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**Mothering a young child with intestinal failure on parenteral  
nutrition: an interpretative phenomenological analysis**

**and clinical research portfolio**

**Volume 1**

(Volume 2 bound separately)

**Leah Cronin**

Submitted in partial fulfilment towards the degree of Doctorate in Clinical Psychology  
(DClinPsy)

University of Glasgow, College of Medical, Veterinary and Life Sciences

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This is for Graeme.

## **CHAPTER 1: SYSTEMATIC REVIEW**

### **Adolescent lived experience of inflammatory bowel disease: a systematic qualitative review**

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## ABSTRACT

**Background and aims:** Inflammatory bowel disease (IBD) has psychological and social implications for developing adolescents, but there is evidence that adolescents can adapt and cope. Qualitative research has aimed to elucidate how adolescents experience this process of challenge and coping; to date, results have not been synthesised. This review aims to systematically examine qualitative studies of the adolescent lived experience of IBD.

**Methods:** Meta-ethnography was used to select and synthesise the studies. Articles were searched for in EMBASE, MEDLINE, CINAHL, PsychINFO, Web of Science and Google Scholar. Reference lists and journals of selected articles were also hand searched. Four studies and two theses were identified for inclusion. Quality was assessed using a rating scale based on an existing quality rating framework.

**Results:** Five themes were identified: (1) physical impact and barriers; (2) psychological impact: the private self; (3) interpersonal impact: the private and public self; (4) coping; and (5) growth. Together, these themes suggest that adolescents experience considerable challenges as they negotiate developmental tasks of developing their identity, gaining independence, and forming relationships. Coping and growth occurs as a result of various individual and interpersonal strategies.

**Conclusions:** Health and education professionals should remain aware of the impact of this disease on adolescents. Collaboration with adolescents and flexibility in response to the changing status of the disease is indicated. Future research could identify specific strategies to up-skill adults in supporting adolescents.

**Key words:** Qualitative systematic review, lived experience, inflammatory bowel disease, adolescent, coping.

## INTRODUCTION

### **Inflammatory bowel disease**

Ulcerative colitis (UC) and Crohn's disease (CD) are collectively known as inflammatory bowel disease (IBD). IBD is a chronic, debilitating and unpredictable condition; symptoms include abdominal pain, diarrhoea, nausea and lethargy (1). IBD impacts on critical areas of development, including weight and linear growth, and puberty/sexual development (2,3). Depending on illness course and severity, individuals can experience frequent school absences, restricted movement, and reduced food choices (4,5). It is estimated that one person in every 250 in the United Kingdom experiences IBD; the most common age for diagnosis is between 10 and 40, with 20 – 25% of sufferers diagnosed during childhood and adolescence (1,6). IBD is equally distributed across gender, and is more prevalent in Caucasians and in urban areas with higher socio-economic status (7-10). Incidence of IBD is increasing, especially in the paediatric population (11-13). Due to the lower incidence of IBD in developing countries, it is suggested that lack of exposure to childhood infections or unsanitary conditions prevents the development of immunity to harmful bacteria (11).

### **Impact of IBD on well-being**

IBD has been associated with psychological morbidity, particularly in individuals with stomas<sup>1</sup> (6,14-17). A meta-analysis of 19 quantitative studies (n = 1167 adolescents) explored psychosocial adjustment in adolescents with IBD compared with healthy cohorts and adolescents with other chronic illness (7). Effect size estimates were calculated for anxiety symptoms and disorders, depressive symptoms and disorders, internalizing symptoms and disorders, externalizing symptoms, quality of life (QoL), social functioning, and self-esteem. Results indicated that youths with IBD had higher rates of depressive disorders and internalizing disorders than youth with other chronic conditions. In addition, they had higher parent-reported internalizing symptoms, lower

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<sup>1</sup> Stoma: This is an artificially created passage for bodily elimination

parent- and youth-reported QoL, and lower youth-reported social functioning compared to healthy adolescents. Another study (6) used semi-structured interviews to elucidate the challenges experienced by children and adolescents with IBD (n = 80, mean age = 13.3 years, range: 7 to 19 years). Themes of distress included IBD-related concerns, vulnerability, lack of control, and negative self-perception. Severity of disease was associated with increased levels of reported distress. Lindfred et al. (2) explored disease-related questions of relevance with adolescents with IBD using a specifically designed questionnaire; a subgroup of the 67 Swedish adolescents reported high disease activity and low satisfaction with their situation.

### **IBD: adherence and coping**

Research indicates that, while children and young people with IBD can struggle to adhere to treatment, adherence is enhanced by family support and positive parent-child relationships (18). In a recent systematic review of 39 published studies exploring coping strategies of both child and adult patients with IBD, strategies were categorised as representing solution or emotion-focused approaches (19). The analysis indicated that solution-focused coping was weakly associated with better psychological outcomes. Adolescence represents a period of development in which specific milestones and challenges must be negotiated (20). In addition, it has been noted that IBD presents more extensively and severely in children and adolescents than in adults (21,22). Consequently, the combined consideration of the coping styles of children and adults may not have allowed for adequate exploration of adolescent experience (19).

### **Qualitative research in IBD and adolescent chronic illness**

While quantitative research indicates that there are elevated levels of distress in adolescents with IBD compared with other chronic illness, it does not explore the individual experience of this distress, and the meaning that adolescents make of their experience. Qualitative research is useful in eliciting idiosyncratic experiences of chronic illness; it is increasingly employed in healthcare research to facilitate awareness of individuals' lived experience. Systematic review and synthesis of findings from such papers generates more comprehensive results (23). A recent systematic review of six

published studies and one unpublished thesis investigated health and social needs of adults with IBD (24). The review identified three main categories of impact including: “detained by the disease” (e.g. the fear of incontinence), “living in a world of disease” (e.g. the effects of living with a chronic condition) and “wrestling with life” (e.g. the “push” to continue normal living). Sargeant et al.’s (25) qualitative study exploring experiences of adolescents with IBD indicated that the disease forced adolescents to negotiate private matters in the public domain. Furthermore, a qualitative literature review of 20 studies examining the experience of living with a chronic illness during adolescence revealed that specific areas can be affected; these included “developing and maintaining friendships” and “experiences of school” (26).

### **The current study**

There are unique characteristics to the presentation, clinical phenotype, and management of adolescent IBD compared with adult or child IBD. Accordingly, it has been recognised that specific evidence for appropriate practice with adolescents is required (27). Synthesis of quantitative research into adolescent IBD has indicated that this population has increased levels of psychological morbidity. Qualitative research has striven to explore the idiosyncratic factors underlying this increased distress, and to explore the individual experience of living with and managing IBD during adolescence. This has been achieved through direct research with adolescents and retrospective research with adults, whereby adults with IBD have reflected on their past experiences of adolescence. To date, this literature has not been synthesised. In order to understand the aspects of IBD that individuals who have experienced IBD during adolescence have identified as important, it would be useful to synthesise existing qualitative research and analyse its<sup>2</sup> quality.

### **Aims**

- to appraise the quality of qualitative research exploring the experience of adolescents with IBD
- to synthesise the challenges faced by adolescents with IBD and the associated coping strategies they employ

## METHODS

### Systematic Search Strategy

It is recognised that qualitative research is difficult to identify using electronic databases, and bibliographic database indexing systems' thesaurus terms are not transferable to qualitative research (28-30-29). In addition, synthesis of qualitative literature can require the researcher to explore "grey" literature (28). Comprehensive search strategies utilising broad and inclusive search terms, while retaining transparency and replicability of the process, are considered good practice (31,32). A broad search strategy using free text was employed, in addition to index terms where possible, to increase the opportunity of identifying relevant material. The following search engines were utilised: Medline (Ovid), Embase (Ovid), CINAHL (EBSCO), PsychINFO (EBSCO), Web of Science (Web of Knowledge) and Google Scholar. Limits were not placed on time span to ensure comprehensiveness of the search. Boolean operators (OR and AND) were used to combine search strings. The same search terms were entered into Google Scholar to find additional papers; this search was stopped after 100 pages of results as there had not been any novel studies identified. The search was conducted between 10/01/13 and 20/01/13.

The search terms and strategy used were as follows:

1. Child and adolescent mapped to index term and exploded OR child\* OR adolescen\* OR paediatric\* OR pediatric\* OR teenage\* OR juvenile\* OR minor\* OR youth\* OR young person OR young people
2. IBD OR inflammatory bowel disease OR ulcerative colitis OR Crohn's disease
3. Qualitative research OR qualitative stud\* OR interview\* OR experience\*

Studies retrieved in the electronic search were assessed against the following criteria:

#### *Inclusion criteria*

- participants have experienced IBD during adolescence and are discussing this experience during adolescence and early adulthood

- qualitative methodology and analysis employed
- explored the experiences of adolescents (including from secondary-school age through to late adolescence) in relation to their IBD
- published in the English language
- data has been subjected to a full analysis

#### *Exclusion Criteria*

- employed quantitative methodology
- included other chronic illness in their exploration, such that the experiences of the participants with IBD could not be distinguished
- included the views of parents in their research such that the views of the participants with IBD could not be distinguished
- had already been included in the 2012 adult meta-synthesis (24). This decision was taken to avoid replicating results.

A two-step process was utilised including: (1) title and abstract review, (2) full text review. Twelve studies were identified as a result of stage 1. Two were rejected due to containing parent and adolescent data, two contained data from adolescents with numerous chronic illness, one contained child and adolescent data, and one study stated explicitly that “full analysis” had not been conducted on the data. Six studies were therefore deemed suitable as a result of this process (33-38). In order to increase the sensitivity of the search, the reference lists from each of the six studies were manually reviewed. This initially yielded a further study, which on closer inspection did not meet inclusion criteria. Finally, the journals from which the final studies were derived were hand searched; this did not yield any further appropriate studies (Appendix 1.2 provides a flowchart of this process).

#### **Quality of Studies**

The challenge of appraising the quality of qualitative research has been rooted in larger epistemological debates concerning the nature of knowledge gleaned from such research (39). Given the multiplicity of theoretical and philosophical underpinnings in the various qualitative methods of analysis, a unified and consistent approach to standard

setting has been difficult to develop (31,40). Despite on-going debate, there have been multiple attempts to develop assessment tools that address traditional indicators of quality in research (41). The level of detail in these tools has been described as not “workable”; accordingly, Walsh & Downe (30) used a redundancy approach to categorise criteria from eight existing qualitative appraisal tools into those considered ‘essential’, ‘desirable’ and ‘optional’. Having extricated the most useful criteria, the authors synthesised them into a single, inclusive guide. The resulting framework consists of eight main stages of focus: scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and relevance/transferability.

An adapted version of the Walsh & Downe (30) tool (Appendix 1.3) was employed for the purposes of this meta-ethnography; each study was compared with 29 criteria. Criteria were not employed to exclude studies from the meta-ethnography, given the difficulty in defining fundamental flaws in qualitative research. Instead, the framework allows for a general discussion of quality. Verification of the reliability of the marking was provided by the contribution of a second reviewer<sup>2</sup> who independently marked each paper. Discrepancies were resolved through discussion and reflection.

### **Meta-synthesis**

Meta-synthesis refers to the process of collating, analysing, and interpreting of data from more than one qualitative study; the term refers to a variety of approaches. One such approach, meta-ethnography, was employed in the present review. Meta-ethnography is based on the work of Noblit and Hare (42) and is a popular approach for the synthesis of healthcare research; it allows for the synthesis of data collected using multiple approaches and the production of a new line of argument (43). The process involves a number of steps which are summarised in the following table, taken from previous work (22).

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<sup>2</sup> A second Trainee Clinical Psychologist

**Table 1: Stages of meta-ethnography**

Stage	Description
1) Getting started	<ul style="list-style-type: none"> <li>• Determine research question</li> </ul>
2) Deciding what is relevant to the initial interest	<ul style="list-style-type: none"> <li>• Defining the focus of the synthesis</li> <li>• Locating relevant studies</li> <li>• Making decisions about inclusion</li> <li>• Quality assessment</li> </ul>
3) Reading the studies	<ul style="list-style-type: none"> <li>• Become familiar with the content and detail</li> <li>• Begin to extract ‘metaphors’ or emerging themes</li> </ul>
4) Determining how studies are related	<ul style="list-style-type: none"> <li>• Create a list of themes and metaphors</li> <li>• Juxtaposition of above</li> <li>• Determine how themes are related</li> <li>• Reduce themes to relevant categories</li> </ul>
5) Translating studies into one another	<ul style="list-style-type: none"> <li>• Arrange papers chronologically</li> <li>• Compare paper 1 with paper 2, and the synthesis of these papers with paper 3 and so on</li> </ul>
6) Synthesising translations	<ul style="list-style-type: none"> <li>• Third order interpretation leading to a line of argument synthesis</li> </ul>
7) Expressing the synthesis	<ul style="list-style-type: none"> <li>• Presentation of results</li> <li>• Publication of findings</li> </ul>

## RESULTS

### Quality Appraisal

In general the scope and purpose of the research was well presented. Each study provided a clear focus, rationale, and explicit statement of purpose. Studies were situated within the context of existing theoretical and empirical literature, and linked

their research to existing knowledge; three studies made explicit reference to having undertaken a literature review (33-36).

Study designs were consistent with research intent and contained a rationale for adopting a qualitative approach; only the two theses made explicit reference to epistemological grounding (33,34). All but one study (38) provided a rationale for their specific choice of qualitative method. Methods of data collection were apparent and appropriate. Two of the studies used triangulation of their data sources (33,35).

The quality and appropriateness of sampling strategies was difficult to assess; only three studies provided specific inclusion criteria and justified their sampling strategy (33,34,36). Study samples were likely to provide thickness of description. Diener (34) experienced difficulty in obtaining her desired sample size of five to seven participants; consequently she recruited three participants and revised her study design. Notably, Diener (34) had a previous relationship with her participants, which she explicitly stated.

Studies appeared to employ appropriate methods of analysis. Diener's (34) auto-ethnographic inclusion of her own account with that of her participants may have benefitted from the input of a second researcher. Only Nicholas et al. (35) discussed seeking deviant data during analysis. Saturation of data was referred to by two studies (37,38). Authors made reference to grounding themselves in the data and re-referring to it during analysis. Finally, two studies (33,36) made explicit reference to the use of field-notes in retaining context during analysis.

Transparency of interpretation varied. Study contexts were not explicitly explored in the articles; only Haas (33) and Diener (34) reflected on the potential impact of embarrassment in relation to the subject matter. Sufficient detail was given by most studies regarding process of analysis replication; in particular Reichenberg et al (37) and both theses (33,34). Studies contained verbatim quotes to support interpretation. Reflexivity was not described in the research articles, although two authors (37,38) made reference to their clinical involvement in IBD. Both theses authors reflected on the impact of their own experiences with chronic illness (33,34).

Most studies, bar Brydolf & Segesten (38), had received approval from an Ethical Committee. Consent was discussed in each study, although lack of detail made it

difficult to ascertain whether the studies operated on an “opt-out” or “opt-in” basis. Two studies did not discuss confidentiality (35,37). In general, both theses (33,34), perhaps because of increased word capacity, devoted more space and reflection to ethical considerations than the four articles.

Finally, the relevance and transferability of findings were sufficiently explored. Results were grounded in existing theory and conclusions were supported by both the results and existing evidence. Only two studies (33,36) explicitly reflected on study limitations. Each study related their findings to either policy or practice, and five studies made reference to potential future research (33,34,35,36,38).

### **Meta-ethnography**

Studies were subjected to the process of meta-ethnography. Table 2 depicts the chronological arrangement of the papers, along with their themes and contextual information concerning: study methodology, participant information, country of study and focus of the paper. The process of meta-ethnography led to the establishment of five over-arching categories of relevance for adolescents with IBD. The categories are inter-related and represent the impact of IBD across various domains of adolescent experience:

1. Physical impact and barriers
2. Psychological impact: the private self
3. Interpersonal impact: the private and public Self
4. Coping
5. Growth

**Table 2: Selected study details and themes ordered by year of publication**

<b>Author (Year) Study type</b>	<b>Number, (age range), diagnoses, and gender of participants</b>	<b>Country</b>	<b>Focus</b>	<b>Data collection method and analytic approach</b>	<b>Themes</b>
Haas (2012) Thesis	7(aged 13 - 17) with CD 2 females, 5 males	Canada	Experiences of adolescents with CD using resilience framework	Interviews Narrative enquiry	<ul style="list-style-type: none"> <li>• Unconditional support</li> <li>• Embracing and accepting differences</li> <li>• Attitudes/personal beliefs</li> <li>• Daily coping strategies</li> </ul>
Diener (2011) Thesis	3 (aged 11 - 16) with IBD Gender not provided.	Canada	Adolescent experiences of IBD	Interviews Thematic analysis, auto- ethnographical accounts (discourse analysis of published and online material not included in current review)	<ul style="list-style-type: none"> <li>• (Not) being Ill</li> <li>• Being normal</li> <li>• Being young</li> </ul>
Nicholas et al (2008) Article	20 (aged 13 – 19) with IBD  11 females, 9 males  N in focus group = 7  Gender ratio in focus group not provided.	Canada	Experiences of adolescents with IBD and an ostomy	Interviews and focus group. Content analysis	<ul style="list-style-type: none"> <li>• Body intrusion and body image challenges</li> <li>• Decreased Independence and control</li> <li>• Secrecy: considerations in deciding whether to tell others about the ostomy</li> <li>• Adjustment over time</li> <li>• Challenges for the family</li> <li>• Sources of strength: family and friends</li> <li>• Benefits and growth</li> </ul>

UC: Ulcerative Colitis; CD: Crohn’s Disease; IBD: Inflammatory Bowel Disease

<b>Author (Year) Study type</b>	<b>Number, (age range), diagnoses, and gender of participants</b>	<b>Country</b>	<b>Focus</b>	<b>Data collection method and analytic approach</b>	<b>Themes</b>
Savard & Woodgate (2008) Article	6 (aged 19 – 24) with IBD, 5 females, 1 male	Canada	Experiences of living with UC and ostomy	Interviews. Thematic analysis	<ul style="list-style-type: none"> <li>• Essence: Concealing and revealing the self</li> <li>• Uneasy feelings</li> <li>• It's hard</li> <li>• Renewed sense of self</li> </ul>
Reichenberg et al (2007) Article	17 (aged 12 – 18) 7 females, 10 male 10 UC - 7 CD	Sweden	How adolescents with IBD respond to experiences of parental concern	Circular Interviews. Grounded theory	<ul style="list-style-type: none"> <li>• Ambivalence</li> <li>• Ability/inability</li> <li>• Compliance/resistance</li> <li>• Trust/distrust</li> </ul>
Brydolf & Segesten (1996) Article	28 males and females with UC (aged 11 – 31) Gender ratio not provided.	Sweden	Living with UC	Interviews. Grounded theory	<ul style="list-style-type: none"> <li>• Alienation</li> <li>• Reduced living space</li> <li>• Support</li> <li>• Lack of support</li> <li>• Confidence in self</li> <li>• Disbelief in self</li> <li>• Role identification (child or patient)</li> <li>• Role as adult</li> </ul>

UC: Ulcerative Colitis; CD: Crohn's Disease; IBD: Inflammatory Bowel Disease

The following is a description of the five categories, with verbatim data to illustrate.

### **1. Physical impact and barriers**

Studies revealed the physical impact of IBD symptoms, including agonising cramps, flatulence, lethargy, diarrhoea, impaired growth, vomiting, and acid reflux (33-38). The impact of IBD medication was evident; participants experienced weight gain, acne and bloating. Every study, excepting Reichenberg et al. (37), discussed the impact of IBD treatments, including stomas and naso-gastric feeding. Participants appeared concerned as to the aesthetic impact, noise, and smell incurred by these treatments.

Five studies (33-36,38) exposed the restricting nature of the physical impact of IBD for adolescents. Frequent hospitalisations due to changing health status meant adolescents were kept physically apart from others. Self-imposed isolation because of fear of the impact of socially un-desirable symptoms emerged as a barrier to accessing sporting or social activities, or to achieving academically. Similarly, some adolescents highlighted that they were prevented from engaging fully in social events in which alcohol was consumed (34). Developing adolescents were frequently physically compromised and isolated.

*“I had all that anxiety about, you know, having to know where all the bathrooms were and having to be prepared for accidents and things like that, I really felt like my ulcerative colitis controlled what I could do and where I could go and when I could go...it definitely, um, definitely had a big control over my life.” (36, pg. 38).*

### **2. Psychological impact: the private self**

Studies highlighted the emotional impact of IBD. Shame, a sense of being different, and fear of evaluation by others emerged as important themes in most studies (33-36,38). Fear was expressed in relation to the long-term physical and social consequences of IBD (33,34,38). Frustration at the unpredictable and limiting nature of the illness was evident. Disappointment also emerged in relation to missed opportunities and multiple failed

treatments (33,34,36,38) as did a sense of guilt at the restrictions IBD placed on family members (35,38).

