

# The Underrepresentation of African Americans in Online Cancer Support Groups

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The Internet is increasingly important for many cancer survivors because it provides access to the latest information on cancer treatments and also allows them to receive support by participating in online cancer support groups. Unfortunately, little is known about why African-American cancer survivors are underrepresented in online cancer support groups. This article reviews the relevant literature and discusses three possible explanations for why African Americans are underrepresented in online cancer support groups: the digital divide/digital inequality, preferences for face-to-face support or culture-specific online support, and trust concerns. We conclude that a health inequity exists with regard to the utilization of information that can be obtained from online cancer support groups. However, with regard to the potential benefits of the psychosocial and emotional support aspect of online cancer support groups, a health inequity may not exist, as African Americans have other preferred avenues for obtaining needed support, and there is no evidence that this is detrimental to their health.

**Key words:** cancer ■ African Americans ■ race/ethnicity

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## INTRODUCTION

The Internet can inform cancer patients about important medical and psychological issues relevant to their illness and its treatment. One extensive review of the literature reported that across a number of studies, 39% of cancer patients on average, have used the Internet for information on cancer topics.<sup>1</sup> That review only included three studies that included African Americans with cancer as part of the sample,<sup>2–4</sup> and only one study reported Internet cancer information use specifically for African Americans at 11% versus 47% for whites.<sup>4</sup> Besides the ability to locate factual information on cancer diagnosis and treatment options, the Internet may also impact psychological functioning through access to online social support<sup>5</sup> and strategies for coping.<sup>6</sup>

Online support groups allow cancer survivors to exchange both information and psychological support. One study used the five search engines of yahoo.com, msn.com, google.com, aol.com and acor.org, and determined that there were a total of 546 different Internet-based cancer support groups.<sup>7</sup> Most of these online cancer support groups targeted broad audiences, but very few targeted minority populations. Only eight groups focused specifically for African Americans, eight specifically for Asian Americans, and eight specifically for combined ethnic minority groups.

Two comprehensive reviews of Internet use for cancer topics among racial/ethnic minorities<sup>8,9</sup> identified only a few studies focused on African Americans. One study among prostate cancer patients concluded that African Americans are less likely than whites to use the Internet for information.<sup>4</sup> A few studies suggest that there may be a limited interest among African Americans with cancer for online support groups. In one study of a sample of cancer patients, caregivers and others, African Americans were less likely than whites to use the Internet for cancer-related services, which included online support groups as one of these services.<sup>3</sup> In another study of a sample of 43 African-American women with breast cancer who participated in an African-American face-to-face support group, only two individuals used the Internet. The Internet was used for obtaining health information and not

for participating in an online support group.<sup>10</sup> Also, in a web-based survey of new subscribers to an online cancer mailing list, only one of the 292 individuals reporting their race/ethnicity was African American.<sup>11</sup> Given that the response rate was 21.4%, this underrepresentation of African Americans could reflect lower participation in the survey or the mailing lists—or most likely both. Nevertheless, the results of this study, combined with the studies cited above consistently suggest that African Americans are less likely than whites to seek cancer information online or to participate in online cancer support groups.

In general, when addressing a topic in which African Americans differ from whites, one should distinguish what Krieger<sup>12</sup> terms “health inequities,” which implies a health concern that is avoidable, unfair and unjust, from “differences,” which has no pejorative connotation. An abundance of literature reports that African Americans have less access to healthcare resources and health insurance than do whites.<sup>13,14</sup> These findings are typically considered health inequities that should be addressed for both health and social justice reasons. There is only one empirical study that specifically addresses disparities and inequities regarding Internet health information use for

cancer survivors. This study is among those with breast cancer and their self-rated health.<sup>15</sup> Whites with fair/poor self-rated health were >5 times as likely to use the Internet to obtain health information as compared to whites with excellent health. On the other hand, racial/ethnic minorities with fair/poor self-rated health had an odds ratio of 0.04 as compared to racial/ethnic minorities with excellent health, indicating minimal likelihood to use the Internet to obtain health information.<sup>15</sup>

