

REACTIONS OF PARENTS OF CHILDREN WITH ANOREXIA AND CONTROLLING EMOTIONS VS. PROFESSIONAL AND NON-PROFESSIONAL SUPPORT

Katarzyna Wojtas^{1A,C,D,E,F}, Małgorzata Babik^{2A,B,C,F}, Iwona Oskędra^{3D,E,F}

¹Department of Clinical Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Krakow, Poland

²Paediatric Ward for Older Children with Gastroenterology Subdivision and Ward for Younger Children with Neonatology and Neurology Subdivision, Provincial Specialist Children's Hospital named after St. Louis, Krakow, Poland

³Department of Nursing Management and Epidemiological Nursing, Institute of Nursing and Midwifery, Faculty of Health Sciences, Jagiellonian University Medical College, Krakow, Poland

Address for correspondence:

Dr Katarzyna Wojtas
Department of Clinical Nursing
Institute of Nursing and Midwifery
Faculty of Health Sciences
Jagiellonian University Medical College
Krakow, Poland
e-mail: katarzyna.wojtas@uj.edu.pl

Authors' contribution:

A. Study design/planning • B. Data collection/entry • C. Data analysis/statistics • D. Data interpretation • E. Preparation of manuscript • F. Literature analysis/search • G. Funds collection

SUBMITTED: 29.08.2023

ACCEPTED: 26.09.2023

DOI: <https://doi.org/10.5114/ppiel.2023.133335>

ABSTRACT

Introduction: Anorexia increasingly affects younger children, and its treatment is a long-term process in which people suffering from the disease, as well as their caregivers, experience many, often negative emotions. In this context, it is important to support caregivers, especially with information, and to understand their behaviour and emotions. The aim of this study was to study the reactions and emotions experienced by parents of children with anorexia or suspected anorexia, and how they are controlled, as well as their opinions regarding support.

Material and methods: The study was conducted on 40 parents using a diagnostic survey method, a questionnaire technique, and a scale technique. The author's survey questionnaire, which included questions about reactions and experienced emotions with regard to the child's disease and its course, support, and socio-demographic data, and the Courtauld Emotional Control Scale (CECS) adapted by Juczyński, were used to collect data. Statistical analysis was carried out using Statistica 13.3. TIBCO by StatSoft and Statistica 13.1 by StatSoft. The Mann-Whitney *U* test and Pearson's χ^2 test were used. Correlation was determined using Spearman's rank correlation coefficient. The level of statistical significance was adopted as $p < 0.05$.

Results: Based on the CECS scale, the subjects scored an average of 51.4 points, indicating suppression of negative emotions. Parents of children with anorexia most often experienced anxiety, helplessness, fear, uncertainty, and tension. They experienced problems coping with daily responsibilities, fulfilling the role of mother/father, and pain. It was shown that the parents' age and the support obtained from medical personnel and family were not related to the control of negative emotions.

Conclusions: Parents of children with anorexia or suspected anorexia experience many negative emotions and daily problems. Considering the expectations of caregivers and the proper provision of support, there is a need for professionals to assess their emotions prior to therapeutic interventions.

Key words: emotions, parents, anorexia, support.

INTRODUCTION

Anorexia nervosa (AN) is an eating disorder affecting mainly girls and young women [1]. It is diagnosed between the ages of 13 and 14 years as well as 17 and 25 years, but is increasingly common among children aged 8-13 years [2, 3] as a result of a combination of psychological, genetic, biological, environmental, and cultural factors [2]. Anorexia nervosa is classified as a mental disorder [2], and there is a coexistence of psychiatric and somatic symptoms [4, 5], which emphasizes the multidimensionality of this disease and its impact on the patient and their loved ones. Treatment of AN in a hospital or on an outpatient basis in-

cludes psycho-, pharmaco-, and physiotherapy, as well as nutritional treatment [2]. The priority of treatment is not to allow the patient's life to be endangered [6], based on cooperation with the child and their family and support from the therapeutic team [5].

