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CONSCIOUSNESS RAISED:

Women Increasing Health Literacy from *Our Bodies, Ourselves* to Breastcancer.org

by

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Nancy A. Hewitt

and approved by

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## ABSTRACT OF THE THESIS

### CONSCIOUSNESS RAISED:

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The personal is political: this revelation sent ripples through the women's liberation movement in the late 1960's and early 1970's and inspired a feminist practice to discuss personal experience openly and collectively in a safe and supportive context. This practice came to be known as consciousness raising (CR). CR helped women recognize that individual struggles were, by and large, fueled by gender politics. A historical practice with a precipitous rise and fall, CR has been revitalized and improved through medical support and education websites. By grounding access to valid health information in the trusted and proven feminist practice of CR, these web based resources add credibility and familiarity to a complex subject. The contemporary American expectation that information be available on demand makes web based resources extremely important. Medical support and education websites that incorporate computer-mediated communication create avenues to medical information – both professional and experiential – that can result in an increased level of health literacy.

This project examines the feminist practice of consciousness raising through a comparative case study of face-to-face and web-based health literacy projects. In both

contexts group discussions of personal realities establish links between subjective experience and larger political themes. This evaluation of the evolution of CR focuses on the Boston Women's Health Book Collective, an early, long-lasting and effective CR group, and Breastcancer.org, a more recent but rapidly expanding web-based tool for raising women's consciousness. Both sites focus on health literacy through education, support and collective discussion. They provide the basis for an in-depth examination of successful CR communication strategies. This study will explore the methods of information distribution utilized by the Boston Women's Health Book Collective and frame those against a web-based breast cancer support and education website, Breastcancer.org. This comparison will establish a connection in the modes of information distribution, communication strategies and support offered via face-to-face and text based CR.

I highlight the effectiveness of breast cancer support and education sites that use a new form of CR to advocate for health literacy. Health literacy does not make an individual a medical expert; rather it provides the necessary information and perspective for women to play an active role in their health care plan. Themes that will be present throughout this project include: consciousness raising as a feminist practice, the role of the Boston Women's Health Book Collective within the women's health movement, breast cancer support and education websites that foster health literacy, and the exchange of ideas, experience and medical knowledge – that is CR – that ties them together.

*For the women who blog on Breastcancer.org*

Although the world is full of suffering, it is also full of the overcoming of it.

-- Helen Keller

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-“Because I am a woman, I must make unusual efforts to succeed. If I fail, no one will say, ‘*She doesn't have what it takes.*’ They will say, ‘*Women don't have what it takes.*’”

-Clare Boothe Luce, (*speech to the National Press Club in Washington, D.C.*)

# Table of Contents

Abstract.....	ii
Acknowledgements.....	v
Table of Contents.....	vii
Introduction.....	1
Chapter 1... Consciousness Raising: From Women's Liberation to the Digital Revolution	
THE END OF ISOLATION: Educate, Reconcile and Resolve Together.....	6
PRESS SEND: Digital Methods of Communication.....	15
DEVELOPING DIGITAL AGENCY: Consciousness Raising in the Blogosphere.....	19
Chapter 2..... The Evolution of Women's Health Literacy	
FROM LIVING ROOM TO CHAT ROOM: Women Raising Consciousness Across Time....	27
MORE OF US CAN JOIN, BUT ARE WE GETTING LESS OUT OF IT?: Challenges and Issues of Diversity Online.....	53
Conclusion.....	65
Appendix 1	
Methods.....	72
Appendix 2.....	78
Bibliography.....	81



## Introduction

It's happening again.

Every once in a while the board goes through a really tough time. Our hearts break for our sisters whose cancers are spreading at frightening rates. We see their selfless, innocent [*stories*] that detail the cancer taking over. How they feel, what they're thinking. What they need. The struggle, the powerlessness, the strength and courage.

I just wanted to pull all you newbies in close and let you know that we've all been there and you are probably absolutely freaking out right now. Chemo has beaten you up, you feel like a shadow of who you used to be. Tired, depressed and overwhelmed.

You may even feel guilty because you are not only sad for these beautiful women, but you are sad FOR YOU. You see yourself in every one of these women that becomes so very sick and then loses the battle.

It's normal to feel this way and it's OK. We understand and so do they. Your mother may not, your husband may not, your friends may not, but we do.

And there's nothing wrong with feeling sad and getting angry. But please remember that the odds are that YOU are going to get better. YOU are going to get your hair back and start to feel well again. YOU are going to get back to the life that you want to lead.

So if you are checking the [*stories*] incessantly right now, reading the latest [*story*], then sobbing and then going back for more.....been there too. You are grieving....this disease is not fair....it's disgusting and ugly and perverse. And it's so much more unfair to certain sisters than others. And there's nothing fair about that.

So grieve for them. Grieve for you. And then remember that you will get better.<sup>1</sup>

The above statement is a heartfelt connection between a woman and her breast cancer support group. This speech was not delivered at a meeting in a church basement or local gym; rather it took place online at a virtual community center. Such emotional and intellectual support, once thought to be available only through face-to-face meetings, has moved beyond such a static limitation. The World Wide Web provides a venue for distant and yet connected women to meet, discuss, and in so doing, improve each other's lives.

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<sup>1</sup> "Newbies.....come here and, let mama Cathy give you a big hug," Young Survivors Coalition: General, June 5, 2006, <http://www.youngsurvival.org/bulletin-board/>. (Accessed April 22, 2009.) There are minor alterations to the quotation above with direct references to electronic media being replaced with less specific terminology. Spelling from original post was edited in an effort to maintain the feeling of discussion. All usernames will be replaced for anonymity.

This is more than just a breast cancer support group hosted online; this website, and others like it, create virtual communities that strengthen health literacy and foster consciousness raising.<sup>2</sup> The US Department of Health and Human Services defines “health literacy” as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” My use of the term encompasses both traditional medical knowledge and health information passed on by patients who have direct experience of particular medical practices and their consequences.

Health literacy among women was one of the many topics discussed by consciousness raising groups in the 1960s and 1970s. Consciousness raising (CR) is, at heart, group discussion of personal realities that establish a link between subjective experience and larger political themes. This connection between the personal and the political allowed feminist’s in the women liberation movement to recognize that individual struggles were fueled by gender politics. As Susan Brownmiller claimed, “Housework is political. Abortion is political. Standards of feminine beauty are political. Women’s oppression is political. A reevaluation of male-female relations is political.”<sup>3</sup> Health care, too, was political. CR helped women understand that their individual discontent —with domesticity, marriage, higher education, childrearing, medical practices, and many other issues— was shared and that feelings of dissatisfaction were not self inflicted.<sup>4</sup> Group

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<sup>2</sup> “Health Literacy.” Government. U.S. Department of Health and Human Services: Health Resources and Services Administration. <http://www.hrsa.gov/healthliteracy/>. (accessed May 27, 2009)

<sup>3</sup> Susan Brownmiller, *In Our Time: Memoir of a Revolution*. (New York, NY. The Dial Press, 1999), 45.

<sup>4</sup> Tracy L. M. Kennedy, “Blogging Feminism: (Web)Sites of Resistance,” *The Scholar & Feminist Online*, published by The Barnard Center for Research on Women 5, no. 2 (Spring 2007): online. (Accessed January 7, 2009.)

discussions were liberating because they addressed subjects such as sex, abortion and rape that were rarely spoken of in a public setting.

Due to the nature of these discussions, camaraderie and trust were required for the effective practice of face-to-face CR, and groups were often formed by women who were already informally connected. This structure created a system of inherent support as participants often felt a deep emotional connection to one another, and the CR group served as a safe space where nothing was off limits.<sup>5</sup> The process raised political awareness on gender issues and created a support network that reinforced the value of such practice.

This project will examine, in detail, the historical practice of consciousness raising and trace the ways it has been revitalized and enhanced through medical support and education websites. CR was a powerful tool utilized by the women's liberation movement to generate feminist discussions and raise awareness on a wide array of issues and to provide the insight necessary to take action. The knowledge imparted in these sessions created personal understanding of sexism, a significant and long overlooked barrier to women leading full lives. This study will document the impact of technology on the revitalization of CR practice. To highlight the connection of historic practice and contemporary technology, it will outline the evolution of CR in the promotion of health literacy from a face-to-face feminist setting to a web-based mechanism of support and education.

As Judy Norsigian, a founding member of the Boston Women's Health Book Collective, one of the most successful CR groups of all time noted, "the

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<sup>5</sup> Anita Shreve, Women Together, Women Alone. (New York: Penguin Books, 1989), 195.

internet is going to affect a lot of this... we are going to have to be much more clever about how we get out there.”<sup>6</sup> In the late 1990’s, Norsigian recognized that a changing political landscape, less leisure time and the advancement of technology would have a tremendous impact on consciousness raising. The internet has created an environment where consciousness raising can thrive once again, an environment without time constraints, without physical space and geographic limitations. It provides an ideal world for CR engagement, a virtual community that is always accessible and where discussions are never forgotten. CR that occurs in this fashion can incorporate personal experience, knowledge and understanding and leaves a documented history of each conversation. Women have constant access to a text-based treasure chest of knowledge, insight, and experience that can be referenced for personal understanding and the expansion of medical knowledge, which allows women to make better-informed choices about their care. The presence of such a resource makes participation in a consciousness raising group possible for any woman with access to the internet.

In addition to the individual benefits of web-based CR the experience engages participants in a form of non-electoral political participation.<sup>7</sup> Michele Berger and Janet Flammang propose that we redefine political participation to understand how women

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<sup>6</sup> Judy Norsigian, “Oral history interviews 1998-1999 (inclusive),” interview by Kathy Davis, CD, October 27, 1998, Schlesinger 2006-M119--2006-M154, Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>7</sup> Michele Tracey Berger, Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS, Princeton University Press; Princeton, 2004, 8. Janet A Flammang, Women's Political Voice, Philadelphia: Temple University Press, 1997. This redefinition should also be expanded to include on-line advocacy as these support groups are empowering women and engaging them in political participation in a non-electoral form. Berger was my first introduction to this idea of community work as political, additional reading on the subject includes, Tera W. Hunter, To 'joy My Freedom: Southern Black Women's Lives and Labors After the Civil War, Cambridge: Harvard University Press, 1997 and numerous studies by Martha Ackelsberg and Nancy Naples.

engage in political activism by addressing social problems. Women's activism has traditionally been manifested in forms that fulfill basic community needs rather than attempt to change political structures. They have attacked problems from the ground up, seeking to create a system of support that overcomes institutional constraints and failures. A bottom up approach to political understanding, non-electoral participation is not designed to affect legislative change, but to directly improve the lives of marginalized people.<sup>8</sup> The communities examined in this project concentrate on two key aspects of improving women's lives, support and education for women with health concerns or crises. They employ CR to help afflicted women come to an understanding of the experience of their illness through the expression and transfer of health literacy. Participation in this dialogue constitutes a form of advocacy, fighting to improve the quality of medical care women receive by exposing them to collective knowledge and understanding. By helping other women navigate through the process, the CR group becomes engaged politically even if they are not always aware of the political nature of their actions.

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<sup>8</sup> Robin D.G. Kelley. Race Rebels: Culture, Politics and the Black Working Class. New York, Simon and Schuster: 1996, 4.

## Chapter 1: Consciousness Raising: From Women's Liberation to the Digital Revolution

### THE END OF ISOLATION: Educate, Reconcile and Resolve Together

Kathie Sarachild coined the term consciousness raising in November, 1968 in a presentation to the first National Women's Liberation Conference.<sup>9</sup> However, women who had become disillusioned with their roles in leftist organizations like the Students for a Democratic Society and the Student Nonviolent Coordinating Committee had participated in similar types of discussion groups for several years.<sup>10</sup> These groups allowed women to recognize common experiences and identify how sexism impacted their lives.<sup>11</sup> Yet they had been chided as "bitch sessions" or "hen parties" by those who did not understand their value.<sup>12</sup> So when Sarachild presented her talk "Radical Feminist Consciousness-Raising" in 1968, she delivered a formal defense of the value of connecting personal experiences to the political issues that created hardships for women.<sup>13</sup> For Sarachild this meant women joining together to discuss personal experiences, which could link their lives to larger feminist issues.<sup>14</sup> It was her belief, and that of many feminists, that the practice held tremendous value to the women's movement.

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<sup>9</sup> Kathie Sarachild, "Consciousness-Raising: A Radical Weapon." In Feminist Revolution, edited by Redstockings and Kathie Sarachild. (New York: Random House, 1978), 144.

<sup>10</sup> Susan Brownmiller, In Our Time: Memoir of a Revolution. (New York, NY: The Dial Press, 1999), 12, 18.

<sup>11</sup> Anita Shreve, Women Together, Women Alone. (New York: Penguin Books, 1989), 5.

<sup>12</sup> Brownmiller, In Our Time: Memoir of a Revolution. Robin Morgan, Sisterhood is Powerful: An Anthology of Writings from the Women's Liberation Movement. (New York: Random House, 1970). Kathie Sarachild, "Consciousness-Raising: A Radical Weapon." 146. Sarachild was shocked by the resistance CR practice met, especially within the feminist movement, and felt that derision of CR was preventing women from understanding its purpose and value.

<sup>13</sup> Sarachild, "Consciousness- Raising: A Radical Weapon." 144.

<sup>14</sup> Ibid.

CR groups attempted to educate, reconcile and resolve life's challenges and, in so doing, end women's sense of isolation.<sup>15</sup> Participants verbalized struggles with difficult issues, such as reproduction, sex, and gender based discrimination that were, by and large, suffered in silence. The collective nature of CR groups was used to formulate an understanding of the issues from a factual and experiential perspective and open discussion to topics previously unmentionable. In so doing, participants were able to use the combined group experiences to construct a base of knowledge. Face-to-face CR brought women together to discuss personal concerns, but the process did more than connect these issues to their political roots. It educated women on the issues in an experiential manner. Women joined CR groups for a number of reasons – access to a feeling of sisterhood, an opportunity to vent frustrations, or the chance to raise their own feminist awareness – but they came away with something more. They were empowered by lay knowledge to take action against a system of female subjugation. Anita Shreve contends it was the influence of CR that caused the women's movement to so quickly become a part of mainstream culture, and that the rapid expansion of the movement in the late 1960's and early 1970's can be attributed, in large part, to CR.<sup>16</sup>

Consciousness-raising groups generated feminist discussion and organization across the United States in the 1960's and rose to their peak of popularity in the early 1970's. In 1973, over 100,000 American women were actively participating, making CR “one of the largest ever educational and support movements” for U.S. women.<sup>17</sup> The unique structure and small size of CR groups allowed members to foster understanding of their connection to the feminist movement and determine what issues were most relevant

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<sup>15</sup> Sarachild, “Consciousness- Raising: A Radical Weapon.” 144.

<sup>16</sup> Shreve, Women Together, Women Alone, 6.

<sup>17</sup> Ibid.

to them. An exceedingly individualized format allowed these groups to function without a formal leadership structure and provided all members with a supposedly equal opportunity to participate. The process promoted individual creativity through self expression and contributed to increased levels of self-esteem in participants.<sup>18</sup> As Paula Costa Eastman notes, “consciousness-raising groups are not formally organized and receive no directives from some higher authority.”<sup>19</sup> Because of this, CR groups generally focused only on the issues that resonated among their particular members, and did so in a way that melded the personal and political in the lives of participants.<sup>20</sup> It was the ability of these groups to show women how their personal experience was linked to a larger system that reinforced gender based discrimination that made the experience so powerful.

Rose Wertz in her examination of groups in Connecticut claims feminist CR “consists of regular meetings in which women discuss and search for similarities among their personal experiences... the overt purpose of these groups is the politico-feminist resocialization of members.”<sup>21</sup> This allowed for what P.C. Eastman calls a “break with the past,” a reinterpretation of their respective reality based on the emotional support and feminist value the discussion fosters.<sup>22</sup> By applying lived experience to the challenges of women’s lives, CR groups facilitated understanding of why issues existed and attempted to “change social situations via politics or personal confrontation with life situations.”<sup>23</sup> Discussion allowed for a refinement of social and political understandings of sexism. The group interactivity of CR, collective discussion and analysis, served as the vehicle to

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<sup>18</sup> Rose Wertz, “Feminist Consciousness Raising, Self-Concept, and Depression.” *Sex Roles* 8, no. 3 (March 1982), 231.

<sup>19</sup> P.C. Eastman, “Consciousness-raising as a resocialization process for women,” *Smith College Studies in Social Work* 43, no. 3 (1973), 161.

<sup>20</sup> Ibid.

<sup>21</sup> Wertz, “Feminist Consciousness Raising, Self-Concept, and Depression,” 231.

<sup>22</sup> Eastman, “Consciousness-raising as a resocialization process for women,” 155.

