An investigation of factors related to adjustment in multiple sclerosis.

By:

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Declaration

This thesis is submitted for the Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted to any other institution or for any other qualification. The work presented is original and all other sources have been referenced accordingly.

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Structure and word counts

Part I: Literature Review

Excluding references and tables	7,974
Including references and tables	14,732

Part II: Research Report

Excluding references and tables	7,984
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Excluding references and tables	15,958
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Lay Summary

Psychological growth and self-compassion are two important qualities for well-being. Psychological growth, also called resilience, is the ability to "bounce back" or grow positively following challenging experiences. Self-compassion is the ability to be kind, accepting and understanding of oneself in times of difficulty. Both of these qualities are important for coping with chronic illnesses, including multiple sclerosis (MS). MS is a health condition where the immune system wrongly attacks the brain and/or spinal cord. This results in a variety of difficulties including physical disabilities, problems with memory and thinking, and emotional difficulties like anxiety and depression.

Research into these areas in MS is fairly new. Some research studies have looked at whether people grow positively from living with MS, but these individual findings have yet to be comprehensively summarised. How self-compassion can help people with MS has only been looked at in one study to date. This work therefore aimed to increase our knowledge of how people cope with MS by comprehensively summarising the results of studies looking at whether people grow positively from living with MS and whether this can improve well-being and reduce distress. This work also looked at whether self-compassion can help people adjust to MS, particularly whether self-compassion is helpful for reducing people's reports of difficulties with their memory and thinking.

Part I combined the results of 22 studies looking at whether people with MS grow positively and whether this improves well-being and reduces distress. Findings show that improved positive growth was connected to reduced distress and improved well-being in MS; these relationships were of medium strength. How positive growth was measured made a difference to these effects with resilience having a larger impact than other types of positive growth.

Part II is a two-part survey looking at self-compassion in MS over time. The study looked at whether higher levels of self-compassion leads to improvements in quality of life, stress, ability to cope and reported difficulties with memory and thinking. It also looked at whether self-compassion improved reported memory and thinking difficulties and whether this improvement was due to reduced stress or an improved ability to cope. The survey was completed by 278 people with MS, then again by 202 people after a 6-week gap. Findings show that higher levels of self-compassion were linked with improvements in quality of life and coping. Higher levels of self-compassion were also linked to reduced stress and lower reported difficulties with memory and thinking. Self-compassion did not lead to improvements in reported memory and thinking difficulties on its own, but as a result of reduced levels of stress. So, higher levels of self-compassion result in lower levels of stress, which in turn reduces people's reported memory and thinking difficulties.

These findings together show that growing positively or "bouncing back", and self-compassion are important for positive outcomes for people with MS, and they protect against poorer outcomes. Future research should focus on looking at psychological interventions aimed at supporting people with MS to grow positively and increase their self-compassion.

Acknowledgements

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A prospective investigation of the role of self-compassion in adjustment to multiple sclerosis.

Part I: Literature Review

Psychological growth and its relation to psychological outcomes in multiple sclerosis: A meta-analysis.

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Abstract

Objectives

Multiple sclerosis (MS) is associated with high levels of distress, however some people experience positive changes related to the process of adjustment (i.e. psychological growth). Psychological growth encompasses qualities such as resilience, posttraumatic growth and benefit-finding, which have been linked to improved outcomes with various chronic health populations including MS. This study aimed to quantify the associations between psychological growth, and psychological outcomes of well-being and distress in MS using a meta-analysis.

Method

Database searches (PsycInfo, Medline, Scopus, & CINAHL) were conducted to identify research reporting relationships between psychological growth (resilience, posttraumatic growth and benefit finding) and distress and/or well-being in MS. Two meta-analyses investigated associations between psychological growth, distress, and well-being. Quality appraisal examined methodological quality of the studies.

Results

Searches identified 316 relevant studies; 22 studies (total $N = 5542$) were included overall. Nineteen studies were included in the distress analysis ($N = 5022$) and 17 studies were included in the well-being analysis ($N = 3963$). Psychological growth was negatively associated with distress ($r = -.37$; 95% CIs [-.48, -.26]) and positively associated with well-being ($r = .41$, 95% CIs [.32, .49]). Type of psychological growth construct measured (resilience vs. posttraumatic growth/benefit finding) was a significant moderator of both associations, with resilience having a larger effect.

Conclusions

Current findings extend adjustment literature for MS by highlighting that psychological growth is beneficial as it is associated with improved well-being and decreased distress. Differences between growth constructs however suggest that psychological growth may not be uniformly beneficial in MS.

Practitioner points

- Psychological growth should be considered by professionals during assessment and formulation with people with MS.
- Understanding factors determining psychological growth would be useful for identifying people with MS most vulnerable to poorer outcomes.
- Further research exploring the effectiveness of interventions aimed at building psychological growth for people with MS is required.

Limitations

- Findings are based on cross-sectional correlational data meaning interpretations about causality cannot be made.
- There was significant variability in the measurement of distress and well-being in this study; this limited the extent to which comparisons could be made across studies.

Keywords: ‘Multiple sclerosis’; ‘meta-analysis’; ‘psychological growth’; ‘distress’; ‘well-being’.

Introduction

The diagnosis of a chronic health condition can be distressing and have significant implications for well-being (Barskova & Oesterreich, 2009). Factors including unpredictable physical symptoms, demands of attending numerous medical appointments, and medical treatment with potentially intolerable side effects contribute to this (Lezak Howieson, & Loring, 2012). Approximately 30% of people in England have at least one chronic health condition (Department of Health; DoH, 2011c) such as arthritis, diabetes and cardiovascular disease (Naylor et al., 2012), leading to an increased risk of mental health difficulties such as depression (Fenton & Stover, 2006) and anxiety (Naylor et al., 2012). Depression is also commonly experienced by people with neurological conditions such as multiple sclerosis (MS) and can have a detrimental effect on quality of life, though recognition and treatment can be poor (Rickards, 2006).

Some people with chronic health conditions however report experiencing positive changes (i.e. psychological growth) as a result of their health condition (Pakenham, 2005; Sirois & Hirsch, 2013). There is evidence that the process of finding benefit from living with MS can be adversely associated with anxiety and depression (Mohr et al., 1999), but the overall extent to which psychological growth influences positive and negative outcomes is somewhat unclear. This highlights the need for quantitative integration of research on psychological growth and psychological outcomes in MS; understanding the direction and magnitude of these associations could have important clinical implications for this population. This meta-analysis therefore aimed to examine the associations between psychological growth, and distress and well-being in MS.

Multiple sclerosis

MS is a chronic neurological condition affecting the central nervous system whereby the immune system mistakenly attacks nerve coatings creating lesions in the

brain and/or spinal cord, disrupting the normal process of message transmission (Mohr & Cox, 2001). For the majority of people with MS (85%), the disease course follows a pattern of relapses followed by remissions which can subsequently become progressive in nature (65%), though approximately 10-15% of people experience progressive symptoms from the beginning (Mohr & Cox, 2001; MS Society, 2016; Patten, Marrie, & Carta, 2017).

The areas in which lesions occur determine the symptoms people have, meaning that a wide array of difficulties can be experienced, and different symptoms can present with each relapse (Lezak et al., 2012). Physical symptoms can include visual impairments, weakness/stiffness/incoordination of limbs, and difficulties with bladder functioning (Mohr & Cox, 2001). Up to 20% of people report fatigue to be particularly disabling (Krupp, 2003). Cognitive difficulties typically include executive dysfunction, difficulties with memory, attention/concentration and processing speed, all of which can be exacerbated by fatigue (Lezak et al., 2012; Lode, 2010). As a result of these symptoms, changes in sexual and social functioning, emotional changes and difficulty maintaining employment are common (Lezak et al., 2012; Lode, 2010). MS is understandably associated with high rates of anxiety (35.7%; Korostil & Feinstein, 2007) and depression (36-54%; Llorca & Samalin, 2015; Bianchi & Pozzilli, 2015). The uncertainty of the unpredictable disease course and progressive prognosis in MS can result in difficulties with adjustment and coping (Lode et al., 2010; Bianchi & Pozzilli, 2015) resulting in a significant impact on quality of life and well-being (Montel & Bungener, 2007).

Resilience and psychological growth

Despite high levels of anxiety and depression reported, some people living with chronic health conditions report experiencing positive changes related to the process of

psychological adjustment (e.g. cancer, Scrignaro, Barni, & Magrin, 2011; and arthritis, Sirois & Hirsch, 2013). Such positive changes related to adjustment have been linked to resilience. Tugade and Fredrickson (2004, p. 320) defined resilience as "the ability to bounce back from negative emotional experiences by flexible adaptation to the changing demands of stressful experiences". The idea of "bouncing back" therefore suggests that someone returns to their level of functioning experienced prior to a trauma (Wald, Taylor, Asmundson, Jang, & Stapleton, 2006). Resilience has been investigated widely within the literature, including following psychological trauma (e.g. Hooberman, Rosenfeld, Rasmussen, & Keller, 2010), physical trauma such as brain injury (e.g. McCauley et al., 2013), and living with a chronic health condition (e.g. rheumatoid arthritis; Strand et al., 2006). Factors contributing to resilience include personal factors (e.g. attachment, personality traits and demographics etc.), biological factors (e.g. genetics and brain development), systemic or environmental factors (e.g. social relationships and support, and wider environmental factors such as education and culture; Herrman et al., 2011). Furthermore, these factors are not static, and all interact with one another (Herrman et al., 2011).

Another related construct is psychological growth i.e. "a positive psychological change experienced as a result of the struggle with highly challenging life circumstances" (Tedeschi & Calhoun, 2004, p.1). Various terms such as posttraumatic growth (PTG), adversarial growth, benefit finding, and thriving have been used interchangeably within the literature to denote psychological growth. Some authors have argued that PTG goes beyond resilience in that some people who experience trauma may find benefit in the experience, and even show *improvement* in personal functioning beyond pre-trauma functioning (Tedeschi & Calhoun, 2004; Wald et al., 2006; Westphal & Bonanno, 2007). PTG is thought to have a strong affective element; Tedeschi and Calhoun (2004, p.5)

described it as “most likely a consequence of attempts at psychological survival, and it can coexist with the residual distress of the trauma”. Therefore, the psychological distress experienced as a result of the trauma is not dismissed, but rather a key simultaneous component of experiencing psychological growth. An example of psychological growth is adjusting positively to the changing demands of a chronic illness (Sirois & Hirsch, 2013).

Psychological growth and chronic health

Improved personal growth, transformations in life goals, and stronger relationships have also been reported in relation to living with a chronic health condition (Pakenham, 2005). Subsequent personal growth could be related to improved coping in the context of a chronic health condition (Barskova & Oesterreich, 2009). Psychological growth has been demonstrated in various health conditions such as rheumatoid arthritis (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992); human immunodeficiency virus (HIV; Bower, Kemeny, Taylor, & Fahey, 1998), and cancer (Cordova, Cunningham, Carlson, & Andrykowski, 2001). Individual studies with MS populations have demonstrated that improvements in depression following treatment were associated with enhanced psychological growth and this association was mediated via increases in positive affect and optimism (Hart, Vella, & Mohr, 2008). Furthermore, a systematic review by Barskova & Oesterreich (2009) of PTG in people with serious medical conditions, including four studies with MS populations, suggested that PTG is potentially adaptive in terms of coping. The findings of this review however must be interpreted with caution due to the very small number of MS studies included and the narrative method which limits conclusions that can be drawn about the impact of psychological growth on outcomes (Barskova & Oesterreich, 2009). To the authors’ knowledge, no attempt has been made to quantitatively integrate psychological growth and psychological outcomes in MS.

Psychological outcomes

Distress. While distress is a challenging concept to define and quantify (Mirowsky & Ross, 2002) it appears to be typified by symptoms of depression and anxiety (Drapeau, Marchand, & Beaulieu-Prévost, 2012), with subsequent significant impact on daily psychosocial functioning (Wheaton, 2007). Distress is typically experienced as a result of difficult life circumstances such as unexpected traumatic events, loss of a loved one or diagnosis of a life-changing health condition (Tedeschi & Calhoun, 2004). The type of event often determines what types of emotional distress are experienced (i.e. sadness and depression in response to loss, anger and anxiety following substantial life changes; Tedeschi & Calhoun, 2004). Exposure to these types of traumatic events and prolonged distress can lead to more enduring psychological difficulties (Rubonis & Bickman, 1991), although not all experiences of significant stressors will result in distress. Wheaton and Montazer (2010) argued that distress will not necessarily be induced from all stressors if contextual factors such as prior experience of the stressor or being able to utilise coping strategies such as accessing support from others are available. This also suggests that the experience of challenging circumstances can lead to opportunities for personal growth, and that growth and distress often co-occur (Tedeschi & Calhoun, 2004). Since distress encompasses many negatively-focused emotions depending on the stressor, a broad definition was adopted for this meta-analysis. Search terms identified therefore included disorder descriptors such as ‘anxiety’ and ‘depression’ along with broader concepts related to distress such as ‘negative mood’ and ‘helplessness’.

Well-being. Well-being can be thought of as two related but separate constructs of psychological functioning: i) hedonic well-being (i.e. happiness) and ii) eudaimonic well-being (human potential; Deci & Ryan, 2008; Keyes, Shmotkin, & Ryff, 2002; Ryan

& Deci, 2001; Waterman, 1993). Hedonic well-being refers to subjective reports of personal functioning including increased positive affect and decreased negative affect (Deci & Ryan, 2008). Eudaimonic well-being (Waterman, 1993) however extends the definition of well-being beyond that of the construct of happiness; the idea being that subjective reports of being 'happy' are not necessarily associated with good psychological functioning (Deci & Ryan, 2008). Eudaimonic well-being therefore is concerned with the idea of fulfilling one's potential (Deci & Ryan, 2008). Consensus within the literature is that although there are critical differences between the two well-being constructs, there is substantial overlap (Deci & Ryan, 2008; Ryan & Deci, 2001). Furthermore, recent research has replicated the finding that hedonic and eudaimonic well-being are highly correlated and may well actually represent one overarching well-being construct (Disabato, Goodman, Kashdan, Short, & Jarden, 2016). Taking this into consideration when identifying relevant search terms, terms related to both hedonic and eudaimonic well-being were therefore included in order to fully capture this multidimensional construct.

Moderators of the psychological growth-psychological outcomes associations

One advantage of a meta-analytic approach was that moderation analysis could be conducted to ascertain which factors might attenuate or amplify the magnitude of these associations. Moderators of interest were i) type of psychological growth construct, ii) type of outcome index (averaged or single effect size), iii) gender, iv) age, and v) years since diagnosis.

Resilience is thought to differ from other forms of psychological growth such as PTG and benefit finding (BF) since resilience represents the idea of "bouncing back" to a previous level of functioning but PTG/BF implies improvement beyond pre-trauma functioning suggesting a change process (Tedeschi & Calhoun, 2004; Wald et al., 2006;

Westphal & Bonanno, 2007). It is therefore possible that PTG/BF requires more resources to achieve compared to resilience, meaning the association of psychological growth with well-being and distress outcomes is larger for resilience than for PTG/BF.

Measurement of several psychological outcomes in one study is common (e.g. depression and anxiety, both of which would fall under the umbrella term of distress). Several effect sizes from various measures in a single study is also a common problem for meta-analysis where one effect size is required per study (Card, 2012). One method for dealing with this is computing an average effect size of the various effect sizes which is then included in the final analysis (Card, 2012). It was expected that many of the included studies would measure distress and/or well-being using multiple measures and averaging of these effect sizes would be required to be included. Averaging effect sizes might increase heterogeneity so it was expected that studies with single effect sizes versus studies with averaged effect sizes would have larger effects.

Gender differences have been identified in levels of PTG, with women reporting higher levels of PTG than men (Vishnevsky, Cann, Calhoun, Tedeschi, & Demakis, 2010). It was therefore expected that there would be gender-related differences in the association between psychological growth and psychological outcomes.

Age was also a potential moderator since older age has been found to be associated with higher levels of resilience in people with physical disabilities (Terill et al., 2016) and the general population (Gooding, Hurst, Johnson, & Tarrier, 2012). It is therefore expected that the associations between psychological growth and outcomes would be moderated by age.

Years since diagnosis has been found to be negatively related to psychological distress in MS such that as years since diagnosis increases, psychological distress decreases (Ryan et al., 2007). This was therefore investigated as a potential moderator

and it was expected that the association between psychological growth and outcomes would be moderated by years since diagnosis.

Current study

This meta-analysis aimed to evaluate the nature and direction of the relationships between psychological growth and psychological outcomes in MS. Moderators which might attenuate or amplify the magnitude of these associations i.e. type of psychological growth construct measured, type of outcome index (i.e. averaged effect size or single), age, gender and years since diagnosis were also tested. Finally, the meta-analysis included assessment of methodological quality of the included studies.

Hypotheses

1) Psychological growth will be negatively associated with distress and positively associated with well-being in MS (Hypothesis 1; H1);
2) Associations between psychological growth and outcomes in MS will vary according to psychological growth scales and will be largest for studies measuring resilience compared to posttraumatic growth/benefit finding (H2);
3) Associations between psychological growth and outcomes in MS will vary according to type of outcome index; studies with single measures of distress or well-being will demonstrate larger effects than those where multiple effect sizes were measured and averaged (H3);
4) There will be gender-related differences in strength of the associations between psychological growth, and distress and well-being (H4);
5) There will be age-related differences in the strength of the associations between psychological growth and distress and well-being (H5);
6) Years since diagnosis will moderate the association between psychological growth and distress and well-being (H6)

Method

Search strategy

Relevant literature was identified through searching four electronic databases (PsycInfo, Medline via Ovid, Scopus and CINAHL) between 9th and 26th November 2018. Email alerts were implemented between 26th November 2018 and 26th January 2019 to ensure any new literature was discovered. Three sets of search terms were identified using an iterative scoping process to ensure that all relevant literature investigating growth-related constructs and both positive and negative psychological outcomes in MS was identified (Table 1).

Table 1.

Summary of literature review search terms (OR used within columns and AND across columns)

i) Multiple sclerosis	ii) Psychological growth	iii) Psychosocial outcomes (positive i.e. well-being and negative i.e. distress)
"multiple sclerosis", "MS"	"post-traumatic growth", "posttraumatic growth", "benefit-finding", "benefit finding", "adversarial growth", "resilience", "thriving", "flourishing", "stress-related growth", "positive life changes"	"well-being" (wellbeing, well being), "happiness", "subjective well-being" (subjective wellbeing, subjective well being), "positive affect", "positive mood", "positive emotions", "life satisfaction", "quality of life", "positive well-being" (positive wellbeing, positive well being)
		"distress", "psychological distress", "emotional distress", "stress", "negative mood", "negative emotions", "anxiety", "depression", "negative affect", "mental health", "global distress", "helplessness"

Searches were performed using keywords, and subject headings and MESH terms were selected where appropriate. In line with best-practice recommendations, ancestry searches were completed by searching reference lists of eligible papers for other relevant papers potentially missed by the searches (Aguinis, Gottfredson, & Wright, 2011). Forward reference searching was also completed by reviewing papers which had cited the eligible papers identified since publication.

Selection criteria

Table 2 summarises the inclusion and exclusion criteria.

Table 2

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
1. Samples which included adult populations	1. Child only populations
2. Clear diagnosis (or reported diagnosis) of MS	2. Samples with no clear MS diagnosis
3. Mixed population samples if MS-only data could be extracted (or provided by author)	3. MS-only data could not be extracted or was not provided by author
4. Quantitative measurement of growth-related construct and a relevant psychological outcome	4. No quantitative measurement of psychological growth or relevant outcomes
5. Sufficient data of associations between psychological growth and outcomes for calculating effect sizes (i.e. correlation coefficient *r*, sample size and demographic information) or data provided upon request	5. Relevant data for calculating effect sizes unavailable or not provided upon request
6. Cross-sectional data from cross-sectional designs, or intervention and longitudinal designs reporting sufficient baseline data which acted as cross-sectional data (or provided on request)	6. Relevant cross-sectional data unavailable or not provided upon request

Grey literature was searched to maximise the number of studies for meta-analysis. The inclusion of grey literature can reduce the quality of the meta-analysis since the data is not published in a peer-reviewed journal and subsequently was not subject to as stringent a review process (Borenstein, Hedges, Higgins, & Rothstein, 2009; Conn, Valentine, Cooper, & Rantz, 2003). The inclusion of grey literature can however improve methodological rigor since it addresses the issue of publication bias (Borenstein et al., 2009). Grey literature was identified through the main searches and by reviewing relevant databases such as Open Grey.

Screening

A PRISMA diagram (Figure 1) summarises the search strategy and screening for this meta-analysis (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009).

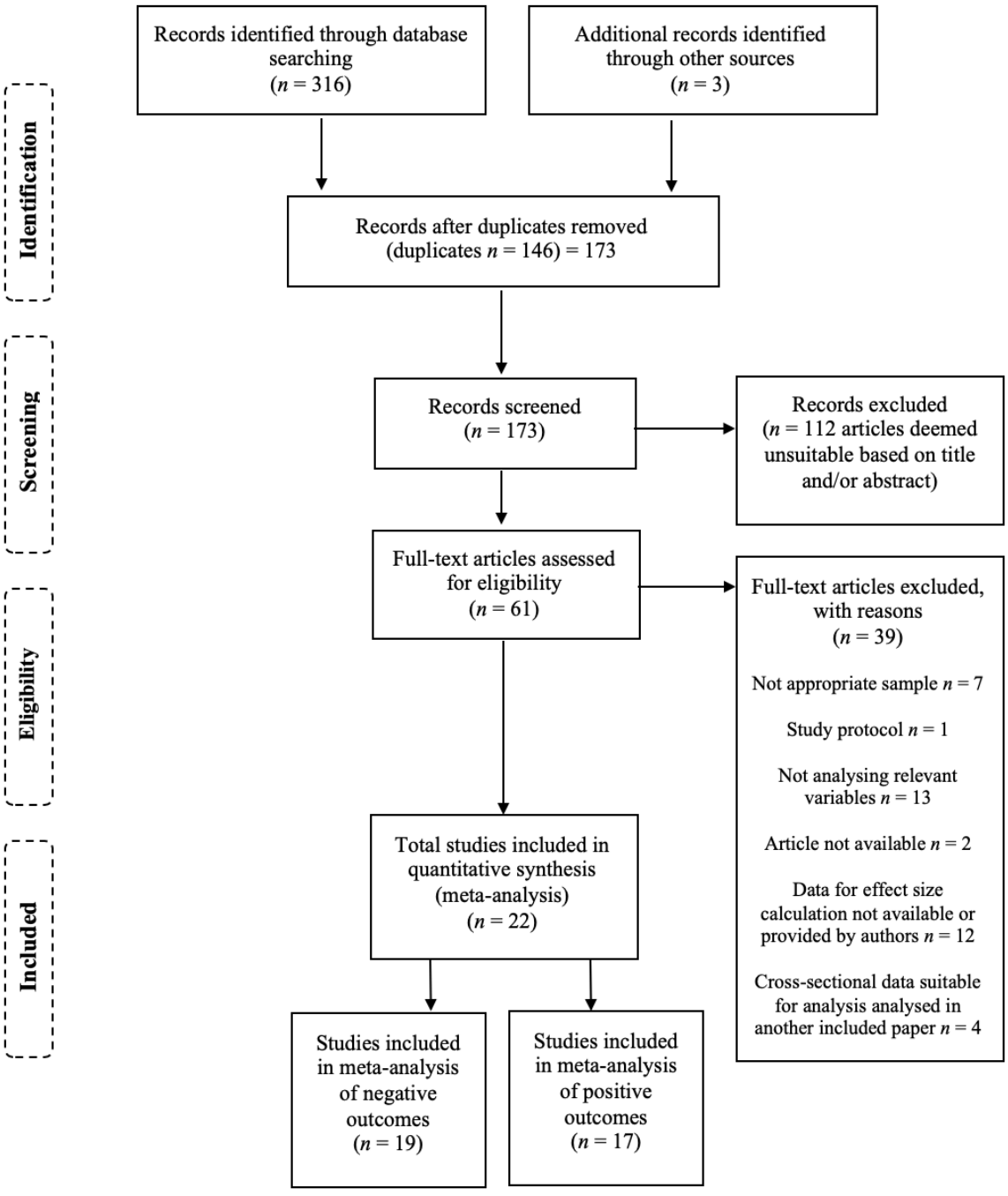

Figure 1. PRISMA diagram summarising the search strategy for meta-analysis

Data extraction

Due to various studies within this meta-analysis measuring both positive and negative outcomes, two separate meta-analyses were conducted ('well-being' and 'distress'). Authors were approached by email when relevant data for effect sizes was not available in the paper. In some cases, studies included a mixed sample of chronic health populations participants; if relevant data could not be isolated for the MS sample authors were emailed to request this. Cross-sectional/baseline data was extracted from longitudinal and intervention studies and analysed as cross-sectional data.

Data extracted for meta-analysis included correlation effect size (*r*) and sample size. Data required for moderator analysis included gender (% female), mean age, details of psychological growth constructs measured (resilience, benefit finding and posttraumatic growth) and the measurement instrument, details of the positive (well-being) and negative (distress) outcomes measured and instruments used, and years since diagnosis (mean). Some studies included more than one measure of either distress or well-being; in such cases correlation values were averaged to create a single effect size for that construct as suggested by Card (2012). Other background descriptive data extracted included country of origin, study design (cross-sectional, longitudinal or intervention), publication status and % Caucasian where reported.

Meta-analytic strategy

Meta-analysis was conducted using Comprehensive Meta-Analysis (CMA, Version 3; Borenstein, Hedges, Higgins, & Rothstein, 2013). As suggested by Hunter and Schmidt (2000) a random-effects model was selected for both meta-analyses in order to reduce the possibility of type-I errors. In this model, the true effect size is hypothesised to differ across studies rather than the true effect being fixed across studies (as is hypothesised in fixed-effects models; Quintana, 2015). This method takes into account

two important types of variance in estimating true effects: variance within studies and variance across studies (Borenstein et al., 2009). Correlation coefficients were extracted from the studies and automatically converted by CMA into Fisher's *z* scores to conduct the analysis before being converted back. The magnitude of the correlation coefficients was considered based upon Cohen's (1992) parameters (small, $r = .10$; medium, $r = .30$; large, $r = .50$).

Variability between study effect sizes was assessed using the Q and I^2 statistics to establish justification for moderator analysis (even if the overall effect was not significant; Sirois, Molnar, & Hirsch, 2017). The Q statistic is sensitive to the ratio of within-study error to the observed variance; a significant Q statistic therefore means that the level of heterogeneity in the sample is significantly more than can be explained by sampling error (Borenstein et al., 2009). Significant heterogeneity based on Q indicates moderator analysis is necessary. The I^2 statistic is concerned with quantifying the proportion of true heterogeneity relative to spurious heterogeneity between studies (Quintana, 2015). The I^2 value can be interpreted using the following criteria: <25% = low, 25-50% = moderate, >75% high heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003).

As suggested by Card (2012), three or more studies per subgroup were required in order to conduct moderator analysis. Growth constructs BF and PTG were considered to be very similar constructs and were therefore grouped to be compared with 'resilience'. Studies with averaged effect sizes were grouped and compared to studies containing single effect sizes. A mixed-effects approach was used to conduct moderator analyses; firstly, the combined subgroups were analysed for within subgroup heterogeneity using a random effects model, and secondly between-subgroup heterogeneity was assessed using a fixed-effects model. The moderating effects of continuous variables such as gender (%

female), age (mean) and years since diagnosis (mean) were assessed using method of moments meta-regression (Quintana, 2015).

Publication bias

The extent to which publication status has an effect on the estimation of the true effect size is an important issue; studies with larger effects tend to be published over studies with small effects and therefore may bias findings (Borenstein et al., 2009; Quintana, 2015). Though unpublished studies were included in this meta-analysis, publication bias was still assessed visually and statistically using several approaches as suggested by Card (2012). Firstly, funnel plots provided a way of visually assessing the study size (standard error) and effect size association; publication bias is indicated by an asymmetrical pattern of study effect sizes around the mean effect size (Borenstein et al., 2009; Egger, Smith, Schneider, & Minder, 1997; Sterne, Becker & Egger, 2005). Duval and Tweedie's (2000) trim and fill method was also used which adjusts for missing studies and provides an estimate of an unbiased effect size (Borenstein et al., 2009). The estimated effect size is displayed alongside the original effect size in a funnel plot so changes to effect sizes can be observed. Egger's regression test additionally provided quantification of bias identified by the funnel plot by regressing the standardised effect on accuracy (Sterne & Egger, 2005) with a significant *p*-value suggesting evidence of publication bias and indicating asymmetry of the funnel plot (Quintana, 2015). Finally, Rosenthal's fail-safe *N* was calculated to estimate the number of missing studies required to be included in the analysis in order for the overall effect to become non-significant (Becker, 2005; Borenstein et al., 2009). A sufficient threshold for fail-safe *N* is indicated by a value exceeding $5k + 10$ (k = number of included studies; Rosenthal, 1979). This threshold was calculated for each meta-analysis and compared to the fail-safe *N* value reported in CMA.

Quality assessment

Quality assessment was conducted to develop an overall picture of the level of methodological quality of the studies in this sample, to aid interpretation of findings and cultivate future research recommendations, but not exclude studies. Methodological quality was assessed by three established checklists (Appendix A).

The Appraisal tool for Cross Sectional Studies (AXIS; Downes, Brennan, Williams, & Dean, 2016) checklist was specifically designed to assess the methodological quality of cross-sectional studies. This checklist does not utilise a scoring system, but each item was deemed to be 'good' if rated 'yes', 'uncertain' if rated 'don't know' and 'poor' if rated 'no'. Items 7 and 14 regarding how non-responders were dealt with was deemed not-applicable (N/A) for the included studies since data is only gathered at one time-point and the reasons for non-responding are therefore usually not available. Items 13 and 19 were reverse coded, whereby an answer of 'no' indicated good quality and 'yes' indicated poor quality.

The Downs and Black Checklist (1998) is a quality tool for randomised and non-randomised intervention studies (Cochrane, 2011). Items were rated either 1 = yes, 0 = no or unable to determine, with the exception of item 5 which was rated 2 = yes, 1 = partially, and 0 = no. In line with other research (Hague, Hall, & Kellett, 2016) item 27 assessing power was adapted to fit the other scoring criteria and was rated based on the presence of a power calculation for sample size (1 = yes, 0 = no). Item 13 was deemed to be N/A for the included studies and therefore excluded. The maximum total score was therefore 27. To enable comparison of quality across studies the following categories were applied for interpretation of scores: >20 = very good, 15-19 = good, 11-14 = fair, <10 = poor (Naylor, Ward, & Polite, 2012; Peek, Cargill, & Huang, 2007; Silva et al., 2016).

Finally, the Critical Appraisal Skills Programme: Cohort Study checklist (CASP, 2018) assessed methodological quality of longitudinal studies. All items were rated based on 'yes' = 1, 'no' = 0 and 'can't tell/unclear' = X, meaning the maximum total score was 13. Item 3 was deemed to be N/A and therefore excluded. Based on other research (Smith et al., 2016) qualitative categories were used to aid interpretation and comparison across studies: 0-6 = low quality, 7-9 = moderate quality and 10-13 = high quality.

A secondary assessment of methodological quality was conducted as advised by Quintana (2015). This approach focused on factors most relevant for correlational studies such as methods reporting, psychometric properties of outcome instruments and sample size. This involved selection of factors most relevant to the research question (Molloy, O'Carroll, & Ferguson, 2014; Quintana, 2015). Items were rated 1 if the paper achieved each criterion, or 0 if it did not, with a maximum score for each study of 4. Informed by a meta-analysis protocol by Baird, Webb, Martin, & Sirois (2017) the following items were chosen:

1. Sample size >85. To detect a medium effect size using *r* and *p*-value of 0.05 a sample size of 85+ is required for sufficient power (Cohen, 1992).
2. Cronbach's alpha of psychological growth measure >.70 for the study sample; this is generally an acceptable level of internal consistency in social science research (Drost, 2011).
3. Cronbach's alpha for distress/well-being measures >.70 for the study sample. As averaged effect sizes were used, studies were rated 1 if all individual Cronbach's alphas exceeded .70, or 0 if one of any of the Cronbach's alphas included in the average effect did not exceed .70.

4. Random sampling method used. Random sampling is important for maximising the representativeness and generalisability of findings beyond the sample studied to the target population (Walker, 2005).

Quality assessment was conducted on all papers by the author. Additionally, a random sample of papers (n = 5) were quality reviewed using the AXIS, Downs and Black, and CASP checklists by a second rater (Trainee Clinical Psychologist). Disagreements were resolved through discussion. Inter-rater reliability was established by Intraclass Correlation Coefficient (ICC; Cicchetti, 1994).

Results

Twenty-two studies were included overall *(*N = 5542; Table 3). Two separate meta-analyses were conducted: 17 studies were included in the well-being meta-analysis (N = 3963) and 19 studies were included in the distress meta-analysis (N = 5022). There was a degree of overlap in the study samples (i.e. data from one sample being used across multiple studies); attempts were made where possible to exclude overlapping study samples to safeguard against additional bias (see PRISMA). The exception to this was Battalio et al., (2017) and Edwards et al., (2017). Both studies used the same sample from an ongoing longitudinal study, but Battalio et al. included data for 36 new participants which did not overlap with the sample from Edwards et al. provided by the author; this data for the 36 new participants only was therefore included in the final analysis for that study.

Four studies measured PTG using the same scale and three studies assessed benefit finding using two different scales (one specifically for MS populations). Fifteen studies measured resilience using six different scales, one specific to MS. Nine different measures of depression were used across 16 studies. Similarly, six different measures of

anxiety were used across 10 studies. Eleven studies measured quality of life using eight different measures (two specifically for MS populations). Positive affect was measured in four studies, using two different measures.

Table 3

Study characteristics, main findings, effect sizes (Pearson's r) and p-values.