A child's chronic disease is an extremely difficult and unexpected situation for parents [7], and changes are made as a result, which may indicate the mobilization of internal forces and stronger integration of household members, or maladaptive changes, i.e. pathological response patterns [8]. Recognition of the child's disease as a form of harm contributes to negative emotions, i.e. grief, anger, a sense of failure, shame [7], and relationships between parents based

on conflict or mutual blame [7]. During AN in a child, parents often show extreme reactions, may be overly directive, hostile, and negative, or overly involved or overprotective, and they can find it more difficult to cooperate with medical personnel, often being overly demanding or irritable [7, 9]. A disease perceived as a threat is a strong stressor, triggering anxiety and fear causing depression [7, 10]. A disease perceived as a challenge is expressed in quick adaptation, choosing the most favourable solutions and thus achieving better treatment results, and parents become experts on their child's disease. However, it is important to have the constant presence of loved ones or a psychologist because, despite acceptance, parents experience crises and negative emotions [7] and require professional and non-professional support.

Non-professional support is mainly provided by relatives and those around them, and it is most often based on emotional, instrumental, and informational dimensions. Professional support from treatment team members plays an important role during a child's hospitalization [11], and it is the most important and most frequently reported need by parents [3]. It consists of conversation, psychoeducation, family consultation, or family therapy [11, 12]. Providing it to parents should begin with learning their resources, evaluating their caregiving options and involvement, because the stress due to their child's disease often causes helplessness and feelings of incompetence [13].

In practice, medical personnel focus mainly on the diagnosis and treatment of the patient, while the patient's family is often marginalized [12], which is why it is necessary to improve the quality of professional support by improving training programs in the medical profession and their focus on, among others, the therapeutic role of the nurse in the process of supporting the patient and family, as well as promoting knowledge about anorexia.

The aim of this study was to analyse the reactions and emotions experienced by parents of children with anorexia or suspected anorexia, and how they are controlled, as well as their opinions on the professional and non-professional support provided.

MATERIAL AND METHODS

The survey was carried out in 2023 in one of the Lesser Poland hospitals and in online support groups, among 40 parents of children with a diagnosis or suspicion of anorexia. The respondents participated voluntarily in the study.

The study used the method of a diagnostic survey, with the author's survey questionnaire and the Courtauld Emotional Control Scale. The author's questionnaire includes questions about reactions and experienced emotions in relation to AN in a child, its course, professional and non-professional support, and so-

ciodemographic data. The CECS scale by Watson and Greer adapted by Juczyński contains 21 statements and allows measurement of subjective control of anger, anxiety, and depression in a difficult situation. The scale consists of 3 subscales, and the total of their scores represents the overall emotion control score, ranging from 21 to 84 points. The higher the score, the higher the level of negative emotion suppression [14].

Statistical analysis of the collected sociodemographic data was carried out using Statistica 13.3. TIBCO package from StatSoft. The Mann-Whitney *U* test was used for evaluation of differences. Correlation was determined using Spearman's rank correlation coefficient. Statistical analysis of the responses contained in the author's questionnaire and the CECS scale was conducted using the Statistica 13.1 package from StatSoft. Correlations were evaluated using Pearson's χ^2 test. The level of statistical significance was adopted as $p < 0.05$.

RESULTS

The respondents comprised 72.5% women ($n = 29$) and 27.5% men ($n = 11$) between the ages of 31 and 53 years; the average age was 43.75 years. 65% of the subjects lived in a city ($n = 26$), 72.5% of the subjects ($n = 29$) had higher education, and 90% ($n = 36$) were married. Half of the respondents were parents of 2 children. Economically active people accounted for 87.5% ($n = 35$) of the total. The financial situation was rated as good by 55% of people ($n = 22$).

Course of the child's disease

The most common reasons for parents reporting to the physician included their child's food restriction (85%, $n = 34$), increased fear of weight gain (72.5%, $n = 29$) and avoidance of high-calorie foods (65%, $n = 26$).

The period of a child's worrisome symptoms that could indicate an eating disorder before diagnosis averaged 6.33 months (1-24 months). On the other hand, the period from the onset of worrisome symptoms in the child to hospitalization averaged 5.13 months (1-18 months). More than half of the surveyed parents (52.5%, $n = 21$) went with their child to the hospital on their own initiative, 37.5% ($n = 15$) in relation to a referral from a physician, and 10% ($n = 4$) on their own initiative having also had a referral. During hospitalization, 47.5% ($n = 19$) of the children were fed orally, while in the rest other methods of nutrition were introduced.

