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1 **Title page**

2 **Systematic review of factors affecting transition readiness skills in patients with**

3 **inflammatory bowel disease**

4

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3

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8 Vifor Pharma, Shield therapeutics, Abbott and MSD.

9

10 **Conference presentation**

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13 2) Poster presentation Adolescent Health Conference: Working together to bridge the
14 gaps, Royal College of Practitioners: Original date 27/3/2020 [rescheduled due to
15 COVID-19]

16

17 **Authors' contributions**

18 Conception and design of the study: LEJ, MJL, GLJ, RST, AJL

19 Data collection and analysis: LEJ, MJL, LRGT, TTM, RST, GLJ, AJL

20 Preparation of manuscript and critical review: LEJ, MJL, LRGT, TTM, AJB, RST, GLJ, AJL

21

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23 Transition, adolescents, systematic review

24

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3

4 **Data Availability Statement**

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

7

8

9

1 **Abstract**

2 **Background and Aims**

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

7 **Methods**

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

14 **Results**

15 Searches identified 822 papers. Sixteen papers were included. Age was positively associated
16 with skills including disease knowledge and performing self-management behaviours (14
17 studies). Improvement often occurs at 18, however, skill deficiency may still remain.
18 Increased self-efficacy (confidence) was associated with greater disease knowledge and
19 performing self-management behaviours (3 studies). Self-efficacy was positively correlated
20 with transition duration (2 studies) and health-related quality of life ($r=0.57$, $p<0.001$) (1
21 study), negatively correlated with depression ($r=-0.57$, $p<0.001$) and anxiety ($r=-0.23$, $p=0.03$)
22 (1 study), and associated with higher education level (2 studies) and a family history of IBD (1
23 study). Females had higher self-management scores (3 studies), and greater healthcare
24 satisfaction was significantly associated with higher knowledge (1 study). Greater transition

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

3

4 Conclusions

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

8

9

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12

1 Introduction

2 Inflammatory bowel disease (IBD) predominantly describes ulcerative colitis (UC) and Crohn's
3 disease (CD), with a small percentage of patients diagnosed with an unspecified subtype (IBD-
4 unclassified (IBD-U)). IBD is characterised by a remitting and relapsing disease course that can
5 vary significantly between patients^{1,2}. The incidence of IBD diagnosed in childhood is
6 increasing worldwide³. In comparison to those diagnosed as adults, patients presenting with
7 IBD in childhood typically experience a more severe and extensive disease course⁴⁻⁶. This
8 brings additional challenges including the potential for growth failure, pubertal delay⁷, and
9 psychological morbidities, including depression⁷⁻⁹.

10

11 Transition from paediatric to adult healthcare is an essential part of disease management for
12 those diagnosed in childhood. Paediatric services are typically more family-focused, with a
13 higher level of parental involvement. This contrasts with adult services where independence
14 and autonomy are encouraged⁹. The time at which healthcare transition occurs may be an
15 unstable period, with concurrent changes in other areas of life including education and
16 employment¹⁰. Patients transferring to adult IBD care are at risk of loss to follow-up, poor
17 adherence to medication and clinic visits, and other adverse clinical outcomes⁵. The
18 importance of good, structured transition care has therefore been emphasised¹¹.

19

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

1 with adult healthcare. These include performance of the skills required to successfully
2 manage a condition on an everyday basis, termed self-management behaviours^{10,11,13,14};
3 medication and disease knowledge^{11,14}, and health-literacy *'the extent to which individuals*
4 *have the capacity to obtain, process and understand basic health information'*¹⁵. Self-efficacy
5 has also been identified¹¹, defined as a perceived confidence in the ability to perform
6 behaviours required for independent management¹⁶. Surveys of adult gastroenterologists
7 have expressed suboptimal levels of these skills in young people with IBD¹⁷.

8

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

11

12

13

1 **Methods**

2 This review was registered on the PROSPERO database (CRD42019152272), conducted with
3 reference to the Cochrane Handbook¹⁸, and reported in line with Preferred Reporting Items
4 for Systematic Reviews and Meta-Analyses (PRISMA) guidelines¹⁹ using a predefined protocol.
5 A copy of the PRISMA checklist is provided in online supplementary data.

7 **Eligibility criteria**

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

16

17 **Information sources and search strategy**

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

1 for the full published text was undertaken if a conference abstract appeared to be relevant.

