VOLUME I

RESEARCH COMPONENT

Understanding transition from paediatric to adult services in young people with gastrointestinal disorders

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A thesis submitted to

The University of Birmingham

for the degree of

DOCTORATE IN CLINICAL PSYCHOLOGY

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May 2015

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Overview

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes: a research component (Volume I) and a clinical component (Volume II).

Volume I

This volume presents a systematic literature review, a qualitative research study and a public domain briefing paper. The literature review explored the current evidence for the barriers and facilitators for a successful transition to adult services for young people with gastrointestinal (GI) disorders. The research study used a qualitative approach to solicit perspectives from young people with coeliac disease, and their parents, on their experience of the transition process from paediatric to adult healthcare services. The public domain briefing paper is an executive summary of the literature review and research study.

Volume II

This volume presents five Clinical Practice Reports, which reflect clinical work conducted during placements completed for the Clinical Psychology Doctorate. Clinical Practice Report 1 describes the case of an 18-year-old woman experiencing anxiety and depression, formulated from cognitive-behavioural and systemic perspectives. Clinical Practice Report 2 presents a service evaluation, conducted in a Community Mental Health Team (CMHT) service, to explore whether all services users open to the team had equal and fair access to psychological therapies. Clinical Practice Report 3 is a single-case experimental design evaluating the effectiveness of a behavioural, exposure and response prevention (ERP)

intervention for food refusal exhibited by a 66-year-old male with a moderate learning disability. Clinical Practice Report 4 describes a case study of a 12-year-old boy with Crohn's Disease (CD), exhibiting repetitive, ritualised behaviours. Clinical Practice Report 5 is an abstract summarising an oral presentation of a case study involving the use of Acceptance and Commitment therapy (ACT) with a 64-year-old man, who was experiencing anxiety and depression in response to a diagnosis of non-Hodgkin lymphoma.

All names and identifying information have been altered or omitted to maintain confidentiality.

Acknowledgements

I would like to thank Heidi Urwin and her colleagues at Coeliac UK for supporting this research and helping in the recruitment of participants. Thank you to the young people and their parents who gave up their valuable time to participate in this research. It was a privilege to meet them and hear their life stories. This project would not have been possible without them.

To Dr Ruth Howard and Dr Gary Law, I am grateful for their dedication to this research and for all their words of wisdom. Their support and guidance throughout this process has been invaluable. Thank you both. I would also like to say a big thank you to Ms Laura Dennick for her continual support with carrying out qualitative research and for the hours she dedicated to my analysis.

Finally and most importantly, I would like to say a very special thank you to my family, whose endless love and support has undoubtedly kept me afloat. Thank you to my wonderful parents, Linda and Chris, for being my champions and never giving up hope in me. Everything I have achieved is because of them. To my brother and sister-in-law, Paul and Michelle, thank you for setting such a good exemplar. If I achieve half of what they have achieved I would consider myself very fortunate. Lastly, but by no means least, to my beautiful niece Juniper, whose smiles and laughter have boosted my spirits and kept me grounded throughout this whole process. Thank you.

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The transition from paediatric to adult health services of young people with gastrointestinal disorders: A systemic review and recommendations for healthcare delivery

Word Count: 7515

Prepared for submission to
Journal of Gastroenterology and Hepatology

Abstract

Objective: The transition from paediatric to adult healthcare services can be a critical time for young people with chronic health conditions, and is often associated with poor physical health and disengagement from services. This review explored the current evidence for the barriers and facilitators for a successful transition for young people with gastrointestinal (GI) disorders.

Method: Electronic databases were searched to identify studies on transitional care in GI disorders. The quality of each paper was systematically reviewed and scored.

Results: Seventeen studies were identified; sixteen investigated inflammatory bowel disease (IBD), and one investigated eosinophilic oesophagitis (EoE). The findings of this review suggest that the transition should be a flexible, gradual process that involves joint care between paediatric and adult services. The competencies of young people need to be assessed and developed to prepare them for adult care, with interventions also including parental involvement, especially concerning responsibility for condition management.

Conclusion: The review highlights multiple factors that need to be taken into consideration, both patient-related and organisational factors (including clinician-related), when facilitating transitional care. The findings of the review must be interpreted with caution due to methodological limitations of the studies, therefore, highlighting the need for further research on transitional care for GI disorders to help understanding of the barriers and facilitators.

Introduction

Adolescence is a challenging time, whereby individuals present with complex and diverse needs that are unique to their age group, including physical, emotional, psychological, and social (Royal College of Paediatrics and Child Health, 2003). Adolescence is even more difficult for young people with disabilities and/or chronic health conditions, as these conditions can create added stress and psychological burden, as well as act as a social barrier (Forbes et al., 2001; Royal College of Paediatrics and Child Health, 2003). Over the last 50 years the incidence of chronic health conditions in adolescents has increased, but so too has the survival rate in conditions historically fatal in childhood, such as cystic fibrosis, spina bifida and congenital heart disease (Hardelid et al., 2014; Newacheck & Taylor, 1992; Sawyer, Drew, Yeo & Britto, 2007).

It has been argued that adolescents require specialist health services that provide care appropriate to their cognitive, psychological and social development, and encourages the individual to develop independence and take responsibility for their health (Royal College of Paediatrics and Child Health, 2003). Young people with chronic health conditions are equally as likely to engage in risky behaviours (e.g. substance use, sexual activity, poor adherence to treatment) as their healthy peers, but are at a greater risk for adverse health outcomes as a result of these behaviours (e.g., acute chest syndrome in sickle cell anaemia; cardiovascular disease in diabetes) (Sawyer et al., 2007). The reality of risky behaviours highlights the need for health professionals to have good knowledge of the specific developmental needs of young people and their families, as well as the importance of individuals possessing the competencies to understand and manage their condition (Sawyer et al., 2007; Whiting-O'Keefe, Fye & Sack, 1991; Young Jr, Rachal, Hackney Jr, Uy & Scott, 1992).

Adolescence is a time of numerous and often concurrent transitions, including puberty, sexuality, independence, identity, moving from school to higher education or employment, as well as health (Blum et al., 1993; Kirk, 2008). Research has shown that transition from paediatric to adult services is a critical time for young people with chronic health problems and their parents, and is often associated with deterioration in physical well-being (Annunziato et al., 2007; Nakhla, Daneman, To, Paradis & Guttmann, 2009; Samuel et al., 2014).

Blum et al. (1993) defined transition as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health-care systems" (p. 570). The authors emphasised that transition is more than just a single event (i.e. transfer), but rather a gradual process that should not only address the medical needs of the young person, but also their developmental, psychosocial and educational/occupational needs (also see de Silva & Fishman, 2014).

The Department of Health/Department for Education and Skills (2006) published an evidence-based good practice guide, 'Transition: getting it right for young people', which provides an overview of the many issues that need to be addressed to ensure a "successful" transition. "Successful" transition includes, but is not limited to, good communication and consultation between all parties involved; timing the transfer appropriately and based on readiness of the young person, and not on chronological age; information about the transition; supporting the young person to develop skills to enable them to navigate adult care; and a clear and co-ordinated transfer. The importance of including and supporting parents in the process was also emphasised. A recent narrative review of current evidence of transition in inflammatory bowel disease made similar recommendations (de Silva & Fishman, 2014). This review suggested several skills necessary to navigate adult care, including disease-related

knowledge and independent information gathering, self-management, and self-advocacy. Independence was also highlighted as important, in order for the young person to be prepared for a culture shift from the nurturing and family-focused style of paediatric services to the autonomous and individual focus of adult services (de Silva & Fishman, 2014).

The Royal College of Paediatrics and Child Health report (2003), 'Bridging the gap: health care for adolescents', discussed the need for sufficient transition planning, and recommended specialist transition clinics. These transition clinics should be multi-disciplinary and include the input of both paediatric and adult services, thereby allowing the individual and their parents to be introduced to adult professionals before transfer. The involvement of psychological services was also favoured, along with the encouragement to discuss a wide range of issues affecting the individual and their family. No widely accepted model for transition has yet been established, although there is evidence to suggest the benefits of joint clinics involving all parties in the transition, patients visiting adult services before transfer, and the involvement of a coordinator (de Silva & Fishman, 2014).

Gastrointestinal (GI) disorders are just some of the many chronic health conditions common in childhood and adolescence. GI, as a term, refers to diseases of the gastrointestinal tract (from the oesophagus to the anus) and the impact on associated organs, such as the liver, gallbladder and pancreas. Conditions include gastro-oesophageal reflux disease, Crohn's disease, ulcerative colitis, coeliac disease and irritable bowel syndrome (Williams et al., 2007). Many of the chronic GI disorders can be self-managed, with minimal assistance from healthcare professionals, if individuals are adequately educated and supported by specialist services (British Society of Gastroenterology, 2006). In light of evidence that health-related behaviours acquired in adolescence continue during adulthood (Royal College of Paediatrics

and Child Health, 2003), it is important that education and self-management begins during adolescence to help ensure better health and quality of life as an adult.

The move from paediatric to adult healthcare services happens at a critical stage in development for young people with chronic health conditions. This review, therefore, explored the current evidence for the barriers and facilitators for a successful transition for young people with gastrointestinal (GI) disorders. The aims of this review are to:

- To summarise literature reporting the experiences of young people with GI disorders (and/or their parents) transitioning from paediatric to adult healthcare services;
- To review evidence on the utility and effectiveness of assessment tools to aid the transition process for young people with GI disorders;
- To summarise literature reporting the perspectives' of clinicians (e.g. gastroenterologists, dietitians, nurses) on the issue of transition from paediatric to adult healthcare services for young people with GI disorders.

Methodology

A literature review protocol, as set out by the Centre for Research Dissemination (2008), was followed to reduce the potential for bias. Initially, a scoping search was conducted to establish whether there was any existing systematic reviews on the topic area, and to assess the feasibility of a systematic review on the topic of transition for young people with GI disorders. The scoping search also allowed for the identification and refinement of key search terms, based on two key concepts of the review question: Gastrointestinal disorders and transition from paediatric to adult services (see Appendix 1 for key search terms). Inclusion and exclusion criteria were also determined for study selection (Table 1).

Table 1: *Inclusion and exclusion criteria*

Inclusion	Exclusion
• The study is about the transition/transfer from paediatric to adult physical healthcare services; • Chronic, incurable Gastrointestinal (GI) disorders: - Inflammatory bowel disease (Crohn's disease; Ulcerative colitis) - Coeliac disease - Irritable bowel syndrome - Oesophageal diseases - Gastro-oesophageal reflux disease - Diverticular disease; • Patients, parents, and healthcare professionals in either child or adult services; • Adolescents / young adults (12-25 years); • Published in English; • Study design: Randomised controlled trial (RTCs); quasi-experimental; observational studies (e.g. cohort, case series, surveys); qualitative studies (e.g. interviews).	• No reference to transition/transfer from paediatric to adult physical healthcare services; • Report non-GI disorders; chronic illness (i.e. studies that explored multiple chronic disorders); • Not published in English; • Publication type: Letter, book chapters, conference abstracts, editorials, supplements, still at trial; • Study design: Review of literature only; no outcomes; • Non-empirical articles.

Six electronic databases were searched to identify studies potentially relevant for review: MEDLINE (1946 – present [09.05.14]); EMBASE (1947 – 2014 May 23); PsycINFO (1967 – present [01.06.14]); Web of Science (ISI) (1900-2014 [01.06.14]); CINAHL Plus (EBSCO) (1982 – present [09.05.14]); and National Center for Biotechnology Information (NCBI) (08.06.14). These databases were selected to ensure a wide search of health literature from medical (including nursing) and psychological perspectives.

Following the results of the above database searches, initial screening was conducted on all the titles and abstracts (n=1328) to identify potentially relevant studies. Studies that clearly did not address the review question (i.e. transition from paediatric to adult healthcare of individuals with gastrointestinal disorders), were not written in the English language and were duplicates, were excluded (n=72 included). Backward reference searching (examining references of the identified studies) and forward reference searching (examining studies that cite the identified studies) was conducted to identify and include any relevant studies missed by the search of electronic databases (n=10). Each remaining study (n=82) was then hand-searched by scanning the full–text to assess its eligibility against the inclusion and exclusion criteria (n=65 excluded). A total of 17 studies were identified as being suitable for full review. See Figure 1 for a flow chart of the study selection process.

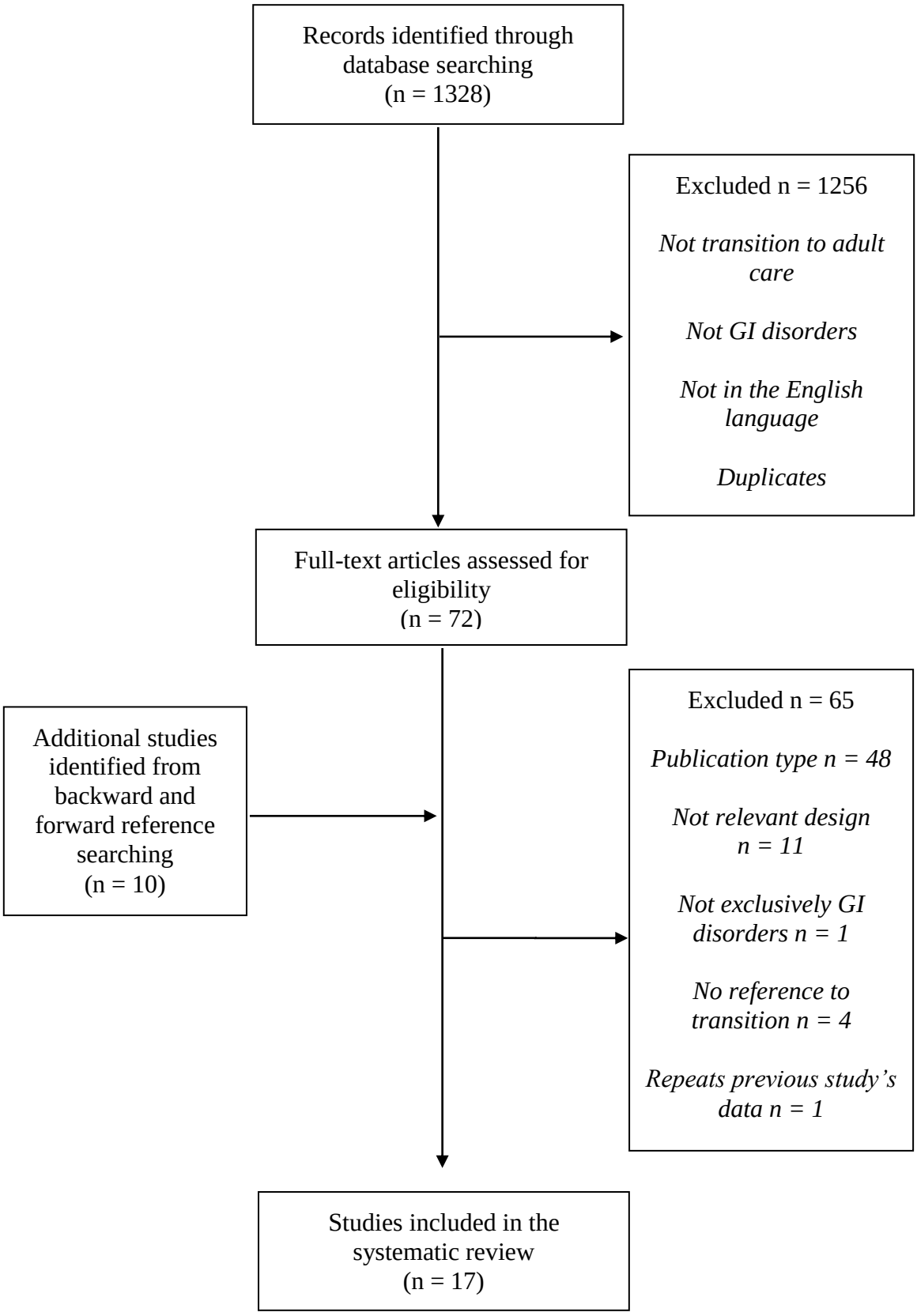


Figure 1: *Flow chart of study selection process*

Description of studies

Table 2 provides a summary of each study.

Country of origin

Of the seventeen studies included, five studies were conducted in the UK, six in the USA, two each from the Netherlands and Canada, and one each from France and Australia.

Study design

All seventeen studies utilised an observational design of which the majority were cross-sectional studies (n=13). Nine evaluated the transition process, two developed measures to aid transition, and two assessed patient competencies (i.e. key skills of self-management). Furthermore, seven of the cross-sectional studies used a comparison group(s) (i.e. patient and parent; patient and clinician; patient, parent and clinician; paediatric and adult clinician). Of the remaining four studies that were not cross-sectional, two were cohort in nature; one used prospective methods (Greveson et al., 2011) and the other used retrospective methods (Bollegala et al., 2013). Goodhand et al. (2010), a retrospective case-controlled study, was the only study to use a control group, and Dellon et al. (2013) used a case series design.

Disease type

Sixteen of the seventeen studies investigated inflammatory bowel disease (IBD). The remaining one study investigated eosinophilic oesophagitis (EoE; Dellon et al., 2013). There were no published studies on transition for coeliac disease or other gastrointestinal diseases such as irritable bowel syndrome, oesophageal diseases, and diverticulitis.

Setting

The patient sample studies (n=11) conducted their research in a specific clinical setting, meaning each study recruited participants from one clinic; the remaining studies involved nationwide recruitment of clinicians as participant samples.

Sample

Eleven studies consisted of samples of patients; three of which also included parents, and one study also included parents and the patients' paediatric gastroenterologists (Zijlstra et al., 2013). The remaining six studies involved clinician participants (e.g. paediatric gastroenterologists and/or adult gastroenterologists, and IBD nurses). Paine et al. (2014) also included psychologists and an administrator, as well as gastroenterologists and nurses.

The total sample size of the patient sample studies ranged from 21 (Greveson et al., 2011) to 100 (Goodhand et al., 2010), excluding a case series with four participants (Dellon et al., 2013). The sample size of parent participants (included in patient studies) ranged from 34 (Dabadie et al., 2008) to 64 (Benchimol et al., 2011); this excludes Fishman et al. (2010) who did not report these data. Five of the six clinician studies were quantitative, with sample sizes ranging from 106 (Houston et al., 2012) to 363 (Hait et al., 2009). The qualitative, clinician sample study included twelve participants (Paine et al., 2014).

The majority of the studies reported a response rate for participation (n=12) that ranged from 24% (Greveson et al., 2011) to 97.5% (Benchimol et al., 2011). Only three studies (Benchimol et al., 2011; Houston et al., 2012; Zijlstra et al., 2013) reported a response rate equal to or more than 65% (an acceptable response rate for questionnaires suggested by Kelley, Clark, Brown & Sitzia, 2003). Plevinsky et al. (2014) reported a high response rate, however this was not based on the number of potential participants (approximately 300), but

on those who had responded to the initial invitation (N = 39) and completed the questionnaire (N = 29). Therefore, the response rate was actually low (9.7%).

Eight patient sample studies reported age of participants, although there was variation in how this information was reported. Huang et al. (2012) reported the youngest age of ≥10 years for their assessment of patient health literacy. The highest reported maximum age was 30 years (Plevinsky et al., 2014) in a retrospective survey of patient experience. Neither study provided a rationale for the age criterion. Of the other studies that reported patient age, the age ranged from 14 to 20 years.

Method

The majority of the studies used non-standardised measures (N = 12), which had been purposefully developed to assess the transition process, whilst only two studies used validated measures (Huang et al., 2012; Zijlstra et al., 2013). Plevinsky et al. (2014) was the only study to use a mixed-methods approach by including both open- and closed-ended questions in their survey, and analysis included both quantitative (e.g. categorical data, Likert-scale) and qualitative (a phenomenological approach) methods. Two studies reviewed case notes to highlight problems and needs encountered during the transition process (Bollegala et al., 2013; Goodhand et al., 2010). Paine et al. (2014) conducted semi-structured interviews and used the constant comparative method to identify themes.

Table 2: *Summary of studies*

Study ***Origin***	**Aims**	**Setting** ***Age criteria***	**Participants** ***N (response rate)*** ***Age (A)*** ***Gender (G)*** ***Disease type (DT)***	**Study design** **Methodology**	**Results**
Clinician sample studies					
Barendse, aan de Kerk, Kindermann, Fishman, Grand, Bartelsman, & Heymans (2011) *the Netherlands*	Repeat Hait et al.'s (2009) survey and assess the perspectives of Dutch adult gastroenterologists on what is required for a successful transition for individuals with IBD.	Nationwide Gastroenterologists identified from Dutch Association of Gastroenterology and Hepatology membership list 69% general hospital, 31% academic *Not stated.*	Adult gastroenterologists *258 (47%)* *(A) Not stated* *(G) 81% males* *(DT) IBD*	Cross-sectional design. Survey: To rank the importance (Likert scale) of patient disease-related knowledge, independence, and ability to discuss social implications of their IBD. To indicate if these issues had occurred in their practice. To rate their competence in addressing needs specific to adolescence.	<u>Expectations regarding transition</u> High ranking factors deemed important: • Patient knowledge of impact of substance use (*social*) (mean = 4.7) • Patient's disease concept (*knowledge*) (mean = 4.6) • Patient initiating contact when experiencing problems (*independence*) (mean = 4.6). <u>Problems experienced in practice</u> • Patients' inability to talk about impact of their disease (60%). • Poor medication knowledge (53%). • Poor knowledge of impact of substance use (53%). <u>Competence rating</u> 34% of adult gastroenterologists felt competent in addressing the developmental issues of adolescence.

Hait, Barendse, Arnold, Valim, Sands, Korzenik & Fishman (2009) *USA*	Explore the perspectives of adult gastroenterologists caring for adolescents and young adults with IBD on what is required for a successful transition.	Nationwide. 69% private practice Adult gastroenterologists identified form the membership lists of the Crohn's and Colitis Foundations of America. *Not stated.*	Adult gastroenterologists *363 (34%)* *(A) Not stated* *(G) 85% males* *(DT) IBD*	Cross-sectional design. Survey: To rank the importance (Likert scale) of patient disease-related knowledge, independence, and ability to discuss social implications of their IBD. To indicate if these issues had occurred in their practice. To rate competence in addressing needs specific to adolescence.	<u>Expectations regarding transition</u> Highest ranking factors deemed important: • Patient knowledge: medication (mean = 4.6), medical history (mean = 4.5); impact of substance use (mean = 4.6). • Patient independence: active participation during visits (mean = 4.4); initiate contact if a problem arises between visits (mean = 4.3). • Paediatric gastroenterologist providing a medical summary before patients' first visit to adult services (mean = 4.6) <u>Problems experienced in practice</u> • Poor medication knowledge (69%). • Poor medical history knowledge (55%). • Poor knowledge of impact of substance use (51%). • Inadequate medical history from paediatric providers (51%). <u>Competence rating</u> 46% of adult gastroenterologists felt competent in addressing the developmental issues of adolescence.
Houston, Lindsay, Jenkins, McCartney, Ahmad, Arnott, Croft, Russell & Sebastian (2012)	Survey the perspectives of nurses who work with IBD patients regarding transition including barriers.	Nationwide adult and paediatric services. 60% worked in teaching hospitals, 11% worked in a paediatric setting. *Not stated.*	IBD specialist nurses *106 (65%)* *(A) Not stated* *(G) Not stated* *(DT) IBD*	Cross-sectional design. Questionnaire (Likert scale) surveying experience of patient-related and organisational-related barriers.	• 44% were involved in the delivery of a transition service. • 24% felt adequately prepared to participate in transition process. • Timing: initiate 15-16 years (58%); complete 18 years (72%). Most important milestone: leaving school. • 71% reported managing the psychological needs of adolescents was

UK					the greatest challenge to transition. Organisational barriers: Lack of support services 45%; Lack of clinic space/time 45%; paediatric colleagues lacked interest 42%; Lack of defined policies/protocol 36%; Lack of funding 34%. Patient barriers: Lack of trust in adult team 58%; Parental reluctance to transfer 52%; Limited understanding of disease 46%; Patient/parents expectations 39%; Lack of self-advocacy 37%. Factors leading to a successful transition: Patients' understanding of the disease 68%; Patients' understanding of treatment 69%; Taking medication unsupervised 59%; Attending clinics alone 23%.
Paine, Stollon, Lucas, Brumley, Poole, Peyton, Grant, Jan, Trachtenberg, Zander, Mamula, Bonafide & Schwartz (2014) *USA*	To explore the perspectives of IBD providers on transition, with the aim of identifying outcomes for evaluation, and barriers and facilitators informed by Schwartz et al.'s (2011) Social–Ecological Model of Adolescent and Young Adult	Nationwide adult and paediatric services. Participants practised in 6 states, Illinois, Maryland, Massachusetts, Missouri, Ohio, and Pennsylvania, and all worked at academic medical centres in urban areas. *Not stated.*	IBD providers: 8 physicians, 2 psychologists, 1 nurse practitioner, and 1 administrator. 8 in paediatric care and 4 in adult care. *12 (not stated)* *(A) Not stated* *(G) 6 males: 6 females* *(DT) IBD*	Cross-sectional design. Semi-structure interview focusing on 3 areas: 1. Measurable outcomes representing successful and unsuccessful transitions; 2. Barriers to success; 3. Facilitators of success.	Measurable outcomes themes • Health care utilisation – not returning to paediatric care; using emergency departments appropriately; adhering to standard care (attending clinics, tests and endoscopies). • Health – preventing or minimising need for treatment (surgeries, hospitalisations, steroids); maintaining stable symptoms; laboratory tests. • Quality of life - e.g., attending school; employment; having a family. Barriers and facilitators • Developmental maturity – abstract reasoning, psychosocial functioning, disease self-management, communication and relationships with

	Readiness to Transition (SMART)			Analysis involved the constant comparative method.	providers. • Parental involvement (i.e. overinvolved, maintaining control of care vs. trusting and collaborative support). • Provider skills and support – addressing needs of patients (e.g. developmental maturity, psychosocial support, education); communication and care-coordination (e.g., networking, handover).
Sebastian, Jenkins, McCartney, Ahmad, Arnott, Croft, Russell & Lindsay (2012) *UK*	Identify the perceived needs of adolescent IBD patients and the barriers to successful transition from the perspective of professionals involved in their care.	Nationwide. Adults were identified from the members of the IBD section of the British Society of Gastroenterology; paediatricians (gastroenterology and general) from British Society of Paediatric Gastroenterology and Nutrition membership. 39% teaching Hospital and 61% district general hospital. *Not stated.*	Adult and paediatric gastroenterologists *358 (49%) adult and 82 (62%) paediatricians* *(A) Not stated* *(G) Not stated* *(DT) IBD*	Cross-sectional design. Questionnaire concerning current status of provision of transition care in the UK, perceived needs for effective transition care in IBD, and the organisational, clinician and patient related barriers to successful transition. Likert scale of 1 to 5 anchored by "1 = not important and 5 = very important and essential".	<u>Suggestions for timing of transfer</u> • Initiate: 16 years (56% paediatricians vs. 70% adults) and complete: 18 years (82% paediatricians vs. 81% adults). • Leaving school was the highest ranked social milestone for completion (42% adult vs. 29% paediatricians). • Significantly more paediatricians ranked disease in remission as important (43% vs. 15%, p=0.0001). <u>Preparedness for transfer</u> • More adults than paediatricians identified inadequacies (79% vs. 42%, p=0.001). • Problems: patient disease-related knowledge and self-advocacy, co-ordination of care. • Patient involvement (vs. non-involvement) in transition aided preparation (r = -0.28, p<0.05).

