Consumer Health Informatics Adoption among Underserved Populations: Thinking beyond the Digital Divide

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Summary

Objectives: Underserved populations can benefit from consumer health informatics (CHI) that promotes self-management at a lower cost. However, prior literature suggested that the digital divide and low motivation constituted barriers to CHI adoption. Despite increased Internet use, underserved populations continue to show slow CHI uptake. The aim of the paper is to revisit barriers and facilitators that may impact CHI adoption among underserved populations.

Methods: We surveyed the past five years of literature. We searched PubMed for articles published between 2012 and 2017 that describe empirical evaluations involving CHI use by underserved populations. We abstracted and summarized data about facilitators and barriers impacting CHI adoption.

Results: From 645 search results, after abstract and full-text screening, 13 publications met the inclusion criteria of identifying barriers to and facilitators of underserved populations’ CHI adoption. Contrary to earlier literature, the studies suggested that the motivation to improve health literacy and adopt technology was high among studied populations. Beyond the digital divide, barriers included: low health and computer literacy, challenges in accepting the presented information, poor usability, and unclear content. Factors associated with increased use were: user needs for information, user-access mediated by a proxy person, and early user engagement in system design.

Conclusions: While the digital divide remains a barrier, newer studies show that high motivation for CHI use exists. However, simply gaining access to technology is not sufficient to improve adoption unless CHI technology is tailored to address user needs. Future interventions should consider building larger empirical evidence on identifying CHI barriers and facilitators.

Keywords
Medical informatics applications, consumer health information, ethnic groups, socioeconomic factors, minority groups, health disparities


Introduction

The digital divide describes “the gap between those who have and do not have access to computers and the Internet” [1]. Systematic reviews of consumer health informatics (CHI) adoption have placed the digital divide as one of the core barriers to securing equal participation in technology-based health management solutions, specifically among underserved populations—groups that disproportionately experience difficulty accessing care due to social, economic, geographic, racial, or ethnic status [2-5].

Internet adoption around the globe, however, has rapidly increased over the past 10 years, including in developing countries [6], groups with low socioeconomic status, and racial and ethnic minority groups in developed countries [7, 8]. Between 2010 and 2012, Hispanic and African-American populations in the U.S. represented the populations with the highest smartphone ownership rates, at 61% and 59%, respectively [9]. Between 2013 and 2015, adults in developing countries who use the Internet at least occasionally or report owning a smartphone increased significantly, from 6% in India up to 31% in Turkey [6].

Tasks previously only possible on desktop computers, such as Internet and e-Health access, are now widely available through mobile phones and tablets. The global trend of increased Internet access and mobile phone ownership offers low-cost, scalable opportunities for CHI to empower individuals. A randomized controlled trial of MyHealthKeeper, a personal health record system from South Korea that allowed for sharing between patients and healthcare providers, resulted in significant improvements in weight-loss and triglyceride levels among users [10]. The Finnish National Archive of Health Information (KanTa), the national health data repository, was developed with the goal for citizens to access their own health information electronically [11]. In Sub-Saharan Africa, mobile and Internet technology penetration has resulted in increased female economic participation [12]. Mobile health applications in developing countries have shown effectiveness in many areas of medical care: improvement in patient follow-up [13], uptake of counseling and testing [14], and improved patient adherence and response to treatment [10, 15].

Given the increased penetration of Internet and mobile technologies across the globe, continuing to assume that basic technology access is the main contributor to health disparity vis-à-vis the digital divide may be insufficient. This lack of context may potentially increase health disparities over time if left unchecked. Improving CHI adoption requires users to remain highly committed and motivated [2, 16-18]. Sustained engagement, necessary for the adoption of any
technology, has proved challenging in other scenarios [19-21].

In this review, we survey articles that were published between 2012 and 2017 about CHI use. Given the changing atmosphere of underserved populations’ technology use, we concentrate on identifying barriers and facilitators. We suggest facilitators for developing future CHI systems that are sensitive to diverse user populations.

Methods

Our goal is to review the past five years of literature to follow up on persistent qualitative barriers and facilitators to CHI use among underserved populations. The goal is not to systematically review all possible literature, but rather update whether more recent literature continues to view the digital divide and motivation to use as the major barriers. We aim to enrich the discussion regarding what facilitators we can employ for future work in developing and evaluating CHI and overcome barriers to this end.

