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A Cancer Education Service (ACES) Program of Research with Minority and Underserved Populations

Ronald E. Myers, PhD, DSW *

* Thomas Jefferson University

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A Cancer Education Service (ACES) Program of Research with Minority and Underserved Populations

A Cancer Education Service (ACES) Program was developed to connect Jefferson's cancer education and research effort with minority populations of the Philadelphia area. The program goals are to: (1) facilitate the provision of education about state-of-the-art cancer care to primary care physicians who serve minority patients, (2) encourage primary care physicians to refer patients and their families for educational counseling about cancer care, and (3) involve community members in program development, implementation, and evaluation.

In mid-1995, a program team was formed to focus on achieving these goals, and to generate a community advisory committee that would ensure that all perspectives on needs, barriers to care, and other factors are considered in program planning. Key staff include persons from Kimmel Cancer Center (KCC), and Community Health Connections--a local health care consulting company.

The team has taken several steps to make the ACES Program operational. First, the program team drafted documents outlining the ACES Program, focusing on ways in which relationships might be forged among KCC, primary care providers, and community-based organizations interested in promoting health and facilitating access to high quality cancer care services. These draft documents include: ACES purpose, values and goals; pathways in the cancer care system; ACES collaborative program model; the framework for a community advisory committee; a draft project plan; and a framework for project working groups. Second, leaders in public health, community-based health care, and cancer support efforts were identified and invited to participate in an orientation session on the ACES Program. The purpose of the meeting was to inform participants about ACES and to invite their participation on the ACES Advisory Committee. In the spring of 1996, two orientation sessions were scheduled and invitations to participate were extended to 30 representatives of diverse community-based, public health, and cancer support organizations. Specific attention was devoted to seek participation from representatives of organizations addressing the needs of underserved populations, particularly ethnic minority communities and women. Several individuals with relevant expertise in cancer care and health education were also invited.

A total of 26 participants attended the spring 1996 meeting. After learning about the KCCs clinical services and research efforts, and the history and development of the ACES Program, the group discussed the potential role and responsibilities of the Advisory Committee. Among the many ideas discussed were ways to establish linkages in the community, program evaluation activities, and how materials developed for research grant application development are reviewed. At the conclusion of the meetings, a survey of participants was completed to explore their perceptions of the orientation session, interests in cancer care, and willingness to join an ACES Program Advisory Committee. Twenty-five (96 percent) of the participants agreed to serve on the Advisory Committee. The committee is comprised of 18 (72 percent) women and 7 (28 percent) men. In addition, 12 (48 percent) committee members are African American, 6 (24 percent) are white, 3 (12 percent) are Asian or Pacific Islanders, and 3 (12 percent) are other. Six members represent public health organizations, six are from community-based health care organizations, six are from community service organizations, six have special expertise in areas

related to cancer care, and one represents an area Medicaid managed care organization. Committee members indicated strong interest in doing work related to breast, cervical, prostate, and colorectal cancers. They also expressed a desire to participate in cancer education and research projects, to help in the establishment of linkages with community sites where research could be done, and to assist in program evaluation. The types of research projects considered included physician and patient cancer education programs, cancer prevention initiatives, and health promotion efforts utilizing community linkages.

We have developed a framework for generating pilot studies and developing research grant applications which are designed to identify ways of delivering cancer care education and support to patients at increased risk for being diagnosed with cancer. This framework reflects the 'working group' organizational approach of the ACES Advisory Committee. The Advisory Committee has been divided into three working groups based on their expertise and interest: Developmental, Implementation, and Evaluation. The responsibilities of the Development Group include reviewing KCC-generated primary care physician and patient educational initiatives and research grant applications. The Implementation Group focuses on establishing linkages and working partnerships in the community through which educational and research initiatives will be made operational. Evaluation Group activities include monitoring the effort of KCC staff and the other working groups and overall evaluation of the ACES Program.

Initially, KCC staff will be responsible for preparing draft study proposals on cancer prevention and control. Proposals will seek to address the need for patient education and support related to screening, the follow-up of abnormal cancer screening test results, and treatment decision-making for persons diagnosed with the disease. As they are developed, proposals will then be distributed to members of the Developmental and Implementation working groups of the ACES Program. Working group members will review each proposal and provide written feedback to KCC staff and members of the Evaluation working group. The comments and suggestions of working group members will be integrated into the draft proposals, with special attention to the identification of health care providers, physicians and patients from minority populations who can be invited to participate in the proposed studies. Through contacts made by Advisory Committee members who will serve as intermediaries, or boundary spanners, KCC staff will establish working relationships with health care providers. These relationships will provide the foundation for developing pilot studies in defined settings. The pilot studies will serve to demonstrate the feasibility of study implementation. Results will be reported in the research applications, which will be submitted to public health agencies and private organizations for funding. Funded projects will allow for further development and testing of methods and materials that can enhance the quality of cancer care. Intervention impact will be measured as part of each research project. In addition, successful interventions will be disseminated in the community, a process that will be monitored by the Advisory Committee. Finally, we have arranged to receive data from the departments of health of the Commonwealth of Pennsylvania, New Jersey, and Delaware on the number of newly diagnosed cancer patients in Philadelphia, socio-demographic background characteristics, and cancer sites and stage of disease for these patients. These data, which are provided on a semiannual basis, will be analyzed to identify changes in cancer care trends as they relate to the larger ACES Program.

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The ACES Program will be presented as a workshop at the Sixth Biennial Symposium on Minorities, the Medically Underserved, and Cancer. This program was scheduled for April 23-27, 1997 in Washington, DC.

About the Author

Ronald E. Myers, PhD, DSW, is Head of Behavioral Epidemiology in the Department of Medicine, Jefferson Medical College, Thomas Jefferson University.