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ORIGINAL ARTICLE

Family matters: examining a multi-family group intervention for women with BRCA mutations in the scope of genetic counselling

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Abstract The availability of family-centred services for women genetically at-risk for breast and ovarian cancer (BRCA) due to deleterious genetic mutations is still scarce, despite the distress that these women and their families may experience. This study describes a multi-family group intervention for women who tested positive for BRCA mutations and their families. Methods include a time-limited psycho-educational programme involving educational and support components and consisting of four semi-structured multi-family sessions. Three families (a total of nine people) attended the programme in genetic counselling for hereditary cancers at a Portuguese public hospital. A focus group interview was performed 1 month after the last session to assess both the practical and the psychosocial impacts and to collect suggestions from participants. The present paper focuses on the practical aspects of the intervention, its development and its evaluation. Participants reported that the programme is well-structured and that responds to the needs of patients and their families by improving coping skills and medical awareness in the adaptation to genetic illness. Results reinforce the need to integrate psychosocial and family-oriented interventions in genetic counselling, addressing the holistic experience of hereditary disease. Recommendations for enhancing the services available are provided. The multi-family discussion group, combining educative and supportive services with a family focus, can be successfully adapted in genetic counselling protocols.

Keywords Genetic counselling · Hereditary cancer · Psychosocial genetics · Psycho-education · Multi-family groups

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Introduction

As genomics continues to expand its expertise in cancer genetics, scientists and clinicians are given the chance to learn more about the illness mechanisms and the available preventive or prophylactic treatments. For those who face an increased genetic risk due to inherited deleterious gene mutations, it is crucial to be able to accommodate this rapidly changing knowledge in their health management and into their lives (Rolland and Williams 2006).

Genetic counselling examines family medical histories to educate clients about their risks for an inherited disorder and the options for dealing with the risk of occurrence (National Society of Genetic Counselors 2006). Cancer risk counselling has grown rapidly in recent years to become a major area of specialisation within genetic counselling. Its main purpose is to evaluate the tumour risk in families whose members have a hereditary predisposition for cancer and to inform them about treatment options and preventive strategies enhancing their ability to make informed decisions (Sifri et al.

2004). These are the typical guidelines for genetic counselling in hereditary tumours, according to the guidelines adopted at the genetic centre where our study was developed: (a) collection of family and individual medical history, (b) genetic risk assessment, (c) predictive testing for genetic susceptibility to cancer and (d) surveillance and preventive screening, treatment and follow-up sessions.

In Portugal, genetic services are generally integrated in the National Health System (NHS), mainly in central hospitals, but also public institutes (partially integrated in the NHS), some medicine faculties and private entities (often assisting with clinical and laboratorial expertise). Cancer genetics services are available in regional oncological hospitals and included under the umbrella of central hospital departments. A National Program of Pre-Symptomatic Test and Genetic Counselling was approved and implemented in the mid-1990s, primarily directed for adult neurological onset disorders and later expanded to other forms of genetic disease (Health General Directory 2004).

Genetic counselling for hereditary tumours commonly exposes the client to a significant degree of uncertainty and various levels of psychological distress, encompassing diverse practical and emotional challenges (Pasacreta 2003; Evers-Kiebooms et al. 2000). The psychological effects of being at increased risk for breast and/or ovarian cancer have been extensively studied, pointing to a frequent experience of distress (Schlich-Bakker et al. 2006). A vast body of literature illustrate the social and emotional effects of genetic conditions, with potentially negative impacts in individuals and families (McAllister et al. 2007; Patenaude 2005). Distress amongst BRCA1/2 carriers fluctuates over a 5-year period and depends on the degree of integration of genetic information attained by individuals (Werner-Lin 2008).

Genetic counselling is increasingly recognised as not solely an individual but also a family matter that poses a complex interweaving of biological and interpersonal interactions across nuclear and extended family members (McDaniel 2005; Peterson 2005). Families exposed to increased genetic risk tend to define their identity based almost exclusively on that experience; this reorganisation around the ambiguous territory of at-risk status and the need to develop coping efforts under emotionally charged contexts are suitable to disrupt key aspects of family functioning, giving the family an identity as a *genetically ill family* (Sobel and Cowan 2000; Patterson and Garwick 1994).

