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HEALTH PSYCHOLOGY IN PEDIATRICS

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1. GENERAL OVERVIEW OF THE FIELD

Clinical care for sick children and adolescents can be practiced by carrying out interdisciplinary team work. Effective work in patient care requires comprehensive developmental psychology knowledge on the part of the healing team, and in addition to the child's chronological age, his or her psychological development and developmental characteristics must also be taken into account. When a disease emerges, it can be stressful for the child to develop symptoms, adapt to an unfamiliar environment, have fearful tests and interventions, and endure painful treatments. Hospital ward examination and treatment sometimes means separation from parents and family members, which can lead to anxiety and fear of being abandoned in young children. Symptoms of regression and mood changes are common among children hospitalized for a prolonged disease or long-term care. Perceived symptoms in most cases do not meet the diagnostic criteria for DSM, yet may lead to impaired functions and in addition to the experienced suffering they may show reduction in active participation needed during the healing process (Bursch & Stuber, 2005). In the care of children, we consider the parent not merely as a source of information whom we have an obligation to inform, but also being trusted with an active role in healing.

Below, I present the process of providing psychological care for children with chronic illness through the example of coping with a common chronic illness, type 1 diabetes (T1DM). Diabetes resulting from autoimmune processes is a model disease in many ways, as the role of psychological factors and coping patterns has a new significance due to the chronic course of the disease. Living with diabetes challenges patients' adaptability and demands self-discipline in their daily lives. The incidence of mental illness among diabetic children and adolescents is high worldwide, which may lead to low glycemic control in the long run (Northam et al., 2004). Among the most common psychiatric disorders depression, anxiety disorders, as well as eating and behavioral disorders deserve special attention. Diabetes-specific emotional distress is associated with negative feelings and specific fears associated with the disease, such as anxiety and depression due to blood glucose values, being overburdened by the day-to-day diabetes management, the lack of social support, or dissatisfaction with medical care (Fisher et al., 2014).

Risk factors that affect the mental health of diabetic children include low emotional control skills, high diabetic distress, and various impulse control and behavioral disorders. Mental disorders or illnesses and conditions associated with intellectual disability, as well as certain personality traits, can negatively affect disease comprehension and compliance. However, underlying childhood compliance problems are often due to an underdeveloped prefrontal cortex, which is responsible for executive functions. Among the environmental risk factors, we need to highlight family conflicts and lack of social support. Joining deviant groups may lead to the emergence of risk behaviors, especially in adolescents. Low socioeconomic status had previously been considered a risk factor in childhood diabetes, but the supply of insulin to children has already become subsidized in public health care, and the provision of dietary meals is required by regulation. Hormonal changes in adolescence affect insulin sensitivity, which can lead to deteriorating carbohydrate metabolism.

Psychosocial changes and the desire for independence by the adolescent may lead to acute situations and adherence problems. In adolescent diabetics, a number of difficulties related to age and life circumstances are associated with distress, such as family conflicts over diabetes management, parental overprotection and overbearing, dissatisfaction with one's body image, degree of independence and responsibility in diabetes management, and fear of the future (Hessler et al., 2016; Markowitz et al., 2012). Adolescents whose parents allow them full independence in diabetes management without adequate cognitive and social maturity are more likely to face deteriorating metabolic problems (ISPAD, 2018).

2. Case Study

In the case study, I present the psychological changes and intervention options in the care of diabetes through the example of a fictitious person created by combining several similar cases in order to protect patients.

2.1. Presentation of the Patient, Conditions of Dismissal

I first met 15-year-old Kata in the diabetes department, where she stayed for a few days for reeducation and prevention because of non-adherence problems. Due to the nature of the problem that warranted her admission to the hospital ward, her doctor requested psychological counseling for her. Having received the consent of the patient and her parents, I looked for a quieter place in the ward to talk to Kata, where I tried my best to create a safe therapeutic atmosphere for her.

Kata is a tall girl, she has an average body type and brown hair. Her behavior was conventional, but she was a little tense in a situation strange for her. She was responsive and cooperative in the conversation, but at times showed signs of anxiety and

sadness. realizing that I restrained from judgement and feeling my empathetic acceptance, her tension eased, but she was reluctant to talk about her difficulties, and she had a hard time sharing her emotions.