2 Duplicates were then removed.

3

4 Study selection

5 Titles and abstracts were screened against the eligibility criteria (LEJ) with secondary review

6 and resolution of queries (TTM). Potentially appropriate texts were read in full to assess

7 suitability for inclusion, with justifications of rejection recorded (LEJ). This process underwent

8 secondary review (TTM).

9

10 Data extraction

11 Data were extracted into pre-designed tables (LEJ) with secondary review (TTM). Extracted

12 data included year of publication, country of origin, study design, primary outcome,

13 secondary outcome(s), sample size with patient details, factors explored for association,

14 strength of association, statistical test used, secondary outcome results, and research setting.

15

16 Quality assessment

17 Study quality was assessed using the Joanna Briggs Institute critical appraisal tools²⁰.

18 Appraisal criteria includes inclusion and exclusion criteria; study subjects and setting;

19 identification of and strategies to address confounding factors; validity and reliability of

20 outcome measurement, and appropriate statistical analysis. Each study was assessed for

21 quality (LEJ) with secondary review (LRGT) and resolution of queries.

22

23 Summary measures

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

3

4 Data synthesis

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

15

16

1 **Results**

2 **Study selection**

3 Initial searches identified 863 papers. After removal of duplicates and secondary searches,
4 822 were screened for inclusion. Twenty-six full texts were retrieved and reviewed against
5 the eligibility criteria. 10 papers were then excluded for the following reasons: factors not
6 assessed (n=3), patients were not part of the transition cohort (n=3), participants assessed
7 did not have IBD (n=1), transition readiness acquisition not assessed (n=1), and the articles
8 were a literature review (n=2). Therefore, sixteen papers were included in the full review. The
9 PRISMA study selection flow chart is shown in Figure 1.

10

11 **Study characteristics**

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

16

17 **Outcomes**

18 The included studies measured a number of different outcomes related to transition skills. A
19 detailed summary of these measures is provided in the online supplementary data. Three
20 papers assessed medication or disease knowledge^{29,30,35} and four evaluated performance of
21 self-management behaviours^{21,23,24,31}. Three studies also assessed self-management in
22 addition to either overall transition readiness²² or knowledge^{25,26}. One study examined
23 knowledge and self-management alongside functional health-literacy, an assessment of
24 comprehension and numeracy level²⁷. Three studies assessed self-efficacy only^{32,33,36} and one

1 paper also examined self-management²⁸. One study evaluated knowledge, self-efficacy, and
2 perception of medical care, which involves how patients' conceptualise their care and
3 relationships with providers³⁴.

4

5 Quality assessment

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

10

11 Factors

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

17

18

1 **Potentially modifiable factors**

2 Provider-related factors

3 ***Transition communication***

4 Three studies examined transition communication^{21,22,30}. *Rosen et al.* found no association
5 between having a conversation about transition with providers and self-management²¹.
6 *Gumidyala et al.*(A) and (B) obtained information from parents and patients regarding the
7 frequency and length of transition discussions. Young people who reported more frequent
8 and longer transition discussions had higher self-management and overall transition
9 readiness scores (communication uniquely explained 4.2% and 25.7% of the variance in self-
10 management and overall readiness scores respectively). Parent reports were also associated
11 with improved overall readiness (8.9%)²². In contrast, improved knowledge was only
12 associated with parent reported communication (4.3% of variance, $p=0.039$)³⁰.

13

14 ***Transition duration***

15 Improved self-efficacy from longer transition duration was demonstrated in two studies^{33,36}.
16 *Yerushalmy-Feler et al.* defined duration from the first referral to a transition clinic to moving
17 services. Significant positive correlations were found between duration and self-efficacy in
18 three out of twelve domains (knowledge of IBD [$r=0.44$, $p=0.02$], medication use [$r=0.57$,
19 $p=0.002$], knowledge of transition [$r=0.56$, $p=0.002$])³³. *Zijlstra et al.* recruited patients still
20 attending a transition clinic and recorded the length of time since the first clinic visit. Duration
21 was positively correlated with three different domains (skills for visits [$r=0.29$, $p=0.04$],
22 behaviour at clinic [$r=0.53$, $p=0.001$], transfer readiness [$r=0.22$, $p=0.02$]). Clinician ($r=0.45$,
23 $p=0.001$) and parent ($r=0.25$, $p=0.03$) scores rating patient independency were also positively

1 correlated with duration, but not adolescent scores ($r=0.23$, $p=0.11$) - though this study did
2 not assess patients when they had completed transition³⁶.

