

# Peer Support in Inflammatory Bowel Disease (IBD): A Systematic Review

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## Research Article

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# Abstract

**Background:** The support provided by people with the same condition, including inflammatory bowel diseases (IBD) has the potential to improve a range of psychosocial outcomes by allowing people with the disease to receive emotional support as well as to learn coping strategies from more experienced peers. The aim of this systematic review was to summarise the evidence on peer support interventions and their effectiveness on people with IBD.

**Methods:** Bibliographic databases, conference proceedings, grey literature, and clinical trial registers were searched from inception to November 2021. Comparative and single-arm studies that evaluated interventions that were solely or contained in part peer support, on people with IBD and/or their carers were included. Effectiveness was evaluated in a range of outcomes relating to physical and psychosocial function, disease control and healthcare utilisation. Data for each of the outcomes were tabulated and presented in narrative synthesis. Study design specific tools were used to assess risk of bias in duplicate.

**Results:** Fourteen completed studies and five ongoing studies met the inclusion criteria. Substantial heterogeneity was observed in the studies in relation to the intervention type. Overall, no significant evidence of beneficial effects of peer support interventions on quality of life and other psychosocial outcomes was found. As all but one of the included studies analysed only the total effect of the interventions, it was not possible to isolate the effect of the peer support components. The appropriateness of outcomes and outcome measurement tools for the assessment of the effects of peer support interventions was a key issue.

**Conclusions:** New randomised controlled trials are needed to evaluate the (net) effects of peer support only. Agreement on the choice of reliable and validated measurement tools and on the outcomes to be targeted by standalone peer support interventions would provide a focus for further intervention design and evaluation.

**Systematic review registration:** The protocol was accepted in the international prospective register of systematic reviews (PROSPERO CRD42020168817).

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## Introduction

Inflammatory Bowel Disease (IBD) is a group of chronic diseases of the gastrointestinal tract, of which Crohn's disease (CD) and ulcerative colitis (UC) are the most common types.<sup>(1)</sup> Genetic and environmental factors (e.g., smoking, stress, diet) as well as immune response play a major role in the pathogenesis of these conditions, although they are not yet fully understood.<sup>(2)</sup>

IBD is prevalent in Europe (ulcerative colitis: 505 per 100,000 in Norway; Crohn's disease: 322 per 100,000 in Germany) and North America (ulcerative colitis: 286 per 100,000 in the USA; Crohn's disease: 319 per

100,000 in Canada), with the incidence rising in newly industrialised countries.<sup>(3)</sup> Early onset IBD in childhood or adolescence has been estimated to occur in approximately 25% of the cases.<sup>(4)</sup> These diseases are characterised by periods of remission with no or very mild symptoms, alternating with relapses or flare-ups which consist of more active symptoms that occur with unpredictable frequency.<sup>(5)</sup>

People with IBD may experience intestinal symptoms such as abdominal pain, frequent bowel movements, and diarrhoea, as well as extraintestinal symptoms including fatigue and arthralgia.<sup>(6)</sup> Complications of IBD include ulceration, perforation or obstruction of the intestine requiring ostomy surgery. Inflammatory conditions such as arthritis and uveitis can also occur.<sup>(7, 8)</sup> These symptoms can lead to repeated absence from work or school,<sup>(9)</sup> cause embarrassment and impact on intimacy and social life.<sup>(10)</sup> This often results in people with IBD experiencing stigma from peers and healthcare professionals and internalising stigma to the detriment of self-care, essential in IBD management.<sup>(11)</sup> Also, people with IBD find it difficult to discuss these challenges with people who do not have direct experience with the disease.<sup>(12)</sup> As a result, these conditions can considerably affect quality of life and psychosocial well-being.<sup>(13)</sup> High rates of anxiety and depression have been found in people with IBD.<sup>(14, 15)</sup> Furthermore, psychological factors have been shown to influence disease activity and are associated with frequency of relapses.<sup>(16, 17)</sup>

Peer support interventions are one potential means to provide support to people with IBD. Peer support in the healthcare context has been defined as the emotional, appraisal, and informational assistance provided by people who have experiential knowledge of a specific condition and similar characteristics to the target population, to complement professional health services by sharing personal experiences in relation to a health-related issue.<sup>(18)</sup>

Peer support can be offered through multiple modes of delivery (e.g. one-to-one, groups, face-to-face, Internet, and telephone) and within diverse settings (e.g. home, hospital, community organization).<sup>(19, 20)</sup> These interventions have the potential to empower people with a chronic condition by learning coping strategies and acquiring self-management skills, enhancing well-being and self-esteem.<sup>(19)</sup> Peer support interventions have been implemented and evaluated in a range of chronic conditions, with evidence suggesting that they have the potential to impact a range of self-management, disease control, and psychosocial outcomes. For example, peer support has been shown to have a favourable effect in improving glycaemic control in patients with type 2 diabetes.<sup>(21)</sup> In addition, people with depression participating in peer support programmes reported greater reduction in mean depression scores when compared to usual care.<sup>(22)</sup>

A scoping search was undertaken in October 2019 in Epistemonikos and EMBASE, using free and index terms, where possible, relating to peer support and IBD. The search identified no systematic reviews evaluating peer support interventions for people with IBD. In the absence of such a review, the composition and effectiveness of IBD peer support interventions and the outcomes that might be targeted by these interventions remain unclear.

