

Narratives of Risk and Collective Identity

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Breast cancer risk tends to focus on the individual woman, and to ascribe responsibility accordingly. There is, however, a significant if marginalized body of scientific research that considers environmental hazards in relation to the disease. In a recent ESRC *Science in Society* funded project, we used a Geographical Information Systems for Participation (GIS-P) tool to map women's narratives of local hazards that might be associated with breast cancer risk. The maps and stories – of workplaces and playgrounds, homes and schools, factories and mines, of dust and the river – that evolved from this research process, reveal the participants' understanding of a shared community of risk. Thus risk becomes part of a collective identity, in relation to a shared and common danger, which shifts the locus of responsibility from the woman to the locale, and eventually to the agencies with authority of governance of those risks. This process contributes to the legitimization of 'lay' narratives of aetiology, both as an ideological, political exercise, and as a pragmatic programme to open up deliberative democratic processes, and accord value and authority to citizens and non-professionals.

INTRODUCTION: MAPPING RISKS¹

Both popular and medical discourse appraise the risks of breast cancer, and accordingly ascribe responsibility through three dominant lenses: as genetic inheritance ('blame the mother'), as the result of lifestyle and behaviour ('blame the woman/victim'), or as the effect of environmental hazards ('blame society'). While the first and second of these lenses can be identified in current policy and epidemiological thinking, the third remains, for the most part, outside the dominant framework of aetiology, resting in the domain of the 'environmental breast cancer movement' (Potts, 2004b). Policy responses to the genetic and the lifestyle explanatory narratives tend to address the individual: through prophylactic interventions, such as surgery or chemo-prevention; or by a change to healthier habits, such as reducing

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excessive weight, exercising regularly and regulating alcohol intake. An individualistic response is even urged in relation to environmental hazards, with popular, 'alternative' health writers suggesting that worried women avoid particular suspected risks, by eating organic foods and not using plastic water bottles, for example. Individual redemption is the millennial order of the day: any modernist notion of social (and environmental) justice (see Rose, 2000) is marginalized and subdued in health policies related to this disease.

A recent project² with women from a South Yorkshire, UK, town, revealed, however, a move away from individuated stories of responsibility towards a sense of the role of place in determining health and illness – and breast cancer specifically. During the research process, participants moved from individualized risk positions to a collective identity in relation to local hazards that might be associated with breast cancer risk. The shared activity of mapping their locality marked a conceptual shift in thinking about the risk of the disease, in terms of their own histories and in terms of their relationship to their lived environment. In moving away from individualized notions of blame and responsibility, they thus began to identify themselves more explicitly as citizens – that is, as a collectivity in relation to the state. This shift of the locus of responsibility from the woman to the locale has implications for the governance of health risks, and for how participation in the science of epidemiological enquiry may be extended and legitimated. It also contributes to the political repositioning of breast cancer as a public health issue amenable to primary prevention policy making.

LAY EPIDEMIOLOGY; LAY NARRATIVE

There is an honourable history of 'lay' people's involvement in controversial questions of health and environment, and evidence of the ultimate value of their narratives to policy makers (see Potts, 2004a; Popay and Williams, 1996; Brown, 1992; Fischer, 2000). Frequently, this has been a process that challenges the 'experts', the professional scientists and policy makers, as these challenges have come from citizens concerned about risks in their local communities. (See Watterson, 2003: 39–49, for a full discussion of participatory research approaches and types of lay epidemiology.) But the involvement of 'lay' people has also been promoted from the top down; as Mayer explains, 'the discredited role of experts and scientists in policymaking has greatly stimulated the intellectual debate in policy analysis and led to proposals for possible alternatives' (1997: 4). The methodology of Geographical Information Systems for Participation used in this project, which allows groups of citizens to make maps of their locality, is predicated on what he describes as 'a participatory turn in policy analysis' (1997: 4); such 'alternative proposals are based on a reappraisal of the concept of participation as a means to develop a new kind of "knowledge", to save and possibly

strengthen the relation between “truth and policymaking” and to re-establish the democratic legitimacy of science and politics in society’ (1997: 4). In the process, the active role of participants positions them as subjects in the enquiry, rather than, more traditionally, as objects of research.

