



Published in final edited form as:

J Cancer Educ. 2022 April ; 37(2): 338–342. doi:10.1007/s13187-020-01819-w.

The Cancer Clear & Simple Story: Developing a Cancer Prevention Curriculum for Rural Wisconsin through a Community Partnership

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Abstract

To address rural cancer disparities the University of Wisconsin Carbone Cancer Center launched a rural cancer project through its Cancer Health Disparities Initiative (CHDI) in 2010. With support from the National Cancer Institute's (NCI) National Outreach Network, CHDI conducted an assessment of rural counties and partnered with Adams County to implement a collaborative cancer education project. Together CHDI and Adams County partners selected an evidence based educational curriculum, Understanding Cancer, as a basis for local adaptation for use with rural Wisconsin communities. The new curriculum, titled Cancer Clear & Simple (CC&S), consists of three modules: (1) cancer basics, (2) cancer prevention, and (3) cancer screening. CC&S has also been culturally tailored for African American and Latino populations. The adaptation utilized community involvement throughout a multi-step process to ensure cultural appropriateness. The process included materials selection, translation, conceptual adaptation, visual adaptation, and validation with target audiences. All adaptations of the curriculum incorporate health literacy principles and are designed to build knowledge and improve health-related decision-making around lung, colorectal, skin, breast, cervical and prostate cancer. Current efforts seek to: (1) increase the evidence of CC&S' effectiveness through additional research, (2) expand its use by new audiences, and (3) adapt it into a web-based platform featuring a cancer prevention serious game.

Keywords

Rural disparities; Cancer education; Cancer prevention; Community-Based Participatory Research; cultural adaptation; adult education; cancer disparities; culturally appropriate

¹CBPR is an applied collaborative approach that equitably involves and enables communities to more actively participate in the full spectrum of research (from conception – design – conduct – analysis – interpretation – conclusions – communication of results) with a goal of influencing change in community health, systems, programs or policies [9, 10].

Background

It is estimated that 46 to 59 million people, or 14% to 19% of the U.S. population live in rural areas [1, 2]. Rural communities often have higher poverty rates, lower education levels, a higher percentage of elderly residents, less access to health services and fewer resources to support public health compared to urban areas [3]. These factors and others often mean rural communities face increased rates of morbidity and mortality, and a higher percentage of excess deaths from all leading causes [4]. A 2017 National Cancer Institute report noted cancer rates were also higher in rural counties compared to metropolitan counties: +12.3 cases per 100,000 people or 2.7% for incidence and +15.9 cases or 9.6% for mortality [5].

The University of Wisconsin Carbone Cancer Center (UWCCC) launched a rural cancer project through its Cancer Health Disparities Initiative (CHDI) in 2010, with support from the National Cancer Institute's National Outreach Network (NON). NON charged CHDI with two sequential tasks. The first was to identify a community with cancer disparities. The second was to implement a collaborative project to develop and evaluate an educational intervention that was culturally appropriate and health literacy informed for the community. We began by conducting a comprehensive assessment of rural cancer control needs in the Carbone Cancer Center's 16 county catchment region in south central Wisconsin. The assessment was led by CHDI's Community Health Educator (CHE) and found that 12 counties in the region had cancer incidence or mortality rates above the state average. Following evaluation of the quantitative data, the CHE conducted interviews with local organizations and community leaders in counties with a higher cancer burden.

Adams County was identified as a county with prominent cancer and health related disparities—the cancer death rate in Adams was nearly 20 percent higher than the state average (216 vs. 182 per 100,000) [6] and Adams ranked 69th (of 72 Wisconsin counties) in the 2012 County Health Rankings [7]. Interviewees in Adams County helped us understand the quantitative data and proposed a promising county partnership with local organizational assets, committed community members, and leaders who were interested in addressing levels of cancer and chronic disease in their community. Following a presentation of the interview results, a cadre of community members—representing Adams County Public Health, Aging and Disabilities Resource Center, Moundview Memorial Hospital (now Gundersen Moundview Hospital and Clinics), and UW-Extension Family Living—decided to work with CHDI and formed the Adams County Cancer Awareness Team (ACCAT).