<sup>23</sup> Eastman, “Consciousness-raising as a resocialization process for women,” 164.



further understanding of gendered experiences. Such knowledge equipped women with the necessary awareness and skills to strive to change traditional modes of female oppression, because, as Shreve argues, change could only occur after “women clearly understood why they were oppressed and how.”<sup>24</sup> CR groups served as a space for women to support one another, to unite and to gain the political perspective necessary to change their lives. They were empowered to come to a new understanding of the world around them.<sup>25</sup>

CR groups played a significant role in creating activists for the women’s movement. For many the experience was much like a light switch turned on for the first time. It brought new awareness and radicalized women who, equipped with a new experiential knowledge of the world around them, desired change.<sup>26</sup> Wendy Sanford of the Boston Women’s Health Book Collective described this radicalizing experience, “that moment in consciousness raising where you feel yes! You know, this is, I’m alright! And we can work together and make changes.”<sup>27</sup> As the popularity of CR grew in the early 1970’s so did the number of women exposed to this awareness. Although many early CR groups were created on college campuses and in urban neighborhoods, CR groups now became a significant gateway through which suburban women involved themselves in the movement.<sup>28</sup> More than any other segment of the nation at this time, they connected to

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<sup>24</sup> Shreve, Women Together, Women Alone, 14.

<sup>25</sup> Nancy Miriam Hawley, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis, CD, January 21, 1999, Schlesinger 2006-M119--2006-M154, Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts. (Hereafter Schlesinger Library) For additional information also see Rimer and Shreve.

<sup>26</sup> Shreve, Women Together, Women Alone, 12.

<sup>27</sup> Wendy Sanford, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis, CD, December 4, 1998, Schlesinger 2006-M119--2006-M154, Schlesinger Library.

<sup>28</sup> The Chicago Women’s Liberation Union produced a manual describing how to establish a CR group that included potential discussion questions and guidelines for participation and meeting flow. This manual was made widely available for use. The Chicago Women’s Liberation Union. “How to start your own

Betty Friedan's "problem with no name," and CR groups gave them the opportunity to shed light on their reality.<sup>29</sup> The CR experience challenged these suburban women to advocate for the issues relevant to their lives.

Most successful CR groups of the time used a similar design for their meetings, and many instituted a policy of confidentiality.<sup>30</sup> The format was non-threatening and comfortable as it allowed every woman in attendance an equal opportunity to participate. A manual produced by the Chicago Women's Liberation Union recommended participants sit in a circle to best accommodate this format.<sup>31</sup> A question was put forth to begin the discussion and each woman would have a chance to discuss her personal feelings or experiences in response. Most groups allowed each woman the chance to talk for as long as she wanted. Discussion questions were left intentionally open ended, and every topic was a potential subject for consciousness raising. Group members often spoke freely about their own experiences in an environment where they did not have to fear being alone.<sup>32</sup> At the end of each session the women came together and attempted to make collective assessments about the issues and experiences discussed. It was in these summations that the personal became political. In these moments participants assessed and shaped the collective understanding of individuals and created a base of empirical

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consciousness-raising group." The CWLU Herstory Website, 1971. (accessed April 4, 2009). This resource was accessed at the CWLU online archives, however, the manual was available via mail from 1971 on. Ms. Magazine dedicated a special issue of the magazine to the same purpose. These tools were frequently the guide from which new CR groups were formed and organized. For more information on Ms Magazine see Amy Erdman Farrell, Yours in Sisterhood: Ms. Magazine and the Promise of Popular Feminism. Chapel Hill: UNC Press, 1998.

<sup>29</sup> Shreve, Women Together, Women Alone, 12.

<sup>30</sup> *Ibid.*, 46.

<sup>31</sup> The Chicago Women's Liberation Union. "How to start your own consciousness-raising group." The CWLU Herstory Website, 1971. (accessed April 4, 2009).

<sup>32</sup> The information compiled to make this assessment came from numerous sources, but most notably the Boston Women's Health Book Collective Archives, The Chicago Women's Liberation Union Herstory Archives, and descriptions of CR groups in Shreve's Women Together, Women Alone and Brownmiller's In Our Time: Memoir of a Revolution.

knowledge. The process opened formalized knowledge to discussion, challenging authority and reshaping context into a format that allowed personal experience to intersect with general understanding.<sup>33</sup> It is here that the true value of CR is found; knowledge forged through the process came to life during collective assessment and empowered women to challenge traditional understandings of gender based systems of oppression.

For most participants the experience was deeply emotional, and while each group took on its own unique dynamic, an overwhelming number of women interviewed by Shreve look back on the experience with longing. “It is impossible not to hear in their voices, not to see in their faces, the profound impact this collective experience has had on their psyches – producing, in turn, strong feelings of gratitude, strong memories of solidarity, and often wistful longings for its return in their lives.”<sup>34</sup> CR allowed women to connect to one another on an extremely personal level that many participants were never able to replicate.

While the CR experience was intensely personal, the resulting base of knowledge extended far beyond the women who attended meetings. “Many original perceptions that pioneer consciousness-raising groups had struggled to express would become received information, routine and unexceptional, to a new generation that would wonder what [the] fuss and excitement was all about.”<sup>35</sup> This understanding of gender oppression and sexism, while revolutionary to CR group participants, had become widely accepted within a single generation. The exposure women gained in “critical areas of adulthood –

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<sup>33</sup> Gareth Williams and Jenny Popay, “Lay knowledge and the privilege of experience.” In Challenging Medicine, edited by Jonathan Gabe, David Kelleher, and Gareth Williams. New York: Routledge, 1994, 118-119.

<sup>34</sup> Shreve, Women Together, Women Alone, 195.

<sup>35</sup> Brownmiller, In Our Time: Memoir of a Revolution, 79 – 80.

sexuality, marriage, work, and motherhood” became commonplace information. The isolation of an unhappy marriage and the reality of domestic violence were no longer issues that were suffered alone; rather, they had been brought to the surface and exposed as social phenomenon that required attention.<sup>36</sup> However, without CR connecting personal realities and feminist issues this enlightenment would never have been so quickly ingrained into mainstream thought.

By the mid to late 1970’s participation in CR groups was beginning to slow significantly. The social, political and economic climate of the United States was evolving, and women were ready to take advantage of the new opportunities that developed. Many CR participants moved on from their group to join feminist organizations, while life changes impacted the availability of younger participants. As the women’s movement made headway, opportunities in education and the workforce began to materialize. Taking advantage of these new possibilities required a significant shift in lifestyle. CR had empowered individuals to pursue their interests and achieve their goals, but dedication to these tasks limited their ability to meet collectively with other women.

Reduced availability did not translate into a decreased desire for the education and support generated by consciousness raising. However, as the number of participants in face-to-face groups dwindled, women sought alternative avenues to attain similar benefits. Historians have typically examined CR exclusively as a group oriented, face-to-face practice, and alternative methods have not been explored with any depth. This lack of attention does not indicate a discontinuation of CR. Rather than engaging in weekly discussion, women engaged authors through reading, communicated via letters, and

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<sup>36</sup> These issues were among many addressed during CR group meetings. Topics covered a wide variety of issues, all directly related to the lives of the women in the group, and all questions were a source of learning.

eventually connected to CR through electronic communication over the internet. The practice of consciousness raising did not disappear from the American landscape; it evolved to meet the changing needs of women. The ability of CR to support and unite women did not fade, only the opportunity for face-to-face participation.<sup>37</sup>

Some women realized the benefits of CR through interaction with feminist literature. The Boston Women's Health Collective, for instance, produced a book, *Our Bodies, Ourselves* based initially on their own experiences with the medical establishment. Reading this book, which eventually appeared in 31 editions, replicated the CR experience for many women who gained shared understanding even as they sat alone at their kitchen tables.<sup>38</sup> The inclusion in the book of personal stories about medical experiences created a connection between readers and the text. Furthermore, readers participated in the process, adding understanding by writing letters to the book's authors and editors. These letters shaped the contents of future editions of *Our Bodies, Ourselves* by adding to the authors' base of knowledge and by demanding attention to issues that the original authors had not experienced themselves.

*Ms.* magazine also served as an outlet for women who sought consciousness raising via reading.<sup>39</sup> The magazine's goal was to bring feminist issues to the mainstream, and it presented political perspectives on the lives of women each month. Readers again participated in the process through letters to the editors and surveys that gathered

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<sup>37</sup> Shreve, *Women Together, Women Alone*, 33.

<sup>38</sup> Wendy Kline, "'Please Include This in Your Book': Readers Respond to *Our Bodies, Ourselves*," *Bulletin of the History of Medicine* 79, no. 1 (2005): 89-90. "The Global Translation/Adaptation Program: Frequently Asked Questions - *Our Bodies Ourselves*," July 2009. <http://www.ourbodiesourselves.org/programs/network/faq.asp>. (Accessed July 29, 2009) In addition, *Our Bodies, Ourselves* has been published in 25 languages.

<sup>39</sup> For more information on *Ms.* Magazine as a source of CR see Amy Erdman Farrell.

significant information from large numbers of women.<sup>40</sup> The ability to attain CR through text-based modes of communication was a significant step in the evolution of practices that will be examined in depth later in this project. While a thorough analysis of the relationship of the readers and authors of *Our Bodies, Ourselves* will be detailed in a later chapter, it is important here to note that text-based communication allowed women to participate in consciousness raising even as personal and professional schedules no longer allowed them the time to meet with a CR group.

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<sup>40</sup> A survey on menopause, for instance, was published in *Ms Magazine* for the Boston Women's Health Book Collective in an attempt to gain collective insight on menopause for a revision to *Our Bodies, Ourselves*. Responses can be found in box 105 NOBOS, Schlesinger Library.

## PRESS SEND: Digital Methods of Communication

In 1968, as Kathie Sarachild presented “Radical Feminist Consciousness Raising,” the U.S. Department of Defense was recruiting scientists to create the Advanced Research Projects Agency Network, or ARPANET, the technology from which the internet was born.<sup>41</sup> ARPANET was developed to facilitate the easy transmission of information and computer programs to decentralized military stations, and usage was originally limited to military personnel.<sup>42</sup> The technology remained primarily a military tool into the 1980’s when it was introduced to computer related departments of study at several U.S. universities.<sup>43</sup> In 1983, an early form of internet accessible by the general public was introduced, however, this incarnation would be unrecognizable to most modern users.<sup>44</sup> Dependent on an entirely text-based interface, the system was difficult to use without formal training.<sup>45</sup>

The early years of ARPANET, much like the early development of CR, saw rapid increases in participation and practice. The first e-mail communication was delivered in 1972, the following year face-to-face CR groups were meeting in peak numbers.<sup>46</sup> Three years later, as face-to-face practice was beginning to decline in favor of text-based resources, the first listserv communication, a subscription based email service, was

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<sup>41</sup> Susan C. Herring, “Computer-Mediated Communication on the Internet.” In *Annual Review of Information Science and Technology*, edited by B. Cronin, 36:109-168. Medford, NJ: Information Today, Inc, 2002, 110.

<sup>42</sup> Susan C. Herring. “Gender and Power in On-line Communication.” In *The Handbook of Language and Gender*, edited by Janet Holmes and Miriam Meyerhoff. Boston: Blackwell, 2003, 203.

<sup>43</sup> Herring. “Gender and Power in On-line Communication” 203.

<sup>44</sup> Ibid.

<sup>45</sup> Ibid.

<sup>46</sup> Susan C. Herring, “Slouching Toward the Ordinary: Current Trends in Computer-Mediated Communication.” *New Media & Society* 6, no. 1 (2004), 29.

successfully delivered.<sup>47</sup> Unlike CR, however, advances made in the ARPANET technology made it easier to use, requiring less time to complete the same tasks. In 1988, at a time when CR existed primarily as a text-based practice, the first real-time web-based chat was held.<sup>48</sup> In 1991, the World Wide Web was introduced and two years later graphical browsers were launched, which created a visual backdrop for online activities.<sup>49</sup>

The purpose of ARPANET was first and foremost a means of information exchange. Thus, it is no surprise that internet based methods of communication, or computer-mediated communication (CMC) were among the first technologies utilized over the web.<sup>50</sup> CMC is a text-based communication composed and read via a digital interface.<sup>51</sup> As people became more familiar with CMC, its use was adopted widely by Americans; email, discussion groups, message boards, instant messaging, blogging and even text messaging are all commonly used forms of CMC. As these digital methods of communication advanced they simultaneously became more interactive and easier to use, resulting in increased rates of adoption.<sup>52</sup> This is due in large part to rapid technological advancement. According to Susan Herring, “Two internet-wide technological trends have affected broadly online communication practices over the past five years (1999 -2004): increased bandwidth, and a growing tendency for different forms of CMC to be made available through web browsers interface.”<sup>53</sup> Faster connection to the internet, and the

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<sup>47</sup> Herring, “Slouching Toward the Ordinary: Current Trends in Computer-Mediated Communication,” 29.

<sup>48</sup> Ibid.

<sup>49</sup> Herring, “Gender and Power in On-line Communication,” 203.

<sup>50</sup> Herring, “Slouching Toward the Ordinary: Current Trends in Computer-Mediated Communication,” 24.

<sup>51</sup> Ibid., 31.

<sup>52</sup> Ibid., 30.

<sup>53</sup> Ibid.



resulting decrease in wait times coupled with an ever increasing ease of use allowed the rapid infiltration of CMC into the communicative practices of Americans.

Computer-mediated communication has the potential to bridge communication gaps in a number of ways. CMC's text-based format creates a conversation that allows users to develop thoughts and edit and refine commentary to ensure effective communication. This allows the user to control the tone and meaning of conversation. In addition, "some users feel more comfortable communicating intimately via CMC, and prefer it to face-to-face interaction, in which they might not have such conversations at all."<sup>54</sup> CMC serves as the platform for modern CR. While CR began in face-to-face group meetings, it evolved to adapt to the changing demands of women's lives. First, CR practice shifted towards a primarily text-based system of communication as women accessed the benefits of consciousness raising by reading literature that was rooted in fact and incorporated personal experience into the narrative. Communication and clarification was conducted through letter writing. This system allowed access to CR at varied intervals and times, but it also had built in delays. While it provided greater flexibility for individuals, it also took a greater amount of time to achieve the kind of collective interaction that happened immediately at face-to-face groups. Texts offered only a one way conversation and letter writing, while interactive, took time as letters were mailed, responded to, and the answer returned. CMC resolved these issues in a way that is reminiscent of face-to-face meetings.

While CR can occur through a variety of CMC, this thesis will examine primarily the potential of discussion board and blog formats. Medical support and education websites use these forms of CMC to create a community culture that leads to effective

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<sup>54</sup> Herring, "Computer-Mediated Communication on the Internet," 134.

CR on a variety of medical conditions. This study examines specifically breast cancer websites to highlight this connection. Breast cancer focused websites were selected because the disease strikes primarily women, thus the community of users is predominantly female. Traditional CR originated as a tool for women to support and educate one another, which its modern incarnation continues to reflect. As such the disease provides a cohort for examination that will be similar to participants in previous modes of CR.

### **DEVELOPING DIGITAL AGENCY: Consciousness Raising in the Blogosphere**

The face-to-face CR experience was deeply emotional and created a strong bond among participants who discussed very personal and private matters. Thus, for web based communication to serve in this capacity, community bonds must be formed.<sup>55</sup> The organization of web-based groups must provide the framework for and support of the community, but they must also allow it to develop on its own, to let the community to function in an emotionally and socially meaningful way.<sup>56</sup> Online bulletin boards are an excellent way to accomplish this. Bulletin boards are online sites for open discussion.<sup>57</sup> They are organized into broad subject areas called forums or message boards, with each divided into specific discussion topics and individual communications called posts.<sup>58</sup> The organizational structure of these technologies is less restrictive to participants and allows them to create threads dealing with nearly any subject area.<sup>59</sup> Reflective of face-to-face CR this technology provides all group members equal opportunity to participate in discussion.

As the message boards on medical support and education websites are tailored specifically to the affected group, they are able to create a positive on-line community of their own. According to Christina Koenig, the head of media relations for the online support group Breast Cancer Network of Strength, this structure is a tremendous asset for

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<sup>55</sup> Anthony Paul Cohen, "Editor's Forward." In *The Symbolic Construction of Community*, edited by Peter Hamilton, 7-10. New York: Routledge, 1985..

<sup>56</sup> Douglas Schuler, *New Community Networks: Wired for Change*. New York: Addison-Wesley, 1996, 253.

<sup>57</sup> "General Forum Usage." vBulletin Community Forum .  
[http://www.vbulletin.com/forum/faq.php?faq=vb3\\_board\\_usage#faq\\_vb3\\_forums\\_threads\\_posts](http://www.vbulletin.com/forum/faq.php?faq=vb3_board_usage#faq_vb3_forums_threads_posts) .  
 (accessed April 19, 2009.)

<sup>58</sup> Ibid.

