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COMMUNITY AND THE PUBLIC
BODY IN BREAST CANCER MEDIA
ACTIVISM

Abstract

In this article, I consider how communities form around health care advocacy and activism. My concern is the place of visual media in the politics of breast cancer. Art photography and film are considered against mainstream images and media campaigns focusing on breast cancer. The primary work considered is the self-portrait photography of the artist Matuschka and the film *The Body Beautiful* by Ngozi Onwurah. I argue that these alternative texts help us to think about the ways in which issues such as race, age and beauty are key aspects in the experience of breast cancer, and not tangential cultural issues or 'appearance-related side effects', as one breast cancer support programme puts it.

Keywords breast cancer; community; body; media; mastectomy; photography

IT WOULD BE impossible to understand health cultures in the US without acknowledging the crucial role of media in their formation. Television, print media, cinema, online discussion groups and medical educational computer programs are important, if underconsidered means through which health issues are taught, communicated and lived. This article considers a few examples of breast cancer media produced by women who identify as activists, alternative media producers and members of the community of women affected by breast cancer. First, though, I want to address some of the problems that have made it difficult to think through questions of identity and community around health culture without also considering the role of media (film, print media, photography, video and digital technologies) in the incorporation of illness and survival as aspects of identity and community. In the discussion that follows, I try to demonstrate the importance of focusing on 'local' or 'minor' media productions – work by independent or alternative media producers, personal video and art photography – rather than mainstream media. As I will try to demonstrate below, the concepts

of *community* and *media* function in highly specific ways within health cultures, demanding analytic strategies that take into account the specificity of media users and audiences.

Health and community

Arenas of political action devoted to health care, illness and disability historically have formed on the basis of collective responses to experiences with illness and the health care system. Advocacy and activist groups, self-help and support groups, and more loosely based networks of individuals organized on the basis of shared experiences which might include having a particular illness and/or treatment, protesting lack of access to medical treatment, advocating for research, managing pain, needing emotional support, negotiating loss of bodily functions, identifying as a survivor, confronting iatrogenic illness, facing ongoing disability, or doing support work or caregiving. Whereas broad social networks have formed around breast cancer generally (for example, the National Breast Cancer Coalition (NBCC)), groups have also organized themselves on the basis of these more delimited issues as well as on the basis of identity or region (the Chicago Lesbian Community Cancer Project, or the Atlanta-based National Black Women's Health Project). What are the implications of using the terms *identity* and *community* to refer to groups that coalesce around illness and/or disability? There are important discontinuities between health status as a category of identity or community and the more familiar identity categories of ethnicity, race, nationality, gender, class and sexuality. Akhil Gupta and James Ferguson present a version of current thinking on community formation that helps me to access this issue. They state:

something like a transnational public sphere has rendered any strictly bounded sense of community or locality obsolete. At the same time, it has enabled the creation of forms of solidarity and identity that do not rest on an appropriation of space where contiguity and face-to-face contact are paramount.

(Ferguson and Gupta, 1992: 9)

In the fragmented world of postmodernity, Gupta and Ferguson argue, space has been reorganized in a way that forces us fundamentally to rethink the politics of community, solidarity and cultural difference. They make this point with regard to an issue wherein space – its occupation and its ownership – is essential in a particular way: they are concerned with the establishment of groups such as displaced and stateless peoples, ethnic groups, exiles, refugees and migrants. But what are the implications of this idea of the obsolescence of bounded community and locality when we consider collective identity as it

forms, provisionally, on the basis of illness, disability and the fight for access to treatment? Do reterritorialized space and transcultural formations become metaphors, or is there a parallel reconfiguration and dispersal of collective identity in the postmodern experience of breast cancer? For example, would it be accurate to describe survivors of breast cancer as a transcultural or transnational community because breast cancer strikes women of all classes, ethnicities and nationalities?

'Community' formation on the basis of health and illness is always highly provisional and unstable, in part because group formation takes place on the basis of a condition or experience that is always strongly determined by more conventional identity categories. Illness is not necessarily attached to, but must always be lived through, other categories of identity and community – categories that come into play at every level of the construction of publics and cultures around disease. In short, illness may take on the trappings of an identity category; it may be the basis for the formation of a (highly conditional) community, and it may be the grounds for the formation of a public sphere. But the experiences and cultures of illnesses none the less are always lived through identity positions and arenas of public and professional discourse that exceed the frameworks and cultures of disease. This is further complicated by the fact that 'illness communities' are comprised of people whose respective identities as ill or disabled shift throughout the course of a disease. Within breast cancer communities, one might occupy the position of caregiver, patient and survivor at different points in time, or even simultaneously.

While distinctions among these positions are fairly well acknowledged within groups formed around health issues, differentials of class, cultural identity, ethnicity and sexuality are quite often bracketed in order to underscore the unifying factor of disease. The online breast cancer listserv, for example, is comprised of women with breast cancer, survivors and their caregivers (doctors, health professionals, hospice workers, friends and family). The individuals who participate in this forum forge conditional bonds on the basis of their day-to-day experiences. But this kind of transcultural alliance sometimes problematically fulfils the conditions of Habermas's concept of a liberal public sphere, rather than becoming an increasingly more interactive, less rigidly class-, race- and nation-based model of a public. In broad-based groups like the breast cancer listserv or the NBCC, participants from disparate backgrounds bracket cultural differences on the basis of a common experience with breast cancer. This approach is to be lauded for its emphasis on the pervasive scope of the disease, but it provides limited means for addressing the class and cultural specificity of the experience, diagnosis and treatment of breast cancer among women of different ages, economic groups, regions and designated races. Following the model of white middle-class women's organizations in the 1970s and earlier, broad-based support groups tacitly uphold the liberal fantasy of a quasi-universal discourse among women.