Despite the integration of psychosocial models has been stated as an essential feature of patient care in genetic counselling services (Cappelli et al. 2009), as well as the need to produce investigation reflecting the use of psychosocial support by families (Douma et al. 2008), standard care in such settings usually comprises a predominantly biomedical-oriented protocol, without ongoing psychosocial or family-based support, especially after genetic testing results are delivered (Werner-Lin 2008). Therefore, it becomes crucial to develop family-oriented models of coping, adaptation and integration in inherited risk management, such as multi-family discussion groups (McDaniel et al. 2006).

This paper describes a psycho-educational programme for women carrying a BRCA1 and/or BRCA2 mutation and their families in the scope of genetic counselling during the post-test period. The programme design and the session's contents will be reported, as well as its evaluation through the participants' views on the structural and practical aspects of the programme and the perceived benefits in their lives. In addition, recommendations will be provided on how to adapt further family-oriented psycho-educational interventions in the scope of genetic counselling for hereditary cancers.

Conceptualising psycho-educational intervention in cancer genetic risk

Recent decades have witnessed the significant development of psycho-educational models, which integrate health education and psychosocial support into a multidisciplinary perspective, aiming to increase the family and patient's sense of competence in dealing with the illness and to promote working partnerships between health professionals, families and patients (McDaniel et al. 2005).

Psycho-educational approaches are shown to be more efficient if developed in multi-family discussion groups (Ostroff et al. 2004); this context promotes a non-pathological atmosphere, allowing families to learn and talk about the illness, namely about the way it *invaded* the family identity and how it interferes in its development. Its effectiveness is recognised in particular because (Ostroff et al. 2004) it reduces family stress, it enhances the sense of competence amongst patients and their families and it increases their adherence to treatments. Multi-family discussion groups are time-limited (four to six sessions); they are especially designed to help family adjustment and coping with illness demands and uncertainty, allowing support from people who are sharing the experience and relieving feelings of isolation (Gonzalez and Steinglass 2002). Such interventions have the potential to be integrated into the genetic counselling protocol, since they address the psychosocial interface between medical, individual and familial issues.

Psycho-educational interventions may provide support for individuals and families at-risk for hereditary cancers, by improving mastery and resilience at key points in the illness adaptation process (Werner-Lin 2008). Karp et al. (1999) reported a six-session support group for BRCA carriers, addressing the issue of prophylactic mastectomy and highlighting intervention benefits and cost-effectiveness as a valuable adjunct procedure to individual genetic counselling. Another 6-week psycho-educational

group for women at high genetic risk for BRCA was designed by Speice et al. (2002), addressing core themes and providing recommendations to meet the needs of affected families. A 6-month supportive–expressive group intervention was used to address the medical and emotional needs of BRCA mutation carriers (Esplen et al. 2004). Such programmes, however, do not include other family members (besides the patient), who may also benefit from participation in these programmes.

Planning

Programme design

This programme was designed based on three main sources: (a) existing literature and research on genetic counselling for BRCA mutation carriers and psycho-educational interventions in medical settings; (b) a previous study developed by our team on the experiences of clients undergoing genetic counselling for hereditary cancers, in which participants reported that there should be made available to them interventions focussing on the following aspects: improving clients' psychosocial adjustment; providing medical education and counselling, given their need to understand genetic information; supporting individuals and their families in the decision making process and assisting them in coping with the demands of genetic illness (Mendes et al. 2010) and (c) needs reported by the women at-risk for BRCA; during the recruitment, potential participants were interviewed about their psychosocial needs and the topics they would like to see included in the programme; participants mentioned the following: medical information about BRCA mutation and its implications, preventive and prophylactic treatments available, coping strategies for promoting well-being and psychological support both at a personal and familial level.

Participant's recruitment

Recruitment is a crucial stage in particular because families that show enthusiasm at the first contact may afterwards give up (Ransom et al. 2006); the abandonment rate in this study was 25% (one family); this family, in comparison to the participant families, comprises a larger number of members (especially siblings) and a more accentuated geographical dispersion of their residencies.