Parents' emotions and reactions with regard to their child's disease

In relation to the suspicion or diagnosis of anorexia in a child, parents were most often accompanied

by anxiety and helplessness (67.5%, $n = 27$ each), fear (57.5%, $n = 23$), and uncertainty and tension (50%, $n = 20$ each).

Parents, as a result of their child's disease, most often experienced problems coping with daily responsibilities (47.5%, $n = 19$), difficulties in fulfilling the role of parent (45%, $n = 18$), and pain, e.g. headache or stomach pain (40%, $n = 16$). Respondents also indicated other symptoms, such as fatigue, the need to be in constant motion, and the desire to help or to act.

Emotions experienced by respondents in relation to their child's hospitalization varied in dimension and were most often hope (57.5%, $n = 23$), a sense of security (45%, $n = 18$), uncertainty (45%, $n = 18$), and tension (45%, $n = 18$).

When faced with a child's disease, respondents most often coped by seeking information about the disease (67.5%, $n = 27$), seeking support from a spouse (57.5%, $n = 23$), and focusing on the current problem (57.5%, $n = 23$).

The ability to control one's emotions was considered definitely insufficient or insufficient by 30% of respondents ($n = 12$). In contrast, 32% of individuals ($n = 13$) reported that they could definitely sufficiently or sufficiently control their own emotions.

Professional and non-professional support in the opinion of surveyed parents

Professional support from medical personnel during hospitalization was received by 77.5% ($n = 31$) of respondents, who usually rated it as sufficient. Parents most often considered support received from

nurses as definitely sufficient, while support from a psychologist was considered definitely insufficient (Table 1).

Respondents tended to consider information support from physicians as sufficient – 52.5% ($n = 21$) as well as information support from nurses – 60% ($n = 24$). The support reported as definitely insufficient was from physicians – 12.5% ($n = 5$) and psychologists – 15% ($n = 6$). The greatest emotional support, described as “sufficient” during hospitalization, the respondents received from nurses – 52.5% ($n = 21$). Definitely insufficient emotional support, in the respondents' opinion, was from physicians and dietitians – 15% each ($n = 6$) and psychologists – 17.5% ($n = 7$). The majority of respondents, 52.5% ($n = 25$), considered the instrumental support received from nurses as sufficient. The fewest were satisfied with instrumental support from psychologists – 22.5% ($n = 9$).

Physicians provided respondents with information support most often. Nurses similarly often supported patients emotionally and instrumentally. Dietitians and psychologists most often provided respondents with informational support (Table 2).

Respondents expected various dimensions of support from the treatment team:

- diagnosis, plan, reliability, factual discernment of the problem, effective treatment, presence (physician),
- patience, gentleness, caring, right attitude, kindness, conscientiousness, appropriate approach to the child, helping the child with meals (nurse),
- more appointments, advice and guidance, working with the child (psychologist).

Table 1. Received support from the personnel during the child's hospitalization according to the respondents

The supporting person	Subjective assessment of support				
	Definitely insufficient % (n)	Insufficient % (n)	Difficult to determine % (n)	Sufficient % (n)	Definitely sufficient % (n)
Physicians	12.5 (5)	12.5 (5)	10.0 (4)	47.5 (19)	17.5 (7)
Nurses	2.5 (1)	5.0 (2)	12.5 (5)	50.0 (20)	30.0 (12)
Dietitian	10.0 (5)	15.0 (6)	27.5 (11)	35.0 (14)	12.5 (5)
Psychologist	20.0 (8)	12.5 (5)	20.0 (8)	37.5 (15)	10.0 (4)

Table 2. Types of support received most often by respondents during their child's hospitalization

The supporting person	Type of support			
	Informational % (n)	Emotional % (n)	Instrumental % (n)	Evaluative % (n)
Physicians	87.5 (35)	0.0 (0)	5.0 (2)	7.5 (3)
Nurses	12.5 (5)	40.0 (16)	42.5 (17)	5.0 (2)
Dietitian	50.0 (20)	7.5 (3)	25.0 (10)	17.5 (7)
Psychologist	42.5 (17)	37.5 (15)	5.0 (2)	15.0 (6)

