The Evolution of IBD Perceived Engagement and Care Needs Across the Life-Cycle: A Scoping Review

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Abstract

Background: The chronic and progressive evolution of Inflammatory Bowel Diseases (IBD), with its prototypical fluctuating trend, creates a condition of psycho-social discomfort, impacting the quality of life in terms of personal, working and interpersonal.

Aims: In this article, we want to identify the nature and extent of the research evidence on the life experiences, the perceived engagement and the psychosocial and medical needs of people affected by IBD across the lifecycle.

Methods: Following the approach set out by Arksey and O'Malley and the PRISMA extension for scoping reviews, we conducted a scoping review in March 2019 and closed the review with an update in October 2019. It was performed using electronic databases covering Health and Life Sciences, Social Sciences and Medical Sciences, such as PubMed, Medline, Embase, Scopus, Cochrane, Web of Science, PsycInfo.

Results: We identified 95 peer-reviewed articles published from 2009 to 2019, that allowed to detect the main needs in children (psychological, need to be accepted, physical activity, feeding, parent style and support, social needs), adolescents (to understand, physical and psychological needs, protection, relational, gratitude, respect and engagement) and adults (information, medical, psychological, social, work-related, practical, future-related, engagement). Although the literature confirms that the majority of the IBD units have planned provision for the different types of transitions, the quality and appropriateness of these services have not been assessed or audited for all the kind of challenges across the life cycle.

Conclusions: The literature shows the relevance of organising a flexible, personalised health care process across all the critical phases of the life cycle, providing adequate benchmarks for comparison in a multidisciplinary perspective and ensuring continuity between hospital and territory.

1. Background

Inflammatory Bowel Disease (IBD) is a group of idiopathic, chronic and relapsing clinical conditions that primarily affect the gastrointestinal tract. IBD includes two different chronic diseases, Ulcerative Colitis (UC) and Crohn's Disease (CD), closely related but with heterogeneous disease processes. Worldwide, the prevalence of IBD is estimated to reach up to 396 people per 100,000 with the highest incidence reported in North America, Northern and Western Europe (1). It is currently estimated that more than 3 million of people in Europe and more than 5 million worldwide suffer from IBD. There is a rising trend, attested that 75% of CD studies and 60% of UC studies stress a rapid increasing incidence. Considering UC, prevalence rates of up to 505 and 249 people per 100,000 individuals are recorded, respectively in Europe and North America (2). In general, the peak age of onset for CD is between 20 and 30 years of age, whether for UC is between 30 and years old (3, 4). Urbanity and rapid industrialization in the Eastern World seems to be related with this trend (2). In particular, among the causes of this buildup, were also listed milk formula feeding, use of appendectomy, lifestyle and changing diets (5).

In the specific case of UC, the episodes of remission and relapse are unpredictable and highly variable from one patient to another: there are patients who experience prolonged asymptomatic periods and those who continually face the symptoms of UC (6, 7). UC often occurs in adolescence and young adulthood, and is characterized by the presence of diarrhoea, flatulence, fecal urgency, abdominal pain and cramps, rectal bleeding and fatigue, symptoms that negatively impact on Quality of Life (Quality of Life, QoL) and the well-being of the person (8). CD, on the other hand, in addition to causing abdominal pain, distension, swelling and vomiting, if restrictive it may precede the development of an internal disease with the formation of fistulas (9), significantly impacting the QoL. Previous studies highlight that also psychological issues may play a negative role on the disease activity and QoL (10, 11). Nevertheless, it is still unclear if and, eventually, how psychological factors can also contribute to the development of IBDs (12).

Growing attention in the last decade has been paid to the role of IBD patients in their care management (13, 14). To enhance IBD patients' participation along their patient journey it is important to understand their care needs and expectation. Improving psychological counselling, social welfare and the overall quality of the medical and pragmatic assistance provided to IBD patients is an urgent goal for bettering patients' wellness and quality of life (15).

The debate about IBD patients care needs and priority is growing although fairly fragmented. Searle and Bennet (16) reviewed a decade of psychological literature debate in order to synthesize the relationship between psychological stress and IBD symptomatology as well as to critically investigate the impact of psychological intervention on IBD symptoms management. Graff and coll. (2009) have systematized the evidences of psychological needs in IBD care by discussing the importance of enhancing psychological counselling to sustain the effectiveness of clinical interventions (17). Kemp and coll. (18) conducted a meta-synthesis of qualitative research evidences about IBD patients care needs by systematizing the psychological tensions and conflicts experienced during daily life between the management of the disease symptoms and the attempt to keep some form of life normality. McCombie et colleagues (2013) reviewed coping strategies of IBD patients and underlined priorities for psycho-therapy and psychological intervention in synergy with medical care (19). However, recent systematizations of the literature about IBD psychological and social welfare needs are lacking. Furthermore, the available reviews are mainly focused on the psychological needs of IBD patients and do not consider their pragmatic and social care needs, which are important in the goal of increasing patients' engagement in self-management. Finally, the reviews available in the literature mainly focus on the adult patients, whereas less attention has been paid to paediatric patients and in particular to their transition to adulthood.

In order to fill these gaps, and to contribute to improve social welfare care and patient engagement initiatives dedicated to IBD patients along their life-course, we conducted this narrative review. More into details, the aim of this narrative/scoping review was to identify and describe the evidences on life experiences, psychosocial and social needs in people with IBD. Psychological needs are essential to mental health and they can be generated either internally or by interactions between the individual and

the environment. The fluctuating nature of IBDs has been described to damage employment, social and leisure activities, relationships and psychological well-being, arising different kind of needs. This review provides the basis for developing broader research on the relatively underexplored topics and consequently improves specific interventions that could address patients' needs.

1.1 Objectives

This scoping review aimed to map the key concepts that characterize the life experiences, the psychosocial and medical needs of people affected by IBD by highlighting the main types of published evidences and sources available. In this case, the scoping review was carried out to explore previous research activity, disseminate findings, and identify gaps in the comprehension of patient's needs.

