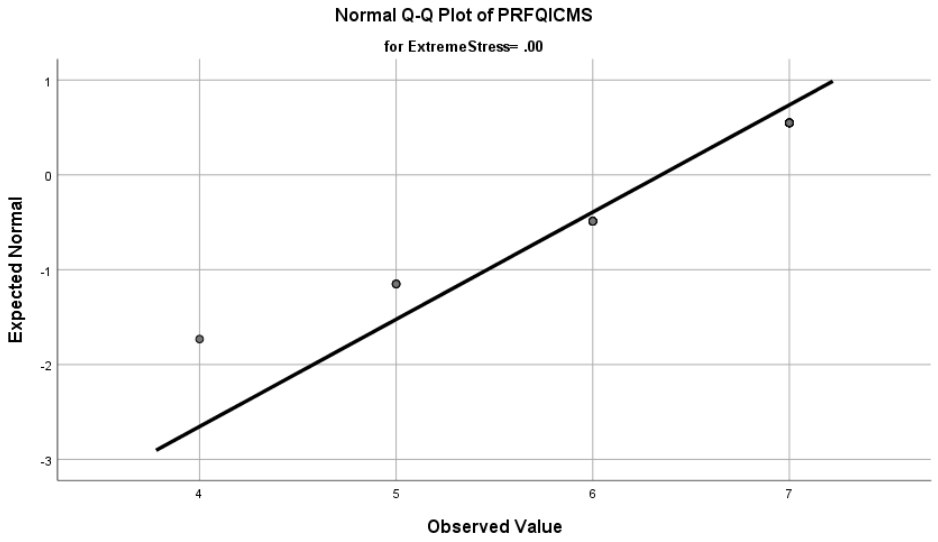

Normal Q-Q Plot of PRFQCMS
for ExtremeStress= 1.00
Expected Normal
Observed Value
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2
1
0
-1
-2
3
4
5
6

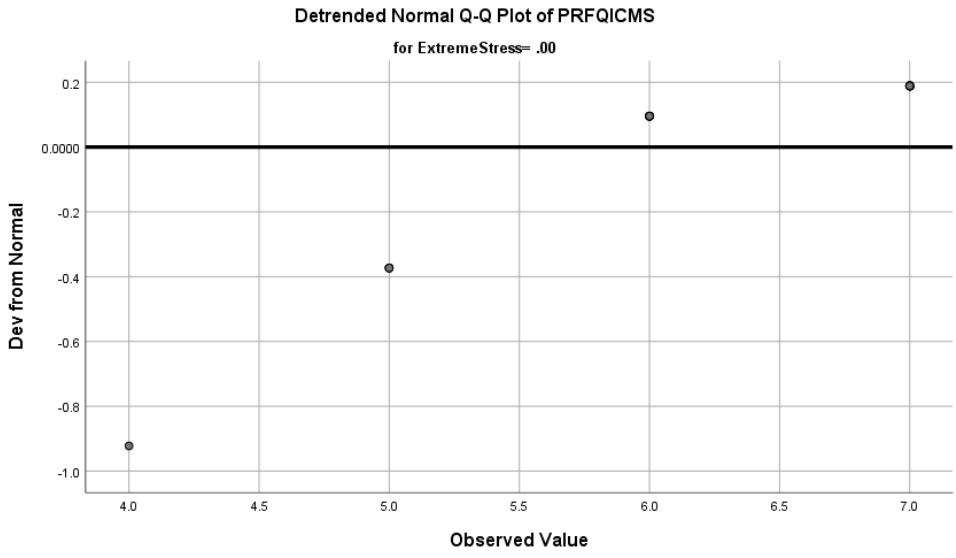

Detrended Normal Q-Q Plot of PRFQCMS
for ExtremeStress= 1.00
Dev from Normal
Observed Value
0.6
0.4
0.2
0.0
-0.2
3.0
3.5
4.0
4.5
5.0
5.5
6.0


PRFQCMS
ExtremeStress
7
6
5
4
3
2
.00
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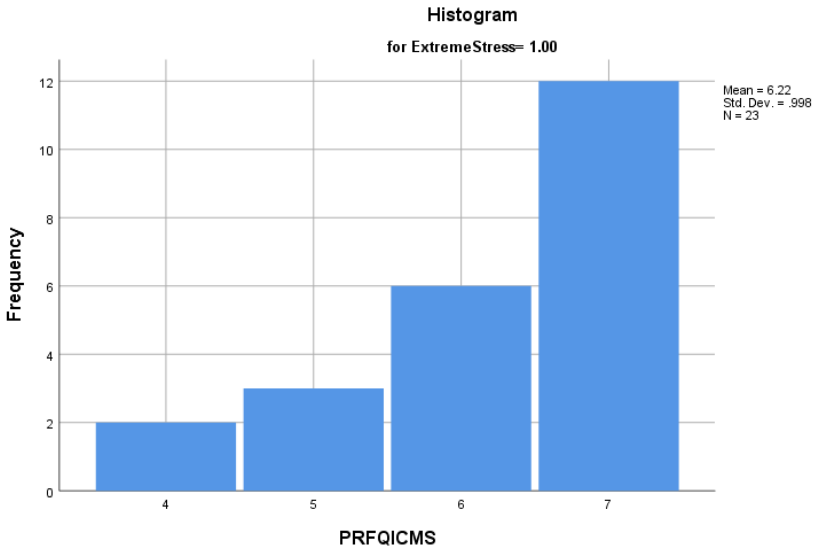
PRFQ-IC – Low Carer Stress Group

