



Diagnostic disclosure to parents of children with developmental disabilities: Experiences and communication preferences

Gelişimsel yetersizliği olan çocukların ebeveynlerine tanının açıklanması: Deneyimler ve iletişim tercihleri

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ABSTRACT

Aim: Communication during developmental disability diagnosis disclosure may influence parents' emotional responses, understanding, and engagement with care. This study investigated parents' experiences and preferences regarding disclosure and their evaluations of the communication behaviors of the person who initially communicated the diagnosis.

Methods: This descriptive cross-sectional web-based survey was conducted between July and November 2020 with 95 parents of children diagnosed with developmental disabilities. A semi-structured questionnaire assessed demographic characteristics, disclosure experiences and preferences, and perceived communication behaviors. Findings were summarized using descriptive statistics.

Results: The most common diagnoses were Down syndrome (22.1%), cerebral palsy (17.9%), and intellectual disability/developmental delay (16.9%). Most parents reported physician-led disclosure (73.7%), whereas 93.7% preferred disclosure by a physician. More than half received the diagnosis in a crowded or shared room (52.6%), while 93.7% preferred a private room. In addition, 31.6% reported receiving inadequate information about their child's medical condition and treatment, and 35.8% stated that the person who initially communicated the diagnosis did not adequately recognize their emotional distress.

Conclusion: Group-level distributions of reported experiences and stated preferences differed descriptively across several aspects of disclosure. The findings indicate areas requiring attention, particularly privacy, information provision, and emotional sensitivity. Because individual-level concordance was not analyzed, these results should not be interpreted as demonstrating within-parent mismatch. Improving privacy, empathy, clarity of information, and post-diagnostic guidance may enhance parental satisfaction and support engagement with care.

Keywords: clinical competence; communication; developmental disability; developmental disorders; diagnostic disclosure

ÖZ

Amaç: Gelişimsel tanıların bildirilmesi sırasında kurulan iletişim, ebeveynlerin duygusal tepkilerini, tanıyı anlamalarını ve bakıma katılımlarını etkileyebilir. Bu çalışma, ebeveynlerin tanı bildiriyle ilgili deneyim ve tercihlerini ve tanıyı ilk açıklayan kişinin iletişim davranışlarına ilişkin değerlendirmelerini incelemeyi amaçlamıştır.

Yöntem: Bu tanımlayıcı kesitsel web tabanlı anket çalışması, Temmuz-Kasım 2020 tarihleri arasında gelişimsel yetersizlik tanısı almış çocukların 95 ebeveyniyle yürütülmüştür. Demografik özellikler, tanı bildiri deneyimleri ve tercihleri ile algılanan iletişim davranışları yarı yapılandırılmış bir anketle değerlendirilmiştir. Bulgular tanımlayıcı istatistiklerle özetlenmiştir.

Bulgular: En sık görülen tanılar Down sendromu (%22.1), serebral palsy (%17.9) ve zihinsel yetersizlik/gelişimsel gecikme (%16.9) idi. Ebeveynlerin %73.7'si tanının bir hekim tarafından bildirildiğini, %93.7'si ise hekim tarafından bildirilmesini tercih ettiğini belirtmiştir. Ebeveynlerin %52.6'sı tanıyı kalabalık veya paylaşımlı bir odada alırken, %93.7'si özel bir oda tercih etmiştir. Ayrıca %31.6'sı çocuklarının tıbbi durumu ve tedavisi hakkında yetersiz bilgi aldığını, %35.8'i ise tanıyı ilk açıklayan kişinin duygusal sıkıntılarını yeterince fark etmediğini bildirmiştir.

Sonuçlar: Bildirilen deneyim ve belirtilen tercihlere ait grup düzeyindeki dağılımlar, tanı bildiriminin çeşitli yönlerinde betimsel farklılıklar göstermiştir. Bulgular özellikle mahremiyet, bilgi sunumu ve duygusal duyarlılık açısından geliştirilmesi gereken alanlara işaret etmektedir. Bireysel düzeyde uyum analiz edilmediğinden, sonuçlar ebeveynlerin kendi deneyimleri ile tercihleri arasında bireysel uyumsuzluk bulunduğu şeklinde yorumlanmamalıdır. Mahremiyet, empati, bilginin açıklığı ve tanı sonrası yönlendirmenin geliştirilmesi ebeveyn memnuniyetini ve bakıma katılımı destekleyebilir.

