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Influence of family communication in the adjustment to genetic cancer risk: A review of reviews

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INFLUENCE OF FAMILY COMMUNICATION IN THE ADJUSTMENT TO GENETIC CANCER RISK: A REVIEW OF REVIEWS

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Resumo

O cancro hereditário é um fenómeno com implicações familiares a vários níveis, incluindo a nível psicológico. Várias revisões sintetizaram diferentes estudos relacionados com aspetos comunicacionais dentro da família, relativamente ao risco de cancro genético, estando as provas atualmente dispersas. Consideramos necessário um resumo estruturado das revisões, para encontrar pontos comuns e temas partilhados. Assim, esta revisão de revisões sistemáticas pretende sintetizar o conhecimento existente sobre a influência da comunicação intrafamiliar no ajustamento psicológico e nos comportamentos de prevenção de cancro hereditário por parte de portadores de variantes patogénicas que aumentam o risco de cancro. Tem como objetivo a resposta às questões:

1) Qual a influência da comunicação intrafamiliar no ajustamento psicológico e no comportamento de prevenção do cancro hereditário? **2)** Quais são os tipos de comunicação intrafamiliar existentes? Entre quem? **3)** Quais são os facilitadores e moderadores da comunicação familiar?

Foi realizada uma pesquisa intensiva de revisões sistemáticas da literatura contendo estudos sobre o impacto da comunicação familiar no teste e aconselhamento genético para o cancro hereditário publicados entre 2000 e 2020 nas bases de dados da EBSCO, PubMed, SCOPUS, Medline, google académico e centre for reviews and dissemination (CRD). Após um processo de triagem sistemática, foram incluídas 8 revisões finais categorizadas em três grupos dentro da comunicação familiar: **a)** Emoções e perceções; **b)** revelação e partilha; **c)** barreiras e facilitadores. O tema mais abordado foi influência da comunicação familiar no ajustamento psicológico em geral, seguido da comunicação entre pais e filhos e da experiência de jovens adultos com a informação genética.

Conclui-se que a Comunicação familiar sobre a informação do risco genético de cancro tem um impacto significativo no ajustamento psicológico. Diferentes emoções podem surgir da revelação desta informação, sendo que a maioria dos indivíduos prefere saber a sua condição para que possa procurar, gerir, prevenir e tomar decisões.

Palavras chave: Cancro hereditário; comunicação familiar; ajustamento psicológico; teste genético; aconselhamento genético; prevenção.

Abstract

Hereditary cancer is a phenomenon with family implications on several levels, including psychological. Several reviews have synthesized different studies related to communicational aspects within the family, regarding the risk of genetic cancer, and the evidence is currently dispersed. We consider that a structured summary of the reviews is necessary to find common points and shared themes. Thus, this systematic review aims to synthesize the existing knowledge about the influence of intrafamily communication on psychological adjustment and hereditary cancer prevention behaviors by carriers of pathogenic variants that increase cancer risk. It aims to answer the questions:

1) What is the influence of intrafamily communication on psychological adjustment and hereditary cancer prevention behavior? **2)** What types of intrafamily communication exist? Among whom? **3)** What are the facilitators and moderators of family communication?

An intensive search of systematic literature reviews containing studies on the impact of family communication on genetic testing and counseling for hereditary cancer published between 2000 and 2020 in the EBSCO, PubMed, SCOPUS, Medline, academic google, and centre for reviews and dissemination (CRD) databases has been conducted. After a systematic screening process, 8 final reviews were included categorized into three groups within family communication: **a)** Emotions and perceptions; **b)** disclosure and sharing; **c)** barriers and facilitators. The most discussed theme was the influence of family communication on psychological adjustment in general, followed by communication between parents and children and the experience of young adults with genetic information.

It is concluded that family communication about genetic risk information of cancer has a significant impact on psychological adjustment. Different emotions can arise from the disclosure of this information, and most individuals prefer to know their condition so they can seek, manage, prevent and make decisions.

Keywords: Hereditary Cancer; Family communication; Psychological adjustment; Genetic testing; Genetic counseling; Risk management

Introduction

The rapid advance in the field of genetic health has created challenges for families because of the ability of genetic prediction tests identifying the probability of an individual and his relatives developing a genetic disorder (Roland & Wiliams, 2005). A genetic prediction test for cancer risk identifies an inherited gene mutation, by searching for specific changes in gene chromosomes. The main reason for carrying out a genetic susceptibility predictive test is that results can confirm or rule out a suspected genetic condition or estimate a person's risk of developing hereditary cancer in their lifetime (GHR, 2020). In case of a positive testing result, it is possible to prevent the onset of the disease or detect it at an early stage, which can be both empowering and threatening at the same time (Metcalfe, Coad, Plumridge, Gill & Farndon, 2008).

A positive result has relevance not only for the individual who decides to undergo the test but also for relatives, because if a mutation is found, it can be transmitted from parent to child within a family. Families need to understand the beliefs and legacies that guide their constructions of meanings about health problems and their relation to care-giving systems and healthcare providers (Rolland, 2005). The impact of a diagnosis of cancer reverberates throughout the family system, leaving no one untouched. Is important for families to understand that medical implications and decisions arise when a relative test is positive. The first decision is the test uptake, which can be experienced as a very remarkable and highly significant life event, due to the set of dilemmas and choices that place people at risk for the disease (Motulsky, Andrews, Fullarton & Holtzman, 1994). It is important that family members undergo genetic education and counseling before testing. This will allow them to understand diagnosis better and make informed and shared decisions regarding the various medical management options (Cancer Genetics Editorial Board, 2020).

The decision whether to perform the test is influenced by high levels of concern about cancer, expectations about the test results and the desire to clarify the genetic status of children (Zagalo-Cardoso & Rolim, 2005). After the test, preventive risk management strategies need to be considered, that can include lifestyle changes, regular screenings or even prophylactic surgery (Reynier et al, 2011).

