School of Psychology
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Parenting a Child Living With a Visible Difference

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Preface

Paper 1

The term ‘visible difference’ refers to any condition, injury or mark which impacts upon a person’s appearance. For children and young people, living with a visible difference can be associated with increased anxiety, lower self-esteem, and problems with body image. Such problems appear to occur irrespective of the associated cause, nature, or significance of impact of the visible difference on appearance. Existing research in the area has usually focused on specific conditions which can impact upon appearance, and no systematic review has yet drawn together the qualitative literature regarding parenting a child with a visible difference.

A systematic search of the literature was conducted resulting in eight relevant UK based studies being identified for inclusion in the review. A three-step synthesis approach was completed. Initially all relevant findings from the identified studies were coded. These codes were organised in a hierarchical way to create initial themes describing the data. These themes were then refined, and two overarching interrelated cross-condition themes were created: 1) The dynamic process of adjustment, and 2) Parenting a child with a visible difference.

Theme one described how parents’ adjustment processes began when they learnt of their child’s visible difference. Parents managed sometimes challenging thoughts and feelings about their child’s different appearance and navigated social experiences, which could interrupt adjustment processes alongside various other factors including transitional times for children, further appearance changes and medical treatment. Parents gathered knowledge about the nature of their child’s visible difference and engaged in practices to enhance their child’s adjustment, which appeared interlinked with their own. Parents supported their children socially and sometimes worked to educate other people more widely to enhance acceptance.

To best support these parents and families, detailed assessments which consider these important factors should be completed. Such assessments could then inform the provision of appropriate psycho-social support for families. Furthermore, education could be beneficial for healthcare professionals to better equip them to speak with and support families, while the provision of information and representation of people who look different could increase compassion and acceptance within wider society. Future research comparing participants from different cultures and with different types of visible differences is needed to build upon the findings presented.

Paper 2

Living with a visible difference can be difficult for children and their families. Families can face such challenges as navigating challenging social encounters and many parents and children experience emotional difficulties. Currently the evidence considering interventions for parents remains in the early stages. Mindful parenting programmes have the potential to improve parent wellbeing and have an indirect positive impact upon children. This study investigated the initial effects of a brief, online mindful parenting programme for parents of children with a visible difference experiencing stress. It was hypothesised that participation in the mindful parenting programme would decrease stress, increase levels of mindful parenting, and indirectly improve child wellbeing.

Nine parent participants participated in the mindful parenting programme entitled ‘Two Hearts’. Children did not take part in the programme or study directly. Parents designed personalised targets around parenting stress and wellbeing, which were sent to them daily throughout each phase of the 12-week study. Standardised questionnaires on parenting stress, mindful parenting and child wellbeing were sent at four timepoints: baseline (week 0), pre-intervention (week 2), post-intervention (week 8), and follow-up (week 12). Over half of participants experienced significant improvements in their personalised target for stress reduction. One third of participants experienced reliable improvements for parenting stress and mindful parenting on standardised questionnaires. Child outcomes were mixed. The mindful parenting programme was feasible and acceptable to parents.

A brief, online, mindful parenting intervention has the potential to be beneficial for parents of children with a visible difference who are experiencing heightened stress. Such a programme has the benefit of being more accessible than traditional mindful parenting programmes, which is important for busy parents. Several suggestions for further research arose from the study. Further large-scale evaluation of interventions of this nature are needed; studies should also investigate how the effects of this type of intervention compare with full-length programmes and similar interventions should be tested with other populations. Such studies would benefit from employing careful measurements of intervention adherence, including outcome measures which are sensitive to enhanced wellbeing.

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Paper One

Parenting a Child with a Visible Difference: A Systematic Review and Meta-Synthesis of UK Studies

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Manuscript prepared in line with the author guidelines for the Journal of Body Image (Appendix A) and following the word count guidance for DClinPsy Thesis submission 2023.

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Key Words

Parent, Caregiver, Mother, Father, Family, Visible difference, Appearance altering condition or injury, Adjustment, Social experience, Stigma, Qualitative

Highlights

- A systematic review of the literature identified eight UK studies pertaining to parenting a child with a visible difference.
- Studies underwent thematic synthesis creating two overarching themes.
- Parental adjustment was influenced by internal and sociocultural factors and interlinked with child wellbeing and parenting practices.
- In clinical practice holistic assessments and responsive provision of interventions are important alongside training for professionals and wider education and representation.
- Further research is needed to investigate individual, cross-condition and cross-cultural differences.

Abstract

Children and young people living with visible differences can experience problems with self-esteem, body image and anxiety. Parents of children with visible differences may experience associated heightened stress and distress. Such problems appear to be present irrespective of the nature, aetiology, or significance of the visible difference. Existing qualitative research in this area has predominantly been condition-specific and integration of the literature is now needed to elucidate cross-condition parental experiences. Systematic searching identified eight UK studies, from which thematic synthesis identified two overarching cross-condition themes. Upon learning of their child's visible difference, parents embark on a process of adjustment which is influenced by internal processes, social experiences, and various ‘interruptions’, resulting in differing levels of acceptance. Parents equip themselves with knowledge and employ strategies to enhance their child’s wellbeing and manage social challenges. Holistic familial assessments are required to identify need and provide appropriate intervention. Furthermore, greater representation and provision of information for professionals and the public could create more compassionate and accepting systems. Finally, cross-cultural and further cross-condition research is required to further inform intervention provision.

A range of factors can affect a child’s appearance including congenital conditions, physical injuries, illnesses, and surgical interventions (Rumsey & Harcourt, 2007; Thompson & Kent, 2001). Across the UK at least 1.3 million children, young people, and adults are estimated to experience an appearance-altering condition or injury; within this paper this will be referred to as a ‘visible difference’ (Changing Faces, 2023). This definition, whilst broad, deliberately avoids the use of negatively framed terms such as ‘disfigurement’ which have been used in the past (Rumsey & Harcourt, 2007).

People living with a visible difference may experience problems with body image and self-esteem, alongside poorer quality of life (Rumsey & Harcourt, 2004) and increased anxiety compared with the unaffected population (van Dalen et al., 2020). Those who are parenting a child living with a visible difference may experience difficulties such as heightened stress (Boztepe et al., 2020; Pope et al., 2005) and guilt (Hawkins et al., 2019; O'hanlon et al., 2012). However, many individuals and their parents adjust well to living with a visible difference and report positive outcomes (Baker et al., 2009; Rumsey & Harcourt, 2007).

The heterogeneity of this population enhances the complexity of considering the issues of appearance concerns. A visible difference may differ with regards to body part(s) affected, noticeability and significance (Rumsey, 2002). Yet factors such as symptom severity alone do not appear to mediate outcomes (Hotton et al., 2020). Instead, individual factors have been noted to be a key source of variation within conditions, with further investigation required (Stock & Feragen, 2016). Considerable cross-condition overlap in people’s experiences have been noted (Rumsey, 2002) with similar domains of adjustment highlighted across different types of craniofacial anomalies (CFAs), including cleft lip/ and or palate (CL/P) (Stock & Feragen, 2019). However, it is important to consider that certain conditions such as CL/P have received more research focus than other appearance-altering conditions (Stock & Feragen, 2019).

Due to the heterogeneity within the visible difference population, it is understandable that cross-condition qualitative research of parental experiences might exclude detail relating to the medical aspects of appearance altering conditions or injuries (Thornton et al., 2021). Yet parents of children with health conditions can face a host of specific stressors (Cousino & Hazen, 2013). Thus, some parents may face both the unique challenges of raising a child who looks different alongside the additional challenges of children’s health needs (Costa et al., 2021). Indeed, recent evidence points to the potential need to consider issues of intersectionality for parents where a child’s visible difference intersects with aspects of health or cognition (Feragen & Stock, 2017). As such, further research is needed to understand more about such individual and cross-condition variation.

Research has shown that appearance matters (Cash, 2004). From as young as three years of age, children have shown a preference for ‘attractive’ peers and associated them with anticipated prosocial behaviour, and the opposite is true for ‘unattractive’ peers (Dion, 1973). Furthermore, adults associated attractiveness with greater success and happiness in both personal and professional realms (Dion et al., 1972). The same appears to be true for people with an unusual appearance. A recent study found that adults made more negative judgements towards images of people with an unusual appearance in comparison with images of the same people after appearance-altering surgery (Jamrozik et al., 2019). Attractiveness stereotypes have been found to be as strong as gender and race biases (Rennels & Langlois, 2014) and resistant to non-conforming information (Ramsey & Langlois, 2002). Thus, humans use information about appearance to inform judgements about the status and value of self and others (Frith, 2012). In line with this, parents of children living with a visible difference may anticipate problems with adjustment, wellbeing, and social success for their children.

Cash (2004) posited that the concept of ‘body image’ cannot be viewed just as a person’s view of themselves but must also incorporate ‘the view from the outside’. Thus, from an individual perspective, internal appearance-related schema appears to consist of an interplay between how a person appraises their own appearance and how important appearance is to them, alongside thoughts, feelings, physiological responses and behaviour (Cash, 2004; Cash et al., 2004). Thompson and Kent (2001) suggested that difficulties with adjustment for visibly different persons are likely the result of an interplay between these individual schema, alongside sociocultural norms and social experiences.

From a social perspective, the aspiration to be seen as ‘attractive’ could be an evolutionary instinct to enhance social capital (Gilbert, 2001). Baumeister and Leary (1995) posited that social anxiety could result from the anticipation of exclusionary or rejecting social encounters. Since visible differences can be devalued and stigmatised, people living with them are more likely to face exclusionary experiences (Goffman, 1968). Indeed, some individuals who are visibly different, and their families, experience challenging social encounters such as staring, unwanted questions, comments and hostile behaviour (Changing Faces, 2023; Rumsey & Harcourt, 2004). Furthermore, children with an unusual appearance, such as misaligned teeth or CL/P, may be more likely to be subject to teasing or bullying (Hunt et al., 2007; Seehra et al., 2011). Such experiences could heighten anxieties in parents and their children.

Evidence indicates that difficult social experiences likely affect the whole family. Parents of children who have been bullied can experience distress, guilt and anger (Benatov, 2019). Stigma has been found to be felt within families where a child has a skin condition (Ablett & Thompson, 2016) and families of burn-injured children can experience feelings of social isolation (Heath et al., 2018).

Although considerable emphasis is placed on physical appearance across cultures and social groups, the sociocultural perceptions of appearance may differ, for example practices such as lip or ear stretching differs across cultural groups (Fallon, 1990; Puhl & Peterson, 2012; Thompson & Kent, 2001). Furthermore, evidence indicates that an unusual appearance may be particularly stigmatised within certain cultures (Chung et al., 2019).

Sociocultural narratives which devalue visibly different appearance may both represent common individually held stereotypes and play a part in the maintenance of social stigmatisation (Puhl & Peterson, 2012). Examples in Western stories include Cinderella, the ‘beautiful’ protagonist who is envied by the ‘ugly’ stepsisters, and The Lion King, where the antagonist ‘Scar’, who has facial scarring, is portrayed as ‘evil’ (Rumsey & Harcourt, 2005; Workman et al., 2021). Understandably, these societal, interpersonal and intrapersonal pressures can result in feelings of distress for people who do not fit within society’s perception of attractiveness (Smolak, 2012).

Parent wellbeing is important in itself and it also has implications for child wellbeing. Smith (2010) posits that parental distress can have negative implications for parenting practices. Such an effect was noted in Pope et al. (2005) where heightened parental stress was associated with child adjustment problems for children with CFAs. Evidence indicates that parents may shape their child’s internal models of appearance through direct influence and modelling (Abraczinskas et al., 2012; Kearney-Cooke, 2002; van den Berg et al., 2002). Therefore, facilitating parental adjustment to their child’s visible difference, and improving parental wellbeing, can promote a supportive family environment and enhance child wellbeing (Bellew, 2012).

Evidence pertaining to appropriate interventions for adults and children living with visible differences and their parents remains in the early stages, with further research required and particular challenges existing around the lack of specific sensitive outcome measures (Costa et al., 2021; Jenkinson et al., 2015; Norman & Moss, 2015; Zelihić et al., 2022). Thus, a growing evidence base has highlighted the complex experiences, challenges, stressors and needs of parents or caregivers of children with visible differences. Furthermore, whilst commonalities of experiences across conditions have been found, individual differences have been noted, and factors pertaining to specific conditions such as associated medical or behavioural concerns merit further investigation (Feragen & Stock, 2017; Rumsey, 2002). There is now enough qualitative literature to bring this together.

Systematic literature reviews draw together, critique, and synthesise collections of studies (Siddaway, Wood, & Hedges, 2019). For qualitative research, this enables researchers to maintain rich contextual detail whilst also providing an overall picture of the research area, with potential to consider similarities and differences (Borgnakke & Hilliyard, 2019; Siddaway et al., 2019). Recent literature reviews have considered parents' experiences of raising children with health conditions which may impact their appearance, highlighting that parents experience difficult emotions, social challenges, and heightened levels of felt responsibility (Ablett & Thompson, 2016; Smith et al., 2015; von der Lippe et al., 2022). However, such reviews have focused specifically on parents' experiences of child skin conditions (Ablett & Thompson, 2016), long-term health conditions (Smith et al., 2015), or rare congenital conditions (von der Lippe et al., 2022). As such, these reviews do not bring a cross-condition perspective specifically relating to experiences of parenting a child with a visible difference, factors influencing adjustment, and associated implications for parenting practices. Thus, the current review aims to address this gap in the literature through the completion of a synthesis of qualitative research pertaining to experiences of parenting a child with a visible difference.

Aims

The aims of this review are to further understand the factors which influence parental adjustment and related parenting practices. This review will also provide information regarding potential interventions for familial wellbeing and what support could be of benefit relative to parenting practices. Finally, insight will be provided on potential intervention on a wider level, such as provision of training for health-care professionals and wider actions to enhance societal acceptance of those with a visibly different appearance.

Method

Protocol and Registration

This systematic review was registered on PROSPERO, the international prospective register of systematic reviews (Ref: CRD42022338928).

A meta-synthesis employing the approach by Thomas and Harden (2008) was conducted. Thematic synthesis was chosen for its clear processes for cross translation of concepts, and production of descriptive and analytic themes (Thomas & Harden, 2008).

Search Strategy

A comprehensive, pre-planned systematic search of the literature was conducted across five databases (APA PsycINFO, Embase, MEDLINE, Scopus, and Web of Science) on 20th December 2022.

The search combined parent terms (Parent* or Carer* of Caregiver or Mother* or Father* or Maternal* or Paternal* or Family or Families), specific visible difference terms (“Visible difference*” or “Visibly different” or Disfigure* or “Appearance concern*” or “Appearance altering condition” or “Appearance altering injury” or “Altered appearance”) or terms associated with specific conditions or injuries (full list of terms available in Appendix B), with methodology terms (Qualitative or Interview or “Focus group*” or “Thematic analysis” or “Discourse analysis” or ““Interpretative phenomenological analysis” or IPA or “Grounded theory” or “Mixed methods” or “Content Analysis”).

No time limit was applied to ensure the search of this specialist topic was comprehensive. A specialist research librarian was consulted in the design and testing of this search; after several iterations, all authors agreed the final search strategy. Terms pertaining to the concept of visible differences and conditions which may impact appearance were identified from the existing literature. Following initial searches, citation and ancestry searches were completed via Google Scholar, which identified four additional articles. To ensure all relevant studies were found, citation and ancestry searches were conducted on related papers identified in the search which did not meet criteria for inclusion, via Google Scholar, resulting in identification of two additional papers.

Eligibility Criteria

Studies were included if the following criteria were fulfilled: a) peer-reviewed journal articles reporting on an empirical study; b) qualitative methodology; c) mixed-methodology that includes qualitative data; d) published in English; e) participants were parents or carers of a child or young person living with a visible difference; f) investigates parent or carer experiences of having a child or young person living with a visible difference. Where parent accounts were combined with accounts of children or professionals, these were included if the data were separable, and the parents’ experiences were elicited and given sufficient consideration.

Studies were excluded if: a) parents or carers participated less than six months following a child or young person’s physical injury; b) quantitative methodology; c) a non-recognised qualitative methodology was used; d) study did not report parental or carer experiences of having a child or young person living with a visible difference; e) parents were consulted primarily to elucidate children's experiences; and f) studies reported a different phenomenon of interest such as a focus on experiences of healthcare.

Study Selection

Studies identified through database searching were transferred into Endnote (The EndNote Team, 2013) and duplicates were removed. Initially titles and abstracts (where necessary) were screened for eligibility. Thorough full text reviews were next completed on potential papers based on the above inclusion and exclusion criteria. The reference lists and citations of studies selected for inclusion were searched in Google Scholar alongside wider citation and ancestry searching of relevant reports to identify any additional studies not found through the original search. Twenty percent of the studies identified, including all papers selected for full text review, were reviewed by a secondary researcher. Where there was uncertainty or discrepancies regarding the decision to include or exclude, these papers were discussed between the two reviewers and the research team until agreement was reached. See Figure 1 for the flowchart illustrating study selection in line with PRISMA guidelines (Page et al., 2021). Relevant study characteristics including study aims, participant characteristics, recruitment strategy, qualitative methodology and overall research findings were extracted to facilitate cross comparison.

Quality Appraisal

Study quality was appraised using the Critical Appraisal Skills Programme (CASP) Qualitative Checklist which has been widely used (Dalton et al., 2017). The ten-item CASP tool for qualitative studies was chosen as it supports researchers to assess the quality of studies considering their validity, credibility and overall merit (Critical Appraisal Skills Programme, 2018). A rating of "Yes", "Can't tell" or "No" is given to state whether studies meet each criterion. "Can't tell" indicates either that a criterion is partially met, or that the provided information is insufficient to make a decision (Long et al., 2020). Scores were allocated to each response (Yes=2, Can’t tell=1 and No=0) to provide further comparable information regarding the overall quality of studies. No studies were excluded based on quality appraisals.

A selection of three articles (25%) were independently appraised by a second reviewer using the CASP tool to enhance reliability (Garside, 2014). Inter-rater reliability was assessed utilising Cohen’s kappa, with an overall kappa score of 0.96 indicating very good reliability (Altman, 1999). Consensus across reviewers was high for the initial studies, a minor discrepancy resolved through discussion, thus double rating of all included papers was not deemed necessary.

Data Synthesis

The three-step process of Thematic Synthesis outlined by Thomas and Harden (2008) was followed. Initially, the entirety of sections titled ‘findings’, ‘results’ and ‘discussion’ were extracted line by line and coded by the researcher in NVivo 1.7.1 Software (QSR International, 2022). One or more codes were applied to each sentence. As coding progressed, data were either coded into appropriate existing codes, or new codes were created where needed. On completion of coding, codes were reviewed and merged where replication was noted, resulting in 314 unique codes (see Appendix C for examples). Through a process of identification of similarities and differences between codes, groups and hierarchical structures were formed (Thomas & Harden, 2008). Four initial key descriptive themes and nine subthemes arose. These initial descriptive themes were discussed with the research team and refined. Through an ongoing process of engaging with the data several potential analytic themes were considered and the concepts brought to the research team to reflectively review. Through this process of review, reflection, and refinement two analytic themes and eight subthemes were created from the descriptive themes.

Results

Systematic searching yielded 1262 records. Following the removal of 481 duplicates, titles and abstracts were screened for the 781 remaining records. Thirty-eight papers were identified for full text review against inclusion and exclusion criteria, resulting in 14 studies initially being selected for inclusion in the review. Citation and ancestry searches via Google Scholar were completed on these records, and other highly relevant papers identified in the search, resulting in six further studies initially identified for inclusion. However, due to cross-cultural variation and the scope of this review, the focus will be on the eight UK based eligible studies identified.

Study Characteristics

Eight peer-reviewed journal articles met the inclusion criteria for this meta-synthesis. The studies were published between 2012 and 2021. Three studies included other perspectives (children and professionals). Only parent perspectives were extracted and analysed for this review. Studies recruited participants from the UK (n=8).

The studies comprised parents of children with a range of appearance-altering conditions and injuries such as neurofibromatosis type 1 (NF1), CL/P, CFAs, vitiligo, limb differences, and cancer. Child ages ranged from four and ½ months to 24 years.

Participants were recruited via health facilities (n=4), social media and communications of charitable organisations (n=6). Data was collected through interviews and focus groups. Analysis methodology varied with such named methodologies as Thematic Analysis, Interpretative Phenomenological Analysis and Grounded Theory.

Figure 1

PRISMA Flowchart Showing Study Selection Process for Qualitative Synthesis of Parenting a Child With a Visible Difference (Page et al., 2021)

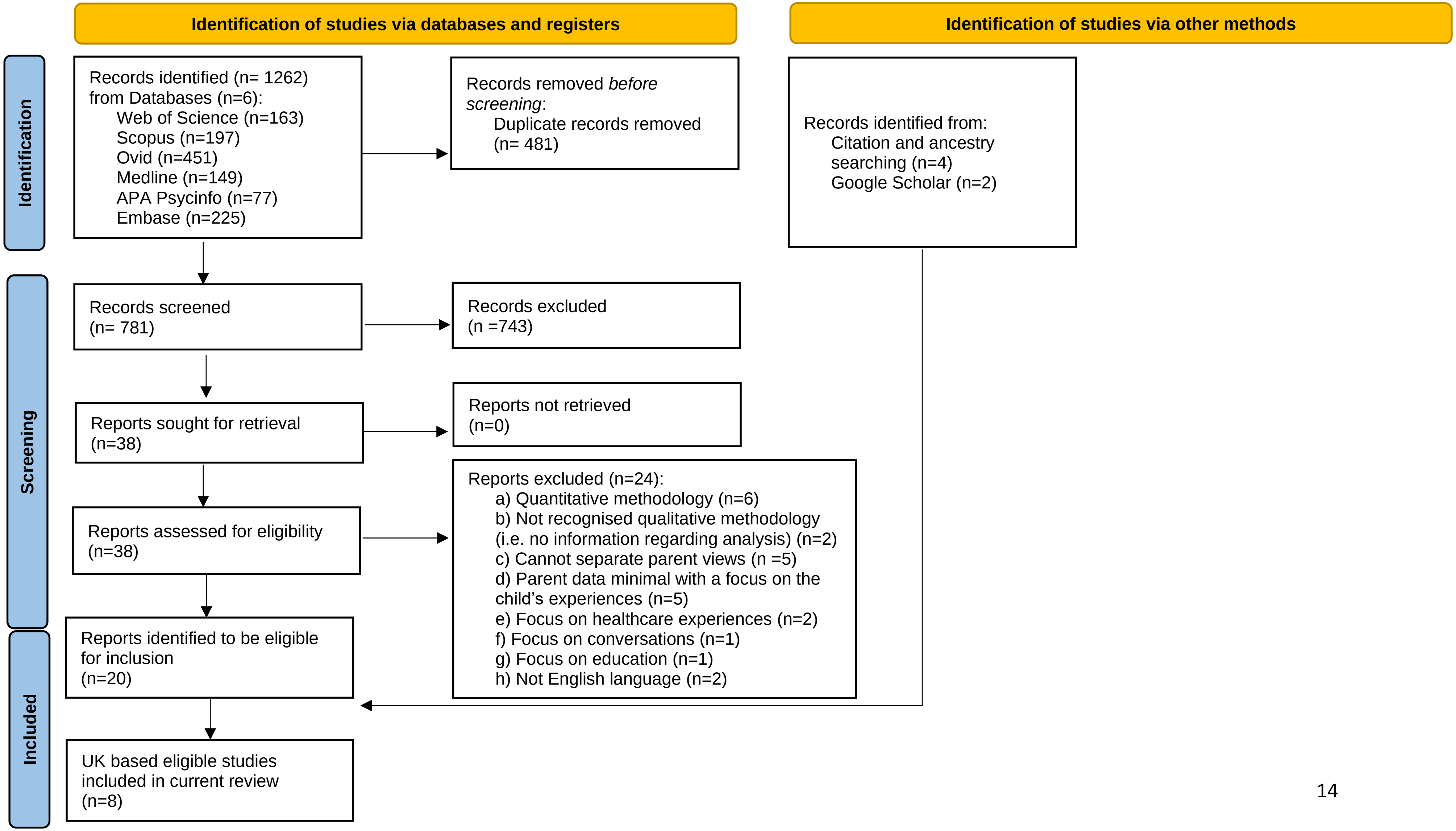

Table 1

Study Characteristics

Author(s) (year)	Title	Country	Aim	Participant Characteristics	Recruitment	Data Collection and Analysis Methodology	Key Findings, Themes (as reported by original authors)
Barke, Coad & Harcourt (2016)	Parents' experiences of caring for a young person with neurofibromatosis type 1 (NF1): a qualitative study.	UK	To explore parents' experiences of caring for a child or young person with Neurofibromatosis type 1 (NF1) and their support needs.	15 Parents (two fathers, five mothers) of children or young people with NF1, aged 14-24 years.	Recruited via ad advert in a Neuro Foundation newsletter, via online forums and social media.	Interviews (mostly face to face, one via telephone). Exploratory in-depth approach. Thematic analysis	Three overarching themes: 1) 'Managing the uncertainty of NF1', 2) 'The impact of altered, appearance', 3) Others' awareness and understanding of NF1.
Moss, Johnston, & Thompson, (2020)	The parent and child experience of childhood vitiligo: An interpretative phenomenological analysis.	UK	To investigate the experiences of parents and children where the child has vitiligo with specific focus on naturalistic adaptation.	4 parent child dyads (3 mothers, 1 father), children aged 7-12 (1 boy, 3 girls) with vitiligo.	Recruited via paediatric dermatology NHS clinic via letter, via Vitiligo Society, social media, and magazine advertisement.	Individual semi-structured interviews (separate parent and child interviews) conducted in person. Interpretative phenomenological analysis methodology.	Four overarching themes: 1) Continuing burden, 2) The significance of the visible difference, 3) Uncertainty, unpredictability, and coping.

Netherton, Horton, Stock, Shaw, Noons, & Evans (2021)	Psychological adjustment in apert syndrome: Parent and young person perspectives	UK	To explore psychological adjustment to Apert syndrome from the viewpoint of both young people and their parents.	4 mother child dyads, young people aged 11-17 years with Apert syndrome.	Recruited via craniofacial units. Initial contact was made by their Clinical Nurse Specialist.	In-person individual interviews. Interpretative phenomenological analysis methodology.	Three overarching themes: 1) Cyclical journeys of acceptance and adjustment, 2) Treatment as a barrier to adjustment, 3) Social support as a facilitator to adjustment.
Nelson, Kirk, Caress & Glenny (2012)	Parents' Emotional and Social Experiences of Caring for a Child Through Cleft Treatment.	UK	To produce an in-depth exploration of the emotional and social experiences of parents caring for children of various ages from birth to young adulthood with CL/P.	35 parents (8 couples and an additional 3 fathers and 16 mothers) to 27 children aged 20 weeks to 21 years with CL/P.	Parents recruited via a specialist cleft centre in England.	In-person semi-structured interviews with couples or individuals. Grounded theory methodology to data generation and analysis.	One overarching theme: 1) Managing emotions. Three subthemes: 1) Conflicting emotions, 2) Uncertainty, 3) Stigmatizing reactions.
Oliver, Dixon, & Murray (2020)	Being the parent of a child with limb difference who has been provided with an artificial limb: an interpretative phenomenological analysis.	UK	To learn about the experiences of parents of a child with limb difference who have received provision of an artificial limb and their understanding of those experiences.	7 parents, all mothers of children aged 5 years – 14 years with limb difference who had a prosthesis available to them for at	Parents were recruited via the social media of limb difference charities.	Semi-structured interviews (6 via telephone, 1 in person). Interpretative phenomenological analysis methodology.	Four overarching themes: 1) Managing initial emotional experiences through development of coping resources, 2) Opportunities via prosthesis use and relationship with 'normality',

				least six months.			3) Managing and interpreting social reactions towards their child, 4) The intrinsic role of support.
Stock & Rumsey (2015)	Parenting a child with a cleft: The father’s perspective.	UK	To explore fathers’ experiences of having a child born with a CL/P.	15 fathers (aged 31 to 58 years) of children aged 4 ½ months to 24 years with CL/P.	Participants were recruited through a press release and advertisements in multiple locations including charity websites.	Semi-structured interviews completed via telephone. Thematic analysis methodology.	Four overarching themes: 1) Variations in the care and support received, 2) Appraisals of the CL/P 3) Perceptions of the child’s treatment 4) Reflecting on personal changes and preparing for the future.
Thornton, Harcourt, Deave, Kiff & Williamson (2021)	“Have We Done Enough?” A Cross-condition Exploration of the Experiences of Parents Caring for A Child with an Appearance-affecting Condition or Injury	UK	1) To explore the experiences and needs of parents of children living with visible differences across conditions, 2) To recognise both risk and protective factors for these parents’ psychosocial adjustment.	45 parents (33 mothers, 12 fathers) of 40 children (25 female, 15 male) with various conditions (acquired, congenital, skin conditions and limb differences).	Interview participants were recruited via social media and websites of charities and the Centre for Appearance Research (CAR). Email invitations were sent to individuals on	Semi-structured interviews completed (n=20) completed via telephone and in-person focus groups (n=25). Critical realist and template analysis methodology.	Three overarching themes: 1) Perceived importance of appearance, 2) Need for vigilance, 3) Parenting approaches.

