REVIEW

Transitioning patients with inflammatory bowel disease (IBD) from adolescent to adult services: a systematic review

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ABSTRACT

Approximately a quarter of patients with inflammatory bowel disease (IBD) are diagnosed before 20 years of age, presenting with more extensive distribution and severity of disease than adult onset. The purpose of this review was to determine facilitators of, and barriers to, successful transition of patients with IBD from adolescent to adult services. A systematic review of IBD transition research was conducted in March 2014 searching PubMed, MEDLINE, PsycINFO, Web of Science and the Cochrane Database of Systematic Reviews databases. A hand search of reference lists and narrative reviews was carried out to maximise the potential for retrieving all relevant manuscripts. Primary studies written in English of full-length peer-reviewed journal articles that investigated transition of paediatric patients with IBD to adult services were included. Studies were excluded if the primary focus was not IBD. The search produced 283 potentially relevant studies. After removing duplicates and screening for suitability, six met our inclusion criteria. Barriers to transition included system inadequacies and a lack of resources, clinical time and training. Successful transition involved joint medical visits, structured transition services, improved communication between paediatric and adult services and improved education for patients and staff. If the transition process for adolescents suffering with IBD is to improve then it is vital that more research is conducted to better our understanding of ways in which we can ensure that defined protocols are in place for a smooth transition for every adolescent, leading to improved standards and minimal disruption to care.

BACKGROUND

Inflammatory bowel disease (IBD) is a group of inflammatory conditions of the

gastrointestinal tract. A long-term chronic disease, the primary subtypes of IBD are Crohn's disease (CD) and ulcerative colitis (UC).¹⁻⁵ IBD-unclassified is the term used when it is difficult to ascertain whether the presenting problem is CD or UC^{4 5} despite repeated reassessment. In the UK alone, there are over 240 000 IBD sufferers.⁶ Its cause remains unclear, with a complex interaction of genetics and environmental factors thought to play a part.¹

IBD impacts on psychological well-being and quality of life,⁷⁻¹³ and can be diagnosed at any age, with onset usually between 15 and 35 years of age,¹⁴ and around a quarter of cases diagnosed under the age of 20 years.¹⁵ Presentation of IBD in young people differs from adult onset, with more extensive distribution and severity of disease in children.¹⁶⁻¹⁸ Patients diagnosed in adolescence are likely to experience 60 years of disease and frequent exposure to higher levels of diagnostic radiation, in addition to being at higher risk of associated malignancies.^{16 19} IBD symptoms profoundly affect children and adolescents^{20 21} with negative psychosocial consequences, including stress, social strain and altered self-image and self-esteem,²²⁻²⁴ which can impact on educational attainment, relationships and psychosexual development.²⁵ Managing IBD in adolescents, therefore, requires a holistic approach to treatment that includes the support of a multidisciplinary team.²⁶

A smooth transition from adolescent to adult service is vital to ensure that individual treatment is guided, and transition takes place causing minimal disruption to the adolescent's illness, in order to avoid recurrence.⁹ Transition is the purposeful,

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planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated healthcare systems.²⁷ Transition of patients with IBD from paediatric to adult service varies, although it usually happens when the patient is between 16 and 19 years of age.⁶ Those managing transition must ensure readiness to change, and despite recent UK guidelines suggesting the need for a defined policy and protocol,⁶ in addition to UK clinical data on IBD transition^{16 28} and a need to understand barriers to successful transition,^{16 29} no systematic review has yet been conducted on IBD and transition in which these could be based. Taking into account the perspectives of patients, parents/carers, and health professionals (such as gastroenterologists) to inform appropriate service development and implementation is essential for developing suitable policies.³⁰

The objective of this review was to determine a holistic understanding of facilitators and barriers to successful transition of patients with IBD from adolescent to adult services. The rationale for focusing particularly on IBD was due to the complexity of illness and varying nature of this chronic condition, which leads to variations in treatment, which can be different to other chronic illnesses.

The specific questions addressed in this review were:

- ▶ What are the barriers to, and principles of, successful transition of patients with IBD from adolescent to adult services?
- ▶ What methodological issues arise in studies of transition of patients with IBD from adolescent to adult services?
- ▶ What future recommendations can be offered?

