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Dietary management for people with an ileostomy: A scoping review

Abstract

Objective: To identify and map the evidence for oral dietary management of ileostomies.

Introduction: Dietary advice is commonly provided for ileostomy management but can be inconsistent, conflicting, and inadequate. There is a lack of high-quality research investigating dietary management of ileostomies. This scoping review highlights gaps in the literature that need addressing to inform practice and identifies dietary strategies and outcomes to be investigated in future studies.

Inclusion criteria: Evidence relating to the use of oral dietary strategies in humans to manage complications and nutritional consequences associated with having an ileostomy. Evidence included all types of original research, i.e. quantitative and qualitative methodologies, and expert opinion articles and consensus guidelines.

Methods: This review followed the JBI methodology for systematic scoping reviews. A pre-determined search of 13 databases, including MEDLINE, Embase and Web of Science, was conducted in August 2019. The search was not limited by date but during screening expert opinion evidence was limited to 2008 onwards. Data extraction was carried out by two reviewers for each study/article using a database tool designed specifically for this review. Results are presented using a combination of tabular summaries and narrative report.

Results: 31 research studies were included; 11 experimental (including four crossover RCTs), three pre-post design, 13 observational (12 cross-sectional, one longitudinal), and four qualitative. 44 expert opinion articles/guidelines were also included. In experimental studies, nine nutrient modifications and 34 individual foods/drinks were investigated. In pre-post studies, ten nutrient modifications, 80 foods/drinks, and 11 eating-related behaviors were investigated. In observational studies, eight nutrient modifications, 94 foods/drinks, and five eating-related behaviors were reported. In qualitative studies, two nutrient modifications, 17 foods/drinks, and one eating-related behavior were reported. In expert opinion articles/guidelines, recommendations relating to 51 nutrient modifications, 339 foods/drinks, and 23 eating-related behaviors were reported. Although large numbers of individual foods and drinks were suggested to be associated with outcomes relating to ileostomy management, findings from observational studies showed these were mostly only reported by <50% of people with an ileostomy. The most common nutrients reported in association with outcomes related to ileostomy management were fiber, fat, and alcohol. Across most outcomes and studies/expert opinion, low fiber and low fat were suggested to be beneficial, while alcohol was detrimental. Other nutrient associations frequently reported in expert opinion (but with minimal attention in research studies), included negative consequences of caffeinated drinks and positive effects of white, starchy carbohydrates on stoma output. Output volume and consistency were the most commonly reported outcomes relating to ileostomy management across all study types. Flatulence and odor were also common outcomes in observational studies.

Conclusions: This review found an abundance of literature, particularly expert opinion, reporting on dietary management for people with an ileostomy. However, this literature was highly heterogeneous in terms of dietary strategies and outcomes reported. It is likely that most dietary advice provided in practice is based on expert opinion with some supported by limited research. High-quality research investigating the effect of the dietary strategies identified in this review on commonly associated outcomes relating to ileostomy management is needed to improve evidence-based advice.

Keywords: diet; ileostomy; nutrition; stoma

Introduction

A gastrointestinal (GI) output stoma is a surgical opening in the abdomen where the GI tract is brought out to the surface for removal of waste products. An ileostomy is a stoma formed from the ileum. If the stoma is formed higher up in the GI tract, from the jejunum, this is called a jejunostomy. Stomas formed lower down the GI tract, from the colon, are colostomies. Stomas of the GI tract are created when part of the intestine must be removed, and/or rested to promote healing, due to disease, surgery or injury.¹ Common conditions requiring ileostomy formation are Crohn's disease, ulcerative colitis, and colorectal cancer.²

People with an ileostomy do not have a functioning colon and will have varying lengths of functioning small intestine above the ileostomy. Following ileostomy formation, the ileum adapts to improve its ability to absorb fluid and electrolytes.³ However, the extent of adaptation depends on the individual, the length of small intestine remaining, and the duration of time since surgery. Therefore, people with an ileostomy can be at risk of dehydration and malnutrition.² Excess fluid and electrolyte losses can manifest as liquid and/or high-volume stoma output.⁴ This not only increases risk of dehydration and electrolyte disturbances but can impact on activities of daily living and quality of life.⁵

People with a colostomy still have some functioning colon, the primary location for fluid and electrolyte absorption. They also have all their small intestine (duodenum, jejunum and ileum) intact for digestion and absorption of nutrients (unless they have had additional surgery to remove sections of small intestine) and risk of dehydration and malnutrition is therefore not significantly increased.⁶ In contrast, people with a jejunostomy have only a short section of their GI tract available for digestion and absorption leading to short bowel syndrome (SBS) with severe fluid and nutritional losses.⁷

Management of GI output stomas aims to prevent or treat complications including high-output, loose output, blockage, wind, and odor. High-output stoma (HOS) has not been consistently defined but is usually considered as an output greater than 1-2 liters per day.^{4,7,8} Potential consequences of uncontrolled high-output include dehydration, acute kidney injury, and malnutrition.^{6,8} Severe complications, including persistent high-output or blockage, may require hospital admission.^{6,9} Complications of having a stoma are a burden to both the individual and to healthcare providers.¹⁰

Dietary advice is commonly provided as an important component of stoma management.⁹ People with an ileostomy may be advised to restrict fiber intake to prevent blockage and high-output,^{6,9,11} and to

add salt to their meals.^{6,12} Fluid restriction and oral rehydration solutions (ORS) may be used to treat high-output.^{4,6} White starchy carbohydrates, for example rice, pasta and bread, and gelatin containing sweets, for example marshmallows and jelly sweets, are recommended to thicken stoma output.^{9,12} Avoidance of specific foods and drinks have been recommended to control wind and odor from the stoma.^{9,13}

