Preparing young people for future decision-making about cancer risk in families affected or at risk from hereditary breast cancer: A qualitative interview study

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Abstract

Purpose: Women carrying the mutated BRCA gene, have approximately an 80% life-time risk of developing breast cancer with 50% risk of their children inheriting the gene mutation. Many parents find it difficult to know when and how to disclose this information to their children and how such disclosure might affect their child's future decision-making.

Method: This study explored the communication of genetic risk information in families using qualitative semi-structured interviews conducted with parents, children (7-11years) and young people (12-18years) affected or at risk from a BRCA gene mutation. Thematic analysis was applied to coded transcripts producing four themes; family communication, perception of cancer risks, risk management strategies and impact of genetic risk communication in children and young people's decision making.

Results: Twenty-seven individuals from 11 families took part, recruited through purposive sampling techniques. Cancer risk caused by a BRCA gene mutation induced a sense of fear in parents about their children's future. As a result, parents with hereditary breast cancer disclosed limited information about the risks associated with prophylactic surgery and/or the psychological and emotional impacts of surgery on body image. This had implications to children and young people's perceptions of prophylactic procedures, which were already influenced by cultural understandings of the 'desirable body' and increasing acceptance and proliferation cosmetic surgery.

Conclusion: Lack of risk management information and the acculturation of cosmetic surgery combined to limit children and young people's understanding of the impact of hereditary breast

cancer; reducing their ability to actualise the physiological, psychological and emotional consequences of surgery.

Highlights

What is known about the topic?

- Health professionals advocate that genetic risk information is communicated in families affected or at risk from an inherited genetic condition. However, parents' feel unsupported in this task and therefore find communication a challenge.
- Good communication of genetic risk information can strengthen parent/child relationships, encourage better coping strategies and improve children and young people's emotional well-being.
- Parents can have difficulty tailoring genetic risk information to their child(ren)'s age, gender, development stage and maturity.

What the paper adds?

- An understanding of how parents disclose risk management information to their children (<18years) and how this information impacts on their future risk management decisions.
- Parents communicate risk management strategies such as prophylactic surgeries in a positive manner to their children.
- The normalisation and proliferation of cosmetic procedures influences children and young people's perceptions of surgical risk and prophylactic procedures.
- Positive disclosure of risk management procedures in conjunction with the normalisation of cosmetic surgery has led to young people to want genetic testing on reaching adulthood for perceived aesthetic benefits to their bodies.

Introduction

Breast cancers caused by a BRCA germ line mutation, make-up 5-10% of all breast and ovarian cancer diagnoses (Easton et al., 1995, Hallowell and Lawton, 2002, Risch, 2001, Stratton et al., 1997). Specific or defined first degree relatives of the diagnosed individual have a 50% risk of carrying the autosomal dominant BRCA gene mutation (Sharff et al., 2011). If female relatives carry the mutated BRCA gene, their life time risk of developing breast cancer is approximately 80% (Easton et al., 1995, Sharff et al., 2011) compared with the 12.5% in the general population (Cancer Research UK 2016). Health professionals advocate that the person carrying the gene mutation communicates genetic risk information to their relatives so that they may engage in prophylactic measures to reduce their risk. Many individuals however, find it difficult to know when, what and how to disclose this information, especially to their children (<18 years) (d'Agincourt-Canning, 2006, Kenen et al., 2004, Kenen et al., 2006, Tercyak et al., 2002, Tercyak et al., 2000). Challenges arise due to feelings of guilt and anxiety, limited understanding of the disease (Kenen et al., 2004, Tercyak et al., 2002, Tercyak et al., 2007, Tercyak et al., 2001) and grief caused by personal experiences of cancer or cancer related deaths within the family (Lillie et al., 2011, Metcalfe et al., 2011).

