

Difficulties Experienced by Mothers in Newly Diagnosed Type 1 Diabetes Mellitus: A Phenomenological Study

Yeni Başlangıçlı Tip 1 Diabetes Mellitusta Annelerin Yaşadıkları Güçlükler: Fenomenolojik Bir Çalışma

ABSTRACT

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Objective: The aim of this study was to explore the experiences of mothers of newly diagnosed Type 1 Diabetes Mellitus (T1DM) children, to identify the difficulties mothers face in diabetes care, and to identify appropriate solutions.

Methods: Mothers of children aged 6-12, who have been newly diagnosed with T1DM, have been included in the workforce due to the adaptation period for school. Online interviews were conducted with the mothers using a phenomenological research design and hermeneutic phenomenological approach.

Results: It was determined that the mothers had concerns about their children diagnosed with T1DM, that the children diagnosed with T1DM had concerns about their siblings, and additionally, they had psychosocial problems. The reasons for these concerns and problems are restrictions or rules, the approaches of the child's friends, and the attitudes of individuals in society. The resources that mothers receive support from in the process are family, friends, health professionals, school administration, school teachers, and a school nurse.

Conclusion: As a result, it was concluded that the school management and teachers, health team, social awareness, psychosocial support groups, and technological developments are or will benefit from them, and that these resources are important in supporting mothers and children to cope with T1DM and increasing positive experiences in follow-up.

Keywords: Type 1 diabetes mellitus, newly diagnosed, mother, psychosocial support

ÖZ

Amaç: Bu çalışmada, yeni Tip 1 diyabetes mellitus (T1DM) tanısı almış çocukların annelerinin deneyimlerini incelemek, annelerin diyabet bakımı sürecindeki zorluklarını belirlemek ve uygun çözüm yollarını belirlemek amaçlanmıştır.

Yöntemler: Yeni T1DM tanısı konulmuş, okula uyum dönemi olduğundan 6-12 yaş aralığındaki çocukların anneleri çalışmaya dahil edildi. Anneler ile fenomenolojik araştırma deseni ve hermenötik fenomenolojik yaklaşım kullanılarak çevrimiçi görüşme yapıldı.

Bulgular: Annelerin T1DM tanısı almış çocuklarına ilişkin kaygıları olduğu, T1DM tanısı almış çocukların kardeşlerine yönelik kaygıları olduğu ve ek olarak psikososyal sorunlar yaşadıkları saptandı. Bu kaygı ve sorunların nedenlerinin; kısıtlamalar/kurallar, bilinmezlik, çocuğun arkadaşlarının yaklaşımları ve toplumdaki bireylerin yaklaşımları olduğu belirlendi. Annelerin süreçte destek aldıkları kaynakların; aile, arkadaşlar, sağlık profesyonelleri, okul yönetimi, okul öğretmenleri, okul hemşiresi olduğu bulundu.

Sonuç: Sonuç olarak, yeni tanı T1DM tanılı çocuğu olan annelerin; okul yönetimi ve öğretmenlerden, sağlık ekibinden, toplumsal bilinçten, psikososyal destek gruplarından ve teknolojik gelişimlerden fayda gördüğü/göreceği, bu kaynakların anne ve çocukların T1DM ile başa çıkmasını desteklemekte ve izlemdeki olumlu deneyimleri arttırmakta önemli olduğu sonucuna varıldı.

Anahtar Kelimeler: Tip 1 Diabetes mellitus, yeni tanı, anne, psikososyal destek

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INTRODUCTION

Type 1 diabetes mellitus (T1DM) is a prevalent chronic disease in children, with an incidence of 15 per 100,000 globally.^{1,2} Diagnosed typically in childhood and adolescence, managing T1DM involves rigorous blood glucose monitoring and insulin administration to maintain optimal glucose levels, minimize hypoglycemia, and prevent long-term complications.³ Initially, parents handle all diabetes management tasks until the child turns 8, after which children gradually assume more responsibility. Despite this, parents continue to bear a significant burden throughout adolescence.⁴ Understanding parents' perspectives on treatment and daily challenges is crucial for effective management.⁵

