

Are family-oriented interventions in Portuguese genetics services a remote possibility? Professionals' views on a multifamily intervention for cancer susceptibility families

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Abstract This article examines genetics healthcare professionals' opinions about a multifamily psychoeducational programme for hereditary cancer susceptibility families, implemented at a Portuguese genetics service. Their views on how a family-oriented approach is envisioned to be incorporated in Portuguese genetic counselling services are also reported. Six focus groups and three individual interviews were undertaken comprising 30 professionals working in the provision of genetic counselling and genetic counsellor trainees. Participants were given a page-summary describing the intervention and asked to comment the strengths and limitations of the multifamily intervention. All interviews were fully transcribed and analysed using the constant comparison method. The qualitative analysis generated data comprising four thematic categories in relation to the professionals' views: (a) usefulness of the programme; (b) programme's methodological and practical obstacles; (c) genetics services constraints; and (d) suggestions for improving the programme and further family-oriented interventions. We reflect on the reported views examining the intervention, and on how current constraints of genetic services limit the provision of psychosocial

support for cancer susceptibility families. The implications of these findings regarding the purpose of genetic counselling are discussed. Results may sensitise stakeholders and policy makers for the need to deliver family-based services in cancer genetic counselling, with adequate planning and collaborative involvement of different professionals.

Keywords Cancer genetic counselling · Family-centred services · Intervention evaluation · Multifamily discussion group · Reliability of qualitative data

Introduction

Genetic counselling and testing are familial experiences that often confront individuals and family members with difficult medical management decisions, commonly involving complex ethical, legal and psychosocial issues. The need to develop family-oriented models of coping, adaptation and integration in inherited risk management has been stated as crucial to fully address the holistic needs of those seeking help from genetic counselling services (McDaniel 2005; Peters et al. 1999; Street et al. 2000).

Group interventions for individuals and their relatives with cancer susceptibility mutations are one of the most common ways to provide psychological support and educational information. Psychoeducational multifamily groups have been well established as family-focused interventions for chronic medical illnesses (Asen 2002). Albeit there is some debate concerning its effectiveness and moderators (Esplen 2011), such approaches have been stated as a useful tool to address the psychosocial interface between medical, individual and familial issues (Rolland and Williams 2005) because they typically include both patient and family members. Whilst it

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has been used for supporting individuals and their families facing several chronic illnesses, including cancer, research on multifamily groups is scarce or non-existent in the field of psychosocial genetics.

Literature is prolific in examples of group approaches for individuals at increased oncogenetic risk. Esplen et al. (2004) studied the use of a supportive–expressive group for BRCA mutation carriers comprising eight weekly sessions followed by four monthly sessions. This intervention addressed the emotional impact associated with having a family history of breast/ovarian cancer and being at high-risk status for developing cancer. Participants were found to have improvements in psychological functioning, by reducing depression and anxiety levels, and several women made decisions concerning prophylactic surgery during and after the intervention; additionally, some of these women also revealed a reduction on grief feelings from pre- to post-intervention measures (Esplen and Hunter 2002). Specific psychoeducational interventions for BRCA carriers comprising educational and psychosocial components are also well established. Wellisch et al. (1999) conducted a pilot study of a psychoeducational group intervention for high-risk relatives of breast cancer patients, reporting a decrease of psychological burden in participants. Kash et al. (1995) reported a randomised controlled trial of a 1-year group intervention, describing a reduced perception of risk and an increased adherence to screening behaviours and in knowledge about participants' high-risk status. In a psychoeducational written intervention consisting of an educational and psychosocial pack, Appleton et al. (2004) also found post-intervention benefits in terms of diminished cancer worry and improved BRCA risk-related information. Karp et al. (1999) described a psychoeducational programme reporting prophylactic mastectomy issues in a group of BRCA carriers, and Speice et al. (2002) conducted a six-session psychoeducational intervention focusing on family-related themes. All of these interventions, however, did not include family members besides the patient, who may also benefit from participation.