Later, I had the opportunity to meet her mother, who was really worried about her daughter. She gave the impression of an organized, rational woman who was always polite. After the conversation, I sensed that she wanted to distance herself from her child's current difficulties. She made her child responsible for the current situation, which made me feel uncomfortable, so I sympathized even deeper with Kata.

2.2. Current Problems, Difficulties

Her doctor found higher blood sugar levels and elevated HbA1c levels in a standard follow-up test, which may have occurred due to irregular insulin administration or increased carbohydrate intake. Kata's behavior had changed lately: she became unmotivated, anxious, deprived, seemingly uninterested in diabetes management, and isolated in the community. Her parents tried to apply even stronger control over diabetes management through ongoing monitoring. Her doctor reacted empathetically and helpfully to the problem, recognizing that she used to be an obedient, mature girl before, and the reason behind the changes could be related to emotional difficulties.

2.3. Anamnesis, Presentation of Subjectively Perceived Symptoms, Relating to the Problem

Kata is currently in the 9th grade, studying in an urban high school to which she was admitted with a high score. During her elementary school years she was a good and hard-working student, with good abilities. She had been looking forward to high school very much, and she expected to find friends and classmates with similar interests. The boys from her elementary school embarrassed her and bullied her for years because of her diabetes and her outstanding academic performance. They thought that Kata would be favored as she had been acquitted from physical education, or because she had been allowed to eat during classes, which was forbidden for others. Bullying and the void of sympathy filled Kata with sadness and frustration; she tried to avoid social situations, and she immersed herself in studying to escape from community activities. She has not yet been able to integrate into the current, new class community, and due to her marginalized role, she has no friends and maintains good relations with only a few classmates. Her grades are still very good; she spends almost all of her free time studying. Her family maintains high expectations regarding her school performance. Her parents work a lot; her older brother didn't disappoint them with his excellent results. At home, Kata was given the role of the perfect child, who "just" had to study well and help with household chores whenever she had been asked. She describes her mother as a perfectionist, controlling person. Kata is emotionally closer to her father, and she can turn to him more often with her problems. Decisions about

upbringing are usually made by the mother, and the father sometimes tries to soften the stringency. Her relationship with her older brother is superficial, she feels that her parents give her brother more autonomy and freedom, and trust him more.

After an infection which she had contracted when she was 7 years old, she was diagnosed with diabetes. Due to the infection, and with the emergence of diabetes symptoms, she lost weight significantly and she became anorexic and easily tired. The fact that the family had to face diabetes hit them unexpectedly and as a shock. Her mother, approaching the crisis situation in a problem-oriented way, tried to gather the necessary knowledge so that they could continue their lives at home. The parents initially tried to protect Kata from the truth, not telling her what her disease was. Kata tolerated the needles and dietary restrictions, hoping she would recover. Her understanding of the disease developed gradually and continuously, and regular medical check-ups provided her with information appropriate for her age. She acquired the necessary knowledge in diabetes management and had already gained independence as an elementary school pupil. Coexistence with diabetes became part of her everyday life, and she accepted the changes in her life and tried to adapt to them.

Towards the end of the 8th grade, seeing her classmates aspiring to be increasingly independent, she experienced a feeling of being restrained because of her disease. She saw her condition as a disadvantage, a restrictive way of life that deprived her from being liberated. She said that she had had experienced depression and the sadness due to being lonely in the upper grades of elementary school.

In the secondary school, starting in 9th grade, her rebellion coincided with the normative crisis of adolescence that materialized in diabetes management. She secretly bought high-carb candies, and consuming them made her blood sugar level fluctuate. Due to high blood sugar levels, she had frequent headaches and difficulties in concentration. She was unable to prepare properly for her tests, and her performance deteriorated. Performing at a high level at school was an important part of her self-image and identity, so when she could not cope with experiencing failure, she became tense and anxious, and her self-esteem decreased. She became even more isolated in the community, her mood became more and more depressed, and she sometimes secretly tried to relieve the emotional tension and pain she could not stand by self-inflicting wounds. She reacted to the problems by becoming helpless and depressed; she felt no one understood her.