The diagnosis of T1DM in childhood is a stressful period for both the child and their parents, emphasizing the continuous nature of diabetes management.⁶ Treating children with T1DM requires daily medical decisions and technical procedures that start immediately upon diagnosis and affect every aspect of family life.⁷ Mothers often bear the primary responsibility for diabetes care, experiencing feelings of abandonment, loneliness, and uncertainty, while fathers typically take on more household tasks to support them.^{8,9} Many studies highlight the significant psychological burden on parents at the time of their child's diagnosis and shortly thereafter.¹⁰⁻¹²

The continuous care required for T1DM poses additional challenges during school hours when children are away from their families.¹³ Responsibility shifts from parents to children and teachers, potentially leading to inconsistencies in care. Mothers often need support in explaining T1DM to their peers, collaborating with teachers, engaging in activities, and managing diet and carbohydrate intake.¹⁴ Many school staff members are not

Table 1 Characteristics of the Particinants

adequately trained to handle emergencies and hypoglycemic events, exacerbating family difficulties.¹⁵ International Society for Pediatric and Adolescent Diabetes (ISPAD) guidelines¹⁶ stress the importance of family involvement in managing diabetes, and studies show that effective family support significantly improves diabetes management in children.^{17,18}

Managing family processes is crucial when a child is diagnosed with T1DM. Mothers often experience shock, intense anger, and denial, bearing more responsibility than fathers. Understanding mothers' experiences allows healthcare professionals to better support families.

AIM

The objective is to evaluate how mothers of children with T1DM feel at the time of diagnosis.

METHODS

Study Design

This hermeneutic phenomenological study focused on the experiences of mothers with children aged 6-12 newly diagnosed with T1DM. Using purposive sampling, mothers whose children were treated at a pediatric endocrinology outpatient clinic in Ankara, Türkiye, were invited to participate. Inclusion criteria were having a child newly diagnosed with T1DM, aged 6-12, mothers without mental illness, ability to conduct online interviews, and voluntary participation.

Participants

The study was conducted with 13 mothers living in Türkiye with children aged 6 to 12 years who were newly diagnosed with T1DM. Relevant introductory characteristics of the mothers and children are listed in Table 1.

Participan t code	Age of participant	Participant's educational status	Number of children in the family	Child's diagnosis age	Age of child	Gender of the child
P1	45	University	2	5 months	10	Воу
P2	40	University	2	9 months	5	Girl
Р3	32	High School	3	5 months	7	Girl
P4	38	High School	2	6 months	9	Girl
P5	51	University	2	7 months	11	Воу
P6	42	Primary School	4	7 months	11	Boy
P7	29	High School	3	8 months	8	Girl
P8	31	Middle School	3	8 months	7	Воу
Р9	36	High School	2	7 months	8	Boy
P10	41	University	1	4 months	11	Girl
P11	48	University	1	2 months	10	Воу
P12	37	University	2	6 months	10	Girl
P13	39	High School	1	3 months	11	Воу

Data Collection

The COREQ guide was used for the study's design, data collection, analysis, and reporting. A pediatric nurse practitioner with a doctorate and qualitative research experience collected the data. Participants were randomly selected, completed an introductory questionnaire, and were interviewed via Zoom.

Table 2. Semi-Structured Focus Interview Questions

- 1. "How did you feel when your child was diagnosed with T1DM?"
- 2. "What challenged you most when you first learned of the diagnosis?"
- 3. "What changes have occurred in your life after diagnosis and discharge from the hospital?"
- 4. "What were the factors that made it more difficult or easier for you to adjust during this process?"
- 5. "How do you think we can make this process more comfortable for you?

To ensure comfort and privacy, interviews were conducted in a secure, private environment. Three researchers participated: one asked questions, and two took notes. Focus group interviews were recorded online, and participants consented to open-ended questions in a semistructured format.

After participants provided consent, the researcher utilized a semi-structured focus group interview format, posing open-ended questions as outlined in Table 2.

Study data were collected between June and September 2022. Each interview lasted between 80 and 100 minutes. In total, the study was completed with four interviews and 13 participants, with the data reaching saturation.

Data Analysis

The thematic analysis method was used to analyze the data. Two researchers conducted the analysis jointly, while the other two researchers analyzed the data independently. Researchers reviewed decoded interviews, coded each interview, and identified important statements. Data collection concluded after the fourth focus group meeting, as important statements were reiterated and deemed satisfactory. Analysis was performed manually by researchers without software assistance.