2. Methods

This scoping review was set out thanks to the approach based on five-stage framework created by Arksey and O'Malley and the PRISMA extension for scoping reviews (20). The five stages are as follows: - identifying the initial research questions; -identifying relevant studies, study selection; -charting the data; - collating, summarising and reporting the results. This approach guarantees the implementation of a rigorous and transparent process, which increases the reliability and replicability of the study findings (21).

2.1 Identifying the initial research question

According to the objectives (cfr. par. 1.1), this review was guided by the following research questions:

- What are the overriding psychological and social welfare needs of people with IBD in the patient journey?
- How do those needs evolve along the IBD patient life cycle?
- What are the factors which may increase IBD patient engagement in their patient journey?

2.2 Identifying relevant studies: the literature search

The literature search was conducted from March to October 2019, using electronic databases covering Health and Life Sciences, Social Sciences and Medical Sciences, such as PubMed, Medline, Embase, Scopus, Cochrane, Web of Science, PsycInfo. In addition, a hand search of the reference list of identified articles and reviews was undertaken as well as the "cited articles" search tool was used to identify any other primary sources within grey literature.

According to Arksey & O'Malley (21), key concepts and search terms were developed to catch available literature related to psychological, medical and social welfare needs in people with IBD. The use of search tools such as educational subject headings and Boolean operators to narrow, widen and combine literature searches were used. The keyword used developed to guide the search are outlined in Table 1.

Table 1
Key words adopted for the search strategy

Key words
("IBD*" OR "inflammatory bowel disease*" OR "Crohn*" OR "ulcerative colitis") AND ("Psych*" OR "social*" OR "famil*" OR "engagement" OR "empowerment") AND ("intervention" OR "trial" OR "program" OR "strateg*" OR "counsel*" OR "treatment" OR "support")

2.2.1 Inclusion and exclusion criteria

Inclusion and exclusion criteria were developed in order to be as comprehensive as possible in the identification of the evidences (Table 2).

Table 2
Inclusion and exclusion criteria

Time period	2009–2019	Studies outside these dates
Language	English (recognized language of international scientific debate)	Non-English
Type of article	Original research, published in a peer review journal. Qualitative or quantitative studies; commentaries, letter, editorial	Articles that were not peer reviewed, only abstract available
Ethics clearance	Studies with approved ethics notification	Studies without approved ethics notification
Study focus	Transitions during the life cycle and therefore in the passages between childhood and adolescence, adolescence and young adulthood, young adulthood and adulthood, adulthood and mature age, mature age and old age	Studies that don't consider transitions during the life cycle
Literature focus	Studies that explicitly discuss socio-assistance and psychological needs, good practices for social assistance, the concept of Patient Engagement, studies on social and /or psychological strategies that enhance the patient's point of view and his experience, studies that enhance the patient's point of view and experience, studies that present a clear theoretical framework on the patients' experience, studies that focus on the experience of using the treatment, quality of life indicators and monitoring, in the context of chronic pathologies considered	Articles that didn't make a passing or token reference to engagement and psychological and/or social welfare needs. Articles that were discussion or personal opinion pieces
Population and sample	Inflammatory Bowel Disease, IBD; Ulcerative Colitis, UC; Crohn's Disease, CD	All the other chronic diseases

2.3 Study selection

Using the key search descriptors, in the different electronic databases, articles were identified and duplicates were excluded (n = 12,569). After a first screening based on title and abstract, the records

examined were 1193. An accurate review of both titles and articles allowed to reveal a large number of papers that showed low level reference to research questions (n = 445) or studies related to other chronic diseases (n = 51). Moreover, other articles were excluded because they were not peer reviewed (n = 78) or only the abstract was available (n = 167). Guided by the inclusion and exclusion criteria, 95 research articles were identified as being relevant to the research topic. The full version of the texts was considered and each paper was reviewed and confirmed to be or not appropriate by the authors (EV; CB). Moreover, this process allowed to consider the reference lists of each article and identify any further additional relevant literature. The process of article selection followed the PRISMA extension for scoping reviews, as mentioned above (20). Figure 1 illustrates the selection's process.

During the process of selection, several studies were excluded because they didn't reflect the eligibility criteria.

2.4 Data charting and collation

Arksey and O'Malley's delineated a fourth passage (21) that aims to chart the selected articles. Data were extracted using standardised forms and entered into Microsoft Excel (Microsoft, Redmond, Washington, USA) by one reviewer (EV) and a 10% sample was checked for accuracy and completeness by another (FP). Reviewers resolved discrepancies through consensus. Given the qualitative and quantitative nature of the included studies, a structured analysis grid according to mixed methods approach was followed: 1) methodological characteristics of the study (e.g. year of publication, country of first author, study design, number of participants); 2) characteristics of the participants (e.g. diagnosis, age group, presence of caregivers); 3) characteristics of socio-welfare and psychological needs (e.g. for which transition phase, type of need expressed, theoretical framework considered) 4) characteristics of the social and / or psychological strategy (if present: type of strategy, tools used, group or individual, theoretical foundations of the same); 5) results obtained (e.g. measured outcomes, method of evaluating results, overall results achieved). Details of the included studies are shown in Table 3 -Supplementary materials.

3. Findings

This review yielded 95 articles from 22 countries. The most of them were conducted in the USA (n = 24, 25.7%) or in the UK (n = 15, 15.8%), followed by Canada (n = 8, 8.4%). Twenty-three articles (24.21%) were published in 2018, followed by 18 (18.9%) published in 2017, 14 (14.73%) in 2016 and 11 (11.6%) in 2015, indicating an increasing trend. A relevant part of the included studies, twenty-four (25.7%) were surveys and cross-sectional surveys. The most part were quantitative studies (n = 65, 68.4%) 8 (8.4%) studies were qualitative, 6 (6.3%) were mixed method studies and 19 (29.2%) were reviews or guidelines.