The impact of IBD on adolescents' body image and self esteem was a recurring theme throughout most studies, excepting Reichenberg (37). A sense emerged of young people who were conscious of being socially undesirable. Four studies cited poor body image and body modification (stomas) as mediating factors in adolescents' ability to form and maintain romantic relationships (34,35,36,38). Reduced choices and opportunities to excel may also have contributed to this sense of self as being "less". Absences from school and training appear to have prevented some young people from achieving academically or extra-curricularly (33,34,35,36,38). In addition, the self-imposed restrictions of young people contributed to their reduced sense of social success (33,34,35,36,38). .

*"I wish I was taller and I feel like the Ulcerative Colitis may have done something to that so that frustrates me a lot um, for basketball but also like for looks. I wish I was taller"*  
(34, pg. 58).

The notion of agency and competence emerged from the data. The debilitating impact of IBD meant that adolescents received more intimate care support from parents than their non-IBD peers. Whether this input was experienced as supportive or restricting of independence appeared to depend on the stage of the illness, and the interaction style of the family (33-38). When parents and medical staff were perceived as excluding adolescents from decision making, adolescents felt infantilised and disempowered (34,35,38). Conversely, growth and adaptation lead to positive self-esteem and purpose; this will be explored in more detail presently.

*"I wasn't allowed to participate in the decision regarding surgery, I wasn't prepared for the consequences. I get angry even now when I think about it."*(38, pg. 44)

### 3. Interpersonal impact: negotiating the private and public self

IBD appeared to mediate adolescents' experience of relationships with family members, peers, teachers and medical staff. The illness required parents to offer extensive psychological and pragmatic support (33 - 38). Reichenberg's (37) finding of the ambivalence that adolescents felt towards this parental support was evident throughout most studies, with adolescents simultaneously appreciating and resenting parental input (33-38). Examples were also given of explicit positive appreciation (33) and resentment of (34,38) parent responses and, overall, experience was mediated by the quality and nature of relationships. A unique aspect of the parent-adolescent relationship was that it allowed adolescents to present their true, vulnerable self; this differed from the public self presented outside the home.

*"They ask you nearly every day how you're doing, whether you've got any stomach problems or anything. They worry about every little thing – should we go to the hospital or something? That's what it's like. It feels as if they nag a bit, but in some ways I think that's good too."*

*(37, pg. 479)*

Three studies explored positive sibling relationships; siblings who also have IBD were referred to as especially supportive (33,35,36). The negative impact that IBD can have on siblings who may receive less attention than their siblings with IBD was discussed (35,38). Furthermore, Brydolf & Segesten (38) revealed some adolescents' awareness that they were given less responsibility than their non-IBD siblings.

*"I think for siblings, it is really difficult. You really need to talk to them and make them feel as if they are needed, and to address their problems. When you have an illness in the family it takes away from a lot of the other siblings, and they also need care"* (35, pg. 5)

Peer relationships presented a particular challenge for these adolescents as they negotiated their developmental tasks of engaging in education and forming their identity. A strong theme emerged from studies, excepting Reichenberg et al. (37), of the distinction between the public and the private self with peers. Adolescents varied the amount of information that they presented to other adolescents in a bid to preserve their social standing.

Poor body image and imagined or actual experience of rejection appeared to maintain the presentation of normality to peers (33, 35,36,38). The issue of IBD as a challenge to overcome when negotiating intimacy in romantic peer relationships was discussed in four studies (34,35,36,38). Some adolescents who strove to engage in normal adolescent interaction, regardless of health status, reported deleterious results for their health. Increased self-acceptance appeared to be associated with an increased willingness to integrate IBD into relationships (33,35,36).

*“I wouldn’t have kind of called acquaintances and told them about it. I think it’s because a lot of people don’t talk about colons or going to the bathroom and it is very hush hush, you don’t hear a lot about it. And it’s kind of embarrassing. I didn’t want too many people to know” (35, pg. 36).*

Relationships with medical staff were characterised as both positive and negative (33,34,35,38). Interactions with teachers emerged as important factors in the adolescent experience. Teachers who were flexible in response to the unpredictable course of the illness were discussed in positive terms (33,34,38). In contrast, some participants found it difficult to have their positions acknowledged or understood by their teachers, in the classroom, and during exams (34,38). Uniquely, Diener (34) identified that some adolescents did not wish to avail of any special academic allowances.

*“If I wasn’t feeling good and had to use the washroom and had to leave [the classroom], they were good about that” (33, pg. 94).*

#### **4. Coping strategies**

Weaving through the studies were examples of the coping strategies employed by adolescents and others (33-38). The relative success of these coping strategies appeared to be mediated by the previous three themes of physical, psychological, and interpersonal experience. Strategies appeared to take three forms: psychological, problem-focused, and interpersonal. As has been explored, adolescents’ minimised or denied the physical and psychological impact of IBD to present a “normal” self to others. In addition, some participants described that they would

employ distraction to deal with the impact of their pain, or make a conscious decision to focus on something non-IBD related (33,34,35). Reappraisal of their own situation and downward social comparison emerged as ways of psychologically negotiating the impact of the illness (33-36,38). Adolescents appeared to reduce the expectations they placed on themselves to accommodate disease impact. Positive social comparison was made between themselves and other adolescents with IBD or other chronic illness (33-36,38). One study suggested this minimisation was not a wholly positive phenomenon, but was partially a manifestation of the pressure experienced by adolescents to appear socially desirable (34).

*“Sometimes I find that for other kids they don’t have as supportive of a background as me. So they find it a lot more difficult to deal with Crohn’s and for me it’s just another thing, really”*  
(33, pg. 105).

Inter-personal strategies were explored in all of the studies. Parents and peers provided support during administration of medical procedures. The theme of similar others emerged (33-35). Some participants deliberately sought out the normalising experience of being around similar others in the clinic, or on-line. Reference was made to the positive impact of knowing family members with IBD (33). Conversely, some adolescents preferred not to align themselves with the IBD adolescent community; this decision was associated with preserving a sense of normality, and was especially prominent during less symptom-laden periods of the illness (33).

*“I think when I just got diagnosed, I think I was part of, like, a web forum for people with Crohn’s and...at the time it was helpful because I didn’t know how I was really going to know...anything, especially...when I started NG [nasogastric] tube feeding ‘cause other people there had gone through it and it’s not, like, something a 12 year old really”* (33, pg. 100).

Practical coping skills, advocacy, and adopting a pragmatic approach emerged as helpful approaches in managing the impact of IBD (33-38). Adolescents provided information as to their needs and the impact of their illness to teachers and lecturers; parents and teachers also fulfilled this duty for younger adolescents. Research into management strategies, such as diet, was discussed.

*“My mother told my teacher about my disease and later on my teacher told my class I was there when she told them I didn’t need to say anything because I found her capable of informing them” (38, pg. 43).*

## **5. Growth**

Post-traumatic growth, and the development of skills and positive attributes, emerged explicitly from all of the studies (33-38) although Reichenberg et al. (37) only focused on growth in terms of the appreciation that adolescents developed for their parents. Adolescents described their enhanced levels of maturity (36-38) and empathy for others (33-36,38). Adolescents’ hard-earned perspective and understanding had guided them towards valued goals and career paths (33-36,38). Some adolescents delivered distinct before and after narratives of how they developed their skills through negotiating IBD; adverse experiences had encouraged an attitude of taking life as it comes.

*“But I think it [ulcerative colitis] was one of the best things that could have happened to me because, uh, I found my career path with it and I also became a better person I think” (36, pg. 39).*

This growth, learning and change in perspective appeared to ameliorate some of the adolescents’ earlier negative experiences. Some participants gained the perspective that the reactions of others were indicative of the measure of that person, as opposed to a realistic reflection of their own value as a person. This led to them using the disclosure of their IBD as a means of ascertaining the quality of relationships, and appeared to protect against the internalising of negative reactions (35,36,37). In general, studies indicated that increased acceptance of self, a sense of hope, and personal growth was associated with successful adaptation to IBD.

*“It’s not so bad because I wouldn’t want to hang around with somebody who thinks ‘oh [she] has something gross’ or ‘let’s not hang around with [her]’. So you find other friends who can take you for who you are, on the inside rather than the outside. That’s better than the other people who can’t accept it.” (35, pg. 4)*

## **DISCUSSION**

### **Public and Private IBD**

The synthesis provides some insight into the experience of adolescents with IBD from early adolescence through to early adulthood. Adolescents appeared to struggle with the unpredictable physical challenges of IBD, as well as the stigmatising aspects of some of the treatments, including stomas and feeding tubes. IBD was sometimes accompanied by psychological distress, difficult emotions, and a sense of dissatisfaction with being different; these findings reflect the elevated levels of psychological distress and lowered levels of social functioning and satisfaction noted in the quantitative adolescent IBD review and other literature (2,7,14,15,16,17). The current findings regarding impacted sense of self, reduced social opportunities, and frustration/powerlessness in regards to disease severity may indicate the aspects of IBD adolescent experience that lead to such problematic levels of distress and social difficulty. Accordingly, these identified aspects may also indicate opportunities for exploration and possible intervention with adolescents with IBD who are struggling psychologically and socially.

Adolescents appeared to invest time and energy into “covering” up their symptoms; a distinction emerged between the public and the private behaviours of the adolescents, echoing previous findings in both adolescent IBD literature (2,25) and the adult IBD qualitative synthesis (24). Self-imposed isolation from others was frequently discussed. Goffman (44) has suggested that withdrawal from social contexts is a means of managing the impact of stigma. For these adolescents, self-imposed isolation may also serve to ameliorate the impact of their lethargy.

### **Concealable stigmas**

Perceived stigma has been identified as influencing psycho-social adjustment to IBD (45). The impact of stigma on identity formation has been previously explored and it has been

hypothesised that concealable stigmas can pose greater threats to psychological well being than explicit stigmas (46). Given the unpredictable nature of IBD, it could be concluded that adolescents are faced with the considerable challenge of negotiating a stigmatising chronic illness that is at times concealable and at times evident. The potential impact of this situation on adolescents' well-being during this crucial period of identity formation should be considered by health professionals, and explored with adolescents.

### **Coping and interpersonal support**

The finding that others can promote coping indicates how adolescents can be supported to adapt to IBD. Adolescents who had felt respected and included in decision-making appeared to have had more positive experiences. The potential for teachers to influence adolescent experience has not been reflected on in the qualitative adult IBD literature, but has been discussed in general paediatric literature (26). Given that adolescents are often in a position of relying on adults in authority, it is vital these adults can appropriately support them. The presence of similar others appeared to be more helpful for some adolescents than others; individual preferences in integrating IBD into identity may mediate this. Adolescents could be made aware of local support groups or on-line resources so that they can access them as and when they deem it appropriate. In general, coping and adaptation appeared to occur through a combination of managing expectations of themselves, adopting solution-focused strategies, and re-evaluating their values and principles. This phenomenon of growth through adversity has been described elsewhere in the adolescent chronic health literature (47). Recognition of this growth and maturity could be demonstrated by allowing adolescents increased autonomy and independence in regards to managing their health.

### **Limitations**

The review has a number of limitations. Four of the studies were published articles; the word limitations imposed by the publishing journals may mean that the end result does not reflect the whole process of the study (48). Four of the six studies were conducted in Canada; this

lack of representation of other countries may reflect the fact that Canada has been noted to have the highest frequency of IBD in the world (12). There was limited information given regarding demographic situations of the participants in the studies; contextual issues such as socio-economic status, quality of healthcare, and pre-morbid quality of interpersonal relationships may all have been influential contextual factors.

Of note, the dearth of literature in this area meant that participants in the study ranged in age from 11 to 31, with adolescent participants commenting on their current experiences and older participants providing retrospective accounts of their adolescent experiences. The use of retrospective reporting remains an area of great debate (49). In addition, the broad age-range made it less possible to extract information that was pertinent to specific developmental stages and tasks of early, mid and late adolescence. It would be useful to conduct research within more specific stages to examine the impact of IBD on the achievement of age-specific developmental tasks, such as individuation and development of romantic relationships.

A sampling bias will be inherent within the data, as it represents the views of those individuals who have agreed to be interviewed. Adolescents who have more extreme perspectives may have been more motivated to participate. None of the studies included non-English speakers; it is possible that cultural context mediates the lived experience of IBD. The synthesis of studies employing different methodologies remains a controversial approach. The decision to include unpublished theses prevented publication bias, however there is continued debate regarding whether so-called “grey literature” should be included in meta-synthesis of qualitative literature (50).

## **Implications**

The results provide a useful addition to the qualitative literature regarding IBD, as well as general literature regarding adolescents with chronic illness. The struggle that adolescents experience to feel confident enough to integrate their private and public selves should be made explicit to healthcare workers. Healthcare professionals could also consider the

potential impact of concerns around body image on adolescents' ability to objectively weigh up the benefits of treatment options, such as stomas. Adolescents could be provided with a forum to discuss the impact of stigma on their sense of identity and self-esteem. Links with similar others, whether on-line or in person, could afford a space to discuss their struggles; this may be particularly pertinent at stages when the disease is most active. Psycho-social support around managing the impact of symptoms may allow adolescents to access greater support from their non-IBD peers.

The ability of adults to alleviate the impact of IBD in the school, hospital and home provides indications for systemic ways of addressing psycho-social adjustment to IBD. Teachers could be provided with information on how to support pupils with IBD (allowing toilet breaks, flexibility with hand-ins etc.). Parents and healthcare workers could be supported to include the adolescent in collaborative decision making. The necessary involvement of adults, with particular reference to parents, in the treatment and management of this disease is one which may present particular challenges to the adolescent developmental tasks of individuation (20). The ambivalence that adolescents feel towards parental support could therefore be normalised in the context of adolescents establishing their identity and independence.

Finally, it has been noted that adolescents can struggle with adherence to IBD treatment regimes (18). It is possible that such struggles to adhere may reflect the findings that some adolescents manage and normalise their experience by "pushing past" and deliberately ignoring or denying IBD symptoms, thereby avoiding limiting their social and personal opportunities. In addition, difficulty with adhering to treatment regimes may reflect the reluctance that some adolescents expressed in relation to being associated with IBD; they appeared to struggle with integrating this stigmatising disease into their identity. The importance of the impact of this struggle could be gently and routinely explored with adolescents in order to normalise their experiences and engage them in meaningful discussions regarding disease and risk management.

## REFERENCES

1. Szigethy E, Levy-Warren A, Whitton S, et al. Depressive symptoms and inflammatory bowel disease in children and adolescents: a cross-sectional study. *J Pediatr Gastroenterol Nutr* 2004;39:395-403.
2. Lindfred H, Saalman R, Nilsson S, et al. Self-reported health, self-management, and the impact of living with inflammatory bowel disease during adolescence. *J Pediatr Nurs* 2012;27:256-64.
3. Decker, J. The effects of inflammatory bowel disease in adolescents. *Gastroenterol Nurs* 2000;23:63–6.
4. Mackner L, Bickmeier R, Crandall W. Academic achievement, attendance, and school-related quality of life in pediatric inflammatory bowel disease. *J Dev Behav Pediatr* 2012;33:106-11.
5. Moody G, Eade J, Mayberry J. Social implications of childhood Crohn's disease. *J Pediatr Gastroenterol Nutr* 1999;28:S43-5.
6. Nicholas D, Otley A, Smith C, et al. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health Qual Life Outcomes* [serial online] May 2007, 5. Available from: doi 10.1186/1477-7525-5-28. Accessed January 20, 2013.

7. Greenley R, Hommel K, Nebel J, et al. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *J Pediatr Psychol* 2010; 35: 857-869.
8. Bernstein C, Shanahan F. Disorders of a modern lifestyle: reconciling the epidemiology of inflammatory bowel diseases. *Gut* 2008;57:1185–91.
9. Baron, M. Crohn's disease in children: this chronic illness can be painful and isolating, but new treatments may help. *Am J Nurs* 2002;102:26-34.
10. Rayhorn N. Treatment of inflammatory bowel disease in the adolescent. *J Infus Nurs* 2001;24:255-62.
11. Molodecky N, Soon I, Rabi D, et al. Increasing incidence and prevalence of the inflammatory bowel diseases with time, based on systematic review. *Gastroenterology* 2012;142:46-54.
12. Cunningham C, Drotar D, Palmero T, et al. Health related quality of life in children and adolescents with inflammatory bowel disease. *Child Health Care [serial online]* December 2007;36:29-43. Available from Lawrence Erlbaum Assoc Inc, Taylor & Francis, PA. Accessed November 09, 2012.
13. Lynch T, Spence D. A qualitative study of youth living with Crohn's disease. *Gastroenterol Nurs* 2007;31:203-31.

14. Engstrom I. Inflammatory bowel disease in children and adolescents: mental health and family functioning. *J Pediatr Gastroenterol Nutr* 1999;28:S238-S33.
15. Rachel Neff Greenley R, Hommel K, Nebel J, et al. A meta-analytic review of the psychosocial adjustment of youth with inflammatory bowel disease. *J Pediatr Psychol* 2010;35:857-69.
16. Erwin-Toth P. The effect of ostomy surgery between the ages of 6 and 12 years on psychosocial development during childhood, adolescence, and young adulthood. *J Wound Ostomy Continence Nurs* 1999;26:77–85.
17. Manworren R. Developmental effects on the adolescent of a temporary ileostomy. *J Wound Ostomy Continence Nurs* 1996;23:210-17.
18. Hommel K, Odell S, Sander E, et al. (2011). Treatment adherence in paediatric inflammatory bowel disease: perceptions from adolescent patients and their families. *Health Soc Care Community* 2011;19:80–8.
19. McCombie A, Mulder R, Geary R. How IBD patients cope with IBD: A systematic review, *J Crohns Colitis* 2013;7:89-106.
20. Erikson E. *Identity: youth and crisis*. New York: Norton; 1968.

21. Goodhand J, Hedin C, Croft N, et al. Adolescents with IBD: the importance of structured transition care. *J Crohns Colitis* 2011;5:509-19.
22. Turunen P, Ashorne M, Auvinen, A, et al. Long-term health outcomes in paediatric inflammatory bowel disease: A population-based study. *Inflamm Bowel Dis* 2009;15:56–62.
23. Atkins S, Lewin S, Smith H, et al. (2008) Conducting a meta-ethnography of qualitative literature: Lessons learnt. *BMC Med Res Methodol* [serial online] April 2008; 8: Available from doi: 10.1186/1471-2288-8-21. Accessed March 15, 2012.
24. Kemp K, Griffiths J, Lovell K. Understanding the health and social care needs of people living with IBD: A meta-synthesis of the evidence. *World J Gastroenterol*, 2012;18:6240 – 49.
25. Sargeant S, Gross H, Middleton D. Public conveniences, private matters: Retrospective narration of adolescent daily life with inflammatory bowel disease. In: *Narrative, Memory & Everyday Life*. Huddersfield: University of Huddersfield; 2005:143-51.
26. Taylor R, Gibson F, Franck L. The experience of living with a chronic illness during adolescence: a critical review of the literature. *J Clin Nurs* 2008;17:3083–91.
27. Markowitz J. Are children with IBD receiving the optimal care? *J Pediatr Gastroenterol Nutr* 2006;43:S43-4.

28. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol* [serial online] July 2008;8(45). Available from doi: 10.1186/1471-2288-8-45. Accessed March 15, 2012.
29. Walters L, Wilczynski N, Haynes R. Developing optimal search strategies for retrieving clinically relevant qualitative studies in EMBASE. *Qual Health Res* 2006; 16:162-8.
30. Barroso J, Gollop C, Sandelowski M, et al. The challenges of searching for and retrieving qualitative studies. *Western J Nurs Res* 2003;25:153-78.
31. Walsh D, Downe S. Appraising the quality of qualitative research. *Midwifery* 2006; 22:108-19.
32. Barbour R, Barbour M. Evaluating and synthesizing qualitative research: the need to develop a distinctive approach. *J Eval Clin Pract* 2003;9:179-86.
33. Haas E. Adolescent perceptions of living with Crohn's disease. Unpublished manuscript (2012), Dalhousie University, Halifax, NS, Canada.
34. Diener, J. Everyone poops but no one wants to talk about it: the lived experiences of young people with inflammatory bowel disease. Unpublished manuscript (2011), Queen's University, Kingston, ON, Canada.