Precision and Reliability of Study Data

The study ensured data accuracy and reliability following principles of credibility, reliability, confirmability, transferability, and transparency. Three researchers held master's or PhD degrees in pediatric nursing, while the fourth was a pediatric endocrinology physician. After each focus group discussion, participants received transcripts to verify accuracy and clarity of their statements before analysis. Thematic analysis was independently conducted by researchers to ensure reliability.

Ethical Considerations

The ethical suitability of the study was reviewed by Hacettepe University Non-interventional Clinical Research Ethics Committee (Date: May 10, 2022, Decision No. 2022/08-20). After approval by the Ethics Committee, the study was announced, and participants who volunteered to participate were informed by the researchers, and their verbal consent was obtained first, followed by their online consent.

RESULTS

The categories, themes, and subthemes that emerged from the thematic analysis of the data after the focus group interview are listed in Table 3.

Negative Experiences / Difficulties

One mother succinctly articulated her fear of stigmatization as follows: "......... for example, my child heard his friends say "he is sick, he faints, he should not be in our team". Everyone labels the child as sick. When he doesn't have such a thought, he gets the thought that I'm sick, I can't do it." Another mother, regarding her child's physiological losses and concerns about her future, said, "When I think about what happens in his body in hypoglycemia and hyperglycemia, I feel like going crazy. Let's see what else he will have to give up in the future. I don't know if he will be able to do the job he wants. Undoubtedly, this situation will affect even the choice of spouse"

Second, theme is "Worries regarding the sick child". Two mothers stated that other children were deprived of attention and their routines changed as follows. *"I mean, for example, because her sister is older, she can do anything. But my little boy is 3 years old and let's check out mom A's blood glucose. I mean, he says if we can eat it, let's eat this". "So you don't want to be unfair to your other children, but on the other hand, A is more prominent". "For example, her older sister or younger brother eats whatever A eats. So it's such a depressing situation. We don't have any of our old order at home"*

Difficulties in Newly Diagnosed T1DM					
Categories	Themes	Subthemes			
Negative Experiences/ difficulties	Worries regarding the sick child	Future			
		Physiological losses			
		Fear of stigmatization			
		Worries about child's			
		death			
	Worries for siblings	Disinterestedness			
		Change in daily			
		routines			
		Fear of having			
		diabetes			
	Psychosocial problems of the mother	State of self-blame			
		Anxiety			
		Overloading			
		Feeling of loneliness			
		Feeling of			
		helplessness			
Factors causing difficulties	Restrictions / Rules				
	Obscurity				
	Peer approach	Stigma			
	Other social	Lack of empathetic			
	environment approaches	approach			
		Ignorance			
		Make it dramatic			
Support resources	Family	Blame The child herself			
		/himself			
		Siblings			
		Husband			
	Friends	Child's friends			
	Lloolth	The mother's friends			
	Health professionals				
	School	Interest and			
	administration	communication			
	and teachers				
		Support and arrangement of care			
	School nurse and infirmary				
	presence				
	Other children	At diagnosis/in			
	with T1DM	hospital			
	WITHTEN	At school/social environment			

Table 3. Themes and Sub-Themes of Mothers'Difficulties in Newly Diagnosed T1DM

Support resources	Technological	Provide instant
	innovations	tracking
		Get reliable results
Expectations and	School	
recommendations	administration	
	and teachers	
	Healthcare	Extending education
	team	and change over a
		longer period of time
		Empathetic approach
		Professionalism of
		the healthcare team
		in diabetes
	Social	Adult public service
	consciousness	announcements
		Placing information
		in favorite programs
		School education
	Psychosocial	For mothers
	support groups	
		For children
	Technological	Application
	development	
		Virtual social
		network support
		Treatment

Finally, the psychosocial problems of mothers were discussed under this theme. One mother expressed her feelings of guilt as follows: "On the one hand, I think I might have done something wrong. We know how it happens, but I can't explain it to myself. I am constantly questioning myself whether I am doing everything right now. I get angry with myself if my child's blood sugar drops or goes up."