				11 health care professionals.	the CAR study registry. Focus group participants were recruited via the Caring Matters Now (CMN) charity conference.		
Williamson, Harcourt, Halliwell, Frith & Wallace (2010)	Adolescents' and parents' experiences of managing the psychosocial impact of appearance change during cancer treatment.	UK	To gain an insight into the experiences of adolescents altered appearance during cancer treatment for adolescent, parent dyads.	Six parents (four mothers, two fathers) alongside their four adolescent children who were receiving cancer treatment were interviewed (18 further adolescents completed an online survey).	Interview participants were recruited via a regional paediatric cancer centre. An online survey recruited further adolescents; this was posted on web pages aimed at young people with cancer.	Semi-structured interviews with parents (n=6) and their adolescent children (n=4). Online survey with (n=18) adolescents. Template analysis methodology.	Six overarching themes identified in combined parent and adolescent data: 1) Perception of changes to appearance, 2) Psychosocial impact of being visibly different, 3) Managing appearance changes, 4) Managing social responses, 5) Support of peers and family, 6) Need for support around appearance change.

Quality Appraisal Findings

Appraisals were completed using the CASP tool. All eight studies were assessed to be high quality as they were given a total CASP score of 17 or more. Only two out of eight studies were considered to meet criteria for consideration of relationship and reflexivity. Research design and qualitative methodology was assessed to be appropriate for all studies and all studies were noted to report both their aims and findings clearly, making them suitable for synthesis. See Appendix D for further details.

Table 2

CASP Quality Appraisals of Included Studies

	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship and reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research	Total score
Barke, Coad & Harcourt (2016)	✓	✓	✓	✓	?	×	✓	✓	✓	✓	17
Moss, Johnston, & Thompson (2020)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	20
Nelson et al. (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	19
Netherton et al. (2021)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	19
Oliver, Dixon, & Murray (2020)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	18
Stock & Rumsey (2015)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	18
Thornton et al. (2021)	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	18

Williamson et al. (2010)	✓	✓	?	?	?	×	?	✓	✓	✓	14
Total	8	8	7	7	6	2	6	8	8	8	

Key: ✓= Yes, ?= Can’t tell, ×=No

Meta-Synthesis Findings

Two interrelated overarching themes were identified: 1) The dynamic process of adjustment, and 2) Parenting a child with a visible difference. Table 3 shows the presence of themes across studies.

Themes present a summary of prevalent concepts which arose across the data. Although these themes do not provide an exhaustive account of parents' experiences, attention has been given to noting instances of divergence within themes and disconfirming findings. Wider consideration was given to the impact of treatment or injury-related experiences relative to adjustment to visible difference. However, such concepts are not described in detail here due to the specific scope of this review.

Table 3

Meta-Synthesis Themes

	The Dynamic Process of Adjustment					Parenting a Child With a Visible Difference		
Article	Discovery of their child’s visible difference	Internal processes	Navigating the social world with their child	Interruptions to, or enablers of adjustment	Acceptance	The perceived power of knowledge	Enhancing child adjustment	Helping children navigate their social world
Total	7	7	8	8	7	7	7	7
Barke, Coad & Harcourt (2016)	✓	✓	✓	✓	✓	✓	✓	×
Moss, Johnston, & Thompson (2020)	×	✓	✓	✓	✓	✓	✓	✓
Nelson et al. (2012)	✓	✓	✓	✓	✓	✓	✓	✓
Netherton et al. (2021)	✓	×	✓	✓	✓	✓	✓	✓
Oliver, Dixon, & Murray (2020)	✓	✓	✓	✓	×	✓	×	✓
Stock and Rumsey (2015)	✓	✓	✓	✓	✓	✓	✓	✓

Thornton et al. (2021)	✓	✓	✓	✓	✓	✓	✓	✓
Williamson et al. (2010)	✓	✓	✓	✓	✓	✓	✓	✓

The Dynamic Process of Adjustment. On learning of the impact of a condition or injury on their child's appearance, parents began an adjustment journey. Adjustment seemed to be influenced by interrelated internal factors and experiences of social connection, or disconnection. Generally, the visible difference became less focal for parents over time, however, social encounters, anticipated future challenges, medical decision making, and further appearance changes could interrupt adjustment processes. Interlinked with these factors, parents differed in their levels of acceptance of their child's different appearance.

Discovery of Their Child's Visible Difference. Most parents' journey began at the moment they learnt of their child's visible difference. Common emotional responses of shock, distress, loss and disappointment were described; *"I was almost in tears, I couldn't look at him for the first couple of days"* (Williamson et al., 2010, p. 170). Some parents reported a calm reaction to their child's appearance, which they attributed to prior knowledge or familiarity with visible differences. Depending upon the aetiology, parents learnt of their child's altered appearance prenatally, at birth, later in childhood, or following illness or injury. Furthermore, some parents were cognisant of the potential visible difference where conditions were known to be genetic in origin. For some parents, feelings of guilt or self-blame arose alongside a sense of perceived responsibility; *"I think it's safe to say my world fell apart when I was told he'd got a cleft...I had to deal with the fact that I'd done it to him, that I'm the reason he's got it"* (Stock & Rumsey, 2015, p. 35).

Internal Processes. Many parents experienced a complex array of sometimes conflicting thoughts and feelings relating to their child's appearance, including, for some, secondary responses of guilt or shame associated with their initial reactions. The importance placed upon appearance differed between parents and for many, appearance was perceived to be of greater importance for girls. This investment in appearance seemed to play an important role in adjustment.

Many parents described the noticeability of their child’s visible difference and spoke about whether the difference could be hidden, camouflaged, or altered through treatment, and indeed, whether it *should* be hidden or altered. In line with this, parents seemed to grapple with ideas about how they *ought* to feel about their child’s appearance; it seemed that some felt appearance *shouldn’t* matter and experienced discontent if, for them, it did. Contrastingly, there was a sense for some that appearance does or doesn’t matter without a sense of conflict. *“I can’t lie to her and say she looks attractive without a wig because she doesn’t, I think it is particularly unattractive because it’s patchy”* (Thornton et al., 2021, p. 423). As part of this process parents made social comparisons and there appeared to be a link between the perceived favourability of these comparisons and increased coping or distress.

> *“I’ve thought ‘well, it’s only your skin colouration’ you know. All his arms and legs work, he’s reasonably intelligent, he can talk and all the rest of it . . . it’s not really that much of a problem anyway you know. It’s just the way that you look, it’s not as if you can’t function.”* (Moss et al., 2020, p. 748)

Navigating The Social World With Their Child. Social factors represented a burden for parents and children. For parents, the presence of social messages that categorised their child as ‘different’ or ‘abnormal’ could be experienced as devaluing or othering, which could cause distress. Furthermore, it appeared that, for some parents, such labels were felt to extend beyond their child to themselves.

Initial encounters with health professionals could be meaningful and influential to parents’ internal experiences. These interactions could be comforting and encouraging, neutral, or at times distressing. Calm, responsive and informed encounters were reported to be more beneficial for parent adjustment. However, many parents inferred implicit or explicit judgements from healthcare professionals around the importance of appearance and its implications for the child and family. For example, professionals raising discussion around the potential for termination of a pregnancy upon the discovery of the visible difference in utero represented explicit devaluation (Stock & Rumsey, 2015).

Familial responses were also important and impactful, and a source of anxiety for some parents; *"There was the whole, how will people interact with him, will he be rejected by family? You worry about it"* (Nelson et al., 2012, p. 353). Familial responses varied within studies and included acceptance, silence, rejection, othering and blame of parent(s), with splitting occurring in some families. For many parents, family and friends were a considerable source of support which fostered or maintained a sense of social inclusion, whether this response was immediate, or after an initial difficult reaction. Furthermore, many parents found being with others with similar conditions beneficial, reducing feelings of 'difference'.

Challenging interactions with members of the public or the wider community were reported across all studies. Social reactions ranged from the absence of positive interactions, to staring and people asking questions, to confrontational, insulting, or dehumanising responses. Participants reported emotional reactions to these interactions, such as feeling invisible, sad, angry, disappointed or, in some cases, tolerant. Parents contended with these experiences directly and indirectly via their child, both of which could cause distress. In anticipation of, or response to, aversive social situations, some parents protectively isolated themselves and their child.

> *"There are just loads of kids like [my child] and parents like us, you know, sometimes you don't even talk about limb differences, you can just sort of sit and know that your child isn't going to be stared at, they are going to be accepted and that everyone is really positive"* (Oliver et al., 2020, p. 1983).

> *"You'd walk past people and they used to look and say, "Oh, can I have a look at your baby?" What used to upset me was hearing them talking behind your back as you're going away. I used to get really annoyed and dead upset, and I used to bottle it in a lot; I wouldn't say naught to nobody, I'd just walk away, and it was all within my mind"* (Nelson et al., 2012, p. 352).

Interruptions to, or Enablers of, Adjustment. The process of adjustment could be influenced by several factors such as surgeries, impending further treatment, ongoing appearance changes, anticipated or actual transitions, social encounters and/or reminders of the difference.

Many parents made decisions about appearance-altering treatment on behalf of their child. For some, this decision-making brought up conflicting emotions as to whether pursuing surgery gave the message to children that they were not acceptable as they were. For parents whose children underwent treatment, diverse responses arose. Some mourned the loss of the child they had known, while for others the change was met with joy and relief, representing a resolution to their distress. More mixed and conflicting feelings were highlighted in some instances.

> *"[My child's] "before" face and his "after" face (...), the difference is huge, and I think that's one of the big things (...), we did a lot of work with the psychologist at the time, working up to it, but you don't know until it actually happens (...). You've lived with that face (...), that was his face for 13 years, and then all of a sudden you've got a different child, and it's quite hard to get your head around. Even now I look at pictures and I miss that face"* (Netherton et al., 2021, p. 467).

Several parents spoke about remaining alert for further appearance changes in progressive conditions (e.g. Barke et al., 2016). Where a child's appearance was more stable, some parents reported that certain experiences, such as seeing their child with fresh eyes, or seeing their child through the eyes of others, could act as a reminder of the visible difference and could be painful.

Over time, actual or anticipated child transitions such as attending a new school, entering adolescence, starting further education, or considering romantic relationships, represented challenging times where initial difficult emotions could resurface. Parents appeared to be vigilant for such potential future threats to their child's wellbeing; *"she's now getting quite into her appearance and so if it goes on to her face – which it hasn't so far, then she will be really devastated"* (Moss et al., 2020, p. 746).

Acceptance. Levels of parental acceptance of a child's visible difference varied, with some appearing resigned or non-accepting. Greater parental acceptance appeared to be associated with positive adjustment, whilst resignation or non-acceptance seemed to be associated with feelings of discontent or seeking external resolutions. Many parents described a process of assimilation of the difference from being a defining feature, to becoming one part of their wider conceptualisation of their child. Parents became used to their child's appearance and some no longer saw the difference, whilst others fell in love with their child's particular appearance.

The meaning parents ascribed to their child's visible difference appeared to influence their acceptance. Where the condition or injury had implications for wider child health, this appeared of particular importance. For example, many parents of children with cancer perceived the appearance change as a symbol of illness, evoking fear; *"wellness and health was gone, it's such a potent, frightening symbol"* (Williamson et al., 2010, p. 170).

Parents spoke with pride about their children, referencing traits such as kindness, resilience, confidence, and determination. Furthermore, some parents discussed individual or familial growth or changes to their outlook resulting from their child's visible difference, such as having greater empathy and acceptance regarding diversity.

> *"It's certainly made my husband and I more, maybe accepting and trying to be more understanding of differences and I think it helps us to teach both of our kids to look beyond outer experiences and accept that people have differences and differences are good"* (Thornton et al., 2021, p. 422).

Parenting a Child With a Visible Difference. Parents appeared concerned that navigating the world could be more difficult for their child due to their different appearance. Parents expressed feeling concerned about, and responsible for, their child's wellbeing, which felt intertwined with their own. Many parents empowered themselves by seeking out and sharing information. Furthermore, they engaged in practices they hoped would enhance their child's adjustment through highlighting their strengths, normalising difference in conversation, or not focusing on the difference. Parents helped their child to navigate the social world by protecting them, encouraging social engagement, and influencing wider systems. It was evident that many parents felt that having a social network was important for their child.

The Perceived Power of Knowledge. The importance and potential influential nature of knowledge was evident from individuals to wider systems. Parents commonly reported feeling they lacked knowledge about the nature of their child's visible difference and expressed uncertainty about how to enhance their child's adjustment. As a result, many parents sought empowerment through the acquisition of knowledge.

Parents sought information from various sources including healthcare professionals, other people, social media, or the internet. For those who received information from professionals, experiences were mixed. Several parents found minimisation of their concerns by professionals unsupportive. For some parents, information helped to manage worries, particularly where uncertainty was reduced, however some found information which represented extreme presentations distressing; *"you look at the information and sometimes it focuses on the extreme so you get a little scared by it"* (Barke et al., 2016, p. 36).

Several parents took responsibility for educating others through talks at schools or their daily interactions. Some parents expressed the hope that through this information sharing, they might increase understanding and acceptance in others to create a more compassionate environment for themselves and their child.

> *"My husband went into the school to give a talk to the teachers about what to expect. They were absolutely fab and they did an assembly for the kids, so everyone's been really accepting of it (...), and he has a good group of friends now" (Netherton et al., 2021, p. 467).*

Enhancing Child Adjustment. Parents expressed concerns about their child's adjustment to their visible difference and were emotionally invested in their wellbeing. Accordingly, parents engaged in strategies to bolster their child's emotional wellbeing, self-acceptance, self-esteem, appearance satisfaction and confidence.

Some parents made efforts to normalise or appreciate difference in others, through strategies such as highlighting celebrities or public figures with a visible difference. Conversely, some parents aimed to avoid focusing on the difference to increase feelings of normality for their child.

> *"I really tried to make him aware of the fact that he has got a little arm, differences are good, everybody's different, daddy is a diabetic and injects himself, mummy's got blonde hair, and you can see differences in everybody"* (Thornton et al., 2021, p. 423).

Many parents were noted to complement their child and particularly emphasise their appearance and non-appearance related attributes; *"you look beautiful, like Sigourney Weaver* *in Alien"* (Williamson et al., 2010, p. 172).

Some parents wondered how and when to talk to their child about their appearance, what was too much or too little. Some parents felt that appearance talk exacerbated their child's concerns or created a problem, while other parents felt this could be helpful or was unavoidable. For many there appeared to be a sense of uncertainty about what was best.

Several parents felt that appearance-altering treatment would be the best way to enhance their child's self-acceptance. Conversely, for many parents, there was a sense that their child's different appearance would not hold them back in life and they endeavoured to transmit this perspective to their child.

Helping Children Navigate Their Social World. Parents considered positive social contact and support to be important for their child's wellbeing, as it was for their own. Due to the prevalence of difficult social encounters, many parents felt that they needed to equip their child to navigate such experiences. It was commonly reported that parents modelled or coached their child around responding in social situations, with an array of different responses encouraged. Parents' own emotional reactions to difficult social encounters, and the nature and frequency of such encounters, likely influenced the responses modelled and encouraged.

> "*I do talk to her a bit; we do a bit of role play. So I'll say I'll pretend to be X in the class, particularly someone in the class who I might think is likely to say 'oh, what's that?' And she'll say, 'oh, they're my white patches'"* (Moss et al., 2020, p. 748).

Many parents reported feeling a strong desire to protect their child. As a result, some made efforts to hide, cover, or camouflage their child's visible difference as a way of avoiding social stigma. Furthermore, several parents spoke of the urge they felt to speak for their child during difficult social encounters. Some parents noted making a particular effort to ensure their child was included with others and encouraged an active social life. In some instances, it appeared that parents' acceptance and confidence that their child would have good social relationships facilitated this. For many, the balance between facilitating autonomy and protecting their child felt delicate.

> *"I find as well sometimes you can step in too quickly, at the swimming pool you have kids coming up to her saying, 'what are the spots on your skin?' And I'd be stepping in and saying something and actually it's better to let her say something so I had to learn to step away"* (Thornton et al., 2021, p. 423).

As noted previously, several parents also attempted to positively influence their child's environments, others chose a stance of non-interference. Finally, many parents felt it was beneficial to help their child connect with similar others to provide them with a safe and inclusive social space.

Discussion

This review aimed to identify and synthesise the qualitative literature considering the lived experiences of parents of children with a visible difference. Drawing these studies together has provided a content rich narrative and comparisons have been drawn across conditions, thus increasing the generalisability of the original research findings (Nye et al., 2016).

Data from 20 studies were extracted and underwent thematic synthesis (Thomas & Harden, 2008), this paper focuses on the findings from the eight UK studies. A critical appraisal of included studies was carried out using the CASP assessment tool (2018) indicating all to be of moderate to high quality. The visible differences studied were of various aetiologies, including, but not limited to, birthmarks, CFAs, CL/Ps, limb differences, scars, and tumours. Overall, considerable commonality was noted across conditions, yet important differences within themes were also identified. Two interrelated overarching themes and eight subthemes were created.

Upon discovery of their child’s visible difference many parents experienced strong emotional reactions which most overcame over time. This process appeared influenced by parents’ internal experiences, sociocultural environment, and support. Further factors could interrupt adjustment processes including transitional times for children, further appearance changes and treatment processes. Parental adjustment and levels of acceptance regarding their child’s visible difference seemed to influence parenting practices.

Parents felt responsible for their child’s wellbeing, which seemed to be interlinked with their own. Many sought to empower themselves, their child, and sometimes others through acquisition and sharing of knowledge about the child’s condition or injury. Parents also engaged in various practices intended to boost their child’s confidence, self-esteem, and appearance satisfaction. Finally, parents supported children to navigate their social world, balancing opposing desires to protect their child in the short term and enable increased autonomy. Many facilitated positive social contact for their child and coached them on responding to difficult social experiences.

These findings build upon existing literature, indicating that parental adjustment to a child’s visible difference results from interrelated internal, social and cultural factors (Thompson & Kent, 2001). An important finding within this review, with cross-theme relevance, was the interconnected nature of parent and child wellbeing, replicating a finding from the literature pertaining to skin conditions (Ablett & Thompson, 2016).

Existing literature has highlighted that due to the presence of associated medical needs and potential for appearance-altering treatments, parents of children with visible differences likely experience similar stressors as parents of children with health conditions (Costa et al., 2021). Thus, it is unsurprising that several of the themes highlighted in this review overlap with the health literature (e.g. Smith et al., 2015; von der Lippe et al., 2022). Areas of overlap include initial distress followed by a journey towards adjustment and acceptance; a smaller proportion remaining distressed and engaging in increased efforts at resolution; the presence of self-blame or guilt; and extensive information seeking. As such, we can understand that parents manage stressors associated with the health needs of their children (where present), alongside additional stressors associated with their child's visible difference (Costa et al., 2021).

In the current review parents contended with feeling that their child was 'set-apart' or 'different', and this feeling appeared to also link to themselves, a theme which has arisen in literature pertaining to parents of children with rare neurodevelopmental conditions (Currie & Szabo, 2020). Thus, some parents experienced a shift in their own identity to which they needed to adjust. This finding appears interlinked with felt social isolation, alongside social and internalised stigma.

The social challenges highlighted in the current review overlap with the experiences described by parents of children whose behaviour may be outside of social norms (Currie & Szabo, 2020). Overtly negative or intrusive social experiences, alongside 'silencing' or the absence of positive experiences, has also been identified for parents of children with rare conditions and those adjusting to their own appearance change (Currie & Szabo, 2020; Konradsen et al., 2012). The present findings are consistent with existing literature for caregivers or families of other potentially stigmatised groups, where stigma may be felt throughout the family (Mitter et al., 2019; Zhang et al., 2018). The extent to which parents internalise and self-direct stigma may vary, of which levels of knowledge and cultural beliefs may be important (Mednick et al., 2013). Existing literature with parents of children with neurodiversity and health conditions has indicated that factors such as self-stigma and self-blame can be associated with increased adjustment problems, stress, anxiety and depression (Ali et al., 2012; Smith et al., 2015; Yip & Chan, 2022).

In addition to the challenges outlined above, which link with the health and social stigma literature, parents face the unique challenge of having a child who looks different. The presence of various potentially conflicting internal feelings appears linked to the widespread over-valuation of appearance within individuals and wider society (Rumsey & Harcourt, 2004; Thompson & Kent, 2001). The importance parents placed on appearance or their 'appearance investment' was influential (Cash et al., 2004) and likely influenced by their own wider systems and sociocultural context. Indeed, the Tripartite model of appearance satisfaction suggests that parents, peers and media messages all influence body image (Cash, 1994; van den Berg et al., 2002). Thus, patterns in appearance investment and evaluation may be intergenerational, which is consistent with findings from the familial literature on skin conditions (Ablett & Thompson, 2016). Further, it may be linked to peer groups, which means that parents with high appearance investment may exist within social and familial networks with similarly high investment, potentially impacting parental adjustment and acceptance. Such factors are important for parents and their children as they could influence treatment decision making and parenting practices, such as the extent to which parents are protective or emboldening of their children. Parents' communication about, and with, their child regarding appearance, alongside their behaviour and parenting practices, likely influence the child's appearance satisfaction (Abraczinskas et al., 2012).

The themes identified in this review have also been identified in studies including participants from a range of geographical regions and cultures, such as; the continent of Africa (e.g. Likumbo et al., 2021), Nordic countries (e.g. Feragen et al., 2022), Turkey (Saydam et al., 2021, p. e.g.), America (e.g. Tanner et al., 1998) and India (Ravindran et al., 2013). Thompson and Kent (2001) highlight the impact of wider socio-cultural context upon adjustment to living with a visible difference. Indeed, in many of these papers, considerable similarities are noted in reports of parent's experiences. However, qualitative literature pertaining to parents experiences of raising children with albinism in Malawi (Likumbo et al., 2021) and CL/P in Ghana (Bonsu et al., 2018) highlights the presence of myths and beliefs about these visible differences and associated stigma. In a qualitative study of mothers experiences of raising a child with a CL/P in Ghana, parental and familial relationships were often significantly impacted by the child's visible difference, reducing levels of social support (Bonsu et al., 2018). This review deliberately focused on UK studies due to their particular relevance to NHS services, nevertheless, future reviews should look to actively synthesize studies conducted in other countries and might also consider specifically reporting on cultural issues.

In the current review, some parents expressed uncertainty regarding approaching appearance-focused conversations, a finding described in-depth in a specific study on the topic (Zelihic et al., 2021). Open communication between parents and children enables the development of a shared narrative, mutual understanding and familial adjustment (Zelihic et al., 2021). Such conversations may also provide an opportunity for co-regulation. Low levels of confidence around appearance talk have also been reported by healthcare professionals (Gee et al., 2019), thus these parents may be left unsupported in this endeavour.

The current review pointed to some potential differences across conditions given factors such as medical treatments and ongoing appearance changes could interrupt adjustment. While some appearance-affecting conditions are progressive, others are stable, and medical treatments may alter appearance (if available, pursued or necessitated). Nes et al. (2014) found parental distress regarding a child's CL/P to be short-lived, which the authors attribute to the treatability of the condition. Indeed, in the current study, some parents reported using short-term avoidance strategies (e.g. Nelson et al., 2012). Where the visible difference was associated with a child's health status, or potential need for further treatments, this could exacerbate parental distress (e.g. Barke et al., 2016; Williamson et al., 2010). Furthermore, some conditions such as neurofibromatosis type 1 are progressive, variable and unpredictable (Yang et al., 2022), increasing uncertainty, which has the potential to negatively impact upon parent wellbeing (Holm et al., 2008). Additionally, any overlap with child cognition and behaviour may be important. As such, Feragen and Stock (2017) identified that when a CFA was associated with a syndrome and cognitive impairments both child and parent wellbeing were negatively impacted. Considering the multitude of different factors parents navigate, it is important to consider issues of intersectionality for families of children living with visible differences (Turan et al., 2019).

Several parents in the current review reported positive outcomes resulting from their child's different appearance, such as increased empathy, growth and compassion, which mirrors existing findings from parents of children with health conditions, CL/P and rare CFAs (Baker et al., 2009; Feragen et al., 2020; Smith et al., 2015), as well as accounts of people living with a visible difference themselves (Rumsey, 2018). He et al. (2022) postulated that the post-traumatic growth identified in those parenting a child with a CL/P may be enhanced by the presence of social support, which was an identified protective factor in the current review. The benefits of social support have also been highlighted for parents of children with neurodiversity and health conditions (Mitter et al., 2019; Smith et al., 2015; von der Lippe et al., 2022). The current findings indicate internal factors, including the meaning parents ascribe to their child's different appearance, could be protective or problematic.

Clinical Implications

This research calls for holistic assessments to occur as part of routine clinical practice. Such assessments should consider individual factors including appearance investment and parent evaluation of child appearance, the meaning ascribed to the visible difference, parents' self-blame and self-stigma, alongside levels of social or familial support and levels of wider sociocultural stigma.

Such assessments would enable the provision of tailored psychosocial interventions. Familial interventions intended to enhance emotional adjustment, self-compassion and acceptance, and which consider issues of appearance satisfaction, could be beneficial alongside guidance around discussing issues of appearance and managing social situations. In order to deliver such assessments and interventions, professionals may require enhanced training around visible differences.

Reduction of internalised and sociocultural stigma of visible differences is also important. This review indicates that increased knowledge, understanding and familiarity with visible differences is one way of reducing such stigma. Increased representation of people with visible differences in the media and public eye could enhance general levels of empathy and acceptance.

Strengths, Limitations and Recommendations for Future Research

Individual readers make their own interpretations of information (Leung, 2015). The researcher of the current review is a parent of a child of usual appearance and is female, white and educated. However, discussions were facilitated with the research team throughout the synthesis process to enhance reflectiveness.

The studies in the current review afforded a cross-condition perspective, which is a strength. However, certain appearance-altering conditions were represented more than others. Furthermore, this review focused on UK studies, therefore limiting the cross-cultural relevance. Further research ought to investigate the way in which visible differences are represented and adjusted to across cultures.

Limitations of this review arise from the studies included. Most study participants were female. Several quality problems were also noted in studies such as a lack of reflexivity and consideration of the relationship between researcher and participant. Thus, further high-quality research addressing these issues is required.

The CASP appraisal tool (2018), although useful for identifying strengths and weaknesses, is reliant on clear and thorough reporting and can lack sensitivity (Leung, 2015). Furthermore, differences exist regarding what constitutes ‘high quality’ qualitative research and what ought to be most valued (Garside, 2014). Second-rater reviewing enhanced reliability of quality assessment in the current review, however future research may consider different ways to appraise quality.

The search employed in this review was systematic, with detailed and carefully considered terms, however the list of conditions included was not exhaustive. Some authors do argue that it may be of less importance to find all research for qualitative meta-synthesis, as additional studies may not elicit new information (Doyle, 2003; Thomas & Harden, 2008). However, to ensure relevant literature was found, extensive ancestry and citation searching was completed on papers identified for inclusion in the review and relevant wider literature.

Future studies should also aim to develop interventions to support parental adjustment to parenting a child with a visible difference. Compassion, acceptance, or mindfulness-based interventions may benefit exploration. In-depth research considering the factors which enable parents to adjust well compared with those who have more difficulty could glean further important information in this area.

Conclusions

Parenting a child with a visible difference comes with unique challenges. Such challenges may exist in addition to managing potential health or learning needs of their children.

Parental adjustment appears influenced by various internal factors alongside sociocultural influences. Holistic assessments are required to clearly identify need. Interventions may target parents directly or address stigma at system level, with particular focus on the importance of facilitating positive social contact. Finally, a more compassionate social environment could be fostered for these families through improved representation of, and information about, visible differences within the public realm. Further research considering barriers and facilitators to parental adjustment to visible differences across conditions and cultures is required.

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Paper Two

The Effectiveness of an Online Mindful Parenting Intervention for Parents or Carers of Children Living With a Visible Difference: A Single Group Case Series Experimental Study.

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Supervised by Professor Andrew Thompson and Dr Lisa-Marie Emerson

Manuscript prepared in line with the author guidelines for the Journal of Body Image (Appendix A) and following the word count guidance for DClinPsy Thesis submission 2023.

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Key Words

Parent, Caregiver, Child, Visible difference, Appearance altering condition or injury, Adjustment, Parenting Stress, Wellbeing, Mindfulness, Mindful Parenting, Single Case Experimental Design.

Highlights

- A brief (six-week) novel online mindful parenting intervention for parents of children living with a visible difference was investigated using a single case series.
- Reductions in parenting stress and improvements in levels of mindful parenting were observed post-intervention and maintained at follow-up for some participants, although less favourable outcomes were obtained for others.
- Mindful parenting programmes have the potential to be effective in supporting bespoke needs of parents of children with a visible difference.
- Further larger scale evaluation of this type of intervention is warranted.

