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Title page

Systematic review of factors affecting transition readiness skills in patients with inflammatory bowel disease

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The data underlying this article are available in the article and in its online supplementary material.

Abstract

Background and Aims

The incidence of inflammatory bowel disease (IBD) diagnosed before adulthood is increasing worldwide. Transition from paediatric to adult healthcare requires certain skills. The aim of this study was to identify factors affecting these skills.

Methods

This review was registered on the PROSPERO database (CRD42019152272). Inclusion criteria: 1) studies of factors affecting transition readiness skills in patients with IBD 2) written in English 3) published since 1999. MEDLINE, CINAHL and PsychINFO databases were searched between 1999-2019. Quality was assessed using the Joanna Briggs Institute critical appraisal tools.

Results

Searches identified 822 papers. Sixteen papers were included. Age was positively associated with skills including disease knowledge and performing self-management behaviours (14 studies). Improvement often occurs at 18, however, skill deficiency may still remain. Increased self-efficacy (confidence) was associated with greater disease knowledge and performing self-management behaviours (3 studies). Self-efficacy was positively correlated with transition duration (2 studies) and health-related quality of life ($r=0.57$, $p<0.001$) (1 study), negatively correlated with depression ($r=-0.57$, $p<0.001$) and anxiety ($r=-0.23$, $p=0.03$) (1 study), and associated with higher education level (2 studies) and a family history of IBD (1 study). Females had higher self-management scores (3 studies), and greater healthcare satisfaction was significantly associated with higher knowledge (1 study). Greater transition

communication improved knowledge, self-management, and overall transition readiness (2 studies).

Conclusions

Potentially modifiable factors have been identified that could be supported in the transitioning IBD population to improve transition readiness. Identification of those with non-modifiable characteristics associated with poor readiness may aid targeted support.

Introduction

Inflammatory bowel disease (IBD) predominantly describes ulcerative colitis (UC) and Crohn's disease (CD), with a small percentage of patients diagnosed with an unspecified subtype (IBD-unclassified (IBD-U)). IBD is characterised by a remitting and relapsing disease course that can vary significantly between patients[1,2]. The incidence of IBD diagnosed in childhood is increasing worldwide[3]. In comparison to those diagnosed as adults, patients presenting with IBD in childhood typically experience a more severe and extensive disease course[4-6]. This brings additional challenges including the potential for growth failure, pubertal delay[7], and psychological morbidities, including depression[7-9].

Transition from paediatric to adult healthcare is an essential part of disease management for those diagnosed in childhood. Paediatric services are typically more family-focused, with a higher level of parental involvement. This contrasts with adult services where independence and autonomy are encouraged[9]. The time at which healthcare transition occurs may be an unstable period, with concurrent changes in other areas of life including education and employment[10]. Patients transferring to adult IBD care are at risk of loss to follow-up, poor adherence to medication and clinic visits, and other adverse clinical outcomes[5]. The importance of good, structured transition care has therefore been emphasised[11].

Transfer refers simply to the physical move of care between services, and is only part of transition which has been defined as *'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic … conditions as they move from child-centred to adult orientated healthcare systems'*[12]. This process requires the development of skills identified as necessary to engage

with adult healthcare. These include performance of the skills required to successfully manage a condition on an everyday basis, termed self-management behaviours[10,11,13,14]; medication and disease knowledge[11,14], and health-literacy *'the extent to which individuals have the capacity to obtain, process and understand basic health information'*[15]. Self-efficacy has also been identified[11], defined as a perceived confidence in the ability to perform behaviours required for independent management[16]. Surveys of adult gastroenterologists have expressed suboptimal levels of these skills in young people with IBD[17].

The aim of this study was to review the literature to identify factors related to transition readiness skills.

Methods

This review was registered on the PROSPERO database (CRD42019152272), conducted with reference to the Cochrane Handbook[18], and reported in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines[19] using a predefined protocol. A copy of the PRISMA checklist is provided in online supplementary data.

Eligibility criteria

Studies considered for inclusion had to be published from the year 1999 onwards and be full-text peer reviewed journal articles reporting primary data. Studies were included if they explored factors associated with transition readiness skills, defined as competencies considered necessary when engaging in adult healthcare. This encompassed the measurement of disease and medication knowledge, self-management behaviours, health literacy, and self-efficacy. Studies needed to focus on patients who were either preparing to transition, were of the age of transitioning, or had transitioned. Papers were excluded if they reported on long-term conditions other than IBD or were not written in English.

Information sources and search strategy

The databases MEDLINE, CINAHL and PsychINFO were searched between 1st January 1999 to the 31st October 2019, during September and October 2019. Searches used no limits and combined free text and thesaurus terms. Key terms included “inflammatory bowel disease”, “Colitis, Ulcerative”, “Crohn Disease”, “IBD”, “Transition to Adult Care”, “transition”, “transitioning”, “transition readiness”, “transition skills”, “transition readiness skills”, “Self-efficacy”, and “Self-Management”. A secondary search of bibliographies from papers that were of known significance, including review articles, was also conducted. A manual search

for the full published text was undertaken if a conference abstract appeared to be relevant. Duplicates were then removed.