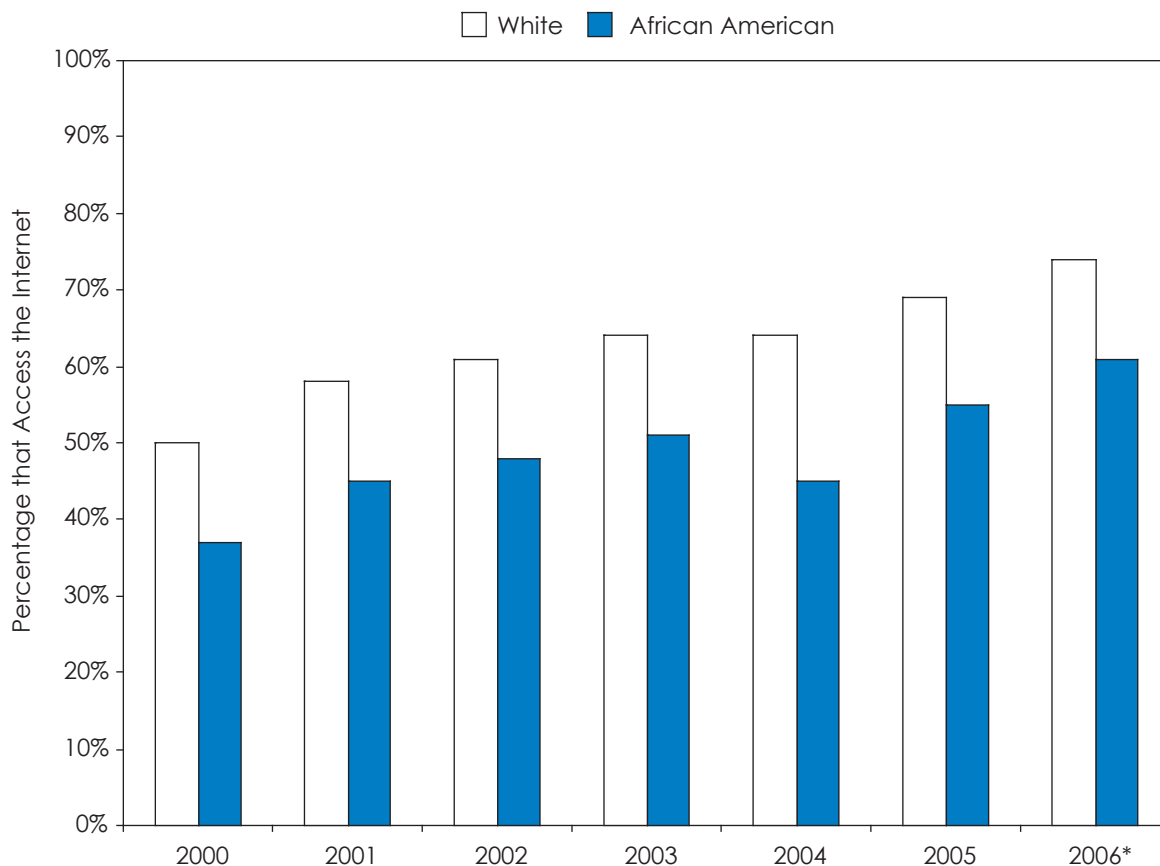
This paper reviews the association between Internet use and African-American race/ethnicity, particularly with regard to online cancer support group participation. Three areas are addressed: 1) the digital divide/digital inequality, 2) culture-specific online support preferences, and 3) trust concerns.

## DIGITAL DIVIDE/DIGITAL INEQUALITY

### Digital Divide

The digital divide refers to differences in Internet access and/or use that are generally measured dichotomously between the “haves” and “have nots.” African Americans are less likely than whites to have a com-

**Figure 1. African-American and white Internet use during the years of 2000–2006**



Data are from the Pew Internet and American Life surveys conducted during the years of 2000–2006. The percentages were created by averaging across multiple studies reported by Pew for each year. AA: African American

puter in the home<sup>16</sup> or to use the Internet.<sup>17</sup> According to the Pew Internet and American Life Project in May to June 2005, 57% of African Americans reported using the Internet versus 70% of whites.<sup>17</sup> Data from the U.S. Department of Commerce<sup>18</sup> show that this pattern also exists for broadband Internet access, where 26% of whites have broadband Internet access in their home versus only 14% of African Americans.

