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Persistently Low Maternal Knowledge on Congenital Hypothyroidism Screening in Newborns

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ABSTRACT

Congenital hypothyroidism is a congenital disorder caused by impaired thyroid gland function in newborns and may lead to growth retardation and permanent intellectual disability if not detected early. Congenital hypothyroidism screening is recommended by the World Health Organization and has been implemented nationally by the Ministry of Health of the Republic of Indonesia as part of newborn screening programs. However, screening coverage in several regions, including Nias Regency, has not yet reached the expected target. Maternal knowledge is considered one of the important factors influencing participation in this screening program. This study aimed to describe pregnant women's knowledge regarding congenital hypothyroidism screening in newborns. This study employed a quantitative descriptive approach involving 21 pregnant women selected through accidental sampling. Data were collected using a structured questionnaire and analyzed using frequency distribution and percentage. The results showed that 28% of respondents had inadequate knowledge regarding screening indications, 24% had inadequate knowledge regarding screening procedures, and 33% had inadequate knowledge regarding screening benefits. Overall, 38% of respondents had inadequate knowledge regarding congenital hypothyroidism screening. These findings indicate that many pregnant women still have inadequate overall knowledge regarding congenital hypothyroidism screening in newborns.

Keywords: congential hypothyroidism screening; knowledge; pregnant women

INTRODUCTION

Congenital hypothyroidism is a congenital disorder in newborns characterized by impaired thyroid gland function or incomplete gland development from birth. This condition may result from structural abnormalities or metabolic disorders affecting thyroid hormone production, including iodine deficiency [1]. The consequences of delayed detection are serious, as untreated cases can lead to growth retardation, developmental delays, and permanent intellectual disability. Therefore, early detection through newborn screening is a critical strategy to prevent long-term adverse outcomes. One of the key approaches is congenital hypothyroidism screening, which involves collecting capillary blood samples from the infant's heel to identify thyroid dysfunction at an early stage [2]. Early diagnosis enables timely therapeutic intervention, thereby preventing complications and supporting optimal child development [3].

According to WHO data (2024) [4], congenital hypothyroidism occurs in approximately 1 in 2,000–3,000 live births, with most cases being asymptomatic in the early stages of life. This highlights the importance of screening as the primary method for early detection. In Indonesia, the situation shows a concerning trend, with the prevalence increasing from 62.3% in 2022 to 77.1% in 2023. Furthermore, medical record data from endocrine clinics in 2022 indicate that most cases are diagnosed after the age of one year, thereby increasing the risk of growth and developmental disorders. Although approximately 1.2 million newborns underwent early detection in 2023, national screening coverage remains suboptimal [5,6].

Infant mortality in Indonesia remains a significant public health concern, influenced by multiple factors, including congenital abnormalities. Congenital hypothyroidism is one of the conditions that can substantially reduce the quality of life of affected children due to its potential to cause permanent disability if not detected early [3]. In North Sumatra Province, the infant mortality rate remains relatively high at 2.6 per 1,000 live births. At the global level, reducing infant mortality is a key target of the Sustainable Development Goals (SDGs), with a target of 7 per 1,000 live births. Despite the national implementation of the program, several challenges persist, including suboptimal coordination, limited data management, budget constraints, and low community participation [7]. In addition, the Indonesian Pediatric Society (IDAI) reports that more than 1.7 million Indonesians are at risk of thyroid disorders, while public knowledge about this condition remains limited [8].

At the regional level, the Nias Regency Government has demonstrated commitment to supporting the program, achieving a screening coverage of 70% of total births in 2025. At the primary healthcare level, UPTD Idanogawo Health Center reported a higher coverage of 79%. However, this achievement has not yet met the expected target, as there are still newborns who have not undergone screening. This gap indicates a discrepancy between program targets and actual implementation, which may hinder efforts to achieve optimal early detection and prevention of congenital disorders, including congenital hypothyroidism.