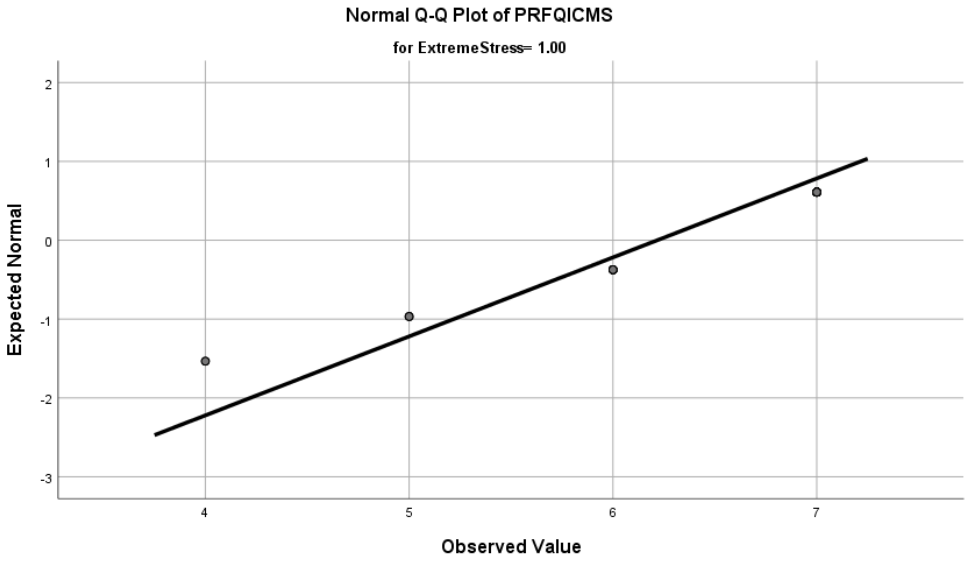


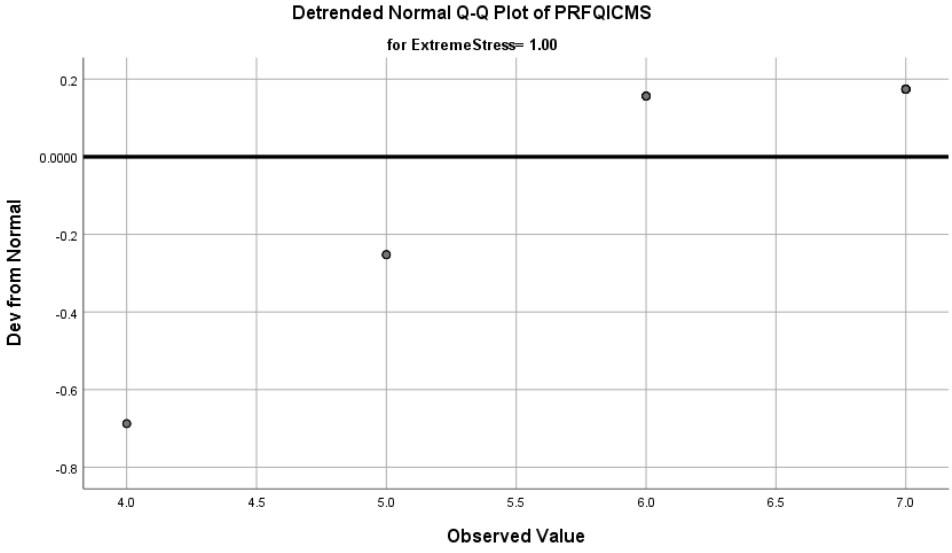


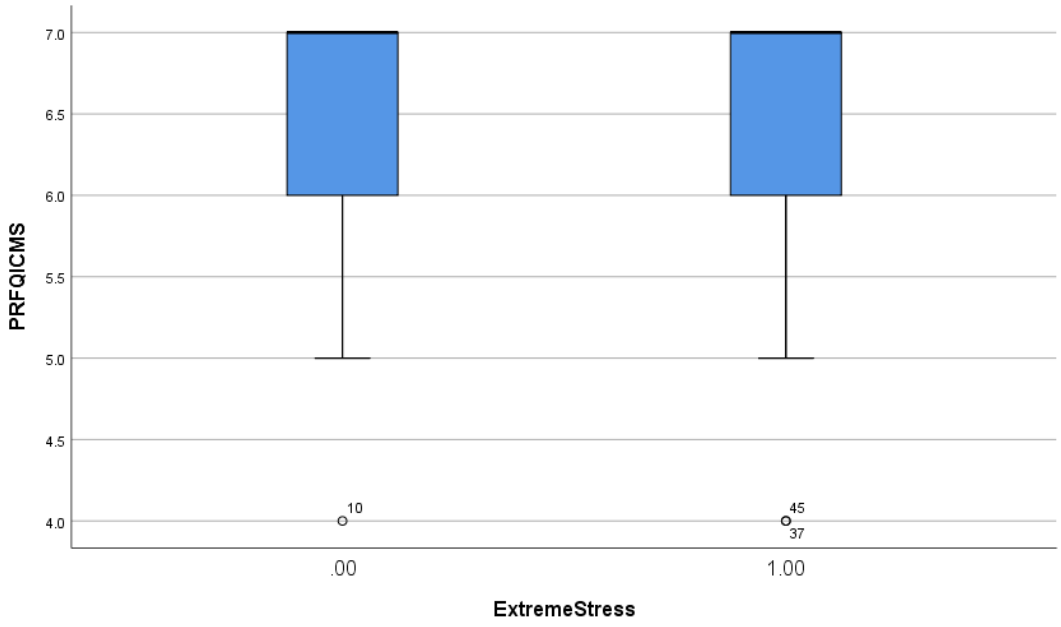


PRFQ-IC – High Carer Stress Group

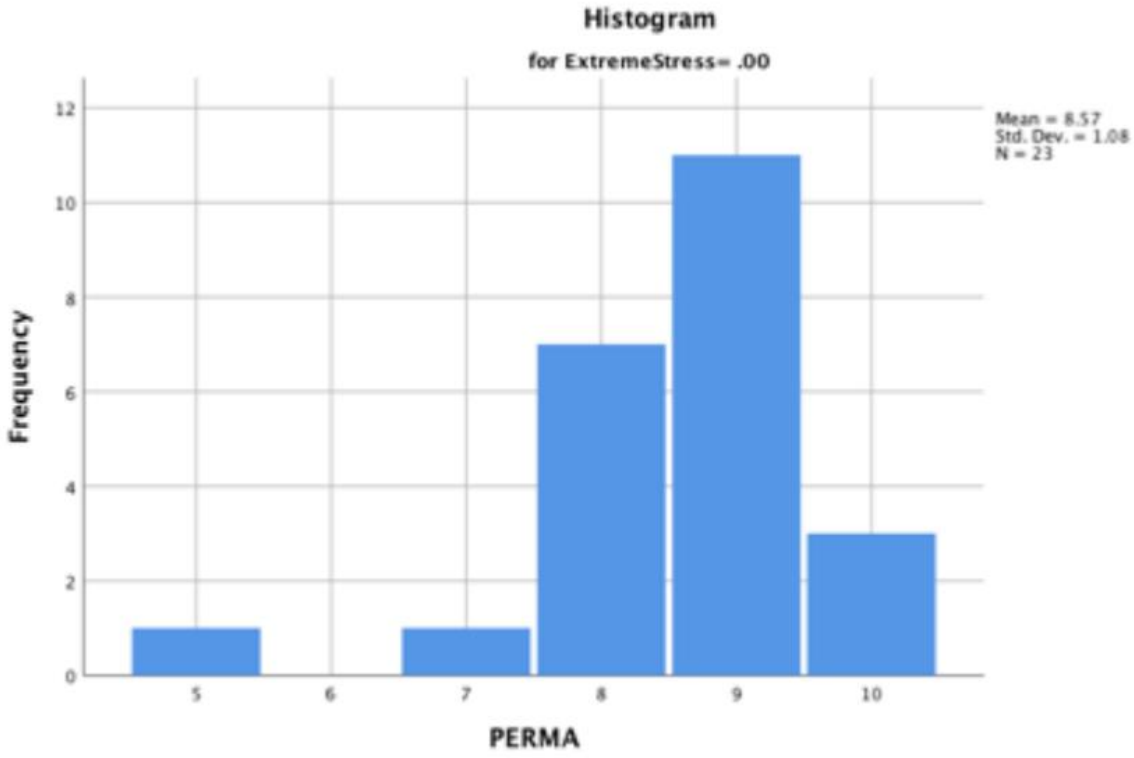


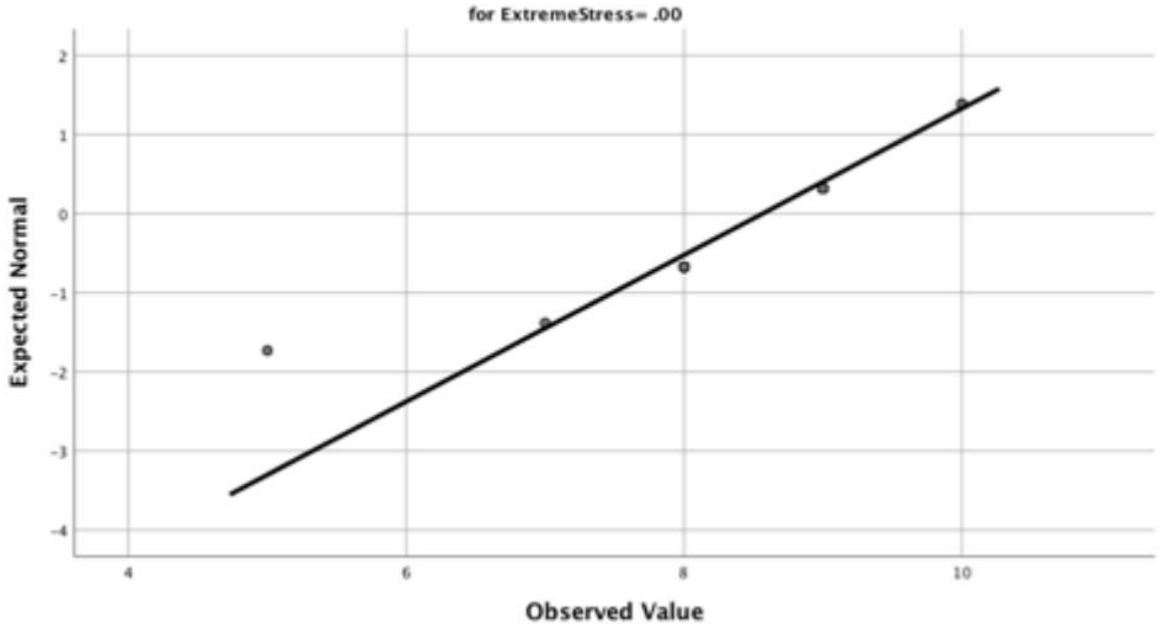


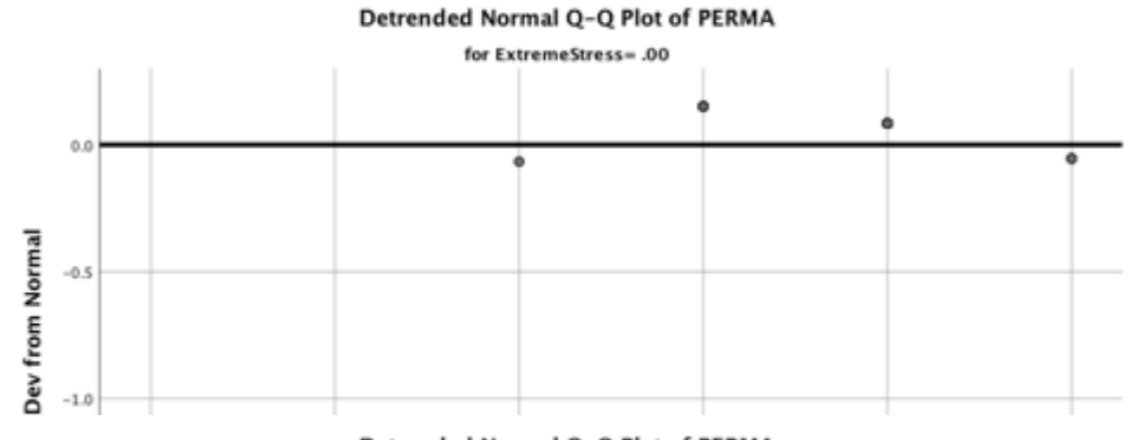




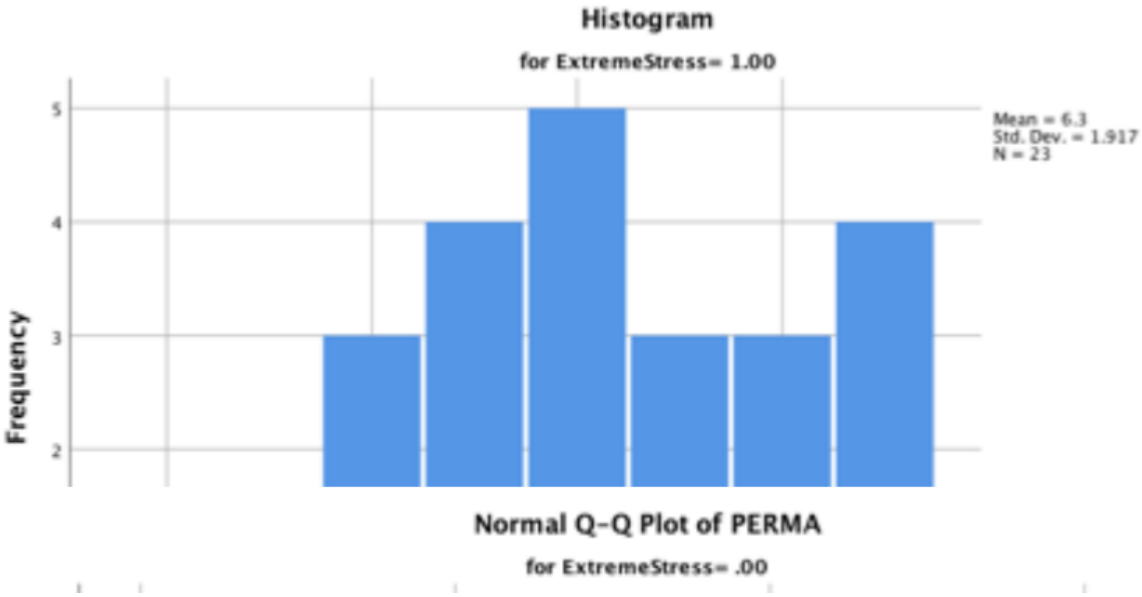
PERMA – Low Carer Stress Group

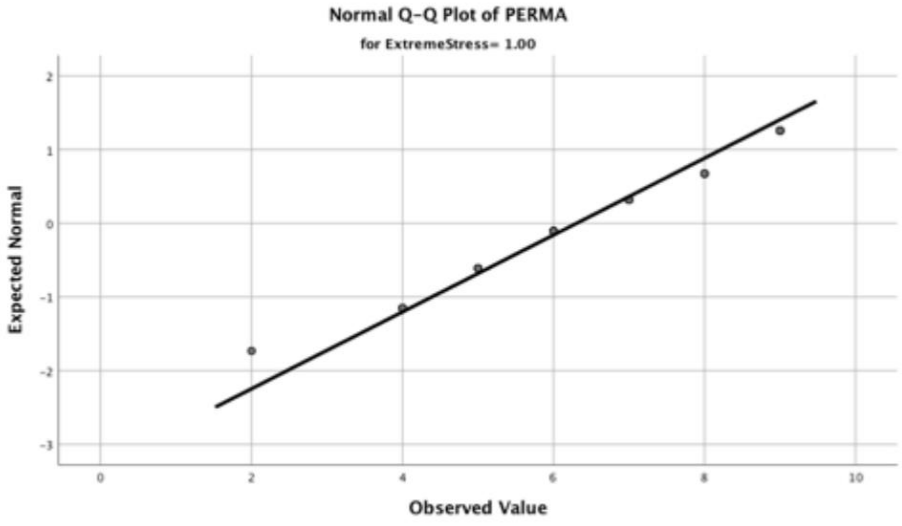


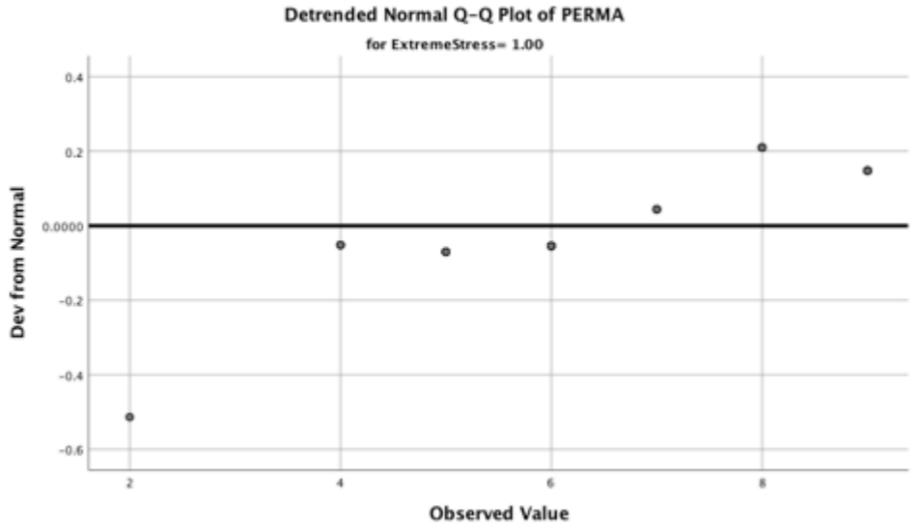


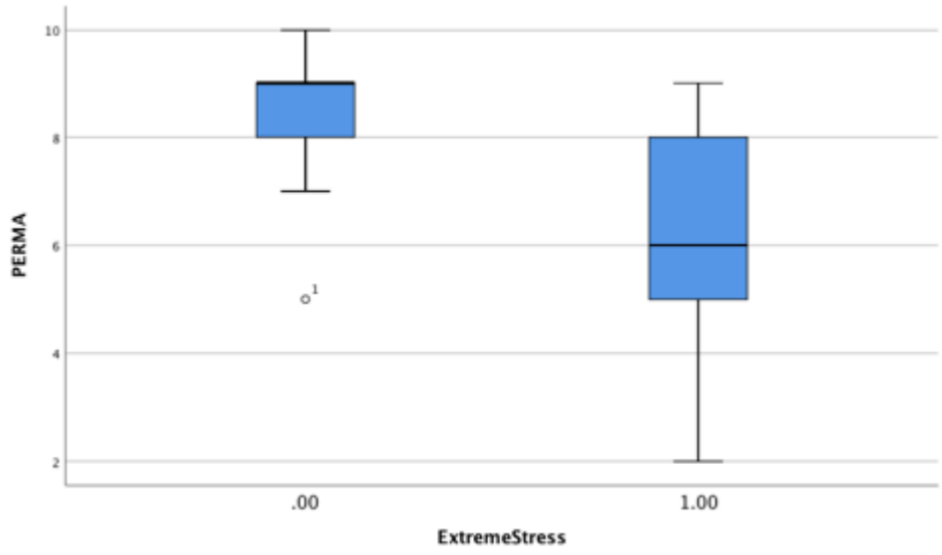


