Parenting in chronic, life limiting and life threatening paediatric illness:
Investigating parenting strategies and the utility of a supportive parenting
intervention.

A thesis submitted to The University of Manchester for the degree of Clinical
Psychology Doctorate (ClinPsyD) in the faculty of Faculty of Biology, Medicine
and Health.

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Table of Contents

List of Tables .................................................................................................................. 4
List of Figures .................................................................................................................. 4
Abstract ............................................................................................................................. 5
Declaration ......................................................................................................................... 6
Copyright statement ......................................................................................................... 6
Acknowledgements .......................................................................................................... 7

Paper 1. Parenting strategies used by parents of children with a chronic, life threatening or life
limiting illness: A systematic review ......................................................................... 8
Abstract ............................................................................................................................. 9
Introduction ......................................................................................................................... 10
Methods ............................................................................................................................. 13
  Inclusion and Exclusion criteria ..................................................................................... 14
  Search Results ................................................................................................................. 14
Identification ....................................................................................................................... 16
Screening ............................................................................................................................. 16
Eligibility ............................................................................................................................. 16
Included ............................................................................................................................... 16
  Data Extraction ................................................................................................................. 17
  Quality Assessment ......................................................................................................... 17
Results ................................................................................................................................ 18
  Study characteristics ....................................................................................................... 18
  Summary of parenting strategies identified .................................................................. 40
Discussion .......................................................................................................................... 48
Limitations ......................................................................................................................... 51
Recommendations for future research ........................................................................... 52
Acknowledgements .......................................................................................................... 53
References .......................................................................................................................... 54

Paper 2: A case series evaluation of a self-directed Positive Parenting Program (Triple P) for
parents of children with a diagnosis of cancer: a feasibility study ................................ 61
Abstract ............................................................................................................................. 62
Introduction ......................................................................................................................... 63
Method ................................................................................................................................. 66
  Design ................................................................................................................................. 66
Participants ......................................................................................................................... 66
Outcome Measures ........................................................................................................... 67
Appendices

Appendix 1: Journal of Clinical Psychology in Medical Settings instructions for authors for manuscript preparation ....................................................... 124
Appendix 2. Criteria for assessing selected studies risk of bias, from Sultan et al (2016) ... 131
Appendix 3. Summary table depicting quality assessment and scores for studies included in the review .................................................................................................................. 133
Appendix 4. Journal of Pediatric Psychology instructions for authors for manuscript preparation ....................................................................................................................... 136
Appendix 5. Telephone Interview Schedule ................................................................................................................................. 140
Appendix 6. National Research Ethics Society Approval Letter ........................................................................................................... 141
Appendix 7. Participant Identification Centre (PIC) approval letter .............................................................................................. 142
Appendix 8. Participant Information Sheet (PIS) .............................................................................................................................. 143
Appendix 9. Participant Consent Form ............................................................................................................................................. 149
Appendix 10: Parent Support Booklet ............................................................................................................................................... 152
Appendix 11: Telephone Interview Consent Form .......................................................................................................................... 153
Appendix 12. Telephone Interview anonymised transcript .................................................................................................................. 155
Appendix 13. Summary table of participants A-D’s individual scores over time on all outcome measures .............................................. 163
Appendix 14. Feedback provided from participants over the course of the intervention, final follow-up and via email ................................................................. 164
Appendix 15. Initial results from a survey conducted by clinicians at the Royal Manchester Children’s Hospital Oncology service ........................................................................... 169

Total word count 23’682 (excluding abstracts, tables, figures, references and appendices)

List of Tables

Table 1. Summary of strategies, characteristics and methodologies of studies included in the review .................................................................................................................................................. 20
Table 2. Measures of parenting strategies used in included studies ........................................................................................................... 37
Table 3. Demographic information of participants and non-completers .................................................................................................................. 75
Table 4. Group pre-post intervention scores for RMH-PQLQ, PECI, PSOC and PS ......................................................................................... 77

List of Figures

Figure 1. PRISMA Flow diagram ........................................................................................................................................................ 16
Figure 2. Consort flow diagram ...................................................................................................................................................... 73
Figure 3. Graphs depicting quality of life and functioning over time on the RMH-PQLQ ...... 78
Figure 4. Graphs depicting changes over time for emotional and behavioural difficulties on the RMH-PQLQ .................................................. 80
Figure 5. Graphs depicting scores over time on the Parenting Scale (PS) .......................................................................................... 82
Figure 6. Scores over time for Parent’s Sense of Competence (PSOC) ................................................................................................. 84
Figure 7. Graph depicting scores over time for Parents Experience of their Childs Illness (PECI) ................................................................. 85
Abstract
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A thesis submitted to The University of Manchester for the degree of ClinPsyD in the Faculty of Biology, Medicine and Health


2016

This thesis explored the challenges of parenting a child with a chronic, life threatening or life limiting illness and the psychological sequelae for both parent and child. Parenting is a challenging and rewarding role, which can be significantly affected when children are diagnosed with life altering conditions. Parenting through a child’s illness can have a significant impact on the child’s quality of life and emotional and behavioural adjustment and thus the strategies parents use are paramount for overall wellbeing.

Paper one provides a systematic review of the literature to better understand the strategies used by parents of children with chronic or life limiting/threatening illness to help inform effective supportive interventions. The review of 32 papers, highlighted how the intricacies of each illness impact parent’s strategy usage. Furthermore, strategies often considered negative were found to have utility within illness populations. The review provides an understanding of the difference between parental strategy and style and provides recommendations for clinicians and researchers for future research.

Paper two details a feasibility study to explore recruitment and retention to a parenting intervention via web based advertising for parents of children with a diagnosis of cancer. Case series methodology was utilised to assess the feasibility of a Triple P Positive Parenting Program, with the primary aim of improving children’s quality of life. A total of four mothers of children aged 4-7 years old completed multiple baseline and data points over the course of the intervention. The results showed some impact on quality of life, reductions in child behavioural difficulties and improvements in parental experience of their child’s illness, demonstrating promise for this intervention in a cancer population.

Paper three provides a critical reflection of the research process, specifically providing the strengths and limitations of papers one and two and personal reflections.
Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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I would like to thank the parents who took part in the study and those who showed interest, their strength and ability to cope throughout such difficult circumstances is inconceivable. Thanks also go to the registered children’s cancer charities for believing in this study and disseminating information to parents, without which this thesis would not have been possible.

To my fellow trainee’s and those I have had the privilege to share the experience of bringing a new life into the world with (Miriam Wade, Annukka Lehtonen, Joanne Middleton and Sarah Woodward) thank you for all of the laughs and your continued friendship.

To my husband, parents and wonderful nana (aka nanoo), thank you for always believing in me and for your patience and love. Last but by no means least I dedicate this thesis to my beautiful daughter Isla, your beaming smile, infectious laugh and mischievousness have made this the most interesting and enjoyable journey.
Paper 1. Parenting strategies used by parents of children with a chronic, life threatening or life limiting illness: A systematic review

The following paper has been prepared for submission to the *Journal of Clinical Psychology in Medical Settings*. The guidelines for authors can be found in Appendix 1.

Formatting changes, including the insertion of tables and figures into the text and reduction of line spacing to 1.5 have been made to the current paper to aid readability.

Word Count 8090 (Excluding abstract, tables, figures and references)
Abstract
Understanding the parenting strategies adopted by parents of children and young people diagnosed with a chronic or life threatening/limiting illness would help inform effective supportive interventions across the illness trajectory. A systematic review of the literature was conducted resulting in 32 papers for inclusion. Children predominantly had a diagnosis of cancer, although a total of 15 diagnoses were identified. Children ranged in age from 3 to 14 years old and occupied a variety of illness phases. Some were in the initial stages of treatment for their illness compared with others considered ‘survivors’. The review focussed on the inclusion of papers which specifically measured parenting strategies relating to observable behaviours (e.g. limit setting) as opposed to attitudes or parenting styles (e.g. permissive). The review highlighted several strategies adopted by parents, which were summarised into the themes of overprotection, autonomy, discipline and positive parenting. Parental overprotection was measured by 19 studies of varying age ranges and diagnoses and therefore appears pervasive. Overprotection was influenced by age, parent gender and parent and child’s adjustment to the diagnosis. However, some studies showed no difference between control or illness groups and therefore overprotection may not be unique or indeed used differently by parents of children with chronic illness diagnosis. There appeared to be greater consensus in relation to discipline, which was more likely to be lax across illnesses. Behavioural restrictions were apparent and related to specific characteristics of the illness, highlighting the potential for strategies previously regarded as negative to have the converse effect. Strategies in some illness populations due to the nature of the illness may be necessary to keep the child safe and provide adequate care. Promotion of autonomy was surprisingly rare across studies and requires further investigation. The use of strategies regarded as positive, such as warmth, involvement and praise were all influenced by parents own mental health. A large degree of variability in study methodology and characteristics made some comparisons difficult. Recommendations for future research were identified.

Keywords: Parenting strategies. Illness. Chronic/Life threatening/ Limiting. Children/adolescents
Introduction

Whilst there is limited data on the collective prevalence of chronic and life threatening conditions in children in the UK, it has been estimated that 71% of children aged 1-18 years in England, Scotland and Wales who died between 2001-2010 had a chronic condition (Hardelid, Dattani, & Gilbert, 2014). The term chronic captures all long-standing or recurrent illnesses, however it is the prognosis which separates such illnesses into life threatening or limiting. Life threatening conditions can often be cured, but treatment can fail. Despite advances in medical treatments and subsequent improvements in survival rates, cancer remains the most common cause of death in children and young people (Treadgold, 2012). Other life threatening conditions include but are not limited to asthma and diabetes. Asthma has a high prevalence and is estimated to affect 1.1 million children in the UK, making it the most common long-term medical condition (Treadgold, 2012). Conversely, life limiting conditions are those in which there is no hope of a cure (Fraser et al, 2011). Life limiting conditions are typically diagnosed in children under 1-year-old and are largely accounted for by congenital anomalies (Fraser et al, 2011).

Historically, there has been an emphasis on the medical management of chronic illness in children, with growing recognition of the impact of chronic illness on not only the child but also on the wider family. Similarly, the Core Care Pathway for life threatening and limiting illnesses stresses the importance of care being needs based and ensuring adequate access to support (Widdas, McNamara and Edwards, 2013).

Children with chronic illness are at increased risk of developing psychological difficulties (Glazebrook, Hollis, Heussler, Goodman and Coates, 2003). In addition, parenting can impact on long-term adaptation to the illness, including adherence to medical regimens (Ellis et al, 2007). As a result, there is increasing interest in parent adaptation and family functioning (Popp, Robinson, Britner, & Blank, 2014), parenting stress (Cousino & Hazen, 2013), parent-child relationships (Pinquart, 2013) and supportive psychological interventions for parents of children with a chronic illness (Eccleston, Palermo, Fisher, & Law, 2012).

One area to receive growing attention is that of how childhood chronic illnesses impact the parent child relationship and parenting behaviours (Levers, Drotar, Dahms, Doershuk, & Stern, 1994; Pinquart, 2013), particularly in regards to developing evidence-based interventions for parents (Morawska, Calam, & Fraser, 2015). There is recognition of differences in the parent child relationship and parenting between
families with and without illness (Pinquart, 2013). However, there is more to be learnt about the impact of life limiting and life threatening illness upon parenting. In addition, there is a requirement for more distinction between parenting strategies and styles. Parenting terms are frequently used interchangeably and behaviours are often referred to as strategies, practices or approaches. Strategies are defined as plans of action to achieve a long-term aim. Practices on the other hand are referred to as the actual application of a method, which shares similarity to an approach often referred to as a way of dealing with a situation or problem. Whilst all three terms are widely used within the parenting literature, and are used interchangeably, we will predominantly refer to parenting strategies throughout this review.

Parenting strategies are observable behaviours which have been distinguished from parenting styles. Parenting styles are often described as underlying attitudes and beliefs, which influence parenting behaviour (Darling & Steinberg, 1993), whereas parenting strategies are considered to be “specific goal directed behaviours through which parents perform their parental duties” (Darling & Steinberg, 1993) (p. 488) and which have a direct effect on children’s outcomes. They are modifiable factors that can increase or decrease a child’s risk of developing mental health problems (Yap, Fowler, Reavley, & Jorm, 2015). Furthermore, they can impact treatment adherence (Hullman et al., 2010a) and the child’s adjustment to their illness (Mullins et al., 2004). In addition, they are often understood in terms of being positive and negative. Spoiling for example is often perceived as a negative strategy due to its association with emotional and behavioural problems in the general population (Owen, Slep, & Heyman, 2012). Conversely, warmth and positive affect often have positive outcomes. These strategies are largely protective and aid the promotion of resilience and parent-child relationship (Owen et al., 2012). In an illness population, such strategies may be important when faced with the impact of managing a chronic illness. A parent’s ability to adopt positive strategies will be paramount in mediating any further risk to the child. There may also be a requirement to utilise strategies more typically considered negative in order to keep the child safe. Understanding the strategies parents use, across their child’s illness trajectory, will enable better identification of children and parents at risk of experiencing adjustment difficulties. In addition, it may aid the identification of when parents have the capacity to undertake targeted interventions.

Parental factors may impede the use of strategies due to parents’ own adaptation to their child’s illness. There is recognition that parental concern and well-being may
influence the behaviours utilised by parents and consequently impact on how children may view their illness. As a result, parents may perceive greater illness uncertainty (Mullins et al., 2007). Parents may be forced to re-evaluate their strategies following their child’s diagnosis due to the perceived limits placed on the child and changes to normal functioning (Banis, Suurmeijer, & van Peer, 1999). As children may become more physically vulnerable, parents may increase their efforts to protect their children and face uncertainty about their child rearing practices (Banis et al., 1999). Thus, the additional demands on parents may result in ineffective or negative parenting practices, which could subsequently impact a child’s social, emotional and behavioural development (Kirk et al., 2011).

Parental overprotection has received consideration particularly in relation to parents of children with a chronic illness. It is a strategy often perceived by professionals working alongside children with a chronic illness to be readily used by parents (Davies, Noll, Destefano, Bukowski & Kulkarni, 1991). The construct of parental overprotection was originally coined as overanxious, over solicitous and overindulgent parenting behaviours (Levy, 1931). Excessive restrictive behaviours such as these may impact on children’s self-confidence and life skills (Brussoni & Olsen, 2013). Consequently, they are highly associated with child anxiety disorders. This is thought to be due to the reinforcement of avoidance and parent’s conveyance of the message to the child that the world is unsafe (Teetsel, Ginsburg, & Drake, 2014).

More recently, overprotection has been described as behaviours to promote security and safety for the child (Thomasgard & Metz, 1997; 1998). These descriptors are conflicting and suggest both positive and negative outcomes, which requires clarification, particularly in an illness population. A recent meta-analysis noted observable differences between parents of children with and without a chronic illness for overprotection (Pinquart, 2013). Interestingly, a Delphi consensus did not cite overprotection in its final parenting guidelines or surveys in relation to the development of affective disorders (Yap et al., 2015), which may indicate a shift in the understanding and purpose of these behaviours. In a general population, less favourable parenting behaviours have been found among mothers who are younger, single, from a low income and educational background and have more than one child (Fox, Platz, & Bentley, 1995). For parents of children with a chronic illness, such strategies may in fact be adaptive and thus further investigation is required as these strategies may not have the same consequences as they do for healthy children.
Many studies have explored child and parental adjustment in relation to discrete parent behaviours. Similarly, previous reviews have sought to identify the differences between parents of children with and without a chronic illness with regards to common parenting behaviours (e.g. responsiveness, demandingness and overprotection) (Pinquart 2013). However, there has been little investigation into the range of parenting strategies used by parents of children with a chronic, life threatening/limiting illness and those which may be illness specific.

The primary aim of this review was to:

1) identify studies measuring parenting strategies used by parents of children with a chronic, life limiting or life threatening illness.

Secondary aims:

1) identify whether there is a consensus on the strategies used across illness groups and those distinct to specific illnesses
2) identify strategies that are reported to have positive or negative impacts on children with differing illness
3) identify factors which increase or decrease the use of parenting strategies
4) identify whether illness related demands, severity, duration and prognosis impact on parenting strategies.
5) identify illness groups, which may be more vulnerable and require intervention, such as parenting support and to provide recommendations for future research.

**Methods**

This systematic review was prepared according to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) (Moher, Liberati, Tetzlaff, & Altman, 2009).

For this review three methods of literature retrieval were used to collect relevant studies. Firstly, five electronic databases were searched in December 2015, including; Web of Science (core collection), Embase, CINAH, PsychInfo and Medline using combinations of the following search terms: “parenting practices”, “child rearing strategies”, “child rearing practices”, “parenting strategies” and “child” and “illness”. No date limits were used. Results were then reviewed by title and abstract for citations. Once relevant articles were retrieved in full text form, the reference sections of each article were examined to locate other articles. The title and abstract of these articles
were reviewed and if deemed relevant the full text article was retrieved. Once a list of studies to be included was developed, a table of reported parenting strategies and associated measures was completed. A further literature search using Web of Science (core collection) using the key identified parenting strategies as search terms (overprotection, discipline, warmth, involvement, laxness and autonomy and illness) was then conducted. All studies reviewed were published in peer reviewed journals.

**Inclusion and Exclusion criteria**

To be included in the review, studies had to report on parenting strategies in relation to parents of children with a chronic, life threatening or life limiting illness. Studies were included that reported on:

- Single or multiple illness groups with or without a comparison group
- Single or multiple parenting strategies
- Qualitative or quantitative and mixed methodologies
- Parental, child or professional accounts of parenting strategies

Studies were excluded that were:

- Solely focussed on parental stress or coping
- Solely focussed on parenting styles or attitudes
- Unpublished dissertations, conference abstracts or posters
- Retrospective (e.g. studies of adults commenting on the perceived parenting strategies they experienced as a child)
- Not published in English
- Related to hearing and vision. Whilst these are chronic conditions, they do not often follow the unpredictable pattern or treatment regimens, associated with conditions like cancer and diabetes.

**Search Results**

The initial search of five databases generated a total of 2205 results, which following de-duplication resulted in 967 results for review. The second search using specific strategy titles (e.g. overprotection) generated a further 150 results. Of the total 1117 results from the first and second searches, 1067 were excluded on the basis of title. Fifty were retrieved in abstract or full text form were available. Of these 23 were excluded, the reasons for which are briefly given on the flow chart of each phase of the review (see figure 1). A further 12 references were identified from paper reference lists, of
which seven were not relevant, resulting in final a total of 32 studies for inclusion in the review.
Records identified through initial database searching (n= 2205)
Duplicates removed (n=1238)
Total for review (n=967)

Records removed (no mention of parenting strategies) (n = 1067)

Records screened (n = 50)

Full-text articles/abstracts assessed for eligibility (n = 50)

Records excluded with reasons (n =23)
- 7 conference abstracts (Berube, Pelicand, Marques, Tluczck, Williams, Williams, Macdonald)
- 5 dissertations (Spear, Angst, Leadbetter, Barzel, Sandler)
- 1 only summary in English, full text in German. (Bieliauskaite)
- 3 Reviews (Jackson, Klunkin and Lohan)
- 4 parenting style (Knafl, Anderson, Greene, Mlynarczyck)
- 1 perceived child vulnerability (Anthony)
- Paternal helpfulness (Gavin)
- Unable to retrieve full text – no response from author (Richardson)
*References available upon request.

Records retrieved through reference lists (n=12)

Studies included in qualitative synthesis (n = 32)

Figure 1. PRISMA Flow diagram
Data Extraction

Articles were screened by the first author (KS) by examining titles and abstracts to identify relevant articles. In cases of doubt, the author discussed the article in question with all authors. Articles were searched for measures of parenting strategies, child rearing practices, or approaches and were independently classified by the first author under each strategy identified. Study characteristics (author, country, aim, illness, illness phase, design and sample) were extracted by the first author. Two independent summary tables were produced to house the data for review by all authors.

Quality Assessment

A quality assessment approach undertaken by Sultan, Leclair, Rondeau, Burns, & Abate (2016)\(^1\) was replicated, which assessed study quality according to the guidelines set out by Cochrane Handbook for Systematic Reviews (Higgins & Green, 2011). Articles were reviewed by the first author and two independent researchers (EW and AL) in relation to the following domains: Reporting, attrition and selection. We also adopted an ‘other’ domain (Sultan et al., 2016) to enable us to assess the following categories; participants, measures, procedures to limit attrition and design. The researchers were sent a file including a selection of studies and a to code each article according to the domains listed above. Any discrepancies were discussed with all of the authors and a consensus achieved. The quality assessment would not deter the inclusion of studies, however provide confidence that the results were reliable and inform recommendations for future research.

Of the 32 articles included, 28 were considered to have an overall low risk of bias and 4 a high risk of bias\(^2\). High risk was most frequently awarded for sites (predominantly mono-centred), recruitment (predominantly convenience sampling) and design domains (predominantly cross-sectional). In addition, with regards to attribution biases, only 16 studies compared an illness population with a non-illness population (healthy control), whereas 16 studies compared to either another illness group or had no comparison group. Effect sizes were rarely considered by studies and 9 studies (28%) had small samples (less than 50 participants).

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\(^1\) For the full criteria used by Sultan et al (2016) see appendix 2.

\(^2\) For a summary of the quality assessment of included papers see appendix 3.
Results

Study characteristics

The studies included are summarised in Table 1. Studies ranged in date of publication from 1980 to 2015 and were from 5 different countries. Most studies were from the United States of America (USA) (24, 75%), five from the United Kingdom (UK) (15.6%), and the remaining three studies took place in the Netherlands, Korea and Australia (9.4%). Many studies were cross sectional (30, 94%) with only two including prospective follow-ups (6%). Twenty-one studies had a comparison group, of which 16 used a healthy control (one of which included healthy siblings) and 5 used another illness group. Three studies included the views of professionals and 3 studies included children’s perception of their parents’ use of strategies. Six studies included observations and/or videotaping of parent-child interactions. Approximately 2738 parents and 40 professionals participated in the included studies, however overlap should be considered. The mean age of children included in the studies was 9.16 years of age, with the youngest recorded child mean age of 3.44 and eldest 14.80 years.

Fifteen diagnoses were identified across the 32 studies. Of these 12 studies included children with a diagnosis of cancer, two included children with heart conditions (Congenital heart disease and bacterial endocarditis), nine studies looked at children with a diagnosis of type 1 or type 2 diabetes, two studies included children with haemophilia, four included children with cystic fibrosis, seven included children with asthma, 2 studies included children with sickle cell anaemia, 2 included children with juvenile rheumatoid arthritis (JRA), one study included children with thalassemia, 1 renal disease (acute glomerulonephritis), one skin disorder (atopic dermatitis), one physical disability (spina bifida) and lastly one study included children diagnosed with a disorder of sex development (DSD). Whilst many of the diagnosis identified in the included papers where illness which are life threatening or limiting (e.g. cancer, haemophilia, and cystic fibrosis). Only one article specifically used the term life threatening in the analysis, delineating the groups into life-threatening and non-life threatening (disorder of sex development (DSD), including 46, XX DSD and 46, XY DSD). Of the studies, which reported time since diagnosis (some not applicable, e.g. sickle cell is usually diagnosed at birth), this ranged from 24.91 days to 9 years.

Reported stage of treatment was variable and at times unclear. The majority of studies reported on children who were receiving some form of treatment or management at a clinic. Two studies reported on children being in remission or off chemotherapy and one
study looked at parenting strategies during medical procedures. The majority of studies included mainly mothers, with only two studies reporting the inclusion of grandparents.
Table 1. *Summary of strategies, characteristics and methodologies of studies included in the review*

**Overprotection and Overprotection/Discipline**

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Illness Phase/ Status</th>
<th>Duration of illness*</th>
<th>Sample N Child</th>
<th>Mean age (Child)</th>
<th>Design</th>
<th>Tool</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Banis et al. (1999)</td>
<td>Netherlands</td>
<td>Haemophilia (Severe)</td>
<td>Majority (51.8 receiving treatment only in cases of bleeding)</td>
<td>N/A</td>
<td>108 (Ms)</td>
<td>Males 6.9 (SD=3.5)</td>
<td>Secondary data analysis of parent interview</td>
<td>OPS</td>
<td>Overprotection was linked to severity of haemophilia. Interestingly, behavioural restrictions were not linked to disease severity but instead a fear of bleeding. Restrictions were more likely to be placed on the type of toys children played with (e.g. not sharp) to ensure children’s safety. This is unlikely to be an issue in other diseases and therefore may be indicative of a disease specific strategy. Behavioural restrictions declined with age, however overprotection was not related to the child’s age therefore providing more evidence for disease specific strategies in this population.</td>
</tr>
<tr>
<td>Bourdeau et al. (2007)</td>
<td>USA</td>
<td>Type 1 diabetes (124), Asthma (48) or Cystic Fibrosis (28)</td>
<td>Attending clinic</td>
<td>7.5 years (range 8 weeks – 17 years)</td>
<td>200 (Ms &amp; Fs)</td>
<td>12.3 (SD=2.8)</td>
<td>Mail survey</td>
<td>PPS</td>
<td>Only 2% parents met clinically significant overprotective behaviour levels, suggesting overprotective strategies are low for parents of children with Asthma, Cystic fibrosis and diabetes. However, as these results are self-reported there is a likelihood that parents may have underreported their use of such strategies, therefore skewing the results. Alternatively, overprotection may be lower for these illness groups, whose children often become particularly self-reliant during the illness duration as opposed to parent-reliant. Due to the study design, which</td>
</tr>
</tbody>
</table>
Cappelli et al. (1989)  USA  Cystic fibrosis  Attending clinic  N/A  29 (18 M, 11 F) (MHC & Ms&Fs)  11.1 years (SD=2.7)  Questionnaire (completed by child in clinic and by parents at home)  PBI  Gender appeared to be significant, with mothers of female children with cystic fibrosis demonstrating significantly higher rates of overprotection. Interestingly, overprotection was associated with lower perception of scholastic competence and behavioural conduct. In addition, high scores of paternal overprotection were associated with behavioural problems for CF group, which may suggest that there is a difference between the way mothers and fathers demonstrate overprotection and requires further investigation.

Colletti et al. (2008)  USA  Cancer  On Treatment  8.53 months (range 1-34)  62 (34 M, 28 F, 85.5% Ms)  5.72 (SD=2.53)  Questionnaire  PPS  Parental overprotection was not a significant predictor of child adjustment outcomes, instead increased parenting stress was significantly associated with poorer child behavioural adjustment. This may be due to higher parent perceptions of child vulnerability. Similarly, parenting stress was associated with poorer emotional adjustment. The study reflects the strategies of parents of children who are receiving treatment for their diagnosis and does not provide a comparison to those not receiving treatment.

Davies et al. (1991)  USA  Cancer (Acute lymphoblastic leukaemia; ALL, Long-term remission or off chemotherapy)  ALL group, 52.25 months, Lymphomas, 14.33  20 & 22 MHC 50 (42Ms &Fs, 12 Prof)  Cancer group: 12.68 (SD=2.84)  Questionnaire  CRP  Professionals anticipated differences between parents of children with cancer and controls on protection/over involvement, difficulties with discipline and concern about child. This may be a perception professionals hold for parents of children with other chronic illness diagnoses, and provides a cross illness comparison, it is difficult to isolate the illness in which parents may utilise more overprotective strategies.
Fedele et al. (2011) | USA | Cancer (Leukaemia, Neuroblastoma, CNS tumours, other) | Attending clinics. | 11.95 (range 2-40 months) | 12 M, 10 F (Ms) | 5.99 (SD=2.81) | Questionnaire | PPS | Parental overprotection declined at follow–up (15.32 months), which may indicate the parent’s adjustment to their child’s illness, although could represent a natural progression alongside the child’s development. Child internalising problems and behavioural symptoms were significantly related to overprotection at Time 1. However, again these difficulties could be indicative of the child’s own adjustment and would require longitudinal follow-up and consideration of development to provide further insight into the impact of parental strategies at different times along the illness trajectory.

