Received: 3 October 2022 | Revised: 31 March 2023 | Accepted: 3 April 2023

DOI: 10.1002/pon.6141

REVIEW

WILEY

Communication about hereditary cancer risk to offspring: A systematic review of children's perspective

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Funding information
Portuguese Foundation for Science and Technology, Center for Psychology at University of Porto, Grant/Award Numbers: EXPL/PSI-GER/1270/2021, UIDB/00050/2020

Abstract

Objective: The present review describes how children experience hereditary cancer risk communication within the family.

Methods: Searches for studies between 1990 and 2020 on PubMed and EBSCO were undertaken, and 15 studies met the inclusion criteria, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. The findings informed: (1) how, when and what is discussed about hereditary cancer risk in the family; (2) how does family communication about hereditary cancer risk impact children on psychosocial and behavioral outcomes; (3) what are the child's preferences regarding hereditary cancer risk communication within the family.

Results: Disclosure is done mostly by both parents, or mothers only, which is in accordance with the children's preferences. Children value open communication about cancer risk with their parents, although they report experiences of fear, surprise, feeling unhappy, and concern about the increased risk of cancer. Regardless of the method of disclosure, children may be particularly sensitive to their parent's emotional state at the time of disclosure, and they learn from their parents' experiences the potential implications of cancer risk. Children also report that it would be helpful to learn more about genetic cancer syndromes via written materials, and/or meet a genetic counselor.

Conclusions: Children rely on their parents as the primary models of the hereditary cancer experience. Therefore, parents play a central role in the psychological adjustment of children. Findings point to the relevance of family-centered care in hereditary cancer risk that targets not only the mutation carrier individually but also their children and partners.

KEYWORDS
cancer, children, communication, family, genetic predisposition to disease, oncology

1 | BACKGROUND

Hereditary cancer syndrome is a type of inherited disorder in which there is a higher-than-normal risk of certain types of cancer.[1] Most genetic syndromes involve autosomal dominant genes, but can also be recessive or de novo, and therefore, inherited and passed down from parent to child. Genetic susceptibility tests can identify specific mutations associated with specific hereditary cancer syndromes and tell if a family member has inherited the same mutation as other members who carry a cancer-associated mutation.[2] However, not everyone who has the mutation will necessarily develop cancer, even if the cancer-predisposing mutation is present in the family.[3] This process of identifying and assessing the hereditary cancer risk is completed through genetic counseling (GC), where health professionals support individuals in managing hereditary cancer risk.[4]

Once genetic risk information (GRI) is distributed among family networks, the moment of becoming aware of the increased susceptibility to cancer can be a disturbing event, both at personal and family levels.[5–7] Growing up in a family with known hereditary cancer risk may involve additional psychosocial burden and be challenging. For instance, when a child is affected by an inherited genetic condition, unaffected siblings can subjugate their feelings and needs and may isolate themselves when coping with it.[8] The impact of hereditary cancer risk information on children, affected or not affected, should not be underestimated. While prior research has contributed to our understanding in how adults perceive, react to and adjust to cancer risk information, there continues to be a need for further research that sheds light on what it means for a child to live in a family affected by hereditary cancer syndromes.[9]

Previous systematic reviews demonstrate agreement between professionals and parents in the role that parents have in being primarily responsible for discussing family genetic information with their children.[9] Also, children have reported their preference for being informed about an existing genetic condition in their family. For example, children from families with a recessive genetic condition reported being curious and demonstrate the ability to assimilate information from a young age.[10] Likewise, children from families affected by Huntington's Disease, a genetic inherited condition, in a retrospective study expressed a preference for early disclosure and open communication in the family.[11] In families with hereditary cancer risk, children have reported feeling upset and frustrated with family secrecy about the disease, which contributed to tense relationships between family members.[9] Families also emphasize the importance of open communication, and report feeling empowered when they openly talk about the condition as it facilitates discussion on concerns as they arise, and reinforces mutual support and care for each other.[9] Emotional impacts can vary and be experienced as negative or positive in relation to receiving genetic information. When open communication exists, young people may mature into adulthood with a cautious mind regarding reproduction and genetic testing decisions, which can empower their own choices and psychological health. In contrast, poor communication has been associated with less optimal choices and emotionally-driven decision-making.[9] Overall, providing information, checking understanding along the way, and explaining and managing the emotional feelings as they emerge seems to be integral to support children's coping with GRI.[9] Thus, communication affects how information is received and has implications for psychological adjustment for the child.[12]

A key finding noted in the literature is that parents are challenged with what and when to tell their children, and have different concerns and questions depending on their children' ages.[9,13,14] A major concern is the extent to which information about hereditary cancer risk affects a child's psychological well-being and development. Two systematic reviews and meta-synthesis synthesized existing evidence on family communication to at-risk relatives for hereditary adult-onset cancers and the support required for parents and children to manage the genetic condition or the risk.[9,15] In particular, studies focused on what facilitates or impedes family communication[15] and the issues surrounding family communication about inherited genetic risk.[9] Most of the conclusions in the literature are based on parental reports. There continues to be a paucity of evidence from the viewpoint of children. This research gap may be related to the fact that the vehicle of information for offspring is mostly the adult parent. Also, when referring to minors, there may be issues related to legal access to genetic testing/context and ethical concerns regarding the highly sensitive nature of genetic information. This is an important gap in the literature, as children's understanding of GRI may differ from that of their parents. Adolescent girls, for example, emphasized more than their parents, the potential psychological risks of carrier testing if undertaken at a young age.[16]