Anahtar kelimeler: gelişimsel bozukluklar; gelişimsel yetersizlik; iletişim; klinik yeterlilik; tanı açıklama

Introduction

Effective communication is a core component of healthcare practice and plays an important role in families' understanding of diagnosis, engagement with services, treatment adherence, and satisfaction with care (Levetown, 2008). In pediatric and developmental disability settings, communication often involves emotionally sensitive issues such as uncertainty, prognosis, long-term care needs, family expectations, and access to intervention services (Fallowfield & Jenkins, 2004; Ptacek & Eberhardt, 1996). Within this context, the disclosure of a child's developmental diagnosis requires not only accurate

information but also empathy, family-centeredness, cultural sensitivity, and continuity of support.

The term breaking bad news has traditionally been used in adult medicine, particularly in oncology and palliative care, to describe the communication of information that may negatively affect a person's expectations about the future (Buckman, 1992; Harrison & Walling, 2010). Similarly, communication protocols such as SPIKES and ABCDE were originally developed primarily for adult clinical contexts and were later adapted for pediatric and developmental disability settings (Baile et al., 2000; VandeKieft, 2001). Therefore, when these



frameworks are applied to childhood developmental diagnoses, their adult-origin background and subsequent adaptation to family-centered pediatric care should be acknowledged. Novak et al. (2019) adapted the SPIKES framework for communicating childhood disability diagnoses to parents and emphasized the importance of honest, individualized, hopeful, and action-oriented communication. Similarly, the Kennedy Krieger Institute resource guide highlights preparation before disclosure, compassionate communication during diagnosis delivery, culturally responsive practice, and structured post-diagnostic support for families (Maryland Center for Developmental Disabilities at Kennedy Krieger Institute, 2021).

Previous research indicates that parents' satisfaction with developmental disability diagnosis disclosure is shaped by the clarity, amount, and quality of information provided, as well as professionals' directness, empathy, communication skills, and sensitivity to parental concerns (Hasnat & Graves, 2000). Studies on cerebral palsy similarly show that delayed diagnosis, insufficient information, and limited support are associated with greater dissatisfaction, whereas clear communication, private settings, written information, early follow-up, and referral to services are recommended as good-practice elements (Baird et al., 2000; Dagenais et al., 2006). More recent literature has moved beyond understanding parents' reactions only through a crisis or burden framework. Although parents may experience distress, uncertainty, grief, guilt, or concerns about the future, their responses also involve adaptation, meaning-making, resilience, and active efforts to support their child. Studies on parental resolution and acceptance indicate that adjustment to a child's diagnosis is a dynamic and ongoing process influenced by knowledge, uncertainty, emotional responses, social support, cultural beliefs, access to services, and continuing interactions with professionals (Naicker et al., 2023; Sher-Censor & Shahar-Lahav, 2022). Therefore, the initial disclosure should be understood as an important component of a broader family adaptation process rather than as the sole determinant of long-term parental adjustment.

Overall, the international literature shows that developmental disability diagnosis disclosure has been examined in specific conditions such as cerebral palsy, autism spectrum disorder, Down syndrome, intellectual disability, and other developmental disabilities (Dent & Carey, 2006; Sheets et al., 2012; Waxler et al., 2013). However, the existing evidence remains relatively fragmented because studies often focus on single diagnostic groups, use different methodological approaches, and are conducted within specific healthcare and sociocultural contexts. In the Turkish context, research directly examining how parents receive developmental diagnoses, who communicates the diagnosis, where disclosure takes place, and how the group-level distribution of these experiences compares with the distribution of parental preferences remains comparatively limited. Therefore, the present study investigates how parents of children with developmental disabilities experienced the disclosure of their child's diagnosis, focusing on by whom, where, and under what circumstances the diagnosis was communicated. Additionally, the study evaluates parents' perceptions of healthcare professionals' communication skills during the diagnostic disclosure process. By examining parents' actual experiences together with their preferences regarding the person, setting, and manner of

disclosure, this study aims to contribute to the development of more family-centered and context-sensitive communication practices in developmental disability services. Accordingly, this study addresses the following research question: How do parents of children with developmental disabilities experience the process of developmental disability diagnosis disclosure, and how do the group-level distributions of their reported experiences compare with the distributions of their stated preferences regarding the person, setting, and manner of communication?

