

Unmet psychosocial needs in adolescents with inflammatory bowel disease

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Submitted: 2016-06-22 *Accepted:* 2016-08-05 *Published online:* 2016-10-30

Key words: **Inflammatory bowel disease; Crohn disease; ulcerative colitis; stigma; treatment; unmet needs; quality of life; psychosocial aspects; psychotherapy; education.**

Neuroendocrinol Lett 2016; **37**(5):395–402 PMID: 28231685 NEL370516A10 © 2016 Neuroendocrinology Letters • www.nel.edu

Abstract

BACKGROUND: Inflammatory bowel diseases (IBD) are severe medical conditions with adverse impact on the quality of life of both children and their caregivers. IBD are associated with many limitations in personal and interpersonal functioning, and it also restricts the patients' ability to use the full potential (extent) of their capabilities. With the progress and humanization in society, the issue of patients' needs became an important topic; however, the psychosocial functioning and quality of life of adolescents suffering from IBD and their caregivers have been understudied. The aim of this article is to provide a comprehensive, up-to-date literature review of the unmet needs of patients with IBD and their caregivers. **METHOD:** A computerized search of MEDLINE publications from 1990 to 2016 using the keywords "inflammatory bowel disease", "Crohn disease", "ulcerative colitis" and "unmet needs". In the period 1990–2016, the MEDLINE searches identified 54 publications. Articles cited in the papers from these searches were also used. The total number of 132 particular articles were collected, sorted by their relevance and key articles (n=72) listed in reference lists were searched. **RESULTS:** Patients' needs differ at various stages of the illness and may have different origins and goals. Thus, we divided the needs into five groups according to their nature; i.e. needs to be connected with symptoms, treatment, quality of life, family and age-related challenges. We provide implications of the patients' needs for pharmacotherapy and psychotherapy. **CONCLUSION:** Following the needs of patients with IBD may be a crucial part of the therapeutic process. Due to the better understanding and cooperation, the impact of disease could be reduced, and the physical and mental condition of the patient could be improved. However, many needs remain unmet due to both medical and social factors.

INTRODUCTION

Crohn disease (CD) and ulcerative colitis (UC), collectively known as inflammatory bowel diseases (IBD), are serious chronic illnesses that often begin in childhood or adolescence (Calsbeek *et al.* 2002, Benchimol *et al.* 2011). IBD is diagnosed during these developmental periods in approximately one-fourth of the IBD population with an incidence rate of 71 per 100,000 (Kapelman *et al.* 2007). International incidence rates are gradually increasing (Benchimol *et al.* 2011). Management of IBD involves both adolescents and their parents, who have to handle demanding and multifaceted decisions, which may include numerous medications, infusions, dietary variations, invasive procedures (i.e., endoscopies, colonoscopies) and surgical interventions, while permanently experiencing sporadic incidents of relapse and remission (Guilfoyle *et al.* 2012).

The severe physical symptoms and burdensome treatment are also associated with the significant psychological suffering of adolescent with IBD and the members of the family (Hallum 1995, Mackner *et al.* 2006, Verhoof *et al.* 2012). These experiences create psychological and social needs of both of these sites that happen during the major psychosocial transformations from the baby to an adult (Cohen *et al.* 1992, Hartman *et al.* 2000, Mackner *et al.* 2006, Stam *et al.* 2006, Maslow *et al.* 2011).

Understanding psychosocial needs of adolescents with IBD stems from the definition of fundamental human needs (Maslow 1968). Abraham Maslow divided human needs into:

- (1) *Physical needs* related to the biological survival of an individual (e.g. air, water, food, sleep, temperature, absence of pain). Some of these needs might not be satisfied in patients with IBD, e.g. their sleep or food intake can be disturbed by pain.
- (2) *Protection, security and safety needs* (e.g. confidence, trustworthiness and constancy; a necessity of structure and boundaries; avoidance of the unknown and threatening). These requirements are frequently not satisfied in patients with IBD because of the worries about future connected with the illness; children might be separated from parents during medical procedures.
- (3) *Relationship needs* (e.g. belongingness, friendship, affection, solidarity, acceptance, and love). Not meeting these needs leads to painful loneliness, ostracism, hostility and rejection. The shame connected with defecation problems, frequent usage of the toilet and feeling different from others can violate these needs in adolescents with IBD by isolation.
- (4) *Gratitude, respect and self-respect needs* (e.g. status, success, self-esteem and gratitude). The process of isolation can also violate these needs as well as a lack of independence, freedom and positive attention.