					<u>Patient competencies for successful transfer</u> Highest ranking factors deemed important: • Understanding of disease (mean = 4.19 adult vs. 4.33 paediatrician) • Understanding of treatment (mean = 4.22 adult vs. 4.47 paediatrician) • Taking medicine independently (mean = 3.97 adult vs. 4.23 paediatrician). <u>Perceived barriers</u> Highest ranking factors deemed important: • Patient-related: poor disease-related knowledge (mean = 4.12 adult vs. 3.09) and lack of self-advocacy (mean = 3.89 adult vs. 4.04). • Organisational: Lack of space/time (mean = 3.93 adult vs. 4.22), lack of funding (mean = 3.59 adult vs. 3.77), lack of supportive services (mean = 3.93 adult vs. 4.22); inadequate training in this area (65% adult vs. 59% paediatricians).
Wright, Williams, Andrews, Day, Gearry, Bampton, Moore, Lemberg, Ravikumaran, Wilson, Lewindon, Radford-	Explore and compare the perceptions of paediatric and adult gastroenterologists on transition requirements for patients with IBD.	Nationwide – Australia and New Zealand. Gastroenterologists under the Australian Inflammatory Bowel Disease Association (AIBDA), Inflammatory Bowel Disease New	Adult and paediatric gastroenterologists *178 (41%). 49 (66%) adult and 25 (34%) paediatric* *(A) Not stated*	Cross-sectional design. Questionnaire. Topics: preparedness; assessing readiness for transition; timing of transition; barriers to successful	<u>Preparedness</u>: 23% felt adolescents were adequately prepared. <u>Factors important in assessing readiness</u>: psychological maturity (mean = 4.3, SD = 0.70) and adult caregiver assessment (mean = 4, SD = 0.72). Self-efficacy received the second highest rating (rated as most important by 36% paediatric vs. 35.4% adult). <u>Timing of transfer</u>: Adult prioritised readiness as assessed by caregiver (rated as

Smith, Rosenbaum, Catto-Smith, Desmond, Connell, Cameron, Alex, Bell & De Cruz (2014) *Australia*		Zealand (IBD-NZ) and the Australian Society of Paediatric Gastroenterology, Hepatology and Nutrition (AusPGHAN). *Not stated.*	*(G) Not stated* *(DT) IBD*	transition; optimal models for transition.	most important by 37.5% paediatric vs. 16% adult). Paediatric prioritised completion of secondary schooling (rated as most important by 40% paediatric vs. 8.3% adult). Barriers: lack of patient self-management (mean = 4.10, SD = 0.82) and poor handover (mean = 4.10, SD = 0.8). Model for structured transition: No clear agreement. 26% flexible, dependent on patient needs; 18% overlap of appointments (i.e. alternating paediatric and adult consultations); 18% single clinic appointment attended by all parties involved.
Patient sample studies					
Benchimol, Walters, Kaufman, Frost, Fiedler, Chinea, & Zachos (2011) *Canada*	To develop a transition tool (MyHealth Passport for IBD) to assess adolescent and parent knowledge of disease characteristics, treatments, medical history, and health services resources.	Hospital for Sick Children (SickKids) (Toronto) *> 14 years*	Patients (and one parent) *78 patients (97.5%) and 64 parents (80%).* *(A) Mean age 16.2 ± 1.25 years (range 14.0 - 18.3 years).* *(G) 48 (61.5%) males and 30 (38.5%) females.*	Cross-sectional (observational design) Separate patient and parent questionnaires to assess knowledge of disease characteristics, medications, medical history and health services resources.	Patients and parents equally named disease characteristics and treatment correctly ($p>0.05$). Parents were more likely to correctly name their insurance company ($p<0.0001$) and pharmacy ($p<0.0001$). Most patients accurately identified IBD classification (78.2%) and listed medications (76.9%). A minority of patients and parents accurately identified disease location (21.8% and 32.8%, respectively). Parents were more likely to know the date of the last colonoscopy ($p=0.04$).

			(DT) 49 (62.8%) CD, 21 (26.9%) UC, and 8 (10.3%) IBD-U.		
Bollegala, Brill & Marshall (2013) *Canada*	To characterise resources utilisation among patients with IBD during the transfer of care from paediatric to adult gastroenterology.	Paediatric gastroenterology at McMaster University Medical Centre to adult gastroenterology affiliated with McMaster University Medical Centre. *Not stated.*	Patients *95 (not stated)* *(A) Not stated.* *(G) 48 female (50.8%)* *(DT) 69 (72.6%) CD and 26 (27.4%) UC*	Cohort study design. Retrospective chart review. Compared resource utilisation (i.e. emergency department (ED) visits, hospitalizations, endoscopies, surgeries, and outpatient clinic visits) during the year before versus the year after transfer.	Frequency of clinic visits was significantly greater during paediatric care (3.05 vs. 2.56 visits per year, p=0.01). ED visits (0.15 vs. 0.18, p=0.71); hospitalisations (0.13 vs. 0.13, p=0.23); surgical interventions (0.03 vs. 0.18, p=0.53); and endoscopies (0.37 vs. 0.25, p=0.11) were not significantly different. Non-adherence was significantly different (29% paediatric vs. 43% adult, p=0.01). Endoscopies revealed disease activity was higher under paediatric care (66.7% vs. 23.8%, p=0.003).
Dabadie, Troadec, Heresbach, Siproudhis, Pagenault & Bretagne (2008) *France*	Ascertain the perceptions of patients (and their parents) with IBD of their experience of transitioning from paediatric to adult	Paediatric gastroenterology unit of the Rennes University Hospital Centre. Transferred to adult-care gastroenterologists within the same centre, or to a	Patient (and parents) *48 (71% response rate for both patients and parents).* *(A) Not stated.*	Cross-sectional design. Patient data were collected from paediatric medical charts. Postal	<u>Type of transition</u> • 34 transferred within the same centre; 14 transferred to a private gastroenterologist. <u>Perception of transition</u> • 33/34 patient/parent respondents received information 'early enough' about transition (approx. one year before).

	gastroenterology care.	private gastroenterologist of their choosing. *Not stated.*	*(G) 37 males, 11 females* *(DT) 38 CD (28 male, 10 female) 10 UC or non-classified colitis (9 male, 1 female)*	questionnaire surveying opinion of transition procedures and joint visit (if applicable).	• 21/34 patient/parent respondents felt choice of new gastroenterologist was a shared decision. • 29/34 patient (25/34 parent respondents) felt 'ready' for the transition. • 38% patient respondents felt self-reliant vs. 79% parent respondents perceived their child as self-reliant. <u>Joint consultation visit</u> • 62% patient/parent respondents felt one joint visit was sufficient. • 100% patient respondents (86% parent respondents) felt one-hour was sufficient duration. Beneficial effects of visit: • new gastroenterologist's knowledge of their care (100% patient/parent respondents); • confident in their new gastroenterologist (94% patients vs. 100% parents). <u>Patients with vs. without joint visit</u> No significant difference about transition procedures (i.e. informed 'early enough'; choice of new gastroenterologist; felt 'ready' for, and apprehensive about transfer).
Dellon, Jones, Martin, Kelly, Kim, Freeman, Dellon, Ferris & Shaheen (2013)	To describe a series of adolescents with eosinophilic oesophagitis (EoE) to highlight issues	Adult gastrointestinal clinic, at the Center for Esophageal Diseases & Swallowing, University of North	Patients *4 (not stated)* *(A) 17 – 21 years* *(G) 2 males, 2*	Case series design. Not stated	4/4 (100%) No formal transition program; 2/4 (50%) Inadequate/absent communication with referring; 4/4 (100%) Readiness not assessed; 3/4 (75%) Inadequate knowledge about medical condition; 1/4 (25%) Inadequate knowledge about

USA	related to health care transition.	Carolina *Not stated.*	*females* *(DT) Eosinophilic esophagitis.*		medical history; 1/4 (25%) Inadequate understanding of intermittent symptoms; 2/4 (50%) Non-adherence to treatment; 3/4 (75%) Yet to develop independence from parents.
Fishman, Barendse, Hait, Burdick & Arnold (2010) *USA*	To determine whether adolescents with IBD had developed key skills to self-management prior to transfer to adult care.	Children's Hospital Boston *16 – 18 years*	Patients and parents *40 (43%)* *(A) Mean = 16.7 years (range 16 – 18 years)* *(G) 25 males and 15 females* *(DT) 28 CD, 11 UC, 1 Indeterminate colitis*	Cross-sectional design. Patient survey on confidence (100 VAS) in disease knowledge and treatment knowledge, and responsibility of health maintenance behaviours (Likert scale). Parents survey on perceptions of child's capabilities.	*Medication*: 95% of medications correctly named by patients. *Disease knowledge*: 98% correctly named their disease type; 87% could describe their disease; overall confidence in knowledge was 89 (±22). *Source of information*: 65% internet, 55% doctor, 10% parents, 15% pamphlets or books, 2% "Don't know" or "Anywhere". *Patients assuming responsibility of health maintenance behaviours*: • 15% scheduling appointments; • 21% getting to appointments; • 23% medication refills; • 16% picking up medication; • 26% contacting doctor; • 79% main talking in clinic; • 90% remembering to take medication. *Parents*: • Viewed their children as "nearly completely able" to name their medicines, the doses and side effects (mean= 4.13, SD 0.99). • 47% viewed their child as "completely" responsible for taking medication.

Goodhand, Dawson, Hefferon, Tshuma, Swanson, Wahed, Croft & Lindsay (2010) *UK*	Characterise patients treated in a transitional adolescent-young adult IBD clinic, and compare with controls from an adult IBD clinic, to highlight the specific problems and needs this group poses.	Barts and London National Health Service (NHS) trust biweekly transition clinic for IBD patients aged 16-24 years, staffed by a paediatric gastroenterologist and IBD nurse. *16 – 24 years.*	Patients *100 adolescents & 100 disease duration matched adult controls (not stated).* *(A) Adolescents: median = 19 (interquartile range 18-20) Adults: median = 37 (interquartile range 33-56)* *(G) Adolescents: 56 males & 44 females Adults: 57males & 43 females* *(DT) IBD.*	Retrospective case-controlled study design. Case note review. Compared IBD disease extent, radiation exposure, therapeutic strategy and surgery.	• Inflammation was more severe in adolescents (75% vs. 59% adults, p<0.001). • Adolescents did not receive more ionizing radiation (3.0 mSv vs. 3.7 mSv adults, p=0.6). • Immunosuppressive therapy was higher in adolescents (53% vs. 31%, p<0.01). • 20% adolescents required biological therapy vs. 8% adults (p< 0.05). • Adolescents missed significantly more appointments (median = 20% vs. adults median = 0%; p<0.0001). • 46% of adolescents required hospital admission since diagnosis vs. 14% adults (p<0.0001). • 18% adolescents required surgery vs. 9% adults (p=0.1).
Greveson, Morgan, Furman & Murray (2011) *UK*	Design and assess the effectiveness of an adolescent IBD transition service that facilitated patient involvement.	Joint, bimonthly transition clinic in a paediatric setting. *16 + years*	Patients *25 (84%)* *(A) Mean age 16 years pre transition, post transition not stated.*	Cohort design. Pre and post Questionnaires. Items: Knowledge of disease and medication, effects of disease, sources of support, readiness for and	<u>Pre-transition</u> • All (n=21) correctly named medications, but only 57% understood their function. • 27% medication non-adherence. • All could recognise a flare-up. • Response to a flare-up: 33% ask a parent; 24% phone IBD nurse, 19% phone GP, and 10% phone GP and ask a parent (14% other).

			(G) Not stated *(DT) 62% CD; 38% UC*	anxiety about transition. Additional Post items: perceived effectiveness of transition service.	• IBD adversely affected: education (e.g. missing lessons due to ill health), body image (e.g. stunted growth, weight loss). • Anxieties about transition: loss of contact with paediatric clinicians, meeting new people and changes in treatment. <u>Post-transition</u> • 5 fully transferred to adult services. • Timing of transfer: flexible, depended on patient perceived readiness, disease in remission. Time spent in clinic: mean = 8 months (range 6–12 months). • All (5) could recognise a flare-up and also showed increased autonomy by stating they would contact hospital themselves. • All (5) correctly named medication and showed increased medication knowledge (e.g. dosage, function). <u>Patient perspectives about the transition</u>: Attending appointments alone, meeting the adult team before transfer, involvement of nurse specialist, and time spent in clinic was deemed adequate by all (n=5) for preparation for transfer.
Huang, Tobin & Tompane (2012) *USA*	Assess health literacy (i.e. gather, process, and understand basic health	Paediatric gastroenterology practice at a tertiary-care academic medical centre in	Patients. *74 (not stated).* *(A) Median = 15*	Cross-sectional design. Patients: TOFHLA; CCKNOW; Self-	<u>Patient health literacy</u> • 74% adequate functional health literacy. • 75% adequate personal medical history

	information to make decisions) of paediatric IBD patients and compare with clinicians' assessment in regard to readiness for transition.	Greater San Diego. *≥ 10 years, no maximum age stated.*	*years (min. 10, max. 20).* *(G) 35 male, 39 female.* *(DT) 42 CD, 30 UC, 2 Indetermined colitis.*	efficacy survey; and personal medical history knowledge survey; PUCAI or PCDAI (chronic disease status) Clinicians: primary gastroenterologist assessed the health literacy readiness of their patient to transition to adult care on a VAS.	knowledge. • 16% adequate disease-related knowledge. • 47% self-efficacy in chronic disease management. Clinician assessment • 11% overall interactive health literacy (i.e. cognitive skills to interact with clinicians and to understand information) (i.e. ready for transition) vs. 47% deemed ready for transition by their gastroenterologist. • Poor agreement between measures-defined and clinician-defined levels of health literacy-related readiness for transition (p=0.18).
Irvine, Srinivasan, Casson, Auth, Crook, Leiper, Rhodes, Greeg, Kneebone & Dalzell (2010) *UK*	To assess patient feedback on the effectiveness of a transition service for paediatric IBD.	Alder Hey Paediatric hospital in Liverpool to adult gastroenterology service at Royal Liverpool University Hospital. *Not stated.*	Patients. *35 (53%).* *(A) Not stated.* *(G) Not stated.* *(DT) IBD.*	Cross-sectional design. Postal questionnaire survey covering 3 aspects: 1. The pre-handover meeting; 2. Joint first clinic appointment; 3. Suggestions for improvement	• Of those who attended the pre-handover meeting, 100% were satisfied (p<0.0001). • 89% felt enough information was provided about the move (p<0.0001). • 86% had the opportunity to discuss changes (p<0.0001). • 68% experienced a reduction in anxiety about transfer as a result of meeting (p<0.0877). • 89% perceived the people who attended the first clinic were relevant (p<0.0001). • 91% found the paediatric team attending first clinic was useful (p<0.0001).

Plevinsky, Gumidyala & Fishman (2014) *USA*	To explore what factors influence a patient's experience of the transition process, including the patient–clinician relationship and patient characteristics (e.g. diagnosis age, disease severity, parent involvement).	Boston Children's Hospital Center *25 – 30 years.*	Patients *Approx. 300 invitations produced 39 initial responders, of which 29 completed participation (74.4%).* *(A) Range 18 and 30 years, M(SD) = 26.8(2.7).* *(G) Not stated.* *(DT) IBD.*	Cross-sectional (observational design) Mixed methods questionnaire (open- and closed-questions). Topics: • Current provider information, • Experiences about transition from a paediatric to adult physician, and • Basic medical history and demographics.	<u>Discussion about the transition</u> • N = 9 no discussions; • N = 4 prepared in advance (prior to penultimate appointment); • N = 5 advised to see specific adult clinician at their penultimate or last appointment; • N = 3 received a list of adult services. • Triggering circumstances: N = 9 chronological age, N = 4 health status <u>Transition process</u> (themes) • Patient-clinician relationship facilitators: trust, collaborative, communication, comfort, independence and parent involvement. • Organisational barriers: problems navigating the new service, finding available clinicians, insurance issues, inadequate transferring of patient records.
Zijlstra, De Bie, Breij, van Pieterson, van Staa, de Ridder, van der Woude & Escher (2013) *the Netherlands*	To design and evaluate the reliability of "IBD-yourself" questionnaire- a measure of self-efficacy, and to then use this to assess the level of self-efficacy of adolescent IBD patients visiting the transition	Transition clinic at Erasmus MC – Sophia Children's Hospital. *14 – 18 years.*	Patients (and parents and treating paediatric gastro-enterologist). *57 (80%).* *(A) Median = 16.3 years (IQR 15.4 – 17.0).* *(G) 22 (44%)*	Cross-sectional design. Questionnaire topics: Overall independence (100 VAS); disease-related knowledge, independence, behaviour during clinic visits, coping with IBD,	<u>Questionnaire validity</u> • "IBD-yourself" questionnaire: "good to excellent internal consistency" (Cronbach's α range 0.64 to 0.93). • Parent questionnaire: Cronbach's α range 0.47 to 0.93. <u>Patient and parent scores</u> • Patients' median self-efficacy scores varied from 70 to 100%. • Parents significantly overestimated their child's disease-related knowledge, self-management of medication, and transfer

	clinic.		*males.* *(DT) 60% CD, 36% UC, 4% IBD-U.* *Parents:* *N = 40;* *Median = 44 years (IQR 42-48);* *70% mothers and 30% fathers.*	knowledge of and readiness for transition process (Likert scales). Parents completed an abbreviated version, and gastroenterologists scored the patient's general independency (VAS).	readiness vs. patient's ratings. • Overall independence: only significant difference was between parents (median = 75) and gastroenterologist (median = 72) (p=0.04). Length of time since first visit to transition clinic positively correlated with: • Independence (p=0.04); • Independent behaviour at clinic (p=0.001); • Transfer readiness (p=0.02); • But not for overall independence (p=0.11).

Notes. Abbreviations: IBD = Inflammatory Bowel Disease; CD = Crohn's Disease; UC = Ulcerative Colitis; IBD-U = Inflammatory Bowel Disease-Unclassified OR = odds ratio; CI = confidence intervals; VAS = visual analog scale; mSv = millisieverts; TOFHLA = Test of Functional Health Literacy in Adults; CCKNOW = Crohn's and Colitis Knowledge; PUCAI = Pediatric Ulcerative Colitis Activity Index; PCDAI = Pediatric Crohn's Disease Activity Index; SD = standard deviation; IQR = Interquartile Range.

Quality Assessment

A quality assessment was conducted for all 17 of the included studies using Kmet, Lee and Cook's (2004) QualSyst tool. The purpose of a quality assessment is to evaluate the methodology of studies, to help determine the reliability and validity of findings (Centre for Research and Dissemination, 2008) and risk of bias. The QualSyst provides two scoring procedures, one for quantitative and the other for qualitative studies, with similar criteria, therefore allowing for the evaluation of a wide diversity of study designs. The checklists' items are consistent with the recommendations highlighted by the STROBE statement; a guide on how to report observational studies (von Elm et al., 2007). Detailed scoring manuals are provided for easy use, and items on the checklists are rated on a scale of 0-2. A score of 0 signifies no evidence, 1 signifies partial evidence, and 2 signifies clear evidence[1]. Furthermore, some items can achieve a not applicable (N/A) rating, and, if marked, the item is not included in the summary score. See Table 3 and Table 4 for findings. Plevinsky et al. (2014) was scored on both checklists due to their use of a mixed-methods approach. Two-thirds of the studies (n=11) were randomly selected for independent assessment by a second-rater, and any disagreements were resolved by discussion. Cohen's κ was calculated to determine the level of agreement between the two raters on the individual items of the QualSyst tool for the eleven studies. There was 'substantial' agreement (Landis & Koch, 1977) between the two raters, $\kappa = .767$ (95% CI, 0.67 to 0.86, $p<0.0001$).

[1] A colour coding system has been included to provide a clear visual representation of the quality assessment outcome. Green signifies clear evidence, amber signifies partial evidence, and red signifies no evidence. Not applicable (N/A) is not colour coded.

Table 3: *Quality assessment of quantitative studies*

Criteria[2]	Barendse et al. (2011)	Benchimol et al. (2011)	Bollegala et al. (2013)	Dadabie et al. (2008)	Dellon et al. (2013)	Fishman et al. (2010)	Goodhand et al. (2010)	Greveson et al. (2011)	Hait et al. (2009)	Houston et al. (2012)	Huang et al. (2012)	Irvine et al. (2010)	Plevinsky et al. (2014)	Sebastian et al. (2012)	Wright et al. (2014)	Zijlstra et al. (2013)
1. Objective described?	1	2	1	1	1	2	2	2	2	1	1	1	2	2	1	2
2. Design evident and appropriate?	2	2	1	2	1	2	2	2	2	2	1	2	2	2	2	2
3. Subject selection described and appropriate?	1	2	2	2	N/A	2	2	2	1	1	2	2	1	1	2	2
4. Subject characteristics sufficiently described?	1	2	1	2	1	2	2	1	1	0	2	0	1	1	1	2
5. Random allocation described?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
6. Blinding of investigators reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
7. Blinding of subjects reported?	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
8. Outcome and means of assessment reported?	2	2	2	1	N/A	2	1	1	1	0	2	2	2	2	1	2

[2] See Appendix 2 for a detailed list of the quality assessment items.