Despite growing evidence demonstrating the importance of communicating genetic risk information to children (Metcalfe et al., 2011, Cavanagh et al., 2010, Forrest Keenan et al., 2009, Kenen et al., 2004, Klitzman et al., 2007), studies analysing family communication about hereditary breast cancer, focus on exchanges between parents and their adult children (Tercyak et al., 2002, Tercyak et al., 2007, Tercyak et al., 2001, Tercyak et al., 2000). There is therefore a lack of studies that explore the communication of genetic risk information (diagnosis, disease

risk and risk management strategies) between parents and their children (<18 years) (Peshkin et al., 2010). This study addresses the gaps in this evidence base.

Research with other genetic conditions has shown that the prospect of communicating genetic risk information is daunting and overwhelming for parents (Cavanagh et al., 2010, Etchegary and Fowler, 2008, Metcalfe et al., 2008a; Klitzman et al., 2007), with many feeling isolated and unsupported in this process due to a lack of available evidence–based resources (McConkie-Rosell et al., 2009, Rowland and Metcalfe, 2012, Sharff et al., 2011). They therefore require advice, guidance and support from health professionals. As hereditary breast cancer is adult onset and gene penetrance is less than 100%, meaning that carrying an affected gene does not necessarily result in the development of cancer, parents are often uncertain whether to discuss risk information with their children or wait until they become adults. Parents who delayed disclosure however, continued to struggle to find the right time to disclose genetic risk information (Kenen et al., 2004, Lillie et al., 2011). Delayed disclosure prevented children and young people from engaging in the necessary preventative measures or screening processes required for early detection.

Whilst, it is unclear whether there are benefits for engaging in early open communication in families affected by hereditary breast cancer, research with other genetic conditions has shown that open communication of genetic risk information improves children's self-esteem, increases family cohesion and enhances reproductive decision making (Fanos et al., 2001, Plumridge et al., 2011, Sharff et al., 2011, Sobel and Cowan, 2000). Increasing their awareness about the range of options, helps young people manage their thoughts and feelings about the risks involved. In contrast, poor disclosure can lead to lowered self-esteem in young people, resulting in risky behaviours such as self-harm and attempted suicide (Forrest Keenan et al., 2009).

With a growing range of risk reducing strategies increasingly becoming available eg. chemoprevention and screening for early detection; young people are likely to have a range of options available to them in adulthood, and young women will need to make decisions about whether they use the contraceptive pill, when they know they are at a higher risk of developing BRCA related cancers.

This study aimed to ask what are the experiences of parents, children and young people when discussing genetic risk in families affected by or at risk from a BRCA gene mutation, and how does the information shared impact on children and young people's views about their future risk.

Methods

Methodologically driven by grounded theory (Birks and Mills, 2011, Bryant and Charmaz, 2010, Denzin and Lincoln, 2005, Glaser and Strauss, 1967, Strauss and Corbin, 1998, Strauss and Corbin, 1994), a purposive sample of families affected or at risk from a BRCA gene mutation were identified and recruited to the study via a Regional Genetics Unit in the UK. Health professionals (nurses, genetic counsellors and clinical leads) were provided with recruitment letters and information sheets and asked to invite families; parents, children (5-12 years) and young people (13-18 years), who had attended clinic in the last two years and where a known BRCA mutation was present, to participate in the study. Snowballing techniques were also conducted with recruited families, who recommended other families they were acquainted with to the study. Exclusions were made if potential participants were; psychologically vulnerable, too young (<5 years old) or if parents had not discussed hereditary breast cancer with their children. Recruitment of participants ceased on reaching data saturation (Bowen, 2008, Guest et al., 2006, Pope et al., 2000). The West Midlands Research Ethics Committee approved the study (REC reference number 11/WM/0080).