One of the key factors contributing to this issue is the level of knowledge among pregnant women regarding congenital hypothyroidism screening. Pregnant women play a strategic role in decision-making related to newborn health examinations. Adequate knowledge of the indications, procedures, and benefits of screening is essential to support maternal readiness and participation in programs. However, in practice, this readiness remains suboptimal, highlighting the need for strengthened health education, enhanced family support, and improved access to healthcare information and services [9] Previous studies have demonstrated that maternal knowledge is associated with participation in newborn screening programs and that education provided during antenatal care (ANC) can improve maternal awareness. However, most studies have assessed knowledge in general terms without identifying specific knowledge components that may be deficient. This limitation reduces the ability to design targeted and effective educational interventions.

This study aimed to describe pregnant women's knowledge regarding congenital hypothyroidism screening in newborns. This study adopts a more focused approach by assessing pregnant women's knowledge based on three key components: knowledge of screening indications, screening procedures, and screening benefits. This approach is expected to provide a more comprehensive understanding of existing knowledge gaps that may influence participation in programs. Thus, this study not only describes the level of maternal knowledge but also contributes to the development of more targeted health education strategies to improve maternal awareness and optimize newborn screening coverage.

METHODS

This study employed a quantitative descriptive approach. The research was conducted from January to February 2026 at UPTD Idanogawo Health Center, Idanogawo District, Nias Regency. The study population consisted of all pregnant women registered at UPTD Idanogawo Health

Center during the study period. The sample size was determined using the Slovin formula, resulting in 21 respondents who were selected using an accidental sampling technique.

The main variable in this study was the level of knowledge of pregnant women regarding congenital hypothyroidism screening. Knowledge was assessed based on three components: knowledge of screening indications, knowledge of screening procedures, and knowledge of screening benefits. Data were collected using a structured questionnaire consisting of closed-ended questions. Each correct answer was scored as 1, and incorrect answers were scored as 0. The total score was then categorized into knowledge levels (good and poor) based on predetermined criteria. In addition to the main variable, respondent characteristics including age, parity, education level, and occupation were also collected to provide a descriptive overview of the study population. Data processing was carried out through editing, coding, and tabulating. The data were analyzed using descriptive statistical methods, specifically frequency and percentage distributions, as the data were categorical in nature.

RESULTS

Based on Table 1, the results of the study conducted among pregnant women at UPTD Idanogawo Health Center showed that the majority of respondents were aged 20–30 years (58%). In terms of parity, most respondents were categorized as grand multipara (42%). Regarding educational background, the majority of respondents had completed junior high school education (47%). In terms of occupation, most respondents were housewives (78%).

The findings reveal that a substantial proportion of respondents still demonstrated inadequate knowledge regarding congenital hypothyroidism screening. Specifically, 28% of respondents had poor knowledge of screening indications, 24% had poor knowledge of screening procedures, and 33% had poor knowledge of screening benefits, representing the highest proportion of inadequate knowledge among the three components. So the mother's total knowledge still amounts to 38 % of respondents had poor general knowledge regarding congenital hypothyroidism screening, indicating that nearly one-third of pregnant women still lack adequate understanding of this screening program.

This pattern indicates that gaps in maternal knowledge are not limited to a single aspect, but are present across multiple critical components of screening. In particular, the relatively high proportion of inadequate knowledge regarding screening benefits suggests that many pregnant women may not fully understand the importance and long-term impact of early detection. Although the majority of respondents were categorized as having good knowledge, the presence of nearly one-third of respondents with insufficient understanding highlights a significant public health concern. In the context of preventive health programs such as, even a moderate proportion of inadequate knowledge can hinder informed decision-making and reduce participation in screening programs. Therefore, these findings suggest that maternal knowledge regarding congenital hypothyroidism screening remains insufficient and unevenly distributed, indicating the need for more targeted and effective health education strategies.

Table 1. Distribution of respondent characteristics

Variabel	Category	Frequency	Percentage
Age	20–30 years 31-40 years 41-45 years	12 8 1	58 40 2
Parity	Primipara Multipara Grand multipara	9 4 9	38 19 42
Education	Primary school Junior high school Senior high school	7 10 4	34 47 19
Occupation	Housewife Farmer Private employee	16 4 1	78 20 2

Table 2. Distribution of pregnant women's knowledge on congenital hypothyroidism screening

Component of knowledge	Category	Frequency	Percentage
Indications	Good	15	72
	Poor	6	28
Procedures	Good	16	76
	Poor	5	24
Benefits	Good	14	67
	Poor	7	33
Overall	Good	13	62
	Poor	8	38