Besides medical implications, this threat of a hereditary pathology causes a significant emotional impact on both individuals at genetic risk and the family group (Zagalo-Cardoso & Rolim, 2005). The state of risk for genetic diseases represents a situation of chronic emotional overload caused by the boundary between health and illness becoming

more blurred by the designation of genetically at risk (Roland & Williams, 2005). Different variables may influence psychosocial adjustment to genetic information, including health system factors such as the type of test, disease status and risk information, but also individual and familial factors, cultural factors and communication (Cancer Genetics Editorial Board, 2020). Families will need to learn how to master the practical and emotional tasks of the immediate situation while dealing with the complexities and uncertainties of cancer in an unknown future (Rolland, 2005). This uncertainty makes psychosocial impact assessment especially important in the genetic counseling process (Rolland, 2005).

So, when talking about genetic testing and counseling, it is necessary to include the period of life of an individual who perceives having a genetic predisposition to an illness but has no symptoms. It is also important to consider the impact of the disease over time (Roland & Williams, 2005). The Roland's Family Systems Genetic Illness (FSGI) model expands the definition of disease, including the time prior to diagnosis and the influences of the genetic information on the family system in long term (Roland & Williams, 2005). This model is designed for examining the relationship between individual and family dynamics with genomic disorders, offering a way of thinking about the pattern of expectable psychosocial demands. Grounded in a strength-oriented perspective, the FSGI views family relationships as a potential resource (Rolland, 2005). Therefore, a family-centered model like FSGI is very important on helping to understand how this information influences coping and adaptation, and the implications for all family members and relationships (Roland & Williams, 2005).

In this process, the role of intra family communication has been investigated. Nycum, Avard and Knoppers (2009) believe that communication within the family of genetic information is very important and one of the factors that influences the psychological adjustment of the individual and their decision making. Although it may look unhelpful to classify family communication, it seems important to find an operational definition of what this communication about genetics should be (Mendes, Paneque, Sousa, Clarke & Sequeiros, 2016). According to DeMarco and McKinnon (2007), family communication of genetic information is both private and shared. Can be defined by obtaining medical information from relatives and/or inform family members of their results and the availability of predictive genetic testing and screening where available, in case a mutation is identified (Wiseman, Dancyger & Michie, 2010). Four functions of communicating within families about genetic risk can be identified: discharging responsibilities for informing the family;

needing to gain emotional support and advice; obtaining family information and preventing illness by telling those at risk (Wiseman et al., 2010).

Family communication styles vary in a continuum, ranging from disengaged to involved and can change over time as family members go through their life cycle. The decision whether to communicate genetic information can be affected by concerns regarding privacy, stigmatization, discrimination, its organization, changes in life cycle, cultural factors and family belief system (Mendes et al., 2017).

The belief systems of a family can have a great influence in communication (Peterson, 2005). These beliefs may relate to the meaning that a given disease has in a family that will impact on the interpretation of and response to risk information, which can last for generations (Walsh, 2015).

While some elements are easier to talk about, others tend to block the communication process. Open communication about genetic information seems to occur more easily between women, first degree relatives or spouses (Wiseman et al. 2010). On the other hand, this information is less likely to be passed on to family members under the age of 18 and mothers find it very difficult to pass this message to their adolescent daughters in the case of a positive result (Croyle & Lerman, 1996). An open family communication approach allows family members to develop a sense of understanding and support, which makes them to cope and adjust better to living with a genetic condition (Croyle & Lerman, 1996).

Providing relevant information about genetic status, risk reducing strategies or regular surveillance for relatives will increase their ability to make informed management decisions, early detection and prevention (Seymour, Addington-Hall, Lucassen & Foster, 2010). Literature shows that individuals want to be informed and knowledgeable about the condition affecting their family so they can accept genetic risk (Rowland & Metcalfe, 2013), pursuit more genetic information and engage in general health behaviors such as exercise, smoking cessation and healthy eating (Young et al., 2017; Rowland & Metcalfe, 2013). Thereby, this suggests that communicating the test result within the family will hopefully be leading to early detection, regular screening and to fewer cancer deaths in these families (Seymour et al., 2010; Wiseman et al., 2010).

There are two review of reviews about family communication focusing on providing guidelines to genetics specialists. The first one from Mendes et al. (2016) focus on how family communication about genetics is approached in genetic counselling practice and the characteristics of the interventions assisting patients in their communication of genetic

information to their relatives. The second one by Peterson et al. (2018) had the purpose to assess currently available reviews of research on communication issues related to Cancer-related genetic and genomic testing. However, none of these summaries explores and analyses intra-family communication issues, related to cancer genetic risk and long-term management.

A preliminary exploration of the literature shows that several reviews have synthetized different studies related to communicational aspects within the family, regarding genetic cancer risk. Specifically, five reviews approaching the influences of family communication of genetic information on the psychological adjustment in general (Seymour et al., 2010; Nycum et al., 2009; Gaff et al., 2008; Wiseman et al., 2010; Eijzenga et al., 2014), two focusing on the communication between parent and child (Metcalfe et al., 2008; Rowland & Metcalfe, 2013) and one exploring the experience of young adults with the genetic information (Young et al.,2017).

Therefore, evidence is currently dispersed and we consider necessary a structured summary of reviews, to find commonalities and shared themes across the studies to understand the process and content of communication, the information needed, and the experience of this communication. More specifically, we aim to understand more about genetic communication existing between the family members, from the disclosure to the uptake of clinical procedures.

Findings from reviews will be summarized to clarify the implications of family communication for clinical practice and families that identify with these problematics.

The objective of this review is to synthesize existing knowledge about the influence of intrafamily communication on psychological adjustment and hereditary cancer prevention behavior, including genetic testing and cancer risk management over time.

Specifically, we aim to provide answers to the following questions:

1) What types of family communication exists? What is this communication about? To whom and between whom?
2) What are the facilitators and barriers of family communication?
3) What is the effect of family communication on the psychological adjustment and preventive behaviors? What are the communication mechanisms involved?

Methods

1. Literature search

To focus on more recent research, a comprehensive electronic literature search of articles published between 2000 to 2020 was conducted by two researchers (A and PG). Following Smith, Begley, Devane & Clarke (2011), for this systematic review of reviews we limited the searches to databases specific to systematic reviews. Therefore, the search included: EBSCO host databases, PubMed and Centre for reviews and dissemination (CRD).

