



# Primary Caregivers' Satisfaction with Healthcare of Children and Adolescents with Type 1 Diabetes Mellitus

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## Abstract

**Aim.** The aim of this study is to investigate the satisfaction of primary caregivers of children and adolescents with type 1 diabetes mellitus regarding healthcare services.

**Methods.** The study was conducted within the Association of Children and Youth with Diabetes in the Sarajevo Canton from October 23, 2021, to February 28, 2022. The study included 50 primary caregivers, 49 mothers and one father, with an average age of  $41.28 \pm 5.64$ . A generic questionnaire for assessing parental satisfaction with healthcare provided to their children, the PedsQLTM Healthcare Satisfaction Generic Module, was used. The statistical analyses used to analyze the data included multiple linear regression, ANOVA test, and t-test.

**Results.** Satisfaction with healthcare services was assessed with average ratings on a scale of 0 to 100 but with wide ranges of scores ( $59.46 \pm 24.34$ , ranging from 16.67 to 98.96). The results showed that two variables play a crucial role in predicting satisfaction with healthcare services: meeting emotional needs (relative contribution=29.8) and satisfaction with information (relative contribution=27.3).

**Conclusion.** An individualized approach and a collaboration with parents of children and adolescents with type 1 diabetes mellitus are necessary to improve the parental experience and their satisfaction with healthcare services.

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## Introduction

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Assessing the quality of healthcare is an essential component of measuring progress towards equitable health outcomes globally (1, 2). Traditionally, a healthcare system's quality was assessed by clinical outcomes, accessibility, and efficiency. However, there is a growing recognition that these factors alone are inadequate for providing a comprehensive patient experience (3). Patient satisfaction has become a pivotal element of a high-quality healthcare system. Patient satisfaction refers to their perception and experience of the healthcare provided, encompassing aspects such as the kindness and empathy of healthcare professionals, respectful and timely communication, patient involvement in decision-making about their treatment, and provision of information about their condition and procedures (4). Patient data (satisfaction, preferences, outcomes, and experience) are increasingly studied with the aim of providing patient-centered healthcare. Collecting data on patient experiences is becoming an increasingly vital component in assessing the quality of healthcare services provided. Understanding patient experiences presents an opportunity for designing healthcare delivery (5), as active engagement and collaboration between patients and healthcare professionals are key to providing quality healthcare services (6,7). The existing literature indicates that the most influential factor directly affecting patient satisfaction with hospital care is patient satisfaction with healthcare professionals. Patient satisfaction depends on the patient's trust in doctors and nurses, the availability of an adequate number of nurses providing care, and effective communication between healthcare professionals in the presence of the patient (4). Type 1 Diabetes Mellitus (T1DM) is one of the most common chronic diseases occurring during childhood and adolescence. Managing the disease requires the active involvement of parents, particularly mothers. The active involvement of mothers in managing a child's diabetes is emphasized due to their central role in caregiving, decision-making, emotional support, knowledge dissemination, and advocacy within the context of the family and healthcare system. Their continuous presence and guidance help ensure that the child receives appropriate care, adheres to the treatment plan, and main-

tains good glycemic control. The active participation of parents, particularly mothers, is vital in successfully managing T1DM in children and adolescents (8). T1DM diagnosis is subtle, with profound psychological and physical demands on mothers and implications for the extended family. To cope with their child's illness, mothers emphasize that the presence of competent and empathetic healthcare professionals is significantly helpful as essential support factors (9). Parental expectations are often influenced by the overall level of healthcare provided, including the professional qualifications of healthcare providers. When parents have higher expectations regarding the quality of healthcare services, they are more likely to evaluate their experiences based on those expectations (10).

The treatment of Type 1 Diabetes Mellitus (T1DM) in young children up to the age of eight is challenging for parents due to their unpredictable behavior, rapid growth and development, frequent infections, and dietary considerations. Often, both children and parents may not recognize symptoms of changes in blood glucose levels or signs of hypoglycemia, adding to parental concerns, especially when children are in daycare, school, or under the care of others (11). On the other hand, the adolescent period represents a critical phase due to the more demanding metabolic control. The increasing independence of adolescents reduces parental supervision, which can contribute to strained family relationships (12).