One mother expressed her feelings of helplessness as follows: "Every time I go, I still ask the doctor, do you ever have a patient who is well? Do you have any patients recovering? Every time I go, I still persistently ask this question. I still haven't accepted it." A mother explained that her burden was too much with the following words: ".....will I be able to run this process? Can I make insulin at home? Will I make my child's condition worse? You have to think about all of these, so for example, fathers are not as responsible as mothers. Fathers are a little more comfortable, but not so for mothers. It also gets harder when you work."

Another mother expressed her burden and loneliness as follows: "Because, as I said, we all have two or three

children. This also affects other children. In other words, since everyone is affected, the pressure is greater. Especially on the mother. Sometimes you do not even know who to catch up with."".....this is means my child is on my mind 24 hours a day. I am sure no mother in our old order ever slept uninterrupted. Preparing food, managing the process......"

Factors Causing Difficulties

One mother expressed that restrictions /rules are a difficulty factor as follows: "In the beginning, we had a hard time because we were going by the clock. We didn't let on that we were struggling, but it was very difficult." Many mothers indicated that they see the unknown as a source of difficulty in the T1DM diagnostic process. Some mother expressions are as follows: "...if only the doctor had explained that you would make this much insulin for such and such meals. The dose to make insulin and how much is up to you. It's something you don't know. We have never injected before. It was a very difficult process, of course". "It's a really difficult situation. For example, will my child be able to be discharged from the PICU? We do not know the disease. Believe me, it is very difficult."

Mothers indicated that peer interaction with their children can also be an important source of difficulty in the new diagnosis process. One mother said, "...for example, she was picked on a lot. 'You're always sick, A. Are you sick?' they asked. I also told the teacher to inform A's friends so that he doesn't face any difficulties."

Social environment approaches, such as spouses, friends, relatives, and neighbors, were also found to be a source of difficulty in the process of rediagnosis. The mothers described their experiences in this regard as follows: *"Then explain it to the children like this, but for example, what happens when the adults eat it, so what happens, what will happen when they eat it?", "There is something you are very sad about, A. We are very sorry for you. That was what worried me the most. Those who come to get well quickly with baklava. Some also brought chocolate.", "The people around me ate chips, was it because of these children? Did you eat too much sugar? Has it gotten better? Is it over? It would be better if there were no such questions from our environment..."*

Support Resources

Under the theme of family, the first sub-theme in this category, mothers noted that they can receive support in numerous ways from all family members, including the child themselves, siblings, and spouses: "... My eldest son was my savior in every way. How can I explain this? I knew from the first moment that you were very upset, but those

words... We'll work it out together, Mom, we'll work it out, won't we, Mom? of course there were many questions and concerns, but especially in the beginning. He opened and read something on the Internet. Later, the questions also became less. My husband was very supportive, I can't deny that. But my oldest son stood by me like a lion". "A much more understanding child, intelligent, able to do anything he was told. For example, we started school, talked with our teacher, constantly exchange information. D. is already able to make his own insulin at school. Fortunately, we haven't had any problems with that. We'll have to live with it. I hope that with the help of our teachers, nurses and children, we'll make it to better times."

On the theme of friends, the second theme in this category, the mothers expressed that they receive support from the child's friends and their friends, saying, "When we come home, their friends blow up balloons, ornaments, and things like that. They celebrated when they saw that S. was very happy. He was in need of it."

In the category of support resources, the theme of health professionals was raised. One mother expressed the support she received from health professionals as "....*Mrs. i., She was our training nurse. She is a very understanding woman. He explained everything to me in detail, she taught me in detail. I consider myself very lucky in this respect."*

The involvement of school management and teachers. One mother expressed the good communication she had with her teacher in these words, "Actually, it was our teacher who comforted us a little bit. We have a sensor, but in fact, sometimes there may be a problem with the sensor, the blood device is in the him pocket. If there is a problem, she looks at the WhatsApp message Ms. A. (teacher). She takes care of it immediately. She sets up a separate room. Fortunately, we have a teacher in charge. It's very reassuring." Another mother stated that the school administration supported the care by making the necessary arrangements in the school as follows, "Our principal organized a refrigerator for me. I put a spare blood meter in the room. I put a Humalog insulin in it. I wrote note everywhere that says, "Do not unplug the refrigerator".

Another theme in this category was the presence of a nurse and a infirmary in the school. One mother expressed her support for this theme by saying, ".....the school has a nurse's station. And the school is a big school, and they have experience in this regard. There are other diabetic children in the school. That is why A. doesn't have insulin with him. One of his Humalog insulin is in the infirmary. With that in mind, you know, they set up a system like this to make us feel comfortable in the school."