In this article, we report findings from an exploratory qualitative study with a sample of Portuguese genetics healthcare professionals on how they assess a multifamily psychoeducational programme for hereditary cancer susceptibility families. The programme design, implementation and evaluation are described elsewhere (Mendes et al. 2010, 2012). Its aim was to assist at-risk families in coping with the ongoing demands of increased genetic risk for hereditary cancers during the post-test period, combining educational and supportive services with a family focus. Two multifamily groups were performed, involving 7 families (4+3) and 28 individuals (19+9) were involved including biological relatives and other family members; the participants attended four weekly sessions. The sessions were co-facilitated by two psychologists trained in medical family therapy and with previous experience with multifamily groups. Participants evaluated the programme

through focus groups, suggesting that the programme is well structured regarding the duration, contents and methodologies, and that it generally responds to the families' needs of adjustment to genetic illness and its increased susceptibility by enhancing their well-being and coping resources.

In Portugal, cancer genetic counselling is available in oncological hospitals and integrated at major hospitals' oncology or genetics departments. The first generation of Portuguese genetic counsellors recently finished their training of a 2-year professionalising master course in genetic counselling, administered from the University of Porto. The course benefited for inter-European experts participation, and national-based institutional support for practical observation. Genetic counselling in Portugal is mainly assured by medical geneticists.

In this paper, we present an additional study reporting genetics healthcare professionals' views on this multifamily programme, and on how they envisage the incorporation of family-oriented approaches in genetic counselling services. Our aim is to enhance credibility to the overall study by cross-checking participant families' and professionals' perspectives and to strengthen the validity and reliability of data through triangulation of qualitative data sources (Patton 1990). We also sought to reflect on the current needs and constraints that Portuguese genetics services face for incorporating suitable psychosocial services for families. We describe our analysis of professionals' qualitative individual and focus group interviews on the usefulness and limitations of the intervention, and how they envisage its incorporation at Portuguese genetics services. Suggestions for further family-oriented themes and interventions in the scope of cancer risk counselling are also described.

Methods

A qualitative study design was used, since the main emphasis was to explore people's experiences and perspectives in an area where little is known to guide research or practice (Glaser and Strauss 1967; McAllister 2001). Semi-structured individual and focus groups interviews were applied according to the interviewees' convenience. Our initial purpose was to perform focus groups; however, three individual interviews were undertaken due to difficulties in finding a common schedule for the focus group. Focus groups were preferred over individual in-depth interviews because the group setting allows individuals to use the ideas of others as cues to fully elicit their own views, which may stimulate topics of discussion and therefore contribute to create a richer source of data (Piercy and Hertlein 2005). Although focus groups are described as a useful method for exploratory approaches, as they use the group dynamics to gain insights and generate ideas, and previous research has indicated its suitability in working with genetics professionals (McAllister et al. 2007, 2010), they also present limitations:

confidentiality is not possible in group settings, and the group setting may be inhibiting to some participants (Piercy and Hertlein 2005).

A list of public institutions working in cancer genetics were identified using the Health General Directory (2004) and by key personnel. An email was sent to the directors of seven medical genetics departments of major and regional hospitals and of three oncological hospitals. The email included an invitation to the genetics healthcare teams to take part in a focus group interview aiming to explore their views on a previously implemented multifamily intervention for at-risk cancer families (Mendes et al. 2010, 2012); professionals from different backgrounds were eligible to participate. From the ten contacted institutions, two declined to participate; motives were not explored due to ethical reasons. The focus group interview guide (Table 1) and a page-summary describing the intervention programme were sent to those who agreed to participate. Subsequent email contacts were established to arrange the interviews. One focus group gathered professionals from two institutions from the same city. Overall, three individual and six focus group interviews were conducted by the first author (AM) and a genetic counsellor from one of the genetics professionals' institution (MP), lasting approximately 1 h. Further details about the intervention were provided at the interview.

A total of 30 professionals working as part of genetics healthcare teams were interviewed, including 17 geneticists (from which four were interns), 2 oncologists, 1 obstetrician, 3 genetic nurses, 3 psychologists and 4 genetic counsellor trainees (three psychologists and one nurse) (Table 2). Participants represented eight institutions delivering cancer genetic counselling (four major hospitals, two regional hospitals, one oncological hospital and one genetics centre); the genetics centre is mainly devoted to genetic counselling for late-onset neurological disorders.