Throughout this project, we explicitly affirmed the participants’ knowledge of their own locality, valuing it alongside the knowledge that epidemiologists or public health workers provided. Legitimizing ‘lay’ expertise is both an ideological, political exercise, and a pragmatic programme, to open up deliberative democratic processes, and accord value and authority to citizens and non-professionals (Potts, 2004a). As Watterson (2003: 44) suggests, such an ‘approach also has the potential to help change attitudes to disease causation, disease prevention and the effectiveness of public health measures . . . It is part of a campaign for positive change’. Such change is urgently needed when the incidence of breast cancer continues to rise in the overdeveloped world, and when there is currently no policy of primary prevention in place to address this escalation.

The maps and stories – of workplaces and playgrounds, homes and schools, factories and mines, of dust and the river – that evolved from this research process, represent the participants’ understanding of a shared community of risk. This can be seen, then, as part of a political project to make visible and calculable the risks that Beck (1992) regards as invisible and incalculable – using methods that give a central importance to lay understandings, and to ‘the turbulent and dynamic social, cultural, political and economic conditions under which (risks) emerge’ (Adam *et al.*, 2004: 17). They also contribute to an environmental discourse of breast cancer aetiology, in which collective identity is figured as importantly as individual factors. This is a project, then, whose methodology aspires to ‘an ethic to reshape knowledge, and with it society’, out of ‘caring respect for people and nature’ (Rose, 1994: 238).

METHODS AND APPROACHES: MAKING MAPS OF COMMUNITY CONCERNS

Krieger (1994) has usefully distinguished between two foci of epidemiological enquiry into the determinants of disease: that which relates to individuals and that which relates to populations. ‘Stated another way . . . between what Rose, a noted English epidemiologist, has aptly termed “the causes of cases” vs “the causes of incidence”’ (1994: 892–93). In understanding the aetiology of breast cancer, then, it is important that factors common to populations be identified, and community mapping enables this to be addressed. For individuals, it has the effect, too, of redressing the imbalance imposed by the dominant epidemiological paradigm, insofar as it allows another, community based, discourse of aetiology to emerge.

Breast cancer activists in the USA, in Long Island, New York State, and Marin County, California (McCormick *et al.*, 2004; Sherman, 2000: 177–87; Davis, 2003: 182–90) have worked with epidemiologists to map local incidence of breast cancer in areas of ‘high risk’. In the UK, the Women’s Environmental Network (WEN) project, *Putting Breast Cancer on the Map* (1997) asked women to draw maps of their locality, to explore their own perceptions of hazards around them, and to collate local knowledge (Lynn and Ward 2002). These projects share a broadly similar purpose met by a broadly similar activity. Ultimately, though, the WEN project had minimal impact on policy making, and very few statutory agencies took notice. The final report was a vivid reflection of a valuable consciousness-raising exercise, and a fine vindication of lay knowledge and expertise, but there was no public recognition of these qualities, or of the findings. By contrast, the alliances established in the USA have effectively begun to open up the policy-making mechanisms, and to insist on the consideration of environmental factors in community breast cancer aetiology (Breast Cancer Action, 1993; Nation, 2003).

The South Yorkshire project used a Geographical Information Systems for Participation (GIS-P) tool developed by the Stockholm Environment Institute at the University of York, England (SEI-Y); GIS-P involves convening citizen consultation groups around spatially significant science based issues, giving a legitimate voice to participants who usually lack access to policy decisions, through a process of collective map making. SEI-Y has previously undertaken research using GIS-P with Local Authorities to identify air quality issues and other land use controversies (see Cinderby and Forrester, 2005), which has been very successful: the authority of the institute is conferred by its well-established and mainstream academic status. Statutory bodies have thus been more ready to accept and utilize the maps of local knowledge generated by communities.

