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# "What is happening to my child?" Parental understanding of the child's experiences during inpatient treatment of anorexia nervosa, strengthened by cooperation with medical personnels

"Co się dzieje z moim dzieckiem?" Sposób rozumienia doświadczeń dziecka przez rodziców w trakcie stacjonarnego leczenia jadłowstrętu psychicznego. Wzmacnianie zrozumienia rodziców dzięki współpracy z personelem medycznym

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# Abstract

**Introduction and objective:** During the inpatient treatment of children with anorexia nervosa, their parents are emotionally burdened and, at the same time, responsible for making key medical decisions; thus, the quality of cooperation with medical personnel is crucial for the treatment outcome. This study aimed to investigate how parents understand the child's experiences in this particular context and how medical staff may support them in this process. **Materials and methods:** The medical records documenting the hospitalisation of two adolescent patients for anorexia nervosa were reviewed. The families were selected from a larger project studying cooperation with medical staff: one perceived as cooperating in a beneficial way and the other struggling with collaboration. In order to obtain an in-depth understanding of the studied phenomenon, qualitative methods were used, including the comparative case study approach and consensual qualitative research methodology. **Results:** Comparing the two clinical cases, it was found that the cooperating family and the one struggling with collaboration differed in their understanding of the child (22 vs. 4 in effective attempts and 6 vs. 14 in failure examples). The second parental couple's comprehension regarded mostly symptoms. **Conclusions:** The personnel's multidisciplinary interventions helped the legal guardians to build their understanding. Better parental understanding of the child's inner world had a beneficial effect on the treatment process.

Keywords: anorexia nervosa, child and adolescent psychiatry, cooperation, family consultations, qualitative research

# Streszczenie

Wprowadzenie i cel: W trakcie hospitalizacji dziecka z jadłowstrętem psychicznym rodzice są obciążeni emocjonalnie, a jednocześnie odpowiedzialni za podejmowanie decyzji medycznych, dlatego jakość współpracy z personelem medycznym ma kluczowe znaczenie. W prezentowanym badaniu starano się odpowiedzieć na pytania, w jaki sposób rodzice rozumieją doświadczenia dziecka w tym szczególnym kontekście i jak personel medyczny może ich wspierać w tym procesie. Materiał i metody: Analizie poddano dokumentację medyczną dwóch nastoletnich pacjentek hospitalizowanych z powodu jadłowstrętu psychicznego. Rodziny wyłoniono z większego projektu dotyczącego współpracy z personelem medycznym; jedna z nich była postrzegana jako współpracująca w korzystny sposób, a druga – jako zmagająca się ze współpracą. Aby dogłębnie zrozumieć badane zjawisko, zastosowano metody jakościowe: badanie konsensualne (consensual qualitative research) i porównawcze

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studium przypadku (*comparative case study*). **Wyniki:** Zestawienie dwóch przypadków klinicznych wykazało, że rodzina współpracująca i rodzina zmagająca się ze współpracą różniły się pod względem efektywnego rozumienia dziecka (liczba skutecznych prób: 22 *vs* 4, liczba niepowodzeń: 6 *vs* 14). Co więcej, rodzice zmagający się ze współpracą trafnie rozumieli głównie kwestie związane z objawami zaburzeń. **Wnioski:** Multidyscyplinarne interwencje personelu pozwoliły opiekunom prawnym na poszerzenie rozumienia dziecka. Lepsze rozumienie wewnętrznego świata nastolatki przez rodziców miało korzystny wpływ na proces leczenia.

**Słowa kluczowe:** jadłowstręt psychiczny, psychiatria dzieci i młodzieży, współpraca, konsultacje rodzinne, badania jakościowe

#### INTRODUCTION

International clinical practice guidelines recommend family therapy as a key element in the treatment of anorexia nervosa (AN) among young adolescents (National Institute for Health and Care Excellence, 2020), and meta-analyses report family-based treatment as the only intervention in AN showing effectiveness in terms of long-term symptomatic remission (Datta et al., 2023; Monteleone et al., 2022; Richards et al., 2018). The existing recommendations for family work concentrate on outpatient treatment, while in severe cases AN is treated on an inpatient basis (Hay et al., 2019).

