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Testing the Responsiveness of and Defining Minimal Important Difference (MID) Values for the CARE Burn Scales: Patient-Reported Outcome Measures to Assess Quality of Life for Children and Young People Affected by Burn Injuries, and Their Parents/Caregivers

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Abstract: The CARE Burn Scales are a portfolio of burn-specific PROMs for people affected by burns, including a Child Form (for children < 8 years (parent-proxy)), a Young Person Form (for young people aged 8–17 years), an Adult Form, and a Parent Form (for parents/carers of children aged 0–17 years). This study aimed to determine the responsiveness and minimal important difference (MID) values of the three scales developed for use in paediatric burn services and research. Participants were recruited by 15 UK Burn Services. Participants completed the appropriate CARE Burn Scale and a set of appropriate comparison validated measures, at three time points: 4 weeks (T1), 3 months (T2) and 6 months (T3) post-burn injury. Spearman's correlation analysis and effect sizes based on Cohen's *d* thresholds were reported and MID values were calculated. At baseline, 250 participants completed the Child Form, 69 completed the Young Person Form, and 320 completed the Parent Form. A total of 85–92% of participants were retained at follow up. The tested CARE Burn Scales were all responsive to change over time. MID values were created for all subscales and ranged from 2 to 11 for the Child Form, 3 to 14 for the Young Person Form and 3 to 10 for the Parent Form. The CARE Burn Scales for children, young people and parents are responsive to change over time. The scales are freely available for clinical and research use.

Keywords: burn injury; children; parents; outcomes; PROMs; scar assessment; CARE Burns

1. Introduction

In the UK, 66,200 children and young people experienced a burn which required medical attention from 2013 to 2015 [1]. Significant advances in UK burn care over recent years have reduced mortality, but meant that a proportion of both children and parents are now facing lifelong challenges, including scarring [2,3].

Whether sustained in childhood or adolescence, and irrespective of its size, location or depth, a burn can have a significant impact on the lives of those directly affected and those supporting them [2]. The impact of the injury and subsequent scarring on a child's physical, social and psychological well-being can be extensive [4,5]. Physical symptoms such as pain, sensitivity and itching of the scar itself are common, together with burden of treatment and psychosocial difficulties such as behavioural problems, trauma symptoms, social anxiety, sleep disturbance and body image distress [6–8]. Unwanted questions and comments about visible scars can be a source of ongoing stress for many children and accounts of

social avoidance, withdrawal, fear of being negatively judged by others, and negative impacts on self-esteem and quality of life are common [2,9]. Scarring concerns can impact on a child's life at nursery or school and as young people grow older, establishing and maintaining romantic and intimate relationships [10–12]. Whilst some children and young people manage the challenges they face very well and may demonstrate positive outcomes and personal growth following a burn [13], others struggle to make the adjustment and to redefine a sense of normality [14].

Surprisingly, the impact on the well-being of parents/carers supporting a child with a burn has been largely overlooked by research. Yet, they too can experience significant trauma and psychosocial difficulties when supporting their child [15,16]. Parents can find social encounters challenging if others look or stare at their child's scars, and they can struggle to know how best to respond and may develop a tendency to avoid social situations. The parental relationship can also suffer when both parents are coming to terms with the event, changing parental roles and the practical and financial challenges of supporting a child with a burn injury [17,18]. Research indicates that parental coping predicts how well a child adjusts to their injury [19]. It is therefore vital for parents' psychosocial needs to be identified and for appropriate support to be provided, to ensure their well-being is addressed and to equip them to cope with supporting their child.

Measuring the wide-ranging impact of burn scarring on the lives of children and their parents is vital in order to effectively assess their post-burn adjustment and identify their support needs. In addition, good burn care provision and practice must be driven by outcome measures that can be reliably implemented and evaluated, and include outcomes reported by patients and their families [20].

Patient-reported outcome measures (PROMs) are tools to help health professionals identify the needs and therapeutic progress of patients and their family members [21]. They are standardised and validated health-related questionnaires which patients complete before and after an intervention (clinical or research) and can be generic or injury/condition-specific. Whilst generic PROMs can be valuable for detecting general health outcomes, they do not identify outcomes that are specific to a particular patient group and may lack the degree of sensitivity necessary to identify condition-specific health needs and treatment progress [22]. In contrast, injury/condition-specific PROMs tend to have greater face validity since they are tailored to the experiences of a specific patient group (such as those affected by a burn) and are therefore more likely to be sensitive to therapeutic change.

In the UK, the Department of Health (London, UK) [23] highlighted the importance of using PROMs to evaluate health care services, and inform commissioning and regulatory decision making, and recommended that all NHS services use PROMs to evaluate outcomes in their service. However, the National Burn Care Review (2001) [24] identified that PROMs were not routinely used in burn care and few burn-specific PROMs existed. The review's conclusion that the development of new PROMs for this population was a key priority was further reinforced by the 2013 National Burn Care Standards [25].

In order to address this need, we developed and validated the CARE Burn Scales, a set of age-appropriate burn-specific quality of life PROMs (Child Form for children < 8 years (parent-proxy), Young Person Form for young people aged 8–17, Adult Form for adults aged 18 and over, and a Parent Form for parents of children and young people aged 0–17 with a burn) [26–29]. The scales measure a wide range of physical, psychological and social aspects of living with a burn injury or supporting a child with a burn. We followed a recognised, rigorous development and validation process [30] based on guidelines for the development of health outcome measures [31]. This involved a step-by-step process for item generation involving literature reviews [32,33], qualitative interviews with over 60 patients/parents and 20 health professionals [34], item reduction (using expert opinion and Rasch analysis) and psychometric evaluation with 1302 participants which provided evidence of construct reliability, internal consistency and validity with other scales [26–29].

However, further psychometric testing is necessary before they are used in large-scale clinical and psychosocial research. Specifically, evidence of their responsiveness (i.e., their ability to detect change in patient-reported outcomes over time) and determining minimal important difference (MID) values are needed in order to demonstrate their clinical efficacy and value in longitudinal research [35].

Aim: to conduct three concurrent studies in order to test the responsiveness of each of the CARE Burn Scales (Child, Young Person and Parent Forms) that have been developed for use in paediatric burn care and research.

2. Materials and Methods

All necessary University and NHS ethics approvals were granted (NHS REC reference: 15/SW/0263). Participants provided written or online informed consent, depending on whether they completed paper-based or online questionnaires (details below).

This study used a longitudinal questionnaire design and recruited children and young people with a burn, and parents supporting a child or young person with a burn. Assessment points were baseline (T1, 4 weeks post-burn), 3 months post-burn (T2), and 6 months post-burn (T3). Following the COSMIN checklist for the design of responsiveness studies [36], the CARE Burn Scales (Child, Young Person and Parent Forms) were tested in comparison to other validated measures which assess similar constructs to determine evidence of responsiveness. Further analysis was conducted to identify the minimal important difference (MID) values of each of the CARE Burn Scale subscales.

The questionnaires (which included a set of demographic questions, the relevant CARE Burn Scale, a set of related single-item transition anchor questions and the relevant comparison measures) were field tested in 15 NHS Burn Services across England, Wales and Scotland.

2.1. Eligibility Criteria

All participants needed to have been treated through the NHS Burn Service for an injury that occurred 4 weeks previously (± 2 weeks). The burn could be any size or location on the body. Participants needed to have a sufficient comprehension of English to complete the questionnaires.

For the Child Form (parent-proxy), parents/carers were eligible to take part if they were supporting a child with a burn injury, under 8 years of age. For the Young Person Form, young people were eligible if they were aged 8–17 years and had experienced a burn injury. For the Parent Form, parents/carers were eligible if they were supporting a child aged 0–17 years with a burn.

2.2. Measures

Demographic information was collected at T1, including the participant's age, gender, ethnicity, education, time since burn, cause of burn and treatments received.

The subscales within each CARE Burn Scale were compared with existing validated measures of similar constructs and with good psychometric properties (see Table 1). They were chosen based on subject domain knowledge which also indicated the expected direction of correlation (see below).

Table 1. CARE Burn Scale subscales and their comparison outcome measures.

CARE Burn Scale	Subscale	Comparison
Child Form (parent-proxy)	Social and Emotional Difficulties	PedsQL Parent Report Form Emotional Functioning Subscale
	Social and Emotional Well-Being	PedsQL Parent Report Form Emotional Functioning Subscale
Young Person Form	Social Situations	PedsQL Social Functioning
	Self Worth	Mood and Feelings Questionnaire
	Negative Mood	Mood and Feelings Questionnaire
	Wound/Scar Dissatisfaction	Patient and Observer Scar Assessment Scale (POSAS)—Overall Opinion
	Positive Growth	Revised Posttraumatic Growth Inventory for Children—Revised
	Romantic Relationships	PedsQL Psychosocial Health Summary Score
Parent Form	Physical Well-Being	RAND SF-36 Physical Health subscale
	Social Situations	Mental Health Inventory—Depression Subscale
	Partner Relationship	Coparenting Relationship Scale—Coparenting Support Subscale
	Self Worth	Mental Health Inventory—Depression Subscale
	Negative Mood	Mental Health Inventory—Depression Subscale
	Parent Dissatisfaction with Child's Wound/Scars	Patient and Observer Scar Assessment Scale (POSAS)—Observer Scale
	Positive Growth	Posttraumatic Growth Inventory—Short Form

- CARE Burn Scale—Child Form (parent-proxy for children aged 0–8 years)

This has 26 items covering 5 domains of quality of life for children living with a burn injury. These 5 domains are represented through 2 individual subscales (Social and Emotional Difficulties; Social and Emotional Well-Being) and 3 checklists (Wound/Scar Treatment; Wound/Scar Discomfort; Physical Well-Being). Checklists are scales that can be used clinically or in research to collect more information about the domain; however, they are not psychometrically valid so they can be used for information but not measurement. Since the purpose of this study was to identify the psychometric responsiveness of the PROM, only the 2 individual subscales (Social and Emotional Difficulties; Social and Emotional Well-Being) were analysed. These two individual subscales are scored on a scale from 0 to 100 so that high scores reflect better health outcomes. Further detail about the development and validation of the scale is available in Griffiths et al. [27].

The CARE Burn Scale (Child Form) was compared with the Emotional Functioning subscale of the Paediatric Quality of Life Inventory (PedsQL, Lyon, France) Parent Report Form [37]. This has 5 items, on a 5-point Likert scale ranging from 0 (Never) to 4 (Almost Always) with a higher score indicating better outcomes. Total scores range from 0 to 100. The PedsQL Parent Report Form has been shown to have good reliability [38], validity [39] and responsiveness [40].