Therefore, this systematic review aims to summarise and critically analyse the evidence relating to the following questions:

- What peer support interventions have been researched in people with IBD; what are the characteristics of peers and people with IBD?
- What is the effectiveness of peer support interventions in people with IBD?

## Methods

This systematic review has been reported according to the Preferred Reporting Items of Systematic Reviews and Meta-Analysis (PRISMA) guidelines (see Supplementary Table 1 for the PRISMA checklist).<sup>(23)</sup> The protocol was accepted in the international prospective register of systematic reviews (PROSPERO CRD42020168817).<sup>(24)</sup>

### SEARCH STRATEGY

The following databases were searched:

- Bibliographic databases: MEDLINE, EMBASE, Cochrane CENTRAL, CINAHL, PsycINFO;
- Conference proceedings: Conference Proceedings Citation Index (via Web of Science);
- Dissertation and theses: ProQuest;
- Grey literature: Open grey.

The databases were searched from inception to December 2019, and updated on 12 November 2021 using index and free terms for IBD (as well as its different subtypes) and peer support. A detailed search strategy was developed for MEDLINE and adapted for each database (Supplementary Table 2). No language restrictions were applied. Trial registries (ClinicalTrials.gov, WHO International Clinical Trial Registry Platform (ICTRP) and International Standard Randomised Controlled Trial Number (ISRCTN) registry) were searched for ongoing trials. Reference lists of included studies and relevant reviews identified at the screening stage were checked to identify further eligible studies.

### SELECTION CRITERIA AND STUDY SELECTION

Study selection criteria were:

#### *Population*

People of any age in any setting diagnosed with IBD as well as carers of people with IBD. Studies on a broader population (e.g., including people with other chronic conditions) were included but considered for analysis only if data specific for the population with IBD were presented as a subgroup or could be extracted.

#### *Intervention*

Peers were defined as someone with experiential knowledge of IBD, as a person with the condition or as a carer of a person with the condition, that provides support in any setting, through any mode of delivery (e.g. group, one to one, face to face, web-based, computer-based, via telephone etc.) to people with IBD or carers of people with IBD.

Peer support could constitute the totality of the intervention or could be one component of a multi-component intervention. In the latter case, studies were included when the peer support was one of the hypothesised intents of the intervention. Conversely, studies in which support from peers occurred in an incidental manner (e.g. peer and people with IBD having the opportunity to chat in the context of a programme aimed at providing professional support) were excluded.

### *Comparator*

Any intervention including different types of peer support, or no intervention (e.g., wait-list group).

### *Outcomes*

Outcomes relating to:

- Disease control (e.g. disease activity and remission, overall survival, occurrence of complications, change in bowel symptoms, pain or discomfort);
- Physical and psychosocial function, and quality of life (e.g., Health-related quality of life, energy and fatigue, self-esteem, well-being, social functioning, anxiety, depression);
- Healthcare utilisation outcomes (e.g., Time spent in hospital, medication use).

### *Study design*

Comparative studies (i.e., randomised controlled trials – RCTs – controlled trials and observational studies) and single-arm studies were included. With regard to the single-arm studies, only before-and-after studies and interrupted time series were considered for the analysis and only those addressing types of intervention, people with IBD, length of follow-up or measuring outcomes not covered by the comparative studies. Both comparative and single-arm studies were assessed for the characteristics of the interventions, peers and people with IBD.

All titles and abstracts were screened for relevance. Articles relevant to the review questions were obtained and assessed for inclusion against the full set of selection criteria. Reasons for exclusion of articles at this stage were documented. Study selection was independently undertaken by two reviewers (AA and CM or DT or JM) with any disagreements being resolved through discussion or, if necessary, referral to a third reviewer (DM).