Table 3. CECS scale results

CECS	Basic descriptive statistics					
	<i>n</i>	<i>M</i>	<i>Me</i>	<i>SD</i>	<i>Min.</i>	<i>Max.</i>
Anger	40	16.20	16.00	4.05	10.00	25.00
Depression	40	17.65	18.00	3.48	8.00	25.00
Anxiety	40	17.55	18.00	3.49	10.00	24.00
Emotions	40	51.40	51.50	7.62	31.00	66.00

n – number of observations, *M* – mean, *Me* – median, *SD* – standard deviation, *Min* – minimum, *Max* – maximum

Table 4. Respondents' control of negative emotions vs. age

Variables	<i>R</i>	<i>p</i>
Anger vs. age	–0.05	0.741
Depression vs. age	–0.02	0.899
Anxiety vs. age	0.04	0.807
Emotions vs. age	–0.02	0.909

R – Spearman's rank correlation test value, *p* – test likelihood ratio

Non-professional support from relatives was received by 92.5% of respondents (*n* = 37) and was rated as definitely sufficient and sufficient by 67.5% of people (*n* = 35).

The most frequent support received by respondents from relatives was emotional support (77.5%, *n* = 31), instrumental support was indicated by 15% of respondents (*n* = 7), and informational support by 5% of people (*n* = 2). When asked what they expected from loved ones, respondents mentioned support, help, understanding, closeness, presence, educating themselves about the disease, kindness, changing certain behaviours, wise accompaniment, interest, to stop judging and “looking for blame”, and situation acceptance.

Results based on the CECS scale

The results representing the subjects' ability to suppress negative emotions were obtained on the basis of the standardized CECS scale, in which the subjects scored an average total of 51.4 points out of a possible 84. The ability to suppress anger was rated at an average of 16.2 points on a 28-point scale, the ability to suppress depression at an average of 17.65 points, and anxiety at an average of 17.55 points (Table 3).

Analysis of the relationship between variables

There was no relationship between the subjects' age and their ability to suppress negative emotions (*p* > 0.05) (Table 4).

Analysis of the relationship between other sociodemographic variables, such as gender, place of residence, education, occupational activity, material situation, and having offspring, did not confirm a significant relationship with the control of negative emotions.

Support from medical personnel had no relationship with respondents' suppression of negative emotions (*p* > 0.05) (Table 5).

Table 5. Respondents' control of negative emotions vs. support from medical personnel

CECS	Support of medical personnel					Lack of support from medical personnel					<i>U</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>Me</i>	<i>1Q</i>	<i>3Q</i>	<i>M</i>	<i>SD</i>	<i>Me</i>	<i>1Q</i>	<i>3Q</i>		
Anger	16.52	4.28	16.00	13.00	19.00	15.11	3.10	15.00	14.00	18.00	112.5	0.388
Depression	17.81	3.24	18.00	15.00	20.00	17.11	4.40	19.00	16.00	20.00	139.0	1.000
Anxiety	17.39	3.63	18.00	15.00	20.00	18.11	3.10	19.00	16.00	21.00	120.5	0.545
Emotions	51.71	7.35	51.00	47.00	56.00	50.33	8.89	52.00	44.00	57	138.0	0.975

M – mean, *SD* – standard deviation, *Me* – median, *Q* – quartile, *U* – Mann-Whitney *U*-test value, *p* – test likelihood

Table 6. Respondents' control of negative emotions vs. support from loved ones

CECS	Support from loved ones					Lack of support from loved ones					<i>U</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>Me</i>	<i>1Q</i>	<i>3Q</i>	<i>M</i>	<i>SD</i>	<i>Me</i>	<i>1Q</i>	<i>3Q</i>		
Anger	16.05	4.16	15.00	13.00	19.00	18.00	1.73	19.00	16.00	19.00	35.5	0.320
Depression	17.78	3.50	18.00	16.00	20.00	16.00	3.46	14.00	14.00	20.00	34.5	0.296
Anxiety	17.76	3.34	18.00	15.00	20.00	15.00	5.20	12.00	12.00	21.00	35.5	0.320
Emotions	51.59	7.73	52.00	48.00	56.00	49.00	6.93	45.00	45.00	57.00	40.5	0.461

M – mean, *SD* – standard deviation, *Me* – median, *Q* – quartile, *U* – Mann-Whitney *U*-test value, *p* – test likelihood

Similarly, support from loved ones had no relationship with respondents' suppression of negative emotions ($p > 0.05$) (Table 6).