Interviews were audio-taped with the participants' consent, fully transcribed and submitted to content analysis. Open coding, to summarise content and representative statements

from recurring themes, and constant comparison between the emerging themes were used (Patton 1990). The first author and an independent researcher performed successive coding refinement through repeatedly reading the transcripts, aiming to develop consensual content categories; categorization titles were given to similar themes and contents (Strauss and Corbin 1998).

Results

The qualitative analysis generated data comprising four main themes, each comprising content categories, in relation to the professionals' views (Table 3): (a) usefulness of the programme; (b) programme's methodological and practical obstacles; (c) genetics services constraints; and (d) suggestions for improving the programme and further family-oriented interventions.

Usefulness of the programme

Throughout the group discussions, the vast majority of participants generally shared their positive views regarding the intervention. They pointed out its usefulness and acknowledged the need to help families' adjustment to their cancer susceptibility status in the scope of genetic counselling. Major perceived benefits regarding the programme relied on (a) enhancement of well-being and (b) mutual support.

Table 1 Interview guide

Topics	Questions
Multifamily intervention in cancer risk counselling	What general considerations do you want to make to the programme?
	What are its potentialities and its limitations?
	What kind of readjustments in its contents and structure do you suggest?
	How do you envisage the incorporation of this programme and other types of family support in Portuguese genetics services? What would be needed?

Table 2 Summary of focus group and individual interviews composition

Focus group	Professional background	Number of participants (n=30)
1	6 geneticists (1 intern)	7
	1 genetic counsellor trainee (psychologist)	
2	1 geneticist	4
	2 nurses	
3	1 genetic counsellor trainee (psychologist)	4
	1 obstetrician	
4	2 oncologists	7
	1 nurse	
5	6 geneticists (3 interns)	2
6	1 genetic counsellor trainee (psychologist)	3
	2 psychologists	
Individual interview	2 geneticists	1
	1 genetic counsellor trainee (nurse)	
	1 psychologist	
2	1 geneticist	1
3	1 geneticist	1

Table 3 Summary of themes and quotes

Themes	Participant quotations
1. Usefulness of the programme	
Enhancement of well-being	“Support outside the biomedical scope, involving psychologists and social workers, are always useful because sometimes people need to cope with difficult decisions and these interventions help to relieve stress”. “We need to look for the entire individual”.
Mutual support	“People may feel bonded and close to others dealing with similar challenges, especially because we are talking of relatively rare diseases”. “I believe this can be very therapeutic as in many cases these families feel isolated and stigmatised”.
2. Programme’s methodological and practical obstacles	
Lack of quantitative outcomes	“A pre- and post-test would be important to measure modifications in key outcomes, such as psychological adjustment or in information management”. “The quality of the genetic counselling people had before will influence how intervention impact participants”.
Sampling and generalisation	“Participant families were probably the more adjusted, with more socio-economic conditions, and the more motivated”.
Recruitment and mobilisation	“I believe that few families are available to be part of an intervention for a month, two hours every week (...) it is very intensive and impossible to universalize”. “It’s not eminently medical, so people will not consider it as absolutely necessary (...) most of these people are active, they work, and in many cases they fear problems at working places because the justifications”.
Group setting constraints	“Some people may feel uncomfortable talking in front of others (...) it is impossible to assure confidentiality in a group setting”.
3. Genetics services constraints	
Scarcity of qualified human resources	“A multidisciplinary team here [in the genetics service] would be vital, with psychologists working fulltime rather than being called from other services; we neither have time or training to do it”.
Physical barriers	“We are facing other needs, such as physical space, available at the hospital”.
Funding	“Usually this kind of interventions are developed in the scope of research projects with someone highly motivated, but afterwards things do not

Table 3 (continued)

Themes	Participant quotations
	go further and people cannot benefit anymore once its over”.
4. Suggestions for improving the programme and futher family-oriented interventions	
Partnerships with community-based services	“I conceive this type of intervention more in the scope of community- based services or patients representatives than at the hospital setting, which may dis suade participation from other family members”.
	“It could be interesting to perform follow-ups to assess new concerns and relevant information”.
Genetic counsellors	“I am optimistic because we’ve started to produce genetic counsellors; they should be encouraged to integrate family-based concepts in genetic counselling training and practice”.