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
1	Ackroyd, Fortune, Price, Howell, Sharrack, & Isaac (2011)	United Kingdom (UK)	Cross-sectional	Published	72 58.34% 47.5 97% 10.3	Posttraumatic growth (PTG) (Posttraumatic Growth Inventory-Short Form; PTGI-SF)	N/A	Depression (Chicago Multi-Scale Depression Inventory; CMDI)	Posttraumatic growth was not significantly associated with depression	**Depression = -.134 (p=.261)**
2	Arewasikporn, Ehde, Alschuler, Turner, & Jensen (2018)	USA	Cross-sectional (Analysis of cross-sectional data from ongoing longitudinal study)	Published	455 82.4% 61.0 88.6% 21.2	Resilience (CD-RISC)	Positive affect (Positive and Negative Affect Scale; PANAS)	Depression (Patient-Reported Outcomes Measurement Information System; PROMIS)	Resilience was moderately positively associated with positive affect and strongly negatively associated with depression	**Positive affect = .47 (p<.001)** **Depression = -.59 (p<.001)**
3	Battalio, Silverman, Ehde, Amtmann, Edwards, & Jensen (2017)	USA	Cross-sectional (Analysis of cross-sectional data from ongoing longitudinal study)	Published	36 (newly recruited participants) 89% 57.4 16.7% -	Resilience (CD-RISC)	Quality of Life (Older People's Quality of Life-Brief; OPQOL-Brief)	Anxiety (PROMIS) Depression (PROMIS)	Resilience was strongly associated with quality of life (positively) and anxiety and depression (negatively)	**QOL = .67 (p=.000)** Anxiety = -.604 (p=.000) Depression = -.631 (p=.000) **Mean distress *r* = -.618**

Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
4	Black & Dorstyn (2015)	Australia	Cross-sectional	Published	196 85.71% 43.94 85% 9	Resilience (CD-RISC)	Positive Affect (PANAS)	Negative Affect (PANAS)	Resilience was strongly positively associated with positive affect. Resilience was moderately negatively associated with negative affect	**Positive affect = .592 (p<.01)** **Negative affect = -.466 (p<.01)**
5	Edwards, Alschuler, Ehde, Battalio, & Jensen (2017)	USA	Longitudinal (Cross-sectional/ baseline data only extracted)	Published	352 83% 54.5 94% -	Resilience (CD-RISC)	N/A	Depression (Patient Health Questionnaire -9; PHQ-9)	Resilience was moderately negatively associated with depression	**Depression = -.491 (p<.001)**
6	Esposito (2017)	USA	Cross-sectional	Unpublished	616 75% 45.73 80% -	Post-traumatic Growth (PTGI-SF)	Life Satisfaction (Satisfaction With Life Scale; SWLS)	Depression (Center for Epidemiologic Studies Depression Scale; CES-D)	Posttraumatic growth was negatively associated with depression and positively associated with life satisfaction	**Depression = -.190 (p<.001)** **Life satisfaction = .34 (p<.001)**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
7	Gromisch Sloan, Zemon, Tyry, Schairer, Snyder, & Foley (2018)	USA	Cross-sectional	Published	932 81.2% 56.35 93.8% 18.06	Resilience (Multiple Sclerosis Resilience Scale; MSRS)	N/A	Depression and Anxiety (Hospital Anxiety and Depression Scale; HADS)	Resilience was strongly negatively associated with depression and anxiety	Depression = -.72 (p<.001) Anxiety = -.56 (p<.001) **Mean distress *r* = -.647**
8	Hadianfard, Ashjazadeh, Feridoni, & Farjam (2015)	Iran	Cross-sectional	Published	100 80% 35.15 - -	Resilience (CD-RISC)	Health-related Quality of Life (Short Form Health Survey; SF-36)	N/A	Resilience was strongly positively correlated with QoL	**Health-related QoL = .515 (p=.000)**
9	Koelmel, Hughes, Alschuler, & Ehde (2017)	USA	Longitudinal (Cross-sectional/ baseline data only extracted)	Published	163 87.1% 52.2 - 12	Resilience (CD-RISC)	General Mental Health Status – Mental Component Summary (MCS) (Short-Form-8 Health Survey; SF-8)	Depression (PHQ-9) Anxiety (PROMIS)	Resilience was moderately positively correlated with general mental health status, and moderately negatively correlated with depression and anxiety	**Mental Health Status = .387 (p<.001)** Depression = -.403 (p<.001) Anxiety = -.461 (p<.001) **Mean distress *r* = -.432**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
10	Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin (1999)	USA	Cross-sectional	Published	94 75% 42.6 - 8.1	Benefit Finding Scale (BFS)	N/A	Depression and Anxiety (Profile of Mood States; POMS)	Benefit finding was weakly positively correlated with anxiety (significant) and depression (not significant)	Depression = .16 (p=.24) Anxiety = .21 (p=.04) **Mean distress *r* = .185**
11	Nakazawa Noda, Ichikura, Okamoto, Takahashi, Yamamura, & Nakagome (2018)	Japan	Cross-sectional	Published	63 66.7% 41.67 - 9.02	Resilience (Japanese Version of RS)	Quality of life (Multiple Sclerosis Quality of Life Inventory-54 Japanese version; MSQoL-54J)	Depression (Beck Depression Inventory; BDI and HADS) Anxiety (HADS)	Resilience was moderately positively correlated with quality of life and moderately negatively correlated with depression and anxiety	**QoL = .325 (p>.05)** Depression: *BDI* = -.41 (p<.001); *HADS* = -.407 (p<.001) Anxiety = -.398 (p<.001) **Mean distress *r* = -.405**
12	Nery-Hurwit, Yun, & Ebbeck (2018)	USA	Cross-sectional	Published	259 84.23% 48.55 90.13% -	Resilience (CD-RISC)	Quality of Life (Functional Neutral Health-Related Quality of Life Short Form)	N/A	Resilience was strongly positively assonated with quality of life	**QoL = .60 (p<.0001)**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
13	Pakenham (2005)	Australia	Longitudinal (Cross-sectional/ baseline data only extracted)	Published	379 (negative) 381 (positive) 77% 57.77 - 9.77	Benefit Finding (BFS)	Positive affect (Bradburn Affect Balance Scale; BABS) Life Satisfaction (SWLS)	Negative Affect (BABS) Global Distress (Brief Symptom Inventory-18; BSI-18)	Benefit finding was not significantly associated with either negative affect or global distress but was weakly positively correlated with life satisfaction and positive affect	Positive affect = .23 (<.0001) Life satisfaction = .12 (p<.01) **Mean well-being *r* = .176** Negative affect = -.04 (p>.05) Global Distress = -.01 (p>.05) **Mean distress *r* = -.025**
14	Pakenham & Cox (2009)	Australia	Longitudinal (Cross-sectional/ baseline data only extracted)	Published	388 82% 49.33 - 10.56	Benefit Finding (Benefit Finding in Multiple Sclerosis Scale; BFiMMS)	Adjustment (Positive States of Mind Scale; PSOM) Positive Affect (BABS)	Anxiety and Depression (Symptom Checklist-90; SCL-90)	Benefit finding was weakly positively associated with adjustment and weakly negatively associated with depression. Benefit finding was moderately but not significantly associated with positive affect (positive) or anxiety (negative).	Adjustment = .221 (p=.000) Positive Affect = .396 (p=1.81) **Mean well-being *r* = .311** Anxiety = -.31 (p=.544) Depression = -.163 (p=.001) **Mean distress *r* = -.238**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
15	Pakenham, Mawdsley, Brown, & Burton (2018)	Australia	Pre-post intervention (only baseline/cross-sectional data extracted)	Published	37 72.97% 49.30 - 9.42	Resilience (RS)	Quality of life – Emotional Well-being (Multiple Sclerosis Quality of Life-54; MSQoL-54)	Depression, Anxiety and Stress (Depression, Anxiety and Stress Scales-21; DASS-21)	Resilience was strongly positively associated with quality of life, and strongly negatively associated with depression, anxiety and stress (i.e. distress)	**Emotional well-being = .69 (p=.000)** Depression = -.61 (p=.000) Anxiety = -.52 (p=.001) Stress = -.52 (p=.001) **Mean distress *r* = -.551**
16	Ploughman, Collins, Wallack, Monks, & Mayo (2017)	Canada	Cross-sectional	Published	743 77.66% 64.62 - 24.82	Resilience (RS)	Quality of Life (Simple Lifestyles Indicator Questionnaire; SLIQ)	Anxiety and Depression (HADS)	Resilience was weakly positively associated with quality of life. Resilience was moderately negatively correlated with anxiety and strongly negatively correlated with depression	**Quality of life = .212 (p=000)** Anxiety = -.382 (p=.000) Depression = -.562 (p=.000) **Mean distress *r* = -.477**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
17	Rainone, Chiodi, Lanzillo, Magri, Napolitano, Morra, Valerio, & Freda (2017)	Italy	Cross-sectional	Published	53 60.4% 20 - -	Resilience (Child and Youth Resilience Measures; CYRM-28)	Quality of Life (Paediatric Quality of Life Inventory; PedsQoL)	Depression (BDI) State Anxiety (State-Trait Anxiety Inventory; STAI)	Resilience was negatively correlated with depression (moderate), state anxiety (strong) and trait anxiety (strong)	**Quality of Life =.34 (p<.01)** Depression = -.31 (p<.01) State anxiety = -.53 (p<.01) **Mean distress *r* = -.426**
18	Schwartz (2014)	USA	Cross-sectional	Unpublished	133 85% 44.4 - 8.3	Post-traumatic Growth (PTGI-SF)	Health-Related Quality of Life (SF-36) – emotional well-being domain	Depression (CES-D)	Posttraumatic growth was weakly correlated with quality of life but not significantly correlated with depression	**Emotional Well-being = .14 (p=.11)** **Depression = .11 (p=.22)**
19	Senders, Bourdette, Hanes, Yadaz, & Shinto (2014)	USA	Cross-sectional	Published	119 78% 51.58 92.4% -	Resilience (CD-RISC)	Health-Related Quality of Life (SF-36) – emotional well-being Adaptive Coping (Brief Coping Orientation for Problem Experiences; B-COPE)	Stress (Perceived Stress Scale; PSS) Maladaptive coping (B-COPE)	Resilience was significantly positively correlated with quality of life (strong) and coping (moderate). Resilience was strongly correlated with stress and maladaptive coping	Emotional well-being = .58 (p<.0001) Coping = .47 (p<.0001) **Mean well-being *r* = .527** Stress = -.55 (p<.0001) Maladaptive Coping = -.58 (p<.0001) **Mean distress *r* = -.565**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
20	Senders, Hanes, Bourdette, Carson, Marshall, & Shinto (2018)	USA	Randomised Controlled Trial; RCT (only baseline/cross-sectional data extracted)	Published	62 77.42% 52.94 - 16.16	Resilience (CD-RISC)	Health-Related Quality of Life (SF-36) – emotional well-being	Depression (PROMIS) Stress (PSS)	Resilience was strongly positively correlated with quality of life and strongly negatively correlated with depression. Resilience was also moderately negatively correlated with stress	**Emotional Well-being = .56 (p=.0001)** Depression = -.58 (p<.0001) Stress = -.39 (p=.0018) **Mean distress *r* = -.491**
21	Tan-Kristanto & Kiropoulos (2015)	Australia	Cross-Sectional	Published	129 90.7% 38.41 - 2.04	Resilience (Resilience Scale for Adults; RSA)	N/A	Depression (DASS) Anxiety (DASS)	Resilience was moderately negatively correlated with depression and anxiety	Depression – 0.443 (p=.000) Anxiety = -.318 (p=.000) **Mean distress *r* = -.382**

(Table 3 continued)

Study no.	Citation	Country	Study Design	Publication status	Sample size (*N*); % female; Age (mean years); % Caucasian; Years since diagnosis (mean)	Psychological growth construct (Measure)	Positive outcomes (Measure)	Negative outcomes (Measure)	Summary of effects	Effect size(s) (p-value)
22	Zeltser (2017)	USA	Cross-sectional	Unpublished	159 86.8% 45.2 86.8% 9.8	Post-traumatic Growth (PTGI-SF)	Quality of Life (Multiple Sclerosis Impact Scale – psychological; MSISpsy)	N/A	Posttraumatic growth was not significantly associated with quality of life	**Quality of Life = .060 (p=.454)**

Note: Where a study reported more than one 'distress' or 'well-being' construct, a mean effect size was calculated and entered into the meta-analysis; correlation values entered into meta-analysis denoted in **bold.** Bradburn Affect Balance Scale, BABS (Bradburn, 1969); Beck Depression Inventory, BDI (Beck, Steer, & Brown, 1996); Brief Coping Orientation for Problem Experiences, B-Cope (Carver, 1997); Benefit Finding Scale, BFS (Mohr et al., 1999); Benefit Finding in Multiple Sclerosis Scale, BFiMSS (Pakenham, 2007); Brief Symptom Inventory-18, BSI-18 (Derogatis, 2001); Conor-Davidson Resilience Scale, CD-RISC (Connor & Davidson, 2003; Campbell-Sills & Stein, 2007); Center for Epidemiological Studies Depression Scale; CES-D (Devins, 1985); Chicago Multi-State Depression Inventory; CMDI (Nyenhuis & Luchetta, 1998); Child and Youth Resilience Measures, CYRM-28 (Liebenberg, Ungar, & Vijver, 2012); Depression, Anxiety and Stress Scales-21, DASS-21 (Lovibond & Lovibond, 1995); Hospital Anxiety and Depression Scale, HADS (Zigmond & Snaith, 1983); Functional Neutral Health-Related Quality of Life Short Form; FNHRQOL-SF (Krahn et al., 2014); Japanese Resilience Scale (Nishi, Uehara, Kondo, & Matsuoka, 2010); Older People's Quality of Life-Brief, OPQOL-Brief (Bowling, Hankins, Windle, Bilotta, & Grant, 2013); Multiple Sclerosis Impact Scale-Psychological, MSISpsy (Hobart, Lamping, Fitzpatrick, Riazi, & Thompson, 2001); Multiple Sclerosis Resilience Scale, MSRS (Gromisch et al., 2018); Multiple Sclerosis Quality of Life-54, MSQoL-54 (Vickrey, Hays, Harooni, Myers, & Ellison, 1995; Japanese version, Yamamoto et al., 2004); Patient Health Questionnaire-9, PHQ-9 (Kroenke, Spitzer, & Williams, 2001); Paediatric Quality of Life Inventory, PedsQoL (Varni, Seid, & Rode, 1999); Profile of Mood States, POMS (McNair, Lorr, & Droppleman, 1981); Patient Reported Outcomes Measurement Information System, PROMIS (Rothrock, Hays, Spritzer, Yount, Riley, & Cella, 2010); Positive and Negative Affect Scale, PANAS (Watson, Clark, & Tellegen, 1988); Perceived Stress Scale, PSS (Cohen, Kamarck, & Merelstein, 1983; 1994); Posttraumatic Growth Inventory-Short Form, PTGI (Tedeschi & Calhoun, 1996) Positive States of Mind Scale, PSOM (Horowitz, Adler, & Kegeles, 1988); Resilience Scale for Adults, RSA (Friborg, Barlaug, Martinussen, Rosenvinge, & Hjemdal, 2005); Resilience Scale, RS (Wagnild & Young, 1993); Satisfaction with Life Scale, SWLS (Diener, Emmons, Larsen, & Griffin, 1985); Short-Form-8 Health Survey, SF-8 (Ware, Snow, Kosinski, & Gandek, 1993); Short-From Health Survey, SF-36 (Ware & Sherbourne, 1992); Symptom Checklist-90, SCL-90 (Derogatis & Unger, 2010); Simple Lifestyles Indicator Questionnaire, SLIQ (Godwin, Pike, Bethune, Kirby, & Pike, 2013); State-Trait Anxiety Inventory, STAI (Spielberger, Gorsuch, & Lushene, 1970).

Meta-analysis

Distress. There was a significant medium-sized negative relationship between psychological growth and distress outcomes (r= -.372; 95% CIs [-.48, -.26]; z = -5.941, p < .001), providing support for H1. As anticipated, there was evidence of significant heterogeneity with a large amount of variance identified between studies, $Q(18) = 344.66$, $p < .001$, $I^2 = 94.78\%$, $T^2 = 0.073$. Size of effects ranged from r = .19 to -.65 (Figure 2).

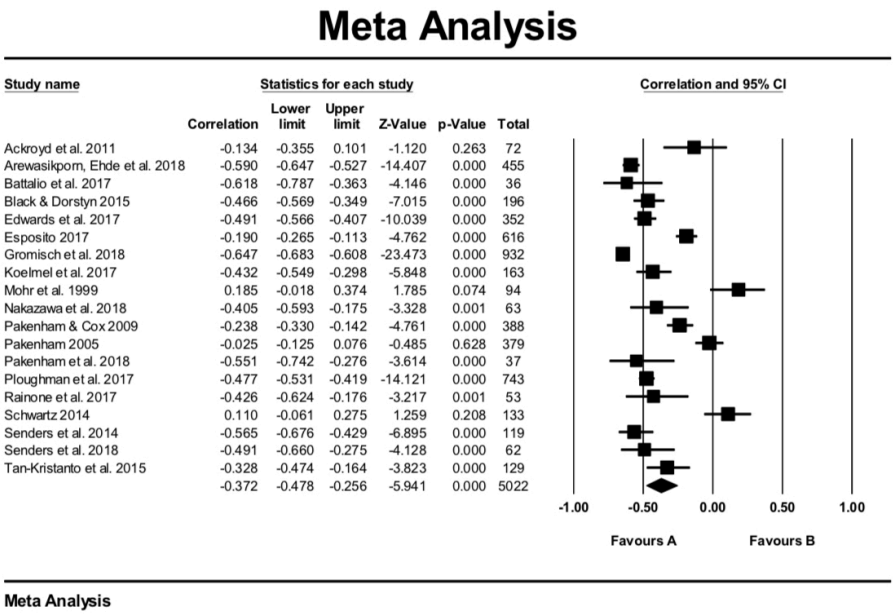

Figure 2. Forest plot for psychological growth and distress meta-analysis.

Well-being. There was a significant medium-sized positive relationship between psychological growth and well-being outcomes (r = .407; 95% CIs [.32, .49]; z = 8.593, p < .001), providing support for H1. Again, there was evidence of significant heterogeneity with a very large amount of variance identified between studies, $Q(16) = 136.6$, $p < .001$, $I^2 = 88.29\%$, $T^2 = 0.034$. Effect sizes ranged from r = .06 to .69 (Figure 3).

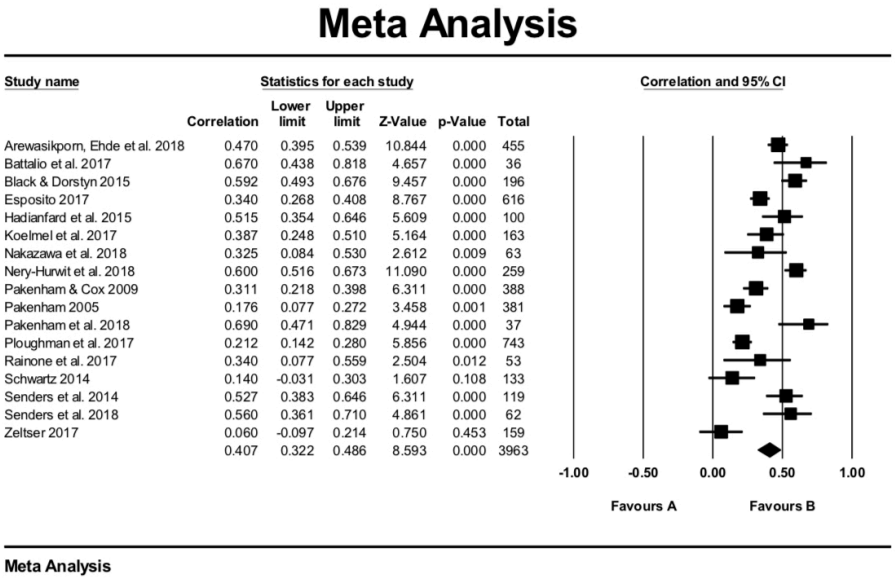

Figure 3. Forest plot for psychological growth and well-being meta-analysis.

As heterogeneity was large in both meta-analyses (i.e. I^2 >75%), sources of heterogeneity among effects were examined using moderator analyses.

Moderator analyses

Growth construct. As expected, effect sizes of psychological growth and distress varied significantly across different growth measures, with resilience having the largest effect size compared to PTG/BF (Table 4). This moderator effect was significant indicating between-group heterogeneity ($Q(1) = 42.271$, $p < .001$). This finding supported H2.

Table 4.

Moderator analysis of growth construct and outcome type with distress

Moderator	Groups	*k*	*n*	Effect size	95% CI	*p*-value
Growth construct	Overall	19	5022	-.387	[-.444, -.326]	.000**
	Resilience	13	3340	-.508	[-.566, -.444]	.000**
	PTG/BF	6	1682	-.064	[-.186, .060]	.314
Outcome index	Overall	19	5022	-.371	[-.481, -.250]	.000**
	Averaged effect size	13	3198	-.398	[-.529, -250]	.000**
	Depression/negative affect	6	1824	-.319	[-.506, -.104]	.004**

Notes: $p < .05$*, $p < .01$**

Effect sizes of psychological growth and well-being varied significantly across different growth measures, with resilience having the largest effect size compared to PTG/BF (Table 5). This moderator effect was significant indicating between-group heterogeneity ($Q(1) = 13.802$, $p < .001$). This finding supported H2.

Table 5.

Moderator analysis of growth construct and outcome type with well-being

Moderator	Groups	*k*	*n*	Effect size	95% CI	*p*-value
Growth construct	Overall	17	3963	.340	[.266, .410]	.000**
	Resilience	12	2286	.493	[.390, .583]	.000**
	PTG/BF	5	1677	.221	[.118, .320]	.000**
Outcome index	Overall	17	3963	.426	[.352, .495]	.000**
	Averaged effect size	3	888	.334	[.153, .494]	.000**
	Positive affect	3	814	.488	[.377, .586]	.000**
	Quality of Life	11	2261	.406	[.284, .515]	.000**

Notes: $p < .05$*, $p < .01$**

Type of outcome index. Associations between psychological growth and distress were comparable across different types of outcome index (i.e. averaged effect sizes or single effect sizes measuring depression/negative affect; Table 4). This meant there was no evidence of significant between-group heterogeneity associated with this moderator

($Q(1) = 0.404$, $p = .525$). Similarly, associations between psychological growth and well-being were analogous across different types of outcome index (Table 5), with no evidence of significant between-group heterogeneity associated with this moderator ($Q(2) = 2.558$, $p = .278$). These findings suggest that the magnitude of the associations between psychological growth and both distress and well-being were not affected by outcome index (single or combined) providing no evidence for H3.

Age. Age significantly moderated the association between psychological growth and distress ($Q(1) = 3.89$, $\beta = -0.01$, $p = .049$, 95% CIs [-.024, -.0001], $z = -1.97$), but not the association between psychological growth and well-being ($Q(1) = 0.12$, $\beta = -0.002$, $p = .726$, 95% CIs [-.01, .01], $z = 0.35$). These findings provided partial support for H4.

Gender. There were no gender-related differences in the associations between psychological growth and distress ($Q(1) = 0.66$, $\beta = -0.63$, $p = .415$, 95% CIs [-2.14, -0.89], $z = -0.81$), or well-being ($Q(1) = 0.14$, $\beta = 0.27$, $p = .713$, 95% CIs [-1.18, 1.73], $z = 0.37$). Associations were therefore consistent across participant gender, which does not support H5.

Years since diagnosis. Years since diagnosis moderated the association between psychological growth and distress ($Q(1) = 5.25$, $\beta = -0.03$, $p = .022$, 95% CIs [-.05, -.004], $z = -2.29$). However, associations between psychological growth and well-being were consistent across years since diagnosis ($Q(1) = 0.01$, $\beta = 0.001$, $p = .93$, 95% CIs [-.02, .03], $z = 0.09$). This provides partial support for H6.

Publication bias

Distress. Visual analysis of the funnel plot revealed some asymmetry of study effect sizes around the effect size mean (Figure 4). Trim and fill processes adjusted for missing studies by imputing two studies to the right of the mean, but this did not significantly adjust the overall effect as observed in the funnel plot. Egger's regression

test was also not significant ($t(17) = 1.067$, $p = .301$). Finally, Rosenthal's (1979) fail-safe *N* indicated that 3255 missing studies with a mean effect of zero would be required for the overall effect to be nullified, which exceeded the fail-safe threshold of 105. These findings taken together suggest the absence of publication bias in the sample.

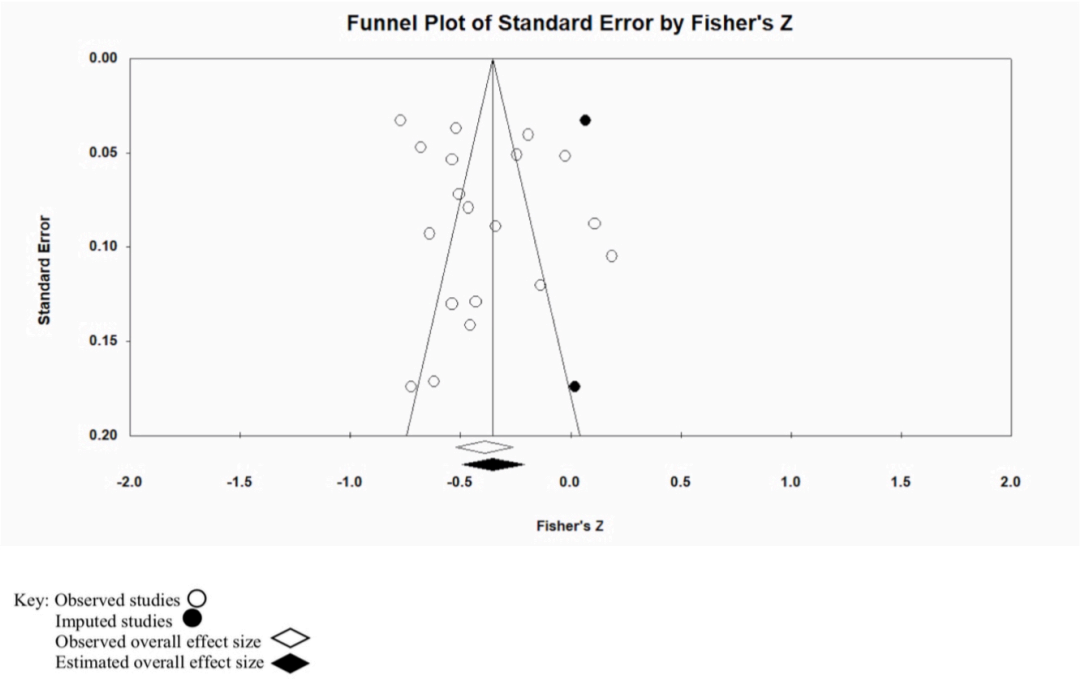

Figure 4. Funnel plot for distress analysis including Duval and Tweedie's (2000) trim and fill

Well-being. Visual analysis of the funnel plot suggests some evidence of asymmetry of study effect sizes around the effect size mean (Figure 5). Trim and fill processes adjusted for missing studies by imputing two studies to the left of the mean, but this did not significantly adjust the overall effect. Egger's regression test was also not significant ($t(15) = 1.656$, $p = .12$). Finally, Rosenthal's (1979) fail-safe *N* indicated that 2323 missing studies with a mean effect of zero would be required for the overall effect to be nullified, which exceeded the fail-safe threshold of 95. These findings taken together suggest the absence of publication bias in the sample.

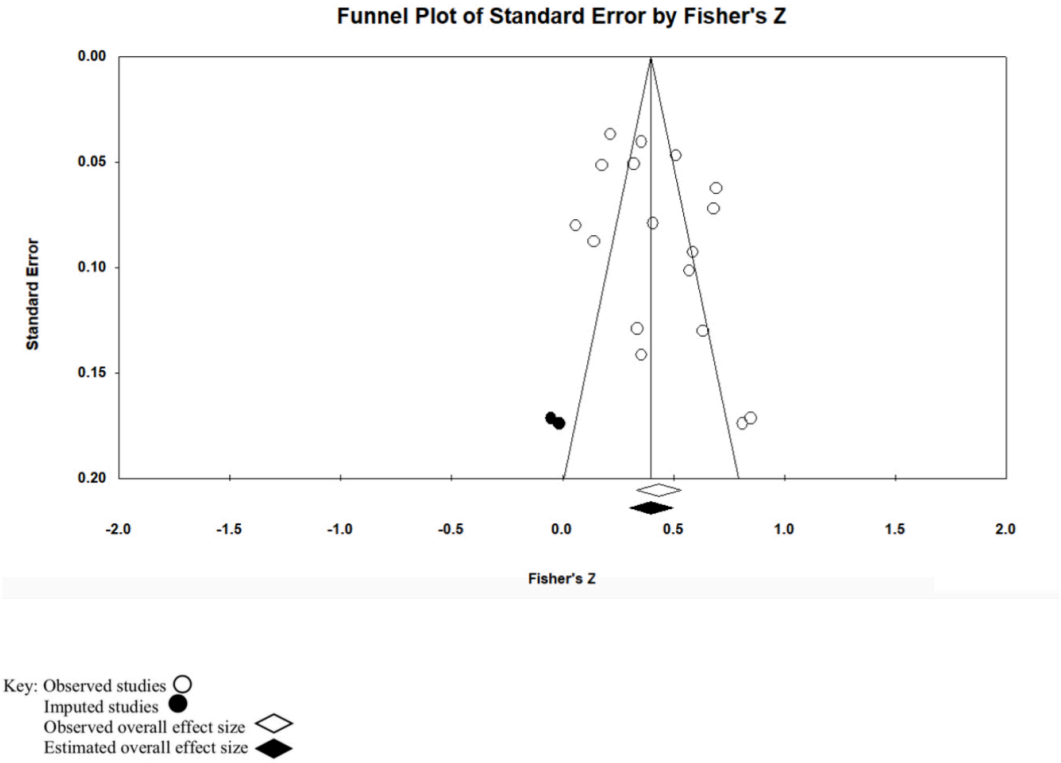

Figure 5. Funnel plot for well-being analysis including Duval and Tweedie's (2000) trim and fill

Quality assessment

Inter-rater reliability for quality assessment was high: *ICC* = .87, 95 CI [.80, .91], $F(87, 87) = 7.624$, $p < .001$ (Cicchetti, 1994). Summary tables of quality assessments can be found in Appendix B.

Cross-sectional studies. Clear aims and objectives, appropriate study design and clear population focus from the outset were observed across all cross-sectional studies ($k = 16$). Outcomes were generally appropriate to address the aims and outcome instruments were reliable and had been previously used. Reporting of power calculations to justify sample size was problematic across studies; determining if studies were adequately powered was therefore difficult. The sampling frame and selection procedures were limited across studies which influenced the representativeness of the samples; studies

scored higher when the sampling frame included multiple sources. Most studies were limited by using self-selected/convenience samples, a common issue with survey designs that can increase bias since participants with certain characteristics tend to take part which will limit the representativeness of the findings to the overall population (Olsen, 2011). Most studies were therefore limited in their generalisability. All but one study described methods and statistical analyses in enough detail to promote replicability. Most studies clearly reported all basic data and statistical analyses including *p*-values and precision estimates, enabling the reader to interpret findings with ease. Level of non-response bias was unclear across studies. The majority of results appeared to be internally consistent. Limitations were discussed clearly in all but one study, and all studies provided discussions and conclusions in line with findings. In all but two studies, ethical approval and consent procedures were clearly stated. Presence of funding sources or conflicts of interest were unclear in several studies making it difficult to conclude whether this would have affected interpretation of the results. No clear differences in methodological quality between unpublished and published studies were identified.

Longitudinal studies. Three longitudinal studies were rated as high quality, with the remaining study being moderate quality (k = 4). All studies clearly outlined the objectives of the research, which investigated a clear issue. One issue across studies was appropriateness of sampling methods; all studies used volunteer sampling methods and recruited from MS charities and organisations, meaning the sample frame might be limited. Representativeness was likely limited due to volunteer sampling (Olsen, 2011). Two studies however, recruited from multiple sources which increased generalisability. All studies measured outcomes and confounders in a way that minimised bias. Most studies had an adequate follow-up length, but it was unclear whether a 3-month follow-up was long enough to detect changes in one study. Two studies were limited in their

reporting through a lack of confidence intervals therefore precision was unclear. Conclusions about whether the studies supported previous research and whether clinical implications were discussed was good.

Intervention studies. Of the two intervention studies, one was a randomised controlled trial (RCT) rated as very good quality, whilst the other was a non-randomised pre-post intervention study rated as good quality. Reporting of relevant characteristics and findings was generally good, but the reporting of confounders and adverse events was not always clear. External validity could have been improved with more details of the representativeness of the sample. Internal validity was generally good in the RCT, but factors related to internal validity such as blinding and randomisation would have improved the quality of other study. A power calculation was reported in the RCT but not the non-randomised study making it unclear whether the sample size achieved adequate power.

Secondary quality analysis. Most studies (k = 16) had a sample size >85 suggesting adequate power. Psychological growth measures had Cronbach's alpha (α) values of >.70 in 16 studies. The remaining studies did not report α for their sample making it difficult to draw conclusions about internal consistency within these samples. Only seven studies measuring distress and nine studies measuring well-being appropriately reported α >.70. Again, the remaining studies either did not report the values for their sample or one of the measures included in averaged effect sizes had a value <.70 meaning that internal consistency was questionable. Only one study utilised randomisation as part of their recruitment/sampling methods by randomly selecting potential participants to contact from a large database of an MS organisation. All other samples relied on convenience/volunteer sampling methods, which are more likely to result in selection bias (Olsen, 2011).

Discussion

This meta-analysis is the first to quantify associations between psychological growth and psychological outcomes in MS. Findings provided support for the hypotheses that psychological growth is associated with increased well-being and reduced distress in MS, with medium-sized effects found. The findings were consistent with the findings of a previous review by Barskova & Oesterreich (2009) that there was generally an inverse association between PTG and distress factors such as anxiety and depression in people with chronic health conditions. This study however went beyond Barskova and Oesterreich's review by quantifying the associations and extending the findings to indicate that psychological growth is important for improved outcomes, but also the absence of psychological growth may have adverse effects in terms of an increased risk of negative outcomes.

The finding that the type of growth construct measured (resilience vs. PTG/BF) moderated the associations was consistent with the hypotheses. Differences observed between these constructs in both analyses perhaps indicates that these processes may not always operate in the same way. PTG/BF may require more psychological and cognitive resources than resilience in order to improve beyond the level of pre-trauma functioning (Tedeschi & Calhoun, 2004), resources which some people with MS simply may not have. Psychological growth therefore may not be uniformly beneficial for people with MS. This also supports previous research suggesting that resilience represents a different type of psychological growth to that of PTG/BF (Tedeschi & Calhoun, 2004; Wald et al., 2006; Westphal & Bonanno, 2007).

The finding that associations between psychological growth and both distress and well-being were comparable whether averaged effect sizes or single effect sizes were used does not support our hypothesis but suggests the associations were robust to the

effect size index used. Moderator analysis did not support previous findings that psychological growth was associated with gender differences (Vishnevsky et al., 2010). This may have been affected by the high proportion of females across the included studies meaning that the sample did not include enough males to detect gender-related differences in the associations. The association between psychological growth and distress – but not well-being - was moderated by age and years since diagnosis which provides partial support for our hypotheses. This indicates that while the psychological growth-well-being association is more robust to these demographic factors, the protective function psychological growth has in terms of reducing distress may be affected by age and duration of disease.

Though efforts were made to explain the heterogeneity between the samples, a large amount of heterogeneity remained unexplained. It is not always possible to identify all possible sources of heterogeneity between studies (Riley, Higgins, & Deeks, 2011). In this study, this could be due to substantial variability in people's experience of MS (Mohr & Cox, 2001). Other relevant factors that could have implications for psychological growth in MS include level of cognitive dysfunction (Mohr & Cox, 2001), disease severity, and other factors related to functioning such as level of fatigue (Kroencke, Lynch, & Denney, 2000) and social support (Lode, 2010). Interpretation of the findings should therefore be made in the context that there may be other important moderators of the strength of these associations. Future studies would benefit from investigating the impact these possible factors have on psychological growth to determine which patients may be most at risk for difficulties in adjustment.

Current findings are in keeping with positive psychology perspectives that distress is most valuably understood when there is consideration of both positive and negative outcomes (Wood & Tarrier, 2010). Positive factors appear to safeguard against negative

outcomes and the lack of these factors therefore represents an important risk factor for poorer outcomes such as increased distress (Wood & Joseph, 2010a; Wood & Tarrier, 2010). The finding that overall effect sizes were of similar magnitude for both well-being and distress increases the confidence with which psychological growth can be argued as important for outcomes in MS. Current findings highlight that not all people with MS experience negative outcomes and a subsection of people are able to adapt and grow from the experience of their health condition.

Methodological considerations

It is important to discuss some key methodological considerations observed. Sample sizes of the included studies varied from 36 to 932, with the majority (k = 15) including samples sizes greater than 100. This suggested that the majority of samples were adequately powered to detect medium effect sizes with correlational data (Cohen, 1992) however studies would have been strengthened by explicitly reporting power calculations to support this. Although most samples were predominately female, this was in keeping with the ratio of women to men affected by MS (3.2:1, Orton et al., 2006) suggesting limited selection bias and representativeness. As effects in this meta-analysis were based on correlational values, conclusions about causation were not possible (Card, 2012). Quality assessment revealed some consistent issues across studies such as convenience sampling methods with limited sample frame, and lack of clarity over internal consistency of the measures used. There was also significant variability in the measures used to assess both psychological outcomes and psychological growth across the studies; a methodological concern also raised by Barskova and Oesterreich (2009). While this does reduce the value of the overall findings, they should be interpreted with this consideration in mind.

Strengths and limitations

This is a growing area of research; all included studies were conducted within the last 20 years, with the majority taking place within the last 5 years. This meant a limited number of studies were available for inclusion. Similarly to Barskova and Oesterreich's (2009) review, the included studies were not comparable in terms of methodological design. The inclusion of cross-sectional correlational data from longitudinal studies is however deemed an acceptable method of assessing correlational data and has been utilised effectively in other meta-analyses (Sirois et al., 2017; Molloy et al., 2014).

There are advantages and disadvantages of including unpublished literature in meta-analyses (Quintana, 2015; Borenstein et al., 2009). While inclusion can reduce the likelihood of publication bias, it potentially reduces the methodological quality of the study since it is not subject to the same scrutiny of published literature (Egger et al., 2003; Quintana, 2015). Importantly, there was no evidence of publication bias in this study and quality assessment did not reveal any clear differences between unpublished and published studies. Significant associations between psychological growth and psychological outcomes identified were therefore robust even if some relevant studies were absent (Sirois et al., 2017).

Averaging effect sizes when multiple outcomes are reported is a common approach in meta-analysis (Card, 2012), and has been utilised effectively by other researchers (e.g. Sirois et al., 2017; Scott, Webb, & Rowse, 2015). Thirteen studies included multiple distress outcomes which were averaged to create a single effect size and the remaining six studies included one measure of either depression or negative affect. Three studies included multiple well-being outcomes which were averaged, three included one measure of positive affect and 11 included one measure of quality of life. The use of combined effect sizes in this study meant that it was not possible to look at the

moderating effects of specific mental health outcomes (e.g. depression vs. anxiety) because many studies included a combined effect size of both of these outcomes. A meta-analysis of PTG in cancer and HIV/AIDS (acquired immune deficiency syndrome) found that different categories of mental health outcomes moderated the association between PTG and negative mental health outcomes (i.e. post-traumatic stress had a larger effect on the association than depression or distress; Sawyer, Ayers, & Field, 2010). Choosing specific mental health categories and investigating their moderating effect in MS would therefore be beneficial for future studies so that conclusions about clinical implications can be more specific.

Using established quality appraisal tools, methodological quality was assessed to be generally adequate across the included studies. It was however difficult to compare quality across the checklists due to the AXIS not providing a scoring system. Scoring systems for quality appraisal have been questioned and some suggest that overall scores have little value due to problems with weighting or summing non-linear scores (Downes et al., 2016; Higgins et al., 2011). Appraisal tools without scoring systems however could be deemed less reliable and objective than a quantifiable approach (Katrak, Bialocerkowski, Massy-Westropp, Kumar, & Grimmer, 2004). Furthermore, there are many available checklists with substantial variability in the areas assessed. Most quality tools are selected due to researcher preference rather than a 'gold standard' recommended checklist (Katrak et al., 2004). A secondary assessment of methodological quality based on factors important for correlational research was conducted as advised by Quintana (2015). This assessment required less subjective interpretation than the established checklists and was therefore a strength of the study.

Clinical implications and future research directions

This study has important implications for clinical practice. As psychological growth is positively associated with psychological outcomes in MS, interventions promoting psychological growth may be a fruitful avenue for exploration. Emerging evidence for these types of interventions is promising; one study included in this analysis piloted a resilience programme for people with MS and found improvements in resilience, quality of life, depression and stress (Pakenham et al., 2018). A similar small-scale pilot RCT of people with MS also found a significant improvement in resilience for the intervention group compared to controls, and trends towards improvements in depression, positive affect and well-being (Alschuler, Arewasikporn, Nelson, Molton, & Ehde, 2018). Further investigating the efficacy of these interventions on a larger scale, for example using RCT's, is a clear avenue for future research. This will have important implications for clinical practice in terms of appropriate psychological interventions that should be available for people with MS.

The majority of studies available for inclusion in this review were cross-sectional in design and all of the studies used correlational data, meaning that conclusions about causality were limited (Barker, Pistrang, & Elliott, 2002). Future research focusing on investigating the mechanisms of psychological growth would be beneficial in helping to understand why psychological growth may not be uniformly beneficial. Understanding what factors predict improved psychological growth would also be important in order to identify those most vulnerable to poorer outcomes and in need of psychological interventions. Early identification of these factors in the adjustment process to minimise the overall impact is key.

Conclusions

This meta-analysis confirms that psychological growth is moderately associated with both increased well-being and reduced distress in people with MS. The finding that distress and well-being have effects of similar magnitude in opposite directions suggests that psychological growth is not more important for one type of outcome than the other, but rather both types of outcome are important for people with MS. Differences between types of psychological growth constructs were found for both distress and well-being, suggesting that psychological growth may not be uniformly beneficial. Future research exploring what factors determine psychological growth is important for understanding who is most vulnerable to poorer outcomes within the MS population. Furthermore, research exploring the effectiveness of interventions which nurture psychological growth in people with MS is required.

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Appendix A: Quality appraisal checklists

Appraisal Tool for Cross Sectional Studies (AXIS)

Introduction

1. Were the aims/objectives of the study clear? *(Yes/No/Don't know)*

Methods

2. Was the study design appropriate for the stated aim(s)? *(Yes/No/Don't know)*
3. Was the sample size justified? *(Yes/No/Don't know)*
4. Was the target/reference population clearly defined? (Is it clear who the research was about?) *(Yes/No/Don't know)*
5. Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation? *(Yes/No/Don't know)*
6. Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation? *(Yes/No/Don't know)*
7. Were measures undertaken to address and categorise non-responders? *(Yes/No/Don't know)*
8. Were the risk factor and outcome variables measured appropriate to the aims of the study? *(Yes/No/Don't know)*
9. Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted, or published previously? *(Yes/No/Don't know)*
10. Is it clear what was used to determine statistical significance and/or precision estimates? *(Yes/No/Don't know)*
11. Were the methods (including statistical methods) sufficiently described to enable them to be repeated? *(Yes/No/Don't know)*

Results

12. Were the basic data adequately described? *(Yes/No/Don't know)*
13. Does the response rate concerns about non-response bias? *(Yes/No/Don't know)*
14. If appropriate, was information about non-responders described? *(Yes/No/Don't know)*
15. Were the results internally consistent? *(Yes/No/Don't know)*
16. Were the results presented for all the analyses described in the methods? *(Yes/No/Don't know)*

Discussion

17. Were the authors' discussions and conclusions justified by the results? *(Yes/No/Don't know)*
18. Were the limitations of the study discussed? *(Yes/No/Don't know)*

Other

19. Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results? *(Yes/No/Don't know)*
20. Was ethical approval or consent participants attained? *(Yes/No/Don't know)*

Critical Appraisal Skills Programme (CASP) for Cohort Studies

Section A: Are the results of the study valid?

