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Self-Compassion and Coping in Chronic Illness Groups

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Thesis Abstract

The aim of this research was to explore self-compassion and its associations with psychological outcomes and coping, in both general and specific chronic illness groups.

In chapter 1, quantitative research that explored the relationships between self-compassion and outcomes of psychological distress (i.e. depression, anxiety and/or stress) and coping was synthesised. This included adult chronic illness populations samples. To identify relevant literature, four academic databases were systematically searched. The findings of the review highlighted self-compassion consistently correlated with depression, anxiety and stress, as well as adaptive and maladaptive coping strategies. It also explained unique variance across studies. Subtle differences were observed across conditions and samples in the strength of relationships, but results overall highlight the need for interventions developed to enhance self-compassion in chronic illness groups.

In chapter 2, a qualitative research study explored coping and self-compassion in a sample of adolescents living with epilepsy. Adolescents were invited to take part in interviews, and Interpretative Phenomenological Analysis (IPA) was used to develop themes from the narratives of five adolescents. Three superordinate themes were constructed: (i) Learning about my condition and my experiences: “Getting answers and people explaining things...it makes massive lifesaving differences”, (ii) Dealing with the thought takeover: “I try not to think on it to move on” and (iii) Being in an accepting bubble: “I know that people have got my back”. These findings indicate how coping and self-compassion are situated within the sample, and what interventions might support how young people manage an unpredictable, individual condition like epilepsy.

In chapter 3, a critical appraisal was conducted to outline the main findings, reflections around the key decisions, the study process and personal considerations noted throughout.

Declaration

This thesis records research activity undertaken between August 2019 and August 2020 for the Doctorate in Clinical Psychology at Lancaster University. The work presented in this thesis is my own except where reference to other authors is made. This work has not been submitted for any other academic award.

Melissa Longworth

7th August 2020

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Chapter 1: Literature Review

Associations between self-compassion, psychological distress and coping in chronic illness: A systematic review

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Abstract

Objective: This systematic review aimed to explore associations between self-compassion, psychological distress and coping in chronic illness samples given the growing body of research highlighting self-compassion as a potentially important predictor in the outcomes.

Method: Four electronic databases and reference lists of relevant articles were searched and set inclusion and exclusion criteria were used to select articles. A narrative review design was used to synthesise findings. **Results:** Twenty-five studies were included in the review involving various populations, designs and outcome measures. Self-compassion was shown to significantly correlate with depression outcomes (20 studies), anxiety (10), stress (7) and both adaptive and maladaptive coping (4). Self-compassion also showed predictive power, yet subtle differences were observed when comparing chronic illness groups, when exploring the relationship longitudinally, and when exploring the two-factor structure of the concept.

Conclusions: Research is continually highlighting links between self-compassion and psychological outcomes in chronic illness samples, with this review showing this relationship is evident across chronic illness groups. Exploring this in practice may allow clinicians and researchers to use resources effectively to develop interventions to enhance self-compassion.

Key words: self-compassion, chronic illness, coping, depression, anxiety, stress

Associations between self-compassion, psychological distress and coping in chronic illness: a systematic review

Approximately 15 million people are diagnosed with a long-term condition in the UK (Department of Health [DoH], 2012), and one in three adults across the world live with multiple health conditions (Hajat & Kishore, 2018). Long-term conditions, also referred to as chronic conditions or illnesses, are defined as lasting longer than six months, with there currently being no cure (Yeo & Sawyer, 2005; Kings Fund, 2012). They require medical management and include conditions such as diabetes, asthma, chronic obstructive pulmonary disease and hypertension (Kings Fund, 2012). In regard to mortality, chronic diseases are causing an increasing number of deaths worldwide, with it being predicted that they will account for nearly three quarters of deaths by the year 2020 (World Health Organisation [WHO, 2014]). In Europe, nine of the top ten causes of death are chronic conditions (WHO, 2014). In addition, chronic conditions often require strict adherence to medications, therapeutic interventions and behaviours to maintain health (e.g., medication adherence in asthma and Parkinson's disease, and glucose control in diabetes; Daley et al., 2012; Kane et al., 2018; Stempell et al., 2005). This can be experienced as burdensome and can lead to clinically significant distress (Kane et al., 2018).

It is therefore not surprising that living with a chronic condition can have a negative impact on health-related quality of life, although this has been found to vary across conditions. For example, musculoskeletal conditions have been found to be associated with the largest impact on quality of life in comparison to other types of chronic conditions (Saarni et al. 2006). It has also been noted that individuals with chronic conditions can make upward comparisons within groups and with healthier individuals (Arigo, Suls & Smyth, 2014; Blalock, De Vellis & De Vellis, 1989), viewing themselves in a more negative light. In addition, mental health problems can be experienced more commonly in those with chronic

health conditions than the general public (Kanani et al., 2016; Baker et al., 2019). For example, individuals with chronic obstructive pulmonary disease, cerebrovascular disease and other chronic conditions have been found to experience triple the rate of mental health problems in comparison to the general population, and those with two or more long term conditions are seven times more likely to experience depression than those without conditions (NICE, 2009).

Not only is psychological distress more likely in those with chronic conditions, but this distress can exacerbate the condition and consequences. For example, a review by Katon and Kroenke (2007) found across 31 studies, individuals with both a chronic condition and low mood or anxiety reported significantly higher numbers of medical symptoms when controlling for severity of medical disorder when compared to those with a chronic condition alone (Katon & Kroenke, 2007). In addition, stress and low mood are known to be disruptive to adherence to medical treatments (DiMatteo, Lepper & Croghan, 2000; Bottonari et al. 2010), and the self-regulation of health behaviours more generally (Burg et al. 2017; Rod et al. 2009).

One quality that is being increasingly recognised as positively influencing psychological distress is self-compassion (Mauder & Levenstein, 2008; Sirois, Molnar & Hirsch., 2015). Self-compassion has been conceptualised in various ways. For example, Gilbert's (2005) social mentalities theory explains the development of compassion through an evolutionary model, with life experience shaping an individual's brain and thus their soothing system through the presence of a secure attachment. A child observes compassion in a role model, which allows them to internalise compassion themselves. Neff views self-compassion as being open to self-suffering and being kind and understanding towards oneself in response. It involves having a non-judgmental attitude toward any inadequacies, and recognising that difficulty is part of the human experience (Neff, 2003a). This social psychological

perspective breaks down self-compassion into three constructs including mindfulness, being able to take a kind psychological stance towards the self, and having a sense of common humanity.

Across research, self-compassion has been consistently and strongly associated with increased psychological well-being and reduced psychological distress, with Leary et al. (2007) proposing that self-compassion may act as a psychological buffer to the impact of negative life events by helping people to evaluate themselves and their experiences in a kinder, more accepting way. Macbeth and Gumley (2012) reviewed this relationship in mental health research, finding strong inverse associations between self-compassion and psychopathology in adults across 14 studies. Barnard and Curry (2011) replicated these associations with depression and anxiety across adult populations, and Pullmer et al. (2019) found significant relationships across 18 studies of depression in adolescents.

In the context of chronic health, self-compassion is thought to facilitate helpful responding by promoting self-kind versus self-blaming responses, and mindful acceptance of challenges (Brion et al. 2014; Friis, Consedine & Johnson, 2015). Thus, those higher in self-compassion should treat themselves with care and concern when unwell, and their compassionate reactions should enhance their ability to self-regulate and self-manage in ways that promote their physical and psychological well-being (Neff et al., 07). More specifically, self-compassionate individuals experience negative events in a more mindful, less reactive manner with less negative affect. As less emotional management is required, less self-regulatory resources are depleted. As a result, their resources are available for other tasks, including adhering to routines and interventions, making behavioural changes monitoring progress toward health goals (Neff, 2003a). Overall, this emotional stability should support individuals in taking responsibility for their health (Friis et al., 2015), thus enhancing self-management.

As well as self-compassion directly influencing wellbeing and psychological distress, it may also indirectly influence these through coping. More specifically, self-compassion is being increasingly recognised as a predictor of coping (Allen, Goldwasser & Leary, 2011). Coping is viewed generally as a response to stressors or negative events (Allen & Leary, 2010). In addition, theoretical models suggest that how an individual appraises a stressor, such as an illness or symptom, explains their emotional and behavioural response to the situation (i.e. how they cope; Gross & John, 2003). This is in line with Folkman and Lazarus' (1984) cognitive transaction model of stress, which highlights the central role of the individual's cognitive and behavioural coping responses in exacerbating or attenuating the stress response. Theoretically, Allen and Leary (2010) hypothesise that those who are self-compassionate are less likely to catastrophize negative situations, experience anxiety following a stressor, and avoid challenging tasks for fear of failure. In line with this, high self-compassion has been strongly associated with more adaptive coping skills in the general population such as positive cognitive restructuring (Allen & Leary, 2010), as well as low self-compassion correlating with avoidance-oriented coping (Neff et al., 2005), lower acceptance (Leary, 2007) and rumination (Neff, 2007).

To date, no systematic review has looked specifically at the relationships between self-compassion and psychological distress in chronic illness groups. Likewise, only two reviews have linked self-compassion to coping, and more specifically, to emotion regulation in those with mental health difficulties (Finlay-Jones, 2017; Inwood & Ferrari 2018), with Finlay-Jones (2017) finding self-compassion to be linked to key mechanisms of coping and emotional regulation in those with anxiety and depression.

Aims

It is evident that individuals living with chronic conditions experience significant consequences that influence mental health, namely increased stress, depression and anxiety.

Self-compassion has been shown to be important for wellbeing and coping in the general population. It is also theoretically postulated to influence wellbeing and the coping strategies that are adopted to manage chronic illnesses, therefore this review sets out to review the empirical literature relating these concepts.

Whilst individual studies have begun to highlight the role of self-compassion in separate chronic illnesses, a synthesis of findings across studies and populations will highlight similarities and differences, and aid conclusions that can be drawn. Therefore the current systematic review aims to synthesise findings across chronic conditions to consider how self-compassion is related to specific outcomes of distress (i.e. depression, anxiety and stress) and coping. By summarising findings, this review will help to inform clinical practice by highlighting a potential factor (i.e. self-compassion) to be targeted through interventions to promote wellbeing in those with chronic conditions. As efforts are being made to better understand distress caused and support ways of managing, as well as reduce healthcare costs, it appears important to understand such links as much as possible. The review question is therefore the following: what are the associations between self-compassion, psychological distress and ways of coping in adults with chronic health conditions?

Method

The review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009). As outlined by the Centre for Reviews and Dissemination guidance (University of York, 2009), the review followed a circular process involving regular reviewing of the literature and development of a research question based on the current evidence base.

Identification of Studies

Following consultation with an academic librarian, the following databases were searched on 20th November 2019; PsycINFO, Medline, Cumulative Index to Nursing and

Allied Health (CINAHL) and Web of Science The named databases were selected in order to gather articles from a range of disciplines (i.e. psychology, medicine and nursing). The Boolean operators AND and OR were used as appropriate to combine the search terms. Databases were searched for terms and keywords associated with self-compassion and chronic conditions listed by the World Health Organisation, as well as those listed as chronic across the research literature. The search for each database is listed within Tables 1.1-1.4. Conditions were searched for individually and thesaurus features were utilised to ensure all relevant conditions and articles were captured, thus a combination of free text searches and subject headings were used. A search was also made through the reference lists of those articles deemed relevant to identify any additional papers. No date limits were placed on the search. Duplicates were removed prior to screening. Articles were then selected for the review via a process of title and abstract screening, followed by full text screening against the inclusion and exclusion criteria.

<Insert Table 1.1, 1.2, 1.3, 1.4>

Inclusion and Exclusion Criteria

Inclusion criteria were used to assess article eligibility (see table 1.5). Papers had to include adult clinical samples (i.e. individuals who have a current medical diagnosis of a chronic condition). Research including only those who were seeking a diagnosis or had recovered from their condition were not included due to the expected heterogeneity in outcomes. Research that involved only individuals who had previously received a diagnosis of cancer were not included. Papers were also not included if it was unclear whether participants were in remission or not, given would likely have a different day to day experience in comparison to those who continue to live with a condition.

<Insert Table 1.5>

Papers were required to have been published in a peer-reviewed journal to ensure a basic standard of quality was reached and the exclusion of studies written in languages other than English was decided upon based on time and cost implications of translating papers in multiple languages. Studies were also required to have used validated measures for the main variables of interest (i.e. self-compassion, psychological distress [depression, anxiety, stress] and coping). Folkman & Lazarus (1984) define coping as an individual's cognitive and behavioural efforts to manage a demand that is appraised as taxing. Therefore, validated measures that measured coping (as defined above) were included. Those involving coping-related questions were also included if once examined, were deemed to be appropriate. Figure 1.1 outlines the study selection process.

<Insert Figure 1.1>

Data Extraction

Data was extracted into three predefined tables developed by the researcher, including study characteristics (country, population, design and outcomes), participant characteristics (number, age range, mean age/standard deviation and gender) and aims and findings. Additional data was captured within to relevant information such as time since diagnoses, comorbidities, where participants were recruited and ethnicity (see Table's 1.6-1.8)

<Insert Table 1.6, 1.7, 1.8>

Risk of Bias in Individual Studies

There is no current gold standard for the assessment of quality in quantitative research and so the Appraisal tool for Cross-Sectional Studies (AXIS; Downes et al., 2016) was chosen for the current review given a large proportion of the studies were observational, cross-sectional studies. The AXIS is a 20-item checklist that assesses quality in relation to the introduction, method, results, discussion and other sections, with the reviewer providing an answer of yes or no to each item depending on whether the point was area was addressed within

each paper. The explanatory help text developed for the appraisal tool was used to support the process. The original AXIS tool is attached in Appendix 1-B, with table 1.9 and 1.10 outlining questions and responses for each paper. Content and construct validity of the tool have been ascertained (Downes et al., 2016). In addition, two questions were added that would capture additional questions for research that was longitudinal in design. These were adapted from the Critical Appraisal Skills Programme (CASP; Singh, 2018) cohort longitudinal checklist and centred around the follow up period, given this was the only area of quality assessment not already captured within the AXIS (see Table 1.9-1.10). The quality appraisal was completed independently by the main researcher, with a subsample of three papers chosen at random and peer inter-rated. The few discrepancies were discussed with final ratings agreed by consensus.

Results

Figure 1 presents the process and numerical outcome of the full search in a PRISMA diagram (Moher et al., 2009). The search yielded 3175 results, with a total of 1571 duplicates removed. From the 1604 records that were screened using the title and abstract, a further 1445 papers were excluded. A shortlist of 159 full-text articles were retrieved and assessed for eligibility in the review. Four articles were removed due to being published in languages other than English and a further 130 were excluded based on the inclusion and exclusion criteria outlined, with reasons in Figure 1. Twenty-five articles were therefore selected for inclusion in this review.

Quality Appraisal

Studies included in this review were assessed for risk of reporting bias using the AXIS checklist (Downes et al., 2016) as described above. A breakdown of raw scores for each paper can be found in Table 1.9 and 1.10. Whilst there was variation in quality, the average yes response across studies and questions was 65.4%. The area that was most limited within papers was methodology, with papers not providing clear information around sample size justification

and non-responders. A large number of studies were also unable to evidence their sample was representative of the larger population, however this was mainly down to the process of recruitment, with most studies using convenience samples and social media to recruit.

Data Synthesis

A meta-analysis was not performed as part of the current review due to the heterogeneity in populations and study characteristics (e.g., outcome measures used) in the included papers (Higgins & Thompson, 2002). A narrative synthesis was therefore conducted, integrating and summarising the findings of each paper (Green, Johnson & Adams, 2006).

Study Characteristics

Descriptive characteristics

Characteristics of the included studies are summarised in Table 1.6, which will be referred to by number for ease of reference. As four studies were part of the same wider study with an overlap in participants (3-6), data from these studies were combined where appropriate. Study publication dates ranged from 2012 to 2020 and were conducted in a diverse range of countries. four were conducted in the UK (1, 7, 9, 14), three in Portugal (3-6, 8, 15), three in Canada (11, 16, 17), six in the USA (2, 12, 20, 21, 23, 24), one in Australia (22) and one in China (25). Four studies included participants from multiple countries, with one including the USA and Puerto Rico (10), a second included 5 countries (13; Canada, China, Namibia, Puerto Rico & USA), a third had participants from Canada, USA, UK, Australia/New Zealand and Europe (18) and the final involved the combination of the UK, Canada and USA (19).

Of the different chronic illness populations involved, two included epilepsy (1, 7), five chronic pain (3-6, 8, 9, 17, 24), five HIV (2, 10, 13, 20, 23), one cancer (25), three diabetes (12, 14, 22), one COPD (11), one IBS (16) and one Parkinson's disease (21). Four studies included mixed chronic illness samples, such as a cancer group and a separate chronic illness

group (15), a combination of arthritis and IBS (18) and one study included 5 medical samples (19; 2 x fibromyalgia, 2 x cancer and 1 chronic fatigue syndrome).

All of the 25 studies adopted a cross-sectional design, exploring associations between self-compassion with outcomes related to depression, anxiety, stress and/or coping. Ten included mediator and/or moderator models as part of their analysis. Three studies also included a longitudinal component in their design, following up women with chronic pain after 6 and 12 months (6), adults with diabetes after three months (12) and individuals with cancer after completion of treatment (25).

Outcome measures

All studies used the Self Compassion Scale (SCS) validated by Neff (2003), with eleven using the full 26-item version (Neff, 2003b) and eleven using the short-form (SCS-SF; Raes et al., 2011) which includes 12 items. No other measures were used to capture self-compassion, highlighting consistency and homogeneity in this variable. The measure includes two domains (positive and negative) and has a two-factor structure. Within each domain are three subscales, with the positive component having self-kindness, common humanity and mindfulness subscales. The negative component has subscales on self-judgement, isolation and overidentification (with thoughts). The SCS-SF is said to have the same higher-order one factor structure as the full scale, alongside six second-order factors (Raes et al., 2011).

All but one of the studies included depression, anxiety or stress as an outcome. Nine studies used the Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995; 3-6, 8, 15, 16, 19, 21). A further two studies used the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983; 1, 11) to measure depression and anxiety in their samples. Measures used to assess depression alone included the Patient Health Questionnaire (PHQ-9/8; Kroenke, Spitzer & Williams, 2003; 7, 14, 22, 25), the British Columbia Major

Depression Inventory (BCMDI; Iverson, 2002; 9), the Centre for Epidemiological Studies Depression Scale (CES-D; Hautzinger & Bailer, 1993; 10, 20, 23), the Beck Depression Inventory (BDI; Beck, Steer & Brown, 1996; 17) and the Positive and Negative Affect Scale (PANAS; Watson, Clark & Tellegen, 1988; 20, 24). The PANAS was developed as a measure of both depression and anxiety). Only one measure was used to capture anxiety (Generalised Anxiety Disorder-7; GAD-7; Spitzer et al., 2006; 7) and stress individually (Perceived Stress Scale; PSS; Cohen, Kamarck & Mermelstein, 1994; 2, 18, 19).

Five studies included an outcome that reflected coping within a chronic illness sample. Again, a number of measures were used, with only one scale being used twice (Coping Strategies Questionnaire; CSQ; Swartzman et al., 1994; 8, 24). Other tools used were the Coping Efficacy Scale (CES; Tucker, Brust & Richardson, 2002; 7), the Cognitive Emotion Regulation Questionnaire (CERQ; Jermann et al., 2006; 12) and the Brief COPE (Carver, 1997; 18).

Participant Characteristics

The characteristics of the participants included across the studies are shown in Table 1.7 outlining the sample size, gender, mean age (and standard deviation), time since diagnosis and where recruited. Data will also refer to 22 studies, given four participant samples overlapped. In total, there were 9142 participants across samples, with the smallest including 86 individuals (5) and 1766 participants in the largest (8). Where specified, ages ranged from 18 to 89 however only 9 of the 21 studies provided age ranges (2, 3, 8, 10, 16, 18, 21, 22, 25). One study (1) provided the number of individuals falling within set age brackets but did not specify actual ages of their participants. In regard to mean ages, 17 of the studies provided mean ages, with the overall grand mean age across papers being 47.74 years. Two (7, 14) alternatively provided medians of 36 and 66 years. Whilst most studies included both genders, one study (with four papers) included females only (3-6) and one study used a male

only sample (20). Of the 18 studies which included both genders, 10 had predominantly female participants (>60%; 1, 3-6, 7, 8, 9, 12, 15, 16, 18, 24).

Studies recruited using convenience samples, with twelve using community samples (i.e. advertisements, newsletters), six using clinical samples (i.e. recruited at routine clinics) and four studies sampling from both clinical and community settings. Out of the 25 studies, 18 documented the participants' time since diagnosis. The mean length of diagnosis for 17 studies ranged from 2.47 years (2) to 14.90 years (22), with 10% of the sample having received their diagnosis less than 6 months ago (15). Eight studies made reference to the proportion of their sample having a comorbid chronic illness, with this ranging from 41% (16) to 67% (13). Finally, twelve of the studies documented the ethnicity of their participants, with six (1, 9, 14, 18, 19, 21) using predominantly white samples (<60%), two using a predominantly African American or black sample (2, 12) and four using a mixed ethnic sample (13, 20, 23, 24).

Significant Findings

The aims and main findings of each of the studies included in the review are presented in Table 1.8.

Relationships between variables

Self-Compassion and Distress

One study on IBS looked at distress operationalised as the combined score of the depression, anxiety and stress questions within the DASS. It found self-compassion was inversely related to psychological distress (large effect size; 16). In addition, self-compassion also mediated the relationship between dispositional mindfulness and psychological distress; whereby those with higher mindfulness had greater self-compassion and lower levels of distress.

Self-Compassion and Depression

Self-compassion was significantly and negatively associated with depression across 20 studies, highlighting that higher scores were correlated with lower scores in depression. Effect sizes ranged from medium (general chronic illness, cancer, Parkinson's; 15, 25, 21) to large (epilepsy, non-epileptic, HIV, COPD, diabetes; 1, 7, 10, 20, 23, 11, 14, 22). Effect sizes in pain were medium to large (3-6, 8, 17, 24). One study (6) also found significant associations across three time points (baseline, 6 and 12 months; large effect).

In the 3 studies that reported scores from the two factor structure of the SCS scale (i.e. the positive and negative domains of self-compassion), depression was found to significantly negatively correlate with the positive domain (which the authors labelled self-kindness, positive self-compassion and self-compassion) with a small to medium effect size. Depression positively and significantly correlated with the negative domain (which the authors labelled self-judgement and negative self-compassion; 10, 15, 25) with medium to large effect sizes. In one longitudinal study (25) with individuals with cancer, negative self-compassion at time 1 (1 week after diagnosis) was significantly associated with depression at time 2 (1 week after starting treatment; medium effect), but not at time 3 (1 week after finishing treatment). Alternatively, positive self-compassion at time 1 was not associated with depression at time 2, but this relationship was significant at time 3 (small effect size).

Ten studies included regression analyses, finding self-compassion accounted for a significant amount of variance in depression, across conditions including epilepsy (1), chronic pain (8, 9, 17, 24), HIV (10), cancer (15, 25), chronic illness generally (15) and diabetes (22). In 6 studies that entered self-compassion into the model independently or referred to unique variance explained, this ranged from 9.4% in a pain sample (8) to 33.8% (1) in an epileptic sample. Two controlled for illness and demographic variables (1, 9) and a third controlled for partner effects (17). One HIV study found self-judgement (the negative domain of the SCS) explained 43.2% variance in depression alongside self-esteem and

symptom management self-efficacy, when controlling for demographic variables. Self-judgement was the strongest predictor, yet self-kindness did not significantly predict variance (10). In another study which similarly used the two factor structure of the SCS (15), self-compassion (the positive domain) and self-judgement (the negative domain) independently accounted for 51% of depression variance in a general chronic illness group and 37% in a cancer group. However, in the first group, self-judgement was significant predictor, whereas in the cancer sample, self-compassion was the significant predictor.

Finally, whilst most studies observed this relationship in a cross-sectional manner, one study in pain (6) also observed how self-compassion at baseline predicted depressive symptoms at 6 and 12 months, which was above and beyond variance explained by functional impairment. A second longitudinal cancer study (25) alternatively highlighted that whilst self-compassion at baseline did initially predict variance in depression, it did not predict later depression when controlling for cancer symptoms.

In addition to correlation and regression models, three studies employed more complex analyses (3, 5, 6) to explore how self-compassion may influence relationships between depression and other constructs in those with chronic pain. More specifically, self-compassion was found to significantly moderate the relationships between pain intensity, cognitive fusion (the degree to which individuals are attached to their thoughts) and depression (3), as well as that between functional impairment and depression (6). A further study (5) found activity engagement moderated the relationship between self-compassion and depression, as well as there being a significant, direct path for self-compassion to depressive symptoms.

Self-Compassion and Anxiety

Self-compassion was inversely associated with anxiety across ten studies, with significant correlations found across conditions. Effect sizes ranged from medium (HIV,

Parkinson's disease, cancer; 20, 21, 25) to large (epilepsy, non-epileptic, COPD, diabetes; 1, 7, 11, 22). Effect sizes in pain were medium to large (8, 17).

When one study used scores from the two-factor structure, self-judgement was more strongly associated with anxiety (15; positive relationship, medium effect) than self-kindness (negative relationship, small effect) in the chronic illness sample. The associations however were not observed in their cancer sample. In a second study (25) using only a cancer sample, the SCS positive subscale score had a small negative association with anxiety, whereas the negative subscale showed a positive medium correlation. In the same study (25), negative self-compassion at time 1 (1 week after diagnosis) was significantly associated with anxiety at time 2 (1 week after starting treatment; medium effect) and time 3 (1 week after finishing treatment; medium). Positive self-compassion at time 1 was significantly associated with anxiety at time 2 (small effect), but this relationship was not observed at time 3.

Six studies included regression analyses, finding self-compassion accounted for a significant amount of variance in anxiety, across conditions including chronic pain (8, 9, 17), HIV (13), diabetes (22) and cancer (25). Each of the studies reported entering self-compassion into the model independently or referred to unique variance explained, with this ranging from 1.4% (8) to 41% (13) in pain and HIV samples. Two controlled for illness and/or demographic variables (9, 13) and a third controlled for "known confounders" (22).

One study found the SCS negative and (to a lesser extent) positive domains at baseline were also significantly associated with anxiety symptoms at baseline, explaining 18% of the variance (25). The same study (25) observed how total self-compassion, positive self-compassion, but not negative, at baseline significantly predicted anxiety at 6 and 12 months, when controlling for cancer symptoms at baseline.

In a moderator analysis in a chronic pain sample, self-compassion was found to moderate the relationship between threatening illness appraisals, cognitive fusion and anxiety

(9). Thus, whilst negative appraisals and fusion to anxious thoughts predicted anxiety, this was mitigated when individuals were self-compassionate.

Self-Compassion and Stress

Seven studies found self-compassion was significantly and negatively related to stress, across conditions. Effect sizes ranged from medium (Parkinson's disease; 21) to large (chronic pain, IBS, arthritis, chronic fatigue syndrome and cancer; 8, 19, 18). For those who looked at the two domains of self-compassion, stress was significantly associated with both the positive and negative domains in a chronic illness and a cancer sample (15). In the chronic illness group, there was a medium effect size for self-compassion (positive domain) and stress, yet a large effect for self-judgement (negative domain) and stress. The reverse relationship was found for the cancer sample.