1. The intervention has the potential to alleviate the psychological burden that some families in this context often carry; it is also seen as an opportunity for non-biomedical support, contemplating a broader care for the individuals.
2. The mutual support atmosphere posed by the group context, mostly stressed as a way to promote paths of successful coping through sharing experiences.

Programme’s methodological and practical obstacles

Despite recognising its potential usefulness, the participants also mentioned the need of practical changes in the intervention in order to meet conditions for its consistent incorporation in genetics services. The mentioned obstacles were the following: (a) lack of quantitative outcomes; (b) sampling and generalisation; (c) recruitment and mobilisation; and (d) group setting constraints.

1. The lack of quantitative outcomes was consistently reported as a methodological limitation of robustness of this intervention. For example, it was argued that the perceived quality of the delivered genetic counselling would influence the counselees’ needs; addressing participants’ previous informative knowledge before the intervention was then reported as necessary. It was presumed that even if participants were unhappy with the quality of the genetic counselling they attended, they would be likely to rate the intervention as useful anyhow.
2. The sampling method was considered problematic by the participants because the programme participants were not representative of the general Portuguese population, as recruitment occurred in a specific area covered by the genetics service where the study was carried out (centre

- region of Portugal); generalisable assumptions about its validity and sustainability were then described as limited.
3. Some professionals reported the intensive nature of the intervention programme (four weekly 90-min sessions) as inadequate and potentially burdensome for the majority of families, limiting recruitment particularly for those coming from distant and rural regions.
 4. Group setting constraints were also mentioned as potentially limiting people's involvement, namely because of privacy issues.

Genetics services constraints

In order to incorporate this programme or to provide family-oriented interventions in genetics services, professionals' reported structural constraints centred on: (a) scarcity of qualified human resources, (b) physical barriers and (c) limited funding.

1. Limited human resources in genetics healthcare teams prevent the delivery of appropriate psychosocial interventions. The lack of a multidisciplinary team including genetic counsellors, psychologists and social workers was consistently described as an obstacle for implementing this and other psychosocial-oriented approaches. In some cases, teams do not integrate full-time practitioners; professionals commonly assist other services at the hospital, generating work overload and affecting directly the availability of specific psychosocial assessment and interventions.
2. Confined space was described as a specific limitation in some genetics departments. Performing group interventions with several families would hardly be possible in some hospitals.
3. Lack of funding is the professionals' attribution for the above-mentioned constraints. With available funds, continuity between time-limited research projects and its subsequent incorporation in the service delivery, if justifiable, would be possible.

Suggestions for improving the programme and further family-oriented interventions

Professionals shared some suggestions to aid the programme applicability:

1. The development of partnerships between genetics clinics and community-based services (such as patients and family representatives' organisations, primary healthcare practitioners, in particular family physicians, and health care centres) was highlighted as a way to enhance the feasibility of this intervention. Namely, establishing referral channels with those services in a local/regional

- basis will possibly help people from distant, rural areas to participate, as well as those with limited financial resources.
2. More pertinent topics for the genetic counselling process should be considered for integrating the programme's contents, such as helping counselees to better communicate with relatives about genetic risk and testing, specific aids to assist decision-making or clinician–patient risk communication. Also, the inclusion of periodic follow-ups was mentioned as a way to provide ongoing support for families and to keep them linked to genetics services for reporting pertinent new information concerning risk management.
 3. In addition, the prospect of integrating newly trained genetic counsellors in Portuguese genetics services is seen as a major potential contribution to enhance a family-oriented approach to genetic counselling.