## **DATA EXTRACTION**

Data extraction was carried out by one reviewer (AA), using a piloted data extraction form, while a second reviewer (CM or DT or JM) checked the data extracted for accuracy and completeness. Disagreements were resolved through discussion or, if necessary, referral to a third reviewer (DM). Extracted data included:

- Study characteristics: study design, aim and setting, inclusion and exclusion criteria;
- Study participants: number of participants, age, gender, type of IBD, disease severity and activity, disease duration;
- Intervention and comparator details: details of the peers, details of the support intervention, mode of delivery, frequency.
- Outcomes: outcome measurement tool, tool scale, outcome data for each group, effect size and measure of uncertainty. If any crossover trials were identified, results from phase I only were extracted and used in the analysis.

Attempts were made to contact trial authors to request missing data.

## **RISK OF BIAS ASSESSMENT**

Study design specific quality assessment tools were used:

- Controlled trials: Cochrane Collaboration's Risk of Bias tool.<sup>(25)</sup> The quality domains relating to randomisation and allocation concealment were not considered for non-randomised trials.
- Observational studies: Newcastle-Ottawa quality assessment form.<sup>(26)</sup>
- Before-and-after studies: National Heart, Lung and Blood Institute (NIH) Study Quality Assessment Tools.<sup>(27)</sup>
- Interrupted time series: Cochrane Effective Practice and Organisation of Care (EPOC) quality checklist.<sup>(28)</sup>

Quality assessment was independently undertaken by two reviewers (AA and CM or DT or JM) with any disagreements being resolved through discussion or, if necessary, referral to a third reviewer (DM).

## **ANALYSIS**

Included studies were grouped by study design, population, intervention (type of peer support and mode of delivery), comparator and outcome. Details on the population, intervention and any model underpinning the intervention were narratively reported. Data for each of the outcomes were tabulated and presented in narrative synthesis.

In the case of continuous outcomes, the mean difference between study groups (accounting for baseline scores) and the mean difference between before and after-study values, along with 95% CI, are reported in the review for comparative and single-arm studies, respectively. If not reported in the articles and where possible, the between-group difference of the mean score changes from baseline was calculated. In case

of insufficient data, p-values relating to the treatment effect are presented in the review, as reported in the articles.

If relevant dichotomous outcomes were encountered, risk ratio, odds ratio or rate ratio, depending on data availability, are reported in the review along with 95% CI.

Where possible, evidence was assessed in relation to short, intermediate and long-term effects of the interventions. Data were categorised into the following follow-up period groups:  $\leq 3$  months,  $>3$  months and  $\leq 1$  year, and  $>1$  year.

## Results

The search strategy identified 5,013 records. After removing duplicates, 3,580 titles and abstracts were screened for relevance and 3,502 records were subsequently excluded. 75 articles underwent full-text selection (full-text was not available for further 3 articles). 53 records were excluded for the reasons indicated in Supplementary Table 3; four conference abstracts were excluded as it was not possible to determine whether the intervention included a peer support component.

After updating the search, a further 1,117 records were identified. After removing 299 duplicates, 1 additional completed study was identified.<sup>(29)</sup> Twenty-two articles were included in the review, corresponding to 18 unique studies. These comprised 13 completed studies (eleven full-text articles and two conference abstracts) and five ongoing studies, described in either trial registers or conference abstracts. The PRISMA flowchart of the study selection process is shown in Figure 1.

**\*\*\*INSERT FIGURE 1 HERE\*\*\***

### STUDY CHARACTERISTICS

Of the completed studies, five RCTs,<sup>(30-33)</sup> two controlled studies without randomisation,<sup>(34, 35)</sup> and seven single-arm studies were included,<sup>(36-42)</sup> and these enrolled a total of 2,077 participants.

The interventions were delivered in IBD centres as either outpatient or inpatient service (n= 8),<sup>(29-34, 36, 42)</sup> in a local community centre (n= 1),<sup>(39)</sup> in summer residential camps (n= 3) (37, 38, 41), within University settings (n= 1) (35) or the specific setting was not specified (n= 1).<sup>(40)</sup> All were based in high-income (European countries, USA, New Zealand) or upper middle-income countries (Brazil, Chile, and China). Interventions lasted between one week and 19 months. The study characteristics are described in Table 1.

