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Communication of carrier status information following universal newborn screening for sickle cell disorders and cystic fibrosis: qualitative study of experience and practice

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Interventions

Methods for and respondents' experiences of communication of carrier results varied considerably within and between regions. Approaches ranged from letter or telephone call alone, to in-person communication in the clinic or at home, with health professionals from haemoglobinopathy, CF, screening and genetics backgrounds, or from community and primary care, such as health visitors with SC carrier results.

Outcome measures

information; knowledge; anxiety or distress among parents

Main results

Health professionals identified pros and cons of different methods, preferring opportunity for face-to-face communication with parents where possible, particularly for CF carrier results. They were concerned by regional variations in protocols, the lack of availability of translated information on SC carrier results, and the feasibility of sustaining more 'specialist' involvement at current levels, particularly for SC carriers. They were positive about involvement of primary care based generalists if appropriately supported, but felt this may be less feasible for rarer and potentially more complex CF results. Parents were often poorly prepared for the possibility of a newborn carrier result. Some had felt overloaded by screening information received during pregnancy or prior to newborn screening, or found this information failed to meet their needs. They sought timely and specific information at each successive stage of the screening and communication pathway. Opportunity for face-to-face communication of results was valued by parents of SC carriers and appeared particularly necessary for those without prior knowledge of SC carrier status or where English was not their first language. Indirect communication of results by letter appeared effective and feasible for parents more aware of SC carrier status from antenatal or earlier experience, and where this communication contained an unambiguous opening statement emphasising 'your child is not ill'. Face-to-face communication of CF carrier results by professionals with screening, CF or genetics backgrounds worked well for parents, but communication and information was crucially lacking at the earlier stage of repeat blood spot testing, which involved midwives or health visitors who could be uncertain of the CF screening process, creating considerable distress among half of respondents. Rather than learning of their newborn's carrier status in itself, untoward anxiety or distress among parents appeared influenced firstly by how information and communication was offered to them during the screening process, and secondly if they had less prior awareness of carrier status or the possibility of a carrier result. Parents could fear their child had a serious problem, particularly while awaiting results or before seeing a professional, and be left in an information vacuum. Parental distress and anxiety appeared mostly transient, subsiding with understanding of carrier status and communication with a professional. Only a minority of parents appeared to have continued concerns about their child. Respondents had no particular preference for the type of health professional who communicated results to them, as long as they were well informed and could answer their queries. Parents who had received written information about carrier results found this useful for reference and for discussion with their families. However, this information could be insufficiently detailed for some, and poorly accessible in content and language for others. Parents regarded carrier results as valuable information gained fortuitously. They sought to share this with their extended families and to inform their children in the future. Respondents felt community awareness and information about SC and CF could be improved. Although there was some evidence of misconceptions about SC, most parents understood the benign implications of carrier status and that it may impact on future reproductive decisions. However, parents needed greater support after communication of results in considering and accessing cascade testing, and negotiating further communication within their families. Extended families' reception of carrier information ranged from being supportive to negative reactions or avoidance of the news.

Authors' conclusions

Methods of communication of newborn carrier results vary considerably across England. Parents' needs for timely and appropriate information may not be met consistently or adequately. Respondents' experiences suggest a need for greater recognition of communication with individuals occurring across a screening pathway, rather than as a discrete event.

http://www.hta.ac.uk/1510

See also

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Keywords

Adolescent; Adult; Genetic Testing; Heterozygote Detection; information; Neonatal Screening; Newborn; non pharmacological intervention - diagn; non pharmacological intervention - psyco-soc-edu-org; pharmacological_intervention; screening; training; carrier status; Genetic Predisposition to Disease; Truth Disclosure; diagnostic procedures; Psychoeducation; non pharmacological intervention - genetic& reprod;