There are many healthcare professionals (HCPs) and other sources who may provide dietary advice to individuals with a stoma. These include stoma nurses, dietitians, surgeons, gastroenterologists, other specialist nurses, and support groups and associations such as the Ileostomy and Internal Pouch Association.^{9,14,15} Although dietary management is commonly used in clinical practice for people with a stoma, there is a scarcity of evidence to inform this.¹⁶ Practice is informed, in the main, by clinical experience and a small number of cross-sectional studies.¹⁶ Some specific components of dietary management, such as ORS and marshmallows, have also been tested in a few small-scale experimental studies.^{6,17,18} Despite considerable variation in length of intestine remaining for digestion and absorption with different types of stoma, as described above, some studies fail to differentiate and acknowledge the implications of this on complications and dietary management.^{19,20}

It has been reported that people with a stoma are often not satisfied with the dietary advice they receive, and that the advice is insufficient, inconsistent, and can be conflicting.^{14,21,22} Discrepancies between expert opinion articles in the dietary advice proposed for stoma management are likely representative of differences in practice between individual clinicians and healthcare professions.¹⁴ For example, one article suggests that, to reduce risk of blockage, all fruit, except for bananas, should be avoided immediately after ileostomy surgery and gradually re-introduced, while another article advises that soft fruit without skins can be consumed.^{9,12}

A preliminary search for existing reviews relating to dietary management of stomas did not identify any systematic reviews or scoping reviews. The following databases were searched: JBI Database of Systematic Reviews and Implementation Reports (JBISRIR), PROSPERO, Cochrane Database of Systematic Reviews (CDSR), MEDLINE, and CINAHL.

Preliminary literature searches indicated a paucity of research investigating dietary management of stomas, with considerable heterogeneity amongst available studies. Since people with an ileostomy potentially have much to gain from appropriately modifying their oral diet, the present scoping review was proposed. This review highlights gaps in the literature that need addressing to inform ileostomy management in clinical practice, and identifies dietary strategies and outcomes requiring investigation in future studies.

The objective of this scoping review was to identify and map the evidence for oral dietary management of ileostomies.

Review question

What oral dietary strategies for managing ileostomies in humans have been reported?

Secondary questions:

- What types of evidence have considered oral dietary strategies for managing ileostomies?
- What aspects of ileostomy management, for example stoma output or flatulence, are the oral dietary strategies considered to affect?
- What sources do people with an ileostomy receive dietary advice from?

Inclusion criteria

Participants

This review included evidence in people with an ileostomy. There are several conditions that may require ileostomy formation, most commonly Crohn's disease, ulcerative colitis, colorectal cancer, and familial adenomatous polyposis.²³ Articles were not restricted to people with a specific condition as common advice for dietary management of ileostomies is provided irrespective of underlying condition.⁹ In practice, dietary management for an underlying condition may need to be integrated with dietary management for the ileostomy.¹⁴

Evidence relating to people with a colostomy or jejunostomy were excluded from this review. This is due to differences in complications and management with different types of GI stoma. People with an ileostomy have greater risk of complications, such as high-output, dehydration and blockage, than people with colostomy.^{24,25} There is therefore a greater requirement for, and differences in, oral dietary management of complications in people with an ileostomy compared to those with colostomy.^{9,24,25} People with a jejunostomy have SBS characterized by severe malabsorption which often requires restriction of oral intake and parenteral nutrition support.⁷

Age or sex was not restricted as these factors have not been identified to affect dietary strategies used for ileostomy management. However, articles relating to babies not yet fully weaned were excluded as dietary management in this group differs considerably. Animal studies were also excluded.

Concept

The concept for this review was oral dietary management of ileostomies. This included modification of the usual foods and drinks a person consumes to manage complications and nutritional consequences associated with the ileostomy. Examples identified in the protocol for this review were: fiber modification; low residue diets; reintroduction diets; added salt; low fat diet; probiotics and/or prebiotics; increased low fiber starchy carbohydrates; regular intake of gelatin containing sweets; specific food/drink avoidance such as onions, nuts, and fizzy drinks; high energy and/or protein diet; oral nutritional supplement drinks.²⁶ Only evidence relating to oral diet was included. Artificial nutrition support (enteral and parenteral nutrition) is a separate concept and was therefore excluded.

Outcomes were ileostomy complications, such as high-output, loose/watery output, blockage, wind, odor, malnutrition, and dehydration, that may be managed through modification of oral diet.²⁷

During the screening process, it was identified that additional criteria for inclusion/exclusion were needed beyond those in the protocol.²⁶ The need for adding post-hoc exclusion criteria is expected in scoping reviews as, by their nature, the variety and extent of related evidence only becomes known through carrying out the review process.²⁸ After agreement by reviewers, the following exclusion criteria were added and applied to the screening process as evidence relating to these concepts did not specifically help to answer the research questions:

- People with an ileostomy used as subjects for the purpose of investigating digestion of specific foods in the small intestine.
- Sodium balance studies not looking at stoma management outcomes.
- Nitrogen balance studies.
- Articles/studies where the purpose was to consider management of short bowel syndrome, not ileostomies specifically.
- Single nutrient supplements.
- Elemental diet.
- Dietary modification to prevent or treat conditions associated with ileostomy complications. For example, renal calculi.
- Dietary management relevant only to a specific subgroup of people with an ileostomy. For example, marathon runners or palliative patients.