**\*\*\*INSERT TABLE 1 HERE\*\*\***

*1) What peer support interventions have been researched in people with inflammatory bowel disease (IBD); what are the characteristics of the interventions, peers and people with IBD?*

### POPULATION CHARACTERISTICS

Seven studies were conducted on adults,<sup>(29-33, 35, 36)</sup> with mean age ranging from 36.3 to 43.9 years (range 18-71) (mean not specified or provided as median in two studies). One study did not report aggregated population characteristic data.<sup>(29)</sup> Five studies were intended for a younger population (age range 9-18 years and mean range 14.5-15.33 years – mean not specified or provided as median in three studies).<sup>(37-41)</sup> With the exception of two studies, a higher percentage of females participated in the studies (range 46%-82%) compared to males, and only adolescent girls were recruited in one study.<sup>(39)</sup> Two studies did not report information on age or gender.<sup>(34, 42)</sup>

In most of the studies, the percentage of participants with a diagnosis of Crohn's disease was greater than 50% (range 54.7%- 92%), with the exception of two studies.<sup>(29, 36)</sup> One study comprised participants with Inflammatory bowel disease arthritis (IBDA).<sup>(29)</sup> The remainder of the participants had ulcerative colitis and, in four studies, IBD type was unclassified for a small proportion of participants (2.1%- 5%).<sup>(31, 36, 38, 42)</sup> Information on type of IBD was not available in two studies.<sup>(34, 35)</sup> All participants were in remission, not experiencing active flares or only having mild disease activity in six studies.<sup>(30-32, 34, 36, 41)</sup> The definition of disease activity and severity was based on different indexes such as the Harvey-Bradshaw index (HBI) and Mayo score for Crohn's disease and ulcerative colitis participants respectively, and the German Inflammatory Bowel Disease Activity Index (GIBDI). In one study, participants were inpatients but their disease status was not specified.<sup>(42)</sup> The remainder of the studies did not provide information regarding disease activity or severity.

## **INTERVENTION CHARACTERISTICS**

### *Group-based interventions*

Thirteen studies described group peer support that was mutually provided by participants, during the course of *ad hoc* face-to-face discussion and Q&A sessions, an online mutual assistance group, or as a result of spontaneous interactions, according to their experience with specific aspects of the condition (no training was received by the peers). In twelve of these studies, peer support was only one component of multi-component interventions delivered by healthcare professionals (i.e. gastroenterologists and/or dietitians and/or nurses and/or psychologists) that were meant to provide professional support or guide the group through the peer support sessions with minimal involvement in the discussions. One of these studies compared peer support with education, peer support and education combined, and treatment as usual.<sup>(29)</sup> In two studies, the programmes were co-led by peers who had personal experience with the disease.<sup>(34, 41)</sup>

These group-based interventions aimed at giving participants the opportunity to express their emotions and share their feelings with peers using an interactive approach.<sup>(32, 35, 40)</sup> Participants were encouraged to share their experiential knowledge of IBD with other participants focusing on coping strategies and self-management skills.<sup>(29-31, 33, 35, 36, 39)</sup> In Zhang 2020, the online peer support group was supported by doctors, nurses, psychotherapists, and nutritionists, who gathered and answered

patients' questions twice a week.<sup>(29)</sup> In Berding 2017 and Reusch 2016, the interventions included 'psychological' modules that differed from 'medical' modules that were also provided.<sup>(30, 31)</sup> The 'psychological' modules took a patient-centred approach that enabled participants to engage in various tasks and discussions where the newly diagnosed could learn from the more experienced (e.g., coping with anxiety, self-confident communicative behaviour in common difficult social situations). Peer support offered in specifically designed adaptation courses contributed to the overall aim of encouraging a healthy lifestyle through group activities and social programmes.<sup>(36)</sup>

In nine studies, the intervention programme also comprised an educational component with information about the clinical aspects of the illness, its epidemiology, pathogenesis and therapy being offered by professionals in the form of a lecture.<sup>(29-33, 35, 36, 39, 40)</sup>

In McDonnell 2014, the programme focused on the concept of self-management through weekly action planning and feedback. Using cognitive strategies, it aimed to improve self-management in an empathic environment using peer facilitators with IBD.<sup>(34)</sup>

In three out of the five studies intended for children and adolescents, peer support was provided in the context of summer camps, where participants engaged in various fun group activities (e.g. sport, dance, cooking, adventure-based activities) without any formal educational or psychotherapeutic sessions.<sup>(37, 38, 41)</sup> Informal conversation and spontaneous interaction among children were expected to occur, and were believed to help children to exchange personal experiences with IBD and in doing so learn coping strategies and improve self-esteem. One of these camps was also followed by the creation of a Facebook group where camp participants could continue the social interaction within the group. Investigators facilitated the online interaction by posting IBD-related questions.

### *One-to-one peer support*

One study described a volunteer peer specialist programme incorporated into an inpatient service.<sup>(42)</sup> Peers were trained volunteers, individually matched to patients based on age, gender and disease experience. Peers offered one-to-one emotional support to patients and their family in their hospital room by sharing their experiences, addressing patients' concerns, and providing tailored educational materials. Unlike the group-based studies, this intervention did not include any other 'non-peer support' components.

