

## **A Qualitative Study of Parents' Recommendations for Improving the Notification Process and Communication between Health Professionals and Families for New Diagnosis of Cystic Fibrosis**

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**Abstract :** Purpose: This descriptive qualitative study aimed to obtain parents recommendations for improving the notification process and communication of positive newborn screening result for cystic fibrosis (CF). Methods: Thematic analysis of semi-structured open-ended interviews with 11 parents of 7 children with confirmed diagnosis of CF between 2 months – 2 years of age. Results: Parents preferred face to face disclosure of positive NBS results by a pediatrician with CF professional qualification. They trusted a pediatrician more than any other professional in providing accurate, credible and comprehensive information about the diagnosis and its implications. Parents recommended that health professionals be knowledgeable and provide clear, succinct and understandable information. Providers should also explore parents concerns and acknowledge feelings and emotions. Most parents reported that they preferred to be notified immediately as soon as the results were available. Several parents preferred to be told once the diagnosis was certain. Most parents regarded open access to CF team as the most significant part of care coordination. In addition to health professionals, most parents used internet as an important source of information, interaction and exchange of experiences. Most parents also used social networking sites such as Facebook groups and smart phone apps. Conclusion: This study provides significant new evidence from parental perspective in emphasizing the pivotal role of good communication skills deployed by a knowledgeable CF specialist in person. Parents use of social media and internet has replaced some traditional methods of information exchange and may reduce the need for professional input for newly diagnosed CF patients.

**Keywords :** care coordination, cystic fibrosis, newborn screening, notification process, parental preferences, professional-paren communication

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