Development of Cancer Clear & Simple

Draft Content

Using community-based participatory research (CBPR) principles [1], we collaborated with ACCAT to determine the best intervention to harness local assets and improve cancer control in their community. ACCAT identified several barriers to appropriate cancer screening and risk reduction behavior in their county. These barriers included internalized attitudes and health practices that prioritize medical intervention rather than prevention behaviors, lack of access to care and insurance coverage, low socioeconomic status, competing demands for time, cultural norms that emphasize self-reliance and autonomy, perceived lack of efficacy

regarding cancer prevention behaviors, and a sense of fatalism surrounding cancer. ACCAT and CHDI decided the best way to support a culture shift towards prevention was to educate how one's own action impacts cancer risk.

CHDI assessed evidence-based cancer educational curricula and presented ACCAT with two options that addressed cancer prevention and screening: Understanding Cancer and Cancer 101. Of the two, ACCAT selected Understanding Cancer, an evidenced-based curriculum created by the Alaska Native Tribal Health Consortium with support from the National Cancer Institute [8]. Understanding Cancer was unanimously chosen because of its community focus, simple charts, preferred layout, and complete content. In addition to the cancer prevention and screening information, ACCAT recommended that cancer basics content be included to increase understanding and motivate behavior change. ACCAT and CHDI proceeded to streamline the Understanding Cancer text, prepare a draft of the new curriculum and design a tiered engagement process to involve community residents, local agency staff, and community leaders in testing and adapting the content for use in a rural culture. Using three tiers for community feedback allowed for extensive input from all participants. The draft curriculum included three modules: 1) Cancer Basics– what cancer is, how a cancer diagnosis is made and the importance of cancer stages; (2) Cancer Prevention– the importance of healthy behaviors, reducing risk and how to make healthier lifestyle choices; (3) Cancer Screening–the benefits of cancer screening, screening methods available for specific cancers, recommended screening guidelines, plus where to access screening facilities and resources in Adams County. This new curriculum became known as Cancer Clear & Simple (CC&S).

Community Adaptation

Educational sessions with local participants were used to test and revise the CC&S curriculum. ACCAT solicited volunteers and recruited participants for each CC&S training according to the tiered process described earlier. These individuals represented a cross-section of the county based upon age, sex, household size, and township of residence. Adams County is a highly networked community and to maintain confidentiality of all participants demographic data is not included. However, due to ACCAT's targeted recruitment strategies, it is reasonable to assume that participants reflected Adams County's socioeconomic data mentioned previously. Each training covered one module and lasted 90 minutes; the training incorporated PowerPoint slides, handouts, worksheets, short videos, interactive activities/games, role-play, and roundtable discussions. CHDI staff collected qualitative and quantitative feedback from each training session, modified the curriculum as indicated, and presented the modified version to the next group in the tiered process.

Several important changes were made to CC&S based on feedback from Adams County community members. Feedback suggested several modifications like removing Oxford commas, using an active voice, increasing text size, and eliminating unnecessary details. Other key changes included: additional simple definitions and illustrations to increase participant understanding of medical terms, expanded information about cancer screening and insurance coverage, a Frequently Asked Questions section, plus Questions to Ask Your Doctor worksheets, and information about local cancer-related resources. Featured local

resources included: availability of cancer screening, financial assistance, home health care, hospice, low cost clinics, medical transportation, how/where to access oncology/cancer services, resource referral agencies, and support groups. CC&S materials were branded with a pinecone image and the ACCAT organizational logos to promote local relevance and easy identification. The Simple Measure of Gobbledygook, or SMOG, readability formula [11] was used to evaluate the readability of CC&S. Ultimately the curriculum reads at an eighth-grade reading level because it includes commonly used medical terms such as metastasis, biopsy, and mammogram. Every effort was made to define these complex terms clearly and simply. Educational images and graphics were frequently used to illustrate some of these complex terms. For example, there is an image that illustrates cancer staging to help cater to visual learners. When these complex terms are removed, the curriculum is rated below a fifth-grade reading level. Each module includes a glossary of terms to bolster the health literacy of learners.

