ORIGINAL RESEARCH



Knowledge, Attitudes, and Practices in Neonatal Diabetes Mellitus Management: the JEnious-NeOnatal-Diabetes (JENODI) Survey

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ABSTRACT

Introduction: We aimed to explore the knowledge, attitude, and management of neonatal diabetes mellitus (NDM) among members of the International Society for Pediatric and Adolescent Diabetes (ISPAD).

Prior Publication: This paper is based on original data. Part of this work was presented at the 50th Annual ISPAD Meeting as Oral Presentation. It has never been published before.

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Department of Pediatrics, University Clinical Hospital in Opole, Opole, Poland *Methods*: Members of the society were invited to complete an online questionnaire posted on the ISPAD website.

Results: We received 108 responses from 45 different countries. Of these, 103 were involved in NDM management. 87.9% of participants would start insulin at diagnosis, and 11% would prefer sulfonylurea (SU); 54.6% would start with an insulin pump, and 80.6% would use continuous glucose monitoring. Genetic testing was suggested by 97.2% (50.9% when diagnosis occurs up to 6 months, 15.7% up to 9 months, and

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30.6% up to 12 months of age), while 79.6% routinely request it in clinical practice. Of the participants, 96.3% consider genetic testing necessary to identify children who can be treated with SU, and 26.9% would try SU before testing/obtaining results. Only 37% received specific training on NDM, while 44.5% felt less confident in managing patients with NDM. Incidence in the country of practice, participant's age, years of experience in the field, number of patients registered in the clinic, and number of patients with NDM followed up were associated with differences in answers.

Conclusions: This survey offers the possibility of informing health providers about the awareness of different aspects of NDM management. Our results provide the opportunity to compare various aspects of diagnosis and treatment of NDM in different geographic areas. Continuous education is needed to boost physicians' confidence in managing patients with this rare form of diabetes.

Keywords: Neonatal diabetes mellitus; Genetics; Education; Insulin; Sulfonylurea

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Key Summary Points

Why carry out this study?

The rarity of neonatal diabetes mellitus (NDM) may limit the awareness of the disease and make physicians feel unconfident about managing these infants.

Despite the availability of international guidelines, managing these patients can be challenging and inconsistent across different countries.

We surveyed the knowledge, attitudes, and practices of members of the International Society for Pediatric and Adolescent Diabetes (ISPAD) regarding the diagnosis and management of NDM to investigate the skills and unmet educational needs of surveyed health-care providers.

What was learned from the study?

Self-confidence in managing these patients is reported as suboptimal, and specific training in clinical practice would be beneficial.

Management and therapeutic approach are different in keeping with incidence, etiology, clinic size, age, and experience of healthcare professionals.

These features affect the level of confidence and influence the perception of neonatal diabetes mellitus in terms of what to look for and the type of therapies.

INTRODUCTION

Neonatal diabetes mellitus (NDM) is a monogenic form of diabetes diagnosed within the first 6 months of life [1]. It is a rare disease with a global incidence that varies, with the highest rate reported among the highly consanguineous Arab populations of northwest Saudi Arabia (1:21,000 live births) [2] and Qatar (1:23,000 live births) [3], compared to Europe (1:90,000) [4, 5].

NDM can be classified as permanent (PNDM) or transient (TNDM) [1], with over 80% of the cases being associated with mutations affecting pancreatic β -cell function [1, δ], with a higher rate

in PNDM than in TNDM [6]. Common genetic causes of the former subtype include mutations in the genes encoding the KATP-dependent channel subunits (KCNJ11 and ABCC8) and the insulin gene (INS) [4, 6, 7]. In highly consanguineous populations, PNDM is more likely due to recessive EIF2AK3 gene mutations, leading to Wolcott-Rallison syndrome and GCK gene mutations [7]. The most common causes of TDNM are genetic defects in imprinted genes or methylation defects on chromosome 6q24 (PLAGL1/ZAC and HYMAI), followed by mutations in the genes encoding the KATP-dependent channel subunits [1, 9, 10]. Distinguishing TNDM from PNDM is complex without genetic analysis, which is crucial for guiding treatment and prognosis [1].