Despite an increase in the percentage of African Americans with Internet access between the years 2000 and 2005, a large divide between African Americans and whites still remains.<sup>17,19</sup> The Pew Internet and American Life Project has conducted numerous telephone surveys with nationally representative samples. In 2000, the Pew Internet and American Life Project reported that the rate of Internet access among African Americans appeared to be rapidly increasing.<sup>20</sup> Though the gap has closed slightly, subsequent Pew data shown in Figure 1 continue to show large differences between whites' and African Americans' access in every year from 2000 to April 2006, with whites continuing to have greater access.<sup>17,21</sup>

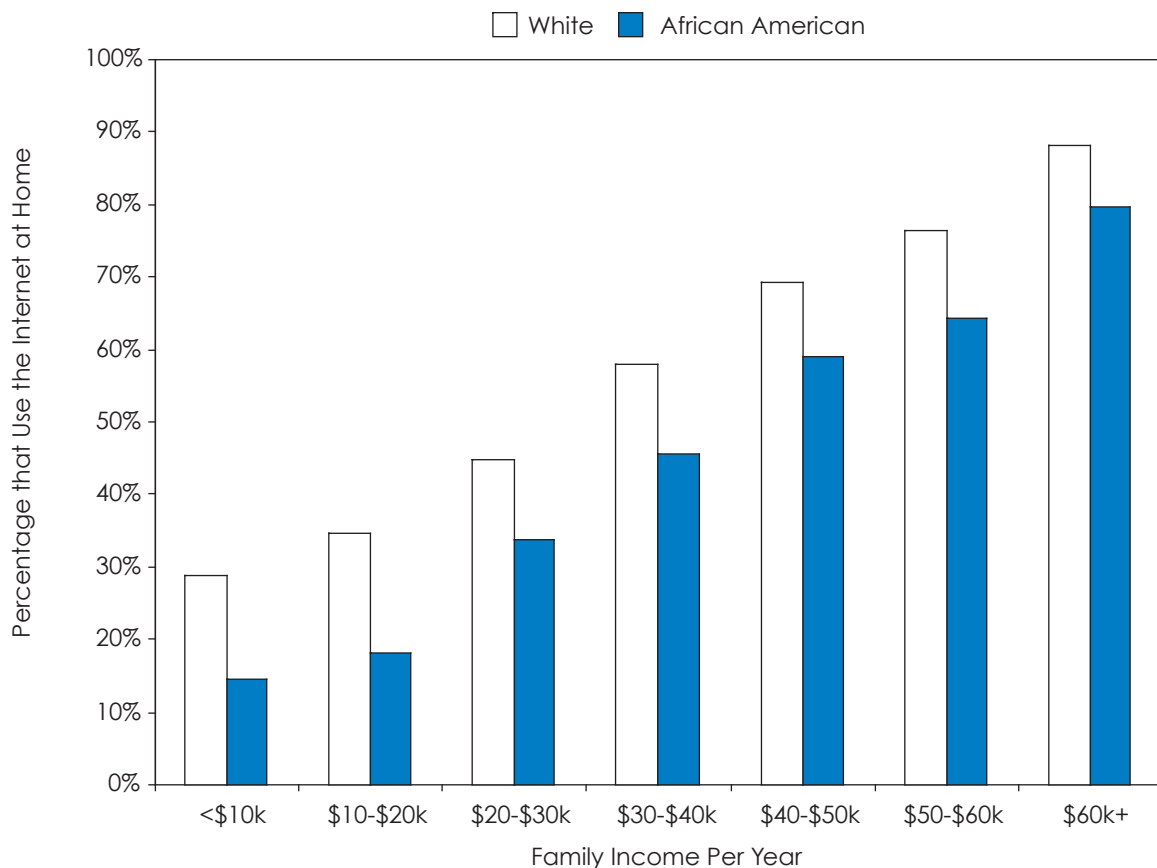
Many researchers have hypothesized that income and education levels contribute to the racial/ethnic differences in Internet access and use.<sup>19</sup> In one analysis, deter-

mining the predictors of Internet access or having a computer in the home, when socioeconomic variables were controlled, race/ethnicity was reported as a significant predictor, while gender and rural residence was not.<sup>22</sup>

