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TOPIC HIGHLIGHT

2015 Advances in Inflammatory Bowel Disease

Tools for primary care management of inflammatory bowel disease: Do they exist?

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Abstract

Healthcare systems throughout the world continue to face emerging challenges associated with chronic disease management. Due to the likely increase in chronic conditions in the future it is now vital that cooperation and support between specialists, generalists and primary health care physicians is conducted. Inflammatory bowel disease (IBD) is one such chronic disease. Despite specialist care being essential, much IBD care could and probably should be delivered in primary care with continued collaboration between all stakeholders. Whilst most primary care physicians only have few patients currently affected by IBD in their caseload, the proportion of patients with IBD-related healthcare issues cared for in the primary care setting appears to be widespread. Data suggests however, that primary care physician's IBD knowledge and comfort in management is suboptimal. Current treatment guidelines for IBD are helpful but they are not designed for the primary care setting. Few non-expert IBD management tools or guidelines exist compared with those used for other chronic diseases such as asthma and scant data have been published regarding the usefulness of such tools including IBD action plans and associated supportive literature. The purpose of this review is to investigate what non-specialist tools, action plans or guidelines for IBD are published in readily searchable medical literature and compare these to those which exist for other chronic conditions.

Key words: Inflammatory bowel disease; Ulcerative colitis; Crohn's disease; Guidelines; Management tools

Core tip: Much inflammatory bowel disease (IBD) care could be delivered in the outpatient setting by primary care physicians. Whilst guidelines for IBD treatment exist, they are intended to support specialist practice and are not designed to use in the primary care setting. Our systematic reviewed found that a striking paucity of IBD outpatient supportive/educational tools for primary healthcare practitioners currently exists. This is despite good evidence of acceptability and usefulness of such tools in other chronic diseases.

Developing and evaluating IBD-specific tools for primary care use may improve health outcomes and reduce healthcare costs.

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INTRODUCTION

Healthcare systems throughout the world continue to face emerging challenges associated with delivering quality, yet affordable, care for chronic disease[1]. In Australia alone, 77% of citizens reported one or more long-term health problems and more than half of those aged 65 years and older had five or more conditions[2]. Driven by past achievements in treating and preventing deaths from acute illness, combined with greater longevity, "modernization" of lifestyle and increasing exposure to many risk factors for chronic disease[3], the number of people with chronic conditions will continue to rise. This changing epidemiology in health care needs is creating a new emphasis on chronic disease management. This requires increasingly complex health care systems and timely and reliable communication, cooperation and support between specialists, generalists and primary health care physicians.

Inflammatory bowel disease (IBD) commonly refers to ulcerative colitis (UC) and Crohn's disease (CD) and is a complex, relapsing and remitting disorder of the gut and a good example of a chronic condition. Despite specialist care being essential, particularly for the more severe IBD phenotypes, much IBD care could and probably should be delivered in primary care. Certainly in several countries worldwide this is already occurring. However, multi-disciplinary management and continued collaboration between all stakeholders is also crucial to optimal patient outcomes including induction and maintenance of remission and prevention of disease associated complications. Treatment guidelines for IBD, both UC and CD, are clearly outlined by several groups[4-8] including the European Crohn's and Colitis Organisation (ECCO)[9,10], however, these guidelines are detailed and complex as they are intended to support specialist, referral level practice. Thus, whilst existing guidelines are helpful, they are not designed for the primary care setting. The epidemiology of IBD is such that most primary care physicians only have 2-10 people currently affected by IBD in their caseload[11]. Despite the low individual case numbers however, the proportion of patients with IBD-related healthcare issues cared for in the primary care setting appears to be widespread[12,13]. One study found that general practitioner's IBD knowledge and comfort in management is suboptimal[11], yet expecting them to adopt detailed guidelines such as the ECCO ones, is unrealistic.

