

A Comparison of Cancer Control Organizations in the United States and United Kingdom

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ABSTRACT

The purpose of this study was to compare cancer support group practices between the United States and the United Kingdom with the goal of facilitating information exchange between the two countries. Observational and interview data found evidence of differences between the two groups in five areas: the setting of the group, the facilitator of the group, the amount of time the group had been in operation, the level of outside engagement undertaken by group members, and the group's willingness to participate in the study. Explanations provided for these differences include individual, community, and nationwide factors.

INTRODUCTION

There were an estimated 12 million new cases of cancer diagnosed worldwide in 2007 and approximately one in eight cancer attributable deaths in the same year, making cancer responsible for more deaths worldwide than AIDS, tuberculosis, and malaria combined (Garcia et.al, 2007). During 2007, the United States alone saw 579,000 cancer related deaths, the equivalent of 23.2% of all deaths in the United States in 2007. During the same year, the estimated number of new cancer diagnoses in the United States reached 1,444,920 (Cancer Deaths, 2007).

Cancer is not an issue faced solely in the United States; The United Kingdom also experiences a significant burden. In 2002, there were 142,000 cancer related deaths in the United Kingdom or 24.5% of all deaths in the country during 2002 (Cancer Country Profiles, n.d.). Because there are so many individuals suffering from cancer worldwide, many ways of battling the disease have emerged. Cancer organizations have proven themselves to be "a powerful force in the struggle to ease the burden of cancer. These organizations perform many different functions, but all are dedicated to understanding cancer, improving patient outcomes, increasing the number of cancer survivors, and assisting those touched by cancer" (Cancer Organizations, 2006).

Support groups are one function of cancer organizations that address the psychosocial ramifications of the disease. "When an individual receives a cancer diagnosis, they may suffer an onslaught of psychosocial problems" (Bottomley, 1997). It is believed that these psychosocial problems will worsen as the treatment regimen for cancer becomes more invasive and demanding on the patient and insurance issues in the United States continue to be a source of stress (Bottomley, 1997). Research has demonstrated better quality of life outcomes for cancer patients whom have a strong network of social support (Psychosocial Support, 2007). This is most likely because the "provision of social support, normalizes the cancer experience, provides peer based hope and reduces the overall sense of social isolation" (Bottomley, 1997).

Those currently suffering from cancer are not the only people who need social support. One in four cancer survivors participates in a support group, meaning more cancer survivors utilize support groups compared to individuals suffering from other chronic conditions (Psychosocial Support, 2007). "Worldwide, in 2002, there were approximately 24.6 million cancer survivors... That number will increase steadily during the coming years, as the average age of the world's population increases. Survivors may face numerous physical, psychological, and financial challenges throughout the remainder of their lives. Effective treatment is the most important strategy to ensure optimal life following a cancer diagnosis. However, many other interventions can improve a survivor's life. Unfortunately, access to these interventions is not available equally around the world. Additional resources are needed to help the millions of cancer survivors worldwide" (Cancer Survivors, 2006).

One important method to improve health promotion programs is to determine how other establishments are running comparable programs. The World Health Organization explains that, "it is necessary to build and coordinate...collaborative efforts and alliances for the prevention and control of non-communicable diseases" (Secretariat Report, 2008). These alliances "facilitate dissemination of information, exchange of experience, and support to regional and national initiatives" (Networking for integrated, 2004).

METHODS

The two main goals of this study were to describe the differences and similarities between the American Cancer Society in Pewaukee, Wisconsin and Macmillian Cancer Support in London, England and to understand the differences and similarities between cancer support groups affiliated with each organization. The observational study was carried out in two phases, one in Milwaukee, WI, USA and one in London, England. Data was gathered in the greater London area in conjunction with Macmillian Cancer Support during the summer of 2008 (n=5) and in the greater Milwaukee, WI area in conjunction with the American Cancer Society Midwest Division during the fall and winter of 2008-2009 (n=5).