The project was based in a town with an unusually stable demographic profile; it has a pattern of breast cancer incidence broadly consistent with national distribution. Two citizen consultation groups contributed to this project: an existing breast cancer support group, which met regularly, and a comparison group of women without the disease, roughly matched for age with the support group participants, and from the same area, who were brought together solely for the purpose of this research. The groups basically functioned as focus groups, the focus activity being to make maps; as Morgan (1988: 9) says, such ‘groups are fundamentally a way of listening to people and learning from them’ – an ethos that fitted well with the project’s lay epidemiological approach. In particular, we attended to the evolution of the discussion, through interaction of group members, and to pivotal moments of significance within the group – of tension, laughter, discomfort or consensus. Both groups were accessed opportunistically through an

undergraduate student whose final year dissertation investigated women's knowledge of environmental risks of breast cancer (Barron, 2003). In this respect, the support group was certainly a 'piggy-back' group (Krueger, 1993: 71), a convenience sample, but as we were looking to build a specific local picture, representativeness was not a particular concern. None the less, all the participants completed a background questionnaire about themselves, to avoid any temptation on the part of the researchers to make assumptions about the participants.

The team of three researchers, Steve Cinderby from SEI-Y, Rachael Dixey, Director of Health Promotion Research at Leeds Metropolitan University, and the author, worked with the breast cancer support group on three occasions, inviting them to make collective maps of suspected environmental hazards in their locality by drawing on Ordnance Survey maps we provided. Through a series of semi-structured interviews, using prompts to encourage the telling of stories about the local environment over time, half the members of the group also contributed individual life narratives of their personal exposures over time; these were digitized by the researchers onto a series of aerial photography maps, to show all the places of work and residence of all those participants. The final meeting checked the printed-out maps back with the full group, and asked for feedback on the process of mapping.

The comparison group was only able to meet once to make a collective map in the same way; no individual maps were made of group members' life histories, due to their time constraints. In addition, all the map-making discussions were taped and then analysed by attention to keywords, vocabulary and syntax, to the processes of group negotiation and tonal shifts, and to the details of the environmental stories of place and time. We are thus able to identify how participants perceived the local hazards they described and their relationship to them, and how the narratives of risk and exposure, vulnerability and imperviousness, evolved in the group discussion. These data can also be combined with hazard data, from governmental and non-governmental professional sources, to yield a rich and deeply detailed picture of the locality; this further stage of the work is not yet complete.

In many respects, then, the research process resembled any focus group, and this is seen as wholly appropriate to the task in hand: 'not to infer but to understand, not to generalize but to determine the range, not to make statements about the population but to provide insights into how people perceived a situation' (Krueger, 1994: 3). Furthermore, as Parker and Tritter (2004) suggest, in focus groups 'collective commonality is the central concern'; in this case, a collective understanding of the participants' community and its potential hazards. The focus of these groups' discussions had, however, an additional element: the making of the maps. The process of making maps gave direct access to re-imagining the locality, acting as a spur to the tasks of judging risks and of recounting past and present exposure to hazards. It was

through this process that collective narratives evolved; the marking on the maps of suspected local hazards provided a check to the comments made – the group had to decide whether or not to include a particular factory, topographical feature or known pollutant. Such decisions evolved, it is important to note, as the result of active negotiation, not though passive acquiescence or as the lowest common denominator. None the less, dominant voices in the groups tended to shape and direct the conversation, and it was to mitigate this effect that we chose also to conduct some in-depth interviews, where participants could tell their own story in their own way.³

Assent within the group as narratives of explanation and attribution emerged was both verbal and non-verbal; quieter group members would affirm their agreement through nods and gestures of recognition. On one significant occasion, dissent was articulated by silence and the withdrawal of eye contact. A visitor to the support group, who arrived halfway through the first group meeting, had preformed opinions on what hazards might be related to breast cancer risk, citing radiation from Chernobyl, and psychological research on stress, and making comparisons with incidences of myeloid leukaemias in Ireland. No-one in the group made any verbal response to this, and, after a polite pause, returned to discussing the pit dust that was always ‘there in the air’ when they were growing up, asserting their own understanding of hazards, established in relation to the active health and safety work of the miners’ trade union. The ‘outsider’ participant was apart from the group: she had a different kind of acquired expertise (Potts, 2004a), an educated and professional status as someone who claimed to ‘have done my own research’, but with very limited local knowledge. In this way the dynamic of the discursive process (Parker and Tritter, 2004) was one that affirmed a parity of specific, localized expertise: they all had stories to tell of where they had lived and what it was like. This interdependence yields ‘a number of positions or views that capture the majority of the participants’ views’ (Parker and Tritter, 2004). In this case, it is the map that similarly captures the majority view.

