

ORIGINAL ARTICLE

Psychoeducation of adolescents with inflammatory bowel diseases and their families

Daniela JELENOVA¹, Jan PRASKO¹, Marie OCISKOVA¹, Eva KARASKOVA², Jana KOLAROVA², Martina HUNKOVÁ¹, David VYDRA², Vladimír MIHAL²

¹ Department of Psychiatry, Faculty of Medicine and Dentistry, University Palacky Olomouc, University Hospital Olomouc, I. P. Pavlova 6, 77520 Olomouc, Czech Republic; ² Department of Pediatrics, Faculty of Medicine and Dentistry, University Palacky Olomouc, University Hospital Olomouc, I. P. Pavlova 6, 77520 Olomouc, Czech Republic

Correspondence to: Jan Prasko, Department of Psychiatry, Faculty of Medicine and Dentistry, Palacky University, Olomouc, University Hospital Olomouc, Czech Republic; e-mail: prasko.jan@seznam.cz

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Abstract

BACKGROUND: Inflammatory bowel diseases (Crohn disease and ulcerative colitis) are chronic disorders that affect the quality of life of the patients and their families. The mental state is connected with the physical one. Psychotherapy resulted in the improvement of psychological outcomes in IBD

METHOD: Psychoeducation group for adolescents and their parents or caregivers was prepared. Pre-selected 13 adolescents at the age of 15–18 years (10 girls and three boys) with IBD (11 Crohn disease, two ulcerative colitis) and their parents and caregivers took part in the 3-hour session. Program based on Positive CBT covered educational topics about IBD, diet, the importance of physical activity, and also practical exercise focused on the mindfulness, relaxation, and problem-solving strategies.

RESULTS: The patients, caregivers, and pediatricians appreciated the psychoeducational session with multi-family discussion; from exercises they especially enjoyed the relaxation and problem-solving strategies, clarification of some false beliefs about some of the recommendation (diet, exercise, regimen). Parents and patients postulated their message for other families with children with IBD, with the focus on positive thinking, hope and family solidarity.

CONCLUSIONS: Psychoeducational groups were appreciated by patients, caregivers, and pediatricians, they revealed possible ways of working with the multi-family setting. The recommendation about medical treatment, routine, diet, exercise, relaxation and learning the skills of problem solving seemed to be the most important parts of psychoeducation session.

INTRODUCTION

Inflammatory bowel diseases (IBD) are chronic disorders with a high impact on quality of life (QoL) of the individuals and their families. This relationship is pres-

ent throughout the whole life of the patients and with no exception in adolescence (Jelenova *et al* 2015b). The term “inflammatory bowel disease” includes the diagnoses of ulcerative colitis and Crohn disease. IBD are lifelong illnesses that can have profound emotional

and social impacts on the individual. The unpredictable nature of the diseases can bring significant stress to the adolescents, and therefore, can lead to higher levels of anxiety and depression (Drell & White 2005). Depression may then predict relapse in adult IBD (Kurina *et al* 2001; Mittermaier *et al* 2004). Also, psychological stress appears to exacerbate both symptom complaints and mucosal disease activity in IBD (Levenstein *et al* 1994). Disability and distress in patients with IBD may be further increased by the presence of concurrent psychiatric disorder (Walker *et al* 1996). Depression has been shown to be a significant predictor of poor quality of life, independent of disease severity in IBD (Zhang *et al* 2013). Even more importantly, depression was a better predictor of subjective impairment in IBD than was inflammatory activity in one study (Cuntz *et al* 1999). Additionally, anxiety and depression can significantly impact disease management (including the impact on patient compliance), and the outcomes (Mussell *et al* 2004). As with other chronic medical illnesses, patients with more profound psychological distress tend to be those with a more severe physical disease and poorer functional capacity (Sewitch *et al* 2001). However, the causality of this relationship is not clear (Sewitch *et al* 2001). The significant connection between the chronic diseases and the mental state of the patients has led to attempts to apply psychotherapy in these patients suffering from long-term medical conditions. Indeed, psychotherapy has been shown to improve psychological outcomes in IBD (Knowles *et al* 2013). Nevertheless, the evidence as to its efficacy in improving physical symptoms and reducing disease severity remains limited and is mixed at best (Knowles *et al* 2013).