<sup>59</sup> Threads are a collection of posts that resemble a conversation online. For example see pages 50-2.

women.<sup>60</sup> "You keep a brave face for your family and your friends and workmates and for your children, and it's wonderful to be able to talk to people like you who have been where you are now, it's anonymous, it's honest and it's immediate."<sup>61</sup> The online format allows women to connect to the emotional and educational benefits of CR in a way that is reflective of modern technology and personal time constraints. Similar to the text-based format of books, magazines and letter writing, web-based resources can be accessed as time allows, saved for later and returned to as necessary. CR that occurs via this computer mediated format manages to provide the ease of text-based CR with the deep emotional connection and the immediacy of face-to-face CR.

The primary purpose of these boards is to offer support to those affected by breast cancer; however, they also serve as a public health resource. Douglas Schuler discusses six key elements that computer-based community networks can employ to effectively communicate health information. The elements, defined by CHESS (Comprehensive Health Enhancement Support System) at the University of Wisconsin include accessibility, convenience, comprehensibility, timeliness, nonthreatening and anonymity.<sup>62</sup> The medical and health related information provided by Breastcancer.org successfully incorporates all of these criteria to more effectively communicate this information to those in need. The message boards at Breastcancer.org have dedicated forums for those who do not have the disease themselves but may be at risk, serve as caregivers, or are looking to educate themselves on breast cancer.<sup>63</sup> In this respect the site holds value as a source of public health information. By providing discussion areas for

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<sup>60</sup> Janet Guttman, "WITNESS: Virtual friends in a cancer world ." News agency. *Reuters*, July 7, 2008. <http://www.reuters.com/article/healthNews/idUSL0422908320080707>.

<sup>61</sup> Ibid.

<sup>62</sup> Schuler, *New Community Networks*, 152-3.

<sup>63</sup> "Discussion Boards." *BreastCancer.org*, (accessed November 10, 2008).

preventative practices and education on symptoms or genetic predisposition

Breastcancer.org serves a dual purpose. It has the potential to educate those who do not have breast cancer while offering support and health literacy for those afflicted with the disease.

The message boards are an informational center, where women can go to access and discuss medical information as it relates to their lives. Interaction with the group helps women understand their experiences and develop their own sense of breast cancer. Involvement in the online community becomes an extremely personal method for developing a conception of what lies ahead. By providing women with medical and experiential knowledge, these resources help create advocates for women's health. Advocacy that occurs in this fashion could be categorized in the scope of Berger's community work.<sup>64</sup> Active involvement in dialogue on breast cancer issues and sharing personal experiences enables others to better navigate the health care process. While this does not generally lead to legislative change it improves quality of life for women struggling with breast cancer.

Internet resources like Breastcancer.org increase health literacy on an issue that for many is unfamiliar and often difficult to understand. Patients who learn they have breast cancer do not always understand the details of their diagnosis. Medical professionals speak in technical terms which can be difficult to comprehend. Susan's story provides an example of the power of medical support and education websites. At 26, Susan was diagnosed with breast cancer. She felt that her doctor simply failed to provide her the information needed to understand her diagnosis and so she turned to the

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<sup>64</sup> Michele Tracey Berger, Workable Sisterhood: The Political Journey of Stigmatized Women with HIV/AIDS, 8.

message boards at Breastcancer.org. Susan provided what little information she knew and asked the group to help her create a list of questions that would generate clarity. Within hours the list was produced, complete with explanations of why each question was important and what information she should look for in response.<sup>65</sup> Susan reached out to this CR community and found immediate support, education and empowerment. “Your words today are great, I have my pre op today and you have given me the strength to go in guns blazing!”<sup>66</sup> Within 24 hours Susan’s outlook had been transformed, and she was able to use the group’s experience to increase personal understanding of her diagnosis and demand answers from her doctors. These sites help bridge the knowledge gap between doctor and patient and help women understand their cancer and how to discuss their illness. The process is empowering as it allows women to take control of their healthcare. Learning from others with similar experiences advances individual and collective agency. In fact, the shared experience serves as a unifying force for the women who utilize these websites and creates an environment for open and uncensored discussion of very personal issues.

Susan’s story offers just a single example of CR’s ability to empower. Her interaction with an online support group helped Susan acquire the knowledge she desired. A comparative analysis of the practice of the Boston Women’s Health Book Collective through *Our Bodies, Ourselves* and what occurs via web-based communication at Breastcancer.org will solidify the connection between CR and advocacy for women’s health. By raising awareness and providing experiential medical knowledge, CR participants are improving quality of life, reducing stress and empowering women who

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<sup>65</sup> “Breast Cancer at 26.” Just Diagnosed, April 21, 2009.

<http://community.breastcancer.org/forum/5/topic/732838>. (Accessed April 22, 2009.)

<sup>66</sup> Ibid.

suffer from breast cancer. In their efforts to provide this support, the community on Breastcancer.org navigates the politics between the cracks. The format of this site allows women to find both emotional support and health information as they have time. This allows them to accomplish tasks that are time sensitive first and still manage to see to their personal needs as it fits into their schedule. The knowledge gained through participation translates into an educated approach to health decisions. Women apply the health literacy gained through group discussion at Breastcancer.org to their personal reality, which includes more than simply a treatment plan. Group participation can provide ideas on how to discuss the disease with children, holistic approaches or even where to find a wig that does not itch. Breastcancer.org, much like *Our Bodies, Ourselves*, provides an outlet for answers not readily available in most personal networks.

On-line interaction empowers women to become medical advocates when they share their knowledge and experience on support sites. This participation is grassroots advocacy in action; users become involved in a virtual community and increase health literacy among lay participants. Posts on the discussion boards frequently address the need for clarification of medical diagnoses, side effects of prescription medications, even questions about lifestyle changes and healthy eating.<sup>67</sup> Conversations are not clinical; in fact these virtual communities develop their own terminology for medical symptoms and side effects. Terms like “chemobrain”<sup>68</sup> and “metalmouth”<sup>69</sup> are descriptive and easy to relate to and help explain an experience that has occurred or should be anticipated.

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<sup>67</sup> There are a significant number of discussions that would fall under this description. Some of the most significant in making this analysis were accessed on November 8, 2008 and can be found at <http://community.breastcancer.org/forum/6> or <http://members.boardhost.com/eating/>.

<sup>68</sup> Breast Cancer Topic: Tips for Getting Through Chemotherapy. Post made December 6, 2006. <http://community.breastcancer.org/forum/69/topic/478386> An article on the medical study of chemo brain appeared Jane Gross, “Lingering Fog of Chemotherapy Is No Longer Ignored as Illusion,” The New York

Wyatt Galusky, in his examination of online activism in the environmental anti-toxin movement, explains this phenomenon thusly; “The internet gives people time to be activists, by making data, expertise, connections, and intervention strategies available all in one place... For those ‘enabled’ by technology, they can use it to accomplish tasks and gather information more quickly.”<sup>70</sup> The particular support sites examined here are working to change the cultural experience of those diagnosed with breast cancer. The ease of access to information creates an environment where information can be exchanged and is used by real people taking charge to address real needs, which becomes an effective form of advocacy.<sup>71</sup> On-line communities provide medical information for the benefit of all and use the availability of this information to help guide others through what can be a difficult process, while cultivating more people who can support, teach and empower. Douglas Schuler refers to this as a community network. The recent adoption of computer based community networks “are intended to help revitalize, strengthen, and expand existing people-based community networks in much the same way that previous civic inventions have helped communities historically.”<sup>72</sup> Discussions that occur on sites like Breastcancer.org serve as modern community networks that build collective awareness and offer much needed support.

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Times, April 29, 2007, sec. Section 1; Column 4; National Desk; Pg. 1, [http://www.lexisnexis.com.proxy.libraries.rutgers.edu/us/lnacademic/frame.do?tokenKey=rsh-20.138904.76902288894&target=results\\_listview\\_resultsNav&reloadEntirePage=true&rand=1226373502500&returnToKey=20\\_T5079608939&parent=docview](http://www.lexisnexis.com.proxy.libraries.rutgers.edu/us/lnacademic/frame.do?tokenKey=rsh-20.138904.76902288894&target=results_listview_resultsNav&reloadEntirePage=true&rand=1226373502500&returnToKey=20_T5079608939&parent=docview) (accessed November 10, 2008).

<sup>69</sup> Post made April 13, 2008, 11:59 am. “Breast Cancer Topic: Spring 2008 TCH Gals “get together”.” Discussion Board. *BreastCancer.org*. <http://community.breastcancer.org/forum/6/topic/704254> (accessed November 1, 2008).

<sup>70</sup> Wyatt Galusky, “Identifying with Information: Citizen Empowerment, the Internet, and the Environmental Anti-Toxins Movement,” in *Cyberactivism*, ed. Martha McCaughey and Michael D. Ayers (New York ; London: Routledge, 2003), 192.

<sup>71</sup> *Ibid.*, 201.

<sup>72</sup> Schuler, *New Community Networks*, 25.



The face-to-face consciousness raising groups of the 1960's and 1970's brought women together to "discuss and search for similarities among their personal experiences."<sup>73</sup> In her work on CR, Wertz examines primarily the psychological impact participation in a consciousness raising group had on the women involved, and identifies increased self-esteem, reduced depression and an increased sense of control over their lives as important benefits.<sup>74</sup> Yet face-to-face CR groups confronted serious challenges that inhibited participation, including the difficulties of scheduling times to meet and the geographical distance among members. Web-based support groups do not confront the same challenges, yet are able to provide support without a significant drop off in effectiveness. In fact, Andrew J. Winzelberg et al, in the study "Evaluation of an Internet Support Group for Women with Primary Breast Cancer" finds that interaction is similar to a face-to-face group, and that "improvement in depression and the reduction of perceived stress are consistent with other studies of face-to-face groups." Not only do web-based support groups have the ability to eliminate several important obstacles that could prevent women from becoming involved, but the interaction remains just as meaningful. Journalist Janet Guttman recounts her own use of a web-based support group: "I don't know their real names, and they don't know mine, yet over the next weeks and months this virtual support network kept prodding me for news, and reminding me that they were rooting for me at every step of the way."<sup>75</sup> She was able to connect with these women and find genuine and immediate support much the way she would in a face-to-face group.

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<sup>73</sup> Rose Wertz, "Feminist Consciousness Raising, Self-Concept, and Depression," *Sex Roles* 8, no. 3 (March 1982): 231.

<sup>74</sup> *Ibid.*, 231-41.

<sup>75</sup> Guttman, "WITNESS: Virtual friends in a cancer world."

This chapter has set forth the foundation for understanding the evolution of consciousness raising. The next chapter will provide evidence of both early face-to-face and later web-based CR. The utilization of a comparative case study creates a parallel of historical face-to-face engagement and the contemporary rebirth of the practice. The study will examine key characteristics of CR as practiced by the Boston Women's Health Book Collective which will then serve as a framework for evaluating the community discussions held on Breastcancer.org. Additional sections are dedicated to identifying key challenges inhibiting effective online CR practice. This section focuses on communications barriers as well as issues of web diversity, and juxtaposes these challenges against their face-to-face incarnations. Finally, I explore the value of online CR and the Boston Women's Health Book Collective's adoption of web based resources.

## Chapter 2: The Evolution of Women's Health Literacy

### FROM LIVING ROOM TO CHAT ROOM: Women Raising Consciousness Across Time

The Boston Women's Health Book Collective was part of a larger social movement that advocated for institutional changes to women's health care. The text, they created, *Our Bodies, Ourselves*, described a feminist form of health care and encouraged women to insist upon proper treatment from medical professionals.<sup>76</sup> "Although it is impossible to measure its impact precisely, *Our Bodies, Ourselves* has been a major influence in informing a generation of women about how to take charge of their own health care."<sup>77</sup> The larger movement, of which this book was a meaningful part, demanded significant change and helped to restore trust in health care for women. The type of activism that *Our Bodies, Ourselves* stimulated led to the creation of the National Women's Health Network. The decades following the text's original publication in 1970 saw a marked increase in the number of female doctors and more discussion of health issues specific to women. The movement led to considerable changes in institutional medicine: "much of what was controversial when it first appeared in *Our Bodies, Ourselves* is now supported by mainstream medical organizations such as the Institute of Medicine."<sup>78</sup> Research funding for women's diseases increased, more women were included in clinical trials, and new methods of labor and delivery were developed.<sup>79</sup>

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<sup>76</sup> Judy Norsigian "Oral history interviews, 1998-1999 (inclusive)," interview by Kathy Davis. Schlesinger Library.

<sup>77</sup> Robert H. Keefe, Sandra D. Lane, and Heidi J. Swarts. "From the Bottom Up: Tracing the Impact of Four Health-Based Social Movements on Health and Social Policies." *Journal of Health and Social Policy* 21, no. 3 (2006): 60.

<sup>78</sup> Nancy W. Brickhouse "Embodying Science: A Feminist Perspective on Learning" *Journal of Research in Science Teaching* Vol. 38, No 3. (200): 290. Linda Gordon & Barre Thorne "Women's Bodies and Feminist Subversions" *Contemporary Sociology* Vol. 25, No 3 (May 1996): 324.

<sup>79</sup> Ibid.

These advances and this restoration of trust set the stage for resources such as Breastcancer.org.

This study examines only the portion of Breastcancer.org that nurtures the CR experience, the web-based community that interacts via a bulletin board system. The message boards at Breastcancer.org, which are housed in a portion of the site labeled “Community Knowledge,” operate without direct interaction from the site administrator. Rather community discussions are derived from the thoughts and experiences of women who engage the group. Content is peer reviewed as stated in the Community Rules: posts made to the discussion board “are not edited, censored, or otherwise controlled by Breastcancer.org. Breastcancer.org does not and cannot screen content provided by you or other users.”<sup>80</sup> So while the Breastcancer.org website has areas that are dedicated to traditional top down distribution of medical information, the message boards function in a separate sphere and a different mode. It is here that the CR practice brought to life by radical feminist organizations in the late 1960s still helps women today. A reconfigured web-based format has duplicated the benefits -- sisterhood, education, and awareness building - in a way that is widely accessible and always available.

In order to highlight the potential impact of early CR groups, I have selected one of the most successful and long lasting for analysis, the Boston Women’s Health Book Collective.<sup>81</sup> The Collective grew out of a workshop offered by Nancy Miriam Hawley on “Women and Their Bodies” at a women’s liberation conference held in May 1969 at Emmanuel College in Boston.<sup>82</sup> The participants came to realize that many women felt

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<sup>80</sup> “Community Rules” <http://community.breastcancer.org/help/rules> (accessed May 30, 2009)

<sup>81</sup> Kathy Davis, *The Making of Our Bodies, Ourselves* (Durham: Duke University Press, 2007), 87.

<sup>82</sup> Sara Rimer, “They Talked and Talked, and Then Wrote a Classic.” *New York Times*, June 22, 1997, sec. Women's Health.

they did not receive adequate health care, and that an overall lack of medical knowledge kept them from finding better treatment.<sup>83</sup> The workshop was scheduled to last two hours, but with the discussion still full of steam, Hawley offered to continue the conversation after the conference.<sup>84</sup> “We had all experienced similar feelings of frustration and anger toward specific doctors and the medical maze in general, and initially we wanted to do something about those doctors who were condescending, paternalistic, judgmental and non-informative.”<sup>85</sup> The group met to create a list of doctors who not only listened to their patients, but explained medical procedures and medications, doctors who would be a “partner in health care.”<sup>86</sup> Despite their best efforts, participants were unable to create such a list, but they refused to sit in idle dissatisfaction.<sup>87</sup>

Members agreed to continue meeting over the course of a summer. In addition, each participant researched a women’s health issue of personal importance and brought the information to the group. Information was uncovered by any means possible: “women did research and either talked to doctors who were willing to talk English, talked to nurses, who are much better at communicating, or got medical dictionaries and demystified and translated for themselves and so there was clear information given in a

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<sup>83</sup> Judy Norsigian, Vilunya Diskin, Paula Doress-Worters, Jane Pincus, Wendy Sanford, and Norma Swenson. “The Boston Women’s Health Book Collective and Our Bodies, Ourselves: A Brief History and Reflection.” *Journal of the American Medical Women's Association* 54 (Winter 1999), 35.

<sup>84</sup> Nancy Miriam Hawley, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis. Vilunya Diskin, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis, December 2, 1998, Schlesinger 2006-M119--2006-M154, Schlesinger Library.

<sup>85</sup> Sanford, Wendy, and Boston Women's Health Book Collective. “A Good Story (Intermediate version),” ca.-1979 1974. Box 1 Folder 2. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts, 2.

<sup>86</sup> Sara Hayden, “Re-claiming Bodies of Knowledge: An Exploration of the Relationship between Feminist Theorizing and Feminine Style in the Rhetoric of the Boston Women’s Health Book Collective,” *Western Journal of Communication* 61, no. 2 (Spring 1997): 135. Nancy Miriam Hawley, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis.

<sup>87</sup> Wendy Kline, “‘Please Include This in Your Book’: Readers Respond to Our Bodies, Ourselves,” 86-7.

non-patronizing and accessible way.”<sup>88</sup> The participants’ research and discussion led them to believe medical information was more valuable when examined within the context of lived experience.<sup>89</sup> The information and the perspective gained through this CR experience was used to create a medical education course that was easy to understand, a course “by and for women” that brought a feminist perspective to healthcare.<sup>90</sup> The handouts for the educational course evolved over time, becoming the text of *Our Bodies, Ourselves*.