Operationalizing the Terms CHI and Underserved Population

We adapted the definition of CHI from the most recently updated publication on CHI ontologies [22], which describes CHI as a technology that is: (1) consumer facing, where consumers refer to patients, caregivers, or healthy individuals with prevention needs; (2) interactive for the consumer, including features such as buttons or links that enable retrieval of further information initiated by the consumer; and (3) providing tailored information, where the tailoring should happen for each consumer (e.g., providing personal health information) or the consumer group (e.g., tailored for cancer survivors group).

Defining underserved populations varies by country-specific political, cultural, and socioeconomic factors. Our review of a Cochrane study and national and international agencies publications settled around a common definition of underserved, or medically underserved, as those groups experiencing barriers to basic health needs due to social (including racial/ethnic minorities), economic, and geographic factors [23-26]. In the U.S., some agencies like the National Institute for Minority Health and Health Disparities (NIMHD), and the Health Resources and Services Administration’s Medically Underserved Areas (HRSA-MUA), which defines underserved as those experiencing a lack of access to basic health care, have operationalized these key characteristics linked to social, economic, and geographic vulnerabilities that are in-step with these global definitions for purposes of research and funding [27-29].

For the present review, we define underserved populations as racial/ethnic minorities in the context of country (e.g., Turkish in Germany, Hispanics and African-Americans in the U.S.), social (e.g., education, literacy, language), economic (e.g., employment, poverty, insurance), or geographic (e.g., rural) barriers.

Data Sources and Searches

We searched PubMed from October 2012 to October 2017 for full-text studies published in the English language regarding barriers and facilitators to CHI use in underserved populations. Staying within the scope of a survey, we restricted keywords to only Medical Subject Headings (MeSH) terms representative of “barriers and facilitators of CHI use among underserved populations” as operationalized above and we avoided custom keywords that might potentially bias the search results if not systematically chosen. We summarize the search strategy in Table 1.

Data Extraction and Synthesis

After a reviewer training phase to ensure inter-annotator agreement, we performed a single review for title and abstract screening. A full review of the selected text was performed by MS and JH, and data abstraction was performed by JH.

From each study selected for full-text review, we abstracted the following: population characteristics, setting, number of subjects, health conditions studied, study type, and barriers/facilitators to CHI use. To identify the paper’s definition for underserved population we abstracted race/ethnicity, income and insurance indicators, education level, and geography. We followed the thematic analysis commonly used in qualitative research methods [30].

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Medical Subject Headings terms used for searching abstracts on PubMed</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Consumer health informatics technology</strong></td>
<td>Consumer facing, Interactive, such as buttons or links that enable retrieval of further information initiated by the consumer, Providing tailored information, where the tailoring should happen for each consumer (e.g., providing personal health information) or the consumer group (e.g., tailored for Spanish speaking groups)</td>
</tr>
<tr>
<td><strong>Consumer</strong></td>
<td>Consumers could refer to patients, caregivers, or healthy individuals with prevention needs</td>
</tr>
<tr>
<td><strong>Underserved population</strong></td>
<td>Racial/ethnic minorities in the study context of the country (e.g., Turkish in Germany, Hispanics and African-Americans in the U.S.) Social barriers (e.g., education, literacy) Economic barriers (e.g., employment, poverty, insurance) Geographic barriers (e.g., rural)</td>
</tr>
<tr>
<td><strong>Barriers and facilitators</strong></td>
<td>Keywords related to access, tailoring, or user-centered design</td>
</tr>
<tr>
<td><strong>Constraints</strong></td>
<td>Full text, Published in the past 5 years, Written in English</td>
</tr>
</tbody>
</table>
We searched for themes that “emerge as being important to the description of the phenomenon” [31] such as, in our case, facilitators and barriers to CHI adoption among the target population. We identified the themes through “careful reading and re-reading of the data” [32]. We recognized patterns within the data, allowing emerging themes to become the categories for analysis. We adapted PRISMA guidelines for our protocol specification, data abstraction, and synthesis [33].

Results
We obtained 639 abstracts after removing missing abstracts from 645 search results. There were no duplicates. We removed 586 abstracts because there was no CHI involved in the study—either because the study did not examine implemented CHI (e.g., interviews and questionnaires about future CHI) or because the CHI being studied did not involve direct interaction with users (e.g., educational videos, one-way text message alert system). We then removed an additional 22 abstracts because the studies reported lacked an underserved population perspective on CHI even if the study did involve CHI.

