The University Of Sheffield.

Parental Wellbeing in Paediatric Inflammatory Bowel Disease (IBD)

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Declaration

I declare that this work has not been submitted for any other degree or to any other institution.

Word Counts

Literature Review

Excluding references and tables: 7,999

Including references and tables: 13,448

Empirical Study

Excluding references and tables: 8,000

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Total

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Lay Summary

Parenting a child with a chronic health condition (CHC) can be stressful and emotionally challenging. Inflammatory bowel disease (IBD) is a CHC that may come with particular practical and emotional challenges for both the children living with the condition and the parents or carers supporting them. Moreover, it is likely that the experiences of parents and children interact and subsequently influence one another. Despite this, there is limited research into the experiences of parents of children with IBD. Child healthcare has also been criticised more broadly for not paying enough attention to those in the child's support system.

Seeking to address these gaps, section one of this report presents a review of the existing literature regarding psychological distress in parents of children with IBD. Psychological distress in this review encompasses any signs, experiences, or symptoms of a discomforting psychological state, such as depression, anxiety, or stress for example. The findings of the 23 included studies were mixed, with evidence to suggest both average and elevated levels of psychological distress in this population. Of note, findings suggest that some parents, such as mothers and those whose children require more medical care, may be more likely to experience psychological distress than others. The quality appraisal process identified several methodological weaknesses of the literature, such as an absence of comparison groups and meaningful outcome data. Findings and subsequent implications should therefore be considered carefully. Nonetheless, this review does not rule out the presence of psychological distress in this population. Future paediatric healthcare and research should therefore seek to understand and support the wellbeing of parents of children with IBD.

Self-compassion interventions may offer one way of appropriately supporting parents in this context. Self-compassion has been defined in relation to three main components: self-kindness; common humanity; and mindfulness. Research has shown the benefits of self-compassion in the context of CHCs and challenging parenting situations. Section two of this report therefore contains a randomised controlled trial which investigated the effectiveness of a brief online self-compassion intervention for parents of children with IBD. The intervention involved reflecting and expressing compassion to oneself in relation to a recent challenging parenting event. 159 parents of children with IBD were randomised to either the intervention or control group, with outcome measures completed before, immediately after the intervention, and two weeks after daily engagement in the intervention.

Findings suggest that the self-compassion intervention effectively increased state self-compassion and reduced state distress, but not state shame, immediately following the intervention. Repeated engagement in the intervention had no effect on trait self-compassion or parental stress. Significant drop-out and several methodological limitations mean that the latter findings cannot be confidently applied to all. Nonetheless, implications regarding the application of brief self-compassion interventions in this context to provide accessible support for parents can be tentatively drawn. Overall, this report provides preliminary support for the applicability and effectiveness of a systemic approach to paediatric IBD research and practice, where the wellbeing of parents is considered and supported compassionately alongside children's care.

Acknowledgments

Firstly, I would like to acknowledge and thank all the parents who participated in this research. Without your willingness to give up your time and be so open and honest in the process, this work would not have been possible. Thank you also to the charities that supported this research.

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Section One: Literature Review

Psychological Distress in Parents of Children with Inflammatory Bowel Disease (IBD): A Systematic Review

Abstract

Objectives

This review aimed to systematically and critically examine the literature regarding psychological distress in parents of children with IBD.

Methods

A systematic search of Medline, CINAHL, PsychInfo, and Scopus was conducted in June 2021. Eligibility criteria was applied to identify studies that examined a quantitative measure of psychological distress in parents of children with IBD. The studies were quality appraised and narratively synthesised to assess findings relative to methodological strengths and weaknesses.

Results

23 studies were deemed eligible for review. Most studies were rated as moderate quality, with several methodological shortcomings identified across the literature. Findings were heterogenous, reporting both average and elevated levels of psychological distress in this population. Sub-groups that might be particularly vulnerable to psychological distress were identified, including mothers and those whose children require more IBD care.

Conclusions

The psychological wellbeing of parents of children with IBD appears to be subjective, with no clear consensus elucidated. Further high-quality studies with generalisable samples and comparison groups are warranted. Paediatric IBD services should also seek to understand and support individual needs of parents.

Practitioner Points

- Findings relating to psychological distress in parents of children with IBD are mixed, with evidence to suggest both average and elevated levels of distress.
- Parents who hold significant responsibility for their child with IBD may be vulnerable to psychological distress.
- Future research and clinical practice should consider and support the psychological wellbeing of those caring for children with IBD.

Keywords: Inflammatory Bowel Disease; Paediatric; Parent; Psychological Distress

Introduction

Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) refers to a group of conditions, including Crohn's disease (CD) and ulcerative colitis (UC), that involve chronic inflammation of the digestive system (Crohn's and Colitis UK [CCUK], 2021). IBD often follows a relapsing-remitting course, with symptoms such as abdominal pain, diarrhoea, weight loss, and tiredness (National Health Service [NHS], 2020). Although there is no current cure for IBD, treatments are available to relieve symptoms and maintain remission. Individual treatments vary, but may include medications, surgery, and diet and lifestyle changes (CCUK, 2021; NHS, 2020). To manage and monitor IBD, individuals are likely to need regular healthcare appointments (CCUK, 2018). It is perhaps unsurprising then that a negative impact of the condition on psychosocial factors, such as quality of life and emotional wellbeing, has been found amongst adults with IBD (Casati et al., 2000; Drossman et al., 1989; Kemp et al., 2012; Larsson et al., 2008).

IBD in Children

Around one in 123 people in the United Kingdom (UK) are estimated to have CD or UC (CCUK, 2021), with a quarter of cases being diagnosed before the age of 16 years (CCUK, 2019; Posford, 2019). Like adult populations, research reports the significant impact of IBD on psychosocial factors for children (De Boer et al., 2005; Nicholas et al., 2007). For example, Nicholas et al.'s (2007) qualitative study identified issues such as disruption caused by symptoms and treatment, a sense of vulnerability and lack of control, and negative social comparison. Given the potential burden of IBD, it is perhaps unsurprising that parents of children with the condition are relied upon to

provide practical and emotional support. Indeed, MacPhee at al. (1998) found that 90% of children with IBD identified parents and siblings as their key source of support.

Parents of Children with Chronic Health Conditions

In recognition of this support network that children exist within, paediatric chronic health conditions (CHCs) are increasingly being understood within systemic frameworks (Emerson & Bögels, 2017; Wood et al., 2015). For example, Emerson and Bögels (2017) discuss the ongoing bidirectional relationship that occurs between the psychosocial functioning of parents and children and how this may impact child outcomes in the context of paediatric CHCs. A key feature of systemic models is the potential for parental psychosocial functioning to have an impact on child health outcomes. It is therefore fundamental to consider the wellbeing of those caring for children with IBD. This is particularly pertinent for psychologists working in paediatric health settings, who have a key role in supporting the physical and psychological wellbeing of children and their families (Jacobs et al., 2012).

In accordance with systemic frameworks, the impact of paediatric health conditions on parental psychosocial functioning has been explored (Abela et al., 2020; Brown et al., 2008; Coffey, 2006; Shudy et al., 2006). Notably, Cousino and Hazen's (2013) systematic review found elevated levels of parenting stress in parents of children with CHCs compared to parents of children without a CHC. Some variability was noted when populations of specific CHCs were compared, however, with parents of children with particular CHCs experiencing more stress than other groups. Parents who held more responsibility for their child's treatment management also reported higher levels of parenting stress. This finding is in accordance with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) which, in the context of

paediatric CHCs, would suggest that parent and child outcomes are determined by a transaction between disease parameters and individual processes such as perceived stress relative to one's coping abilities (Thompson et al., 1993; Thompson et al., 1992). As IBD is a non-curable CHC characterised by unpredictable relapsing-remitting symptoms that require continuous monitoring and treatment, we can hypothesise that parents' perceptions of IBD-related stress may be greater than their perceived ability to cope. In this context, Lazarus and Folkman's (1984) model would suggest that parents of children with IBD may be at risk of increased parental stress.

There are, however, several methodological shortcomings of Cousino and Hazen's (2013) systematic review that limit conclusions. For example, the quality of included studies was not assessed and the findings are not therefore considered critically. Moreover, the review does not include any IBD samples, thus limiting the generalisability of the findings to the population in question. Despite the potential burden of IBD, it appears that this population is largely absent from other past reviews in this field (Brown et al., 2008; Shudy et al., 2006). An up-to-date review may therefore provide the opportunity to identify and synthesise studies that include this population.

Parents of Children with IBD

The limited research that does explore parents of children with IBD presents important findings that support the notion of a bidirectional relationship between parent and child outcomes in this population (Plevinsky et al., 2018). For example, a systematic review by Brooks et al. (2016) found that parental stress was a significant risk factor for psychological morbidity in children with IBD. Furthermore, Cushman et al. (2020) recently presented a narrative review of studies assessing parent and family functioning within IBD. The findings from this review suggest that mothers of children

with IBD may experience more psychosocial difficulties than normative populations, with some evidence to suggest that this finding also extends to comparisons with other illness populations. Findings related to parenting stress, however, suggest that parents of children with IBD report comparable or lower levels of parenting stress than parents of children with other illnesses. Although these findings are preliminary and inconsistent, the review importantly highlights the relationships that are present between parent and family functioning and child outcomes, particularly in regard to child psychosocial outcomes. They also infer that psychologists working in paediatric IBD settings need to be considering the wellbeing of children and their families through systemic assessments and treatments, thus supporting the significance of the current review for the field of clinical psychology.

There are several limitations of Cushman et al.'s (2020) review that warrant a further review in this area. Firstly, they did not use a systematic search strategy with clear eligibility criteria, thus introducing the risk that some relevant studies may not be included. Similar to Cousino and Hazen (2013), they did not assess the quality of studies and their interpretations of the given findings are therefore limited. Furthermore, Cushman et al. (2020)'s review is broad in that it explores parent, family, and child outcomes across several distinct domains, the interpretation of most relying on few or single studies. Whilst it is important to attain a broad understanding of paediatric IBD going forward, understanding how specific parental psychological factors are affected may be more useful when considering the advancement of paediatric psychology services and research.

Current Review

To the best of our knowledge, no reviews have yet systematically and critically reviewed the literature regarding psychological distress in parents of children with IBD. The current paper intends to address this gap, with the primary aim of: 1) quantifying psychological distress in this population. Dependent on available data, secondary aims included: 2) understanding the nature of psychological distress in this population; and 3) comparing psychological distress in this population to other groups.

There is no clear, well-accepted definition of psychological distress in the literature. Instead, its conceptualisation is widely contested (Drapeau et al., 2012; Horowitz, 2007; Wheaton, 2007). Psychological distress has, however, been summarised as a discomforting psychological state in response to personal threats or stressors (Faessler et al., 2016; Ridner, 2004). Furthermore, it has been linked to various affective and cognitive responses; most commonly, depression and anxiety (Kemeny, 2011; Wheaton, 2007). The current review consequently adopts a broad definition of psychological distress, including any signs, experiences, or symptoms of a discomforting psychological state (e.g. depression, anxiety, stress) as indication of its presence.

Method

Search Strategy

Initial scoping searches on Medline using key terms revealed that there was sufficient, albeit limited, research available to explore the current questions. Additional scoping searches of PROSPERO and The Cochrane Library did not find any duplicate existing reviews, hence a protocol for this review was developed and registered on PROSPERO (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021255543).

A systematic search of titles, abstracts, and keywords in Medline, CINAHL, PsychInfo, and Scopus was conducted in June 2021. Backward and forward reference searches, as well as searches of relevant authors, were completed to identify any additional studies. The database searches were also ran again before synthesising the studies (December 2021) to check for any newly published studies. Grey literature searches were also conducted on British Library E-theses Online Service (EThOS), ProQuest, Google scholar and Grey Literature Report.

Search terms (Table 1) and eligibility criteria (Table 2) were informed by the PICOS (population, intervention/issue, comparison, outcome, study design) framework, scoping searches, and relevant literature. Variations of the key search terms were combined using the Boolean operator 'AND'. Relevant subject headings available within each of the databases were also included. No restrictions were placed on publication dates.

Table 1

Search Terms

Search Term	Variations Searched
1. Parent	parent* OR maternal OR paternal OR mother* OR father* OR caregiv* OR family OR families
2. Child	child* OR youth OR adolescen* OR "young person" OR "young people" OR teen* OR infant OR paediatric* OR pediatric* OR offspring
3. Inflammatory Bowel Disease	"inflammatory bowel disease" OR ibd OR "ulcerative colitis" OR colitis OR "crohn* disease" OR crohn*
4. Psychological Distress	"psychological distress" OR distress OR stress OR psychopathology OR "mental health" OR "mental distress" OR "mental illness" OR "mental disorder*" OR "mental ill-health" OR "emotion*" OR anxiety OR depress* OR "psycho* factors" OR functioning

Note. * symbol used for truncation.

Table 2

Inclusion and Exclusion Criteria

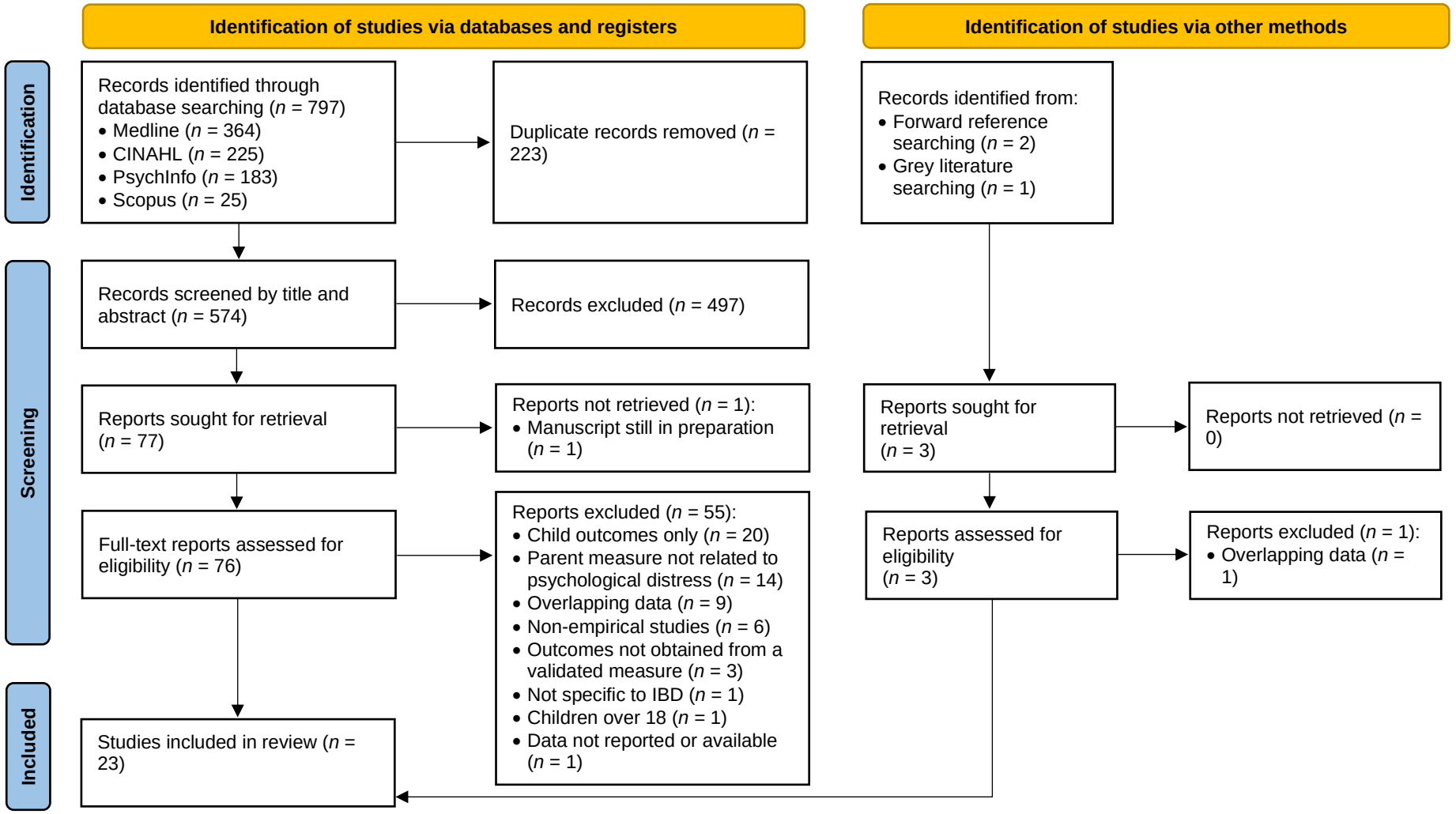
PICOS Domain	Inclusion Criteria	Exclusion Criteria
Population	Extractable data from parents or caregivers of children (under 18 years old) with a diagnosis of IBD.	Parents or caregivers of children over 18 years old. Broader population from which data relating to parents or caregivers of children under 18 years old cannot be extracted. Studies that contain overlapping data (i.e., the same or a sub-set of the same sample) with another study identified for inclusion.
Intervention/issue	Child has a self-reported diagnosis of IBD (CD, UC, or other).	Child has a diagnosis of irritable bowel syndrome (IBS) or another CHC.
Comparison	Not applicable.	Due to the limited research in this area, studies were not excluded based on the presence or absence of comparison groups.
Outcome	Validated outcome measure of parental psychological distress (as defined in the introduction).	Child outcomes only. Parent measure not related to psychological distress. Outcome measure not validated.
Study design	Includes a quantitative observational element. Published in English.	Purely qualitative studies. Non-empirical articles (e.g., reviews, book chapters, discussion articles).

Study Selection

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Page et al., 2021), a flow diagram summarising the selection process is presented in Figure 1. The database searches returned 797 studies, with 574 studies remaining after removing duplicates in EndNote. Titles and abstracts were then screened using inclusion and exclusion criteria (Table 2), leaving 77 studies. As one study was still in preparation, 76 full texts were retrieved for further screening. Forward reference and grey literature searching yielded three additional studies. The full texts of these studies were assessed for eligibility, identifying 23 studies for inclusion. This selection process was conducted by the primary researcher, with supervision available throughout.

Figure 1

PRISMA Flow Diagram



Data Extraction and Synthesis

Study characteristics and key findings were extracted, tabulated, and synthesised narratively by the primary researcher to address the review questions. To improve accuracy, a Trainee Clinical Psychologist independent to the review repeated the data extraction and tabulation process for a random selection (20%, *n* = 5) of the studies, with any inconsistencies in the extracted data resolved through discussion and further reviewed across all studies (Centre for Reviews and Dissemination [CRD], 2009). A narrative synthesis, rather than a meta-analysis, was used to synthesise findings due to the expected variability across studies in relation to outcomes and comparison groups. According to relevant guidelines (CRD, 2009), this process initially involved visually organising extracted findings into groups to locate individual and collective patterns of data relevant to the review aims. This preliminary synthesis was then contextualised in regard to study characteristics and quality appraisal results. A textual narrative of the resultant synthesis was then developed, organised according to each of the review aims.

Quality Appraisal

There is a paucity of quality appraisal tools that thoroughly assess cross-sectional studies (Downes et al., 2016; Sanderson et al., 2007). The Joanna Briggs Institute (JBI) Checklist for Analytical Cross-Sectional Studies (2020) was initially considered, however a bespoke version of the Appraisal tool for Cross-Sectional Studies (AXIS; Downes et al., 2016; Appendix A) was used to allow for a more relevant and thorough quality assessment. Modifying quality appraisal tools is recommended to ensure items are suited to specific review questions (CRD, 2009; Quintana, 2015). The AXIS allows for a thorough assessment of study design and quality, as well as

reporting, with the aim of determining the reliability, worth, and relevance of included studies (Downes et al., 2016). Eleven AXIS items were deemed relevant for the current review and therefore retained, alongside an additional question regarding the minimum sample size recommended for detecting a medium effect using t-tests to assess the difference between two independent means at a significance level of $p < .05$ (Cohen, 1992). An additional parameter was added to the existing question regarding the acceptable response rate of studies, which was set as >70% based on existing research and guidelines (Gordon et al., 2002; Sivo et al., 2006).

The primary researcher applied the modified AXIS to included studies, categorising each of the items as 'yes' (met criteria, 1), 'no' (did not meet criteria, 0), or 'don't know/unclear' (0). The scores were added together to calculate a total score (0-12) for each study. Scores were categorised as low (0-6), moderate (7-9), or high (10-12) quality. These categories were developed by the primary researcher in line with previous reviews that have used modified versions of the AXIS (Sirois & Owens, 2021). The Trainee Clinical Psychologist independent to this review also appraised a random selection (20%, $n = 5$) of the studies. Inter-rater agreement was assessed using Cohen's Kappa (κ) coefficient (Cohen, 1992). Any items that were not initially agreed on were discussed and subsequently reviewed across all studies.

Results from the quality appraisal were tabulated and incorporated into the synthesis to understand and explain findings relative to the studies' strengths and weaknesses. The quality appraisal was also used to inform directions for future research and clinical practice. As this is a relatively new and small research area, studies were not excluded based on quality assessment.

Results

Study Characteristics

Key study characteristics and findings are summarised in Table 3. Studies were published between 1991 and 2021, with 2015 being the median year of publication.

Design

19 studies used a cross-sectional design. Of the remaining studies, three used a pre-post design to assess an intervention (Ahola Kohut et al., 2021; Oseran et al., 2021; Reed-Knight et al., 2012). For these studies, only baseline cross-sectional data obtained prior to any intervention was extracted. Although the one remaining study (Wilson, 2015) describes a longitudinal design, only baseline cross-sectional data was available.

Participants

Data from 1563 parents of children with IBD was included. Eleven of the included studies were conducted in America, with the remaining studies conducted in Canada; Sweden; Italy; the Netherlands; Greece; Czech Republic; Israel; the United Kingdom; France; and Switzerland. All participants were recruited from specified hospitals, IBD clinics, or other medical services within the geographic region of each study.

At least 61% of the parents included were mothers, although five studies did not provide this demographic data (Cohen et al., 2019; Jelenova et al., 2015; Reed-Knight et al., 2012; Scullion, 2009; Wilson, 2015). In line with the eligibility criteria, all children were under 18 years old, with a range of 1-18. Four studies, however, did not report specific ages (Burke et al., 1994; Oseran et al., 2021; Szajnberg et al., 2011; Tran et al., 2021). Approximately 63% of the children were diagnosed with CD, 35% with UC, and 2% with other IBD diagnoses (e.g., IBD-U or Indeterminate Colitis). Two

studies, however, did not clearly report the specific IBD diagnoses (Carlsen et al., 2019; Reed-Knight et al., 2012).

Comparison groups were included in eight studies, comprising of parents of children with another CHC (Burke et al., 1994; Guilfoyle et al., 2012; Lindström et al., 2010); parents of children without a CHC (Diederen et al., 2018; Engström, 1991; Jelenova et al., 2015; Lindström et al., 2010); a normative adult sample (Werner et al., 2014); and parents of children in remission from IBD (Giannakopoulos et al., 2016). The latter comparison group will be recognised in the synthesis as an IBD group, whilst also contributing to the understanding of how different clinical presentations impact parental psychological distress.

Outcome Measures

The included studies utilised various outcome measures of psychological distress. In line with inclusion criteria, all measures were validated by corresponding psychometric articles. The majority of studies (n = 17) measured general psychological distress, whilst four studies measured psychological distress specific to parenting a child with a CHC, and two measured psychological distress specific to parenting more broadly. The most used (n = 4) measures were the Pediatric Inventory for Parents (PIP; Streisand et al., 2001), a measure of paediatric parenting stress; and the Symptom Checklist (SCL; Derogatis & Cleary, 1977), a measure of psychological problems and symptoms of psychopathology. In descending order, other measures used less routinely ($n \leq 3$) included the Beck Depression Inventory (BDI; Beck et al., 1961); the Beck Anxiety Inventory (BAI; Beck et al., 1988); the Brief Symptom Inventory (BSI; Derogatis, 1993); the Distress Thermometer (DT; Haverman et al., 2013); the Millon Clinical Multi-Axial Inventory (MCMI; Million, 1987); the Hospital

Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983); the Depression, Anxiety and Stress Scale (DASS; Henry & Crawford, 2005); the Adult Schedule for Affective Disorders and Schizophrenia (SADS; Endicott & Spitzer, 1978); the Shirom-Melamed Burnout Questionnaire (SMBQ; Melamed et al., 1999); the Perceived Stress Scale (PSS-10; Cohen et al., 1983); the Profile of Mood States (POMS; McNair et al., 1971); the Stress Index for Parents of Adolescents, Parent Domain Subscale (SIPA; Sheras et al., 1998); the Positive and Negative Affect Schedule (PANAS; Watson et al., 1988); and the State Trait Anxiety Inventory (STAI; Gauthier & Bouchard, 1993).

Table 3

Summary of Included Studies

Author(s), Year & Country	Study Design	Participant Characteristics	Comparison Group	Measure of Psychological Distress	Key Findings	Quality
Ahola Kohut et al. (2021) Canada	Pre-post (extracting baseline data only)	37 parents (86% mothers) of children (aged 4-17) with IBD (51% CD)	None	DASS	Findings indicate depression in the normal range, anxiety in the normal-mild range, and distress symptoms in the mild range in parents of children with IBD.	Moderate
Bramuzzo et al. (2020) Italy	Cross-sectional	152 parents (59% mothers) of children (8-18) with IBD (45% CD)	None	DT HADS	Findings from the DT indicate clinically significant distress in around half of the parents of children with IBD, with significantly more mothers falling in this range than fathers (p = .05). On the HADS, few parents of children with IBD fell in the abnormal range for anxiety (13.8%) or depression (7.9%), although significantly more mothers than fathers fell in this range for anxiety (p = .02).	High
Burke et al. (1994) America	Cross-sectional	72 mothers of children (mean age = 12.22, ± 2.71) with IBD (62% CD)	44 mothers of children (mean age = 12.21, ± 3.23) with Cystic Fibrosis	A-SADS-L	Findings indicate that few mothers of children with IBD met the criteria for depression (10%), although this was a higher rate than mothers of children with Cystic Fibrosis (4.5%; not statistically tested).	Moderate

Carlsen et al. (2019) America	Cross-sectional	22 parents (79% mothers) of children (16-18) with IBD	None	PIP	Findings indicate that, on average, parents of children with IBD experienced 71% of the parental stressors included in the PIP. No cut-offs or normative values available for further interpretation.	Low
Cohen et al. (2019) Canada	Cross-sectional	133 parents of children (8-17) with IBD (65% CD)	None	PIP	Findings indicate less frequency and difficulty of parental stress in parents of children with IBD compared to previously published samples of parents of children with cancer (Streisand et al., 2001), obesity (Ohleyer et al., 2007), SCD (Logan et al., 2002) and BE (Mednick et al., 2009), but similar frequency and higher difficulty of parental stress compared to a previously published sample of parents of children with diabetes (Streisand et al., 2005; not statistically tested).	Moderate
Diederen et al. (2018) Netherlands	Cross-sectional	87 parents (92% mothers) of children (8-18) with IBD (67% CD)	401 parents (57% mothers) of children without a CHC (8-18)	DT-P	Findings indicate clinically significant distress in around half of parents of children with IBD (47.1%), and this was not significantly different from parents of children without a CHC (40.6%, p = .344).	High
Engström (1991) Sweden	Cross-sectional	40 parents (50% mothers) of children (7-18) with IBD (45% CD)	40 parents (50% mothers) of matched children without a CHC	SCL-90	Findings indicate more mental health symptoms in mothers of children with IBD compared to parents of children without a CHC (p = .003) and fathers of children with IBD (p = .007). No cut-offs or normative values available for further interpretation.	Low

Giannakopoulos et al. (2016) Greece	Cross-sectional	43 parents (80% mothers) of children (8-18) with active IBD (70% CD)	42 parents (83% mothers) of children (8-18) in IBD remission	SCL-90-GSI	Findings indicate more mental health symptoms in parents of children with active IBD compared to the remission group ($p < .001$). The parent mental health symptoms of both groups were, on average, higher than a previously published normative sample (Schmitz et al., 2000), perhaps indicating elevated mental health symptoms in parents of children with IBD (not statistically tested).	High
Guilfoyle et al. (2012) America	Cross-sectional	62 parents (89% mothers) of children (13-17) with IBD (79% CD)	422 parents of children with other chronic health conditions (32% type 1 diabetes; 30% cancer; 17% obesity; 16% SCD; 5% BE)	PIP	Findings indicate that parents of children with IBD experience less frequency and difficulty of parental stress compared to parents of children with cancer, obesity, SCD, and less difficulty than parents of children with BE (all $p < .001$). However, similar frequency and difficulty of parental stress in parents of children with IBD compared to parents of children with diabetes was indicated.	High
Jelenova et al. (2015) Czech Republic	Cross-sectional	29 parents of children (13-16) with IBD (66% CD)	40 parents of children without a CHC (13-16)	BDI-II BAI	Findings indicate that, on average, parents of children with IBD didn't meet criteria for depression or anxiety. However, fathers of children with IBD experienced significantly more depression than fathers of children without a CHC ($p < .0005$), whilst mothers of children with IBD experienced significantly more anxiety than mothers of children without a CHC ($p < .0005$).	Moderate

Lindström et al. (2010) Sweden	Cross-sectional	38 parents (55% mothers) of children (1-18) with IBD (44% CD)	251 parents (57% mothers) of children with type I diabetes mellitus (1-18) and 124 parents (59% mothers) of children without a CHC	SMBQ	Findings indicate that 33.3% of mothers and 17.6% of fathers of children with IBD met the criteria for clinical burnout, which was not significantly different from mothers (20.5%; p = .054) and fathers (19.6%; p = .750) of children with children without a CHC. Less parents of children with IBD met the criteria for clinical burnout compared to mothers (44.4%) and fathers (31%) of children with diabetes (not statistically tested).	Moderate
Loreaux et al. (2015) America	Cross-sectional	86 parents (92% mothers) of children (11-17) with IBD (76% CD)	None	BSI-DEP	Findings indicate that, on average, parents of children with IBD fall within the average range for depression scores.	High
Oseran et al. (2021) Israel	Pre-post (extracting baseline data only)	26 parents (73% mothers) of children with IBD (73% CD)	None	PSS-10 POMS	Findings indicate that, on average, parents of children with IBD experienced similar levels of perceived stress compared to previously published normative samples (Cohen et al., 1983; not statistically tested). No cut-offs available for further interpretation of PSS-10 or POMS.	Moderate
Reed-Knight et al. (2016) America	Cross-sectional	83 parents (81% mothers) of children (11-18) with IBD (76% CD)	None	SCL-90-R-DEP	Findings indicate that, on average, parents of children with IBD fall within the average range for depression scores, although 23% scored in or above the 84th percentile of depression scores.	High

Reed-Knight et al. (2012) America	Pre-post (extracting baseline data only)	31 parents of female children (11-18) with IBD	None	SIPA	Findings indicate that, on average, parents of children with IBD fall within the average range for parental distress.	Moderate
Roberts et al. (2019) America	Cross-sectional	107 parents (83% mothers) of children (10-18) with IBD (54% CD)	None	BSI-GSI	Findings indicate that, on average, few parents of children with IBD met the criteria for clinically significant general distress (9.35%).	Moderate
Scullion (2009) United Kingdom	Cross-sectional	57 parents of children (13-17) with IBD (75% CD)	None	BDI-II BAI	Findings indicate that, on average, parents of children with IBD fall within the minimal range for depression and the mild range for anxiety.	Moderate
Szajnberg et al. (1993) America	Cross-sectional	27 parents (56% mothers) of children (4-15) with IBD (73% CD)	None	MCMI	Findings indicate that few parents of children with IBD met the criteria for anxiety disorder (15%), with this being more prevalent in mothers (20%) than fathers (8%; not statistically tested). No other axis I disorders were identified in parents of children with IBD.	Low
Szajnberg et al. (2011) America	Cross-sectional	21 mothers of children (mean age = 12.8) with IBD (76% CD)	None	MCMI	Findings indicate that no parents of children with IBD met the criteria for axis I disorders (e.g. mood disorders, anxiety disorder).	Low

Tojek et al. (2002) America	Cross-sectional	62 mothers of children (11-18) with IBD (58% CD)	None	PANAS	Findings indicate that, on average, mothers of children with IBD do not score unusually high on NA or unusually low on PA according to published percentile tables (Crawford & Henry, 2004; not statistically tested). No cut-offs available for further interpretation.	Moderate
Tran et al. (2021) France	Cross-sectional	88 parents (80% mothers) of children with IBD in remission (74% CD; 85% without FAP)	None	STAI-Y BDI	Findings indicate that, on average, parents of children with IBD (with and without FAP) fall within the average range (t-scores 46-57) for trait and state anxiety. However, parents of children with IBD and FAP experience more state and trait anxiety than parents of children with IBD without FAP. This difference was not present for depression, however, and most (89.8%) parents of children with IBD (with and without FAP) did not meet criteria for depression.	Moderate
Werner et al. (2014) Switzerland	Cross-sectional	231 parents (54% mothers) of children (4-17) with IBD (56% CD)	890 adults (58% female) from a normative sample	SCL-27	Findings indicate that, on average, mothers of children with IBD experience poorer mental health than fathers of children with IBD (p = .000). Findings also indicate that mothers of children with IBD experience poorer mental health than a normative sample (p = .05), whilst fathers of children with IBD experience better mental health than a normative sample (p = .000), although these latter differences were small. No parents of children with IBD met criteria for a diagnosis of a mental disorder.	Moderate

Wilson (2015) America	Longitudinal (only baseline data available)	29 parents of children (9-17) with IBD (63% CD)	None	HADS PIP	Findings indicate that, on average, parents of children with IBD who are seen as inpatients experience more anxiety and depression than parents of children with IBD who are seen as outpatients. However, few parents of children with IBD fall in the abnormal range for anxiety (11%) or depression (11%). Findings also indicate that, on average, parents of children with IBD who are seen as inpatients experience more frequency and difficulty of parental stress compared to previously published samples of parents of children with cancer (Streisand et al., 2001), diabetes, (Streisand et al., 2005), obesity (Ohleyer et al., 2007), SCD (Logan et al., 2002) and BE (Mednick et al., 2009). However, parents of children with IBD who are seen as outpatients experience similar or less frequency and difficulty of parental stress compared to these previously published samples (not statistically tested).	Moderate

Note. A-SADS-L = Adult Schedule for Affective Disorders and Schizophrenia, Lifetime Version; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory; BDI-II = Beck Depression Inventory, Second Version; BE = Bladder exstrophy; BSI-DEP = Brief Symptom Inventory, Depression Subscale; BSI-GSI = Brief Symptom Inventory, Global Severity Index; CHC = Chronic Health Condition; CD = Crohn's Disease; DASS = Depression, Anxiety and Stress Scale; DT = Distress Thermometer; DT-P = Distress Thermometer for Parents; FAP = Functional Abdominal Pain; HADS = Hospital Anxiety and Depression Scale; IBD = Inflammatory

Bowel Disease; MCMI = Millon Clinical Multi-Axial Inventory; NA = Negative Affect; PA = Positive Affect; PANAS = Positive and Negative Affect Schedule; PIP = Pediatric Inventory for Parents; POMS = Profile of Mood States; PSS-10 = Perceived Stress Scale; SCD = Sickle Cell Disease; SCL-27 = Symptom Checklist-9-Revised, Short Form; SCL-90 = Symptom Checklist-90; SCL-90-GSI = Symptom Checklist-90, Global Severity Index; SCL-90-R-DEP = Symptom Checklist-90-Revised, Depression Subscale; SIPA = Stress Index for Parents of Adolescents, Parent Domain Subscale; SMBQ = Shirom-Melamed Burnout Questionnaire; STAI-Y = State Trait Anxiety Inventory, Form Y.

Quality Appraisal

Quality appraisal ratings are summarised in Table 4 and considered throughout the synthesis. Six studies were deemed to be of high quality (Bramuzzo et al., 2020; Diederen et al., 2018; Giannakopoulos et al. 2016; Guilfoyle et al., 2012; Loreaux et al., 2015; Reed-Knight et al., 2016). However, most studies (*n* = 13) were rated as moderate quality and the remaining four as low quality (Carlsen et al., 2019; Engström, 1991; Szajnberg et al., 1993; Szajnberg et al., 2011).

Inter-rater agreement between quality assessors was good (κ = .73, $p < .001$), with complete agreement later reached through discussion and the amendment of the primary reviewer's ratings for two items. No further changes were required upon review of the disputed items across all studies.

A strength of the studies was that they all clearly defined their samples, increasing the confidence in which the target populations are reflective of the overall population of interest. Moreover, most studies (*n* = 19) described a recruitment process whereby all eligible families had an equal chance of participating, thus providing some support for the generalisability of this review. However, according to the parameters of the modified AXIS, nine studies had small sample sizes (*n* < 64), thus compromising this initial generalisability and raising the issue of statistical power. Furthermore, the response rate was under 70% or not reported in around half the studies (*n* = 12), with few studies (*n* = 3) providing information to determine whether non-responders were comparable to responders. Non-response bias may therefore be present within this review, further undermining the generalisability of findings. Overall, although there is some preliminary support for the generalisability of the

current findings, limitations relating to sample size and responder bias mean that generalisability cannot be assumed based on the strengths initially mentioned.

Although varied outcome measures were used, most measured psychological distress appropriately and clearly, using validated and reliable means in line with the inclusion criteria. However, two studies (Carlsen et al., 2019; Engström, 1991) scored negatively on this domain due to not scoring measures clearly and correctly as described in corresponding psychometric papers, thus making it difficult to determine and make accurate sense of their findings.

Ten studies (Burke et al., 1994; Carlsen et al., 2019; Engström, 1991; Reed-Knight et al., 2012; Roberts et al., 2019; Scullion, 2009; Szajnberg et al., 1993; Szajnberg et al., 2011; Tojek et al., 2002; Wilson, 2015) did not clearly describe their methods, with a particular issue arising regarding the absence of data analysis plans. This makes it hard to infer the rationale for the statistical methods used within these studies, and whether the results were presented for all planned analyses. As statistical methods determine findings, there is a possibility of bias in these studies. Nonetheless, most studies discussed their findings appropriately and fairly, with only four studies insufficiently discussing limitations (Engström, 1991; Szajnberg et al., 1993; Szajnberg et al., 2011; Tran et al., 2021).

Table 4

Quality Assessment of Included Studies

Author(s) (Year of Publication)	1. Aims	2. Power	3. Target Population	4. Recruitment	5. Response Rate	6. Non-Responders	7. Outcomes	8. Replicability	9. Internal Consistency	10. Results	11. Discussion	12. Limitations	Total Score / 12	Quality Rating
Ahola Kohut et al. (2021)	1	0	1	1	0	0	1	1	1	1	1	1	9	Moderate
Bramuzzo et al. (2020)	1	1	1	1	1	0	1	1	1	1	1	1	11	High
Burke et al. (1994)	1	1	1	1	X	0	1	0	1	X	1	1	8	Moderate
Carlsen et al. (2019)	1	0	1	X	0	0	0	0	0	1	1	1	5	Low
Cohen et al. (2019)	1	1	1	1	X	0	1	1	0	1	1	1	9	Moderate
Diederen et al. (2018)	1	1	1	1	1	1	1	1	1	1	1	1	12	High
Engström (1991)	1	1	1	1	1	0	X	0	0	1	0	0	6	Low
Giannakopoulos et al. (2016)	1	1	1	1	1	1	1	1	1	1	1	1	12	High
Guilfoyle et al. (2012)	1	1	1	1	0	0	1	1	1	1	1	1	10	High
Jelenova et al. (2015)	1	1	1	X	X	0	1	1	1	1	1	1	9	Moderate
Lindström et al. (2010)	1	1	1	1	0	0	1	1	0	1	0	1	8	Moderate
Loreaux et al. (2015)	1	1	1	1	0	0	1	1	1	1	1	1	10	High
Oseran et al. (2021)	1	0	1	1	0	0	1	1	1	1	0	1	8	Moderate
Reed-Knight et al. (2016)	1	1	1	1	1	1	1	1	1	1	1	1	12	High

Reed-Knight et al. (2012)	1	0	1	1	0	0	1	0	1	X	1	1	7	Moderate
Roberts et al. (2019)	1	1	1	1	1	0	1	0	1	X	1	1	9	Moderate
Scullion (2009)	1	0	1	1	1	0	1	0	1	1	1	1	9	Moderate
Szajnberg et al. (1993)	1	0	1	X	1	0	1	0	1	X	1	0	6	Low
Szajnberg et al. (2011)	1	0	1	1	1	0	1	0	0	X	0	0	5	Low
Tojek et al. (2002)	1	0	1	1	1	0	1	0	1	X	1	1	8	Moderate
Tran et al. (2021)	1	1	1	1	X	0	1	1	0	1	1	0	8	Moderate
Werner et al. (2014)	1	1	1	1	0	0	1	1	0	1	1	1	9	Moderate
Wilson (2015)	1	0	1	0	1	0	1	0	1	X	1	1	7	Moderate

Note. ‘Yes’ (met criteria, 1) = green; ‘No’ (did not meet criteria, 0) = red; ‘Don’t know / unclear’ (X) = yellow. Low quality = 0-6;

Moderate quality = 7-9; High quality = 10-12.

Synthesis

The below synthesis first addresses the primary review aim, by exploring the levels of psychological distress reported by parents in these studies. This evidence is synthesised under each of the various outcomes assessed, helping to fulfil the secondary aim of understanding the nature of psychological distress in this population. Findings from sub-samples that provide further insight into the level and nature of psychological distress in parents of children with IBD are then considered. Finally, findings that compare the psychological distress of parents of children with IBD with other populations are considered to address the additional secondary aim.

Levels of Psychological Distress

Most studies suggest that levels of psychological distress experienced by parents of children with IBD fall within the average range. This evidence will be synthesised below, with weight given to counterevidence where it exists.

Depression.

Several high and moderate-quality studies report that most parents of children with IBD fall within the average range on measures of depression (Ahola Kohut et al., 2021; Bramuzzo et al., 2020; Burke et al., 1994; Jelenova et al., 2015; Loreaux et al., 2015; Reed-Knight et al., 2016; Scullion, 2009; Tran et al., 2021; Wilson, 2015). However, evidence from these moderate-quality studies is weakened by small samples (Ahola Kohut et al., 2021; Jelenova et al., 2015; Scullion, 2009; Wilson, 2015), some which do not include many fathers (Ahola Kohut et al., 2021; Burke et al., 1994; Tran et al., 2021). This latter limitation is of particular significance due to findings from one study suggesting that depression is one aspect of psychological distress that fathers of children with IBD may experience (Jelenova et al., 2015). Nonetheless, the

included studies predominantly suggest that parents of children with IBD do not experience elevated levels of depression.