Hypoglycemia was becoming more frequent in her as a result of fluctuating blood glucose levels and school performance anxiety. Once, while writing a test at school, she experienced malaise intensively, similar to a panic attack due to her low blood sugar. Since then her safety concern had intensified, became more cautious, further reinforcing her belief that she needs to keep her blood sugar levels high so that her malaise does not reoccur. As a result of the malaise, her new classmates had also become aware of

her illness, which she had tried to keep secret because she feared that she would be bullied and mocked in her new community as well.

Her parents, when they noticed the problems, banned her from taking part in community activities, controlled her diabetes management and eating even more strictly, which led to frequent friction and tensions in the family, especially straining the mother–daughter relationship. They tried to conceal the elevated blood sugar levels from the outside world and the healers, in the hope of being able to take care of the problem domestically. However, a three-month diabetic follow-up study revealed a higher HbA1c level and immediate treatment was recommended by members of the healing team.

2.4. Relating to Illness, Recovery, Health Care. How Motivated and Able Is the Patient to Work Together, to Induce Change?

Kata initially refused the opportunity to be admitted to the hospital, arguing that she would fall behind with her studies in the middle of the school year if she missed school for a few days. She downplayed the problem, locked herself up, and tried to find a solution on her own. She politely attended the training of the dietitian and the education nurse, but tried to escape the conversations that were unpleasant for her as soon as possible. Psychological counseling initially took place in the same manner. Validation of her emotions, unconditional acceptance, and honest communication provided an opportunity for her to be able to articulate her difficulties, which resulted in her distance being reduced somewhat.

Family tensions were identified by her as a primary problem which increased during everyday diabetes management. She sees any change in her relationship with her parents as hopeless; she herself drifts helplessly between expectations. In this inevitably vulnerable state, the use of limited parental re-care (a schematic method in which we try to satisfy a patient's emotional needs with a sincere, accepting, intimate, caring attitude similar to that of a good parent, but within a limited range of adopting therapy) allowed her to accept the psychological help offered, proven to establish a therapeutic alliance in the long run (Vizin & Farkas, 2020). The assistance offered focused on finding common solutions to adherence problems. Kata was able to self-reflect and had insight into the problem. The resources of her personality which had been aware of–good intellect, compliance, and discipline–made me feel confident in the prospective success of our working. Her motivation could be identified in reducing suffering, restoring emotional stability, and improving interpersonal relationships.

2.5. Presentation of Interventions and Changes in the Patient During the Process

We initially entered a contract with Kata and her parents for 15 appointments, to which three additional parent consultations were added. The health check conversation

allowed us to get a thorough picture and jointly understand the problem that affected her mood and diabetes management, and to jointly formulate the goals of working together. Prior to the contract, I consulted her mother in a separate consultation because I really wanted her to be involved in the process. During the conversation, I sensed the mother's guilt and shame for not being able to raise her daughter in a way when adherence problems would not surface. The mother accepted the possibility of parental consultation, which focused on understanding how Kata is experiencing her illness and the challenges she is facing in her current life situation, and how the mother can help Kata while improving her relationship with her child. From the consultations, I hoped that if the mother managed to feel empathy and acceptance for her daughter, she could find better solutions to help her effectively.

As a first step, Kata and I undertook to explore the link between glycemic control and anxiety. Psychological interventions were aimed at mapping the psychological processes underlying the fear of hypoglycemia and reducing anxiety. The trigger was the experienced hypoglycemia during a school test, which was associated with anxiety and fear. Later she mistakenly identified the occurrence of vegetative symptoms of anxiety with signs of hypoglycemia. Psychoeducation aimed to enable her to differentiate between real and deceptive symptoms in the relationship between hypoglycemia and anxiety. It was also part of the education to make her understand the effects of stress on her blood sugar level and how mood and frame of mind affect blood sugar levels. Increasing awareness of the combined effects of diet, insulin administration, and exercise, which contribute to better physical and mental health, was also used to regain her control over diabetes.

