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Improving cervical cancer health literacy in Arabic-speaking immigrant women in the United States through an online patient education tool

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Abstract

Background: Low health literacy rates especially among the medically underserved have called for more understandable and actionable resources to involve patients in their health. The online audio-visual Reproductive Health Network (ReproNet) cervical cancer tool was shown to improve cervical cancer health literacy among marginalized English- and Spanish-speaking populations and Arab and Afghan immigrants in a group setting.

Objective: This study aimed to determine whether or not the cervical cancer tool positively impacts health literacy for Arabic-speaking Middle Eastern or North African first- and second-generation immigrant women in the United States when self-administered.

Design: In this single-group pre–post interventional study, a convenience sample of 95 Arabic-speaking immigrant women in the United States, ages 18 and over, reviewed an online cervical cancer patient education tool and completed pre- and post-tests.

Methods: Participants received links to the tool and to pre- and post-tests, using the cervical cancer literacy assessment tool. We conducted McNemar tests and paired *t*-tests to compare pre- and post-test results in health literacy per participants. A multivariate regression model was fitted to test the association between demographic variables and the change of cervical cancer literacy content domains, controlling for the baseline scores before administering the tool.

Results: Out of 118 participants, 95 participants had complete pre- and post-tests. Health literacy increased overall after self-administration of the tool, specifically in terms of cervical cancer prevention and control ($p < 0.01$). There were no significant differences in knowledge in U.S.-born versus foreign-born Arabic-speaking women ($p = 0.6660$).

Conclusion: The self-administration of the ReproNet cervical cancer tool most significantly increases awareness and knowledge of cervical cancer prevention in Arabic-speaking first- and second-generation immigrant women, thus pointing to increased quality of the provider–patient relationship.

Keywords

cervical cancer, Middle Eastern/North African, health literacy, Arabic-speaking immigrant women, patient education tool

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Introduction

Immigrants, including Middle Eastern refugee women, are oftentimes unable to afford care or are restricted due to health coverage. These factors have historically led to such marginalized populations having lower access to sexual and reproductive health (SRH) services compared to non-immigrants, a phenomenon that has only worsened with the onset of the COVID-19 pandemic.[1] Immigrants, including refugees, also experience high rates of structural racism and discrimination that pose additional barriers to SRH care.[2] In areas such as Afghanistan, Iraq, and Syria, cultural perspectives often deem women's SRH a sensitive and private topic that is rarely discussed and therefore ignored. Moreover, government policy in specific Middle Eastern countries causes barriers to accessing experts in the field of SRH. Specifically, procedures such as pap smear tests are denied in countries including Iran and Afghanistan, even if patients are in dire need of treatment.[3] Conditions of geopolitical instability, restrictive health policy, lack of health education, and low socioeconomic status (SES) are specific factors that have contributed to refugee women's health illiteracy.[4] Often after immigration, women from Arabic-speaking countries face challenges such as acculturative stress, medical mistrust, language barriers, and low social cohesion in adapting to a new country, which then also adds to the problem of low health literacy.[4,5] This phenomenon impacts cervical cancer screening as immigrant women from this minority population are less likely to undergo screening.

The Healthy People 2030 definition of "health literacy" involves "personal health literacy," which is defined as "the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others."[6] In addition to increased awareness and knowledge ("understanding"), this new Healthy People 2030 objective focuses on the use of health information and increased ability to be an active part in health decisions, for example, whether or not to participate in screening or how to follow-up on abnormal screening test results.[6] Given this effort to improve communication between health organizations and the patients they serve, it is important to recognize that it has been shown that lower health literacy rates lead to health inequities, both of which are more commonly seen in racial or ethnic minority populations compared to nonminorities.[7] Lower health literacy in minorities, with the lowest rates most commonly cited in Hispanic or African American groups, has been attributed to factors including a lack of adequate education, medical mistrust, racism, and a lack of cultural understanding in the healthcare system.[7] Racial minorities including African Americans and Hispanics more commonly have health literacy rates categorized as "below basic," and correspondingly see worse health outcomes compared to White Americans.[7]

Despite the growing attention to improving understanding in healthcare among medically underserved populations, there has not been much research dedicated to identifying gaps in understanding among Arabic-speaking immigrant women from the Middle East and North Africa.