1) Did the study address a clearly forced issue? *(Yes/No/Don't know)*
2) Was the cohort recruited in an acceptable way? *(Yes/No/Don't know)*

Is it worth continuing?

3) Was the exposure accurately measured to minimise bias? *(Yes/No/Can't tell)*
4) Was the outcome accurately measured to minimise bias? *(Yes/No/Can't tell)*
5)
    a) Have the authors identified all important confounding factors? *(Yes/No/Can't tell)*
    b) Have they taken account of the confounding factors in the design and/or analysis? *(Yes/No/Can't tell)*
6)
    a) Was the follow-up of subjects complete enough? *(Yes/No/Can't tell)*
    b) Was the follow-up of subjects long enough? *(Yes/No/Can't tell)*

Section B: What are the results?

7) What are the results of the study? *(Yes/No/Can't tell)– rated yes if results presented clearly*
8) How precise are the results? *(Yes/No/Can't tell) - rated yes if precision estimates (e.g. confidence intervals) given*
9) Do you believe the results? *(Yes/No/Can't tell)*

Section C: Will the results help locally?

10) Can the results be applied to the local population? *(Yes/No/Can't tell)*
11) Do the results of this study fit with other available evidence? *(Yes/No/Can't tell)*
12) What are the implications of this study for practice*? (Yes/No/Can't tell) – rated yes if clinical/practice implications discussed and appropriate*

Downs and Black for intervention (randomised and non-randomised) studies

Appendix

Checklist for measuring study quality

Reporting

1. *Is the hypothesis/aim/objective of the study clearly described?*

yes	1
no	0

2. *Are the main outcomes to be measured clearly described in the Introduction or Methods section?*
   If the main outcomes are first mentioned in the Results section, the question should be answered no.

yes	1
no	0

3. *Are the characteristics of the patients included in the study clearly described ?*
   In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case-control studies, a case-definition and the source for controls should be given.

yes	1
no	0

4. *Are the interventions of interest clearly described?*
   Treatments and placebo (where relevant) that are to be compared should be clearly described.

yes	1
no	0

5. *Are the distributions of principal confounders in each group of subjects to be compared clearly described?*
   A list of principal confounders is provided.

yes	2
partially	1
no	0

6. *Are the main findings of the study clearly described?*
   Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests which are considered below).

yes	1
no	0

7. *Does the study provide estimates of the random variability in the data for the main outcomes?*
   In non normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0

8. *Have all important adverse events that may be a consequence of the intervention been reported?*
   This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events. (A list of possible adverse events is provided).

yes	1
no	0

9. *Have the characteristics of patients lost to follow-up been described?*
   This should be answered yes where there were no losses to follow-up or where losses to follow-up were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.

yes	1
no	0

10. *Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?*

yes	1
no	0

External validity

All the following criteria attempt to address the representativeness of the findings of the study and whether they may be generalised to the population from which the study subjects were derived.

11. *Were the subjects asked to participate in the study representative of the entire population from which they were recruited?*
    The study must identify the source population for patients and describe how the patients were selected. Patients would be representative if they comprised the entire source population, an unselected sample of consecutive patients, or a random sample. Random sampling is only feasible where a list of all members of the relevant

population exists. Where a study does not report the proportion of the source population from which the patients are derived, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

12. *Were those subjects who were prepared to participate representative of the entire population from which they were recruited?*
The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.

yes	1
no	0
unable to determine	0

13. *Were the staff, places, and facilities where the patients were treated, representative of the treatment the majority of patients receive?*
For the question to be answered yes the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a specialist centre unrepresentative of the hospitals most of the source population would attend.

yes	1
no	0
unable to determine	0

Internal validity - bias

14. *Was an attempt made to blind study subjects to the intervention they have received ?*
For studies where the patients would have no way of knowing which intervention they received, this should be answered yes.

yes	1
no	0
unable to determine	0

15. *Was an attempt made to blind those measuring the main outcomes of the intervention?*

yes	1
no	0
unable to determine	0

16. *If any of the results of the study were based on "data dredging", was this made clear?*
Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.

yes	1
no	0
unable to determine	0

17. *In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls ?*
Where follow-up was the same for all study patients the answer should yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.

yes	1
no	0
unable to determine	0

18. *Were the statistical tests used to assess the main outcomes appropriate?*
The statistical techniques used must be appropriate to the data. For example non-parametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.

yes	1
no	0
unable to determine	0

19. *Was compliance with the intervention/s reliable?*
Where there was non compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.

yes	1
no	0
unable to determine	0

20. *Were the main outcome measures used accurate (valid and reliable)?*

For studies where the outcome measures are clearly described, the question should be answered yes. For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.

yes	1
no	0
unable to determine	0

Internal validity - confounding (selection bias)

21. *Were the patients in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population?*
For example, patients for all comparison groups should be selected from the same hospital. The question should be answered unable to determine for cohort and case-control studies where there is no information concerning the source of patients included in the study.

yes	1
no	0
unable to determine	0

22. *Were study subjects in different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time?*
For a study which does not specify the time period over which patients were recruited, the question should be answered as unable to determine.

yes	1
no	0
unable to determine	0

23. *Were study subjects randomised to intervention groups?*
Studies which state that subjects wererandomised should be answered yes except where method of randomisation would not ensure random allocation. For example alternate allocation would score no because it is predictable.

yes	1
no	0
unable to determine	0

24. *Was the randomised intervention assignment concealed from both patients and health care staff until recruitment was complete and irrevocable?*
All non-randomised studies should be answered no. If assignment was concealed from patients but not from staff, it should be answered no.

yes	1
no	0
unable to determine	0

25. *Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?*
This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In non-randomised studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.

yes	1
no	0
unable to determine	0

26. *Were losses of patients to follow-up taken into account?*
If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.

yes	1
no	0
unable to determine	0

Power

27. *Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%?*
Sample sizes have been calculated to detect a difference of x% and y%.

	Size of *smallest* intervention group	
A	$<n_1$	0
B	n_1–n_2	1
C	n_3–n_4	2
D	n_5–n_6	3
E	n_7–n_8	4
F	n_9+	5

Appendix B: Quality assessment ratings

Table 6.

Summary of quality appraisal of cross-sectional studies – AXIS (Downes et al., 2016)

Study no:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1							N/A							N/A						
2							N/A							N/A						
3							N/A							N/A						
4							N/A							N/A						
6							N/A							N/A						
7							N/A							N/A						
8							N/A							N/A						
10							N/A							N/A						
11							N/A							N/A						
12							N/A							N/A						
16							N/A							N/A						
17							N/A							N/A						
18							N/A							N/A						
19							N/A							N/A						
21							N/A							N/A						
22							N/A							N/A						

***Notes**:* Green = yes, amber = can't tell/not clear, red = no; items 13 and 19 was reverse coded with yes indicating poor quality and no indicating good quality; items 7 and 14 were deemed to be not applicable (N/A) to the included studies and were therefore omitted. For the purposes of the inter-rater reliability assessment, green items were coded 2, amber coded 1 and red coded 0.

Table 7.

Quality appraisal of longitudinal studies – CASP (2018)

Study no:	1	2	3	4	5a	5b	6a	6b	7	8	9	10	11	12	Total score (/13) and quality rating
5	1	X	N/A	1	1	1	1	1	1	1	1	X	1	1	11 (high)
9	1	X	N/A	1	1	1	1	1	1	1	1	X	1	1	11 (high)
13	1	0	N/A	1	1	1	1	X	1	X	1	X	1	1	9 (moderate)
14	1	0	N/A	1	1	1	1	1	1	X	1	X	1	1	10 (high)

Notes: 1 = yes, 0 = No, X = Can't tell/unclear, N/A= Not applicable; Maximum total score = 13 (when item 3 excluded as N/A). Item score summed to create total score. Qualitative categories = 0-6 = low quality, 7-9 = moderate , 10-13 = high quality

Table 8.

Summary of quality appraisal for randomised and non-randomised intervention studies - Downs and Black (1998)

Study no:	1	2	3	4	5*	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	Total score (/27) and quality rating
15	1	1	1	1	1	1	1	0	1	1	0 (UTD)	0 (UTD)	N/A	0	0	1	1	1	1	1	1	0 (UTD)	0	0	1	1	0	17 (good)
20	1	1	1	1	1	1	1	1	1	1	0 (UTD)	0	N/A	0	1	1	1	1	1	1	1	1	1	0	1	1	1	22 (very good)

Notes: 1 = yes, 0 = not or unable to determine (UTD), *item 5: 2 = yes, 1 = partially, 0 = no; N/A = not applicable; Maximum total score = 27 (when item 13 excluded as N/A). Item score summed to create total score then percentage calculated. Qualitative categories for quality assessment: >20 = very good, 15-19 = good, 11-14 = fair, <10 = poor

Table 9.

Quality coding summary based on Quintana (2015) methodology for distress and well-being analysis

Study name (Author, Year)	Sample >85	Alpha PG measure >.70	Alpha Distress measure(s) >.70	Alpha Well-being measure(s) >.70	Random sampling method	Total Quality score (Distress)	Total Quality score (Well-being)
Ackroyd et al., (2011)	0	1	1	N/A	0	2	N/A
Arewasikporn, Ehde et al., (2018)	1	1	0	1	0	2	3
Battalio et al., (2017)	0	1	1	1	0	2	2
Black & Dorstyn (2015)	1	1	1	1	0	3	3
Edwards et al., (2017)	1	1	0	N/A	0	2	N/A
Esposito (2017)	1	1	1	1	0	3	3
Hadianfard et al., (2015)	1	1	N/A	0	0	N/A	2
Gromisch et al., (2018)	1	1	0	N/A	0	2	N/A
Koelmel et al., (2017)	1	0	0	0	0	1	1
Mohr et al., (1999)	1	1	0	N/A	0	2	N/A
Nakazawa et al., (2018)	0	0	0	0	0	0	0
Nery-Hurwit et al 2018	1	1	N/A	1	0	N/A	3
Pakenham & Cox (2009)	1	1	1	1	0	3	3
Pakenham (2005)	1	1	0	1	1	3	4
Pakenham et al., (2018)	0	1	1	1	0	2	2
Ploughman et al., (2017)	1	0	0	0	0	1	1
Rainone et al., (2017)	0	1	0	1	0	1	2
Schwartz (2014)	1	0	0	0	0	1	1
Senders et al., (2014)	1	0	0	0	0	1	1
Senders et al., (2018)	0	0	0	0	0	0	1
Tan-Kristanto & Kiropolous (2015)	1	1	1	N/A	0	3	N/A
Zeltser 2017	1	1	N/A	0	0	N/A	2

Notes: 1 point assigned for each answer = Yes, 0 if answer = No. Maximum total score = 4. N/A = not applicable; PG = Psychological Growth.

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Part II: Research Project

A prospective investigation of the role of self-compassion in adjustment to multiple sclerosis.

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Abstract

Objectives

Self-compassion has been identified as playing an important role in adaptive coping in the face of chronic stressors and been linked to reduced stress and improved quality of life (QoL). There is however little evidence investigating the role of self-compassion in multiple sclerosis (MS). This study aimed to assess the pathways in which self-compassion operates in adjustment to MS, with a focus on examining how self-compassion influences perceived cognitive functioning.

Method

A prospective survey design was used. People with MS completed the survey at Time 1 (n = 278), and six weeks later at Time 2 (n = 202). The survey included measures of adjustment factors in MS (self-compassion, stress, coping efficacy, QoL, and perceived cognitive functioning). Correlations examined relationships between these key variables. Path analysis investigated the possible pathways linking self-compassion and perceived cognitive functioning.

Results

Analyses revealed that self-compassion was positively associated with QoL and coping efficacy, and negatively associated with stress and perceived cognitive functioning both cross-sectionally and over time. Path analyses found that stress, but not coping efficacy, significantly mediated the relationship between self-compassion and perceived cognitive functioning both cross-sectionally and over time.

Conclusions

Findings suggest that self-compassion is important for adjustment to MS. Self-compassion plays a significant role in reducing perceived cognitive dysfunction through a

negative relationship with stress in MS. Interventions aimed at cultivating self-compassion may be helpful in supporting adjustment to this unpredictable condition.

Practitioner points

- Self-compassion is important for coping and quality of life in MS and is related to reduced stress and perceived cognitive dysfunction.
- People with MS with lower levels of self-compassion may find it more difficult to cope with the ongoing stressors of the condition including more subjective cognitive functioning complaints and may be most likely to present to services.
- Self-compassion should be explored by professionals as part of assessment, formulation and intervention for people with MS.
- Third-wave interventions aimed at cultivating self-compassion such as Mindfulness-Based Stress Reduction, Compassion Focused Therapy and Acceptance and Commitment Therapy should be explored both clinically and in future research.

Limitations

- The sample was highly-educated indicating possible selection bias.
- Objective cognitive functioning was not measured, limiting the generalisability of the findings beyond perceived cognitive functioning.
- A relatively short time period between time-points was a potential limitation as the constructs assessed appeared to be relatively stable. A longer period between measurement may have provided more information about the variability of the key variables.

Keywords: 'Multiple sclerosis', 'self-compassion', 'perceived cognitive functioning', 'stress', 'coping'.

Introduction

Physical health fundamentally relates to emotional and mental health (Felton & Revenson, 1984), particularly in chronic illnesses such as multiple sclerosis (MS). MS is a demyelinating autoimmune condition affecting the central nervous system in which the immune system erroneously attacks the coating surrounding nerves (Mohr & Cox, 2001). This causes disruption to message transmission through the body's nerve fibres by creating lesions in the brain and spinal cord (Arnett & Rabinowitz, 2010). The condition is highly unpredictable and often debilitating, leading to uncertainty about patients' prognosis, coping abilities and the future (Bianchi & Pozzilli, 2015; Lode, 2010). Considerable burden is placed on personal resources in order to cope with changes in need for support, social and familial roles, and health needs (Lode, 2010).

Coping with the unpredictable nature and impact of MS can cause significant distress with high rates of anxiety (35.7%) and depression (36-54%) among the MS population (Llorca & Samalin, 2015; Bianchi & Pozzilli, 2015). Many people however adjust and cope with the fluctuating stressors of chronic illness (Lode, 2010; Maes, Leventhal, & De Ridder, 1996; Bianchi & Pozzilli, 2015). The question of what factors determine better coping in MS is therefore important. One resilience factor that could help with managing the challenges of MS is self-compassion. Self-compassion is the ability to adopt the stance of being kind, accepting, and understanding of oneself in times of struggle and consists of three components: self-kindness, common humanity, and mindfulness (Neff, 2003b; Allen & Leary, 2010). While self-compassion is related to improved coping in other physical health conditions (inflammatory bowel disease (IBD) and arthritis; Sirois, Molnar, & Hirsch, 2015), there is little research on the role of self-compassion in adjustment to MS. This study therefore aimed to examine the relationships between self-compassion, quality of life (QoL), coping efficacy, stress and perceived

cognitive functioning (PCF) in people with MS. The study also aimed to understand the pathways explaining adjustment, with a focus on examining how self-compassion influences PCF.

Multiple sclerosis

MS is broadly characterised by relapsing subtypes (RS) and progressive subtypes (PS). RS is characterised by periods of active disease followed by partial or complete remission. RS affects 85% of people with MS (hereafter referred to as pwMS) and is typically diagnosed between ages 20-40 years (MS Society, 2016). For 65% of people with RS, symptoms will become progressive approximately 15 years following initial diagnosis. Primary progressive MS is characterised by progressive symptoms from the beginning, is diagnosed later (e.g. ages 40-50), and affects 10-15% of pwMS (MS Society, 2016). The prevalence of MS in the United Kingdom is approximately 1 in 600 people, with incidence rates being higher among women than men (2.3-3.5:1, Harbo, Gold, & Tintore, 2013; 3.2:1, Orton et al., 2006).

Symptoms of MS vary depending on the location demyelination occurs in the brain and/or spinal cord (Lezak, Howieson, & Loring, 2012). PwMS can therefore experience widespread physical, cognitive, and psychological/emotional symptoms, and subsequent changes in social functioning, sexual functioning, and occupation (Arnett & Rabinowitz, 2010; Lezak et al., 2012; Lode, 2010). High rates of emotional distress are common (Bianchi & Pozzilli, 2015; Lode et al., 2010). Depression is also associated with difficulties with executive functioning, working memory and attentional processing (Arnett, 2005; Arnett & Rabinowitz, 2010). These factors have significant implications for adjustment i.e. the ability to grow and adapt (Lode et al., 2010), whilst retaining a constructive attitude irrespective of the demands associated with MS (Irvine, Davidson,

Hoy, & Lowe-Strong, 2009). The remainder of this section will explore important aspects of adjustment in MS.

Quality of Life

Given the impact of living with MS and resulting uncertainty about the future it is unsurprising QoL is adversely affected (Ryan et al., 2007). Studies have demonstrated that pwMS experience reduced QoL compared to people in the general population with physical disabilities (Aronson, 1997) and with controls (Murphy et al., 1998). Self-reported factors strongly associated with QoL include level of disability and level of emotional adjustment (Benito-León, Morales, Rivera-Navarros, & Mitchell, 2003). Furthermore, mental health difficulties such as depression and anxiety are important predictors of QoL in MS (Fruehwald, Loeffler-Stastka, Eher, Saletu, & Baumhackl, 2001). QoL therefore appears to play an important role in adjustment to MS, however there are many factors that influence QoL such as stress.

Stress

Stress appears to have a detrimental effect on QoL in MS; reductions in stress following intervention have resulted in patient-rated level of disability having less of a negative impact on QoL (Mitsonis, Potagas, Zervas, & Sfagos, 2009). In general, evidence suggests prior to diagnosis many patients report dealing with ongoing stress in everyday life (Mohr & Cox, 2001). The disease itself is also associated with various factors that increase stress and influence adjustment including the future being uncertain and significant fatigue (Buelow, 1991; Mitsonis et al., 2009). Moreover, increased stress relates to exacerbation of MS symptoms (Mohr & Cox, 2001; Mohr, Hart, Julian, Cox & Pelletier, 2004) and development of new lesions (Mohr, Goodkin, Nelson, Cox, & Weiner, 2002). The causal nature of this relationship has not been clearly established

(Mohr & Cox, 2001) but psychologically it is important to consider that pwMS may experience distress, guilt and shame if they believe their inability to manage everyday stressors has contributed to their deteriorating condition (Mitsonis et al., 2009). It is therefore crucial to understand ways in which people cope with the ongoing stress of a demanding health condition to adjust more effectively.

Coping

Coping plays a crucial role in the adjustment process of chronic health conditions like MS (Goretti, Portaccio, Zipoli, Razzolini, & Amato, 2010). Coping is the process of dealing with internal and/or external demands using behavioural and cognitive strategies when personal resources are appraised as being insufficient (Bianchi & Pozzilli, 2015). One model of stress highlights the role coping strategies play in alleviating or intensifying the impact of stress (Lazarus and Folkman, 1984). Adaptive coping, by cognitively reappraising the event or altering behaviour to deal with the stressor, serves a protective function by attenuating feelings of stress and the resulting negative consequences of stress (Lazarus and Folkman, 1984). Research has focused on two key styles of coping: problem-focused strategies (action in response to a stressor) and emotion-focused strategies (regulation of emotion experienced in a stressful situation; Bianchi & Pozzilli, 2015). PwMS utilise more emotion-focused strategies compared to controls, which are thought to be less adaptive than problem-focused strategies (Lode et al., 2010). Both styles are however important for dealing with ongoing stressors associated with chronic illness, but individual differences in ability to cope with chronic illness may have differential effects (Felton & Revenson, 1984).

Since it is difficult to say whether a particular coping strategy will be uniformly beneficial in the context of chronic illness, an alternative approach is to investigate coping efficacy i.e. one's confidence in their current ability to manage their health

condition (Gignac, Cott, & Badley, 2000). Living with a chronic illness involves managing a number of enduring day-to-day stressors; coping with ongoing stress in this context therefore requires the successful management of a group of strategies as opposed to utilising just one coping strategy (Gignac et al., 2000). Coping efficacy thus provides a way of attaining how successfully a group of coping strategies are in handling multiple stressors related to chronic illness (Sirois et al., 2015).

Coping is therefore important for maintaining well-being in MS i.e. the extent to which pwMS experience negative psychological and emotional responses is related to how well variable symptoms are coped with (Bianchi & Pozzilli, 2015). Given the sometimes-debilitating consequences of MS, understanding the mechanisms contributing to improved coping and reduced stress is therefore crucial to maintaining and improving the emotional well-being of pwMS. One such quality that influences coping and stress is self-compassion.

Self-compassion

Self-compassion is a quality known to contribute to adaptive coping in the context of chronic illness (Sirois et al., 2015); it is the capacity to adopt the stance of being kind, accepting, and understanding of oneself in times of struggle and consists of three components: self-kindness, mindfulness, and common humanity (Neff, 2003b; Allen & Leary, 2010). Self-kindness is the ability to show compassion and care to oneself in times of difficulty rather than demonstrating a self-critical attitude and judging oneself punitively (Sirois et al., 2015). The ability to evaluate negative emotions in a more balanced way so as not to amplify or quash them characterises mindfulness. This skill enables negative emotions to be held in mind alongside positive ones so they can be observed rather than judged, and we do not become enmeshed with negative thoughts and feelings (Neff, 2003b). Common humanity refers to the capacity to recognise suffering

and pain are universal human experiences, rather than something experienced in isolation by oneself (Neff, 2003b; Sirois, 2014). The process of self-regulation of negative emotions in the face of difficult and challenging situations facilitated by these qualities is thought to diminish stress (Neff, Kirkpatrick, & Rude, 2007). Indeed, people who are more self-compassionate have greater capacity for reappraising stressors more positively, leaving more resources for utilising behavioural strategies to cope with the stressor (Sirois et al., 2015). Self-compassion therefore appears to play a crucial role in reducing stress by supporting more adaptive coping.

Self-compassion seems to play a central role in coping in the context of chronic illness (Sirois et al., 2015). Indeed, poorer neurological, psychological and physical outcomes are associated with enduring stress in MS (Senders, Bourdette, Hanes, Yadav, & Shinto, 2014). Self-compassion may allow pwMS to view daily stressors and symptoms associated with their condition with kindness rather than criticism or self-blame therefore promoting improved adjustment. For people with human immunodeficiency virus (HIV) self-compassion is associated with better adjustment, and lower stress and shame (Brion, Leary, & Drabkin, 2014). Furthermore, self-compassion is associated with more adaptive coping styles and less maladaptive coping in the context of illness-related stress in IBD and arthritis (Sirois et al., 2015). To date little investigation of the role of self-compassion in MS has taken place. One recent study found higher levels of self-compassion were directly related to improved health-related QoL and indirectly related to QoL through resilience in pwMS (Nery-Hurwit, Yun, & Ebbeck, 2018). However, this study was cross-sectional which limited the conclusions that could be drawn about relationships over time (Nery-Hurwit et al., 2018) and other relevant variables such as stress and coping were not investigated. There is therefore a need for further research to explore the role of self-compassion in adjustment over time in MS.

Furthermore, as self-compassion enables people to cope more effectively with stressors by minimising their impact which ultimately reduces stress and improves QoL, one interesting hypothesis that has yet to be investigated is whether being more self-compassionate serves a protective function against the impact of perceived cognitive dysfunction in MS.

Cognitive functioning

Cognitive dysfunction occurs in 40-65% of pwMS (Amato, Zipoli, & Portaccio, 2006). Typically, difficulties include speed of information processing, attention/concentration, executive functioning and memory all of which can be exacerbated by fatigue and stress (Langdon, 2011; Lezak et al., 2012; Lode, 2010). Cognitive dysfunction is exhibited throughout disease progression and following acute relapses (Foong et al., 1998). Cognitive dysfunction has been linked to reduced activity (Kalmar et al., 2008), poorer social functioning, reduced employment (Amato, Ponziani, Siracusa, & Sorbi, 2001), reduced physical independence (Rao et al., 1991), and reduced QoL (Barker-Collo, 2006). Preliminary evidence suggests that increased instrumental coping is related to a decreased association between stress and new lesions (Mohr et al., 2002), indicating that adaptive coping in response to stress could be protective against further lesions, and further cognitive deterioration.

While cognitive dysfunction has been identified on objective neuropsychological tests (e.g. Beatty & Monson, 1994; Brassington & Marsh, 1998; Mohr & Cox, 2001; Thornton & Raz, 1997) various studies have found that objective performance and people's perceptions of their difficulties are not significantly related (Maor, Olmer, & Mozes, 2001; Middleton, Denney, Lynch, & Parmenter, 2006). Studies suggest that subjective difficulties are over-emphasised relative to objective performance (Middleton et al., 2006). Higher rates of depression and fatigue are thought to contribute to over-

reporting cognitive dysfunction (Maor et al., 2001). Indeed, reductions in fatigue and depression following intervention was linked to reductions in subjective reports of cognitive functioning but not objective performance (Kinsinger, Lattie, & Mohr, 2010). Cognitive dysfunction is also related to distress for individuals with MS (Arnett, Higginson, Voss, Randolph, & Grandey, 2002) and is negatively impacted by stress. PwMS who perceive their cognitive difficulties as more disabling tend to report increased distress associated with these difficulties (Ryan et al., 2007). There is also some suggestion that engaging in or developing effective coping strategies may be difficult for pwMS due to the cognitive difficulties they experience (Goretti et al., 2010). Perception of cognitive difficulties therefore appears to be important for coping and adjustment in MS. This raises the question of whether self-compassion could help protect against distress associated with perceived cognitive dysfunction.

Current study

This study aimed to replicate and extend the findings by Nery-Hurwit et al., (2018) by investigating how dispositional self-compassion relates to QoL, coping efficacy, stress, and PCF in MS using a prospective design. It is expected that self-compassion will be associated with improved QoL and coping, and reduced stress and perceived cognitive dysfunction. This study also aimed to explore the possible pathways that link these factors. A main aim was to understand how self-compassion operates in relation to PCF in MS since this relationship has yet to be investigated. Self-compassion is associated with improved coping, which appears to be protective against stress (Sirois et al., 2015). Furthermore, increased stress has been linked to cognitive dysfunction and disease progression, while adaptive coping may play a role in ameliorating this association (Mohr et al., 2002). One possible pathway in which self-compassion operates for PCF is through indirect relationships with coping efficacy and/or stress (Figure 1).

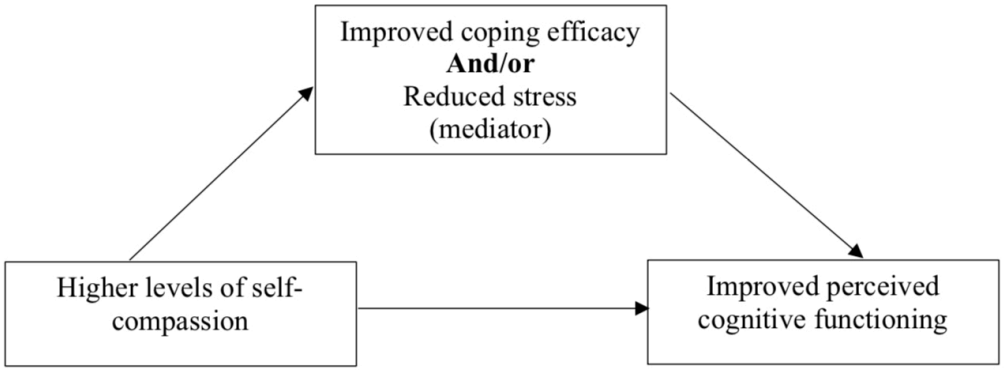

Figure 1. Illustrates the hypothesis that improved coping efficacy and/or reduced stress will mediate the relationship between self-compassion and improved perceived cognitive functioning at baseline and time-point 2.

Hypotheses

1. Self-compassion will be positively associated with coping efficacy and QoL, and negatively associated with stress and PCF cross-sectionally (Hypothesis 1, H1) and prospectively (H2);
2. Higher levels of self-compassion will predict increased coping efficacy, and decreased stress and PCF cross-sectionally (H3) and PCF prospectively (H4);
3. Coping efficacy and/or stress will mediate the relationship between self-compassion and PCF cross-sectionally (H5) and prospectively (H6).

Method

Design

A prospective within-subjects design was utilised; two online surveys (administered six-weeks apart) collected data using convenience sampling across a large geographical area. Time 1 (T1) data collection took place from February 2018-December

2018, with Time 2 (T2) data collection commencing six weeks following completion of T1 (April 2018-January 2019).

Sample

A priori power analysis was conducted using Cohen's tables (Cohen, 1992) and corroborated using G*Power 3.1 (Faul, Erdfelder, Lang & Buchner, 2007) to determine adequate sample size. An estimated attrition rate of 50% at T2 was selected based on previous research by Sirois and Wood (2017) with two chronic illness groups using a similar design. We aimed to detect a medium effect size, with an alpha = .05, and seven demographic and disease-related predictors (disease duration, disease severity, gender, age, MS subtype, fatigue, and T1 scores). To detect an effect of 80% power, $N = 102$ (at T2) was required; accounting for attrition $N = 204$ at T1, was therefore required to reveal a significant effect of 80% power at T2.

Participants and recruitment

Google searches identified MS organisations in English speaking countries: United Kingdom, Ireland, Canada, United States of America, Australia, and New Zealand. These organisations were contacted by email (Appendix A) and asked to advertise the study invitation (Appendix B) via websites, email lists and social media platforms. The study was also advertised and distributed to the staff and student University volunteers lists, and via other relevant platforms for advertising psychological research including social media. Table 1 summarises inclusion criteria.

Table 1

Inclusion criteria

Diagnosis (or reported diagnosis) of MS (RS or PS)
Over 18 years old
Able to read and write in English

Four-hundred and eighty-three participants began the survey; 415 participants consented, five declined consent and 63 closed the window before consenting. Three-hundred and sixty-four people provided email addresses and started T1; 66 participants had significant missing data. Due to an error with the initial coding of the survey the first 20 participants had significant missing data and were therefore excluded from the analysis. The final T1 sample was n = 278. Two-hundred and twenty-seven participants completed T2; 25 participants had significant missing data and were excluded leaving n = 202 participants (72.66%) at T2. Attrition rate was 27.33% so the final sample significantly surpassed that indicated by the power analysis (n = 102).

Procedure

The survey was accessed through a Qualtrics website link in the study invitation; participants received relevant study information including the participant information sheet (Appendix C) and consent form (Appendix D) which included confirmation that participants met inclusion criteria. After consenting, participants were asked to enter their email address to be contacted six-weeks later for T2. The demographics form was presented at the start of the T1 questionnaire (Appendix E). To account for possible order effects, the order of the questionnaires within the survey was randomised with the exception of the demographic questions, disease severity scale and self-compassion measure which were presented first. Following completion of the questionnaire, a

resource sheet (Appendix F) was presented including relevant listening services (Appendix G).

Six-weeks after completion of T1, participants received an email (via Qualtrics reminder system) inviting them to complete T2 (Appendix H). Two comparable email reminders were sent to participants who did not complete T2 following the first email (Appendix I). A brief information sheet (Appendix J) preceded the T2 questionnaire. Participants were asked to enter their email address so T1 and T2 responses could be matched. After completing the T2 questionnaire (Appendix K), a debriefing statement (Appendix L) was shown which provided more details about the study including the prize draw to win a £50 (or equivalent currency) Amazon voucher as a thank you for participation.

Ethics

The University of Sheffield's Department of Psychology Research Ethics Committee approved this study (Appendix M). The information sheet provided participants with all relevant information. When participants declined consent, they were exited from the survey page and omitted from the final dataset. Password-protected computers, accessible only to the researcher, stored data securely; email addresses were additionally stored in a password-protected document. Emails were deleted from the data file once T1 and T2 data were matched. Email addresses were kept separately until the prize draw was completed and then deleted immediately following confirmation by the winning recipient. Contact details for the researchers was provided in the event participants had questions or complaints about the study. The amount chosen for the prize draw was deemed to be proportionate for the participants time and did not induce participation (British Psychological Society; BPS, 2014). BPS guidance on internet conducted research was adhered to throughout (BPS, 2017).

Measures

Internal consistency of the included measures was good in this sample (see Table 3 for Cronbach's alpha values for all measures at both time-points). All measures were presented at both time-points (excluding demographics which were only gathered at T1). The full survey can be found in Appendix E.

Demographics. Data regarding gender, age, employment status, relationships status, country, and years of education was obtained at T1.

Disease-specific items. Disease-specific items included disease duration, type of MS (RS or PS) and medication. Impact of MS on daily living (i.e. disease severity) was assessed using one item: "to what extent does MS affect my daily activities" rated on a 4-point Likert Scale from 1 (not at all) to 4 (a lot) with higher scores indicating higher severity. This method was utilised effectively in a study with arthritis and IBD groups (Sirois et al., 2015).

Self-compassion. Self-compassion was assessed using the 12-item Self-Compassion Scale-Short Form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011; Neff, 2003a). The SCS-SF examines three key factors of self-compassion along with their negative equivalents: Self-kindness (Self-judgement), Common Humanity (Isolation), and Mindfulness (Over-identification). The SCS-SF includes both positively and negatively laden items, rated on a Likert Scale from 1 (almost never) to 5 (almost always). Negative items on the scale are reverse coded and the means of the subscales are averaged to calculate an overall score, with higher scores indicating higher levels of self-compassion. The SCS-SF total score almost perfectly correlates (r = .98) with the total score of the long SCS (Raes et al., 2011).

Coping efficacy. Self-reported ability to cope with common challenges of chronic illness was measured by a three-item scale developed by Gignac et al., (2000).

The scale assessed three common themes associated with coping in chronic illness: symptoms, emotional aspects, and day-to-day problems. Initially designed for use with arthritis populations, it has been successfully reworded and adapted for other conditions (e.g. Sirois et al., 2015). Items were adapted to be specific for MS and rated on a Likert scale from 1 (strongly disagree) to 5 (strongly agree), with higher scores indicating greater coping efficacy.

Perceived stress. The Perceived Stress Scale (PSS; Cohen & Williamson, 1988) is a widely used measure of general stress and has been used extensively in research. Events experienced within the past month are assessed by 10-items in terms of perceived stress experienced on a 5-point scale from 0 (Never) to 4 (Very often). Positive items are reverse coded so that higher scores indicated more stress. The PSS has good test-retest reliability (r = .85; Cohen, Kamarck, & Mermelstein, 1983).

Quality of Life. Three subscales of the Functional Assessment of Multiple Sclerosis (FAMS; Cella et al., 1996) assessed QoL: Symptoms (7 items), Emotional Well-being (7 items), and General Contentment (7 items). Items are rated on a 5-point Likert scale from 0 (Not at all) to 4 (Very much), with a maximum score of 28 on each scale and higher scores indicating greater QoL. Negative items were recoded (e.g. 'I have nausea' on Symptoms scale, 4 was rated as representing increased symptoms of nausea but this was reversed so that all scores were in the same direction 4 = 0, 3 = 1, 2 = 2, 1 = 3, and 0 = 4). These subscales were selected as they represented the most relevant aspects of QoL of interest; it also helped to limit the number of items to reduce participant burden.

Fatigue. The Modified Fatigue Impact Scale-5 item version (MFIS-5; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994b) from the Multiple Sclerosis Quality of Life Inventory (MSQLI; Ritvo et al., 1997) assessed fatigue. The MFIS-5 is an

abbreviated version of the 21-item long form, and assesses physical, psychosocial, and cognitive fatigue. Items are rated on a 5-point Likert scale from 0 (Never) to 4 (Almost always). Scores ranged from 0-20 with higher scores indicating increased fatigue.

Cognitive functioning. Three measures were used to gain a thorough assessment of PCF. The Perceived Deficits Questionnaire-5 item version (PDQ-5; Sullivan, Edgley, & Dehoux, 1990) from the MSQLI; Ritvo et al., 1997) is an abbreviated version of the 20-item long form and assesses attention, retrospective memory, prospective memory, planning and organisation. Items are rated on a 5-point Likert scale from 0 (Never) to 4 (Almost always). Scores range from 0-20 with higher scores indicating higher levels of perceived cognitive dysfunction. While PDQ-5 scores do not correlate highly with objective neuropsychological scores, the measure was not used to assess cognitive dysfunction per se but rather individual's perception of their cognitive difficulties (Ritvo et al., 1997). The PDQ was the primary measure of cognitive functioning as it incorporated a broader assessment of PCF than the other measures, with the two remaining measures acting as secondary outcomes.

The Everyday Memory Questionnaire-Revised (EMQ-R; Royle & Lincoln, 2008) is a 13-item revised and abbreviated version of the 28-item long form and assesses everyday memory failures. Items are rated on a 5-point Likert scale (0 = once or less in a month; 1 = more than once a month but less than once a week; 2 = about once a week; 3 = more than once a week but less than once a day; 4 = once or more in a day). Scores range from 0-52, with higher scores indicating more perceived difficulties.

The final measure was the Attentional Control Scale (ACS; Derryberry & Reed, 2002); a 20-item measure of attentional focusing and shifting, which has been used in relation to assessing psychopathology associated with attentional processes (Derryberry & Reed, 2002). Items are rated on a 4-point Likert scale from almost never (1) to always

(4), and reverse items are included. Higher scores on the ACS indicate superior attentional control.

Covariates

Variables identified from the literature as possible covariates included gender, age, disease severity, disease duration, MS subtype and fatigue. Levels of stress and coping styles in MS have been found to vary according to gender (i.e. higher stress and more emotion-focused coping in females versus males; Matud, 2004). Similarly, gender differences in levels of self-compassion have been identified with males demonstrating slightly higher levels of self-compassion (Neff & Lamb, 2009; Yarnell et al., 2015). There is also some evidence that self-compassion increases with age (Homan, 2016). Disease severity has been linked to stress by associations between increased stress and disease exacerbation (Mohr & Cox, 2001). Cognitive dysfunction has been found to be significantly greater in PS compared to RS suggesting that cognitive dysfunction varies according to MS subtype; this has implications for disease duration in that cognitive dysfunction is more pronounced as duration of disease increased (Chiaravalloti & DeLuca, 2008). Gender differences have been noted in fatigue, with women having more changes in levels of fatigue (Schwartz, Coulthard-Morris, & Zeng, 1996). Furthermore, stress is often exacerbated by fatigue in MS (Krupp, Alvarez, LaRocca, & Scheinberg, 1988).