Controlled vocabulary (MeSH, and PsycInfo Subject Headings) and keywords were used. The broad categories for search terms included**:** Hereditary Cancer, Family communication, Psychological adjustment, Decision making and test uptake, Genetic testing, Genetic counseling, Risk management, Family Disclosure, Adaptation, Prevention, Emotions. The following terms were defined and searched as: ("Hereditary Cancer" OR "Gene* cancer" OR "Hereditary syndrome" OR Inherited OR "Lynch syndrome" OR "Nonpolyposis Colorectal" OR "breast and ovarian" OR BRCA* OR "Familial adenomatous polyposis" OR "Gastric Diffuse" OR "Juvenile Polyposis" OR PALB* OR Li-Fraumeni) AND (Famil* OR Couple* OR Kindred OR Sibship* OR Marital OR Parent-child OR Spouse* OR brothers OR sisters) AND ("Family communication"[tiab] OR Communicat* OR disclosure OR Shar* OR Transmit* OR Advice OR Expe* OR support OR information OR issues OR Charact*) AND (Adaptation OR psych* OR emotional OR distress OR anxiety OR anger OR worry OR fear OR "risk perception" OR meanings OR outcomes OR decision* OR prevent* OR uptake OR test* OR counsel* OR mastectomy OR Colectomy OR Gastrectomy OR Colonoscopy OR Suveillance OR managment OR "risk management" OR prophylatic OR barriers OR facilitators OR adjustment OR depression OR trauma OR Personali* OR Programs OR knowledge OR Treat*). In addition, the indexes of three relevant journals (European Journal of Human Genetics; American Journal of Human Genetics; Hereditary Cancer in Clinical Practice; Cancer Genetics; Familial Cancer; Health Psychology and Psycho-Oncology) were hand searched to identify additional relevant articles missed by this strategy.

PRISMA guidelines were followed throughout (Moher et al., 2009). The review was prospectively registered on the PROSPERO database and the protocol has the registration number: CRD42020199092.

2. Inclusion and exclusion criteria

Two authors (A and PG) independently evaluated each of the 201 reviews for possible inclusion. For the current analysis, any peer-reviewed English language systematic or scoping review that synthesized empirical studies was included if it was published in 2000 or later. Studies were also eligible if included variables related to family communication about genetic testing and/or hereditary cancer management focus on communication between family members about cancer related genetic risk. Articles were excluded from the study when they were determined to be commentaries, narrative reviews without a systematic search process, contained less than two empirical studies focused on cancer-related genetic risk. The inclusion and exclusion criteria are shown on Table 1.

A total of 201papers were initially identified through databases search using the filters Meta-Analysis, Review and Systematic Review according to our study design inclusion and exclusion criteria. Two authors (A and PG) independently evaluated each of the 201 reviews for possible inclusion, initially using the title and abstract from the citation and papers were excluded when both reviewers agreed that inclusion criteria were not met. Disagreements were re solved by discussion until an agreement was reached. After duplicates removed 185 records were elected for title and abstract screening where 164 were excluded, leaving 21 articles for full text assessment.

Of those 21 articles, 13 were excluded with reasons. Five reviews had “wrong outcomes”, meaning that the focus was on health care professionals and patient communication and not on the communication within the family. Six reviews had “wrong study design”, being commentaries or narrative reviews without a systematic search process. One Review was excluded for not being an English language review and the last one was excluded for having the “wrong patient population”, focusing on children’s adjustment to the disease.

At the end, 8 papers were deemed eligible for final inclusion as shown in the full PRISMA 2009 flow chart for this review (Figure 1). All the remaining papers were eligible for quality appraisal.

Table 1

Inclusion and Exclusion criteria

	Include	**Exclude**
Participant	**1)** age ≥ 18 years; **2)** History of family genetic cancer; **3)** tested for inherited cancer risk; **4)** undergo prophylactic treatments; **5)** unaffected mutation carriers;	**2)** affected mutation carriers (oncological patients).
Intervention	Studies describing the influence of family communication in genetic counseling.	Studies not focusing on communication between family members about cancer related genetic risk.
Comparator	N/A	N/A
Outcome	Studies exploring: **1)** genetic test; **2)** Cancer risk management; **3)** genetic counseling; **4)** decision making; **5)** prophylactic treatments; **6)** barriers and facilitators. **AND** The impact of family communication in: **7)** psychological adjustment; **8)** emotional status of the individual and their family.	-
Study Design	**1)** systematic reviews **2)** metanalysis **3)** English language published between 2000 and 2020	**1)** commentaries, narrative reviews without a systematic search process. **2)** contained less than two empirical studies focused on cancer-related genetic risk