PERMA – High Carer Stress Group




Normal Q-Q Plot of PERMA
for ExtremeStress= 1.00
Expected Normal
Observed Value


Detrended Normal Q-Q Plot of PERMA
for ExtremeStress= 1.00
Dev from Normal
Observed Value


PERMA
.00
1.00
ExtremeStress

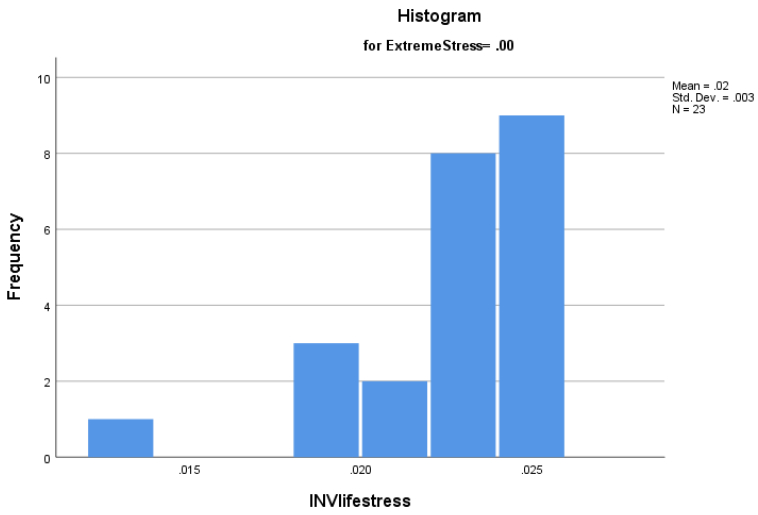
Appendix D.

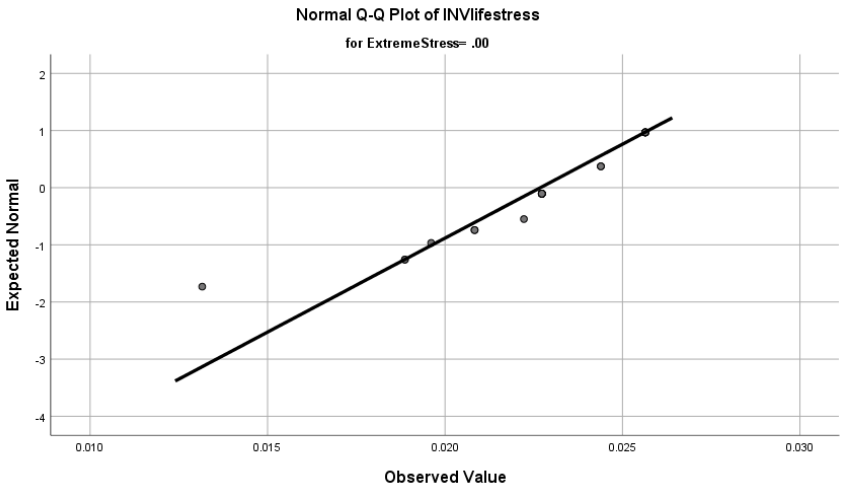
Normality Distributions of Transformed Variables

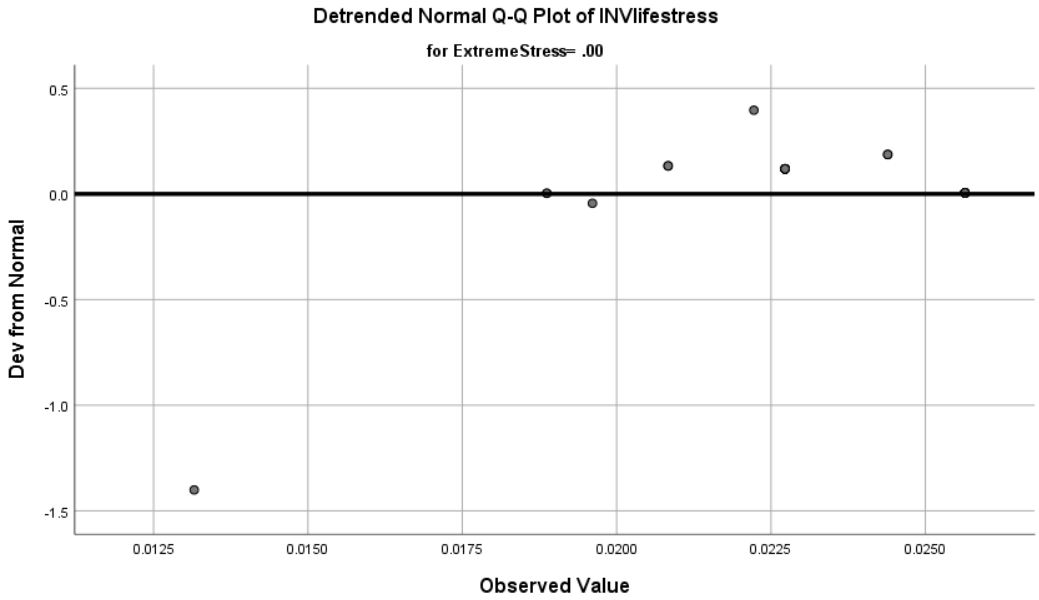
Table showing normal distribution data of all variables by stress group.