Data analysis

Statistical Package for the Social Sciences (SPSS, Version 25; IMB corp, 2017) was used to conduct data analysis. Missing data was identified by running descriptive statistics. The survey was coded in Qualtrics to prompt participants to complete all items; questionnaires could therefore be skipped without responding to all items, in line with BPS (2017) guidance. At T1, all scales except CE, MFIS and PDQ had a small amount of

missing data. At T2, all scales had a small amount of missing data except CE. A time-point was considered incomplete if there was at least one full incomplete scale; these data were then excluded from the analysis. Scales were included in the analysis if 80% completed, and linear interpolation was used to deal with missing data. Linear interpolation is one recommended longitudinal imputation method deemed suitable for small amounts of missing data (Twisk & de Vente, 2002; Noor, Abdullah, Yahaya, & Ramli, 2015). Checks were made on the data for coding and scoring errors, but none were identified. Following interpolation of missing data, relevant items were recoded and reversed as required.

Results

Descriptives and baseline analyses

Demographic data and study variables were analysed descriptively (means, frequencies and standard deviations). Group differences (i.e. 'completers' versus 'non-completers' and RS versus PS subtypes) were analysed for demographic data using independent *t*-tests (continuous variables) and Chi-square tests (categorical variables; Table 2). When assumptions of Chi-Square were violated (i.e. more than 20% of expected cells <5 for analyses greater than 2x2) the Likelihood Ratio statistic was reported (McHugh, 2013).

There were some demographic differences between completers and non-completers. A higher proportion of completers were employed full-time and a higher proportion of non-completers were unable to work due to their MS. A higher proportion of completers were married/living with intimate partner whereas a higher proportion of non-completers were never married.

MS subtype groups differed across several variables. Age and mean number of years since diagnosis was significantly higher in the PS group than the RS group. The PS group was more likely to be unable to work due to their MS or retired leaving a greater proportion of the RS group in employment. Unemployment was higher in the RS group. These findings are unsurprising given that mean age and years since diagnosis was higher in the PS group. A higher proportion of people were never married in the RS group and a higher proportion 'separated' in the PS group. Overall, both RS and PS groups were highly educated but there were marginally more people with RS with some high school, high school graduate or bachelor's degree. A higher proportion of people with RS reported taking medication.

Table 2

Demographic data, descriptive statistics, and test statistics for differences between groups

Variable	*n* (%)	Entire sample mean (SD)	MS subtype analysis			Completer analysis		
			RS *n* (%) or mean (SD)	PS *n* (%) or mean (SD)	Test statistic RS vs. PS	Completers *n* (%) or mean (SD) *n* = 202	Non-completers *n* (%) or mean (SD) *n* = 76	Test statistic Completers vs. non-completers
Age (*n* = 252, range 22-75 years)		46.33 (11.69)	43.8 (11.3)	53.9 (9.6)	$t(123.2) = -6.882$, $p = .000$**	46.4 (11.5)	46.1 (12.3)	$t(250) = 0.205$, $p = .838$
Gender (*n* = 278)								
Female	228 (82)	N/A	170 (82.6)	57 (80)	$\chi^2 = 0.842$, $p = .656$	160 (79.2)	68 (89.5)	$\chi^2 = 4.658$, $p = .097$
Male	49 (17.6)		35 (17)	14 (20)		41 (20.3)	8 (10.5)	
Transgender (male)	1 (0.4)		1 (0.4)	0 (0)		1 (0.5)	0 (0)	
Country (*n* = 278)								
Canada	7 (2.5)	N/A	4 (1.9)	3 (4.2)	$\chi^2 = 4.191$, $p = .522$	6 (3)	1 (1.3)	$\chi^2 = 2.989$, $p = .702$
Ireland	30 (10.8)		25 (12.1)	5 (7)		22 (10.9)	8 (10.5)	
New Zealand	27 (9.7)		22 (10.7)	5 (7)		18 (8.9)	9 (11.8)	
UK	98 (35.3)		69 (33.5)	29 (40.8)		74 (36.6)	24 (31.6)	
USA	110 (39.6)		81 (39.3)	28 (39.4)		79 (39.1)	31 (40.8)	
Other	6 (2.2)		5 (2.4)	1 (1.4)		3 (1.5)	3 (3.9)	
Ethnicity (*n* = 278)								
White	259 (93.2)	N/A	190 (92.2)	68 (95.8)	$\chi^2 = 2.834$, $p = .418$	189 (93.6)	70 (92.1)	$\chi^2 = 2.357$, $p = .502$
Black or African American	2 (0.7)		1 (0.5)	1 (1.4)		1 (0.5)	1 (1.3)	
Asian	6 (2.2)		5 (2.4)	1 (1.4)		3 (1.5)	3 (3.9)	
Other	11 (4)		10 (4.9)	1 (1.4)		9 (4.5)	2 (2.6)	
MS subtype (*n* = 277)								
Relapsing	206 (74.1)	N/A	N/A	N/A	N/A	151 (75.1)	55 (72.4)	$\chi^2 = 0.220$, $p = .639$
Progressive	71 (25.5)					50 (24.9)	21 (27.6)	
Years since diagnosis (*n* = 277)		11.41 (9.96)	9.62 (8.78)	16.68 (11.31)	$t(100.8) = -4.778$, $p = .000$**	10.81 (9.07)	13.03 (11.95)	$t(107.3) = -1.460$, $p = .147$

(Table 2 continued)

Variable	*n* (%)	Entire sample mean (SD)	MS subtype analysis			Completer analysis		
			RS *n* (%) or mean (SD)	PS *n* (%) or mean (SD)	Test statistic RS vs. PS	Completers *n* (%) or mean (SD) *n* = 202	Non-completers *n* (%) or mean (SD) *n* = 76	Test statistic Completers vs. non-completers
Relationship status (*n* = 277)								
Married/living with an intimate partner	202 (72.7)	N/A	152 (74.1)	50 (70.4)	$\chi^2 = 13.323$, $p = .010$*	157 (77.7)	45 (60)	$\chi^2 = 10.401$, $p = .034$*
Widowed	8 (2.9)		5 (2.4)	3 (4.2)		6 (3)	2 (2.7)	
Divorced	20 (7.2)		14 (6.8)	5 (7.0)		13 (6.4)	7 (9.3)	
Separated	7 (2.5)		1 (0.5)	6 (8.5)		4 (2)	3 (4)	
Never married	40 (14.4)		33 (16.1)	7 (9.9)		22 (10.9)	18 (24)	
Employment (*n* = 276)								
Full-time	96 (34.5)	N/A	84 (41)	12 (17.1)	$\chi^2 = 46.567$, $p = .000$*	81 (40.3)	15 (20)	$\chi^2 = 10.004$, $p = .040$*
Part-time	47 (16.9)		42 (20.5)	5 (7.1)		32 (15.9)	15 (20)	
Currently unemployed	20 (7.2)		19 (9.3)	1 (1.4)		13 (6.5)	7 (9.3)	
Unable to work due to health condition	83 (29.9)		47 (22.9)	35 (50)		55 (27.4)	28 (37.3)	
Retired	30 (10.3)		13 (6.3)	17 (24.3)		20 (10)	10 (13.3)	
Education (*n* = 277)								
Some high school	12 (4.3)	N/A	4 (2)	8 (11.3)	$\chi^2 = 14.662$, $p = .041$*	7 (3.5)	5 (6.6)	$\chi^2 = 10.145$, $p = .180$
High school graduate	17 (6.1)		16 (7.8)	1 (1.4)		12 (6)	5 (6.6)	
Some college but no degree	53 (19.1)		37 (18)	15 (21.1)		35 (17.4)	18 (23.7)	
Associate degree in college (2-year)	21 (7.6)		15 (7.3)	6 (8.5)		16 (8)	5 (6.6)	
Bachelor's degree in college/university	95 (34.2)		74 (36.1)	31 (29.6)		68 (33.8)	27 (35.5)	
Master's degree	61 (21.9)		45 (22)	16 (22.5)		46 (22.9)	15 (19.7)	
Doctoral degree	10 (3.6)		8 (3.9)	2 (2.8)		10 (5)	0 (0)	
Professional degree (JD, MD)	8 (2.9)		6 (2.9)	2 (2.8)		7 (3.5)	1 (1.3)	
Medication (*n* = 278)								
Yes	223 (80.2)	N/A	171 (83)	51 (71.8)	$\chi^2 = 4.146$, $p = .042$*	164 (81.2)	59 (77.6)	$\chi^2 = 0.440$, $p = .507$
No	55 (19.8)		35 (17)	20 (28.2)		38 (18.8)	17 (22.4)	

Note: SD = Standard deviation, RS = relapsing subtype, PS = progressive subtype, χ^2 = Chi-Square Statistic, *t* = independent t-test statistic, *$p < .05$, $p < .01$**

Independent *t*-tests assessed differences between groups on experimental variables (Table 3). Since normality tests (e.g. Kolmogorov-Smirnov) can be receptive to small deviations in normality with large samples (Field, 2009), various analyses were used to assess continuous variables for normality. Histograms and Q-Q plots were reviewed as well as Kolmogorov-Smirnov's test of normality, skewness and kurtosis (see Appendix N for summary). Slight skews were observed on Histograms and Q-Q plots for 'years since diagnosis', emotional well-being (FAMS-EWB at T1 and T2) and a measure of cognition (EMQ T1 and T2). The statistics used were however felt to be robust enough to manage small deviations in normality with the large sample (Field, 2009). All test variables were therefore treated as normally distributed.

Coping efficacy was significantly higher in completers compared to non-completers. Stress, memory difficulties (EMQ T1) and 'symptoms' were higher for the non-completer group versus completers (represented for FAMS-S-T1 by a lower score in the non-completer group due to items being recoded so that higher scores indicate better QoL). These findings suggest factors affecting completion of the study were increased stress, symptoms and perceived memory difficulties, and lower levels of coping efficacy.

There were also differences between MS groups. Impact of MS on daily life (IDL) was greater for people with PS than RS at both time-points. There were higher levels of coping efficacy at T1 in the RS group compared to PS group. Scores on QoL indices emotional well-being (FAMS-EWB), general contentment (FAMS-GC) and total QoL were lower at both time-points for people with PS compared to people with RS. Finally, fatigue was higher at both time-points for people with PS than people with RS. These findings suggest that MS had a greater impact on daily life, quality of life and fatigue when it was progressive. Furthermore, coping with the demands of MS was harder for PS relative to RS.

Table 3

Cronbach's alphas, descriptive data of study variables, and test statistics for differences between groups

Variable	*n*	α	Entire sample mean (SD)	MS subtype analysis			Completer analysis		
				RS mean (SD) T1 *n* = 206	PS mean (SD) T1 *n* = 71	Test statistic RS vs. PS	Completers mean (SD) *n* = 202	Non-completers mean (SD) *n* = 76	Test statistic Completers vs. non-completers
Impact on daily life T1	278	N/A	2.8 (0.9)	2.5 (0.9)	3.4 (0.7)	*t*(157.2) =-8.85, *p* =.000**	2.7 (0.9)	2.9 (0.9)	*t*(276) = -1.557, *p* =.121
SCS T1	278	.87	3.1 (0.8)	3.1 (0.8)	3.1 (0.7)	*t*(275) = -0.123, *p* =.903	3.1 (0.8)	3.0 (0.9)	*t*(276) = 0.985, *p* =.326
CE T1	278	.89	3.3 (1.0)	3.4 (1.0)	3.0 (1.1)	*t*(275) = 2.986, *p* =.003**	3.5 (0.9)	3.0 (1.2)	*t*(111.4) = 3.274, *p* =.001**
PSS T1	278	.89	2 (0.7)	1.9 (0.7)	2.1 (0.7)	*t*(275) = -1.265, *p* =.207	1.9 (0.7)	2.1 (0.7)	*t*(276) = -2.177, *p* =.03*
FAMS-S T1	278	.84	17.9 (6.2)	18.2 (6.2)	17.0 (6.1)	*t*(275) = 1.407, *p* =.161	18.5 (5.9)	16.1 (6.7)	*t*(276) = 2.919, *p* =.004**
FAMS-EWB T1	278	.93	17.4 (7.3)	18.6 (6.9)	14.0 (7.5)	*t*(275) = 4.727, *p* =.000**	17.9 (7.0)	16 (8.0)	*t*(120.3) = 1.856, *p* =.066
FAMS-GC T1	278	.87	14.9 (6.3)	15.7 (6.1)	12.5 (6.2)	*t*(275) = 3.839, *p* =.000**	15.2 (6.4)	14.0 (6.1)	*t*(276) = 1.463, *p* =.145
QoL total T1	278	.93	50.1 (16.4)	52.6 (15.5)	43.5 (17.0)	*t*(275) = 4.12, *p* < .001**	51.7 (15.7)	46.1 (17.6)	*t*(276) = 2.55, *p* = .011*
MFIS T1	278	.88	12.1 (4.5)	11.5 (4.5)	13.7 (4.2)	*t*(275) = -3.585, *p* =.000**	12 (4.5)	12.5 (4.6)	*t*(276) = -0.827, *p* =.409
PDQ T1	278	.88	9.3 (4.8)	9.2 (4.5)	9.5 (5.6)	*t*(102.9) = -0.396, *p* =.693	9.0 (4.6)	10.1 (5.2)	*t*(276) = -1.658, *p* =.098
EMQ T1	278	.94	1.4 (1.0)	1.4 (1.0)	1.3 (1.0)	*t*(275) = 0.424, *p* =.672	1.3 (0.9)	1.6 (1.1)	*t*(114.6) = -2.573, *p* =.011*
ACS T1	278	.88	49.8 (10.5)	50.0 (10.3)	49.5 (10.6)	*t*(275) = 0.397, *p* =.691	49.8 (10.5)	49.7 (10.4)	*t*(276) = 0.099, *p* =.92

(Table 3 continued)

Variable	*n*	α	Entire sample mean (SD)	MS subtype analysis			Completer analysis		
				RS mean (SD) T2 *n* = 151	PS mean (SD) T2 *n* = 50	Test statistic RS vs. PS	Completers mean (SD) *n* = 202	Non-completers *n* or mean (SD) *n* = 76	Test statistic Completers vs. non-completers
Impact on daily life T2	202	N/A	2.6 (0.9)	2.4 (0.8)	3.4 (0.7)	*t*(199) = -8.797, *p* =.000**	N/A	N/A	N/A
SCS T2	202	.89	3.1 (0.8)	3.1 (0.8)	3.1 (0.8)	*t*(199) = 0.182, *p* =.855	N/A	N/A	N/A
CE T2	202	.90	3.4 (1.0)	3.5 (1.0)	3.3 (1.1)	*t*(199) = 1.294, *p* =.197	N/A	N/A	N/A
PSS T2	202	.90	1.9 (0.7)	1.9 (0.7)	2.0 (0.7)	*t*(199) = -0.896, *p* =.371	N/A	N/A	N/A
FAMS-S T2	202	.84	18.5 (6.0)	18.7 (6.1)	18.1 (5.6)	*t*(199) = 0.644, *p* =.520	N/A	N/A	N/A
FAMS-EWB T2	202	.92	18.4 (7.1)	19.4 (6.7)	15.7 (7.2)	*t*(199) = 3.290, *p* =.001**	N/A	N/A	N/A
FAMS-GC T2	202	.89	15.2 (6.7)	15.8 (6.5)	13.6 (6.9)	*t*(199) = 2.055, *p* =.041*	N/A	N/A	N/A
QoL Total T2	202	.93	52.1 (16.5)	53.9 (15.7)	47.4 (17.4)	*t*(199) = 2.48, *p* = .014	N/A	N/A	N/A
MFIS T2	202	.88	11.5 (4.7)	11.1 (4.7)	12.8 (4.3)	*t*(199) = -2.248, *p* =.026*	N/A	N/A	N/A
PDQ T2	202	.88	8.9 (4.7)	8.9 (4.5)	8.6 (5.3)	*t*(73.2) = 0.351, *p* =.726	N/A	N/A	N/A
EMQ T2	202	.94	1.3 (0.9)	1.4 (0.9)	1.2 (0.9)	*t*(199) = 0.822, *p* =.412	N/A	N/A	N/A
ACS T2	202	.92	49.8 (11.2)	49.8 (10.8)	50.1 (11.9)	*t*(199) = -0.185, *p* =.853	N/A	N/A	N/A

Notes: T1 = Time 1; T2 = Time 2; SD = Standard deviation; SCS = Self-compassion Scale; CE = Coping Efficacy; PSS = Perceived Stress Scale; FAMS-S = Functional Assessment of Multiple Sclerosis-Symptoms; FAMS-EWB = Functional Assessment of Multiple Sclerosis-Emotional Well-being; FAMS-GC = Functional Assessment of Multiple Sclerosis-General Contentment; MFIS-5 = Modified Fatigue Impact Scale-5; PDQ-5 = Perceived Difficulties Questionnaire-5; EMQ = Everyday Memory Questionnaire; ACS = Attentional Control Scale; *t*= independent t-test test statistics; *p < .05; **p < .01

Bivariate analyses

Bivariate relationships between study variables at both time-points (self-compassion, stress, QoL, coping efficacy and PCF) were examined using Pearson's Product Moment correlations (H1 & H2; Table 4). Relationships between covariates and the main independent variable (self-compassion) and dependent variable (PCF) were examined (Appendix O). Positive correlations >r = .50 between all T1 and T2 scores were observed suggesting good temporal stability of the measures. Medium to very large correlations were observed between quality of life indices (FAMS-S, FAMS-EWB and FAMS-EWB) so scores were combined to create a QoL total score for each participant (Table 3)

Age demonstrated small to medium positive correlations with disease severity (impact on daily life) and self-compassion at both time-points Age also demonstrated small negative correlations with stress at both time points and measures of cognitive functioning at T1 (PDQ and EMQ).

Self-compassion correlated significantly with most variables except disease severity (T1 & T2); the majority being medium to large correlations. One measure of PCF (EMQ) however exhibited small negative correlations at each time-point with self-compassion. Self-compassion demonstrated medium positive correlations with coping efficacy (T1 & T2), as well as large negative correlations with stress at T1 and T2. This indicates that as self-compassion increases, coping efficacy also increases and stress decreases. Large positive correlations were observed between self-compassion and QoL (T1 and T2). Finally, small to medium correlations between self-compassion and PCF were observed at T1 and T2; as self-compassion increases, perceived cognitive dysfunction decreases. These findings strongly support H1 and H2 that self-compassion is

positively associated with coping efficacy and QoL, and negatively associated with stress and perceived cognitive dysfunction cross-sectionally and prospectively.

Coping efficacy significantly correlated with the other main variables (stress, QoL and PCF), suggesting coping efficacy is an important variable in understanding the relationships between key variables of interest. Similarly, stress was significantly correlated with all other variables at T1 and T2. Medium to large correlations between stress and PCF were observed, suggesting that as stress increased, perceived cognitive difficulties also increased.

Table 4

Pearson's r Correlations Coefficients between T1 and T2 variables

	Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1	Age	-																		
2	IDL T1	.23**	-																	
3	SCS T1	.31**	-.08	-																
4	CE T1	.07	-.35**	.45**	-															
5	PSS T1	-.26**	.33**	-.69**	-.55**	-														
6	QoL total T1	.08	-.54**	.57**	.69**	-.71**	-													
7	MFIS T1	-.03	.59**	-.35**	-.39**	.56**	-.64**	-												
8	PDQ T1	-.19**	.31**	-.33**	-.31**	.53**	-.51**	.62**	-											
9	EMQ T1	-.18**	.29**	-.26**	-.25**	.45**	-.42**	.54**	.82**	-										
10	ACS T1	.12	-.23**	.37**	.32**	-.51**	.43**	-.53**	-.69**	-.65**	-									
11	IDL T2	.34**	.77**	-.03	-.24**	.26**	-.49**	.51**	.25**	.19**	-.19**	-								
12	SCS T2	.20**	-.12	.80**	.39**	-.64**	.51**	-.27**	-.24**	-.13	.36**	-.12	-							
13	CE T2	.03	-.30**	.47**	.62**	-.59**	.71**	-.44**	-.33**	-.23**	.35**	-.39**	.49**	-						
14	PSS T2	-.16*	.32**	-.65**	-.49**	.80**	-.68**	.51**	.49**	.37**	-.45**	.33**	-.69**	-.69**	-					
15	QoL Total T2	-.022	-.47**	.52**	.59**	-.66**	.90**	-.56**	-.47**	-.36**	.41**	-.48**	.55**	.80**	-.76**	-				
16	MFIS T2	.05	.52**	-.33**	-.43**	.54**	-.65**	.79**	.63**	.54**	-.52**	.59**	-.35**	-.56**	.59**	-.67**	-			
17	PDQ T2	-.03	.26**	-.31**	-.30**	.50**	-.46**	.59**	.84**	.75**	-.65**	.28**	-.24**	-.32**	.49**	-.46**	.63**	-		
18	EMQ T2	-.07	.26**	-.23**	-.24**	.35**	-.37**	.51**	.76**	.78**	-.55**	.25**	-.17*	-.26**	.40**	-.39**	.56**	.79**	-	
19	ACS T2	.06	-.21**	.33**	.33**	-.48**	.37**	-.47**	-.66**	-.63**	.86**	-.21**	.35**	.33**	-.47**	.40**	-.52**	-.70**	-.60**	-

Note: T1 *n*=278; T2 *n*=202; YSD = years since diagnosis; IDL =Impact on daily life; SCS = Self-compassion Scale; CE = Coping Efficacy; PSS = Perceived Stress Scale; QoL Total = Quality of Life total (combined FAMS-S = Functional Assessment of Multiple Sclerosis-Symptoms, FAMS-EWB = FAMS-Well-being; FAMS-GC = FAMS-General Contentment); MFIS-5 = Modified Fatigue Impact Scale-5; PDQ-5 = Perceived Difficulties Questionnaire-5; EMQ = Everyday Memory Questionnaire; ACS = Attentional Control Scale; * p <0.05; ** p < .01

Paired-samples *t*-tests assessed whether changes occurred between T1 and T2 DV scores; no significant differences between any of the DVs were identified (Appendix P). Constructs were therefore stable over time and a longer time-gap may be required to detect any significant changes.

Path analysis

Path analysis was conducted using the Hayes PROCESS macro (version 3; Hayes, 2012; 2017) for SPSS with bootstrapping using 5000 bootstrapped samples (Hayes, 2012; 2017). Path analysis tested pathways linking self-compassion and PCF, specifically whether coping efficacy and/or stress mediated the relationship between self-compassion and PCF cross-sectionally (H5) and prospectively (H6). Embedded within the path analyses were tests of H3; whether self-compassion predicted coping efficacy and stress (a paths), and PCF (c' path) cross-sectionally. Path analysis also enabled test of H4; whether self-compassion predicted PCF prospectively (c' path). As PDQ was the primary PCF measure, it was the only measure assessed in the mediation models. Path analysis was conducted with and without relevant covariates to observe the impact of covariates and minimise the risk of generating false positive findings (Simmons, Nelson, & Simonsohn, 2011). Of the covariates, age, years since diagnosis, fatigue and disease severity significantly correlated with self-compassion and/or PCF (Appendix O). Neither gender nor MS subtype correlated with self-compassion or PCF so were not included as covariates. PDQ T1 was added as a covariate when PDQ T2 was analysed.

Stress. Figure 2 shows the mediation analysis for stress without covariates. Self-compassion significantly predicted stress (path a; H3) and stress significantly predicted PCF (path b). Self-compassion had no direct effect on PCF T1 (path c'; H3) but there was an indirect effect on PCF T1 via stress (path a x b; H5). When covariates were included (Figure 3), the same pattern of findings was observed. Self-compassion predicted stress

(H3) and stress predicted PCF. Self-compassion did not directly predict PCF cross-sectionally (H3) but the indirect effect of self-compassion on PCF via stress remained significant (H5) when covariates were included. The model overall with covariates explained 44% of variance in PCF T1 (R^2 = .44, F(6, 244) = 31.94, p<.001).

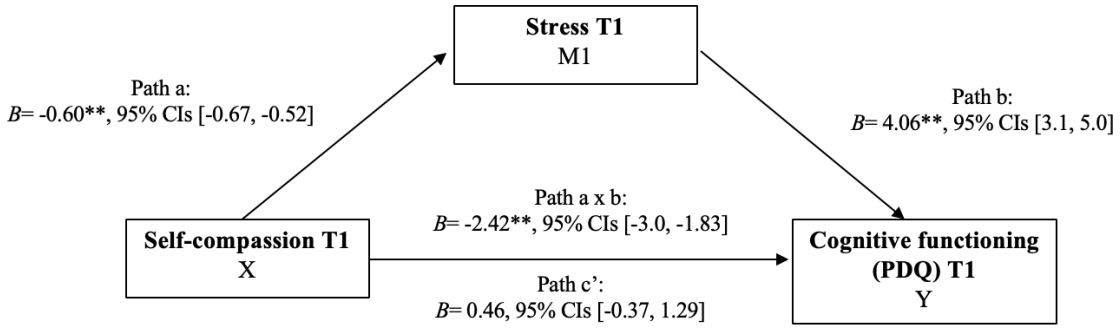

Figure 2. Stress (PSS T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T1), without covariates. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 278

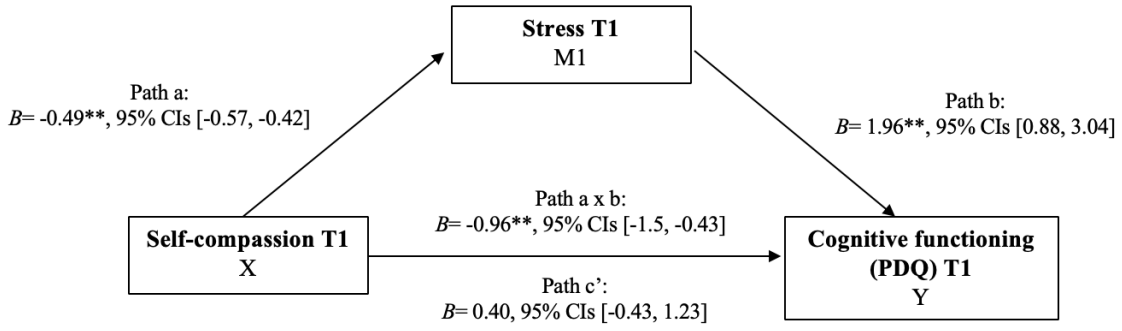

Figure 3. Stress (PSS T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T1), with covariates (Fatigue T1, years since diagnosis, disease severity and age) included but not pictured. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 251

A similar pattern was observed when PCF T2 was the DV. When covariates were not included (Figure 4), self-compassion predicted stress (path a; H3), and stress predicted PCF over time (path b). There was no direct effect of self-compassion on PCF over time (path c'; H4), but self-compassion indirectly predicted PCF over time via stress (path a x b; H6). When covariates were included (Figure 5), the same pattern was observed; self-compassion predicted stress (H3) and stress predicted PCF over time. Self-compassion did not directly predict PCF over time (H4) but continued to indirectly predict PCF over time via stress even when relevant covariates were included (H6). All variables (including covariates) in model explained 74% of variance in PCF T2 (R^2 = .73, $F(7, 179) = 68.93$, $p<.001$).

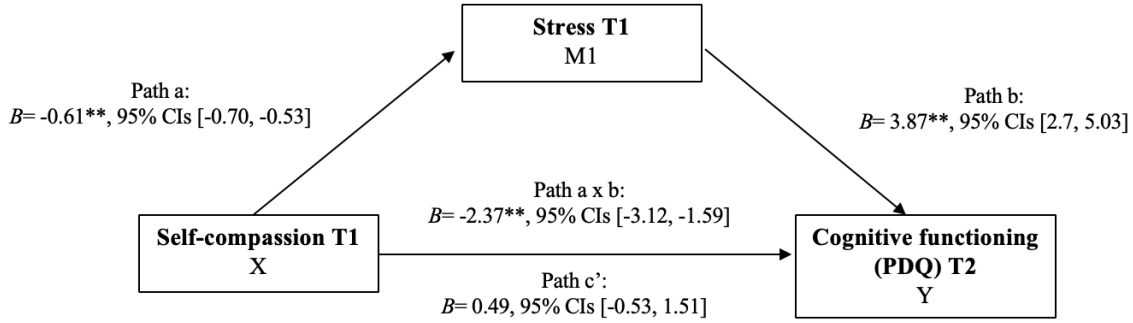

Figure 4. Stress (PSS T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T2), without covariates. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 202

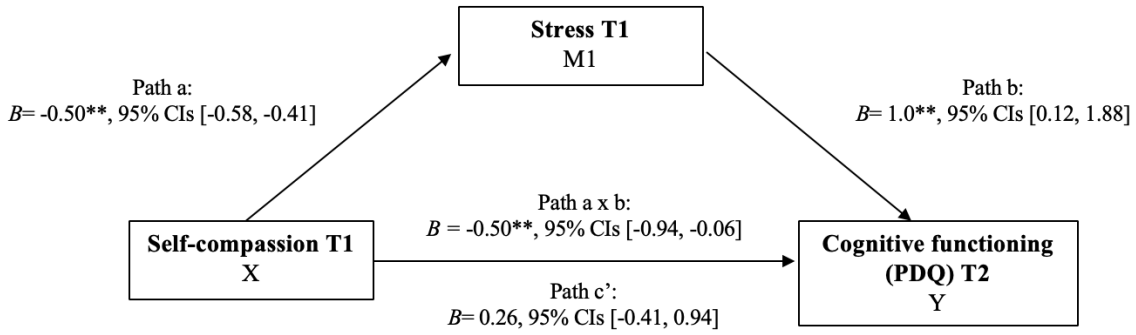

Figure 5. Stress (PSS T1) as a mediator of the relationship between self-compassion (SCS T1) and perceived cognitive functioning (PDQ T2), with covariates (Fatigue T1, years since diagnosis, disease severity, age and PCF T1) included but not pictured. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 187

Coping efficacy. When coping efficacy was assessed as the mediator without covariates (Figure 6), self-compassion predicted coping efficacy (path a; H3) and coping efficacy predicted PCF T1 (path b). There was also a direct effect of self-compassion on PCF (path c'; H3), and evidence of an indirect relationship between self-compassion and PCF through coping efficacy (path a x b; H5). When the covariates were included however, self-compassion remained predictive of coping efficacy (H3), but coping efficacy was no longer predictive of PCF. There was also no direct effect of self-compassion on PCF (H3), and no indirect effect via coping efficacy cross-sectionally (H5). The full model explained 41% of variance in PCF T1 (R^2 = .41, F(6, 244) = 28.59, p<.001).

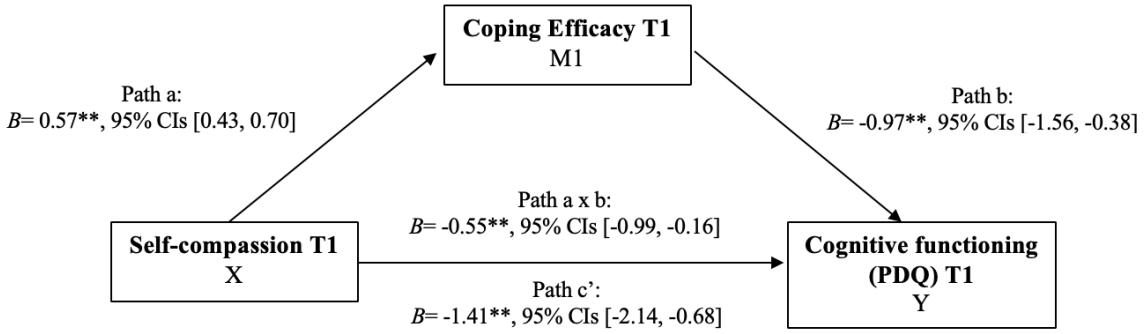

Figure 6. Coping efficacy (CE T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T1), without covariates. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 278

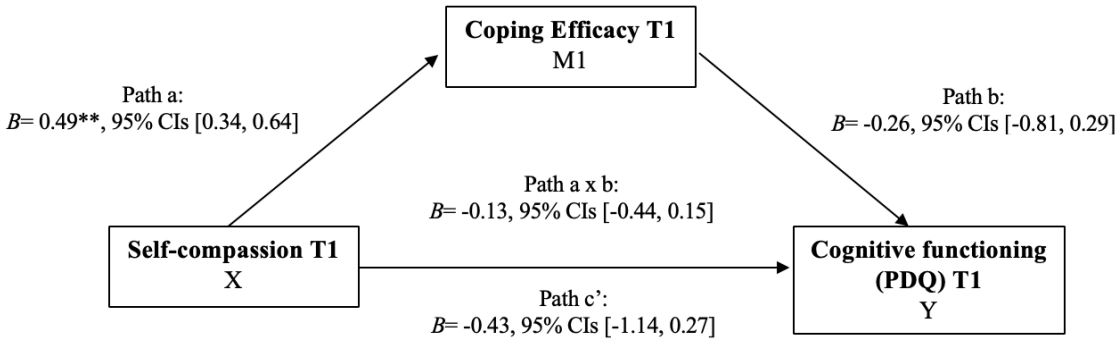

Figure 7. Coping efficacy (CE T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T1), with covariates (Fatigue T1, years since diagnosis, disease severity and age) included but not pictured. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 251

A similar pattern was observed when PCF T2 was the DV. When covariates were not included (Figure 8), self-compassion predicted coping efficacy (path a; H3), and coping efficacy predicted PCF over time (path b). Self-compassion directly predicted PCF over time (path c'; H4), and indirectly predicted PCF over-time via coping efficacy (path a x b; H6). When covariates were included (Figure 9), self-compassion still predicted coping efficacy (H3), but coping efficacy did not PCF over time. There was no

direct (H4) or indirect (H6) effect of self-compassion on PCF over time when covariates were included. All variables in model (including covariates) explained 72% of variance in PCF T2 (R^2 = .72, F(7, 179) = 66.57, p<.001).

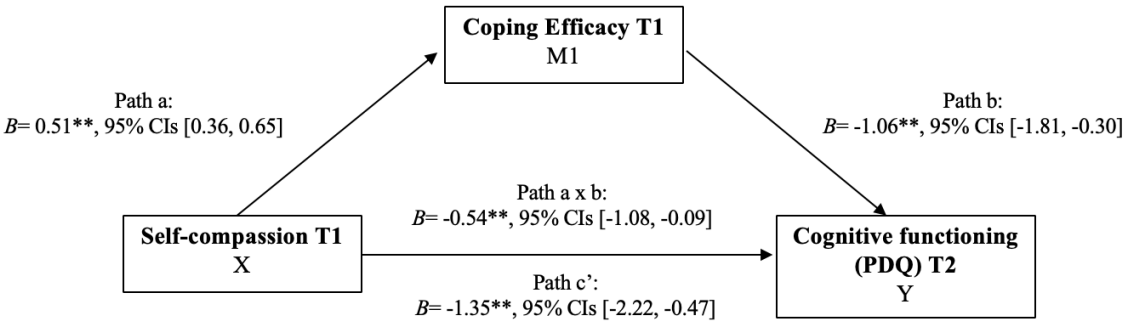

Figure 8. Coping efficacy (CE T1) as a mediator of the relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T2), without covariates. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 202

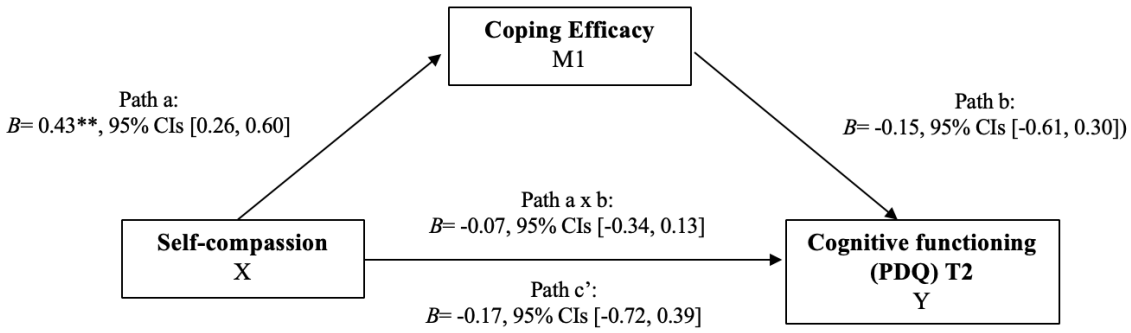

Figure 9. Coping Efficacy (CE T1) as a mediator of the prospective relationship between Self-compassion (SCS T1) and perceived cognitive functioning (PDQ T2), with covariates (Fatigue T1, years since diagnosis, disease severity, age, PCF T1) included but not pictured. Unstandardised coefficients (*B*) are presented; p<0.05*, p<0.01**, *n* = 187

Fatigue was a significant predictor in both the stress and coping efficacy models. Fatigue significantly predicted PCF cross-sectionally (B = 0.63, 95% CIs [0.5, 0.77]) and prospectively (B = .16, [0.04, 0.28]) in the coping efficacy model, and the stress model cross-sectionally (B = 0.56, [0.42, 0.70]) and prospectively (B = 0.14, [0.14, 0.26]).

Discussion

This prospective study investigated the role of self-compassion for PCF in MS, and the possible pathways that explain this association over time. Self-compassion was positively associated with coping efficacy and quality of life, and negatively associated with stress and perceived cognitive dysfunction. Additionally, PCF was negatively associated with coping efficacy and quality of life, and positively associated with stress. There was limited evidence that self-compassion directly predicted PCF. However, stress, but not coping efficacy, consistently mediated the relationship between self-compassion and PCF over and above that accounted for by covariates. Higher levels of self-compassion are therefore predictive of improved PCF through the relationship with stress. This can have important implications in terms of understanding the psychological and cognitive impact of MS. Self-compassion seems to protect against stress in MS, which in turn serves a protective function against perceived cognitive dysfunction. This suggests that someone's experience of cognitive difficulties in MS may be influenced by their ability to manage stressors and their ability to relate to themselves with kindness in the face of a limiting chronic health condition. Current findings support previous research with other chronic health conditions that have demonstrated relationships between self-compassion and stress (e.g. Brion et al., 2014), and self-compassion and coping (e.g. Sirois et al., 2015). Furthermore, this finding supports previous research with MS populations that demonstrated self-compassion is related to improved quality of life (e.g.

Nery-Hurwit et al., 2018). To the best of our knowledge, this is the first study to demonstrate relationships between self-compassion and PCF in MS.

The findings also confirm that self-compassion plays an important role in adjustment to MS through associations with stress, coping efficacy and QoL. This is congruent with previous research which found self-compassion to be a good predictor of QoL in cancer patients (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2013) and in MS (Nery-Hurwit et al. 2018), and stress and coping in HIV, IBD and arthritis populations (Brion et al., 2014; Sirois et al., 2015). Current findings also extend those by Nery-Hurwit et al., (2018) by establishing these relationships in MS over time.

Another important finding from this study was evidence of fatigue being a highly important factor in the adjustment for MS. Indeed, a large proportion of pwMS report fatigue to be a daily, debilitating symptom (Fisk et al., 1994; Freal, Kraft, & Coryell, 1984; Krupp, Alvarez, LaRocca, & Scheinberg, 1988). Furthermore, fatigue has been associated with increased difficulties in cognitive functioning (Krupp et al., 1988; Schwartz, Coulthard-Morris, & Zeng, 1996) which is consistent with the findings of this study. There is limited evidence in the literature however that this relationship holds when cognitive functioning is examined objectively using neuropsychological tests (Bol, Duits, Hupperts, Verlinden, & Verhey, 2010; Parmenter, Denney, & Lynch, 2003). This suggests that fatigue is an important factor when considering cognitive difficulties of pwMS, but perhaps more importantly when perceptions of functioning are considered.