Positive cognitive-behavioral therapy (Positive CBT), is a strengths-based psychotherapeutic style with roots in positive psychology. The focus of this style is not on “what’s wrong” with the client, but on “what is right” for them and what kinds of potential they may foster. A Positive CBT therapist concentrates on building patients’ strengths and uses specific strategies that patients can learn adaptive stress coping strategies. The psychotherapeutic strategies consist of building resilience, setting goals, or fostering hope and optimism. Positive CBT with adolescents and families involves talking about the inner strengths; they already have, and how they could be further enhanced (Bannink 2012). A Positive CBT therapist restricts “problem talk” as much as possible, even when talking with parents of the patients. When clients start to delve into their issues and suffering, the therapist acknowledges their frustration and then moves on to a “strengths and solution talk” (Bannink 2012).

Still, individuals with chronic diseases often deal not only with the emotional and social impacts of the disease and its psychological correlates. They may also experience physiological consequences of chronic stress. Many authors propose that adult patients with chronic somatic or mental conditions show signs of an

autonomic dysfunction and reduced heart rate variability (HRV) (Maunder *et al* 2006; Coruzzi *et al* 2007; Ganguli *et al* 2007; Sharma *et al* 2009; Maunder *et al* 2012; Virtanen *et al* 2003; Latalova *et al* 2010; Prasko *et al* 2011). The autonomic imbalance could be an important pathophysiological mechanism connected with the chronic distress also in children and adolescents with chronic medical conditions (e.g. obese children (Taşçılar *et al* 2011), young prehypertensives (Pal *et al* 2013), pubertal girls with type 1 diabetes (Cho *et al* 2014), and psychiatric conditions, e.g. adolescent depression (Tonhajzerova *et al* 2009)). In several chronic disorders, the autonomic dysfunction can be reversed by regular exercise (Ritz *et al* 2013; Pal *et al* 2013; Bond *et al* 2015). The autonomic imbalance could be positively influenced by regular aerobic exercises, like running, swimming, bicycling, dancing or other endurance sports training (Bond *et al* 2015; Edmonds *et al* 2015; Vasconcellos *et al* 2015). Jelenova *et al* (2015a) compared the HRV as a possible marker of chronic distress in adolescents with inflammatory bowel disease (IBD) with HRV frequencies in the healthy controls. There was a lower HRV variability in adolescents with IBD than in healthy controls. This result could reflect chronic distress of the children suffering from IBD but also cardiovascular deconditioning due avoidance of physical exercises and training (Benarroch 2012; Ritz *et al* 2013). In our study (Jelenova *et al* 2015b) the quality of life measured by questionnaires did not differ between the adolescent participants with IBD and healthy controls, but there were significantly lower scores on quality of life in the parents of the children with IBD than in the parents of the healthy controls. The parents of the IBD children scored lower in the Family Impact Module Total Scale Score and the parental Health-Related QoL Summary Score. The fathers of the IBD children also had a lower level of the Family Functioning Summary Score and a higher degree of depression than fathers of healthy controls. The mothers of IBD children had a higher degree of anxiety than mothers of controls. However, there wasn’t any difference in the levels of anxiety and depressive symptoms among the IBD adolescents and the controls.

During the year 2014 and 2015, we created a psycho-educational program for adolescents and their relatives. The aim of the program session was to help patients and their caregivers to map and ventilate the distress connected with the disorder, look for the positive side in the life, and brainstorm possibilities how to improve their healthy-related quality of life.

