

The human drama of genetics: 'hard' and 'soft' media representations of inherited breast cancer

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Abstract

This paper examines media coverage of 'breast cancer genetics' and explores its implications for public understanding. We present a content analysis of coverage in British newspapers and look at a variety of popular forms, including women's magazines, television soap opera and radio drama. Genetic/inherited risk receives a great deal of coverage across a wide range of media formats and outlets. Much of this attention has focused on individuals from 'high risk families' and dilemmas around prophylactic mastectomies. Through examining media coverage, combined with interviews with media personnel and their sources, we show why this story proved so attractive to the media and highlight the different production values which influence coverage. Finally, we introduce preliminary findings from focus group discussions to demonstrate how such 'human interest' framing has engaged audience attention and influenced public understandings. The paper concludes by highlighting the implications for analysing, predicting, and engaging with, media representations of science.

Keywords: public understanding, media, fiction, documentary, mastectomy, science.

Introduction

The media are a crucial source of public information about health and illness (Chapman and Lupton, 1994; Miller *et al.* 1998, Philo 1999). However, the conflicting priorities of scientific and media communities have been well documented (Friedman, *et al.* 1986, Karpf, 1988; Wilkie, 1991; Nelkin, 1996, Peters, 1995). Certainly, the media do not necessarily prioritise the risks judged to be most important by epidemiologists, doctors or scientists. Media values are not the same as those of 'the experts' (Kitzinger, 1999).

One approach to examining the coverage of scientific issues is to track the media reporting of articles from key journals, such as Nature or the BMJ. Such studies tend to focus on news around scientific discoveries (Miller, 1995) or specialist reports on the science and health pages (Entwhistle, 1995; Mouer *et al.* 1995). However, there is also widespread acknowledgement that broader representations of science (such as those expressed through the Frankenstein metaphor) may also be crucial (Turney, 1998) and that 'the gene' has become a cultural icon in the broadest sense (Nelkin and Lindee, 1995). Studies of public understandings of biomedicine have highlighted how images from popular fiction

may be referenced in public discourse (Kerr *et al.*, 1998) and have pointed to the role of non-news outlets such as women's magazines (Richards *et al.*, 1995). A recent Wellcome Trust study of 'Public perspectives on human cloning' concludes that research participants' concerns about the social implications of this science 'were often described in the context of popular cultural imagery such as science fiction films and media stories portraying the lives of public figures. Scientific news coverage appeared to have a lesser impact upon views' (The Wellcome Trust, 1998, 4).

In studying how breast cancer genetics was reported in the media we could have focused solely on the reporting surrounding the discoveries of the two 'breast cancer genes': BRCA1 and BRCA2 (reported in 1994 and 1995 respectively). However, to examine such reporting in isolation would have ignored the way in which these discoveries diffused into the media and became integrated into a 'cultural repertoire' for understanding inherited risk. This paper reports our work into media reporting which adopted a broader approach, including exploring how genetic/inherited risk translated from the hard news arena into human interest stories, women's magazines 'true life tales' and fiction. We use this study to argue for a three-dimensional approach to studying the media which takes into account the importance of human interest approaches to science coverage.

Methods

This paper draws on research, funded by the NHS Executive, designed to examine how media representations of breast cancer were shaped, what form the coverage took, and how this might influence public understandings¹. The project involved three intertwined levels of enquiry.

1. The first stage was an analysis of media production processes. This involved interviews with journalists (including medical/science specialists, feature writers and non specialists) and also with documentary makers, scriptwriters and magazine editors. We also interviewed press officers from cancer charities as well as relevant pressure groups. In total 40 interviews were completed (mostly lasting half an hour to an hour). These were tape-recorded and transcribed.
2. The second stage of the research was an analysis of media content. This involved two main samples. We monitored a selection of press coverage for three years (1995-1997). We also collected a broader sample which included television, magazines and radio for a four month period (September-December 1997).
3. The third stage of the research focused on audience reception of the coverage. This was explored through 30 tape-recorded focus group discussions which were then transcribed and coded onto the data analysis programme, NUDIST. Twenty five groups were conducted with women with

no known special interest in breast cancer. These women (from a range of backgrounds and areas in Britain) were accessed through community centres, clubs and work places. For example, the sample included people who worked together (e.g. waitresses) and groups who met for social, political or support purposes (e.g. a bridge club, a youth group, a black women's community group and members of an 'over 60's' group). The aim was to access a diverse range of women and to facilitate relaxed discussion. Where possible, sessions were conducted in places familiar to participants, such as their local community centre or, sometimes, in women's own homes. In addition to these 25 groups with 'ordinary women', a further five sessions were conducted with medical practitioners, breast cancer support workers and breast cancer survivors. In total there were 164 group participants (143 'ordinary women' and 21 people with special interest in the issue). The average group involved 5 or 6 participants and lasted between one and two hours. Most of the sessions were facilitated by Cherise Saywell (see Saywell et al., 1999).