Gerhardt et al. (2003) | USA | Juvenile Rheumatoid Arthritis (JRA) | Receiving treatment (active n=32, full or partial remission n=32) | 69.77 months (SD=35.89) Range 10-149 | JRA group: 64 Ms & 45 Fs. HC: 64 Ms, 40 Fs 16 Prof | JRA group: 11 (SD =1.6) Control group: 11.7 (SD=1.6) | Questionnaires completed in parent home with a research assistant | CRP | Mothers of children with JRA were more protective (e.g. stopped children playing rough games) than parents of healthy controls. Mothers of children with JRA reported more worry about their child’s health compared to healthy controls, which is to be expected. Fathers of children with JRA reported difficulty punishing their child and reported worry about their child’s health compared to healthy controls. In other conditions (e.g. asthma) there was also an indication that fathers struggled with discipline, often using negative physical punishments.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Sample Size</th>
<th>Sample Description</th>
<th>Measure</th>
<th>Control</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holmbeck et al. (2002)</td>
<td>USA</td>
<td>Spina Bifida</td>
<td>Not reported</td>
<td>37 M, 31 F &amp; MHC</td>
<td>Spina Bifida group: 8.34 (SD=0.48) Able bodied group: 8.49 (SD=0.50)</td>
<td>Questionnaire and Observation</td>
<td>CRP BI</td>
</tr>
<tr>
<td>Hullman et al. (2010a)</td>
<td>USA</td>
<td>Cancer (57 Leukaemia or lymphoma, 21 solid brain tumour)</td>
<td>Receiving treatment</td>
<td>89 parents (72 Ms, 14 Fs, 3 GPnts)</td>
<td>6.50 (SD=3.07)</td>
<td>Questionnaire</td>
<td>PPS</td>
</tr>
<tr>
<td>Hullman et al. (2010b)</td>
<td>USA</td>
<td>Diabetes, Cancer, asthma, cystic fibrosis</td>
<td>Attending clinics</td>
<td>425 Parents (361Ms, 50 Fs, 14 GPnts)</td>
<td>9.71 (SD=4.34)</td>
<td>Questionnaire</td>
<td>PPS</td>
</tr>
</tbody>
</table>
Kirk et al. (2011) | USA | Disorder of sex development (DSD) & Type 1 Diabetes Mellitus (T1DM) | Attending clinics | DSD 5.62 years, T1DM 3.26 years | DSD group: 49, T1DM group: 49 (98 caregivers) | DSD group: 5.70 (SD=4.74) T1DM group: 10.60 (SD =4.36) | Mail questionnaires | PPS | Significant levels of stress and negative parenting practices found for both groups. Whilst these groups are under the endocrine service they are significantly different and there is no comparison to a healthy control group therefore these results may not be generalizable. More parents of children with T1DM met cut offs for perceived child vulnerability. This is likely due to the unpredictability of the condition and would warrant comparison against a healthy control group.

Markova et al. (1980) | UK | Haemophilia | Registered with hospital | N/A | 16 M & HMC | 8 aged 3-5 years, 8 aged 8-13 years | Open ended interview | Base d on Levy (1943) | Fathers of children with haemophilia reported caring for the child more as a baby and spending more time with the child than fathers of controls. This is interesting, and raises questions as to whether this is due to the heightened vulnerability of the child with haemophilia. Children with haemophilia trained in responsibility more than healthy children, which may be describing the promotion of autonomy. Mothers had more views about child rearing and rated themselves as stricter than mothers of healthy children. It is difficult to ascertain whether this relates to overprotection or discipline or both and suggests these concepts may overlap. Mothers of children with haemophilia worried about the child being out of her sight, playing with potentially dangerous toys and about schooling. Whilst there may be some reference to autonomy, within this condition a physical protection appears necessary, which is not reported in other illness groups.
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Disease/Clinic</th>
<th>Methodology</th>
<th>Duration</th>
<th>Sample</th>
<th>Parenting Measure</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mullins et al. (2004)</td>
<td>USA</td>
<td>Type 1 diabetes</td>
<td>Attending clinics</td>
<td>3 years</td>
<td>43 (15 M, 28 F)</td>
<td>Questionnaire</td>
<td>Two parents (4.6%) met cut off for parental overprotection. This study did not compare to a healthy control group so it is difficult to ascertain whether the same would be true in a non-illness population. Overprotection was self-reported by parents in a questionnaire, and therefore may have underreported their use of protection strategies or infract the child’s age and adjustment to the illness. High perceived child vulnerability and parenting stress associated with higher rates of child depression.</td>
</tr>
<tr>
<td>Mullins et al. (2007)</td>
<td>USA</td>
<td>Type 1 diabetes mellitus or Asthma</td>
<td>Not reported</td>
<td>5.52 years</td>
<td>164 (82 children, 38 M, 44 F) and 82 adolescents (44 M, 38 F)</td>
<td>Questionnaire &amp; Interview</td>
<td>Mothers reported significantly higher parenting stress than fathers. Parenting stress and perceived vulnerability significantly predicted youth illness uncertainty. Parental overprotection was not associated with youth illness uncertainty. 14.6% of parents reported clinically significant levels of overprotection behaviours.</td>
</tr>
<tr>
<td>Noll et al. (1998)</td>
<td>USA</td>
<td>Sickle Cell Disease (SCD)</td>
<td>Receiving treatment</td>
<td>N/A</td>
<td>Sickle cell group: 48 Control group: 48 Prof: 12</td>
<td>Questionnaire &amp; Interview in family home</td>
<td>Professionals perceived caregivers of children with SCD as more protective, more worries and less effective with discipline. Primary caregivers of children with SCD reported more worry about the health of their children and that they did not want their child to be viewed as different from others. No global changes in parenting practices were reported. The ages of the children in this study are such that they have likely had a longer period of adjustment which may explain the lack of differences in parenting practices or indeed suggest that they are not affected by this illness.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Condition</td>
<td>Intervention Details</td>
<td>Sample Characteristics</td>
<td>Observational Task</td>
<td>Parental Interaction</td>
<td>Findings</td>
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<tr>
<td>Power et al. (2003)</td>
<td>USA</td>
<td>Rheumatoid arthritis</td>
<td>Attending clinic over 2-year period</td>
<td>Not reported</td>
<td>Illness group 9.96 (SD=2.40) Healthy group 10.96 (SD=2.91)</td>
<td>Mother–child Interaction Task</td>
<td>Significant effects for rule setting and structure were particularly used by mothers of children with more severe arthritis. Similarly, mothers of children with severe arthritis were observed to be more overprotective. Whilst the medical condition may be indicated in the use of overprotectiveness other factors may have been indicated such as parents own mental health.</td>
</tr>
<tr>
<td>Tillery et al. (2014)</td>
<td>USA</td>
<td>Cancer (22% Acute lymphoblastic leukaemia, 7.3% Acute Myeloid Leukaemia, 14.1% Hodgkin’s and non-Hodgkin’s lymphoma, 40.5% solid tumour, 16.1% brain tumour)</td>
<td>Attending outpatient clinics</td>
<td>1-6 months (23.9%), 6-24 months (24.9%), 2-5 years (23%), &gt;5 years (27.3%)</td>
<td>Cancer group: 13.6 (SD=2.33), Control group: 13.2 (SD=2.36)</td>
<td>Questionnaire PBI</td>
<td>Parental overprotection and care were found to decrease as the child got older. Furthermore, parental care was significantly associated with child depression and anxiety. Similarly, child distress was linked to greater perceived parental overprotection. The study compared to a healthy comparison group and included parents of children with varying lengths of diagnosis, which aids the identification of when interventions may be most needed. The study used a questionnaire design, and is therefore reliant on accurate self-reporting by parents. Parents may have under or overreported their difficulties.</td>
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</table>

Autonomy
<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Illness Phase/ Status</th>
<th>Duration of illness*</th>
<th>Sample N Child*</th>
<th>Mean age (Child)</th>
<th>Design</th>
<th>Tool</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Holmbeck et al. (2002)</td>
<td>USA</td>
<td>Spina Bifida</td>
<td>Not reported</td>
<td>N/A</td>
<td>37 M, 31 F &amp; MHC</td>
<td>Spina Bifida group: 8.34 (SD=0.48) Able bodied group: 8.49 (SD=0.50)</td>
<td>Questionnaire and Observation</td>
<td>CRP BI PBI</td>
<td>Overprotection was displayed more by mothers and was associated with lower willingness to grant autonomy in the future and decision making autonomy in preadolescents. Less behavioural autonomy was associated with overprotection. There seems to be some likeness to the parenting strategies used by parents of children with haemophilia with regards to physical and behavioural protection. It is interesting to consider what elements of these illnesses warrant this type of protection.</td>
</tr>
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</table>

**Discipline**

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<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Illness Phase/ Status</th>
<th>Duration of illness*</th>
<th>Sample N Child*</th>
<th>Mean age (Child)</th>
<th>Design</th>
<th>Tool</th>
<th>Summary of results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carey et al. (2002)</td>
<td>USA</td>
<td>Congenital Heart disease (CHD) (moderate-severe)</td>
<td>Attending clinic</td>
<td>N/A</td>
<td>30 &amp; MHC (Ms)</td>
<td>CHD group: 3.44 years (SD=0.93) Controls: 3.45 (SD = 0.94)</td>
<td>Video-taped mother and child interaction &amp; Questionnaires</td>
<td>PBC</td>
<td>Mothers of children with CHD reported using differential discipline and being concerned about comments from other parents. There were no significant differences between parents on discipline or nurturing practices. Parent stress levels did not differ. Mothers of children with CHD had lower expectations for their child. Qualitative data showed mothers of children with CHD reported higher vigilance. Which may refer to overprotection, however is not defined as this. Children in this study were young, therefore it</td>
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</table>
Dahlquist et al. (1994) | USA | Cancer | During medical procedures | 30.4 months | 66 (2 age groups, 30F, 36M, 71% Ms) | Group 1: 5.74 (SD=1.54), Group 2: 12.08 (SD=2.64) | Observation and Questionnaire | PDI | Less consistent, more punitive and less organised parenting was used more frequently by anxious parents of younger children. Anxious parents of younger children less likely to set rules and used less responsive discipline practices. These parents perceived their children as more anxious prior to their procedure and children showed more behavioural difficulties. Maladaptive behaviours were observed during medical procedures, including ignoring and agitation when children exhibited distress. The results from this study relate to a very specific situation which cannot be compared to a healthy control group. It is expected that most children would become anxious prior to a medical procedure. It would have been useful to assess whether parents used these strategies globally or whether they were purely specific to medical procedures which would help to inform interventions.

Dolgin et al. (1990) | USA | Chronic life threatening illness group: Cancer (20 Leukaemia, 11 solid tumour) | Active treatment phase & Ongoing treatment | Chronic life threatening group 44.7 months, non-life threatening mean 61.5 | 89 (47 M, 42 F, Ms) | 8.9 (SD=2.6) | Survey | CDQ | Poor prognosis was related to increased maternal reinforcement of dependency. The quality of the child’s health impacted parenting behaviour. Parents of children with a poorer prognosis fostered more dependency and used less punitive measures. Highly anxious mothers used less efficient strategies (e.g. More force than modelling or reassurance) in managing children’s fear behaviour. Mothers with lower socioeconomic status more likely to use threat of punishment as a strategy. This study provides a
<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Condition</th>
<th>Methodology</th>
<th>Sample Characteristics</th>
<th>Measures</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eckshtain et al. (2010)</td>
<td>USA</td>
<td>Type 1 or Type 2 Diabetes</td>
<td>Attending clinic or during hospitalisation</td>
<td>4.42 years (range 0.48-15.06)</td>
<td>Questionnaires</td>
<td>Parental depression was significantly associated with inconsistent discipline and lower monitoring. Low parental monitoring and youth depression were linked to poor diabetes management. There was no comparison to a healthy control group therefore it is difficult to ascertain whether these difficulties may also be seen in a non-illness population. Parental mental health difficulties such as depression are likely to make it difficult for any parent to be present and provide consistent parenting and may therefore not be diabetes specific.</td>
</tr>
<tr>
<td>Eiser et al. (1991a)</td>
<td>UK</td>
<td>Asthma</td>
<td>Regularly attending hospital for treatment</td>
<td>Mean age of diagnosis 16.52 months, range 6-84</td>
<td>Interviewed at family home Devised by authors</td>
<td>Children with asthma were perceived by their parents to be less healthy and more susceptible than healthy controls. Parents reported everyday situations to be more stressful. No differences were identified between the asthma and control group on the frequency of the use of discipline strategies. No differences were found between types of discipline strategy parents employed. Mothers were more likely than fathers to praise good behaviour and tell children that they are</td>
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naughty or good. Overall, chronic illness had little impact on parenting strategies.

<table>
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<tr>
<th>Study</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Methodology</th>
<th>Duration</th>
<th>Sample Size</th>
<th>Interview Setting</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eiser et al. (1991b)</td>
<td>UK</td>
<td>Asthma</td>
<td>Regularly attending hospital for treatment</td>
<td>16.52 months</td>
<td>37 Families</td>
<td>Interviewed at family home</td>
<td>Mothers were more involved than fathers and the severity of asthma was not associated with the frequency of discipline strategies. Discipline strategies were different for mothers and fathers. Fathers of children with mild asthma were more likely to threaten physical punishment or promise treats. This study showed some impact of asthma which is contrary to the aforementioned results.</td>
</tr>
<tr>
<td>Eiser et al. (1993)</td>
<td>UK</td>
<td>Diabetes</td>
<td>Not reported</td>
<td>4.15 years</td>
<td>30 M, 32 F (Ms&amp;Fs)</td>
<td>Questionnaires</td>
<td>Limit setting accounted for 6.2% of the variance. Firmer limit setting was endorsed by more confident mothers. Whether confidence is a factor is difficult to ascertain as there was no comparison to a non-illness group, similarly, confidence may reflect the sample of parents who chose to take part and had the confidence to complete the questionnaire and may not reflect the wider population of parents of children with diabetes.</td>
</tr>
<tr>
<td>Hillman. (1997)</td>
<td>USA</td>
<td>Cancer</td>
<td>Unclear</td>
<td>Time from diagnosis 1 month to 9 years (36% diagnosed 1 year before the study)</td>
<td>36 &amp; 36 HC (47 Fs, 69 Ms)</td>
<td>Questionnaires</td>
<td>CRP R</td>
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</table>
they were due to the length of time since diagnosis. These strategies may reflect parent’s adjustment to the illness and aiding compliance with treatment regimens, however this is not clear.

<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Chronic Illness Group</th>
<th>Attending Clinics</th>
<th>Duration (range)</th>
<th>Parent Group</th>
<th>Questionnaire</th>
<th>CRP Q</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>King (1981)</td>
<td>USA</td>
<td>Chronic illness group (asthma, seizure disorder, juvenile onset diabetes, acute glomerulonephritis, bacterial endocarditis with heart block and thalassemia) &amp; well sibling</td>
<td>Attending clinics</td>
<td>4.66 years (range 6 months to 12 years)</td>
<td>19 (Ms &amp; Fs)</td>
<td>Chronic illness group: 9.62 (SD = 2.79) well sibling: 9.60 (SD = 3.01)</td>
<td>Questionnaire</td>
<td>Differences were shown in relation to child rearing with regards to the gender of the parent. Parenting practices were not altered as a result of having a chronically unwell child. Mothers were more likely to distort their answers when they used punishments. The use of well siblings as a control group may have biased the results as siblings may have been directly influenced by growing up with an unwell sibling. This may account for why there were few differences in parenting practices identified, thus a non-related healthy control group may have provided greater differences.</td>
</tr>
<tr>
<td>Levers et al. (1994)</td>
<td>USA</td>
<td>Cystic Fibrosis, Insulin Dependent Diabetes (IDDM) &amp; Healthy controls</td>
<td>Attending clinics</td>
<td>IDDM group: 3.22 years, CF group 7.87 years</td>
<td>CF group: 9.73 (SD = 2.71) IDDM group: 9.35 (SD = 2.84)</td>
<td>Interviewed using standard questionnaire</td>
<td>IPBI</td>
<td>All groups scored within IPBI norms. Groups were significantly different for limit setting. Mothers of children in the IDDM and CF group were less likely to set limits than mothers healthy controls. Whilst this study incorporated a healthy control group, they did not include fathers, which in other studies have shown to differ from mothers with regards to discipline strategies, furthermore</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Disease/Condition</td>
<td>Setting</td>
<td>Methodology</td>
<td>Results</td>
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<tr>
<td>Schuman et al. (1992)</td>
<td>USA</td>
<td>Sickle Cell Disease (SCD) (20 homozygous condition, 5 with HbSS, heterozygous condition)</td>
<td>Attending weekly outpatient</td>
<td>Structured interview, questionnaire &amp; videotaped interaction</td>
<td>Mothers of children with SCD had significantly higher discipline knowledge. Children with SCD had significantly less contact with friends, which is not well explained and may imply overprotection. No differences were found with regards to the use of effective/ineffective discipline techniques. Mothers of children with SCD treated children as significantly more competent than mothers of healthy children, which may imply some willingness to grant autonomy but is not recorded as this.</td>
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<tr>
<td>Steele et al. (2003)</td>
<td>USA</td>
<td>Cancer (Acute lymphoblastic leukaemia and acute myeloid leukaemia)</td>
<td>Attending hospital</td>
<td>Questionnaire</td>
<td>Higher reported control by mothers was significantly associated with caregiver burden. Increased parental consistency was reported at 12-14 weeks’ post diagnosis. It would have been useful to see if these results were maintained following this period. This study may indicate that early intervention could be useful however, a natural adjustment may occur following this period which is not identified.</td>
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| Williams et al. (2014) | Australia | Cancer (Acute Lymphoblastic Leukaemia) | Treatment Maintenance Phase | Mail out survey | Parents of children with cancer showed higher levels of lax parenting, spoiling and bribing. 25% of children in the cancer group experienced emotional and behavioural problems compared to 13% in the control group. Lax parenting was an independent predictor of child difficulties. A
Positive Parenting Strategies

<table>
<thead>
<tr>
<th>Reference</th>
<th>Country</th>
<th>Diagnosis</th>
<th>Phase/Status</th>
<th>Duration of illness*</th>
<th>Sample N</th>
<th>Mean age (Child)</th>
<th>Design</th>
<th>Tool</th>
<th>Summary of results</th>
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<tr>
<td>Eckshtain et al. (2010)</td>
<td>USA</td>
<td>Type 1 or Type 2 Diabetes</td>
<td>Attending clinic or during hospitalisation</td>
<td>4.42 years (range 0.48-15.06)</td>
<td>61 Parents (92% Ms, 38% M, 62% F)</td>
<td>14.35 (SD= 2.2)</td>
<td>Questionnaires</td>
<td>APQ</td>
<td>Parental depression was significantly associated with low warmth/involvement. Additionally, low warmth and involvement were linked to youth depression and poor diabetes management. There is no indication as to whether parent mental health problems existed prior to the illness onset, thus low warmth and involvement may not have been attributable to the illness.</td>
</tr>
<tr>
<td>Eiser et al. (1991a)</td>
<td>UK</td>
<td>Asthma</td>
<td>Regularly attending hospital for treatment</td>
<td>Mean age of diagnosis 16.52 months, range 6-84)</td>
<td>37 (25 M, 12 F) 37 HC</td>
<td>54.34 months</td>
<td>Interviewed at family home</td>
<td>Devised by authors</td>
<td>Mothers were found to show higher levels of involvement. Children are relatively young (4.5 years) and therefore higher levels of parental involvement, particularly with regards to managing a chronic illness might be expected and necessary.</td>
</tr>
<tr>
<td>Cappelli et al. (1989)</td>
<td>USA</td>
<td>Cystic fibrosis</td>
<td>Attending clinic</td>
<td>N/A</td>
<td>29 (18 M, 11 F) (MHC)</td>
<td>11.1 years (SD=2.7)</td>
<td>Questionnaires (completed by child in clinic and by PBI)</td>
<td>Low maternal care was associated with child behavioural problems and higher perception of scholastic competence, suggesting perception of vulnerability may impact care. There were few bribing qualitative interview would have provided an opportunity to identify when spoiling and bribery were necessary and may have indeed indicated that this occurred at times of treatment. No differences were reported between groups on parental overprotection, positive parenting or inconsistent discipline.</td>
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<tr>
<td>Study</td>
<td>Country</td>
<td>Condition</td>
<td>Intervention</td>
<td>Duration</td>
<td>Participants</td>
<td>Instruments</td>
<td>Findings</td>
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<tr>
<td>Dahlquist et al. (1994)</td>
<td>USA</td>
<td>Cancer</td>
<td>During medical procedures</td>
<td>30.4 months</td>
<td>66 (2 age groups, 30F, 36M, 71% Ms)</td>
<td>Group 1: 5.74 (SD=1.54), Group 2: 12.08 (SD=2.64)</td>
<td>Observation and Questionnaire</td>
<td>Differences between groups, thus indicating cystic fibrosis may not directly impact the use of positive strategies.</td>
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<tr>
<td>Holmbeck et al. (2002)</td>
<td>USA</td>
<td>Spina Bifida</td>
<td>Not reported</td>
<td>N/A</td>
<td>37 M, 31 F &amp; MHC</td>
<td>Spina Bifida group: 8.34 (SD=0.48), Able bodied group: 8.49 (SD=0.50)</td>
<td>Questionnaire and Observation</td>
<td>PDI</td>
<td>Less nurturing parenting was used more frequently by anxious parents of younger children. Parents provided less reassurance prior to medical procedures. For some children, less reassurance may in fact help to reduce the child’s distress and reflect familial coping strategies which are functional for each family and circumstances.</td>
</tr>
<tr>
<td>Im &amp; Kim (2011)</td>
<td>Korea</td>
<td>Atopic Dermatitis</td>
<td>Receiving treatment</td>
<td>6.75 (range 0.5 to 12.8)</td>
<td>102 (48M, 54 F)</td>
<td>9.51 (SD=2.43)</td>
<td>Questionnaire</td>
<td>Higher levels of responsive, warm and supporting parenting were highly correlated with resilience. Resilience may be intrinsic and therefore not a direct product of parenting strategies but several variables.</td>
<td></td>
</tr>
<tr>
<td>Steele et al. (2003)</td>
<td>USA</td>
<td>Cancer (Acute lymphoblastic leukaemia)</td>
<td>Attending hospital</td>
<td>Initial 6 months of diagnosis and treatment,</td>
<td>65 Ms</td>
<td>Mean: 8.3 years (SD=2.9)</td>
<td>Questionnaire</td>
<td>PDI</td>
<td>Higher reported distress was associated with higher responsiveness. However, distress was shown to reduce over time, likely in response to adjustment to the child’s diagnosis. Parental strategies (e.g. nurturance) remained stable over</td>
</tr>
</tbody>
</table>
and acute myeloid leukaemia. Positive strategies may in fact show little variation despite chronic illness. Initial distress may serve as a protective factor to enable parents to be ready and responsive to the child’s needs at the time of diagnosis.

NB. *Some illnesses are diagnosed at birth, therefore illness duration may not applicable. Sample is children unless otherwise specified. M=Male, F=Female, Ms=Mother, Fs= Fathers, HC= Healthy controls, HMC= healthy matched controls, GPnts= Grandparents, Prof=Professionals, See table 2 for full list of measures.
A total of 16 standardised questionnaires were identified to measure several parenting strategies, summarised in table 2. Five studies used non-standardised measures.
Table 2. Measures of parenting strategies used in included studies

<table>
<thead>
<tr>
<th>Category</th>
<th>Acronym</th>
<th>Instrument</th>
<th>N Studies*</th>
<th>Concepts measured (where specified)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overprotection (OP)</td>
<td>CDQ</td>
<td>Child Development Questionnaire</td>
<td>2</td>
<td>Punishment, force, reinforcement of dependence</td>
</tr>
<tr>
<td></td>
<td>CRBQ</td>
<td>Child Rearing Behaviour Questionnaire</td>
<td>1</td>
<td>Denial of child’s autonomy, verbal assaults, negative emotion or attitude toward child</td>
</tr>
<tr>
<td></td>
<td>CRPBI</td>
<td>Child Report of Parent Behaviour Inventory</td>
<td>1</td>
<td>Acceptance-rejection, firm control-lax control, psychological control-psychological autonomy</td>
</tr>
<tr>
<td></td>
<td>OPS</td>
<td>Overprotection Scale</td>
<td>1</td>
<td>Parental overprotection</td>
</tr>
<tr>
<td></td>
<td>PBI</td>
<td>Parental Bonding Instrument</td>
<td>3</td>
<td>Allowance of independence, development of autonomy vs OP, intrusion and infantilising</td>
</tr>
<tr>
<td></td>
<td>PPS</td>
<td>Parent Protection Scale</td>
<td>9</td>
<td>Supervision, Separation, dependence, and control. Higher scores indicate higher OP.</td>
</tr>
<tr>
<td></td>
<td>RI</td>
<td>Restriction index</td>
<td>1</td>
<td>Behavioural restrictions imposed on child</td>
</tr>
<tr>
<td>Discipline (D)</td>
<td>APQ</td>
<td>Alabama Parenting Questionnaire</td>
<td>1</td>
<td>Corporal Punishment, Inconsistent Discipline, Poor monitoring</td>
</tr>
<tr>
<td></td>
<td>APS</td>
<td>Alabama Parenting Scale</td>
<td>1</td>
<td>Inconsistent Discipline</td>
</tr>
<tr>
<td></td>
<td>CRPBI</td>
<td>Child Report Behaviour Inventory</td>
<td>1</td>
<td>Lax Discipline</td>
</tr>
<tr>
<td></td>
<td>CRPQ</td>
<td>Child Rearing Practices Questionnaire</td>
<td>1</td>
<td>Use of punishment vs reason, Promotion of independence and level of rules of behaviour</td>
</tr>
<tr>
<td></td>
<td>CRPR</td>
<td>Child Rearing Practice Report</td>
<td>4</td>
<td>Authority discipline and control strategies</td>
</tr>
<tr>
<td></td>
<td>DM/DKQ</td>
<td>Discipline Knowledge and Methods Questionnaire</td>
<td>1</td>
<td>Discipline methods (e.g. scolding, redirecting)</td>
</tr>
<tr>
<td></td>
<td>IPBI</td>
<td>IOWA Parent Behaviour Inventory</td>
<td>2</td>
<td>Limit setting, reasoning guidance (e.g. explaining consequences)</td>
</tr>
<tr>
<td>Test</td>
<td>Description</td>
<td>Scale Series</td>
<td></td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>-------------</td>
<td>--------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>PBC</strong></td>
<td>Parent Behaviour Checklist</td>
<td>1</td>
<td>Discipline subscale</td>
<td></td>
</tr>
<tr>
<td><strong>PDI</strong></td>
<td>Parenting Dimensions Inventory</td>
<td>2</td>
<td>Amount of control, e.g. rule setting, type of control of discipline</td>
<td></td>
</tr>
<tr>
<td><strong>APS</strong></td>
<td>Arnold Parenting Scale</td>
<td>1</td>
<td>Laxness</td>
<td></td>
</tr>
<tr>
<td><strong>CRBQ</strong></td>
<td>Child Rearing Behaviour Questionnaire</td>
<td>1</td>
<td>Permissiveness-non-intervention (over acceptance, surrender, indifference, non or less optimal intervention)</td>
<td></td>
</tr>
<tr>
<td><strong>APQ</strong></td>
<td>Alabama Parenting Questionnaire</td>
<td>1</td>
<td>Warmth of relationship and strength of affective bond</td>
<td></td>
</tr>
<tr>
<td><strong>CRBQ</strong></td>
<td>Child Rearing Behaviour Questionnaire</td>
<td>1</td>
<td>Responsiveness, trust, support, nurturance, help to develop autonomy</td>
<td></td>
</tr>
<tr>
<td><strong>CRPR</strong></td>
<td>Child Rearing Practice Report</td>
<td>4</td>
<td>Expression of emotion in interaction</td>
<td></td>
</tr>
<tr>
<td><strong>PBC</strong></td>
<td>Parent Behaviour Checklist</td>
<td>1</td>
<td>Nurturing</td>
<td></td>
</tr>
<tr>
<td><strong>PBI</strong></td>
<td>Parenting Bonding Inventory</td>
<td>3</td>
<td>Warmth, affection, empathy, reciprocity vs coldness, indifference and neglect</td>
<td></td>
</tr>
<tr>
<td><strong>PDI</strong></td>
<td>Parental Dimensions Inventory</td>
<td>2</td>
<td>Nurturance, responsiveness to child’s input, and non-restrictive attitudes.</td>
<td></td>
</tr>
<tr>
<td><strong>IPBI</strong></td>
<td>IOWA Parent Behaviour Inventory</td>
<td>2</td>
<td>Responsiveness, expressions of feeling and intimacy</td>
<td></td>
</tr>
<tr>
<td><strong>Spoiling and Bribing (SB)</strong></td>
<td>Devised by Authors (Williams et al, 2014) 4 items</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Positive Parenting (PP)</strong></td>
<td>Alabama Parenting Scale</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CDQ</strong></td>
<td>Child Development Questionnaire</td>
<td>2</td>
<td>Positive Reinforcement, Modelling and Reassurance</td>
<td></td>
</tr>
<tr>
<td><strong>DMQ</strong></td>
<td>Decision Making Questionnaire</td>
<td>1</td>
<td>Whether parents told children what to do, discussed issues but had the final say.</td>
<td></td>
</tr>
<tr>
<td><strong>W GAS</strong></td>
<td>Willingness to Grant Autonomy Scale</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Summary of parenting strategies identified**

**Overprotection**

Nineteen articles (59%) were identified as measuring parental overprotection (see table 2). Whilst some of these did not refer to overprotection specifically, many measured features of parental overprotection behaviours, including exerting control and discouraging independence or reported results in relation to overprotection. Under the umbrella of the term overprotection, parenting behaviours were captured by a total of eight measures (see table 2). Due to the number of articles measuring overprotection, information from these studies will be synthesised and discussed to identify factors which may contribute to the use of this strategy under the subheadings of age, parent gender, child and parental adjustment and autonomy.