It is crucial for healthcare professionals to adopt a partnership approach with both children/adolescents and their parents. This approach allows them to feel secure and supported throughout the treatment and healthcare process. A partnership approach enables open communication and information exchange among all involved parties. Healthcare professionals can better comprehend the specific needs, preferences, and goals of the patient and tailor the treatment approach accordingly (13). Therefore, healthcare professionals should exert extra effort to provide support to children and adolescents with type 1 diabetes, as well as their parents, to ensure better health outcomes, improved quality of life, psychological well-being, empowerment, and long-term health management.

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## Aim

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1. To examine the satisfaction of primary caregivers of children and adolescents with type 1 diabetes mellitus regarding healthcare services in the Sarajevo Canton, Bosnia and Herzegovina according to the PedsQL TM Healthcare Satisfaction Generic Module
2. To identify the most significant predictors of overall satisfaction with healthcare services
3. To determine the impact of the duration of the child's treatment on the satisfaction of primary caregivers with healthcare services

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## Methods

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### Study design

The study is a cross-sectional research conducted using a descriptive-analytical method.

### Sample

Participation in the study was offered to 69 parents who were members of the Association of Children and Youth with Diabetes at the time of the research and who had children/adolescents aged 2 to 18 years who had been diagnosed with Type 1 Diabetes Mellitus for more than six months. Parents were informed that the study required the participation of the primary caregiver of the child/adolescent. The objectives of the study were explained to the participants. Out of the total of 69 parents, 51 parents agreed to participate in the research, while 18 parents declined to participate. One participant was excluded from the study because their child had been diagnosed with the disease for less than six months. The study included 50 primary caregivers (72,46 % response rate): 49 (98%) mother, and one (2%) father with an average age of  $41.28 \pm 5.64$ .

Data obtained from the Institute of Public Health of Sarajevo Canton indicates that, over the past three

years, an average of 101 cases of type 1 diabetes mellitus have been reported annually among children and adolescents up to 18 years old. However, not all of them are members of the Association of Children and Youth with Diabetes in which the research was conducted.

## Instruments

### PedsQL TM Healthcare Satisfaction Generic Module

A generic questionnaire was utilized to assess parental satisfaction with healthcare provided to their children. The questionnaire comprised 24 items divided into six subscales: information (5 items: the amount of information about the disease, the course of treatment, side effects during treatment, the timeliness of information about tests, and the frequency of receiving information), family involvement (4 items: sensitivity towards the family, willingness to answer questions, efforts to involve the family in discussions about the child's treatment, and the time allocated for asking questions about the child's treatment), communication (5 items: how well the child's condition is explained to them in a way they can understand, the time dedicated to parents in order to explain the child's health condition and treatment clearly, whether the staff listens to parents' concerns, satisfaction with preparing parents for what to expect during medical examinations and tests, and satisfaction with preparing the child for what to expect during examinations and tests), technical skills (3 items: whether the medical staff responded to the child's needs, whether they made efforts to ensure the child was comfortable and pain-free whenever possible, and the time dedicated to assisting with the child's transition back home), emotional needs (4 items: the amount of time for play and talking with the child about their feelings, the amount of time dedicated to helping the child transition back to school, the amount of time devoted to the child's emotional needs, and the amount of time dedicated to the parents' emotional needs), and general satisfaction (3 items: comprehensive care, how friendly and helpful the staff is, and the manner in which the child was treated). Each item is scored on a Likert scale (0 = never; 1 = sometimes; 2 = often;

3 = almost always; 4 = always; N/A). The items were reverse-scored and linearly transformed into a scale of 0-100 (0=0, 1=25, 2=50, 3=75, 4=100), with higher scores indicating higher satisfaction. The original questionnaire Cronbach's alpha: average  $\alpha=0.92$  (14);  $\alpha=0.94$  (15). A questionnaire, provided by Mapi Research Trust and available in multiple languages, including Croatian, one of the official languages in Bosnia and Herzegovina, was used.

