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Leadership and the Breast Cancer Movement

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mother died of breast cancer at age 36. My family most certainly carries the breast cancer gene (BRCA1), forcing my sister and me to think about the implications that has for us in the future. The knowledge that I may one day face breast cancer drives me towards getting involved in the activism in the breast cancer movement. Obviously, I want to find a cure.

As a leadership studies major, I am intrigued about the women behind this movement. Who are they? Why are they involved? How did they bring it to such prominent national attention? What kinds of leadership qualities do they possess? Thus, my research into this phenomenon began. I studied the women leaders in the breast cancer
Enhance the self-worth of others: “One of the byproducts of sharing information and encouraging participation is that employees feel important. During the interviews, the women leaders discussed other ways they build feelings of self-worth in co-workers and subordinates. They talked about giving others credit and praise and sending small signals of recognition. Most important, they expressed how they refrain from asserting their own superiority, which asserts the inferiority of others.”

The breast cancer movement stays away from power struggles and superiority complexes. These women figured out that in order to stay organized and in control, every woman needed to feel included. The nature of the issue of the movement helps as well. Since most of these women fought the disease either themselves or with others, they understand how important a supportive environment contributes to a person’s well-being. This support flows into the movement and contributes to the sense of togetherness. Some women are more prone to leadership than others, but that does not mean that they are somehow superior. Their disease taught them how they want to be treated, and that is how they treat others. This does not seem to be an issue-- these women are too busy fighting.

Energize others: “The women leaders spoke of their enthusiasm for work
and how they spread enthusiasm to make a work challenge exhilarating and fun. The women leaders talked about it in those terms and claimed to use their enthusiasm to get others excited."

Excitement is not a word often used to describe the movement, but energy stands as an important component. Keeping people interested, and having a lot of energy, is catching and helps many stay involved. No one wants to participate in something that does not move, they want action. The leaders are catalysts for that action through the amount of energy they possess.

Along with the importance of energy, in Women Leading, Collins, et. al. advise women leaders to work on their stamina and “develop thick skin.” They contest that women need to understand that they will win sometimes and lose sometimes, and to keep working through it all. In the breast cancer movement, the women deal with gains and losses on a daily basis and must find a way to keep going. Although their positives outweigh their negatives, a simple “no” could potentially ruin an organization. That is why these women leaders must possess the energy to go on and encourage others to do so as well.

Another way in which women lead is through networking. Women and the Politics of Empowerment, edited by Ann Bookman and Sandra Morgen, is an anthology of articles about the ways in which women change
their world. One articles in particular supports the research thoroughly. “Gender and Grassroots Leadership,” by Karen Sacks explores the ways in which women create movements through a study of hospital workers. She found that women tend to form networks to organize. These networks have a social bent to them, the women know that by giving a sense of belonging to others they will receive labor in return.

Women in the breast cancer movement have found similar success through building these networks. The formation of the National Breast Cancer Coalition exemplifies this perfectly. Any woman or group may join and they automatically receive the links they need to communicate with other women across the country about important issues (Whitehouse and Slatalla). This network helps members plan rallies, lobby their legislators, and provides guidance for new organizations. This networking is an effective tool that these women mastered.

A Social Movement

Vaclav Havel said in a May 31, 1990 speech, “society is a very mysterious animal with many faces and hidden potentialities, and...it’s extremely shortsighted to believe that the face society happens to be presenting to you at a given moment is its only true face. None of us knows all the potentialities that slumber in the spirit of the population.”
The women involved as leaders in the breast cancer movement show their potentialities loudly today. From a leadership point of view, these women started a social movement that shows little sign of winding down. They act from their conflicts, from their struggles, from their hearts. The anger they share is channeled into a force that is gaining power day by day. Motivation is boundless, empowerment is great--these women are ready to conquer their cancer once and for all.

There are a wide range of characteristics of social movement leadership, and the breast cancer movement and its leaders exemplify them all in one way or another. In answering the question, “What is unique about social movements,” Dr. Richard Couto outlines the following answers, and I provide additional responses to how they apply to the breast cancer movement.

