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Healthcare professionals' experiences on the communication of genetic information from parents to their young children: a scoping review protocol

Seidi, C[1]; Sousa, L[2]; Mendes, Á[3].

Corresponding author:
Catarina Seidi

seidic@ua.pt

Author Affiliation:
CINTESIS@RISE; Department of Education and Psychology, University of Aveiro; UnIGENe, IBMC, i3s.

ADMINISTRATIVE INFORMATION

Support - FCT.

Review Stage at time of this submission - Data analysis.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 03 November 2023 and was last updated on 03 November 2023.

INTRODUCTION

Review question / Objective This scoping review aims to map the evidence on healthcare professionals' (HCPs) and experiences regarding the communication of genetic information from parents to their young children (≤ 24 years).
Review questions: (1) What are HCPs experiences regarding the communication of genetic information from parents to their young children (≤24 years)? (2) What challenges, barriers, and facilitators HCPs describe in the communication from parents to their child (≤24 years)? (3) What HCPs and in what contexts?
Population- HCPs (e.g. physicians, psychologists, nurses, social workers).
Concept- HCPs practice, roles, and facilitators/ barriers regarding communication of genetic information by parents to their young children (≤24 years).
Context- all healthcare contexts in which the communication of genetic risk information between parents and children from the perspective of HCPs is addressed.

Background Inherited genetic conditions (IGCs) result from a gene alteration that can be passed on to offspring (1). Genetic testing identifies whether blood relatives of affected individuals carry the gene mutation responsible for the IGC. Carriers of these mutations have an increased risk of developing the familial disease.
Families with IGCs must adjust to living with the condition and manage genetic risk information for next generations. Parents often feel the responsibility to inform their young children about the IGC. They may wish to discuss an IGC that is already known to affect children or inform their children about the risk of inheriting the IGC (2). Parents often express concerns to HCPs and seek guidance on the best time, circumstances, and

language for sharing information about the IGC with their children (3).

In genetic counselling, HCPs help people understand and adapt to the medical, psychological, and familial implications of IGCs. Guidelines recommend that HCPs encourage parents to disclose genetic risk information to their children as soon as is reasonable (4).

The literature indicates that parents often struggle between the desire to protect their children from potentially distressing information and the wish to foster open communication to ensure understanding of genetic risk and appropriate emotional support (5,6). This struggle may be influenced by the parent's ongoing adjustment to their own genetic status, feelings of guilt about potentially transmitting the gene mutations to their children, and concerns about children ability to handle complex genetic information (7). HCPs play a central role in this process, acting as gatekeepers of genetic knowledge while empowering parents on how to approach these conversations (3). However, there is a lack of clarity regarding the role of HCPs in supporting the communication of genetic information by parents to their young children. In addition, the literature is limited in describing the experiences of HCPs in facilitating this communication.

This scoping review aims to map the evidence on HCPs experiences regarding the communication of genetic information between parent and young children (≤ 24 years).

1. Wakap, S., Lambert, D.M., Olry, A., Rodwell, C., Gueydan, C., Lanneau, V., et al. (2020). Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. European Journal of Human Genetics, 28, 165–173. https://doi.org/10.1038/s41431-019-0508-0

2. Etchegary, H., & Fowler, K. (2008). 'They had the right to know': genetic risk and perceptions of responsibility. Psychology and Health, 23, 707–727. https://doi.org/10.1080/14768320701235249

3. Forrest Keenan, K., Finnie, R. M., Simpson, W. G., McKee, L., Dean, J., & Miedzybrodzka, Z. (2019). Parents' views of genetic testing and treatment of familial hypercholesterolemia in children: A qualitative study. Journal of Community Genetics, 10, 129–141. https://doi.org/10.1007/s12687-018-0373-5

4. Bush, L.W., Bartoshesky, L.E., David, K.L., Wilfond, B., Williams, J.L., & Holm, I.A. (2018). Pediatric clinical genome sequencing and the engagement process: encouraging active conversation with the older child and adolescent: points to consider-a statement of the American College of Medical Genetics and Genomics (ACMG). Genetics in Medicine, 20, 692–694. https://doi.org/10.1038/gim.2018.36

5. Rowland, E., & Metcalfe, A. (2013). Communicating inherited genetic risk between parent and child: a meta-thematic synthesis. International Journal of Nursing Studies, 50, 870–880. https://doi.org/10.1016/j.ijnurstu.2012.09.002

6. Middleton, J., Calam, R., & Ulph, F. (2018). Communication with children about sickle cell disease: a qualitative study of parent experience. British Journal of Health Psychology, 23, 685–700. https://doi.org/10.1111/bjhp.12311

7. Plumridge, G., Metcalfe, A., Coad, J., & Gill, P. (2011). Parents' communication with siblings of children affected by an inherited genetic condition. Journal of Genetic Counseling, 20, 374–383. https://doi.org/10.1007/s10897-011-9361-1.