Written consent of parents was required before asking children and young people under 16 years for their written assent to participating, with all participants having several days in which to change their minds. Assent and consent of all participants was rechecked immediately prior to interview and it was explained to children and young people that they still did not have to take part if they did not wish to. Several different age appropriate information sheets and assent forms co-designed and tested with children and young people were used. Continued assent was checked during the interview, and all participants understood that they could say if they wished to stop the interview at any time. Semi-structured interviews were undertaken by two researchers (AM and GP) in participants' homes between December 2011 and March 2012. All the families had one person, the mother, who had tested positive for a BRCA mutation and all their children were at risk until they could undergo genetic testing themselves, which is not until a minimum of 18years old. Interviews were conducted separately with parents and their children or young people unless participants specifically wanted to be interviewed together. Two pairs of siblings requested to be interviewed together, however no children or young people asked to be interviewed with their parents. An interview schedule was used to guide the researcher's questions and child-centred methodologies were used to engage the children and young people in the research (O'Kane, 2000, Punch, 2000, Punch, 2002).

All interviews were recorded using encrypted digital dictation and transcribed verbatim. Transcripts were read and re-read allowing the research team (AM, GP and ER) to become familiar with, and observe patterns in the data (Braun and Clarke, 2006, Fereday and Muir-Cochrane, 2006, Pope et al., 2000). Transcripts were inputted into ATLAS Ti. 6.2.27 (Friese, 2012) for data management and transcripts were independently coded by one researcher (ER) and verified by a second (AM). Codes were produced inductively (Boyatzis, 1998, Patton, 1990, Strauss and Corbin, 1998, Thomas, 2006) as they emerged from the data and deductively (Boyatzis, 1998, Crabtree and Miller, 1999, Hayes, 1997) drawing on knowledge and

experience from previously conducted research (Metcalfe et al., 2011). Family communication models; family systems theory (Segrin and Flora, 2005, Spey, 1999), Role Theory (Yerby et al., 1995) and Family Life Course Theory (Cooper, 1999) aided the coding process. Codes were discussed iteratively and definitive codes applied to all interview transcripts. Codes were translated into four themes, which were reviewed and refined by two researchers (AM and ER) (Braun and Clarke, 2006, Fereday and Muir-Cochrane, 2006, Joffe and Yardley, 2004).

Any names or potentially identifying information is removed from the quotes to protect confidentiality, and specific ages of children are not included for the same reason.

Results

Eleven families with mothers (n=10) or a father (n=1) affected by a BRCA mutation participated in the study. This equated to 27 participants; 14 parents and 13 children and young people, with children and young people between 10 and 21 years of age. No attrition occurred within the family members volunteering to participate, however there were family members who chose not to participate in the research. Reasons for non-participation included; too young to participate (1), hereditary breast cancer had not yet been disclosed, or they had limited information of the disease (4), choose not to participate (7) or were unavailable during the data collection period (1).

The themes structure the reported findings; (1) family communication of risk information, (2) selective communication of risk information, (3) children and young people's understandings of genetic risk information and (4) implications for future decision making.

Findings

1. Family communication of risk information

Mothers affected or at risk of BRCA gene mutation predominately disclosed genetic risk information to their children, in the home, typically in the children's bedroom. Where siblings

were of similar ages, gender and personalities disclosure took place simultaneously. When siblings were of different genders and/or of larger age gaps, information was disclosed individually allowing information to be tailored to the child or young person's needs.

Information disclosed fell into four age categories; 8-11, 12-14, 15-17 and >18 years. In the majority of families with children <11 years old, information focused on events that the child would witness for example reasons for hospitalisation, which included discussions surrounding a family gene and breast cancer diagnosis, (prophylactic) mastectomy and/or breast reconstruction. For this age group parents often used simplistic language to describe breast cancer; "poorly boobs", "poorly tummy", cancer treatments were; "magic medicine" and prophylactic procedures and reconstructive surgeries were; "new boobies" or "boob job". Parents perceived this language "not too babyish" but sufficiently informative, allowing children to grasp the key concepts of the disease and risk management procedures without causing fear.

At 12-14 years old disclosure centred on the hereditary nature of the BRCA gene mutation and parents' risk rather than discussing the young person's own risk. By 15-17 years old, young people were considered adequately mature to cope with and understand the potential risk of breast cancer to themselves and were given more information about risk management strategies. At 18 years old, discussions focussed on genetic testing and the implications to the young person's future off-spring.