- CARE Burn Scale—Young Person Form (for young people aged 8–17 years)

This has 51 items covering 9 domains of quality of life for young people living with a burn injury: 6 individual subscales (Social Situations; Self Worth; Negative Mood; Wound/Scar Dissatisfaction; Positive Growth; Romantic Relationships (which is only completed by young people aged 12 and over)) and 3 checklists (Wound/Scar Treatment; Wound/Scar Discomfort; Physical Well-Being). The 6 individual subscales were analysed

in this study. Total scoring for each of the individual subscales is from 0 to 100, with higher scores reflecting better outcomes.

The CARE Burn Scale—Young Person Form was compared with the following measures:

The Social Functioning subscale and Psychosocial Health Summary scale from the Paediatric Quality of Life Inventory (PedsQL) Version 4 Child Report Form [37]. Items are measured on a 5-point Likert scale ranging from 0 (Never) to 4 (Almost Always) with a higher score indicating better outcomes, on a 0–100 scale. This measure has good reliability [41], validity [42] and responsiveness in young people [40].

The Short Mood and Feelings Questionnaire (SMFQ) [43]. This is a 13-item measure of depression. Items are measured on a 3-point Likert scale from 0 (Not true) to 2 (True) with a higher score indicating better outcomes on a 0–26 total score scale. In studies with adolescents, it has shown good reliability and validity [44] and responsiveness [45].

The Patient and Observer Scar Assessment Scale (POSAS, Beverwijk, The Netherlands)—Overall Opinion item [46]. This is a 1-item scar assessment scale which measures a patient's overall opinion of the severity of their scars compared to normal skin, on a 10-point Likert scale ranging from 1 (as normal skin) to 10 (very different). POSAS has good reliability and validity in adult populations [47], and whilst the scale's developers believe it is suitable for use with a younger population, it has not yet been tested with adolescents.

The Revised Posttraumatic Growth Inventory for Children (PTGI-C-R) [48], a 10-item measure of posttraumatic growth measured on a 4-point Likert scale ranging from 0 (No change) to 3 (A lot) with a higher score indicating better outcomes. Total scores range from 0 to 30. It has evidence of reliability and validity in young people [49].

- CARE Burn Scale—Parent Form

The CARE Burn Scale—Parent Form has 40 items covering 8 domains of quality of life for parents supporting a child with a burn. There are 7 individual subscales (Physical Well-Being; Social Situations; Partner Relationship; Self Worth; Negative Mood; Parent Dissatisfaction with Child's Wound/Scars; Positive Growth) and 1 checklist (Confidence with Managing Burn Wound/Scar Treatments). The 7 individual subscales were analysed in this study. Total scoring for each individual subscale ranges from 0 to 100, with higher scores reflecting better outcomes.

The CARE Burn Scale—Parent Form was compared with:

The Physical Role Functioning subscale of the RAND SF-36 (SF-36) [50]. This was used as a measure of physical health. It consists of 4 items with 2 response categories (Yes = 1) or (No = 2). Total scores range from 4 to 8, with a higher score indicating better outcomes. Studies have shown it has shown good reliability [51] and responsiveness [52] with adult populations.

The Depression subscale of the Mental Health Inventory (MHI) [53], which is a 8-item measure on a 6-point Likert scale ranging from 1 (All of the time) to 6 (None of the time), with a higher score indicating better outcomes. It has shown good reliability and validity in adult populations [54].

The Coparenting Support subscale of the Coparenting Relationship Scale [54] was used as a measure of parental relationship. This 6-item subscale is measured on a 7-point Likert scale ranging from 0 (Not true of us) to 6 (Very true of us). Total scores range from 0 to 36, with a higher score indicating better outcomes. This scale has shown good validity [55] and reliability in parents [56].

The Patient and Observer Scar Assessment Scale (POSAS)—Observer Scale [46] is a 6-item scar assessment scale, measured on a 10-point Likert scale ranging from 1 (No, not at all/As normal skin) to 10 (Yes, very much/Very different). Total scores range from 6 to 60, with a higher score indicating worse outcomes. The measure has shown good reliability and validity in adult and (parental report) child burn patients [47].

The Posttraumatic Growth Inventory-Short Form (PTGI-SF) [57] is a 10-item measure of posttraumatic growth. Items are measured on a 6-point Likert scale ranging from 0 (I did not experience this change) to 5 (I experienced this change to a very great degree). Total score ranges from 0 to 50, with a higher score indicating better outcomes. The measure has

shown good reliability in adults [58] and the full measure (PTGI) has shown validity in adult trauma survivors [59].

- Anchor questions to calculate the minimal important difference (MID) values:

For the anchor-based MID analysis, a single-item transition question was included for each subscale on each CARE Burn Scale. These transition questions were completed at T2 and T3 and specifically asked participants whether they thought they or their child (as appropriate) had changed in the domain being assessed by that subscale, since the last time they completed the questionnaire (e.g., Since the last time you did this survey, how much has your physical health changed?). For each transition question there were 5 response categories to report perceived level of change. These were: a lot better, a little better, no change, a little worse, or a lot worse (with exact wording adjusted to suit each domain, as appropriate).

2.3. Procedure

Staff who were not directly involved in the treatment of patients at the participating study sites identified potential participants either at burn clinics or via regular and frequent patient database searches. We aimed to recruit a consecutive sample to obtain a representative sample of patients and parents/carers with burn injuries that ranged in size (TBSA: percentage Total Body Surface Area) and location.

The study information informed potential participants that the project was testing a questionnaire which measured the health and well-being of children/young people living with a burn injury, or parents/carers supporting a child/young person with a burn. At baseline (T1), paper questionnaires were posted to those who had been identified by the searches of patient databases. Several sites also displayed study posters in clinic waiting rooms and, at one site, research nurses gave out study packs in person. Participants could complete the questionnaire on paper or online via a web survey link (www.qualtrics.com, accessed on 1 November 2018).

At T2 and T3, participants were either sent a paper questionnaire pack to complete and return using a pre-paid envelope, or a web link to complete the questionnaire online. This depended on participant preference expressed at T1. Those who had not completed their follow-up questionnaire within one week were reminded via email, telephone call, or post.

Participants received a £10 online shopping voucher for taking part at each time point (T1, T2 and T3).

2.4. Statistical Analysis

Sample size: This study is predicated on an assumption of a mutually correlated system between a burn scale, its comparator, changes in the burn scale, changes in the comparator and the single-item anchor measure. In a two-sided test of correlation, sample sizes of 84, 96, 112 and 138 would have at least 80, 85, 90 and 95% power, respectively, for a correlation of at least 0.3 ($\alpha = 0.05$).

- Responsiveness analysis:

Three change scores were calculated for each CARE Burn Scale subscale and the related comparison measure by simple differencing between each time point, i.e., T3 and T2; T2 and T1; T3 and T1. All the subscales and comparison measures were computed in accordance with the scoring instructions.

Spearman's correlation analyses were conducted between the CARE Burn Scale subscales and the comparison measures, and related constructs were compared for each change score time point [60]. Analyses were undertaken using IBM SPSS Statistics 23 [61].

Cohen's criteria was used as a guide for the magnitude of correlations. Absolute values of a correlation between 0.1 and 0.3 are viewed as being "small", with values between 0.3 and 0.5 considered "medium" and values above 0.5 as being "large" [62].

2.4.1. Hypotheses

As per the COSMIN guidelines, tests of responsiveness are concerned about whether the direction and magnitude of the correlations are in the expected direction and magnitude for the construct and comparison measure being compared [36]. When comparing measures of similar constructs, at least moderate correlations (approximately 0.3) would be expected.

Hypotheses were determined based on the premise that constructs in each CARE Burn Scale would moderately correlate with similar constructs in other validated patient-reported outcome measures. The expected direction of effects were determined a priori, but they were not published in a publicly available protocol prior to the study end.

Specifically:

The hypotheses related to the change scores for each subscale of the CARE Burn Scale—Child Form (parent-proxy) were that for each time point:

- Social and Emotional Difficulties would have moderate and positive correlations with the PedsQL Emotional Functioning subscale;
- Social and Emotional Well-Being would have moderate and positive correlations with the PedsQL Emotional Functioning subscale.

The hypotheses related to the subscales of the CARE Burn Scale—Young Person Form were that for each time point:

- Social Situations would have moderate and positive correlations with PedsQL Social Functioning;
- Self worth would have moderate and negative correlations with the Mood and Feelings Questionnaire;
- Negative Mood would have moderate and negative correlations with the Mood and Feelings Questionnaire;
- Wound/Scar Dissatisfaction would have moderate and negative correlations with the POSAS Overall Opinion;
- Romantic Relationships (for young people aged 12 and over) would have moderate and positive correlations with the PedsQL Psychosocial Health Summary score;
- Positive Growth would have moderate and positive correlations with the Posttraumatic Growth Inventory for Children—Revised.

The hypotheses related to the subscales of the CARE Burn Scale—Parent Form were that for each time point:

- Physical Health would have positive moderate correlations with the RAND SF-36 Physical Health subscale;
- Social Situations would have positive moderate correlations with the Mental Health Inventory—Depression subscale;
- Partner Relationship would have positive moderate correlations with the Coparenting Support subscale of the Coparenting Relationship Scale;
- Self Worth would have positive moderate correlations with the Mental Health Inventory—Depression subscale;
- Negative Mood would have positive moderate correlations with the Mental Health Inventory—Depression subscale;
- Parent Dissatisfaction with Child's Wound/Scars would have negative moderate correlations with the Patient and Observer Scar Assessment Scale—Observer scale;
- Positive Growth would have positive moderate correlations with the Posttraumatic Growth Inventory—Short Form.

2.4.2. MID Analysis

Based on the literature, our definition of the MID for this study was: a positive and bi-directional measure of central location of those reporting a small but important change. It should be able to effectively discriminate between those who report no change, and so should be set as a value for which not too many of the 'no change' group have a value equal to or greater than the MID. It should also be able to effectively discriminate between

those who report a large change and so it should be set as a value for which not too many of the big change group have a value less than the MID.

There are a range of methods for calculating MID values. Anchor-based methods, which are recommended because they are patient-led, involve asking the patients/family members themselves an anchor question where they report the degree to which their health has changed and these data are used to determine MID values. Alternatively, distribution-based MID calculations are based on the statistical attributes of the data (i.e., means and standard deviations). This study followed the recommendations of Revicki et al. [63] that both anchor-based and distribution-based methods are used and the results triangulated to reach final MID values.

- Anchor-based MIDs

To calculate MIDs using anchor-based methods, the minimum threshold for the correlation between the anchor and the change score is ≥ 0.3 [63]. For each CARE Burn Scale subscale, the single-anchor transition questions and the change scores were used to first calculate the MID values, using the T2 single-item transition question and the change score between T2 and T1. These MID values were then examined using the T3 single-item transition question and the change scores between T3 and T2.

We calculated the change score, reversed the sign of the score for those reporting a poorer outcome, and use a derived self-reported anchor with categories 'no change', 'small but important change', 'large and important change'.