Following approval by the ethics committee, participants were selected at the Hereditary Tumours Consultation of the Centre of Medical Genetics and Human Reproduction of the University Hospital of Coimbra (Coimbra, Portugal). Recruitment criteria included that: At least one member of the family was supposed to have tested positive for deleterious BRCA1 and/or BRCA2 mutation. In this study, all family members were eligible to participate in the group, whether or not they had done genetic testing and whether or not they were mutation carriers because genetic risk is a family issue that emotionally affects all family members, men and women, either related or not by bonds of consanguinity (McDaniel 2005; Peterson 2005).

The recruitment process involved the following steps: searching through the service database for eligible participants; making a phone call to present the aims of the study to participants and ask for their collaboration with assured confidentiality; sending letters to those users who agreed to participate, in order to confirm the previously given information and make the same information accessible to other family members and to provide them with an informed consent form to be delivered at the first session; a second phone call was made to deal with practical issues concerning the scheduling of sessions (all were scheduled ahead of time), including a previous family interview; finally, family interviews with the potential participants were made (mostly at the participants home or at the hospital) to collect demographical and psychosocial data and to assess needs.

Participants

One group was set up involving three families and nine people. Participant families included two to four elements (Table 1). Participants were all females linked by blood kinship, including sisters, daughters, grandmothers and aunts (all participants had carried out the genetic test and had increased risk for breast and/or ovarian cancer). The only exception was the husband of a participant, who attended the last session.

Procedure

The programme was implemented in a multi-family discussion group format. There were four semi-structured sessions (Table 2), coordinated by two facilitators, with training in medical family therapy and with previous experience facilitating multi-family groups for patients facing cancer (Chiquelho et al. 2010). Facilitators adopted an active and empathetic posture, in order to assist participants in normalising feelings, reinforce family competencies and resources and mediate the interaction between group participants.

Each session was expected to last 90 min, but time invariably extended to 120 min. All sessions were videotaped with the permission of all participants. The sessions were scheduled at the participants' convenience at weekends (Saturdays, 10:30 a.m.–12:00 p.m.), and they were free of charge for participants. The programme comprised two components: (a) education, aiming at providing up-to-date medical information about BRCA mutations, prophylactic

Table 1 Participants' demographics and cancer history

Participants' demographics and cancer history	*N*=9
Mean age	43.5 (24–74)
Sex	9 females
Race	9 Caucasians
Marital status	
Married	7
Single	2
Average years of education	11 (4–20)
Mean number of months since last genetic testing	21.6 (8–36)
Genetic risk status	9 BRCA mutation carriers
Personal history of cancer	4 affected (1 symptomatic)
Mean number of BRCA in the family	5.66 (2–8)
Average number of at-risk individuals in the family	4.33 (2–7)
Average number of cancer-related deaths in the family	2 (1–3)
Number of participant families	3

treatment options and community-based resources, and (b) support, including disclosure and family reactions to testing, emotional reactions and coping strategies, and addressing family identity. Each session had the flexibility needed to integrate themes that spontaneously emerged from the participants.

First session

The aim of this session was to explore the impact of genetic risk awareness in the family. Initially, the need to maintain confidentiality amongst participants was underlined, and permission to videotape all sessions obtained. After presentations of both participants and facilitators (who also introduced the programme format and contents), participants were gathered by family and encouraged to share the negative and positive aspects that had emerged. It was emphasised that such knowledge is commonly perceived as alarming; however, thinking about family functioning opens the possibility of recognising the significant aspects of such an experience. The positive aspects highlighted by participants were family union and affective strength, whilst the negative aspects included the face of uncertainty in the future, excessive concern with symptoms and increased anxiety and distress. Next, families were invited to think about how they could overcome the negative aspects, having mentioned that such effort may be achieved if closeness and solidarity amongst family members is improved and if access to medical education is provided. Conclusions were shared amongst all participants. This was an emotionally intense phase, creating thus empathy amongst participants and facilitators. Finally, a home task was requested: Each family was asked to gather and discuss their doubts and concerns about their genetic risk condition, in order to discuss these with the doctor, who should be present at the following session.