In a study that used 2003 Current Population Survey data collected by the U.S. Census Bureau,<sup>23</sup> income and education accounted for part, but not all, of the differences between African-American and white computer ownership and Internet use at home. Racial/ethnic differences are smaller among higher-income levels, but they still exist. In every income category reported, there were substantial discrepancies in access between African Americans and whites. Even with all these data, about 50–60% of the variance between African-American and white use of the Internet at home remains unexplained by sociodemographic variables.<sup>23,24</sup> Data showing rates of Internet use for African Americans and whites stratified by income level are shown in Figure 2.<sup>25</sup>

A recent multilevel analysis of Internet access, based on census data by ZIP code and a 2001 national telephone survey that oversampled respondents from high-poverty areas, found that measures of income and educational attainment at the community level predict home Internet access. When these variables are considered,

**Figure 2. African-American and white home Internet use from the October 2003 current population survey**



AA: African Americans

race/ethnicity is no longer a significant predictor of access.<sup>26</sup> Mossberger and colleagues<sup>26</sup> also found a significant interaction between African-American race/ethnicity and community median income. African Americans living in impoverished communities were less likely to have Internet access, whereas African Americans living elsewhere were slightly more likely than other racial/ethnic groups to have home Internet access.

Cost contributes to decisions about obtaining Internet access. When asked why they did not have an Internet connection at home, African Americans were more likely to cite cost first, then lack of a computer and then “don’t need/not interested.” Whites were more likely to cite “don’t need/not interested,” followed by cost and then lack of a computer.<sup>19</sup>

Lack of a computer at home is a common barrier for home Internet access. Individuals are more likely to own a computer if their family, friends and neighbors own one, even after controlling for income, education, age and city-level environmental characteristics.<sup>27</sup> Greater computer experience levels and intensive computer use levels are related to a greater likelihood for purchasing a home computer.<sup>27</sup>

## Digital Inequality

Digital inequality is conceptually similar to the digital divide but refers to differences not just in Internet access but also among those with Internet access. Many prefer this conceptualization because it offers social reasons for differences in Internet use. Digital inequality may also explain why some interventions that concentrate on providing access to the Internet have been relatively unsuccessful.<sup>28,29</sup>

Digital inequality has five dimensions: equipment, autonomy of use, skill, social support and purpose for which the technology is employed.<sup>30</sup> The equipment aspect includes access to a computer and Internet connection that are adequate for the activities that the user wishes to perform. Many Internet applications require a powerful processor and a broadband Internet connection, leaving users with older and less expensive equipment only able to access basic online services. Autonomy of use refers to the extent to which users have unmonitored access to the Internet which may not be possible at work or in a public library. Skill includes knowledge of Internet applications and the extent to which users possess the ability to perform their desired tasks online. Social support is support specifically from more-experienced Internet users, which may increase the motivation levels of new and inexperienced users. The purpose for which the technology is employed includes issues of differential use of the Internet once online, rather than differential access.<sup>30</sup>

Several studies have examined racial/ethnic experiences related to Internet use behavior patterns. African-American online activity differs from that of whites. African Americans are more likely than whites to use the Internet for job searches, research, entertainment

and religion.<sup>20</sup> African Americans are also more likely than whites to use instant messages and chat, and are less likely than whites to use e-mail. African Americans with a high-school education or less are 50% less likely than similarly educated whites to send e-mail from a home computer, and African Americans with a college education are 20% less likely to do so.<sup>19</sup>

Differences also exist in use of the Internet for health applications. African Americans are less likely than whites to search for health information, buy medicine or communicate with a healthcare provider online.<sup>31,32</sup> Such differences may contribute to digital inequality, particularly if some applications utilized at lower rates by racial/ethnic groups have beneficial health effects.