Abstract

Visible difference has been defined as any condition, mark, or injury which affects a person's appearance. Children with visible differences and their families may experience challenging social experiences. Some children with a visible difference report associated distress and some parents report heightened stress. Mindful parenting programmes could reduce parenting stress and secondarily improve child wellbeing. The current study investigated whether an online mindful parenting programme reduced parenting stress for parents of children living with a visible difference. The study also examined effects on levels of mindful parenting and child wellbeing, alongside feasibility and acceptability. Nine participants participated in a single case experimental design study evaluating the online Mindful Parenting intervention entitled 'Two Hearts'. Personalised measures of parenting stress and wellbeing were requested daily throughout a two-week baseline phase, six-week intervention, and four-week follow-up. Measures of parenting stress, mindful parenting, and child strengths and difficulties were completed at the start and end of each phase. More than half of participants experienced improvements in parenting stress, there is some evidence that these improvements were associated with increased mindful parenting. Child outcomes were mixed. The intervention was deemed feasible and acceptable. Further research comprising robust methodology is required to extend the current findings.

The transition to becoming a parent or carer is significant, and whilst the role can bring great contentment and joy, it requires considerable responsibility, energy and resources, and may be associated with stress and worry (Bögels & Restifo, 2014). Indeed, Deater-Deckard and Panneton (2017) describe the role of parenting as inherently stressful and such stresses are encompassed within the term 'parenting stress' (Deater-Deckard, 1998).

Families facing additional pressures, where a child has a visible difference, are more likely to experience heightened parenting stress (Changing Faces, 2022). One in 124 children and young people under 16 years old are affected by a visible difference or an appearance-altering condition or injury, which can be described as any scarring, condition, disability or mark that affects a person's appearance (Changing Faces, 2017). Children and young people living with a visible difference may experience stigma and discrimination, behavioural difficulties, low mood, and negative self-perceptions (Changing Faces, 2017; Feragen & Borge, 2010; Maddern et al., 2006; Rumsey & Stock, 2013). Research has highlighted stress, distress and worry in parents specifically associated with the visible nature of their child's condition, such as cleft lip and/or palate (CL/P) (Boztepe et al., 2020), craniofacial anomalies (Klein et al., 2006) and skin conditions (Ablett & Thompson, 2016). Thornton et al. (2021) identified the presence of similar psychological difficulties, such as distress, stress and anxiety, for parents of children living with a visible difference, irrespective of the cause or nature of that visible difference. Parents may face similar difficulties to those parenting a child with a health condition, alongside the additional unique challenges associated with their child looking different (Costa et al., 2021).

Lazarus and Folkman (1984) posited that stress can occur when the presence of physical, social and environmental demands, which are appraised to be potentially threatening, exceed a person's capacity to cope (Biggs et al., 2017). Bodenmann (1997) proposed that in close relationships, both stress and coping are transactional dyadic processes. Heightened stress in itself is problematic, and it is associated with poorer health outcomes due to the direct impact on the body and negative impact on health-related behaviours (O'Connor et al., 2021).

Elevated parenting stress is associated with poorer outcomes for children, such as worse child socio-cognitive development, increased rates of child behaviour problems (Barroso et al., 2018), and poorer management of paediatric health conditions (Guajardo et al., 2009; Tsiouli et al., 2013). This association has been attributed in part to the negative impact of parenting stress on parenting practices (Jackson & Choi, 2018; Masarik & Conger, 2017). Research has highlighted the importance of familial psychological health, home environment and availability of support for child adjustment to a visible difference, thus relational interventions may help both reduce parenting stress and improve outcomes for children (Dennis et al., 2006; Maddern et al., 2006).

The evidence base regarding interventions for families of children living with a visible difference remains underdeveloped. A systematic review of intervention studies (n=12) intended to improve wellbeing for children living with a visible difference was completed by Jenkinson et al. (2015). The review identified a range of interventions including residential social camps, group or individual Social Skills Training (SST), Cognitive Behavioural Therapy (CBT), psychoeducation, exercise and counselling. Overall evidence was inconclusive with only small positive effects noted for interventions employing CBT and SST. Limitations were noted for the included studies such as small sample sizes, high risk of bias, limited use of comparison groups and underdefined theoretical underpinning (Jenkinson et al., 2015).

More recently, Zelihić et al. (2022) conducted a randomised control trial of an online psychosocial intervention for distressed adolescents with a visible difference (n=189, age range 11-18 years). The online intervention comprised seven weekly self-guided 30–40-minute sessions comprising video, audio and written content based on SST and CBT principles. Resultant lowered levels of social anxiety (moderate effect size) were found compared with participants receiving care as usual, however no effect was found for measures of body esteem, life disengagement or perceived stigma (Zelihić et al., 2022). At present, it is unclear whether these effects remain long-term.

Pertaining to parents of children living with a visible difference, Costa et al. (2021) completed a systematic review comprising 15 studies investigating the effectiveness of interventions for parents of children with atopic dermatitis, eczema, CL/P and burns. Studies evaluated established parenting programmes, interventions described as parent training and education, web-based programmes and a programme intended to improve outlook. The review identified that the established parenting programmes and parent education interventions resulted in beneficial outcomes such as reduced stress, distress and anxiety, and improved quality of life (Costa et al., 2021). Many of the included studies were noted to lack rigour and comprise unrepresentative samples, while attrition rates were not reported. Thus, further research is required to glean additional information regarding which interventions are beneficial and acceptable for this population (Costa et al., 2021).

At present, provision of psychosocial support for families of children living with a visible difference is clearly limited, while families face long waiting times and referrals are often reactive rather than preventative (Jenkinson et al., 2015; Rumsey & Harcourt, 2007). Therefore, there is a need to develop effective psychological supports for these parents which both address their own wellbeing and have the potential secondarily to improve the wellbeing of the child.

Mindfulness-based interventions (MBIs) are known to be effective for stress reduction (Khoury et al., 2015; Pascoe et al., 2017) and therefore may also have merit for addressing this need. Kabat-Zinn (2005) refers to mindfulness as a way of being which is purposefully present and aware, noticing internal and external experiences non-judgementally. In this sense, mindfulness can be understood as a disposition, which varies between individuals (Baer et al., 2006). Mindfulness training is known to enhance or cultivate this disposition by teaching the individual specific mindfulness meditations or practices (Kiken et al., 2015). Cultivating mindfulness may be particularly beneficial for the current population. For example, longitudinal research considering the effects of experienced stigma for parents of children with autism spectrum conditions have identified that trait mindfulness has the potential to mitigate the link between experienced stigma with stress, depression and anxiety for these parents (Yip & Chan, 2022).

Mindfulness-based approaches applied to parenting are similar to traditional MBIs, but are notably different in nature which enhances the potential to extend further benefits to wider family systems (Bögels & Emerson, 2019). The term 'mindful parenting' has been used to refer to a non-judgemental, active presence in familial interactions (Bögels & Restifo, 2014; Kabat-Zinn & Kabat-Zinn, 1998). Several mindful parenting approaches have been developed (e.g. Bögels & Restifo, 2014; Duncan et al., 2009; Singh et al., 2007).

Early research has indicated that mindful parenting could be beneficial for parents of children with visible differences. Utilising a single group experimental case series design, (Heapy et al., 2022) investigated a mindful parenting group for parents of children with eczema or psoriasis. The study intervention was based upon the Bögels and Restifo (2014) Mindful Parenting training, delivered through eight weekly three-hour in-person sessions, and one follow-up session with daily home practice encouraged. Overall improvements were noted for personalised targets of parenting stress associated with the child's skin condition for all participants from baseline through follow-up. All participants were retained and positive parent feedback evidenced acceptability (Heapy et al., 2022). However, the authors noted that participants reported that it was difficult to adhere to the home practice requirements. The 'dose' of MBIs regarding session length and intervention duration has been found to be unrelated to outcomes for clinical and non-clinical samples (Fischer et al., 2020). Rather, frequency of mindfulness home practice and the extent to which mindfulness concepts are integrated into a person's life has been associated with positive outcomes (Fischer et al., 2020; Lloyd et al., 2018).

Given this, and the fact that the existing interventions (e.g. Heapy et al., 2022) are time consuming, there is a need to develop and test lower intensity interventions that might be more widely acceptable and deliverable.

It is known that factors such as geographical location, transportation and financial pressures may present barriers to accessing in-person interventions, and group interventions which may run for several hours can also present childcare issues for parents (Cartreine et al., 2010; Perle & Nierenberg, 2013).

Improved outcomes are also associated with increased intervention adherence (Cillessen et al., 2020). Yet high attrition rates are a limitation of both parenting interventions (around 50%) (Chacko et al., 2016) and MBIs delivered both in-person (around 30%) (Nam & Toneatto, 2016) and online (around 50%) (Cavanagh et al., 2013). However, guided online MBIs have been shown to have greater effects than self-guided MBIs (Spijkerman et al., 2016).

By overcoming geographical barriers and reducing time demands, online interventions may increase equity of access for busy populations (Jayawardene et al., 2017). A meta-analysis comprising eight randomised controlled trials considering the effects of online MBIs in non-clinical populations found significant improvements on self-reported stress (medium effect size) and mindfulness (small effect size) (Jayawardene et al., 2017). Furthermore, remote interventions have been found to be beneficial for a range of mental and physical health problems (Sloan et al., 2011; Speyer et al., 2018). Provision of online parenting interventions can be beneficial for parent-child dyads (Nieuwboer et al., 2013). Thus, provision of guided online brief interventions could enable increased accessibility and increased engagement.

Potharst et al. (2019) employed a randomised wait-list controlled design to evaluate a self-directed, online, eight-week mindful parenting intervention with mothers (n=76) of preschool children experiencing elevated stress. This intervention was informed by the Bögels and Restifo (2014) model alongside a toddler-specific intervention (Potharst et al., 2021) and recommended 10-20 minutes home practices daily. The main outcome was parental stress measured using the Parental Stress Questionnaire (Vermulst et al., 2012). Participation resulted in reduced parental stress (small effect size), compared with a wait list control. The average time participants spent practicing mindfulness exercises was lower than recommended, at around 15 minutes per week. Furthermore, participants completed only 50% of sessions on average, and only 15.5% completed the training. Thus, future interventions need to explore strategies to improve engagement with practice and enhance intervention adherence.

Recently, Sherwood et al. (2023) have investigated the feasibility, acceptability, and initial effects of a mindful parenting intervention named the ‘Two Hearts’ programme on parenting stress as measured by the Parenting Stress Index (Abidin, 2012) in non-clinical populations. Six participants completed the four-week online programme with two optional individual support sessions. Text message prompts were sent twice weekly during the intervention phase. All participants were retained and 50% showed a reliable reduction in parenting stress. Self-reported home practice levels were noted to be higher than those in the (Potharst et al., 2019) study. Participant evaluation data indicated that parents found the programme acceptable. Thus, this intervention merits further evaluation with different populations.

Aims and Hypotheses

The current study sought to investigate the feasibility, acceptability, and initial effects of delivering the ‘Two Hearts’ mindful parenting programme online for parents of children living with a visible difference. The study has the following hypotheses:

- Completion of the intervention will result in reductions in parenting stress on both nomothetic and personalised measures, and these improvements will be maintained on follow-up.
- Completion of the intervention will result in an improvement in child wellbeing on nomothetic measures, and these improvements will be maintained on follow-up.
- Completion of the intervention will increase levels of mindful parenting as measured using a nomothetic measure. These improvements will be maintained on follow-up.
- Increased levels of mindful parenting will be associated with improved outcomes on idiographic (personalised) and nomothetic measures.

Method

Design

This study implemented an A-B-A^1 single case experimental design (SCED: Morley, 2018). The methodology was chosen because the use of personalised measures provides a large amount of detailed meaningful data (Morley, 2018). This design has been used with other samples to address similar aims (Heapy et al., In press.; Heapy et al., 2022). A two-week baseline phase (Phase A) preceded a six-week online intervention (Phase B), ending with a four-week follow-up (Phase A^1). The main outcome variable was general parenting stress, measured in a personalised way. Secondary outcome variables comprised standardised measures of mindful parenting, parenting stress and parent reported child wellbeing. Feasibility was assessed through participant engagement data, intervention adherence and participant retention. Participant evaluation form responses were reviewed to assess intervention acceptability.

Participants

This study was approved by the Cardiff University Ethics Committee (See Appendix E). Parents read an information sheet about the study and were invited to ask the researcher any questions, before informed consent was obtained electronically prior to participation (see Appendix F & G). Study participation was voluntary, participants were informed of their right to withdraw, and data anonymity was assured. At the beginning of the study participants received a sheet outlining where they could receive further support if needed (see Appendix H). On completion of the study participants were provided with a written debrief (see Appendix I).

Twelve participants (10 women, 2 men) were recruited to the study. Such numbers were warranted as recent pilot studies of this intervention indicated that small groups of around five to seven participants would be preferable to create a sense of group cohesion. Small samples are usual for SCED studies as each participant acts as their own control (Morley, 2018). A broad recruitment strategy was completed. Various UK-based charitable foundations, such as Headlines Craniofacial Support and Caring Matters Now (CMN), shared study advertisements on their social media pages and websites (see Appendix J). Snowball sampling was enabled to allow wide distribution (Dempsey et al., 2016; Sadler et al., 2010). The following inclusion criteria were employed: (a) able to communicate in English; (b) parent participants only; (c) parent of child(ren) aged between four (4) to 16 years, living with an appearance altering mark, condition, or injury; (d) presence of self-reported parenting stress associated with the child’s visible difference; (e) parent not currently accessing psychological therapy or a parenting programme; (f) parent not currently experiencing severe symptoms of psychological distress or thoughts of suicide or self-injury; (g) parent had not previously completed a mindful parenting programme; (h) parent's child not currently in an acute phase following an injury. Extended criteria are available in Appendix K. No participants were excluded based on these criteria.

Measures

Demographic Data. Information comprising parent reported age, ethnicity, gender, relationship status and education background, as well as their child's age and nature of the visible difference (i.e. skin condition, mark, injury etc.), were gathered at baseline.

Intervention Adherence and Retention. Intervention adherence was measured by recording completion of online materials and group attendance. Participants reported weekly engagement and home practice levels during the intervention phase. Further information regarding home practice was recorded on evaluation forms.

Intervention Acceptability. An evaluation form adapted from Bögels and Restifo (2014) was used at follow-up to ascertain participant engagement and satisfaction with the intervention. Responses were multiple choice or yes/no. See Appendix L for full form.

Personalised Idiographic Measures of Parenting Stress and Wellbeing. Parents identified two personal targets for change around parenting stress and wellbeing. One target was increase-framed for improvement (e.g. how much were you able to engage with your family whilst out in public today) and one reduction-framed target (e.g. how concerned have you felt about social responses to your child today). Questions were rated on a scale of 0 (not at all) to 100 (extremely/very much so).

Standardised Measures. The following standardised measures were implemented.

Mindful Parenting. The extended Interpersonal Mindfulness in Parenting scale (IM-P) (de Bruin et al., 2014; Duncan et al., 2009) was employed to measure mindful parenting. The 31-item measure comprises six constructs: "1) Listening with full attention, 2) Compassion towards the child, 3) Non-judgmental acceptance of parental functioning, 4) Emotional non-reactivity in parenting, 5) Emotional awareness of the child, and 6) Emotional awareness of the self", and scores summed to achieve an overall mindfulness level (de Bruin et al., 2014). A five-point Likert scale is used, and total scores range from 31 to 155, with higher scores indicative of higher levels of mindful parenting. Reliability and validity of the IM-P have been deemed good with the exception of the sixth factor (total score α=0.83) (de Bruin et al., 2014). See Appendix M for full IM-P measure.

Parenting Stress**.** Parenting stress was measured using the Parenting Stress Index- Short Form- Fourth edition (PSI-SF-4) (Abidin, 2012; Abidin & Guarino, 1995). The 36-item measure comprises three constructs: 1) Parental distress, 2) Dysfunctional parent-child interactions, and 3) Difficult child, and an overall stress level. A five-point Likert scale is employed to rate items with factor scores totalled, and total scores range from 36 to 180. Higher scores indicate increased parenting stress with scores of 115 or above indicating clinically significant stress (Abidin, 2012). The PSI-SF-4 has demonstrated good reliability and validity (total score: α=0.82) (Abidin, 2012).

Child Difficulties and Wellbeing. Child emotional and behavioural outcomes were measured using the Strengths and Difficulties questionnaire (SDQ) (Goodman et al., 2010; Goodman, 1997). The SDQ can be completed by parents (and teachers) of children aged 4-17 years old. The 25-item measure comprises five constructs: 1) Emotional problems, 2) Conduct problems, 3) Hyperactivity, 4) Peer problems, and 5) Prosocial behaviour, and items 1 to 4 can be summed to achieve a total difficulties score. On items 1 to 4 higher scores are indicative of greater difficulty, while on item 5 higher scores are indicative of greater levels of prosocial behaviour. Items are rated on a scale of 0 to 2 and total difficulties scores range from 0 to 40. Scores above 17 on SDQ total difficulties are rated 'high', and scores below 6 on prosocial behaviour are rated 'low'. The SDQ demonstrated acceptable internal consistency (α: Total difficulties=0.82, Prosocial behaviour=0.65) and test-retest reliability (mean: 0.62) (Goodman, 2001). See Appendix N for full SDQ measure.

Procedure

Parents were initially interviewed for eligibility via telephone (See Appendix O for outline). Suitable individuals accessed the information sheet and consent form hosted online within Cardiff University Qualtrics. On receipt of informed consent, the researcher supported participants to identify personalised measures of parenting stress and wellbeing.

Personalised targets were sent via text message through a secure online platform (PageOnes JanetTxT) daily from baseline through follow-up. Weekly engagement and home practice was collected weekly via the same method.

The following data was collected via surveys hosted in Cardiff University Qualtrics. Demographic data was collected at baseline, standardised measures were completed at baseline, pre-intervention, post-intervention and follow-up. Finally, evaluation forms were completed at follow-up.

Intervention

The Two Hearts mindful parenting is an online programme based on the Bögels and Restifo (2014) Mindful Parenting programme and was developed by an expert panel (L-M. Emerson, S. Bögels, J. Paynter). The programme was found to be acceptable when piloted with parents from a community population with 100% participant retention (Sherwood et al., 2023). The programme was free for participants.

The Two Hearts programme comprises four self-directed online modules: Module 0) Introduction, Module 1) Mindful Awareness in Parenting, Module 2) Mindful Parenting in Action, Module 3) Compassion in Parenting. Modules involve video and audio content supported by a PDF Parent Workbook. The introductory module consists of initial reading and an audio file to support home practice. The following three modules comprise a series of two to four short videos and audio files to support mindfulness practices hosted on a dedicated web platform, alongside reading from the Parent Workbook. Mindfulness practices include three-minute breathing space, body scan and mindful movement and 20 minutes home practice, five days per week was encouraged.

Four online group support sessions via videoconferencing were completed at the start of the programme (introduction) after week two, week four and week six. Group sessions followed a predesigned outline and facilitated discussions around barriers to home practice and content engagement alongside consolidating learning. Daytime and evening groups were facilitated to improve accessibility, individual catch up sessions were facilitated when necessary. The initial group marked the beginning of the intervention phase, access to the online content and PDF workbook was given after this session. Modules were made available sequentially bi-weekly. The online platform remained accessible to parents throughout the follow-up period. Text message reminders we sent twice per week during the six-week intervention period and once per week during the four-week follow-up period. See Table 1 for an overview of intervention content and processes. See Appendix P for full programme outline.

Table 1.

'Two Hearts' Mindful Parenting Intervention Content and Processes

Intervention Phase Processes and Timeline	Module Title & Format	Themes	Mindfulness Practice & Specific Mindful Parenting Exercise	Home Practice
Week 0 • Access provided to Module 0 (online) prior to the baseline phase ending • Group Support Session 1 began the intervention phase • Access to Module 1 (online) and the full parent workbook provided following the group	Module 0 - Introductory Module • Programme overview • Group Support Session	• Basic principles of mindfulness and compassion; • Relevance of mindfulness and compassion in parenting stress; Introduction to home practices	• Body Scan (Williams et al., 2007) • Informal practice (i.e., mindful coffee)	N/A
Week 1 & 2 • Group Support Session 2 at the end of week 2	Module 1 - Mindful Awareness in Parenting • Four short videos, • Audio file,	• Introduction to Mindful Parenting and orientation to programme;	• 3-min Breathing Space	• Parent Workbook readings;

• Access was provided to Module 2 (online) following the group	• Program workbook, • Home practices • Group Support Session	• The evolution of parenting stress; • Body awareness and the stress response; • Finding a Breathing Space	• Imagination: parenting stress exercise	• 15 min guided Body Scan practice (1 pd, 5 times pw); • 3-min Breathing Space (2 pd, 5 times pw) • Mindfulness home practice record (optional)
Week 3 & 4 • Group Support Session 3 at the end of week 4 • Access provided to Module 3 (online) following the group	Module 2 - Mindful Parenting in Action • Four short videos, • Home practices • Group Support Session	• Automatic pilot parenting; • Body awareness and Mindful Movement; • Rupture and Repair	• Mindful Movement • Imagination: Rupture and Repair exercise	• Parent Workbook readings; • 15 min guided Body Scan practice (1 pd, 5 times pw); • Breathing Space (2 pd, 5 times pw, and use during stressful interaction); • Parenting Stress Diary (1-3 entries pw); • Rupture and Repair process at home; • Mindfulness home practice record (optional)
Weeks 5 & 6 • Group Support Session 4 at the end of week 6	Module 3 -Compassion in Parenting • Two short videos, • audio file,	• Compassion, Stress and the Body; • Growing Self-Compassion	• Soothing Rhythm Breathing (Gilbert, 2009)	• Parent Workbook readings; • ‘*What Do I need?*’ reflective exercise

	- *Useful Resources* PDF, - Home practices - Group Support Session	- Self-Compassion Break (Neff & Germer, 2013) - Imagination: compassion for self during parenting stress exercise	(Bögels & Restifo, 2013; Germer & Siegel, 2012); - Individualised commitment practice; - Self-Compassion practices; - Mindfulness home practice record (optional)

Note. N/A = not applicable; pw = per week; pd = per day

Intervention Fidelity. The intervention comprised a workbook and online content developed based on the Bögels and Restifo (2014) programme by L-M. Emerson, S. Bögels and J. Paynter. Video content was delivered by a provisional Psychologist who had ten years established mindfulness practice and had completed mindfulness training. The additional group support sessions were facilitated by the researcher (a Trainee Clinical Psychologist) who received four supervision sessions from L. M. Emerson over the intervention period. The following structure was employed for each group session: introductory mindfulness practice, looking back at the previous two weeks, exploring mindfulness in daily life, looking forwards to the next two weeks, closing practice.

Results

Participant Characteristics

Twelve participants were recruited to the study (10 female, 2 male) and nine participants (7 female, 2 male) completed the study. See Table 2 and 3 for participant characteristics.

Table 2.

Characteristics of Parent Participants

ID	Age Range (Years)	Relationship Status	Ethnicity	Gender	Education Level
1	31-40	Married	White Other	Female	Undergraduate degree
2	31-40	Married	White British	Male	Masters degree
3	31-40	Co-habiting	White British	Female	A Level
4	31-40	Co-habiting	White British	Female	Professional qualification
5	41-50	Married	White British	Female	Undergraduate degree
6	31-40	Married	White British	Female	Undergraduate degree
7	41-50	Married	White British	Female	Undergraduate degree
8	41-50	Married	White British	Female	GCSE
9	31-40	Married	White Other	Male	Post-graduate degree eq.

Table 3.

Child Characteristics

Parent participant ID	Child age (years)	Child Condition or Injury
1	5	Birthmarks (CMN)
2	5	Craniofacial condition
3	9	Craniofacial condition
4	8	Limb difference
5	10	Alopecia
6	8	Alopecia and limb difference
7	8	Limb difference
8	10	Tumours (face and mouth)
9	6	Birthmarks (CMN)

Note. Table 3 shows characteristics of the children of parent participants, children did not participate in study processes or the mindful parenting programme directly.

Personalised Measures of Parenting Stress and Wellbeing

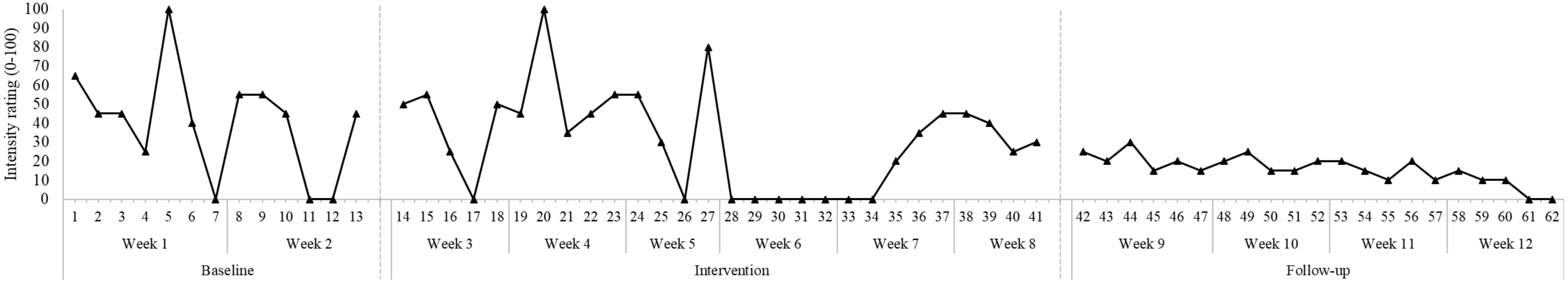
Participants identified personalised targets around parenting stress and wellbeing. Chosen targets varied in the extent to which they were linked to the child's visible difference, health related factors or general parenting stress. Two participants (P1 and P2) developed targets closely linked with their child's visible difference. Seven participants developed targets which more closely aligned with general parenting stress. All parents reported experiencing some stress associated with their child's visible difference, and that this stress could be exacerbated by situational or environmental factors, such as medical appointments or difficult interactions. Parents reported that certain times could feel more stressful due to their child's visible difference, such as dressing for school, playing at the park, going out for dinner, or talking about emotions. Some parents reported feeling more distractable in interactions with their child due to worries linked to children's visible differences. For some parents worries and stresses about their child's visible difference overlapped with health needs. Parents developed targets around how the complex array of stresses they experienced in their lives impacted them personally. The targets displayed on graphs have simplified to enhance anonymity.

Idiographic data for the nine participants were organised and graphed in excel for visual analysis of trends, variability and data patterns (Morley, 2018). See Figures 1 and 2 for graphs displaying the daily idiographic responses of the nine participants who completed the study (see Appendix Q and R for graphs displaying visual analysis process). Participants received questions daily, however response rates were variable (range of total responses = 39 to 79, average weekly response range = 3.3 to 6.6). Thus, the number of datapoints displayed on the graphs varies across participants, numbers on the horizontal (x) axis represents these data points, the week and phase are also provided for context of time.

Figure 1.

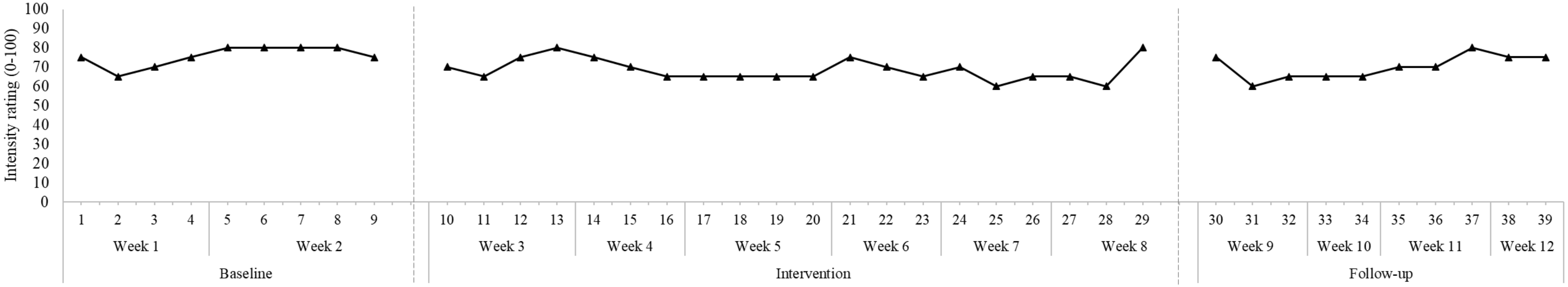
Graphs Displaying Responses to Personalised Increase-Framed Targets (Question 1)

Participant 1 – Feeling calm about how my child was at school.

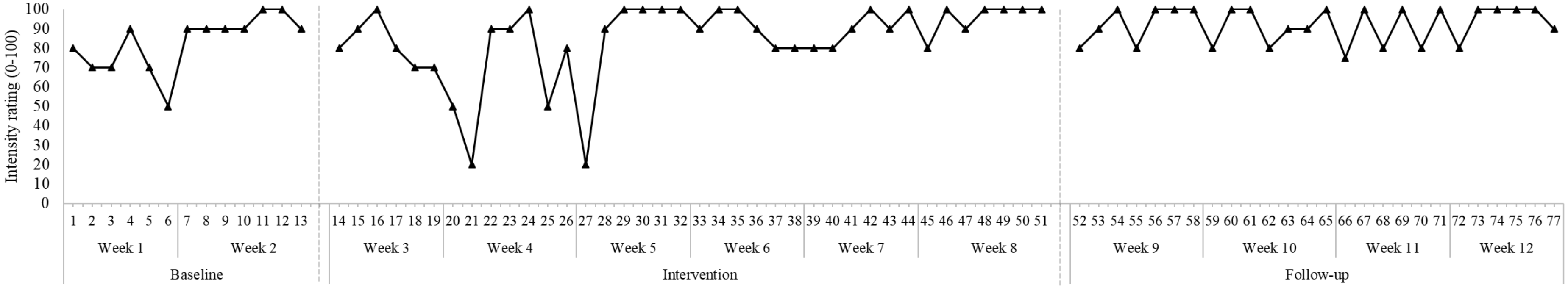


Note. For participant 1's increase framed data, it is possible that the graph ought to be viewed in reverse as increase-framed questions may have been rated on a decrease basis with lower score indicating improvement. As noted, for these graphs the numbers represented on the x axis represent datapoints received within the outlined timeframes.

