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Establishing the Infrastructure to Comprehensively Address Cancer Disparities: A Model for Transdisciplinary Approaches

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Summary

The Center for Equal Health (CEH), a transdisciplinary Center of Excellence, was established to investigate cancer disparities comprehensively and achieve health equity through research, education, training, and community outreach. This paper discusses challenges faced by CEH, strategies employed to foster collaborations, lessons learned, and future considerations for establishing similar initiatives.

Keywords

Health disparities; cancer; research; education; training

Eliminating health disparities by achieving health equity is a *Healthy People 2020* goal.¹ In pursuit of this goal, the National Institute on Minority Health and Health Disparities (NIMHD) funds Centers of Excellence to address health disparities through research, education, training, and community engagement.² The NIMHD advocates for a transdisciplinary approach which encourages working *across* disciplines to address health issues, such as cancer, where racial/ethnic disparities in incidence, prevalence, and mortality are significant.³⁻⁵

Through a NIMHD Exploratory Center of Excellence award, the University of South Florida (USF), Moffitt Cancer Center (Moffitt), and key community partners established the Center for Equal Health (CEH) to investigate cancer health disparities collaboratively. Much preparatory work was necessary in obtaining NIMHD funding and designation as a Center of Excellence. This paper shares information regarding establishing the infrastructure of a research center focused on cancer disparities.

Purpose

The CEH was established to develop an infrastructure that would support a comprehensive approach to addressing cancer disparities. Since USF's and Moffitt's mutual areas of interests aligned with the priorities of the Tampa Bay community, this partnership was a natural development. Specifically, CEH's overall purpose is to utilize a transdisciplinary approach to develop novel interventions that address cancer health disparities among minority and medically underserved communities in Florida. The CEH operates with a vision to achieve health equity in the community through cancer research, education, and training. In order to accomplish its purpose, the following Specific Aims were created: 1) to develop and sustain four cores; 2) to support an innovative research project focused on minority health and health disparities; 3) to create opportunities for students and scientists from underrepresented groups through research training, education, and career development activities; 4) to develop and establish an innovative model of community engagement and outreach that can readily be exported and transferred for broad application to other settings and populations for reducing cancer health disparities; 5) to serve as an intellectual and administrative nexus for the stimulation of cancer health disparities research interests, discussions, and planning sessions among center participants as well as other cancer research colleagues; 6) to be a resource on minority health and cancer disparities for public and private organizations as well as community-based organizations in Florida. The four core areas are: Administrative, Research Training and Education, Community Engagement and Outreach, and Research, including a clinical trial research project. A fifth core was added in Year 2 with funding for Comparative Effectiveness Research for Eliminating Disparities (CERED). The core areas work in tandem to achieve the CEH vision. Each core's function and specific aims are listed in Box 1. The overall CEH framework is depicted in Figure 1. The framework highlights how the infrastructure of CEH operates to achieve its goals, strategies, and outcomes.

History

The foundation for CEH was established with the creation of a health disparities work group (comprising community leaders, USF and Moffitt researchers), who met monthly for two years prior to the release of the NIMHD Center of Excellence Requests For Applications. During these meetings, participants discussed community health priorities and strategies for addressing them, and reviewed grant opportunities that best matched the expertise of the work group members. These two years of monthly meetings not only allowed intellectual exchange, but also provided an opportunity for relationship-building and assessment of needs and assets. This was critical in obtaining a clear understanding of the community's needs, expectations, and subsequent commitment to the project. The extensive pre-application process ensured that CEH would address the needs of the defined target population—patients at increased risk for cancer, students, faculty, and community members in three adjacent Florida counties.

In Year 1 of funding, individuals from the community were named as Community Co-Directors. The Community Co-Directors co-chair a Community Advisory Board (CAB) which provides congruency with the needs of the community as it relates to addressing cancer. The CAB meets monthly to assist with articulating the attitudes and beliefs of the people they represent; setting research priorities and shaping research questions; and educating their peers about the community. The External Advisory Board (EAB) was also assembled in Year 1 to review CEH activities, provide recommendations for improvement, and share professional expertise to assist the CEH in fulfilling its overall purpose. Key partnerships were also formed with stakeholders, such as the Florida Department of Health, which positioned the CEH to better address state-wide health concerns.