Internet use for health information may be particularly challenging for African Americans because of the many types of skills required to successfully find and use health information online. Internet skill levels and choice of search terms play a major role in the content identified and retrieved.<sup>33</sup> “Warm experts,” or people who mediate between specialized knowledge and the specific needs of individuals, can help inexperienced users successfully search the Internet for health information.<sup>34</sup> These warm experts may not be as easy to find in African-American social networks as in white social networks, since fewer people in predominantly African-American neighborhoods have computers.<sup>26</sup>

The digital divide and/or digital inequality topics reviewed suggest that lack of use of online cancer support groups by African Americans is more than just a difference. This is similar to what has been previously reviewed that a disparity exists for Internet health communication patterns among racial/ethnic groups.<sup>35</sup>

## CULTURE-SPECIFIC SUPPORT PREFERENCES

The relatively low utilization among African Americans of online cancer support is only problematic if it damages their health, which has not been empirically proven. There is some modest evidence that online support groups can reduce psychological strain among white cancer patients.<sup>36</sup> However, a comprehensive review by Eysenbach<sup>37</sup> found no robust evidence that online support groups improve health and social outcomes.

An important aspect of online support communities for diseases is their provision of medical information about the illness and its treatment. In a study of reasons for using an online cancer support group, the reason of “get information about how to deal with cancer” was rated as “strongly agree” by 62% of participants and “get information about treatment options” as “strongly agree” by 53% of participants, while the emotional support item of “get support from other people with my cancer” was rated as “strongly agree” by 42% of participants.<sup>11</sup> Friends, family, clergy and other social network members may provide as much or more emotional support

than does the Internet, but they are unlikely to be experts on the treatment of cancer. Two studies from the Comprehensive Health Enhancement Support System (CHESS) research program indicated that African Americans with cancer may value and benefit from online information. Relative to whites, African-American postings to a restricted CHESS-participant Internet cancer support group significantly differed and focused on breast cancer treatment and side effects rather than social support for daily living.<sup>38</sup> Furthermore, as compared to whites, African Americans spent significantly most of their time online looking at information resources rather than exchanging emotional social support, and this improved their objective knowledge about cancer over time.<sup>39</sup>

One other relevant study showed that in a combined sample of African-American, Asian-American and Hispanic-American women, those who used the Internet for cancer information also had high levels of social support at a significantly greater level than whites.<sup>40,41</sup> This social support comprised both emotional and informational aspects. Unlike the CHESS program, which consists of specific participants who are part of the specialized program, this study involved typical Internet use as one would search for information that is readily available to those with Internet access. However, because this study included only eight minority women who used the Internet and was cross sectional, these findings await replication.

One may think to suggest that computer access is a key factor for these differences. However, the CHESS studies mentioned above<sup>38,39</sup> provided comparable access to all racial/ethnic groups, yet African Americans still made less use overall of the online components of the CHESS system than did whites. Furthermore, the U.S. National Cancer Institute offers a telephone-based cancer information service, and it serves fewer African Americans than whites, even though telephone access is virtually universal in the United States.<sup>42</sup>

Preferences for type of support may contribute to the differences in Internet support seeking. Henderson and Fogel<sup>10</sup> studied African-American women who were participating in African-American-centered face-to-face support groups. Besides the support group participation, these women also had a number of additional support networks. Even though this sample was composed of women who clearly were interested in seeking outside social support, <5% of them sought Internet-provided support.<sup>10</sup> When African-American breast cancer patients have been included in Internet support studies (i.e., when they already have a computer, Internet connection and training in how to use a specialized CHESS program) and even with key barriers removed, a preference remains for not seeking Internet-based emotional support.<sup>38,39</sup>

Where else would African Americans prefer to receive support? Seeking social support is crucial to African Americans coping with cancer.<sup>43</sup> In the study of African-American cancer support group attendees mentioned above, God

was the most common preferred support network among >50% of the participants.<sup>10</sup> African Americans attend religious services, pray and read religious literature more than do whites.<sup>44,45</sup> All of these religious sources of support may be more culturally congruent for many African Americans than is Internet-based support. A major provider of online support groups to cancer patients, ACOR hosts quite a few groups that discourage extensive religious content and messages.<sup>46</sup> These guidelines exist to avoid flame wars and off-topic arguments that have often erupted in the past over controversial topics, including religion and politics. This system may inadvertently make the service less appealing to African Americans.