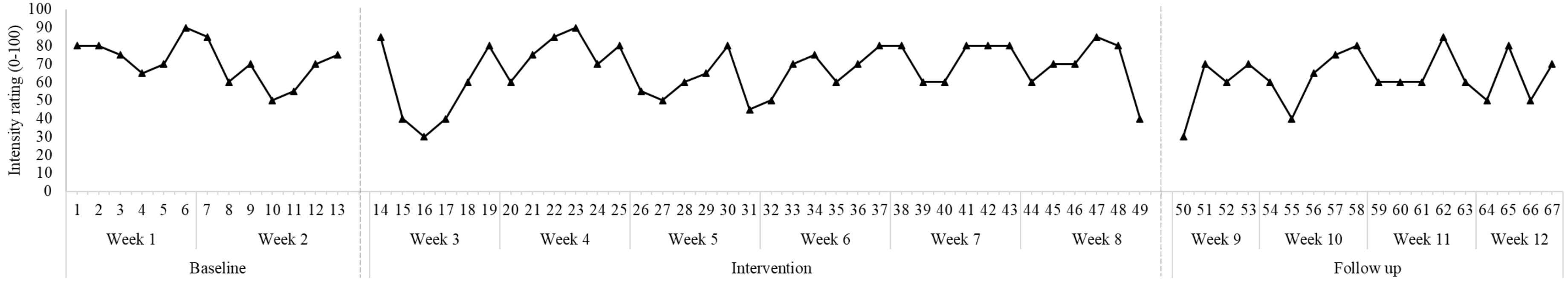
Participant 2 – Being present and engaged in public places with my child.



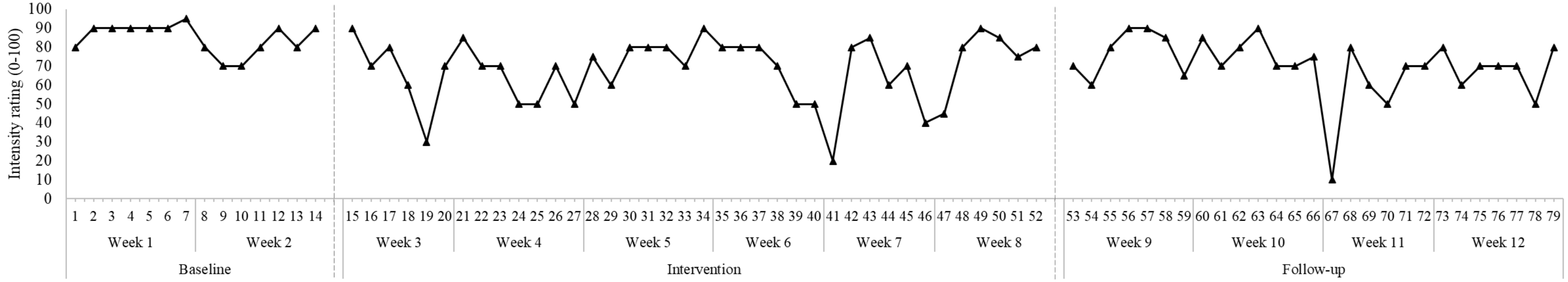
Participant 3 – Responding with openness and acceptance regarding my child's difficulties.



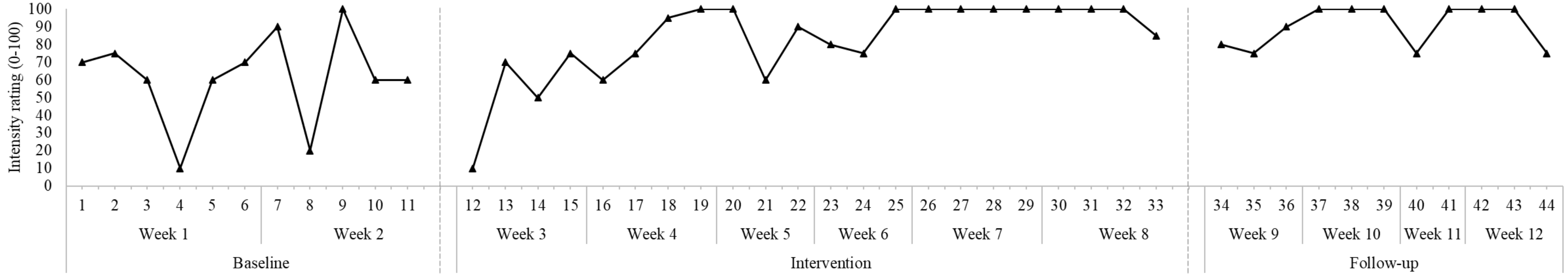
Participant 4 – Being present and engaged during interactions with my child.



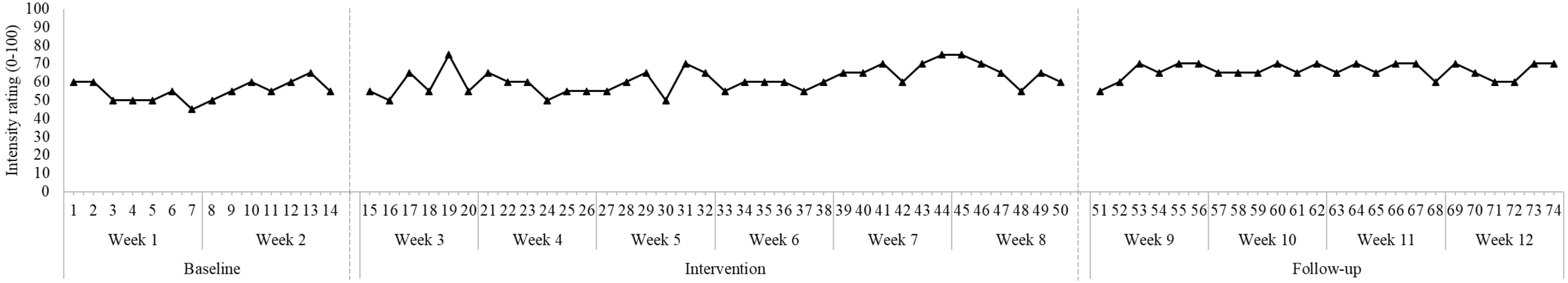
Participant 5 – Being present and actively listening to my child.



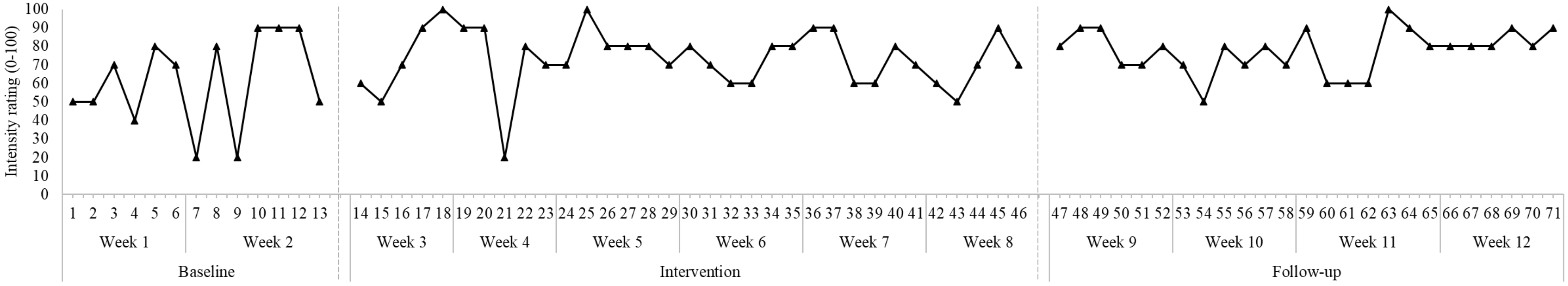
Participant 6 – Being fully with my child during interactions.



Participant 7 – Being actively engaged and enjoying positive interactions with my child.



Participant 8 – Being calm and focused during interactions with my child.



Participant 9 – Having headspace to be proactive and make plans for child.

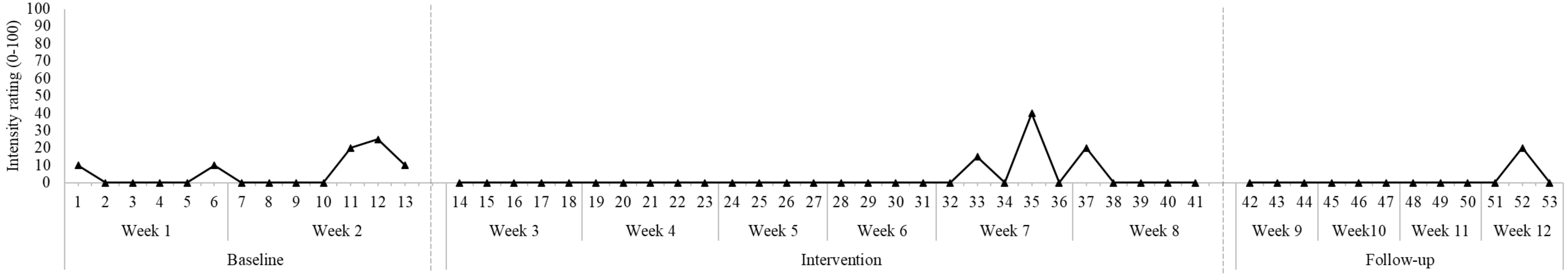
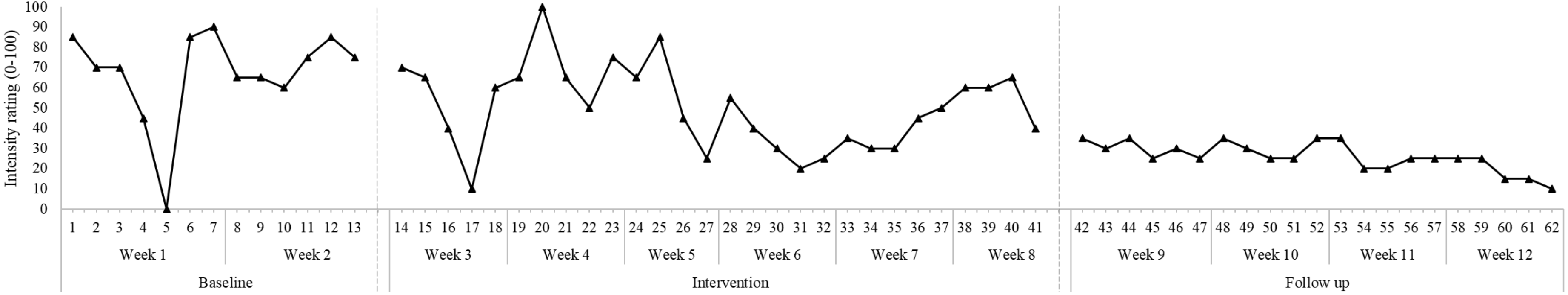


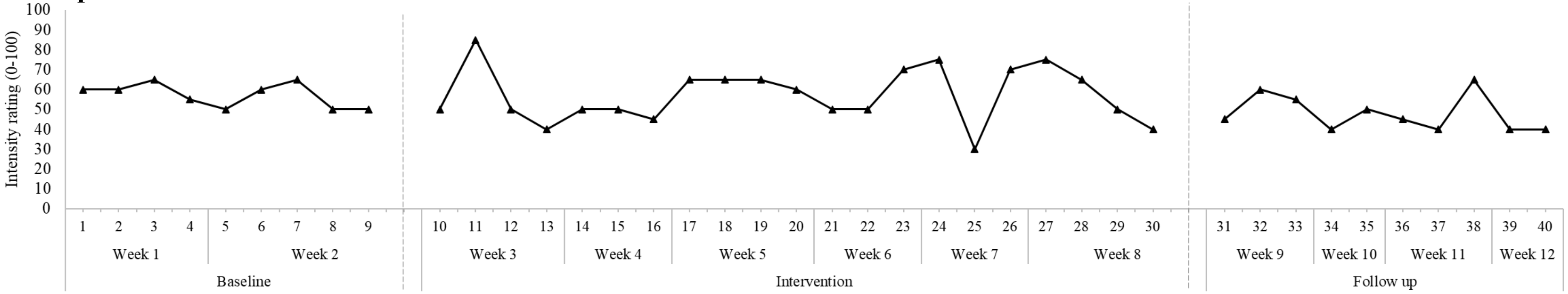
Figure 2.

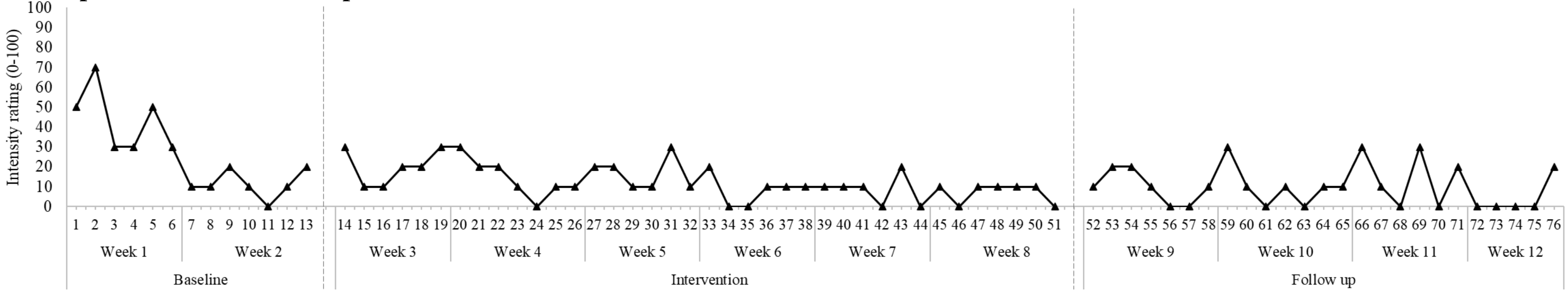
Graphs Displaying Responses to Personalised Decrease-Framed Targets (Question 2)

Participant 1 – Feeling worried about child wellbeing and self-acceptance.

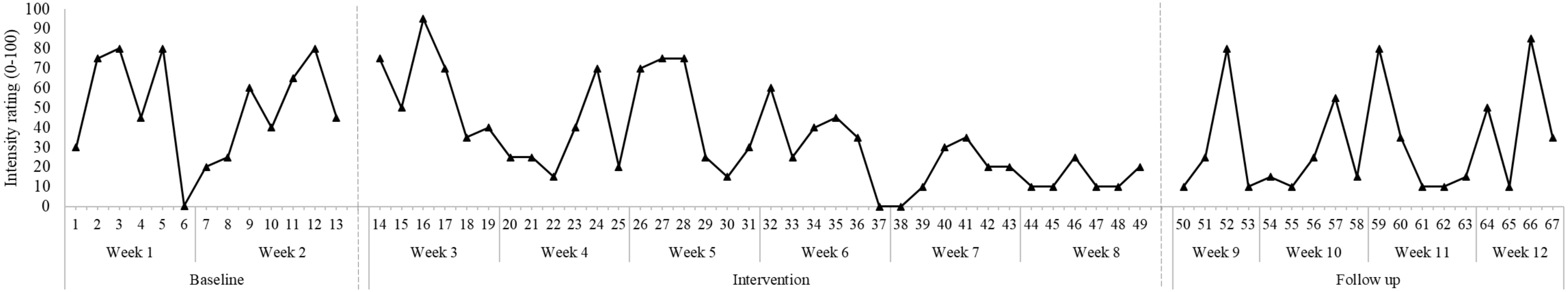


Participant 2 –Emotional reactions to social reactions of others.

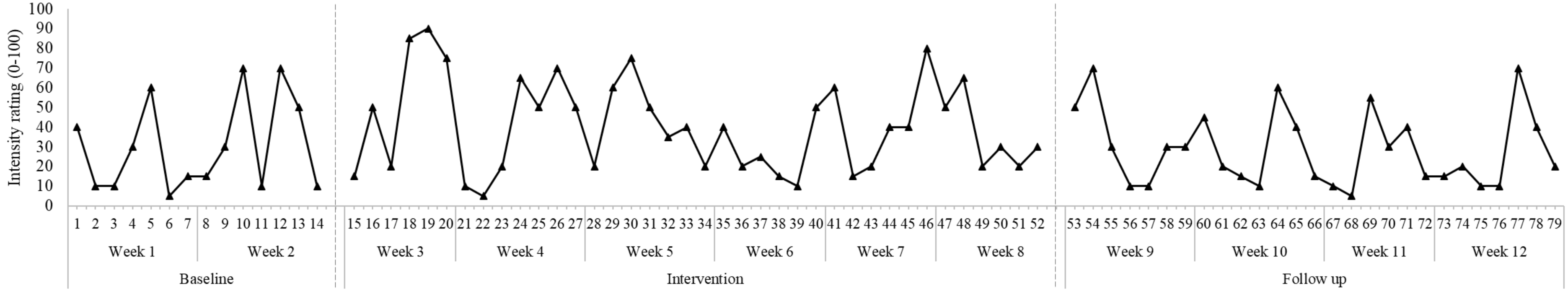




Participant 3 – Emotional responses to difficult conversations with child.

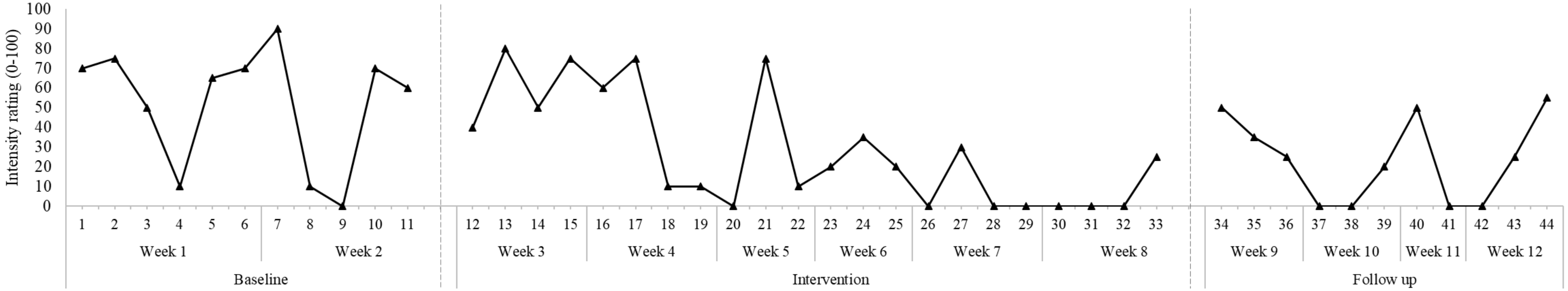


Participant 4 – Stress during difficult situations with child.

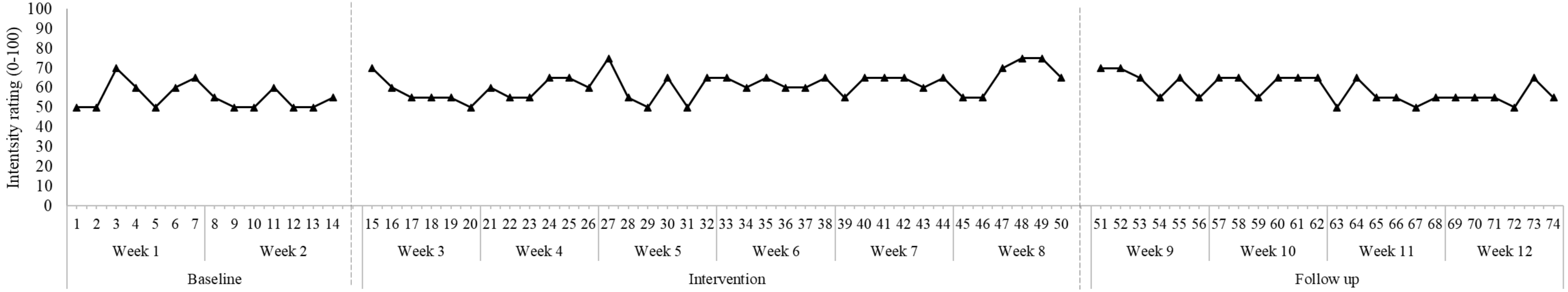


Participant 5 - Being reactive or responding abruptly with my child.

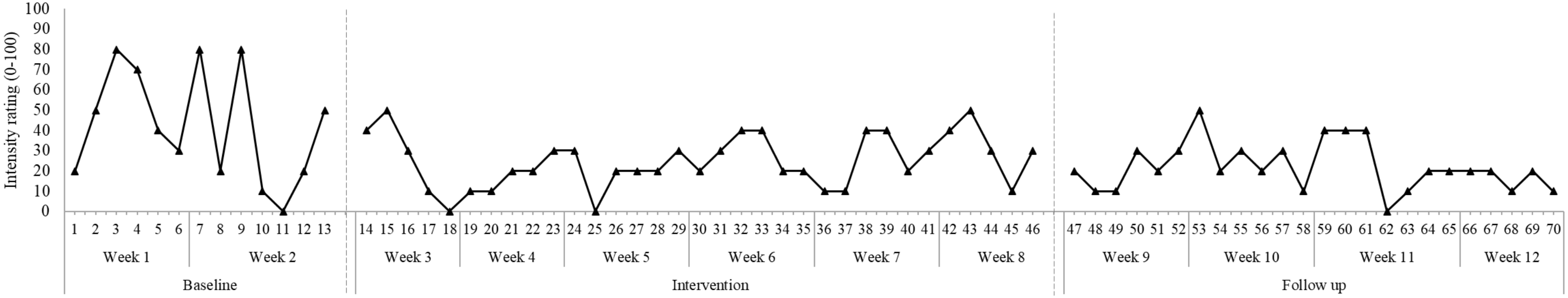
Participant 6 – Feeling distractable and attempting many tasks at once.



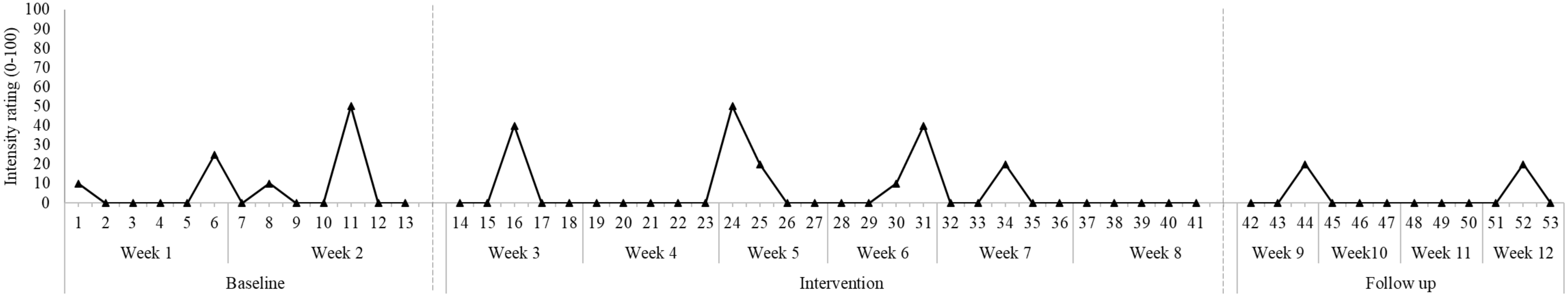
Participant 7 – Reactivity or being abrupt with my child.



Participant 8 – Intensity of difficult emotions related to parenting role.



Participant 9 – Intensity of own response to child's behaviour.



Increase-Framed Measures of Parenting Stress. A downward trend across phases beginning in the baseline was identified for participant 1. A slight upward trend in the baseline, downward trend in the intervention and upward trend in the follow-up phase was noted for participant 2. Upward trends throughout the baseline and intervention, tailing off in the follow-up phase were noted for participant 3. No identifiable trend within or across phases were noted for participant 4. No identifiable trend within phases was noted for participant 5, however a downward trend was noted from the baseline into the intervention. An upward trend was identified in the intervention, tailing off in the follow-up phase for participant 6 and 7, with this trend becoming notable in the baseline for participant 7. A slight upward trend in the baseline, a very slight downward trend in the intervention and a slight upward trend in the follow-up was noted for participant 8. A floor effect was noted for participant 9.

High variability in the baseline phase was noted for three participants (P1, P6 and P8), extending into the intervention for participant 1. Variability reduced to moderate in the intervention period for two participants (P6 and P8) which was sustained for participant 8. Variability reduced to low by the mid-point of the intervention for two participants (P1 and P6). Low to moderate variability was visible across all phases for participant 3 except for a period of high variability noted early in the intervention phase. Initial low variability shifted to moderate to high levels of variability within the baseline, continuing across the intervention and follow-up phases for two participants (P4 and P5). Low variability was noted across phases for three participants (P2, P7 and P9).

Decrease-Framed Idiographic Measures of Parenting Stress. A slight upward trend in the baseline followed by a downward trend in the intervention continuing into the follow-up was noted for two participants (P1 and P5). A downward trend beginning in the baseline, flattening in the intervention, and then continuing in the follow-up was noted for participant

2. A slight downward trend beginning in the baseline continued into the intervention and tailed off in the follow-up phase was seen for two participants (P3 and P6), with a steeper baseline trend noted for participant 3. A downward trend beginning in the intervention switching to an upward trend in the follow-up was noted for participant 4. A slight downward trend in the baseline switching to an upward trend in the intervention followed by a slight downward trend in the follow-up phase is noted for two participants (P7 and P8). A floor effect is noted for participant 9.

Variability was low for four participants (P2, P3, P7 and P9) although several outliers were noted in data for two participants (P2 and P9). Variability was generally high for three participants (P4, P5 and P6), with a period of lower variability noted in the second half of the intervention phase for two participants (P4 and P6). Variability was high in the baseline for two participants (P1 and P8) reducing to moderate to low in the intervention which persists follow-up for participant 8. High variability continued into the intervention for participant 1 reducing to low around the mid-point of the intervention and remaining into the follow-up.

Tau-U Analysis

Idiographic data were analysed with Tau-U (Parker et al., 2011) via an online calculator (Vannest et al., 2016). Tau-U examines data non-overlap between study phases (baseline, intervention, follow-up) and is particularly useful where there is lack of stability in baseline data. Baseline scores were initially analysed for trend and any significant trend was corrected for. Weighted averages were calculated. See Tables 4 and 5 for details of data output.

Table 4.

Tau-U Results for Personalised Increase-Framed Targets (Question 1)

Participant ID		Tau	SD Tau	*p*	90% CI
Participant 1	Baseline to intervention	-0.21	0.20	0.293	[-0.53, 0.12]
	Baseline to follow-up	-0.55	0.21	0.008**[3]	[-0.89, 0.21]
	Intervention to follow-up	-0.35	0.17	0.037*[3]	[-0.63, -0.07]
Participant 2	Baseline to intervention	-0.61	0.24	0.010**[2]	[-0.1, -0.22]
	Baseline to follow-up	-0.51	0.27	0.060	[-0.96, 0.06]
	Intervention to follow-up	0.15	0.23	0.509	[-0.22, 0.52]
Participant 3	Baseline to intervention	0.12[1]	0.19	0.538	[-0.19, 0.42]
	Baseline to follow-up	0.28[1]	0.20	0.153	[-0.04, 0.61]
	Intervention to follow-up	-0.03[1]	0.15	0.854	[-0.27, 0.22]
Participant 4	Baseline to intervention	-0.13	0.19	0.497	[-0.44, 0.18]
	Baseline to follow-up	-0.35	0.21	0.097	[-0.71, -0.00]
	Intervention to follow-up	-0.18	0.17	0.283	[-0.46, 0.1]
Participant 5	Baseline to intervention	-0.63	0.18	0.001**[2]	[-0.93, -0.33]
	Baseline to follow-up	-0.62	0.19	0.001**[2]	[-0.94, -0.31]
	Intervention to follow-up	0.04	0.15	0.790	[-0.2, 0.28]
Participant 6	Baseline to intervention	0.53	0.22	0.014*	[0.18, 0.89]
	Baseline to follow-up	0.77	0.25	0.002**	[0.36, 1]
	Intervention to follow-up	0.16	0.22	0.457	[-0.2, 0.52]
Participant 7	Baseline to intervention	0.50	0.18	0.007**	[0.19, 0.8]
	Baseline to follow-up	0.86	0.20	0.000**	[0.54, 1]
	Intervention to follow-up	0.42	0.15	0.006**	[0.17, 0.68]
Participant 8	Baseline to intervention	0.25	0.19	0.184	[-0.06, 0.57]
	Baseline to follow-up	0.36	0.20	0.074	[0.03, 0.69]
	Intervention to follow-up	0.15	0.15	0.334	[-0.11, 0.4]
Participant 9	Baseline to intervention	-0.26	0.20	0.193	[-0.58, 0.07]
	Baseline to follow-up	-0.29	0.24	0.221	[-0.68, 0.1]
	Intervention to follow-up	-0.02	0.20	0.906	[-0.36, 0.31]
Weighted Average	Baseline to intervention	-0.04	-	0.515	[-0.15, 0.07]
	Baseline to follow-up	0.00	-	0.994	[-0.12, 0.12]
	Intervention to follow-up	0.04	-	0.535	[-0.06, 0.14]

Note. Significance level: *= p>0.05, **=p>0.01

[1] Baseline corrected. [2] Indicative of a significant deterioration. [3] Should be viewed tentatively due to likely difficulty regarding direction of reporting.