As a result, after the abstract screening, 31 articles remained, from which we excluded 18 articles through the full-text screening (see Figure 1). Reasons for exclusion during full-text review included one or more of the following reasons: no data on the underserved (n=5) or on facilitators and barriers to technology adoption (n=5), the article was only about the study protocol and was lacking outcome data (n=3), the technology was not CHI (n=4), or the study did not empirically test technology on human subjects (n=2). As a result, 13 articles remained for full-text analysis.

The CHI solutions evaluated in these 13 articles included patient education tools (n=7) [34-40], patient portals (n=4) [41-44], and technology-based illness intervention (n=2) [45, 46]. Nine articles presented mixed methods [35-39, 42-44, 46], nine included interviews and focus groups [34-39, 43, 44, 46], five included surveys [2, 36, 39, 42, 44], three included trials [37, 45, 46], and three included a cohort analysis [41, 42, 46]. The total sample size ranged from 21 patients to more than 200,000 patients. The studies were from two countries: U.S. (n=12) and Netherlands (n=1) [34]. Six health areas were covered: cancer (n=4) [35, 36, 38, 39], cardiometabolic risk and nutrition (n=2) [34, 40], HIV/AIDS (n=1) [44], environmental health for prenatal patients (n=1) [37], medication adherence (n=1) [46], and dementia (n=1) [45]. Two articles covered the use of general patient portals, not specific to an illness [41, 42] and two specified “chronic conditions” without further detail [42, 43]. Eligibility criteria included older adults in five studies [40, 42, 43, 45, 46]. Four articles focused only on Hispanic populations [35, 37, 44, 46], four only on African-Americans [36, 38, 39, 43], two on Hispanic and African-Americans [40, 45], and the rest on one or more ethnic minorities [34, 41, 42]. Nine focused on low-income patients [36-38, 40-44, 46], and 11 on low health literacy or low education populations [34-40, 42-45]. Tables 2 and 3 display a summary of the final articles.

Barriers
We found three main barriers to CHI adoption among underserved populations: (1) low health literacy [34, 40-43] and lack of experience with information technology use [38, 42, 43]; (2) challenges in accepting the presented information [34, 35, 38, 43, 44, 46]; and (3) poor usability and clarity of content [38, 43, 44, 46].

- Low health literacy and lack of experience with information technology use

Many study participants did not have experience in using the Internet from school or work, lacked cellphones with Internet access, and had little contact with Internet technology [38, 42, 43]. This inexperience hindered their...
### Table 2: Characteristics of CHI and population in the selected studies