METHOD

Eligibility criteria

Studies were included in this review if they (1) investigated transition of paediatric patients with IBD to adult services, (2) were written in English, (3) full-length peer-reviewed journal articles and (4) primary studies (retrospective or prospective, quantitative and/or qualitative). Studies were excluded if the primary focus was not IBD.

Search strategy

To maximise potential for finding all relevant articles, subject-specific databases (PubMed, MEDLINE, PsycINFO, Web of Science and the Cochrane Database of Systematic Reviews) were systematically reviewed in March 2014. Each database was searched using the following terms, combined with Boolean operators: (1) inflammatory bowel disease (2) IBD (3) Crohn's disease (4) colitis (5) #1 OR #2 OR #3 OR #4 (6) adolescen* (7) teen* (8) youth (9) young (10) #6 OR #7 OR #8 OR #9 (11) transition (12) transfer (13) #11 OR #12 (14) #5 AND #10 AND #13. Then a hand search through reference lists of all relevant articles and narrative commentaries on healthcare

transition was performed. The searches were conducted in March 2014, and were not limited to a specific time frame.

Selection process

Titles and abstracts retrieved were screened for potential eligibility by TC. The full text of potential articles was then examined by TC and JL to determine eligibility for inclusion in the review using predesigned study eligibility verification forms. If disagreement occurred between the two authors regarding appraisal or inclusion of a study, a third independent person would have been brought in. Data were collated and identification numbers assigned to each study. Data collected from each study included author(s), country, year published, aim, sample size (including a breakdown in males and females, IBD subtype, patient or health professional, mean age at transition or diagnosis), study design and response rate, key findings and suggestions made by authors.

Quality audit

The quality of the selected studies was then assessed by TC and JL. Qualitative studies identified would be critically appraised using the CASP checklist³¹ for qualitative studies, and quantitative studies were assessed using the Quality Assessment Tool for Quantitative Studies.³² For the latter, quality was assessed using the six components of the assessment tool, (1) selection bias, (2) study-design confounders, (3) blinding, (4) data-collection method, (5) withdrawals and (6) dropouts. The studies were rated as strong, moderate or weak for each criterion according to the Quality Assessment Tool for Quantitative Studies Dictionary³² and then given a global rating that scored studies as strong, moderate or weak overall, depending on ratings for the individual components. Heterogeneity of the reports meant that no meaningful outcome would have come from pooling this data, so a meta-analysis was not feasible.

RESULTS

As can be seen in [figure 1](#), the search strategy produced 283 potentially relevant studies, 124 duplicates were removed from the list, leaving 159 titles and abstracts to be screened. Of these, 141 studies were excluded because titles or abstracts revealed topics outside of the focus of this review, and a further 12 studies were excluded as they were not primary studies. The remaining six full-text articles were retrieved^{16 28 29 33–35} and examined by TC and JL to determine eligibility for inclusion, and all of these fulfilled the inclusion criteria. A manual search of the references cited in the six studies^{16 28 29 33–35} and narrative commentaries on transition of care revealed no further studies for inclusion in this review.

As summarised in [table 1](#), all studies explored transition of patients with IBD from adolescent to adult

Figure 1 Selection process.

services. Bollegala *et al*²⁹ examined resource usage in the year prior to transfer and the first year of transfer, Dabadie *et al*³³ explored patients' and parents' perspectives and Goodhand *et al*¹⁶ investigated the effect of age on onset of IBD and the specific problems posed to make recommendations for transition clinics. The remaining studies^{28 34 35} investigated gastroenterologists' views on perceived needs and barriers to successful transition. All studies were retrospective and quantitative in nature. Bollegala *et al*²⁹ and Dabadie *et al*³³ adopted a chart review method, as opposed to self-report survey, which was used by the remaining studies.