Table 5.

Tau-U Results for Personalised Decrease-Framed Targets (Question 2)

Participant ID		Tau	SD Tau	*p*	90% CI
Participant 1	Baseline to intervention	-0.53	0.20	0.007**	[-0.86, -0.21]
	Baseline to follow-up	-0.85	0.21	<0.001**	[-1.00, 0.51]
	Intervention to follow-up	-0.72	0.17	<0.001**	[-0.99, -0.44]
Participant 2	Baseline to intervention	-0.02	0.23	0.946	[-0.40, 0.37]
	Baseline to follow-up	-0.59	0.27	0.031*	[-1.00, -0.14]
	Intervention to follow-up	-0.44	0.23	0.052	[-0.81, -0.07]
Participant 3	Baseline to intervention	-0.33[1]	0.19	0.076	[-0.64, -0.02]
	Baseline to follow-up	-0.38[1]	0.20	0.059	[-0.71, -0.05]
	Intervention to follow-up	0.08[1]	0.15	0.598	[-0.17, 0.33]
Participant 4	Baseline to intervention	-0.44	0.19	0.019*	[-0.76, -0.13]
	Baseline to follow-up	-0.48	0.21	0.025*	[-0.83, -0.13]
	Intervention to follow-up	-0.12	0.17	0.480	[-0.40, 0.16]
Participant 5	Baseline to intervention	0.29	0.18	0.110	[-0.93, -0.33]
	Baseline to follow-up	0.02	0.19	0.912	[-0.94, -0.31]
	Intervention to follow-up	-0.31	0.15	0.034	[-0.20, 0.28]
Participant 6	Baseline to intervention	-0.39	0.22	0.073	[-0.74, -0.03]
	Baseline to follow-up	-0.59	0.25	0.020*	[-1.00, -0.17]
	Intervention to follow-up	-0.05	0.22	0.804	[-0.41, 0.30]
Participant 7	Baseline to intervention	0.49	0.18	0.008**[2]	[0.19, 0.80]
	Baseline to follow-up	0.37	0.20	0.061	[0.54, 1.00]
	Intervention to follow-up	-0.15	0.15	0.338	[0.17, 0.68]
Participant 8	Baseline to intervention	-0.35	0.19	0.071	[-0.66, -0.03]
	Baseline to follow-up	-0.42	0.20	0.037*	[-0.75, -0.09]
	Intervention to follow-up	-0.13	0.16	0.396	[-0.39, 0.12]
Participant 9	Baseline to intervention	-0.08	0.20	0.685	[-0.40, 0.24]
	Baseline to follow-up	-0.14	0.24	0.550	[-0.53, 0.25]
	Intervention to follow-up	-0.06	0.20	0.768	[-0.39, 0.27]
Weighted Average	Baseline to intervention	-0.15	-	0.028*	[-0.28, -0.02]
	Baseline to follow-up	-0.32	-	<0.001**	[-0.47, -0.18]
	Intervention to follow-up	-0.21	-	0.001**	[-0.32, -0.09]

Note. Significance level: *= p>0.05, **=p>0.01

[1] Baseline corrected. [2] Indicative of a significant deterioration.

Tau-U Findings for Increase-framed Personalised Targets. Improvements were noted for four of nine (4/9) participants (P3, P6, P7 and P8) for their personalised increase-framed measures of parenting stress (Q1) from baseline through intervention, this improvement continued through follow-up for three (3/9) participants (P6, P7 and P8). Significant improvements were identified for two (2/9) participants (P6 and P7) from baseline through intervention, this improvement continued through follow-up for one participant (P7). Deteriorations were noted for increase-framed idiographic measures of parenting stress for five (5/9) participants (P1, P2, P4, P5 and P9). Two (2/9) participants (P2 and P5) showed significant deterioration on these measures from baseline through intervention and two (2/9) participants showed significant deterioration from baseline through follow-up (P1 and P5). It is recommended that this finding is viewed with caution for participant 1 due to likely reporting error. No significant trend was noted for weighted averages regardless of inclusion or exclusion of non-completers.

Tau-U Findings for Decrease-Framed Personalised Targets. Seven (7/9) participants (P1, P2, P3, P4, P6, P8, P9) showed improvements in their personalised decrease-framed measures (Q2) from baseline through intervention, with improvements continuing through follow-up for six (6/9) participants (P1, P2, P4, P6, P8, P9). Of these, significant improvements were identified for two (2/9) participants (P1 and P4) from baseline through intervention. Significant improvements were noted from baseline through follow-up for five (5/9) participants (P1, P2, P4, P6 and P8) on these measures. Deteriorations were noted on these items from baseline though intervention for two (2/9) participants (P5 and P7), although it is noteworthy that a trend towards improvement was noted for these participants from intervention to follow-up. One participant (P7) showed significant deterioration on this measure from baseline to follow-up. Weighted averages indicated significant overall improvements on this measure for participants across phases.

Secondary Outcome Data

Differences between phases (baseline, intervention, and follow-up) on secondary outcome measures were examined using Jacobson's reliable change index (Jacobson & Truax, 1992). The distribution of scores on these measures was gathered from existing literature to generate reliable change criteria (Abidin, 2012; de Bruin et al., 2014; Goodman, 2001; Meltzer et al., 2003). The following scores were utilised for reliable change calculations for different measures: IM-P = 10.93; PSI-SF-4 = 15; SDQ (total difficulties) = 6.82; SDQ (prosocial) = 2.62. Analyses were completed employing the Leeds Reliable Change Indicator (Morley & Dowzer, 2014). See Table 6 for details.

Parent Measures. Reliable improvements were noted for mindful parenting scores from pre to post intervention for three of nine (3/9) participants (P1, P2 and P8). These improvements were maintained at follow-up. Reliable improvements were also noted for mindful parenting from baseline to pre-intervention for two (2/9) participants (P4 and P9). A reliable deterioration was noted from pre-intervention to post intervention for one participant (P6).

Reliable improvements were identified for parenting stress scores from pre to post intervention for three (3/9) participants (P1, P7 and P8). These improvements were maintained at follow-up. Reliable improvements were also noted from post-intervention to follow-up for two (2/9) participants (P3 and P5). Reliable improvements were also noted from baseline to pre-intervention for two (2/9) participants (P4 and P5). A reliable deterioration was noted from baseline to pre-intervention for one participant (P3).

Table 6.

Nomothetic Scores for Each Participant Across Timepoints

Participant ID	Timepoint	Mindful parenting (IM-P)	Parenting stress (PSI-SF-4)	Strengths and difficulties (SDQ) total difficulties	Strengths and difficulties (SDQ) prosocial behaviour
Participant 1	Baseline	111	97	11	9
	Pre-intervention	109	98	10	9
	Post-intervention	132[1]	72[1]	9	10
	Follow-up	131	69	9	10
Participant 2	Baseline	102	72	7	6
	Pre-intervention	97	72	9	6
	Post-intervention	115[1]	77	9	5
	Follow-up	109	78	11	5
Participant 3	Baseline	114	78	13	8
	Pre-intervention	110	91[2]	12	10
	Post-intervention	112	97	15	9
	Follow-up	117	83[1]	14	10
Participant 4	Baseline	89	90	11	9
	Pre-intervention	102[1]	81[1]	1	9
	Post-intervention	99	83	9	9
	Follow-up	99	79	11	10
Participant 5	Baseline	98	89	18	10
	Pre-intervention	104	79[1]	17	10
	Post-intervention	109	77	17	10
	Follow-up	113	61[1]	13[1]	9
Participant 6	Baseline	109	59	2	10
	Pre-intervention	101	53	2	10
	Post-intervention	88[2]	55	2	10
	Follow-up	-	-	-	-
Participant 7	Baseline	83	102	12	8
	Pre-intervention	88	102	13	7
	Post-intervention	96	92[1]	8[1]	6
	Follow-up	97	96	12[2]	9[1]
Participant 8	Baseline	91	102	14	9
	Pre-intervention	90	108	17	9
	Post-intervention	104[1]	97[1]	12[1]	8
	Follow-up	110	99	10	9
Participant 9	Baseline	91	96	9	10
	Pre-intervention	102[1]	94	7	10
	Post-intervention	101	95	11[2]	10
	Follow-up	-	-	-	-

Note. Possible range of scores: IM-P (31-155); PSI-SF-4 (36-180); SDQ total difficulties (0-40); SDQ prosocial scale (0-10). Higher scores indicate higher levels of mindful parenting and child prosocial behaviour, thus increases on these measures indicate improvement. Higher scores on parenting stress and child total difficulties indicate greater difficulties, therefore decreases on these scores indicate improvement.

[1] reliable improvement indicated, please note that change which occurs baseline to pre intervention cannot be attributed to the mindful parenting programme. [2]Reliable deteriorations noted.

Parent Rated Child Measure. Reliable improvements were identified for total difficulties from pre to post intervention for two of nine (2/9) participants (P7 and P8), and these improvements were maintained through to follow-up for participant 8. Reliable improvement was noted from post-intervention to follow-up for one participant (P5). Reliable deterioration was noted on this measure for one participant (P9) pre to post intervention.

Reliable change was noted on the measure of children's prosocial behaviour for one participant from post-intervention to follow-up, however it should be noted that this represents a return to baseline. No other reliable changes were noted on this measure.

Intervention Engagement, Adherence and Attrition

Attrition during the baseline phase was two participants of the 12 recruited (2/12). Attrition during the intervention phase was one from the remaining 10 (1/10).

The programme comprised a PDF workbook, three modules hosted online and four online group sessions. Attendance rates for online support sessions and engagement with online modules were recorded by the researcher, though it was not possible to measure engagement with the parent workbook. Six of nine (6/9) participants (P1, P2, P3, P5, and P8) completed more than 50% of programme components. The following engagement with the online modules was observed: four (4/9) participants (P1, P2, P5 and P7) completed all modules;

two participants (P3 and P8) accessed all three modules but did not complete the final module; one participant (P4) completed the first module only and two participants (P6 and P9) did not engage with the online content. Engagement with the parent workbook was not measured separately.

Four group support sessions were offered to participants and attendance rates were as follows: six participants (P1, P2, P3, P5, P7 and P9) attended three sessions; two participants (P4 and P8) attended two sessions; one participant (P6) did not attend any sessions. No participants attended every session.

Weekly engagement with all programme content and minutes spent completing home practice was collected via text message. Response rates to these questions varied and missing data is noted for all participants. One participant (P6) did not provide any engagement data; therefore, the following data is provided for the remaining eight participants only. The following findings should be interpreted with caution due to high levels of missing data. Missing values were replaced with participants' average reports for the overall average calculations provided below. Engagement data indicates that participant time spent using programme content varied significantly within and across participants over the six-week period. The range for time spent engaging with materials across participants was 0 to 120 minutes with an average of approximately 34 minutes per week. Participants were encouraged to complete 20 minutes home practice, five days a week (total 100 minutes per-week). Practice levels were highly variable (average minutes home practice per week = 73 minutes, range = 10 to 210 minutes per week). Engagement with both programme content and home practice reduced somewhat towards the middle of the intervention phase, increasing towards the end of the intervention.

Further information regarding home practice levels can be gleaned from evaluation form responses. Seven participants (P1, P2, P3, P4, P5, P7, P8) out of nine completed the evaluation form. Two participants (P6 and P9) did not complete the evaluation form. The seven participants who completed the evaluation form reported the following average weekly levels of formal practice during the intervention and follow-up phases. During the intervention phase, four participants (P2, P5, P7 and P8) reported practicing formal exercises 3-4 times weekly on average during the intervention, two participants (P3 and P4) reported practicing 1-2 times weekly, and one participant (P1) reported practicing 5-7 times weekly. During the follow-up phase six participants (P1, P2, P3, P4, P5, and P8) reported practicing 1-2 times weekly and one participant (P7) reported practicing 3-4 times weekly. This data indicates that practice levels reduced from the intervention to the follow up phase.

Programme Acceptability

The following findings were reported for the seven participants (P1, P2, P3, P4, P5, P7, P8) out of nine who completed the evaluation form. Participants selected from multiple choice responses to each item. Six participants (P1, P2, P3, P5, P7, P8) out of seven (85%) reported taking something of lasting value from the programme. All participants noticed becoming more ‘conscious’ in their parenting and reported making changes to their lifestyle, familial interactions, or parenting practices as a result of participating in the programme. All participants reported the intention to continue practicing conscious awareness of daily living and six (P1, P3, P4, P5, P7, P8) intended to continue formal mindfulness exercises. Six participants (P1, P3, P4, P5, P7, P8) out of seven found the programme to be sufficient to meet their needs.

Six participants (P1, P3, P4, P5, P7, P8) reported being more present (or much more present) and paying closer attention to their child during interactions following the training, while one participant (P2) noted no change on this dimension. All participants noted some positive change in knowing how to take better care of themselves and six participants (P1, P2, P4, P5, P7, P8) noted actual changes to their self-care. All participants noted some positive change to the intensity of their experiences of stress or frustration, and six (P1, P3, P4, P5, P7, P8) noted some positive change relative to the duration of these experiences. All participants noted some positive change to their perceived potential to improve familial relationships. Six participants (P1, P2, P3, P5, P7, P8) noted some positive change to their self-confidence relative to their parenting role and feelings of hopefulness. One participant (P4) noted no change on these dimensions. All participants reported some positive change to their ability to manage strong emotions as parents. All participants reported improved awareness of stressful parenting situations in the moment, six (P1, P2, P3, P4, P7, P8) reported an enhanced awareness of causes of stress in their lives, one participant reported no change (P5). Six participants (P1, P2, P3, P5, P7, P8) reported an improved ability to handle stressful situations, with no change reported by one participant (P4). No participants reported deteriorations in any of these areas following participation in the mindful parenting programme.

Discussion

A single case experimental design (Morley, 2018) was used to examine the feasibility, acceptability, and initial effects of the ‘Two Hearts’ online mindful parenting programme for parents of children living with a visible difference. Parent and child outcomes were measured through baseline, intervention, and follow-up phases.

It was hypothesised that the mindful parenting intervention would reduce parenting stress with effects maintained at follow-up. A standardised questionnaire was employed and to measure parenting stress and wellbeing idiographically, participants developed personalised targets to be measured daily throughout the study. As noted, individual targets varied in the extent to which they related to the child’s visible difference, or general parenting stress.

Seven participants (7/9) showed some improvement in decrease-framed personalised measures of parenting stress. Furthermore, five participants (5/9) improved significantly on their decrease-framed targets from baseline through follow-up. Significant overall group improvement was seen from baseline through intervention, with a stronger effect noted from baseline to follow-up. However, no overall group trend was identified for personalised increase-framed targets. Additionally, one third of participants (3/9) showed reliable improvements on standardised measures of parenting stress post-intervention, which were maintained at follow-up. One further participant experienced reliable improvements from pre-intervention to follow-up. Improvement effects were strongest from baseline through follow-up, indicating sustained benefits beyond the intervention phase, reflecting an existing effect in the literature (Burgdorf et al., 2019).

No participants reported clinically significant levels of parenting stress on standardised measures. Four participants reported somewhat heightened parenting stress (75th to 80th%ile) pre-intervention and three of these participants experienced reliable improvements following programme participation. A similar finding was noted in previous research utilising this intervention (e.g. Sherwood et al., 2023). It is theorised that when stress levels are already low, reliable reductions may be less achievable. Thus, the mindful parenting intervention was effective in reducing general parenting stress for some parents of children living with a visible difference, with benefits maintained at follow-up, however it did not result in improved wellbeing on personalised targets. Improvements on personalised measures indicate that the intervention also has potential to reduce parenting stress specifically related to children's visible differences, however further research is required for firm conclusions to be drawn.

The second hypothesis was that the mindful parenting intervention would improve parent-reported child wellbeing and that effects would be maintained at follow-up. Reliable improvements for child total difficulties were found for two participants (2/9), with the improvements maintained at follow-up for one. However, reliable deterioration was noted for one participant at post-intervention. Therefore, the Mindful Parenting programme may have positive implications for child outcomes, however our findings are inconclusive and further research is needed.

The third hypothesis was that participation in the Mindful Parenting Intervention would improve levels of mindful parenting on a standardised measure, with improvements maintained at follow-up. Eight participants (8/9) showed increased levels of mindful parenting from baseline to follow-up. Improvements were reliable for one third of participants (3/9) post-intervention, which were maintained at follow-up. Thus, participation resulted in stable increases in mindful parenting for some participants.

The final hypothesis was that increased levels of mindful parenting would result in improved parent and child outcomes. Reliable increases in mindful parenting were associated with significant reductions in parenting stress on decrease-framed personalised measures for three (3/9) participants from baseline through follow-up; reliable reductions on standardised measures of parenting stress for two participants (2/9) at post-intervention; and reliable improvement on child total difficulties for one participant (1/9). Thus, there is some evidence that improvements in parenting stress and child total difficulties were associated with increases in mindful parenting for some participants. However, the small sample size in this study prevents firm conclusions from being drawn.

Feasibility of the Mindful Parenting intervention was assessed through participant attrition and intervention adherence. Participant attrition from the intervention was 10%. This rate is greater than the zero attrition rate reported in Heapy et al. (2022) and Sherwood et al. (2023). However, it compares favourably to the reported attrition rates for guided online mindfulness programmes and parenting programmes (Cavanagh et al., 2013; Chacko et al., 2016). Programme adherence and home practice levels were generally good, comparing favourably to Potharst et al. (2019). Thus, the Mindful Parenting programme was deemed to be feasible for participants.

Intervention acceptability was assessed via an evaluation form. Of the seven participants who completed the evaluation form, all participants reported some positive change as a result of participation. Six (85%) responded that they had found the programme of lasting value. Bögels and Restifo (2014) recommended that over 80% endorsement of this statement is indicative of programme acceptability, Thus, the intervention was deemed to be acceptable to participants - although this finding should be held lightly in the context of the missing data for two participants.

While these findings show participant benefits, the personalised outcomes compare unfavourably to Heapy et al. (2022) where a full length in-person mindful parenting intervention was evaluated for parents of children with skin conditions. In this study, all participants improved on both positive and negative valanced personalised measures from baseline to follow-up. Similarly, in a previous study employing an earlier version of this intervention (Sherwood et al., 2023), half of participants experienced a reliable improvement on standardised measures. However, a proportionately higher level of elevated parenting stress was noted for participants in Sherwood et al. (2023), and participant involvement in the design of the intervention due to Covid-19 related complications, alongside recruitment from a pool of participants who were not eligible for a different study, may have enhanced engagement.

In line with existing research by Jayawardene et al. (2017), findings from the current study indicate that the online mindful parenting intervention was accessible for busy parents and the programme was deemed to be acceptable in such a format. The participants who practiced at least three to four times weekly more often showed improvements than those who practiced less frequently or did not report frequency data. Showing some support for the evidence indicating that frequency of home-practice is a key factor related to positive outcomes from MBIs (Fischer et al., 2020). However, the small sample size in the current study prevents form conclusions from being drawn.

The ‘Two Hearts’ mindful parenting programme employed in this study was designed for general parenting stress, however discussions around visible difference arose during group support session. The parents in this study included children with various conditions (craniofacial conditions, birthmarks, tumours, alopecia, and limb differences). One sense that arose from participant discussions was that the level of perceived family stress brought about by the visible nature of the child’s condition varied. Times of active treatment or exacerbations in associated health concerns may be particularly stressful for families (von der Lippe et al., 2022) and families differed with regards to where they currently were on this journey, with some receiving active treatment during the programme. Transitions at school or meeting new people were also reported to be challenging for some. Therefore, the stressors faced by these parents are complex and interconnected.

The extent to which parents personalised targets were impacted by their child’s visible difference varied, although all parents reported experiencing some impact. As such, the extent to which the mindful parenting programme influenced stresses particularly related to children’s visible differences likely also varied. The stressors experienced by parents of children living with a visible difference in this study were complex and related to child health (for some), appearance related difficulties and general parenting (Costa et al., 2021).

Strengths, Limitations, Clinical Implications, and Future Directions

Reliable improvements occurred from baseline to pre-intervention on measures of mindful parenting and parenting stress for two participants. It is possible that this is due to measurement effects associated with the SCED daily measurements from baseline through intervention. Research has found that asking participants questions can result in behaviour change (Godin et al., 2008). However, one participant experienced a reliable deterioration in parenting stress at pre-intervention. Therefore, these changes may reflect the complexity of stressors within this population.

It is usual in SCED studies to have both positive and negative valanced targets, however this felt difficult for some participants in the current study. A future study may consider sending targets in separate text messages to enhance clarity around the rating scale for each question.

This study has limited generalisability due to the small sample size. Despite this, SCED research is beneficial as the development of personally meaningful targets are important for truly measuring effectiveness, feasibility, and acceptability of interventions. Future research studies are needed to build on the findings presented here in larger randomised control trials.

Although the presence of parenting stress was specified as an inclusion criterion, low levels were reported on standardised measures at baseline for several participants. A similar issue was reported in two recent similar studies (Heapy et al., 2022; Sherwood et al., 2023). Using this measure to identify change is therefore limited. Future studies could utilise wellbeing measures alongside stress measures to investigate different mechanisms of change. Furthermore, the current mindful parenting programme should be trialled with samples who report more elevated stress or distress.

Furthermore, the SDQ used to measure child outcomes was chosen for its brevity and use in clinical practice over such measures as the child behaviour checklist (Achenbach & Edelbrock, 1991; Goodman & Scott, 1999). However, this measure is intended to be used as a screening tool over longer periods of time (six months to one school year), and therefore may not have been sensitive enough to measure change within the current study. A future study might consider utilising a quality-of-life measure if conducting research with non-clinical child populations.

One limitation of this study is that online group sessions were facilitated by the same researcher who conducted data collection. While participants were informed that group support sessions were provided following a pre-described structure and encouraged to provide honest feedback, this may still have had a bearing on participant evaluation form responses. Thus, it may be preferable to have these two roles designated separately.

The participants in the current study were predominantly female, all were white and educated to GCSE level or above. This underrepresentation is a limitation that has been recognised across psychology research generally (Henrich et al., 2010) and MBIs specifically (Bautista et al., 2022). Enhanced engagement work within the visible difference community may support equity of access.

Some participants reported that they would prefer all intervention materials, including worksheets, to be on the webpage rather than in online and PDF format. Future developments to the programme might consider fully integrating all content into an online format. This adjustment would also improve measurability of engagement.

Future randomised studies should be employed to further investigate the effects of this Mindful Parenting Programme with a larger sample in order to draw firmer conclusions regarding the effectiveness. Furthermore, ‘dose’ effects should be measured through a two-arm comparison study.

Conclusions

In conclusion, participation in the brief, online Mindful Parenting programme ‘Two Hearts’ resulted in reductions in parenting stress for some parents of children living with a visible difference, thus such an intervention may be beneficial for this population. Improvements may be associated with increased levels of mindful parenting. The programme appears to be feasible and acceptable to parents, with the benefits of overcoming issues of access to traditional in-person mindful parenting programmes. Further research should employ randomised controlled designs to explore the effects of this intervention further with consideration of ‘dose’ effects, effects for different populations, choice of outcome measures, and techniques to accurately assess intervention adherence.

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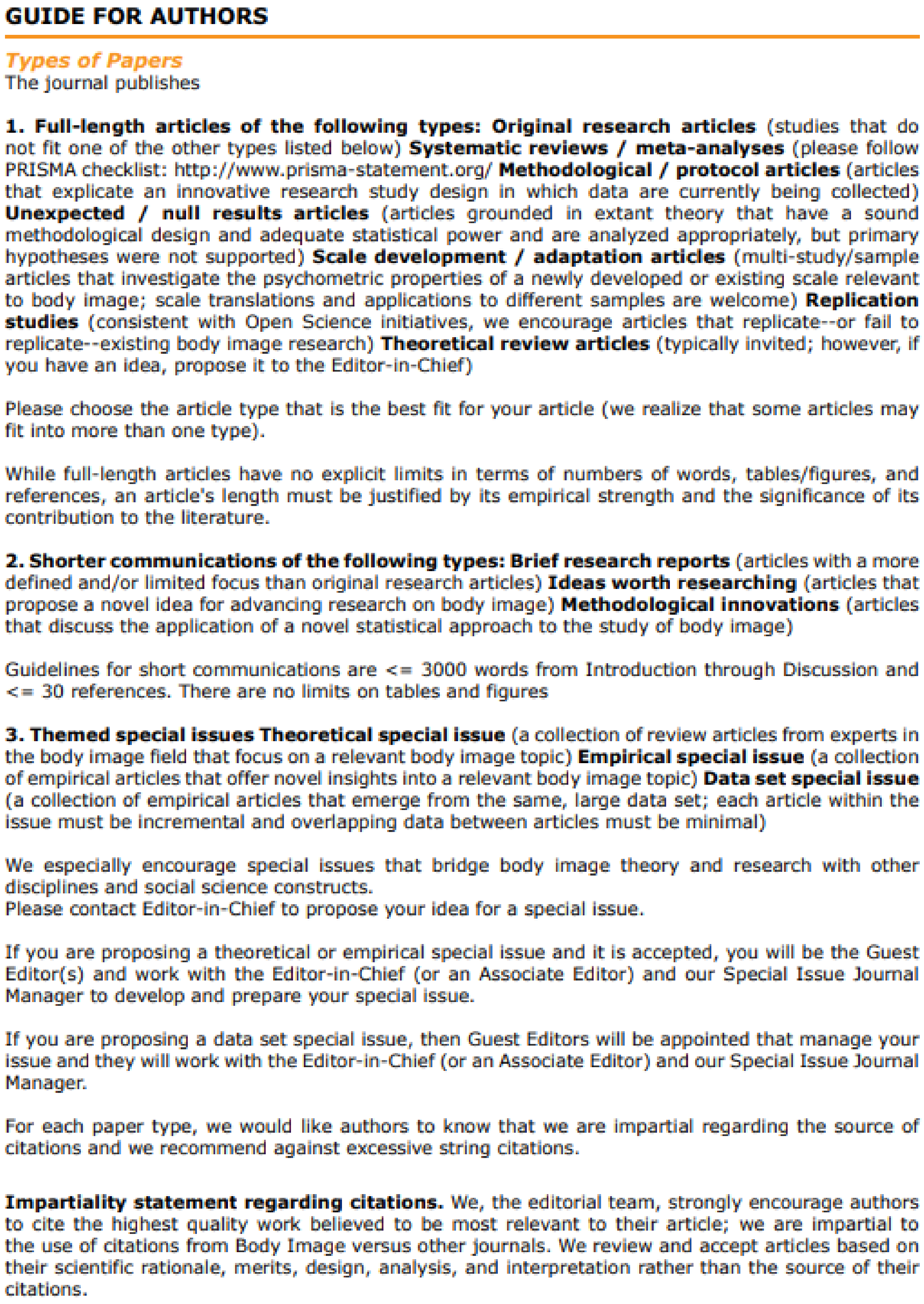
Appendices

Appendix A: Manuscript Submission Guidelines: Body Image



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Please choose the article type that is the best fit for your article (we realize that some articles may fit into more than one type).

While full-length articles have no explicit limits in terms of numbers of words, tables/figures, and references, an article's length must be justified by its empirical strength and the significance of its contribution to the literature.

2. Shorter communications of the following types: Brief research reports (articles with a more defined and/or limited focus than original research articles) **Ideas worth researching** (articles that propose a novel idea for advancing research on body image) **Methodological innovations** (articles that discuss the application of a novel statistical approach to the study of body image)

Guidelines for short communications are <= 3000 words from Introduction through Discussion and <= 30 references. There are no limits on tables and figures

3. Themed special issues Theoretical special issue (a collection of review articles from experts in the body image field that focus on a relevant body image topic) **Empirical special issue** (a collection of empirical articles that offer novel insights into a relevant body image topic) **Data set special issue** (a collection of empirical articles that emerge from the same, large data set; each article within the issue must be incremental and overlapping data between articles must be minimal)

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If you are proposing a theoretical or empirical special issue and it is accepted, you will be the Guest Editor(s) and work with the Editor-in-Chief (or an Associate Editor) and our Special Issue Journal Manager to develop and prepare your special issue.