Sixty articles (63.15%) are related to needs in adults, 56 (58.9%) are inherent to transitional needs, 68 (71.5%) regard needs in adolescents and 20 (21.05%) in children. A total of 23,776 participants with an age range of 31.55 were included. It is relevant to note that most articles cover more than one area of need (Table 4). Fifty studies (52.6%) focus on IBDs in general without any sort of specification, 4 (4.2%)

are related to UC and 7 (7.3%) regard CD. The others remaining specified clearly how many patients had what kind of diagnosis.

Table 4

Articles included in the review and divided considering the main theme and phase of the life cycle

Children	Number of records	References
Psychological needs and need to be accepted	3	Zmeskalova et al., 2016; Bokemeyer et al., 2013; Dignass et al., 2015
Needs related to physical needs and physical activity	2	Mählmann et al., 2017; Vedrana, Bramhagen, Idvall, & Wennick, 2017
Needs related to feeding	10	Pituch-Zdanowska et al., 2019; Miele et al., 2018; Rocha, Sousa, Reis, & Santana, 2019; Tomar, Sanjeevani K; Kedia, Saurabh; Upadhyay, Ashish D, Bopanna, Sawan et al., 2017; Cohen, Aaron B; Lee, Dale; Long, Millie D; Kappelman, Michael D., et al., 2014; Hou, Jason K; Lee, Dale; Lewis, James, 2014; De Vries, Jeanne H.M.; Dijkhuizen, Milou; Tap, Petra Witteman, Ben J.M., 2019; Kakodkar, Samir, Mutlu, Ece A, 2017
Parenting style and support	3	Kluthe et al., 2018; Lindström, Åman, Anderzén-Carlsson, & Lindahl Norberg, 2016; Zmeskalova et al., 2016
Social needs	2	Vedrana et al., 2017; Vejzovic, Bramhagen, Idvall, & Wennick, 2018;
Adolescents	Number of records	References
Need to understand	9	Olsen, Jensen, Larsen & Sorensen, 2016; Gumidyala et al., 2017; Cho et al., 2018; Cho et al., 2018; Fu et al., 2017; McCartney, 2011; Gumidyala et al., 2018; Gray et al., 2015; Klostermann, McAlpine, Wine, Goodman & Kroeker, 2018;
Physical needs	3	Olsen, Jensen, Larsen & Sorensen, 2016; Zmeskalova et al., 2016; Smith & Gettings, 2016;
Psychological needs	8	Gamwell et al., 2018; Wu & Zhong, 2018; Zmeskalova et al., 2016; Smith & Gettings, 2016; Cho et al., 2018; Cho et al., 2018; Hummel et al., 2013; Lugasi, Achille & Stevenson, 2011;
Need of protection, safeness	3	Gray et al., 2018, 2015; Reiss, Gibson, & Walker, 2017; Smith & Gettings, 2016;
Relational and social needs	13	Hummel et al., 2013; Vedrana et al., 2017; Adler & Sc, 2016; Olsen, Jensen, Larsen & Sorensen, 2016; Gamwell et al., 2018; Wu & Zhong, 2018; Zmeskalova et al., 2016; Cho et al., 2018; Cho et al., 2018; De Silva & Fishman, 2014; Rohatinsky, Risling, Kumaran, Hellsten & Thorp-Frosli, 2018; McCartney, 2011; Gumidyala et al., 2018; Gray et al., 2015;

Children	Number of records	References
Need for gratitude, respect and respect for your needs	1	Olsen, Jensen, Larsen & Sorensen, 2016;
Engagement needs	31	Stollon et al., 2017; Zeisler & Hyams, 2014; Rosen, Annunziato, Colombel & Benkov, 2015; Cho et al., 2018; Plevinsky, Gumidyala & Fishman, 2015; Gray et al., 2018; Yerushalmy-Feler et al., 2017; Escher, 2009; van Groningen, Ziniel, Arnold & Fishman, 2012; Karim, Porter, McCombie, Geary & Day, 2019; Timmer et al., 2017; Adler, 2016; Szeto et al., 2018; Fishman, Mitchell, Lakin, Masciarelli & Flier, 2016; Fu et al., 2017; Fishman, Barendse, Hait, Burdick & Arnold, 2015; Jeganathan et al., 2017; De Silva & Fishman, 2014; Rohatinsky, Risling, Kumaran, Hellsten & Thorp-Froslic, 2018; McCartney, 2011; Bennett, Moore, Bampton, Bryant & Andrews, 2016; Otto et al., 2019; Cole et al., 2015; Gumidyala et al., 2018; Maddux, Ricks & Bass, 2017; Schmidt, Herrmann-Garitz, Bomba & Thyen, 2016; Gray et al., 2015; Gray et al., 2015; Van den Brink et al., 2019; Klostermann, McAlpine, Wine, Goodman & Kroeker, 2018; Lugasi, Achille & Stevenson, 2011;
Adults	Number of records	References
Needs of information	11	Wu & Zhong, 2018; Butcher, Law, Prudham & Limdi, 2011; Bernstein, Promislow, Rawsthorne, Walker & Bernstein, 2011; Catalan-Serra et al., 2015; Gordon, Mcewan, Maguire, Sugrue & Puelles, 2015; McDermott et al., 2018; van Deen et al., 2017; Wardle & Mayberry, 2014; Baker, Lee, Jones, Brown & Lobo, 2018; Kamp & Brittain, 2018; Mikocka-Walus, Power, Rook & Robins, 2015;
Medical needs	1	Baker DM et al., 2018
Psychological needs	13	Jordan, Ohlsen, Hayee & Chalder, 2018; Knowles, Andrews & Porter, 2018; Klag et al., 2017; Goodhand, Wahed & Rampton, 2009; Chiarini at al., 2017; van Erp et al., 2017; Mcdermott et al., 2015; Tribbick et al., 2017; Vegni et al., 2018; Muller, Prosser, Bampton, Mountifield & Andrews, 2010; Wang et al., 2016; Trindade, Ferreira & Pinto-Gouveia, 2017; Gurková & Soósová, 2018;
Social and work related needs	8	Calvet et al., 2018; Leso, Ricciardi & Iavicoli, 2015; Restall et al., 2016; Schreiner et al., 2017; van der Have et al., 2015; Haapamäki, Turunen, Roine, Färkkilä & Arkkila, 2009; Froes et al., 2018; Muller, Prosser, Bampton, Mountifield & Andrews, 2010;
Support needs	10	Jordan, Ohlsen, Hayee & Chalder, 2018; Garcia-Sanjuan, Lillo-Crespo, Sanjuan-Quiles, Gil-Gonzalez & Richart-Martinez, 2016; Knowles, Andrews & Porter, 2018; Lahat, Neuman, Eliakim & Ben-Horin, 2014; Chiapponi, Witt, Dlugosch, Gulberg & Siebeck, 2016; Klag et al., 2017; Goodhand, Wahed & Rampton, 2009; Iglesias et al., 2009; Dibley et al., 2018; Kamp & Brittain, 2018;