Second session

This session aims to provide information about the medical aspects of BRCA, to dissipate doubts and allow for a better genetic illness management. A doctor (geneticist) was present in the session in order to provide up-to-date medical information on BRCA1/2 testing, treatment options and related concerns, as well as to answer participants' questions and talk about their doubts. The following themes were addressed: genetic and hereditary illness significance, mechanisms of hereditary transmission of genetic susceptibility and

Table 2 Programme summary

Session	Segment	Contents
1	Presentation support	Presentation
		Impact of increased genetic risk in the family
2	Education	Medical information
		Community-based resources
3	Support	Embracing family identity
4	Support; ending	Problem-solving techniques
		Stress management strategies

prophylactic treatment options for genetic risk management; some community-based resources were also made available, such as Internet networks and forums. Then, participants discussed their doubts with the doctor; the more recurring query topics were medical surveillance procedures, reproductive and childbearing issues, latest technological advances in genetics, informative resources and preventive measures for descendants. Participants were actively involved in this session; they considered it was easier for them to ask questions to the physician in this setting.

Third session

The main goal of this session was to help families keep a sense of continuity in their own history and identity (past—impact of genetic risk, present—current challenges and future—upcoming projects). The session started with a brief explanation about how a crisis like the threat of genetic risk for cancer may affect families, creating a gap between the family's past identity and the frightening present and putting the future on hold. Aiming to explore how genetic risk shaped the sense of family identity, facilitators invited each family to think about their values before, during and after the genetic positive test result, asking them to disclose about the family functioning main features in each period. Families stated that their values remained the same across time, although the involvement in genetic counselling and the *arrival* of testing results had increased solidarity and unity amongst family members, including extended family and significant others. In this session, participants reported a sense of vagueness, as well as problems with understanding clearly what they were meant to do or think about; facilitators shared the same opinions as participants regarding this matter.

Fourth session

The last session aimed at helping the participants develop stress management strategies, since high levels of stress and anxiety are commonly reported amongst genetic illness patients. Two types of coping strategies were addressed: problem-solving and relaxation techniques. Concerning the first strategy, facilitators stated the universal nature of experiencing problems when facing the challenges of an illness, or of a potential illness, and then asked each family to share some of their current problems; a problem-solving exercise was developed based on decisions concerning involvement in prophylactic surgery, following these steps: identifying the problem, naming it, sharing points of view, finding possible solutions, deciding on one alternative, carrying out that decision and monitoring to evaluate its effectiveness (McDaniel et al. 2006). As for the stress management, the normative character of stress was underlined through examples that showed how stress becomes "natural" in certain circumstances of uncertainty. Cognitive and progressive muscle relaxation training were introduced and performed as an additional resource to the strategies they could use to manage stress.

Programme evaluation

Objectives and methodology

The programme was evaluated through a focus group semi-structured interview (Krueger and Casey 2000), in order to collect opinions and suggestions from the participants to better adjust the programme to their needs and identify the individual and family benefits/impacts. The purpose was to improve the programme and make it suitable for incorporating the genetic counselling protocol for hereditary cancers as a complementary family-focused tool to address a better psychosocial adjustment. This qualitative method was chosen because (Krueger and Casey 2000) it is pertinent for exploratory approaches, since it is a rich method of revealing experiences and perceptions, and it is appropriate for sensitive topics, which is the case of an intervention addressing genetic illness experiences, as it provides a safe environment for participants to share their thoughts and feelings.

The focus group took place 1 month after the last session and was conducted by the programme facilitators. The interview was approximately 90 min in length and was videotaped, transcribed and submitted to content analysis. All participants agreed to cooperate. The interview was applied according to the guidelines for conducting focus groups (Piercy and Hertlein 2005), comprising the following topics: the functional aspects, contents and activities of the programme; individual and family benefits and suggestions to increase the sense of well-being.