### **COMPARATOR CHARACTERISTICS**

In five out of seven controlled studies, the comparator group did not engage in any alternative activities or received the same intervention later during the course of the study.<sup>(30, 32-35)</sup> In Reusch 2016, instead, the comparator included medical sessions that were identical to those of the intervention.<sup>(31)</sup> However, the psychological modules were delivered in a lecture-based format as opposed to the more interactive sessions delivered in the intervention group. In Zhang 2020, peer support was compared with education,

peer support and education combined, and treatment as usual.<sup>(29)</sup> Details on the population, interventions and comparators can be found in Table 1.

2) *What is the effectiveness of peer support interventions in people with inflammatory bowel disease?*

## **RISK OF BIAS ASSESSMENT**

Substantial heterogeneity relating to type of intervention, comparators and outcome measurement tools was noted in the included studies and precluded the possibility of undertaking meta-analysis. Risk of bias assessment is detailed in the Supplementary Table 4.

The main limitation of included studies was the lack of blinding of participants, especially considering the use of patient-reported outcomes, although this may be due to the difficulty of designing a sham peer support intervention. In seven studies (3 controlled and 4 single-arm), another common quality concern was data completeness with a high proportion of study participants not completing questionnaires (up to 88.6%.<sup>(30, 33, 34, 36, 37, 41, 42)</sup> Whilst in one study no differences in participants characteristics were observed between participants completing the study and those whose outcome data were not available,<sup>(30)</sup> in the remainder of the studies no reasons for dropout were provided and risk of attrition bias cannot be excluded.

With regard to the controlled studies, two studies used appropriate methods of allocation concealment,<sup>(30, 31)</sup> although details on the randomisation sequence method were not given in one study.<sup>(31)</sup> Two studies did not describe the randomisation method.<sup>(32, 33)</sup> No randomisation occurred in one study which used convenience samples.<sup>(34)</sup> In another study, participants in the two groups did not seem to be recruited from the same source population.<sup>(35)</sup>

Overall, the representativeness of the study participants can be questioned, as people who are more health conscious and/or in need for support may be more likely to participate in this kind of intervention.

## **EFFECTIVENESS OF PEER SUPPORT INTERVENTIONS**

A narrative synthesis is presented below and results are also shown in Supplementary Tables 5-11. Meta-analysis was not feasible for any of the outcomes considered, owing to heterogeneity in type of intervention, comparators, measurement tools and data availability.

### *Health-related quality of life*

Eleven studies measured the effects of peer support interventions on health-related quality of life (HRQoL).<sup>(30-39, 41)</sup> Eight of these studies used disease-specific quality of life measurement tools such as IMPACT II or III (n=4), Inflammatory Bowel Disease Questionnaire (IBDQ) (n=2) and Short Inflammatory Bowel Disease Questionnaire (SIBDQ) (n=2). Generic questionnaires evaluating HRQoL were chosen in five studies, namely SF-36 (n=2), the short form SF-12 (n=2) and 15-D (n=1).

## Randomised Controlled Trials (RCTs)

In the four RCTs,<sup>(30-33)</sup> the mean difference between study groups accounting for baseline imbalances was not reported, nor could it be calculated due to lack of available data.

An increase in HRQoL was observed at 3 months and 6 months, with a slight decrease at 12 months both in the intervention group and control groups but the difference between the groups was not statistically significant.

## Non-randomised controlled studies

Neither of the two non-randomised studies reported the mean difference between study groups (nor could it be calculated due to lack of available data),<sup>(34, 35)</sup> In Krause 2003, the authors found statistically significant difference between the study groups at the end of the intervention (1 year) for the intestinal domain of the SIBDQ questionnaire (p=0.030)<sup>(35)</sup>. However, the baseline data were not provided to judge any imbalances at baseline that could contribute to results.

## Before-and-after studies

In the adaptation courses, improvements from baseline in HRQoL were seen at the end and after the intervention (6 and 12 months). The changes from baseline exceeded the minimal clinically important difference (i.e. 0.015 with questionnaire scale being 0-1) at all time points (end of course, 6 and 12 months) (data provided by the author).<sup>(36)</sup>

Benefits to quality of life were also observed at the end of the summer camp weeks (mean change from baseline 8.09 [95%CI 3.24, 12.93] and 5.7 [95%CI 0.52, 10.88] (Supplementary Table 6) but not at 2 months after participation to the Facebook group.<sup>(37, 38)</sup>

Mean change from baseline could not be calculated for the remainder of the before-and-after studies.

## *Anxiety and depression*

Seven studies explored the effects of peer support interventions on anxiety and depression.<sup>(29-31, 34, 36, 37, 40)</sup> Various self-report questionnaires were used to carry out the evaluation, such as the Patient Health Questionnaire-4 (PHQ-4) (n=2), STAI (State-Trait Anxiety Questionnaire) (n=2), Beck's Depression Inventory (BDI) (n=1) and Hospital Anxiety and Depression scale (HADS) (n=2).