During the child's hospitalisation, the goal of the parents and medical personnel is the same: to achieve a symptomatic improvement in the patient's condition; hence their cooperation is necessary, as it impacts the treatment success, but might be sometimes challenging (Bryniarska et al., 2022). It may be challenging for parents to understand the egosyntonic characteristics of AN (Couturier and Lock, 2006), recognise the patients' belief that they are not sick (Guarda et al., 2007), or conceive the patient's perception of the AN consequences as positive and adaptive (Abbate-Daga et al., 2013). Parents might not understand the mechanisms underlying the eating disorders and may need to cope with difficult emotions due to their child's prolonged hospitalisation (Kästner et al., 2018).

## **AIM OF THE STUDY**

This study is part of a larger project addressing the issue of cooperation between the parents of young adolescent patients and medical personnel. This paper is a "look under the microscope" at parental understanding of their child during psychiatric inpatient hospitalisation. More specifically, the purpose of the study was to investigate how parents may perceive their child's mental states at this time, how they understand their child's experiences, and whether they have difficulties doing so. Additionally, the study aimed to determine how personnel might react to support parents in critical moments, and establish whether the quality of cooperation could influence the treatment process.

#### **MATERIALS AND METHODS**

# **Participants**

Real-world clinical data were used, derived from the AMMS (Asseco Medical Management Solutions) programme which maintains medical records at St. Louis Regional Specialised Children's Hospital in Krakow, Poland.

The participants of our study were recruited from the medical personnel working at the inpatient Psychiatric Ward at St. Louis Regional Specialised Children's Hospital for adolescents under 14 years old in 2017–2020. In both cases,

	Variables	Victoria	Kate
Before hospitalisation	Duration of symptoms [weeks]	7	16
	Minimum weight [kg]	42.4	42.8
	Maximum weight [kg]	51	53
	Height [cm]	167	161
	BMI at admission [kg/m²]	15.2	16.7
	Bradycardia at admission	Yes	No
	Number of previous hospitalisations for AN	0	0
Course of hospitalisation	Duration of hospitalisation [days]	108	72
	Number of passes	5	2
	Number of individual therapeutic sessions	22	13
	Number of family consultations	5	5
	Neuroleptics	Yes	No
	Antidepressants	Yes	Yes
	Benzodiazepines	No	Yes

Tab. 1. Description of the sample (AN symptoms and course of hospitalisation)

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	Quantity	Examples	Quantity	Examples
Understanding of the child	22	(V-a) "The parents describe Victoria as calmer and in control. They note her sensitivity and greater ability to manage her emotions" (V-b) "The mother attributes her daughter's difficulties to being overburdened by domestic responsibilities, strong sensitivity, disenchantment, and opinions of others"	4	(K-a) "Mum describes situations indicating an increase in eating symptoms in emotionally difficult situations" (K-b) "They describe Kate's mood as moderately depressed"
Misunderstanding of the child	6	(V-c) Mother to Victoria: "I won't get angry, as long as you tell me everything" (V-d) "Mum claims that Victoria's continued hospitalisation in the ward will ruin Christmas for the whole family, as they will have to commute to X and take her on day walks"	14	(K-c) "The parents perceive their daughter's current scratching habit as copying the behaviour of other patients" (K-d) "The father perceives his daughter's behaviour as insubordinate, especially when she does not follow the expectations of parents in implementing the contract"

Tab. 2. Categories of parents' understanding - quantity and examples

the author of individual consultations and family meetings was the same male psychotherapist after psychodynamic-systemic training. Additionally, there were eight medical doctors and eight nurses providing their daily reports. The reliability of the comparison stems from the fact that both cases were described by the same authors; however, it should be noted that the descriptions might be influenced by the authors' own interpretation.