## Data collection procedure

The study was conducted within the Association of Children and Youth with Diabetes in the Sarajevo Canton from October 23, 2021, to February 28, 2022. After obtaining consent from the Association and gaining access to the Association's Viber group, data of the members were accessed, and appointments were scheduled for interviewing the participants. After contacting the parents, meetings were scheduled with primary caregivers who agreed to participate in the study. The investigation took place at strategically chosen venues, accommodating the participants, intermittently spanning public locales and private residences. Individualized sessions were conducted with each primary caregiver. The study's objectives were systematically elucidated to the participants, and subsequent to the procurement of written informed consent, participants underwent the survey procedure. Written consent and a license from Mapi Research Trust were obtained for the use of the questionnaire. The required time for completing the questionnaire was between 8 and 10 minutes; however, after completing the questionnaire, parents expressed a strong desire to share their opinions about the healthcare system in Canton Sarajevo.

## Ethics

The research was approved at the 10th meeting of the Ethics Committee of the Faculty of Health Studies, number 04-7-12/21, held on February 12, 2021. The implementation of the doctoral dissertation project was approved on September 29, 2021, by the Senate of the University of Sarajevo, under reference number 01-14-169/21. Written consent was obtained from the president of the Association of Children and Youth with Diabetes of Sarajevo Canton, provided that each parent independently decides on participation in the study.

## Statistics

Statistical analysis was conducted using IBM SPSS Statistics 26.00 software (IBM Corporation, Armonk, New York). The questionnaire's reliability was tested using Cronbach's alpha. Normality of data distribution was tested with Shapiro-Wilk test due to the small number of subjects ( $N=50$ ). A total of 24 variables were tested for normality, of which 15 had normal distribution. After testing kurtosis and skewness, it was determined that 9 variables exhibited slightly right-skewed distributions. However, the deviations were not substantial, and therefore, a t-test was applied. The results of descriptive statistical analysis were presented using the following parameters: mean value with standard deviation. Multiple linear regression was employed to test and model relationships between one dependent variable (Y) and one or more independent variables (X). Additionally, in this study, the IBM SPSS Automatic Linear Modeling module was incorporated to determine which variable has the highest predictor importance for overall points. To test differences between three groups based on duration of disease, the ANOVA test was utilized. Sum points of every segment of satisfaction were tested with overall total grade using paired sample t test. Pearson correlation was used to determine connection between age and examined variables. Statistical significance was set at a  $p$ -value  $< 0.05$ .

## Results

A total of 50 primary caregivers participated in the study. In 98% of cases, the primary caregiver was the child's mother. The average age of the respondents was  $41.28 \pm 5.64$ . The results of Pearson correlation indicate that as respondents age, their overall satisfaction with healthcare services tends to decrease ( $r=-0.302$ ,  $p=0.039$ ). Specifically, older respondents reported lower satisfaction in key areas such as communication ( $r=-0.299$ ,  $p=0.041$ ), technical skills ( $r=-0.401$ ,  $p=0.005$ ) and general satisfaction ( $r=-0.346$ ,  $p=0.017$ ).

Table 1. Participant characteristics		
Participant characteristics	N	%
<b>Primary caregiver</b>		
Mother	49	98
Father	1	2
<b>Educational level of the primary caregiver</b>		
Elementary school	2	4
Secondary school	33	66
University degree	15	30
<b>Employment status of the primary caregiver</b>		
Employed	32	64
Unemployed	18	36
<b>Marital status</b>		
Married	45	90
Divorced	2	4
Single parent	3	6

Most primary caregivers had completed secondary education (66%), while 64% were employed. Most primary respondents were married, making up 90%.

Satisfaction with healthcare services had an overall average score of 59.46. Satisfaction with information and involvement in treatment averaged around 59.80 and 60.46, respectively, while meeting emotional needs was the lowest-rated aspect, with the lowest scores given by primary caregivers, that is 40.82. General parental satisfaction was the highest, with an average of 72.67. Reliability analysis showed high overall reliability (Cronbach's  $\alpha=0.971$ ), with all sections demonstrating strong consistency. The sections on general satisfaction and communication had slightly lower reliability (Cronbach's  $\alpha=0.875$  and  $0.877$ , respectively), but still exhibited acceptable levels of reliability, with all other sections scoring above 0.9.