## Randomised Controlled Trials (RCTs)

For the first two RCTs, results from ANCOVA analyses could not be obtained. The differences at follow-up in both anxiety and depression scores between the groups were very small and not statistically significant.<sup>(30, 31)</sup> In Zhang (2020), Kruskal–Wallis H-test was used to compare treatment groups (peer support, health education, peer support and health education combined, and routine treatment).<sup>(29)</sup>

Depression scores of patients receiving combined education and peer support were significantly lower than the other three groups  $fF/\chi^2 = 19.92$  ( $p < 0.0001$ ). Depression scores for peer support and health education groups separately were significantly lower compared to routine treatment, though no significant difference was detected between health education and peer support groups.

### Before-and-after studies

A statistically significant decrease in depression score was shown after the end of the adaptation courses (-2.85 [95%CI -2.18, -3.53]) and it was maintained at 6 and 12 months (-2.76 [95%CI -1.58, -3.95] and -2.12 [95%CI -1.03, -3.21], respectively – data provided by author).<sup>(36)</sup> The initial BDI score was 11.8, which is only 1.8 higher than a score indicating no mood disturbances, suggesting a population with lower severity of depression participating in the study.

It was not possible to get full results from the other three studies (one non-randomised controlled study and two before-and-after studies). Descriptive results are provided in Supplementary Table 8.

### *Other outcomes*

*Disease activity and severity.* One RCT measured disease activity and severity using the German Inflammatory Bowel Disease Activity Index (GIBDI) for both patients with Crohn's disease and ulcerative colitis.<sup>(30)</sup> This study found no evidence of difference between the study groups (mean differences were not reported, nor could they be calculated).

Haapamäki 2018 used specific measures for each of the conditions (Mayo score and Harvey-Bradshaw index – HBI).<sup>(36)</sup> At baseline both participants with ulcerative colitis and Crohn's disease had mild disease but were not in remission. A decrease in disease severity was observed at 6 and 12 months for ulcerative colitis participants (1.52 [95%CI 1.06, 1.98] and 1.12 [95%CI 0.56, 1.68]) but not for those with Crohn's disease (0.30 [95%CI -1.25, 1.86] and 0.55 [95%CI -1.51, 2.61]). Also, in the former group the Mayo score decreased to values indicative of remission.<sup>(36)</sup>

No additional outcomes related to disease control (e.g., complications, change in bowel symptoms, pain or discomfort) have been measured in any of the included studies. However, a reduction in the use of healthcare services such as visits to health professionals and investigations was seen in Haapamäki 2018 (Supplementary Table 11).

*Psychosocial function.* Berding 2017 reported an improvement in the outcomes assessed (IBD concerns, fear of progression, coping with anxiety, coping with the disease) in the intervention group compared to the waitlist group at 2 weeks and 3 months.<sup>(30)</sup> In particular, better scores at follow-up were achieved in all dimensions of coping including handling of emotions and development of strategies. However, the improvements appeared to be small and their clinical relevance remains unclear<sup>(30)</sup>. No statistically significant between-group differences were shown in Reusch 2016 for these outcomes (31). In Oxelmark

2007, no significant differences in sense of coherence between the intervention and control groups were obtained at 6 and 12 months.<sup>(32)</sup>

*Social connectedness and social support.* In one before-and-after study, participants at the summer camp were surveyed regarding social connectedness and social support. The study showed no significant improvement in these outcomes but greater satisfaction with the support received was noted 2 months after children joined the Facebook group (Supplementary Table 11).<sup>(38)</sup>

*Knowledge of disease.* Two RCTs evaluated participants' knowledge about coping strategies and medical aspects of the condition as well as impact of such knowledge on their attitudes.<sup>(30,31)</sup> Even though an effect in time was observed in the groups receiving peer support, the between-group difference was very small and in Reusch 2016, not statistically significant.<sup>(30,31)</sup>

A significant increase in knowledge was shown 1 month after a children camp, using a questionnaire specifically addressing children with IBD (IBD-KID), and at the end of the adaptation courses.<sup>(36,41)</sup> The effect on participants' disease knowledge was also confirmed after the end of the intervention at 6 and 12 months.