The research was not designed to focus on genetics per se. However, this soon emerged as an important issue at every level. Inherited/genetic risk received a large proportion of media attention, it was frequently mentioned by journalists as a key story and it was raised spontaneously by participants in the focus groups. As we will demonstrate, however, both media reporting and public discussion often addressed the issue without framing it as a story about science. The focus was often more on family history or inheritance. The significance of this will become clear later, here we just wish to note that this is why we use the term 'genetic/inherited' risk.

The media coverage: introducing the two samples

As this paper focuses on media content we will describe the methods for this part of the research in greater detail. The aim was to (a) look at a substantial amount of coverage over a long time scale and (b) examine a range of coverage across different media outlets. In order to achieve this we had two sampling strategies. First, we examined three years of press coverage (1995-97) in eight different newspapers. The newspapers were selected to reflect different readership/political profiles. We chose two daily 'tabloids' (newspapers with a large and predominantly working class readership): The Sun and The Mirror. We also examined three 'broadsheets', (newspapers with a narrower and predominantly middle class readership): The Guardian, The Independent, and The Times. In addition, we included 3 broadsheet Sunday newspapers (The Observer, The Independent and The Sunday Times). Articles were located from the tabloids via a manual search, but CD rom searches were used to identify articles in the broadsheets.² The search terms used included words such as mammography and mastectomy in addition to breast cancer to ensure we accessed all relevant articles. Those which simply referenced breast cancer in passing (e.g. obituaries) were then excluded.

This three year sampling strategy generated 708 news reports, feature articles, editorials and columns. These were coded onto a specially designed computer programme to allow for systematic quantitative analysis. Each item was indexed by headline, journalist's name and specialism, newspaper and page on which it appeared. We also recorded the main focus of each item (e.g. 'causes', 'screening' or 'treatment'). Additional details were coded such as the type of images used, which risk factors were mentioned, the use of statistics and which sources were cited.

This three year sample of press reporting (N=708) was complemented by a second sample which covered a substantially shorter time period (September-December 1997) but which included a broader range of media. This included all national UK newspapers and the 10 top selling women's magazines as well as television news, documentaries, chat shows, soaps and a selection of radio programmes. In addition, we monitored the TV Times during the course of the project (1997-1998) and recorded additional items where advance publicity indicated that they were about breast cancer.

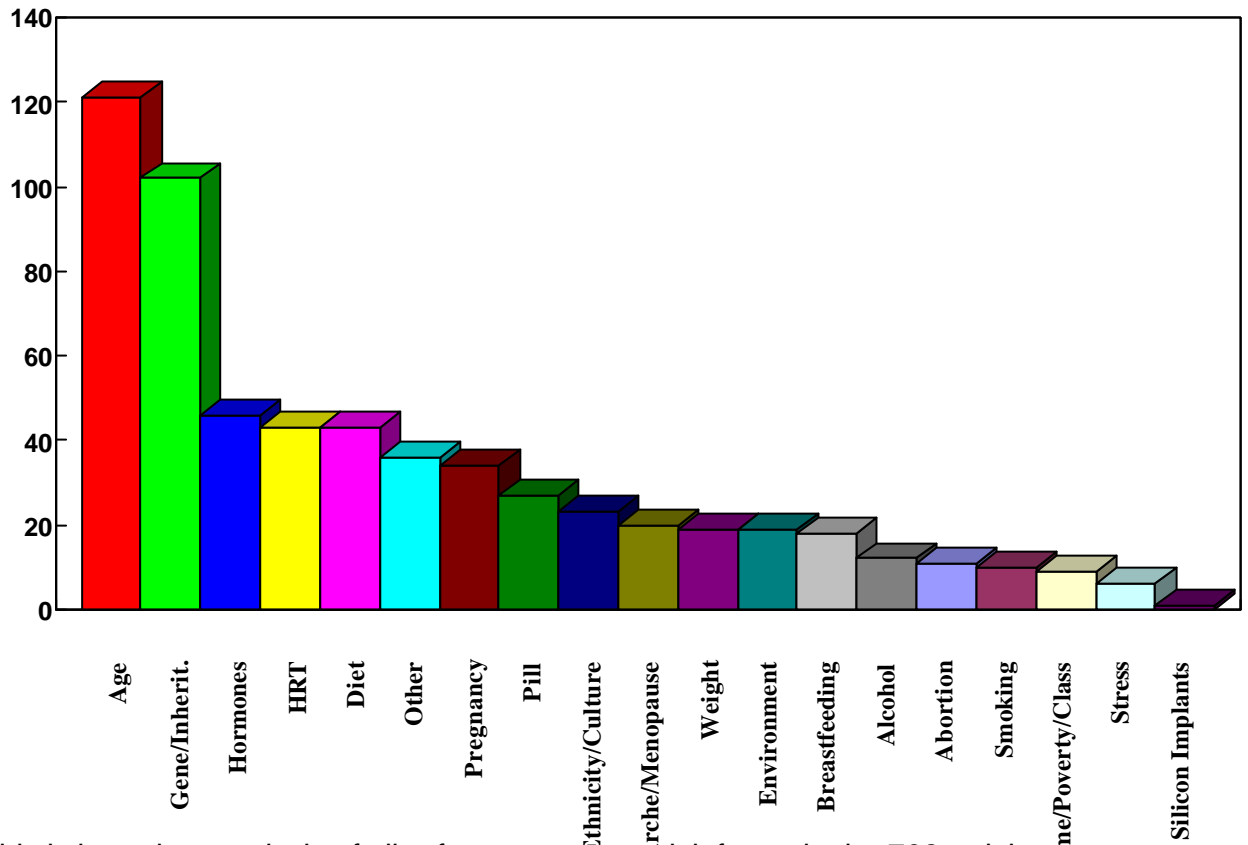
In the next section we focus on our first sample: the three year sample of press reporting. We use this to present some basic statistics about the profile of inherited/genetic risk in the newspapers and highlight the emphasis on human interest accounts. We then draw on our sampling from television, magazines and radio to illustrate how this emphasis ran through other media outlets too and to give a flavour of the nature of this reporting.