Strengths and limitations

Worldwide online recruitment increased the geographical reach of the survey and is a study strength. Convenience sampling methods however are prone to selection bias (Bethlehem, 2010) which could explain the high level of educational attainment observed within the sample. Another issue of online studies is that recruitment will be limited to

those participants with access to the internet and therefore the sample may not be representative of the target population (Bethlehem, 2010). However, this approach facilitated improved efficiency, access to more diverse participants which likely increased response rates and a more secure way of storing large amounts of data (Lefever, Dal, & Matthiasdottir, 2007; Wright, 2017). Whilst the sample was predominately white in ethnicity, the demographics in this study were consistent with other prospective surveys including pwMS (e.g. Edwards, Alschuler, Ehde, Battalio, & Jensen, 2017). Differences in relationship status, employment, coping efficacy, levels of stress and symptoms and perceived memory difficulties between the completer group and non-completers suggests the completer group was not fully representative of the whole sample and may be limited in terms of generalisability.

One argument within the literature is that cross-sectional mediation analysis can lead to bias about longitudinal processes since 'time' cannot be controlled for with respect to the predictor, mediator or outcome (Maxwell & Cole, 2007; Maxwell, Cole, & Mitchell, 2011). This means that conclusions about causality longitudinally cannot be made on the basis of cross-sectional mediation analysis (Shrout, 2011). An advantage of using a prospective design in this study was that causality could be explored while controlling for the effects of variables at previous time-points (Lynn, 2009). Comparison of cross-sectional and longitudinal mediation in this study meant that it was possible to confirm the effects were present and that they held over time. The prospective nature of the design also allowed for within-subject comparison and assessment of the stability of key variables to be made (Lynn, 2009; Rajulton, 2001).

One common problem with longitudinal research is sample attrition (Lynn, 2009; Twisk & De Vente, 2002). This may be more problematic with a chronic health sample where repeated measurement may be more burdensome. Effort was made to reduce the

burden on participants and the low attrition rate in this study suggests that the study was acceptable to participants. A strength was that the sample size was large for both time-points, indicating that the study was adequately powered.

A potential limitation was the focus on PCF rather than objective performance. While the PDQ is considered a good measure of PCF, it does not have strong associations with objective neuropsychological tests (Fisk et al., 1994), limiting the conclusions about associations between self-compassion and cognitive function to perceived rather than actual functioning. PCF was examined in this study since it appears to be influenced by psychosocial factors such as fatigue, disability and mood compared to objective performance (Middleton et al., 2006). It was felt that self-compassion may play a role in understanding this phenomenon in MS. Future research examining whether self-compassion plays a role in objective neuropsychological performance would be helpful to determine the extent to which self-compassion is beneficial for cognitive functioning in MS.

An alternative analytic method for this study was structural equation modelling (SEM); SEM involves testing theoretical models of observed and latent variables (Lomax & Schumacker, 2004). Little difference has however been demonstrated between mediation effects using the PROCESS macro versus SEM when models focus on observed variables (Hayes, Montoya, & Rockwood, 2017). Mediation analysis via PROCESS was chosen for this study on this basis, however future research in this area may benefit from exploring latent variables using more complex analytical methods such as SEM.

Future directions

There are some important points for future research raised by this study. Firstly, the findings should be replicated since this study was the first to investigate relationships

between self-compassion and cognitive functioning. Further assessment of change in these variables may be of interest; utilising a design with a longer period of assessment (e.g. 6 months+) as utilised by Sirois and Hirsch (2013), with an arthritis population, may be suitable to investigate this. Finally, as self-compassion has a positive impact on adjustment, it would be important to understand what factors predict increased self-compassion in MS.

Clinical implications

This study has important clinical implications; in keeping with findings by Nery-Hurwit et al., (2018) self-compassion appears to be beneficial for adjustment in MS. Psychological therapies that facilitate cultivation of self-compassion could therefore be helpful for pwMS. Third-wave psychological therapies such as Compassion-Focused Therapy (CFT; Gilbert, 2009), Acceptance and Commitment Therapy (ACT; Hayes, 2004) and Mindfulness-Based Stress Reduction (MBSR; Kabat-Zinn, 1990) place the self-compassion at the heart of their models. Rather than a focus on treating negative symptoms, the emphasis is on living well and compassionately despite difficult experiences. Preliminary evidence suggests that MBSR has a significant positive effect on anxiety, depression, fatigue, pain and QoL (Bogosian et al., 2015; Grossman et al., 2010) and on self-compassion and some aspects of cognitive functioning in MS (Blankespoor, Schellekens, Vos, Speckens, & de Jong, 2017). Future research aimed at assessing the efficacy of these interventions for pwMS using randomised designs would therefore be beneficial. Finally, in terms of clinical practice, self-compassion should be explored by professionals as part of assessment, formulation, consultation and intervention for people with MS.

Conclusions

This study was the first to explore the role of self-compassion for PCF in MS. Self-compassion was predictive of stress and coping efficacy cross-sectionally and prospectively. While self-compassion did not directly predict PCF, stress mediated the relationship between these variables both cross-sectionally and over time. This suggests that self-compassion plays a significant role in reducing perceived cognitive dysfunction through a negative relationship with stress in MS. The findings support and extend previous research in MS and other chronic illness populations that self-compassion is beneficial for adjustment by highlighting that self-compassion may in fact affect how pwMS experience their symptoms, including cognitive difficulties. Future research should focus on identifying factors that predict self-compassion in MS and on exploring psychological interventions that cultivate self-compassion to support people through the adjustment process.

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Appendix A: Email to MS charities and organisations

To whom it may concern,

My name is Sophie Day, and I am a Trainee Clinical Psychologist at the University of Sheffield (United Kingdom). I am currently conducting my doctoral research project investigating the role of self-perceptions in adjustment to multiple sclerosis (MS).

The quality of this project has been reviewed and approved by the University of Sheffield's Research Ethics Committee.

I would be delighted if you could kindly disseminate my research invitation to members of your charity/organisation/group either by newsletters or by adding a link to your webpage or social media platforms. Please see attached documents for Twitter and Facebook posts I kindly ask you to post.

Participation will be voluntary. Participants will be asked to complete a series of questionnaires at two time-points (6 weeks apart). The questionnaires will take roughly 20 minutes to complete at each time point. Following completion of the second set of questionnaires, participants will be entered into a prize draw to win a £50 (or currency equivalent) Amazon voucher. Participants email addresses will be used to match their responses at the two time-points, once their responses are matched their email address will be deleted from the data set so their responses will be anonymous. The email addresses will be stored separately and securely to complete the prize draw, following which they will be deleted completely.

Please see the attached participants' information sheet, advertisements, social media posts and confirmation of ethical approval from my university (including some emails confirming approval from the ethics committee following minor amendments to the study).

Please let me know if you require any further information. I look forward to hearing from you.

Kind regards

Sophie Day
Trainee Clinical Psychologist

Appendix B: Study adverts

Multiple sclerosis research study

Participants wanted – investigating the role of self-perceptions in adjustment to multiple sclerosis.

We are inviting individuals with multiple sclerosis (MS) to take part in a study looking at the role of self-perceptions in adjustment to MS. Some of the topics discussed in the questionnaires include current experiences of stress, the impact of MS on various areas of life, your self-perceptions, and perceived ability to cope with the difficulties associated with MS.

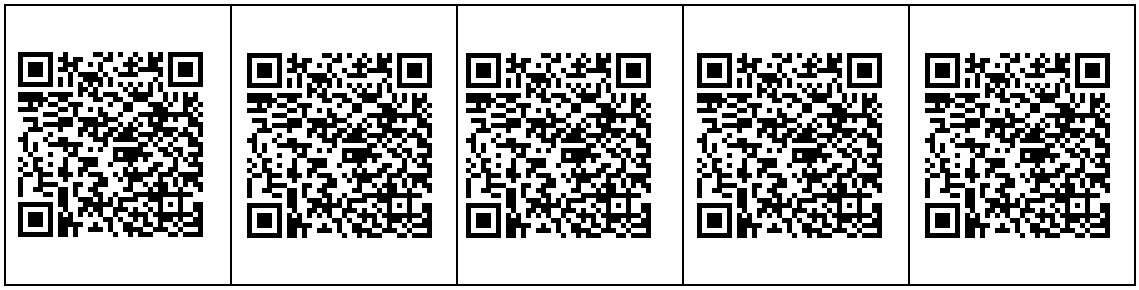
The study consists of two parts and requires you to complete a questionnaire at two time-points. By following the link below, you will be directed to a series of questionnaires, which should take no longer than 20 minutes to complete. You will be invited to complete the second part six weeks following the first questionnaire.

Upon completion of the second part of the study, you will be entered into a prize draw to win a £50 Amazon voucher or equivalent in your currency. The prize draw will take place in June 2019.

If you are interested in taking part, please take one of the tabs below and use your smartphone to scan the QR code to access the study link. Alternatively, copy the link below.

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2mhOHHns0hHCY1n

QR code



Facebook

Participants wanted – investigating the role of self-perceptions in adjustment to multiple sclerosis.

We are inviting individuals with multiple sclerosis (MS) to take part in a study looking at the role of self-perceptions in adjustment to MS. Some of the topics discussed in the questionnaires include current experiences of stress, the impact of MS on various areas of life, your self-perceptions, and perceived ability to cope with the difficulties associated with MS.

The study consists of two parts and requires you to complete a questionnaire at two time-points. By following the link below, you will be directed to a series of questionnaires, which should take no longer than 20 minutes to complete. You will be invited to complete the second part six weeks following the first questionnaire.

Upon completion of the second part of the study, you will be entered into a prize draw to win a £50 Amazon voucher or equivalent in your currency. The prize draw will take place in June 2019.

If you are interested in taking part, please click the link below:

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2mhOHHns0hHCY1n

Twitter

PARTICIPANTS WANTED: Investigating the role of self-perceptions in adjustment to MS (https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2mhOHHns0hHCY1n).

Appendix C: Time 1 participant information sheet

Investigating the role of self-perceptions in adjustment to multiple sclerosis

Thank you for your interest in this survey. Please read the information carefully before continuing.

We are investigating the role of self-perceptions in adjustment to multiple sclerosis (MS). By following the link, you will be asked to complete a questionnaire about these topics. The study consists of two parts; you will be asked to complete the second part six weeks after the first part. Each part should take no longer than 20 minutes to complete. After the second questionnaire, you will be entered into a prize draw to win a £50 (or equivalent currency) Amazon voucher.

Your participation in this study is voluntary and you have the right to withdraw from the study at any time up to one week after completing the second part of the study by contacting the researcher. You can also withdraw before submitting your responses by closing your Internet browser.

Only the research team will have access your responses. Your email address will be required to match your responses in part 1 and 2 but this will be stored securely, and your responses will be made anonymous by deleting your email address from the data file once they are matched. Email addresses will be kept separately from the data until the prize draw has been completed and the winner contacted, at which point all email addresses and therefore identifying information will be deleted.

The results of the study will be written up and submitted as a doctoral thesis as part of the Clinical Psychology Doctorate (DClinPsy) at the University of Sheffield. Additionally, the study will be submitted for publication in a scientific journal. Information regarding individual participants will not be included and you will not be identifiable from any reports or publications of the study. The anonymised data will not be destroyed, and it is possible it will be made available to other researchers (e.g. via the Open Science Framework or alongside any peer-reviewed papers that arise as a result of the research).

The study was reviewed and approved by the University of Sheffield Research Ethics Committee. Some of the topics discussed in the questionnaire may be distressing as they ask about current and past experiences and feelings. Contact information for listening and support services will be provided at the end of the study.

If you have any questions or concerns with respect to this study, please do not hesitate to get in touch using the contact information below:

Sophie Day (Trainee Clinical Psychologist) – sday3@sheffield.ac.uk
Fuschia Sirois (Research supervisor) – f.sirois@sheffield.ac.uk
Georgina Rowse (Research co-supervisor) – g.rowse@sheffield.ac.uk

Thank you for taking the time to read this information and for providing your support with this study. Please do not hesitate to contact me if you have any queries or comments.

Appendix D: Consent form

I agree to participate in this study, and I have made this decision based on the information I have received about it.

Please click the "I agree" box below to indicate that you:

- Have read the information page and understand its contents.
- Confirm that you are over 18 years of age.
- Note that your data will be identifiable by your email address until your responses from Time 1 and Time 2 have been matched, at which point your email address will be deleted from the data file and it will be anonymous.
- Understand that the issues addressed in this study may be somewhat distressing.
- Understand that you have a right to withdraw from the research at any time up to one week after completing the questionnaires at Time 2 and you do not have to provide a reason.
- Understand that if you withdraw from the research any data included in the results will be removed where possible (You understand that once anonymous data has been collated into other data sets it may not be possible to remove that data).
- Understand that your data will be kept securely and confidentially, and agree to your data being used for future reports or publications
- Understand that anonymised data will not be destroyed and it is possible it will be made available to other researchers (e.g. via the Open Science Framework or alongside any peer-reviewed papers that arise as a result of the research).
- Confirm that you are willing to be a participant in the above research study.
- Agree to being contacted again by email in six weeks time to complete the second part of the study.

Do you wish to continue? To acknowledge that you have read and understood this information and would like to continue with the research study, please click on "I agree".

I agree **No, thank you**

Appendix E: Time 1 questionnaire including demographics

Please complete the following demographic information:

Country of residence:

- Australia
- Canada
- Ireland
- New Zealand
- United Kingdom
- United States of America
- Other _____

Age: ____

Gender:

- Male
- Female
- Other: _____

Ethnicity:

Choose one or more races that you consider yourself to be:

- White
- Black or African American
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Pacific Islander
- Other

What is your first language? _____

Relationship status (please check the one that applies best to you):

- Married/living with an intimate partner____
- Never married ____
- Separated/divorced_____
- Widowed_____

- Other: _____

Employment status:

- Full-time_____
- Part-time_____
- Currently unemployed_____
- Unable to work due to health condition_____
- Retired_____

Highest level of education:

- Some high school_____
- High school graduate_____
- Some college but no degree_____
- Associate degree in college (2-year)_____
- Bachelor's degree in college/university (3 or 4-years)_____
- Master's degree_____
- Doctoral degree_____
- Professional degree (JD or MD)_____

Please provide any other important information related to your current life circumstances:

Some examples may include: Being a parent (please state the age and number of children); age of retirement; whether you receive benefits due to your health condition.

Other information:

Please indicate what type of electronic device was used to complete the study:

- Desktop computer or laptop
- Tablet or iPad
- Smartphone

Please tell us how you heard about this study:

- Online advert by MS organisation
- Professional
- Social media
- Friends, family or colleagues
- Other_____

MS related information

When were you diagnosed with MS?
DD/MM/YYYY

What category does your MS currently fall into?

- Relapsing subtype (e.g. RRMS) – characterised by periods of active disease (relapse) and partial or complete remission (remitting).
- Progressive subtype (e.g. Primary progressive MS, PPMS; Secondary progressive MS, SPMS; or Progressive relapsing MS, PRMS)
    - o PPMS is characterised by symptoms progressively deteriorating from the beginning.
    - o SPMS usually follows from RRMS and is characterised by a current pattern of progressive deterioration, in the absence of previous experienced episodes and relapses and remissions.
    - o PRMS is characterised by symptoms progressively deteriorating from the beginning, plus addition relapses with symptoms significantly deteriorating on top.

Do you take medication due to MS?

Yes No

If yes, please list the medication that you take:

Impact on daily living:

To what extent does multiple sclerosis affect my daily activities?

Not at all 1	2	3	**A lot** 4

Self-compassion Scale – Short Form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. When reading each statement, think about how you act toward yourself. To the right of each item, indicate how often you behave in the stated manner, using the following scale.

1	2	3	4	5
ALMOST NEVER	**OCCASIONALLY**	**ABOUT HALF OF THE TIME**	**FAIRLY OFTEN**	**ALMOST ALWAYS**

1) When I fail at something important to me I become consumed by feelings of inadequacy.	1 2 3 4 5
2) I try to be understanding and patient towards those aspects of my personality I don't like.	1 2 3 4 5
3) When something painful happens I try to take a balanced view of the situation.	1 2 3 4 5
4) When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1 2 3 4 5
5) I try to see my failings as part of the human condition.	1 2 3 4 5
6) When I'm going through a very hard time, I give myself the caring and tenderness I need.	1 2 3 4 5
7) When something upsets me I try to keep my emotions in balance.	1 2 3 4 5
8) When I fail at something that's important to me, I tend to feel alone in my failure	1 2 3 4 5
9) When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1 2 3 4 5
10) When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1 2 3 4 5
11) I'm disapproving and judgmental about my own flaws and inadequacies.	1 2 3 4 5
12) I'm intolerant and impatient towards those aspects of my personality I don't like.	1 2 3 4 5

Coping Efficacy (Gignac, Cott, & Badley, 2000)

Instructions

These following items are about one's experience of coping with multiple sclerosis (MS). Please read the following items carefully before answering. Please rated each item using the scale below:

	Strongly disagree				**Strongly agree**
1. I am successfully coping with the symptoms of my MS	1	2	3	4	5
2. I am successfully coping with the emotional aspects of my MS	1	2	3	4	5
3. I am successfully coping with the day-to-day problems of my MS	1	2	3	4	5

Perceived stress Scale (PSS; Cohen & Williamson, 1988)

Instructions

The following questions ask you about your thoughts and feelings during the past month. Please read each item carefully before answering. In each case, please indicate how often you felt or thought a certain way using the scale below:

	Never	**Almost never**	**Sometimes**	**Fairly often**	**Very often**
1. In the past month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the past month, how often have you felt unable to control the important things in your life?	0	1	2	3	4
3. In the past month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the past month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the past month, how often have you felt that things were going you way?	0	1	2	3	4
6. In the past month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the past month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the past month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the past month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the past month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Functional Assessment of Multiple Sclerosis (FAMS; Cella et al., 1996)
Three subscales: Symptoms, Emotional Well-being, and General Contentment

***** copy of FAMS measures removed in line with copyright legislation***

***** copy of FAMS measures removed in line with copyright legislation***

Modified Fatigue Impact Scale – 5-item version (MFIS-5; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994b)

Instructions

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then **select the one number** that best indicates how often fatigue has affected you in this way during **the past 4 weeks. Please answer every question.** If you are not sure which answer to select, please choose the one answer that comes closest to describing you.

Because of my fatigue
During the past 4 weeks…

	Never	**Rarely**	**Sometimes**	**Often**	**Almost always**
1. I have been less alert	0	1	2	3	4
2. I have been limited in my ability to do things away from home.	0	1	2	3	4
3. I have had trouble maintaining physical effort for long periods.	0	1	2	3	4
4. I have been less able to complete tasks that require physical effort.	0	1	2	3	4
5. I have had trouble concentrating	0	1	2	3	4

Perceived Deficits Questionnaire – 5-item version (PDQ-5; Sullivan, Edgley, & Dehoux, 1990)

Instructions

Everyone at some point experiences problems with memory, attention, or concentration, but these problems may occur more frequently for individuals with neurologic diseases like MS. The following questions describe several situations in which a person may encounter problems with memory, attention or concentration. Please select the appropriate response (0, 1, 2,...) based on your cognitive function during the **past 4 weeks**. **Please answer every question.** If you are not sure which answer to select, please choose the one answer that comes closest to describing you.

During the past 4 weeks,
how often did you....

	Never	**Rarely**	**Sometimes**	**Often**	**Almost always**
1. Have trouble getting things organised?	0	1	2	3	4
2. Have trouble concentrating on things like watching a television programme or reading a book?	0	1	2	3	4
3. Forget the date unless you looked it up?	0	1	2	3	4
4. Forget what you talked about after a telephone conversation?	0	1	2	3	4
5. Feel like your mind went totally blank?	0	1	2	3	4

Everyday Memory Questionnaire-Revised (EMQ-R; Royle & Lincoln, 2008)

Instructions
Below are listed some examples of things that happen to people in everyday life. Some of them may happen frequently and some may happen rarely. We should like to know how often on average you think each one has happened to you over the **past month**. Please select the most appropriate item which describes you over the **past month**.

	Once or less in the past month	**More than once a month but less than once a week**	**About once a week**	**More than once a week or less than once a day**	**Once or more in a day**
1. Having to check whether you have done something that you should have done	0	1	2	3	4
2. Forgetting when it was that something happened; for example, whether it was yesterday or last week.	0	1	2	3	4
3. Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.	0	1	2	3	4
4. Starting to read something (a book or an article in a newspaper, or a magazine) without realizing you have already read it before.	0	1	2	3	4
5. Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.	0	1	2	3	4
6. Completely forgetting to do things you said you would do, and things you planned to do.	0	1	2	3	4
7. Forgetting important details of what you did or what happened to you the day before.	0	1	2	3	4

8. When talking to someone, forgetting what you have just said. Maybe saying 'what was I talking about?'	0	1	2	3	4
9. When reading a newspaper or magazine, being unable to follow the thread of a story; losing track of what it is about.	0	1	2	3	4
10. Forgetting to tell somebody something important, perhaps forgetting to pass on a message or remind someone of something.	0	1	2	3	4
11. Getting the details of what someone was told you mixed up and confused.	0	1	2	3	4
12. Forgetting where things are normally kept or looking for them in the wrong place.	0	1	2	3	4
13. Repeating to someone what you have just told them or asking someone the same question twice.	0	1	2	3	4

Attentional Control Scale (ACS; Derryberry & Reed, 2002)

Instructions
This questionnaire consists of 20 statements. Please indicate to what extent each statement applies to you. Do this by selecting one of the numbers. There are no right or wrong answers.

	Almost never	**Sometimes**	**Often**	**Always**
It's very hard for me to concentrate on a difficult task when there are noises around. (R*)	1	2	3	4
When I need to concentrate and solve a problem, I have trouble focusing my attention. (R)	1	2	3	4
When I am working hard on something, I still get distracted by events around me. (R)	1	2	3	4
My concentration is good even if there is music in the room around me.	1	2	3	4
When concentrating, I can focus my attention so that I become unaware of what's going on in the room around me.	1	2	3	4
When I am reading or studying, I am easily distracted if there are people talking in the same room. (R)	1	2	3	4
When trying to focus my attention on something, I have difficulty blocking out distracting thoughts. (R)	1	2	3	4
I have a hard time concentrating when I'm excited about something. (R)	1	2	3	4
When concentrating I ignore feelings of hunger or thirst.	1	2	3	4
I can quickly switch from one task to another.	1	2	3	4
It takes me a while to get really involved in a new task. (R)	1	2	3	4

It is difficult for me to coordinate my attention between the listening and writing required when taking notes during lectures. (R)	1	2	3	4
I can become interested in a new topic very quickly when I need to.	1	2	3	4
It is easy for me to read or write while I'm also talking on the phone.	1	2	3	4
I have trouble carrying on two conversations at once. (R)	1	2	3	4
I have a hard time coming up with new ideas quickly. (R)	1	2	3	4
After being interrupted or distracted, I can easily shift my attention back to what I was doing before.	1	2	3	4
When a distracting thought comes to mind, it is easy for me to shift my attention away from it.	1	2	3	4
It is easy for me to alternate between two different tasks.	1	2	3	4
It is hard for me to break from one way of thinking about something and look at it from another point of view. (R)	1	2	3	4

*(R) indicates reverse items and won't be visible to participants

Appendix F: Resource sheet

End of part 1:

Thank you very much for taking the time to complete the first questionnaire.

We hope you have found the experience useful and interesting so far. We will contact you again in six weeks time to ask you to complete the second questionnaire.

If you have any questions or concerns about the study, please get in touch using the contacts below. If you have experienced any emotional or psychological distress as a result of the issues raised you can contact the relevant services listening, support, and healthcare provider services highlighted below:

[UK examples]

- **Samaritans -** 116 123 (UK; available 24 hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress. Alternatively, you can email: jo@samaritans.org.
- **UK MS Society.** 0808 800 8000 **(**Monday to Friday, 9:00am to 7:00pm, excluding bank holidays) for information or emotional support for anyone living with MS. This helpline is available). The helpline is free from UK landline and mobile numbers. The service is confidential. Alternatively, you can email: helpline@mssociety.org.uk.
- Your GP or healthcare provider.

Please remember that if you wish to withdraw your data at a later data, you can do so by emailing the researcher and confirming your email address used to register responses. You can withdraw your data up to one week after completing the second part of the study (in six weeks time).

Contacts

If you have any questions or concerns with respect to this study, or wish to withdraw your data from the study please contact:

- Sophie Day (Trainee Clinical Psychologist)
- Email: sday3@sheffield.ac.uk

Furthermore, you can contact the researchers supervising this project in the first instance:

- Fuschia M. Sirois, PhD. (f.sirois@sheffield.ac.uk) - Psychology Department, University of Sheffield.
- Dr Georgina Rowse (g.rowse@sheffield.ac.uk) - Clinical Psychology Unit, Psychology Department, University of Sheffield.

If you do not feel satisfied with the response, you can contact the research support officer:

- Amrit Sinha (a.sinha@sheffield.ac.uk) - Clinical Psychology Unit, Psychology Department, University of Sheffield.

If you know another person who fits the inclusion criteria* for this study and would like to take part in this study, please feel free to share this link with them:

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2mhOHHns0hHCY1n

***Inclusion criteria:**

Individuals with a diagnosis of Multiple Sclerosis over 18 years of age who can read and write in English and who currently reside in one of the following countries Australia, Canada, Ireland New Zealand, United Kingdom, and United States of America.

Appendix G: Contacts for listening services

United Kingdom

- **Samaritans -** 116 123 (UK; available 24 hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress. Alternatively, you can email: jo@samaritans.org.
- **UK MS Society.** 0808 800 8000 **(**Monday to Friday, 9:00am to 7:00pm, excluding bank holidays) for information or emotional support for anyone living with MS. This helpline is available). The helpline is free from UK landline and mobile numbers. The service is confidential. Alternatively, you can email: helpline@mssociety.org.uk.
- Your GP or healthcare provider.

Wales

- **Samaritans -** 116 123 (UK; available **24** hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress. Alternatively, you can email: jo@samaritans.org.
  Welsh language line: 0808 164 0123 (7pm-11pm, 7 days a week)
- **UK MS Society.** 0808 800 8000 **(**Monday to Friday, 9:00am to 7:00pm, excluding bank holidays) for information or emotional support for anyone living with MS. This helpline is available). The helpline is free from UK landline and mobile numbers. The service is confidential. Alternatively, you can email: helpline@mssociety.org.uk.
- Your GP or healthcare provider.

Australia

- **Australia Samaritans –** 135 247 (available 24 hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress. Alternatively, you can email: **support@thesamaritans.org.au**
- **Lifeline Australia –** 1-300-13-11-14
- **MS Connect through MS Australia –** 1800 042 138 (8:30am-5:00pm, Monday to Friday)

- Your GP or healthcare provider.

Canada

- **Suicide prevention –** www.suicideprevention.ca/need-help. Click the link for local crisis centres and telephone numbers for Canadian services
- **MS Society of Canada** – 1-800-268-7582 (National office) or 1-844-859-6789 (MS Navigator)
- Your GP or healthcare provider.

New Zealand

- **Samaritans –** 0800 726 666 or www.samaritans.org.nz - available **24** hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress.
- **LifeLine NZ** – 09-5222-999 (within Auckland) or 0800-543-354 (outside Auckland)
- **MS New Zealand –** MS Line (0800 MS LINE or 0800 675 463); +64 4 499 4677
- Your GP or healthcare provider.

Ireland

- **Samaritans –** 1850 60 90 90 (available **24** hours a day, 365 days a year) for advice and support. They provide confidential support for anyone experiencing any kind of emotional or psychological distress.
- **1Life –** 1 800 247 100 or text HELP to 51444
- **MS Ireland –** MS Information Line – 1850 233233 or email info@ms-society.ie
- Your GP or healthcare provider.

United States of America

- **National Hopeline Helpline –** 1-800-SUICIDE or 1-800-784-2433
- **National Suicide Prevention Lifeline –** 1-800-273-8255
- **National Multiple Sclerosis Society –** 1-800-344-4867

Appendix H: Email invite for Time 2

Subject: MS research study (Part 2) – Investigating adjustment to MS

Good morning,

Many thanks for agreeing to participate in this study investigating self-perceptions in adjustment to multiple sclerosis. I would be very grateful if you would complete the second part of the study now by clicking on the link below.

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_b7AHTohLQrQj9UF

After completing this follow-up survey, you will be entered into a prize draw to win a £50 (or equivalent currency) Amazon voucher.

Thank you again for your time and responses, it is very much appreciated!

Best wishes

Sophie Day
Trainee Clinical Psychologist

Appendix I: Reminder emails for Time 2

Subject: MS research study (Part 2) REMINDER – Investigating adjustment to MS

Good morning,

Many thanks for agreeing to participate in this study investigating self-perceptions in adjustment to multiple sclerosis. This is a friendly prompt to complete the follow-up survey now by clicking on the link below.

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_b7AHTohLQrQj9UF

After completing this follow-up survey, you will be entered into a prize draw to win a £50 Amazon voucher (or equivalent currency).

Thank you again for your time and responses, it is very much appreciated!

Best wishes

Sophie Day
Trainee Clinical Psychologist

Subject: MS research study (Part 2) FINAL REMINDER – Investigating adjustment to MS

Good morning,

Many thanks for agreeing to participate in this study investigating self-perceptions in adjustment to multiple sclerosis. This is a friendly **final** reminder to complete the follow-up survey now by clicking on the link below.

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_b7AHTohLQrQj9UF

After completing this follow-up survey, you will be entered into a prize draw to win a £50 Amazon voucher (or equivalent currency).

Thank you again for your time and responses, it is very much appreciated!

Best wishes

Sophie Day
Trainee Clinical Psychologist

Appendix J: Time 2 participant information sheet

The role of self-perceptions in adjustment to multiple sclerosis.

This is the second part of the study investigating the role of self-perceptions in adjustment to multiple sclerosis. The questionnaire should take no longer than 20 minutes to complete. You will be asked to enter your email address so that we can match your responses.

At the end, you will be entered into a prize draw to prize draw to win of a £50 Amazon Voucher or equivalent in your currency. The prize draw will take place and the winner will be announced in June 2019.

Thank you for your participation!

Sophie Day (Trainee Clinical Psychologist)
sday3@sheffield.ac.uk

Appendix K: Time 2 questionnaire

MS related information

Have there been any changes to your medication for MS since you completed the first part of this study?

Yes No

Impact on daily living:

To what extent does multiple sclerosis affect my daily activities?

Not at all 1	2	3	**A lot** 4

Self-compassion Scale – Short Form (SCS-SF; Raes, Pommier, Neff, & Van Gucht, 2011)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. When reading each statement, think about how you act toward yourself. To the right of each item, indicate how often you behave in the stated manner, using the following scale.

1	2	3	4	5
ALMOST NEVER	**OCCASIONALLY**	**ABOUT HALF OF THE TIME**	**FAIRLY OFTEN**	**ALMOST ALWAYS**

13) When I fail at something important to me I become consumed by feelings of inadequacy.	1 2 3 4 5
14) I try to be understanding and patient towards those aspects of my personality I don't like.	1 2 3 4 5
15) When something painful happens I try to take a balanced view of the situation.	1 2 3 4 5
16) When I'm feeling down, I tend to feel like most other people are probably happier than I am.	1 2 3 4 5
17) I try to see my failings as part of the human condition.	1 2 3 4 5
18) When I'm going through a very hard time, I give myself the caring and tenderness I need.	1 2 3 4 5
19) When something upsets me I try to keep my emotions in balance.	1 2 3 4 5
20) When I fail at something that's important to me, I tend to feel alone in my failure	1 2 3 4 5
21) When I'm feeling down I tend to obsess and fixate on everything that's wrong.	1 2 3 4 5
22) When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.	1 2 3 4 5
23) I'm disapproving and judgmental about my own flaws and inadequacies.	1 2 3 4 5
24) I'm intolerant and impatient towards those aspects of my personality I don't like.	1 2 3 4 5

Coping Efficacy (Gignac, Cott, & Badley, 2000)

Instructions

These following items are about one's experience of coping with multiple sclerosis (MS). Please read the following items carefully before answering. Please rated each item using the scale below:

	Strongly disagree				**Strongly agree**
1. I am successfully coping with the symptoms of my MS	1	2	3	4	5
2. I am successfully coping with the emotional aspects of my MS	1	2	3	4	5
3. I am successfully coping with the day-to-day problems of my MS	1	2	3	4	5

Perceived stress Scale (PSS; Cohen & Williamson, 1988)

Instructions

The following questions ask you about your thoughts and feelings during the past month. Please read each item carefully before answering. In each case, please indicate how often you felt or thought a certain way using the scale below:

	Never	Almost never	Sometimes	Fairly often	Very often
1. In the past month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the past month, how often have you felt unable to control the important things in your life?	0	1	2	3	4
3. In the past month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the past month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the past month, how often have you felt that things were going you way?	0	1	2	3	4
6. In the past month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the past month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the past month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the past month, how often have you been angered because of things that were outside of your control?	0	1	2	3	4
10. In the past month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

Functional Assessment of Multiple Sclerosis (FAMS; Cella et al., 1996)
Three subscales: Symptoms, Emotional Well-being, and General Contentment

***** copy of FAMS measures removed in line with copyright legislation***

***** copy of FAMS measures removed in line with copyright legislation***

Modified Fatigue Impact Scale – 5-item version (MFIS-5; Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994b)

Instructions

Following is a list of statements that describe how fatigue may affect a person. Fatigue is a feeling of physical tiredness and lack of energy that many people experience from time to time. In medical conditions like MS, feelings of fatigue can occur more often and have a greater impact than usual. Please read each statement carefully, and then **select the one number** that best indicates how often fatigue has affected you in this way during **the past 4 weeks. Please answer every question.** If you are not sure which answer to select, please choose the one answer that comes closest to describing you.

Because of my fatigue
During the past 4 weeks…

	Never	**Rarely**	**Sometimes**	**Often**	**Almost always**
1. I have been less alert	0	1	2	3	4
2. I have been limited in my ability to do things away from home.	0	1	2	3	4
3. I have had trouble maintaining physical effort for long periods.	0	1	2	3	4
4. I have been less able to complete tasks that require physical effort.	0	1	2	3	4
5. I have had trouble concentrating	0	1	2	3	4

Perceived Deficits Questionnaire – 5-item version (PDQ-5; Sullivan, Edgley, & Dehoux, 1990)

Instructions

Everyone at some point experiences problems with memory, attention, or concentration, but these problems may occur more frequently for individuals with neurologic diseases like MS. The following questions describe several situations in which a person may encounter problems with memory, attention or concentration. Please select the appropriate response (0, 1, 2,...) based on your cognitive function during the **past 4 weeks**. **Please answer every question.** If you are not sure which answer to select, please choose the one answer that comes closest to describing you.

During the past 4 weeks,
how often did you....

	Never	**Rarely**	**Sometimes**	**Often**	**Almost always**
1. Have trouble getting things organised?	0	1	2	3	4
2. Have trouble concentrating on things like watching a television programme or reading a book?	0	1	2	3	4
3. Forget the date unless you looked it up?	0	1	2	3	4
4. Forget what you talked about after a telephone conversation?	0	1	2	3	4
5. Feel like your mind went totally blank?	0	1	2	3	4

Everyday Memory Questionnaire-Revised (EMQ-R; Royle & Lincoln, 2008)

Instructions
Below are listed some examples of things that happen to people in everyday life. Some of them may happen frequently and some may happen rarely. We should like to know how often on average you think each one has happened to you over the **past month**. Please select the most appropriate item which describes you over the **past month**.

	Once or less in the past month	**More than once a month but less than once a week**	**About once a week**	**More than once a week or less than once a day**	**Once or more in a day**
1. Having to check whether you have done something that you should have done	0	1	2	3	4
2. Forgetting when it was that something happened; for example, whether it was yesterday or last week.	0	1	2	3	4
3. Forgetting that you were told something yesterday or a few days ago, and maybe having to be reminded about it.	0	1	2	3	4
4. Starting to read something (a book or an article in a newspaper, or a magazine) without realizing you have already read it before.	0	1	2	3	4
5. Finding that a word is 'on the tip of your tongue'. You know what it is but cannot quite find it.	0	1	2	3	4
6. Completely forgetting to do things you said you would do, and things you planned to do.	0	1	2	3	4
7. Forgetting important details of what you did or what happened to you the day before.	0	1	2	3	4

8. When talking to someone, forgetting what you have just said. Maybe saying 'what was I talking about?'	0	1	2	3	4
9. When reading a newspaper or magazine, being unable to follow the thread of a story; losing track of what it is about.	0	1	2	3	4
10. Forgetting to tell somebody something important, perhaps forgetting to pass on a message or remind someone of something.	0	1	2	3	4
11. Getting the details of what someone was told you mixed up and confused.	0	1	2	3	4
12. Forgetting where things are normally kept or looking for them in the wrong place.	0	1	2	3	4
13. Repeating to someone what you have just told them or asking someone the same question twice.	0	1	2	3	4

Attentional Control Scale (ACS; Derryberry & Reed, 2002)

Instructions
This questionnaire consists of 20 statements. Please indicate to what extent each statement applies to you. Do this by selecting one of the numbers. There are no right or wrong answers.

	Almost never	**Sometimes**	**Often**	**Always**
It's very hard for me to concentrate on a difficult task when there are noises around. (R*)	1	2	3	4
When I need to concentrate and solve a problem, I have trouble focusing my attention. (R)	1	2	3	4
When I am working hard on something, I still get distracted by events around me. (R)	1	2	3	4
My concentration is good even if there is music in the room around me.	1	2	3	4
When concentrating, I can focus my attention so that I become unaware of what's going on in the room around me.	1	2	3	4
When I am reading or studying, I am easily distracted if there are people talking in the same room. (R)	1	2	3	4
When trying to focus my attention on something, I have difficulty blocking out distracting thoughts. (R)	1	2	3	4
I have a hard time concentrating when I'm excited about something. (R)	1	2	3	4
When concentrating I ignore feelings of hunger or thirst.	1	2	3	4
I can quickly switch from one task to another.	1	2	3	4
It takes me a while to get really involved in a new task. (R)	1	2	3	4

It is difficult for me to coordinate my attention between the listening and writing required when taking notes during lectures. (R)	1	2	3	4
I can become interested in a new topic very quickly when I need to.	1	2	3	4
It is easy for me to read or write while I'm also talking on the phone.	1	2	3	4
I have trouble carrying on two conversations at once. (R)	1	2	3	4
I have a hard time coming up with new ideas quickly. (R)	1	2	3	4
After being interrupted or distracted, I can easily shift my attention back to what I was doing before.	1	2	3	4
When a distracting thought comes to mind, it is easy for me to shift my attention away from it.	1	2	3	4
It is easy for me to alternate between two different tasks.	1	2	3	4
It is hard for me to break from one way of thinking about something and look at it from another point of view. (R)	1	2	3	4

*(R) indicates reverse items and won't be visible to participants

Appendix L: Debriefing statement

Thank you very much for taking the time to complete both questionnaires!