What I am arguing against here is the idea that disease is the great leveller, or that coalition politics can or should smooth over differences as they impact on experiences of disease and disability. Much of mainstream breast cancer media so far has elided these differences. For this reason, I have chosen to focus on media texts that emphasize the specificity of different women's experiences with breast cancer. The work I have singled out for attention falls into the categories of alternative or activist media. Rather than looking at material like public service advertisements, *Primetime* feature stories and Lifetime television specials, I will be considering activist and art photography and video. Before turning to this work, however, I want to look more closely at some presuppositions that often accompany the analysis of non-mainstream media.

Health care and alternative media

The analysis of activist media often relies on a binary model that sets off local, oppositional, community-based groups against the globalizing force of mainstream medicine and media institutions. Much recent health care activism, however, crosses the boundaries between these two spheres. Groups like ACT UP (AIDS Coalition to Unleash Power) and the NBCC include among their members media and medical professionals with entrenched institutional practices as well as patients and lay advocates. In many areas of political organizing, alliances, however uneasy, have been forged across genders, classes, professions and cultures. What is new here is not what counts as community or coalition, but the fact that the crisis of illness, and not an aspect of shared identity in the conventional sense, is the basis for alliance. In the past decade we have seen an unprecedented degree of influence over medical policy brought to bear by medical countercultures composed of patients, activists and nonprofessional caregivers. The very idea of a counterculture as an extra-institutional force becomes complicated when we consider this traffic between the medical professions and activist groups and the role of laypersons in policy making.

Some of the more significant media activity shaping US health culture is taking place through advocacy, activist and community health groups using visual media as a prime form of public intervention. It is essential to consider how agents within these arenas gain a public voice; how they acquire access to decision making at the level of the institution or the state; and what the relationship is between media productions that originate from a position of activism or community politics (AIDS videos, breast cancer awareness pamphlets) and those that originate within 'minor' public spheres whose position at the margins of public culture does not necessarily stem from oppression, or from a stance of opposition. Progressive work in medicine is not necessarily coming only from practices identified as countercultural or as oppositional, as I will try to demonstrate below in the case of the work of photographer Matuschka. When we look

at the interaction among various media forms (political cinema, mainstream photojournalism) and various public constituencies, it becomes difficult to theorize 'media activism' as a unitary sphere situated outside institutional medicine, or outside a mass public culture.

Viewed in this light, the binaries of a public and a counterpublic, mainstream and activist politics become less than productive analytic models. These formulations parallel the media studies binaries of broadcasting and narrowcasting, mainstream media and alternative media. The terms *counterpublic* or *countercultures* suggest oppositionality, when in fact many alternative publics are forged around the increasingly fragmented special interests that constitute the global market. Likewise, the term *narrowcast* implies marginality of those cultures targeted (ethnic groups, special interest groups, exilic cultures, language groups, and so on), when in fact these groups are often comprised of financially and politically powerful, if numerically small, sectors of the viewing public.¹

Within media studies, the concept of the local more often appears in writings about alternative media production, decentralized community-based programming, and activist media. The term carries connotations of appropriation and resistance to mainstream media politics and institutionally sanctioned uses of technology. If much of the literature on media assumes a singular monolithic form, failing to account for the specific conditions of discrete media forms and uses, writings about alternative media often construct the flip side of that image – what Coco Fusco (1988) has dubbed 'fantasies of oppositionality', totalizing accounts of resistant media strategies that do not take into account the partial and specific constituencies, locations and effects of particular media interventions.

In the case of the breast cancer media texts I consider below, gender, class and cultural identity become key factors in the formation of distinct public cultures around breast cancer. Moreover, I argue, within these cultures, there is no unitary concept of breast cancer. The disease is represented and lived through issues such as class, beauty, fashion and ageing. Emotions such as anger, pain and fear are tied to the correlated effects of disease and ageing, hair loss through chemotherapy, and the physical, visible transformation of that iconic and fetishized body part, the breast. Audre Lorde emphasized this cultural aspect of breast cancer in *The Cancer Journals* (1980) when she criticized 'other one-breasted women' for 'hiding behind the mask of prosthesis or the dangerous fantasy of reconstruction' promulgated by groups like Reach to Recovery, the American Cancer Society's signature programme for women with breast cancer (Lorde, 1980: 16). R2R, developed by breast cancer patient Therese Lasser in 1952 (when the Halsted radical mastectomy was the conventional treatment), was based on the then radically new idea that laywomen who had experienced breast cancer could provide a unique kind of emotional support for other women in recovery. In officially adopting this programme in 1969, the ACS placed certain topics off limits for discussion, such as family relationships, doctors and the scar

itself, emphasizing instead the goal of convincing women with mastectomies that they do not have a handicap but a condition from which they can recover – given the right attitude, clothes and prosthesis. Lorde cautioned that this sort of ‘cosmetic sham’ would undermine the sense of community and solidarity necessary for women with breast cancer to organize effectively (Lorde, 1980: 16).²