DISCUSSION

The findings of this study reveal a nuanced and multilayered picture of pregnant women's knowledge regarding congenital hypothyroidism screening at the UPTD Idanogawo Health Center, Nias Regency, North Sumatra. Although the majority of respondents were categorized as having good knowledge across the three assessed components indications, procedures, and benefits a substantial and clinically meaningful proportion demonstrated inadequate understanding in each domain. Specifically, 28% of respondents exhibited poor knowledge of screening indications, 24% demonstrated inadequate understanding of screening procedures, and 33% showed insufficient knowledge of screening benefits. These figures, while seemingly representing a minority, carry significant public health implications when considered in the broader context of neonatal preventive care. Congenital hypothyroidism (CH) is widely recognized as one of the most common preventable causes of intellectual disability and neurodevelopmental delay in newborns worldwide, with a global incidence of approximately 1 in 2,000 to 4,000 live births [10]. In Indonesia, the incidence has been reported as high as 1 in 2,513 newborns, and the national newborn screening program, heavily centered on, has faced persistent coverage challenges reaching less than 2% of all newborns until 2020 and only 21% of the 10% target coverage even in 2022 [11]. Against this backdrop, maternal knowledge represents a critical upstream determinant of participation in and acceptance of the CH screening program. This discussion critically examines the study findings across each knowledge domain, integrates them with existing theoretical frameworks and empirical evidence, and proposes evidence-based recommendations to address the identified gaps.

Knowledge of congenital hypothyroidism screening indications

The finding that 28% of respondents demonstrated poor knowledge of screening indications is a concern that warrants careful interpretation within both the individual and systemic dimensions of maternal health literacy. Screening indications refer to the circumstances and criteria that determine when and why a newborn should be screened in this case, all newborns within 48–72 hours of birth through dried blood spot (DBS) testing on filter paper. Inadequate understanding of these indications implies that a significant proportion of mothers may not recognize the universal nature of, potentially leading to the belief that screening is only necessary for symptomatic infants or those with a family history of thyroid disorders. Such misconceptions are particularly dangerous in the context of CH, as the clinical manifestations of the condition are characteristically absent or subtle at birth, and overt symptoms develop slowly due to the protective transplacental transfer of maternal thyroxine[12]. This creates a deceptive window during which parents may feel that screening is unnecessary if their newborn appears clinically healthy.

The World Health Organization (2023) emphasizes that structured and consistent maternal education is essential to ensure awareness of neonatal preventive interventions, particularly in settings where health literacy levels are variable [4]. The present findings are consistent with earlier research by Batha Tariq et al. (2018), who assessed knowledge, attitudes, and practices toward among pregnant women in Pakistan and found that the majority of mothers were unaware of CH and its implications, with education identified as a key driver of knowledge improvement [13]. The study further demonstrated that targeted health education interventions significantly improved maternal knowledge scores, reinforcing the actionability of this gap. In the Indonesian context, Pulungan et al. (2024) conducted a national cross-sectional survey on experiences and challenges with newborn screening and identified limited maternal awareness as one of the primary structural barriers to adequate screening uptake across provinces [14]. The Idanogawo findings are therefore not isolated but rather reflect a systemic pattern of inadequate knowledge dissemination that extends across Indonesia's primary healthcare landscape.

A critical dimension of this finding relates to the quality and consistency of health education delivered during antenatal care (ANC). While ANC provides the most accessible and systematic touchpoint for reaching pregnant women with health information, the content and depth of education delivered during these visits vary considerably between facilities and individual healthcare providers. A study examining maternal health literacy and ANC adherence among Indonesian pregnant women found that knowledge acquisition through ANC visits was significantly correlated with literacy levels and educational attainment, suggesting that the same information is absorbed and retained very differently depending on the recipient's socio-demographic background [15]. In communities like Idanogawo, where the majority of respondents had completed only primary or junior high school education, the assumption that standard verbal counseling during ANC visits is sufficient to achieve adequate maternal knowledge of specific screening indications may be fundamentally flawed. Healthcare providers must therefore move beyond information delivery toward active knowledge verification, using contextualized, culturally adapted, and iterative educational methods.