*Stress during hospitalisation.* Stress during hospitalisation was one of the two outcomes reported by Hashash 2016 and was measured through a survey among the hospitalised people who received peer support (IBD connect programme).<sup>(42)</sup> The questions were not validated. Stress decreased on average from 56% to 18% among the 77 patients that responded to the survey.<sup>(42)</sup>

*Sleep.* One RCT measured sleep efficiency (the ratio of total sleep time to bedtime) at the end of the intervention (4-6 weeks).<sup>(29)</sup> Quality of sleep was significantly greater for peer support and narrative education combined compared to peer support and narrative education alone, and routine treatment. Only narrative education and narrative education and peer support combined were significantly improved between the beginning and end of intervention.

*Arthralgia.* One RCT measured arthralgia at the end of the intervention (4-6 weeks).<sup>(29)</sup> Pain was significantly lower for peer support and narrative education combined compared to peer support and narrative education alone, and routine treatment. There were no significant differences between all other conditions, though pain was significantly reduced between the beginning and end of the interventions.

*Irritable Bowel Syndrome.* One RCT measured the presence or absence of Inflammatory Bowel Syndrome (IBS) via medical record review at the end of the intervention (4-6 weeks).<sup>(29)</sup> IBS was indicated in significantly fewer participants receiving peer support and narrative education combined after 6 weeks, with no significant differences noted between all other interventions nor between the beginning and end of all other interventions.

## Discussion

This systematic review found no significant and sustained evidence of beneficial effects of interventions that include peer support components for IBD on HRQoL, anxiety, depression and other outcomes related to psychosocial function. Even when a small between-group difference was observed, the possibility that knowledge of group allocation might have inadvertently affected participants' responses in the questionnaires, particularly in the case of waitlist control groups, resulting in an overestimation of the interventions' effects, cannot be ruled out. Some of the single-arm studies seemed to suggest a beneficial effect on a limited set of outcomes. However, due to the nature of the study design, a regression to the mean cannot be excluded. Uncertainties also arise over the sustained impact of children's camps on quality of life, whose effects were only observed immediately after the end of the programme.

The recruitment of a relatively healthy IBD population could explain some of the results (i.e., ceiling effect). In Berding 2017, the HRQoL baseline score is close to that of the general population in Germany (the country where the study was conducted) for both physical and mental domains.<sup>(43)</sup> In Oxelmark 2007, the mean IBDQ score of participants at baseline was marginally outside of clinical remission. Despite the study eligibility criteria being inclusive, skewed recruitment of individuals in remission who are also committed to enhancing their self-management skills and well-being, might have occurred.<sup>(32)</sup> As for the before-and-after studies, improvements in quality of life and depression were shown after the intervention in Haapamäki 2018 where participants had, instead, mild disease. In this case, such improvements were accompanied by a decrease in disease severity in people with ulcerative colitis only.<sup>(36)</sup>

It should be noted that, as the included studies on the whole analysed the total effect of multi-component interventions, it was not possible to isolate the effect of the peer support components. Of the multi-component interventions, Reusch compared the addition of a peer support element to the intervention group, but without demonstrating the effectiveness of this.<sup>(31)</sup>

Indeed, possibly one of the key observations from our review is that to date there have been few attempts to evaluate the effectiveness of standalone peer support interventions. One exception in this review is the IBD CONNECT programme,<sup>(42)</sup> targeted at inpatients in an attempt to reduce the stress related to hospitalisation. However, Hashash 2016 utilised a bespoke study-specific outcome measure potentially lacking wider applicability and validation. Also, Zhang 2020 compared peer support, narrative education, and peer support and narrative education combined, though the peer support group also received 2 initial 5-minute appointments and were prescribed mesalamine (2.0g/d).<sup>(29)</sup>

The issue of outcome selection and the appropriateness of outcomes for the assessment of the effects of peer support interventions is also a key issue. Our review demonstrates that a broad range of outcomes and measurement tools have been included in studies to date, with little consistency across studies. Categories of outcomes included HRQoL, anxiety and depression, psychosocial function, disease severity and knowledge, and standalone outcomes such as stress during hospitalisation. Perhaps a key area for further reflection is the core target outcomes for peer support interventions and how these should be assessed, as well as the mechanisms by which peer support interventions might realise their effect. As

peer support approaches might be theorised to act upon and via psychosocial function and processes, it could be argued that these should be the key foci for assessment, with other categories of outcome (e.g. HRQoL, knowledge, disease severity and clinical measures) as secondary outcomes.

### *Strengths and limitations of the included studies*

The included studies showed substantial heterogeneity in relation to the intervention type. Peer support was only one of the components of various multi-component interventions that also aimed at providing professional support and medical knowledge and that differed in settings, frequency and mode of delivery. The extent to which the interaction among peers contributed to the observed results remained unclear.