A review of studies on the disclosure and communication process involved in hereditary cancer syndromes *from the child's perspective* will provide important new knowledge that can be considered along with the literature on parents' and professionals' perspectives. To our knowledge, this is the first systematic review of the literature focusing on children's viewpoints of their experience, impact and needs, within a family that is affected by hereditary cancer risk. Specifically, from the children's perspective, we aim to describe: (1) how, when and what is discussed about hereditary cancer risk in the family; (2) how does family communication about hereditary cancer risk impact children on psychosocial and behavioral outcomes; and (3) what are the child's preferences regarding hereditary cancer risk communication within the family.

2 | METHODS

The protocol was registered on PROSPERO and followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement guidelines.[17] Search terms were adapted from Metcalfe et al. (2008) and Seymour et al. (2010; see Appendix A). The search was conducted by two independent researchers on PubMed (MEDLINE) and EBSCO (PsychINFO) electronic databases, for studies published between 1990 (when the breast cancer [BRCA1] gene was identified[18]) and 2020. Relevant journals and authors were hand-searched to identify additional relevant articles that could be

missed by the search strategy. Forward and backwards citation searches were undertaken on Web of Science and Scopus for included papers. Search results were exported to the reference manager EndNote, and both digitally and manually identified duplicates were discarded. Resulting titles and abstracts were transferred into Excel and reviewed for relevance, and the full-text articles were reviewed for inclusion and data extraction. All titles and abstracts of the identified studies were independently assessed by two authors for inclusion or exclusion in the review, until a good level of agreement was reached (97%). The inclusion and exclusion criteria were based on the population, concept, and context of the research question (see Table 1). In particular, we included studies with samples of minors (<18 years old), or adults who were retrospectively describing their experiences as minors ("retrospective children"). Papers were excluded when all reviewers agreed that inclusion criteria were not met and disagreements were resolved by discussion to reach consensus. Eleven (1.6% of 695 eligible abstracts) studies met all of the inclusion criteria, and four additional studies were identified through other sources. The eligible papers were assessed for quality using the Mixed Methods Appraisal Tool (MMAT[19]). Two independent judges responded "Yes", "No" or "Can't tell" to the screening questions according to the MMAT checklist, depending on the appropriate category of the study appraise (see Appendix B). The included studies were of relatively high quality: 80% had clear research questions, and 93.33% addressed them by the collected data. Ninety-eight percent of the qualitative and 96% of studies with mixed-method methodology were of good quality (see Appendix B). Finally, two independent researchers extracted information from the included articles using tables that recorded study outcomes, study design and the main findings (see Table 2). We then compiled all the information for each topic and summarized the results according to the research questions they addressed.

3 | RESULTS

3.1 | Available literature

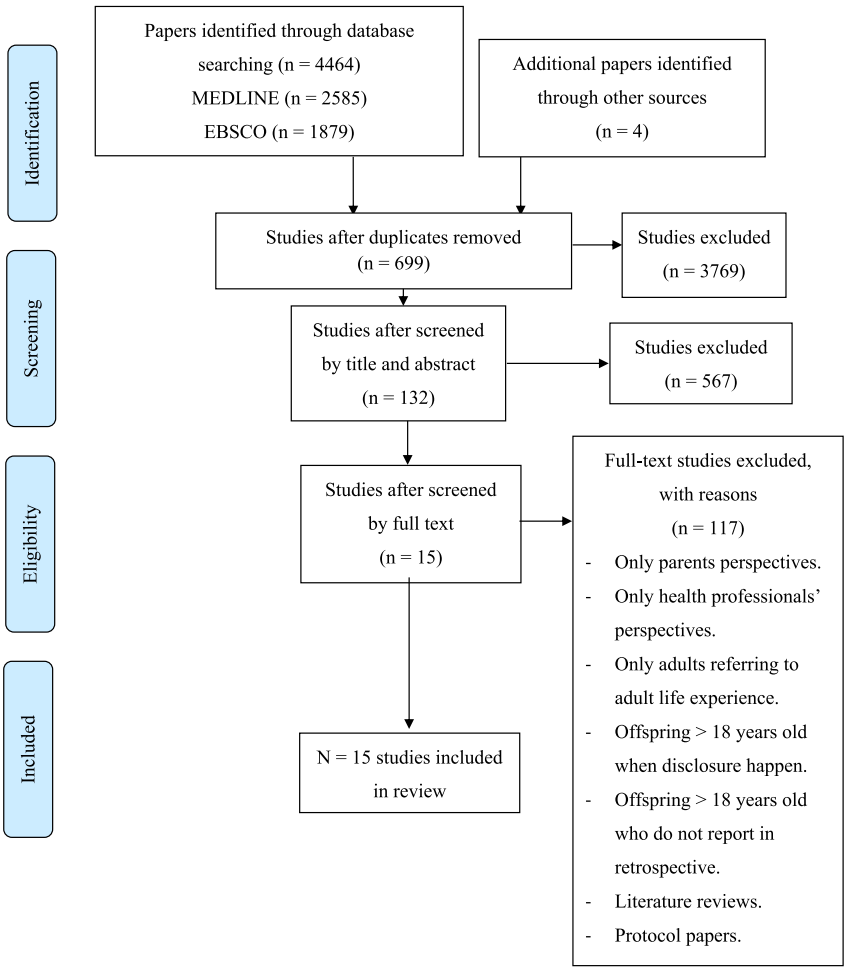
The search returned 15 articles (see Table 2) that met the inclusion criteria (see Table 1): 10 qualitative (66.67%), and 5 mixed-method designs (33.33%). These studies were conducted in the United States (n = 10, 66.67%), Australia (n = 2, 13.33%), United Kingdom (n = 2, 13.33%), and the Netherlands (n = 1, 6.67%). Studies included semi-structured interviews and questionnaires. One article involved an intervention with focus groups. The studies' samples included children and retrospective children of families at risk for breast and ovarian cancer (n = 10, 66.67%), Li-Fraumeni syndrome (LFS; n = 1, 6.67%), multiple syndromes including familial adenomatous polyposis (n = 2, 13.33%), or other syndromes including Lynch syndrome (n = 2, 13.33%). Overall, the population of this study included 20% male and 76.5% female children and young adults (about 3.25% of the population was not described). There were two (13.33%) papers with only