Anxiety.

Similarly, several studies suggest that parents of children with IBD do not experience heightened anxiety (Ahola Kohut et al., 2021; Bramuzzo et al., 2020; Jelenova et al., 2015; Scullion, 2009; Szajnberg et al., 1993; Tran et al., 2021; Wilson, 2015). Overall, however, there are less robust studies supporting this assumption relative to the above conclusion regarding depression. Again, small sample sizes significantly weaken this evidence (Ahola Kohut et al., 2021; Scullion, 2009; Szajnberg et al., 1993; Wilson, 2015). Furthermore, several studies found that anxiety was slightly elevated compared to depression (Ahola Kohut et al., 2021; Bramuzzo et al., 2020; Scullion, 2009). For example, Scullion (2009) found that parents of children with IBD fall within the minimal range for depression, but the mild range for anxiety. Nonetheless, this study had several weaknesses, notably including the inconsistent reporting of cut-offs used for the anxiety measure. Moreover, the differences between anxiety and depression within these studies are not statistically tested and cannot therefore be assumed. In summary, although there is some evidence to suggest that few parents of children with IBD fall within an abnormal range for anxiety, this is less definitive than the above conclusion regarding depression.

Distress.

When measuring psychological distress using the DT, both Bramuzzo et al. (2020) and Diederen et al. (2018) report clinically significant distress in around half of participating parents. Although this may initially indicate elevated levels of psychological distress, it is important to note that it seems common for around half of

parents to meet the criteria for clinically significant distress on the DT (Haverman et al., 2013), suggesting that this finding is not unique to the current population. For example, Diederen et al. (2018) found that this rate of clinically significant distress was not significantly different from that of their comparison parent group. These high-quality studies therefore indicate that parents of children with IBD do not experience elevated levels of psychological distress relative to other parents. This is further supported by several moderate-quality studies (Ahola Kohut et al., 2021; Reed-Knight et al., 2012; Roberts et al., 2019). The generalisability of these findings may be limited, however, as fathers were largely absent from Ahola Kohut et al.'s (2021) and Roberts et al.'s (2019) studies, and only parents of female children were included in Reed-Knight et al. (2012)'s study.

Stress.

Carlsen et al. (2019) found that parents of children with IBD experienced 71% of the parental stressors listed on the PIP, providing initial indications that they may experience heightened stress. However, this low-quality study scored the PIP incorrectly; using a simple count of whether parents have experienced the stressors listed on the measure (yes/no), despite the validated version of the measure involving a more sophisticated rating of the frequency and difficulty of such stressors. The validity of Carlsen et al.'s (2019) findings may therefore be questioned, limiting their application.

There is a general absence of any cut-offs or normative values available for the outcome measures of stress (e.g. PIP, PSS-10) included in this review. For the studies that don't include comparison groups, it is therefore difficult to accurately interpret findings relating to the stress of parents of children with IBD. Nonetheless, the

reviewer's preliminary comparisons of findings from Cohen et al. (2019) and Oseran et al. (2021) with previously published data (Cohen et al., 1983; Streisand et al., 2001; Streisand et al., 2005; Ohleyer et al., 2007; Logan et al., 2002; Mednick et al., 2009) provides some evidence to suggest that stress is experienced within an average range by parents of children with IBD.

Supporting this latter conclusion are findings from Guilfoyle et al.'s (2012) high-quality study that benefitted from multiple comparison groups. They found that parents of children with IBD experience significantly less frequency and difficulty of parental stress than parents of children with other CHCs. Overall, however, despite this high-quality study providing robust evidence to support the indication that parents of children with IBD do not experience elevated levels of stress compared to other groups, their findings are not sufficiently substantiated by other studies to enable clear conclusions.

Mental Health Conditions.

Several of the included studies report that few or no parents of children with IBD meet diagnostic criteria for a mental health condition (Szajnberg et al., 1993; Szajnberg et al., 2011; Werner et al., 2014). These studies, however, have several methodologic weaknesses. Although Werner et al.'s (2014) study benefitted from a large sample size (*n* = 231), the response rate of participants (<70%) raises concerns regarding non-response bias that may limit the credibility of their findings. Furthermore, Szajnberg et al.'s (1993) and Szajnberg et al.'s (2011) low-quality studies are weakened by small sample sizes and several reporting issues.

In contrast to the above, Giannakopoulos et al.'s (2016) high-quality study provides some evidence to suggest that parents of children with IBD may experience

elevated mental health symptoms. For example, they found that parents of children with active IBD reported significantly more mental health symptoms than those whose children were in remission. Moreover, the mental health symptoms of both IBD groups in this study were, on average, higher than a large previously published normative sample (Schmitz et al., 2000). However, this latter comparison is not statistically tested and is based on the reviewer's observations only. Moreover, as with Engström's (1991) study that also assesses mental health symptoms, Giannakopoulos et al. (2016) do not refer to cut-offs or normative values for their outcome measure, thus limiting meaningful interpretations. Robust conclusions regarding mental health conditions among parents of children with IBD cannot therefore be drawn.

Affect.

In regard to affect, Tojek et al. (2002) found that mothers of children with IBD do not report unusually high negative affect or unusually low positive affect on the PANAS. Furthermore, an assessment of the mean POMS scores reported in Oseran et al.'s (2021) study suggest that their small sample did not score particularly high on the negative affect subscales, or particularly low on the positive vigor subscale. However, it is important to note that neither of these measures have readily available cut-offs and these interpretations are therefore based on the possible range of scores for the POMS and percentile tables published elsewhere for the PANAS (Crawford & Henry, 2004). The understanding of this outcome in the current population is therefore limited.

Burnout.

One study measured burnout as an indicator of psychological distress in parents of children with IBD (Lindström et al., 2010). This moderate-quality study did

not find elevated levels of clinical burnout in their small sample. Although this contributes to the overall picture that this population likely experiences average levels of psychological distress, further high-quality studies with larger samples are required to make conclusions regarding this specific outcome.

Psychological Distress of Sub-Samples

Mothers.

The psychological distress of mothers relative to fathers of children with IBD was explored in six studies (Bramuzzo et al., 2020; Engström, 1991; Jelenova et al., 2015; Lindström et al., 2010; Szajnberg et al., 1993; Werner et al. 2014). Overall, these studies suggest that mothers of children with IBD may experience elevated levels of psychological distress compared to fathers. For example, Bramuzzo et al.'s (2020) high-quality study reported that significantly more mothers met the criteria for clinically significant distress than fathers. Furthermore, not only did Werner et al. (2014) find that mothers of children with IBD experienced poorer mental health than fathers of children with IBD, but they also found that fathers of children with IBD reported better mental health than fathers of children without a CHC. It should be noted, however, that this latter finding only demonstrated a small effect size (d = 0.26), and no parents included in this study met diagnostic criteria.

In support of the above findings, Engström (1991) found more mental health symptoms in mothers compared to fathers, whilst Szajnberg et al. (1993) found that more mothers met the criteria for anxiety than fathers. However, both studies were rated as low quality due to issues such as poor reporting, as well as an oversight of their respective limitations. Szajnberg et al.'s (1993) findings were also based on a small sample (n = 27) which may not be representative of the target population. The

impact of these findings regarding the psychological distress of mothers of children with IBD compared to fathers is therefore limited.

Jelenova et al. (2015) reported that mothers of children with IBD experienced significantly more anxiety than mothers of children without a CHC, a difference that wasn't present between the two groups of fathers. However, they also found that fathers of children with IBD experienced significantly more depression than fathers of children without a CHC, a difference that wasn't present between the two groups of mothers. This latter finding may suggest that, whilst some aspects of psychological distress appear to be elevated in mothers, there may be other difficulties, such as depression, that fathers are more likely to experience. This conclusion is drawn with caution, however, as a small sample size (n = 29) limits statistical power and generalisability.

Clinical Presentation of IBD.

Findings suggest that some clinical presentations of paediatric IBD may be associated with elevated levels of parental psychological distress. For example, one high-quality study reported that parents of children with active IBD experienced poorer mental health symptoms than parents of children in IBD remission (Giannakopoulos et al., 2016). Furthermore, Tran et al.'s (2021) recent study found that parents of children with IBD and functional abdominal pain (FAP) reported more anxiety than parents of children with IBD but without FAP. In a small sample, Wilson (2015) similarly found that parents of children who were inpatients experienced more anxiety, depression, and parental stress than an outpatient sample. Taken together, these studies suggest that parents of children with active symptoms who require ongoing or intensive medical care may experience elevated levels of psychological distress.

Nonetheless, the latter finding regarding elevated levels of parental stress in an inpatient compared to an outpatient sample (Wilson, 2015) was not statistically tested and is therefore based solely on the reviewer's observations of available data. Furthermore, Wilson (2015) found that few parents of children with IBD across the inpatient and outpatient samples fell within the abnormal range for anxiety (11%) or depression (11%). Moreover, Tran et al.'s (2021) study found no difference in depression outcomes between parents of children with and without FAP. Thus, although there may be some initial findings that indicate heightened psychological distress in parents of children with more significant IBD presentations, further high-quality studies are required to determine this conclusion.

Comparisons with Other Groups

Parents of Children Without a CHC.

Two studies suggest that parents of children with IBD experience more psychological distress than parents of children without a CHC (Engström, 1991; Jelenova et al., 2015). However, notable methodological weaknesses of these studies, such as issues regarding the clarity and transparency of reporting, undermine this conclusion. The generalisability of these findings are further limited by small sample sizes across groups in Jelenova et al.'s (2015) study (n = 29; n = 40).

Diederen et al. (2018) found comparable distress rates in parents of children with IBD and parents of children without a CHC, further weakening the above findings. This high-quality study benefits from sufficient sample sizes in both the IBD and comparison group. Furthermore, Lindström et al.'s (2010) study found no significant difference in clinical burnout between parents of children with IBD and parents of children without a CHC. However, a small IBD sample (n = 38) weakens this study's

support of Diederen et al.'s (2018) findings. The current picture regarding how the psychological distress of parents of children with IBD compares to that of parents of children without a CHC is therefore unclear.

Parents of Children with Other CHCs.

Guilfoyle et al.'s (2012) high-quality study found that parents of children with IBD reported less frequency and difficulty of parental stress compared to parents of children with cancer, obesity, and sickle cell disease. The frequency and difficulty of parental stress in parents of children with IBD was similar to parents of children with diabetes. Overall, these findings suggest that parents of children with IBD experience similar or less stress than parents of children with other CHCs.

This finding is somewhat supported by Lindström et al. (2010), who found that less parents of children with IBD met the criteria for clinical burnout compared to a diabetes sample. This latter comparison, however, was not statistically tested and is based on the reviewer's observations of available data, hence the extent to which it verifies Guilfoyle et al.'s (2012) findings is limited. Moreover, Burke et al. (1994) reported contrary evidence that the rate of depression in mothers of children with IBD was higher than mothers of children with cystic fibrosis. It is important to note, however, that this latter finding was also not statistically tested and both groups essentially report low rates of depression (10% and 4.5% respectively). This paper was also published nearly 30 years ago and only includes mothers, thus limiting the generalisability of findings to parents of children with IBD today who may have different experiences due to the ongoing advancements in IBD care (IBD UK, 2021). As such, the evidence available predominantly supports the above inference that parents of

children with IBD experience better, or at least comparable, rates of psychological distress than parents of children with other CHCs.

Normative Samples.

Werner et al. (2014) statistically compared the mental health of a large sample of parents of children with IBD to a previously published normative sample (Hardt et al., 2006). They found that mothers of children with IBD reported poorer mental health than the normative sample. Interestingly, however, fathers were found to report better mental health than the normative sample. These findings therefore substantiate earlier inferences made that mothers may be more likely to experience elevated levels of psychological distress than fathers in this context. However, the significant differences found in this study between the respective parents of children with IBD and the normative sample are undermined by small effect sizes ($d < 0.26$). Without further studies, it is therefore difficult to ascertain whether the difference in psychological distress between parents of children with IBD and normative samples is substantial.

Discussion

This is the first review to systematically and critically evaluate literature on psychological distress in parents of children with IBD. The 23 included studies used various measures and contributed largely diverse findings regarding the level and nature of psychological distress in this population. The methodological weaknesses identified limit the applicability of findings to all parents of children with IBD. Although conclusions should therefore be drawn with caution, some meaningful implications for future research and clinical practice can be made.

Overall, there is a paucity of high-quality evidence to suggest that parents of children with IBD experience elevated levels of psychological distress. Rather, the

synthesised findings indicate that this population experience psychological distress within an average range. These conclusions are tentative, however, due to the notable absence of clear cut-offs and normative data for the outcome measures used. This makes it hard to draw clinically and theoretically meaningful inferences. Further compounding this issue is the lack of comparison groups included in this literature. Without being able to consistently compare scores across populations, it is hard to quantify the level of psychological distress experienced by parents of children with IBD.

The included studies do not provide clear and robust evidence regarding psychological distress in parents of children with IBD compared to parents of children without a CHC. However, it is possible to make some inferences from studies that include parents of children with other CHCs as a comparison group. On the whole, parents of children with IBD appear to experience lower, or at least comparable, levels of psychological distress relative to parents of children with other CHCs. This conclusion supports the preliminary findings presented in Cushman et al.'s (2020) review regarding parenting stress and psychosocial difficulties. It is also in line with Cousino and Hazen's (2013) review that found varying levels of parenting stress across different groups of CHCs. However, when considering the potential burden of paediatric IBD (CCUK, 2018; CCUK, 2021; De Boer et al., 2005; NHS, 2020; Nicholas et al., 2007) within the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), it is somewhat surprising that it is not a CHC characterised by increased levels of parental psychological distress relative to other populations. The fact that few studies assessed psychological distress specifically in relation to parenting a child with IBD may have contributed to this finding, as parents may not have focused on this

experience in their self-reports. Alternatively, this finding may be indicative of important protective psychological factors within this population.

This review provides insight into the circumstances in which psychological distress may be a particular problem for parents of children with IBD. For example, psychological distress seems greater in mothers than fathers of children with IBD, particularly in regard to anxiety. One explanation of this finding is that mothers may be more likely to be the primary caregiver involved in the treatment and management of their child's IBD, a process which can be demanding (CCUK, 2018; CCUK, 2021; NHS, 2020). Indeed, in line with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), Cousino and Hazen (2013) found that parents who held greater responsibility for their child's CHC experienced more stress. Perhaps mothers experience and perceive greater levels of stress associated with their child's IBD, and consequently report elevated levels of psychological distress compared to fathers. However, fathers were largely underrepresented in the current review and these findings should therefore be considered with caution. Furthermore, the reported prevalence of psychological distress in the general population is similarly higher in females than males (World Health Organization, 2002), thus suggesting that these findings are not unique to this population.

This review indicates that parents of children with active IBD symptoms that require particularly intensive or ongoing medical care may also be particularly vulnerable to psychological distress. This finding can similarly be explained by the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). For example, the additional parental responsibility that comes with this clinical presentation might contribute to a greater perception of threat relative to one's coping abilities. Thus, this finding supports previous findings that greater parental responsibility may be an

important risk factor to consider in regard to the wellbeing of those caring for children with CHCs (Cousino & Hazen, 2013). This finding also supports the notion of a bidirectional relationship between parent and child biopsychosocial factors in the context of paediatric CHCs (Brooks et al., 2016; Emerson and Bögels, 2017; Plevinsky et al., 2018). Although the cross-sectional nature of included studies limits any conclusions regarding the temporal association between variables, there does seem to be an interaction between child biological and parent psychological outcomes in paediatric IBD (Giannakopoulos et al., 2016; Tran et al., 2021; Wilson, 2015).

Strengths and Limitations of the Review

There are several limitations of this review. Firstly, the decision not to explore child outcomes in relation to parental psychological distress limits the conclusions that can be drawn regarding the bidirectional relationship between parent and child factors in paediatric IBD. Nonetheless, the decision to focus on parental factors only was made to address the limitations of Cushman et al.'s (2020) review regarding the broad number of distinct factors they attempted to synthesise. It could be argued that focusing even more specifically on one outcome of psychological distress, such as parental stress in line with Cousino and Hazen's (2013) review, may have facilitated more consistent and reliable conclusions. This review can also be critiqued for not focusing on outcome measures specific to the experience of parenting a child with a CHC. As most studies used generalised measures of psychological distress, and only cross-sectional data was available, it is hard to infer a causal relationship between IBD and the psychological distress reported by parents.

This review adhered to good-practice guidelines (Page et al., 2021; Appendix B). For example, a comprehensive, pre-registered search of published and grey

literature was conducted, increasing the probability that all relevant studies at the time of searching were identified. Nonetheless, publication bias may be present from the exclusion of studies not published in English. Furthermore, the reliability and accuracy of the selection of studies could have been improved by having a second reviewer independently check this process. Independent checks were included for the data extraction and quality assessment processes, however.

The validity and reliability of the numerical system used to categorise the quality of studies cannot be determined as it was subjectively developed by the primary researcher. Scoring and categorising the quality of studies in this way can also wrongly assume equal weighting across items and reduce the flexibility and depth of the appraisal process (CRD, 2009; Downes et al., 2016). The set parameter used to determine the adequacy of sample sizes can be further critiqued for similar reasons. It may have been more appropriate to appraise sample sizes according to the specific aims and methods of individual studies. Nonetheless, both the categories and parameter were developed in line with a previous review (Sirois & Owens, 2021) that used a similar modified AXIS. Furthermore, by incorporating rich appraisals of individual items relating to study design and reporting within the synthesis, an in-depth overview of the quality of studies is retained.

Finally, without being able to conduct a meta-analysis, the objective conclusions that can be drawn from the current review and the subsequent understanding of psychological distress in parents of children with IBD remain limited.

Directions for Future Research

Further robust studies that address the limitations noted in this review are required to extend the current understanding. For example, studies should seek to

include large and representative samples, paying particular attention to the inclusion of fathers in their samples. This will allow for more generalisable findings going forward. Furthermore, studies should accurately implement reliable outcome measures that offer cut-offs and normative data to allow for more clinically meaningful inferences to be made. The inclusion of relevant comparison groups, such as parents of children with other or no CHCs, would further improve the clinical significance of future findings.

The findings of the current review offer additional directions for future research. As the findings of this review suggest that parents of children with IBD may experience psychological distress to a lesser extent than other CHC populations, it would also be valuable for future research to explore the potential protective and positive psychological factors among this population. Given the inferred significance of a systemic approach to paediatric IBD, future research should also explore ways in which the psychological wellbeing of parents of children with IBD can be supported in clinical practice when indicated.

Once more high-quality and expansive evidence is available, it would be pertinent for a meta-analysis of the literature to be conducted in order to make more conclusive assumptions regarding the psychological wellbeing of parents of children with IBD.

Implications for Clinical Practice

When considering clinical implications, it is important to highlight the lack of clear and robust evidence to suggest that parents of children with IBD experience elevated levels of psychological distress and therefore have an increased need for psychological support. Instead, it is pertinent to encourage a systemic approach to

paediatric IBD healthcare where the psychological needs of parents are individually considered as part of routine practice. Where support is then indicated, services and professionals should help parents strengthen and utilise their existing coping resources, in line with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984). This approach is particularly pertinent given the findings that suggest the presence of protective and positive psychological factors among this population.

Particular attention should be paid to parents who seem to hold significant levels of responsibility for supporting their child. However, the absence of any obvious need for increased responsibility would not discount the need to support the wider system. Indeed, some parents may experience heightened psychological distress due to their appraisal of the situation relative to their perceived coping abilities (Lazarus & Folkman, 1984), rather than the situation as observed objectively. Another group who may hold a greater sense of responsibility for their child and therefore require particular consideration and support are mothers. However, this latter inference may be due to the under representation of fathers in research. Hence caution should be taken not to enact this in clinical practice by overlooking fathers and other significant people within a child's support system.

Conclusions

Overall, the reviewed literature does not present a consistent picture regarding psychological distress in parents of children with IBD. Rather, there is evidence for both elevated and average levels of psychological distress within this population. This varied picture may reflect significant methodological weaknesses across the literature, which denotes the need for further high-quality studies to address such limitations going forward. Of note, evidence does suggest that particular groups within this

population, such as parents who bear substantial responsibility for supporting their child, may be at an increased risk of experiencing heightened psychological distress. It is also important to consider that the varied picture may also reflect a subjective and heterogenous experience, indicating that one assumption will not be generalisable to all. Future research and clinical practice should adopt a comprehensive, systemic approach to paediatric IBD that seeks to understand and support the psychological wellbeing of the system around each individual child.

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Appendix A

The Bespoke Version of the Appraisal Tool for Cross-Sectional Studies (AXIS; Downes et al., 2016)

For each of the included studies, the following 12 items are scores 'yes' (1), no (0), or don't know / can't determine (X). The 12 scores together are added together to calculate a total score ranging from 0-12. Scores between 0-6 indicate low quality, 7-9 moderate quality, and 10-12 high quality (Sirois & Owens, 2021).

1. Were the aims / objectives / hypotheses of the study clearly defined?

2. Was the sample size > 64?

3. Was the target population clearly defined? (i.e. is it clear who the research was about?)

4. Was the selection process likely to select participants that were representative of the target/reference population under investigation (i.e. did everyone in the e.g. clinic/hospital have an equal chance of participating?)

5. Is the response rate high enough (> 70%) to minimise concerns about non-response bias?

6. Is any information (e.g. baseline, demographic) on the non-responders available, and if so, are they comparable to those that did respond?

7. Were the outcome variables of interest measured and scored correctly using validated and reliable means?

8. Were the methods (including statistical methods) sufficiently described to enable them to be repeated?

9. Were the results internally consistent?

10. Were the results presented for all the analyses described in the methods?

11. Were the authors' discussions and conclusions justified by the results?

12. Were the limitations of the study discussed?

Appendix B

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Page et al., 2021) Checklist

Section and Topic	Item #	Checklist item	Page # where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2-3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	6-8
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	8
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	10, 28
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	8-9
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	8-9, 59
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	9-10
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	12

Section and Topic	Item #	Checklist item	Page # where item is reported
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	10, 14-15
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	12
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	12-13
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	16-23
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	12
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	12
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	12
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	12-13
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	12-13

Section and Topic	Item #	Checklist item	Page # where item is reported
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	9, 11
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	11
Study characteristics	17	Cite each included study and present its characteristics.	13-23
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	24-27
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	16-23
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	13-27
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	24-27
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	24-27
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	39-40
	23b	Discuss any limitations of the evidence included in the review.	38

Section and Topic	Item #	Checklist item	Page # where item is reported
	23c	Discuss any limitations of the review processes used.	41
	23d	Discuss implications of the results for practice, policy, and future research.	42-44
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	8
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	8
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	12
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	N/A
Competing interests	26	Declare any competing interests of review authors.	N/A
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	N/A

Section Two: Empirical Study

A Self-Compassion Intervention for Parents of Children with Inflammatory Bowel Disease (IBD)

Abstract

Objectives

This study aimed to examine whether a brief online self-compassion intervention (SCI) increased state self-compassion and reduced state shame and distress in parents of children with IBD. Secondary aims were to investigate whether daily engagement in the SCI for two weeks would increase trait self-compassion and reduce parental stress.

Methods

159 parents of children with IBD were randomised to a SCI or control condition in a single-blind randomised controlled trial. Primary measures of state self-compassion, shame, and distress were completed at baseline and immediately post-condition. Secondary measures of trait self-compassion and parental stress were completed at baseline and after two weeks of daily engagement in the SCI.

Results

Statistical analyses revealed increased state self-compassion and reduced state distress in the SCI group immediately post-condition when compared to the control group. No effect of the SCI was found on state shame and no effect of repeated engagement in the SCI was found on trait self-compassion or parental stress.

Conclusions

Brief online SCIs have the potential to enhance self-compassion and lessen distress, but not shame, in the immediate moment for this population. The sustained effects of SCIs in this population remain uncertain due to methodological limitations and high attrition.

Practitioner Points

- Brief SCIs may offer an accessible way to informally support parents in paediatric IBD settings.
- Parents should be supported on an individual basis as these findings may not be broadly generalisable.
- Further longitudinal studies with large representative samples are needed.

Key Words: Inflammatory Bowel Disease; Paediatric; Parent; Self-Compassion

Introduction

Inflammatory Bowel Disease

Inflammatory Bowel Disease (IBD) is a term used for conditions, such as Crohn's disease (CD) and ulcerative colitis (UC), that are characterised by parts of the gut becoming swollen, inflamed, and ulcerated (Crohn's and Colitis UK [CCUK], 2021b). Symptoms can include abdominal pain, diarrhoea, weight loss, and tiredness (National Institute for Health and Care Excellence [NICE], 2015). Although IBD is a lifelong condition, there are several treatments available which aim to achieve and maintain remission of symptoms (CCUK, 2021b; NICE, 2015). These may include pharmaceutical treatments, surgery, and diet and lifestyle changes (CCUK, 2021b; National Health Service [NHS], 2020). IBD is likely to have a significant impact on the day-to-day lives of those living with and close to the condition, as the symptoms and healthcare needs interact with factors such as social relationships, finances, work, and leisure (CCUK, 2018; CCUK, 2019a; Popov et al., 2021). Accordingly, research has reported an impaired quality of life and emotional wellbeing in this population (Drossman et al., 1989; Larsson et al., 2008; Neuendorf et al., 2016).

The prevalence of IBD in children is thought to be rising, with around 25% of diagnoses occurring before the age of 16 (CCUK, 2019b; Posford, 2019). Symptoms, treatments, and regular appointments associated with paediatric IBD may impact school attendance and progress, as well as peer relationships (Crohn's In Childhood Research Association [CICRA], n.d.; Nicholas et al., 2007). Studies have also reported psychological distress in children with IBD (Halloran et al., 2021; Mackner & Crandall, 2006). Unsurprisingly, children with IBD are likely to depend on others for support, particularly their parents (MacPhee at al., 1998; Popov et al., 2021). Thus, it is

fundamental to extend our understanding of psychological wellbeing in IBD to those in the system surrounding children living with the condition.

Parents of Children with IBD

Despite the potential burden of paediatric IBD, a recent unpublished systematic review (Wray, 2022) found little robust evidence to suggest that parents experience psychological distress in this context. Nonetheless, findings indicated that parents who hold substantial levels of responsibility for supporting their child with IBD, such as mothers or those whose children require particularly intensive or ongoing medical care, may be vulnerable to experiencing psychological distress. This is in line with Cousino and Hazen's (2013) earlier systematic review and meta-analysis that found varying levels of parenting stress across different groups of chronic health conditions (CHCs), but noted elevated levels of stress in parents who held significant responsibility for their child's CHC. Taken together, the findings of these reviews support the application of the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) in this context. That is, parents of children with IBD may experience stress when the perceived challenges and demands they face outweigh their perceived coping capabilities. It is therefore important that we develop an understanding of how parents of children with IBD can be supported, so that services can provide appropriate systemic support when indicated.

In discussing parental reactions to the diagnosis of CHCs in children, Emerson & Bögels (2017) refer specifically to guilt and shame as common feelings that may arise. Although both self-conscious emotions, shame is distinct from guilt in that it encompasses a global negative evaluation of the self, rather than focusing on a specific behaviour (Tangney & Dearing, 2002). Research suggests that feelings of

shame may be particularly pertinent when considering IBD (Murphy et al., 2022; Trindade et al., 2017), as it is a frequently stigmatised condition due to the perceived social unacceptability of symptoms such as bowel urgency and incontinence (Daniel, 2002; Saunders, 2014).

Given the closeness of parent-child relationships, a parent's sense of self is likely to encompass their child and their role as a parent (Aron et al., 1991). Parents of children with IBD may therefore experience shame in relation to the potential challenges associated with their child's condition, and a negative evaluation of themselves in relation to their abilities to overcome these difficulties. Werner et al. (2015) support this assumption in their findings of increased social phobia and feelings of inferiority in mothers of children with IBD compared to controls, which they hypothesised to be a consequence of the challenges their children face in social situations due to their condition.

Feelings of shame are likely to be negatively related to other aspects of wellbeing in this context. For example, Sunavsky et al. (2022) found that shame significantly mediated the relationship between IBD and stress in adolescents. This is supported more broadly, with a large meta-analytic review reporting significant associations between shame and depression (Kim et al., 2011). This review found particularly large effect sizes when examining external shame, which involves negative evaluations of the self as perceived from others. This is pertinent when considering parenting, as the fear of negative evaluations from others has been shown to compound the relationship between the feeling that one is not meeting idealised parenting standards and shame in mothers (Liss et al., 2013). Furthermore, Henderson et al. (2016) report that the pressure to meet idealised parental expectations contributes to higher levels of stress and anxiety in mothers. The above

evidence highlights the importance of exploring and supporting the psychological wellbeing of parents of children with IBD within research and clinical practice, with shame being a potentially valuable target of ensuing interventions.

The Relationship Between Parent and Child Outcomes

Furthering the rationale attending to parents in this context is the increasing understanding of paediatric CHCs within a systemic framework (Emerson & Bögels, 2017; Wood et al., 2015). In line with broader family systems theories (Bowen, 1966; Bronfenbrenner, 1977; Rolland, 1999), Emerson and Bögels, (2017) emphasise the continuous bidirectional relationship between parent and child biopsychosocial outcomes in paediatric health. The application of such models to paediatric IBD is supported by empirical research (Reed-Knight et al., 2018). Of note, a systematic review identified parental stress as a significant risk factor for psychological morbidity among children with IBD, which in turn had an impact on a range of child outcomes such as symptoms and treatment adherence (Brooks et al., 2016). Baudino et al. (2021) also found a transactional relationship between the stigma parents experienced in relation to their child's IBD and child outcomes such as illness intrusiveness and depression. Furthermore, Plevinsky et al.'s (2018) study suggests that the stress experienced by parents of children with IBD can be explained by child physical and psychological outcomes. Thus, evidence seems to support the notion of a reciprocal interaction between parent and child biopsychosocial outcomes in paediatric IBD.

Despite the increasing recognition of the role parents hold in supporting children with IBD and the subsequent importance of caring for the family as a whole (CCUK, 2021a; NICE, 2015), paediatric healthcare has been broadly criticised for failing to target parental factors (Emerson & Bögels, 2017).

Self-Compassion

When considering how to support the wellbeing of parents of children with IBD, self-compassion may be of particular significance. Self-compassion has been defined by Neff (2003a) in relation to three components: self-kindness, rather than self-judgement; common humanity, rather than isolation; and mindfulness, rather than overidentification. There is increasing evidence to suggest that self-compassion can be positively cultivated through compassion-focused interventions (Ferrari et al., 2019; Gilbert & Procter, 2006; Kirby et al., 2017). Whether considered as a trait or a state, the benefits of self-compassion for psychological wellbeing are well-established within the literature (Ferrari et al., 2019; Gilbert & Procter, 2006; Kirby et al., 2017; Leary et al., 2007; Neff, 2011; Zessin et al., 2015).

Specific to individuals living with IBD, Trindade and Sirois (2021) recently found significant associations between self-compassion and mental health outcomes over time, supporting the applicability of compassion-based interventions in the context of this condition. Furthermore, the association between self-compassion and mental health outcomes has been found to be mediated by shame (Johnson & O'Brien, 2013). There is also some evidence to suggest that self-compassion has the potential to moderate negative feelings about the self in response to events that typically involve failure, rejection, embarrassment (Neff et al., 2005; Leary et al., 2007), thus further supporting its relevance in the context of paediatric IBD where such feelings related to shame may be present (Baudino et al., 2021; Daniel, 2002; Murphy et al., 2022; Saunders, 2014; Sunavsky et al., 2022; Trindade et al., 2017).

Additional research supports the application and value of self-compassion in the context of CHCs (Sirois & Rowse, 2016) and varying challenging parenting

situations (Garcia et al., 2021; Lilley, 2019; Neff & Faso, 2015; Robinson et al., 2018; Shenaar-Golan et al., 2021; Sirois et al., 2019). A recent meta-analysis highlighted the value of parenting interventions that include a self-compassion component in increasing self-compassion and decreasing depression, anxiety, and stress among parents (Jefferson et al., 2020). Furthermore, brief self-compassion interventions (SCIs) have been found to increase state self-compassion and reduce state shame in parent samples (Lilley, 2019; Sirois et al., 2019). Research has also found that parents who score higher on trait self-compassion are likely to report less parenting stress (Gouveia et al., 2016; Neff & Faso, 2015).

Further supporting the relevance of self-compassion in this context is preliminary evidence which suggests that, despite the potential burden associated with IBD, some parents of children with the condition do not experience elevated levels of psychological distress (Cushman et al., 2020; Wray, 2022). In line with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), it is therefore hypothesised that parents of children with IBD may hold important protective factors that help them to cope with IBD-related stressors. Self-compassion, although rooted in Buddhist origins, has been linked to the evolving Western positive psychology movement (Neff & Davidson, 2016; Seligman & Csikszentmihalyi, 2000). For example, research has found significant associations between self-compassion and positive aspects of psychological wellbeing (Neff et al., 2007). As such, it may be pertinent to explore and strengthen self-compassion as a positive psychological factor which may further protect the wellbeing of parents of children with IBD.

The Current Study

Although there is limited evidence to suggest that parents of children with IBD universally experience elevated levels of psychological distress and therefore require routine psychological support, research indicates that certain groups of parents may be vulnerable to such experiences and that this can potentially impact child outcomes. Despite evidence supporting the associated application of self-compassion in this context, no study to our knowledge has yet explored this directly. One unpublished doctoral thesis reported benefits of a brief self-compassion intervention (SCI) in increasing state self-compassion and reducing state shame in parents of children with broad CHCs (Lilley, 2019). Thus, the primary aim of this study was to build on these existing findings by exploring the effectiveness of a similar SCI in increasing state self-compassion and reducing state shame and distress in parents of children with IBD. Previous studies have made recommendations for future research to explore the longer-term effects of SCIs in this context (Lilley, 2019; Sirois et al., 2019). As such, the secondary aim of this study was to explore whether repeated engagement in the SCI for two weeks would increase trait self-compassion and reduce parental stress in this population.

Hypotheses

Primary Hypotheses. In comparison to a control group, participants receiving the SCI will:

1. Report increased state self-compassion immediately following the SCI.
2. Report reduced state shame immediately following the SCI.
3. Report reduced state distress immediately following the SCI.

Secondary Hypotheses. In comparison to a control group, participants receiving the SCI will:

4. Report increased trait self-compassion after repeated engagement in the SCI for two weeks.
5. Report reduced parental stress after repeated engagement in the SCI for two weeks.

Method

Design

The current study was a randomised, single-blind online intervention trial. The independent variable (IV) was the condition, with participants randomly allocated to the SCI or control group. The primary dependent variables (DVs) included immediate post-condition (T2) measures of state self-compassion, shame, and distress, and secondary DVs were follow-up (T3) measures of trait self-compassion and parental stress.

Ethics

Ethical approval was granted by the University of Sheffield Ethics Board (Appendix A). The British Psychological Society's (BPS) guidance on ethics and online research (BPS, 2017) was adhered to throughout. Participants were given the chance to win a £50 gift voucher for taking part, which was thought to be a proportionate and non-coercive reward.

Participants

Parents or carers with parental responsibility for children under 18 years old with a self-reported diagnosis of IBD were eligible to participate. As participation required completion of an online English-written survey, those who are unable to read and write in English or had no access to the internet were excluded.

Recruitment

Participants were recruited using opportunistic sampling methods between April and December 2021. The study was advertised (Appendix B) via relevant charities (CCUK, CICRA, Catherine McEwan Foundation), social media platforms (e.g. Facebook, Twitter, Instagram), and an email list of University staff and student volunteers. The advert contained a link to the Qualtrics® survey for participation.

An a priori power analysis was conducted using G*Power 3 (Faul et al., 2007). 128 participants in total (64 per group) were deemed necessary in order to detect a medium effect size, with 80% power and a critical p-value of .05. A medium effect size was predicted according to the findings of a similar study (Lilley, 2019). The power and critical significance levels were set at .8 and .05 respectively as recommended in psychological research (Field, 2009). To account for potential attrition, the target participant number was inflated by 20% to 154 (77 per group).

Procedure

All data was collected on Qualtrics® between April and December 2021. Participants were asked to read the information sheet (Appendix C), confirm their informed consent (Appendix D), and answer a screening question to determine eligibility (Appendix E) before being able to proceed with the study. Participants were then asked to complete a brief demographic questionnaire and baseline (T1) measures of state self-compassion, state shame, state distress, trait self-compassion and parental stress (presented in a randomised order). Next, participants were prompted to recall a recent parenting event they felt ashamed of and briefly write about this in a text box provided (Appendix F). A one-item question was then administered as a manipulation check to assess whether feelings of shame were elicited by the

recall task (Appendix G). The randomiser tool on Qualtrics® then allocated participants to the SCI or control condition. The control group were asked to think about the parenting event they had just recalled and make brief factual notes about the event (e.g. time of day, who was present; Appendix H). The SCI instructions are detailed in the 'SCI' section below. All participants were then asked to complete post-condition (T2) measures of state self-compassion, shame, and distress (presented in a randomised order). To end this initial survey, participants were prompted to complete a mood neutralisation task (Appendix I) to neutralise any potential distress. This procedure is a version of that detailed in Sirois et al. (2019), adapted for the current study.

Following completion of the above survey, Qualtrics® sent all participants a pre-programmed email with instructions for the two-week follow-up (Appendix J). The control group were not asked to do anything else until the follow-up (T3) survey. The rationale for not actively engaging the control group during this time was to improve our confidence in assuming that any changes observed in follow-up (T3) measures between the two groups could be attributed to the SCI. Participants in the SCI group received pre-programmed daily reminder emails with a link to complete the daily SCI task described in the 'SCI' section below.

After two weeks, pre-programmed emails were sent to all participants with a link to another Qualtrics® survey which asked them to complete follow-up (T3) measures of trait self-compassion and parental stress (presented in a randomised order). An adherence question was also administered to assess how often the SCI group engaged in the task over the two-weeks (Appendix K). Finally, all participants were emailed a debrief information sheet and information on how to access or continue engaging in the SCI materials (Appendix L).

SCI

During the initial administration, participants in the SCI group were instructed to reflect on their recalled parenting event and to think about it in a self-compassionate manner, before expressing this perspective to themselves in writing (Appendix H). The prompt is designed to induce the three elements of self-compassion: self-kindness; common humanity; and mindfulness (Neff, 2003a). Versions of this SCI have been found to effectively induce state self-compassion in previous research (Johnson & O'Brien, 2013; Lilley, 2019; Leary et al., 2007; Sirois et al., 2019). The same instructions, in the context of parenting and looking after a child with IBD generally rather than a specific event, were provided daily during the two-week follow-up (Appendix J).

Measures

Demographic Information

Participants completed a baseline demographic survey (Appendix M) to gather parent (age, gender, household size, IBD diagnosis, primary caregiver status, number of children with IBD) and child (age, age at diagnosis, gender, IBD type, medication, surgery, disease activity, stoma status) information.

State Self-Compassion

Five items developed and used by a similar study (Sirois et al., 2019) based on previous research (Breines & Chen, 2012) were used to assess state self-compassion at T1 and T2 (Appendix N). Participants used a seven-point Likert scale to rate how they felt ‘right now’ on five items corresponding to the three components of self-compassion (Neff, 2003a). A total score is generated by reversing one item and averaging all item responses, with higher scores indicating greater state self-

compassion. This measure has been used to assess state self-compassion in previous similar studies, demonstrating good internal reliability (α ≥ .74) and sensitivity to change following similar interventions (Lilley, 2019; Sirois et al., 2019). In the current study, internal consistency was acceptable-good (T1 α = 77; T2 α = 85).

State Shame and Distress

Fourteen items from the Positive and Negative Affect Schedule-Expanded Form (PANAS-X; Watson & Clark, 1994) that make up the six-item guilt subscale and 10-item negative affect subscale were used to assess state shame and distress respectively at T1 and T2 (Appendix O). The negative affect subscale has been described as a general dimension of emotional distress (Watson et al., 1988) and the guilt subscale has been used as a measure of state shame in similar studies (Lilley, 2019; Sirois et al., 2019). Participants used a five-point Likert scale to rate what extent they were experiencing each item 'right now'. A total score for each subscale is calculated by summing the relevant item responses, with higher scores indicating greater state shame and distress respectively. Both subscales demonstrate good internal reliability (guilt: α ≥ .85; negative affect: α ≥ .84) across samples (Watson & Clark, 1994). In the current study, internal consistency was excellent for state distress (T1 α = .91; T2 α = .90) and good-excellent for state shame (T1 α = .86; T2 α = .94).

Trait Self-Compassion

The 26-item Self-Compassion Scale (SCS; Neff, 2003b; Appendix P) was used to assess trait self-compassion at T1 and T3. Participants used a five-point Likert scale to rate how often they respond in different ways to assess each of the three components of self-compassion (Neff, 2003a). Negative items are reversed before averaging relevant item responses to calculate six subscale scores that reflect the

three components of self-compassion. A total score is then generated by averaging the six subscale scores. Higher scores indicate greater trait self-compassion. The SCS has demonstrated good internal reliability (α = .92, Neff, 2003b). In the current study, internal consistency was excellent (T1 α = .93; T2 α = .96).

Parental Stress

The Pediatric Inventory for Parents (PIP; Streisand et al., 2001; Appendix Q) was used to assess parental stress at T1 and T3. Participants used a five-point Likert scale to rate both the frequency and difficulty of 42 items related to caring for children with CHCs. Relevant item responses are summed to generate separate scores of frequency and difficulty across four domains of parental stress: communication; medical care; role functioning; and emotional distress, as well as total parental stress frequency (PIP-F) and parental stress difficulty (PIP-D) scores. In all cases, higher scores indicate greater illness-related parental stress. The PIP has previously demonstrated good internal reliability (α ≥ .90) in similar samples, including parents of children with IBD (Gray, et al., 2013; Gray et al., 2015; Guilfoyle et al., 2012; Plevinsky et al., 2018). In the current study, internal consistency was excellent for PIP-F (T1 α = .96; T2 α = .97) and PIP-D (T1 α = .96; T2 α = .97).

Data Analysis

All data was analysed using IBM SPSS Statistics for Windows, Version 26.