Psychoeducation alone did not bring about a change in diabetes management, but it did contribute to a better understanding of the disease, which somewhat increased Kata's sense of being in control. The change required mapping and cognitive restructuring of negative automatic thoughts related first to hypoglycemia and then to school anxiety, to reduce her anxiety as a result of more realistic, adaptive thoughts. She realized that her avoidance behavior – keeping her blood sugar high and eating food containing a lot of carbohydrates – did not contribute to reducing her symptoms. Activating Kata's role in diabetes management and continuing to support it further increased her sense of control and reduced her anxiety. We set short-term, well-defined, realistic and achievable goals that did not impose an additional burden on her, but still led her to achieve success. Her attempts were not always successful, which provided an opportunity for us to discuss that stumbling is not the same as a relapse. She became able to exercise control over her illness, becoming more independent, and not only did her blood sugar levels improve, but her mood and temper also improved.

At the parent consultation, we also focused on activating Kata's role, while involving the parent to take an active part in creating an agenda that helps Kata to plan and perform her daily exercises. The mother took part in going along with Kata to swimming

classes three times a week, which, in addition to having a positive effect on blood sugar values, also provided an opportunity for them to get closer to each other. We also explored the topic of shared responsibility, in which the mother recognized her own role but refused to give up the idea that her daughter should behave much more responsibly. She was still not open to understanding Kata's struggles, nor did she appreciate her efforts.

After 15 occasions, we evaluated the results of our work together. In addition to the gradual results, Kata felt a need to continue working on her problems, so we prolonged the contract for 30 more appointments, with a focus on coping with the disease and improving the regulation of her emotions.

In the next phase, we examined accepting the stages of the disease, and Kata realized that her behavior had previously been dominated by disregard. Because the anxiety she felt about living with diabetes and the angst due to the bullying by her classmates were intertwined, she tried to ignore both, making her unable to express any feelings about her experiences for a long time. In connection with the processing of her experiences in primary school, she began to feel more and more anger towards the boys who bullied her, and later the same feeling appeared in connection with her diabetes. The feeling of anger brought to the surface the pain of losing her health, but despite her suffering, her numbness and helplessness dissolved, and she became able to express her emotions. Her desire to regain self-esteem was stronger than ever, so we continued to process the mental burdens and injuries caused by the bullying. In the meantime, she mastered relaxation techniques, which provided additional effective help in reducing anxiety and increased her self-awareness. She became more and more capable of self-reflection, beginning to recognize her mood swings.

By this time, we had been working together for more than a year, and although she had achieved significant results in the process of accepting the disease and managing diabetes, she still remained alone in terms of social support. She could not get closer to her classmates, she could not establish friendships. Despite her excellent academic performance, she felt inferior, which she sought to compensate with perfectionism, failure avoidance, and increased control. Though she continued to require support, the frequency of our meetings was reduced to one appointment in two to three weeks. During the summer holidays, however, her mood deteriorated rapidly, because she didn't have to study, she couldn't really occupy herself, and she lacked the joyful activities in her everyday life. Her parents still didn't allow her to attend programs on her own because they didn't trust her to take proper care of herself. As a result of the isolation, her depression increased, she became unmotivated, her circadian rhythm was upset, her self-esteem deteriorated, she reverted to self mutilation by cutting her skin again, and suicidal thoughts reappeared.

In this situation she was able to recognize her condition and the supportive therapeutic relationship allowed her to seek help. After a rapid assessment of her health situ-

ation and with the involvement of a child psychiatrist, it became possible to examine the mood changes after having been admitted to a ward, and after the diagnosis of a moderate depressive episode was established, medication was prescribed.

The emergence of her depression resulted in another crisis in the family, with a minor conflict with her mother who by no means wanted her daughter to go to a psychiatrist. After Kata's admission to the psychiatric ward, during a discussion with her mother it was revealed that she felt ashamed of her daughter's depression, which originated from the negative feelings and beliefs about the history of psychiatric patients and their treatment in her own family. We worked on these feelings with the mother for a long time, until she was able to separate her own difficult feelings from the feelings about her daughter and see her child in her own, discreet reality. Through her insights, she began to see her daughter's personality in a more and more realistic and detailed light. Her empathy for her daughter increased and she was able to handle conflicts with her adolescent daughter more and more effectively.

In the end, Kata and I worked for another two years until she graduated from secondary school at the age of 18. It became necessary to provide support for her more regularly and set new goals in the therapy because of her depression. As a result of the medication as well as her mother's change of attitude, her mood improved and she became more balanced. Developing social skills increased her adaptability, but she had still not been able to build close friendships with her peers.