‘IN OUR LAY PERSON’S MIND’: EXPLAINING BREAST CANCER

Both groups regarded breast cancer risks as being a relatively new phenomenon, and as coming from within the woman herself, as the following comment illustrates: ‘when I grew up not one lady had breast cancer. I don’t think you could say anything brings on breast cancer: I think it’s born within you’ (support group). Or it might be provoked by modern habits that are ‘not natural – we’re going against nature’ (support group), such as processed foods, HRT and the contraceptive pill, and modern lifestyles. Participants in both groups revealed markedly similar ideas of what caused breast cancer; several examples are given here, to reflect the dominance of

this genetic discourse, and the insistence with which it was articulated (although only an estimated 5–8 per cent of breast cancers can be explained by known mutations: Sasco, 2001). Others from the support group speculated, ‘that cell that was there, did HRT kick it off in me?’; they perceived the cancer as ‘a little seed that will appear’ or themselves as ‘being genetically predisposed – a gene goes wrong at some stage, something triggers it off’, or as ‘that little cell moving through your body ... this one rogue cell’. Similarly, in the comparison group, women suggested that ‘it might have been sown in my teenage years’, or ‘that naughty thing may cause cancer, your own little cogs working’. Overlaid on the contemporary genetic discourse is a sense of life events acting as ‘triggers’ to ‘kick off’ cancer; this was generally represented as a trauma – it could be a ‘shock’, or a ‘knock’, or an emotional upset. As Blaxter (1993: 137) suggests in her article ‘Why do victims blame themselves?’ the ‘constant emphasis on life events’ was a significant ‘link’ in ‘the chain of cause’. Kenneth Olden, director of the US National Institute of Environmental Health Sciences, used a similar metaphor when he addressed the launch of the University of California at San Francisco Bay Area Breast Cancer and Environmental Research Center: ‘It has been said that genetics loads the gun but it’s the environment that pulls the trigger’ (Nation, 2003).

These aetiological explanations reflect what Brown *et al.* (2001) found in relation to professional epidemiological studies of breast cancer aetiology: that the dominant paradigm centres on genetics and on individual lifestyle factors. Given the popular media representations of stories about breast cancer (Saywell, 2000), this is not surprising; indeed, Barron’s work (2003) with the same sample as our own, shows that most of these women’s knowledge came from just the kind of popular sources (women’s magazines, TV and local radio) that articulate this paradigm. Notably, though, and overlaying this dominant medical paradigm, the groups in this research also emphatically asserted stress and trauma as causing the disease. Stories of divorce, caring for dying parents and struggling with poverty and social disruption around the miners’ strike of the mid-1980s were all cited as significant factors. In both the focus groups and in the individual interviews with women who had had breast cancer, participants were not likely (and despite knowing our research focus) to make any association initially between breast cancer and the environment. A comparison group participant commented, ‘I think environment is quite a long way down in the way I perceive it ... I’ve never ever thought of it as an environment thing’. The consensus in the group agreed with her: ‘the highest is your mam, family, that’s the top of the list; next down the list ... is stress’. What is important for our attempt to understand how people figure environmental risk of breast cancer, is that these explanations which participants offered most readily, as starting points in discussing aetiology and in the early parts of the focus group discussions, all

locate risks as integral to the individual's body and biography, assimilated into her personal identity, and not something you could do anything about.

'WHY ME? WHY NOT ME?' PERSONAL STORIES OF EXPOSURE AND VULNERABILITY

While neither the support group nor the comparison group participants had previously thought that their environment might be associated with a risk of breast cancer, they were very aware of hazards publicly associated with cancer generally, and very able to list factors of which they were suspicious. The following list, compiled from the comments of both groups, is of exogenous factors about which they expressed concern:

- 'all the chemicals we use nowadays';
- 'the rate we spray things';
- 'having our hormones messed around with';
- 'chemicals in food to make it last and last';
- 'dust from the pits in the air';
- 'power lines';
- 'additives in food';
- 'the clothing factories – what we breathe in';
- 'radiation that comes our way'.