Data Preparation

Checks for impossible values, missing data, and outliers within the data set were carried out. As no impossible values were found, it was assumed that any outliers reflected a true range of scores and they were therefore not removed by default (Field, 2009).

To allow for accurate calculation of subscale and overall scores on individual outcome measures, responses were removed where <80% of the measure was completed. Where ≥80% of the outcome measure was completed, missing data was estimated using linear interpolation, which has been found to provide a good fit to data when there is a small number of missing survey data (Noor et al., 2014). For intention-to-treat (ITT) analyses only, missing data that remained was estimated using the last observation carried forward (LOCF) imputation method, with T1 scores carried over where possible. LOCF is commonly used as a conservative estimate of missing data (Hamer & Simpson, 2009; Woolley et al., 2009).

Tests of assumptions for analysis of covariance (ANCOVA) were conducted. Skewness and Kurtosis statistics were examined alongside Kolmogorov-Smirnov and Shapiro-Wilk tests to assess the distribution of data (Appendix R). As these statistical tests are likely to be significant in large samples even when data is normally distributed (Field, 2009), histograms and Q-Q plots were also visually inspected (Appendix S). PANAS-X data for outcomes of state shame and state distress were positively skewed and were consequently transformed using square root transformation, as recommended for positively skewed data (Field, 2009). This resulted in normal distributions (Appendix T). All subsequent analyses therefore employed parametric tests, using transformed data for state shame and state distress.

The Levene's test was used to test for the assumption of homogeneity of variance, which was met by non-significant results across all variables (Appendix U). Where correlations between covariates were >.7, one of the correlated covariates was removed from the corresponding ANCOVA to meet the assumption of multicollinearity (Appendix V). Scatterplots of DV residuals against covariate values were examined to confirm the additional assumption that the relationships between the covariates and

DVs were linear (Appendix W). Scatterplots, alongside tests to assess the interaction between the condition and covariates for each DV, were examined to test for the assumption of homogeneity of regression (Appendix X). One outlier was removed from the trait self-compassion data to meet this assumption.

Preliminary Analyses

Descriptive Analysis. Descriptive demographic and outcome data was generated for overall and sub-samples. Chi-squared and independent samples t-tests were used to compare descriptive data for the two groups (SCI and control), as well as for completers and non-completers at T3. Completers were defined as participants who had provided ≥80% of at least one post-condition outcome measure for the relevant time point (T2 or T3). Completer status also required participants in the SCI group to have adhered to the intervention without major protocol deviations. At T2, this required participants to have written a response to the one-off SCI prompt. At T3, participants were required to have engaged in the SCI for at least 'some of the days (5-9 days)' or more during the follow-up period.

Manipulation Check. A paired-sample t-test was conducted to check whether participants' scores of state shame on the one-item question completed after the recall task reflected increased shame relative to scores on this item at T1.

Regression Analysis. A regression analysis was conducted to identify any significant predictors of change (e.g. demographic variables, T1 scores) in each of the DVs at T2 and T3 to be included as additional covariates in the ANCOVAs.

Main Analyses

Primary and secondary hypotheses were tested using several one-way independent ANCOVAs, with the condition (SCI or control) as the between-groups IV,

the relevant T2 or T3 outcome as the DV, and any demographic variables or T1 scores that significantly predicted the outcome as covariates. In line with previous research exploring the effect of SCIs (Johnson & O'Brien, 2013; Sirois et al., 2019), baseline trait self-compassion scores were also included as a covariate in all analyses. Both intention-to-treat analysis (ITT) and completers analyses were conducted for primary and secondary ANCOVAs. ITT analyses included all participants randomised to a condition, with missing data for non-completers generated using the LOCF method where possible. Completers analyses only included data from completers at the respective time point, as defined above.

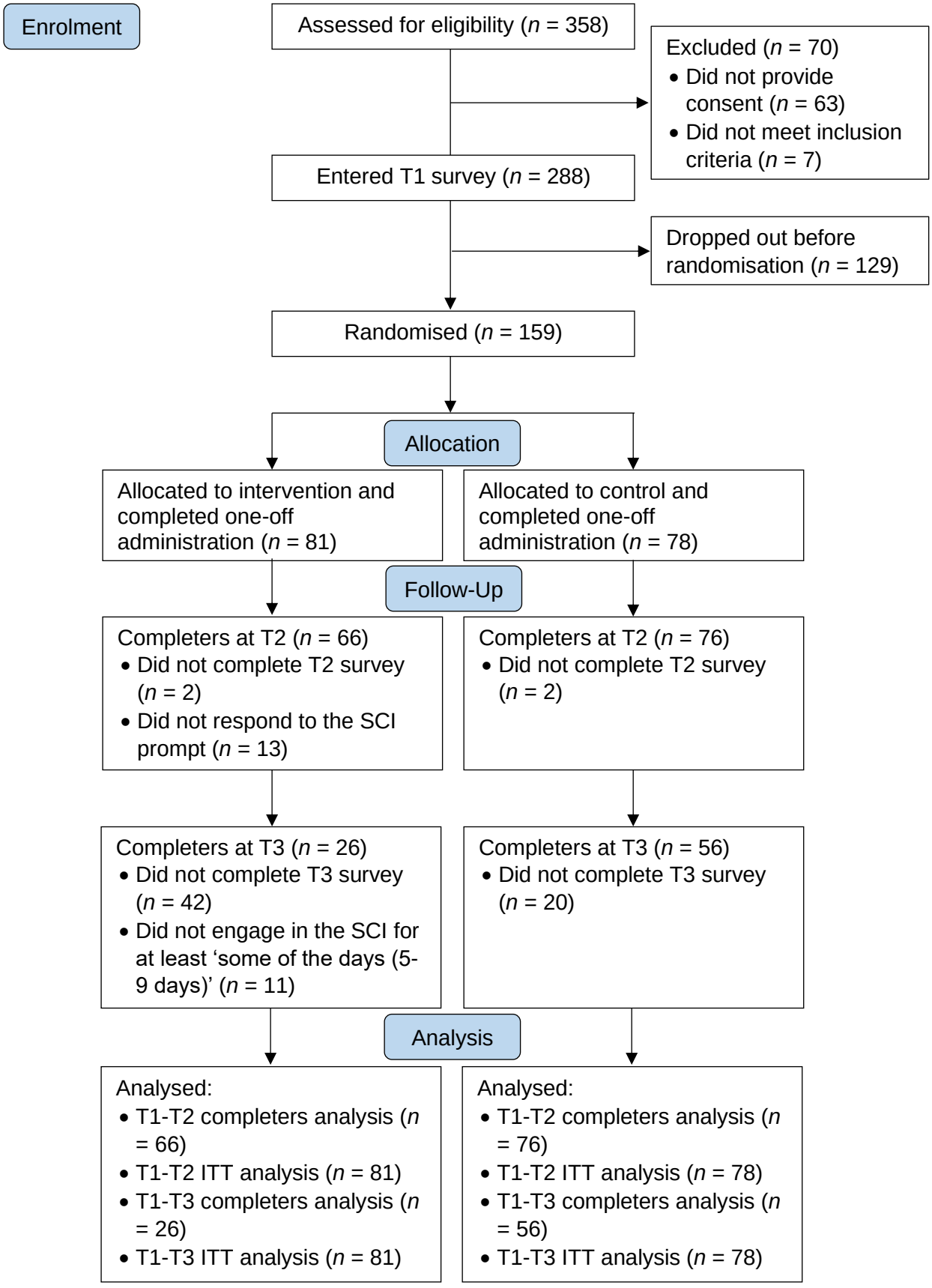
Results

Participant Flow

A Consort Diagram (Schulz et al., 2010) illustrating the flow of participants through the study is presented in Figure 1. 159 participants were randomised to either the SCI (*n* = 81) or control (*n* = 78) group. In the SCI group, 66 participants (81.5%) completed T2 and 26 (32.1%) completed T3. Of the 81 participants who were randomised to the SCI group, 68 (84%) adhered to the SCI without major protocol deviations for the one-off administration, whilst 26 (32.1%) met adherence criteria for the follow-up. In the control group, 76 participants (97.4%) completed T2 and 56 (71.8%) completed T3.

Figure 1

Consort Diagram



Preliminary Analyses

Descriptive Analysis

Table 1 and 2 show descriptive demographic data, categorised by condition and completion status at T3. Descriptive data for T1 outcome measures are summarised in Table 3 and 4, also categorised by condition and completion status at T3. Although parents in the SCI group (M = 44.20, SD = 6.02) were significantly younger than parents in the control group (M = 42.28, SD = 6.35), $t(157) = 2.03$, p = .04, no further significant differences were found between the two groups, indicating effective randomisation. Trait self-compassion scores at T1 were significantly higher in T3 completers (M = 2.91, SD = 0.61) compared to T3 non-completers (M = 2.69, SD = 0.69), $t(156) = 2.12$, p = .04. No further significant differences were found between completers and non-completers.

No cut-offs are available for the outcome measures used in this study. However, descriptive outcome data (Table 3) can be contextualised using existing research that has implemented the same measures in similar or normative samples. T1 state self-compassion scores were slightly lower (indicating lower state self-compassion) than scores from a general sample of parents (Sirois et al., 2019; M = 4.50, SD = 1.09), but slightly higher (indicating greater state self-compassion) than a sample parents of children with CHCs (Lilley, 2019; M = 3.52, SD = 1.07). Both T1 state distress and shame scores were higher (indicating greater state distress and shame respectively) than scores from an undergraduate sample (Watson & Clark, 1994; distress, M = 15.80, SD = 5.90; shame, M = 8.70, SD = 4.00). T1 trait self-compassion scores were comparable to scores from a sample of parents of children with CHCs (Lilley, 2019; M = 2.74, SD = 0.74), but lower (indicating lower trait self-

compassion) than scores from a community sample (Neff, 2003b; *M* = 3.95, *SD* = 0.65). T1 parental stress frequency and difficulty scores were higher (indicating greater parental stress) than scores from another sample of parents of children with IBD (Cohen et al., 2019; Frequency, *M* = 88.41; Difficulty, *M* = 84.07). Participants' T2 and T3 scores compared similarly to this existing data across all outcome measures. On average, it seems that the current sample experienced each of the outcomes similarly or worse than other samples at baseline and follow-up time-points, suggesting some clinical 'caseness' at baseline that remained at follow-up. However, it is important to note that these comparisons are not statistically tested and are based on the researcher's observations of available data alone for the purpose of contextualising data.

Table 1

Descriptive Demographic Data Overall and by Condition, with SCI vs. Control Group Analysis

Demographic Variable	Overall (*n* = 159)	SCI (*n* = 81)	Control (*n* = 78)	SCI vs. Control Group Analysis
Parent's gender, *n* (%)				
Female	150 (94.3)	77 (95.1)	73 (93.6)	$\chi^2 = 1.05$,
Male	8 (5)	4 (4.9)	4 (5.1)	$p = .59$
Didn't answer	1 (0.6)	0	1 (1.3)	
Parent has IBD, *n* (%)				
Yes	10 (6.3)	4 (4.9)	6 (7.7)	$\chi^2 = .51$,
No	149 (93.7)	77 (95.1)	72 (92.3)	$p = .48$
Didn't answer	0	0	0	
Child's gender, *n* (%)				
Female	70 (44)	35 (43.2)	35 (44.9)	$\chi^2 = .05$,
Male	89 (56)	46 (56.8)	43 (55.1)	$p = .83$
Didn't answer	0	0	0	
Child's IBD type, *n* (%)				
Crohn's Disease	89 (56)	45 (55.6)	44 (56.4)	$\chi^2 = .18$,
Ulcerative Colitis	52 (32.7)	26 (32.1)	26 (33.3)	$p = .92$
Other	18 (11.3)	10 (12.3)	8 (10.3)	
Didn't answer	0	0	0	
Child on medication, *n* (%)				
Yes	148 (93.1)	77 (95.1)	71 (91)	$\chi^2 = 2.79$,
No	10 (6.3)	3 (3.7)	7 (9)	$p = .25$
Didn't answer	1 (0.6)	1 (1.2)	0	
Child had surgery, *n* (%)				
Yes	29 (18.2)	17 (21)	12 (15.4)	$\chi^2 = 1.21$,
No	127 (79.9)	62 (76.5)	65 (83.3)	$p = .55$
Didn't answer	3 (1.9)	2 (2.5)	1 (1.3)	
Child's symptom status, *n* (%)				
Active	89 (56)	48 (59.3)	41 (52.6)	$\chi^2 = .72$,
Remission	70 (44)	33 (40.7)	37 (47.4)	$p = .40$
Didn't answer	0	0	0	
Child has stoma, *n* (%)				
Yes	8 (5)	4 (4.9)	4 (5.1)	$\chi^2 = .00$,
No	151 (95)	77 (95.1)	74 (94.9)	$p = .96$
Didn't answer	0	0	0	
Parent's age (years), *M (SD)*	43.23 (6.21)	44.20 (6.02)	42.28 (6.35)	$p = .04$*
Child's age (years), *M (SD)*	12.17 (3.99)	12.63 (3.91)	11.69 (4.02)	$p = .14$
Child's age at diagnosis (years), *M (SD)*	9.51 (4.46)	10.07 (4.17)	8.93 (4.69)	$p = .11$
Number of people in household, *M (SD)*	4.04 (1.14)	4.06 (1.19)	4.03 (1.11)	$p = .84$
Number of children, *M (SD)*	1.04 (0.19)	1.01 (0.12)	1.06 (0.23)	$p = .17$

Note. SCI = self-compassion intervention; IBD = inflammatory bowel disease.

*Significant at $p < .05$.

Table 2

Descriptive Demographic Data by Completion Status at T3, with Completers vs. Non-Completers Analysis

Demographic Variable	T3 Completers (*n* = 82)	T3 Non-Completers (*n* = 77)	Completer vs. Non-Completer Analysis
Parent's gender, *n* (%)			
Female	80 (97.6)	70 (90.9)	$\chi^2 = 3.51$, $p = .17$
Male	2 (2.4)	6 (7.8)	
Didn't answer	0	1 (1.3)	
Parent has IBD, *n* (%)			
Yes	5 (6.1)	5 (6.5)	$\chi^2 = .01$, $p = .92$
No	77 (93.9)	72 (93.5)	
Didn't answer	0	0	
Child's gender, *n* (%)			
Female	37 (45.1)	33 (42.9)	$\chi^2 = .08$, $p = .77$
Male	45 (54.9)	44 (57.1)	
Didn't answer	0	0	
Child's IBD type, *n* (%)			
Crohn's Disease	46 (56.1)	43 (55.8)	$\chi^2 = .91$, $p = .63$
Ulcerative Colitis	25 (30.5)	27 (35.1)	
Other	11 (13.4)	7 (9.1)	
Didn't answer	0	0	
Child on medication, *n* (%)			
Yes	75 (91.5)	73 (94.8)	$\chi^2 = 2.47$, $p = .29$
No	7 (8.5)	3 (3.9)	
Didn't answer	0	1 (1.3)	
Child had surgery, *n* (%)			
Yes	12 (14.6)	17 (22.1)	$\chi^2 = 4.10$, $p = .13$
No	67 (81.7)	60 (77.9)	
Didn't answer	3 (3.7)	0	
Child's symptom status, *n* (%)			
Active	42 (51.2)	47 (61)	
Remission	40 (48.8)	30 (39)	$\chi^2 = .1.55$, $p = .21$
Didn't answer	0	0	
Child has stoma, *n* (%)			
Yes	4 (4.9)	4 (5.2)	$\chi^2 = .01$, $p = .93$
No	78 (95.1)	73 (94.8)	
Didn't answer	0	0	
Parent's age (years), *M (SD)*	42.93 (6.40)	43.55 (6.02)	$p = .53$
Child's age (years), *M (SD)*	12.03 (3.85)	12.31 (4.13)	$p = .96$
Child's age at diagnosis (years), *M (SD)*	9.42 (4.32)	9.61 (4.63)	$p = .62$
Number of people in household, *M (SD)*	4.05 (1.02)	4.04 (1.27)	$p = .65$
Number of children, *M (SD)*	1.03 (0.17)	1.04 (0.21)	$p = .79$

Note. IBD = inflammatory bowel disease.

Table 3

Descriptive Outcome Data at T1 Overall and by Condition, with SCI vs. Control Group Analysis

T1 Outcome Measure	*n*	Overall, *M (SD)*	*n*	SCI, *M (SD)*	*n*	Control, *M (SD)*	SCI vs. Control Group Analysis
State Self-Compassion	159	4.17 (0.96)	81	4.31 (0.95)	78	4.02 (0.95)	$p = .06$
State Distress	159	23.99 (9.21)	81	23.12 (8.60)	78	24.90 (9.77)	$p = .23$
State Shame	159	12.02 (5.27)	81	11.70 (5.12)	78	12.35 (5.44)	$p = .44$
Trait Self-Compassion	158	2.80 (0.66)	80	2.86 (0.66)	78	2.75 (0.65)	$p = .29$
PIP-F	157	121.39 (33.48)	80	117.86 (34.84)	77	125.05 (31.82)	$p = .18$
PIP-D	151	122.88 (36.20)	76	117.46 (36.96)	75	128.37 (34.81)	$p = .06$

Note. SCI = self-compassion intervention; PIP-F = parental stress frequency, PIP-D = parental stress difficulty.

Table 4

Descriptive Outcome *Data at T1 by Completion Status at T3, with Completers vs. Non-Completers Analysis*

T1 Outcome Measure	*n*	T3 Completers, *M (SD)*	*n*	T3 Non-Completers, *M (SD)*	Completer vs. Non-Completer Analysis
State Self-Compassion	82	4.30 (0.95)	77	4.03 (0.969	$p = .08$
State Distress	82	23.37 (8.98)	77	24.66 (9.45)	$p = .38$
State Shame	82	11.62 (4.75)	77	12.44 (5.78)	$p = .33$
Trait Self-Compassion	81	2.91 (0.61)	77	2.69 (0.69)	$p = .04$*
PIP-F	81	118.06 (31.88)	76	124.93 (34.97)	$p = .20$
PIP-D	79	119.84 (34.89)	72	126.22 (37.55)	$p = .28$

Note. PIP-F = parental stress frequency, PIP-D = parental stress difficulty.

*Significant at $p < .05$.

Manipulation Check

A paired-sample t-test indicated that the recall task successfully elicited state shame in participants, with significantly higher scores following the recall task compared to T1, $t(156) = -8.97$, $p < .001$.

Regression Analysis

The regression analysis identified several significant predictors of change in each of the DVs at T2 and T3 that were consequently included as covariates in the respective ANCOVAs. State shame at T1 was found to significantly predict state self-compassion at T2 (β = -.10, $p < .001$). Meanwhile, state self-compassion at T1 was a significant predictor of state shame at T2 (β = -2.42, $p < .001$). Significant predictors of state distress at T2 included state shame at T1 (β = .58 $p < .001$), state self-compassion at T1 (β = -2.27 $p = .001$), PIP-F at T1 (β = .07 $p = .031$), child's age (β = -.82 $p = .006$), child's IBD type (β = 1.26 $p = .041$), and child's stoma status (β = -8.99, $p = .001$). State self-compassion at T1 was found to be a significant predictor of trait self-compassion at T3 (β = .45, $p < .001$). PIP-D at T1 was found to significantly predict PIP-F at T3 (β = .42, $p = .004$). Finally, significant predictors of PIP-D at T3 included PIP-F at T1(β = .57 $p < .001$) and state self-compassion at T1 (β = -11.41, $p = .013$). As the correlation between PIP-F and PIP-D scores at T1 violated the assumption of multicolliniarity ($r = .87$, $n = 150$, $p < .001$), only the corresponding T1 score was included as a covariate for the ANCOVAs assessing these outcomes.

Main Analyses

The results of the main analyses can be found in Tables 5-8.

Primary Hypotheses

State Self-Compassion. A one-way independent ANCOVA of data from T2 completers found that the SCI group had significantly higher state self-compassion scores at T2 compared to the control group after controlling for T1 scores of state self-compassion, trait self-compassion, and state shame, $F(1,136) = 9.17$, $p = .003$, with a medium effect size[1] ($\eta_p^2 = .06$). The ITT analysis also found this significant difference, $F(1,153) = 5.97$, $p = .016$, with a small effect size ($\eta_p^2 = .04$).

State Distress. A one-way independent ANCOVA of data from T2 completers found that the SCI group had significantly lower state distress scores at T2 compared to the control group after controlling for T1 scores of state distress, trait self-compassion, state shame, PIP-F, state self-compassion, and for demographic variables of the child's age, IBD type, and stoma status, $F(1,128) = 4.26$, $p = .041$, with a small effect size ($\eta_p^2 = .03$). The ITT analysis also found this significant difference, $F(1,146) = 4.99$, $p = .027$, with a small effect size ($\eta_p^2 = .03$).

State Shame. The completers and ITT one-way independent ANCOVAs found no significant differences in T2 state shame scores between the SCI and control group after controlling for T1 scores of state shame, trait self-compassion, and state self-compassion.

[1] $\eta_p^2 = .02$ (small effect), $\eta_p^2 = .06$ (medium effect), $\eta_p^2 = .14$ (large effect) (Cohen, 1988).

Table 5

Summary of Completers ANCOVAs for Primary Hypotheses

T2 Outcome	Group	*n*	*M*[a]	*SE*	*CI*	ANCOVA Results			
						df	*F*	*p*	η_p^2
State Self-Compassion	SCI	65	4.27	0.08	4.11-4.43	1, 136	9.17	.003*	.06
	Control	76	3.93	0.08	3.79-4.08				
State Distress	SCI	63	21.87	0.65	20.58-23.17	1, 128	4.26	.041*	.03
	Control	75	23.72	0.60	22.54-24.90				
State Shame	SCI	64	12.80	0.56	11.68-13.91	1, 135	.24	.628	.00
	Control	76	13.17	0.52	12.15-14.19				

Note. ANCOVA = analysis of covariance; *SE* = standard error; *CI* = confidence interval; SCI = self-compassion intervention.

[a]Adjusted means after controlling for covariates.

*Significant at $p < .05$.

Table 6

Summary of ITT ANCOVAs for Primary Hypotheses

T2 Outcome	Group	*n*	*M*[a]	*SE*	*CI*	ANCOVA Results			
						df	*F*	*p*	η_p^2
State Self-Compassion	SCI	80	4.26	0.07	4.11-4.40	1, 153	5.97	.016*	.04
	Control	78	4.00	0.08	3.85-4.14				
State Distress	SCI	79	21.65	0.57	20.52-22.77	1, 146	4.99	.027*	.03
	Control	77	23.48	0.58	22.34-24.61				
State Shame	SCI	80	12.68	0.49	11.72-13.64	1, 153	.364	.547	.00
	Control	78	13.10	0.49	12.12-14.08				

Note. ANCOVA = analysis of covariance; *SE* = standard error; *CI* = confidence interval; SCI = self-compassion intervention.

[a]Adjusted means after controlling for covariates.

*Significant at $p<.05$.

Secondary Hypotheses

Trait Self-Compassion. The completers and ITT one-way independent ANCOVAs found no significant differences in T3 trait self-compassion scores between

the SCI and control group after controlling for T1 scores of trait self-compassion and state self-compassion.

Parental Stress Frequency. The completers and ITT one-way independent ANCOVAs found no significant differences in T3 PIP-F scores between the SCI and control group after controlling for T1 scores of PIP-F, trait self-compassion and state self-compassion.

Parental Stress Difficulty. The completers and ITT one-way independent ANCOVAs found no significant differences in T3 PIP-D scores between the SCI and control group after controlling for T1 scores of PIP-D, trait self-compassion and state self-compassion.

Table 7

Summary of Completers ANCOVAs for Secondary Hypotheses

T3 Outcome	Group	*N*	*M*[a]	*SE*	*CI*	ANCOVA Results			
						df	*F*	*p*	η_p^2
Trait Self-Compassion	SCI	25	2.95	0.08	2.79-3.11	1, 76	.79	.377	.01
	Control	55	2.86	0.06	2.75-2.97				
PIP-F	SCI	25	120.40	4.22	111.98-128.82	1, 72	1.78	.187	.02
	Control	52	113.50	2.91	107.71-119.29				
PIP-D	SCI	25	119.76	4.31	111.16-128.35	1, 68	.42	.520	.01
	Control	48	116.27	3.07	110.14-122.41				

Note. ANCOVA = analysis of covariance; SCI = self-compassion intervention; *SE* = standard error; *CI* = confidence interval; PIP-F=parental stress frequency; PIP-D=parental stress difficulty.

[a]Adjusted means after controlling for covariates.

Table 8

Summary of ITT ANCOVAs for Secondary Hypotheses

T3 Outcome	Group	*N*	*M*[a]	*SE*	*CI*	ANCOVA Results			
						df	*F*	*p*	η_p^2
Trait Self-Compassion	SCI	80	2.82	0.03	2.76-2.89	1, 154	1.75	.188	.01
	Control	78	2.76	0.03	2.69-2.83				
PIP-F	SCI	79	119.97	1.94	116.14-123.80	1, 151	.679	.411	.00
	Control	77	117.68	1.96	113.81-121.56				
PIP-D	SCI	75	121.53	1.93	117.73-125.34	1, 145	.37	.545	.00
	Control	75	119.87	1.93	116.06-123.67				

Note. ANCOVA = analysis of covariance; SCI = self-compassion intervention; *SE* = standard error; *CI* = confidence interval; PIP-F=parental stress frequency; PIP-D=parental stress difficulty.

[a]Adjusted means after controlling for covariates.

Discussion

The current findings support the primary hypotheses that, compared to a control group, parents of children with IBD will experience increased state self-compassion and reduced state distress immediately following a brief SCI. No support, however, was found for the hypothesis that state shame would also be reduced immediately following a brief SCI. Furthermore, the SCI group did not significantly differ from the control group on outcomes of trait self-compassion and parental stress after repeated engagement in the SCI for two weeks, and so the secondary hypotheses cannot be supported. This study therefore provides some support for the immediate benefits of a brief SCI in this population, with further research needed to determine long-term effects.

The current finding that state self-compassion is increased following a brief SCI is consistent with previous research (Johnson & O'Brien, 2013; Lilley, 2019; Leary et al., 2007; Sirois et al., 2019). This reinforces the application and potential value of

targeting self-compassion in the context of parenting (Garcia et al., 2021; Jefferson et al., 2020; Lilley, 2019; Neff & Faso, 2015; Robinson et al., 2018; Shenaar-Golan et al., 2021; Sirois et al., 2019), whilst also extending this assumption to parents of children with IBD.

Furthermore, the finding that state distress in parents reduced following the brief SCI is consistent with reports of a negative association between self-compassion and factors of psychological distress (Ferrari et al., 2019; Jefferson et al., 2020; Leary et al., 2007; Neff, 2011; Zessin et al., 2015). It may be hypothesised that, by cultivating a state of self-compassion, the SCI helped parents apply their existing resources that consequently minimised their distress. This would be accordant with the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984), which would posit that parents' perceived capacity to cope with the challenges of parenting a child with IBD has the potential to moderate the impact of perceived stress. However, statistical analyses revealed that the SCI only reduced state distress to a small effect, which was lower than that of the effects on state self-compassion. This may be explained by the primary focus of the SCI used in this study, which was to induce the key elements of self-compassion (Neff, 2003a), rather than to directly minimise distress.

Given the body of literature that suggests an inverse association between self-compassion and shame (Gilbert & Procter, 2006; Johnson & O'Brien, 2013; Lilley, 2019; Sirois et al., 2019), the finding that state shame was not reduced by the SCI in the current study is surprising. Moreover, mean shame scores increased slightly in both groups following their respective conditions, further contradicting the existing literature. Of note, Lilley (2019) and Sirois et al. (2019) both report significant reductions in shame in their studies that implemented brief SCIs and measures of state shame synonymous to those used in the current study. It may therefore be

hypothesised that the absence of reduced shame following the SCI in this study is a finding unique to parents of children with IBD. Feelings of shame, that are characterised by the evaluation of a globally 'bad' self (Kim et al., 2011; Tangney & Dearing, 2002), may indeed be elevated in the current population due to the stigma and embarrassment that typically surrounds IBD (Daniel, 2002; Saunders, 2014; Trindade et al., 2017). Furthermore, shame was intentionally elicited during the recall task that participants were asked to complete prior to the experimental conditions. Thus, perhaps the brief SCI and the way in which state shame was measured in this study were not intensive or thorough enough to shift and subsequently detect changes in shame within this population. Indeed, other studies that report reductions in shame have often implemented more comprehensive and sustained compassion-focused interventions (Gilbert & Procter, 2006; Johnson & O'Brien, 2013). Although repeated engagement in the SCI was tested in the current study, no follow-up measures related to shame were included, thus limiting conclusions as to whether a more intensive SCI would reduce shame for parents of children with IBD. Further investigation is therefore warranted to explore the impact of SCIs on shame in this population.

As recommended (Lilley, 2019; Sirois et al., 2019), the secondary aspect of this study extends previous findings by assessing the longer-term impact of repeated engagement in the SCI. However, no significant effects of the SCI on trait self-compassion or parental stress were found after the two-week follow-up period. This contrasts with the findings of Jefferson et al.'s (2020) recent meta-analysis, which found significant reductions in parental stress and improvements in self-compassion following compassion-focused parenting interventions. This is despite most studies included in this review using the SCS to measure self-compassion, as in the current study. Nonetheless, it is important to note that most interventions included in Jefferson

et al.'s (2020) review were more intensive and longer in duration than the brief online SCI used in the current study, with most involving several weekly face-to-face sessions. As such, it may again be hypothesised that the SCI and the two-week follow-up period were not intensive or long enough to alter and subsequently detect changes in these trait constructs. For example, without the specific recall task, the SCI administered during the follow-up period may have failed to cultivate self-compassion in relation to the participants' experiences of caring for a child with IBD. Furthermore, previous research has found the association between self-compassion and outcomes such as depression to be mediated by shame (Johnson & O'Brien, 2013). The absence of any effects of the SCI at follow-up may therefore also be explained by the lack of any significant effects of the intervention on shame in the current population.

Strengths and Limitations

The strengths and limitations of the current study should be considered when interpreting findings. The primary analyses were sufficiently powered by a large sample of parents of children with IBD, thus increasing the validity of findings and filling an important gap in the literature. Nonetheless, opportunistic sampling methods that relied on volunteer participants may have introduced some bias to the sample. The sample were also mostly female. Although this is not uncommon in parenting research (Lilley, 2019; Neff & Faso, 2015; Robinson et al., 2018; Sirois et al., 2019), the current findings may be specific to mothers. Additional demographic data would have enabled further conclusions to be drawn regarding the external validity of findings. However, demographic variables were limited to factors that may interact with the intervention effect to avoid unnecessary participant burden and collection of extraneous data.

The secondary aims and analyses of this study advance previous research in this field. Nonetheless, there are several weaknesses pertaining to this aspect of the study that limit the validity and subsequent implications of these findings. For example, a longer, more specific, and intensive follow-up procedure may have provided more insight into the longitudinal effects of a repeated SCI. Although the simplified procedure and short follow-up period were in part implemented to minimise attrition, a high number of participants were still lost to follow-up. This attrition may reflect the inevitable barriers parents face in participating in research and therapeutic interventions, due to existing demands and lack of time. Indeed, high attrition rates have been reported in other brief online studies that include parent samples (Lilley, 2019; Mitchell et al., 2018). It is important to note, however, that baseline trait self-compassion scores were significantly higher in completers of the current study compared to non-completers. This suggests that individuals who are less self-compassionate to begin with may find it hard to engage in subsequent compassion-focused actions and interventions. This is consistent with previous reports of an association between the fear of compassion and engagement in compassion-focused experiences (Gilbert et al., 2011; Lennard et al., 2021). Not only does this attrition generate bias within the current findings, but the statistical power of the secondary analyses is also weakened, thus increasing the chances of a type II error.

Despite high attrition, ITT analyses using the LOCF method were conducted to provide an estimate of the effect of the SCI based on all randomised participants (McCoy, 2017). Although LOCF is a simple method that is commonly applied to estimate missing data (Hamer & Simpson, 2009; Woolley et al., 2009), it faces increasing criticism in respect to the potential bias it can introduce (Lachin, 2016). Due to the amount of missing data that was estimated using LOCF at follow-up, the findings

from the secondary ITT analyses should therefore be considered with additional caution. Confidence in these findings is increased, however, as the same conclusions were drawn from ITT and completers analyses. Furthermore, it could be argued that the transformation of PANAS-X data was unnecessary for the robust ANCOVA and could have in fact created distance between the stated findings and what empirical meaning the original data had (Games & Lucas, 1966; Grayson, 2004).

The sole reliance on self-report measures may also be critiqued as scores are likely to be determined by the participants' motivation, honesty, and ability to communicate accurate appraisals of their feelings (Meyer et al., 2001), thus introducing some response bias. Self-report measures, however, were deemed the most appropriate method of assessing internal feelings, that may have otherwise been unobservable (Andrews & Withey, 1976). The absence of specific validated measures to assess state shame and distress further weakens the internal validity of the current study. However, the application of the PANAS-X guilt and negative affect subscales (Watson & Clark, 1994) was justified, given the underlying constructs they intend to measure (Watson et al., 1988) and their use in previous studies (Lilley, 2019; Sirois et al., 2019). Finally, no cut-offs were available for the outcome measures used in this study. Although previously published data was considered to help contextualise scores, this is not a true indicator of clinical 'caseness' and it may have therefore been problematic and unrealistic to examine and expect significant change in the current sample.

Directions for Future Research

Future research should address these limitations where possible. Firstly, diverse samples should be recruited and additional demographic variables collected

in order for findings to be confidently generalised. Particular efforts should be made to improve the awareness and accessibility of research participation among fathers.

Longitudinal studies are also warranted, to provide further clarity on the lasting effects of SCIs in this population. Within this, the effect of SCIs on shame should be further explored with a validated measure, to assess whether existing research regarding the benefits of SCIs for shame (Gilbert & Procter, 2006; Johnson & O'Brien, 2013; Lilley, 2019; Sirois et al., 2019) applies to parents of children with IBD.

Study designs should be considered carefully to protect against the loss of participants and resultant missing data. Practical steps, such as sending regular reminder emails or notifications to participants may be beneficial (Clarke et al., 2005; Rübsamen et al., 2017). Studies should also be designed in collaboration with the target population, to ensure the research seems relevant, convenient, and trustworthy enough to maintain engagement (Mathieu et al., 2012; Todkill & Powell, 2013).

The assessment of child outcomes in studies that implement interventions for parents of children with CHCs would be a useful direction for future research. This would develop the theoretical understanding of paediatric CHCs within a systemic framework (Emerson & Bögels, 2017; Wood et al., 2015). Furthermore, family systems theories (Bowen, 1966; Bronfenbrenner, 1977; Rolland, 1999) would encourage the extension of research to other people in the system surrounding children, such as siblings and healthcare professionals.

Preliminary evidence exists to suggest that parents of children with IBD may be able to utilise existing positive psychological resources to foster strength and resilience within their experiences (Cushman et al., 2020; Wray, 2022). Thus, in line with the positive psychology movement (Seligman & Csikszentmihalyi, 2000), which self-

compassion has been increasingly associated with (Neff & Davidson, 2016; Neff et al., 2007), future studies should measure the effect of SCIs on positive psychological outcomes. The inclusion of the PANAS-X positive affect subscale (Watson & Clark, 1994), for example, may develop the current understanding of how self-compassion can support parents. Qualitative research may also provide further insight into how this population perceive and give meaning to the application of self-compassion.

Implications for Clinical Practice

As discussed, the current study observed an immediate, albeit small-medium, effect of a brief one-off SCI in increasing self-compassion and reducing distress. Although the bidirectional relationship between parent and child outcomes was not assessed in the current study, the findings suggest that parents of children with IBD may benefit from support for their own wellbeing. A systemic approach to paediatric IBD research and practice is therefore encouraged, in which parents are considered and supported alongside their children.

Brief and accessible interventions or informal means of support that help to cultivate self-compassion in parents may be of particular use. Interventions such as the SCI implemented in this study could be particularly advantageous in busy and stretched healthcare services that continue to work within the context of the COVID-19 pandemic. Parents could be encouraged in-person or through online communication to be kind and understanding towards themselves, to recognise their feelings as part of the universal human experience, and to hold a balanced awareness of their experiences as they arise (Neff, 2003a).

However, the current findings and above implications cannot be confidently applied to all parents of children with IBD. For example, fathers were largely

underrepresented in the current sample and may therefore need to be considered individually in clinical practice. Furthermore, drop-out data suggests that parents who experience less self-compassion to begin with may struggle to engage in and consequently benefit from such interventions. Previous research also suggests that individuals who experience higher stress levels may be less likely to engage in online activities (Rübsamen et al., 2017). Care should therefore be taken to understand the needs of individual parents and provide tailored and specialised support for those who have existing psychological needs. Indeed, Gilbert et al. (2011) suggest that individuals who experience fears and resistances to engaging in compassion-focused interventions need to be supported to explore such barriers in a closer, more personalised therapeutic context.

Conclusions

The current findings provide evidence to suggest that brief SCIs may improve state self-compassion and reduce state distress in parents of children with IBD. Contrary to previous research, however, no effects of the SCI were found on state shame. Furthermore, repeated engagement in the SCI for two weeks was not found to have any significant effects on trait self-compassion or parental stress. Additional research addressing the limitations of the current study is required to provide a clearer and more comprehensive understanding of the benefits of self-compassion for this population. Robust longitudinal designs that evaluate the effect of more intensive SCIs would be particularly beneficial. Nonetheless, this study is the first to explore and discover the benefits of self-compassion for parents of children with IBD. The findings therefore have novel and important implications that support the ongoing advancement of paediatric IBD research and practice within a systemic framework.

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Appendix A

Ethical Approval

Downloaded: 19/03/2021
Approved: 04/01/2021

Annabel Wray
Registration number: 190217909
Psychology
Programme: Doctorate in Clinical Psychology

Dear Annabel

PROJECT TITLE: A Self-compassion Intervention for Parents of Children with Inflammatory Bowel Disease (IBD)
APPLICATION: Reference Number 036770

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 04/01/2021 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 036770 (form submission date: 11/12/2020); (expected project end date: 31/12/2021).
- Participant information sheet 1085364 version 1 (11/12/2020).
- Participant consent form 1085365 version 1 (11/12/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

Department Of Psychology Research Ethics Committee
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

Recruitment Advertisement

Are you the parent of a child (under 18) with Inflammatory Bowel Disease (IBD)?

The University Of Sheffield.

We understand that this experience can raise some emotional challenges and so **we'd like to invite you to take part in an online study** to help us research ways that you can be better supported!

What will this involve?

You will be asked to complete some online questionnaires and tasks related to your experiences of parenting a child with IBD. Some, but not all, participants will also be asked to complete a short online task every day for two weeks. We will then invite all participants to repeat some of the online questionnaires after two weeks.

For participating you will be given a chance to win a £50 Amazon voucher.

This study has been ethically reviewed and approved by The University of Sheffield's Research Ethics Committee.

How do I take part?

For more information or to take part, please follow this link or QR code:

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_bNn5Vj8CD5JKhy6

You can also contact the main researcher, Annie Wray (Trainee Clinical Psychologist, University of Sheffield), on awray1@sheffield.ac.uk for any further queries.

Please also pass this advertisement on to anyone you know who may be eligible and interested in taking part!

Appendix C

Participant Information Sheet

Research Project: Supporting parents of children with Inflammatory Bowel Disease (IBD).

Invitation

You are being invited to take part in a research project. Before you decide whether or not to participate, it is important that you understand why the research is being done and what it will involve. Please take your time in reading the following information and considering whether or not you wish to take part. Please contact the researcher using the contact details below if you would like any further information or clarification. We thank you for your careful consideration.

What is the purpose of the research project?

We understand that there can be many challenges in parenting a child with IBD. This research therefore aims to explore how parents of children with IBD can be better supported. We hope that the findings will enable healthcare providers to better understand and support the needs of parents and carers of children and young people with IBD. This project is being completed as part of a Doctorate in Clinical Psychology degree programme.

Why have I been chosen?

You have been chosen because you have a child with IBD. We will be aiming to recruit around 150 parents and carers of children with IBD.

Do I have to take part?

No, it is up to you to decide whether or not to participate in this research. If you do decide to take part, we will ask you to confirm your informed consent. If you decide that you no longer wish to take part in this research, you can withdraw at any time without question within two weeks of completing the final questionnaires. After two weeks has passed, your data will be anonymised, making it impossible for your data to be identified and extracted from the research. To withdraw, please contact the researcher using the contact details below within this time frame.

What will happen if I do participate?

If you decide to participate in this research, you will take part in a randomised-controlled trial to test an online intervention aiming to help parents manage the difficulties they may experience in parenting a child with IBD. This will involve completing several online questionnaires relating to how you feel in the context of parenting for your child with IBD and difficult situations more generally. You will then be asked to complete a task that will either be part of the online intervention or an alternative task. Some participants may also be asked to engage in this task every-day for two-weeks, which is expected to take between 10 and 20 minutes each day. Other participants will not need to do anything additional until we ask all participants to repeat some of the online questionnaires after two-weeks.

Following the final round of questionnaires, you will receive some further information about the research, as well as instructions and materials for you to begin or continue the online intervention should you wish. This will be provided for use in your own time and you will not need to complete the questionnaires again.

We will ask you to provide your email address so that you can be entered into a £50 Amazon voucher prize draw. When the study is closed, we will select one random winner per study, and notify them by email.

What are the possible disadvantages and risks of taking part?

We do not anticipate that there will be any risks to you in taking part in this research. However, we understand that filling out questionnaires and completing the tasks may feel time consuming. We also appreciate that there may be some discomfort during this process as the questionnaires and tasks are related to the difficulties you may face as a parent of a child with IBD.

If you do feel that you need further support at any time during this research, you should approach a healthcare professional (e.g. your GP, the professionals involved in your child's care) for support. You can also access 24/7 support by phoning the Samaritans on 116 123. The following charities may also be able to support you:

Crohn's and Colitis UK: https://www.crohnsandcolitis.org.uk/

CICRA: https://www.cicra.org

What are the possible benefits of taking part?

Although there are not any immediate benefits for those participating in the project, it is hoped that you will find it meaningful and helpful to contribute your experiences of parenting a child with IBD. All participants will also receive access to instructions and materials for an online intervention which aims to help parents manage the difficulties they may experience in parenting a child with IBD either during or following their participation in this research study. You will also be entered into a £50 Amazon voucher prize draw.