Discussion

Similarly to other psychoeducational interventions for onco-genetic high-risk individuals, our programme addressed the implications of increased cancer susceptibility on family relationships, facilitated coping skills and provided medical information about risk. However, as the new genetics has reconfigured the family unit as the patient when inherited conditions are diagnosed, our intervention included both the patient and other *non-ill* family members, differently from the majority of known psychoeducational interventions (Esplen et al. 2004; Karp et al. 1999; Kash et al. 1995; Speice et al. 2002; Wellisch et al. 1999). Although support groups for families and caregivers are common, groups joining patients and their relatives remain unusual. Moreover, while other interventions generally took a quantitative evaluation from participants, our study qualitatively analysed genetic health professionals' views on the programme and how they envisage the incorporation of a family-orientated approach into genetic counselling services.

Since participant families' views on the adequacy of the programme concerning its structure and contents were previously addressed (Mendes et al. 2010, 2012), in this study, we pursued to refine the programme's evaluation through an inter-professional reflective process. To our knowledge, this is the first study to report the evaluation of a psychosocial intervention from the healthcare professionals' perspective. In spite of its limitations, this study represents a participatory strategy for engaging providers of genetics services with a family-focused perspective. It also contributes for providers to be reflective about their work, a useful professional tool since a shift in models of service delivery has been discussed (Battista et al. 2011; Wham et al. 2010). As Portugal, like many other countries, lacks an integrated plan for the provision of oncogenetic services, feedback from

professionals represents a key aspect when considering the development of supportive interventions for those at increased risk and their families. Furthermore, it is a valuable input in terms of the formative and process components of programme evaluation, namely in negotiation and planning its development and implementation (Metcalf et al. 2008).

Genetics healthcare professionals working in the provision of cancer genetic counselling, with different training and experiences, shared their views whether the intervention provides a feasible and useful tool to help at-risk families. While professionals reflected on how to enhance the programme structure and effectiveness for its incorporation in genetics services, current constraints affecting the delivery of appropriate psychosocial services in the scope of cancer genetic counselling were also highlighted, lending further insight to the barriers families experience when attending genetics services. Such limitations also stress the need for integrating adequately trained healthcare professionals in cancer genetics services. Therefore, this study provides an exploratory account on the current challenges genetics services in Portugal are facing in order to provide integrative genetic counselling services for at-risk cancer individuals and their families.

Learning from our experience

The positive endorsement from participating families (Mendes et al. 2010; 2012) parallels the professionals' views on the usefulness of the programme. However, despite the growing awareness of the need for a family-focused approach in the scope of increased genetic susceptibility, some barriers may contribute to explain the paucity of time-extended group interventions. Aspects such as recruitment restrictions to a mainly urban population, the need to regularly coordinate scheduling demands with participant families, financial costs and the lack of staff trained in family systems are among some obstacles for the universalisation of this intervention. Therefore, a condensed version of the programme in a 1-day multifamily workshop may overcome such difficulties, besides its potential for cost-effectiveness and for allowing a more realistic dissemination of psychosocial care in distant regions from genetics centres. Such model was performed for chronic medical illnesses (Steinglass et al. 2011) as well as in the scope of genetic risk (McKinnon et al. 2007), comprising components of lectures and small group discussions around specific themes (medical updates on cancer risk management, family communication and genetic testing or spouse/partner issues). However, by contemplating just one single 'moment', this model may result as a scarce effort for embracing the ongoing psychosocial demands of those facing oncogenetic risk and their families. In order to potentiate a broader impact, follow-up 'booster' sessions after an intensive 1-day workshop experience have been argued by Steinglass et al. (2011) and already used by Esplen et al. (2004).

Psychoeducational written material including information on scientific and psychosocial aspects of familial risk for cancer may also be distributed, as described in the study of Appleton et al. (2004).

Methodological limitations pointed out by professionals need to be acknowledged for the programme's applicability purposes. The absence of summative evaluation components weakens the validity of the intervention. Collecting baseline data for comparison with post-intervention short- and long-term information and psychosocial effects, or, better still, using randomised groups, are core issues that may well be taken into account in future developments. As with many exploratory studies, the sample was small and purposive and therefore not representative. Our aim, however, was not to make generalisable empirical claims about a wider population, but rather to use the data qualitatively to address how participants evaluate the programme's structural and practical aspects and the perceived benefits in their lives. Moreover, professionals' reports about the programme's lack of objective outcomes and sampling representativeness evidence the assumption that research in genetics should mainly assume quantitative purposes. This assertion may perhaps be fuelled by the participants' dominant medical sciences background, greatly rooted in a predominantly quantitative, evidence-based orientation in the field of enquiry.