**Age**

Behavioural restrictions were predicted by age in a haemophilia population, with fewer restrictions reported with increasing age (Banis et al., 1999), which is to be expected with general child development of independence and reduction of dependence on parents. Similarly, overprotection was also shown to decrease with the increasing age of the child in a cystic fibrosis group (Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989), and asthma and cystic fibrosis groups (Bourdeau et al, 2007). However, mothers of children with cystic fibrosis aged 10–12 showed higher levels of overprotection in comparison to healthy controls (Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989). However, Banis et al (1999) and Bourdeau et al (2007) did not have a healthy control group for comparison. In a cancer population, total parental protection score correlated with child and parent age, however there were no significant differences between illness groups for overprotection (Hullman, Wolfe-Christensen, Ryan et al, 2010b).

**Parent gender**

Interestingly, overprotection may be specific to parental roles and illness. In some cases, parental overprotection was found to be significantly higher in mothers of female children with cystic fibrosis as opposed to males (Cappelli et al., 1989). Similarly, mothers of children with juvenile arthritis were more likely to discourage their children from engaging in rough and tumble play (Gerhardt et al., 2003). Conversely, fathers of children with haemophilia saw themselves in the role of providing care and protection of their child, which was not demonstrated by fathers of healthy controls (Markova,
Macdonald, & Forbes, 1980). This also suggests that the gender of the child themselves may also be a factor, however as we have only identified three studies, this requires further investigation.

**Child and parent adjustment**

High scores for parental overprotection were reported by parents of children with cystic fibrosis and spina bifida, which were associated with higher behavioural and conduct problems (Cappelli et al. 1989; Holmbeck et al., 2002). In a cancer population, the same was observed, however these difficulties seemed dependent on timing and were shown to occur close to the time of diagnosis but were not reported at follow-up (Fedele, Mullins, Wolfe-Christensen, & Carpentier, 2011). Similarly, a lack of overprotective behaviours was reported by parents of children with a diagnosis of cancer during the maintenance phase of treatment (Williams et al, 2014), although higher parental overprotection was shown to significantly relate to lower levels of health related to quality of life for children with a diagnosis of cancer (Hullmann, Wolfe-Christensen, Meyer, McNall-Knapp, & Mullins, 2010a). However, for asthma and type 1 diabetes rates of overprotection were found to be low with only 14.6% of parents meeting cut off for clinically significant levels of overprotective behaviours (Mullins et al., 2004). In the case of these groups, parents’ perception of their child’s vulnerability was not associated with overprotection (Mullins et al., 2004). Mothers who are more anxious were found to use less positive strategies and more force, which may further impact the child’s level of self-confidence and independence, when little independence or allowance of autonomy is already present. Whilst treatment phase may be a factor in overprotective strategy usage, each illness has its own medical regimen and trajectory and therefore it is important to consider the illness intricacies and be mindful of the generalisability of such results from studies which provide specific cross sections for an illnesses trajectory.

Not all studies which included children with a diagnosis of cancer identified a detrimental impact of parental overprotection. Parental overprotection was found to not be significantly related to child adjustment outcomes and instead the results suggested that overprotection may serve a positive function and be adaptive in a cancer population (Colletti et al., 2008). However, overprotection and parental laxness were significantly associated with increased behavioural and emotional difficulties in children with or without illness, with parental laxness being the strongest indicator of these difficulties (Williams, Lamb, & McCarthy, 2014). This suggests that it is lax parenting rather than
overprotection that may be more detrimental to any child regardless of illness. However, in some illness populations parental overprotection is present and can have positive and negative impacts on child adjustment, which may be illness dependent.

Two studies using the Child Development Questionnaire (CDQ) found that parents of children with a poorer prognosis (e.g. cancer) fostered more reinforcement of dependency and used lax strategies (Dolgin, Phipps, Harow, & Zeltzer, 1990). Conversely, parents of children with sickle cell disease were treated with less overprotection and instead as more competent than healthy children (Schuman, Armstrong, Pegelow, & Routh, 1993). It comes as no surprise that a poor prognosis may impact on the parent’s ability to provide the child with more independence and be less overprotective. Little is known about the impact of these behaviours on the child at specific stages of their illness. In cases of children with a diagnosis of haemophilia, parental protection was related to a fear of bleeding and manifested in parents controlling children’s activities, such as not playing with toys with sharp edges to prevent injury (Markova, Macdonald, & Forbes, 1980). These parents rated themselves as stricter than parents of healthy controls and were considered well informed with regards to discipline, punishment and reward (Markova et al., 1980). One study including only two illness groups and no healthy control identified significant levels of negative parenting practices (Kirk et al., 2011). Perceived vulnerability was higher in the type 1 diabetes group, than those with a life-threatening disorder of sex development (DSD) (Kirk et al., 2011). We can hypothesise that the discrepancy in perception may be due to the requirement of stricter adherence to medical regimens and implications for morbidity. In which case, overprotection in some illness groups may indeed be functional and adaptive and be influenced by development. Whilst we know that overprotection is linked to perception of vulnerability (Thomasgard and Metz, 1997), this may differ across illness populations and illness severities. Similarly, how the child internalises overprotective behaviours and consequently views the world (e.g. the world is dangerous), may impact their development and could lead to increased anxiety and adjustment difficulties. Authors did not report whether parents had been on prior parenting training or received parenting support. It is therefore important to consider if some parents have innate abilities with regards to parenting strategies, which may be passed through generations, or indeed whether they seek out further support as a result of their changing role and coming to terms with their child’s illness. Alternatively, these parents may in fact be offered more support by the services they are receiving.
Autonomy

One study identified parent’s abilities to provide behavioural autonomy and willingness to grant autonomy to their children in the future using two questionnaires (Holmbeck et al, 2002; see table 2). Mothers of children with a diagnosis of spina bifida showed decision making autonomy and willingness to grant autonomy in the future was negatively associated with overprotection. Furthermore, less decision-making autonomy was also associated with overprotection (Holmbeck et al., 2002). The authors concluded that in fact they had further measured excessive protection behaviours. However, more overprotective parents were less likely to grant autonomy to their children (Holmbeck et al., 2002), which likely preserves dependency on the parent. Holmbeck et al (2002), found significant relations between psychological control and overprotection, which was more highly associated than other parenting practices (e.g. behavioural control). Mothers and fathers of children with spina bifida showed higher levels of overprotective behaviours compared to parents of able bodied children. Due to only one study considering these strategies it is difficult for us to make inferences with regards to other conditions. It is interesting to consider why such a strategy was researched and in relation to this condition. Children with spina bifida have been identified to experience delays in autonomy development (Friedman, Holmbeck, DeLucia, Jandask and Zebracki, 2009). It is therefore useful to consider whether this delay is illness related or partly due to parental overprotection. It is possible that autonomy was also considered by two further studies (Markova et al, 1980; Schuman et al, 1992) yet was defined as responsibility and competence. These studies referred to parents enabling children to become more competent and responsible for their illness management/life in general therefore likely promoting autonomy. Due to only three studies being identified and concepts being ill defined it is difficult to draw meaningful conclusions and is an area that requires further study.

Overall, overprotection was not observed in all illness groups. Only 2% of parents of children with a diagnosis of cystic fibrosis or Type 1 diabetes met the clinical cut off for overprotection as measured by the Parent Protection Scale (PPS) (Bourdeau, Mullins, Carpentier, Colletti, & Wolfe-Christensen, 2007). Therefore, overprotection may be more likely in more life-threatening illness at specific times in the illness trajectory and requires further investigation.
Discipline

Parental discipline is described as having rules and consequences for a child’s behaviour (Yap et al., 2015). Conduct disorder and aggression have been frequently linked to low monitoring and inconsistent discipline (Barber, Stolz, & Olsen, 2005). A total of fifteen studies measured parental discipline using a total of 9 measures and 1 observational measure (see table 2).

Across the fifteen studies, three studies of contrasting illness found no differences in comparison with controls with regards to the use of parental discipline (Carey, Nicholson, & Fox, 2002; Schuman et al., 1993; Williams et al., 2014). One study claimed to measure lax discipline using five items from the Child Report Behaviour Inventory (CRBI), however the results of this are not commented upon within the article (Holmbeck et al., 2002). In a study of parents of children with a diagnosis of cancer an effect was found for parents of younger children using less consistent and organised discipline, instead using more punitive methods and setting fewer rules (Dahlquist, Power, Cox, & Fernbach, 1994). Interestingly, these children demonstrated more behavioural distress and parents perceived their child to be more anxious prior to cancer treatment procedures. Steele et al (2003) also found parents of children with cancer to use less consistent discipline strategies. These were specific to a particular time point in the child’s illness trajectory, approximately 12-14 weeks’ post diagnosis. Two studies of parents of children with a diagnosis of asthma identified gender differences with regards to the types of discipline used. Fathers were found to seldom tell their children they were good or praise good behaviour as often as mothers. Fathers were more likely to physically discipline their child and more likely to promise treats depending upon disease severity (mild or moderate). This was also true in a juvenile arthritis group whereby fathers of children with a diagnosis reported having difficulty punishing their child (Gerhardt et al., 2003). Severity of illness was not linked to perceived effectiveness of discipline strategies in an asthma population (Eiser et al, 1991a; Eiser et al, 1991b). However, rule setting and structure was significant for children with more severe arthritis (Schuman et al., 1993). Conversely, in a study of three illnesses versus healthy controls significant effects were observed for limit setting, with mothers of children with a chronic illness less likely to set limits than parents of healthy children (Levers et al., 1994)

Williams et al (2014) found that parents showed higher levels of lax parenting and reported more incidences of spoiling and bribery in children receiving treatment for cancer. Consistent with previous research from a non-illness population, both strict and
lax parenting can both have significant impacts on children’s development both in healthy and illness groups. It is important to note that spoiling and bribery were not specifically measured by the Parent Protection Scale (PPS) and instead were measured by four separate items added by the authors. It is therefore difficult to determine whether parents of children with other diagnoses may also use these strategies as these concepts were not reported by any other study. Similarly, these strategies were seen specifically in children receiving cancer treatment and therefore may reflect a strategy, which is specific and potentially adaptive for this stage of the illness. Research into chronic illness has shown that medical adherence can be improved through positive reinforcement, such as using sticker charts (Luersen et al., 2012). Whilst these behaviours are referred to as ‘spoiling and bribing’ they may indeed reflect parent’s strategies to increase their children’s motivation to undergo demanding and exhausting treatments.

Only one study (Williams et al., 2014) specifically studied parental laxness using the 11-item laxness subscale from the Arnold Parenting Scale (APS). Parents of children with a diagnosis of cancer showed higher levels of lax parenting than the healthy control group. Lax parenting was associated with higher rates of child emotional and behavioural difficulties, which were higher than healthy controls. Comparatively, in another study of parents of children with cancer vs. healthy controls, parents rated themselves to have strict and well established rules for their child in comparison to controls (Hillman, 1997). A further study however used a permissiveness-non-intervention subscale of the Child Rearing Behaviour Questionnaire (CRBQ), which measured over-acceptance, surrender, indifference and non or less optimal intervention (Im & Kim, 2011). The authors of this review perceive this to describe parental laxness. However, in children with atopic dermatitis, no association was found between permissiveness-non-intervention and child resilience.

Professionals’ views of discipline were assessed by two studies which found that professionals anticipated differences between parents of children with an illness compared to healthy controls. Specifically, professionals perceived the parents of children with sickle cells disease would be less effective at implementing discipline (Noll, Mckellop, Vannatta, & Kalinyak, 1998).

As discipline encompasses a range of terms and behaviours within this strategy, it is difficult to draw conclusions to provide a global understanding of discipline in chronic illness populations due to the variation in study design and concept measurement.
Positive Parenting Strategies

There is clear evidence for the role of parental warmth, involvement and nurturance in regards to child psychological and behavioural adjustment (Suchman, Rounsaville, DeCoste, & Luthar, 2007). Low parental responsiveness has been shown to affect attachment security and can result in insecure ambivalent or avoidant attachment styles (George, Cummings, & Davies, 2010). There is a wealth of literature to support the need for consistent, responsive and supportive parenting, which is undoubtedly important for children facing a chronic illness. Fifteen of the included studies referred to the measurement of warmth, support, involvement or care, which are discussed below (see table 2).

Parental Warmth/Involvement

Studies which identified lower parental care identified mental health difficulties for the parent or child or both (Eckshtain, Ellis, Kolmodin, & Naar-King, 2010; Holmbeck et al., 2002). Two studies of youth with diabetes were identified in which youth depressive symptoms were related to metabolic control, which in turn was associated with lower care and involvement from parents (Eckshtain et al., 2010). Thus, parental well-being and their ability to provide positive parenting strategies can be important in the management of a chronic illness and can have cyclical impacts on the child’s adjustment. Furthermore, anxious parents were identified to provide less reassurance and nurturing during children’s medical procedures for cancer and instead showed levels of agitation. Thus, parents’ well-being and ability to cope is particularly important in terms of their ability to support their child during their illness and its associated treatments (Dahlquist et al., 1994). Whilst meta-analyses have shown no quantifiable differences in parental responsiveness (Pinquart, 2013), qualitative differences do exist and are important to highlight with regards to identifying support for specific illness groups.

Higher affective difficulties experienced by the parent correlated with higher responsiveness to the child in a cancer group (Steele, Long, Reddy, Luhr, & Phipps, 2003). This is consistent with previous research in a non-illness population, which showed that maternal anxiety resulted in greater intrusiveness in situations with high expressed anxiety or anger (Hudson, Comer, & Kendall, 2008). Further child adjustment difficulties were described in a study of children with cystic fibrosis, whereby low maternal care was correlated with child behavioural problems (Cappelli et
al., 1989). However, similar degrees of care were shown to exist across both the illness and the control group with fathers and mothers providing a similar level of care, compared to higher maternal care in a healthy control group. In parents of children with asthma, mothers were shown to provide higher levels of involvement (Eiser et al., 1991a; Eiser et al., 1991b). Higher levels of paternal warmth, responsive and supportive parenting was shown to be highly correlated with resilience in an atopic dermatitis group. Thus, children were shown to have better relationships with both teachers and peers (Im & Kim, 2011). Warmth – acceptance was found to be the highest scored in comparison to other parenting behaviours and was high for both mothers and fathers. However, children’s resilience was mediated by the duration of their illness, thus supporting the importance of fostering parental warmth and involvement from an early age to give children the foundations of resilience as these may waiver when facing a chronic illness. In in a general population it may be expected that parental care would decrease with age as children become more independent and require less involvement from their parents. The opposite might be expected in an illness population, particularly in cases whereby the illness is life shortening.

**Praise, Reinforcement and Promotion**

One study particularly identified measuring ‘positive parenting’ specifically, using three items from the Alabama parenting scale (APS). Items included statements such as “you praise your child if he/she behaves well”. No significant differences for positive parenting were observed (Williams et al., 2014). Two further studies (Dolgin et al., 1990; Schuman et al., 1993) measured positive reinforcement, modelling and reassurance using the Child development questionnaire (CDQ). Parents were found to use fewer positive strategies when they themselves were anxious (Dolgin et al., 1990) supporting previous findings (Dahlquist et al., 1994). Both studies included children with a diagnosis of cancer, which can be life threatening and have a significant impact on a family. Parents may therefore experience more anxiety and thus have greater difficulties accessing positive strategies than for example parents of children with diabetes. Although diabetes can be life threatening, it can generally be managed with medication and lifestyle changes. In a study of children with a diagnosis of cancer (Eiser, Eiser, & Greco, 2002), parents were observed to provide more promotion (nurturance related parenting) as opposed to prevention strategies (vigilance, concern about failure). However, this was dependent on diagnosis, with more prevention strategies being used by mothers of children with CNS tumours. However, prevention
strategies were linked to quality of life regardless of diagnosis. Positive strategies, such as parent’s nurturance and being sensitive to a child input were linked to improved treatment adherence.

Discussion
This review sought to build upon our existing understanding of parenting strategies used by parents of children with a chronic, life threatening or life limiting illness to identify illness groups which may require more targeted support. We hoped to identify and assess whether there is a consensus on the strategies used across illness groups and those distinct to specific illnesses. Furthermore, we aimed to identify factors which may increase or decrease the use of strategies and what impact such strategies have on children with differing illnesses.

From this review, it is apparent that several characteristics are associated with the type of strategies parents select and this is not always wholly reliant on their child’s illness. However, illness does seem to have an impact on strategy usage with regards to discipline, whereby some parents seem to adopt more lax strategies overall in comparison to parents of children without illnesses. Precise reasons for parents of children with a chronic, life threatening or life limiting illness struggling to provide discipline are unclear. Fathers of children with juvenile rheumatoid arthritis reported difficulty in punishing their child (Gerhardt et al., 2003). Similar findings were observed for cancer populations (Dahlquist et al., 1994; Steele et al., 2003). This may hold true across many illness groups and requires more investigation as to whether perceived child vulnerability or illness type and severity impacts parent’s ability to instil boundaries and what impact of this could have on the child. We can hypothesise that parents may experience guilt or tend to be more lenient to their children due to their illness. Discipline often has negative associations and is linked with control and punishment (Nieman and Shea, 2004). However, effective discipline strategies; such as consistency, boundaries and the avoidance of empty threats are important and enable children to develop their own self-discipline and build trust between the parent and child (Nieman and Shea, 2004).

Our review of protection strategies (e.g. overprotection) were not as clear cut. Previous research has identified group differences for overprotection behaviours when comparing parents of children with and without chronic illnesses (Pinquart, 2013). However, individual differences exist with regards to how these behaviours manifest across illness groups. Levels of overprotection varied by age and illness, parent gender
and had varying impacts on child and parental adjustment. Overprotection was associated with greater behavioural problems and poorer health related quality of life. Differences were shown to exist between mothers and fathers in some illness groups, with some mothers using more reinforcement and fewer punishments than fathers. On a day to day basis overprotection may serve to aid adherence to treatment, which in the case of Type 1 diabetes can be multiple times per day. In addition, it may be useful to consider parents’ perceptions of children as too young to have to cope with the burden of a diagnosis. Parents may therefore retain control and overprotect to preserve their child’s childhood. Similarly, children may expect increased support from their parents, resulting in over-dependence and then striving for independence in adolescence (Theofanidis, 2007). However, it is important to note that not all parents of children with a chronic illness are overprotective or lax. In fact, some foster independence and promote competence in their children, although these behaviours may be dependent on illness type and the parents own emotional reaction to the child’s illness. In some cases, parents encouraged their children to become more responsible for themselves in relation to their illness. However, in illnesses such as cancer parenting strategies were more overprotective in the initial stages of the illness and became progressively more lax. This may have positive and negative outcomes for the child and may reflect the parents own adjustment to their child’s diagnosis and prognosis. Interestingly, whilst not associated with the aims of this review one study did identify that children were found to not differ from healthy controls with regards to their perceptions of parental overprotection (Tillery, Long, & Phipps, 2014). This was however mediated by the child’s level of distress, which was found to be associated with parental overprotection and care. Thus, children’s perception of overprotection may be dependent upon their own psychological well-being. Conversely, parental overprotection may foster child distress and vice versa.

Parents’ own adjustment is important to consider. Collectively, parents were found to use more negative practices when they were anxious themselves. This is interesting to highlight as in the cases of diabetes and haemophilia for example, children may be encouraged to take a more active role in their illness care. However, in illness such as cancer, parents may become progressively more involved in their child’s care, which may alter their use of strategies and may account for parents of children with cancer becoming more lax and self -reporting themselves to be less efficient in their use of parenting strategies. That said, these strategies may in fact be adaptive and functional. Parents of children with a diagnosis of cancer may be more likely to take an
active role in physically caring for their child. One cancer study found that parents worried about over-involvement (Davies et al., 1991), whereas another found that maternal reinforcement of dependency was associated with prognosis (Dolgin et al., 1990). Thus, illness trajectory, whereby despite the illness being life limiting, may play a role in the use of parenting strategies. Incidentally, parent’s perception of the illness and their child’s vulnerability are likely important factors in strategy selection. It may be important to consider that alongside parenting support, support is required for parents themselves to aid their own adjustment to the child’s diagnosis. It is likely that when children are diagnosed parents do not prioritise themselves, however by not doing so they run the risk of impeding their child’s adjustment and resorting to less functional parenting strategies.

It is important to consider normal age appropriate development with regards to the strategies parents adopt. Ten of the included studies recruited children over the age of 10. Middle childhood and adolescence are a stage when children often begin to become less dependent on their parents and develop skills for functioning in adult roles (Power, Dahlquist, Thompson, & Warren, 2003). Parents are largely responsible for helping to develop these skills, through granting autonomy. Parents of a child with an illness may be less likely to do this or may not do this at a developmentally appropriate time. Therefore, interventions to support parents to develop strategies which enable them to provide support to their child whilst recognising what is developmentally appropriate should be considered.

Parents who provide warmth and structure foster resilience in their children. Resilience, is defined as positive adaptation despite significant adversity and has been shown to be associated with close relationships with parents (Fee & Hinton, 2011). Due to the number of stressors experienced during a chronic illness (e.g. physical and social limitations on lifestyles) children are at increased risk of developing mental health problems (Barlow & Ellard, 2006). These risks are not confined only to the children diagnosed and can also affect parents and siblings (Barlow & Ellard, 2006). Whilst not all parents and siblings struggle with the experience of a loved one having a chronic or life limiting illness, some parents and families may be at greater risk. The current review has identified that parental warmth can be mediated by parents and children’s own affective well-being. Whilst parental care has been linked to behavioural problems, this may not be impacted further by a chronic illness diagnosis. In fact, care may be dependent on the child’s individual needs. However, illness may impact parental care through the potential to cause mental health problems or adjustment issues (e.g.
behavioural and emotional problems). Parents who are highly anxious or show high affective responses to a child’s diagnosis may struggle to provide a child with adequate care and involvement or conversely become overinvolved. This has been referred to as miscarried helping and parents run the risk of hindering typical development as a result of their involvement leaking into areas it is not required (Pinquart, 2013). A lack of care may consequently affect the child’s mental health and adjustment, which may further impact on the mental health of the parent, producing a circular maladaptive pattern of relating. Thus, it is important that the well-being of the parent and child, plus siblings are carefully monitored. Interventions to aid parent’s abilities to provide effective discipline specific to their families’ unique needs are required. This should be augmented with support to the parent to help promote their own confidence, coping and well-being to enable positive parenting. Such interventions will increase the possibility of positive adjustment for families and improve adherence to medical regimen.

Limitations

Whilst this review has made steps to draw together information pertaining to parenting strategies used in illness populations it has been limited due to the type and quality of studies currently available. The most common diagnosis was cancer, and therefore whilst this review can provide some insight into the parenting strategies and adjustment difficulties experienced by this population, the lack of singular studies comparing one illness population to a healthy control group makes it difficult to draw useful conclusions at this stage.

Cancer itself can vary widely in terms of its treatment, prognosis and complications, with some cancers, such as central nervous system (CNS) tumours having a poorer outcome than for example Acute lymphoblastic leukaemia (ALL) (Eiser et al., 2002). Cross illness comparisons can be difficult. There is a need for more high quality research into this important area to ensure parents who are already under extreme burden both physically, emotionally and often financially can receive adequate support.

This review has also been potentially limited by the search terms and strategies used to locate the literature. For example, more literature may have been discovered if other terms had been incorporated in the search, such as ‘condition’ or ‘disease’ as opposed to only using ‘illness’. Although searching by illness was undertaken to the extent project resources allowed, we may not have identified all of the papers potentially available. Searching of specific terminology, would have been particularly
labour intensive, particularly for example in relation to cancer which is an umbrella term describing several diseases. Furthermore, date limits were not used, therefore some studies may not reflect up to date information relevant to today’s population. In addition, whilst some studies were excluded on the basis of not being published articles, no studies were rejected on the grounds of methodological quality, although quality was reviewed.

The majority of studies were cross sectional; therefore, little is still known about parenting strategies at different stages of a child’s illness. Most studies were completed in western countries and therefore may not reflect the strategies adopted by all ethnic groups. In addition, health care services can vary widely between for example the UK and the USA and therefore the experiences and the treatment families receive may also impact on the strategies they use. This review includes illnesses, which are non-comparable in terms of their treatment and prognosis. Furthermore, we have included studies which document a range of illness stages, which may hinder useful comparisons due to the variable nature of some illnesses and treatments. Considering this we make some recommendations for future research below.

**Recommendations for future research**

Future research should ensure measurement of parental affect (e.g. anxiety) as this was shown to impact parents’ use of strategies. Additionally, research into the mechanisms behind why parents struggle to provide boundaries and discipline needs further investigation. Methodologically, research should aim to avoid multiple illness comparisons and instead provide comparison to a healthy population group. By doing this the true impact of the illness can be investigated independently. Participants should be recruited based on specific criteria, such as length of time since diagnosis, so that the impact of the illness can be assessed at particular time points. With this in mind, longitudinal as opposed to cross sectional designs would be beneficial, particularly as there is the possibility of parents and children adapting to the illness, which may impact their use of strategies and adjustment.

Future research should take into consideration previous parent support/training received as this is essentially a confounding variable. In addition, the age of children recruited should be carefully considered in relation to child development, particularly because middle childhood and adolescence are important times of change as children strive to develop their independence. The assessment of like for like illness groups would aid meaningful comparisons to capture perceived seriousness and impact. Similarly, standardised measures should be incorporated to ensure strategies are being
measured accurately. Real time observations of parent-child interactions to compare with parent reports may provide rich information to inform interventions.

Acknowledgements

This review was conducted by the first author as part of their Doctorate in Clinical Psychology at the University of Manchester. The latter authors were involved in the review as part of their employment with the Royal Manchester Children’s Hospital, United Kingdom and The University of Manchester. We gratefully acknowledge Emma Wells (EW) and Annuka Lehtonen (AL) for their contribution to the quality analysis. The authors have full control of all data, which is available to the journal upon request. No funding source.

3 As per the journals requirements a statement of compliance with ethical standards was prepared however has not been included in the thesis.
References


Paper 2: A case series evaluation of a self-directed Positive Parenting Program (Triple P) for parents of children with a diagnosis of cancer: a feasibility study

The following paper has been prepared for submission to the Journal of Pediatric Psychology. The guidelines for authors can be found in Appendix 4. Formatting changes have been made to the current paper to aid readability: Tables and figures have been inserted within the text and the line spacing has been decreased to 1.5.