#### Measures

The examination was based on medical documentation and aimed at presenting contrasting examples of cooperation. Since the "how" and "why" of the hospitalisation intervention was reviewed, the methodology was based on consensual qualitative research (CQR) (Hill et al., 2005) and comparative case study (CCS) approach (Goodrick, 2014). The data for CQR involves words, narratives, and stories rather than numbers, and the approach served to distinguish the categories of understanding the child (Hill and Knox, 2021). The CCS is a specially-designed six-step procedure used in many scientific fields to compare cases, yielding not only a detailed description, but especially an in-depth contextual comprehension (Campbell, 2010). The CCS was applied to trace the dynamics of cooperation between the personnel and parents at crucial points of hospitalisation.

The data is structured narratively, and the notes consist of patient evaluation on admission, one report from a doctor and two reports from a nurse daily, five notes from family consultations in both cases, and 13 or 22 individual consultations. A total of 585 records were analysed, and the excerpts regarding the understanding of the child were chosen and then analysed in detail. Each record had between one and a dozen sentences. In the case of family meetings, the notes were more extensive, up to 37 sentences, and the primary evaluation was even longer.

#### **Procedure**

The crucial part of the qualitative analysis was conducted by two authors independently and then with the supervision of a third one. Small excerpts of the study material were analysed in order to explore how medical staff describe the parents' understanding of the child and attempt to support this process. In line with the CQR, at every stage, the final conclusion was achieved through recurrent discussions among the research members (Walker and Lloyd, 2011). The details of the CQR procedure employed in this project might be found in Bryniarska et al. (2022).

In accordance with the CCS design, we followed the six-step methodology (Goodrick, 2014). Firstly, the purpose of our study was defined, as cited above. Secondly, the theories to focus on were identified: the systemic approach and the importance of cooperation between family members and professionals (Johns et al., 2019). Then, the cases were defined: they were chosen from a deliberate sample (Kaarbo and Beasley, 1999) based on similarities in symptomatology and treatment course (Tab. 1). Then, all the excerpts that referred to the topic under study were selected. Thanks to the diverse sources of material, we traced the time perspective, i.e. which intervention followed which event. The alternatives to explanations regarding the relationship with the parents, such as the influence of peers or the health status of family members, were also taken into consideration. However, no such variability over time or impact on the course of symptoms was found in this area. The last step, reporting findings, was conducted separately for each case, presenting one essential, carefully selected event, when the parents' understanding was limited and the staff responded adequately.

The families were selected from a larger project analysing young adolescents with the diagnosis of AN during their inpatient treatment (Bryniarska et al., 2022). The study aimed to present contrasting examples of cooperation with medical personnel, which is why one family struggling with cooperation and another one with beneficial cooperation were chosen from the previous part of the project (Bryniarska et al., 2022).

The final case selection consisted of two nuclear families, married parents, all aged around 40 years, mothers with secondary education and fathers with primary education, two or three siblings. Both patients, Victoria (13 years old, 7<sup>th</sup> grade pupil) and Kate (12 years old, 6<sup>th</sup> grade pupil), applied quantitative and qualitative food restrictions, and self-induced vomiting or purging; additionally, Kate cooled her body.

Menstrual cessation occurred in both of them. They had been hospitalised in the paediatric hospital just before admission, but neither had been fed through a tube there. In the psychiatric ward, the patients were treated using the same model, however they differed in the course of therapy (Tab. 1)

All data was anonymised, pseudonyms were used, and all necessary consents were obtained: from the Head of the Ward, Hospital Directors, and the Jagiellonian University Bioethics Committee (Decision No. 1072.6120.168.2020). The parents described and compared in the study also provided their signed consent.

#### **RESULTS**

# How parents understand their child

In Tab. 2, the moments when the parents succeeded in understanding their child and when they had difficulties with it, are presented. The phrase "effective understanding" is an abbreviated term for the data that describe the parents' responses that were beneficial for the child's treatment process, and "ineffective understanding", where parental difficulties were perceived. The differences between the parents of the two patients proved to be significant (22 vs. 4 in effective understanding) (Tab. 2).