Transformed Variable	*M*	*SD*	*Skewness*	*Kurtosis*	*Shapiro-Wilks*
Life Stress(Inverted)					
High carer stress	0.02	0.005	-0.32	-1.2	0.077
Low carer stress	0.022	0.003	-1.5	3.1	0.002
PRFQ-IC(Reflect and Logarithm)					
High carer stress	0.19	0.22	0.57	-1.2	0.000
Low carer stress	0.17	0.21	0.7	-1	0.000

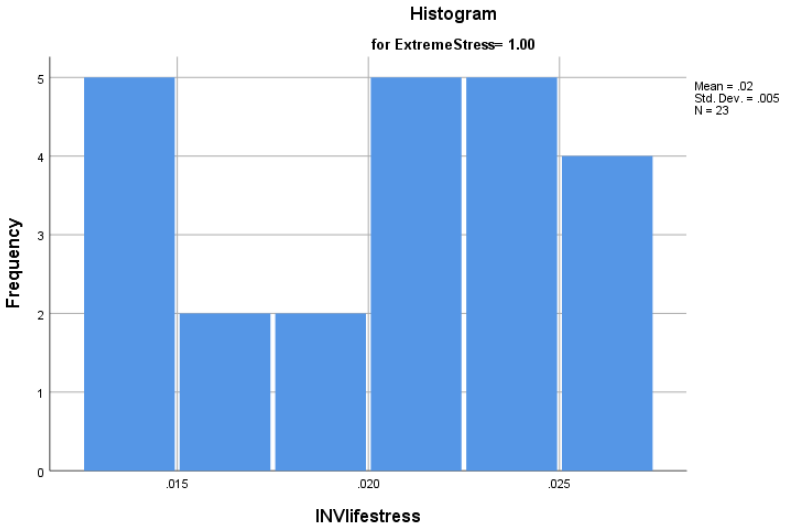
Transformed Life Stress – Low Carer Stress Group

