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The Patient–Consumer–Advocate Nexus

The Marketing and Dissemination of Gardasil, the Human Papillomavirus Vaccine, in the United States

The 2006 availability of Merck’s human papillomavirus (HPV) vaccine, Gardasil, in the United States provides an opportunity to examine the pharmaceutical company’s creation of patient awareness for one of the most common sexually transmitted infections and its related cancer. In spite of the ubiquity of gynecological screening, prior to the vaccine’s dissemination, most U.S. women were not familiar with either the infection or its association with cancer. Merck’s role in encouraging a patient advocacy community mimics existing breast cancer patient advocacy culture in the United States while also demonstrating marked popular culture differences between the two women’s health concerns and their respective advocacy groups. This article draws on ethnographic fieldwork with an HPV/cervical cancer advocacy organization to demonstrate how the group and its members engaged in an activism of awareness that disavows larger political aims. [HPV vaccine, patient advocacy, pharmaceutical marketing, women’s health, cancer]

Introduction

In the fall of 2007, 15 months after the U.S. Food and Drug Administration (FDA) approved the human papillomavirus (HPV) vaccine, Gardasil, a small cervical cancer/HPV advocacy organization, the Cervical Cancer Group (CCG), held its first conference in a major east coast city. Women made the trip from all over the country. One of the founders, Gary,¹ opened the conference enthusiastically, “Today is the day you’ve asked for, and what you’ve asked for is information.” He repeatedly stressed the almost exclusively female audience’s ownership of the conference and their entitlement to information, emphasizing the need to de-stigmatize cervical cancer (CC). Renaming cervical cancer “cervix cancer” and invoking war metaphors, he argued cancer research required a broad attack and that cancer eradication efforts “need[ed] to have a prevention arm [and] the detection arm. And we have that [Pap smears] with cervix cancer. It’s not a hundred percent; we know it’s not a hundred percent, but since the 1960s rates of cervix cancer have gone down.” In spite of progress, he reminded the audience that the research efforts still had far to go. Alluding to the last 18 months of public debate about the availability of Gardasil and whether it should be required for girls starting at age 11, he set the tone of the conference:

You’re here, you’re an example that it’s [cancer reduction] not good enough. Imagine being able to stop the cancer before it starts. ... We have a situation [Gardasil] where we can make that the case. We can stop the cancer before it occurs. There seems to be politics associated with that. I don’t want to get into politics on any of that ... but we can stop the cancer, and that’s everything.

Gary tried to preempt discussion of proposed HPV vaccine school requirements that were widely discussed that year. He didn't need to, as many of the attendees were avid supporters, although almost none were eligible for the vaccine, approved for girls/women 9–26 years old. Gary directed the CCG to participate in a specific form of advocacy around CC and Gardasil, an “everyday” activism (Selleck 2010:123) of awareness, rather than a politically motivated activism. “Early detection saves lives. Early detection saves lives,” he intoned. For him, it was consciousness-raising “advocacy work [that] matters.” He beseeched everyone to “Communicate the message and get it out there” and incited the group to yell out, “Cancer Sucks!” When the crowd's response was not sufficiently enthusiastic, he made the women repeat it with more gusto. In spite of Gary's (and thus the CCG's) deflection of politics, I will show that such rhetoric of awareness advocacy cannot be decoupled from the overtly political field of women's health, in which Gardasil, HPV, and CC are all implicated.

Since early 2006, before Gardasil's U.S. approval, I have been intrigued by how Merck and Co., Inc. produced the convenient slippage that framed Gardasil as a cancer vaccine, rather than as a preventive for a ubiquitous and easily transmissible STI. Of the more than 40 sexually transmitted types of HPV, 13 types cause CC whereas other types cause genital warts. Men and women can both get HPV, which may lead to oral, cervical, anal, and much less often, penile cancers (Guiliano and Salmon 2008). A quadrivalent vaccine, Gardasil protects against genital wart-causing HPV (6, 11) and two types (16, 18) associated with CC.

Although HPV has no cure besides “watchful waiting” and is an extremely common, difficult-to-prevent STI, mortality due to CC in the United States reflects other racial and socioeconomic health discrepancies and about 4,000 women die annually (Campbell et al. 2012; Singh 2012). These are also women who may have the greatest difficulty affording the most expensive vaccine on the market. Gardasil confers some meaningful benefit to its recipients, but it fails to eliminate HPV-related morbidities or the risk of CC entirely.

The emphasis on cancer in Merck's marketing and in patient-led campaigns is worthy of deeper examination; interesting parallels emerge between the HPV/CC advocacy movement, invigorated by Gardasil's availability, and the U.S. breast cancer advocacy movement. The staunchly apolitical and corporately complicit HPV/CC awareness movement emulates a strand of breast cancer awareness bathed in (nonthreatening) pink. Both movements are implicitly steeped in gender and health care politics, but corporate sponsorship and allegiance are not an inevitable outcome of health-based social movements. Although such an alliance provided mainstream legitimization of CCG members' health experiences, it also produced an unproblematized and interdependent relationship on a company whose marketing fails to disseminate more accurate information about HPV/CC or the broader challenges of reducing the spread of HPV. As I will show, the CCG embraced Merck's definition of empowerment and deliberately renounced political aims.

