

"This is something I will never forget." - Parents' perceptions and comments on the first notification of their child's abnormal newborn screening result

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Context

Communicating an abnormal newborn screening (NBS) result should convey the urgency of further investigation without unnecessarily alarming the parents. Ideally, this is done by a person who is well informed about both the procedures and the condition and who has been trained in communication skills [1,2]. In Germany, the sender of the blood sample, typically an obstetric facility, has so far been responsible for notifying the parents [3], which has been the subject of some debate [4]. The present analysis examines parents' perceptions and comments on their experience of receiving an abnormal NBS result.

Material and Methods

As part of the long-term NBS follow-up study in Bavaria, parents of children with a disease detected by NBS were asked to recall their memories of the notification of the NBS result and of the final diagnosis in written questionnaires after one year (n=758) and after 18 years (n=288). The questionnaires contained a series of multiple-choice questions and space for free further comments, which 165 parents used for additional information and 169 parents for evaluative statements. Analyses were quantitative and qualitative, using inductive categorisation [5].

Results

After 18 years, 98.1% of parents still remembered the initial information about the NBS result, which was rated lower in content and communication than the final diagnosis information. Of the 169 evaluative comments, 74.6% were negative/critical, 16.0% were positive, and 9.5% were combined negative and positive. Negative statements were most frequently associated with an increase in parental anxiety due to insufficient, unspecific, or alarming information, a lack of expertise or empathy on the part of the person providing the information, and a too long waiting time until further clarification. Positive statements were related to professional competence and communication skills, as well as appropriate content and information materials.

Conclusion

The evaluation indicates that parents tend to perceive their child's abnormal NBS result as particularly distressing when it is communicated to them by an individual who lacks the appropriate knowledge and preparedness to handle the situation. It can be inferred that parents desire clear and honest information from a trained and competent individual who is proficient in the procedures, content, and communication. They also want subsequent diagnostic procedures to be provided in a timely manner. The provision of adequate information material can support the communication [1,2,6–9].

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