DISCUSSION

A child's disease and hospitalization are a difficult situation for parents [15], who often appreciate the instrumental activities undertaken by the therapeutic team, but also need support, especially emotional support. Accompanying anxiety, a sense of confusion does not allow one to think and act, and therefore it is so important to be empathetic [12] during contact with parents, especially on the part of nurses.

Some of the parents expressed significant interest in the subject of study addressed, because in their opinion the topic of anorexia is not sufficiently disseminated, and conducting such studies can help the children, parents, and medical personnel to understand the needs of patients and their families as well as to adapt adequate care by, among others, establishing contact with parents and preparing them to cooperate during the child's hospitalization.

Social media often address the subject of appearance, creating the ideal of a beautiful figure, which, when confronted with reality, can become a cause of lack of acceptance of oneself and one's body, and it is related to the development of eating disorders [16-18]. Therefore, it is important to develop preventive programs on the risk factors of eating disorders, and to sensitize parents to observe their child, teach them to think critically in order to reduce the negative influence of social media, and recognize worrying symptoms present in a child/teenager [17].

Giles *et al.* in their study emphasized the importance of preventive measures and interventions for parents of children with eating disorders [19].

Their study showed that the most common reasons for parents to report to a medical appointment with their child included the child's restriction of eating, increased fear of gaining weight, avoidance of high-calorie foods, as well as significant weight loss, emaciation, and reduced mood. Bąba-Kubiś *et al.* showed that the above symptoms are usually the first signs of anorexia [20]. Both studies suggest that figure change and significantly reduced weight represent alarming signals of AN.

The data obtained in the present study showed that the symptoms indicative of anorexia lasted an average of 6 months, and the time elapsed between the onset of these symptoms and hospitalization averaged 5 months. Similar results were obtained by Bąba-Kubiś *et al.* This is a short period, which is why early diagnosis of disorder symptoms is so important for further management [20].

Most parents visited the hospital with their child on their own initiative. This may suggest a lack of ad-

equate measures in primary care. During hospitalization, almost half of the children among the parents surveyed were fed orally, while the remainder were fed by enteral nutrition *via* probe or parenteral nutrition. Jabłońska *et al.* stated that nutrition depends on the patient's condition and can be oral, enteral, or parenteral [5]. Our own study showed that more than half of the children were significantly cachectic. However, it should be considered that the children were treated in the Department of Paediatrics and Gastroenterology, indicating that their condition may have required urgent therapeutic intervention or expanded diagnosis for eating disorders.

Parents of children diagnosed with anorexia or suspected anorexia experienced anxiety, helplessness, uncertainty, tension, and problems in daily life. Caring for a sick child causes severe stress, intensity of negative emotions, and even anxiety and depression. In addition, it causes feelings of guilt, isolation, betrayal, and loss [10, 13, 19]. Caregivers of children with AN show significantly higher levels of distress compared to parents of patients with other mental disorders [19]. Duclos *et al.* found that parental strain and sadness have a relationship with more severe clinical conditions in children, and strain in both parents is related to parental grief and the child's clinical condition [21]. In comparison, the results of a study conducted by Mazur *et al.* showed that caregivers experience feelings of guilt and helplessness [13]. Our study did not address the issue of perceived guilt and the relationship between the psychological burden of parents and the clinical condition of the child.

Our study confirmed that parents experience emotions associated with their child's hospitalization, ranging from hope and a sense of security to tension and uncertainty. A study conducted by Philipp *et al.* showed that parents reveal extreme patterns of emotional reactions [9]. In comparison, Franta *et al.* confirmed the prevalence of highly expressed emotions among caregivers [22]. It is noteworthy that in our study, parents also affirmed a sense of security and hope despite their concerns about hospitalization. This may be an important indication of professionals' demonstration of sensitivity to the family's needs, and an understanding of the emotions experienced and reactions expressed.

According to our research, parents in the situation of their child's disease sought information, focused on the problem, or sought support from their spouse. However, such means may not be sufficient, and therefore it is necessary to inform parents about sources of help. Grzesiak emphasized the value of systemic therapy, which allows for optimal and multi-contextual insight into the problems of children and adolescents [23].