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Of note, the recommendation to avoid string citations does not apply to: Statements that include more than one finding. For example, "Over the past 10 years, researchers in a number of countries have begun to explore the relationship between positive body image and psychological well-being" needs multiple citations because authors are referring to researchers and countries (both plural. However, reference to all work that has explored this relationship is probably not needed.
As another example, "research shows that body dissatisfaction is correlated with disordered eating, anxiety, and depression" may include multiple citations, with different citations supporting different aspects of this statement. Systematic reviews and meta-analyses whereby the citations are linked to relevant themes/data that are included in the analysis.

The presence of string citations alone is not a reason to reject an article. If submitted articles contain string citations, the editorial team will simply note this, and it will be up to the author to decide whether to retain or remove citations if asked to revise and resubmit their article.

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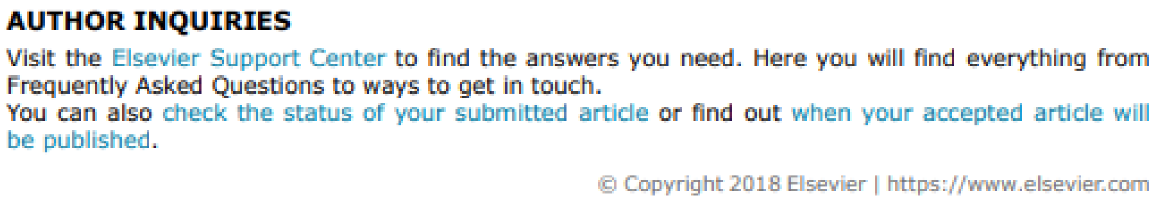


AUTHOR INQUIRIES

Visit the Elsevier Support Center to find the answers you need. Here you will find everything from Frequently Asked Questions to ways to get in touch.
You can also check the status of your submitted article or find out when your accepted article will be published.

Appendix B: Search Strategy

1 Parent*

2 Carer*

3 Caregiver*

4 Mother*

5 Father*

6 Maternal*

7 Paternal*

8 Family

9 Families

10 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9

11 “Visible difference*”

12 “Visibly different”

13 Disfigure*

14 “Appearance concern*”

15 “Appearance altering condition”

16 “Appearance altering injury”

17 “Altered appearance”

18 11 or 12 or 13 or 14 or 15 or 16 or 17

19 Alopecia

20 Scar

21 Scarring

22 “Skin condition*”

23 Albinism

24 Vitiligo

25 “Epidermolysis bullosa”

26 Psoriasis

27 Eczema

28 “Limb difference”

29 Limb defect

30 Limb deform*

31 Neurofibromatos?s

32 Craniofac*

33 Orbitofacial*

34 “Cleft lip”

35 “Cleft Palate”

36 “Congenital Melanocytic Nev*”

37 CMN

38 Port-Wine Stain

39 Hemangioma

40 Vascular Malformations

41 Birthmark

42 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41

43 “Social experience*”

44 “Social reaction*”

45 “Social response*”

46 Stigma*

47 Bullied

48 Bullying

49 43 or 44 or 45 or 46 or 47 or 48

50 42 and 49

51 18 or 50

52 Qualitative

53 Interview

54 “Focus group*”

55 “Thematic analysis”

56 “Discourse analysis”

57 “Interpretative phenomenological analysis”

58 IPA

59 “Grounded theory”

60 “Mixed methods”

61 “Content Analysis”

62 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61

10 and 51 and 62

1. (Parent* or Carer* of Caregiver or Mother* or Father* or Maternal* or Paternal* or Family or Families)

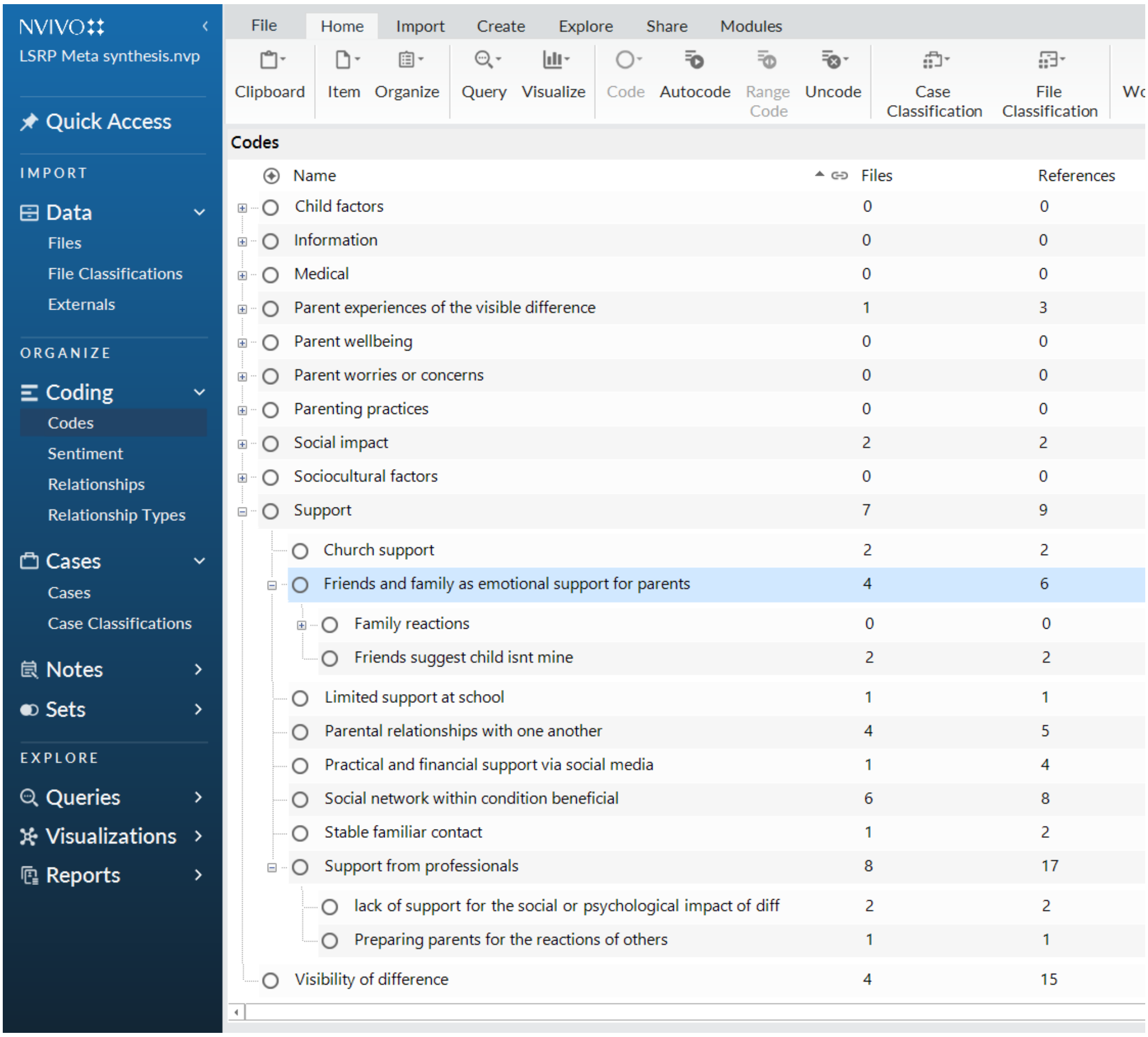
And

2. (“Visible difference*” or “Visibly different” or Disfigure* or “Appearance concern*” or “Appearance altering condition” or “Appearance altering injury” or “Altered appearance”) or ((Alopecia or Scar or Scarring or “Skin condition” or Albinism or Vitiligo or “Epidermolysis bullosa” or Psoriasis or Eczema or “Limb difference” or “Limb defect” or “Limb deform*” or Neurofibromatos?s or Craniofac* or Orbitofacial* or “Cleft lip” or “Cleft Palate” or “Congenital Melanocytic Nev*” or CMN or Port-Wine Stain or Hemangioma or Vascular Malformations or Birthmark) and (“Social experience*” or “Social reaction*” or “Social response*” or Stigma* or Bullied or Bullying))

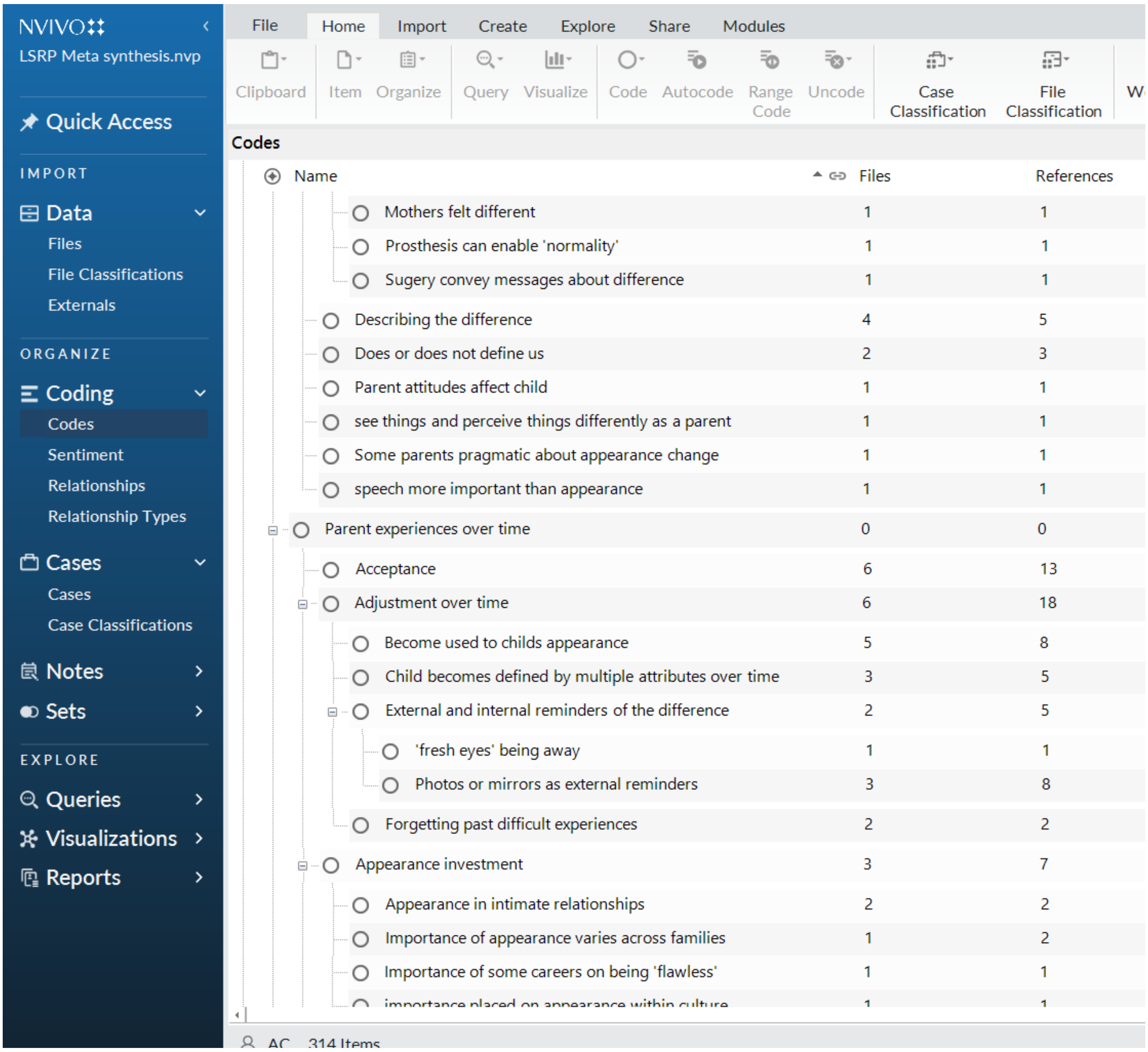
And

3. (Qualitative or Interview or “Focus group*” or “Thematic analysis” or “Discourse analysis” or “Interpretative phenomenological analysis” or IPA or “Grounded theory” or “Mixed methods” or “Content Analysis”)

Appendix C: Synthesis Process Examples

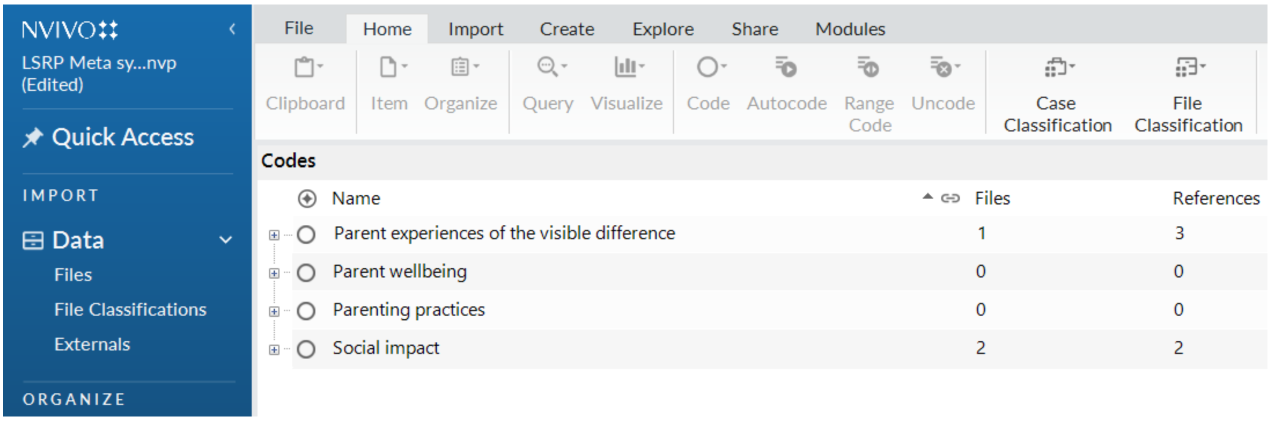


Name	Files	References
Child factors	0	0
Information	0	0
Medical	0	0
Parent experiences of the visible difference	1	3
Parent wellbeing	0	0
Parent worries or concerns	0	0
Parenting practices	0	0
Social impact	2	2
Sociocultural factors	0	0
Support	7	9
Church support	2	2
Friends and family as emotional support for parents	4	6
Family reactions	0	0
Friends suggest child isnt mine	2	2
Limited support at school	1	1
Parental relationships with one another	4	5
Practical and financial support via social media	1	4
Social network within condition beneficial	6	8
Stable familiar contact	1	2
Support from professionals	8	17
lack of support for the social or psychological impact of diff	2	2
Preparing parents for the reactions of others	1	1
Visibility of difference	4	15



Codes

Name	Files	References
○ Mothers felt different	1	1
○ Prosthesis can enable 'normality'	1	1
○ Sugery convey messages about difference	1	1
○ Describing the difference	4	5
○ Does or does not define us	2	3
○ Parent attitudes affect child	1	1
○ see things and perceive things differently as a parent	1	1
○ Some parents pragmatic about appearance change	1	1
○ speech more important than appearance	1	1
○ Parent experiences over time	0	0
○ Acceptance	6	13
○ Adjustment over time	6	18
○ Become used to childs appearance	5	8
○ Child becomes defined by multiple attributes over time	3	5
○ External and internal reminders of the difference	2	5
○ 'fresh eyes' being away	1	1
○ Photos or mirrors as external reminders	3	8
○ Forgetting past difficult experiences	2	2
○ Appearance investment	3	7
○ Appearance in intimate relationships	2	2
○ Importance of appearance varies across families	1	2
○ Importance of some careers on being 'flawless'	1	1
○ importance placed on appearance within culture	1	1



Codes

Name	Files	References
○ Parent experiences of the visible difference	1	3
○ Parent wellbeing	0	0
○ Parenting practices	0	0
○ Social impact	2	2

Appendix D: CASP Quality Appraisal Details

	Clear aims stated	Qualitative methodology appropriate	Research design appropriate	Recruitment strategy appropriate	Data collection appropriate	Relationship and reflexivity	Ethical considerations	Rigorous data analysis	Findings clearly stated	Value of research	Total score
Barke, Coad & Harcourt (2016)	✓ Yes - to explore parents experiences of caring for a child or young person with NF1 and their support needs. 2/2	✓ Yes – qualitative methodology used to complete an in-depth exploration of parents' experiences. 2/2	✓ Yes – TA was used to maintain rich data where there are diverse experiences. 2/2	✓ Yes – inclusion and exclusion criteria is outlined and recruitment strategy discussed. 2/2	? Can't tell – interviews were conducted, audio recorded and transcribed verbatim. However, it is not clear whether there was a topic guide. 1/2	X No – neither the relationship between the researcher and participant or reflexivity was discussed. 0/2	✓ Yes – ethical approval noted, consent processes appear thorough. 2/2	✓ Yes – clear process of data analysis steps including verification of these processes throughout with second and third authors. 2/2	✓ Yes – clear statement of findings linked to the original research question with exemplar quotation, verification processes with second	✓ Yes- findings are considered in relation to existing research. Clinical implications and areas for future research discussed. 2/2	17

									and third authors outlined. 2/2		
Moss, Johnston, & Thompson (2020)	✓ Yes – to explore parent and child experiences of childhood vitiligo with specific focus on naturalistic adaptation. Reason and rationale clear.	✓ Yes – to understand experiences and adaptation. 2/2	✓ Yes – explanation for use of multi-perspective IPA to investigate how a phenomena is experience by connected individuals. 2/2	✓ Yes – recruitment strategy and inclusion/ exclusion criteria discussed. 2/2	✓ Yes – semi-structured interview informed by an interview schedule. Audio recorded data. Saturation not discussed. 2/2	✓ Yes – relationship between researcher and participants considered and reflexivity discussed. 2/2	✓ Yes – ethical approval granted and informed consent / assent received however limited detail given. 2/2	✓ Yes – analysis processes clearly stated including notation of thoughts, observations, and reflections. 2/2	✓ Yes – statement of findings clear and linked to research question, audit of analytic process noted to ensure credibility of findings. 2/2	✓ Yes – findings discussed in relation to existing evidence, theoretical and clinical implications discussed. 2/2	20

	2/2										
Nelson, Kirk, Caress & Glenny (2012)	✓ Yes – To complete an in-depth exploration of parents emotional and social experiences of caring for children with clefts across age ranges from birth to young adulthoo	✓ Yes – To gain an in-depth understanding of the complex beliefs and behaviours of parents to produce an interpretive account. 2/2	✓ Yes – explanation of the use of grounded theory in line with their theoretical perspective that knowledge is socially constructed through interactions and situated. 2/2	✓ Yes - inclusion and exclusion criteria clearly outlined and justified.	✓ Yes – use of a topic guide to support conversational style interviews, audio recorded and transcribed verbatim. Discussion around saturation. 2/2	✓ Can’t tell – reflexivity discussed considering expertise and various perspectives of the team however, relationship of interviewers to the participants specifically was not covered. 1/2	✓ Yes – details of ethical approval and informed consent provided. Researchers have considered participants potential support needs after the interview and informed consent as emergent. 2/2	✓ Yes – analysis processes clearly explained, clear discussion of the team processes to enhance rigor including searching for disconfirming evidence. 2/2	✓ Yes – explanation the one category will be discussed in detail. Findings clearly related to the research question. Good discussion of variation within subthemes. Various aspects	✓ Yes – contribution to the evidence base, links with other literature, implications for policy and clinical practice and suggestions for further research all	19

	d. Reason and rationale clear. 2/2								of methodological rigor discussed including multiple analysts. 2/2	discussed. 2/2	
Netherton, Horton, Stock, Shaw, Noons, & Evans (2021)	✓ Yes –to explore psychological adjustment to Apert syndrome from the viewpoint of both young people	✓ Yes –a broad explanation of family's experiences was sought. 2/2	✓ Yes - justification given for the use of IPA. 2/2	✓ Yes - inclusion and exclusion criteria clearly outlined and justified. 2/2	✓ Yes - semi-structured in-person individual interviews employing a topic guide, audio recorded and transcribed verbatim.	? Can't tell - the authors note drawing on their expertise in the area, reflecting on their own experiences and engagement with support and feedback	✓ Yes – ethical approval was granted. Informed assent and consent was gained. 2/2	✓ Yes – analysis process clearly explained. Reflectiveness evident. 2/2	✓ Yes – findings are clearly stated and linked to the research question. Secondary analysis by	✓ Yes – contribution to existing evidence noted and links made, implications identified for policy and	19

	and their parents. 2/2				2/2	from colleagues. 1/2			another author and team review improves credibility. 2/2	clinical practice, finally suggestions for further research discussed. 2/2	
Oliver, Dixon, & Murray (2020)	✓ Yes – to learn about the experiences of parents of children with limb difference who have been	✓ Yes – to learn about parents' experiences and how they make sense of these experiences. 2/2	✓ Yes – rationale for choice of IPA to explore meaning and sense-making of phenomena. 2/2	✓ Yes – recruitment strategy and sample size discussed, inclusion/exclusion outlined, and rationale given. 2/2	✓ Yes – could have included more information about choice of telephone interviews. Use of topic guide described, audio recording	? Can't tell – the author describes reflexivity. Relationship between researcher and participants not discussed. 1/2	? Can't tell – noted institutional ethics committee approval granted. No discussion of consent processes. 1/2	✓ Yes – noted a stance of reflexivity brought to the analysis process. Process clearly explained. Another	✓ Yes – clear statement of findings linked with original research question; second author audited	✓ Yes – discussed findings in relation to existing research, implications, and transferability of findings.	18

	provided with an artificial limb and their sense making. Reason and rationale clear. 2/2				and transcription noted. 2/2			author audited processes. 2/2	processes. 2/2	2/2	
Stock & Rumsey (2015)	✓ Yes – to explore fathers experiences of having a child born with a cleft lip and/or palate.	✓ Yes – a qualitative approach is employed to explore father's experiences to collect rich data. 2/2	✓ Yes - thematic analysis was employed to identify and organise patterns within rich data to provide a	✓ Yes - the inclusion criteria are outlined and rationale provided for broad inclusivity (exploratory study).	✓ Yes - it was not explained why telephone interviews were used. Audio recorded interviews which employed a	X No - relationship between the researcher and participants or reflexivity was not discussed. 0/2	✓ Yes - ethical approval obtained, the authors refer to ethical codes of conduct and key processes.	✓ Yes - the analysis process is described in depth, how themes were identifie	✓ Yes - the findings are clearly stated, the two authors discussed themes, completed	✓ Yes - links made to existing literature, areas for further research discussed, implicati	18

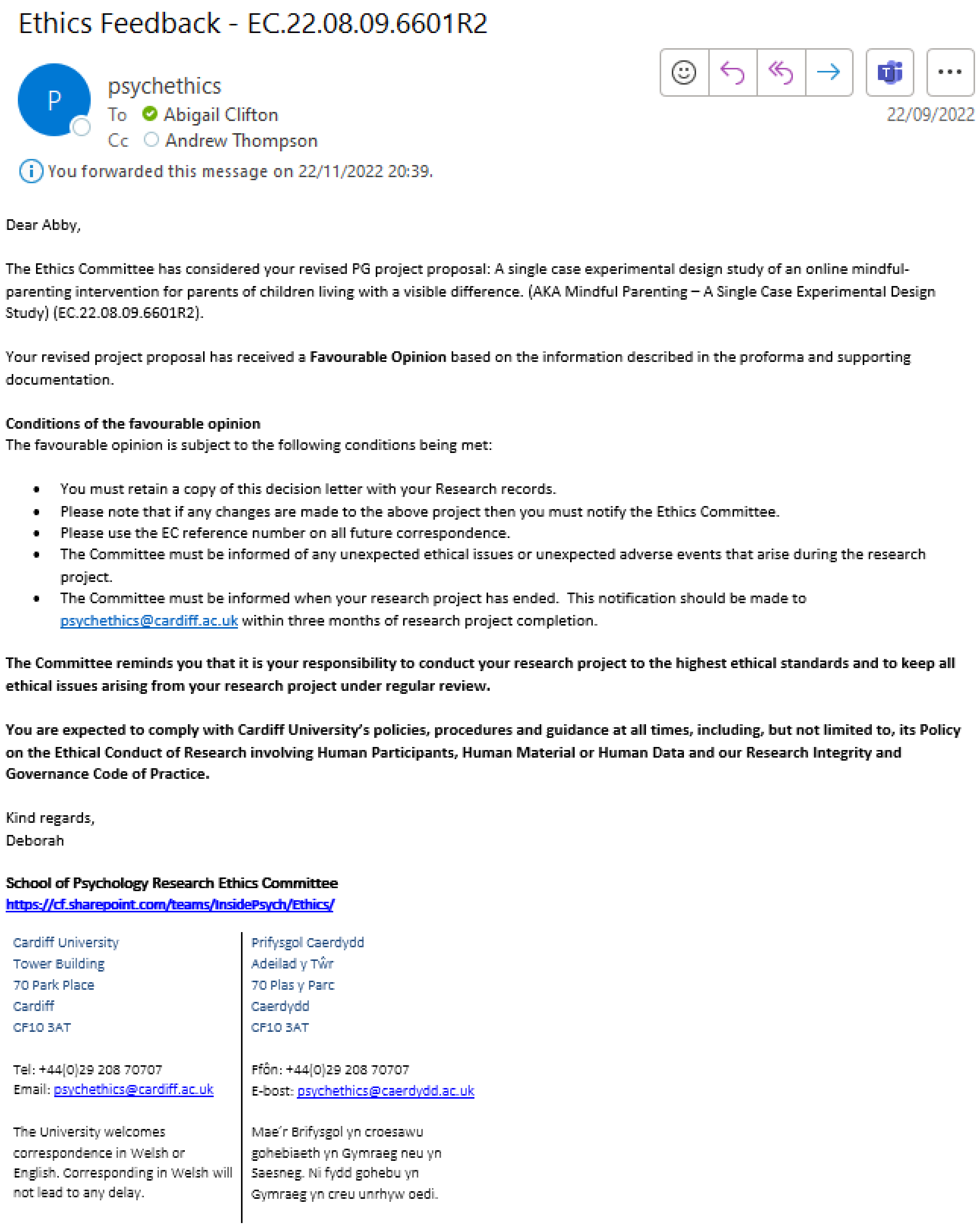
	2/2		rich overall description. 2/2		topic guide. Saturation discussed. 2/2		Professional boundaries and emotional/ support needs of clients considered. 2/2	d is outlined. 2/2	respondent validation, and linked findings to the original research question. 2/2	ons for practice outlined, generalisability considered. 2/2	
Thornton, Harcourt, Deave, Kiff & Williamson (2021)	✓ Yes - 1) To explore the experiences and needs of parents of children living with visible	✓ Yes - to explore experiences, support needs, risk factors and protective factors for parents of children living with a visible difference.	✓ Yes - rationale provided for the use of a critical realist perspective, via semi-structured interviews for systematic exploration	✓ Yes - noted the use of purposive sampling to capture diverse experiences and cross-condition themes and opportunistic sampling	✓ Yes - noted telephone, videoconferencing and in-person interviews to enhance accessibility. In-person focus groups. Employed	X No - the researchers acknowledge the clinical expertise brought to the data analysis and the resultant use of template analysis. No other	✓ Yes - ethical approval obtained and informed consent processes noted. Lack of further details.	✓ Yes - the analysis process is clearly defined, the authors noted that cross condition themes only were	✓ Yes – findings are clearly outlined and linked to original research question, second coder reviewin	✓ Yes - links made to existing research, identification of further research, transferability considered.	18

	differences across conditions, 2) to recognise both risk and protective factors for these parents’ psychosocial adjustment. 2/2	2/2	of topics and focus groups with an interactive element which may increase depth of injury. 2/2	for focus groups. 2/2	a topic guide. Interviews were audio-recorded and transcribed verbatim. Unclear how focus group data was recorded. 2/2	discussion around reflexivity or the relationship between participants and researcher. 0/2	2/2	highlighted. 2/2	g increases credibility of findings. 2/2	2/2	
Williamson, Harcourt, Halliwell, Frith and	✓ Yes – to investigate: 1) adolescents’	✓ Yes - to gain a practically useful and detailed insight into	? Can't tell - authors describe the use of photographs to enhance the	? Can't tell - information regarding recruitment is limited. No inclusion,	? Can't tell - Combination of in person semi-structured interviews	X No – neither reflexivity or the relationship between participants and	? Can’t tell – ethical approval obtained. Lack of further details	✓ Yes - the analysis process is clearly defined. Sufficient data is	✓ Yes - findings are clearly outlined and linked to	✓ Yes - links made to existing research, identification of	14

Wallace (2010)	perceptions of appearance change during cancer treatment 2) psychosocial and personal impact of appearance change for these adolescents 3) how do adolescents and their families	experiences. 2/2	interview process and state the use of template analysis but the detail is limited. 1/2	exclusion criteria noted, participant approach processes not stated. 1/2	and online surveys. Rationale for addition of survey noted. Use of topic guide likely, but not noted. Interviews were transcribed verbatim, likely audio recorded but not stated. No discussion of saturation. 1/2	researcher were discussed. 0/2	regarding consent processes. 1/2	presented, including variability within themes. 2/2	original research question, team review of findings and response validation enhances the credibility of findings. 2/2	further research, and transferability of findings considered. 2/2	

	manage this 4) how might provision of care meet populations needs. 2/2										

Appendix E: Ethical Approval Letter



Ethics Feedback - EC.22.08.09.6601R2

psychethics
To Abigail Clifton
Cc Andrew Thompson

22/09/2022

You forwarded this message on 22/11/2022 20:39.