TABLE 1 Inclusion and exclusion criteria used for screening articles.

	Include	Exclude
Population	Children as minors—affected and siblings (<18 years old). Hereditary cancer risk families (syndromes: Breast and ovarian cancer, familial adenomatous polyposis, Lynch syndrome, Cowden syndrome, LFS, hereditary diffuse gastric cancer, retinoblastoma).	Only parents referring to their children. Only health professionals' views. Studies that include offspring >18 years old.
Concept	Family communication. Perspective, experience, and opinions on family communication about hereditary cancer risk. Family communication impact. Familial discussion/disclosure.	Only reports of parental perspectives on their children's experience and opinions of family communication about hereditary cancer risk.
Context	Qualitative and quantitative studies with any study design. Trials. Correlational studies. Studies on development of or testing of decision aids. Expected outcomes from literature about family communication: Emotional reactions (e.g., anxiety, distress, depression). The age at which children were told about the family genetic information and who told that. Communication impact: Emotional, behavioral outcomes, impacts on self-esteem, self-concept, self-conscious, identity, body image, body stigma, body, concerns, psychological adjustment, psychological development, vulnerability, arm concerns, well-being, quality of life. GC adherence behavior; health behaviors; sharing of information behavior.	Literature reviews undertaken by other researchers. Protocol papers.

Abbreviation: LFS, Li-Fraumeni syndrome.

TABLE 2 Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of study identification and selection process (Moher et al., 2009).



children as participants, five (33.33%) papers with retrospective children (adults referring to their experiences as < 18 years old), one (6.66%) paper with children AND retrospective children, and seven (46.66%) papers with mixed sample (children AND adults AND/OR families). Quantitative data were present in five (33.33%) mixed-methods studies. Descriptive data are summarized in Appendix C.

3.2 | How, when and what is discussed about hereditary cancer risk in the family?

Information regarding "who" provided the disclosure of the genetic condition to the child was present in only six (40%) of the selected studies. For the most part, children indicate that they came to know about the genetic risk in the family through their mother. Parents typically shared the test results alone, or with their spouses. In some cases, the offspring's siblings or other family members were present during disclosure. Offspring tended to learn GRI either in a non-formal family meeting, for example, by telephone or while engaged in another activity such as driving in the car,[20] or through a more intentional private conversation (see Table 3).[20,21] Daughters of mothers with mutations on the BRCA1/2 genes were more likely to learn about the family risk from mothers alone, compared to patterns of disclosure of GRI to sons. Genetic counselors facilitated family communication and families appreciated the emotional support in order to process their experiences related to hereditary cancer risk.[22] Overall, children and young adults reported experiences of open communication in conversation with parents and genetic counselors about test results, risk management, hopes, and fears.

In relation to the age of the child at the time of disclosure, the youngest age of an offspring learning of a genetic test result was reported as being 8 years old.[23] Only one study indicated the specific age at the time of disclosure,[24] while the remaining selected studies used age categories (e.g., "> 13 years old", "12–15 years old", etc.), or developmental stages (e.g., "teenager", "emerging adult", etc.). The most common estimated age categories of offspring at disclosure were 18–21 years and 16–17 years. The time interval between the parent receiving the test result and disclosure to offspring varied,

TABLE 3 Examples of quotes from the included studies.