Presence of neighborhood and school peers with T1DM. Journal of Nursology 2024 27(2):120-128 / doi: 10.17049/jnursology.1431267 One mother expressed the support she received from another T1DM Patient at the time of diagnosis in these words, "......And then there was B., who had T1DM. That was very helpful for A. Because A could not accept the disease at first. I mean, she cried a lot, she never got her first insulin or anything. B was already using a pump. He showed it himself, so I know, I use it too. He helped us a lot."

Finally, in this category, mothers reported that technological innovations are a source of support because they allow immediate follow-up and provide reliable results. One mother made the following comment about the sensor, "...the data comes from my sensor to my phone. This way I can continue the process conveniently. Otherwise, it would be very difficult to start working or something."

Expectations and Recommendations

In this category, they indicated that they expect school administrators and teachers to organize training to recognize and intervene in the symptoms of T1DM, which includes all staff and students, and to make the necessary physical arrangements for teachers, nurses, and school staff to support the care of the child in school to manage the child's diabetes. "... so now the child is not always with his teacher. What happens if his blood glucose level drops in the bathroom or in the backyard and he passes out? In other words, I am not saying that everyone in front of them should be able to check blood glucose and give a shot, but this child's blood glucose drops, he faints, his sugar comes out, he faints, so those in the know should" "...our children have diabetes and they need help. Teachers can not know everything. So there are a lot of people who say, "I can not do this. I can not take that responsibility. There are a lot of people who say, I am not going to take this on. Imagine your child faints at school, and the teacher says, I can not do that. They called the ambulance, but your child could not be treated until the ambulance arrived. I mean, I do not even want to think about it"

Another theme in this category was expectations of the healthcare team. One mother expressed her expectation that education and change would take place over a longer period of time, "The child had a hard time at the beginning. I do not think there is such a thing. It's not right to smother children all at once and deprive them of the things they love. If the child eats something, we are aware of it, but I have gone through this a lot. For example, he had a crisis. He wanted dessert."

In the category of expectations, the third theme was the acquisition of social awareness. One mother expressed her expectation as follows, "...sooner both teachers and Journal of Nursology

students can be informed about chronic diseases in this way, at least in schools. For example, English lesson. Now it starts in first grade and continues in second grade. The kids can understand that. I think they can understand that, too. I would request that they be taught that as a little lesson, even if it's superficial."

In the expectations and recommendations category, the fourth theme identified was psychosocial support groups. The subthemes of psychosocial support for mothers and children among psychosocial support groups were determined with the following statements: "..... But now that I'm listening to friends like that, I'm looking at that, that's really good for me. I also felt the need to speak. I wish this would have happened sooner."....though there is no child with type 1 diabetes near me. Something else you don't know the name of seems foreign. Those drug names over there, for example, Novorapid. I had a hard time pronouncing them. I'm going to learn it as I live and practice."

Under the theme of technological development, subthemes such as various mobile applications for T1DM, the establishment of professionally moderated social networks in the virtual realm, and technological advancements for treatment were identified within the category of expectations and recommendations. One mother succinctly expressed this expectation with the following words: "It makes our lives easier. When the child is outside eating a hamburger, I say, stop now, let's get her and go home. Let's go home and weigh some sandwiches. At least I'm not torturing the kid by saying, let's separate this from the meatballs, let's look at the potatoes or something."

DISCUSSION

In this study, four main categories were identified: "negative experiences/difficulties," "factors causing difficulties," "support resources," and "expectations and recommendations." Initially, the category "negative experiences/difficulties" emerged due to the anxiety mothers felt after their children's T1DM diagnosis and the fear of potential stigmatization. Similar findings were reported by Khandan et al. (2018), who observed that mothers of diabetic children experience high levels of anxiety and face challenging circumstances. Additionally, our study revealed that mothers of children with T1DM experience significant anxiety, consistent with the findings of previous research.²⁰ Another study indicated that mothers also experience general stress and parenting stress related to the disease. ²¹ Similarly, Rossiter et al. (2019) found that parents experience anxiety and fear

regarding potential stigmatization of their children.²² The "negative experiences/difficulties" category encompasses concerns about the future, physiological losses, stigmatization, and fear of losing the child. These challenges faced by mothers may stem from inadequate support systems during the diagnostic process. Many parents undergo significant stress following their child's initial diagnosis, with depressive symptoms often worsening over time.²⁴ Offering emotional support, education, practical resources, and financial assistance can enhance the well-being of both parents and children, resulting in improved diabetes management and overall quality of life. Lack of support networks for parents to share their difficulties and negative thoughts can exacerbate these challenges further.