To assess the efficacy of one health education tool in increasing cervical cancer knowledge and cervical cancer health literacy, we administered a patient education cervical cancer tool.[8] The online cervical cancer patient education tool is publicly available[9] and aims to assist women in understanding cervical cancer screening guidelines, emphasize the role of human papillomavirus vaccination in preventing cervical cancer, encourage them to ask questions to their providers, and assist in evaluating the risks and benefits of screening intervals and of management choices for abnormal cytology. The tool was developed in English and Spanish at a sixth-grade reading level and has an audio version. The combination of pictures, words, short videos, and interactive buttons designed to engage participants was extensively tested in focus groups, cognitive interviews, and community and clinician stakeholder input. Effectiveness of the tool was assessed in a comparative effectiveness study.[10–12] In 2019, the Refugee Reproductive Health Network (ReproNet) added audio-text in Arabic, Pashto, and Dari and evaluated the impact of its use in group health literacy training sessions.[8] The ReproNet tool not only increases knowledge and awareness but also improves comfort when communicating with a provider, as well as providing information for personal decision-making. However, given the option for self-administration, we do not yet know whether Arab immigrant women would find the audio version helpful and informative. Therefore, this study aims to determine to what extent the ReproNet cervical cancer tool[8] was effective in increasing cervical cancer literacy in Arabic-speaking first- and second-generation immigrant women.

Materials and methods

Study participants and setting

Study eligibility criteria included Arabic-speaking first- and second-generation immigrant women from Middle Eastern or North African countries, aged 18 and above residing in the United States. We excluded individuals under 18, as incentives to minors could be perceived as coercion. Recruitment was conducted via outreach within local public academic institutions and community associations, ensuring that none had prior exposure to the ReproNet cervical cancer tool.[8] A total of 118 qualifying women completed the pre-test, while 102 women completed the post-test. A total sample of 95 women who completed both the pre-test and post-test were included in final analytic data.

We have followed the relevant guideline for our study. There is no checklist for a single-group pre- and post-test design that could be applied to https://www.equator-network.

org/. Instead we completed the JBI checklist for quasi-experimental appraisal which can be found at chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://jbi.global/sites/default/files/2020-08/Checklist_for_Quasi-Experimental_Appraisal_Tool.pdf.

Instrument

We used the cervical cancer literacy assessment tool (C-CLAT)[13] to measure information regarding cervical cancer knowledge and awareness. The C-CLAT[13] was validated and employed in English, Spanish, and Arabic. The 22-item tool assesses the 3 cervical cancer content domains: (1) Cervical Cancer Awareness, (2) Cervical Cancer Knowledge and Screening, and (3) Prevention and Control. Each content domain's score was calculated using the mean of pertaining questions. All missing answers were considered wrong answers, so there is no missing data on all questions. Additional demographic questions prompted participants to provide immigration status, education level, country of origin, age when immigrated, etc.

Within the C-CLAT, there were 18 questions which prompted participants to choose between true and false. Four questions had multiple response options, including "all of the above" and "none of the above." The Awareness content domain consisted of four questions which were all true/false. The Knowledge and Screening domain consisted of eight questions, six of which were true/false and two of which had multiple response options. The Prevention and Control domain consisted of 10 questions, 8 of which were true/false and 2 of which had multiple response options. In data analysis, correct answers were coded with a "1," while incorrect answers were coded with a "0."

Survey administration and data collection

Participants answered the same survey questions in the post-test as the pre-test to evaluate the change in responses. The mean difference between pre-and post-test scores quantified the efficacy of the ReproNet cervical cancer tool[8] in increasing cervical cancer awareness in a self-administered intervention approach with the target population of Arabic-speaking immigrant women.

The cervical cancer study includes data collection from first- and second-generation Arabic-speaking immigrants from North Africa and the Middle East, who are living in the United States. Participants were sent consent forms to allow them to choose whether or not they would like to be a part of the study. If participants agreed to join the study, they were sent a consent form with links to the Arabic and English versions of the pre-test and post-test alongside the C-CLAT with directions on how to participate.[13] To determine that we only received data from Arabic-speaking participants we omitted respondents who answered outside of Arabic-speaking countries before data analysis. The survey would automatically terminate if minors, defined as anyone under the age of 18, or non-Arabic speakers attempted to take it.

Upon completing both the pre-test and post-test, participants received a $10 gift card.