Thereafter, the MID was the value of the change score for the outcome measure in the 'small but important change' group data such that it lies in the inter-quartile range and is close to the median. The specific value for the MID is that change score which jointly minimises the percentage of those reporting no change having outcome values greater than or equal to the MID while simultaneously minimising the percentage of those in the big change category having outcome values less than the MID.

- Distribution-based MIDs

For the distribution-based approach, changes in comparison quality of life measures and scar assessment were used as an anchor. Absolute changes of less than 0.2 standard deviations were taken as 'no change'; absolute changes of between 0.2 to 0.5 standard deviations were taken as a 'small but important change', and absolute changes beyond 0.5 standard deviations were taken as a 'large and important change'. These thresholds are informed by the thresholds tentatively advanced by Cohen for social science research, where absolute values of d under 0.2 SD are typically interpreted as representing a trivial or no change; between 0.2 and 0.5 SD as being a small effect, and 0.5 SD being the lower bound of a medium-sized effect [62]. Thereafter, the same algorithmic process for identifying the MID in the anchor-based approach was used with the derived distribution anchor.

In order to triangulate methods for creating MID values, the distribution-based MID values were compared with the MIDs from the single-item transition question (from T2 and T3) and if consistent, these data would provide further validation of the anchor-based MID thresholds. In instances when there were differences between the MIDs developed via anchor and distributional methods, the anchor-based MIDs were retained as these focused directly on the phenomenon of interest, i.e., self-reported change in the domain and specifically reflected the research question rather than a proxy measure of change used in the distribution-based approaches.

3. Results

Participant demographics for each CARE Burn Scale at T1 including gender, age, time since burn and cause of burn are presented in Appendix A. All scales showed excellent participant retention rates at follow up. Specifically, in the parent-proxy sample (completing the Child Form), there were 250 parents at T1, 230 (92% retained) at T2 and 217 (86.8% retained) at T3. For the young person sample, 68 young people took part at T1, 60 (88.2% retained) at T2 and 58 (85.3% retained) at T3. In the parent sample (completing the Parent

Form), 320 parents participated at T1, 286 (89.4% retained) at T2 and 274 (85.6% retained) at T3.

3.1. Responsiveness Analysis

Most of the subscales had at least one or more moderate change score correlation with the prior reasoned comparator measure (2/2 subscales in the Child Form, 5/6 subscales for the Young Person Form, and 6/7 subscales in the Parent Form). However, the strength of the correlations varied, with some being reasonably high and others being low. These are detailed below.

- Child Form (parent-proxy)

Table A4 (Appendix B) shows the means and standard deviations, Cronbach's alphas, intraclass correlation coefficients (ICCs) and level of missing data for all subscales. Throughout this study, a threshold of >0.7 was used to indicate acceptable ICCs.

All scales exceeded criteria for validity and consistency. Scale consistency was supported by high Cronbach's alpha coefficients ($\alpha > 0.86$) and moderate to good intraclass correlation coefficients (0.5–0.75 = moderate and 0.75–0.90 = good). The level of missing data across the three time points was 2.4% to 15.4% for Social and Emotional Well-Being, and 18.2% to 22.9% for Social and Emotional Difficulties.

Both subscales in the Child Form improved at each time point, which reflected improving health outcomes over time. Hypotheses relating to correlations between the Child Form and PedsQL Emotional Functioning subscale were generally supported through moderate change score correlations (Table A7, Appendix C).

Both Social and Emotional Difficulties, and Social and Emotional Well-Being had low to moderate positive correlations with the PedsQL Emotional Functioning subscale. For Social and Emotional Difficulties, the change scores T2–T1 and T3–T1 showed moderate correlations with the PedsQL Emotional Functioning subscale and had low correlations for the T3–T2 change score. For Social and Emotional Well-Being, the change score from T3–T2 showed moderate correlations with the PedsQL Emotional Functioning subscale and the change scores T2–T1 and T3–T1 had low correlations.

- Young Person Form

Table A5 (Appendix B) provides the means, standard deviations, Cronbach's alphas, intraclass correlation coefficients and level of missing data for all subscales.

Scale consistency was supported by high Cronbach's alpha coefficients ($\alpha > 0.82$). All scales had moderate to good intraclass correlation coefficients (0.5–0.75 = moderate and 0.75–0.90 = good), apart from Self Worth, which had ICCs of 0.3.

The level of missing data was good, with less than 10% missing for all subscales at T1, except for Romantic Relationships (47.8%). This subscale was only completed by young people over the age of 12 (70% of the total young person sample). Additionally, some of those over 12 may not have wanted to discuss their romantic relationships, and therefore this level of missing data for the Romantic Relationships scale is understandable. Missing data increased at follow-up time points for most subscales, ranging from 13.0% to 18.8%, which is in line with the small participant attrition over the follow-up period. For Romantic Relationships, missing data rose slightly from 46.4% to 47.8%, respectively, for the two follow-up time points.

All subscales in the Young Person Form improved over each time point, which reflected improving health outcomes. Hypotheses relating to correlations between the Young Person Form subscales and the comparison measures were generally supported through moderate change score correlations with related constructs (Table A8, Appendix C).

As predicted, Self Worth and Negative Mood had moderate to strong negative correlations with the Moods and Feelings Questionnaire (MFQ), Romantic Relationships had positive and moderate correlations with the PedsQL Psychosocial Health Summary score, Social Situations had low to moderate positive correlations with the PedsQL Social Functioning subscale, and Wound/Scar Dissatisfaction had low to strong negative correlations

with the POSAS—Overall Opinion subscale. Positive Growth had low positive correlations with the Posttraumatic Growth Inventory and was the only subscale not to have any moderate correlations with its comparator measure.

- Parent Form

Means and standard deviations, Cronbach's alphas, intraclass correlation coefficients and level of missing data for all Parent Form subscales are shown in Table A6, Appendix B.

Scale consistency was supported by high Cronbach's alpha coefficients ($\alpha > 0.85$). All scales had moderate to good intraclass correlation coefficients (0.5–0.75 = moderate and 0.75–0.90 = good), apart from Negative Mood, which had low ICCs. Level of missing data was under 10% for all subscales at T1, except for Partner Relationship (13%). Missing data increased at follow-up time points for most subscales, ranging from 10.9% to 28.3%, in line with the participant attrition over the follow-up period.

All subscales on the Parent Form improved over each time point, reflecting improving health outcomes over time. Hypotheses relating to correlations between the Parent Form and the comparison measures were generally supported through moderate change score correlations with related constructs (Table A9, Appendix C).

As predicted, Physical Health had positive moderate correlations with the RAND SF-36 Physical Health subscale. Social Situations, Self Worth and Negative Mood all had positive moderate correlations with the Mental Health Inventory (MHI)—Depression subscale. Partner Relationship had positive moderate correlations with the Coparenting Relationship scale. Parent Dissatisfaction with Child's Wound/Scars had negative moderate to strong correlations with the Patient and Observer Scar Assessment Scale (POSAS) Observer scale. Positive Growth had low positive correlations with the Posttraumatic Growth Inventory-Short Form and was the only subscale to not have any moderate correlations with its comparator measure.

3.2. MID Analysis

- MID analysis results for the Child Form (parent-proxy)

Anchor-based approach: As expected, correlations between the anchor and its related domain change score were negative, but they were weaker than the expected moderate correlations (ranging between -0.04 and -0.22) (Table A10, Appendix D).

All MID values derived from the T2 anchor question produced similar levels of accuracy at T3 in delimiting between 'no change', 'small about important change' and 'large and important change' (Table A13, Appendix E), providing validation of the MID values, which ranged from 2 to 11. Overall accuracy ranged from 51% to 62%, with an average accuracy of 56%. The percentage of participants reporting a small change ranged from 41 to 48% across the subscales, with an average of 44%.

Distribution-based MIDs: For the distribution-derived anchors, the overall accuracy ranged from 50 to 51%, with an average accuracy of 51% (Table A14, Appendix E). The percentage of participants reporting a small change ranged from 33 to 67% (average 49% across the subscales). All of the MID values derived using the distribution-based method were identical to those using the anchor-based methods, and therefore all anchor-based MIDs were retained for the final set of MID values (see Table 2; MID values are presented in bold for ease).

Table 2. Final MID values for the CARE Burn Scale: Child Form.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social and Emotional Difficulties	T2	2	46% (43/93)	41% (11/27)	64% (34/53)	51% (88/173)	43 to 58
	T3	2	60% (64/106)	42% (10/24)	39% (18/46)	52% (92/176)	45 to 60
Social and Emotional Well-Being	T2	11	64% (75/117)	48% (21/44)	60% (37/62)	60% (133/223)	53 to 66
	T3	11	76% (96/127)	44% (14/32)	37% (17/46)	62% (127/205)	55 to 68

* Binomial Proportion calculated by Wilson's Method.

- MID results for Young Person Form

Anchor-based approach: The correlations between the anchor and its related domain change score were low to moderate, ranging between 0.00 and -0.36 (Table A11, Appendix D).

All MID values derived from the T2 anchor question produced similar levels of accuracy at T3 in delimiting between 'no change', 'small change' and 'large change' providing validation of the MID values (Table A15, Appendix E). MID values ranged from 3 to 14, overall accuracy ranged from 46% to 86%, with an average accuracy of 59%. The percentage of participants reporting a small change ranged from 17 to 61%, with an average of 40% of participants reporting a small change across the subscales.

Distribution-based approach: For the distribution-based anchors, the overall accuracy ranged from 41 to 72%, with an average accuracy of 55% (Table A16, Appendix E). The percentage of participants reporting a small change ranged from 0 to 83%, with an average of 40% of participants reporting a small change across the subscales.

There were very small differences in the MID values between the anchor-based and distribution-based approaches for Social Situations, Self Worth and Positive Growth. In these instances, the anchor-based MIDs were retained as these focused directly on the phenomenon of interest (i.e., self-reported change in the domain) and specifically reflected the research question rather than a proxy measure of change used in the distribution-based approaches. Additionally, for these subscales, the MID is marginally greater using the anchor-based method, and therefore these higher MIDs provide increased security in guarding against false positives (i.e., identifying an improvement in outcomes when there has not been an improvement). The subscale Parent Dissatisfaction with Child's Wound/Scars had a much lower estimated MID in the anchor method compared with the distribution-based approach (6 versus 13). A value of 13 is too far in excess of the median in the observed 'small change' category (i.e., if a MID of 13 is applied to the observed anchor data then the performance would be inadequate), and therefore the anchor-based MID was retained. See Table 3 for final set of MID values for the Young Person Form; as above, MID values are presented in bold for ease.