Other sources where African-American cancer patients may obtain support include kin networks, fellow church members and from grown children.<sup>47</sup> In old age (the time of life with the highest risk for cancer), African Americans receive more intergenerational support than do elderly whites.<sup>48</sup> African Americans are also more likely to belong to racial/cultural voluntary associations than are whites.<sup>49</sup> In terms of face-to-face support groups for emotional and life crisis problems (including those that meet in churches), African Americans are as likely to attend, as are whites.<sup>50</sup> In geographic areas where African Americans are a majority, African Americans appear more likely than whites to attend face-to-face self-help groups, at least for addictions.<sup>51</sup>

Not all differences among races are due to racism and its proximal manifestations. Culture may help explain the difference under discussion. Cultural historians and anthropologists have long noted differences in the relative emphasis on written versus oral expression among whites and African Americans.<sup>52</sup> African Americans may not prefer to use online cancer support groups because the information is disseminated to all group members rather than customized to the individual. Also, African Americans may view online cancer support groups as online counseling. As the support group participants are not known to the African-American individual, there may be a concern about sharing private and personal information with others in the group. There is evidence from online dating website use that African-American men have different online communication preferences than white men,<sup>53</sup> and this may be occurring too with regard to online cancer support groups. The Internet is, at the moment, primarily a medium based on writing: one's thoughts, feelings, questions and ideas must be typed out. African Americans may prefer communicating in this respect less than they do through verbal or face-to-face communication. For example, among African-American cancer patients, the most appealing feature of the CHESS program was often the streaming video featuring patients telling stories.<sup>54</sup>

## TRUST ISSUES

Do trust issues affect African-American behavior with regard to use of online cancer support groups?

Trust is a significant issue that must be addressed among healthcare providers for the African-American community. Historically, African Americans found it difficult to trust healthcare providers, especially after the Tuskegee Syphilis Study (1932–1972) in which African Americans were treated inhumanely by the federal government and knowingly denied treatment for syphilis.<sup>55</sup> Even though this study was concluded 35 years ago, it still remains dominant in the memories and stories of many African Americans when health topics are discussed. Stronger relationships among African Americans and their healthcare providers are positively correlated with a greater level of trust, which has an impact on adherence to treatment and improved health status.<sup>56,57</sup> Thus, just as it is imperative for face-to-face healthcare providers to gain the trust of African Americans, those providing online cancer support groups would similarly need to do so.

Little is known about trust issues surrounding the use of Internet cancer support groups among African Americans. In one survey of oncology patients,<sup>58</sup> a question asked individuals to evaluate the accuracy of Internet information with a Likert-style scale ranging from 1=inaccurate to 7=accurate. African Americans had an average value of 4.6, which was significantly lower than the average white value (note: average white value was not reported). The authors suggest from the lower accuracy ratings that African Americans did so because of a general African-American suspicion of the medical establishment and of medical information.<sup>58</sup> Hesse et al.<sup>31</sup> investigated online health activities, levels of trust and source preference among a diverse racial/ethnic sample. Whites used information for health-related activities on the Internet for general purposes more than African Americans and other racial/ethnic groups. Although both African Americans and whites reported higher levels of trust in face-to-face physician information than information from the Internet, African Americans had higher odds ratio values than whites for this level of trust. These two studies suggest that African Americans have trust issues concerning Internet health information.

In order to build the trust of African Americans to participate in online cancer support groups, healthcare providers must take into account African Americans' cultural beliefs, attitudes and healthcare practices about cancer. In general, African Americans are often fearful of a cancer diagnosis<sup>59,61</sup> and view a cancer diagnosis as an automatic death sentence.<sup>62,66</sup> Culturally targeted cancer interventions in the African-American community are helping to address these above concerns, but many cancer-related myths and misperceptions remain that reduce seeking of appropriate support and information.<sup>62,65,67,68</sup>