Only two families decided not to communicate genetic risk information to their children. In the first family, the parents felt that because their son's breast cancer risk was low, disclosure would cause unnecessary upset. The parents stated that they would disclose genetic risk information when he reached adolescence. In the second family, parents thought their children did not want to know as they did not ask questions.

2. Selective communication of risk information

In the majority of families, mothers disclosed their own risk of breast cancer with their children, but often avoided disclosing information about their child's risk of hereditary breast cancer because they did not want to frighten them. Genetic risk information was therefore carefully selected to "shield" children from perceived harmful information.

Genetic risk information was also selectively communicated according to the child's gender, with mothers disclosing less genetic risk information to their sons, despite them sharing the same level of risk of carrying the gene mutation as their daughters. This may be because in their consultations genetic counsellors tend to emphasise the female cancer risk associated with the BRCA 1 and BRCA 2 gene mutations and de-emphasise the risk to male carriers (Genetic counsellor A: personal communication, Sept; 2012). Discussions with genetic counsellors may therefore have led mothers to believe that their sons were not at risk. Additionally, mothers provided their daughters with more genetic risk information because they were more anxious about their susceptibility to breast cancer due to their developing bodies.

> *"[My daughter] is starting to develop now because she is ten and a half, and she's had a lump...she said to me one day mummy, – just feel this for me... I felt her boob and it was rock hard, of course alarm bells immediately...right ok we'll go to the doctors and see what she says and I'm thinking please no, no, no, not another one [family member affected by breast cancer]..."*
> (Mother with BRCA gene mutation affected by breast cancer of two children <12 years)

> *"I've just had my hysterectomy and I've done everything I can to prevent this cancer coming back again, my anxieties are not finished with, because, obviously, I look at [my daughter], you know, my fears are all about her really"*

> (Mother with BRCA gene mutation affected by cancer of one child and two young people < 16 years)

Mothers were also selective about the communication of risk management decision-making. Mothers avoided disclosing information about the psychological impacts of prophylactic

procedures on their body image, self-esteem, and emotional well-being. Many of the women interviewed had opted for prophylactic surgery to minimise their risk of developing breast cancer. Whilst reducing the risk, the removal and reconstruction of the breast(s) was highly emotive for women, impacting on both their perceived body image and gendered identities. Some women talked favourably about their reconstructed breasts following bilateral mastectomy because they were much "perkier", with one woman demonstrating her satisfaction with her altered body image by stating "the weirdest part is when you take your bra off, they don't fall down, [laughter]...they just stay there".

Other women however, struggled to come to terms with their post-surgical body image. This led a minority of women wishing that they had delayed reconstructive procedures, believing that they should have given themselves more time to contemplate the psychological and emotional impacts that surgery might have on their self-esteem, relationships, body image and gendered identities. Interestingly, despite their role in reproduction, the removal of women's ovaries did not appear to have the same psychological and emotional impact as breasts. This may be because the majority of women participating in the study had already had their families and or had gone through (early) menopause due to the side-effects of cancer treatments and therefore were not planning to have more children. Furthermore, the ovaries are hidden within the body and therefore women may have less emotional attachment to them.

> *"I think the breasts are a little bit more, you know, in the forefront, because they are quite, you know they're out. I think it's because they are outside the body...it's visible, you know your ovaries and bits and pieces, when they take it from inside your body, it's not...but your breasts, very much part of a woman"*

(Mother who carries BRCA gene mutation with four young people >13 years)

Due to the impacts on their emotional and psychological well-being, many women wanted to protect their children from the impacts of their surgery and risk management decisions. Many mothers therefore used jokes and humour as a defence mechanism to play-down their

emotions and conceal their lowered self-esteem from their children. Whilst some mothers were successful in protecting their children, some young people were aware that their mothers were putting on a "brave face". This comprehension did not however, encourage communication because children and young people were afraid that asking questions would upset their mothers further.