There was a strong similarity in all the accounts the participants gave of their perceptions and experiences of hazards in the locality we were researching, and little substantive difference in what the two groups chose to map. (Each group marked 'air pollution' for where they lived, in a very general way, and each assumed that the air quality where they did not live, be it urban or rural, was better.) Although not perfectly matched in other respects, demographically and biographically there was much in common between the two groups, and they had a shared social and cultural relation to their community. The sources of their knowledge about the environment and about breast cancer were also then, not surprisingly, found to be very similar (Barron, 2003). This makes it more interesting to consider, as I shall now, their very divergent thinking about the relationship of these perceived hazards to their own health, and the health of those close to them.

The significant difference was in how the groups positioned themselves in relation to those hazards they identified: their risk positions contrasted quite starkly, with these distinctions appearing, initially and most patently, to be predicated on the experience of disease, which had revealed participants' vulnerability and provoked a need to find out why they had got ill. Thus, support group participants commented: 'when you have cancer, this (why?) is what you really think about'; 'when you get any cancer you think what could I have done'; 'you think about stupid things ... when I was in hospital ... we

were four ladies ... studying about things, what we could have done to prevent it, in our lay person's mind'. The support group participants were practised in interrogating their own lives and behaviours, and thus more ready to locate some of the possible causes outside themselves. Their sense of 'risk and danger, as experienced in relation to 'ontological security' (Giddens, 1990: 111) had been honed by the experience of life-threatening disease. By contrast, the comparison group generally felt that, 'You don't think about it ... you think nothing is suspect'; this group had not previously considered environmental risks to their health. Insofar as the experience of illness can be understood as a 'biographical disruption' (Bury, 1982), the support group participants' accounts suggest that such disruption has two notable effects: it changes the relationship of the sufferer to the known and trusted world, and it constructs her in a different risk position in relation to that world. (It is not, however, only illness that acts to disrupt those relations: other biographical factors have a similar effect. One comparison group participant recounted that her new work, and exposure to known hazardous substances, had made her 'become more aware that what's out there can cause your cells to mutate or whatever'.) The experience of breast cancer most strikingly leads to this reappraisal of hazards. For participants in the support group, an embodied relation to some kind of risk was already manifest through their status as women who had had breast cancer; their risk positions are thus, to that extent, given and fixed in their biographies.

None the less, in assessing what local risks might be, *both* groups applied what Lash (2000: 53) calls 'reflexive judgments', which 'take place not through the understanding but through the imagination and more immediately through sensation'. The epistemological foundation to both groups' reflexive judgements is the same, but their risk positions are strikingly different on the basis of their perceptions of empirical evidence of harm. The comparison group participants also relied explicitly on their own felt and experienced knowledge as the basis of their claims about risks, even without disease experience as a prompt. Thus, one woman in the comparison group expressed concern about a possible hazard in these words: 'the only thing I've ever read and gone hmmm, is those power lines things' because 'I know what power lines does to my car radio, so I wouldn't live under one; if it's doing that to my radio then ...'. But for the most part, their experience of ill-health effects was much more limited than the support group's, which allowed them to position themselves much more securely in relation to any possible hazards.

Thus a notable feature of the comparison group discussion was the insistence in the accounts of participants that the majority of local hazards posed no real threat, at least to themselves and others they knew. In response to a facilitator's question about the possible effects on health of the noise, dust and chemicals she had described when telling of her work in weaving

sheds in the past, the participant replied: 'it could possibly have, but it didn't affect mine'; another added, 'it never affected me', and when the facilitator asked if they knew of effects on others, replied 'not to my knowledge'. If there was no embodied evidence of ill effects, they were able to dismiss the possibility of a hazard posing a risk. Later in the discussion, the same participant said, 'it's awful – it's awful – it doesn't affect me, I'll ignore it'; similarly, another commented about 'all the fields we're surrounded by, just a few yards from my window when he's spraying ... you don't think about it'; 'oh heck, I'd not thought' responded a further participant. Thus the comparison group women were able to characterize themselves as 'unaffected', not vulnerable to the hazards that they identified in their communities; and as they perceived themselves to be unaffected, so they felt no need to engage with the possible risks involved. Their words here, with their emphasis on 'not thinking' are in marked contrast to the comments from the support group, about how having breast cancer 'makes you think'. The comparison group discussion produced an active example of this process of disengagement from risk: one participant began to speak (halfway through the session) of power stations nearby. 'From my window I can count seven ... (names several) ... on the skyline, I can see the whole lot. When they're all producing you can see the layer drifting our way'. This was the only (and thus significant) moment of prolonged and uncomfortable silence in this group's discussion; significantly too, they did not mark these power stations on the map. After the silence, the group moved to laughter, the atmosphere relaxed, and discussion turned to how 'recent developments are environmentally friendly in a way older industries wouldn't have been'.