Dear Abby,

The Ethics Committee has considered your revised PG project proposal: A single case experimental design study of an online mindful-parenting intervention for parents of children living with a visible difference. (AKA Mindful Parenting – A Single Case Experimental Design Study) (EC.22.08.09.6601R2).

Your revised project proposal has received a **Favourable Opinion** based on the information described in the proforma and supporting documentation.

Conditions of the favourable opinion
The favourable opinion is subject to the following conditions being met:

- You must retain a copy of this decision letter with your Research records.
- Please note that if any changes are made to the above project then you must notify the Ethics Committee.
- Please use the EC reference number on all future correspondence.
- The Committee must be informed of any unexpected ethical issues or unexpected adverse events that arise during the research project.
- The Committee must be informed when your research project has ended. This notification should be made to psychethics@cardiff.ac.uk within three months of research project completion.

The Committee reminds you that it is your responsibility to conduct your research project to the highest ethical standards and to keep all ethical issues arising from your research project under regular review.

You are expected to comply with Cardiff University's policies, procedures and guidance at all times, including, but not limited to, its Policy on the Ethical Conduct of Research involving Human Participants, Human Material or Human Data and our Research Integrity and Governance Code of Practice.

Kind regards,
Deborah

School of Psychology Research Ethics Committee
https://cf.sharepoint.com/teams/InsidePsych/Ethics/

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The University welcomes correspondence in Welsh or English. Corresponding in Welsh will not lead to any delay.	Mae'r Brifysgol yn croesawu gohebiaeth yn Gymraeg neu yn Saesneg. Ni fydd gohebu yn Gymraeg yn creu unrhyw oedi.

Appendix F: Participant Information Sheet

Participant Information Sheet

Study title: A single case experimental design study of an online mindful-parenting intervention for parents or carers of children living with a visible difference.

You are invited to take part in a research study about an online mindful parenting programme for parents or carers of children aged 4-16 years living with a visible difference (any appearance affecting scarring, condition, or mark). The aim of the study is to learn whether parents or carers find the programme acceptable, practical, and helpful. As part of this research, we are inviting parents or carers of children living with a visible difference to take part in a six-week online mindful parenting programme called ‘Two Hearts’. Please see below details of this study.

Please take time to read this information sheet carefully. It is important that you understand what is involved in the study, before deciding whether you would like to participate.

Who is conducting this study?

The study is being conducted by Abigail Clifton (Trainee Clinical Psychologist) as part of her clinical psychology doctoral training. The study is being supervised by Dr Andrew Thompson, a Professor at Cardiff University and Dr Lisa Marie Emerson, a Senior Lecturer at Canterbury University.

What is the purpose of this study?

The purpose of the study is to learn whether the Two Hearts online mindful parenting programme is practical and acceptable to parents or carers of children living with a visible difference, and whether taking part reduces parental stress and enhances child wellbeing. To my knowledge, no studies to date have researched mindful parenting programmes with parents of children living with a visible difference.

Why have I been invited to participate in this study?

Research has indicated that living with a visible difference can be challenging for children, young people, and their families. Previous studies have shown that taking part in mindful parenting programmes can reduce parental stress and enhance wellbeing in their children. From this study we hope to learn more about potential interventions to support these families.

If I take part, will my information be confidential?

Yes, all identifiable information will be removed or altered. During group support sessions, all participants will be reminded to keep information shared in the sessions confidential. Participants will not be asked to share any personal information in these sessions if they do not wish to do so.

Do I have to participate in this study?

No, taking part in the study is completely voluntary. You can choose not to participate. If you choose to take part, but later change your mind, you can do so without having to give a reason.

Who can participate in this study?

You can participate in this study if:

- You are a parent or carer of a child who is living with a visible difference aged between four (4) and 16 years old
- You are aged 16 or over
- You are experiencing stress, worry or concern associated with your child's visible difference

Who cannot participate?

Unfortunately, you will not be eligible to participate in this study if:

- You are a parent or carer under 16 years old
- You are currently receiving psychological support from mental health services
- You are currently experiencing active thoughts of suicide or self-injury
- You have experienced a psychotic episode or engaged in deliberate self-injury over the past year
- You have started taking mood altering medications (such as antidepressants) in the last two months
- You have taken part in a mindful parenting programme in the past
- Your child living with a visible difference is currently in an acute phase following a physical injury
- The co-parent in your household is taking part in this study

What happens if I take part?

If you decide to take part in this study, you will complete an initial interview with Abigail Clifton (the researcher) to determine whether this study will be suitable for you. If you are found to be eligible to take part in the study, you will be asked to complete a consent form and provide some information about yourself and your child via an online questionnaire platform (Qualtrics). The questionnaires will ask you about parenting stress, mindfulness, and your views about your child's general wellbeing. You will be asked to start the Two Hearts mindful parenting programme once enough participants have been recruited; this will be at least two weeks after completing the initial questionnaires. The mindful parenting programme consists of a booklet split into an introduction and three modules, three mindfulness audio exercises and ten brief video exercises to be completed over six weeks. Four group support sessions will be scheduled throughout the programme via videoconferencing. The intention of these sessions is to problem solve any difficulties participants may be having with the mindful parenting programme. To support participants to access and make use of the programme materials and complete home practice. As part of the programme, you will be encouraged to practice mindfulness as part of your daily life. This daily practice is important for the programme to be beneficial. You will also be invited to take part in an exit interview whether or not you complete the programme.

What will happen to my data?

The data you provide will be securely retrieved from Qualtrics. This data will be stored with an anonymous participant number assigned on a spreadsheet on a password protected computer managed by Abigail Clifton.

You will only be contacted by members of the study team named above. Your personal data, such as your telephone number and email address will only be retained for the study period, it will then be deleted. If you decide to withdraw from the study and do not wish to participate in an exit interview, then your information will be deleted at your request.

If you choose to participate in the exit interview an additional information sheet and consent form will be provided to you. The exit interview will be audio recorded or notes will be taken in line with your preference. Abigail Clifton will transcribe any audio data collected. Audio data will be stored on an encrypted memory stick and deleted within six weeks of the completion of the interview.

The anonymised results from this study will be reviewed by the study team named above. These anonymised results will be incorporated into Abigail Clifton's doctoral thesis. We also hope to publish results in a research paper. This anonymised data will be kept for five years in line with university policy.

What are the risks of taking part?

The mindful parenting programme will take around 14 hours of your time, watching the online videos, and completing practices. In addition, you will be encouraged to spend at least 20 minutes each day, five days a week, completing home practice.

Not everyone finds mindfulness-based programmes helpful, some may even find them unhelpful. You will be asked to complete a screening interview to check the programme will be appropriate for you, this will take approximately 20-40 minutes. You will be provided with a list of services that you can contact if you are experiencing high levels of distress.

You will be asked to provide the following information as part of this study:

- You will be asked to complete some questionnaires when you sign up to the study, just before you begin the programme, when you have completed the six-week programme, and four weeks after you completed the programme. It is estimated that this will take 20-40 minutes each time. This will include providing information about the nature of your child's visible difference.
- You will be asked to provide a response to two questions (providing only two numerical responses) daily via secure text message, this should take less than five minutes each day.
- You will also be asked to complete feedback weekly about how much time you have spent using programme materials and engaging in home practice, this should take less than five minutes each week.
- Finally, you will be asked to take part in an exit interview, this will take about 30-60 minutes.

If you choose to participate in the exit interview an additional information sheet and consent form will be provided to you. The interview will either be audio recorded or notes will be taken in line with your preference. Abigail Clifton will transcribe any audio data collected. Transcribed recordings or notes taken will be fully anonymised and stored on a secure computer. Audio data will be stored on an encrypted memory stick and deleted within six weeks of the completion of the interview.

The support sessions will be completed as part of a group and will involve interacting with other parents taking part in the study. At the beginning of these sessions participants will be reminded that any information shared in these sessions is to remain confidential and not to be shared outside of the session. No data will be collected during these sessions other than attendance data.

What are the benefits of taking part?

We hope that taking part may be of benefit to some individuals and families. It is possible that engaging in the mindful parenting programme may improve wellbeing in parents or carers and children. Taking part in this programme may help others as it will enable us to learn how we might better support families with a child who is living with a visible difference.

How do I take part?

If you are interested in taking part, please contact Abigail Clifton on cliftona3@cardiff.ac.uk. You will be invited to complete a telephone or videoconference-based screening interview. If you are then invited to take part in the study, you need to carefully read and complete the consent form which will be shared with you following your screening interview. If you have any questions about the study, please contact Abigail Clifton on cliftona3@cardiff.ac.uk.

If you have any concerns about this study and would like to speak to someone outside of the research team, please contact the School of Psychology Research Ethics Committee.

School of Psychology Research Ethics Committee
Secretary to the Research Ethics Committee School of Psychology
Tower Building
70 Park Place, Cardiff, CF10 3AT
Email: psychethics@cardiff.ac.uk
Tel: 029 2087 0707

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

Appendix G: Consent Form

Please tick the appropriate boxes	Yes	No
Taking part in the project		
I have read and understood the study information sheet (V.1.0 EC.22.08.09.6601R2) or the study has been fully explained to me. (I*f the answer to this question is 'No', please do not proceed with this consent form until you are fully aware of what your participation in the study will mean*.)		
I have been given the opportunity to ask questions about the study.		
I understand that taking part in the study will include the following:		
• Completing a range of questionnaires, some of which will cover issues around mental health and wellbeing.		
• Completing an online mindful parenting programme which will comprise video, audio, and workbook content comprising an introduction and three modules over a period of six weeks. This includes the completion of home practice exercises.		
• Being interviewed about my experiences of the mindful parenting programme.		
I agree to take part in the above study.		
I understand that my taking part is voluntary and that I can withdraw from the study at any time before the 23rd of February 2023; I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.		
How my information will be used during and after the study		
I understand that if the research team were to become very concerned about my wellbeing or the wellbeing of my child that this information may need to be shared with appropriate outside agencies to ensure mine or my child's safety.		
I understand that my personal information such as my name, phone number, address and e-mail address etc. will remain confidential, that is, it will not be revealed to people outside of the research team.		
I understand that my personal information will be stored on a secure database managed by Abigail Clifton and only accessible by Abigail Clifton and Dr Andrew Thompson.		
I understand that my information will be deleted when I complete the study and by October 2023 at the latest.		

I understand and agree that the study team (Abigail Clifton, Dr Andrew Thompson and Dr Lisa Marie Emerson) will have access to anonymised data collected in this study. Anonymised data will be stored for 5 years in line with university policy.		
I understand and agree that my words may be quoted in research outputs such as: publications, reports, and web pages. Any quotations will be fully anonymised, that is, they will not include any identifiable information about me.		
I understand and agree that other authorised researchers may use my anonymised data in research outputs such as: publications, reports, and web pages.		

Name of participant [printed] Signature Date

Contact information:

Researcher: Abigail Clifton cliftona3@cardiff.ac.uk

Principal Investigator: Professor Andrew Thompson thompsona18@cardiff.ac.uk

Appendix H: Further Support Sheet

Further support

If you feel like you need further help and support, there are several different options available.

Your GP

Your GP can help you with any concerns that you may have about yours or your child's mental health, as well as any concerns you have about your child.

NHS services

If your concerns about your mental or physical health are more urgent, then you can contact the NHS helpline on **111.** This service is available 24 hours a day, 365 days a year.

In the event of an emergency, or if you or someone else is in immediate risk of serious harm or injury, then contact emergency services by dialling **999** and stating which service you need.

Alternatively, in the case of an emergency, visit The Accident & Emergency department at your nearest hospital.

Other helplines

There are a range of helplines available that you can call for advice or support.

- **The Samaritans** also offer emotional support for people experiencing mental distress, including those experiencing suicidal thoughts. The Samaritans can be contacted **24 hours a day, 7 days a week** on **116 123**, or you can email **jo@samaritans.org**.
- **SHOUT** offer a free and confidential text messaging based support service for anyone in need of immediate support with mental distress. The service is available **24 hours a day, 7 days a week**. To contact them **text SHOUT** to **85258**.

Alternatively visit www.nhs.uk/livewell/mentalhealth/pages/helplines.aspx for a directory of help lines.

Online resources

The following websites offer a range of information and advice for people experiencing mental distress:

- **C.A.L.L.** https://callhelpline.org.uk/
- **Mind** (https://www.mind.org.uk/)
- **Sane** (http://www.sane.org.uk/)

Appendix I: Participant Debrief Letter

Thank you for taking part in this study. This study was conducted to learn whether a mindful parenting programme would be possible and practical for parents of children living with a visible difference. We also hoped to learn whether or not parents and their children could benefit from the programme. The responses to questionnaires you completed during the study will be compared over time. All questionnaire responses and feedback that you provided during this study has been anonymised. Any personal data collected for study purposes such as your chosen name, email address and telephone number will be deleted now you have competed the study. If you decide that you would like to have your data withdrawn from the study, you can do this without providing a reason before the 1st of February 2023. After this time unfortunately this research will be in preparation for submission as part of Abigail Clifton's Doctoral Thesis and it will not be able to be removed. For more detailed information about this study, you are welcome to access the study information sheet [Information sheet link].

We hope that you did not find any part of completing this study distressing, if you did or if you have any questions or concerns about the study please get in touch with Abigail Clifton (researcher) via email on cliftona3@cardiff.ac.uk. Or, if you would prefer to share any concerns with someone outside of the research study team, you can contact the School of Psychology ethics department:

School of Psychology Research Ethics Committee
Secretary to the Research Ethics Committee School of Psychology
Tower Building
70 Park Place, Cardiff, CF10 3AT
Email: psychethics@cardiff.ac.uk
Tel: 029 2087 0707

Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. The University has a Data Protection Officer who can be contacted at inforequest@cardiff.ac.uk. Further information about Data Protection, including your rights and details about how to contact the Information Commissioner's Office should you wish to complain, can be found at the following: https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection

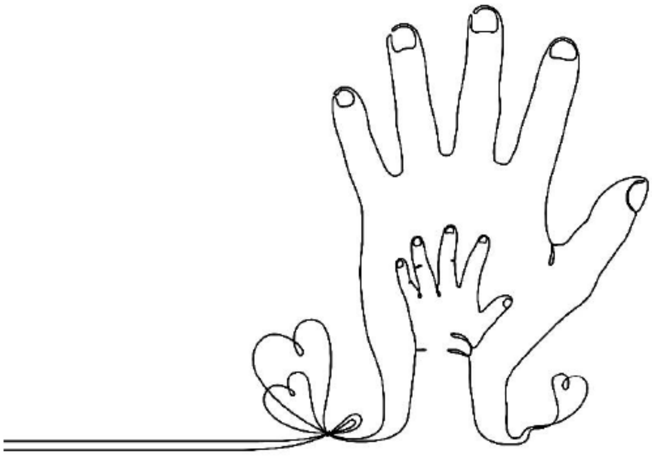
Appendix J: Study Recruitment Advert

Are you a parent or carer of a child who is aged 4-16 years and living with a visible difference?

We are looking for parents or carers of children who are aged 4-16 years and are living with a visible difference. We would like to invite these parents or carers to take part in a six-week, online, Mindful Parenting programme called ‘Two Hearts’, designed to reduce stress and enhance wellbeing.

If interested, please contact Abigail Clifton on

cliftona3@cardiff.ac.uk



Appendix K: Full Eligibility Criteria

Inclusion criteria:

- Parents aged over 16 years, of children aged between four (4)-16 years living with a visible difference
- All types and aetiologies of child visible differences including any scarring, condition, disability, or mark that affects a person's appearance, with confirmation via self-report
- Parent experiencing self-reported stress associated with the child's visible difference
- Able to communicate in verbal and written English
- Access to a computer/tablet with an active internet connection

Exclusion criteria:

- Parent currently accessing psychological therapy for their own wellbeing, including parenting programmes
- Parent experiencing active thoughts of suicide or self-injury
- Parent experienced a psychotic episode or engaged in deliberate self-injury over the past year
- Parent commenced medications for mood in the last two months
- Parent previously accessed a mindful parenting intervention
- Child currently in an acute phase following a physical injury
- Only one parent or carer per household can take part

Appendix L: Evaluation Form

Evaluation of the Mindful Parenting Online Intervention and Personal Change – Adapted from (Bögels & Restifo, 2014)

1. Do you feel you've got something of lasting value of importance because of taking the training?
   a. Yes / No
2. Have you made any changes in your lifestyle, in interactions with your child or family, or in your childcare practices because of the training?
   a. Yes / No
3. Did you become more "conscious" in your parenting because of the training? Did this change something in relation to your thoughts, feelings, and/or your responses to your thoughts and feelings as a parent?
   a. Yes / No
4. Do you intend to keep on practicing the formal exercises, i.e. body scan, sitting practices, 3 min breathing space etc.?
   a. Yes / No
5. Do you intend to continue to practice conscious awareness in everyday life?
   a. Yes / No
6. Has the training been sufficient to move on with your life as a parent?
   a. Yes/no
7. On average, how many times a week did you practice the mindfulness exercises (e.g. body scan, 3-minute breathing space etc.) during the training?

a. Never 1-2 times 3-4 times 5-7 times

8. How much do you ‘pay attention’ to your child when you are together, compared to before the training?

Less than before	As much as before	More than before	Much more than Before

Did, as a result of the Mindful Parenting training, something change on the following issues? (please circle)

Knowing to take better care of myself	Negative change	No change	Some positive change	Positive change
Actually taking better care of myself	Negative change	No change	Some positive change	Positive change
Periods of parental stress or frustration	Negative change	No change	Some positive change	Positive change
Intensity of parental stress or frustration	Negative change	No change	Some positive change	Positive change
Believing that I can improve the relationship with my child and family	Negative change	No change	Some positive change	Positive change
Feeling self-confident as a parent	Negative change	No change	Some positive change	Positive change
Feeling hopeful as a parent	Negative change	No change	Some positive change	Positive change
Dealing with emotions (anger, sadness, fear) in parenting	Negative change	No change	Some positive change	Positive change
Awareness of what is stressful in my life	Negative change	No change	Some positive change	Positive change

Awareness of stressful parenting situations at the time they are happening	Negative change	No change	Some positive change	Positive change
Ability to handle stressful situations appropriately	Negative change	No change	Some positive change	Positive change

Did, as a result of the Mindful Parenting training, something change on the following issues? (please circle)

Parenting	No	Maybe	Yes
Own problems	No	Maybe	Yes
Child’s problems	No	Maybe	Yes
Partner relation problems	No	Maybe	Yes
Family Problems	No	Maybe	Yes

Appendix M: Interpersonal Mindfulness in Parenting Scale (de Bruin et al., 2014)

IMP English (to be completed online, therefore will look different)

Instructions: The following statements describe different ways that parents interact with their children on a daily basis. Please tell me whether you think the statement is “Never True”, “Rarely True”, “Sometimes True”, “Often true”, or “Always True” for you. Remember, there are no right or wrong answers and please answer according to what *really reflects* your experience rather than what you think your experience *should be*. Please treat each statement separately from every other statement.

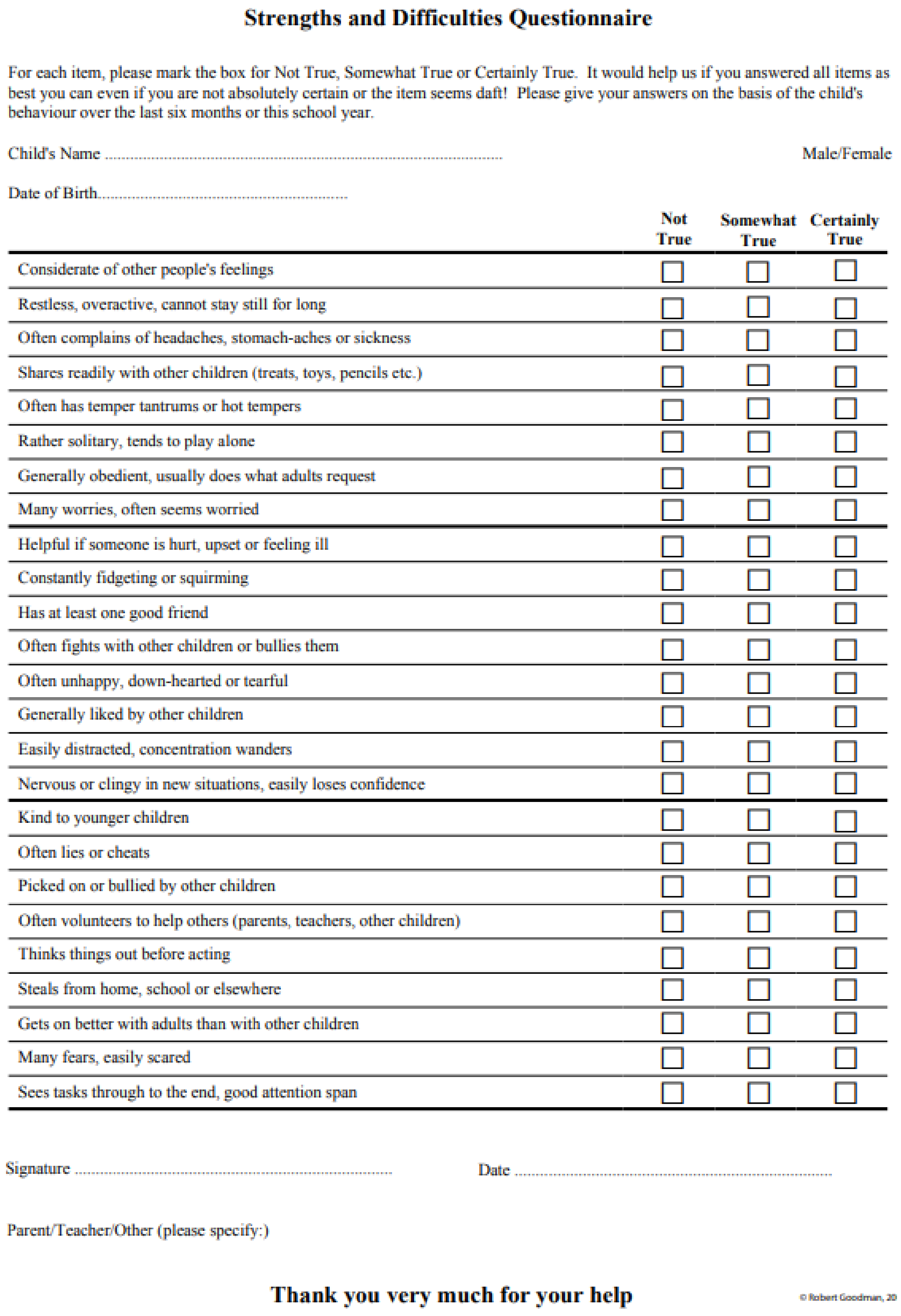
Scoring:

“Never True = 1”, “Rarely True =2”, “Sometimes True =3”, “Often true =4”, or “Always True =5”

1. Not listening to child with full attention.
2. When upset with child, notice feelings before acting.
3. Aware of impact of child mood on own mood.
4. Nonjudgmental listening to child.
5. React too quickly to child.
6. Aware of link between own mood and parenting behaviour.
7. Nonjugdmental receptivity to child emotion.
8. Calmly tell child how feeling when upset.
9. Rushing through activities with child.
10. Trouble accepting child individuation.
11. Emotions affect parenting.
12. Unaware of child’s feelings.
13. Distracted while engaged with child.
14. Regretting parenting actions when upset.
15. Self-critical of parenting mistakes.
16. Effort to keep emotional balance when upset with child.
17. Self-blame during challenges with child.
18. Acceptance of parenting challenges.
19. Busy thinking, not listening to child.
20. Forgiving of self when regret parenting actions.

21. Non-reactivity in difficult moments with child.
22. Aware of child’s worries.
23. Self-criticism of self as parent.
24. Pay attention to child when together.
25. Kind to child when upset.
26. Self-critical comparison with other parents.
27. Caring for child when struggling.
28. Openness to child’s point of view.
29. Emotional reactivity in response to child behaviour.
30. Aware of child’s unspoken feelings.
31. Patient with child when struggling.

Appendix N: Strengths and Difficulties Questionnaire Parent or Carer Completed (Goodman, 1997)



Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Name .... Male/Female

Date of Birth..

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	☐	☐	☐
Restless, overactive, cannot stay still for long	☐	☐	☐
Often complains of headaches, stomach-aches or sickness	☐	☐	☐
Shares readily with other children (treats, toys, pencils etc.)	☐	☐	☐
Often has temper tantrums or hot tempers	☐	☐	☐
Rather solitary, tends to play alone	☐	☐	☐
Generally obedient, usually does what adults request	☐	☐	☐
Many worries, often seems worried	☐	☐	☐
Helpful if someone is hurt, upset or feeling ill	☐	☐	☐
Constantly fidgeting or squirming	☐	☐	☐
Has at least one good friend	☐	☐	☐
Often fights with other children or bullies them	☐	☐	☐
Often unhappy, down-hearted or tearful	☐	☐	☐
Generally liked by other children	☐	☐	☐
Easily distracted, concentration wanders	☐	☐	☐
Nervous or clingy in new situations, easily loses confidence	☐	☐	☐
Kind to younger children	☐	☐	☐
Often lies or cheats	☐	☐	☐
Picked on or bullied by other children	☐	☐	☐
Often volunteers to help others (parents, teachers, other children)	☐	☐	☐
Thinks things out before acting	☐	☐	☐
Steals from home, school or elsewhere	☐	☐	☐
Gets on better with adults than with other children	☐	☐	☐
Many fears, easily scared	☐	☐	☐
Sees tasks through to the end, good attention span	☐	☐	☐

Signature .... Date ....

Parent/Teacher/Other (please specify:)

Thank you very much for your help

Appendix O: Suitability Interview Outline

Participants will be asked about:

1. Child age.
2. Nature of their child's visible difference (to ensure the child is not in an acute phase following an injury).
3. Parent age (i.e. over 16).
4. Their access to a tablet or computer to complete the intervention and literacy (able to communicate in verbal and written English).
5. Parental mental health (including the use of medications), whether parent has engaged in any self-injurious behaviour over the last year, whether parent has any current thoughts of harming themselves in anyway, and whether the parent is currently accessing any psychological therapy.
6. Parental Stress (current and over the past year).
7. Parental experience of mindfulness or meditation.

Information obtained from the screening interview will be used to assess eligibility for the study.

Appendix P: Two Hearts Program Outline

Intervention Phase Processes and Timeline	Module Title & Format	Themes	Mindfulness Practice & Specific Mindful Parenting Exercise	Home Practice
Week 0 The Introductory module (online) was made available to participants prior to the baseline phase ending. The first Group Support Session marked the start of the intervention phase, following this session access was provided to Module 1 (online) and the full parent workbook.	Module 0 - Introductory Module - Programme overview - Group Support Session	- Basic principles of mindfulness and compassion; - Relevance of mindfulness and compassion in parenting stress; Introduction to home practices	- Body Scan (Williams et al., 2007) - Informal practice (i.e., mindful coffee)	N/A
Week 1 & 2 The second Group Support Session was completed at the end of week 2, following this	Module 1 - Mindful Awareness in Parenting - Four short videos, - Audio file,	- Introduction to Mindful Parenting and orientation to programme;	- 3-min Breathing Space	- Parent Workbook readings; - 15 min guided Body Scan practice (1 pd, 5 times pw);

session access was provided to Module 2 (online).	• Program workbook, • Home practices • Group Support Session • Approximately 3 hours	• The evolution of parenting stress; • Body awareness and the stress response; • Finding a Breathing Space	• Imagination: parenting stress exercise	• 3-min Breathing Space (2 pd, 5 times pw) • Mindfulness home practice record (optional)
Week 3 & 4 The Third Group Support Session was completed at the end of week 4, following this session access was provided to Module 3 (online).	Module 2 - Mindful Parenting in Action • Four short videos, • Home practices • Group Support Session • Approximately 3 hours	• Automatic pilot parenting; • Body awareness and Mindful Movement; • Rupture and Repair	• Mindful Movement • Imagination: Rupture and Repair exercise	• Parent Workbook readings; • 15 min guided Body Scan practice (1 pd, 5 times pw); • Breathing Space (2 pd, 5 times pw, and use during stressful interaction); • Parenting Stress Diary (1-3 entries pw); • Rupture and Repair process at home; • Mindfulness home practice record (optional)
Weeks 5 & 6	Module 3 -Compassion in Parenting	• Compassion, Stress and the Body;	• Soothing Rhythm Breathing (Gilbert, 2009)	• Parent Workbook readings;

The final Group Support Session was completed at the end of week 6, marking the end of the intervention phase and beginning of the follow up phase.	• Two short videos, • audio file, • *Useful Resources* PDF, • Home practices • Group Support Session • Approximately 3 hours	• Growing Self-Compassion	• Self-Compassion Break (Neff & Germer, 2013) • Imagination: compassion for self during parenting stress exercise	• ‘*What Do I need?*’ reflective exercise (Bögels & Restifo, 2013; Germer & Siegel, 2012); • Individualised commitment practice based on practices learned to date; • Self-Compassion practices; • Mindfulness home practice record (optional)
	Group Support Sessions (up to 5 parents) • Videoconferencing • Up to 90 minutes, four times during the programme • Online content was released following each Group Support Session.	• Review of individual mindfulness practice and mindful parenting scenarios. • Positive reinforcement of parent efforts. • Collaborative problem-solving of barriers and challenges in mindfulness practices	N/A	N/A

Note. N/A = not applicable; pw = per week; pd = per day

Appendix Q: Figure Showing Visual Analysis With Best Fit, Median, and Range Lines for Increase-Framed Targets

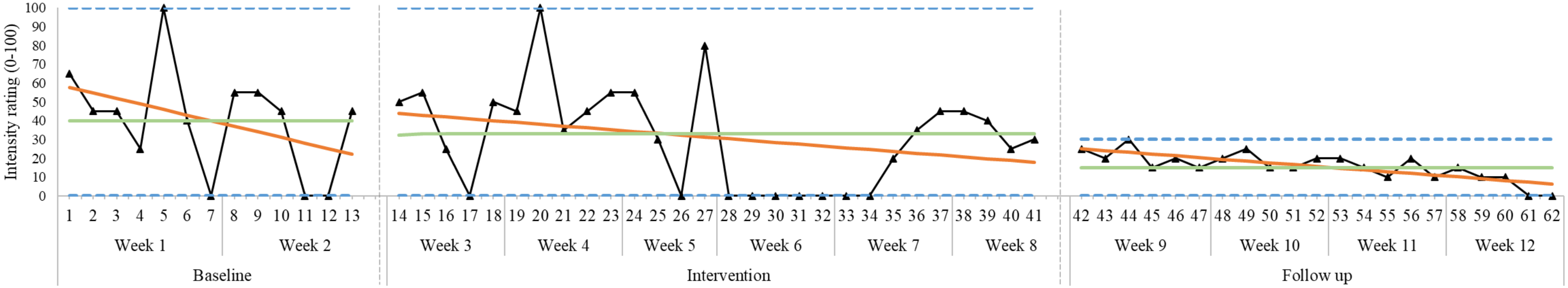
Figure Key.