Children	Number of records	References
Practical needs	11	Limdi, Aggarwal & McLaughlin, 2016; Limdi, 2018; Kakodkar & Mutlu, 2017; De Vries, Dijkhuizen, Tap & Witteman, 2019; Larussa et al., 2019; Hou, Lee & Lewis, 2014; Cohen et al., 2014; Rocha, Uli, Reis & Santana, 2019; Tomar et al., 2017; Albenberg et al., 2019; Schreiner et al., 2019;
Needs related to the future	2	Nutting & Grafsky, 2018; Ghorayeb, Branney, Selinger & Madill, 2018;
Engagement needs	5	Dibley et al., 2018; Kamp & Brittain, 2018; Siegel et al., 2016; Mikocka-Walus, Power, Rook & Robins, 2015; Carpio et al., 2016;
Transitions	Number of records	References
Transition to school	0	
Transition to adolescence	2	Cullen & Beattle, 2009; Fu et al., 2017;
Transition to adulthood	46	van Groningen, Ziniel, Arnold & Fishman, 2012; Cullen & Beattle, 2009; Van den Brink et al., 2019; Stollon et al., 2017; Yerushalmy-Feler et al., 2017; Timmer et al., 2017; Gray et al., 2018; Plevinsky, Gumidyala & Fishman, 2015; Cho et al., 2018; Zeisler & Hyams, 2014; Rosen, Annunziato, Colombel & Benkov, 2015; Karim, Porter, McCombie, Gearry & Day, 2019; Adler, 2016; Szeto et al., 2018; Fishman, Mitchell, Lakin, Masciarelli & Flier, 2016; Fu et al., 2017; Fishman, Barendse, Hait, Burdick & Arnold, 2015; Jeganathan et al., 2017; De Silva & Fishman, 2014; Rohatinsky, Risling, Kumaran, Hellsten & Thorp-Frosllie, 2018; McCartney, 2011; Bennett, Moore, Bampton, Bryant & Andrews, 2016; Otto et al., 2019; El-Matary, 2009; Elli et al., 2019; Clarke, Tilean, Lusher & Joanne, 2016; Afzali & Wahbeh, 2017; Bincy & Stacy, 2014; van Rheenen et al., 2017; Brooks et al., 2017; Brooks, Smith & Lindsay, 2018; Cole et al., 2015; Shapiro et al., 2019; Leung, Heyman & Mahadevan, 2011; Gumidyala et al., 2018; Hummel et al., 2013; Maddux, Ricks & Bass, 2017; Bollegala & Nguyen, 2015; Schmidt, Herrmann-Garitz, Bomba & Thyen, 2016; Gray et al., 2015; Gray et al., 2015; Van den Brink et al., 2019; Trivedi, Holl, Hanauer & Keefer, 2016; Klostermann, McAlpine, Wine, Goodman & Kroeker, 2018; Lugasi, Achille & Stevenson, 2011; Goodhand, Hedin, Croft & Lindsay, 2011;
Transition during the adulthood	3	Gordon, Mcewan, Maguire, Sugrue & Puelles, 2015; Ghorayeb, Branney, Selinger & Madill, 2018; Nutting & Grafsky, 2018
Transition to remissions	1	Iglesias et al., 2009;
Transition to/from surgery	4	Olsen, Jensen, Larsen & Sorensen, 2016; Kamp & Brittain, 2018; Dibley et al., 2018; Baker, Lee, Jones, Brown & Lobo, 2018;

Children	Number of records	References
Transition to ageing	0	
No transition	53	Smith & Gettings, 2016; Gumidyala et al., 2017; Zmeskalova et al., 2016; Gamwell et al., 2018; Wu & Zhong, 2018; Butcher, Law, Prudham & Limdi, 2011; Carpio et al., 2016; Bernstein, Promislow, Rawsthorne, Walker & Bernstein, 2011; Catalan-Serra et al., 2015; McDermott et al., 2018; van Deen et al., 2017; Wardle & Mayberry, 2014; Jordan, Ohlsen, Hayee & Chalder, 2018; Garcia-Sanjuan, Lillo-Crespo, Sanjuan-Quiles, Gil-Gonzalez & Richart-Martinez, 2016; Knowles, Andrews & Porter, 2018; Lahat, Neuman, Eliakim & Ben-Horin, 2014; Chiapponi, Witt, Dlugosch, Gulberg & Siebeck, 2016; Klag et al., 2017; Calvet et al., 2018; Froes et al., 2018; Leso, Ricciardi & Iavicoli, 2015; Restall et al., 2016; Schreiner et al., 2017; van der Have et al., 2015; Siegel et al., 2016; Limdi, Aggarwal & McLaughlin, 2016; Limdi, 2018; Kakodkar & Mutlu, 2017; De Vries, Dijkhuizen, Tap & Witteman, 2019; Larussa et al., 2019; Schreiner et al., 2019; Hou, Lee & Lewis, 2014; Cohen et al., 2014; Rocha, Uli, Reis & Santana, 2019; Tomar et al., 2017; Chiarini et al., 2017; van Erp et al., 2017; Gurková & Soósová, 2018; McDermott et al., 2015; Tribbick et al., 2017; Vegni et al., 2018; Muller, Prosser, Bampton, Mountifield & Andrews, 2010; Wang et al., 2016; Trindade, Ferreira & Pinto-Gouveia, 2017; Mikocka-Walus, Power, Rook & Robins, 2015; Albenberg et al., 2019; Pituch-Zdanowska et al., 2019; Miele et al., 2018; Haapamäki, Turunen, Roine, Färkkilä & Arkkila, 2009; Goodhand, Wahed & Rampton, 2009;
No needs	13	El-Matary, 2009; Elli et al., 2019; Clarke, Tilean, Lusher & Joanne, 2016; Afzali & Wahbeh, 2017; Bincy & Stacy, 2014; van Rheenen et al., 2017; Brooks et al., 2017; Brooks, Smith & Lindsay, 2018; Shapiro et al., 2019; Leung, Heyman & Mahadevan, 2011; Bollegala & Nguyen, 2015; Trivedi, Holl, Hanauer & Keefer, 2016; Goodhand, Hedin, Croft & Lindsay, 2011;