35. Nicholas D, Swan S, Gerstle T, et al. Struggles, strengths, and strategies: an ethnographic study of exploring the experience of adolescents living with an ostomy. *Health Qual Life Outcomes* [serial online] December 2008; 6. Available from: doi: 10.1186/1477-7525-6-114. Accessed January 12, 2012.
36. Savard J, Woodgate R. Young peoples' experiences of living with ulcerative colitis and an ostomy. *Gastroenterol Nurs* 2009; 32: 33-41.
37. Reichenberg K, Lindfred H, Saalman R. Adolescents with inflammatory bowel disease feel ambivalent towards their parents concern for them. *Scand J Caring Sci* 2007;21:476–81.
38. Brydolf M, Segesten K. Living with ulcerative colitis: experiences of adolescents and young adults. *J Adv Nurs* 1996; 23: 39-47.
39. Popay J, Rogers A, Williams J. Rationale and standards for the systematic review of qualitative literature in health services research. *Qual Health Res* 1998;8:341-51.
40. Dixon-Woods M, Shaw R, Agarwal S, et al. Developing research: the problem of appraising qualitative research. *Qual Saf Health Care* 2004;13:223-25
41. Tobin G, Begley C. Methodological rigour within a qualitative framework. *J Adv Nur* 2004;48:388-96.

42. Noblit G, Hare R. *Meta-ethnography: synthesising qualitative studies*. London: Sage; 1988.
43. Ring N, Ritchie K, Mandava L, Jepson R. *A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews*. 2010. Available from: <http://www.nhshealthquality.org/nhsqis/8837.html>. Accessed May 05, 2012.
44. Goffman E. *Stigma: Notes on the management of spoiled identity*. New Jersey: Prentice Hall; 1963.
45. Taft T, Keefer L, Leonhard C, et al. Impact of Perceived Stigma on Inflammatory Bowel Disease Patient Outcomes. *Inflamm Bowel Dis* 2009;15:1224-32.
46. Quinn D, Earnshaw V. Concealable stigmatized identities and psychological well-being. *Soc Personal Psychol Compass* 2013;7:40–51.
- 47 Barakat L, Alderfer M, Kazak A. Posttraumatic Growth in Adolescent Survivors of Cancer and Their Mothers and Fathers. *J Pediatr Psychol* 2006;31:413–19.
- 48 Sandelowski M, Barroso J. Reading qualitative studies. *Int J Qual Methods* [serial online] 2002; 1: Article 5. Available from <http://www.ualberta.ca/~ijqm/>. Accessed June 02, 2012.

- 49 Hardt J, Rutter M. Validity of adult retrospective reports of adverse childhood experiences: review of the evidence. *J Child Psychol Psychiatry* 2004;45:260-73.50
- 50 Bondas T, Hall E. Challenges in approaching metasynthesis research. *Qual Health Res* 2007;17:113–21.

## **CHAPTER 2: MAJOR RESEARCH PROJECT**

### **Mothering a young child with intestinal failure on parenteral nutrition: an interpretative phenomenological analysis**

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## LAY SUMMARY

Children with certain intestinal diseases who cannot eat normally can be kept alive by parenteral nutrition (PN). This involves injecting a mixture of important liquid nutrients overnight into a child's bloodstream through a large vein in their chest; it is usually done at home. Research has shown that families with children who are fed this way can experience social and psychological difficulties, but they can learn to cope. This study aimed to find out what it is like for mothers of children up to the age of five who are fed by parenteral nutrition, and what circumstances allow them to cope. Seven mothers were interviewed about their experiences with their children. The results showed that mothers experienced four stages: (1) a difficult early stage when the children are first diagnosed with illness; (2) learning about the illness and how to use parenteral nutrition; (3) bringing their child home and trying to adjust to home life; and (4) thinking about what they have learned and how they want their future to be. The results showed that, although each stage is challenging, there are lots of ways that mothers can be supported to cope. Some suggestions include: making services flexible, supporting mothers to meet and help each other, providing support around living without food, and working with mothers in the hospital so they feel included in their children's care. Sharing information about the four stages could also help mothers to make sense of their experiences.

## ABSTRACT

**Background and aims:** Parenteral nutrition is a complex, risky procedure administered by parents to children with intestinal failure. Previous research has demonstrated that, while psychological and social challenges are associated with the procedure, families can adapt to their circumstances. The mechanisms through which coping occurs have not been explored. Age-specific exploration, such as feeding and attachment in the early developing child, is also required. This study aims to examine the experience of living and coping with intestinal failure and parenteral nutrition during early childhood (age 0 – 5) from mothers' perspectives.

**Methods:** Seven mothers with children aged between 0 – 5 years were interviewed using a semi-structured interview schedule. Transcripts were analysed using Interpretative Phenomenological Analysis.

**Results:** A four stage model of experience emerged from the data with specific tasks to negotiate in each stage: experiencing trauma, preparing to launch, transitioning home, and reflection and re-organising. Adjustment and coping in each stage was mediated by individual, interpersonal and environmental/systemic factors.

**Conclusions:** The model of parenteral nutrition has implications for enhancing clinicians', policy makers' and health care providers' understanding of the experience and impact of this procedure on families with young children. Suggestions are made for improvements in the delivery of care and treatment for these children, such as supporting mothers to meet and help each other and providing support around living without food.

**Key words:** Parenteral nutrition, lived experience, attachment, intestinal failure, early child development

## INTRODUCTION

### **Intestinal failure and Parenteral Nutrition**

Parenteral Nutrition (PN) is a life-saving procedure that involves the direct administration of nutrients into the bloodstream through a central intravenous catheter<sup>1</sup>, bypassing the gut (1,2). It is primarily used in intestinal failure. PN is a complex procedure that requires the individual to be attached to a central line for 12 to 16 hours, for a frequency of two to seven days a week (3). The majority of children with intestinal failure are weaned from PN within 12 weeks; however a small proportion of children will continue to require long term PN (4,5).

Prolonged intestinal failure can occur because of abnormality of the gut, genetic conditions, or extensive gut resection preventing normal nutrition and growth (6,7,5,4,8). The age of onset of a child's condition is vital when considering the risks associated with long-term PN; prolonged use is associated with iatrogenic complications<sup>2</sup>. The most common complications include sepsis (life threatening infection), lack of venous access, liver dysfunction, impaired growth, and pulmonary embolism (6,7,9). The mortality rate of children on long term PN is high, although survival rates have increased (6). It is difficult to establish prevalence rates for long term PN, but a point prevalence of two children per million has been estimated for the UK (9). There are currently ten children engaged in home PN in the West of Scotland, with a further three waiting to be trained (Christina McGuckin, Specialist Home Parental Nutrition Nurse, personal correspondence).

### **Home-based or hospital-based?**

Extended hospital-based PN has been associated with mild global developmental delay in paediatric patients, due to the restricted opportunities for social interaction (10,11). Home

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<sup>1</sup> Central Venous Catheter: catheter placed into a large vein in the neck, chest or groin

<sup>2</sup> Iatrogenic complications: term relates to illness caused by medical treatment

PN, whereby parents and, wherever possible, children are instructed in the technical process of administering PN was developed in the 1970's (12). The advancement of home PN addressed previous restrictions, and has been demonstrated to reduce the incidence of some iatrogenic complications, including sepsis (5,13). The decision to allow a child and family to participate in home PN is mediated by a number of medical, practical, and interpersonal factors such as the child's medical status, the motivation and psychological health of the parent, and the suitability of the home environment (8, 10). Such caution is required given the complexity of the process. Training can take two to four weeks prior to leaving hospital (14,10). It is standard practice for two adults to be trained in home PN; single parent families may require a dedicated care package including social and home nursing assistance (8).

### **Quality of life and psychosocial impact of PN**

Home PN aims to maximise the quality of life (QoL) of those with prolonged intestinal failure (8,9). A recent review demonstrated a limited number of quantitative studies have explored the psycho-social impact of home PN on the child and family; none have concentrated on the families' experiences of hospital-based PN (15). Earlier studies focused on the neurodevelopment of home PN patients or used concrete indicators of the impact on QoL, such as access to holidays and education, and rates of divorce. Researchers concluded that home PN allowed for adequate QoL and family cohesion (10,12,16). Recent studies have employed more specific measures of impact, and achieved varying results. Gottrand et al. (17) employed validated, self-reported, non-disease-specific questionnaires to rate perceived satisfaction in a range of domains for Swedish children, siblings and parents involved in the home PN process (n = 72, median age of child on PN = 4 years). Quality of life scores for children and siblings did not differ significantly from reference population scores of "healthy" children, but QoL was significantly impaired in parents, particularly mothers, in the domains relating to work, inner life and freedom.

Reduced parental QoL has previously been demonstrated in other areas of paediatric chronic illness (18). Responses from parents to a questionnaire issued as part of the British

Artificial Nutrition Survey (n = 15 families) highlighted the factors mediating the impact of PN on parental QoL (9). Social issues (difficulty finding someone to look after child), reduced emotional support (deterioration in family life and social activities), impaired sleep (PN is usually administered at night), uncertainty regarding the child's future, unpredictability of hazardous events, and struggle to balance domestic and employment responsibility were implicated (9,19). Parents in a study by Wong et al. (20) also indicated they had experienced deterioration in their sex life and relationships as a result of their child's illness and use of PN.

Engström et al. (14) found that children and adolescents on PN (n = 21 families) were distressed psychologically, although causation was not established. Additionally, parental satisfaction with quality of attachment to others was lower than normed scores, using a validated attachment measure. It was hypothesised that the presence of multiple others at home, such as medical staff, prevented parents from developing deeper emotional attachments. The potential for chronic illness to act as a stressor on the parent-child attachment process has been discussed in the general literature (21). Furthermore, studies of parents with children in neonatal intensive care units have indicated that separation from the child, and characteristics of the healthcare environment, can challenge the transition into parenthood (22,23). The issue of attachment in relation to the potential disruption of PN in the feeding and bonding process has not been explicitly examined in the PN literature, despite the importance that has historically been allocated to this particular task (24).

### **QoL, food and feeding**

Adult literature on PN has highlighted that “food and feeding are invested with substantial emotional importance for each individual” (25, p. 224). The dynamic interaction between the physical and the psychological/social functions of food and feeding has been recognised; the cultural rituals of eating facilitate social interaction and sense of group membership (26-30). Traditional QoL models do not explicitly address nutritional satisfaction; accordingly, they may not be sufficient to capture the impact of PN on QoL (28, 29). In a qualitative exploration of the meaning ascribed to food and eating by adults on PN, Winkler et al. (28)

identified three purposes of eating: for survival, for health benefits, and for socialisation. The researchers developed a QoL model that recognised the importance of enjoying food in self-reported QoL, and urged clinicians to consider the social and emotional importance of food in PN. The concept of food as an important socialisation process is pertinent to the infant and paediatric PN population, considering the interruption that intestinal failure and PN present to feeding (3). It is necessary to explore how patients and their carers mediate the social aspect of food and eating in the context of PN across childhood.

### **Qualitative research**

Qualitative research into the experiences of parents of chronically ill children has revealed the mechanisms underlying the observed increased levels of psychological distress in this population (31). There has been limited qualitative investigation into the lived experience of PN. Wong et al.'s (20) research with 11 parents of children on long term PN utilised quantitative and qualitative methods of data extraction, however the published results do not make specific reference to the qualitative findings. To date, there have been two published qualitative studies exploring PN. Judson (32) conducted semi-structured interviews with American mothers of children on PN (n = 19; child mean age = 10; range = 2-19 years; length of time on PN = 2 months - 16.5 years). Judson formulated a theory of protective care comprised of gaining, taking, and maintaining control. Themes of protective care included: committing to care, watching over, challenging the system, promoting normalcy, putting life into perspective, and celebrating the positive. Judson's research demonstrates the challenges of mothering in the context of PN, while exploring the growth and adaptation demonstrated by the mothers. Judson recommended future qualitative researchers focus on children in specific age groups (32).

Emedo et al.'s (33) qualitative study with children involved in long term home PN, (n=7, mean age=13, range: 7-17 years) indicated that, although the participants faced difficulties, it was possible for them to exhibit resilience, maintain a positive outlook, and cope. Difficulties noted included: frequent hospital admissions, living a restricted life, and challenges to identity formation. Factors associated with promoting coping in the children

included: parental support, understanding of their own illness and treatment, positive peer and sibling relationships, participation in usual childhood activities, and presence of household pets. The study suggested that future research should explicitly aim to investigate how young people and their families formulate coping strategies (33).

### **Managing paediatric illness: resilience and post-traumatic growth**

The focus on coping in PN is important, given the growth and resiliency identified in the discussed qualitative studies (32,33), and in other areas of paediatric illness (34). Of note, parental coping has previously been demonstrated to impact physical and psychological adjustment in chronically ill children (35). Familial resilience has been hypothesised as being demonstrated across four, related domains: intrinsic family characteristics (e.g. positive outlook), family member organisation (e.g. open communication), responsiveness to stress (e.g. patience for attainment of goals) and external orientation (e.g. maintaining co-operative relationships with health professionals) (34). Transformational growth through negotiating adverse events has also been identified to occur in several individual domains: self-perception, perspective on relationships, changed philosophy of life and deepened existential understanding (36-38). Previous exploration of coping styles in both adult and paediatric chronic illness, such as inflammatory bowel disease, indicated that solution-focused coping styles were associated with greater psychological well-being than emotion-focused coping styles (39).

### **The current study**

The period of early childhood, from birth to age five, has been identified as a time of vital significance in terms of social, psychological, emotional, and intellectual development (40-42). For families in which their young infant or toddler experiences intestinal failure, there is a difficult trajectory of hospital stays, operations, and traumatic experiences, often culminating in long-term PN or, in the worst case, death of the child. It is important to explore the experience of parents in this critical time, as they negotiate their role and the

reality of their situation. The issue of food, feeding, and parent-child bonding requires further exploration in this period, and may be more usefully explored in the first instance by concentrating on the mother-child relationship. A more thorough understanding of these themes could provide guidelines for professionals involved with families in which hospital and home PN is a reality.

### **Aim**

- To elucidate the experiences of mothers with children on PN in early childhood (aged 0 – 5).
- To explore the challenges mothers and families have faced, and the ways in which they have coped, in hospital and at home

## **METHOD**

### **Sample**

Ten children in the West of Scotland were on long-term PN at the time of recruitment and the population in the West of Scotland was 1,476,460 (<http://www.gro-scotland.gov.uk>). Additionally, the clinical team had contact details for children who had previously been on, or who had died while on, PN. The parents of the children currently on PN were invited to participate by a member of the clinical gastroenterology team, along with some of the parents who had previously been involved with the team (for ethical reasons, this number was undisclosed by the team). The resulting sample consisted of seven mothers of children who were currently on long term PN, although some of the participants had previously lost other children. Recruitment ceased once data saturation had been reached.

## **Inclusion and Exclusion Criteria**

Inclusion and exclusion criteria were developed to recruit as homogenous a sample of mothers as possible. Women were invited to participate if their child had commenced PN before the age of five, and had been on PN for a minimum of six months. This was considered to be a sufficient time for mothers to have developed an accurate idea of the impact of PN on their lives. Exclusion criteria included non-English speaking and concern that participation in the study would be unhelpful to a parent's psychological health.

## **Recruitment**

Participants who met the study's inclusion and exclusion criteria were identified by the gastroenterology team. An information sheet (Appendix 2.1) and stamped envelope addressed to the researcher's place of work were posted to potential participants. The information sheet instructed participants to express interest by returning the tear off slip, or by verbally instructing a gastroenterology team member over the phone/during a hospital appointment. A gastroenterology team member then rang the parents to allow them the opportunity to discuss the study. Six parents subsequently expressed interest to participate by post; one contacted the team by phone. Once interest was expressed, the researcher contacted the parents. Participants were selected on a first come first serve basis, until data saturation was achieved. Recruitment occurred between February and May 2013; the final sample represented 70% of the PN-dependent West of Scotland families at that time.

## **Choice of analytic approach**

Interpretative Phenomenological Analysis (IPA) was chosen due to the idiographic emphasis of this analytic approach; the purpose of the study was to gain in-depth knowledge of the lived experience of a small group of women in a particular context. In addition, IPA recognises the interpretative aspect of qualitative analysis; this is in keeping with the author's own philosophical understanding of the nature of qualitative research. IPA is a culmination of two theoretical stances: phenomenology, in which emphasis is placed on the perception of

objects or events, and symbolic interaction, which posits that the process of meaning-making occurs as a result of social interactions (44,45). Data therefore represents a researcher making sense of a participant making sense of their experience (43-45).

## Participants

The final number of seven participants is in accordance with recommendations for Doctoral research studies employing IPA; the number facilitates data saturation and sufficient exploration of participants' narratives (43, 44). Given the small sample from which participants were drawn, and the fact that results would be presented to their current medical team, protecting family anonymity was vital. Consequently, table 1 provides demographic information collectively. Information regarding time of the child's commencement on PN and duration on PN were taken from the parents report. Current child age was not restricted but the final sample consisted of a small age range of young children, allowing for greater homogeneity and proximity to the time span being discussed. The Scottish Index of Multiple Deprivation (SIMD) determined the socio-economic status of participants. The SIMD provides ranked postcodes derived from seven domains: income, employment, health, education, skills and training, housing, and geographic access and crime. Ranked data are then divided into quintiles with 1 = most deprived area and 5 = least deprived area.

**Table 1: Demographic information for children on parenteral nutrition (N=7)**

	Mean <sup>1</sup> , mode <sup>2</sup> , median <sup>3</sup>	Range
<b>Child age</b>	3 years, 2 months <sup>1</sup>	2 years, 0 months to 3 years, 11 months
<b>Duration of child on PN</b>	2.5 years <sup>1</sup>	10 months to 3.5 years
<b>Age commencing PN</b>	Birth <sup>2</sup>	Birth to 2 years
<b>Nights on PN/week</b>	5 nights <sup>3</sup>	3 – 7 nights a week
<b>Hours on PN a night</b>	12 hours <sup>2</sup>	12 – 14 hours a night
<b>Scottish Index of Multiple Deprivation</b>	3 <sup>rd</sup> quintile <sup>2</sup>	1 <sup>st</sup> to 4 <sup>th</sup> quintile

## **Semi-structured Interview**

Data were gathered using a semi-structured interview schedule (Appendix 2.2) developed from past research regarding topics pertinent to the study including: parenteral nutrition, parenting, attachment, parent-health care provider interactions, resilience and coping. The schedule was further shaped through liaison with the gastroenterology team's Consultant Gastroenterologist, PN Nurse Specialist, and Clinical Psychologist. The resulting schedule covered experiences and feelings towards their child's diagnosis, hospital experiences prior to PN, early experience of PN, transition to home PN, psychological and social impact of PN, impact on the parent-child relationship and other relationships, and child/parent adjustment and coping with PN. Questions were worded so that they were as non-directive and open as possible, in keeping with recommendations for developing IPA interview schedules (43). Prompts were developed to allow for further exploration of themes, in the event of a participant struggling to answer. The schedule was intended to be used as a flexible guide; the intention was to allow the participants to direct the interview as much as possible and allow for the generation of novel, previously unidentified topics of discussion.

Prior to commencing the interview, the researcher made it explicit that she was interested in the participants' view, and encouraged them to introduce topics that were relevant to them. Time was spent preparing participants prior to interview and encouraging them to ask for a break or a change in subject, should they feel uncomfortable or distressed. This was especially pertinent given the personal and potentially difficult interview content, particularly as some participants had previously lost children to intestinal failure. Summaries of the participants' experiences were provided throughout the interview, to allow for clarity or correction by the participants. Time was spent debriefing the participants once the interview was completed. Participants were advised that they could seek input from the psychologist attached to the team, should they require support. In addition, the researcher frequently liaised with the gastroenterology team and was in a position to pass on concerns.

## **Procedure**

Interviews were digitally recorded and were conducted in clinic rooms on hospital premises which the family attended for routine care; six interviews were coordinated to coincide with hospital appointments. On attending the interview, mothers were invited to read the information sheet again and to ask questions. They were then invited to sign the consent form agreeing to the interview being voice recorded and to quotations being used in published reports (Appendix 2.3). Interviews lasted in length from 49 minutes to 116 minutes. On interview completion, participants were advised that a brief results summary would be sent to them, via the gastroenterology team.