The decision was made to exclude articles focusing on dietary management in SBS and/or intestinal failure because these conditions commonly occur in people with jejunostomy but more rarely in people with ileostomy, require specific management, and often require supplementary IV fluids and/or parenteral nutrition.⁷ Furthermore, although ORS and fluid management protocols were initially given as examples for inclusion within the review,²⁶ subsequently studies that focused on these aspects were excluded. Strict fluid management including use of ORS in combination with medication such as loperamide and codeine is key to management of SBS and intestinal failure. Similar medical management is also common for HOS; however, there is a clear distinction between this and general fluid advice for stoma management e.g. limiting caffeinated, fizzy, and alcoholic drinks (which were included in the review).

Context

All settings were included as dietary advice provided in one setting may be relevant to ileostomy management, and continue to be followed, in another setting. For example, dietary advice provided in hospital may be followed after discharge.²⁹

There was no restriction by country or language, to enable the full extent of the evidence to be mapped.

There was no restriction on date stated in the protocol.²⁶ However, during the screening process, the decision was made by reviewers to limit expert opinion articles to the last 10 years. Therefore, expert opinion articles published before 2008 were excluded from this review. This decision was made for

the following reasons: 1) the large number of expert opinion articles identified; 2) contemporary expert opinion articles are likely to be most relevant in terms of current advice being given in clinical practice; 3) to prevent excessive repetition.

Types of studies

All types of original research, quantitative and qualitative designs, were included. Reviews, including narrative reviews and expert opinion articles termed as reviews, were also included. The only text and opinion-based evidence included was expert opinion. Inclusion criteria included consensus guidelines in peer-reviewed publications. Guidelines and documents disseminated by associations, societies or institutions were excluded as they are not usually peer-reviewed publications or research.

Methods

This review was conducted following the JBI methodology for systematic scoping reviews.³⁰ The a priori protocol for this review has previously been published.²⁶

Search strategy

The search strategy was designed to find all published and unpublished research studies along with published reviews of the literature, consensus guidelines, and expert opinion articles relevant to the topic of dietary management in people with an ileostomy. Following JBI guidance, a three-step search strategy was performed.³⁰ In step 1, an initial limited search of MEDLINE and CINAHL was carried out followed by analysis of the text words contained in the title and abstract, and of the index terms used to describe the article. Identified keywords and index terms were included in the full search strategy. In step 2, the full search strategy was performed in each of the specified databases. Appendix I contains the full search strategy for MEDLINE. This search strategy was tailored to each database. Searches were carried out first in 2018 and updated in August 2019. In step 3, reference lists of all included articles were screened to identify additional relevant articles. The final list of included articles was checked for completeness by subject experts. No date limitation was included in the search strategy; however, expert opinion articles were only included if published in the 10 years prior to first full search in 2018 (2008-2019), as discussed above.

Databases searched: MEDLINE, Embase, and AMED via Ovid, CINAHL via EBSCO, Web of Science, CDSR, and JBI Database of Systematic Reviews and Implementation Reports (JBISRIR). Trial registers searched: ClinicalTrials.gov, WHO ICTRP, and Cochrane Central Register of Controlled Trials. Databases searched for unpublished studies: OpenGrey, EThOS, ProQuest – Nursing and Allied Health Source Dissertations, Google Scholar.

Study selection

Records returned from the database searches were collated using EndNote X9 (Clarivate Analytics, PA, USA) and duplicates removed. Two independent reviewers screened all titles and abstracts, assessing against the inclusion/exclusion criteria. Articles failing to meet the criteria for inclusion were

discarded and full texts for all remaining articles acquired. Full texts were then assessed in detail against the inclusion/exclusion criteria by two independent reviewers. Full text articles not meeting criteria for inclusion were excluded. Full texts excluded with reasons for exclusion are detailed in Appendix II. Any disagreements between reviewers were resolved through discussion, and where necessary a third reviewer was involved. Where something was unclear that affected the decision of whether to include a study, authors were contacted for clarification.

Data extraction

Data were extracted from included studies, consensus guidelines, and expert opinion articles into an electronic charting form based on the draft form detailed in the protocol.²⁶ The charting form was piloted by two reviewers and some changes made to improve consistency. An outline of the final charting form used for data extraction can be found in Appendix III. Data extraction was carried out by two independent reviewers. Any disagreements arising between reviewers were resolved through discussion or with a third reviewer.

Data synthesis

Summaries of all included studies and articles are presented in tables according to study design or article type. This was done to differentiate between levels of evidence since experimental studies can suggest causality, observational studies can indicate associations, and expert opinion articles suggest common views in clinical practice. Data synthesis of dietary strategies and associated outcomes is presented as a tabular and narrative summary.

Results

Study inclusion

Database searches of published literature and registered trials returned 8,055 results (Appendix IV). An additional 427 records were identified from other sources. After title and abstract screening, 195 records were retrieved for full text screening of which 118 were excluded at this stage (Figure 1;³¹ Appendix III).

Data were extracted from 31 individual research studies and 44 expert opinion articles (including two reporting guidelines based on expert consensus)^{32,33}, and were included in the data synthesis reported in the results (characteristics and findings/recommendations for individual studies and expert opinion articles/guidelines are in Appendix V). In addition, seven records presented data from a study reported in another included article,³⁴⁻⁴⁰ two were related to reported expert opinion articles,^{41,42} and six were review articles.^{16,43-47} Reference lists from review articles were included in hand searches. One in-progress registered trial was identified, which aims to investigate physiological effects of probiotic dairy drinks in adults with established ileostomy.⁴⁸

<Insert Figure 1 here>

Characteristics of studies/articles

Characteristics of the 31 eligible research studies are summarized in Table 1. Eleven were experimental (four crossover randomized controlled trials (RCT),^{17,49-51} six non-randomized crossover trials,⁵²⁻⁵⁷ and one non-randomized controlled trial⁵⁸), three used a pre-post design (evaluating a new protocol or process of patient education and support),^{6,59,60} thirteen were observational (12 cross-sectional,^{23,61-71} one longitudinal⁷²), and four were qualitative.^{14,73-75} Most were from the UK (11 studies), USA (7 studies), and Australia (6 studies). People with ileostomy due to Crohn's disease or ulcerative colitis were the populations most frequently studied, followed by people with ileostomy due to colorectal cancer.