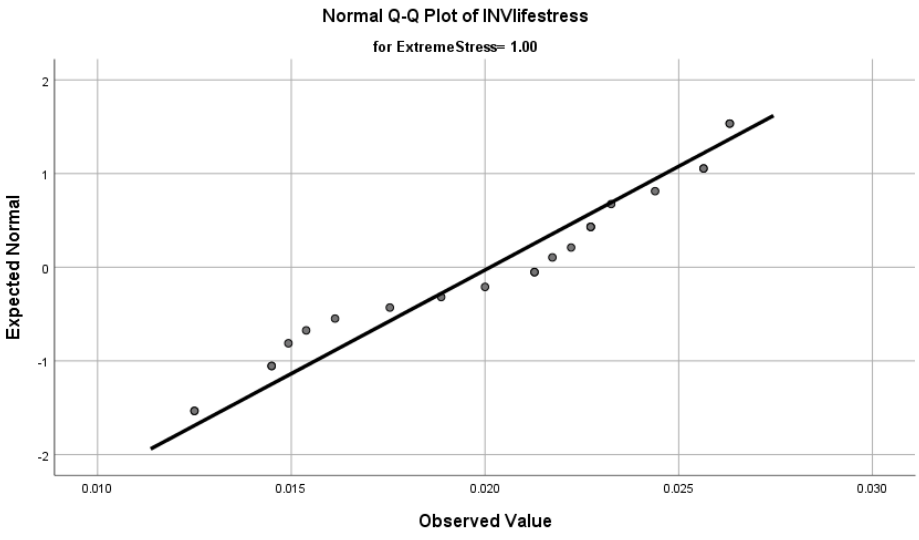


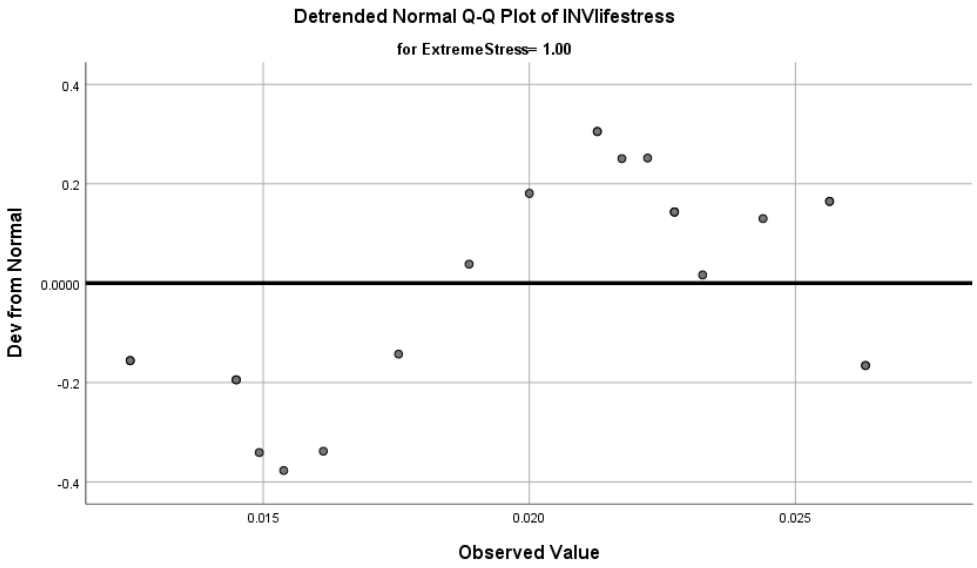


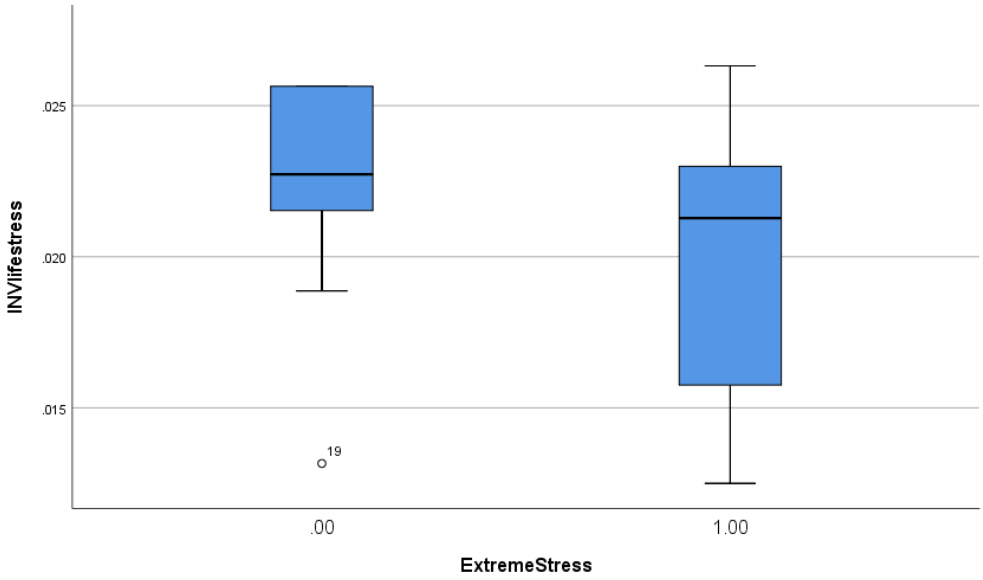


Transformed Life Stress – High Carer Stress Group

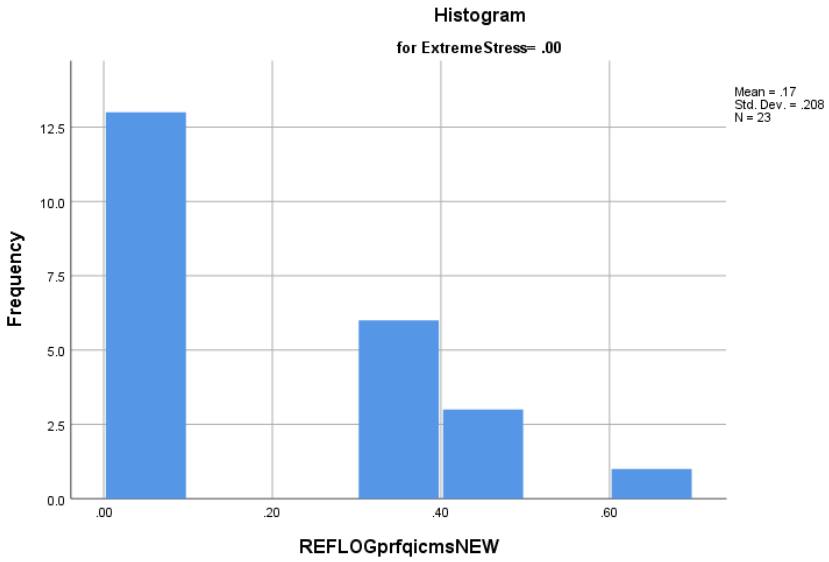


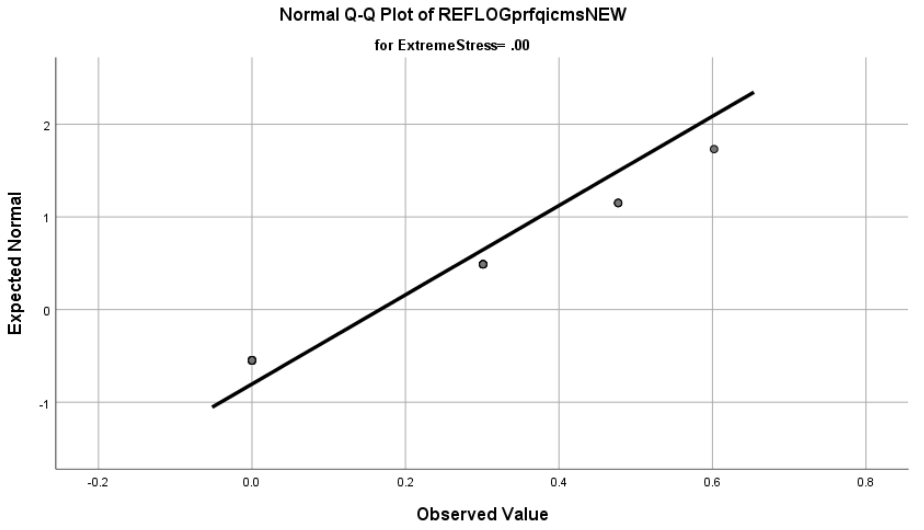


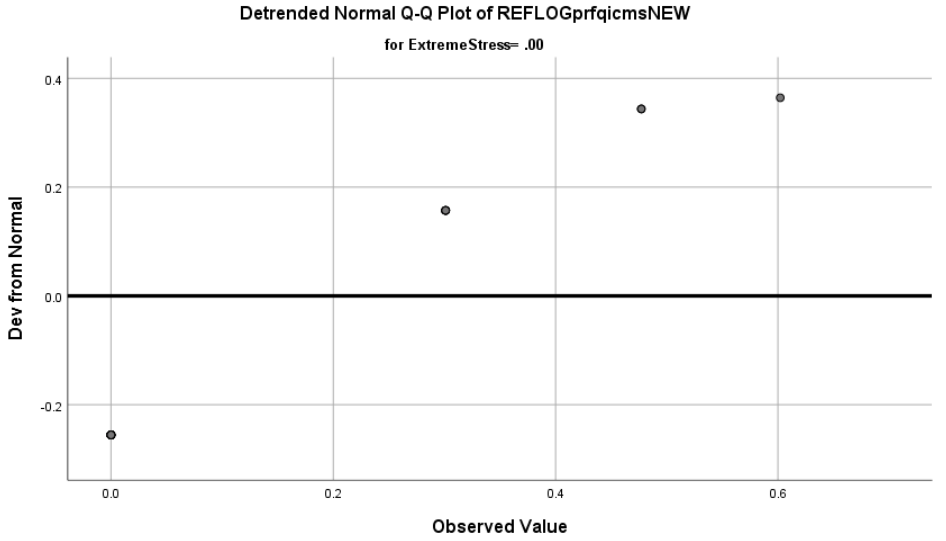




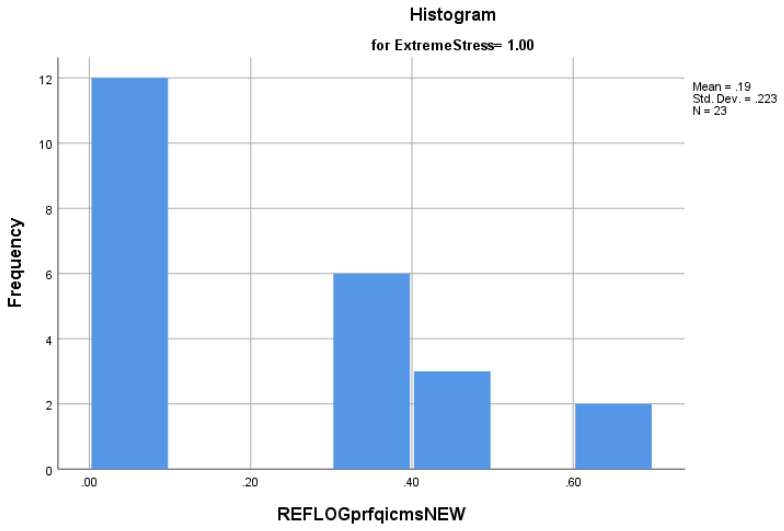
Transformed PRFQ-IC – Low Carer Stress Group

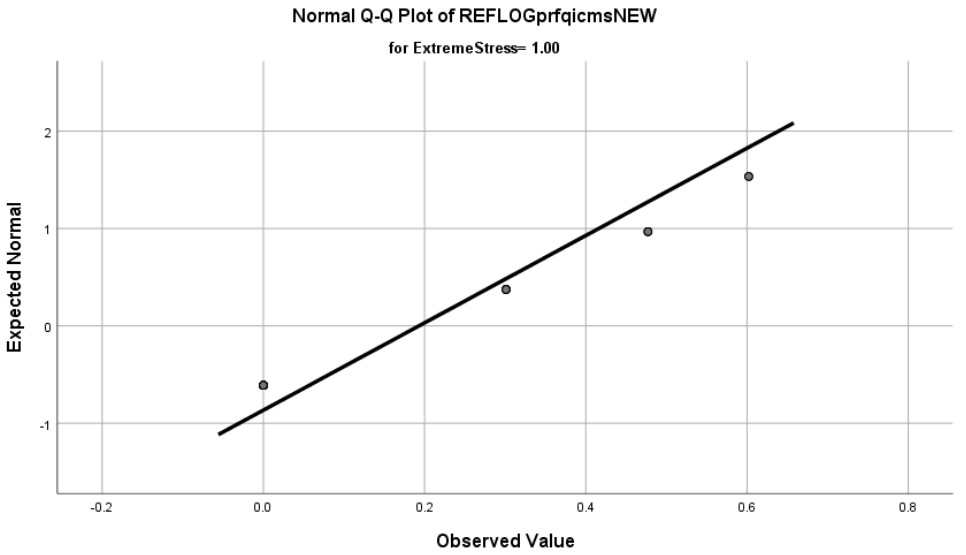


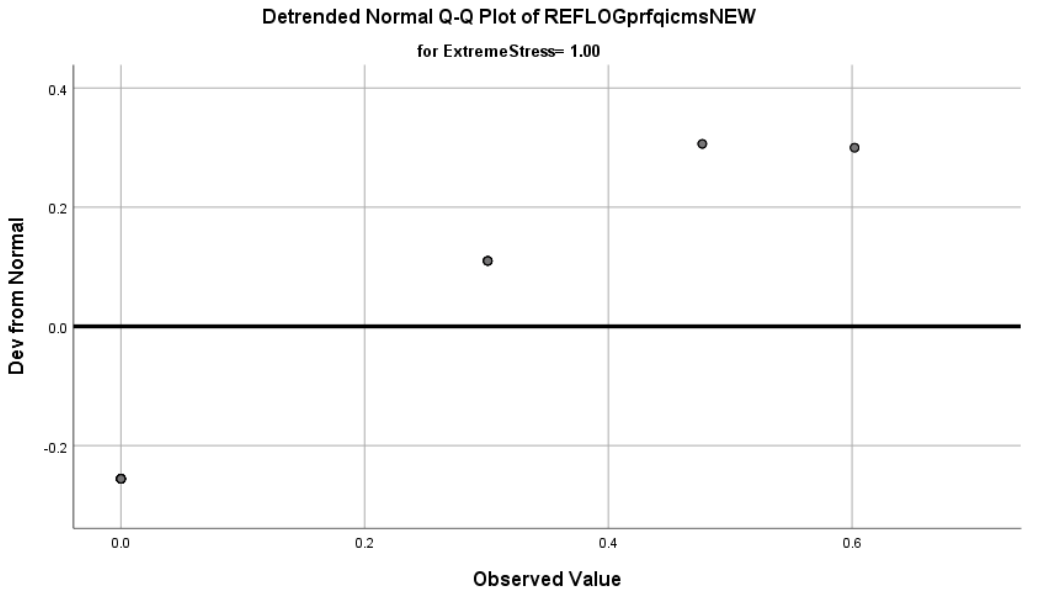


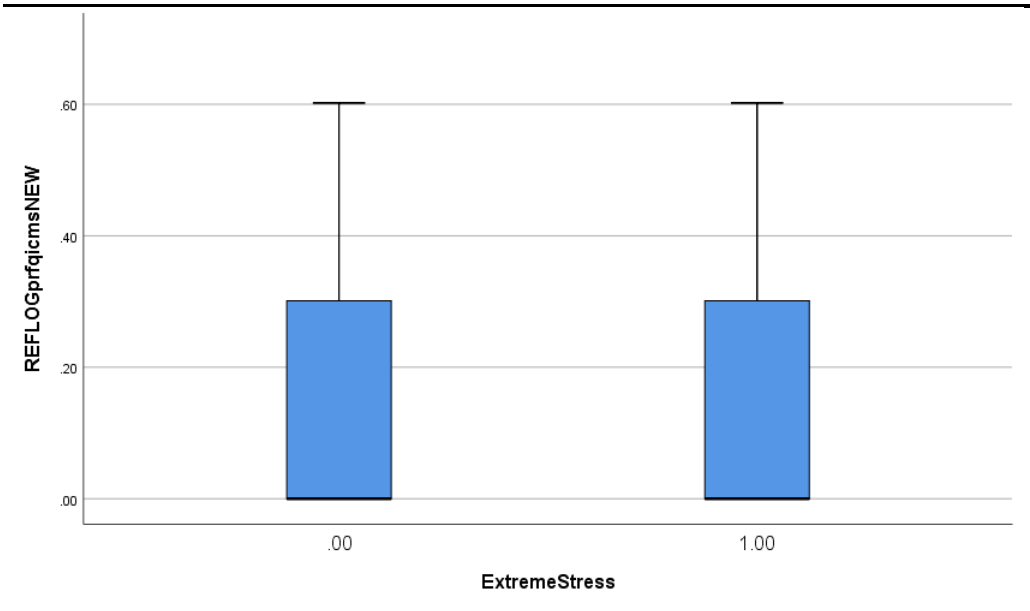


Transformed PRFQ-IC – High Carer Stress Group




Normal Q-Q Plot of REFLOGprfqicmsNEW
for ExtremeStress= 1.00
Expected Normal
2
1
0
-1
-0.2
0.0
0.2
0.4
0.6
0.8
Observed Value


Detrended Normal Q-Q Plot of REFLOGprfqicmsNEW
for ExtremeStress= 1.00
Dev from Normal
0.4
0.2
0.0
-0.2
0.0
0.2
0.4
0.6
Observed Value


REFLOGprfqicmsNEW
.60
.40
.20
.00
.00
1.00
ExtremeStress

Appendix E.