The primary methods of data collection were face-to-face interview with support group facilitators and support group observation. Access to the facilitators of cancer support groups was gained through their affiliated organizations. During the summer of 2008, in person interviews were conducted with Macmillian employees and support group leaders. Observation was completed in support groups (n=2) as well as Macmillian sponsored training sessions for support group facilitators. Due to the summer holiday season in the United Kingdom, not all support groups in England were meeting during the data collection period. When group observation was not possible, in person interviews were completed with the group facilitator (n=2). One group sent information in the mail following the data collection period (n=1).

Data was gathered in a similar fashion in the Milwaukee area. Names of support group leaders were obtained via an ACS Patient Navigator and were contacted throughout the fall. Some agreed to allow observation of the support group (n=3) while others, due to confidentiality issues, agreed to phone interview only (n=2).

RESULTS

Differences Between Organizations

Both Macmillian Cancer Support and the American Cancer Society are well known organizations in their respective countries, with the ultimate goal of improving the lives of those affected by cancer. Both Macmillian and ACS rely heavily on public contributions for funding, such as donations, legacies, and fundraising from special events. To a smaller extent, both organizations receive funding through government grants. (Cancer Care Research, n.d.; Research Program and Funding, 2009). In order to manage the breadth of their services, both organizations are divided into separate geographic regions (six in the UK and thirteen in the United States) as well as different areas of service (Cancer Care Research, n.d.; Research Program and Funding, 2009).

The American Cancer Society is divided into the four distinct branches of research, education, advocacy, and patient service. Macmillian is an organization focused almost exclusively on patient support and service. They do engage in education, research, and advocacy, but these areas are viewed as distinct forms of patient support as opposed to separate entities. Macmillian lists its branches as emotional support, financial support, practical support, and informational support. In addition, they fund nurses and other healthcare professionals and engage in campaigns to ensure everyone affected by cancer can receive the support they need (Cancer Care Research, n.d.; Research Program and Funding, 2009).

Like the American Cancer Society, Macmillian is involved in research, however, the focus their research is “on improving the quality of life for people affected by cancer and turning the results into practical solutions and better quality services” (Cancer Care Research, n.d.). This differs from the American Cancer Society, which is the United States’ “largest private, not-for-profit source of funds for scientists studying cancer”. (Research Program and Funding, 2009). ACS has an intramural research division, which addresses topics such as cancer epidemiology, behavioral factors of cancer, and cancer prevention. The extramural research division provides grant money for both research and the training of health professionals. (Research Program and Funding, 2009).

Differences Between Support Groups

The differences that emerged between the cancer support groups associated with the American Cancer Society and Macmillian can be put in five categories: the setting the support groups were held in, the facilitator of the group, the length of time the group had been in operation, the extent to which members of the support groups engaged in activities that were additional to regular meetings, and the group’s willingness to allow observation of group activities.

Setting. The majority of the support groups in the United States were associated with a hospital or other medical facility. These settings provide a convenient location because patients can receive treatment and attend support group meeting in the same outing. Hospitals commonly provide meeting space, refreshments, and compensation for parking, which keeps operation costs of the group low and makes the role of coordinator quite

painless. While using a hospital for support group activities makes the group easy to run, it may not be convenient for cancer survivors to return to the hospital for group meetings.

British support groups were mainly held in community central locations. While it is not unheard of to use hospital space, many more groups in the United Kingdom appeared to use community centers and other less medically oriented spaces. Instead of having a treatment facility in common, a characteristic of support groups in the United States, members of British groups often had a neighborhood or community in common.

Facilitation. Support groups in the United States are most often facilitated by medical professionals, such as nurses, physicians assistants, and social workers who ensure patients will have informational support in regard to side effects, treatments, or other medical concerns. These professionals, especially Social Workers, may also have the ability to link patients with other assistance programs, which will provide further support.

