Inclusion of Underserved Racial and Ethnic Groups in Cancer Intervention Research Using New Media: A Systematic Literature Review

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Background	An increasing number of behavioral and psychosocial cancer interventions incorporate new media elements that are digital, networked, and interactive. However, it is unclear to what extent new media is being leveraged to benefit underserved racial and ethnic groups who disproportionately bear the burden of cancer. This inquiry is timely in light of growing evidence that these groups are receptive to new media. A systematic literature review was conducted to assess the inclusion of these groups in research on cancer-related new media interventions and use of new media to reduce racial and ethnic cancer disparities.
Methods	A systematic search of three databases was conducted for articles published between January 2000 and March 2012 that presented studies of user experience with a behavioral or psychosocial cancer-related intervention with at least one new media component.
Results	Thirty-six articles were included in the final review. In about one-quarter of the studies, less than 20% of participants were African American, Latino, Asian American, or American Indian. In less than 10% of the studies, 80% or more of the samples were members of the aforementioned groups. Almost one-third of the studies reviewed were categorized as disparity focused but limited data were available on racial and ethnic differences in responses to new media interventions.
Conclusions	Findings suggest that the promise and potential of new media cancer interventions are largely unrealized among the underserved. Additional research is needed to investigate a wide range of issues related to the development and delivery of such interventions in diverse racial and ethnic groups.

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There is mounting evidence that Internet-based interventions are effective in improving cancer-related psychological and behavioral outcomes (1,2). Advances in technology are now offering new opportunities to enhance the effectiveness of these interventions through new media: information and communication technologies that offer instant updates, the capability to personalize and customize content, and the chance to share with others (3). This definition is consistent with three key concepts that are integral to new media (4). First, new media are digital, meaning that data are processed and stored in binary numeric form rather than analog form, thus enabling readability and integration across digital systems. Second, new media are networked so that content is available from multiple sources and across platforms and devices. Third, new media are interactive and facilitate user participation and customization. Indeed, there is consensus that interactivity is a defining element of new media, enabling intense personal engagement through user-generated and user-driven content and multidirectional communication flow (5).

New media have much to offer cancer interventions and may substantially expand their reach and impact. This may be especially true among historically medically underserved racial and ethnic groups: African Americans, Latinos, Asian Americans, and American Indian/Alaska Natives. It has been well documented that these groups often bear a greater cancer burden compared with whites in terms of higher rates of cancer incidence, late stage diagnosis, morbidity and mortality, as well as lower rates of survival, receipt of substandard cancer care, and poor survivorship outcomes (6–9). Efforts to eliminate these disparities through behavioral and psychosocial interventions might be accelerated by new media but the extent to which new media are used in such interventions is unclear.

Past discussion of technology use among diverse racial and ethnic groups has tended to focus on the "digital divide" and disproportionately low computer and Internet access and use among certain groups, including health-related use (10). However, there is evidence that this divide is narrowing, especially when devices other than desktop computers are considered. Recent national survey data reveal that significantly more African Americans and Latinos own a cell phone compared with whites, and African Americans are more likely to own a smartphone (11,12). African Americans and Latinos are significantly more likely than whites to use a cell phone to access the Internet, and African Americans are more likely to download apps on a cell phone (13). African Americans and Latinos are also significantly more likely to use their cell phones to look for health information online and African Americans more likely to receive health information via text messages (14,15). These trends are especially

Table 1. Selected eligible articles: 1) studies with 20% or more African American (AfAm), Latino (L), Asian American (AA), or American Indian/Alaska Native (AI/AN) participants and 2) studies with a cancer disparities focus*