Table 3. Relative contribution of predictors to overall satisfaction with healthcare services			
Overall Satisfaction			
R <sup>2</sup>	S.E.	F	p
0.999	0.69487	9910.42	<0.0001
Predictors	$\beta$	p	Relative Contribution (%)
Emotional Needs	0.164	<0.0001	29.8
Information	0.229	<0.0001	27.3
Communication	0.206	<0.0001	16.8
Inclusion of Family	0.156	<0.0001	13.3
Technical Skills	0.131	<0.0001	8.6
General Satisfaction	0.116	<0.0001	4.2

Table 2. Satisfaction with healthcare services and internal consistency of the questionnaire				
	The number of items	Mean	SD	Cronbach's alpha
Overall Satisfaction	24	59.46	24.34	0.971
Information	5	59.80	27.72	0.941
Inclusion of family	4	60.46	27.89	0.904
Communication	5	58.10	26.09	0.877
Technical Skills	3	69.83	26.61	0.910
Emotional Needs	4	40.82	34.21	0.946
General Satisfaction	3	72.67	25.09	0.875



Table 3 shows the predictors of individual satisfaction segments with overall satisfaction, along with their relative contribution in rating overall satisfaction with healthcare services. The total percentage of variance explained by the predictors is 99.9%, which is expected given that the overall satisfaction score is derived directly from the predictors included in the questionnaire. Since these predictors were carefully selected and validated (15), their combined effect on overall satisfaction is well captured in the model, supporting the argument that the tool was well-constructed to capture the key factors contributing to overall satisfaction. All satisfaction segments (emotional needs, information, communication, inclusion of family, technical skills, and general satisfaction) is a significant predictor of overall satisfaction as indicated by their p-values ( $p < 0.0001$ ). Emotional Needs ( $\beta = 0.164$ ) has the largest relative contribution (29.8%) in explaining overall satisfaction. This means that emotional needs have the strongest impact on users' satisfaction with healthcare services. Information ( $\beta = 0.229$ ) has a slightly higher coefficient, indicating that information also plays a significant role, contributing 27.3%. Communication ( $\beta = 0.206$ ) and Inclusion on Family ( $\beta = 0.156$ ) have a moderate impact, with relative contributions of 16.8% and 13.3%, respectively. Technical Skills ( $\beta = 0.131$ ) and General Satisfaction ( $\beta = 0.116$ ) contribute less (8.6% and 4.2%), but they are still significant predictors in explaining overall satisfaction.

The analysis of satisfaction with healthcare services based on the duration of the child's illness showed no statistically significant differences in satisfaction levels related to the length of the illness.

Discussion

The main goal of this study was to evaluate the satisfaction of primary caregivers of children and adolescents with type 1 diabetes mellitus (T1DM) concerning healthcare services.

In the Sarajevo Canton, children and adolescents with type 1 diabetes face inadequate support from the healthcare system, primarily due to a shortage of healthcare professionals involved in their treatment and care (16).

The evaluation of primary caregiver satisfaction, utilizing the PedsQL™ Healthcare Satisfaction Generic Module, revealed slightly lower average scores on a 100-point scale. The most influential predictor was the fulfillment of emotional needs. Primary caregivers rated satisfaction with emotional needs the lowest, and these ratings contributed to a decrease in the overall satisfaction with healthcare services. However, the wide range of responses underscores the necessity for a personalized and tailored approach in healthcare delivery. Older respondents reported lower satisfaction in key areas such as communication, technical skills and general satisfaction. This trend indicates that age might shape expectations or perceptions of healthcare quality, highlighting the need for tailored approaches to address the specific concerns of older caregivers within the healthcare system.