## **Researcher reflexivity**

In IPA, the experiences and belief systems that the researcher brings to the process are acknowledged, as is the active, mediated quality of the interpretative process (43, 44). Therefore, care was taken to acknowledge the researcher's own experiences and beliefs, and to reflect on how these may influence and shape her interpretation of the experiences and perspectives the participants shared with her. The researcher had spoken at length to clinicians in this field; she was aware of some of the issues facing participants. She had worked clinically with loss and adjustment in a therapeutic setting. As a trainee clinical psychologist with an interest in narrative psychology and critical health psychology, she understood human experience to result from the interplay between intra/interpersonal experiences and socially constructed systems/organisational structures. She was naturally orientated towards focusing on the strengths and resiliencies demonstrated by individuals in challenging circumstances. Specific areas of interest (psycho-political influences on mental health, power differentials within healthcare systems, responses to trauma) as well as her general understanding of models of child development (attachment, models of "normal" development") will have contributed to her conduct during the interview and subsequent interpretation of the data. As a woman at a stage in life where she would be considering starting a family, she remained aware of her personal reactions to the themes of paediatric illness and child loss.

## **Data analysis**

On completion of each interview, the researcher entered impressions of the interview and the participant, including personal reactions and thoughts, into a research journal; this was to allow for context in the analysis of the data, and to ensure a rigorous and transparent process. Interviews were then transcribed verbatim; participants were assigned pseudonyms and identifying information was removed. Analysis was undertaken immediately post-interview; this approach allowed for the identification of data saturation and prevented the researcher from conducting unnecessary interviews (43).

IPA analysis involved repeated and careful reading of the transcripts whilst listening to the digital recordings. Preliminary codes including descriptive, analytical, and language-based, were noted line by line (Appendix 2.4: sample of coded interview). The researcher then re-read the transcripts, analysed the codes in relation to each other, and noted recurring themes. Emerging themes for each interview were compared and integrated, noting consistencies and discrepancies between and among them. Themes were clustered together and their relationship to each other considered, generating super ordinate themes; this process resulted in the formation of a model of experience

The transcripts were re-read in order to ensure that super-ordinate themes and sub-themes were grounded in the data. Identified themes were discussed in research meetings as a means of audit, and two transcripts were analysed independently by two research supervisors to further verify the reliability of the analyses (46). As internal coherence and presentation of evidence are important in addressing validity and reliability, emergent themes are supported by participants' discourse (42-46).

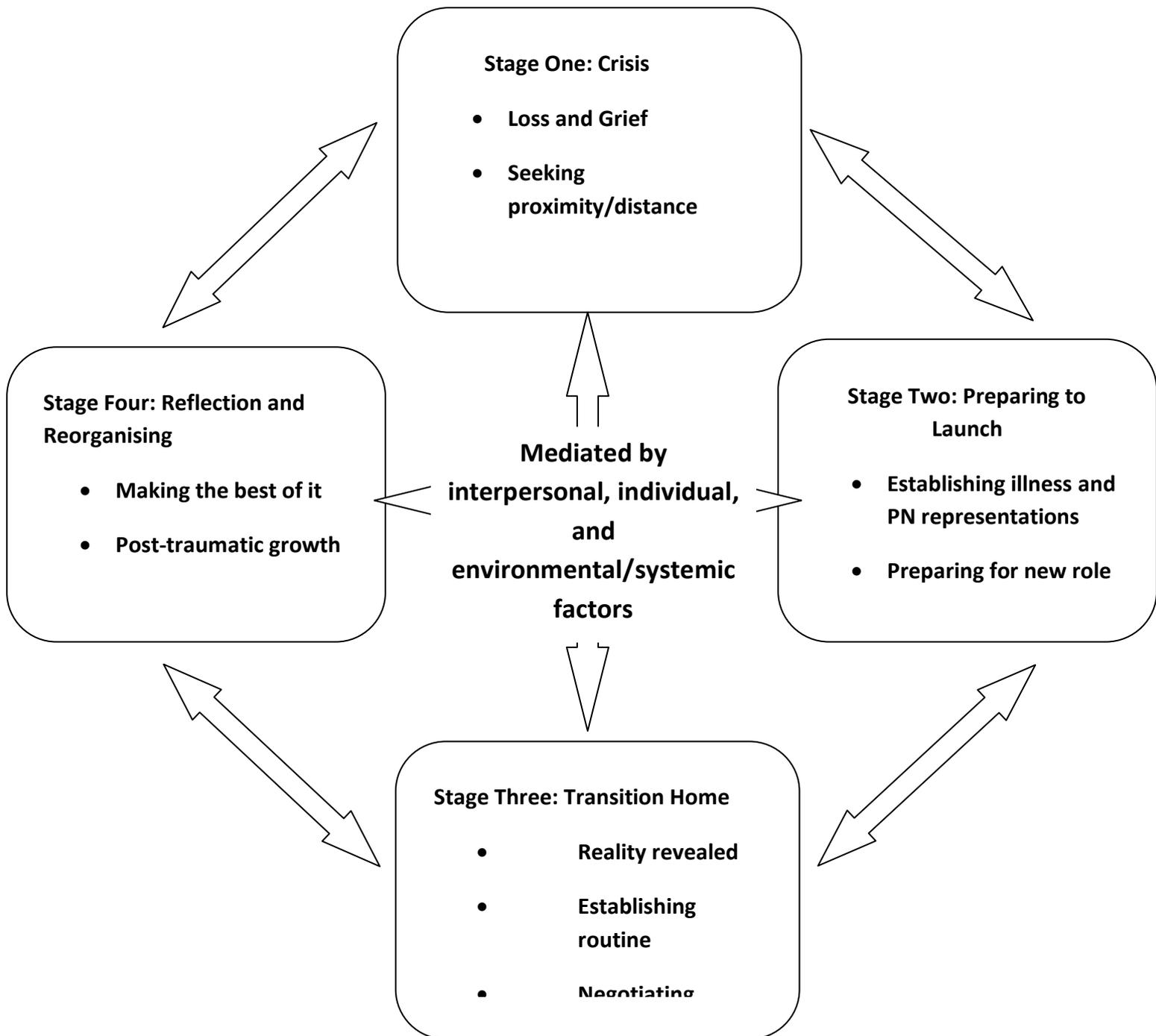
## **Ethical approval**

Ethical approval was awarded by the relevant NHS ethics committee (Appendix 2.5).

## RESULTS

The following model (Figure 1) depicts the journey of experience that emerged from the data. The journey can be best understood as consisting of four stages. Each stage posed particular challenges and tasks to the mothers, requiring them to manage by utilising various strategies. The stages were reflexive and inter-dependent. Experience of challenge and adjustment was positively and negatively mediated by a number of individual, interpersonal, and environmental/systemic factors. The unpredictable prognosis and course of PN, and early childhood gastrointestinal illness, meant that individuals found themselves having to re-negotiate earlier stages. The model is followed by detailed exploration of each stage, and the factors that influenced participant experience. Examples are illustrated with italicised direct participant quotes. Indications (laughs, sighs) and explanatory amendments made by the author are in square brackets and italicised. Spoken input from the author is in round brackets and not italicized.

**Figure 1: Process of PN model (PPN)**



**Note:** Each stage influences the next. For some participants, stages came in close succession or merged. The nature of the illness means that some individuals may find themselves having to re-negotiate earlier stages as prognosis shifts. Impact and coping is affected by individual, interpersonal, and environmental /systemic factors, and some tasks are on-going.

## **Stage One: Crisis**

### Tasks

Each mother's story began with a crisis point in which they were thrown into the painful experience of negotiating trauma in hospital. The psychological consequences of such experiences included loss, pain, anger, confusion, guilt, grief, helplessness, and resentment of others with "normal" babies and toddlers. Participants expressed the nightmarish quality of these early significant events using evocative language such as "terror" and "horrible". For some, their crises and separation from their child occurred at the child's birth; these mothers lost expected roles (as nurturing new mothers), expected children, and bonding opportunities. For others, crises occurred later in their toddler's life; children who previously ate were transformed into children who could not eat, and loss was experienced by both mother and child. Mothers described the powerlessness associated with feeling unable to ease their child's distress.

*"I never got a chance to breastfeed, I mean I didn't get any milk in or nothing, I don't know if it was just the shock eh as I say because [of difficult birth], I never got a choice in the matter anyway" Julie*

### Coping

Mothers turned to partners, family members and staff for support during these overwhelming experiences. Some mothers strove to increase their involvement in child care, attempting to ameliorate the impact of their circumstances. Others described increasing physical proximity but emotionally distancing themselves; this was a way of managing the overwhelming possibility of losing their child. These memories evoked strong emotional responses in the mothers during their recollections.

*"It was from thinking one minute you were going to be taking him home to the next minute not knowing if he was going to make it through the night, so I think I just kind of distanced myself from him, eh didn't want to [cries] like [pause] cos then I I really couldn't touch, all's I could do was wipe his eyes eh with bits of cotton wool" Karen*

Parents recalled using emotion-focused coping skills, such as focusing on the present and trying to keep hopeful in the absence of a definite prognosis.

*“So I just tried and tell myself that it wouldnae last forever, I mean for all I know it could have, but just telling myself that kind of made me feel a wee bit better” Claire*

### Mediating Factors

The quality of mothers’ interpersonal experiences influenced their experience of this stage. Parents who perceived others as inclusive, empathic, and transparent felt included in their child’s world. These parents described experiences of being gently guided and supported to contribute to their child’s care.

*“it was nice to be able to take over and do the little things like changing nappies washing and dressing them and let them deal with the more important things, do you know what I mean?”*

*Rebecca*

Conversely, parents who experienced others as not acknowledging their importance as a parent, not including them in decision making, or as being actively adversarial, appeared to feel unsupported, misunderstood and disempowered.

*“they had just totally lied eh [and] they just dinnae take my word for it, ken? I’m his mum and I’m not going to tell them that he gets medicine that he doesnae get, or that he doesn’t get medicine that he’s meant to get, but nah they just go ahead and do whatever they feel*

*like” Karen*

Individual factors, such as illness course, further exacerbated experiences of crises. For some, these crises represented a re-traumatising evocation of children who had previously died. Environmental factors, such hospital proximity and financial circumstances were important. Mothers had mixed experiences of supported accommodation; some found it helpful, others found it a hostile environment. Acknowledging the emotional impact of the crises to others was important for relationships to withstand the extreme circumstances.

*“And you obviously try and not to take it out on your partner, if you’ve got a partner, try and explain to them if you’re feeling something rather than just biting their heads off and stuff like that cos you don’t want that, I’m pretty sure it probably has like broke people up before the stress and having to deal with it” Rebecca*

## **Stage Two: Preparing to Launch**

### Tasks

In the second stage, mothers were faced with the difficult prospect of establishing representations of their child’s illness, and of the unknown phenomenon of PN itself. Mothers’ described the overwhelming emotions that they experienced as they tried to amass information such as prognosis, time-line, and consequences. PN often entered their lives inconspicuously, and participants experienced a burgeoning sense of panic and shock as they came to understand the transformative implications of PN.

*“that’s what we thought they were, just fluid bags, going to keep him hydrated, we didn’t realise it was his new source of food” Lauren*

The overwhelming responsibility mothers felt in relation to their new role of PN provider was often accompanied by self-doubt, terror, and a need for reassurance. Some described their visceral fear at the thought of leaving the supportive environment of the hospital. Others expressed the sense of determination and impatience they felt to “get trained up”, so they could get their child out of the development-limiting environment of the hospital.

*“when you’re doing it in the hospital if anything goes wrong, there’s someone here, there’s always someone that you can say this is not working or this has happened and then when you [think about going] home it’s all on you, so you have to make the decisions of what to do next so it was really really scary” Claire*

## Coping

Mothers navigated this stage in a number of ways. Some engaged in active information seeking, via the internet or conversation with other parents or staff members; others preferred to accrue information on a “need to know” basis. Building relationships with similar others appeared to give participants a sense of group membership and solidarity. The goal driven aspect of training resulted in parents feeling more confident and prepared; some were surprised at how well they managed to accrue the new skill.

*“So like I was just going from the dummy straight to Jess and doing that day or night, and I was in every single day and every single night just doing the exact same thing so you’re just settling it into your head eh? And then that’s probably why I’ve got so much done [Both laugh] But you you get things done that way you get things done that way, so that’s, but I never thought I would be that [pause] goal-driven if that makes sense” Tracey*

Although parents made concerted efforts to understand the implications of PN, their actual understanding was theoretical at this stage, given the false environment of the hospital. Some parents reflected on the negative impact of this lack of informed awareness in the context of one of the main tasks of this stage: identifying the level of support that they would require on leaving the hospital.

## Mediating Factors

Communication and interpersonal experiences were paramount in managing the goals of this phase: parents who perceived that they were properly reassured and introduced to the notion of PN approached the task of training with a feeling of self-efficacy and competence. Some participants expressed that there was a lack of written information regarding PN; this led to a bias towards noticing negative information during self-directed research on the internet, or in conversations with parents who had “horror stories”. In contrast, some parents felt empowered by the knowledge they gained on the internet.

*“I had looked on the internet and just all these things, and that’s what was - you concentrate on the things that can go wrong eh? You just, you dinnae see the good points, it’s all the bad points that stick out at you, so no but that was all I really got tel’t about that eh?” Karen*

Training in PN involved a performative aspect, whereby parents had to demonstrate that they had achieved certain competencies. In addition, parents were routinely provided with a social worker; some parents explained that this increased the pressure to appear in control, gave them an uncomfortable feeling of being assessed, and challenged their identity as competent mothers. In general, mothers felt that the flexibility of training around their own schedules was sensitively provided and family-centred; staffing shortages were cited as negatively mediating the provision of training.

*“I mean they say you’re not under suspicion but you’ve just, you’ve got that in the back of your head when they’re talking about yis, if you’re going into the room and they stop talking, and you think “they’re talking about me” do you know what I mean?” Julie*

*“Eh it was terrifying, absolutely terrifying I remember the first time after we were trained up on PN they said right you have to do this yourself now we’ll supervise you and you have to get you know boxes ticked to say you passed that one you did that one you’re competent in that one ahm which is quite nerve wracking you were being watched” Rose*

### **Stage Three: Transition Home**

#### Tasks

The launching of mothers from hospital was followed by a chaotic and anxiety-provoking stage, in which mothers attempted to integrate PN into their life. During this stage, when the threat of other types of loss and risk receded, other types of loss were fully revealed: work role, spontaneity, freedom, time with siblings, partners or friends. The notion of risk and hyper-vigilance dominated this phase. Parents’ sleep was interrupted as a result of their

repeated checking that the PN lines had not strangled their child, this is due to the multiple lines involved in the PN process. Unsurprisingly, this resulted in prolonged fatigue.

*“Ahm [sigh] I think it becomes more apparent when you’re getting trained but [pause] it is different when you get home, It’s much more full on, you know you’re a couple of hours if not longer up in the bedroom doing the PN, or wherever you choose to do it and then you’re constantly checking [pause] that everything’s ok as well” Rose*

The task of creatively occupying young children who were struggling, but obliged, to stay in situ was discussed. PN also impacted on children’s bodily functions. Parents described situations whereby their children’s cots and bedrooms would be completely soiled, despite their best efforts to keep their children clean through frequently changing nappies, or trying multiple types of nappies. Many mothers also had to manage the distress and impact of children who vomited frequently.

*“Getting out the door is a battle, Aye getting up and organised in the morning, aye, eh because Anna’s got to be stripped down and bathed every morning because sh, just everywhere, I cannot find a nappy that will hold this lassie, I’ve tried every nappy on the market and I can’t find one that suits her but eh [laughs]” Julie*

*“It was the sickness that was my biggest bugbear and Jess’s biggest bugbear it wasn’t she wasn’t having any quality of life proper life” Tracey*

The challenge of managing wounds, stomas, dressings, and a central line with an increasingly curious and mobile toddler presented parents with various learning experiences. Some parents advised that they struggled to tolerate their child engaging in rough and tumble play during this phase, because of the child’s central line. Mothers worried that the central line would get pulled out, thereby increasing their chance of infection.

*“He, he is actually is, is good but yeah, you still need to watch them because cos they forget as well, cos they’re kids, they forget and you see them sometimes getting a little bit too boisterous” Lauren*

Including children in the social aspect of eating emerged as challenging. Some mothers had to support children to cope with the loss of food; others were faced with the task of encouraging reluctant children to eat. Negotiating risk in the context of social situations was central to the tasks of managing social relationships; parents concomitantly wanted their child to be perceived as normal by others whilst hoping people could remain consistently vigilant to risk. The challenging task of accessing nursery was portrayed as vital in promoting the development of the child, and increasing their chance of being seen as normal.

*“This is why he’s at nursery, he needs to be like any other normal 3 and a half year old, dinnae draw attention to him” Karen*

Some negotiation of role was reported by some mothers, who noticed their sense of feeling “half nurse half mum”; ultimately the role of mum was more prominent. Parents had to deal with professionals in the community with whom they had not had prior contact. Parents without partners had to become accustomed to negotiating multiple paid carers. Each mother had to negotiate working with the company that provided and delivered the PN supplies; this involved a high level of planning and communication.

### Coping

Establishing a routine emerged as the primary way of coping during this phase; the routine was spoken of in almost reverential terms, and mothers were humorously self-deprecating in their description of their adherence to it. The theme of teamwork and experimentation of roles arose; whether between parents, or parents and carers. Routine provided parents with a sense of predictability in an unpredictable illness.

*“Ahm well myself and my husband did it together we worked as a team (Yeah) So em my husband preferred to actually put up the PN, and I would be his assistant, “Doctor-Nurses” we called it” Rose*

Some parents sought respite when they realised that their earlier assessment of their support needs had been an underestimate. Mothers used advocacy and information building

on behalf of their children in order to increase the awareness of others within and outwith the family, and facilitate their child's admission to social and educational environments. Nursery staff, and in some situations certain family members, were trained in lower level emergency procedures.

*“Em well I think Specialist PN nurse's been out [to the nursery] and they've obviously [pause] got the basic of you know of obviously his central line and stuff [Yeah] Em, sometimes they do ask questions and like I think maybe just before Christmas they were asking you know what, what exactly is TPN? [laughs]” Claire*

Families discovered various creative ways to include children at mealtime, providing their child with toys at the dinner table or allowing them to lick or hold certain types of food. Some parents adjusted their eating routine, or allowed their child to feed them. Similarly, developing roles for children in the process of PN emerged as a successful way of managing the child's curiosity and wish to be included. Siblings were encouraged to engage in dialogue about PN.

*“We've just had to try to develop wee things to let him be involved, it's the same with his brother, ehm his brother likes to try and press the button at the end when his PN goes on, but we've had to do it, cos we felt when we first initially went home and we told him, no you can't touch that, can't touch that, they wanted to touch” Lauren*

*“Yeah well they just em he still everyday when they're having snack they let him sit and play and stuff (Ok), and he doesn't, no matter what we give him, he likes crisps he likes to pick a pack of crisps, and he'll take one out sometimes he'll have a little lick of it, Am he likes to smell them, I think like really strong flavours, and he'll hold it and hold it and then just chuck it away” Claire*

### Mediating Factors

A number of individual, inter-personal, and environmental factors influenced mothers' experiences during this stage. The impact of “before and after” emerged; children who

experienced the loss of food were described as struggling more than children who had never eaten. Similarly, loss of a work role was more significant for some than others. Parents' perceptions of risk mediated their ability to allow others to engage with their child on PN. Mismatches between parents and others' understanding of the complexity and risk of PN and central lines were destructive. The following mother described that such a misunderstanding had led to the deterioration and eventual dissolution of certain friendships:

*“How do I put this, I feel as if I’ve lost my pals, Obviously I’ve got a different lifestyle from them now (Yeah) Eh but I’m like they just hear what they want to hear” Julie*

Mothers felt that the PN team were accessible if needed. A difficulty emerged regarding the method of instruction in managing transitions. Some participants felt that certain advice could have been more successfully adhered to if it had been presented with support and guidance. There was a sense that the reality of adjusting to PN was not always fully understood by some professionals.

*“I think definitely that thing I was saying about, the food [and] the support there, no I don’t think we got great support looking into that. We were just told, “well he can’t eat, he could become ill” [pause] trying to tell a two year old that” Lauren*

Environmental proximity of significant others, age of child, and child health status impacted on mothers' experience of this phase. The presence of available family members appeared to act as a buffer for the isolation experienced by other mothers. A distinction was drawn between the types of support others could offer; parents and paid carers remained the only individuals who could administer PN. Consequently, some mothers advised they had not had time out with their partner at night for months at this point. Earlier interpersonal dynamics, such as feeling trusted or feeling under surveillance, continued to mediate adjustment in this phase.