Study selection

Titles and abstracts were screened against the eligibility criteria (LEJ) with secondary review and resolution of queries (TTM). Potentially appropriate texts were read in full to assess suitability for inclusion, with justifications of rejection recorded (LEJ). This process underwent secondary review (TTM).

Data extraction

Data were extracted into pre-designed tables (LEJ) with secondary review (TTM). Extracted data included year of publication, country of origin, study design, primary outcome, secondary outcome(s), sample size with patient details, factors explored for association, strength of association, statistical test used, secondary outcome results, and research setting.

Quality assessment

Study quality was assessed using the Joanna Briggs Institute critical appraisal tools[20]. Appraisal criteria includes inclusion and exclusion criteria; study subjects and setting; identification of and strategies to address confounding factors; validity and reliability of outcome measurement, and appropriate statistical analysis. Each study was assessed for quality (LEJ) with secondary review (LRGT) and resolution of queries.

Summary measures

Statistical methods and summary measures used in each study were recorded and presented with confidence intervals and tests of significance (p-values) where appropriate.

Data synthesis

This review was prepared as a narrative synthesis of factors, identified as those associated with transition readiness skills. Factors were categorised into potentially modifiable and non-modifiable, then grouped by type of factor. This review defines modifiable factors as those that could potentially be amenable to intervention by a healthcare professional or the healthcare system. Factors such as education level could be viewed as modifiable in the wider context of a patient's life, however it is unlikely these could be impacted by possible strategies employed by healthcare professionals. Age was included as a modifiable factor as although this cannot be changed, the age at which transition occurs could be modified. This review set a reported alpha significance level of less than 0.05 with regards to determining the significance of potential factors.

Results

Study selection

Initial searches identified 863 papers. After removal of duplicates and secondary searches, 822 were screened for inclusion. Twenty-six full texts were retrieved and reviewed against the eligibility criteria. 10 papers were then excluded for the following reasons: factors not assessed (n=3), patients were not part of the transition cohort (n=3), participants assessed did not have IBD (n=1), transition readiness acquisition not assessed (n=1), and the articles were a literature review (n=2). Therefore, sixteen papers were included in the full review. The PRISMA study selection flow chart is shown in Figure 1.

Study characteristics

The sixteen included studies were published between 2010 and 2019 and reported on 1762 patients aged between 10 and 29. Studies were conducted primarily in the USA (n=12)[21-32] and outpatient clinics were the principal research setting (n=13)[21-23,25,26,29-36]. Fourteen of the studies were cross-sectional[21-24,26-32,34-36], and two longitudinal[25,33].

Outcomes

The included studies measured a number of different outcomes related to transition skills. A detailed summary of these measures is provided in the online supplementary data. Three papers assessed medication or disease knowledge[29,30,35] and four evaluated performance of self-management behaviours[21,23,24,31]. Three studies also assessed self-management in addition to either overall transition readiness[22] or knowledge[25,26]. One study examined knowledge and self-management alongside functional health-literacy, an assessment of comprehension and numeracy level[27]. Three studies assessed self-efficacy only[32,33,36] and one

paper also examined self-management[28]. One study evaluated knowledge, self-efficacy, and perception of medical care, which involves how patients' conceptualise their care and relationships with providers[34].

Quality assessment

Issues were noted around inadequate reporting of inclusion and exclusion criteria[24,32-34] and recruitment time period and study location[21,22,26,27,30]. Six studies did not use validated tools to measures outcomes[26-29,31]. Nine studies did not account for multiple testing[26-28,31-34,36], eight of which also did not assess and correct for potentially confounding factors[26-28,31-34,36].

Factors

Factors were divided initially into potentially modifiable and non-modifiable. Modifiable factors were further categorised into provider-related and other, and non-modifiable into demographic and disease-related factors. Further details regarding the method of factor assessment and statistical results of individual papers are provided in online supplementary data.

Potentially modifiable factors

Provider-related factors

Transition communication

Three studies examined transition communication[21,22,30]. *Rosen et al.* found no association between having a conversation about transition with providers and self-management[21]. *Gumidyala et al.(A)* and *(B)* obtained information from parents and patients regarding the frequency and length of transition discussions. Young people who reported more frequent and longer transition discussions had higher self-management and overall transition readiness scores (communication uniquely explained 4.2% and 25.7% of the variance in self-management and overall readiness scores respectively). Parent reports were also associated with improved overall readiness (8.9%)[22]. In contrast, improved knowledge was only associated with parent reported communication (4.3% of variance, p=0.039)[30].