Three studies included regression analyses, finding self-compassion accounted for a significant amount of variance in stress, across HIV (2) chronic pain (8), chronic illness generally (15) and cancer (15). Only one study made reference to controlling for confounders however (i.e. gender, 2) The HIV study (2) found self-compassion predicted lower stress and the chronic pain study (8) reported how self-compassion significantly accounted for an additional 8.1% in stress scores. In a study which used the two factor structure (15), self-compassion and self-judgement independently accounted for 48% of stress variance in a general chronic illness group and 33% in a cancer group. However, as with depression, self-judgement was the significant predictor in the chronic illness group, whereas in the cancer sample, self-compassion was the only global predictor.

In assessing this further through a path analysis (18), when accounting for indirect mediating relationships (i.e. self-compassion – coping – stress), the direct relationship between self-compassion and stress remained significant. Therefore, self-compassion was

linked to lower stress through routes beyond coping, and this did not differ for the IBS or arthritis sample.

Self-Compassion and Coping

Across four studies, self-compassion was found to be significantly correlated with different aspects of coping (2, 8, 12, 18, 24). More specifically, in one pain sample (8), self-compassion was positively associated with rational coping (medium effect), and negatively with detached coping and experiential avoidance (large effect). It was not, however, significantly associated with avoidant coping. In IBS (18), self-compassion was significantly and positively associated with adaptive coping strategies (active coping, planning, positive reframing, acceptance; medium effect sizes) and significantly and negatively associated with maladaptive (self-blame, behavioural disengagement, denial; medium effect sizes). Whilst it was significantly linked to instrumental support seeking, this effect size was small. The same pattern of results were found in the same study in a sample with arthritis. The only difference was that the relationships between self-compassion and denial, and self-compassion and acceptance in the arthritis sample had small effect sizes and self-compassion and positive reframing, and self-compassion and self-blame had large effect sizes

In a study that reported the positive and negative aspects of self-compassion in a diabetes sample (12), the self-compassion positive domain significantly correlated with positive coping strategies (i.e. acceptance and positive reframing; small effect), and the SCS negative domain positively and significantly correlated with negative coping strategies (i.e. catastrophising; medium effect). In another pain sample (24), self-compassion was significantly and negatively correlated with pain catastrophising (medium effect size).

Three studies included regression analyses, finding generally that self-compassion significantly predicted more successful coping (8, 12, 24), with self-compassion accounting for 29% of variance in pain acceptance, 7% in traditional pain coping, 23% in flexibility in

pain coping in a chronic pain sample when controlling for physical symptoms (12). Similarly, self-compassion significantly accounted for an additional 8.1% in stress scores, on top of rational, avoidance and detached coping bringing the variance explained to 34.4% in a second chronic pain sample (8). One HIV study (2) found self-compassion predicted more successful coping, when controlling for gender.

Discussion

Summary of Findings

The current review aimed to explore and synthesise research on associations between self-compassion, psychological distress and ways of coping in adults with chronic health conditions. Whilst it is an area of research in its infancy, with the earliest study included published in 2012, the current review highlighted relatively consistent results across studies. Twenty studies measuring the relationship demonstrated significant correlations between self-compassion and depression across eight chronic illness population groups. Ten studies also found significant associations between higher self-compassion and lower anxiety across seven chronic illness groups, as well as seven showing significant associations between higher self-compassion and lower stress. Across the studies and outcomes, effect sizes were also relatively consistent, ranging from medium to large in size. This is consistent with a review in adults with mental health difficulties (Macbeth & Gumley, 2012), finding a large effect size in the relationship between compassion and psychopathology across 14 studies.

Whilst research has been largely correlational in nature, studies extended their findings using regression and pathway analyses. Self-compassion explained significant amounts of variance in depression, anxiety and stress levels across chronic illness groups, when controlling for demographic and illness variables, and when alongside co-variables such as coping and self-esteem. Self-compassion however was consistently the more powerful predictor. This is again in line with previous research highlighting self-compassion as a

significant predictor in variance in distress when again controlling for demographic variables in healthy adult populations (e.g. Ozyesil & Akbag, 2013; Van Dam et al., 2011). This was observed over time, with self-compassion predicting depression at 6 and 12 months in a chronic pain sample (Carvalho et al., 2020).

When studies used the two-factor structure of the SCS, the negative domain (sometimes labelled self-judgement) was consistently a stronger predictor of distress than the positive domain, as found in previous depression research (e.g. undergraduate students; Soysa & Wilcomb, 2013). In the current review, three papers found self-judgement significantly correlates with and predicts a larger amount of variance in depression than the positive domain (self-compassion). Between group differences were however observed, with self-judgement predicting more variance in depression in the chronic illness group, whereas self-kindness predicted more variation in the cancer group (Pinto-Gouveia et al., 2014). This same pattern was found in a second study using a cancer-only sample (Zhu et al., 2019), highlighting agreement across studies on group differences, particularly in relation to cancer. Authors suggest that the trajectory of a cancer diagnosis can be a particularly difficult experience, and thus may leave individuals being more likely to go on to treat themselves kindly and adopt a common humanity perspective in comparison to those with other chronic conditions (Pinto-Gouveia et al., 2014).

Longitudinally however, self-judgement did not significantly predict variance in depression or stress as time went on in a cancer sample, whereas self-kindness predicted more variance over time (Zhu et al., 2019). Researchers suggest that this may be explained by the fact for those confronting lifelong conditions, being kind and understanding of suffering at the offset supports more adaptive future functioning (Zhu et al., 2019). Alternatively, a different relationship was noted for anxiety, with self-judgement, not self-kindness, predicting significantly more variance over time in cancer (Zhu et al., 2019). It may be that

given this illness trajectory, worry and anxiety is more present, perhaps explaining why the relationship remains significant during the course of treatment. These longitudinal findings using the two-factor structure however begin to shed new doubt over previous findings that being low in self-compassion as an overarching concept may make an individual vulnerable to depression (Carvalho et al., 2020), given that a different relationship is observed when the concept is deconstructed.

In addition, self-compassion moderated the relationship between depression, cognitive fusion, pain intensity, activity engagement and functional impairment, as well as mediating the link between depression and distress and mindfulness in a pain samples. For anxiety, it moderated the relationship with illness appraisals and cognitive fusion, and finally between stress and adherence. However, only a limited number of studies and conditions have begun to explore how self-compassion may mediate or moderate relationships with outcomes, with these also being diverse in the outcomes they have included.

Alongside the clear link between self-compassion and psychological distress in chronic illnesses, self-compassion was also associated with ways of coping in five studies. Whilst measures of coping were diverse, significant associations were found for strategies labelled as both adaptive and maladaptive. These were also found across four different clinical groups. Those higher in self-compassion were found to use more adaptive coping strategies (e.g. reframing, acceptance), whereas when self-compassion was lower, less helpful strategies (e.g. denial, avoidance, catastrophising) were reported to be employed across the groups. This is fitting with Allen and Leary (2010) who propose theoretically that because individuals are more self-compassionate in relation to their difficulties, they are less likely to engage in unhelpful strategies such as catastrophising, experience less emotional distress as a result and approach situations more openly in the future. Findings are in line with research in adults generally, with self-compassion being a significant predictor of coping in adults

(Allen, Goldwasser & Leary, 2011). It has also been found to be positively associated with adaptive coping skills in the general population (Allen & Leary, 2010) and negatively with lower acceptance (Leary, 2007) and rumination (a cognitive coping strategy; Neff, 2007).

Whilst it was not the focus of the review to highlight differences in self-compassion across chronic illness groups, subtle differences were observed in the studies included. In studies which compared groups, individuals with cancer reported higher self-compassion and lower distress than those with other chronic illness (15), as did individuals with type 2 diabetes in comparison to those with type 1 diabetes. A key influencing factor that may underpin this difference is the longevity and variation in chronicity across illnesses. More specifically, whilst a diverse number of conditions are classed as chronic, some may require lifelong treatment, whereas others may require intense treatment over a shorter period, such as those with cancer. This has led to difference in thought as to whether cancer is deemed to be a chronic illness. Similarly, type 1 is often linked to more longer term, more invasive management than type 2 diabetes. This highlights that whilst a generalised “chronic condition” appears to be linked to lower self-compassion (e.g. Pinto-Gouveia et al., 2014), how manageable this is considered to be is likely to play an important influence on self-compassion levels.

Furthermore, it is important to consider factors that may have strengthened relationships observed across groups, such as longevity mentioned above, medication adherence associated with conditions such as diabetes, or unpredictability of conditions such as epilepsy, perhaps influencing how individuals feel about themselves and their condition. In addition, individuals with conditions associated with increased levels of stigma and self-blame, such as HIV, are inherently prone to higher levels of self-criticism (Earnshaw et al., 2018). Similarly, it is reported that self-compassion involves a motivational orientation to action which is said to be similar to the construct of behavioural activation in depression

(Gilbert et al., 2017). It may be the inherently similar constructs overlap in self-compassion and depression, which may inflate the association between the two.

Limitations of the Literature

An important limitation to discuss is the widely used measure of self-compassion; the SCS. The measure itself has caused recent debate in relation to its factor structure. For example, most studies within the current review used the total scale score, as originally recommended by Neff (2003b). However, numerous studies have referred to problems in doing so as the negative subscales have been shown to be more strongly linked to mental health problems than positive subscales, resulting in an inflated relationship between overall self-compassion and symptoms of mental health and distress (e.g., Lopez, 2018; Muris & Petrocchi 2016). To add to the confusion, Lopez (2015) showed using a confirmatory factor analysis how the SCS's six-factor structure also recommended by Neff could not be replicated, with an exploratory factor analysis instead suggesting a two-factor solution. In the current review, only four studies (Eller et al., 2013; Kane et al., 2018; Pinto-Gouveia et al., 2014; Zhu et al., 2019) utilised the two factor structure (i.e. the positive and negative domains of the measure). In doing so, it was found that the negative domain (labelled self-judgement) was a stronger predictor of distress than the positive domain (referred to as both self-kindness and self-compassion; 10, 15) in chronic illness but not cancer samples. This will be an important consideration to overcome in future research, especially if a pattern continues to emerge around one domain being more strongly connected to outcomes in specific groups.

In considering other factors to be mindful of when interpreting or generalising findings, it is important to note that studies were largely conducted in westernised countries. These are typically associated with a more independent way of living, with such populations thus dedicating less time to self-reflection and self-care, which are often involved in self-compassion. To illustrate this, Montero-Marin et al. (2018) observed the positive items of the

SCS to be of more importance in operationalising the self-compassion construct, yet cultural values shaped the way self-compassion was manifested. For example, having a long-term orientation and aligning with individualism could influence the strength and value associated with the positive items. Future research would benefit from conducting research in collective cultures to assess if these findings are culture-specific. In addition, whilst two studies referred to their samples being predominantly African American (Kane et al., 2018, Ventura et al., 2019), the majority of other studies included predominantly white samples. This may therefore unknowingly influence associations if limited to specific cultures. Furthermore, a number of papers were not available in the English language, which may have provided extra cultural insight. A large proportion of studies also used predominantly female samples, limiting generalisations that can be made across the genders.

Studies were heterogeneous in the use of a range of measures used to capture distress, and in particular for coping, making generalisations difficult to make. A number also included a wide variety of secondary measures, increasing the complexity of the analyses as well as making it difficult to compare findings across groups. Where some measures were used more consistently (e.g. across the chronic pain studies), these were often by the same author or research group, which may skew results. Finally, studies were mainly cross-sectional in their design, and thus were unable to prove causation for the relationship between self-compassion and distress or coping.

Strengths and Limitations of the Review Process

The review attempted to follow PRISMA guidelines as closely as possible, as well as using a rigorous methodology that can be replicated at a later point. Reporting bias was reduced by conducting the quality appraisal after data extraction. The review overall did not have the aim to exclude papers of poorer quality, therefore, all papers identified using the search that met the inclusion criteria were included. Multiple databases were consulted and

relevant papers were subsequently hand searched, meaning it was unlikely appropriate papers were omitted, yet unpublished or non-peer reviewed were removed.

However, grey material was not included and some papers were not assessed due to being unavailable in the English language. Similarly, it should be noted that there may be the presence of publication bias, given all studies reported significant findings. In considering the inclusion criteria, samples included were participants who had received a diagnosis and were not classed as “recovered” whereas those seeking a diagnosis or those who previously had a diagnosis may have provided additional insight into the challenges faced.

Clinical Implications

The findings of the current review have important clinical implications given the number of individuals living with chronic conditions around the world. By identifying risk factors, professionals across services can work together to assess the impact or presence of these risks, as well as developing preventative programmes that may promote healthier adjustment. In line with this, while conclusions are tentative given the largely cross-sectional nature of the data, current findings suggest that enhancing self-compassion may be useful in reducing psychological distress such as depression, anxiety or stress in such groups. In considering ways of doing so, a recent review (Austin, 2020) highlighted that compassion-based interventions utilised across twenty studies revealed positive results in reducing anxiety and depression in those with chronic conditions. This included both brief and comprehensive interventions (e.g. Compassion Focused Therapy [CFT]; Gilbert, 2009), ranging from providing a single compassion exercise to up to 12 sessions. CFT draws on evolutionary and developmental psychology alongside neuroscience, with the intervention using compassionate mind training to help individuals develop experiences of inner warmth, safeness and soothing via compassion and self-compassion. Whilst samples were mainly those with cancer or pain, most rated sessions as accessible, with additional benefits

including condition acceptance, improved emotion regulation and reduced feelings of isolation. In addition, a classroom mindfulness-based intervention has demonstrated efficacy in improving self-compassion and coping self-efficacy (Taylor et al., 2020). Furthermore, Biber and Ellis (2017) found self-compassion interventions were just as effective as other behaviour change interventions at improving the self-regulation of health behaviour, which will be important for the field to build upon based on group differences in self-compassion.

When providing interventions however, it is important to be mindful of the shortfall of compassion measures as mentioned, with Strauss (2016) explaining that without adequate measures of compassion, it is difficult to study, measure or evaluate whether interventions designed to enhance this are effective. It is also important to consider differences within groups as outlined above, and thus whether it may be more useful to target a particular domain of self-compassion based on the population. Overall, research to date highlights both potentially successful and feasible ways for clinical services to support individuals to not only improve their wellbeing and ways of coping, but it may also have a positive impact on their condition.

Future Directions

Based on the above, future research would benefit from exploring differences between chronic condition samples in order to provide interventions that are tailored to specific areas of difficulty (e.g., self-judgement). Employing longitudinal, predictive research designs that explore self-compassion and the positive and negative domains will hopefully add to unpick what relationships do exist, as well as implying causation. Additional research across genders, non-western countries and cultures and additional conditions (both those that require daily management and those that do not) will also hopefully allow understanding around levels of self-compassion, as well as how interventions might support groups differently, ultimately allowing the field to develop. Whilst it was not the aim of this

research, future studies could benefit from including non-clinical samples (e.g. those who have not sought a diagnosis, or have been referred to as “recovered”) to understand any differences between groups, and whether or not different outcomes are found when the “chronicity” label is removed. Younger groups (i.e. children and teenagers) were also not included in the current review due to the likelihood their coping may differ greatly due to their stage of life, yet two samples used predominantly elderly groups, which may have similar diverse differences in lifestyle and coping (Edwards et al., 2019; Eller et al., 2013). Therefore, assessing different age groups in the future may again shed light on any group specific differences in self-compassion.

Whilst a handful of studies included both distress-related and coping outcomes, only one (Sirois, Molnar & Hirsch, 2015) made links between the two in relation to how self-compassion connected the two concepts. This will be an interesting area of exploration moving forward, potentially highlighting how the two either interact or predict one another. In addition, given the shortfalls of the SCS measure outlined above, research would also benefit from incorporating additional measures of compassion in order to validate relationships that have emerged in research so far, given the SCS is based on Neff’s (2003a) definition alone. One such measure might include the Sussex-Oxford Compassion Scales (SOCS; Gu et al., 2020).

Conclusions

Based on the studies included in this review, research highlights higher self-compassion is associated with lower levels of distress, and the use of more adaptive coping strategies across chronic illness samples. These associations were also consistently medium to large in effect size. The conclusions however are tempered by concern around the way self-compassion is measured, as well the use of cross-sectional designs across studies. Further research using well-validated measures and longitudinal designs are needed.

Understanding the importance of compassion is important clinically to facilitate the development of interventions which support adjustment and management throughout the disease course given the lifelong duration of such conditions.

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Figure 1. PRISMA Flow Diagram of Papers (Moher et al., 2010)

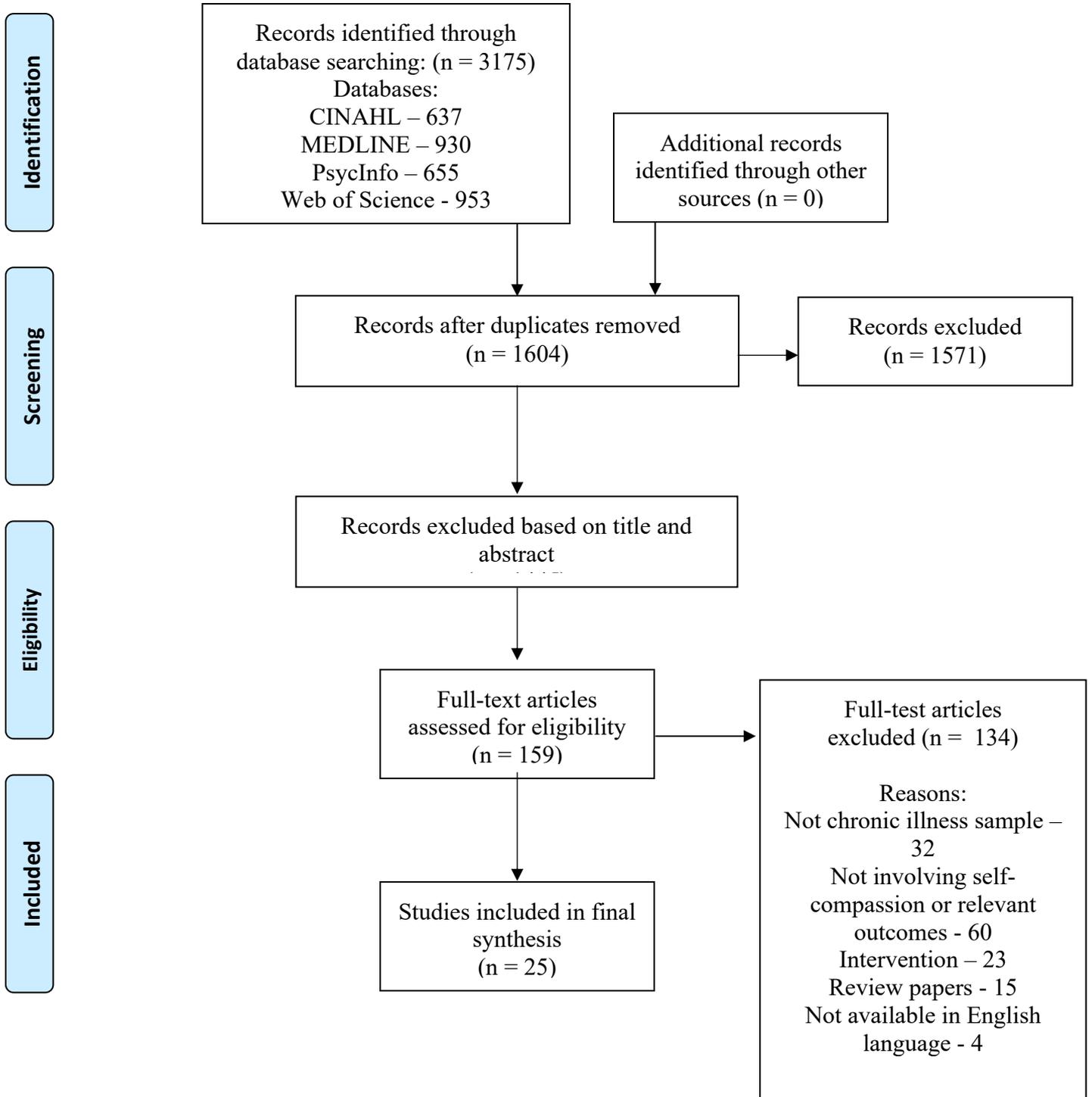


Table 1.1: Search strategy for PsycInfo

	Search Terms (Boolean)
	(DE "Self-Compassion") OR "self-compassion" OR "self compassion" OR "compassion"
AND	DE "Chronic Fatigue Syndrome" OR DE "Chronic Illness" OR DE "Chronic Obstructive Pulmonary Disease" OR DE "Chronic Pain" OR DE "Diabetes" OR DE "Diabetes Insipidus" OR DE "Diabetes Mellitus" OR DE "Cerebrovascular Accidents" OR DE "Cerebrovascular Disorders" OR DE "Respiratory Tract Disorders" OR DE "Dementia" OR DE "Dementia with Lewy Bodies" OR DE "Hypertension" OR DE "Heart Disorders" OR DE "Neoplasms" OR DE "Neuromuscular Disorders" OR DE "Neuropathic Pain" OR DE "Neuropathology" OR DE "Cardiovascular Disorders" OR DE "Arthritis" OR DE "Kidney Diseases" OR DE "Multiple Sclerosis" OR DE "Parkinson's Disease" OR DE "Migraine Headache" OR DE "Huntingtons Disease" OR DE "Epilepsy" OR DE "Epileptic Seizures" OR DE "HIV" OR DE "Obesity"
OR	"chronic illness*" OR "chronic health" OR "chronic condition*" OR "chronic diseas*" OR "diabet*" OR "asthma*" OR "cancer*" OR "stroke" OR "motor neuron*" OR "chronic fatigue" OR "fibromyalgia" OR "irritable bowel*" OR "IB*" OR "COPD" OR "chronic obstructive pulmonary*" OR "chronic pain" OR "respiratory" OR "dementia" OR "hyperten*" OR "heart failure" OR "heart disorder" OR "arthritis" OR "neuromuscular" OR "cardiovascular" or "kidney dis*" OR "multiple sclerosis" OR "parkinson*" OR "migraine" OR "headache" OR "obes*" OR "HIV" OR "epil*" OR "huntington*" OR "Alzheimer*"

Note: DE (PsycInfo subject heading/thesaurus term)

Table 1.2: Search strategy for MEDLINE

	Search Terms (Boolean)
	"self-compassion" OR "self compassion" OR "compassion
AND	(MH "Fatigue Syndrome, Chronic") OR (MH "Chronic Disease") OR (MH "Pulmonary Disease, Chronic Obstructive") OR (MH "Chronic Pain") OR (MH "Diabetes Mellitus") OR (MH "Cerebrovascular Disorders") OR (MH "Dementia") OR (MH "Frontotemporal Dementia") OR (MH "Dementia, Vascular") OR (MH "Dementia, Multi-Infarct") OR (MH "Lewy Body Disease") OR (MH "Hypertension") OR (MH "Arthritis") OR (MH "Neuromuscular Diseases") OR (MH "Cardiovascular Diseases") OR (MH "Kidney Diseases") OR (MH "Multiple Sclerosis") OR (MH "Parkinson Disease") OR (MH "Migraine Disorders") OR (MH "Headache Disorders") OR (MH "Huntington Disease") OR (MH "Epilepsy") OR (MH "Neoplasms") OR (MH "Obesity") OR (MH "HIV")
OR	"chronic illness*" OR "chronic health" OR "chronic condition*" OR "chronic diseases*" OR "diabet*" OR "asthma*" OR "cancer*" OR "stroke" OR "motor neuron*" OR "chronic fatigue" OR "fibromyalgia" OR "irritable bowel*" OR "IB*" OR "COPD" OR "chronic obstructive pulmonary*" OR "chronic pain" OR "respiratory" OR "dementia" OR "hyperten*" OR "heart failure" OR "heart disorder" OR "arthritis" OR "neuromuscular" OR "cardiovascular" or "kidney dis*" OR "multiple sclerosis" OR "parkinson*" OR "migraine" OR "headache" OR "obes*" OR "HIV" OR "epil*" OR "huntington*" OR "Alzheimer*"

Note: MH (MEDLINE subject heading/thesaurus term)

Table 1.4: Search strategy for Web of Science

Search Terms (Boolean)	
	("Self-Compassion") OR "self-compassion" OR "self compassion" OR "compassion"
AND	"chronic illness*" OR "chronic health" OR "chronic condition*" OR "chronic diseases*" OR "diabet*" OR "asthma*" OR "cancer*" OR "stroke" OR "motor neuron*" OR "chronic fatigue" OR "fibromyalgia" OR "irritable bowel*" OR "COPD" OR "chronic obstructive pulmonary*" OR "chronic pain" OR "respiratory" OR "dementia" OR "hyperten*" OR "heart failure" OR "heart disorder" OR "arthritis" OR "neuromuscular" OR "cardiovascular" OR "kidney dis*" OR "multiple sclerosis" OR "parkinson*" OR "migraine" OR "headache" OR "obes*" OR "HIV" OR "epil*" OR "huntington*" OR "Alzheimer*

Note: there is no thesaurus function on Web of Science

Table 1.5: Inclusion and exclusion criteria used to identify relevant papers

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> • Quantitative studies exploring the relationship between self-compassion and psychological distress (depression, anxiety and/or stress), or self-compassion and coping • Adults with one or more chronic illnesses (current diagnosis) • Includes a validated measure of self-compassion and a validated measure of coping, depression/anxiety/stress • peer-reviewed 	<ul style="list-style-type: none"> • Studies written in a language other than English • Case studies • Studies that do not report relationship between self-compassion and psychological distress or coping

Table 1.6: Summary of Study Characteristics

Authors, year and study no.	Country	Population/ diagnosis	Design/ analysis	Measure of SC	Other outcomes
1. Baker, Caswell & Eccles (2019)	UK	Adults with a diagnosis of epilepsy	Correlational – associations, regression	SCS	HADS, BRS
2. Brion, Leary & Drabkin (2013)	USA	People living with HIV	Correlational - regression	SCS-SF	PSS, RIQ, subscales of the HARS
3. Carvalho et al. (2018)	Portugal	Women diagnosed with a chronic pain condition	Correlational – associations, mediator moderator analysis	SCS-SF	DASS-21, NPRS, CFQ
4. Carvalho et al. (2019)	Portugal	Women with chronic musculoskeletal pain	Correlational – associations, mediator analysis	SCS-SF	DASS-21, NPRS, CPAQ-8, MAAS
5. Carvalho et al. (2019)	Portugal	Women diagnosed with a chronic pain condition	Correlational – associations, mediator analysis	SCS-SF	DASS-21, FCS, SSPS, NPRS, WSAS
6. Carvalho et al. (2020)	Portugal	Women with chronic musculoskeletal pain	Correlational & longitudinal - associations, analysis of variance over time, moderator analysis	SCS-SF	DASS-21, NPRS, WSAS, MAAS

