

5. Discussion

5.1 Risk dominated by genetics

Those included in this study perceive that genetic factors are by far the strongest element when assessing their risk of developing breast cancer. This is consistent with the findings of Lemon et al. (2004) & Spector (2007). In many cases discussion of this issue during interviews lead to strong statements of a fatalistic nature, indicating that the individuals have a deep-seated belief that they have very little control over their risk level. There may be a number of elements which contribute to this strong view. There is a clear indication that they feel they have a special situation regarding the risk of developing breast cancer, and that their risk is driven by different factors than for the general population, this is clear from the common use of statements such as “for me” and “in my case” when describing risk factors. The ‘cancer burden’ amongst this group is very high with only 2 of the 20 subjects not having had breast or ovarian cancer or having had a first degree relative with breast or ovarian cancer. Almost all of those studied recounted very strong family history of breast cancer and the direct nature of their experience of breast cancer is likely to be a powerful factor in their perception of their risk. This may also explain why we could identify no difference in beliefs and behaviours between those affected and those unaffected by breast cancer, or between confirmed BRCA1 or BRCA2 carriers and those at 50% risk. This perception that they are amongst a special risk group which is dominated by genetic factors is likely to be reinforced by their positive BRCA diagnosis and attendance at family history clinics. At these clinics their individual genetic predisposition is discussed with several different experts and

authoritative figures. In many cases the belief that family history and BRCA diagnosis completely overrides other risk factors is illustrated by the fact that most participants quoted specific percentage odds with no modification for any factors other than genetics. In order to extract views on other possible risk factors, in most cases it was necessary to probe further with prompts. When discussing other possible sources of risk it became clear that most accepted that their risk could be reduced by surgical intervention and that age of child bearing was believed to have some effect. Again these are elements which are likely to have been discussed in clinical setting with authoritative 'expert' figures. Of the other risk factors described by the group there are few which are common and very little indication of conviction that these do have significance for the individuals themselves. This group's wide variation in responses for 'possible' causes underlines their suspicion that the environmental and lifestyle factors are not really understood and that they feel that there is no clear and unambiguous guide on exactly which behaviours reduce their specific breast cancer risk. Given this background it is understandable that individuals develop a somewhat fatalistic view of their risk of developing breast cancer and begin to look at ways to cope with the situation as much as at ways to reduce risk. For some individuals there was a clear intention to avoid letting this affect how they got on with their lives, 'life is for living' seemed to be one of the coping strategies employed by some of the group.

5.2 Strong desire to find ways to exert control

Theoretical models that have been developed to help understand and predict health behaviours, such as the Health Belief Model and the Theory of Planned Behaviour, propose that an individual needs to feel that a particular behaviour will have an impact on their health in order to make that change to their behaviour. These models have had some success in predicting behaviour change (Keesling & Friedman, 1987; Nejad, Wertheim & Greenwood, 2005). Taking our study groups response to the question of perceived causes of breast cancer for themselves, these models would predict that behaviour change is not likely, due to the group's significant and widespread belief that the dominant risk factor is hereditary. However it is clear from the interview responses that this is not the case, there is a clear intention by most to do what they can to positively affect their health even amongst those who do not sight behaviour change as a modifier for risk factors. Other qualitative studies have also identified this intent (Beagan & Chapman, 2004; Chapman & Beagan, 2003; Spector, 2007). Many of the individuals have identified ways in which they believe behaviour changes will benefit their health. Amongst this study group there were three types of perceived health benefit; positive effects on the outcome if they do develop breast cancer, positive effect on their general health and how they feel, and doing whatever is possible to reduce possible other causes. Consistent with Spector's (2007) study of 10 BRCA carriers our study group reported a significant increase in their level of screening, stating that this would ensure that they would be aware of any cancer as early as possible and implying that this would improve their likely outcome. Several of the women commented that by following what

they felt was a healthier lifestyle, mainly relating to diet and exercise, they would be in a better position to battle the disease should they develop cancer.

“Well you've got to do something to make yourself well, and make yourself like fit and strong or whatever, it runs alongside knowing that if I could fight a common cold then I might have a little bit more of a chance of fighting a possible cancer somewhere down the road. I consider it to give me control over like how I'd cope if I was ill.”

It is interesting that several of the group stated that ‘feeling better’ was a benefit that they felt they obtained from making behavioural changes which they related to ‘healthy lifestyle.’ Even if they did not feel that there was a clear or defined benefit in terms of how they viewed their cancer risk.

“I feel my lifestyle..... I like to keep active and fit and healthy, and that helps me to just get through everything.....because it keeps your body healthier.”

The third type of benefit that was perceived by several of the group was in dealing with what they felt was uncertainty over possible causes or triggers for breast cancer. This also seemed to involve some element of feeling that they had done whatever they could even if they may not believe that these behaviours are directly linked to reducing risk.

“You know just try and eat as healthy as you can and just generally try and keep as well as possible to try and eliminate any possible causes.”

It would seem that although this group may not feel that behaviour changes have a strong effect on their risk of developing breast cancer, they do feel there are clear benefits to be obtained by behavioural changes. These beliefs seem to be driven by both perceptions that being healthier will give them some control over the disease and also as a coping strategy that allows them to feel that they are doing something positive despite their increased cancer risk. Most of the group make strong statements that they have made behaviour changes or are ready to make behaviour changes. This is despite believing that these may not have a large impact on their risk of developing breast cancer. This should be seen as an encouragement to those seeking to find behavioural modifications which do have an impact on the risk of developing breast cancer for this population. If a direct benefit can be shown and can be communicated in a clear and consistent manner through those the group see as experts, then this may become a focus for the strong desire the group show to find ways to control their risk level.