Knowledge of congenital hypothyroidism screening procedures

The finding that 24% of respondents had poor knowledge of screening procedures the second smallest proportion of inadequate knowledge among the three components nevertheless reflects a meaningful gap in maternal understanding of one of the most procedurally critical aspects of neonatal care. Knowledge of screening procedures encompasses awareness of when the blood sample is taken (ideally 48–72 hours after birth), how the dried blood spot sample is collected from the newborn's heel, where the sample is sent for laboratory analysis, and what the anticipated timeline for receiving results is. A mother who lacks this procedural knowledge may fail to advocate for her newborn to receive screening if it is not routinely offered, may not understand why her newborn needs to be briefly separated for sample collection, or may not follow up on results if the process is not clearly explained.

The WHO (2023) highlights that adequate parental understanding of screening procedures is a critical determinant of both participation in newborn screening programs and compliance with follow-up procedures, particularly in settings where parental anxiety about needle-based procedures may lead to refusal [4,16].This concern is amplified in rural and peri-urban settings like Idanogawo, where cultural perceptions of invasive procedures on newborns may be influenced by traditional beliefs and community practices that are not always aligned with biomedical models of newborn care. Research conducted in Indonesia on maternal health literacy in rural and remote settings has consistently shown that healthcare providers particularly midwives serve as the primary and often sole source of health information for mothers who do not have access to digital health information or formal health education programs [17,18]. This places an immense responsibility on frontline health workers to communicate procedural information clearly, repeatedly, and in language that is accessible to diverse educational backgrounds.

Furthermore, a systematic review synthesizing nine studies on health education approaches for CH screening found that parental refusal and early postnatal discharge were among the key barriers to adequate screening uptake, both of which are directly related to maternal understanding of the procedure and its timing [19]. Early discharge increasingly common in Indonesia's primary health center-based births means that the 48–72-hour optimal window for blood spot collection may be missed if mothers are not explicitly informed of this critical timing [20]. The review further identified that integrating CH education into antenatal care rather than relying solely on postnatal counseling was a more effective strategy for ensuring that mothers arrive at the delivery knowing what to expect from the screening process. This finding directly challenges the conventional approach of leaving education to the postpartum period, when mothers are cognitively and emotionally occupied with immediate postnatal concerns.

Knowledge of congenital hypothyroidism screening benefits: The most critical gap

The most significant finding of this study is the knowledge gap regarding screening benefits, with 33% of respondents categorized as having poor knowledge representing the highest proportion of inadequate knowledge among all three assessed components. This finding is particularly consequential because understanding the benefits of screening is the most powerful motivator for health-seeking behavior. According to the Health Belief Model, one of the most widely applied theoretical frameworks in health behavior research, the perceived benefits of a health action are a central determinant of whether individuals choose to engage in preventive health behaviors [10]. When mothers do not fully understand the tangible, long-term benefits of screening specifically, the prevention of intellectual disability, growth retardation, hearing impairment, and developmental delay through early detection and treatment with levothyroxine they are unlikely to be intrinsically motivated to ensure their newborn receives screening.

The clinical implications of untreated or late-detected are severe and irreversible. Rose et al. (2023) in their updated clinical practice guidelines published in Pediatrics confirm that early diagnosis through newborn screening, followed by prompt and adequate treatment, results in grossly normal neurocognitive outcomes in adulthood a stark contrast to the permanent intellectual disability associated with delayed diagnosis [12]. The European Society for Paediatric Endocrinology consensus guidelines further underscore that disability due to primary is greatest in patients not treated before the age of three months [21], making the first weeks of life the critical therapeutic window. These clinical realities should be communicated clearly and emphatically to all pregnant women as part of antenatal education. Yet the present findings suggest that a substantial proportion of mothers in Idanogawo have not internalized this message, indicating a fundamental disconnect between the evidence base for screening and its communication at the community level.

The Indonesian Ministry of Health (2022) has designated congenital hypothyroidism screening as a national strategy aimed at preventing disability due to congenital disorders, and has progressively expanded the program's reach with 11 referral laboratories as of 2022 [1]. However, as reflected in the national coverage data and corroborated by the present findings, the expansion of laboratory infrastructure has not been accompanied by proportional improvements in community-level maternal knowledge particularly regarding the benefits that justify participation. This gap between policy intent and community-level understanding represents a critical implementation failure that must be addressed through more targeted health communication strategies [22,23]. Purnama and Widyastuti (2025) demonstrated in their study at a health center in

Tangerang that structured health education interventions specifically addressing the benefits of screening significantly improved maternal knowledge scores, suggesting that the deficiency identified in the present study is not intractable but rather responsive to well-designed educational programming [24].