Table 3. Final MID values for the CARE Burn Scale: Young Person Form.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social Situations	T2	5	65% (13/20)	44% (7/16)	46% (10/21)	53% (30/57)	40 to 65
	T3	5	71% (17/24)	17% (2/12)	56% (10/18)	54% (29/54)	41 to 66
Self Worth	T2	4	71% (22/31)	53% (9/17)	70% (7/10)	66% (38/58)	53 to 76
	T3	4	67% (22/33)	38% (6/16)	50% (4/8)	56% (32/57)	43 to 68
Negative Mood	T2	10	69% (25/36)	40% (4/10)	17% (2/12)	53% (31/58)	41 to 66
	T3	10	78% (28/36)	29% (2/7)	39% (4/13)	61% (34/56)	48 to 72
Parent Dissatisfaction with Child's Wound/Scars	T2	6	27% (7/26)	58% (7/12)	68% (13/19)	47% (27/57)	35 to 60
	T3	6	57% (20/35)	23% (3/13)	38% (3/8)	46% (26/56)	34 to 59
Romantic Relationships	T2	3	94% (29/31)	33% (1/3)	0% (0/1)	86% (30/35)	71 to 94
	T3	3	72% (18/25)	50% (3/6)	33% (1/3)	65% (22/34)	48 to 79
Positive Growth	T2	14	67% (18/27)	61% (11/18)	71% (5/7)	65% (34/52)	52 to 77
	T3	14	75% (27/36)	17% (2/12)	17% (1/6)	56% (30/54)	42 to 68

* Binomial Proportion calculated by Wilson's Method.

- MID Results for Parent Form

Anchor-based approach: The correlations between the anchor and its related domain change score were in the expected negative direction and were low to moderate, ranging between -0.03 and -0.32 (Table A12, Appendix D).

All MID values derived from the T2 anchor question produced similar levels of accuracy at T3 in delimiting between 'no change', 'small change' and 'large change' providing validation of the MID values (Table A17, Appendix E). MID values ranged from 3 to 10, overall accuracy ranged from 44% to 65%, with an average accuracy of 54%. The percentage of participants reporting a small change ranged from 36 to 58%, with an average of 46% of respondents reporting a small change across the subscales.

Distribution-based MIDs: For the distribution-based anchors, the overall accuracy ranged from 48 to 69%, with an average accuracy of 58% (Table A18, Appendix E). The percentage of participants reporting a small change ranged from 31 to 66%, with an average of 47% of participants reporting a small change across the subscales. There were very small differences in the MID values between the anchor-based and distribution-based approaches for Physical Health, Partner Relationship, Negative Mood, Parent Dissatisfaction with Child's Wound/Scars, and Positive Growth. In these instances, the anchor-based MIDs were retained as the anchor-based MIDs focused directly on the phenomenon of interest. For most of these subscales, the MID is marginally greater using the anchor method, and therefore these higher MIDs provide increased security in protecting against false positives (i.e., identifying an improvement in outcomes when there has not been a real improvement). See Table 4 for the final set of MIDs for the Parent Form; as above, MID values are presented in bold for ease.

Table 4. Final MID values for the CARE Burn Scale—Parent Form.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Physical Health	T2	8	62% (116/188)	53% (40/76)	72% (13/18)	60% (169/282)	54 to 65
	T3	8	73% (122/168)	46% (37/80)	31% (5/16)	62% (164/264)	56 to 68
Social Situations	T2	10	72% (94/130)	56% (40/72)	61% (40/66)	65% (174/268)	59 to 70
	T3	10	74% (107/145)	36% (18/50)	52% (27/52)	62% (152/247)	55 to 67
Partner Relationship	T2	9	40% (67/169)	44% (17/39)	79% (19/24)	44% (103/232)	38 to 51
	T3	9	76% (108/143)	38% (16/42)	38% (11/29)	63% (135/213)	57 to 70
Self Worth	T2	3	62% (105/169)	52% (41/79)	71% (25/35)	60% (171/283)	55 to 66
	T3	3	66% (105/158)	41% (29/71)	51% (22/43)	57% (155/272)	51 to 63
Negative Mood	T2	3	51% (79/155)	52% (50/97)	67% (16/24)	53% (145/276)	47 to 58
	T3	3	63% (103/164)	44% (33/75)	39% (9/23)	55% (145/262)	49 to 61
Parent Dissatisfaction with Child's Wound/Scars	T2	7	60% (62/104)	58% (50/86)	68% (59/87)	62% (171/277)	56 to 67
	T3	7	80% (109/136)	42% (24/57)	42% (26/62)	62% (159/255)	56 to 68
Positive Growth	T2	7	65% (107/164)	41% (29/71)	31% (11/36)	54% (147/271)	48 to 60
	T3	7	73% (116/158)	47% (27/57)	49% (19/39)	64% (162/254)	58 to 69

* Binomial Proportion calculated by Wilson's Method.

4. Discussion

This study suggests that the CARE Burn Scales developed for use in paediatric burn care and research are responsive and can identify changes in outcomes over time. The majority of subscales had at least one or more moderate change score correlation with the prior reasoned comparator measure (2/2 subscales in the Child Form, 5/6 subscales for the Young Person Form, and 6/7 subscales in the Parent Form). The correlations (reported in Tables A10–A12) were in the hypothesised direction, but they vary considerably in strength. Whilst some are reasonably high, others are very low and this is a limitation.

The majority of MID values correctly identified 40–50% of participants who reported a small improvement. However, this does mean that approximately 50–60% were not correctly identified. The MID values were developed using T2 data and were subject to validation using data at T3. In general, the predictive accuracy of the MIDs at T3 was not overly discrepant from the accuracy at T2 for the single anchors providing validation on predictive accuracy. The distributional approach triangulated the findings from the anchor approach. It is noted that at T3, the percentage correct in the No Change Category for the anchor method is always greater than or equal to the percentage correct in the small change category. This provided a quality check to indicate that the MID thresholds have not been set too low (i.e., not claiming too many to have changed when they in fact report no change), providing extra confidence that safeguards against false findings for researchers and clinicians.

However, in common with other scales of measurement, the MID is context-dependent and MID values are likely to differ depending on patient demographics, baseline data and the anchors used [64]. The MID values reported in this paper may therefore have been different if alternative anchors and a different population were involved. When interpreting the current findings it is important to consider these aspects of this study, and the limitations of our sample (detailed below) which may not be representative. Furthermore, other factors that were not assessed in this study could impact on MID. For example, the size (Total Burn Surface Area: TBSA) or cause of the burn, treatment received, indicators of deprivation, and psychosocial factors including coping strategies were not considered in this analysis.

4.1. Comparing the CARE Burn Scales: Child, Young Person and Parent Forms with Existing Burn-Specific PROMs

There are two other existing PROMs which include some items that measure the impact of supporting a child with a burn on the parent's/caregiver's own well-being. The Brisbane Scar Profile has two Parent/Caregiver Forms [65], which include items

that measure 'Parent and Family Concerns' and 'Parent Worry' for parents/carers of children aged less than 8 years, or 8–18 years. Similarly, the Children's Burns Outcome Questionnaire for ages 5–18: Parent-report Form [66] also has two sets of items which measure the impact of their child's health or behaviour on the parent's own life (such as their domestic and social life and work) and their worry or concern about their child's health and recovery after a burn. Whereas these are brief items of parental well-being within measures that focus on the parent's opinions of their child's health, the CARE Burn Scale—Parent Form has been developed to solely and specifically measure, in-depth, a parent's own well-being and quality of life when supporting a child with a burn.

In relation to the Child Form, other burn-specific parent-proxy measures of a child's quality of life and well-being after a burn injury include the Brisbane Burn Scar Impact Profile (BBSIP) questionnaires [67] and the Children Burns Outcome Questionnaires (CBOQ) [66,68]. Similar to the CARE Burn (parent-proxy) Child Form, these parent-proxy versions measure the negative emotional impact of a burn injury on children. However, the CARE Burn Scale—Child Form is the only parent-proxy scale to include a domain measuring positive aspects of a child's social and emotional health (Social and Emotional Well-Being). It is vital to measure both positive and negative social and emotional aspects, in order to fully understand and capture the long-term impact of burns on children.

In terms of the Young Person Form, the BBSIP [68] and the CBOQ [66] also have Young Person Forms; however, the CARE Burn Scale—Young Person Form is the only measure to include subscales assessing self worth, negative mood, romantic relationships (for young people aged 12 and over) and positive growth.

These differences in content of burn-specific PROMs may be due to the different contexts and populations in which they were developed. When comparing the available measures and considering their use in future research and burn care, it is important to give due consideration to the context and population with which they would be used. The paediatric CARE Burn Scales were developed in the UK and offer burns care professionals tools which measure additional domains not currently assessed by other burn-specific PROMs.

4.2. Limitations

Consecutive patients and parents/carers at each participating site who met the inclusion criteria were invited to take part. Whilst the recruitment method reduced the likelihood of selection bias, unfortunately we do not have data from each site to show the proportion of the total population sampled, how many study packs were given out or how many would have been eligible. We cannot therefore claim that the uptake of consecutive patients/parents were representative of those treated at each site or at burn services nationally.

Despite recruiting through burn services across England, Scotland and Wales, the proportion of participants reporting their ethnicity as being other than White British was very low. Since there is evidence of significant differences in the patterns of burns in ethnic minority groups in the UK [69], it will be important to gather further evidence of the CARE Burn Scales' use with a larger sample of children, young people and parents from ethnic minority backgrounds.

Whilst different versions of the PedsQL are available (e.g., Child Self Reports for ages 5–7, 8–12 and 13–18 years), we used the PedsQL 4.0 as a comparison with subscales on the Young Person Form and Child Form. The complexity of this study meant it was not feasible or logistically possible to use multiple versions of the scale according to young people's age. We therefore chose to use version 4.0 that has been shown to have good feasibility, reliability, and validity to assess paediatric health outcomes amongst children aged 2–16 years [37]. Not using the range of PedsQL measures that have been created to be developmentally appropriate could be considered a limitation.

The follow-up data collection period was up to six months post-burn. Therefore, the longer-term impact of living with or supporting a child with a burn after this time period, as assessed using the CARE Burn Scales, is unknown. Research indicates that measures such

as the Burn-Specific Health Scale [70] and the SF-36 [50] lose their sensitivity to identify clinical changes after 6 months post-burn [53]. Future research could examine whether the CARE Burn Scales can identify clinical changes over a longer follow-up period.

The sample completing the Young Person Form was small, which reflects the lower incidence of burn injuries in this age group in the UK. Within this participant group, there was a high level of missing data (approaching 50%) for the Romantic Relationships subscale, which was only due to be completed by those aged 12 years or over. Therefore, until further data are available from a larger sample, we suggest caution when interpreting the data for this subscale.

4.3. Strengths

This is the first study to identify MID values for burn-specific PROMs. Given that burn injuries are one of the most common childhood injuries which can impact the child and their parent [71], MID values are vital so that PROMs can be used to identify the impact on health for those affected by burns and to inform evidence-based decision making.