Transition duration

Improved self-efficacy from longer transition duration was demonstrated in two studies[33,36]. *Yerushalmy-Feler et al.* defined duration from the first referral to a transition clinic to moving services. Significant positive correlations were found between duration and self-efficacy in three out of twelve domains (knowledge of IBD [r=0.44, p=0.02], medication use [r=0.57, p=0.002], knowledge of transition [r=0.56, p=0.002])[33]. *Zijlstra et al.* recruited patients still attending a transition clinic and recorded the length of time since the first clinic visit. Duration was positively correlated with three different domains (skills for visits [r=0.29, p=0.04], behaviour at clinic [r=0.53, p=0.001], transfer readiness [r=0.22, p=0.02]). Clinician (r=0.45, p=0.001) and parent (r=0.25, p=0.03) scores rating patient independency were also positively

correlated with duration, but not adolescent scores (r=0.23, p=0.11) - though this study did not assess patients when they had completed transition[36].

Healthcare satisfaction

Patient healthcare satisfaction was associated with increased knowledge (satisfaction explained 8.9% of score variance, p=0.004)[30].

Care setting

Self-management scores were not significantly different when comparing patients being managed in either paediatric or adult services (p=0.43)[21].

<u>Other</u>

Age

Fifteen studies examined the relationship between age and transition readiness skills. Six of these studies evaluated the association between age and knowledge[26,27,29,30,34,35]. One paper found no significant relationship (r=0.103, p>0.05)[34] and another reported that in patients aged 14-18, younger participants were more likely to recall having undergone a small bowel X-ray (OR 0.59 [0.35-0.996], p=0.048)[35]. The remaining four studies however demonstrated that older age was associated with increased knowledge[26,27,29,30]. For every age increase of one year, the odds of correctly naming a current biologic therapy or the adverse effects of medication increased by 38% (OR 1.38, p<0.001) and 13% (OR 1.13, p<0.001) respectively[29]. Additionally, participants older than 18 scored significantly higher on measures of IBD knowledge. Comparisons between patients younger and older than 14 also showed significant differences in knowledge of past-medical history (p=0.01)[27].

Seven studies assessed self-management[21-24,27,28,31]. In one study, no difference in ability to perform self-management behaviours was identified for patients aged 16-18[28]. In the remaining six papers, older age was significantly associated with improved self-management[21-24,27,28,31]. Participants older than 18 had significantly higher self-management scores than those younger than 18[24,27]. Other studies also demonstrated however that comparing participants aged 18 and above with even older patients still produced significant age differences. Participants older than 24 had significantly higher self-management scores in comparison to those aged between 18-20 (median 4.64 IQR 4.3-4.8 vs 3.97 IQR 3.4-4.4, $p<0.0001$)[21] and in another study, only 7.3% of participants older than 18 met the study's pre-determined benchmark for adequate self-management scores[23].

Assessing knowledge and self-management together, older age was again significantly associated with higher scores[25,28]. *Stollon et al.* found that approximately half of the assessed domains were not mastered until the age of 18 or above[25]. Parent ($p<0.01$) and patient ($p<0.001$) reported overall transition readiness also had significant positive relationships with age[22]. Evaluating functional health literacy, participants older than 18 again demonstrated higher scores ($p=0.03$)[27]. Perception of medical care was not correlated with age ($r=-0.150$, $p>0.05$)[34].

Four studies assessed self-efficacy with relation to age[28,32-34]. Two studies found no relationship[28,32] and one, a significant positive relationship ($r=0.367$, $p<0.01$)[34]. *Yerushalmy-Feler et al.* evaluated participants both before and after a transition clinic. Older age was positively correlated with coping with IBD after transition was complete ($r=0.43$, $p=0.004$). Evaluating the difference in scores between the two time points however, younger age was

associated with better improvement in the domains 'coping with IBD' (r=-0.44, p=0.02) and 'knowledge of transition' (r=-0.38, p=0.04)[33]. Unlike other outcomes, the effect of age on self-efficacy seems inconsistent and small.

Self-efficacy

Four papers assessed whether self-efficacy influenced other transition readiness skills[22-24,30]. No difference was found in self-management scores when asking patients to rate their confidence in their ability to manage their disease[23]. The remaining three studies used validated self-efficacy measures. Greater self-efficacy was associated with both increased knowledge (self-efficacy explained 4.3% of score variance, p=0.039)[30] and self-management, explaining 16% of the variance in self-management scores in one study (p=0.001)[24] and 3.9% in another (p<0.05)[22]. Self-efficacy was also positively related to parent reported transition readiness (6.7%, p<0.05)[22].

Autonomy granting

Gumidyala et al.(A) assessed parent autonomy granting, the extent to which parents delegate appropriate levels of control and independent behaviour to their child[37], and found no association with knowledge[30].

Mental health

Three studies examined the effects of mental health[21,24,32]. Resilience did not predict self-management[24]. No significant association was found between overall self-management scores and anxiety or depression. Depression however was associated with talking more openly with providers (r=0.29, p=0.04)[21]. Contrastingly, depression (r=-0.57, p<0.001) and

anxiety (r=-0.23, p=0.03) were both related to lower self-efficacy scores. Self-esteem did not have an association with self-efficacy (r=0.23, p=0.05)[32].

Adherence

Rosen et al. defined non-adherence as failure to either adhere to medication dosages or attend an appointment. Patients classified as 'non-adherent' did not have significantly different overall self-management scores, however did score significantly lower in the domain 'managing medications' (median: 4.35 [IQR 3.3-4.8] vs 4.75 [IQR 4.3-5] p<0.01)[21].