# How to support parents' understanding of their child

Regardless of the differences described above, in both cases, a moment of parental difficulties in understanding their child appeared. They were described on a case-by-case basis with a focus on how the crisis occurred and what interventions were provided by the staff to respond to it.

#### **Victoria**

The patient, during individual psychotherapy sessions, spoke of her "fear of expectations and pressure from the family. [...] The family pressures her to 'try harder', by achieving the weight required for hospital discharge. Victoria, on the other hand, resists by talking about her lack of readiness for such rapid growth".

The following day, the parent's behaviour highlighting the child's concerns could be observed. The physician on duty noted that the girl "was being fed by her mother during the visit, most likely to get her body weight to the next stage". The nurses intervened immediately: "it was pointed out to the mother that this was too much in too short a time".

A family meeting was held the following day with the focus on parental understanding. The intervention was conducted through several logical steps. The girl's feelings of pressure were discussed with her parents ("she perceives her efforts so far as insufficient"). Then, the patient's "ambivalence about contesting her own needs with the desire to please others" was intervened upon. In relation to this,

special attention was paid to an incident from the previous day, when the mother overfed her daughter during a visit. In this context, "the impact of their own expectations on the relationship with their daughter was discussed with the parents". At the end of the meeting, the patient was also invited to join. She spoke of her anxiety regarding outpatient treatment, which "will make her angry, and she equates the expression of anger with the loss of family relationships – especially with her father".

Hospitalisation in an inpatient ward created unique circumstances for cooperation. The following therapeutic interventions focused on building the child's autonomy beyond the anorectic symptoms, involving the parents in the process by strengthening their ability to understand the child. Thanks to the exchange of information between the professionals, the situation could be discussed in a family meeting, during which the staff created space for reflection, clarified their intentions regarding the prohibition of sudden feeding, and tried to describe the girl's feelings and intentions to the parents.

Three weeks later, in an individual conversation with a psychotherapist, the patient was talking about a greater sense of self-awareness and autonomy: "Victoria [...] refers to the treatment process – she presents the changes she notices in herself. She talks about being bolder, and able to be close to someone, at the same time putting a limit to her privacy, and being able to express her emotions without fear of losing her loved ones".

#### Kate

Kate was crying after her mother's visit and refused to talk to either the doctor or the nurses, instead seeking comfort in the peer group. The doctor on duty contacted the parents to understand the recent events and heard that "Kate became angry with her mother because of the photographs on her mother's phone - according to her mother, these are normal pictures of Kate that were taken with her knowledge. The mother does not know what could have been the cause of her daughter's outburst". Members of the medical personnel immediately noticed the patient's discomfort and reacted properly, responding to the needs of the patient, inter alia, by acting towards the parents. Three days later, during her individual therapy, the girl "mentions the sense of her parents' misunderstanding. She focuses on their anger as overwhelming. She discusses parental involvement in the treatment process and building their understanding of the illness". Using the possibility of individual contact with a psychotherapist, Kate was able to identify and describe her emotions and needs towards her parents. On the same day, during the first family consultation, "the parents received psycho-education on eating disorders, forms of support, and parallel family work".

In the above excerpt, one can clearly see how difficulties in understanding in the parent–child relationship affected the psychological state of the child and caused feelings of helplessness, ignorance, and lack of competence in the parent.

It also showed the mother's difficulties in understanding the internal world of her daughter. At the family meeting, the psychotherapist tried to deepen the comprehension of the anorexia symptoms associated with a disturbed body image, and emphasised the role of parental support in the treatment process, which could be seen as a corrective experience.

Later during her hospitalisation, the effects of improved communication between Kate and her parents were evident, as the individual psychotherapist described: "Kate is more cheerful. She notices a positive change in her mood. She relates that her mother has made an evident effort, focusing on the change of communication with Kate; less shouting from her mother – less guilt and anger from Kate. She acknowledges reduced tension levels and improved sleep as an effect".