> *YP1: "Like she tried to make it look like it didn't affect her..."*
> *YP2: "She made like – not a joke out of it but she made it seem like everything was ok, like she didn't ever show us how she really felt about it, even when it did really have a bad effect on her. Like we know how she felt about it but at the time, [but] she just clammed up"*

(At risk young people >13 years, mother has BRCA gene mutation and has been affected by breast cancer)

Despite mothers' anxieties about undertaking "major surgical procedures", they often did not communicate to their children about the surgical risks associated with prophylactic procedures and the implications to their health such as; increased osteoporosis, early menopause, depression, poor health, infections, scarring, pain and fatigue. Instead, mothers talked positively about (prophylactic) mastectomies and breast reconstruction, often referring to the procedures as a "boob job" and emphasising the benefits of surgery for reducing cancer risk. Some mothers discussed the aesthetic benefits of breast reconstruction, for example their ability to choose their breast size, which they were often choosing for the best surgical outcomes rather than cosmetic reasons. However this was not always clarified with the children.

Positive discussions were conducted to reduce children and young peoples' anxiety and fear surrounding cancer, which may have developed due to witnessing multiple cancer related deaths in the family, from an early age. Selective communication however, did not seem to reduce children and young people's anxiety. On the contrary, field notes showed that children and young people participating in this research appeared more upset and frightened by the

disclosure of cancer risk than children and young people with other inherited genetic conditions.

3. Children and young people's understanding of genetic risk information

In attempting to protect children and young people from the emotional and psychological impacts of breast cancer and (prophylactic) breast surgeries, parents inadvertently inhibited their child's understanding of the risk caused by the BRCA gene mutation. Gendered disclosure lead several young males to perceive their risk of the BRCA gene mutation was minimal, despite the gene's presence increasing their risk of other types of cancer including prostate, pancreatic and male breast cancer, as well as having implications for their future offspring.

> *YP: ... I understand [BRCA mutation] doesn't affect males that much, it like only gives them like a marginal chance more, whereas females...it gives them a massive chance of getting [breast cancer]. So I couldn't see the interest...it's not something I'd get worried about, me myself...Obviously mum's going to, auntie's going to, [sisters] going to but it hasn't affected me as much as it would them probably...*
> (At risk young male >13 years of mother is BRCA gene mutation carrier – no cancer)

Furthermore, in response to their parent's cautious or partial disclosures, some, children and young people developed a blasé attitude towards surgical procedures. This was compounded by children and young people's cultural understandings of cosmetic procedures with breast augmentation normalised by media images portraying surgically enhanced celebrities. This lead children and young people to not differentiate between breast reconstruction for prophylactic reasons or for cosmetic purposes and was highlighted by a father who stated:

> *"They are aware that [their mother] had surgery, but you know, unless you told them what sort of surgery, it probably wouldn't register. I mean people are on telly having breast enlargements constantly aren't they? Everything they watch nowadays, everybody's got...surgically enhanced breasts and so they're aware of things and that's normal anyway isn't it now in life?"*

(Father whose wife has BRCA gene mutation but no cancer, has one child and two young people)

4. Implication for decision making

Selective genetic risk information in conjunction with the normalisation of cosmetic surgery impacted on children and young people's attitudes towards breast cancer and risk management procedures. Some young female participants wanted genetic testing as soon as possible, perceiving it meant that they could have free breast augmentation.

> *"With the double mastectomy, it's a free boob job basically on the NHS because you get to choose your consultant; you can choose your size – bigger or smaller, whatever. And that is the reason why I wanted to be tested quicker, because I thought...If I've got it, I can have my boob job as well and I don't have to pay for it, but then if I don't have it I can still have it anyway"*

(At risk young female >13 years, Mum tested positive for BRCA gene mutation but unaffected by cancer)

Withholding or down playing genetic risk information therefore affected young people's risk management decision making as they were unaware of the implications of the disease and prophylactic surgery on their body, gendered identities and emotional and psychological well-being. One young female participant demonstrated she understood the importance of monitoring and screening as a risk management strategy but she appeared frustrated that the extra vigilance required will prevent her from having cosmetic surgery to enhance her body aesthetic.