Inherited risk: the media profile of 'family' breast cancer **The quantity of coverage**

The first important finding from our content analysis is the high level of media attention devoted to genetic/inherited risk relative to other risks. This high profile was evident at several levels. Analysis of the eight selected newspapers for the three years identified 708 articles about breast cancer (excluding letters to the editor). One hundred and fifty two of these focused on risk factors for breast cancer and 51 focused on genetics/inheritance. In other words, genetics (or inherited risk) was the main topic of one out of every three articles focused on discussing risks.

In addition, family history was often mentioned in passing in articles about other aspects of breast cancer. In fact the only risk factor to be referenced more often was age³. Thus genetic/inherited risk had a much higher profile than a host of non-genetic factors which might modify the risks of breast cancer, including the contraceptive pill, HRT, pregnancy, hormones, class, diet or smoking. (**See Figure 1**). This is in spite of the fact that BRCA1 and BRCA2 are believed to account for just 5 to 10 per cent of breast cancers (Easton *et al.*, 1994; Wooster *et al.*, 1994).

Figure 1. Showing the number of articles referencing different potential risk factors for breast cancer *



*This is based on analysis of all references to any risk factor in the 708 articles about breast cancer which appeared in eight newspapers, 1995-97. Some articles concentrated entirely on one risk factor, others referenced more than one factor in passing, some made no mention of risk factors at all.

The nature of the coverage and its diffusion into different formats and diverse media outlets

The second important finding, evident from our content analysis concerned diffusion of coverage. Analysis of our three year sample showed that the issue of genetic/inherited risk had permeated beyond the traditional news format. Less than half of the reports about genetics/inheritance were news reports (n=21). The rest were features or personal accounts (n=25) or took other forms such as personal observations by columnists e.g. 'Why I won't search for the deadly gene' (Nigella Lawson, *The Times* 28 February 1996). In addition, inherited risk was not just discussed on the science/health pages, but also appeared in readers' stories, on advice pages and even, in one instance, on the fashion page. *The Mirror* published a feature entitled: 'The secret fear I share with mum: TV's Leslie tells of her cancer scare' (17 May 1995). This showed television actor, Leslie Ash, modelling a 'short and snazzy: bright orange dress £520, by Moschino' and 'gold strappy evening shoes £49.99'. The article did include a brief discussion of Leslie Ash's feelings and fears about breast cancer, but was primarily being used to promote clothing sales.

Most of the reporting of Inherited/genetic breast cancer, however, fell clearly into one of four categories: a) scientific discoveries; b) debates about testing; c) controversies over patenting; d) 'human interest stories'.

Early reporting focused on the first of these categories. The discoveries of BRCA1 and BRCA2 were reported on the front page and discussed within regular science/medical slots. The discovery of BRCA1 was announced prior to the start of our sample (in 1994). Even so, genetic discoveries (mainly around BRCA2) accounted for 18 per cent of the reports about genetics in our three year sample. Headlines included: 'UK scientists claim breast cancer gene breakthrough' (*The Independent*, 21 December 1995); 'Breast cancer gene isolated' (*The Guardian*, 21 December 1995) and 'Second gene linked to breast cancer' (*The Times*, 21 December 1995).

However, long after the announcement of the discoveries of BRCA1 and BRCA2, inherited/genetic risk continued to attract media interest in other ways. Controversy around insurance and patenting, for example, generated extensive debate, at least within the broadsheets, particularly in response to European directives. Discussion about patenting accounted for 26 per cent of the articles about breast cancer genetics in our sample e.g. 'Protest over patents goes global' (*The Times*, 6 December 1995); 'Whose genes are they anyway?' (*Independent on Sunday*, 9 November 1997). Similarly, a flurry of reports mentioning breast cancer followed the publication of a code of practice by the Advisory Committee on Genetic Testing. Debates about testing were the primary focus of 21 per cent of the newspaper articles discussing breast cancer genetics e.g. 'Alarm at genetic testing by post' (*The Daily Telegraph*, 24 September 1997)

and 'Codes of practice to regulate sale of DIY gene tests' (The Times, 24 September 1997).