The circumstances that Lorde described in 1980 – the depoliticizing cosmetic cover-up of not just the (missing or altered) breast but the cultural and personal difficulties surrounding the disease and its aftermath – have taken on new proportions. In 1988, the ACS launched ‘Look Good, Feel Better’, an initiative conducted jointly with a charitable foundation set up by cosmetic manufacturers in which women receiving breast cancer treatment are invited to their hospitals for LGFB programmes, essentially group makeover workshops in which they get tips on such things as devising stylish head coverings and applying makeup. Anthropologist Janelle Taylor, in a critique of the marketing of beauty products to women under the guise of charity, describes an LGFB advertisement that appeared in *Mirabella* concerning ‘appearance-related side effects of breast cancer’. The advertisement argues that ‘When you give yourself an original Oscar de la Renta design, you’re not the only one who gets something beautiful . . . you’re helping in the fight against breast cancer. . . . So give. And get’ (quoted in Taylor, 1994: 30). Often marketed in the conjuncture of breast cancer and fashion are particular items which take on status as fetish and icon (the scarf as a means of concealment and adornment, standing in for lost hair; the shoe as a fetish object *par excellence*). A similar message is conveyed in an ad for Larry Stuart shoes, part of a spread promoting the autumn 1994 three-day charitable event of the Fashion Footwear Association of New York (or FFANY, an acronym that suggests displaced attention from the breast to the buttocks). The event, sponsored by 800 companies, was a shoe sale held at the Plaza Hotel in New York. The advertisement presents a photograph of mud-covered hiking boots with the caption ‘these are for war’. Below this is a second image of shoes – classy black suede T-strap pumps with a matching evening bag. These shoes, the advertisement tells us, ‘are for the war on breast cancer’.

If these are part of the uniform for the war on breast cancer, we might ask the question: Where is the battleground? Apparently ‘the foot that comes down against breast cancer’, to borrow a line from the Larry Stuart advertisement, is shod in the signifiers of conservative femininity. My issue with this advertisement is not that it suggests that activists might wear heels, or that I think corporate America is not a viable battleground for cancer activism (it most certainly is). Rather, it is part of a broader trend in which liberal and right-wing campaigns appropriate the strategies and language of more progressive campaigns and movements, changing their constituencies and goals in the process. It has been widely acknowledged that AIDS activism of the 1980s and early 1990s was a model for the development of a broad-based campaign against breast cancer in the 1990s. But whereas in the 1980s AIDS activism was hardly a mainstream

campaign, by 1996 breast cancer has emerged, in the words of journalist Lisa Belkin (1996), as the year's hot charity.

Lorde (1980) argued that 'the socially sanctioned prosthesis is merely another way of keeping women with breast cancer silent and separate from each other.' The advertisement and programmes of the 1990s described above, all of which promote beauty aids as prosthetic means of recovery, suggest instead that the media cultures of fashion and beauty technologies do provide a resource for community building. However, this process appears to be occurring predominantly among those women concerned about breast cancer who are invested in conventional notions of gender, body and beauty. The problem we face is not that women are depoliticized, silent or separate, but that the media-savvy breast cancer activism that has emerged in the late 1990s constructs the breast cancer community around a set of signifiers that includes white, straight, middle and upper class, urban, educated, professional and conservative. In addition to marginalizing women who are poor or working class and/or less well educated (and who are less likely to have access to information and treatment), this concept of community also fails to acknowledge the lifestyles and concerns of women who do not share the politics, fashion preferences or sexual orientation of the collective profile tacitly generated by this media campaign.

In the texts I consider below, alternative media producers take up breast cancer via beauty and fashion in reflective and innovative ways to provide new, non-normative ways of constructing the post-operative body. The formation of communities and public cultures on the basis of breast cancer politics entails a reconfiguration of the post-operative female body in public space. Breast cancer culture becomes a crucial site for the re-evaluation of what counts as a beautiful body, and what meaning age, race and cultural identity have in a culture where disease and health technologies are reconstructing what a healthy body is, and what particular body parts mean.

Activist photography

Alisa Solomon's important essay chronicling breast cancer activism, 'The politics of breast cancer', appeared in the *Village Voice* in May 1991.³ Significantly, the article begins with an ironic anecdote about a post-op breast surgery patient named Miriam who is visited by a R2R volunteer – a woman with big hair and nails and a body-hugging Lana Turner-style sweater. To Miriam's consternation, the volunteer's main agenda is the prosthetic recovery of Miriam's breast – that is, her body's public return to normative standards of female bodily form. Until the early 1990s, the typical media image of a woman with breast cancer was the smiling, middle-aged white woman, identified as a survivor – a woman whose clothed body and perfectly symmetrical bustline belied the impact of breast cancer. A 1995 episode of *Chicago Hope* typifies this public fantasy of survival as

physical restoration. The episode features a teenage girl. She is African-American and beautiful – and, tragically, she has breast cancer. This perfect young body loses a breast to mastectomy. However, by the end of the episode a skilful plastic surgeon returns the girl's body to its near-perfect state. We are given a view of the young woman's reconstructed body as her mother exclaims to the doctor: 'How do you do what you do?' Here the body of the woman with breast cancer is finally made public. However, the body which this episode makes available for public display is a black woman's body, a move that replicates the medical tradition of using the bodies of black women for teaching demonstrations and textbook examples. The privacy of white women's experience with breast cancer is thus maintained. Moreover, this episode culminates by displaying the body of the woman with breast cancer at a moment when all signs of disease and its treatments are erased. Elided is not only the scar of the unreconstructed breast, but the fact that the great majority of women with breast cancer are far from young. Like many print advertisements promoting mammograms, the *Chicago Hope* episode makes invisible the factors of age and associated issues of beauty that are relevant to the majority of women with breast cancer, while including black bodies only to replicate a centuries-old problem in Western medical representation.

