

Communicating Down syndrome: professional insensitivity must not bring down the parental experience

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Commentary on: Tenorio D, Sagner-Tapia J, Garibaldi R, *et al* Your baby has Down syndrome: a reflexive thematic analysis of breaking the news to parents. *BMC Pregnancy Childbirth* 2025;25:536.

Implications for practice and research

- ▶ Clinical teams must implement standardised, private disclosure protocols that include both parents simultaneously to prevent symbolic obstetric violence.
- ▶ Future longitudinal studies should evaluate the impact of empathetic communication training on maternal mental health.

Context

The communication of a Down syndrome diagnosis is a transformative life event that profoundly impacts maternal emotional well-being. Globally, intellectual disability remains stigmatised, often framing such diagnoses as 'bad news'. In Chile, the prevalence of Down syndrome is notably high, approximately 2.4/1000 births.^{1,2} This high incidence, combined with restrictive legal frameworks regarding pregnancy, makes the quality of initial communication paramount. This research highlights a critical professional issue: the lack of humanised communication protocols. Key terminology includes 'symbolic obstetric violence,' defined here as the dehumanising treatment or exclusion of mothers during the diagnostic process.

Methods

This qualitative study used reflexive thematic analysis to explore maternal experiences. 40 Chilean mothers of children with Down syndrome (aged 12–44 months) were interviewed. Recruitment occurred via non-governmental organisations (NGOs) and social media. Semistructured interviews explored diagnosis delivery across prenatal (42.5%), peripartum (17.5%) and postnatal (40%) stages. Analysis followed Braun and Clarke's framework and was guided by a parent advisory group ('experts by experience'), ensuring findings remained grounded in lived maternal reality.

Findings

Four key themes emerged from the study: *who and how*: many mothers reported a lack of empathy and received pessimistic, incorrect prognostications from staff; *timing*: prenatal diagnosis was preferred for allowing emotional preparation; *setting*: news was frequently delivered in inappropriate, non-private locations like corridors or operating rooms; *exclusion*: in 27.5% of cases, fathers were informed before mothers—a practice mothers identified as symbolic obstetric violence and a violation of their rights.

Commentary

The study by Tenorio *et al*³ serves as a vital call for professional sensitisation. When clinicians 'downplay' the importance of sensitivity, they bring down parents with unnecessary trauma. Framing the exclusion of mothers from initial conversations as 'symbolic obstetric violence' elevates communication from a 'soft skill' to a

fundamental human right. Existing evidence confirms that the provider's emotional tone significantly influences parental adaptation. However, this study reveals that clinicians often rely on stigma-driven pessimism due to inadequate training.

A major strength of this research is its solid methodology and the use of a participatory design involving 'experts by experience,' which addresses a significant gap in the literature of the 'Global South'. However, a notable weakness lies in the recruitment through NGOs and social media, which may introduce a selection bias by excluding mothers with fewer resources or those without access to support services.

Standardising a universal protocol for Down syndrome disclosure remains complex, as it must account for vast socio-cultural differences and varying jurisdictions. For instance, the experience in Chile, where abortion is legally prohibited for Down syndrome, differs significantly from countries with different legislative frameworks. There are existing protocols that provide valuable guidance on how to convey bad or fatal news, covering aspects such as the appropriate manner, setting and timing for communication, as well as the rights of the patient (eg, PEWTER: P – Prepare; E – Evaluate; W – Warning; T – Tell; E – Emotional response; R – Regret / Respond; SHARE: S – Setting up the interview; H – How to deliver the bad news; A – Additional information; R – Reassurance and emotional support; E – Emotional support / Encourage questions; and GRIEV_ING: G – Gather; R – Resources; I – Identify; E – Educate; V – Verify; I – Inquire; N – Nuts and bolts; G – Give). While these protocols were not created with Down syndrome in mind, there are some important aspects that could be taken from them; for example, PEWTER⁴ contains a step called PREPARE (P – Prepare; R – Relate; E – Elicit; P – Provide; A – Acknowledge; R – Realistic hope; E – Encourage questions), which expects medical staff to be aware of their own biases, beliefs and values to adequately convey the news.

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, SHARE and GRIEV_ING).^{4–6} While these protocols were not created with Down syndrome in mind, there are some important aspects that could be taken from them; for example, PEWTER⁴ contains a step called PREPARE, which expects medical staff to be aware of their own biases, beliefs and values to adequately convey the news.

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