The second category, "factors causing difficulties," was identified. Within this category, themes such as restrictions and exceeding rules due to the disease, ambiguity, peer and societal attitudes towards the children, emerged. Managing T1DM involves adherence to numerous rules and regulations.²⁵ Parents often find meal preparation for their children particularly challenging. Key aspects of diabetes management include adjusting insulin doses, modifying diet, following exercise recommendations, monitoring blood glucose levels day and night, and providing constant supervision.⁴ These requirements can intensify the caregiving burden and create challenges in disease management. Conversely, in a study involving 11-year-old children with T1DM, parents noted concerns about situations like sleepovers, despite wanting their children to feel capable and independent.²⁶ Mothers also express concern that their children may believe their diabetes will impact their future opportunities.²² Moreover, they worry about society's inappropriate attitudes towards their children's condition. Studies have shown that many parents fret over how diabetes will influence their children's future prospects.^{19,27,28} The diagnosis of T1DM in a child can be emotionally overwhelming for mothers, leading to feelings of shock, guilt, anxiety, and stress. Additionally, mothers may struggle to acquire the necessary knowledge and skills effectively child's manage their diabetes. to Comprehensive education, emotional support, practical tools, and resources from healthcare professionals can empower mothers to navigate the complexities of their child's T1DM condition successfully.

The third category, "support resources," was identified. Based on interview data, sources of support included family, friends, healthcare professionals, school administrators and teachers, school nurses, other children with T1DM, and technological innovations. Lindström et al. (2017) discovered that parents received support from relatives who lacked knowledge of the disease.²⁸ While one study highlighted ample support from Facebook groups, others noted difficulties in accessing professional diabetes teams.^{19,30} Parents also reported insufficient education about diabetes after their child's diagnosis, receiving conflicting messages from different medical professionals, which exacerbated their psychological and emotional distress.³¹ Rankin et al. (2016) found that parents felt overwhelmed post-diagnosis and required more emotional support before receiving specific guidance on training and nutrition for managing their child's diabetes.³² A study in Saudi Arabia underscored the need for tailored support methods addressing the psychosocial and cultural needs of newly diagnosed children and their mothers.³³ Mothers of children with T1DM play a pivotal role in helping their children cope with challenging responsibilities, emphasizing the importance of recognizing and addressing their support needs.

The fourth category, "expectations and recommendations," was identified. Within this category, mothers expressed expectations of the school administration, healthcare team, society, support groups, and advancements in technology. Mothers emphasized the importance of effective communication and receiving information from staff at their children's school or daycare regarding physical activity and nutrition.¹⁴ However, many school staff lacked training in diabetes management, as highlighted in several studies.¹⁵ Parents stressed the significance of schools in successfully managing their child's diabetes, noting that better-trained school staff and teachers resulted in improved monitoring and control of their children's blood glucose levels, providing parents with peace of mind. Additionally, positive relationships with the healthcare team motivated parents to adhere to diabetes care protocols.³⁴ Some parents experienced increased anxiety due to the desire to constantly monitor their child's blood glucose levels, leading to greater use of diabetes technology and associated expectations.³⁵ Moving forward, it is crucial to assess and implement the recommended actions to effectively meet these mothers' expectations and create an environment supportive of their children's well-being and success. By actively evaluating and integrating these recommendations, improvements can be made to the overall support system, enhancing the quality of life for both mothers and children living with T1DM.

Strenghts and Limitations of the Study

The study's strength lies in the researchers not being primary care providers, ensuring unbiased interviews. Participants were not pre-interviewed, and contacts were made and interviews completed on the same day by telephone, conducted sensitively and nonjudgmentally. This facilitated participants' ease of expression. However, the results may not generalize to populations with different sociodemographic characteristics, necessitating further studies for confirmation.

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