Authors, year and study no.	Country	Population/ diagnosis	Design/ analysis	Measure of SC	Other outcomes
7.Clegg, Sirois & Reuber (2019)	UK	Adults with epilepsy, psychogenic nonepileptic seizures and controls	Correlational – associations, comparison of means	SCS-SF	GAD-7, CES, PHQ-9, EQ-5D-3L, LSSS-3
8. Costa & Pinto-Gouveia (2013)	Portugal	Individuals with rheumatoid arthritis and chronic pain	Correlational – associations, regressions	SCS	DASS, CSQ, AAQ-II
9.Edwards et al. (2019)	UK	Adults with chronic pain	Correlational – regression	SCS	BCMDI, SIP, CPAQ, CPVI, BPCI-2, PASS
10.Eller et al. (2013)	USA & Puerto Rico	Persons living with HIV	Correlational – associations, regression	SCS-SF	CES-D, RSES, HIVSMSES
11.Harrison et al. (2017)	Canada	Adults with COPD	Correlational – associations, comparison of means	SCS-SF	HADS, BFNE, SGS, COPD items, CRQ-SR, PRAISE
12.Kane et al. (2018)	USA	Adults with T2 diabetes	Correlational & longitudinal - associations, prediction over time	SCS	Physical symptom burden, CERQ, IPQ-R
13.Kemppainen et al. (2013)	Various	Persons living with HIV	Correlational – associations, comparison of means	SCS-SF	SCL-90, SSC-HIVrev

Authors, year and study no.	Country	Population/ diagnosis	Design/ analysis	Measure of SC	Other outcomes
14.Morrison et al. (2019)	UK	Adults with T2 diabetes	Correlational – associations	SCS	PHQ-9, DDS-17
15.Pinto-Gouveia et al. (2014)	Portugal	Cancer patients, patients with chronic illnesses and controls	Correlational – associations, regression, comparison of means	SCS	DASS, WHOQOL-BREF
16.Potter, Hunter & Morrison (2020)	Canada	Adults with IBS	Correlational – associations, mediator moderator analysis	SCS	DASS-21, Rome III, HFRDIS
17. Santerre-Baillargeon et al. (2018)	Canada	Women with vulvovaginal pain (provoked vestibulodynia) and their partners	Correlational – associations, actor-partner independence model	SCS	Trait scale of STAI, BDI, FSDS, numerical pain rating, CSI
18.Sirois, Molnar & Hirsch (2015)	Various	Individuals with arthritis and IBD	Correlational – associations, comparison of means, mediator moderator analysis	SCS	Brief COPE, CE, PSS
19.Sirois & Hirsch (2019)	UK, USA, Canada	5 samples (2 x fibromyalgia, 2 x cancer, 1 x CFS)	Correlational – associations, mediator analysis	SCS-SF	DASS-21, PSS, MOS-GA

Authors, year and study no.	Country	Population/ diagnosis	Design/ analysis	Measure of SC	Other outcomes
20. Skinta, Fekete & Williams (2019)	USA	People living with HIV	Correlational – associations, mediator moderator analyses	SCS-SF	CES-D, STICSA, PNAS, HIV Stigma Scale, HIS
21. Stutts et al. (2020)	USA	Individuals with Parkinson's Disease	Correlational – associations, regressions	SCS	DASS, LOS, PGI, SLS
22. Ventura et al. (2019)	Australia	Adults with T1 or T2 diabetes	Correlational – associations, regression, comparison of means	SCS-SF	PHQ-8, GAD-7, SDSCA
23. Williams, Fekete & Skinta (2019)	USA	People living with HIV	Correlational – associations, mediator analysis	SCS-SF	CES-D, ISS, ULS-8, support seeking, AAQ-II, health covariates
24. Wren et al. (2012)	USA	Obese patients with chronic musculoskeletal pain	Correlational – associations, regression	SCS	Pain, PNAS, CPSES, CSQ, PDI
25. Zhu et al. (2019)	China	Individuals with a cancer diagnosis (various)	Correlational & longitudinal - associations, regressions, prediction over time	SCS-SF	PHQ-9, STAI-6, CIS

Notes: SCS (Neff Self-Compassion Scale), HADS (Hospital Anxiety and Depression Scale), BRS (Brief Resilience Scale), SCS-SF (Self-Compassion Scale Short Form), DASS-21 (Depression, Anxiety and Stress Scale-21), NPRS (Numeric Pain Rating Scale), CFQ (Cognitive Fusion Questionnaire), FCS (Fears of Compassion Scale), SSPS (Social Safeness and Pleasure Scale), WSAS (Work and Social Adjustment

Scale), CPAQ-8 (Chronic Pain Acceptance Questionnaire-8), MAAS (Mindful Attention Awareness Scale), GAD-7 (Generalised Anxiety Disorder-7), CES (Coping Efficacy Scale), PHQ-9 (Patient Health Questionnaire-9) EQ-5D-3L (European Quality of Life – 3 Dimensions Scale), LSSS-3 (Liverpool Seizure Severity Scale- Revised), AAQ (Acceptance and Action Questionnaire), CSQ (Coping Styles Questionnaire), BCMDI (British Columbia Major Depression Inventory), SIP (Sickness Impact Profile), CPVI (Chronic Pain Values Inventory), BPCI-2 (Brief Pain Coping Inventory-2), PASS (Pain Anxiety Symptom Scale), CES-D (Centre for Epidemiological Studies Depression Scale), RSES (Rosenberg Self-Esteem Scale), HIVSMSSES (HIV Symptom Management Self-Efficacy Scale), Mini-MAC (Mini Mental Adjustment to Cancer), COPE (Brief COPE Inventory), FACT-G (Functional Assessment of Cancer Therapy-General), BFNE (Brief Fear of Negative Evaluation), SGS (Shame and Guilt Scale), COPD items (specific items related to self-consciousness), CRQ-SR (Chronic Respiratory Questionnaire Self-Reported), PRAISE (Pulmonary Rehabilitation Adapted Index of Self-Efficacy), CER-Q (Cognitive Emotion Regulation Questionnaire), IPQ-R (Illness Perception Scale-Revised), SCL-90 (Symptom Checklist – 90), SSC-HIVrev (Revised Sign and Symptom Checklist), EACS (Emotional Approach Coping Scale), GRCS (Gender Role Conflict Scale), EPIC-CP (Expanded Prostate Cancer Index Composite for Clinical Practice), DDS-17 (Diabetes Distress scale), WHOQOL-BREF (World Health Organisation Quality of LifeBREF), Rome III (IBS Symptom Frequency), HFRDIS (IBS Interference Scale), PSS (Perceived Stress Scale), MOS-GA (Medical Outcomes Study Measure of Patient Adherence – General), Brief COPE (shortened COPE scale), CE (Coping Efficacy ratings), PHQ-8 (Patient Health Questionnaire-8), SDSCA (Summary of Diabetes Self-Care Activities), ISS (Internalised Shame Scale), ULS-8 (UCLA Loneliness Scale Short-Form), AAQ-II (Acceptance and Action Questionnaire), PNAS (Positive and Negative Affect Scale), CPSES (Chronic Pain Self-Efficacy Scale), CSQ (Coping Strategies Questionnaire), PDI (Pain Disability Index), PSS (Perceived Stress Scale), RIQ (Response to Illness Questionnaire), HARSII (HIV and Abuse-Related Shame Inventory), STAI (State-Trait Anxiety Inventory), BDI (Beck Depression Inventory), FSDS (Female Sexual Distress Scale), CSI (Couple Satisfaction Index), STICSA (State-Trait Inventory for Cognitive and Somatic Anxiety), HIS (Internalised Homophobia Scale), LOS (Life Orientation Scale), PGI (Posttraumatic Growth Inventory), SLS (Satisfaction with Life Scale), CIS (Checklist Individual Strength)

Table 1.7: Participant characteristics

Study no.	Number of participants (% female)	Mean age (SD)	Time since diagnosis	Where recruited
1	270 (76.2)	Not given (41-50 most common bracket)	-	Epilepsy Action via advertisement, social media, newsletter
2	187 (35.3)	45.9 (8.28)	2.47 mean	Flyers and snowball sampling
3	231 (100)	48.51 (10.89)	55.4% 10+, 23.4% 5-10	Advertisement online via 3 chronic pain associations
4	107 (100)	50.84 (11.20)	60.7% 10+, 26.2 5-10, 13.1 1-5	Advertisement online via 3 chronic pain associations
5	231(100)	48.51 (10.89)	55.4% 10+, 23.4 5-10	Advertisement online via 3 chronic pain associations
6	86 (100)	50.73 (10.84)	59.3% 10+, 26.7 5-10, 14% 1-5	Advertisement online via 3 chronic pain associations

Study no.	Number of participants (% female)	Mean age (SD)	Time since diagnosis	Where recruited
7	74 epilepsy (68.6), 46 PWPNES (76.1), 89 controls (75.3)	Median and IQR: 35 (17.5), 41 (25.5), 33 (20)	Median P 7.21y duration	Clinics, social media, advertisements (controls – students)
8	103 (79.6)	60.81 (13.24) for males, 59.53 (14.61) for females		Purposively sampled from two health units (primary care setting)
9	343 (71)	51.66 (14.58)		Pain clinic
10	1766 (29.1% depressed, 25.5% non-depressed)	45.4 (8.9) depressed, 47.4 (9.8) non-depressed		HIV clinics or AIDS service organizations
11	131 - 70 COPD (56%), 61 controls (64.2)	70.8 (9.4) COPD, 66.2 (12.9) controls	Mean 8.8 years	Clinic at rehabilitation center (controls – family and friends, posters, emails)
12	120 (64.2%)	56.2 (9.7)	Mean 12.9 years	Hospital clinics
13	1986 (28%)	45 (9.4)	Mean HIV 12 years	Advertisements via clinics, university, organisations

Study no.	Number of participants (% female)	Mean age (SD)	Time since diagnosis	Where recruited
14	176 (31.8%)	Median and IQR: 66 (60.71)	Mean 11Y	Postal mailing of those identified in database searches of GP practices and clinics
15	63 cancer patients (82.5%) 68 with chronic illnesses (75%) 71 healthy controls (73.2%)	S1 males: 55.45 (13.24) S1 females: 52.65 (10.01) S2 males: 51.94 (14.12) S2 females: 51.16 (10.48) S3 males: 49.84 (13.75) S3 females: 50.46 (17.33)	31% 1-5y, 16 6m-1y, 10% <6m, 6% <5y	Hospital clinics
16	144 (80.6%)	21.65 (5.22)		University participant pool
17	48 women (100), 48 partners	26.83 (5.98) women, 28.71 (7.93) partners	73.85m	Specialist pain centres, advertisements, social media, universities
18	155 IBS (83.1), 164 arthritis (91.5)	38.84 (12.8) IBD, 47.44 (11.6) arthritis		Community notices, electronic support groups, web pages, newsletters

Study no.	Number of participants (% female)	Mean age (SD)	Time since diagnosis	Where recruited
19	709total: 1.Fibromyalgia – 319 (96.1) 2.Fibromyalgia – 152 (89.4) 3.CFS – 61 (83.8) 4.Cancer – 55 (62) 5.Cancer survivor – 122 (64.4)	1. 47.89 (12.7) 2. 41.51 (14.02) 3. 33.91 (14.8) 4. 61.24 (11.24) 5. 61.47 (12.39)		1 – advertisements in local groups 2/3 – university students/social media 4/5 – cancer organisation/social media
20	90 (0)	43.5 (11.7)	12.24	Advocacy centre advertisements, social media, word of mouth
21	140 (42.1)	68.72 (7.62)	7.15y	Pain organisation advertisements
22	1907 (50)	53.1 (14.94)	14.90y	Advertised to NDSS registrants who had consented to take part in research, social media
23	181 (24.9)	42.81 (11.0)	11.71y	Use of flyers (e.g. local HIV advocacy centers), social media advertisements, word of mouth

Study no.	Number of participants (% female)	Mean age (SD)	Time since diagnosis	Where recruited
24	88 (71.6)	53.93 (9.65)	11.79	Pain and palliative care clinic
25	153 (65.8)	50.78 (11.61)		Tumour hospital

Table 1.8: Aims and Findings

Study no.	Aims	Findings	Statistics
1	To examine the extent to which self-compassion (SC) predicted depression and anxiety when controlling for demographic and illness-related variables	SC significantly predicted lower depression and anxiety when sociodemographic and illness-related variables were accounted for	SC and depression ($r = -.585, p < .001$), anxiety ($r = -.608, p < .001$), and resilience ($r = -.595, p < .001$)/ SC explained 33.8% of the variance in depression
2	To investigate whether those high in SC cope better with HIV (i.e. lower stress and negative affect)	SC was related to better adjustment (lower stress, anxiety). SC significantly predicted lower stress and more successful coping.	SC predicted lower stress and more successful coping ($sr = .52, t(161) = 7.69, p < .001$)
3	To test the mediator role of cognitive fusion between pain intensity and depression, and the moderator effect of self-compassion in this mediation.	The model explained 63% of depressive symptoms, with cognitive fusion mediating pain intensity and depressive symptoms. Self-compassion moderated this.	SC and depression ($r = -.55, p < .001$)
4	To explore the relationship between SC, fears of SC and depression	The relationship between SC and depressive symptoms was significant	SC and depression ($r = -.53, p < .001$)
5	To test the mediating role of pain willingness and activity engagement in the relationship	Mindful activity and SC were positively related to each other and negatively with depressive symptoms	SC and depression ($r = -.55, p < .001$)

Study no.	Aims	Findings	Statistics
	between mindfulness and SC, and depressive symptoms		
6	To explore longitudinally the role of SC as a predictor of depressive symptoms in a sample of women with chronic pain	SC, not mindfulness, significantly predicted depressive symptoms at T1 and T2 above and beyond depressive symptoms and functional impairment.	SC alongside mindful awareness predicted 59% in depression symptomology, on top of pain intensity and functional impairment
7	To investigate whether SC is associated with adjustment in people with epilepsy and people with psychogenic nonepileptic seizures.	SC was associated with adjustment in epilepsy and non-epileptic attach disorder. SC was negatively related to anxiety and depression in both groups and positively related to coping efficacy.	E - SC and depression ($r = -.57, p < .001$), anxiety ($r = -.64, p < .001$), coping efficacy ($r = .40, p < .001$). NEAD - SC and depression ($r = -.69, p < .001$), anxiety ($r = -.74, p < .001$), coping efficacy ($r = .37, p < .05$)
8	To explore associations between coping, experiential avoidance, SC and psychological distress in the presence of chronic pain, and in the prediction of distress	SC was highly and negatively correlated with depression, and moderately with anxiety and stress. HRA showed experiential avoidance and SC are the factors that mostly explain PD.	SC and depression ($r = -.609; p < .001$), anxiety ($r = -.373; p < .001$) and stress ($r = -.588; p < .001$). SC and rational coping ($r = .494; p < .001$), avoidant ($r = .211, p < .05$), detached ($r = .624, p < .001$) and experiential avoidance ($r = -.690, p < .001$) On top of rational, avoidance and detached coping, SC accounted for 9.4% of the variance in depression (26.5%), 1.4% of the variance in

Study no.	Aims	Findings	Statistics
9	To understand the association between SC and measures of functioning in a sample of patients with chronic pain	Higher SC was associated with lower pain-related fear, depression, as well as greater pain acceptance, success in valued activities and utilization of pain coping strategies.	anxiety (9.5%; not significant) and 8.1% in stress scores (34.4%). HR – SC accounted for 32% variance in depression, 29% in pain acceptance, 7% in traditional pain coping, 23% in flexibility in pain coping, 23% pain anxiety
10	To examine differences in self-esteem, HIV management self-efficacy and SC between those with HIV living with and without depressive symptoms	Depressive symptoms were significantly negatively correlated with self-esteem, HIV symptom self-efficacy and self-kindness, and significantly positively correlated with self-judgement (this was the strongest).	Depression and self J ($r = .60, p < .01$), self K ($r = -.284, p < .01$). 43.2% of the variance in depressive symptoms was explained by a combination of self-esteem, symptom management self-efficacy and self-judgement (SJ being the strongest predictor)
11	To explore the extent to which self-conscious emotions are expressed, to explore any associations with adverse health outcomes in COPD	Self-conscious emotions were associated with reduced mastery, heightened emotions and elevated anxiety and depression. Those with COPD reported lower SC, higher shame and less pride than healthy controls.	SC and depression ($r = -.51, p < .001$), anxiety ($r = -.50, p < .001$)
12	To evaluate the relationships between positive and negative aspects of cognitive emotion	SC negative domains were significantly associated with lower cognitive emotion regulation	SC Negative & CERQ-P ($r = .03$) SC N & CERQ-N ($r = .48, p < .001$) SC Positive & CERQ-P ($r = -.28, p < .001$)

Study no.	Aims	Findings	Statistics
	regulation and SC to diabetes distress, at baseline and over time.		SC P & CERQ-N ($r = -.10$)
13	To examine associations between SC and anxiety in a multinational sample of persons living with HIV.	Anxiety was significantly and inversely related to SC across individuals in all countries, and for both genders.	Linear regression analysis for the total sample showed that anxiety was significantly and inversely related to SC ($\beta = -0.410$, $P = 0.000$)
14	To explore levels of SC in T2 diabetes and their association with depression, diabetes related distress and glycemic control.	Higher levels of SC and lower levels of DS were associated with significantly better long-term diabetes control.	SCS and depression ($r = -.58$, $p < .001$)
15	To examine if SC and self-critical judgement would distinctively predict general psychopathological symptoms and QoL in 3 groups (cancer, chronic illness and healthy subjects)	Significant associations were found between lower SC and increased depressive and stress symptoms, and lower QoL dimensions in the patient samples. The opposite pattern was found for self-critical judgement	CI – SC depression ($r = -.47$, $p < 0.01$), SC anxiety ($r = -.27$, $p < 0.01$), SC stress ($r = -.46$, $p < 0.01$), SJ depression ($r = .69$, $p < 0.01$), SJ anxiety ($r = .47$, $p < 0.01$), SJ stress ($r = .68$, $p < 0.01$), Cancer – SC depression ($r = -.59$, $p < 0.01$), SC anxiety ($r = -.10$, NS), SC stress $r = -.58$, $p < 0.01$), SJ depression ($r = .35$, $p < 0.01$), SJ anxiety ($r = .23$, NS), SJ stress ($r = .35$, $p < 0.01$). SC and SJ sign accounted for 51% of depression variance in CI (SJ most global predictor, then SC), and 37% in

Study no.	Aims	Findings	Statistics
			cancer (SC was the only global predictor). SC and SJ sig accounted for 48% of stress variance in CI (SJ most global predictor, then SC), and 33% in cancer (SC was the only global predictor).
16	To identify possible mechanisms responsible for the association between mindfulness and wellbeing in IBS, including symptom interference and SC.	Mindfulness significantly correlated with psych distress, SC and symptom interference. SI and SC were significant mediators of the observed relationship between M and psych distress.	SC and DASS ($r = -.51, p > .01$)
17	To investigate SC in vulvodynia and its associations with psychological adjustment	For women and their partners, higher SC was associated with lower anxiety and depression	W - SC and anxiety ($r = -.64, p < .01$), depression ($r = .48, p > .01$). SC accounted for 41% variance in anxiety and 23.8% depression
18	To test theory and research on SC, coping and stress by examining their associations in those with IBD and arthritis.	Path analyses revealed significant indirect effects for adaptive CS (active, positive reframing, acceptance) and negatively for maladaptive CS (behavioural disengagement and self blame) in both samples. The balance of the two CS by SC individuals is	IBS – SC and stress ($-.56, p < .05$). Arthritis - SC and stress ($-.56, p < .05$). IBS – SC and IN (.19, $p < .05$). Arthritis - SC and IN (.18, $p < .05$). IBS – SC and ACT (.41, $p < .05$). Arthritis - SC and ACT (.48, $p < .05$). IBS – SC and PLAN (.33, $p < .05$). Arthritis - SC and PLAN (.41, $p < .05$). IBS – SC and DEN ($-.28, p < .05$). Arthritis - SC and DEN (-

Study no.	Aims	Findings	Statistics
		associated with better coping outcomes in the context of chronic illness.	.17, $p < .05$). IBS – SC and PRF (.32, $p < .05$). Arthritis - SC and PRF (.52, $p < .05$). IBS – SC and ACC (.37, $p < .05$). Arthritis - SC and ACC (.28, $p < .05$). IBS – SC and BDIS (-.35, $p < .05$). Arthritis - SC and BDIS (-.42, $p < .05$). IBS – SC and SB (-.46, $p < .05$). Arthritis - SC and SB (-.50, $p < .05$) IBS – SC and CSE (.43, $p < .05$). Arthritis - SC and CSE (.47, $p < .05$)
19	To examine the association between SC and adherence across 5 samples and the extent to which perceived stress accounted for this.	SC was positively associated with adherence. On average, 11% of the variance in medical A explained by SC could be attributed to lower perceived stress.	Fibromyalgia 1 – SC and stress (-.584, $p < .01$) Fibromyalgia 1 - SC and stress (-.601, $p < .01$) CFS.- SC and stress (-.628, $p < .01$) Cancer - SC and stress (-.625, $p < .01$)
20	To examine SC as a moderator of the links between HIV stigma, internalized homophobia and psychological wellbeing in gay men	SC was negatively strongly and significantly correlated with both depression and anxiety.	SC and depression ($r = -.71$, $p < .001$), anxiety ($r = -.49$, $p < .001$). SC and negative affect ($r = -.63$, $p < .001$), positive affect ($r = .39$, $p < .001$)
21	To describe levels of SC in those with PD and explore the relationship between positive	Participants reported moderate levels of SC, and higher SC was a significant predictor of	SC and depression ($r = -.37$, $p < 0.1$), anxiety ($r = -.30$, $p < .01$) and stress ($r = -.39$, $p > .01$).

Study no.	Aims	Findings	Statistics
	psychological variables and psychological health	lower depression, anxiety and stress (in regressions)	HR - High SC was a sig predictor of lower D (35%), A (12%) and S (17%), with it alongside optimism (although not a significant predictor)
22	To determine the associations between SC and diabetes-related health behaviours and clinical outcomes, and emotional health outcomes.	SC was significantly lower among those with severe diabetes distress or mod-severe symptoms of depression/anxiety, as compared to those with no/mild symptoms. SC was significantly associated with all outcomes, with the strongest associations in emotional outcomes.	T1 – SC and depression ($r = -.61, p < 0.001$), T2 - ($r = -.57, p < 0.001$). T1 – SC and anxiety ($r = -.52, p < 0.001$), T2 - ($r = -.52, p < 0.001$). In T1 diabetes, SC accounted for 23% and 25% of variance in depressive and anxiety symptoms. In T2 diabetes, SC accounted for 26% and 28% of variance in depressive and anxiety symptoms
23	To examine whether SC among PLWH was associated with lower levels of internalized shame, and in turn, better psychosocial outcomes.	There was initial support for lower levels of internalized shame as a potential mechanism that may explain how SC comes to be associated with better outcomes in PLWH.	SC and depression ($r = -.658, p < .01$) SC and exp avoidance ($r = -.625, p < .01$)
24	To examine the relationship of SC to pain, psychological functioning, pain coping and disability in MS	A HLR showed after controlling for depression variables, SC was a significant predictor of negative affect	SC and neg affect ($r = -.52, p < .01$). SC and pos affect ($r = .31, p < .01$). SC and pain SE ($r = .25, p < .05$). SC and pain cat ($r = -.40, p < .01$). SC accounted for an additional 20% of the variance in neg affect (over and above), and was a significant,

Study no.	Aims	Findings	Statistics
25	To investigate the predictive role of SC at the time of cancer diagnosis and the period of receiving treatment, and the reports of anxiety and depression	SC total score and negative components of SC (positive to a lesser extent) were significantly related to depression and anxiety. When controlling for symptoms at T1, positive SC sig predicted all outcomes at T3. No predictive value of negative SC	independent predictor. It added an additional 7% in explaining positive affect T1 SC T1 depression -.38 (.01). T1 SC T1 anxiety -.40 (.01). T1 SC T2 depression -.33 (.01). T1 SC T2 anxiety -.42 (.01). T1 SC T3 depression -.15. T1 SC T3 anxiety -.24 (.01). T1 neg SC T1 depression -.40 (.01). T1 neg SC T1 anxiety -.34 (.01). T1 neg SC T2 depression -.32 (.01). T1 neg SC T2 anxiety -.30 (.01). T1 pos SC T2 anxiety -.25 (.01). T1 pos SC T3 depression -.23 (.01). T1 pos SC T3 anxiety -.18 (.01). R – SC T1 sig explained 18% variance in depression and 16% in anxiety. SC at T1 only significantly predicted symptoms of anxiety at T2 and T3, when controlling for symptoms at T1 (and not symptoms of depression and fatigue).

Note = SC (Self-compassion)

Table 1.9: Quality Assessment for Studies 1-13

Study no.	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Were the aims/objectives clear?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
2. Was the study design appropriate for the aims?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
3. Was the sample size justified?	Y	N	Y	Y	Y	Y	Y	N	N	N	N	N	N
4. Was the target population clearly defined?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
5. Was the sample frame taken from an appropriate population base?	N	N	N	N	N	N	N	N	N	N	N	N	N
6. Was the selection process likely to select those representative?	N	Y	N	N	N	N	DK	N	N	N	N	N	DK

Study no.	1	2	3	4	5	6	7	8	9	10	11	12	13
13. Does the response rate raise concerns about non-response bias?	DK	DK	N	N	N	N	N	N	DK	DK	DK	DK	DK
14. Was info about non-responders described?	N	N	Y	Y	Y	Y	N	Y	N	N	N	N	N
15. Were results internally consistent?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
16. Were results presented for all analyses described in method?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
17. Were the authors discussions/conclusions justified by the results?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
18. Were limitations discussed?	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
19. Were there any funding sources/COI?	N	DK	N	N	N	N	N	DK	DK	DK	N	N	N

Study no.	1	2	3	4	5	6	7	8	9	10	11	12	13
20. Was ethical approval/consent attained?	Y	DK	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
<i>Was the follow-up period long enough? (longitudinal)</i>						Y						Y	
<i>Was the follow-up of the subjects complete enough? (longitudinal)</i>						Y						Y	

Study no.	14	15	16	17	18	19	20	21	22	23	24	25
18. Were limitations discussed?	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
19. Were there any funding sources/COI?	Y	DK	N	N	N	N	DK	N	N	DK	N	N
20. Was ethical approval/consent attained?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the follow-up period long enough? (longitudinal)					Y							
Was the follow-up of the subjects complete enough?(longitudinal)					Y							

Appendices

Appendix 1-A: Author guidelines

Instructions for authors

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Appendix 1-B: AXIS quality checklist

Appraisal of Cross-sectional Studies

	Question	Yes	No	Don't know/ Comment
Introduction				
1	Were the aims/objectives of the study clear?			
Methods				
2	Was the study design appropriate for the stated aim(s)?			
3	Was the sample size justified?			
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7	Were measures undertaken to address and categorise non-responders?			
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results				
12	Were the basic data adequately described?			
13	Does the response rate raise concerns about non-response bias?			
14	If appropriate, was information about non-responders described?			
15	Were the results internally consistent?			
16	Were the results presented for all the analyses described in the methods?			
Discussion				
17	Were the authors' discussions and conclusions justified by the results?			
18	Were the limitations of the study discussed?			
Other				
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
20	Was ethical approval or consent of participants attained?			