In other chronic diseases such as asthma, diabetes mellitus (DM) and congestive cardiac failure (CCF), management tools and action plans have been developed to support non-specialist management[14-16]. However, to our knowledge, few non-expert management tools or guidelines exist for IBD and scant data have been published regarding the usefulness of such tools including IBD action plans and associated supportive literature. Importantly, a Canadian National Physician Survey in 2010[17] found that 46% of family physicians use flow sheets and checklists for many conditions, and that more than half of physicians who do not have or use these tools indicated that tools such as these would be beneficial to their practice.

The current study therefore sought to perform a systematic review of the literature to: (1) investigate what tools, action plans or guidelines for the assessment and management of IBD are published for health professionals other than gastroenterologists (*i.e.*, non-specialists) in readily searchable published medical literature; and (2) compare what resources are available for IBD to those which exist for other chronic conditions such as asthma, DM and CCF.

LITERATURE SEARCH

A systematic review was performed using PubMed, EMBASE and Ovid Medline databases on May 19 2014 with the following search string: ("Inflammatory Bowel Disease" or "ulcerative colitis" or "Crohn's disease") and ("non-specialist" or "primary care physician" or "general practitioner" or "family physician") and ("Guidelines" or "Management" or "tool"). When the database allowed we exploded terms to be more inclusive. There was no publication date, publication language or publication status restriction.

This search was then repeated on June 10, 2014 with the assistance of an experienced research librarian at the University of Adelaide to ensure no relevant articles were missed. The search was performed on PubMed with the following more detailed search strategy: IBD [MH] or IBD*[TW] OR IBD[TW] OR Ulcerative Colitis[TW] OR CD[TW] OR CD[TW])) and (General Practi*[TW] or GP[TW] or GPs[TW] or Physicians, Family[MH] or Family Physician*[TW] or Physicians, Primary Care[MH] or Primary care physician*[TW] or Non-specialist*[TW] or General practice[MH] or Family practice[TW])) and (Practice Guideline [PT] or Guideline* [TW] or Manag* [TW] or Action plan*[TW] or Tool* [TW]. Titles of all articles were reviewed from both searches and abstracts of those which appeared suitable were read. Articles were selected if they outlined IBD management guidelines or discussed IBD educational tools which provided

