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Diagnostic communication by healthcare professionals: “One doctor set my sun; another doctor made it rise again”

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ABSTRACT

Receiving a chronic, unexpected and unpredictable diagnosis is a turning point that fundamentally changes people's lives. Diagnostic communication is often treated as an individual clinical skill, yet growing evidence suggests that it is shaped by hierarchical, biomedical, and paternalistic structures that may exacerbate emotional distress, particularly for mothers receiving disability diagnoses for their children. This research aims to examine the impact of healthcare professionals' practices in delivering diagnoses on mothers' in-depth subjective experiences of the moment of diagnosis and its aftermath, their processes of meaning-making, and their relationships with the healthcare system. A qualitative research design was employed; in-depth semi-structured interviews were conducted with mothers of children diagnosed with Down syndrome in Turkey to explore their diagnostic experiences and post-diagnosis trajectories, and the data were analysed using thematic analysis. The findings revealed that the initial shock and emotional collapse experienced at the time of diagnosis, information gaps, uncertainty, and fear, stigmatisation, social exclusion, and concerns about the future, as well as the non-linear nature of the acceptance process, were the main themes. Furthermore, the findings show that the language and approach used by healthcare professionals in diagnostic communication play a decisive role in mothers; therefore, the traumatising role of healthcare professionals in diagnostic communication and the empowering effect of professional and supportive diagnostic communication emerged as other main themes. In conclusion, the research emphasises that diagnostic communication is not merely a matter of individual communication skills but rather an institutionalised infrastructure that reflects the values, priorities, and power relations of the healthcare system.

KEYWORDS: diagnostic communication; Down syndrome; maternal experiences; qualitative research.

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INTRODUCTION

Receiving a chronic, unexpected, and unpredictable diagnosis is a turning point that fundamentally transforms people's lives [1], [2], [3], [4], [5]. The life-altering nature can be emphasised: “the diagnosis operates, in the majority of cases, as a ‘before and after’ in the life of the subject” [6]. In other words, the diagnosis prompts a fundamental re-evaluation of life's meaning and priorities and can cause significant distress, disrupting an individual’s sense of meaning in life and purpose in living [7]. Indeed, the person receiving the diagnosis (generally patients and/or their partners/families, etc.) can directly recall the diagnostic statements made by healthcare professionals, emphasising the emotional impact of these words [2]. As a result, healthcare professionals' diagnostic approach can increase the person receiving the diagnosis's distress, becoming an additional source of trauma [8].

Emotional responses to diagnostic communication were consistently described in severe terms across clinical contexts. Common emotional responses include shock [9], denial [10], anger [11], fear, despair, and a sense of loss of control [12]. The person receiving the diagnosis reports profound distress [8], biographical disruption [8], and feeling emotionally and physically abandoned [13]. Although the diagnostic communication process is often reduced to the attitudes of medical authorities, it should, in fact, be considered a structural practice shaped by the hierarchical, specialist-centred, and autonomy-limiting organisational form of the healthcare system and the prevailing medical discourse. In this sense, from a medical authority's perspective, presenting a diagnosis is not merely a technical act of informing, but rather an arena in which the power relations established by the healthcare system with the person receiving the diagnosis and their relatives are concretised. In this context, diagnostic communication requires greater empathy and awareness of the psychosocial impact [2], and emerges not merely as a clinical act but as a deeply institutionalised social practice that demands ethical, organisational, and policy-level transformation.