Despite nearly 50 years of scientific awareness of the link between HPV and CC (zur Hausen 1977, 1996), the general public's knowledge of HPV appears to have been inconsistent before Gardasil. In a 1999 *New Yorker*, a physician framed HPV as an infection almost no one knew about (Groopman 1999), a lacuna that endured through the initial availability of Gardasil (Zimet et al. 2000, 2005). Similarly, there is a paucity of social science literature on CC and HPV prior to the vaccine, with the exception of a few scholars (Casper and Clarke 1998; Howson 1998, 2001; Kaufert 2000; Kavanagh and Broom 1998). The marketing of Gardasil thus provided HPV's first mainstream representations.

Distinct from 30 years of vocal U.S. advocacy for breast cancer research and awareness, Gardasil's arrival offers the opportunity to consider an advocacy organization and its cultural signifiers as it emerged in the early 2000s. In particular, I examine how an organization like the CCG, which embraced a depoliticized patient–consumer advocate position, and the corporate-sponsored “education” around Gardasil de-fanged CC/HPV advocates’ rhetoric.² Starting with a critique of a particular form of U.S. breast cancer advocacy, this article contextualizes CC survivor advocacy in relation to its predecessor of patient advocacy. Gardasil’s U.S. availability produced an awareness of HPV and CC framed by “corporate models of care” (Jain 2007), in which participation in consumptive behaviors demonstrates a combination of choice, autonomy, and ownership of one’s illness. However, this framing ignores the vaccine’s epidemiological limitations, producing an incomplete form of empowerment.

Methods

The research in this article builds on five years of fieldwork, during which time I followed Gardasil-related social and cultural debates. My fieldwork included observations in a Los Angeles community of non-vaccinating and “slow” vaccinating natural health parents, among whom I conducted 12 repeat interviews with mothers, to better understand U.S. parents’ forms of resistance to vaccination and how it might be similar to or differ from resistance to the HPV vaccine. I conducted six interviews with public health officials in the L.A. County departments of women’s health, immunization, and sexually transmitted disease, and with three physicians at a low-income family practice clinic in south central L.A. I attended the 2006 FDA hearings for the initial approval of Gardasil, the 2007 and 2008 CCG conferences, and the 2008 annual CDC immunization conference in Atlanta; I also conducted traditional and online media analyses.

Research included participation observation with two grassroots organizations—one a black women’s health organization and the CC group I discuss here. With both groups, I volunteered time to help them with various initiatives. In May 2006, via email, I requested an interview with Merck’s biologics director, which was passed to Richard M. Haupt, Merck’s vaccine division’s executive medical director of Policy, Public Health & Medical Affairs. In Dr. Haupt’s response, an email exchange between the two men was accidentally included, noting “we may want to make sure she [Samantha] actually is a graduate student.” After multiple emails to set up a conference call, it was rescheduled repeatedly and ultimately cancelled with no explanation. Thus, all interpretations of Merck’s intentions depend on public materials or Gary’s explanations of CCG’s relationship with Merck.

Gary, who owned a molecular/pathology laboratory, but is not a doctor, co-founded the nonprofit organization with his wife, Margie, 15 years ago. At the time of the CCG’s founding, neither had cancer, but a couple of years later, Margie died of a non-cervical cancer. Gary expanded the CCG’s scope, often invoking Margie’s influence and commitment to the project. After Margie’s death, Gary met Larissa, a woman who would identify herself, including in a popular national magazine article about Gardasil, as having “a very strong, persistent virus [HPV].” Gary and Larissa ran the organization together, sharing leadership roles, but Gary was its public representative.

I first met Gary and Larissa at the 2007 CCG conference. After moving to Los Angeles, we discussed how I could volunteer for the organization. Gary and Larissa ran the nonprofit out of their home, north of Los Angeles, in addition to holding full-time paying jobs. The CCG had no dedicated office space and existed mainly as an online presence, with the annual conference

as the group's main event. Much of the work they asked me to do was to be done remotely via email correspondence. I helped synthesize existing materials for one of their projects, "Parents Educating Parents," and they hoped I would become a contributor to future projects, although I demurred at producing new content to better observe the information they generated around HPV/CC.

CCG's members lived across the United States, joined by shared medical diagnoses. The advent of fairly ubiquitous access to online content resulted in an increase in members' participation over the years of my fieldwork. During the research period (2006–10), CCG's website added a virtual community board where people posted discussions, seeking support and affirmation through others' experiences with HPV/CC. The community board's hosting site changed during my research. Originally exclusively run by the CCG, the newer website was an umbrella site for communities of people with a variety of health concerns; its slogan proclaimed, "Together we're better." I had limited in-person contact with CCG's members but was able to observe interactions online through forums and CCG's regular newsletters. This form of fieldwork has become increasingly common. It nevertheless poses certain limitations, including ambiguity in one's relationship to the community (whether one is a participant or an observer) as well as questions of whether one ought to read the community as a text or understand it as place (Milner 2011). Although written forms of communication can be revealing, many of the ideas I developed about the people who posted on discussion boards could not be contextualized beyond the personal narratives presented there. This project followed institutional review board ethical guidelines for participants met in person; for online data, it used publicly available information collected such that persons were not identifiable.