Best Fit Line —

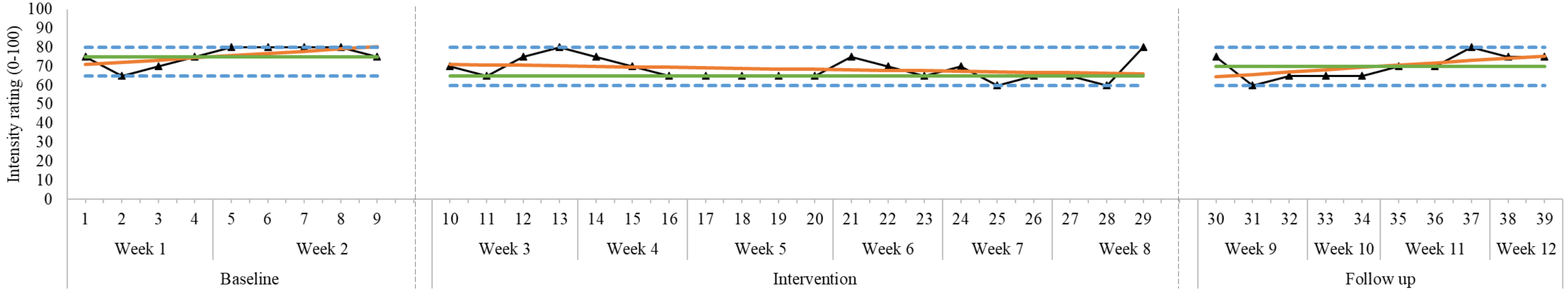
Median —

Range - - - -

Participant 1



Participant 2



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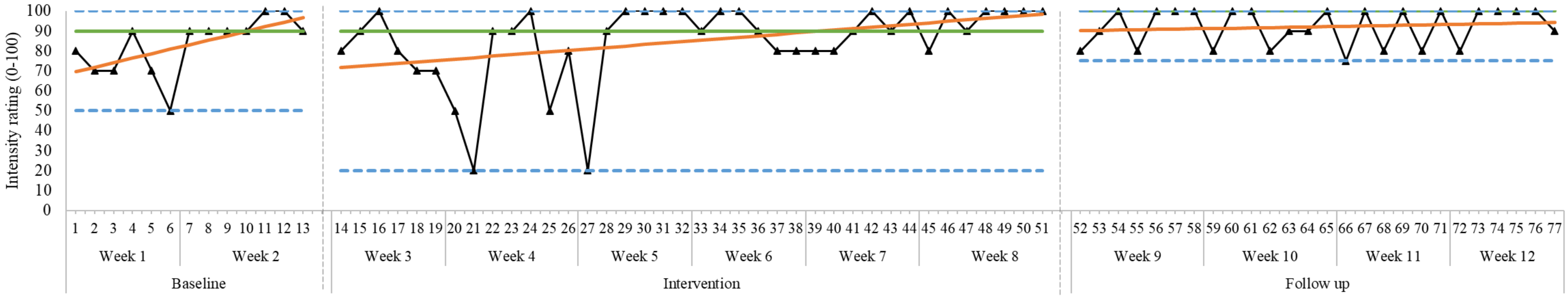

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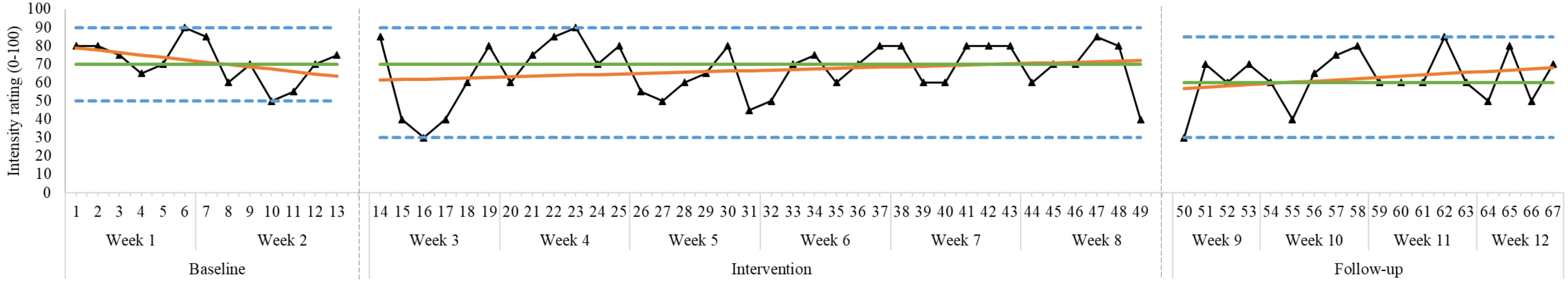

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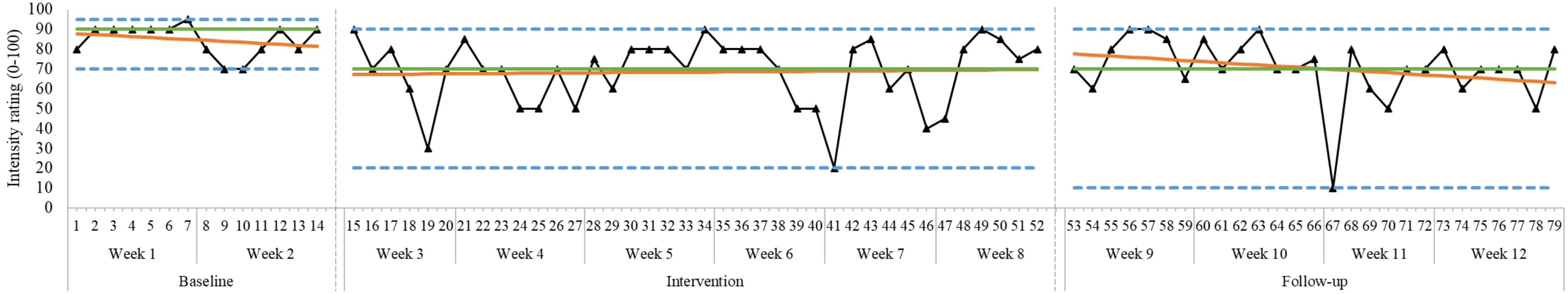

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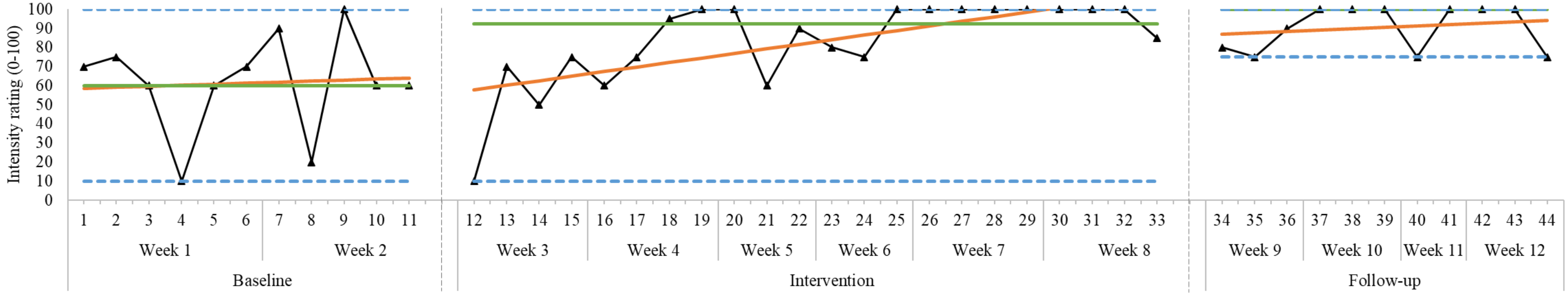

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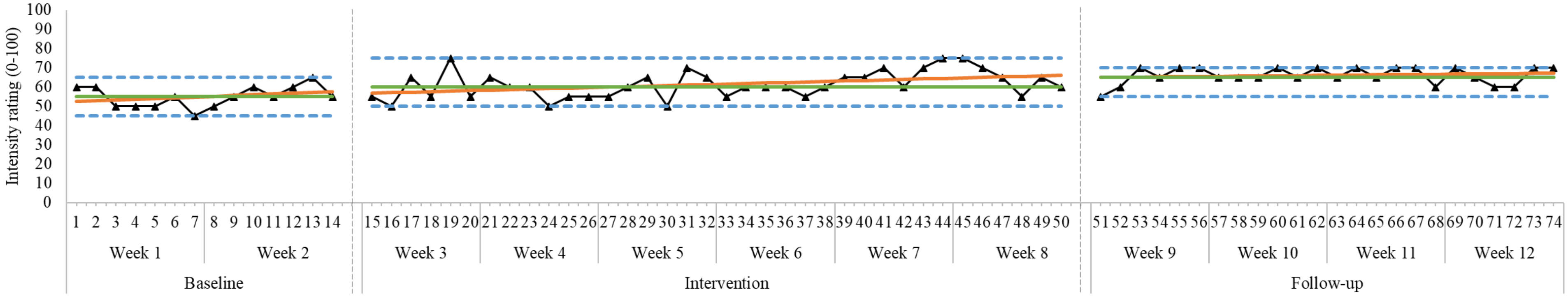

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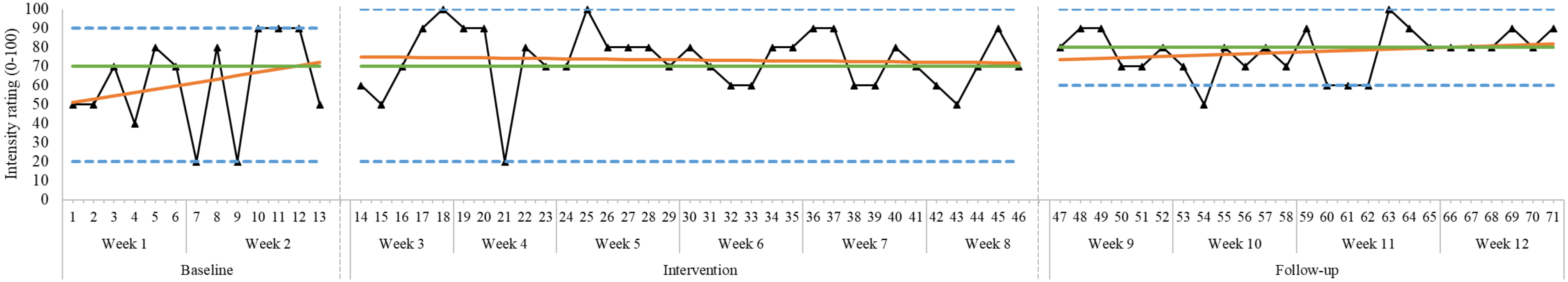

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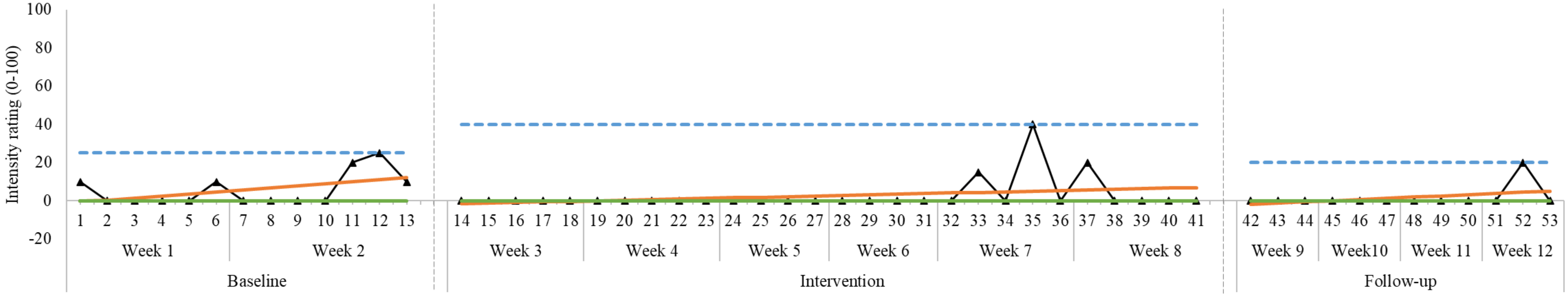
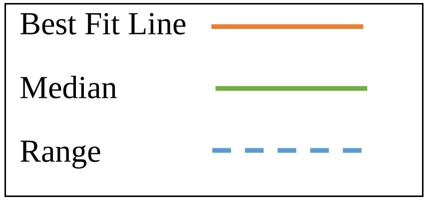
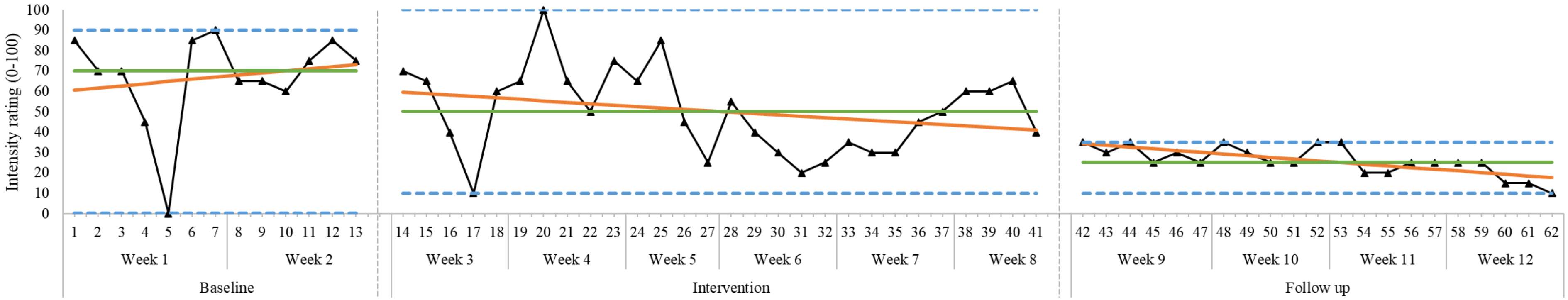


Appendix R: Figure Showing Visual Analysis With Best Fit, Median, and Range Lines for Decrease-Framed Targets

Figure Key.



Participant 1



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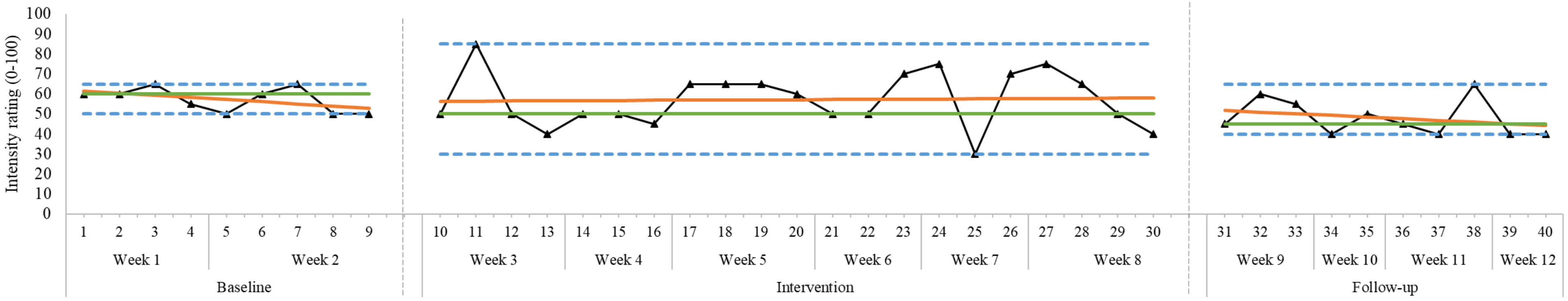
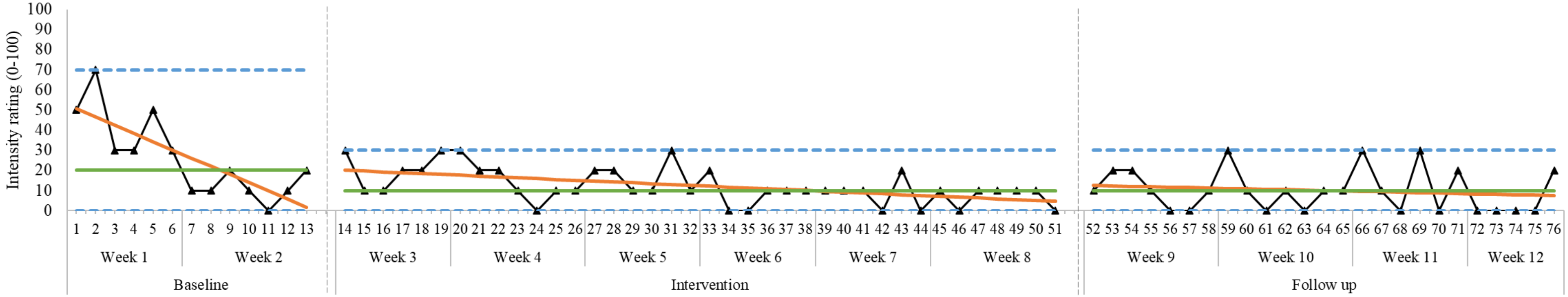
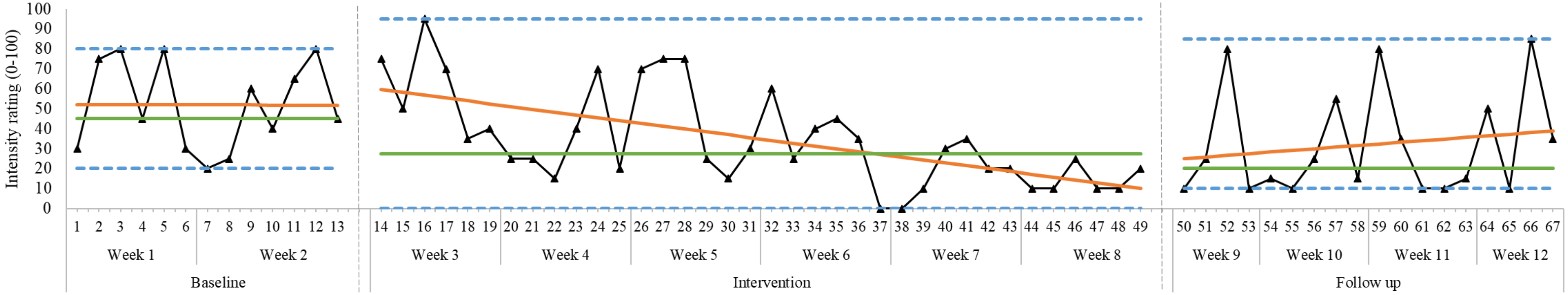


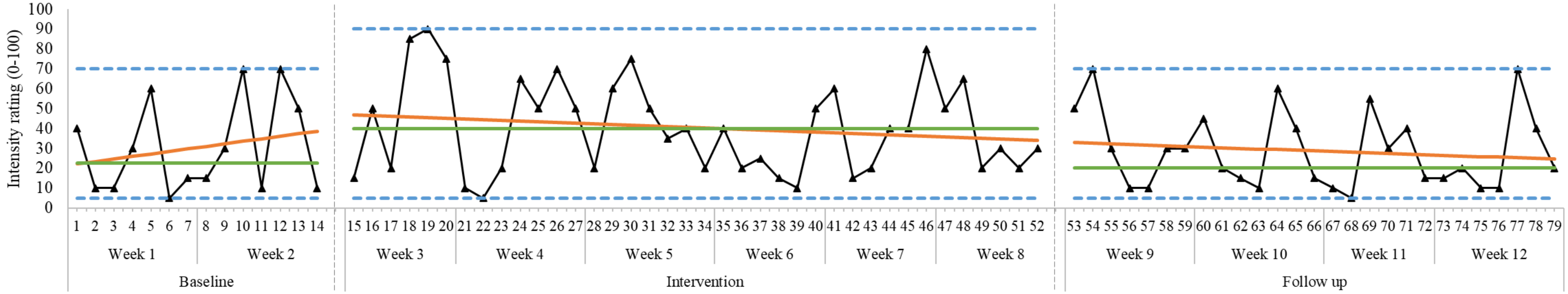
Participant 3



Participant 4



Participant 5



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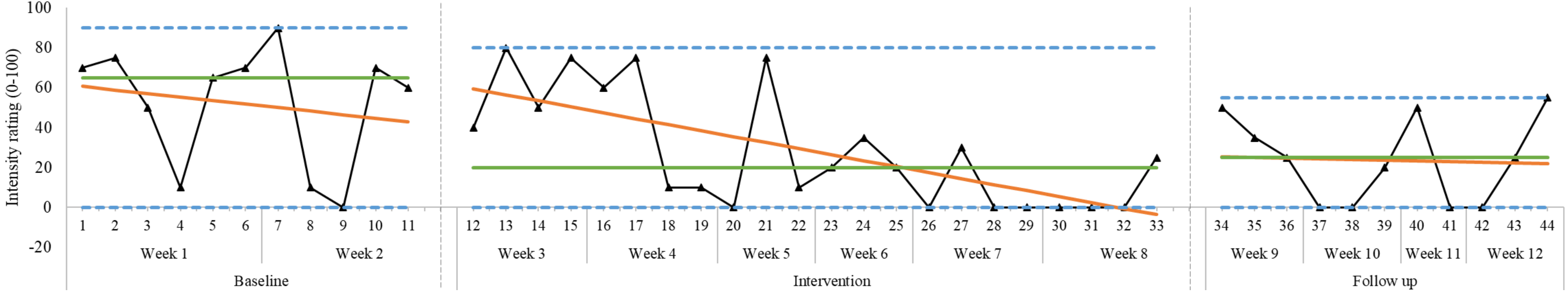

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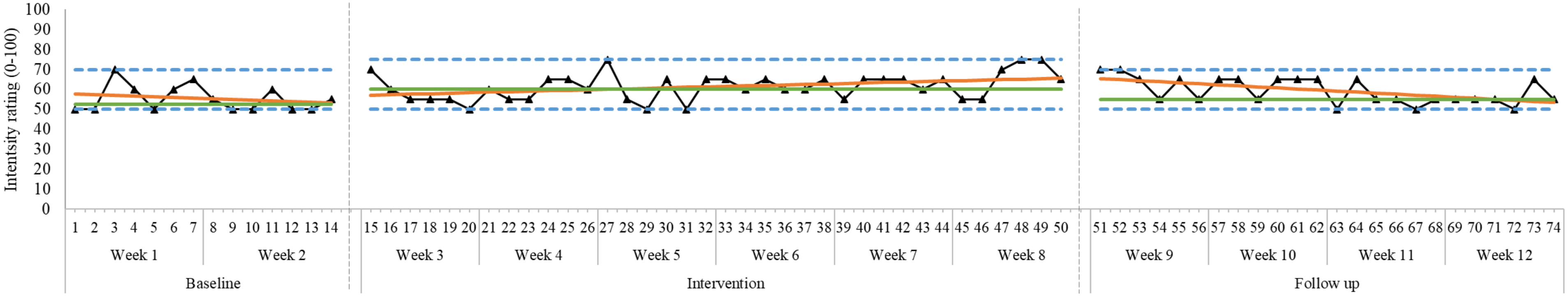

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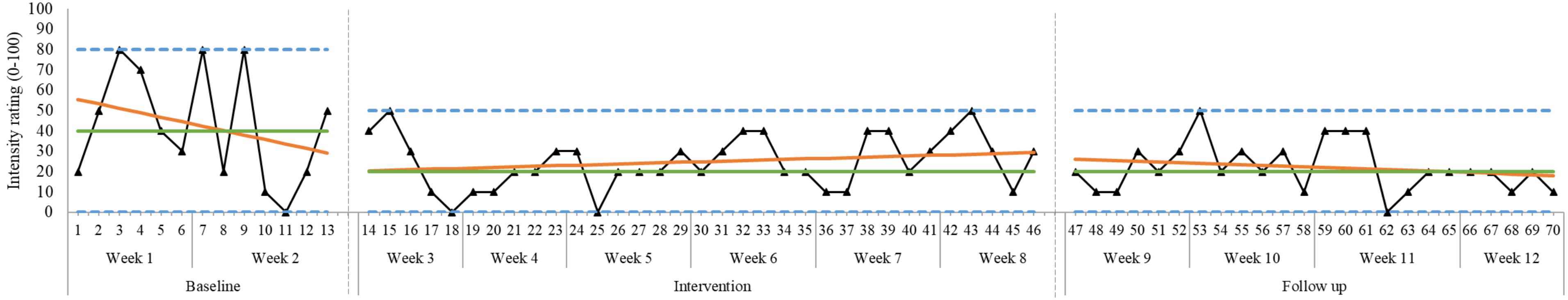
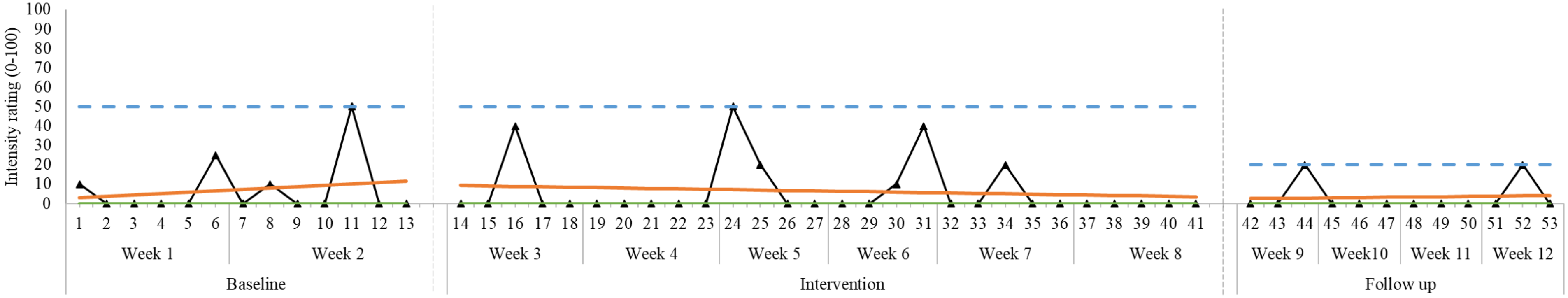


Participant 9



Appendix S: Epistemology

Both the meta-synthesis and single case experimental design study were of Critical Realist epistemology. Critical realism acknowledges the impact of our person perceptions, knowledge and interpretations can have on what we observe. The research team members for both papers have an interest in parenting and parenting stress. Professor Andrew Thompson and the current author also have particular interest in visible difference, with accompanying knowledge of relevant theories and models. Furthermore, all have completed or near completed clinical psychology doctoral training and have experience of working directly with children and families. Furthermore, the current author is a parent of a young child thus has lived experience of parenting stress. Dr Lisa Marie Emerson is an experienced mindfulness practitioner, who developed the mindful parenting intervention utilised in this study alongside other experts. All authors had some experience of using mindfulness in their clinical work and hoped the mindful parenting intervention might be of benefit to participants. These factors may have influenced the way that information has been interpreted. However, reflexive team discussions were facilitated, and time was spent in supervision sessions exploring the impact of both personal and professional experiences, and existing knowledge on how information was being interpreted.