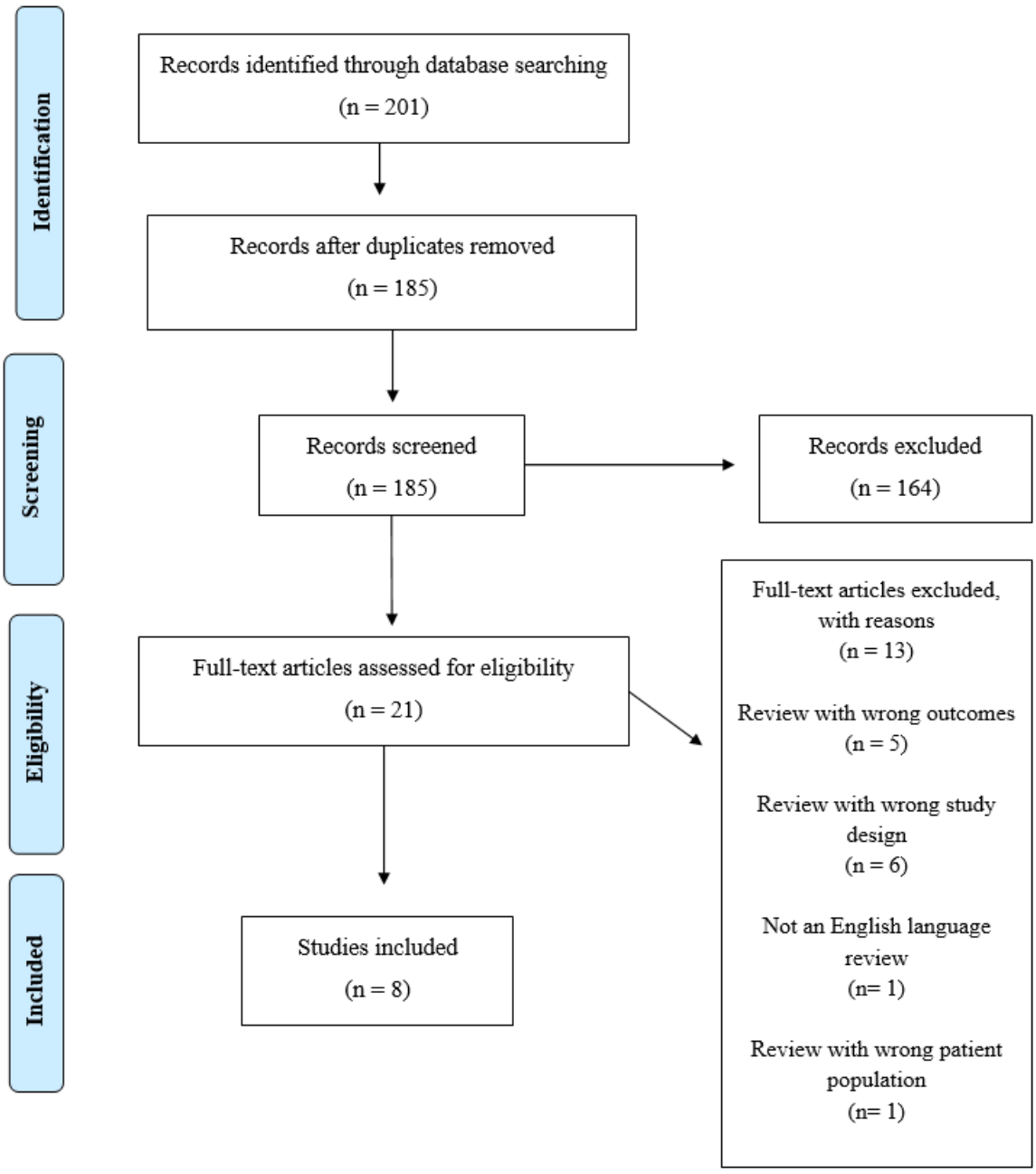

Figure 1**. PRISMA 2009 flow diagram (Moher, 2009).**

3. Quality assessment of reviews

Quality can be defined as the likelihood that the design of a systematic review will generate unbiased results (Shea et al., 2009). In this analysis, the quality and relevance of each paper were assessed using the Quality Assessment Tool AMSTAR. This instrument is easy to use, recently tested and shows a good agreement, reliability, construct validity and feasibility to assess the quality of systematic reviews (Shea et al., 2009).

The two authors (A and PG) independently assessed the articles and rated them (see Table 2). The ratings were compared, and discrepancies were resolved by discussion to achieve consensus. No reviews were excluded regarding lack of quality.

Table 2

Quality assessment

Article / Criteria for quality assessment	Rowland et al., 2013	Wiseman et al., 2010	Seymour et al., 2010	Young et al., 2017	Eijzenga et al, 2014	Gaff et al., 2007	Metcalfe et al., 2008	Nycum et al., 2009
Was an 'a priori' design provided?	✗	CA	✓	✗	✗	✗	✗	✗
Was there duplicate study selection and data extraction?	✓	✓	✓	✓	✓	✓	✓	✓
Was a comprehensive literature search performed?	✓	✓	✓	✓	✓	✓	✓	✓
Was the status of publication (i.e. grey literature) used as an inclusion criterion?	✓	✓	✓	✗	✗	✓	✓	✓
Was a list of studies (included and excluded) provided?	✓	✗	✓	✓	✓	✓	✓	✗
Were the characteristics of the included studies provided?	✓	✓	✓	✓	✓	✓	✗	✗
Was the scientific quality of the included studies assessed and documented?	✓	✗	✓	✓	✗	✗	✗	✗
Was the scientific quality of the included studies used appropriately in formulating conclusions?	✗	✗	✗	✓	✗	✗	✗	✗
Were the methods used to combine the findings of studies appropriate?	NA	NA	✓	NA	✓	NA	✓	NA
Was the likelihood of publication bias assessed?	✗	✗	✗	✗	✗	✗	✓	CA
Was the conflict of interest stated?	✓	✓	✗	✓	✗	✓	✓	✓

Yes - ✓ / No - ✗/ Can't answer - CA / Not applicable – NA

4. Data extraction and analysis

Consistent with a review of reviews analysis methodology (Smith Begley, Devane & Clarke, 2011), the units of analysis for this study were the reviews themselves and not the individual studies synthesized in each review. The first author extracted the data into tables detailing each study's contribution to addressing the research questions. The second researcher read the papers and discussed and agreed the findings to minimize researcher bias methodology (Smith Begley et al. 2011). Data extracted were developed into a final set of analytical categories, and categorized by relevant findings across the cancer genetic counseling communication continuum, including: **(a)** emotions and perception; **(b)** disclosure and sharing; **(c)** Barriers and facilitators of communication.

Each review could be included in more than one category and only relevant results to this analysis were included. For example, the reviews may discuss different topics, but only the data related to family communication empirical studies were included.
The studies are summarized on Table 3.

Table 3:

Summary of the reviews included

Author, year	Design	Focus	Population	Aims
Rowland et al., 2013	Qualitative meta-synthesis and thematic analysis	Disclosure from parents to children	Parents of children with Cystic Fibrosis, Duchenne Muscular Dystrophy, Familial Adenomatous Polyposis, Hereditary Breast and Ovarian Cancer, Huntington's Disease, Neurofibromatosis and Sickle Cell Anaemia.	To understand what factors influence the how, what and when genetic risk information is disclosed within the family; To identify the emotional and psychosocial implications of disclosure or non-disclosure on families; To explore what kind of genetic information do children and young people need; To identify what recommendations would better support family communication.
Gaff et al. 2007	Systematic review	Process and outcome in communication of genetic risk within families	Families with hereditary cancer syndromes, Huttington's Disease, Cystic Fibrosis and Chromosome anomalies.	To understand the process by which communication occurs within the family as well as its outcomes.