METHOD

Population

Patients have been recruited from the Department of Pediatrics, University Hospital Olomouc. Participants were 13 adolescents with the age between 15–18 years with mean age 17.86 ± 1.10 . All of them suffered from

Tab. 1. What helps us with well-being?

-
- Divide group into two subgroups: (a) subgroup of adolescents and (b) subgroups of parents
 - Introduce yourself to others and speak about your favorite hobbies and activities and favorite activities in your family;
 - Make a list of the most pleasurable activities in your subgroup
 - Introduce somebody from your subgroup to the other subgroup and speak about his/her favorite hobbies and activities and about favorite activities in his/her family
 - Discuss the most pleasurable activities in both subgroups – what is the same and what is different
-

IBD. There were three boys and ten girls. There were also 13 caregivers (ten mothers, one father, and two grandmothers).

All patients had been dispensaries for IBD; eleven were diagnosed with Crohn disease and two with ulcerative colitis. Patients had to be diagnosed with IBD for at least two years before the group session. According to PUCAI (Pediatric Ulcerative Colitis Activity Index) and PCDAI (Pediatric Crohn's Disease Activity Index) at the time of group session, nine adolescents were in remission and four presented mild disease activity.

Group psychoeducation

Topics of group psychoeducation. The findings of our research (Jelenova *et al* 2015a, Jelenova *et al* 2015b), knowledge from the clinical practice, and a review of the literature (Jelenova *et al* 2016 in press) were used as a base for the preparation of the psychoeducational program.

Philosophy of group psychoeducation. Positive psychoeducation in an interactive group program facilitates open atmosphere with interest and enjoyment. The group session begins with the exploration of the strengths of the adolescents and their families through brainstorming with the intention to find more options to increase the quality of life of children and the entire family.

Aim of group psychoeducation

- Bringing individuals experiencing life with IBD together (the patients and their families)
- Creating a safe and productive atmosphere in the group to support openness and creativity of the participants
- Mapping and fostering the adolescents' strengths in their coping with the disorder
- Mapping and further developing the family strengths in their dealing with the disorder
- Increasing the knowledge of the participants about health improving strategies appropriate for adolescents with IBD (nutrition, stress management, exercises, pleasurable activities)

Group session overview. Trying to prepare the best atmosphere in the psychoeducational group, the group

would be divided into two subgroups at start – the subgroup of the adolescents with IBD and the subgroup of the parents. The session begins with the exercise in couples using positive topics (Table 1), each participant talks about himself and tries to remember the answers from his partner so that he could introduce him in front of the whole subgroup. The subgroups discuss typically enjoyable activities and share their findings with the entire group of adolescent and parents. The introduction topics are by Positive Psychotherapy stale. They focus on the positive things in the families and pleasant experiences.

In the mapping phase of the problems, we found that adolescents with IBD do not suffer from higher rates of depression and anxiety than healthy controls (Jelenova *et al* 2015b). However, mothers and fathers had a lower quality of life in comparison with parents of healthy peers. Additionally, adolescents with IBD displayed impaired autonomic vegetative regulation measured by heart rate variability (HRV) (Jelenova *et al* 2015b). The impairment of HRV is connected with the poor physical condition and can be a sign of the chronic stress. This is why we decided to ask about exercising directly in the psychoeducation group. We also planned to speak about the importance of physical movement once they are in the state of remission.

Next part of the group session is the presentation of Problem-solving strategy using a discussion about favorite kinds of sports and physical exercise and possible ways of planning those activities. (Table 2) The results of the discussion in subgroups are presented in the big group of adolescents and parents. The following discussion is focused on increasing the awareness

Tab. 2. The physical activity and exercises.

-
- Divide group into two subgroups: (a) subgroup of adolescents and (b) subgroups of parents
 - Discuss your favorite sport or physical activity
 - Which sport would you like to try and why
 - Share the topics with another subgroup, discuss the similarities and differences
-

Tab. 3. Mapping of the issues in family related to IBD.