The initial treatment is based on insulin, but the need of very small doses and unpredictable feeding are a challenge for clinicians, requiring frequent blood sampling to avoid blood glucose excursion [11, 12]. Furthermore, the infants' small size and limited subcutaneous fat may pose challenges for intravenous infusion and needle insertion, particularly when using an insulin pump, which enables more flexible insulin treatment based on the feeding regimen, or for the application of a glucose sensor.

The rarity of this disease may limit the awareness of NDM and make physicians feel unconfident about managing these infants. As a result, its management may be challenging despite the availability of international guidelines aimed at improving clinicians' practice and awareness of diagnosing and treating NDM [1].

This survey aimed to ascertain the knowledge, attitudes, and practices of members of the International Society for Pediatric and Adolescent Diabetes (ISPAD) regarding the diagnosis and management of NDM. It also explored the skills and unmet educational needs of surveyed healthcare providers regarding NDM.

METHODS

Study Design

The JEnious-NeOnatal-DIabetes (JENODI) survey is a cross-sectional electronic survey supported

and launched by the ISPAD JENIUOS group. It was uploaded to the ISPAD website on March 5, 2023, and was left open for responses until November 27, 2023. Participants were invited to answer the survey questions through a web link provided on the ISPAD website. They received an initial invitation via e-mail or other electronic channels, which explained the study's rationale and requirements for participation. The voluntary nature of the study and the strict confidentiality of the survey were emphasized in these communications. After obtaining approval from each participant, responses were collected anonymously and stored electronically. At the end of the study, summary statistics were prepared for each question, with percentage adjustments to account for any missing responses.

The survey was reviewed and approved by the Arab Society for Pediatric Endocrinology and Diabetes (ASPED) research committee. As an anonymous survey that did not collect any personal information or participant views, this study is exempt from ethical approval, similar to other previously published surveys. Participants were informed that their response would be used as part of a publication. No copyright was required for the questionnaire.

The Survey Questionnaire

The questionnaire is detailed in Box 1. Suppl. Box 1 displays the correct answers based on ISPAD Clinical Guidelines [1, 16]. The survey comprised 42 multiple-choice questions, based on an existing questionnaire from the Arab Society for Pediatric Endocrinology and Diabetes (ASPED) [13], which fully approved it for research use. In the "Introduction" section, respondents provided demographic information, including their specialties, age group, and the duration and volume of their practice in NDM. In the "Methods" section, participants were presented with a case scenario and following the case scenario, participants answered questions regarding their approach to diagnosis and management of NDM. To make the paper easier to read, the question number is reported where appropriate.

 Table 1 Characteristics of the participants

Feature (question)	Responses	Number of participants (%)
Age (Q1)	Under 30 years old	4 (3.7%)
	30–40 years old	31 (28.7%)
	40–50 years old	33 (30.6%)
	Over 50 years old	40 (37.0%)
Geographical area (Q2)	Europe	46 (42.6%)
	Middle East	18 (16.6%)
	Africa	16 (14.8%)
	Asia	15 (13.9%)
	North America	6 (5.5%)
	Oceania	4 (3.7%)
	South America	3 (2.9%)
Institutional classification (Q3)	Tertiary care center	83 (76.9%)
	Teaching facility	55 (50.9%)
	Research facility	35 (32.4%)
	Secondary care	12 (11.1%)
	Primary care	4 (3.7%)
	Other institutions	2 (1.9%)
Discipline (Q4)	Pediatric endocrinologists/diabetologists	97 (89.8%)
	Adult endocrinologists/diabetologists	4 (3.7%)
	Other physicians or diabetes team members	7 (6.5%)
Experience in the field of pediatric diabetes (Q5)	Less than 3 years	16 (14.8%)
	Between 3 and 5 years of experience	10 (9.3%)
	Between 5 and 10 years	14 (13.0%)
	Over 10 years of experience	68 (63.0%)
Clinic size (Q6)	Fewer than 100 patients	9 (8.3%)
	101–300 patients	29 (26.9%)
	301–500 patients	22 (20.4%)
	501–1000 patients	27 (25.0%)
	More than 1000 patients	21 (19.4%)
Experience in managing children with Neonatal Diabetes	Fewer than 5 individuals managed	67 (62.0%)
Mellitus (NDM) (Q29)	5–10 cases	30 (26.9%)
	10–15 cases	3 (2.8%)
	More than 15 cases	9 (8.3%)