Participants are recruited from IBD clinics, hospitals, outpatients clinics, national charities, community based study and media advertisements.

We resumed in the following sections the main findings related to our research questions (cfr. par. 2.1).

3.1 The needs in children with IBD

The main needs in children with IBD cover five areas.

Psychological needs and need to be accepted

Children may express anxiety and, sometimes, distress, because of the chronic symptoms or exacerbations experienced. In general, the needs of a child tend to be in relation to those expressed by the parents and the pediatrician who takes care of them, since everyone has the unconscious desire to completely disappear the symptoms. In the specific case of children, tolerance, empathy, hope, safety and control, need to be carefully managed also towards parents and paediatricians (22). Psychological problems such as depression, helplessness, anxiety, family arguments and school difficulties have not

been recognized as associated with IBD (23). Similarly, non-specific symptoms such as, for example, fatigue, dizziness, headache, frequent infections or shortness of breath, were not considered associated with IBD (24).

Needs related to physical needs and physical activity

Children report desire to feel healthy and tend to be afraid to talk about their pathology. They say that they can only rarely share with their parents how they feel physically and their thoughts because they are afraid of raising further concerns. Furthermore, the changes in one's body that could occur if it were necessary to remove the intestine provoke fear. In particular, they are embarrassed if they have to confide in someone the need to often resort to the toilet so they tend not to talk about it with anyone. For this reason, they often skip physical activities (25, 26).

Needs related to feeding

Studies stress how, due to their dietary beliefs, parents of children with IBD, commonly introduce dietary restrictions. Despite malnutrition and specific nutritional deficiencies are frequent among IBD patients, and the majority of them need nutritional treatment, there are no evidences for answer to this need in children (27, 28). Moreover, only few studies have considered nutritional status as a risk factor associated to higher rates of hospitalization and the time passed at a clinic (29). Miele and colleague tried to defined the steps in instituting dietary or nutritional management in light of the current evidence and to offer a useful and practical guide to physicians and dieticians involved in the care of pediatric IBD patients, paying a peculiar attention to the alimentary options available (e.g. Exclusive Enteral Nutrition (EEN); Partial Enteral Nutrition (PEN); Specific carbohydrate diet (SCD); Lactose free diet (LFD); Crohn's disease exclusion diet (CDED)) (30).

Parenting style and support

The type of parenting style is important: indeed, scientific literature has shown that one of the parents, usually the mother, tends to be overprotective towards the children, facilitating the development of the "perpetually sick child", which would significantly obstacle responsibility's development. While both parents may show significant fear and/or apprehension about their child's health, usually the responsibility for most home and health care activities is placed on the mother. However, there are very few studies about the role of parents in both the infant and adolescent care processes. The reason of this scarcity of literature could be related to the fact that, with a child affected by a chronic disease, parents tend physiologically to be more apprehensive and have difficulty managing normal boundaries. Parents reported a change in how they responded to their children's health and physical ability after diagnosis. While some parents feel they don't have to insist as much as they did before diagnosis, others actively encourage their children to be as active as possible. Parents are also often concerned about how their children are doing compared to their friends, or a baseline considered "healthy" or "normal". Furthermore, the majority of parents after the diagnosis are concerned with the preparation and consumption of food with greater attention than in the past. Whether it is supporting your children by moving the whole family

on a special diet or by making an effort not to eat foods that your child cannot take. Discussion of parenting techniques in this context can be helpful (22, 31, 32).

Social needs

A large number of articles reported that children with IBD experience fear of being excluded or feelings of deep loneliness, sometimes preferring this latter, because they are afraid that others perceive them as “sick” or “different”. For this reason, while appreciating the help of teachers and nurses at school, they tend not to often ask for help, because they live it with embarrassment or humiliation (26). The children indicate that they have some close friends, with whom they can share their thoughts and “talk about everything”. However, it seems that they are more likely to talk about their condition in general, avoiding referring to specific physical states attributable to the pathology. In addition, many of them report having more pleasure in sharing how they feel and their thoughts with those who live the same condition, because they are perceived as more able to understand their feelings and experiences (33). Additional resources noted that the children feel themselves as healthy, but they are afraid of not being able to control the need for “triggers”, especially during school hours. The constant fear that something unpleasant may happen limits them in their daily life and induces fear of being excluded. In this situation, they are also concerned that they will no longer receive future invitations from the group of classmates due to frequent absences (26).

3.2 The needs in adolescents with IBD

Researches highlight a significant misalignment in the estimation of health concerns between IBD adolescent patients and their paediatricians (34) (Tables 3 and 4).

Need to understand

Younger patients are often characterized by poor basic knowledge of their medical condition and possible treatments. Among the most relevant knowledge to be transmitted are the basic medical history and the nature of the clinical condition, its duration, the names and doses of drugs, allergies, the names of the medical team and how to contact the team in case of need (35). The reactions to the diagnosis are described by the adolescents as different according to the previous degree of knowledge of the pathology itself: indeed, those who have previous knowledge due to family experiences or readings about the pathology, generally feel more quiet; on the contrary, those who have no idea what IBD is, feel dismay or apathy. Despite this, a commonly expressed feeling is represented by the relief of being able to name your suffering, although awareness of the possibility or reality of a life of management and treatment of IBD is shocking for many (31). Increased knowledge has the potential to improve both physical and mental health outcomes during the transition from paediatric to adult care (36, 37). The increasing knowledge of their body led the adolescents to try to identify triggers and patterns as well as to recognise the flare-ups. This situation gives them control over their illness, improving their decision-making (36), even if they can feel helpless or misunderstood. Finally, other factors have been associated with greater knowledge of the

disease include self-efficacy, health satisfaction, previous positive treatment experiences and communication (36).