Chapter 2: Research Paper

Self-compassion and coping in adolescents living with epilepsy

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Abstract

Objective: Adolescents with epilepsy face particular challenges as they experience and manage the impact of an unpredictable chronic condition alongside the typical social, emotional and physical changes associated with adolescence. As self-compassion has been recognised as an important quality for reducing stress, the current study aimed to explore the experiences of adolescents living with epilepsy and their experiences of coping and self-compassion. **Design:** Interpretative phenomenological analysis was used to develop themes from the narratives of five adolescents living with epilepsy. **Results:** Three themes were constructed: (i) Learning about my condition and my experiences: “Getting answers and people explaining things...it makes massive lifesaving differences”, (ii) Dealing with the thought takeover: “I try not to think on it to move on” and (iii) Being in an accepting bubble: “I know that people have got my back”. These findings indicate the strategies adolescents attempt to employ to overcome the consequences of their condition, alongside a process of learning with this process being gradual and changeable in nature. **Conclusions:** These findings are important to bear in mind clinically when considering ways of supporting young people with epilepsy, what is important to them and also what methods of coping are found to be most useful to enhance wellbeing in this population.

Key words: epilepsy, coping, self-compassion, adolescents, IPA

Introduction

Epilepsy is a chronic neurological condition characterised by recurrent seizures which are typically brief episodes of involuntary movement (Fisher et al., 2005). It currently affects approximately 70 million people in the world (Ngugi et al., 2010). Epilepsy incidence is higher in childhood than adulthood, with 1 in every 220 young people (0-16 years; Forsgren, 2004; Joint Epilepsy Council, 2011) diagnosed in the UK. This makes it one of the most common neurological diseases across the lifespan (World Health Organisation [WHO], 2004). There are over 60 types of epilepsy, with seizures presenting differently depending on the area and proportion of the brain affected (WHO, 2004, Epilepsy Action, 2018). Epilepsy can influence motor function, cognition, behaviour, an individual's emotional state and consciousness (Fisher et al., 2005). People living with epilepsy report uncertainty and fear of seizures as being the worst parts of the condition, alongside the impact on lifestyle, school, driving and employment (Baker et al., 2008; Fisher et al., 2000). Baker et al. (2008) report young people on average miss around seven school days per year due to their condition, with over a third expecting epilepsy to hinder their future.

Adolescence is the life stage characterised by the most intense emotional and physical transformation (Kwong et al., 2016), alongside hormonal changes and academic and social pressures (Sheth, 2002; Dockray, Susman & Dorn, 2009; Bluth, 2016). In a review centred around the experience of living with a chronic illness during adolescence (Taylor, Gibson & Franck, 2008), themes of developing and maintaining friendships, being normal/getting on with life, the importance of family, attitude to treatment, experiences of school, relationship with healthcare professionals, and the future were found to be important.

Approximately 1.5-2% of adolescents receive a diagnosis of epilepsy during this key period worldwide, and findings specific to this group suggest it can influence the development of independence, autonomy and social skills (Appleton & Neville, 1999; Chew,

Carpenter & Haase, 2019). Adolescents with epilepsy have been found to be at a greater risk of experiencing psychological problems in comparison to the general population, with up to 28.6% of children and young people having a co-existing psychiatric difficulty (Camfield et al., 1996; Ekinici et al., 2009). Studies have found an increased prevalence of low mood and anxiety in young people with epilepsy compared to other conditions (e.g. asthma) and compared to healthy controls (Kwong et al., 2016; Schraegle & Titus, 2017), with such psychological difficulties subsequently impacting on quality of life (Johnson, Jones, Seidenberg & Hermann, 2004). Due to the outlined pervasive impact, unpredictability, and physical manifestations of seizures, self-esteem is also thought to be more compromised in adolescents with epilepsy than in those with other non-neurological chronic diseases (Kwong et al., 2016). This is especially key given self-esteem is thought to be an important factor contributing to psychosocial wellbeing (Johnson et al., 2004).

Adolescents with chronic conditions (those with and without epilepsy) view the condition negatively, and can perceive the condition to have a more adverse impact than other conditions. Wirrel and Cheung (2005) interviewed healthy adolescents and those with epilepsy, asthma, diabetes and migraines regarding their perceptions of the impact of eight chronic diseases. Epilepsy was viewed as having more negative physical consequences than other conditions, being perceived to more frequently cause cognitive impairment, injuries to the individual and bystanders, as well as believing it can more frequently lead to death. Epilepsy was also seen to have a more negative social impact, particularly on behaviour, honesty, popularity, adeptness at sports, and fun. In addition, significantly more adolescents expressed reluctance to befriend peers with epilepsy, both from their own and their perceived parental perspectives (Wirrell & Cheung, 2005).

Living with epilepsy is therefore challenging for young people and they have to learn how to cope with the condition. The strategies an individual uses to cope are thought to

largely influence the impact a condition can have (Compass et al., 2012). Coping is generally viewed as any strategy employed to handle stress, with Lazarus and Folkman (1984) describing it as an individual's cognitive and behavioural efforts to manage a taxing demand. In their model of coping, they suggest it is the appraisal of the stressful situation that is central to how a person goes on to cope, rather than the occurrence or the severity of the event itself. The appraisal involves an evaluation of the impact of a problem, as well as considering what may be done to overcome this. This process of coping is said to mediate the effect of stress on wellbeing. Lazarus and Folkman (1984) categorised ways of coping as either problem focused (i.e. employed to manage the problem), or emotion-focused (i.e. aimed at managing the associated emotion)

However, not all authors use this categorisation, with coping styles often being grouped in different ways throughout research. To illustrate this diversity, Skinner, Edge, Altman, and Sherwood (2003) identified 400 types of coping in their review. Nevertheless, avoidance, such as denial of the condition and behavioural disengagement, has been associated with a lowered quality of life in adults with epilepsy (Bautista, Shapovalov & Shoraka, 2015). Similarly, adolescents with epilepsy have been found to use more emotion-focused coping (e.g. withdrawal, worry) than problem focused strategies, which have been linked to poorer psychosocial functioning (Cengel-Kultur, Ulay & Erdag, 2009; Clarke & Critchley, 2016). However, little research exists on coping in adolescents from a qualitative perspective, with there being a lack of understanding as to what is viewed as helpful, and how coping is experienced and situated in the adolescents' everyday lives. Only one such study exists (Eklund & Sivber, 2003) and found adolescents in Sweden utilised certain strategies to cope with the emotional strains caused by epilepsy, such as finding support, being in control and experimenting. Whilst less directly focused on coping, Chew et al.

(2019) similarly found in a qualitative study with adolescents, that protective factors against the stress of living with epilepsy included having support from family and friends.

Self-compassion has been recognised as an important quality for reducing stress and increasing resilience in the face of difficulties such as health concerns (Neff, Kirkpatrick, & Rude, 2007). Neff defines the term as treating oneself with kindness and acceptance when confronted with difficulties, which involves understanding one's suffering and recognising that challenge is part of the human experience (Neff, 2003). For illness, it is thought those high in self-compassion will treat themselves with care and concern when unwell, with their compassionate reactions enhancing their ability to self-regulate and self-manage in ways that promote their physical and psychological well-being (Neff et al., 07).

Theoretically, Allen and Leary (2010) suggest self-compassionate individuals experience lower stress as self-compassion supports more effective coping. However, whilst high self-compassion in adolescents has been linked to better psychological wellbeing and lower physiological stress (Bluth et al., 2016), there is limited support for the hypothesis that those high in self-compassion use more adaptive (e.g. problem-focused) coping styles and less maladaptive coping. Even less is known about how self-compassion relates to or influences coping in the context of a chronic stressor. In the studies that have examined self-compassion quantitatively in adults with chronic neurological conditions, self-compassion was found to be related to fewer mood related difficulties (e.g. Baker, Caswell & Eccles, 2019; Clegg, Sirois & Reuber, 2019; Stutts et al., 2020).

In summary, adolescents with epilepsy face particular challenges including learning to live with a serious medical condition whilst navigating a key stage in social and emotional development. This adjustment and period learning to cope is also likely to be done independently from parents, which may be different for young children living with the condition. Furthermore, given the perceived unhelpful ways of managing in this group and

the unpredictability of epilepsy, it appears important to understand if and how young people with the diagnosis mitigate its impact. This study was designed to gather rich, qualitative information from a sample of young people with epilepsy, with the research question “how do adolescents living with epilepsy experience coping and self-compassion?”. It was hoped findings would inform theory and larger, quantitative research to more systematically explore the relationships, ultimately allowing healthcare professionals to support young people as effectively as possible in the future.

Method

Design

Interpretative phenomenological analysis (IPA; Smith, 1999) was chosen to explore young people’s experiences of self-compassion and coping with epilepsy. IPA is employed to explore complexity or novelty within narratives (Smith & Osborn, 2004) and was therefore deemed suitable to answer the research question. Smith (1996) has argued IPA to be both experimental and experiential, drawing on theoretical ideas from phenomenology and hermeneutics alongside engaging with subjective experience and personal accounts. Together, the approach allows for understanding to be developed around how meaning is constructed through both an individual’s social and personal world (Smith 2009).

A flexible, open data collection structure was implemented to allow for relationships to be investigated, without limiting exploration to predefined coping categories. The interview schedule (see Ethics Section, Appendix 4-B) began with a more general focus centred around living with epilepsy and its impact, followed by questions that generated discussion around ways in which the person has coped. The interview then turned to self-compassion, at which point the interviewer prompted young people to read a brief information page on the concept. This age-appropriate information page was developed for the interview and was informed by Neff’s conceptualisation of the concept (Neff, 2003; Neff

& Lamb, 2009). Once the participant understood the concept, questions about self-compassion followed, as well as questions which linked coping and self-compassion (e.g. “Have you noticed times when you are kind or unkind to yourself? Feedback on the schedule was gained from a small sample of young people attending an epilepsy clinic, with adjustments made to ensure language and concepts were accessible and meaningful to the target population.

Participants

Unlike other qualitative analysis methods that aim to achieve data saturation in research, IPA emphasises saturation within each dataset (Smith, Jarman & Osborn, 1999). There is no set requirement in regard to sample size for IPA, with this depending upon factors such as richness of the data collected (Smith & Osborn, 2004). The original aim of this current study was to interview approximately 6-12 participants. This range was used as it was predicted interviews would be shorter due to the age of the target population, and therefore additional interviews may be needed. Participants were recruited from one UK National Health Service (NHS) hospital trust. As recruitment occurred during the onset of the COVID-19 pandemic when recruitment through the NHS became restricted, the final sample was slightly smaller than anticipated, with a total of five participants interviewed.

Participants were aged 13-18 years with a primary diagnosis of epilepsy. They were under a medical consultant in a tertiary care hospital, thus the sample included adolescents who typically had a more severe type of epilepsy, given the need for more regular neurology review. Individuals were recruited solely from this type of service in order to ensure homogeneity with regards to severity of illness, as homogeneity is a requirement of IPA in regard to participant samples (Smith & Osborn, 2004). It was also assumed, given the type or severity of epilepsy of those under tertiary care, that strategies to manage the condition may be used more frequently. Individuals were required to have had their diagnosis for at least six

months, as those with a newer diagnosis may not have experienced the condition for long enough to have employed management strategies. Furthermore, participants were required to have language abilities and hearing abilities to enable them to take part in an interview in English. Whilst no exclusion criteria was placed around type of epilepsy or seizures given the diversity across the condition, this information alongside other relevant demographic details was gathered to understand the needs and profile of the subgroup of participants in this study to situate the sample (see Table 2.1).

<Insert Table 2.1>

Participants involved in the final sample were aged between 13 and 16, with a mean age of 14. The age of onset ranged from birth to 14 years, with one participant waiting 13 years to receive a diagnosis. Three of the five participants had more than one type of epilepsy, and tonic clonic seizures were most commonly experienced across the group, with four of the five participants experiencing this variation.

Procedure

Participants were recruited in two ways. Firstly, a clinical psychologist within the epilepsy clinical team identified adolescents listed on an internal database who met the study inclusion criteria. These individuals were sent a letter of invitation alongside study information in the post by the service (i.e. age appropriate participant information sheet and consent/assent forms). Secondly, the same information and documents were given out at clinics by members of the multi-disciplinary team.

For young people aged 16-18 years, the information packs sent in the post were addressed to the young person. The packs included a participant information sheet for the young person only and a consent to participate form. For those aged 13-15 years, packs were addressed to the parent/carer. It was requested that parents/carers pass this information on to the young person to help guide their decision as to whether to take part. Both the young

person and the parent/carer received a participant information sheet. Contact information (phone number and email) was provided for individuals to contact the main researcher if they were happy to participate or had any queries around the study. Young people were then invited to interview with the main researcher. A consent to participate form was addressed to and required to be completed by a parent/carer and an assent form was completed by the young person. All participant materials and ethics information can be found in Appendix 4.

Interviews could be held in person (before lockdown restrictions due to COVID-19 prevented this) or online. If meeting in person, written consent/assent was obtained at the interview. For those who had their interview online (e.g., skype), consent/assent forms were returned to the main researcher prior to the interview taking place. Interviews were audio recorded on a digital device and transcribed verbatim by the researcher prior to analysis. Only one interview took place in the hospital due to circumstances mentioned above meaning face to face interview contact was no longer possible.

Rigour

According to Spencer and Ritchie (2012), the quality of qualitative research concerns contribution, credibility and rigour. In line with the latter two principles, one transcript alongside emerging and superordinate themes were shared with two supervisors to enhance validity of the data. A clear analysis trail was maintained and feedback from supervisors was used to amend any changes. To adhere to the contribution principle (i.e. what a researcher contributes to their work), a reflexive stance was adopted throughout via a diary. Reflexivity is considered to be the researcher's ability to reflect explicitly on their role and interpretations and their relationship with the subject or population group (Smith et al., 1999). In addition, given the double hermeneutic component of IPA, it is acknowledged that other researchers may interpret the data differently (Shaw, 2010). This is considered an inevitable bias within IPA (Smith et al., 2009). Regardless, considering the researcher's role, background and

assumptions is important (Elliot et al., 1999). The researcher was a 29-year-old trainee clinical psychologist working in the UK. Having worked in a paediatric setting prior to commencing training, the researcher had experience and interest in the wellbeing of young people experiencing short and long term health conditions, including epilepsy.

Data Analysis

The data were analysed following guidance from Smith et al. (2009). The IPA process began with the researcher becoming familiar with the data through the re-reading of individual transcripts. Notations were made regarding the descriptive, conceptual and linguistic nature of the text (see Appendix 2-B for an example). The notes from each transcript were clustered together to reflect conceptually-similar themes. To maintain a commitment to ideography (Smith et al., 2009), attempts were made to put this knowledge to one side when moving on to the next transcript. After all five transcripts had been individually analysed, groupings were compared across the sample to identify any patterns and differences present. These were then clustered into higher order superordinate themes, conveying shared experiences across the data set (Smith, 1996; Smith et al., 2009). These were then given titles to reflect the experiences of the participants.

Results

Three superordinate themes were generated and are as follows: (i) Learning about my condition and my experiences: “Getting answers and people explaining things...it makes massive lifesaving differences”, (ii) Dealing with the thought takeover: “I try not to think on it to move on” and (iii) Being in an accepting bubble: “I know that people have got my back”. Each theme is outlined below, with quotes to illustrate key points.

Theme One: Learning about my condition and my experiences: “Getting answers and people explaining things...it makes massive lifesaving differences”

Theme one describes the individuals' experiences of seeking to understand their condition, by finding answers and information. More specifically, individuals outlined how they moved through a process of learning about their condition, how it impacts on them and what helps them to feel better. This learning could come from others (e.g. parents or health care professionals) as well as learning by experience, and it appeared to be a gradual process that supported their ability to accept and manage the condition.

Participants commented on tuning into physical sensations, describing a process of learning to understand how they experienced epilepsy: "sometimes I'll know because I'm like dribbling and stuff, or I'll forget whatever I've done for like the whole day, and stuff. That's pretty much how I tell. Usually I also feel quite numb all over my body" (Ben). Having this awareness appeared to allow him to predict oncoming seizures, as well as adapting his day to mitigate seizure impact and avoid riskier situations: "whenever I feel like I'm not right, like I might have a small seizure, then I do stay at home. Like if I want to go out with my friends, I won't and instead I'll stay at home" (Ben). This illustrates how learning about how his body behaves in relation to epilepsy has enabled him to take appropriate action to feel safer.

Others also reflected on learning what adjustments needed to be made, by identifying triggers for the seizures, which were individual given the diverse presentations of epilepsy. One participant had identified how the sun could trigger her seizures: "I can't do certain things. Like if where we are playing, let's say on holiday we were playing bat and ball, I'll have to face the opposite way from where the sun is facing just to be careful or something" (Josie). Again, this knowledge enabled action to prevent seizures. Similarly, when referring to hobbies such as swimming and going to the cinema, Becky explained: "for like, certain like activities that I do, they have to be changed in a different way so that I'm actually like

able to do it” (Becky). Both of the above accounts highlight how Josie and Becky have learnt to make certain changes in order to still be able to pursue their interests and activities.

The participants’ learning could then also be communicated to others, to reduce the potential impact of epilepsy. As Josie noted “let’s say if the sun is coming in to the class, I’ll just say to the teacher can you just close that blind because I’m not allowed to be near the sun”. Whilst Josie and Becky made reference to using their learning to prevent seizures and thus exert some control over their situation, Sam and Lucy commented on dealing with the impact of the seizures when they were unable to exert control. They appeared to demonstrate acceptance and understanding around a lack of control being the reality of their condition, “they [friends] put me on the floor so I don’t hit my head. That’s all that you can do” (Sam).

As well as learning through experience, the involvement of others in learning, such as being given information, was particularly pertinent across one account. Lucy explained “getting answers and people explaining things. It makes such a difference. I didn’t realise at the time that getting an answer, someone explaining it to you and sitting and taking the time. It makes massive lifesaving differences”, highlighting her belief that gaining an understanding from others was important to her. Others also supported her in learning about her tendency to be self-critical, which appeared to be a stand out memory. More specifically, when asked how she might support a friend going through a similar experience, she described “there was a time when my mum said to me, if someone else was going through this or having those feelings, what would you say to them?... I think that was something quite powerful to make me think (Lucy)”. She reported how this was noticed by a medical professional, leading her to reflect on how observable this must be, encouraging her to consider her self-care needs and how she could be kinder towards herself.

Finally, even though diagnoses were relatively new across all participants, the gradual nature of learning was common across accounts. Individuals’ reported developing a better

understanding over time as they lived through their experiences, and were more able to comprehend these. When asked about whether there were differences having epilepsy as a teenager and having it as a child, Ben explained, “yeah because I can understand it a lot better. When I was little I just didn’t understand” (Ben). This highlights again the importance of sense-making and this being an easier process to navigate as one grows older and gains more experiences.

Theme Two: Dealing with the thought takeover: “I try not to think on it to move on”

Theme two centres around thoughts and thought management strategies experienced by the participants. Thoughts were likely influenced by the above theme, with individuals thinking about their condition and its impact the more they learnt about it and understood it. The two dominant experiences in the current theme centred around being overwhelmed and all consumed with thoughts related to epilepsy, as well as employing strategies to gain distance and be kinder to oneself in order to manage thoughts on a daily basis.

Ben explained that what made the experience of epilepsy worse for him was that “I couldn’t stop thinking of it, I couldn’t stop”, with Lucy adding “whatever I was worrying about or whatever was stressing me, it always went back to epilepsy”. This illustrates the dominating nature of epilepsy on participants’ thoughts, almost seeming inescapable and difficult to avoid. Individuals also reflected on how epilepsy left them with unavoidable reminders of the potential, serious consequences of their condition. For example, Sam remarked: “I could be cycling down, I could be doing 40-50 mph down a road and if I have a seizure, I would lose control of the bike and anything could happen” (Sam). The above narratives highlight how individuals experience anxious thoughts as a consequence of living with an unpredictable condition, which may result from learning about and tuning into their experiences as outlined in theme one.

It seemed participants attempted to control their thoughts and their condition, but they reported difficulty in separating themselves from the worries, particularly when there were physical reminders: “I try to ignore it, but I can’t. Because my hands, I’m just going to show you, shake [lifted hands] constantly” (Becky). Furthermore, individuals made reference to the associations between thoughts, memories and epilepsy: “the way stress used to trigger my seizures, now stress will instead trigger bad memories or bad thoughts” (Lucy). This reflection appears to highlight the cumulative effect of the condition for this participant, whereby difficult thoughts related to epilepsy are experienced because of the association they have with the condition, even though the seizures themselves may no longer be occurring.

Participants made reference to strategies utilised to try to minimise the dominant nature of thoughts, which largely centred around an ability to acknowledge and put the thoughts to one side. For example, one individual explained, “I try not to think on it and then just move on... I just kind of carried on with my life and kept it the same” (Ben). These experiences were mirrored across accounts and highlighted a way of coping that involved the adolescents not engaging with their condition-related thoughts in order to maintain normality. Participants also emphasised the role of focusing on the positives: “I would normally kind of like forget about it and just try to think good things” (Josie). Sam reflected on how he would compare himself positively to others with the condition, explaining, “there’s always somebody worse than me. People have had well worse seizures than me. Like when I went to hospital for a check-up, there was a girl who had autism and epilepsy” (Sam).

Other individuals referred to more active ways of coping and caring for themselves. For example, Sam researched self-help strategies to become more skilled in managing thoughts and increase control over them: “I tried to do a bit of research into how to get thoughts out of your head” (Sam). Lucy found exercise to be important in providing space from thoughts, “if I have worries about something, it’s what I do [running]...one of the

biggest things was going for a run to clear my head, which really really helped”. As well as exercise, she explained “when my seizures picked up, I wrote in a diary as well which I found really helpful in letting everything out rather than every day it building up”. In summary, the above reflections highlight the common experience of attempting to put thoughts to one side, whether done in an active (i.e. through active self-care) or more passive way.

Whilst being able to manage epilepsy-related thoughts seemed important, the ability appeared dependant on other factors such as being occupied. For example, Sam reflected on his ability to distract himself: “whilst I’ve got something else in my mind I don’t think about them, but then when I go to bed, I’ll be rolling around for 20 minutes thinking”. Similarly, Ben explained that when his seizures were more frequent, this impacted on his tendency to think about them more and be more self-critical, which are thoughts he finds particularly hard to distance from. Both of these accounts emphasise the desire to gain freedom from thoughts by trying to control them entering their mind, although other factors made this difficult. It also demonstrates how efforts to control the uncontrollable might be exhausting and at times an ineffective way of coping.

Theme Three: Being in an accepting bubble: “I know that people have got my back”

Theme three revolves around the participants’ common narrative of feeling alone with the condition, believing that others could not understand their experiences. This was alongside the process of seeking out others living with the condition and the positives of doing so, as well as the comfort felt in being surrounded by others, without epilepsy who nonetheless accepted them and their condition. Thus, whilst the above two themes centre largely around internal factors and sources of coping, the current focuses on external sources.

All participants emphasised how even though they acknowledged having individuals around them who offered support, they often felt isolated based on having a diagnosis others did not have, “I feel like I can be completely alone in a room full of people” (Sam).

Alongside this, they desired to be like others who did not have the condition: “it gets like annoying...I just want to be like everyone else”, appearing to see themselves as different and separate to “everyone” based on having epilepsy. They believed those without epilepsy could not understand their experiences which was as highlighted across accounts: “every time I get upset I’ll be like “well you don’t understand cos you don’t have it” (Josie).

In attempts to feel less alone, individuals sought to find others with similar experiences in their families or school networks, with Sam describing his search through his family history: “there’s no one else, literally. I think we went up about 12 generations and we couldn’t find anyone. We were asking, and I think like one fourth cousin has it” exacerbating a sense of being alone in his experiences. Sam also thought epilepsy was much less talked about and understood generally in society: “with a heart condition, you know exactly what it is so it’s easier to talk about it. With epilepsy, there are so many variables...for autism, there’s like autism awareness day, diabetes awareness, but epilepsy doesn’t really get the same coverage” (Sam). This highlights a process of comparison to not only his support system, but to chronic conditions more generally, further enhancing his sense of being isolated and unfortunate.

When individuals did find others who they could identify with and share experiences with, it was evident how powerful this was. This appeared to allow individuals to feel understood and as a result, have their experiences validated. For example, when asked what it is like having a friend or family member with epilepsy, Ben said “we understand each other. We understand what’s happening...they know what it’s like so you can talk to them. They know how you feel”. For those who did not know others personally, they felt they were still able to find this connection in other ways, such as via online forums “I follow the young epilepsy channel, so I do. The amount of times there’s been things said on that and I think

“oh yes I get that!” or “oh yes I understand that” and I think that’s quite comforting to see other people with the same issues” (Lucy).

As well as connecting with others with epilepsy, the individuals all highlighted the value of having family, close friends or teachers around to help them to manage the condition and its impact. This support appeared to be in various forms, with the first being in relation to practical support at school in the case of a seizure occurring: “my friends were really good about it. They all know what to do in case I have a seizure” (Sam). For others, they reflected on the emotional support friends provided, such as when peers made unfair comments related to epilepsy: “I’ve talked to my friends about it so they like kind of stick up for me about it, so they help me with it” (Josie). Ben added “all my friends really just understood yeah it’s a problem I have but it doesn’t change who I am sort of thing... I’m good to have them as a friend. Its good people like that accept it” (Ben). This specifically illustrates the comfort individuals experience when they perceive peers accept them and their condition, as well as how their emotional support allows them to feel safe in the face of poor treatment from others. One participant described the process of a friend learning about the condition, which allowed them to better support the individual and others during the onset of a seizure, “my best friend, she was always very helpful. If someone else didn’t know, she would have explained it to them” (Lucy).

Alongside the key role of friends supporting individuals, emphasis was also placed on the role of family members in helping the young person to feel safe: “I forget about it but then after I come out of it, my mum and dad are always careful with me... I know that people have got my back” (Josie). Teachers were also seen as able to provide help and safety: “I just get my teachers and they get me to stay [still]. They make sure I’m in a safe area just in case it is like a tonic clonic, like a bad seizure” (Ben). This support appears more practical than

that provided by peers, which was largely emotional in nature, allowing the individuals to feel physically safe in their environment.

Discussion

Summary of findings

The current study set out to understand the experiences of a sample of adolescents living with epilepsy in relation to how they cope and experience self-compassion. Three themes were constructed based on data collected throughout the interviews. The first theme involved participants learning to understand their condition, and making adaptations based on knowing their triggers and seizure consequences. These could be made both prior to and as a result of seizures, and learning appeared to occur gradually. This is in line with findings from Eklund and Sivberg (2003), who found adolescents with epilepsy referred to the need to gain control over their condition through knowing their condition and what helps them to manage. Theoretically, this maps onto an individual's sense of coherence. Antonovsky (1998) proposed that a strong sense of coherence enables a person to feel less stress due to being able to comprehend a situation and manage its impact. Learning about epilepsy supported participants in the current study to begin to comprehend it, allowing them to achieve manageability and control, whether achieved through experience or listening to others.