Patient involvement has been at the heart of the programme of research to develop and test the CARE Burn Scales. Initially, we interviewed and consulted with people who have experienced burn injuries themselves, family members of those who have had burns, and health professionals working in NHS burn services in order to inform the content of the scales. This qualitative work and the subsequent drafting and validity/reliability testing of the PROMs involved a total of 1302 people with burns, their family members and psychosocial specialists in this field [26–29]. A total of 637 paediatric patients and parents/carers from burn services in England, Scotland and Wales took part in this longitudinal study. Not relying on recruitment from a single burn service or a limited geographical region is a strength of this study.

As part of the MID analysis using anchor-based approaches, patients and parents were asked the extent to which they thought they had changed in each CARE Burn Scale domain (e.g., Negative Mood, Physical Well-Being). This ensured that patients' and parents'/carers' own opinions were incorporated into the responsiveness and MID analysis, as recommended by Devji et al. [72].

Participants were given a choice of completing a paper-based or online set of measures. The majority completed a paper-based version at T1 (Child Scale 66.4%; Young Person Scale 72.5%; Parent Scale 67.9%) but, in each group, the proportion of respondents choosing to complete paper-based questionnaires reduced at T2 (Child Scale 43.1%; Young Person Scale 52.5%; 43.3%) and was lower still at T3 (Child Scale 33.6%; Young Person Scale 46.4%; Parent Scale 33.6%). Our response rates indicate the benefits of offering participants a choice about how to take part, and previous research [39] with a sample comparable to that in the current study (children aged 0–16 years who attended hospital having sustained an injury, and their parents) has shown that PedsQL data were consistent regardless of mode of survey delivery (paper, online or telephone).

It is important that researchers and clinicians consider all potential outcomes after burn injuries but, until now, burn-specific PROMs for young people and parents had not assessed positive growth. Posttraumatic growth is an important under-researched topic, particularly amongst young people with burns [73] and parents of children with burn injuries and, although the positive growth subscales on the Parent and Young Person scales had low correlations with their comparator measures, they have could facilitate attention being given to this overlooked area.

4.4. Using the CARE Burn Scales

The paediatric CARE Burn Scales (Child, Young Person and Parent Forms) are now freely available for clinical and research use to identify patients' and parents' needs and to ascertain therapeutic progress, and conduct service evaluation and research.

The full set of CARE Burn Scales and scoring spreadsheets are available at www.careburnscales.org.uk (accessed on 3 November 2021).

Clinicians and researchers can use the CARE Burn Scales and MID values to identify whether the quality of life of the children or parents they are working with has meaningfully changed between two time points. In order to use the MID values reported in this study, we encourage health professionals to identify the relevant Form (i.e., Child, Young Person or Parent), score them using the scoring templates, identify the relevant MID table and MID values (in this paper) and then compare subscale scores between the two time points for the patient or parent. If the absolute difference between the two time periods are greater than or equal to the MID value, it can be ascertained that that person has meaningfully changed (improved/deteriorated depending on whether scores have increased or decreased in the follow-up time point) on that subscale.

5. Conclusions

This study has shown that the CARE Burn Scales developed for use in paediatric burn care and research are responsive and can identify changes in outcomes over time. The scales have been recommended for use in NHS Burn Services in the 2018 National Standards for Provision and Outcomes Adult and Paediatric Burn Care [74] and are freely available at www.careburnscales.org.uk (accessed on 3 November 2021).

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Institutional Review Board Statement: This study was conducted according to the guidelines of the Declaration of Helsinki, and approved by the NHS Ethics Committee (NHS REC reference: 15/SW/0263) and the University of the West of England Ethics Committee.

Informed Consent Statement: Informed consent was obtained from all subjects involved in this study.

Data Availability Statement: The data presented in this study are available in the article and accompanying appendices (Appendix A–E).

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Appendix A. Demographics Tables for All CARE Burn Scales

Table A1. Demographic Information of participants completing Child Form (parent-proxy) at T1.

	Demographics	N	%
Parent Age	Mean 33.29 (SD 6.03), range 19 to 52	250	
Parent Gender	Male	43	17.0
	Female	207	81.8
Parent Marital Status	Married	143	56.5
	Civil Partnership	8	3.2
	Single, never married	31	12.3
	Separated	4	1.6
	Divorced	3	1.2
	Cohabiting	53	20.9
	In a relationship but not living together	6	2.4
Widow/Widower	1	0.4	

Table A1. Cont.

	Demographics	N	%
Parent Ethnicity	White British	200	79.1
	White Other	15	5.9
	Asian or Asian British: Indian	9	3.6
	Asian or Asian British: Pakistani	6	2.4
	Asian or Asian British: Bangladeshi	2	0.8
	Asian or Asian British: Other	1	0.4
	Black or Black British: Black African	5	2.0
	Chinese or Other Ethnic Group	2	0.8
	Mixed: White and Black Caribbean	1	0.4
	Mixed: White and Black African	2	0.8
	Mixed: White and Asian	1	0.4
	Mixed: Other	1	0.4
	Other	1	0.4
Rather not say	4	1.6	
Parent Highest Level of Education	GCSEs/O-levels	52	20.6
	AS/A-levels	35	13.8
	Apprenticeship	13	5.1
	Undergraduate degree/certificate/diploma of higher education	99	39.1
	Master's degree	36	14.2
	Doctorate/PhD	9	3.6
Child Current Age	Mean 2.19 (SD 2.02), range 0 to 8	249	
Child Age at Injury	Mean 2.11 (SD 2.03), range 0 to 8	249	
Time Since Injury (Days)	Mean 19.18 (SD 11.60), range 1 to 55	250	
Child Gender	Male	158	62.5
	Female	91	36.0
Child Injury Status	Burn wound	94	37.2
	Burn scar	77	30.4
	Both wound and scar	44	17.4
	No wound or scar	34	13.4
Child's Body Part Affected	Head or face	38	15.0
	Neck	27	10.7
	Chest	53	20.9
	Abdomen	24	9.5
	Back	12	4.7
	Lower arms	38	15.0
	Upper arms	34	13.4
	Hands	80	31.6
	Fingers	50	19.8
	Bottom	3	1.2
	Genitalia	1	0.4
	Upper legs	32	12.6
	Lower legs	23	9.1
	Feet	38	15.0
Other	2	0.8	
Cause of burn	Flame	4	1.6
	Liquid	126	49.8
	Contact	105	41.5
	Electricity	0	0
	Chemical/acid	7	2.8
	Other	16	6.3
Treatments received from burns service	Surgery	20	7.9
	Physiotherapy/occupational therapy	20	7.9
	Nursing support	238	94.1
	Psychological support from a psychologist or counsellor	22	8.7
	Other support	23	9.1
Overnight hospital stay(s) (days)	Yes (mean 4.08 (SD 3.32), range 1 to 14)	43	17.0
	No	187	73.9
Surgery for burn (number of operations)	Yes (mean 1.59 (SD 1.58), range 1 to 7)	17	6.7
	No	213	84.2

NB. Percentages in the above table may not sum to 100% as they show the share of given group in the whole sample of 250 participants.

Table A2. Demographic Information of participants completing Young Person Form at T1.

	Demographics	N	%
Current age	Mean 12.63 (SD 2.40), range 9 to 17	68	
Age at injury	Mean 12.88 (SD 2.50), range 9 to 18	68	
Time since injury (Days)	Mean 18.04 (SD 10.27), range 1 to 46	68	
Gender	Male	34	50
	Female	34	50
Ethnicity	White British	58	84.1
	White Other	1	1.4
	Asian or Asian British: Bangladeshi	1	1.4
	Asian or Asian British: Indian	2	2.9
	Asian or Asian British: Pakistani	2	2.9
	Black or Black British: Caribbean	1	1.4
	Black or Black British: Other Black	1	1.4
	Mixed: White and Black African	1	1.4
	Rather not say	1	1.4
Injury status	Burn wound	30	43.5
	Burn scar	19	27.5
	Both wound and scar	14	20.3
	No wound or scar	5	7.2
Body part affected	Head or face	3	4.3
	Neck	4	5.8
	Chest	1	1.4
	Abdomen	7	10.1
	Back	4	5.8
	Lower arms	9	13.0
	Upper arms	9	13.0
	Hands	22	31.9
	Fingers	20	29.0
	Bottom	1	1.4
	Genitalia	2	2.9
	Upper legs	22	31.9
	Lower legs	12	17.4
	Feet	7	10.1
Other	3	4.3	
Cause of burn	Flame	6	8.7
	Liquid	33	47.8
	Contact	10	14.5
	Electricity	1	1.4
	Chemical/acid	3	4.3
	Other	17	24.6
Treatments received from burns service	Surgery	3	4.3
	Physiotherapy/occupational therapy	10	14.5
	Nursing support	66	95.7
	Psychological support from a psychologist or counsellor	1	1.4
	Other support	3	4.3
Overnight hospital stay(s) (days)	Yes (mean 1.80 (SD 1.14), range 1 to 4)	11	15.9
	No	57	82.6
Surgery for burn (number of operations)	Yes (mean 1.00 (SD 0.000))	4	5.8
	No	64	92.8

NB. Percentages in the above table may not sum to 100% as they show the share of given group in the whole sample of 68 participants.

Table A3. Demographic Information of participants completing Parent Form at T1.

	Demographics	N	%
Parent age	Mean 35.28 (SD 7.30), range 19 to 57	319	
Parent gender	Male	48	15.0
	Female	270	84.1
Parent marital status	Married	182	56.7
	Civil Partnership	7	2.2
	Single, never married	36	11.2
	Separated	8	2.5
	Divorced	14	4.4
	Cohabiting	59	18.4
	In a relationship but not living together	7	2.2
	Widow/Widower	2	0.6
Parent ethnicity	White British	257	80.1
	White Other	21	6.5
	Asian or Asian British: Indian	10	3.1
	Asian or Asian British: Pakistani	6	1.9
	Asian or Asian British: Bangladeshi	2	0.6
	Asian or Asian British: Other	1	0.3
	Black or Black British: Black African	6	1.9
	Chinese or Other Ethnic Group	2	0.6
	Mixed: White and Black Caribbean	1	0.3
	Mixed: White and Black African	2	0.6
	Mixed: White and Asian	1	0.3
	Mixed: Other	1	0.3
	Other	4	1.2
Rather not say	5	1.6	
Parent highest level of education	GCSEs/O-levels	69	21.5
	AS/A-levels	42	13.1
	Apprenticeship	16	5.0
	Undergraduate degree/certificate/diploma of higher education	127	39.6
	Master's degree	46	14.3
	Doctorate/PhD	13	4.0
Child current age	Mean 4.46 (SD 4.55), range 0 to 18	318	
Child age at injury	Mean 4.40 (SD 4.55), range 0 to 17	318	
Time since injury (Days)	Mean 19.44 (SD 11.36), range 1 to 55	319	
Child gender	Male	132	41.4
	Female	185	57.6
Child injury status	Burn wound	123	38.3
	Burn scar	96	29.9
	Both wound and scar	57	17.8
	No wound or scar	42	13.1
Child's body part affected	Head or face	46	14.3
	Neck	31	9.7
	Chest	59	18.4
	Abdomen	32	10.0
	Back	17	5.3
	Lower arms	54	16.8
	Upper arms	49	15.3
	Hands	102	31.8
	Fingers	66	20.6
	Bottom	3	0.9
Genitalia	2	0.6	

Table A3. Cont.