Non-modifiable factors

Demographic

Gender

Twelve studies examined participant gender[22-25,27,28,31-33,35,36]. Three studies found that female participants had higher self-management scores[22,23,31] for example, they were more likely to order refills (p=0.017) or prepare questions for appointments (p=0.009)[31]. *Zijlstra et al.* however found that male participants had higher median self-efficacy scores in three out of twelve domains[36]. *Benchimol et al.* also found that male participants were more likely to remember the correct date of their last admission (OR 6.82 [95% CI 1.75-26.6], p<0.01) and colonoscopy (OR 2.83 [95% CI 1.03-7.80], p<0.05)[35].

Socioeconomic status

Carlsen et al. found no association between self-management and any socioeconomic indicators[24]. In another study however, those from higher socioeconomic groups had greater increases in knowledge and self-management scores over time (p=0.01), though there was no

difference in baseline scores[25]. In contrast, *Huang et al.* reported that a higher percentage of participants from a lower socioeconomic group had a health literacy level classified as adequate for transition compared to those from a higher socioeconomic group (25% vs 6%, $p<0.02$)[27].

Race / Ethnicity

Izaguirre et al. found no association between race/ethnicity and self-efficacy[32]. Two other papers grouped participants into 'white' and 'other'. Those classified as 'white' had significantly higher knowledge and self-management scores at baseline (p=0.01), but not over time (p=0.09)[25]. A higher percentage of 'white' participants also had a health literacy level classified as adequate for transition (18% vs 3%, white vs non-white; percentage ready to transition p=0.03). Higher scores for knowledge and functional health-literacy were also reported, however self-management was not influenced by race/ethnicity[27].

Education level

Education level did not influence self-management in one study[21]. Only one self-efficacy domain was significantly higher for those with a higher education level (knowledge of diagnostic tests, 90% vs 81% [high vs. low], p=0.009)[36]. *Izaguirre et al.* found that those in middle school had lower self-efficacy scores than those in high school (p=0.01) and college (p=0.007), but not in graduate school or the workforce[32].

Disease related

Diagnosis

Seven studies evaluated the influence of diagnosis[24,28,31-33,35,36]. Two studies demonstrated significant effects, with both reporting different findings[35,36]. Patients with IBD-U were more likely to be aware of their diagnosis (OR 17.2, 95% CI 2.81-105.4, p=0.009) and those with UC more likely to correctly recall whether they had undergone a small bowel X-Ray (OR 5.59, 95% CI 1.29-24.2, p=0.008)[35]. In another study however, participants with CD had higher self-efficacy scores for independent behaviour during clinics (p=0.04)[36].

Disease duration and age at diagnosis

Eleven studies assessed disease duration[22-24,26,28-33,35] and two studies found conflicting results[35,33]. Duration was positively associated with correctly recalling undergoing a small bowel X-ray (OR 1.38 [95% CI 1.06-1.83] p<0.05)[35] and negatively associated with improvement in self-efficacy scores for coping with IBD after transition (r=-0.55, p=0.003)[33]. *Stollon et al.* found no association between age at diagnosis and either knowledge or self-management[25]. When *Carlsen et al.* evaluated just participants over the age of 18, older age at diagnosis was associated with lower self-management scores [F(1) 5.50; R^2=0.10; p=0.02][24].

Disease activity

Six studies examined disease activity[21-23,33]. *Rosen et al.* also collected information concerning the number of emergency department visits and hospitalisations during a 6-month follow-up period and found no relationship with self-management[21]. An association was found between increased absence from school and lower self-management scores [F(1)4.26; R^2=0.31; p=0.001][24]. A significant positive correlation was also demonstrated between health-related

quality of life and self-efficacy (0.57, $p<0.001$)[32]. The same study found no effect for presence of extraintestinal symptoms ($p=0.67$) or previous IBD related surgery ($p=0.33$)[32].

Family history

A family history of IBD was associated with significantly higher self-efficacy scores ($p=0.01$)[32].

Medication type

Medication type did not significantly influence self-efficacy[33].

Discussion

This systematic review identified potentially modifiable and non-modifiable factors associated with transition readiness. These are important to consider in clinical encounters and service design. The identification of modifiable factors enables the development of interventions, and the recognition of non-modifiable factors should encourage clinicians to adapt care for individual patients to improve transition readiness.

Self-efficacy has been measured as both an outcome and a contributory factor for transition readiness in this review – reflecting existing literature[24,36]. Effect sizes where relatively small, however higher levels of self-efficacy did positively influence self-management and knowledge[22,24,30]. This may be due to assessment of similar measures, or alternatively, confidence may support the development of other skills; belief in one's ability has been associated with successful IBD transition[11]. Unlike other skills, self-efficacy did not have a strong relationship with age. Interventions that support confidence development may improve transition readiness regardless of age. In adults with Crohn's disease, an individualised behavioural programme which helped patients identify and reach personal goals significantly improved self-efficacy[38]. A meta-analysis of community-based education programmes for long-term conditions also demonstrated self-efficacy improvements[39]. The association between transition duration and self-efficacy[33,36] suggests that transition as a planned, gradual process may assist in building confidence[40,41]. A positive relationship with family history[32] also indicates the potential importance of familiarity with the medical environment or the easy availability of a peer or mentor.

