

Community Health Program Planning 2009: Field Action Report

Assessing Cancer Support Needs of the Southern Connecticut Region: Establishing a Wellness Community

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Overview

The National Institute of Health (NIH) recognizes that cancer care often fails to meet individuals' psychosocial health needs. The Wellness Community (TWC) is a non-profit organization that provides free mind-body therapeutic support to those affected by cancer nationally and abroad. This project aims to assess current therapeutic services and their utilization, in order to establish a TWC within the Southern Connecticut area. We report here on the second phase of a three-part needs assessment documenting the services available in this region. The overall assessment addresses availability of medical treatment and psychosocial support for cancer survivors and their families, while also identifying gaps in services that add the full psychosocial needs of patients or offer free and accessible psychological and physical health therapies.

The second phase focused on key-informant interviews with CT-based cancer stakeholders to assess the community's current supports, needs, and service utilization. The completed first phase consisted of a mixed model (quantitative-qualitative) feasibility analysis of community demographics, cancer incidence and current available resources. The third stage, which will be carried out in the near future, includes conducting focus groups with cancer survivors.

Data analysis from interviews in the second phase showed that existing services around therapeutic cancer care support focus primarily on specific cancer types and therapies—which suggests a need for a TWC within the Southern Connecticut Region.

Project Description

The Wellness Community (TWC) is a non-profit organization whose mission is to provide support, education and hope to people with cancer and their loved ones¹. TWC provides free services by licensed professionals to anyone affected by cancer, at any stage of his or her cancer journey in a supportive, non-medical atmosphere. The Wellness Community - Southern Connecticut (TWC-SC) is dedicated to alleviating the burden of cancer on survivors and families by engaging individuals in professional, psychosocial programs in the areas of New Haven, Fairfield, Middlesex and New London counties (The Wellness Center-Southern Connecticut, 2008).

Despite medical advances in cancer care, it is well documented that psychosocial supportive services offer a host of benefits, including improved physical well-being, increased energy level, increased hopefulness, improved sleep quality and stress reduction (Institute of Medicine of the National Academies, 2007). NIH has acknowledged the limitations that cancer care will continue to face until these patient needs are met. The Institute of Medicine (IOM) has led the mission to improve the delivery of psychosocial services to cancer patients and their families (Institute of Medicine of the National Academies, 2007) and has cited TWC as an example of an existing organization providing such services.

Methods:

13 Key Informant interviews: (See Fig. 1 for relationships with cancer of key informants)

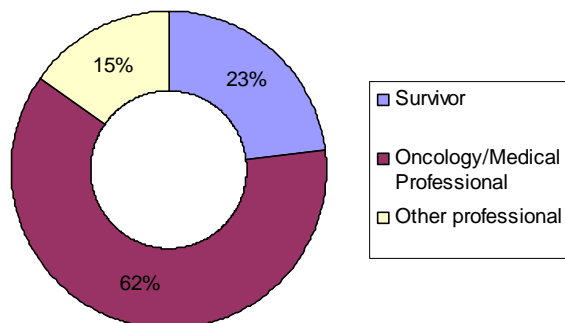
Selection criteria: Participant had some relationship to cancer or a stake in the psychosocial services provided in Southern Connecticut

Tool: Semi-structured, open-ended response format across four categories: demographics and general information, perceived psychosocial needs, existing services for cancer survivors, and location.

Objectives: Assess the psychosocial services of the catchment area, in order to help the Wellness Team to:

1. Determine the demographics and needs of the community to tailor its therapeutic services to meet these needs;
2. Determine the communities' interest and openness to this facility to determine ways to advertise the Wellness Community; and
3. Determine the current services available to establish service collaborations with other organizations that overlap with its goals

Figure 1. Relationship with Cancer



Discussion and Evaluation

Theme analysis from the key informant interviews provided information at three levels: 1) perception of most important psychosocial needs, 2) current or existing resources, and 3) areas for improvement and lacking resources.

Results for Perception of Most Important Psychosocial Needs: Emotional support stood out as the predominant need for both caregivers and patients. Informational support was also important and included access to pamphlets, brochures, and websites. Both providers and patients felt a large issue within the area was lack of information about the resources available and how to navigate these services. Access to alternative therapies, such as Reiki, as well as guidance on healthy eating and nutrition were relevant factors while financial assistance was noted as a considerable need for this cancer population.

Results for Current and Existing Support Services: For current and existing support services, both emotional and informational support remained prominent themes. Specifically, informational support was transmitted via medical treatment centers and community and/or national organizations.

Results for Areas of Improvement and Lacking Resources: Among the current supports available, areas for improvement concerned sex, cancer site, and cancer stage specific information. For example, the "Look Good, Feel good" program and "Why me?" are both targeted for women but not men. Similarly, it was felt that needs vary at different stages of cancer of the cancer journey and that nutritional needs vary dependent on the physical location or type of cancer.

Results for Location: The interviews also asked participants to comment on the need for a TWC within the Southern CT region and the logical location for this resource. In response, the majority emphatically felt that a TWC in Southern Connecticut was a good idea. Many noted that it should be a complement to already existing services, particularly given the concerns expressed around communication and utilization of these services. Collaborations with organizations such as the Yale Cancer Center, the Connecticut Cancer Partnership and Matrix Public Health Solutions were also noted. The majority of participants felt that New Haven would be an optimal location given its proximity to the Yale Cancer Center thus giving patients easier access to additional support services as well as public transit and major highways.

Identified Needs for The Wellness Community

- *Support in navigating existing resources and services* was seen as an important need and a current gap in the cancer support system of Southern Connecticut.
- Many participants highlighted the *necessity of collaborating with and complementing cancer organizations and services that are already in place* in the Southern Connecticut Region to maximize the benefits for all patients and stakeholders and to reduce repetition.
- *A wider range of psychosocial services and support specific to caregivers/families* or tailored to the wide-variety of cancer patients (e.g., by age, cancer site, gender) were seen as both necessary and currently lacking in Southern Connecticut.

Next Steps

The third phase will include focus groups with cancer survivors to further delineate similarities and differences between the services offered by TWC-SC and other local programs and also assess what services patients of different groups want and need most. Focus group questions will be based on the themes drawn from the key informant interviews and can be seen in Appendix C.

The TWC-SC will also continue to foster collaboration with Matrix Public Health Consultants in conjunction with the Needs Assessment currently being conducted by the Connecticut Cancer Partnerships for the State of Connecticut.

Educational and Community Resources

1) The Wellness Community: a non-profit organization dedicated to providing free emotional support, education and hope for people with cancer and their loved ones throughout all stages of their cancer journey. <http://www.thewellnesscommunity.org/corporate/>

2) The American Cancer Society: the ACS's concentrates on capacity building and collaboration with other cancer-related organizations throughout the world to provide support and information for all cancer survivors. www.cancer.org

3) The National Cancer Institute: provides comprehensive cancer information as a part of the US National Institute of Health. www.cancer.gov

4) The Connecticut Cancer Partnership: this partnership unites the members of CT's diverse cancer community through a comprehensive plan to reduce the suffering due to cancer, and improve the quality of life of Connecticut cancer survivors. <http://ctcancerpartnership.org/>

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