*The relation of power, position, and authority:*

In the breast cancer movement, the activists have to fight for legitimate power, the power of authority, in order to make any sort of change (Hughes 116). Some of their successful lobbying efforts were fruitful because the women used their influence to persuade others. Hughes, et al. would define them as “inspirational appeals.” Inspirational appeals are designed to arouse emotion and enthusiasm(131). Once they
got into the game, the women were able to make changes, but they tackled a large power base to get there. Today, their position enables them to wield this power in better, more effective, and legitimate ways than before.

*Action for social change:*

The women leaders in the breast cancer movement see changing society’s attitudes towards women with cancer as one of their barriers to overcome. This action includes the push for funding, preventative care, insurance coverage, and other issues associated with the movement. Along with those concrete goals, helping others understand what these women go through, and increasing general awareness about the disease are really the factors that change a society. Changing the heart is extremely important because it provides the emotion needed for motivation, as mentioned earlier.

*The central place of conflict:*

Obviously, the women involved in this movement strive towards the same goal—eradication of the disease. Having a vision is another way in which this could be described. Kouzes and Posner write in *The Leadership Challenge*, “The vision is a mental picture of what tomorrow will look like.” (111). Strong leaders tend to build visions that inspire others to join them.
The vision also helps the followers focus on the reason they are working towards their goals. Leaders in the breast cancer movement have few goals, but they are large ones. This enables them to create a vision without overburdening the follower with too many issues. In social movements, this central place of conflict gives the movement focus, as the leaders provide vision and keep the women involved.

*Action in the face of uncertainty:*

An important issue that the women face is uncertainty, not only about winning the small battles, but in losing their leaders to the disease. The uncertainty lies in the changing faces of the leaders and where their visions connect. Thus, the cancer itself is an uncertainty that hinders the leadership process. Fortunately the leaders lead by example and when put into a desperate situation, new leaders have the model to follow and continue in the paths of their predecessors. In a way, this provides even more motivation. Death increases anger and desire, and in many cases encourages the survivors to fight even harder.

*Risk of reprisals and loss:*

Once again, the loss of life hurts the movement more than the loss of legislation. The small battles may be easily conquered, but with an ever-changing leadership, it can be difficult to organize followers towards the
goal. Flexibility stands as the key to a leader’s and her organization’s success. Through the nature of the disease, the women learned how to adapt to change and use it to their benefit.

Dr. Couto further outlines characteristics of social movement leaders in his handout, “Characteristics of Social Movement Leadership.” The following is yet another outline of these characteristics and how the leaders of the breast cancer movement possess them.

*Build on local people and past events:*

Many of the women who formed groups built them locally and based them on their personal experience. An example of this is the One in Nine club started on Long Island. Two friends, both cancer survivors, got together and held a meeting. They expected about ten to fifteen people to show up; forty-seven came and filled the meeting room. That local organization has grown exponentially since then (Whitehouse and Slatalla).

*Opposition from authorities and established organizations:*

The opposition that the women leaders of the breast cancer movement face is invisible. Ignorance from the medical community and the cancer research establishment stand in these leaders’ way. Women in the movement fight for increased research finding and for other support services. Breaking down the ignorance of some of these establishments
was not easy at the beginning. It has taken a long time for male doctors, who have not had personal experiences with breast cancer, to listen to the women's needs. Congress, another male dominated institution, had a difficult time understanding the issue and granting funds. This began to change as representative's wives, mothers, and sisters helped them comprehend the implications of funding research. For example, Senator Tom Harkin had two sisters die of cancer, which helped him become involved in the movement (Beil).

_Opposition or lack of support from “group” members:_

Lack of support has not been an issue for the breast cancer movement, as much as intra-group conflict has occurred. The problem lies in two issues: prevention versus research. Some women feel that prevention should be more focused upon, while others demand more focus on research to find a cure. Both camps are interested in both issues because they help save lives, they just have different opinions about time and funding parceling.

_Protest of laws and mores:_

The women help change laws that affect insurance coverage and social security, but they have not made any drastic moves towards changes in the laws. As far as mores are concerned, however, when the movement
started no one ever talked about breast cancer, especially in public. In the 1970’s, having a breast cancer story on the news was scandalous. Breaking the social barrier proved to be one of the most difficult challenges in the beginning of the movement. This did not truly happen until the late 1980’s when large groups of women collectively decided to speak out. They had to force people to discuss the issues through their campaign.