Study	Intervention	New media component	Study design	Participants and setting	Racial/ethnic demographics of the sample
Clayman et al. (23)	Cancer CareLinks, a patient education program for newly diagnosed breast cancer patients	A website that allows patients to create individualized treatment flowcharts and personalize their health-care team with photos and information on each provider, tailored across health-care settings	Descriptive, qualitative	30 breast cancer patients receiving consultation at a cancer center; mean age = 52 y; age range = 29–80 y; also 22 health-care providers	W: 80.0%; AfAm: 13.3%; AA/PI: 7.7% (patients only; provider race/ethnicity not reported)
Dorfman et al. (25)	An internet-based prostate cancer screening decision tool	Website through which users enter screening history to tailor information received; also includes an interactive values clarification component	Descriptive, qualitative	14 men with no prostate cancer diagnosis recruited in treatment settings; mean age = 54.0 y	W: 50.0%; AfAm: 50.0%
Gustafson et al. (26)	CHESS	Internet-based eHealth system with specific information, support, and decision services, including facilitated discussion and support groups via bulletin board, access to experts, and tailored decision services	Randomized controlled trial, quantitative	229 women within 1 y of diagnosis or with metastatic cancer, living at or below 250% of federal poverty line; patients recruited as part of a DDPP; also included a comparison group (n = 51, demographics not reported)	W: 62.9%; AfAm: 37.1%
Han et al. (29)	CHESS	See Gustafson et al. (26)	Observational, quantitative	294 breast cancer patients within 180 d of diagnosis; mean age = 51 y; portion of sample recruited through DDPP; see Gustafson et al. (26)	W: 68.2%; AfAm: 31.8%
Jaja et al. (33)	The P4, an internet-based treatment decision support system for men with localized prostate cancer	Interactive website assessing patient data, symptoms, and preferences for decisional control to provide customized decision support	Descriptive, quantitative and qualitative	12 community-dwelling men (no other sample characteristics reported)	AfAm: 100%
Johns et al. (34)	The INCPAD telecare management intervention combining a nurse–physician team with automated symptom monitoring	Option to complete automated system monitoring either through interactive voice recorded telephone calls or web-based surveys	Observational, quantitative	202 cancer patients recruited in treatment settings meeting criteria for clinically significant depression or persistent pain; mean age = 58.7 y	W: 79.0%; AfAm: 20.0%; other: 1.0%
Kroenke et al. (36)	The INCPAD intervention. See Johns et al. (34)	See Johns et al. (34)	Randomized controlled trial, quantitative	405 cancer patients in treatment settings meeting criteria for clinically significant depression or persistent pain; mean age: intervention arm = 58.7 y, control arm = 59.0 y	Intervention arm—W: 79.0%; AfAm: 20.0%; other: 1.0%. Control arm—W: 80.0%; AfAm: 16%; other: 3.0%
Namkoong et al. (39)	CHESS for breast cancer patients	See Gustafson et al. (26)	Observational, quantitative and qualitative	177 low-income women (<250% of federal poverty level); breast cancer within 1 y of diagnosis; mean age = 51 y; recruited as part of DDPP; see Gustafson et al. (26)	W: 76.3%; non-white: 23.7%

(Table continues)

Table 1 (Continued).