- (5) *Self-actualizing needs* (i.e., realization of person's full potential for development and growth and maximum use of person's talents and skills). The fight against IBD accompanied with stress can limit the adolescents' potential to develop and grow.

According to Maslow, unmet needs generate unrest and displeasure and are characteristically counteracted by satisfying the lower needs to fulfill higher needs (Maslow 1968).

METHOD

Articles were obtained by MEDLINE search and papers published between years 1990 and 2016 were considered. Following keywords were used: "inflammatory bowel disease", "Crohn disease", "ulcerative colitis" and "unmet needs". The MEDLINE searches identified 54 publications. Articles cited in the papers from these searches were also used. The total number of 132 particular articles were collected, sorted by their relevance and key articles (n=72) listed in reference lists were searched.

RESULTS

For the purpose of examining the needs of patients with IBD, we divided the needs into four categories according to their common elements: needs connected with symptoms, treatment, quality of life and family.

Needs connected with symptoms

Many unmet needs are linked to the IBD symptoms. The adolescents may express distress about chronic or exacerbated symptoms as they struggle to deal with them. In general, the needs of an adolescent with IBD connected with the symptoms are analogous to the needs of the family and the pediatrician, since they all want to make the symptoms disappear. Additionally, the patients require tolerance, empathy, enhanced feelings of hope for improvement, safety, and long-term symptom control. To accomplish these needs, it is critical to focus on treatment and the adherence to it.

Unsatisfactory disease control may lead to a decreased quality of life (QoL) and even potentially lethal conditions including psychological, psychiatric and psychosocial problems (Bokemeyer 2015). Psychological problems such as depression, helplessness, anxiety, family issues, and impaired school functioning were frequently not recognized as connected with IBD (Bokemeyer *et al.* 2013). Equally, common and nonspecific physical complications such as symptoms of anemia (e.g. weakness, dizziness, shortness of breath, headache, chest pain or frequent infections) were also not regarded as associated with IBD. What is even more surprising, treating iron deficiency anemia was neglected even if the blood test results were available

and clearly showed a need for intervention (Dignass *et al.* 2015). The primary focus of clinicians treating IBD is, rightfully, controlling an inflammation – this should minimize the impact of IBD and the possibility of associated sequelae. However, the second objective should be to diagnose and treat – and ideally prevent – secondary complications of IBD. Clinicians should, therefore, be alert for signs and symptoms of anemia and reduced mental wellbeing because these can cause significant additional morbidity.

A survey of more than 4000 patients with IBD in 25 European countries revealed that 54% of patients thought they did not get a chance to tell their gastroenterologist something potentially significant and 64% thought their gastroenterologist should have asked more probing questions (Lonnfors *et al.* 2014). Therefore, it is important that healthcare professionals not only ensure that patients have a chance to raise concerns but also adopt a proactive approach to help identify signs of complications as early as possible. In many cases, the opportunities for change are unnoticed, at least, to some extent because the problems or symptoms do not seem to be related to the gastrointestinal tract or abdominal cavity. Symptoms are also associated with stress and higher levels of anxiety and depression (Kurina *et al.* 2001).

Adolescents with IBD are at an increased risk for the development of anxiety, depression and poor IBD management (Guilfoyle *et al.* 2014). The prevalence of psychosocial, emotional and other psychological difficulties in adolescents with IBD is higher compared with healthy teenagers (Jelenova *et al.* 2015b). Depression and anxiety disorders are the most prevalent psychiatric problems in adolescents with IBD and could considerably impair quality of life and school abilities (Zhang *et al.* 2013) and even lead to suicide (Hammad *et al.* 2006). Expectedly, depression increases patients' needs for health care: persistent or recurrent depression is associated with increased number of outpatient visits, hospitalizations and surgical procedures (Bokemeyer *et al.* 2013). Depression may subsequently predict the relapse of IBD in adult IBD (Kurina *et al.* 2001; Mittermaier *et al.* 2004).