Word count 7330 (Excluding abstract, tables, figures and references)
Abstract

Objective To assess the recruitment, retention to and feasibility of a Positive Parenting Program (Triple P) self-directed workbook for parents of children aged 3-10 years with a diagnosis of cancer. Methods A feasibility study using multiple non-concurrent baseline single case series design. Recruitment was predominantly online supported by national advertising through cancer charities and associated media (e.g., Twitter, Facebook). Data were collected via online survey. The intervention was a 10-week self-directed workbook, during which weekly outcome, interim and post-intervention measures were recorded. Results Four mothers participated in the case series, completing measures throughout. Visual analysis showed reductions in behavioural difficulties and parental laxness, verbosity and over-reactivity and increases in parent’s emotional resources. Conclusion The findings suggest a supportive parenting self-directed workbook may be useful to parents of children with a diagnosis of cancer and warrants further exploration, particularly in relation to facilitation of access to parenting skills intervention.

Keywords: Cancer, Children, Parenting, Triple P, Case Series.
Introduction

The increased understanding of the psychosocial implications of paediatric cancer has led to the integration of psychological consideration in routine care of children with a diagnosis of cancer (Jacobsen & Wagner, 2012; NICE, 2014). In the United Kingdom, an average of 1603 new cases of childhood cancer were identified between 2008-2010, with higher incidences in boys than girls (NICE, 2014). Despite some children achieving good psychological adjustment (Patauaude & Kupst, 2005; Nazari et al, 2014), there is increasing recognition of emotional and behavioural problems in child cancer survivors.

Psychological sequelae of a diagnosis of cancer in children have been reported to manifest in behaviour and mood changes, including temper tantrums and being uncooperative. These difficulties were reported by 84.1% of parents of children with a diagnosis of Leukaemia (Clarke et al, 2005). In addition, children with a diagnosis of cancer have been shown to have significantly higher scores for hyperactivity/impulsivity, rule-breaking behaviours and aggressive behaviours when compared to healthy controls (Liang et al, 2008). An excess of problem behaviours and underachievement have also been identified in children with a diagnosis of acute lymphoblastic leukaemia (ALL) (Buizer et al, 2006). Similarly, a study of 2,979 cancer survivors and 649 siblings found significantly elevated scores for depression/anxiety, attention deficit, and antisocial domains. Specifically, they noted that those with a history of leukaemia, CNS tumours or neuroblastoma may be at greater risk for adverse behavioural and social outcomes and suggest the development of interventions for these difficulties (Schultz et al, 2007).

Interest in the quality of life of children with a diagnosis of cancer has increased in the past decade due to improved survival rates. Quality of life of those with an illness diagnosis is often termed health related quality of life (HRQoL) and is associated with satisfaction or happiness in areas of life which may be impacted by illness (e.g., social, cognitive) (Kreitler & Kreitler, 2012). Emotional and functional wellbeing as well as illness symptoms are often considered with regards to HRQoL and it is therefore considered a multidimensional construct (Kreitler & Kreitler, 2012). Overall rates of quality of life in paediatric cancer patients have been shown to be lower dependent on cancer type, with leukaemia patients often showing the lowest levels. Similarly, stage of cancer has been shown to impact on the different domains of quality of life, with those in latter stages having more difficulties in the emotional domains (Kreitler & Kreitler, 2012).
 Whilst HRQoL has been shown to be significantly influenced in the first six months’ post-diagnosis (Tsai, et al, 2013), there is evidence to support ongoing difficulties particularly in relation to emotional adjustment (Landolt, Vollrath, Niggli, Ghnem, & Sennhauser, 2006). Quality of life is usually rated by proxy via parents, with often only a handful of studies including child ratings. Family cohesion and good family routines have been shown to improve quality of life for children with cancer (Bakarat, Marmer & Schwartz, 2010; Santos, Crespo, Canavarro & Kazak, 2015). Similar findings have been reported in children with other health conditions whereby better quality of life has been observed through the use of positive parenting strategies, such as the promotion of autonomy (Aran, Shalev, Biran, & Gross-Tsur, 2007). Therefore, interventions to improve the selection of positive parenting practices may be useful in improving health related quality of life.

Chronic illness, such as cancer, can affect parenting, with general parenting practices becoming more difficult and causing greater uncertainty for parents with regards to how to respond or make allowances (Edwards & Titman, 2010). Parents of children presenting with emotional and behavioural difficulties often experience significant burden, as these children require increased attention and supervision (Meltzer et al, 2011). Caring for a child with a diagnosis of cancer brings about several additional challenges. Often parents have a role in the child’s medical care whilst also trying to maintain daily family functioning (Vance & Eiser, 2004). Studies have shown that parents of children with a diagnosis of cancer report poorer quality of life when compared to population norms (Klassen et al, 2008). In addition, parenting and parent health have shown to have many implications for the care of the child with a cancer diagnosis. For example, parenting stress has been linked to poorer child behavioural adjustment (e.g., acting out), and poorer social and emotional adjustment (Colletti et al, 2008). Furthermore, treatment adherence had been linked more supportive, nurturing parents who often then delay and cancel fewer appointments (Manne et al, 1993). Similarly, parents who are less inclined to set boundaries or reprimand their children often show greater difficulties with cooperation to procedures, such as oral care and physical examinations (LaMontagne et al, 1999).

Prevention of mental health and social difficulties, as well as greater adherence to illness management, can be achieved through parenting interventions (Sanders & Kirby, 2015). A recent review by Eccleston et al (2015) of 47 studies highlighted the benefits of problem solving approaches in improving parenting behaviour. However,
they note an overall paucity of interventions aimed at parents of children with a chronic illness.

One option for identifying suitable interventions is to test the appropriateness of applying existing interventions in this context, with appropriate tailoring. Whilst multiple parenting programmes exist (e.g. The Incredible Years; Webster-Stratton, 2015) to our knowledge, Triple P is the one of the only programs to investigate the efficacy of a self-directed parenting intervention for parents of children with chronic illness and was therefore selected for this reason Self-directed Teen Triple P has been shown to be effective in reducing illness related conflict and behavioural problems in adolescents with Type 1 Diabetes (Doherty et al, 2013). The Triple P – Positive Parenting Program is a successful treatment for emotional and behavioural difficulties designed to improve the quality of parenting advice available to parents through a multilevel system intervention (Sanders, 2008). The programme was developed in Australia and has advanced into a public health model (Sanders, 2008). The system, based on social learning principles, aims to offer prevention and treatment of severe behavioural, emotional and developmental difficulties in children and adolescents (Sanders, 1999; Sanders, 2008; de Graff et al, 2008). The programme works through enhancing parents’ knowledge, skills and confidence through five levels of intervention and can be used with children from birth to aged 16 years (Sanders, 2008). It targets developmental stages and ranges in intensity to be accessible and flexible to differing levels of dysfunction and behavioural disturbance (de Graaf et al, 2008). The five levels of intervention range from psycho-education and brief interventions for mild behavioural difficulties, to enhanced behavioural family interventions for families where parenting difficulties are complicated by other factors (de Graaf, 2008). Self-directed Triple P is one delivery mode in which parents receive a detailed parenting workbook (Every Parents Self-Help workbook; Markie-Dadds, Sanders & Turner, 2001). The workbook outlines a 10-week-programme consisting of set readings and suggested homework tasks for parents to complete. All forms of Triple P have shown to have moderate to large effects on parent reported child behaviours (Thomas & Zimmer-Gembeck, 2007).

A need for parenting information in an oncology population has been demonstrated by Williams et al (2012) who report that parents require information about parenting strategies, particularly to manage the challenging behaviours being exhibited by their child. The current study examined the feasibility and efficacy of a self-directed version of the Triple P - Positive Parenting Program for parents of children
with a diagnosis of cancer using a case series design. The primary aims of the current study were to assess the feasibility of recruitment and retention for a self-directed intervention in an oncology population and whether the intervention could improve the quality of life for children with a diagnosis of cancer. Secondary aims included reducing parent reported behavioural and emotional difficulties, promoting change in parenting behaviours, parent self-confidence and parents’ experience of their child’s illness and assessing the feasibility of online recruitment.

Method

Design
The current study was a feasibility study influenced by the Medical Research Council guidance for the development and evaluation of complex interventions (Craig, Dieppe, Macintyre, Michie, Nazareth & Petticrew, 2008) to test the procedures and their acceptability, whilst assessing recruitment and retention through quantitative and qualitative methods. An initial survey was conducted by clinicians at the Royal Manchester Children’s Hospital with parents of children with a diagnosis of cancer to inform the selection, format and delivery of an appropriate parenting intervention and gauge interest from parents. Feasibility of online recruitment was assessed via a select survey system developed by the University of Manchester, which provides automatic calculation of sign up. The intervention was assessed using a case series design with a non-current multiple baseline period as described by Watson and Workman (1981) and utilised by Bevan, Wittkowski and Wells (2013). A concurrent baseline period could not be used due to the method of recruitment; as participants, did not start the study/intervention at the same time (Watson & Workman, 1981). The study employed an A-B multiple baseline design, whereby A is the baseline phase and B is the intervention phase. Participants were then followed up at 1 month following completion of the B phase. Baseline periods of one to three weeks were randomly allocated to analyse stability of scores pre-intervention and ensure any improvements in scores on the outcome measures could be attributed to the intervention (Ferron & Scott, 2005).

Participants
Parents/caregivers (aged 18 and over) of children aged 3-10 years with a diagnosis of cancer were primarily recruited via national advertisement on registered children’s cancer charity websites and associated social media sites (e.g., Facebook and Twitter).
Participants (parents) were eligible if they were the parent/caregiver of a child with a diagnosis of cancer, who had been diagnosed for six months. Participants were excluded if they had a diagnosis of a significant mental health difficulty (e.g., schizophrenia) and could not read unsupported because these difficulties would require more individualised support. No restrictions were placed on the type of cancer diagnosis.

**Outcome Measures**
The following outcome measures were used in the study. Missing data were minimised because participants could only move to the next item by completing the former.

**Baseline, Week 5, 10 and Post Intervention outcome measures**

*Family Background Questionnaire (FBQ) (Initial Questionnaire only)*
The FBQ (Sanders, Markie-Dadds, & Turner, 1999) was used to record demographic information. Its 16 items collate background information including gender, age of parent and child, living arrangements, socioeconomic status and level of education. All 16 items were used. However, due to overlap with some of the initial items on the Royal Marsden Hospital Paediatric Oncology Quality of Life Questionnaire (RMH-PQLQ), these questionnaires were amalgamated and formatted to include the general background section of the RMH-PQLQ. In addition, the authors added some specific cancer diagnosis categorisation, including blood cancer, solid cancer, brain and central nervous system (CNS) and other please specify.

*Royal Marsden Hospital Paediatric Oncology Quality of Life Questionnaire (RMH-PQLQ)*
This measure assesses health related quality of life in a paediatric oncology population (Watson et al, 1999). The questionnaire (78 questions) provides scores for emotional and behavioural difficulties, functional status, global health, physical symptoms, cognitive functioning and global quality of life rating, with an optional section regarding communication of the diagnosis and treatment. The measure shows good reliability for 7 of the 8 subscales (Cronbach α = .80; Watson et al, 1999).

*Parents Experience of Child Illness (PECI)*
The PECI (Bonner et al, 2006) assesses parental adjustment in relation to caring for a child with a chronic illness. The short form includes 25 items to be completed by parents, which assess the following factors: Guilt and Worry, Emotional Resources,
Unresolved Sorrow and Anger, and Long-term Uncertainty. The measure shows good internal reliability (Cronbach $\alpha = 0.72$ to $0.89$) and construct validity (Bonner et al, 2006).

*Parenting Scale (PS)*

The Parenting Scale provides an assessment of discipline practices and has been validated in pre-school and young adolescent populations (Arnold, O’Leary, Wolff & Acker, 1993; Irvine, Biglan, Smolkowski & Ary, 1999). It is a 30-item questionnaire, based on three factors, including parental laxness, verbosity and over-reactivity. The scale is correlated with parental behavioural observations and has good internal consistency (Cronbach $\alpha = 0.84$; Arnold et al, 1993).

*Parenting Sense of Competence Scale (PSOC)*

The PSOC is a 16-item questionnaire measuring parenting satisfaction and efficacy (Johnston & Marsh, 1989). Scores range from 16-96 and higher scores are indicative of higher parental confidence in their skills. The internal consistency of the scale is satisfactory ($\alpha = 0.79$; Johnston & March, 1989).

*Weekly Follow-ups*

Follow-ups were undertaken to monitor weekly progress of the intervention in reducing behavioural and emotional difficulties. Weekly follow-ups consisted of 33 questions from the RMH-PQLQ emotional, behavioural, social and cognitive difficulties section (questions 35 to 67).

*Treatment Integrity*

A module checklist was administered to participants to track adherence to the workbook. Participants were required to record whether they had read the workbook modules and provide yes or no responses as to whether they found the module useful and relevant.

*Telephone Interview*

A telephone interview (please see appendix 5) for those who did not choose to complete the intervention, included a total of nine questions with prompts for further information, under three sections which included; 1) reasons for showing interest in the research study, 2) overall parenting experience and 3) relevance to population of parents.
Procedure

After gaining full ethical approval from the East Midlands National Research Ethics Committee (15/EM/0101; see appendix 6 for a copy of the approval letter) and The University of Manchester’s research ethics committee, a list of contact information for UK children’s cancer charities was created from charity registration websites. A total of 53 children’s cancer charities were contacted via a standard email of which nine replied. Eight agreed to provide support with recruitment via their websites and social media. One charity emailed parents on their mailing list. Secondary recruitment was via leaflets, posters and clinician contact at The Royal Manchester Children’s Hospital (RMCH). A further 19 hospital charities were contacted, of which three responded; however, they could not facilitate recruitment.

Charities were asked to display a study access link on their social media sites, such as Twitter and Facebook. When requested, charities were sent the full study protocol. A study Facebook page and twitter account were also set up to enable further advertising and contact with charities. In addition, approval to use RMCH as a Participant Identification Centre (PIC) was granted by Central Manchester Foundation Trust’s Research and Development department (see appendix 7) and posters and leaflets were printed and displayed around the hospital. The leaflets and posters provided basic study information and advised participants to enter the study access link into their computer internet browser for further information and to sign up. The study access page provided an access link to the Participant Information Sheet (PIS; see appendix 8). Once participants had read the PIS they were directed to a page providing three options: 1) to sign up to take part to complete the workbook, 2) to complete a one-off telephone interview and 3) to not take part. Participants who selected options 1 or 2 were directed to a set of screening questions to check they met the study inclusion criteria and then on to the consent form (see appendix 9) for the relevant option. Participants who completed the consent form to complete the workbook were then directed to subsequent pages in the online survey, which included the outcome measures. Page logic prevented those who answered questions suggesting they did not meet eligibility criteria from continuing and advised them to contact the researcher for a discussion. Once participants had completed the initial online questionnaire in full the lead researcher would contact the family to advise their baseline allocation. Baseline periods (no-intervention) ranged from one to three weeks whereby participants would complete a subset of questions to monitor emotional and behavioural difficulties (33 questions in total). Following the baseline period, participants were sent (via post) a copy of the
Triple P Every Parent’s Self Help Workbook (Markie-Dadds, Sanders & Turner, 2001) to be completed over 10 weeks, a treatment integrity form and return envelope. Participants were also sent a parent support booklet specifically developed for the study by the authors (see appendix 10), which provided information on useful resources, such as telephone numbers and websites. Weekly questions were sent via email to each participant individually as per their specific timeline. Where required, email reminders were sent one week apart. A survey link to the full battery of outcome measures was emailed to participants and repeated at weeks 5 and 10 and 1 month following completion of the workbook. Participants had the option to leave feedback via free-text boxes, which were provided at the end of each full data set or weekly questionnaire. Participants who selected to complete a telephone interview were directed to a PIS (see appendix 8) and consent form (see appendix 11) providing specific information about the interview. Following completion, the lead researcher emailed the participant to arrange a suitable time and date to call the participant. Conversations were recorded via Dictaphone, transcribed verbatim and stored on an encrypted memory stick. A gift voucher of £10 was provided a thank you for the time taken to complete all of the study questionnaires/interviews.

Data Analysis
As case series designs typically yield sample sizes too small for complex inferential statistics, the primary source of analysis was visual inspection via time series graphs. This method allows for identification of any increases or decreases in scores from baseline, which may suggest an intervention effect (Bevan, Wells & Wittkowski, 2013). For the emotional and behavioural outcome measures, data from each week from baseline, throughout the intervention, and at one-month follow up were examined. Furthermore, the less frequently collected data (PS, PSOC, PECI) from all other outcome measures were also graphically represented. Group pre- and post-intervention means and population standard deviations were also calculated to observe any group differences and demonstrate group change from the initial data. Feedback and telephone interview data were analysed using summative content analysis (Hsieh & Shannon, 2005). Summative content analysis enables the identification and quantification of content and words to devise the meaning (Hsieh and Shannon, 2005). Quotes providing similar content were selected to give an overview of the participant’s

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4 Please see paper 3: Critical Reflections for a discussion on data analysis.
feedback throughout the study period, which would not lend well to more formal and conventional content analysis.

Results

Feasibility study recruitment
A survey conducted by clinicians from the paediatric psychosocial service at the Royal Manchester Children’s Hospital was completed by 55 parents of children with a diagnosis of cancer. This formed the initial stage of the feasibility process to identify parent need. Of the 55 parents who completed the survey, the majority were parents of children with a diagnosis of Leukaemia (78%), with 6% having a brain tumour diagnosis and 9% lymphoma. The majority of the sample (97%) agreed that parenting support information should be available following their child’s cancer diagnosis. Parents reported requiring support with getting back to normal after treatment (82%), returning to school (71%), child’s mood (57%), changes in behaviour and mood when on steroid treatment (49%), mealtimes and eating (49%) and tantrum behaviour/angry outbursts (43%). Parents reported being interested in written materials and individual sessions with a psychologist as their preferred delivery formats. Barriers to participation were reported to be attending sessions at the hospital, not having time and not having their needs met.

These initial results informed the development and implementation phase of the research. We sought to identify an intervention which would meet the needs identified by parents through the survey which was evidenced based and had been previously implemented within a chronic illness population. As the Triple P self-directed workbook met these criteria we aimed to assess the feasibility of recruiting parents of children with a diagnosis of cancer to a self-directed parenting intervention for the duration of the 10-week intervention and follow-up and assess whether the intervention could improve the quality of life for children with a diagnosis of cancer.

A total of 358 parents accessed the select survey website to open the participant information sheet and survey (see Figure 2 Consort Diagram). Of these, one parent did not meet the eligibility criteria (indicated a mental health difficulty) and three declined to complete the workbook. A further 346 declined to sign up to the study, the reasons for which are unknown. A total of six mothers and two fathers consented to the study (see Table 3), of whom two completed the initial survey in full but indicated they did not want to proceed to complete the workbook. One participant did not complete the
questionnaire and one declined to complete the intervention, but did complete the telephone interview\(^5\). These figures suggest that online recruitment was not feasible. Whilst the study cleared piqued the interest of parents of children with a diagnosis of cancer, the sign up was incredibly low and provides little insight into the reasons as to why parents did not consent to the study. The initial survey may have reflected a cross-section of parents from a particular area of the UK and may not have captured the national needs of parents of children with a diagnosis of cancer, which requires further investigation. The results of the case series are detailed below.

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\(^5\) Please see appendix 12 for a copy of the telephone interview transcript.
Total number of parents to access study gateway page from Jan - August 2016 (n=358)

Excluded (n=350)
Not meeting inclusion criteria (n=1)
Declined to participate (n=3)
Reason unknown (n=346)

Consented (n=8)

Randomly allocated a baseline period (n=4)

Completed Intervention (n=4)

Completed follow-up & included in analysis (n=4)

Excluded (n=4)
Declined to complete workbook (n=3)
Did not provide contact information (n=1)

Consented

Follow-up & Analysis

Allocation

Enrollment

Figure 2. Consort flow diagram


**Case Series Sample**

The primary aim of the study was to improve quality of life, with the secondary aims to reduce parent reported behavioural and emotional difficulties, promote change in parenting behaviours, parent self-confidence and parents’ experience of their child’s illness.

The participants were four mothers with a mean age of 37.5 (SD 2.71, range 35-41), all of which completed the 10-week-intervention and final follow-up. All the participants were married, educated to undergraduate or post-graduate university level and described themselves as White-British or White. Two mothers were not working, one worked full time and one part-time. Spouses ranged from 35-38 years of age and were all in full time employment. The children were three males and one female aged between four and seven years old (mean 5.25, SD 1.5). Time from diagnosis (sign up date minus date of diagnosis) ranged from 282 to 650 days (mean 484.25, SD 170.95). Each child had one sibling (two brothers and two sisters) ranging in age from 3 to 8 years (mean 6, SD 2.16) and lived within their original family (both biological or adoptive parents present). All the participants were recruited via cancer charity advertisements.

Data from four female participants are discussed and graphically represented below. Time taken to complete the study was greater than the total estimated 18 weeks. Time from start date to completion of the intervention ranged from 13 to 32 weeks (mean 20.25 weeks, SD 7.70). Total length of participation from start date to final follow-up ranged from 17 to 36 weeks (mean 24.5 weeks SD 8.02). Two participants (A and C) returned their treatment integrity questionnaires which showed 95% completion of the modules. The provision of weekly feedback provided another indicator of adherence as parents commented on specific items in the workbook that they were working on.

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* A supplementary table of participants individual scores can be found in appendix 13.
Table 3. *Demographic information of participants and non-completers*

<table>
<thead>
<tr>
<th>Participants relationship to child</th>
<th>Completers</th>
<th>Non-Completers</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Participant A</td>
<td>Participant B</td>
</tr>
<tr>
<td>Participants relationship to child</td>
<td>Mother</td>
<td>Mother</td>
</tr>
<tr>
<td>Participant age</td>
<td>35</td>
<td>36</td>
</tr>
<tr>
<td>Gender of child</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Age of child</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Type of cancer</td>
<td>Blood</td>
<td>Blood</td>
</tr>
<tr>
<td>Time since diagnosis (days)</td>
<td>599</td>
<td>406</td>
</tr>
<tr>
<td>Receiving treatment</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>A chronic illness (other than cancer) e.g. Asthma, Eczema</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Physical disability</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Developmental delay</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Attending school</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

* = Not reported
Quality of Life and Functioning

Over the course of the intervention period children showed increased physical and functional difficulties (see Table 4 and Figure 3). However, some improvements in cognitive and social functioning were rated. There were no group differences between how parents rated their child’s overall physical health and quality of life across the intervention period. At final follow-up improvements in global quality of life were only observed for participant C, whilst participants A, B and D remained the same. Social and cognitive functioning remained the same for participant’s A and D, whereas participant’s B and C reported small reductions in difficulties in these areas at final follow-up. Participants C and D reported reductions in physical difficulties at final follow-up, whereas participant A reported an increase in the four-week-period from post to final follow-up. Participant B returned to baseline for physical difficulties. All participants reported decreases in functional status at final follow-up.
Table 4. *Group pre-post intervention scores for RMH-PQLQ, PECI, PSOC and PS*

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Pre</th>
<th>Post</th>
<th>Change</th>
</tr>
</thead>
<tbody>
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<td><strong>RMH-PQLQ</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Global Physical</td>
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<td>2.75 (0.43)</td>
<td>0</td>
</tr>
<tr>
<td>Global QOL</td>
<td>3.25 (0.83)</td>
<td>3.25 (0.43)</td>
<td>0</td>
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<tr>
<td>Social</td>
<td>7.75 (2.38)</td>
<td>5.25 (1.09)</td>
<td>-2.5</td>
</tr>
<tr>
<td>Cognitive</td>
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<td>6.00 (1.22)</td>
<td>-1.00</td>
</tr>
<tr>
<td>Physical</td>
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<td>43.25 (5.89)</td>
<td>+2.00</td>
</tr>
<tr>
<td>Functional</td>
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<td>13.75 (5.07)</td>
<td>+0.5</td>
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<tr>
<td><strong>PECI</strong></td>
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<tr>
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<td>2.12 (0.52)</td>
<td>1.98 (0.40)</td>
<td>-0.14</td>
</tr>
<tr>
<td>Unresolved sorrow and anger</td>
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<td>1.13 (0.47)</td>
<td>-0.4</td>
</tr>
<tr>
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<tr>
<td></td>
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<td>3.93 (0.90)</td>
<td>3.19 (0.48)</td>
<td>-0.74</td>
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NB. RMH-PQLQ = Royal Marsden Hospital Paediatric Oncology Quality of Life Questionnaire (Watson et al, 1999); PECI = Parents Experience of Child Illness (Bonner et al, 2006); PSOC= Parents Sense of Competence (Johnston & Marsh, 1989) & PS= Parenting Scale (Arnold et al, 1993).
Figure 3. Graphs depicting quality of life and functioning over time on the RMH-PQLQ
Emotional and Behavioural Difficulties

Behaviour scores for participants at the pre-intervention time point ranged between 18-33 (mean 24.25, SD 5.49). These scores were slightly elevated in comparison to those recorded by Watson et al (1999) (mean 19.05, SD 5.19, range 12-33). Post-intervention follow-up showed a group reduction in behavioural problems of 5.25, with post-intervention scores ranging from 12-17 (mean 19, SD 6.28). Final follow-up scores showed stability and continued reductions in behavioural difficulties. Participant C showed the greatest continued reduction in behavioural difficulties post-intervention, whereas scores for participant’s A and D remained stable. Emotional difficulties showed a smaller group reduction at post-intervention and final follow-up. Pre-intervention scores ranged from 27-29 (mean 27.5, SD 1.12), which were again similar to those recorded by Watson et al (1999) (mean 30.05, SD 5.58, range 12-41). Post-intervention scores ranged from 21-29 (mean 26.25, SD 3.11), showing very little group reduction. Individually, only participant’s C and D showed reductions in emotional difficulties post-intervention; however, these were not maintained at final follow-up. Similarly, participant A reported a subtle increase in emotional difficulties post-intervention, and maintained this score at follow-up. Overall, the intervention showed little impact on the emotional difficulties of children with a diagnosis of cancer, but some effects on reducing behavioural difficulties (see Figure 4).
Figure 4. Graphs depicting changes over time for emotional and behavioural difficulties on the RMH-PQLQ


**Parenting Scale**

Group reductions were seen on all three subscales on the PS: laxness, over-reactivity, and verbosity (see Figure 5). Baseline scores for this sample were slightly lower than those reported by parents who attended a clinic for extreme difficulties in handling their children’s behaviour for laxness (Arnold et al, 1993). However, the current sample reported higher scores for both over reactivity and verbosity, indicating high levels of difficulty in these areas. All participants showed an individual decrease in parental laxness at week 5. However, at post-intervention this effect was only maintained for participants’ A and C. At final follow-up, all participants showed reductions in parental laxness from their initial scores. With regards to over-reactivity, decreases were observed for all participants at post-intervention and were maintained at follow-up. Participants A and C also saw an individual reduction in verbosity at post-intervention, which was maintained at follow-up. However, participant D showed a variable profile on this subscale, showing an initial increase at week 5, then decreasing post-intervention. However, this decrease was not maintained at final follow-up and the participant returned to the week 5 level. Only two participants (A and B) showed continued reductions in verbosity at final follow-up.
Figure 5. *Graphs depicting scores over time on the Parenting Scale (PS)*
Parenting Sense of Competence

The PSOC provides an algorithm for parental confidence, beginning with the low range indicated by a score of 16-50, moderate confidence 51-69 and high parental confidence, 70-96. A group improvement in parental confidence was observed, with parents reporting confidence in the moderate range post-intervention (see Table 4). Participants A and D showed the biggest increases in confidence. Participant A moved from the low confidence range (48) to the moderate confidence range (68), whereas participant D progressed from moderate (61) to high parental confidence (76). Participants B and C remained in their respective baseline ranges at post intervention (B = moderate, C = high) (see Figure 6). At final follow-up increases from post-intervention were observed for participant’s A and C, remained stable for participant D and reduced for participant B. However, all participants continued within their respective post-intervention confidence range.