Table showing the analysis of difference between groups based on demographic variables using a chi-squared analysis.

	p	*φ*	*Low Stress* *n, %*	*High Stress* *n, %*
Gender	0.67*	0.19		
Female			19 (47.5%)	21 (52.5%)
Male			4 (66.7%)	2 (33.3%)
Ethnicity	1.0*	0.00		
White British, Irish, or any other white background			22 (51%)	21 (49%)
Any other ethnic group			1 (33%)	2 (67%)
Full Time Carer	0.54	0.37		
Yes			16 (55%)	13 (45%)
No/Work Alongside Fostering			7 (41%)	10 (59%)
Biological Children	0.46*	-0.55		
Yes			20 (54%)	17 (46%)
No			3 (33%)	6 (67%)
Foster Carer Age	0.07	4.6		
25-60			15 (42%)	21 (58%)
60+			8 (80%)	2 (20%)
Length of Time Fostering	0.24	2.2		
1-10 years			10 (40%)	15 (60%)
11 years+			13 (62%)	8 (38%)
Single carer?	1.0*	0.0		
Single Carer			3 (43%)	4 (57%)
Co-habit			20 (51%)	19 (49%)
Total Children Fostered	0.75	0.41		
1-5			6 (43%)	8 (57%)
6+			17 (53%)	15 (47%)
Previous Fostering Experience	0.19*	1.7		
Yes			22 (55%)	18 (45%)
No			1 (17%)	5 (83%)

*Fisher's Exact Probability Test was used due to low participant numbers in a group.

Appendix F

Table showing the frequencies of scores on the PERMA subscales.

	Frequency	*%*	*Cumulative %*
PERMA Overall			
2	1	2.2	2.2
4	3	6.5	8.7
5	5	10.9	19.6
6	5	10.9	30.4
7	4	8.7	39.1
8	10	21.7	60.9
9	15	32.6	93.5
10	3	6.5	100
PERMA Health			
0	1	2.2	2.2
2	2	4.3	6.5
3	3	6.5	13.0
4	2	4.3	17.4
5	3	6.5	23.9
6	2	4.3	28.3
7	3	6.5	34.8
8	10	21.7	56.5
9	10	21.7	78.3
10	10	21.7	100
PERMA Negative Emotion			
1	5	10.9	10.9
2	8	17.4	28.3
3	10	21.7	50
4	5	10.9	60.9
5	9	19.6	80.4
6	5	10.9	91.3
7	3	6.5	97.8
8	1	2.2	100
PERMA Loneliness			
0	15	32.6	32.6
1	4	8.7	41.3
2	4	8.7	50
3	3	6.5	56.5
4	1	2.2	58.7
5	2	4.3	63
6	6	13	76.1

7	5	10.9	87
8	3	6.5	93.5
9	1	2.2	95.7
10	2	4.3	100

Executive Summary

Introduction to the study

Foster carers who look after children in the care system can be faced with multiple challenges. Current research suggests that foster carers experience higher carer stress than biological parents and face more behaviours that challenge from the children they care for. Attachment theory tells us that children with attachment difficulties often experience relationships as threatening. They might use self-preservation strategies, or show behaviours that challenge. Providing sensitive, nurturing care for a child who appears not to accept or want this care is difficult. Research tells us that higher levels of behaviours that challenge are related to foster carers having more carer stress. It is therefore vital to explore the challenges and stresses foster carers face when supporting a child with an insecure attachment style.

Research in this area suggests that one of the factors that may positively impact on the security of an attachment between a foster carer and their child is reflective functioning. This is the ability to be able to see a young person as their own person, understand and empathise with what they are thinking, feeling, and needing. It helps carers see past someone else's obvious behaviours and use their imagination to understand what lies beneath that.

Finally, research shows that when foster carers feel fulfillment in their role, a personal motivation to continue, and socially supported and connected, they are more likely to carry on a placement. We aimed to explore whether wellbeing factors, like positive emotions, having meaning in your life, and having good relationships, mean foster carers feel less carer stress. We want to see if this also helps the foster carer be able to use parental reflective functioning better.

Our research questions were:

1) Do higher levels of behaviours that challenge relate to higher levels of parental stress in foster carers?
2) Do foster carers who experience higher levels of carer stress have lower levels of reflective functioning?
3) Does better wellbeing relate to lower levels of carer stress?
4) Does wellbeing change the impact behaviours that challenge have on foster carer stress?

How the study was carried out

UK foster carers aged 18+ were asked to take part. We recruited using social media and by contacting local authorities across the UK. We asked foster carers some important demographic information to check if there were any differences based on these. These were: whether they were long or short term foster carers, placement length, number of years of fostering experience, number of children fostered, age, gender, ethnicity, occupation, and whether they co-habited or were a single carer. Foster carers completed an online survey which had four questionnaires looking at: parenting stress, behaviours that challenge, reflective functioning, and wellbeing.

What we found

A total of 78 foster carers took part. We compared the 46 foster carers who scored highest and lowest on carer stress. We found that foster carers with higher levels of parental stress rated their child as having more behaviours that challenge. Foster carers who had lower parental stress had better wellbeing, and felt a greater sense of accomplishment, positive emotions, and support in their relationships. If the child is rated as having high behaviours that challenge, a foster carer will still feel more carer stress even if their wellbeing is good. Interestingly, we did not find any difference in reflective functioning abilities between the most and least stressed foster carers.

Limitations and suggestions for future research

The way we asked foster carers to take part may have meant that those who did not have a lot of stress were more willing to take part. They may have also been carers who were really open to reflecting and thinking deeply about their child. Future research is encouraged to compare foster carers who are really stressed and accessing specialist support services to help prevent placement breakdown with foster carers in the general population. The sample was also fairly small, and research needs to carry studies out with larger samples of foster carers on these issues. Finally, foster carers fed back that a key contributor to their stress is the wider social care system, which we did not measure. We also did not measure how many children they currently have at home, and if any of their children have additional needs. Having more caring duties might mean more responsibilities, which might lead to more carer stress. We encourage future studies to look at these factors.

Conclusions

This study highlighted some helpful things. Like other studies, we found that behaviours that challenge do have an impact on how stressed foster carers feel. It also suggests that carers with better wellbeing have lower levels of carer stress. We found that overall, foster carers can continue to use reflective functioning when their stress levels are below the extreme clinical thresholds. It is important to keep adding to the research and evidence base available to find out what helps foster carers carry on providing the valuable role they do in the face of stressful or challenging situations.

Connective/Reflective Narrative

My main passion is child and developmental psychology. I saw having three research projects as an opportunity to explore various interests that stemmed from clinical experience. Having worked in CAMHS, paediatrics, and social care, I wished to contribute to the evidence-base. A theme connecting all three projects was the focus on wider systemic factors - whether that was who cared for the child, or the services they accessed. This matched my professional view that to effectively understand and support children, you must understand and support their system. I aspire to shape services and contribute to the evidence to better support children to thrive.

Theoretically Driven (Main) Research Paper

Through my work as an Assistant Psychologist in a CAMHS Looked After Children's pathway, one of my professional values evolved; the importance of a strengths-focused approach. I initially wanted to explore resilience factors in young people who are cared for by local authority. Often research begins with "blue skies thinking". I recall sitting in meetings passionately pitching my idea. It was through a difficult process that I realised the constraints of conducting novel research with a sparse evidence-base within the scope of clinical training. Finally, I decided to explore factors that add to foster carer's stress, and ways they continue to persevere in the face of challenges. After all, by exploring factors which facilitate foster carers in their roles, the children would be better supported. I was fortunate to have two experienced, knowledgeable supervisors; Dr Ciorsdan Anderson and Dr Claire Holdaway.

However, the pandemic caused delays in obtaining University ethics due to COVID research being prioritised. After many months, I received approval. My elective

placement was in the ATTACH team, which enabled me to work with foster carers. However, local authority wanted the project to undergo their new ethical approval process. I knew that awaiting their decision meant further delays. The course arranged for the local authority board to accept the CUREC approval. I realised that multiple systems inadvertently create barriers by implementing separate ethics procedures. My hope is that ethical approval becomes more streamlined.

Recruitment was enjoyable. I linked in with charities, used Twitter and podcasts, and emailed all the children's services in England. The privilege of hearing stories from foster carers, and their enthusiasm to participate, reignited my interest in the project.

I found data analysis challenging. At undergraduate, I greatly enjoyed statistics. Yet after years out of practice, I needed to relearn basic analyses. Under time pressure, I spent hours running and reading about the analyses. Dr Myra Cooper from the research team was an incredible support. My supervisors shared any expertise they had, but were candid about their limited knowledge. I realised that many clinical psychologists do not feel confident with statistics. This process helped me re-engage with statistics, seeing them as a helpful tool.

Although the findings did not help us understand factors that reduce foster carer stress, I am proud that we contributed to the scarce evidence-based. I am left curios to find out what helps foster carers persevere. The wonderful thing about research is that every answer always sparks more questions.

Service Improvement Project paper

Working as an assistant psychologist with neurodevelopmental conditions, I realised that post-diagnostic support for young people was limited nationwide. Meeting

Dr James Stacey, I zealously pitched how this contradicts our professional values. He was equally as dedicated, and I valued his person-centred approach.

Lockdown made recruitment difficult. Its impact on service provision was evident. I was determined, and made huge efforts to engage young people virtually. The enthusiasm parents and young people had motivated me. It was important to me to keep the voices of young people central to the project. The biggest barrier was engaging large numbers in the project to hear more voices of autistic young people. I would have liked more co-production on this project, yet COVID made that challenging.

I enjoyed the whole project. I value service-improvement, its collaborative approach, and real-world implications. I found having the young people's voices central to how they want support most valuable. I continue to be passionate for improving the support available for autistic young people, and will continue this service improvement work in my qualified post.

Critical Review of the Literature Paper

In our systemic teaching, a lecturer once said: "OCD doesn't live in the person, it lives in the family". I am intrigued by the idea of seeing the problem within the system, beyond the person. From my clinical work, I was interested in OCD, and felt the opportunity to conduct research with Professor Paul Salkovskis was invaluable. His enthusiasm about my proposal was encouraging.

I found the process of conducting a systematic review of the literature time consuming yet valuable. When doing literature reviews for academic work previously, I felt that there may have been key papers I had overlooked, buried in the vast literature base. Although coming up with robust search terms was challenging, this helped me

feel confident in how thorough the review was. Immersing myself deeply into a topic and feeling like I held some level of expertise also satisfied my academic side.

I enjoyed working with a peer reviewer. I sometimes could get easily lost in the dense database, however having another critical set of eyes and someone to discuss the process with was helpful. Having to develop a quality assessment tool due to the lack of available ones for cross-sectional research was also valuable experience. Seeing the themes and synthesis of my narrative coming together was a fulfilling process.