Indeed, healthcare professionals can maintain conversational dominance through multiple mechanisms. For example, in diagnostic communication, healthcare professionals speak 83% of the total time while the person receiving the diagnosis speaks only 10% [14]. This dominance can be further reinforced through linguistic strategies, such as the preferential use of first-person plural pronouns and technical terminology, and shapes both the framing and interpretation of diagnostic information [14]. Also, controlling information flow through medical jargon and selective disclosure, which subtly aligns medical authority with institutional legitimacy while marginalising patients’ voices. Such diagnostic communication practices concretise broader hierarchical relations embedded within healthcare systems, and emotional and social dimensions are neglected [15], [16]. Beyond conversational dominance, healthcare professionals exercise power through information gatekeeping. Healthcare professionals decide what information to disclose and when; this selective disclosure reflects provider-determined assessments of what the person receiving the diagnosis “should” know rather than their preferences for information [17]. Consequently, despite having significant information needs, people receiving the diagnosis frequently report that these needs remain unmet [2], [11]. In other words, although information needs are prominent for the person receiving the diagnosis, they are often unmet [2], [11]. This inadequacy compounds emotional distress and contributes to persistently low levels of perceived support and information [18], [19], [20], [21]. Despite policy-level commitments to patient-centred care and shared decision-making, empirical evidence indicates that diagnostic communication remains predominantly paternalistic in practice [20], [23]. This practice led to a quick diagnosis delivery within biomedical frameworks that neglect emotional responses and social context [15]. Such practices not only intensify emotional distress but also risk reinforcing learned helplessness and deference, thereby obstructing pathways toward self-empowerment and psychosocial well-being [24].

In particular, careful execution of this process is even more essential in certain situations and diagnoses, because some diagnoses profoundly and permanently affect people's lives. For instance, informing to parents that their child will be children with intellectual disability is not merely information; but also a critical turning point that fundamentally transforms the future outlook by producing lifelong social, emotional, and care-based consequences for the parents and the concerned child, necessitates the reorganisation of roles within the family, and essentially transfers the responsibility of care to the family, often to the mother [25], [26], [27], [28]. Therefore, the language, approach, and communication style used in presenting the diagnosis directly shape not only the transfer of information but also the parents' processes of understanding, accepting, and coping with the situation [29], [30], [31]. Indeed, mothers disproportionately bear the emotional and practical burden of the diagnosis process due to gender-based caregiving responsibilities [28], [32]. In general, mothers are attributed to as “natural caregivers” who are also expected to be emotionally resilient in the presentation of diagnosis, rendering their vulnerability invisible and weakening support mechanisms [33], [34], [35].

This research aims to examine the consequences of communication about disability diagnoses with mothers within the context of the structural and discursive characteristics of the healthcare system, rather than focusing on people's communication skills. Through qualitative analysis based on mothers' narratives, it examines how healthcare professionals' diagnostic communication practices are institutionalised by the healthcare system and the prevailing medical discourse, how they shape mothers' experiences, and under what conditions they lead to restorative or traumatic effects. The research aims to open up a discussion on diagnostic communication as a fundamental ethical and policy area that requires transformation within the healthcare system.

METHODOLOGY

Research Design

This research is based on a qualitative design and aims to examine the impact of healthcare professionals' practices in delivering diagnoses on mothers' in-depth subjective experiences of the moment of diagnosis and its aftermath, their processes of meaning making, and their relationships with the healthcare system. In other words, it examines the prevailing medical discourse, how it shapes mothers' experiences, and under what conditions it produces restorative or traumatic effects, through qualitative analysis of mothers' narratives. Therefore, semi-structured in-depth interviews and thematic analysis were adopted. These methods enable the examination of the meanings individuals attribute to their experiences within a social and institutional context. The research's outcomes aim to open a discussion on diagnostic communication as a fundamental ethical and policy area that requires transformation within the healthcare system.

Participants and Sampling

The participants in the research were mothers who learned about an unexpected diagnosis concerning their babies during the prenatal or postnatal period through healthcare professionals. Specifically, mothers who learned that their children would have Down syndrome were interviewed. The reason for this is that a Down syndrome diagnosis is a critical turning point that profoundly transforms future expectations, necessitates the reorganisation of roles within the family, and often transfers caregiving responsibilities to the mother, with lifelong social, emotional, and care-based consequences for both parents and children [25], [26], [27], [28].