	How, when and what is discussed about hereditary cancer risk in the family?			
	Quote	Participant provided information[a]	Family syndrome/ at-risk syndrome	Study
How	"[My mother] sat me down and told me, 'I am not going to die like [my aunt, my mother's sister].' I was older and understood more, so it was OK because the cancer was so small and early."	Female, minor	HBOC	Norris et al. (2009)
What	"My mom explained that she wasn't sick, but she was getting preventative surgeries so she doesn't get breast or ovarian cancer in the future. She was doing it for us because she wants to be around, unlike her mother who died of ovarian cancer."	Female, 18 years old, 11 years old at disclosure	HBOC	Bradbury et al. (2009)
	"He [dad] said that testing had been done on his side of the family and a gene was found that makes women prone to breast cancer. He had testing and then brought it up over dinner one evening. He basically said that he is a carrier and at increased risk for cancer in family. Also, that we could be carriers."	Male, 26 years old, 17 years old at disclosure	HBOC	Bradbury et al. (2009)
	"But she [mother] had always pushed just how serious it was and that it was kind of a big deal… it kind of scared me. But she also - she wouldn't say it in a scary way she would just sort of stress it and I sort of preferred not to think about it."	Female, age range 18–24	HBOC	Patenaude et al. (2013)

[a]The included articles only sometimes provided all the information regarding the participants.

ranging from hours to a few days following disclosure to the family member,[20] to years.[24,25] Among the young adults who reported retrospectively, they expressed difficulty in recalling the length of time between when they received information from that of their parent learning of a test result.[20]

Information regarding the content of disclosure was present in only four (26.67%) of the selected studies. In some cases, the specific genetic mutation itself was not described, although the parents did discuss the hereditary risk of cancer in the family. The most frequently reported information when disclosing to children was content concerning the implications of the test result for the risk of developing cancer—*"He [dad] said that testing had been done on his side of the family and a gene was found that makes women prone to breast cancer (…)"*[24] (see Table 3) - and the eligibility of the offspring for genetic testing. Risk reduction strategies (cancer screening, prophylactic surgeries, and avoiding tobacco) were a less frequent topic of discussion at the time of disclosure.[24] However, the disclosure-related content can vary depending on the age of the child or depending upon the preventive/current health activities of the parent. For example, disclosure of the mother's BRCA1/2 mutation status to daughters was sometimes conflated with the news that the mother would shortly be undergoing preventive surgery.[20] For children <11 years old, information tended to focus on events that the child would witness (e.g., hospitalization of a parent). For younger age groups, parents tended to use simplistic language to describe breast cancer: "*poorly boobs*", "*poorly tummy*", "*magic medicine*", "*new boobies*", "*boob job*".[21] For the 12–14 years old age group, disclosure centered more on the hereditary nature of the gene mutation and parent's risk level. For the 15–17 years old age group, young people were more often given information about risk management strategies. And, when disclosing to offspring at 18 years old, content of discussions focused more on genetic testing and the implications for the young person's future offspring.[21] Male breast cancer content was only mentioned in two (13.33%) of the selected studies and rarely discussed within families.[21,22]

3.3 | How does family communication about hereditary cancer risk impact children on psychosocial and behavioral outcomes?

In relation to emotional reactions among offspring, feelings of being frightened or disturbed, surprised concerning GRI, unhappy surrounding the event, or having concerns about receiving a cancer diagnosis, were described in most studies. The trajectory of distress reported by offspring varied.[20] For example, when told about their mother's positive mutation status for hereditary breast and ovarian cancer (HBOC), daughters reported a peaked sense of fear and worry. These feelings appeared to diminish over time, as daughters further learned about risk-reducing options. In some cases, the emotional impact was postponed. For example, at the time young women were told (in their teens) about a genetic cancer risk, the implications for themselves felt distant—*"It didn't sink in at first, but once I started having to get all of the testing, it sunk in that I am going to have to deal with this for the rest of my life"*[26] (see Table 4). When daughters entered adulthood, fears about developing breast and ovarian cancer tended to increase.[20]

Regarding family communication, children reported a multiplicity of positive, neutral, and negative responses to disclosure of hereditary risk in the family. Responses differed depending on the nature of the test results and were not necessarily associated with the child's developmental level.[12] When mothers received negative test results,

TABLE 4 Examples of quotes from the included studies.