Will my information be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential and will only be accessible to members of the research team. You will not be identified in any reports or publications.

How will my data be processed?

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that 'processing is necessary for the performance of a task carried out in the public interest' (Article 6(1)(e)). Further information can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general

The University of Sheffield will act as the Data Controller for this study and will therefore be responsible for looking after your information and using it properly. The University of Sheffield will destroy any personal information you provide (your email address) once the whole project is complete and we have selected a participant for the prize draw.

The only people in The University of Sheffield who will have access to personal information that identifies you (your email address) will be the research team for the purpose of sending you instructions of how to complete the study, and to let you know if you win the £50 Amazon voucher prize draw. All email addresses will be encrypted and not shared. After the study has ended, all email addresses will be securely deleted. Your personal information will not be accessed or used at any other times during the research.

What will happen to the results of the research project?

The results of the research project will form part of a thesis for a Doctorate in Clinical Psychology degree programme. We also aim to publish the results of this project in a relevant academic journal. Participants will not be identifiable in these reports as all data will be anonymous. If you would like a copy of the report once it is ready, please contact the researcher and ask to be added to our circulation list.

Who is organising and funding the research?

The project is being conducted by Annabel Wray (Trainee Clinical Psychologist) as part of a Doctorate in Clinical Psychology degree programme at the University of Sheffield. Dr Georgina Rowse is supervising this project and Dr Rebecca Yeates is acting as a collaborator, both are based at the University of Sheffield.

Who has ethically reviewed this project?

This project has been ethically reviewed and approved by The University of Sheffield's Research Ethics Committee.

How do I make a complaint?

If you would like to make a complaint about this project, in the first instance you should contact the researcher or their supervisor using the contact details below. If you do not feel satisfied that your complaint has been dealt with appropriately you can contact Prof. Elizabeth Milne (head of the Department of Psychology) by emailing e.milne@sheffield.ac.uk, or Dr Jilly Gibson-Miller (chair of the Department of Ethics Subcommittee) by emailing jilly.gibson@sheffield.ac.uk.

Who can I contact for further information?

Annabel Wray (researcher): awray1@sheffield.ac.uk.

Dr Georgina Rowse (supervisor): g.rowse@sheffield.ac.uk

Alternatively, you can email Amrit Sinha (Research Support Officer, University of Sheffield) by emailing a.sinha@sheffield.ac.uk or leaving a telephone message with him on 0114222 6650. Amrit will then ask the trainee to contact you.

Thank you for your time.

Appendix D

Online Consent Form

If you have read and considered the participant information carefully and made the decision to participate in this research project, please complete this following form.

Please check the agree box to indicate that…	**Agree**
I have read and understood the participant information. (If you haven't, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean by reading the participant information.)	
I have been given the opportunity to ask questions about the project.	
I agree to take part in the project and understand that this will include completing several questionnaires and tasks over the period of two-weeks.	
I understand that my taking part is voluntary and that I can withdraw from the study at any time within two-weeks of completing the final questionnaires. I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	
I understand my personal details (e.g. your email address) will not be revealed to people outside the project and will only be used to send you prompts for the next research tasks and questionnaires, or let you know if you win the £50 Amazon voucher prize draw.	
I understand and agree that other authorised researchers will have access to this anonymous survey data for the purpose of analysis only.	
I understand and agree that other authorised researchers may use my anonymous survey data in publications, reports, web pages, and other research outputs.	
I give permission for the anonymous survey data that I provide to be archived in an appropriate repository, so it can be used for future research and learning.	
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.	
I provide informed consent that I would like to participate in this research project.	

Appendix E

Screening Question

Are you a parent/carer with parental responsibility for a child under 18 years old with a diagnosis of Inflammatory Bowel Disease (IBD)?	Yes
	No

Appendix F

Recall Task

We would like you to think about a recent parenting-related event with your child with inflammatory bowel disease (IBD) which made you feel ashamed. It should be an event that you can recall fairly easily, and one which you still feel a bit troubled about.

This might have involved your own behaviour (e.g. you made a mistake and felt ashamed for doing so), or your child's behaviour (e.g. your child behaved in a way that made you feel ashamed as a parent).

If you feel comfortable doing so, please recall what happened and how you were feeling in this situation as clearly as you can, and try to imagine yourself back in this situation and what it felt like. Then, in the space below, please briefly describe this parenting event in as much detail as possible, so that we can understand what happened and how you were feeling. We ask that you do not rush through this task.

Appendix G

Manipulation Check

Please mark the appropriate answer on the scale to indicate to what extent you feel this way right now/in the present moment.

	1	2	3	4	5
	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
Ashamed					

Appendix H

Instructions for the Initial Administration of the SCI and Control Condition

Control Group Instructions

Thinking about the parenting event that you just recalled and wrote about, please write a couple of sentences in the space below describing only the factual details of this event, such as what time of day and week it was, who you were with, what the weather was like.

SCI group instructions

Thinking about the parenting event that you just recalled and wrote about, we would now like you to consider the fact that making mistakes and feeling uncertain while looking after a child with IBD is very common, and almost everyone in your position will have experienced something similar at some point. You are not the first person who has felt like they have made a mistake when looking after their child, nor will you be the last.

When troubling parenting events happen, like the one you just wrote about, it is very common for people to be hard on themselves. But being hard on yourself won't change what happened, and may make things worse.

Try instead to take a balanced perspective when thinking about this parenting event. Be kind, accepting, and compassionate towards yourself about what happened.

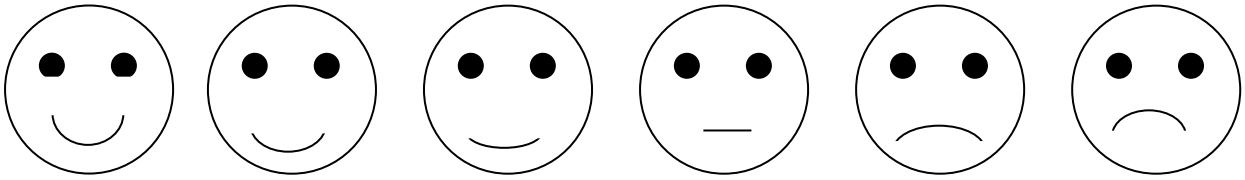
We would like you to now write a couple of sentences in the space below expressing this kindness, understanding, and balanced perspective to yourself in relation to the parenting event you described above. Write in the same way that you might if you were supporting a friend who had gone through something similar.

Appendix I

Mood Neutralisation Task

Now we would like you to think about a time when you were really proud of your parenting, that is, you or your child did something, and you felt really good about this. It could have been something big or small, but the main thing was that you were happy and proud that your parenting had been influential in the event.

Take a moment to think about this time when you were proud of your parenting and briefly describe what happened below. Overall, how do you feel right now after thinking about the situation you described above? Please use the slider below to choose the face that expresses how you are feeling in this moment.



Appendix J

Instructions for the Follow-Up Period for the SCI and Control Condition

Instructions Emailed to the Control Group

Dear Participant,

Thank you for your participating in the research project, 'Supporting parents of children with Inflammatory Bowel Disease (IBD)'. You have done everything you need to do for now. In two-weeks, we will email you another link so that you can complete the final questionnaires.

If you have any questions, please do not hesitate to contact the researcher by emailing awray1@sheffield.ac.uk.

Many thanks,

Annie

Instructions Emailed Daily to the SCI Group

Dear Participant,

Thank you for your continued participation in the research project, 'Supporting parents of children with Inflammatory Bowel Disease (IBD)'.

Please follow this link to complete your next daily task:

[LINK INSERTED HERE]

Please note, you will receive this email at the same time every-day for two-weeks to remind you to complete the task at least once a day. You do not have to wait to receive this email before completing the task if a different time of day suits you better. The link will be the same every-day so you can just click on the link from a previous email to complete the task.

After two-weeks, we will email you a different link so that you can complete the final questionnaires.

If you have any questions, please do not hesitate to contact the researcher by emailing awray1@sheffield.ac.uk.

Many thanks,

Annie

Instructions Contained Within the Daily Qualtrics® Link for the SCI Group

Thinking about parenting and looking after a child with IBD, we would like you to consider the fact that making mistakes and feeling uncertain is very common, and almost everyone in your position will have experienced this at some point. You are not the first person who has felt like they've made a mistake when looking after their child, nor will you be the last.

It is very common for parents to be hard on themselves in relation to their parenting. But being hard on yourself won't change what happened, and may make things worse.

Try instead to take a balanced perspective when thinking about your parenting and looking after a child with IBD. Be kind, accepting, and compassionate towards yourself.

We would like you to write a couple of sentences in the space below expressing this kindness, understanding, and balanced perspective to yourself in relation to your parenting. Write in the same way that you might if you were supporting a friend who was parenting and looking after a child with IBD.

Appendix K

Adherence Question

How often did you engage in the task?	
Every day (14 days)	☐
Most days (10-13 days)	☐
Some of the days (5-9 days)	☐
Not many of the days (1-4 days)	☐
None of the days (0 days)	☐

Appendix L

Debrief Information

Research Project: Supporting Parents of Children with Inflammatory Bowel Disease (IBD).

Thank you for taking part in this research that explored whether an online self-compassion intervention, that focuses on helping parents respond to themselves in a kinder and more accepting way, increases self-compassion and reduces the parental distress, including feelings of guilt or shame, in parents of children with IBD.

We did this by comparing two groups of participants – one group completed the online self-compassion intervention, while the other group acted as our control group. We expect participants in the self-compassion intervention group to show greater improvements on the measures of wellbeing you completed. If you would like a copy of the report once it is ready, please contact the researcher and ask to be added to our circulation list.

If you would like to access or continue accessing the online self-compassion intervention now you have taken part in this research, please refer to the instructions overleaf. Dr Kristian Neff also provides access to a number of similar self-compassion exercises and guided meditations on her website https://self-compassion.org/.

I would like to take this opportunity to say thank you for participating in this research. I hope that you found it meaningful and helpful to contribute your experiences of parenting a child with IBD, and that the self-compassion interventions can be of some benefit to you.

Who can I contact for further information?

Annabel Wray (researcher): awray1@sheffield.ac.uk.

Dr Georgina Rowse (supervisor): g.rowse@sheffield.ac.uk

Alternatively, you can email Amrit Sinha (Research Support Officer, University of Sheffield) by emailing a.sinha@sheffield.ac.uk or leaving a telephone message with him on 0114222 6650. Amrit will then ask the trainee to contact you.

Thank you for your time.

Self-Compassion Intervention Instructions

Thinking about parenting and looking after a child with IBD, we would like you to consider the fact that making mistakes and feeling uncertain is very common, and almost everyone in your position will have experienced this at some point. You are not the first person who has felt like they have made mistakes when looking after their child, nor will you be the last.

It is very common for parents to be hard on themselves in relation to their parenting. But being hard on yourself won't change what happened, and may make things worse.

Try instead to take a balanced perspective when thinking about your parenting and looking after a child with IBD. Be kind, accepting, and compassionate towards yourself.

Write a couple of sentences in the space below expressing this kindness, understanding, and balanced perspective to yourself. Write in the same way that you might if you were supporting a friend who was parenting and looking after a child with IBD.

Appendix M

Demographic Questionnaire

Please complete the questions below to help us understand a little about you and your child. This information will only be used for the purpose of this study. If you have any questions about this or require further guidance, please contact the researcher on awray1@sheffield.ac.uk.

How old are you?

Please specify: _____

What is your gender identity?

Please specify: _____

How many people currently live in your family home?

Please specify: _____

Do you have a diagnosis of inflammatory bowel disease (IBD) yourself?

Yes: ☐

No: ☐

Are you the primary caregiver for your child?

Yes: ☐

No: ☐

How many children do you have with IBD?

1: ☐

Please specify if >1: _____ *

**Please note, if you have more than one child with IBD we would like you to choose one to reflect on for the duration of this study.*

How old is your child with IBD?

Please specify: _____

How old was your child when they were diagnosed with IBD?

Please specify: _____

What is your child with IBD's gender identity?

Please specify: _____

What type of IBD is your child diagnosed with?

Crohn's disease: ☐

Ulcerative colitis: ☐

Other: ☐

Is your child on any medication?

Yes: ☐

No: ☐

If so, please specify: _____

Has your child had any surgery for their IBD?

Yes: ☐

No: ☐

If so, please specify: _____

Are your child's symptoms…

Active: ☐

In remission: ☐

Does your child have a stoma?

Yes: ☐

No: ☐

No, but they have in the past: ☐

Appendix N

Five Items Developed and Used by a Similar Study (Sirois et al., 2019) Based on Previous Research (Breines & Chen, 2012) Used to Assess State Self-Compassion at T1 and T2

Please read each of these questions carefully before answering. To the right of each question, indicate how you feel right now, using the indicated scale:

1. Right now, how kind do you feel towards yourself?

1	2	3	4	5	6	7
Not at all kind			Moderately kind			Extremely kind

2. Right now, how accepting do you feel towards yourself?

1	2	3	4	5	6	7
Not at all accepting			Moderately accepting			Extremely accepting

3. Right now, how critical do you feel towards yourself?

1	2	3	4	5	6	7
Not at all critical			Moderately critical			Extremely critical

4. Right now, how much do you see your weaknesses as part of being human?

1	2	3	4	5	6	7
Not at all			Somewhat			Very much

5. Right now, how much are you trying to take a balanced view of the situation?

1	2	3	4	5	6	7
Not at all			Somewhat			Very much

Appendix O

Fourteen Items from the Positive and Negative Affect Schedule-Expanded Form (PANAS-X; Watson & Clark, 1994) Used to Assess State Shame and Distress at T1 and T2

This scale consists of a number of words and phrases that describe different feelings and emotions. Read each item and then mark the appropriate answer on the scale next to that word. Indicate to what extent you feel this way right now/in the present moment.

	1	2	3	4	5
	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
1. Afraid					
2. Scared					
3. Nervous					
4. Jittery					
5. Irritable					
6. Hostile					
7. Guilty					
8. Ashamed					
9. Upset					
10. Distressed					
11. Blameworthy					
12. Angry at self					
13. Disgusted with self					
14. Dissatisfied with self					

Appendix P

The 26-item Self-Compassion Scale (SCS; Neff, 2003b) Used to Assess Trait Self-Compassion at T1 and T3

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost never				Almost always
1	2	3	4	5

_____ 1. I'm disapproving and judgmental about my own flaws and inadequacies.
_____ 2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.
_____ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.
_____ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.
_____ 5. I try to be loving towards myself when I'm feeling emotional pain.
_____ 6. When I fail at something important to me I become consumed by feelings of inadequacy.
_____ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.
_____ 8. When times are really difficult, I tend to be tough on myself.
_____ 9. When something upsets me I try to keep my emotions in balance.
_____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
_____ 11. I'm intolerant and impatient towards those aspects of my personality I don't like.
_____ 12. When I'm going through a very hard time, I give myself the caring and tenderness I need.
_____ 13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.
_____ 14. When something painful happens I try to take a balanced view of the situation.
_____ 15. I try to see my failings as part of the human condition.
_____ 16. When I see aspects of myself that I don't like, I get down on myself.
_____ 17. When I fail at something important to me I try to keep things in perspective.
_____ 18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.
_____ 19. I'm kind to myself when I'm experiencing suffering.
_____ 20. When something upsets me I get carried away with my feelings.
_____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.
_____ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.
_____ 23. I'm tolerant of my own flaws and inadequacies.
_____ 24. When something painful happens I tend to blow the incident out of proportion.
_____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.
_____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

Appendix Q

The Pediatric Inventory for Parents (PIP; Streisand et al., 2001) Used to Assess Parental Stress at T1 and T3

PEDIATRIC INVENTORY FOR PARENTS

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. Please complete both columns for each item.

EVENT	HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
1. Difficulty sleeping	1 2 3 4 5	1 2 3 4 5
2. Arguing with family member(s)	1 2 3 4 5	1 2 3 4 5
3. Bringing my child to the clinic or hospital	1 2 3 4 5	1 2 3 4 5
4. Learning upsetting news	1 2 3 4 5	1 2 3 4 5
5. Being unable to go to work/job	1 2 3 4 5	1 2 3 4 5
6. Seeing my child's mood change quickly	1 2 3 4 5	1 2 3 4 5
7. Speaking with doctor	1 2 3 4 5	1 2 3 4 5
8. Watching my child have trouble eating	1 2 3 4 5	1 2 3 4 5
9. Waiting for my child's test results	1 2 3 4 5	1 2 3 4 5
10. Having money/financial troubles	1 2 3 4 5	1 2 3 4 5
11. Trying not to think about my family's difficulties	1 2 3 4 5	1 2 3 4 5
12. Feeling confused about medical information	1 2 3 4 5	1 2 3 4 5
13. Being with my child during medical procedures	1 2 3 4 5	1 2 3 4 5
14. Knowing my child is hurting or in pain	1 2 3 4 5	1 2 3 4 5
15. Trying to attend to the needs of other family members	1 2 3 4 5	1 2 3 4 5
16. Seeing my child sad or scared	1 2 3 4 5	1 2 3 4 5
17. Talking with the nurse	1 2 3 4 5	1 2 3 4 5
18. Making decisions about medical care or medicines	1 2 3 4 5	1 2 3 4 5
19. Thinking about my child being isolated from others	1 2 3 4 5	1 2 3 4 5
20. Being far away from family and/or friends	1 2 3 4 5	1 2 3 4 5
21. Feeling numb inside	1 2 3 4 5	1 2 3 4 5
22. Disagreeing with a member of the health care team	1 2 3 4 5	1 2 3 4 5

Randi Streisand, Ph.D.

EVENT	HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
23. Helping my child with his/her hygiene needs	1 2 3 4 5	1 2 3 4 5
24. Worrying about the long term impact of the illness	1 2 3 4 5	1 2 3 4 5
25. Having little time to take care of my own needs	1 2 3 4 5	1 2 3 4 5
26. Feeling helpless over my child's condition	1 2 3 4 5	1 2 3 4 5
27. Feeling misunderstood by family/friends as to the severity of my child's illness	1 2 3 4 5	1 2 3 4 5
28. Handling changes in my child's daily medical routines	1 2 3 4 5	1 2 3 4 5
29. Feeling uncertain about the future	1 2 3 4 5	1 2 3 4 5
30. Being in the hospital over weekends/holidays	1 2 3 4 5	1 2 3 4 5
31. Thinking about other children who have been seriously ill	1 2 3 4 5	1 2 3 4 5
32. Speaking with my child about his/her illness	1 2 3 4 5	1 2 3 4 5
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing)	1 2 3 4 5	1 2 3 4 5
34. Having my heart beat fast, sweating, or feeling tingly	1 2 3 4 5	1 2 3 4 5
35. Feeling uncertain about disciplining my child	1 2 3 4 5	1 2 3 4 5
36. Feeling scared that my child could get very sick or die	1 2 3 4 5	1 2 3 4 5
37. Speaking with family members about my child's illness	1 2 3 4 5	1 2 3 4 5
38. Watching my child during medical visits/procedures	1 2 3 4 5	1 2 3 4 5
39. Missing important events in the lives of other family members	1 2 3 4 5	1 2 3 4 5
40. Worrying about how friends and relatives interact with my child	1 2 3 4 5	1 2 3 4 5
41. Noticing a change in my relationship with my partner	1 2 3 4 5	1 2 3 4 5
42. Spending a great deal of time in unfamiliar settings	1 2 3 4 5	1 2 3 4 5

Appendix R

Tests for the Distribution of Outcome Data Across Groups

Variable	Group	*n*	Skewness (*SE*)	*Z*-Score[a]	Kurtosis (*SE*)	*Z*-Score[a]	Kolmogorov-Smirnov Test	Shapiro-Wilk Test
T2 State Self-Compassion								
	SCI	79	0.104 (0.271)	0.38	0.192 (0.535)	0.36	.128**	.970
	Control	76	0.499 (0.276)	1.81	1.218 (0.545)	2.24*	.143***	.945**
T2 State Distress								
	SCI	78	0.842 (0.272)	3.10**	0.130 (0.538)	0.24	.110*	.926***
	Control	76	0.440 (0.276)	1.59	-0.705 (0.545)	1.29	.110*	.957*
T2 State Shame								
	SCI	78	1.064 (0.272)	3.91***	0.254 (0.538)	0.47	.159***	.867***
	Control	76	0.763 (0.276)	2.77**	-0.586 (0.545)	1.08	.171***	.883***
T3 Trait Self-Compassion								
	SCI	36	0.453 (0.393)	1.53	0.251 (0.768)	0.33	.081	.984
	Control	56	0.795 (0.319)	2.49*	0.586 (0.628)	0.93	.111	.949*
T3 PIP-F								
	SCI	36	0.094 (0.393)	0.24	-0.999 (0.768)	1.30	.108	.956
	Control	54	0.139 (0.325)	0.43	-0.780 (0.639)	1.22	.102	.971
T3 PIP-D								
	SCI	35	0.169 (0.398)	0.43	-1.072 (0.778)	1.38	.094	.957
	Control	51	0.115 (0.333)	0.35	-0.546 (0.656)	0.83	.059	.978

Note. PIP-F=parental stress frequency, PIP-D=parental stress difficulty.
[a]Significance cut-offs for skewness and kurtosis z-scores taken from Field (2018)
*Significant at $p<.05$
**Significant at $p<.01$
***Significant at $p<.001$