Methods

Design and participants

This cross-sectional, web-based descriptive study was conducted between July and November 2020, during the COVID-19 pandemic, in three special education and rehabilitation centers. The target population consisted of parents of children receiving services at these centers during the data collection period. Eligible participants were mothers or fathers aged 18 years or older who had a child enrolled in one of the participating centers, were able to read Turkish, and provided electronic informed consent. No predefined age restriction was applied to the children; eligibility was based on enrollment in one of the participating centers during the study period. Individuals who were not the child's mother or father, were younger than 18 years, did not provide informed consent, or did not complete the questionnaire were excluded from the final analysis. Participants were instructed/requested that only one parent per child respond. Diagnostic information was obtained from the clinical or administrative records maintained by the participating centers. The diagnoses had previously been established by the relevant physicians or clinical teams and were not reassessed by the research team. A convenience sampling approach was used. All eligible parents who could be reached during the data collection period were invited to participate. A formal sample size calculation based on a known population was not performed because the study was exploratory and aimed to include all accessible eligible parents within the three predefined centers. A total of 108 parents were invited, and 95 completed the questionnaire. The diagnostic categories were grouped operationally because all children had childhood-onset conditions associated with developmental or functional support needs and were receiving services within the same special education and rehabilitation context. This grouping was not intended to imply a shared etiology, diagnostic pathway, age of diagnosis, or disclosure process across conditions. The study focused on broad, service-level experiences of diagnostic disclosure rather than diagnosis-specific clinical pathways.

The questionnaire link was not disseminated through public social media announcements. Because face-to-face data collection was restricted during the COVID-19 pandemic, physiotherapists working at the participating centers shared the link only with eligible parents through center-based WhatsApp groups or direct messages. Thus, access was restricted to parents of children registered at the three participating centers. Before accessing the questionnaire, potential participants were presented with electronic participant information and informed consent form explaining the purpose of the study, the voluntary nature of participation, and their right to discontinue the questionnaire before submission. Only participants who provided electronic informed consent were allowed to proceed.

No directly identifying information, such as names, telephone numbers, or email addresses, was collected, and responses were recorded anonymously. No technical restriction was used to prevent multiple submissions; however, participants were instructed to submit only one response, and the dataset was reviewed for apparent duplicate records before analysis. After data collection, the responses were downloaded and stored on a password-protected computer accessible only to the research team. The data were not shared with individuals outside the research team.

Measures

The questionnaire was developed by the research team based on a review of the literature on diagnostic disclosure, pediatric communication, communication of difficult clinical information, and parents' experiences of receiving a developmental disability diagnosis. Its general structure was informed by Krauss-Mars and Lachman (Krauss-Mars & Lachman, 1994), which is one of the foundational studies examining disclosure experiences among parents of children with disabilities. Since there is no widely accepted standardized instrument specifically designed to assess diagnostic disclosure experiences in this context, similar studies commonly use researcher-developed semi-structured questionnaires or interview schedules based on literature review and expert input. Accordingly, the questionnaire items in the present study were structured to cover key domains emphasized in the literature, including who communicated the diagnosis, when and where the diagnosis was communicated, whether the parent was alone or accompanied, the adequacy and clarity of information, the opportunity to ask questions, the empathic attitude of the healthcare professional, and perceived recognition of parental emotional distress. The English translation of the original Turkish preferred-timing item was: "When would you have preferred to be informed about your child's diagnosis?" The response options were "during pregnancy," "within 0–1 year after birth," "when the child was 1–3 years old," "when the child was 3–6 years old," and "after the child was 6 years old." The item assessed a retrospective and hypothetical preference regarding the timing of disclosure. It did not assess whether prenatal diagnosis was clinically feasible for the child's specific condition or distinguish prenatal diagnosis from disclosure at the earliest clinically possible time. The questionnaire was reviewed by a senior researcher with expertise in the field for content relevance and clarity before data collection. The questionnaire consisted of three sections:

- Demographic Information: Parent age, gender, education level, occupation, number of children, and child characteristics.
- Clinical Information and Diagnostic Disclosure Experiences: Source, timing, setting, accompaniment status, and parental preferences regarding diagnostic disclosure.
- Communication Skills Assessment: Parent perceptions of healthcare professionals' communication skills during diagnostic disclosure.