As shown in [table 2](#), the majority of studies received a global rating of weak, with Goodhand *et al*¹⁶ receiving a moderate global rating. Four of the studies were rated as weak with regard to selection bias,^{28 29 34 35} as the response rate was low^{28 34 35} or not applicable.²⁹ Dabadie *et al*³³ were rated as moderate as the response level was higher, and Goodhand *et al*¹⁶ were rated as moderate as the individuals selected were representative of the target population. Studies using a retrospective survey design were rated as weak,^{28 33–35} and Bollegala *et al*²⁹ and Goodhand *et al*¹⁶ received a moderate rating as they used a cohort design and case-control, respectively. Only Sebastian *et al*³⁴ and Goodhand *et al*¹⁶ accounted for confounders and, therefore, received a rating of strong, and all remaining studies were rated as weak as they did not account for confounders such as diagnosis, age or comorbidities. For most studies, ratings for data collection method were weak for using self-report data without any reliability or validity. Those with strong ratings for data collection method used medical records.^{16 29}

Overall, the results illustrate mixed findings; however, all studies identify a need for either IBD transition-of-care policies, training for adult gastroenterologist or specific IBD transition programmes or clinics, as summarised in the [box 1](#).

DISCUSSION

The aim of this review was to investigate barriers to, and principles of, successful transition of patients with IBD from adolescent to adult services. This review aimed to highlight the methodological issues arising in such studies and to provide recommendations for future research. Six studies met the review criteria, highlighting a shortage of research that has focused specifically on transition of patients with IBD from adolescent to adult services and also the difficulty in drawing any firm conclusions in which policies or clinical procedures to manage transition in IBD can be drawn. However, barriers to, and principles of, successful transition were identified in the limited amount of research that was available for review. Barriers included inadequacies in the preparation of adolescents for adult services defined by adult gastroenterologists and a lack of resources, clinical time and training needs identified by both paediatric and adult healthcare providers.

Supporting previous evidence that IBD is more severe in adolescence than adulthood,^{16 17} this review highlights the need for effective transition on this basis. The studies included in this review offer suggestions for achieving successful transition, such as adult gastroenterologists understanding the complexity of IBD diagnosed in childhood and paediatric gastroenterologists understanding the needs of adult providers.³⁵ In addition, improved education about medical history

Table 1 Studies included

Study	Research aim	Sample	Design	Data analysis	Key finding	Suggestion*
Bollegala <i>et al</i> (2003), ²⁹ Canada	Resource usage during transfer of care in IBD	N=95 47 male, 48 female 69 CD, 26 UC Mean diagnosis age 12.9 years Mean transition age 18 years	Retrospective chart review 1999–2008. Resource usage compared during, year before transfer and year after transfer	Wilcoxon signed-rank t test and McNemar's test	Disease activity higher during paediatric care Adult care=few clinic visits ($p<0.05$), more documented non-compliance ($p<0.05$)	Comprehensive transition programmes that address these shortfalls are needed to optimise care
Dabadie <i>et al</i> (2008), ³³ France	Explored patients and parents perceived transition of care in IBD	N=34 28 CD, 6 UC Mean age at diagnosis 11.8 years Mean age at transition 18 years	Retrospective survey for patients who visited a transition centre 1988–2005, separate parent survey. Survey sent to 48, response rate 71%	χ^2 and Fisher's exact test	85% of patients and 74% of parents felt they were ready for transition. All patients rated joint visits as beneficial for transferring records, and 93% considered them helpful in building confidence in new gastroenterologist. 79% of parents visited adult care with their child	Effective planning, including a joint medical visit to enable coordinated transition
Hait <i>et al</i> (2008), ²⁸ America	Explored gastroenterologists' perspectives on improving transition of care in IBD	N=363 adult gastroenterologists 85% male, 69% private practice, 62% >15 years of experience	Retrospective survey of adult gastroenterologists. Survey sent to 1132, response rate 34%	χ^2 and Fisher's exact test	55% reported knowledge of medical history as important, 69% reported knowledge of medical regimen as important. 51% received inadequate medical history from paediatric providers. 19% were less concerned about the patient's ability to identify previous healthcare providers or attend visits themselves (15%). 46% felt competent addressing developmental aspects relating to adolescents	Further training for adult providers in adolescent issues, formal transition checklist, education on diagnosis and medical history for patients
Sebastian <i>et al</i> (2012), ³⁴ UK	Identified perceived needs and barriers to successful transition	82 paediatric gastroenterologists 358 adult gastroenterologists	Retrospective survey of 132 paediatric gastroenterologists and 729 adult gastroenterologists. Response rates 62% and 49%, respectively	Wilcoxon signed-rank test and Spearman's correlation	Structured transition service perceived as very important by 80% paediatric gastroenterologists versus 47% adult gastroenterologists ($p<0.01$). Both groups ranked age as the most important criterion for transition with suggested age being 16 years (56% paediatric and 70% adult) and 18 years (82% paediatric and 81% adult). 43% paediatric staff suggested transition during remission versus 12% adult staff. 79% of adult services identified inadequacies in preparation of transition versus 42% paediatrics. Main areas of perceived deficiency in preparation by adult gastroenterologist were patients' lack of knowledge about condition and treatment and coordination of care; for paediatric, it was problems in self-advocacy and coordination of care. Lack of resources, clinical time and	Bridge gaps between paediatric and adult gastroenterologists, address training deficiencies to help remove barriers to transition