Physical needs

Loss of control impacts on the feeling to be independent in adolescents. They suddenly experience feelings of embarrassment and alienation in relation to both themselves and to others, because they are dependent on constant access to toilet facilities. Moreover, they experience low energy and, if surgery is required, adolescents may suffer from pain and bloody diarrhoea and are burned by anxiety. Some patients experience stomach pain, side effects such as weight gain or changes in facial form and acne before and/or after the intervention (38).

Psychological needs

Young adults who are confronted with a chronic disease are often embarrassed and resentful because of the greater degree of physical and emotional dependence they experience at a time when, socially, they should be active, healthy, successful. These feelings of embarrassment can be very important to consider in relation to even the earliest deeper love relationships that they find themselves experiencing (39). Given that IBD is often diagnosed in young adulthood, a time when building intimate relationships and sexuality are particularly important, the difficulties relating to body image emerge with particular relevance at this stage. In particular, young women tend to overestimate the physical aspect in defining their personal and social value. As a result, being a woman with IBD is considered a risk factor for developing a negative body image and about 70% of female IBD patients report body dissatisfaction (40). Moreover, depression and anxiety are the most common psychiatric problems in adolescents with IBD and can significantly impair their quality of life and school skills and even lead to suicide (41).

Need of protection, safeness

Unlike chronic diseases and/or disabilities diagnosed in early childhood, IBDs can be diagnosed on average around 15 years of age, subjecting adolescents to an accelerated transition path, and facilitating the experience of negative feelings such as, for example, embarrassment or vulnerability, and negative emotional experiences such as lack of control or social isolation (42, 43). In particular, they are more prone to have low self-esteem, behavioral problems, alterations in the perception of body image and difficulties in social skills. Further concerns concern not knowing what to expect in adult care, not appreciating their environment, not trusting new doctors and health professionals in general, and having to repeat their history, making sure that medical records are transferred to appropriately (44).

Relational and social needs

In an adult environment, you should have communication, negotiation and assertiveness skills, so that you can assert your views effectively. Maturity and experience play an important role in developing these skills. Many adolescents suffering from IBD are intelligent, which is why their difficulty in self-promotion and social development may not be detected, with consequent delays in reaching developmental goals such as, for example, holidays without adults, work during school secondary and beyond, and falling in

love for the first time (45). Diagnosis and treatment of IBDs pose challenges in participating in social activities, leading to the loss of opportunities to devote to leisure or school due to symptoms or frequent medical appointments (22, 26). Furthermore, it has been shown that patients aged 18 and over do not feel completely autonomous if the medicinal therapy to be taken is by injection or infusion or, again, in recognition of the need to resort to the support of a doctor or to be actively involved during a visit, especially if the symptoms are subtle in nature. Patients are more likely to be successful when they have greater self-efficacy, which is the belief of their ability to complete specific tasks and achieve goals. To encourage mastery and self-efficacy, substantial areas of self-management can be broken down into smaller tasks (46, 47).

Need for gratitude, respect and respect for your needs

Patient satisfaction with health care is recurrent and transversal in the different stages of IBDs, and it is defined as the degree to which aspects of care considered important by the patient are met by experience. There are different factors that contribute to patient satisfaction and can be related to the patient characteristics, disease related characteristics and the health care provider. The main indicators of quality of care are synthesized in two categories: timing/logistics (i.e., usual time in waiting room or in consultation) and diagnosis/treatment (i.e. seeing the IBD doctor on a regular basis, using maintenance therapy...)(48).

3.3 Needs in transition

From a specialized pediatric team to specialized adult team

Caring for a child with a chronic disease poses complex challenges in which the whole family is involved. The request for autonomy grows progressively during the course of development and becomes pregnant in the transition to adulthood, during which the young person takes responsibility for his/her own self: this step is also reflected in the transition between paediatric and adult care (49). The transition is configured as a planned and gradual process through which the adolescent passes from a child-centred care system to an adult-centred one (50–52). There are two main elements of this transition process which impact on its success: one is the passage of care from the primary caregiver (parent) to the patient, and the other is the transfer of responsibility from the paediatric gastroenterologist to one specialized in the care of adult subjects (53). Improving transition preparation skills, including knowledge of the disease, has the potential to reduce gaps in continuity of care. Indeed, discontinuation of care put adolescents at risk for poorer health-related outcomes, including higher levels of non-adherence and non-engagement, potential loss of follow ups (54), increased risk of relapse of the disease, and poorer overall health (55).

The transition process was conceptualized as having a beginning (the decision to switch to an “adult care”), an intermediate period (preparation for the transition, developing the necessary skills and behaviours that support self-care; effective health decision making and self-help) and end (effective transfer of care from a paediatric to an adult care) (36).

The unpredictable course and the possible complications that characterize IBDs include a great variety of events whose nature can also be embarrassing with repercussions on the quality of life and, in particular, on some psychological, social and physical aspects.

Psychology in transition

In the transition between adolescence and young adulthood, adolescents can express their disputed discomfort between anxiety of leaving a well-known reference doctor and the need for independence and control over their illness. They need an effective communication, education and more information to facilitate their independent control.

Adolescents live relevant changes in their body, self-image and identity. Therefore, they could feel as not treated as an adult, which can compromise the alliance on the ward. In this direction, they ask for advice on contraception, alcohol, smoking. Finally, a complex transition is often related to a dependent personality or anxiety, where parents use to manage the illness (56).