Parent Experience of Child Illness and Parenting Scale

At post-intervention, participants A, B and D all showed increases in emotional resources as measured by the PECI, whereas participant C remained stable overtime (see Figure 7). Participants A and D showed small decreases in guilt and worry post-intervention, whereas participant C remained stable and B showed a slight increase. With regards to unresolved anger and sorrow, participant’s A and D showed decreases, whereas participant B remained stable and participant C showed a slight increase. Long-term uncertainty increased for participants’ C and D and only decreased for participant A, with participant B remaining the same. At final follow-up, further subtle reductions in guilt and worry were observed for participants’ C and D, whereas participants’ A and B remained stable. All participants showed subtle reductions in unresolved sorrow and anger and long-term uncertainty at final follow-up. Participants A and C showed continuing increases in emotional resources at final follow-up. Baseline scores for this sample were slightly elevated compared to those recorded in the original article for the scale (Bonner et al, 2006), which was validated with 149 parents of children with a brain cancer diagnosis. However, this sample showed lower baseline levels of unresolved sorrow and anger.
Figure 6. Scores over time for Parent’s Sense of Competence (PSOC)
Figure 7. Graph depicting scores over time for Parents Experience of their Childs Illness (PECI)
**Telephone Interview**

One participant completed the telephone interview to identify potential barriers to engagement and ascertain were further support or additions to the programme may be indicated. The interview highlighted bringing parents together and the participant suggested an online forum may be useful to augment the programme (e.g. closed Facebook group). Similarly, the parent advocated being able to speak to someone who is informed and knowledgeable, as well as providing support for siblings and managing their behaviour. Of note were the references to parent’s unique situations and the emotional struggles they face, including feelings of guilt.

**Feedback**

Weekly feedback was collated for each participant. Feedback was provided 26 times out of a possible 46 (57%), averaging two participants leaving feedback per week. However, in some instances the feedback box was used to convey messages to the researcher (e.g. “I have been ill this week “). Participant quotes are depicted in bold text.  

Overall, feedback generally reflected comments on particular information from the workbook that participants had found useful or had success with. Participants showed interest in examining their children’s behaviour off and on treatment for cancer and how their behaviour influenced their child’s reporting:

‘It was interesting looking at the patterns of behaviour. Next week isn’t a chemo week so it will be interesting to do a comparison to see if the same problems arise and also my responses to them.’

Participants particularly found the ‘Ask, Say, Do’ principles useful and found this approach worked quickly and constructively, particularly helping with child initiated play.

‘The ask, say and do works really well. I was so surprised at how quickly it made an impact on our morning routines as that has always been a site of contention.’

Participants found the workbook helped them to consider positive parenting practices and good behaviour, reflecting on how they could develop their skills but also mindfully acknowledging the impact of chemotherapy and other situations on their child.

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7 Please see appendix 14 for a full version of the Feedback provided by the participants.
‘The workbook has been good at reassessing how I deal with good behaviour as well as bad. I have struggled with some of the exercises because of chemo weeks where everything is uncertain and my son can get incredibly tired and just need rest. He isn’t naughty during these periods just exhausted.’

In addition, two participants commented on the value of the strategies in relation to treatment adherence.

‘Using strategies to help, X was able to have their 32nd MRI Scan without anaesthetic for the first time although the run up to the scan and awaiting results has seen X being more anxious than usual.’

Whilst some parents acknowledged that implementation of strategies was not always easy at times of disruption in routine or when out of the home environment.

‘Although the techniques in the book are good, putting them into practice is very difficult when stressed or particularly annoyed with the disruptive behaviour. However, simply reading the book has helped me bring the way I deal with the children’s’ disruptive behaviour to the fore, which consequently has (hopefully!) improved the way I deal with it. So regardless of whether I put the techniques into practice, simply being more aware, is helpful.’

Generally, participants seemed to value the resource in helping them with their selection of appropriate parenting strategies and approaches to parenting, improving relationships and increasing their overall awareness of their parenting behaviours.

Discussion

This is the first study to test the feasibility of recruitment and retention for a self-directed intervention of Triple P for families of children with a diagnosis of cancer, examining outcomes using a case series approach. Recruitment, including online approaches via relevant organisations, yielded low uptake relative to the number of parents who accessed the study link. Although, four participants engaged and completed the intervention in full, recruitment via these methods does not appear feasible. The barriers to engagement in a study of this kind must therefore be carefully considered and investigated further.

Reviews of barriers to engagement in parenting support interventions have identified to include personal factors (e.g., income status), structural factors (e.g., inconvenient timing), perceptual (e.g., too demanding), programme factors (e.g.,
content, delivery), and programme design factors (e.g., flexibility) (Whittaker & Cowley, 2012).

For parents of children with cancer there are likely a number of other factors, which impact a parent’s ability to prioritise these types of intervention despite need and efficacy. Like their children, these parents have to make huge adjustments to their child’s condition. In some cases, parents leave work to provide full time care for their children and this care can include usual parenting behaviours but also medical behaviours. The significantly high interest in this study shows that there is a need and interest in supportive interventions in this population. However, perhaps the delivery or perceptions of this intervention hindered sign up. Whilst the study sought to fulfil the criteria identified from the initial survey through providing written materials, which could be completed in parents own time within their own home, this presumably did not appeal to a number of parents and further assessment of the needs of parents within an oncology population is required. Perhaps telephone interviews with parents in the first instance or a large-scale survey of parent need on a national scale with questions regarding recruitment methods may have helped to devise a more feasible recruitment strategy and intervention package.

As part of assessing the value of this approach, improving quality of life for children with a diagnosis of cancer was the main outcome measure. One participant reported an improvement in their child’s global quality of life score, whilst two further participants reported stability on this outcome. The lack of differences observed might have been due to the sensitivity of the measure to identify global change because this was only measured by one question on the RMH-PQLQ.

Secondary aims included reducing parent-reported behavioural and emotional difficulties. Whilst there was no effect of the intervention on emotional difficulties, reductions in behaviour difficulties were reported. The high levels of emotional difficulties observed in this sample are consistent with previous research of psychosocial difficulties experienced by children with a diagnosis of cancer (Wakefield, et al,2010). As parents rated these difficulties and parents sometimes tend to perceive children’s psychosocial difficulties as higher than they in fact might be rated by the child themselves (Kreitler & Kreitler, 2012), it would have also been useful to record children’s ratings. In future, research could incorporate a coping skills element for children themselves to promote individual coping.

With regards to behaviour, some of the reductions in behavioural difficulties recorded could be attributed to children being unwell during cancer treatment. All of our
sample were receiving treatment, thus higher levels of behavioural difficulties might have been attributable to treatment effect fluctuations. Participant A showed the largest decrease in behavioural difficulties yet recorded the largest increase in physical difficulties from baseline to final follow-up. We might therefore speculate that physical treatment difficulties had little impact on behavioural difficulties and that these can be independent of one another. The feedback provided by participants suggested that these results might have been due to effective and consistent use of the Triple P strategies, which was corroborated by the completion of treatment integrity questionnaires and warrants further investigation.

Promoting change in parenting behaviours, parent self-confidence and experience of illness were also investigated. Individual and group reductions in parental laxness, over-reactivity and verbosity were observed at post-intervention, which were maintained to final follow-up. Higher levels of parental laxness have been identified in parents of children with a diagnosis of cancer and are associated with higher levels of emotional and behavioural difficulties (Williams et al, 2014). Therefore, the Triple P programme may have specific utility in reducing this particular parenting behaviour.

With regards to parental confidence it was noteworthy that two parents who rated themselves as moderately and highly confident chose to sign up to the study because we anticipated that the study might attract parents who were predominantly low in confidence. When considering all the parents who signed up to the study (including non-completers), only one parent rated themselves in the low range of confidence. Considering the low numbers of parents who consented and completed the study, parental confidence may be a factor worthy of further investigation. Our sample perhaps reflects parents who were indeed confident enough to sign up, whereas for some parents their low confidence might have inhibited them to partake. Incidentally, some parents could have over- or under-estimated their confidence.

Parents’ ability to cope with the experience of their child’s illness showed improvement. Interestingly, means from our sample of which children predominantly had a diagnosis of blood cancer were similar to those from a sample of parents of children with a brain tumour diagnosis (Bonner et al, 2006). It is unknown whether the experience of paediatric cancer for parents may be similar regardless of cancer type; due to the discrepancies in sample sizes, further investigation would be merited. Previous investigations have noted higher guilt and sorrow and uncertainty rated by parents of children on treatment versus those not receiving treatment (Bonner et al, 2008). Thus,
further investigation of the impact of Triple P for parents of children not receiving treatment would be of use.

The weekly qualitative information provided by parents in the online survey provided some insight into the perspectives of parents. One parent reported how their child was not naughty but indeed exhausted. Perhaps parents had a perception that an intervention of this kind was aimed at children who displayed predominantly negative and disruptive ‘naughty’ behaviour as opposed to one which fostered the usage of positive parenting strategies. There was an overall sense that parents did not have a lot of time to reflect on their child’s behaviour and their responses to such behaviours. It may be difficult for parents to prioritise these types of interventions when family life is extremely busy and complicated by medical regimens.

Limitations of the case series included a small sample size and potential risk of sampling bias. Only four parents completed the intervention, therefore the results must be interpreted with caution. Parents who completed the intervention were all married, White/White British mothers who were educated to university degree or higher. Thus, this study does not provide insight into the experiences of minority ethnic groups, fathers or single, low socio-economic/education parent families. Similarly, three of the four children included were male. Whilst this was to be expected because there are higher incidences of cancer in boys (NICE, 2014), it provides little insight into the difficulties experienced by each gender. Similarly, the survey was administered to one illness population and therefore the results might reflect the intricacies of an oncology population and are not generalizable to other illness groups.

The results are based upon self-reported difficulties, which might be biased and observations could augment and validate such reports. Data analysis was primarily visual inspection of time series graphs. A larger sample would have allowed for further statistical analysis, which could have confirmed the significance of the changes from baseline and provided more assurances that these were due to the intervention.

Cancer treatment received during the intervention was not recorded. Treatments, such as chemotherapy, can have huge physiological and psychological effects on children and therefore may have significantly impacted on quality of life and other outcome measurements during these times. Feedback provided indicated that at least one child had received chemotherapy treatment during the course of the intervention, which had significantly impacted the child. Thus, whilst children are receiving such invasive treatments, it may be difficult to alter global quality of life. One participant reported the interventions utility in improving treatment adherence, specifically an MRI
scan and therefore assessment of treatment adherence might have shown more substantial change than QOL.

A further limitation might have been the length of participation. The case series approach required parents to remain engaged for up to 18 weeks, which parents may have perceived unachievable when their lives were already demanding and putting pressure on their resources. Further work to assess a parent’s current ability to prioritise and problem solve how taking part in a supportive intervention might fit around their current priorities may help to increase the likelihood of taking part. One parent perceived the study to be more suitable for children currently receiving treatment due to questions about this on the initial survey. A telephone conversation to explain the study to parents before proceeding with the questionnaire might have been beneficial. This could ensure that parents could be accurately screened against the inclusion criteria and could ask questions directly to the researcher.

Interest and sign up coincided with the addition of the offer of a voucher as a thank you for participant’s time and social media promotion by larger charities. We are therefore unable to identify which of the two had effect or perhaps if it was indeed the combination. Interestingly, the four completers signed up before the monetary incentive was offered. In addition, one of these participants refused the voucher. Thus, monetary incentive may have had no bearing on sign up for some participants. Other methods, such as a closed Facebook group for participants or peer recruitment whereby parents could hear about the programme from other parents or ‘buddy’ with another experienced parent could have augmented sign up (Eckenrode & Hamilton, 2000). Such methods have been found to be useful in weight-management and smoking cessation interventions (Palmer, Baucom & McBride, 2000).

No participants were recruited from The Royal Manchester Children’s Hospital despite this being the site of the initial pilot work and a participant identification centre. One non-completer stated that they had seen the advertisement through the hospital children’s cancer ward Facebook page, and therefore it seems that social media has more presence in comparison to more traditional recruitment methods.

Many eHealth initiatives are not successful for a variety of reasons, such as the lack of human centeredness and ability for the intervention to correspond with the user’s daily life (van Gemert-Pijnen et al, 2011). Paediatric settings are considered an area with distinct challenges and attrition and adherence to programme is typically assumed to be low (van Gemert-Pijnen et al, 2011). Overall, in comparison to interest, sign up to
the study was poor and more work needs to be undertaken to explore the barriers to uptake further in this population.

**Conclusions**

This study yielded poor recruitment and uptake to the intervention, demonstrating that the procedures utilised were not feasible as only four parents were recruited and retained. However, the results from this small sample provide some preliminary insight into the type of parents who may demonstrate interest into such interventions, who may benefit from supportive parenting interventions and where greater support may be required, such as children’s emotional wellbeing. Further work is required to identify the barriers to recruiting parents of children with a diagnosis of cancer and identify need.

**Acknowledgements**

We gratefully acknowledge the dedication of the families who took part in this study. We also thank the clinicians at the Royal Manchester Children’s Hospital, particularly Dr Guy Machin and Representatives of the following charities Candlelighters, CLIC Sargent, The Brain Tumour, Cyclists Fighting Cancer, Friends of O.S.C.A.R, Petal Childhood Cancer Research, Neuroblastoma UK and the Children’s Cancer and Leukaemia Group (CCLG) for their continued support for the study and assistance with recruitment.
References


Doherty, F. M., Calam, R., & Sanders, M. (2013). Positive Parenting Program (Triple P) for families of adolescents with Type 1 diabetes: a randomised controlled trial of


Paper 3: Critical Review and Personal Reflections

Word Count 8262 (Excluding tables, figures and references)
Critical Review and Reflective Paper

The current paper provides a critical reflection on the multiple elements of the research undertaken for this thesis from the beginning of the research process to the end. This paper provides a review of the development and execution of the research including strengths, limitations and difficulties. Furthermore, I provide reflections on how this thesis has influenced my professional and personal development.

Overview of the papers

This body of work aimed to provide further insight into the difficulties faced by parents of children with chronic, life threatening or life limiting illnesses and assess the feasibility of recruitment and retention to supportive interventions, which might ameliorate such difficulties. Whilst preparing for this project I noticed a lack of qualitative understanding regarding parenting a child with a health condition, particularly in relation to the parenting strategies they adopt. The specific aims were to provide an up to date systematic review of the literature to identify the parenting strategies used by parents of chronically ill children, and assess the feasibility of a Positive Parenting Program (Triple P) in improving quality of life and reducing illness sequelae (e.g. emotional and behavioural difficulties) in a cancer population. To achieve these aims a systematic review of the literature was undertaken to collate and qualitatively synthesise information pertaining to parenting strategies in multiple illness groups. This produced 32 papers for inclusion, the findings of which indicated higher levels of lax parenting in illness populations, overprotection strategies and the impact of parental factors (e.g. anxiety) on the use of strategies. Illness specific strategies were identified, such as protection from sharp toys and objects in a haemophilia population to keep children safe, which are functional, yet if viewed collectively with other illness groups would not be identified this way. Therefore, this review has begun to fill a grey area and help answer the question as to which strategies are functional and adaptive when considering specific illness populations. Similarly, this the review would aim to help to identify which illness populations require more support and may use parenting strategies which are not conducive to theirs or the child’s wellbeing. Studies ranged in design, quality and targets of interest offering insight into the literature generally. However, these factors were also limitations, as studies were often cross sectional, thus limiting our understanding of illness trajectories and used a range of measures to survey similar concepts. The juxtaposed findings from the cancer population studies coupled
with previous investigation by clinicians working at the Royal Manchester Children’s Hospital provided a good rationale for the second paper. The review highlighted that whilst some parents and children adapt well to chronic illnesses such as cancer, some do not and parenting strategies can vary widely and impact on the wellbeing of both the parent and child.

The empirical study was borne out of a successful randomised controlled trial in a Type 1 diabetes population (Doherty, Calam & Sanders, 2013). In addition, a clinical need for parenting support was identified via a survey by clinicians working at the Royal Manchester Children’s Hospital (See appendix 15). Due to the success of the Triple P intervention in a Type 1 Diabetes teen population (Doherty, Calam & Sanders, 2013) further testing of its utility in a different illness population was indicated to see if results could be replicated. Despite much interest from parents in the study, demonstrated by the number of times the survey was accessed, there were significant recruitment difficulties. Regardless of these difficulties, the case series yielded interesting results and provided much needed information on recruitment to supportive parenting interventions via online recruitment in this population. Overall results from the case series were encouraging. Whilst limited impact was measured on overall quality of life, there appeared to be positive trends for reducing behavioural difficulties and improving parental confidence and emotional resources. In addition, there was also qualitative acknowledgement that treatment adherence was affected. These novel findings provide a springboard for future research to provide timely, effective supportive interventions across the illness trajectory.

**Paper 1: Systematic Literature Review**

Paper 1 reports a systematic review of the literature in relation to the parenting strategies utilised by parents of children with a chronic, life limiting or life threatening illness. A previous review in this area (Pinquart, 2013), which focused predominantly on the parent-child relationship of parents of children with a chronic illness population also investigated the use of only three parenting strategies. Therefore, the current review aimed to address a gap in the literature, by adopting a qualitative narrative synthesis approach to investigate the strategies reported to be utilised by parents of children with a chronic/ life threatening/limiting illness. The quantitative review undertaken by Pinquart (2013) yielded some interesting results about the collective use of distinct parenting behaviours (overprotection, responsiveness and demandingness) in relation to multiple illness groups. However, did not provide illness specific information, due to
utilising a meta-analytic approach. This information is important as it may aid the
development of parenting support interventions tailored to specific illness groups, and
therefore a grey area in the literature was identified.

Chronic and life threatening/limiting illness are heterogeneous. Within the
umbrella term ‘Cancer’ a range of types exist (e.g. blood cancers, tumours), which can
have varying treatments and prognoses. Therefore, quantitative collation does not
enable the identification of the illnesses’ intricacies and may not be wholly useful due to
significant differences between illnesses. For example, one cannot meaningfully
quantitatively compare visual difficulties with types of cancer, such as leukaemia.
However, a qualitative exploration of a diverse range of illnesses can aid the
identification of individual areas of need. The review was prepared according to the
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)
guidelines, which provide a rigorous basis for reporting to ensure clarity and
transparency (Moher, Liberati, Tetzlaff & Altman, 2009).

Whilst the empirical paper always planned to focus on a cancer only population,
the systematic review was intended to incorporate other illness groups. The decision to
identify parenting strategies in multiple illness groups was to enable identification of
any further illness groups whom may benefit from parenting support interventions and
inform future research. Triple P interventions have been efficacious in a Type 1 teen
diabetes group (Doherty, Calam & Sanders, 2013), however less so in an asthma
population (Clarke, Calam, Morowska & Sanders, 2013). In light of this I needed to
consider that there may be certain illness characteristics that make parenting more
difficult and where interventions may be indicated. Asthma often requires inhaler
treatment administered by the child themselves. From my experience of working in a
paediatric diabetes service, diabetes for example particularly type 1 and depending upon
the age of the child may require substantial input from the parent with regards to
carbohydrate counting, dietary management and insulin administration. Similarly,
ilnesses such as cancer may also require parental input as often there is a demanding
treatment regimen to uphold and multiple investigations. Whilst I expected a large
number of cancer studies due to cancer being the most common cause of death among
children and young people (Smith & Phillips, 2012), the studies for inclusion were
dominated by this group. There was consideration after the fact to narrow the review to
cancer only studies, however with the wider body of research in mind a plethora of
illness were included. This would enable us to further identify how this large group
differ or are indeed similar from other illness groups, which could inform an
intervention and the empirical research. However, due to the dominance of cancer-related studies, caution needed to be taken when considering the results generalisability. As the Pinquart (2013) review was narrow in its identification of parenting behaviours in chronic illness groups, focussing on the range of parenting strategies utilised by parents of children with chronic, life limiting and life threatening illness became the topic for the review.

**Search terms and inclusion/exclusion criteria**

Whilst previous reviews have considered parenting strategies in a general population (Yap et al., 2015) the lists included are not extensive and may not be relevant to illness populations. Therefore, broad terms to try to capture these concepts (e.g. parenting strategies) were chosen for this reason. In hindsight the term ‘parenting behaviours’ should have been incorporated as through reading the literature I identified this terminology is also often used. However, as the terms strategies and behaviours are often used interchangeably the review has incorporated papers using this terminology. Individual illness terms were not included as initial searches identified unmanageable numbers of papers, which were predominantly not relevant. Similarly, as I hoped to capture chronic, life threatening and life limiting illness the range of potential illness titles within these criteria would have been colossal. However, following initial searches to ensure I identified as many relevant papers as possible, which identified the phenomena of interest, a search of specific parenting strategy terms was undertaken (e.g. overprotection). This search may have benefitted from prior identification of outcome measures which measure parenting strategies as then the names of these measures could also have been incorporated in the search terms. However, searches of only these terms may have resulted in exclusion of qualitative papers.

Dissertation papers and those not published in English were excluded from the review. Dissertation papers were excluded due to not being peer reviewed to ensure good quality research was included. However, it is likely that due to this we have missed relevant papers and thus not been wholly inclusive, potentially biasing the review to papers which only report significant findings (Garg, Hackam & Tonelli, 2008). Similarly, review papers and conference abstracts were excluded due to not providing enough individual and specific information, which original empirical study papers are able to do so. Papers not published in English were also excluded as often translations can be incorrect and require sensitive resources to enable accuracy. However, exclusion of non-English papers will have resulted in a language bias in the
review (Garg et al, 2008). Although, due to the difficulties identified this seemed the best decision and the inclusion of international papers, will have likely reduced this bias. Future work with available translation resources could address this issue to overcome a language bias.

**Quality assessment**

Quality of papers was assessed according to a process utilised by Sultan, Leclair, Rondeau, Burns, & Abate (2016), which appraised study quality according to the guidelines set out by Cochrane Handbook for Systematic Reviews (Higgins & Green, 2011). Although these guidelines best lend themselves to interventional quantitative studies, the slight adaptations used by Sultan et al (2016) to assess qualitative methodologies made them feasible for mixed methods papers. Furthermore, whilst other quality assessment tools were available, the Cochrane guidelines for systematic reviews are highly regarded for their rigor. In addition, I had previous experience of the Cochrane quality assessment process through applying it in a previous publication (Moniz-Cook et al, 2012), and therefore felt confident in conducting a valid and reliable assessment. Whilst peer reviewed papers were not excluded on the basis of quality, it was useful to reflect on the methodological imperfections and successes in each paper to inform recommendations for future research. To ensure accurate quality analysis, a total of 10 papers were also assessed by two trainee clinical psychologists, who were independent of the research team. Where consensus was not achieved this was discussed and a common rating agreed. As I had spent a significant amount of time reading the papers, having two external raters reduced bias I may have contributed and also identified shortcomings in the studies I perhaps hadn’t identified.

**Screening**

Screening of papers was arduous due to screening against pre-determined inclusion and exclusion criteria, with many papers reporting parenting styles as opposed to strategies. This required careful consideration as sometimes these concepts can be intertwined despite being distinctive. An initial 1067 papers were excluded on the basis of title and abstract due to these reasons. Similarly, a number of conference abstracts were identified however due to the limited amount of information provided in these and no further published articles being available these had to be excluded as data and meaningful conclusions could not be extracted. When I was unclear if studies met the
review criteria these articles were debated with the other authors until a consensus to exclude or include was reached.

**Narrative synthesis**

As no meta-analysis of the data was to be undertaken, a narrative synthesis approach was adopted as this approach is useful in ‘telling the story’ of the data included in each article (Popay, et al, N. D). As the focus of the review was to investigate parenting strategies it seemed fitting to structure the review in accordance with the strategies identified. This involved assessing themes across the included papers and identifying commonalities, however anomalies were also considered. At times I had a tendency to shift from the identification of outcomes (e.g. resilience) as opposed to strategies (e.g. warmth). Supervision was particularly useful at ensuring I noticed when this was happening and aiding me to adhere to the questions and aims of the review. I also had to keep in mind the intricacies of each illness and ensure not to lose these differences in the text.

**Reflections on completing the systematic review**

This review process has aided the way I appraise research papers and I feel I am more likely to now question the methodological shortcomings or selective reporting, which can sometimes be present. I have become more adept at searching for literature and now have a wider knowledge of a number of databases that are useful. I am also more aware of the potential biases that can influence a review, such as language bias. As this review has been supported by clinicians working in the National Health Service the process has made me more aware of the clinical implications of this type of research. Discussing the findings with clinicians brought this to the forefront and made me aware of how I might similarly appraise and incorporate new research into my clinical work.

**Paper 2: Empirical Paper**

**Choice of research area and research development**

The initial proposal for this study differed in some key respects to the finished piece of work. When I embarked upon the research project a four phase plan had already been devised by clinicians working in the field of psychosocial oncology and Professor Rachel Calam from the University of Manchester as part of the Parenting and Families Research Group (PFRG). The phases included 1) identifying specific parenting
needs, 2) parent advisory groups to establish content, 3) piloting of materials and approach and 4) a trial of a chosen Triple P approach. A discussion with the clinicians and Professor Calam solidified my interest in the project and I could see its importance in terms of clinical relevance.

A survey to fulfil the requirements for phase one had already been undertaken at the Royal Manchester Children’s hospital (RMCH) by clinicians working in the field (see appendix 15). They surveyed 55 parents of children with a diagnosis of cancer (78% Leukaemia, 6% brain tumour, 9% lymphoma). Almost all of the parents surveyed agreed (97%) that parenting support should be available following a child’s diagnosis of cancer. Parents identified that they required support with getting back to normal following their child’s diagnosis, helping their child return to school, changes in mood/behaviour in relation to steroid treatment, mealtimes and tantrums/angry outbursts. Parents indicated they were most interested in two delivery formats, which included individual sessions with a psychologist and written materials. Parents main perceived barriers to participation included not having the time, difficulty attending the hospital and the intervention not meeting their needs.

Focus groups were attempted by clinicians at RMCH however coordination around parents already demanding schedules proved difficult, which was in keeping with the barriers identified by parents in the survey. Self-directed Triple P can be delivered via a parenting workbook and therefore would enable parents to complete the intervention in their own homes at their own pace. It was therefore decided that on the basis of previous research and this preliminary survey information a pilot trial would be undertaken of the Triple P self-directed workbook. As there are clinically significant rates of behavioural and emotional difficulties (6-15%) in the 3 to 12 age range in a general population (Egger & Arnold, 2006) an age range of 3-10 years of age was selected as this is also in keeping for this workbook’s target audience. Similarly, this age range was appropriate as there is much evidence to suggest the role for early intervention through evidence based parenting interventions to reduce children’s difficulties (Weiz & Kazdin, 2010). Identification of the preferred intervention fulfilled phase 3 and therefore all that was remaining was the trial of the chosen approach to be completed.

A pilot Randomised Controlled Trial (RCT) was initially considered as they are the most rigorous for establishing cause and effect relationships between treatments and outcomes (Sibbald & Roland, 1998). Furthermore, an RCT was the design utilised by a previous doctoral trainee who had success in a Type 1 diabetes population (Doherty,
Calam and Sanders, 2013), although less favourable results were found in an Asthma population (Clarke, Calam, Morawska and Sanders, 2013). We also hoped to incorporate an initial survey, which would look at the potential predictors of parents who sign up to supportive interventions.

The University of Manchester Research Subcommittee meeting in October 2013 highlighted concerns about the chosen design. They suggested revising the design so that the feasibility and acceptability of the intervention could be tested first. My supervisors and I felt that the acceptability of the intervention in an illness population had been well demonstrated in the diabetes study and we therefore needed to assess the feasibility of recruitment and retention in other illness populations. I could understand the concerns raised and it was important at this point to reflect on whether we had selected the most appropriate design. However, my supervisors and I were still confident that this design (a pilot RCT) would be the most rigorous approach to ensure we could make accurate conclusions about the effect of the intervention. Ethical approval from the University of Manchester Research Ethics committee (UREC) was sought and granted. The UREC requested National Research Ethics Service (NRES) approval due to the study involving clinicians working in the National Health Service (NHS). Some changes were required by UREC, such as correspondence with the participants General Practitioner (GP) to advise that their patient was taking part in research. The decision was made to write to the parent’s GP only as they were considered the participant, not the child. Whilst I have conducted research in previous employment roles, this gave me further experience of liaising with numerous professionals and agencies and gave me an understanding of the processes of conducting research within the NHS. Final approval for this design was granted by UREC in August 2014. However, NRES approval was also sought. The IRAS form was started in August 2014 and authorised in November 2014. Delays in submission were due to the completion of the form itself, survey testing and amendments to documents, such as consent forms. This process added further delays to starting the project, however would ensure completeness with regards to meeting the UREC and NRES requirements. It was hoped that the study would commence before I went on maternity leave (November 2014-2015), and we had made a plan for a research assistant working in the department to oversee the project until my return. However, this was not possible as approvals were not granted in time.