Statistical analysis

Statistical analysis was performed using SPSS version 20.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used to summarize demographic, clinical, and diagnostic disclosure-related characteristics. Continuous variables were presented as mean and standard deviation, while categorical variables were presented as frequencies and percentages. Experience and preference responses were summarized as separate

group-level frequency distributions. Individual-level concordance between each participant's reported experience and stated preference was not examined.

Ethical disclosures

The study protocol adhered to the principles of the Declaration of Helsinki, and ethical approval was obtained from the İstinye University Health Sciences Research Ethics Committee (Protocol ID: 57, Date: June 25, 2020).

Results

A total of 108 parents were approached, and 95 completed the questionnaire. The children's mean age was 7.79 ± 4.35 years, and the majority were male (62.1%). Most parents were mothers (95.8%) with a mean age of 36.2 ± 7.4 years. Detailed demographic and clinical characteristics of parents and children are presented in Table 1.

Table 1. Demographic characteristics of the parents and children

Characteristics	Mean (SD) / n (%)
Children's age (years)	7.79±4.35
Children's gender (F/M)	36 (37.9) / 59 (62.1)
Respondent's age (years)	36.2±7.4
Respondent's gender (F/M)	91 (95.8) / 4 (4.2)
Number of children	
1	25 (26.3)
2	44 (46.3)
3	19 (20)
4	5 (5.3)
5	2 (2.1)
Birth order of disabled children	
1	59 (62.1)
2	21 (22.1)
3	11 (11.6)
4	4 (4.3)
Respondent's educational level	
Primary school	20 (21.1)
Secondary school	34 (35.8)
High school	34 (35.8)
University	7 (7.4)
Relationship to child	
Mother	91 (95.8)
Father	4 (4.2)
Monthly household income	
Below the national poverty threshold (<2300 Turkish Liras)	16 (16.8)
Above the national poverty threshold (>2300 Turkish Liras)	79 (83.2)
Diagnosis	
Down syndrome	21 (22.1)
Cerebral palsy	17 (17.9)
Intellectual disability/developmental delay	16 (16.9)
Autism	11 (11.6)
Brachial plexus injury	8 (8.4)
Neuromuscular diseases (DMD, SMA)	5 (5.3)
Spina bifida	3 (3.2)
Others (Williams syndrome, etc.)	14 (14.8)
The period of treatment in the special education and rehabilitation centre (year)	5.03±2.99
Time elapsed since diagnostic disclosure (years)	4.97 ± 3.57

F: Female; M: Male; SD: Standard Deviation.

Experiences and preferences regarding diagnostic disclosure

Parents' reported experiences and stated preferences regarding the diagnostic disclosure process are presented in Table 2. At the group level, 73.7% reported physician-led disclosure, whereas 93.7% preferred physician-led disclosure.

Similarly, 52.6% reported receiving the diagnosis in a crowded or shared room, whereas 93.7% preferred a private room; 62.1% reported that a family member was present, whereas 89.5% preferred family presence. These findings represent separate group-level frequency distributions and do not indicate within-participant concordance.