Results

All participants considered that all functional aspects of the programme were adequate (number of sessions, duration and frequency), as that they prevented dispersion without being a burden to personal and family life:

> I think the program was well planned; the once-a-week format was ideal, otherwise some people would probably have to leave other things behind [Rita,[1] 28 years old]

The way sessions were structured and its contents were pointed as useful because it focused on specific topics and

[1] All participants' names have been changed for confidentiality purposes.

encouraged the conversational engagement of all participants. Nevertheless, some deviation from the given proposed subject has occasionally emerged (3/9):

> I liked the balance between working on a specific topic and sharing our stories freely without rigidly limit our conversation [Andrea, 25 years old]
> Sometimes I felt that the group had dispersed from the topic we were discussing; but I agree that such 'freedom' was very important for us all, otherwise we probably had stayed more passive [Rita, 28 years old]

The multi-family discussion format was highly approved and one of the key benefits for participants', since it allowed the creation of an atmosphere which encouraged the sharing of personal and family experiences:

> Sharing this problem with other people facing the same is very important; of course I can talk with friends, but here we were all connected with this issue [Isabel, 23 years old]

The main benefits were centred on the group experience of sharing, which removed the inadequacy of some feelings and thoughts and prevented isolation. A sense of closeness also appeared as significant:

> The opportunity to exchange experiences and listen to stories from other people facing the same difficulties made me feel that I was not alone in the world, with my worries and fears… I'd never met anyone that had the same problem! [Ana, 36 years old]

> For me it wasn't just a matter of sharing; here we could feel close and bonded to each other… despite our differences we were very similar, in our needs, fears, doubts… [Maria, 53 years old]

The access to simple coping strategies enabled a positive integration of the at-risk status in participant's lives (2/9); differences were acknowledged in the way they were *thinking* and *seeing themselves* about living with increased genetic risk:

> I feel that now I have strategies to live better with this [increased genetic risk]; I am able to face it not as a deficiency, or incapacitation, but as something that is part of me and that I carry with myself everyday… [Andrea, 25 years old]

All participants felt the informative session as very important, allowing an effective integration of medical information because it was easier for them to ask questions to the physician in this setting:

> The second session was central for me; questioning the doctor directly about our doubts was very important because during the medical consultations we used to be very anxious and couldn't process everything… [Sofia, 47 years old]

> This field [genetics] is constantly evolving and changing; that session updated what I knew since when I undergone testing, four years ago [Ana, 36 years old]

An increased self-assurance when considering decision making about undergoing prophylactic surgery treatments was also mentioned as a benefit (4/9); two women reported an improved confidence to undergo risk reduction procedures such as oophorectomy and subcutaneous mastectomy:

> I used to postpone because I was really scared to face all the necessary medical steps for prevention (which I will, now I can say it), and now I feel more secure and confident about it [Andrea, 25 years old]

The oldest woman in the group shared her relief to see that the family accepted to participate in these sessions:

> This family has already suffered great pain with losses, and I fear for my daughters and for my granddaughter; I am glad because I feel that they are more relaxed and confident [Claudia, 74 years old]

Participants' reported the facilitator's role as adequate, namely their interest in "equally listening to us all", and the use of practical strategies "focusing not only in our personal experience, but also in family relations". Yet, a more directive approach was mentioned as potentially adequate in order to avoid thematic dispersion (2/7):

> In some occasions perhaps you [facilitators] could have been more directive, preventing some 'side-talking'… maybe by establishing a more formal structure, like limiting our time to talk… [Rita, 28 years old]

When asked about the negative aspects of the programme, two participants pointed some parts of the third session; albeit considering it "useful", they mentioned a sense of vagueness regarding what they were meant to do or think about; facilitators shared the same opinions as participants on this matter:

> I got the sensation that in the third session we ended up talking about other things that weren't what you had planned… [Ana, 36 years old]
> I felt that we had done something very similar to what we'd already done in a previous session [first session] … [Isabel, 23 years old]