<Insert Table 1 here>

Most expert opinion articles/guidelines were from the UK (23 articles) and USA (15 articles). Specialist nurses (including stoma nurses) contributed to two-thirds of them (29/44; 66%), and dietitians to a smaller proportion (5/44; 11%).

Overview of dietary modifications for management of ileostomy-related problems

Dietary modifications associated with ileostomy-related problems in research studies are presented in tables 2-8. The large range of oral dietary modifications reported were grouped into three types of dietary strategy: 1) nutrient modifications 2) foods and drinks 3) eating-related behaviors. All reported nutrient modifications and eating-related behaviors are shown in the tables. However, due to the large number of individual foods and drinks reported across studies, only those reported in more than one study are included in the tables (a full list of all individual foods and drinks reported across studies is provided in Appendix VI). Time frames covered by the studies included the initial post-operative healing period (most pre-post and qualitative studies, and some experimental studies) and beyond the initial 6 to 10 week healing period (most observational studies, and some experimental studies). Expert opinion articles recommended a wide range of dietary modifications for ileostomy management in both the initial post-operative healing period and beyond (Appendix VI).

The number of nutrient modifications, individual foods and drinks, and eating-related behaviors reported to be associated with aspects of ileostomy management varied considerably across the different study types. In experimental studies (n=11), nine nutrient modifications and 34 individual foods and drinks were investigated, but no eating-related behaviors. In pre-post studies (n=3), ten nutrient modifications, 80 foods and drinks, and 11 eating-related behaviors were investigated. In observational studies (n=13), eight nutrient modifications, 94 foods and drinks, and five eating-related behaviors were reported. In qualitative studies (n=4), two nutrient modifications, 17 foods and drinks, and one eating-related behavior were reported. In expert opinion articles/guidelines (n=44), 51 nutrient modifications, 339 foods and drinks, and 23 eating-related behaviors were suggested to have either positive or negative consequences for ileostomy management.

Volume and consistency of stoma output

Nutrient modifications reported to reduce volume of stoma output in experimental studies were low fiber,⁵⁶⁻⁵⁸ low fat,⁵¹ low Fermentable Oligo-, Di-, Mono-saccharides And Polyols (FODMAP),⁴⁹ high refined carbohydrate,⁵⁰ and restricted fluid intake⁵³ (Table 2). A low FODMAP diet was also shown to thicken output consistency in one study.⁴⁹ One observational study reported increased output volume with a high fat diet,⁶⁹ and a pre-post study also suggested high fat to be associated with loose, watery output. Alcohol was suggested to increase output in two pre-post studies,^{6,60} and was associated with increased loose, watery output in one observational study.⁷⁰

<Insert Table 2 here>

In terms of individual foods and drinks, 32 were tested in experimental studies where output volume was reported (22 made no difference, eight had a negative effect, and two had a positive effect; Appendix VI). In pre-post studies, people were advised to avoid/limit 13 foods and drinks to reduce output volume, and 27 foods and drinks were suggested to alter output consistency. In observational studies, 33 foods and drinks were reported to increase output volume, and 40 were associated with loose, watery output. Across all studies, 23 of the foods and drinks were associated with output volume and/or consistency in more than one study (Table 2). Most were fruit, vegetables, and dairy products and intake was adversely associated with output volume/consistency, although there was suggestion of a beneficial effect of marshmallows. However, some conflicting evidence between different study types was observed (e.g., beer, banana, cheese, fruit, and potato were associated with both beneficial and adverse changes in stoma output; Table 2). The proportion of participants within studies that reported associations between specific foods/drinks and output, however, was highly variable and mostly <50% (see Appendix V for key findings by study).

For dietary behaviors, some pre-post studies advised eating more in the daytime and less in the evening to manage stoma output,^{59,60} but consuming fluids with meals (during the initial post-operative period) was suggested to increase output volume⁶ (Table 2).

In expert opinion articles and guidelines, over 30 nutrient modifications were reported to have positive or negative consequences for stoma output volume, and 20 for output consistency (Appendix VI). The most common advice was that alcohol increases volume of output (eight articles)^{27,76-82} and causes loose, watery output (seven articles).^{9,77,80,81,83-85} It was also frequently reported that caffeine causes high and/or loose, watery output (six articles),^{27,76,77,80,81,83} while low fiber, and high starch, diets were reported to prevent or help to resolve this (five^{11,86-89} and eight^{4,33,79,87,88,90-92} articles respectively). However, there was conflicting advice on whether a high fiber diet was beneficial or detrimental for managing high and/or loose, watery output (two reported it as beneficial^{10,93}, four as detrimental^{9,11,79,90}). Insoluble fiber was suggested to have a negative consequence while soluble fiber was recommended as positive (two articles).^{81,94} High fat and high sugar diets were reported to have negative consequences for stoma output (three articles respectively).^{10,27,79,82,93} Advice to reduce hypotonic fluids to reduce stoma output was common and consistent (five articles).^{4,27,33,79,88} Less frequently, advice extended to also reduce hypertonic fluids.^{27,33} Isotonic/rehydration drinks were

recommended in three articles,^{4,76,86} and three provided general advice to decrease fluid intake if high and/or loose, watery output occurred.^{81,93,95} Three articles recommended the consumption of fluids between, rather than with, meals to prevent high volume of stoma output.^{4,27,90} Small, frequent meals were also recommended in several articles to manage stoma output.^{79,91,94,96}

Over 100 specific foods and drinks were reported in expert opinion articles and guidelines in relation to volume and consistency of stoma output (Appendix VI). Refined, starchy carbohydrate foods and gelatin containing sweets were commonly reported to be beneficial for management of stoma output. Common types of foods and drinks reported to be detrimental were fruits, vegetables, wholegrain foods, fried and spicy foods, along with caffeinated and fizzy drinks.