The repression of the image of scar tissue, hair loss and ageing is not limited to the popular media. Two years after the publication of Solomon's essay, her title, 'The politics of breast cancer' was given to a flurry of feature articles published in the scientific, liberal feminist and mainstream presses. In 1993, *Science* (Marshal *et al.*, 1993) and *Ms* (Rennie *et al.*, 1993) both published special sections with the same title. Interestingly, neither series features the female body in any significant way. *Ms* used a typeface graphic design on its cover and illustrated the personal vignettes that were scattered throughout the essays with small, flattering portraits of smiling 'survivors' with symmetrical bustlines. *Science* opted for what the editors described as 'a statistical portrait of breast cancer' (a display of graphs and charts) along with the great men of science approach (the only actual portraits in the piece were head shots of scientists credited with research breakthroughs).

Surprisingly, it was the *New York Times Magazine's* variation on Solomon's title theme that provided a radical twist on the mainstream tendency to disembodify breast cancer. To illustrate 'The anguished politics of breast cancer' by Susan Ferraro, the cover story for 15 August 1993, the *New York Times Magazine* editors chose for the cover a photograph of a stylishly thin woman wearing a high-fashion white sheath and headscarf, her dress cut low on the diagonal to reveal the woman's mastectomy scar (Figure 1). The prominently placed publication of this image, a self-portrait by the artist Matuschka titled 'Beauty out of damage', marked a watershed in media representations of breast cancer. Matuschka, an ex-fashion model and photographer, not only exposes her scar to public view, but artfully frames and lights it for optimal display. As she puts it, 'If I'm going to



Figure 1 q Matuschka 1993 *Beauty Out of Damage*

bother putting anything on my chest, why not install a camera?' (Matuschka, 1992: 33). The scar occupies the space closest to the centre of the page, a locus towards which the eye is drawn by angles cut by Matuschka's arm and the shadows created by her prominent bone structure and the gown's neckline. Matuschka's head is in profile, turned away from the camera, as if to dramatize the large caption that fills a portion of the page to pronounce: 'You Can't Look Away Anymore.'

The publication of 'Beauty out of damage' was a watershed in the public representation of breast cancer because it rendered public an image previously familiar only to medical students and doctors, and women and their caregivers, families and close friends. The image stunned the *New York Times* public because it exposed physical evidence of breast cancer surgery that previously had been subject to repression in the mainstream press, with its images of smiling survivors and charts. It generated a vast outpouring of commentary by readers both in support of and in opposition to the paper's editorial decision to use this image on its magazine cover. While some readers saw in the photograph the message that women who have undergone mastectomy are not victims to be pitied and feared, and the altered or missing breast as something not to be prosthetically and journalistically covered over and restored, others saw the image as an inappropriate display of private parts and private matters. The issues that concern me most, though, are the photograph's representation of age, beauty and agency, and its apparent evocation of the natural and the technological as they pertain to these issues.

Solomon, in her account of Miriam and the Reach to Recovery volunteer, suggests that the volunteer projects an outmoded politics of the body onto the post-operative Miriam. She relates that Miriam is offended by the volunteer's assumption that prosthetic simulation or restoration is the first step to recovery. Solomon seems to advocate, along with Lorde, a public body that bears its scar as a natural and perhaps even healthy condition. This body is represented in a photograph used to illustrate her *Village Voice* essay of 1991, photographer Hella Hammid's 1977 portrait of Deena Metzger, titled 'The warrior'.

Metzger was 41 years old when she was diagnosed with breast cancer in 1977. In a recent interview she recalls that after her mastectomy 'When I went to a health club – even a women's health club – I noticed that I was the only one in the place with a mastectomy. I began to understand that women who had mastectomies were not showing their bodies.' A poet and novelist who had been fired from her tenured professorship for reciting a poem she had written about censorship (she eventually won an appeal in the Supreme Court), Metzger was not one to comply with the times and hide her body. Instead, she adorned her scar with a tattoo to better display it. 'If I were sitting in a sauna or I would be swimming or something, because my chest was tattooed, it was implicit that someone could look at my body,' she explains. 'In this intimate setting, women would turn to me and say, "Thank you," and they felt relief. They saw having a mastectomy was not the end of the world.'⁴

Wishing to document the scar and tattoo, Metzger contacted Hammid, whose previous work included child photography shown in *The Family of Man* exhibition curated by Edward Steichen for the Museum of Modern Art in the 1950s. 'The warrior' features the nude torso of Metzger, her white skin, naturally curly hair and exuberant expression framed against a backdrop of clouds. Her arms reach out in a gesture of openness to nature and the cosmos – a gesture that also exposes fully her single breast and her scar and tattoo, itself an image evoking nature (a tree branch). Like the image of Matuschka, this photograph puts a positive and politicized spin on the scar and the one-breasted female body, evoking Lorde's fantasy of an army of one-breasted women confronting the medical establishment. But the two images differ in an important way: Metzger's curly hair, unclothed torso and setting evoke an aesthetic of natural beauty and health. She is shot against the sky, as if euphorically reaching to recovery without the aid of technology. As journalist Delaynie Rudner has remarked, the image 'draws you in with a touch of innocent hippie celebration' (1995: 15). Rudner describes Hammid's photograph of Metzger as the perfect 'first' in the non-medical imaging of a mastectomy scar. Whether or not this is true, the image certainly presented a stunning alternative to the ongoing medical tradition of representing mastectomies, wherein women's faces are blacked out or their heads cropped off to maintain anonymity. 'The warrior' sends a clear invitation to look and to acknowledge that a mastectomy can be healthy and happy without being physically 'restored'.