Participants reported learning about and avoiding external triggers, but for many, they noticed more subtle internal sensations that might signify seizure onset in the absence of an external trigger. This highlights the complexity, individuality and unpredictability of the condition, and how the process of learning about how to live with epilepsy may be different to a condition that is more static and universal. For all participants, their diagnoses were also new, perhaps explaining why the process was particularly pertinent in this sample. Additionally, individuals are navigating the process of learning about epilepsy whilst

navigating crucial parts of adolescence such as social and identity development, making this experience perhaps different to adults diagnosed with the condition, for example.

The second theme centred around epilepsy-related thoughts and distancing from these. Individuals attempted to forget about epilepsy to maintain normality, with other studies likewise finding escape-avoidance and cognitive-distancing being widely reported as a coping strategy in those with epilepsy (Eklund & Sivberg, 2003; Goldstein et al., 2005). They also attempted to find the positives in situations, as found in other adolescent and self-compassion research (Klingle & Van Vliet, 2019; Gilbert, 2009). More specifically, adolescents reported that a major part of self-compassion from their perspective was practicing a positive outlook during times of hardship (Klingle & Van Vliet, 2019). Both methods can be understood in relation to Lazarus and Folkman's (1984) theoretical model of coping, which outlines how the appraisal of the stressful situation is central to how a person copes. Thus in the current sample, adolescents appraise the situation in a less threatening manner by not dedicating thinking time to the stressor, or by thinking of the situation positively. This allows them to cope from their perspective, even though avoidance and distance-based coping types are typically viewed as unhelpful in the coping literature (Lazarus and Folkman, 1984). Gilbert (2009) however explains self-directed compassionate behaviour includes any behaviour that distracts from stressful life events. Therefore, whilst long term avoidance may not be the goal of self-compassion, it can redirect a person from suffering temporarily, which is more compassionate than pushing through emotional pain (Germer & Neff, 2013). This also ties with theme one, with individuals utilising behavioural avoidance (i.e. avoiding going out) as a result of learning about their condition and understanding potential risks.

The success of both thought-management strategies appeared fluid and situation-dependant, being influenced by an individual's mood state and their level of pre-occupation.

Self-compassion has too been found to be a changeable process that ebbs and flows in research with adolescents (Klinge and Van Vliet, 2019). This is in line with the dynamic shift from intrapersonal to interpersonal during adolescence, as they transition into adulthood and make sense of their world. The second theme also highlighted aspects of the overidentification versus mindfulness component of self-compassion (Neff, 2003).

Individuals commented on how they could find it very difficult to separate from difficult thoughts related to epilepsy, as well as referring to the use of mindfulness strategies in response to this. This demonstrates how both across and within participants, they could be high and low domains of self-compassion, highlighting the complexity and changeability of the concept.

For the third theme, individuals reflected on experiencing comfort in finding others who live with and understand epilepsy, as well as reporting the value of having others close to them who help them to feel accepted for who they are. Whilst this could involve family and teachers, emphasis was placed particularly on peers. This theme was very similar to the one known study exploring the relationship between coping and epilepsy in adolescents (Eklund & Sivberg, 2003), who found the majority of their data was centred around practical and emotional support from parents, teachers, professionals, but peers especially. Given that adolescence is a time when individuals develop their sense of self, often in the context of peer relationships (Dockray, Susman & Dorn, 2009), this emphasis on peers is not surprising. Brown and Larson (2009) further describe how peer relationships become more salient in adolescence, with individuals putting greater emphasis on their opinions, as well as friendships being characterised by similarity. This adds to explain why those with epilepsy may seek out relationships with those also living with the condition.

Identifying with a wider, online community was also deemed to be of great value in the current theme. This may be linked to the growth in the use of social media, technology

and the societal move towards communicating in this way (Asamoah, 2019). In addition, research highlights a preference for online interaction in children and adolescents (Leung, 2011), as well as using online methods to not only to develop new relationships, but also reinforce those existing. Online interaction may also be relied upon more in adolescents with epilepsy in comparison to healthy individuals or predictable conditions, given the restrictions the condition can place on their ability to interact in other ways.

Interestingly, within the study by Klinge and Van Vliet (2019), healthy adolescents described putting themselves at the centre and making themselves a priority. A key part of adolescence involves the emotional and self-concept development (Rosenblum & Lewis, 2003, Sebastian et al., 2008), involving a transition from being other-focused to self-focused. This narrative may have been less apparent throughout the current findings given four of the five participants fell in the 13-15 age bracket and were thus at an earlier point in their adolescent development (Kroger, 2006). It may also differ for those with chronic conditions, who may depend on others more in order to feel safe and supported, feeling less inclined to become self-focused for this reason (Olsson et al., 2003).

Kindness, a key element of self-compassion, was less evident in the participants' narratives even though it was explicitly explored within interviews. Whilst it is unclear whether this was due to the concept being less familiar, or difficult to talk about, self-evaluations within adolescence have been found to be predominantly unfavourable (Steinberg & Morris, 2001), potentially explaining why this concept may have been less common. In addition, through research with an adolescent sample, Bluth & Blanton (2014) outline a process model of self-compassionate abilities occurring in line with typical adolescent development. They postulate as adolescents become more self-focused and aware of their thoughts, they are able to recognise a degree of self-judgement and rumination, allowing them to develop greater self-kindness and self-compassion, and become ultimately more

accepting of oneself. Given the majority of the current sample were at the beginning of adolescence, with new diagnoses, it is not surprising that awareness of and ability to be self-compassionate was limited. However, while self-kindness was not explicitly relied upon, participants did reflect on the use of self-care to feel better, which is a manifestation of self-kindness.

This model (Bluth & Blanton, 2014) also maps on to the connections that appear to exist between the constructed themes. Throughout accounts, there appears to be an interplay between an evolving process of understanding epilepsy alongside developing identity. This learning can leave adolescents thinking about their condition and thus their difficulties more so, with attempts to control this often being unhelpful. Putting these to one side however allowed individuals to move closer towards acceptance, which was also facilitated by others. highlighting the importance of both internal and external acceptance. In summary, the current findings and previous literature highlight the subtle yet complex relationship between coping and self-compassion in adolescents with epilepsy.

Clinical implications

In supporting adolescents struggling to manage the demands of epilepsy, clinical psychologists can offer a diverse set of skills based on their integrative way of working. Offering appropriate early support, signposting them to self-help and self-care information and encouraging individuals to access support from their close networks to feel less isolated would hopefully be a first step to minimise the impact of the condition. Interventions enhancing self-compassion will also be key, given the components they do recognise appear to enhance their ability to cope. Studies have begun to look into efficacy of interventions for adolescents, finding self-compassion levels can be enhanced feasibly in a group format (Bluth 2017), via a practical skills-based course (Lathren et al., 2018), and over a mobile application (Donovan, 2016). Adolescents reported how formats promoted connection as well

as enjoying the experience. Similarly, in their six week mindful self-compassion group, Bluth (2016) found adolescents developed a more compassionate inner voice, an increase in their life satisfaction and a drop in anxiety, depression and stress in comparison to wait-list controls. This group format appears important given the emphasis on peers in the current findings and in previous research (Eklund & Sivberg, 2003; Kohut et al., 2014), and would allow clinical psychologists to provide a space for new networks to develop. In addition, broader interventions, such as educational campaigns, support groups and school interventions may educate schools and society around the concept of self-compassion, whilst providing an additional supportive group space for young people to connect.

Focus on specific elements of self-compassion may also be useful clinically. For example, thought fusion is thought to be a barrier to self-compassion and is common in adolescence ((Tanti, 2008; Piaget, 1950). Therefore, it is not surprising that supporting individuals to use mindfulness skills (Grossman et al., 2010) or unpick thoughts through cognitive-based self-compassion training (Reddy et al., 2013) has been useful in adolescent samples. Exploring the effectiveness of this in adolescent groups living with epilepsy may provide individuals with the skills to manage their experiences more effectively long term. A further method of addressing this may be through Acceptance and Commitment Therapy (ACT; Hayes et al., 2006) given the emphasis on both thought control and avoidance in the current interviews. Within ACT, concepts such as experiential avoidance (i.e. the attempts to avoid internal experiences) are discussed to help those with epilepsy think about how they notice and respond to difficult or distressing thoughts, emotions and sensations, focusing on willingness and openness to challenges. The model has recently shown to be promising in its application in a review with adults with chronic conditions (Graham et al., 2016).

Strengths and Limitations

This study adds to the literature by asking exploratory questions around self-compassion to see if and how it is experienced by adolescents with epilepsy. This is important given that most self-compassion research has focused on adult populations, potentially overlooking the significance of age and development as factors in shaping how it is experienced.

Due to recruitment difficulties experienced during a global pandemic and subsequent NHS research restrictions, a smaller sample size potentially influenced the variety in narratives shared. Whilst this sample size is deemed as appropriate in IPA (Smith, 1999), a larger sample was aimed for given the nature of the sample. It is also important to note how themes are embedded primarily within a western, white perspective. More specifically, in exploring differences across subscales of self-compassion, previous research has found self-compassion can vary amongst western and eastern cultures, with those with Buddhist influences often encouraging a more compassionate view of oneself and their struggles (Neff et al., 2008; Birkett, 2014). The current study also sought to attract participants who felt comfortable speaking about their experiences, as well as those who were happy to do this via video call, potentially not reflecting the experiences of those who did not feel comfortable in taking part. Participants all had relatively new diagnoses, and their epilepsy types reflect a specific subgroup, thus likely rendering their experiences different to what another sample may have reported.

Future research

Whilst the current study provides novel and exploratory findings in relation to coping and self-compassion in adolescents with epilepsy, future research in this area using larger sample sizes, other qualitative methods and diverse chronic illness groups will hopefully continue to shed light on how the two are connected in order to inform interventions to promote self-compassion and coping moving forward. It will also hopefully continue to

unpick what is deemed as helpful in this specific population, perhaps shifting narratives around traditional “unhelpful” ways of coping.

Higher rates of co-existing mental health difficulties have also been found in young people with epilepsy in comparison to other long term conditions such as asthma (Kwong et al., 2016). This has similarly been the case in adult self-compassion research, with cancer samples often demonstrating higher self-compassion than epilepsy when comparing effect sizes (Baker, Caswell & Eccles, 2019; Zhu et al., 2019). Therefore exploring qualitatively how self-compassion might differ across groups appears important. Future quantitative research will also help to explore links systematically by using validated tools to capture the relationships across large samples and multiple chronic illness groups. The two types of research together will hopefully provide rich insights, as well as allowing more generalisability. In addition, research would benefit from comparing any differences across genders and cultures, especially given previous research has highlighted how female adolescents, and often those older, show lower levels of compassion than males (Bluth 2015, Cunha 2016).

Furthermore, in work with healthy adolescents Bluth (2016) found individuals developed a more compassionate inner voice, as well as an increase in their life satisfaction and a drop in anxiety, depression and stress in comparison to wait-list controls. It would be useful to explore this relationship in chronic illness adolescent samples, such as epilepsy, to support clinicians in the field in providing appropriate interventions. It is promising however how third wave approaches outlined above, such as those focused on compassion, mindfulness and ACT, are beginning to demonstrate throughout the literature how they can support individuals living with chronic conditions to cope. A future direction would be to more widely apply research and models to adolescent samples living with epilepsy to understand how these may be received.

Conclusion

In summary, this study explored the experiences of adolescents living with epilepsy in relation to coping and self-compassion. Epilepsy largely affects identity and social aspects of adolescence, as well as the associated trajectory of cognitive and emotional development. With this underpinning narratives, interview accounts highlighted how coping largely centred around the process of learning about their individual condition, and developing ways of managing the impact it can have. Adolescents found it important to try to develop strategies to manage just how much they think over their condition, as well as surrounding themselves by either others with the condition, or individuals who were accepting of them and their epilepsy. This felt particularly relevant to their life stage, given the emphasis on peers and self-concept development. Whilst self-compassion as an overarching concept was not heavily discussed throughout narratives, individual components were present, such as thought overidentification versus mindfulness. It appeared in the current sample that participants could identify with both the positive and negative domains, thus highlighting that whilst some could be self-compassionate at times, this could fluctuate. This again mirrored the changeability and development of many concepts during adolescence, and it was clear that themes connected to one another. Understanding this relationship in more detail and in more diverse groups in the future will allow clinicians to identify which components are most useful in supporting coping, and which we could target through interventions (small and large scale) to enhance coping in such populations.

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Tables

Table 1. Participant characteristics

Gender	Pseudonym	Age	Type of Epilepsy/Seizures	Age at Diagnosis
Female	Becky	16	Photosensitive, absences	14
Female	Josie	13	Photosensitive, tonic clonic	11
Male	Sam	14	Tonic clonic	10
Male	Ben	13	Tonic clonic	11
Female	Lucy	15	Gelastic & Tonic Clonic	13 (onset from birth)

Appendices

Appendix 2-A: Self-compassion sheet

Self-Compassion

What is it?



Being kind and caring to yourself when you are struggling or have something difficult going on in your life.

This is instead of being critical or judging yourself.

Noticing if you are having a hard time. For example, you might be having thoughts or feelings that aren't easy to have.

Trying not to ignore these feelings but also not getting too caught up in them.



Noticing that you are not the only one who can struggle, and that we all might at times. This is part of being a human. You are not alone.

Appendix 2-B Example of theme development

Participant	Step 1: Initial notations	Step 2: Developing emergent themes	Step 3: Connects across participants	Step 4: Higher order interpretation
Ben: “sometimes I’ll know because I’m like dribbling and stuff, or I’ll forget whatever I’ve done for like the whole day, and stuff. That’s pretty much how I tell. Usually I also feel quite numb all over my body”	Tuning into experiences or changes in the body and making links. Learning to identify what are indicators of seizures Recognising that seizures are occurring with some predictability Physical and cognitive impact of seizures	Awareness of patterns Predictability Understanding of how the condition impacts individuals	<u>Learning by Experience</u> Tuning into triggers Awareness of internal sensations Using experiences to learn and increase control Accepting lack of control for some Physical adaptations	Making sense of my experiences: “Getting answers and people explaining things...it makes massive
Josie: “I can’t do certain things. Like if where we are playing, let’s say on holiday we were playing bat and ball, I’ll have to face the opposite way from where the sun is facing just to be careful or something”	Being unable to do certain things in the face of epilepsy, having to make adjustments or stopping some activities (i.e. bat and ball) Having to do certain things to prevent seizures, thus taking some control yet limiting oneself	A life with adjustments Epilepsy as limiting Preventative measures Exerting some control	<u>Learning from Others</u> Learning about the condition through being taught Others helping self-understanding and self-reflection Involving others in learning <u>A Process to be Navigated</u> Learning as a process that occurs over time, regardless of how it happens	lifesaving differences”
Becky: “for like, certain like activities that I do, they have to be changed in a different	Making changes based on knowing what they can and cant do in relation to epilepsy. Adaptations helping them to continue	Making adaptations Understanding my condition and needs Maintaining normality		

<p>way so that I'm actually like able to do it"</p>	<p>to do what they enjoy (i.e. self-care)</p>	
<p>Sam: "they [friends] put me on the floor so I don't hit my head. That's all that you can do"</p>	<p>Sense of there being little you can do to manage a seizure, as though they are all powerful and in control. Involving others and learning from them what they can do in the moment.</p>	<p>At the hands of seizures Acceptance Lack of control</p>
<p>Lucy: "getting answers and people explaining things. It makes such a difference. I didn't realise at the time that getting an answer, someone explaining it to you and sitting and taking the time. It makes massive lifesaving differences",</p>	<p>Emphasis on answers and understanding Places importance on another "explaining it", perhaps validating and providing sense Answers as life saving</p>	<p>Hearing from others Making sense Answers as life saving External learning</p>

Chapter 3: Critical Appraisal

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Critical Appraisal

The aim of the critical appraisal is to summarise the research findings, considering how they fit with and contribute to the literature around self-compassion and coping in adolescents with epilepsy. After providing an overview of the findings, I will consider the importance of reflexivity in qualitative research, alongside my personal reflections on the various research processes (e.g. choosing the topic, recruitment and data analysis). I will also consider the strengths and limitations of the research, whilst suggesting future directions for study and clinical practice.

Summary of Findings

The systematic literature review explored associations between self-compassion, psychological distress and coping in chronic illness populations. Higher self-compassion was associated with lower levels of anxiety and depression and the use of more adaptive coping strategies, and this was relatively consistent across various samples. Understanding these links and the importance of self-compassion will allow clinicians to develop and utilise interventions which support coping and management throughout the illness course given the lifelong duration of such conditions.

The research paper sought to understand the experiences of adolescents living with epilepsy in relation to coping and self-compassion. This sample was chosen given adolescents with epilepsy face particular challenges; namely living with an unpredictable condition during a key stage in social and emotional development (Rosenblum & Lewis, 2003). A qualitative design was utilised, and semi-structured interviews were conducted with five young people. The interviews were transcribed verbatim and analysed using interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009). Three themes were constructed from the data: (i) Learning about my condition and my experiences: “Getting answers and people explaining things...it makes massive lifesaving differences”, (ii)

Dealing with the thought takeover: “I try not to think on it to move on” and (iii) Being in an accepting bubble: “I know that people have got my back”. The findings were consistent with previous research that likewise explored coping in adolescents with epilepsy (Eklund & Sivberg, 2003) as well as research that explored self-compassion in adolescents generally (Klinge & Van Vliet, 2019; Gilbert, 2009). Subtle differences were also noted, such as the emphasis placed on seeking support via social media/online forums, as well as adolescents being less self-focused than found previously.

Whilst self-compassion as an overarching concept was not heavily relied upon throughout narratives, individual components were present, such as thought overidentification vs mindfulness, and being alone vs common humanity. These subtle yet complex findings emphasise the need to further understand this relationship, and in more diverse groups, for clinicians to support coping through the most appropriate interventions.

The Importance of Reflexivity

Kleinsasser (2000) describes reflexivity as the process of our critical self-reflection on our biases, theoretical predispositions and preferences. It also involves the individual seeking to understand their place within the context and social phenomena being explored, and the potential influence of this on our biases, and the overall research. Qualitative researchers place significant emphasis on the use of reflexivity within research to ensure data and its subjectivity is seen as an opportunity rather than a problem (Finlay & Gough, 2003).

In order to maintain a reflexive stance, I kept a diary from the initial development of this project, capturing reflections and relationships between myself, the data collected and the overall study. I hoped this would support me in recognising any power imbalances that might exist between myself (the researcher) and the participants (Hertz, 1997), such as participants feeling the need to answer questions in a desirable way. I also believe the process of keeping a diary has strengthened the validity of the findings, giving me the opportunity to explore and

interpret my responses. Personal reflections have been outlined below to document considerations I had during the research process.

My Research Motivation

The decision to conduct research in this field was based upon a number of factors, which I spent time reflecting upon both prior to, during and whilst analysing my research to consider how they link with my values and interests. Firstly, my clinical experiences prior to beginning the doctorate were mainly in neuropsychological services, which have largely influenced my interests. In particular, working in a neuropsychology team within a children's hospital fuelled my desire to work with and support children and families experiencing chronic neurological conditions. I noticed a growing passion to provide care to minimise the impact of adversity in young people, in line with documents released at the time. These highlighted the importance of providing all children and young people with the support they require in relation to their health, education, social and psychological needs (such as "Every Child Matters", 2011) and government guidance set out on how best to support children with medical difficulties at school (Department for Education, 2015; Healthy Children, 2016). More specifically, clinical experiences highlighted the psychological impact that chronic conditions could have on a young person, which can at times be overlooked (Compas et al., 2012). I reflected upon one significant memory of witnessing an adolescent experience a seizure within the therapeutic room. I observed the embarrassment and self-criticism felt at the unpredictability and uncontrollability of their experience. A team meeting discussion also highlighted that this lack of self-kindness was evident across medical conditions, sparking my initial interest in the concept of self-compassion.

In summary, these experiences, values and interests combined led me to question how young people cope with a condition such as epilepsy, and how caring they are to themselves in light of this. This felt especially key during a period of time that is associated with

emotional development alongside emphasis placed on the importance of how they are viewed by others (Schwartz et al., 2006). However, I was mindful that having an attachment to the topic area and hospital service itself may unknowingly influence the way in which I approached the research (i.e. over-identifying with participants; Kitson et al., 1996), which I made a conscious effort to reflect on and take to supervision.

Designing the Study

In designing the study, I aimed to capture the experiences of coping specific to epilepsy. Individuals under a tertiary service require medical care and monitoring from a consultant, thus this service felt most suited to recruit the desired sample given the severity of their condition. However, as recruitment of adolescents can often be more challenging than other age groups (Bassett et al., 2008), a large sample estimate was used. Consideration was also made in relation to language used in the ethics materials and interview schedule, in order to ensure this was age appropriate, as well as adapting this to different ages within the adolescent age range. This is especially important given language abilities, abstract thinking and ability to give consent are thought to differ between the ages of 13-18 (Broome, 1999; Berman, 2004; Dumontheil, 2014). Whilst I initially felt a dilemma in regard to younger individuals assenting and adults consenting on their behalf, Grady et al. (2014) found most adolescents found the assent and consent process in research to be satisfactory and respectful of their wishes.

A further challenge during the design of the interview was the method used to outline self-compassion, given individuals are not always familiar with the concept (Pauley & McPherson, 2010). Previous research (Campion & Glover, 2017) has utilised video material explaining the term, illustrated with examples. However, a conversation was held amongst myself and my supervisors based on feeling this material was adult-orientated and did not feel age-appropriate for the client group in question. A decision was therefore made to

alternatively create a crib sheet based on the definition of the concept provided by Neff (2003) in order to better illustrate the concept in relation to language and experiences more common at this age. This was piloted with a small sample.

Underpinning the above was my awareness of how my experiences may shape hypotheses, which may influence the data collected. I reflected on this in supervision when designing a schedule to interview adolescents about their experiences of coping and self-compassion, such as being aware of leading questions that might have been informed by my own opinions and beliefs. I also shared one audio recording and multiple transcripts with my research supervisors, which allowed me to critically reflect on my questioning and the data, searching for possible biases and using this to inform subsequent interviews.

Recruitment

Whilst recruitment in research can be difficult across any service, it can be particularly difficult in hospital environments due to the competing demands of staff and individuals accessing services (Patel, Doku & Tennakoon, 2003; Van Horn et al., 2008). Therefore, the first challenge was recruiting in an environment where other demands took priority. More specifically, professionals involved in epilepsy clinics who were asked to distribute research packs often reported in retrospect that this had not occurred. This was mostly due to the amount of time available during the appointment, alongside the tendency to forget to do so. This may be explained by both the recency effect in psychology (Baddeley & Hitch, 1993), as well as the likelihood we will not encode and therefore forget information that does not feel of upmost importance to us (Pastotter & Bauml, 2007). This led me to experience frustration given the lack of control had as a researcher, especially given the contact details of participants identified could not be shared for confidentiality reasons. This heightened a sense of helplessness when uptake of participants was slower than anticipated.

Alongside these initial difficulties, the onset of COVID-19 resulted in a pause in recruitment given identification through clinics was temporarily not possible. A discussion was had around a potential amendment to recruit online via third sector organisations, however this left me concerned that the sample would diversify, significantly moving away from the homogeneous sample sought after in IPA (Smith, 1999) research. For example, it would be harder to be sure of the severity of epilepsy and online recruitment would mean those unable to access technology or social media may not have the opportunity to take part. Ethically, I also felt some discomfort in approaching charities and promoting research via social media during a time of international crisis. Given that there is no set requirement in regard to sample size for IPA, with this depending upon factors such as richness of the data collected (Smith & Osborn, 2004), a decision was instead made to end recruitment early at five participants after weighing up the above risk of heterogeneity alongside a smaller, less rich data set. As the initial target sample was 6-12 in size, it was deemed a sample of five would not differ greatly in the data collected. Previous child research has also used five-participant size samples in IPA (Tyerman et al., 2019).

Conducting Interviews

In order to increase accessibility, interviews were offered in a location convenient for the young person, with the first participant choosing an interview in the hospital, given this felt familiar to them. This is in line with Gans and Brindis (1995) who explain the choice of interview setting should be appropriate for the research questions posed. However, given the hospital environment is associated with medical care and thus the condition, it may be that this could have the potential to influence interviews in either a positive or negative way based on the individual's experience.

This choice and flexibility were removed again as a result of COVID-19 and lockdown restrictions, resulting in families and the researcher being unable to leave their

homes for non-essential reasons. Interviews were only able to take place online, which perhaps shaped the sample given the reasons outlined above (i.e. accessibility), as well as some feeling discomfort at this. Furthermore, after conducting one face to face interview, it became apparent how having the physical space and time to allocate to rapport building at the beginning of the interview was important in enhancing comfort. This is further illustrated by research finding rapport building over video calling to be experienced less favourably (Jowett, Peel & Shaw, 2011; Weller, 2017). In addition, Gans and Brindis (1995) found an underreporting of difficulties to be more common in household samples. However, being aware of these potential influences, additional time was added to explore and account for this and so rapport did not appear to be impacted on through interviewing in this modality. This adaptability may have also been influenced by the age of the sample, with adolescents being more familiar with interacting on online forums in comparison to adult populations (Leung, 2011).

Alongside COVID-19 impacting on the interview location, I had concern that the adolescent's current context of coping might be very different, with participants coping with their condition as well as COVID-19 and its consequences. I was mindful that not only might the data gathered be different to that prior to the pandemic, but the data collected online during lockdown may differ to that collected prior to this. Furthermore, IPA requires participants to reflect on their most salient experiences at that moment in time, which again may mean the data may be more reflective of coping with the current context (Smith, 1999). This was something that was discussed in supervision, and a conscious effort was made to explore this explicitly with the individual and/or their parent prior to beginning the interview. This did not however appear to be an issue in any interview.

Secondly, as mentioned, self-compassion is a relatively new self-related concept and can be a difficult concept to understand (Barratt, 2017). As a result, this could be difficult to

explore in interviews, with most research in self-compassion being quantitative and involving the use of the Self-Compassion Scale (Neff, 2003b). Direct language and concrete examples were used throughout interviews, however I felt apprehension around providing suggestions and taking meaning away from individual experiences. I was therefore conscious of checking in around the applicability of examples for the young person, as well as trying to unpick whether the difficulty in accessing components of the concept (e.g., self-kindness) was due to it being difficult for the adolescents to describe, it being an unconscious experience, or whether it was merely not something they experienced.

Individual differences

In a similar vein, I was aware of the need to be mindful of additional considerations in working with adolescents. As outlined in the research paper, this period represents a time of change and transition (Rosenblum & Lewis, 2003, Sebastian, Burnett & Blakemore, 2008), with cognitive, social and emotional skills developing across the span. This presented a particular challenge when considering adaptations that may need to be made at different stages of the research project, based on individuals being at different points throughout the stage. When comparing interviews and the need for language adaptations, I noted the differences between participants in their comfort and ability to reflect on both internal and external experiences. One participant in particular used a limited range of words and phrases to describe their experiences, often providing one-word answers to questions, or reflecting back previous points. I was also mindful of any subtle cognitive problems that may exist as a result of time away from school, seizures or an effect of medication, which again influenced my choice of language.