Appendix S

Graphs for the Distribution of Outcome Data Across Groups

Figure S1

Histogram for T2 State Self-Compassion, SCI Group

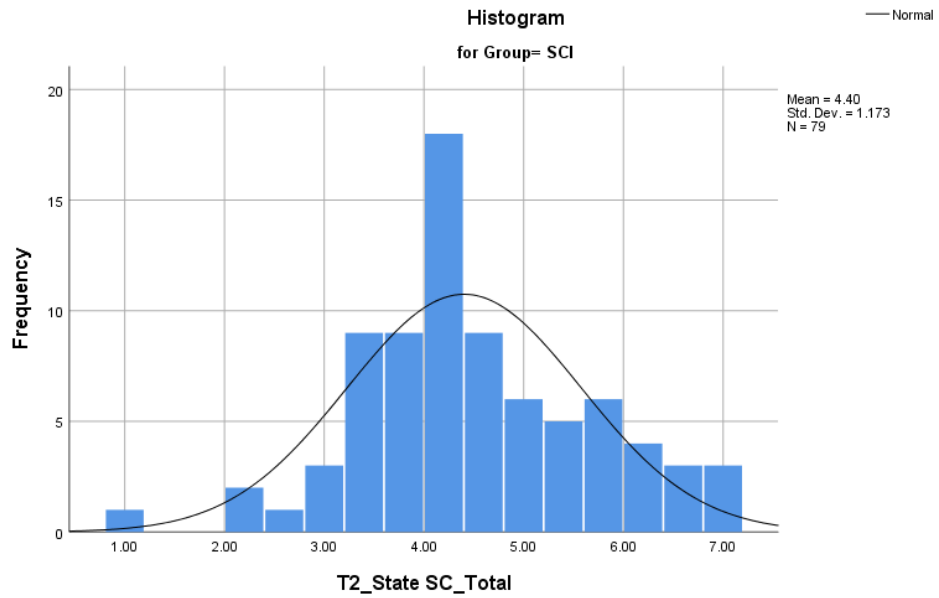


Figure S2

Q-Q Plot for T2 State Self-Compassion, SCI Group

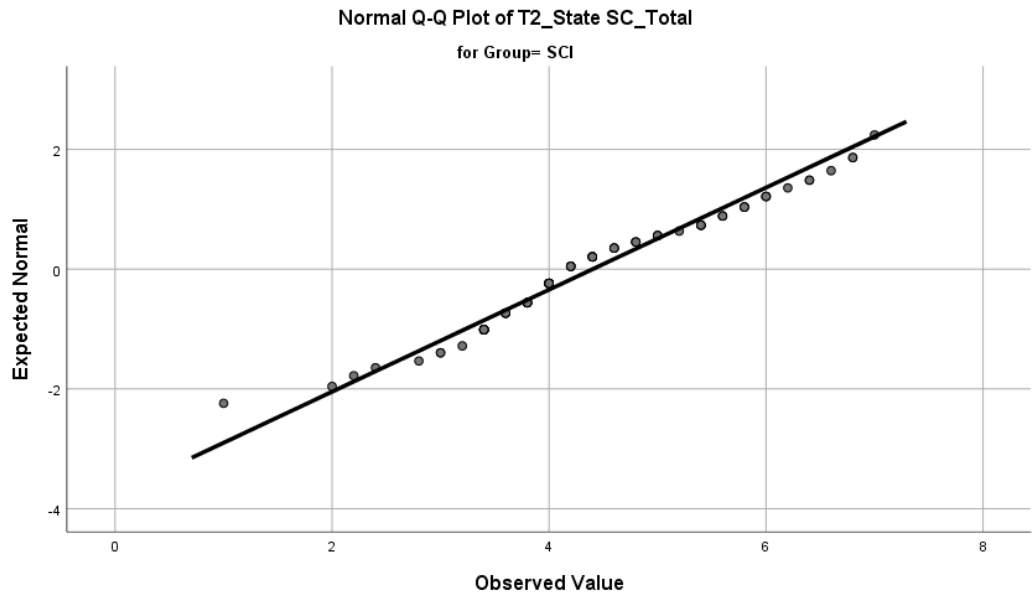


Figure S3

Histogram for T2 State Self-Compassion, Control Group

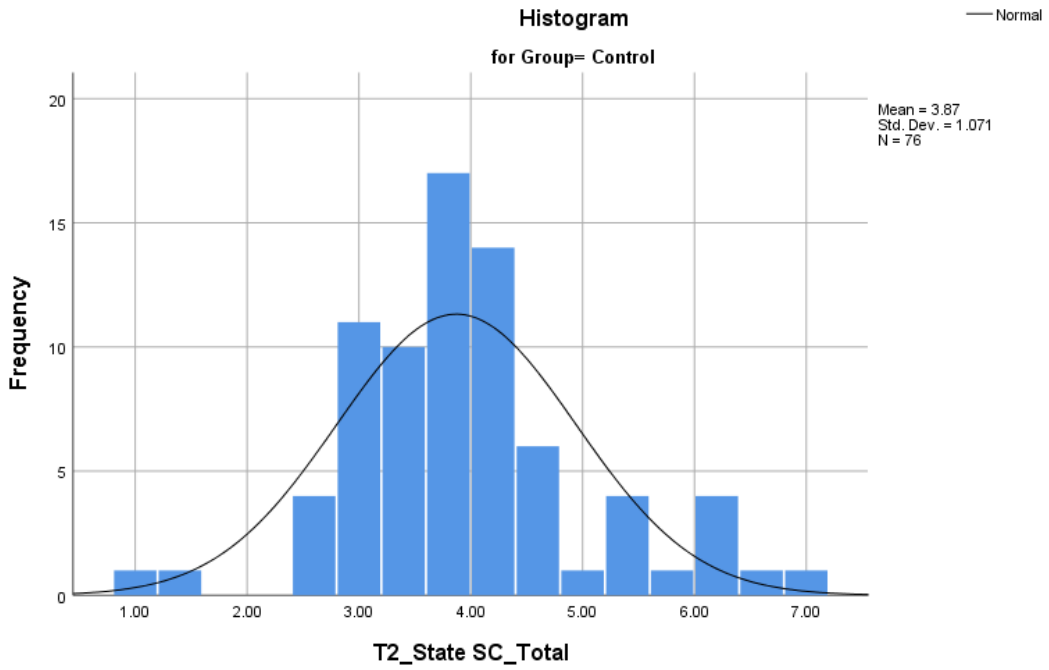


Figure S4

Q-Q Plot for T2 State Self-Compassion, Control Group

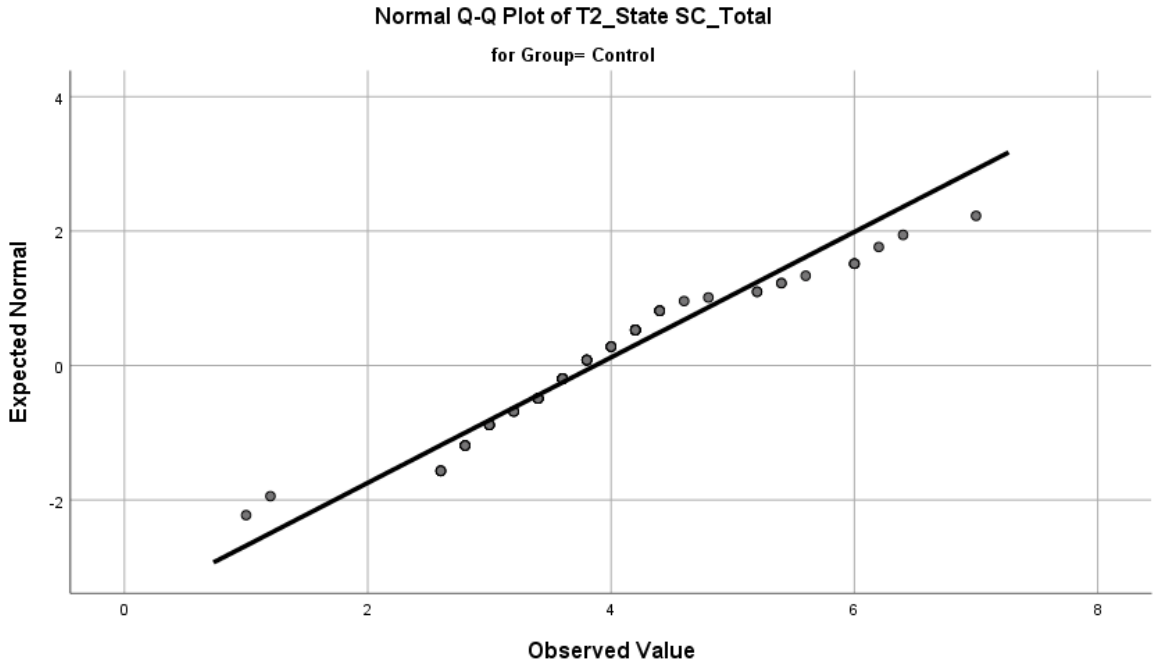


Figure S5

Histogram for T2 State Distress, SCI Group

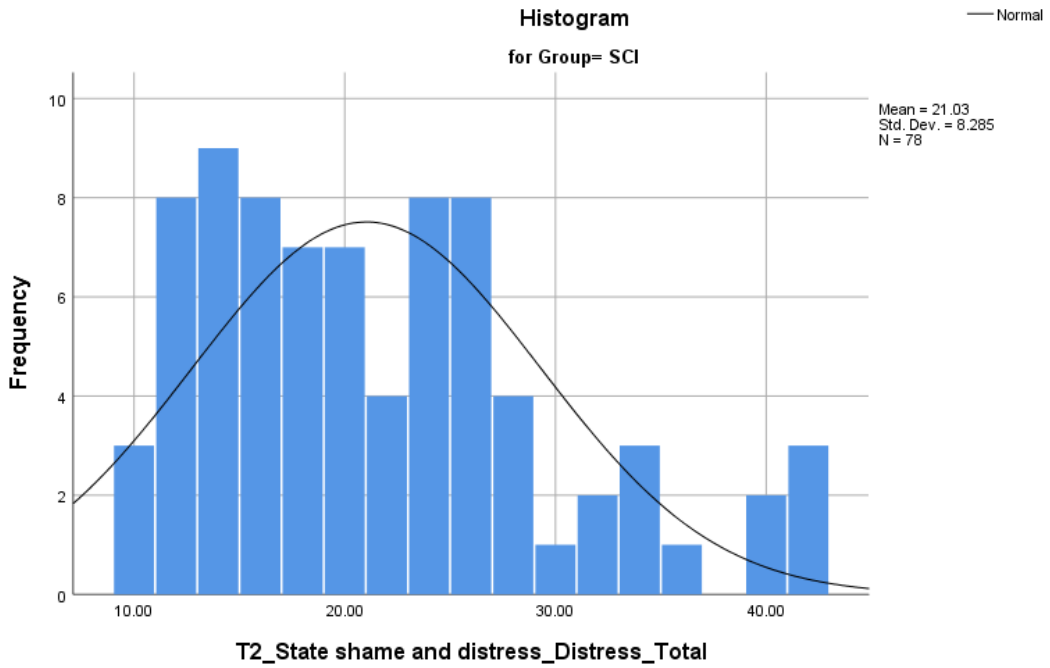


Figure S6

Q-Q Plot for T2 State Distress, SCI Group

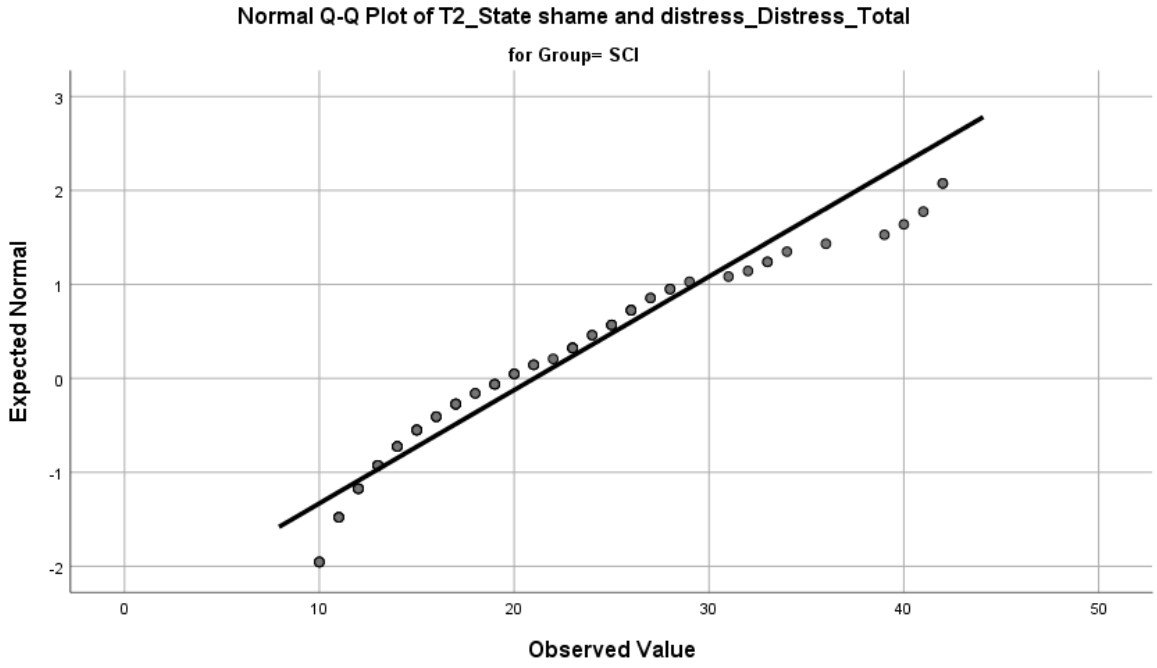


Figure S7

Histogram for T2 State Distress, Control Group

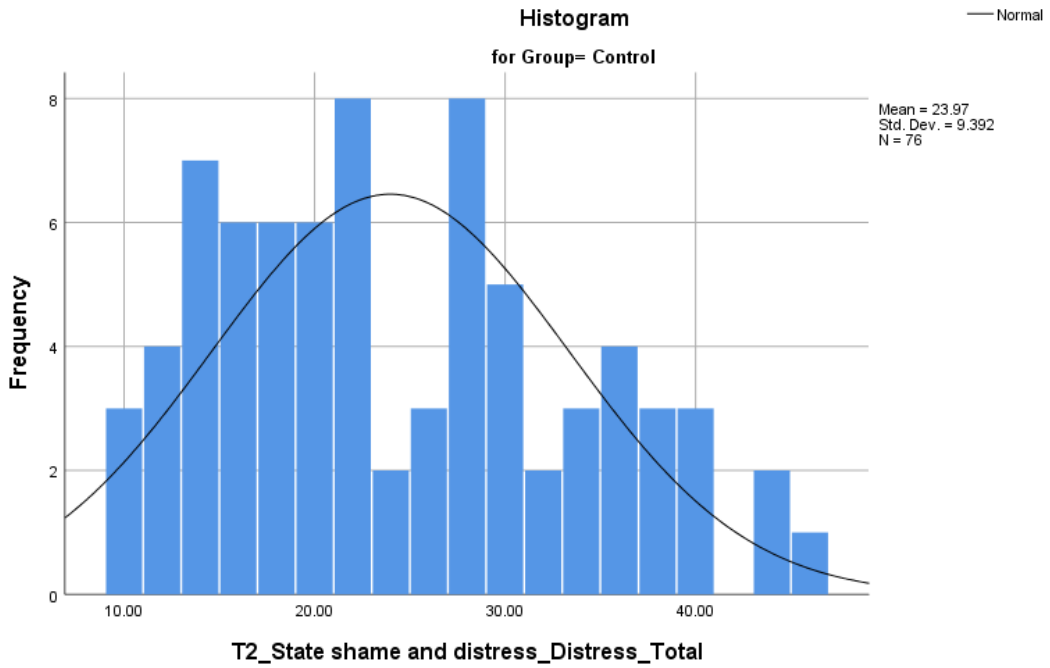


Figure S8

Q-Q Plot for T2 State Distress, Control Group

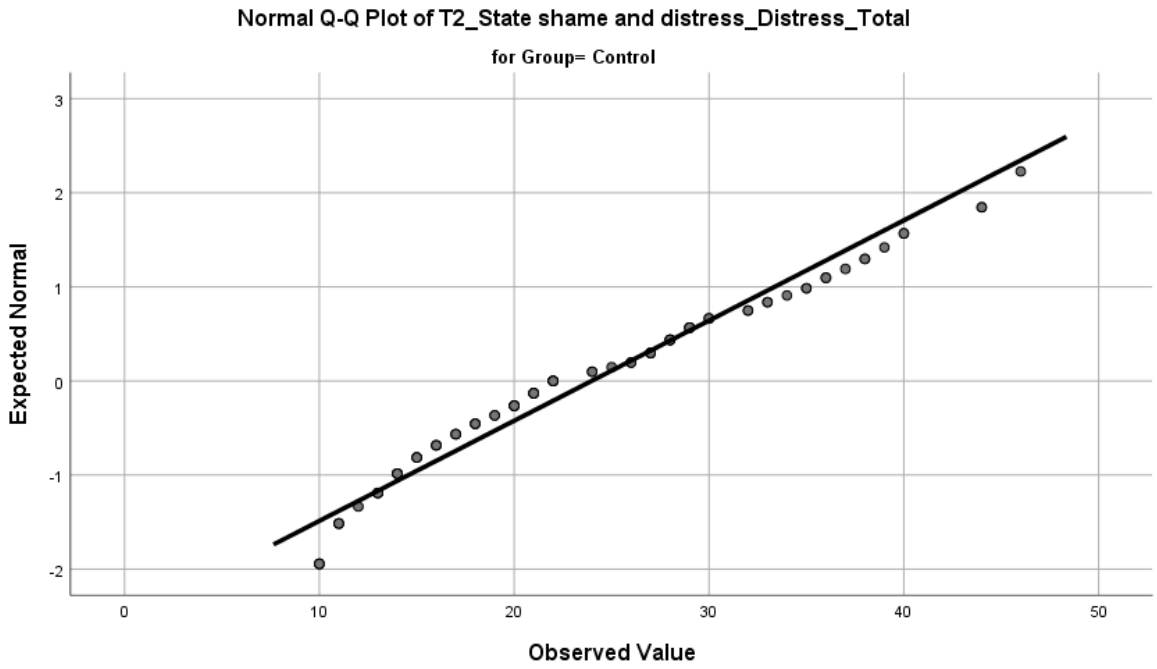


Figure S9

Histogram for T2 State Shame, SCI Group

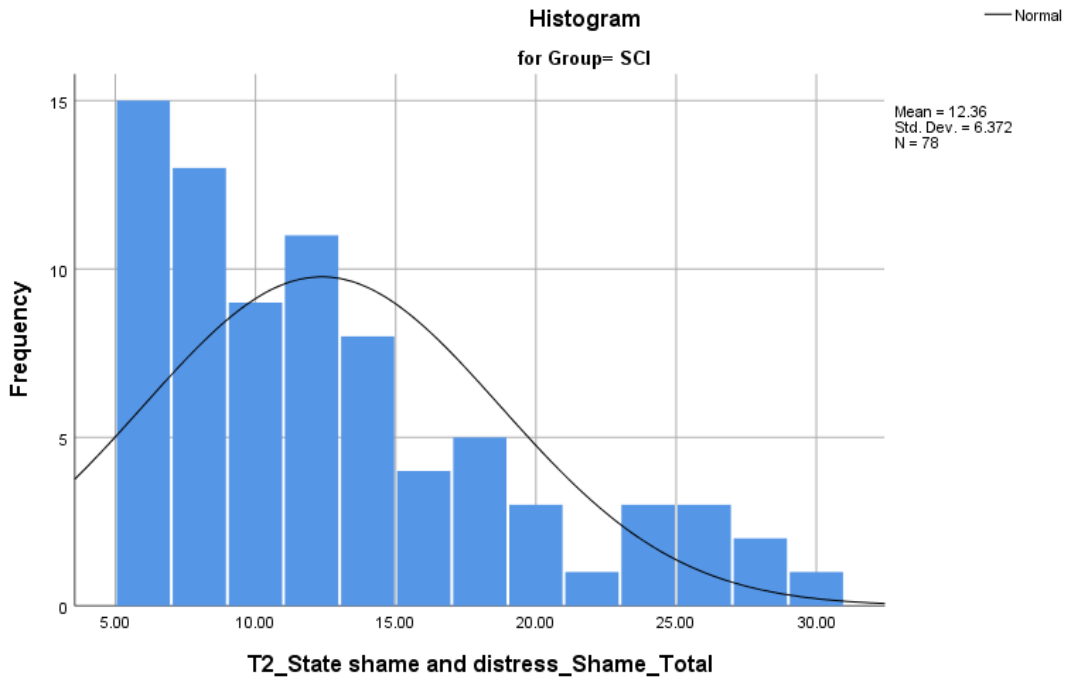


Figure S10

Q-Q Plot for T2 State Shame, SCI Group

Figure S11

Histogram for T2 State Shame, Control Group

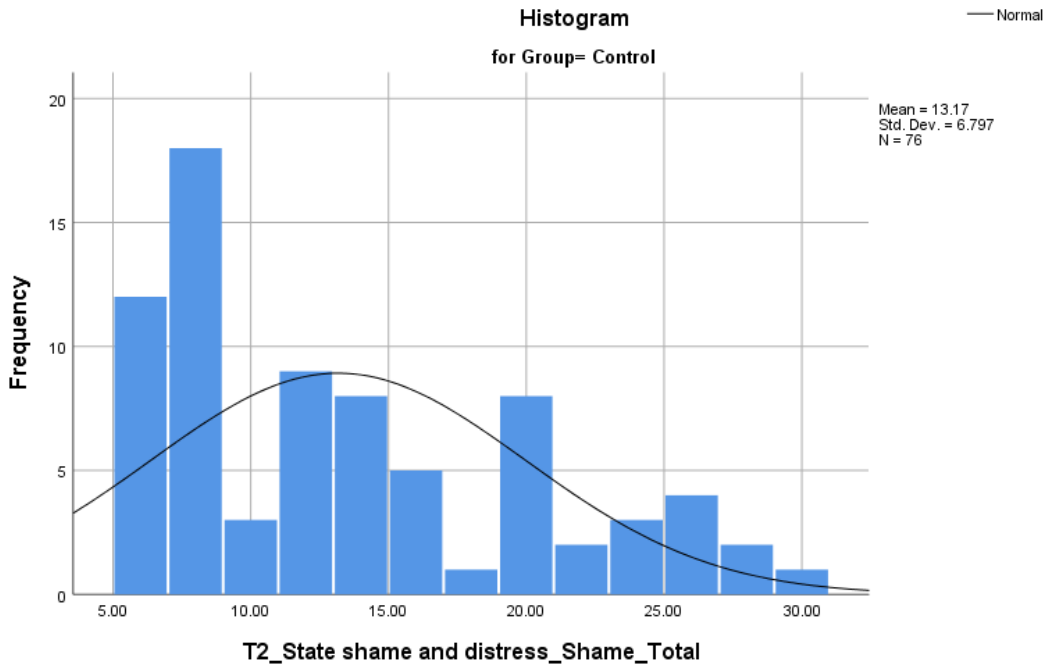


Figure S12

Q-Q Plot for T2 State Shame, Control Group

Figure S13

Histogram for T3 Trait Self-Compassion, SCI Group

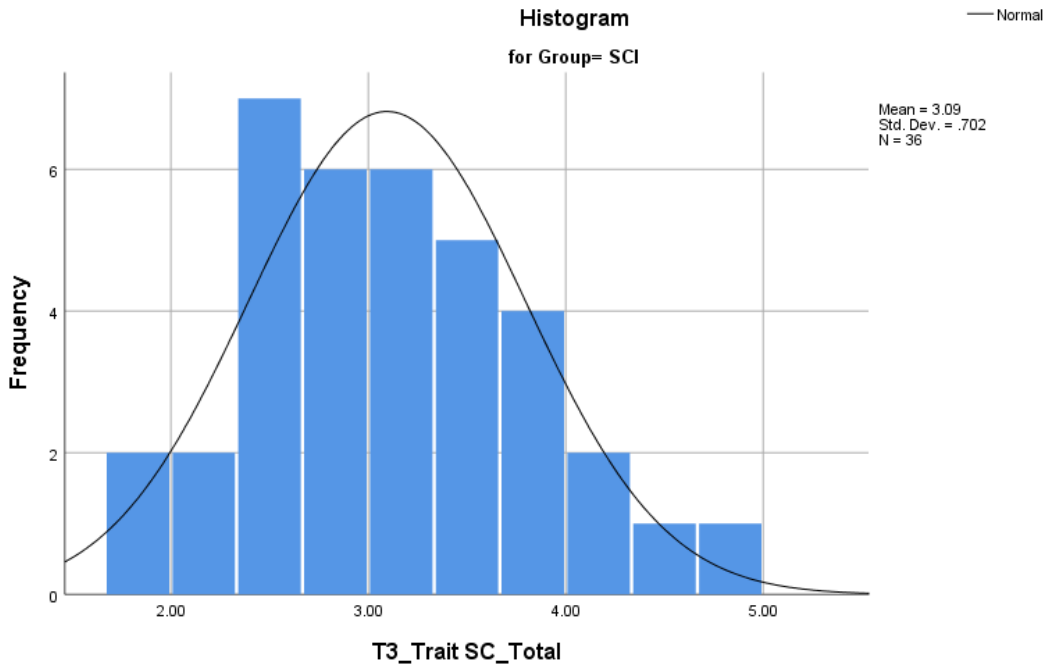


Figure S14

Q-Q Plot for T3 Trait Self-Compassion, SCI Group

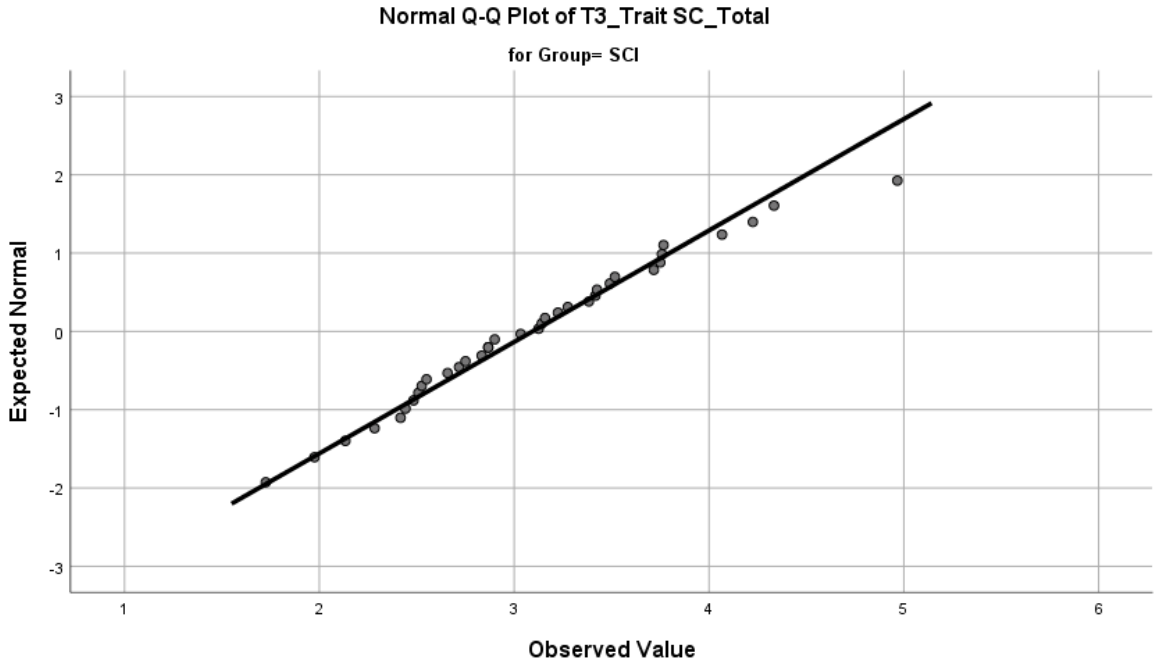


Figure S15

Histogram for T3 Trait Self-Compassion, Control Group

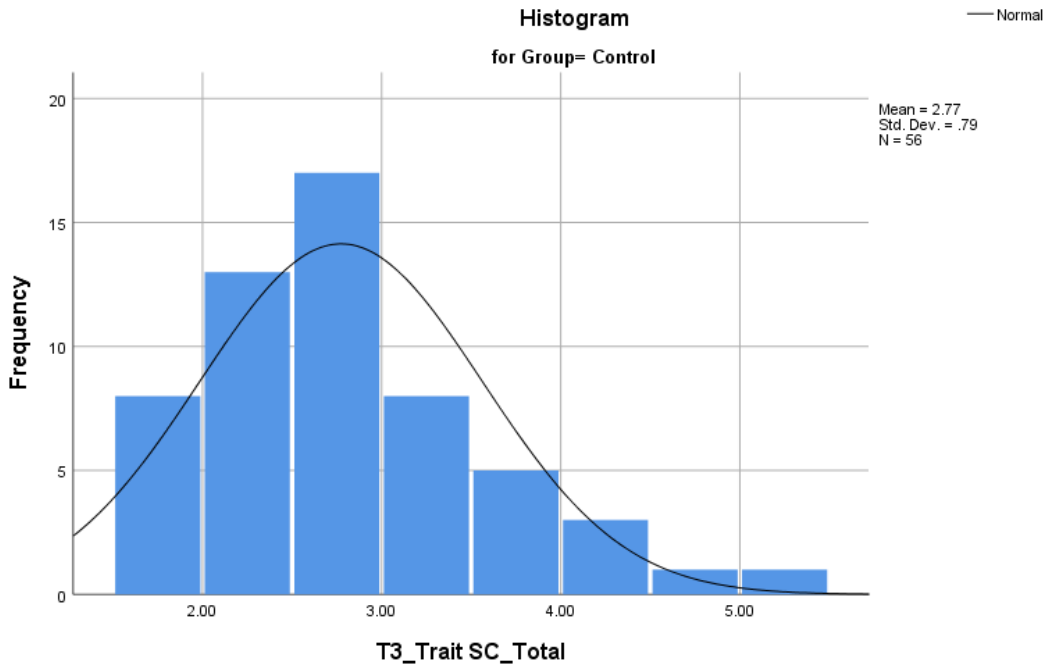


Figure S16

Q-Q Plot for T3 Trait Self-Compassion, Control Group

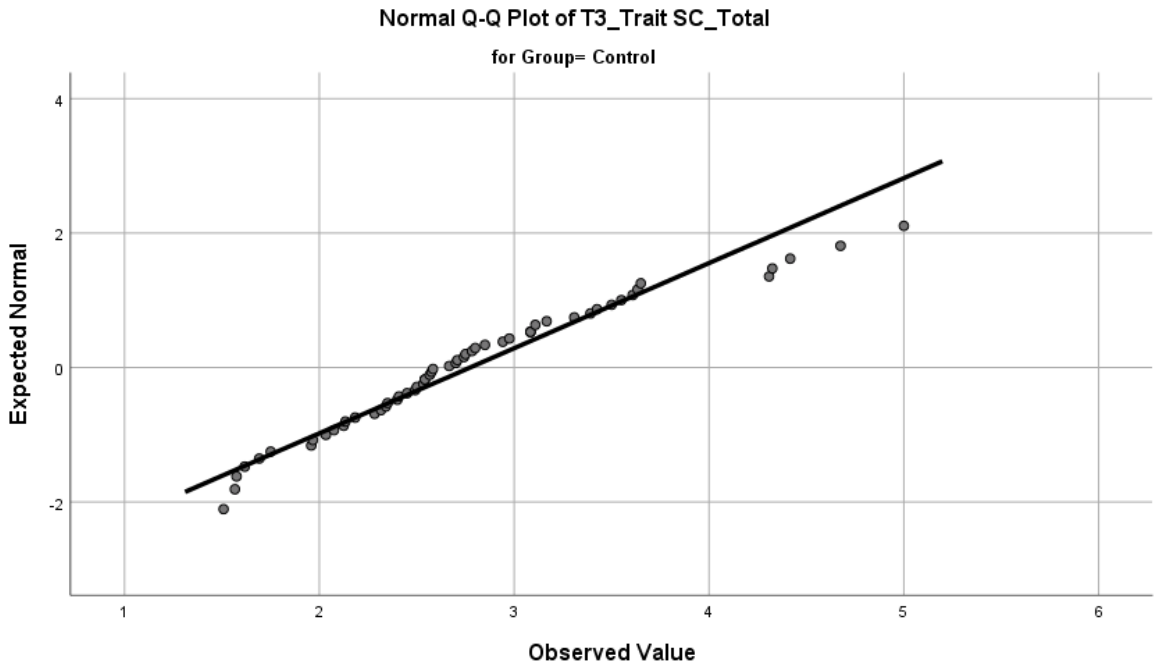


Figure S17

Histogram for T3 Parental Stress Frequency, SCI Group

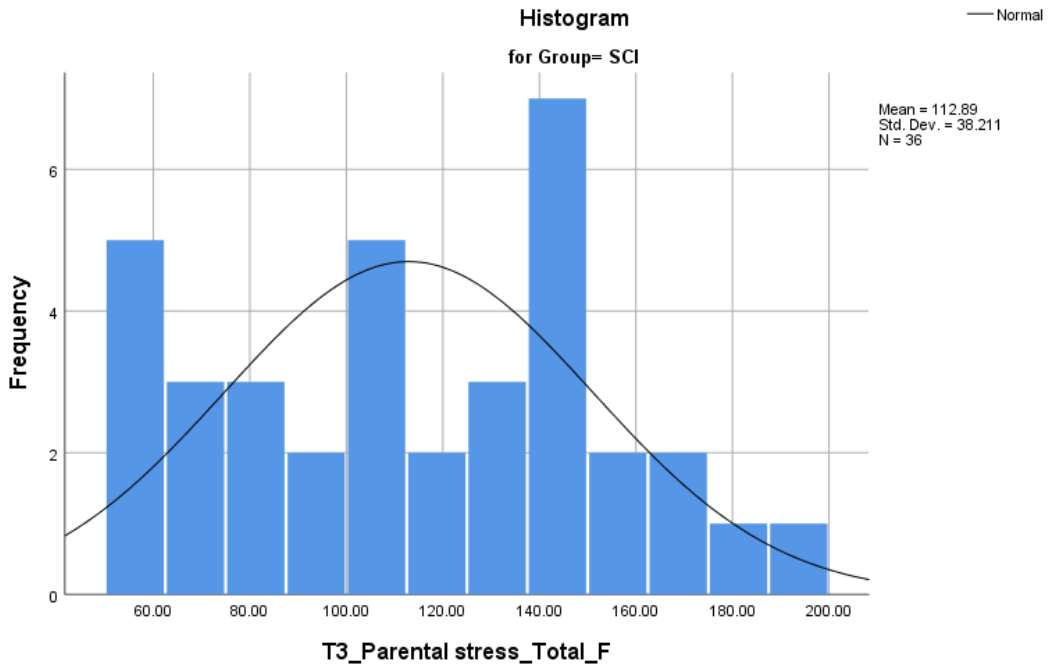


Figure S18

Q-Q Plot for T3 Parental Stress Frequency, SCI Group

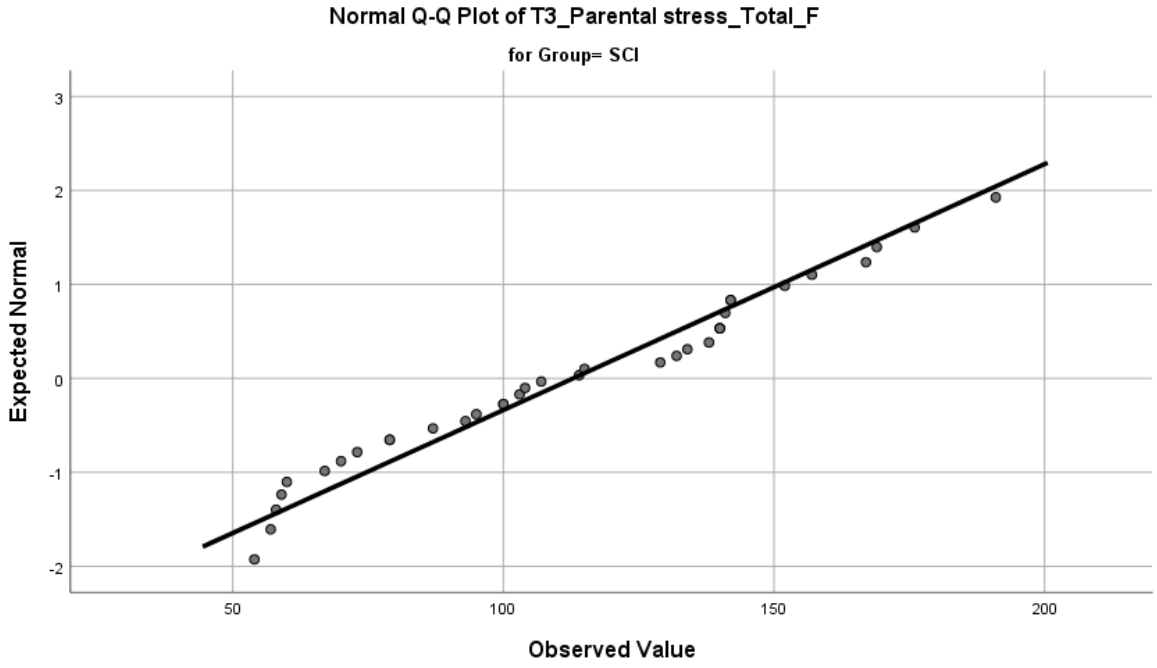


Figure S19

Histogram for T3 Parental Stress Frequency, Control Group

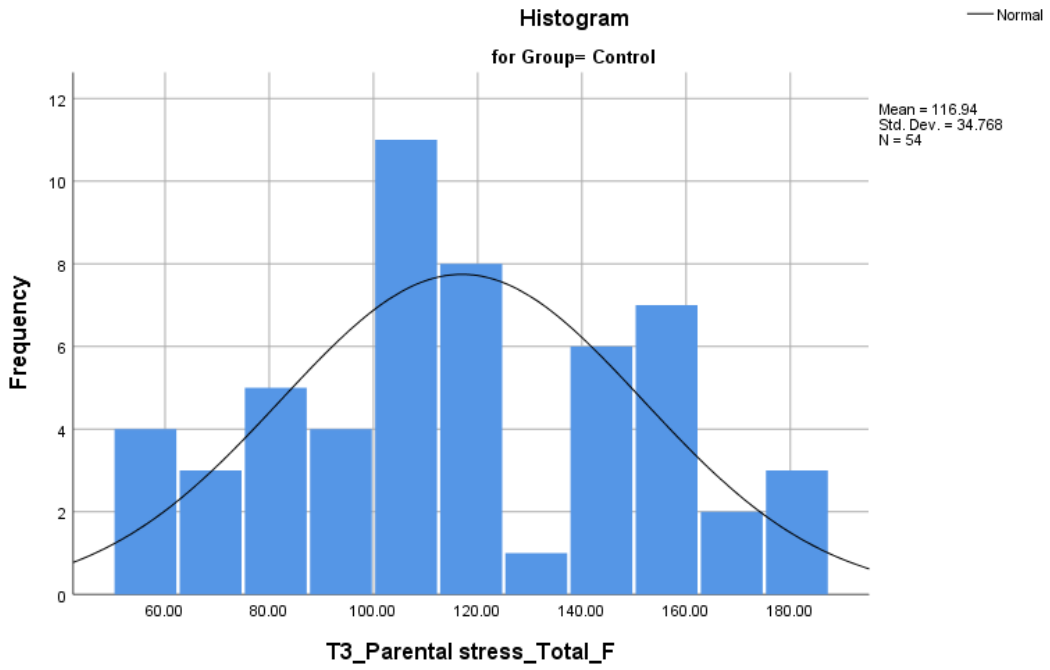


Figure S20

Q-Q Plot for T3 Parental Stress Frequency, Control Group

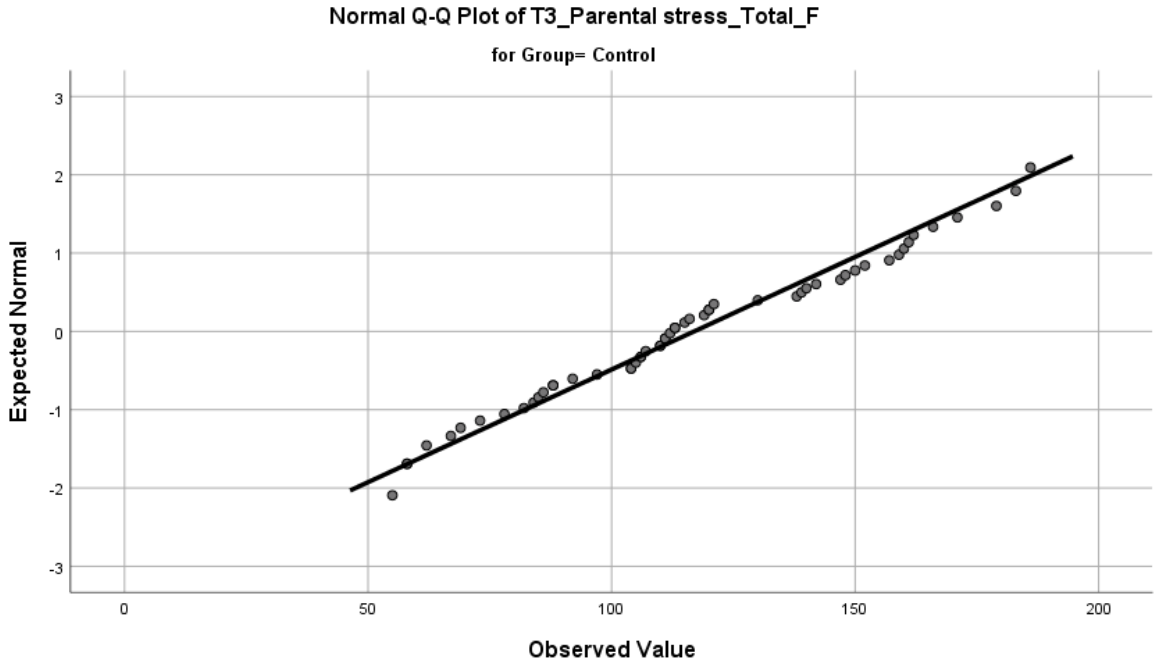


Figure S21

Histogram for T3 Parental Stress Difficulty, SCI Group

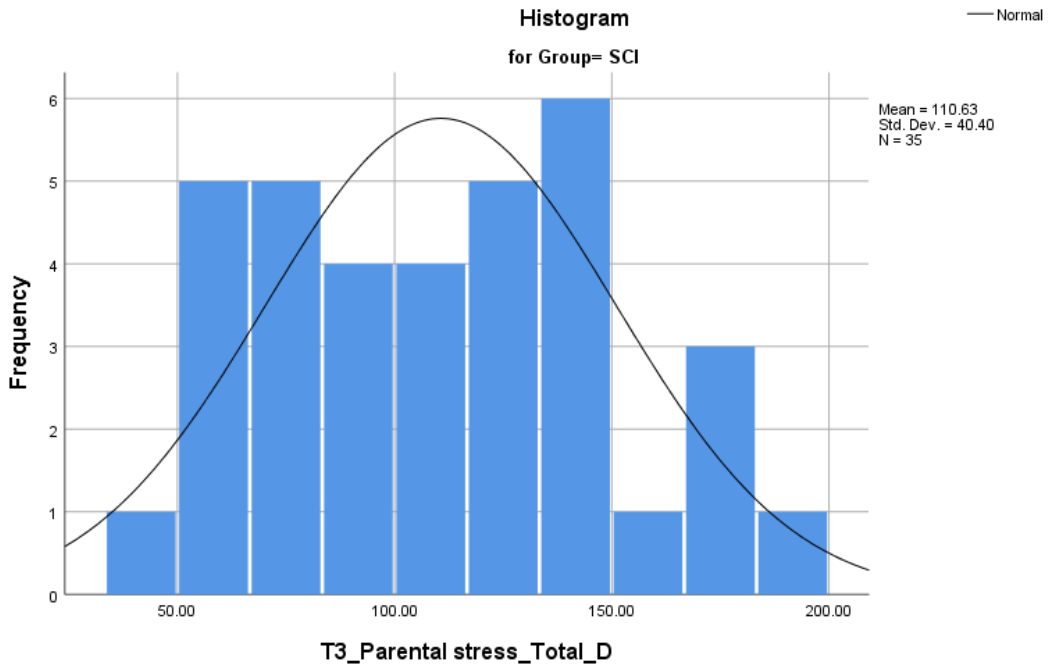


Figure S22

Q-Q Plot for T3 Parental Stress Difficulty, SCI Group

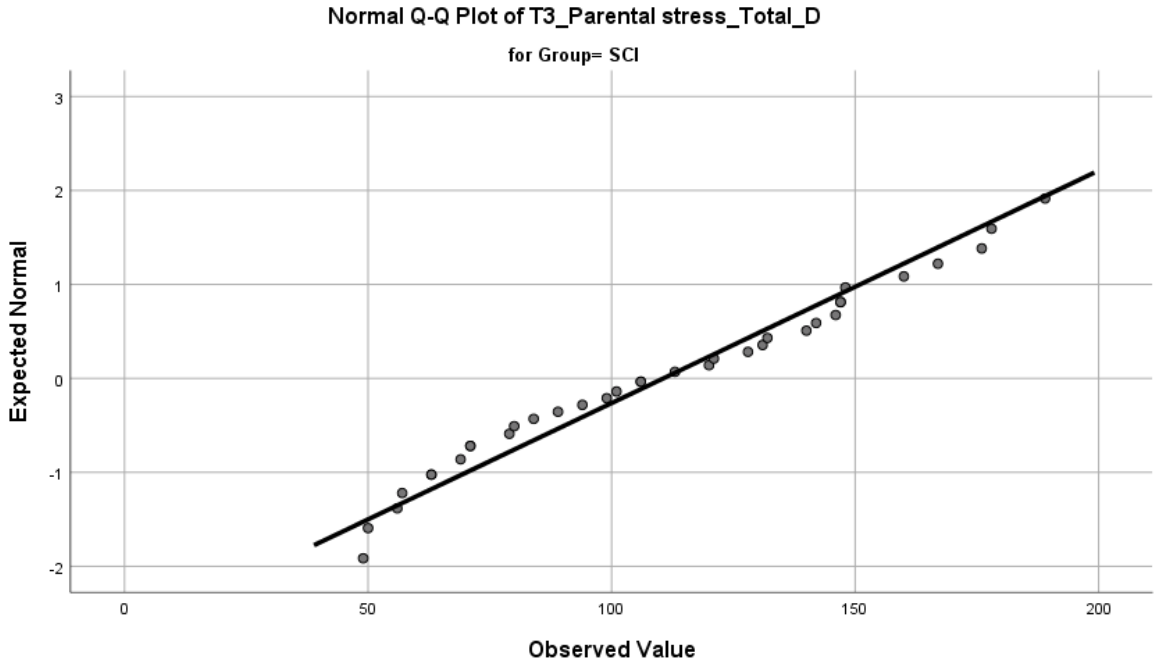


Figure S23

Histogram for T3 Parental Stress Difficulty, Control Group

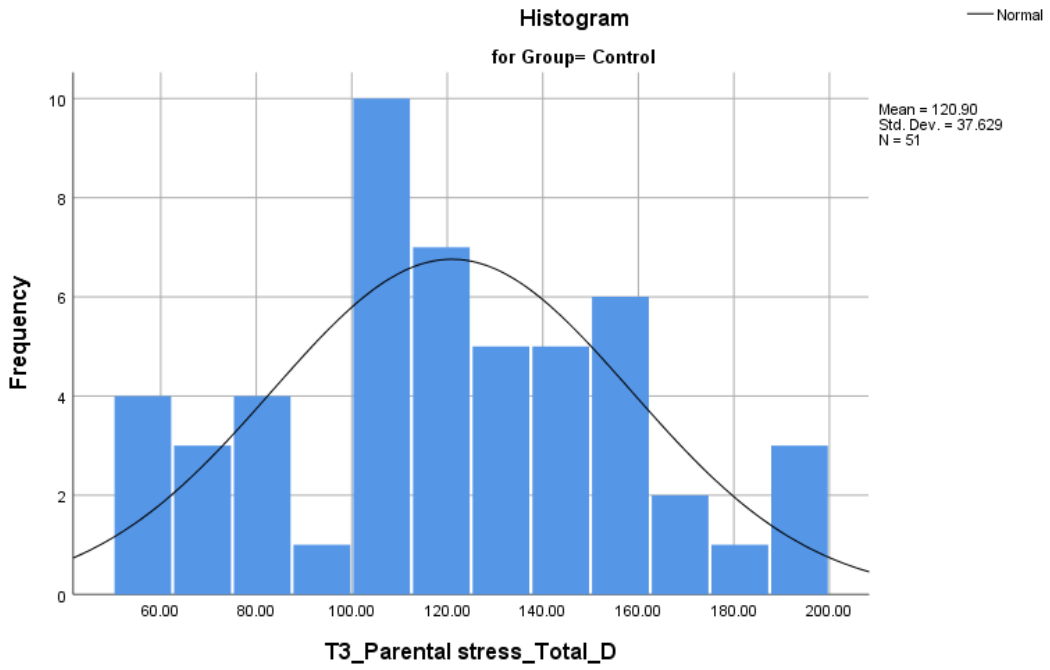
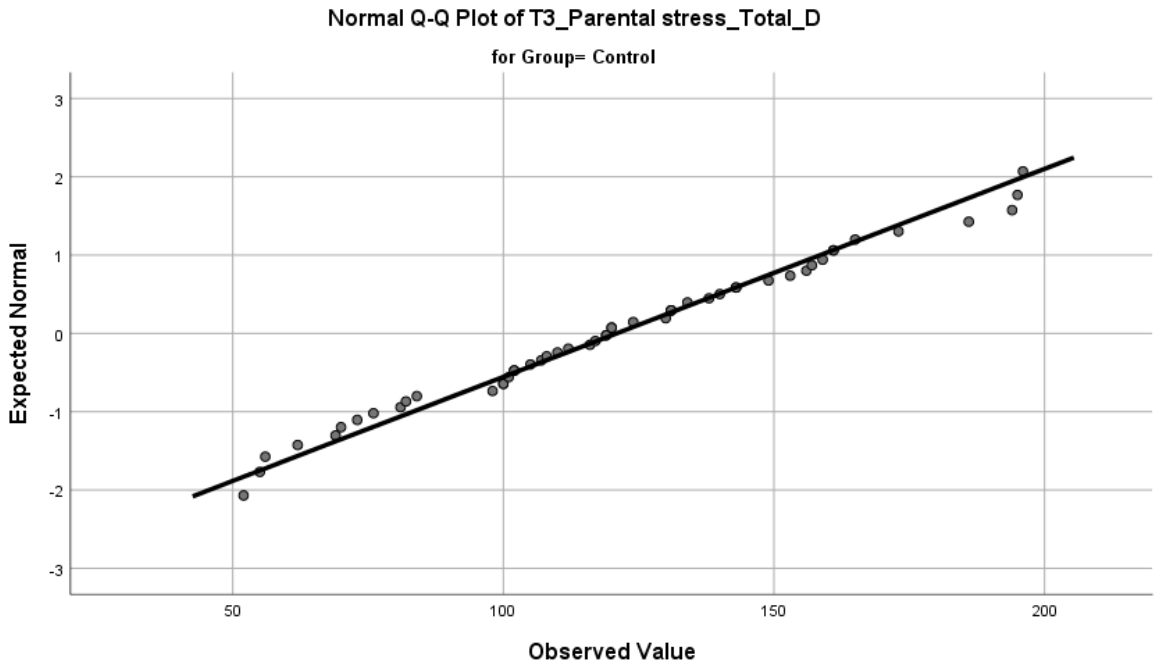