Sample size

To estimate that the survey is sufficiently powered, we used the data of the intervention and comparison group from the evaluation of understanding of cervical cancer screening among English- and Spanish-speaking patients. We used summary statistics of the control group (mean = 3.82, SD = 1.00) as pre and of the intervention group (mean = 4.46, SD = 0.82) as post. Thus, we have an estimate of the difference between post minus pre as $4.46 - 3.82 = 0.64$ and an estimate of the standard deviation of the differences to be 1.16 [based on the formula $\mathrm{Var}(X - Y) = \mathrm{Var}(X) + \mathrm{Var}(Y) - 2\mathrm{SD}(X)\_\mathrm{SD}(Y)\mathrm{Corr}(X, Y)$] corresponding to an effect size of approximately 0.5. Thus, a sample size of 34 data pairs achieves 80.8% power to reject the null hypothesis of zero-effect size when the population effect size is 0.5 and the significance level (alpha) is 0.05 using a two-sided paired *t*-test. With an expected dropout rate of 20% between pre- and post-test ($n = 9$), we estimated that we will need a minimum of 43 participants to ensure that the survey is sufficiently powered to detect differences between pre- and post-test.[14–17]

Statistical analysis

Descriptive statistics were summarized for demographic variables using the sample. Means and standard deviations were calculated for pre- and post-test content domains, and paired *t*-tests were conducted to test the mean differences between pre- and post-test scores. McNemar's tests were also conducted for each individual question. Summary descriptive statistics were calculated for change of score in each content domain (post-test score − pre-test score) per demographic category. Using change of score as the outcome, a multivariate regression model was fitted to test the association between demographic variables and change of score, controlling for the baseline score from the pre-test, before administering the ReproNet cervical cancer tool.[8] All statistical analyses were performed on SAS 9.4 (SAS Institute, Cary, NC, USA). Statistical significance was set at $p < 0.05$, using two-tailed tests.

Results

A total of 95 women were included in data analysis. Participants who did not meet eligibility criteria or who did not complete both the pre-test and post-test were excluded.

Table 1 lists the demographic criteria of participants. Most women who fully completed the study were in the age range of 18–24 years old (73%) and most were U.S.-born

(63.2%), as seen in Table 1. Ninety-four percent of women opted to complete the pre-test and post-test in English, while 6% completed the pre-test and post-test in Arabic. The largest group of participants self-identified as Egyptian, with Syrian women being the next largest group (Table 1). A third of participants achieved a high school education or less while 65% had a college education or more (Table 1).

Table 2 shows the mean frequency and percentage of correct answers on the pre-test and post-test and the mean change in correct answers between the two tests. Most significantly, in the Awareness content domain, the mean change within pre- and post-test responses was 0.11, with a *p*-value of 0.003. For the three content domains tested via the C-CLAT, namely Awareness, Knowledge and Screening, and Prevention and Control, there was a statistically significant increase in women's scores for Awareness and Prevention and Control, but not for Knowledge and Screening (Table 2). Prevention and Control had the most statistically significant mean increase in scores between pre-test and post-test, followed by Awareness (Table 2).

Table 1. Improving cervical cancer health literacy in Arabic-speaking immigrant women in the United States through an online patient education tool demographics (total $N = 95$).

Age groups	Numbers ($N = 95$)	Percentages
18–24	69	73
25+	26	27
Country of birth		
U.S.-born	60	63.2
Syria	9	9.5
Egypt	5	5.3
Iraq	5	5.3
Other MENA countries	16	16.7
Education level ($N = 94$)[a]		
High school or less	33	35
College level or more	61	65
Age when immigrated (if not U.S. born) ($N = 29$)[b]		
13 and under	12	13.5
>13	17	19.1

[a]Missing value for one participant.
[b]Missing value for six participants.

Upon screening each individual question by content domain, three out of four questions in Awareness showed a significant increase in correct answers between the pre-test and post-test based on McNemar's test (see Supplemental Table 1). In Knowledge and Screening, two out of eight questions yielded a significant increase in correct answers, while one question yielded a significant decrease in correct answers between the pre- and post-tests (see Supplemental Table 1). In Prevention and Control, 5 out of 10 questions showed a significant increase in correct answers from pre- to post-test while 1 question showed a significant decrease in correct answers between pre- and post-test (see Supplemental Table 1).