THE LIVED ENVIRONMENT: COLLECTIVE STORIES

Most of the participants, in both groups, regarded their local environment as basically healthy. This derived from their perception of the area as being rural, and so safe, or surrounded by a rural setting that mitigated any ill effects; 'I don't relate that kind of muck (dirty rivers, pig farming) to cancer at all' (support group). Only towards the end of the discussions were rural pollution and its potential health hazards problematized in any way; the initial discussions, in both groups, about what to put on the maps centred on looking for local industrial locations. Even women who had worked in industries generally regarded as 'noisy' or 'dirty', such as weaving, felt protected by 'coming out of that environment into fresh air again and being quite active' (comparison group). To the surprise of the researchers, they also alleged that 'there was no pollution' in the past, when they were growing up, after having told stories of the filth in the air then, from 'smoke in chimneys', and 'the collieries all round' (support group participants). This seems to echo what Blaxter found in her analysis of the Health and Lifestyle

Survey (Blaxter, 1990): ‘another strong and almost universal theme: the wish to present the days of their youth as in some sense “healthier”, with simple good food, fresh air and sensible living. This was an obvious appeal to a “golden age” of the past’ (1993: 129) – but a past that was as tough for these participants as it was for most of the Survey respondents. This ‘golden age’ reflection was brought out in all the discussions, and particularly in the individual interviews in relation to the ‘real’, health-giving food – ‘meat pies and vegetables’ – that they ate when they were growing up.

There was a sense in both groups that the participants did not know what to think about environmental risks to their health. This expression of their lack of adequate information, of not knowing about hazards, relates to the participants’ perceptions of themselves as unfit to make what Lash (2000: 52) calls (after Kant), ‘determinate judgements ... these are objective judgements. They have objective validity.’ These are the kind of assessments they might be able to make, if they had the ‘right’ knowledge – the kind of assessments, too, favoured by Public Health Observatories, and other evangelists for evidence based medicine. As a comparison group participant reflected, ‘We’re all saying it’s not affected us – it might be doing and we might not know it’; another commented that there are ‘all these issues around that we don’t know’. While Watterson (2003: 44) convincingly suggests that ‘lay epidemiology has the potential to sustain and empower communities and individuals in an organizational and possibly social context’, the participants in this project suggest that they are not sufficiently empowered to make a judgement of risk with any confidence. This indicates that much more extensive work with communities is required to enable them to participate fully in such public health work. The work being done in Marin County in the Bay Area of California⁴ is resourced to be able to empower local women, through training and education, and the Women’s Environmental Network (1997) project, *Putting Breast Cancer on the Map*, ran local workshops to raise awareness of environmental hazards. The participants in this project had not benefited from this kind of input and tended to regard the researchers as a resource, reflecting, perhaps, the concern generated by the discussions, and the paucity of relevant information available to them (Barron, 2003). To withhold such information would have been unethical, but we emphasized how we valued what they had to say first of all, and offered what was requested after the group discussions (see Potts, 2004c for a discussion of these issues).

O’Neill (2002: 16) has suggested that ‘mistrust sometimes arises ... because it is too hard to distinguish accurate information from misinformation and disinformation’, and certainly the participants in both groups felt it was hard to know what to believe about environmental risk, hard even to identify what they did know. As a comparison group participant commented rather angrily, ‘the bottom line is we don’t know what we’re eating, we

don't know what we're using, we don't know what's in any of these things, in our food, our products'. Without this kind of knowledge, how are they to know whether their world is risky or not? The positions open to them were articulated as the 'not thinking about it' mentioned above, or 'just getting on with life' (comparison group). In the absence of knowledge, 'we take it on trust – but we don't really know, and we don't know what it's doing to us' (comparison group). This echoes an earlier comment in their discussion: 'trust – that's the magic word ... we take it on trust – but we really don't know'. The participants in the comparison group were, however, implicitly critical of their own position in relation to the list of hazards they suspected of being risky and which they drew on their map; while they characterized themselves as trusting, they were aware that this was a precarious position: 'we're too trusting, we assume it's being looked after for us and maybe that's where we're going wrong'. This was a key moment in the focus group (Barbour and Kitzinger, 1999), marking a turn in the discussion; from this point, a secondary theme of uncertainty, and a need to know more, emerged and disrupted the primary theme of being 'not affected' and 'not thinking'.