Figure S24

Q-Q Plot for T3 Parental Stress Difficulty, Control Group



Appendix T

Graphs for the Distribution of Transformed Outcome Data Across Groups

Figure T1

Histogram for Transformed T1 State Distress, SCI Group

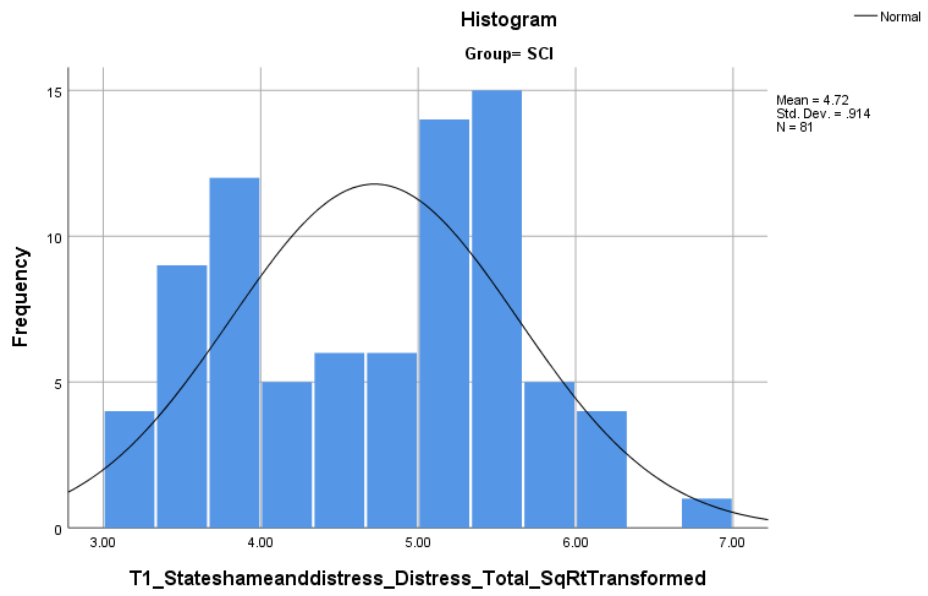


Figure T2

Q-Q Plot for Transformed T1 State Distress, SCI Group

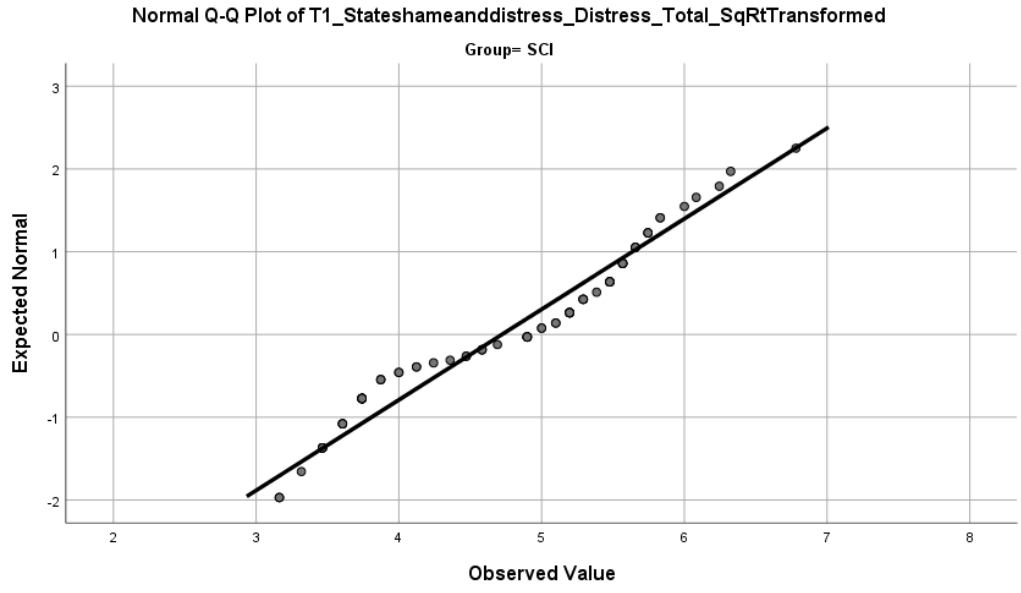


Figure T3

Histogram for Transformed T1 State Distress, Control Group

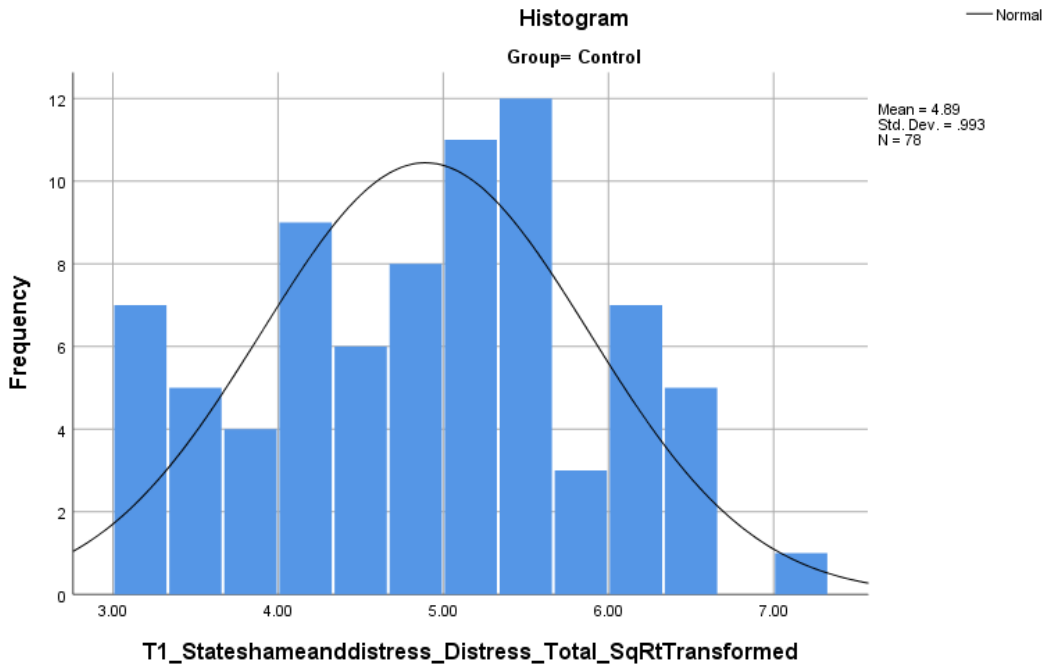


Figure T4

Q-Q Plot for Transformed T1 State Distress, Control Group

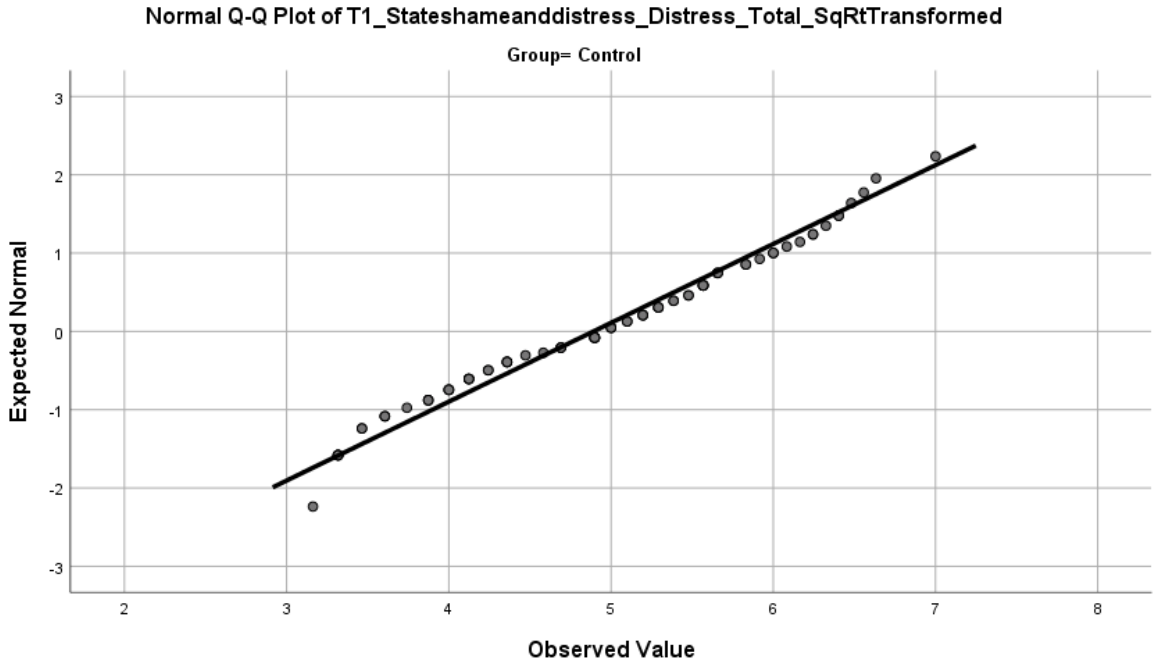


Figure T5

Histogram for Transformed T1 State Shame, SCI Group

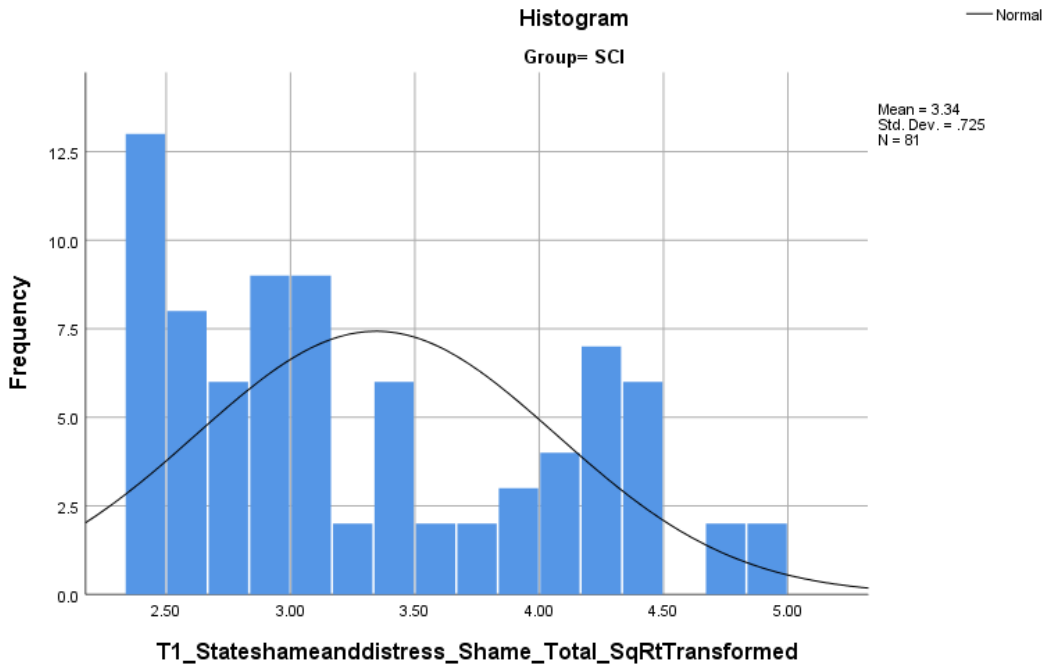


Figure T6

Q-Q Plot for Transformed T1 State Shame, SCI Group

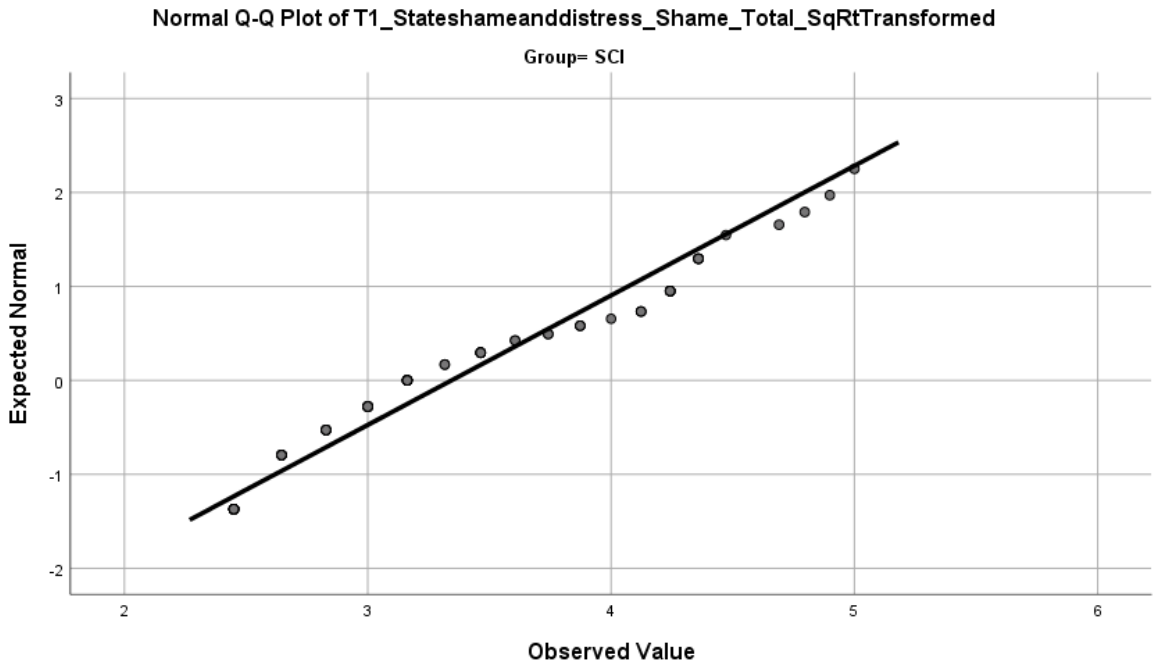


Figure T7

Histogram for Transformed T1 State Shame, Control Group

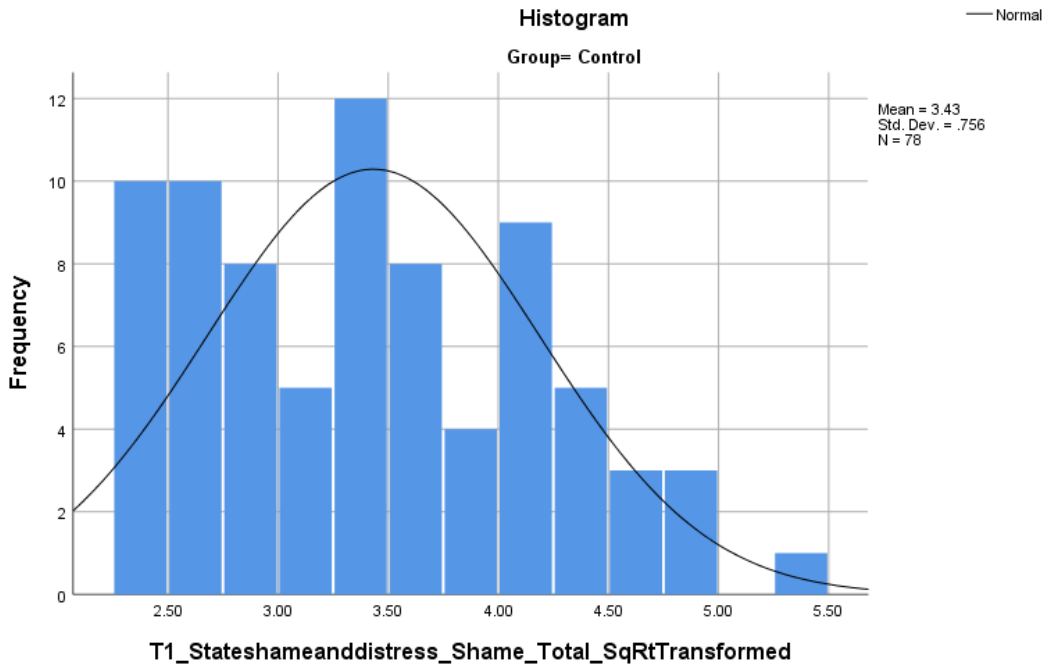


Figure T8

Q-Q Plot for Transformed T1 State Shame, Control Group

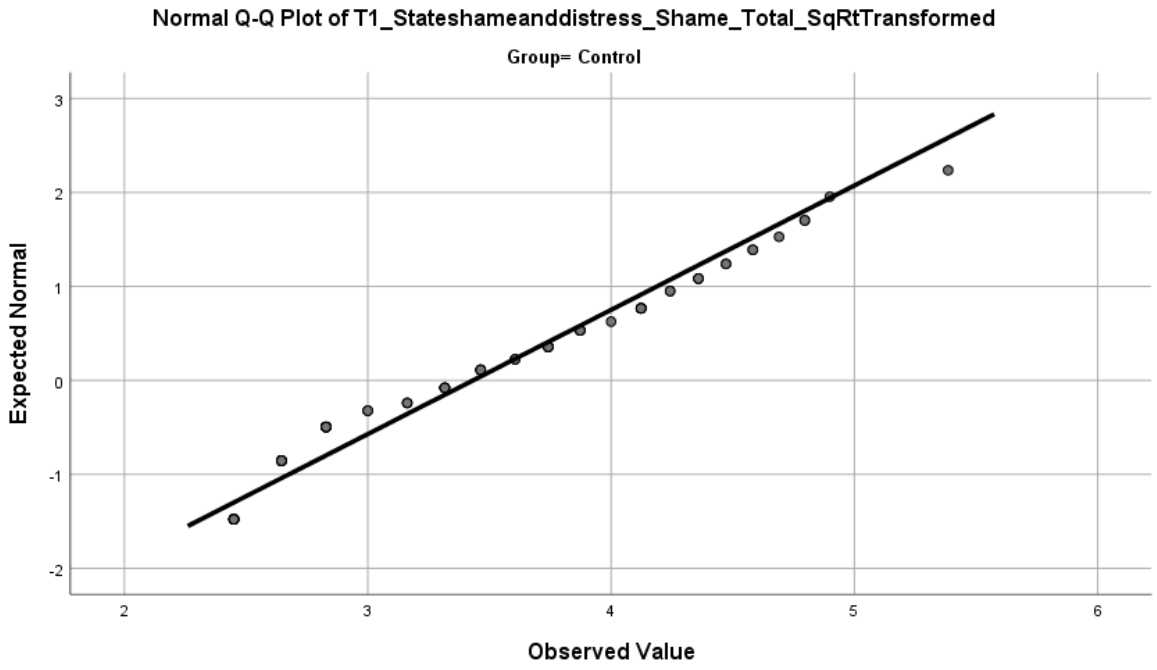


Figure T9

Histogram for Transformed T2 State Distress, SCI Group

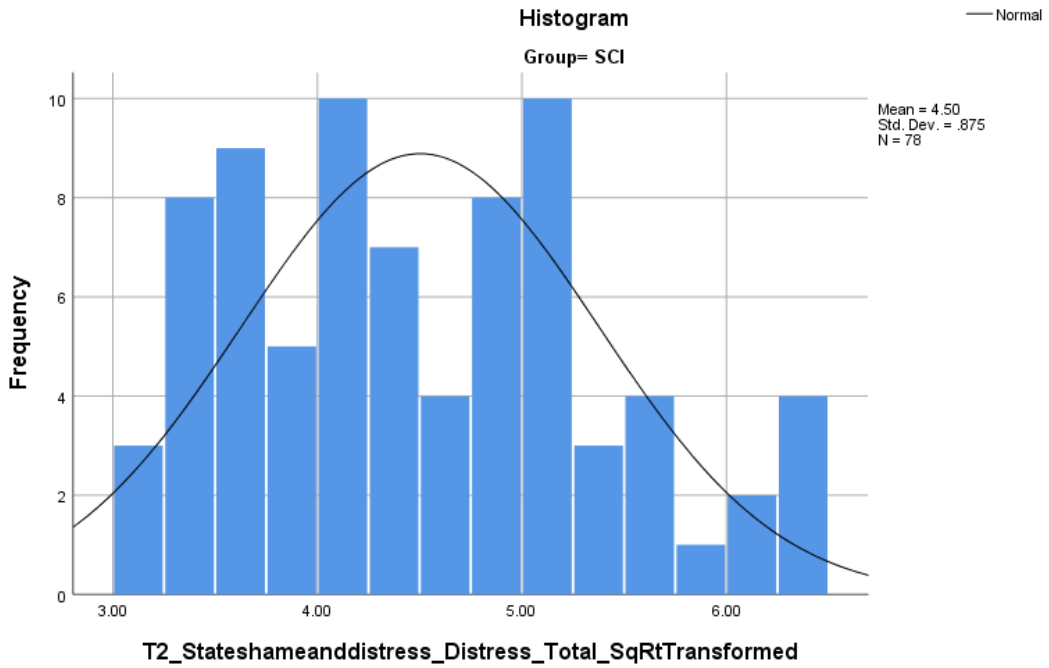


Figure T10

Q-Q Plot for Transformed T2 State Distress, SCI Group

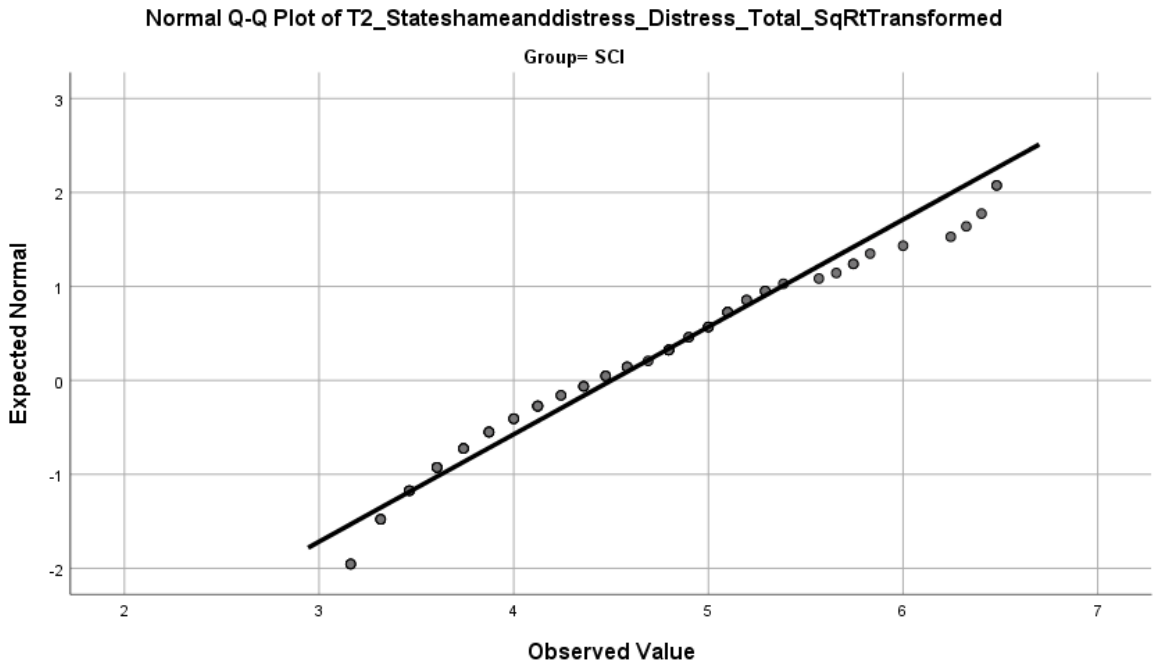


Figure T11

Histogram for Transformed T2 State Distress, Control Group

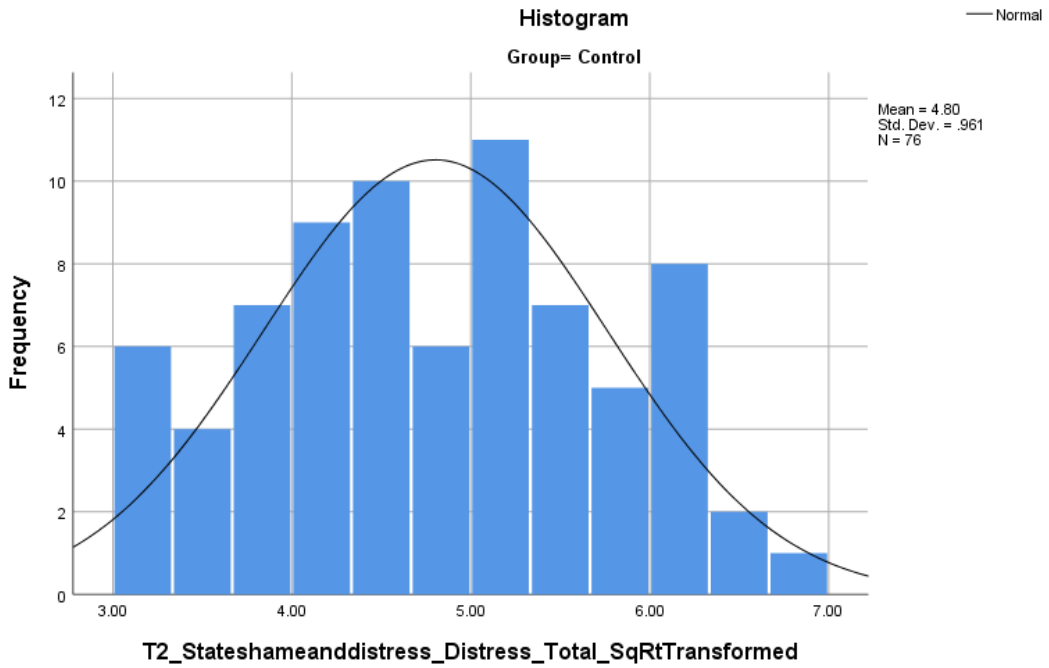


Figure T12

Q-Q Plot for Transformed T2 State Distress, Control Group

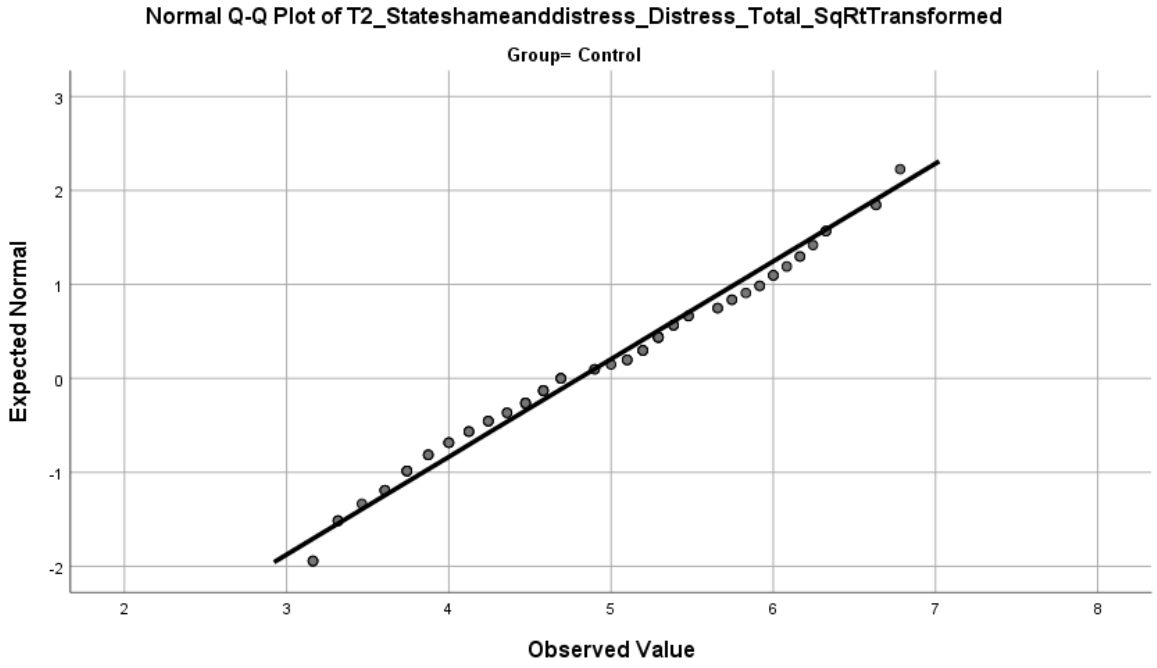


Figure T13

Histogram for Transformed T2 State Shame, SCI Group

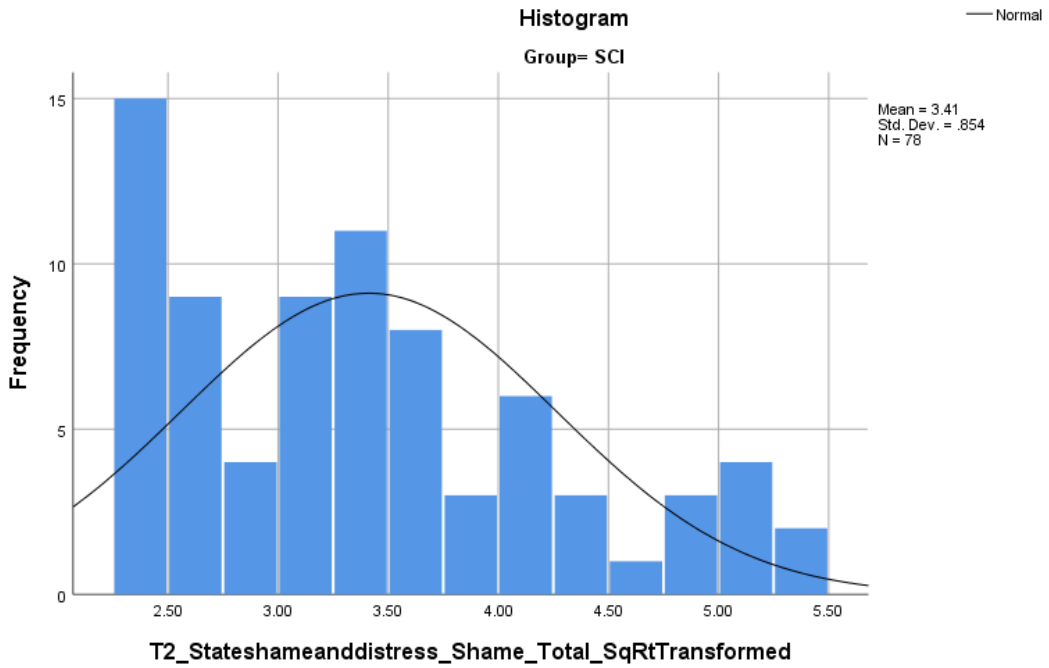


Figure T14

Q-Q Plot for Transformed T2 State Shame, SCI Group

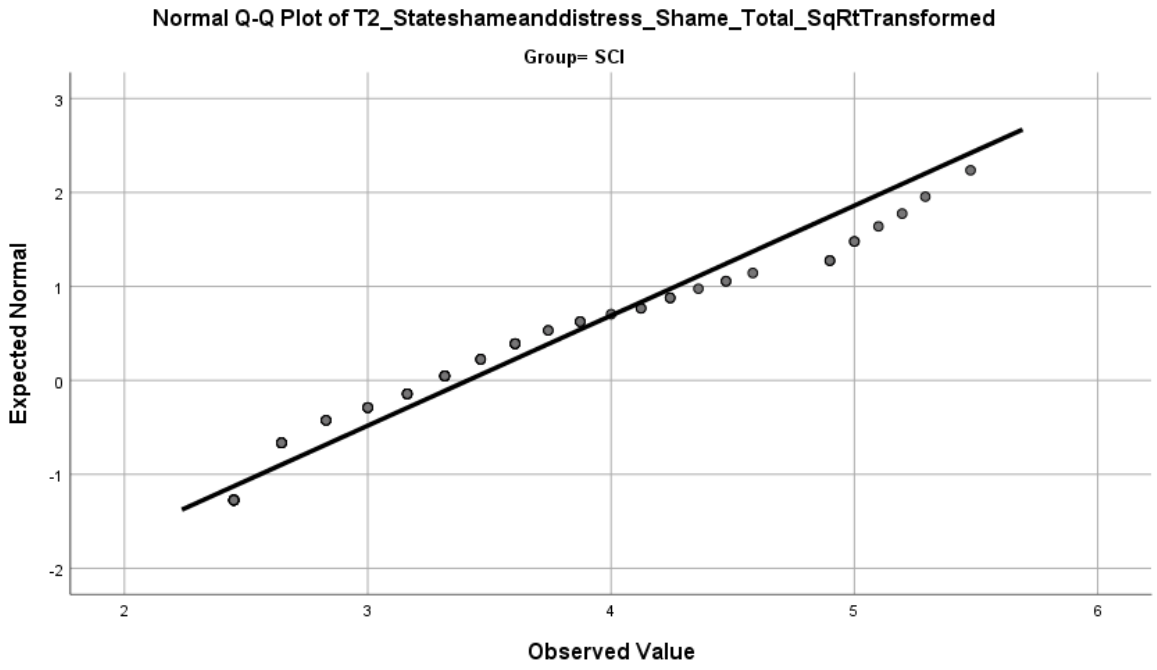


Figure T15

Histogram for Transformed T2 State Shame, Control Group

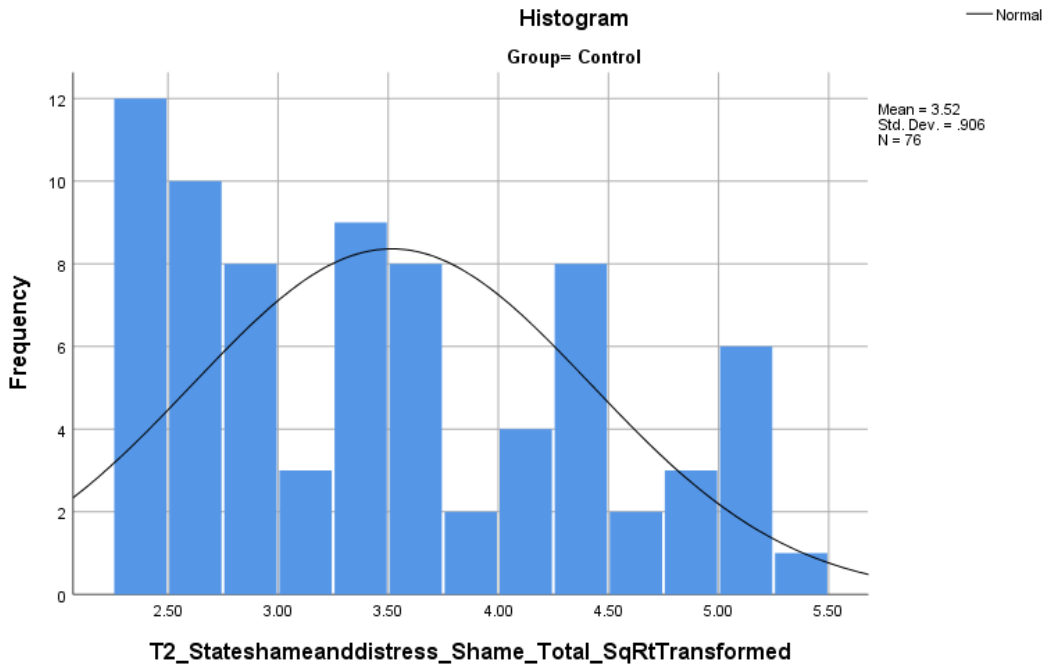
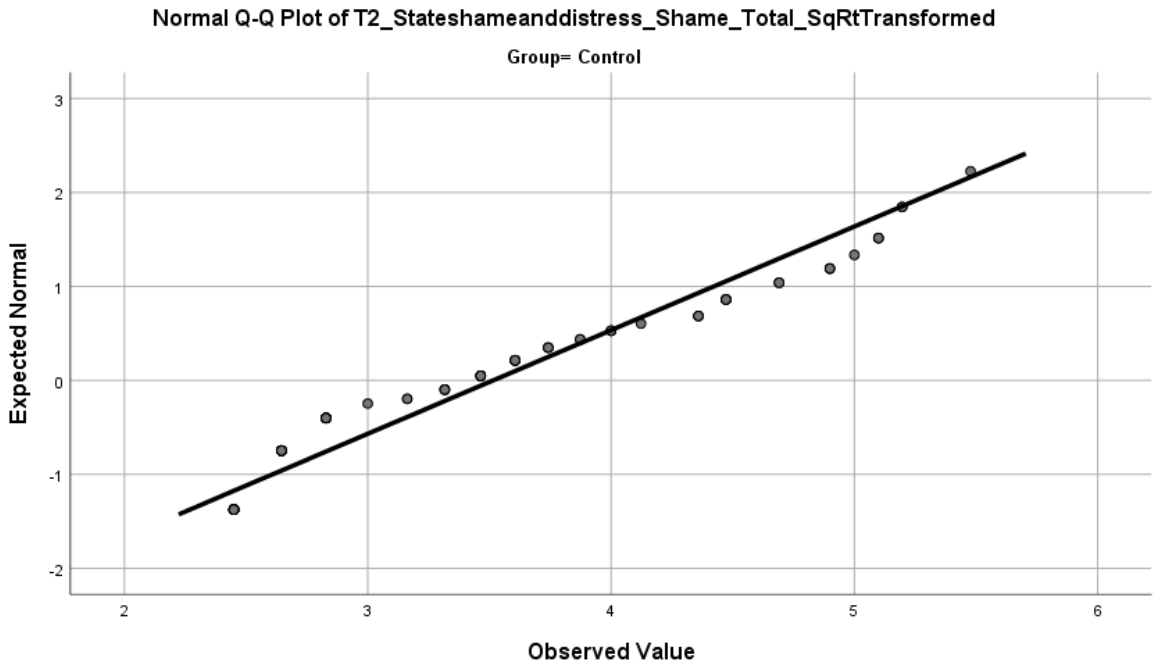


Figure T16

Q-Q Plot for Transformed T2 State Shame, Control Group



Appendix U

Levene's Test for Homogeneity of Variance

Test of Homogeneity of Variance

		Levene Statistic	df1	df2	Sig.
T1_State SC_Total	Based on Mean	.182	1	157	.671
	Based on Median	.104	1	157	.748
	Based on Median and with adjusted df	.104	1	156.994	.748
	Based on trimmed mean	.205	1	157	.652
T1_State shame and distress_Distress_Total	Based on Mean	.765	1	157	.383
	Based on Median	.909	1	157	.342
	Based on Median and with adjusted df	.909	1	151.166	.342
	Based on trimmed mean	.719	1	157	.398
T1_State shame and distress_Shame_Total	Based on Mean	.207	1	157	.650
	Based on Median	.413	1	157	.521
	Based on Median and with adjusted df	.413	1	156.820	.521
	Based on trimmed mean	.196	1	157	.658
T1_Trait SC_Total	Based on Mean	.022	1	156	.882
	Based on Median	.082	1	156	.775
	Based on Median and with adjusted df	.082	1	155.398	.775
	Based on trimmed mean	.031	1	156	.860
T1_Parental stress_Total_F	Based on Mean	2.569	1	155	.111
	Based on Median	2.254	1	155	.135
	Based on Median and with adjusted df	2.254	1	154.853	.135
	Based on trimmed mean	2.588	1	155	.110
T1_Parental stress_Total_D	Based on Mean	1.904	1	149	.170
	Based on Median	.993	1	149	.321
	Based on Median and with adjusted df	.993	1	148.261	.321
	Based on trimmed mean	1.838	1	149	.177
T2_State SC_Total	Based on Mean	1.395	1	153	.239
	Based on Median	1.145	1	153	.286
	Based on Median and with adjusted df	1.145	1	152.758	.286

	Based on trimmed mean	1.507	1	153	.221
T2_State shame and distress_Distress_Total	Based on Mean	2.491	1	152	.117
	Based on Median	2.022	1	152	.157
	Based on Median and with adjusted df	2.022	1	151.514	.157
	Based on trimmed mean	2.527	1	152	.114
T2_State shame and distress_Shame_Total	Based on Mean	.980	1	152	.324
	Based on Median	.965	1	152	.327
	Based on Median and with adjusted df	.965	1	151.570	.327
	Based on trimmed mean	1.024	1	152	.313
T3_Trait SC_Total	Based on Mean	.202	1	90	.654
	Based on Median	.108	1	90	.744
	Based on Median and with adjusted df	.108	1	85.441	.744
	Based on trimmed mean	.147	1	90	.703
T3_Parental stress_Total_F	Based on Mean	1.106	1	88	.296
	Based on Median	1.224	1	88	.272
	Based on Median and with adjusted df	1.224	1	87.375	.272
	Based on trimmed mean	1.125	1	88	.292
T3_Parental stress_Total_D	Based on Mean	.871	1	84	.353
	Based on Median	.827	1	84	.366
	Based on Median and with adjusted df	.827	1	83.653	.366
	Based on trimmed mean	.875	1	84	.352

Appendix V

Correlations Between Covariates to Test for Multicollinearity

Correlations

		Participant Info_Age of child with IBD	Participant Info_IBD type	Participant Info_Stoma?	T1_State SC_Total	T1_State shame and distress_Distress_Total	T1_State shame and distress_Shame_Total	T1_Trait SC_Total	T1_Parental stress_Total_F	T1_Parental stress_Total_D
Participant Info_Age of child with IBD	Pearson Correlation	1	-.128	.092	-.012	-.167*	.007	.003	-.016	-.039
	Sig. (2-tailed)		.108	.250	.882	.036	.926	.968	.840	.638
	N	159	159	159	159	159	159	158	157	151
Participant Info_IBD type	Pearson Correlation	-.128	1	.090	.028	-.021	-.062	-.066	-.036	.013
	Sig. (2-tailed)	.108		.258	.722	.791	.437	.408	.651	.875
	N	159	159	159	159	159	159	158	157	151
Participant Info_Stoma?	Pearson Correlation	.092	.090	1	.016	-.150	-.001	.093	.004	.014
	Sig. (2-tailed)	.250	.258		.837	.059	.992	.247	.958	.866
	N	159	159	159	159	159	159	158	157	151
T1_State SC_Total	Pearson Correlation	-.012	.028	.016	1	-.447**	-.458**	.696**	-.412**	-.440**
	Sig. (2-tailed)	.882	.722	.837		.000	.000	.000	.000	.000
	N	159	159	159	159	159	159	158	157	151

T1_State shame and distress_Distress_Total	Pearson Correlation	-.167*	-.021	-.150	-.447**	1	.650**	-.344**	.664**	.669**
	Sig. (2-tailed)	.036	.791	.059	.000		.000	.000	.000	.000
	N	159	159	159	159	159	159	158	157	151
T1_State shame and distress_Shame_Total	Pearson Correlation	.007	-.062	-.001	-.458**	.650**	1	-.440**	.525**	.529**
	Sig. (2-tailed)	.926	.437	.992	.000	.000		.000	.000	.000
	N	159	159	159	159	159	159	158	157	151
T1_Trait SC_Total	Pearson Correlation	.003	-.066	.093	.696**	-.344**	-.440**	1	-.357**	-.318**
	Sig. (2-tailed)	.968	.408	.247	.000	.000	.000		.000	.000
	N	158	158	158	158	158	158	158	156	150
T1_Parental stress_Total_F	Pearson Correlation	-.016	-.036	.004	-.412**	.664**	.525**	-.357**	1	.874**
	Sig. (2-tailed)	.840	.651	.958	.000	.000	.000	.000		.000
	N	157	157	157	157	157	157	156	157	150
T1_Parental stress_Total_D	Pearson Correlation	-.039	.013	.014	-.440**	.669**	.529**	-.318**	.874**	1
	Sig. (2-tailed)	.638	.875	.866	.000	.000	.000	.000	.000	
	N	151	151	151	151	151	151	150	150	151

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Appendix W

Scatterplots to Test for Linearity Between Covariates and Dependent Variables

Figure W1

Scatterplot to Test for Linearity Between T1 State Self-Compassion and T2 State Self-Compassion

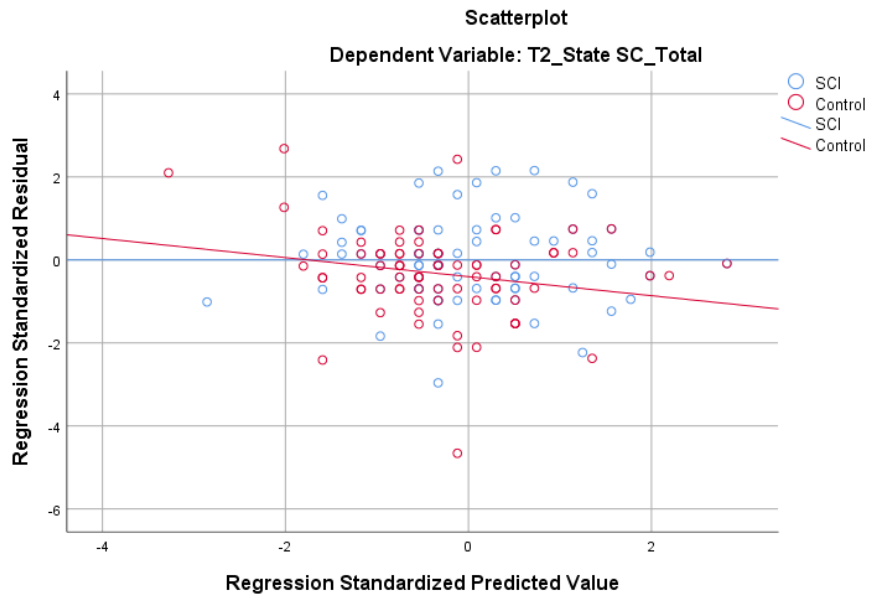


Figure W2

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T2 State Self-Compassion

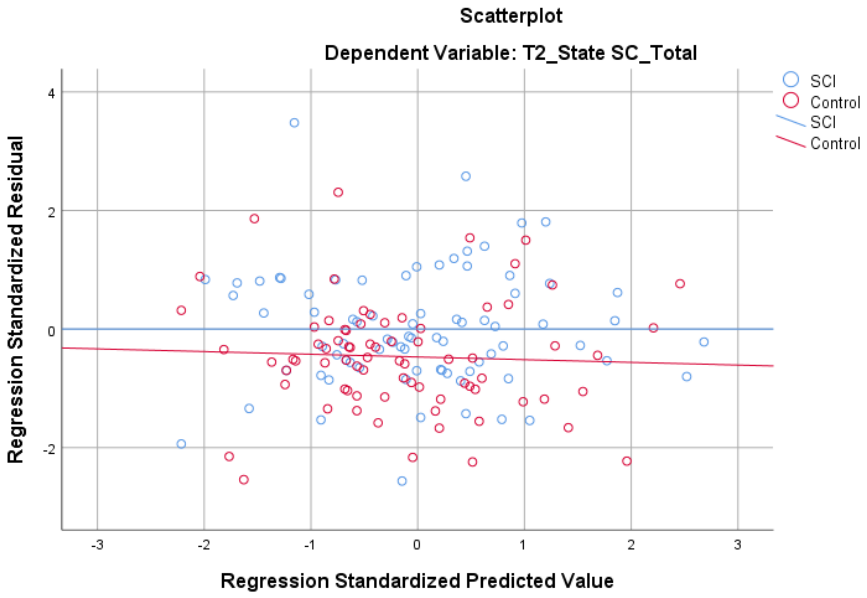


Figure W3

Scatterplot to Test for Linearity Between T1 State Shame and T2 State Self-Compassion

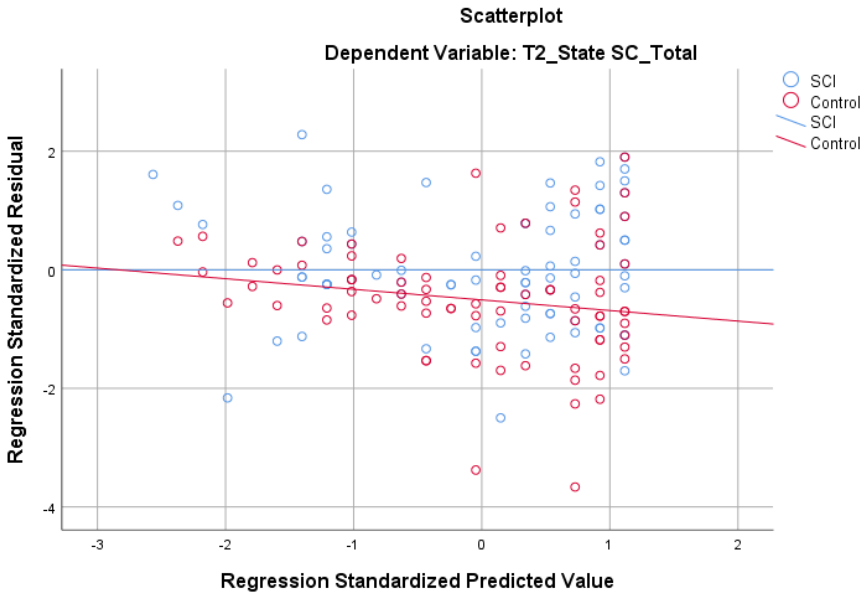


Figure W4

Scatterplot to Test for Linearity Between T1 State Distress and T2 State Distress

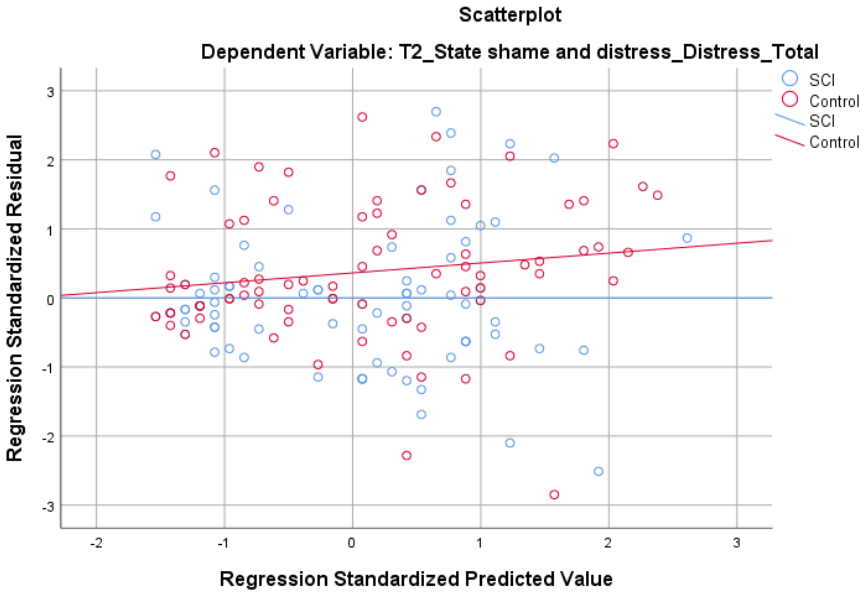


Figure W5

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T2 State Distress

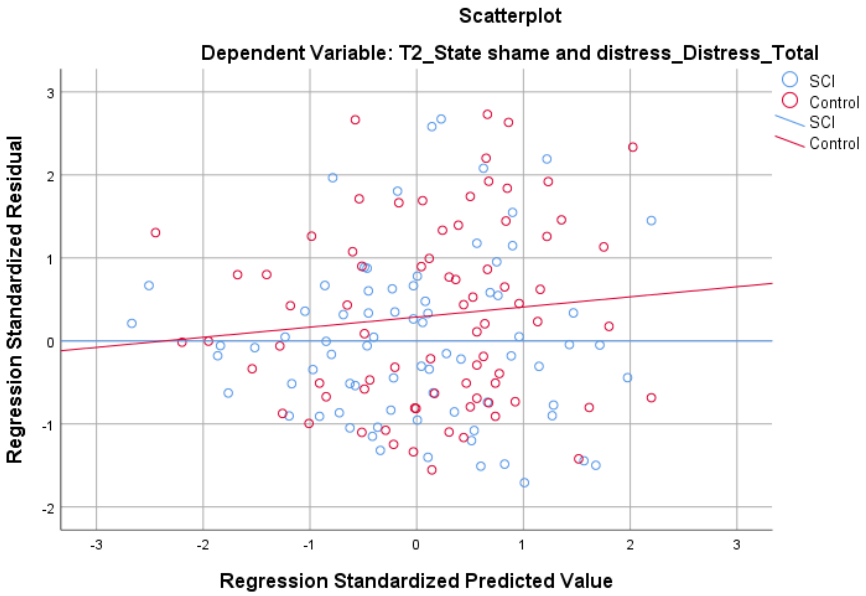


Figure W6

Scatterplot to Test for Linearity Between T1 State Shame and T2 State Distress

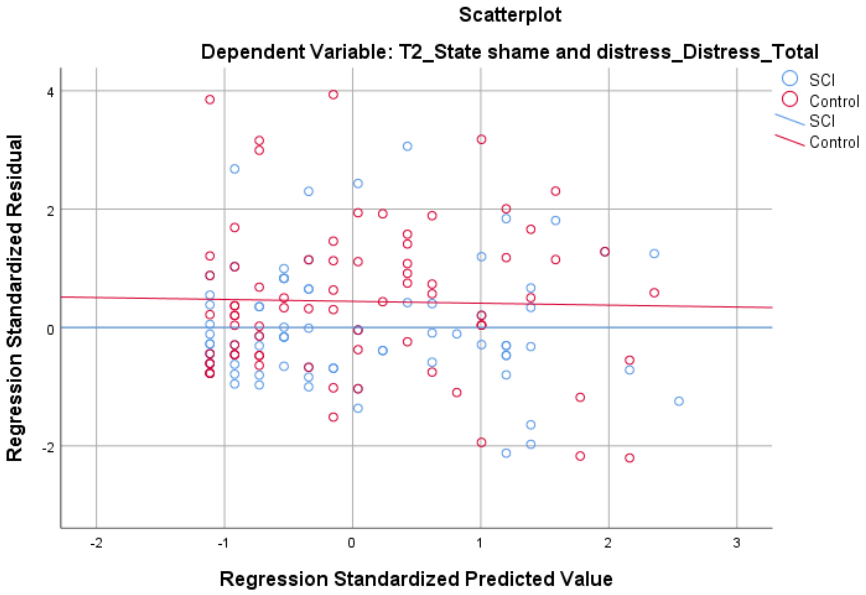


Figure W7

Scatterplot to Test for Linearity Between T1 Parental Stress Frequency and T2 State Distress