Criteria[3]	Barendse et al. (2011)	Benchimol et al. (2011)	Bollegala et al. (2013)	Dadabie et al. (2008)	Dellon et al. (2013)	Fishman et al. (2010)	Goodhand et al. (2010)	Greveson et al. (2011)	Hait et al. (2009)	Houston et al. (2012)	Huang et al. (2012)	Irvine et al. (2010)	Plevinsky et al. (2014)	Sebastian et al. (2012)	Wright et al. (2014)	Zijlstra et al. (2013)
9. Sample size appropriate?	1	1	1	1	N/A	1	1	0	1	2	1	1	1	1	1	2
10. Analytic methods described and appropriate?	2	2	2	2	N/A	2	2	0	2	0	2	1	2	2	2	2
11. Estimate of variance is reported for the main results/outcomes?	2	2	0	2	N/A	1	1	0	2	0	2	0	1	1	1	2
12. Controlled for confounding?	N/A	2	0	0	N/A	0	1	0	N/A	N/A	1	N/A	N/A	1	0	2
13. Results reported in sufficient detail?	2	2	2	2	1	2	2	1	2	1	2	1	2	2	2	2
14. Do the results support the conclusions?	2	2	1	2	0	1	1	0	1	2	2	1	1	1	1	2
Total / Possible Total	**16/20**	**21/22**	**13/22**	**18/22**	**4/10**	**17/22**	**17/22**	**9/22**	**16/20**	**9/20**	**18/22**	**11/20**	**15/20**	**16/22**	**14/22**	**22/22**
Summary score[4]	**0.8**	**0.95**	**0.59**	**0.82**	**0.4**	**0.77**	**0.77**	**0.41**	**0.8**	**0.45**	**0.82**	**0.55**	**0.75**	**0.73**	**0.64**	**1.0**

[3] See Appendix 2 for a detailed list of the quality assessment items.
[4] Summary score = Total / Possible Total (28 – (number of "N/A" x 2)

Table 4: *Quality assessment of qualitative studies*

Criteria	Paine et al. (2014)	Plevinsky et al. (2014)
1. Question / objective sufficiently described?	2	2
2. Study design evident and appropriate?	2	2
3. Context for the study clear?	2	1
4. Connection to a theoretical framework / wider body of knowledge?	2	2
5. Sampling strategy described, relevant and justified?	1	1
6. Data collection methods clearly described and systematic?	2	2
7. Data analysis clearly described and systematic?	2	2
8. Use of verification procedure(s) to establish credibility?	2	2
9. Conclusions supported by the results?	2	2
10. Reflexivity of the account?	0	0
Total / Possible Total	**17/20**	**16/20**
Summary score[5]	**0.85**	**0.8**

[5] Summary score = Total / Possible Total (20)

Strengths

The studies included in this review provided clear descriptions of their sample selection process (e.g. sample framing, inclusion/exclusion criteria), as well as clear descriptions of their collection methods, including measures and outcomes, therefore allowing for reproducibility. Furthermore, the qualitative studies used the verification procedure of inter-rater reliability (i.e. two or more independent researchers qualitatively coding), thereby helping to enhance credibility of findings.

Most of the studies, except Houston et al. (2012), Greveson et al. (2011) and Irvine et al. (2010), also provided clear descriptions of the analytical methods (in line with the QualSyst tool's instructions for quality assessment, Dellon et al. (2013) was exempted as this study presented a descriptive case series). Studies used statistical tests appropriately for the types of data collected.

The majority of the quantitative studies (n=11) provided some estimate of variance, therefore providing an understanding of the distribution of data and the differences in participants' responses. However, a portion of studies did not provide an estimate of variance for all of their major outcomes (n=5). Results are reported in sufficient detail to enable a clear understanding of the major outcomes, and overall, the conclusions were supported by the results.

Weaknesses

The majority of the studies included small sample sizes and low response rates, limiting the generalisability of the findings to the target population, which also impacts the quality of the conclusions made by the studies. Of the patient sample studies, generalisability is further restricted by the recruitment of patients from a specific service per study. The clinician

participants were recruited from gastroenterology societies, presenting a risk of bias as the samples were self-selecting, and consequently their responses may not be representative of the population.

Survey was the main method of data collection, and although questionnaires can provide useful information, there is always the risk of social desirability bias. Furthermore, none of the survey questionnaires had been standardised and differed for each study. Therefore, it is difficult to determine the validity of the results of these studies. Zijlstra et al. (2013) and Huang et al. (2012) were the only studies to have used validated tools to assess patient skills. Bollegala et al. (2013), Goodhand et al. (2010) and Dabadie et al. (2008) conducted retrospective medical chart review. This design presents a high risk of measurement bias because data collected are dependent on outcome measures conducted as part of routine care, rather than standardised, pre-determined outcome measures, and therefore relevant information may have been missed (Kooistra et al., 2009).

All seventeen of the studies were observational in design, with the majority utilizing a cross-sectional design. Although this was assessed as appropriate to address the studies' questions, this design does have its limitations including little control of confounding variables, and the fact that it does not permit conclusions about a cause and effect relationship between exposure and outcome (Mann, 2003). Furthermore, the studies included in this review lacked the use of control groups; Goodhand et al. (2010) was the only exception. A control group would allow for a comparison between care approaches (e.g. transition programme intervention vs. direct transfer to adult care), and would strengthen the validity of results (Betz, Smith & Macias, 2010; Crowley, Wolfe, Lock & McKee, 2011; Spaic et al., 2013; Van Walleghem, MacDonald & Dean, 2008).

The place of origin varies across the studies, therefore limiting the generalisability of the results to any one population, as countries vary in their healthcare systems, which makes it difficult to consolidate the results to infer an accepted framework of factors that need to be considered for a successful transition. Validity of the findings is further compromised by the utilisation of a cross-sectional design, and an absence of cohort or case-control designs, and therefore the influence of confounding variables cannot be ignored. Therefore, in summary, the findings and conclusions of this review about factors that facilitate and impede the transition to adult services must be interpreted with caution, and are regarded as preliminary.

The overall quality scores of the studies by Dellon et al. (2013), Greveson et al. (2011) and Houston et al. (2012) were low and their results were deemed to be unworthy of further consideration, therefore it was decided, following discussions in supervision, to exclude these studies from the review.

Results

The findings of this review have been amalgamated into five subthemes common across the fourteen studies. Themes include the exploration of current models of transition; the timing at which transition starts and ends; the suggested patient competencies required before transfer; potential tools to assess competencies in order to assess transfer readiness; the organisational barriers to a successful transition; and the potential impact of parental involvement.

1. *Model of transition*

Five studies in this review explored models of transition; three from the perspectives of patients (Dabadie et al., 2008; Irvine et al., 2010; Plevinsky et al., 2014) and two from the perspectives of clinicians (Paine et al., 2014; Wright et al., 2014). Only two patient sample studies involved a structured transition programme. The clinic explored by Irvine et al. (2010) involved a gradual approach with transition discussions starting at 13-14 years of age. The timing of transfer was based on individual needs, and was initiated by a 'pre-handover' meeting at the paediatric services where the patients and parents met the new adult team. The process ended with the first appointment with adult services, which the paediatric team also attended. Participants were "satisfied" with this approach, and felt that it helped to reduce their anxieties about the transition. The approach investigated by Dabadie et al. (2008) involved a joint visit whereby patients (and parents) attended an appointment at the adult services along with their paediatric team. However, compared to patients who had not attended the joint visit, there was no significant difference with regards to the young person's readiness for transfer, anxiety about the transition and confidence in their new gastroenterologist.

Across both young people and clinician groups in the Irvine et al. (2010) and Dabadie et al. (2008) studies, the results suggested a preference for joint working and care-coordination between paediatric and adult services, along with patient involvement. However, because of differences in opinion between participants about their experience of a specific transition approach, and in light of the quality of these studies and a lack of reporting of variance, it is difficult to conclude in an accepted framework of factors that need to be considered for a successful transition, whether it be a minimum of one joint clinic appointment, an alternation of paediatric and adult appointments, or a gradual, flexible approach based on the needs of the patient.

Other important transition procedures highlighted by the patient group included receiving plentiful information about the transfer and having the opportunity to discuss its impacts (Dabadie et al., 2008; Irvine et al., 2010). Furthermore, from both a patient perspective (Plevinsky et al., 2014) and a clinician perspective (Paine et al., 2014), the patient-clinician relationship appeared to also be an important contributor to a successful transition. The relationship should encompass trust, collaboration and comfortable and open communication, and it is important that the clinician understands and can address the unique developmental needs of adolescent patients. Lastly, patient recommendations to improve the transition process included the involvement of GPs and dietitians at transition meetings, and the use of an email forum for patients to share information and experiences with their peers (Irvine et al., 2010).

2. Timing of transition

Six studies made reference to the determining factors for timing of transition (Dabadie et al., 2008; Irvine et al., 2010; Paine et al., 2014; Plevinsky et al., 2014; Sebastian et al., 2012;

Wright et al., 2014). One such factor was chronological age, although overall results were unclear on what the optimal ages are for initiation and completion of transfer as there was variation amongst the studies. There were suggestions from both patients and clinicians of beginning the process between 14 and 16 years (Dabadie et al., 2008; Sebastian et al., 2012), with actual transfer taking place between 16 and 19 years (Irvine et al., 2010; Sebastian et al., 2012; Wright et al., 2014). No rationales were provided for these suggested age arranges.

Milestones were also suggested by both patients and clinicians as triggers for transfer, mainly health status (i.e., disease in remission) (Dabadie et al., 2008; Plevinsky et al., 2014; Sebastian et al., 2012; Wright et al., 2014) and completion of school or exams (Irvine et al., 2010; Sebastian et al., 2012; Wright et al., 2014). Whilst findings on the timing of transition are varied, studies have suggested that the process should begin in advance of the actual transfer, and that several determining factors need to be considered when deciding on the optimal time for transfer (i.e., age, milestones and other transitions, disease activity).

3. Patient competencies

Bollegala et al. (2013) and Goodhand et al. (2010) looked at disease characteristics and resource utilisation of young adults with IBD to explore the healthcare needs during the transition process. Compared to care under adult services, it was found that disease activity was more severe, and that patient knowledge of and adherence to their treatment (e.g. symptoms, medication, appointments, diet) was poorer. These results highlight that transition is a critical time associated with poor health and self-management, which need to be assessed and managed by services during the transition period.

Patient competencies refer to the key skills deemed necessary for the young person to be ready for transfer to adult services. Young people were expected by clinicians to have

knowledge about their condition, its treatment, and their medical history (Barendse et al., 2011; Hait et al., 2009; Sebastian et al., 2012). Studies that assessed patient knowledge found that young people were able to identify their disease type, as well as correctly name medications and doses (Benchimol et al., 2011; Fishman et al., 2010). Some areas of identified difficulty included naming major side effects (Fishman et al., 2010) and recalling medical investigations history (e.g. surgery, colonoscopies, x-rays) (Benchimol et al., 2011). Specific to disease-related knowledge, Huang et al. (2012) reported that only 16% young people in paediatric services had "adequate" knowledge.

Another competency for transfer, from the clinicians' perspective, concerned self-management skills, such as taking medication (Sebastian et al., 2012), participating in appointment discussions and independently accessing services (e.g. making appointments, making contact outside of clinic visits, prescriptions requests) (Barendse et al., 2011; Hait et al., 2009). Some studies also proposed the importance of self-efficacy for self-management, and in turn for readiness for transfer (Huang et al., 2012; Wright et al., 2014; Zijlstra et al., 2013). Findings on the patients' self-management skills pre-transfer were varied, with Huang et al. (2012) finding only 47% of patients scored $\geq$74 out of 100 on their self-efficacy scale, whereas Zijlstra et al. (2013) found high levels of self-efficacy in their patient sample, with median scores ranging from 70 to 100%. Fishman et al. (2010) found that patients had assumed responsibility for taking medication and leading clinic discussions, but deferred responsibility for accessing services to their parents.

Three studies explored the need and utilisation of objective assessment tools to identify deficiencies in patient competencies as a means of determining transfer readiness (see Table 5). The "IBD-yourself" is a self-efficacy questionnaire and was shown to have good to excellent internal consistency (Zijlstra et al., 2013). The MyHealth Passport for IBD assesses

disease-related knowledge, but had yet to be assessed for validity and reliability (Benchimol et al., 2011). Huang et al. (2012) used a battery of assessment tools to measure health literacy, which consisted of both validated and non-validated measures. The studies proposed that the identification of deficiencies in the young person's competencies could allow clinicians to devise and deliver an individualised educational intervention, and this in turn would increase autonomy and self-management, and ultimately prepare the young person for adult services (Huang et al., 2012).

Table 5: *Transition assessment tools*

Study	Measure of readiness	Utility
Benchimol et al. (2011)	MyHealth Passport for IBD, a portable, wallet-sized medical card for patients containing their medical information, which is created by completing an online questionnaire. 4 domains of disease-related knowledge: disease characteristics, treatments, investigations, and health services resources. • Parents also completed the questionnaire to assess their knowledge of their child's disease and medical history.	Patient (and parent) completion of the questionnaire can identify gaps in their knowledge and therefore highlight areas for intervention before transfer to adult services. The portable medical card can help patients during discussions with clinicians, and therefore encourages autonomy.
Huang et al. (2012)	Functional health literacy (i.e. basic comprehension and numeracy ability) measures: • Test of Functional Health Literacy in Adults (TOFHLA; Parker et al., 1995) • Crohn's and Colitis Knowledge (CCKNOW) scale (Eaden et al., 1999) Interactive health literacy (i.e. advanced cognitive skills to interact with clinicians and to understand information) measures: • Self-efficacy in condition management (e.g. discussing medical history, booking appointments, filling prescriptions) self-report survey (Likert scale). • Medical history knowledge (e.g. condition type and location, name of doctor, medication and doses) questionnaire. Clinicians assessed the health literacy readiness to transition to adult care on a visual analogue scale (VAS; 0–100).	A battery of measures to conduct a global assessment of transfer readiness based on health literacy determinants. Comparison between patient and clinician ratings can highlight inaccuracies in clinician perceptions of their patient's capabilities and readiness for transfer.

Zijlstra et al. (2013)	• "IBD-yourself" questionnaire to assess self-efficacy of adolescents visiting the transition clinic. 12 domains covering areas of disease and treatment knowledge, independence to utilise services, self-management, and readiness for transfer. • Parent version of the "IBD-yourself" questionnaire to assess their perceptions of their child's self-efficacy. Treating paediatric gastroenterologist rated their patient's general independence on a VAS (0-100).	Can detect specific areas in which the individual patient needs further support from clinicians, therefore facilitating an individualised transition programme. Comparison between patient and parent responses can highlight inaccuracies in parent perceptions of their child capabilities and readiness for transfer.

Clinicians surveyed by Wright et al. (2014) viewed parents' judgement of their child's readiness to be important in the assessment of readiness for transfer. Some studies compared parental perceptions with their child's self-reports and, in general, found discrepancies; parents overestimated disease-related knowledge (Fishman et al., 2010; Zijlstra et al., 2013) and independence (Dabadie et al., 2008); however, one study found that parents could also underestimate independence (Zijlstra et al., 2013). Therefore, studies have highlighted that parents are not necessarily reliable assessors of their child's competencies and readiness for transfer. Furthermore, Huang et al. (2012) found that clinicians can also overestimate their patients' competencies and readiness.

Given the studies that addressed competencies were of relatively high quality, it can be concluded that there is a need to educate young adult patients about their disease and its treatment, as well as to enhance their self-management skills to prepare them for the transfer to adult care. Although there is no universal measure for the assessment of transition readiness, there is evidence that tools are being developed. However, there still remains the question of what the long-term behavioural and clinical outcomes are for educational interventions conducted before transfer to adult services.

4. Organisational issues

Service-related barriers perceived by clinicians to interfere with the transition process included lack of space and time to organise joint clinics, inadequate support from other professionals (Paine et al., 2014; Sebastian et al., 2012), and poor care-coordination and handover between services (Paine et al., 2014; Wright et al., 2014). Patient feedback highlighted logistical problems, such as a lack of transferring medical records, difficulties navigating the new health service (parking, making appointments) and finding an available clinician, the responsibility for which appears to have fallen on many patients (Plevinsky et al., 2014).

Another barrier highlighted concerns with clinicians' lack of skills and knowledge to address the specific developmental needs of young adult patients. Hait et al. (2009) reported that 54% of their sample of adult gastroenterologists felt inadequate in this area, whilst this was the case in 66% of Barendse et al.'s (2011) sample. Sebastian et al. (2012) similarly found that majority of both adults (65%) and paediatricians (59%) felt they had not received adequate training in the area of transition.

5. Parental involvement

Parental reluctance to transfer and over-involvement in their child's care were reported to be important issues to address in the transition process (Paine et al., 2014; Sebastian et al., 2012). Paine et al. (2014) found that young adult patients who had been inhibited by their parents from developing self-management skills before transfer, were more likely to experience disease-management problems in later life.

Regarding patients' ability to attend clinic appointments at adult services without a parent, from a professional's perspective this was not necessarily one of the most important issues

that needed to be addressed (Hait et al., 2009; Sebastian et al., 2012). Plevinsky et al. (2014) alluded to the importance of autonomy and reducing parent presence at clinics, but did not provide detailed findings to aid clear conclusions about the patient perspective on parental involvement. No other patient sample studies addressed this issue.

Discussion

This review has resulted in a greater understanding of the barriers and facilitators to a successful transition from paediatric to adult healthcare services for young people with gastrointestinal (GI) diseases. The review highlights that there are multiple factors that need to be taken into consideration, both patient-related and organisational factors (including clinician-related issues), when facilitating transitional care.

Clinical Implications

Model of transition

Current models of transition for GI diseases vary across services and countries, and furthermore, the approaches to transition healthcare can be inconsistent within services, if present at all (Dabadie et al., 2008; Irvine et al., 2010; Plevinsky et al., 2014; Wright et al., 2014). However, there appears to be some consensus among patients and clinicians that the most effective model is joint working between the paediatric and adult services that also involves the patient and parents (Barendse et al., 2011; Dabadie et al., 2008; Hait et al., 2009; Irvine et al., 2010; Paine et al., 2014; Sebastian et al., 2012; Wright et al., 2014). Joint working is in line with UK national clinical guidelines and standards (Department of Health/Department for Education and Skills, 2006; Royal College of Nursing, 2013b; Royal College of Paediatrics and Child Health, 2003), which state that all specialities need specialist transition clinics that involve joint care, either within the paediatric or adult services. The guidelines further state that a multi-disciplinary team, including psychologists, should facilitate transition clinics and that clear protocols should be developed by all disciplines to ensure standardised care. Additional recommendations include the need for a co-ordinator, such as a nurse specialist or a health professional, other than a doctor. Their role is to oversee

the process, as well as support the young person and their family throughout the process, through education and involving the young person, to ensure that they are prepared for the transfer. None of the studies included in this review explored the involvement of psychologists, or a care-coordinator, and only one study highlighted a patients' recommendation for the involvement of a dietitian and GP in the transition process (Irvine et al., 2010).

Reported benefits of joint clinics found by this review include reduction of anxieties about the transition process, increase in confidence about the capabilities of the adult professionals, and readiness for transfer (Dabadie et al., 2008; Irvine et al., 2010; Paine et al., 2014; Sebastian et al., 2012). It is unclear what specific joint working approach is most effective for GI diseases, either a single appointment or one that is flexible, with an undetermined number of appointments, that takes into account the needs of the patient and parents (Dabadie et al., 2008; Wright et al., 2014). Clinical guidelines emphasise the importance of flexibility and recommend that the length of joint care vary for each patient to ensure that the individual needs are addressed (e.g. developmental maturity (cognitive, emotional), health status) (Department of Health/Department for Education and Skills, 2006; Royal College of Nursing, 2013a).

Research in other chronic health conditions, such as diabetes, juvenile rheumatoid arthritis (JRA), neuromuscular disorder with chronic ventilation (NMD) and kidney disease, similarly found joint clinics to be the most advantageous and patient-preferred approach (Crowley, Wolfe, Lock & McKee, 2011; Harden et al., 2012; Sonneveld, Strating, van Staa & Nieboer, 2013). Crowley et al.'s (2011) review of various chronic illnesses (physical and mental) or disabilities also found evidence for the benefits of out-of-hours telephone support, enhanced follow-up (when patients did not attend clinic) and the presence of a care-coordinator. The

integrated transition service for young people with kidney failure evaluated by Harden et al. (2012) included an additional young adult clinic provided by the adult service, based in the community and run by a youth worker, with positive effect.

Timing of transition

It is clear from this review that the timing of transfer should not solely be based on the chronological age of the patient, and that there is not a definitive age for transfer. The evidence is in favour of a gradual approach, with the process starting well in advance of when transfer takes place. There is evidence to suggest starting the process as young as 13/14 years (Irvine et al., 2010; Sebastian et al., 2012), and completing by 18 years (Bollegala et al., 2013; Sebastian et al., 2012) or even as late as the early 20s (Dabadie et al., 2008; Goodhand et al., 2010). Milestones have also been suggested as important considerations, especially in relation to leaving school and disease remission (Dabadie et al., 2008; Irvine et al., 2010; Plevinsky et al., 2014; Sebastian et al., 2012; Wright et al., 2014). Similarly, research in other chronic conditions found the need for flexibility, a wide age range in which transfer can occur, and the consideration of other milestones (education, employment), as well as the patient's developmental level (e.g. social, independence, autonomy) (Harden et al., 2012; Tuchman, Slap & Britto, 2008). The importance of patient agreement was also highlighted, as imposed deadlines can create feelings of being unprepared (Harden et al., 2012; Tuchman, Slap & Britto, 2008). A flexible approach that considers various determining factors for timing of transfer on an individualised basis is in line with clinical guidelines, which also recognise that the transition process could take three or more years. It is important that the patient is allowed the time to develop the skills (e.g., decision-making, communication, independence) and responsibility (i.e., self-care) necessary to function in adult services (Department of

Health/Department for Education and Skills, 2006; Royal College of Nursing, 2013a; Royal College of Paediatrics and Child Health, 2003).

Readiness for transition

This review suggests that young adult GI patients need to possess several key skills before transferring to and navigating adult services. The main competencies discussed were self-efficacy (Fishman et al., 2010; Huang et al., 2012; Wright et al., 2014; Zijlstra et al., 2013), disease-related knowledge (Benchimol et al., 2011; Fishman et al., 2010; Huang et al., 2012; Wright et al., 2014), and self-management skills, for example, taking medication (Sebastian et al., 2012) and utilising services (Barendse et al., 2012; Fishman et al., 2010; Hait et al., 2009; Plevinsky et al., 2014; Zijlstra et al., 2013).

Unfortunately, there is a dearth of literature on the utilisation of assessment tools that can reliably assess a patient's readiness for transition. The "IBD-yourself" self-efficacy questionnaire was the only IBD-specific validated measure found (Zijlstra et al., 2013). While the MyHealth Passport for IBD appears to be a useful tool, its validity has not yet been evaluated. Other measures suggested to be useful include health literacy measures, such as the Test of Functional Health Literacy in Adults (TOFHLA; Parker et al., 1995) and the Crohn's and Colitis Knowledge (CCKNOW; Eaden et al., 1999) (Huang et al., 2012). Schwartz et al. (2014) conducted a systematic review on measures of readiness for transition for chronic physical health conditions, which included both generic and disease-specific measures (n = 10). The most prominent components were knowledge and self-management, however, there were clear absences of psychosocial factors (e.g., relationships between patient, parent and/or clinicians), as well as the perspective of parents and clinicians. The authors concluded that there is no universal measure, but were in favour of the Transition Readiness Assessment

Questionnaire (TRAQ; Sawicki et al., 2009) and the TRxANSITION scale (Ferris et al., 2012).

Some of the studies in this review assessed parent and/or clinician judgements of readiness for transition and found discrepancies with those of the patients. Parents overestimated their child's disease-related knowledge (Fishman et al., 2010; Zijlstra et al., 2013), as well as their independence skills (Dabadie et al., 2008), but could similarly underestimate them too (Zijlstra et al., 2013). Similarly, Huang et al. (2012) found that clinicians overestimate readiness. These findings suggest that parents and clinicians may not correctly assess patient competencies, and therefore may not be reliable judges of readiness for transition. This highlights the need for validated, standardised transition assessment tools, and also the importance of adopting a person-centred care approach and involving the young person in the assessment and planning of their care needs.

Parental involvement

Parental involvement was also found to be an important consideration, as over-involvement in the young person's life and an inability to 'let go', as well as a reluctance to transfer can be barriers to a successful transition (Paine et al., 2014; Sebastian et al., 2012). Fishman et al. (2010) found that majority of 16 to 18 years old patients deferred responsibility to parents for liaising with services and managing prescriptions, although most of the patients did lead clinic discussions and were able to take medication independently. Regarding patients' ability to attend clinic appointments at adult services without a parent, from the professionals' perspective this is not necessarily one of the most important issues that need to be addressed (Hait et al., 2009; Sebastian et al., 2012). Unfortunately, none of the patient sample studies presented any findings regarding patient perspective on parental involvement,

and how this can facilitate and/or impede the transition process. Research in other chronic conditions that explored patients' perspectives demonstrated that parental involvement is a multifaceted issue. Parental support and encouragement to be autonomous contributed to a successful transition (Racine, Larivière-Bastien, Bell, Majnemer & Shevell, 2013; Tuchman, Slap & Britto, 2008), whereas parental over-involvement prevented, or at least hindered, patients from being involved in decision-making processes (Racine et al., 2013; Sonneveld et al., 2013). Some young people may be ambivalent about parents decreasing their involvement and this may be due to a wish to be sheltered from anxiety-provoking situations, such as receiving bad news or initially navigating adult services (Hilderson et al., 2013; Sonneveld et al., 2013), or to trust in their parent's decision-making skills (Racine et al., 2013).