I considered that I was asking individuals questions about difficult experiences that may involve reflecting on ways of managing emotions and struggles, which can require emotional vocabulary and awareness. For some of the individuals, it was one of the first

times that they had been encouraged to talk about emotional experiences, and therefore may have not had the opportunity to describing them previously. I reflected that this could impact upon the content of the interviews, as a lack of emotional expression and vocabulary can act as a barrier to the efficacy of semi-structured qualitative methodological approaches (Affleck, Glass & Macdonald, 2012). As a result of reflection, I carefully used my own emotional vocabulary to build rapport with participants, aiming to create a safe environment and allowing me to listen to and understand their experiences (Collins & Cooper, 2014). Given the potential barriers around language and expression, alternative forms of qualitative methodologies could be considered in future research, to ensure that any limitations around language are accounted for (Partington, 2011). Examples of alternative approaches may be the use of creative, visual methods that may rely less on verbal expression. This may help to include and represent participants who may have previously been missed.

To add to this, I reflected upon what my expectations might be of the adolescents' tendency to be self-compassionate based on previous clinical experience, which I actively attempted to 'bracket'. This is a concept suggested by qualitative researchers, in which we attempt to put to one side our predetermined ideas and beliefs (Tufford & Newman, 2010). I was also mindful of my own privilege, in having not had a chronic illness, and how this at times led to personal concern around being unable to fully identify with the narratives shared by participants. I instead drew upon my clinical skills of containment (Haigh, 2013) and empathy (Greenberg et al., 2001) to share as much of their experiences as possible. Whilst employing these skills in a virtual environment could prove more challenging, it felt even more important to do in order to provide a sense of safety to the individual.

Furthermore, Kitson et al. (1996) discusses how researchers exploring difficulties and loss may experience anxiety, which I ensured I dedicated time to process either through reflection or through discussion with peers to prevent this impacting on the interview process.

In a similar vein, I could often be left with difficult feelings after interviews, especially if experiences shared were negative and had a lasting impact on the individual. I chose to reflect on these feelings, and I attempted to keep in touch with this experience during transcribing and analysis. The insight gained around how upsetting the experiences were and how at times I could feel a sense of helplessness, provided additional data as well as ensuring I did not minimise the emotions based on finding them difficult to tolerate myself.

Data Analysis

Considering my own position as a psychologist with a passion to provide support to young people as early as possible in order to mitigate the impact this may have on their future, I contemplated how this might influence the data analysis. For example, I was aware how I may formulate hypotheses based on the most salient data (i.e. considering how we can support those struggling to cope or be self-compassionate), potentially missing less obvious narratives that may paint a different picture. Being a younger researcher with siblings close in age to participants, I hoped this may positively influence my understanding and insight when performing the analysis. All in all, awareness of such biases and regular reflection on these both individually and in supervision enabled me to make explicit efforts to understand and interpret the experiences shared.

Since completing the analysis, I have reflected on the perspectives and experiences gathered within the research as well as those potentially missed. For example, the research recruited those who had a diagnosis for more than 6 months, however one participant had their diagnosis for one year but seizures from birth. This led me to consider perhaps those in a similar position, thus whilst their diagnosis may have been very new, they may have had to learn to manage and cope with their experiences for a much longer time. In addition, some individuals may have felt dissuaded to take part due to currently finding it difficult to cope with their condition and/or perhaps not feeling able to talk about this to others. A review of

the literature outlines barriers individuals may face when considering involvement in research, with factors including stigma attached, mistrust of those deemed to be in authority (i.e. professionals, academics), fear or sharing difficult experiences, and barriers around accessibility or language (Woodall et al., 2010). Research has suggested involving caregivers or a trusted individual in interviews to overcome such barriers (Connell, Shaw, Holmes & Foster, 2001), which was one benefit of parents being involved in the current study.

Likewise, the current sample was relatively homogeneous in regard to ethnicity and age, with all participants being white British, and all but one being in the 13-15 age bracket. This may mean other diverse groups and their experiences may have been missed.

Post analysis reflections

Wider context and influences

In reflecting on the results and the process of completing the research, I spent some time considering systemic and societal influences that may have shaped findings or be important to consider. In conversations with participants, it became quickly apparent that psychology input and support was not a consistent part of a young person's hospital care. Generally, their care was medically focused, with only two participants having met with a psychologist within the hospital. This was something I reflected upon given my most recent clinical experience has been largely in adult mental health, whereby psychology may have a much clearer role within an multi-disciplinary team. In addition, given the widely held societal view around mental health and thus psychology input (Nearchou et al., 2018), I reflected on how now participants may have had a preconceived view that my involvement may be related to something pathological. In addition, this also meant a number of the individuals had not shared the impact of their condition with a professional, which was reflected in the apparent value in having time to talk through this. This however could at times make it more difficult to shift the focus of the interview to coping, striking a balance

between validation versus exploration. Linking in with this, I reflected upon the view of psychology generally within society, and the “expert” view that is often held, with those using services often seeking to be fixed. This is especially present in hospital, medical environments where the patient doctor relationship is more evident.

The research and me

Throughout the research, I was keen to reflect upon the balance between my role as a researcher and my role as a clinician and therapist. Firstly in relation to the analysis chosen, a strength of IPA is that it is line with our clinical stance in exploring experiences, thus it focuses on the experiences of the individual. I also thought about this balance in relation to my responses, given my personal interests in the topics around this research project, and my responses as a therapist. Consequently I was mindful of how I may typically respond to distress as a clinical therapist, utilising skills of empathy and exploration (Conoley et al., 2015). Stahlke (2018) discusses the concept of ‘ethical distress’ within research, based on Epstein and Delgado’s (2010) definition, stating that distress occurs when we become aware of the right action to take, but are unable to do so, due to particular constraints (i.e. due to being in a researcher role). It is suggested that there is a significant risk to researchers of experiencing distress, based on sensitive information provided by participants (Stahlke, 2018). Therefore, I was mindful of not only invalidating experiences by adhering to my research agenda, but I was also conscious of encouraging a conversation that I could not contain due to the set-up of the interview. To overcome concerns around this, I spent more time reviewing my responses and experiences throughout the research in my reflective journal, aiming to understand my responses and how these could influence the data collection and analysis, and also maintain the appropriate focus on participant safety and awareness of my reflexivity statement and stance within such a topic.

Conclusion

The current findings highlight the value of self-compassion in chronic illness groups, as well as the complexity of the relationship it can have with outcomes such as coping. When interpreting findings however, the current reflections highlight how biases as individuals researchers, depending on our values, context and experience can shape the these. They may influence the research from beginning to end, and whilst this is largely done unknowingly, it highlights the importance of reflection to ensure transparency and learning to interpret findings as accurately as possible.

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Chapter 4: Ethics Section

Ethics Application for Research Paper:

Self-Compassion and Coping in Adolescents living with Epilepsy

Melissa Longworth

Doctorate in Clinical Psychology

Division of Health Research Lancaster University.

Word count: 4023

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IRAS Application Form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Self-compassion and coping in adolescents living with epilepsy

1. Is your project research?

Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
- Basic science study involving procedures with human participants
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
- Study limited to working with data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? Yes No
- b) Will you be taking new human tissue samples (or other human biological samples)? Yes No
- c) Will you be using existing human tissue samples (or other human biological samples)? Yes No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

- England
- Scotland

- Wales
 Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
 Scotland
 Wales
 Northern Ireland
 This study does not involve the NHS

4. Which applications do you require?

- IRAS Form
 Confidentiality Advisory Group (CAG)
 Her Majesty's Prison and Probation Service (HMPPS)

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

- Yes No

5. Will any research sites in this study be NHS organisations?

- Yes No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or Medtech and In Vitro Diagnostic Cooperative in all study sites?

Please see information button for further details.

- Yes No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

- Yes No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes No

9. Is the study or any part of it being undertaken as an educational project?

Yes No

Please describe briefly the involvement of the student(s):
The study is being undertaken as part of a Doctorate of Clinical Psychology at Lancaster University. As such, the student will contribute the majority of work in terms of data collection, analysis and preparation of the final report, in consultation with the research and field supervisors.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

Integrated Research Application System
Application Form for Research involving qualitative methods only

IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
 Self-compassion and coping in adolescents living with epilepsy

Please complete these details after you have booked the REC application for review.

REC Name:
 Yorkshire & The Humber - Leeds East

REC Reference Number:
 19/YH/0308

Submission date:
 06/08/2019

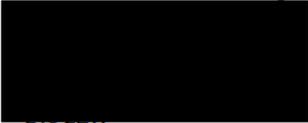
PART A: Core study information
1. ADMINISTRATIVE DETAILS
A1. Full title of the research:

Self-compassion and coping in adolescents living with epilepsy

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Ms	Melissa	Longworth
Address			
Post Code			
E-mail	m.longworth@lancaster.ac.uk		
Telephone	01524592970		
Fax			

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Doctorate in Clinical Psychology

Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Fiona	Eccles
Address	Doctorate in Clinical Psychology Furness College Lancaster University		
Post Code	LA1 4YG		
E-mail	f.eccles@lancaster.ac.uk		
Telephone	01524592807		
Fax			

Academic supervisor 2

	Title	Forename/Initials	Surname
	Dr	Will	Curvis
Address	Doctorate in Clinical Psychology Furness College Lancaster University		
Post Code	LA1 4YG		
E-mail	w.curvis@lancaster.ac.uk		
Telephone	01524593096		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Ms Melissa Longworth	<input checked="" type="checkbox"/> Dr Fiona Eccles <input checked="" type="checkbox"/> Dr Will Curvis

A copy of a [current CV](#) for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

Student
 Academic supervisor
 Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname Ms Melissa Longworth
Post	Trainee Clinical Psychologist
Qualifications	BSc Psychology Upper Second Class MSc Applied Clinical Psychology Distinction
ORCID ID	
Employer	Lancashire Care NHS Foundation Trust
Work Address	Doctorate in Clinical Psychology Furness College Lancaster University
Post Code	LA1 4YG
Work E-mail	m.longworth@lancaster.ac.uk
* Personal E-mail	melissalongworth@hotmail.com
Work Telephone	01524592970
* Personal Telephone/Mobile	07508023589
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname Ms Becky Gordon
Address	Deputy Head of Research Services Lancaster University Lancaster
Post Code	LA1 4YG
E-mail	sponsorship@lancaster.ac.uk
Telephone	01524592981
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	N/A
Sponsor's/protocol number:	N/A
Protocol Version:	0.1
Protocol Date:	01/07/2019
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	N/A

Additional reference number(s):

Ref.Number	Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open

access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

Epilepsy is a condition affecting 1 in every 220 young people in the UK, with one third of cases beginning before the age of 20 years. Adolescence alone involves physical, academic and social pressures. These challenges, alongside managing a condition like epilepsy can be difficult for a person to tolerate, often meaning they may struggle with low mood as well as having a poorer quality of life.

Epilepsy has been found to have a more negative impact on young people than other conditions, What can make this worse is the coping strategies used to manage difficult experiences. Self-compassion, which is being kind to oneself during difficult times, promotes helpful coping such as more positive thought restructuring and less avoidance. High self-compassion in adolescents generally has been linked to better psychological and physical outcomes, and lower rates of depression. However, less is known about how self-compassion is linked to, and perhaps underpins, coping in adolescent, chronic illness populations.

This study will aim to explore self-compassion and coping in an adolescent epilepsy population (i.e. 13-18 years), recruited from a tertiary service within a local hospital service. This will involve young people who have their care monitored by a specialist consultant, and thus given the complexity and the impact of their epilepsy, may be those most likely to rely on coping strategies. They will be recruited through routine clinic appointments and from an internal clinical database search completed by a member of the clinical team. It is hoped between 6-12 young people will be recruited, with interviews lasting approximately 60 minutes in a location convenient for the individual. These will involve open-ended questions to explore experiences, with data being subsequently analysed to develop common themes. Findings will be shared formally and informally to help understanding and shape practice as much as possible.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Recruitment

One potential issue that may impact on recruitment may be in relation to participant age and motivation, and thus their desire to engage in research. This will be overcome by providing thorough detail on the project, as well as leaving all choice to the young person so no coercion or pressure is felt. The chief investigator will arrange interviews at a time and location suitable for individual and their parent/carer. The chief investigator will not access personal data during recruitment, with potential participants being identified by the clinical team only. Personal data will only be accessed by the chief investigator once individuals make contact with them.

Confidentiality

Participant confidentiality will be maintained during the project, however individualised quotes will be used within academic submissions as well as in any published work. Interview transcripts will be anonymised and the researcher

will provide all participants with a detailed summary of confidentiality prior to each interview. If confidentiality needs to be breached due to a risk of harm to the self or others, participants and their parents/carers will be made aware of this. Regular meetings will occur between the main researcher and supervisors to ensure any ethical or practical concerns are discussed.

There are no issues expecting to arise from processing identifiable data due to adhering to the following:
Participant confidentiality will be maintained throughout the project. Confidentiality of data will be maintained by storing identifiable documents electronically (i.e. consent forms and other personal information) using participant assignment numbers, as well as storing these separately to interview audio files. Electronic documents, audio data and electronic transcripts of interviews will be stored and transferred electronically on Lancaster University's encrypted network. Data will also be backed up on the university VPN. Audio-tape recordings will be transcribed anonymously. Anonymised typed copies of interviews with participant identifier numbers will be transcribed and analysed on the researcher's personal laptop under password protection and encryption, which will be accessed via the VPN.

On completion of the research project, research data and consent forms will be stored electronically on Lancaster University's encrypted network for ten years. Any paper documents (i.e. original consent forms) will be destroyed after they have been scanned and stored electronically. Academic supervisors will have responsibility for storing and deleting the data once the student has submitted the thesis and completed the course. Confidential, personal data will be destroyed after the study is completed. Participants will be made aware that direct quotes will be used in the final report and that every effort will be made to ensure that the information used is not personally identifiable. Participants will be sent information about the overall findings of the study and can request a copy of the final report.

Informed consent

Participants will be given time to consider whether they want to participate to ensure informed consent is obtained, as well as assent from participants aged 13-15 years. For these younger participants, parents will also be given time to consider if they are happy for their child to take part. Participants and parents, where applicable, will be informed verbally and on the information sheet that they have a right to withdraw up until analysis.

Risk and burdens

It is not expected that participants will be placed in any discomfort or danger as a result of taking part. Participants will be given the choice as to whether to interview at a time that is suitable for them and their parent/carer to minimise inconvenience. The interview questions will not be purposefully distressing or sensitive, although, the process of talking about experiences may elicit upsetting responses. If a participant becomes upset whilst being interviewed, they will be made aware that they can stop the interview at any time, and the interviewer will make a judgement about when to stop the interview. The researcher will use clinical skills to provide support for participants when they are upset and help to contain these emotions. Whilst it will be advised that interviews should take place with only the young person to create a safe and exploratory environment, parents will be able to remain in the room if specifically requested. The participants will be given a debrief sheet after the interview which will include details of support should they feel they need it. Supervision will be sought by the interviewer to clarify any other means of supporting participants and to allow the researcher to debrief from the interview.

Participants can withdraw their participation in the study at any time, however they cannot withdraw their data from the study after analysis. This is due to the difficulties of removing individual information once all data has been incorporated into themes.

Lone working

It is not expected that there will be any risks to the researcher, however the Lancaster University Lone Working guidance will be followed during the project. Specific situations where lone working is inadvisable will be avoided (i.e. confined spaces) and if meeting with participants away from the hospital or university sites, will contact a project supervisor to confirm safety. The researcher will use a university email address and research mobile phone for speaking to participants or their parents/carers. Regular contact and supervision will be sought between the researcher and supervisors to provide a forum for discussion should participants talk about anything that is potentially upsetting for them or the researcher.

Service-related issues

There are no service-related issues expected to cause any concern during the study.

There are no conflicts of interest with this study.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply.

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

How do adolescents cope living with epilepsy, and how might self-compassion influence this?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

This research is interested in:

- 1) How do adolescents cope with epilepsy?
- 2) What ways of coping are perceived to be helpful/unhelpful and why?
- 3) Do adolescents with epilepsy identify as self-compassionate or not?
- 4) Does being self-compassionate influence ways of coping?

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

Epilepsy is a neurological condition affecting 1 in every 220 young people in the UK, with one third of new cases onsetting before the age of 20 years. There are believed to be over 60 types of epilepsy, with seizures presenting differently depending on the area and proportion of the brain affected (Epilepsy Action, 2018). As expected, this can impact on individuals significantly with effects including reduced self-esteem, social anxiety, difficulties with educational achievement and subsequent employment (Sillanpää, Haataja & Shinnar, 2004; Aldenkamp, Weber, Over-Plandsoen, Reijs & van Mil, 2005; Cianchetti et al., 2015).

Adolescence alone involves physical and hormonal changes (Sheth, 2002; Dockray, Susman & Dorn, 2009) alongside academic and social pressures (Bluth, 2016). These challenges, compounded by the management of a chronic condition such as epilepsy, have been found to impact on young people in a number of ways. For example, studies have found an increased prevalence of low mood and anxiety in young people with epilepsy compared to other conditions (e.g. asthma) and compared to healthy controls (Kwong et al., 2016; Schraegle & Titus, 2017), with such psychological difficulties subsequently impacting on quality of life (Johnson, Jones, Seidenberg & Hermann, 2004).

Alongside psychological difficulties, epilepsy has also been found to have a more adverse physical and social impact on adolescents in comparison to other conditions. This includes the influence it can have on perceived popularity, as well as how it can leave others reluctant to befriend individuals with epilepsy (Wirrell & Cheung, 2005). What can worsen this impact is the coping strategies used to manage difficult experiences, with denial and behavioural disengagement being associated with lowered quality of life and perceived stigma in adults with epilepsy (Bautista, Shapovalov & Shoraka, 2015). Similarly, adolescents with epilepsy have been found to use lower problem-focused and more emotion-focused coping (i.e. withdrawal, worry), which are linked to poorer psychosocial functioning (Cengel-Kultur, Ulay & Erdag, 2009; Clarke & Critchley, 2016). Only one qualitative study exists that has explored coping and its function in depth (Eklund & Sivber, 2003), with there being little understanding as to what makes a coping technique helpful or not or how these are situated in the everyday lives of adolescents with epilepsy.

Self-compassion, defined as treating oneself with kindness and acceptance when confronted with difficulties (Neff, Kirkpatrick & Rude, 2007), has been recognised as an important quality for reducing stress and increasing resilience in the face of challenge (Neff, Kirkpatrick, & Rude, 2007). Theoretically, Allen and Leary (2010) suggest self-compassionate individuals experience lower stress because of their use of effective coping strategies. Whilst high self-compassion in adolescents has been linked to better psychological wellbeing and lower physiological stress responses (Bluth et al., 2016), there is limited and mixed support for the hypothesis that people high in self-compassion use more adaptive, problem-focused coping styles and less maladaptive coping styles. What complicates this is the number of coping categorisations that exist, resulting in styles being grouped in different ways throughout research (i.e. active or passive; problem focused or emotion focused). More specifically, Skinner, Edge, Altman, and Sherwood (2003) identified 400 types of coping, showing little agreement among theorists in the best ways to conceptualize categories of coping strategies.

To complicate this further, even less is known about how self-compassion influences coping in the context of a chronic stressor. Whilst a few studies have examined this in adult chronic condition populations, finding self-compassion and willingness around acceptance of the condition to be related to fewer mood related difficulties for example (Costa & Pinto-Gouveia, 2013), none have explored this in young epilepsy groups. Given the challenges of adolescence, the impact of an unpredictable chronic illness such as epilepsy and the perceived unhelpful coping styles utilised in this group, it appears important to explore these links in depth by hearing experiences of those concerned. A qualitative study will hopefully gather rich information in a sample clinical epileptic group to begin to understand adolescents' experience. This may inform theory and support larger, quantitative research to more systematically explore the relationships, ultimately allowing teams to support young people as effectively as possible. Providing appropriate support early on may also minimise the impact this condition has on their transition into adulthood.

This project therefore aims to explore self-compassion and coping in an adolescent epilepsy population, and how they arise in young people's everyday experience. We will gather exploratory, qualitative information using semi-structured interviews, which may inform future quantitative research projects. Given the mixed findings around coping, having a flexible, open data collection should allow for relationships to be unpicked further, without limiting exploration to predefined coping categories.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Design:

This study will use a qualitative approach. Semi-structured interviews will be conducted and analysed based on Smith's (1999) interpretative phenomenological analysis (IPA) epistemology and methodology.

Procedure:

Participants will be recruited from one tertiary epilepsy service in a UK children's hospital, but this may be extended to a second centre depending on the number of participants who meet the study criteria and are willing to participate. Recruitment will occur in two ways. A member of the clinical team will identify adolescents listed on an internal clinical database who meet the study criteria. These individuals will be sent a letter of invitation alongside study information in the post by the service (i.e. age appropriate participant information sheet, consent/assent forms). The same information and documents will be given out at clinics to those appropriate by the multi-disciplinary team. The team will have access to the study inclusion and exclusion criteria at the weekly epilepsy clinic.

The study will aim to recruit between 6-12 participants. For young people aged 16-18 years, information packs will be sent in the post and addressed to the young person. This will include a participant information sheet for the young person only, as well as a consent to participate form. For those aged 13-15 years, packs will similarly be sent in the post but will be addressed to the parent/carer. It will be requested for parents/carers to pass this information on to the young person to help guide their decision. Both the young person and the parent/carer will receive a participant information sheet. A consent to participate form will be addressed to and required to be completed by a parent/carer. An assent form will be required to be completed by the young person.

Contact information (phone number and email) will be provided for individuals to contact the main researcher if they are happy to participate or have any queries around the study. Young people will then be invited to engage in an interview with the main researcher centred around their experiences, with written consent/assent to be obtained at the interview. For those who choose to engage in an interview online or via phone (i.e. skype), consent/assent forms will be required to be returned to the main researcher prior to the interview taking place. These will be approximately one hour in duration, will be audio recorded on a digital device and subsequently transcribed verbatim in preparation for analysis.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

A small subset of adolescents living with epilepsy were approached to provide informal feedback around the design of the study (i.e. questions asked during the interview, language used). After sharing all of the relevant documents, it was reported that the language and the concepts outlined were deemed to be understandable, with only wording from one section of the information sheet altered to make this as accessible as possible.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- Blood
- Cancer
- Cardiovascular
- Congenital Disorders
- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Gender:

Male and female participants

Lower age limit: 13	Years
Upper age limit: 18	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Individuals will have a primary diagnosis of epilepsy and will be required to be adolescents (13-18 years). They will be under a medical consultant in a tertiary care hospital and will also be required to have had their diagnosis for at least six months in order to gain a better sense of the coping strategies that have been developed over time by this group. Those with a newer diagnosis may not have experienced the condition for long enough to have had to employ strategies. Furthermore, participants will be required to have language abilities and hearing abilities to enable them to take part in an interview in English.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Young people outside of the age range (13-18 years), those who have not had a diagnosis for a significant length of time (6 months) and those who do not have a primary diagnosis of epilepsy (i.e. epilepsy occurs secondary to another condition such as a head injury). Those who are unable to speak English, or feel their language or hearing abilities would prevent them from engaging in an interview would also be excluded.

RESEARCH PROCEDURES, RISKS AND BENEFITS**A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.**

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Reading of invite to participate	1	0	5	Participant. Participant's home address.
Reading of participant information sheet (parent and young person)	1	0	10	Participant. Participant's home address.
Consent being provided by parents and young people (see method for a breakdown of this; assent for young people under the age of 16 years)	1	0	5	Chief investigator, trainee clinical psychologist. Participant's home address/interview venue.
Semi-structured interviews	1	0	60	Chief investigator, trainee clinical psychologist. Address convenient for the participant and their parent/carer.
Reading of debrief sheet	1	0	5	Chief investigator, trainee clinical psychologist. Address chosen for interview.

A21. How long do you expect each participant to be in the study in total?

Participants may be in the study for a maximum of 12 months from recruitment to receiving results. Depending upon recruitment processes, they will only be required to meet face to face with the researcher on one occasion to complete a semi-structured interview. This will be up to around 1.5 hours, including a pre-interview discussion (i.e. ensuring consent/assent is given).

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

There are not expected to be significant risks for participants by taking part in this study. It is not expected that participants will be placed in any discomfort or danger as a result of taking part, other than possible emotional discomfort through talking about experiences. Participants will be given the choice as to whether to interview at the hospital, the university, online, via phone or at another place convenient for them, as well as at a time suitable for them to minimise inconvenience. Participants will be given time to consider whether they want to participate to ensure informed consent is obtained. Participants will be informed verbally and on the information sheet that they have a right to withdraw at any point up until the point of analysis.

As mentioned above, participants may become distressed or upset when talking about their experiences of living with epilepsy. The interview questions will not be purposefully distressing or sensitive, although, the process of talking may elicit upsetting responses. If a participant becomes upset whilst being interviewed, they will be made aware that they can stop the interview or withdraw at any time, and the researcher will make a judgement about when to stop the interview. The researcher, who is a trainee clinical psychologist, will use clinical skills developed throughout both clinical experience and doctoral training to provide support for participants when they are upset and help to contain these emotions. The participants will be given a debrief sheet after the interview which will include details of support they can access should they feel they need it. Supervision will be sought by the interviewer to clarify any other means of supporting participants and to allow the researcher to debrief from the interview.

A conversation will also take place with the participant and their parent/carer around the usual procedure followed when a seizure occurs, so that a plan to manage that may occur during the interview can be agreed and followed. Contact details of the parent/carer will also be taken to use in an emergency. If interviewing a young person (13-15 years) via skype, it will be ensured that they are not alone in the house when the interview takes place. For those aged 16-18, their home address will be sought prior to the interview taking place in order for any relevant support to be directed to the individual (i.e. an ambulance) based on the procedure typically followed during seizures.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

A24. What is the potential for benefit to research participants?

Although there are not any direct benefits to participants for taking part in this study, they may find the experience of talking and reflecting during the interview to be positive and rewarding. It is hoped that the results from the study will help services and professionals to better understand the role of self-compassion and coping in adolescents living with epilepsy.

A26. What are the potential risks for the researchers themselves? (if any)

It is not expected that there will be any risks to the researcher, however the Lancaster University Lone Working guidance will be followed during the project. Specific situations where lone working is inadvisable will be avoided (i.e. confined spaces) and if meeting with participants away from the hospital or university sites, will contact a project supervisor to confirm safety. The researcher will use a university email address and research mobile phone for speaking to participants or their parents/carers. Regular contact and supervision will be sought between the researcher and supervisors to provide a forum for discussion should participants talk about anything that is potentially upsetting for them or the researcher.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).

The field supervisor working within the epilepsy clinical team in the hospital will identify those eligible to take part through searching the internal clinical database of young people under the care of the team. Potential participants will be sent research materials providing information about the study via the post from the hospital. These will include a letter of invitation alongside an age appropriate participant information sheet and consent/assent forms. The same information and documents will be given out at clinics to those who meet the criteria by the multi-disciplinary team. The team will have access to the study inclusion and exclusion criteria at the weekly epilepsy clinic.

