

Psychosocial consequences of a positive newborn screening result

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Introduction To date, in Germany, the sender of a dry blood card - usually the maternity clinic - is informed by the newborn screening (NBS) laboratory about findings and need for further testing. The sender proceeds this information to the parents. A positive NBS result is not to be taken lightly, especially when it comes to newborns and the content is full of terms unknown from everyday language (Burgard 2017). The aim was to identify core issues regarding the consequences for families after obtaining first information of a positive NBS result.

Material und Methods Medline and hand search for results as close as possible to initial information of a positive NBS result.

Results Investigation on effects of NBS has a long tradition and is methodologically diverse, including qualitative, quantitative studies and reviews (Awiszus und Unger 1990; Chudleigh et al. 2022; Lastrucci et al. 2023; Tluczek et al. 2022). Although measuring the real time impact of the communication of a positive NBS result is difficult, there is concordance that most parents report feeling shocked, stunned, helpless, panic, anxiety, worry, grief, and confusion about an unexpected result. However, parents also showed the need to focus mostly on understanding what was wrong with their baby, what and how to do, and how to get a sense of orientation. Feelings can be mitigated when information providers are perceived to be informed, honest, and calm; avoid jargon, listen carefully, encourage questions, recognize parental distress, offer realistic reassurance, pace amount and rate of information, and refer to specialists. Perceived lack of knowledge of the person communicating rather than the actual NBS result has been linked to parental distress (Ulph et al. 2015).

Conclusions Positive NBS results should not be communicated as bad news. Fulfilling all screening criteria (Wilson et al. 1968) NBS is a powerful means to prevent otherwise devastating conditions. The literature seems to confirm that the parents' needs in the moment of the communication of a positive NBS result are mostly related to information and understanding the pragmatic aspects of the situation (Lastrucci et al. 2023; ReSPoND_Parent_Video). Parents expect reliable information on what there is and what can be done in a comprehensible way (Burgard und Lindner 2018). Health care providers should be aware that screening of diseases was already identified as a public health issue where ChatGPT, a language model developed by OpenAI, could provide information and support individuals making informed decisions (Biswas 2023).

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