A review of the literature on the shift of responsibility of illness management from the parent to the young person highlights that parental involvement is a complex issue, the decrease of which needs to be gradual, and based on the young person's abilities (Reed-Knight, Blount & Gilleland, 2014). It is emphasized that if done too early the individual may be inadequately prepared, and, if too late, they may miss opportunities to practise. Furthermore, ongoing parental supervision is important to ensure sufficient learning, as well as to monitor for any decline in health care behaviours, which is a common occurrence in young people with chronic health conditions.

Organisational issues

Both professionals and patients identified logistical problems as one of the main organisational barriers to the transition process. Examples included a lack of space/time, lack of funding, poor care-coordination, including handover and transferring of medical records, and patient difficulties in navigating adult services (Paine et al., 2014; Plevinsky et al., 2014;

Sebastian et al., 2012; Wright et al., 2014). A lack of support from other disciplines (e.g. nurses) and a lack of trust between services were also found (Sebastian et al., 2012).

The Department of Health recognises the unique needs of the adolescent patient population, and therefore emphasises the importance of healthcare professionals possessing the knowledge and skills to address generic adolescent health and psychosocial issues, in addition to their specialty. This is essential for professionals developing and working in transition clinics (Department of Health/Department for Education and Skills, 2006). However, this review found that gastroenterologists had not received adequate training in this area, and that they did not feel comfortable or competent to address the developmental and mental health needs of this population (Barendse et al., 2011; Hait et al., 2009; Sebastian et al., 2012). Transition to adult services tends to occur simultaneously with other life changes including educational/vocational, and leaving the family home, and for this reason it is recognised that health professionals may need to support the individual in planning for and managing these areas, taking into consideration their condition and disability (Royal College of Paediatrics and Child Health, 2003).

Future research

Although the designs of most of the reviewed studies were viewed as lacking in rigour, it is recognised that including observational studies in a systematic review is useful, especially when there is a dearth of empirical evidence on important healthcare issues, as is the case for the issue of transition to adult care (Alderson, Green & Higgins, 2004; Papanikolaou, Christidi & Ioannidis, 2006). Observational studies can raise interesting hypotheses and consequently guide future, more rigorous research. Therefore, it will be beneficial for future research to utilise randomised controlled trials (RCTs), for example, to determine what model

of transition is the most appropriate to facilitate an effective transition to adult services (Dabadie et al., 2008; de Silva & Fishman, 2014; Wright et al. 2014). This has been demonstrated in other chronic conditions, whereby structured transition programmes are compared to standard care. Such programmes include group training workshops (Betz et al., 2010), technology-based (e.g. mobile- and web-based) training (Huang et al., 2014), and the involvement of a Transition Coordinator (Spaic et al., 2013; Van Walleghem et al., 2008).

It may also be favourable for future longitudinal studies to involve long-term follow-up of patients several years after the transition process is completed, and to assess effectiveness of the intervention by measuring clinical outcomes, quality of life and treatment adherence (Benchimol et al., 2011; Plevinsky et al., 2014; Wright et al. 2014; Zijlstra et al., 2013).

This review has highlighted the need for future research into the development and application of transition readiness measures. Schwartz et al. (2014) make recommendations about their development, including testing for psychometric properties, using heterogeneous samples, to be theory-driven, to involve all stakeholders, and the need to evaluate the use of measures for intervention planning. Furthermore, in the wider literature, it is currently unclear whether the use of a disease-specific measure is more beneficial than a generic measure that can be used in any speciality (Schwartz et al., 2014). There is also an apparent need to develop validated measures to evaluate transition interventions. These should identify relevant outcomes, for instance health (e.g. disease activity), service utilisation (e.g. treatment adherence, clinic attendance), psychosocial outcomes and quality of life (Crowley et al., 2011; Paine et al., 2014; Wright et al., 2014).

Conclusion

At present there is no one accepted framework of factors that need to be considered to ensure a successful transition. However, there is some consensus that the transition process should involve joint care, be flexible and gradual to address individual needs of the young person in order to prepare them to utilise adult services successfully. The young person needs to develop several competencies to ensure a successful transition to adult services, including disease-related knowledge, self-management skills, and self-efficacy. In addition, there is also a need to address parental involvement, especially concerning responsibility for disease management. Unfortunately, due to methodological limitations of the studies included in this review, it is difficult to make firm conclusions, especially about the effectiveness of transition interventions. Therefore, there is a clear need for more rigorous research in this area to understand better the most effective model of transition, as well as to develop validated measures to inform and evaluate the process.

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Transition from Paediatric to Adult Services: An Interpretative Phenomenological Analysis of the experiences of young people with coeliac disease

Word count: 8768

Prepared for submission to
European Journal of Gastroenterology and Hepatology

Abstract

Objective: Research on the transition from paediatric to adult services has been conducted in a variety of chronic health conditions. However, there is an absence of literature on the transition in coeliac disease (CD). This study explored the transition experience of young people with CD, from the perspective of both young people and their parents.

Methods: Seven young people and six parents were interviewed. The data were analysed using the Interpretative Phenomenological Analysis (IPA) approach.

Results: Three super-ordinate themes were identified for each subgroup, which overlapped extensively: 'Absence of discussion and abandonment', 'Understanding my coeliac disease and me' and 'Responsibility is an evolving process'. A lack of discussion and involvement in the transition process was associated with feelings of abandonment and apprehension about the future. Many participants felt their CD-knowledge and psychosocial needs were not sufficiently addressed during the process. Assuming responsibility for the utilisation of services varied across the young people according to the situation and their needs, and the involvement of parents did not necessarily end with transfer to adult services.

Conclusions: The transition process should ensure continuity of care, including the assessment and support of educational and psychosocial needs, and include clear communication between all relevant parties. Further, rigorous research is required to better our understanding of the key elements of an effective transition service.

Introduction

Coeliac disease (CD) is an autoimmune disease, affecting 1 in 100 people in the UK (Murch et al., 2013), and is characterized by an adverse reaction to gluten, a protein found in wheat, barley and rye. Consuming gluten causes *villous atrophy*, the flattening of the villi of the small intestine, which absorb nutrients (Ciclitira, Dewar, McLaughlin & Sanders, 2010). Clinical presentation can vary from asymptomatic to severe, with symptoms including diarrhoea, constipation, abdominal pain, anaemia, and chronic fatigue (The National Institute for Health and Care Excellence [NICE], 2009). CD is associated with heightened long-term risks for osteoporosis, intestinal malignancy (e.g. lymphoma), endocrine disorders, infertility and nervous system diseases (e.g. epilepsy and migraine) (Ciclitira et al., 2010).

CD is present in both children and adults and can be diagnosed at any time, but is most commonly diagnosed between the ages of 40 and 60 years (Ciclitira et al., 2010). A screening blood test followed by an intestinal biopsy is the current standard method for a definitive diagnosis and, if diagnosed, treatment is a life-long gluten-free diet (GFD; NICE, 2009); there is no cure for CD. Benefits of the GFD include resolution of symptoms and nutrient deficiencies, as well as the prevention of long-term complications (Murch et al., 2013). Therefore, strict adherence and dietary self-management are essential. However, adherence difficulties have been evidenced, with adherence rates ranging from 42% to 91% in adults (Hall, Rubin & Charnock, 2009) and 45% to 81% in children and young people (Garg & Gupta, 2014; Hill et al., 2005). It is important that individuals receive ongoing healthcare to monitor dietary self-management (Pietzak, 2005), as a lack of healthcare has been linked with poor dietary management and heightened risk of otherwise preventable complications in later life (O'Leary et al., 2004). The British Society of Gastroenterology (BSG) states that patients with CD should be reviewed annually and receive support from dietetic services, and a

gastroenterologist if necessary. However, follow-up care varies hugely within the UK, from specialist clinics, to general practitioners, to an absence of any form of healthcare (Bebb, Lawson, Knight & Long, 2006; Ciclitira et al., 2010).

It is universally regarded as imperative to promote and establish positive health behaviours (e.g. physical exercise, medical treatment adherence) in childhood and adolescence, as this period forms the foundation for health behaviours in adulthood (Royal College of Paediatrics and Child Health report, 2003). For children and young people with chronic health conditions, it is viewed as the responsibility of clinicians[6] to instil this knowledge and skills in order for them to manage their condition and adhere to their treatment (Michaud, Suris & Viner, 2004). For clinicians to effectively achieve this for patients with CD, they must understand and address the psychological and emotional issues of managing CD and the GFD (Mulder & Cellier, 2005; Howard & Law, 2014), as well as the common, yet complex and diverse developmental needs that are unique to adolescence (Royal College of Paediatrics and Child Health, 2003). Furthermore, as young people with CD progress into adulthood, it is important that their healthcare is continuous as it transfers to adult services. This seamless, uninterrupted move from paediatric to adult services is now commonly referred to as *transition*; "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health-care systems" (Blum et al., 1993, p. 570). Transition is more than just a single event (i.e. transfer) - it should be a gradual, person-centred process that ensures optimal care management that goes beyond biomedical care. Services should be developmentally appropriate and address all of the individual's needs, including psychosocial and educational/occupational, with the aim of improving quality of life (Department of Health/Department for Education and Skills, 2006).

[6] For the purposes of the thesis, the term 'clinicians' refers to all professionals providing healthcare, such as medical doctors, dietitians, and nurses.

Currently, there is a paucity of research in the area of transitional care in young people with CD (Craddock, 2015). However, research has been conducted in other chronic health conditions, such as diabetes and chronic kidney disease (Tong et al., 2013), inflammatory bowel disease (IBD) (de Silva & Fishman, 2014), congenital heart disease (Clarizia et al., 2009) and cystic fibrosis (Towns & Bell, 2011). The literature highlights a consensus across conditions on a number of key components of good practice for the transition process, including joint and coordinated care between paediatric and adult services; and a gradual transition to allow time for the patient to prepare for the transfer, which includes initiating the process in early adolescence and developing the patient's competencies to enable them to assume self-management responsibilities. Competencies most commonly discussed include condition-related knowledge, self-efficacy and self-management, and self-advocacy and decision-making (Betz, Lobo, Nehring & Bui, 2013; de Silva & Fishman, 2014; Tong et al., 2013). For the transitioning patient with CD, focus should be on self-management of the GFD, as existing evidence has shown this to be compromised in the adolescent population. Influencing factors include social struggles (e.g. poor availability of gluten-free food, social inconvenience and embarrassment), poor knowledge about complications and an absence of immediate symptoms (Olsson, Hörnell, Ivarsson & Sydner; 2008), as well as low self-efficacy in adhering to the GFD (Howard & Law, 2014). It is important that clinicians educate and support transitioning patients to assume self-management of their CD and the GFD. However, the protective, lenient nature of paediatric services (which can ignore growing independence; Royal College of Paediatrics and Child Health, 2003) has been viewed by transitioning patients as fostering "learned dependence" (Tong et al., 2013, p. 299), which prevents the opportunity to develop autonomy. In contrast, adult services encourage active involvement in their treatment and decision-making processes (Kirk, 2008; Tong et al., 2013).

No universal model for transition exists (While et al., 2004), although services have developed their own transition clinics or adapted programmes based on condition type and available resources. However, joint and coordinated care between paediatric and adult services has been consistently recommended across services and conditions, and favoured by patients (Betz et al., 2013; Gleeson & Turner, 2012). Examples include interdisciplinary transition clinics, alternating clinic appointments and advance visits to adult services (Betz et al., 2013; de Silva & Fishman, 2014; Tong et al., 2013). Benefits of joint working include improvements in patient knowledge, establishing a trusting relationship with their new clinicians, alleviating concerns about the process, the prevention of patients being overwhelmed by the differing culture and practices of adult services (e.g. test procedures, less vigilant follow-up), and safeguarding against non-adherence and subsequent deterioration in health (Betz et al., 2013; de Silva & Fishman, 2014; Tong et al., 2013; Towns & Bell, 2011). Furthermore, communication with patients about the transition process, as well as involving them in care planning and decision-making, can also help prevent uncertainty and confusion (Betz et al., 2013; Kirk, 2008). Communication between services, such as the handover of medical information, has also been cited as aiding the transition process and continuity of care (Hait et al., 2009; Towns & Bell, 2011), and can be valuable after transfer, as well as before, for example, to clarify missing information, or to discuss attempts made by the patient to contact paediatric services post transfer to adult services (de Silva & Fishman, 2014).

Literature regarding the timing of transfer emphasises that it should not be determined by the patient's chronological age alone, but also by a range of individual needs, including social maturity, health status (comorbidities, disease stability) and milestones, such as leaving school (Betz et al., 2013; de Silva & Fishman, 2014; Tong et al., 2013; Viner, 2008). There are recommendations that the process should start "early", as patients appreciate the advance

notice (Tuchman, Slap & Britto. 2008), and should be graduated to allow time for the patient to prepare for the transfer (Tong et al., 2013). However, the literature presents diverse evidence regarding the timeframe of the transition process, with suggestions ranging widely between 11 and 25 years of age. In the UK, 18 years of age was found to be the universal age by which transfer is completed (Crowley, Wolfe, Lock & McKee, 2011; de Silva & Fishman, 2014; Harden et al., 2012; Tong et al., 2013). Ideally, transfer should be based on patient readiness (Schwartz, Tuchman, Hobbie & Ginsberg, 2011), which has been linked to patient's accepting responsibility for their condition and self-efficacy for their treatment regime (Kirk, 2008; van Staa, van der Stege, Jedeloo, Moll & Hilberink, 2011).

In order for the transitioning young person with CD to assume responsibility and independence of the management of their condition and GFD, parental involvement also needs to be addressed in the transition process. The recommendation is for a phased approach (e.g. seeing the clinicians alone for part of the appointment), which should be negotiated between the patient, parent and clinician (Kirk, 2008). The inclusion of parents in the transition process is imperative, as research has shown that parents can influence its success, with anxieties about the transfer and overprotectiveness towards the young person commonly presenting as obstacles (Abraham & Kahn, 2014; McDonagh, 2005), whilst support and encouragement are facilitators (de Silva & Fishman, 2014), for example, in the young person's acquisition of self-management and self-advocacy skills (e.g. decision-making and liaising with services) (Kirk, 2008).

Aims

To date, the experiences of young people with coeliac disease (CD) transitioning to adult healthcare services remain unexplored. To address this gap in knowledge, the present study

solicited perspectives on transition from young people with CD (16 to 19 years) and parents, from across the UK. The young people in the sample had recently made the move to adult services. The main objectives were to understand the nature of the experience of the young people and parents and how they made sense of the transition process and its outcome from their particular perspectives. This research will help to improve our understanding of the facilitators of a good transition, and therefore contribute to the establishment of evidence-based recommendations.

Methodology

Design

Interpretative Phenomenological Analysis (IPA) is a qualitative approach that allows for an in-depth exploration of individuals' lived experiences (Smith, Flowers & Larkin, 2009). IPA theoretically derives from phenomenology, hermeneutics and idiography, and is concerned with how individuals make sense of their experiences, and what meanings these experiences hold for that individual. There are various qualitative approaches, such as narrative analysis, which explores people's life stories and how they use these to interpret the world; or grounded theory, which generates theories that explain how something 'works'; or discourse analysis, which is interested in communicative interactions and the function of language and power in specific contexts (Smith, Flowers & Larkin, 2009). IPA was deemed the most appropriate approach for the current study due to of a lack of research conducted to date in the area of transitional care for young people with CD. Therefore, there is a need to describe and understand *what* is happening, which is necessary before understanding and explaining *why* it might be happening (Barker, Pistrang, & Elliott, 2002).

Procedure

Ethical approval was granted by the University of Birmingham's Science, Technology, Engineering and Mathematics Ethical Review Committee (Appendix 4).

To access participants from across the UK, participants were recruited through Coeliac UK (the main UK charity for people with coeliac disease) via advertisements on their website and their 'Crossed Grain' magazine, posts on the Coeliac UK Facebook page, and through a flyer circulated to leaders of local coeliac support groups (Appendix 5). Potential participants were advised to contact the lead researcher if they were interested in participating, after which an

information sheet (Appendices 6 and 7) was sent and a screening checklist completed over the telephone (Appendices 8 and 9) to determine eligibility for participation (see Table 6 for inclusion and exclusion criteria).

Table 6: *Inclusion and exclusion criteria*

Inclusion criteria	Exclusion criteria
Young person with coeliac disease	
• Age 16 – 19 years. • Confirmed diagnosis of CD before the age 14 years. • Have received at least 2 years of care from paediatric services for CD (thus sufficiently able to reflect on their experiences of receiving care from paediatric services). • Discharged from paediatric services ≥ 6 months ago (thus sufficiently able to reflect on their experiences post discharge from paediatric services). • Demonstrate an understanding of, and ability to speak, English, as required for method of data collection and analyses, and due to lack of resources for interpreters and translators.	• Comorbid health condition of diabetes (specialist services are available for children and young people with a dual diagnosis of CD and diabetes, and thus these children and young people might have different experiences of services and transition than those with just CD). • Diagnosed learning disability.
Parent	
• Parent of a child with CD who is participating in the research project and has consented for parent to participate[7]; • Understands, and is able to speak English as required for method of data collection and analyses, and due to lack of resources for interpreters and translators.	• Co-morbid physical and/or mental health condition(s), with the exception of CD, that are likely to have a significant impact on the meaning and experience of care and management of children with CD. • Diagnosed learning disability.

Data collection involved individual, semi-structured interviews (approximately 60 minutes in length) completed by the lead researcher, which took place in participants' homes. To ensure confidentiality, the young person and parent interviews were conducted separately. All interviews were digitally audio-recorded and transcribed verbatim for analysis. Informed

[7] Young people were able to participate regardless of whether their parents participated. However, a parent could only participate if their child was also participating, as well as met the inclusion criteria. If a parent expressed an interest in participating, but their child declined/wasn't eligible to participate, the parent's participation was withdrawn. Therefore the sample is not necessarily made up entirely of dyads.

consent was obtained prior to the interviews (Appendices 10 and 11). It was recognised that discussing personal experiences might evoke distress and therefore participants were debriefed after their interviews and given information about available support services (Appendix 12). Participants were sent a copy of their interview transcript for accuracy checking before analysis, and also for approval of the use of quotations in the final thesis and any other potential publications.

Two semi-structured interview schedules were devised in line with IPA guidance (Smith et al., 2009), one for the young people and one for parents (Appendices 13 and 14). The research aims, and a review of the relevant literature, guided the development of key themes and questions. The research supervisors, who were experienced in CD, child and adolescent healthcare, as well as in IPA, also reviewed the interview schedules. The schedules were piloted with one participant from each of the relevant sample groups, in order to identify any potential limitations of the interview schedule, and if deemed necessary, assist in the revision of questions before continuation of data collection. No amendments were made after the pilot interviews and therefore the pilot data were included in the analysis.

Participants

There is no current specific criterion regarding sample size for IPA studies, however, Smith et al. (2009) suggest that between four and ten interviews (to allow for participants to be interviewed twice if necessary) are appropriate for the purpose of research within professional doctorates. A total of 13 participants took part in the study, seven young people and six parents, creating six child-parent pairings. One parent was not eligible to participate and therefore the seventh young person was not part of a child-parent pairing. Therefore, the

sample consisted of two homogeneous subgroups. Demographics of the young people subgroup are presented in Table 7, and those of the parent subgroup are presented in Table 8.

Data analysis

Analysis was conducted in line with IPA guidance (Smith et al., 2009). The process started with initial reading and re-reading of the data (i.e. the transcripts), whilst making exploratory notes on the semantic content and language (Appendix 15). This involved the identification of key objects of concern (e.g. processes, events, values and relationships) and the meanings participants attached. There was also interpretation about how and why the participant had these concerns, for example, by considering the context and the language used by the participant. Connections were then made between similar exploratory notes to facilitate the development of emerging themes, with an ongoing process of evaluation. This process was repeated for each transcript, and then connections across transcripts were examined to develop super-ordinate themes shared across cases, which included both converging and diverging experiences (Appendix 16).

Table 7. *Young Person demographics*

Young person[8]	Gender	Age (yrs)	Ethnicity	Education	Occupation	Residence	Age at Diagnosis	Age at discharge (yrs)	Care transferred to[9]	Other family members with CD
Elizabeth	Female	19	White-British	A Levels	Full time employment	Parental home	23 months	18	GD	Paternal cousin
Kitty	Female	18	White-British	A Levels	Student	Parental home	1 yr	16	GP	None
Mary	Female	16	White-British	GCSEs	Student	Parental home	2 yrs	16	GP	None
Lydia	Female	17	White-British	A Levels	Student	Parental home	10 yrs	17	GP	Mother
Jane	Female	16	White-British	GCSEs	Student	Parental home	7 yrs	15	GD	None
Caroline	Female	16	White-British	A Levels	Student	Parental home	12.5 yrs	16	GP	Father & younger sister
Georgia	Female	17	White-British	A Levels	Student	Parental home	8 yrs	16	GP	None
Median **Mean** *SD*		**17** *1.16*					7 yrs *4.49*	**16.29** *0.95*		

[8] Pseudonyms have been assigned for anonymity.
[9] GD = Gastroenterology department at their local hospital, GP = General Practitioner

Table 8. *Parent demographics*

Parent[10]	Gender	Age (yrs)	Ethnicity	Marital status
Catherine	Female	44	White-British	Married
Emily	Female	52	White-British	Married
Louisa	Female	47	White-British	Separated
Maria	Female	53	White-British	Married
Sally	Female	52	White-British	Married
Susan	Female	48	White-British	Married
Mean *SD*		**49.33** *3.56*		

Reflexivity

To aid the credibility of qualitative research, it is important for researchers to reflect on the shared and overlapping experiences between themselves and participants (i.e. intersubjectivity; Biggerstaff & Thompson, 2008). This awareness encourages the acknowledgement of potential influences on analysis and therefore interpretations of the data can be adapted accordingly.

I am a White-British, 30-year-old female, in the third year of a doctorate in clinical psychology. Although I am of the same ethnicity as the participants, I am not the same age as either the young people or the parents, therefore positioning me as a third party.

I do not have a chronic health condition; however, I have Dyslexia, which was diagnosed in childhood, and consequently my parents moved me to a different school to ensure that I received specialist support. These experiences were difficult and associated with feelings of anxiety, embarrassment and perceptions of being 'different'. My relationship with Dyslexia

[10] Pseudonyms have been assigned for anonymity.

has been one of a dynamic nature, and with personal development I have grown to accept the condition. These experiences have made it easy for me to empathise with participants during the course of the interviews, and connect more readily with themes regarding living with an incurable condition, as well as transition. However, to ensure that I assumed the role of a researcher rather than the role of a clinician I made frequent use of supervision and a peer IPA group. This process included reading a subsection of a transcript and comparing exploratory notes, as well as discussing the themes within and across cases. This helped to question assumptions, as well as hold aside my personal experiences to minimise their influence on analysis. For example, I found myself wondering why some participants did not question the absence of a transition process more or take this up with services, especially of those participants who had not heard from adult services since discharge from paediatric services. Supervision and IPA group discussions allowed me to see when I was making these assumptions. This minimised the impact of my personal beliefs on the analysis as it allowed me to be free to 'hear' what the participants were saying, rather than formulate their behaviour.

Results

The large number of participants (both young people and parents) naturally created a large amount of data. Initially, the young people and parents' transcripts were analysed separately according to subgroup. Three super-ordinate themes were identified for each subgroup, which overlapped extensively. To ensure a succinct illustration of the results, and to avoid repetition of data, only the data from the young people will be presented in depth. The parent's data will be summarised, highlighting the overlaps with the young people's data, as well as any idiographic data indicated only by the parents.

Young People

Three super-ordinate themes and seven sub-ordinate themes were identified from the young people's data (Table 9). This section is organised by super-ordinate themes, and a narrative account is provided for each theme, along with extracts[11] from participants as evidence.

Table 9: *Summary of young people's themes*

Super-ordinate theme	Sub-ordinate themes
1. Absence of discussion and abandonment	• Dismissed and ignored • Ambivalence: uncertainty, apprehension and hope • Rejection and abandonment
2. Understanding my coeliac disease and me	• Realising the seriousness of coeliac disease should start in paediatric and continue in adult services[12] • There is more to me than my coeliac disease
3. Responsibility is an evolving process	• I still need my parents but not as much as I did before • Assuming responsibility is part of the transition into adulthood

[11] For brevity, unnecessary text within extracts is replaced with …

[12] For the purposes of the thesis, all services looking after participants post-transfer will be referred as "adult services" even though for the majority this meant GP care.

Super-ordinate theme 1 – Absence of discussion and abandonment

Young people commonly perceived the transition to adult care as inadequate and dismissive, as participants experienced a lack of involvement in and control over the process. There also appeared to be feelings of abandonment for many participants due to a lack of follow-up by adult services.