In Years 2 and 3, the CEH continued strengthening the CAB, EAB, and community-based research collaborations. The CEH was awarded institutional support for pilot research projects and established diverse means of internal and external communication to facilitate dialogue and collaboration amongst its growing partner network. Years 3 and 4 also included completing the work of the pilot projects, continued development of the CAB, writing manuscripts, and continuing the efforts to increase accrual to the clinical trial and CERED research projects. Thus, the first four years were marked by unprecedented growth in membership and partnership with community-based organizations, students, faculty, and local and national research collaborators.

Outcomes

The CEH strives to achieve health equity through implementing several research, training, education, and outreach strategies. Particularly, four key components have led to the success of the CEH in achieving the overarching specific aims mentioned earlier.

1. Address cancer health disparities through collaborative efforts that support the successful implementation of the work of the CEH

The four cores of CEH are anchored by an experienced leadership team of research and clinical faculty, administrators, students, and community members, as well as four advisory

committees—a CAB, EAB, Internal Scientific Advisory Committee, and Community Research Council. The inclusion of these advisors enhances governance and accountability of the CEH with collaborating institutions, and within the community-at-large. Additionally, it allows the CEH to be a cancer disparities resource center and to collaboratively address the needs of the community, learn from others, and capitalize on best practices regarding research, training, education, and outreach. This outcome is measured by successful implementation and day-to-day management of the center, including effective troubleshooting and conflict management among collaborators. Surveys of individuals and organizations that use the services of the center are given to assess satisfaction and perceived quality of services in stimulating their minority cancer health/health disparities interests.

2. Contribute to the science of cancer health disparity research by building on the strengths of the CEH collaborators

The CEH is actively engaged in the discovery and dissemination of research that will expand the science of cancer health disparities. Health disparities research methodology is taught both practically and experientially through seminars, lab work, and community-based research. Considerable expertise exists at Moffitt and USF to address prostate cancer research so much of CEH's research addresses prostate cancer disparities. Prostate cancer is the most commonly diagnosed cancer among African American (AA) men and the second leading cause of cancer death, nationally and in Florida.⁶ Thus, the CEH's *Phase II Clinical Trial of Purified Isoflavones in Prostate Cancer* tests the effect isoflavones have in contributing to a decrease of stabilization of disease progression between AA and White men diagnosed with localized prostate cancer. It is hypothesized that AA will benefit more from the intervention because the androgen receptor in their prostate cells is transcriptionally more active than Whites. Additionally, the CEH's CERED study explores the prostate cancer informed decision-making process. Additional CEH research includes two postdoctoral fellow research projects, and several junior faculty pilot grants. The expected outcome for this aim is the completion of the projects resulting in enhanced scholarly activities evaluated by the number of joint presentations, publications, patents, copyrights, and extramural grants funded based on research findings.

3. Attract and cultivate students, researchers, and health professionals who are dedicated to eliminating disparities

The CEH engenders health disparities training across the continuum of education from middle school to junior faculty by offering a broad array of training and educational opportunities to cultivate future leaders in cancer health disparities. As an example, the CEH provides cancer-focused summer internships for underrepresented minorities in healthcare disciplines (e.g., Project INSPIRE), offers travel awards to health disparities conferences, funds Career Catalyst Research Awards for junior faculty, sponsors career development programs that foster collegiality and networking amongst young scientists (e.g., Research Day, social events), and offers an online health disparities course. The expected outcome for this strategy is a significant increase in the number of minority cancer scientists with an interest in cancer disparities. Specifically, Project INSPIRE is evaluated based on the students completing their research project, attending monthly meetings, present their results

to scientific audience, and completing a five-page research manuscript. Participants evaluate the quality of the training program, satisfaction with their experience, and mentor-mentee relationships. The post-doctoral fellows are expected to present at least two abstracts at a national conference, publish two peer-reviewed manuscripts, and obtain extramural grant funding. All of the students are monitored throughout the training programs and are followed-up *via* online survey one year after completion of the program.

