

THE DEVELOPMENT OF A DISTRACTION-BASED COPING INTERVENTION FOR WOMEN WAITING FOR GENETIC RISK INFORMATION: A PHASE 1 QUALITATIVE STUDY

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SUMMARY

This study explored the emotional and coping responses of women referred for cancer genetic risk assessment and the acceptability of a written distraction-based coping intervention. Fifteen women recently referred into the Cancer Genetics Service for Wales (CGSW) took part in a focus group study. The women were divided into two groups, each of which met twice. During the first session, each group discussed their psychological responses to the referral and how they coped with their worries. Women discussed the potential role of the intervention in minimising distress. Analysis of the transcripts revealed that most women welcomed the referral to CGSW and that it did not create distress. However, there was concern for family members and anxiety about subsequent stages of the assessment process. The intervention was considered appropriate and potentially effective. Copyright © 2005 John Wiley & Sons, Ltd.

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INTRODUCTION

Specialist genetics services provide eligible individuals with information about their risk of developing cancer, based upon an assessment of their family history. Research suggests that a small percentage of people experience psychological distress whilst waiting to learn their risk of cancer (Cull *et al.*, 1999; Fry *et al.*, 2003). Despite this, there has been little attempt to develop an appropriate coping intervention.

This paper describes the development of a brief intervention intended to reduce distress in women referred for cancer genetic risk assessment. The intervention is based upon the transactional theory of stress and coping (e.g. Folkman and Lazarus,

1988), which describes how individuals engage in cognitive and behavioural activities when coping with stressful situations. One form of coping that may help individuals cope whilst waiting for genetic risk information is distraction. Distraction involves focusing attention away from intrusive worries, and has effectively reduced distress across a range of conditions (Harvey and Payne, 2002; Fauerbach *et al.*, 2002).

Despite the conceptual simplicity of distraction and the relative ease with which distraction techniques can be taught, no trials testing the effectiveness of 'self-help' written distraction techniques have been reported. In the field of cancer genetic risk assessment, such an intervention is novel and may prove effective where there is little possibility of a practitioner-based intervention. In order to investigate whether such an intervention may reduce distress whilst waiting for genetic risk information, there was a need to investigate women's reactions to their referral for cancer genetic risk assessment. Focus group methodology

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was chosen as the interactive nature of the group discussions would enable the researcher to develop a strong understanding of participants' experiences and to elicit opinion about the intervention. Accordingly, the study explored:

1. Women's experiences of being referred for cancer genetic risk assessment and how they coped with any worries.
2. The acceptability of a distraction-based coping intervention.

METHOD

The intervention

A self-help written distraction-based coping leaflet was developed. It describes distraction techniques (see Table 1) and encourages readers to write down how they might use such techniques to help control their worries. As distraction may prevent individuals from processing important issues (e.g. Wegner, 1994), the leaflet encourages readers to allow specific times to think about their concerns.

Recruitment procedure

Study packs were distributed to 108 female referrals into the Cancer Genetics Service for Wales (CGSW) between April and July 2002. Women were invited to participate in a group discussion about their experiences of their referral and to consider the appropriateness of a new coping leaflet. Nineteen women consented and 15 women attended the focus groups (age range 31–62 years). This low response rate of 13.8% is not atypical of focus group studies, for which

recruitment is known to be difficult (Bloor *et al.*, 2001). Six participants had a personal diagnosis of cancer. Fourteen participants were referred because of their family history of breast/ovarian cancer, and one because of a diagnosis of two unrelated cancers within 6 months. None had previously undergone cancer genetic risk assessment.

Data collection and analysis

Participants were recruited into two focus groups, each of which met on two occasions. The groups were facilitated by the researcher (CP) with a genetic counsellor in attendance. The discussions followed a semi-structured topic guide, with the first exploring participants' experiences of their referral and any worries they had. Participants were asked to make use of the coping leaflet before the second meeting, whenever they experienced worries. The second discussion focused on participants' reactions to the coping leaflet.

Each discussion was tape-recorded, transcribed and thematically analysed. Emerging issues were identified by studying the transcripts repeatedly by hand and exploring possible meanings. Segments of text were coded and grouped under different themes. Axial coding was used to link subordinate themes to the main themes and other subordinate themes. Participant validation was achieved by asking participants to confirm that written summaries were an accurate representation of the discussions.

RESULTS

Psychological responses to the referral

The referral as a positive step. Several women discussed how they felt relieved and grateful upon referral. Many had long been concerned about their family history but had not found their health professionals to be interested or knowledgeable about genetics.

Clare: For me personally, relief, that actually somebody was actually taking me seriously, because my GP, I'd asked him on several occasions and he just didn't want to know...

For some participants, relief was associated with an increased feeling of control over their situation,

Table 1. Distraction techniques included in the coping leaflet

Things you can think
Counting to 50, while imaging the numbers in your head
Thinking of a calm or favourite place
Thinking of a holiday or other enjoyable times or plans
Things you can do
Talk to someone about anything other than the worry in your mind
Absorb yourself in something interesting or fun to do
Take some exercise—keep fit as well as distract from your worries!

and appeared to help with their long-term worries about cancer. It was clear that, for many, the decision to undergo genetic risk assessment had been motivated by their desire to benefit their family.

Jane: Its relief for the family it is isn't it...its not for myself, you know...its just relief that the other children and family members will be screened....

Anxieties about the referral. Whilst acknowledging the referral as a positive step, a small number of women expressed concerns about the implications of their referral.

Sally: I wouldn't say more worried but I think there are a lot of questions there which I would like to have answered now...