British support group facilitators were most commonly cancer survivors who empowered the support group members to assist with planning and facilitation. In these groups, medical professionals are often brought in as guest speakers to provide informational support, but the social support aspects are organized by the group itself. While these groups may lack the constant presence of a medical professional, members appear to be empowered by their self-sufficiency.

Time. Many of the participating groups in the United States have been in operation for over ten years. These well established groups are advantageous because longer running groups will likely be well known within a community and seasoned facilitators will have gained an understanding of the most effective ways to manage the particular group. However, a negative side effect of a well-established group may be stagnation. If the activities associated with a well-seasoned group become repetitive, members may not feel they are receiving the social support they seek. This is especially important for groups who serve a large number of cancer survivors as opposed to those who work mainly with those currently receiving treatment.

Cancer support groups in general seem to be a newer concept in the United Kingdom. Out of the groups observed in the U.K., only one had been in operation longer than ten years. This contrasts data gathered in the United States where only one group had been operating less than 10 years. While there are always new groups forming and others disbanding, it appears that formal support groups have been common in the U.S. for a longer period of time.

Outside Engagement. United States based support groups appeared less interested in engaging in activities other than regular meetings. During discussions with group facilitators in the United States, there were rarely activities mentioned that took place in different locations or at times. When facilitators discussed the types of activities support groups engaged in, some mentioned they had attempted to plan group outings or additional social events, which were not widely attended by members.

Almost all cancer support groups in the United Kingdom discussed participating activities such as fundraising, social outings, and recruitment of new members, all of which were additional to regular meetings. Members of these groups appeared to allocate much more of their time to support group activities when compared to the United States. British support group members spoke enthusiastically about these events and seemed to gain more personal gratification from planning fundraisers or attending holiday gatherings than they did from attending regular informational meetings. In the UK, informational meetings appeared to be more supplementary while in the United States, they were the primary activity of cancer support Groups.

Confidentiality. Confidentiality was the central concern of almost every participating American support group with several groups refused to allow observation due to patient confidentiality concerns. When compared with UK support groups, those in the U.S. were less interested in participating in research and much more apprehensive to allow observation of group activities. In the UK, both support group facilitators and members were interested in the study and happy to have a visitor with whom they could discuss group activities. Some groups went out of their way to ensure they could accommodate the needs of the investigator. When time constraints made it impossible to observe group activities, one group gathered information to mail to the researcher; another arranged a special meeting during the UK holiday season in order to participate.

DISCUSSION

There are several possible explanations to account for the differences found between American and British cancer support groups. It is likely the true explanation for these differences is a combination of factors that vary depending on the individual groups being compared.

Cyclical Nature of Group Characteristics

One unique aspect of each cancer support group may drive another. In the United States, support groups may be held at medical locations because this is a convenient setting for the medical professionals who facilitate the groups.

Conversely, medical professionals may be drawn to support group facilitation because the hospital provides a convenient setting for group activities. The identity of the facilitator may be tied in to the support group location in a similar way in the United Kingdom. Support Groups may elicit facilitation by cancer survivors and patients themselves because they are held in community central locations. This may also work in a reverse fashion, where community members who begin a cancer support group will be more likely to choose a community setting as opposed to a hospital setting.

The setting of the support group may also be connected to the outside activity of the support groups. British support group members appeared to be more proactive in planning social events, developing fundraisers, and advertising their support groups. This may be because a community based setting creates an environment where the cancer support group takes on a more social or extramural role than groups held in the hospital. Support groups held within the community may also be more proactive out of necessity. Hospital settings often provide the funding for group activities, but those held in other locations may need to engage in fundraising activities in order to sustain group operation. This need for funds creates a need for group members to commit their time group activities. This need may initially appear as a negative aspect to a community setting, however, fundraising activities in the United Kingdom provide group members with the opportunity to bond with one another and invest their time in activities they feel are important.