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- Divide the group into two subgroups: (a) subgroup of adolescents and (b) subgroups of parents. Discuss the following questions in subgroups:
 - Are there any issues connected to the IBD, which stress your family? What are positive attempts of the family to improve it?
 - Do these issues influence the communication in the family? If yes, in which way?
 - Are any topics connected with the IBD leading to tension in the family? What are the sources to change it?
-

Tab. 4. Message for others.

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- Create the family subgroups (adolescent with his parents). Discuss the following questions:
 - What would be your advice to the family with the child experiencing IBD? What would you tell them about problems, obstacles, and stresses that might happen?
 - Try to make a list of most various barriers and advice how to solve them
 - Share together with other families. Which are similar and which are different?
-

about possibilities of physical activities and potential obstacles.

The next topics were the problems in the families, especially communication problems connected with the IBD. According to our clinical experience, hyperprotection of the caregivers may give rise to the tension or conflicts in the families of the chronically ill adolescents. The purpose of this task is to enhance communication between adolescents and their families, especially within topics that might be difficult to talk about, secrets or just unspoken problems. Speaking about some general intergeneration problems connected with the disease of the child might happen in this activity focused on mapping the problems.

The next exercise “Message for others” was designed to increase problem-solving thinking in the family. Family (adolescent and caregiver/s work together) is creating the advice for the other (fictive) family with the child with the same disease (Table 4).

Next exercise (recommended after the short break) is focused on mindfulness in pleasant daily activities. “Trances of everyday life” is exercise used to enable recognizing and experiencing the life “here and now,” which could help the families to improve their quality of life (Table 5).

The next exercise was aimed to improve problem-solving skills (both in individuals and also in the families). Using the list of typical situations that cause stress in families of adolescents with IBD (Table 6), teenagers and their parents think about possible ways of solving those problems.

The last exercise is focused on the ability to relax. The imagination of “Safety place” is used as the main technique. Little lecture about the importance of relaxation and its impact on the body followed by the discus-

sion with the group seems to be beneficial opening of this exercise (Table 7).

Timetable of the psychoeducational group session.

The agenda for group session was prepared. It had 3 parts: (1) Introduction and preparation of the safety and open group atmosphere; (2) Short lectures with longer interactive exercises made by the child physicians and psychiatrist about treatment, diet, exercises, pleasure activities and psychological aspects of illness;

Tab. 5. Trances of everyday life.

Individually:

- One needs to switch off, stop the working or studying activities for some moment (parasympathetic)
- Every day there are dozens of situations, where this is possible
 - Some situations you might remember lying down in the bathtub;
 - coming home from freezing weather and drinking hot tea;
 - eating something that tastes good;
 - listening to the music;
 - lying in freshly made bed;
 - hugging a loved one; etc.
- Try to imagine one of these «trances» with closed eyes step by step, moment by moment

In family subgroups:

- Make a plan how to put such “trances” into your own and family life more frequently
-

Tab. 6. Problem solving.

- Divide group into two subgroups: (a) subgroup of adolescents and (b) subgroups of parents
 - List typical problems in your family (especially connected with life with IBD) and choose the problem you consider as the most interesting one
 - Design the solving of this problem step-by-step
 - Create the family subgroups and discuss the following questions:
 - Choose another problem that your family recognize as the most significant
 - Design the solving of this problem step-by-step
 - Share together with other families
-

Tab. 7. Imagination of the Safety place.

- Since the childhood, we seek the place, where we feel safe and where we like to rest, where nobody would disturb us

Individually think about:

- The moments from your childhood, the secret places you once used to have, at home or outside
- Create such a safe place in your mind
- It can be real place from your childhood, or safe place from nowadays, or imaginary place

Imagine:

- How does it look like? What are you experiencing, what things, colors, sounds are there?
 - What are you doing in that location? (Sitting, watching, lying, etc.)
 - How do you feel inside? (Relax, calm, lazy, etc.)
-

Tab. 8. Timetable of group session.