Table 4. Satisfaction with healthcare services based on the duration of the child/adolescent's treatment								
Duration of treatment Number of Participants (N)	6 months-2 years N 9		3-5 years N 13		>5 years N 28		F	p
	Mean	SD	Mean	SD	Mean	SD		
Overall Satisfaction	54.40	± 17.11	58.11	± 14.87	61.72	± 10.86	0.33	0.72
Information	48.33	± 19.38	66.54	± 15.97	60.36	± 9.74	1.17	0.32
Inclusion on family	57.64	± 22.50	65.22	± 14.81	59.15	± 9.73	0.26	0.77
Communication	56.11	± 21.24	49.23	± 16.05	62.86	± 10.77	1.26	0.29
Technical Skills	68.52	± 17.54	64.74	± 15.27	72.62	± 7.85	0.39	0.68
Emotional Needs	29.86	± 27.30	35.94	± 22.82	46.43	± 13.93	0.96	0.39
General Satisfaction	75.93	± 18.07	68.59	± 15.81	73.51	± 8.72	0.26	0.78

## **Satisfaction of primary caregivers of children and adolescents with type 1 diabetes mellitus regarding healthcare services**

Satisfaction with healthcare services in this study was evaluated with an overall score of 59.46. A significant factor influencing this rating was the subscale assessing technical skills, which reflects the healthcare professionals' ability to provide effective treatment for the child. This aspect was strongly linked to the overall satisfaction, as it directly impacts the caregivers' perception of the quality of care their child receives. This highlights that parents of children place significant importance on healthcare professionals who demonstrate competence in providing high-quality care. Parental satisfaction was also a key factor in the general satisfaction rating, which indicated friendly and approachable staff who were willing to help, with an average score of 72.67. Additionally, according to Yoo SY and Cho H (17), the quality of healthcare is influenced by factors such as the experience and professional self-efficacy of nurses. According to Gavurova et al. (4), the satisfaction of healthcare professionals significantly influences overall patient satisfaction with hospital care. Additionally, Kruszecka-Krówka et al. (10) emphasize that parental satisfaction with healthcare services can be intricately linked to their expectations. Recognizing the pivotal role of active patient participation, studies such as Dunsch et al. (6) underscore the importance of establishing partnerships and fostering shared decision-making. Actively involving patients in their healthcare journey is crucial for motivating them to enhance self-care behaviors, serving as the bedrock for improving the health status of individuals with diabetes.

The collaborative approach advocated by Letta S et al. (18), actively involving patients in their healthcare decisions, empowers them to take ownership of their health. This, in turn, enables informed decision-making and effective self-management practices. Such a patient-centered strategy not only promotes better health outcomes but also enhances the overall care experience for individuals with diabetes. In the context of children and adolescents with T1DM in the Sarajevo Canton, adopting a patient-centered approach is imperative to address the observed gaps in healthcare services and improve the overall satisfaction of primary caregivers.

## **The most significant predictors of overall satisfaction with healthcare services**

A substantial variation in responses was evident among participants across all facets of satisfaction with healthcare services. This underscores the imperative for healthcare services customized to meet the specific needs of families with children and adolescents affected by T1DM. The aspect garnering the lowest rating pertains to satisfaction with emotional needs, significantly influencing the overall satisfaction score with healthcare services. In this study, the fulfillment of emotional needs, coupled with satisfaction regarding the information provided, emerges as the most pivotal predictor of overall satisfaction.

Drawing insights from Dunsch et al. (6), it is noted that certain patients value their involvement in the decision-making process concerning medical interventions. The current study reveals a rating of 59.80 for satisfaction with the information received and 60.46 for satisfaction with the level of involvement in treatment. Although all factors exhibited significant associations with satisfaction in healthcare services and were substantial predictors of overall satisfaction among primary caregivers, it becomes evident that primary caregivers prioritize healthcare professionals who demonstrate empathy, support, understanding, and provide comprehensive information about their child's illness. Healthcare professionals with advanced qualifications and expertise are more likely to meet or exceed parental expectations, resulting in higher levels of satisfaction. This includes professionals who demonstrate excellent clinical skills, effective communication, empathy, and a patient-centered approach.

Conversely, when healthcare services fail to meet parental expectations, this can result in dissatisfaction and a negative perception of the quality of care. This underscores the critical need to ensure that healthcare professionals undergo appropriate training, possess up-to-date knowledge and skills, and can deliver comprehensive and compassionate care.

## **The correlation of the duration of the child's treatment on the satisfaction of primary caregivers regarding healthcare services**

Gavurova et al. (4) advocate for a focus on increasing patient satisfaction to foster trust between patients

and healthcare professionals, culminating in the development of loyal relationships and contributing to higher job satisfaction among healthcare professionals. The lack of statistically significant differences in satisfaction levels based on the duration of the child's illness suggests that familiarity with the healthcare process over time does not necessarily improve caregiver satisfaction. This may indicate that factors such as the quality of communication, emotional support, and the responsiveness of healthcare professionals have a greater impact on satisfaction than the length of treatment.