Metcalfe et al. 2008	Qualitative Meta-Synthesis	Disclosure from parents to children	Parents and children from families with hereditary. conditions	Explore parents and their children communication about inherited genetic risk.
Seymour et al. 2010	Systematic review and meta-synthesis of qualitative research	Family communication following genetic testing of cancer risk	Families with hereditary cancer.	To review the qualitative literature about facilitators and barriers of family communication following genetic testing for cancer risk.
Wiseman et al. 2010	Systematic Review	Family communication of genetic risk information	Families with hereditary cancer.	To review evidence about communication of genetic risk information within families.
Young et al. 2017	Systematic Review with Narrative synthesis	Family communication, risk perception and cancer knowledge	18 to 40-year-old individuals identified with mutation in the BRCA 1/2 gene or who have a parent identified with the same mutation.	To assess how parents communicate about cancer risk with their young adult children; To evaluate the knowledge of young adults from families identified with the BRCA ½ mutation about hereditary cancer; To describe the experiences of adults aged 18-25 regarding family communication and coping with hereditary cancer risk
Eijzenga et al. 2014	Systematic review and Meta-analysis	Psychosocial issues of individuals in genetic counseling	Individuals undergoing genetic counseling for cancer.	To provide an overview of specific psychosocial issues encountered by individuals undergoing genetic counseling for cancer and o identify overreaching themes that contain the most important problems found.
Nycum et al. 2009	Systematic Review	Intrafamilial communication of HBO genetic information	Adults with higher risk for hereditary breast and ovarian cancer.	To review the factors influencing intrafamilial communication of HBOC information at individual family and community levels. Explores also cross cutting factors such as the complexity of this information and the responsibilities that it can give rise to.

Results

The literature search covered periods from 2000 to 2020 and in total, this analysis included eight English Language systematic reviews of the literature with three including a metanalysis. The number of studies included in the reviews ranged from 12 to 33 (M = 20).

Overall, the papers reviewed addressed different topics: 5 of the reviews approached the influences of family communication of genetic information on the psychological adjustment in general (Eijzenga et al. 2014; Gaff et al., 2008; Nycum et al., 2009; Seymour et al., 2010; Wiseman et al., 2010.), 2 focused on the communication between parent and child (Metcalfe et al., 2008; Rowland & Metcalfe, 2013) and 1 explored the experience of young adults with the genetic information (Young et al., 2017).

However, it is important to note that all literature reviews included in this study highlight the enormous emotional burden associated with family communication about the risk of genetic cancer. Furthermore, 7 of the reviews (Gaff et al., 2007; Metcalfe et al., 2008; Nycum et al., 2009; Rowland & Metcalfe, 2013; Seymour et al., 2010; Wiseman et al., 2010; Young et al., 2017) focus on the process of family disclosure of this risk and 4 (Gaff et al., 2007; Nycum et al., 2009; Seymour et al., 2010; Wiseman et al., 2010) clearly indicate barriers and facilitators to family communication.

1. Emotional burden in communication

Families experience a wealth of emotions associated with the communication of genetic risk information (Rowland & Metcalfe, 2013). For some individuals, genetic testing was a negative experience, imbued with guilt, burden, responsibility, anxiety, and shame (Wiseman et al., 2010). Terms like stress, fear, cancer worries, shock and distress, anger, frustration or disappointment, loneliness, resentment, jealousy and feelings of loss are common (Eijzenga et al., 2014; Metcalfe et al.,2008).

Feelings of guilt (Young et al., 2017) isolation and burden responsibility (Eijzenga et al.,2014; Seymour et al., 2019; Nycum et al, 2009; Wiseman et al., 2010; Gaff et al., 2007) are related to being the one who gives the ‘bad news’ (Eijzenga et al.,2014; Nycum et al., 2009; Seymour et al., 2019; young et al., 2017). Guilt is associated with passing a mutation to their children (; Nycum et al., 2009; Wiseman et al., 2010; Young et al., 2017). There’s also guilt when themselves test negative and reporting a negative result to other family members who tested positive or already have the disease (Eijzenga et al., 2014; Nycum et

al., 2009; Young et al., 2017; Wiseman et al., 2010). Several different types of guilt were expressed by unaffected siblings based on their feelings and behavior towards their ill sibling including guilt about feeling relieved that they were not affected, and also guilt that they could leave the family home on reaching adulthood (Metcalfe et al., 2008). Adults with their own children described guilt for potentially passing on the mutation, yet there were no reported regrets about the decision to have children (Metcalfe et al., 2008; Young et al., 2017.).

When it comes to fear, individuals are concerned about how family members might react to the information (Rowland & Metcalfe, 2013), or about the mutation status of the relative and feelings of frustration where relatives chose not to be tested, or did not view the risk as serious (Wiseman et al., 2010). Young adults say fear for their parent's health, themselves and for future generations may arise from this communication (Young et al., 2017). The feeling of fear leads to lowered self-esteem contributing to being bullied, suicidal thoughts or engaging in risky behaviors such as self-harm (Rowland et al., 2013). Although a short percentage reported a continuing uncertainty over time and increased fear of cancer (Young et al., 2017), for some individuals fears reduce over time by having more genetic information and engaging in health behaviors, causing acceptance (Young et al., 2017).

To pass on genetic information was seen as emotionally demanding and a heavy responsibility to carry (Eijzenga et al., 2014; Gaff et al., 2007; Nycum et al., 2009; Seymour et al., 2019). Sometimes individuals feel a dilemma between responsibility to inform and not wanting to cause harm or distress, which poses tension to the informant (Seymour et al., 2010). Some individuals say the main motivation for undergoing genetic testing is the fact that they want to gain information for their families (Nycum et al., 2009; Seymour et al., 2019). Particularly women experience conflicting senses of responsibility and some saw testing as an opportunity to take up a moral obligation to family members (Nycum et al., 2009). Females can easily talk about this kind of information and do not consider it an issue (Seymour et al., 2009). Parents' expressed emotions of anxiety worry and concern with many relying on their own experiences of a genetic condition in the family to inform how they handle information giving to their own children (Metcalfe et al., 2008).