The indoor setup of these different locations may also give their respective groups a different focus. Hospital based support groups are held in a lecture hall or conference room, while community centers provide meeting spaces more conducive to small group conversation and mingling. It may be that community based groups have more active proactive members because they have greater opportunity to engage one another and discuss ideas. In the more formal lecture setting, the group takes on an informational focus that may not create the same kind of group cohesion as the community setting.

Impact of Organizational Characteristics

The nature of the larger organizations associated with the support groups may also be responsible for the differences between the support groups held in each country. Macmillian is an organization focused solely on cancer support. Because they provide training and funding for cancer survivors to begin their own support groups they create an environment conducive to community lead support groups. Macmillian also provides financial and informational support that allows groups use to engage in the proactive activities that characterize British support groups. The American Cancer Society does not have as direct of a role in the development of support groups. ACS has a directory that is used to refer patients to support groups, however, the organization does not provide the type of support to group leaders that Macmillian does. Medical professionals in the U.S. may step in as support groups leaders because cancer patients and survivors are not empowered to develop their own support groups.

Another concept that emerged as a possible reason for the differences between support in the United States and the United Kingdom is medicalization. "Medicalization describes the process by which non-medical problems becomes defined and treated as medical problems, usually in terms of illnesses or disorders" (Conrad, 1992, p. 209). Medicalization has been discussed in literature since the 1970's and has been applied to conditions such as menopause, Attention Deficit Hyperactivity Disorder, aging, and alcoholism (Conrad, 1992). At one time these conditions were not under the jurisdiction of modern medicine; however, as time has gone on, they have become increasingly defined in medical terms and viewed as illnesses, which require medical attention. One early writer on medicalization described it as a "process whereby more and more of everyday life has come under medical dominion, influence, and supervision" (Conrad, 1992, p. 210).

Differences in cancer support groups may be due to social support in the United States becoming medicalized. The majority of support groups in the United States are held at hospitals or other medical institutions and facilitated by medical professionals. What once may have been a group of cancer patients providing support to one another appears to have become a medical necessity for cancer patients, one that is too complex for individuals without a professional degree to oversee. American patients often seem to view their support group as form of treatment, where British patients view support group attendance as a social outing.

Policy Effects

Countrywide policies may also have an affect on how support groups are run. One of these policies is the structure of the health care system in each country. The United States has a complex health care system where most citizens receive health insurance through their employer. The United Kingdom has a government run healthcare system that does not depend upon employment. These differing health insurance systems may affect the amount of free time cancer patients have. Some patients in the United Kingdom said they quit their jobs during their cancer experience in order to focus on their health. It is less likely Americans would have the ability to do the same because

they would be afraid of losing their insurance coverage. This may mean members of British support groups have more time to engage in support group activities and therefore create the more involved, enthusiastic, and proactive groups seen in the UK.

Confidentiality is another difference between British and American support groups that may be explained by countrywide policy. British support groups had very few concerns about allowing observation of support groups while this was a core concern of many American groups. This widespread concern over patient privacy may be due to U.S. regulations such as the U.S. Health Insurance Portability and Accountability act of 1996. The Privacy Rule within this act “provides federal protections for personal health information held by covered entities and gives patients an array of rights with respect to that information.” (Health Information Privacy, n.d.). This privacy rule “was intended to strike a balance between protecting the privacy of individually identifiable health information and preserving the legitimate use and disclosure of this information for important social goals” (Ness, 2007, p. 2164). Despite the reference to disclosure of personal health information to achieve social goals, many researchers have found the HIPAA Privacy Rule to be a complication in health related research in terms of uncertainty of results, cost, and delay (Ness, 2007). As policies like HIPAA have become commonplace in American society, it appears, so has the belief that all personal medical information is extremely confidential. It is possible that as cancer support groups in the United States become increasingly medicalized, they will also tighten restrictions in order to protect confidentiality of members because the support groups will be viewed from a medical standpoint and therefore fall under the jurisdiction of HIPAA regulations.