Study	Intervention	New media component	Study design	Participants and setting	Racial/ethnic demographics of the sample
Rose et al. (44)	A CCS intervention for advanced cancer patients	Intervention promotes e-mail contact with CCS practitioner	Observational, quantitative	161 stage IV (or stage III lung or pancreatic) cancer patients recruited in treatment settings; middle-aged patients: mean age = 53.4 y; young-old patients: mean age = 68.5 y	Middle-aged patients— W: 48.8%; AfAm: 46.3%; other: 4.9%. Young-old patients—W: 63.3%; AfAm: 35.4%; other: 1.3%
Ruffin et al. (45)	Colorectal Web, an interactive electronic tool to promote colorectal cancer screening	Colorectal Web is a website or stand-alone program that prompts users to submit screening preferences and makes individualized recommendations	Randomized controlled trial, quantitative	Community sample of 174 adults, 50–70 y, not previously screened for colorectal cancer; median age: intervention arm = 56.9 y, control arm = 57.4 y	Intervention arm—W: 54.0%; AfAm: 46.0%. Control arm—W: 52%, AfAm: 48%
Shaw et al. (46)	CHESS	See Gustafson et al. (26)	Observational, quantitative	144 women diagnosed with breast cancer recruited in treatment and community settings; mean age = 44.5 y, age range: 30–60 y	W: 74.3%; AfAm: 18.9%; L: 0.5%; AA: 1.1%; AI: 1.1%
Shaw et al. (47,48,49)	CHESS	See Gustafson et al. (26)	Observational, quantitative	231 recently diagnosed low-income breast cancer patients (<250% of federal poverty level); mean age = 51.6 y, recruited as part of DDPP; see Gustafson et al. (26)	W: 62.3%; AfAm: 35.9%; other minorities: 1.7%
Song et al. (50)	LIFECommunity, a mobile social networking and video sharing intervention for young adult survivors of childhood cancer	Video sharing and social networking site developed on an open-source mobile web platform through which participants recorded and posted their own video narrative and commented on videos	Observational, quantitative and qualitative	14 young adult survivors of childhood at least 2 y posttreatment and recruited through a cancer registry; age range: 18–29 y	L: 85.7%; AA: 7.1%; AI: 7.1%
Wise et al. (53)	CHESS	Didactic information and both text-based and videotaped narratives of cancer survivors within CHESS; see Gustafson et al. (26)	Observational quantitative	353 breast cancer patients; mean age = 51.15 y; portion of sample recruited as part of DDPP; see Gustafson et al. (26)	W: 67.8%; AfAm: 32.5%
Zulman et al. (55)	Internet version of the FOCUS program, a communication intervention for cancer patients and their caregivers	Internet-based program that uses a dyadic interface to obtain data from patient and caregiver and provide tailored feedback	Descriptive, quantitative and qualitative	19 cancer patient–family member dyads (38 in total); mean age = 52.6 y	W: 60.5%; non-white: 39.5%

* CCS = coping and communication support; CHESS = Comprehensive Health Enhancement Support System; DDPP = Digital Divide Pilot Project; INCPAD = Indiana Cancer Pain and Depression; P4 = Personal Patient Profile – Prostate; PI = Pacific Islander; W = white.

relevant to mobile health or mHealth: the integration of health information searches and communications into nonvoice data applications accessible via cell phone (16). Data on technology use among Asian Americans are limited but suggest that Internet use among English-speaking Asian Americans exceeds that of other groups (17). Even fewer data are available for American Indian/Alaska Natives, but results of a survey of more than 120 tribes indicated that almost 90% of respondents reported recent Internet use (18).

These trends strongly suggest that new media are becoming integral parts of daily life among underserved groups and can be leveraged to address racial and ethnic cancer disparities. For example, the networked aspect of new media offers convenience and access to timely information and can increase an intervention's potential reach to these groups (19). Interactivity also allows one to create or author a record of one's own experiences. This may be especially compelling to those who have been historically marginalized based on race or ethnicity because new media platforms provide people of color with the means to construct and control the discourse around their experiences. Although new media hold tremendous potential for reducing cancer disparities, prior emphasis on the digital divide may discourage researchers from either pursuing adequate representation of these groups in study samples or incorporating new media into disparity-focused interventions. Therefore, the primary goal of the current systematic literature review was to assess 1) the inclusion of underserved racial and ethnic groups in research on cancer-related new media interventions and 2) the use of new media to address specific racial and ethnic cancer disparities in cancer control.

Methods

Search Strategy

Databases used for the literature search were PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and PsycINFO. The search was limited to English-language articles published in academic peer-reviewed journals from January 2000 to March 2012. Within each database, searches were conducted by combining four categories of search terms. The first category included variations of 16 key words relevant to behavioral, psychological, and social aspects of the cancer care continuum (eg, communication, detection, education, symptom, and treatment). A single broad search term was then created that included all of these keyword subsearches. The second category of search term included a combination of key words "intervention" and "program." The third category combined the key words "cancer" and "neoplasm." The final category included new media key words, reviewed by an expert panel, that were placed into 31 subcategories, some with single key words and others with multiple key words (eg, blog, e-mail, mobile app, online social network, photo sharing, telehealth and telemedicine, text messaging, webcast and webinar, and YouTube). This strategy resulted in 31 searches within each database that combined the first three search term categories with each of the new media subcategories.