Depression has been shown to predict the poor quality of life in IBD independent of disease severity (Zhang *et al.* 2013) and reflected subjective impairment even better than inflammatory activity (Cuntz *et al.* 1999).

Treatment of psychiatric comorbidities is necessary for some adolescents, usually using antidepressants or psychotherapy (Wachsmuth and MacMillan 1991, Pipe and Wait 1995, Rikard-Bell and Waters 1992). Psycho-educational or behavioral strategies are the methods of first choice (Haapamäki *et al.* 2013, Virta and Kolho 2014) and can help adolescents with adjustment disorders. Management may include methods for relieving distress or assisting persons. Supportive counseling, individual psychotherapy using cognitive-behavioral

principles and family therapy are promising (Feder *et al.* 1994, Pipe and Wait 1995).

Benzodiazepine treatment is employed in IBD patients, but it can lead to the onset of disinhibition symptoms that may be misinterpreted as higher anxiety. Depressive symptoms are mutual and seldom develop into seriously retarded depression with somatic syndrome responding to antidepressants

It is necessary to notice the problems, make the diagnosis and motivate the adolescent (Zhang *et al.* 2013). The first challenge is to distinguish whether adolescent with IBD suffers from psychological problems or psychiatric disorder. Therefore, pediatricians should be not only aware of the frequent occurrence of distress and psychiatric disorders in patients with IBD but also have practical skills to diagnose them. There is a need for education on psychological consequences of IBD regarding pediatricians but also adolescents with IBD and their families. Placing simple questionnaires assessing the degree of anxiety and depression at pediatric departments, providing basic training in psychiatric diagnostics to pediatricians and launching informational materials and websites for patients and their families could be helpful (Jelenova *et al.* 2016b).

Needs connected with treatment

Despite advances in modern treatment, the greatest unmet need of adolescents with IBD and their caregivers is finding the best possible treatment including pharmacotherapy, biological therapy, surgery, nutrition, and regimen. Concerns include treatment availability, drug dosing, and adequate information about treatment, side effects, outcomes, and prevention of relapse. Inadequate expectations, both too high and too low, are frequent and lead to distress.

The treatment of IBD itself is stressful for many adolescents (Calsbeek *et al.* 2002). Therefore, it should be conducted with respect and emphasis on emotional needs of security, acceptance, and appreciation. To reduce stress, every adolescent should be adequately informed by the physician, including alternative treatment options. It is important to explain appropriate each step of the treatment process and its purpose and also clarify possible gains and losses including limitations in life that the treatment of IBD may bring (Knowles *et al.* 2013). It helps to cope with what the patient with his/her family expects.

Similar to other pediatric chronic diseases, non-adherence rates vary between 38%-66% in children and adolescents with IBD (Oliva-Hemker *et al.* 2007, Hommel *et al.* 2013). Preadolescents and young people with IBD reported increased complexity of medication and perceived side effects to be the barriers to adherence; adherence was better in patients on monotherapy than in those on multiple medications (Greenley *et al.* 2010). Family dysfunction, including poor family structure, cohesion, and discipline, is a risk factor for

nonadherence in the adolescent population (Hommel *et al.* 2013). Patient's psychological functioning may also represent a barrier to adherence. Finally, psychological stressors including low self-esteem, anxiety and depression were associated with poor adherence in adolescents with various chronic health conditions (Oliva-Hemker *et al.* 2007). Although adherence to medication is crucial to optimize outcomes, assessment of nonadherence is extremely challenging. Strategies that may improve adherence are multifaceted and involve rationalization of treatment regimens, adoption of strategies to organize medication, education of patients, encouraging the appropriate and efficient development of autonomy and measures to address psychological and social factors for poor adherence (Bishop *et al.* 2014). Future research of different domains of barriers and their importance (i.e., treatment regimen barriers versus behavioral functioning barriers versus family barriers) would be of value. Current findings confirmed the existence of barriers and their implications for adherence among adolescents with IBD (Greenley *et al.* 2010).