Older age was consistently associated with improved transition readiness skills, confirming findings from other long-term conditions[42]. Studies with a wider age range were included in this review due to the current uncertainty surrounding the appropriate age for transition. Some insight has been provided to this, with significant improvements in knowledge, self-management, and health literacy seen at the age of 18. However, there remain inadequacies even in those older than 18. This may indicate the need for an older transition age, allowing for transition to occur at a "developmentally appropriate" time[43], or for a more prolonged, individualised process. The prefrontal cortex - one of the final areas of the brain to mature in young adulthood - is key for executive functioning. This encompasses the use of certain cognitive skills regarded as necessary for engaging in adult healthcare[10,11], including working memory, planning and organisation, problem-solving, and self-control[10,44]. Young person specific clinics may extend the timeline for which patients are expected to acquire these necessary competencies[5]. Adolescents with long-term conditions also reportedly desire feelings of 'normality'[45], which may be provided through regular contact with others undergoing similar experiences at young person specific clinics[45,46]. Peer programmes in young people with IBD can offer valuable support and facilitate the discussion of issues affecting patients[47].

The positive relationship between skill acquisition and transition communication[22,30] supports literature stating that good, early communication in transition services is important[41,48]. A study assessing transfer readiness in adolescents with various long-term conditions found that participants who described increased discussion regarding future transfer felt more ready[49]. The slightly conflicting findings regarding the influence of both parent and patient reported transition communication suggests that there may be a process of readiness

preparation outside the clinical setting, related to behaviours in the family social unit. The one study assessing healthcare satisfaction found a significant relationship with knowledge[30], potentially indicating a further avenue of research or intervention. Satisfaction has been associated with desirable outcomes including appointment adherence[50] and is reportedly higher when patients feel involved in their healthcare[51]. Nevertheless, parent-autonomy granting was not significant in this review. It was however only examined by one study[30], and literature has identified parental over-involvement as a transition barrier and encourages patients to attend appointments alone[52]. More robust investigation is therefore necessary to understand the relationship between autonomy and transition readiness skills.

Female participants demonstrated a tendency for improved self-management[22,23,31]. Male patients elicited higher scores in some areas[35,36], but the effect sizes were small and confidence intervals wide for one study[36]. This apparent self-management advantage for female patients may be important to consider, however these findings were not consistent, with more papers not reporting any significant effects for gender. Socioeconomic status and race/ethnicity were other identified factors, supported by literature demonstrating both the economic and ethnic disparities regarding transition readiness and other healthcare outcomes[53-55]. Within this review however, the included population was predominantly white. Studies also had discrepant findings, with increased readiness levels associated with both higher and lower socioeconomic status.

There are limitations to this review. Methods of assessing transition readiness are not consistent, making comparison of the primary outcome difficult. This variation arises as there is no consensus on the best measure, making it difficult to ascertain the true strength of

associations. This was reflected in the variable assessment of quality related to outcome measurement. This issue also meant that statistical meta-analysis and robust quantitative investigation could not occur. Future studies should seek to address these issues.

Factors, such as transition communication, were also variably defined. The evidence base for many factors also remains relatively small, with only a limited number of studies examining their effects. Individual measures, such as skill levels, may also not be accurate surrogate measures for successful transition, and longitudinal studies are needed to examine this relationship. Quality assessment found that studies were not of universally high quality, with relatively consistent failure to address potentially confounding factors. Studies also undertook univariate analyses, leaving them open to error when assessing relationships. Another source of potential bias is the self-reported element of outcomes, perhaps therefore not providing an objective measure. The majority of included studies were conducted in the US, thus potentially making it difficult to extrapolate results to other regions where different systems for transition and caring for young people with IBD may exist.

Conclusions

This study has identified potentially modifiable factors associated with improved transition readiness. These factors should undergo further rigorous and systematic evaluation to identify whether intervention can improve outcomes. Further research is necessary to obtain agreement on measures of transition readiness with longitudinal studies to demonstrate the impact of changes in the approach to individual patients and the service as a whole.

1 **Acknowledgements**

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Figure legends

Figure 1.

PRISMA flow chart (*n=number of studies)*

Figure 2.

Significant potentially modifiable factors affecting transition readiness skills identified in this systematic review

Figure 3.

Significant non-modifiable factors affecting transition readiness skills identified in this systematic review

Figure 4.