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Type of CHI applications</th>
<th>Total number of participants</th>
<th>Reported age of participants</th>
<th>Characteristics of CHI and population in the selected studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ancker, 2017 [41]</td>
<td>Patient portal: Medline connected links in medical records</td>
<td>12,877</td>
<td>18-24: 18.5%, 25-44: 43.5%, 45-64: 30%, 65+: 8%</td>
<td>Latinos by language preference, Black, White, Other, Unknown; Patients at Federally Qualified Health Centers (FQHC); n/a</td>
</tr>
<tr>
<td>Gordon, 2016 [42]</td>
<td>Patient portal: Kaiser North California</td>
<td>231,082</td>
<td>65-79</td>
<td>English speaking non-Hispanic White, Black, Hispanic, Filipino, and Chinese; 30.3% had low income; [Survey] 22% Latino seniors and 4% others did not graduate from high school; Kaiser HMO</td>
</tr>
<tr>
<td>Damman, 2016 [34]</td>
<td>Patient education tool: Web-based cardiometabolic disease risk calculator and information</td>
<td>23</td>
<td>40-66</td>
<td>n/a; n/a; Low health literacy</td>
</tr>
<tr>
<td>Kukafka, 2015 [35]</td>
<td>Patient education tool: Web-based decision aid for breast cancer prevention</td>
<td>34</td>
<td>Mean age: 53.4 (SD = n/a)</td>
<td>Hispanic; More than half had income lower than $39,999/yr; 41% had low numeracy; n/a</td>
</tr>
<tr>
<td>Owens, 2015 [36]</td>
<td>Patient education tool: Computer-based decision aid</td>
<td>21</td>
<td>37-66</td>
<td>African-American; 14% finished high school; 20% Medicaid or no coverage or other insurance</td>
</tr>
<tr>
<td>Smith, 2015 [43]</td>
<td>Patient portal: Registration and utilization of a patient portal</td>
<td>534</td>
<td>55-74</td>
<td>African-American; FQHC and ambulatory care clinic; 17.4% had low health literacy, 14.8% graduated from high school or less; n/a</td>
</tr>
<tr>
<td>Rosas, 2014 [37]</td>
<td>Patient education tool: Kiosk, interactive game for prenatal and environmental health</td>
<td>152</td>
<td>n/a</td>
<td>Hispanic; Low income, FQHC; Low literacy; n/a</td>
</tr>
<tr>
<td>Odlum, 2014 [44]</td>
<td>Patient portal: Internet-based electronic personal health, management tools</td>
<td>42 [Survey], 15 [Focus groups]</td>
<td>24-63</td>
<td>Hispanic; 80.9% earned less than $10,000/yr; 83% graduated from high school or General Educational Development (GED); Medicaid Special Needs Plan</td>
</tr>
<tr>
<td>Cogbill, 2014 [38]</td>
<td>Patient education tool: Online colorectal cancer education website</td>
<td>18 [Focus groups], 60 [Trial]</td>
<td>45-75</td>
<td>African-American; [Focus groups] 16.7% earned $10,000/yr or less, [Trial] 33.3% earned $10,000/yr or less; [Focus groups] 33.3% graduated from high school or less, [Trial] 31.7% graduated from high school or less; n/a</td>
</tr>
<tr>
<td>Canja, 2013 [45]</td>
<td>Technology-based intervention: In-home and videophone technology, multi-component psychosocial intervention</td>
<td>110</td>
<td>Mean age: 60.9 (SD: 12.8)</td>
<td>Hispanic, African-American; n/a; 40% of the intervention group and 36.5% of the control group had less than high school education; n/a</td>
</tr>
<tr>
<td>Bass, 2013 [39]</td>
<td>Patient education tool: Low-literacy computer touch-screen colonoscopy decision aid</td>
<td>102</td>
<td>50-74</td>
<td>African-American; n/a; Low literacy; less than 6th grade REALM score [87]; n/a</td>
</tr>
<tr>
<td>Lapone, 2012 [46]</td>
<td>Technology-based intervention: Tailored DVDs on medication adherence</td>
<td>326 [Telephone survey], 106 [First focus group], 16 [Second focus group]</td>
<td>Eligibility: At least 65 years old; n/a for actual participants</td>
<td>Hispanic; Low-income; n/a; n/a</td>
</tr>
<tr>
<td>Neuen-schwan, 2012 [40]</td>
<td>Patient education tool: Web-based nutrition education program</td>
<td>123</td>
<td>18-30: 48%, 31-50: 39.8%, 51-70: 10.6%, 71+: 1.6%</td>
<td>Hispanic, African-American; SNAP-Ed eligible; 43% graduated from high school or less; n/a</td>
</tr>
</tbody>
</table>
ability to adopt and use CHI solutions without appropriate training. In a trial involving nutrition education websites in a low-income community in the U.S. Midwest [40], understanding medical language, or health literacy, was a barrier to using the tool. Conversely, an in-person meeting was perceived as being more useful than the CHI intervention. Furthermore, participants did not think they could use a CHI application [38, 42]. This result was supported by a patient portal use study among older adults in Northern California [42] and a feasibility trial of an online colorectal cancer education program with African-American older adults [38]. Focus groups conducted in the latter study showed that texting might not be feasible for the population because the participants either did not own cell phones or, when they owned one, did not know how to use it or feared that texting would constitute a financial burden [38].

* Challenges in accepting the presented information
In some studies, even when participants had access to technology, some of them did not find the presented information useful [38, 44]. In another study [34], the presented information contradicted what participants believed about their own health, or they misinterpreted the materials. For instance, in a Dutch study involving low health literacy individuals, participants were provided their cardiovascular risk using technology-based educational materials [34]. The participants either did not believe or misconstrued their risk based on how the information was visualized. Similarly, a study displayed breast cancer risk using a web-based decision aid tool where the majority of participants were Hispanic women with low numeracy. The participants, who felt uncertain about the models presented to them, attributed the reason of their distrust with their healthcare providers to their past interaction with the providers [35]. Odlum et al. [44] studied the use of Internet-based electronic personal health management tools among a mostly minority, low-income HIV/AIDS urban clinic population. The participants preferred to enter their own health history rather than accepting the data generated by the clinic, which they found confusing.