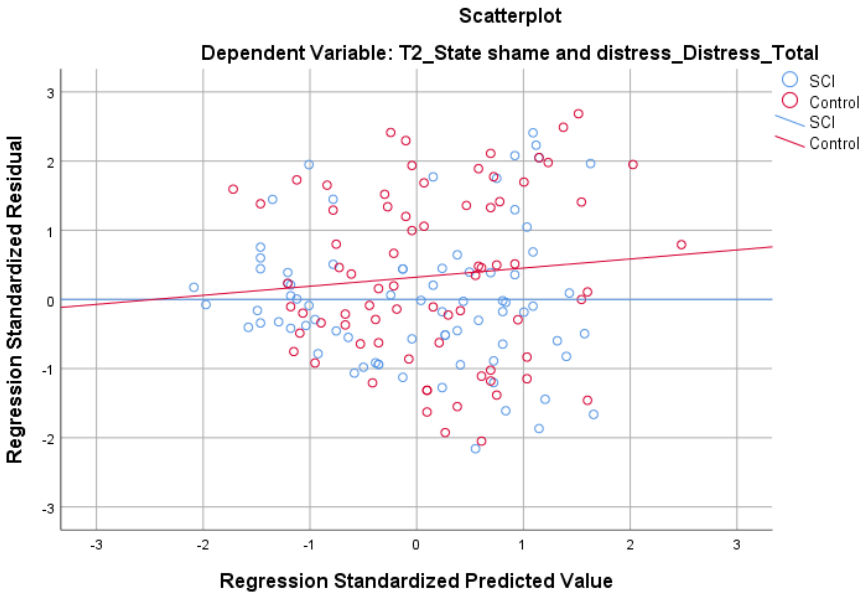


Figure W8

Scatterplot to Test for Linearity Between Age of Child and T2 State Distress

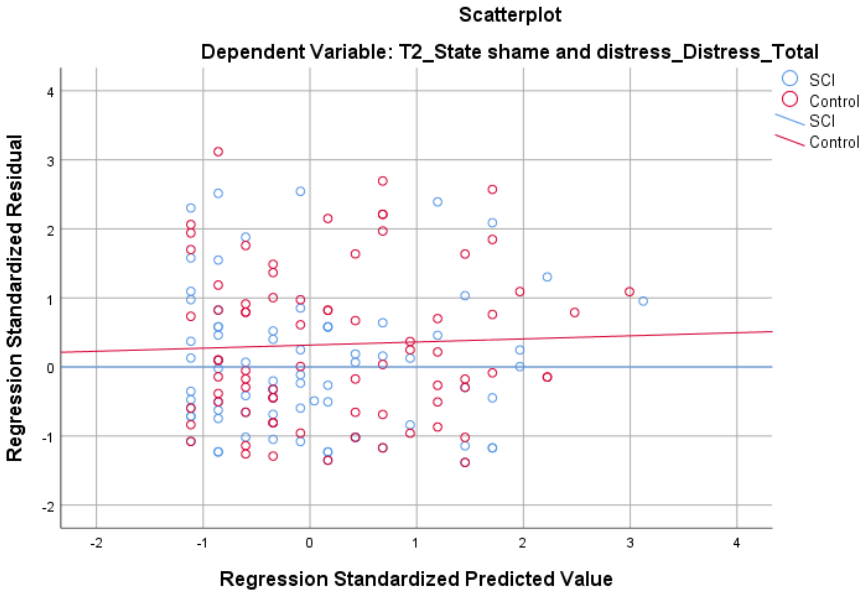


Figure W9

Scatterplot to Test for Linearity Between Child's IBD type and T2 State Distress

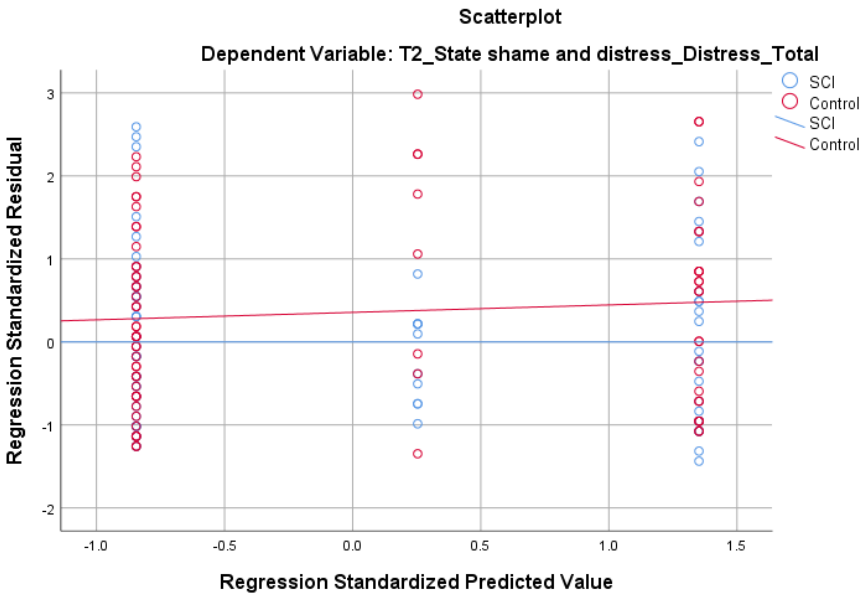


Figure W10

Scatterplot to Test for Linearity Between Child's Stoma Status and T2 State Distress

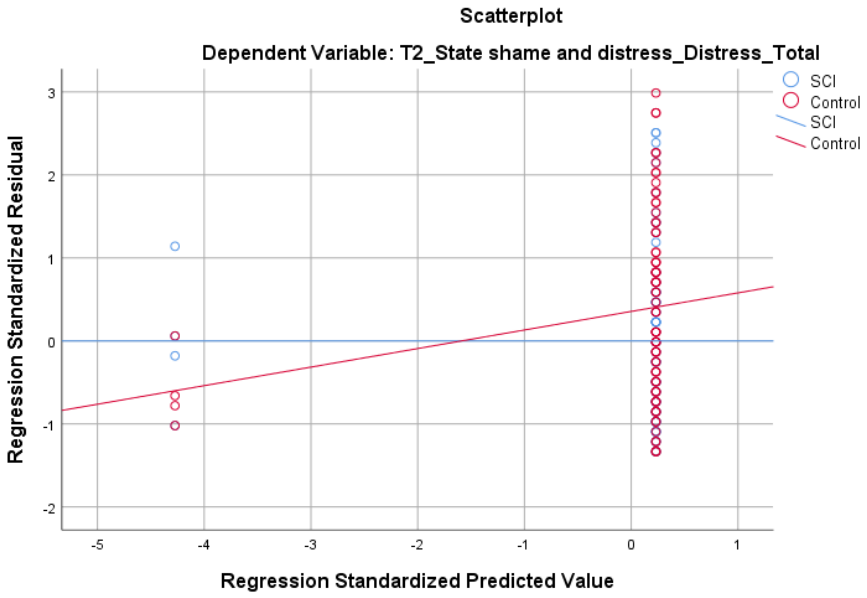


Figure W11

Scatterplot to Test for Linearity Between T1 State Shame and T2 State Shame

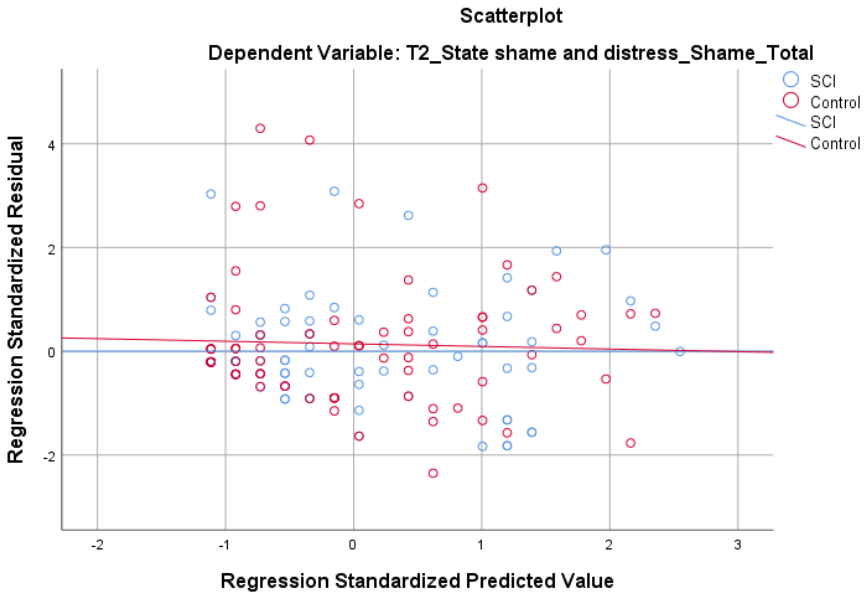


Figure W12

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T2 State Shame

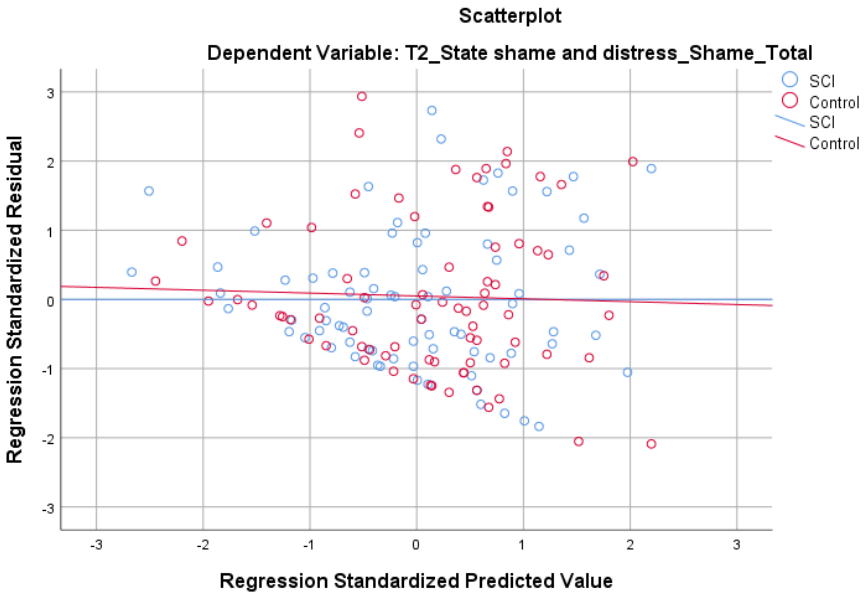


Figure W13

Scatterplot to Test for Linearity Between T1 State Self-Compassion and T2 State Shame

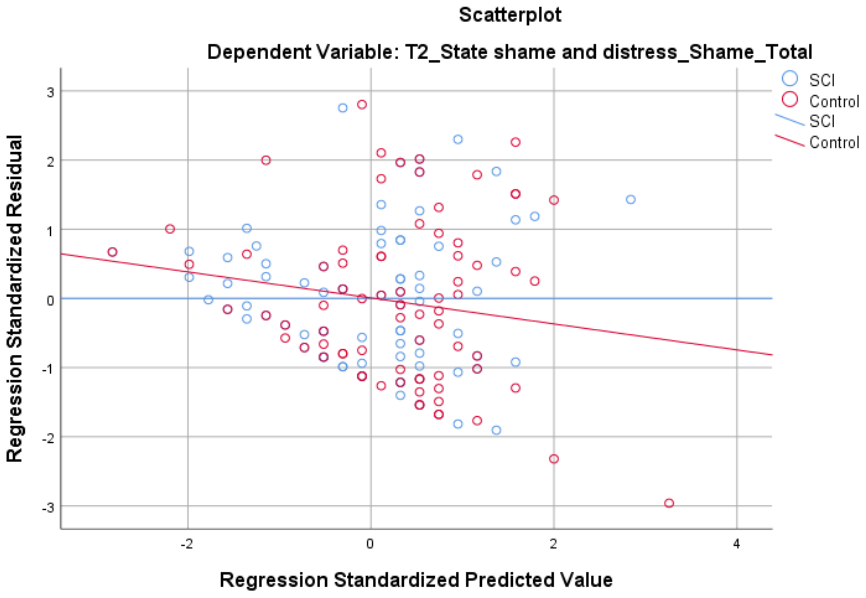


Figure W14

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T3 Trait Self-Compassion

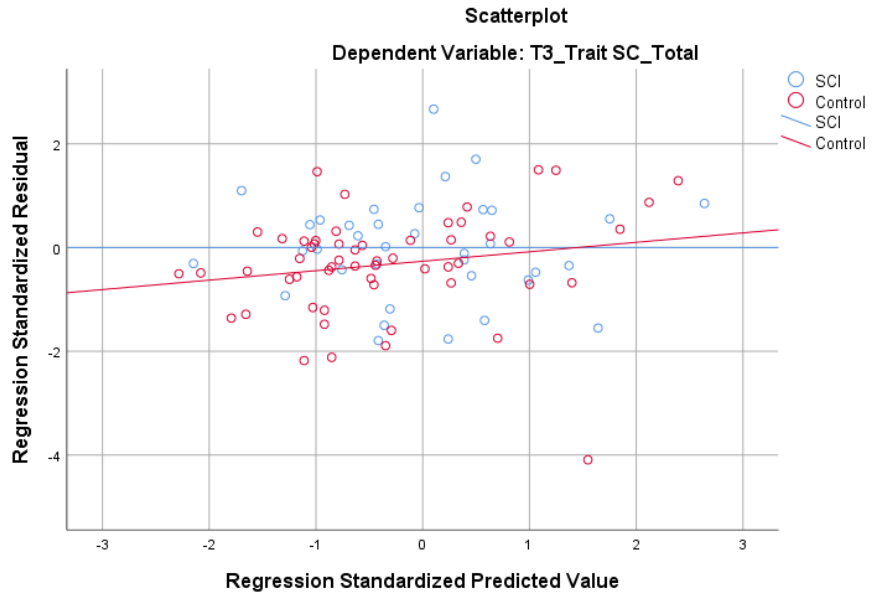


Figure W15

Scatterplot to Test for Linearity Between T1 State Self-Compassion and T3 Trait Self-Compassion

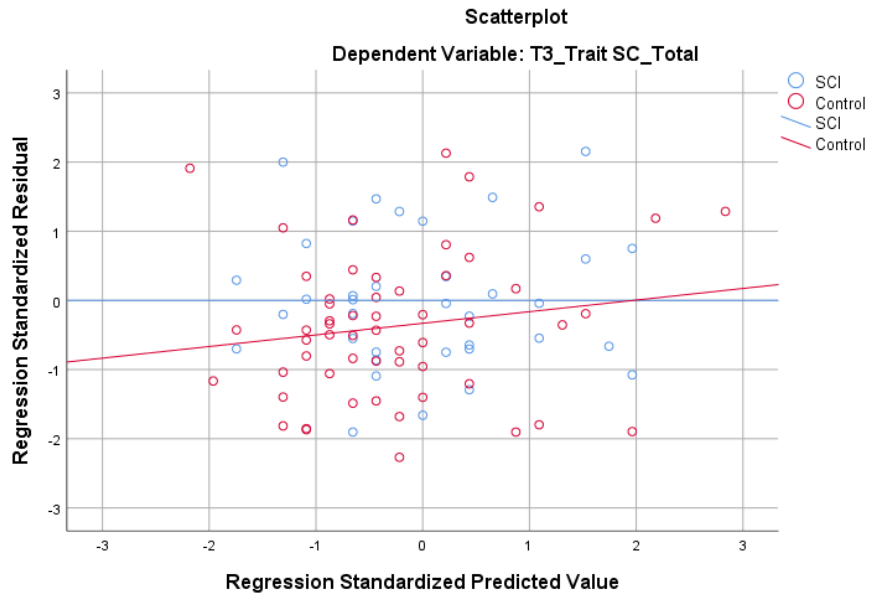


Figure W16

Scatterplot to Test for Linearity Between T1 Parental Stress Frequency and T3 Trait Self-Compassion

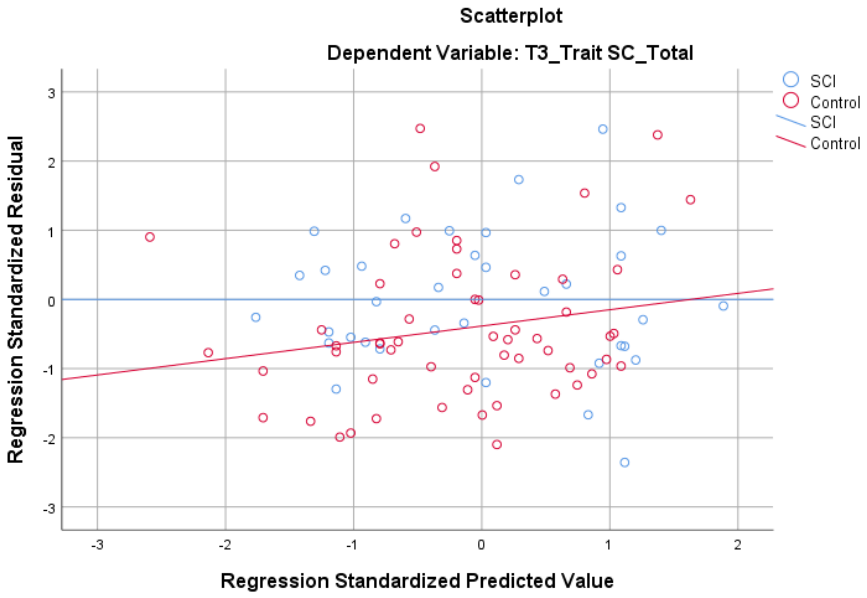


Figure W17

Scatterplot to Test for Linearity Between T1 Parental Stress Frequency and T3 Parental Stress Frequency

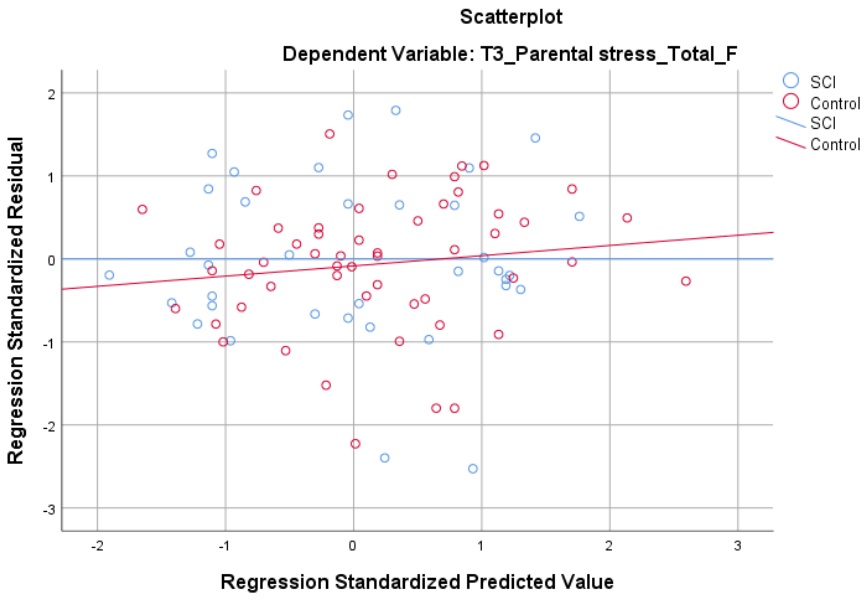


Figure W18

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T3 Parental Stress Frequency

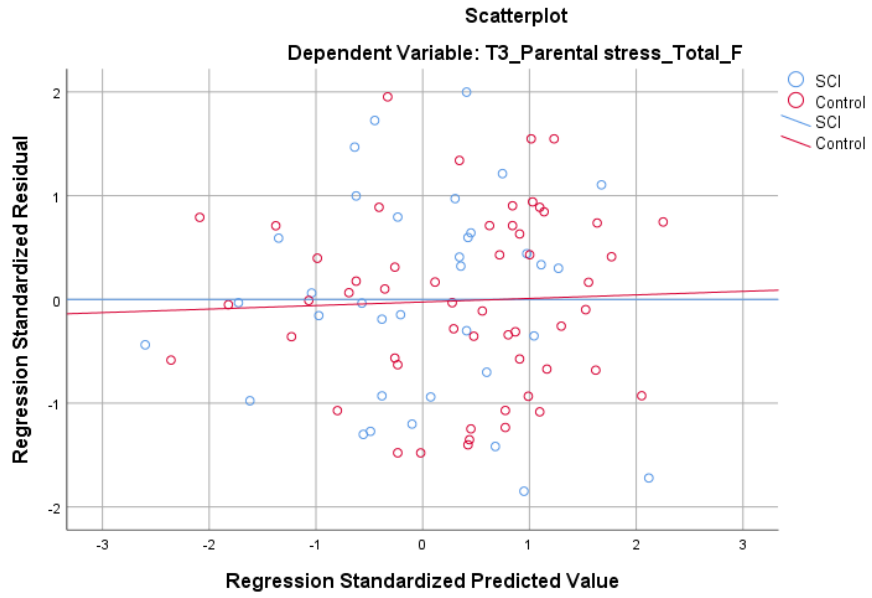


Figure W19

Scatterplot to Test for Linearity Between T1 State Self-Compassion and T3 Parental Stress Frequency

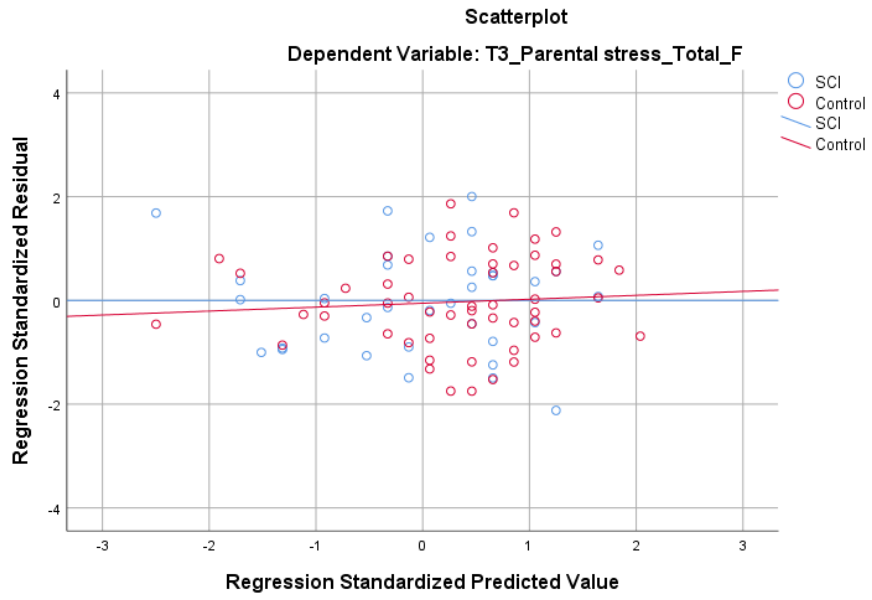


Figure W20

Scatterplot to Test for Linearity Between T1 Parental Stress Difficulty and T3 Parental Stress Difficulty

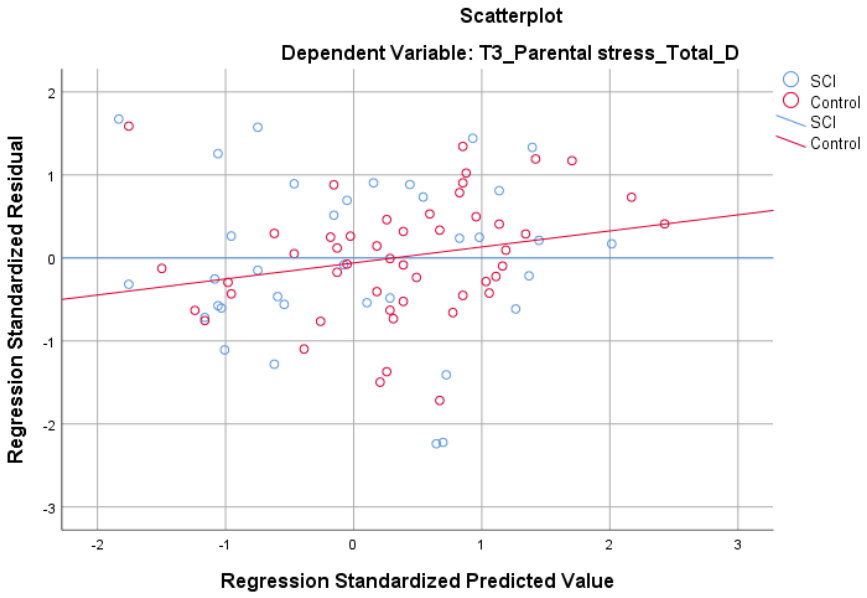


Figure W21

Scatterplot to Test for Linearity Between T1 Trait Self-Compassion and T3 Parental Stress Difficulty

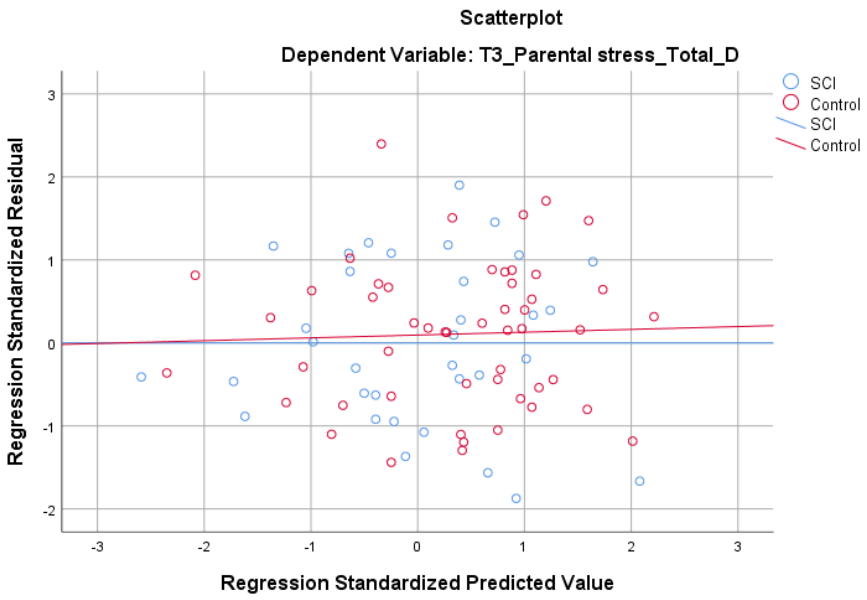
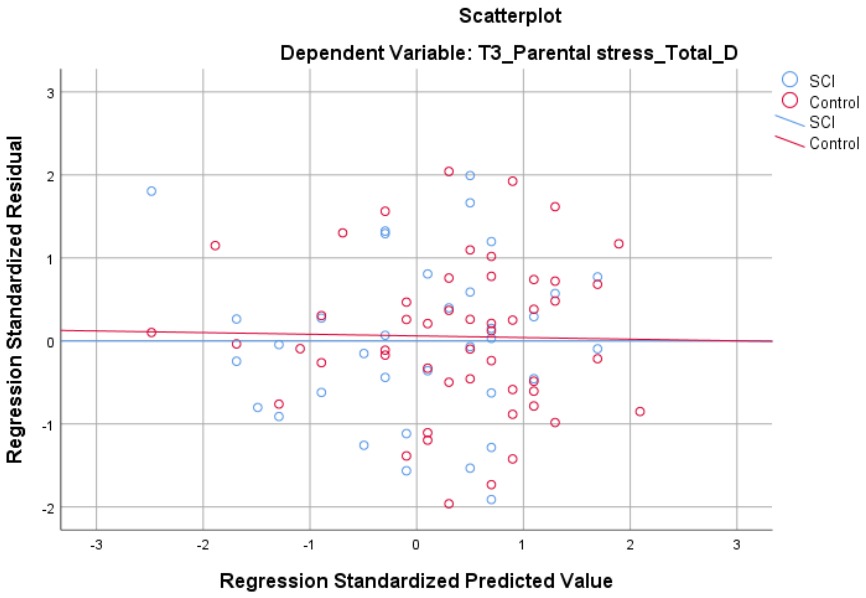


Figure W22

Scatterplot to Test for Linearity Between T1 State Self-Compassion and T3 Parental Stress Difficulty



Appendix X

Scatterplots and ANCOVA Models to Test for Homogeneity of Regression

Table X1

*Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Self-Compassion*

Tests of Between-Subjects Effects

Dependent Variable: T2_State SC_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	125.879[a]	3	41.960	80.693	.000
Intercept	.966	1	.966	1.859	.175
Group	.388	1	.388	.747	.389
T1_StateSC_Total	113.580	1	113.580	218.427	.000
Group * T1_StateSC_Total	1.009	1	1.009	1.940	.166
Error	78.518	151	.520		
Total	2863.520	155			
Corrected Total	204.397	154			

a. R Squared = .616 (Adjusted R Squared = .608)

Table X2

*Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Self-Compassion*

Tests of Between-Subjects Effects

Dependent Variable: T2_State SC_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	105.902[a]	3	35.301	58.656	.000
Intercept	4.486	1	4.486	7.454	.007
Group	.098	1	.098	.163	.687
T1_TraitSC_Total	96.028	1	96.028	159.561	.000
Group * T1_TraitSC_Total	.049	1	.049	.081	.776
Error	90.274	150	.602		
Total	2814.520	154			
Corrected Total	196.176	153			

a. R Squared = .540 (Adjusted R Squared = .531)

Table X3

*Group*T1 State Shame Interactions for Dependent Variable T2 State Self-Compassion*

Tests of Between-Subjects Effects

Dependent Variable: T2_State SC_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	56.254[a]	3	18.751	19.113	.000
Intercept	692.470	1	692.470	705.822	.000
Group	5.010	1	5.010	5.107	.025
T1_Stateshameanddistress_Shame_Total	43.603	1	43.603	44.444	.000
Group * T1_Stateshameanddistress_Shame_Total	1.204	1	1.204	1.227	.270
Error	148.144	151	.981		
Total	2863.520	155			
Corrected Total	204.397	154			

a. R Squared = .275 (Adjusted R Squared = .261)

Figure X1

*Scatterplot Showing Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Self-Compassion*

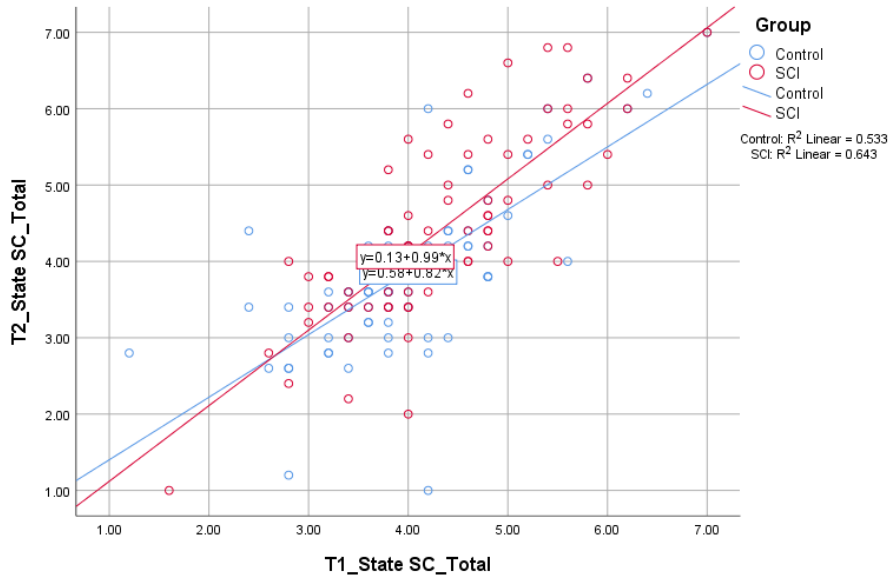


Figure X2

Scatterplot Showing Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Self-Compassion

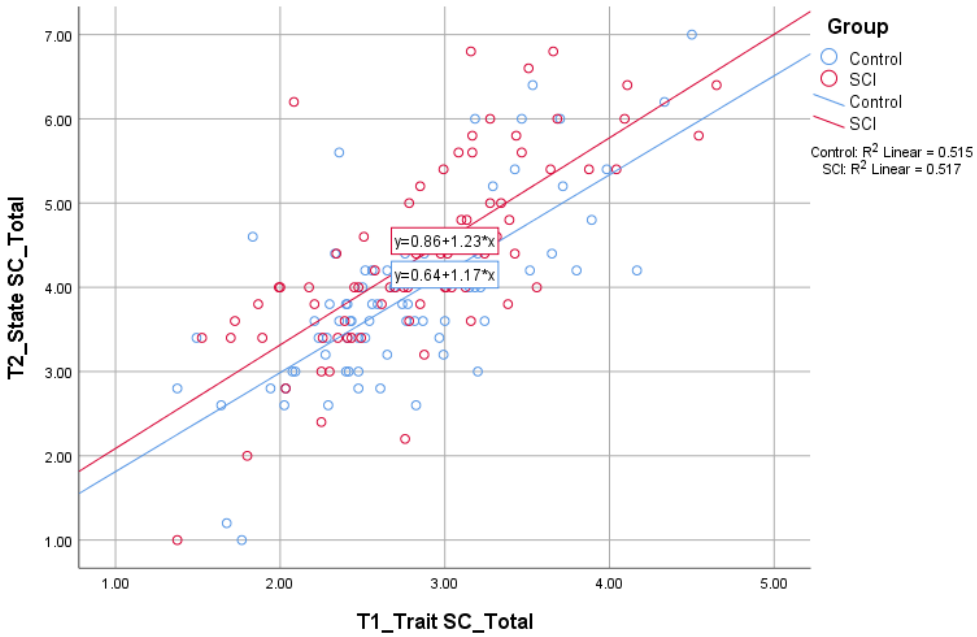


Figure X3

Scatterplot Showing Group*T1 State Shame Interactions for Dependent Variable T2 State Self-Compassion

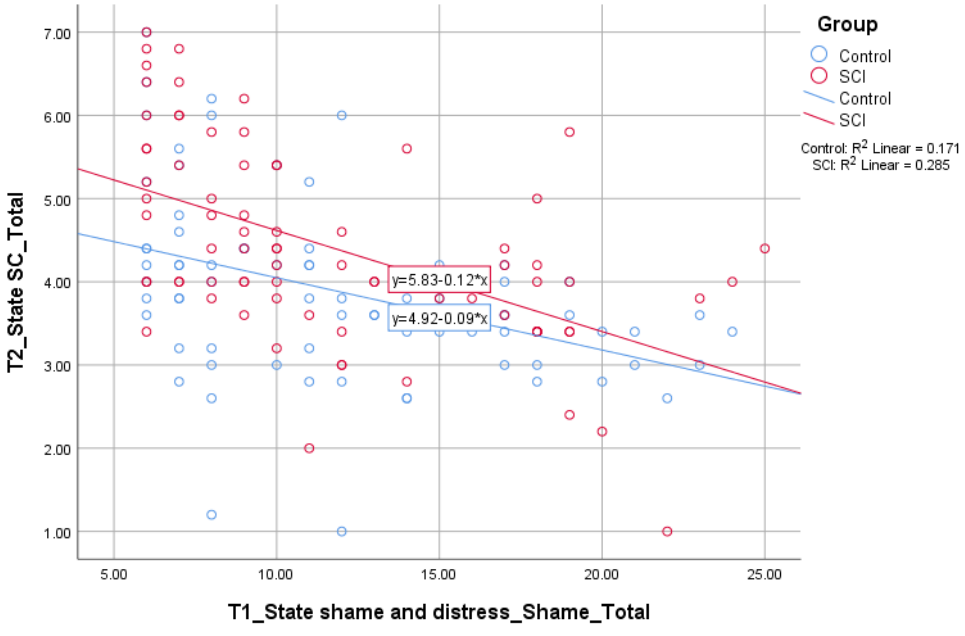


Table X4

*Group*T1 State Distress Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	7657.378[a]	3	2552.459	83.613	.000
Intercept	352.224	1	352.224	11.538	.001
Group	.076	1	.076	.002	.960
T1_Stateshameanddistress_Distress_Total	7191.094	1	7191.094	235.564	.000
Group * T1_Stateshameanddistress_Distress_Total	26.022	1	26.022	.852	.357
Error	4579.064	150	30.527		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .626 (Adjusted R Squared = .618)

Table X5

*Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	2786.504[a]	3	928.835	14.787	.000
Intercept	12565.014	1	12565.014	200.031	.000
Group	72.845	1	72.845	1.160	.283
T1_TraitSC_Total	2462.681	1	2462.681	39.205	.000
Group * T1_TraitSC_Total	30.554	1	30.554	.486	.487
Error	9359.469	149	62.815		
Total	89895.000	153			
Corrected Total	12145.974	152			

a. R Squared = .229 (Adjusted R Squared = .214)

Table X6

*Group*T1 State Shame Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	5026.471[a]	3	1675.490	34.858	.000
Intercept	2224.802	1	2224.802	46.286	.000
Group	57.990	1	57.990	1.206	.274
T1_Stateshameanddistress_Shame_Total	4681.028	1	4681.028	97.387	.000
Group * T1_Stateshameanddistress_Shame_Total	1.400	1	1.400	.029	.865
Error	7209.971	150	48.066		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .411 (Adjusted R Squared = .399)

Table X7

*Group*T1 Parental Stress Frequency Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	4575.524[a]	3	1525.175	30.049	.000
Intercept	78.751	1	78.751	1.552	.215
Group	1.468	1	1.468	.029	.865
T1_Parentalstress_Total_F	4210.362	1	4210.362	82.953	.000
Group * T1_Parentalstress_Total_F	22.836	1	22.836	.450	.503
Error	7511.844	148	50.756		
Total	88140.000	152			
Corrected Total	12087.368	151			

a. R Squared = .379 (Adjusted R Squared = .366)

Table X8

*Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3621.756[a]	3	1207.252	21.021	.000
Intercept	13888.764	1	13888.764	241.833	.000
Group	3.072	1	3.072	.053	.817
T1_StateSC_Total	3265.862	1	3265.862	56.866	.000
Group * T1_StateSC_Total	15.609	1	15.609	.272	.603
Error	8614.686	150	57.431		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .296 (Adjusted R Squared = .282)

Table X9

*Group*Age of Child Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	555.941[a]	3	185.314	2.380	.072
Intercept	9890.176	1	9890.176	127.009	.000
Group	53.053	1	53.053	.681	.410
ParticipantInfo_AgeofchildwithIBD	214.546	1	214.546	2.755	.099
Group * ParticipantInfo_AgeofchildwithIBD	5.388	1	5.388	.069	.793
Error	11680.500	150	77.870		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .045 (Adjusted R Squared = .026)

Table X10

*Group*Child's IBD Type Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	525.239[a]	3	175.080	2.242	.086
Intercept	13534.857	1	13534.857	173.358	.000
Group	18.422	1	18.422	.236	.628
IBDtype1	169.447	1	169.447	2.170	.143
Group * IBDtype1	21.350	1	21.350	.273	.602
Error	11711.202	150	78.075		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .043 (Adjusted R Squared = .024)

Table X11

*Group*Child's Stoma Status Interactions for Dependent Variable T2 State Distress*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Distress_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	723.306[a]	3	241.102	3.141	.027
Intercept	5370.151	1	5370.151	69.966	.000
Group	227.781	1	227.781	2.968	.087
Stoma1	255.494	1	255.494	3.329	.070
Group * Stoma1	133.530	1	133.530	1.740	.189
Error	11513.135	150	76.754		
Total	90064.000	154			
Corrected Total	12236.442	153			

a. R Squared = .059 (Adjusted R Squared = .040)

Figure X4

Scatterplot Showing Group*T1 State Distress Interactions for Dependent Variable T2 State Distress

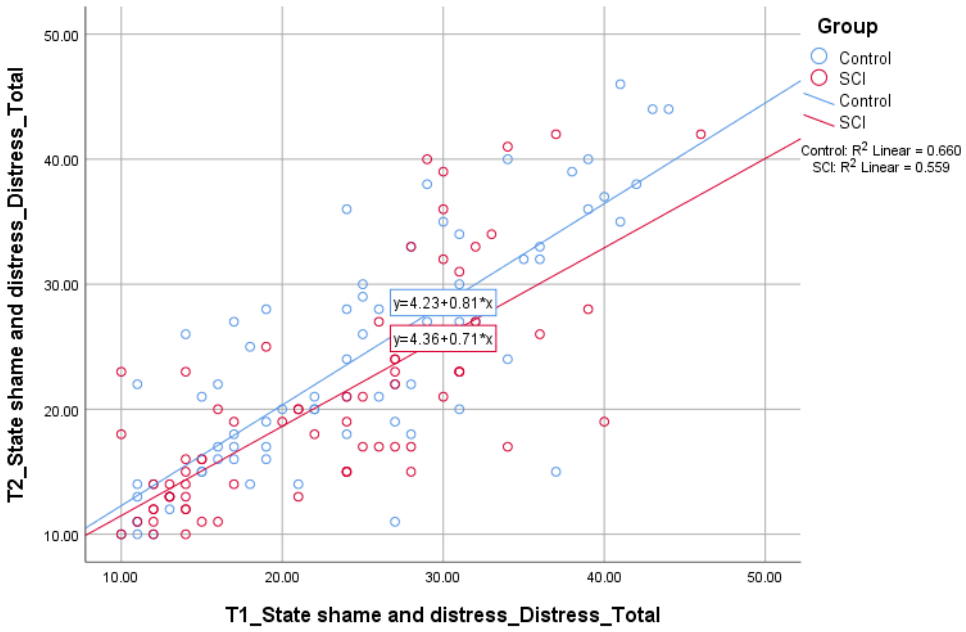


Figure X5

Scatterplot Showing Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Distress

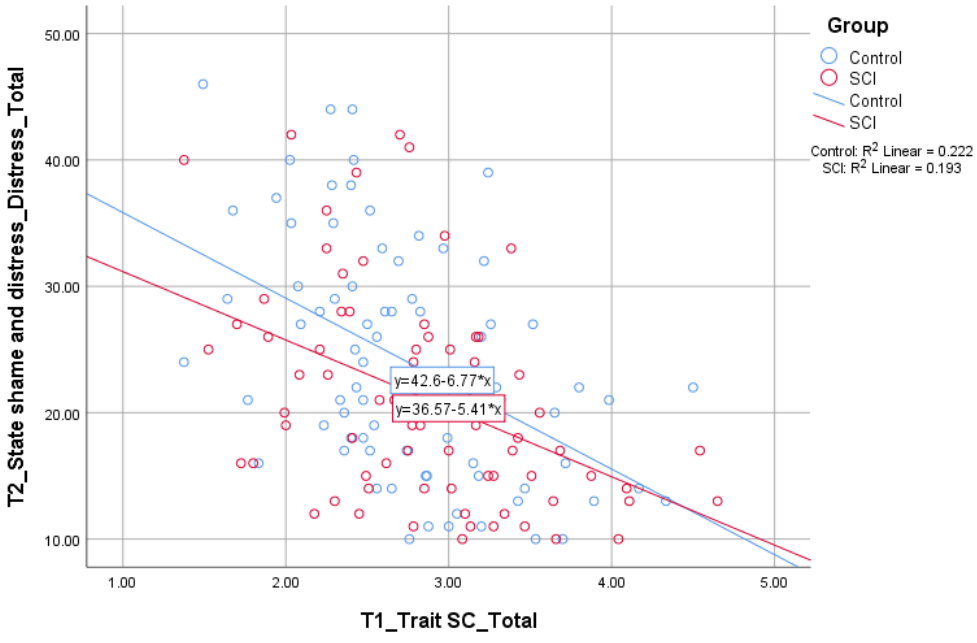


Figure X6

Scatterplot Showing Group*T1 State Shame Interactions for Dependent Variable T2 State Distress

