20 Years Later: Continued Relevance of Cancer, Culture, and Literacy in Cancer Education for Social Justice and Health Equity

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The persistence of health disparities is no longer a novel observation, but a well-documented reality whereby many populations have markedly unrelenting poorer levels of health. Inequities are influenced by complex historical and contemporary relationships between health and biology, and further affected by racism, discrimination, socioeconomic status, physical environment, literacy, and sexual orientation/gender identity to name a few [1, 2]. Recognition of such factors is essential for a norm of inclusion for achieving health equity [3]. As society globalizes through technological innovations and migration of populations, increasing prominence of cultural- and literacy-based research opportunities evolves in the field of cancer education. Crucially important is a need to assess, recognize, and address the effect of changing trends and recent events on cancer health disparities. In this editorial, we highlight the continued relevance of culture and health literacy in cancer education, and the promising opportunity that technology may play to advance health equity and social justice.

Culture and Health Literacy

Culture and health literacy shape the experience of health and illness and are inherently interconnected due to the relationship between people's background and beliefs, as well as how people process, synthesize, and consume information in

response to their everyday lives [4]. *Culture* is a type of shared identity, a way in which people make sense of and derive meaning from their reality. Importantly, culture adds informative contextual perspectives [5], which are crucial to the development of meaningful cancer education programs and interventions. *Health literacy* denotes the ability of people to use their "world of information" to make well-informed health choices [6]. Likewise, comprehending information is associated with how that information is presented and processed by the individual reflecting both the individual's cultural identity and literacy level [7]. As in the COVID-19 pandemic, this means recognizing measures that protect oneself from risk of exposure and spread (e.g., 20-second handwashing with soap and water, wearing a mask, social distancing), and signals comprehending terms like "flattening the curve" or "herd immunity" with a goal of helping people to go about their daily lives in a safe and healthy manner [8].

Too often, a critical discovery-delivery disconnect exists between scientific evidence and operational measures enacted (not merely suggested) to actualize the reduction of cancer health disparities [5, 9]. Available literature on healthcare disparities continue to highlight extant issues with cancer prevention, screening and survivorship, clinical trial enrollment, therapy adherence, and treatment modality variations (access and selection) among underserved and racial/ethnic minority populations [10–12], suggesting that many inequities stem from the fact that people experience and interpret disease and treatment differently (*cultural influences*), and many groups have different and unequal access to healthcare services and information (*health literacy influences*).

Reflecting on our own team's efforts in this field, eight Cancer Culture and Literacy biennial meetings were held (2000–2012) in Clearwater, FL, attracting over 2000 individuals. From 2002 to 2005, the Cancer, Culture, and Literacy Institute (CCLI-R25E) engaged 86 cancer control investigators in a 5-day institute, web-based modules, and mentoring activities to build momentum integrating culture and literacy into their research, education, and

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practice paradigms [13]. Fast forward a few decades, many past CCL participants are now prominent leaders in the fields of cancer prevention, cancer education, and health disparities, carrying out critical research and trainings that consider culture and literacy. To conceptualize a fresh training approach for the next generation of researchers, in 2019, a 2-day roundtable was convened with 32 CCLI participants to explore emerging CCL topics and methods, identify knowledge gaps and opportunities in research, and recommend training directions.

Topics addressed in previous CCL training activities were judged still relevant (e.g., worldview perspectives, community-based participatory research [CBPR], development of low literacy materials, cultural/ linguistic dimensions and expressions of health). Yet, new topics surfaced such as interdisciplinary research, workforce development in community partner engagement, dissemination and implementation science to support systems change, big data analyses (i.e., GIS, network analysis), and particularly emerging technologies as well as historical and current events that play a role in people's learning, motivation and health decision-making in the context of the larger world system and local community realities (Fig. 1).

Several recommendations materialized including:

- Amplify contemporary focus of culture and literacy in cancer education, practice, and research
- Advance interdisciplinary collaborations to invigorate research methods
- Restart CCLI and expand training initiatives to “educate the educators”
- Harness technology to increase research connectedness and information reach to intergenerational, at-risk, and geographically dispersed groups

- Increase visibility of cancer, culture, and literacy in scientific/lay literature

A commonality within these recommendations is a need for innovative technical skills that illuminate the nexus of culture and literacy—especially beyond the current dichotomous or nominal methods that tend to mask the significance of culture and literacy as social determinants of health [5]. In order to facilitate the technical education necessary, roundtable participants agreed that other disciplines—such as Engineering, Computer Science, Communications/Design, and Geography—that regularly use technologies be integrated into cancer education and health disparity research partnerships to provide expertise and training. Technological innovation requires cancer educators to be knowledgeable of technical and methodological skills lacking in current cancer disparity research and education workforce; otherwise, ameliorating health disparities remains an aspiration rather than an achievement.

Continued Discourse: a Modern Look at Culture and Literacy in Cancer Education, Research, and Practice

Culture and literacy considerations have been apparent in many national imperatives [14–16]; nonetheless, headway in reducing cancer health disparities is slow. What lacks may be a connection between how we apply what we know and what we keep discovering about culture and literacy [9], along with information technologies that might facilitate the observation of how culture and literacy affect health outcomes in different dimensions, such as both geographically and temporally. The cancer education

Fig. 1. CCL Interdisciplinarity Concept

field can progress rapidly through extensive information and technical skill exchange, fostered at multiple levels of workforce development. Our greatest strengths are our interdisciplinarity—meaning we as a scientific community can, have, and must continue to influence policies and institutions to eliminate structural inequalities to reduce cancer health disparities. Thus, we must further the inclusion of culture and literacy in cancer research, training, and practice, and stimulate improved conceptualization of culture and literacy including the application of technological innovations.

There exist successful integrations of technology-infused culture- and literacy-specific cancer education to empower at-risk groups and marginalized communities. Wallace and Behringer [17] draw from the traditional cultural influence of religion and spirituality by training clergy members from rural Appalachia on the National Library of Medicine's [MedlinePlus.gov](https://pubmed.ncbi.nlm.nih.gov/) database using iPads, with the intent to lay the foundation for a health ministry for their respective churches. As a result, clergy developed new perspectives for promoting healthy lifestyles and improving health literacy information in their congregations. Research by Im et al. [18] reflects on their experiences recruiting Asian-American breast cancer survivors in a technology-infused intervention. They found subethnic and linguistic preferences for being contacted by “culturally matched” study staff for recruitment and follow-ups, and distinct communication “app” preferences based on subethnic Asian-American groups.

Summary

To keep “CCL” at the forefront of our field, we need to develop guiding research and practice paradigms that integrate culture and literacy, intersectional frameworks, and policy change informed by fresh critical perspectives to bring to light social, historical, economic, and political conditions that give rise to both health and disease. Transdisciplinary research must be **bold**—and critically delve into fundamental influences of racial injustice that affect underlying social determinants of health. Heightened focus is needed to embark on dynamic cancer educational and technological innovations and inspired examples of transdisciplinary cancer training efforts for the current and prospective cancer health disparities workforce. As cancer educators, our resolve toward social justice and health equity should be further strengthened through proactive inclusivity and authentic and accelerated discovery, development, and dissemination. We must *start* to learn from history. Our collective CCL efforts everywhere must prioritize equal justice and health equity for all populations.

“Injustice anywhere is a threat to justice everywhere.”

Martin Luther King Jr.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflicts of interest.

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