According to Jespersen et al. (19), families place importance on healthcare professionals being kind and clear in their communication - a consideration professionals should bear in mind when delivering healthcare services. Yoo et al. (20) highlight that the concept of family-centered care involves collaborative decision-making about healthcare between the patient's family and healthcare professionals, emphasizing the importance of respecting the patient's dignity, cultural background, values, and beliefs. Suggesting that Person-Centered Care, centered on partnership with healthcare professionals, is the contemporary gold standard of healthcare, Thunberg et al. (21) stress the necessity of identifying the patient's individual needs within a holistic approach. Various communication methodologies may be essential to cultivate a partnership between patients and healthcare professionals. Lohiya et al. (22) propose that a holistic family-centered approach is essential in delivering healthcare services to children and adolescents with T1DM. This approach includes routine assessment of emotional problems, treatment adherence issues, and social support concerns, aiming to assist families in navigating stressful situations.

A partnership approach among healthcare professionals, children/adolescents, and their parents enhances the quality of healthcare, improves treatment adherence, promotes self-care, and contributes to better health outcomes (13). The study's findings indicate the necessity for enhancing the partnership with parents of children and adolescents with type 1 diabetes mellitus in the Sarajevo Canton to improve parental satisfaction with healthcare services. Healthcare professionals should prioritize evidence-based healthcare, aligning with the recognized importance of forming partnerships with patients and their families.

However, this study also opens up several potential directions for future research. For instance, explor-

ing differences in satisfaction levels across various healthcare settings (e.g., public vs. private healthcare providers) could provide valuable insights into how healthcare delivery models impact caregiver satisfaction. Further, expanding the sample size to include a larger and more diverse cohort of caregivers could help in obtaining more generalized findings. Additionally, future studies could investigate the effectiveness of specific interventions aimed at improving emotional support and communication between healthcare professionals and parents, examining how these factors influence long-term satisfaction and health outcomes.

## Limitations

The study has limitations. Although the healthcare system support in the Sarajevo Canton is insufficient, we have not investigated whether the shortage of healthcare professionals is a potential cause of reduced satisfaction with healthcare services. It solely detected satisfaction based on questionnaires. The study included 50 participants, with an average of 101 cases reported annually. Future research should include all parents in the Sarajevo Canton and, in addition to questionnaires, incorporate qualitative research methods in healthcare to delve deeper into the reasons for reduced satisfaction with healthcare services. Moreover, it is important to include both parents in the research to gain a more comprehensive understanding of their experiences and satisfaction.

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## Conclusion

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Caregivers particularly emphasized the importance of emotional support and detailed information about their child's condition. The study identified that emotional needs, information provided, and the level of involvement in treatment were the most significant predictors of overall satisfaction. Meeting these expectations is essential for enhancing caregiver satisfaction. Empathy, communication, and competence in healthcare professionals are pivotal in shaping caregivers' perceptions of care quality. Healthcare professionals should undergo continuous training to improve their technical skills, communication, and



empathy to better meet the needs of children with type 1 diabetes and their families. A family-centered approach should be adopted, emphasizing active collaboration with parents in decision-making, providing comprehensive information, and addressing both emotional and practical needs.

These findings underscore the importance of focusing on both the technical and emotional aspects of healthcare provision, aiming to enhance satisfaction and improve the overall healthcare experience for children, adolescents, and their families.

### Author contributions

Conceptualization (EM, JM); Data Curation (EM, JM); Formal Analysis (EM, JM); Investigation (EM); Methodology (EM, JM, SB, HK, VĐ); Project Administration (EM, JM, SB, HK, VĐ); Supervision (EM, JM, SB, HK, VĐ); Validation (EM, JM, SB, HK, VĐ); Visualization (EM, JM, SB, HK, VĐ); Writing - Original Draft (EM); Writing - Review & Editing (EM, JM, SB, HK, VĐ).

### Conflict of interest

The authors declare no conflicts of interest.

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