Sub-ordinate theme: Dismissed and ignored

The transition was frequently described negatively, with participants reporting that they were *told* they would be transferred to adult services rather than being involved in a decision-making process, *"No. It was not like, 'oh are you okay with not coming here?' I think they said, "You can just go".*" (Mary; line 311). Participants also described an absence of notice about the transfer, with five of the seven participants being informed only in their last appointment with their paediatrician, "*It was just, "this is your final appointment" so it was the same as every other year, but just "we don't need to see you anymore, you're okay".*" (Kitty; line 267).

Georgia was informed about the transfer in her penultimate paediatrician appointment, and although there was an absence of collaborative discussion about what would happen, in contrast to other participants, she was relieved that the decision was made for her, "*It's okay. I hate making decisions so yeah I don't mind. And yeah I understand that things need to be done*." (Georgia; line 612).

Lydia was the only participant with whom transition was discussed. She viewed this as a beneficial experience. She felt she had choices and that it was for her to make the final decision about when the transfer would happen, indicating a sense of control over her transition.

> *I think really it was up to us. It was made very clear it was up to us, that it was what we wanted. So we said, erm we said to the child services that we didn't really feel like we needed to see them again for another year, that it would just be easier to be transferred erm because it would like, might interfere with like exam times and stuff because I usually see them in May anyway which is the middle of exam time. And then yeah it was really what was easiest for us, they did, it was quite a good thing really.* (Lydia; line 243)

All but Mary had some sense of the reason for the transfer and why it happened at a particular point in time, with chronological age being the most cited reason.

> *Because I'll be sixteen and after that I would be moving into adults service because obviously children are younger. So from 17 I would be classed as an adult in terms of the services for that.* (Georgia; line 496)

The timing of transfer ranged between 15 and 18 years, and as reflected in Georgia's excerpt (above), this was viewed as dictated by services, with a clear divide between paediatric and adult services. Caroline had a different understanding, believing the transfer occurred because her doctor viewed her condition as stable.

> *Erm. He, I guess he just looked at all of the data and stuff and he just really [pause] … and then he must have just decided that he felt that it was okay. Erm. He did explain, I'm sure he did. And he just--it's probably just because I was--I'm healthy, I'm fine.* (Caroline; line 149)

Several participants, who were dissatisfied with their transition experiences, suggested approaches that would improve the transition process, including clear, detailed discussions about the transfer and the practice style of the new service. Another suggestion was for these discussions to occur over a series of appointments to allow the young person time to prepare. The involvement of adult clinicians in the final paediatric appointment, and transparent communication between all parties, were also proposed.

> *Maybe discuss it more. I think they should have mentioned it a couple of times before I was moved up, cus then you can get use to the idea. It's not like, oh telling me now and then your next appointment is at adult services. I think they should have done it a bit more gently.* (Elizabeth; line 350)

> *… maybe on the last appointment with the child services, having the adult services in as well. Or having some communication between the two, with you. And then getting it*

> *clear [pause] like giving a clear knowledge of who the adult services are and who to speak to and when…kind of more information about that.* (Georgia; line 615)

Sub-ordinate theme: Ambivalence: uncertainty, apprehension and hope

All participants described experiencing a range of positive and negative emotions about the transition. Some felt sad about leaving what was familiar, as well as anxious about entering the unknown.

> *And then like having to get use to a new consultant or having them get use to you, that's always a bit kind of--I don't know--worrying or [pause] just yeah. Kind of having to go through all of the things again with them.* (Georgia; line 603)

> *Gutted, because I won't see her. It's just that whole comfortable thing, comfortable about talking about it with her. But then I was excited that I was an adult but it's kinda of nerve-racking as well.* (Elizabeth; line 350)

Elizabeth's excerpt (above) also illustrates a positive perspective taken by some of the participants. She explained that she felt optimistic about future opportunities, such as meeting new people (i.e. peers) with whom she could "*share experiences*". Some participants gave an account of feeling ready for the transfer. Jane, whose family took the lead in initiating her transfer, reflected that meeting and getting to know her adult consultant before the official transfer alleviated her anxieties.

> *I was kind of a bit nervous about being properly moved over the adult care but because I had already seen [name], once I realised he was going to be my main doctor erm, I was fine, I wasn't too bad with it because I had already met him and he was really nice.* (Jane; line 277)

Similarly, Georgia's experience of going to the adult department for blood tests whilst still under paediatric services helped her to slowly adapt to adult care (e.g. undertake blood tests without pain relief).

> *A few years ago my blood tests--they changed … instead of the child blood tests, I had to go to the adult like blood test place, and I didn't like that at first. But erm I don't know I think that got me use to being treated more adultly [sic]….* (Georgia; line 670)

More than half of participants did not have a clear understanding of where they would be transferred to or what to expect when they were discharged from paediatric services, leaving them feeling confused and anxious about the future of their care.

> *I felt somewhat worried because as I said, I didn't realise that I could still get the blood tests and stuff, so I thought it was all pretty much ending unless I needed to like talk to someone about something. So that was a bit worrying because its nice to have--you know, when you're going to see them, so if anything did happen that you needed to ask them about then you already have a time when you can talk to them.* (Georgia; line 596)

Similarly, Kitty believed that her CD was no longer being treated by any service, *"... I thought that was the end."* (Kitty; line 281). However, she was relieved not to attend appointments, as it meant that she was no longer required to take blood tests, which she disliked. Kitty's care was eventually followed-up by her GP, but she was still uncertain about the nature of that care, "… *It's nice to know what's going on. ... Whether I'm going to have to have blood tests every year, forever or whether just once in a while*." (Kitty; line 506)

Elizabeth, Jane and Lydia remembered that they knew where they were going with certainty and what to expect following discharge from paediatric services. Lydia, who felt involved in the discussions and decision to transfer, indicated a willing acceptance of transition.

> *Erm and then I think it was only a couple of weeks before the appointment we'd got the letter from the GP to say they had started running their own service. Erm, and I think we pretty much had it in our minds that we'd go to the GP anyway. So I think, there wasn't really any uncertainty, we know what we want to do, we know this is going to happen, we've just got to embrace the change really.* (Lydia; line 285)

<u>*Sub-ordinate theme: Rejection and abandonment*</u>

Four participants indicated feeling rejected by paediatric services, such as noticing a lack of care or concern, "… *it was just very dismissive ...*" (Mary; line 302); "*There was no like special thing or like a goodbye or anything*." (Elizabeth; line 281).

> *… they were running late so I didn't even have it with the main consultant person. It was just with this woman. I think she was a dietitian--I'm not sure. … And she just went through my bloods and stuff and said they were perfect. Erm. And yeah told me that the adult services would be in touch with me.* (Georgia; line 470)

Two participants (Mary and Caroline) indicated feeling unwanted and unimportant, "*I felt like what I have is not as important as what someone else might have. I felt like discarded, not like I wasn't wanted there.*" (Mary; line 299); "*... he just wanted to stop seeing me, didn't he.*" (Caroline; line 135)

Four participants indicated feelings of abandonment by services, describing being "forgotten" and "left" to manage alone, as they had not been contacted by adult services since their discharge from paediatric services. This was associated with feelings of anxiety, sadness and loneliness.

> *Well it kind of feels like--get worried that--you're just forgotten about or lost in the connection between the two. Because I don't know how well they communicate because they don't really tell me. I don't know if they give information about me or how much information they give about me to them or what they say.* (Georgia; line 638).

> *I don't feel like I have--obviously I've got support from my family but not doctor support, like support from anyone who really knows that disease so I just feel like I don't really have anyone to go to about anything. It just feels lonely, [pause] unsupported and that I just have to deal with it by myself and no one really cares.* (Mary; line 263)

In summary, this super-ordinate theme suggests some helpful and unhelpful means of communicating and conducting the transition process. Short notice, a lack of explanation about what to expect, as well as a lack of involvement in the decision-making process, were frequently associated with feelings of apprehension, rejection and abandonment. Providing choices and supporting the individual to make an informed decision, as well as meeting adult clinicians before transfer, appear to alleviate anxieties and prepare the individual for transfer.

Super-ordinate theme 2 – Understanding my coeliac disease and me

Data from this super-ordinate theme highlighted the importance of clinicians recognising and providing appropriate support that met the educational, psychosocial and developmental needs specific to participants' coeliac disease. This super-ordinate theme is divided into two sub-themes.

Sub-ordinate theme: Realising the seriousness of coeliac disease should start in paediatric and continue in adult services.

Many of the young people began to realise the seriousness of their coeliac disease (CD) during the transition process. This understanding extended beyond the immediate symptoms that occur after ingesting gluten to an appreciation of the long-term complications of untreated CD, and the importance of good dietary self-management.

> *The dietitian, I said to her about like the hula hoops, and she wasn't very impressed, she was saying about you can get bowel cancer and be infertile, and that's something I want most, like having a family. So now that she has told me that and it's explained it to me properly, it's kinda realisation and that I've got to do everything right, otherwise I wouldn't go anywhere, like having a family and I'd be really poorly.* (Elizabeth; line 65)

Elizabeth's narrative above also reflects the perceived role of clinicians to educate and support the young person. In this respect, Elizabeth felt 'let down' by paediatric services, as she felt they had not provided her with all the care and support that she had wanted. However, she felt she was now receiving her desired care with adult services, "*I don't think I would have had weight problems now, if they had done the right things and done what my dietitian is doing now.*" (Elizabeth; line 264). Similarly, Mary was of the opinion that it was the duty of her paediatrician to have told her about the long-term complications, but felt he/she failed in doing so.

> *But when I found out I was like 'oh my goodness am I going to be okay? What's going on?' It was really worrying. Really worrying. I was really angry that they hadn't told me about that, because it's a really important thing that I should have know about before*. (Mary; line 199).

However, it is possible that her paediatrician assumed she had already acquired the knowledge and skills and was capable of managing the condition, as her blood tests were always negative and they perceived her condition to be controlled.

> *I just get waved off as someone who is fine and they can deal it for themselves. Which I guess is a positive thing but it just makes me a bit curious as to [pause] 'are you sure I'm okay?' I'm not entirely sure.* (Mary; line 172)

Mary's excerpt (above) also illustrates the notion of uncertainty about fully understanding the condition and her ability to manage it. Similarly, Georgia appeared unsure whether she knew everything that needed to be known, "*I think I kind of know what I should know. I think.*" (Georgia; line 562)

How clinicians communicated also appeared to be an important factor in helping the young person to develop their understanding. Jane's description of her first experience of learning about the long-term complications of untreated CD, in paediatric services, indicated shock and a feeling of being attacked.

> *I just really wasn't expecting it I guess because all the ones before it'd just been really like laid back and they'd just been talking about stuff I already knew. And then he just like suddenly came at me like "you do realise even if you stick to your diet you've got a high risk of getting diabetes and back problems and cancer" and I was like "I didn't know that actually, thanks." So that was yeah, he just didn't--it's like he didn't really know how to talk to children.* (Jane; line 161)

Jane explained that this led her to be "*paranoid*" about any physical pain (e.g. stomach ache), as she believed she was "*guaranteed to get all of these problems*" (Jane; line 176). It was this experience that led her to first see her adult clinicians, who clarified her misunderstandings, and whom she described as "*nice*" and "*helpful*".

Five of the seven young people had their care transferred to their GP, three of whom expressed doubts about their GP's ability to provide adequate care for their CD, perceiving them to lack the knowledge and resources.

> *I think the GP, they just--they don't have any specialist advice for you. They just tell you your results. They don't say how you can--they don't have any specialist knowledge of it. Whereas at the hospital they would have a dietitian who would talk to you and make sure you're okay. I think that would be much better.* (Mary; line 396)

> *… well alright she didn't have the knowledge but maybe, … Yeah, I think maybe like we just need to give it time to see how it goes and then if we need to like be transferred over to the hospital we know we have the options of doing that still.* (Lydia; line 502).

Lydia's excerpt (above) also indicated self-reassurance about the situation, as she indicated awareness of the possibility to be transferred to the hospital should the coeliac clinic run by the GP fail to improve. In contrast, both Georgia and Kitty reflected on feeling reassured that they were receiving some form of healthcare for their CD, albeit it came from the GP. Jane and Elizabeth were the only participants under an adult gastroenterology service, and both particularly valued the education and guidance from their dietitians. Useful advice included nutrient intake, optimum use of prescriptions, and awareness of new gluten-free foods.

Sub-ordinate theme: There is more to me than my coeliac disease

Four participants transitioned to adult services still struggling to accept their CD, describing experiences of feeling 'different', 'weird' and 'awkward', for example in relation to their friends. Prior to transition they had not fully accepted their diagnosis and what it meant for them.

> *Sometimes I wish life was different. But I don't know what I feel. I think my last dietitian appointment I was really upset because she said I had to come to terms with it. That was upsetting. But it's just sad. I just get sad over it.* (Elizabeth; line 189)

> *I was really embarrassed about how much I had to eat and like how it was different to everyone else's food. And so I preferred to just--and like if I went out with my friends I'd prefer not to eat than to eat my food, so I kinda went through phases where I was just wasn't eating very much and I was making myself kind of ill with that. And she was really helpful with that and helping me get back to a proper kind of schedule.* (Jane; line 263)

Jane and Elizabeth went on to express an appreciation of the supportive environment and relationships in adult services, where they felt cared for and were able to have open

discussions about their experiences of living with coeliac disease, which in turn made their care feel more meaningful, "*... they also talk to me as well rather than just talking at me, its kind of like to me rather than just sort of directed. Yeah it's more personal than just general.*" (Jane; line 434)

> *... she's so caring and you can tell that she genuinely loves her job. I like people like that. Always want to help people and she is--she's really kind. And the research that she does and she sends me things through the post, like leaflets on gluten-free foods, and what I can do to help my coeliac disease by sticking to foods I should be eating. She's good.* (Elizabeth; line 427)

For Georgia and Mary, having transferred to GP care, there was a perception of a loss of psychological and emotional support, such as the loss of the ability to discuss their experiences of living with CD.

> *It's nice to see a familiar face and kind of [pause] talk about stuff like school, like how stuff is going. They were more interested in me and how stuff was going than the GP would be, because they never--they don't really have time to discuss anything outside of the ailment.* (Georgia; line 422)

There was an indication that clinicians should be respectful and supportive towards the young person, and that they adapt their communication style according to the developmental maturity of each young person. Jane and Lydia expressed frustration at feeling ignored by their paediatric clinicians, as both felt it was essential that they be central to discussions and that they were capable of understanding and taking on this level of communication. This was interpreted as an indication that their paediatric clinicians had not recognised their readiness to assume responsibility for their condition.

> *... the consultant and the dietitian always spoke to my mum and dad and dismissed the fact I was there. And it was kind of 'I'm here. This is my--like something that affects me' it does affect them but it affects me, I need to know this ...* (Lydia; line 198)

> *... I was kind of like 'you can talk to me about it, I do understand it' but they just spoke to me like I was a really little child and I kinda felt a bit like...I can't think of the word. Erm, like patronising sort of, and I didn't really like that. Erm, so that's why I prefer it at the adults now because they actually talk to me, like they direct the*

> *questions at me, so I feel like I am the main purpose there and I should be there and there is actually a point of this meeting.* (Jane; line 109)

Jane went on to reflect the benefits of experiencing active involvement in adult services, which she described as a comfortable experience whereby she felt listened to and recognised as the adult she perceived herself to be.

> *… that's why I prefer it at the adults now because they actually talk to me, like they direct the questions at me, so I feel like I am the main purpose there and I should be there and there is actually a point of this meeting.* (Jane; line 113)

This super-ordinate theme suggests that young people with CD transitioning to adult services have diverse needs, which go beyond the medical treatment of their condition. Post-transfer, the young people made frequent comparisons between their paediatric and adult care, and with hindsight discussed the importance of clinicians recognising their educational, psychosocial and developmental needs and adapting their approach accordingly, both before and after transfer. The facilitation of a supportive environment that educates, as well as encourages open discussions about the emotional and social experiences of living with CD, whilst acknowledging them as a mature individual capable of contributing to their own care, may help them to achieve a good quality of life where they can function effectively in their individual and social lives.

Super-ordinate theme 3 - Personal responsibility is an evolving process

In this final super-ordinate theme, all seven participants were observed to make frequent and continuous use of the terms "we" and "us" when discussing both past and present experiences, and this was interpreted as an indication of a shared journey with their parents.

> *… it's always been a thing in the family, like if I have an appointment she'll come along and if she's got an appointment I generally go with her so it was just, yeah keeping up with what we usually do to be honest.*" (Lydia; line 326)

Although parents continued to be involved in the care of the young person's CD, the level of parental involvement appeared to be slowly reducing, with the young person assuming more responsibility.

Sub-ordinate theme: I still need my parents but not as much as I did before

Although the young people were now under adult services, none of them identified themselves as independently and solely responsible for their CD, with the continuing level of parental involvement varying across participants. Kitty was the only participant who attended her appointments independently, which appeared to have been difficult initially but subsequently gave her a sense of achievement, "… *I had to go for a blood test myself the other week. So I'd walk there from school and then up again, which was brave*" (Kitty; line 208). Kitty felt she was now more responsible regarding utilising services, however she appeared ambivalent about this, "*You have to remember stuff and be a bit more responsible. Talk to people on the phone which is not always fun, but it's okay.*" (Kitty; line 459)

For participants whose parents accompanied them to appointments with adult services, there was some indication that this was unquestionable, regardless of their transfer to adult services. However, involvement in the appointments appeared to have changed, from leading discussions to collaboratively working with their child.

> *Well, mum, it's always been mum who comes with me, and sometimes dad comes as well, but it's mainly mum. She just always does. At my last dietitian's appointment they both came and they both asked questions and were listening to what he was saying and what I had to say. Erm, and I think they quite like the fact that they also talk to me as well rather than just talking at me, its kind of like to me rather than just sort of directed."* (Jane; line 430)

Elizabeth discussed a realisation of the value of her mother's involvement and support at appointments.

> *But now that I am an adult I can see why she's there to support me, and we talk about it together with the dietitian like a three way conversations. Like instead of mum sitting there and saying nothing, we discuss it together and it will be like a conversation of 'oh yeah we had this and we tried that' and how we both felt about it.* (Elizabeth; line 468)

Conversely, Lydia was of the opinion that, having attended her first appointment with adult services with her mother, she would go to future appointments on her own and assume more independence and responsibility, in parallel to other areas of her life.

> *Erm, mum came down with me this time just with it being the first appointment and because we had like a few concerns before we went down. Obviously mum wanted those answers as well but I think generally I'll end up just going on my own with like me being at that age now, I go to most appointments on my own anyway if I'm seeing the GP. So I think it is very much they're going to take a step back now and I need to get on with it and deal with it myself now really.* (Lydia; line 542)

The role of the parent was frequently perceived as a supportive one, whereby they would offer reassurance and help, which varied in accordance with the young person's fluctuating needs.

> *It's different all the time. Sometimes I'm kinda like stressed about it, and then she'll just step back and just let me get on with stressing out. And other times when I get upset about it she will cuddle and carry on talking for me.*
> (Elizabeth; line 202)

Elizabeth's excerpt (above) highlights the diverse nature of parental support, from moral support to taking the lead, "*I phoned mum up from work and I was just distraught and she made a complaint about her but in my sort of words"* (Elizabeth; line 444). Georgia explained that she felt uncomfortable discussing her medical problems, as well as doubting her own ability to do this, meaning she valued her parent speaking on her behalf.

> *Erm. Well with doctors, or dentists or any kind of professional thing, except for teachers, erm I've never liked talking to them about what's wrong with me. And I've always found my mum is more eloquent; and she's better at discussing them--yeah than me.* (Georgia; line 450)

For Lydia and Jane, who had some degree of involvement in their transition to adult services, this decision-process appeared to have been primarily led by their parents, indicating that they required the guidance of their parents with the transition process.

> *So mum was always like "well there's no point you coming to here if you are going to be treated like well. If you can go somewhere else and like have a better treatment then that's definitely going to be the way forward."* (Lydia; line 306)

> *... my mum wasn't very happy about how they were like going about things ... she knew people in the adults hospital so like she thought it would be better for me to go, because obviously she knew me better than the doctors at the children's and she knew that I was kinda a bit more mature and I could like, I would be fine at the adults.* (Jane; line 314)

Parents also maintained the roles of "organiser" and "enforcer", which included managing appointments and prescriptions, indicating that the young person had not yet assumed complete responsibility for their condition, "*They still write down all the appointments in their diaries and stuff to make sure I don't forget."* (Kitty; line 466). Mary's mother continued to arrange appointments for her with the GP even though Mary saw this as pointless.

> *... my mum does it all for me. She books the appointment because I'm not very--when we go I don't get told very much, I'm not very interested in making sure I have my next appointment. It's not that important to me.* (Mary; line 415)

Sub-ordinate theme: Assuming responsibility is part of the transition into adulthood

A small subset of participants indicated that assuming responsibility in accessing adult services was a natural development, alongside other life transitions, such as moving out of the family home "*… you know you're going to have to do it in a couple of years anyway when you're all on your own.*" (Kitty; line 178)

> *I feel like an adult now. Like going in to do my prescription fees and paying it out of my own wages; I've earned to pay that. ... I feel like I should do it because like what am I going to do if I move out and all that kind of stuff.* (Elizabeth; line 527)

Lydia described a sense of feeling ready and comfortable with assuming independence, helped by her experience of autonomy in other areas of her life.

> *Not too bad because like I said a lot of my appointments I go to on my own anyway, through personal choice. So erm, I quite like the independence of doing it on my own anyway so it doesn't really faze me to be honest.* (Lydia; line 553)

Kitty, however, indicated a sudden change in assuming responsibility the moment her care was transferred to adult services. It also appeared that she perceived this change to be dictated by the adult healthcare system, and one that she felt forced, rather than willing, to accept, "*They have to talk to you on the phone because you're over 18 and they have to send you all the letters and information."* (Kitty; line 455)

This super-ordinate theme suggests that the young person's experience of services has been one they have continuously shared with their parents, and that parental involvement does not immediately stop the moment they transfer to adult services. The adoption of personal responsibility for utilising services appears to be a gradual, but natural process for the young person that differs in timing and style for each individual.

Parents

Three super-ordinate themes and six sub-ordinate themes were identified from the parent data (Table 10). This section provides a summary of the parents' super-ordinate themes that overlap with the young people data, as well as any idiographic data indicated only by the parents (Appendix 17).

Table 10: *Summary of parents' themes*

Super-ordinate theme[13]	Sub-ordinate themes
1. Absence of discussion and abandonment	• Absence of discussion • Abandoned and anxious
2. Care should be specialist and developmentally appropriate	• The young person's care should be specialist • Clinicians should interact appropriately with the young person
3. Withdrawal of parental involvement is an evolving process	• They still need our support • Withdrawing support is a gradual, natural process that requires adjustment

Similar to the young people, the parent data also highlighted a super-ordinate theme of an absence of discussion and abandonment; parents felt they had received little notice, if any, and described "ambiguous" communications by clinicians about the transfer. This was frequently associated with feelings of apprehension and abandonment, as parents felt uncertain about the transition process, as well as the future of their child's care due to a lack of contact from adult services. Uncertainties included whether the transfer had happened, as well as a lack of understanding of what would happen next, including to whom their child's care would be transferred, and when care under the new service would commence. Only one parent described a positive experience, explaining that they felt involved and in control of the process.

The parents' second super-ordinate theme 'Care should be specialist and developmentally appropriate' indicates a strong preference amongst parents for their child's care to be transferred to a specialist gastroenterology service, as opposed to the GP, as the latter was perceived to be ill equipped (e.g., lack knowledge and resources, time-limited) to care for their child's CD. Some parents highlighted the importance of clinicians adapting their care approach according to the young person's developmental maturity, as well as acknowledging

[13] Each of the parents' super-ordinate themes overlaps with the corresponding young people's super-ordinate themes.

the young person as an equal partner in their own care. These data overlapped with the young people's super-ordinate theme 'Understanding my coeliac disease and me', which highlighted a perception of the importance of clinicians, preferably within a specialist service, recognising and providing appropriate support that meets their educational, psychosocial and developmental needs.

Similar to the young people, the parents' data also highlighted a third super-ordinate theme of the withdrawal of parental involvement as an evolving process, and one that varied across participants. Many parents indicated that post-transfer they were still involved to a great extent in their child's utilisation of services, and that very minimal, if any, changes have occurred regarding their involvement. There was the perception amongst some of the parents that their child was not ready for complete independence, whilst others indicated that their child had assumed independence in utilising services. The most common change indicated was that parents were no longer taking the lead in discussions with clinicians.