3

4 ***Healthcare satisfaction***

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

7

8 ***Care setting***

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

11

12 Other

13 ***Age***

14 Fifteen studies examined the relationship between age and transition readiness skills. Six of
15 these studies evaluated the association between age and knowledge^{26,27,29,30,34,35}. One paper
16 found no significant relationship ($r=0.103$, $p>0.05$)³⁴ and another reported that in patients
17 aged 14-18, younger participants were more likely to recall having undergone a small bowel
18 X-ray (OR 0.59 [0.35-0.996], $p=0.048$)³⁵. The remaining four studies however demonstrated
19 that older age was associated with increased knowledge^{26,27,29,30}. For every age increase of
20 one year, the odds of correctly naming a current biologic therapy or the adverse effects of
21 medication increased by 38% (OR 1.38, $p<0.001$) and 13% (OR 1.13, $p<0.001$) respectively²⁹.
22 Additionally, participants older than 18 scored significantly higher on measures of IBD
23 knowledge. Comparisons between patients younger and older than 14 also showed
24 significant differences in knowledge of past-medical history ($p=0.01$)²⁷.

1 Seven studies assessed self-management^{21-24,27,28,31}. In one study, no difference in ability to
2 perform self-management behaviours was identified for patients aged 16-18²⁸. In the
3 remaining six papers, older age was significantly associated with improved self-
4 management^{21-24,27,28,31}. Participants older than 18 had significantly higher self-management
5 scores than those younger than 18^{24,27}. Other studies also demonstrated however that
6 comparing participants aged 18 and above with even older patients still produced significant
7 age differences. Participants older than 24 had significantly higher self-management scores
8 in comparison to those aged between 18-20 (median 4.64 IQR 4.3-4.8 vs 3.97 IQR 3.4-4.4,
9 $p<0.0001$)²¹ and in another study, only 7.3% of participants older than 18 met the study's pre-
10 determined benchmark for adequate self-management scores²³.

11

12 Assessing knowledge and self-management together, older age was again significantly
13 associated with higher scores^{25,28}. *Stollon et al.* found that approximately half of the assessed
14 domains were not mastered until the age of 18 or above²⁵. Parent ($p<0.01$) and patient
15 ($p<0.001$) reported overall transition readiness also had significant positive relationships with
16 age²². Evaluating functional health literacy, participants older than 18 again demonstrated
17 higher scores ($p=0.03$)²⁷. Perception of medical care was not correlated with age ($r=-0.150$,
18 $p>0.05$)³⁴.

19

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

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

4

5 ***Self-efficacy***

6 Four papers assessed whether self-efficacy influenced other transition readiness skills^{22-24,30}.
7 No difference was found in self-management scores when asking patients to rate their
8 confidence in their ability to manage their disease²³. The remaining three studies used
9 validated self-efficacy measures. Greater self-efficacy was associated with both increased
10 knowledge (self-efficacy explained 4.3% of score variance, $p=0.039$)³⁰ and self-management,
11 explaining 16% of the variance in self-management scores in one study ($p=0.001$)²⁴ and 3.9%
12 in another ($p<0.05$)²². Self-efficacy was also positively related to parent reported transition
13 readiness (6.7%, $p<0.05$)²².

14

15 ***Autonomy granting***

16 *Gumidyala et al.(A)* assessed parent autonomy granting, the extent to which parents delegate
17 appropriate levels of control and independent behaviour to their child³⁷, and found no
18 association with knowledge³⁰.

19

20 ***Mental health***

21 Three studies examined the effects of mental health^{21,24,32}. Resilience did not predict self-
22 management²⁴. No significant association was found between overall self-management
23 scores and anxiety or depression. Depression however was associated with talking more
24 openly with providers ($r=0.29$, $p=0.04$)²¹. Contrastingly, depression ($r=-0.57$, $p<0.001$) and

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

3

4 **Adherence**

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

9

10 **Non-modifiable factors**

11 Demographic

12 **Gender**

13 Twelve studies examined participant gender^{22-25,27,28,31-33,35,36}. Three studies found that
14 female participants had higher self-management scores^{22,23,31} for example, they were more
15 likely to order refills ($p=0.017$) or prepare questions for appointments ($p=0.009$)³¹. *Zijlstra et*
16 *al.* however found that male participants had higher median self-efficacy scores in three out
17 of twelve domains³⁶. *Benchimol et al.* also found that male participants were more likely to
18 remember the correct date of their last admission (OR 6.82 [95% CI 1.75-26.6], $p<0.01$) and
19 colonoscopy (OR 2.83 [95% CI 1.03-7.80], $p<0.05$)³⁵.