CONCLUSIONS

This study was a preliminary look into the nature of cancer support groups in the United States and United Kingdom. As opposed to making causal claims, the goal of this study was to facilitate information exchange between cancer support groups by describing observed differences between groups held in each country. Further research in the area of cancer support should utilize a larger sample size, develop more concrete assessment tools, and ensure equal representation of each area. Along with further investigation of the differences between cancer support group activities, the psychosocial outcomes and mortality rates of American and British cancer support group attendees should be compared to find if one method of social support for cancer patients and survivors is more effective.

REFERENCES

- Bottomley, A. (1997). Cancer Group Interventions- A Cancer Group Intervention In Need Of Testing. *Clinical Psychology and Psychotherapy*, 4(1), 51-61. Retrieved March 13, 2008, from EBSCOhost database: <http://search.ebscohost.com/>
- Cancer Care Research. (n.d.). *We Are Macmillian. Cancer Support*. Retrieved May 25, 2009, from Macmillian Cancer Support Web site: http://www.macmillan.org.uk/About_Us/Force_for_change/Cancer_care_research/Cancer_care_research.aspx
- Cancer Country Profiles. (n.d.). *WHO Global InfoBase*. Retrieved March 17, 2008, from WHO Global InfoBase database: <http://www.who.int/infobase/report.aspx?rid=126>.
- Cancer Deaths Drop For Second Consecutive Year. (2007, January 17). *American Cancer Society*. Retrieved March 13, 2008, from American Cancer Society Web site: http://www.cancer.org/docroot/MED/content/MED_2_1x_Cancer_Deaths_Drop_for_Second_Consecutive_Year.asp?sitearea=MED&viewmode=print&
- Cancer Organizations. (2006). *Global Cancer Atlas Online*. Retrieved March 13, 2008, from Global Cancer Atlas Online database: <http://apps.nccd.cdc.gov/dcpcglobalatlas/>
- Cancer Survivors. (2006). *Global Cancer Atlas Online*. Retrieved March 13, 2008, from Global Cancer Atlas Online database: <http://apps.nccd.cdc.gov/dcpcglobalatlas/>
- Conrad, P. (1992). Medicalization and Social Control. *Annual Review of Sociology*, 18, 209-232. Retrieved May, 2009, from <http://arjournals.annualreviews.org/doi/abs/10.1146%2Fannurev.so.18.080192.001233>
- Economic Costs. (2006). *Global Cancer Atlas Online*. Retrieved March 13, 2008, from Global Cancer Atlas Online database: <http://apps.nccd.cdc.gov/dcpcglobalatlas>
- Garcia M, Jemal A, Ward EM, Center MM, Hao Y, Siegel RL, Thun MJ. *Global Cancer Facts & Figures 2007*. Atlanta, GA: American Cancer Society, 2007.
- Health Information Privacy. (n.d.). *U.S. Department of Health and Human Services*. Retrieved May 26, 2009, from <http://www.hhs.gov/ocr/privacy/hipaa/understanding/index.html>

- Ness, R. B. (2007, November 14). Influence of HIPAA Privacy Rule on Health Research. *Journal of the American Medical Association*, 208(18), 2164-2170. Retrieved May 25, 2009, from <http://jama.ama-assn.org/cgi/content/abstract/298/18/2164>
- Networking for integrated prevention and control of non-communicable diseases in the SEA region [Electronic version]. (2004, March/April). *World Health Organization*, 1-24.
- Psychosocial Support for Cancer Survivors Needs Strengthening. (2007, May 14). *American Cancer Society*. Retrieved March 13, 2008, from American Cancer Society Website: http://www.cancer.org/docroot/MED/content/MED_2_1x_Psychosocial_Support_for_Cancer_Survivors_Needs_Strengthening.asp
- Research Program and Funding. (2009). *American Cancer Society*. Retrieved May 26, 2009, from http://www.cancer.org/docroot/RES/RES_0.asp
- Secretariat Report. (2008, January). Prevention and Control of Non-communicable Diseases: Implementation of The Global Strategy [Electronic version]. *World Health Organization*, 1-23.