A high proportion of patients with chronic disease (81%) has been associated with the use of complementary and alternative medicine (CAM) in children and adolescents (Birdee *et al.* 2010). The most usually reported forms of CAM use among children with IBD included probiotics, fish oils, herbs, dietary modifications and megavitamin therapy. As CAM use is frequent, physicians should familiarize with the core ideas of CAM. The possible pharmacological interaction or the toxicity of certain CAM products requires awareness and hence physicians should actively ask patients and their parents about CAM use (Nousiainen *et al.* 2014).

Needs connected with quality of life

each disease impairs the quality of life, especially chronic illness (Cohen *et al.* 1992, Calsbeek *et al.* 2002, Drell and White 2005). The quality of life can be affected in the field of partnership, family relationships, school and leisure time (Stam *et al.* 2006, Verhoof *et al.* 2013). The adolescent is involved in some social activities, which may be limited by the disease (Hartman *et al.* 2000, Law *et al.* 2006, Lindsay 2011).

Teenagers' health-related quality of life considerably correlates with satisfaction and degree of closeness in their significant relationships. In a study by MacPhee *et al.* (1998), chronically ill youths involved extended family rather than peers in their social support networks. Also, the teenagers' quality-of-life health scores were influenced more by the parental coping styles than by the children coping styles (MacPhee *et al.* 1998).

In teenage years, parents bump into strange encounters, such as teenagers in the quest for freedom (Berger 2011). The quality of life evaluated by the adolescents correlated with positive parenting styles of both parents and autonomous parenting style of mothers and

negatively correlated with hostile parenting styles of both parents and inconsistent parenting style of fathers (Jelenova *et al.* 2016a). These findings are consistent with clinical practice and with literature (Santrock 2007, Alizadeh *et al.* 2011, Knez *et al.* 2011, Morris *et al.* 2013).

Some studies show the quality of life in patients with IBD is decreased (Cuntz *et al.* 1999; Drell & White 2005). However, our study of adolescents with IBD did not confirm these results (Jelenova *et al.* 2016b), but we found the considerably poorer quality of life was observed in parents of the youths with IBD than in parents of the healthy controls (Jelenova *et al.* 2016a). The reason is unknown, but it is possible that the parents restricted their lives because of the child's illness. This suggestion is consistent with Jarret (1994), Coffey (2006) and Brown *et al.* (2008)

Needs connected with family

IBD in an adolescent affects the whole family (Pipe and Wait 1995, Jelenova *et al.* 2016a). The psychosocial functioning of caregivers of adolescents with IBD has been understudied. However, poor caregiver functioning can expose the adolescent to inappropriate disease management (Guilfoyle *et al.* 2012). According to Knez *et al.* (2011), parents of children with IBD reported considerably worse psychological health compared with parents of healthy controls. An association between chronic illness in an adolescent and parental adjustment has been proposed (Jarrett 1994, Brown *et al.* 2008).

With the onset of the disease, relatives must modify family customs, habits, organization, and schedule. Many parents reported a lack of time for siblings of the ill child and were worried about possible consequences (Coffey 2006). Parents typically suffer from tension, the burden of illness and some parents are finding themselves providing all the care to ill children (Coffey 2006). Some studies described the detrimental impact of a chronic illness of the child on the marital bond (Youngblut *et al.* 2000).

Participation of parents is crucial in all phases of the treatment (Rikard-Bell 1992, Vereker 1992). One family member, typically the mother, is often overprotective of the child, which leads to a permanent sick role that can be difficult to change. The loss of peer group interactions strengthens the adolescent's dependence on the family (Garralda 1992).