The ongoing studies (Table 2) demonstrate a substantial change in mode of peer support provision, with 1:1 mentor-mentee relationships being increasingly used instead of group-based interventions, and remote support via telephone, email or videocall being preferred to face-to-face contact in most cases. In addition, the interventions being evaluated within ongoing studies are predominantly standalone peer support interventions focused on psychosocial support, as opposed to multi-component education and self-management interventions with a peer support component. Four of the ongoing studies are due to be completed between May 2020 and February 2024 when an update to this systematic review may be warranted.

A wide range of outcome measurement tools have been used, which are likely to differ in reliability and sensitivity to change. In addition, poor reporting has been a recurring issue. Relevant information was often missing with respect to the weight attributed to peer support as compared to other elements of the interventions. This led to the exclusion of a number of studies where uncertainties remained. For example, Larsson 2003<sup>(44)</sup> evaluated an education programme led by professionals covering general medical information about IBD, treatment options, diet and how to adapt and cope with this chronic condition, allowing time for group discussion. As part of the participants' evaluation of the programme, meeting other individuals with IBD and exchanging experiences were particularly valued. However, whether the 'peerness' of this programme was intentional could not be clarified.

Furthermore, the minimal clinically important difference was rarely reported by authors. Between-group difference (or within-group difference for non-comparative studies) as well as outcome data for each of the groups were often not provided, which resulted in inability to adequately interpret the findings.

### *Strengths and limitations of the review*

The main strength of this review was the comprehensive and updated search, which was based on multiple index and free terms relating to the condition and interventions, with no temporal or language restriction. Attempts to overcome publication bias were made by searching conference abstracts, grey literature and trial registries. Hand-searching proved essential in ensuring that no relevant studies were missed: the intervention evaluated in Krause 2003, whose record had otherwise been excluded at the

screening stage (based on the information reported in the abstract), was detailed in a review identified through checking references of included studies, which led to the final inclusion of the study. Moreover, the eligibility criteria were broad enough to allow inclusion of studies in which peer support did not constitute the sole or main component of the intervention, as these could be valuable in showing additional ways of delivering this form of support.

However, there are also some limitations. Efforts were made to contact authors for clarity on data. For one conference abstract it was not possible to obtain further information.<sup>(40)</sup> For another conference abstract, the full-text study was published in February 2020 (i.e., after the review's cut-off date) while missing data had been requested from the study's author.<sup>(41)</sup> In addition, due to the heterogeneity observed in both intervention and outcomes, meta-analysis was not feasible. With regard to the single-arm studies, the results provided in the review were based on the mean change from baseline, which could also be explained by the regression to the mean, especially considering that long-term effects were not assessed in most cases. Comparative studies evaluating the same interventions could provide more reliable estimates of effect.

### *Recommendation for future research*

There is need for new RCTs that evaluates the (net) effects of peer support only. Moreover, effects on psychosocial function and processes should be the focus of future evaluation, whilst supported by data on quality of life and disease severity/activity.

Consistencies in the choice of reliable and validated measurement tools is key when planning future studies. Effort should also be made to improve study reporting, in particular for treatment effect, statistical analysis and outcome measures. However, limitations in the assessment of patient-reported outcomes due to lack of participants' blinding are anticipated.

## **Conclusion**

This systematic review has summarised the available evidence from a comprehensive range of sources on the effectiveness of peer support interventions for people with IBD. At present, there is a lack of good evidence of the effect of peer support interventions on the range of outcomes detailed here. This is partly due to poor study design and quality, but also because of a lack of standalone peer support interventions that target specified psychosocial processes and outcomes that are amenable to evaluation. The ongoing studies may provide more robust estimates of the effects of targeted peer support for certain groups of IBD patients, including young people. Agreement on the outcomes to be targeted by standalone peer support interventions would provide a focus for further intervention design and evaluation.

## **Declarations**

### *Ethics approval and consent to participate*

Not applicable.

### ***Consent for publication***

Not applicable.

### ***Availability of data and materials***

Included study data are included in this report's supplementary information files.

### ***Competing interests***

The authors declare that they have no competing interests.

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### ***Authors' Contributions***

JM conceived the research in conjunction with LB, and DT and CM conducted scoping searches. AA performed initial searches, and DT updated the searches. AA prepared the first draft of the manuscript, and DT amended the manuscript following search update. MP provided overview of statistical content. DM provided methodological input to develop the protocol and assisted with drafting the manuscript. Each author revised the manuscript for important intellectual content and gave approval of the final version. Screening was performed by AA, DT, CM, and JM. Data extraction performed by AA. DT, CM, and JM validated data extraction for accuracy and completeness. Quality assessment was performed by AA, DT, CM, and JM.

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## Tables

Tables 1 to 2 are available in the Supplementary Files section

## Figures

### Figure 1

PRISMA flowchart of study selection process

## Supplementary Files

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