However, the single most dominant strand of reporting about genetic/inherited risk during 1995-1997 focused on issues surrounding prophylactic mastectomies and the experiences of women from 'high risk families'. This was particularly, but not exclusively, true of the popular (and more widely read) tabloid press. This 'human interest' type of reporting accounted for 27 per cent of the total number of articles about breast cancer genetics in our three year sample and these articles were usually much longer than those about the gene discoveries, patenting or testing debates. Stories about individual women's feelings and dilemmas often covered several columns and there were even some double page spreads. Typical headlines included: 'Cutting deadly odds: These sisters are healthy yet they each want both breasts removed' (The Mirror, 29 May 1996); 'Women at risk of cancer agonise over mastectomy' (The Times, 26 February 1996); 'I didn't want to wait for it to come and get me' (The Guardian, 29 April 1996) and 'Big sacrifice for survival' (The Mirror, 6 May 1997).

These types of article are worth close examination as they formed a distinct genre of coverage which recycled similar narrative and images. A feature article in The Observer headlined 'The Breast Cancer Family' (The Observer, 30 June 1996) condensed many of the main themes in its opening paragraph:

Her mother died of it. Her aunt has it. She'll get it too. And her three daughters? 'I'm young and healthy and I'm going to have my breasts cut off. That sounds so ghastly. And of course I'm scared. What will I look like? What will I feel like? How will I cope and what will I become, who will I be?' (The Observer, 30 June 1996)

Such stories were frequently accompanied by reproductions of women's wedding photographs or portraits showing them with their mothers or daughters. The Mirror, for example, reproduced three such images under the headline '9 of my family got breast cancer so I had my breasts removed in case I was the next' (The Mirror, 14 February 1996). One picture showed the extended family with the subtitle 'A picture of tragedy', another displayed a diagram of 'Wendy's tragic family tree' representing those who carried 'the cancer gene' as black circles and squares.

It was these types of images and stories which were also reflected in a wide range of media over and above the newspapers. Stories based around 'high risk families' appeared in women's magazines, TV chat shows and documentaries. They also featured in soap operas and radio fiction. It is here that our broader sampling strategy which included magazines, television and radio provided useful additional data, especially as our focus group work showed that it was these types of stories and variety of outlets that had made most impression on women's understandings of genetic risk.

Accounts about breast cancer outside traditional news slots were often less about 'science' than about family relationships, drama and dilemmas. They frequently appeared in slots traditionally reserved for the exploration of sexuality and emotions. An article in the women's magazine, Bella, for example, explored the impact of the breast cancer gene on a woman and her partner. This was placed within a regular slot within the magazine called: 'Relationships: how we got through it' (Bella, 8 October 1997). Two documentaries about genetic breast cancer also emphasised relationships and family dynamics. The BBC2's documentary Homeground (13 May 1997) told the same story as the Bella article, while Channel 4's The Decision: Living In the Shadow followed another woman, Wendy Watson, and her family through the genetic testing and decision-making process (27 February 1996). This latter episode was part of a series devoted to difficult medical dilemmas and borrowed much from the detective genre as it portrayed Watson's quest to trace her family history and eventual discovery that nine relatives had contracted breast cancer at a young age. Narrative suspense was maintained by Wendy Watson's own test results too – a test which had only become available after her she had undergone prophylactic surgery.

Inherited risk did not just feature in 'true stories' and documentaries, producers of fictional programmes also recognised the potential of such accounts. Women with a family history of breast cancer were the focus of two fictional representations during the course of our research project: a storyline in the medical soap opera, Peak Practice (ITV, 12 January 1998) and a radio play (Radio 4, The Monday Play, 19 May 1997). The former followed a young woman's discovery of a breast lump, her emotions around her own mother's early death, her desires for a double mastectomy and her fears for her daughter. The Radio 4 play echoed similar themes with its focus on 'Joy' and her sister 'Vita'. The plot of this drama also paralleled that of The Decision in following the two women through the process of being tested and discovering the results. Drama was heightened by the device of making Joy have 'the gene' while Vita does not. The play explored how genetic knowledge may ricochet through family relationships. Dramatic tensions were further increased by Joy's decision to become pregnant with eggs donated by her sister.

Both the radio play and the episode of Peak Practice explored the human cost of knowledge and explored uncertainty. Neither suggested that science and medicine offered clear cut solutions. Indeed, in the radio play, as Joy considers prophylactic treatment her husband asks: 'What is this? Self-destruction? Self-preservation?' She replies: 'Aren't they the same thing for me now?'. He responds by stating simply: 'What a mess.'

We have described these media representations in some detail in order to illustrate the saturation of certain themes and story lines across different media formats/outlets and to highlight the way in which this one aspect of risk became

widely reported across a range of coverage using very similar motifs. Other dimensions of the story (such as scientific discoveries or patenting debates) did not have such broad attraction for the media.