*“I’ve got three sisters, who are all very helpful, (Okay) Yeah, if i didn’t have them, it would be impossible” and then his, my mum and dad (Okay) So, my mum and dad, are of that age, they wouldn’t want to learn to do the pump, they’re not, not that they don’t want to learn, they’re too frightened.” Lauren*

In addition, individual preferences mediated mothers' perception of support: some mothers felt community input was unwarranted; others were vocal that they required further input. The following mother explains why she felt respite should be offered to parents involved in PN:

*“Because you you just become this robotic couple who you're trying to bring up this this child that's got all these needs, and then at night you quickly have your dinner then you go upstairs, you get everything set up, you put them on PN, you put them to bed , and two hours later you go back down the stairs and you're tired and you don't have that quality time and (Yeah) You want to talk about something else but you find it very hard, so time alone time away [from PN] is so important” Rose*

Of note, parents were reassured by observing their children's adjustment. Mothers spoke with pride and admiration at their children's capacity to adapt. PN appeared to be externalised as an adversary to be overcome; mothers were united with their family against PN, and showed evidence of mentalising about the impact of PN on their child. Child distress was conceptualised as understandable in the context of their situation. Continued involvement with other children on PN meant children's progress was assessed in relation to a PN peer-group, allowing them greater chance for being perceived as succeeding. Mothers appeared to have age-appropriate expectations for their children.

*“But sometimes she's like “no I don't want to do PN” she's too busy doing something else, but we try and explain to her that [it's important] but she's still too young. I mean we say it to her but we don't expect her to to take it in and understand it” Rebecca*

## **Stage Four: Reflection and Re-Organising**

### Tasks

The final stage in the process results from the culmination of the experiences and skills developed in the previous stages. This stage involves a concomitant reflection on what has

been learned, consideration of priorities, and re-evaluation of the usefulness of coping strategies. Many of the mothers described relaxing adherence to their routine and adjusting the PN schedule to facilitate their family's priorities.

*“Craig can't do as much with his brother when his lines are on at night or in the morning so obviously he can miss out on quite a bit, but we try, that's why we try and set the times so he doesn't miss out [on time with brother]” Lauren*

Mothers described how they felt increasingly comfortable allowing their child to spend time without them, although they remained reluctant to be a burden on their family members. Some parents were able to negotiate time away as a couple, albeit in an environment close to home. Parents, who were able to do so, began to experiment with devices to increase mobility; they described being more open to considering possibilities such as going on holiday or to soft play. Earlier instincts regarding allowing their children to participate in the process of PN paid off, as children became more involved and comfortable with the process.

*“we were lying on the couch and he went “mum” I went “what?” he went [does dramatic sigh and speaks the following in a comedy sulky voice] “you've not done my dressing” [Both laugh], And I went “oh I'll get it in the morning” and he went “no do it the now” and I says to him I went “right you run up and get a dressing and I'll get the trolley and that sorted” so away he went up got a dressing came back down and he just lies there, he just lies, I didn't even need to tell him to lie down (Wow) He just lies there on the floor and he's like “right” [laughs]” Karen*

In addition to identifying how to move towards valued goals, mothers also reflected on some of the positive impacts that had emerged from coping with PN. Some spoke of developing skills: strength, technical skill, maturity, advocacy, assertiveness, diplomacy, and increased empathy. Mothers' broadened perspective of the hidden world of paediatric illness allowed them greater empathy for other parents in similar situations; they also reflected that certain relationships, with partners or close family members, had been strengthened by their experiences. In particular, parents advised they felt the relationship and quality of attachment with their child had been strengthened by their mutual experiences.

*“And that’s I think now I think because of it I think I’ve got a stronger bond with him now than anything (Um-hmm) Because he does not leave my side [laughs]” Karen*

*“And I’m quite lucky I’ve got a good man do you know what I mean he’s stuck through for the last X years so I’ve got a good man” Julie*

Siblings were spoken about as being compassionate, mature, and skilled. Reference was made to PN motivating parents and siblings towards pursuing careers in paediatric medicine. The children with PN themselves were described as tough, resilient, adaptable, and joyous. During this phase, parents reflected on their concerns for the future, and deliberated on how to support their children to cope with future challenges.

*“I mean I know she’s nearly [age] but she’s very mature for her age, and very grown up, and she’s obviously seen a lot, [and I] think she does very very well so she does, very very well”*

*Claire*

### Coping

Parents and families had to tolerate the anxiety that accompanied the relaxing of their routine and decrease in hyper-vigilance; this was frequently achieved through mutual support and negotiation between parents and carers.

*“Aye I’m a worrier I start kind of freaking out and then he’s, Kevin brings me back down and says relax it’s fine, (Yeah) Don’t worry about it she’s fine and I’m “look it [central line] just looks a bit wet” and he’s like “no it’s fine don’t worry about it [laughs]” Rebecca*

An additional tactic that facilitated re-organising and reflection was that of focusing on the achievable, and maximising the use of non-PN time. Mothers presented an ethos of making every second count when the child was not tied to a line, and encouraging their child to see PN as relaxing time. In addition, parents advised that friends and family became flexible to accommodate the constraints of PN.

*“So I must admit a lot of my friends do a lot of stuff round me which is really good, if we’re going swimming we’ll go five to seven (Ok) Ahm rather than them rather than them saying right well she can’t do it so we’ll just go and leave her sort of thing” Claire*

Recognition of success and growth was facilitated by a shift in perspective. Expectations were adjusted so that notions of success became related to the child’s context, as opposed to a general peer population. Mothers celebrated the little things: there was a sense of perspective gained in stage one that permeated through parents presentations of their children. Finding the extraordinary in the ordinary emerged as a way of adapting and celebrating their lives. Parents strove to promote a sense of normality, and to minimise the identification of their child with a sick role.

*“And it will just have to be saying to him just obviously you don’t eat like other people, I think he’ll he’s quite bright, Harry, so I think he’ll click on quite quickly, but it is good that, I do love it now when we take him off his milk and he goes “I’m free!” [laughs]” Claire*

*“And she does this with her nose to your nose [mimes rubbing noses] do you know what I mean and you think “you shouldnae be doing that, because you werenaе supposed to do all this and look at you now” do you know what I mean” Julie*

A sense of community emerged from these mothers; shared earlier experiences in hospital appear to have provided mothers with an extended family who celebrated each others’ successes and grieved each others’ losses. This was also true of some of the hospital staff; mothers described mutually respectful relationships.

*“And I do think it’s a nice thing, to be able to speak to other parents who actually understand. Cos if you’ve got, obviously you’ve got your family, I have got a close family. But they don’t actually understand, as much as someone else who actually goes through it.”*

*Lauren*

Mothers were frequently obliged to return to the hospital due to the variability of their children’s health; they would find themselves back in stage one or two, struggling to cope with a new crisis or new illness representations. Having established control over their routine at home, parents described the anxiety and fear they experienced being back in the hospital.

These difficult emotions were provoked by their awareness of the greater risk of line damage in hospital, and their need to establish their role as PN provider with unfamiliar nurses. Mothers had to be assertive in advocating for themselves and their child.

*“so you know when we come in I have learned as time has went on, before when Laura was ill and if anything was annoying me I used to build it up and build it up and then I’d have a nervous breakdown (Ok) So this time I’ve learned that if I have anything to say I say it then and there (um-hmm) Ahm and eh I have found it works much better if I’ve got any problems or anything I’m not happy with I just say it [to staff] Claire*

### Mediation

Reaching this stage was an ideal which could be inhibited by a number of setbacks. Relaxing the routine could only occur in the context of a child’s health status being stable. Similarly, opportunities to maximise the off-PN time were more plentiful for children who had nights off PN. Individual circumstances influenced the opportunities that mothers had to spend time away from their child. On an individual level, successful resolution of earlier loss and grief appeared to be a pre-requisite of reducing vigilance. Perception of risk was altered when children’s conditions worsened sporadically. The following mum described her ambivalence towards PN in this stage:

*“It’s a good it’s a love hate relationship with PN I think (Yeah? Why do you say that?) Well because it’s good for the fact that it’s there to keep babies alive, I mean obviously when Grace was born, it kept Grace alive when she was born, she couldnae have oral food but then again it’s bad it’s not natural and it can damage your liver” Rebecca*

In general, mothers referred to the passage of time as facilitating growth. As children grew and became more risk-aware, families habituated to PN and became less anxious; despite this, mothers continued not to have other people trained in providing PN. Some mothers were afraid that they, or their child, would be perceived as a burden if others got trained up; others advised that the provision of training during working hours prevented working relatives from being involved. Furthermore, some stated their own anxieties and

need for control had not abated sufficiently to allow others to help. Finally, the quality of interpersonal relationships continued to mediate how parents adjusted and managed during this time of reflection and re-organising. Mothers perceived those around them who were accepting, and did not place their child in a sick role, as positive. Additionally, parents who developed strong, familial relationships with hospital staff appeared to continue feeling trusted and included in their child's care.

*“But they’ve got their own lives so I dinnae really want to have to feel like we’re a burden or like I am a burden or Jess’s a burden (Um-hmm) Not that we are, but like at the same time they have go their own lives, and I’d rather be more independent as well than rely on my mum and dad eh? Tracey*

### **Summary of results**

Participants described a journey in which they passed through various stages: from early trauma to positive mothering experience, from being in a state of unawareness to being in a position of knowledge and expertise. Each individual's experience was mediated by a number of individual, interpersonal and environmental factors. Parents utilised a number of strategies to manage the tasks of each stage, and reference was made to the growth and learning that they and their family had acquired.

## **DISCUSSION**

### **Relation to existing literature**

The four-staged PPN model provides insight into the lived experiences of mothers with young children under the age of five who are fed with PN. The results supported the earlier findings of both positive and negative aspects of PN (9, 14, 17, 19, 20,32,33). Given the

sample homogeneity, the differences that emerged are as interesting as the commonalities. The individual, interpersonal, and environmental mediating factors help to explain variations in reported quality of life (9,10,16,17,19). Some of these factors, such as PN schedule, can be controlled for in quantitative research design. Others, such as previous traumatic experiences and quality of interpersonal relationships, are difficult to operationalise; they may only ever be fully examined within a qualitative environment. Given the breadth of difference within the sample, tailored family-centred approaches are indicated for professionals.

The PPN model contributes to the research into the role of illness representations in coping with illness (47) and research identifying post-traumatic growth in paediatric populations (34). The participants described a new sense of their own abilities, a transformed perspective on what is important in life, and a sense of wonder at the ordinary; these experiences have been documented elsewhere (36 - 38).

The resilience demonstrated by these mothers and their families was evident throughout each stage; the multiple influences on families' experiences of PN that emerged from the results can be understood and categorised in the context of the four aspect framework of resilience provided by previous researchers (34). It is interesting that none of the mothers identified difficulties in their relationships with their children, despite the literature surrounding the importance of early bonding experiences for attachment and positive parent-child relationships (21-24). It is possible that this understanding of child development does not adequately reflect families' resilience and potential to adapt and develop their own idiosyncratic and equally important processes of bonding, especially when they are sensitively provided with appropriate resources. This hopeful message of the potential for development has implications for how clinicians can think and speak about childhood chronic illness, both to service users and each other.

Furthermore, while some literature has indicated that problem-focused coping is more beneficial than emotion-focused coping (39), mothers in this study appeared to utilise different coping styles depending on the situation. For example, some parents used avoidance during the trauma stage, while others used problem solving. Given this finding, it may be most useful to conceptualise coping and adaptive strategies as being context dependent.

### **Loss of food and feeding**

The social aspect of food (27-29) was evident throughout the mothers' discourse. Parents lamented the loss of their child's ability or motivation to eat. Reference was made to the frustration mothers experienced when clinicians minimised the impact of this loss, and gave instructions without support. Mothers were creative in developing strategies to include children in the social aspect of eating; some let their children lick or hold food, eat ice/drink water, or feed their parents and siblings. Other adjusted their eating schedule so the child was not forced to watch their family eat without them. Support and guidance in this aspect of PN for mothers new to the area would be beneficial. This could include professional input regarding weaning off or on to food, as well as practical input from experienced mothers.

### **Modelling the service around the journey of awareness**

The burgeoning awareness of the impact of PN throughout the stages was referred to by every mother. The implication of this in the context of service-provision is vital. Some services, such as respite, are offered during stage two (establishing illness representations). The data indicated that parents have not sufficiently grasped the psycho-social implications of PN to make informed choices at this stage. The reality of living on reduced sleep and with reduced freedom may prove over-whelming for some parents, regardless of the various coping mechanisms that they employ. It may be useful to feed this back to services, and explore flexible care pathways that allow people to quickly revisit earlier options, if necessary. In addition, the financial implications of having a young child on PN should be considered. Extra funds could address the unseen costs of PN (extra nappies, electricity for washing bedding). In determining funds, the financial benefits of facilitating parents to continue PN provision in the home, rather than in hospital, should be kept in mind (19).

Consideration of need is especially pertinent given the finding that, regardless of availability of family members, only mothers and partners/carers were trained in administering PN. Mothers indicated this was due to not wanting them or their child to be perceived as a burden, not feeling confident leaving PN in the hands of another person in

terms infection management, and family members being unable to take time off work to train in PN. The first two factors could be addressed in the context of a supportive therapeutic relationship, although it should be noted that mothers did not express a wish to change these perceptions. The third barrier could be addressed by offering PN training outside of office hours, although staffing may prove difficult, particularly in light of participants' sense that the PN team are already under-staffed.

### **Information and peer support in the journey of awareness**

Mothers described a tendency to find negative material more salient during their self-directed learning, and wished they had been provided with some balanced, printed material before they began training. Some mothers stressed that, initially, acknowledging the riskiness of PN can be terrifying; they suggested that risk would be easier to come to terms with if they had accurate material and support. The importance of perceived social support in mediating the psychological impact of coping with a chronically ill child has been demonstrated in previous research (48). Mothers appeared to utilise each other as one source of such support; providing reassurance and guidance to mothers new to PN. This self-supporting model makes sense: long-term PN is a relatively rare occurrence and mothers have to be creative in creating links, finding commonalities, and determining what to expect from their children. This strength of the PN population, and the myriad benefits offered by such a sense of community and understanding, should be capitalised on. Opportunities to promote and sustain these links, through social groups and “days out”, could be explored and supported. Furthermore, the results indicate that a group model of psychological support could be explored for this group of parents. Such a model could be co-facilitated by a member of the psychology team, but posit parents in a co-facilitator expert role. This could be a powerful way to support mothers new to PN, and provide other mothers with a chance to share their knowledge and skills.

### **Nurturing and teaching: the role of the mother**

Despite the pain experienced by the families, these experiences appeared to have impacted positively on their relationships with their children. Children were discussed in positive, miraculous terms; mothers' respect and admiration was evident. It is possible that the intimate nature of the PN process, particularly given the finding that parents did not wish others to provide PN, affords bonding opportunities similar to breast or bottle feeding. This aspect of Furthermore, Emedo et al.'s (33) results indicated that child understanding of illness and treatment was related to good adjustment to their PN; the mothers in this study described the various sensitive, appropriate, and playful ways they explained PN to their children, and allowed them to feel included in the process. In this manner, parents appeared to use the time spent engaged in PN as an opportunity for nurturing, bonding with, and teaching their child; these adaptive family processes have been discussed elsewhere in regards to family resilience and chronic illness.

### **The pervasive nature of trauma and need for staff awareness?**

These mothers had experienced seeing their child critically ill, and potentially had to consider the possibility of their child's death. The impact of such early trauma on parent experience has been explored in other literature (22,23). The impact of early trauma on parents' perception of risk, and their need to be sensitively included in decision-making, should be recognised and honoured. Some mothers had experienced others as insensitive, leaving them feeling disempowered, neglected and actively mistrusted. The negative impact of such relationships on parents and their children in hospital has been previously explored and evidenced (49). Early negative experiences may encourage parents to make certain attributions about staff, and discourage them from seeking support for fear of similar experiences being repeated. An important element of the parents' sense of being "under scrutiny" was social worker involvement. Some mothers discussed their fear of having their children removed from them if they were perceived as providing insufficient care. This is an understandable fear; there have been recent UK examples of children on home PN who have been placed into foster care as a result of recurring sepsis (50). These extreme cases are likely

to increase parents' sense of needing to "perform" for others; they also highlight the need to adequately assess the level of support that parents require at home.

Considering the necessity of these parents to develop and continue positive working relationships with staff on their multiple returns to hospital, it is vital that they are supported to feel as included, respected, trusted and understood as possible. This is especially important given parents' awareness of the increased risk of line infection in hospital and the importance of staff/family relationships in models of family resilience. Staff-wide training of the importance of collaborating with parents, and supporting them to continue their PN routines on their return to hospital, would be a useful way of implementing change at a system level. In addition, explicit and safe pathways through which parents can communicate their opinions and concerns should be considered. The mothers' message to other mothers about the need for them to "speak up" could be shared in educational materials.

### **The role of the researcher: a further reflection**

The interviewer's previous relative lack of exposure to PN was a strength of this study. Entering into the interviews with an awareness of the mothers' expertise meant they were truly posited as having the answers. Mothers were forthcoming in introducing topics into the interview and the resulting data were as much provided spontaneously by the mothers as by the interview schedule. Given the sensitive nature of the subject matter, the researchers training in recognising and responding appropriately to distress was also beneficial in terms of protecting the participants.

### **Limitations**

Given the small sample, results must be generalised with some caution. IPA is most usefully employed with homogenous groups (43) but this may limit the applicability of the results to mothers from others cultures. It is possible that sensitive topics may be difficult to explore with a person with whom you do not have a pre-existing, supportive relationship. Conversely,

some participants relayed that it was liberating to speak openly to someone unconnected with the clinical team. Parents were aware that the gastroenterology team would be presented with the study results; this may have influenced the style of their responses. Given the small sample, demographic information was provided collectively for the group. While this decision preserved the anonymity of the mothers, the lack of context may inhibit the impact of the verbatim data and make it difficult overall to interpret the data. It would be useful to have a follow-up session, in which the results of the study could be discussed with the mothers.

In addition, the mothers' responses in regards to how siblings and partners experience PN may not reflect how those individuals would have answered the questions themselves. The voice of the father is conspicuous by his absence in this study; on reflection, it would have been equally useful to explore these experiences from fathers' perspectives.

### **Future Research and Clinical Implications**

The study has presented many indications for supporting mothers of young children to cope, and ultimately adapt, to PN. The resilience that was evident in mothers should be supported through reflection on the appropriateness of service design, facilitating access to respite, and promoting opportunities for parents to share time and expertise with similar others through social or psycho-social groups. Such changes would benefit both parents and children, as Emedo et al's (33) study indicated. The PPN model could be clinically useful for working therapeutically with parents who are struggling to adapt to PN. Providing parents with an idea of what to expect in each stage of this unpredictable journey may increase their sense of control over their environment. Judson's (32) work with mothers pointed to the importance of feeling in control in regards to coping with PN. This may also be facilitated through the production of literature containing the model and illustrated with quotes and indications from the current study. Future research could test the validity and usefulness of the model for parents with older children. Given the level of adaptation, creativity, commitment, and care required of mothers, it is vital that their expertise is recognised and utilised. The PPN model provides a starting point from which services and clinicians can develop greater

understanding of the lived experience of families involved in PN, in regards to the challenges they face and the potential that they demonstrate. Such increased understanding may contribute to services in which family challenges and strengths are equally recognised, and the resilience of families is supported and encouraged.

## REFERENCES

1. Colomb V, Dabbas-Tyan M, Taupin P, et al. Long-term Outcome of Children Receiving Home Parenteral Nutrition: A 20-year Single-center Experience in 302 Patients. *J Pediatr Gastroenterol Nutr* 2007; 44(3):347-53.
2. Irving S, Simone SD, Hicks F, et al. Nutrition for the Critically Ill Child: Enteral and Parenteral Support. *AACN Clin Issues* 2000; 11(4):541-58.
3. Koletzko B, Goulet O, Hunt J, et al. Home parenteral nutrition in children. *J Pediatr Gastroenterol Nutr* 2005; 41:S70-5.
4. Gupte G, Beath S, Kelly D, et al. Current issues in the management of intestinal failure. *Arch Dis Child* 2006; 91(3):259-64.
5. Johnson T, Sexton E. Managing children and adolescents on parenteral nutrition: Challenges for the nutritional support team. *Proc Nutrition Society* 2006; 65(3):217-21.
6. Olieman J, Penning C, Marjolein S, et al. Long-term impact of infantile short bowel syndrome on nutritional status and growth. *Br J Nutr* 2012; 107:1489-97.
7. Sadlier C. Intestinal failure and long-term parenteral nutrition in children. *Paediatr Nurs* 2008; 20:37-43.