	Demographics	N	%
	Upper legs	45	14.0
	Lower legs	29	9.0
	Feet	42	13.1
	Other	6	1.9
Cause of burn	Flame	9	2.8
	Liquid	161	50.2
	Contact	113	35.2
	Electricity	3	0.9
	Chemical/acid	12	3.7
	Other	33	10.3
Treatments received from burns service	Surgery	24	7.5
	Physiotherapy/occupational therapy	29	9.0
	Nursing support	304	94.7
	Psychological support from a psychologist or counsellor	28	8.7
	Other support	24	7.5
Overnight hospital stay(s) (days)	Yes (mean 3.57 (SD 2.93), range 1 to 14)	61	19.0
	No	259	80.7
Surgery for burn (number of operations)	Yes (mean 1.54 (SD 1.38), range 1 to 7)	24	7.5
	No	295	91.9
Present when their child had their burn injury	Yes	206	64.2
	No	113	35.2

NB. Percentages in the above table may not sum to 100% as they show the share of given group in the whole sample of 319 participants.

Appendix B. Consistency and Validity Tables for All CARE Burn Scales

Table A4. Consistency and validity table for Child Form including intra-class correlation (ICC).

Scale	Data Quality			Scaling Assumptions			
	N	Missing Data (%)	Possible Range	Actual Range	Mean Score (SD)	Cronbach's Alpha	ICC
Social and Emotional Difficulties							
Time 1	195	22.9	0–100	0–100	58.64 (23.12)	0.86	0.347
Time 2	207	18.2	0–100	0–100	66.21 (24.97)	0.91	0.396
Time 3	195	22.9	0–100	0–100	68.77 (25.00)	0.91	0.425
Time 2—Time 1 change score	175	30.8	–100–100	–73–80	5.70 (23.53)		
Time 3—Time 2 change score	176	30.4	–100–100	–48–80	2.89 (20.50)		
Time 3—Time 1 change score	158	37.5	–100–100	–80–50	9.68 (26.56)		
Social and Emotional Well-Being							
Time 1	247	2.4	0–100	0–100	55.20 (30.70)	0.90	0.670
Time 2	228	9.9	0–100	0–100	65.96 (29.20)	0.92	0.710
Time 3	214	15.4	0–100	0–100	68.81 (28.00)	0.90	0.661
Time 2—Time 1 change score	223	11.9	–100–100	–100–100	11.12 (29.45)		
Time 3—Time 2 change score	205	19.0	–100–100	–100–100	1.55 (27.06)		
Time 3—Time 1 change score	210	17.0	–100–100	–100–100	13.98 (33.38)		

Table A5. Consistency and validity table for Young Person Form including intra-class correlation (ICC).

Data Quality			Scaling Assumptions				
Scale	N	Missing Data (%)	Possible Range	Actual Range	Mean Score (SD)	Cronbach's Alpha	ICC
Social Situations							
Time 1	67	2.9	0–100	26–100	69.33 (24.46)	0.89	0.430
Time 2	60	13.0	0–100	0–100	75.57 (24.30)	0.90	0.485
Time 3	57	17.4	0–100	0–100	77.77 (28.29)	0.94	0.660
Time 2—Time 1 change score	68	15.9	–100–100	–46–70	5.40 (23.60)		
Time 3—Time 2 change score	56	18.8	–100–100	–100–63	2.18 (26.39)		
Time 3—Time 1 change score	55	20.3	–100–100	–80–70	8.42 (26.12)		
Self Worth							
Time 1	68	1.4	0–100	35–100	75.57 (18.42)	0.86	0.246
Time 2	60	13.0	0–100	23–100	78.97 (19.99)	0.89	0.294
Time 3	58	15.9	0–100	0–100	81.62 (21.61)	0.93	0.329
Time 2—Time 1 change score	59	14.5	–100–100	–55–51	2.81 (17.00)		
Time 3—Time 2 change score	57	17.4	–100–100	–66–38	3.35 (16.75)		
Time 3—Time 1 change score	57	17.4	–100–100	–62–51	6.42 (18.05)		
Negative Mood							
Time 1	68	1.4	0–100	0–100	66.49 (25.21)	0.86	0.451
Time 2	60	13.0	0–100	23–100	71.52 (22.68)	0.82	0.407
Time 3	57	17.4	0–100	30–100	72.46 (22.61)	0.88	0.499
Time 2—Time 1 change score	59	14.5	–100–100	–46–78	2.95 (20.91)		
Time 3—Time 2 change score	56	18.8	–100–100	–49–49	1.55 (17.35)		
Time 3—Time 1 change score	56	18.8	–100–100	–49–60	5.71 (23.03)		
Wound/Scar Dissatisfaction							
Time 1	68	1.4	0–100	0–100	54.93 (29.17)	0.92	0.566
Time 2	59	14.5	0–100	0–100	70.81 (28.34)	0.93	0.614
Time 3	58	15.9	0–100	0–100	76.29 (27.44)	0.94	0.674
Time 2—Time 1 change score	58	16.9	–100–100	–44–72	16.33 (20.55)		
Time 3—Time 2 change score	56	18.8	–100–100	–28–57	5.70 (18.99)		
Time 3—Time 1 change score	57	17.4	–100–100	–30–100	20.74 (24.52)		
Romantic Relationships							
Time 1	36	47.8	0–100	0–100	51.03 (25.50)	0.93	0.620
Time 2	36	47.8	0–100	0–100	47.58 (24.19)	0.91	0.564
Time 3	37	46.4	0–100	0–100	53.16 (23.89)	0.90	0.522
Time 2—Time 1 change score	36	47.8	–100–100	–15–5	–3.44 (4.51)		

Table A5. Cont.

Data Quality			Scaling Assumptions				
Scale	N	Missing Data (%)	Possible Range	Actual Range	Mean Score (SD)	Cronbach's Alpha	ICC
Time 3—Time 2 change score	34	50.7	−100–100	−31–65	3.21 (19.79)		
Time 3—Time 1 change score	34	50.7	−100–100	−31–59	−0.44 (20.20)		
Positive Growth							
Time 1	64	7.2	0–100	0–88	38.52 (21.92)	0.85	0.506
Time 2	59	14.5	0–100	0–100	48.66 (24.06)	0.92	0.692
Time 3	56	18.8	0–100	0–100	47.23 (26.27)	0.92	0.701
Time 2—Time 1 change score	54	21.7	−100–100	−60–50	10.26 (24.58)		
Time 3—Time 2 change score	55	20.3	−100–100	−62–43	0.24 (20.25)		
Time 3—Time 1 change score	52	24.6	−100–100	−60–72	10.96 (26.97)		

Table A6. Consistency and validity table for Parent Form including intra-class correlation (ICC).

Data Quality			Scaling Assumptions				
Scale	N	Missing Data (%)	Possible Range	Actual Range	Mean Score (SD)	Cronbach's Alpha	ICC
Physical Health							
Time 1	319	0.3	0–100	0–100	62.11 (25.75)	0.91	0.687
Time 2	286	10.9	0–100	0–100	67.76 (24.43)	0.94	0.715
Time 3	274	14.6	0–100	0–100	69.56 (24.56)	0.94	0.701
Time 2—Time 1 change score	285	11.2	−100–100	−100–80	5.43 (26.75)		
Time 3—Time 2 change score	264	17.8	−100–100	−100–100	1.66 (24.94)		
Time 3—Time 1 change score	274	14.6	−100–100	−100–80	7.42 (27.25)		
Social Situations							
Time 1	317	1.2	0–100	0–100	68.02 (29.32)	0.92	0.780
Time 2	273	15.0	0–100	0–100	73.75 (28.50)	0.93	0.801
Time 3	264	17.8	0–100	0–100	77.74 (28.44)	0.93	0.819
Time 2—Time 1 change score	270	15.9	−100–100	−100–89	6.54 (25.79)		
Time 3—Time 2 change score	250	22.1	−100–100	−100–100	2.99 (26.68)		
Time 3—Time 1 change score	262	18.4	−100–100	−100–100	9.21 (28.48)		
Partner Relationship							
Time 1	278	13.4	0–100	0–87	64.61 (21.25)	0.88	0.566
Time 2	241	24.9	0–100	0–100	71.61 (24.20)	0.88	0.377
Time 3	230	28.3	0–100	0–100	72.03 (24.89)	0.89	0.437
Time 2—Time 1 change score	235	26.8	−100–100	−59–57	6.83 (18.31)		
Time 3—Time 2 change score	214	33.3	−100–100	−67–67	0.03 (19.29)		

Table A6. Cont.

Scale	Data Quality			Scaling Assumptions			
	N	Missing Data (%)	Possible Range	Actual Range	Mean Score (SD)	Cronbach's Alpha	ICC
Time 3—Time 1 change score	228	29.0	−100–100	−42–83	6.99 (20.61)		
Self Worth							
Time 1	319	0.6	0–100	0–100	67.47 (18.50)	0.91	0.648
Time 2	285	11.2	0–100	0–100	69.51 (18.05)	0.93	0.700
Time 3	272	15.3	0–100	15–100	70.32 (19.00)	0.94	0.747
Time 2—Time 1 change score	294	8.4	−100–100	−75–42	2.19 (14.85)		
Time 3—Time 2 change score	272	15.3	−100–100	−57–100	0.84 (15.13)		
Time 3—Time 1 change score	271	15.6	−100–100	−57–85	2.97 (17.51)		
Negative Mood							
Time 1	317	1.2	0–100	14–80	57.34 (12.78)	0.88	0.396
Time 2	285	11.2	0–100	24–80	59.89 (12.42)	0.87	0.366
Time 3	274	14.6	0–100	1–80	60.06 (12.80)	0.89	0.390
Time 2—Time 1 change score	281	12.5	−100–100	−25–45	2.43 (9.87)		
Time 3—Time 2 change score	263	18.1	−100–100	−54–56	0.52 (9.40)		
Time 3—Time 1 change score	272	15.3	−100–100	−68–47	2.80 (11.91)		
Parent Dissatisfaction with Child's Wound/Scars							
Time 1	319	0.3	0–100	0–100	67.73 (28.31)	0.94	0.794
Time 2	281	12.5	0–100	0–100	79.42 (26.62)	0.96	0.840
Time 3	268	16.5	0–100	0–100	82.22 (25.34)	0.96	0.852
Time 2—Time 1 change score	280	12.8	−100–100	−90–100	12.00 (26.63)		
Time 3—Time 2 change score	257	19.9	−100–100	−70–73	3.20 (18.94)		
Time 3—Time 1 change score	268	16.5	−100–100	−71–100	15.67 (25.39)		
Positive Growth							
Time 1	315	1.9	0–100	0–100	58.08 (24.36)	0.85	0.573
Time 2	277	13.7	0–100	0–100	58.13 (23.53)	0.88	0.621
Time 3	271	15.6	0–100	0–100	61.92 (25.16)	0.92	0.718
Time 2—Time 1 change score	272	15.3	−100–100	−86–100	0.19 (22.31)		
Time 3—Time 2 change score	255	20.6	−100–100	−89–100	3.75 (22.20)		
Time 3—Time 1 change score	267	16.8	−100–100	−89–100	4.09 (23.07)		

Appendix C. Correlations Tables for All CARE Burn Scales and the Comparison Measures for Each Change Score

Table A7. Child Form change score correlations (r) with comparison quality of life measures.