This permeation of one aspect of the genetic/inherited risk issue has important implications for the amount of overall coverage for two reasons. Firstly, if an issue is addressed in a range of different formats/outlets then the media's '*carrying capacity*' for that issue is greatly increased (Hilgartner and Bosk, 1988). Secondly, such diffusion may generate its own 'intra-media momentum becoming both a sign of, and contribution to, a 'snowball effect' (Kitzinger and Reilly, 1997). Editors will decide to cover an issue because 'everyone is talking about it' (Kitzinger, 1998). In addition, a symbiotic relationship develops between different media outlets, whereby, for example, a documentary-maker will encourage pre-broadcast publicity through a newspaper article, and, after broadcast, the same story might be picked up by women's magazines (see for example the Bella article based on the Homeground documentary).

The permeation of a story beyond straight forward news presentations can also have important implications for the nature and effect of the coverage. This is because non-news formats/outlets can prioritise different production values. In addition, non-news formats are also likely to reach a different (and wider) audience and may generate a distinct type of audience engagement.

In the following section we draw on interviews with media personnel and their sources (e.g. press officers) in order to explore why stories about individuals from 'breast cancer families' proved so 'media-friendly'. We will also briefly highlight the perceived advantages and disadvantages of this approach (from the perspective of journalists and of different source organisations). We then go on to examine how such media stories related to the ways in which inherited/genetic risk was discussed among ordinary women in our focus groups.

'Hard and soft' media values: views from media personnel

In order to understand how the media cover genetics, it is useful to locate our findings within existing media studies theory about 'hard' and 'soft' media values. The terms 'hard' and 'soft' are commonly used by media sociologists and journalists alike to describe media output. Put simply, hard news is 'serious'; 'fact-based' coverage and soft news involves 'light' or 'human interest' stories (see Carter et al, 1998). Both terms relate to the subject matter, the positioning of the story, the sources used, the journalist who covers it and the implied readership.

Hard news concerns traditional front page and TV news stories which address the important issues of the day. Such reports usually rely on elite news sources (such as government departments and scientific laboratories). They are in this sense, concerned with 'matters of State' or 'hard science' and are sometimes seen as coterminous with 'real news'. By contrast, soft news is more likely to

address lower status issues (such as health or social aspects of life). It is considered more attractive to a female or youth audience and might include stories about 'abortions, lost babies, the Royal Family, fashions, the Cruft's dog show' (Schlesinger, 1987: 155) or 'relationships, fashion, beauty and childcare' (Allan, 1998: 132-4). In recent years however several researchers have argued that the traditional divisions between hard and soft news have become blurred. This is either seen as a process of 'dumbing down' or as a real effort to take on the public aspects of 'private domains' (e.g. around health and sexuality). In part such changes are certainly encouraged by media organizations' increasing attempts to pursue female readers and the youth market (see Carter et al 1998; Aldridge, 1994).

Several journalists interviewed for our study were quite clear that breast cancer was peculiarly 'media friendly' in part because of 'soft news' values and the pursuit of women readers

[It is] a way of talking up the women's vote, if you like. Let's play the female card. Women are bound to want to read this and let's make newspaper more female friendly is the big drive. (Medical/health correspondent, broadsheet)

Breast cancer was generally identified as an 'easy story' for any journalist, one for which he or she could be sure of editorial support. As one former medical/health correspondent explained:

It [breast cancer] is incredibly newsworthy. It will virtually walk into a paper compared to trying to write about other forms of cancer of arguably greater social consequences. [...] You only have to go up to the news desk and say 'There is something about breast cancer' and they will say 'We will have it' and 'Go and do it'.

Although many breast cancer stories are, in media terms, newsworthy, breast cancer genetics has the added dimension of soft value appeal. This can be clearly seen in the nature of reporting around different elements of genetic/inherited breast cancer.

For example, the initial reporting which followed announcements of the discovery of BRCA1 and 2 was clearly informed, in part, by a hard news agenda. Coverage headlined the 'news of the day' about research 'breakthroughs' and relied on high status sources such as the Institute of Cancer Research press conference and interviews with research scientists. However, the initial TV media announcements about the genetic discoveries moved swiftly to the reactions of individuals who might benefit from these discoveries and this strategy was also adopted by the press. So, for example, a double page spread in The Mirror about BRCA2 juxtaposed the work of Professor Stratton who 'beat the world to find a gene that increases women's risk of breast cancer' with the personal testimony of

a young woman, Annmarie. The headline read: 'Saved by the Gene Genius: After four years of research Mike Stratton found the gene which causes breast cancer...two weeks later Annmarie had a blood test that changed her life' (28 July 1997). This woman tested negative for BRCA2 so decided not to proceed with a prophylactic mastectomy. The health editor responsible for this article commented that this case study was included because it allowed readers to 'understand what it meant' to have (or not have) the gene and because the story provided 'drama', prophylactic mastectomies being such a shocking operation to contemplate.

Indeed, the example of prophylactic mastectomies may even be introduced into news stories that have little to do with breast cancer per se. One broadsheet health editor we interviewed, for example, was in the process of writing a report about a new British Medical Association book on human genetics. The book, she said, 'is not at all about breast cancer', however, 'In fact I have just written a paragraph: "There are some women who face breast cancer genes and some women opt to have a mastectomy".' She had chosen this way of introducing the issue because:

It is quite emotive in the genetics side of it because of the prophylactic removal. It is such a dramatic thing for a woman to do but that makes it quite newsworthy. (Health editor, broadsheet)

Personal stories can put a 'human face' to the science and were seen as an accessible way of exploring social implications and personal dilemmas (a theme illustrated in most depth in The Decision) as well as capturing audience attention.