Early on the Collective spent as much time discussing their personal lives as they did the business at hand.<sup>91</sup> This was fairly common among CR groups since they related to the feminist movement through their life experiences. The Collective had a great deal in common with most CR groups at the beginning, including the group’s overall organization.<sup>92</sup> It was loosely structured with no formal hierarchy; decisions were made by consensus rather than being handed down by an elected leader.<sup>93</sup> This lack of structure helped the group function as a collection of individuals rather than taking on the focus or shape of only one or two dominant participants. Since no one individual was in a position of authority, each dissenting argument was heard and considered, every opinion was deemed valuable.<sup>94</sup> CR groups strived but often failed to achieve a stable structure without an established hierarchy, but the Boston group did so. Members believed that discussion was as important as any decision, and their ability to function in this way

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<sup>88</sup> Wendy Sanford, “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis, CD, December 4, 1998, Schlesinger 2006-M119--2006-M154, Schlesinger Library, Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>89</sup> Kline, ‘Please Include This in Your Book’: Readers Respond to *Our Bodies, Ourselves*,” 87.

<sup>90</sup> Hayden, “Re-claiming Bodies of Knowledge,” 135.

<sup>91</sup> Davis, *The Making of Our Bodies, Ourselves*, 104.

<sup>92</sup> Eastman, “Consciousness-raising as a resocialization process for women,” 161.

<sup>93</sup> Davis, *The Making of Our Bodies, Ourselves*, 104.

<sup>94</sup> Ibid.

contributed to their longevity.<sup>95</sup> The group's long-term survival, however, may have been due to one other factor that differentiated them from most CR groups: the Collective embraced the goal of creating a book on women's health. Their commitment to challenging the exclusion of women's concerns in the medical establishment kept the group together and discussing issues of healthcare. The structure of the Boston Women's Health Book Collective allowed them to manage this process cooperatively rather than as individuals, but it was the book that differentiated them from most other CR groups.<sup>96</sup>

The reach of the Collective would eventually extend beyond the boundaries of the group. Initially, using their own experiences and research gathered from medical texts, women met weekly to discuss their findings and compile information. The results, first presented in 1970, reflected only the personal medical issues and interests of the group, which left substantial issues such as menopause and minority women's health lacking. The members of the Collective, all white women ranging in age from their 20's to 40's, did not have firsthand experience with these topics.<sup>97</sup> Like many early CR groups, the members were racially and socially similar; for the members of the Boston Women's Health Book Collective this meant white, college educated and mostly middle class.<sup>98</sup> They lacked the personal knowledge required to tackle a diverse range of issues, so many topics were simply left out of early discussions and examinations. As the purpose of the Collective changed, they set out to create an educational course that would foster health literacy among women more generally and, they began to educate themselves on a wider array of topics. Moreover, in 1970, the Collective was approached by two female

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<sup>95</sup> Davis, *The Making of Our Bodies, Ourselves*, 104.

<sup>96</sup> Judy Norsigian, "Oral history interviews 1998-1999 (inclusive)," interview by Kathy Davis, CD, October 27, 1998, Schlesinger 2006-M119--2006-M154, Schlesinger Library.

<sup>97</sup> Norsigian et al., "The Boston Women's Health Book Collective and *Our Bodies, Ourselves*: A Brief History and Reflection," 35.

<sup>98</sup> Davis, *The Making of Our Bodies, Ourselves*, 94.

employees of the New England Free Press. A small publishing house, the Free Press was interested in printing the materials used in the course for wider distribution. This, too, encouraged them to focus on issues beyond their own immediate experiences. The Collective agreed to work with the Free Press, and 250,000 copies were sold in the first year under the name *Women and Their Bodies: A Course by Women for Women*.<sup>99</sup>

The book was the means through which the Collective shared their experiential knowledge. At its very core the Collective was a CR group, but the issues they discussed and the information they unearthed was sought after by a wide audience of women in search of alternative sources of information. The audience was created in part by significant shifts in the practice of medicine that occurred in the 1960's and created an atmosphere of distrust toward the medical profession. These changes allowed women to see doctors as fallible.<sup>100</sup> As a result women wanted to be more involved in the medical decisions that affected their lives.<sup>101</sup> According to Susan Bell, an author and editor of the 1984 edition, one goal of the Collective was to "translate the conclusions of science so that women can use them to make choices..."<sup>102</sup> The work of the Collective provided a pathway to education and empowered women with the information required for active involvement in their own medical care. As individual women developed a better understanding of their illness and potential treatments, this knowledge could be used to achieve a greater degree of control over their care. Women were equipped to advocate for themselves in the doctor's office to make diagnosis and treatment a conversation, not a

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<sup>99</sup> Kline, "'Please Include This in Your Book'," The title was changed for a second printing in 1971 and became known as *Our Bodies, Ourselves*.

<sup>100</sup> Ibid., 84.

<sup>101</sup> Irving Kenneth Zola, "Bringing Our Bodies and Ourselves Back In: Reflections on a Past, Present, and Future "Medical Sociology"." *Journal of Health and Social Behavior* 32, no. 1 (March 1991), 3.

<sup>102</sup> Susan E. Bell, "Translating Science to the People: Updating The New *Our Bodies, Ourselves*," *Women's Studies International Forum* 17, no. 1 (1994): 11.



declaration. While the Boston Women's Health Book Collective functioned as a small and closely knit CR community, their discussions were distributed on a worldwide scale. The book has now been published in eight editions, has sold more than four million copies, and has been printed in eighteen languages.<sup>103</sup>

*Our Bodies, Ourselves* was written and structured in a way that replicated the experience of CR. Women reading the book felt connected to it, feeling as if they shared in the discussion.<sup>104</sup> New England Free Press asked women to do just that by including a request in the 1971 edition for personal stories and suggestions.<sup>105</sup> Wendy Kline, in her analysis of these responses, asserts that readers "perceived *Our Bodies, Ourselves* as a broader collective in which the readers as well as the writers all shared responsibility for the outcome."<sup>106</sup> The Collective received a multitude of letters, some expressing gratitude for what the book meant to them, some asking for more information, and others noting their disappointment that the information they needed was not included or was incomplete. In 1982, for instance, one woman wrote "I was treated for breast cancer last year. Because of this, I want to urge you to give some space in the new edition to the various forms of treatment, but most particularly to the lumpectomy/radiation treatment, which is now very advanced in terms of technology."<sup>107</sup> These responses indicated a strong connection between authors and readers. Letters were addressed to the authors by first name, or simply to "sisters" or "friends."<sup>108</sup> The inclusion of personal stories and

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<sup>103</sup> "Our Bodies, Ourselves: A New Edition for a New Era Fact Sheet," *Our Bodies, Ourselves*, <http://www.ourbodiesourselves.org/uploads/pdf/factsheet.pdf>. (Accessed November 22, 2008)

<sup>104</sup> Davis, *The Making of Our Bodies, Ourselves*, 90.

<sup>105</sup> *Ibid.*, 23. This information came from a group interview held by the author on July 21, 2000.

<sup>106</sup> Kline, "'Please Include This in Your Book'," 100.

<sup>107</sup> "Letter, Dear Sisters," March 20, 1982, 109.11. NOBOS, 1984. Letters, 1981-1982. Breast cancer/lumps, Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>108</sup> Cambridge, Massachusetts, Schlesinger Library, Radcliffe Institute, Harvard University, Boston Women's Health Book Collective. Records, 1905-2003 (inclusive), 1972-1997 (bulk).

firsthand accounts allowed women to connect to the text in a way that “enabled readers to experience CR at their own kitchen tables.”<sup>109</sup> By integrating life experience with medical knowledge, *Our Bodies, Ourselves* helped women better understand their bodies in a way that was similar to face-to-face CR. In a letter to the authors dated January 18, 1972, one reader suggested that reading the book inspired the desire to take part in a CR group: “It has helped me tremendously towards finding my own identity as a woman. I would like to carry my reading one step further and talk with other young women in their 20’s and 30’s about their thoughts and feelings in relation to my own. I would like to share my experiences with you and others... please let me know if I can contribute my services to you in any way.”<sup>110</sup>

Women found it very easy to relate to the text. As Kathy Davis notes in *The Making of Our Bodies, Ourselves*, “the origin story was so powerful precisely because it could stand in for similar epiphanies that were occurring across the United States. It allowed women who were not there at the very beginning to participate in shared history. It became an exemplary and infinitely repeatable story of how women became feminists.”<sup>111</sup> Kline echoes this sentiment, arguing that the inclusion of personal stories and individual voices brought to the text an element of appeal; it simply resonated with the lives of women.<sup>112</sup> In addition, the Boston Women’s Health Book Collective was comprised of women who were relatable figures. They presented themselves as ordinary individuals who together discussed issues of health and sexuality.<sup>113</sup> While the authors were not necessarily all “average” women, they offered something the average woman

<sup>109</sup> Kline, “‘Please Include This in Your Book’,” 90.

<sup>110</sup> Miller, Shari. Letter. “To the Authors,” January 18, 1972. Box 52 Folder 15. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>111</sup> Davis, *The Making of Our Bodies, Ourselves*, 91.

<sup>112</sup> Kline, “‘Please Include This in Your Book’,” 88.

<sup>113</sup> Davis, *The Making of Our Bodies, Ourselves*, 94-95

wanted: accurate and accessible medical information.<sup>114</sup> The book served as a means to distribute, into the hands of the women, information they needed and let the original CR group reach a larger audience than would have been otherwise possible.

*Our Bodies, Ourselves* allowed the Collective to transcend the spatial limitation of most CR groups. According to one reader, “my friends and I have treasured it and given it to other friends to serve as the beginning to a raised consciousness, or saved it to help our daughters grow.”<sup>115</sup> It armed women with a tool to increase health literacy and did so without the necessity of one’s physical presence in a CR group. Woman had access to critical information, and to personal stories and experiences, in a written form. More so, *Our Bodies, Ourselves* allowed the Boston Women’s Health Book Collective to do for millions what the process had done for them, change how medical information was passed on.<sup>116</sup> Evidence of an informal network of distribution can be found in the Boston Women’s Health Book Collective archives, where numerous letters detail their experience in sharing the information found in the book with others. Friends, mothers and sisters were able to borrow, loan and purchase the book.<sup>117</sup> Self education on medical issues allowed women to ask informed questions and to interact with doctors. Rather than a treatment plan dictated to them, *Our Bodies, Ourselves* empowered women to push for information and to be active in the process. After the births of her two previous children

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<sup>114</sup> The founding members of the Boston Women’s Health Book Collective were all college educated, white and financially secure, as such these women had access to resources many women would not. While it is impossible to define what is “average,” the Collective as a whole could be considered advantaged.

<sup>115</sup> Saylor, Adriane. Letter. “Sisters,” November 1, 1981. 109.17. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>116</sup> Nancy Poole, “Using Consciousness-Raising Principles to Inform Modern Knowledge Translation Practices in Women’s Health.” *Canadian Journal of Nursing Research* 40, no. 2 (June 2008): 76-93.

<sup>117</sup> Libby Bouvier, The Women’s Education Center. Letter. “Dear People,” November 21, 1974. Box 53 Folder 6. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts. The Boston Women’s Health Book Collective negotiated a 70% discount with Simon and Schuster for health clinics when purchasing the book. The Collective wanted to provide inexpensive access for the women who needed this information even with a commercial publisher.

in a hospital Ingrid Briles felt she wanted to take control of the birth of her third child. She requested information about home child-birth from her doctor, which went unanswered, and so turned to the Collective, who replied with their research on the matter.<sup>118</sup>

Irving Kenneth Zola argues that bodily experiences are a central part of personal identity and that understanding those experiences is essential to understanding the individual.<sup>119</sup> *Our Bodies, Ourselves* helped women to understand their bodies and protect them against health professionals who made diagnoses without regard to the desires of the patient. Health decisions are never strictly medical; rather treatment is a personal decision with complicated social and political ramifications.<sup>120</sup> Yet many people, including the members of the Boston Women's Health Book Collective and Zola himself, experienced a lack of consideration for the individual from medical professionals. This failure to consider the person, Zola argues, is an invalidation of personhood.<sup>121</sup> The Collective created an alternative source of medical information, one that drew on personal perspectives and took into consideration more than a diagnosis. *Our Bodies, Ourselves* actively reduced the gap in medical understanding between doctors and patients.<sup>122</sup> By providing readers an explanation of medical information that considered the experience of illness, the Collective brought a feminist perspective to healthcare that valued the individual as much as the medicine.<sup>123</sup> In some cases even professionals relied on the book as a resource. As a third year medical student Sharon

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<sup>118</sup> Briles, Ingrid. Letter. "Dear Sisters," June 19, 1976. Box 53 Folder 12. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>119</sup> Zola, "Bringing Our Bodies and Ourselves Back In ", 2.

<sup>120</sup> Ibid., 3.

<sup>121</sup> Ibid.

<sup>122</sup> Kline, 'Please Include This in Your Book', 87.

<sup>123</sup> Norsigian et al, "The Boston Women's Health Book Collective and *Our Bodies, Ourselves* : A Brief History and Reflection," 35.

Stancliff found that the language of medicine often made it difficult to communicate with her patients and turned to the book for answers. “I refer to the book often, sometimes for facts, sometimes for insight into how to speak intelligently to the women I see.”<sup>124</sup> *Our Bodies, Ourselves* thus provided both female patients and doctors with a resource to improve understanding of women’s health and how to discuss the most sensitive issues.<sup>125</sup>

Today women still desire accurate medical information in a non-clinical capacity and rely on non-traditional sources to fulfill this need. According to Judy Norsigian, “the need for good information is still at an all time high even though paradoxically there’s more stuff out there than ever. But a lot of it isn’t well balanced, a lot of it is commercial, a lot of it is misleading.”<sup>126</sup> Perhaps the most prolific alternative source of medical information today is the internet. On-line breast cancer support and education resources serve a similar purpose as *Our Bodies, Ourselves*; they increase health literacy on issues that for many are unfamiliar and difficult to comprehend. Websites help women understand their disease and how to talk about it. This is an empowering process as it allows women to take their healthcare into their own hands. By “speaking” with others who have similar experiences, these women are able to claim agency. The shared experience serves as a unifying force for those who utilize these websites and creates an environment where personal issues can be discussed in an uncensored manner.

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<sup>124</sup> Stancliff, Sharon. Letter. “Dear Women of the Boston Collective,” January 20, 1986. 110.31. Schlesinger Library, Radcliffe Institute, Harvard University, Cambridge, Massachusetts.

<sup>125</sup> Multiple letters are found in the archives from doctors addressed to the Boston Women’s Health Book Collective acknowledging the books use as a medical resource for both women’s health information and how to talk with patients about their health.

<sup>126</sup> Judy Norsigian “Oral history interviews, 1998-1999 (inclusive),” interview by Kathy Davis.

Breastcancer.org is a non-profit educational organization founded by Marissa Weiss M.D, the Director of Breast Radiation Oncology and Director of Breast Health Outreach at Lankenau Hospital in Wynnewood, Pennsylvania.<sup>127</sup> The site is dedicated to helping “women and their loved ones make sense of the complex medical and personal information about breast cancer, so they can make the best decisions for their lives.”<sup>128</sup> Breastcancer.org has a significant capacity to offer health literacy. In today’s world where information is almost instant, a quick internet search is an oft utilized and convenient way of searching for information. A Google search for “breast cancer” will list Breastcancer.org as the first resource, a Yahoo search will see the same site placed in the top five listings. This can generate a tremendous amount of traffic to the site simply by its placement in the queue of available information.<sup>129</sup> And as part of the mission of Breastcancer.org to disseminate information on breast cancer and health issues related to it, this has the potential to provide a sizable impact on those looking for accurate information on the internet. Since the goals of this site are heavily oriented around the distribution of medical information, a wide array of research and personal accounts can be found.<sup>130</sup> The community message boards are of particular importance as a venue where consciousness raising occurs among women.<sup>131</sup>

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<sup>127</sup> Elizabeth Bernstein. “Girl Talk: Early Education Eases Breast Cancer Fears.” *Wall Street Journal*, September 2, 2008, sec. Health. [http://online.wsj.com/public/article/SB122030515570188261.html?mod=2\\_1566\\_leftbox](http://online.wsj.com/public/article/SB122030515570188261.html?mod=2_1566_leftbox). “Marissa Weiss, M.D., President and Founder,” *BreastCancer.org*, August 13, 2008 [http://www.breastcancer.org/about\\_us/team/marisa\\_weiss.jsp](http://www.breastcancer.org/about_us/team/marisa_weiss.jsp). (Accessed May 9, 2009)

<sup>128</sup> “About Us.” *BreastCancer.org*, June 19, 2008. [http://www.breastcancer.org/about\\_us/](http://www.breastcancer.org/about_us/).