Young people and their parents/carers who consent to taking part will be recruited into the study.

Personal data will not be accessed by anyone other than the clinical member of the team prior to recruitment. Only the participants can give the chief investigator personal data with consent.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

Only the field supervisor, who is a member of the clinical care team, will have access to personal data prior to participants requesting to take part. Once contact has been made by participants, personal data will be passed on to the main researcher. This will not be accessed by anyone outside of the research or clinical team. Only the participants can give the chief investigator personal data with consent.

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

A29. How and by whom will potential participants first be approached?

Participants will be recruited into the study in two ways. They may be recruited via post after identification during the search of an internal clinical database by a member of the clinical team. They may also be given the same documents in person during a routine clinic appointment if a member of the multi disciplinary team identifies that they meet the study criteria. Documents will include an invite to interview, an information sheet about the project, and consent/assent forms based on the age of the young person. Participants will be given the researcher's email and telephone details to express interest in the study, as well as the field supervisor's contact information (clinical team member).

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

After participants and their parents (for those aged 13-15 years) have received an invite to participate, information sheet and consent form, it will be requested that they contact the main researcher to express their desire to participate. This will ensure they do not feel coerced or pressured, and are making an informed consent based on the information provided to them. Interview dates will be arranged via telephone. On the telephone, the researcher will check with participants that they fully understand the study and the researcher will answer any potential questions. Once participants and parents (where necessary) give verbal consent to take part in the study, interviews will be arranged.

At the beginning of the interviews, participants and parents (13-15 years) will be required to give their completed written consent form sent in the post. This will include information about audio recording during the interview, and an explicit explanation of confidentiality. For those wishing to take part via a phonecall/online platform, written consent/assent will be required to be posted to the researcher prior to the interview taking place.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be given as long as they require to decide on whether they would like to participate or not, or until recruitment ends.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

As per the exclusion criteria, young people who are unable to speak English, or feel their language or hearing abilities would prevent them from engaging in an interview would also be excluded from taking part.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.
- Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers

- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

Participant confidentiality will be maintained both during the project and after submission. Interview transcripts will be anonymised and the researcher will provide all participants with a detailed summary of confidentiality prior to each interview. Confidentiality of data will be maintained by storing identifiable documents electronically (i.e. consent forms and other personal information) using participant assignment numbers, as well as storing these separately to interview audio files. Electronic documents, audio data and electronic transcripts of interviews will be stored and transferred electronically on Lancaster University's encrypted network. These are backed up on the university VPN. Audio-tape recordings will be transcribed anonymously. Anonymised typed copies of interviews with participant identifier numbers will be transcribed and analysed on the researcher's personal laptop under password protection and encryption, which will be accessed via the VPN. Audio copies will be destroyed once the research has been submitted for examination.

On completion of the research project, research data will be stored electronically on Lancaster University's encrypted network for ten years. Academic supervisors will have responsibility for storing and deleting the data once the student has submitted the thesis and completed the course. Confidential, personal data (with the exception of consent forms) will be destroyed after the study is completed. Consent forms will be kept electronically for 10 years, separately to the research data. Participants will be made aware that direct quotes will be used in the final report and that every effort will be made to ensure that the information used is not personally identifiable. Participants will be sent information about the overall findings of the study and can request a copy of the final report.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Confidentiality of data will be maintained by storing identifiable documents electronically (i.e. consent forms and other personal information) using participant assignment numbers, as well as storing these separately to interview audio files. Electronic documents, audio data and electronic transcripts of interviews will be stored and transferred electronically on Lancaster University's encrypted network. Anonymised typed copies of interviews with participant identifier numbers will be transcribed and analysed on the researcher's personal laptop under password protection and encryption. Confidential, personal data will be destroyed after the study is completed. Scanned copies of consent forms will be kept for 10 years, as described above. Paper copies will be destroyed after scanning.

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

The chief investigator will adhere to the EU General Data Protection Regulation (GDPR) and the UK Data Protection Act (2018) in relation to ensuring the confidentiality of personal data. Interviews will be transcribed anonymously and original recordings will be deleted from the digital recorder as quickly as possible once it has been transferred to the University's encrypted network. In the meantime, the recorder will be stored securely. File copies of audio recordings will be deleted once the project has been submitted and examined. Other research data will be retained for up to 10 years electronically on Lancaster University's encrypted network. The research supervisors will have responsibility for deleting the data after 10 years once I have submitted the thesis and completed my course.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

Interviews will be transcribed anonymously and original recordings will be deleted from the digital recorder as quickly as possible once it has been transferred to the University's encrypted network, which only the research and supervisory team. Prior to this, the recorder will be stored securely in a locked filing cabinet in the department of the relevant trust. Only the chief investigator will access this. The researcher's supervisors will have access recordings and to anonymised transcripts to check accuracy of the analysis process. During the study, names and addresses will be accessed by the chief investigator.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

Audio data and electronic copies of interviews will be stored and transferred electronically on Lancaster University's encrypted network. Audio recordings will be transcribed anonymously. Anonymised copies of interviews with participant identifier numbers will be transcribed and analysed on university computer's under password protection and encryption. Anonymised copies of transcripts and the results from analysis will be accessed by the chief investigator's supervisors in order to inform the analysis.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title Forename/Initials Surname
	Dr Fiona Eccles
Post	Lecturer
Qualifications	DClinPsy, DPhil, MPhys, GradDipPsy
Work Address	Doctorate of Clinical Psychology
	Furness College
	Lancaster University
Post Code	LA1 4YG
Work Email	f.eccles@lancaster.ac.uk
Work Telephone	01524592807
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
 3 – 6 months
 6 – 12 months
 12 months – 3 years
 Over 3 years

If longer than 12 months, please justify:

Whilst personal data generally will be accessed for 3 months, consent forms will be stored electronically on the university encrypted network for 10 years.

A44. For how long will you store research data generated by the study?

Years: 10
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

On completion of the research project, research data and consent forms will be stored electronically on Lancaster University's encrypted network for 10 years. The research supervisor will have responsibility for deleting the data once I have submitted the thesis.

Personal data other than consent forms will be destroyed after the study has been completed. Original tape recordings will be deleted from the digital recorder as quickly as possible once it has been transferred to the University's encrypted network. In the meantime, the recorder will be stored securely. File copies of audio recordings will be deleted once the project has been submitted and examined.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

Yes No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

The intention is to publish the study in a public journal. The researcher is currently unaware of any suitable public database on which to register the study.

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

The overall results from this study will also be sent to participants and they will be made aware that they can request a copy of the research paper part of the thesis.

Verbal feedback of the results are likely to be given to psychology teams in the services. Feedback will also be given at research meetings for the research and development departments.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Every effort will be made to ensure that direct quotations used from interviews will not identify participants. This will be made explicit to participants on the participant information sheet.

A53. Will you inform participants of the results?

- Yes No

Please give details of how you will inform participants or justify if not doing so.

The overall results from this study will be sent to participants and they will be made aware that they can request a copy of the research paper part of the thesis.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

The project proposal was reviewed and feedback was provided by the Chief Investigator's research and field supervisors. The proposal was anonymously peer-reviewed by the research team at Lancaster University's Doctorate of Clinical Psychology Exam board and given approval.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 12
 Total international sample size (including UK): 12
 Total in European Economic Area: 12

Further details:

It is expected that between 6-12 participants will take part in this study. The project will recruit a targeted sample of adolescents living with epilepsy who meet the inclusion criteria using a purposive sampling method.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The number of participants is in line with recommendations from Smith (1999) who suggest that up to 10-12 interviews should suffice for most researchers using IPA. Moreover, Charmaz (2014) argues that a smaller sample can produce in-depth interviews of lasting significance.

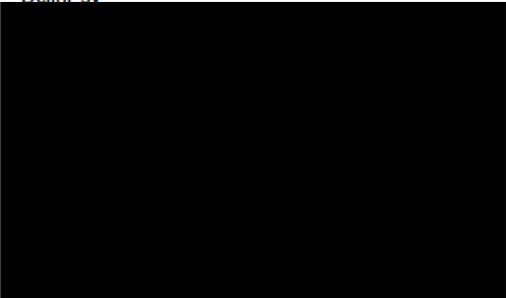
A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

An interpretative phenomenological analysis (IPA) epistemology and methodology has been chosen and will be employed to explore young people's experiences of epilepsy and management of this. IPA is used when there is complexity, process or novelty and this method is therefore suitable given there stands a lack of understanding around the research question, and the exploration of what may be a complex relationship. It is hoped IPA will provide a rich and detailed account of coping and self-compassion in epilepsy, as well as the meaning associated with the experiences that link the two.

Interviews will be digitally recorded and transcribed verbatim. The analysis will be conducted on data collected from the open-ended interview questions described above in order to generate knowledge to inform theoretical and clinical understanding. The process will begin with familiarisation of the data through re-reading of transcripts, followed by the identification and labelling of emerging themes. These themes will then be clustered into higher order superordinate themes, conveying shared experiences across the data set (Smith, 1996; Smith et al., 2009). A clear analysis trail will be maintained throughout to highlight the process of generating themes, with support from supervisors.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Victoria	Gray
Post	Consultant Clinical Psychologist		
Qualifications	DclinPsy		
Employer			
Work Address			
Post Code			
Telephone			
Fax			
Mobile			
Work Email			

A64. Details of research sponsor(s)**A64-1. Sponsor****Lead Sponsor**

- Status: NHS or HSC care organisation
 Academic
 Pharmaceutical industry
 Medical device industry
 Local Authority
 Other social care provider (including voluntary sector or private organisation)
 Other
- Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation Lancaster University
Given name Becky
Family name Gordon
Address Research Services, Lancaster University
Town/city Lancaster
Post code LA1 4YW
Country UNITED KINGDOM
Telephone 01524592981
Fax
E-mail sponsorship@lancaster.ac.uk

A65. Has external funding for the research been secured?

Please tick at least one check box.

- Funding secured from one or more funders
 External funding application to one or more funders in progress
 No application for external funding will be made

What type of research project is this?

- Standalone project
 Project that is part of a programme grant
 Project that is part of a Centre grant
 Project that is part of a fellowship/ personal award/ research training award
 Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.

Yes No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
Organisation			
Address			
Post Code			
Work Email			
Telephone			
Fax			
Mobile			

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 02/09/2019

Planned end date: 02/09/2020

Total duration:

Years: 1 Months: 0 Days: 1

A71-1. Is this study?

Single centre
 Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

England
 Scotland
 Wales

- Northern Ireland
 Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?

- Yes No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- NHS organisations in England 1
 NHS organisations in Wales
 NHS organisations in Scotland
 HSC organisations in Northern Ireland
 GP practices in England
 GP practices in Wales
 GP practices in Scotland
 GP practices in Northern Ireland
 Joint health and social care agencies (eg community mental health teams)
 Local authorities
 Phase 1 trial units
 Prison establishments
 Probation areas
 Independent (private or voluntary sector) organisations
 Educational establishments
 Independent research units
 Other (give details)

Total UK sites in study: 1

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

- Yes No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

The research supervisor and research director for Lancaster's University Clinical Psychology Doctoral programme will monitor the conduct of the research. The local collaborator will also be responsible for ensuring professional and ethical conduct of the research. Both the researcher's supervisors will review all aspects of the final report in addition to providing feedback on initial codes and analysis.

Participants will be made aware that if they have any complaints or issues with the research then they can contact the Research Director at Lancaster University Doctorate of Clinical Psychology.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
 Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
 Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
 Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

- Yes No Not sure

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

Participants will be young people with a primary diagnosis of epilepsy who are under a hospital consultant between

the age of 13-18 years. Given that the project is centred around the experiences of adolescents living with epilepsy, this age range has been included to capture individuals deemed to be adolescents, which is viewed at around 13 years of age. For those aged 13-15 years however, both assent and consent from parents/carers will be required in order for a young person to take part in the study.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

NA

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

A participant information sheet and a consent to participate form will be sent to children aged 16-18 years. Those in this age range will provide written consent to interview. For those aged 13-15 years, an age-appropriate information sheet and an assent form will be sent alongside separate documents for parents/caregivers (i.e. information sheet, consent form). Therefore, these children will give written assent to interview, and their caregivers will provide written consent. For those wishing to take part via a phonecall/online platform, written consent and/or assent (as outlined) will be required to be posted to the researcher prior to the interview taking place.

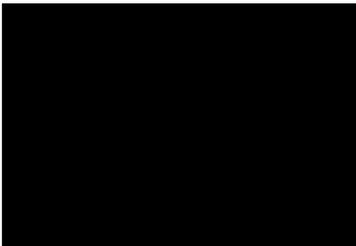
4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

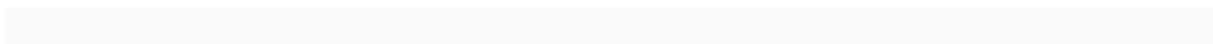
As described above, a participant information sheet and a consent to participate form will be sent to children aged 16-18 years. Two versions will exist depending on the age of the young person. For those aged 13-15 years, an adapted information sheet and an assent form will be sent alongside separate documents for parents/caregivers (i.e. information sheet, consent form). This will include age-appropriate language and explanations, and each age-adapted form will be presented to a service-user representative to ensure all documents are understandable.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For further information please refer to guidance.

Investigator identifier	Research site	Investigator Name
IN1	<input checked="" type="radio"/> NHS/HSC Site <input type="radio"/> Non-NHS/HSC Site	Forename Melissa Middle name Family name Longworth Email m.longworth@lancaster.ac.uk Qualification (MD...) BSc, MSc Country UNITED KINGDOM
	Organisation name Address Post Code Country	



Appendices

Appendix 4-A: Research Paper Protocol

1) Title

Self-compassion and coping in adolescents living with epilepsy

2) Name of applicant and supervisors

Trainee/applicant: Melissa Longworth

Supervisor (research): Dr Fiona Eccles, Lancaster University

Supervisor (research): Dr Will Curvis, Lancaster University

Supervisor (field): Dr Vicky Gray, [REDACTED]

3) Introduction

Epilepsy is a neurological condition affecting 1 in every 220 young people in the UK, with one third of new cases onsetting before the age of 20 years. There are believed to be over 60 types of epilepsy, with seizures presenting differently depending on the area and proportion of the brain affected (Epilepsy Action, 2018). As expected, this can impact on individuals significantly with effects including reduced self-esteem, social anxiety, difficulties with educational achievement and subsequent employment (Sillanpää, Haataja & Shinnar, 2004; Aldenkamp, Weber, Over-Plandsoen, Reijts & van Mil, 2005; Cianchetti et al., 2015).

Adolescence alone involves physical and hormonal changes (Sheth, 2002; Dockray, Susman & Dorn, 2009) alongside academic and social pressures (Bluth, 2016). These challenges, compounded by the management of a chronic condition such as epilepsy, have been found to impact on young people in a number of ways. For example, studies have found an increased

prevalence of low mood and anxiety in young people with epilepsy compared to other conditions (e.g. asthma) and compared to healthy controls (Kwong et al., 2016; Schraegle & Titus, 2017), with such psychological difficulties subsequently impacting on quality of life (Johnson, Jones, Seidenberg & Hermann, 2004).

Alongside psychological difficulties, epilepsy has also been found to have a more adverse physical and social impact on adolescents in comparison to other conditions. This includes the influence it can have on perceived popularity, as well as how it can leave others reluctant to befriend individuals with epilepsy (Wirrell & Cheung, 2005). What can worsen this impact is the coping strategies used to manage difficult experiences, with denial and behavioural disengagement being associated with lowered quality of life and perceived stigma in adults with epilepsy (Bautista, Shapovalov & Shoraka, 2015). Similarly, adolescents with epilepsy have been found to use lower problem-focused and more emotion-focused coping (i.e. withdrawal, worry), which are linked to poorer psychosocial functioning (Cengel-Kultur, Ulay & Erdag, 2009; Clarke & Critchley, 2016). Only one qualitative study exists that has explored coping and its function in depth (Eklund & Sivber, 2003), with there being little understanding as to what makes a coping technique helpful or not or how these are situated in the everyday lives of adolescents with epilepsy.

Self-compassion, defined as treating oneself with kindness and acceptance when confronted with difficulties (Neff, Kirkpatrick & Rude, 2007), has been recognised as an important quality for reducing stress and increasing resilience in the face of challenge (Neff, Kirkpatrick, & Rude, 2007). Theoretically, Allen and Leary (2010) suggest self-compassionate individuals experience lower stress because of their use of effective coping strategies. Whilst high self-compassion in adolescents has been linked to better psychological

wellbeing and lower physiological stress responses (Bluth et al., 2016), there is limited and mixed support for the hypothesis that people high in self-compassion use more adaptive, problem-focused coping styles and less maladaptive coping styles. What complicates this is the number of coping categorisations that exist, resulting in styles being grouped in different ways throughout research (i.e. active or passive; problem focused or emotion focused). More specifically, Skinner, Edge, Altman, and Sherwood (2003) identified 400 types of coping, showing little agreement among theorists in the best ways to conceptualize categories of coping strategies.

To complicate this further, even less is known about how self-compassion influences coping in the context of a chronic stressor. Whilst a few studies have examined this in adult chronic condition populations, finding self-compassion and willingness around acceptance of the condition to be related to fewer mood related difficulties for example (Costa & Pinto-Gouveia, 2013), none have explored this in young epilepsy groups. Given the challenges of adolescence, the impact of an unpredictable chronic illness such as epilepsy and the perceived unhelpful coping styles utilised in this group, it appears important to explore these links in depth by hearing experiences of those concerned. A qualitative study will hopefully gather rich information in a sample clinical epileptic group to begin to understand adolescents' experience. This may inform theory and support larger, quantitative research to more systematically explore the relationships, ultimately allowing teams to support young people as effectively as possible. Providing appropriate support early on may also minimise the impact this condition has on their transition into adulthood.

This project therefore aims to explore self-compassion and coping in an adolescent epilepsy population, and how they arise in young people's everyday experience. We will gather

exploratory, qualitative information using semi-structured interviews, which may inform future quantitative research projects. Given the mixed findings around coping, having a flexible, open data collection should allow for relationships to be unpicked further, without limiting exploration to predefined coping categories.

4) Method

Design

An interpretative phenomenological analysis (IPA) epistemology and methodology was chosen and will be employed to explore young people's experiences of epilepsy and management of this (Smith, 1999). IPA is used when there is complexity, process or novelty (Smith & Osborn, 2004). This method is therefore suitable given the lack of understanding around the research question, and the exploration of what may be a complex relationship. It is hoped IPA will provide a rich and detailed account of coping and self-compassion in epilepsy, as well as the meaning associated with the experiences that link the two.

Data will be collected via semi-structured interviews that will take place at a time and in a location convenient for the young person and their carer (i.e. hospital setting, university, online via Skype or other online communication platform) to ensure the target number of participants is met (6-12). The data collected will be qualitative in nature with the hope that this will allow pertinent experiences and themes relevant to the research questions to be explored using IPA. Riiskjaer, Ammentorp and Kofoed (2012) highlighted how individuals found gathering patients' views through open-ended questions was more "useful", than closed questions in informing patient-centred care. Whilst a semi-structured schedule has been developed, questions will be used to guide further exploration and discussion where possible.

The interview schedule explores how self-compassion and coping feature in the lives young people with epilepsy. This begins with a more general focus centred around living with epilepsy and the impact of this, followed by questions that will generate discussion around ways in which the person has coped. The interview schedule then shifts to self-compassion by outlining the concept, followed by questions that tap into underlying factors (i.e. is being kind to yourself something you find easy or difficult living with epilepsy?). The two concepts are then linked via specific questions (e.g. “have you noticed times when you are kind or unkind to yourself? how did that leave you feeling/what did you do?”). The questions are informed by the self-compassion literature (Neff, 2003; Neff & Lamb, 2009). These were piloted with a small number of young people living with epilepsy, with adjustments made after feedback to ensure language and concepts are explained in an age-appropriate way, thus being accessible and meaningful to the population.

Participants

Whilst there appears to be no set requirement guidelines in regards to sample size for IPA, this should depend on factors such as richness of the data collected. As a distinctive feature of IPA is the commitment to a detailed interpretative account of cases, a small sample (i.e. 6-12) is often recommended (Smith & Osborn, 2004). The aim of this current study would be to interview approximately 6-12 participants. This slightly larger range will be used given interviews may be potentially shorter due to the age of the target population.

Participants will be young people with a primary diagnosis of epilepsy who are under a hospital consultant. Hospital databases will be searched by the field supervisor to identify young people who may be suitable to take part in the study. A list of the criteria will also be

provided during weekly review clinics for professionals involved to also identify potential participants.

Individuals will have a primary diagnosis of epilepsy and will be required to be adolescents (13-18 years). They will be under a medical consultant in a tertiary care hospital and will also be required to have had their diagnosis for at least six months in order to gain a better sense of the coping strategies that may be used by the group. Those with a newer diagnosis may not have experienced the condition for long enough to have had to employ strategies.

Furthermore, participants will be required to have language abilities and hearing abilities to enable them to take part in an interview in English. Whilst no exclusion criteria will be placed around type of epilepsy or seizures given the diversity across condition, this information alongside other relevant demographic details will be gathered to understand the needs and profile of the subgroup of participants in this study. It should however be noted that those under a consultant typically have a more severe type of epilepsy given its need to be managed on a regular basis. More specifically, demographic information will be collected to situate the sample, alongside clinical information. This will include age, gender, time since diagnosis, type of epilepsy, seizure frequency, medication and family demographics to understand the population participating and experiences as much as possible.

Procedure

Participants will be recruited from one tertiary epilepsy service in a UK children's hospital, but this may be extended to a second centre depending on the number of participants who meet the study criteria and are willing to participate. Recruitment will occur in two ways. A member of the clinical team will identify adolescents listed on an internal clinical database who meet the study criteria. These individuals will be sent a letter of invitation alongside study information in the post by the service (i.e. age appropriate participant information

sheet, consent/assent forms). The same information and documents will be given out at clinics to those appropriate by the multi-disciplinary team. The team will have access to the study inclusion and exclusion criteria at the weekly epilepsy clinic.

For young people aged 16-18 years, information packs will be sent in the post and addressed to the young person. This will include a participant information sheet for the young person only, as well as a consent to participate form. For those aged 13-15 years, packs will similarly be sent in the post but will be addressed to the parent/carer. It will be requested for parents/carers to pass this information on to the young person to help guide their decision. Both the young person and the parent/carer will receive a participant information sheet. A consent to participate form will be addressed to and required to be completed by a parent/carer. An assent form will be required to be completed by the young person.

Contact information (phone number and email) will be provided for individuals to contact the main researcher if they are happy to participate or have any queries around the study. Young people will then be invited to engage in an interview with the main researcher centred around their experiences. If meeting in person written consent/assent will be obtained at the interview. For those who choose to engage in an interview online (i.e. skype), consent/assent forms will be required to be returned to the main researcher prior to the interview taking place. Interviews will be audio recorded on a digital device and subsequently transcribed verbatim by the main researcher in preparation for analysis.

Analysis

The IPA process will begin with familiarisation of the data through re-reading of transcripts, followed by the identification and labelling of emerging themes. These themes will then be clustered into higher order superordinate themes, conveying shared experiences across the

data set (Smith, 1996; Smith et al., 2009). A clear analysis trail will be maintained throughout to highlight the process of generating themes, with support from supervisors.

5) Ethical Concerns

Confidentiality

Participant confidentiality will be maintained throughout the project and post-submission. All interview transcripts will be anonymised and the researcher will provide participants with a comprehensive explanation of confidentiality prior to the interview beginning. Participants will be made aware that confidentiality will be breached if the researcher feels that there is a risk of harm or has concerns about the participant or another person. In the event of this, the relevant trust policies and procedures will be adhered to and advice will be sought from supervisors. Regular meetings will take place between the researcher and supervisors which will provide a forum for discussion of any ethical or practical concerns.

Informed consent

Participants will be given time to consider whether they want to participate to ensure informed consent is obtained. Participants will be informed verbally and on the information sheet that they have a right to withdraw at any point up until the point of analysis.

Potential risk or distress

There are not expected to be any risks for participants by taking part in this study, however there is potential for individuals to become distressed or upset when talking about their experiences of living with epilepsy. The interview questions will not be purposefully distressing or sensitive, however if a participant becomes upset whilst being interviewed, they will be made aware that they can stop the interview or withdraw at any time, and the interviewer will make a judgement about when to stop the interview. The researcher will use

clinical skills to provide support for participants when they are upset and help to contain these emotions. Whilst it will be advised that interviews should take place with only the young person to create a safe and exploratory environment, parents/carers will be able to remain in the room if specifically requested. The participants will be given a debrief sheet after the interview which will include details of support they can access should they feel they need it. Supervision will be sought by the interviewer to clarify any other means of supporting participants and to allow the researcher to debrief from the interview.

A conversation will also take place with the participant and their parent/carer around the usual procedure followed when a seizure occurs, so that a plan to manage that may occur during the interview can be agreed and followed. Contact details of the parent/carer will also be taken to use in an emergency. If interviewing a young person (13-15 years) via skype, it will be ensured that they are not alone in the house when the interview takes place. For those aged 16-18, their home address will be sought prior to the interview taking place in order for any relevant support to be directed to the individual (i.e. an ambulance) based on the procedure typically followed during seizures.

Lone working

It is not expected that there will be any risks to the researcher, however the Lancaster University Lone Working guidance will be followed during the project. Specific situations where lone working is inadvisable will be avoided (i.e. confined spaces) and if meeting with participants away from the hospital or university sites, will contact a project supervisor to confirm safety. The researcher will use a university email address and research mobile phone for speaking to participants or their parents/carers. Regular contact and supervision will be sought between the researcher and supervisors to provide a forum for discussion should participants talk about anything that is potentially upsetting for them or the researcher.

6) Timescale

September 2019 - January 2020 – Recruitment and data collection

January - March 2020: Data analysis

May 2020: Submit thesis

The above time scales are approximations and will depend on the speed of recruitment and availability of those willing to participate. Data collection may be extended if difficulties arise in collecting data.

7) Dissemination

The findings of this project will be produce a thesis, which will become publicly accessible after 5 years online. It will also be disseminated within academic journals. They will also be shared within a hospital-based Clinical Psychology meeting to inform psychologists working with young people, as well as across professionals (psychology and non-psychology) within and external to the hospital setting (i.e. paediatric psychology network) in an attempt to broaden awareness and potentially influence practice across services. Findings will also be summarised and communicated to participants who took part in the study, as well as potentially being presented at conferences and special interest groups.

8) References

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Appendix 4-B: Interview Schedule

Introduction:

‘I am hoping that we can talk through your ideas and experiences today related to epilepsy. There are no right or wrong answers. It is your experiences and thoughts that I am most interested in. I will probably ask you all at different times to explain to me in more detail or in a different way what you have said because I am interested in what you have to say and want to understand it better.’