Matuschka's self-portrait is a far cry from this upbeat late 1970s depiction of pleasure in the post-operative body in its 'natural' state. Matuschka occupies a stark environment suggesting both clinic and urban art studio – sites where bodies and body images are technologically transformed. Like Metzger, she looks away from the camera; however, her expression is serious if not severe. She is clothed in a form-hugging sheath that suggests both a hospital gown and formal evening wear, a garment that suggests the body's discipline and restriction within the terms of high fashion. Her headscarf, covering short dark hair, is reminiscent of the turbans preferred by some women to conceal the fact of their hair loss as a result of chemotherapy treatments. Matuschka's public image of breast cancer clearly advocates pushing the envelope of cultural expectations about the body within the fashion industry: she 'looks forward to the day *Vogue* magazine would consider devoting an entire issue to the dozens of beautiful one-breasted women who live all over the world' (Matuschka, 1992: 33). While Metzger's scar is displayed in a manner that seems to promote its joyous revelation, Matuschka's is artfully lit and framed to emphasize the role of concealment and display in its disclosure. And whereas 'The warrior' puts forth the post-operative woman as a naturally beautiful figure, 'Beauty out of damage' suggests a concept of beauty whose aesthetic involves an appreciation of the fashioning of the body. The photograph seems to suggest that far from destroying beauty, mastectomy can be appropriated for a politicized display of high-tech beauty. In a new twist on techno-aesthetics, mas-

tectomy joins the repertoire of body-altering surgical techniques that have gained currency in 1990s mainstream fashion, techniques that include breast prosthetics, implants and reconstruction; liposuction; face lifts; tummy tucks; eyelid reconstruction, and body piercing. While some of these techniques are associated with the impetus to render the body closer to cultural norms, others appeal to cultural constructions of the exotic or the unique.

While the association of one-breastedness with disease makes it unlikely that this condition will ever be incorporated into mainstream beauty culture, Matuschka's photograph goes a long way towards placing the fact – and the look – of this bodily state into public consciousness. I am not arguing that Matuschka's self-portrait critiques the technological alteration of the body offered in processes like breast reconstruction or the use of prostheses. Rather, my point is that this portrait foregrounds the scar as a physical and aesthetic transformation of the body that is as significant to the experience of breast cancer as these other techniques and their more conventional (and familiar) results. In this image, Matuschka has opted to reclaim the scar as an object of aesthetic and political significance and, more profoundly, as an object of fascination, if not beauty.

Despite its appearance in such a well-respected public site, Matuschka and her photograph, 'Beauty out of damage', were not embraced by the breast cancer community as universal signifiers of the current state of breast cancer politics. The magazine cover image was nominated for a Pulitzer prize in 1994, but this moment did not necessarily mark a shift in the public politics of breast cancer. The photograph, like previous and subsequent work produced by Matuschka, was not received with universal enthusiasm. That some readers were dismayed by this editorial decision is clear from some of the many letters to the editor which followed the story's publication. Indeed, author Susan Ferraro forewarned readers of the controversial nature of Matuschka's work: 'Her poster-size self-portraits have shocked even some of her mainstream sisters,' she writes. This is not surprising, since Matuschka's work circulated primarily in activist and art venues such as demonstrations and exhibitions including the Women's Health Show, a multi-site show mounted in gallery spaces around New York City in the winter of 1994.

Despite this public perception of Matuschka as too controversial or radical a figure, her identity as an activist and member of a health care counterculture is far from secure. Originally a photographer's model, Matuschka's transition into breast cancer activism was, in her own words, by chance. Although a member of the Women's Health Action Mobilization (WHAM!), an activist group close to ACT UP in its tactics and structure, Matuschka's relationship to health activism seems to have been largely through the group's embrace of her work. As she explained in an interview,

WHAM! discovered me. I didn't even know what WHAM! was. I was at a talk-out on breast cancer in Washington, D.C., in front of the legislature

and various other politicians back in 1991. I was on chemotherapy. I was wearing a blonde wig, and I had already made a bunch of posters. . . . Evidently, when I got up and spoke I moved a lot of the audience. There were two or three WHAM! members there, and they had just started a breast cancer department. They said that they would like to use one of my images, and asked me to come to one of their meetings. So I went to their meetings. That's how it began.⁵

Conventions like the DC talk-out provided Matuschka with a venue to market her photographs in the form of postcards and posters. It was at the Breast Cancer Coalition Convention in California in May of 1993 that Susan Ferraro encountered Matuschka by chance, displaying her posters on her own body, sandwich-board style (she had been barred from selling them). Andrew Moss, the editor of the *New York Times Magazine*, explained that Matuschka was called when the magazine decided to run Ferraro's story, which included material on Matuschka, at the eleventh hour, and they had only a few days to locate a cover image. According to Matuschka, the magazine specified that they wanted an image with a face but no breast. Moss's account suggests that the photo struck the editorial team 'like a hammer', leaving them unanimously committed to using it for the cover.⁶

Matuschka's ambiguous status as, on the one hand, conventional model and art photographer and, on the other, activist-by-default, allowed her to emerge as a public icon of breast cancer activism in a mainstream media venue like the *New York Times*. Likewise, her ambiguous status as both youthful/beautiful and 'damaged' (to quote the term she chose for her photograph's title) allowed her image to play a particular role for a particular set of readers. For the photograph in question was undoubtedly targeted to a very specific readership, those who get the *New York Times* – those women whom Ferraro identifies as the 'mainstream sisters' who might be offended by Matuschka's more daring work (Figure 2). Presumably these women might be willing to participate in 'activism' in the form of liberal political pressure groups and advocacy organizations – FFANY, for example. *The Times* tacitly marketed Matuschka the activist as an evocative but acceptable symbol of white, urban, middle-class, professional women's breast cancer activism. Ferraro's article documents and constructs an activist countersphere whose ties to nineteenth-century liberal counterspheres of women-only voluntary associations are strikingly apparent, if not stated outright. Breast cancer, in this formulation, is a disease with its own class aesthetic, culture and constituency.