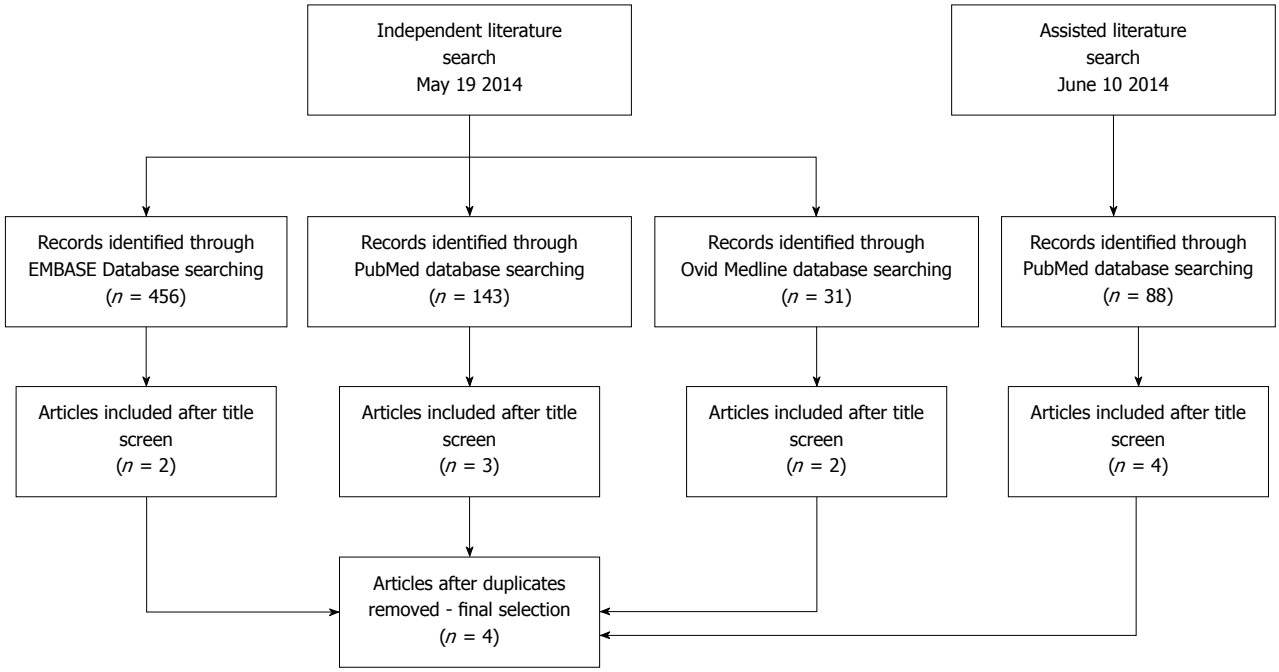

Figure 1 Literature search.

information regarding assessment and treatment of such patients. These tools were required to be directed at "non-specialists" and not at gastroenterologists.

To compare results between IBD and other chronic medical conditions, the search was repeated on PubMed using the detailed search strategy compiled with the research librarian. The term "IBD" was replaced by "Asthma[MH]", "Diabetes Mellitus[MH]" and "Congestive Cardiac Failure[MH]". A further, more specific search was conducted using Ovid Medline with the terms "action plan" AND "Inflammatory Bowel Disease". This search was then repeated for the same three other chronic diseases. An action plan was defined as a written set of instructions prepared by the doctor that aims to help the patient or their carer recognize worsening *of the relevant chronic disease* and also then gives clear instructions on what to do in response to this. Articles were only chosen if they had the search term "action-plan" in the title.

IBD FOCUSED LITERATURE SEARCHES

A total of 630 articles were identified by the initial literature search (Figure 1). Screening by title excluded 627 articles, leaving three articles to review. The repeated search performed with the assistance of a research librarian returned 88 articles. Screening by title excluded 84 articles, leaving 4 articles to review. Three articles had originally been identified in the initial search, leaving one additional article.

A summary of the articles is shown in Table 1. The first two articles[12,13] appeared to be ideally suitable for our search; however, the full-text article was not available in English. The remaining two articles[14,15] were written in English; however both papers discussed guidelines that were not solely focused on primary physician care. They were based upon guidelines for specialists, surgeons and primary care physicians as opposed to the first two articles where the focus was upon primary care physicians.

OTHER CHRONIC DISORDERS LITERATURE SEARCHES

In the comparative initial literature searches, a total of 982 asthma, 1709 diabetes, and 406 CCF asthma articles were identified. Screening by title and limiting the search to the past five years resulted in 11, 10 and 7 articles respectively, as shown in Table 2.

"ACTION PLAN" LITERATURE SEARCHES

A total of 278 articles were identified from the search when using the search terms "asthma" and "action plan". Fifty relevant articles remained after screening by title. This compared to no relevant articles regarding action plans for IBD, Diabetes Mellitus and CCF remaining after title screen from 1, 49 and 7 articles respectively. Detailed results obtained following the search for action plans are shown in Table 3.

DISCUSSION

Here we show that despite IBD being a worldwide chronic condition with increasing incidence[47,48], there is a near complete absence in the literature of tools to assist primary care doctors in delivering appropriate, evidence-based care. This is in contrast to the situation

Table 1 Article summary

Title	Author	Country	Language	Journal	Year
Inflammatory bowel disease: A «survival kit» for general practitioners	Kesseler Brondolo *et al*[18]	Switzerland	French	*Revue Medicale Suisse*	2010
Clinical practice guideline on diagnosis and treatment of Crohn's disease - summary for the general practitioner	Preiss *et al*[19]	Germany	German	*Medizinische Klinik*	2009
Production and evaluation of guidelines for the management of inflammatory bowel disease: The Leicester experience	Read *et al*[20]	United Kingdom	English	*Postgraduate Medical Journal*	1999
[1]Evidence-based clinical practice guidelines for Crohn's disease, integrated with formal consensus of experts in Japan	Ueno *et al*[21]	Japan	English	*Journal of Gastroenterology*	2013

[1]Additional article found by supervised search with librarian.