4. Establish and enhance community-academic partnerships through community engagement and outreach activities

Strong community-academic partnerships are vital to the success of the CEH and are facilitated via community engagement and outreach efforts. These efforts include conducting community-based cancer awareness activities, including small group, educational sessions called *talking circles* and large, community events such as, health fairs and cancer education town hall meetings. Each year, CEH conducts three to four talking circles, participates in over 20 community health fairs, and facilitates at least one or two cancer education town hall meetings. Additionally, the CEH created a series of cancer prevention and research messages in print and video, and uses local print media outlets to disseminate messages about educational events and trainings and to provide a synopsis of past sponsored activities. The message dissemination, via podcasts, involves cancer survivors sharing their stories and experiences with cancer. The CEH also established a Community Health Worker (CHW) training program. The CHW training program provides necessary knowledge and skills for lay people to be leaders in their communities by addressing health initiatives and acting as a liaison between researchers and their communities. The unique community engagement and outreach characteristics of the CEH are designed to motivate community members to take action in the form of participating in health promoting behaviors and increase knowledge of and capacity to address health disparities. This is evaluated through surveying our partners in the community on their ability to address cancer health disparities and the participants on their behaviors and knowledge of disparities.

Lessons Learned

Currently, over 200 members (faculty, staff, undergraduate and graduate students, postdoctoral fellows, and community members) constitute the CEH. Implementing a Center of this magnitude with such a diverse group of stakeholders inevitably gives rise to challenges.

As the Center has a large and diverse membership, communication and information sharing among all its members has become a challenge, but is essential to CEH's success. To address communication needs for students, faculty, and community members (which often differ) the CEH has implemented varying strategies. These include the use of Twitter, Facebook, LinkedIn, YouTube, Microsoft Share Point, a CEH website and a CEH email account, as means to foster communication. Additionally, monthly meetings and annual retreats have been conducted to foster collaboration. Students prefer communication *via* social media, while researchers prefer e-mail, and community members consistently request

face-to-face meetings and retreats. Having all communication vehicles ensures effective communication to all interested parties.

In the Phase II clinical trial, the recruitment of African American men is especially challenging given barriers such as the lack of awareness and education and the issue of trust among participants.⁷⁻⁹ Much like other investigators around the country, CEH investigators are addressing these barriers by researching novel marketing techniques to educate communities about the need for African American males participation in clinical trials, targeting strategies to enlist physicians with large numbers of African American male patients in effective recruitment, and inviting other hospitals around the state to join in recruiting patients.

In community-based research, challenges exist in meeting the competing needs of researchers and community members. Often the timelines and academic pressures of researchers do not match those of community leaders and organizations. Allotting enough time to educate researchers regarding such matters as effective community-based research and educating community members regarding the demands of funding agencies, and Institutional Review Board (IRB) requirements, is a challenge. The CEH's community-based research employs strategies of training and equipping community health workers to assist in the research process.¹⁰ Community health workers assist by delivering culturally competent information to research participants. Additionally, community members and researchers have been trained to create community-based workshops on grant writing skills and IRB processes and have a Community Research Council to advocate for and oversee clinical and translational research activities.

Funding the many CEH training and educational programs has also posed a challenge. Specifically, more student-funding was needed for periods longer than originally budgeted. CEH was able to obtain strong institutional support, including website advertisement for positions, computer and office supplies, workspace, faculty incentives for mentorship, funding for eight undergraduate students *via* Project INSPIRE, three full-time post-doctoral fellows, and three Career Catalyst Awardees. Pilot grant funding was also provided from Moffitt and USF in the amount of \$100,000.