*Creation of avenues for group improvement and not individual escape:*

Not only do the local activist groups help all women in terms of raising funds and increasing awareness, it helps their psyches as well. Many of these women help gain some semblance of control, and the action provides a channel for their anger. This improvement of the individual only more completely assists the group and solidifies it. Experience leads to understanding, which leads to help and action.

*Acknowledgement of sympathetic but quiet members of the “other” group:*

Since the breast cancer issue claims no true opposition in the classic sense, (who supports women dying at a more rapid rate?), the silent “others” are those that sympathize, but do not act. More and more men are coming into the fold of the movement, but it is still mostly female driven. This is understandable since the disease physically affects mostly women, but many men suffer emotionally as well. Men are not the only “others.”
Women whose lives have not been touched by cancer are also the “other.” The movement has such a large number of women involved already that they are not hurting for these others. They do need them, they could always use more help, but the energy level remains high without these “others” as well. It’s not an easy issue for people to handle, and that is understandable to many of these women. All they ask for is support.

*Provoke conflict within the ranks of authority and established organizations:*

The battle with the National Institutes of Health illustrates how the leaders of the breast cancer movement exert their will. The NIH feels bombarded by the claims for more money for research, and they argue that it takes away from other cancers. The women turn around and demand a bigger pie, rather than a bigger piece. The movement caused so much conflict, that money for this research found in the Department of Defense was earmarked for breast cancer research to appease the leaders (Scott).

*Courage to break precedent:*

This relates once again to the lack of talk about the disease in general. The early activists took a chance by speaking out against breast cancer and changing societal norms. Today, they break precedent through
monetary requests that grow larger and larger. The number of women involved in the movement grows daily, as does the number of corporations like Avon, that give money to the movement.

Courage to confront personal fear:

These women fear dying. Facing that on a daily basis is awful enough, and working for change helps them confront that fear. The fear of rejection becomes slight compared to the fear of dying. A goal that they work towards is making things better for those that come after them—especially when they have daughters that may be affected by the disease.

Personal transformation:

As mentioned throughout the paper, this component represents a large part of what motivates these women to become leaders in the movement. Volunteering for the cause is therapeutic; these women feel a sense of control and accomplishment that their cancer takes from them. Some of these women never thought they would ever lead, but their cancer changed them and caused them to speak out to help other women and themselves.

James C. Scott further proves these characteristics with a psychological study that focuses on the outcome of forced compliance. Women in the breast cancer movement were forced to comply with the
status quo. Scott found two main results. The first is that forced compliance causes, "a reaction against such attitudes," that try to keep the movement silent. This includes issues such as breaking down the social norms. Second, people do not voluntarily comply, even through coercion. Although they may physically comply, emotionally and psychologically they do not. An example of this is the way women were treated by the medical and research communities and how it encouraged them to fight even harder.

This relates to the breast cancer movement because women went from having virtually no rights on the operating table and in the political arena, to becoming a loud voice to be reckoned with. The lack of attention paid to the disease was the coercion they faced, and this obstacle was overcome. Women now ask for more information, are given more information, and demand greater funding, research, and prevention.

AN ORGANIZATIONAL MODEL

Now that the characteristics of both women leaders and leaders of social movements have been described, an organizational model is needed to support these findings. The LINC organization and its founders fit these
leadership criterion as an organization of women striving for change and assistance of others.

The idea for the Legal Information Network for Cancer came from a conference that Phyllis Katz and Ann Hodges spearheaded. Both breast cancer survivors with career backgrounds in the law, they created a conference to educate lawyers about issues that affect women with the disease. This conference achieved great success and grew into an organization that provides counseling to women with legal questions and needs. In their brochure, LINC describes itself as,

"LINC, or Legal Information Network for Cancer, is an organization of volunteers committed to helping cancer patients resolve non-medical issues arising from the diagnosis or treatment of cancer. Serving the Central Virginia community, LINC provides information, education, counseling and referral services for legal assistance to individuals confronted with the overwhelming array of choices and dilemmas associated with cancer."