8. Berthold K, Goulet O, Hunt J, et al. Guidelines on Paediatric Parenteral Nutrition of the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and the European Society for Clinical Nutrition and Metabolism (ESPEN), Supported by the European Society of Paediatric Research (ESPR). *J Pediatr Gastroenterol Nutr* 2005; 41: S1-S4.
9. Holden C. Review of Home Paediatric Parenteral Nutrition in the UK. *Br J Nurs* 2001; 10(12): 782-88.
10. Bisset W, Stapleford P, Long S, et al. W.M., Stapleford, P., Long, S. et al. HPN in chronic intestinal failure. *Arch Dis Child* 1992; 6: 109-14.
11. Ralston C, O'Connor M, Ameny M, et al. Somatic growth and developmental functioning in children receiving prolonged home total parenteral nutrition. *J Pediatr* 1984;105:842-6.
12. Carlsson G, Hakansson A, Rubensson F, et al. Home parenteral nutrition in children in Sweden. *Paediatr Nurs* 1997; 23: 272-74.
13. Gorski A, Goulet O, Lamor M, et al. Home parenteral nutrition in children. Evaluation after 8 years' activity with 88 patients. *Arch Fr Pediatr* 1989; 46(5): 323-9.
14. Engström I, Björnastam B, Finkel Y. Psychological Distress Associated With Home Parenteral Nutrition in Swedish Children, Adolescents, and Their Parents: Preliminary Results. *J Pediatr Gastroenterol Nutr* 2003; 37: 246-51.

15. Sexton E, Holden C, Coad J. A review of homecare packages developed for home parenteral nutrition patients and their families. *Br J Nurs* 2005; 14: 1028-32.
16. Ricour C, Gorski A, Goulet S, et al. Home parenteral nutrition in children: 8 years of experience with 112 patients. *Clin Nutr* 1990; 9(2): 65-71.
17. Gottrand F, Staszewski P, Colomb V, et al. Satisfaction in Different Life Domains in Children Receiving Home Parenteral Nutrition and Their Families. *J Pediatr* 2005; 146: 793-97.
18. Hatzmann J, Maurice-Stam H, Hugo S, et al. A predictive model of Health Related Quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system. *Health Qual Life Outcomes* [serial online] July 2009; 7: Available from doi:10.1186/1477-7525-7-72. Accessed February 02, 2013.
19. Brook G. Quality of Life Issues: Parenteral Nutrition to Small Bowel Transplantation – A review. *Nutr* 1998; 14(10): 813-16.
20. Wong C, Akobeng A, Miller V, et al. Quality of life of parents of children on home parenteral nutrition. *Gut* 2000; 46(2): 294-5.
21. Ødegård W. Chronic Illness as a Challenge to the Attachment Process. *Clin Child Psychol Psychiatry* 2005; 10(1): 13-22.
22. Shin H, White-Traut R. The conceptual structure of transition to motherhood in the neonatal intensive care unit. *J Adv Nurs* 2007; 58(1): 90-8.

23. Jackson K, Ternstedt B, Schollin J. From alienation to familiarity: experiences of mothers and fathers of preterm infants. *J Adv Nurs* 2003; 43(2): 120-9.
24. Britton J, Britton H, Gronwaldt V. Breastfeeding, Sensitivity, and Attachment. *Paediatrics* 2006; 118(5): 1436-43.
25. Stern J. Home parenteral nutrition and the psyche: psychological challenges for patient and family. *Proc Nutr Socb* 2006; 65: 222-26.
26. Fischler C. Food, Self and Identity. *Soc Sci Inf Stud* 1988; 27: 275-93.
27. Bisogni et al Who we are and how we eat: a qualitative study of identities in food choice. *J Nutr Educ Behav* 2002; 34(3): 128-39.
28. Winkler M, Hagan E, Wetle T, et al. An exploration of Quality of Life and the experience of living with home parenteral nutrition. *J Parenter Enteral Nutr* 2010; 34(4): 395-407.
29. Winkler M. Quality of Life in Adult Home Parenteral Nutrition Patients. *J Parenter Enteral Nutr* 2005; 29(3):162-70.
30. Gustafsson U, Draper A. The social aspects of food and nutrition. *J Hum Nutr Diet* 2009; 22(2): 87-8.
31. Coffey J. Parenting a child with chronic illness: A metasynthesis. *Pediatr Nurs* 2006; 32(1): 51-9.

32. Judson L. Protective care: Mothering a child dependent on parenteral nutrition. *J Fam Nurs* 2004; 10(1): 93-120.
33. Emedo M, Godfrey E, Hill S. A qualitative study of the quality of life of children receiving intravenous nutrition at home. *J Pediatr Gastroenterol Nutr*; 50(4), 431-40.
34. Lee I, Lee E, et al. Concept development of family resilience: a study of Korean families with a chronically ill child. *J Clin Nurs*; 13, 636-45.
35. Drotar D. Relating Parent and Family Functioning to the Psychological Adjustment of Children with Chronic Health Conditions: What Have We Learned? What Do We Need To Know? *J Pediatr Psychol* 1997; 22(2): 149-65.
36. Meyerson D, Grant K, Smith Carter J, et al. Posttraumatic growth among children and adolescents: A systematic review. *Clin Psychol Rev* 2011; 31(6); 949-64.
37. Calhoun L, Tedeschi R. *Facilitating post-traumatic growth: A clinician's guide*. Mahwah, NJ: Lawrence Erlbaum; 1999.
38. Calhoun L, Tedeschi R. The foundations of posttraumatic growth: An expanded framework. In Calhoun L, Tedeschi R, eds. *Handbook of posttraumatic growth: Research and practice*. Mahwah, NJ: Erlbaum; 2006: 3-23.
39. McCombie A, Mulder R, Geary R. How IBD patients cope with IBD: A systematic review. *J Crohns Colitis* 2013; 7(2): 89-106.

40. Mustard J. Experience-based brain development: Scientific underpinnings of the importance of early child development in a global world. *Paediatr Child Health* 2006; 11(9): 571–72.
41. Knudsen E. Sensitive Periods in the Development of the Brain and Behavior. *J Cogn Neurosci* 2004; 16(8): 1412-25.
42. Gerhardt S. *Why love matters: How affection shapes a baby's brain*. London: Routledge; 2004.
43. Smith J, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage; 2009.
44. Smith J, Osborn M. Interpretative Phenomenological Analysis. In Smith J, ed. *Qualitative Psychology: A Practical Guide to Research Methods*. London: Sage; 2008.
45. Smith J. Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health and psychology. *Psychology and Health* 1996; 11(2): 261-71.
46. Reid K, Flowers P, Larkin M. Exploring lived experience. *Psychologist* 2005; 18(1): 20-3.
47. Leventhal H, Meyer D, Nerenz D. The common sense representation of illness danger. *Contributions to Medical Psychology*; 2: 7-30.

48. Speechley K, Noh S. Surviving childhood cancer, social support, and parents' psychological adjustment. *J Pediatr Psychol* 1992; 17(1): 15-31.
  
49. Heller K, Solomon M. Continuity of care and caring: What matters to parents of children with life-threatening conditions. *J Pediatr Nurs* 2005; 20(5): 335-46.
  
50. Zamvar V, Lazonby G, Puntis J. Recurrent life-threatening sepsis in intestinal failure: transplantation or foster care? *Arch Dis Child* 2013; 98(7): 556-7.

**CHAPTER 3: ADVANCED PRACTICE 1**  
**CRITICAL REFLECTIVE ACCOUNT**

**A reflection on communication: Process issues, professional bilingualism,  
and authenticity inside and outside of the clinic room.**

**(Abstract only)**

## ABSTRACT

**Introduction:** Effective communication is one of the core competencies required of a qualified clinical psychologist. I have used this account to reflect on some of the key experiences that have shaped my understanding of communication and power dynamics.

**Reflection:** Throughout the course of my training, I have been facilitated to broaden my understanding of what constitutes successful communication; this has happened through the interdependent processes of direct experience, research, reflection, discussion, and experiments in different types of approach. Theoretical approaches, such as discourse analysis, and experiences with clients have encouraged me to be cognisant of attending to the power of spoken and written words. I have learned to try not to let words distract me from non-verbal processes and communications in the clinic room. The task of assimilating my psychological perspective into teams which are often saturated with medical language has challenged me; I have reflected on the kinds of language and communicative stances that can bridge the divide between diagnostic-lead versus formulation-lead approaches. I have developed a respect for the need for honest communication within the supervisor-supervisee relationship, and the growth and learning that such discussions can promote. I have also been struck by the privileged position of the psychologist in advocating for those who, for multiple reasons, find themselves without a voice.

**Meta-reflection:** I hope to use my professional voice to facilitate change at a policy level, when I am qualified. I see this as a duty and privilege of psychologists; I have also come to understand that inputting at a system level is a vital way of keeping a sense of professional purpose when working with people who are constrained by inequality and punitive systems.

**CHAPTER 4: ADVANCED PRACTICE 2**  
**CRITICAL REFLECTIVE ACCOUNT**

**Moving beyond listening: Challenges in translating qualitative research  
into service development**

**(Abstract only)**

## ABSTRACT

**Introduction:** The usefulness of qualitative research in elucidating the lived experiences and challenges faced by service-users, and identifying associated areas for service development, has been increasingly recognised in healthcare (Biggerstaff & Thompson, 2008). Despite the increase in popularity, qualitative methods are still regarded with reservation by some clinicians. The Chief Scientist Office (2009) has raised the challenge to researchers that their results must be translational; that is, they should translate into perceptible gains for participants and the wider public.

**Reflection:** In order to strive for translational results, I have had to proactively and creatively address other disciplines' concerns, and consider how to make my results accessible to the wider healthcare system. Experience has also taught me to be aware of my own reactions when designing a piece of research and identifying appropriate participants. Any anxiety that I feel towards the inclusion of individuals who have experienced adverse events should be addressed, so that it does not lead to paternalism under the guise of beneficence. I feel that clinicians have much to learn from the considered and safe inclusion of resilient individuals who are able and willing to share their story. Continued contribution to the evidence base is an important role in clinical psychology. The changing organisational world in which I will enter as a qualified clinical psychologist will mean that my contribution may be offered through the indirect modes of supervision, teaching, and training.

**Meta-reflection:** I have benefitted from reflecting on my commitment to promoting the use and awareness of qualitative methods in health research. I will bring my reflection on beneficence versus paternalism into any future direct or indirect research experiences.

## **APPENDICES**

## **Appendix 1: Systematic Review**

## Appendix 1.1:

### Instructions for authors: Journal of Pediatric Gastroenterology and Nutrition

#### SCOPE

The *Journal of Pediatric Gastroenterology and Nutrition* publishes original articles, special reports, review articles, rapid communications, case reports, letters to the editor, short communications, and commentaries on all aspects of pediatric gastroenterology, hepatology, and nutrition.

The journal follows the International Committee of Medical Journal Editors' *Uniform Requirements for Manuscripts Submitted to Biomedical Journals* (URM). Manuscripts must be prepared in accordance with the URM (N Engl J Med 1997; 336:309-15 and updated at <http://www.icmje.org/>). **Manuscripts not prepared according to the Instructions to Authors will be returned to the author(s) without review.**

#### ARTICLE TYPES

**Original Articles:** Original articles are full-length reports of original research. Original articles are accepted based on their scientific relevance, the originality of the work, and the priority of the work for JPGN and its readership. Authors should aim for accuracy, clarity, and brevity. Long introductions, repetition of data among tables, figures, and the text, and unfocused discussions should be avoided. No more than 50 references permitted.

#### MANUSCRIPT PREPARATION

Manuscripts that do not adhere to the preceding guidelines and following instructions will be returned to the corresponding author for technical revision before undergoing peer review. Concise, clearly written articles are more likely to be accepted for publication in the Journal of Pediatric Gastroenterology, JPGN. Authors whose first language is not English are encouraged to ask a native English-speaking colleague or a professional author's editor, preferably with knowledge in the subject matter contained in the manuscript, to edit their manuscript before submission. A list of editing services is available at <http://journals.lww.com/jpgn/layouts/1033/oaks.journals/editservices.aspx>.

**Title page:** Include on the title page (a) complete manuscript title; (b) authors' full names, in order first name (given name) then last name (family name), highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and e-mail address; (d) address for reprints if different from that of corresponding author; (e) all sources of support, including pharmaceutical and industry support, that require acknowledgment; (f) disclosure of funding received for this work from any of the following organizations: National Institutes of Health (NIH); Wellcome Trust; Howard Hughes Medical

Institute (HHMI); and other(s); and (g) the word count of the manuscript body (excluding abstract, keywords, references and figure legends), number of figures and number of tables.

**Title length:** The manuscript title should include no more than 120 characters, including spaces.

**Structured abstract and key words:** Limit the abstract to 250 words. Do not cite references in the abstract. Limit the use of abbreviations and acronyms. Use the following subheads: Objectives, Methods, Results, and Conclusions. List three to five key words.

**Text:** Organize the manuscript into four main headings: Introduction, Materials and Methods, Results, and Discussion. Define abbreviations at first mention in text and in each table and figure. If a brand name is cited, supply the manufacturer's name and address (city and state/country).

**Data Analysis:** Description of data analyses should provide the specific methods used, their rationale, their assumptions, whether data met those assumptions, and how any missing data were handled.

**Abbreviations:** For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

**References: Please adhere to the reference limits noted for each article type above.** The authors are responsible for the accuracy of the references. Key the references (double-spaced) at the end of the manuscript. Cite the references in text in the order of appearance. Cite unpublished data—such as papers submitted but not yet accepted for publication and personal communications, including e-mail communications—in parentheses in the text. If there are more than three authors, name only the first three authors and then use et al. Refer to the List of Journals Indexed in Index Medicus for abbreviations of journal names, or access the list at <http://www.nlm.nih.gov/tsd/serials/lji.html>. Sample references are given below:

#### **Journal article**

1. Rautava S, Lu L, Nanthakumar NN, et al. TGF- $\beta$ 2 induces maturation of immature human intestinal epithelial cells and inhibits inflammatory cytokine responses induced via the NF- $\kappa$ B pathway. *J Pediatr Gastroenterol Nutr* 2012;54(5):630-8.

#### **Book chapter**

2. Todd VR. Visual information analysis: frame of reference for visual perception. In: Kramer P, Hinojosa J, eds. *Frames of Reference for Pediatric Occupational Therapy*. Philadelphia: Lippincott Williams & Wilkins; 1999:205-56.

#### **Entire Book**

3. Ming S-C, Goldman H. *Pathology of the Gastrointestinal Tract*. Philadelphia: Lippincott Williams & Wilkins; 1998.

**Software**

4. Epi Info [computer program]. Version 6. Atlanta: Centers for Disease Control and Prevention; 1994.

**Online journals**

5. Friedman SA. Preeclampsia: a review of the role of prostaglandins. *Obstet Gynecol* [serial online] January 1988;71: 22-37. Available from: BRS Information Technologies, McLean, VA. Accessed December 15, 1990.

**Database**

6. CANCERNET-PDQ [database online]. Bethesda, MD: National Cancer Institute; 1996. Updated March 29, 1996.

**World Wide Web**

7. Sullivan D. Major search engines and directories. SearchEngineWatch Web site. <http://www.searchenginewatch.com/links/article.php/2156221>. Published May 8, 2011. Accessed July 13, 2012.

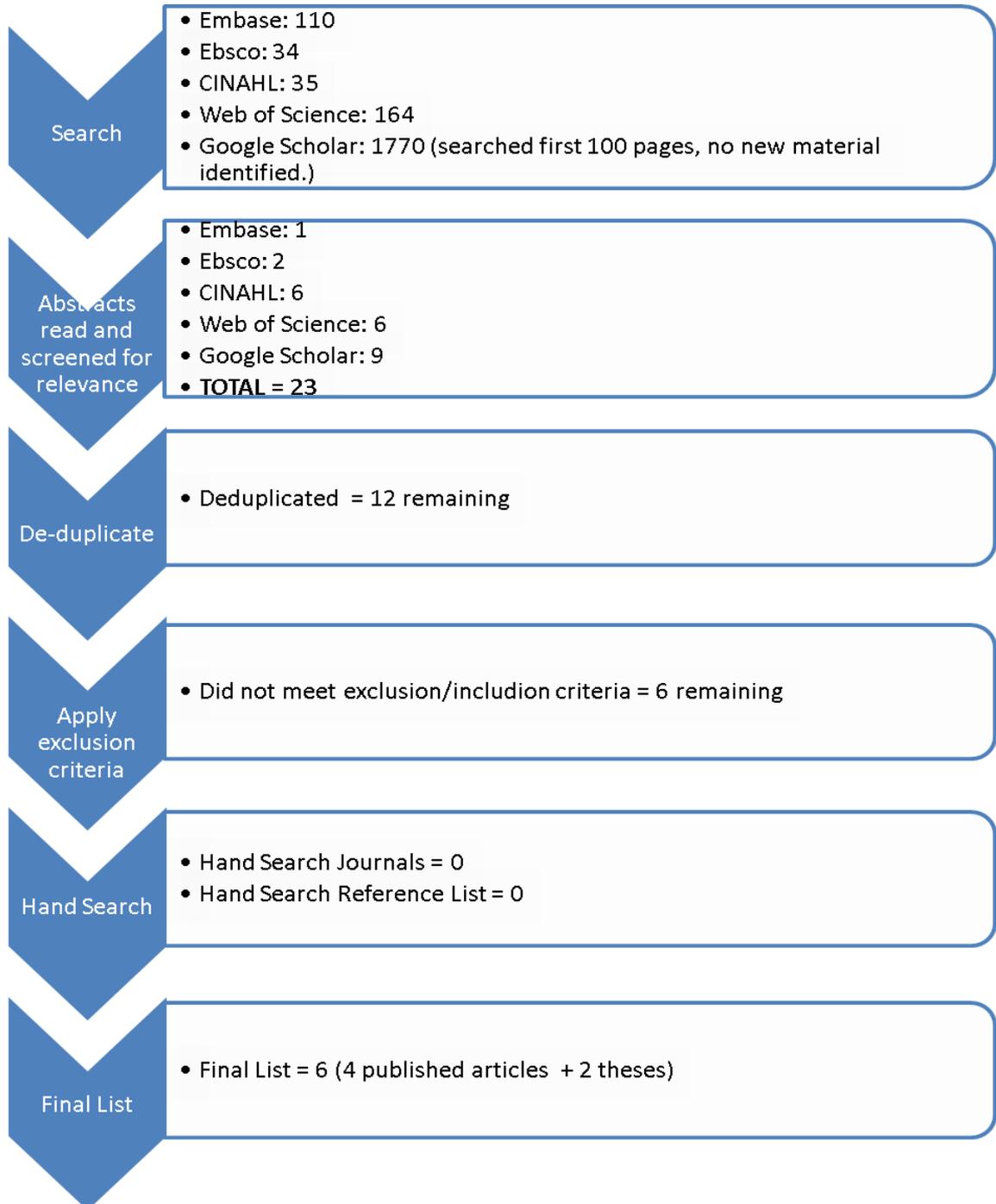
**Tables:** Cite tables consecutively in the text and number them in that order. Each table should be submitted as a separate Word document in text format. Each table must have a title. Use footnotes to define abbreviations and for other explanatory detail in a legend below the Tables. Tables should be self-explanatory and must supplement, rather than duplicate, the material in the text. Please let the editors and reviewers know if any of the tables are appropriate for the on-line supplemental material rather than needing to be in-print version.

**Figure legends:** Each figure must have a legend. Legends should be brief and should be typed on a separate manuscript page, directly following the reference list. Use scale markers in the image for electron micrographs, and indicate the type of stain used. Please let the editors and reviewers know if any of the figures are appropriate for the on-line supplemental material rather than needing to be in-print version.