CARE Burn Scale—Child Form Subscale Change Scores	Comparison Measure Change Scores	r	95% Confidence Intervals
Social and Emotional Difficulties Change Score (T2–T1)	PEDSQL Emotional Functioning Change Score (T2–T1)	0.25 **	0.11, 0.38
Social and Emotional Difficulties Change Score (T3–T2)	PEDSQL Emotional Functioning Change Score (T3–T2)	0.18 *	0.03, 0.32
Social and Emotional Difficulties Change Score (T3–T1)	PEDSQL Emotional Functioning Change Score (T3–T1)	0.38 **	0.24, 0.51
Social and Emotional Well-Being Change Score (T2–T1)	PEDSQL Emotional Functioning Change Score (T2–T1)	0.23 **	0.10, 0.35
Social and Emotional Well-Being Change Score (T3–T2)	PEDSQL Emotional Functioning Change Score (T3–T2)	0.26 **	0.13, 0.38
Social and Emotional Well-Being Change Score (T3–T1)	PEDSQL Emotional Functioning Change Score (T3–T1)	0.20 **	0.06, 0.33

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

Table A8. Young Person Form change score correlations (r) with comparison measures.

CARE Burn Scale—Young Person Form Subscale Change Scores	Comparison Measure Change Scores	r	95% Confidence Intervals
Social Situations Change Score (T2–T1)	PedsQL Social Functioning Change Score (T2–T1)	0.30 *	0.05, 0.52
Social Situations Change Score (T3–T2)	PedsQL Social Functioning Change Score (T3–T2)	0.23	−0.04, 0.47
Social Situations Change Score (T3–T1)	PedsQL Social Functioning Change Score (T3–T1)	0.42 **	−0.04, 0.47
Self Worth Change Score (T2–T1)	SMFQ Change Score (T2–T1)	−0.41	−0.60, −0.17
Self Worth Change Score (T3–T2)	SMFQ Change Score (T3–T2)	−0.34 **	−0.55, −0.08
Self Worth Change Score (T3–T1)	SMFQ Change Score (T3–T1)	−0.67 **	−0.79, −0.49
Negative Mood Change Score (T2–T1)	SMFQ Change Score (T2–T1)	−0.46 **	−0.64, −0.23
Negative Mood Change Score (T3–T2)	SMFQ Change Score (T3–T2)	−0.43 **	−0.62, −0.19
Negative Mood Change Score (T3–T1)	SMFQ Change Score (T3–T1)	−0.60 **	−0.75, −0.40
Wound/scar dissatisfaction Change Score (T2–T1)	POSAS Overall Opinion Change Score (T2–T1)	−0.15	−0.40, 0.12
Wound/scar dissatisfaction Change Score (T3–T2)	POSAS Overall Opinion Change Score (T3–T2)	−0.15	−0.40, 0.12
Wound/scar dissatisfaction Change Score (T3–T1)	POSAS Overall Opinion Change Score (T3–T1)	−0.45 **	−0.64, −0.21
Romantic Relationships Change Score (T2–T1)	PedsQL Psychosocial Health Summary Change Score (T2–T1)	−0.3	−0.59, 0.05
Romantic Relationships Change Score (T3–T2)	PedsQL Psychosocial Health Summary Change Score (T3–T2)	0.37 *	0.02, 0.64
Romantic Relationships Change Score (T3–T1)	PedsQL Psychosocial Health Summary Change Score (T3–T1)	0.27	−0.10, 0.57
Positive Growth Change Score (T2–T1)	PTGI-C-R (T2–T1)	0.20	−0.12, 0.48
Positive Growth Change Score (T3–T2)	PTGI-C-R (T3–T2)	0.08	−0.24, 0.39
Positive Growth Change Score (T3–T1)	PTGI-C-R (T3–T1)	0.08	−0.25, 0.39

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

Table A9. Parent Form change score correlations (r) with comparison measures.

CARe Burn Scale—Parent Form Subscales Change Scores	Comparison Measure Change Scores	r	95% Confidence Intervals
Physical Health Change Score (T2–T1)	SF-36 Change Score (T2–T1)	0.28 **	0.17, 0.38
Physical Health Change Score (T3–T2)	SF-36 Change Score (T3–T2)	0.31 **	0.20, 0.42
Physical Health Change Score (T3–T1)	SF-36 Change Score (T3–T1)	0.29 **	0.18, 0.40
Social Situations Change Score (T2–T1)	MHI Depression Subscale Change Score (T2–T1)	0.25 **	0.12, 0.36
Social Situations Change Score (T3–T2)	MHI Depression Subscale Change Score (T3–T2)	0.23 **	0.11, 0.34
Social Situations Change Score (T3–T1)	MHI Depression Subscale Change Score (T3–T1)	0.24 **	0.12, 0.35
Self Worth Change Score (T2–T1)	MHI Depression Subscale Change Score (T2–T1)	0.36 **	0.25, 0.46
Self Worth Change Score (T3–T2)	MHI Depression Subscale Change Score (T3–T2)	0.44 **	0.33, 0.53
Self Worth Change Score (T3–T1)	MHI Depression Subscale Change Score (T3–T1)	0.43 **	0.33, 0.52
Negative Mood Change Score (T2–T1)	MHI Depression Subscale Change Score (T2–T1)	0.37 **	0.26, 0.47
Negative Mood Change Score (T3–T2)	MHI Depression Subscale Change Score (T3–T2)	0.34 **	0.23, 0.44
Negative Mood Change Score (T3–T1)	MHI Depression Subscale Change Score (T3–T1)	0.44 **	0.34, 0.53
Partner Relationship Change Score (T2–T1)	Coparenting Relationship Scale Change Score (T2–T1)	0.35 **	0.23, 0.46
Partner Relationship Change Score (T3–T2)	Coparenting Relationship Scale Change Score (T3–T2)	0.28 **	0.15, 0.40
Partner Relationship Change Score (T3–T1)	Coparenting Relationship Scale Change Score (T3–T1)	0.29 **	0.17, 0.40
Parent Dissatisfaction with Child's Wound/Scars Change Score (T2–T1)	POSAS Change Score (T2–T1)	–0.40 **	–0.50, –0.29
Parent Dissatisfaction with Child's Wound/Scars Change Score (T3–T2)	POSAS Change Score (T3–T2)	–0.30 **	–0.41, –0.18
Parent Dissatisfaction with Child's Wound/Scars Change Score (T3–T1)	POSAS Change Score (T3–T1)	–0.55 **	–0.63, –0.46
Positive Growth Change Score (T2–T1)	PTGI-SF Change Score (T2–T1)	0.08	–0.04, 0.20
Positive Growth Change Score (T3–T2)	PTGI-SF Change Score (T3–T2)	0.12	0.00, 0.24
Positive Growth Change Score (T3–T1)	PTGI-SF Change Score (T3–T1)	0.07	–0.05, 0.19

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

Appendix D. Correlations between the Anchor Questions and CARE Burn Scale Subscales Change Scores

Table A10. Child Form change score correlations (r) with anchor questions.

CARE Burn Scale—Child Form	Anchor Questions	r	95% Confidence Intervals
Social and Emotional Difficulties Change Score (T2–T1)	Social and Emotional Difficulties Anchor Question Time 2	−0.14	−0.28, 0.01
Social and Emotional Difficulties Change Score (T3–T2)	Social and Emotional Difficulties Anchor Question Time 3	−0.06	−0.21, 0.09
Social and Emotional Well-Being Change Score (T2–T1)	Social and Emotional Wellbeing Anchor Question Time 2	−0.22 **	−0.34, 0.09
Social and Emotional Well-Being Change Score (T3–T2)	Social and Emotional Wellbeing Anchor Question Time 3	−0.04	−0.18, 0.10

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

Table A11. Young Person Form change score correlations (r) with anchor questions.

CARE Burn Scale—Young Person Form Change Scores	Anchor Questions	r	95% Confidence Intervals
Social Situations Change Score (T2–T1)	Social Situations Anchor Question Time 2	−0.04	−0.30, 0.22
Social Situations Change Score (T3–T2)	Social Situations Anchor Question Time 3	−0.15	0.40, 0.12
Self Worth Change Score (T2–T1)	Self Worth Anchor Question Time 2	−0.36 *	−0.79, 0.31
Self Worth Change Score (T3–T2)	Self Worth Anchor Question Time 3	−0.29 *	−0.51, −0.03
Negative Mood Change Score (T2–T1)	Negative Mood Anchor Question Time 2	−0.1	−0.35, 0.16
Negative Mood Change Score (T3–T2)	Negative Mood Anchor Question Time 3	−0.16	−0.41, 0.11
Scar Dissatisfaction Change Score (T2–T1)	Scar Dissatisfaction Anchor Time 2	0.08	−0.18, 0.33
Scar Dissatisfaction Change Score (T3–T2)	Scar Dissatisfaction Anchor Time 3	0.09	−0.18, 0.34
Romantic Relationships Change Score (T1–T2)	Romantic Relationships Anchor Question Time 2	0.00	−0.57, 0.05
Romantic Relationships Change Score (T3–T2)	Romantic Relationships Anchor Question Time 3	−0.29	−0.57, 0.05
Positive Growth Change Score (T2–T1)	Positive Growth Anchor Question Time 2	−0.30 *	−0.53, −0.03
Positive Growth Change Score (T3–T2)	Positive Growth Anchor Question Time 3	−0.04	−0.30, 0.23

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

Table A12. Parent Form change score correlations (r) with anchor questions.