The breakthrough was achieved in a camp for diabetic children the following summer, where Kata was finally able to become a carefree child among younger children and played along with the 12 to 14-year-olds. Friendships formed in the camp proved to be long lasting, and through these relationships she began to open up, to accept her "imperfections". As an older, clever, maturing girl she was also given simpler leadership roles, which also benefitted her self-esteem. In an accepting, safe and friendly atmosphere, she had the opportunity to notice the struggles of other diabetic children and understand that others were facing similar difficulties. Realization brought her relief, and she was finally able to relax her strict expectations of herself.

Over time, her personality matured, she was able to develop more relations with friends successfully, which came as a surprise even to herself. She was no longer ashamed of the use of the pump and sensor among friends, she was able to successfully represent her interests and took care of herself. Her blood sugar levels were in the safe range, with no complications. Her academic achievements continued to strive matching her abilities, but she was less performance-focused, relieved by her convulsive endeavors, and overall she became more liberated and happy.

As a graduation gift, she asked her parents to allow her to have a tattoo which was in the end approved by them. The tattoo depicted a T1 symbol which is worn by people with type 1 diabetes as a badge. Her adaptation to the disease was expressed in this symbol, which she wore proudly.

2.6. Closing and Summarizing the Case

Kata's case highlights that the particular difficulties of chronic diseases are intertwined with the emotional problems due to the characteristics of social development in childhood and adolescence in the background of adherence problems. It has to be noticed during the treatment of chronic illnesses that on the road leading to adaptation we have to take both the development of personality and the formative effect of the environment into consideration.

The expertise and empathy of the healing team made providing psychological help available after recognizing the emotional problems. During the course of psychological counseling the foundation of the therapy requires building confidence, empathy and unconditional acceptance. The process needs to be based on honest and supportive communication, and should be made transparent, setting its goals should be shared, to enable gradual personality and health development changes. In the process, Kata was supported by the emerging results in reducing anxiety and regulating emotions to regain control of her health and to be able to take an active part in self-care.

Psychological intervention was primarily focused on strengthening adherence, which played a key role in establishing better physical and mental health. With the help of supportive techniques her self-esteem was improved, efficiency and confidence were increased, and her ability to adapt was improved. Monitoring changes in her mood, recognizing a depressive episode, and providing child psychiatric care allowed for effective treatment of the disease and contributed to preventing complications.

It was again instructive for me to recognize that it is worth involving parents closely in the therapy of their children, thereby supporting the consolidation of positive turns in everyday life along with the development of parent-child relationships. The shared responsibility between parent and child leads to an increase in adherence in childhood. From adolescence onwards, the gradual assumption of responsibility and self-care by the child, the non-intrusive presence of parents, self-efficacy and at the same time the emergence of the adolescent's independence lead to better physical and mental health.

3. Discussion

In pediatrics, the treatment and care of patients in a bio-psycho-social-spiritual approach is of exceptional importance. Based on international experience, early detection and treatment of psychiatric disorders associated with injury, life-threatening and chronic illness is possible through regular psychological consultations and pre-planned screening. Assessing psychosocial factors and identifying disease-specific distress can play a significant role in the prevention of mental disorders. In order to make the screening tests more efficient, it is necessary to develop and validate the Hungarian adaptation of the individual disease-specific questionnaires.

In the case of administering interventions inducing significant pain, it may be effective to incorporate anxiety management into the pain management program (Sheridan et al., 1997; Stoddard & Saxe, 2001). The introduction of prevention programs and psychoeducation could lead to a reduction of the emergence of anxiety and depression in examinations and interventions associated with significant distress and pain. In Hungary, a storybook called *The Courage Test* for children suffering from leukemia or cancer and for their parents is aimed to support them in coping the disease. *The Courage Test* helps the child to adapt to hospital conditions, to understand the disease, and to prepare for the expected examinations and interventions. Protagonists with similar ages, symptoms and their fabled stories could help children to empathize with these fairy-tale heroes. Studies have shown that observational learning reduces children's anxiety and increases cooperation when seeing a child of their age on video successfully coping with a difficulty (Melamed et al., 1978).