The focus group format prompted professionals to discuss about the most common perceived needs of their counselees and to envisage the inclusion of other ways to support families in oncogenetic counselling. Alternative and more critical themes were identified as potentially adequate to be included as contents in this programme, performed in a complementary fashion to genetic counselling, such as decision-making for risk reduction options, or facilities to enhance families' communication skills to disseminate genetic risk information to other potentially at-risk relatives. Individuals and families attending oncogenetic services need psychosocial support in other ways besides multifamily interventions. As multifamily groups are primarily effective for cohesive families (Campbell 2003), clinics must provide diverse psychosocial tools for supporting not only less cohesive families, but patients (and their families) with other characteristics as well.

Family-oriented interventions in genetics services: a remote possibility?

The concepts of family system theory and recommendations for the inclusion of family therapy trained professionals have been envisioned for genetic counselling practice as genetic diseases have been recognised as familial diseases (Eunupu 1997; McDaniel 2005). Although the incorporation of family dimensions as an intrinsic part of the genetic counselling delivery has been stated as an important feature

in cancer genetic counselling (Kenen et al. 2003; Street et al. 2000), professional's accounts evidence several limitations to such endeavour, at least in the Portuguese scenario. One of the issues discussed at length in the interviews was the lack of qualified human resources, notably those more markedly rooted in a psychosocial orientation (psychologists, social workers or family therapists), and in some cases of physical conditions at the genetics services, as a way to explain the scarce provision of psychosocial support for families. In some cases, such support is given by professionals from other internal, and even external, services. One might consider that these constraints only represent the visible part of these unmet needs.

A wider approach to genetics services, and specifically considering the genetic counselling protocol, may represent an initial step towards a more psychosocial sensitive delivery, suitable to include family support. Community-based facilities, such as patient or family representative's organisations, were stated by some professionals as a more appropriate setting to deliver these interventions instead of the hospital. Community services may indeed perform an important role as an adjunct facility of genetics services, linking tertiary and primary assistance, although demanding a careful management of ethical and coordination issues. The role of primary care physicians should also be considered. Lack of training and confidence of these professionals to carry out medical genetics tasks has been stated (Nippert et al. 2011). Given the amount of patients referred for oncogenetic services by primary care physicians, training in specific issues about genetics, namely in how to make appropriate referrals for cancer risk counselling, may indeed improve the service.

Such endeavours require a significant policy shift in the current provision of cancer genetic counselling in Portugal, and, perhaps more importantly, in its planning. Theoretical and practical education is required in order to gain understanding and skills in implementing specific interventions (Jacobsen 2009); besides the harmonisation of practices and professional recognition, the training of (non-) genetics healthcare professionals is currently one of the greatest challenges for genetic counselling across many countries (Skirton et al. 2010).

Although Portugal is among the group of European countries having specific legal provisions on genetic counselling practice (EuroGentest and Unit 3 Expert Group 2008), the outlined constraints emerge as encapsulated by the inexistent tradition of psychosocial practice in genetics settings, which may in some extent perpetuate the assumption that family support and genetics are incompatible matters. As genetics service providers receive adequate training in psychosocial issues, healthcare professionals' levels of confidence in dealing with more family-oriented tasks may increase and thus be suitable for inclusion as a feature of patient care. The inclusion of newly trained genetic counsellors in the mainstay of cancer genetics services may represent an opportunity for the

provision of more psychosocial-oriented interventions, namely by assisting patients and their families throughout the genetic counselling protocol, helping with psychosocial assessments and establishing links between the genetics clinic, primary care and community-based resources.

Implications for cancer genetic counselling

The need to provide adequate psychosocial accompaniment was envisioned as a cornerstone for services based on mutation-based predictive technology (Stiefel et al. 1997). Kessler's teaching and counselling models are commonly touted as the primary approaches for genetic counselling practice (Kessler 1997). Such models were inherited from different professional backgrounds, posing genetic counselling as a frontier discipline between the realms of biomedical and psychosocial healthcare (Lewis 2002). In fact, genetic counselling can include both approaches through a psycho-educational focus adapted to different contexts (as oncogenetics), to consultants' idiosyncrasies and to local services peculiarities (Biesecker 2001).