Table 2 Comparison search of educational tools and guidelines for other chronic diseases

Title	Author	Country	Language	Journal	Year
Asthma					
[Allergic asthma in adults: diagnosis and clinical management]	Allali *et al*[14]	Switzerland	French	*Rev Med Suisse*	2013
Guideline for the management of acute asthma in children: 2013 update	Kling *et al*[22]	South Africa	English	*S Afr Med J*	2013
[On general practitioners' care of patients with asthma]	Von Voshaar *et al*[23]	Germany	German	*MMW Fortschr Med*	2012
[Guidelines for "Asthma in children (ages 0-19)" for youth healthcare]	Breuning-Boers *et al*[24]	The Netherlands	Dutch	*Ned Tijdschr Geneeskd*	2012
An asthma action plan created by physician, educator and patient online collaboration with usability and visual design optimization	Gupta *et al*[25]	Canada	Asthma	*Respiration*	2012
[Management of acute asthma]	Saulnier *et al*[26]	France	French	*Rev Mal Respir*	2012
[Management of asthma in primary care medicine]	Pasche *et al*[27]	Switzerland	French	*Rev Med Suisse*	2010
Guideline for the management of chronic asthma in children--2009 update	Motala *et al*[28]	South Africa	English	*S Afr Med J*	2009
Development of an electronic pictorial asthma action plan and its use in primary care	Roberts *et al*[29]	United Kingdom	English	*Patient Educ Couns*	2010
[Asthma and pregnancy. Review of the current literature and management according to the GINA 2006-2007 guidelines]	Piette *et al*[30]	Belgium	French	*Rev Mal Respir*	2009
Summary of the 2008 BTS/SIGN British Guideline on the management of asthma	Levy *et al*[31]	United Kingdom	English	*Prim Care Respir J*	2009
Diabetes mellitus					
[Practice guideline. Diagnosis and treatment of type 2 diabetes mellitus][1]	Gil-Velázquez *et al*[15]	Mexico	Spanish	*Rev Med Inst Mex Seguro Soc*	2013
Intensification of insulin therapy in patients with type 2 diabetes mellitus: An algorithm for basal-bolus therapy	Abrahamson *et al*[32]	United States	English	*Ann Med*	2012
Managing chronic kidney disease in type 2 diabetes in family practice	Scott *et al*[33]	United States	English	*J Natl Med Assoc*	2011
Insulin management of type 2 diabetes mellitus	Petznick[34]	United States	English	*Am Fam Physician*	2011
Type 2 diabetes mellitus: practical approaches for primary care physicians	Gavin *et al*[35]	United States	English	*J Am Osteopath Assoc*	2011
Incretins: Clinical perspectives, relevance, and applications for the primary care physician in the treatment of patients with type 2 diabetes mellitus	Unger[36]	United States	English	*Mayo Clin Proc*	2010
[Management of type 2 diabetes in 2010. Insulins and injectable drugs: Role of the general practitioner]	Renneboog[37]	Belgium	French	*Rev Med Brux*	2010
Type 1 diabetes in children - emergency management	Siafarikas *et al*[38]	Australia	English	*Aust Fam Physician*	2010
Type 2 diabetes: An expanded view of pathophysiology and therapy	Unger *et al*[39]	United States	English	*Postgrad Med*	2010
Practical guidance to insulin management	Meneghini *et al*[40]	United States	English	*Prim Care Diabetes*	2010
Congestive cardiac failure					
Management of heart failure	Krum *et al*[16]	Australia	English	*Med J Aust*	2013
Effective strategies to improve the management of heart failure	Mills *et al*[41]	United States	English	*Prim Care*	2012
End stage heart failure patients - palliative care in general practice	Davidson *et al*[42]	Australia	English	*Aust Fam Physician*	2010
Echocardiography in heart failure - a guide for general practice	Prior and Coller[43]	Australia	English	*Aust Fam Physician*	2010
Heart failure management - a team based approach	Stewart[44]	Australia	English	*Aust Fam Physician*	2010
Chronic heart failure - management in general practice	Charles[45]	Australia	English	*Aust Fam Physician*	2010
1st national guideline for chronic heart failure. Essential responsibilities for the family practitioner	Aumiller[46]	Germany	German	*MMW Fortschr Med*	2010

Table 3 Articles relating to disease management "action plans"

Chronic disease	Articles identified following search	Remaining articles following title screen
Asthma	278	50
Congestive cardiac failure	7	0
Diabetes	49	0
Inflammatory bowel disease	1	0

for other chronic disorders such as asthma, DM and CCF (diseases with high prevalence rates[49-51]), where such tools are readily found and moreover, at least for asthma, action plans are also easily discovered.