We hope you have found this experience useful and interesting. The specific aims of the study are to investigate the impact of self-compassion on one's perceived ability to cope with multiple sclerosis, stress, quality of life, and cognitive functioning. This will help to inform development of support services for people with multiple sclerosis.

As a thank you for taking part in the study, you will be entered into a prize draw to win a £50 (or currency equivalent) Amazon voucher. We will contact you by email if you are the winner in June 2019.

None of your details will be identifiable from the results of the study. The research did not use deception. If you would like to receive a summary of the findings of the research, or have any questions or concerns about the study, please use the contact information below to get in touch. I will not contact you again.

If you have any questions or concerns about the study, please get in touch using the contacts below. If you have experienced any emotional or psychological distress as a result of the issues raised you can contact the relevant services listening, support, and healthcare provider services highlighted on the next page.

Please remember that if you wish to withdraw your data at a later date, you can do so by emailing the researcher and confirming your email address used to register responses. You can withdraw your data up to one week after completing the second part of the study.

Contacts
If you have any questions or concerns with respect to this study, or wish to withdraw your data from the study please contact:

- Sophie Day (Trainee Clinical Psychologist)
- Email: sday3@sheffield.ac.uk

Furthermore, you can contact the researchers supervising this project in the first instance:

- Fuschia M. Sirois, PhD. (f.sirois@sheffield.ac.uk) - Psychology Department, University of Sheffield.
- Dr Georgina Rowse (g.rowse@sheffield.ac.uk) - Clinical Psychology Unit, Psychology Department, University of Sheffield.

If you do not feel satisfied with the response, you can contact the research support officer:

- Amrit Sinha (a.sinha@sheffield.ac.uk) - Clinical Psychology Unit, Psychology Department, University of Sheffield.

If you know another person who fits the inclusion criteria* for this study and would like to take part in this study, please feel free to share this link with them:

https://sheffieldpsychology.eu.qualtrics.com/jfe/form/SV_2mhOHHns0hHCY1n

***Inclusion criteria:**
Individuals with a diagnosis of Multiple Sclerosis over 18 years of age who can read and write in English and who currently reside in one of the following countries Australia, Canada, Ireland, New Zealand, United Kingdom, and United States of America.

Appendix M: Ethical approval

Downloaded: 28/11/2017
Approved: 22/11/2017

Sophie Day
Registration number: 160124525
Psychology
Programme: Doctor of Clinical Psychology (DClinPsy)

Dear Sophie

PROJECT TITLE: The role of self-perceptions in adjustment to multiple sclerosis (MS).
APPLICATION: Reference Number 016928

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 22/11/2017 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 016928 (dated 21/11/2017).
- Participant information sheet 1037169 version 1 (14/11/2017).
- Participant information sheet 1037168 version 2 (21/11/2017).
- Participant consent form 1037170 version 2 (21/11/2017).

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.

Yours sincerely

Thomas Webb
Ethics Administrator
Psychology

Correspondence re: ethical approval amendments

Inbox x

Sophie Day <sday3@sheffield.ac.uk> Fri, 29 Dec 2017, 14:20
to Fuschia, Georgina, Thomas

Hi Tom

Please find attached the completed "Form for requesting an amendment", along with amended Questionnaire documentation (version 4) which includes the new questionnaires (in place of the Trail Making Task, TMT). Please let me know if you require any further information.

Best wishes

2 Attachments

Thomas Webb <t.webb@sheffield.ac.uk> Mon, 1 Jan, 06:24
to me, Fuschia, Georgina

Thanks for letting the committee know about these proposed changes Sophie.

I'm happy that including the Everyday Memory Questionnaire and Attentional Control Scale do not pose any additional ethical issues beyond those considered in your original proposal. I am therefore happy to approve these amendments as a Chair's action.

With best wishes for the New Year.

Tom

As Chair, DESC

Sophie Day <sday3@sheffield.ac.uk> Mon, 8 Jan, 14:57
to Thomas, Fuschia, Georgina

Many thanks Tom.

BW

Sophie Day <sday3@sheffield.ac.uk> Tue, 30 Jan, 18:01
to Thomas

Hi Tom

Apologies for another email about this, but my supervisors and I just realised we did not check the box to distribute to CiCS volunteer lists. This was an oversight. Do I need to do another

amendment for this?

Many thanks

Thomas L Webb <t.webb@sheffield.ac.uk> Tue, 30 Jan, 18:43
to me

Yes, sadly you will need to request another amendment if you want to change your proposed means of recruitment...

Tom

Sophie Day <sday3@sheffield.ac.uk> Thu, 1 Feb, 08:04
to Thomas

Hi Tom

Please find attached final amendments request form.

Kind regards

Attachments area

Thomas Webb <t.webb@sheffield.ac.uk> Thu, 1 Feb, 12:56
to me

Thanks Sophie - I'm happy to approve this minor change to your recruitment procedures as a Chair's action.

You may proceed with your research.

With best wishes,

Tom

--
Thomas Webb, PhD
Department of Psychology
The University of Sheffield
https://www.sheffield.ac.uk/psychology/staff/academic/thomas-webb

Students - you can book an appointment to meet with me via this link
http://bit.ly/2cGUY8N

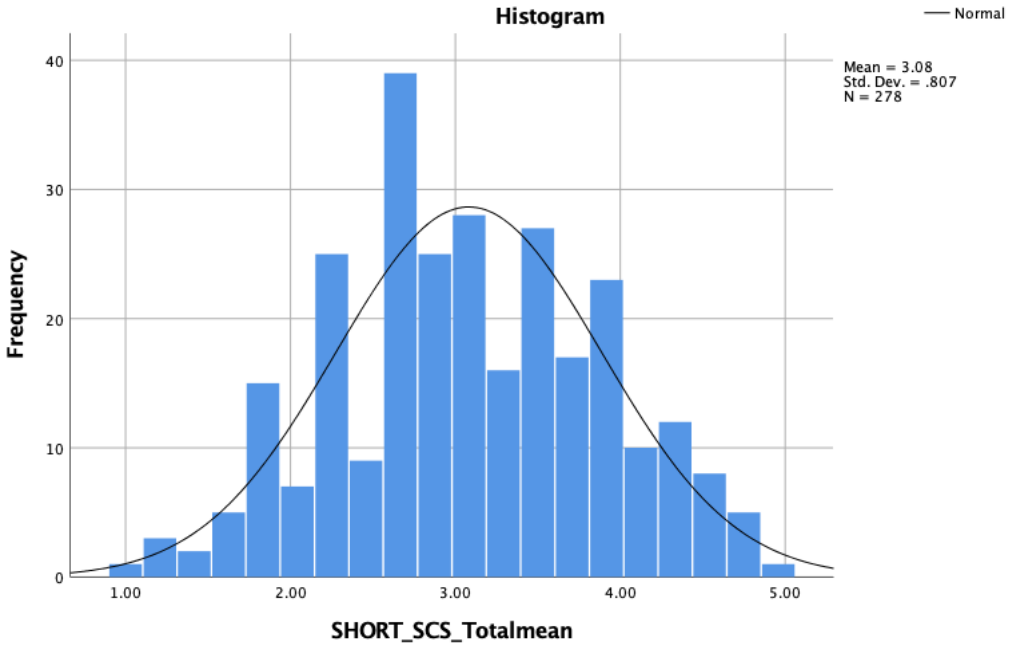
Appendix N: Summary of normality analyses

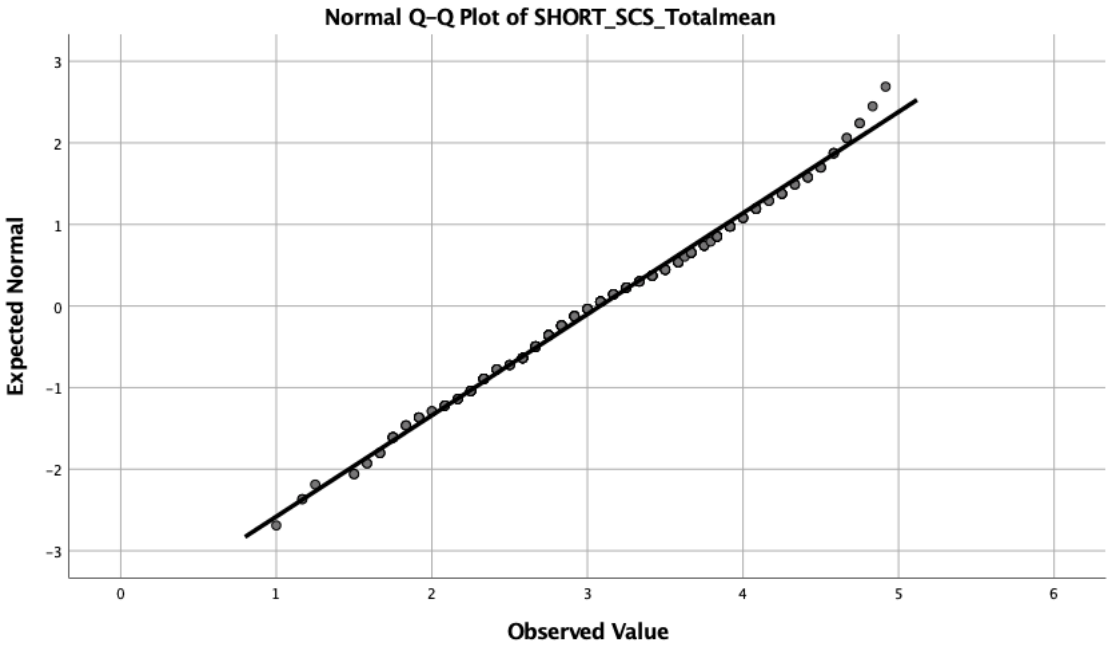
Table 5

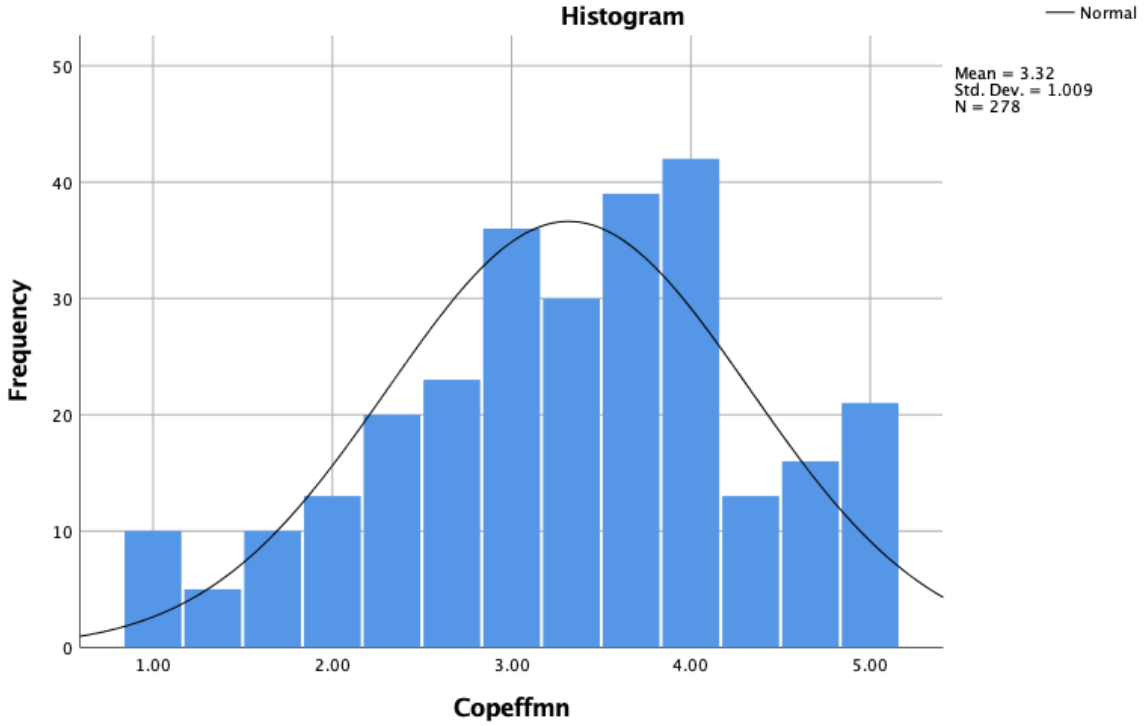
Summary of tests of normality (skewness, kurtosis and Kolmogorov-Smirnov test)

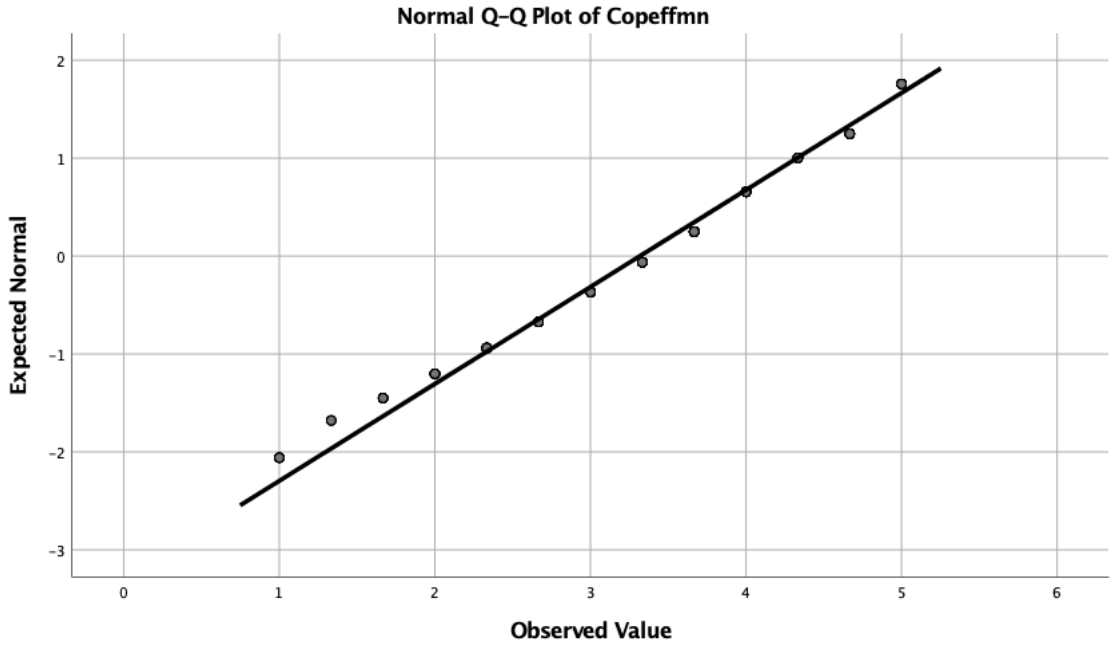
Variable	Skewness (SE)	Kurtosis (SE)	Kolmogorov-Smirnov's test
Age	0.014 (0.153)	-0.935 (0.306)	0.069**
Years since diagnosis	1.59 (0.146)	2.92 (0.292)	0.151**
Impact on daily life T1	-0.021 (0.146)	-1.038 (0.291)	0.233**
SCS T1	-0.012 (0.146)	-0.503 (0.291)	0.052
CE T1	-0.343 (0.146)	-0.377 (0.291)	0.106**
PSS T1	-0.133 (0.146)	-0.178 (0.291)	0.077**
FAMS-S T1	-0.469 (0.146)	-0.337 (0.291)	0.094**
FAMS-EWB T1	-0.640 (0.146)	-0.612 (0.291)	0.115**
FAMS-GC T1	-0.212 (0.146)	-0.702 (0.291)	0.068**
MFIS T1	-0.532 (0.146)	-0.117 (0.291)	0.089**
PDQ T1	0.09 (0.146)	-0.646 (0.291)	0.077**
EMQ T1	0.750 (0.146)	-0.211 (0.291)	0.107**
ACS T1	0.031 (0.146)	-0.538 (0.291)	0.044
Impact on daily life T2	0.254 (0.171)	-0.940 (0.341)	0.280**
SCS T2	0.002 (0.171)	-0.363 (0.341)	0.060
CE T2	-0.352 (0.171)	-0.343 (0.341)	0.107**
PSS T2	-0.056 (0.171)	0.031 (0.341)	0.061
FAMS-S T2	-0.430 (0.171)	-0.436 (0.341)	0.092**
FAMS-EWB T2	-0.672 (0.171)	-0.420 (0.341)	0.134**
FAMS-GC T2	-0.338 (0.171)	-0.702 (0.341)	0.091**
MFIS T2	-0.217 (0.171)	-0.447 (0.341)	0.084**
PDQ T2	0.104 (0.171)	-0.614 (0.341)	0.070*
EMQ T2	0.689 (0.171)	-0.415 (0.341)	0.123**
ACS T2	0.181 (0.171)	-0.148 (0.341)	0.077**

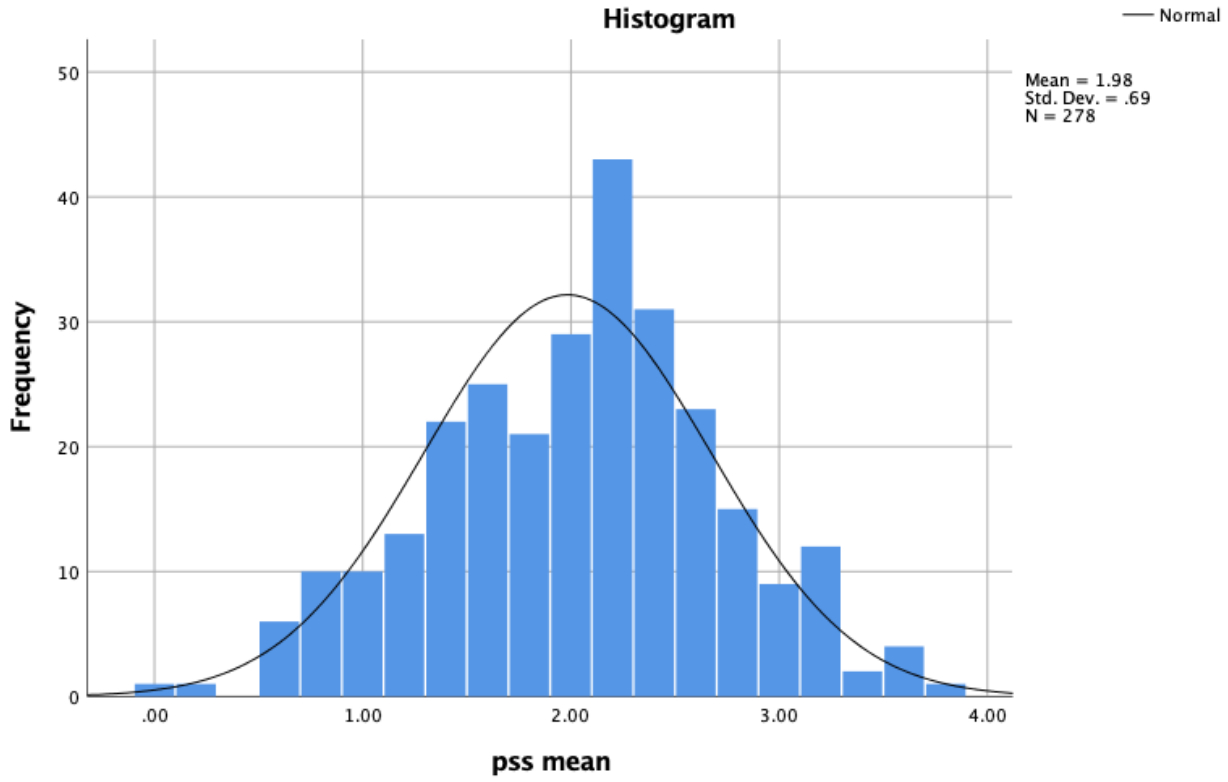
Notes: T1 = Time 1; T2 = Time 2; SD = Standard deviation; SE = Standard error; SCS = Self-compassion Scale; CE = Coping Efficacy; PSS = Perceived Stress Scale; FAMS-S = Functional Assessment of Multiple Sclerosis-Symptoms; FAMS-EWB = Functional Assessment of Multiple Sclerosis-Emotional Well-being; FAMS-GC = Functional Assessment of Multiple Sclerosis-General Contentment; MFIS-5 = Modified Fatigue Impact Scale-5; PDQ-5 = Perceived Difficulties Questionnaire-5; EMQ = Everyday Memory Questionnaire; ACS = Attentional Control Scale; $p<.05$*, $p<.01$**


Histogram
Normal
Mean = 3.08
Std. Dev. = .807
N = 278
Frequency
40
30
20
10
0
1.00
2.00
3.00
4.00
5.00
SHORT_SCS_Totalmean


Normal Q-Q Plot of SHORT_SCS_Totalmean
Expected Normal
3
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value


Histogram
Normal
Mean = 3.32
Std. Dev. = 1.009
N = 278
Frequency
50
40
30
20
10
0
1.00
2.00
3.00
4.00
5.00
Copeffmn


Normal Q-Q Plot of Copeffmn
Expected Normal
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value


Histogram
Normal
Mean = 1.98
Std. Dev. = .69
N = 278
Frequency
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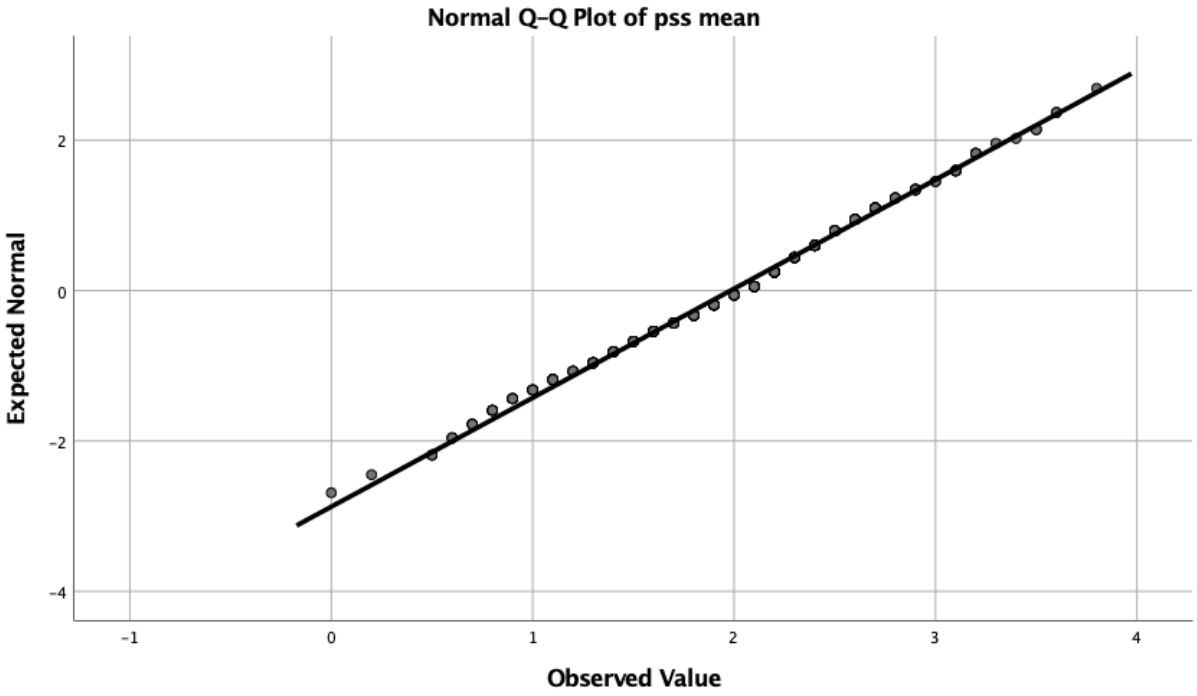
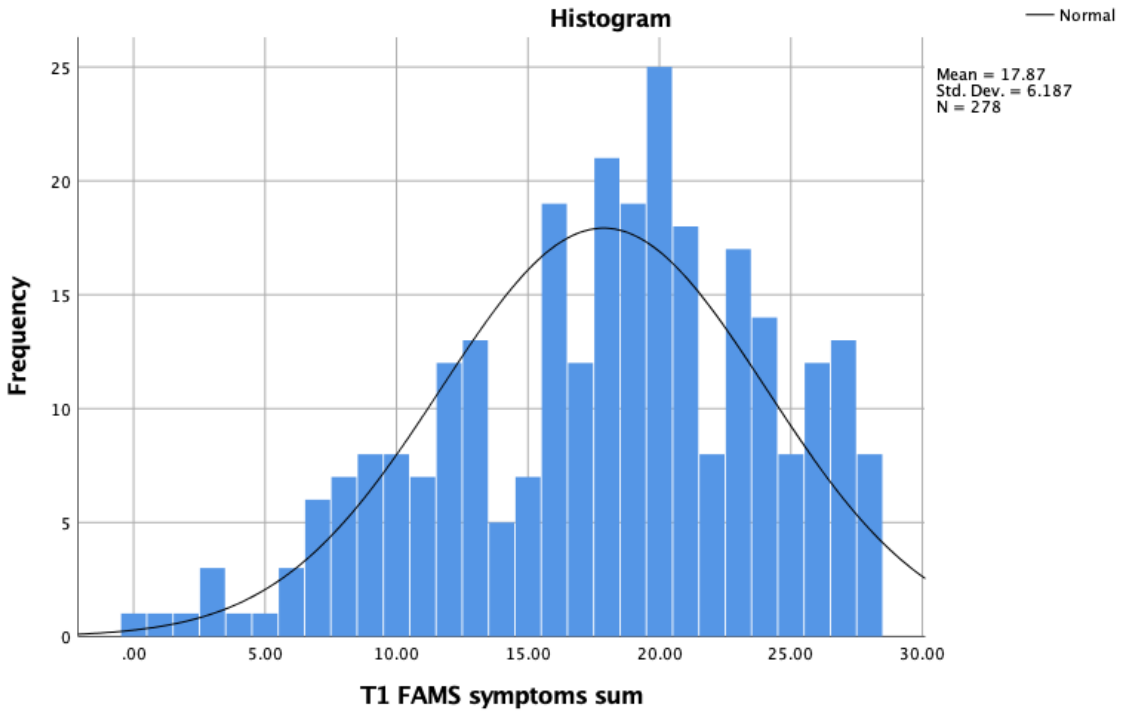
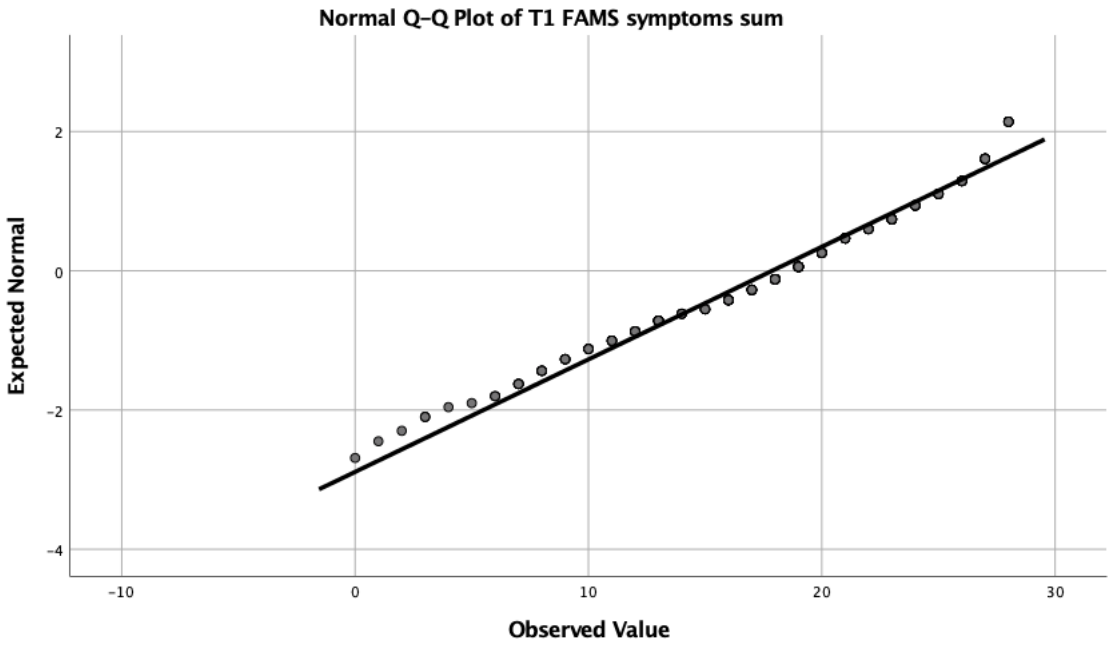
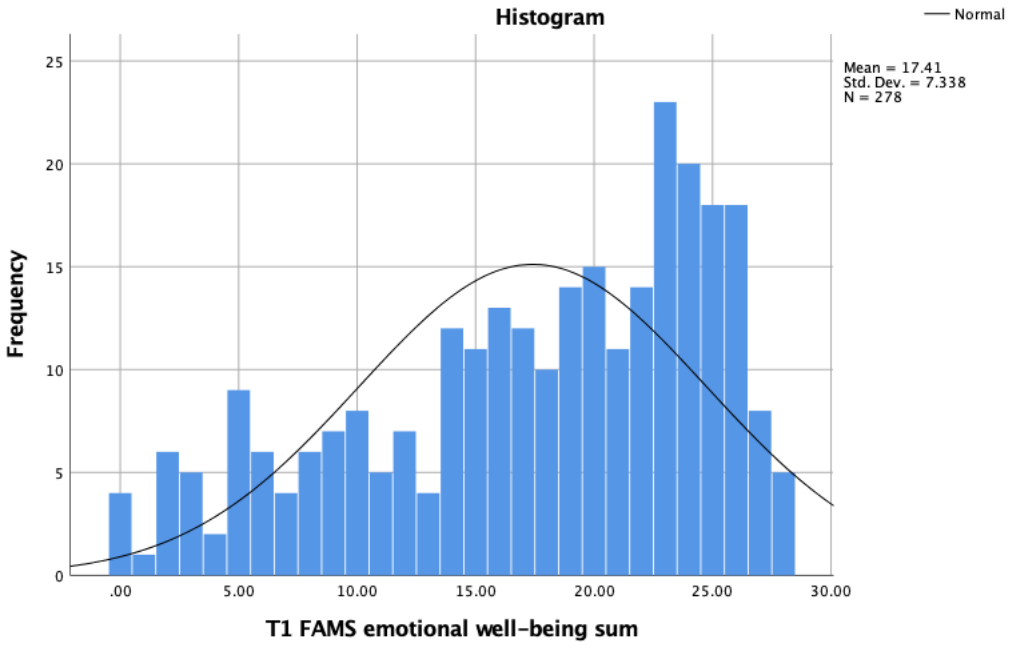
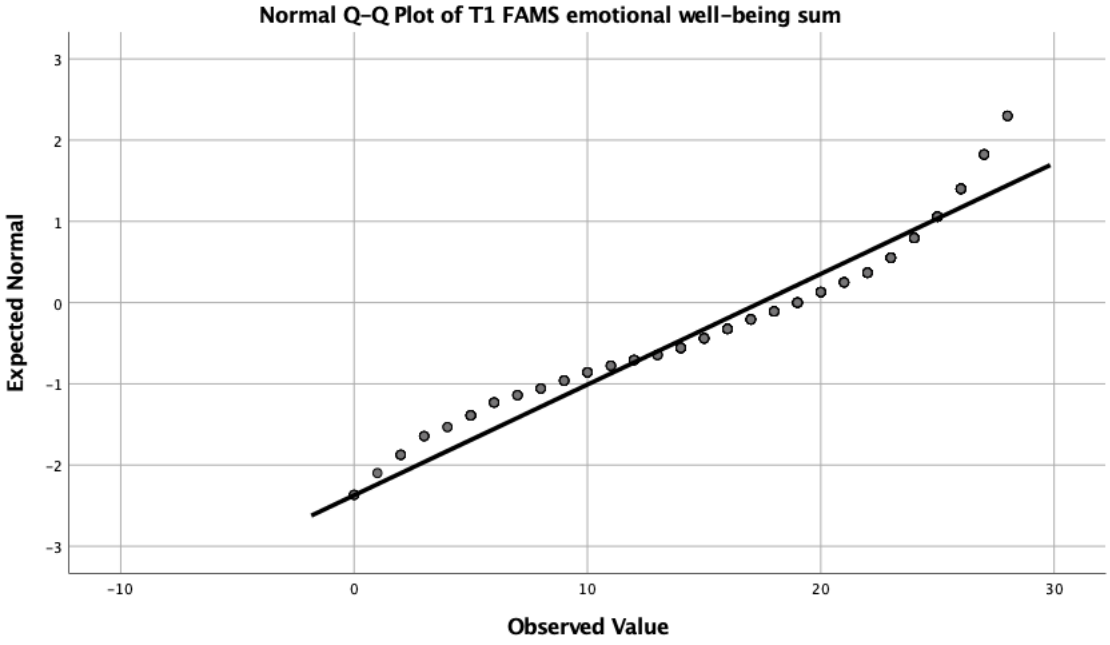
40
30
20
10
0
.00
1.00
2.00
3.00
4.00
pss mean

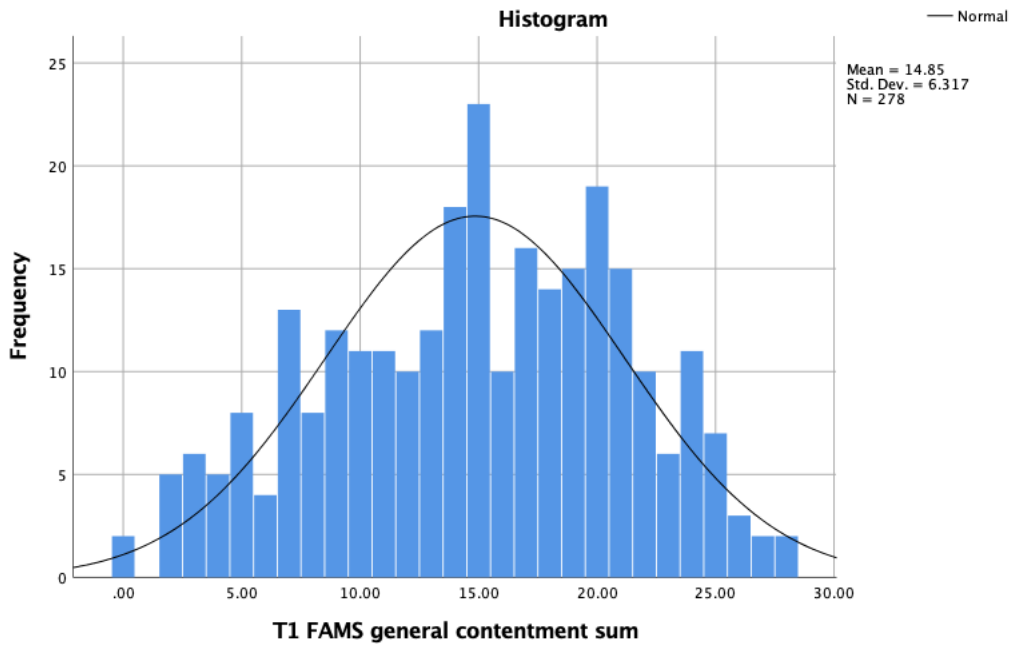

Normal Q-Q Plot of pss mean
Expected Normal
2
0
-2
-4
-1
0
1
2
3
4
Observed Value

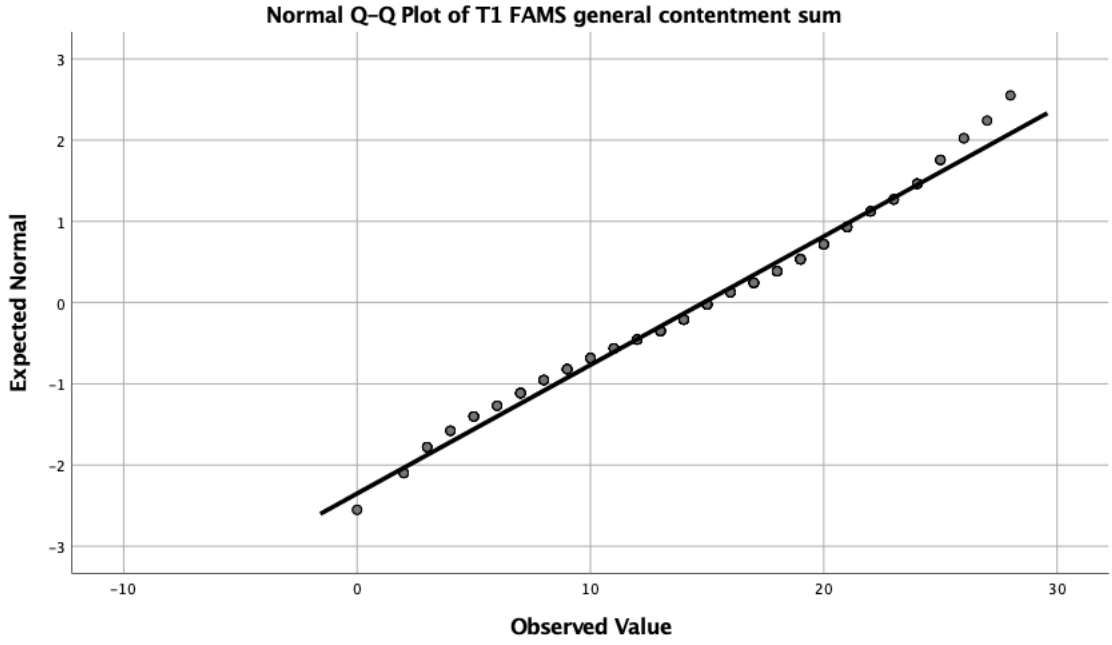

Histogram
Normal
Mean = 17.87
Std. Dev. = 6.187
N = 278
Frequency
T1 FAMS symptoms sum