**For full details see:** <http://edmgr.ovid.com/jpgn-na/accounts/ifaauth.htm>

## Appendix 1.2

### Flowchart detailing systematic identification of articles



### Appendix 1.3

#### Quality Rating Criteria (based on Walsh & Downe, 2006)

Stage	Essential Criteria	Present or Absent
Scope and Purpose	<ul style="list-style-type: none"> <li>- Clear statement of focus for research</li> <li>- Rationale for research</li> <li>- Questions/aims/purpose</li> <li>- Study thoroughly contextualised by existing literature</li> </ul>	1: 2: 3: 4:
Design	<ul style="list-style-type: none"> <li>- Method/design apparent</li> <li>- Above consistent with research intent</li> <li>- Rationale given</li> <li>- Data collection strategy apparent</li> <li>- Data collection strategy appropriate</li> </ul>	5: 6: 7: 8: 9:
Sampling Strategy	<ul style="list-style-type: none"> <li>- Sample and sampling method explained</li> <li>- Above justified</li> <li>- Above appropriate</li> </ul>	10: 11: 12:
Analysis	<ul style="list-style-type: none"> <li>- Analytic approach explained</li> <li>- Above appropriate</li> <li>- More than one researcher involved if appropriate</li> <li>- Participant involvement in analysis</li> <li>- Evidence of data saturation/discussion or rationale if did not</li> </ul>	13: 14: 15: 16: 17:
Interpretation	<ul style="list-style-type: none"> <li>- Context described</li> <li>- Context taken account of in interpretation</li> <li>- Clear audit trail (sufficient so others can follow decision trail)</li> <li>- Data used to support interpretation</li> </ul>	18: 19: 20: 21:
Reflexivity	<ul style="list-style-type: none"> <li>- Researcher reflexivity demonstrated</li> </ul>	22:
Ethical Dimensions	<ul style="list-style-type: none"> <li>- Ethical approval granted</li> <li>- Documentation of how consent was managed</li> <li>- Documentation of how confidentiality and anonymity were managed</li> </ul>	23: 24: 25:
Relevance and Transferability	<ul style="list-style-type: none"> <li>- Relevance and transferability evidence</li> <li>- Links to theories and literature</li> <li>- Limitations/weaknesses outlines</li> <li>- Outlines further directions for research</li> </ul>	26: 27: 28: 29:

Qualities marked as present or absent to provide an overview of the strengths and weaknesses of the papers, as opposed to exclude any of the material.

## **Appendix 2: Major Research Project**

## Appendix 2.1

### Parent Information Sheet

#### University of Glasgow

Department of Mental Health and Wellbeing

Gartnavel Royal Hospital

Administration Building

1055 Great Western Road

Glasgow, G12 0XH



#### Parent/Guardian Information Sheet

#### **Study Title: The experience of parenting a young child on parenteral nutrition**

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like some more information.

#### **Who is conducting the research?**

The research is being conducted by Leah Cronin and Dr Alison Jackson from Glasgow University's Academic Unit for Mental Health and Well-being alongside Dr Janie Donnan from the Medical Paediatric Department of Clinical Psychology, Dr Diana Flynn, Consultant Paediatric Gastroenterologist and Christina McGuckin, Paediatric Parenteral Nutrition Clinical Nurse Specialist, at the Royal Hospital for Sick Children.

#### **What is the purpose of this study?**

We want to find out what it is like to parent a child who has to be fed with parenteral nutrition. We hope that the information we discover might help the hospital services by identifying the particular

difficulties and challenges that parents might face. It might help us to develop ways to deal with these challenges.

### **Why have I been invited to take part?**

You have been invited to take part because you are a parent of a child who has been on parenteral nutrition for at least 6 months before the age of five and attends Yorkhill hospital gastroenterology services.

### **Do I have to take part?**

Participation is completely voluntary and confidential. It is up to you whether or not you wish to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form to show you have agreed to take part. You are free to withdraw from the study at any time, either during the interview or afterwards. You would not have to give a reason for withdrawing. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that you or your child receives or any future treatment.

### **What will happen if I take part?**

The researcher will meet with you to talk about your experiences parenting your child on parenteral nutrition. You might discuss both past experiences and more recent ones. This interview will take approximately 60 minutes and will be voice recorded. This recording will only be used for the purposes of this research. The recordings will then be erased immediately.

### **What happens to the information?**

You are in control of the amount of information and type of information you share with the researchers. You are not obliged to discuss anything that you are unwilling to discuss. You and your child's identity and personal information will be kept completely confidential and known only to the researchers. The voice recordings will be written out word-for-word (transcribed). Before the recordings are transcribed, any personal information that you give (such as names or addresses) will be changed. In this way, the transcribed scripts become anonymous and your personal information will not be stored. Transcriptions will be kept on an encrypted (safeguarded) computer so that only the research team will be able to access them. Once the transcription has been checked, the recording will be erased. The data will be held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission. Confidentiality would only have to be breached if child protection issues became apparent during the interview. This means that, if you said something during the interview that indicated that you or your child was at serious

risk of harm, the researcher would have to share their concerns with others. Some relevant sections of your medical notes and the data collected may be looked at by the regulatory authorities, such as NHS Greater Glasgow and Clyde and the University of Glasgow, for purposes of audit and where it is relevant to you taking part in this research.

### **What are the possible risks of taking part?**

There are no direct risks from taking part, although you might find it distressing talking about some of your experiences. You are entitled to take a break during the interview or tell the researcher if you wish to stop talking about any particular topic. You will be given a sheet on the day of the interview with contact details of routes to follow if you feel that you would like some support with any difficult emotions that you have about your experiences.

### **Who has reviewed the study?**

This study has been reviewed by the NHS West of Scotland Research Ethics Committee 1.

### **If you are interested in taking part?**

If you would like to take part, you have three options. You can complete the tear-off slip below, including a number on which to contact you. First, you can return it in the stamped addressed envelope provided or pass it on to a member of the gastroenterology team. Secondly, you can contact Christina McGuckin on 0141 2321878 or leave a voicemail saying that you wish to take part and giving the best number to call you on. You can also directly tell a member of your clinical team when you are in the clinic to pass on your contact details to the researchers.

Finally, you also have the option to directly contact Leah Cronin or Alison Jackson on 0141 211 3917.

Following this, you will be contacted by Leah Cronin, and an appointment will be made to meet with you after your child's next appointment in Yorkhill. Alternatively, you could suggest another time to meet in Yorkhill.

If you would like some further information about the study, please do not hesitate to contact Leah Cronin or Alison Jackson on 0141 211 3917.

Alternatively, if you would prefer to talk to an independent person, out-with the research team, please contact Dr Suzy O' Connor at the School of Medicine University of Glasgow, on

0141 211 0607.

**If you have a complaint about any aspect of the study?** If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance, but the normal NHS complaint procedure is also available to you.

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

*(Tear off Slip)*

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Research Study: **The experience of parenting a young child on parenteral nutrition**

Chief Investigator: Leah Cronin

Trainee Clinical Psychologist (University of Glasgow)

Participant Name \_\_\_\_\_

Signature \_\_\_\_\_

Telephone Number: \_\_\_\_\_

*For office use: A qualitative exploration of the experience of parenting a child on parenteral nutrition during the years of early development (both hospital and home based)*

**Participant number:** \_\_\_\_\_

## **Appendix 2.2**

### **Interview Schedule Version 2.**

The below questions have been developed from themes in the literature regarding parenteral nutrition, parenting, attachment, parent-health care provider interactions and coping. They are intended to be used as a guide in order to initiate discussion. The nature of the schedule is such that it allows for the introduction of new ideas and topics from the participant. Prior to commencing the interview, the participant will be reminded that they are entitled to pause for a break at any time, request a change of subject, or stop the interview completely. They will also be reminded that the information will be anonymised.

#### **A. Intestinal Failure**

Q. Can you tell me about your child's illness?

Prompt: What are the symptoms? How is it caused? What does it mean for them? How does it impact on them on a daily basis?

#### **B. Parenteral Nutrition**

Q. What PN Schedule does your child have?

Prompt: How long does it take for them? Who administers the PN? How does it work?

#### **C. Initial experience of Intestinal Failure**

Q How did you find out that your child had this illness?

Prompt: When did you first notice something was wrong? How did you know something was wrong? What did you think was happening? What was that like for you? What do you remember most about that time?

#### **D. Feeding before PN**

Q. What way did you feed your child before they required PN **OR**

What way had you planned to feed your child when you were pregnant??

Prompt: did you breast or bottle feed/manually feed/plan to do so? How would you describe that experience? How important was that for you?

**F. Discovering about PN**

Q. How did you find out about PN?

Prompt. Who told you about PN? How did they explain it? What did it mean to you at the time? How much did you understand it? What did you think it would mean for you and your child long-term?

**H. Initially experiencing PN**

Q. What was it like when your child first began being fed with PN?

Prompt. What did you think about PN? What was it like being trained in PN? How much control did you feel you had with your child's care? What was the hardest thing for you? What was the best thing about it?

**G. Experiencing the hospital staff**

Q. What was your experience of the staff during this time?

Prompt. How included were you in making decisions? How much control did you have in your child's care?

**E. PN and relationships**

Q. How has PN impacted on your relationship with your child, if at all?

Q. How has PN impacted on your child's other relationships (siblings, peers, family members), if at all?

**F. Child's experience:**

Q. What was it like for your child when they first started PN?

Prompt. How much did your child understand what was happening? Were there any particular difficulties with it? How did they react emotionally?

**I. Experience as a parent**

Q. How did PN impact on your experience as a mother, if at all?

**J. Coping during the process, Parent**

Q. How did you manage to do XYZ?

Q. What was your experience of the other people around you?

Prompt. How much do you think hospital staff understood what was going on for you? How much do you think family members and friends understood what was happening or what you needed?

**K. Experience of PN, Child.**

Q. How do you think they have coped with PN?

Prompt. How well have they adjusted? How quickly did they adjust? Is there anything new that they do now that they did not do before? Was there someone or something they found particularly helpful?

**L. Overall reflection on the experience**

Q. Thinking back over your whole experience, is there anything you would advise a parent who has just found themselves in the position of learning that their young child is going to be fed with parenteral nutrition?

Prompt. Is there anything you would or wouldn't do again now that you have the knowledge and experience of PN? Is there anything in particular that you feel they could only find out from another parent?

Q. In your opinion, what would a good psychological service need to know about to help parents in the position that you found yourself in with your young child?

Prompt. Is there anything that you would have liked to have been told or warned more about? Is there any particular part of the process that you would have liked more input? What kind of practical measures would be helpful?

Q. What's the most important thing you've learned from this process?

Q. Is there anything that I haven't discussed that you think would be important for me to know about in order to understand what PN was like for you and your family?

## Appendix 2.3

### Consent Form

#### University of Glasgow

Department of Mental Health and Wellbeing

Gartnavel Royal Hospital

Administration Building

1055 Great Western Road

Glasgow, G12 0XH



#### Participant number:

**The experience of parenting a child on parenteral nutrition**

#### Parent/Guardian Consent Form

I confirm that I have read and understand the information sheet dated (version 3) for the above study and have had the opportunity to ask questions

I understand that this is voluntary and that I can withdraw at any time, without giving a reason and that this will not affect any aspect of my child's care.

I am aware that the interview will be recorded by the researcher, Leah Cronin, and only used for the purposes of the research study, as described in the information sheet.

I understand that all names, places and anything that could identify my child or me will be removed and nothing that identifies my child or me will appear for others to see.

I agree to take part in the above study

-----	-----	-----
Name of Participant	Date	Parent Signature
-----	-----	-----
Name of Researcher	Date	Signature

*1 copy to the patient, 1 copy to the researcher, 1 Original for the patients' notes*

## Appendix 2.4

### Sample of coded interview and emergent themes

- Plain text = Content
- *Italicised text* = Discourse
- **Bold text** = Interpretation

Emergent themes		Interview	Notes/Codes	Line Number
	I	So just, if you wouldn't mind starting by telling me a bit about Craig's illness, if that's okay		1.
Early signs of difficulty  Changing course of illness	P	Well, Craig, from when Craig was born after a couple of days he came in to Paediatric Hospital, ehm because he started bring up green bile, ehm so he came in and went under a urologist because his bladder was very extended and floppy and he was retaining over a litre of urine, so before it was all kind of bladder related. So he was in as a baby for few months. Then he basically, constipation took over	Early signs of difficulty  <i>Green bile – idea of how difficult this was</i>  Initial bladder problems  <b>Changing diagnoses and focus for intervention</b>  In hospital for something else  <b>Sense of starting a story</b>  Focus changed from bladder to constipation	2.
	I	Mmmmm		3.
Child as vulnerable	P	But they tried to treat it just with giving him suppositories and they thought maybe it was just because his body, his body wasn't formed properly yeah	Initial efforts to treat him didn't work  Early diagnosis related to his body not being formed	4.

			<i>Not formed –why?.</i> <b>I wonder what reason they attached to this, what attributions they made?</b>	
	I	Okay		5.
Before and after PN	P	Okay, so the this went on for a couple of years and it kind of taken us to doing rectal washouts at home	Story of Pre-PN at home <b>There is a before and after in this story</b> Mum involved in rectal washouts at home	6.
	I	Okay		7.
Shocking change in expectation  Fright and shock	P	Ehm, then all of a sudden, in October there, one day he just kind of became really ill. He’s been in and out of hospital, obviously the last two years cos he’s suffered from dehydration a lot	<i>All of a sudden – sense that something changed quickly for her – a fright a shock?</i>  There were still signs of sickness – dehydration	8.
	I	Hmmmm		9.
Child’s health deteriorates	P	Cause, cause he doesn’t do any stools, or when he does its once every fortnight, and he’s on (medicine) for them, so aft-, come October we he came in, he just, it was dehydration basically	He doesn’t do stools  Dehydration	10.
	I	Hmmm, okay		11.
Changing course of illness  Emergency	P	He was really sick, bringing up the green bile and we brought him in for a couple of days, but we thought maybe it was just the same kind of thing. Let back out, and a day later he just got	Change in his presentation  They thought it was the same thing, it wasn’t  <b>Expectation of one thing – what was it like when</b>	12.

procedure		really sick. And when he came in his full body was septic so that was when they decided that they had to take out his bowels, ehm [pause], and then from then on in he's been on TPN since	<b>things got worse</b> His body was septic His bowels had to be removed. <b>An emergency procedure</b> <i>Ehm, she pauses. She is remembering a difficult time?</i>	
Trauma				
Shifting expectations				
	I	Okay		13.
Working diagnosis	P	He is still a working diagnosis	<i>"a working diagnosis"</i> <b>They still don't have all the answers for their child</b>	14.
	I	Okay		15.
	P	Not got a fully diagnosis for Craig yet,		16.
	I	Okay		17.
Searching for answers	P	Eh, he's goes straight to Specialist Hospital the next two months	He's going to see a specialist <b>Bringing him to another hospital – needing a 2<sup>nd</sup> opinion?</b>	18.
	I	Okay		19.
Body not working	P	There's lots of, obviously its affect his, his, it's basically the muscles in his body, his bowels and the bladder don't work properly	The disease he has affects his muscles, bowels and bladder <b>Body not working properly, sense of something wrong inside</b>	20.
Multiple impacts				
	I	Okay		21.
Time line	P	So, from there, so he's, obviously come October when	<i>Many operations – they have been through an ordeal</i>	22.

Sense of the journey		he came in after he got his bowels removed, after, <i>many</i> of other operations, in the last seven months he's now got the stoma	Situated in time, 7 months later he has a stoma <b>This is a journey, there is a timeline emerging</b>	
	I	He's got the stoma		23.
Introduction of PN to story	P	And a button put in for, to get some milk put in via the button, and he's now fed not by mouth, but via TPN,	Introduction of Stoma and button for milk <b>PN now part of story</b>	24.
	I	So, now, eh uh, how was he feeding prior to that, I know you were say-		25.
Before and after PN	P	Craig ate	Craig ate – the simplicity of this statement covers a complex change  <b>This is a little boy who ate – loss of something here, comparison</b>	26.
	I	He ate		27.
He didn't eat a lot  Loss of (healthy boy, eating boy)  Child defied the odds  Pride and wonder	P	He didn't eat a lot, he didn't eat a lot, he always felt full, but he suffered from extended stomach, so we put it down to that, but he was growing, he was growing, he used to drink a lot of cow's milk, and we think that's why. Ehm, he shouldn't have been able to tolerate the food, which he was eating, but somehow he did manage to tolerate it, up until two and half	He didn't eat a lot  <i>“He was growing “repeated – she was seeing him grow, we get a sense of what a shock all of this has been - something was working which is now broken, Loss</i>  He shouldn't have been growing due to disease – he defied the odds. <b>Is there a sense of pride here?</b>	28.

## Appendix 2.5

## Appendix 2.5: Letters of Ethical Approval



University of Glasgow | College of Medical,  
Veterinary & Life Sciences

TMcM/LC/ST

7<sup>th</sup> August 2012

Leah Cronin  
2/2  
4 Mingarry Street  
Glasgow  
G20 8NT

Dear Leah,

**Doctorate in Clinical Psychology Major Research Project**  
**A qualitative exploration of the experience of parenting a child on parenteral nutrition during the years of early development (both hospital and home based)**

The above project has been reviewed by your University Research supervisor and by a member of staff not involved in your project and has now been deemed fit to proceed to ethics.

Congratulations and good luck with the study.

Yours sincerely,

T M McMillan  
Professor of Clinical Neuropsychology  
Research Director

Doctorate in Clinical Psychology  
Programme Director: Dr Hamish McLeod

Mental Health and Wellbeing  
Admin Building, Gartnavel Royal Hospital  
1055 Great Western Road  
GLASGOW G12 0XH  
Direct line: +44(0) 141 211 3920/0607 Fax: +44(0) 141 211 0356  
Email: [mhwb-dclnpsy-students@gl.ac.uk](mailto:mhwb-dclnpsy-students@gl.ac.uk)

The University of Glasgow, charity number SC004401

**WoSRES**  
**West of Scotland Research Ethics Service**



**West of Scotland REC 1**

Ground Floor, Tennent Building  
Western Infirmary  
38 Church Street  
Glasgow  
G11 6NT

Ms Leah Cronin  
Trainee Clinical Psychologist  
NHS Glasgow and Clyde  
Admin Building,  
Gartnavel Royal Hospital, 1055 Great Western  
Road,  
Glasgow  
G12 0XH

Date 24<sup>th</sup> January 2013  
Direct line 0141-211-6270  
Fax 0141-211-1847

Dear Ms Cronin

**Study title:** **A qualitative exploration of the experience of parenting a child on parenteral nutrition during the years of early development: both hospital and home based.**

**REC reference:** **12/WS/0284**  
**Protocol number:** **GN12 KH45L**  
**IRAS project ID:** **112252**

Thank you for your letter of 06 January 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC on 22<sup>nd</sup> January 2013.] A list of the sub-committee members is attached.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Laura Sawiuk, [laura.sawiuk@ggc.scot.nhs.uk](mailto:laura.sawiuk@ggc.scot.nhs.uk).

**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, subject to the conditions specified below.

## Ethical review of research sites

### NHS sites

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

### Non-NHS sites

## Conditions of the favourable opinion

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

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

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

*Sponsors are not required to notify the Committee of approvals from host organisations*

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

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Interview Schedules/Topic Guides	1	26 August 2012
Investigator CV		
Other: Dr Alison Jackson (Academic Supervisor)		
Other: Email from Leah Cronin		06 January 2013
Participant Consent Form	1	03 August 2012
Participant Information Sheet: tracked changes	3	24 January 2013
Protocol	5	04 August 2012
REC application		17 October 2012

**Statement of compliance**

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

**After ethical review**Reporting requirements

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

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

Further information is available at National Research Ethics Service website > After Review

**12/WS/0284****Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



On behalf of

**Dr John Hunter**  
**Chair**

Email: [sharon.jenner@ggc.scot.nhs.uk](mailto:sharon.jenner@ggc.scot.nhs.uk)

*Enclosures: List of names and professions of members  
who were present at the meeting and those who submitted written  
comments*

*"After ethical review – guidance for  
researchers" [SL-AR2]*

*Copy to: Ms Joanne McGarry, NHS Glasgow and Clyde*

**West of Scotland REC 1**

**Attendance at Sub-Committee of the REC meeting on 22 January 2013**

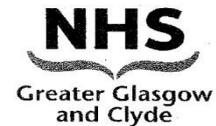
**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr John Hunter	Chairman West of Scotland (1) Ethics	Yes	
Dr Peter Hutchison	Vice Chair/GP	Yes	
Dr John D McClure	Statistician	Yes	
Dr Audrey Morrison	Research Practitioner	No	
Mr Robin Sim	Investments (retired)	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Sharon Jenner	Assistant Coordinator
Mrs Laura Sawiuk	Coordinator

R&D Management Office  
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Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

6<sup>th</sup> Feb 2013

Dr Janie Donnan  
Principal Clinical Psychologist  
Department of Clinical Psychology  
R H S C  
Dalnair Street  
Glasgow  
G3 8SJ

### NHS GG&C Board Approval

Dear Dr Donnan

**Study Title:** A qualitative exploration of the experience of parenting a child on parentaleral nutrition during the years of early development.  
**Chief Investigator:** Ms Leah Cronin  
**GG&C HB site:** RHSC  
**Sponsor:** NHS GG&C Health Board  
**R&D Reference:** GN12KH454  
**REC Ref:** 12/WS/0284  
**Protocol no:** V5 dated 04/08/12

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information related solely to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file.