Feeling of apprehension may arise about the potential harmful nature of the information (Seymour et al., 2010) and some individuals expressed concerns regarding to relatives' reactions (Nycum et al., 2009; Wiseman et al., 2010.) that there would be blame, backlash or negative impact in relationships (Nycum et al., 2009). Informants reported a mixture of responses from relatives involving emotional aspects, such as sadness or surprise,

and practical aspects, such as desire to be tested or screened (Wiseman et al., 2010). For others, telling a relative that they had a mutation led to extreme negative responses, such as distress, silence, confusion, and blame (Wiseman et al., 2010).

In contrast, Eijzenga (2014) e Wiseman (2010) indicated that the majority of the individuals report positive emotions after the communication of the genetic cancer risk information, that include feeling reassured, relief, reduced anxiety and/or worries. Some feel greater awareness and empowerment from knowing (Metcalfe, 2008; Young et al., 2017.), and some only express frustration when they wanted to proactively mitigate their risk by pursuing risk management options but were considered too young (Young et al., 2017).

2. Family disclosure of the risk

It seems that disclosure of the test result should be a process, rather than a single one-off event, and differ from person to person (Rowland & Metcalfe, 2013). Some individuals wait for the right time, others schedule a family meeting to do it and, when there's a history of cancer in the family, individuals usually discuss the history with a close family member, so the information is passed before de consultation, facilitating open communication (Nycum et al., 2009). Some needed to time to absorb the information and make decisions while others found sharing their information helped them do this (Seymour et al., 2010).

The right 'time' appears to refer to both life stage, for example, availability of surveillance for cancer, forthcoming marriage, or children, and to the right opportunity, for example during normal social contact (Gaff et al., 2007). Death and disease in the family made it difficult to initiate discussions and most of the times they wait until receipt is in a better place to deal with the information (Rowland & Metcalfe, 2013; Seymour et al., 2010; Young et al., 2017).

When an individual does not 'immediately' communicate information about genetic risk to their relatives, it appears that they undergo a period of deliberation in which decisions about disclosure are made (Gaff et al., 2007): (1) consideration of the effects of disclosure, (2) selection of what information to disclose, and (3) planning the timing of disclosure. Communication disclose with relatives happens within a week and late disclosure is less common (Gaff et al., 2007). Individuals who did not have increased genetic risk, disclosure was unproblematic unless disclosing to family members who did have increased genetic risk (Wiseman et al., 2010).

The decision to disclose or not, was often based on the anticipated reactions of family members or their perceived receptivity (Gaff et al., 2007; Seymour et al., 2010) and can have significant impacts on family cohesion or the commitment to the long term care which can lead to tensions that may result in family breakdown or divorce (Rowland & Metcalfe, 2013). Discussing genetic risk with life partners, where individuals reported that committed relationships ended after disclosure of positive mutation status (Wiseman et al., 2010). Also, different relationships were formed because of the genetic risk in their family (Wiseman et al., 2010) and roles and responsibilities were adapted after disclosure (Wiseman et al., 2010). On the other hand, some did not perceive a change in their relationships following communication about genetic risk, where changes were reported individuals who were at risk perceived their relationship to become closer (Wiseman et al., 2010).

The authority to disclose followed "vertical" patterns through the family, and occurs often from parent to child (Gaff et al., 2007; Seymour et al., 2010) and both parents and children believe that parents should be the main people to provide genetic risk information (Rowland & Metcalfe, 2013). When it comes to disclosure most parents carefully considered: when to share information, what their child needed to know and how much they felt the child could handle at that time (Metcalfe et al., 2008). Disclose broad categories are, child's potential risk or carrier status, parent's genetic counselling experience, the newborn screening or test process, symptoms, the impact to future children or other family members affected by the condition (Rowland & Metcalfe, 2013).

Parental disclosure of genetic test results to their child usually occurred immediately after the parent's genetic result was disclosed, usually in a casual, open forum, with the tested parent alone (Rowland et al., 2013; Young et al., 2017). One-on-one maternal disclosure was more likely to occur with daughters than with sons (Young et al., 2017) and mothers were often viewed as the best sources of information and support by children and young people (Metcalfe et al., 2008). Parents prefer to disclose information during childhood but depending on child's age, developmental stage and maturity (Rowland et al., 2013; Metcalfe et al., 2008). Some show concerns to harm their children if they disclose information too early, or if their children are not emotionally or cognitively ready to understand the information. However, they do not want to harm their children by communicating risk too late (Rowland & Metcalfe., 2013). Parents believe that early disclosure will allow their children to cope better with the implications of the genetic condition (Rowland & Metcalfe., 2013) and studies show that the critical age is typically between 9–10 years old (Rowland & Metcalfe., 2013).

Parents choose whether to disclose information to all the children in the family or to target children according to whether they are affected, not affected or at risk (Rowland & Metcalfe., 2013). They often waited for children to ask questions or for the topic naturally come up in conversation, before they gave any information or explanation (Rowland & Metcalfe., 2013). Although some said that they started to introduce the idea of inheritance from preschool afraid of an information leak from other sources (Metcalfe et al., 2008). Parents were often motivated to keep their children informed as a reaction because they recall finding out information from a variety of sources which often resulted in misconceptions (Metcalfe et al., 2008).

3. Barriers and facilitators of communication

Six factors were consistently found to influence communication of genetic risk within families, motivating or inhibiting communication: perceived responsibility to tell, relationship type and quality, deciding who to tell, anticipation of relative's reactions, mutation status, and personal feelings (Wiseman et al., 2010).

The main barriers and facilitators of communication are based on the age, maturity level, life stage and perceived risk of the informer (Nycum et al., 2009). If perceived that there's not enough maturity or not at an at-risk life stage communication with them is more difficult to occur (Nycum et al., 2009; Wiseman et al., 2010). Communication is also harder to occur or delayed if an individual is too old or to young, or experiencing an important life event (Gaff et al., 2007; Nycum et al., 2009).

The complexity of risk information is a barrier because it is hard understanding and transferring information to other relatives can be highly defective (Gaff, 2007; Nycum et al., 2009). The comprehensiveness of the communication will differ depending on several factors, such as type of genetic disorder, severity of the disorder, level of predictability and whether treatment or prevention are available (Nycum et al., 2009). The certainty or uncertainty associated with genetic cancer can create barriers to communication (Gaff, 2007; Nycum et al, 2009).