* Poor usability and clarity of content
Lastly, usability problems and a lack of message clarity hindered CHI adoption. For instance, losing an access code after registration deterred older adults from using a patient portal [43]. Confusing user interfaces made it difficult to use patient portals or to benefit from patient education materials [38, 43, 44]. Tailored educational materials (DVD) for medication adherence

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**Table 3**  Barriers, facilitators, and study context of the reviewed articles

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Health condition of interest</th>
<th>Study or instrument type</th>
<th>Barriers</th>
<th>Facilitators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ancker, 2017 [41]</td>
<td>n/a</td>
<td>Cohort study</td>
<td>Low health and computer literacy</td>
<td>Needs for more information</td>
</tr>
<tr>
<td>Gordon, 2016 [42]</td>
<td>Chronic disease</td>
<td>Cohort study, survey</td>
<td>Low health and computer literacy</td>
<td>Help from proxy users</td>
</tr>
<tr>
<td>Damman, 2016 [34]</td>
<td>Type 2 diabetes, cardiovascular disease, chronic kidney disease</td>
<td>Interviews</td>
<td>Low health and computer literacy, challenges accepting the presented information</td>
<td></td>
</tr>
<tr>
<td>Kukafka, 2015 [35]</td>
<td>Breast cancer</td>
<td>Focus groups, survey</td>
<td>Challenges accepting the presented information</td>
<td></td>
</tr>
<tr>
<td>Owens, 2015 [36]</td>
<td>Prostate cancer</td>
<td>Focus groups, survey</td>
<td></td>
<td>Early user engagement in design</td>
</tr>
<tr>
<td>Smith, 2015 [43]</td>
<td>One or more chronic conditions</td>
<td>Interviews</td>
<td>Low health and computer literacy, challenges accepting the presented information, poor usability and clarity</td>
<td>Early user engagement in design</td>
</tr>
<tr>
<td>Rosas, 2014 [37]</td>
<td>Pregnancy, environmental health</td>
<td>Pre/post test, open-ended interviews</td>
<td></td>
<td>Early user engagement in design</td>
</tr>
<tr>
<td>Odlum, 2014 [44]</td>
<td>HIV/AIDS</td>
<td>Focus groups, survey</td>
<td>Challenges accepting the presented information, poor usability and clarity</td>
<td>Needs for more information</td>
</tr>
<tr>
<td>Cogbill, 2014 [38]</td>
<td>Colorectal cancer</td>
<td>Focus groups, a 5-week feasibility trial</td>
<td>Low health and computer literacy, challenges accepting the presented information, poor usability and clarity</td>
<td>Early user engagement in design, needs for more information</td>
</tr>
<tr>
<td>Craja, 2013 [45]</td>
<td>Caregivers of patients with dementia</td>
<td>A 5-month randomized clinical trial</td>
<td></td>
<td>Early user engagement in design, needs for more information, proxy users’ help</td>
</tr>
<tr>
<td>Boss, 2013 [39]</td>
<td>Colorectal cancer</td>
<td>Focus groups, survey, segmentation analysis</td>
<td></td>
<td>Early user engagement in design</td>
</tr>
<tr>
<td>Lupone, 2012 [46]</td>
<td>Medication adherence</td>
<td>Cohort study, focus groups, survey</td>
<td>Challenges accepting the presented information, poor usability and clarity</td>
<td>Early user engagement in design</td>
</tr>
<tr>
<td>Neuenschwander, 2012 [40]</td>
<td>Nutrition</td>
<td>1-month randomized, block equivalence trial</td>
<td>Low health and computer literacy</td>
<td></td>
</tr>
</tbody>
</table>
aimed at older adults were mainly critiqued for their background color rather than their content [46]. In a study of a colorectal cancer screening education tool with African-American men, the participants felt that the messages were vague and should be further tailored—otherwise they would not motivate behavior change [38].