Statistical Analysis

Results were reported as percentages. Comparison between groups was run based on (a) NDM

incidence in the country of practice: high-incidence countries because of high consanguinity rate [14], arbitrarily defined as more than one patient in 50,000 newborns (Sub-Saharan

countries, India, Pakistan, and Gulf states), or low-incidence countries, arbitrarily defined as less than one patient in 50,000 newborns (all the other countries) (see supplementary Table 1 for the list of all countries where respondents originated); (b) participants' experience: (i) age (senior participants defined as over 50 years of age, otherwise junior participants), and (ii) experience in the field of pediatric diabetes (more experienced participants defined as more than 10 years of experience in the field of pediatric diabetes, otherwise less experienced); (c) clinic features: (i) number of patients registered in the clinic (a large clinic is defined as at least 501 patients, otherwise it is considered a small clinic), and (ii) patients with NDM followed up in the clinic (less than or at least five patients).

The chi-square test with Fisher's exact test when appropriate was run. A p value < 0.05 was

considered statistically significant. Statistical analysis was run with SPSS v. 28.0 for macOS.

RESULTS

Background of the participants

A total of 108 respondents participated in the survey and 95.4% had experience in managing children with NDM (Q41). The characteristics of all participants are displayed in Table 1.

Table 2 Dose, dilution, and regimen of insulin treatment (the percentage of answers provided is highlighted in bold)

If you chose insulin, with what	<0.3	0.3-0.6	0.7-1.0	1.0	
dose would you start the treat- ment (IU/kg/day)?	40.7%	47.2%	10.2%	1.9%	
If you use insulin, would you dilute it?	Yes, with distilled water	Yes, with normal saline	Yes, with 5% dextrose/Yes with either distilled water or normal saline or 5% dextrose	No	
	11.1%	55.6%	7.4%	25.9%	
If a neonate/an infant required insulin treatment, which short acting insulin would you prefer to use?	Analogue	Regular	No preference		
	71.3%	24.1%	4.6%		
If a neonate/an infant would require insulin treatment which basal insulin/s would you use? (you can tick more than one)	Glargine	Detemir	NPH	Degludec	
	51.9%	38.9%	31.5%	16.7%	
If a neonate/an infant would require insulin treatment what	<30%	30-40%	40-50%	50-60%	60- 70%/>70%
% of the total insulin require- ment would you give as basal insulin?	20.4%	37%	20.4%	9.3%	12.9%

NPH Neutral protamine Hagedorn

Table 3 Responses to question Q20–24 about the management of genetic testing

Question	Responses	Number of participants (%)
Do you think all infants with diabetes require genetic testing? (Q20)	Yes. The cut-off age at diagnosis to request genetic testing is 6 months	57 (52.8%)
	Yes, the cut-off age at diagnosis to request genetic testing is 9 months	15 (13.9%)
	Yes, the cut-off age at diagnosis to request genetic testing 12 months	33 (30.6%)
	Yes, the cut-off age at diagnosis to request genetic testing 24 months	1 (0.9%)
	No	2 (1.9%)
Do you request genetic tests for all your infants with neonatal diabetes? $\left(Q21\right)$	Yes	86 (79.6%)
	No, because of cost/logistic difficulties	21 (19.4%)
	No, because it is clinically not important	1 (0.9%)
	No, because it takes long time to receive the results	
Do you request diabetes-related autoantibodies in	Yes	80 (74.1%)
infants suspected of having neonatal diabetes? (Q22) $$	No	28 (25.9%)
To what extent do you agree with this statement? "Genetic testing for neonatal diabetes mellitus	Agree	104 (96.3%)
(NDM) is important because it identifies patients	Neutral	3 (2.8%)
who can be treated with Sulfonylurea (SU) instead of insulin" (Q23)	Disagree	1 (1.9%)
Are you aware of genetic testing for NDM available in	Yes	84 (77.8%)
some international laboratory for free under research funding? (Q24)	No	24 (22.2%)