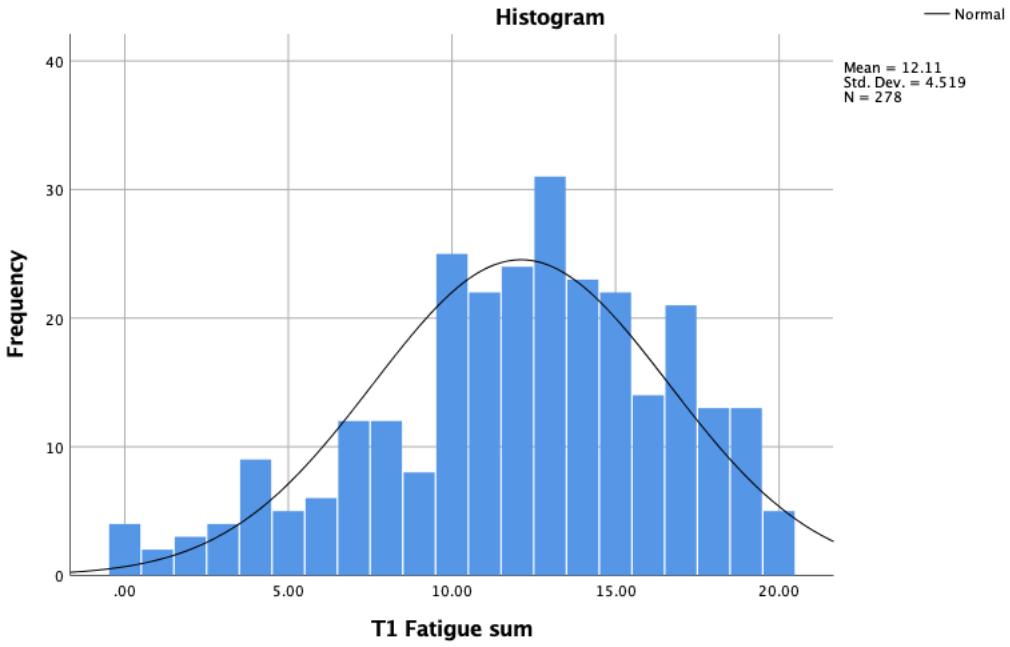

Normal Q-Q Plot of T1 FAMS symptoms sum
Expected Normal
Observed Value

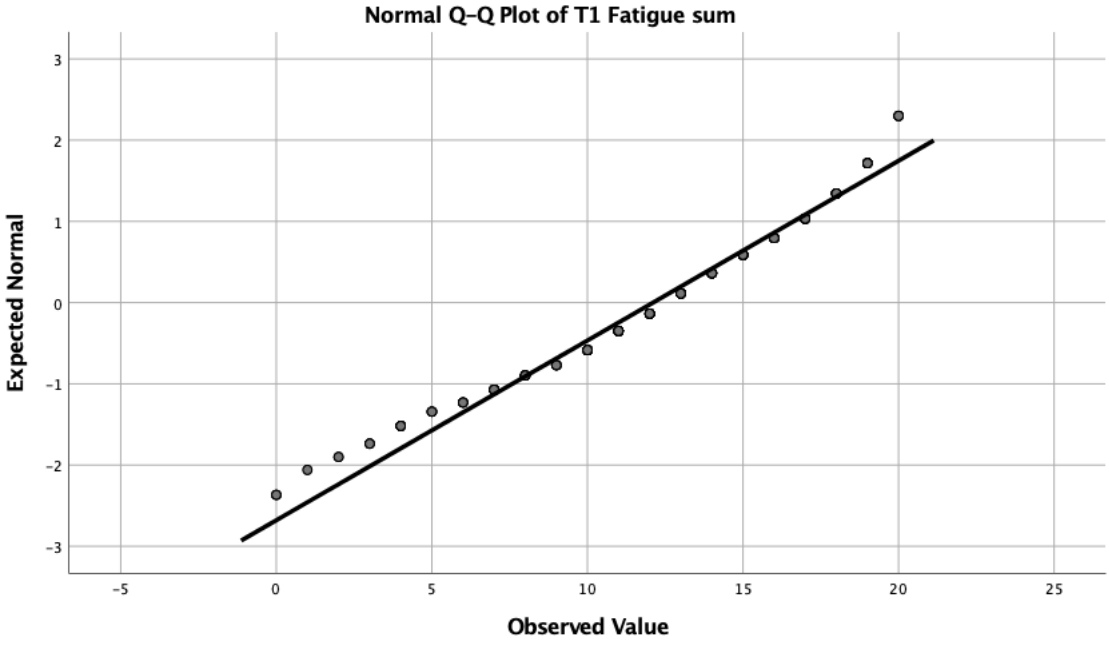

Histogram
Normal
Mean = 17.41
Std. Dev. = 7.338
N = 278
Frequency
T1 FAMS emotional well-being sum

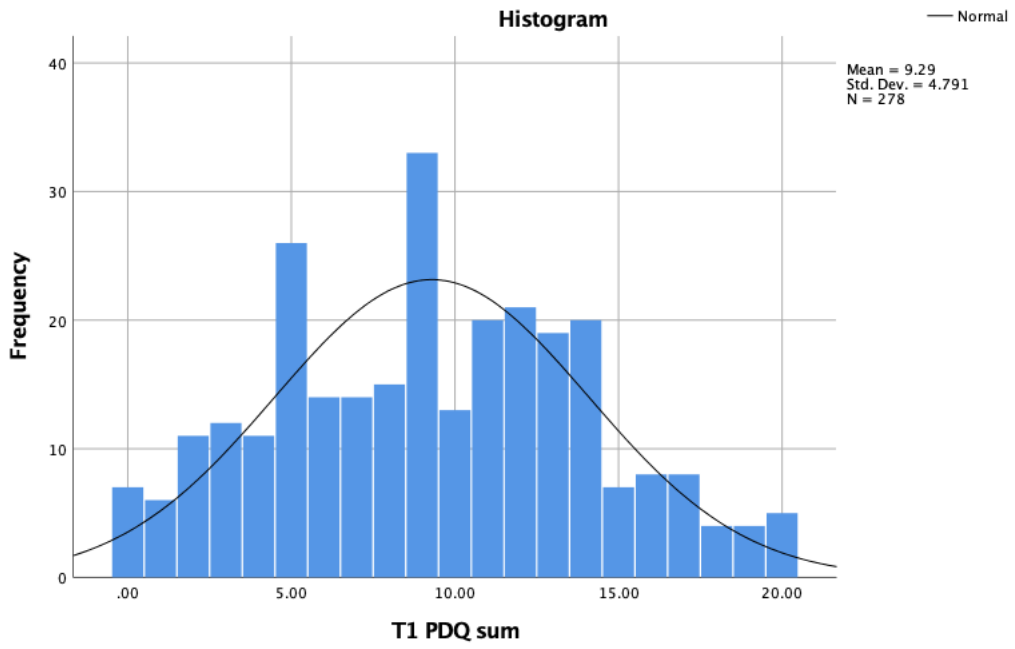

Normal Q-Q Plot of T1 FAMS emotional well-being sum
Expected Normal
Observed Value

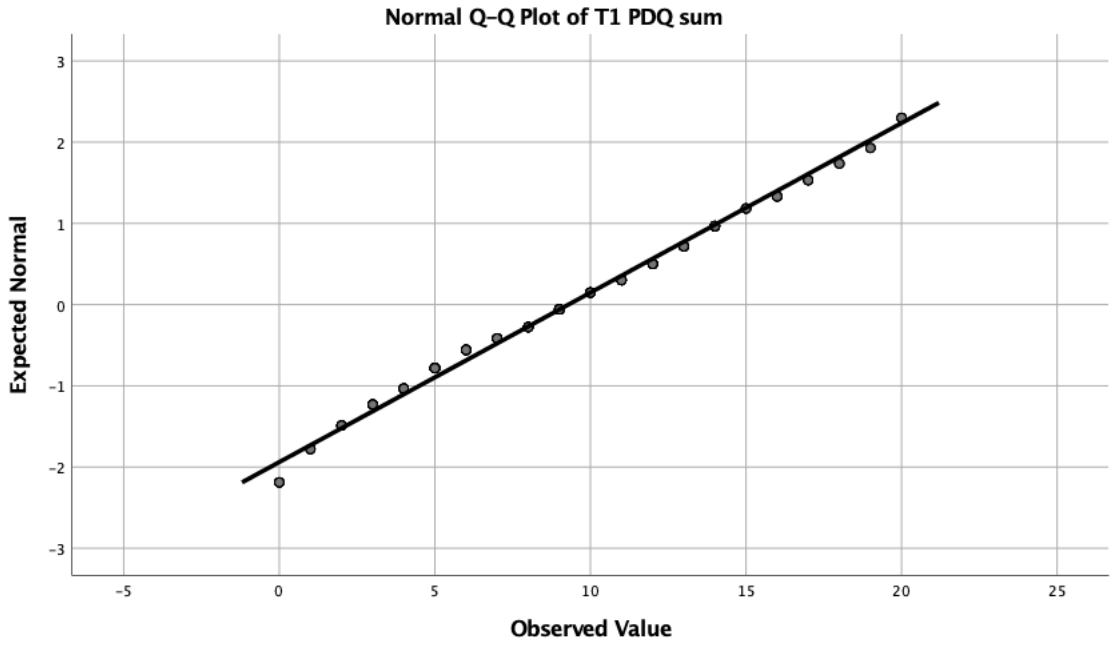

Histogram
Normal
Mean = 14.85
Std. Dev. = 6.317
N = 278
Frequency
T1 FAMS general contentment sum

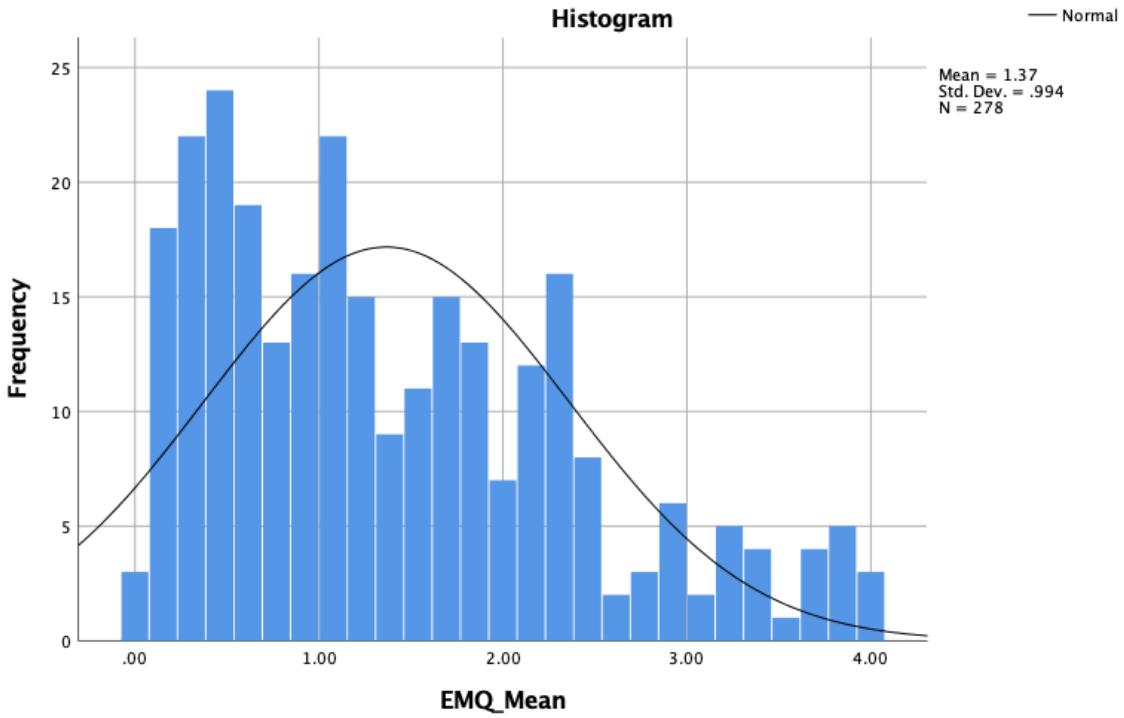

Normal Q–Q Plot of T1 FAMS general contentment sum
Expected Normal
Observed Value

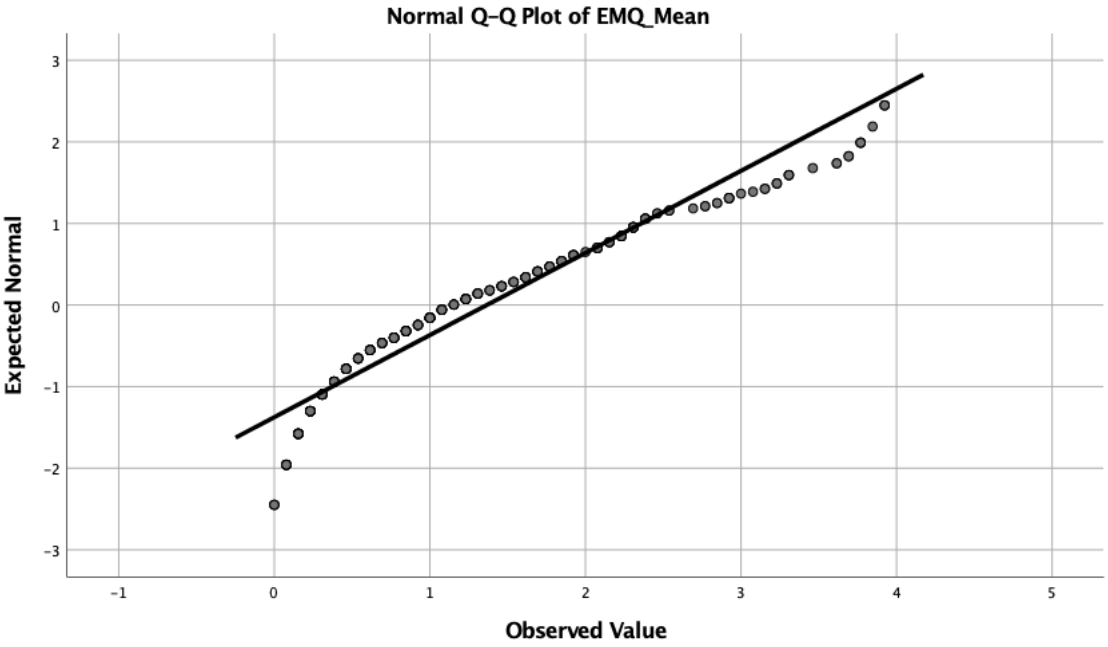

Histogram
Normal
Mean = 12.11
Std. Dev. = 4.519
N = 278
Frequency
40
30
20
10
0
.00
5.00
10.00
15.00
20.00
T1 Fatigue sum

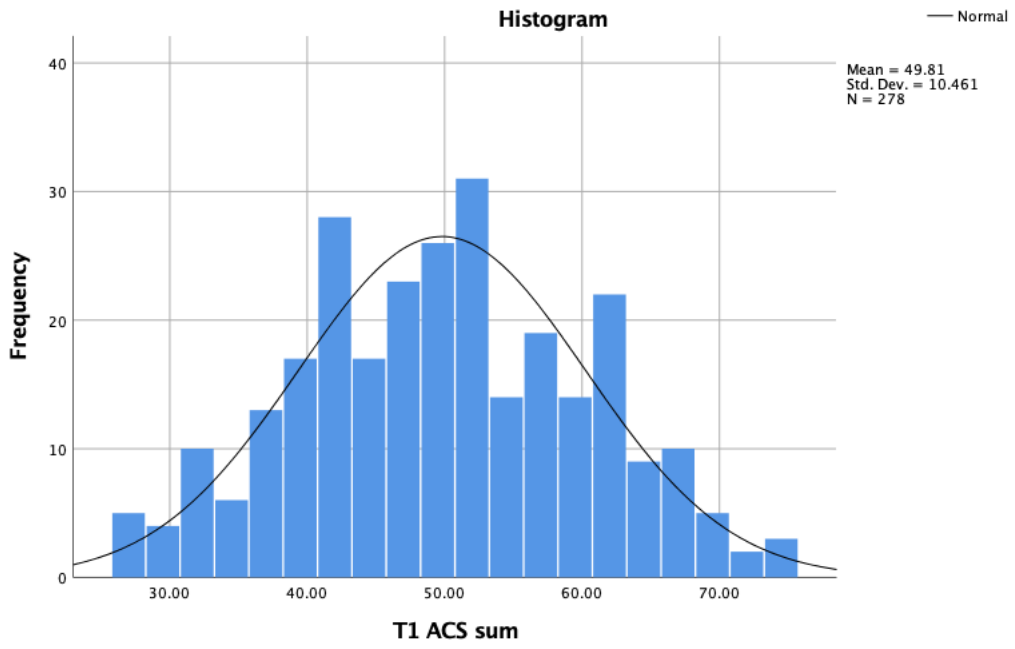

Normal Q-Q Plot of T1 Fatigue sum
Expected Normal
3
2
1
0
-1
-2
-3
-5
0
5
10
15
20
25
Observed Value

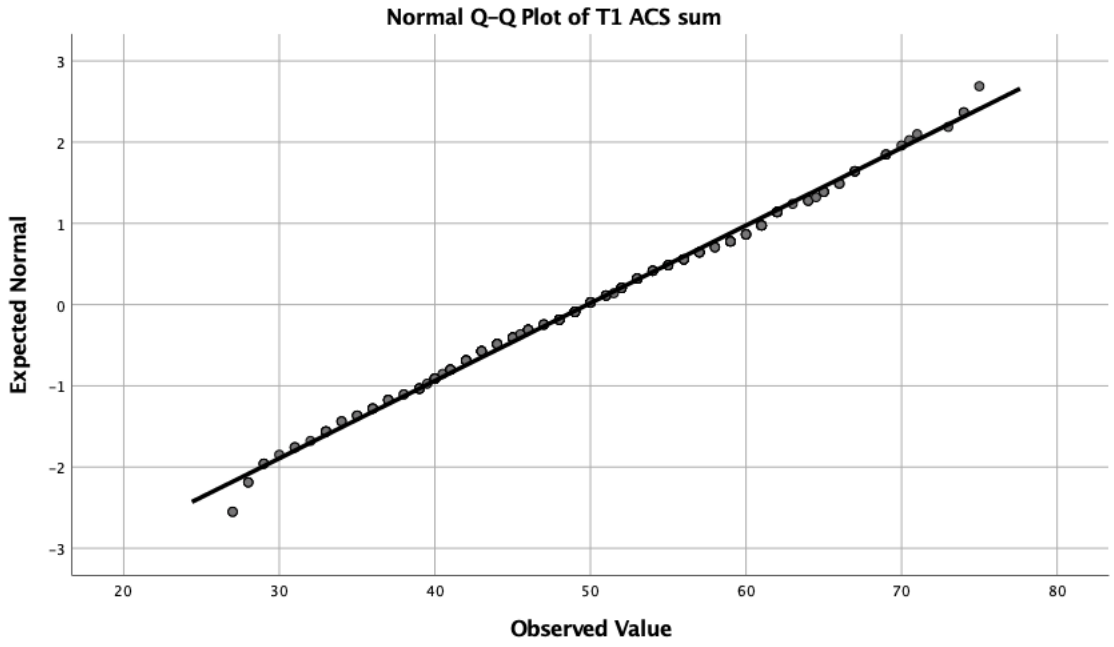

Histogram
Normal
Mean = 9.29
Std. Dev. = 4.791
N = 278
Frequency
T1 PDQ sum

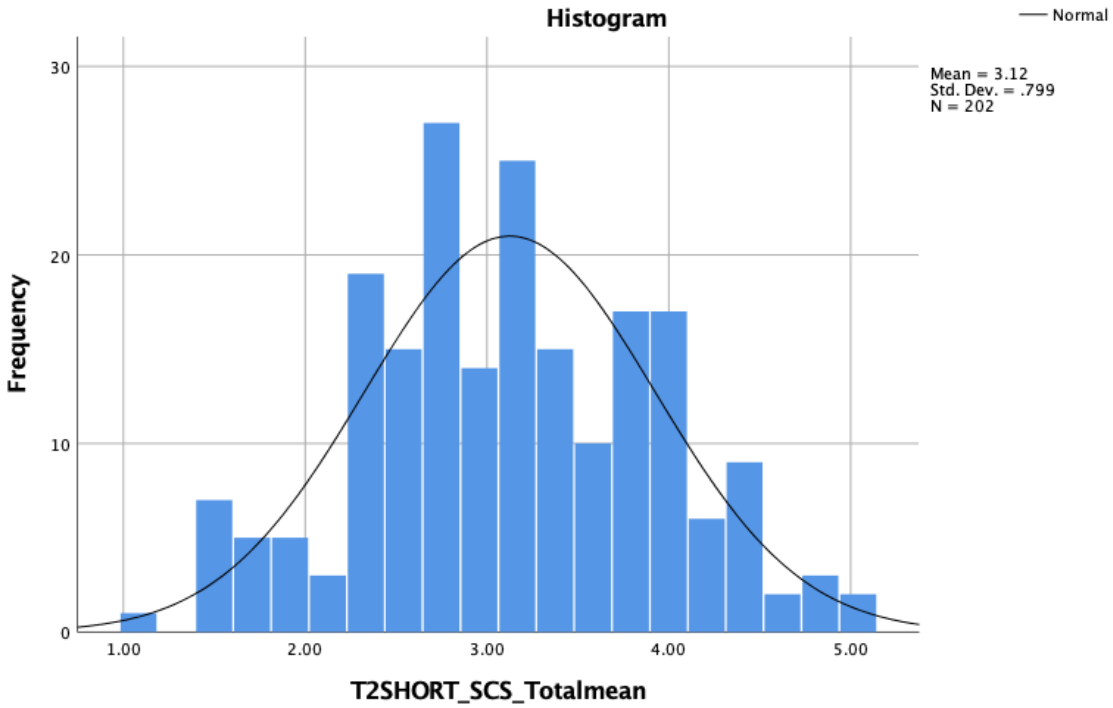

Normal Q-Q Plot of T1 PDQ sum
Expected Normal
Observed Value

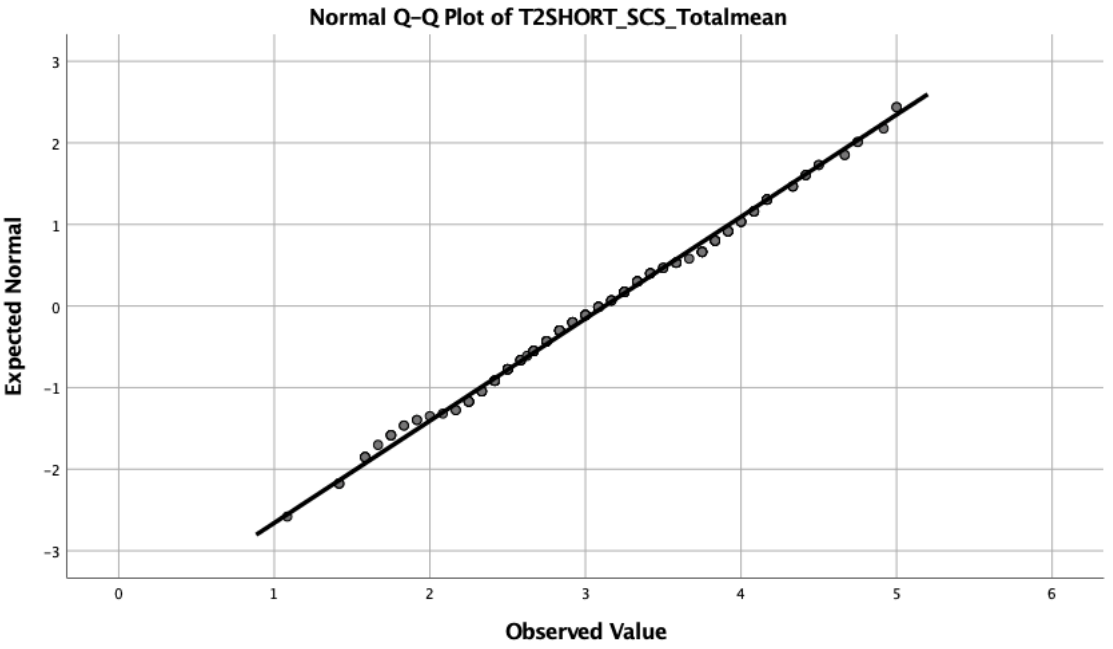

Histogram
Normal
Mean = 1.37
Std. Dev. = .994
N = 278
Frequency
25
20
15
10
5
0
.00
1.00
2.00
3.00
4.00
EMQ_Mean

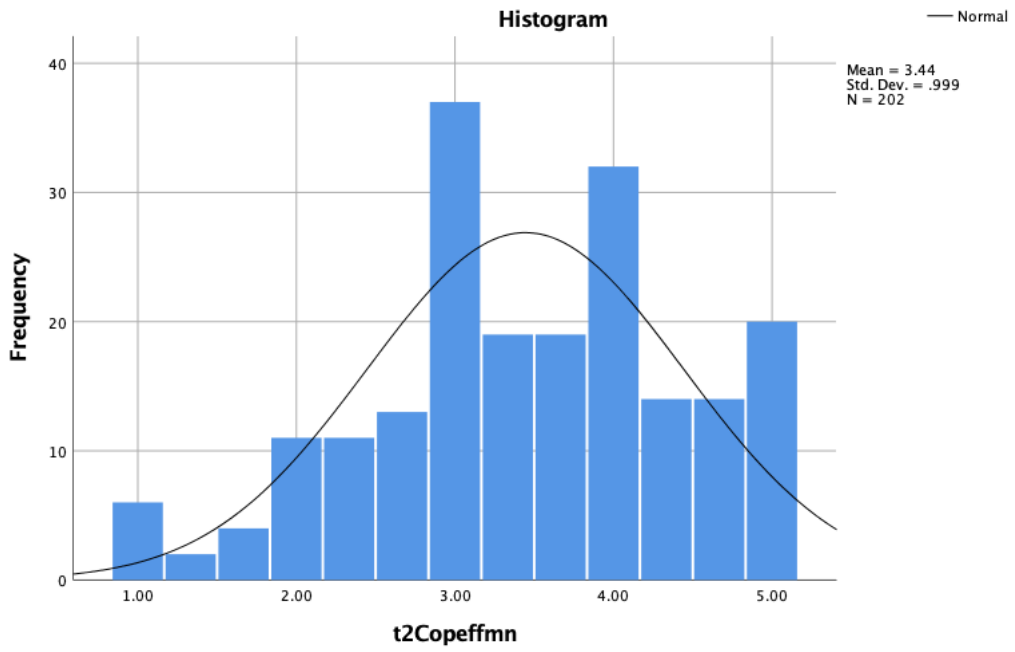

Normal Q-Q Plot of EMQ_Mean
Expected Normal
3
2
1
0
-1
-2
-3
-1
0
1
2
3
4
5
Observed Value


Histogram
Normal
Mean = 49.81
Std. Dev. = 10.461
N = 278
Frequency
T1 ACS sum


Normal Q-Q Plot of T1 ACS sum
Expected Normal
Observed Value


Histogram
Normal
Mean = 3.12
Std. Dev. = .799
N = 202
Frequency
30
20
10
0
1.00
2.00
3.00
4.00
5.00
T2SHORT_SCS_Totalmean


Normal Q-Q Plot of T2SHORT_SCS_Totalmean
Expected Normal
3
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value


Histogram
Normal
Mean = 3.44
Std. Dev. = .999
N = 202
Frequency
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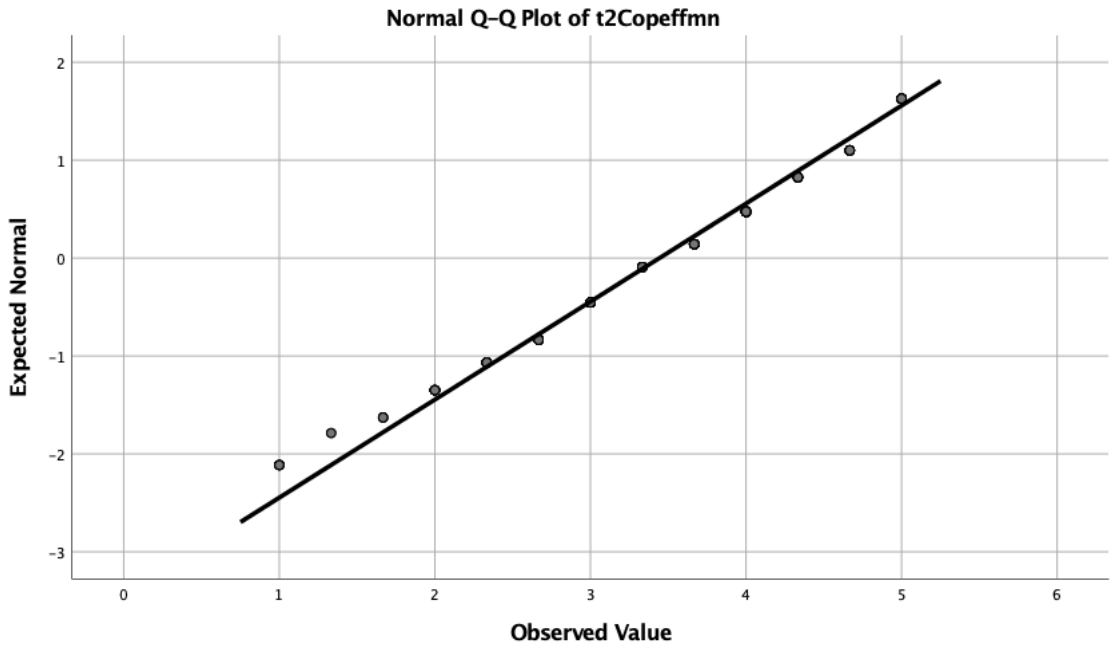
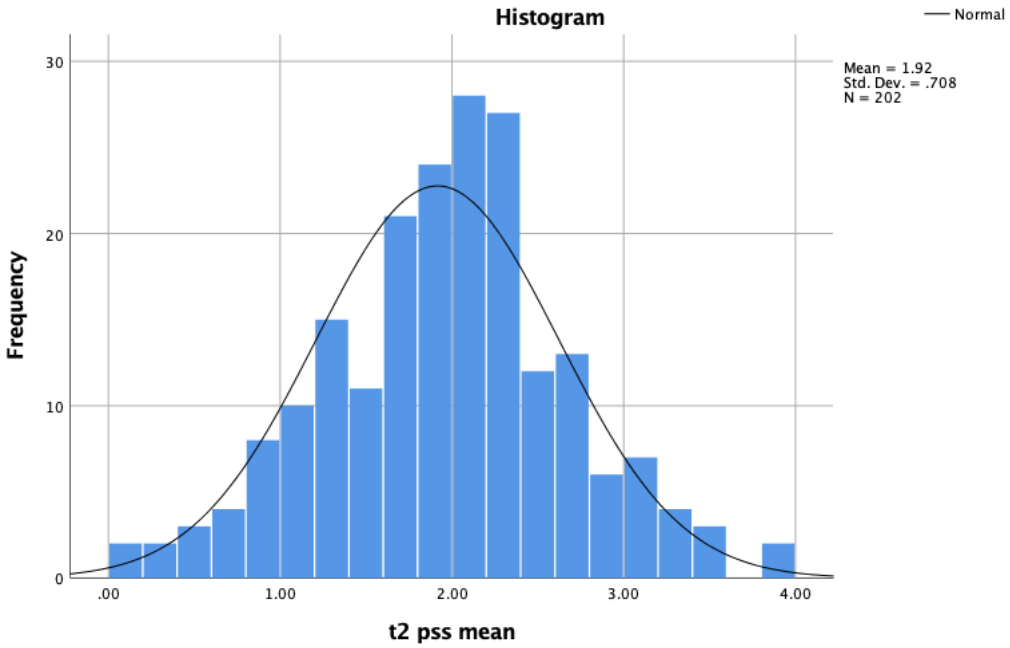
30
20
10
0
1.00
2.00
3.00
4.00
5.00
t2Copeffmn


Normal Q-Q Plot of t2Copeffmn
Expected Normal
2
1
0
-1
-2
-3
0
1
2
3
4
5
6
Observed Value


Histogram
Normal
Mean = 1.92
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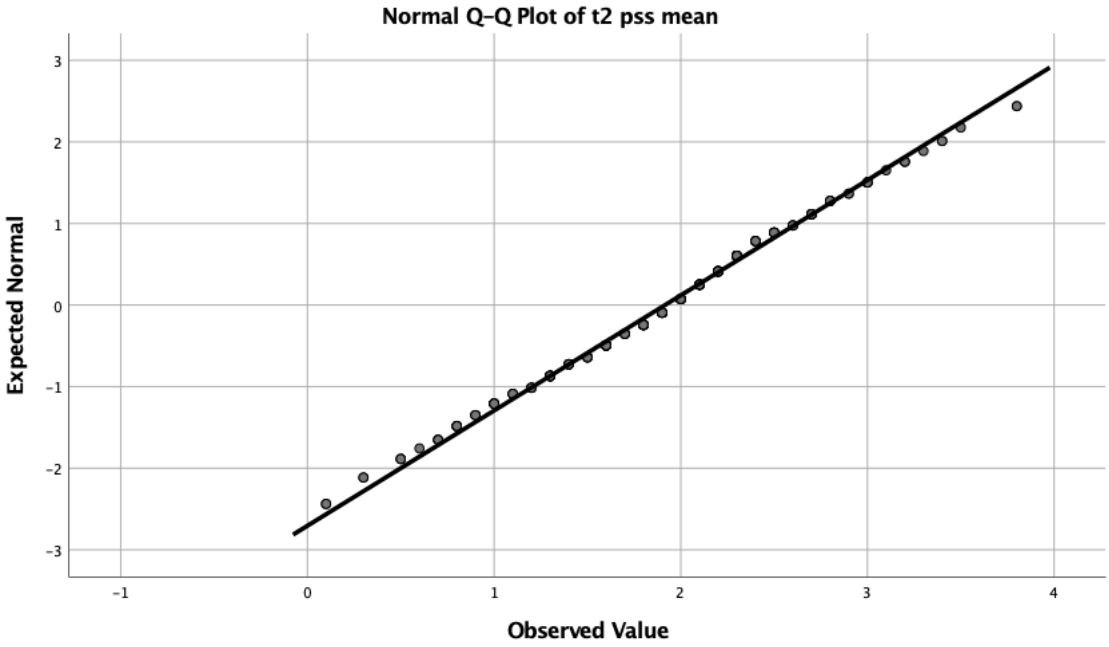
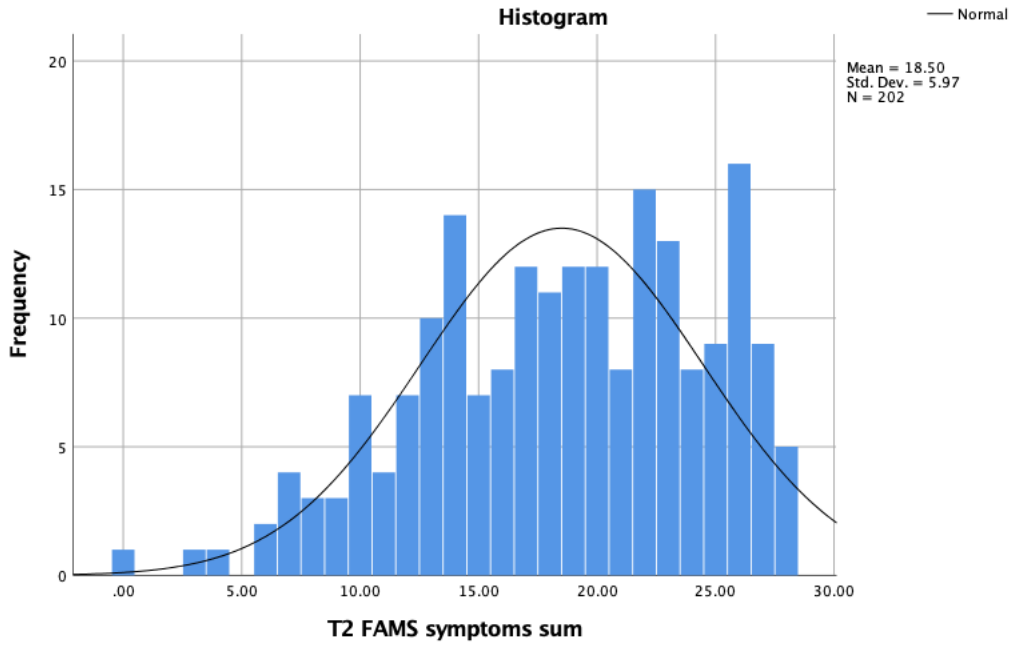
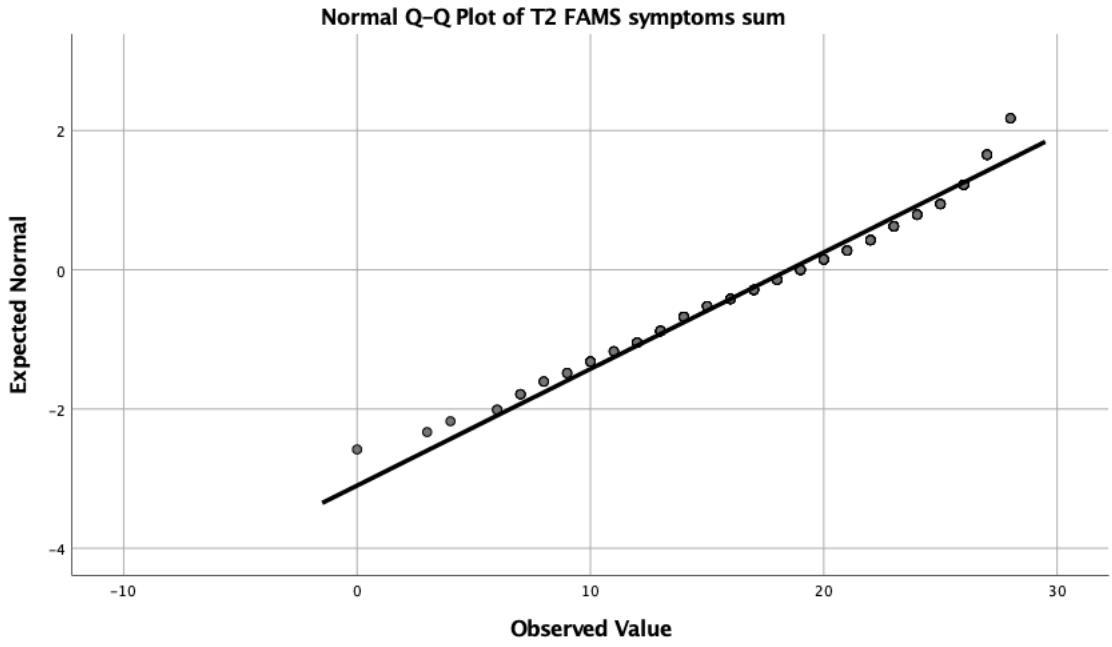
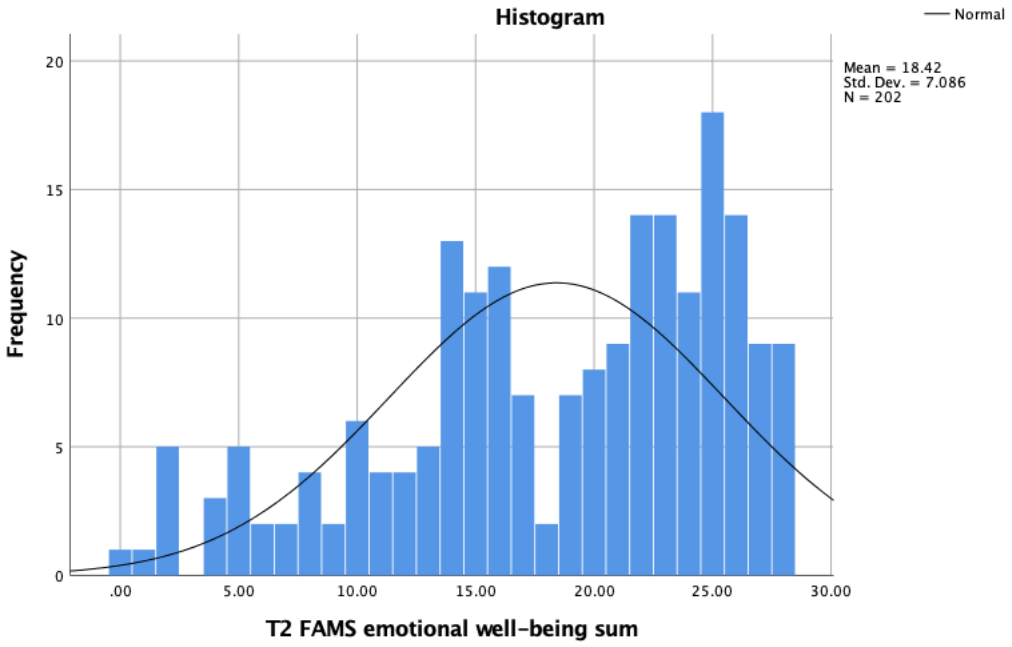
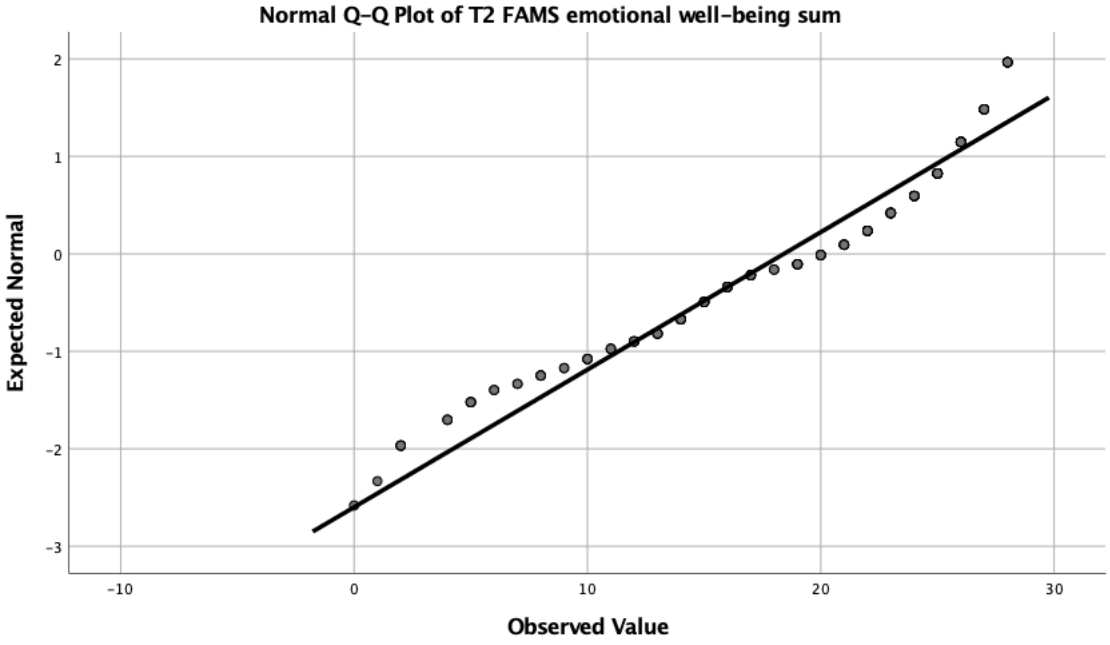
N = 202
Frequency
30
20
10
0
.00
1.00
2.00
3.00
4.00
t2 pss mean