One of the effects of identifying risks can be to engender an anger that is felt more personally, that seems again to blame the victim (Naidoo and Wills, 1994: 209) for having failed to protect herself from exposure to hazards of which she had no knowledge. Thus, a comparison group participant responded: 'it's almost labeling as something they did do or didn't do and I have a problem with that'; and a few minutes later she interjects with this theme again, 'I find it almost offensive, offensive, that you could have avoided it if you'd done this ... to women in that position – offensive is the only word you can use ... they're struggling enough with the aftermath of surgery without thinking they're responsible for it'. A woman in the support group expressed a similar feeling: 'don't you think, if you go too far into it, the causes though, you start blaming yourself and that's not quite good for a patient to have to blame yourself – it's just something else to take on board. And bolting the stable door ...'. Beck-Gernsheim (2000: 131) comments thus on these kind of themes: 'like health, responsibility is a major value of the modern age ... the person who does not take part in this kind of responsibility is seen as a failure: blame comes in'. But as citizens, we should rather be able to assume, to trust, that statutory and regulatory bodies charged with protecting our health are doing just that. And as O'Neill (2002: 121) points out, 'in practice we have to take a view and to place our trust in some others for some purposes', and address more directly 'the practical demands of placing trust'.

Participants' comments reveal how the group's discussion began to reframe recently changed awareness, with uncertainty and distrust provoking the change in perspective. On several occasions, throughout the comparison group discussion, this 'not knowing' was characterized as naive: on

realizing that ‘things can get in through your skin’, one participant remarked, ‘how naive am I?’, to which another responded, ‘aren’t we all?’ The choice of word, also used earlier in the following comment, suggests that ‘naivety’ is a personal quality, a deficit, but the tone of the comments, not always apparent from the written words, was one of cynicism and anger: ‘up till this, I’ve never thought well what was it that induced it [her mother’s breast cancer], in my naivety’. These feelings of cynicism and anger succeed the discussion of being too trusting, and mark a new and unquiet relation to the state, to ‘them’, those in whom trust might be placed. The key issue, however, is not whether or not a generalized trust in policy makers, the state, ‘them’, is or is not well placed, but rather what harms exist and what protective policies are in place.

CONCLUDING THOUGHTS: OF RISK AND JUSTICE

Making maps together, talking about their memories of the locality and their contemporary perceptions of it, and, of course, the evident emphasis given by the researchers to possible environmental hazards associated with breast cancer, began to generate a different knowledge of both the place they lived in, and the aetiology of breast cancer. To some extent the research process itself had impacted on their perceptions of their local environment, from an initial comment that ‘I must say when I first got your letter I began to think ... (about the environment)’ (comparison group) to the consensus view in the evaluative session with the support group that ‘I’d never thought about it like this before’. But it is very apparent that the process of map making contributed to the participants beginning to be able to locate risks, and responsibility, outside themselves: exogenous factors gradually began to have more resonance for them as the negotiation of hazards to include on the maps developed. And from talking about their own individuated personal exposures, they began to talk about ‘here’ and ‘us’, to question how there is ‘so much more now being used in the way of chemicals’, ‘what’s tipping into the river now from farming’, and ‘the air ... we’re talking about the whole area for that (comparison group)’. These are macro/environmental elements, which, while interacting with the micro/personal elements, such as food and other consumer products mentioned earlier by the groups, are generically experienced and shared in a more collective way. Thus, importantly, the participants share a relationship to these that is not the case in relation to their diet or lifestyles. Marking these macro/environmental factors on the map very graphically set them outside the individual woman and her endogenous risk of breast cancer. The participants shared a relationship to these, a relationship that is given not chosen, and over which they have had little control. And their responsibility for the state of the water supply, the amount of agro-chemicals used, the air quality downwind of power

stations, is clearly very different from the responsibility conferred on us all, more complicatedly, to watch our weight, diet, alcohol intake and exercise levels. It is the responsibility of the collective, of a group of citizens in relation to the state.