Diagnostic Approaches

After reviewing the case scenario, 60.2% of respondents considered that the diagnosis of NDM could be confirmed, 38% thought that the diagnosis was suspected, and 1.8% felt that the infant did not meet the criteria for NDM (Q7). The majority (82.4%) stated that it is impossible to predict at presentation whether NDM will be permanent or transient (Q8).

Treatment Practices

For initial treatment, 88% of respondents suggested starting insulin therapy, 11.1% recommended trying oral SU, and 0.9% advocated for diet and caloric restriction (Q9). Detailed responses regarding insulin dosage, dilution, and regimen are displayed in Table 2 (Q10–15). Most respondents (80.6%) would use continuous glucose monitoring (CGM) in infants with NDM (Q16). Supplemental Figs. 2–6 show the family and personal history aspects that participants would collect (Q17–19).

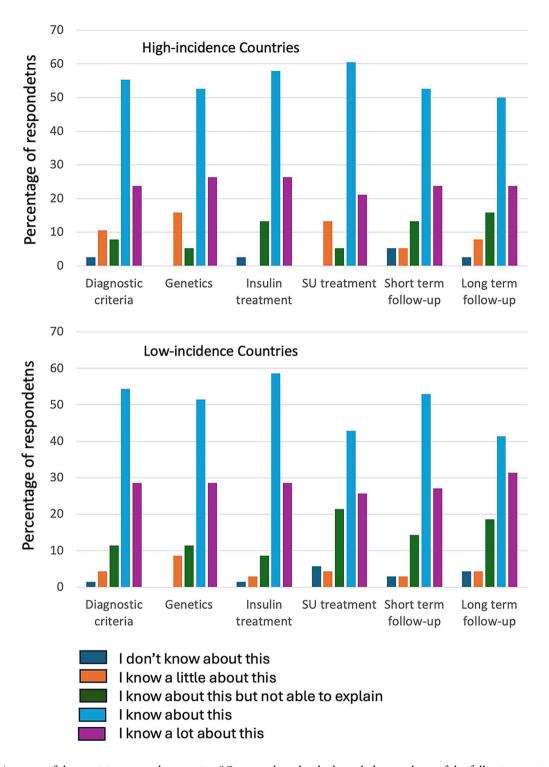


Fig. 1 Answers of the participants to the question "Can you describe the knowledge you have of the following topics related to neonatal diabetes mellitus (NDM)?" split into high vs. low incidence countries. *SU* Sulfonylurea

Genetic Testing

Nearly all respondents (98.1%) agreed that all infants with NDM should undergo genetic testing. The preferred cut-off for genetic testing was 6 months for 50.9%, 9 months for 15.7%, 12 months for 30.6%, and 24 months for 0.9% of the respondents (1.9% would not perform genetic testing in all patients) (Q20). Table 3 displays the responses to question Q20–24 about the management of genetic testing.

Most participants (73.1%) would not try SU before genetic testing, and 58.3% would not use SU while awaiting results (Q25–26). Nonetheless, 68.5% would try SU if genetic testing facilities were unavailable (Suppl. Fig. 7 displays data split into high vs. low incidence countries) (Q27). The preferred dose for successful SU treatment of 0.31–0.6 mg/kg ranked first (45.4% of the participants), 0.01–0.3 mg/kg second (26.9%), and above 0.6 mg/kg third (12%) (15.7% of participants did not suggest any dose) (Q28).

Education and Confidence

Knowledge of various NDM-related topics is illustrated in Fig. 1 (Q33). Only 37% of respondents received specific training on the diagnosis and management of NDM (Q34). Despite that, 97.2% indicated that acquiring specific knowledge and practical skills related to NDM should be mandatory for diabetologists/endocrinologists (Q35). Regarding confidence in managing NDM, 18.5% felt completely confident, 37% fairly confident, 31.5% somewhat confident, and 13% slightly or not confident at all (Q42).