Informed by these sources, I explore how one grassroots organization responded to Merck's positioning of Gardasil as an apolitical female empowerment commodity. In particular, I trace how the marketing of Gardasil intersected with self-identified HPV and CC survivors' advocacy efforts, in which advocates staked a claim as consumers, not as patients or political activists, and thus as subjects who could invoke choice and knowledge through forms of consumptive practices. This article situates the construction of HPV/CC advocacy in the context of a similarly corporately informed breast cancer advocacy. This evolution of patient as consumer is not new, but its ubiquity in HPV/CC awareness illuminates an increasingly common practice that invokes well-established practices in breast cancer activism.

Patients as Consumer Advocates

Breast cancer has gained increasing attention in the last two decades and has become one of the more prominent women's health concerns in the late 20th century. Calling breast cancer a rallying cause for women, regardless of political affiliation or beliefs about other women's health needs (such as contraceptive access), Ehrenreich (2009) acerbically argues that "[t]o some extent, pink-ribbon culture *has* replaced feminism as a focus of female identity and solidarity" (www.salon.com/mwt/2009/12/02/womens_health). Worldwide, breast cancer is the most commonly diagnosed cancer and the leading cause of death for women (Jemal 2011:71). In the United States, it is the second most commonly diagnosed cancer. The National Cancer Institute estimates that 230,480 U.S. women will be diagnosed annually and that 39,520 of them will die (<http://www.cancer.gov/cancertopics/types/breast>). In contrast, the very low U.S. rates of CC mortality have received significantly less attention and produced less publicly recognized social

movements than breast cancer. CC's necessary and preceding infection, HPV, however, is considered the most common STI in the United States.

Scientists long suspected CC might have a sexual transmission component, but it was not until the 1980s that scientists confirmed the association between HPV and CC (zur Hausen 1977, 1996). Most contemporary research suggests that the development and subsequent institutionalization of the Papanicolaou (Pap) smear reduced U.S. CC deaths (Casper and Clarke 1998).³ Indeed, cancer-causing HPV has no visible symptoms, adding to patients' difficulty in recognizing the infection and necessitating physicians to intentionally screen for the virus. Men do not get screened, and there is no male universalized, institutionalized intervention like the Pap smear. Although breast cancer advocates protested extensively after mammogram screening guidelines shifted (Lakoff 2009), there has been no comparable public outrage as a result of ongoing CC screening guideline changes in the last 15 years. There are multiple reasons for this.

Cervixes and the required gynecological interventions differ from breasts' visible prominence and connotation of sex and maternalness, even as the cervix is an essential part of sex and childbirth, an indicator of a baby's imminent arrival. Unlike breast cancer, CC remains a hush-hush condition,⁴ partly due to its association with sex and the quasi-invisibility of the cervix. Breasts connote femininity in a way that cervixes do not. Confronting this visibility, some breast cancer activists have engaged with a variety of embodied practices, such as bearing their scarred chests post-mastectomy or refusing prosthetic breasts (Klawiter 1999) that have no parallel for CC survivors. Without en masse Annie Sprinkle-like performativity of the cervix, markers of CC demand intimacy, usually reserved for one's gynecologist.

The transformation of illness into an accessorizable self-identity (and risk) can be seen in the breast cancer movement (Kolker 2004), as well as other U.S. patient communities. The demand for a "cure" for breast cancer (King 2006:xviii–xi) exemplifies broader U.S. shifts in patient advocacy, namely the consumerization of health and patients' declaration of embodied knowledges (Howson 1998; Kavanagh and Broom 1998) as a challenge to medical and scientific authorities. I consider embodiment here as an "ownership" of one's disease state that may transform patient experiences into consumer practices. Diagnosis is then phenomenological, but it is also something that a woman carries with her, an accessory to her identity, as part of a risk state (Kavanagh and Broom 1998). This differs from lifestyle or environmental risks, in which the threat is external/behavioral rather than a bodily threat. Through disease ownership, advocacy may become implicated in consumerism.

The increased advocacy for breast cancer research coincided with a broader push for equality in health research for women and minorities. In 1993, the National Institutes of Health formalized the importance of explicitly including women in biomedical research (Epstein 2004). Kolker (2004) suggests that breast cancer advocates succeeded in prioritizing the disease by transforming breast cancer from a private to a public concern.⁵ In so doing, breast cancer research advocates produced a cause that funders and researchers found difficult to ignore; in this demand for public recognition, advocacy elided with consumer practices.