Dehydration

Findings in relation to dehydration include only dietary advice/modifications provided to people with an ileostomy in general. As stated in the methods, studies/articles where the concept was fluid management for an acute/severe problem in people with an ileostomy (e.g., high output requiring hospital admission), were not included in this review.

Very few research studies reported on dietary management of dehydration in this context. One observational study suggested that increasing fluid intake was beneficial⁶³ and one pre-post study that consuming adequate fluid in line with standard recommendations for healthy individuals and rehydration fluids were beneficial (Table 3).⁶⁰

<Insert Table 3 here>

In expert opinion articles/guidelines, 14 nutrient modifications were advised to manage dehydration (Appendix VI). The most common advice was to ensure adequate fluid intake in line with standard recommendations for healthy individuals (seven articles),^{85,90,91,97-100} consume higher amounts of salt/sodium (13 articles),^{9,12,27,78,83-85,89-91,95,100,101} and consume isotonic/rehydration fluids (10 articles).^{10,12,76,79,81,82,84,87,95,100} Other advice was to increase fluid intake (four studies)^{9,27,81,89} and to limit or avoid caffeine (three articles)^{76,90,100} and alcohol (one article).⁷⁶ Hypertonic fluids or excessive amounts of hypotonic fluids were reported to contribute to dehydration, as was consumption of fluids with meals (one article each).^{10,12,95} High sugar drinks (three articles)^{76,95,100} and a diet high in sugar or fat (one article)¹⁰ were reported to negatively affect hydration. A high potassium diet was advised to be beneficial with regard to dehydration (two articles).^{83,91} The advice regarding fiber was unclear with a low fiber diet advised to be beneficial in one article⁸⁴ and conflicting recommendations between two articles on whether a high fiber diet was advisable.^{95,100}

Thirty-one specific foods and drinks and consumption of five specific fluids in excessive quantity were reported in expert opinion articles/guidelines in relation to dehydration with an ileostomy (Appendix VI). Two articles suggested that increasing water intake was beneficial,^{94,100} while two advised that water, particularly in excessive amounts, had a negative effect.^{10,95} There was also contradictory advice between articles on consumption of fruit juice.^{10,76,95} Coffee^{10,76,81,95} and diet drinks^{89,90} were reported to be detrimental, while milk and squash were recommended.^{76,83}

Flatulence and odor

A high fiber diet increased flatulence,⁵⁶ while a low fiber diet reduced flatulence and odor^{57,58} in experimental studies (Table 4). A pre-post study suggested that alcohol was associated with increased flatulence and odor,⁶⁰ and this association was also reported in an observational study.⁷⁰

No individual foods and drinks were reported in experimental studies in relation to flatulence or odor as outcomes. In pre-post studies, 21 foods and drinks were suggested to increase flatulence, and 27 to affect odor (20 increased, seven reduced odor). In observational studies, forty-two foods and drinks were associated with increased flatulence, and 37 with odor (three of which were reported to be beneficial) (Appendix VI). Across all studies, 17 of the foods and drinks were associated with flatulence and/or odor in more than one study (Table 4). Common foods and drinks reported to increase flatulence and odor were fibrous vegetables, beans, animal products, and fizzy drinks.

<Insert Table 4 here>

In pre-post studies, patients were advised that eating quickly and chewing gum increases flatulence (Table 4).^{59,60} No other studies mentioned eating-related behaviors in relation to flatulence or odor.

In expert opinion articles/guidelines, alcohol was reported to increase flatulence in three articles.^{81,102,103} One article suggested that a high fat diet increases flatulence and odor,⁷⁸ and another that a high fiber diet increases flatulence.⁹⁰ A vegetarian diet was also reported to increase flatulence in one article.¹⁰⁴ Fifty-five foods and drinks (some only if consumed in excessive quantity) were reported to increase flatulence, and 13 to reduce flatulence (Appendix VI). Thirty-eight foods and drinks were reported to increase odor, and 21 to reduce odor. Types of foods and drinks reported to increase flatulence and/or odor were most commonly fibrous vegetables, beans, animal products, and fizzy drinks.

Eating-related behaviors suggested to increase flatulence were chewing gum (eight articles),^{12,27,78,81,83,89,94,103} drinking through a straw (five articles),^{27,83,89,94,103} talking while eating (three articles),^{12,89,94} drinking quickly/gulping,¹² rushing meals,⁸⁹ eating with mouth open,⁸³ sucking sweets,⁸³ and infrequent meals²⁷ (one article). Small, frequent, and regular meals were recommended to reduce flatulence,^{89,94,96,100,105} and chewing well (one article).¹⁰⁵ Gradual reintroduction of foods after surgery was also suggested as a strategy to manage flatulence and odor in one article.⁹¹

Blockage

In experimental studies, a low fiber diet reduced risk of blockage in the initial post-operative healing period (Table 5).⁵⁸ In one pre-post study, avoiding high intakes of insoluble fiber prevented blockage.⁶ Another suggested that consuming fluids between meals reduced risk of blockage.⁵⁹ A high fiber or high residue diet was associated with increased risk of blockage in observational studies,^{65,72} and this association was also reported in two qualitative studies.^{73,74}

<Insert Table 5 here>

No foods and drinks were tested in experimental studies in relation to blockage, but in one study, All-bran caused obstruction resulting in discontinuation of testing.⁵³ Patients were advised to be cautious with 16 individual foods in one pre-post study due to risk of blockage.⁶⁰ Nine foods and drinks in observational studies, and four in qualitative studies, were associated with blockage (Appendix VI). Across all studies, six foods were reported in more than one study to be associated with blockage or obstruction and were those high in insoluble fiber i.e. fruits, vegetables, nuts, and wholegrains (Table 5).