Rationale This scoping review focus the perspective of HCPs working with people at risk or with IGCs. A variety of IGCs will be considered, with different inheritance patterns, age at onset, morbidity, and life expectancy.

METHODS

Strategy of data synthesis Search was conducted in the following databases: Scopus, Web of Science, PubMed and PsycINFO. For PubMed and PsycINFO an advanced search on title and abstracted was conducted. For Web of Science and Scopus was searched for keywords.

Terms were searched in each database: ("health professional*" OR "healthcare professional*" OR "healthcare provider*" OR clinician* OR "healthcare practitioner*") AND ("parent-child*" OR "parent*" OR "offspring*" OR "minor*" OR "child*" OR "teen*" OR "adolescent*" OR "young adult*" OR "infant*" OR "relative*") AND ("genetic* disease*" OR "genetic* condition*" OR "inherit* disease*" OR "inherit* condition*" OR "genetic* information" OR "genetic* risk*" OR "hereditar*" OR "genetic counsel*") AND ("need*" OR "barrier*" OR "challenge*" OR "inform*" OR "transmit*" OR "facilitat*" OR "disseminat*" OR "communicat*" OR "shar*" OR "disclos*").

Eligibility criteria Inclusion criteria: Original peer-reviewed empirical studies published from 1997 onwards; published in English, Portuguese, Spanish and French; empirical research studies reporting quantitative, qualitative and mixed-methods studies;

Population: HCPs (e.g., physicians, psychologists, nurses, social workers);

Concept: HCPs experiences regarding the communication of genetic information from parents to young children (≤24 years);

Context: all contexts. Relevance of clinical, genetic and health care contexts;

Exclusion criteria: Published before 1997 (year marked by major developments in human genetics); not peer-reviewed; studies not available;
Population: Focus on parents' and/or children's views, without providing the view of HCPs; reporting impacts or outcomes of parent-children communication;
Concept: Children's views on genetic testing uptake or parental views on prenatal testing or carrier testing of their young children; focus on interventions; studies not focusing specifically on parent-child communication.

Source of evidence screening and selection Using Zotero, duplicated records were first eliminated. Based on the title and abstract, screening was conducted. After this phase, screening was based on full text. Screening was performed by one of the authors. A second author met to solve any doubt in the selection. If there was any disagreement, a third author would have been evolved, to solve it.

Data management Data was managed using Zotero and Microsoft Office (Word). Zotero served to remove duplicates and for screening. Microsoft Office (Word) was used to synthesize results.

Reporting results / Analysis of the evidence Data from selected studies was extracted. Results will be analyzed through content analysis. It will be an iterative process that will initiate with an open coding refined according to data (1). Synthetized findings will report following PRISMA-ScR (2;3).
1. Miles, M. & Huberman, A. (1994) Qualitative data analysis. Thousand Oaks: Sage Publications.
2. Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C., & Khalil, H. P. S. A. (2020). Updated methodological guidance for the conduct of scoping reviews. JBI Evidence Synthesis, 18(10), 2119–2126. https://doi.org/10.11124/jbies-20-00167
3. Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., . . . Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-SCR): Checklist and explanation. Annals of Internal Medicine, 169(7), 467–473. https://doi.org/10.7326/m18-0850.

Presentation of the results This scoping reviews results will be presented according with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for scoping reviews (PRISMA-ScR) (1;2). Data will be presented also in tables and text.
1. Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C., & Khalil, H. P. S. A. (2020). Updated methodological guidance for the conduct of scoping reviews. JBI Evidence Synthesis, 18(10), 2119–2126. https://doi.org/10.11124/jbies-20-00167
2. Tricco, A. C., Lillie, E., Zarin, W., O'Brien, K. K., Colquhoun, H., Levac, D., Moher, D., Peters, M. D. J., Horsley, T., Weeks, L., Hempel, S., Akl, E. A., Chang, C., McGowan, J., Stewart, L., Hartling, L., Aldcroft, A., Wilson, M. G., Garritty, C., . . . Straus, S. E. (2018). PRISMA Extension for Scoping Reviews (PRISMA-SCR): Checklist and explanation. Annals of Internal Medicine, 169(7), 467–473. https://doi.org/10.7326/m18-0850.

Language restriction Studies conducted in other languages than English, Portuguese, Spanish and French will not be included.

Country(ies) involved his scoping review was conducted in Portugal.

Keywords genetic counselling; genetic risk; healthcare professionals; hereditary disease; parent-children communication; young children.

Contributions of each author
Author 1 - Catarina Seidi.
Email: seidic@ua.pt
Author 2 - Liliana Sousa.
Email: lilianax@ua.pt
Author 3 - Álvaro Mendes.
Email: alvaro.mendes@ibmc.up.pt