# **DISCUSSION**

Many researchers describe the family as the primary resource that guarantees the well-being of the child, particularly in crisis situations, such as illness or hospitalisation (Carbonell et al., 2020). In this study, the trialogue (Jespers, 2022) between the young patient, the parents, and the medical staff was analysed.

Inpatient psychiatric hospitalisation might be a challenge (Kästner et al., 2018), but it can also be seen as an opportunity (Bryniarska et al., 2022). As illustrated by the analysis of two cases, a well-designed working model of 24-hour care, an intensive therapeutic process, and good cooperation between specialists might be beneficial not only for the treatment of the child, but also for the relationships within the family. This might happen through a series of interventions with the involvement of medical practitioners, nurses, and psychotherapists.

Our review showed the differences between a cooperating family and one struggling with collaboration in understanding the child. However, in both cases, a critical moment appeared, linked to insufficient understanding of the mechanisms underlying the disease: weight restitution principles or disturbed body image. In those moments of crisis, quick and appropriate interventions helped the parents to overcome the predicament. This leads to the clinical implication suggesting that the families struggling with cooperation might need even more support from the medical staff, and their readiness to intervene. Among the clinicians, such narrations (White and Epston, 1991) as "a difficult family" sometimes appear, and they could be used not to build an emotional distance from the patients' parents, but as a warning for professionals that special support is necessary. It might be a valuable insight for medical professionals that parents' difficult behaviour is not a reflection of their unwillingness to support the healing process, but rather their lack of understanding, which might make them lost or puzzled.

In inpatient wards, a special role in linking the staff, parents, and children is played by the psychotherapists. They connect and accommodate varying perspectives, while reinforcing the understanding of one other. This is particularly

important at times of crisis, when there is tension in the collaboration. As illustrated in the reported cases, during family consultations, the psychotherapist encourages the parents to better understand their children in a broader perspective: through psychoeducation about the symptoms of AN and the relevance of emotions to daily functioning. The therapist also concentrates on critical moments and tries to show the patient's perspective on it. In the existing studies, parents have highlighted the supportive role of health professionals who understand eating disorders (Gilbert et al., 2000). At an earlier stage of this project, it was shown that creating an opportunity to express doubts had a protective effect against withdrawal or discharge on request (Bryniarska et al., 2022).

Delving into the child's inner world and trying to understand their experiences might also be called mentalisation (Bateman and Fonagy, 2013). The epistemological status of our clinical data did not allow to directly investigate the mentalisation process; however, it could be observed how the parents understood their children in these specific moments. Interestingly, when the parents struggling with cooperation succeeded in imagining their child's internal world, it regarded mostly the symptoms, which could be understood as familiar perpetuating mechanisms of AN (Józefik and Iniewicz, 2004). It was also explored how members of medical staff could help the parents with transcending their perspective, which is momentarily narrowed, and how they might stimulate the parental "mentalising muscle" (Bateman and Fonagy, 2019).

## **CONCLUSIONS**

Application of the comparative case study methodology does not allow drawing general conclusions, but it contributes to understanding the complexity of interactions occurring during the child's hospitalisation, in the trialogue of professionals, patients, and their parents. Moreover, it might be a valuable insight for clinicians that the parents' difficult behaviour does not reflect their unwillingness to support the healing process, but rather their lack of understanding, which might make them lost or puzzled. It is thus worth exploring the described phenomena in a larger sample size. In further research, it would also be beneficial to broaden the methodology by combining quantitative questionnaires with self-reporting and observational qualitative studies.

#### Conflict of interest

The authors do not report any financial or personal connections with other persons or organisations which might negatively affect the contents of this publication and/or claim authorship rights to this publication.

# **Author contributions**

Original concept of study: AB, BW, BJ. Collection, recording and/or compilation of data: AB, BW, LP. Analysis and interpretation of data: AB, BW, BJ. Writing of manuscript: AB, BW, BJ. Critical review of manuscript: AB, BW, BJ. Final approval of manuscript: AB, BW, BJ.

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