Difficulties in understanding patterns of inheritance, as well as family myths about disease can contribute to communication barriers (Nycum et al., 2009). Rules of family interactions and authority dictate family life and therefore communication patterns (Seymour et al., 2010). Family culture may play a more important role in determining family communication rather than the results of the genetic test itself. Families in which

communication was difficult through conflict or taboo about cancer and its inheritance reported difficulties talking about genetic risk (Wiseman et al., 2010). There may be a failure to inform due to poor or nonexistent communication patterns and a low sense of responsibility to that individual (Gaff et al., 2207).

Experience with cancer within a family may also play a role in communication. In some families' cancer is a taboo which may be a barrier to with the exchange of genetic information and open communication (Nycum et al., 2009). There were also concerns about activating emotions related to the death or illness of a family member and various feelings of guilt, anxiety, and personal exposure were reported as inhibiting communication (Wiseman et al., 2010).

Proximity of the family may be a barrier or to communication when there is a lack of social contact with distant relatives or facilitator to communication. Some of the reasons are difficulty on establishing contact, geographical distance and not feeling emotionally close to them (Nycum et al., 2009; Seymour et al., 2010 Wiseman et al., 2010). Emotional, genetic and demographic distance plays a role in family communication following genetic testing (Seymour et al., 2010). Emotional ties, rather than the genetic relationship, often influenced who was told about predictive testing. Relatives who were more distant, emotionally or physically, were communicated with via telephone or letter (Gaff et al., 2007; Wiseman et al., 2010; Seymour et al., 2010). Brothers are the most difficult to communicate with and friends seem to be the most unconditionally support group (Nycum et al., 2009). Reconstituted families are often at the root of communication barriers (Nycum et al., 2009). Family rifts, tensions, divorce, separation and adoption all create barriers of genetic information (Nycum et al., 2009; Seymour et al., 2010).

Reported difficulties in communication can be also: information not believed or testing rejected; failure or difficulty in understanding; failure to convey results; speaking about cancer; timing; informing the unsuspecting; nonspecific; content or knowledge; emotional reactions (Gaff et al., 2007).

When it comes to facilitating communication, if there is a history of cancer in the family, individuals usually discuss the history with a close family member, so the information is passed before de consultation (Nycum et al., 2009). Some studies found that communication may be seen as a support seeking behavior, finding a decrease in psychological distress among those who tested positive and had communicated their genetic risk with a relative (Nycum et al., 2009).

Family cohesion may facilitate communication and open family communication patterns are likely to extend to genetic cancer communication and minimize cancer related distress (Nycum et al., 2009). Strength of the relationship between relative have influence on family communication (Nycum et al., 2009) and close relatives, socially or biologically communicate more often and tend to have a more open communication (Nycum et al., 2009). Partners and sister tend to communicate more. Perceptions that they were physically and emotionally close to family members facilitated communication of genetic risk information (Wiseman et al., 2010).

So, reported facilitators of communication can be: undergo genetic testing with the intention of gaining information for other family members as well as for themselves; have a sense of duty to warn others of potential risk; have taken time to process the information before telling others; have close relationships with their relatives; and have been encouraged and supported by his/her genetic practitioner to engage in family communication (Seymour et al., 2010). Lastly, the cultural context may also act as a barrier or facilitator. Personal and genetic information is more readily conceived of a as familial information in some cultures, these contexts facilitate communication of genetic cancer information (Nycum et al., 2009).

Discussion

This review summarizes the findings of eight review papers related to family communication of genetic cancer risk information within the family. While there was significant heterogeneity between the reviews because the studies approached distinct topics, we have identified important information that allow us to answer to our investigation questions.

So, in order to verify the first questions, we found out that are different forms of family communication about genetic cancer risk, some initiate before the test, when an individual is trying to find out more about family history and get support for what is coming. Another form is disclosure of test results that is the most studied topic; after that usually family members also communicate about the increased risk for them and the relatives and finally individuals want to have more information about their options, so they can make an informed decision.

Individuals have some careful considerations before communicating this information, such as, when to share, how much relatives need to know and what they feel they can handle at the time (Gaff et al., 2007; Metcalfe et al., 2008; Seymour et al., 2010). The main categories talked are the children's potential risk or carrier status, genetic counselling experience, the test process, symptoms and the impact to future children or family members affected by the condition (Rowland & Metcalfe, 2013). Open styles of communication allow disclosure to become a process as they encourage parents to prepare and gradually inform their children of their risk (Rowland & Metcalfe., 2013). Where open communication existed, young people as they matured into adulthood were cautious about their reproductive decisions and understood the possibility of genetic testing and its consequent effect on their choices and psychological health (Metcalfe et al., 2008; Rowland & Metcalfe, 2013). It was felt that openly discussing the condition empowered the family and enabled individuals to discuss matters and concerns as they arose and increased their support and care for each other (Metcalfe et al., 2008). In families where the communication was more closed, children often felt upset and frustrated with family secrecy (Metcalfe et al., 2008)

Thus, it seems that the communication of genetic cancer risk should be a process, rather than single event, but usually occurs in scheduled family and majority waits for the right time or opportunity to do it, which mainly refers to the individuals life stage, like marriage or children and a normal social contact (Gaff et al., 2007; Nycum et al., 2009; Seymour et al., 2010; Rowland & Metcalfe, 2013; Young et al., 2017). The challenge of

finding the 'right words' is often intensified by anxieties aroused by limited knowledge about the condition and its implications to the future health and reproductive choices (Rowland & Metcalfe, 2013). However, the involvement of family members in the testing process at an early age may minimize the anxiety associated with the information (Nycum et al., 2009), some counselees did not feel understood or supported by their partner or family members (Eijzenga et al., 2014).

Whilst disclosure is reported to improve family cohesion and strengthen relationships (Eijzenga et al., 2014; Gaff et al., 2007;) other research shows that parents fear that disclosure will weaken family relationships resulting in non-disclosure (Rowland & Metcalfe., 2013). In families whose parents were able to contain their own anxieties about the genetic condition decisions to withhold information did not have an impact on family relationships, before or after disclosure (Rowland & Metcalfe, 2013). In general, the functions of disclosure can be: discharging responsibility for informing the family; gain emotional support and advice; obtaining information from the family; and preventing illness through telling those at risk of their risk status (Wiseman et al., 2010).