2. **For all studies** the following information is required during their lifespan.
  - a. Recruitment Numbers on a monthly basis
  - b. Any change of staff named on the original SSI form
  - c. Any amendments – Substantial or Non Substantial

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Page 1 of 2

NonCommApproval\_R&D\_041010\_V3

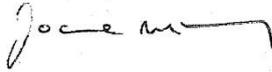
- d. Notification of Trial/study end including final recruitment figures
- e. Final Report & Copies of Publications/Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely



**Joanne McGarry  
Research Co-ordinator**

**CC: Ms Leah Cronin, Chief Investigator and Student, GRH  
Dr Alison Jackson, Academic Supervisor, GRH**

## Appendix 2.6

### Major Research Proposal

**“A qualitative exploration of the experience of parenting a child on parenteral nutrition during the years of early development (both hospital and home based)”**

Date of Submission: 30th July 2012

Version Number Five

Word Count: 3247

#### **Abstract**

*Background:* Parenteral nutrition (PN) is a life-saving procedure involving direct administration of nutrients into the blood stream. It is primarily used in intestinal failure. Previous studies involving children receiving home based PN have indicated that PN can impact on the quality of life and psychological health of parents and children, but can also be associated with resilience and coping. The experiences of parents of children involved in hospital based PN have not been represented. The potential impact of being unable to feed your child during the critical years of child development (age 0 – 5 years) on parental satisfaction, sense of parental efficacy, and attachment has not been explored and the area of coping and adjustment merits further exploration.

*Aims:* The current study aims to illustrate the experience of parenting an early developing child undergoing PN (home and hospital based) and to explore coping.

*Methods:* Semi-structured interviews will be conducted with parents of children who had a first incidence of PN before the age of five. The interviews aim to retrospectively elucidate the parents' individual experiences.

*Applications:* Findings may inform the development of a preventative gastroenterology psychology service in Yorkhill.

## 1.0 Introduction

### 1.1 Parenteral Nutrition

Parenteral nutrition (PN) is a life-saving procedure that involves the direct administration of nutrients into the blood stream. It is primarily used in intestinal failure, when nutrients cannot be absorbed from the gut. Intestinal failure can occur because of abnormality on the gut, genetic conditions (such as Short Bowel Syndrome and Congenital disorders of the intestinal epithelium) resulting in impaired absorption of food, or extensive gut resections leaving insufficient remaining intestine to allow for normal nutrition and growth (Johnston & Sexton, 2006). In some cases PN is a short term requirement, however, many children and families will have to adjust to PN as a permanent feature in their lives. Advances in medical knowledge in the 1970's resulted in the development of home PN whereby the parents and, wherever possible, the child are instructed in the technical process of administering PN (Carlsson et al., 1997).

### 1.2 A Focus on Home PN

It has been suggested that hospital based PN limits the child's opportunities for play and mixing with peers and may be associated with mild global delay (Ralston et al., 1984; Bisset et al., 1992). Home PN addresses these difficulties and has also been associated with a reduced risk of septicaemia or line damage (Johnston & Sexton, 2006, Gorski et al., 1989). However, the decision to allow a child and family to participate in home PN is mediated by a number of medical, practical and interpersonal factors such as the motivation and ability of the parent (European Society for Paediatric Gastroenterology, Hepatology and Nutrition, 2005; Bisset et al, 1992). Such caution is required given the complexity of the process; training can take two to four weeks prior to leaving the hospital (Engström et al., 2003; Bisset et al., 1992).

### 1.3 Quality of Life and Psychosocial impact of PN

There are a limited number of studies exploring the psycho-social impact of PN, all of which focus on individuals involved in home PN (Sexton et al., 2005). Earlier studies focused on the neurodevelopment of home PN patients and used concrete indicators of Quality of Life (QoL) such as access to holidays, access to education, and rates of divorce to assess impact. These studies concluded that home PN allowed for a good quality of life and family cohesion (Bisset et al., 1992; Carlsson et al., 1997).

Later studies have employed more in-depth measures of impact and achieved varying results. Gottrand et al (2005) employed validated, self-reported, non-disease-specific questionnaires to rate perceived satisfaction in a range of domains for children, siblings and parents involved in the home PN process (n = 72, median age = 4 years). QoL scores for the children and siblings did not differ from "healthy" children but QoL was significantly impaired in parents, particularly mothers, in the

domains relating to work inner life and freedom. The findings of impaired parental QoL are in keeping with research into general paediatric chronic illness (Hatzmann et al., 2009).

Factors cited as mediating the impact of PN on QoL include impaired sleep (PN is often administered at night) and reduced social activities, uncertainty regarding the child's future, unpredictability of hazardous events, and struggle to balance domestic and employment responsibility (Holden et al., 2001; Brook, 1998. Engström et al. (2003) conducted research with 21 families in which a child was accessing home PN. The researchers found that children and adolescents were distressed psychologically "although the reasons were unclear". The researchers also found that, while the social integration of the parents was high, levels of attachment were negatively affected. They hypothesised that attachment was adversely affected because of the presence of multiple others in the families' lives preventing "deeper, emotional relations". The issue of attachment in relation to the potential disruption of PN in the feeding and bonding process has not been examined previously although some psychodynamic adult literature on PN has highlighted that "food and feeding are invested with substantial emotional importance for each individual" (Stern, 2006).

In 2010, Emedo et al. conducted a qualitative study with seven children aged seven to seventeen years (mean age of 13) who were involved in long term home PN. The study found that, although their participants faced difficulties, it was possible for them to exhibit resilience, maintain a positive outlook, and cope well with illness-related demands. Factors associated with coping included: parental support, good understanding of illness and treatment, good peer relationships, emotional support from siblings, participation in usual childhood activities, and household pets. The study suggested that future research should aim explicitly to investigate how young people and their families formulate coping strategies (Emedo et al., 2010).

#### *1.4 Gaps in the research: qualitative studies, impact on parent experience in the early years, and exploring coping*

Studies in PN have not examined the experiences of those involved in hospital based PN and the area of attachment and early developing relationships for children who cannot be fed by their parents has not been explored. To date, there is only one piece of qualitative research that has been conducted with parents of children on PN; it is briefly referred to in a general article by the researchers but the results have not been published (Wong et al., 2000). Previous qualitative research into the experiences of parents caring for children with various chronic illnesses has produced meaningful and useful data that explain the mechanisms underlying the increased levels of psychological distress often noted in this population (Coffey, 2006). While it is helpful to assess the difficulties experienced by parents of children requiring PN, it would also be helpful to identify whether there are any particular factors that encourage successful adjustment to living in these unusual set of conditions, such as the growth-enhancing aspects and resiliency identified in Emedo et al.'s (2010) study and in other areas of paediatric illness (Barakat, Alderfer, & Kazak, 2006). The importance of considering parental coping and adjustment in relation to the physical and psychological adjustment in an ill child has previously been demonstrated in other areas of paediatric chronic illness (Drotar, 1997).

### *1.5 The current study*

The current study is unusual in that it aims to explore the unique experiences of parents whose children require PN both at home and in the hospital during the early years of child development. It will endeavour to explore factors that mediate coping. The decision to employ qualitative methods stems from the novelty of the area being explored and the sensitivity of the subject matter. The emphasis will be on the participants' unique experiences and the recognition of the participants as experts in the area being discussed. Positing the participants as experts allows for novel data generation- or "the ability to reveal unanticipated phenomena" (Shaw, 2001). Semi-structured interviewing will allow for "topically relevant, subjective perspectives" (Flick, 2002) to be elucidated.

## **2.0 Aims**

The study aims to explore the impact of hospital based and home based PN on the experience of parenting a young child in the early years of childhood development. It will examine issues such as parental satisfaction, sense of autonomy, attachment experiences, and ways of coping and making meaning.

## **3.0 Plan of Investigation**

### *3.1 Participants*

Purposive sampling will be employed. Participants will be recruited from Yorkhill hospital gastroenterology clinic. They must have parented a child who required PN during the period of early development (0 years – 5 years) for a 6 month minimum duration. This will include parents of children who no longer require PN (due to recovery or transplant). Currently, there are twelve children whose parents would meet participant criteria. Ten of these children are within the age of 0 – 5 years. The remaining children are aged 6 and 13 years respectively. There is nothing in the qualitative literature that indicates a maximum lapse of time between the experience being explored and the time of the interview, however, exclusion of the parents of the thirteen year old may lead to a more homogenous group.

### 3.2 Inclusion/Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Have parented a child on PN for at least 6 months before the age of 5	Have parented a child who required PN after the age of 5
Have sufficient command of the English language to communicate their views effectively	Need a translator to communicate to an English speaker (funds are not available to employ a translator)
Attend gastroenterology clinics at Yorkhill Hospital	Experiencing mental ill-health to the extent that the interview may be unhelpful for them (e.g. severe depression)

### 3.3 Recruitment Procedure

#### 3.3 (a) Recruitment

A member of the gastroenterology team will alert potential participants to the study. The principal researcher will then attend a routine PN clinic to give information in relation to the study. She will provide potential participants with information sheets that can be taken home and considered. A follow-up phone call will be made by a member of the gastroenterology team to record any expressed interest. They will also request an indication of how participants wish to be contacted and pass this information on to the principle researcher. An appointment will subsequently be arranged with interested participants, either at the time of their next gastroenterology clinic appointment, or a time that is more convenient for them. A follow-up phone call will be made during the interim. Participants will be recruited on a first come basis; this will continue until the required number of participants has been met, or thematic saturation has been achieved.

#### 3.4 Interview

A semi-structured interview will be conducted on an individual basis. This interview will be recorded using a digital voice recorder.

#### 3.5 Design

The study will use a qualitative design that involves conducting in-depth interviews with parents who attend Yorkhill hospital with their children. The interviews will be structured using a topic guide developed through discussion with the principal researcher and supervisors, using a health psychology model, literature on parenting and attachment, and ordered according to clarity and sensitivity (Smith,

1995). The topic guide will be piloted with a subset of the sample in order to practice interview technique and assess the suitability of the interview schedule. Subsequently, the schedule will be revised according to the emerging themes in the pilot interviews. Further, to ensure reliability of the analysis a second researcher with experience in Interpretative Phenomenological Analysis (IPA) will discuss themes and use samples of the transcripts to corroborate.

### 3.6 *Justification of Sample Size*

In accordance with Guest and colleagues (2006), between six and twelve participants will be recruited to reach data saturation, dependent on respondent rates. Smith and Eatough (2006) indicate that this will sufficiently allow the researcher to explore the participants' narratives and experiences.

### 3.7 *Settings and Equipment*

Interviews will be conducted by the principle researcher within an available private room in Yorkhill hospital. The interview will be conducted on an individual basis and will be audio recorded using a digital voice recorder. They will be transcribed verbatim by the principle researcher, and all identifiable information will be removed to preserve anonymity. The recordings will be stored on an encrypted laptop and destroyed on completion of transcription.

### 3.8 *Data Analysis*

The interviews will be transcribed using a complete account of what was said with an indication for pauses and breaks as is suggested for this form of analysis (Marks & Yardley, 2004). The use of the qualitative methodology Interpretative Phenomenological Analysis (IPA) will be employed to analyse this data (Smith & Osborn, 2003). IPA is an experiential, qualitative approach where the researcher tries to make sense of the meanings participants attribute to events and experiences. Analysis involves the identification of themes within data and the subsequent forging of connections between themes and across participants. This method allows the researcher to gain a deeper understanding of the participants' individual experiences, whilst taking into consideration the principle researchers own thoughts and theoretical concepts of such experiences.

## **4.0 Health and Safety Issues**

### *4.1 Researcher Safety Issues*

The interviews will be conducted on an individual basis, within normal working hours in the gastroenterology unit, and will comply with standard safety procedures. When participants are being interviewed, hospital staff will be nearby and available if required. Domiciliary visits will not be conducted.

### *4.2 Participant Safety Issues*

On the day of the interview, participants will again be provided with a detailed information sheet explaining the study; following this they will be asked to provide written informed consent. The opportunity to ask further questions will be available prior to the interview taking place and the opportunity to opt-out (with no repercussions) at any time throughout the research process will be made clear. Confidentiality will be explained to participants at the outset. If any participant discloses information which indicates that they or others are at risk, those involved will act professionally and appropriately, respecting the limits of confidentiality. It is acknowledged that the interview content may be personal and sensitive, and could potentially cause distress. Measures will be in place should a participant become distressed during the interview (such as taking a break, stopping the interview) and all participants will be provided with a leaflet with details of support sources and contact details.

If psychological difficulties are reported, or are otherwise apparent, this will be discussed with the participant and they will be signposted towards appropriate services.

## **5.0 Ethical issues**

Constitutional ethical approval will be sought from West of Scotland NHS Trust Ethics Committee as well as the local Research and Development department at Yorkhill hospital. Parents will be asked to provide written informed consent to participate in this study. They will have the opportunity to opt-out (with no repercussions) at any time from the study, and will receive written information sheets explicitly explaining that their responses are confidential and will not influence their future treatment in any way. Participants will be offered the opportunity to review a lay thesis summary of the results of the study, if they indicate interest. Data will be handled in accordance with The Data Protection Act (1998), the Freedom of Information Act (2000) and the NHS Confidentiality Code of Practice Guidelines (2003). All identifying information will be removed to preserve anonymity. Audio recordings will be stored on an encrypted laptop which will only be available to the researcher. When

transcription has been completed, each recording will be destroyed. Given the young age of the children being discussed, and the focus of the study on the experience of the parents, it is deemed unnecessary to obtain consent from the children of the participants.

## **6.0 Financial Issues**

Equipment costs will amount to one digital voice recorder (to be borrowed from The University of Glasgow) and photocopying costs.

## **7.0 Timetable**

April 2012:	Submit proposal to University
May/June 202:	Proposal assessed
July - Sept 2012:	Apply for ethical approval
October 2012:	Begin recruitment
Feb/March 2013:	Analysis
April-June 2013:	Write up research
July 2013:	Submit research to University
September 2013:	Viva

## **8.0 Practical Applications**

The Psychology Service provided to patients with PN in Yorkhill Children's Hospital is currently operating using a reactive model. The current study may result in the identification of psychosocial factors that may adversely affect parents' coping and adjustment; these in turn could inform the development and implementation of a preventative psychological service. To this end, the team are keen for this research to be undertaken.

## References

Barakat, L., Alderfer, M., & Kazak, A. (2006). Posttraumatic growth in adolescent survivors of cancer and their families. *Journal of Pediatric Psychology, 31*, 413 – 419.

Bisset, W.M., Stapleford, P., Long, S. et al. (1992). HPN in chronic intestinal failure. *Archives of Disease in Childhood, 6*, 109-114.

Brook, G. (1998). Quality of life issues: Parenteral nutrition to small bowel transplantation – a review. *Nutrition, 14*(10), 813-816.

Carlsson, G., Hakansson, A., Rubensson, F. et al. (1997). Home parenteral nutrition in children in Sweden. *Paediatric Nursing, 23*, 272-274.

Coffey, J. (2006). Parenting a child with chronic illness: A metasynthesis. *Pediatric Nursing, 32*(1), 51 – 59.

*Data Protection Act 1998*. (1998). London: Stationery Office.

Drotar, D. (1997). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What have we learned? What do we need to know? *Journal of Pediatric Psychology, 22*, 149 – 165.

Emedo, M., Godfrey, E., & Hill, S. (2010). A qualitative study of the quality of life of children receiving Intravenous Nutrition at home. *Journal of Pediatric Gastroenterology & Nutrition, 50* (4), 431–440.

Engström, I., Björnestam, B. & Finkel, Y. (2003). Psychological Distress Associated With Home Parenteral Nutrition in Swedish Children, Adolescents, and Their Parents: Preliminary Results. *Journal of Pediatric Gastroenterology and Nutrition, 37*, 246–251

European Society for Paediatric Gastroenterology, Hepatology and Nutrition. (2005). Home Parenteral Nutrition in Children. *Journal of Pediatric Gastroenterology and Nutrition*, 41(2). S70 - S75.

Flick, U. (2002). *An Introduction to Qualitative Research*. London, California, New Delhi: SAGE.

Gorski, A.M., Goulet, O., Lamor, M., Postaire, M., Lalondrelle, F., Corriol, O., Cauchefer, V., Nihoul-Fekete, C., Revillon, Y. & Jan, D. (1989). Home parenteral nutrition in children. Evaluation after 8 years' activity with 88 patients. *Archives Françaises De Pédiatrie*, 46 (5), 323-9.

Gottrand, F., Staszewski, P., Colomb, V., et al. (2005). Satisfaction in different life domains in children receiving home parenteral nutrition and their families. *Journal of Paediatrics*, 146, 793-797.

Guest, G., Bunce, A & Johnson, L (2006). How Many Interviews Are Enough? An Experiment with Data Saturation and Variability. *Field Methods*, 18, 59-82.

Hatzmann, J., Maurice-Stam, H, Heymans, H., & Grootenhuis, M. (2009). A predictive model of Health Related Quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system. *Health and Quality of Life Outcomes*, 7, 72 – 80.

Holden, C., Marinos, E., Russel, C., Shaffer, J., Micklewright, A., Wood, S., Wheatley, C., Meadows, N., Thomas, A., Stratton, R., Scott, D. (2001). Review of home paediatric parenteral nutrition in the UK. *British Journal of Nursing*, 10(12), 782-788.

Johnson, T. & Sexton, E. (2006). Managing Children and Adolescents on Parenteral Nutrition: Challenges for the Nutritional Support team. *Proceedings of the Nutrition Society, BAPEN Symposium 1 on 'Nutritional Support in Children and Adolescents*, 65, 217-221.

Marks, D. F. & Yardley, L. (2004). *Research methods for clinical and health psychology*. London: Sage.

National Health Service (2003). *Confidentiality Code of Practise Guidelines*. London: Stationery Office.

Ralston, C., O' Connor, M., Ameny, M., Berquist, W., Parmalee, A. (1984). Somatic growth and developmental functioning in children receiving prolonged home total parenteral nutrition. *Journal of Pediatrics*, 105, 842 – 846.

Sexton, E., Holden, C. & Coad, J. (2005). A review of homecare packages developed for home parenteral nutrition patients and their families. *British Journal of Nursing*, 14, pp. 1028 – 1032.

Shaw, R. (2001). Why use interpretative phenomenological analysis in Health Psychology? *Health Psychology Update*, 10 (4), 48-52.

Smith, J. A. (1995). "Semi-Structured Interview and Qualitative Analysis". In: Smith, J. A., Harre, R. & Langenhove, L. V. (Eds.) *Rethinking Methods in Psychology* (Eds.) 9-26. London: Sage Publications.

Smith, J. A. and Eatough, V. (2006). Interpretative Phenomenological Analysis. In: Breakwell, G. M., Hammond, S., Fife-Schaw, C & Smith, J. A. *Research Methods in Psychology*. Sage Publications Ltd.

Smith, J.A. and Osborn, M. (2003). Interpretative phenomenological analysis. In JA Smith (Ed) *Qualitative Psychology*. London: Sage.

Stern, J. (2006). Home parenteral nutrition and the psyche: psychological challenges for patient and family. *Proceedings of the Nutrition Society*, 65, 222 – 226.

Tarbell, S.E. & Kosmach, B. (1998). Parental Psychosocial Outcomes in Pediatric Liver and/or Intestinal Transplantation: Pretransplantation and the Early Postoperative Period. *Liver Transplantation and Surgery*, 4(5), 378-387.

*The Freedom of Information Act (2000)*. London: Stationery Office.

Wong, C. , Akoben, A., Miller, V., & Thomas, A. (2000). Quality of life of parents of children on home parenteral nutrition. *Gut*, 46(2), 294–295.

## **Appendix One: Lay Summary**

“A qualitative exploration of the experience of parenting a child on parenteral nutrition during the years of early development (both hospital and home based)”

### **Summary**

Children with certain stomach and intestine complications are not able to take in nutrients from the food that they eat. This can have a negative effect on their growth and overall health. Parenteral nutrition (PN) is a life-saving procedure which involves directly injecting a special mixture of important liquid nutrients into a child's bloodstream. It is a complicated process that can be provided at home to children. Not every family is considered suitable for home PN; these families are not spoken about in the literature on PN. PN has been shown to impact on parents and children in a number of ways. PN reduces the freedom families have to leave the house and socialise and can often interrupt sleep. Despite this, there is some evidence that families can continue to function well and cope. There are a number of questions this study would like to explore with parents of children who had to have PN in the early years of development (0 – 5) in both the home and hospital setting. How does it make you feel when you cannot feed your child using breast or bottle? What particular challenges does PN present to being a parent and continuing on with family life? How did you cope with these challenges and was there any particular help you would like to have had? What would you like to have been prepared for when your child was diagnosed? It is hoped that exploring these areas in an open way will provide us with vital information that can be drawn from to develop ways to support families experiencing PN.