Another major challenge for CEH has been identifying and sustaining partnerships with community groups in a tri-county area. Early on, most activities focused on one county due to the infrastructure of some communities being much more established for research, training and outreach, whereas, other areas needed more capacity-building assistance to participate in an effective partnership. Even so, realizing that partnerships are vital to developing health promotion programs that meet the vast array of community health needs,¹¹ CEH has directed considerable effort to engage as many communities as possible in county-wide events and speaking engagements. Over time, more of the CEH catchment area has become involved in research, training, education, and outreach to address cancer health disparities.

Conclusion

Health disparities are created and sustained by an interlocking social, economic, political, and cultural context in which race, ethnicity, socioeconomic status, gender, and other crucial factors place individuals at risk for premature disease and death. The CEH is committed to addressing and overcoming associated challenges in order to be an effective change agent for cancer health disparity elimination. This collaborative between USF, Moffitt, and community partners supplements national cancer health disparity elimination efforts by employing innovative strategies to understand and reduce cancer health disparities within racial/ethnic minority and medically underserved populations. The CEH engages community members, students, and health professionals, in a model of synergistic activities including training and education, community outreach, and research.

Having implemented several strategies over four years, in its fifth and subsequent years, the CEH plans to increase fiscal sustainability; expand the geographical reach of community-based education and outreach activities; enrich institutional and community educational offerings; enhance research study recruitment and participation; design and conduct evaluation activities; and share processes, best practices, and research outcomes via publications and presentations. By integrating these approaches, the CEH will strengthen its infrastructure while acting as the nucleus for the exchange of transdisciplinary research ideas, intellectual discussions, and strategic planning that will best lead to discovery, development, and delivery of mechanisms to address cancer health disparities in Florida and beyond.

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Notes

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Box 1

CENTER FOR EQUAL HEALTH (CEH) CORES, PRIMARY FUNCTION, AND SPECIFIC AIMS

Core Name	Primary Function	Specific Aims
Administrative Core	Provide oversight and management of the overall center and foster integration of each core's activities	Provide administrative oversight, guidance, and coordination; Provide grants management support and coordination; Organize and coordinate support for three advisory bodies (EAB, ISAC, CAB); Monitor core activities; Plan and develop a web-based communication platform; and Plan and implement an evaluation mechanism.
Research Training and Education Core	Cultivate competent minority researchers and healthcare professionals who will be prepared to effectively address cancer disparities through comprehensive coursework and training activities	Establish two on-line didactic courses; Increase the knowledge and exposure of undergraduate students to health disparities research and career options; Provide opportunity and support for post-doctoral fellows; Establish Graduate/Post-Doctoral Travel Awards; Solicit and fund a junior minority researcher each year; Promote training and professional interaction regarding cancer health disparities issues; Support the CEOC in the creation and implementation of Community-Based Participatory Research Training Institute
Community Engagement and Outreach Core	Stimulate and expand community-academic partnerships that positively impact health disparities through innovative community awareness and outreach activities.	Create a robust infrastructure that engages community and academic partners; Disseminate research knowledge using novel delivery methods; Cultivate community interest in research participation and promote community ownership of research studies
Research Core Research Project	Promote innovative research projects, seminars, and mentoring activities as well as oversee a Phase II Clinical Trial	Oversee the conduct and successful completion of a cancer disparity research project; Assist investigators in the development and submission of new research projects for extramural funding
Comparative Effectiveness Research for Eliminating Disparities Core	Compare the effectiveness of community-based education to usual care regarding prostate cancer informed decision making among AA men	Evaluate effectiveness of the enhanced Patient Decision Aid (PtDA); Evaluate a CHW training program; Compare the effectiveness of a CHW guided, community-based education program (with an enhanced PtDA) to usual care