This issue was addressed in a paper by the ECCO Quality of Health Care group, regarding optimization of quality of health care in IBD through one avenue of a consensus of simple guidelines for GP's[52], and a booklet has been produced by the American Gastroenterology Association outlying IBD patient's self-management strategies through the use of "action plan tools"[53]. These documents however, were not found through the systematic review indicating the need for a broader exposure. The articles do however give an evidence base to support the development of the proposed tools in the future.

IBD, both UC and CD predominantly have their onset in paediatric or young adult years[4]. It is currently observed largely in the developed countries of the world with data showing the highest prevalence values for IBD exist in Europe (UC, 505 per 100000 persons; CD, 322 per 100000 persons) and in North America (UC, 249 per 100000 persons; CD, 319 per 100000 persons)[54]. However, the prevalence is rising rapidly in other nations, especially in Asia, as they become more "westernized"[55]. By 2020, the number of people with CD and UC in Australia alone is projected to increase by 19.6% and 25% respectively[56], and this increasing prevalence is being mirrored around the world. Although various phenotypes exist, in both UC and CD, intermittent flares occur, requiring medication adjustments, specialist visits, hospitalizations and also operations with 50%-80% of CD patients ultimately requiring surgery for complications such as fistulas, strictures, abscesses and perforations[57]. Despite this, the vast majority of care occurs in the outpatient setting with various models of care involving primary care physicians, surgeons and gastroenterologists in varying roles, existing.

Two general practitioner studies reported that in a population of IBD patients, between 30%[12] and 70%[58] of patients were under specialist care. This suggests that a large proportion of people with IBD are predominantly managed in primary care. The majority of patients affected by UC do not require immunomodulator therapy, with 5-aminosalicylic acid (5ASA) formulations proven to be effective for the induction[59] and maintenance[60] of remission in patients with mildly to moderately active disease. Consequently primary care physicians are already managing a substantial proportion of IBD (although only a few patients each), so why are there not tools to help them?

A local example of such outpatient care can be taken from two South Australian (SA) tertiary IBD centers at the Royal Adelaide Hospital (RAH) and Flinders Medical Centre (FMC). A recent interrogation of their respective IBD databases revealed 1100 RAH and 1300 FMC patients with IBD. Given that approximately 4700 people are estimated to have IBD in SA based upon 2005 statistics[56], approximately 50% are having care either entirely through private specialists or predominantly *via* primary care physicians, general surgeons and rural physicians. Furthermore, those who are on the IBD databases are often also regularly seen by primary care physicians for minor issues also, especially those located outside of metropolitan regions. Internationally, an English general practice cohort found that in the first 12 mo after diagnosis there was a mean ± SD of 3.94 ± 3.15 specialist consultations, together with 3.34 ± 3.55 GP consultations specifically related to IBD, and that 55.4% UC and 43.0% of CD patients had been discharged from specialist follow-up[12]. Another United Kingdom study showed that about 32% of patients were under the care of a GP alone[13]. Patients appear to receive some or much care at a primary healthcare level and so we need to ensure this care is delivered well.