Continued

Table 1 Continued

Study	Research aim	Sample	Design	Data analysis	Key finding	Suggestion*
Wright <i>et al</i> (2014), ³⁵ Australia and New Zealand	Explored perceived needs of gastroenterologists and identified barriers to effective transition	N=73 66% adult, 34% paediatric 10% New Zealand, 90% Australian	25-item web-based survey 178 responses Response rate 41%	Mann–Whitney U test	critical mass of patients were factors ranked highest by both groups as barriers to transition care. The majority of staff highlighted suboptimal training in adolescent medicine for adult gastroenterologists Psychological maturity and readiness as assessed by adult caregiver were the most important factors in determining timing of transfer. Self-efficacy and readiness as assessed by adult caregiver were considered the two most important factors to determine timing of transition by both groups of gastroenterologists. Poor medical and surgical handover and patients' lack of responsibility for their own care were perceived as major barriers to successful transition by both paediatric and adult gastroenterologists	Standardise transition care practices with strategies aimed at optimising communication, patient education, self-efficacy and adherence to improve outcomes
Goodhand <i>et al</i> (2010), ¹⁶ UK	Effect of age of IBD onset and specific problems for adolescents and adults	100 adolescents in transition clinic matched to 100 adults. Disease duration was comparable, median 4 years (range 3–6 years). Median age at diagnosis 15 years for adolescents, 39 years for adults	Retrospective case note review versus control with 5 year follow-up	Mann–Whitney U test, χ^2 and Fisher's exact test	CD was significantly more common in the adolescents. Disease distribution was ileocolonic in 69% of adolescents and 28% of adults, restricted to the ileum in 20% of adolescents and 47% of adults, and colonic only in 11% and 22%, respectively. Upper gastrointestinal involvement occurred in 23% of adolescents, but was not seen in adults ($p<0.01$). Total UC was seen in 67% of adolescents and 44% of adults ($p<0.01$). Contrary to previous data, adolescents did not receive more ionising radiation than adults. Requirement for immunosuppressive therapy was higher in the adolescent group (53% vs 31%, respectively, $p<0.01$). Likewise, 20% of adolescents had required biological therapy versus 8% adult cohort ($p<0.05$)	Generate transition clinics to assist adult gastroenterologist manage patients with severe disease and ongoing inflammation who have failed multiple therapeutic regimens

*Highlights at least one suggestion made by authors.

CD, Crohn's disease; IBD, inflammatory bowel disease; UC, ulcerative colitis.