The sample was determined using purposive sampling. This method aims to reach participants who have personally experienced the diagnosis presentation and are directly related to the research content. Participants were selected to exhibit diversity in terms of age, educational level, socioeconomic status, and time elapsed since diagnosis. This diversity was considered to reveal how interactions with the healthcare system are experienced in different contexts.

Participants were eligible to take part if they were the birth mother (18 years+) of a child with Down syndrome 2 years or older. Participants were eligible if they were living in Turkey during their pregnancy and after. The children's ages ranged from 2 to 35, while the mothers' ages ranged from 35 to 60. The fact that the children's ages ranged from 2 to 35 and the mothers' ages ranged from 35 to 60 allowed the research to encompass experiences across different life stages. The research, conducted with 15 participants, contributed to the collection of in-depth and detailed data.

Procedure

Recruitment consists of mothers who bring their children with Down syndrome to education at two different special education and rehabilitation centres in Istanbul. Data were collected through semi-structured in-depth interviews. The interview guide was designed to cover the form of communication at the time of diagnosis, the language used by health professionals, the mothers' initial emotional responses, their experiences of accessing information, and the processes of meaning-making that developed over time. The interviews were conducted in environments where participants felt safe; they were audio-recorded with the participants' consent. Each interview lasted an average of 60–90 minutes.

Analysis

The collected data were analysed using Braun and Clarke's (2006) thematic analysis approach [36]. The analysis process consisted of the following stages:
(1) familiarisation with the data,
(2) creation of initial codes,
(3) identification of themes,
(4) review of themes,
(5) naming and defining themes,
(6) reporting the findings.

The analysis process considered not only individual experiences but also how these experiences related to the discursive and institutional structures of the healthcare system. Therefore, the coding and theme development process was conducted in dialogue with critical health studies and disability literature.

Ethical Considerations

Ethical considerations were strictly adhered to throughout the research process. Ethical approval was granted by the University of Bogazici Institutional Review Board in Social Sciences and Humanities. Participants were provided with detailed information about the purpose, scope, and principles of voluntariness of the research; written and verbal informed consent was obtained. Participants' identities were kept confidential, and interview recordings were anonymised. Given that the diagnosis process is an emotionally sensitive experience, participants' boundaries were respected during interviews, and it was clearly stated that they could terminate the interview at any time.

Reliability and Validity

Multiple strategies were employed to enhance the reliability and validity of the research. The participant's voice was made visible by directly including interview excerpts, ensuring researcher reflexivity in the analysis process, and systematically documenting the coding process. Furthermore, the consistency and conceptual clarity of the themes were reviewed through discussions with researchers experienced in qualitative research.

FINDINGS

This section presents findings from in-depth interviews conducted with mothers of children diagnosed with Down syndrome. The findings revealed that the initial shock and emotional collapse experienced at the time of diagnosis, information gaps, uncertainty, and fear, stigmatisation, social exclusion, and concerns about the future, as well as the non-linear nature of the acceptance process, were the main themes. Furthermore, the findings show that the language and approach used by healthcare professionals in diagnostic communication play a decisive role in mothers; therefore, the traumatising role of healthcare professionals in diagnostic communication and the empowering effect of professional and supportive diagnostic communication emerged as other main themes.

The Initial Shock and Emotional Collapse Experienced at the Time of Diagnosis

Mothers' narratives show that learning about the diagnosis causes intense shock, numbness, and emotional paralysis. This initial reaction is often intertwined with physical reactions (inability to eat, speak, or faint) and prolonged grief reactions.

“We were shocked that day. My husband was even more shocked. He couldn't even speak... he couldn't say a single word.” (Mother 1)

"My heart was broken. I could not eat or drink anything. I was in shock. I cried constantly." (Mother 3)

“I was devastated, I cried, I was sad... I can say it lasted six months...” (Mother 5)

“At that moment, I experienced the biggest shock of my life. I don't know, it was a moment I had never experienced before in my life.” (Mother 14)

The diagnosis was experienced by mothers not only as medical information but also as an unexpected turning point in their lives. The sudden and unprepared manner in which the diagnosis was delivered particularly deepened the shock.