	How does family communication about hereditary cancer risk impact children on psychosocial and behavioral outcomes?			
	Quote	Participant provided information[a]	Family syndrome/at-risk syndrome	Study
Psychosocial outcomes	"It didn't sink in at first, but once I started having to get all of the testing, it sunk in that I am going to have to deal with this for the rest of my life."	16 years old	LFS	Alderfer et al. (2017)
	"I was nervous for her [mother] more than myself right away and I was nervous for like a year after when my cousin had it and that just really made me think, like, wow, I could have it too."	Female, age range 18–24	HBOC	Patenaude et al. (2013)
	"A feeling of guilt that I don't have it. My brother and sister need to deal with this for the rest of their lives."	23 years old	LFS	Alderfer et al. (2017)
	"It probably brought me and my sister closer together because we now have something (testing positive) that we can closely relate to."	16 years old	LFS	Alderfer et al. (2017)
	"And then when she [mother] got the testing, I was still, like I didn't like talking about it [BRCA] because I keep things to myself. I don't know whether it's, like, a sense of I need to not make people think that I'm scared of things. I don't know. I just don't, like, openly express my [fears]."	Female, age range 12–17	HBOC	Tercyak et al. (2019)
	"I didn't have a lot of women in my lifetime, family members in my lifetime that I was talking to about [cancer]. I wished I had a woman there I could talk with but that just wasn't the case. I mean I had girlfriends and stuff, but we weren't talking about that kind of thing."	Female, age range 43–45	HBOC	Bakos et al. (2008)
	"Going on the beach and wearing a bikini, I think that was one of the factors with my mum, like you know [in choosing] to have a reconstruction, and I know that would affect me as well… because that's when it will knock my confidence and stuff… if that is going to happen, I hope it happens later on when I've got a family and I'm settled down and stuff."	Female, age range 10–21	HBOC	Rowland et al. (2006)
	"With the double mastectomy, it's a free boob job basically on the NHS because you get to choose your consultant; you can choose your size - bigger or smaller, whatever. And that is the reason why I wanted to be tested quicker, because I thought… If I've got it, I can have my boob job as well and I don't have to pay for it, but then if I don't have it I can still have it anyway."	Female, age range 10–21	BRCA	Rowland et al. (2016)
Behavioral outcomes	"I think I want to get tested as soon as possible, even though my mom thinks I don't really need to, just because, why not? Just to, kind of, know. Because I am already assuming I have it. So nothing will change if I do have it, but a lot could change if I don't."	Female, age range 18–24	HBOC	Patenaude et al. (2013)
	"I understand [BRCA mutation] doesn't affect males that much, it like only gives them like a marginal chance more, whereas females… it gives them a massive chance of getting [breast cancer]. So I couldn't see the interest… it's not something I'd get worried about, me myself… Obviously mum's going to, auntie's going to, [sisters] going to but it hasn't affected me as much as it would them probably…"	Male, age range 10–21	BRCA	Rowland et al. (2016)
	"It's worth it to know so that you can have the screenings done… making it so that you can take better care of yourself. It's just something else to know about your body, you know, about your history, so you can take care of yourself in the best way possible"	25 years old	LFS	Alderfer et al. (2017)

Abbreviations: BRCA, breast cancer gene; LFS, Li-Fraumeni syndrome; NHS, National Health Service.

[a]The included articles only sometimes provided all the information regarding the participants.

children reported feeling "*relief*" and being "*glad*" about the information, both in terms of their own health and in relation to that of their mother's. When a positive test result was received by a parent, children may also experience a favorable reaction that appeared to be due to the empowering nature of the knowledge that the test result provides in relation to health prevention strategies, treatment options, and future plans.[12] The negative responses to disclosure among offspring included feeling apprehensive about their own future health and that of their mothers'—*"I was nervous for her [mother] more than myself right away (…)"*[20] (see Table 4). Some cases of dispassionate and neutral responses to the disclosure process were described as children simply feeling *"not surprised by the news"*.[12] When having siblings, on the one hand, young adults reported feeling guilty when a close sibling tested positive (and they don't carry a mutation)—*"A feeling of guilt that I don't have it (…)"*[26] (see Table 4). On the other hand, children can also feel closer to their siblings as they experience having something in common—*"It probably brought me and my sister closer together (…)"*[26] (see Table 4). Young adults who received genetic information often expressed having the responsibility to inform younger siblings and cousins, so that they obtain accurate information.[22]

Although the majority of children articulated thoughts and feelings about how they wanted parents to communicate over time with them about a hereditary risk, children did not always engage in family communication in follow-up with their own parents, as they often had difficulty articulating their feelings. Some children reported that they did not address their own stress/anxiety, even when recognizing concerned others would support them—*"(…) I had a sense of I need to not make people think that I'm scared of things (…)"*[12] (see Table 4). Younger children reported that they wished to avoid negative feelings.[12] Children's psychological adjustment may be related to their beliefs about health and thoughts of illness. For example, children with more psychological symptoms experienced more frequent thoughts of becoming sick, about developing cancer, and had worries about cancer developing in a family member.[27]

Some studies indicated that the testing results have had no impact on family relationships,[26] within or outside the family.[24] However, one study found that sadness and social isolation could be triggered by watching older family members die from the same disease. These participants described a void related to familial mentoring relationships—*"(…) I wished I had a woman there I could talk with (…)"*[28] (see Table 4).

Through their mothers' experiences of breast cancer and their risk management decisions, young women in HBOC families appeared to realize the potential implications of breast cancer risk for their own psychological wellbeing, particularly in relation to their self-esteem and body confidence—*"Going on the beach and wearing a bikini, I think that was one of the factors with my mum, like you know [in choosing] to have a reconstruction, and I know that would affect me as well… because that's when it will knock my confidence and stuff (…)"*[21] (see Table 4). In relation to BRCA mutations, there were few studies reporting on male offspring, however, one study showed that males perceived that they were at lower risk for breast cancer (which is accurate)—*"I understand [BRCA mutation] doesn't affect males that much (…). Obviously, mum's going to, auntie's going to, [sisters] going to but it hasn't affected me as much as it would them probably"*[21] (see Table 4). The authors in this paper also indicated that partial disclosure of GRI may have resulted in males minimizing their risk for other cancers, despite being at increased risk for example, for prostate cancer.