I found the results fascinating, and it has made me keen to work towards developing assessment tools that can capture all types of parental accommodation. I feel the review I conducted showed me the purpose, utility, and essence of a good systematic review. It helped me realise the value of conducting systematic reviews in my work as a clinical psychologist.

Acknowledgments

To all my personal heroes, who have stood by me, supported me, believed in me, and pushed me to higher heights. I am grateful to you always.

To Ms. Lorna Hogg, whose kindness, level headedness, and unwavering values have provided me with a strong platform on which to grow.

To my research supervisors, who believed in my vision and found faith in my projects during those times in which I was doubtful.

And finally, to my darling H, who will always live strong in my heart. You will always be the reason I strive to show other humans that there is another way out. Your legacy continues through the people you've touched. I will forever miss you.

Research Appendices

Appendix A

Ethical Approval for Theory Driven (Main) Research Paper – CUREC 1

MEDICAL SCIENCES INTERDIVISIONAL RESEARCH ETHICS COMMITTEE
Research Services, University of Oxford, Wellington Square, Oxford, OX1 2JD
Tel: +44(0)1865 616577 Fax: +44(0)1865 280467
ethics@medsci.ox.ac.uk

CONFIDENTIAL

Alexandra Harper
Oxford Institute for Clinical Psychology Training (OxICPT)
Isis Education Centre
Warneford Hospital
Oxford

18 December 2020

Dear Alexandra,

Research Ethics Approval - CUREC 1

Ethics Approval Reference: R70354/RE001

Study title: Stay close to me: An exploration of foster carers' abilities to maintain closeness and mentalise when faced with parental stress and challenging child behaviour.

The above application has been considered on behalf of the Medical Sciences Interdivisional Research Ethics Committee (IDREC) in accordance with the procedures laid down by the University for Ethical Approval of all research involving human participants.

I am pleased to inform you that, on the basis of the information provided to the IDREC, the proposed research has been judged as meeting appropriate ethical standards, and approval has been granted for a period of **18 months**, commencing on 05 November 2020.

Approval is **subject to:**

a) **You agreeing to follow Approved Procedure 02**
b) **you following the BPS guidelines for online research**
c) **the PI agreeing to comply with the requirements for administering any tests or questionnaires and, if in doubt, to contact the publisher of those tests or questionnaires**
d) **the PI ensuring that, where new research staff are engaged, they are suitably qualified by training and/or experience.**

I would like to remind you that your study may be selected for review by the MS IDREC for the purposes of monitoring and/or audit.

Amendments

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

Please do not hesitate to contact me if you have any queries.

Yours Sincerely

H. Barnby-Porritt

Dr. Helen Barnby-Porritt
Research Ethics Manager, Medical Sciences

Appendix B

Audit Approval Email for Service Improvement Project

Re: Audit Form Proposal

Bale Rob (RNU) Oxford Health <Rob.Bale@oxfordhealth.nhs.uk>
Tue 15/10/2019 12:47 PM
To:

Cooke Tracey (RNU) Oxford Health <Tracey.Cooke@oxfordhealth.nhs.uk>

Cc:

Ampofo Jelena (RNU) Oxford Health <Jelena.Ampofo@oxfordhealth.nhs.uk>;

Alexandra Harper <alexandra.harper@hmc.ox.ac.uk>

Approved

Regards
Rob
Dr Rob Bale
01865 902759

On 15 Oct 2019, at 12:25, Cooke Tracey (RNU) Oxford Health <Tracey.Cooke@oxfordhealth.nhs.uk> wrote:

Hi Rob,

Please find attached project proposal for your approval.

Many thanks,

Kind Regards,
Tracey

Tracey Cooke
Quality and Clinical Standards Facilitator
Oxford Health NHS Foundation Trust
AG Palmer House, Response Building I Littlemore Mental Health Centre I Littlemore I Oxford I OX4 4SU
Mobile: 07876 038126
Email: tracey.cooke@oxfordhealth.nhs.uk

Appendix C

Instructions for Authors: Critical Review of the Literature Paper: Behavioural and Cognitive Psychotherapy

Preparing Your Manuscript

Articles must be under 5,000 words at the point of submission, excluding references, tables and figures. Manuscripts describing more than one study may exceed no more than 6000 words but please make this clear in your cover letter.

The journal strongly encourages blind review. Authors who want a blind review should indicate this at the point of submission of their article, omitting details of authorship and other identifying information from the main manuscript. Authors who do not omit this information will be assumed as submitting a non-blinded manuscript.

All submissions should be submitted via this portal: http://mc.manuscriptcentral.com/babcp

Main

Reports of original research employing experimental or correlational methods and using within or between subject designs. Review or discussion articles that are based on empirical data and that have important new theoretical, conceptual or applied implications.

Style Guide

The following should be included in all manuscripts:

Title page

This should be a separate file to the main text to ensure blind review.

The title should phrase concisely the major issues. Author(s) to be given with departmental affiliations and addresses, grouped appropriately. A running head of no more than 40 characters should be indicated.

The following statements should be included on the title page:

Acknowledgements

You may acknowledge individuals or organizations that provided advice, support (non-financial).

Conflict of Interest

Authors should include a Conflicts of Interest declaration in their title page. Conflicts of Interest are situations that could be perceived to exert an undue influence on an author's presentation of their work. They may include, but are not limited to, financial, professional, contractual or personal relationships or situations. Conflicts of Interest do not necessarily mean that an author's work has been compromised. Authors should declare any real or perceived Conflicts of Interest in order to be transparent about the context of their work. If the manuscript has multiple authors, the author submitting the title page must include Conflicts of Interest declarations relevant to all contributing authors.

Example wording for your Conflicts of Interest declaration is as follows: "Conflicts of Interest: Author A is employed at company B. Author C owns shares in company D, is on the Board of company E and is a member of organisation F. Author G has received grants from company H." If no Conflicts of Interest exist, your declaration should state "Conflicts of Interest: None".

Data Availability Statement

This is a brief statement about whether the authors of an article have made the evidence supporting their findings available, and if so, where readers may access it. More information on Data Availability Statements and example statements can be found here. Please note that if you are not making your data publicly available, we ask you to state the reason why in your cover letter to the Editor.

Financial support

Please provide details of the sources of financial support for all authors, including grant numbers. For example, "This work was supported by the Medical research Council (grant number XXXXXXX)". Multiple grant numbers should be separated by a comma and space, and where research was funded by more than one agency the different agencies should be separated by a semi-colon, with "and" before the final funder. Grants held by different authors should be identified as belonging to individual authors by the authors' initials. For example, "This work was supported by the Wellcome Trust (A.B., grant numbers XXXX, YYYY), (C.D., grant number ZZZZ); the Natural Environment Research Council (E.F., grant number FFFF); and the National Institutes of Health (A.B., grant number GGGG), (E.F., grant number HHHH)". Where no specific funding has been provided for research, please provide the following statement: "This research received no specific grant from any funding agency, commercial or not-for-profit sectors."

Main Text (anonymised with no author information)

This should be uploaded as a .doc file with the following running order. The following format is based on APA style which should be followed throughout: http://www.apastyle.org/

Abstract

Should consist of no more than 250 words and structured under the following five headings: Background, Aims, Method, Results, and Conclusions. Include up to six key words that describes the article.

Main Text

This should contain the sections Introduction (including overview and theoretical background), Method (participants, design, data analyses and Ethical Statement- see below), Results (described in detail with summary figures and tables), Discussion (including conclusions and limitations).

Ethical statements

All papers should include a statement indicating that authors have abided by the Ethical Principles of Psychologists and Code of Conduct as set out by the BABCP and BPS. Authors should also confirm if ethical approval was needed, by which organisation, and provide the relevant reference number. If no ethical approval was obtained, the authors should state what governance arrangements were in place (e.g. audit committee approval).

References

Please use APA style for the in-text citations and references. In the reference list there is an additional requirement that author names be listed in bold face. For example:

Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. Psychology of Popular Media Culture, 8(3), 207–217. https://doi.org/10.1037/ppm000...

Authors are encouraged to make use of referencing software packages (e.g. Endnote, Mendeley, Reference Manager etc.) to assist with formatting - extensions for APA formatting are easily accessible. Authors are also reminded to use bold face for author names in the reference list.

Tables and Figures

Manuscripts should usually not include more than five tables and/or figures. These should not be included in the body of the manuscript text but uploaded as individual files.

Use text anchors to show their intended position within the paper within the manuscript.

Numbered figure captions should be provided.

Tables should be provided in editable Word format. They should be numbered and given explanatory titles

Figures

Colour figures are free of charge for online published articles but if authors wish figures to be published in colour in the print version the cost is £200.

Numbered figure captions should be provided.

All artwork should be submitted as separate TIFF format files.

Please follow this link for further guidance on artwork.

Supplementary Information – Online only

Where unpublished material e.g. behaviour rating scales or therapy manuals are referred to in an article, copies should be submitted as an additional document (where copyright allows) to facilitate review. Supplementary files can be used to convey supporting or extra information to your study, however, the main manuscript should be able to 'stand-alone'. Supporting documents are reviewed but not copyedited on acceptance of the article. They can therefore be submitted in PDF format, and include figures and tables within the text. There is no word limit for supporting online information.

Appendix D

Instructions for Authors: Brief Report, Research in Autism Spectrum Disorders.

MANUSCRIPT PREPARATION & SUBMISSION

Use of word processing software

Files must be saved in the native format of the word processor and the text should be in 10-point Arial font, single-column format, double spaced, with standard 1 inch page margins (2.54 cm). Please keep the layout of the text as simple as possible, as most formatting codes will be replaced on processing the article. In particular, do not use the options to justify text or hyphenate words. However, do use bold face, italics, subscripts, superscripts etc. Note that source files of figures and text graphics will be required whether or not you embed them in the text. See also the section on Electronic artwork below for details on preparing figures and graphics.

Language (usage and editing services)

Please write your text in good English (American or British usage is accepted, but not a mixture of these). Authors who feel they require support in editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English may wish to use the English Language Editing service available from Elsevier's WebShop (https://webshop.elsevier.com/language-editing-services/language-editing/).