Guidelines and Training

Guidelines for the management of NDM were available in 35.2% of the participants' units (Q36). Of the total participants, 60.2% were aware of ISPAD guidelines, 25.9% were familiar with both ISPAD and ESPE guidelines, 12% were unaware of any international guidelines and 1.9% of the participants used other international society guidelines (Q37). Interdisciplinary guidelines would be appreciated, as 88.9% of participants do not know any (Q39). Online training, such

as webinars, was the preferred method for education about NDM (44.4%), followed by dedicated sessions during international scientific meetings (38.9%). Websites, e-mails, or other tools were considered appropriate for teaching about NDM by 10.2% of the participants (Q40).

NDM Incidence in the Country of Practice

No differences were found based on NDM incidence in the country of practice concerning experience and clinic features (supplementary Table 2). Participants from high-incidence countries would start treatment more frequently with MDI than with CSII (55.3% and 28.9%, respectively) than participants from low-incidence countries (21.4% and 68.6%, respectively) (p < 0.001) (Q12), and would use CGMS less frequently (60.5% and 91.4%, respectively, *p*<0.001) (Q16). Only 63.2% of respondents from high-incidence countries require genetic testing (90.0% in low-incidence countries, p=0.003) (Q21). Participants from highincidence countries would try SU before genetic testing in 42.1% of the cases versus 18.6% of the other participants (p=0.008) (Q25). Supplemental Figure 1 shows the rate of the most frequent cause of NDM split into high- and low-incidence countries (Q30). Wolcott-Rallison syndrome was the most frequent cause (18.4%) in high-incidence countries (0% in low-incidence countries; p < 0.001). More frequent hypoglycemic episodes in infants with NDM compared to older children with diabetes were seen by 63.2% of participants from high-incidence countries than from lowincidence countries (20%; p<0.001) (Q31). Participants from high-incidence countries scored better results on knowledge about SU treatment than participants from low-incidence ones (p=0.031) (Q33).

Experience of the Participants

Among the more experienced participants, 94.1% would start treatment with insulin, while 5.9% would choose SU. In contrast, among the less experienced participants, 77.5% would opt for insulin, and 20% would select SU (p=0.03) (Q9). Short-acting insulin (82.4%) and regular

insulin (14.7%) were preferred by the more experienced participants (less-experienced participants: short-acting insulin 52.5%, regular insulin 40.0%) (p = 0.004) (Q13). SU would be tried before sending genetic testing by 42.5% and 17.6% of less and more experienced participants, respectively (p=0.005) (Q25). Moreexperienced participants scored better results concerning knowledge of insulin treatment in NDM (p=0.011), short-term (p=0.004) and longterm follow-up (p=0.005), and more confidence in the management of NDM (p=0.018) than less experienced participants (Q33); 1.5% of the former and 10% of the latter have never been involved in the management of NDM (p=0.042) (Q41).

The K-ATP channel gene mutations were indicated as the most frequent cause of NDM by 72.5% of senior participants and 41.2% of junior participants (p=0.014) (Q30). Senior participants scored better results about the knowledge of long-term follow-up (p=0.045) and confidence in the management of NDM (p=0.022) than junior ones (Q33).

Clinical Features

Participants from larger clinics would start the treatment with short-acting analogue (83.3%; regular insulin 16.7%), more frequently than participants from smaller clinics (61.7%; regular insulin 30.0%) (p = 0.021) (Q13) and would use CGMS more frequently (89.6%; smaller clinics 73.3%, p = 0.034) (Q16). At least five infants with NDM were followed up by 60.4% and 20% of participants from larger and smaller clinics, respectively (p<0.001) (Q29). Eight of nine participants with more than 15 patients with NDM in follow-up worked in larger clinics. Participants from larger clinics scored higher results concerning knowledge of insulin treatment (p=0.011), SU treatment (p=0.039), shortterm (p<0.001) and long-term follow-up issues (p=0.003), and confidence in the management of NDM (p=0.013) (Q33). Finally, 45.8% of participants from larger clinics have guidelines in their unit for NDM (26.7% of participants from smaller clinics, p=0.038) (Q36).