The finding also gains additional significance when contextualized within the existing literature on parental health literacy and its relationship to screening program outcomes. A systematic review published in the Journal of Health Promotion and Behavior (2026) found that parents with more intensive and specifically tailored educational exposure tended to develop a stronger perception of the benefits of newborn screening programs and demonstrated higher rates of follow-up compliance [10]. This aligns with the theoretical construct of 'perceived benefits' in the Health Belief Model, reinforcing the argument that benefit-focused communication should be the cornerstone of any CH screening education program. Critically, the study's finding that benefit-related knowledge was the weakest domain suggests that current health education efforts at the Idanogawo Health Center may focus disproportionately on procedural information while underemphasizing the 'why'—the compelling clinical rationale that makes participation not merely recommended but essential.

The role of socio-demographic characteristics in shaping knowledge gaps

The demographic profile of respondents in this study provides an important contextual lens through which the observed knowledge gaps can be understood. The majority of respondents (47%) had completed only junior high school education, with an additional 34% having only primary school education. Only 19% had attained senior high school level a distribution that reflects the broader educational landscape of Nias Regency and many similar rural districts in North Sumatra, where access to quality secondary education remains constrained. This educational profile is not merely a descriptive characteristic but a structural determinant of health literacy, defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [16].

Research on maternal health literacy in Indonesia has consistently demonstrated that educational attainment is one of the strongest predictors of a woman's ability to understand and act on health information. A qualitative phenomenological study on maternal health literacy among pregnant women in Indonesia found that those with lower educational backgrounds relied almost exclusively on healthcare providers as their sole source of health knowledge, making the quality and accessibility of provider communication the single most critical determinant of health knowledge outcomes in these populations [25]. This finding is directly relevant to the Idanogawo context, where the majority of respondents were housewives (78%) with limited exposure to formal or digital health information channels. When healthcare provider communication is not sufficiently adapted to the comprehension level of this population using simple language, visual aids, and repeated reinforcement the likelihood of adequate knowledge acquisition is significantly reduced.

The parity distribution in this study with 43% classified as grand multipara (three or more deliveries) might intuitively suggest a degree of familiarity with neonatal health services. However, it is important not to conflate repeated exposure to maternity services with accumulated knowledge about specific preventive programs such as CH screening. As noted in the results section, most grand multipara respondents in this study did not demonstrate higher knowledge scores compared to primipara respondents. This is consistent with evidence from the broader literature suggesting that repeated service utilization does not automatically translate into improved health knowledge if educational content is not consistently reinforced and if earlier exposures were insufficient. Regional disparities in ANC quality across Indonesia, including rural areas in North Sumatra, mean that the content and depth of maternal education vary considerably between facilities and individual service contacts [26]A grand multipara who received incomplete or minimal CH education in previous pregnancies may carry forward the same knowledge deficit into subsequent ones.

Age distribution also warrants consideration. The majority of respondents in this study were between 20–30 years of age (72%), a demographic often considered more receptive to new health information due to greater engagement with digital media and health-seeking behaviors compared to older women. However, in rural communities like Idanogawo, the digital divide significantly limits younger mothers' access to online health information. The British Journal of Midwifery (2023) study on ANC in Indonesia noted that in rural areas, low attendance at antenatal care was primarily attributed to a lack of education and economic difficulties, particularly in relation to transportation costs [27], factors which simultaneously limit both ANC utilization and exposure to health education. For young mothers in such environments, the health center may be their only reliable source of health information, making the adequacy of education delivered at these facilities particularly consequential.

Implications for health education and service delivery

The aggregated findings of this study with knowledge gaps across all three components of screening present a clear and actionable mandate for strengthening health education within the UPTD Idanogawo Health Center and similar primary health facilities serving rural and peri-urban populations in North Sumatra. The evidence base for effective health education in this domain is robust, and the systematic review by the Journal of Health Promotion and Behavior (2026) synthesizing nine relevant studies identified several high-impact strategies that are directly applicable to the Idanogawo context [10].