<sup>129</sup> Shari Thurow, *Search Engine Visibility* (Indianapolis: New Riders, 2003). A practice called search engine optimization (SEO) is used to increase the frequency a website appears in web searches. By editing web content to include keywords that people use in their web search it becomes more likely that a webpage will appear in the queue of information.

<sup>130</sup> “About Us.” *BreastCancer.org*, June 19, 2008. [http://www.breastcancer.org/about\\_us/](http://www.breastcancer.org/about_us/).

<sup>131</sup> See p 19 PRESS SEND: Digital Methods of Communication for analysis of the importance of community discussion as a site for CR.

The layout of Breastcancer.org is modern and easy to navigate. Women who arrive at the site in search of discussion and support will find direct links to these areas placed on the home page. The same holds true for users looking for the latest news on breast cancer research or basic information on symptoms; they also have forum pages in the “Community Knowledge” section. Ease of use is important; to function as a support and education resource, information must be accessible. Each unique visitor, particularly first-time users, must be able to find the information they want. The “Forum Index” contains a listing of all the message boards grouped according to their purpose.<sup>132</sup> Women who are concerned about future problems with breast cancer can easily find discussion on this topic in boards labeled “Not Diagnosed but Concerned,” while a woman looking to connect to others with the same type of cancer will be able to do so on the forums labeled “Connecting With Others Who Have a Similar Diagnosis.”<sup>133</sup> The site contains over fifty unique forums for communication that make searches as accessible as possible.<sup>134</sup> As a result, Breastcancer.org has fostered a community that is robust and active.<sup>135</sup> The discussion boards have over 42,000 registered users,<sup>136</sup> and in excess of 22,000 discussion threads<sup>137</sup> that provide ample opportunity for women to foster a relationship with their “cybersisters.”<sup>138</sup> The forum index provides a general description

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<sup>132</sup> “Forum Index” Breastcancer.org Discussion Boards. <http://community.breastcancer.org/> (Accessed June 1, 2009)

<sup>133</sup> Ibid.

<sup>134</sup> This includes both discussion boards and chat rooms.

<sup>135</sup> On November 1, 2008 at 5:52 p.m. twenty nine of the forty nine boards available had been utilized in the last hour, and an additional twelve had been used in the last twenty four hours, over eighty percent used in one twenty four hour period. On February 16, 2009 at 4:40 p.m. 20 of the 49 boards available had been used in the last hour, and over ninety percent used in the last 24 hours.

<sup>136</sup> “Breast Cancer Treatment Information and Pictures,” BreastCancer.org, <http://www.breastcancer.org/>. (Accessed October 27, 2008)

<sup>137</sup> Janet Guttsman. “WITNESS: Virtual friends in a cancer world.” News agency. *Reuters*, July 7, 2008. <http://www.reuters.com/article/healthNews/idUSL0422908320080707>.

<sup>138</sup> “Discussion Boards.” Discussion Board. *BreastCancer.org*, October 30, 2008. <http://www.breastcancer.org/community/discussion/>. (Accessed November 30, 2008.)

of the boards included in each heading, which are further divided into individual threads. The forum index serves a purpose similar to that of the table of contents in *Our Bodies, Ourselves*. The table of contents at the front of the book offers a quick reference guide for finding particular information. Additionally, much like the individual discussion threads at Breastcancer.org the book was divided into chapters that highlighted certain health issues or problems.

The authors of *Our Bodies, Ourselves* worked to create an informational text that was medically accurate and told from a feminist perspective. Through extensive research the Collective was able to shape their findings into a form that was easily understood. They challenged modes of information distribution and questioned the paternalistic nature of medicine in an effort to acquire trustworthy information. Information from their own lived experience, medical journals, nurses, and, at times, doctors were all relied on.<sup>139</sup> Because the Collective initially faced great difficulty in acquiring the most current medical information, members had to use every possible resource to their advantage.

Group participants on Breastcancer.org have significantly more access to current medical findings than the Collective was able to gain. Technological advances have increased the availability of information and the speed with which it is distributed. The internet is a valuable resource in the search to acquire new sources and study results. At Breastcancer.org women post internet links and stories related to current medical findings on the “Clinical Trials, Research, News, and Study Results” discussion board. The board provides a place for the community to relay and discuss findings in a personal context. Jessica for example gained access to and posted a news item regarding a medical study

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<sup>139</sup> The doctors they worked with often practiced at clinics, were educators, women, or were feminist. Over time the medical profession saw the value of *Our Bodies, Ourselves* and doctors became regular contributors of content.



presented just hours earlier at a breast cancer conference. The article detailed a study indicating that use of specific antidepressants “can virtually wipe out the benefit Tamoxifen [A frequently prescribed breast cancer medication] provides.”<sup>140</sup> The post started an immediate discussion of the impact of the study’s results on individual participants. Robin was able to use this information to her immediate advantage. “Wow! Thank you for posting this! I have spent the afternoon doing research on this issue, since I was told about it. This article is just what I needed to know. I take Paxil for anxiety and have been for years, and I was trying to decide whether to take Tamoxifen or not. Thanks!”<sup>141</sup> The article offered critical insights to help Robin make difficult personal choices as she sought to improve her individual medical outcomes.

Breastcancer.org specializes in providing both emotional support and accurate medical information. The website provides an array of resources on the topic of breast cancer that allows women to make informed decisions, and also serves as a platform for educational discussion and emotional support. In this regard, Breastcancer.org and *Our Bodies, Ourselves* serve a similar purpose. They disseminate information to increase women’s health literacy in readily available formats. Breastcancer.org provides medical information and a venue for collective discussion. Conversations that occur provide the individual narratives necessary to connect personal experience to the gender based politics of health care. Additionally, the structure of the online community creates a system of inherent emotional support as women utilize the site and become familiar with

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<sup>140</sup> “BC Survivors May Risk Relapse with Certain Drug Combos” Clinical Trials, Research, News, and Study Results, May 30, 2009. <http://community.breastcancer.org/forum/73/topic/735046> (Accessed June 1, 2009)

<sup>141</sup> Ibid.

other participants. Frequent users quickly take an active interest in the personal experiences; the successes and failures of other participants.<sup>142</sup>

The site functions as a CR group in that it provides a forum for women to collectively share life experiences and to use them to develop critical perspectives on dominant institutions like science and medicine. A thread started by Charlotte in the “Clinical Trials, Research, News, and Study Results” discussion board highlights how online collective discussion can lead to CR. Charlotte posts links to several studies that contradict other medical studies as it relates to breast cancer. She poses the question “who are you to believe?”<sup>143</sup> The discussion that follows connects personal experience to the politics of medicine. Theresa comments on the influence of funding upon published results explaining that “bias is showing in too many research papers.”<sup>144</sup> Andrea provides personal insight from her experience working in the pharmaceutical research field, claiming that “unless the drug looks like it could be profitable (prescribed by lots of physicians), the study rarely gets off the ground.”<sup>145</sup> The conversation turns to the side effects of prescription medication, and doctor’s failure to sympathize with patients, and more importantly what patients can do about it.

I can not believe how belittled the side effects from Tamoxifen, Arimidex, Femera etc. are in a large part of the research and medical community, at least until recently. So raising this issue with the drug companies and our doctors and nurses is a must do. One of the ladies in the hormone thread recently called AstraZenaca and complained about tendon pain, and the company actually

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<sup>142</sup> Examples of supportive relationships rapidly appearing are numerous on support and education websites. See “please help,” Just Diagnosed, September 11, 2007, <http://community.breastcancer.org/forum/5/topic/692045?page=1>. (Accessed February 21, 2009) and “When does it feel real,” Just Diagnosed, May 9, 2009, <http://community.breastcancer.org/forum/5/topic/733918> (Accessed May 15, 2009) for examples.

<sup>143</sup> “Disgusted with research articles - anyone else?” Clinical Trials, Research, News, and Study Results, July 21, 2007. <http://community.breastcancer.org/forum/73/topic/735046> (Accessed June 2, 2009)

<sup>144</sup> Ibid. Posted July 22, 2007 by Theresa.

<sup>145</sup> Ibid. Posted July 22, 2007 by Andrea.

asked for more calls and confirmed trigger finger is a side effect of these drugs. They say they may do a study on this. I hope it's not just p.c. PR!<sup>146</sup>

This discussion is fundamentally similar to traditional CR practice; experiential knowledge is shared and evaluated leading to group understanding of the experience and its social context. The discussion evolves as each new participant adds her own perspective. Over time the group formulates a shared understanding of the problem and provides commentary on what individual women can do to fight against it. Kline argued “the emotional expressiveness” of letters written to the authors of *Our Bodies, Ourselves* “reveals readers desire to be part of a virtual community of health feminists, from locations all over the United States.”<sup>147</sup> The same can be said of conversations that occur on support and education discussion boards. The emotionally charged conversations are reflective of a group interested in participating in a virtual community dedicated to health issues. Breastcancer.org serves as a cyber living room where users gather to engage in dialogue on health care as it relates to their lives. It has expanded the conversation so it is held simultaneously in homes, public libraries and internet cafes, making every computer with access to the internet a potential site of CR.

Tracy L. M. Kennedy labels CR that occurs in this fashion “feminist virtual consciousness-raising.”<sup>148</sup> She argues web posts are a source of feminist self expression, similar in nature to the experience of participating in a face-to-face CR group. Kennedy suggests the power of web-based communication to connect academics, community

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<sup>146</sup> “Disgusted with research articles - anyone else?” Clinical Trials, Research, News, and Study Results, July 21, 2007. <http://community.breastcancer.org/forum/73/topic/735046> (Accessed June 2, 2009) Posted July 23, 2007 by Connie.

<sup>147</sup> Kline. “‘Please Include This in Your Book’: Readers Respond to *Our Bodies, Ourselves*,” 89.

<sup>148</sup> Kennedy, “Blogging Feminism: (Web)Sites of Resistance,” (Accessed January 7, 2009.) For additional information on socio-cultural implications of social interactions in on-line spaces and the domestication of the Internet see [netwomen.ca/Blog/](http://netwomen.ca/Blog/) or other Kennedy articles.

activists and “everyday citizens,” while placing personal “experiences within broader sociocultural contexts” begins “a larger feminist process of engaging collectively to pursue social reform.”<sup>149</sup>

A debate in the “IDC” (Invasive Ductal Carcinoma) forum demonstrates Kennedy’s argument. In a thread entitled “Cost of Cancer” the Breastcancer.org community has become engaged in a discussion about U.S. health care, the individual cost of care, and the cost billed to insurance companies. After some disagreement due to partisan political philosophy of several participants, Sonya reminds them of the purpose of this discussion.

I think we need to listen to one another and recognize and validate one another's struggles. Personally, worrying about the insurance/payment conundrum is much more stressful for me (and where I need some compassionate support) than worrying about losing my hair....and I am grieving losing my hair.

I'm not going to let people who feel as you do label and try to censure the issues I bring to this group. I am putting a lot of time and energy into advocating for healthcare for ALL citizens; it is one thing I can do to empower survivors of breast cancer. I think we need to be educating ourselves about the critical condition of our healthcare system and how it is affecting millions of Americans including many breast cancer victims everyday. We need to rally empathy for others whose situations are not as fortunate but who, nonetheless, have to wage the same ongoing physical and emotional struggle against this disease which has a way of never completely leaving one's life. .We don't need to scare people with wrong or incomplete [information] or hide behind the excuse that there is no perfect answer to minimize the scope of the problem.<sup>150</sup>

The discussion places critical issues of individual care into a larger social context and in so doing engages this group in a discussion that educates and empowers. The messages posted cover a range of health care issues: prescription coverage, holistic treatment

<sup>149</sup> Kennedy, “Blogging Feminism: (Web)Sites of Resistance,” (Accessed May 16, 2009.)

<sup>150</sup> IDC (Invasive Ductal Carcinoma): Just diagnosed, in treatment, or finished treatment for IDC. “Cost of Cancer” <http://community.breastcancer.org/forum/96/topic/733416?page=3> (Accessed May 31, 2009)

strategy, laws that prevent doctors from collecting kickbacks for prescribing unnecessary tests, and flaws in currently existing foreign national health care plans are all addressed.<sup>151</sup> By contributing personal experience to the message board at Breastcancer.org, women are engaging a community interested in discussion on women's health. While this communication takes place in a different format than the face-to-face CR groups of the 1960's and 70's, the purpose and results are strikingly similar. Discussion on web-based postings helps women make the connection between personal feelings and the political realities that reinforce them.<sup>152</sup> When coupled with the interactive interface provided via blogs and message boards, collective engagement -- a key element of traditional CR -- occurs.<sup>153</sup>

The virtual consciousness raising Kennedy describes is similar to the involvement of the readers of *Our Bodies, Ourselves* through letter writing. Both provide women with access to consciousness raising without having to be part of a formal group. Technology has enhanced this process by eliminating the time associated with mailing a letter, and, more importantly, opens the conversation to a larger audience. When a letter was submitted to the Boston Women's Health Book Collective, it initiated a personal correspondence that involved only the woman who penned the letter and the authors of *Our Bodies, Ourselves*.<sup>154</sup> When a post is made on a message board or blog, the conversation becomes public; the information can be viewed and commented on by a nearly limitless number of participants. Rather than an interaction that allowed for only the enlightenment of a very small group, this format allows discussions to be generated

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<sup>151</sup> IDC (Invasive Ductal Carcinoma): Just diagnosed, in treatment, or finished treatment for IDC. "Cost of Cancer" <http://community.breastcancer.org/forum/96/topic/733416?page=3> (Accessed May 31, 2009)

<sup>152</sup> Ibid.

<sup>153</sup> Sarachild, "Consciousness- Raising: A Radical Weapon," 148-150.

<sup>154</sup> Kline, "Please Include This in Your Book", 100

for the betterment of a significantly wider audience. When *Our Bodies, Ourselves* left a reader with the feeling that she was alone, isolated or unrepresented, the Collective had little to offer aside from consolation and a promise to rectify the situation in future editions of the book.<sup>155</sup> Clearly, writing and responding to individual letters was inefficient in comparison to the capabilities of web-based communication. The Collective had to individually respond to each question, even duplicate questions, in order to reach out to their audience. Web-based interaction allows for communication with large numbers of people in a public and searchable forum. This not only reduces duplication but also allows for community input to further understanding and connect women quickly who feel isolated while educating individuals on topics that have not been appropriately addressed.

This process is evidenced in a discussion in the “Waiting for Test Results” forum of Breastcancer.org. Martha posts a question regarding an expander and drains installed after her medical procedure.<sup>156</sup> This query involves a series of questions related to a medical procedure that was performed, but never fully explained by her doctor. Not completely understanding her prognosis and living with pain, she turned to a group of women who would understand. Within minutes, the first response was left offering advice, and a stream of responses was available within hours. Responses began almost immediately and quickly took on a conversational tone. The speed at which the posts were entered and responded to fostered a positive emotional experience, but also facilitated the distribution of health literacy. The information provided could be used to ease Martha’s pain, both physical and emotional, and address the concerns of other

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<sup>155</sup> See footnote 107 for example.

<sup>156</sup> “Drain Questions?????” Waiting for Test Results, February 16, 2009, <http://community.breastcancer.org/forum/62/topic/728759>. (Accessed February 16, 2009)

women who had not yet undergone the procedure. The answers to her questions reached across a broad spectrum from a simple “it will get better” to a recommendation for a type of clothing designed specifically to accommodate the tubes and drains that accompany breast cancer surgery.<sup>157</sup> The ability for a varied audience to receive and respond to health care questions allows women to contribute a significant body of knowledge and support in a short period of time. This creates faster access to a well rounded understanding. Such web based interaction replicates CR by allowing the entire community to contribute personal knowledge and experience and thus provides emotional support and supplements understanding without traditional face-to-face interaction.

Moreover, web-based CR offers a distinct advantage over traditional face-to-face groups in its ability to generate new participants. Between November 2008 and April 2009, Breastcancer.org has seen a dramatic increase in the number of registered users on its message boards; the total number of registered users has increased over twenty percent.<sup>158</sup> This serves a dual purpose. First, it allows for new resources, as survivors move beyond their cancer and participate less. The accessibility of on-line CR makes this process significantly easier than the traditional face-to-face form. Secondly, the possibility of having 46,000 participants allows fresh perspectives and a variety of personal experiences to be interjected into almost any discussion. The ability to draw from a diverse pool of participants is a significant benefit for online CR. While many women related on a personal level to the stories in *Our Bodies, Ourselves*, the authors

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<sup>157</sup> “Drain Questions?????”, “Waiting for Test Results, February 16, 2009. (Accessed February 19) Posted Responses are from Amanda and Marissa respectively.

<sup>158</sup> In November 2008, the Breastcancer.org landing page, [www.breastcancer.org](http://www.breastcancer.org), was changed to reflect an increase of 3,000 registered users from 39,000 to 42,000. By April 2009 the total number of registered users has increased nearly 10% to 46,822. Current registration numbers can be found in the Community Member List. <http://community.breastcancer.org/members>

were unable to connect with all readers. With more diverse sources of information and experiences, web-based CR offers women who feel isolated or alone an improved chance to connect with individuals with similar concerns or from similar backgrounds.