Table 2 Quality assessment ratings of included studies

Study	Selection bias	Study design	Confounders	Blinding	Data collection method	Withdrawals and dropouts	Global rating
Bollegala <i>et al</i> (2013) ²⁹	Weak	Moderate	Weak	Moderate	Strong	Weak	Weak
Dabadie <i>et al</i> (2008) ³³	Moderate	Weak	Weak	Moderate	Weak	Weak	Weak
Hait <i>et al</i> (2008) ²⁸	Weak	Weak	Weak	Moderate	Weak	Weak	Weak
Sebastian <i>et al</i> (2012) ³⁴	Weak	Weak	Strong	Moderate	Weak	Weak	Weak
Wright <i>et al</i> (2014) ³⁵	Weak	Weak	Weak	Moderate	Weak	Weak	Weak
Goodhand <i>et al</i> (2010) ¹⁶	Moderate	Moderate	Strong	Moderate	Strong	Weak	Moderate

and treatment to empower patients^{16 28 34} improved education for adult providers on adolescent issues^{16 28} and formal transition checklists.¹⁶

Improving communication between paediatric and adult healthcare providers,²⁸ was an important factor that came out of this study. This review supports the creation of specific adolescent transition clinics^{16 29} as a response to fears that adult gastroenterologists would inherit patients with severe disease and multiple failed treatment regimens³⁵ and patients with increased non-adherence and poor clinic attendance.^{29 35} Principles of successful transition were described as a structured transition service³⁴ or the use of joint medical visits that were beneficial for both patients and parents in terms of transitioning information and building confidence in new gastroenterologists.³³

Readiness to transfer was not identified here, despite research suggesting age and disease remission as possible factors of consideration,^{9 36} which has also been reported as an important component of successful transfer by both paediatric and adult professionals.²⁸ Future considerations for studies carried out in transition clinics are that a full explanation of the processes used in the clinic is used to draw conclusions or to make comparisons.²⁹

The current review is limited by the methodological quality of the studies included. Similar to previous reviews conducted on transition,^{37 38} the use of

convenience and purposive sampling was adopted for all samples included here, making it difficult to draw conclusions that are representative of all patients who have IBD. The sample sizes of studies included in the review varied, with studies using patient populations having smaller sample sizes ($n < 100$) than those using health professionals ($n > 300$). However, regardless of variations in sample sizes, all studies were relatively small, and none of the studies calculated the necessary sample size needed to detect statistical significance. There was also a shortage of valid and reliable measures used by the studies in this review, particularly those adopting survey designs. This lack of standardisation makes comparison difficult. Methodological issues raised by this review are comparable with that of other reviews on transition.^{37 38} A strength of this review is that it draws on the perspective of health professionals when investigating the barriers to, and principles of, successful transition. Future studies are necessary for capturing the needs and attitudes of health professionals, both paediatric and adult, in IBD and other chronic conditions. Patient, family and both paediatric and adult healthcare provider perspectives are important for determining the most appropriate processes for transition, with the aim of developing mutually agreed transition programmes, to ensure a holistic approach to treatment.²⁶ Additionally, research should consider carrying out randomised control studies on the benefits of transition clinics, variations in models of transition and approaches to IBD management in adulthood for those diagnosed in childhood, in which to base clinical practice. Clear patient outcomes, including rates of clinical and endoscopic remission, steroid use, surgery, hospitalisation, quality of life and cost-effectiveness, need to be measured for a comprehensive evaluation of transition clinics. Prospective studies should recruit large representative samples using standardised instruments. Finally, longitudinal studies would be useful to measure the long-term impact of transition.

In summary, the present review demonstrates a clear gap for further research on transition for IBD as current understanding is somewhat limited. Improved knowledge of the factors that contribute to or impede a smooth transition programme can lead to improved clinical practice where there are defined protocols that

Box 1 Summary of findings

- ▶ Six retrospective qualitative studies were included.
- ▶ Five studies had a weak global quality assessment rating, and one study, a moderate rating.
- ▶ Overall, the results illustrate mixed findings; however, all studies identify a need for either inflammatory bowel disease (IBD) transition-of-care policies, training for adult gastroenterologist or specific IBD transition programmes or clinics.
- ▶ Barriers to successful transition include inadequacies in the preparation of adolescents for adult services defined by the adult gastroenterologists, lack of resources, clinical time and training needs as identified by both paediatric and adult providers.

ensure a smooth transition is in place for every child, minimal disruption in care and a better standard of care for patients with IBD.

Contributors TC and JL developed the idea and plans for this review. TC searched databases. JL and TC carried out quality audit. TC wrote first draft of manuscript. JL and TC subsequently revised and edited the submitted manuscript.

Competing interests None declared.

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