Table 2. Parents' reported experiences and stated preferences regarding the diagnostic disclosure process (n=95)

Characteristics	Experience n (%)	Preference n (%)
Person communicating the diagnosis		
Physician	70 (73.7)	89 (93.7)
Physiotherapist	8 (8.4)	0 (0.0)
Spouse/relative	6 (6.3)	5 (5.3)
Teacher	5 (5.3)	1 (1.1)
Other	6 (6.3)	0 (0.0)
Timing of diagnostic disclosure		
During pregnancy	15 (15.8)	49 (51.6)
0–1 years	42 (44.2)	36 (37.9)
1–3 years	24 (25.3)	4 (4.2)
3–6 years	4 (4.2)	2 (2.1)
>6 years	10 (10.5)	4 (4.2)
Setting of diagnostic disclosure		
Crowded/shared room	50 (52.6)	2 (2.1)
Private room	37 (38.9)	89 (93.7)
Other	8 (8.4)	4 (4.2)
Accompaniment during diagnostic disclosure		
With a family member	59 (62.1)	85 (89.5)
Alone	36 (37.9)	10 (10.5)

Data are presented as n (%). Experience and preference responses are presented as separate group-level frequency distributions and do not represent within-participant agreement or mismatch.

Communication skills of healthcare professionals

Parents' evaluations of healthcare professionals' communication skills during the diagnostic disclosure process are presented in Table 3. Thirty parents (31.6%) reported that they did not receive adequate information about their child's medical condition or treatment. 35.8% felt that healthcare professionals did not adequately recognize or respond to their emotional distress. While most parents (86.3%) reported being able to ask questions, 34.7% found the explanations difficult to understand, and 28.4% stated that some statements made by healthcare professionals were hurtful.

Discussion

This study examined parents' experiences and preferences regarding the disclosure of developmental diagnoses in their children. At the group level, the distributions of reported experiences and stated preferences showed descriptive differences, particularly regarding the professional communicating the diagnosis, the disclosure setting, and the

presence of a family member. These comparisons do not establish within-participant mismatch because individual-level concordance was not analyzed. Separately, some parents reported limitations in the clarity of information, information provision, and professionals' recognition of parental emotional distress. The findings concerning the preferred timing of diagnostic disclosure require cautious interpretation. The conditions represented in this study differ substantially in their etiology, diagnostic pathways, age at which a reliable diagnosis can be established, and availability of prenatal testing. Prenatal identification is therefore not clinically feasible for all diagnostic groups included in the sample. In addition, the questionnaire item did not distinguish a preference for prenatal diagnosis from a preference for receiving information at the earliest clinically possible time. Accordingly, selection of the "during pregnancy" response category should be interpreted as a retrospective and hypothetical preference for earlier information rather than as evidence that prenatal diagnosis was feasible or should have been provided for every condition represented in the study.

The person communicating the diagnosis

In the present study, most parents reported that their child's diagnosis was communicated by a physician; however, the preference for physician-led disclosure was even higher. This may reflect parents' expectation that the professional communicating the diagnosis should provide reliable information, explain the condition clearly, and guide families regarding prognosis, treatment, rehabilitation, and available services. This aligns with previous studies linking parental satisfaction with disclosure to information quality, professional sensitivity, and communication skills (Baird et al., 2000; Dagenais et al., 2006; Hasnat & Graves, 2000).

Recent studies similarly emphasize that parents need honest and clear information, good communication skills, and emotional and practical support after diagnosis (van der Kemp et al., 2024). Miller et al. (2025) also reported that, although many caregivers perceived healthcare providers as sympathetic and clear, relatively few were directed to reliable information sources or informed about their child's strengths and future possibilities. Therefore, parents' preference for physician-led disclosure should not be interpreted solely as a preference for professional hierarchy, but as a broader need for trustworthy, comprehensive, and action-oriented communication. Although parents in the present study strongly preferred physician-led disclosure, the quality of the disclosure process depends not only on who communicates the diagnosis, but also on how the diagnosis is communicated and what support is provided afterwards. Novak et al. (2019) emphasize that communicating a childhood disability diagnosis

Table 3. Parents' assessments of the communication behaviors of the person who communicated the diagnosis

Communication behavior	Yes, n (%)	No, n (%)
Remembered the name of the person who communicated the diagnosis	59 (62.1)	36 (37.9)
Described the person as kind and concerned	70 (73.7)	25 (26.3)
The person recognized the parent's emotional distress	61 (64.2)	34 (35.8)
Was able to ask the person questions	82 (86.3)	13 (13.7)
Found the person's explanations understandable	62 (65.3)	33 (34.7)
Reported hurtful statements by the person	27 (28.4)	68 (71.6)
Received satisfactory information about the child's medical condition and treatment	65 (68.4)	30 (31.6)
Received satisfactory answers to questions	61 (64.2)	34 (35.8)