5.3 Application of diet and exercise

When describing their health behaviours and behaviour changes the group focused on diet and exercise as the key elements of healthy lifestyle. The majority of the group either believe that they were already following a healthy lifestyle or stated that they had made changes to make their diet healthier or to increase the amount of exercise they took. The specific dietary changes made varied significantly and included items such as reduced alcohol consumption,

decreasing intake of dairy products, reduction in red meat and increases in fruit and vegetable consumption. The studies of Beagan and Chapman (2004), Chapman and Beagan (2003) and Spector (2007) also report that many different types of dietary change are made under the description of healthy eating. This wide variation in actual dietary changes is in line with the wide variety of possible controllable elements that the group describe. It is striking that the health behaviours and behaviour changes reported by the individuals in the study are not uniformly correlated with their perceptions of what are risk factors. Several individuals who did not perceive diet or exercise to be risk factors for themselves made clear statements that they purposely followed a healthy lifestyle. This is consistent with the findings of Beagan and Chapman (2004). Other studies have shown that diet changes are often reported by individuals during and after a health crisis (Maskarinec, 2001 in Beagan & Chapman, 2004). This is illustrated by the response given below;

“I can’t say that I’ve been doing the healthy eating thing primarily to stop me getting cancer, it’s primarily to make me feel better about myself. The well being.”

This illustrates that the relationship between individuals and their diet patterns reminds complex even in the presence of significant health related events such as being identified as a BRCA mutation carrier or a cancer diagnosis.

The individuals who took part in this study were open to the idea of taking part in future breast cancer prevention trials. However there was a very clear preference

for diet and exercise based trials and strong reticence to be involved in future drug based trials. Almost all those in the study were concerned about possible dangers of side effects which could be related to drug based trials. This negative perception of drug trials may be due to recent poor publicity but once again it should be recognised that 90% of this group have suffered from cancer or had a first degree relative who have suffered from cancer and therefore may have direct experience of chemotherapy. In the majority of cases the reason given for wanting to take part in possible future lifestyle based trials was the possibility of helping others in the future. We found very little evidence that body image was a motivator for wanting to join such a trial. It should be recognised that the interviewer was seen as a health professional researcher by the interviewees and may have affected their stated willingness to join future trials. This study is based on data collected from 20 volunteers out of 111 eligible candidates, it cannot be assumed that this group's preference for lifestyle over drug based trials necessarily holds for the wider BRCA population.

5.4 Future research

Our study provides some qualitative evidence that there is a strong motivation amongst those with a BRCA mutation to find ways to exert some level of control over their risk of developing breast cancer. It also indicates a clear willingness to become involved in future diet and exercise based studies into possible links between lifestyle and incidence of breast cancer. It is hoped that future larger scale qualitative studies will be undertaken to confirm that these views are consistent across the wider BRCA population. This should provide a foundation for large scale randomised control trials to investigate the proposed link between

health behaviours and incidence of breast cancer amongst BRCA carriers. Of particular interest would be the link between diets targeted at reducing DNA damage and reduced breast cancer rates such as have been proposed by Kotsopoulos and Narod (2005). Further expansion of this theme to encompass the rapidly emerging science of nutritional genomics would be recommended as a future direction for this work.

The findings of this study could also be used to inform the promotion of healthy lifestyle amongst this population group. Of particular significance are the findings that behaviour change is not solely related to an individual's perception of breast cancer risk factors and that this population's interpretation of a healthy diet varies significantly, suggesting that clear and targeted nutritional education for this group would be beneficial.

5.5 Limitations

The uptake for this study was only 18%, this implies that we have opinions from a relatively small section of the BRCA carrier population. We also specifically excluded those women who opted to have a risk reducing mastectomy, in order to target the subgroup that would be most willing to adopt lifestyle interventions. Because of this it is possible that the beliefs and behaviours of this subgroup, are not representative of the wider BRCA population. However this study of 20 individuals is significantly larger than the previously published qualitative study of the lifestyle behaviours of 10 BRCA carriers (Spector, 2007).

To further enhance the reliability and validity of this study, there are additional reliability and validation strategies which could have been employed. Triangulation through a mixed methods approach or respondent validation would have increased the validity of the study. Respondent validation would have been the most appropriate method of validation and could have been achieved by sending a synopsis of the key findings to each participant with an open ended questionnaire for feedback. Their responses would be checked against the data analysis to confirm that the findings were a true reflection of the participant's views. The inclusion of 2 different methods of data collection e.g. interviews and focus groups to investigate the same phenomenon would have allowed for constant checking across data and interpretations. Although a systematic approach was employed in this study to help minimise any potential bias, analysis of a selection of data by an independent researcher experienced in qualitative research would have helped to reduce the incidence of investigator bias and anecdotalism.

Due to the use of a third party transcribing service and some delay in receiving transcriptions of the interviews, concurrent data collection and analysis was not always possible. Concurrent data collection and analysis allows emerging concepts from interviews to be tested out at subsequent interviews, providing a further validity check.

Recording the numbers, age and most recent clinic weight of BRCA women not wishing to enter the study would have established whether the participants in the study are representative of BRCA carriers on the database. This data, which was

not complete in the data base, would have been a measure of the external validity of the study. This level of extended data processing was beyond the scope of this study.

By applying the process of reflexivity the following points relating to validity were recognised. The original information sheet was revised to include examples of questions to be asked during the interview at the request of the ethics board. This gave participants the opportunity to think about possible answers to give to these questions and to discuss the questions with family members, therefore responses given during the interviews may have been influenced by others rather than being solely their own. Although I introduced myself as a researcher it was clear on information sheets that the lead investigator is a research dietitian, this may have influenced the results as participants may have thought they needed to include diet and lifestyle into their answers. For example, in one response a participant stated “Lifestyle, smoking, diet. I know that's like part of this study.....”