The inclusion of a pre-counselling psychosocial assessment, performed by adequately trained professionals, may enhance the genetic counselling process, as information needs, personal and family medical history, risk perception and beliefs and family communication patterns and resources may be explored. This is suitable to alleviate the counselling agenda and to focus communication within subsequent sessions. Furthermore, in accordance with previously assessed needs, tailored family-focused psychoeducational modules delivered at key points of the genetic counselling protocol may constitute a suitable way for providing pre- and post-testing and ongoing support for consultants and families.

Conclusion

The findings from this study call for collaborative work amongst different healthcare providers working at primary, secondary and tertiary levels as a way to improve reliability of a multifamily intervention, and more broadly, to enhance a family-oriented focus in cancer genetic counselling. This study provided an exploratory cross-checking to the examined programme and mapped the needs for developing further and more adequate family-based interventions for cancer susceptibility families. Validated and tailored interventions may improve the quality of genetic counselling services, arguably contributing to counselees' and their families' empowerment, a qualitative outcome for genetics services that is currently under refinement (McAllister et al. 2010). As the first generation of Portuguese genetic counsellors recently completed their training, these findings may sensitise stakeholders and policy makers for the need to integrate psychosocial support

for families in the scope of cancer genetic counselling, an effort that will require adequate planning and collaborative involvement of different genetics healthcare professionals.