The support group women were notably more suspicious of the health effects of all kinds of things in their immediate and domestic environments, and in the wider environment too. So their personal biographies, and individual identities, in association with this shared experience, bring a different sense of vulnerability, of exposure to the hazards in an environment. Their consensus view on the usefulness of the mapping process was that it had given them 'an idea of what kind of place we're in', its qualities and characteristics, that they had not been aware of before, not put together in this way. So for them too, risk was now being written outside of the individual body (with its 'rogue cell', a 'little seed that will appear'), and onto their lived environment. But this group notably spoke of things being 'frightening' and of all they 'worried about' – particularly the unknown, unseen hazards. And, of course, the importance is that 'the environment' interacts with people's biologies and biographies. This group was particularly interested to know 'what you can do about it', and to know about groups (such as Women's Environmental Network and Friends of the Earth) who were actively campaigning about these issues. And this begins to position them not as victims, but as citizens with rights to a healthy environment.

The changed perception noted in both the GIS-P group mapping exercises is a shift from being an individual at risk to being able to identify potential hazards in a particular locality. Thus risk becomes part of a collective identity, a shared and common danger. A further stage of this work would, then, be to use a participatory research method (see Fischer, 1993 for a full consideration of these processes), for instance what Brown (1990: 78) calls a 'popular epidemiology', to engage local knowledge with professional expertise. The kind of participatory research approach that has begun to shape work in the Bay Area, with activists and epidemiologists working alongside each other (McCormick *et al.* 2004), may prove to fulfil what Krieger proposed in 1994: an eco-social model of breast cancer aetiology, which does not view 'populations simply as the sum of individuals and population patterns of disease as simply reflective of individual cases' (1994: 892), but develops community epidemiological models that are able to represent the complexity of different factors involved. This research has demonstrated the potential of GIS-P to build on the deep, detailed insights of local communities, generating maps of the present and maps of the past, so that the temporal elements central to understanding breast cancer aetiology can be revealed too. This provides an innovative focus to epidemiological enquiry, and a sound basis for public health policy; the maps that are made can be used in conjunction with the vast amounts of data generated by, for instance, statutory agencies,

such as Cancer Registries, the Environment Agency and NHS Trusts, or by NGOs that document local pollution hazards. In this way ‘citizen expertise’ (Potts, 2004a) can be given legitimacy and a genuinely participatory policy analysis developed as integral to political process – not as an occasional bolted-on extra feature. Most importantly, this process might contribute to a meaningful policy for the primary prevention of the disease that now affects over 40,000 women a year in the UK (Cancer Research UK, 2003).

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A related conference paper, “‘I wouldn’t have thought of it like that’”: re-mapping self and the environment as the result of illness’, was presented at the British Sociological Association conference in March 2004.

NOTES

1 Some definitions may be helpful: ‘Hazard: Damage that might be caused by an Activity or Substance ... Exposure: Amount or Intensity (Dose) of the Activity or Substance that some Humans ... might Experience ... Risk: Will Someone be Damaged? How Much?’ (O’Brien, 2000: 19–20).

2 ‘Public Involvement, Environment and Health: evaluating Geographical Information Systems for Participation’; Economic and Social Research Council *Science in Society* programme, award number L144250045, July 2002 – January 2003; working with colleagues Steve Cinderby, John Forrester and Paul Rosen at the Stockholm Environment Institute, University of York, UK, and Rachael Dixey at Leeds Metropolitan University, UK.

3 From these we learned of another shared, though non-environmental, factor relevant to breast cancer: in the 1950s and 1960s, five of the nine women interviewed with breast cancer had had frequent and regular chest X-rays. They said that respiratory problems were common in the area, as a result of all the pit dust in the air, and so they were regularly X-rayed in mobile vans and hospital clinics – and so exposed to radiation.

4 see <http://www.breastcancerwatch.org/press/news_101503.html>

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