The period of maternity leave enabled time to reflect, and at keep in touch meetings I began to express my concerns about the methodology we had chosen and the
achievability of running an RCT in the time left on the course. A contingency plan was outlined in the proforma submitted to the research subcommittee and it was important to consider whether this should be actioned. I wanted to ensure that we were using the most appropriate methodology to answer the research questions and enabling enough time for recruitment. Upon my return in November 2015 it was agreed that we would action the study’s contingency plan and implement a case series methodology. I would still aim to recruit 100 participants for the survey aspect of the research with the aim of looking at predictors of uptake to the study, but only 10 participants would complete the intervention. Whilst this re-design required a substantial amendment to the NHS Research Ethics Committee, resulting in further delays, on reflection it has been pivotal for this study, which would likely have failed as an RCT due to the difficulties with recruitment.

The final design was much more in keeping with the requirements of the UREC in terms of doing further preliminary work to inform a trial. Case study methodology also offered a lot of positives and would allow me to identify the phenomena in question through multiple lenses (Baxter and Jack, 2008). In hindsight a lot of time was lost and should this design have been implemented sooner or indeed at the start of the study there would have been more time to make amendments to recruitment methods to try to boost uptake to the intervention. The study gained UREC, NRES and Participant Identification Centre Approvals to enable commencement of the study on 7th January 2016.

Theoretical underpinnings

Why Triple P?

As previously stated the Triple P program had been tested in two chronic health conditions and a study was also being developed to look at its utility within teenagers with cystic fibrosis (Wells, Calam, Murray & Wells, 2016, in preparation). Triple P was devised in Australia (Sanders, 1999) and is a renowned behavioural family intervention aimed at modifying parenting behaviours, which may maintain children’s difficulties. It is based on social learning theory principles, behaviour analysis and family behaviour therapy and has a preventative stance (Nowak & Heinriche, 2008). Triple P has developed in to a public health model (Sanders, Markie-Dadds, & Turner, 2012) due to the fundamental impact parenting can have on a child’s development.

The approach is multi-level and varying in intensity and delivery formats. There is a focus to improve child behavioural outcomes, however the strategies presented also
aim to improve parent-child relationships in a positive way. The self-directed ‘Every parent’s self-help workbook’ is a level 4 intervention, which guides parents through structured learning over 10 weeks. Whilst other successful parenting programs are available, such as The Incredible Years program (Webster-Stratton, 2015), Triple P was selected for its previous success in a Type 1 diabetes population, which was also explored through a doctoral thesis study and its extensive usage for a range of other difficulties, including neurodevelopmental conditions, such as ADHD (Franke, Keown, and Sanders, 2016). Therefore, its international success and recent utility in chronic illness, seemed like a good fit for this study and the decision was made to offer this intervention. The intervention was offered as a self-directed workbook as this fit with the ‘written materials’ suggested by parents in the RMCH survey.

**Why Case Study Methodology?**

One of the benefits of adopting case study methodology as opposed to an RCT was the ability to have closer collaboration with the participants. Case study designs are often based on constructivists paradigms to identify the participants view of their reality (Crabtree and Miller, 1999). On reflection the methodology outlined in paper two did allow more collaboration with participants and due to this enabled them to feel empowered and able communicate any delays in completion of parts of the workbook due to their personal circumstances (e.g. child unwell after chemotherapy, holidays). Similarly, the feedback boxes allowed participants to communicate their realities and tell their stories, which is one of the positive aspects of this type of methodology. An RCT would likely not have been able to achieve this as readily as it would have likely been on a larger scale and blinded making it difficult to have these levels of interaction with participants.

To further facilitate the exploration of the parent’s experience and reality, it may have been useful to have participants complete a journal or diary of their experiences of completing the intervention and implementing it with their children. Similarly, participants could have documented more treatment related occurrences, such as improvements in adherence to cancer treatments or difficulties implementing the intervention due to the sequelae of treatment. However, this may have been burdensome alongside the already quite large battery of outcome measures and may have resulted in attrition. Exploratory case studies allow for the study of data within a specific context, in this case parents of children with a diagnosis of cancer. Whilst initial hypotheses were developed for the RCT methodology, these were still held in mind for the case
study but a more exploratory approach was adopted to the data. Whilst case studies are usually criticised for their lack of rigor I tried to overcome this by utilising a randomly allocated multiple baseline design. This had to be non-consecutive due to participants not starting the intervention at the same time but would allow me to identify a truer baseline specific to each participant’s unique circumstances and enable more confidence when assessing the results in relation to effects of the intervention.

Disadvantages of this design include its ability to only provide a cross section of data. Whilst we employed a one-month follow-up to see if the effects of the intervention were maintained over time, it would have been useful to assess parents continued use of the intervention and its effects over a longer period of time. Due to the population studied these results are not generalizable to other health conditions or the general population. Similarly, as the majority of the participant’s children had a diagnosis of blood cancer the results may only reflect this population and may not hold true to other cancer diagnoses (e.g. tumour). However, as Leukaemia is one of the most common forms of cancer in children this maybe reflective of the wider oncology population (Cancer Research UK, 2014). This is also the case due to the demographics of the population studied, which included only mothers of predominantly male children.

Selection of outcome measures

The selection of outcome measures was in part governed by the usual battery utilised by Triple P researchers, which included the parenting scale, parental sense of confidence questionnaire and the family background questionnaire. Using these measures would allow comparability to other Triple P research. The identification of an appropriate questionnaire to measure quality of life was not as straightforward. We originally considered The Paediatric Quality of Life Inventory (PedsQL; Varni, Burwinkle, Katz, Meeske, and Dickinson, 2002). This inventory also includes a cancer specific module to measure health related quality of life, however whilst this measure is free to use, it required using multiple age specific questionnaires, which did not lend well to an online survey. I therefore sought to find a measure validated in oncology which would cover our 3-10-year age range.

We also required a measure of emotional and behavioural difficulties for which we firstly considered the Eyberg Child Behaviour Inventory (ECBI; Eyberg and Ross, 1978). However, after much deliberation and consideration of a variety of measures a consensus was reached to use the Royal Marsden Hospital Paediatric Oncology Quality of Life Questionnaire (RMH-PQLQ; Watson, Edwards, von Essen, Davidson, Day and
Pinkerton, 1999). I took the time to do a comparison between this measure and the ECBI and found that this measure overlapped significantly with the behavioural questions on the ECBI, therefore fulfilling this requirement. Similarly, the RMH-PQLQ included questions pertaining to emotional difficulties, quality of life and functioning (including physical symptoms) and had been specifically developed and validated for use in a paediatric oncology population. This measure therefore seemed the best fit for the study and would eradicate the use of multiple measures, which could result in making the completion of the survey considerably lengthy.

The RMH-PQLQ also records family background and therefore we amalgamated the Family Background Questionnaire (FBQ; Sanders, Markie-Dadds, & Turner, 1999) with these questions to ensure all of the necessary demographic and cancer specific information was covered. As participants qualitatively fed back on the impact of the workbook on treatment adherence it would have been useful to include a formal measure of this. Similarly, a measure of when children were undergoing chemotherapy and similar treatments would have been useful to compare against behavioural and emotional difficulties. Such measures could be included in future studies to overcome these issues.

We were interested in parent’s experience of their child’s illness as there is much research to show the impact of parents’ own well-being on their parenting behaviours and the child’s psychosocial well-being (Bonner, Hardy, Willard, Hutchinson and Guill, 2008). The Parent Experience of Illness Scale (PECI; Bonner et al, 2006) was validated in oncology and contains subscales which are clinically relevant and also useful as outcome measures of parental outcome regarding the child’s illness.

Extensive testing of the survey was completed to ensure the survey did not require too much of the parent’s time. Once the survey was built within select survey, I emailed a non-clinical sample who were able to help identify typographical errors, user issues and the length of time required to complete. The decision was made to only include a handful of items for weekly follow-ups to ensure parents did not feel burdened, yet ensure we were capturing a sufficient amount of data, which was a fine balance to strike. The initial questionnaire was quite lengthy, which in hindsight may have deterred parents from signing up. However, each measure was incredibly valuable and for those that did complete, I feel each measure has been useful to develop an overall understanding of the difficulties parents and children with a diagnosis of cancer face on a regular basis.
Sample size

A case series is described as “a collection of patients with common characteristics used to describe some clinical, pathophysiological or operational aspects of a disease, treatment or diagnostic procedures” (Porta, 2008). Five participants have been suggested as the minimum number for which to statistically combine data (Abu-Zidan, Abbas and Hefny, 2012). Therefore, the number recruited must exceed this to allow for attrition. It was decided that we would aim to recruit 10 participants to complete the workbook but that if further interest was shown this could be extended. A review of 586 case series articles identified a median of 7 participants (Abu-Zidan, Abbas and Hefny, 2012). It was disappointing to only have four participants complete, however I was pleased that the minimum number of recommended participants for case series was achieved (Abu-Zidan, Abbas and Hefny, 2012) and this provides a springboard for future research. Unfortunately, I quickly realised that we would not achieve the numbers required for the survey (100 required) to be able to analyse predictive factors of parents who sign up to online studies and take part in parenting interventions and therefore this had to be stopped. However, data from the four participants could provide some insight into the types of parents who sign up and could inform future research.

Recruitment

Original optimism for high numbers was borne out of good recruitment to the diabetes Teen Triple P study (n =79; Doherty et al, 2013) and encouraged by the completion of the survey by 55 parents at the Royal Manchester Children’s Hospital. We therefore did not anticipate difficulties in recruiting 10 participants to the case study. Recruitment via Cancer Charities was considered a good method as these charities have large followings on social media (e.g. Facebook and Twitter) and therefore their participation would allow large national distribution of the study information to parents. Similarly, this method proved effective for the randomized controlled trial in a diabetes population (Doherty, Calam and Sanders, 2013). However, difficulties began with low response rates from approached charitable organisations. Charities were emailed information about the study, and on reflection follow-up phone calls should have been undertaken, however those that responded were particularly helpful and engaging via email. Once a couple of charities had agreed to aid recruitment, a snowball effect occurred and willingness to aid the research seemed to improve. The largest spike in recruitment was shown when the largest organization CLIC Sargent began advertising
the study through their social media platforms. One charity felt they could not aid recruitment due to the values of the charity, which may have been true of other charities who did not respond. Whilst they referred to the study as ‘invaluable’, they stated that as a charity they ‘aim to provide a total escape from the difficulties of diagnoses and hospitals, and our promotion of this research project may conflict with that’. However, whilst hit rates were high (number of people clicking onto the survey), sign up remained low. This may have been due to unclear information in the participant information sheet. One participant who part completed the initial survey and later completed a telephone interview eluded to not being sure whether she was eligible to take part and felt the study was aimed at parents of children with a diagnosis of cancer who were receiving treatment.

Other reasons for low sign up may have included the length of participation. The first round of recruitment only included an option to complete the workbook and did not include options to take part in a telephone interview or monetary recompense for the time spent completing questionnaires. Whilst hit rates in round two (when these options were added) were higher, this may also be attributable to larger charities coming on board to aid recruitment. Incidentally, when a participant was advised they were now entitled to a monetary voucher due to approval of an ethical amendment they declined to receive it on the grounds that they felt grateful to have taken part. The age range identified for recruitment may also have been problematic. Participants were required to have a child between the ages of three and 10 years of age as this was the age range identified by clinicians and initial surveys to show the greatest emotional and behavioural difficulties. However, difficulties may exist outside of this age range and therefore in future it may be useful to scope the difficulties experienced nationally by parents of children aged 11+.

Secondary recruitment was through clinicians and advertising through the use of leaflets and posters in the Royal Manchester Children’s Hospital. This large, regional centre was the only NHS site selected to trial recruitment using this method, which could inform the selection of further participant identification centres (PIC’s) if required. Targeting other participant identification centres with specialisms in paediatric oncology may have improved awareness. Recruitment to parenting support programmes is renowned for difficulties with attendance and engagement (Whittaker and Cowley, 2012). Further assessment of these difficulties in the first instance through telephone interviews or interviews during clinic attendance may have been useful to understand these barriers for this specific population in more detail. Whilst we provided a programme which was accessible, could be done in the parents own time and is evidenced based, something was preventing parents from taking part. We could
hypothesise that parents of children with a diagnosis of cancer receiving treatment may perceive a greater need for these types of intervention, however these parents of course have greater impacts on their resources both practically and emotionally. It was particularly surprising that no participants were recruited from RMCH despite the initial survey, which demonstrated the need for this intervention taking place here.

It has been useful to reflect on why recruitment to an RCT was successful in a diabetes population and yet would not have been successful in a cancer group. As per the systemic review, illnesses such as cancer and diabetes are heterogeneous and therefore perhaps the initial ideas regarding replicating Doherty et al’s (2013) study in a different illness population were flawed. Children with Type 1 diabetes often require some parental help to get started with their treatment but can achieve independence and can live generally normal lives. Cancer can have multiple outcomes depending on the type of cancer diagnosed and as such children often require more input from parents. As such, parents of children with diabetes may have had more time to complete the research and intervention, particularly as this was completed with parents of teenagers who are likely more established with their diabetes management and care. Participants in the study were parents to relatively young children who had not had as much adjustment time. Whilst we stipulated children had to have been diagnosed for 6 months or more to be included, perhaps this needed to be significantly increased or indeed the intervention be aimed at those in remission/off treatment.

**Study procedure and data collection**

A protocol was developed to outline the study processes and procedures. Whilst this changed a couple of times due to the modification of the design, the final procedure required parents to sign up via a web-link, read the participant information sheet online and complete a consent from online. Following this they were contacted by a researcher by email and advised about their baseline period allocation and study start date. Workbooks were then posted and email survey links sent when required on the basis of the participant’s individual study schedule. A strength of the study is that it was participant centred and participants seemed comfortable to email when they for example were unwell or were going on holiday and had to have a week off completing the workbook. Participants seemed happy with email contact and although telephone contacts were offered, these were often declined in favour of email correspondence. I noticed that often emails were sent by parents at the weekends or evenings, which might reflect when parents had time available for themselves. I do not think participants would
have continued to remain engaged if participants had to strictly adhere to completing the intervention within a 10-week period and I think the flexibility provided ensured completion of the intervention and subsequent measures. However, providing this flexibility for four participants did require significant management and meant that survey links could not be pre-programmed and sent via a calendar date.

Online data collection was extremely useful and ensured the data could be downloaded easily and survey links generated and sent when required. However, again this took regular management and checking to ensure those that had signed up were contacted in a timely manner.

A telephone interview was added later to enable me to capture information about the reasons for participants showing interest in the study yet not signing up. A separate consent form was devised and the main survey altered to incorporate options as to whether participants wanted to progress through the study or alternatively take part in a telephone interview. Unfortunately, only one participant consented to this option, however it was useful to reflect on their comments regarding who they thought the study was directed to and that they would have taken part and felt the study was useful. Further telephone interviews would have been useful to glean information about the types of interventions parents would consider useful and any changes they may have made to the current format of the study. Future research is required to understand this further, however, as focus groups and the method I employed were not wholly successful, such information may have to be gained from consultation with parents during their child’s clinic sessions, which may not always be appropriate. Perhaps, if clinicians were able to gain consent for researchers to have a telephone conversation with parents in the first instance this may serve as a good introduction and be less time consuming for parents.

Data analysis

Whilst previous case studies with low numbers of participants have included formal statistics, such as paired sample t tests (Bevan, Wittkowski and Wells, 2013), advice from Julie Morris, Head of medical sciences statistics at the University of Manchester advised against such statistics for four participants. I had considered the Reliable Change Index (RCI), however was advised against this approach as it involves the standard error of the values (equalling the difference pre to post for an individual divided by the standard error) and due to having only four participants in the sample a reliable estimate of the standard error could not be derived. Similarly, I identified a
multiple baseline case series of four adolescents (Tolin et al, 2009), which utilised Youngs (1941) C statistic, which can be used to determine non-random changes over time. However, I again discussed this approach with the statistician who advised against it. Concerns regarding this approach have been raised by Crosbie (1989) who suggested that significant autocorrelation in the baseline creates a risk of a Type I error (incorrectly rejecting the null hypothesis) when intervention data are added. Similarly, the approach is unable to address whether the change was caused by the intervention and therefore only identifies the size of the change when the intervention data is added to the baseline data, therefore not providing any clinical significance of the change (Tolin et al, 2009). The advice provided was to present individual profiles with some simple summary statistics. Therefore, consistent with case study methodology, time series graphical representation of the data was chosen, augmented by some pre-post means and population standard deviations and individual scores for pertinent data relating to the aims of the study were reported as suggested by the statistician.

As the qualitative data was not consistently provided by each participant, a summative content analysis approach was used. A summative approach was considered the right approach for the data as it enables the identification and quantification of content and words to devise the meaning (Hsieh and Shannon, 2005). This allowed me to select quotes providing similar content to give an overview of participant’s feedback throughout the study period, which would not lend well to more formal and conventional content analysis approaches.

**Results**

Whilst the sample was small, the results provided some insight into this population. Although we have no ability to compare how many strategies were adopted by each parent or how consistently they were used over the course of the intervention, two participants documented 95% adherence to the intervention, which is very encouraging. The graphical representation of the data was useful in looking at patterns over time for each participant, particularly the reductions on a number of the outcome measures. However, one aspect of the data which particularly surprised me was the amount of feedback provided by each participant and the richness of this feedback. Some of the feedback was emotive, whereby parents documented the death of their children’s friends and this gave real insight into the world that these parents and children are living in, in which death is likely commonplace. I was astounded at the parent’s strength and in their ability to cope and continue to implement the intervention
during such traumatic times and pleased that the interventions strategies could be of some use. The feedback regarding the improvement in adherence to undertake an MRI scan was particularly poignant, and brought the idea of treatment adherence to the fore. Future research in this area would benefit from recording adherence. Similarly, the telephone interview highlighted the potential value of an online forum for parents to support the intervention. In addition, future research could also consider the impact on siblings, which was also highlighted in the telephone interview.

Writing up

During all aspects of this research I have been mindful of being respectful to the participants involved and in the ways that the challenges that parents face are described. I have been conscious to describe children with a chronic illness appropriately, such as saying children ‘with a diagnosis of cancer’ as opposed to using the terminology ‘with cancer’ for example, which suggests the illness is all consuming. Referring to the illness as the diagnosis provides a separation and allows the child to be recognised as a person and individual. Having worked with children with chronic illness diagnoses including cancer and diabetes has made me more mindful of this distinction as I have often heard children refer to themselves as their illness (e.g. ‘I am diabetes’) and it has been helpful to aid them in identifying aspects of themselves and their lives which are not dictated by their illness.

Ethical dilemmas

In the first instance, it was important to reflect on the proposed area and population of study. We were proposing to study parents who were undoubtedly going through significant life changes and stress as a result of their child’s diagnosis. It was therefore decided that we would not recruit any parents of children who were newly diagnosed and that they had a minimum 6-month adjustment period post diagnosis before taking part in the study. A further ethical dilemma also arose when I proposed introducing a monetary recompense for parent’s time completing the survey. It was important to consider that whilst providing incentives is common place in research in countries such as the United States of America, such incentives can influence participants in a number of ways and can impact the types of participants attracted to the study and recruited (Grady, Gensler and Emanuel, 2005). It was important to ensure the wording of this in the participant information sheet reflected my intention to thank
parents for their time due to the questionnaires being lengthy and potentially time consuming.

**Limitations**

Whist I have reflected upon limitations throughout the aforementioned sections, it is useful to collectively reflect on the study and findings as a whole and identify areas of weakness. Further preliminary work could have been conducted before implementing the case series methodology, such as telephone interviews with parents to further augment the results of the hospital survey to identify need and guide recruitment and methodology. The sample size of this study is small. A larger sample would have provided the opportunity to conduct statistical analyses and identify significant impacts of the intervention and causality. A post intervention telephone call to participants may have been useful to gain further qualitative feedback to inform future research and areas in which the intervention could be adapted, such as the addition of coping skills materials for children. Reduction of the number of outcome measures or the intervention time may have been more appealing to parents of children with a diagnosis of cancer who already have busy schedules.

**Clinical implications of papers 1 and 2**

Both these lines of inquiry have been very useful in informing our understanding of parents of children with a chronic, life limiting or threatening diagnosis. Paper 1 has helped to identify that parenting practices which may be viewed negatively for the general population are sometimes necessary for these children and families. Similarly, it has highlighted the difficulties parents face with implementing discipline and boundaries and promotion of autonomy, highlighting areas for future research and observation in clinical settings.

In paper 1 I provide recommendations for future research to ensure meaningful cross illness comparisons can be made. Paper 2 has demonstrated that parenting support may have utility in treatment adherence, which warrants further investigation. Similarly, parenting support may aid the wellbeing of parents of children with a diagnosis of cancer by improving their emotional resources and aiding the reduction of their child’s behavioural difficulties. Such findings may aid clinician’s selection of interventions and strategies they may use themselves when assisting children with their treatment.
Implications for my practice

My previous experience of research was useful throughout this thesis; however, each piece of research incorporates its own unique challenges. This study has particularly challenged my IT knowledge and prowess, and I am extremely grateful to Austin Lockwood for his time in helping to resolve these challenges. This process has made me more aware of the clinical implications of research and how valuable research is in informing clinical practice. The results have aided me to reflect on my current practice and the utility of supportive parenting interventions in other clinical settings. I currently provide consultation to nurses working with children who have injections to combat the effects of precocious puberty. The feedback from this study on the improvements in adherence to medical regimen have aided my thinking around strategies which might be useful in other contexts. It has also helped me to reflect on the need to be thorough and careful in the development of research and the utility of pilot studies for informing future research.

Self-care has been important throughout this body of work due to the nature of the area of study. Discussing and thinking about unwell children and speaking with bereaved parents has been highly emotive and I have found that reflection and supervision have been paramount in aiding my ability to manage my emotions. These are transferable skills I will continue to take forward into my new role as principal clinical psychologist in child development.

This research has encouraged me to ensure my practice is evidence based and that the advice and consultation I give to parents reflects this. I hope to conduct research in the future and will continue to reflect on the strengths and weaknesses and skills I have developed throughout this process to guide me. Incidentally, should I have the opportunity to supervise research students, I hope to show supervisees the level of dedication and support I have been shown by my supervisors and tutors for which I am extremely grateful.

Conclusions

Completion of this thesis has been challenging but an overall rewarding experience. I am pleased to have had the opportunity to contribute to a growing evidence base and highlighted grey areas which require further study. I truly hope that research in this area continues as I think both papers one and two have shown the requirement for further research into the challenges faced by parents of children with an illness diagnosis and
interventions which show potential in reducing some of the psychosocial difficulties experienced by these families.
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Appendices

Appendix 1: Journal of Clinical Psychology in Medical Settings instructions for authors for manuscript preparation

Journal of Clinical Psychology in Medical Settings

General

In general, the journal follows the recommendations of the 2010 Publication Manual of the American Psychological Association (Sixth Edition), and it is suggested that contributors refer to this publication.

Manuscript Submission

Manuscripts, in English, should be submitted to the Editor via the Journal's web-based online manuscript submission and peer-review system: http://jocs.edmgr.com. In queries regarding Journal policy and other such general topics should be sent to the Editor:

Gerald Leventhal
jerryumdnj@aol.com
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Manuscript Style

Submit the original, including copies of all illustrations and tables.

Add continuous line numbering and page numbering to the manuscript.

Title Page

A title page is to be provided and should include

the title of the article

author’s name (no degrees)

author’s affiliation

and suggested running head

The affiliation should comprise

the department

institution (usually university or company)

city

and state (or nation)

and should be typed as a footnote to the author’s name. The suggested running head should be less than 80 characters (including spaces) and should comprise the article title or an abbreviated version thereof.

For office purposes, the title page should include the complete mailing address, telephone number, and e-mail address of the one author designated to review proofs.

Abstract
An abstract is to be provided, preferably no longer than 150 words.

Key Words

A list of 4–5 key words is to be provided directly below the abstract. Key words should express the precise content of the manuscript, as they are used for indexing purposes.

References

List references alphabetically at the end of the paper and refer to them in the text by name and year in parentheses. References should include (in this order):

last names and initials of all authors,

year published

title of article

name of publication

volume number

and inclusive pages

The style and punctuation of the references should conform to strict APA style and follow guidelines of the Publication Manual of the American Psychological Association, Sixth Edition — illustrated by the following examples:

Journal Article


Book


Contribution to a Book


Footnotes

Footnotes should be avoided. When their use is absolutely necessary, footnotes should be numbered consecutively using Arabic numerals and should be typed at the bottom of the page to which they refer. Place a line above the footnote, so that it is set off from the text. Use the appropriate superscript numeral for citation in the text.

Illustration Style

Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of Arabic numerals. The captions for illustrations should be typed on a separate page. Photographs should be large, glossy prints, showing high contrast. Drawings should be prepared with India ink. Either the original drawings or good−quality photographic prints are acceptable. Artwork for each figure should be provided on a separate page. Identify figures with the author’s name and number of the illustration. Electronic artwork should be in the TIFF or EPS format (1200 dpi for line and 300 dpi for half−tones and gray−scale art). Color art should be in the CYMK color space.

Tables should be numbered (with Arabic numerals) and referred to by number in the text. Each table should be typed on a separate page. Center the title above the table, and type explanatory footnotes (indicated by superscript lowercase letters) below the table.

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After a manuscript has been accepted for publication and after all revisions have been incorporated, a final manuscript should be submitted through the online submission system. The electronic file submitted must be the finalized version of the manuscript. The author may track the status of a submission via the online submission system at the time. At the proofreading stage, the author is solely responsible for ensuring the
accuracy and correctness of the typeset article. It is not possible to make further corrections once the article has been published online.

Authors must indicate whether or not they have a financial relationship with the organization that sponsored the research. They should also state that they have full control of all primary data and that they agree to allow the journal to review their data if requested. Upon acceptance of their manuscripts, authors must complete “Statement of Conflict of Interest and Informed Consent” form (found at http://www.springer.com/medicine/journal/10880), which they will then be required to submit to the editorial office.

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No data have been fabricated or manipulated (including images) to support your conclusions

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Authors should include the following statements (if applicable) in a separate section entitled “Compliance with Ethical Standards” when submitting a paper:

Disclosure of potential conflicts of interest

Research involving Human Participants and/or Animals

Informed consent

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Authors must disclose all relationships or interests that could influence or bias the work. Although an author may not feel there are conflicts, disclosure of relationships and interests affords a more transparent process, leading to an accurate and objective assessment of the work. Awareness of real or perceived conflicts of interests is a perspective to which the readers are entitled and is not meant to imply that a financial relationship with an organization that sponsored the research or compensation for consultancy work is inappropriate. Examples of potential conflicts of interests that are directly or indirectly related to the research may include but are not limited to the following:

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The corresponding author will include a summary statement on the title page that is separate from their manuscript, that reflects what is recorded in the potential conflict of interest disclosure form(s).

See below examples of disclosures:

**Funding:** This study was funded by X (grant number X).

**Conflict of Interest:** Author A has received research grants from Company A. Author B has received a speaker honorarium from Company X and owns stock in Company Y. Author C is a member of committee Z.

If no conflict exists, the authors should state:

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**Research involving human participants and/or animals**

1) **Statement of human rights**

When reporting studies that involve human participants, authors should include a statement that the studies have been approved by the appropriate institutional and/or national research ethics committee and have been performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

If doubt exists whether the research was conducted in accordance with the 1964 Helsinki Declaration or comparable standards, the authors must explain the reasons for their approach, and demonstrate that the independent ethics committee or institutional review board explicitly approved the doubtful aspects of the study.

The following statements should be included in the text before the References section:

**Ethical approval:** “All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.”

For retrospective studies, please add the following sentence:

“For this type of study formal consent is not required.”

2) **Statement on the welfare of animals**

The welfare of animals used for research must be respected. When reporting experiments on animals, authors should indicate whether the international, national, and/or institutional guidelines for the care and use of animals have been followed, and that the studies have been approved by a research ethics committee at the institution or practice at which the studies were conducted (where such a committee exists).

For studies with animals, the following statement should be included in the text before the References section:

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If applicable (where such a committee exists): “All procedures performed in studies involving animals were in accordance with the ethical standards of the institution or practice at which the studies were conducted.”