While both parents may show significant fear and apprehensions, one parent, typically mother, is often acknowledged as the principal caregiver. The responsibility for the health care activities in addition to the majority of housework has led to the designation of mothers as "carrying the burden" (Hirose & Ueda 1990). Parents of teenagers with IBD often have to deal with complex management procedures, unpredictable episodes of relapse and remission, fears about long-term sequelae of IBD (e.g., colorectal cancer), discus-

sions about IBD (e.g., need for frequent restroom use during lessons), functioning as supporter within the health system and with individual feelings. This can be perceived as troublesome and contribute to stress and poor adjustment. Psychosocial functioning of parents of adolescents with IBD has been understudied. Most studies predominantly focused on psychopathological aspects of parental functioning, identifying higher rates of psychiatric symptoms in maternal caregivers (Burke *et al.* 1994; Engstrom 1991; Engstrom 1999).

Anxiety or depression may occur in patients but also in parents and siblings (Guilfoyle *et al.* 2014). Parents of the adolescents with IBD expressed increased levels of anxiety (mothers) and depression (fathers) than parents of the healthy controls (Jelenova *et al.* 2016a) which may be explained by worries about the children. Fathers of the children with IBD had slightly elevated symptoms of depression due to limitations and tension in their families induced by a chronic health condition of the child. Future studies using prospective longitudinal design should address this issue. Parental distress predicts depressive symptoms in adolescents with IBD (Guilfoyle *et al.* 2014). Parenting stress and adolescents' depression should be recognized early, probably in the framework of routine outpatient visits. Van Oers *et al.* (2014) also found greater scores of anxiety and depression in the mothers of persistently ill children. A similar finding of anxiety and worries in parents of chronically ill children was described in a meta-analysis by Coffey (2006). These apprehensions are more frequent among the mothers than among the fathers of the ill children (Coffey 2006, Sallfors and Hallberg, 2003). Maternal anxiety and paternal depression may further have a negative impact on the family functioning (tendency to overparenting, low use of the autonomy parental style), the quality of life of the children and parents, and the quality of the relationship between the parents. These tendencies may lead to parental styles common in the families with a chronically ill child – “the managing mother” and “the waiting father” (Sallfors and Hallberg 2003).

With a chronically disordered youngster in the family, parents often find it hard to retain the normal boundaries. For example, punishing an ill child may be accompanied by parental feelings of guilt; this could lead to growing nervousness of the adolescent whose hostility gradually increases to test the limits. Discussion regarding parenting techniques in this context may be helpful. Parents tend to control the ill adolescent and be overprotective. If disproportionate it may inhibit the child's growth, but to a modest amount, it may be helpful (Gledhil and Garralda 2009).

It is important that pediatrician ask parents how they manage to cope with stress. Educational materials on IBD should also mention stress, depression, anxiety and other psychic disorders. The Pediatric Inventory for Parents (PIP; Streisand *et al.* 2001) evaluates parental stress unique to caring for adolescents with chronic

illness. Parental stress scores in IBD were usually lower than those in other chronic conditions such as cancer, bladder exstrophy, sickle cell disease and obesity, but comparable to scores in type 1 diabetes mellitus (Guilfoyle *et al.* 2012). Communication among caregivers, health care providers, and family were recognized as the main stressor for young caregivers (Guilfoyle *et al.* 2012) who may have fewer resources and less experience and thus, take in greater parenting stress (Streisand *et al.* 2001, Guilfoyle *et al.* 2014). Lack of psychosocial resources (e.g., social support, coping) may also contribute to elevated levels of parenting stress of young caregivers (Guilfoyle *et al.* 2012).

Needs connected with age related challenges

due to advances in treatment and improved outcomes, the attention has moved to the age-related needs of adolescents with chronic illness (Perrin *et al.* 2007). It is estimated that 2-3% of children suffer from diseases that are severe enough to interfere with growth, development, school performance or social relationships (Cohen *et al.* 1992) and the link between psychiatric difficulties and somatic illness in children and adolescents was addressed in psychiatric epidemiology (Cohen *et al.* 1992, Chavira *et al.* 2008, Merikangas *et al.* 2009).