The attractions of breast cancer genetics as a way of making genetics 'dramatic' and 'accessible' have not gone unnoticed by those on 'the other side' of the media presentation process: the sources. Press officers and campaigners in the field all mentioned the 'human drama' of genetics. A spokesperson for one pressure group summarised the observations of many when he commented that journalists seemed to be interested in breast cancer genetics because it allowed them to tell stories involving 'death, sex, love, motherhood and the right to choose'. We would add that genetic/inherited breast cancer can evoke powerful emotions, fear and tragedy (early death, multiple bereavement). It can disrupt or intensify relationships (sisters, mothers, daughters, lovers). It also sets the scene for secrets, discovery, and decision-making (how do you tell other members or your family, should you have prophylactic treatment?). In addition, these accounts can involve considerable narrative suspense (will she/won't she test positive?). These are all the standard characteristics of 'soft news' or even soap opera, but can be drawn upon in a wide range of media accounts (Henderson, 1999). This is all good news for the media, but the implications may be less welcome for those seeking to promote public understanding of cancer or genetics.

'Hard and soft' media values: views from source organisations and individuals

The mobilisation of dramatic themes in 'soft' representations of genetic/inherited breast cancer provoked mixed reactions from press officers and campaigners. Responses among those we interviewed depended, in part, on their individual/organisational priorities and whether they were considering specific reports/programmes or the cumulative effects of a genre. Often the same programme would receive contradictory verdicts from different interviewees.

A common complaint against 'straight' news reporting of genetic discoveries is that science is celebrated uncritically and social-ethical issues ignored. By contrast some 'soft' presentations clearly allow space for exploring problematic implications and the 'messiness' of the choices to be made. This was welcomed by some of those sceptical about what they perceived to be an unrelenting discourse of 'progress' in science reporting.

Making breast cancer genetics accessible, allowing viewers to engage in the psycho-social dynamics, and reaching a broad audience in new ways, can all also be seen as positive aspects of the 'human interest' framing. A representative from Breast Cancer Care, for example, who collaborated with the Peak Practice episode discussed earlier, told us that the programme had led to a dramatic increase in calls to their telephone helpline and commented on the number of calls from women at 'high risk' who were seeking advice for the first time.

However, some of the 'soft' presentations of genetic/inherited breast cancer were criticised as distorting the 'true picture' about genetics, playing up drama over 'fact' and focusing on tragedy and pathos. Wendy Watson has extensive experience as a media source. She has frequently presented her own personal experience and is now an activist in the field (e.g. promoting information to women with a family history of the disease). She expressed mixed feelings about the media. Although praising The Decision and many newspaper reporters, she complains that some journalists tried to play up the terror of her experience. 'One magazine wrote this absolutely vile article...They managed to find this glum picture, you know, this stony face, and then: "So scared of breast cancer I had my breasts removed".' She told us how another women's magazine published a letter purporting to be from her which totally misrepresented her experience and described how some journalists tried to manipulate her story while they were interviewing her. One women's magazine journalist, for example, was clearly influenced by previous media representations of Breast Cancer Family Trees (showing those with cancer genes as black circles and squares). She tried to persuade Wendy Watson to represent her own story in these terms ⁴

[One] writer wanted me to say 'I looked at the paper and I saw all these black circles and then I decided that [prophylactic mastectomy] was what I must do'. But it wasn't like that. [The journalist] said: 'I really like this black

circle business'. I said: 'well, I never saw any black circle, you know, you can't quote me on black circles'.

Even without such obvious manipulation of 'first person' accounts, the coverage of genetic/inherited risk was viewed with concern by some cancer organisations. Charities sometimes criticised representations for being unclear about the nature of inherited risk and the sheer extent of attention to genetic causes was also problematised by some.

A lot of people think if they've got some dim and distant relative who has had breast cancer then it's a sure fire thing that they're also going to get breast cancer...Breast cancers at the moment have got to be genetic breast cancers. I think largely the media are responsible for that. (Breast cancer charity representative)

Clearly judgements about the impact of different representations are not straightforward. Each of the speakers we have quoted draws on different types of experience and feedback from women. In the final section of this paper we will add our own reflections to this debate by drawing on our focus group data to explore how women talked about genetic/inherited risk and how they related to the media.

A brief look at women's understandings of genetic/inherited risk

Our 25 focus group discussions with 143 ordinary women confirmed observations made by those working with members of the public on a day-to-day basis. Research participants tended to over-estimate the role of genetics in the aetiology of breast cancer and were often unclear about the nature of genetic risk.

During the course of the research sessions, participants were asked to estimate the proportion of women with breast cancer who had developed it because of a family history of the disease. Most women opted for a figure over 50 per cent. In only five groups did anyone offer estimates lower than 20 per cent.