There was also a view that the reduction of parental involvement is a natural occurrence, and one that is universally associated with parenthood and the young person's transition into adulthood. Two parents (Emily and Maria) also indicated "*mixed feelings*" about the reduction of their involvement with services, which included feelings of loss, not only of their role, but also of their child, as well as an ongoing adjustment to this change in role.

> *I'd say pride that I have raised this person who can manage herself and her relationship with other adults, and be responsible for her own health, which she is. But also a slight degree of ... what's the right word [pause] I suppose it's loss because I won't know how she is unless she chooses to tell me. So having been in control for however long it is, I've lost that control now. She has to do it herself.* (Emily; line 354)

> *I have to accept that she wants to deal with it on her own. ... Sometimes I feel as though I don't -- I'm not fully in touch with what she's -- what's going on with her anymore, but that's just age, isn't it? A lot of people will go through that so, yeah, there's not a lot I can do about that."* (Maria; line 512)

Discussion

Research on the transition from paediatric to adult services has been conducted in a variety of chronic health conditions (Clarizia et al., 2009; Tong et al., 2013; Towns & Bell, 2011). However, there is an absence of literature on the transition in coeliac disease (CD) (Craddock, 2015). To our knowledge, this study is the first to explore the transition experience of young people with CD, from the perspective of both young people and their parents. The data from the two subgroups were analysed separately, and three overarching themes were identified for each subgroup, which overlapped extensively: 'An absence of discussion and abandonment'; 'Understanding my coeliac disease and me'; and 'Personal responsibility is an evolving process'.

The majority of both young people and parents in this study described experiences of transition that they felt had impacted negatively on them. They felt there was an absence of notice and information about the transition, including to whom care would be transferred and/or the protocols of the new service. This resonates with a US national survey of over 5400 individuals, where it was found that only 15% of adolescents (14-17 years) with special healthcare needs had received information and support in the healthcare aspects of transition to adulthood (McPherson et al., 2004). The current study also found a perception amongst both young people and parents of being *told* about the transfer, rather than being involved in the decision-making process. Understandably, a lack of discussion and involvement in the transition process was frequently associated with feelings of apprehension, rejection and abandonment. A lack of understanding about what follows discharge from paediatric services created feelings of uncertainty and anxiety about the future of their care. The lack of interest in the transition by paediatric clinicians was associated with feelings of rejection; whilst the absence of contact from adult services left participants feeling abandoned and alone. Some

individuals also spoke about feelings of loss and sadness when the relationship with their paediatric clinicians ended. This is consistent with current findings in the transitional care literature, which have shown that the move to adult services is associated with sadness and anxiety. This includes sadness about the loss of long-standing relationships, and anxiety about the unknown due to a lack of communication and involvement in the process (Kirk, 2008; Tuchman, Slap & Britto, 2008).

A few individuals reported helpful experiences that aided the transition, for example, involvement in and control over the process; meeting the adult team before transfer; and experiences of adult procedures (e.g. undertake blood tests without pain relief) whilst under paediatric services. These experiences alleviated anxieties and helped the individuals to feel prepared for adult care. Wider literature also indicates a preference amongst young people with various chronic conditions to meet adult providers prior to transfer, either as a one-off visit, or joint paediatric/adult clinics (Crowley et al., 2011; Tuchman, Slap and Britto, 2008). Reported benefits of joint clinics include a reduction in anxiety (Dabadie et al., 2008; Paine et al., 2014); improvements in service use outcomes (e.g. clinic attendance rates, low hospital admissions); and disease-specific health outcomes (e.g. reduced prevalence of acute and chronic complications) (Cadario et al., 2009; Crowley et al., 2011).

Within the theme 'Understanding my coeliac disease and me', both young people and parents reflected on the condition-specific educational, psychosocial and developmental needs of the young person; and the need for clinicians to recognise and address them appropriately during the transition process. Many of the young people believed they lacked knowledge about CD when they were discharged from paediatric services and expressed a wish that their paediatric clinicians had provided this education. Furthermore, they indicated an association between their level of understanding and having good dietary self-management. This is

supported by evidence from research on adherence to the GFD, which has shown that poor understanding is associated with poor adherence (Ludvigsson et al., 2014; Ukkola et al., 2012). The lack of knowledge among the young people in this study may not necessarily be due to an absence of education, but rather an issue of how information was communicated by clinicians. There is evidence demonstrating that person-centred communication is key in helping young people understand their condition, for example, effective education should be ongoing and include repetition of information (Butterworth, Banfield, Iqbal & Cooper, 2004; Lewis and Noyes, 2013; Case, 2005).

Several young people in this study discussed the importance and benefits of psychosocial support from clinicians to address struggles such as acceptance, fear of developing long-term complications, and social embarrassment. Current guidelines for the management of CD scarcely refer to psychosocial issues (Ciclitira et al., 2010) although research has shown that the psychosocial effects of CD are extensive, for example, anxiety and depression (Howard & Law, 2014; Leffler et al., 2008; Rose & Howard, 2014); and associations with poor dietary self-management (Edwards-George et al., 2009; Wagner et al., 2008). A meta-analysis of the relationship between treatment adherence (for various conditions) and social support (practical, emotion and unidimensional) found that an absence of emotional support increased the risk of non-adherence; and that this risk was even greater among individuals who had not received practical support (DiMatteo, 2004). It is the responsibility of clinicians to assess the psychosocial issues of their patients, and to collaboratively identify sources of support available to them (DiMatteo, Haskard-Zolnierek & Martin, 2012; Howard & Law, 2014). Ring-Jacobsson, Friedrichsen, Göransson and Hallert (2012) found that a group-based educational programme improved the psychological well-being of women with CD,

demonstrating the importance of patient knowledge, alongside the benefits of meeting others with the same condition and sharing experiences.

There was a strong preference amongst both young people and parents in this study for follow-up to be under specialist gastroenterology services, as opposed to their GP. It was commonly viewed that GPs lacked knowledge and resources (such as access to dietetic services) to treat CD effectively, as well as lacking the time to discuss other, non-medical issues associated with living with CD (e.g. psychosocial issues). Current guidelines from the British Society of Gastroenterology (BSG) and the National Institutes of Health (NIH) state that patients with CD should be reviewed annually, and treatment should involve regular dietetic support, along with access to a gastroenterologist if required, either in primary or secondary care, as long as the care is sufficient (James, 2005; Ludvigsson et al., 2014). Consistent with this, literature on the perspectives of patients with CD has frequently demonstrated a preference for long-term care with a dietitian and appropriately trained medical clinicians (Haines, Anderson & Gibson, 2008; Ciclitira et al., 2010). However, it is currently unclear whether all patients with CD necessarily need long-term specialist follow-up, especially if their condition is controlled and they only require support to self-care (Bebb et al., 2006; Haines et al., 2008; Gleeson & Turner, 2012).

The young people and parents in this study were in agreement that the young person assuming responsibility for the utilisation of services is a gradual, evolving process. Assuming responsibility varied across the young people according to situation and their needs. Many parents still attended appointments with their children in adult services, although it was the young person now leading the discussions. Furthermore, adopting responsibility was consistently viewed as a natural process, and often perceived as a future consideration. The evolving process of assuming responsibility may be best understood in terms of the

developmental period of ‘‘emerging adulthood’’ (Arnett, 2000); it is proposed that it is between the ages of 18 and 25 years when young people learn to assume adult roles and responsibilities, and become self-sufficient. For the young person with a chronic condition, this includes taking on increasing responsibility for condition management (Palladino et al., 2013).

Emerging adulthood is a period whereby individuals no longer view themselves as adolescents, but are not yet confident to describe themselves as adults. The young people in this study were transferred to adult services between the ages of 16 and 18 years, and had not yet achieved the milestones necessary to become self-sufficient, such as financial independence and/or moving out of the parental home; therefore they may have only just been at the beginning of this developmental period and process of assuming responsibility (Arnett, 2000). Research and guidelines (Department of Health/Department for Education and Skills, 2006; Rapley & Davidson, 2010) advocate that transfer should be based on developmental readiness, and not dictated by chronological age. However, UK health services make clear age distinctions between paediatric and adult services, with 18 years of age being the cut-off at which they can remain in paediatric services.

Methodological Considerations

Five of the seven young people had been transferred to their GP. This may have influenced the findings, in that the participants interviewed generally expressed dissatisfaction with their adult care being managed by their GP, and not by specialist services. Consequently, individuals who felt strongly dissatisfied may have been more inclined to participate out of a need to express their frustrations. Therefore, it may have been useful to focus solely on young people to allow for the inclusion of more participants and consequently a wider exploration of

their experiences. However, the inclusion of parents is a strength of this study, as this allowed triangulation of the data and the inclusion of different dimensions of the same phenomenon. It may have also been beneficial to review the researcher's interpretation of the data with participants, as this would have aided the credibility of the findings (Clancy, 2013).

Clinical implications

This study found that an absence of formal transition planning could leave young people with CD, and their parents, feeling abandoned and apprehensive about the future of their care. This is an important consideration as research on transition for other conditions has demonstrated that abandonment is associated with disengagement from services (Lewis & Noyes, 2013). Furthermore, absence of healthcare for people with CD has been linked to poor management of the GFD and consequently the risk of long-term complications in later life (O'Leary et al., 2004). Therefore, the transition to adult services should involve continuity of care, which may be best achieved through the joint working of paediatric and adult services, and transparent communication between all relevant parties regarding transfer procedures. Where young people are being transferred to the care of the GP, it is recommended that patients are made aware that they can access dietetic and/or gastroenterology services should future problems arise, as well as information and services provided by charitable organisations (e.g. Coeliac UK) aimed at supporting people with CD, as stated by BSG guidelines (Ciclitira et al., 2010).

The young people and parents interviewed spoke about the importance of clinicians recognising and addressing the educational and psychosocial issues associated with living with and managing CD. Service and clinician awareness of these issues is essential, as research has shown that a lack of CD-knowledge and psychosocial struggles can cause GFD

transgressions. It is recommended that clinicians conduct rigorous assessments, including clinical interviewing and measures (e.g. KIDSCREEN-27; Ravens-Sieberer et al., 2007), to help identify and address needs (Howard & Law, 2014). This will better prepare young people for the transfer to adult services and increasing responsibility for self-management (van Staa et al., 2011).

The assumption of responsibility by the participants for the utilisation of services only began once they were under the care of adult services, if at all. Consequently, at the time of the study, they were not self-sufficient in the management of their condition. It may be beneficial to develop a transitional service for young adults between the ages of 18 and 25 years where they are supported to increasingly assuming new responsibilities for self-management, through the mastery of disease-related knowledge and self-efficacy (Arnett, 2000). It is also important to involve parents in self-management interventions as this can boost confidence in allowing their child to shoulder more responsibility (Kirk et al., 2013; Lewis & Noyes, 2013).

Future research

Although there is an absence of research on transitional care for young people with coeliac disease, research on other conditions (physical and mental health) has been increasing over the last decade. However, there is still a lack of robust research on transitional care, as the current literature is based largely on observational studies (e.g. surveys of patients and clinicians) (Royal College of Nursing, 2004). While there is an indication that individualised transition plans and education are beneficial, it is currently unclear what key elements are necessary for a "successful" transition, and what interventions need to be implemented to achieve a positive clinical outcome. Experimental design studies (e.g. randomised controlled

trials) would help to gain better understanding of the effectiveness of formalised transition interventions, such as educational programmes, the involvement of a care-coordinator and joint paediatric-adult clinics, and this would support service development.

Further research is warranted on the education and training of clinicians, both paediatric and adult providers, for example, in respect of their skill in providing transitional care for young people with chronic conditions. This study also raises the question of where the care of the young adult with coeliac disease is best served, with their GP or with a specialist gastroenterology service. Research investigating the long-term clinical outcomes, such as health behaviours (e.g. adherence to the GFD) and quality of life, would strengthen the evidence base, and ensure patients receive the right care at the right time. For example, a large-scale quantitative study may be beneficial in order to access large amounts of data across a diverse sample, with the aim of finding objective truths.

Conclusion

This study explored the lived experiences of young people with coeliac disease (and parents) transitioning to adult services. There was a clear absence of formal, structured transition processes, suggesting fidelity problems of transition guidelines in clinical practice. Findings revealed that an absence of discussion and clear information about the transition, as well as a lack of involvement of young people and their parents in decision-making processes, can leave them feeling abandoned and apprehensive about the future of their care. It was also shown that the transitioning young person has diverse condition-specific needs, including educational and psychosocial, that warrant both paediatric and adult clinicians to adopt a developmentally appropriate approach to best serve these needs. Lastly, the young person assuming responsibility for the utilisation of services does not necessarily coincide with transfer to adult services, and therefore adult providers should not necessarily expect their young adult patients to be independent. Further rigorous research is required to better our understanding of the key elements of an effective transition service.

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Public Domain Briefing Paper

Understanding transition from paediatric to adult services in young people with gastrointestinal disorders.

This paper presents a summary of a literature review and a qualitative research paper exploring the move from paediatric to adult services for young people with long-term gastrointestinal disorders.

Overall context

The move of young people from paediatric to adult services is known as "transition". This process addresses the young people's developmental, psychological, social and educational needs in order to prepare them for adult care in relation to their health condition. Research has shown that transition to adult services can be a stressful and a critical time for young people, and is often associated with poor physical health (Samuel et al., 2014) with the potential for disengaging from services (Lewis & Noyes, 2013), which is detrimental to the individual's health. Therefore, it is important that all young people with long-term health conditions have planned and coordinated care during the transition to ensure long-term good health.

Literature Review

Introduction

Gastrointestinal (GI) disorders relate to the gastrointestinal tract, which runs from the oesophagus to the anus. Conditions of the GI tract include inflammatory bowel disease (including conditions such as ulcerative colitis & Crohn's Disease), gastro-oesophageal reflux disease (GORD), coeliac disease (CD) and irritable bowel syndrome (IBS). With good

knowledge of their condition and support in building confidence, many people can manage their condition well with minimal assistance from healthcare professionals (British Society of Gastroenterology, 2006). The aim of the literature review was to explore what research had been conducted in the area of transition to adult services in young people with GI disorders to better understand what worked best and produced the best outcomes for young people.

Method

A search of relevant databases identified studies that focussed on transition experiences for young people with GI disorders, their parents and clinicians involved in their care.

Results

Seventeen studies were included in the review, sixteen investigating inflammatory bowel disease (IBD), and one investigated eosinophilic oesophagitis (EoE), a condition in which people can have problems swallowing food. Not all the papers were found to be of high quality and therefore the findings of the review must be interpreted with caution.

Young people and clinicians preferred joint working and coordinated care between paediatric and adult services. Patients and parents needed plentiful information about the transfer and preferred the opportunity to discuss the impact transition might have on them and their health condition. Findings on when transition should start were varied, although the preference was for the process to begin in advance of the actual transfer to adult services, and that the optimal time for transfer should be considered in the light of factors such as age, developmental milestones and individuals' disease activity. An emphasis across studies was placed on assessing transfer readiness, as defined by a series of competencies, which included disease-related knowledge and self-management skills, which many transitioning young

people did not have at the point of transfer. The development of these self-management skills were found to be hindered by parents – they were often reluctant to hand-over care to their child and remained "over-involved" in some cases. The use of assessment tools to measure these necessary competencies was recommended. Organisational barriers to good transition were also noted, including a lack of time and space to organise joint clinics, poor handover, and poor transfer of medical records; clinicians were also found to lack the skills and knowledge to address the specific developmental needs of the young people.

More rigorous research in this area is called for to explore potentially effective models of transition, as well as to develop validated measures to inform and evaluate the transition process.

Research study

Introduction

Coeliac disease (CD) is an incurable, chronic condition and is characterized by an autoimmune response to gluten, a protein found in wheat, barley and rye. The only current treatment is a life-long gluten-free diet (GFD; NICE, 2009). The British Society of Gastroenterology (BSG) recommends that patients with CD should be reviewed annually and receive support from a dietitian, as well as access to a gastroenterologist if necessary (Ciclitira et al., 2010). As young people with CD progress into adulthood, it is important that their healthcare is continuous as it is transferred to adult services. To date, the experiences of young people with CD transitioning from paediatric to adult services remain unexplored. To address this gap in knowledge, the present study interviewed young people with CD (16 to 19 years) and parents, from across the UK.

Method

Seven young people and six parents took part. Data was analysed using the Interpretative Phenomenological Analysis (IPA) approach, which allows for an in-depth exploration of individuals' experiences (Smith, Flowers & Larkin, 2009).

Findings

Three super-ordinate themes were identified for each subgroup, which overlapped extensively. These included: (i) 'Absence of discussion and abandonment', (ii) 'Understanding my coeliac disease and me' and (iii) 'Responsibility is an evolving process'. The majority of the young people and parents spoke of an absence of discussion and clear information about the transition, as well as a lack of involvement in the decision-making processes. They felt abandoned and apprehensive about the future of their care. Furthermore, they talked about how important it was that clinicians educated the young people about their CD and addressed their feelings about their condition in a way that was appropriate for their stage of development. Poor knowledge of their condition and emotional struggles including social embarrassment, particularly in relation to the gluten-free diet, often created high levels of anxiety for the young people, and impacted on the way they managed their diet. Five of the seven young people had been transferred to their GP and the young people and parents were concerned about this; they perceived GPs to lack the expertise to treat CD effectively. How much responsibility young people took on in terms of managing their condition and engaging with adult services varied and the involvement of parents in their child's CD did not necessarily end with transfer to adult services.

Implications and Recommendations

Previous research has shown that a poor experience of transition can lead young people to disengage with services (Lewis & Noyes, 2013). As good dietary self-management is vital for the continued well-being of people with CD, the transition to adult services should ensure continuity of care and include clear communication between all relevant parties to avoid feelings of abandonment and anxiety. Clinicians need to be aware of the young people's level of knowledge about CD, as well as any psychological difficulties, especially at the point of transition. Where young people are being transferred to the care of the GP, it is recommended that patients are made aware that they can access dietetic and/or gastroenterology services should future problems arise, as well as the information and services provided by charitable organisations aimed at supporting people with CD. Young people do not necessarily reach the optimum stage for taking on responsibility for their CD at the point where a service wishes to transfer them. Therefore, adult providers should not necessarily expect their young adult patients to be independent in all aspects of their CD. Further research on transitional care is required, as it is currently unclear what key elements are necessary for a "successful" transition, and what interventions need to be implemented to achieve a positive clinical outcome.

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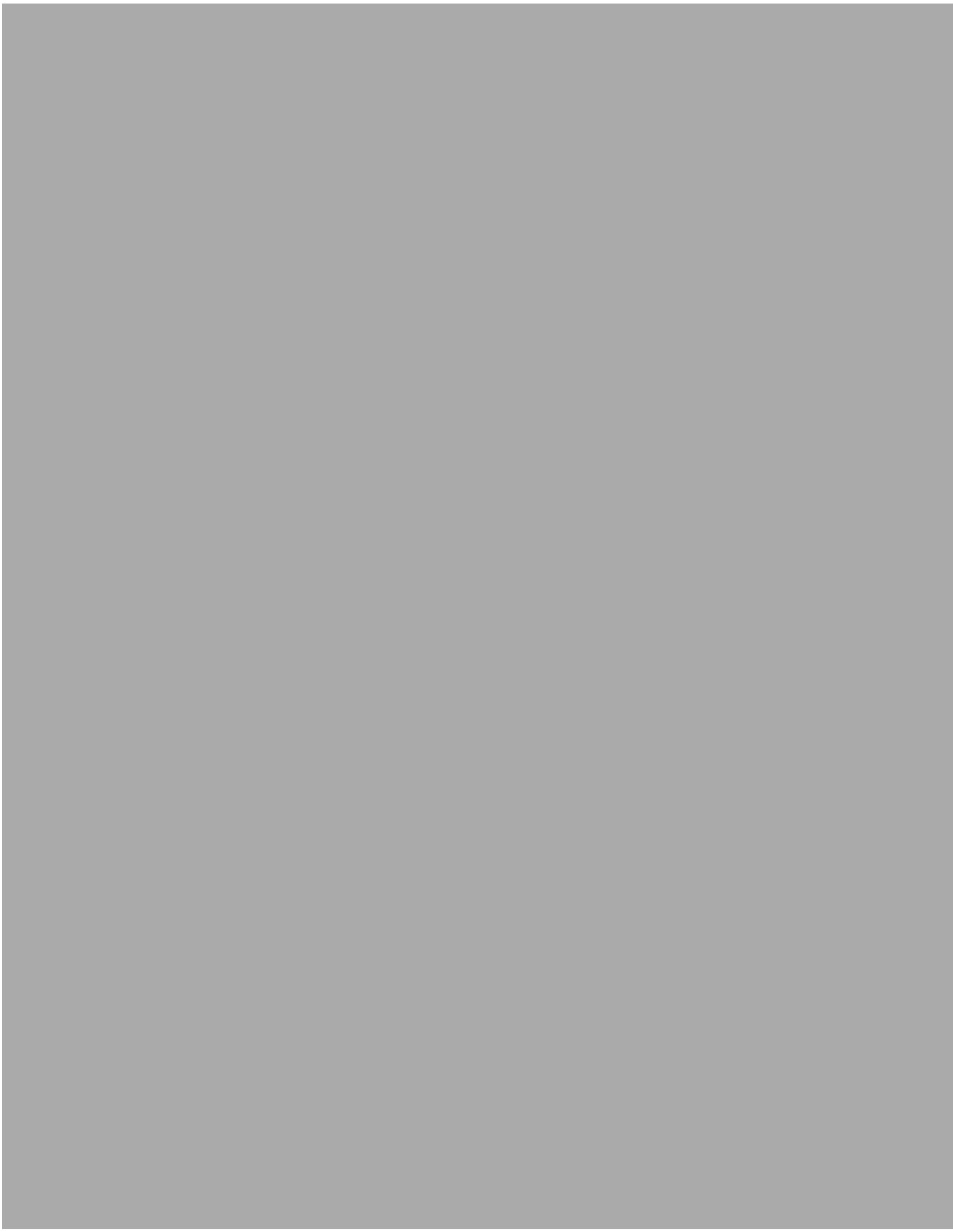
Appendix 1: Key search terms

Exp*gastrointestinal disease OR Exp*colon disease OR Exp*ulcerative colitis OR Exp*crohn disease OR Exp*inflammatory bowel disease OR Exp*celiac OR c*eliac.mp OR Exp*gastroenterology OR Exp*irritable colon OR Exp*irritable bowel syndrome	AND	((transition* OR transfer) adj5 (adult OR p*ediatric OR child OR care)) OR Exp*Transition of care OR Exp*Transition to adult care OR Exp*Continuity of patient care OR Transitional programs OR Adolescent health services OR Health transition OR Exp*continuum of care

Appendix 2: Quality assessment criteria items for quantitative studies

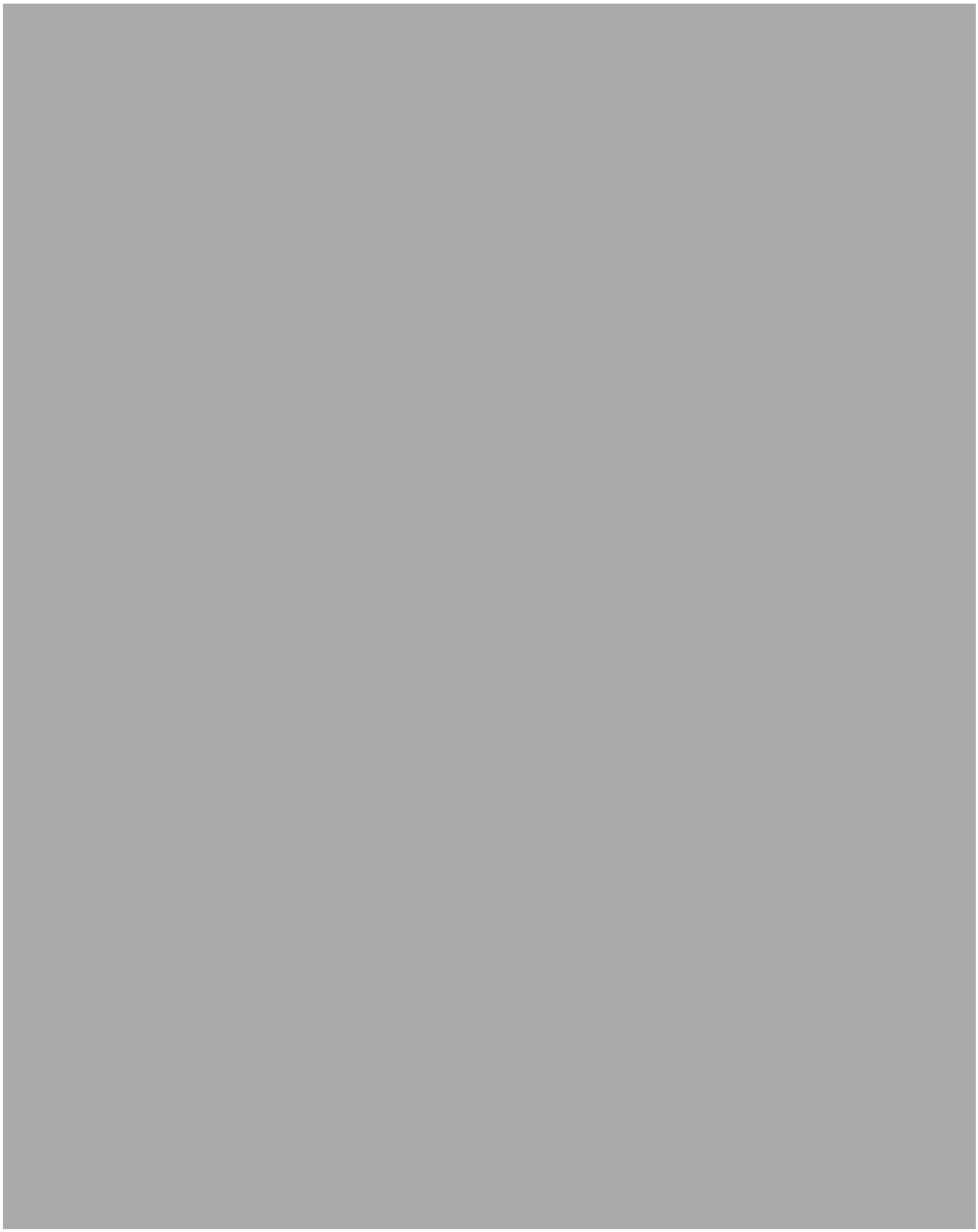
1. Question / objective sufficiently described?
2. Design evident and appropriate to answer study question?
3. Method of subject selection (and comparison group, if applicable) or source of information/input variables is described and appropriate?
4. Subject (and comparison group, if applicable) characteristics or input variables/information sufficiently described?
5. If random allocation to treatment group was possible, was it described?
6. If interventional and blinding of investigators was possible, was it reported?
7. If interventional and blinding of subjects was possible, was it reported?
8. Outcome and (if applicable) exposure measure(s) well defined and robust to measurement / misclassification bias? Means of assessment reported?
9. Sample size appropriate?
10. Analytic methods described/justified and appropriate?
11. Some estimate of variance (e.g., confidence intervals, standard errors) is reported for the main results/outcomes (i.e., those directly addressing the study question/objective upon which the conclusions are based)?
12. Controlled for confounding?
13. Results reported in sufficient detail?
14. Do the results support the conclusions?