3.4 The needs in adults with IBD

Needs of information

The information preferences are oriented to medical treatment, clinical manifestations and surgery and the order of preference of methods for provision is as follows: face-to-face conversation, telephone, written dialogue (i.e., chats). The aspects on which an adult patient think to have fewer resources to access information are related to social rights (i.e. disability, financial aid management, tax benefits...), work right, risk of cancer and/or of death. They prefer to have the opportunity to talk to the Gastroenterologist than to the General Practitioner or the Surgeon, consider a rate of satisfaction of 96% (57, 58). In this life phase, a series of questions are also related to treatment failure and response with first-line and second-line biologic therapy with these two anti-TNF α agents (59). Adults believe in the importance of receiving IBD education, trusting in its relevance to improve quality of life and self-management (58) and coping strategies (60). Finally, quality of life is considered more relevant than the disease control (61).

Medical needs

Patients considering surgery for UC, express their need of informational shortcomings, especially related to the long-term effects of surgery, practicalities of daily living and long-term support. Moreover, they frequently ask for peer support during and after the intervention (62).

Psychological needs

Jordan and colleagues found that extreme perceptions of the illness, being stressed and adopting coping strategies focussed on the emotions, lead to worse mental health outcomes, situation that is maintained when controlling the impact of clinical factors (63, 64). They usually express stigma, feelings of shame or of being dirty, due to the lack of control over their symptoms, powerlessness, humiliation, impacting on

their self-image and self-esteem and resulting in isolation. Moreover, some studies describe the perceived lack of support during the recovery process, with a sense of being left after to adopt postoperatively. Rates of depression after surgery for UC range 11–17% and some participants report also difficulties related to body image and sexual life (62, 65, 66).

Social and work-related needs

According to Calvet and colleagues (67), in some cases, illness influences the kind of job performed or people lost or had rejected a job due to IBD. In particular, IBD patients with back/joint pain report a significantly low productivity at work related to a low quality of life (68, 69).

Support needs

People with IBDs report wanting to make sense of the illness, their emotions and coping strategies. In order to reach this aim, overwhelming participants look for psychological support from someone professional, with a specialized knowledge of IBD, its symptoms and emotional impact (64). Nevertheless, the degree of psychological distress don't correlate with seeking mental health support (70). Klag and colleagues found that psychotherapy demand depends on fear of progression, quality of life, previous experience, smoking and previous surgery (71).

Some patients define as useful talking to other people with IBD in a group setting, because it helps to normalise the experience of the illness and reduce the sense of being alone or being misunderstood (64). Social support is principally provided by family and close friends, health professionals and self-help groups for people affected. The support received by the family helps to increase acceptance of the symptoms and to cope with them (72, 73). On the other hand, the health care providers' support is appreciated because they are supposed to know more about the symptoms, making patients feel confident and safe (74).

Practical needs

Most of the practical needs are related to the IBD symptoms. If considering the case of the CD, for example, the limitation of social life is represented by the organization of a trip, which is subject to the presence of toilets in the chosen destination area. The fear of incontinence and fear of unpredictability have important consequences on behaviour: indeed, for many this fear induces an avoidance of work, social and daily activities. Some persons try to cope with IBD, carrying potties and spare clothes, wearing nappies or identifying toilets prior to travel. They need to take in consideration extra time for travelling and control their bowel frequency (75). At an institutional level, it becomes important to ensure continuity in the organization of public awareness campaigns (e.g. school, work), meetings that encourage the connection between IBDs services and those less specialized (e.g. General Practitioner), facilitation of bureaucratic procedures (e.g. exemptions, invalidity ...). It could also be relevant to offer the possibility to a person suffering from IBD, thanks to a card or a special ticket, to access the toilets in public businesses.

Moreover, it is relevant to note that a self-prescribed dietary regiment is common among IBD patients as an attempt to improve their physical conditions and prolong remission intervals. Some foods, for

instance, are recognised as a trigger for the induction of symptoms, leading to the risk of a serious nutritional deficiency (29, 76, 77). Larussa and colleagues (77) noted that only 61% of the patients receive nutritional or dietary advice and 78% ask for more information. Therefore, dietary habits should be considered as relevant during the routine visits and some recommendations should be provided (78, 79).

Needs related to the future

Future planning is often hindered by increased anxiety and ambiguity about the disease trajectory. Chronic illness can impact on the decision for bearing and raising children, because of worries about the implications of IBD (39). According to Calvet et al. (67), some patients with UC report that illness influences their decision to have a baby (17.2%) or their ability to take care of children (40.7%), with higher percentages among women and in younger people (80).

Engagement needs

□ Disease management is a complex process where patients make decisions regarding care, symptoms, treatments, dietary modification, stress management, medications, and emotional components of their disease. The patients need information on both illness and the treatments options, including surgery, from an early stage. The decision-making process involves multiple factors, including disease status and the set of beliefs of the patients. Patients are often worried that, after surgery, the stoma bag would be seen or leak or smell. In addition, they are worried they would no longer be attractive to their partner. Sometimes, they are afraid about the impact of a stoma on their ability to bear a child or to have poor control over bowel function, limiting the possibility of a relationship or sporting (81). All the elements arisen above, including psychosocial factors such as social support, fear of surgery, fear of relapse, worries about self-image, provider recommendations contribute to the decision-making process (82, 83). Finally, it is important to note that when the patient is actively involved in the decision making process, the engagement is higher and the likelihood of a successful treatment outcome is maximised (84).

4. Discussions

This scoping review aimed to highlight the overriding psychological and social welfare needs of people with IBD as well as their evolutions over the life cycle. Moreover, it allowed to identify and define the main research gaps in the literature about IBD's needs and their evolution. In particular, this scoping review allowed to note some elements of particular interests. First of all, it should be pointed out that chronic inflammatory bowel diseases, due to their complexity, require a multi-perspective management, including psychological, practical, social, welfare and existential goals. It is emphasized the need to take into consideration the psychological aspects in the management of IBD since the developmental age, identifying promptly patients and families who are at risk of distress. In this regard, it is desirable that the pediatric gastroenterologist would be accompanied by a psychologist since the first visit, also through the use of specific validated psycho-diagnostic tools, as well as by nurses able to carry out actions of support. In this line, where necessary, provide nutritional advice that can give families adequate information on the diet. □ Although a number of transition clinic models currently exist, there is paucity of

data and gap in the management of psychological, but also social, work-related and practical needs caused by IBD and influencing the quality of life of patients and their caregivers (85, 86).