Joan's experience is a testament to the powerful benefit of having a large and diverse CR group. Cancer was prevalent in her family history; her grandmother endured a double mastectomy, and her mother died of ovarian cancer at a young age.<sup>159</sup> Joan had a very difficult time coming to grips with her own medical diagnosis; she neither understood exactly what the terminology meant nor was she able to emotionally comprehend the undertaking. A series of responses following her post offered emotional support and encouraged her to take a more active role in her health care.<sup>160</sup> Nancy was able to relate directly to the fears and feelings of Joan.

I have to tell you [Joan] , I Felt **EXACTLY** like you do. I felt like the world had stop[ped] and I got off and then it kept turning and I was on the outside looking at everyone around me living life as I had before all this devastating stuff happened. After I was diagnosed, I remember waking up, and for a moment I was fine and then boom, oh yeah life is over as I knew it cause of this beast called breast cancer... I wanted to say screw surgery, screw chemo, and most of all screw this diagnoses of breast cancer!<sup>161</sup>

Joan saw herself in this message, "your post is from my heart almost...I hope I have as much courage to see this through...." She was able to gain support and guidance from someone who not only had survived a similar diagnosis, but who could also relate to her

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<sup>159</sup> "please help," Just Diagnosed, September 11, 2007, <http://community.breastcancer.org/forum/5/topic/692045?page=1>. by Breastcancer5. (Accessed February 21, 2009)

<sup>160</sup> Ibid. A series of posts in response spanning seven pages was used to make this assessment.

<sup>161</sup> "please help," Excerpt from a response posted 9/11/07 by Breastcancer6. (Accessed February 21, 2009) Text from web-based posts is typically informal, in an effort to maintain the overall tone and feeling I leave all posters messages intact.



personal challenges.<sup>162</sup> Joan's sense of isolation seemed to diminish, and she frequently returns to this series of messages, providing medical updates, and looking for emotional and medical guidance. Participating in this discussion thread through two years of her personal struggle with cancer, Joan has relied on the community she now refers to as her sisters.<sup>163</sup>

Joan developed a deep emotional connection with this group, reminiscent of the face-to-face experience, and was able to use their collective knowledge to improve her personal medical experience. The information and support she received empowered her to fight for the attention of her doctors, to vocalize her concerns with her recommended treatment plan and to seek help for depression and sleeping problems. Knowledge gained through these online interactions allowed Joan to recognize the benefits of speaking up about her problems and finding solutions. The group urged Joan to become an advocate for her own medical care. They armed her with tactics that had proved successful in their battles with institutional medicine, and in so doing, she and her supporters became politically engaged. Certainly Joan's consciousness was raised, and she was empowered to take the action necessary to improve her quality of life.

This experience is common on Breastcancer.org. Margaret was able to take information shared on the site and translate it directly into a more aggressive approach to her breast cancer treatment. She was diagnosed with Lobular Carcinoma In Situ (LCIS) a stage 0 non-invasive breast cancer. Concerned with the assessment of her surgeon that no

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<sup>162</sup> "please help," Just Diagnosed, September 11, 2007, <http://community.breastcancer.org/forum/5/topic/692045?page=1>. (Accessed February 21, 2009)

<sup>163</sup> "please help," Just Diagnosed, February 18, 2009, <http://community.breastcancer.org/forum/5/topic/692045?page=1>. (Accessed February 21, 2009)

immediate treatment was necessary, and that she only needed a mammogram the following year, Margaret reached out to the community at Breastcancer.org.

**Margaret:** had my follow-up with the surgeon a few days ago and she told me that I do not have cancer (woohoo) and that I don't need to have another mammogram now until December 09. I thought that I would be more closely monitored now so I'm not sure what to think of this.

**Mary:** [Margaret] - I am also surprised that your MD is so casual. I think you will [find] a number of threads here that discuss the close monitoring generally suggested with your dx. I am not sure what country you are in, but most women in the US are getting bilateral dx mammograms 2 x a year or a mammogram and MRI on opposite 6 months periods. In addition, there are visits for a professional breast exam on the other quarters - essentially some kind of monitoring every three months. You may want to discuss the plans w/ an oncologists....

**Silvia:** [Margaret]---do you have an oncologist? Surgeons, while they can be excellent at what they do, are specialists in surgery, not cancer--oncologists are. An oncologist can help figure out your overall risk of invasive bc as well as your risks and benefits from taking preventative medications such as tamoxifen or evista and be an overall coordinator of your care with the LCIS....

**Margaret:** Hey everyone! Thanks for your quick replies to my post! [Mary] - I agree, my surgeon is just a little TOO casual. Very nice doctor but I'm definitely not comfortable with waiting until December. I already have anxiety and waiting that long would just put me near the edge of insanity! Some kind of monitoring every 3 months seems reasonable to me. I will be scheduling an appt tomorrow with a new GYN as my previous GYN had back surgery last year and cut back her hours. Hopefully this new doc can refer me to an oncologist. I actually had a much better day today... no throbbing at all. I finally took the surgical tapes off the other night and the incision looks great! Much better than I thought it would look. ...

[Silvia], I do not have an oncologist... yet. I wonder why my surgeon didn't mention an oncologist for follow-up? Thanks for the info you provided...

**Silvia:** [Margaret] ---you will find there is a LOT of controversy surrounding LCIS as to what exactly it is or what it should be called; technically it is a stage 0 in-situ non-invasive bc; meaning the cells are cancerous but they have not moved from the lobules into the surrounding breast tissue. Many in the medical community still feel it is just a marker for increased risk of invasive bc in the future. Personally, I've decided that I really don't care what it is called (although all my docs believe it is cancer, and so do I) as long as it is treated appropriately...

I would recommend finding an oncologist; he/she can coordinate your care--order MRIs, mammos, US, do breast exams, help figure out your overall risks of invasive bc and your risks and benefits of taking preventative medications (tamox or evista) if that's what you want to do.

**Margaret:** Good news everyone! I left a message with my surgeon today and she left me a message two hours later and said that she is going to refer me to an oncologist. Woo-hooo! I feel so much better now!<sup>164</sup>

This exchange highlights how valuable a tool participation in an online CR community can be. Margaret was uncomfortable with the treatment that was recommended to her and would prefer a more aggressive approach. Her interaction with the Breastcancer.org discussion board community empowered her not only by helping her understand her diagnosis, but also equipping her with a strategy to fight for the type of treatment plan she deemed best. The experience connected her personal experience to larger themes of the politics of medicine, attributing her surgeon's lack of concern to "a LOT of controversy surrounding LCIS as to what exactly it is or what it should be called."<sup>165</sup> The group also explored the possibility that Margaret's surgeon may not be able to provide the best treatment options. "My surgeon was pretty clear - he cuts, oncologists treat."<sup>166</sup> Margaret's participation raised her consciousness, not only on the disease, but on how her

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<sup>164</sup> "Just diagnosed with LCIS" LCIS (Lobular Carcinoma In Situ), April 4, 2009.  
<http://community.breastcancer.org/forum/95/topic/731939?page=2> (Accessed May 30, 2009)

<sup>165</sup> Ibid.

<sup>166</sup> Ibid.

treatment was effected by larger debates in the medical establishment. The participation of women advocating for and with Margaret increased her health literacy and the quality of care she received as a result.

## **MORE OF US CAN JOIN, BUT ARE WE GETTING LESS OUT OF IT?: Challenges and Issues of Diversity Online**

While face-to-face support groups have shown their benefit to women, they also come with a number of limiting factors. Web-based support groups are able to overcome many of these hurdles without sacrificing the benefit of participation. The nature of the technology allows participation to occur over time rather than set at intervals. This approach thus eliminates the requirement of traditional CR groups for gathering at a specific time with an adequate meeting space and relative proximity among members.<sup>167</sup> The group “meets” in cyberspace rather than a physical space, and discussion occurs as a series of documented messages rather than in person. This provides an additional benefit, participation that is as anonymous as individual participants desire.<sup>168</sup> Lastly, online support creates an outlet for women who attempt to hide signs of their illness or deny feelings of anger or grief in traditional interpersonal relationships.<sup>169</sup>

While on-line communication reduces barriers to participation web-based CR brings a set of unique challenges as well. According to John Suler, a sense of false intimacy, or what he has labeled the online disinhibition effect, offers potential benefits and challenges to internet based interaction.<sup>170</sup> Suler examines six contributing factors to this effect, of which three are relevant to the discussion boards evaluated in this study: anonymity, invisibility and asynchronicity. These factors allow users to disconnect their

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<sup>167</sup> Helen R. Winefield et al., “A Comparison of Women with Breast Cancer who Do and Do Not Seek Support from the Internet,” *Australian Journal of Psychology* 55, no. 1 (2003): 30-4.

<sup>168</sup> Users can remain completely anonymous on public forums, if they choose to hold a more intimate conversation there are private messaging functions available through the Breastcancer.org discussion boards.

<sup>169</sup> Victoria Pitts, “Illness and Internet Empowerment: Writing and Reading Breast Cancer in Cyberspace,” *Health* 8, no. 1 (2004): 38.

<sup>170</sup> John Suler, “The Online Disinhibition Effect,” *CyberPsychology & Behavior* 7, no. 3 (June 2004): 321.

true self from their on-line persona in web-based discussion.<sup>171</sup> This perceived separation can lead to the disclosure of information the individual would be unlikely to share in a face-to-face relationship. Suler attributes this false intimacy in online communication, in large part, to a lack of personal recourse. The individual does not have to see the group with which she interacts. This anonymity makes users more likely to offer personal information that they may not divulge in a face-to-face scenario.<sup>172</sup> This false intimacy allows the relationship to develop over the internet at a greater speed than would be possible face-to-face.<sup>173</sup> Again, this provides both advantages and challenges to internet users.

While the disinhibition effect may pose difficulties in a variety of interpersonal relationships, the willingness to share additional narratives and experiences is potentially beneficial in on-line support and education. Suler describes two distinct forms, benign and toxic.<sup>174</sup> Individuals who experience benign disinhibition, “reveal secret emotions, fears, wishes. They show unusual acts of kindness and generosity, sometimes going out of their way to help others.”<sup>175</sup> He postulates benign disinhibition is attributed to an individual desire to better “understand and develop oneself, to resolve interpersonal and intrapsychic problems or explore new emotional and experiential dimensions to one’s identity.”<sup>176</sup> The desire for support and education from a community that understands creates the opportunity for benign disinhibition to manifest itself.

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<sup>171</sup> Suler, “The Online Disinhibition Effect,” 322.

<sup>172</sup> Ibid., 321-5.

<sup>173</sup> Ibid.

<sup>174</sup> Suler, “The Online Disinhibition Effect,” 321.

<sup>175</sup> Ibid., 322.

<sup>176</sup> Suler, “The Online Disinhibition Effect,” 321

Turner, Grube and Meyers contend that online support groups are “a ripe context” for benign disinhibition, or as they have labeled it hyperpersonal communication. In this context, “strong, personal relationships and exchanges” occur.<sup>177</sup> It is their contention that an uncontrollable medical event can drive participants in search of emotional support, and that the shared experience of breast cancer yields personal exchanges and leads to the formation of relationships via CMC.<sup>178</sup> Walther, the originator of hyperpersonal communication theory confirms this belief. “When electronic partners experience commonality, anticipate longer-term associations, and are able to conduct them, they idealize their partners, present themselves to one another through text in selectively positive and intimate ways, and reciprocate these exaggerated expressions. Communication becomes more intimate and positive than even accrues in parallel face-to-face settings.”<sup>179</sup> Cancer patients frequently feel socially isolated as they “have few peers experiencing their own concerns.”<sup>180</sup> Women with breast cancer utilize these sites to connect to others who understand their experience. The messages posted on such sites reinforce a collective identity as breast cancer patients.<sup>181</sup> When paired with anonymity and the ability for participants to plan responses, this commonality creates an environment where more intense interpersonal communication is possible than in a face-to-face setting.<sup>182</sup> Benign disinhibition reflects a desire to raise one’s consciousness, and

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<sup>177</sup> Jeanine Warisse Turner, Jean A. Grube and Jennifer Meyers. “Developing an Optimal Match Within Online Communities: An Exploration of CMC Support Communities and Traditional Support” *Journal of Communication* June, 2001. 233

<sup>178</sup> Ibid. 233 - 235

<sup>179</sup> Joseph B. Walther. “Time Effects in Computer-Mediated Groups: Past, Present, and Future.” In *Distributed Work*, edited by Pamela Hinds and Sara Kiesler, 475. Cambridge: MIT Press, 2002, 249.

<sup>180</sup> Ibid, 236.

<sup>181</sup> Ibid.

<sup>182</sup> Joseph B. Walther. “Time Effects in Computer-Mediated Groups: Past, Present, and Future,” 236.

in so doing meaningfully engage a community via web-based communication, which leads to more frequent and intense communication.

Toxic disinhibition, however, manifests itself in forms of hatred, anger and contempt. The nature of breast cancer support and education communities creates an environment where individuals seek positive engagement. However, issues of healthcare, money and control over one's body are topics that can frequently lead to emotionally charged conversations. It is impossible to be open to diverse viewpoints without the presence of anger, contempt or other negative emotions. The discussion forums at Breastcancer.org have empowered members of the community to control the discussions that exhibit toxic disinhibition, thus minimizing their effect on the community as a whole.

The "Alternative, Complementary & Holistic Treatment" discussion forum is one area where toxic disinhibition has been observed.<sup>183</sup> A thread entitled "A checklist on how to promote alternative medicines" provides an example. The original post offers a list of subtle accusations that question the credibility of alternative and homeopathic treatments.<sup>184</sup> The post is viewed as an attempt to belittle the belief system of women who utilize alternative treatments.<sup>185</sup> In this instance, the community has chosen to defend their beliefs through posted responses. Arguments that provide evidence both of the effectiveness of alternative treatments as well as faults with traditional medicine are

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<sup>183</sup> Commentary regarding homeopathic treatment of breast cancer appears to be a notable exception to this rule. Supporters of medicine frequently question the effectiveness of holistic treatment and advice. While these communications are of a questionable nature they do not appear to be overtly hate filled but are aggressively pro-medicine as the only treatment plan.

<sup>184</sup> This post makes twelve statements portraying alternative treatments as irresponsible medicine. These statements do not use profanity or contain offensive content as defined by the community rules.

<sup>185</sup> Alternative, Complementary & Holistic Treatment. "A checklist on how[ to promote alternative medicines" <http://community.breastcancer.org/forum/79/topic/732757?page=1> (Accessed June 5, 2009)



composed and left as responses to the original thread.<sup>186</sup> Lorraine composes a message identifying the original poster as a “troll,” an individual who attempts to interrupt conversation and create negative and contentious arguments. Lorraine goes on to counter each point left in the original, problematic, message. This is one way that the Breastcancer.org community can respond to and control the effect of a disinhibition event.

The discussion forums also provide a more direct method of dealing with toxic disinhibition. Registered participants have the ability to remove any inflammatory or spam messages without involving the site administrator through use of the Report This Post function.<sup>187</sup> The community has been empowered to police posted messages and report them for removal if the content is “threatening, abusive or hateful.”<sup>188</sup> If multiple unique user id’s report a post, it is automatically removed from the site. Offenders will be temporarily suspended from the ability to post on Breastcancer.org discussion boards.<sup>189</sup> Frequent violation of this policy will result in a permanent ban.<sup>190</sup> Users who report content for removal that does not violate the community rules can also be temporarily or permanently suspended.<sup>191</sup> Additionally, the ability to block from view all posts from an identified user is available. This function will allow a participant to avoid all content

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<sup>186</sup> Alternative, Complementary & Holistic Treatment. “A checklist on how[ to promote alternative medicines” <http://community.breastcancer.org/forum/79/topic/732757?page=1> (Accessed June 5, 2009)

<sup>187</sup> “Report this post” Comments, Suggestions, Feature Requests. April 30, 2009. <http://community.breastcancer.org/forum/93/topic/733373> (Accessed June 3, 2009)

<sup>188</sup> Discussion Boards Help “How do I report spam or Community abuse?” <http://community.breastcancer.org/help> (Accessed June 5, 2009) Community members have been granted the power to report any posts which they find to violate the community rules, these include solicitations and spam as well as incidents of toxic disinhibition which has been classified as community abuse by Breastcancer.org.

<sup>189</sup> Ibid.

<sup>190</sup> Ibid.