ESTIMATE OF INDOLENT AND MILD IBD COURSES

Currently, treatment *via* primary care doctors would be appropriate for patients with indolent to milder disease courses[61,62]. These patterns have been evidenced in older epidemiological cohorts from Copenhagen[63,64] during therapy with 5ASA and steroids and confirmed in Europe when immunological therapy was possible[63]. Calculations were then presented at thesis[56]. The proof that indolent to mild IBD disease exist in larger scale has been evidenced in unselected cohorts showing that indolent, mild-moderate and severe disease in UC and CD followed in Copenhagen from diagnosis and subsequent 8 years respectively shows 21%, 70% and 9% in UC (Figure 2) and 44%, 36% and 20% in CD[64] (Figure 3). Burisch[63] recently showed in new epidemiologic cohorts in Europe that 15% UC patients *vs* 9% CD patients run a severe and aggressive course after 1 year with the IBD diagnosis. The indolent to mild cases are ideal for handling predominantly in primary

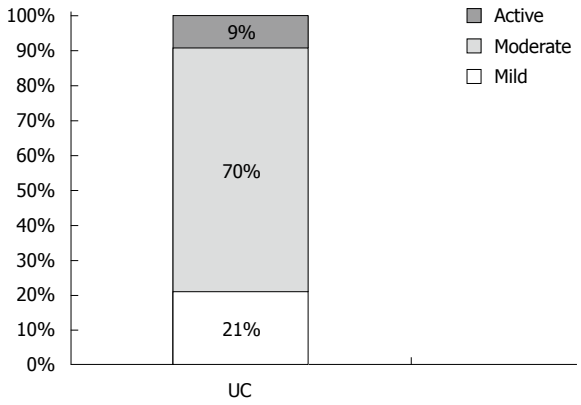

Figure 2 Ulcerative colitis disease severity in a copenhagen cohort. 1157 ulcerative colitis phenotypes, 8 years after diagnosis in an inception cohort 1962-1987, Copenhagen. 5-aminosalicylic acid and steroids therapy were available[64]. UC: Ulcerative colitis.

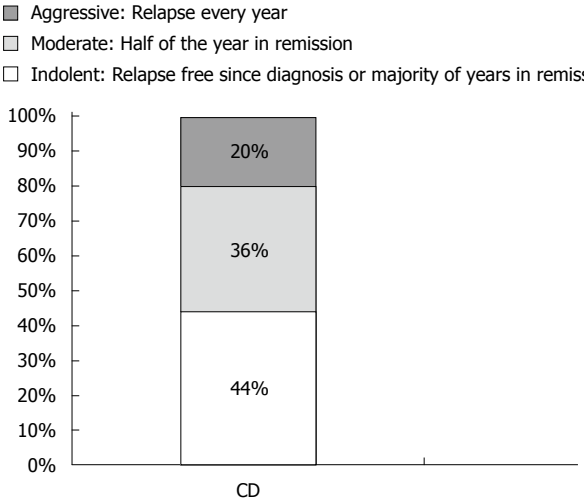

Figure 3 Crohn's disease severity in a copenhagen cohort. Three hundred and seventy-three Crohn's disease phenotypes, 8 years after diagnosis in an inception cohort 1962-1987, Copenhagen. 5-aminosalicylic acid and steroids therapy were available[64]. CD: Crohn's disease.

care.

SPECIALIST CARE

As research continues, additional therapeutic agents are entering the realm of IBD management. The choice of therapeutic strategy should be influenced by the activity, distribution, and pattern of disease and the balance between drug potency and side-effect profile; previous response to treatment and the presence of extra-intestinal manifestations[9]. Whilst, for IBD patients with aggressive or refractory disease, highly specialized knowledge and experience are required for providing optimal treatment[65], in community based cohorts, a large proportion of patients with UC never require steroids and nor do many with CD. This cluster would appear to have a milder phenotype and consequently does not necessarily require specialist intervention. For those who do however, this does not preclude their primary care doctors from meaningfully contributing to their care.

Few would argue that IBD patients should be managed without some specialist review or input into their care as data has shown that IBD patients who were treated by an IBD-non specialist are more likely to have uncontrolled diseases status[65]. However, there are a number of ways in which better primary physician care would enhance IBD outcomes, and these practitioners are ideally situated to follow up IBD patients more. If they were also supported by clinical tools, better IBD management is likely to be possible.

Specialist care is often limited by financial costs, waiting times to access specialists, lack of specialist services in region and distance to specialist services. Economically, primary care physicians can provide a more efficient service by being located closer to patients, having reduced fees and being able to address other healthcare issues during standard review. It therefore makes sense to give them tools to support them in providing better IBD care.