**Facilitators**

We found three main CHI facilitators: (1) early user engagement through iterative user-centered design [36-39, 43, 45, 46]; (2) engaging users early in the design development process and identifying their health information needs [38, 41, 44, 45]; and (3) proxies, such as caregivers or family members, who are more familiar with technology, and use CHI on behalf of the users [42, 45].

- Early user engagement through iterative user-centered design

Participants were more willing to use CHI when the system was usable, engaging, trusted, and tailored [36-39, 43, 45, 46]. To meet these requirements, one aspect frequently discussed was that CHI should allow for customized communication modes. In a study evaluating an environmental health education intervention for pregnant Hispanic women via a kiosk, researchers communicated information through both audio and text on the screen. Some participants preferred voice to text whereas others preferred reading the information on-screen [37]. Conversely, participants in a colorectal cancer screening study that used text messages versus emails to assess an educational tool had contrasting preferences for receiving reminders and learning materials [38]. Factors influencing their decisions included perceived cost of texting, ease of use, annoyance, and likelihood to grab attention. Bass et al. developed a colonoscopy decision aid for African-American men [39]; survey and focus group results showed that photographs were preferred over graphics in depicting educational materials. As a result, the aid included photographs coupled with testament videos from the actual clinic patients. While web-based nutrition education was as effective as in-person counseling for low-income participants in Neuenschwander et al.’s study [40], some topics (e.g., nutrition facts labeling) benefited from a combination of web-based and in-person approaches.

Three studies used varied methodological contexts and study scales (sample size ranging from 21 to 534) [36, 43, 46]. These studies emphasized the importance of early engagement of end-users into the design process through user-testing and improvement of functionality [36, 43]. This process helped add tailored information that met user needs. For instance, a mixed methods study presented the development of a touch-screen decision aid for low health literate African-Americans with colorectal cancer [39]. The study revealed that psychosocial issues related to the colonoscopy rather than medical information on colorectal cancer were the more critical factors in decision-making. In the health-education study with prenatal Hispanic women, adding games helped children, partners, and all family members engage in learning about environmental exposures using a kiosk [37]. Further examples of tailoring included adding actors for a video intervention, who were relatable to the user population [46].

- Intrinsic needs for more information

Consumer health informatics use was facilitated when participants had an intrinsic need for more information [44]. The works by Ancker et al. [41] and Odlum et al. [44] demonstrated that participants found that practical tips for provider engagement and health management were most useful. In a study with Medicaid users, participants felt that information on facilitating provider visits was useful as a personal health management tool [44]. African-American participants from a colorectal cancer screening tool study expressed that they wanted tips on free or low-cost screening [38]. A videophone-based intervention for dementia patients and their caregivers showed that having access to a support group was helpful and that some participants wanted more information on accessing support groups as part of these interventions [45].

- Proxy users’ help

For those with low computer literacy, having a delegated person who could help use the CHI had an impact on CHI adoption [42, 45]. As evidenced by the videophone study involving dementia patients and their caregivers, caregivers felt motivated to use the technology when it allowed them to better understand their patients’ illness. CHI could contribute to an increase in caregivers’ abilities to help patients take care of the illness [45].

**Discussion**

The barriers and facilitators discussed in the present review—low health literacy, tailoring, and the digital divide—have all been considered at length in prior literature [3, 46-49]. Studies published in the past 5 years shows a lag in CHI adoption among the underserved when compared to the general public. Additionally, our results further show that a digital divide persists [50-53]. At the same time, increased mobile technology adoption by underserved populations has slowly changed the state and nature of the digital divide [9, 54]. Furthermore, newer studies suggest an increased willingness to engage with CHI tools among underserved populations [41, 55]. Our findings lead us to discuss how the digital divide, literacy, and user-centered design of CHI should be approached.

**Re-thinking the Digital Divide, Motivation, and Perceived Usefulness**

A 2008 systematic review report to the Agency for Healthcare Research and Quality (AHRQ) [3] concluded that users found the majority of the evaluated CHI tools to be usable. A 2010 report to the Office of the National Coordinator for Health Information Technology (ONC) [4] showed that health and technological literacy, culture and language, level of comfort in interacting with the health care system, and digital divide added to the evidence of these factors as barriers to CHI adoption. A more recent systematic review in 2011 [5] further confirmed these findings, identifying perceived benefits of health information technology, and conversely highlighting a lack of trust, technical problems, limited access to computers or
hardware, technology fears, and cognitive and physical disabilities as persistent barriers to CHI adoption among underserved populations. These reports emphasize a lack of user-motivation and barriers to technology access rather than the design of CHI systems as the main drivers of the low adoption rate.