<sup>191</sup> Ibid. This reduces the occurrence of material that is not objectionable, but does represent an alternative viewpoint from being removed.

posted by a user they have identified as objectionable.<sup>192</sup> These community controls limit toxic disinhibition's overall effect on the community.<sup>193</sup>

Suler believes individuals' emotional needs play an active role in the manifestation of disinhibition. Thus, the desire for support on breast cancer web sites limits the potential for toxic disinhibition to manifest and increases the chance for benign disinhibition to be present<sup>194</sup> Turner et al attribute this to an "optimal match," specific stress events have a correlating type of support that best helps individuals cope. In the case of an illness that carries a wide range of effected domains, such as interpersonal relationships, financial stress, and physical ability, social support that can address all needs is the most beneficial.<sup>195</sup> The opportunity to connect to those with a similar experience can fulfill this need.<sup>196</sup> Such a network provides a positive emotional outlet that is unlikely to be available among their face-to-face relationships. Even in the most supportive face-to-face CR group, a woman diagnosed with breast cancer might not find another member who shared her experience. Thus, many patients will not have access to a group that understands the full impact of their illness. Face-to-face support groups do not offer the sheer number of affected women as is possible via CMC. "The advent of online support communities addressing specific concerns within individuals' lives, and the thousands of participants within these communities the mathematical probability of a

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<sup>192</sup> Discussion Boards Help "How do I report spam or Community abuse?" <http://community.breastcancer.org/help> (Accessed June 5, 2009)

<sup>193</sup> Toxic disinhibition is not unique to online CR. Many CR groups developed rules about how to communicate with participants to guard against its manifestation. However conflicts did arise, and there was often no easy way to resolve disagreement. As the CR group was supposed to be a safe space where all opinions were respected, members with philosophical disagreements could develop a toxic relationship. For more information on relationship guidelines in a CR group see The Women's Collective. "Consciousness-Raising - CWLU Herstory Project: The Online History of the Chicago Women's Liberation Union." CWLU Herstory Project. <http://www.cwluherstory.org/consciousness-raising.html>. (Accessed August 1, 2009)

<sup>194</sup> Suler, "The Online Disinhibition Effect," 324

<sup>195</sup> Turner et al. 234 (For more on Optimal Match Theory see Cutrona and Russell, 1990)

<sup>196</sup> Ibid.

person finding someone with the same illness and treatment alternatives increases exponentially.”<sup>197</sup>

Online support and education websites, like Breastcancer.org, provide access to a wealth of experiential knowledge and support. This support is available twenty four hours a day and from the comfort of an individual’s home. This support network develops a shared understanding and provides the depth of social support required to best serve the needs of women suffering from breast cancer, and it is available whenever the individual requires. Thus, women who are looking for support and education are less likely to manifest negative characteristics and responses. This is reflective of the sites evaluated in this project as limited examples of negative effects of disinhibition were found. The result is what Helen Winefield refers to as “hyper-personal” support, an intensive and extremely effective source of support.<sup>198</sup>

Some would contend that use of a web-based support and education site indicates a minimalist effort. While CR that occurs in this fashion does allow for claims of participation with just a few button clicks, a recent study published in *Health Psychology* shows “that even less than an hour of weekly Internet use is associated with greater social support and less loneliness among breast cancer patients.”<sup>199</sup> Even minimal engagement can result in an emotional benefit. Additionally, passive participation occurs invisibly. It is possible to read the posts and peruse the medical information without ever interacting with another person. While the scope of support received in this fashion would be less than that available to active participants, an individual who interacts in this way would

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<sup>197</sup> Turner et al., 234. (For more on Optimal Match Theory see Cutrona and Russell, 1990)

<sup>198</sup> Helen R. Winefield et al., “A Comparison of Women with Breast Cancer who Do and Do Not Seek Support from the Internet,” *Australian Journal of Psychology* 55, no. 1 (2003): 30-4.

<sup>199</sup> Joshua Fogel et al., “Internet Use and Social Support in Women With Breast Cancer,” *Health Psychology* 21, no. 4 (July 2002): 402.

not raise distrust or harm community dynamics as it might in a face-to-face setting.

Participation is private; unless a user chooses to post the community remains unaware of their presence. In a face-to-face CR setting, each individual would be expected to participate; failure to do so would be evident and group reaction would vary widely.

The Boston Women's Health Collective represented the ideal form and functional format of a typical CR group in the 1960's and 70's. A small group of women that lived within close proximity to one another, gathered at predetermined intervals, and held discussions. This format had several unintended consequences that allowed for greater group cohesion, but also limited diversity among participants. Since the women physically gathered in one place, it was not feasible for individuals to participate who did not live within a reasonable traveling distance. In a white middle class neighborhood, participants were generally white middle class women. This allowed them to relate more readily to one another's experiences, but also limited the range of knowledge and frame of reference for the CR group. In the case of the Boston Women's Health Book Collective, members were initially unable to discuss or write on menopause, minority health, and lesbian health issues because the group's homogeneity limited their personal experiences.<sup>200</sup> For the Collective this was a significant challenge, as *Our Bodies, Ourselves* was generated primarily from the experience and interest of group members. Important aspects of women's health were simply omitted from early editions. Over time, as the members of the collective grew older and additional voices were added to the

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<sup>200</sup> Davis, *The Making of Our Bodies, Ourselves*, 23. Norsigian et al., "The Boston Women's Health Book Collective and *Our Bodies, Ourselves* : A Brief History and Reflection," 36.

editorial staff, unaddressed topics and reader suggestions were incorporated. This can be seen in the growth of the text over time.<sup>201</sup>

Homogeneity represented a challenge not only to the Boston Women's Health Book Collective but to many traditional CR groups. The issue of diversity poses less of a challenge to online CR. Geography is no longer an obstacle as a user can engage in discussions from any computer with access to the internet regardless of location and time. This widespread availability serves to increase diversity as well as participation. As the digital divide, the comparative gap in technological usage and skills between racial groups and income levels, continues to shrink, participants become ever more heterogeneous.<sup>202</sup> At Breastcancer.org this is reflected not only in the discussions created, but also in the variety of discussion boards offered. The Support and Community Connections forums offer a platform for young women, African American women, single women, and lesbians to reach out to one another.<sup>203</sup> The "Community Connections" forums are not as active as the general discussions, but are used with some regularity.<sup>204</sup>

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<sup>201</sup> Boston Women's Health Book Collective Staff, *Our Bodies, Ourselves: A New Edition for a New Era* (New York: Simon & Schuster, 2005). Since the original publication over 700 pages of text have been added to *Our Bodies, Ourselves*.

<sup>202</sup> Jan van Dijk and Kenneth Hacker, "The Digital Divide as a Complex and Dynamic Phenomenon," *The Information Society: An International Journal* 19, no. 4 (September 2003): 315-326. Lee Rainie et al., *The Internet Life Report: Tracking Online Life: How Women Use the Internet to Cultivate Relationships with Family and Friends, Family, Friends & Community* (Washington DC: Pew Internet & America Life Project, May 10, 2000), <http://www.pewinternet.org/pdfs/Report1.pdf>. This study is ongoing and updated statistics are available through [pewinternet.org](http://www.pewinternet.org). The December 2008 survey results indicate a 5% increase in internet user rates among African Americans and a 4% increase among households earning less the \$30,000 per year.

<sup>203</sup> Canadian women, older women and friends and family of breast cancer patients also have community forums to connect. It cannot be ascertained at this time if these boards were created due to a request from the community or from a perceived need by site developers.

<sup>204</sup> "Discussion Boards," Discussion Board, BreastCancer.org, October 30, 2008, <http://www.breastcancer.org/community/discussion/>. These forums represent 564 topics and over 7,000 posts, all but one of which has seen multiple posts over the last seven day period. (Accessed November 11, 2008)

With over forty thousand registered users, these specialized areas for discussion are utilized by and service multiple segments of their community. The sheer quantity of users allows Breastcancer.org to have twelve discussions dedicated to different diagnoses, eight of which have multiple conversations being contributed to on a daily basis.<sup>205</sup> Their large audience allows them to provide areas for groups of women who have similarities to discuss issues relevant to them as well as the larger issues associated with breast cancer. This feature presents the opportunity for a diverse group of women to discuss an issue with a broad group and at the same time discuss it in depth with a community of women that is culturally similar to them. Thus, a single user could simultaneously participate in multiple communities to expand the emotional support and understanding available.

The presence of these boards indicates a willingness to embrace the needs of a diverse user community and to recognize that minority and lesbian women have distinctive struggles. These discussion boards provide a comfortable place to talk about issues that require the unique understanding specific to these communities. Yet, their existence creates an unintended danger, potentially establishing a white heterosexual lifestyle as the norm of the general space. If a perception is created that the general space is for white heterosexual women and the “Support and Community Connection” forums are for minority and lesbians with breast cancer, it challenges the ability to serve these women. They will not participate, engage and embrace the community if they do not see themselves represented in it.<sup>206</sup> Despite this potential complication, the general discussion areas appear to maintain a very diverse participant base. An examination of

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<sup>205</sup> “Discussion Boards.” This assessment was made by viewing the individual discussion boards to examine posts contributed to each of these twelve forums. (Accessed October 27, 2008)

<sup>206</sup> Zola, “Bringing Our Bodies and Ourselves Back In,” 3.

thirty unique user ids of participants in the “Support and Community Connection” forums showed that twenty-nine of the thirty users sampled actively contributed in general discussion forums as well as culturally specific forums.<sup>207</sup> Users of individualized group discussions frequently participate in threads of both a culturally specific and general nature. Thus far, the discussion boards have avoided the appearance of a white heterosexual norm.

Still, internet support groups are often critiqued due to a digital divide that prevents this service from reaching many women who need emotional support. The digital divide represents a significant obstacle especially for women of color and low income households. While this gap is closing, the latest available demographics from The Pew Research Center reflects continued disparity in internet usage based on ethnicity and income levels.<sup>208</sup> African Americans and households earning less than \$30,000 a year are at a significant disadvantage when it comes to access to the internet, and even more so in the skill required to successfully locate and utilize the information needed.<sup>209</sup> The structure of these sites simply is not able to accommodate those who do not have the technological access or skills to use their services. This is an obstacle that will limit the reach of these sites in a way that is not inclusive. But when minority women are able to find access to these resources, they seem to experience a more significant feeling of

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<sup>207</sup> This sample was conducted on February 16, 2009 and included user ids that had posted in African American and lesbian specific forums.

<sup>208</sup> Lee Rainie et al., *The Internet Life Report: Tracking Online Life: How Women Use the Internet to Cultivate Relationships with Family and Friends*, Family, Friends & Community (Washington DC: Pew Internet & America Life Project, May 10, 2000), <http://www.pewinternet.org/pdfs/Report1.pdf> (accessed November 11, 2008). While recent statistical evidence reflects a lessening of the digital divide, the current economic crisis may affect recent gains. Statistics do not yet reflect the impact of recession, thus, it is reasonable to believe the worsening economy may play a role in increasing disparity for minority women and low income households.

<sup>209</sup> “Demographics of Internet Users.” *Pew Internet & American Life Project*, (July 22, 2008), [http://www.pewinternet.org/trends/User\\_Demo\\_7.22.08.htm](http://www.pewinternet.org/trends/User_Demo_7.22.08.htm) (accessed November 11, 2008).. The compiled result of a May 2008 survey.

support than white women. The experience of women surveyed in “Racial/Ethnic Differences and Potential Psychological Benefits in Use of the Internet by Women With Breast Cancer” are reflective of this. According to the report “Minority women had much greater increases in social support associated with Internet use for breast health issues.”<sup>210</sup> For English speaking Latino women, internet usage has actually surpassed that of white Americans percentage wise; but for African American women the divide, while significantly reduced as compared to the past, is still present.<sup>211</sup>

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<sup>210</sup> Joshua Fogel et al., “Racial/Ethnic Differences and Potential Psychological Benefits in Use of the Internet By Women With Breast Cancer,” *Psycho-Oncology* 12, no. 2 (2003): 113.

<sup>211</sup> “Demographics of Internet Users.”



## Conclusion

The American Cancer Institute has estimated that 182,460 women were diagnosed with breast cancer in 2008 alone.<sup>212</sup> In addition, over 41,000 deaths were caused by breast cancer that year, ranking the disease as the sixth cause of death for women in America, and ranking second in cancer related deaths overall.<sup>213</sup> When you consider that one in every eight women will be diagnosed with breast cancer at some point in their life, these are daunting numbers and make breast cancer a very real health issue for many Americans.<sup>214</sup> While it is estimated that nearly 2.5 million women in the United States have a history of breast cancer, a survival rate of nearly eighty-eight percent means that most overcome the disease, but many still need an emotional support system both during their battle with cancer and in its aftermath.<sup>215</sup> Consciousness raising, a concept first developed by feminists in the 1960's, can be a valuable tool for the millions of women who have or will encounter breast cancer in their life time. CR practice involves the support and education of women in a form designed to suit their needs. When applied specifically to health literacy, CR has the potential to empower women to play an active role in their own health care through the application of group experiences to individual realities. This can change the nature of dialogue with medical professionals, provide a source of information on treatments and side effects, or simply provide the emotional support that is frequently lacking in medical institutions.

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<sup>212</sup> "Breast Cancer." National Cancer Institute. <http://www.cancer.gov/cancertopics/types/breast/>. (accessed October 23, 2008). The most recent statistics available from the Center for Disease Control and Prevention (CDC), for the year 2004, are consistent with this estimate.

<sup>213</sup> Ibid.

<sup>214</sup> "Surveillance Epidemiology and End Results." *National Cancer Institute*. <http://seer.cancer.gov/statfacts/html/breast.html>. (accessed April 4, 2009).

<sup>215</sup> Ibid. Some studies suggest that such support systems can improve quality of life for breast cancer patients.

CR has many benefits, including the emotional support and education that may improve patients' quality of life, similar in nature to support groups. Pamela J. Goodwin et al in "The Effects of Group Psychosocial Support on Survival in Metastatic Breast Cancer" highlight this value. The study concludes that participation in a support group improves mood and self esteem, and can even reduce worsening of pain.<sup>216</sup> These benefits are in addition to the education that develops through participation. This combination of emotional support and education contribute to an improved quality of life for participants. Health related CR provides a space for women to discuss the personal reality of their medical diagnosis and to seek a nontraditional source of information. This engagement connects women to others who have shared their experience allowing for a deep emotional connection that is typically unavailable in their everyday face-to-face relationships.<sup>217</sup> Such bonds reduce feelings of isolation and provide an emotional outlet with the depth of support and knowledge necessary to cope with life changing medical events.

While the knowledge exchanged through CR groups does not create medical professionals, it provides women with the foundational information required to take control of their health care plan.<sup>218</sup> Health literacy aids in the demystification of medical diagnosis. It facilitates discussion and influences how women interact with their doctors. Empowered to inquire about alternative treatments beyond the scope of traditional medicine and educated on the potential side effects of medication, women know they do

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<sup>216</sup> Pamela J. Goodwin et al., "The Effect of Group Psychosocial Support on Survival in Metastatic Breast Cancer," *New England Journal of Medicine* 345, no. 24 (December 13, 2001): 1719-20, 1723-4. These findings are consistent with Winzelberg et al., who determine that support groups result in reduced levels of depression and perceived stress. Andrew J. Winzelberg et al., "Evaluation of an internet support group for women with primary breast cancer," *Cancer* 97, no. 5 (2003): 1170.

<sup>217</sup> Turner et al., 234.

<sup>218</sup> Williams and Popay. "Lay knowledge and the privilege of experience," 133.

not have to accept a doctor's recommendation as the only solution.<sup>219</sup> Health literacy allows for a discussion of diagnoses rather than information simply handed down from doctor to patient. CR can provide the knowledge that allows participants to better understand their medical options and advocate for improving the conditions surrounding their care. It may also inspire women to seek improved treatments or better facilities for other breast cancer patients. Such activism is meaningful to the individual and is in line with the original intention of CR. Women come together to discuss issues relevant to their lives and connect them to larger structures, in this case, the health care system. These groups were a significant force behind the women's liberation movement, a safe space where women could gather and discuss issues that were personally significant. The intimate structure and small size of these groups allowed members to foster understanding of their connection to the feminist movement and determine what issues were most relevant to them. Today this format for discussion has been transformed to serve new audiences in modern ways; it has shifted to a virtual space on the internet.

The value of CR has not diminished over the past forty years, but the nature of practice has evolved. Once it involved only face-to-face meetings reaching over 100,000 active participants, but CR has shifted to fulfill the needs and constraints of an ever changing society and an ever growing population.<sup>220</sup> Contemporary practice is conducted in large part via computer-mediated communication. Technology created an environment where CR was available at anytime and from virtually any location, allowing groups of women from all over the world to come together and discuss the issues that are most pertinent in their lives and communities. Practice conducted in this manner is

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<sup>219</sup> Williams and Popay, "Lay knowledge and the privilege of experience," 133.

<sup>220</sup> Shreve, Women Together, Women Alone, 6.

documented in interactive threads and remains available for anyone to access thereby avoiding the limitations of traditional, face-to-face groups. The elimination of a physical space and required proximity allows the number of participants to grow without limits. The range of ideas, opinions and experiences within the group expands with each new addition allowing for a more diverse community, while simultaneously increasing the likelihood of shared understanding. Web-based CR provides the benefits of traditional practice with an increased level of ease and privacy, yet does so without suffering decreased effectiveness. Breastcancer.org has over 42,000 users and the number is growing daily.<sup>221</sup> Moreover, Breastcancer.org is just one of many breast cancer sites, and represents only a tiny fraction of all websites dedicated to health literacy, much less issues of activism, support and women's education. CR practice has become widely available to a vastly larger and more diverse audience than was ever possible during the height of the women's movement.