As for suggestions to improve the programme, one participant recommended the inclusion of a "physical

liberating and cathartic ritual", allowing participants to actively express feelings of anger and despair mainly because others (2/9) felt that relaxation techniques were not suitable for them. Two of the younger participants suggested, as a complement to group sessions, the availability of an individual therapeutic setting centred on more personal issues. Participants (6/9) also suggested the inclusion of other professionals to provide medical information within the domains of plastic surgery, radiotherapy and gynaecology/obstetrics. For this purpose, an additional informative session might be considered:

> A surgeon, and maybe a radiologist, could also be present; it would be useful for those who have doubts regarding mammary reconstruction... [Sandra, 45 years old]

Discussion

This qualitative exploratory study provide insight on the adequacy of the intervention previously described in helping patients and their families to adjust to the challenges of increased genetic risk for BRCA. Results suggest that the programme is well-structured, taking into account its duration, contents and the methodologies used, and that it meets family needs in terms of adjustment to face a genetically linked condition.

Regarding the practical aspects of the programme, it would be useful to consider the redesign of the third session. As both participants and facilitators reported a sense of vagueness and similarity with a previous session, although acknowledging its relevance, we suggest addressing the families' identity through another configuration. Therefore, by asking families to think about objects suitable of symbolizing families' values across time (such as photographs, or material items inherited through generations) and to bring them to the session in order to evoke and share its meaning, families are thus encouraged to recall stories (Trees et al. 2010) based on central aspects of family life that may have been shadowed by the current distress associated to genetic illness issues; this way it seems possible to activate the creation of a narrative promoting a sense of continuity in their own history and embracing families' identity.

As for the psychosocial impact of the programme, the multi-family group format represents an opportunity for participants to listen to others experiencing similar circumstances, enabling emotional expressiveness; the group format helped to enact a mutual, supportive atmosphere that allowed the normalisation of feelings about genetic risk. Also, experiencing bonding and extra-familial networks seemed to have contributed to relieve the psychosocial burden at both personal and family levels. In addition, this programme helped to create a sense of control over one's health management, as the session with the clinician provided a chance to increase medical awareness regarding genetic information and consequent self-assurance on decision making about prophylactic and risk reduction treatments.

Participants' accounts acknowledge the relevance for at-risk individuals and families to share their stressful experiences, such as coping to genetically inherited illnesses, through recounting them (Trees et al. 2010). Through the reciprocal process of listening and narrating their medical family history, as well as their identity values, families were allowed to revise and frame stories about genetic risk, helping to create a sense of mastery and empowerment concerning living with a genetic condition. Overall, this programme seems to provide a useful tool towards the incorporation of family-centred interventions in follow-up support for BRCA at-risk individuals and their families, complementary to the more biomedical-oriented and person-centred protocol of genetic counselling.

Recommendations

The following suggestions may enhance a family-centred focus on genetic counselling; these topics are suitable to address individual and family needs, as more research data become available:

1. Integration of a professional trained on psychosocial genetics in the genetic health care team to assess routine concerns and provide support to clients and families
2. The availability of psycho-educational multi-family support groups, throughout genetic counselling protocols (pre- and post-testing)
3. Incorporation of participants' suggestions in the multi-family groups structure, such as the inclusion of a plastic surgeon in the informative component, the integration of diverse relaxation techniques and the access to an optional individual therapeutic setting as a complement to group sessions for people who do not feel comfortable in group or family settings
4. Referrals to mental health professionals in cases of persistent psychosocial distress or related symptoms

These multidisciplinary family-oriented recommendations call for collaborative work amongst different health care providers, in order to develop innovative psychosocial interventions addressing the holistic needs of those seeking help from genetic counselling services (Speice et al. 2002; McDaniel et al. 2005; Werner-Lin 2008).

Limitations and research perspectives

Further research should include a larger sample and be carried out in other genetics services to evaluate the

applicability of the presented programme. It would also be useful to perform focus groups amongst genetic health care practitioners examining the strengths and limitations of incorporating this intervention in the mainstay of genetic services and what health professionals would be involved. Research should also produce data regarding the adaptability of this intervention, namely in the pre-test phase and immediately after disclosure of genetic test results, adapting the programme contents to the psychosocial characteristics of each phase (Rolland and Williams 2006).

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