The importance attributed to family history was also evident in the way that women discussed their own risk. Women with just one relative, or a couple of elderly relatives, who had breast cancer, sometimes gave this as a reason for feeling at risk. Others, with no known family history, interpreted this to mean that there was very little risk of them contracting the disease: 'I don't think there's a risk of it because it's not in my family' (Group 9); 'I associate it with mostly with hereditary type things and I know I haven't got a family history at all, so I'm sort of quite complacent that way' (Group 13); 'My awareness of it [breast cancer] is purely a genetic thing' (Group 18).

The emphasis placed on inherited risk cannot, of course, be entirely attributed to specific media coverage. Other factors come into play including personal

experience and questioning about family history by doctors as well as pre-existing cultural ideas about the importance of inheritance (Davison, 1992) and the increasing overall cultural 'geneticisation' of illness (Nelkin and Lindee, 1995). However, the key role of the media in informing women's assessments was clearly evident in the way in which women referred to the media to explain and justify their emphasis on family history. The sheer quantity of reporting about genetic/inherited risk was one factor. 'It must be high', declared one woman 'because such a big deal is made of it' (Group 7). 'I would have said more than 60 per cent of breast cancers were due to inherited risk', commented another, 'It's certainly the one that's pushed the most' (Group 1). 'I think whenever I've heard of people having it' observed a third research participant, 'it seems to run in the family.' (Group 12)

The nature of the coverage, particularly the human interest coverage, was also key. Women spoke at length about magazine articles, documentaries, fictional representations and chat shows. The focus was on the dramatised personal accounts of 'breast cancer families'. It was these, rather than routine news reports about genetic discoveries (or patenting or testing debates), which had made most impression. Indeed, in several groups it became clear that people were unaware that any 'breast cancer genes' had been discovered and only three women mentioned news reports (press or TV) as informing their sense of inherited risk and one of these women explicitly stated that it was: 'one of those sorts of human interest stories at the end' (Group 18).

Not only were such human interest stories raised spontaneously in most of the group discussions but it was also clear that they had often generated conversation between people prior to the research session. In addition, even if the women could not specify where they had seen the story (and people do not necessarily correctly attribute their source) they often had quite vivid memories which allowed us to identify the type (if not the precise source) of account to which they were referring. Research participants often, for example, recalled visual images such as family photographs or diagrams of the family tree. They also could often describe the narrative structure of the accounts. The following quote is typical of the way research participants recalled media stories about genetic/inherited risk:

They took their family tree all the way back and right through their families. The amount of women that had died early from [breast cancer] was heartbreaking. [...] [One woman] was in her 20s, they both had wee kiddies, and they were both going to have to do that [have prophylactic mastectomies]. They were heartbroken but they had made the decision. (Group 5)

Stories about women from 'high risk families' had made a profound impression on them, women said, because of the youth of those affected: 'they were quite young, so, that's the one that sticks out' (Group 6). Such stories were also

memorable because: 'the fear just came across so much' (Group 25); 'It can blight a family' (Group 13) 'It seems such a drastic thing for any woman to do' (Group 24). Some research participants recalled the stories because they were 'so weird' ('I thought how could they do that to themselves, just in case. That seemed horrific, like self-mutilation', Group 11). Often it was also clear that research participants had empathised with women's dilemmas: 'That must be a terrible thing, if you know there's nothing wrong with you, to go in and be operated on, you know, healthy breasts' (Group 3); 'They chose mastectomies...Imagine having to make that choice.' (Group 18)

We will be doing further analysis to explore women's understandings of genetic/inherited risk. Here, we simply wish to highlight the fact that human interest stories were the types of media coverage which generated conversation, thought and reflection and were most vividly recalled. Some of the women who could reconstruct the images and narrative structures of such coverage in great depth knew very little about genetics (e.g. being unaware of how risks were calculated, and even, in some cases, being unaware that any 'gene' had been identified at all). It seems that such media accounts may convey ideas about inherited risk independently from knowledge about research discoveries and genetic 'facts'.

Conclusion

This paper points to the ways in which genetic 'discoveries' have been explored through diverse media coverage. We have highlighted the media values which may promote certain types of stories and presentational styles over others. We have also suggested ways in which this influences public understandings. These preliminary findings have implications both for predicting how coverage of genetics might evolve and for developing future media research and intervention strategies.

Implications for predicting media coverage of genetics: This paper has focused on coverage of breast cancer, however it suggests patterns in how other genetic/inherited risks might be represented. Clearly, genetic risk appeals to a broad range of media because it is about inheritance and family relationships (as well as uncertainty, tragedy, and decisions). It offers the potential to explore the dilemmas of 'The Decision' when 'Living in the Shadow' or exploit the drama of 'a family curse'. Such stories can contain elements of the most popular hospital drama and family complications of *Dynasty* proportions. Genetics per se will thus be of interest to a broad range of media personnel working in diverse formats and outlets, particularly for those working with a 'soft' agenda.