In addition to a glossary, local resources were added to each module to aid in learners' ability to access additional information and care. These included, the local hospital and clinic, the Aging and Disability Resource Center, the Public Health Department, the Wisconsin Well Women Program, the University of Wisconsin Carbone Cancer Center, and others. Community engagement experts also suggested adding blank space where local partners and facilitators could add their information. This space, coupled with a blank notes section, allowed individual learners to add supplemental information and resources most relevant to them.

A locally adapted version of the Suitability Assessment of Materials (SAM) survey instrument was employed in order to also assess the readability, usability and suitability of the educational modules [12]. As presented in Table 1, the SAM survey results showed that participants found the materials "above average" to "outstanding" in the areas of content, literacy, graphics, layout, engagement and motivation and cultural appropriateness.

Community Ownership and Sustainability

From the beginning of the collaboration, ACCAT was acutely aware of the growing isolation and declining number of "crosscutting ties" among local residents and organizations. ACCAT knew this would hamper their efforts to increase awareness of CC&S and sustainably implement it. Consequently, ACCAT members consciously sought to build a network in Adams County that linked volunteer groups, membership organizations and boards across local economic, social, and political structures. Their goal was to expand community ownership of the cancer prevention initiative in order to increase its impact. To that end, ACCAT members made 20 presentations to various organizations in the first six months of the partnership, including Lions Clubs, Moundview Memorial Hospital & Clinics provider group and hospital board, Adams County Extension Home and Community Educators, faith groups, Adams County Board of Supervisors, the local Chamber of Commerce, and Midstate Technical College board, to name a few. This effort was complimented by an extensive publicity campaign ranging from articles in the local county newspaper, postings on multiple organizational websites, a television news story, and grocery bag fliers. As a result of these efforts, ACCAT successfully recruited and trained

multiple CC&S community volunteer trainers. Since then, they have received a request to present to the Governor's statewide Rural Economic Development Council, secured an external multi-year grant to support an innovative allied project, developed a research study to test the efficacy of CC&S, and was given an award from the Wisconsin Cancer Collaborative (formerly the Wisconsin Cancer Council). They viewed these outcomes as evidence of the project's impact in Adams County and supportive of the broader dissemination of CC&S.

Due to growing interest, CHDI and ACCAT decided to develop a train-the-trainer strategy to disseminate the CC&S curriculum and ensure its sustainability. The team developed a training manual that incorporated adult learning principles, interactive activities and session evaluation tools, in addition to a guide on how to facilitate a CC&S education session. CHDI also developed over 45 one-to-two-page topical handouts to compliment the three modules and training manual. Subsequent work on the project emphasized recruiting and training local volunteer trainers, as well as conducting educational sessions. In 2014, implementation of CC&S educational sessions was expanded to neighboring Juneau and Waushara Counties. Local coalitions were formed, and volunteer recruitment and training implemented using the new Facilitator Guide. During this period, CHDI staff successfully collaborated with African American and Latinx community representatives in Dane County, Wisconsin to culturally adapt and translate CC&S for use with these populations.

Expansion, Lessons Learned, and Limitations

Expansion

The UW-Extension Family Living Educator in Adams County provided significant support in the development of CC&S and its dissemination to neighboring counties. The involvement of the Family Living Educator drew the attention of the UW-Extension Family Living Director who approached CHDI about a funding opportunity to expand CC&S statewide in Wisconsin. The County-based Extension Educator, state Extension leaders, and CHDI agreed to collaborate and developed the "Reducing Rural Cancer Disparities Together" project which was funded through a two-year Health and Safety Grant from the United States Department of Agriculture (USDA) National Institute of Food and Agriculture. The project included the development of a new facilitator website and training videos, expanded tracking and evaluation, statewide in-person trainings, and a coaching component to support local coalitions in promoting systems change. This project resulted in 71 new CC&S-trained facilitators, including staff from UW-Extension, clinical systems, tribal health departments, non-profit organizations, and community volunteers serving more than 30 rural counties in Wisconsin.