Data are presented as n (%). Participants evaluated the person who initially communicated the diagnosis. All items were answered by 95 participants, and percentages were calculated using n = 95.

should be a structured, family-centered process that includes preparation, honest and individualized information, empathic responses to parental emotions, practical guidance, follow-up, and referral to early intervention and support services. Similarly, Church et al. (2025) highlight the importance of coordinated communication involving medical providers and therapy teams to provide consistent information, answer parents' questions, and guide families to reliable resources. Therefore, while physician-led disclosure was strongly preferred in this study, the overall disclosure process should be supported by an interdisciplinary and continuous care pathway.

Setting, privacy, and family presence during diagnostic disclosure

One of the largest descriptive contrasts between the group-level distributions of reported experiences and stated preferences concerned the setting in which the diagnosis was communicated. More than half of the parents reported that the diagnosis was communicated in a crowded or shared room, whereas most preferred disclosure in a private room. This finding is consistent with recommendations that diagnostic disclosure should occur in a quiet, private, and prepared environment where interruptions are minimized and sufficient time is allowed for parents to process the information (Novak et al., 2019). Similar concerns have also been reported in cerebral palsy disclosure, where some parents described being informed abruptly, alone, or without adequate consideration of their feelings (Baird et al., 2000). In pediatric communication more broadly, Zanon et al. (2020) emphasized that the context of communication, emotional responses, language, and communication "noise" can influence how difficult information is received. Similarly, Geal-Dor and Adelman (2018) highlighted the importance of an appropriate setting, sensitivity to cultural and language differences, and the availability of an interpreter when needed in the disclosure of childhood hearing loss.

In the present study, most parents also preferred having a family member present during diagnostic disclosure. This suggests that privacy should not be equated with receiving the diagnosis alone; rather, it should mean receiving the diagnosis in a protected environment with the support persons preferred by the parent. This interpretation is supported by Bullock et al. (2026), who reported that parents of children with rare genetic diseases wanted providers to ask where results should be given and whether other family members should be included. In Türkiye and similar family-oriented sociocultural contexts, family members may also have an important role in care, communication, and health-related decision-making. Previous literature on Turkish cultural contexts has reported that family members often assume a central role in care, communication, and decision-making during serious illness, and that Turkish physicians may involve family members more frequently during difficult diagnostic conversations (Kizilhan & Ag, 2024). Therefore, clinicians should not assume a single ideal model for disclosure, but should directly ask parents whether they would like someone to accompany them and individualize the disclosure process according to parental preference, cultural context, and emotional readiness.

Informational and emotional needs during diagnostic disclosure

The findings of the present study also highlight important unmet informational and emotional needs during diagnostic disclosure. Nearly one-third of parents reported that they did

not receive satisfactory information about their child's condition and treatment, and more than one-third felt that healthcare professionals did not adequately recognize their emotional distress. Recent studies further suggest that parents need not only diagnostic information, but also practical guidance about what to do next. Miller et al. (2025) reported that only a minority of caregivers recalled being directed to reliable information sources or being told about their child's strengths and future possibilities. Similarly, van der Kemp et al. (2024) identified transparent information, a supportive professional attitude, and parental involvement in the disclosure process as key needs of parents receiving a cerebral palsy diagnosis. In rare genetic disease and Williams syndrome literature, parents also emphasized the importance of written information, realistic hope, information about quality of life and medical management, and connection with other families (Bullock et al., 2026; Waxler et al., 2013). Taken together, these findings suggest that diagnostic disclosure should balance accurate information with emotional sensitivity and practical direction. Parents may need information to be repeated, written down, and linked to concrete next steps such as rehabilitation, early intervention, social support, and reliable resources. Therefore, professionals should avoid overly technical or deterministic language, acknowledge parents' emotional responses, and provide balanced information that includes both possible challenges and the child's strengths and developmental potential.