The limited studies that have focused on the cancer experience among African Americans indicate that African Americans value support groups that are culturally tailored to their needs and concerns.<sup>10,69,70</sup> Afri-

can-American cancer survivors rely more on informal support networks such as family members and friends, as compared to formal support networks such as support groups to cope with breast cancer.<sup>10,69</sup> Also, many African-American cancer survivors find greater satisfaction and fulfillment in participating in face-to-face groups with other African Americans to discuss and share information about cancer.<sup>66,70</sup> In one study,<sup>70</sup> African-American women who participated in a face-to-face African-American-centered breast cancer support group described the group as a very personable and positive experience that helped them cope effectively with a breast cancer diagnosis. These African-American women reported how participating in an African-American-centered breast cancer support group allowed them to share personal issues and information about resources specific to their needs and concerns that may have been different if they had participated in a traditional support group. Participating in a traditional online cancer support group would place African Americans in a situation of discussing their personal health information with individuals from other racial/ethnic backgrounds, which may be uncomfortable for some African Americans.

## IMPLICATIONS FOR PRACTICE

Many African Americans believe that health issues in general and cancer in particular are private issues to which only trustworthy people such as family members and friends should be privy.<sup>69,71</sup> This belief may lessen African Americans' trust in online cancer support groups. It may be challenging for African Americans to participate in an online cancer support group with individuals that they do not know, cannot see and with whom they do not have an established trusting relationship to discuss their personal issues and concerns about a cancer diagnosis. Henderson and Fogel<sup>10</sup> found that among a number of support networks, African-American breast cancer survivors relied most on God to cope with breast cancer, followed by family, friends, healthcare professionals—and, lastly, the Internet. A possible solution would include if family or friends recommend an online cancer support group which may then be considered an extension of the traditional African-American supportive network. This may provide a sense of security and trust among African Americans to access and utilize an online cancer support group.

African Americans also report that health information on the Internet is confusing and complex.<sup>31,58,71</sup> This can delay cancer treatment, which can adversely impact the health outcomes of African Americans diagnosed with cancer. For example, in one study, African-American couples coping with a cancer diagnosis shared with their physicians about feeling overwhelmed and anxious about using the Internet as a source of support.<sup>71</sup>

Many physicians recognize the potential benefits of cancer patients participating in support groups.<sup>72</sup> It may

be useful for physicians to emphasize, without pressuring, the potential benefits of participating in an online cancer support group among African-American patients and families. Healthcare providers may consider incorporating relevant Internet use questions as part of the patient visit. For example, one question suggested as part of a patient visit is, "Is there any information that you read on a website or heard about from an online support group about treatment that you would like to discuss?"<sup>75</sup> This can be an open-ended way to introduce the topic. Additionally, those few African-American cancer survivors who may have benefited from an online cancer support group may want to serve as advocates for other African Americans to participate in an online cancer support group. This is a promising idea because some African-American cancer survivors feel compelled to spread the word about cancer and help other African Americans who may be confronted with a cancer diagnosis.<sup>66,70</sup>

There are many reasons to suggest that online cancer support groups are less likely to be trusted by African Americans. Numerous studies show that lack of trust in healthcare is associated with harm and potential harm.<sup>57,73-76</sup> Therefore, this lack of trust in online support groups indicates an inequity with regard to African Americans not using this potentially helpful medium. One important factor to keep in mind is that earning trust in the African-American community is a gradual process.<sup>77</sup>

## CONCLUSION

African Americans appear to be utilizing online health resources and online cancer support groups at lower rates than whites. We theorize that the digital divide and digital inequality help contribute to this health inequity. Similarly, there is evidence that a health inequity exists with regard to receiving information from online cancer support groups. However, there is not sufficient evidence at this time to conclude that a health inequity exists with regard to the emotional support aspect of online cancer support groups. This is because African Americans have cultural preferences for a number of different types of face-to-face support, and this has no demonstrated adverse impact on their health. Trust issues are important to African Americans and, at this time, a health inequity exists where many African-American cancer patients are hesitant to trust the Internet for a variety of health information and emotional concerns. Clinicians, community leaders and public health practitioners may want to consider the potential beneficial impact of both Internet cancer health information and online cancer support groups for African Americans and work both independently and together towards addressing this health inequity. This may help African Americans feel empowered with knowledge and supportive networks and to better survive the challenges associated with a cancer diagnosis.

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