For mean change in pre-test and post-test responses, we found no significant difference in scores between U.S.-born and immigrant participants. We also found no significant difference in scores between groups of participants aged 18–24 and 25 years of age and older. Between immigrants 13 years of age or below versus immigrants older than 13 years of age, the sample size was too small to conduct statistical analysis.

Discussion

This study's objective was to determine whether or not the ReproNet cervical cancer tool[8] was successful in increasing cervical cancer health literacy when self-administered in Arabic-speaking immigrant women in the United States. Findings show that the tool was successful in increasing awareness and prevention and control within this population. The Knowledge and Screening content domain did not show a statistically significant mean increase. Cervical cancer Awareness showed the most statistically significant increase in scores before versus after viewing the ReproNet cervical cancer tool, thus reflecting increased quality of the provider–patient relationship.[8] The mean change for Knowledge and Screening was modest (from 0.75 on the pre-test to 0.78 on the post-test as seen in Table 2). The ReproNet tool[8] thus had more of an impact on changes in Awareness and Prevention and Control. The baseline score for awareness is relatively lower (0.62 based on Table 2), and the tool has a strong emphasis on prevention and control

Table 2. Improving cervical cancer health literacy in Arabic-speaking immigrant women in the United States through an online patient education tool comparison of pre-test versus post-test means (total $N = 95$).

Cervical cancer literacy content domain	Pre-test mean	Pre-test standard deviation	Post-test mean	Post-test standard deviation	Mean change	*p*-Value (from paired *t*-test)
Awareness	0.62	0.24	0.73	0.22	0.11	0.0003
Knowledge and screening	0.75	0.15	0.78	0.14	0.03	0.0506
Prevention and control	0.75	0.15	0.83	0.15	0.08	<0.0001
All	0.73	0.13	0.79	0.12	0.06	<0.0001

(risk factors for cervical cancer, getting an Human papillomavirus vaccine, and lifestyle change to prevent cervical cancer like nonsmoking) that explains the statistically significant increase in Prevention and Control and perhaps the slightly insignificant increase in Knowledge and Screening. Both questions which showed a significant decrease in understanding required participants to recall knowledge about Pap smears (see Supplemental Table 1). Thus, perhaps the ReproNet tool[8] was not specific or comprehensive enough in addressing and clarifying concepts surrounding when to get a Pap smear and for whom they are needed.

Findings from our study agree with existing literature related to the positive impact of health literacy tools in increasing awareness of important health concepts. Other studies have shown there to be a positive correlation between increasing reproductive knowledge and better health outcomes.[18] Though studies are limited, health literacy is considered an important part of the physician–patient relationship, specifically in a reproductive health context.[18] A recent study has also shown that higher health literacy in minority populations has worked to improve the health of minorities who are at risk for sexually transmitted diseases. The study goes further in saying that it is important for patients not only to have access to health information, but to be able to understand and apply information.[19] Our study similarly focused on encouraging participants to interact with the ReproNet cervical cancer tool[8] in an individual setting and subsequently testing their understanding through the C-CLAT.[18]

Findings from our study that demonstrated higher understanding for health literacy are consistent with results from meta data that showed improvement in health literacy rates in low- and middle-income countries, whose survey populations showed improved survey metrics to health literacy-based questions postintervention.[20] Multiple health literacy intervention strategies improved health literacy rates, especially with respect to knowledge and awareness.[20] Though our study did not find a statistically significant increase in the Knowledge and Screening content domain between the pre- and post-test, the result was very close to being statistically significant ($p = 0.0506$), which indicates the result was trending toward significance. A recent study which also utilized a pre-test and post-test design with a health awareness intervention in a population of Southeast Asian women of reproductive age showed that participants had a higher degree of confidence in managing their health postintervention.[21] While our study did not go so far as to assess confidence with respect to managing or treating cervical cancer, the ReproNet cervical cancer tool[8] was used as an intervention to assess the change in health literacy rates as a result of its use. Given the increase in confidence as a result of health literacy interventions when it comes to managing health in populations of women of reproductive age; however, it is evident that more research should be conducted to investigate how health literacy interventions should be implemented in marginalized populations to further improve health outcomes.