If articles do not contain studies with human participants or animals by any of the authors, please select one of the following statements:

“This article does not contain any studies with human participants performed by any of the authors.”

“This article does not contain any studies with animals performed by any of the authors.”

“This article does not contain any studies with human participants or animals performed by any of the authors.”
Informed consent

All individuals have individual rights that are not to be infringed. Individual participants in studies have, for example, the right to decide what happens to the (identifiable) personal data gathered, to what they have said during a study or an interview, as well as to any photograph that was taken. Hence it is important that all participants gave their informed consent in writing prior to inclusion in the study. Identifying details (names, dates of birth, identity numbers and other information) of the participants that were studied should not be published in written descriptions, photographs, and genetic profiles unless the information is essential for scientific purposes and the participant (or parent or guardian if the participant is incapable) gave written informed consent for publication. Complete anonymity is difficult to achieve in some cases, and informed consent should be obtained if there is any doubt. For example, masking the eye region in photographs of participants is inadequate protection of anonymity. If identifying characteristics are altered to protect anonymity, such as in genetic profiles, authors should provide assurance that alterations do not distort scientific meaning.

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"Additional informed consent was obtained from all individual participants for whom identifying information is included in this article."

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English language tutorial

Nature Research Editing Service

American Journal Experts

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<th>‘High risk’ of bias</th>
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| **Discussion/Conclusions** | Conclusions based on results  
Limitations acknowledged  
If preliminary study/pilot: acknowledged  
No conflict of interest (source of funding acknowledged)  
Conclusions depart from results  
Limitations are not acknowledged  
If preliminary study/pilot: not acknowledged  
Conflict of interest (source of funding not acknowledged) |
| **Participants** | Large sample (Ratio of participants to predictors satisfying Tabachnick & Fidell’s (2007) guidelines: \( N > 50 + 8p \), where \( p \): number of predictors)  
Small sample (Ratio of participants to predictors not satisfying Tabachnick & Fidell’s (2007) guidelines: \( N > 50 + 8p \), where \( p \): number of predictors) |
| **Measures**   | Structured clinical interview  
Measures with satisfactory pre-established psychometric properties  
Multimodal assessment (e.g. medical records and self-reports)  
Measures have not been validated or insufficient pre-established psychometric properties (e.g. ad hoc or home-made measures)  
Composite measures (e.g. combining subscales of parental distress and other constructs) |
| **Procedures** | Use of procedures to maximise response rate or limit attrition  
No procedures used to limit attrition |
| **Design**     | Longitudinal  
Data analysis strategy appropriate for exploring longitudinal causal effects (e.g. predicted outcome controlled for at baseline)  
Cross-sectional |
### Appendix 3. Summary table depicting quality assessment and scores for studies included in the review

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<th>Quality assessment criteria</th>
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| Participants | L | L | H | L | L | L | H | H | L | L | L | L | H | L | H | H | L | L | L | L | L |
| Measures     | L | L | L | L | L | L | L | H | H | L | L | L | L | L | L | L | L | U | L | L | L | L |
| Design       | U | U | L | L | L | L | L | U | U | L | L | U | L | U | L | U | L | L | L | U | L |
| Type         | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H | H |
| Analysis     | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N | N |
| strategy     | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A | A |

| Scores       | L=15, H=2, U=7 |
|             | L=13, H=5, U=6 |
|             | L=15, H=6, U=6 |
|             | L=18, H=5, U=1 |
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|             | L=20, H=3, U=4 |
Appendix 4. Journal of Pediatric Psychology instructions for authors for manuscript preparation

MANUSCRIPT PREPARATION

Instructions to Authors

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• Review articles
• Commentaries

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Length of manuscript: Original research articles should not exceed 25 pages, in total, including title page, references, figures, tables, etc. In the case of papers that report on multiple studies or those with methodologies that necessitate detailed explanation, the authors should justify longer manuscript length to the Editor in the cover letter. Case reports should not exceed 20 pages. Review articles should not exceed 30 pages. Commentaries should not exceed 4 pages. The Journal of Pediatric Psychology no longer accepts brief reports but will accept manuscripts that are shorter in length than the 25 page manuscripts.

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(a) The academic degrees of authors should be placed on the title page following their names, and
(b) a structured abstract of not more than 150 words should be included. The abstract should include the following parts:

1. Objective (brief statement of the purpose of the study);
2. Methods (summary of the participants, design, measures, procedure);
3. Results (the primary findings of this work); and
4. Conclusions (statement of implications of these data).

Key words should be included, consistent with APA style. Submissions should be double-spaced throughout, with margins of at least 1 inch and font size of 12 points (or 26 lines per page, 12-15 characters per inch). Authors should remove all identifying information from the body of the manuscript so that peer reviewers will be unable to recognize the authors and their affiliations. E-mail addresses, whenever possible, should be included in the author note.

Informed consent and ethical treatment of study participants. Authors should indicate in the Method section of relevant manuscripts how informed consent was obtained and report the approval of the study by the appropriate Institutional Review Board(s). Authors will also be asked to sign a statement, provided by the Editor that they have complied with the American Psychological Association Ethical Principles with regard to the treatment of their sample.
In Pediatric Psychology should be incorporated into the manuscripts. There is no special section on clinical implications, but authors should integrate implications for practice, as appropriate, into papers.

Terminology should be sensitive to the individual who has a disease or disability. The Editors endorse the concept of "people first, not their disability." Terminology should reflect the "person with a disability" (e.g., children with diabetes, persons with HIV infection, families of children with cancer) rather than the condition as an adjective (e.g., diabetic children, HIV patients, cancer families). Nonsexist language should be used.

**Special instructions for types of manuscripts**

1. **Treatment studies/Randomized controlled trials:** If you are submitting a manuscript of a randomized clinical trial to JPP, you are required to submit a flowchart of your research showing the steps found in the Consort E-Flowchart. This should be submitted as a figure. The Consort E-Flowchart and a checklist of items to be included when reporting a randomized trial can both be found on http://www.consort-statement.org Please clearly indicate the page numbers where each checklist item is reported in the manuscript. Please upload this checklist as supplementary material when you submit your manuscript for consideration.

2. **Case Studies:** Although there may be some exceptions, most case studies should be sent to Clinical Practice in Pediatric Psychology (CPPP). Single-subject studies that employ rigorous A-B-A-B designs and/or statistical strategies can be sent to JPP. All others will probably fit better with CPPP. Case reports should not exceed 20 pages. Case reports are appropriate to document the efficacy of new treatment applications; to describe new clinical phenomena; to develop hypotheses; to illustrate methodological issues, difficult diagnoses, and novel treatment approaches; and to identify unmet clinical or research needs. Guidelines for case study submissions can be found in Drotar, D. (2009). Editorial: Case Studies and Series: A Call for Action and Invitation for Submissions, *Journal of Pediatric Psychology*, 34, 795-802; Drotar, D. (2011). Editorial: Guidance for Submitting and Reviewing Case Reports and Series in the *Journal of Pediatric Psychology*, 36, 951-958.


4. **Review articles:** Please consult the recent editorial (New Guidelines for Publishing Review Articles in JPP) which describes new guidelines for review articles, and the Checklist for Preparing and Evaluating Review Articles.

   a) **Topical reviews:** Topical reviews summarize contemporary findings, suggest new conceptual models, or highlight noteworthy or controversial issues in pediatric psychology. They are limited to 2,000 words, contain no more than 2 tables or figures, and have an upper limit of 30 references. Supplementary online material (e.g., additional tables) may be considered on a case by case basis.

   b) **Systematic reviews:** Systematic reviews should not exceed 30 pages. Authors are required to attach the PRISMA checklist and flow diagram as supplementary material for each submission. Authors can find the PRISMA checklist and flow diagram in downloadable templates that can be reused at this URL, http://www.prisma-statement.org/statement.htm. Authors of systematic reviews that do not include a meta-analysis must provide a clear statement in the manuscript explaining why such an analysis is not included for all or relevant portions of the report.

5. **Commentaries:** Commentaries are invited on all topics of interest in pediatric psychology, and should not exceed 4 pages, including references.

6. **Historical Analysis in Pediatric Psychology** is a special series of papers devoted to the history of pediatric psychology. Authors interested in submitting a paper for this series should contact the Editor of JPP to discuss potential papers prior to submission. There is no deadline for these papers (they may be submitted anytime). All submissions will be peer reviewed and should comply fully with the JPP Instructions to Authors. Papers in this series should be tightly focused contributions that expand our understanding of the roots, evolution, and/or impact of pediatric psychology as a discipline. Manuscripts may focus on the influence of individuals, published works, organizations, conceptualizations, philosophies or approaches, or clinical and professional activities. Successful
papers should articulate a clear purpose/question and develop a compelling argument for the topic. Contributions should include a breadth of coverage, such that contradictory data are included and potential biases acknowledged. Historical analysis is more than a recounting of the “facts” and should include a thoughtful and scholarly interpretation of the subject matter. Papers should rely on primary sources and must be clearly and appropriately referenced. Supplemental materials to accompany the article may be posted online.

**Additional Guidance:**

The following links provide additional guidance for authors and reviewers. Editorial Policy, Authors' Checklist, Guidelines for Reviews, Suggestions for Mentored Reviews, "People First," NIH policy, Replication of research, Duplicate and redundant policies Conflict of interest

See the following articles for detailed guidance concerning preparation of manuscripts: Editorial: Thoughts in Improving the Quality of Manuscripts Submitted to the Journal of Pediatric Psychology: How to Write a Convincing Introduction.; Methods: Editorial: How to Report Methods in the Journal of Pediatric Psychology; Results and Discussion: Editorial: How to Write an Effective Results and Discussion Section for the Journal of Pediatric Psychology.

**Funding**

Details of all funding sources for the work in question should be given in a separate section entitled ‘Funding’. This should appear before the ‘Acknowledgements’ section.

The following rules should be followed:
- The sentence should begin: ‘This work was supported by …’
- The full official funding agency name should be given, i.e. ‘the National Cancer Institute at the National Institutes of Health’ or simply ‘National Institutes of Health’, not ‘NCI’ (one of the 27 subinstitutions) or ‘NCI at NIH’ (full RIN-approved list of UK funding agencies)
- Grant numbers should be complete and accurate and provided in parentheses as follows: ‘(grant number xxxx)’
- Multiple grant numbers should be separated by a comma as follows: ‘(grant numbers xxxx, yyyy)’
- Agencies should be separated by a semi-colon (plus ‘and’ before the last funding agency)
- Where individuals need to be specified for certain sources of funding the following text should be added after the relevant agency or grant number ‘to [author initials].’

Oxford Journals will deposit all NIH-funded articles in PubMed Central. See http://www.oxfordjournals.org/for authors/repositories.html for details. Authors must ensure that manuscripts are clearly indicated as NIH-funded using the guidelines above

**Color Figure Charges**

Authors are charged for the print reproduction of color figures. The cost is $600/€525/£325 per color page. Figures can be published in black and white in the print edition and in color online for free. If you choose this option, please ensure that your figures are clear and readable in both black and white and color.

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**Language Editing**

Language editing, if your first language is not English, to ensure that the academic content of your paper is fully understood by journal editors and reviewers is optional. Language editing does not guarantee that your manuscript will be accepted for publication. For further information on this
service, please click here. Several specialist language editing companies offer similar services and you can also use any of these. Authors are liable for all costs associated with such services.

Updated January 2016
Appendix 5. Telephone Interview Schedule

RESEARCH QUESTION: To investigate the feasibility and efficacy of a Triple P Self-directed workbook for parents of children with a diagnosis of cancer.

A. Explanation of the aims of the interview and the topics to be covered.
B. Explanation of ground rules during interview (e.g. anonymity, value of opinions regardless of how unusual, no right or wrong answers, taking notes, format of the interview).
C. Ask if they have any question before beginning the interview.

The following questions are indicative of the areas to be covered in the interview. (* indicates questions to be completed by parents who do not consent to participate in the intervention but who are happy to have a discussion about reasons why not taking part)

Reasons for showing interest in the research study
1. What initially interested you in putting forward your contact details for this study?*
2. What are/ were you hoping for or looking for from the parenting intervention?*

Overall parenting experience
3. How do you find parenting your child?*  
(Main difficulties, concerns, worries, problems affecting the family in general, what has been difficult post diagnosis)
4. What support would you like with regards to parenting?
5. Have you ever received any parenting support/ participated in any parenting training before? What was this? What was helpful/unhelpful about this support/training?
6. What strategies are you putting into practice with your family? How are they working for you?*

Relevance to Population of Parents
7. Do you think there are any modifications to be made for this program which would make it easier for you to be able/ willing to take part? Or help others in your position (What would you modify to make it more relevant to you?)*
8. Can you tell me a bit about why you chose not to take part in the programme?*
9. How much time would you want to/ be able to commit to parent support interventions and what mediums of support would be most useful (i.e. groups, social media, face to face contact, booklets etc)?*
Appendix 6. National Research Ethics Society Approval Letter

16 March 2015

Mrs Katie D Swift
Trainee Clinical Psychologist
Manchester Mental Health and Social Care Trust
Section for Clinical Psychology, University of Manchester
2nd Floor Zochonis Building, Brunswick Street
Manchester
M13 9PL

Dear Mrs Swift

<table>
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Thank you for your letter of 13 March 2015, responding to the Proportionate Review Sub-Committee’s request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Vic Strutt, NRESCommittee.EastMidlands-Northampton@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

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

Conditions of the favourable opinion

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

You should notify the REC in writing once all conditions have been met (except for site
Appendix 7. Participant Identification Centre (PIC) approval letter

Central Manchester University Hospitals
NHS Foundation Trust

Research Office
1st Floor, The NOWGEN Centre
29 Grafton Street
Manchester
M13 9WU
Tel: 0161-276-3585
Fax: 0161-276-5766

Mrs Katie Swift,
School of Psychological Sciences,
University of Manchester,
Brunswick Street,
Manchester,
M13 9PL.

29 January 2016

Our Ref. CMFT-PIC-R04212

Dear Mrs Swift,

Study: Triple P for Parents of Children with a diagnosis of cancer
PIN: R04212
Sponsor: University of Manchester
Chief Investigator: Katie Swift
Local Liaisons: Dr Louise Robinson and Dr Ruth Hurrell

We have received a request for authorisation for our Trust to become involved as a Participant Identification Centre (PIC) for the above study.

Following receipt of the documentation listed at the foot of this letter, we have completed the checks required for a PIC site and can confirm our agreement.

I would like to take this opportunity to wish you well with your research.

Yours sincerely

Ms Elizabeth Mainwaring
Research Support Manager

Cc: Alison Robinson – Divisional Research Manager; Louise Robinson – Local Collaborator; Ruth Hurrell – Local Collaborator

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<td>UOM Public, Product and Employers liability</td>
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Version 1. 17/07/15

Page 1
Appendix 8. Participant Information Sheet (PIS)

Cancer and Parenting Support

PARTICIPANT INFORMATION SHEET

http://www.psych-sci.manchester.ac.uk/students/TriplePforCancer

Does your child have cancer?
Is your child aged between 3-10 years old?

Thank you for reading this. You are being invited to take part in a research study investigating a self-directed parenting support programme for parents of children with a diagnosis of cancer.

Long-term illnesses like cancer can impact on families in many ways. For instance, parents of children with a diagnosis of cancer often find themselves taking on many new roles and responsibilities to aid the physical care of their child. Families have to find ways to adapt to aid their child’s treatment and recovery where possible. It is therefore important to provide appropriate support that parents can benefit from. Our research team is running a project using the Triple P - Positive Parenting Program. It has been adapted for use with families with a child with a long-term illness with the aim of promoting healthy and happy family life.

Before you decide whether to take part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Who will conduct the research?

Katie Swift, School of Psychological Sciences, The University of Manchester.

What is the aim of the research?

Triple P is used worldwide to help families build on their own knowledge, skills and confidence. It offers positive parenting advice and focuses on making small changes to Parenting Support & cancer_PIS_Version 1.2 5.3.16
enhance a child’s development. We want to see if the “Triple P- Every Parents Self-Help Workbook” can be a helpful tool for parents of children with a diagnosis of cancer. The information collected will be used to inform the development of parenting interventions specifically aimed at long-term illnesses.

Why have I been chosen?

We are inviting parents and primary caregivers of children aged 3-10 years with cancer to take part in research developing Triple P for use with long-term illnesses. It is anticipated that approximately 10 parents will complete the workbook. These parents will receive a £10 amazon voucher as a token of our appreciation for their time completing questionnaires. Parents who do not choose to sign up will be invited to complete a one-off telephone interview to answer some questions about why they did not sign up and what if any support would be useful to them. These parents will also receive a £10 amazon voucher for their time completing the interview.

The resource is suitable for either or both parents to use. However, it is asked that just one person registers on the project, and the same individual completes the information requested. The resources are suitable to use if you have more than one child with cancer.

However, we ask that you complete all questionnaires in relation to one child only. This is to ensure consistency with the data collected.

Are there any reasons why I could not take part?

The study involves reading Triple P resources (e.g. workbook and questionnaires). Therefore, it would not be suitable to take part if:

- you require assistance with reading and do not have anyone who could help you
- your child has additional significant health difficulties
- you or your child have been diagnosed with a serious mental health difficulty

Unfortunately, participation would not be suitable because these issues may require more specific and individualised support.

If it is not suitable for you to take part, some alternative services are listed in the section “What if I need further help or advice”, which you may find helpful.

What would I be asked to do if I took part?

In the first instance, we will ask you to complete some online questionnaires (30 minutes) about your family background, your child’s cancer diagnosis, your experience of your child’s illness, how you rate your child’s quality of life and their behaviour in general. Once you have completed the questionnaires you will be asked if you would like to sign up to complete the workbook.

Before you start the workbook, we will contact you on a weekly basis for a variable period of between 1-3 weeks to complete 33 questions over the telephone/online/via post about your child’s emotional status and behavioural difficulties. If you do not want to be contacted by telephone, we can post the questions to you or you can complete them online. Once we have these measures we will provide you with a copy of the every parents self-help

Parenting Support & cancer_PIS_Version 3.2 5.3.16
workbook which you will complete over 10 weeks for 1 hour per week. The workbook contains helpful advice for general parent/child relations. You will also be required to complete a brief questionnaire about your completion of the workbook. On completion of the workbook, you will be asked to repeat the questionnaires you completed at the start of the study (30 minutes). You will be able to complete all parts of the Triple P programme at home and will not need to attend any extra appointments at the hospital as part of the research.

End of study questionnaires: We will contact you 4 weeks after your final completion date of the workbook to complete the full survey questionnaires again (30 minutes). This will help us to see if the advice from the Triple P workbook has been helpful to your family and whether any benefits have continued since completing the workbook. Should you wish to leave any feedback, there will be a box at the end of each survey where you can provide any comments you may have on your experience of the Triple P workbook and the study in general, however this is not compulsory. These comments may be used anonymously in reports once the research has finished.

If you are interested in the study but decide that you are unable to take part, we will ask for your permission to have a short one-off telephone conversation (15-30 minutes) with the researcher about the reasons why you might be unable to take part and to ask you for your ideas about what types of parent support you would prefer or find more helpful. As with the main study, you can decline to take part in this interview or withdraw at any time without giving a reason. Any information that we get from interviews will inform researchers of the types of interventions and support that families may benefit most from.

If for any reason you cannot complete the initial and final questionnaires online but would still like to participate, please contact the research team who can arrange for the questionnaires to be posted to you or completed over the telephone instead.

What happens to the data collected & will the outcomes of the research be published?

Data will be accessed by a member of the research team and will be entered onto a computer, encrypted and analysed anonymously. Anonymous data may also be used for future research. All the data collected online is stored directly on the University’s secure servers and will be held for 10 years according to our information governance policies. Outcomes of the research will be submitted for publication in a scientific journal. The work will also be described at conferences. Published results and presentations will not contain any information that could identify any participant(s) involved. A summary of findings will also be published on the Research Website and shared with organisations that have supported recruitment (e.g. cancer charity).

How is confidentiality maintained?

All information will be kept strictly confidential. Data received will only be accessible by the research team. Personal identifying data will be stored separately to questionnaire data to ensure anonymity. Paper based data will be held securely in locked storage. Data entered online will be held securely and password protected. Both online and paper-based data will be stored securely at the University of Manchester in line with the Data Protection Act. Individuals from the University of Manchester or regulatory authorities may need to access the data being collected to make sure that the study is being carried out as planned. Only authorised
individuals will have access and they will have a duty of confidentiality to everyone taking part in the study.

**What happens if I do not want to take part or if I change my mind?**

It is entirely up to you if you wish to take part or not. If you decide to take part you are still free to withdraw at any time, without stating a reason. If you decide not take part this will not affect any of the care you are currently receiving and any identifiable information collected about you or your child will be destroyed.

**What is the duration of the research?**

*Initial Survey:* The survey will take approximately 30 minutes to complete.

*Triple P Workbook:* Should you be one of the first 10 parents to opt in to complete the Triple P workbook, the duration of participation will be as follows:
Part 1: Survey

- Approximately 30 minutes

Part 2: Triple P

- Research participation will be either for a minimum of 15 weeks to a maximum of 17 weeks. The time involved will depend on which initial data collection schedule you are allocated to (e.g. either 1, 2, or 3 weeks). During which you will complete 33 questions each week for the specified schedule (e.g. 2 weeks).

- The "Triple P" time will be approximately 10 hours over the 10 week period (1 hour per week). A further ten minutes will be required to complete 33 questions on a weekly basis, which will be completed with the researcher over the telephone or online/ by post. During this time you will also be required to complete a short form about your completion of the workbook. On completion of the workbook and one month following this, you will be asked complete the majority of the questions from the original survey (1 hour total).

If you do not wish to take part, we would like to contact you to complete a brief telephone interview (maximum 30 mins) to ask you about your reasons for not participating and what support you think would be useful to parents of children with a diagnosis of cancer.

Where will the research be conducted?
Participants will be recruited from across the UK and from the Royal Manchester Children's Hospital. The data from the study will be analysed at The University of Manchester.

Who will be notified that I am taking part in the research?
Should you decide to take part in the research we would like to send a standard letter to your GP to notify them that you are taking part in the research.

What if I need further help or advice?
You should contact Katie Swift (details below) if you have any queries or concerns in relation to the research project and he will direct your enquiry to the appropriate person. The following services may also provide further assistance if required for medical issues:

- You can contact your GP/Consultant
- Your child’s cancer care team, or
- NHS Direct Tel: 0845 4647 (24 hour health advice)

- Further psychological help/parenting support: If you feel you need further help, contact your GP.

What if there is a problem?
Parenting Support & cancer_PIS_Version 1.2 5.3.16
Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk.

Harm

In the unlikely event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or NHS Trust but you may have to pay your legal costs. The normal NHS complaints mechanisms will still be available to you.

Thank you very much for considering taking part in our research.

If you decide to take part, please proceed to the next page to complete the consent form and complete the survey. Please ensure you have enough time to complete all of the questions in one sitting (approximately 30 minutes) as you cannot leave the page and return to the questions at a later date.

Should you agree to continue to complete the workbook, once you have completed the consent form and questionnaires, the research team will be in touch to provide you with further details. If you decide not to take part, you will be invited to complete a telephone interview about your reasons for not signing up.

For further information please contact:
Katie Swift, Trainee Clinical Psychologist and Chief Investigator
School of Psychological Sciences, 2nd Floor
Zochonis Building, University of Manchester
Oxford Road
Manchester
M13 9PL
Tel: 0161 306 0403
Email: katie.swift@postgrad.manchester.ac.uk

Parenting Support & cancer_PIS_Version 1.2 5.3.16
Appendix 9. Participant Consent Form

Study Number: 15/EM/0101

CONSENT FORM

Title of Project: Triple P for Parents of Children with a diagnosis of cancer

Name of Researcher: Katie Swift

If you are happy to participate, please complete the consent form below.
By completing the consent form you are consenting to take part in this research project.

1. I confirm that I have read the participant information provided on the above project and I have had the opportunity to consider the information and ask questions.
   Yes No

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason.
   Yes No

3. I understand that all my personal information will be kept confidential and that the results of the study will be used for scientific objectives.
   Yes No

4. I understand that data collected during the study, may be looked at by individuals from the University of Manchester or from regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
   Yes No

5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
   Yes No

Consent Form _Online Version 1.2 5.3.16
6. I understand that it is not guaranteed that this study will provide any benefits to my child.
   Yes No

7. I am happy for my GP to be contacted to inform them I am taking part in the research.
   Yes No

8. I am happy to be contacted by the researcher by telephone to complete weekly questionnaires if I chose not to complete them online.
   Yes No

9. I am happy for any feedback I provide (i.e. from survey feedback boxes or interviews with the research team) to be used in any possible publications of the research findings and that the researcher will make attempts to anonymise quotes as much as possible, but that full anonymisation is not guaranteed.

10. I would like to be sent a study newsletter detailing the results of the study.
    Yes No

11. I am aware that I will receive a £10 amazon voucher following my completion of the study questionnaires a thank you for my time.
    Yes No

12. I am aware I may be contacted to be invited to undertake a one off telephone interview should I not complete the survey or opt in to complete the workbook.
    Yes No

13. CONTACT DETAILS (If you chose to opt in to phase two of the study, to enable the Research team to contact you weekly and to forward your Triple P resources to you please provide your contact details below)
    Name:

Consent Form _Online Version 1.2 5.3.16
12. Where did you hear about this study? (please select one of the following options)

Cancer charity Website (box)
Poster/Leaflet (box)

Thank you for agreeing to take part in this research project. To continue please proceed to the next page.
Appendix 10: Parent Support Booklet

Useful Websites

This website provides information about how cancer can affect the family and gives advice on how to cope:
www.cancer.gov/cancertops/when-someone-else-your-family

The Charity Clic Sargent offer social, emotional and practical support to children, young people and adults under the age of 35 years old who have been affected by cancer: www.clicsargent.org.uk

Children’s Cancer and Leukaemia Group. This website has information for families with links to useful booklets and leaflets: http://www.cclg.org.uk/index.php

The Cancer Information Service and cancer counseling service. Its website contains a wide range of information: www.cancersupport.org.uk

The Cancer Counselling Trust offers a series of free, confidential sessions, both face to face and over the phone to anyone affected by a cancer diagnosis. To enquire about counselling call 030 7943 2520 and talk to the counselling co-ordinator.
http://www.cancer Counselling.org.uk

Further information about the Triple P Positive Parenting Program can be found at the following website: www.triplep.net

Contact Information

If you would like support to access a service or require any further information about the project please contact Katie Swift, Trainee Clinical Psychologist and Chief Investigator
Tel: 0161 300 0403
Email: Katie.Swift@postgrad.manchester.ac.uk

Parent Support Booklet: Where Can I Get Help For Me and/or my Child?

Thank you very much for taking part in this research project.

As a result of completing the questionnaires, you might feel that you and/or your child could benefit from extra help and support, emotionally or socially. This booklet contains some relevant people you might want to contact.

You might not want any help at the moment. Please keep this booklet somewhere safe, just in case you want to contact one of these services at a later date.

Psychology Services available at your child’s hospital

Some hospitals offer a psychology service which is there to provide psychological and emotional support to patients and their families.

The service can help in the following areas:
- Depression / low mood
- Anxiety and worry
- Anger / behavioural problems
- Problems relating to identity and body image
- Posttraumatic Stress
- Problems with memory and learning
- Family problems

This is not a comprehensive list, and the psychology team may be able support you or your child in other areas also.

Please phone your local hospital if you would like to talk to someone about getting help for you and/or your child. This team is also able to refer onto or find appropriate support locally.

Other Support

Child Cancer Helpline: 0800 197 0068

(This FREE helpline is open between 9am-5pm, Monday to Friday and offers emotional support and practical information)

Your GP/Your child’s GP

You may want to speak to your GP who can put you in touch with local services that may be able to help with any emotional or behavioural problems you have.
Appendix 11: Telephone Interview Consent Form

TELEPHONE INTERVIEW CONSENT FORM

Title of Project: Triple P for Parents of children with a diagnosis of cancer

Name of Chief Investigator: Katie Swift, Trainee Clinical Psychologist

Thank you for taking the time to show interest in this study. You have informed us that you do not wish to take part in the Triple P intervention but that you are happy for the research team to have a short one off telephone interview (15-30 minutes) about your reasons for not taking part and what types of support might be helpful for you and your child. If you are still happy to do this, please tick the boxes below to confirm.