Hodges states that the true purpose of LINC is to keep women from having to get so far through the system that they have to rely on lawyers. Lawyers can become expensive, and on top of all the medical costs, many women cannot afford the legal help they need. When there are cases that have to be sent to lawyers, LINC has a network set up for the different services clients need. Many of the cases fit into the pro bono, or providing
free services to those who cannot afford it, criteria that each attorney must fulfill yearly in the State of Virginia. (This is based on an hourly figure that varies from attorney to attorney and state to state). The counselors are volunteers trained to assist people with different needs, ranging from denials of insurance claims to employment rights. The following lists typical LINC clients and cases:

- Sally sought the help of LINC when her company, which was self-insured, agreed to pay for her bone marrow transplant but refused to pay for the testing of bone marrow donors. The testing would have cost $25,000 up front, and LINC was able to convince the employer to pay for the testing.
- She was receiving hospice services and her health insurance plan was refusing to pay for her home health nurse.
- During her treatment for breast cancer, she was demoted to a position with significantly lower scope of authority.
- His employer was expressing displeasure with the ten days of leave taken to care for his wife who was hospitalized with terminal cancer; the husband was afraid of the threatened negative actions.

This organization and its leaders fit into the categories that characterize women leaders and social movement leaders for many different reasons. First, when asked to describe the counselors, Hodges says that they are mostly people whose lives have been touched by breast cancer, either personally, or as a friend or relative of a victim. “They feel passion about the issue,” she says. Passion is what drives members of a social movement. Katz and Hodges “transform” these volunteers and help
Hodges also spoke about how LINC empowers the clients. This relates to the women leaders research by Rosener that is empowerment-focused. The volunteers give the clients a sense of control that they desperately need. They "share information" and "energize" these struggling women. Volunteers feel this and are able to share in the receiving. By helping others, they feel a sense of accomplishment and gain some control themselves.

This control helped Katz as well. While she was struggling with her own cancer she said that she needed her own lifeline and found that lifeline through helping others. Katz is in charge of employee relations for the state of Virginia. Many of her employees began coming to her with medical problems that were legal in nature, and through this she formulated the idea for LINC. She found how to handle that central source of conflict and knew how to face adversaries in insurance companies and the government as discussed in social movement leadership.

Hodges, a law professor at the University of Richmond, helped spearhead the project and the two began facing the trials and tribulations of starting an organization. They had to raise funds. They took risks, fought the establishment, and won. Although they lost two grants, they
found others. LINC has a board and many volunteers. Through Katz' and Hodges' leadership, passion for the issue and help of others, they created a program from an idea and added to the breast cancer movement in a new way, from the legal standpoint.

As mentioned above, their leadership styles correlate with those typical of women leaders. They are integrative leaders that share power, information, and concentrate on open communication. They have a program director, Allison Held, whom they rely on to keep the organization functioning. When they speak to groups, they encourage others to volunteer, if not with them, then with another organization. Lobbying excites Katz and she wants to move towards that arena soon. As their organization becomes more formal, they realize that they will phase out soon to start new projects. Above all else, they inspire others through their leadership. Both women are transformational leaders that share the power they have gained through building an organization and taking a stance against the status quo. They both survived breast cancer and are helping others to go on as well. They created an organization that grows quickly. They teach others how to live, even if they are afraid, even if they need help; they teach them about life.
CONCLUSION

This research exemplifies a number of leadership issues. Women tend to be transformational leaders, especially in highly emotional situations, like social movements. Their passion, anger, and need for control in their lives motivates them to fight for their cause. The nature of the movement itself thwarts power struggles, as these women learned that sharing power leads to healing and motivation. The movement itself is not only striving for social change, but is a movement of support and caring for all women, infected or not.

Women are changing society. They push their agendas to the national forefront. Every breast cancer story inspires others to join the cause. Words like empowerment, conflict, support, motivation, vision, power, and change all complete a vocabulary that describes the ways in which these women not only lead, but change their world. Jose Luis Guerrero said, "If you believe something should change, then you must try to change it, no matter if there are risks." The risk taking is the easy part. Survival is the real challenge. These leaders extend their lives to the fullest giving of themselves for their cause. No book definition of leadership comes close to touching that--the sheer will to succeed, and the will to survive to see the results of the effort.
WORKS CITED


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