How to assess the gaps identified in the literature, related to future study design

Tables

Table 1. Summary of included papers with study characteristics including age of patients assessed, transition readiness skill(s) assessed and method of assessment

Paper	Sample Size	Age of patients assessed	Transition readiness skill(s) assessed	Summary of method of skill assessment
Benchimol 2011	n=78	Range: 14-18 Mean: 16.2±1.25	Medication and disease knowledge	Patient completed survey
Fishman 2011	n=294	Mean: 16.7±3.5	Medication and disease knowledge	Patient completed survey
Gumidyala 2017	n=75	Range: 16-20 Mean: 17.39±1.2	Medication and disease knowledge	Patient completed survey
Carlsen 2017	n=87	Range: 16-23 Median: 19 (IQR 17-20)	Performance of self-management behaviours	TRAQ (Transition Readiness Assessement Questionnaire)
Gray 2015	n=195	Range: 16-25 Mean: 18.08±1.86	Performance of self-management behaviours	TRAQ
Rosen 2016	n=95	Mean in adult setting: 23.5±2.2 Mean in paediatric setting: 20.5±1.6	Performance of self-management behaviours	TRAQ

van Groningen 2012	n=294	Range: 10-29 Mean: 16.2	Performance of self-management behaviours	Patient completed survey
Gumidyala 2018	n=75	Range: 16-20	Performance of self-management behaviours and overall transition readiness	Readiness to Transition Questionnaire (RTQ): 1. RTQ-Overall 2. RTA-AR (Adolescent responsibility) Completed by patient and parent
Stollon 2017	n=144	Range: 12-22 Mean: 15.9±2	Disease and medication knowledge and performance of self-management behaviours	TRxANSITION Scale
Whitfield 2015	n=67	<14: (n=12) 14-17: (n=37) 18+: (n=18)	Disease and medication knowledge and performance of self-management behaviours	Patient completed survey
Huang 2012	n=74	Range: 10-20 Mean: 15	Disease and medication knowledge, performance of self-management behaviours, functional health-literacy, and overall adequate rates for transition	Patient completed surveys and questionnaires

Izaguirre 2017	n=95	12-17: (n=42) (44.2%) 18-25: (n=51) (53.7%)	Self-efficacy	IBD-Self-Efficacy Scale for Adolescents (IBD-SES-A)
Yerushalmy-Feler 2017	n=36	Range: 17-27 Mean: 19±1.8	Self-efficacy	IBD-yourself
Zijlstra 2013	n=50	Median: 16.3 (IQR 15.4-17)	Self-efficacy	IBD-yourself
Fishman 2010	n=40	Range: 16-18 16: (n=17) 17: (n=17) 18: (n=6)	Performance of self-management behaviours and self-efficacy	Patient and parent completed survey
Hammerman 2019	n=63	Mean: 16.6±2.1	Disease and medication knowledge, self-efficacy, perception of medical care	Patient completed questionnaire

1 *n (number of participants) IQR (Interquartile range)*

Table 2. Included studies and factors assessed for association with transition readiness skills. Associations found are demonstrated.

Paper	Transition skill assessed	Modifiable									Non-modifiable									
		Provider-related				*Other*					*Demographic*				*Disease-related*					
		Trans. Comm.*	Trans. Dur.**	Healthcare satisfaction	Care setting	Age	Self-efficacy	Autonomy granting	Mental health	Adherence	Gender	SES+	Race / Ethnicity	Edu. Level++	Diag.±	Dur.ε	Age at Diag.δ	Disease activity	Family history	Med.θ
Benchimol 2011	**Knowledge**					✓(-)					✓(M)				✓(IBD-U, UC)	✓(+)				
Fishman 2011	**Knowledge**					✓(+)					✓(x)					✓(x)				
Gumidyala 2017	**Knowledge**	✓(+)		✓(+)		✓(+)	✓(+)	✓(x)								✓(x)				
Carlsen 2017	**Self-management**					✓(+)	✓(+)		✓(x)		✓(x)	✓(x)			✓(x)	✓(x)	✓(-)	✓(-)		
Gray 2015	**Self-management**					✓(+)	✓(x)				✓(F)					✓(x)		✓(x)		
Rosen 2016	**Self-management**	✓(x)			✓(x)	✓(+)			✓(-)	✓(+)				✓(x)				✓(x)		
van Groningen 2012	**Self-management**					✓(+)					✓(F)				✓(x)	✓(x)				
Gumidyala 2018	**Self-management, overall transition readiness**	✓(+)				✓(+)	✓(+)				✓(F)					✓(x)		✓(x)		

Stollon 2017	**Self-management, knowledge**					✓(+)					✓(x)	✓ (+)	✓(w)				✓(x)		
Whitfield 2015	**Self-management, knowledge**					✓(+)										✓(x)			
Huang 2012	**Self-management, knowledge, health-literacy**					✓(+)					✓(x)	✓(-)	✓(w)						
Izaguirre 2017	**Self-efficacy**					✓(x)			✓(+)		✓(x)		✓(x)	✓(+)	✓(x)	✓(x)		✓(-)	✓(+)	
Yerushalmy-Feler 2017	**Self-efficacy**		✓(+)			✓(+/-)					✓(x)				✓(x)	✓(-)		✓(x)		✓(x)
Zijlstra 2013	**Self-efficacy**		✓(+)								✓(M)			✓(+)	✓(CD)					
Fishman 2010	**Self-management, self-efficacy**					✓(x)					✓(x)				✓(x)	✓(x)				
Hammerman 2019	**Self-efficacy, knowledge, perception of care**					✓(+)														

1 **Transition communication **Transition duration ⁺Socioeconomic status ⁺⁺Education level ±Diagnosis ᵋDisease duration ᵟAge at diagnosis ᶿMedication type (+) Positive association found (-)*

2 *Negative association found (x) No association found (M) Male gender (F) Female gender (w) 'white' race/ethnicity*

Figures

Figure 1.