In expert opinion articles/guidelines, a diet high in fiber^{9,83,90,91,98,106-108} or specifically insoluble fiber^{27,33} was commonly reported to increase risk of blockage (eight and two articles, respectively). Recommendations to prevent blockage were to ensure adequate fluid intake in line with guidance for healthy individuals (four articles)^{91,96,97,100} or increase fluid intake (two articles),^{33,102} and to follow a low fiber diet during the initial post-operative healing period (one article).⁸³ Eighty foods were reported to increase risk of blockage (Appendix VI). Types of foods commonly reported to increase risk were those high in insoluble fiber including fruits, vegetables, nuts, and wholegrains. By far the most common eating-related behavior recommended to reduce risk of blockage was to chew well (17 articles).^{9,27,84,85,89-91,94,97,99-103,107,109,110} Other behavioral advice reported was to reintroduce foods gradually,^{9,27} cook food until soft,⁹¹ and to consume small, frequent meals, avoiding large portions.^{100,110}

Malnutrition and malabsorption

In one experimental study, a low fiber diet reduced malnutrition during the initial post-operative healing period (Table 6).⁵⁸ In another, corn was visible in the stoma output, showing it had not been digested.⁵⁴ Fourteen foods were reported in observational studies to be visible in stoma output (Appendix VI) but only nuts were reported in more than one study (Table 6).^{62,68}

<Insert Table 6 here>

Dietary advice for malnutrition was uncommon in expert opinion articles/guidelines. However, a diet high in energy,⁸⁸ protein,⁹⁰ calcium,⁹⁰ vitamin B12,⁹⁶ and salt⁹⁴ was recommended to prevent or treat malnutrition (Appendix VI). Low fat sources of protein were advised,⁹⁶ and supplement use recommended in the initial post-operative period.⁹⁰ The following were reported to contribute to malnutrition: high sugar, high soluble fiber, excessive consumption of hypotonic or hypertonic fluids, alcohol, and caffeine.²⁷ Snacks between meals were recommended in two articles to prevent malnutrition.^{90,94} Three foods (corn, nuts, and vegetables) were reported to be visible in stoma output, but only in one article (Appendix VI).⁹³

Pain and leakage

In an experimental study, participants in the high and low FODMAP intervention groups reported pain while on the diet.⁴⁹ Alcohol was also associated with pain in one observational study (Table 7).⁷⁰

Thirty-three foods and drinks were associated with pain in observational studies, and three in qualitative studies (Appendix VI), but only nuts and skins were reported in more than one study to be associated with pain (Table 7).^{64,66}

Leakage was only reported as an outcome associated with diet in two observational studies. High fat and fluids,⁶⁹ consuming most of daily intake in the evening (Table 7),⁶⁴ and four foods,⁶⁹ all high in insoluble fiber, were associated with leakage (Appendix VI).

<Insert Table 7 here>

In expert opinion articles and guidelines, only pulses and green vegetables were reported to cause pain,¹⁰⁴ and none for leakage (Appendix VI). No specific nutrients or eating-related behaviors were reported in relation to either pain or leakage.

Unspecified outcomes

Certain nutrient modifications (e.g., low fiber, high salt), foods/drinks (e.g., beans, fizzy drinks, fruit, nuts, vegetables), and eating-related behaviors (e.g., chew well, small frequent meals) also reported within the outcomes sections above were suggested to be associated with ileostomy management but the specific outcome(s) they related to (e.g. high stoma output or blockage) was not identified. A full list of these nutrient modifications and eating-related behaviors that were reported in research studies, along with individual foods and drinks reported in more than one study (n=16), are presented in Table 8. Details of all foods and drinks reported without specified outcome are included in Appendix VI as well as dietary modifications reported in expert opinion articles/guidelines.

<Insert Table 8 here>

Discussion

This is the first review to systematically and comprehensively search and synthesize the literature relating to oral dietary strategies for ileostomy management. A large range of oral dietary strategies have been reported which could be grouped into three types of dietary strategy: 1) nutrient modifications 2) foods and drinks 3) eating-related behaviors. The research evidence for most dietary strategies came primarily from observational studies, nearly all of which were cross-sectional and relied on participant self-report. Ten outcomes relating to ileostomy management were identified in relation to these dietary strategies: volume and consistency of stoma output, dehydration, flatulence, odor, blockage, pain, malnutrition, food visible in output, and leakage.

Quality assessment of studies was not included as part of this scoping review. Heterogeneity of studies in terms of dietary strategies reported and outcomes measured prevented the possibility of providing evidence-based recommendations for practice. Only four RCTs had been published (each investigating a different dietary strategy) and all had small sample sizes, the largest being 28 participants.^{17,49-51} None of the 11 experimental studies (including non-RCTs) had a sample size over 50, and over half had less than 10 participants. This limitation in sample size meant that the majority

were under powered and had poor generalizability of findings. Pre-post studies included a combination of dietary strategies in the intervention. The benefit of this is that it represents real-world practice; however, it is impossible to determine which components of the intervention contributed to its effectiveness. In observational studies, the reliance on self-report of diet and ileostomy-related outcomes is a common weakness. Integral to this, specifically in the context of the aims of this review, is the inability to determine from the findings whether reported associations between specific dietary strategies/components and a particular outcome were based on practical experience of the participant or advice they received and followed. Inclusion of qualitative studies helped ensure the full range of potential dietary strategies for ileostomy management was mapped. However, due to the nature of the included qualitative studies, little insight can be gained into the effectiveness of any dietary strategy reported, or how widely it is used.