However, 10 years later, the digital divide does not appear to persist due to a lack of technology adoption, especially given the increased mobile technology use and Internet adoption among underserved populations globally [9, 54, 56]. Instead, the digital divide is driven by more complex, multi-dimensional factors. Ancker et al. showed from their 2017 study on patient portals at Federally Qualified Health Centers (FQHCs) [41], that ethnic minorities, such as Hispanics and African Americans, were more likely to use hyperlinked patient education materials in patient portals than were Caucasian users. Ancker et al. posited two possible causes: first, users’ motivation to understand the medical jargon, and second, a strong association between low health literacy and the need for further explanations. In either case, the study shows intrinsic motivation to learn by those often labeled a “disengaged” population [57-59]. All people, regardless of their privilege status, were highly motivated, had intrinsic needs for information [41], wanted to manage their own health information and to share it with their providers [44], wanted tips on free or low cost ways of accessing care [38], or wanted to learn more on how to use CHI [41, 44, 60].

Our review also found that motivated use was not limited to the target user of CHI. If the patients themselves could not use the CHI tool, caregivers became highly motivated, assuming CHI user roles [42, 45]. This concept of a proxy user aligns with past findings that refer to caregivers’ effective use of technology either for themselves [60] or as helpers for patients [61, 62]. A systematic review of older adults’ use of patient portals identified technical assistance and family and provider advices as the main facilitators for patient portal use [51]. In an interview study about patient portal use in safety net hospitals, caregivers expressed interest in using patient portals to interpret health information, advocate for quality care, or manage health behaviors and medical care of patients [63].

Engaged and motivated users should receive sustainable and culturally appropriate support to help improve computer and health literacy. A recent study by the University of Kansas [64] found that low-income African-Americans wanted to learn how to use computers but study participants felt that the educators were condescending and hence they lost their motivation to return to the education sessions. A similar report was published in 1991, where African-American women engaged in a literacy improvement program were discouraged from going back to the classes because “the instructors were too mean” [65]. Such breach of trust between innovation disseminators and end-users must be repaired, and assumptions around technology adoption in underserved populations should be reconsidered and addressed in design and dissemination.

Institutional response to health disparities, or variation in access, quality, and care, has been incremental and piecemeal [66]. Thus, CHI interventions must not only consider barriers related to technology adoption, but also culturally competent care delivery, health equity, and significant institutional barriers. Understanding the values and beliefs of underserved populations must be a priority given the growing racial, ethnic, and linguistic diversity of many countries.

Internationally, similar principles apply. For instance, McBride et al. used SMS to help with maternal health among ethnic minorities in Vietnam [67]. A U.K. based systematic review reported, when developing ethnic-specific dietary assessment tools, using customized portion sizes by sex and age, household utensil usage, and literacy levels are critical [48]. The growing focus on patient-centered care serves as an opportunity to secure institutional buy-in to tailor healthcare [68-70]. Culturally and linguistically appropriate care could aid CHI diffusion for underserved populations across the globe given universal health care, along with rapid Internet for low-resource and rural areas [66].

Although the digital divide still exists, barriers to technology access will likely diminish, but general computer literacy will likely continue to impede progress globally. Research groups such as the 2G Lab at the University of Michigan [71] are responding to emerging digital literacy gaps by redesigning and repurposing older technologies (e.g., non-smart phones). Such endeavors consider tailoring needs to the individual a technology innovation in and of itself. This focus on the individual may be the key to CHI development for underserved populations.

It is no longer sufficient to state that the core barriers to CHI adoption by underserved populations are the lack of access to technology, or the lack of motivation or perceived usefulness of CHI applications by the end users as past studies suggested [72-74]. Rather, it is currently more important to determine how CHI can be tailored to support culturally relevant, intrinsic, and personalized information needs.

Re-thinking CHI Usability Evaluations for Underserved Populations

Usability and design problems can discourage even highly motivated users. In some of the studies reviewed [38, 43, 44, 46], participants did not find information useful because the display was confusing or they could not relate to the content or the actors communicating the information. These findings contradict the general consensus of the AHRQ report [3], which found the reviewed CHI systems’ usability to be high.