20

21 **Socioeconomic status**

22 *Carlsen et al.* found no association between self-management and any socioeconomic
23 indicators²⁴. In another study however, those from higher socioeconomic groups had greater
24 increases in knowledge and self-management scores over time ($p=0.01$), though there was no

1 difference in baseline scores²⁵. In contrast, *Huang et al.* reported that a higher percentage of
2 participants from a lower socioeconomic group had a health literacy level classified as
3 adequate for transition compared to those from a higher socioeconomic group (25% vs 6%,
4 $p < 0.02$)²⁷.

5

6 ***Race / Ethnicity***

7 *Izaguirre et al.* found no association between race/ethnicity and self-efficacy³². Two other
8 papers grouped participants into 'white' and 'other'. Those classified as 'white' had
9 significantly higher knowledge and self-management scores at baseline ($p = 0.01$), but not over
10 time ($p = 0.09$)²⁵. A higher percentage of 'white' participants also had a health literacy level
11 classified as adequate for transition (18% vs 3%, white vs non-white; percentage ready to
12 transition $p = 0.03$). Higher scores for knowledge and functional health-literacy were also
13 reported, however self-management was not influenced by race/ethnicity²⁷.

14

15 ***Education level***

16 Education level did not influence self-management in one study²¹. Only one self-efficacy
17 domain was significantly higher for those with a higher education level (knowledge of
18 diagnostic tests, 90% vs 81% [high vs. low], $p = 0.009$)³⁶. *Izaguirre et al.* found that those in
19 middle school had lower self-efficacy scores than those in high school ($p = 0.01$) and college
20 ($p = 0.007$), but not in graduate school or the workforce³².

21

22

1 Disease related

2 **Diagnosis**

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

9

10 **Disease duration and age at diagnosis**

11 Eleven studies assessed disease duration^{22-24,26,28-33,35} and two studies found conflicting
12 results^{35,33}. Duration was positively associated with correctly recalling undergoing a small
13 bowel X-ray (OR 1.38 [95% CI 1.06-1.83] p<0.05)³⁵ and negatively associated with
14 improvement in self-efficacy scores for coping with IBD after transition (r=-0.55, p=0.003)³³.
15 *Stollon et al.* found no association between age at diagnosis and either knowledge or self-
16 management²⁵. When *Carlsen et al.* evaluated just participants over the age of 18, older age
17 at diagnosis was associated with lower self-management scores [F(1) 5.50; R²=0.10; p=0.02]²⁴.

18

19 **Disease activity**

20 Six studies examined disease activity^{21-23,33}. *Rosen et al.* also collected information concerning
21 the number of emergency department visits and hospitalisations during a 6-month follow-up
22 period and found no relationship with self-management²¹. An association was found between
23 increased absence from school and lower self-management scores [F(1)4.26; R²=0.31;
24 p=0.001]²⁴. A significant positive correlation was also demonstrated between health-related

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

3

4 ***Family history***

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

6

7 ***Medication type***

8 Medication type did not significantly influence self-efficacy³³.

9

1 Discussion

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

7

8 Self-efficacy has been measured as both an outcome and a contributory factor for transition
9 readiness in this review – reflecting existing literature^{24,36}. Effect sizes were relatively small,
10 however higher levels of self-efficacy did positively influence self-management and
11 knowledge^{22,24,30}. This may be due to assessment of similar measures, or alternatively,
12 confidence may support the development of other skills; belief in one's ability has been
13 associated with successful IBD transition¹¹. Unlike other skills, self-efficacy did not have a
14 strong relationship with age. Interventions that support confidence development may
15 improve transition readiness regardless of age. In adults with Crohn's disease, an
16 individualised behavioural programme which helped patients identify and reach personal
17 goals significantly improved self-efficacy³⁸. A meta-analysis of community-based education
18 programmes for long-term conditions also demonstrated self-efficacy improvements³⁹. The
19 association between transition duration and self-efficacy^{33,36} suggests that transition as a
20 planned, gradual process may assist in building confidence^{40,41}. A positive relationship with
21 family history³² also indicates the potential importance of familiarity with the medical
22 environment or the easy availability of a peer or mentor.