The Initial Shock and Emotional Collapse Experienced at the Time of Diagnosis

The vast majority of mothers state that they had no prior knowledge about Down syndrome before diagnosis. This lack of information deepens feelings of fear, panic, and loss of control in the period following diagnosis.

“First of all, we didn't know what Down syndrome was, so we were scared. We didn't know what we were dealing with.” (Mother 8)

“Until I found out, I honestly didn't know anything about Down syndrome.” (Mother 14)

Information gaps emerge as a fundamental structural element that shapes mothers' emotional experiences and influences subsequent processes of acceptance, adaptation, and resilience.

Stigmatisation, Social Exclusion, and Concerns about the Future

With their children's diagnosis, and due to a lack of information, mothers' minds often conjure up the most negative and stereotypical images; disability is interpreted through stigmatising social representations from the past. Particularly, the concern about “what the community will say” and the child's future social status are significant sources of anxiety.

“We were afraid of being excluded from our community.” (Mother 8)

“The image of the village idiot in the Yeşilçam (Yeşilçam, roughly equivalent to Hollywood in the Turkish context, refers to the classical Turkish cinema industry that dominated film production from the 1950s to the 1980s. Yeşilçam films frequently relied on melodramatic narratives and stereotypical representations, including portrayals of disability framed in terms of pity, tragedy, or moral redemption.) movies came to mind.” (Mother 8)

Additionally, mothers carry intense anxiety about the future of their children after their own deaths:

“But of course, among those initial feelings and thoughts, the anxiety about what would happen in the future was very intense. The fear of what would happen to a newborn baby if we died...” (Mother 8)

This situation shows that disability is experienced not only as an individual vulnerability but also as a familial and intergenerational one.

The Non-linear Nature of the Acceptance Process

These findings reveal that acceptance is not a one-time decision or a short-term phase, but rather a fluctuating and continuous process. Initial expressions of acceptance may be replaced over time by renewed emotional ups and downs.

‘’Of course, there are still difficulties. But of course, it was difficult when I first heard it. I don't know which was harder: accepting it or my mother's sadness? My feelings were very mixed. They still are, to be honest.’’ (Mother 2)

“The decision to always be there and support them comes quickly, but afterwards the emotional ups and downs continue.” (Mother 8)

This finding shows that acceptance is not a static experience, but rather one that unfolds over time and is repeated.

The Traumatising Role of Healthcare Professionals in Diagnostic Communication

Mothers' narratives show that the manner in which the diagnosis is presented has a decisive and sometimes traumatic effect on the mother's experience. Inappropriate language, stigmatising expressions, and a lack of empathy have seriously damaged the psychological well-being of mothers.

“It was very painful for me. Now two doctors stood over me. They asked questions like, ‘Is there consanguinity in the family? How old are you? Is there anyone disabled in the family?’ When I asked what the problem was, the doctor looked me in the face and said, ‘Your daughter is idiot.’” (Mother 9)

“The doctor asked me if I had any other children, and I said yes. He said, ‘Okay, forget about the child with Down syndrome, have another one because she is nothing." He told me not to waste my energy on my child with Down syndrome.” (Mother 14)

“The moment my child was born, the doctors told me that my child was disabled and would never be a normal child. That is what the doctors told me. I immediately fainted there; I had already lost consciousness.” (Mother 16)

These forms of communication become an experience that questions not only the diagnosis but also motherhood, parental adequacy, and the child's value.

The Empowering Effect of Professional and Supportive Diagnostic Communication

On the other hand, empathetic, non-judgmental, and hopeful diagnostic communication plays a healing and empowering role in mothers' experiences.