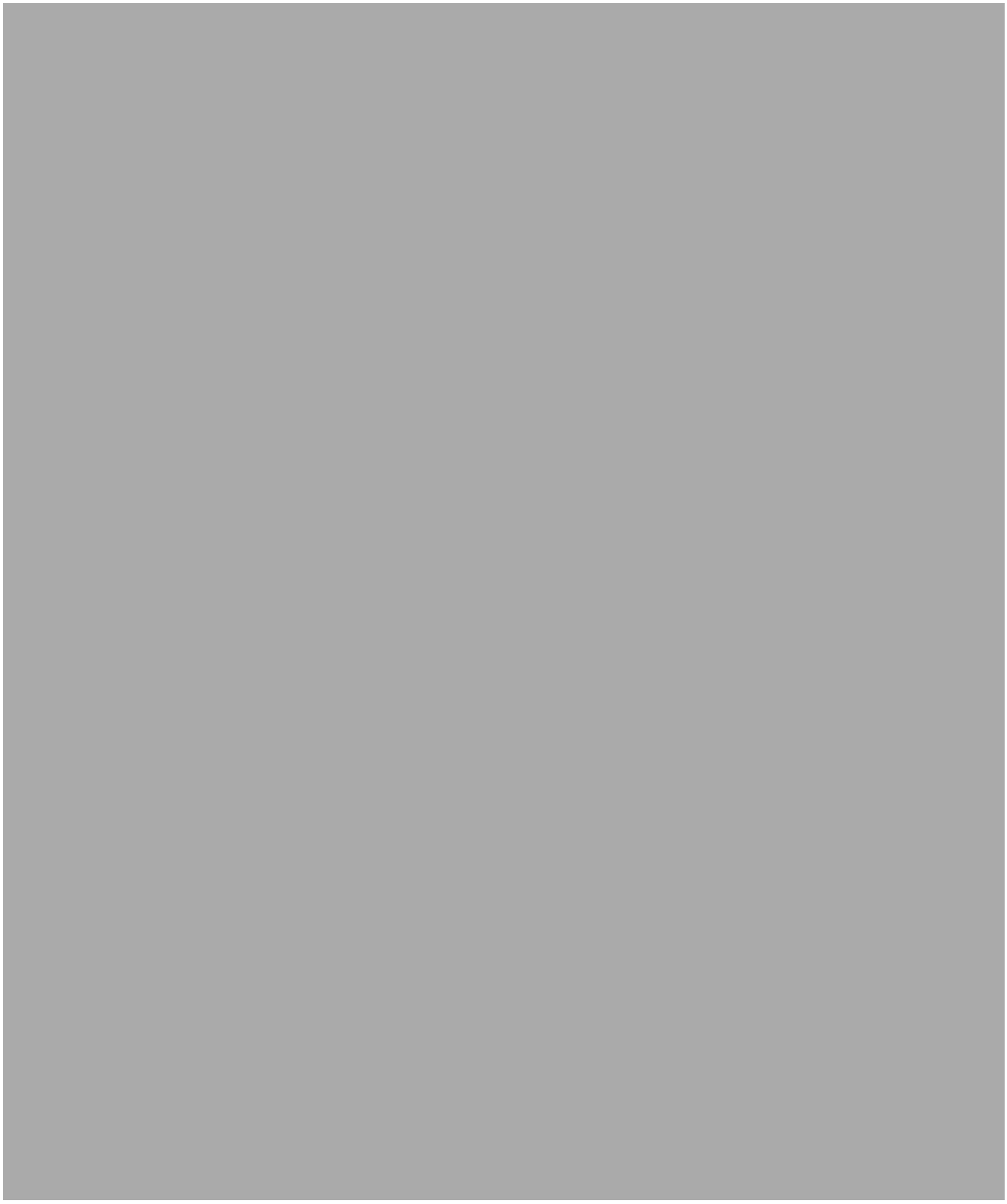
Appendix 3: Instructions for authors - Journal of Gastroenterology and Hepatology



[redacted]

Appendix 4: Ethical approval confirmation email





Appendix 5: Participant Recruitment Flyer



Researchers at the University of Birmingham want to learn what it felt like to move from services for young people with coeliac disease to services for adults.

Who can take part?
The researchers would like to meet with some young people with coeliac disease who have made this move recently.

If you would like to take part in the study you must be:

- Age 16-19 years;
- Have received a confirmed diagnosis of coeliac disease before your 14th birthday;
- Have been under the care of child services for the treatment of your coeliac disease for a minimum of two years
- Have been discharged from child services for at least six-months.

In addition, the researchers would also like to interview one parent of each participant where possible.

What would it involve?
All participants will be to interview individually. This is anticipated to take approximately one-hour. All participants will be entered into a prize draw for a £50 high street voucher as a thank you for their participation.

It is hoped that this study will help to gain a better understanding of how young people and their parents can be best supported by professionals and services to ensure that this move is successful.

How to take part:
If you are interested in taking part in the study, or would like more information, please contact the research Ms Natalie Craddock at [redacted]

This is a Doctorate in Clinical Psychology research study at the University of Birmingham, and has been approved by the Science, Technology, Engineering and Mathematics Ethical Review Committee, at the University of Birmingham.

Appendix 6: Young Person Participant Information Sheet

UNIVERSITY OF BIRMINGHAM

Natalie Craddock
Trainee Clinical Psychologist
School of Psychology
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

Date: 28th October 2013; Version 1

Participant Information Sheet (Young Person)

Title of Study: Transition from Child to Adult Services: A qualitative study of the experiences of young people with coeliac disease.

Dear

Thank you for expressing an interest in my research study. My name is Natalie Craddock and I am a Trainee Clinical Psychologist. I am doing this research study as part of my qualification in Clinical Psychology at the University of Birmingham. I am being supervised by Dr Ruth Howard and Dr Gary Law.

Before you decide if you would like to take part in this study here is some information that may help answer any questions you may have about my research. Please read this information carefully.

What is the purpose of this research?
The purpose of this study is to explore how it feels to move from services for young people with coeliac disease to services for adults. It is hoped that this research will help to gain a better understanding of how young people and their parents can be best supported by professionals and services to ensure a successful transition from child to adult services.

Why have I been invited to take part?
You have been asked to take part because you have recently been discharged from child services where you received treatment for your coeliac disease. I would like to ask you some questions about your experiences of this ending and what has happened since, including if you did or did not move to adult services.

What do I mean by transition?
Transition in this research study means the planned movement of young people with long-term conditions (in this case coeliac disease) from services specifically for children and young people to healthcare services for adults. In this research study, we are particularly interested in how young people with coeliac disease experienced the time when their care under child services came to an end, and whether or not they transitioned to adult services, and what this move was like.

Why is this research important?
So far, only a few studies have been conducted looking at the transition from child to adult services for young people with long-term conditions. However, no research has been conducted that specifically looks at the experiences of young people with coeliac disease. It is hoped that this research study will help professionals and services improve their support of young people with coeliac disease as they move through the transition process.

What will happen to me if I agree to take part?
It is entirely up to you whether you take part. If you decide to take part I will contact you to discuss the study and to answer any questions or concerns you may have about it. If after this short initial discussion you are still happy to take part, we can arrange another time to meet when I will conduct a research interview. During this meeting I will ask you some questions about how you found leaving child services. There are no right or wrong answers to the questions I ask. I am just interested in hearing about your experience.

The interview will last about an hour but this will be flexible depending on how you feel at the time. With your consent I will record the session using a digital voice recorder. Before I start recording I will show you the equipment and how it works. You may stop the recording at any time during the interview.

The interview will take place where it suits you best. This could be at your home if you wish, or at the University of Birmingham, Edgbaston campus.

What will happen if I do not want to carry on with the study?
It is entirely up to you to decide whether you wish to take part. If you decide not to take part this will not affect the support and treatment you might be receiving at the moment and/or in the future.

If you do agree to take part but later change your mind, you are free to withdraw at any time before and during the research interview, without giving any reason. You will also have a two-week period after the interview for reflection, during which time you can withdraw. After this two-week period you can no longer withdraw the use of your interview for analysis.

Does my interview need to be recorded?
Yes. It is important that I can listen to your interview after we have met so I do not miss or forget important things that you have told me. After the interview, I will type it out word by

word. This will help me to develop a good understanding of your experiences and our discussion. The recording of your interview will not be listened to by anyone else. The tapes will be destroyed once I have typed up the interview which will be approximately one month after our interview. The recordings will be kept in a locked draw in my office and no one else will have access to them.

Will my participation in the study be kept confidential?
Yes, your information will be kept confidential. Everyone taking part in the study will be given a code name. This code name will be used whenever I discuss the interviews with my academic supervisors and also when direct quotations are used in the final thesis. Only I will know your name and which interview is yours.

If you inform me of any issues that indicate that you may be at risk of harm to yourself and/or others, I will need to inform my academic supervisors and the appropriate child protection and safeguarding procedures will be followed. Whenever possible, I will try to tell you if I need to do this.

Expenses and payments
Any travel expenses will be reimbursed and you will also be entered into a prize draw for a £50 high street voucher as a thank you for your participation.

What will happen to the results of the research study?
The results will be written up as a thesis for my qualification of ClinPsyD. It is hoped that the research may also be published in an academic journal. If this is the case, then the results will be available to be viewed by the general public. However, I will ensure at all times that you are not identifiable in anything that is written.

I will send you a transcipt of your interview so you can check it for accuracy and so you can consent to or decline the use of quotations in the final thesis and any other potential publications.

Who has reviewed this study?
The University of Birmingham is involved in the organisation and funding of this study. The study has been reviewed by the ClinPsyD Course in the School of Psychology to ensure that it meets standards of scientific research, and has gone through appropriate ethical review by the University of Birmingham.

What happens if I have any concerns or get upset during or after the interview?
If you find yourself getting upset at any time during the interview just let me know and will be able to take a break or stop the interview. You may also contact any of the following services/organisations if you feel you need any further support following the interview:

- Your GP

- Samaritans on 08457 90 90 90 (available 24hrs and day 365 days a year)
- Coeliac UK Helpline on 0845 305 2060 (available Monday to Friday 9am - 5pm)

Contact Details

My contact details are as follows:



Thank you.

Appendix 7: Parent Participant Information Sheet

UNIVERSITY OF BIRMINGHAM

Natalie Craddock
Trainee Clinical Psychologist
School of Psychology
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

Date: 28th October 2013; Version 2

Participant Information Sheet (Parent)

Title of Study: Transition from Child to Adult Services: A qualitative study of the experiences of young people with coeliac disease.

Dear

Thank you for expressing an interest in my research study. My name is Natalie Craddock and I am a Trainee Clinical Psychologist. I am doing this research study as part of my qualification in Clinical Psychology at the University of Birmingham. I am being supervised by Dr Ruth Howard and Dr Gary Law.

Before you decide if you would like to take part in this study here is some information that may help answer any questions you may have about my research. Please read this information carefully.

What is the purpose of this research?

The purpose of this study is to explore how it feels for young people with coeliac disease to move from child to adult services. It is hoped that this research will help to gain a better understanding of how young people and their parents can be best supported by professionals and services to ensure a successful transition from child to adult services.

Why have I been invited to take part?

You have been asked to take part because your child has recently been discharged from child services where they received treatment for their coeliac disease. I would like to ask you some questions about your experiences of this ending and what has happened since, including if your child did or did not move to adult services.

What do I mean by transition?
Transition in this research study means the planned movement of young people with long-term conditions (in this case coeliac disease) from services specifically for children and young people to healthcare services for adults. In this research study, we are particularly interested in how young people with coeliac disease experienced the time when their care under child services came to an end, and whether or not they transitioned to adult services, and what this move was like.

Why is this research important?
So far, only a few studies have been conducted looking at the transition from child to adult services for young people with long-term conditions. However, no research has been conducted that specifically looks at the experiences of young people with coeliac disease. It is hoped that this research study will help professionals and services improve their practice and support of young people with coeliac disease as they move through the transition process.

What will happen to me if I agree to take part?
We are only able to interview parents of young people with coeliac disease who have also agreed to be interviewed. It is entirely up to you whether you to take part. You do not have to take part if your child is participating. If you decide to take part I will contact you to discuss the study and to answer any questions or concerns you may have about it. If after this short initial discussion you are still happy to take part, we can arrange another time to meet when I will conduct a research interview. During this interview I will ask you some questions about how you found the experience of your child leaving child services. There are no right or wrong answers to the questions I ask. I am just interested in hearing about your experience.

The interview will last about an hour but this will be flexible depending on how you feel at the time. With your consent I will record the session using a digital voice recorder. Before I start recording I will show you the equipment and how it works. You may stop the recording at any time during the interview.

The interview will take place where it suits you best. This could be at your home if you wish, or at the University of Birmingham, Edgbaston campus.

What will happen if I do not want to carry on with the study?
It is entirely up to you to decide whether you wish to take part. If you decide not to take part this will not affect the support and treatment you and your child might be receiving at the moment and/or in the future.

If you do agree to take part but later change your mind, you are free to withdraw at any time before and during the research interview, without giving any reason. You will also have a two-week period after the interview for reflection. After this two-week period you can no longer withdraw the use of your interview for analysis.

Does my interview need to be recorded?
Yes. It is important that I can listen to your interview after we have met so I do not miss or forget important things that you have told me. After the interview, I will type it out word by word. This will help me to develop a good understanding of your experiences and our discussion. The recording of your interview will not be listened to by anyone else. The tapes will be destroyed once I have typed up the interview, which will be approximately one month after our interview. The recordings will be kept in a locked draw in my office and no one else will have access to them.

Will my participation in the study be kept confidential?
Yes, your information will be kept confidential. Everyone taking part in the study will be given a code name. This code name will be used whenever I discuss the interviews with my academic supervisors and also when direct quotations are used in the final thesis Therefore only I will know your name and which interview is yours.

If you inform me of any issues that indicate that you may be at risk of harm to yourself and/or others, I will need to inform my academic supervisors and the appropriate child protection and safeguarding procedures will be followed. Whenever possible, I will try to tell you if I need to do this.

Expenses and payments
Any travel expenses will be reimbursed and you will also be entered into a prize draw for a £50 high street voucher as a thank you for your participation.

What will happen to the results of the research study?
The results will be written up as a thesis for my qualification of ClinPsyD. It is hoped that the research may also be published in an academic journal. If this is the case, then the results will be available to be viewed by the general public. However, I will ensure at all times that you are not identifiable in anything that is written.

I will send you the transcipt of your interview so you can check it for accuracy and so you can consent to or decline the use of quotations in the final thesis and any other potential publications in the public domain.

Who has reviewed this study?
The University of Birmingham is involved in the organisation and funding of this study. The study has been reviewed by ClinPsychD Course in the School of Psychology to ensure that it meets standards of scientific research and has gone through appropriate ethical review by the University of Birmingham.

What happens if I have any concerns or get upset during or after the interview?
If you find yourself getting upset at any time during the interview just let me know and will be able to take a break or stop the interview. You may also contact any of the following service/organisations if you feel you need any further support following the interview:

- Your GP
- Samaritans on 08457 90 90 90 (available 24hrs and day 365 days a year)
- Coeliac UK Helpline on 0845 305 2060 (available Monday to Friday 9am - 5pm)

Contact Details
My contact details are as follows:

Thank you.

Appendix 8: Young Person Screening Checklist

Thank you for showing an interest in this research study. To see if you might qualify for this study I would appreciate if you could complete the following checklist, by answering either Yes or No to the following statements. Please delete as applicable.

1. I am between the ages of 16 – 19 years (inclusive). Yes / No
2. I have a confirmed diagnosis of coeliac disease. Yes / No
3. My diagnosis of coeliac disease was confirmed before my 14th Birthday. Yes / No
4. I was under the care of child services for the treatment of my coeliac disease. Yes / No
5. I was under the care of child services for the treatment of my coeliac disease for a minimum of 2 years. Yes / No
6. I am still under the care of child services for the treatment of my coeliac disease. Yes / No
7. I have been discharged from child services for at least six-months. Yes / No
8. I understand and can speak English. Yes / No
9. I have a diagnosis of diabetes. Yes / No
10. I have a learning disability. Yes / No
11. I give permission for the researcher to contact a parent to ask if they are also willing to participate in this study. Yes / No

    If Yes, please write their name and contact details below.

    Name: _____

    Telephone: _____

    Email: _____

Thank you for completing this checklist. Please email me your responses at NXC243@bham.ac.uk.

Appendix 9: Parent Screening Checklist

Thank you for showing an interest in this research study. To see if you might qualify for this study I would appreciate if you could complete the following checklist, by answering either Yes or No to the following statements. Please delete as applicable.

1. I have a child with a confirmed diagnosis of coeliac disease. Yes / No
2. My child with coeliac disease is also willing to participate in this research project. Yes / No
3. I understand and can speak English. Yes / No
4. I have a long-term physical health condition (with the exception of coeliac disease). Yes / No
5. I have a long-term mental health condition. Yes / No
6. I have a learning disability. Yes / No
7. I give permission for the researcher to contact my child with coeliac disease to ask if they are also willing to participate in this study. Yes / No

   If Yes, please write their name and contact details below.

   Name: _____

   Telephone: _____

   Email: _____

Thank you for completing this checklist. Please email me your responses at NXC243@bham.ac.uk.

Appendix 10: Consent Form (Young Person)

UNIVERSITY OF BIRMINGHAM

Research site: .....

Study Number: ERN_13-0585

Title: Transition from Child to Adult Services: A qualitative study of the experiences of young people with coeliac disease.

Researcher: Natalie Craddock

Participant Identification Number: .....

Please initial box

1. I confirm that I have read and understood the participant information sheet dated 28th October 2013 (version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time before and during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. ☐

3. I understand that the interview will be tape-recorded solely for the purposes of the research study as described in the Participant Information Sheet dated 28th October 2013 (version 1). ☐

4. I understand that following the research interview I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. I understand that after this two-week period I can no longer withdraw the use of my data for analysis. ☐

5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. This may include the academic supervisors, independent researchers part of a small voluntary analysis group who will check credibility of analysis, and individuals from regulatory ☐

authorities. I give permission for these individuals to have access to my data. I am aware that my data will be anonymised by use of code names and therefore none of these individuals will know my name.

6. I understand that the researcher will send me the transcipt of my research interview for me to review and consent or decline the use of quotations in the final thesis and any other potential publications in the public domain. I am aware that the researcher will contact me two weeks after receiving the transcript to discuss this. ☐

7. I understand that if I consent, direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that no personal information will be published. I also understand that it is possible my views may be identified by my family and/or friends by the publication of direct quotations in the final thesis. ☐

8. I understand that if I inform the researcher of any issues that indicate that I may be at risk of harm to myself and/or others, the research will need to inform their academic supervisors and the appropriate child protection, and safeguarding procedures will be followed. Whenever possible, the researcher will try to tell me if they need to do this. ☐

9. I agree to take part in the above study. ☐

.....	.....	.....
Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

Appendix 11: Consent Form (Parent)

UNIVERSITY OF BIRMINGHAM

Research site: .....

Study Number: ERN_13-0585

Title: Transition from Child to Adult Services: A qualitative study of the experiences of young people with coeliac disease.

Researcher: Natalie Craddock

Participant Identification Number: .....

Please initial box

1. I confirm that I have read and understood the Participant Information Sheet dated 28th October 2013 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time before and during the research interview, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. ☐

3. I understand that the interview will be audio-recorded solely for the purposes of the research study as described in the Participant Information Sheet dated 28th October 2013 (Version 2). ☐

4. I understand that following the research interview I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my own or my loved one's medical/social care or legal rights being affected. I understand that after this two-week period I can no longer withdraw the use of my data for analysis. ☐

5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. This may include the academic supervisors, independent researchers part of a small voluntary analysis ☐

group who will check credibility of analysis, and individuals from regulatory authorities. I give permission for these individuals to have access to my data. I am aware that my data will be anonymised by use of code names and therefore none of these individuals will know my name.

6. I understand that the researcher will send me the transcipt of my research interview for me to review and consent or decline the use of quotations in the final thesis and any other potential publications in the public domain. I am aware that the researcher will contact me two weeks after receiving the transcript to discuss this. ☐

7. I understand that if I consent, direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that no personal information will be published. I also understand that it is possible my views may be identified by my family and/or friends by the publication of direct quotations in the final thesis. ☐

8. I understand that if I inform the researcher of any issues that indicate that I may be at risk of harm to myself and/or others, the researcher will need to inform their academic supervisors and the appropriate child protection, and safeguarding procedures will be followed. Whenever possible, the researcher will try to tell me if they need to do this. ☐

9. I agree to take part in the above study. ☐

.....	.....	.....
Name of participant	Date	Signature
.....	.....	.....
Name of researcher	Date	Signature

Appendix 12: Participant Debrief Sheet

UNIVERSITY OF BIRMINGHAM

Research site: .....

Study Number: ERN_13-0585

Title: Transition from Child to Adult Services: A qualitative study of the experiences of young people with coeliac disease.

Researcher: Natalie Craddock

Participant Identification Number: .....

Thank you for taking part in this study.

The purpose of this study is to explore how it feels to move from services for young people with coeliac disease to services for adults. So far, only a few studies have been conducted looking at the transition from child to adult services for young people with long-term conditions. However, no research has been conducted that specifically looks at the experiences of young people with coeliac disease. It is hoped that this research study will help professionals and services improve their practice and support of young people with coeliac disease as they move through the transition process.

The results will be written up as a thesis for my qualification of ClinPsychD. It is hoped that the research may also be published in an academic journal. If this is the case, then the results will be available to be viewed by the general public. However, I will ensure at all times that you are not identifiable in anything that is written.

You are free to withdraw at any time from now and up to two-weeks after today's interview. After this two-week period you can no longer withdraw the use of your interview for analysis. Please contact me if you wish to withdraw. If I do not hear from you within this two-week period I will assume that you consent for your interview to be included in the analysis.

In addition, I will send you a transcipt of your interview so you can check it for accuracy and so you can consent to or decline the use of quotations in the final thesis and any other potential publications.

Talking about personal experiences can be upsetting for some people, for different reasons. If you find yourself feeling upset please discuss this with me if you feel comfortable to do so. Alternatively, you may contact any of the following service/organisations if you feel you need any further support following today's interview:

- Your GP
- Samaritans on 08457 90 90 90 (available 24hrs and day 365 days a year)

- Coeliac UK Helpline on 0845 305 2060 (available Monday to Friday 9am - 5pm)



Thank you again for your participation.