- (1) Introduction and preparation for the safety and open atmosphere
 - Introduction exercise in little groups (parent and adolescent sit in separate subgroups)
 - Exercises about pleasurable family activities and strengths
 - (2) Lectures and interactive exercises about main topics
 - Short lecture about diet made by child physician
 - Short lecture about physical exercise made by child physician
 - Exercise in subgroups about exercise
 - Short lecture about pleasure activities and mindfulness made by psychiatrist
 - Exercise in subgroups about pleasure activities
 - (3) Problem-solving exercises
 - Problem-solving exercise about implementing the changes to improve more healthy quality of life
 - Problem-solving exercise about how to help other families with the same problems
-

(3) Problem solving with exercises how to implement the healthy lifestyle into the family (Table 8).

RESULTS

Our former study (Jelenova *et al* 2015a) mapping the real mental and somatic state of adolescents with IBD (group of 29 adolescents compared with 35 healthy controls of the age 13–16 years) found out patients had lower heart rate variability that indicate lower adaptability to stress and also their families experience lower quality of life, higher level of depression and anxiety. Adolescents and their families from our prior study were offered participation in a psychoeducational program. 13 adolescents agreed. Divided into three groups (3–6 adolescents with parents or caregivers) took part in one 3-hour session. The session was opened by pediatricians, who are well known for those patients and their families since these doctors take care of them in the entire outpatient and most of the inpatient setting. Through short presentation followed by a discussion the doctors clarified some aspects of the possible ways of treatment, recommended diet and therapeutic regiment. Icebreaker technique focused on positive topics within the subgroup of adolescents, and a subgroup of parents helped to create a positive atmosphere. Subgroups discussed their free time activities, hobbies, favorite sports. This exercise was aimed not only to introduce participants but also working with their listening skills and orientation in positive aspects. Discussion about physical activity revealed patients would like to spend their free time with more physical exercises and be engaged in peer activities while their families often discourage them in the name of unnecessary fear from worsening IBD somatic symptoms. Clarification from the doctors softened their worries and opened the environment for future family discussion about adolescents' engagement in the common activities. The problem-solving exercise was applied on topics from everyday family life concerning different points of view on spending free time and worries about the future of adolescents when not under the supervision of parents. The common issue of families with chronic illness of children was presented, with the discrepancies between the level of controlling and maturation of adolescents and dependency and the need for letting go. The exercise of Message for other families became quite emotional while families took a history tour at the beginning of their lives with IBD, the untold worries and uncertainty of the parents from those times arose. Parents' main messages concerned the importance of the positive attitude, hope, and trust in the medical professionals and recommended routines. Adolescents' messages revealed similar aspects, the value of staying calm and have a positive look to believe in improvement. The family solidarity revealed as a significant feature. Teenagers and parents enjoyed the mindfulness exercise Trances of everyday life and relaxation technique Imagination of safety place. Both

patients and caregivers were happy they got the opportunity to meet with people with similar problems. They suggested this kind of meeting to be a way of learning about the disease in the beginnings of other patients and their families. Pediatricians appreciated the multi-family discussion (in contrast to their common one-to-one medical examination during check-ups or ward rounds) where they could better enhance the knowledge about the medical recommendation, also to clarify and disprove any potential false beliefs and support patients and their families.

LIMITATION

Limitation of this work was that the experience was based only on single psychoeducational sessions, without qualitative assessments of the impact on the adolescents and their relatives. The sample of participants was small, and there were only patients in remission who were accepting the presence of the disease in their lives. The experience can hardly be extrapolated to the patients in whom the disease has only just started, or who are in an acute attack of the disease. In these patients, there is also a need to apply psychoeducational interventions and adapt it to their needs.

CONCLUSION

Results from three groups of one 3-hour psychoeducation are interesting, and it seems that the format of the group session is suitable. It is important to try and accommodate the content and approach with the patients and their family members also in the acute phase of the disorder.

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