Emotions accompanying parents of children with anorexia cause different reactions and behaviours.

In our study, parents' ability to control emotions was considered "difficult to determine", and they mostly suppressed negative emotions. Unfortunately, emotions that are repeated or persistent and unexpressed are the cause of neurotic disorders and psychosomatic diseases. According to psychologists, expressing negative emotions is beneficial and recommended in many forms of psychotherapy [14]. For children with AN and their parents an important aspect of therapy is support from personnel and loved ones. In the authors' study, most parents rated the support they received from medical personnel and loved ones as sufficient. What is more, most of the respondents rated the emotional and instrumental support received from nurses as sufficient, which can be optimistic and indicates that nurses provide care at a level that satisfies parents. There is no doubt that the nursing team plays an important role in the care of the child and their family [6]. Different results were obtained by Wu and Chen, who indicated that nurses lacked positive feelings in the care of patients with anorexia, and even questioned their ability to provide quality care [1].

It is noteworthy that in our study, psychologists were rated lowest in terms of support. This may be due to insufficient contact with parents in the form of permanent or ad hoc visits to the ward. A psychologist should provide professional psychological assistance, psychosocial support, help solve current problems, and identify possible sources of help [24, 25]. Therefore, there is great need for more support by psychologists in hospital wards.

Our survey showed that parents expect professionals to provide mainly informational and emotional support. They mentioned the need for understanding, openness, information, professionalism, teamwork, and commitment. Mazur *et al.* pointed out that caregivers of a hospitalized patient expect, above all, professional help from the treatment team, specific guidance, understanding, and encouragement in a difficult situation [13]. In both the authors' study and the above, the children's caregivers expected support in various dimensions; hence, a high need for support can be drawn. Caregivers should be provided with a sense of security, and a trusting relationship should be established. The study conducted by Chang *et al.* emphasizes the importance of trust in the therapeutic relationship during anorexia treatment. Respondents described positive encounters as those in which they felt safe, valuable, understood, and in a better mood. Establishing a therapeutic alliance is an important aspect in dealing with anorexia patients and their caregivers [26]. A study conducted by Philipp *et al.* found that it is beneficial to teach parents strategies for coping with stress because this reduces their burden. Understanding parents' beliefs about anorexia may be a necessary condition for successful clinical intervention [10].

In addition to professional support, non-professional support shown by the family or the environment is extremely important. According to Twarduś, its essence is the creation of strong emotional relationships [7]. Most of the parents surveyed felt support from loved ones, and expectations of support included understanding, closeness, education about the disease, and acceptance. A study conducted by Rafa *et al.* pointed out that bonds with others positively affect an individual's well-being and contribute to maintaining vitality [27]. According to Juczyński, social support is an important psychological resource, and its impact is revealed especially in difficult and crisis situations, and the effects can be seen both in direct impact through the perception of stressful events and in indirect impact through neutralization and mitigation of their negative effects [28].

Statistical analysis of the results showed that the parents' age had no significant relationship with the ability to suppress negative emotions. Different results showing correlations between age and emotions were presented by Juczyński [14] and Cepuch *et al.* [29]. It was also shown that there was no relationship between support from medical personnel and family and parents' suppression of negative emotions. There are studies confirming the importance of support in releasing stress, expressing anxiety, and building hope [13]. Duclos *et al.* stated that high levels of emotional burden, anxiety, and grief should be the target of support for parents of adolescents with anorexia. Providing them with support can improve both their mental health and caregiving skills [21].

RESEARCH LIMITATIONS

The results of the presented study expand the available database in this area, but they should be treated with some reserve due to the limited group of respondents. Prior to the study, permission was sought from the managements of 3 institutions in the Lesser Poland region. Consent was granted only by the management of one of the institutions, while in the other institutions the possibility of conducting the study was denied on the grounds that the desired number of people eligible for the study group was not available, doubts were raised about the personnel's ability to support parents, and other studies were already being conducted.

CONCLUSIONS

Parents of children with anorexia experience different emotions and reactions regarding their child's disease, and they suppress negative emotions.

In the context of medical development, especially in its instrumental aspect, the ability to provide individualized support in many dimensions to both the

child and their family should be a standard in the therapeutic interventions undertaken.

Disclosure

The authors declare no conflict of interest.

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