Children with chronic disease are anticipated to go through similar developmental phases as their healthy peers (Hallum 1995). Diagnosis of IBD frequently falls in the period of adolescence, which is a time of physical, cognitive psychological and social changes and it is also accompanied by emotional ups and downs (Calsbeek *et al.* 2002, Mackner *et al.* 2006). In the majority of adolescents with IBD, appropriate age-related markers, and functional development is reached in early adulthood (Gledhil and Garralda 2009, Jelenova *et al.* 2015b). However, adolescents with chronic disorders, regardless of the diagnosis, are more limited in their participation in daily life than their schoolmates (Law *et al.* 2006, Stam *et al.* 2006) and adolescents with incapacities often exhibit unusual age-related patterns in comparison with healthy teens (Hartman *et al.* 2000, Stam *et al.* 2005, Verhoof *et al.* 2014) They are at risk of adverse educational, career and social outcomes in adulthood (Calsbeek *et al.* 2002, Stam *et al.* 2006, Lindsay 2011, Maslow *et al.* 2011).

Several criteria have been designated to detect increased probability of developing psychiatric disorder (Gledhil and Garralda 2009):

- nature of the physical illness, effects of the disease and treatment procedures;
- stage of the disease;
- the severity of the illness or degree of life threat;
- psychosocial risk and protective factors in the family;
- age and developmental stage.

An adaptation of adolescents depends on the disease course, treatment efficacy and side effects including the long-term side effects (e.g., growth and puberty delay). Development of the emotional regulation, the cognitive ability, and impulse control can also affect the adjustment to the disorder. In general, children who developed chronic illness at a younger age have a tendency to integrate better the disease into their self-concept. In adolescents, whose self-identity is unstable, dealing with the disease can be especially difficult, e.g. because of fecal incontinence, poor body image due to steroid-induced weight gain, social fears and loss of social learning opportunities caused by school absenteeism. Factors such as age, family, social support, the degree of disruption of the usual activities and presence of life stressors may impact the adolescents' response to IBD (MacPhee et al. 2015, Brown et al. 2008).

Schooling, contact with peer groups and social and recreational activities have to be interrupted for the shortest time possible (Dale et al. 1992). There is evidence that the opposing "wait and see" tactic is counterproductive (Bell et al. 1991). Dynamic managing includes a diversity of approaches determined by the degree of patient's disability, the opinion of the family and the access to resources (Wessely et al. 1999). It involves the whole family and includes encouraging greater activity and reducing illness behavior. Behavioral activation packages (Feder et al. 1994, Vereker 1992, Wachsmutd 1991, Sidebotham et al. 1994) have given promising outcomes, often connected with family therapy (Pipe and Wait 1995).

CONCLUSION

IBD is a chronic illness that has an adverse impact on the physical health and also on the mental health. The disease affects not only patients themselves but also their parents and relatives. Many needs of adolescents with IBD and their families remain unmet due to medical and social factors. Stress, anxiety or depression are frequently experienced with an adverse impact on quality of life and family functioning of patients and their relatives. This is among other caused by burdensome treatment, unpredictable course of the disease, frequent admissions, and social isolation.

Monitoring and following patients' and caregivers' needs is an important concern in the treatment of adolescent patients with IBD. It is necessary to make a maximum therapeutic effort to achieve and maintain long-term remission of IBD so that the patients can return to their previous lifestyle and hobbies. Despite recent advances in treatment, a small proportion of patients do not achieve remission and their psychosocial status requires special attention. Clinical, psychological and/or psychopharmacological intervention is necessary for adolescents with IBD suffering from psychological problems and for their parents experiencing

increased parenting stress that interferes with their ability to manage their child's disease adequately.

Child psychologists and psychiatrists cooperate closely with pediatricians to identify adolescents at risk of psychiatric disorder and provide treatment as well as support and advice. Their joint effort is to nurture the physical and mental health and fulfill developmental needs of adolescents and their families.

CONFLICT OF INTEREST STATEMENT

The authors proclaim that the article was written without any profitable or financial relations that could be understood as a possible conflict of interest.

ACKNOWLEDGMENT

Supported by IGA MZ CR NT 14281-3, NPU LO 1304.

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