23

1 Older age was consistently associated with improved transition readiness skills, confirming
2 findings from other long-term conditions⁴². Studies with a wider age range were included in
3 this review due to the current uncertainty surrounding the appropriate age for transition.
4 Some insight has been provided to this, with significant improvements in knowledge, self-
5 management, and health literacy seen at the age of 18. However, there remain inadequacies
6 even in those older than 18. This may indicate the need for an older transition age, allowing
7 for transition to occur at a “developmentally appropriate” time⁴³, or for a more prolonged,
8 individualised process. The prefrontal cortex - one of the final areas of the brain to mature in
9 young adulthood - is key for executive functioning. This encompasses the use of certain
10 cognitive skills regarded as necessary for engaging in adult healthcare^{10,11}, including working
11 memory, planning and organisation, problem-solving, and self-control^{10,44}. Young person
12 specific clinics may extend the timeline for which patients are expected to acquire these
13 necessary competencies⁵. Adolescents with long-term conditions also reportedly desire
14 feelings of ‘normality’⁴⁵, which may be provided through regular contact with others
15 undergoing similar experiences at young person specific clinics^{45,46}. Peer programmes in
16 young people with IBD can offer valuable support and facilitate the discussion of issues
17 affecting patients⁴⁷.

18

19 The positive relationship between skill acquisition and transition communication^{22,30} supports
20 literature stating that good, early communication in transition services is important^{41,48}. A
21 study assessing transfer readiness in adolescents with various long-term conditions found
22 that participants who described increased discussion regarding future transfer felt more
23 ready⁴⁹. The slightly conflicting findings regarding the influence of both parent and patient
24 reported transition communication suggests that there may be a process of readiness

1 preparation outside the clinical setting, related to behaviours in the family social unit. The
2 one study assessing healthcare satisfaction found a significant relationship with knowledge³⁰,
3 potentially indicating a further avenue of research or intervention. Satisfaction has been
4 associated with desirable outcomes including appointment adherence⁵⁰ and is reportedly
5 higher when patients feel involved in their healthcare⁵¹. Nevertheless, parent-autonomy
6 granting was not significant in this review. It was however only examined by one study³⁰, and
7 literature has identified parental over-involvement as a transition barrier and encourages
8 patients to attend appointments alone⁵². More robust investigation is therefore necessary to
9 understand the relationship between autonomy and transition readiness skills.

10

11 Female participants demonstrated a tendency for improved self-management^{22,23,31}. Male
12 patients elicited higher scores in some areas^{35,36}, but the effect sizes were small and
13 confidence intervals wide for one study³⁶. This apparent self-management advantage for
14 female patients may be important to consider, however these findings were not consistent,
15 with more papers not reporting any significant effects for gender. Socioeconomic status and
16 race/ethnicity were other identified factors, supported by literature demonstrating both the
17 economic and ethnic disparities regarding transition readiness and other healthcare
18 outcomes⁵³⁻⁵⁵. Within this review however, the included population was predominantly
19 white. Studies also had discrepant findings, with increased readiness levels associated with
20 both higher and lower socioeconomic status.

21

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

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

4

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

16

17 **Conclusions**

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

23

1 **Acknowledgements**

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- 24

1 **Figure legends**

2

3 **Figure 1.**

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

5

6 **Figure 2.**

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

9

10 **Figure 3.**

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

13

14 **Figure 4.**

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

16

17

18

1 **Tables**2 **Table 1.** Summary of included papers with study characteristics including age of patients

3 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 Assessment 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)

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

2

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					✓(+)													