First, integrating structured education into routine ANC visits rather than relying on opportunistic or postnatal counseling is essential. Prenatal education has been shown to be more effective at shaping maternal attitudes and intentions toward neonatal screening than postnatal approaches, as it allows mothers to process and internalize information before the stress and cognitive demands of labor and early postnatal recovery. Specifically, education should be introduced no later than the second trimester and reinforced at each subsequent ANC contact, following the WHO-recommended model of a minimum of eight ANC contacts [20]. This reinforcement schedule is particularly important for populations with low literacy, where a single educational exposure is rarely sufficient for durable knowledge acquisition.

Second, the educational content must be explicitly benefit-focused, given that the greatest knowledge deficit identified in this study relates to the benefits of screening. Messages should go beyond describing what screening is and how it is conducted, and should directly and compellingly communicate the consequences of undetected including permanent intellectual disability, stunted growth, and developmental delay and the transformative potential of early detection and treatment. Visual communication tools, including pictorial flipcharts, illustrated brochures, and short video content in the local language, have demonstrated effectiveness in increasing health knowledge among low-literacy populations in similar Indonesian settings [28]. Leveraging community health workers (kader) and village midwives as extension educators for awareness campaigns could further extend the reach of health center-based education into households and community settings where formal health service contact is infrequent.

Third, health center staff should receive continuous and standardized training on screening communication, with particular emphasis on culturally sensitive and literacy-adaptive counseling techniques. The systematic review noted that insufficient formal training for healthcare providers remained one of the key barriers to effective screening promotion [10]. Inconsistent or incomplete provider knowledge inevitably translates to inconsistent maternal knowledge, creating a cascading knowledge deficit that is difficult to correct without structural investment in provider capacity building. The role of midwives in this regard is especially critical: as the primary frontline health workers in most primary care settings in Indonesia, midwives who are well-informed, confident, and skilled communicators about screening are uniquely positioned to close the maternal knowledge gap identified in this study.

This study makes a meaningful contribution to the empirical evidence base on maternal knowledge of CH screening in a context rural Nias Regency that remains substantially underrepresented in the published literature. By assessing knowledge across three distinct and clinically relevant components (indications, procedures, and benefits), rather than through a single composite score, the study provides a more granular and actionable diagnostic picture of where knowledge deficits are most concentrated. This component-level analysis is particularly valuable for designing targeted educational interventions, as it avoids the risk of allocating resources to address knowledge domains that are already relatively well understood while under-investing in the domains that are most deficient.

The study does, however, have limitations that should be acknowledged. The cross-sectional design precludes causal inference regarding the determinants of maternal knowledge, and the relatively small sample drawn from a single health center limits the generalizability of findings to other districts or regions in North Sumatra or Indonesia more broadly. Future research should employ larger, multi-site samples and longitudinal designs to track the impact of specific educational interventions on maternal knowledge trajectories over the antenatal-to-postnatal period. Additionally, qualitative methods such as in-depth interviews or focus group discussions would enrich understanding of the experiential barriers to knowledge acquisition that cannot be captured through structured questionnaires alone. Research exploring the influence of family support systems, spousal involvement in ANC, and community-level cultural perceptions of neonatal health practices on maternal knowledge would also be valuable for designing more holistic intervention strategies.

CONCLUSION

This study shows that many pregnant women still have inadequate knowledge regarding congenital hypothyroidism screening in newborns. Limited understanding is observed across the main aspects of screening, particularly related to its benefits, indicating that maternal awareness of the importance of newborn screening remains suboptimal. Therefore, strengthening continuous and targeted health education is necessary to improve maternal understanding and encourage participation in newborn screening programs.

Ethical consideration, competing interest and source of funding

-This study considered ethical aspects, including obtaining informed consent from respondents and ensuring the confidentiality of participants' identities. Ethical approval was obtained from the relevant ethics committee with certificate number 076/KEPK/UNPRI/1/2026, and research permission was granted by the authorized institution with letter number 500.16.7.4/0004/PMPTSP/SKP/II/2026.

-The authors declare that there are no competing interests regarding the publication.

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