In relation to behaviors following disclosure, some participants reported that learning about their mother's result on HBOC had an immediate impact of a strong personal interest in pursuing genetic testing. Other participants felt more distance in relation to the need for testing for themselves. And others thought that they might not want testing until after they begin having mammograms or when they are ready to have children, with several thinking that they might decide against having children to prevent the passing of the gene mutation.[20] In families with HBOC, young daughters specifically described their motivations for genetic testing—*"I think I want to get tested as soon as possible, even though my mom thinks I don't really need to, just because, why not? Just to, kind of, know. Because I am already assuming I have it. So, nothing will change if I do have it, but a lot could change if I don't."*[20] (see Table 4). In another study on HBOC families, children reported on important reasons for testing (when reaching adulthood), which included (in order of importance): to pay closer attention to one's own health; to make more informed decisions about family; to feel better; to make better decisions about smoking or using tobacco; to plan for school or work.[27] Genetic testing in general was reported as having the advantage of allowing opportunity for efforts in disease prevention, supporting living a healthier lifestyle through health preventive behaviors (e.g., exercising regularly, eating a healthy diet and avoiding tobacco), and engaging in early screening for disease detection and treatment[24,26] (see Table 4). However, age was often experienced as a barrier to addressing cancer risk as children reported being told that they were too young for conventional screening measures. Some young adults described feeling pressured by their parents to act before reaching a certain age perceived as being unsafe, as a sense of urgency in risk management.[29]

3.4 | What are the child's preferences regarding hereditary cancer risk communication within the family?

3.4.1 | Family communication

Concerning the family communication process, children generally perceive that parents have the primary role in disclosing to a child about hereditary risk.[23] However, six (40%) of the included studies indicate that children wished that their parents had given them more GRI. Children aged between 15 and 17 years indicated that they valued knowing about the cancer risk (concerning an adult-onset disorder) from a young age and reported tending to learn more details as they got older.[23] For children, having conversations about the

syndromes and/or testing initially and revisiting the topic over time was deemed very important.[12,23] Open communication was valued in six (40%) of the selected studies. Children described preferences in parents communicating the information honestly in a way that is reassuring, with less potential to frighten the child—*"(…) I'd rather know the full truth"*[23] (see Table 5). Children also identified tone as being relevant.[23]

Regarding the involvement in testing decisions and the satisfaction with it, adolescents and young adults reported that they had received enough input concerning information on the decision-making process within the family. Children stated that they trusted their parents' judgment, as having their best welfare in mind[26] (see Table 5).

3.4.2 | Professional care

A key theme identified in the review was that children have interest in knowing, as future adults, about their risk for developing cancer.[27] In all studies, offspring showed interest in learning more about genetics and hereditary disease. In one study, quantitative data demonstrated an average of 9, on a scale from 1 to 10, indicating the need for information.[30] Despite 12 studies (80%) reporting that the family attended GC, only one study indicated that the children were included in the service.[31] Qualitative and quantitative findings showed that young adults who received GC expressed satisfaction with the care that they received, and when participants indicated that they were not satisfied, this was related to the experiences associated with a lack of continuity of care. Continuity of care was especially valued—*"(…) It's almost like they [genetic professionals] are a family member"*[31] (see Table 5). Some young adults indicated that GC[29,31] and multi-family discussion groups[32] had prompted debate among family members concerning the implications of knowing about a hereditary condition in the family.

Children and young adults reported a perception of guilt being experienced by their parents for passing the mutation on to them.[12,22,29] With this experience, when there were joint GC sessions (with parents), young adults reported a tendency to hide their worries, denied concerns, or refrained from asking critical questions about the implications of their mutation status, their cancer risk, or on methods of risk reduction, in an attempt to protect their parents from potential additional burden and emotional distress.[29] Children expressed being aware that their mothers were putting on a "*brave face*" and felt that by asking questions they may cause upset to their mothers.[21]

Only four (26.67%) studies described using tools (e.g., written materials, professional journals, or the internet) to support the disclosure process. Offspring who received written materials indicated that they found the information helpful. Among offspring who did not receive written materials, the majority felt that written materials would have been helpful, either for themselves or for others. Offspring also suggested value in having opportunity to meet with a genetic counselor or other health professional.[22,24,31]

Regarding testing, there are reports from sons and daughters supporting the genetic testing of minors for adult-onset syndromes[26,30,33]—*"It should be their choice (to test). We should leave it open to people"*[33] (see Table 5). Among offspring who expressed caution against testing of minors, the primary reason identified was the lack of medical indication for children.[33] In relation to the recommended age for genetic testing, various recommendations were offered. For example, in one study on HBOC and Lynch syndrome: 2% of the participants suggested from birth, 4% suggested starting at 16 years, 24% starting 18 years, 20% from 20 years, 18% from age between 21 and 24 years, 18% from 25 years, and 2% from 30 to 35 years; 12% did not report a recommended age for testing, stating that it depends on the person.[30] Overall, this review found that there was no strong agreement in terms of the age preferences for testing, although we note that the studies included did not specifically consider this topic, regarding either adult-onset versus youth-onset disorders. Adult-onset and youth-onset conditions differ in relation to the age eligibility for genetic testing.