Participants who followed up at least five infants with NDM scored higher results concerning knowledge of diagnostic criteria (p=0.022), genetics (p=0.009), insulin treatment (p=0.002), SU treatment (p=0.008), short-long (p<0.001) and long-term follow-up issues (p<0.001) (Q33). Among participants who follow up with at least five patients, 51.2% have specific guidelines in their unit (vs. 25.4% of the other participants, p=0.006) (Q36) and scored better results regarding confidence in the management of NDM (p=0.01) (Q42).

DISCUSSION

This survey offers the possibility of comparing various aspects of diagnosis and treatment of NDM in different geographical areas. The results are useful for informing health providers about the awareness of different aspects of NDM management with a special interest in the treatment. In 2020, Habeb et al. [13] surveyed perceptions and practices of NDM management among physicians practicing in the ASPED countries and reported good awareness of the diagnosis and the utility of genetic testing with variations in clinical practice. The limitation of that survey was the restricted geographical area, featured by a high rate of consanguinity and thus a high incidence of syndromic NDM [2, 3]. Prompted by these findings, our survey aimed to capture a global perspective on NDM management: it covered 45 countries, providing a broader overview.

The presented case scenario was considered indicative of NDM by most respondents, aligning with current guidelines and suggesting appropriate diagnostic skills and awareness of the clinical course. Initially, all infants with NDM require insulin treatment, but further treatment may vary depending on the genetic etiology. The need of precise small doses, unpredictable feeding, and need of frequent blood glucose sampling to define the appropriate insulin dose make the management of NDM very challenging [11, 12]. Subcutaneous or intravenous insulin may not address all the needs of these infants, prompting clinicians to evaluate more

effective ways of administration and blood glucose monitoring as well. Infections and displacement may complicate the management of intravenous infusion, and thus CSII may also be a valid technique to deliver insulin even in newborns with very low birth weight.

Over the last years, insulin pumps and CGM systems [11, 15] have significantly improved the management of diabetes mellitus. Automated insulin delivery (AID) systems, which use embedded algorithms to adjust insulin delivery based on CGM data, offer an additional tool for optimizing insulin treatment. They help optimize insulin delivery and prevent hypoglycemia, which is the primary goal in these infants. Therefore, the use of an insulin pump is particularly recommended for infants and neonates with NDM. [16]. However, the last generation of AID systems require at least 8 IU/day to work effectively, cannot be prescribed in infants below 1 year of age, and most of them cannot be used below 7 years of age. Even though insulin pumps and CGMs were the most commonly chosen options in this survey, they are notably used more frequently in low-incidence countries than in high-incidence countries. We suggest that differences in countries' income levels account for this disparity, as more than 75% of high-incidence countries were classified as low-income, compared to less than 25% of low-incidence countries.

Most carriers of KATP-dependent channel gene mutations can respond better to oral SU with significant improvement of glycemic control and minimal episodes of hypoglycemia [17], and thus genetic testing is mandatory in infants with NDM to tailor the precision medicine approach [18]. Nearly all respondents considered genetic testing necessary to identify infants who could be treated with SU, but it is disappointing to see that cost and logistic difficulties prevented about 20% from requesting genetic testing, highlighting a significant barrier to optimal care. High-incidence countries have a lower rate of participants requiring genetic testing, suggesting that some work has yet to be done overall

in these countries to allow genetic testing in all cases when indicated.

In this survey, nearly 75% of the respondents would not try SU before genetic testing, and about 58% would not use SU while awaiting genetic results. SU is recommended for infants with KNCJ11 or ABCC gene mutations, where it has shown long-term efficacy and safety [19, 20]. A trial of SU in patients without a genetic diagnosis or a different genetic etiology is discouraged since it can cause inappropriate expectations for the parents and unnecessary distress [21]. Furthermore, in the case of ABCC8 and KCNJ11 gene mutations but unsuccessful try, a dose above 2.0 mg/kg/day to reach insulin independence has been reported [22-24]. Interestingly, in the high-incidence countries, participants who requested genetic testing less frequently had better confidence about SU treatment and would try SU even before genetic testing, very likely because of the barriers to run. In this case, international collaborations or funding opportunities should be chased to bridge this gap. Notably, genetic testing is available in some laboratories and it may be free of charge in some of them based on research funding. This information may be particularly valuable for clinicians working in resource-limited settings.