Table 4 Health issues potentially addressed by primary care physicians

Management of non-IBD related illnesses
Monitoring/treating IBD related compilations
Osteoporosis
Iron deficiency
Cardiovascular disease
Cancer
Preventative medicine
Vaccinations
Pap smears
Quit smoking
Skin checks (associated non-melanoma skin cancer risk with thiopurine use)
Addressing psychosocial confounding factors
Sexual health
Reproductive health
Psychological health
Medication compliance
Prompt recognition of IBD relapse and/or acute severe colitis

IBD: Inflammatory bowel disease.

PRIMARY CARE PHYSICIAN'S ROLE IN SHARED CARE OF IBD PATIENTS

With evolving therapeutic strategies in the care of IBD patients, evidence now suggests that outcomes are dependent on the quality of management, particularly in early years of diagnosis[66]. Early referral to a gastroenterologist for diagnosis and a structured management plan therefore, is vital[67]. However, referral does not transfer all care of the patient to a specialist and it is recognized now more than ever that shared or multidisciplinary care is the key to achieving optimal health-care outcomes. Opportunities for primary care physicians to promptly recognize IBD

relapse and/or acute severe colitis, contribute to other areas of quality IBD care and to reinforce specialist management are listed in Table 4.

EHEALTH

Other techniques to improve the out-patient management of IBD patients have also been investigated. One such strategy has been to focus on improving self-management as this has been demonstrated to improve outcomes of symptoms, psychological well-being, and health-care resource use[67] and to use it as a component of distance management. eHealth telemedicine itself is a form of distance management where patients have the ability to partly self-manage their illness through this technology. Patients are empowered by using eHealth tools. Distance management of IBD has been shown to significantly decrease clinic visit utilization, but at this stage does not significantly affect relapse rates or hospital admission rates[68]. eHealth internet-based technology is a tool that can be utilized to both promote and enhance gastrointestinal disease management whilst at the same time reduce healthcare costs in IBD[69]. It would seem likely that combining eHealth support for patients' self-management with tools to support their primary care doctors may synergistically improve non-specialist IBD care.

PRIMARY PHYSICIAN KNOWLEDGE AND EXPERIENCE WITH IBD

This systematic review documents that few tools exist to enhance the knowledge of primary healthcare physicians or non-experts to manage patients with IBD. This may seem surprising given one survey reported 30% of GPs felt uncomfortable managing IBD in general and 71% and 91% were uncomfortable with the use of immunomodulators and biologic agents respectively, whilst more than 70% would appreciate such clinical support tools[11]. A separate survey also reported 71.8% of GPs indicated that they needed better instruction regarding IBD[70]. If primary physician knowledge and experience with IBD is low it may lead to suboptimal management of IBD in the outpatient setting which may lead to consequences such as delayed recognition of acute severe colitis, inappropriate use of steroids, overuse of aminosalicylates in poor responders or delayed intervention in a relapse.

Written actions plans for chronic illnesses have been shown to improve health outcomes. This has been shown in asthma where as part of self-management education, action plans improve health outcomes including hospital admissions, emergency medical contacts, days missed from work, nocturnal asthma symptoms and quality of life in adults[71]. A meta-analysis of self-management in children and adolescents (2-18 years) also showed improved lung function, reduced morbidity and utilization of healthcare resources[72]. Written actions plans have also been found to be acceptable and useful in the setting of COPD[73] and asthma[74].

In conclusion a gap currently exists in the provision of supportive education tools for primary care practitioners for IBD outpatient care shown by our systematic review, which is in contrast to other chronic diseases. Current levels of non-specialist knowledge and confidence in treating IBD patients has been shown in the past to be suboptimal. A large proportion of IBD care occurs in the outpatient setting and consequently adequate knowledge of the condition and its basic management by primary care physicians is important to improve IBD outcomes and is likely to also be cost effective. Developing tools that address this issue and that are critically appraised by those who will use them, is first step to enhancing this patient care and closing the gap.

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