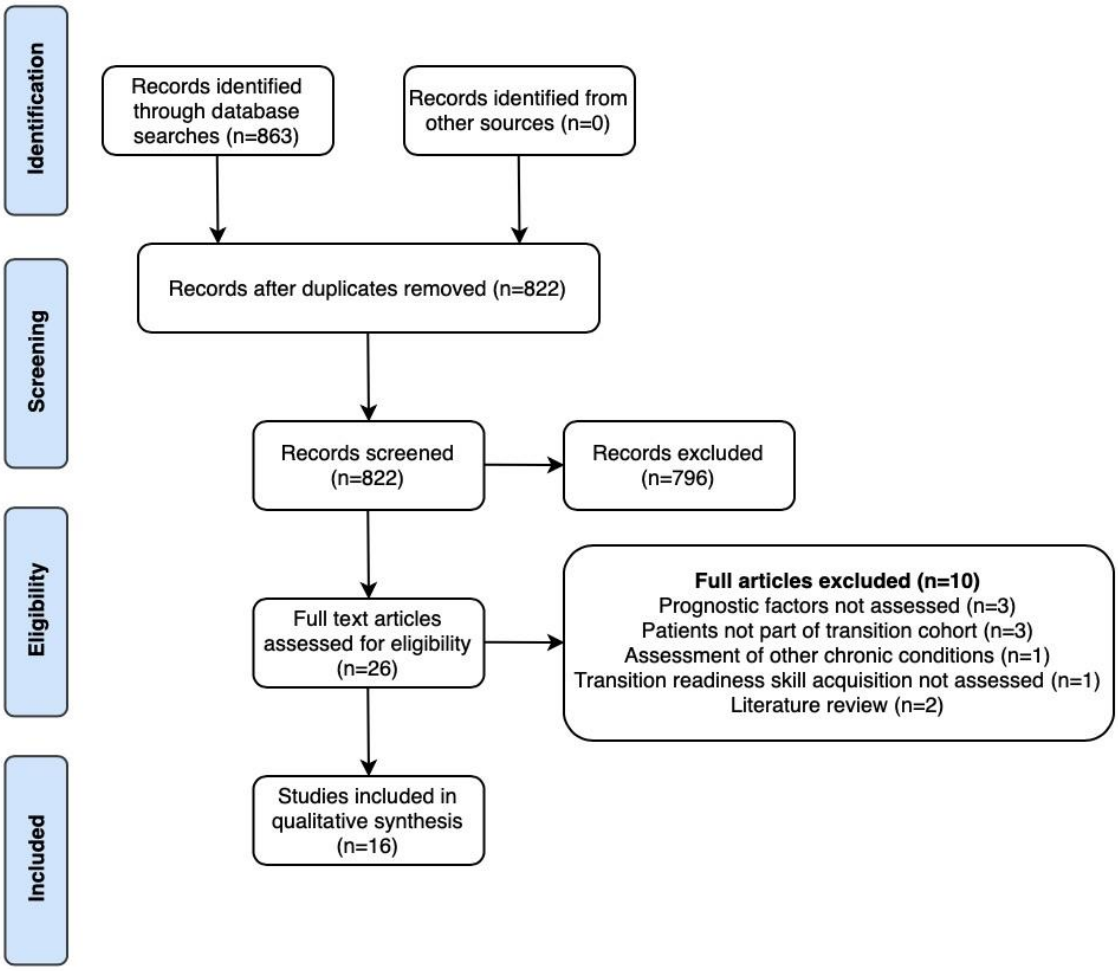

Figure 2.