In relation to terminology, we ask that authors carefully consider their choice of wording when describing the patterns of strengths and difficulties that are associated with autism. Specifically, based on a paper by Kenny et al., (2015; http://aut.sagepub.com/content/early/2015/06/10/1362361315588200.abstract) we ask authors not to describe participants as 'low-functioning' or 'high-functioning' but to provide precise information about participants' abilities and areas of difficulty instead, ideally as assessed using relevant standardised tools. Autism should also not be described as a 'disease' or 'illness'. Finally, authors are encouraged to avoid language that inappropriately pathologizes certain characteristics or behaviours of autistic individuals (e.g., 'abnormality', 'impairment', 'deficit' etc) choosing less laden descriptions instead (e.g., 'difference'; 'tendency', 'preference', etc) - we note, however, that there are contexts where it may be appropriate to describe certain characteristics as, for example, an impairment (e.g., language impairment).

Types of Articles

Research in Autism Spectrum Disorders publishes the following types of manuscripts:
Brief reports: Papers of no more than 2,500 words that report an original piece of research of limited scope and/or that serves as proof-of principle for larger-scale studies.

Manuscript Format

All manuscripts must include a Title, Abstract and Highlights on separate pages, followed by the main manuscript text. The main manuscript text of brief reports, regular

articles and quantitative reviews should include subsections carrying the headings Introduction, Methods, Results, Discussion & Implications. Reviews may deviate from this structure but must include a methods section that provides details on how the relevant literature was searched. The structure of commentaries is at the discretion of authors.

Essential Title Page Information

Title:Titles must be concise and informative and should have no more than 20 words. Titles are often used in information–retrieval systems. Avoid abbreviations and formulae where possible.
Author names and affiliations: Please clearly indicate the given name(s) and family name(s) of each author and check that all names are accurately spelled. Present the author's affiliation addresses (where the actual work was done) below the names. Indicate all affiliations with a lowercase superscript letter immediately after the author's name and in front of the appropriate address. Provide the full postal address of each affiliation, including the country name and, if available, the e–mail address of each author.
Corresponding author: Clearly indicate who will handle correspondence at all stages of refereeing and publication, also post-publication. **Ensure that the e–mail address is given and that contact details are kept up to date by the corresponding author**.
Present/permanent address: If an author has moved since the work described in the article was done, or was visiting at the time, a 'Present address' (or 'Permanent address') may be indicated as a footnote to that author's name. The address at which the author actually did the work must be retained as the main affiliation address. Superscript Arabic numerals are used for such footnotes.

Abstract & Keywords

The abstract page must include a structured abstract of no more than 250 words that includes the following subsections:
Background: A brief summary of the research question and rationale for the study.
Method: A concise description of the methods employed to test the stated hypotheses, including details of the participants where relevant.
Results: A brief description of the main findings.
Conclusions: This section must include a clear statement about the implications of the findings for practice.

Immediately after the abstract, a maximum of 6 keywords should be provided, avoiding general and plural terms and multiple concepts (for example, avoid 'and', 'of'). Be sparing with abbreviations: only abbreviations firmly established in the field may be eligible (e.g., ADOS, ASD, etc). These keywords will be used for indexing purposes.

Graphical Abstract

Graphical abstracts are optional but encouraged to draw more attention to the online article. The graphical abstract should summarize the contents of the article in a concise, pictorial form designed to capture the attention of a wide readership. Graphical abstracts should be submitted as a separate file in the online submission system. Please provide an image with a minimum of 531 X 1328 pixels (h X w) or proportionally

more. The image should be readable at a size of 5 X13 cm using a regular screen resolution of 96 dpi. Preferred file types include TIFF, EPS, PDF or MS Office files. See https://www.elsevier.com/graphicalabstracts for examples. Authors can make use of Elsevier's Illustration and Enhancement service to ensure the best presentation of their images.
https://webshop.elsevier.com/illustrationservices/

Introduction

The introduction should develop a clear rationale for the presented work on the basis of a concise overview of the relevant literature. Detailed literature reviews should be avoided.

Methods

This section will typically include sub–headings for a description of the Participants, Materials & Design, Procedures and Analysis. However, alternative sub–headings may be used to suit particular research approaches (e.g., case–studies, meta–analyses, imaging studies etc.)

The participants section should provide demographic information (age, sex, ethnicity, socio–economic status, etc.), and include details on where and how participants were recruited and how relevant clinical diagnoses were verified. Additional clinical information (e.g., intellectual functioning, co–morbidities, use of medication etc.) is desired and may be necessary for some research designs. Sample sizes should be justified by suitable power calculations although it is appreciated that it is not always feasible to obtain desired numbers of participants.

The materials, design and procedures must be described in sufficient detail for the work to be replicable. Authors must also include a statement confirming that the work was carried out in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Declaration of Helsinki as revised in 2000. In this context confirmation should also be given that participant or guardian informed consent was obtained where appropriate.

The analysis section should provide details of the statistical methods used including information on the significance thresholds and the methods used to correct for multiple comparisons where necessary. Information on inter–rater reliability and any data filtering / transformation that was applied should also be included here.

Results

The results should be set out transparently and in full and should conform to the formatting style of the American Psychological Association (http://www.apastyle.org/). Effect sizes must be reported for all significant and non–significant effects, and sufficient descriptive statistics must be provided for the effect size calculations to be replicated.

Tables

Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. The formatting of tables should conform to APA guidelines (http://www.apastyle.org/).

Figures & Artwork
General points

• Make sure you use uniform lettering and sizing of your original artwork.
• Embed the used fonts if the application provides that option.
• Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use similar fonts.
• Number the illustrations according to their sequence in the text.
• Use a logical naming convention for your artwork files.
• Provide captions to illustrations separately.
• Size the illustrations close to the desired dimensions of the published version.
• Submit each illustration as a separate file.

For Vector drawings, the recommended file format is EPS or PDF (embed all used fonts).
For all other artwork, please use TIFF or JPEG file formats with the following resolutions:
• Colour or grayscale photographs (halftones): 300 dpi
• Pure black & white line drawings: 1000 dpi
• Combination halftone and black & white: 500dpi

Please do not:
• Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG)
• Supply files that are too low in resolution;
• Submit graphics that are disproportionately large for the content.

If, together with your accepted article, you submit usable colour figures, Elsevier will ensure, at no additional charge, that these figures will appear in colour online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in colour in the printed version. **For colour reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article**. Please indicate your preference for colour: in print or online only. For further information please see https://www.elsevier.com/artworkinstructions.

Video Data
Elsevier accepts video material and animation sequences to support and enhance presentation of your scientific research. Authors who have video or animation files that they wish to submit with their article are strongly encouraged to include links to these within the body of the article. This can be done in the same way as a figure or table by referring to the video or animation content and noting in the body text where it should be placed. All submitted files should be properly labeled so that they directly relate to the video file's content. In order to ensure that your video or animation material is directly usable, please provide the files in one of our recommended file formats with a preferred maximum size of 150 MB. Video and animation files will be published online in the electronic version of your article in Elsevier Web products, including ScienceDirect: http://www.sciencedirect.com.

Please supply 'stills' with your files; you can choose any frame from the video or animation or make a separate image. These will be used instead of standard icons and will personalize the link to your video data. For more detailed instructions, please visit our video instruction pages at https://www.elsevier.com/artworkinstructions. Note: since video and animation cannot be embedded in the print version of the journal, please provide text for both the electronic and the print version for the portions of the article that refer to this content.

3D neuroimaging

You can enrich your online articles by providing 3D neuroimaging data in NIfTI format. This will be visualized for readers using the interactive viewer embedded within your article, and will enable them to: browse through available neuroimaging datasets; zoom, rotate and pan the 3D brain reconstruction; cut through the volume; change opacity and colour mapping; switch between 3D and 2D projected views; and download the data. The viewer supports both single (.nii) and dual (.hdr and .img) NIfTI file formats. Recommended size of a single uncompressed dataset is maximum 150 MB. Multiple datasets can be submitted. Each dataset will have to be zipped and uploaded to the online submission system via the '3D neuroimaging data' submission category. Please provide a short informative description for each dataset by filling in the 'Description' field when uploading a dataset. Note: all datasets will be available for downloading from the online article on ScienceDirect. If you have concerns about your data being downloadable, please provide a video instead. For more information see: https://www.elsevier.com/3DNeuroimaging.

Discussion and Implications

The discussion section should draw together the findings and must end with a clear indication of the implications of the findings for practice under a separate subheading (Implications).

Acknowledgements

Collate acknowledgements in a separate section at the end of the main manuscript text and before the references. List here any sources of funding (including grant numbers where relevant) and briefly describe the role of the sponsor(s), if any, in study design; the collection, analysis or interpretation of data; the writing of the report; and the decision to submit the article for publication. If the funding source(s) had no such involvement then this should be stated.

Conflict of interest

At the end of the main manuscript text and before the references, authors must disclose any actual or potential conflict of interest including any financial, personal or other relationships with other people or organizations within three years of beginning the submitted work that could inappropriately influence, or be perceived to influence, their work. If no such conflict of interest exists, this must be clearly stated. For further information and examples of conflict of interest statements please visit the following: https://www.elsevier.com/conflictsofinterest https://service.elsevier.com/app

/answers/detail/a_id/286/supporthub/publishing A decision may be made by the Journal not to publish on the basis of the declared conflict.

References

In–text citations should conform to the formatting style of the American Psychological Association (http://www.apastyle.org/). Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full.

Appendix E

Journal Submission Guidance: Adoption & Fostering

2. Editorial policies

2.1 Peer review policy

Adoption & Fostering operates a strictly anonymous peer review process in which the reviewer's name is withheld from the author and the author's name from the reviewer. The reviewer may at their own discretion opt to reveal their name to the author in their review but our standard policy practice is for both identities to remain concealed. Each manuscript is reviewed by at least two referees. All manuscripts are reviewed as rapidly as possible, and an editorial decision is generally reached within 6-8 weeks of submission.

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.

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.

4.2 Artwork, figures and other graphics

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

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our guidelines on submitting supplementary files.

4.4 Reference style

Adoption & Fostering adheres to the SAGE Harvard reference style. View the SAGE Harvard guidelines to ensure your manuscript conforms to this reference style.

If you use EndNote to manage references, you can download the the SAGE Harvard EndNote output file.

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.