Eligibility Criteria

All abstracts were initially reviewed by one author (HST) to determine appropriateness for full review. Five authors (HST, RCS, JM, TE, and PV) then fully and independently reviewed the articles for eligibility and to extract data. Each article was reviewed by at least two authors and disagreements were resolved either through review by additional authors or through discussion and consensus. Article eligibility was based on the following inclusion criteria: 1) publication in a peer-reviewed journal; 2) presentation of outcomes data related to the user experience of a specific behavioral, educational, or psychosocial intervention targeting cancer screening, treatment, or posttreatment cancer survivorship (prevention was excluded because such studies were often not limited or specific to cancer); 3) the intervention was intended for direct use by a patient or layperson rather than a medical professional; 4) the study was conducted in part or entirely in the United States; and 5) the intervention had at least one new media component that was digital, networked, and interactive such that user engagement was an explicit element of the intervention. For example, if an intervention used text messages or e-mail messages as reminders or prompts for behavior and participants were passive recipients such that their response via these channels was not encouraged or expected, that article was excluded.

Results

Literature Search

The systematic search yielded 1357 abstracts. Each of these abstracts was reviewed and 1227 abstracts were excluded because they either did not meet eligibility criteria or the abstract was a duplicate of another already identified. This resulted in 130 articles for full review. There were disagreements between the two assigned reviewers regarding inclusion for 20% of these articles (n = 26). In total, 94 articles were excluded, resulting in a final sample of 36 eligible articles (20–55) (selected articles are presented in Table 1. Supplementary Table 1, listing all eligible, reviewed articles, is available online).

Sample Characteristics

Characteristics of this sample of articles are presented in Table 1. Of the 36 eligible articles, half were published between 2009 and 2012. The majority of the intervention studies presented in these articles focused on breast cancer. Furthermore, the majority focused on both the treatment and posttreatment/survivorship phases of the cancer care continuum. Most studies included adult samples, used an observational study design, and collected and analyzed quantitative data.

New Media Elements of Interventions

A range of new media elements were identified, with many interventions incorporating more than one element. Almost all of the interventions mentioned the involvement of the Internet as the primary means of networking versus an intranet or other closed computer or server network. About half of the interventions described an interactive website through which a user could submit personal data as a way of customizing the intervention experience. For example, in the OncoLife intervention, cancer survivors, their caregivers, or health-care providers could submit diagnostic and treatment information to generate a survivorship care plan tailored to that survivor's needs (32). A similar proportion of interventions offered the user some sort of personalized feedback, often through

interactive websites as described above. About one-fifth of the interventions gave users the opportunity to develop personalized content. For example, Cancer CareLinks is a website that allows users to personalize their health-care team across health-care settings with provider photos and biosketches in an interactive address book (23). Several interventions incorporated asynchronous communication, such as use of e-mail or bulletin boards that enabled text-based communication outside of real time, whereas only a few used some form of synchronous conferencing that allowed real-time interaction. One example is the web-based Hope Intervention Program (HIP), which used a voice over Internet protocol to conduct a multimedia session with small groups that included audio and video through use of web cameras (22). Less commonly used forms of new media included blogs or video sharing and only one intervention for adolescent survivors of childhood cancer incorporated electronic or video games (40).

Racial and Ethnic Diversity Within Study Samples

In about 28% of the studies, fewer than 20% of participants were African American, Latino, Asian American, or American Indian/Alaska Native (see Table 2). In half of these studies, members of these groups represented less than 10% of the sample. In only about 6% of studies included, 80% or more of the sample were members of the aforementioned racial and ethnic groups and these samples were completely composed of individuals from these groups. Interestingly, 22% of all studies did not report any racial or ethnic information about their sample.

Studies Addressing Racial and Ethnic Disparities

Table 2 also presents the proportion of studies that addressed a racial or ethnic disparity. About 30% of the studies were categorized as disparity focused. Although not all of these studies explicitly reported disparity reduction as a goal, they were categorized as such because either a separate study goal was closely aligned with disparity reduction or an aspect of recruitment supported this mission.