1. I confirm that I have read and understand the information sheet (Version 1.2; dated 5/3/2016) for the above study and have had the opportunity to think about it and to ask questions.
   Yes No

2. I agree for the researcher to ask me some questions about my experiences of parenting my child with cancer, reasons for not taking part, and preferred ways to gain support.
   Yes No

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without mine or my child's medical care or legal rights being affected.
   Yes No

4. I understand that the interview information that I give will only be seen by members of the research team, and that this information will be anonymised as much as possible and stored securely on university computers or encrypted devices.
5. I understand that my interview will be recorded and transcribed for use in research papers that may be published. I agree for quotes to be used in any possible publications, but that full anonymisation is not guaranteed.

Yes No

6. I understand that for monitoring and auditing purposes, study data and materials may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust.

Yes No

7. I would like to receive a written summary of the overall findings of the study

Yes No

8. I am happy for my GP to be contacted to inform them I am taking part in the research.

Yes No

9. CONTACT DETAILS

Name:
Email:
Mobile/Home telephone number:
Address:
Town/City:
Postcode:
Name GP:
Address GP:
Appendix 12. Telephone Interview anonymised transcript

Telephone Interview Participant E Completed 930am on 19th May 2016.

To maintain anonymity, aspects of the conversation have been altered and are depicted as X. The participant had read a participant information sheet and completed a consent form prior to undertaking this interview.

Verbatim Transcription: K= Katie P = Participant

K: Thank you for taking my call today
P: No worries
K: Basically today is to conduct a telephone interview and just to let you know I am recording the conversation at the moment via a Dictaphone and that it will be transcribed and saved on a secure memory stick, if that’s ok with yourself?
P: Yeah, no problem
K: Great. So the interview today is basically about why you were interested in the study, what you were hoping for, why you weren’t able to continue with it and any kind of support that you think actually for your beneficial to your family, If that’s ok.
P: Yes, no worries.
K: Obviously everything will be kept anonymous if there’s any of the quotes taken and put into published articles everything will be anonymised and you wouldn’t be identifiable.
P: Ok
K: I value all of your opinions and there’s no right or wrong answers so please be as honest and open as you can be really. I might take some notes as we go along just to keep jogging my memory of things we have discussed if that’s ok
P: Yes, absolutely
K: Are you ok for time?
P: Yes, I’m absolutely fine
K: Do you have any questions before we start?
P: No I don’t think so
K: Great, first question: 1. What initially interested you in putting forward your contact details for this study?*

Erm, Well obviously I’ve had a child who’s been affected by childhood cancer, and so in any way that being a parent who’s been through that process I am keen to do anything that might make the process easier for anyone else who’s going through that now if you see what I mean and you know trying to collate as much information as possible so people have got literature to read and so they’ve got something to fall back on which is what I found when we were first diagnosed to read literature from different organisations, knowledge is, you know if your informed even if you’ve got no control
over the situation you’re in, if you feel like informed at least you can ask questions which then might make you feel slightly more at ease with the situation.

K: and can I ask when your child was diagnosis

P: sure X was diagnosed on the X 2012

K: and what was his diagnosis

P: With acute lymphoblastic leukemia

K: right ok, and is X currently on any treatment

P: no

K: 1. What are/ were you hoping for or looking for from the parenting intervention?*

I’m hoping it might bring other parents together, I think at the moment if you are looking for support it is quite disjointed, I think there’s, there are lots of different ways that you can get in touch with other parents but sometimes it not that structured so social media sites and other bits and pieces but as a new parent you start reading some of those social media sites it can be quite frightening because obviously everyone is quite emotional and everyone’s stories are different and then you start analyzing the information that you have taken on board there which isn’t sort of you know, even though its what’s parents are going through, it isn’t necessarily all right there’s emotions that are in it as well so I think it’s just bringing all that information together and having a bit more support for parents. I think sometimes parents get lost in situations like this, obviously there’s a lot of concentration on the child and as that parent your life, is just someone’s just drawn a line in the sand and your completely lost, so I think the more support the better.

K: had you heard of triple p before you signed up to the study or was there something that specifically interested you in triple P?

P: no I had never heard of it until I got the email

K: when you read the information about the study was there anything that you specifically identified with or thought oh that would be useful?

P: I think just generally just collating the information and being able to make that process easier is always a good thing, I would like to help in any way I can to make things easier for unfortunately the next lot of families going through the same thing.

K: yes, yeah,

3. How do you find parenting your child?*

(Main difficulties, concerns, worries, problems affecting the family in general, what has been difficult post diagnosis)

P: erm, I think it’s trying to find a balance, because erm X’s is different from other children but you don’t, I don’t want home to be different, it’s trying to continue a normal life as much as you possibly can without, when they have low immunity it’s very difficult to make the decision whether they should go and play with their friends and whether they should go to birthday parties and even though it seems really cruel to not let them sometimes you just have to, it’s all about tough love and it’s about making
decisions on their behalf, erm and then that is tricky and then schooling is tricky, not wanting them to fall behind, fortunately my son is, X’s the oldest in his school year which was a massive benefit to us cos you know X was diagnosed just when erm so X had a year before X started school and if X had been 2 weeks older X would have missed a year of school of X’s life, so we feel quite lucky that if it’s going to happen that it happened at the right time but then it’s just having to manage hospitals, when they did start school obviously with leukemia the treatment goes on for quite a long time it’s trying to manage X work and making sure that X doesn’t fall behind.

K: and did you notice any difficulties in his emotional and behavior wellbeing at home that prompted you to think about a parenting intervention?

P: yeah, X is, X’s quite a unique child, we’ve obviously got another child as well, and erm has always been old for their years, X’s got a very mature head on his shoulders, I’ve noticed, and we haven’t quite decided if this is a product of his situation or whether this is his personality but X in some circumstances it’s a good thing and other times it’s not, X’s really articulate with adults, so X can express themselves really well and X can hold a very intelligent conversation with an adult and people will say oh wow I can’t believe that you know that of a X year old and we don’t know if that’s because X’s spent so much time around adults whilst X was in hospital or whether actually X had always been like that anyway but also it means that the boundaries have slightly been blurred and sometimes X forgets who is the grown up and who is the child and X will then try and X’ll try and be very authoritative to me and my husband and X sometimes forgets X’s place if you see what I mean, and then X gets quite cross about it

K: ok, so would you say that’s one of the problems that effects your family the most or that kind of effects the family dynamics?

P: Erm, I mean to be honest I think looking at referring to other families that haven’t been affected by childhood cancer they have their own issues so I don’t think actually if you looked at ours and you looked at several other families yes you’ve got different things going on but actually I don’t think it is any more extreme or X’s behavior is any more extreme than any other family unit I think there’s ups and downs that’s part of having children but X is just incredibly stubborn so we just have to work with that but my X got other things I’m not sure it’s particularly a product of what’s happened

K: ok, and have there been any noticeable difficulties post diagnosis that kind of spring to mind

P: physically or emotionally?

K: erm, both

P: Both, ok, physically definitely his mobility, so X has a, I can’t remember the terminology they use at school X has some kind of special plan in place at school because his balance isn’t as good as X’s peers, and the strength in X’s legs as obviously X’s had different chemotherapy has affected X’s stamina which is getting better actually but certainly for the first two years X was definitely behind physically in comparison to another child erm, emotionally other than being I mean X does get quite cross, but it’s not quite cross every day, it catches you out as X’s actually quite a level child most of the time and then every month X will when X gets cross X gets really really cross (laughs).
K: and is there usually something that triggers that or?

P; erm, X doesn’t like surprises, so erm the way we have dealt with treatment and how to deal with X’s level of fear for some things that are going to happen is that I have always prepared X, for instance, X had to have once, X had to have and MRI scan and X hadn’t had one before, and X was only X at this stage, so X said to the nurse X was really poorly X was an impatient X didn’t really want to do it because X was scared about it, what X said to me it that X would go a have a look at what X had to do because X had to lie still for a certain amount of time, X’d go and have a look at it and then X would do it tomorrow, so the next day and the nurses were quite you know quite skeptical about that, but actually that is how X works, and has always been the same, so we did we went to have a look, X took on board what was expected of X, and X said I will do it tomorrow, and the next day X went in the MRI machine and didn’t move for 15 minutes, and did everything that was asked of X, but X, that’s the way we have to do everything with X, we have to prepare X, and X doesn’t do surprises, so we can’t just go to the hospital and they suddenly say you’re going to have a blood test, we need to know that the day before otherwise X just won’t do it, there’s no talking X around, there’s no saying we will have an ice-cream afterwards, X’s not interested, X has to be prepared

K: ok so rewards and things don’t work, it’s the preparation and the planning that’s important
P: yeah, they don’t work at all, it all has to be talked about in advance

K: and 4. What support would you like with regards to parenting? Obviously you have been affected by childhood cancer so what for your family would be beneficial?

P: Er, I think sometimes erm, a bit more, it’s being able to speak to someone who, it’s not about speaking with other families actually, it’s being able to speak to someone who is informed and that you can ask questions to and of course you’ve got the consultants at the hospital, but actually sometimes you don’t see them, for instance, I’ll tell you about a situation that happened to us about 6 weeks ago, so X is off treatment, but has periodic blood tests to check his blood, and we had a routine blood test and we had a phone call from a nurse to tell us that his blood tests had tested positive for some leukemia back in his blood, you know for us was a huge revelation, and very upsetting and we were told that on a Monday evening at 5 o clock and I said well I need to speak to a consultant and there weren’t any consultants there, so we were left overnight worrying about this situation and X was retested and then we got the results a week later, so we had a week of worry and then the nurse rang us and said it was absolutely fine it was contaminated by the machine, ok, which is amazing, however we had a week of not being able to talk to anyone and actually we really needed some support because we thought our world had just fallen apart again and there was no one there to support us in that situation at all

K: gosh, and had you shared that information with your son about the results?
P: No, fortunately not, because we decided that we wouldn’t tell X until we knew there was absolutely something to tell and obviously that was the right decision if we had of told X, X would of then been terrified, has a clever X and then maybe we would have had you know more emotional issues to deal with. No we decided to just try and pretend to carry on as normal until we we were told different
K: ok, gosh what a hard experience that must have been for you
P: not it wasn’t fun
K: no it must have been a nerve wracking week
P: yeah it was, and you are you feel very very alone and I’m very lucky we have lots of
friends and family and who you know we live in a small X and have lots of support, erm
and you worry, some of my friends have commented after that event saying so at the
time our daughter was X months when X was diagnosed and we missed out on lots of
her younger childhood because I was in hospital with my X, it seems I’m holding on to
quite a lot of guilt for that, and then when we thought X was going to be poorly again, I
was then really worried about how I was going to manage her and X at the same time.
So it’s definitely support for siblings as well, it’s a major impact on their lives

K: have you noticed difficulties with her emotional wellbeing and any behavioural
difficulties as a result of the situation

P: Yes she is definitely, she’s insecure and she’s got detachment issues, so she’s only in
reception at school, she’s got detachment issues, so she’s really happy at school and
really enjoys it, but when I drop her off in the morning, she still cries every morning and
doesn’t want to leave me, but once she’s gone through that process she has a really
lovely day but she’s definitely insecure, she’s unsure within herself and if I tell her off
for instance then she gets very upset and wants to cuddle and worries about it and I
think that is definitely a product of mummy not being there for a good proportion of
when she was younger, even though she was fine she was with her dad and
grandparents but it’s not, at X months old it’s not ideal.

K; Gosh, it’s certainly been a really difficult situation for you hasn’t it, and there have
been a number of factors really to consider.

P: it has, it is, but then you always look at the other people around you who are going
through the same thing and what I noticed was that we are a husband and wife and two
children and we’ve got grandparents, we are a complete conventional family and we are
there to support each other, who I felt sorry for when I was in hospital was single
parents who have got four children who are trying to juggle that situation, I mean it was
bad for us but I dread to think how it is for them

K: yes, absolutely. 4. Have you ever received any parenting support/ participated in any
parenting training before? What was this? What was helpful/unhelpful about this
support/training?

P: No
K: Ok, is that something that you have ever looked into before?
P: no I’ve never looked into it, pretty much when you’re going through that process
you’re on autopilot and they give you lots and you read it and if it isn’t offered you kind
of think it’s not there

K: ok, and 6. What strategies are you putting into practice with your family? How are
they working for you?*

P: so, I just try and just live a normal life as possible, and with X we prepare him for
everything, for the last couple of weeks X’s just had his key stage 1 sats which X’s, he
wouldn’t be worried about doing them from the point of view that he’s quite able, but
he needs again, the whole process about being prepared, this is what’s going to happen,
this is what it expected of you and as long as so if I hadn’t, I think the teachers try to
keep it low key so children don’t get anxious about it but I would rather talk to x about
it, because otherwise if he’s just thrown into the situation you must sit there and read this paper for an hour then he’s going to be more anxious by that than if we haven’t talked about it, so preparation, every day

K: it sounds like you do lots of good preparation, lots of talking to your children about issues and worries and things that are coming up which sounds great

P: yes, and I think it maintains a level of trust between X and I, there are things that aren’t very nice that he has to have done and he says what’s it going to be like and I’m not sure it’s going to be very nice, but you’ve got to do it because of this so I try not to, I just try and tell the truth so that there’s no surprises and then he’s not going to be cross with me and then he’s not going to trust me the next time we go through something

K: that sounds like it’s a good strategy that’s working for you as a family, so that’s great to hear – have you ever struggled to put into place strategies like setting limits and boundaries, especially perhaps when X has been quite poorly and that kind of thing

P: yes, he was on very high dose steroids for quite a long time, that really really affected him, they told us, the consultant said they never seen a child that had reacted on the quite so badly, so what I think they do, they take your personality and magnify it, so a bit of X’s personality is that he is stubborn and he gets cross. It was that 100 fold, so he was horrendous and very very difficult to manage, very very argumentative, really indecisive, he didn’t really know what he wanted to make the situation better, definitely the worst part of treatment for us was steroids and he was quite aggressive as well so he would lash out and obviously it was a really fine line trying to instil that that wasn’t good behaviour and that wasn’t acceptable at the same time it was you know, really difficult to see your baby being really poorly and that’s not what you want to be doing you don’t want to be telling them off because you feel sorry for them and it’s not their fault at the end of the day it’s the medicine making him like that, I then also then didn’t want my daughter who was at a very impressionable age to then copy that behaviour and think it was acceptable, so definitely that was incredibly hard to manage

K: yes, it sounds it, really difficult, in terms of the triple p study that I was offering which obviously was a self-directed work book to complete in your own time over 10 weeks, do you think there are 7. any modifications that can be made to the program which would make it easier or make you’re more willing to participate in the program?

P: I was really willing to participant, but when I was going through the work book (participant was referring to the initial questionnaire), a lot of the questions applied to if your child was on treatment now, and that’s why I stopped as I suddenly thought whether I should be doing this, as some of the questions weren’t particularly appropriate at this time, so I thought maybe they don’t want people who are now off treatment. People who are going through it, so that’s the only reason why I stopped.

K: right ok, well I’m sorry about that confusion and that’s really useful feedback as I will look into the questions and how they are worded, obviously if this study was to be taken forward, erm then we would definitely have a look at that, I guess in terms of the programme being self-directed I know you have mentioned about wanting support from other parents do you think it would have been better delivered in a group or would there be a different way of delivery that would have been more appropriate?

P: No I think, peoples situations are so unique even when you get the same diagnosis you go down how that diagnosis is dealt with it really depended on how the child kind
of reacts to the treatment, so our son went down a completely different way to 90% of the other children with that same diagnosis, so I think it can’t be done initially as a group, it then, then it could be analysed, different people could be put into group further down the line which was obviously appropriate to their situation.

K: do you think, that doing it self-directed for the workbook was ok, or would of you have preferred some telephone contact throughout that if you were to complete it or any other form of contact during that 10 weeks.

P: no I wouldn’t, I think I would have been absolutely fine with the workbook, if the questions – the way they were asked, I would have been fine with the workbook.

K: ok great, 9. How much time would you want to/ be able to commit to parent support interventions and what mediums of support would be most useful (i.e. groups, social media, face to face contact, booklets etc.)? and what would be most useful to families in your situation?

P: Erm, if there was some kind of parent forum that people could log on to, that’s a really good way and that can be live so you can then talk to other parents at the same time, I live in quite a rural location and so to go to meetings, I mean our hospital is are an hour and 15 minutes away from us, so you don’t necessarily see people from X, I only see them when I go to hospital and I haven’t particularly, I know some people make friendships with people when they go to hospital and they maintain those maybe for the rest of their lives, I’ve really really struggled, I am quite a sociable person most of the people in our village you know, I get involved I’m chair of our X so I am really sociable but I really struggled but I didn’t really want to be anyone’s friend in that situation because it’s like it just felt, how do I word it, I didn’t want to have in common you know your attracted to people who have similar things going on, I didn’t want that going on in my life even though obviously I have accepted it, I didn’t want, when you have a baby you make friends with people who have got babies, and you sit round and you talk about your babies, I didn’t want to make friends with people because my child had cancer and so did theirs and then all we were going to do it sit and talk about cancer because it didn’t feel very positive to me and I’m always a really positive person and therefore I didn’t want to be put with someone who wasn’t because it might start to play on my mind and drag me down. So I think from a social media point of view, and having an online forum you can dip in and out of it and if there’s a discussion that actually you think I don’t want to be part of this you can just log off you know and it’s not so invasive but it’s there at the click of a button if you want it

K: That’s a fantastic suggestion actually and not something we had considered so far with regards to the delivery of this intervention, so that’s fantastic thank you that’s really useful thank you

P: talking about friends and people being in the same situation, so probably the person I have related to most out of our whole journey was a family from X we came across on a forum, and their child, there’s not many children who have quite been through the same treatment as our son has and he had exactly and she’s probably now the person that I would always email to support each other and the friendship we have built the biggest friendship, their sons the same age and same kind of family life and they are on the other side of the world so it doesn’t need to be you know a group were you go somewhere and you meet people
K: yes, absolutely, and I guess one of the things we tried to do with this was you know open it up nationally online so that we could be able to target people all over the country and offer it that way rather than in one locality but I can see how a forum could be really really useful actually especially if people want to discuss elements of the workbook or things like that and that they have tested and found useful then they would have somewhere to discuss that with other parents

P: Absolutely

K: so that’s a fantastic suggestion thank you, could I just ask as well how you found out about this study in the first instance

P: Erm, I remember something definitely came up, it must of come up on social media, or I must had an email about it, somehow, it was definitely computer related, well, did it come from X, do you have any dealings with them

K: I do yes, they have been doing some advertising for me and a number of other charities have as well, including C.

P: it might have been them as well, so it might have been X or actually now you have said X I think it was X because I must have been on their Facebook page, I liked their page because they donated a X to my son and I follow their page as quite a few friends have raised some money for them

K: yes they everyone that received a X from them, because they have a mailing list they then emailed everybody on their mailing list who received a bike so that’s probably how it came through to you, that’s good to know – obviously we have been trying a number of different methods either by posting things on social media and twitter but getting charities to post things and tweet and obviously email via mailing lists and things, do you think there’s any other ways that it could have been better advertised to make parents aware?

P: I think that when things come through the door people just have a tendency to put it in the bin (laughs) but I think being blunt I think the best way is text message, is a really good way because people are attached to their phones all of the time and its definitely for instance as I was saying earlier I am chair of the X for our X our X has all of the parents phone numbers to text and we have had lots more response that way than we ever had from a flyer in a child’s book bag so that’s a really good way and again social media, I think face book is a really good way and so parenting up with X who have a massive presence on Facebook who pretty much anyone’s child who has been diagnosed would have liked their page you know are going to get the information that way

K: Hmm they have been really helpful, that’s brilliant thank you, and I am very sorry that the way the first bit of the information was worded that it was kind of confusing and not clear really as obviously you would have been eligible for the study and obviously if you still feel like you would still like to complete the workbook, your very welcome to, just let me know.

32 minutes and 2 seconds

I thanked the participant for their time and advised them that I would send them their £10 amazon voucher immediately via email as a thank you for their time.
## Appendix 13. Summary table of participants A-D’s individual scores over time on all outcome measures

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Appendix 14. Feedback provided from participants over the course of the intervention, final follow-up and via email

**Weekly feedback**

**Week 1**

Participant A: 28/01/2016

*It was interesting looking at the patterns of behaviour. Next week isn't a chemo week so it will be interesting to do a comparison to see if the same problems arise and also my responses to them.*

Participant B: 16/02/2016

*I have been focusing on the part of the book that talks about the concept of my behaviour influencing theirs and as such have been trying not to shout and get angry when the children don't do what they are told or when they tantrum. Instead I have been trying to remain calm and use phrases such as 'how can I help you' or 'I'm ready to listen to you when you have calmed down'*

Participant C: 29/02/2016

*I have previously worked in Early Years education and am already familiar with the Triple P programme. However, I have never been in the role of 'participant' before. It is very useful to be re-reminded of some of the information and techniques because, in my role as a parent, it is all too easy to forget the advice I have given other people!*

Participant D: 25/04/2016

*The models for recording behaviours were useful and the First Chapter gave a lot of room for reflection and helping to begin to ascertain the types and causes of certain behaviours of both child and parent.*

**Week 2**

Participant A: 04/02/2016

*The ask, say and do works really well. I was so surprised at how quickly it made an impact on our morning routines as that has always been a site of contention.*

Participant B: 28/02/2016

*It's made me think about my own behaviour and how to control that in an attempt to reduce her tantrums and shouting.*

Participant C: 01/04/2016

*The 'Ask, Say, Do' has been a good reminder of a constructive way to lay out instructions and check understanding - particularly useful when feeling frazzled with day-to-day tasks and patience is running a bit thin!*

Participant D: 03/05/2016
Tried to spend more quality time doing child initiated play and also letting child choose activities. Also managed to do more day to day things due to child's health condition this week.

Week 3
Participant A: 12/02/2016
This week has been quite a difficult one as x has been away and it it x’s 4th birthday so it has been quite an over excited household. I only had to use quiet time once.

Participant B: 07/03/2016 NONE

Participant C: 18/04/2016
Despite an extensive background in working with children, your own often know which buttons to press far more successfully than other people's! This has been a great reminder of techniques to help step back and think about incidences of difficult behaviour more calmly. A very worthwhile resource for the future. Thank you.

Participant D: 09/05/2016
Using charts from earlier chapters to monitor behaviours and strategies for dealing with misbehaviour.

Week 4
Participant A: 18/02/2016 NONE
Participant B: 16/03/2016
My daughter has been particularly bad this week and last so I don't know whether this will skew your results... It's been difficult trying to implement anything as it's been difficult to find any good behaviour to reward and using time out continually would simply mean her living there and never being able to get on with things as she's refusing to listen to anything at all!

Participant C: 02/05/2016 NONE

Participant D: 17/05/2016
Used and monitored positive parenting strategies. From this, was able to identify Strengths & areas to develop in parenting.

Week 5
Participant A: 28/02/2016
The workbook has been good at reassessing how I deal with good behaviour as well as bad. I have struggled with some of the exercises because of chemo weeks where everything is uncertain and my son can get incredibly tired and just need rest. He isn't naughty during these periods just exhausted.
Participant B: 17/04/2016

Although in theory the book makes sense and I agree with much of it. I do find that putting it into practice isn't always practical. For example, when out and about, it's very difficult to use time out or quiet time.

Participant C: 09/05/2016 NONE

Participant D: 23/05/2016 NONE

**Week 6**

Participant A: 06/03/2016 NONE

Participant B: 13/05/2016 NONE

Participant C: 21/05/2016 NONE

Participant D: 01/06/2016

Still continuing to use the strategies selected. Also attending school a small amount has had a positive effect on behaviour and positive character traits

**Week 7**

Participant A: 11/03/2016

I have been ill this week so have to roll over the exercises until I'm better. Sorry.

Participant B: 07/06/2016 NONE

Participant C: 06/06/2016 NONE

Participant D: 12/06/2016 NONE

Using strategies to help, x was able to have his 32nd MRI Scan without anaesthetic for the first time although the run up to the scan and awaiting results has seen him being more anxious than usual.

**Week 8**

Participant A: 24/03/2016

Sorry I'm so late posting this. It has been a busy week.

Participant B: 29/06/2016 NONE

Participant C: 17/06/2016 NONE

Participant D: 19/06/2016

Using strategies for planned activities have noticed improvement. Found discussing the plans with son has had a positive impact also.
Week 9
Participant A: 03/04/2016 NONE
Participant B: 10/08/2016 NONE
Participant C: 01/07/2016 NONE
Participant D: 03/07/2016

Has been more challenging even though implementing routines and strategies. Possible due to x returning from work overseas after a month away and breaking up for summer school holidays so lots of disruption to routine.

Week 10
Participant A: 11/04/2016

It has been an interesting experience. I have taken aboard more of the encouraging aspects as I lacked this some times and it has helped me get closer to the children.

Participant B: 25/08/2016 NONE
Participant C: 10/07/2016 NONE
Participant D: 10/07/2016

The workbook reinforced a lot of the strategies we used but made me more mindful of using them consistently and as a regular method of handling behaviour.

Final Follow-up
Participant A: 12/05/2016

My son has been ill this past month which has been stressful. He didn't bounce back from chemo very well and then developed a cough which meant extra trips to the hospital to ensure it wouldn't progress to anything dangerous to him. He has also had a lumbar puncture with chemo. He has coped so well despite continually feeling rotten. He doesn't really misbehave when he isn't feeling right but it is a worry all the same.

Participant B: 20/09/2016

Although the techniques in the book are good, putting them into practice is very difficult when stressed or particularly annoyed with the disruptive behaviour. However, simply reading the book has helped me bring the way I deal with the children's disruptive behaviour to the fore, which consequently has (hopefully!) improved the way I deal with it. So regardless of whether I put the techniques into practice, simply being more aware, is helpful.

Participant C: 08/08/16 NONE

Participant D: 06/08/2016

The workbook and strategies do work when used consistently. There are time when I notice my child is not so cooperative during periods of anxiety (recently his friend from
hospital passed away) and during disrupted routines such as school holidays but after identifying these have used strategies to help.

**Other feedback provided by email**

Although I appreciate the gesture you really don't have to give the voucher. The study has been really eye opening and I'm grateful to have taken part.
Appendix 15. Initial results from a survey conducted by clinicians at the Royal Manchester Children's Hospital Oncology service

**Parenting children with cancer**

- **Phase 1** - Identify specific parent needs
- **Phase 2** - Parent advisory groups to establish content
- **Phase 3** - Piloting of materials and approach
- **Phase 4** - Trial of chosen Triple P approach

**Preliminary survey results: 55 parents**

- 78% leukaemia
- 6% brain tumour
- 9% lymphoma

Do you think parents should routinely be given information about parenting support available following a child’s diagnosis with cancer?

97% Yes

(Hurrell)
Parents want support with:

<table>
<thead>
<tr>
<th>Item</th>
<th>Percent of sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting back to normal after diagnosis and treatment</td>
<td>82%</td>
</tr>
<tr>
<td>Returning to school and help at school</td>
<td>71%</td>
</tr>
<tr>
<td>Child’s mood</td>
<td>57%</td>
</tr>
<tr>
<td>Changes in mood/behaviour when on steroid treatment</td>
<td>49%</td>
</tr>
<tr>
<td>Meal times and eating</td>
<td>49%</td>
</tr>
<tr>
<td>Tantrum behaviour/angry outbursts</td>
<td>43%</td>
</tr>
</tbody>
</table>

Interest in delivery formats

![Bar chart showing interest in delivery formats](chart_image)
What barriers, if any, would get in the way of you participating in parenting support interventions?

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would not meet our needs</td>
<td>6</td>
</tr>
<tr>
<td>Difficult to get to hospital</td>
<td>10</td>
</tr>
<tr>
<td>Not enough practical support</td>
<td>4</td>
</tr>
<tr>
<td>Improvements not needed</td>
<td>2</td>
</tr>
<tr>
<td>Get too upset</td>
<td>2</td>
</tr>
<tr>
<td>Don't have time</td>
<td>14</td>
</tr>
</tbody>
</table>