

Bridging the Gap Between Communities and Research

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LEARNING OBJECTIVES STATEMENT

By the end of reading this paper, you will be able to:

- Demonstrate knowledge about the role of organizations in the fight for health equity and literacy
- Incorporate facts about community-based groups who act as a bridge between the public and healthcare systems

INTRODUCTION

Community-based organizations are not consistently recognized for their efforts to support individuals with breast cancer and, more broadly, spread health literacy among the communities they serve. Yet, these groups and organizations are essential to supporting those with breast cancer because they are uniquely positioned outside the typical medical sphere. Developing and sustaining relationships founded on trust and open communication allow breast cancer patients and survivors to connect with individuals in ways they might not connect with medical providers.

Groups such as faith-based organizations, LGBTQIA+ support groups, and other community stakeholders create new opportunities for trusted individuals to share accurate health information with their members. In addition to promoting health advocacy, they can also provide different types of emotional, spiritual, mental, and monetary support that other institutions cannot administer (Wilson et al., 215). Sometimes, these groups are the only forms of support individuals with breast cancer can rely on. Therefore, these entities should be recognized as valuable resources and assets to support patients. This paper will highlight the indispensable work organizations do to support individuals diagnosed with breast cancer.

FAITH-BASED APPROACH TO HEALTH

The literature surrounding coping mechanisms among Black women breast cancer survivors has grown. Research demonstrates that many Black women credit their religious beliefs, particularly identifying with the Christian religions, to reaching the survivorship phase of breast cancer due to their relationship with God and steadfast faith (Gaston-Johansson et al. 121; Gullatte et al. 64).

Faith-based organizations play an essential role in the spiritual and physical health of their members. They can empower individuals through faith "...to be passionate and effective leaders for creating healthier communities" (UCSD School of Medicine). The Black Church has been a foundational institution in the Black community (Lomax 78). In times of heightened racial and economic tensions, the Black Church has offered a place of solace and hope for its members (Townes 101). The unique position of the Black Church also offers an opportunity to connect their congregation and the local community to teach about healthy lifestyles.

Several churches across the U.S. have implemented adult-based health programs to create a positive atmosphere that opens discussions about diseases in the community. One church that has created a strong network of health education and support is the Trinity United Church of Christ (TUCC, or "Trinity" for short) in Chicago, IL. Located in the Washington Heights community on the South Side of Chicago, Trinity has been globally recognized for its efforts in paving the way for social justice. In addition, this church has nurtured its Health and Wellness Ministry in ways that other churches can replicate. Trinity believes in holistic well-being and offers community members the chance to connect.

Of Trinity's seven sub-Health and Wellness groups, they have a ministry dedicated to fellowship with individuals diagnosed and caregiving for loved ones with cancer. The group is not limited to breast cancer support but all types of cancer. The ministry is called Can-Cer-Vive, and its aim is "...to provide spiritual support and information on caregiving/receiving, health care..." which allows community members to gather together and lean on each other for support. Religious institutions like the Black Church allow individuals to find a sense of purpose and meaning in managing their health. By incorporating a faith-based approach to health, churches like Trinity can allow cancer patients, survivors, and caregivers to feel like they can connect, ask questions, and create new strategies to living a new normal with cancer.

LGBTQIA+ CANCER SUPPORT GROUPS

Cancer support groups that help members of the LGBTQIA+ community are another essential avenue for patients and survivors to receive assistance and encouragement. In addition, several organizations have been established to allow cancer patients and survivors to connect.

One group is called <u>Live Through This</u>, and Stewart O'Callaghan founded it in London, United Kingdom (U.K.). They were diagnosed with Chronic Myeloid Leukemia in 2016. After they and their partner sought LGBTQIA+ friendly resources in the healthcare system and came up short, Stewart decided to launch their organization to be the necessary middle ground for their community. Through research, education, and public engagement, Stewart amplifies the concerns of LGBTQIA+ who have and support those with cancer. The organization collaborates with the U.K.'s National Health Service (NHS) to enhance cancer care for everyone.

The organization's efforts can be seen in the U.S. from its partnership with the organization CoppaFeel. The two groups collaborated to share important health education with their members. The partnership aims to expand breast health knowledge by emphasizing that every one of all gender identities has breast tissue which means they can get diagnosed with breast cancer. One of their goals is to reach

individuals who identify as transgender and non-binary to be aware of checking for changes during their transition. By visiting the <u>Self-Checkout page</u>, individuals can answer questions that best pertain to how they feel about their bodies and the changes they are experiencing. Organizations like Live Through This and CoppaFeel create resources for individuals who may not receive them from their healthcare providers.

BARBER & BEAUTY SHOPS MODEL FOR HEALTHY LIFESTYLES

The Black community prides itself on its love for the culture and expressing one's individuality. Barbershops and beauty salons are staples in the community. The act of getting one's hair done can boost their self-esteem. These shops and salons offer members another pathway to finding support and healing.

Research illustrates that barbershops and salons are "culturally relevant portals for health education and delivery of public health and medical services in the community" (UMD School of Public Health). A strong history identifies beauticians and barbers as critical stakeholders in the Black community (Luque, Ross, and Gwede 181). Not only are shop owners entrepreneurs, but they also improve the quality of life in the residential neighborhoods they work in (UMD School of Public Health).

As trusted individuals and leaders within the communities they serve, shop owners can become community health advocates (Wilson et al. 217). Some community members are more likely to take advice on their health from their barber or hairstylist than from a medical professional; the trust built from individuals working with a barber or stylist is unparallel to other relationships.

There has been a growing initiative to improve community health outcomes, and one of the ways this can be achieved is through training shop owners and their team members to speak about health to their clients (Wilson et al. 220). In addition to the type of health-based education stylists and barbers receive, it is also vital that they are appropriately trained in communicating them to the clients they serve (Wilson et al. 218). Training and the delivery of the message are essential in fostering healthy clients and communities.

As it pertains to breast cancer, a research study in 2008 set out to determine the influence of positive breast health messages by Black and Afro-Caribbean stylists in hair salons (Wilson et al. 216). The study was conducted in 40 randomly selected salons located in communities of color in New York. These salons were then put into two groups which included experimental and control.

The clients receiving services from the experimental salons got their hair styled and were exposed to breast health messages (Wilson et al. 222). The clients who received services from the control group of salons continued to get their hair styled without any breast health information from their stylists. In addition, clients took surveys and assessments before and after the study to evaluate the effectiveness of the information they received during the study. The research demonstrated that hair salons could be essential to promoting health-based knowledge associated with breast cancer.

CONCLUSION

There is a benefit to leveraging community stakeholders in the efforts of promoting healthy lifestyles. Organizations centered on providing support to members of the communities they serve allow health equity to be achieved. The Tigerlily Foundation also serves as an organization that offers community, support, and advocacy for breast cancer patients and survivors. Community members rely on various groups to find answers to their problems and find peers who can relate to what they are going through. Community stakeholders help build bridges between the public and medical sphere.

Sources

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