4 | DISCUSSION

This is the first systematic review of children's experiences and preferences regarding communication about hereditary cancer risk within the family. Results confirm that disclosure of genetic information is usually performed by parents, and children explicitly indicate that this is their preferred way to learn that there is genetic cancer risk in their families. In the reviewed studies, the person disclosing was typically the mother, which is in line with previous findings indicating that women often take on the primary role in disclosure and act as family "representative", "kin keeper",[34] or "gatekeeper".[35,36] Children didn't report preferences regarding the method of disclosure, either in a formal or informal way. However, they may be particularly sensitive to their parent's emotional state. When children perceive their parents as being uncomfortable, distressed, or not giving space for questions, communication about genetic risk can be hindered. Children may hide their worries and anxiety, or refrain from asking questions (despite wishing for more information), to protect a parent from additional emotional distress. Dynamics of "protective buffer" have been described between the couple, or from parents toward their children, in families affected by genetic cancer syndromes.[6] Our review identified similar protective buffer processes experienced by children toward their parents. In addition to the time where the presence of the genetic risk is revealed, children also expressed their preference for receiving GRI over time gradually, in an open and honest manner. There may not be a specific or "one" strategy or timepoint recommended for all families as they navigate through the process of talking about GRI with offspring. However, research shows the importance of parents' emotional readiness and the existence of a plan for providing information gradually according to the offspring needs, favoring emotional awareness and sharing according to the pace of the child. The initial disclosure is thus part of a long-term communication process between family members.[14,37,38] Werner-Lin et al. (2018) recommend that parents tune with and regulate their own emotions, as a

TABLE 5 Examples of quotes from the included studies.

	What are the child's preferences regarding hereditary cancer risk communication withing the family?			
	Quote	**Participant provided information**[a]	**Family syndrome/ at-risk syndrome**	**Study**
Family communication	"My mom just pretty much told me, 'you're getting a blood test to see if you have this or not.' (do you feel like you should have had more say in the decision?) no. I was younger and if my mom said, 'hey, do you want to go check to see if you have this or not?' I would have probably said yes anyway"	16 years old	LFS	Alderfer et al. (2017)
	"You can't sugar coat it. You just have to tell them exactly what it is. If you tell them everything's 100-percent perfect and just about won't affect them, it's not true. I'd rather know the full truth"	Age range 15–17	Hereditary cancer	Stuttgen et al. (2020)
	"My mom, when she first told us she spoke very calmly and explained it in depth and she didn't get too emotional about it, which helped us not immediately freak out and assume that the worst was going to happen"	Age range 15–17	Hereditary cancer	Stuttgen et al. (2020)
Professional care	"The (genetic professional) that we go to see has been with us throughout our entire life. So we're very privileged to have someone throughout all those years with us. It's almost like they're a family member."	Male, age range 19–29	Cancer-related genetic syndrome	McGill et al. (2019)
	"Knowing what's going on medically with my body is better than not. I am more mature now and have come to respect certain things. I want to learn more"	Male, 24 years old, 17 years old at disclosure	HBOC	Bradbury et al. (2009)
	"Well, I feel like they didn't explain it enough. I mean, they didn't make me feel scared, but they didn't explain it enough for me to fully grasp it. I didn't really understand the full concepts of this mutation and how it might affect me"	Age range 15–17	Hereditary cancer	Stuttgen et al., (2020)
	"It should be their choice (to test). We should leave it open to people."	Male, 26 years old	HBOC	Bradbury et al. (2008)

Abbreviation: LFS, Li-Fraumeni syndrome.

[a]The included articles only sometimes provided all the information regarding the participants.

preparatory step to communicate about genetic cancer risk with their children. The authors of our study noted that these findings are consistent with their clinical experience with offspring. We have observed clinically that adult offspring often report that they "knew" or sensed when their parents kept information from them when they were young, and report feeling that they would have liked relevant GRI in their youth.

Hereditary cancer risk impact is emotionally laden information and can result in psychological distress in young people. Offspring can fear for their family's health and their own, and also in relation to their future. The distress levels vary; for some, it peaks immediately at disclosure, while for others it is delayed. Girls may experience negative impacts on self-esteem and body confidence associated with the HBOC syndrome of their mothers. Research on daughters of breast cancer patients has reported a similar negative impact on their body image which may be associated with their mother's illness.[39,40] However, to date, there are few studies that have assessed the psychological impact of growing up knowing about the existence of a genetic risk of cancer in the family, and therefore, interpretations should be applied with caution. Our review indicated unanimity in the children's preference of knowing as soon as possible about the presence of the syndrome in the family and we did not find evidence of the impact of being notified as being harmful.

Children describe coming to realize what genetic risk is, and its possible impact and meaning in their lives, by observing how it affects other family members, especially in relation to the parent that carries the mutation. This includes, for example, the mother's adaptation to her new body image after prophylactic surgery. These vicarious intrafamily learning phenomena have been found in the adaptation process of mutation carriers, both in the adjustment phase to the genetic test result and in the long-term cancer risk management phase.[6,7] The present review adds to these findings by showing that these intra-familial modeling processes start early during adolescence, years before it is possible to undergo genetic testing (e.g., after 18 years old for late onset syndromes). Thus, the adaptation process of the mutation carrier parent can shape health-related behaviors of the future generation, and it is plausible that it influences offspring attitudes and adherence to genetic testing. A related result found in this review was that how children interpret and assimilate GRI is shaped by past and ongoing health events occurring within the family (e.g., a hereditary cancer diagnosis, a surgery of a parent, a loss of a family member to cancer). Previous research with adult family members undergoing genetic testing has found that prior experiences associated with a cancer diagnosis in the family during their youth or childhood can be associated with higher levels of distress during the genetic testing process.[40] Therefore, family health-related events may have important emotional resonance over time in offspring, and contribute to new concerns and meanings attributed to GRI, and suggests the need for ongoing monitoring and support. Such emotional monitoring and support may not have to be exclusively performed by parents, as studies in our review demonstrated the desire of offspring to meet with a genetic counselor or other health professional. However, we note that children in the reviewed studies expressed preference for parents as having the *primary role* in revealing GRI and in helping them to keep pace with the learning process of living with hereditary cancer risk. Good communication by parents to children has been linked to positive long-term effects.[9] This can be a difficult task for parents, particularly among those who are emotionally affected themselves by the genetic information and who may feel unprepared in how or what content specifically to provide to an offspring member of their family.