Breast cancer has generated a multi-million dollar industry that explicitly ties consumer practices to finding a cure (Jain 2007; Kolker 2004). The pink ribbon campaign, begun by cosmetics company Estée Lauder in the early 1990s (King 2006), directs funds from purchases of pink-colored products to the Susan G. Komen Foundation, whose activities include the annual "Race for the Cure" (Silverstein 2011). Many U.S. companies have participated in the breast cancer awareness movement, branding their products with the pink ribbon or selling special

versions of existing products in unconventional baby pink, with promises that an undisclosed portion of any purchase price will support breast cancer research (Ehrenreich 2009).

October is now National Breast Cancer Awareness Month, started by a chemical company turned pharmaceutical company, Zeneca (now known as AstraZeneca⁶) in the mid-1980s (King 2006:xx–xi; Klawiter 2002). Nearly 30 years later, the October pink-branding, or pink-washing, publicity remains ubiquitous: from a *New York Times* Styles’ cover story “Laughing at the Big C” and a large ad for breast cancer awareness directly below the story’s second page (October 9, 2011) to “31 Days of Pink Action” (<http://ww5.komen.org>) to dedicated October issues of women’s magazines, which intersperse articles and “advertorials” featuring pink products (*Self* 2011: 98–121). Breast cancer public campaigns for pink-branded products often come from companies that do not explicitly stand to gain from consumers who may be treated for cancer. Some have argued companies that donate to breast cancer research produce products that contain toxins believed to contribute to the rise of breast cancer (<http://bcaction.org/our-take-on-breast-cancer/environment/>).

Breast cancer public awareness corresponds with increasing consumerization of patients and the harnessing of advocacy to consumptive practices (Ehrenreich 2001, 2009; Gibbon 2006; Jain 2007; King 2006). Organizations like Komen have produced “everyday activists,” through purchasing practices and pink bracelet adornments (Selleck 2010:123). These forms of participation do not foment change but rather claim identification with those affected by breast cancer or those who have survived it (King 2004:478).

These shifts have produced a corporate construction of disease, replacing, I argue, the social construction of illness as a preeminent way of knowing one’s illness and related treatments (Applbaum 2006; Moynihan et al 2002). Indeed, the U.S. approval of direct-to-consumer advertisements by pharmaceutical companies in the 1990s coincides in suggestive ways with a rise of health social movements (Barker 2008; Kolker 2004) and “disease awareness campaigns” (Applbaum 2009). Health is its own ideology (Chrysanthou 2002:471), and, in turn, patient identities may form “disease constitutencies” (Epstein 1995:410). U.S. market-based structure of healthcare delivery, with profit-oriented insurance companies and pharmaceutically funded health research, has also contributed to the transformation of patients into consumers.

Due to increasing restrictions on how pharmaceutical sales representatives may court prescribing doctors, known as pharmaceutical detailing, and after many years of decadent meals, all-expense-paid trips, and other indirect benefits to garner allegiance to a particular drug brand (Carlat 2007; Oldani 2004), companies now focus on increasingly vocal patient communities. Patients become instrumental in the distribution of pharmaceutical products, shifting from “recipients of medical care to active consumers,” which, in turn, affirms patients’ “self-determination through choice” (Applbaum 2006:0446–47). Physicians become “providers,” and patients are transformed into healthcare consumers, replete with the expectations of consumer behavior and choices: “A consumer is guided by ‘caveat emptor’... an adversarial injunction and hardly a sentiment that fosters the atmosphere of trust so central to the relationship between doctor or nurse and patient” (Hartzband and Groopman 2011:1373).

The CCG advocacy movement exemplifies these semantic shifts concretely. Unlike the politically and scientifically engaged breast cancer and AIDS activists who demanded changes to established practices, the CCG activities, fueled by Gardasil’s availability, epitomize an activism of awareness, which avoids political claims, challenges to existing practices, and prioritizes self-actualization (e.g., screening for cervical abnormalities and vaccination of one’s children) as

empowerment. I consider the contours of this newer subject position, the patient–consumer–advocate, as manifested in Merck’s marketing of Gardasil.

Gardasil and the Corporate Construction of Disease

Shortly after the vaccine’s FDA approval, 22 state legislatures attempted to pass laws requiring the vaccine for school entry (Saul and Pollack 2007). These days, school entry requirements for vaccination do not often elicit broad public resistance as such laws are common in the United States (Colgrove 2006). Yet by early 2007, only six months after the vaccine’s FDA approval, all but two proposed bills failed in their state legislatures, possibly undermined by the revelation that Merck actively lobbied for these bills (Pollack and Saul 2007; Saul and Pollack 2007).

Most dramatic was Texas governor, and subsequent 2012 presidential candidate, Rick Perry’s attempt to override legislative debate by instituting the school entry requirement (Blumenthal 2007). Parents threatened to sue him, and the Texas legislature overturned the mandate, accompanied by national coverage of the incident and accusations that Merck’s contributions to Perry’s election campaign had motivated his actions (Hart 2007).