Appendix 13: Interview schedule – Young person version

Their Coeliac story

1. Can you tell me about your experience of being diagnosed with Coeliac Disease (CD)?

   Prompts: *How did you (or your parents) know something was different?*
   What happened?
   Did you think anything at the time? Feel? React in any way?
   What has it been like living with CD?
   How do you feel about your CD now?

Their experiences of child services

2. Could you describe your experiences of child services for the treatment of your CD?

   Prompts: *Positive and negative aspects.*
   Can you tell me about your appointments? How did you feel?
   Can you tell me about what your parents' involvement and role was like?
   Looking back, how do you feel about your experiences of child services now?

Transition process

3. Can you tell me about how your time with child services came to an end?

   Prompts: *When did you first realise that you would be leaving?*
   Was it discussed with you?
   Did you think anything at the time? Feel? React in any way?
   How was the transition to adult services done?
   Can you tell me about any involvement you had in the process*?*
   How did your parent(s) react? Were they involved?
   Do you have any suggestions about how to improve the transition?

Experiences of adult services for the care and treatment of their CD

4. Have you started going to specialist adult services for your CD since leaving child services?

   Yes
   Could you describe your experiences of adult services?

   Prompts: *Positive and negative aspects.*
   Is it different from your experience with child services? Can you tell me about your appointments? How do you feel?
   Can you tell me about what your parents' involvement and role is like now? How do you feel about it? How do they feel about it?

   No
   Can you tell me how you are feeling about this?

   Prompts: *What do you imagine it is going to be like?*

Self-management of gluten-free diet

5. Can you tell me about the current management of your gluten-free diet?

   Prompts: *What does it involve?*
   Who is responsible?
   How do you feel about it?
   Do you seek support? If so, where from?
   Do you treat the diet differently now compared to when you were a child?

6. Is there anything you would like to add?

Appendix 14: Interview schedule – Parent version

Their child's coeliac story

1. Can you tell me about your experience of [child's name] being diagnosed with coeliac disease (CD)?

   Prompts: *How did you know something was different?*
   What happened?
   What did you think at the time? Feel? React?
   Did [child's name] feel anything at the time? React in any way?
   What was that like for you? Did you feel anything at the time? React in any way?
   What has it been like living with CD?
   How do you feel about [child's name] CD now?

Their experiences of child services

2. Could you describe your experiences of child services for the treatment of [child's name] CD?

   Prompts: *Positive and negative aspects.*
   Can you tell me about the appointments? How did you feel? How did [child's name] feel?
   Can you tell me about any involvement or role you had at the time?
   Looking back, how do you feel about your experiences of child services now?

Transition process

3. Can you tell me about how [child's name] time with child services came to an end?

   Prompts: *When did you first realise they would be leaving?*
   Was it discussed with you and [child's name]?
   How did you feel at the time? React?
   How was the transition to adult services done?
   Can you tell me about any involvement you had?
   Did [child's name] feel anything at the time? React? Can you tell me about any involvement they had?
   Do you have any suggestions about how to improve the transition?

Experiences of adult services for the care and treatment of their CD

4. Has [child's name] started going to specialist adult services for their CD since leaving child services?

   Yes
   Could you tell me about this experience?

   Prompts: *Positive and negative aspects.*
   Is it different from your experience with child services? How?
   Can you tell me about any involvement and role you have now? How do you feel about it? How do they feel about it?
   Can you tell me about the appointments? How do you feel?

   No
   Can you tell me how you are feeling about this?

   Prompts: *What do you imagine it is going to be like?*
   How does [child's name] feel about this?

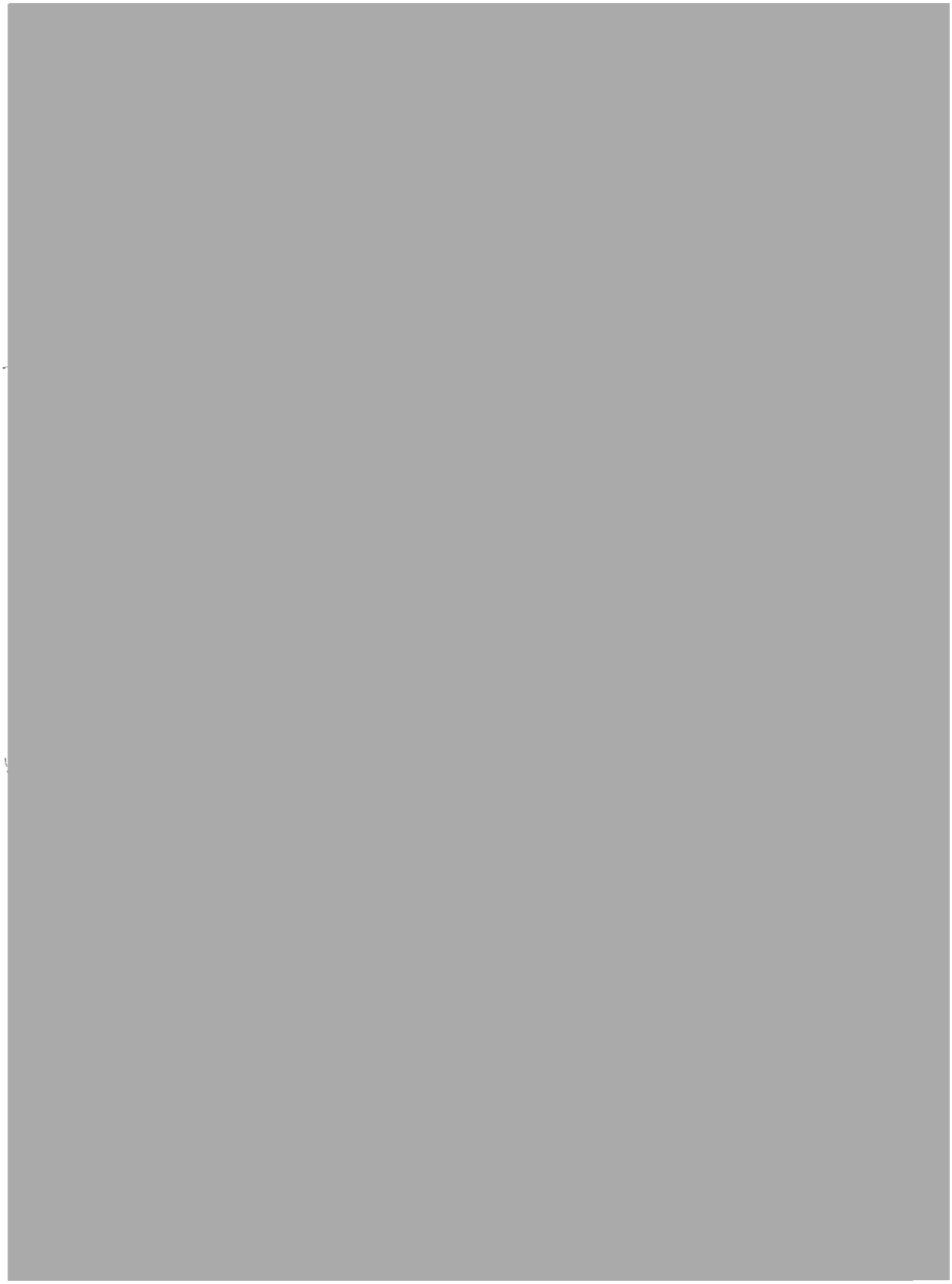
Self-management of gluten-free diet

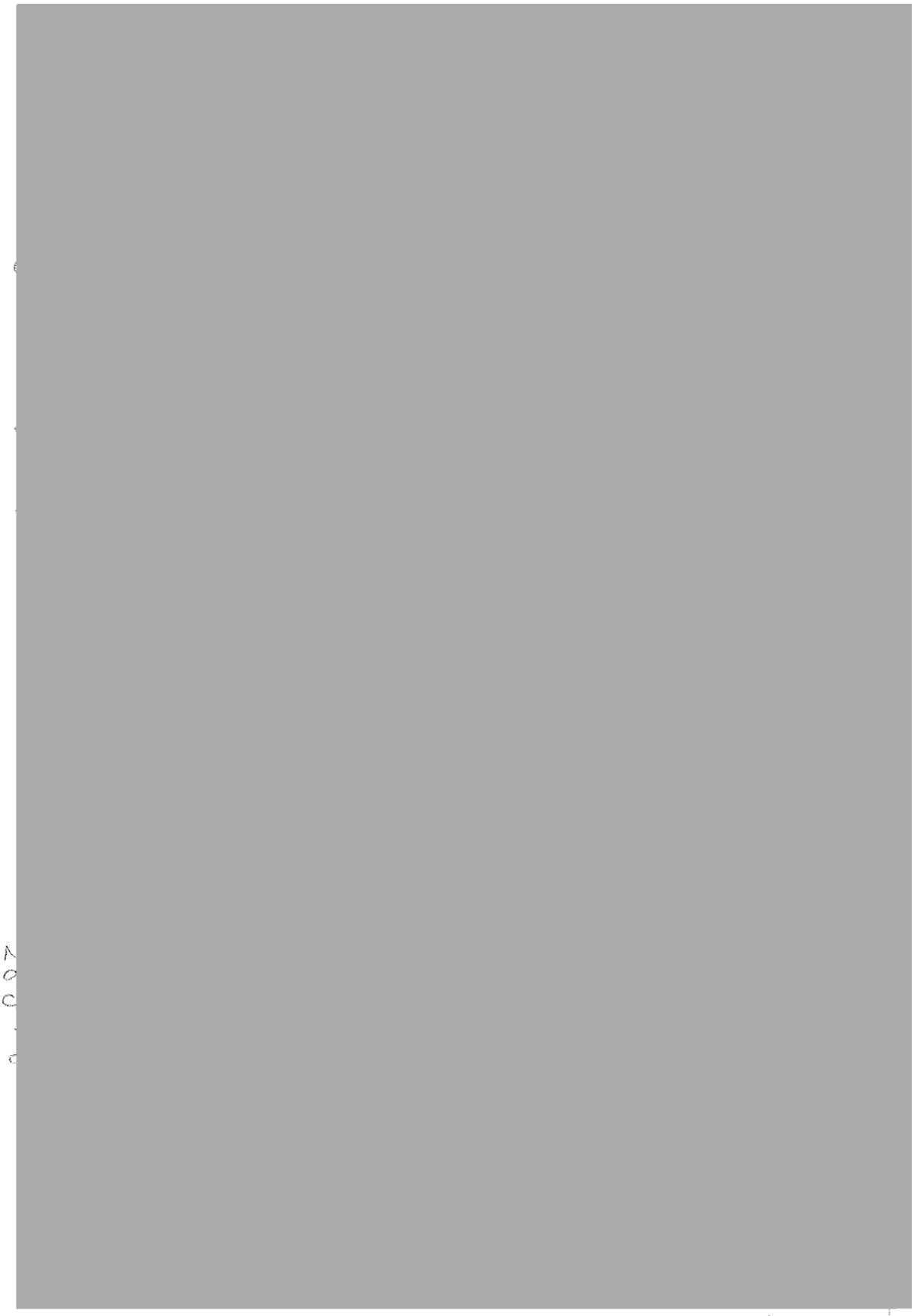
5. Can you tell me about the current management of [child's name] gluten-free diet?

   Prompts: *What does it involve?*
   Who is responsible?
   Can you tell me about any role you may have?
   How do you feel about it? How do they feel about it?
   Does [child's name] seek support? If so, where from?
   Do you treat the diet differently now compared to when [child's name] was a child?

6. Is there anything you would like to add?

Appendix 15: An example of exploratory notes of a young person's transcript





Appendix 16: Patterns across cases - Young People

Transition discussions

Ps	Discussion	Trigger	Prepared	Rejecting - not important to them	Abandoned	Suggestions
YP 1 Elizabeth	Told, no involvement Struggling to recall discussion Last apt	Age	"I was kind of a bit mmmm." Just move over What they were and do	No special goodbye		Gradual - told in advance A goodbye
YP 2 Kitty	Told, no involvement No discussion Last apt	Age	This is your last apt No mention of what follows		Nothing for 2 years - fell off - the end No explanation about what follows Happy - wanted to be left alone	
YP 3 Mary	Told, no involvement Last apt	GP is capable	This is your last apt I wanted to stay Unclear what follows - just go to your GP	Letting me go - dismissive Don't want to have anything to do with me Not important	No one has been in contact No explanation about what follows	Signposting - information, who will be there to offer support
YP 4 Lydia	Discussed, choice (who, timing) Penultimate apt	Age, exams GP new service No point coming again - nothing new to tell us	Chose now (vs. next apt) Embrace change No uncertainty			Transfer medical records and share medical history
YP 5 Jane	Told, no involvement	Officially: age (i.e. actual transfer) Unofficially: self-initiation because of poor care from child's	Gradual-saw both services simultaneously Reassured because knew consultant before transfer Unclear about logistics of adults - what to expect	Brief		

YP 6 Caroline	Told, no involvement Struggling to recall any discussion Last apt	Healthy - he felt everything was fine	Don’t know about adult services Okay with Dr's opinion about "healthy" Last apt	Wanted to stop seeing me		More information - verbal and written What follows - where to go and what to expect
YP 7 Georgia	Told, no involvement Penultimate	Age	Next apt will be your last Wasn’t ready for blood tests with adult services	no goodbye with dr, only other prof	"Forgotten about" No one has been in contact Don’t know what will happen next	Meet adult services in last child apt Communication about what's happen between all parties Clear explanation about what follows

Unmet needs

Ps	Psychosocial support	Disease-related knowledge	Feeling cared for	Self-efficacy	GP not good enough	Maturity development
YP 1	Struggling to accept CD Only about CD	Long-term complications Linked to poor diet adherence	Insensitive communication Unrealistic demands Lack of person centred care - not addressing personal goals (low weight)			
YP 2						

YP 3	Only about CD Wants to talk to someone (adults) Angry	Poor disease knowledge (including prescriptions) Linked to poor diet adherence Linked to anxiety about future		Doubts self-reliance	Doesn't have specialist knowledge - uninformative, pointless Linked to anxiety about ability to care esp. in crisis Should have specialist care (dietitian, consultant)	
YP 4		Insensitive communication - rude, unwanted	Detached (vs. always available, overprotective)		Doesn't have specialist knowledge - uninformative, pointless Specialist services know Pointless - anger	Addressing young adult patient as a child - addressing parents Perceived self to have the maturity to handle adult services
YP 5	Social embarrassment Fearmongering linked to not eating	Fearmongering linked to misunderstanding about complications	Insensitive communication - Fearmongering, tactless Linked to self-initiation of transition Absence of support - pointless			Perceived self to have the maturity to handle adult services
YP 6						
YP 7	Only about CD Not seeing the person (adults)	Doubts CD knowledge Services offer reassurance doing okay	Psychosocial support would mean receiving the right care Lack of person centred care - not addressing personal goals (low weight, tiredness)		Doesn't have specialist knowledge Lack time	

Responsibility is evolving

Ps	Parents are still involved	Part of transition to adulthood	Needs support from others
YP 1	Their duty Shared responsibility - different roles Support varies according to need	Natural Diet and utilising services: linked to leaving home - there is a future need Linked to financial independence - pay for own prescriptions	Parents/family & profs - diet
YP 2	Due to individual's reluctance I.e. monitor/enforcer/organiser Shared - different (family) roles Mum blogs about it - stuff gets sent to them	Diet: linked to uni/leaving home - there is a future need No choice - services are legally obliged to talk to adults Linked to social independence	I don't want services I know how to look after myself
YP 3	Due to individual's reluctance - pointless I.e. monitor/enforcer/organiser		Needs to right support from services
YP 4	Shared - different (family) roles	Linked to age which is linked to maturity Linked to social independence Personal choice (with services) -attending apts alone linked to maturity	
YP 5	Shared - different (family) roles Attend adult apts with her	Linked to social independence Natural	
YP 6	Shared - different (family) roles They know it all	Linked to social independence	Parents are only source of support
YP 7	Shared - different (family) roles - always been the case Depends on mum to recall apt info	Edu in early years when with child's allowed her to take over diet Self-initiated	

Mixed emotions

Ps	Happy	Sad	Anxious	Passive / emotional avoidance	Anger
YP 1	Excited about new possibilities E.g. meet new ppl with CD	Loss of profs have known a long time			
YP 2	When services ended - no more blood tests I'm okay on my own		"No" "they said they'd stop"	It's okay - accept and get on with it	
YP 3		Alone		It's okay - accept and get on with it	
YP 4	Knew what to expect		About going to specific hospital because of mother's experience		
YP 5			Change Something new		
YP 6			Future care	Don’t think about it - I'm fine. Accept Dr's opinion - he knows best	
YP 7			Meeting new prof Future care - linked to abandonment	I'm fine with less support - accept situ	Not being told what will happen next

Appendix 17: Parents' Super-ordinate and Sub-ordinate themes and example excerpts

Super-ordinate theme 1 – Absence of discussion and abandonment

Sub-ordinate theme: An absence of discussion
Parents perceived being told that the transfer will happen and that they were given short notice about it. *It was just at her last appointment with [doctor]. She just said to us "I see that you are coming up to 18 so I won't be seeing you again now." She said, I think she said paperwork, I can't remember, she said "you'll be put over to adult services now".* (Catherine; line 421)
There was a perception that the discussion was "ambiguous" and "unresolved", to the degree that two parents (Sally and Maria) didn't know that it was going to happen. *So there was never any official 'you're not under our care anymore'. … There was a couple of mentions of "oh you know you can easily do this at the GP, they're perfectly well qualified to do it". … but there was--there seemed to be no system, or like this stopped when she was sixteen.* (Louisa; line 157) Furthermore, the majority of the parents did not have an understanding of what to expect would happen next, following the official transfer to adult services, including which service their child would be transferred to. *Oh yeah, I didn't know what was going to happen. I was expecting that she would be referred to a gastro but it was kind of, magic will happen.* (Emily; line 237)
Maria was the only parent to speak positively about her experiences of the transition process, explaining that she and her daughter were involved in decisions about when the transfer would take place, and where care would be transferred. *Well at the time we--moving on would be within the hospital itself, just to the adult services, but since that time my own GPs have set up their own coeliac clinic and we've made the decision to just stick with them rather than go to the hospital each time.* (Maria; line 323)
Sub-ordinate theme: Abandoned and anxious
A feeling of being abandoned by services was also indicated, by both child services lack of interest in the transition and/or adult services lack of follow-up, which was also associated with feelings of doubt. *And I thought 'oh thanks for that mate' so I said…you know they're kind of washing their hands of her …"* (Sally; line 297) *I thought 'Oh is that it? She's gone!' and 'Where do I go now?' I don't know where to go now. I don't know what to do. Because I don't know whether they are going to get in touch, from the doctors. Or whatever. I don't know.* (Susan; 654)
Some parents were apprehensive about the transfer. Reasons included concern about its impact on their child, doubts about the readiness of their child to be transferred to adult services, and concerns about the competencies of the new service/clinicians. *I was a bit apprehensive cos it was a doctor who we were use to seeing and [daughter] was use to seeing her and I was worried that the transition might be uncomfortable for [daughter]."* (Catherine; line 495)

You know, she is still only sixteen; sixteen is still quite young to go, you know … (Sally; line 503)
Positive views about the transition included feelings of hope about the new adult service and the care they would provide, as well as optimism about how the transition would be conducted. *But I had that hope in my mind that maybe now they'll listen to her and not just me.* (Catherine; line 505) *… we assumed it would be a smooth transition and everything would be in place. So we weren't really worried about moving on, we just thought it would be okay."* (Maria; line 319)

Super-ordinate theme 2 – Care should be specialist and developmentally appropriate

Sub-ordinate theme: The young person's care needs to be specialist
All four parents whose child had been transferred to their GP expressed doubt about the suitability of this, and perceived hospital-based gastroenterology services to be better equipped to meet their child's needs, "*I still do think that would be the best location for her, to be seen by a specialist*". (Emily; line 269) The most common doubt concerned the GP's lack of knowledge about coeliac disease, "*… there's a big gap in their knowledge and understanding of it …"* (Louisa; line 168), and the absence of expert clinicians (e.g. dietitians), *At the moment she doesn't have any access to a dietitian automatically.* (Emily; line 410)
Emily and Maria both indicated self-reassurance regarding their daughters' care with their GP, as they perceived their daughters to be healthy and capable to manage their gluten-free diet, as well as hoped that the GP would refer them to a gastroenterologist if necessary. *But I did know that she was possibly unusually compliant and healthy, so I wasn't unduly concerned when it ended up being the GP really because I think the GP would refer back to a gastro if necessary. If she had a problem, they would escalate it again*. (Emily; line 266) *Probably they would be at the hospital, but obviously we've moved away from there so it's not a service that's available to us at the moment. I'm sure we could go back if we wanted to, but we'll have to see. If we feel as though we're not getting answers it may be something we'll consider as time goes by.* (Maria; line 494)
Specialist care, however, was only perceived as adequate if they provided information and support. Catherine and Sally, whose daughters were transferred to adult gastroenterology services, reflected on their experiences with paediatric services in light of the care they were now receiving with adult services, which they deemed to be more involved and informative. *… we were told she is actually allowed fourteen units per month and we had no idea. Now we've been going since she was seven and nobody has told us that's*

what she was allowed. … he said "oh she can get extra luggage allowance" so he's written a letter … that is something the GP or the dietitian at the children's should have told us … in a way I feel cheated. (Sally; line 574)

But you know she's been so open and so honest with [daughter]. I didn't feel that she was soft coating anything, you know nothing was sugar coated. She's told her straight but in such a lovely way that [daughter]'s just--like I said, I have spent 6 years trying to explain to her that you're not going to grow out of it [daughter] and I'm her mum, and she's done it in one sentence. And you know, you can't beat that. (Catherine; line 638)

Maria, who also has a diagnosis of coeliac disease, had personally been a recipient of adult gastroenterology services, her experience of which she described negatively. She did not feel there was one clinician overseeing her treatment, and she was unhappy about the "*attitude*" of a nurse. This left her feeling "*frustrated that the Adult Services are not as good and I don't think there are any experts there who--to advise us now*." (Maria; line 246)

Sub-ordinate theme: Clinicians should interact appropriately with the young person

Half of the parents made reference to the nature of clinicians' interactions with their adolescent child, indicating the importance of recognising the young person as an equal partner in their care. Catherine perceived the paediatric clinician to have ignored her daughter as central in her own care, "*looking back on it, it was like oh that's a child, it's not quite so important, you know we'll just talk over them to the parent*." (Catherine; 457) Whereas now with adult services, she feels her daughter "*… is more respected by them … they just listen more to her and its how she's feeling that counts*." (Catherine; line 687)

Sally discussed an incident when a clinician made "*throwaway statements*" regarding long-term complications, which was a "*traumatic*" experience for her daughter and led her to stop eating for fear of developing these complications.

Emily indicated the importance of clinicians recognising the developmental maturity of the young person and adapting their care approach accordingly.

I also think that by the time the child is sixteen she doesn't need to have the Where's Wally book presented to her to find, as a distraction technique, to find Wally while they're trying to get the blood out of her. (Emily; line 312)

Super-ordinate theme 3 - Withdrawal of parental involvement is an evolving process

Sub-ordinate theme: They still need our support

Four of the parents indicated that there had been very little change in their involvement of their child's utilisation of services since the transfer to adult services, "*I still feel that*

I'm her mum and that I should be looking after her ..." (Louisa; line 400).

> *I'll always go to her appointments as long as she wants me to ... I'm not going to get this far and then say right you're on your own now chicken, off you trot, go the hospital. I think she'd be a bit lost up the hospital without her partner in crime to be with her*. (Catherine; line 539)

Sub-ordinate theme: Withdrawing support is a gradual, natural process that requires adjustment

Some parents indicated that there had been some reduction in their involvement with services, for example, no longer taking the lead in discussions and liaisons with clinicians, "She has started to take the lead a little bit more which is quite nice." (Sally; line 538)

> *I'm just there to support her, I'm just there for a shoulder if she needs me but I could just sit outside really because she does, she tells them, she tells them what she wants to tell them, she asks them what she wants to ask them, she demands the answers from them now.* (Catherine; line 647)

There was a perception that the reduction of parental involvement is a natural occurrence, and one that is universally associated with parenthood and the young person's transition into adulthood. This was also the view of Emily, "*But that's true for any parent of a young adult, it's something they will have to learn to do themselves and we have to step back and let them do it."* (Emily; line 360)

For Louisa, who still assumes full responsibility to utilise and liaise with services, she did indicate awareness of future need for her daughter to take personal responsibly, linking this with other life events and transitions (e.g. moving out of the family home), "*Then I guess at some point in the next couple of years when she goes off to uni or whatever, she'll have to look after it herself*." (Louisa; line 172)

Appendix 18: Instructions for authors - European Journal of Gastroenterology & Hepatology