In sum, this image that apparently functioned as a mass public icon was in fact identified with a relatively elite sector of women. The public image of breast cancer which it puts forth tacitly incorporates whiteness, youth, thinness and urban chic as core elements of the collective body for which the activist feminist body collectively speaks. Yet very rarely do we see public representations of



Figure 2 q Matuschka 1994 *Which Side Do You Want?*

older women (in their fifties and sixties, say), who constitute the greater majority of breast cancer cases in this country and who certainly comprise a large percentage of the *New York Times Magazine* readership. Photographs like the self-portrait of artist Hannah Wilke and her mother, from a series produced between 1978 and 1981, are much less likely to circulate in public venues. This image documents Wilke's mother's breast cancer. Wilke, like Matuschka, built her career on self-portraits, many of which featured her nude and youthful, slender body. In the early 1990s, Wilke ended her career with 'Intra-Venous', a series of nude self-portraits of her own ageing and cancer-ridden body. Not surprisingly, this series, which documents her treatment for lymphoma (the disease from which she died in 1993), received far less attention than her earlier work.

These points about the factor of age in representations of breast cancer lead me dangerously close to making an argument in favour of some sort of media realism: 'breast cancer campaigns should depict older women' and so forth. This is hardly my goal. Rather, I am in favour of representations that take up the complexities of age and beauty as they pertain to specific groups of women for whom breast cancer is most immediately a concern (women in their fifties and sixties) as well as those women categorically left out of discussions about breast cancer media (for example, black women). It is worth recounting here a well-known tenet of feminist film theory: audience members do not always or necessarily recognize themselves in images of 'their own kind' – that is, older women may not necessarily identify any more with images of other older women than they will with images of, say, younger women. (If this were not the case, Matuschka's image would not have received the broad-based response it got.) Perhaps the inordinate number of representations of youthful, slender bodies in mainstream breast cancer media campaigns is not an error on the part of media producers, but an effective use of the mechanisms of identification and fantasy that invite viewers to look at and identify with particular bodily ideals and particular cultural norms, regardless of their own age and appearance.

To elaborate on this possibility, I will turn to a second media text, Ngozi Onwurah's *The Body Beautiful*, a 1991 experimental documentary film about the relationship between a young woman – a teenage bi-racial fashion model – and her mother, a white woman in her fifties who is disabled by rheumatoid arthritis and who bears the memories and the scars of breast cancer surgery. This loosely autobiographical film foregrounds the cultural aspects of breast cancer that are repressed not only in the erasure of the post-operative body, but in the elision of cultural difference among women impacted by the disease.

The Body Beautiful

In the United States, Onwurah has been represented as a black British filmmaker, a documentary film-maker whose work circulates in the women's film

festival circuit. These designated categories of race, nationality and genre inform the reception of her three best-known films currently in circulation in this country (*Coffee-Colored Children*, 1988; *The Body Beautiful*, 1991, and *Welcome to the Terror Dome*, 1994). However, what is less than clear from the promotion of her work in the US is that Onwurah is not only British but also Nigerian. Whereas in the US she is most often identified as a black film-maker, in England she is recognized (and identifies herself) as mixed-race. Her films are also difficult to categorize within the limited terms of US film criticism: they combine techniques of conventional and experimental documentary and narrative, resisting categorization within any of the groups of 'black British cinema' familiar to US independent film audiences.

By introducing Onwurah in this manner, I mean to highlight the fact that race is as provisional and circumstantial a category as illness or disability. As *The Body Beautiful* aptly demonstrates, cultural identity and disability can also be inter-constitutive categories. While Onwurah shares a history, a national identity and representational politics with many black British film-makers, her work is structured through a discontinuity that also shapes cultural identity and representational strategies in highly particular ways – that is, in ways that, for Onwurah, have to do not only with having been raised in Nigeria and exiled to England at the age of 9, but with her subsequent experience as an exoticized beauty, a professional model whose commodity is her light-skinned body and her ambiguously African-Anglo features. Both *The Body Beautiful* and Onwurah's earlier film *Coffee-Colored Children* demonstrate that race is a historical category that can be structured through experiences such as exile, loss of a father, a mother's disability, and a general loss of the unity and stability of such basic categories as family and body. Onwurah's identity is deeply informed by her status as the daughter of a white, disabled and scarred mother – a woman with whose body she strongly identifies, and a woman whose erotic and identificatory investment in the beauty, youth and colour of her daughter's body is also profoundly deep. *The Body Beautiful* is primarily about Madge and Ngozi Onwurah's relationship to public perceptions of ageing, disfigurement and disability. But, as in the print media breast cancer coverage discussed above, questions of identity (nationality, race, class, sexuality and gender) and related issues (health, beauty, ageing) are the fundamental terms through which this film engages with public views about breast cancer.

In the central scene of the thirty-minute film, Ngozi convinces her mother to accompany her to a sauna (coincidentally also the site of Metzger's enlightenment about the public repression of the scar). Inside the sauna, women lounge bare to the waist. Madge keeps her towel wrapped up high, covering her mastectomy scar. But she dozes off and the towel slips, exposing her scar. While Madge sleeps, Ngozi witnesses the stares of the women in the sauna as they look and turn away from her mother's scar. Madge wakes up, almost instantly feeling for her towel and pulling it up over her chest, looking around in shame to see if anyone has noticed.