Although many proponents of the vaccine expected resistance to its dissemination to be about sex and (young) female sexuality (Pollitt 2005), most critiques focused on parents’ rights to determine what was best for their children’s health. Gardasil public debates referenced preceding and ongoing U.S. conversations around vaccines and government regulation of parenting. The lobbying for Gardasil and media representations of parents’ responses neatly sidestepped the underlying implication of the vaccine: Someday, everyone’s daughters will be sexually active (Braun and Phoun 2010). Instead, Gardasil was *the* cancer vaccine, and combating cancer is a nearly unimpeachable cause in the United States.

From its inception, Gardasil’s marketing strategy tapped into the power of the testimonial and confessional with its “Tell Someone” campaign, tacitly acknowledging the public ignorance of HPV *without confronting the STI protection that the vaccine offers*. Merck’s campaign teasers began prior to FDA approval, providing little explicit explanation of what one ought to tell. The advertisements promoted female intimacy and confidences; women proclaimed, “Cancer caused by a virus? I didn’t know that!” In November 2006, Merck changed its slogan to “One Less” and later to “I Chose,” reflecting classic tropes of health promotion and intervention. Messages were gendered and evoked cultural norms of maternal responsibility that a good mother vaccinates her daughter (Mamo et al. 2010). As a Merck representative explained in an industry newsletter:

“The insight there was that young women really want to be responsible for their own healthcare and take control of their own lives,” says [Bev] Lybrand [Merck representative for adult and adolescent vaccines], “and moms want to do everything they can to protect their children.” Advertising by DDB NY employed a forthright tone, with young women speaking directly to the camera, meant to communicate authenticity to cynical younger viewers used to being bombarded with health and safety messages in ads. [Arnold 2008]

Though unsurprising, there were no advertisements of fathers expressing concern for their daughters’ health. Merck initially sought approval for boys and girls in 2006, but FDA approval for boys did not occur until October 2009 due to the limitations of the 2006 research done on males.⁷ Thus, the focus on young women draws on both historical and cultural norms of

female bodies as sites of regulation, intervention, and surveillance, including the entrenched practice of the Pap smear and the institutionalized expectation that women bear the responsibility for healthy reproductive tracts. Although men and women are both affected by HPV, Gardasil remained a gendered product for its first three years on the market, further obscuring its STI protection and emphasizing CC.

Merck concurrently developed multiple websites, which did not explicitly reveal their link to Gardasil, promoting female empowerment and camaraderie around CC and HPV. One website, Make the Connection, formally sponsored by the Step Up Women's Network and the Cancer Research and Prevention Foundation, with "support from Merck," offered a bracelet-making kit that women could receive by mail (www.maketheconnection.org). Like the Lance Armstrong Foundation's "LiveStrong" yellow rubber bracelets, are now synonymous with generalized cancer awareness, the Make the Connection beaded bracelet suggested a visible way to raise public awareness for CC/HPV. Yet the Make the Connection campaign did little to attract the publicity that Armstrong's foundation has generated. Merck offered to give \$1 to charity per kit, but they did not keep the offer open indefinitely.

When I requested a kit in August 2006, less than a year after the program's inception, the website informed me that they no longer provided the kits. Unlike "LiveStrong," represented and driven by a celebrity spokes-patient, Merck's marketing budget, rather than a social good, drove their bracelet campaign. In October 2011, the site informed visitors that one ought to contact the site's owners, a public relations firm, for more information (www.maketheconnection.org).

Thus, six years later, the campaign no longer has a public presence, which is strange, since HPV and CC rates have not radically diminished since Gardasil's approval. Nevertheless, for CCG members, the new HPV vaccine seemed revolutionary, an option that many wished they had received before developing cervical abnormalities. Many were CC survivors, although some self-identified as having "persistent HPV." In every CCG public presentation, Gary reminded everyone to "vaccinate early!" along with other pre-vaccine era reminders: "Pap test regularly" and "HPV test when recommended." One of the CCG's missions was to empower CC patients and to minimize the shame many of its members felt. De-stigmatization included a proactive management of HPV and CC narratives. As I observed in the annual conferences, members with persistent HPV or CC proclaimed their survivor's perseverance. Most of the stories started with the clinical encounter, when the amorphous infection became something un-invisible.

In contrast, breast cancer diagnosis usually begins with the palpation of the breast. A woman feels a lump. Or, unsuspecting any pathology, a woman goes to get her mammogram, and the abnormality is visible to doctor and patient alike (with the physician's translation for the patient). HPV and CC diagnoses diverge from the breast cancer narrative. There's the duck-billed speculum, a physician crouched between a woman's legs, and the pathology lab's inspection of millions of cells trying to identify something amiss in the midst of hazy clusters. A doctor may share with her patient data and risk prognoses transformed from a visual representation of cellular activity. These practices highlight the technologies and medicalization intrinsic to the women's health practice that has long been considered the gold standard of public health screening tools (Clarke and Casper 1996).