4.1 | Clinical implications

Our findings have implications for GC and psychosocial care. Genetic counseling and other health professionals can provide support and psychoeducational guidance, which is crucial to support parents to cope with and manage their own personal feelings and experiences through the disclosure process[13,14,41] (see Forrest et al. (2007) for some guidelines). Parents can also be supported to consider how the information they provide is received in relation to its accuracy and encouraged to pay attention to children's responses, comprehension and health beliefs. Evidence-based interventions have shown benefits in supporting family communication about cancer risk.[42–44]

The literature recommends follow-up visits or appointments with a psychosocial specialist to discuss potential impacts of cancer/risk knowledge, the progress of family communication,[38] and to support adaptation to new information.[9] Our findings showed that offspring directly expressed a need for accurate information regarding genetics and hereditary disease, to help inform and support their adjustment to the genetic risk and understanding of what it means for themselves. We also found the existence of age-specific preferences for content of health literacy (e.g., more detailed information needs in emergent adults). Thus, in addition to reducing uncertainty and potential distress, genetic health literacy for offspring may reduce health beliefs biases, such as the one that we found in young males, who perceived their risk of the BRCA gene mutation as being minimal, despite their increased risk for other types of cancer including prostate, pancreatic and male breast cancer. Greater attention and publicity concerning genetic risk and male breast cancer are needed, as well as gender-neutral communication and information material.[45] This review supports a family-centered approach in GC and risk management care, that targets the psychological adaptation of the family unit, especially when there are children. Genetic counselors can support communication within the family system by assisting the primary recipient in their plans for, and process of disclosure of GRI to family members and reinforce the importance of ongoing open communication channels over time.

4.2 | Study limitations

One limitation of this review is that it provides little information about the perspectives and experiences around genetic testing for cancer from offspring across various cultures. We could only identify

15 articles from four countries (mostly United States, United Kingdom, and Australia), addressing mostly two genetic cancer syndromes (HBOC and LFS). Cultures are known to vary in relation to family belief systems and values which may impact responses and adjustment to genetic information,[34] so further international studies are needed. Another limitation of this review was the small number of studies with only children as participants, which informed our decision to also include studies with adult offspring who retrospectively reported on their experiences as children (when they were <18 years old). Thus, our review relies on the inclusion of data sustained by a few articles. The experiences described by offspring may have altered over time, leading to a different meaning as people enter adulthood and assimilate information over developmental life stages. Not including parents' perspectives in this review also limited the scope of admissible studies. Furthermore, we also were unable to find studies that investigated families who decided not to disclose GRI to offspring. A family is a system and in not having every member's perspective (which may differ) and across various situations (e.g., in families choosing not to disclose GRI to offspring) calls for caution about the generalization of these findings. We note that we also included papers with multiple goals and that did not specifically focus on minors' experiences of being in an at-risk family. Finally, it is important to note that we included studies with samples that involved both pediatric and adult-onset syndromes. This is an important limitation to note, as the age eligibility for genetic testing differs between that for early onset versus an adult-onset disorder. We were unable to ascertain differences between the types of disorders in relation to specific offspring reactions.

5 | CONCLUSIONS

Perceptions and experiences among children growing up in a family affected by hereditary cancer syndromes have less often been investigated, representing an important gap in the genetic psycho-oncology field. Children report relying on their parents as being primary informants and models for the hereditary cancer risk experience, and therefore, parents play a central role in the psychological adjustment of children. Parents' personal adjustment to cancer risk influences the openness of children to share their needs and emotions. Offspring are open to, and have a preference for being included in the GC processes to address issues concerning their own potential cancer risk, even before the recommended age for genetic testing. Findings point to the relevance of a family-centered care in hereditary cancer risk that targets not only the mutation carrier individually but also their children and partners.

ACKNOWLEDGMENTS

This work was funded by the Portuguese Foundation for Science and Technology (FCT) (grant EXPL/PSI-GER/1270/2021).

CONFLICT OF INTEREST STATEMENT

We have no known conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

PROSPERO REGISTRATION

CRD42021229926, https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021229926.

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How to cite this article: Lima E, Esplen MJ, Martins F, Alves M, Sales CMD. Communication about hereditary cancer risk to offspring: a systematic review of children's perspective. *Psychooncology*. 2023;32(6):875-887. https://doi.org/10.1002/pon.6141