This scene performs a function not unlike that of Matuschka's photograph: the taboo mastectomy scar is placed on display, shocking a public audience, while the performer of this scene averts her gaze from the eyes of the viewer. But there are crucial differences between these texts. Whereas Matuschka's youthful and fashionably thin body is framed by a high-fashion sheath, Madge's plump, ageing torso is haphazardly draped with a towel. Moreover, while Matuschka clearly poses for her photograph, we gaze on Madge while she sleeps, ostensibly unaware of her position as spectacle. And while Matuschka as photographer actively professes her body as both icon and model of what breast cancer can mean (albeit for women of a particular age, culture and class), Madge (who, significantly, plays herself in the film) performs at the direction of her daughter, who is behind the camera (and is played by an actor). If Matuschka's image is a performance of defiant pride and an assertion of the agency of the woman with breast cancer, Madge's is a staging of public embarrassment for the benefit of Ngozi's (and the viewer's) enlightenment. Ngozi (we) learns compassion and awareness of the meaning of Madge's difference through Madge's humiliation.

Matuschka's distinction, due in part to her status as media icon, buffers her availability as an identificatory figure for women viewers. Her function as a highly symbolic image precludes the shock of recognition available in the representation of Madge. In the scene in which Madge's body is exposed to the gaze of other women, the camera provides us with subjective shots taken from the point of view of the various women in the sauna, intercut with shots of these women from Ngozi's line of sight. The organization of shots invites the viewer to see Madge through the eyes of her daughter. We see Madge being seen by those women who clearly are made uncomfortable at the sight of Madge's body. It might be argued that Madge's body represents not only the unimaginable, unimage-able fear that any woman might one day be disfigured by breast cancer, but that age itself inevitably will generate bodily changes (sagging, weight gain, loss of muscle tone) – aspects of female bodily transformation held in general public contempt and denial. In a sense, the missing breast is just one signifier of Madge's bodily ageing; but the scene also represents Ngozi's shift from a strong identification with the body of the mother to her ability to see that body from a distanced, public eye. By shifting the emphasis from the scarred body as iconic (as in the case of Matuschka's photograph) to that body as a locus in the shifting politics of looking, *The Body Beautiful* is able to direct its viewers to work self-consciously through complex responses like recognition, identification and denial of bodily signs of disease and ageing.

The theme of the negotiation of the public eye and the iconic status of the marked body carries over from Onwurah's earlier film, *Coffee-Colored Children*, an experimental documentary devoted to recounting mixed-race Ngozi and her brother Simon's experience of growing up in Britain. In *Coffee-Colored Children*, we see the siblings as children being taunted with racial slurs, attempting to wash off their skin colour, and eventually coming to terms with the complex public

meanings of their bodies. *The Body Beautiful*, then, functions, like the earlier film, as a means of coming to terms with the body of the mother as a white body, but as a body that is also marked by a complex of other cultural identities and conditions. This is not to say that physical disability and racial identity are alike, but that disability is a process implicated in the construction of cultural identity along with race, class and gender; and that historically there has been continual slippage between the classification and ranking of bodies according to racial typologies and according to categories of health, disability and illness.

I want to consider this point more fully through one of the more controversial scenes in *The Body Beautiful*: a fantasy/memory scene featuring Madge. Leaving the sauna, Madge and Ngozi stop for a cup of tea. Madge spies a young black man playing pool and exchanging sexist banter with his friends, a conversation in which a woman's breasts are referred to as 'fried eggs'. As Madge looks on, the man catches Ngozi's disapproving narrowing of the eyes, and he returns her look with interest. This exchange of looks prompts Madge to recall a memory of her Nigerian husband. Madge states in voice-over, 'I saw the look in his eyes and remembered it from somewhere in the past. A single caress from him would smooth out the deformities, give me the right to be desired for my body and not in spite of it.' The shots that follow demonstrate the strength of the identificatory bond that exists between mother and daughter on the basis of one another's bodies. As Madge and the young man make love, the sound-track gives us Madge's subjective memories of the young Ngozi and her brother arguing. Intercut with this scene are shots of Ngozi the model, her lips and breasts being made up for a photo shoot, and Madge looking on and directing the love scene from an ambiguously situated off-screen space. Just as the mother lives through her daughter's public body, as if it were a prosthetic extension of the sexuality and youth she feels she has lost, so Ngozi imagines herself in control of the enlivening of her mother's sexual desires. Above all, Ngozi wants to return to her mother the sexual life she feels she has lost with the loss of her breast and (subsequently) her youth. However, rather than visually restoring her mother's body to some prior state of completion for the purpose of the fantasy, Ngozi demands that the scar itself must be rendered a site of sexual pleasure for both her mother and the young man. The shots of love-making between Madge and the young man are intercut with shots of Ngozi being made up and shot by a fashion photographer who commands, 'pump it up, give me some passion'. Like the photographer who directs her performance from off-screen space, the character Ngozi directs her mother's love-making scene from extradiegetic space. As the young man moves down Madge's torso with caresses and kisses, he hesitates at the scar. 'Touch it', Ngozi commands from her directorial position in off-screen space, 'touch it, you bastard'.