Findings from this study point to the significance of educating and informing understudied populations of women regarding their reproductive health and for advocating for the implementation of functional health literacy interventions. Even in a study of high-income Arab women in the United Arab Emirates, overall health literacy rates were deemed low.[22] Thus, the implementation of health literacy interventions and increased research on highly adhered interventions are needed worldwide and across economic statuses. In a previous study on sexual and reproductive health literacy (SRHL) in Lao PDR, it was determined that SRHL was significantly positively correlated with multiple factors, including knowledge of SRH and functional knowledge of how to use condoms.[23] Not only has health literacy proved its importance in improving health outcomes and disseminating information to populations, but it seems that patients' ability to functionally use, understand, apply this information is a major component in health outcomes.[23]

Strengths and limitations

The intervention-based approach and use of a pre-test and post-test strengthens the study because results are extrapolated in comparison to baseline knowledge per participant. This allows for an accurate measure of the efficacy of the audio-visual cervical cancer tool in increasing cervical cancer health literacy. Furthermore, the use of the C-CLAT, a previously validated cervical cancer literacy assessment tool used in African American and Hispanic populations, allows for standardized and accurate cross-population comparisons between underrepresented minorities. The bilingual aspect of all three parts of the study (pre-test, Repronet tool,[8] and post-test) given in both Arabic and English also allowed for full participation of a wider participant sample in an unbiased manner, at least with respect to cultural factors and translation difficulties.

One potential limitation of the study is that in comparing scores of immigrants who came to the United States. Thirteen years of age or younger versus older than 13 years old, there were not significant sample sizes to draw statistically significant conclusions. Only descriptive statistics could be run, which limited conclusions drawn regarding cervical cancer health literacy as impacted by the difference in preadolescent and post-adolescent immigrant experiences. A larger sample size would have allowed us to determine if such trends were statistically significant.

Another limiting factor is that the pre-test and post-test did not ask about healthcare coverage as a proxy to SES. Medicare and Medicaid are oftentimes linked to SES and may be correlated with health literacy levels due to the strict income requirements for insurance coverage eligibility. However, education level and age were assessed in the

study, which act as covariates to SES. This can be aided by implementing a question that describes the health insurance that is current to the individual as well as income questioning. Further research is needed to determine whether cervical cancer health literacy differs by country of origin. Our study did not have a significant sample size of participants per Middle Eastern or North African country to determine whether factors such as gross domestic product and infrastructure differences impacted baseline or increase in knowledge and awareness of cervical cancer. This can also be further improved by drawing on larger sample sizes to have improved quality and data quantity.

Last, our study did not include a control group in order to compare the statistically significant results to a baseline population. Using a control group of participants who would take the pre-test and post-test without using the ReproNet tool would improve the study design by increasing confidence in the tool's efficacy.

Conclusion

This study reports that the ReproNet cervical cancer tool significantly increased cervical cancer health literacy for Arabic-speaking first- and second-generation immigrant women, with the exception of the content domain of knowledge and screening, which only trended toward significance. The findings documented that changes in cervical cancer health literacy were not significantly associated with whether or not participants were born in the United States. With Arabic-speaking Middle Eastern and North African women being a marginalized group in healthcare and especially with respect to SRH, the study has proven to be useful in taking an intervention-based approach to educating this population. Although results prove self-administered audiovisual tools in Arabic and English to be significant, there is still limited research regarding other factors such as SES and education level when assessing health literacy rates. Gathering a larger sample size is key to better understanding the factors which limit and contribute to the SRH knowledge of women in marginalized communities.

Declarations

Ethical considerations

This study was deemed approved for IRB exemption, by the University of California Irvine Kuali Research Board, with approval number 4724.

Consent to participate

Participants were required to provide informed written consent before starting the pre-test and post-test.

Consent for publication

Not applicable.

Author contribution(s)

Amira M Zayed: Conceptualization; Writing – original draft; Writing – review & editing; Methodology; Investigation; Visualization.
Saria Nassar: Methodology; Writing – review & editing; Investigation; Visualization.
Jenny Chang: Formal analysis.
Layla Dalati: Writing – review & editing; Investigation.
Heike Thiel de Bocanegra: Conceptualization; Writing – review & editing; Project administration; Supervision.

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Competing interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability

The data supporting the study is contained within the manuscript and supplementary materials.

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Supplemental material

Supplemental material for this article is available online.

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