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References

- Appleton S, Watson M, Rush R, Garcia-Minaur S, Porteous M, Campbell J, Anderson E, Cull A (2004) A randomised controlled trial of a psychoeducational intervention for women at increased risk of breast cancer. *Br J Cancer* 90(1):41–47
- Asen E (2002) Multiple family therapy: an overview. *J Fam Ther* 24:3–16
- Battista RN, Blancquaert I, Laberge AM, van Schendel N, Leduc N (2011) Genetics in health care: an overview of current and emerging models. *Pub Health Genomics* 15(1):34–45
- Biesecker BB (2001) Goals of genetic counselling. *Clin Genet* 60(5):323–330
- Campbell TL (2003) The effectiveness of family interventions for physical disorders. *J Marital Fam Ther* 29(2):263–281
- Esplen MJ (2011) Group interventions: what models? For who? Are they effective? *Familial Cancer* 10(2):S79–S80
- Esplen MJ, Hunter J (2002) Grief in women with a family history of breast cancer. *Prim Psychiatry* 9(5):57–64
- Esplen MJ, Hunter J, Leszcz M, Warner E, Narod S, Metcalfe K et al (2004) A multicenter study of supportive-expressive group therapy for women with BRCA1/BRCA2 mutations. *Cancer* 101:2327–2340
- Eunupu D (1997) Systemically-based psychotherapeutic techniques in genetic counseling. *J Genet Couns* 6(1):1–20
- EuroGentest, Unit 3 Expert Group (2008) Recommendations for genetic counselling related to genetic testing. <http://www.eurogentest.org/web/files/public/unit3/guidelines%20of%20GC%20final.pdf>. Accessed 18 Aug 2011
- Glaser B, Strauss A (1967) *The discovery of grounded theory*. Aldine, New York
- Health General Directory (2004) Rede de referência hospitalar de genética médica. Direção-Geral da Saúde, Lisboa
- Jacobsen PB (2009) Promoting evidence-based psychosocial care for cancer patients. *Psychooncology* 18(1):6–13
- Karp J, Brown K, Sullivan M, Massie M (1999) The prophylactic mastectomy dilemma: a support group for women at high genetic risk for breast cancer. *J Genet Couns* 8(3):163–173
- Kash KM, Holland JC, Osborne MP, Miller DG (1995) Psychological counseling strategies for women at high risk for breast cancer. *Monogr Natl Cancer Inst* 17:73–79
- Kenen R, Eeles R, Arden-Jones A (2003) Family stories and the use of heuristics: women from suspected HBOC. *Families Sociol Health Illn* 25(7):838–865
- Kessler S (1997) Psychological aspects of genetic counseling IX: teaching and counseling. *J Genet Couns* 6(3):287–295
- Lewis L (2002) Models of genetic counseling and their effects on multicultural genetic counseling. *J Genet Couns* 11(3):193–212
- McAllister M (2001) Grounded theory in genetic counselling research. *J Genet Couns* 10(3):233–250
- McAllister M, Payne K, Nicholls S, McLeod R, Donnai D, Davies L (2007) Improving service evaluation in clinical genetics: identifying effects of genetic diseases on individuals and families. *J Genet Couns* 16(1):71–83
- McAllister M, Dunn G, Todd C (2010) Empowerment: qualitative underpinning of a new clinical genetics-specific patient-reported outcome. *Eur J Human Genet* 19(2):125–130
- McDaniel S (2005) The psychotherapy of genetics. *Fam Proc* 44(1):25–44
- McKinnon W, Naud S, Ashikaga T, Colletti R, Wood M (2007) Results from an intervention for individuals and families with BRCA mutations: a model for providing medical updates and psychosocial support following genetic testing. *J Genet Couns* 16(4):433–457
- Mendes Á, Chiquelho R, Santos TA, Sousa L (2010) Family matters: examining a multifamily group intervention for women with BRCA mutations in the scope of genetic counselling. *J Community Genet* 1(4):161–168
- Mendes Á, Chiquelho R, Santos TA, Sousa L (2012) Embracing family support in genetic counselling: a multi-family discussion group for colorectal cancer at-risk individuals and their families. *J Fam Ther* (in press)
- Metcalfe SA, Aitken M, Gaff CL (2008) The importance of program evaluation: how can it be applied to diverse genetics education settings? *J Genet Couns* 17(2):170–179
- Nippert I, Harris H, Julian-Reynier C, Kristofferson U, ten Kate LP, Anionwu E et al (2011) Confidence of primary care physicians in their ability to carry out basic medical genetics tasks—a European survey in five countries- part 1. *J Community Genet* 2(1):1–11
- Patton MQ (1990) *Qualitative evaluation and research methods*. Sage, California
- Peters JA, Djurdjinovic L, Baker D (1999) The genetic self: the human genome project, genetic counseling, and family therapy. *Fam Syst Health* 17:5–24
- Piercy F, Hertlein K (2005) Focus groups in family therapy research. In: Sprinkle D, Piercy F (eds) *Research methods in family therapy*. Guilford, New York
- Rolland J, Williams J (2005) Toward a biopsychosocial model for 21st century genetics. *Fam Proc* 44(1):3–24
- Skirton H, Voelckel MA, Patch C (2010) Using a community of practice to develop standards of practice and education for genetic counselors in Europe. *J Community Genet* 1(4):169–173
- Speice J, McDaniel S, Rowley P, Loader S (2002) Family issues in a psychoeducation group for women with a BRCA mutation. *Clin Genet* 62(2):121–127
- Steinglass P, Ostroff J, Steinglass A (2011) Multiple family groups for adult cancer survivors and their families: a 1-day workshop model. *Fam Proc* 50(3):393–409
- Stiefel F, Lehman A, Guex P (1997) Genetic detection: the need for psychosocial support in modern cancer prevention. *Support Care Cancer* 5(6):461–465
- Strauss A, Corbin J (1998) *Basic of qualitative research: techniques and procedures for developing grounded theory*, 2nd edn. Sage, London
- Street E, Soldan J, Gray J (2000) A family affair: themes and perspectives of counselling in genetic services. *Counsell Psychol Rev* 15:4–11
- Wellisch D, Hoffman A, Goldman S, Hammerstein J, Klein K, Bell M (1999) Depression and anxiety symptoms in women at high risk for breast cancer: pilot study of a group intervention. *Am J Psychiatry* 156(10):1644–1645
- Wham D, Vu T, Chan-Smutko G, Kobelka C, Urbauer D, Heald B (2010) Assessment of clinical practices among cancer genetic counselors. *Fam Cancer* 9(3):459–468