Without question, *The Body Beautiful* is about constructing a public image of breast cancer that goes beyond generalized notions of illness, disability and cultural identity. As Onwurah explains,

It wasn't simply just a mother–daughter thing. [The film] had all of the obvious stuff about the body and beauty, but it had quite a lot about race in it, too, almost by accident – things that I hadn't really thought about. For example, her fantasy sequence would need to be with a black man, and I wanted to try to get out of that. This sequence involved black–white, young–old, disabled–nondisabled. Just for this fantasy sequence, the film was going to take on all of these missions. At one point I was going to try to have a white guy in there, but mom was really insistent that her fantasies weren't just abstract fantasies. They were fantasies to do with her, and she wanted this black guy.⁷

The Body Beautiful demonstrates that public discourse on disability is always about issues such as desire and pleasure, race and age. But how does this film function within public cultures of health specifically? Who is the audience for this film? In the US, *The Body Beautiful* circulates through independent film venues. It has been shown at women's and experimental film festivals, academic conferences, and in university film and women's studies classrooms. In the United States, it is not a 'movement' film in the sense that it is not often screened among groups formed on the basis of health issues. However, the film has a very different set of venues in Britain. Onwurah explains:

In England, we have something called the WI [Women's Institute]. It's the kind of organization that Miss Marple would have belonged to in the rural areas. They have the largest women's health support network in the U.K. Their groups have actually used *The Body Beautiful*. And they're the most right-wing, the most conservative, that you can get. But I think that here [in the US] you actually have more restrictions or self-censorship on things to do with nudity, sex, or violence. I'm just beginning to realize this.

And

The Body Beautiful wasn't meant to be an educational film. It isn't a film for women who have just learned that they have breast cancer. You have to be a little bit down the journey to see the film. But still, it's used widely. Quite often my mom goes out with it, and it's a completely different experience then. It's still mainly a filmmakers' film, a women's festival film. It's just too blunt. If someone diagnosed me with breast cancer and I saw the film the next day I think I'd go out and kill myself the day after, it's so confrontational.⁸

The contradictions here are striking. In England the film is used in the most conservative sector of women's advocacy groups, yet it is too confrontational for even its own producer to tolerate if she were to watch it as a woman with breast

cancer. Here we see the same contradictions evident in the appropriation of activist Matuschka's demonstration posters for the *New York Times Magazine* story. This suggests that perhaps in England as in the US we are seeing a blurring of boundaries between institutional health cultures and countercultures, and between mainstream and alternative media venues and audiences. Onwurah herself emphasizes the importance of recognizing local conditions of use and context:

In Britain there is a burgeoning disabilities movement, and I definitely saw [the film] in the context of that. It had a place within the issues surrounding the rights and disabilities movements. I've gotten involved because my mother's always been disabled and my grandmother was deaf since the age of two, so we used to sign with her.⁹

Earlier I posed the questions: What are the implications of this idea of the obsolescence of bounded community and locality when we consider collective identity as it forms, provisionally, on the basis of illness, disability, and the fight for access to treatment? Do reterritorialized space and transcultural formations become metaphors, or is there a parallel reconfiguration and dispersal of collective identity in the postmodern experience of breast cancer? *The Body Beautiful* speaks to these questions insofar as it addresses viewers across the bounded communities of health educators, the British and American independent film communities and disabilities movements, while also addressing issues of identity and its relationship to race, age, illness and disability. But while the film addresses with great complexity the specific cultural issues framing experiences of breast cancer, it none the less fails to generate a sense of community among its diverse audiences. Most immediately, the film's display of an intergenerational and interracial sexual fantasy and a physically close mixed-race mother–daughter relationship place its message beyond the interests of many mainstream viewers. Onwurah's own admission that she would not want to see the film if she herself were facing breast cancer has been echoed by numerous women who have been in audiences where I showed the film and spoke about it. These points leave me facing a troubling contradiction: How are these issues to be raised and worked through, if not by women to whom they are of the most concern? Would it be better to bracket differentials of class, cultural identity, ethnicity and sexuality in order to underscore the shared experiences of disease? Are the effective media texts those that provide easy answers (for example, prosthetic recovery) and false closure (a return to some ideal of a normal life)? I would argue that work like Matuschka's and Onwurah's, 'difficult' as it may be, performs the crucial task of widening the pool of collective images, expanding the possibilities of what can be seen beyond outmoded norms and altering historical concepts of the body beautiful to incorporate the effects of breast cancer's limited treatment options.

Notes

- 1 See, for example, Hamid Naficy's study of the Iranian exilic community in southern California that both produces and views Persian-language programming – narrowcast cable shows that more often than not embrace family values and political views which would be regarded as conservative within Euro-American cultural standards (Naficy, 1993).
- 2 For a brief discussion of R2R and similar groups see Batt (1994: 221–37).
- 3 This essay, titled 'The politics of breast cancer', was republished in *Camera Obscura*, 28 (1992).
- 4 Quoted in Rudner (1995: 14–15). I am indebted to Rudner's essay for the information regarding the Hammid/Metzger photograph. He notes that the photograph was originally the inspiration for a book of poetry by Metzger titled *Tree*. When the publisher refused to use the image for the book's cover, Metzger used it to accompany a poem she wrote for a poster that became a cult item in feminist circles around the country. In 1992, in the third of its four printings, *Tree* was finally published with 'The woman warrior' on its cover (by Wingbow Press). Hammid died the same year of breast cancer (Rudner, 1995: 15–16).
- 5 From an unpublished interview with Matuschka by the author.
- 6 Moss and Matuschka are quoted in Rudner (1995: 24–6).
- 7 In Cartwright, 1994.
- 8 In Cartwright, 1994.
- 9 In Cartwright, 1994.

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