In research studies, approximately 20 nutrient modifications, over 100 individual foods and drinks, and approximately 15 eating-related behaviors were reported for the dietary management of ileostomies, with an even greater number in expert opinion articles. The most common nutrient modifications across research studies and expert opinion were fiber, fat, and alcohol. Across most outcomes and articles, low fiber and low fat were suggested to be beneficial, while alcohol was detrimental. Other nutrient associations frequently reported in expert opinion (but with minimal attention in research studies), included negative consequences of caffeinated drinks and positive consequences of white, starchy carbohydrates on stoma output. Eating-related behaviors were infrequently reported in research studies and, where they were, this was usually as part of a multi-component intervention in pre-post studies, or occasionally in observational studies, and usually not associated with a specific outcome. As expected, the issues commonly addressed were the same as those that caused difficulty for large numbers of people with an ileostomy in a recent survey, namely very loose or watery stoma output, wind or gas, high volume of stoma output, and increased odor from stoma bag.²² Volume and consistency of stoma output were the outcomes most commonly reported across all study types, but it is likely that there was some overlap in the findings related to these outcomes as volume (over a short time period) usually increases when output is more loose and watery. Flatulence and odor were also common outcomes in observational studies. Other overlaps in findings may occur. For example, volume and consistency of output, and amount of gas produced (flatulence), will also contribute to the risk of leakage, and pain may be caused by wind or blockage.

Many studies and articles included in this review reported on a low fiber diet, and others a low residue diet. However, variation in terminology around fiber and residue is confusing due to a lack of clarity in definitions.¹¹¹ It is particularly difficult to define a low residue diet since some GI residue is produced by all foods. As the majority of GI residue is produced by foods containing fiber, and fiber content can be measured, it would seem prudent for future clinical research and practice to follow the recommendations made by Vanauwaert et al.,¹¹¹ in their review of low residue and low fiber diets, to redefine the low residue diet as a low fiber diet. In our review, and that of Vanauwaert et al.,¹¹¹ there was considerable variation between studies in the quantitative definition of a low fiber diet or meal. Therefore, clinicians need to be aware of how low fiber was defined in different studies when using

research to inform advice on a low fiber diet for patients, including those with an ileostomy. Vanauwaert et al.¹¹¹ recommend that a low fiber diet be defined as a diet containing $\leq 10\text{g}$ fiber/day.

Dietary fiber is made up of soluble and insoluble fiber. The evidence included in our review consistently suggested that insoluble fiber is associated with negative outcomes such as blockage and high or loose output in people with an ileostomy. However, the role of soluble fiber in ileostomy management is unclear although some sources have reported it to be beneficial.^{81,94,112,113} Thus, if the relative contributions of soluble and insoluble fiber to total intake are not reported in studies investigating high versus low fiber diets in people with an ileostomy, it will not be possible to conclude whether findings are due to total fiber intake, or the amount of insoluble or soluble fiber consumed.

Our search found a large amount of expert opinion published in the last 10 years. Despite limited research evidence for any one dietary strategy, this abundance of expert opinion reflects the common provision of dietary advice for people with an ileostomy in clinical practice.²² In line with results from a recent survey of people with an ileostomy in the UK and Ireland showing a high prevalence of conflicting dietary advice,²² there was considerable variation in the oral dietary strategies recommended by expert opinion for ileostomy management. Lists of foods and drinks that could cause a specific negative outcome, e.g. high output, were often reported without guidance on whether people with an ileostomy should limit, avoid completely, or cautiously consume and only avoid if problematic, these foods and drinks. Other articles did acknowledge individual differences in tolerating certain foods and drinks, suggesting a gradual trial and error approach following ileostomy surgery. This approach is supported by findings from observational studies where many individual foods and drinks were reported by some to be problematic; however, most people with an ileostomy could tolerate the same foods and drinks well. In some studies, a small number of foods were reported as problematic by a high proportion of people with an ileostomy, but most were problematic to $<50\%$.^{23,62,65,68-70} Many of the foods and drinks reported to be problematic for ileostomy management are those known to have varying levels of negative GI consequences, e.g. causing wind or diarrhea, in the general population.¹¹⁴ For example, beans and onions are known gas-producing foods. Therefore, educating people with an ileostomy, and all HCPs who provide diet advice, to have a basic understanding of digestion by-products could aid dietary management.

Underlying active disease of the functioning GI tract, e.g. Crohn's disease, is a potential confounding factor when considering the effect of diet on outcomes relating to ileostomy management.⁶⁸ People with an ileostomy who also have active disease and/or have had other surgery to their small intestine, e.g. inflammation or resection resulting in anastomoses or stricture, have a greater physiological propensity to experience consequences of dietary intake on ileostomy management.⁹⁰ In addition to these factors, whether a certain food is problematic is likely to vary depending on the quantity and frequency of consumption, how the food has been prepared (e.g. vegetables that have been very well cooked until soft have been suggested to be better tolerated), how well the person chews the food, and what it is consumed with.^{91,110} Most information about how a food was prepared and consumed is unknown and/or unreported in studies. Furthermore, in observational studies, it is often unclear whether a participant who reports avoiding a specific food or drink does so because they have been

advised of the potential adverse consequence or because they have personally experienced a problem.