Secondly, based on the included articles, patients' preferences and needs are relevant to sustain and facilitate engagement. Partnering with IBD people throughout the lifespan with illness is a critical but essential step for shaping strategies and interventions. IBD people is more willing to be actively involved in the health care process if can gain more information about the illness as well as the treatment options. The patient and caregivers' engagement aim to foster greater accountability of the person with informed management of his/her illness, in a partnership with the health care providers. An individual effectively involved in his/her course of treatment, in addition to being more adherent to medical prescriptions is also more able to activate himself/herself properly at the first signs and symptoms of the disease and to benefit from the services offered by the system in a more effective and satisfactory way. This process can also enhance the IBD awareness and understanding in society, sustaining people with IBD in their daily struggle with practical, social and psychological needs (87, 88).

Thirdly, the transition process to the management in adulthood of IBDs might focus on the promotion of the patient's self-management and engagement, implementing the appropriate usage of monitoring tools (89, 90). Due to the continue evolution of the needs, it could be important to build also a transitional IBD-Clinic managed by the collaboration between adult and pediatric professionals. This transitional IBD-Clinic might sustain the adolescent from the pediatric to the adult ward, encouraging a gradual assumption of responsibility for appropriate lifestyles, consolidating the levels of engagement already developed. It is essential to support the pediatric patient and his / her caregiver in the critical phases of the disease path: diagnosis (through psychological assessment and early psychological intervention), hospitalization, relapse of the disease, surgical intervention. It is also relevant to remember the multiple contexts in which the adolescent grows up: therefore, promoting a personalized network that connects the health dimension with the daily life (i.e., school, family, peer group, sport clubs) according to the complexity and multi-component nature of the concept of health.

Furthermore, the presence of an extensive team (inside and outside the hospital) with varied and integrated skills, as well as the ability to stimulate the active role and participation in the care process need to be present along all the life cycle. On the basis of the previous literature, in fact, continuity of care is an important but less explored need. Maintaining the same doctor, and preferably the same care team, is a guarantee of consistent work. In an already established therapeutic setting, digital technologies can be an effective support for maintaining therapeutic continuity and promoting the doctor-patient alliance (91). In particular, the importance of sharing information between the specialist team and general practitioners is noted. In this direction, it also relevant to note the scarce attention payed to the transition to ageing, where comorbidities and cognitive impairments might compromise more the clinical feature of the patient. It can therefore be noted that the needs emerged in this scoping review and which characterize the different evolutionary phases, change in the life cycle of patients, requiring personalized and dedicated interventions depending on the life phase.

Nonetheless, this study has several limitations. Firstly, we only included articles from after 2009. However, in order to limit this potential source of exclusion, additional material was identified following up the reference lists of articles included, without founding any previous consideration. Moreover, taking into account the last ten years gave us the possibility to pay attention to the contemporary needs, those more related to the last cultural and social changes. Nevertheless, as every scoping review, does not formally evaluate the quality of evidence and often gather information from a wide range of study designs and methods. Although a thorough search of the databases was performed, it is possible that this scoping review omitted relevant articles and did not cover the extent of the research available on this topic. Specifically, transitions in care as well as need are relatively broad concepts, lacking a universal definition, resulting in a lack of standardized terminology in the current literature databases. In order to minimize the possibility of missed articles, our search strategy was adapted for a variety of databases and included all key words and Mesh headings relating to transitions in care and needs. A more rigorous definition of these terms is required. Furthermore, future studies needed to help personalize and multi-professionals transition care practices, that pay attention to all the different needs related to IBD along the life circle, including all the transition phases and not only that to adulthood. Due to the few studies exploring patient perspectives during care transitions, especially during adulthood and towards ageing, future research should seek to examine overall health and well-being during the different challenges of life.

5. Conclusions

This study provided an overview of the different kind of needs and their evolutions in IBD along the life cycle. The findings can be adopted to inform the development of personalized health care processes as well as to identify, prioritize, and display gaps in the management of IBDs. The literature shows the value of organizing the clinical intervention in a multidisciplinary perspective (through the enhancement of the IBD-Unit) and the broader active involvement of the patient and caregiver (s) (if requested by the patient and if necessary) through interventions to support and promote engagement. In this line, it is necessary to pay attention to the transition process to the management in adulthood of IBDs, promoting the patient's self-management and engagement as well as his/her ability to manage medical, lifestyle self-management and the health care process, also through the use of appropriate monitoring tools such as self-assessment checklists. The information obtained from this review stressed the need to reflect on current policies regarding effective transitions in the health care process, utilization of services to improve IBD patient's experiences. Finally, it highlighted the need for timely and accurate information-sharing and promotion of engagement along all the life cycle.

Abbreviations

Inflammatory Bowel Disease (IBD)

Ulcerative Colitis (UC)

Crohn's Disease (CD)

Quality of Life (QoL)

Exclusive Enteral Nutrition (EEN)

Partial Enteral Nutrition (PEN)

Specific carbohydrate diet (SCD)

Lactose free diet (LFD)

Crohn's disease exclusion diet (CDED)

Declarations

Ethics approval and consent to participate:

Not applicable.

Consent for publication:

Not applicable.

Availability of data and materials:

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request

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The authors declare that they have no competing interests

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GG and FP were involved in planning and supervised the work, EV and CB processed the literature search and the selection of the studies included. EV and FP performed the data charting and collation, drafted

the manuscript and designed the figures. EP, SL and AA aided in interpreting the results and worked on the manuscript. All authors discussed the results and commented on the manuscript.

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Table

Due to technical limitations, table 3 is only available as a download in the Supplemental Files section.

Figures

Figure 1

PRISMA Flow Diagram for article selection

Supplementary Files

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