Only one study by Jaja et al. (33) was explicit in its cancer health disparity focus: to increase prostate cancer and treatment knowledge among African American men. This study examined the usability of the Personal Patient Profile–Prostate (P4), an Internet-based treatment decision support system for men with localized prostate cancer (33). In a second study, Ruffin et al. (45) did not explicitly describe a disparities reduction goal but reported that recruitment communities were chosen for presence of minority populations, specifically African Americans. The intervention under investigation was Colorectal Web, an interactive web-based or stand-alone program to promote colorectal cancer screening, which was compared with a "standard, state-of-the art, noninteractive format," a website created by a leading national cancer prevention and control organization. In a third study by Song et al. (50), authors did not describe disparity reduction as a goal, but the entire sample was composed of Latino, Asian American, or American Indian cancer survivors, a fact the authors never acknowledged or discussed. The intervention was LIFECommunity, a mobile social networking and video sharing intervention program providing identity formation support for young adult survivors of childhood cancer. Eight additional studies (26,28,29,39,47–49,53) did not explicitly investigate disparities but did so indirectly through a focus on the digital divide and communication disparities affecting underserved populations. All of these studies examined the Comprehensive Health Enhancement Support System (CHESS), a home-based and Internet-based eHealth program to improve quality of life among breast cancer patients described in detail by Gustafson et al. (26).

Racial/Ethnic Differences in Responses to New Media Interventions

Studies in which 20% or more of participants were African American, Latino, Asian American, or American Indian were reviewed to explore racial differences in user experience of the intervention. However, few studies examined and reported differences in intervention use, evaluation, or outcomes across race or ethnicity. Gustafson et al. (26) found that although white breast cancer patients accessed CHESS more often, there were no racial differences in total time spent using CHESS. Furthermore, African American patients spent more time using CHESS' information and decision analysis and support services, whereas white patients spent more time using communication services. White patients were also more likely to use CHESS' discussion group (within communication services) compared with African Americans (29), and African American patients reported more positive health-care participation and clinical communication as a result of both didactic and narrative information service use (53).

In the randomized controlled trial testing Colorectal Web, authors reported no racial differences in refusal to participate in the study, study eligibility, or impact of the intervention (45). On the other hand, racial differences were reported in use of the Indiana Cancer Pain and Depression (INCPAD) intervention such that African American cancer patients were significantly less likely to engage in automated symptom monitoring compared with whites (34). However, participants had the option of monitoring symptoms via website or telephone so the extent to which differences are related to the intervention's new media element is unknown.

Discussion

The primary goal of the current review was to determine the extent to which medically underserved racial and ethnic groups have been included in research on behavioral and psychosocial cancer interventions with a new media component. Results showed that only a modest number of cancer-specific interventions incorporated new media. However, results also showed a substantial increase in such publications from 2000 to 2012 and it is likely the number of publications will continue to increase. It is useful to contextualize the current findings in relation to other reviews relevant to new media. Ryhanen et al. (56) examined Internet and interactive computer-based patient educational programs for breast cancer patients and identified 14 articles for review. However, those programs did not have to be networked to be included, a feature important to the current review. In a recent review of studies of Web 2.0 activities and interventions, Chou et al. (57) emphasized interactivity but did not limit their review to cancer and identified 34 health promotion intervention studies with user-generated components or multidirectional communication. The current review included 36 new media interventions for cancer alone, suggesting that our criteria for interactivity may have been more liberal.

Table 2. Sample characteristics (N = 36 articles)

	%	N
Publication year		
2000–2003	5.6	2
2005–2008	44.4	16
2009–2012	50.0	18
Cancer type		
Breast	44.4	16
Prostate	8.3	3
Colorectal	2.8	1
Hematologic	5.6	2
Pancreatic	2.8	1
Childhood cancers	11.1	4
Multiple cancers	25.0	9
Phase of cancer care continuum		
Detection/screening	5.6	2
Treatment	16.7	6
Treatment and posttreatment/ survivorship	47.2	17
Posttreatment/survivorship	30.6	11
Developmental stage of participants		
Adolescent	2.8	1
Adult	97.2	35
Study design		
Descriptive	22.2	8
Observational	55.6	20
Experimental	22.2	8
Type of data collected		
Quantitative	72.2	26
Qualitative	11.1	4
Quantitative and qualitative	16.7	6
New media components*		
Networked via internet	93.9	31
Interactive website	48.5	16
Personalized feedback	39.4	13
Personalized content	18.2	6
Synchronous conferencing	9.1	3
Asynchronous communication	27.3	9
Interactive e-games	3.0	1
Video sharing	3.0	1
Blogging/microblogging	12.1	4
Addresses racial/ethnic disparities?		
Yes	30.6	11
No	69.4	25
Proportion of sample representing underserved racial/ethnic groups		
0%–19%	27.8	10
20%–39%	36.1	13
40%–59%	8.3	3
60%–79%	0.0	0
80%–100%	5.6	2
Not reported	22.2	8