This contradiction may be explained by differing variables and tasks chosen for the usability evaluation. For instance, Greenberg and Buxton described this phenomenon in their seminal article, “Usability Evaluation Considered Harmful (Some of the Time)” [75]. They discussed the importance of choosing appropriate evaluation techniques to the problem and the stage of the design cycle. Otherwise, the results can be meaningless. Depending on the user groups tested and the tasks chosen, the results may not reflect how the technology would actually evolve for its intended audience and actual use. Aspects
of user-centered design other than usability, such as understanding requirements, considering cultural aspects, and developing and showing stakeholders design alternatives, should be taken into account when evaluating technology use.

Many “quick and dirty” usability evaluation solutions exist that have proven to be as equally reliable and powerful as more comprehensive measurements [76-79]. However, these methods should be carefully chosen when involving populations who may have linguistic, cultural, and literacy challenges. For instance, Bangor et al. discussed how simpler usability measurements, such as the System Usability Scale Survey (SUS) [80], should be accompanied by other measurements [81]. The language used for the survey items in the SUS, because of its terseness, can cause comprehension problems for non-native English speakers [82-84]. Peres et al. warned that shorter surveys meant to be designed for non-usability specialists can in fact hinder a correct interpretation of the results if a facilitator was not present for clarifications [85]. These studies demonstrated the need for careful consideration while interpreting scores in evaluating a system.

Lessons learned for improving CHI adoption among the underserved include assuring user-centered design has been deployed before dissemination and evaluation. In their 2012 systematic review [47], Montague and Perchonok suggested providing tailored, relevant, and contextually situated health technology to enable behavior change among underserved populations. Simply translating English to Spanish, for instance, has been shown to be an ineffective solution to increasing technology adoption [86]. Personalizing the tool for each individual and understanding intrinsic needs of users and utilizing proxy users, such as caregivers or younger family members, should help motivate CHI adoption by underserved populations.

Limitations and Future Directions

We confined our search to PubMed indexed publications and our search strategy was very specific. We adopted a definition of underserved population that, though promulgated by U.S. health agencies [27-29], is race/ethnicity neutral. However, we acknowledge that this perspective might not agree with other definitions developed outside the U.S. While we attempted to be as inclusive as possible of the international context, several studies were excluded during the abstract or full text screening process. We restricted publications to English only, which may have eliminated studies of CHI in underserved populations. We did not employ pre-specified procedures to assess the risk of bias in individual studies. Nevertheless, we have referenced selected studies within this review outside of the context of our data synthesis. Future research may consider using inclusion and exclusion criteria that are specifically designed to address non-U.S. contexts to complement what might have been lost in this review. We need more empirical research reporting facilitators and barriers that can apply to a broader international context and address the ‘research divide’ shown from the results of our screening process.

On the 31 screened articles, many did not discuss factors that impacted CHI adoption. However, studies that incorporated qualitative methods, such as conducting focus groups after a trial or coupling surveys with interviews provided insights into what might have been barriers or facilitators to CHI adoption but were not generalizable. These studies did not empirically confirm factors around barriers and facilitators for generalization, perhaps because they were derived from qualitative feedbacks from a small number of individuals. Future studies should consider testing the effectiveness of facilitators and barriers in CHI adoption in a larger, confirmatory study setting to understand scalability and generalizability issues that are predominant among underserved population groups. Furthermore, user-centered design techniques that result in reliable methods for tailoring, such as expected scenarios of use, reflections, case studies, and participatory critique should be considered in addition to usability methods.

Conclusion

The digital divide and few perceived benefits of CHI use were previously considered as the dominant barriers to CHI adoption among underserved populations. The narrowing digital divide, due to increasing technology access, will not by itself solve the problem of low adoption rates. Digital divide can come from a variety of factors, including lack of net neutrality and geographic constraints that require resolution before asserting improved technology access as a solution. Contrary to misleading assumptions that underserved populations, who may suffer from low health and computer literacy, are largely disinterested in engaging with technology, studies published in the past five years indicate high motivation to adopt technology and improve literacy. CHI development should benefit from varied user-centered design techniques that address context and individualized needs of each user. At the same time, there is still much to be learned about underserved populations’ CHI use. Future studies should develop systematic methods of evaluating effective user-centered design and adoptability of CHI use among underserved populations.

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