> *"I've got a friend whose just had a boob job...and I was like I really want to have it done, I can't have it done now...because there's a barrier...my mum said...if you've got silicone it's like a barrier and you won't be able to feel a lump...but other than that, I don't know it's just a barrier...it's annoying"*

(At risk young female >13 years Mum affected by breast cancer)

Some parents observed that young people from aged 15 years stopped focusing on themselves and their body image and became more erudite and knowledgeable about the BRCA gene mutation. At this time young people began to realise the potential implications of breast cancer risk for their own psychological wellbeing, particularly to their self-esteem and body confidence. This insight was normally actualised through young people's reflections of their mothers' experiences of breast cancer and their risk management decisions.

"...going on the beach and wearing a bikini, I think that was one of the factors with my mum, like you know [in choosing] to have a reconstruction, and I know that that would affect me as well...because that's when it will knock my confidence and stuff...if that is going to happen, I hope it happens later on when I've got a family and I'm settled down and stuff".

(At risk young female >16 years, mother had breast cancer)

Greater knowledge of the BRCA mutation also caused young people to consider the impact that breast cancer risk might have on their future relationships and subsequently their future offspring. They therefore wanted to be genetically tested to make informed reproductive decisions:

"She said. I want to be tested; because I want children, and I want to know. I don't want to be passing this onto my kids. That was her main concern...It wasn't about herself was it? It was about having children...she's thinking ahead about having children."

(Mother who carries BRCA gene mutation but unaffected by cancer with one young person >16 years)

Mastectomy was the main focus of discussions about risk prevention and parents did not report discussing with their children other options of chemoprevention or early detection through screening, the emphasis was on reducing the risk to the lowest possible via surgery.

Discussion

Presenting original insights into how parents communicate genetic risk information to their children, the research exposes mother's anxieties about the risks associated with the BRCA gene mutation. Parents tried to be open about the risks but feared upsetting their children and causing them worry, when they did not feel fully prepared to deal with the emotional consequences for the children or themselves. Whilst parental risk was discussed with children, mothers were less likely to discuss the surgical risks associated with (prophylactic) mastectomy and reconstructive surgeries and the impacts to their psychological well-being. Matloff (2009) demonstrated that women affected by a BRCA gene mutation found their altered body

"grotesque" (Matloff et al., 2009). Mothers in this research struggled to come to terms with their altered body image often resulting in poor self-esteem and body confidence. By avoiding risk communication parents thought that they were protecting their children from harmful information however, avoiding or delaying disclosure had three profound effects on children and young people's perceptions of risk and to their risk management decision-making.

First, down-playing surgical risk lead to children and young people to develop a blasé attitude towards prophylactic procedures and breast reconstruction, preventing them from understanding that these procedures are major surgeries that carry risks. Second, over-emphasising the benefits of prophylactic surgical procedures prevented children and young people from understanding that breast reconstruction is not the same as breast augmentation for cosmetic reasons. Furthermore children and young people's understanding of breast reconstruction was influenced by cosmetic procedures undertaken by celebrities to create a desirably curvaceous body. The over exposure of cosmetic surgery in the media (Featherstone, 1982, Holliday and Taylor, 2006, Morgan, 1991) caused children and young people to perceive that a surgically enhanced body would improve self-esteem and body confidence. They did not therefore contemplate that mastectomy and breast reconstructive surgery could induce the opposite, or that there might be other options rather than surgery. However this group is potentially biased because most of the participating mothers had or were awaiting mastectomies and no families came forward where the women at risk or affected were not taking a surgical option; this possibly delayed the need for these parents to talk to their children and therefore they did not fit our study criteria. By contrast mothers who were undergoing mastectomy had little choice but to explain to their children what was happening. Future studies should recruit this group, especially as there are more studies now underway to look at risk-reduction via chemoprevention.