Prior to developing CC, women can also be diagnosed with a range of pre-cancerous states. The advent of the HPV DNA test has allowed providers to tell women if their abnormality indicates the high-risk (associated with potential progression to CC) or low-risk HPV. Women may also receive false-positive Pap smear results, false-negative results, or overtreatment with highly invasive methods. The progression from initial diagnosis to cancer is full of uncertainties

and varied diagnoses (Howson 2001), and this is true across cancer types, as evidenced by recent concerns about other cancer diagnostic tests, like the prostate specific antigen test. Even if not explicitly affecting awareness of HPV and CC, these muddled scientific and medical trajectories may contribute to the absences of and gaps in public representations of HPV and its related cancer (Braun and Phoun 2010), none of which is radically disrupted by Gardasil's availability. What Gardasil offered CCG members discursively is nonetheless important, as the vaccine promised to open up new ways of talking about HPV and brought their experiences into public discourse.

There are, of course, consequences to the CCG's embrace of Merck's Gardasil rhetoric. Legitimization of CCG members' experiences produced by the vaccine entailed members' tacit buy-in as consumer advocates, transforming the disempowered patient into the beholden consumer. The CCG was the perfect complement to Merck's marketing, as a small, grassroots advocacy and support group. A couple of months after the 2007 CCG conference, I met with Gary at his home. Describing the projects he imagined for the organization, Gary mentioned a "Parents Educating Parents" presentation on Gardasil that he wanted to disseminate across the country and that he hoped I would help to develop. Gary imagined it as a grassroots movement. He envisioned generating interest among parents, which might lead to legislators paying attention to CC and Gardasil. I asked if that were his goal, to get it made into policy, and he insisted that they "don't play politics." He smiled at me, as though I had tried to get him to say something incendiary. I mistakenly assumed that advocacy included an explicitly political element. Instead, he saw it as an opportunity to persuade parents hesitant to vaccinate their daughters with Gardasil to do so. Gary sought an awareness of the general public and private actions that did not necessitate broader social action.

Gary's ambiguous grassroots-movement language and his refusal to call their activities political confused me. He sought a response from the legislative sector, and it certainly had political implications. His apolitical claims also denied the last year and a half of politically framed Gardasil debates, as well as the history of U.S. debates around women's sexual health, more generally. For a movement that drew on past patient advocacy movements, such as the breast cancer movement, to decouple it from politics seemed a willful refusal of how politicized health care is in the United States and the cultural implications of targeting young female bodies for intervention. Gary's term "parents educating parents" evoked Merck's framing of Gardasil as a benevolent project, with shared investment in knowledge, rather than (Merck's) opportunity for market expansion. Just as Merck's campaigns and their invocation of female camaraderie positioned the vaccine as a health necessity rather than a commodity, CCG reproduced Merck's careful strategy to avoid potentially contentious aspects of the vaccine. Like Merck calling it a cancer vaccine, Gary's insistence that they were not playing politics replicated Merck's evasion of the most politically charged elements of the vaccine: its STI protection.

Strategic Alliances

Gary explained that Merck would contribute to the parents' project.⁸ Unprompted, he expounded that just because they received pharmaceutical money, it was not necessarily bad. He acknowledged that some people believe that pharmaceutical money implied compromised efforts; CCG did not agree. In January 2008, CCG's website republished a marketing article dubbing Merck an "All-Stars Company of the Year": "Gardasil, the HPV vaccine that turned Merck's corporate reputation from disgrace to that of life-saving innovator, has also provided a

case study in the company's global marketing muscle" (Arnold 2008). CCG honed their ability to straddle private industry funding to ensure that their goals were met. It would be unfair to criticize CCG's mission to improve women's health, but Gary's disavowal of politics and willingness to accept pharmaceutical money seemed untenable. As Gary's acceptance of Merck resources and framing of Gardasil suggest, the synergy between Merck's and CCG's rhetorics was strategic to both parties.

The CCG's occasional newsletter, "Inspirational Tales," featured CC survivors' intimate familiarity with the disease. One newsletter included four pages of testimonials from women who endured CC diagnoses and treatments. The newsletter proclaimed: "Here are ... our members [*sic*] stories of struggle, determination survivorship [*sic*] and HOPE!" All nine testimonials acknowledged previous ignorance about CC and HPV. One survivor echoed Gardasil's pre-licensure campaign: "Just like the commercial says, '*Tell Someone—Anyone who will listen*'" [*italics added*]. Another young woman stated, "I know I can't get the word out to very many people [*sic*] but if I can teach just one person more about this terrible thing then I feel that I have saved a life." Thus, information dissemination stands in for any sort of action. One woman reinterpreted Merck's campaign, "Now I want to let every woman know cervical cancer is no longer a death sentence." In spite of knowing that Gardasil does not prevent cancer but its cause, HPV, these testimonials appropriated the story Merck sought to sell.