Playing together with a parent, even in a hospital ward, also helps to overcome the frustration and anxiety that comes from vulnerability and helplessness. The contribution of the "Clown Doctors" is also invaluable in reducing the suffering pressure of small patients. During children's recovery time, play therapy, fairy tale therapy and art therapies can be well integrated into the hospital treatment process, which gives young children the opportunity to process stressful experiences and learn new and more effective coping strategies.

In the event of loss of health and life-threatening conditions, crisis support should be available not only to the sick child but also to their parents and siblings. In this situation, it is important for the siblings to have an age-appropriate explanation of what is happening and to have an emotionally accessible adult nearby who can be temporarily be present in the children's lives, answer their questions, and support them.

In the case of diseases that cause permanent damage to health, informing the child's environment and, if necessary, educating them is essential. The importance of social support is highlighted in a study which found that high levels of social support from classmates reduced depression levels in chronically ill children (von Weiss et al., 2002). The empathy and cooperation of peers could be increased if they are educated according to their age and knowledge about their classmate's illness. Nationwide, doctors treating chronically ill patients in clinical centers, many non-governmental organizations and peer support communities organize educational programs in schools and kindergartens. Sick children themselves and their parents need – in addition to the psychological counseling available – peer support communities, where the inspiring and hopeful examples of parents and children who have experienced and coped with similar difficulties can guide them and give them strength to move forward.

Lessons learnt from this case

The first encounter of a sick child with the healing team is a decisive experience in which the healers' supportive, empathetic attitude can minimize the child's anxiety and facilitate the adaptive coping needed for healing, which will later become a cornerstone of health behaviors.

REFERENCES

Bursch, B., Stuber, M. (2005). Pediatrics. In J. L. Levenson (Ed.), *Textbook of Psychosomatic Medicine* (761–786. o.). The American Psychiatric Publishing.

Fisher, L., Gonzalez, J. S., Polonsky, W. H. (2014). The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision. *Diabetic Medicine, 31*(7), 764–772.

Hessler, D., Fisher, L., Polonsky, W., Johnson, N. (2016). Understanding the areas and correlates of diabetes-related distress in parents of teens with type 1 diabetes. *Journal of Pediatric Psychology, 41*(7), 750–758.

ISPAD – International Society for Pediatric and Adolescent Diabetes. (2018). Guideline for Diabetes in Childhood and Adolescence. (online). https://www.ispad.org/page/ISPAD Guidelines2018

Markowitz, J. T., Volkening, L. K., Butler, D. A., Antisdel-Lomaglio, J., Anderson, B. J., Laffel, L. M. B. (2012). Re-examining a measure of diabetes-related burden in parents of young people with type 1 diabetes: The Problem Areas in Diabetes Survey-Parent Revised version (PAIDPR). *Diabetic Medicine, 29*(4), 526–530.

Melamed, B., Yurcheson, R., Fleese, E. (1978). Effects on film modelling on the reduction of anxiety related behaviours in inviduals varying in the level of previous experience in the stress situation. *Journal of Consulting and Clinical Psychology, 46*(6), 1357–1367.

Northam, E. A., Matthews, L. K., Anderson, P. J., Cameron, F. J., Werther, G. A. (2004). Psychiatric morbidity and health outcome in type 1 diabetes – perspectives from a prospective longitudinal study. *Diabetic Medicine, 22*(2), 152–157.

Sheridan, R. L., Hinson, M., Nackel, A., Blaquiere, M., Daley, W., Querzoli, B., Spezzafaro, J., Lybarger, P., Martyn, J., Szyfelbein, S., Tompkins, R. (1997). Development of a pediatric burn pain and anxiety management program. *Journal of Burn Care & Rehabilitation, 18*(5), 455–459.

Stoddard, F. J., Saxe, G. (2001). Ten-year research review of physical injuries. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(10), 1128–1145.

Vizin, G., Farkas, K. (2020). A kognitív viselkedésterápia lehetőségei az onkológiai ellátásban. *Magyar Onkológia, 64*(1), 62–69.

von Weiss, R. T., Rapoff, M. A., Varni, J. W., Lindsley, C. B., Olson, N. Y., Madson, K. L., Bernstein, B. H. (2002). Daily hassles and social support as predictors of adjustment in children with pediatric rheumatic disease. *Journal of Pediatric Psychology, 27*(2), 155–165.