* Does not equal 100% because some interventions had more than new media element. If an intervention was the focus of more than one study, media elements were not repeated in the count.

In almost half of the studies, African Americans, Latinos, Asian Americans, and American Indian/Alaska Natives made up less than 20% of the sample (far less in many cases) or the article failed to report on race or ethnicity altogether. Most of the studies did not address a racial or ethnic cancer disparity, a finding that suggests that the promise and potential of new media interventions are largely unrealized among the underserved. It is important to acknowledge here that new media interventions are not appropriate for every segment of these populations. However, intervention development and implementation must be considered in the context of a dynamic new media environment in which new forms are constantly introduced and access to the devices and technology that support new media in personal (eg, home) and public (eg, public libraries, commercial spaces) environments is growing.

Although data were limited, results of the current review indicate some differences in response to new media interventions across race and ethnicity. Data suggest that people of color are as willing as whites to engage with such interventions and often spend as much time engaging with these interventions, but the ways in which individuals engage may differ. For example, studies of CHESS reported that although white breast cancer patients spent more time using CHESS to communicate with others, including peers and medical experts, African American patients were more likely to use CHESS to seek information or create action plans (29). These findings are especially interesting in light of data indicating that physicians offer less biomedical information and psychosocial counseling to African American and non-white cancer patients compared with white patients, engage in less partnership building, and are perceived as less supportive (58,59). The difficult patient–physician interactions more often experienced by patients of color may drive cancer-related new media use in a compensatory way. However, new media use may ultimately improve such communication and overall quality of care, as suggested by data showing that African American patients experienced greater benefit than whites from using diverse information services within CHESS in terms of their perceived quality of communication with physicians (53).

Limitations of the current literature review must be acknowledged. First, it could be argued that the definition of new media applied was narrow and a broader definition would have resulted in the review of a larger number of interventions that were more racially and ethnically inclusive. However, the more rigid criteria were consistent with an emphasis on the features of new media that may be particularly appealing and effective among the racial and ethnic groups of interest. Studies of mHealth may have been especially susceptible to exclusion if they described e-mail or text message–based interventions that did not explicitly demonstrate interactivity through multidirectional communication flow. In fact, of the 130 articles that underwent full review, there was only one article describing an e-mail or text message–based intervention for which lack of interactivity was the sole reason for exclusion. Second, we were not able to assess how well the study samples reflect the actual distribution of race and ethnicity in the population or geographic area being studied or the intent of investigators to include racial and ethnic minorities in their study. For example, in geographic areas where certain racial and ethnic groups are not well represented, the enrollment of diverse groups may have been desirable but not possible.

In spite of these limitations, the current review provides insight into the extent to which people of color have been excluded in the rapidly growing area of cancer-related new media intervention and identifies gaps in the development and implementation of new media interventions targeting racial and ethnic disparities. For example, only one intervention used an advanced feature of a smartphone in a way that maximized user interactivity and participation (50). Synchronous conferencing is another understudied

area, including voice over Internet protocols, such as Skype, that increase options for communication while retaining the visual and contextual cues associated with in-person contact. Finally, studies of the intervention potential of social networking sites, blogging, and microblogging are lacking but much needed in light of data showing that more African Americans and Latinos report accessing sites such as Facebook and Twitter compared with whites (60,61). Results of the current literature review suggest that researchers have only scratched the surface of new media's potential for eliminating racial and ethnic cancer disparities and there is a wide range of new media strategies that may be applied and investigated in future work.

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