As CCG increased its public presence, shortly after Gardasil's availability, the parallels in the CCG's promotional strategy and Merck's exhortation to tell someone became increasingly less subtle. Tying consumer choices into a form of advocacy and social identification, CCG sent out frequent emails announcing new affiliations with a variety of online fundraising and social networking sites. Providing an indirect way to raise money, CCG's website included sidebars that encouraged its members to sign up for "eScrip" that offered, "3 easy ways to earn for our [CCG] group." When people purchased products online through the link, CCG would get a small portion of the profits. The CCG's website included promotional links to Facebook, MySpace, and iGive.com, which revealed a desire to engage with the increasingly common use of the Internet for social networking as a revenue stream. Advocacy groups that accept pharmaceutical funds or tie their advocacy work to corporate sponsorship are, in fact, complicit in creating the marketing and consumer loyalty for which manufacturers strive. The participation in consumer-patient-advocacy identity allows the corporation to define what conditions deserve attention. As Jain argues,

[I]n these models of corporate care, everyone has their role and the scripts for these roles seem to be provided by, on the one hand, the caring corporation that allows us to play our roles through consumption ... and, on the other hand, the role of "survivor," which seems to revel in narratives of the gift of cancer. [2007:520]

Further, "the role of capital is incidental to none of this—neither the production of cancer, the models of treatment, nor the core centrality of the nuclear family as the consumptive unit" (Jain 2007:528). The CCG's awareness activism endorsed the patient-consumer-advocate, which pharmaceutical companies have crafted carefully and intentionally. Through traditional and social media representations, the CCG members produced public narratives about CC/HPV that they were eager to share. Their uncertainty about their disease and their skepticism of

medical authorities were more genuine than if Merck had enlisted celebrity spokespeople to promote the vaccine.

The appropriation of Merck's advertisements and other health promotional phrases allowed participants to celebrate public depictions of their experience, representations that were absent prior to Gardasil. No longer diagnosed with an invisible or stigmatized condition, CCG members defended knowledge of their own bodies. These contestations reiterate pharmaceutical and medical framings that intertwine citizenship with the "power of the consumer's purse" (Jasanoff 2004:91). Gardasil marketing endorsed such interrelated consumerism and citizenship, and the CCG purposefully built on these.

As bearers of the disease, many members of the CCG articulated their shared identities through their medical experiences. The opportunities for "biological citizenship" (Rose and Novas 2002) and "contemporary practices of identity" (Novas and Rose 2000) were expressed in the CCG members' demand for accountability from medical experts at CCG annual conferences, challenging "professional expertise" through "their very distinct experience-based knowledge" (Lehoux and Blume 2000: 1088; see also Callon et al. 2009; Epstein 1995). This expression of embodied expertise resists others' claims of authority as alienating and abstract (Kavanagh and Broom 1998; Reventlow et al. 2006). At the same time, in CCG members' appropriation of the rhetoric of Merck's advertising campaign, we can see how information dissemination replaces action for which some of the breast cancer movement has fought, namely agitation for broader political changes in gynecological care and/or cancer research. Indeed, although Gardasil's clinical benefit is the reduction of morbidities and decreased risk for CC, research on U.S. CC deaths also suggests that women who die due to CC are women who lack access to care and are disproportionately non-white (Singh 2012). Gardasil's promise and CCG's embrace of it thus fail to address one of the core reasons for continued CC deaths: lack of access to care and larger social inequalities. Instead, the CCG advocated an apolitical stance of self-awareness that, I argue, cannot be parsed from consumer identity.

Indeed, on the release of Gardasil, CCG focused its mission on supporting the vaccine. In December 2007, a major women's fashion magazine included a two-page spread paid for by CCG, reiterating health consumer empowerment language and Merck's assertion that vaccination was the responsible choice: "Learn the Truth about HPV" and "Educate Yourself" (implied: because no one else will). Self-actualization was encouraged, from acquiring knowledge ("Learn the truth") to "Help protect yourself," as though not choosing the vaccine were an abandonment of self-care. It echoed language I heard elsewhere: in the L.A. County's quarterly immunization coalition meetings' promotion of overall vaccination practices; in CDC immunization materials and its annual immunization conference; and among physicians I interviewed who promoted the HPV vaccine as an uncomplicated choice. Now the right choice was clearly to vaccinate, while the irrational one was to leave one's cervical health to (unvaccinated) chance. CCG's magazine advertisement was interrupted in the middle by Merck's own Gardasil advertisement, an ad inside an ad.

Although CCG's public service advertisement emphasized knowledge, education, and truth, the Merck insert muddled the distinction between the corporation and the advocacy organization. The branded promotion undermined the non-profit organization's intended beneficent tone. On the first page of CCG's page, under CCG's "Learn the truth," the advertisement was "Brought to you by the [CCG] and Merck & Co., Inc." Accepting money from Merck, as Gary had admitted, was a compromise needed to accomplish their advocacy work.

CCG did not seek to endorse the particular vaccine, as a commercial object, but they did want to promote *an* HPV vaccine for women, as a medical intervention. Due to the absence in the U.S. market of the GlaxoSmithKline HPV vaccine, Cervarix, which would not receive FDA approval until late 2009, those who promoted an HPV vaccine were tacitly, if not explicitly, endorsing one pharmaceutical company and one vaccine. In this instance, the *branded* nature of the medical intervention shaped how individuals might understand the vaccine preventive.