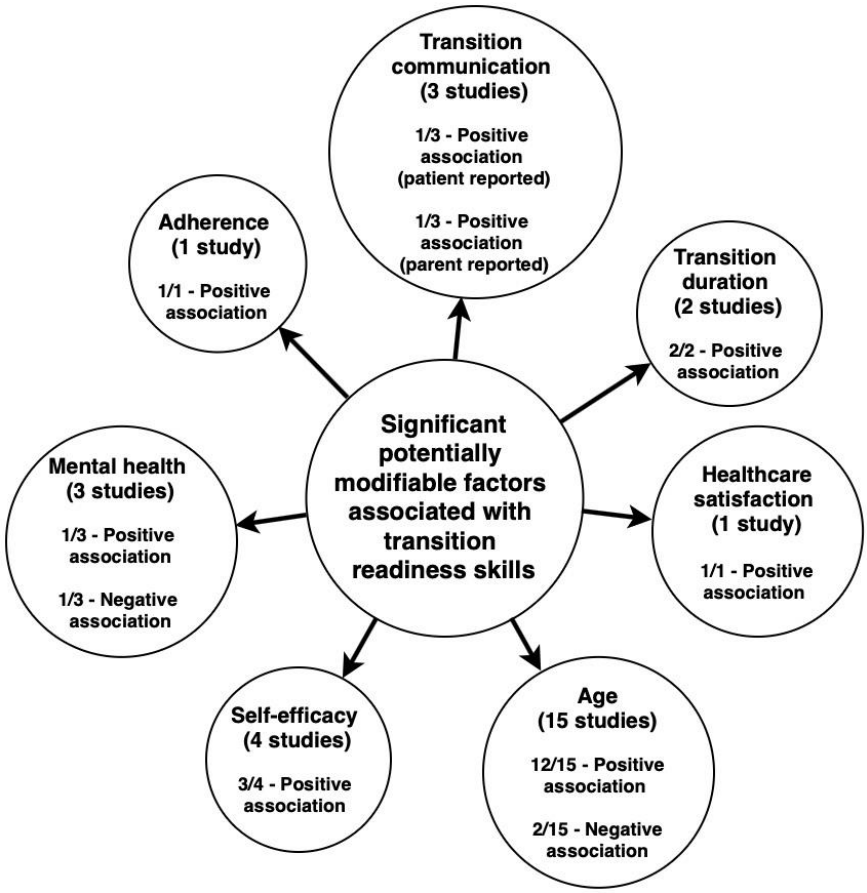

Figure 3.

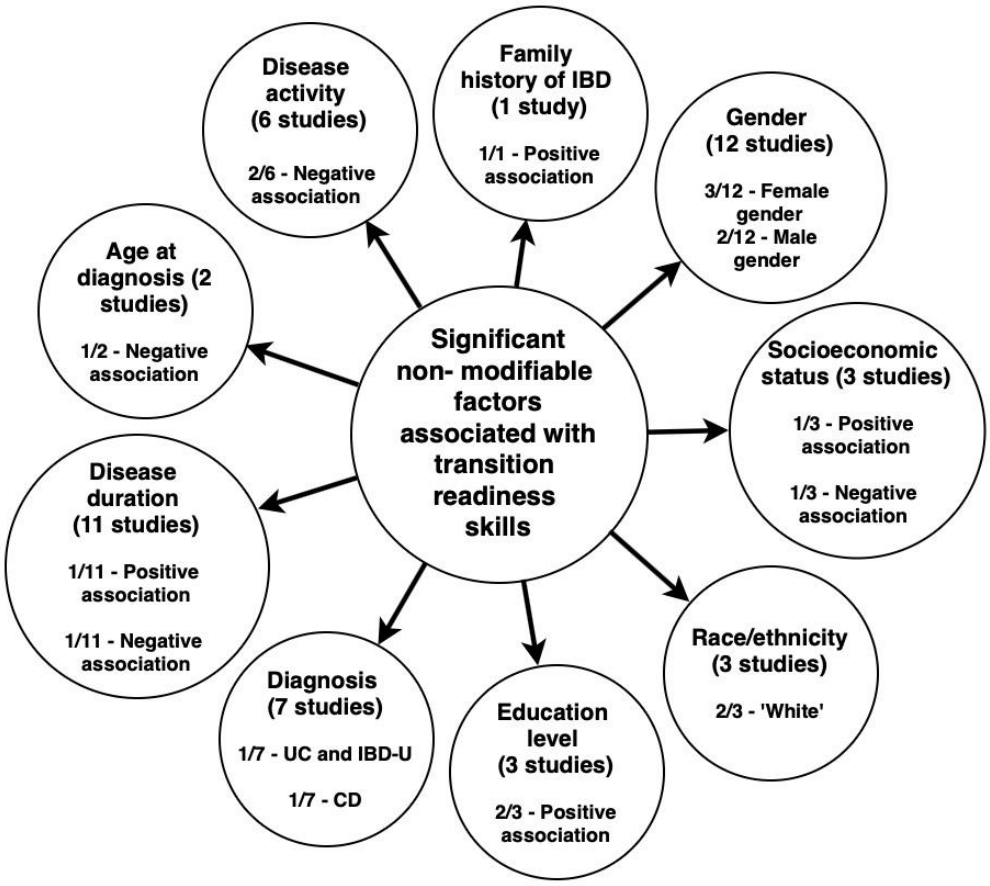

Figure 4.

How to assess the gaps identified:

- **Outcome measurement –**
    1. Assessment of self-management using TRAQ
    2. Assessment of knowledge using a subjective measure for example, asking about personal medical history and using the medical record to evaluate accuracy
    3. Survey examining knowledge of IBD itself
- Use of a validated self-efficacy measure to further examine the effects of self-efficacy on the above outcomes
- Agreeing standardised tools or methods of measuring the influencing factors
- Assessing how transition readiness skills impact transition outcomes. Evaluating skill levels against a standardised set of measurements for example, appointment or medication adherence, loss to follow-up.