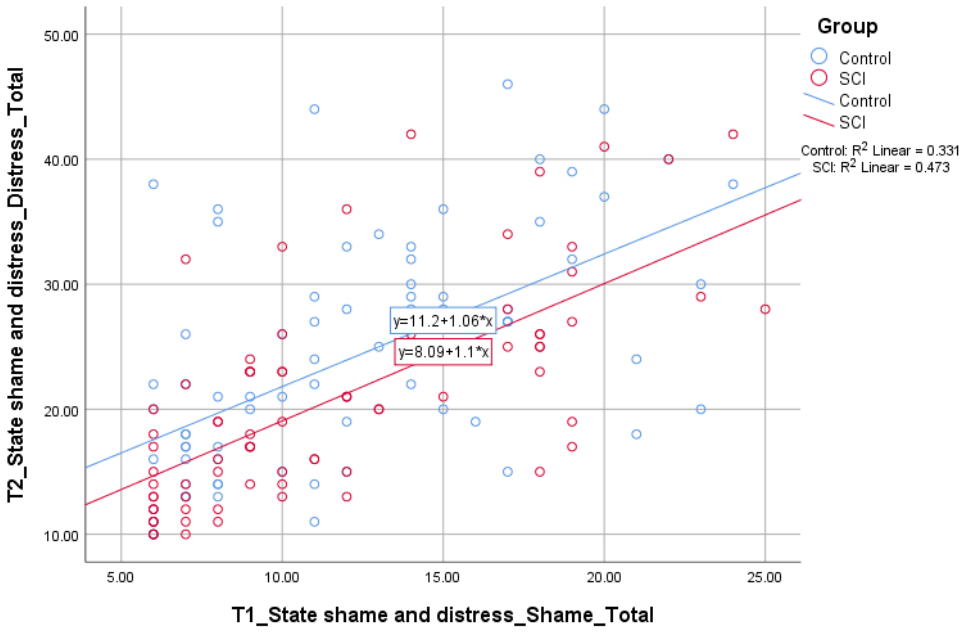


Figure X7

Scatterplot Showing Group*T1 Parental Stress Frequency Interactions for Dependent Variable T2 State Distress

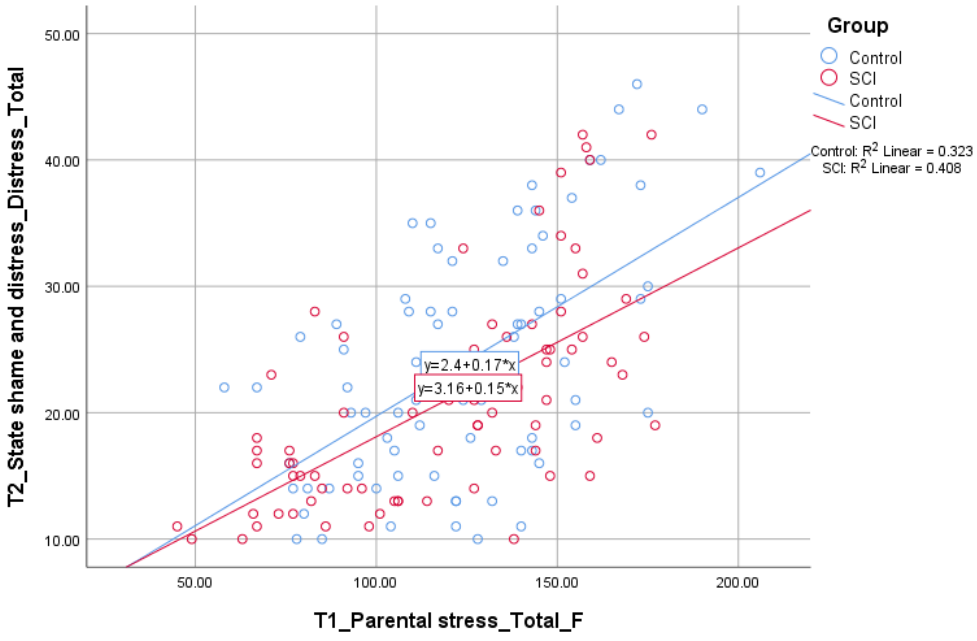


Figure X8

Scatterplot Showing Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Distress

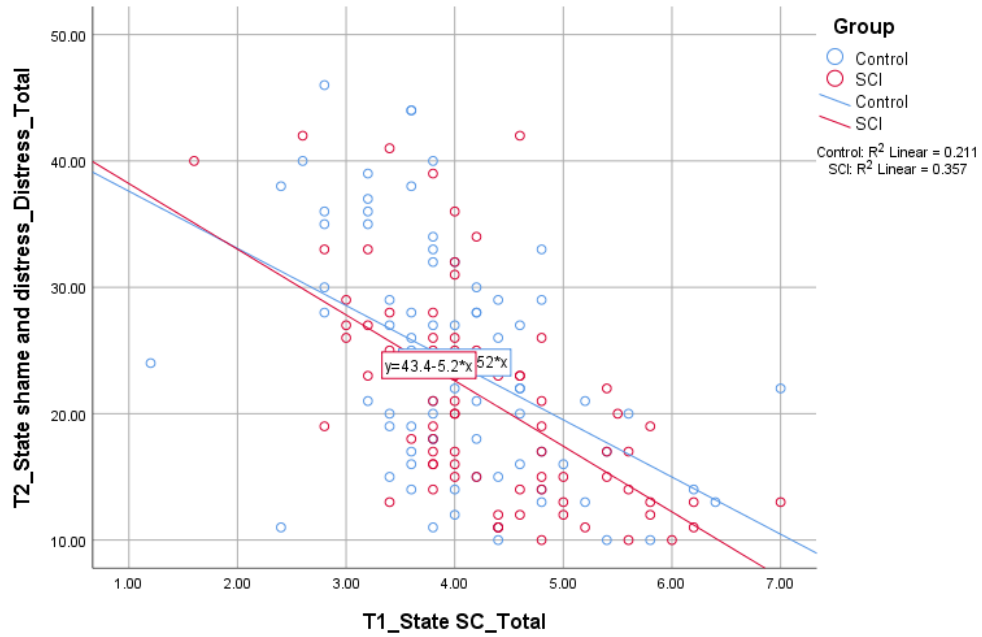


Figure X9

Scatterplot Showing Group*Age of Child Interactions for Dependent Variable T2 State Distress

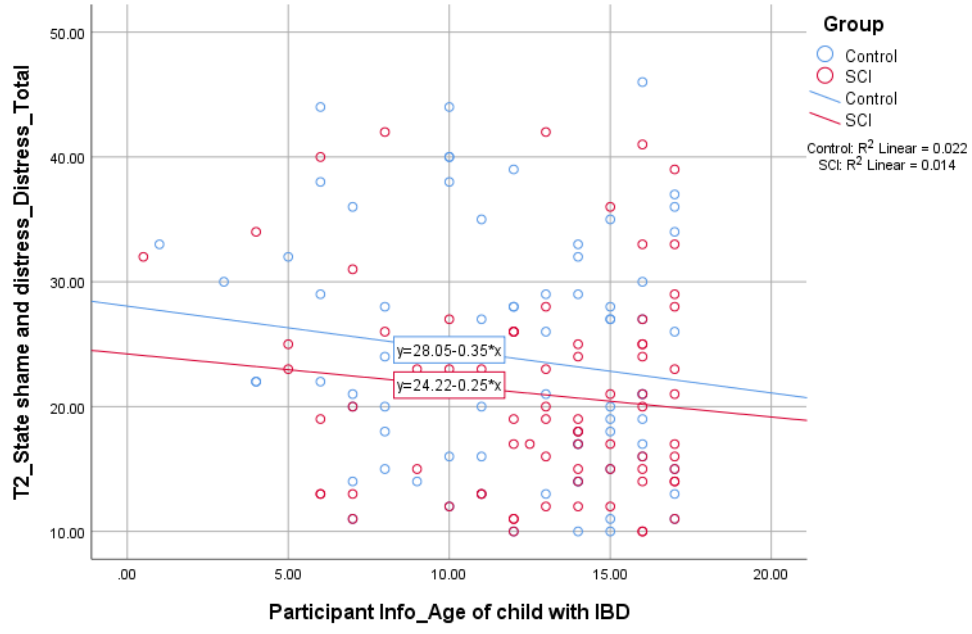


Figure X10

Scatterplot Showing Group*Child's IBD Type Interactions for Dependent Variable T2 State Distress

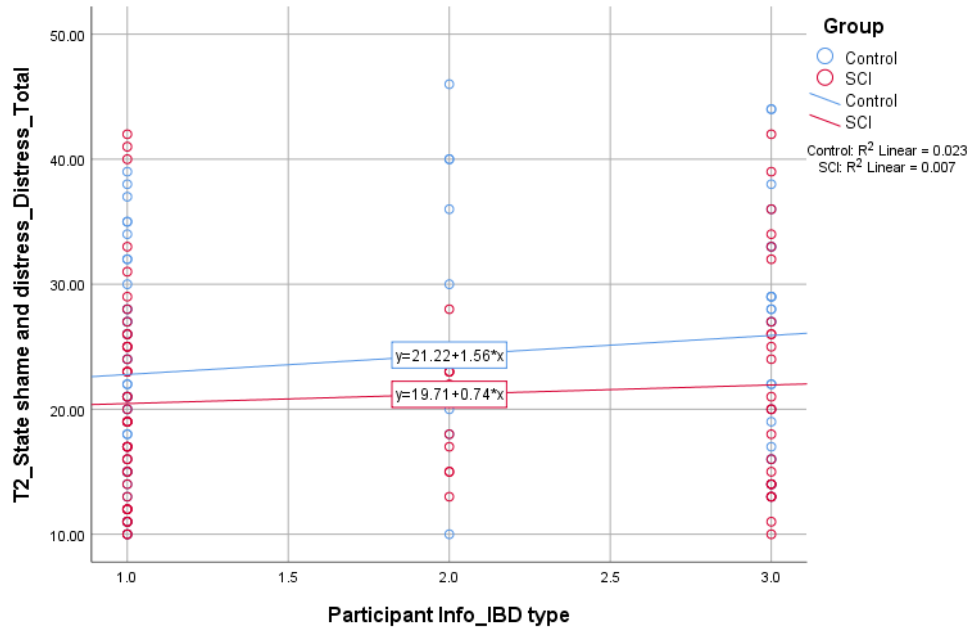


Figure X11

Scatterplot Showing Group*Child's Stoma Status Interactions for Dependent Variable T2 State Distress

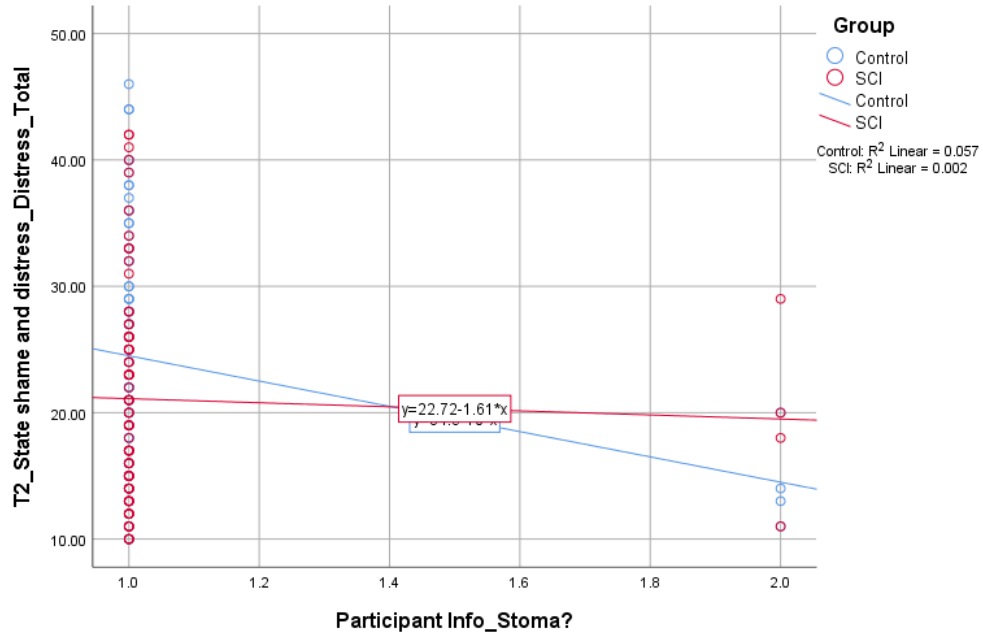


Table X12

*Group*T1 State Shame Interactions for Dependent Variable T2 State Shame*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Shame_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3571.013[a]	3	1190.338	58.635	.000
Intercept	60.753	1	60.753	2.993	.086
Group	6.365	1	6.365	.314	.576
T1_Stateshameanddistress_Shame_Total	3536.211	1	3536.211	174.192	.000
Group * T1_Stateshameanddistress_Shame_Total	1.507	1	1.507	.074	.786
Error	3045.098	150	20.301		
Total	31689.000	154			
Corrected Total	6616.110	153			

a. R Squared = .540 (Adjusted R Squared = .531)

Table X13

*Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Shame*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Shame_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1454.829[a]	3	484.943	14.126	.000
Intercept	5340.821	1	5340.821	155.569	.000
Group	.963	1	.963	.028	.867
T1_TraitSC_Total	1427.202	1	1427.202	41.572	.000
Group * T1_TraitSC_Total	1.916	1	1.916	.056	.814
Error	5115.289	149	34.331		
Total	31653.000	153			
Corrected Total	6570.118	152			

a. R Squared = .221 (Adjusted R Squared = .206)

Table X14

*Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Shame*

Tests of Between-Subjects Effects

Dependent Variable: T2_State shame and distress_Shame_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	1455.561[a]	3	485.187	14.103	.000
Intercept	5138.820	1	5138.820	149.368	.000
Group	38.450	1	38.450	1.118	.292
T1_StateSC_Total	1386.179	1	1386.179	40.292	.000
Group * T1_StateSC_Total	38.396	1	38.396	1.116	.292
Error	5160.550	150	34.404		
Total	31689.000	154			
Corrected Total	6616.110	153			

a. R Squared = .220 (Adjusted R Squared = .204)

Figure X12

*Scatterplot Showing Group*T1 State Shame Interactions for Dependent Variable T2 State Shame*

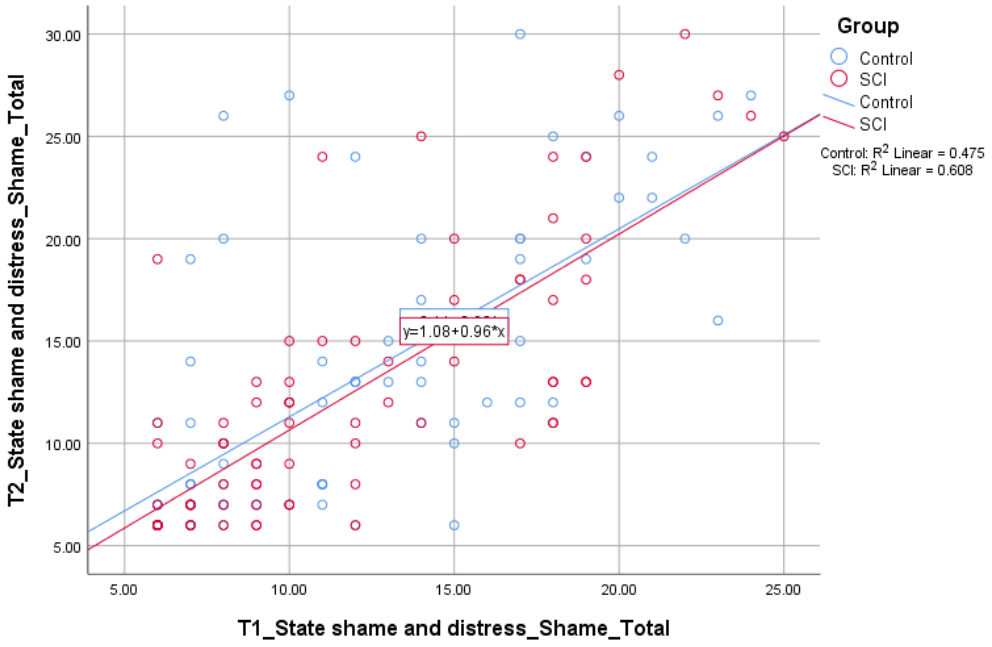


Figure X13

Scatterplot Showing Group*T1 Trait Self-Compassion Interactions for Dependent Variable T2 State Shame

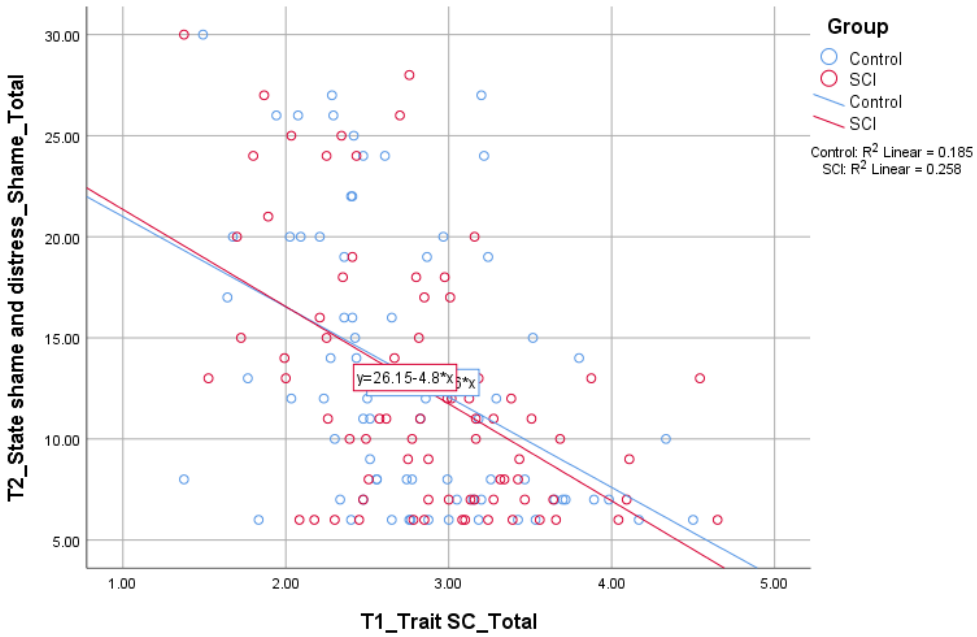


Figure X14

Scatterplot Showing Group*T1 State Self-Compassion Interactions for Dependent Variable T2 State Shame

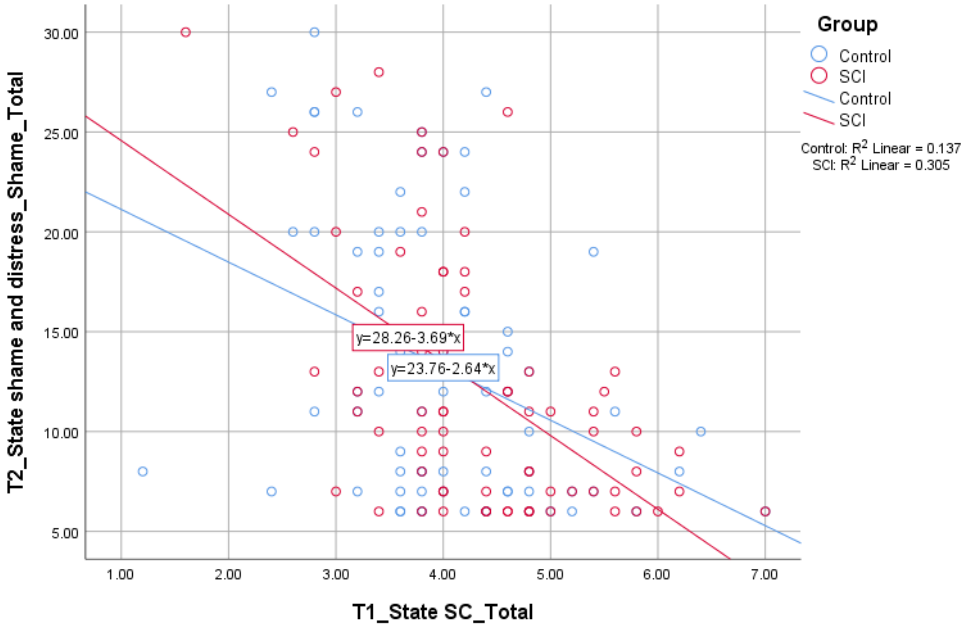


Table X15

*Group*T1 Trait Self-Compassion Interactions for Dependent Variable T3 Trait Self-Compassion*

Tests of Between-Subjects Effects

Dependent Variable: T3_Trait SC_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	39.943[a]	3	13.314	84.237	.000
Intercept	.002	1	.002	.013	.910
Group	.199	1	.199	1.259	.265
T1_TraitSC_Total	33.773	1	33.773	213.675	.000
Group * T1_TraitSC_Total	.119	1	.119	.751	.389
Error	13.909	88	.158		
Total	827.040	92			
Corrected Total	53.852	91			

a. R Squared = .742 (Adjusted R Squared = .733)

Table X16

*Group*T1 State Self-Compassion Interactions for Dependent Variable T3 Trait Self-Compassion*

Tests of Between-Subjects Effects

Dependent Variable: T3_Trait SC_Total

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	22.479[a]	3	7.493	21.018	.000
Intercept	2.401	1	2.401	6.736	.011
Group	.404	1	.404	1.132	.290
T1_StateSC_Total	18.057	1	18.057	50.650	.000
Group * T1_StateSC_Total	.204	1	.204	.571	.452
Error	31.372	88	.357		
Total	827.040	92			
Corrected Total	53.852	91			

a. R Squared = .417 (Adjusted R Squared = .398)

Figure X15

Scatterplot Showing Group*T1 Trait Self-Compassion Interactions for Dependent Variable T3 Trait Self-Compassion

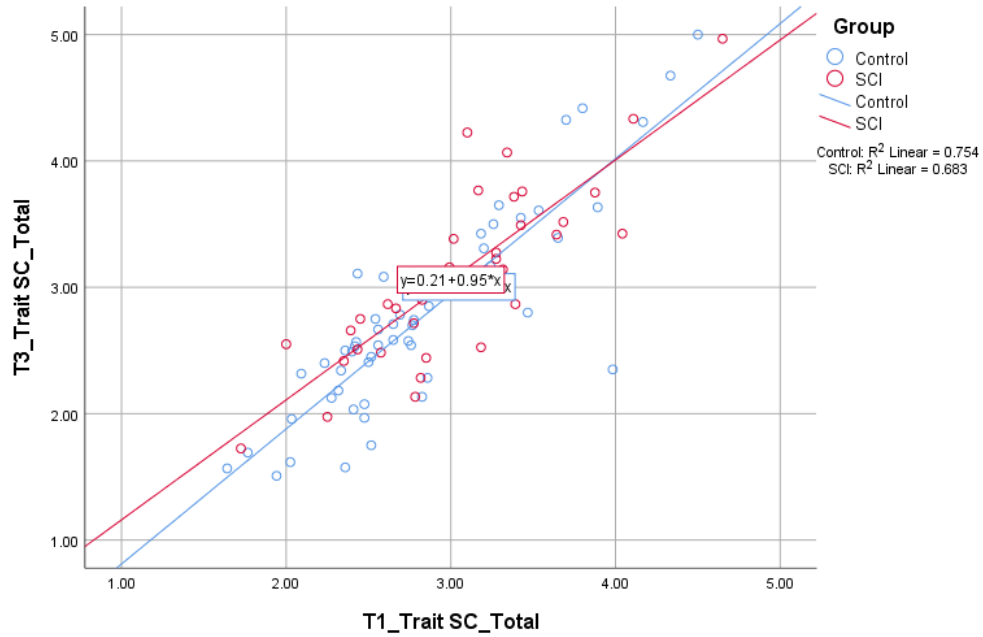


Figure X16

Scatterplot Showing Group*T1 State Self-Compassion Interactions for Dependent Variable T3 Trait Self-Compassion

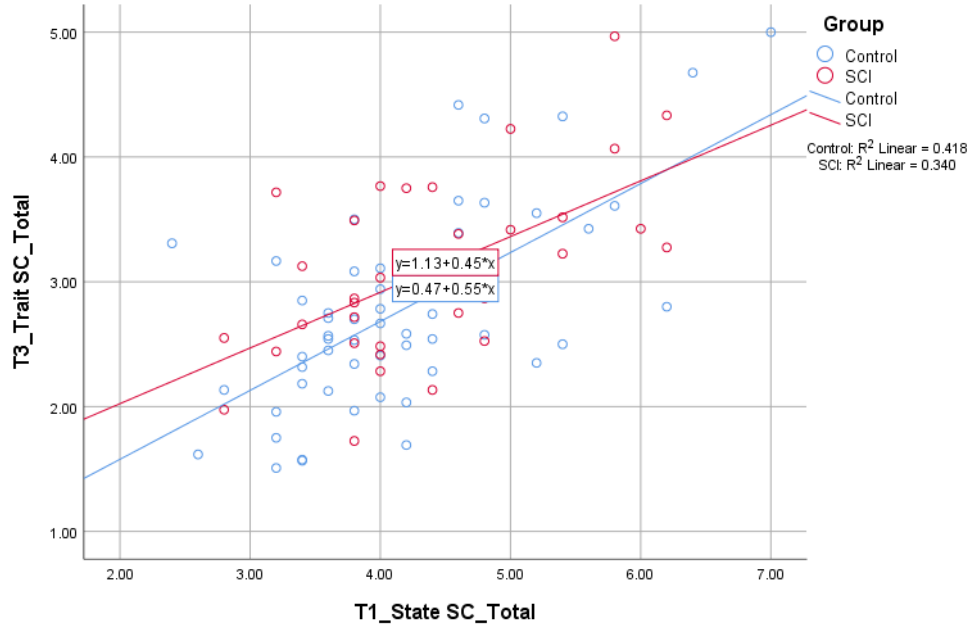


Table X17

*Group*T1 Parental Stress Frequency Interactions for Dependent Variable T3 Parental Stress Frequency*

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_F

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	69989.539[a]	3	23329.846	44.148	.000
Intercept	1054.235	1	1054.235	1.995	.161
Group	255.335	1	255.335	.483	.489
T1_Parentalstress_Total_F	68159.469	1	68159.469	128.980	.000
Group * T1_Parentalstress_Total_F	199.192	1	199.192	.377	.541
Error	44918.281	85	528.450		
Total	1292853.000	89			
Corrected Total	114907.820	88			

a. R Squared = .609 (Adjusted R Squared = .595)

Table X18

*Group*T1 Trait Self-Compassion Frequency Interactions for Dependent Variable T3 Parental Stress Frequency*

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_F

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	20144.384[a]	3	6714.795	6.006	.001
Intercept	120262.354	1	120262.354	107.573	.000
Group	24.272	1	24.272	.022	.883
T1_TraitSC_Total	18057.206	1	18057.206	16.152	.000
Group * T1_TraitSC_Total	33.036	1	33.036	.030	.864
Error	95026.493	85	1117.959		
Total	1294497.000	89			
Corrected Total	115170.876	88			

a. R Squared = .175 (Adjusted R Squared = .146)

Table X19

Group*T1 State Self-Compassion Frequency Interactions for Dependent Variable T3 Parental Stress Frequency

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_F

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	23913.336[a]	3	7971.112	7.483	.000
Intercept	143970.237	1	143970.237	135.153	.000
Group	102.922	1	102.922	.097	.757
T1_StateSC_Total	22477.531	1	22477.531	21.101	.000
Group * T1_StateSC_Total	144.137	1	144.137	.135	.714
Error	91610.320	86	1065.236		
Total	1312453.000	90			
Corrected Total	115523.656	89			

a. R Squared = .207 (Adjusted R Squared = .179)

Figure X17

Scatterplot Showing Group*T1 Parental Stress Frequency Interactions for Dependent Variable T3 Parental Stress Frequency

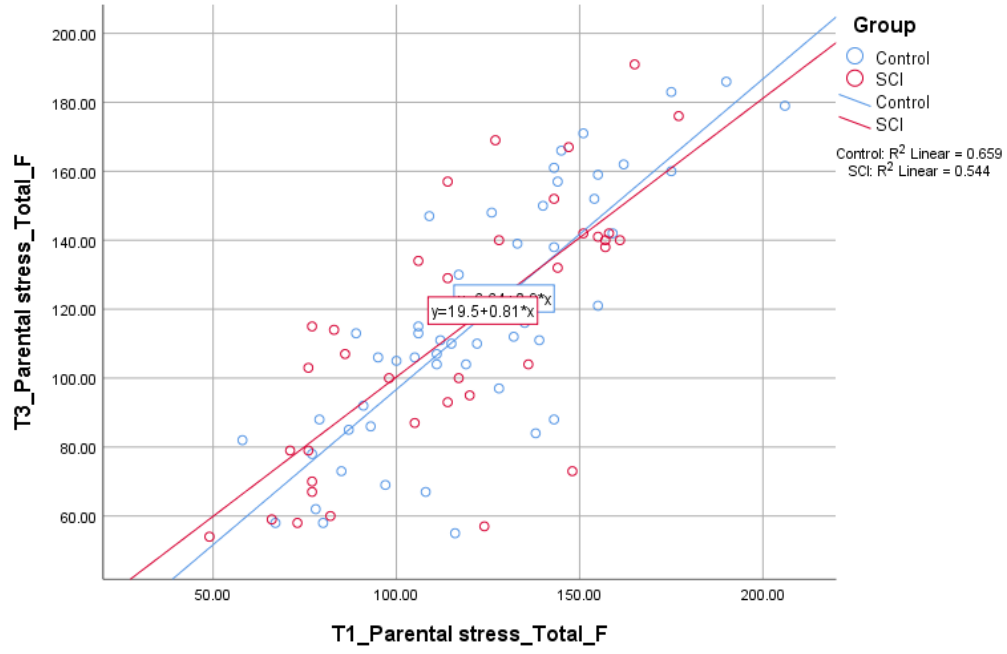


Figure X18

Scatterplot Showing Group*T1 Trait Self-Compassion Frequency Interactions for Dependent Variable T3 Parental Stress Frequency

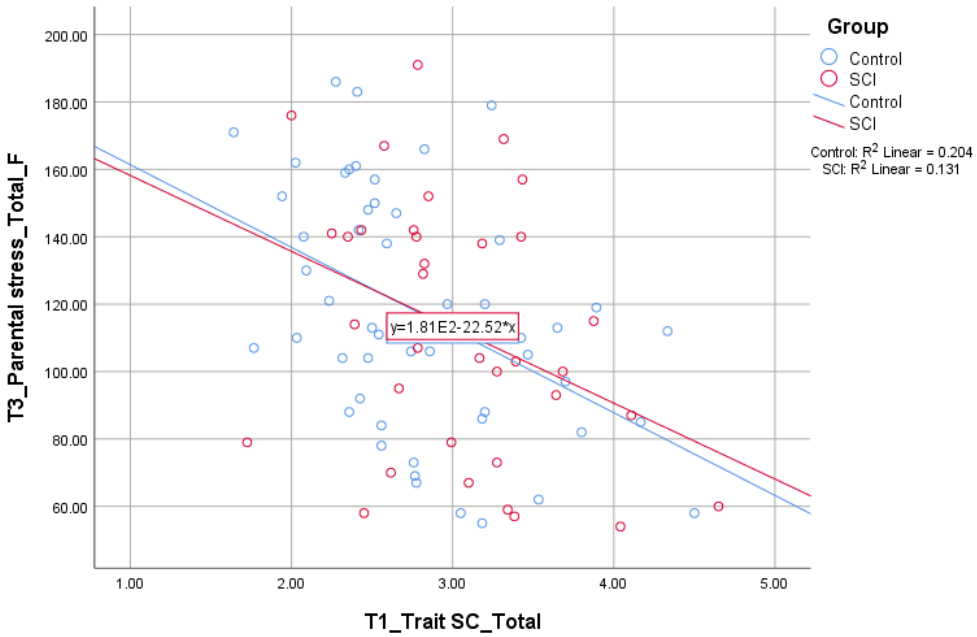


Figure X19

Scatterplot Showing Group*T1 State Self-Compassion Frequency Interactions for Dependent Variable T3 Parental Stress Frequency

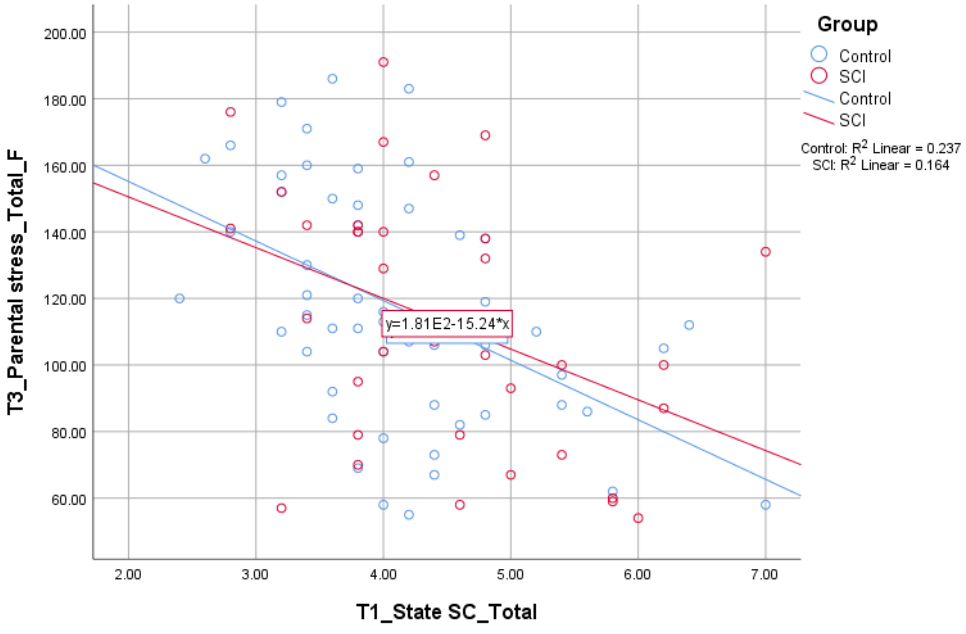


Table X20

*Group*T1 Parental Stress Difficulty Interactions for Dependent Variable T3 Parental Stress Difficulty*

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_D

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	80099.981[a]	3	26699.994	50.584	.000
Intercept	1361.487	1	1361.487	2.579	.112
Group	494.164	1	494.164	.936	.336
T1_Parentalstress_Total_D	76470.190	1	76470.190	144.875	.000
Group * T1_Parentalstress_Total_D	493.809	1	493.809	.936	.336
Error	42226.912	80	527.836		
Total	1271501.000	84			
Corrected Total	122326.893	83			

a. R Squared = .655 (Adjusted R Squared = .642)

Table X21

*Group*T1 Trait Self-Compassion Interactions for Dependent Variable T3 Parental Stress Difficulty*

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_D

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	29402.876[a]	3	9800.959	8.014	.000
Intercept	137029.879	1	137029.879	112.042	.000
Group	81.980	1	81.980	.067	.796
T1_TraitSC_Total	25767.038	1	25767.038	21.068	.000
Group * T1_TraitSC_Total	32.423	1	32.423	.027	.871
Error	99064.418	81	1223.018		
Total	1287357.000	85			
Corrected Total	128467.294	84			

a. R Squared = .229 (Adjusted R Squared = .200)

Table X22

*Group*T1 State Self-Compassion Interactions for Dependent Variable T3 Parental Stress Difficulty*

Tests of Between-Subjects Effects

Dependent Variable: T3_Parental stress_Total_D

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	44396.904[a]	3	14798.968	14.432	.000
Intercept	183216.118	1	183216.118	178.674	.000
Group	.896	1	.896	.001	.976
T1_StateSC_Total	41431.109	1	41431.109	40.404	.000
Group * T1_StateSC_Total	8.590	1	8.590	.008	.927
Error	84084.398	82	1025.419		
Total	1300126.000	86			
Corrected Total	128481.302	85			

a. R Squared = .346 (Adjusted R Squared = .322)

Figure X20

*Scatterplot Showing Group*T1 Parental Stress Difficulty Interactions for Dependent Variable T3 Parental Stress Difficulty*

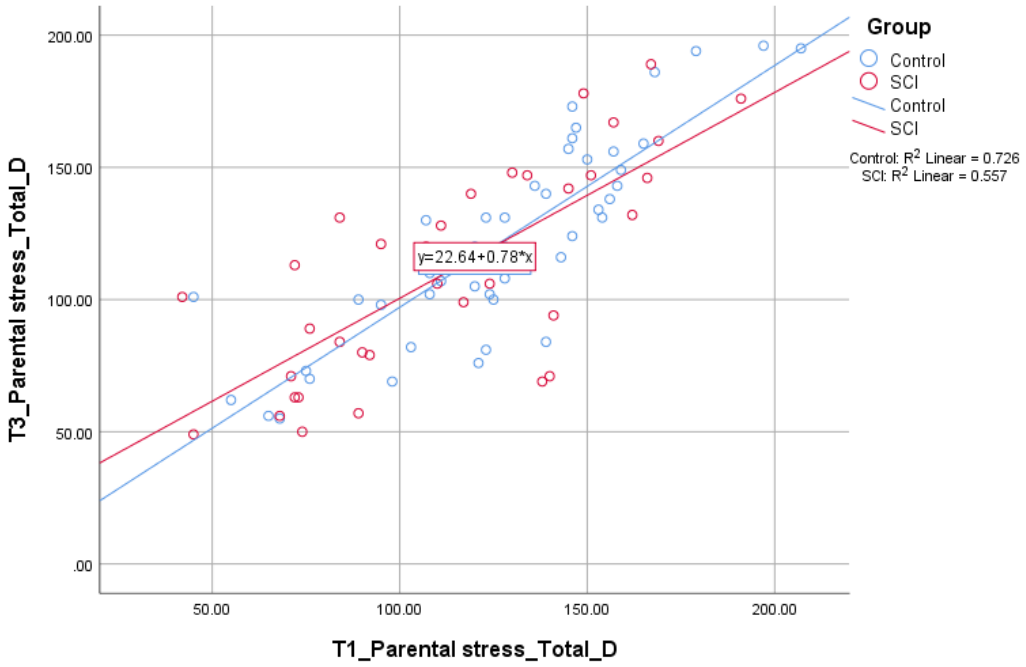


Figure X21

Scatterplot Showing Group*T1 Trait Self-Compassion Interactions for Dependent Variable T3 Parental Stress Difficulty

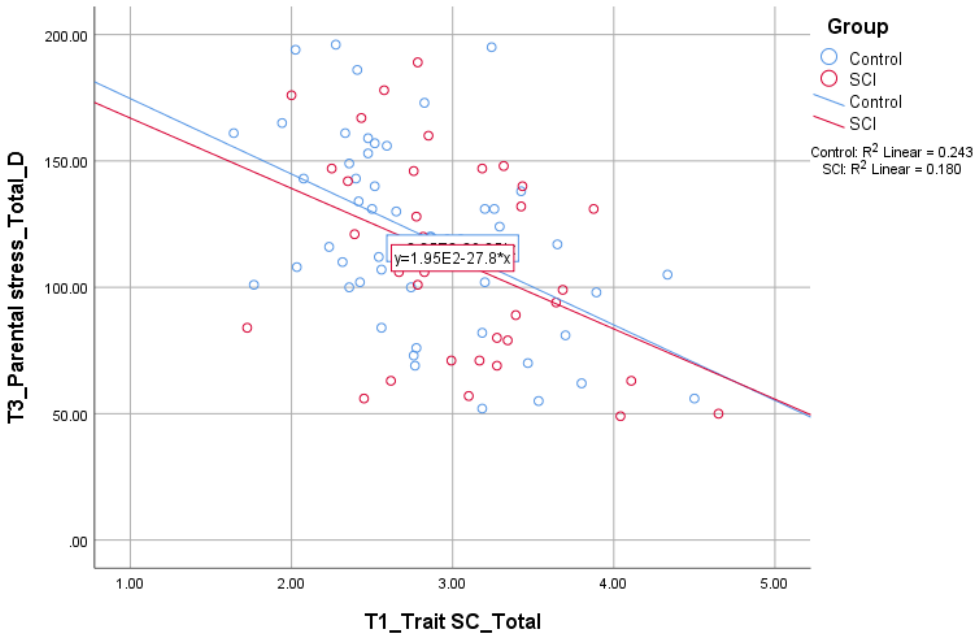


Figure X22

Scatterplot Showing Group*T1 State Self-Compassion Interactions for Dependent Variable T3 Parental Stress Difficulty