The Boston Women's Health Book Collective, which emerged out of a CR group in 1970, has recognized the potential of the internet as a system of communication, and, since 2005, has utilized web-based resources to distribute health information.<sup>222</sup> The *Our Bodies, Ourselves*' website has incorporated an interactive blog, and includes a women's health center, which serves as a resource for medical information.<sup>223</sup> "Our Bodies, Our Blog" allows for a rapid distribution of new information where readers can respond in a public domain that is available for anyone to view.<sup>224</sup> The blog provides the opportunity

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<sup>221</sup> "Breast Cancer Treatment Information and Pictures," BreastCancer.org, <http://www.breastcancer.org/>. (Accessed October 27, 2008)

<sup>222</sup> Judy Norsigian "Oral history interviews, 1998-1999 (inclusive)," interview by Kathy Davis.

<sup>223</sup> "Information on Women's Health & Sexuality - Our Bodies Ourselves," <http://www.ourbodiesourselves.org/default.asp>. (Accessed March 17, 2009)

<sup>224</sup> Our Bodies Our blog, <http://www.ourbodiesourblog.org/>. (Accessed March 17, 2009)

to rapidly release new information, connect women to personal narratives similar in nature to those contained within the pages of the published text, and to advocate for action.<sup>225</sup> The website removes some of the obstacles the Collective faced in distributing information via printed text, providing an avenue for distribution of truly current findings. Additionally, by turning to the internet, The Collective is able to distribute the medical content and the consciousness raising experience to a wider audience than the text alone could accomplish.

The consciousness raising that occurs on breast cancer support and education discussion boards is a contemporary incarnation of the expansion of health literacy *Our Bodies, Ourselves* provided to women in previous decades. It educates and empowers women to put agency into action. The format creates an atmosphere that meets multiple needs in an anonymous environment. This allows participants to build relationships united under a common experience without social or physical cues. For some women this experience develops the camaraderie and increased level of comfort that eventually leads to a face-to-face meeting. Breastcancer.org, for instance, has a message board dedicated to the organization of “get togethers” for site participants.<sup>226</sup> The organization of in person gatherings allows relationships developed through this online support network to grow.<sup>227</sup>

Yet, the websites of Breastcancer.org and the Boston Women’s Health Book Collective platform serve as a source of education and support for women whether or not

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<sup>225</sup> Our Bodies Our blog, <http://www.ourbodiesourblog.org/>. (Accessed June 15, 2009) Blog posts contain commentary on current events, links to published media stories on feminist and health issues, political calls to action to support legislation and personal narratives of health experiences.

<sup>226</sup> Get Togethers. <http://community.breastcancer.org/forum/34> (Accessed June 15, 2009)

<sup>227</sup> Ibid., and “Events.” *BCsupport.org*. <http://bcsupport.org/bc2/events.html> (accessed November 11, 2008).

they are comfortable or able to participate in a face-to-face setting. Still, even for women who do not attend face-to-face gatherings, connections are not confined to an entirely virtual world. As online relationships and emotional connections develop, some participants desire a personal interaction that goes beyond the internet. Kathie Sarachild, who coined the term consciousness raising, envisioned a constantly evolving form of practice: “In our groups, let's share our feelings and pool them. Let's let ourselves go and see where our feelings lead us. Our feelings will lead us to ideas and then to actions. Our feelings will lead us to our theory, our theory to our action, our feelings about that action to new theory and then to new action.”<sup>228</sup> Fluidity in practice allows CR to manifest in many forms and any environment to meet the needs of the participant community. All forms are valid and beneficial, but from its start a diverse approach and lack of predetermined format has allowed CR to mold itself to the needs of participants. The discussion housed at Breastcancer.org is a manifestation of CR that educates and advocates on issues of health literacy.

Consciousness raising has held a place of historical importance, not just for the advancement of health literacy, but for its role in the women's movement as a whole. The significance it has played in helping women understand that personal experience transcends daily life and is fueled by larger political and structural factors cannot be overstated. While the widespread use of CR as a tool for feminist expression waned over time, its relevance to the history of the movement and its effectiveness in practice did not. Thus, it is not surprising that CR has resurfaced in a new forum to be utilized by new generations side-by-side with those who came before. By linking a trusted and practical

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<sup>228</sup> Sarachild, Kathie. “A Program for Feminist “Consciousness Raising” (1968).” In *Public Women, Public Words*, edited by Dawn Keetley and John Pettegrew. Rowman & Littlefield, 2005, 167.

method with modern technology, the gap between generations is bridged and successful practice is reintegrated for the betterment of women.

## Appendix 1-METHODS

This project attempts to connect the historic practice of face-to-face consciousness raising and the use of modern day breast cancer support and education websites. In order to fully explore this relationship, I have collected and analyzed the collected data for a comparative case study. This approach permits fluid examination of two unique periods of history and modes of communication. According to Charles Ragin, a comparative case study is a useful tool in the examination of specific characteristics of social phenomenon within the unique historical and political contexts of each case.<sup>229</sup> The cases examined here both involve significant contributions to women's health advocacy; however they are part of distinct political moments and movements. This methodology allows for the exploration of philosophical similarities despite organizational differences in the two groups approach to information distribution. Moreover, conducting a comparative case study permits an examination of these organizations on an equal footing, accounting for the reach and effectiveness of each within their own historical frame of reference.

Two organizations were selected for this study: the Boston Women's Health Book Collective and Breastcancer.org. They were selected with two key criteria in mind -- their ability to reach a wide, and ultimately diverse audience, and a shared organizational purpose of communicating personal health information for the benefit of a large group. They fit neatly within the theoretical framework of my study as communities that advocate for women's health literacy and provide a platform for consciousness raising. The Boston Women's Health Book Collective and their text, *Our Bodies, Ourselves*, are entrenched in the tradition of the women's health movement and consciousness rising.

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<sup>229</sup> Charles Ragin. *The Comparative Method Moving Beyond Qualitative and Quantitative Strategies*. Berkley: University of California Press, 1989, ix.



Arguably the most successful CR group in United States history, the collective provides an example of the form and function of traditional, face-to-face groups. By examining this organization, key aspects of CR are brought to light and transitions in the practice can also be examined. As the purpose of the Collective evolved so, too, did their methods of information distribution. They shifted from a small CR group to become authors of a CR network based on a text, and then a non-profit venture circulating information on a global scale. The success of this organization highlights the potential for successful CR practice in multiple forms, including small groups and text-based communication without a face-to-face element.

The Boston Women's Health Book Collective Archives at the Schlesinger Library, traces the development of the way CR functioned at the various stages of organizational evolution. Close reading of narratives recounting the development of the group from a conference breakout session to a worldwide health literacy organization provides extensive contextual cues as to CR practices over time. Additionally, archived interviews with the founding members of the Collective provide insight into over three decades of group interaction and organizational development. The text-based communications between readers of *Our Bodies, Ourselves* and the Boston Women's Health Book Collective also document the fact that both authors and readers were aware that the book was a tool for CR practice. It is through this acknowledgement that a direct connection between archived letters and posts in online message forums can be made. Similarities in tone, content and perceived purpose all link the two forms of communication as a source of consciousness raising.

Breastcancer.org was selected as the comparative case because of the scope of its mission, its reach and the size of its participatory community. Breastcancer.org utilizes internet communication as a mode of delivering CR and health literacy directly to the homes of women with breast cancer. The use of computer-mediated communication (CMC) as a pathway to CR reflects a shift in practice. The Boston Women's Health Book Collective was able to bring CR to women via a published text; the online experience builds on textual CR by increasing the speed at which responses can be gained. Records of interaction at Breastcancer.org are extensive and readily available for analysis as discussions are archived on the website and can be accessed from any computer connected to the internet.<sup>230</sup> The importance of the Boston Women's Health Book Collective to the women's health movement and of CR to women's liberation led me to select a health resource focused primarily on women. Breast cancer is a predominantly female disease; as such it could be presumed that women would constitute the vast majority of website participants, similar to face-to-face CR practice. Traditional CR originated as a tool for women to support and educate one another, the modern incarnation serves this same purpose. As such Breastcancer.org provides a community for examination that will be similar in many ways to those used in earlier modes of CR.

In conducting a comparative case study, I have been able to juxtapose the uniqueness of two organizations while recognizing the similar functions of each. This model was extremely useful as a method of examining a small sample of CR experiences. However, this case study did not permit a quantitative analysis of numerous medical support and education websites found on the internet. The sites examined, which include

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<sup>230</sup> As communication can be quite personal, I have removed all user identification and replaced them with pseudonyms to maintain the anonymity of participants.

Breastcancer.org as well as Bcsupport.org, are reflective of CR practice as defined in this work.<sup>231</sup> Information on the analysis of BCsupport.org is available in appendix 2.

Additional websites that fulfill a similar purpose were not considered, thus it is unknown if these findings are transferrable to a wide array of breast cancer support and education sites. By limiting the size of this examination I acknowledge that the findings of the case study are unique to the experiences of the Boston Women's Health Book Collective and Breastcancer.org. Thus, it remains unclear whether the CR experience is replicated on all breast cancer support and education websites. However, the purpose of this project, highlighting the relevance of meaningful online discussion through a linkage to traditional feminist practice, is most suited to a comparative case study despite its non-transferability.

My conclusion that discussions occurring on Breastcancer.org constitute a form of CR is not based on individual participants' claims that they have engaged in the practice. But such direct personal acknowledgement from participants is not required to make such an assessment. The similarity between CR group experiences and user interactions that occur at Breastcancer.org is substantiated by observational evidence rather than participant interview. The discussions observed are consistent with CR practices via text-based communication examined in the Boston Women's Health Book Collective Archives. The archived letters provide acknowledgement of CR through text based communication and are similar in emotion and tone to the communication on Breastcancer.org discussion boards. A request was made to Breastcancer.org to partake in a brief interview to better understand both the organization's development and levels of

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<sup>231</sup> Consciousness raising as defined in this study, is group discussion of personal realities that establish a link between subjective experience and larger political themes.

familiarity of the site administrators with *Our Bodies, Ourselves* as well as CR practice.

The request was accepted, but at this time the questionnaire has not been returned.

In order to successfully complete a comparative case study of an organization whose work transpires primarily in a virtual location, critical examination of a number of web-based resources was required. It is my contention that messages and threads posted to the forums at breast cancer support and education websites provide a narrative history of the expansion of health literacy and consciousness raising in participants.<sup>232</sup> In my examination of the Boston Women's Health Book Collective a wide array of organizational materials, documents and archived interviews were referenced to recreate the complex history and evolution of the group. However, for a web-based organization, the interactions, history and evolution are not archived using traditional methods; rather they are housed within the on-line content. Computer-mediated communication serves as a written record of conversations among members, and it replicates the experience of letter writing, interviewing, diary entries, even autobiographies. Each message posted becomes a glimpse into the life of a single participant, and each thread a written record of group dynamics. The compilation that is left behind thus offers a narrative history of both the individual and the group that can be analyzed. These personal and often emotional accounts provide a window into the virtual living room of a CR group.

In the course of my research, I examined approximately 200 unique threads including thousands of posts and responses in a sample that includes each of the fifty-five forums on Breastcancer.org. It was my intent to evaluate only topics that could represent a group discussion, thus topic selection was determined by the minimum number of posts

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<sup>232</sup> Peter S. Bearman and Katherine Stovel. "Becoming a Nazi: A model of narrative networks." *Poetics* 27, no. 2-3 (March 2000): 69-90.

present. For inclusion in the sample, I required a minimum of 5 posted responses to the original topic. This minimum was intended to insure that some level of interaction had occurred and that the topic was of interest to the participant community. This is indicative of the decision to utilize a purposive sampling strategy. Topics were selected from the discussion forums most likely to indicate a deep emotional connection and evidence of CR.<sup>233</sup> Rather than searching for samples that would be representative of a larger population, selections documented in this case study are chosen for theoretical relevance to the argument.

An examination of user participation rates in the “Support & Community Connection” category highlights the purpose of such a method. A sample of recent participation best assessed the diversity of the Breastcancer.org community. The number of registered users has increased significantly, from 39,000 users in November 2008 to over 51,000 users in June 2009. This represents an increase of nearly 20 percent of total user registrations over an eight month period, but fails to acknowledge user id’s that are no longer active. Thus, consideration of recent activity is required if analysis is to be reflective of the current community. I also compared the participation of individuals using culturally specific forums to their participation on general forums. This provided insight into the inclusive nature of the general discussion forums. My investigation examined the history of 30 unique user ids of recent and active topics, on the “African Americans with breast cancer,” “Lesbians with Breast Cancer,” and “Young Women with Breast Cancer” forums. This sample provided understanding of the current patterns of communication among the Breastcancer.org participant community.

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<sup>233</sup> Michael Quinn Patton. Qualitative Evaluation and Research Methods. 2nd ed. Newbury Park: Sage, 1990, 177.

## Appendix 2- BCsupport.org

In a previous study I evaluated BCsupport.org as an alternative online source of CR. The information contained herein is reflective of a support and education network that is smaller than Breastcancer.org, yet maintains a similar level of commitment. This evaluation provides evidence of CR, indicating an occurrence in more than a single breast cancer support and education venue.

BCsupport.org has been serving women with breast cancer since 1998. While it generates less web traffic than Breastcancer.org the participant community is still active. BCsupport.org maintains eleven discussion boards; on a range of topics including grieving, caregivers and men affected by the disease, a place to discuss moments of laughter or joy, and their primary discussion board, “Meeting Place for Survivors.”<sup>234</sup> One unique characteristic of this site is the dedication of each discussion board to a woman who made an impact on the site’s community. The “hosts” of the site appear to go out of their way to make visitors feel welcome and to let them know they are not alone.<sup>235</sup> By providing their first names the hosts seem more connected to the community than a traditional webmaster or moderator would. The “Meeting Place for Survivors” and “Grief Support Board” house the most active discussions on the site with a number of active threads daily.<sup>236</sup> The remaining boards also receive regular usage, with all but two having seen conversation over the last week.<sup>237</sup>

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<sup>234</sup> “Breast Cancer Support” <http://www.bcsupport.org/> (Accessed November 3, 2008)

<sup>235</sup> The two individuals responsible for the upkeep of the site refer to themselves as hosts rather than moderators or webmasters as is typically found on websites. The hosts have identified themselves as “Elizabeth” and “David.”

<sup>236</sup> On Monday, November 03, 2008 at 9:47 p.m. the “Meeting Place for Survivors” and “Grief Support Board” had 13 discussions that had at least one comment posted that day. Site accessed through BCsupport.org or “The Meeting Place for Survivors.” Message Board. *BCsupport.org*, (November 3, 2008), <http://members.boardhost.com/survive/>.

BCsupport.org is a non-profit organization. The site, unlike Breastcancer.org, is not run by doctors and is more oriented to the emotional well being of the site's visitors than as a source of medical information.<sup>238</sup> The site clearly states "this forum of interaction with breast cancer survivors is to help those who need support and generally what to expect from surgery, radiation and chemotherapy from those that have previously undergone the treatments."<sup>239</sup> So while the site does not serve as an authority on medical information it does provide information on what others have experienced. In addition, BCsupport.org has a discussion board for up to date information regarding cancer and the site complies with the HONcode for trustworthy medical information. Medical information from experts is kept separate from the rest of the discussion and the general public does not have the ability to post their comments in this area.

One aspect that makes BCsupport.org stand out is the community that utilizes the site takes active steps to foster a more personal sense of community. The site is host to forty five pages of images posted by users of themselves, and in some cases their families and friends.<sup>240</sup> The support network of this particular website also extends offline. Regional gatherings have been organized to allow the relationships developed through this online support network to grow in a face-to-face environment.<sup>241</sup> This practice is notable, as active steps are being taken to compliment the "virtual" aspect of this resource. Members of the site organized their first national gathering in 2001, and several

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Grief Support Board <http://members.boardhost.com/grief/> and "Grief Support Board." Message Board. *BCsupport.org*. <http://members.boardhost.com/grief/>.

<sup>237</sup> This was true as of Monday, November 03, 2008 at 9:51 p.m.

<sup>238</sup> "About Us." *BCsupport.org*. <http://bcsupport.org/> (accessed October 13, 2008).

<sup>239</sup> Breast Cancer Support." *BCsupport.org*.

<sup>240</sup> "Survivor Photo Album." *BCsupport.org*. <http://bcsupport.org/bc2/photo.html> (accessed November 6, 2008).

<sup>241</sup> Ibid., and "Events." *BCsupport.org*. <http://bcsupport.org/bc2/events.html> (accessed November 11, 2008).

regional gatherings have been held. The community while not as large as that found at Breastcancer.org is very committed to the site and to one another.



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