“Then we went to the genetics department of a university hospital. There was a psychiatrist there. He told us, ‘The defect is neither in the mother nor the father; it's not your fault. This is a gift from God.’ When he said that, my sun suddenly rose again. I swear I was living in darkness. One doctor set my sun; another doctor made it rise again." (Mother 9)

“Then we went from doctor to doctor, everywhere. ... Then we went to one last doctor. He said the only thing that would help this child is education. Education. That gave me hope.” (Mother 16)

These narratives reveal that presenting a diagnosis is not merely a transfer of information but also provides emotional guidance and psychosocial support. In this context, it has been observed that traumatic and stigmatising diagnostic communication negatively affects the mother's experience; conversely, empathetic, supportive, and informative communication strengthens the processes of acceptance and resilience. The findings reveal that the diagnosis process is not merely a moment of medical information sharing, but rather a multi-layered experience with emotional, social, and relational dimensions.

DISCUSSION

The Diagnosis as a Critical Turning Point

Evidence consistently shows that receiving a diagnosis of intellectual or developmental disability in their child is a profoundly significant moment that fundamentally transforms family life. In this context, the moment of diagnosis has been reported to trigger feelings of grief comparable to mourning. According to the literature, this experience is conceptualised as involving the loss of the “ideal” child and the disruption of expectations surrounding “normal” parenthood [37]. In parallel, mothers have emphasised mourning the loss of the “healthy or perfect child” they had anticipated [38], [39]. This grief response may be further intensified by feelings of guilt and self-blame; notably, several studies have documented psychosomatic symptoms accompanying such emotional distress [40]. In such cases, parental mental health is significantly lower compared to normative samples, and the severity of the child's intellectual disability is negatively related to the parents' mental and physical health and quality of life, and positively related to parental anxiety [41]. While this situation aligns with the early stages of Kübler-Ross's [42] model of grief, the prolonged emotional ups and downs observed in mothers' accounts indicate that acceptance is not a linear and complete process. In other words, comparative findings point to the necessity of considering that delivering a diagnosis is not a "final stage," but a continuous experience renegotiated at different stages of motherhood. In this sense, the process during and after diagnostic communication follows a nonlinear trajectory, passing through stages such as shock, denial, struggle, and acceptance [43], [44].

Moreover, it reveals that mothers experience the post-diagnosis process not merely as an individual adaptation issue, but strongly within the context of social stigmatisation. References to Yeşilçam representations, in particular, show how disability is interpreted through cultural images in the Turkish context. When evaluated within the framework of Goffman's [45] theory of stigmatisation, mothers' concerns are directed not only toward their children's future but also toward their own and their families' social status. This finding reveals that disability continues to be mainly addressed within the medical model and that the risk of social exclusion is central to the parental experience [45], [46]. In addition, diagnostic communication also requires effectively transferring care responsibilities to families and comprehensively reorganising family roles and responsibilities [28]. Especially, mothers disproportionately bear the emotional and practical burden of the diagnosis process due to gender-based caregiving responsibilities, being positioned as primary caretakers [32], and expected to maintain emotional resilience while processing their own grief [35]. The consistent finding that mothers bear a disproportionate burden reflects deeply embedded cultural expectations that transcend geographic boundaries [32]. On the other hand, that burden is rendered invisible by expectations of emotional resilience [35]. Consequently, traditional gender structures and cultural expectations that mothers serve as “natural caregivers” render their vulnerability invisible [34]. Moreover, mothers experience significantly more distress than fathers when recalling the diagnosis [33], yet they face weakened support mechanisms because of these expectations [35]. This situation also creates a systematic support gap that perpetuates gender-based inequalities in caregiving.

Diagnostic Communication and Its Impact on Parental Outcomes

Anecdotally, family members often report that they will never forget the receipt of such significant diagnoses, and that the memory of when they first were given the news will stick with them for years to come [2], [43], [47]. In this context, one of the most striking findings of the research concerns the role of healthcare professionals in diagnostic communication. The findings show that the language and approach used can have a deepening or restorative effect on mothers [48], [49]. On the other hand, dissatisfaction with diagnostic communication is widespread [48]: 58% of parents in one research reported dissatisfaction [30], and over 50% described negative experiences in another research [50]. Especially, Down syndrome, parents were 45% likely to report that healthcare professionals discussed negative aspects of DS than positive aspects [43].