Finally, the normalisation of cosmetic surgery and an avoidance of open communication about genetic risk caused children to misunderstand the full implications of risk management decision making. This led children and young people (<15 years) to desire genetic testing to establish whether they were entitled to a "free boob job" rather than embark on risk management strategies. Kenen et al. (2004) suggested that once a child formulates a view about a disease it is often difficult to challenge (Kenen et al., 2004). Further research is required to ascertain whether young people's views do change as they mature or whether there is a need for parents provide more accurate and developmentally appropriate genetic risk information to their children to prevent them from creating false assumptions about their breast cancer risk and the surgical risks associated with prophylactic procedures.

In addition to the novel findings above, this study's findings were analogous with previously conducted research with families affected or at risk from other inherited genetic conditions (Easton et al., 1995, Metcalfe et al., 2008, Rowland and Metcalfe, 2012). All family members believed that it was the parents' responsibility to communicate inherited genetic risk information (Etchegary and Fowler, 2008, Forrest Keenan et al., 2009, Klitzman et al., 2007, Metcalfe et al., 2011). Communication was inherently gendered, with mothers taking primary responsibility for disclosure (Forrest Keenan et al., 2009, McConkie-Rosell et al., 2009, Plumridge et al., 2010) and fathers provided children with emotional support and reassurance when their mothers were in hospital receiving cancer treatments or undergoing surgical procedures (Klitzman et al., 2007).

Genetic risk information is usually disclosed around two time frames which was also observed in this study, relating to the life-cycle and disease trajectory / medical course (Klitzman et al., 2007). Mothers disclosed their own personal risk to their children more or less straight away following their cancer diagnosis (Forrest et al., 2006, Forrest et al., 2003), after genetic testing or when undertaking breast reconstructive surgery, particularly to young people. However those

parents with younger children who did not have a cancer diagnosis said they would wait until their child was old enough to understand.

Children and young people at risk of a BRCA gene mutation, appreciated disclosure from family members however, in addition they wanted an opportunity to speak with health professionals (Klitzman et al., 2007, McConkie-Rosell et al., 2009, Metcalfe et al., 2011). Children and young people sought information from the internet (McConkie-Rosell et al., 2009, Plumridge et al., 2010), TV programmes (Forrest Keenan et al., 2009), leaflets and books to supplement the information provided by their parents. In our study some young people also used this additional information to educate their parents about hereditary breast cancer.

Conclusion

Interviews highlighted a discrepancy between parental perceptions of risk and what they disclosed to their children. Selective communication and playing down risks, particularly related to prophylactic surgery, impacted on children and young people's understandings of their own breast cancer risk and surgical risk, which was also influenced by the acculturalisation of cosmetic surgery. This had implications for young people's decisions to engage with genetic testing.

To re-address children and young people's perceptions of breast cancer risk and surgical risks associated with breast surgeries parents need support to communicate balanced risk information to their children, in a developmentally appropriate manner. Incorporating information about the emotional impacts of breast cancer and the range of risk management options available will assist young people in distinguishing between surgery for cosmetic reasons and prophylactic need. It will also help them to make informed risk management decisions and prepare them for the impacts of prophylactic procedures on their body image, gendered identities and emotional and psychological well-being. The study highlights the dilemmas that parents find themselves

facing, yet they all thought they received little assistance or advice from health professionals in knowing how and when to explain the cancer risk and its implications to their children. Oncology nurses and specialist cancer nurses have a pivotal role in assisting parents and facilitating their discussions with their children about inherited cancer risks and subsequent choices.

The study is limited by quite a small self-selecting sample size but included different types of family structures and socio-economic backgrounds and data saturation was achieved. The study's strengths lie in its in-depth analysis of family communication from multiple family members' perspectives. Consequently this research provides essential insights for nurses counselling and supporting families affected by hereditary breast cancer, to assist them in providing risk information and ensuring that the next generation at risk from a BRCA gene mutation can be more prepared to cope with the decisions and choices facing them.

Acknowledgements

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