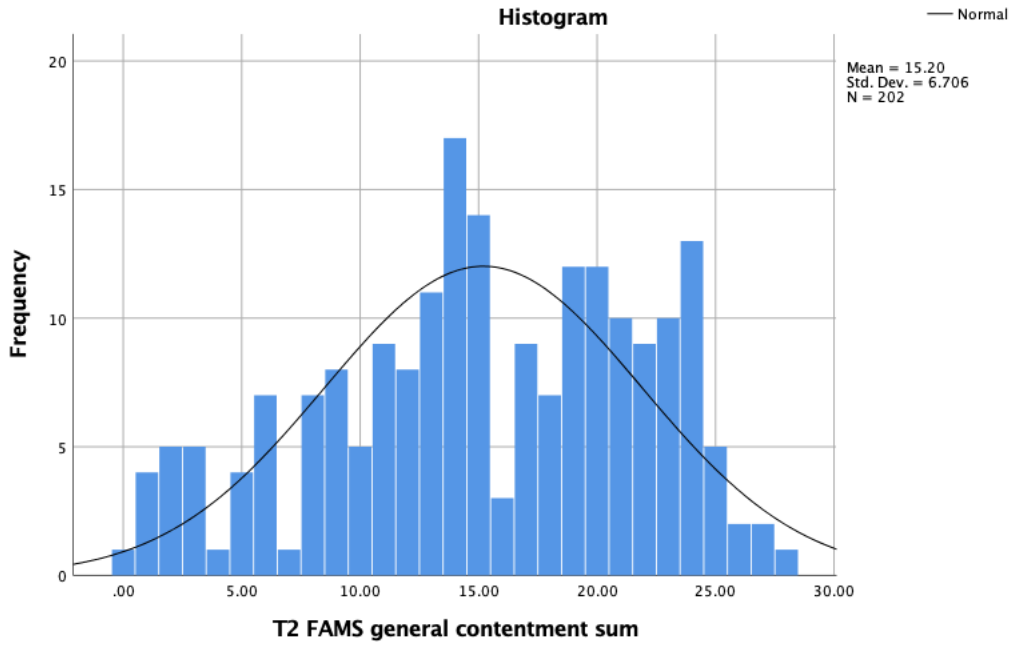

Normal Q–Q Plot of t2 pss mean
Expected Normal
3
2
1
0
-1
-2
-3
-1
0
1
2
3
4
Observed Value

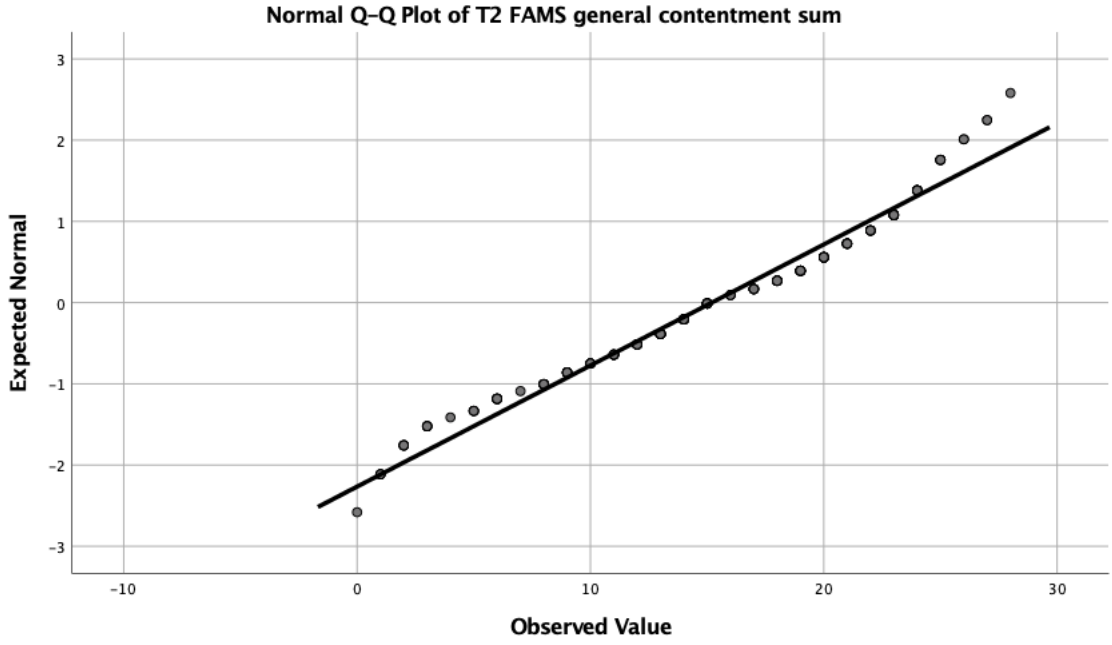

Histogram
Normal
Mean = 18.50
Std. Dev. = 5.97
N = 202
Frequency
T2 FAMS symptoms sum

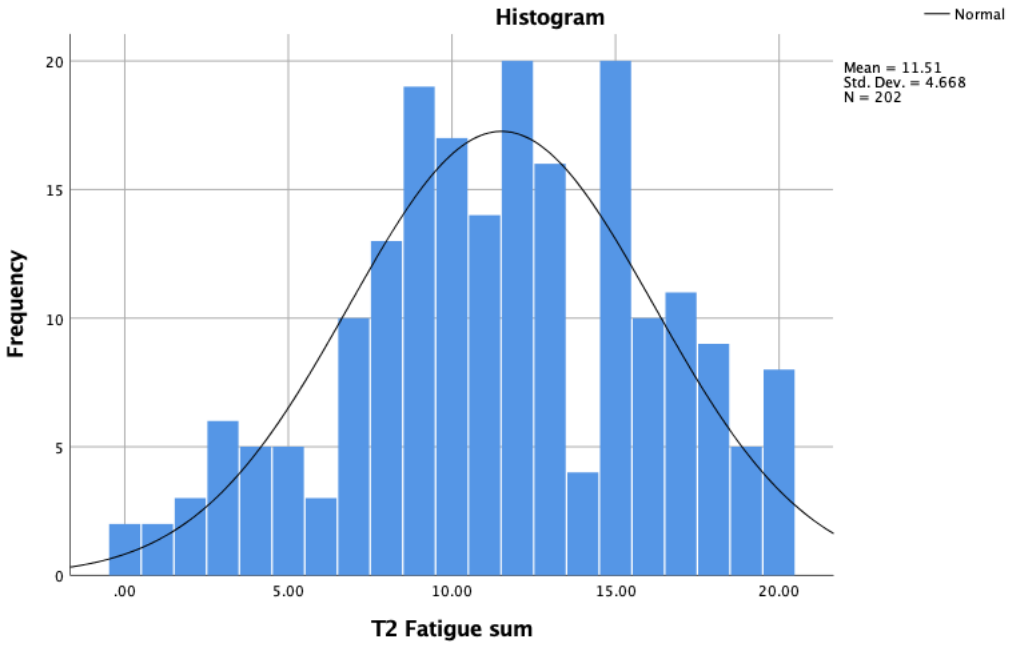

Normal Q-Q Plot of T2 FAMS symptoms sum
Expected Normal
Observed Value

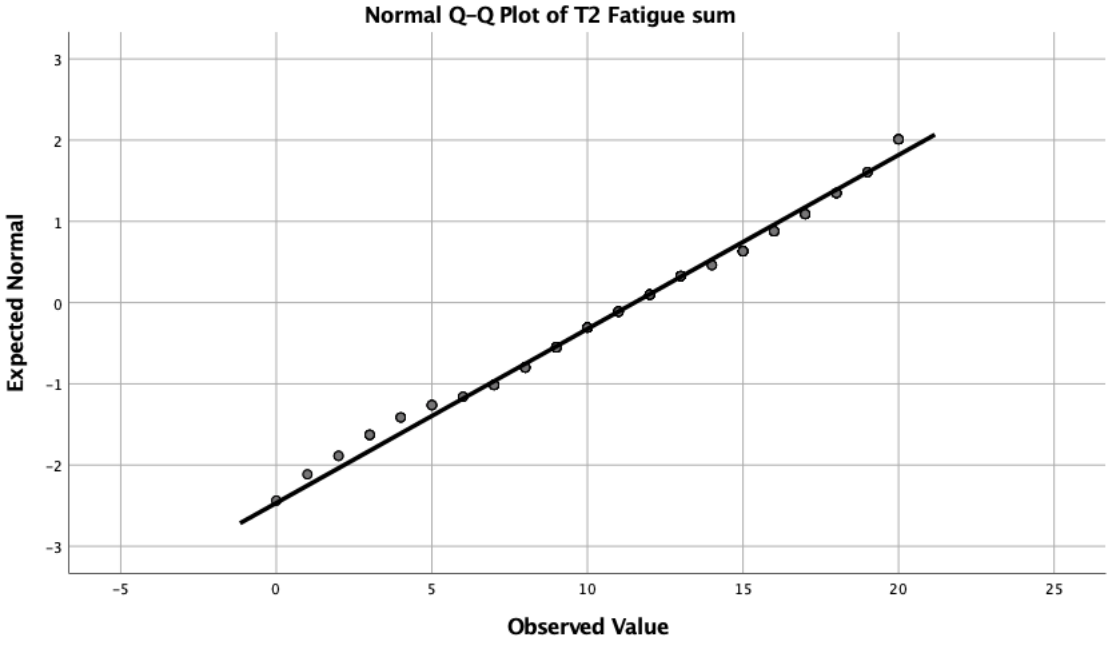

Histogram
Normal
Mean = 18.42
Std. Dev. = 7.086
N = 202
Frequency
T2 FAMS emotional well-being sum

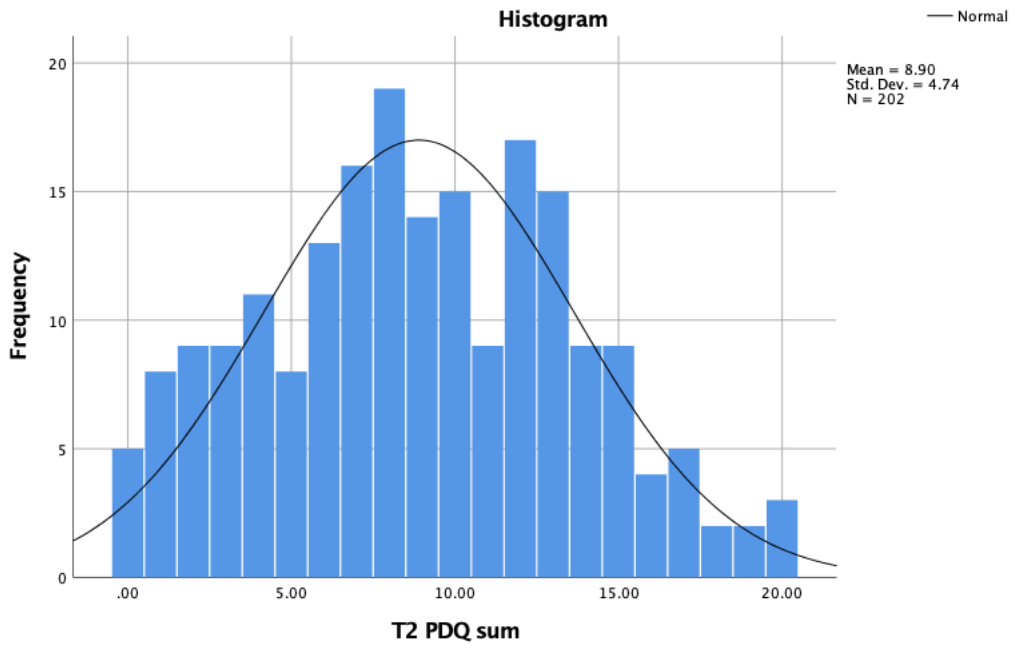

Normal Q-Q Plot of T2 FAMS emotional well-being sum
Expected Normal
Observed Value

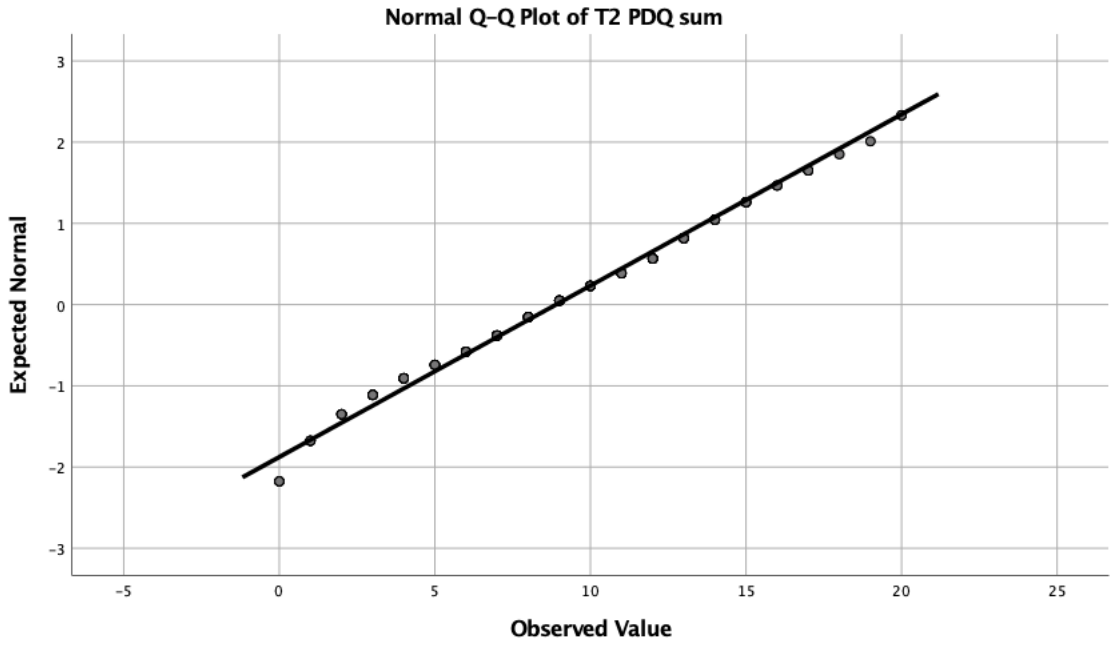

Histogram
Normal
Mean = 15.20
Std. Dev. = 6.706
N = 202
Frequency
T2 FAMS general contentment sum

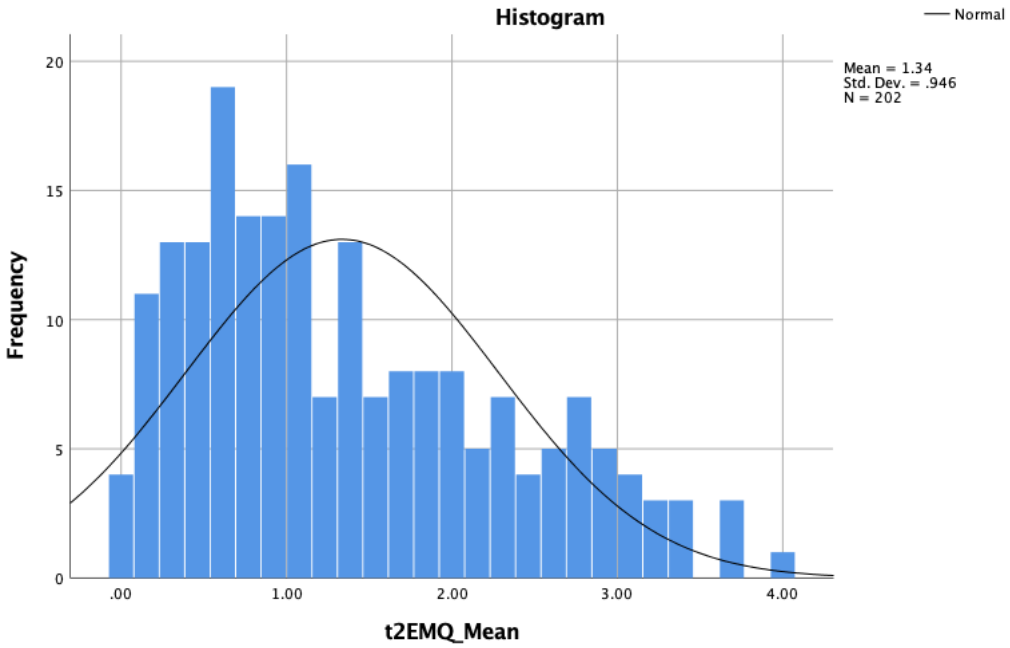

Normal Q–Q Plot of T2 FAMS general contentment sum
Expected Normal
Observed Value

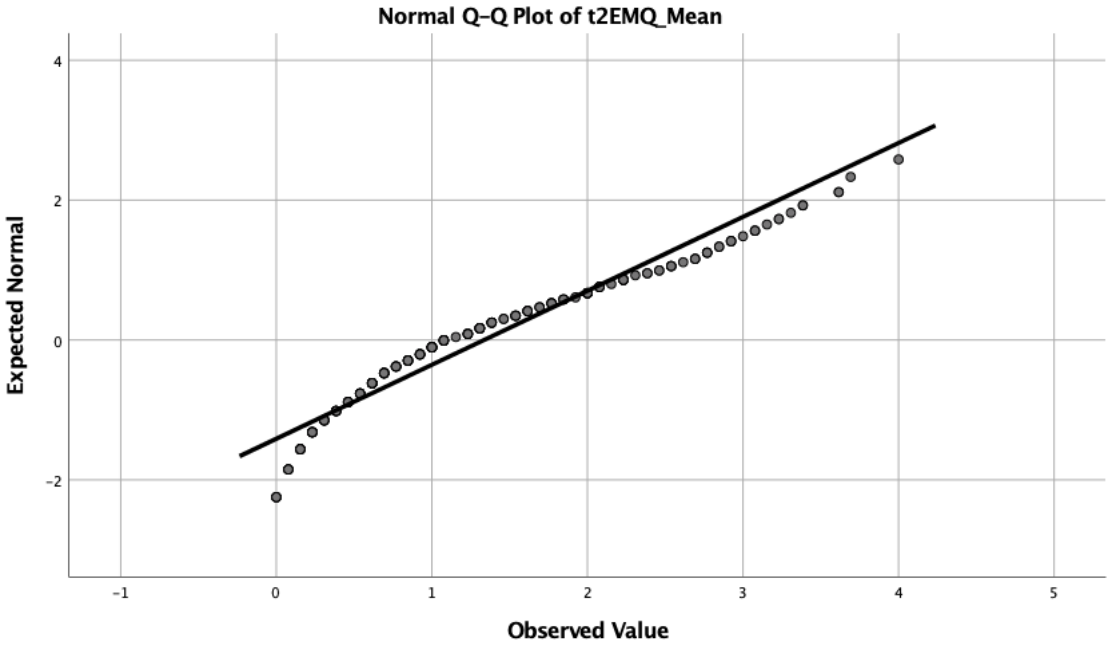

Histogram
Normal
Mean = 11.51
Std. Dev. = 4.668
N = 202
Frequency
T2 Fatigue sum

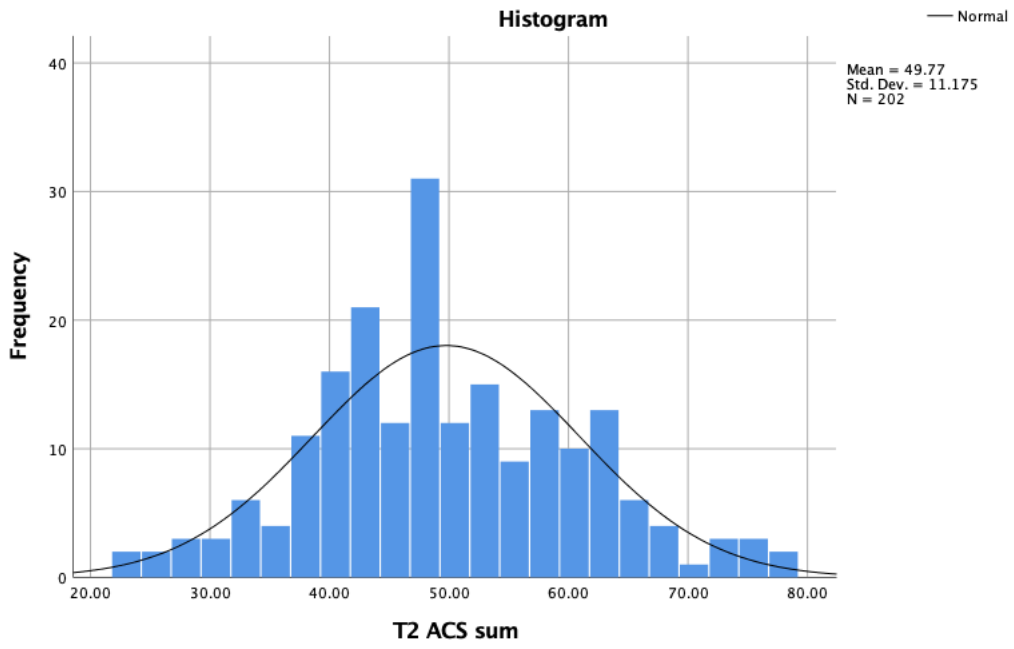

Normal Q-Q Plot of T2 Fatigue sum
Expected Normal
Observed Value

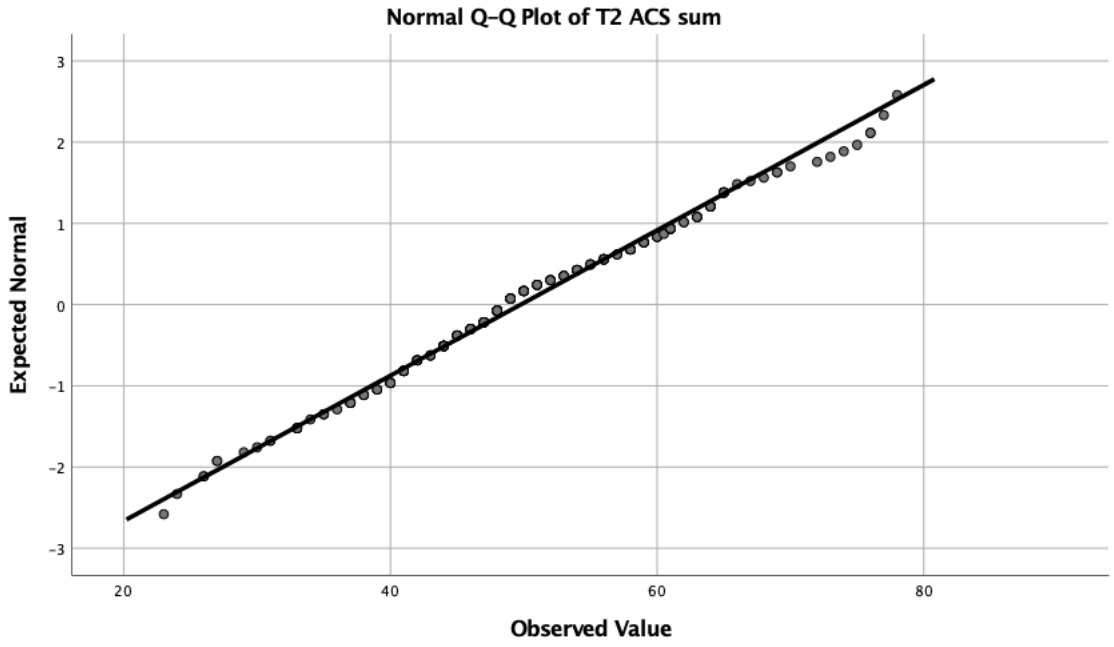

Histogram
Normal
Mean = 8.90
Std. Dev. = 4.74
N = 202
Frequency
T2 PDQ sum

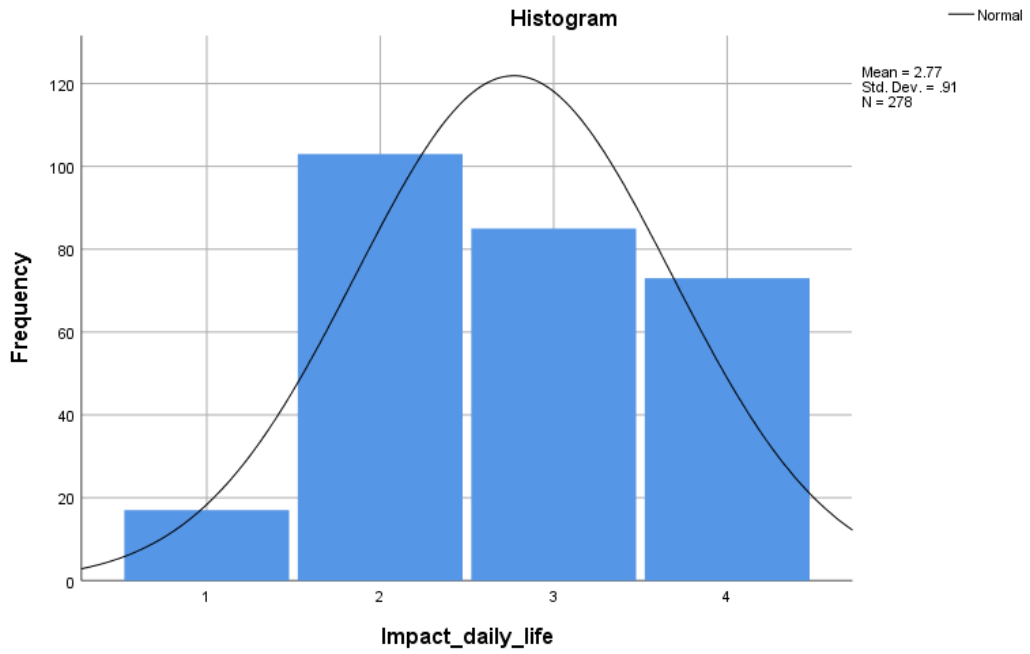

Normal Q-Q Plot of T2 PDQ sum
Expected Normal
Observed Value

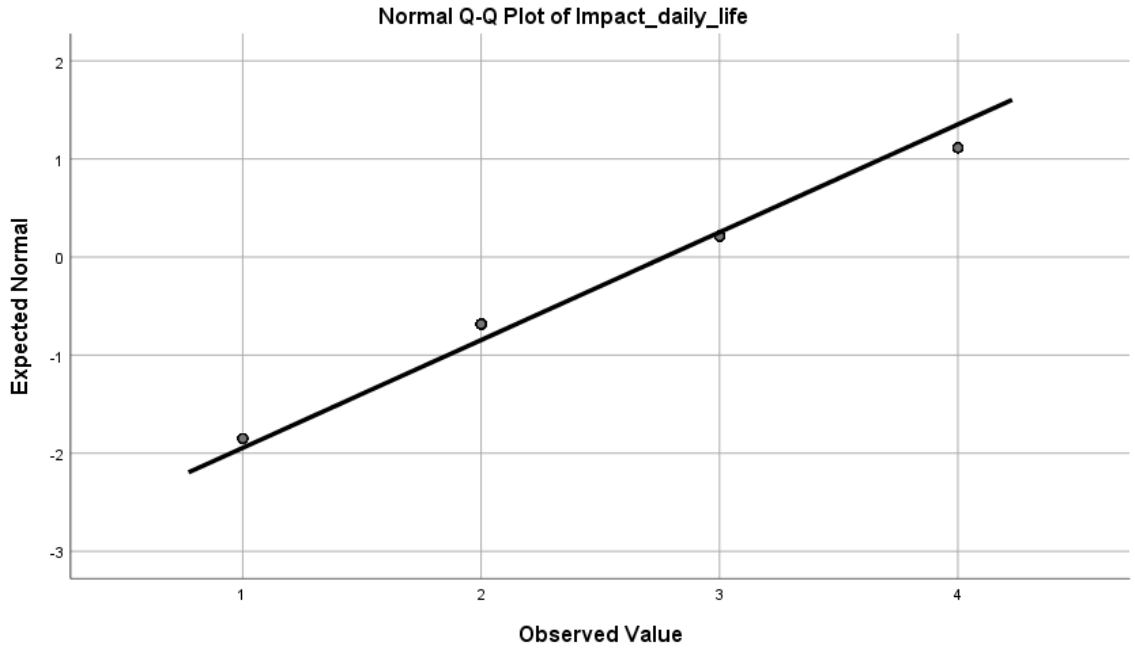

Histogram
Normal
Mean = 1.34
Std. Dev. = .946
N = 202
Frequency
t2EMQ_Mean

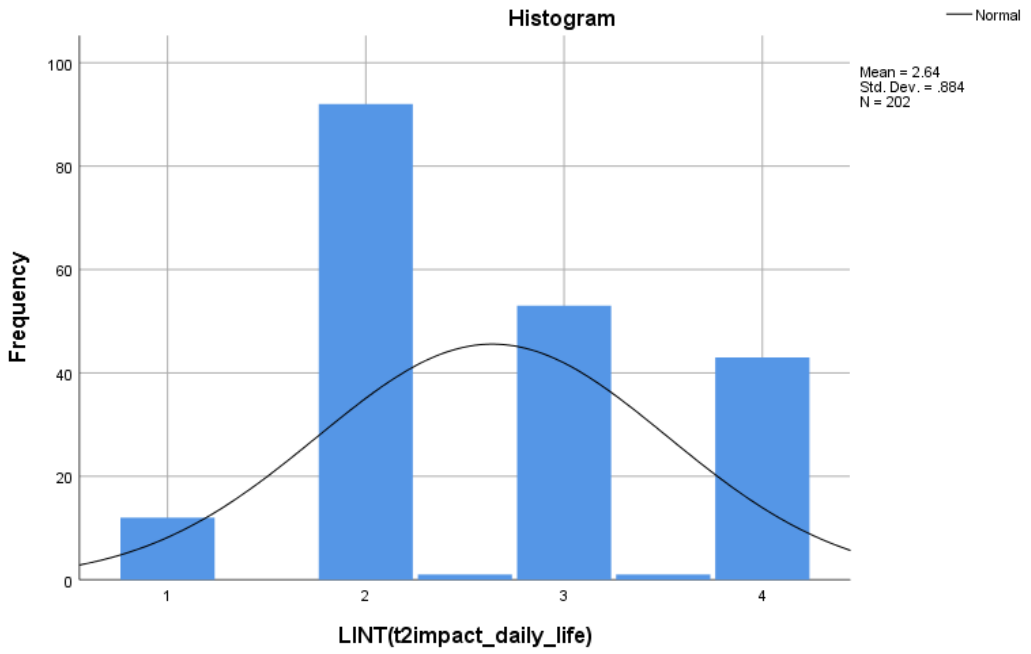

Normal Q-Q Plot of t2EMQ_Mean
Expected Normal
Observed Value

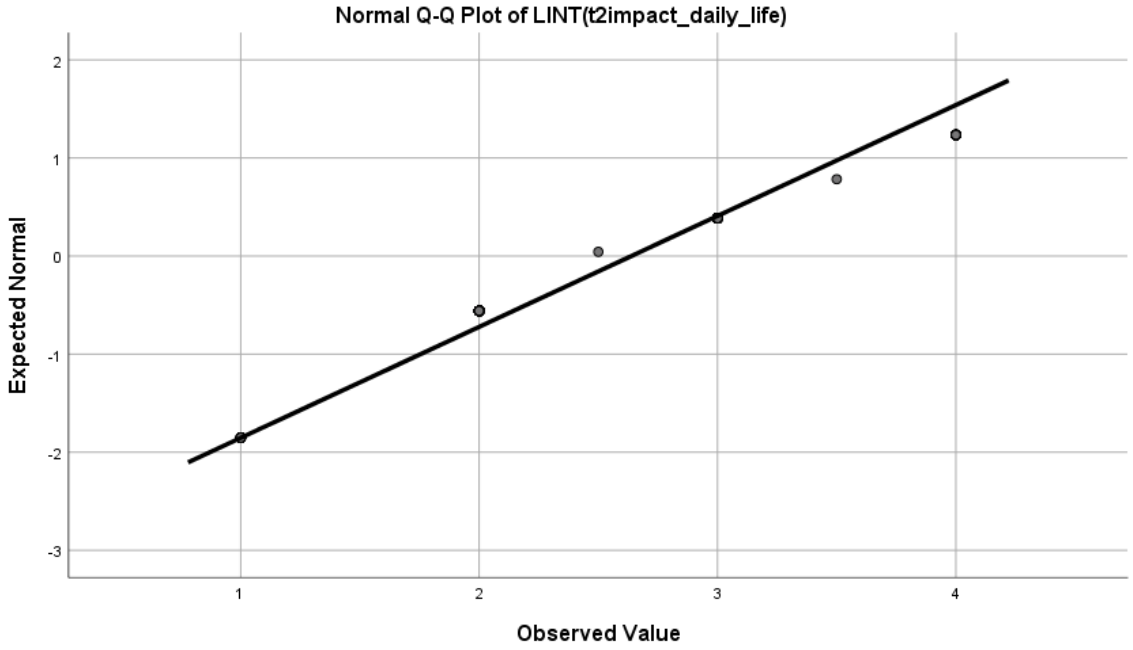

Histogram
Normal
Mean = 49.77
Std. Dev. = 11.175
N = 202
Frequency
T2 ACS sum


Normal Q-Q Plot of T2 ACS sum
Expected Normal
Observed Value


Histogram
Normal
Mean = 2.77
Std. Dev. = .91
N = 278
Frequency
120
100
80
60
40
20
0
1
2
3
4
Impact_daily_life


Normal Q-Q Plot of Impact_daily_life
Expected Normal
2
1
0
-1
-2
-3
1
2
3
4
Observed Value


Histogram
Normal
Mean = 2.64
Std. Dev. = .884
N = 202
Frequency
100
80
60
40
20
0
1
2
3
4
LINT(t2impact_daily_life)


Normal Q-Q Plot of LINT(t2impact_daily_life)
Expected Normal
2
1
0
-1
-2
-3
1
2
3
4
Observed Value

Appendix O: Summary of correlations between covariates, IV and DV

Table 6

Supplemental correlations between covariates, IV (SCS) and DV's (PDQ)

	SCS T1	PDQ T1	PDQ T2
Age	.31**	-.19**	-.03
Gender	-.08	-.02	.04
MS subtype	.007	.03	-.03
Years since diagnosis	.18**	-.14*	-.12
Impact on daily life	-.08	.31**	.26**
Fatigue	-.35**	.63**	.60**
PDQ T1	-.33**	1	.84**

Notes: T1 = time 1, T2 = time 2; SCS = self-compassion scale; PDQ = Perceived deficits questionnaire; p<.05*, p<.01**

Appendix P: Paired-samples t-tests comparing Time 1 and Time 2 scores

Table 7

Paired samples t-test of differences between T1 and T2 scores

Variable	Test statistic (*t*)	p-value	95% CIs
SCS	-0.42	.676	[-0.8, 0.5]
CE	0.11	.911	[-0.1, 0.1]
PSS	0.40	.689	[-0.1, 0.7]
QoL Total	-0.89	.372	[-1.5, 0.6]
PDQ	0.56	.573	[-0.3, 0.5]

Notes: SCS = Self-Compassion Scale; CE = Coping Efficacy; PSS = Perceived Stress Scale; QoL Total = Quality of Life Total score; PDQ = Perceived Deficits Questionnaire; *t* = paired samples t-test; CIs = confidence intervals; $p<0.05$*, $p<0.01$**