CARE Burn Scale—Parent Form Change Scores	Anchor Questions	r	95% Confidence Intervals
Physical Health T1–T2 Change Score	Physical Health Anchor Time 2	−0.23 **	−0.34, −0.12
Physical Health T3–T2 Change Score	Physical Health Anchor Time 3	−0.20 **	−0.31, −0.08
Physical Health T3–T1 Change Score	Physical Health Anchor Time 3	−0.32 **	−0.42, −0.21
Social Situations T2–T1 Change Score	Social Situations Anchor Time 2	−0.30 **	−0.41, −0.19
Social Situations T3–T2 Change Score	Social Situations Anchor Time 3	−0.17 **	−0.29, −0.05
Social Situations T3–T1 Change Score	Social Situations Anchor Time 3	−0.19 **	−0.31, −0.07

Table A12. *Cont.*

CARe Burn Scale—Parent Form Change Scores	Anchor Questions	r	95% Confidence Intervals
Partner Relationship T2–T1 Change Score	Partner Relationship Anchor Time 2	–0.14 *	–0.26, –0.01
Partner Relationship T3–T2 Change Score	Partner Relationship Anchor Time 3	–0.22 **	–0.34, –0.09
Partner Relationship T3–T1 Change Score	Partner Relationship Anchor Time 3	–0.18 **	–0.30, –0.05
Self Worth T2–T1 Change Score	Self Worth Anchor Time 2	–0.26 **	–0.37, –0.15
Self Worth T3–T2 Change Score	Self Worth Anchor Time 3	–0.17 **	–0.28, –0.05
Self Worth T3–T1 Change Score	Self Worth Anchor Time 3	–0.25 **	–0.36, –0.13
Negative Mood T2–T1 Change Score	Negative Mood Anchor Time 2	–0.14 *	–0.25, –0.02
Negative Mood T3–T2 Change Score	Negative Mood Anchor Time 3	–0.15 **	–0.27, –0.03
Negative Mood T3–T1 Change Score	Negative Mood Anchor Time 3	–0.17 **	–0.42, –0.21
Parent Dissatisfaction with Child’s Wound/Scars T2–T1 Change Score	Parent Dissatisfaction with Child’s Wound/Scars Anchor Time 2	–0.32 **	–0.42, –0.21
Parent Dissatisfaction with Child’s Wound/Scars T3–T2 Change Score	Parent Dissatisfaction with Child’s Wound/Scars Anchor Time 3	–0.24 **	–0.35, –0.12
Parent Dissatisfaction with Child’s Wound/Scars T3–T1 Change Score	Parent Dissatisfaction with Child’s Wound/Scars Anchor Time 3	–0.23 **	–0.34, –0.11
Positive Growth T2–T1 Change Score	Positive Growth Anchor Time 2	–0.03	–0.15, 0.09
Positive Growth T3–T2 Change Score	Positive Growth Anchor Time 3	–0.21 **	–0.32, –0.09
Positive Growth T3–T1 Change Score	Positive Growth Anchor Time 3	–0.09	–0.21, 0.03

** Correlation is significant at the 0.01 level (2-tailed). * Correlation is significant at the 0.05 level (2-tailed).

Appendix E. Tables of Anchor-Based and Distribution Based MID Values for All CARe Burn Scales

Table A13. Child Form—anchor-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social and Emotional Difficulties	Time 2	2	46% (43/93)	41% (11/27)	64% (34/53)	51% (88/173)	43 to 58
	Time 3	2	60% (64/106)	42% (10/24)	39% (18/46)	52% (92/176)	45 to 60
Social and Emotional Well-Being	Time 2	11	64% (75/117)	48% (21/44)	60% (37/62)	60% (133/223)	53 to 66
	Time 3	11	76% (96/127)	44% (14/32)	37% (17/46)	62% (127/205)	55 to 68

* Binomial Proportion calculated by Wilson’s Method.

Table A14. Child Form—distribution-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social and Emotional Difficulties	Time 2	2	50% (18/36)	45% (14/31)	54 (58/107)	52% (90/174)	44 to 59
	Time 3	2	67% (29/43)	50% (9/18)	47% (53/113)	52% (91/174)	45 to 60
Social and Emotional Well-Being	Time 2	11	62% (32/52)	33% (12/36)	50% (63/127)	50% (107/215)	43 to 56
	Time 3	11	79% (37/47)	67% (14/21)	40% (53/134)	51% (104/202)	45 to 58

* Binomial Proportion calculated by Wilson’s Method.

Table A15. Young Person Form—anchor-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social Situations	Time 2	5	65% (13/20)	44% (7/16)	46% (10/21)	53% (30/57)	40 to 65
	Time 3	5	71% (17/24)	17% (2/12)	56% (10/18)	54% (29/54)	41 to 66
Self Worth	Time 2	4	71% (22/31)	53% (9/17)	70% (7/10)	66% (38/58)	53 to 76
	Time 3	4	67% (22/33)	38% (6/16)	50% (4/8)	56% (32/57)	43 to 68
Negative Mood	Time 2	10	69% (25/36)	40% (4/10)	17% (2/12)	53% (31/58)	41 to 66
	Time 3	10	78% (28/36)	29% (2/7)	39% (4/13)	61% (34/56)	48 to 72
Parent Dissatisfaction with Child's Wound/Scars	Time 2	6	27% (7/26)	58% (7/12)	68% (13/19)	47% (27/57)	35 to 60
	Time 3	6	57% (20/35)	23% (3/13)	38% (3/8)	46% (26/56)	34 to 59
Romantic Relationships	Time 2	3	94% (29/31)	33% (1/3)	0% (0/1)	86% (30/35)	71 to 94
	Time 3	3	72% (18/25)	50% (3/6)	33% (1/3)	65% (22/34)	48 to 79
Positive Growth	Time 2	14	67% (18/27)	61% (11/18)	71% (5/7)	65% (34/52)	52 to 77
	Time 3	14	75% (27/36)	17% (2/12)	17% (1/6)	56% (30/54)	42 to 68

* Binomial Proportion calculated by Wilson's Method.

Table A16. Young Person Form—distribution-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Social Situations	Time 2	4	67% (16/24)	63% (5/8)	54% (14/26)	60% (35/58)	47 to 72
	Time 3	4	60% (18/30)	30% (3/10)	40% (6/15)	49% (27/55)	36 to 62
Self Worth	Time 2	3	71% (24/34)	33% (2/6)	11% (2/18)	48% (28/58)	36 to 61
	Time 3	3	67% (24/36)	33% (2/6)	21% (3/14)	52% (29/56)	39 to 64
Negative Mood	Time 2	10	79% (27/34)	83% (5/6)	56% (10/18)	72% (42/58)	60 to 82
	Time 3	10	81% (25/31)	17% (1/6)	35% (6/17)	59% (32/54)	46 to 71
Wound/Scar Dissatisfaction	Time 2	13	35% (7/20)	56% (9/16)	78% (14/18)	56% (30/54)	42 to 68
	Time 3	13	77% (27/35)	17% (2/12)	20% (1/5)	58% (30/52)	44 to 70
Romantic Relationships	Time 2	3	100% (11/11)	80% (4/5)	44% (7/16)	69% (22/32)	51 to 82
	Time 3	3	69% (9/13)	0% (0/7)	18% (2/11)	35% (11/31)	21 to 53
Positive Growth	Time 2	12	62% (8/13)	56% (9/16)	73% (8/11)	63% (25/40)	47 to 76
	Time 3	12	71%(10/14)	43% (6/14)	0% (0/11)	41% (16/39)	21 to 57

* Binomial Proportion calculated by Wilson's Method.

Table A17. Parent Form—anchor-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Physical Health	Time 2	8	62% (116/188)	53% (40/76)	72% (13/18)	60% (169/282)	54 to 65
	Time 3	8	73% (122/168)	46% (37/80)	31% (5/16)	62% (164/264)	56 to 68
Social Situations	Time 2	10	72% (94/130)	56% (40/72)	61% (40/66)	65% (174/268)	59 to 70
	Time 3	10	74% (107/145)	36% (18/50)	52% (27/52)	62% (152/247)	55 to 67
Partner Relationship	Time 2	9	40% (67/169)	44% (17/39)	79% (19/24)	44% (103/232)	38 to 51
	Time 3	9	76% (108/143)	38% (16/42)	38% (11/29)	63% (135/213)	57 to 70
Self Worth	Time 2	3	62% (105/169)	52% (41/79)	71% (25/35)	60% (171/283)	55 to 66
	Time 3	3	66% (105/158)	41% (29/71)	51% (22/43)	57% (155/272)	51 to 63
Negative Mood	Time 2	3	51% (79/155)	52% (50/97)	67% (16/24)	53% (145/276)	47 to 58
	Time 3	3	63% (103/164)	44% (33/75)	39% (9/23)	55% (145/262)	49 to 61
Parent Dissatisfaction with Child's Wound/Scars	Time 2	7	60% (62/104)	58% (50/86)	68% (59/87)	62% (171/277)	56 to 67
	Time 3	7	80% (109/136)	42% (24/57)	42% (26/62)	62% (159/255)	56 to 68
Positive Growth	Time 2	7	65% (107/164)	41% (29/71)	31% (11/36)	54% (147/271)	48 to 60
	Time 3	7	73% (116/158)	47% (27/57)	49%(19/39)	64% (162/254)	58 to 69

* Binomial Proportion calculated by Wilson's Method.

Table A18. Parent Form—distribution-based MID results.

Subscale	Time Point	MID	% Under MID (No Change)	% Greater or Equal to MID (Small Change)	% Greater or Equal to MID (Big Change)	Overall Accuracy	Overall Accuracy 95% CI *
Physical Health	Time 2	6	69% (110/161)	47% (20/43)	66% (49/74)	64% (179/278)	59 to 70
	Time 3	6	68% (103/152)	35% (14/40)	26% (18/69)	52% (135/261)	46 to 68
Social Situations	Time 2	10	63% (76/120)	41% (26/63)	56% (48/86)	56% (150/269)	50 to 62
	Time 3	10	73% (112/154)	40% (19/48)	45% (21/47)	61% (152/249)	55 to 67
Partner Relationship	Time 2	10	38% (44/116)	51% (42/83)	61% (20/33)	46% (106/232)	39 to 52
	Time 3	10	77% (82/107)	38% (28/74)	50% (16/32)	59% (126/213)	52 to 66
Self Worth	Time 2	3	66% (82/124)	55% (36/65)	65% (60/92)	63% (178/281)	58 to 69
	Time 3	3	71% (113/160)	62% (33/53)	72% (34/47)	69% (180/260)	63 to 75
Negative Mood	Time 2	1	50% (62/123)	66% (43/65)	70% (64/92)	60% (169/280)	55 to 66
	Time 3	1	60% (96/61)	45% (24/53)	69% (33/48)	58% (153/262)	52 to 64
Parent Dissatisfaction with Child's Wound/Scars	Time 2	4	71% (37/52)	55% (21/38)	59% (104/175)	61% (162/265)	55 to 67
	Time 3	4	85% (117/138)	47% (25/53)	49% (26/53)	69% (168/244)	63 to 74
Positive Growth	Time 2	6	69% (63/92)	40% (27/67)	37% (39/106)	52% (139/265)	46 to 58
	Time 3	6	68% (71/105)	31% (15/49)	36% (36/99)	48% (122/253)	42 to 54

* Binomial Proportion calculated by Wilson's Method.

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