EAB = External Advisory Board

ISAC = Illinois Student Assistance Commission

CAB = Community Advisory Board

CHW = Community Health Workers

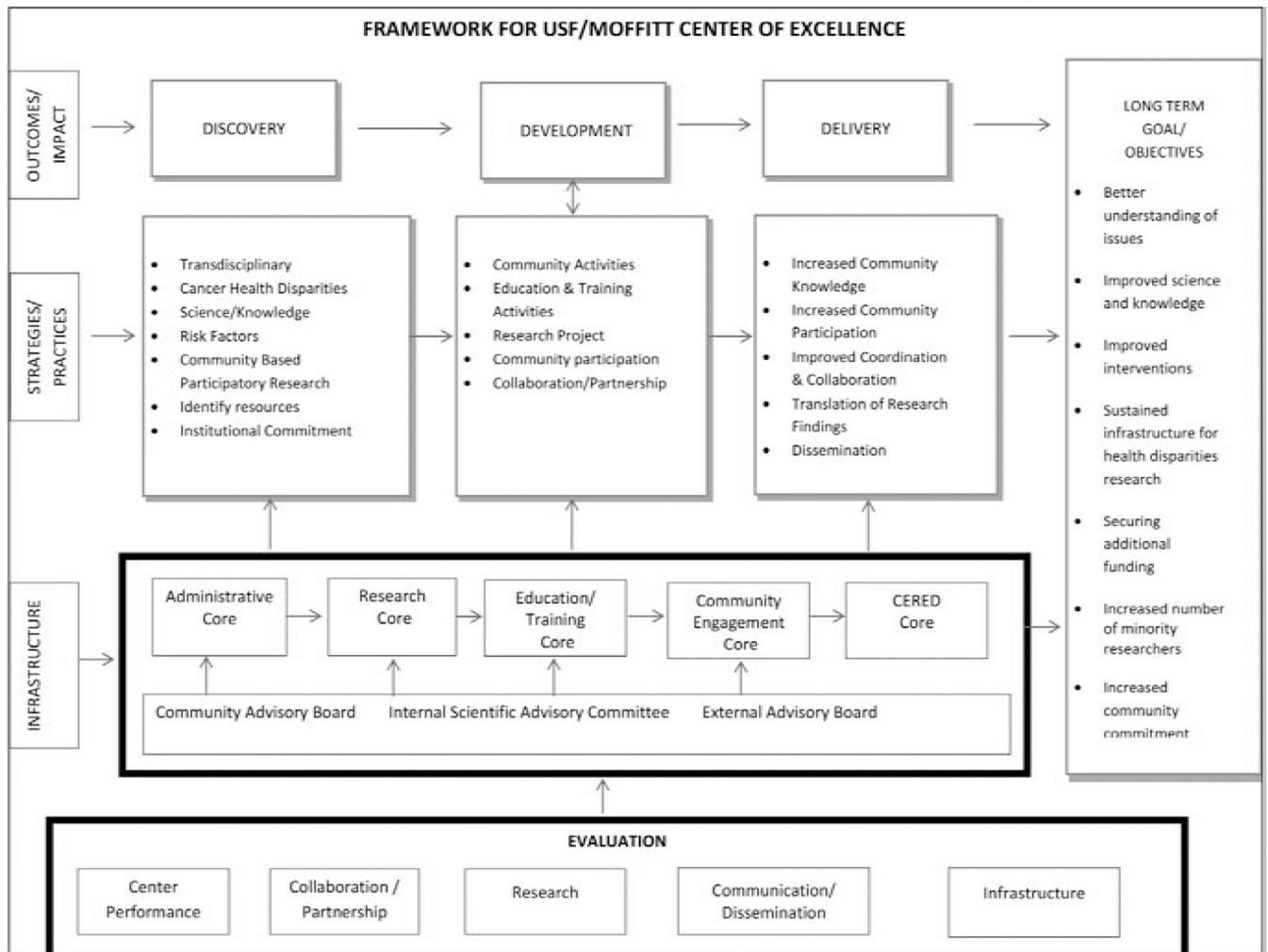


Figure 1.
Framework for the Center for Equal Health