1) Living with epilepsy/impact of this

- What is it like to have epilepsy? Can you describe it?
- What does it look like for you? What may happen during a seizure?
- What might life be like if you did not have epilepsy?
- Does epilepsy impact on you in any ways? (consider prompts/exploration around activities, relationships, school, feelings) Does it get in the way of anything?
- How do others respond to the fact you have epilepsy?

2) Coping strategies

- How do you cope with/manage epilepsy?
- Given XX (impact described above), how do you cope with this?
- Is there anything you do to try and make life with epilepsy easier?
- What helps/does not help when trying to manage epilepsy? (Explore how/why)

3) Self-compassion

(Begin by showing short video on compassion produced by Neff)

- Based on the video, is self-compassion something you are familiar with? Can you think of a time when you have been self-compassionate?
- Based on our previous discussions, do you think that you acted self-compassionately during your time with epilepsy?

Self-kindness vs. self-judgement

- How kind are you to yourself in the face of epilepsy? Is being kind to yourself something you find easy or difficult living with epilepsy?
- If something goes wrong, or it feels like a bad day, how do you tend to react?
- Can you think of what might be good/not so good about being able to be kind to yourself? Can you think of what might be good/not so good about judging yourself?
- Does epilepsy get in the way to be kind towards yourself? (compare to times when epilepsy is around a lot, and a little).
- Does epilepsy make you think about yourself in a particular way?

Mindfulness vs. overthinking

- How easy or hard do you find it to separate yourself from your thoughts and feelings?
- How easy or hard do you find it to separate yourself from epilepsy?
- Do you find when your seizures are worse that it is more difficult to separate yourself from your thoughts and feelings and to be as objective as you would like to be?
- What sorts of things can happen to you if you are not able to separate your thoughts and feelings?

Common humanity vs. isolation

- Do you feel as if you have similar experiences to other people?
- Is it helpful when you are experiencing something upsetting or challenging to think that you are not the only person who has experience this? (Why/why not?).
- Does this change when your seizures are worse?

Self-compassion and coping

- Do you think that you act self-compassionately when faced with tough experiences in epilepsy? If so, how does this help you to cope with it?
- You mentioned a time when [you were kind to yourself], how did that leave you feeling/what did you do?
- Other examples:
Do you think being kind to yourself would help you to cope? How?
How might separating yourself from your thoughts help you to cope? How?
By feeling similar to others/alone with epilepsy, how might this influence how you manage your epilepsy? How does this help/not help?

Appendix 4-C: Participant Information Sheets

Participant information Sheet 13-15 years



Participant Information Sheet (13-15 years) – Version 0.2, 05/09/2019

Study Title: **Self-compassion and coping in adolescents living with epilepsy**

My name is Melissa Longworth and I am doing this research as a trainee clinical psychologist on the Doctorate in Clinical Psychology programme at Lancaster University, United Kingdom.

What is the study about?

The aim of this study is to hear about if teenagers with epilepsy are kind to themselves and how they cope with their condition. Epilepsy can affect people in lots of ways and we understand people cope with it in different ways.

Being kind to yourself during difficult times is thought to help people to cope so we would like to hear more about if this is something young people with epilepsy do or not. We hope this will help us to think about how we support teenagers now and in the future who also live with epilepsy, to cope as best as they can with their condition.

Why have I been approached?

You have been asked to take part as you are a teenager with a diagnosis of epilepsy and are under a medical consultant who monitors this.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you do not want to take part, that is completely fine and will not affect your care in any way.

What will I be asked to do if I take part?

If you would like to take part, you or your parent/carer can get in touch on the number or email below. We will answer any questions you have and we will then arrange an interview. This will just involve us meeting up to chat about your epilepsy and your experiences of living with it. You can choose where this is (i.e. at the hospital, university, or via skype/phone), and it will last around one hour. Our voices will be recorded so that I can transcribe the interview (turn the words in to a written document) afterwards. We will ask you to complete a form saying you agree to take part beforehand. We will ask your parent to sign one too.

Will my data be identifiable?

The things you talk about will be anonymous, which means no names or information about you will be used in the study. Some of the sentences from your interview may be used in the study report, but your name will not be attached to them. The interview data will be kept securely online on a university computer. Only the researchers involved in the study will be able to see this:

- Audio recordings (the recordings of our voices) will be deleted once the project has been submitted for examination
- The written version of the interview will be encrypted in word documents (that is no-one other than the researcher and their supervisors will be able to access them)

- At the end of the study, the written data will be kept securely on a secure university system for 10 years. At the end of this period, they will be destroyed.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some things we can't keep confidential. If what is said in the interview makes me think that you or someone else could be unsafe, I will have to break confidentiality and speak to a member of staff and your parent/carer.

What will happen to the results?

The results will be summarised and sent in as part of a thesis for a university course. This is a large piece of research that is done at the end of a doctorate degree. It may also be sent to an academic or professional journal, or conferences so that the public also read the findings. This will mean more people will get to understanding and learn from your experiences.

The results will be shared in team meetings in the hospital, where relevant. You can request a summary of the results once the study has finished.

Are there any risks?

There are not thought to be any risks with taking part in this study. However, if you at any point feel upset, we would like you to tell the researcher or the one of the people whose details are given at the end of this sheet.

Are there any benefits to taking part?

This project will hopefully help us to understand links between being kind to yourself, coping and epilepsy, as well as helping services to give the best support possible to young people around managing their epilepsy and their wellbeing. Whilst there may be no direct benefits to you as an individual, you may find it a positive and valuable opportunity to talk through your experiences.

Who has reviewed the project?

This study has been approved by a Health Research Authority NHS Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact a member of the team.

Main researcher

Melissa Longworth:

m.longworth@lancaster.ac.uk
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YW
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Field supervisorResearch supervisors

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Dr Will Curvis:

w.curvis@lancaster.ac.uk

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YW

Tel: 01524 593096

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood
Doctorate in Clinical Psychology
b.sellwood@lancaster.ac.uk
01524 593998
Lancaster University
Lancaster
LA1 4YW

Thank you for taking the time to read this information sheet.

If you would like to seek support or advice as a result of reading this information sheet, please be aware of the following professionals and/or charities who can offer this:

Clinical Psychologist within the research team:

Dr Vicky Gray – 

Local Children's Epilepsy Charity:

<https://www.youngpilepsy.org.uk>

Participant information Sheet 16-18 years



Participant Information Sheet (16-18 years) – Version 0.2, 05/09/2019

Study Title: Self-compassion and coping in adolescents living with epilepsy

My name is Melissa Longworth and I am doing this research as a trainee clinical psychologist on the Doctorate in Clinical Psychology programme at Lancaster University, United Kingdom.

What is the study about?

The aim of this study is to explore self-compassion and coping in teenagers living with epilepsy. Epilepsy can affect people in lots of ways and we understand people cope with their condition in different ways. Given that being self-compassionate and being kind to yourself during difficult times is thought to help people to cope, we would like to hear more about if this is something young people with epilepsy do or not. We hope this will help us to think about how we support teenagers now and in the future who also live with epilepsy, to cope as best as they can with their condition.

Why have I been approached?

You have been approached as the study aims to gather information from teenagers who have a diagnosis of epilepsy and are under a medical consultant who monitors this.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. If you do not want to take part, that is completely fine and will not affect your care in any way.

What will I be asked to do if I take part?

If you decide you would like to take part, you or your parent or carer can contact us on the number or email below to discuss this further. We will answer any queries you may have and organise a suitable time for an interview. This will involve us meeting up to chat about your epilepsy and your experiences of living with it. This can take place in a location convenient for you (i.e. at the hospital, university, or via skype), and will last for approximately one hour. This will be audio recorded so that I can transcribe the interview (write it up) afterwards. We will ask you to complete a consent form beforehand too.

Will my data be identifiable?

The information you provide will remain anonymous, with no names or information about you used throughout. The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data. Data will be transferred electronically onto a secure university server and will be password protected:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for examination
- Transcribed interviews will be encrypted in word documents (that is no-one other than the researcher and their supervisors will be able to access them)

- At the end of the study, data will be kept securely on a secure university system for 10 years. At the end of this period, they will be destroyed.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some limits to confidentiality. If what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff and your parent or carer about this.

What will happen to the results?

The results will be summarised and reported as part of a thesis for a university course. This is a large piece of research that is done at the end of a doctorate degree. It may be submitted for publication in an academic or professional journal, or conferences so that the public also read the findings. This will hopefully result in more people understanding and acting upon your experiences. They will be shared within team meetings within psychology and wider multidisciplinary meetings, where relevant. You can request a copy of the results once the study has finished.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the researcher or the individuals provided at the end of this sheet.

Are there any benefits to taking part?

This project will hopefully help us to understand links between self-compassion, coping and epilepsy, as well as helping services to tailor support currently given to young people around managing their epilepsy and their wellbeing. Whilst there may be no direct benefits to you as an individual, you may also find it a positive and valuable opportunity to talk through your experiences.

Who has reviewed the project?

This study has been approved by a Health Research Authority NHS Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact a member of the team.

Main researcher

Melissa Longworth:

m.longworth@lancaster.ac.uk
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YW
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Doctorate in Clinical Psychology

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Lancaster University

Lancaster

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Tel: 01524 592807

Dr Will Curvis:

w.curvis@lancaster.ac.uk

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YW

Tel: 01524 593096

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Doctorate in Clinical Psychology
b.sellwood@lancaster.ac.uk
01524 593998
Lancaster University
Lancaster
LA1 4YW

Thank you for taking the time to read this information sheet.

If you would like to seek support or advice as a result of reading this information sheet, please be aware of the following professionals and/or charities who can offer this:

Clinical Psychologist within the research team:

Dr Vicky Gray - [REDACTED]

Local Children's Epilepsy Charity:

<https://www.youngpilepsy.org.uk>

Participant information Sheet Parent



Doctorate in
Clinical Psychology



Participant Information Sheet for Parents – Version 0.2, 05/09/2019

Study Title: Self-compassion and coping in adolescents living with epilepsy

My name is Melissa Longworth and I am conducting this research as a trainee clinical psychologist on the Doctorate in Clinical Psychology programme at Lancaster University, United Kingdom.

What is the study about?

The purpose of this study is to explore self-compassion and coping in adolescents living with epilepsy. Epilepsy can affect people in lots of ways and we understand people cope with their condition in different ways. Given that being self-compassionate and being kind to yourself during difficult times is thought to help people to cope, we would like to hear more about if this is something young people with epilepsy do or not. We hope this will help us to support adolescents now and in the future who also live with epilepsy.

Why has my child been approached?

Your child have been approached as the study aims to gather information from adolescents who have a diagnosis of epilepsy and are under a medical consultant who monitors this.

Does my child have to take part?

No. It's completely up to you and your child to decide whether or not they would like to take part.

What will my child be asked to do if they take part?

If your child decides they would like to take part, we will ask you to contact us on the number or email included to discuss this further, answer any queries you may have and organise a suitable time for an interview. This will just involve me chatting to your child about their epilepsy, the impact of this and how they cope with their condition. This can take place in a location convenient for you (i.e. at the hospital, university, or via skype). This will be audio recorded so that I can transcribe the interview afterwards. We will ask you to complete a consent form, and your child to complete an assent form beforehand.

Will your child's data be identifiable?

The information your child provides will remain anonymous throughout. The typed version of the interview will be made anonymous by removing any identifying information including their name. Anonymised direct quotations from the interview may be used in the reports or publications from the study, but names or information will not be attached to these. The data collected for this study will be stored securely and only the researchers conducting this study will have access to this data. Data will be transferred electronically onto a secure university server and will be password protected. In addition:

- Audio recordings will be destroyed and/or deleted once the project has been submitted for examination
- Transcribed interviews will be encrypted in word documents (that is no-one other than the researcher will be able to access them)

- At the end of the study, data will be kept securely on a secure university system for 10 years. At the end of this period, they will be destroyed.
- All personal data will be confidential and will be kept separately from interview responses.

There are some limits to confidentiality however. If what is said in the interview makes me think that your child, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this, as well as you as their parent/carer. If possible, I will tell your child if I have to do this.

What will happen to the results?

The results will be summarised and reported within a thesis for the university course and may be submitted for publication in an academic or professional journal. They will be shared within team meetings within psychology and wider multidisciplinary meetings, where relevant. You and your child will also receive a copy.

Are there any risks?

There are no risks anticipated with participating in this study. However, if your child experiences any distress following participation, we encourage them/you to inform the researcher or the individuals provided at the end of this sheet to talk through this further.

Are there any benefits to taking part?

There are no direct benefits from taking part. However, this project will hopefully contribute to the support currently given to young people around managing their epilepsy and their wellbeing, by better understanding what can influence this. They may also find it a positive and valuable opportunity to talk through their experiences.

Who has reviewed the project?

This study has been approved by a Health Research Authority NHS Research Ethics Committee.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact a member of the team.

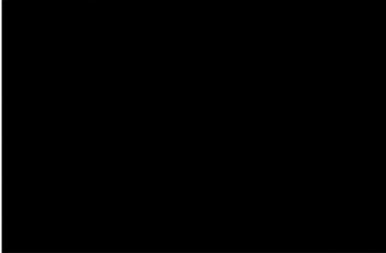
Main researcher

Melissa Longworth:

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Doctorate in Clinical Psychology
Furness College
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LA1 4YW
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Field supervisor

Dr Vicky Gray:

Research supervisors

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If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood
Research Director – Doctorate in Clinical Psychology
b.sellwood@lancaster.ac.uk
01524 593998
Lancaster University
Lancaster
LA1 4YW

Thank you for taking the time to read this information sheet.

If you would like to seek support or advice as a result of reading this information sheet, please be aware of the following professionals and/or charities who can offer this:

Clinical Psychologist within the research team:
Dr Vicky Gray – [REDACTED]

Local Children's Epilepsy Charity:
<https://www.youngpilepsy.org.uk>

Appendix 4-D: Consent & Assent Forms Assent Form (13-15 years)



Assent Form - Version 0.2, 05/09/2019

Study Title: Self-compassion and coping in adolescents living with epilepsy

Self-compassion is when a person is kind to themselves when times are hard.

We are asking if you would like to take part in a study that is going to look at self-compassion and how teenagers with epilepsy cope with their condition.

Epilepsy and adolescence both affects people in lots of ways. This means that how teenagers with epilepsy cope can be important. As self-compassion (being kind to yourself) is thought to help coping, we want to know if it helps you. This will help us to offer better support to you and others.

Before you agree to take part in the study, we would like you to first read the participant information sheet and put your initials in each box below if you agree. If you have any questions about the study, please speak to Melissa Longworth before you complete this form.

1. I have read the information sheet (or had it explained to me) and understand what the study involves
2. I have been able to ask any questions I want to
3. I understand that my voice will be recorded when I talk and this will be written up, but my name will not be used anywhere in the study
4. I understand that my voice recordings will be kept until the study has been marked.
5. I agree to Lancaster University keeping written scripts of the interview for 10 years after the study has finished.
6. I understand that taking part is my choice and that I can change my mind at any time without saying why
7. I understand that once my data has been made anonymous (no names included) and summarised, it might not be possible for it to be taken out of the study. The researcher will try to remove it if I change my mind up until the study is completed.
8. I understand that the information from my interview will be put together with other young people's responses. None of this will include any names.
9. I agree for what I say in my interview to be used in reports, conferences and training events.
10. I understand that the researcher will talk about data with their supervisor if they need to.
11. I understand that any information I give will be kept private (confidential) and without names unless it is thought either me or someone else is not safe. The researcher will need to share this information with their supervisor if so.
12. I agree to take part in the study

Please initial each box

IRAS Project ID: 266833

Name of Participant _____ **Signature** _____ **Date** _____

Name of Researcher _____ **Signature** _____ **Date** _____

Consent Form (16-18 years)



Doctorate in Clinical Psychology



Consent Form Young Person - Version 0.2, 05/09/2019
Study Title: Self-compassion and coping in adolescents living with epilepsy

We are asking if you would like to take part in a study that is going to look at self-compassion (being kind to yourself) and how teenagers with epilepsy cope with their condition.

Before you agree to take part in the study, we ask that you read the participant information sheet and initial each box below if you agree. If you have any questions about the study, please speak to Melissa Longworth before you sign this form.

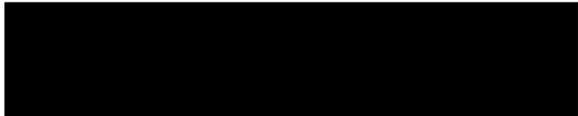
Please initial each box

- 1. I have read the information sheet and fully understand what the study involves
2. I have been able to ask any questions I want to
3. I understand that my voice will be recorded when I talk, and a written transcript will be made. My name will not be used anywhere in the study.
4. I understand that my voice recordings will be kept until the study has been marked.
5. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
6. I understand that taking part is my choice and that I can change my mind at any time without saying why
7. I understand that once my data have been made anonymous and summarised, it might not be possible for it to be withdrawn. The researcher will attempt to remove my data if I ask for this, up to the point when the study is completed.
8. I understand that the information from my interview will be put together with other participants' responses, anonymised and may be published.
9. I consent to information and quotes from my interview being used in reports, conferences and training events.
10. I understand that the researcher will discuss data with their supervisor as needed.
11. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share this information with their supervisor.
12. I consent to take part in the above study

Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Consent Form Parent


 Doctorate in
Clinical Psychology


Consent Form Parent/Carer - Version 0.2, 05/09/2019

Study Title: Self-compassion and coping in adolescents living with epilepsy

We are asking if your child would like to take part in a project that aims to explore self-compassion and coping in adolescents with epilepsy.

Before you consent for your child to participate in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the form please speak to the principal investigator, Melissa Longworth.

- | | Please initial each box |
|---|--------------------------|
| 1. I confirm that I have read the information sheet and fully understand what is expected of me/my child within this study | <input type="checkbox"/> |
| 2. I confirm that I have had the opportunity to ask any questions and to have them answered. | <input type="checkbox"/> |
| 3. I understand that my child's interview will be audio recorded and then made into an anonymised written transcript. | <input type="checkbox"/> |
| 4. I understand that audio recordings will be kept until the research project has been examined. | <input type="checkbox"/> |
| 5. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. | <input type="checkbox"/> |
| 6. I understand that my child's participation is voluntary and that they are free to withdraw at any time without giving any reason | <input type="checkbox"/> |
| 7. I understand that once my child's data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract his/her data, up to the point of assignment submission. | <input type="checkbox"/> |
| 8. I understand that the information from my child's interview will be pooled with other participants' responses, anonymised and may be published. | <input type="checkbox"/> |
| 9. I consent to information and quotations from my child's interview being used in reports, conferences and training events. | <input type="checkbox"/> |
| 10. I understand that the researcher will discuss data with their supervisor as needed. | <input type="checkbox"/> |
| 11. I understand that any information my child gives will remain confidential and anonymous unless it is thought that there is a risk of harm to themselves or others, in which case the principal investigator will need to share this information with their research supervisor. | <input type="checkbox"/> |
| 12. I consent for my child to take part in the above study | <input type="checkbox"/> |

**Appendix 4-E: Sponsorship and ethical approval letters
NHS Ethical Approval Letter**



**Health Research
Authority**

Yorkshire & The Humber - Leeds East Research Ethics Committee

NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

17 September 2019

Ms Melissa Longworth
6 Addingham Road
Allerton
Liverpool
L18 2EW

Dear Ms Longworth

Study title: Self-compassion and coping in adolescents living with epilepsy
REC reference: 19/YH/0308
Protocol number: N/A
IRAS project ID: 266833

Thank you for your letter of 5th September 2019, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of



the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For [clinical trials of investigational medicinal products \(CTIMPs\)](#), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: <https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/>

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:



- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Document]	0.1	05 August 2019
Interview schedules or topic guides for participants [Interview Schedule]	0.2	05 September 2019
Interview schedules or topic guides for participants [Topic handout]	0.1	05 September 2019
IRAS Application Form [IRAS_Form_06082019]		06 August 2019
IRAS Checklist XML [Checklist_05092019]		05 September 2019
Letter from sponsor [Lancaster University Sponsorship Letter]	0.1	30 July 2019
Letters of invitation to participant [Letter of Invite (13-15y)]	0.1	01 July 2019
Letters of invitation to participant [Letter of Invite (16-18y)]	0.1	01 July 2019
Letters of invitation to participant [Letter of Invite (Parent)]	0.1	01 July 2019
Other [Researchers response to REC and Assessment points]		05 September 2019
Participant consent form [Assent Form]	0.2	05 September 2019
Participant consent form [Consent form (16-18 years)]	0.2	05 September 2019
Participant consent form [Consent form (parent)]	0.2	05 September 2019
Participant information sheet (PIS) [Participant Information Sheet (13-15 years)]	0.2	05 September 2019
Participant information sheet (PIS) [Participant Information Sheet (16-18 years)]	0.2	05 September 2019
Participant information sheet (PIS) [Participant Information Sheet (Parent)]	0.2	05 September 2019
Research protocol or project proposal [Research Protocol]	0.2	05 September 2019
Summary CV for Chief Investigator (CI) [Melissa Longworth]	0.1	01 July 2019



Research CV]		
Summary CV for supervisor (student research) [FE Research Supervisor CV]	0.1	31 July 2019
Summary CV for supervisor (student research) [WC Research Supervisor CV]	0.1	31 July 2019
Summary CV for supervisor (student research) [VG Field Supervisor CV]	0.1	31 July 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

19/YH/0308	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely

Thomas Fairman
HRA Approvals Manager

On behalf of

Dr Deborah Fox
Chair

Email: nrescommittee.yorkandhumber-leedseast@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to:



Letter confirming study sponsorship

Applicant name: Melissa Longworth
Supervisor: Fiona Eccles
Department: Department of Health Research

30 July 2019

Dear Melissa

Re: Self-compassion and coping in adolescents living with epilepsy

The University of Lancaster undertakes to perform the role of sponsor in the matter of the work described in the accompanying grant application. As sponsor we assume responsibility for monitoring and enforcement of research governance. As principal investigator you will confirm that the institution's obligations are met by ensuring that, before the research commences and during the full term of the grant, all the necessary legal and regulatory requirements are met in order to conduct the research, and all the necessary licenses and approvals have been obtained. The Institution has in place formal procedures for managing the process for obtaining any necessary or appropriate ethical approval for this grant. Full ethical approval must be in place before the research commences and should be reviewed at all relevant times during the grant.

Yours sincerely,

A handwritten signature in black ink that reads "R. E. Case".

PP Professor Roger Pickup
Associate Dean for Research
Deputy Chair Faculty of Health and Medicine Research Ethics Committee.

Letter confirming HRA approval

Ms Melissa Longworth
6 Addingham Road
Allerton
Liverpool
L18 2EW

Email: hraapproval@nhs.net
HCRW_approvals@wales.nhs.uk

23 September 2019

Dear Ms Longworth

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

Study title:	Self-compassion and coping in adolescents living with epilepsy
IRAS project ID:	266833
Protocol number:	N/A
REC reference:	19/YH/0308
Sponsor	Lancaster University

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

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

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

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

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

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

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **266833**. Please quote this on all correspondence.

Yours sincerely

Joanna Ho
Approvals Specialist

Email: hra.approval@nhs.net

Copy to:



Lancaster University

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Insurance Document]	0.1	05 August 2019
Interview schedules or topic guides for participants [Interview Schedule]	0.2	05 September 2019
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IRAS Application Form XML file [IRAS_Form_06082019]		06 August 2019
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Letters of invitation to participant [Letter of Invite (Parent)]	0.1	01 July 2019
Organisation Information Document [Organisation Information Document]	0.1	31 July 2019
Other [Researchers response to REC and Assessment points]		05 September 2019
Participant consent form [Assent Form]	0.2	05 September 2019
Participant consent form [Consent form (16-18 years)]	0.2	05 September 2019
Participant consent form [Consent form (parent)]	0.2	05 September 2019
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Participant information sheet (PIS) [Participant Information Sheet (16-18 years)]	0.2	05 September 2019
Participant information sheet (PIS) [Participant Information Sheet (Parent)]	0.2	05 September 2019
Research protocol or project proposal [Research Protocol]	0.2	05 September 2019
Schedule of Events or SoECAT	1	07 August 2019
Summary CV for Chief Investigator (CI) [Melissa Longworth Research CV]	0.1	01 July 2019
Summary CV for supervisor (student research) [FE Research Supervisor CV]	0.1	31 July 2019
Summary CV for supervisor (student research) [WC Research Supervisor CV]	0.1	31 July 2019
Summary CV for supervisor (student research) [VG Field Supervisor CV]	0.1	31 July 2019

Information to support study set up

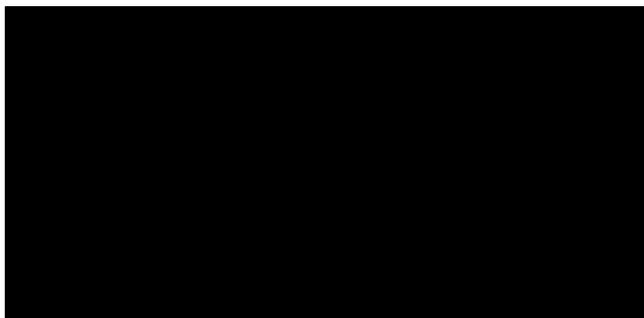
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
This is non-commercial single centre study where all participating NHS organisations will be undertaking all research activities as described in the IRAS application. There is only one site-type in this study.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted as an agreement between sponsor and the participating NHS organisation(s); sponsor is not requesting and does not expect any other site agreement to be used.	No funding will be provided to participating NHS organisations as indicated in the Organisation Information Document.	A Principal Investigator should be in place at each participating NHS organisation.	Local staff substantively employed by the participating NHS organisation will be undertaking research activities as described in the IRAS application. No HR access arrangements are therefore expected for this study. Where arrangements are not already in place, network staff employed by another Trust or University (or similar) undertaking any of the research activities listed in A18 or A19 of the IRAS form (except for administration of questionnaires or surveys), would be expected to obtain an honorary research contract from one NHS organisation (if university employed), followed by Letters of Access for subsequent organisations. This would be on the basis of a Research Passport (if university employed) or an NHS to NHS confirmation of pre-engagement checks letter (if NHS employed). These should confirm enhanced

					DBS checks, including appropriate barred list checks, and occupational health clearance. For research team members only administering questionnaires or surveys, a Letter of Access based on standard DBS checks and occupational health clearance would be appropriate.
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Other information to aid study set-up and delivery

<i>This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.</i>
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Letter confirming R&D approval (letter of access)

20th December 2019

Melissa Longworth
Email to: m.longworth@lancaster.ac.uk

Dear Melissa

Letter of Access for Research

This letter confirms your right of access to conduct research through [REDACTED] NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 20th December 2019 and will end 1st September 2020, unless terminated earlier in accordance with the clauses below.

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

The information supplied about your role in research at [REDACTED] NHS Foundation Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

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

While undertaking research through [REDACTED] NHS Foundation Trust you will remain accountable to your employer, Lancaster University, but you are required to follow the reasonable instructions of your Research Supervisor, Victoria Gray, in this NHS organisation or those given on their behalf in relation to the terms of this right of access.

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

You must act in accordance with [REDACTED] NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health

and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED]'s NHS Foundation Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

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

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

[REDACTED] NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Recruitment

[REDACTED] NHS Foundation Trust