Our survey indicated that the education of healthcare professionals on NDM is limited, with less than 40% of our responders receiving specific training and nearly all participants believing that specific training should be mandatory for pediatric and adult endocrinologists/diabetologists. Interestingly, participants working in larger clinics, those who are senior, more experienced, and those managing a higher number of infants with NDM in follow-up scored higher in their knowledge of various NDM-related issues compared to others. We suggest that these could be the features of the health care professional specialized in NDM. Furthermore, in most clinics where these participants work, guidelines are in place, facilitating the standardization of clinical practice. For the benefit of the reader, a small box highlighting some selected ISPAD

recommendations on the management of NDM has been included as supplemental Box 2.

This survey has some limitations. First, as it is a survey-based study, it captures perceptions rather than real-world practices and outcomes. Second, despite broad geographic representation, some regions, particularly Oceania and the Americas, were underrepresented (12% of the participants). Third, there may be a potential response bias, particularly due to the survey's reliance on self-reported knowledge and practices. The response rate cannot be calculated as we do not know how many clinicians received and read the invitation to participate. Furthermore, non-responders may have less experience or interest in NDM, potentially skewing the results. Additionally, not all ISPAD members participated in the survey, meaning the responses reflect only the views of those who did. On the other hand, a key strength of this survey is that nearly all participants had managed at least one infant with NDM, with nearly 40% having treated more than five children, indicating substantial experience with the condition.

CONCLUSIONS

In conclusion, this survey shows the awareness and knowledge of NDM diagnosis, management, and treatment among respondents. Selfconfidence in managing NDM is reported as suboptimal, highlighting the need for routine inclusion of NDM training in clinical practice. Differences in incidence and thus etiology, clinic size, age, and experience of the healthcare professional account for different management and therapeutic approaches. These features vary the level of confidence and influence the perception of NDM in terms of what to look for and the type of therapies. The results of this survey suggest that while awareness on NDM is increasing, confidence in management varies significantly based on geographic region and clinical experience. This highlights an ongoing need for targeted education. Therefore, given the global variability in diagnostics and treatment approaches, standardized clinical guidelines and increasing access to genetic testing and technologies for diabetes appear to be crucial steps in improving NDM management and outcome worldwide.

ISPAD may play a pivotal role in addressing unmet needs because its "mission is to advance clinical and scientific knowledge, promote education, and advocate for better care and treatment for young people affected by diabetes". The ISPAD Clinical Practice Consensus Guidelines [1] are being updated 4-yearly, and they are the most comprehensive paper on the topic. Other international documents, produced by the American Diabetes Association and the Juvenile Diabetes Research Foundation (JDRF), appear to be less detailed and exhaustive.

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Data Availability. All data generated or analyzed during this study are included in this article and its supplementary material files.

Declarations

Conflict of Interest. All the authors (Maurizio Delvecchio, Claudia Piona, Agata Chobot, Laura Cudizio, Asma Deeb, Nancy Elbarbary, Tiago Jeronimo Dos Santos, Abdelhadi Habeb) do not declare any competing interests. Maurizio Delvecchio is an Editorial Board member of Diabetes Therapy. Maurizio Delvecchio was not involved in the selection of peer reviewers

for the manuscript nor any of the subsequent editorial decisions.

Ethical Approval. The survey was reviewed and approved by the Arab Society for Pediatric Endocrinology and Diabetes (ASPED) research committee. As an anonymous survey that did not collect any personal information or views of the survey participants, the study is exempt from ethical approval, similarly to other survey already published. Participants were informed that their response would be used as part of a publication. No copyright was required for the questionnaire.

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