In addition, ACCAT expressed interest in increasing the number of working age adults exposed to CC&S and evaluating its impact. CHDI supported ACCAT's goals, vetted an experienced health disparities researcher, Elizabeth Jacobs, MD, and introduced her to ACCAT. Dr. Jacobs and ACCAT agreed to partner, and together with CHDI, set out to design a research project that would adapt CC&S for use in a workplace setting as well as test its efficacy. A two-year CBPR pilot study, "A Community Based Approach to Reducing Rural Cancer Disparities," was submitted to the American Cancer Society under a Pilot and

Exploratory Studies RFA for Cancer Control and Prevention Research. Following revision, the study was funded and successfully implemented, and the project team was subsequently recognized with a UW Madison Chancellor's Community-University Partnership Award.

Lessons Learned

The Cancer Clear & Simple story underscores the value of a good assessment that identifies an interested community with capacity, as well as need. The iterative adaption process we used was effective in developing a locally tailored curriculum, and the use of a train the trainer model to disseminate CC&S was successful because it built upon local knowledge and networks and was designed to promote sustainability. The Cancer Clear & Simple story also underscores the value of a deep ongoing collaboration with University Extension to enhance and expand local health education. While the use of volunteer facilitators helped quickly expand the work, quick growth and relying on volunteer time limited quality tracking and evaluation. Finally, adapting an existing evidence-based curriculum to develop a new educational tool means the new curriculum will require formal testing in order to demonstrate its effectiveness and build an evidence base.

Limitations

The original creation of CC&S had a local focus for one, high-need, rural county in Wisconsin. Due to this specific context of implementation and vast differences in rural populations across America, additional research is needed to determine if the curriculum is effective in other communities. ACCAT and community partners chose to focus on implementation and sustainability, rather than evaluation and testing the CC&S curriculum. To our knowledge, no other cancer education curriculum focuses on prevention and awareness has been tailored for rural communities limiting potential direct comparisons.

Conclusion

The development, sustainability, and expansion of Cancer Clear & Simple is a success story that illustrates the value, importance, and impact of a community-academic partnership founded on CBPR principles. CHDI worked closely with local community members to understand the assets and needs of their community and identified a way to collaborate and help achieve their community's cancer control goals. Together, ACCAT and CHDI then designed an intervention, tested its suitability and acceptability, modified it, and implemented and expanded it. Throughout its evolving history, this community-driven project has benefited greatly from early and ongoing support from the Adams County community members who formed ACCAT, UW-Extension Educators in Adams County and across the state, and the UW Carbone Cancer Center. Current efforts seek to: (1) increase the evidence of CC&S' effectiveness through additional research with larger, more diverse populations, (2) expand its use by new audiences in other states and internationally, specifically in Lagos, Nigeria, and (3) adapt it into a web-based platform featuring a cancer prevention serious game.

Acknowledgements

The authors would like to thank Carol Johnson, Adams County Resident; Sarah Grosshuesch, Adams County Health & Human Services Department; Leah Ekstein, Adams County Health & Human Services Department; Maureen Bruce, Gundersen Moundview Hospital and Clinics

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Table 1.

Suitability Assessment of Materials (SAM) Survey Results *

Participants	Content	Literacy	Graphics	Layout	Engagement & Motivation	Cultural Appropriateness
Community Leaders	4.64	4.88	4.30	4.76	4.64	4.47
Community Agency Staff	4.40	3.91	4.07	4.34	4.26	4.38
Community Residents	4.74	4.66	4.67	4.58	4.76	4.70

* Scale: 1 = unacceptable, 2 = below average, 3 = average, 4 = above average, 5 = outstanding