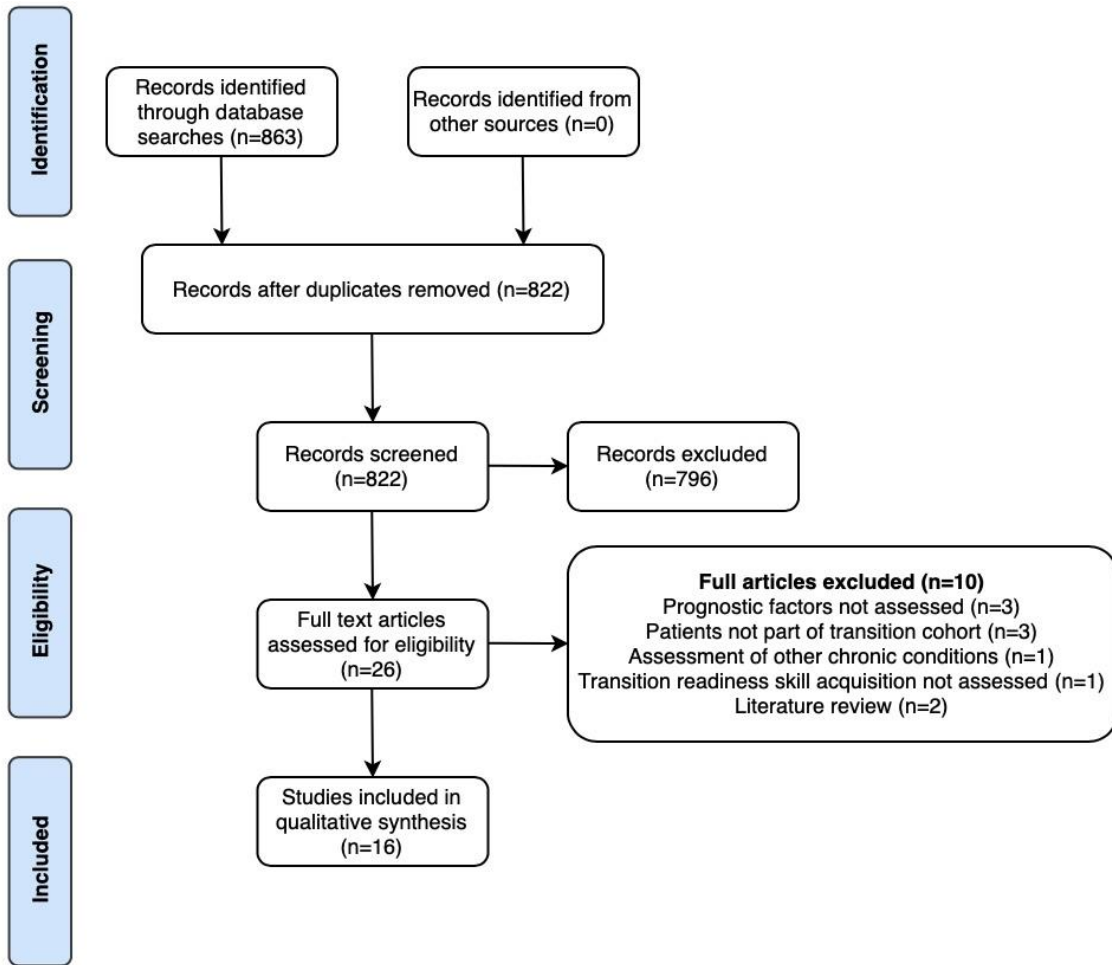
1 *Transition communication **Transition duration +Socioeconomic status **Education level ±Diagnosis εDisease duration δAge at diagnosis θMedication type (+) Positive association found (-)