This kind of communication follows vertical patterns trough the family, meaning that occurs more often from parent to child (Gaff et al., 2007; Seymour et al., 2010). Communication of genetic risk information occurs more often with females' relatives and first-degree relatives rather than more distant relatives or males (Wiseman et al. 2010). Women often appeared to take responsibility for initiating contact with a genetic counsellor and for passing on information within the family (Nycum et al., 2009; Seymour et al., 2010; Wiseman et al., 2010). Communication of genetic risk was found to be a 'gendered' activity, in that women held the responsibility for disseminating results within the family and did most of the statement (Nycum et al., 2009; Rowland & Metcalfe, 2013; Wiseman et al., 2010). Therefore, women are described as "gatekeepers" of genetic information, and they take responsibility for family health care. With this, a disproportionate burden is created for them (Metcalfe et al., 2008; Nycum et al., 2009; Rowland & Metcalfe, 2013).

In this sense, Nycum and collaborators indicated that men seem more comfortable sharing good news, using avoidance as a coping mechanism and are more likely to communicate non carrier status. Men only disclose limited information and its implications to their children (Gaff et al., 2007) and are more likely to recruit intermediaries to inform other relatives particularly (Gaff et al., 2007). Different strategies were observed in men, from complete openness, limited disclosure, to a total secrecy (Gaff et al., 2007). Note that friends seem to be the most unconditionally support group and easy to talk to, just like

partners (Nycum et al., 2009). Brothers are the most difficult to communicate (Nycum et al., 2009).

Beyond this, regarding to the barriers and facilitators to communication, several factors were found to have influence in communicating genetic risk within family such as perceived responsibility, relationship type and quality, deciding who to tell, anticipation of relative's reactions, mutation status and personal feelings (Wiseman et al., 2010).

On one hand, we identified some barriers to communication, like the complexity of risk information which makes its comprehensiveness hard and the uncertainty associated with genetic cancer test (Gaff, 2007; Nycum et al., 2009). Family culture, history and myths about the disease can lead to difficult communication, especially when there was a conflict or taboo about cancer and its inheritance (Nycum et al., 2009; Wiseman et al., 2010). Proximity of the family is a huge barrier, when there is a lack of contact seems more difficult to stablish contact due to not feeling emotionally close (Nycum et al., 2009; Seymour et al., 2010; Wiseman et al., 2010). Reconstituted families are usually on top of communication barriers, just like family rifts, tensions, divorce, separation and adoption (Nycum et al., 2009; Seymour et al., 2010).

On the other hand, we also found facilitators of communication, like family cohesion, strong relationship and being close to a relative socially or biologically (Nycum et al., 2009). Perception of being emotionally close to family members and family culture are other good factors, in some cultural contexts is just easy to talk about genetic cancer information and not a taboo (Nycum et al., 2009; Wiseman et al., 2010). Having a history of cancer in the family also is a facilitator because the topic arises easily and when individuals undergo genetic testing already with the intentions of gaining information for the family, have a sense of duty to warn other and have been supported by their genetic counselor to engage in family communication, the communication arises easily (Seymour et al., 2010).

Lastly, through this investigation we identified important overarching implications of family communication on the psychological adjustment and preventive behaviors. Consistent with previous studies, we predicted that communication could have a major influence in psychological adjustment, and if it is not carried in the right way can cause problems within the family and individuals himself.

The transmission of genetic cancer risk information was seen as emotionally demanding and feelings of guilt, fear and anxiety normally occurred before the communication, for trying to perceive how to do it and how family members would react. The children who are kept in the dark about their condition, often have a sense that something

is wrong and that the family is keeping a secret from them (Rowland & Metcalfe, 2013) and adults who had the truth hidden from them by their parents expressed resentment and continued distrust (Metcalfe et al., 2008).

In families where there was more open communication, children were reported to be more emotionally and psychologically resilient and were often pragmatic in response to genetic risks for themselves (Metcalfe et al., 2008). A limited communication protected the individuals initially, but the inability to openly discuss resulted in tense relationships between family members, even where there were no difficulties in communication (Gaff et al., 2007; Metcalfe et al., 2008).

Majority of the individuals reported positive emotions, and better psychological adjustment from the communication of this information, demonstrating feeling of awareness and empowerment that they can be proactive and pursuit risk management options (Eijzenga (2014); Metcalfe, 2008; Young et al., 2017; Wiseman (2010). Some even report that by having this information, uncertainty and fear reduces over time, because they could search for more genetic information, engage in health behaviors and make supported decisions (Young et al., 2017).

We note that we did not found relevant information about the mechanisms behind family communication.

The reviews found, only superficially link the family communication with the psychological adjustment, talking about the communication process itself and the way it triggers various psychological responses by those involved. Thus, it is not clear in the studies whether there is in fact a direct influence of communication on the family adjustment, or whether, on the other hand, only the psychological responses regarding the communication of genetic information are reported.

This shows that there are not many summaries of evidence focusing on this relationship between family communication and psychological adjustment, so future research should be focusing more on that.

Conclusion

Intrafamilial communication around cancer genetic risk information is a process with many sources of influence in different levels. Genetic risk information can be both empowering and threatening depending on the context in which it is used, how it is relayed and delivered, and the level of support in promoting understanding but also managing the feelings evoked (Metcalfe, 2008). A healthy family communication can have a huge impact on individuals' psychological adjustment and help them to cope better.

Most families still complain about lack of information and report the need of more follow-up by experts in genetic counseling. They feel that if they could have more knowledge on the subject, they could provide better information to their relatives, leading to fewer constringent to communication and therefore better psychological adjustment

Additionally, given the rise of genetic testing, more focus is needed in this area. More practical and effective interventions are needed to minimize the difficulty and the distress related to sharing genetic information are needed to prepare individuals and provide them with coping strategies. It seems necessary to have a "framework" for professional to try and understand the different patterns of communications within families, so they can help families communicate openly and realize at an early stage what communication style exists and what is best way to go. There is a need to be aware of the complex intrafamilial communication dynamics and think about how they can engage families to have a healthy communication, because the reality is that this kind of information can affect the entire extended family.

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