The present study contributes to the literature by examining diagnostic disclosure across a heterogeneous group of developmental disabilities rather than focusing on a single diagnostic category. While previous studies have often addressed specific conditions such as cerebral palsy, autism spectrum disorder, Down syndrome, Williams syndrome, or rare genetic diseases, this study provides data on parents of children with different developmental disabilities within the same healthcare and rehabilitation context. In addition, by presenting parents' reported experiences alongside their stated preferences, the study identifies areas in which the group-level distributions differ descriptively, including the professional communicating the diagnosis, timing, setting, and family presence. The study also identifies reported concerns regarding information quality and emotional sensitivity.

These findings suggest that developmental disability diagnosis disclosure should be approached as a structured, family-centered, and continuing communication process. Healthcare professionals should prepare an appropriate private setting, ask parents whether they would like a family member or support person to be present, communicate the diagnosis clearly and sensitively, and provide written and reliable information about the condition, treatment options, rehabilitation services, and next steps. Disclosure should also include referral to early intervention, psychosocial support, and family support resources when needed. These practices may make diagnostic disclosure more responsive to the preferences commonly reported by parents in this sample and support more family-centered communication in developmental disability services.

Several limitations should be considered. First, the study used convenience sampling and included parents from only three rehabilitation centers. No formal sample size calculation based on a known population was performed; therefore, the findings should be regarded as exploratory and may not be

generalizable to all parents of children with developmental disabilities in Türkiye. In addition, data were collected through an online questionnaire during the COVID-19 pandemic, which may have restricted participation to parents who could be reached digitally through the participating centers.

Second, the findings were based on retrospective parental reports. The mean time elapsed since diagnostic disclosure was 4.97 ± 3.57 years, and responses may therefore have been influenced by recall bias, subsequent healthcare and rehabilitation experiences, changes in the child's developmental status, and the parents' current psychological state.

Third, the study used a non-standardized questionnaire that was not formally pilot-tested with parents. Although the questionnaire was developed based on relevant literature and reviewed by a senior researcher for content relevance and clarity, the absence of a validated instrument may have introduced measurement variability. Furthermore, experience and preference responses were summarized as separate group-level distributions; therefore, within-participant concordance could not be determined. The preferred-timing item also did not distinguish between a preference for prenatal diagnosis and a preference for receiving information at the earliest clinically possible time, nor did it assess whether prenatal identification was medically feasible for each condition. Accordingly, responses in the "during pregnancy" category should be interpreted as retrospective and hypothetical preferences rather than as support for prenatal diagnostic disclosure across all conditions represented in the sample. The diagnostic heterogeneity of the sample represents an additional limitation. The conditions included in the study differ in etiology, age of onset, diagnostic pathway, diagnostic certainty, and the feasibility and timing of disclosure. Consequently, the pooled results should not be interpreted as representing a uniform disclosure process applicable to every diagnostic group. In addition, 95.8% of respondents were mothers; therefore, the findings primarily reflect maternal perspectives rather than a balanced representation of mothers' and fathers' views.

Conclusion

At the group level, parents more frequently preferred physician-led disclosure, a private setting, and the presence of a family member than reported experiencing these conditions. These findings represent group-level differences and do not demonstrate within-participant mismatch. The preferred-timing results should also be interpreted cautiously, as the "during pregnancy" response may reflect a retrospective preference for earlier information rather than the clinical feasibility of prenatal diagnosis across all conditions. Overall, diagnostic disclosure should be a structured, family-centered process that includes clear and sensitive communication, privacy, preferred family support, reliable information, and appropriate referral to relevant services.

Ethics Committee Approval

Ethics committee approval was obtained from İstinye University Health Sciences Research Ethics Committee (Protocol ID: 57) on June 25, 2020.

Informed Consent

Informed consent was obtained from all participants prior to participation.

Peer-Review

Externally peer-reviewed.

Author Contributions

Z.Y.: Conceptualization, Methodology, Data Curation, Formal Analysis, Investigation, Writing Original Draft, Writing – Review & Editing.

İ.Y.: Conceptualization, Supervision, Resources, Formal Analysis, Writing – Review & Editing.

Conflict of Interest

There is no conflict of interest.

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