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

1 **Figures**

2

3 **Figure 1.**



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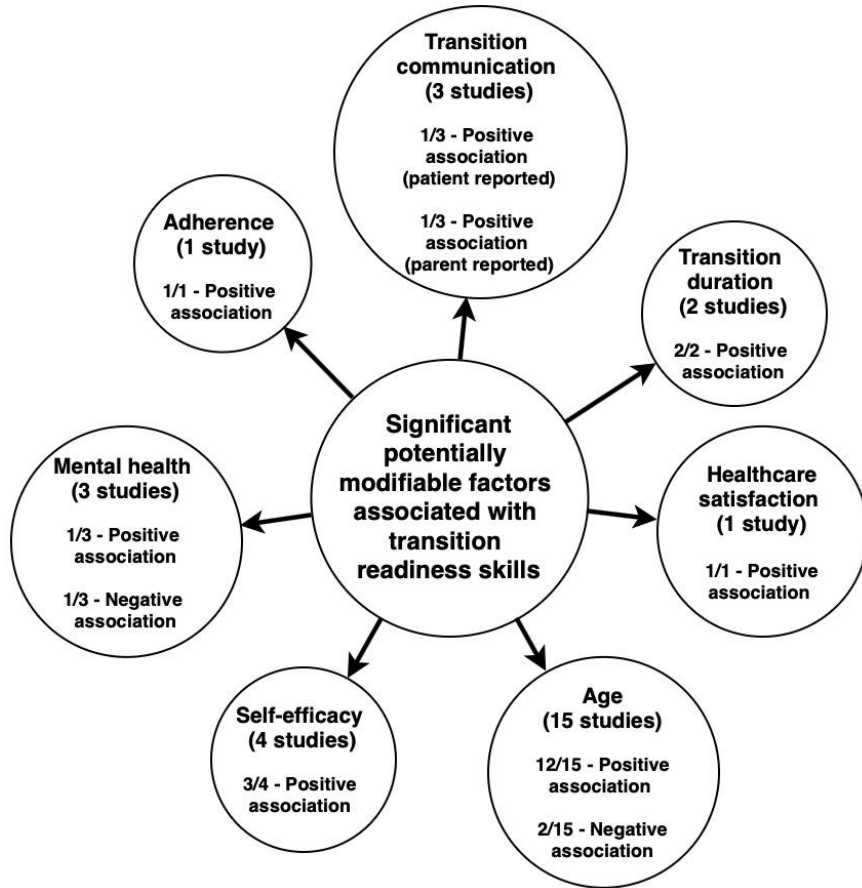
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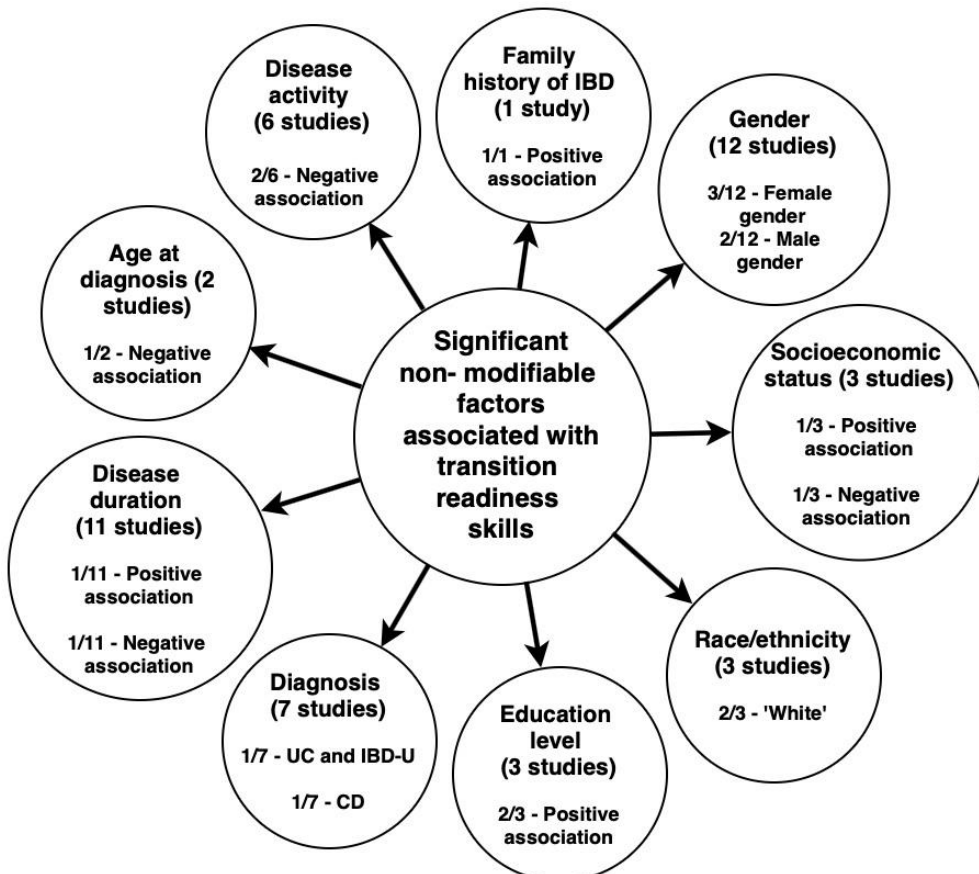
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1 **Figure 2.**



14 **Figure 3.**



24

1 **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.