As active health consumers, CCG members did not define themselves as spokespeople; they offered intimate testimonials, thus producing a consumer-as-advocate persona that is increasingly common in non-health settings. In the process of consumer endorsements and advocacy trumpeting the vaccine, Gardasil's availability shifted the framing of gynecological interventions, as though one were not still at risk for CC after the vaccine (which is the case). "A woman who does not have her three shot prevention vaccine and her regular Pap test screen and HPV test when recommended, significantly increases her chances of developing cervical cancer" (CCG website). Thus, the conflation of *not* vaccinating with an increased risk for CC positions women as consumers who ought to choose to participate in a clear consumptive practice. Without intending to, the CCG admonitions reframed possible stigma, failure to vaccinate makes one culpable for one's cancer (risk). By refusing a political form of activism, the CCG accepted and co-created a prescribed form of engagement, one manufactured by a company with its own profit objective.

Discussion and Conclusion

This article contributes to the literature on health advocacy movements by examining how patient advocacy may transform patients into consumers. Merck's marketing of Gardasil offers insight into the creation of this patient-consumer-advocate identity. Although the data do not draw on direct research with the pharmaceutical industry, I have focused on public representations of HPV/CC by Merck and the effects on its target audience: women and girls. Merck's own media reveal a deliberate decision to frame Gardasil's value by dodging its more controversial benefits. Although the breast cancer advocacy movement developed out of diverse forms of activism (King 2006; Klawiter 1999, 2002, 2004), both by agitation for more research and better access to treatment, as well as by beribboned commodified forms of advocacy, the CCG staked its role and advocacy community on the campaign of a publicized and marketed medical intervention.

This article suggests that it was the Merck-led campaign that helped CCG coalesce its own position and gather momentum for its longstanding cause rather than politicized demands for treatment and more research that can be seen in the earlier days of breast cancer advocacies. Merck had more to gain from the collaboration than CCG or its members. As with the pink-branded breast cancer awareness, the apolitical patient-advocate-consumer identity serves larger corporate interests and raises questions about the benefits to the patient community themselves. A recent visit to CCG's site (March 2012) announced that it had been incorporated into a larger coalition of sexual health groups.

The power of consumer identity tied to patient advocacy of course outlives the examples discussed here. The 2011 FDA decision to revoke the manufacturer Genentech's right to market Avastin for metastatic breast cancer because it was neither safe nor effective elicited an outpouring of objections from women for whom the drug worked. In spite of population data that suggested the risks of Avastin outweighed the benefits, women stepped forward, offering their

bodies as proof-positive that they were alive because of their access to the drug (Pollack 2011). As with CCG's Gardasil advocacy, breast cancer survivors claimed intimate expertise to support their pleas to the FDA. Genentech's rallying of women as testament to Avastin's effectiveness is yet another example of the confounding of citizenship, advocacy, and consumer behaviors that is increasingly difficult to disentangle.

Cancer drugs, in particular, have received more lenient approval in the last ten years or so, as advocacy organizations have increasingly pressured the FDA to allow for experimental treatments (Harris 2009). As pharmaceutical companies have been restricted from targeting physicians to generate sales, the turn toward the patient as advocate *and* consumer has generated new forms of patient activism, which I have argued is the apolitical activism of awareness. Gardasil and Avastin provide examples of patients, women specifically, as powerful marketing mechanisms at a pharmaceutical company's disposal. Gardasil was not the first nor will it be the last, but it exemplifies one manufacturer's cultivation of a visible and active patient population that willingly endorsed a corporately defined medical intervention.

Notes

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1. All names are pseudonyms.
2. As distinct from the very visible and political HIV/AIDS activism of the 1980s, when patients agitated for recognition and improved treatment options.
3. Some scholars dispute the role of the Pap smear in reducing cervical cancer deaths (Löwy 2007; Teixeira and Löwy 2011).
4. One counter-example is Jade Goody, a U.K. reality TV star, who was publicly diagnosed and subsequently died of cervical cancer. Public representation of cervical cancer death has no parallel in the United States.
5. Concurrent with reframing of the public imagination of breast cancer was the discovery of HIV/AIDS and a growing movement throughout the 1980s of AIDS activists (Epstein 1995). The gay rights' movement around HIV/AIDS has significantly affected health advocacy movements, but I will not explore it in this article.
6. AstraZeneca is the manufacturer of the commonly used breast cancer drug Tamoxifen.
7. The 2012 advertisements for vaccinating boys and girls simply state "Both," or "One Less," with the "o" incorporating a symbol for both male and female, the cross pointing down (female) and the arrow angling out to the right (male). The presumed universality of the vaccine has not elicited comparable debates or objections as the initial availability (for girls' vaccination) did, but there has been no accompanying policy push for male vaccination.
8. In one email exchange between a Merck communications' employee and Gary, Merck offered as a spokesperson a woman whose daughter had died of cervical cancer at a young age.

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