Additionally, participants had anxieties about how their children would cope with knowledge of their risk.

Martha: I would be anxious mind, my youngest son is 21 and my older son is 24 nearly, and alright, if we knew, I don't know how they would cope with it, I really don't...

One participant became anxious when completing the family history questionnaire (FHQ) because it made her realise the extent of her family history of cancer; others recounted difficulty in obtaining the correct information from family members and uncertainty regarding how much information to include. Participants also expressed concern about how their referral would progress and what timescales were involved.

Clare: the query I had was—whether there could be any kind of timescale in the information we get...- a flow chart—once you've done your questionnaire, where does it go?

Coping with cancer genetic risk assessment

Participants described a variety of activities which helped them distract from worries they had about undergoing cancer genetic risk assessment, such as yoga, gardening and socialising. Positive appraisal was also considered an important coping strategy, although participants felt

that they should not be made to feel guilty if they did not always think positively.

Margaret: it's about the balance isn't it—having time to sit and reflect on it and cry if you need to, and time to look at your kids and feel happy because of them or whatever'

Participants discussed how too much or inappropriate information could increase their anxiety. Many were concerned about the role of the media in producing anxiety-provoking information. One participant described how listening to a radio programme about ovarian cancer made her anxious, but also inspired her to finally contact her GP.

The level and nature of social support available to participants varied widely. Some women had a strong social support network; others appeared not to receive or seek out social support. Opinion was divided as to whether a regular support group would be of benefit, as there was concern that a support group which was not organised by a healthcare professional may result in people feeling more worried.

The coping leaflet

Most participants had tried the distraction techniques described in the leaflet between the first and second meetings. Many women reported that specific distraction techniques helped them control their worries, with some finding particular distraction techniques more effective during the night than during the day and vice versa. Whilst many already used distraction, the women agreed that the techniques would be useful for people going through cancer genetic risk assessment (see Table 2).

Participants also found other information contained in the leaflet reassuring and useful. Some also found it beneficial to be asked to think through and plan their own distraction techniques. However, some participants stated that they wondered whether they should be more worried than they were having read the leaflet.

DISCUSSION

The women in this study generally perceived their referral to be a positive step towards learning the

Table 2. Comments about the coping leaflet

Jane: Yeah, yep, it was quite simple to read—not difficult to understand—you don't realise that you are doing these techniques, they're a nice gentle reminder to do them, and how helpful they can be.... Yeah I quite liked it...

Clare: I mean there's always the option isn't there of a piece of paper, like we said last time, whether you want to read it or not, if you want to ignore it then fine.

Jill: I think it's quite a good idea.

Hannah: I think you need 2 sets really don't you—one for the day and one for in the middle of the night...

Heidi: Yeah it is the nights isn't it...

Clare: Overall, I found it really good really interesting, I like the fact you've got a space 'cos I think that actually actively makes you think when you're there, at that point, what things might work for me, and make a list, so I think that's quite good I like that

Leanne: I think as well because its asked you to think of things for yourself as well, its not just said 'you should do this, this and this' its said well no, have a think about it, think what would work for you, and I think that was good

Margaret: It did make me wonder whether I should be worrying.....because I read it and I thought well I'm not really worried about waiting, I suppose it's because I've waited so long anyway...

level of risk for themselves and other family members. The concern for family as a motivator for undergoing cancer genetic risk assessment is consistent with other research (Murphy, 1999). There is a need to be aware, however, that the lack of self-reported distress may be due to this self-selected sample having lower levels of distress than women who chose not to participate (Lerman *et al.*, 1997).

Some participants reported long-existing anxieties about developing cancer, whilst others found the completion of the FHQ anxiety-provoking. Such women may not have come to terms with their family history of cancer (Foster *et al.*, 2002). These women hoped that cancer genetic risk assessment would either allay these fears or result in increased surveillance. The results suggested that the coping leaflet may help such women to control their intrusive worries during this waiting period.

For some women, actively seeking referral to CGSW appeared to increase feelings of control and to be linked to a desire to reduce uncertainty and plan for the future (Lerman *et al.*, 1995; Lodder *et al.*, 1999). Once referred, emotion-focused coping, primarily in the form of positive reappraisal and distraction, was commonly reported. Participants therefore appeared to be using the most adaptive form of coping for this stage of the assessment process, given the uncertainty and lack of information available (Folkman and Lazarus, 1984). However, individual differences in information-seeking preferences suggest that it may be important to adapt information to the

individual's coping style, in order to reduce any unnecessary distress (Miller, 1989; Nordin *et al.*, 2002).

The coping leaflet was considered to be an appropriate and potentially effective intervention. The already existing use of distraction techniques by many participants suggests that the intervention is appropriate. Additionally, participants found other components of the leaflet helpful. In particular, information acknowledging that going through the genetic risk assessment process could be distressing for some appeared to reassure participants that they were not the only ones feeling anxious or concerned. Conversely, it was felt important to acknowledge that not everyone would be worried, and that this too was a normal reaction.

Finally, many participants found the discussions positive, although the fact that some reported an increase in intrusive thoughts after the focus groups highlights the difficulties in identifying psychological interventions which can account for individual differences in coping.

CONCLUSIONS

This study has provided valuable data about the range of psychological responses to the early stages of cancer genetic risk assessment. The results suggest that the distraction-based coping leaflet may be an effective intervention for women worried about undergoing this process. The

feedback about the intervention will inform its development, and the psychological impact of the coping leaflet will be evaluated through a randomised controlled trial.

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