The heterogeneity of GI history among people with an ileostomy combined with the complexities of dietary intake, described above, makes designing research studies to investigate associations between individual foods or drinks and ileostomy-related problems difficult, particularly with respect to establishing generalizable findings to inform dietary advice. Despite the complexities, priority must be given to high quality research studies investigating associations between diet and ileostomy management since people with an ileostomy report a clear need for better, more consistent support.^{14,21,22,115} Over half (55%) of respondents in a UK study had experienced anxiety relating to their diet, and confusion and frustration were also common (reported by approximately one in three).²²

Stoma nurses are the healthcare professionals who most frequently provide dietary advice to people with an ileostomy, followed by dietitians and colorectal surgeons.²² This is reflected in this review where the expert opinion literature was dominated by the voices of stoma nurses. Stoma nurses are specialists in stoma management, including ileostomies, while dietitians are specialists in clinical nutrition and providing individualized dietary advice. A recent study showed that people with an ileostomy want more dietary advice from a dietitian, in addition to advice from their stoma nurse.²² It is therefore important for stoma nurses and dietitians to work together to provide the most relevant and consistent dietary advice. Multidisciplinary working with other HCPs who provide care to people with an ileostomy, i.e. colorectal surgeons and IBD/colorectal specialist nurses, is likely to further improve patient experience and outcomes.

Strengths and limitations

Strengths of this scoping review include development and publication of an a priori search strategy and protocol.²⁶ Inclusion of contemporary published expert opinion in addition to research studies enabled us to report findings that can inform discussion around clinical practice. Specifically, our results show the extent of, and variation in, dietary advice for people with an ileostomy that, in recent years, clinical experts have believed to be beneficial, and promoted. By presenting this information from clinical practice alongside a synthesis of the research evidence, the extent to which research findings inform and are reflected in the dietary advice provided to people with an ileostomy can be seen. Understanding current perspectives and behaviors in clinical practice also helps to inform priorities for future research. Another strength of this review was that a multidisciplinary team of reviewers was involved at all stages of the review process providing diversity of clinical and methodological perspectives.

There are also some limitations. Due to the sheer number of individual foods and drinks reported across studies, only those reported in more than one study were presented within the main tables. This may suggest that these foods/drinks were definitively associated with outcomes, but as discussed above the evidence was not clear cut for most foods. Another limitation that readers should keep in mind is that this review did not include acute fluid management or dietary management in people with short bowel syndrome. There is a large body of literature in this area which lends itself to

a separate review since these findings and recommendations are not appropriate for inclusion within general dietary advice for people with an ileostomy.

There were a small number of full texts we were unable to access for screening (Appendix III), but these were generally expert opinion articles or articles published a long time ago. In addition, some foreign language articles may have been missed due to use of all English search terms. However, we did include eligible foreign language articles from our database searches. Since the purpose of this scoping review was to map the evidence available to inform dietary management for people with an ileostomy, the small amount of evidence that we were unable to access is unlikely to have added much to the findings or meaningfully changed the conclusions.

Conclusions

This review has shown that there is an abundance of literature reporting on dietary management for people with an ileostomy. However, this literature is highly heterogenous in terms of the dietary strategies and outcomes reported. The quantity of expert opinion far outweighed the number of research studies, and it is likely that most dietary advice provided in practice is based on expert opinion with some supported by limited research. As demonstrated by the variation in advice between expert opinion articles published in the last decade, the lack of a robust evidence-base to inform advice may lead to it being inadequate, inconsistent, and often conflicting. Dietary advice may also be overly restrictive without strong evidence to support the need for this. These findings go some way to explaining why people with an ileostomy are frequently dissatisfied with the dietary advice they receive. This combination of insufficient research evidence along with multidisciplinary provision of dietary advice for people with an ileostomy supports a need for local multi-disciplinary team (MDT) consensus with collaborative development of literature/advice on dietary management, to improve clarity and consistency of advice. Acknowledgement by HCPs of the uncertainty in dietary advice for ileostomy management and potential for individual differences in response to diet is also important to increase understanding and trust.

Recommendations for Research

- Longitudinal studies investigating associations between well-defined dietary strategies and outcomes related to ileostomy management are needed, particularly RCTs, to improve understanding of causality. For example, we need to better understand whether dietary strategies to prevent adverse outcomes for ileostomy management are effective in the short- and/or long-term following ileostomy surgery, and whether the same or different dietary strategies are effective in managing/resolving common issues when they arise. A potential intervention study might provide standardized dietary information immediately following ileostomy formation, with follow-up sessions during the six months post-surgery to monitor intake and GI symptoms, and provide tailored dietary advice based on the individual patient experience.

- Future studies should include larger sample sizes, justified by sample size calculations, and ideally be powered for subgroup analyses, for example to compare participants with extensive small bowel resection versus those with ileostomy only.
- Our review highlights a need for research into relative contributions of soluble and insoluble fiber (in the diet overall and in specific foods or meals) to outcomes relating to ileostomy management, when adjusting overall fiber intake.
- Observational studies have shown large variation in the extent and components of dietary strategies used by people with an ileostomy. Inter-individual factors contribute to differences in response to specific dietary strategies. As such, there is a need for future research to investigate individual risk of problems with ileostomy management and how this could be measured, and to test associations with diet in groups with different level risk i.e. low versus moderate versus high risk.
- Future research should include quantitative assessment of adherence to dietary strategies, and a qualitative approach to understanding participant attitudes, barriers, and facilitators to dietary management of ileostomies. This represents a current gap in the literature and is essential to inform implementation of effective provision of dietary advice to people with an ileostomy.
- Patient and public involvement (PPI) should underpin future research to ensure we answer salient research questions, design studies that are practical for participants, and produce findings that inform clinical practice.

Conflicts of interest

The authors declare no conflict of interest.

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