At the same time it is important to acknowledge that coverage of any particular genetic risk will vary depending, for a start on the scientific/policy context for that particular gene. For example, coverage will be influenced by progress not only in identifying a gene, but also in developing a test for it, and, perhaps, intervention procedures. Such 'progress' will shift media attention onto the dilemmas raised

for individuals. Our earlier research suggested that the traditional news media are not well adapted for considering the potential social implications of on-going scientific research in any consistent and sustained way (see Kitzinger and Reilly, 1997). Such considerations have traditionally been addressed within futuristic, science fiction type genres. However, once the media can access 'real people' actually facing choices around testing and treatment then attention will increase and diffuse into a wider range of media outlets.

Coverage of any particular genetic risk will also vary depending on the social context and characteristics with which that gene is associated. Media attention will be influenced by questions such as: who is this gene supposed to affect, how, when, with what consequences? In the case study presented here we have shown how coverage of breast cancer genetics was influenced by the widespread nature of breast cancer and its impact on young women, combined with media efforts to target female audiences. Elsewhere, we have also argued that coverage was influenced by the social acceptability of breast cancer and celebrity alignment with the disease, as well as the particular cultural fascination and horror associated with mastectomy (see Saywell *et al.* 1999). Such specifics need to be taken into account when considering the media profile of any particular gene. Not all genes will have the same media appeal. For example, genes around behaviour, such as the so-called 'crime gene', may be more controversial than genes associated with ill health, and different types of coverage will be generated in relation to the 'gay gene' or the gene for Alzheimer's (Kitzinger and Reilly, 1997; Conrad, 1998, Cunningham-Burley *et al.*, 1998).

Implications for research strategies: The data reported here demonstrate that it is insufficient only to examine straightforward health/ science reporting. It is crucial to include 'human interest' representations and 'soft' outlets such as women's weekly magazines. This is vital if we are to establish a full picture of the representations actually reaching and influencing the public.

Our study shows that different formats and outlets may prioritise different themes and that some issues (such as prophylactic mastectomies) translate across different formats/outlets, while others (such as the patenting debate) may not. This has implications for the quantity, but also for the nature, of representation. The process of translation between different formats and outlets may reiterate particular representations, but may also shift them. On the one hand there is considerable overlap between 'soft' and 'hard' media agendas. On the other hand 'soft' reporting may introduce new problems and new potential. Soft reporting might be more accessible than hard reporting but it might mask scientific information behind emotive stories. It might be better at addressing the psycho-social aspects of an issue, but may also distort these into a series of clichés. A soap opera story-line can reach out to a new constituency, encouraging people to seek further information, but it can also heighten fear or complacency. Detailed attention to specific representations, as well as

examination of cumulative influence, would therefore be needed to explore which programmes and stories have which effects under what circumstances.

What our research does suggest, however, is that soft values may actually invert many of the values of 'hard news' (as traditionally defined). Where hard values privilege high status official sources, soft values prioritise 'ordinary' women's accounts (however these might be twisted in the process). Where hard values lead reporters to abhor uncertainty (preferring clear cut 'breakthroughs' or controversy around sharply opposing positions), it is precisely uncertainty which may provide the drama in a personal account or fictional presentation. Where hard news about scientific discoveries often rely heavily on scientific press releases and may ignore potential problems, soft presentations and fictional accounts may explore the shades of grey. As news reporting is increasingly seen to adopt 'soft values' it is vital to understand the implications of this shift. It is important to engage with diverse formats and outlets (as researchers and campaigners) in ways which do not dismiss 'soft' reporting as inherently weaker without due consideration of its potential as well as its limitations.

In conclusion, as the science develops and as social researchers, practitioners, the media and the public become increasingly interested in the social and psychological aspects of genetics, attention to a diversity of cultural representation and 'soft' forms is particularly important. It may be here that new problems with representation might be identified. However, it may also be here that opportunities for debate and communication might be found.

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² British newspapers are traditionally referred to as 'tabloid' or 'broadsheet', which technically relates to the paper size. However, these terms also relate to readership, influence and news values. Thus broadsheet signifies 'serious, high income readership, lower sales but more influence' (papers such as The Times). Tabloid papers divide into two groups: the 'mid-market' Daily Mail and Daily Express which cater to those with a middle-income and The Sun and the Daily Mirror aimed primarily at low-income readership. These last two are the top selling newspapers in Britain (see Aldridge, 1994 for more detail).

³The age of a woman was often only mentioned as a risk factor in an implicit way. Press articles which contained statements such as 'she was only 33 so it was a shock to have cancer' were coded as referencing age as a risk factor.

⁴ Not all women's magazines adopt the same approach. Good Housekeeping, for example was frequently referred to by cancer charity press officers and focus group participants as an important conduit for high quality, factual health information. The Health Editor of Good Housekeeping, explained that her

position as 'health editor', combined with the production team's perceptions of the magazines' readership, influenced how genetics was covered: 'We're quite unusual amongst women's magazines in that [...] we actually have a specialised health editor whereas women's magazines have health-and-beauty editors so they tend to do less research. But Good Housekeeping does normally cover the research side of health. We're very conscious that our readers are at the age where they need health coverage that enables them to make decisions, to make choices. [...] They want information that they can take down to the doctor's surgery and they're not just interested in fluff or psychological side so we do try and give them quite strong medical information, stuff they can use.'