When 79% of people receiving the diagnosis report that healthcare professionals did not adequately address their concerns, this represents a systematic rather than incidental failure [22]. In this context, the consistency of problematic patterns across diverse clinical contexts, healthcare systems, and diagnoses suggests that communication failures are not primarily attributable to individual provider deficits; rather, they reflect structural features. Indeed, the literature and current research findings demonstrate that the delivery of diagnoses serves as a revealing indicator of healthcare system values and priorities. The hierarchical organisation of healthcare systems positions healthcare professionals as authoritative information-holders while limiting the agency of the person receiving the diagnosis. This hierarchy is reinforced through training, professional socialisation, and organisational incentives that prioritise biomedical competence over relational skills. When communication is quick, unilateral, and biomedical framed [14], this reflects institutional prioritisation of efficiency and clinical competence over relational care. When the person receiving the diagnosis experiences “abandonment” [13], and “biographical disruption” [8], this indicates systemic failure to recognise and support the human significance of the diagnosis. Mothers who received diagnoses delivered abruptly, insensitively, or with “coldness” reported more severe psychological reactions. Healthcare professionals who approached the diagnosis as a “tragedy” exacerbated maternal distress [35]. The person receiving the diagnosis may internalise healthcare professionals’ expectations, and in some cases, healthcare professionals' condescension may push the person receiving the diagnosis toward “renunciation” of active engagement [14]. These initial reactions are compounded by substantial information gaps, as healthcare professionals often provide insufficient, unclear, or negatively framed information, with consultations frequently lasting less than five minutes [29].

While communication skills training may help [15], recommendations consistently emphasise organisational and policy changes, including: pre-diagnostic counselling and follow-up appointments [51]; adequate time and privacy [18]; integration of psychosocial support [52]; and transformation from paternalistic to genuinely patient-centred organisational cultures [53]. Importantly, information tailoring to individual needs and circumstances improves comprehension and reduces distress [54]. Rather than solely protocol-driven, identical approaches, effective communication adapts to patients’ cultural level [15], provides information tailored to the individual, and recognises the importance of good information, balancing qualitative and quantitative dimensions adjusted to each patient [18]. A “bilingual” approach using both biomedical and non-technical language facilitates understanding [18]. As a result, the apparent tension between studies emphasising the primacy of affective communication factors versus those highlighting informational needs can be reconciled through understanding the temporal nature of parental needs.

The Role of Language and Communication Style

It is known that healthcare professionals' communication style plays a decisive role in shaping mothers' emotional responses, perceptions of their child, and trust in the healthcare system. The evidence unequivocally demonstrates that the language, approach, and communication style used in presenting the diagnosis directly shape parents’ processes of understanding, accepting, and coping with the situation. These findings are consistent with a broad body of literature showing that the process of communicating a diagnosis of intellectual disability to families, particularly mothers, is not only a medical experience but also an emotional, social, and structural one [55].

Indeed, the diagnostic communication process involves profound emotional stages, with mothers struggling to cope and seeking various support mechanisms [56]. They employ both palliative strategies (denying, questioning, wishful thinking) and problem-solving strategies (searching for information, seeking social support, reframing, seeking spiritual support) to cope with their children’s diagnoses [57]. The effectiveness of coping is directly influenced by the quality of professional communication and support received. Although parents need opportunities to actively cope with their situation, many feel unsupported by healthcare professionals [57].

Sensitive and supportive communication helps moderate emotional responses [31]; that is why health professionals should deliver diagnoses of Down syndrome in a sensitive manner that is appreciated by expectant parents [58]. In parallel, the studies consistently highlight the importance of supportive, empathetic communication and comprehensive support systems for mothers navigating this challenging experience [59], [60]. For example, one research of mothers who received a Down syndrome diagnosis for their children found that mothers whose doctors were more positive in conveying the diagnosis expressed more optimism and less fear and anxiety than those whose doctors were more negative when conveying the diagnosis [25]. Indeed, as this research's findings show, diagnostic communications that eliminate feelings of guilt, foster empathy, and allow for meaning-making have been shown to rebuild mothers' feelings of hope and empowerment. The quotation, ’One doctor set my sun; another doctor made it rise again,’ strikingly summarises the decisive role of healthcare professionals in this process.

Provider behaviours that prioritise empathy and collaboration also facilitate better outcomes. Therapeutic alliance, characterised by “feelings of collaboration, trust, and social-emotional rapport”, was identified as essential for effective diagnostic communication [52]. Healthcare professionals’ willingness to answer questions, provide honest information while maintaining realistic hope, and encourage discussion of symptoms improved patient satisfaction [16]; thus, sensitive and empathetic patient-healthcare professionals' communication was consistently stressed as paramount [61]. As a result, healthcare professionals’ emotional responsiveness strongly predicts maternal satisfaction [30], and the odds of positive diagnostic experiences increase substantially when healthcare professionals adhere to emotional and social recommendations [50].

CONCLUSIONS

This research demonstrates that the process of communicating a Down syndrome diagnosis to mothers is not merely an informative clinical act; rather, it is a structural, discursive, and ethical practice that profoundly shapes mothers' emotional responses, their maternal identities, their construction of meaning regarding their children, and their relationship with the healthcare system.

The research reveals that the biomedical and paternalistic discourses dominant in the healthcare system render mothers' information needs invisible and lead to these needs not being systematically met. The failure to provide adequate, timely, and contextual information at the time of diagnosis and afterwards deepens the emotional distress experienced by mothers, lowers the perceived level of support, and increases the risk of internalised stigma. This situation shows that the emotional consequences of diagnostic communication are related to structural communication deficiencies rather than individual vulnerabilities.

However, the research also clearly shows that diagnostic communication does not have to be inevitably traumatic. Communication styles that are empathetic, non-judgmental, free from accusatory language, and balance hope with realism have a healing and empowering effect on mothers. In this context, diagnosis is not only a moment of loss and rupture; under appropriate conditions, it can also be a starting point for meaning-making, resilience, and self-empowerment. In conclusion, the research emphasises that diagnostic communication is not merely a matter of individual communication skills but rather an institutionalised infrastructure that reflects the values, priorities, and power relations of the healthcare system. It argues that the diagnostic communication process should be a healthcare practice that can be adapted to individual needs and circumstances, requiring restructuring from the perspectives of ethical responsibility and gender equality.

LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

This research used a qualitative design to focus on mothers' narratives; while this provides in-depth and contextual insights, it also has limitations. Future research could address the multi-actor nature of diagnostic communication more holistically through comparative studies involving different stakeholders (fathers, healthcare professionals, extended family members). In particular, examining fathers' experiences and healthcare professionals' practices of delivering diagnoses under institutional pressures would contribute to making structural issues more visible.

Furthermore, comparative studies across different types of disabilities, chronic illnesses, and socio-cultural contexts would allow for the differentiation between common patterns and context-specific dynamics in diagnostic communication. Also, quantitative and mixed-methods research could contribute to measuring the long-term psychosocial outcomes of the communication practices identified in this research and evaluating the impact of policy interventions.

Finally, it is important that future research position diagnostic communication not only around the question of “how can it be better communicated?” but also around broader ethical and political questions concerning the legitimisation of knowledge in diagnostic processes, the establishment of the social value of life, and how care responsibilities are distributed. Such research questions will make it possible to rethink diagnostic communication not as an individual clinical skill, but as an area requiring transformation in health systems based on justice, equality, and human dignity.

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