Asian/Pacific Island Nursing Journal

Devoted to the exchange of knowledge in relation to Asian and Pacific Islander health and nursing care
Volume 9 (2025) ISSN 2373-6658 Editors-in-Chief: Hyochol (Brian) Ahn, PhD, MSN, MS-ECE, MS-CTS, APRN, ANP-BC, FAAN

Contents

Review

Original Papers

COVID-19–Related Racism and Mental Health Among Asian Americans: Integrative Review

Tania Von Visger*, PhD, APRN; Amy Lyons*, MLS, EMBA, AHIP; Yanjun Zhou*, BSN; Kayla Wardlaw*, MSN, RN, CCRN, CNE; Eunhee Park*, RN, APHN BC, PhD; Yu-Ping Chang*, PhD, RN

School of Nursing, State University of New York at Buffalo, 3435 Main St, Wende Hall Suite #201F, Buffalo, NY, United States

*all authors contributed equally

Corresponding Author:
Tania Von Visger, PhD, APRN
School of Nursing, State University of New York at Buffalo, 3435 Main St, Wende Hall Suite #201F, Buffalo, NY, United States

Abstract

Background: Racism against Asian Americans escalated during the COVID-19 pandemic. About 31% - 91% of Asian American adults and children reported experiencing various types of racism during the pandemic. According to the Federal Bureau of Investigation hate crime statistics, anti-Asian hate crime incidents increased from 158 in 2019 to 279 in 2020 and 746 in 2021. In 2022, the incidents decreased to 499, corresponding to the downward trend of the pandemic. The degree of impact racism has on mental health and wellness among Asian Americans requires investigation, specifically during the COVID-19 pandemic.

Objective: We aim to describe racism-related mental health problems experienced by Asian Americans living in the United States and propose implementation strategies for mitigating their consequences.

Methods: We conducted an integrative review of peer-reviewed publications in English reporting anti-Asian sentiments and racism's impacts on mental health among Asian Americans in the United States.

Results: The 29 eligible articles report on studies that utilized cross-sectional survey designs with various sample sizes. Racism is directly correlated with the prevalence of depression and anxiety experienced by victims of racist acts. The prevalence of in-person direct racism (racist expression aimed directly at the victim) is lower than in-person indirect racism (racist expression aimed at the ethnic group the victim belongs to). During the COVID-19 pandemic, the incidence of explicit online racism was lower than online indirect racism.

Conclusions: COVID-19–related racism exacerbated preexisting racism, contributing to worse depression and anxiety among Asian Americans. To address this issue, we propose 2 main approaches: increase public awareness and education about recognizable racist sentiments/acts and systematized reporting of racially motivated crimes to guide political action. At an individual level, culturally responsive, trauma-informed interventions promoting cultural support and cohesion for various Asian American groups will foster this empowerment. These proposed actions will help alleviate racism by reducing stereotypes, empowering victims, and chipping away at the systemic racism structure.

(Asian Pac Isl Nurs J 2025;9:e63769) doi:10.2196/63769

KEYWORDS

racism; anti-Asian sentiment; integrative review; psychological distress; mental health; review; Asian American; Asian; wellness; psychological; distress; COVID-19; pandemic; cross-sectional survey; survey; depression; anxiety

Introduction

Background

In June 2021, the National Commission to Address Racism in Nursing defined racism as "assaults on the human spirit in the form of actions, biases, prejudices, and an ideology of superiority based on race that persistently causes moral suffering and physical harm to individuals and perpetuates systemic injustices and inequities" [1]. From this broad perspective, there are ranges of defining characteristics depending on how the perpetrators commit the assault and whether the assault is overt, as well as the detrimental outcomes (physical or emotional) of the assaults. More importantly, displays and the impacts of racism vary in form and intensity and can have long-lasting deleterious effects on the social environment. Because racism broadly exists at 3 connected levels, multiple approaches to addressing the issue are necessary. These levels include institutional racism (policies and practices that allow inequity), cultural racism (ideology of inferiority of particular groups), and discrimination (individual level) [2].

Observable and objective consequences of racism, such as physical harm, occur less often than other forms of racism; however, other forms may be more challenging to identify, and psychosocial suffering may be hidden and rarely discussed [3,4].

The complexity of these multiple dimensions and domains of racism (eg, displays of racism [beliefs, words, or actions]; impacts of racism [emotional or physical harms]; and reach of racism [individual, family, community, or society]) presents challenges for defining and measuring constructs of racism and the true psychological impacts on victims. The relationships between racism, perpetrators of racism, and victims of racism do not exist in a vacuum; they are shaped by many cultural racism-related social factors throughout US history [5,6]. The stereotypes baked into the human psyche turn into norms and environmental structures of institutional or systemic racism [7-9]. Systemic racism becomes part of our society and social structure, perpetuating systemic injustices and inequities embedded and reinforced in laws and regulations and unconsciously in biases and prejudices [10].

Verbal or written expressions of racist attitudes toward a specific racial-ethnic group are considered "hate speech." Regardless of the delivery method of racist expression (direct vs indirect) and the intensity of the racist expression (subtle microaggressions to overtly racist remarks), individual-level racism (such as hate speech) and discrimination are associated with poor mental health and a higher risk of psychiatric disorders across minority groups [11]. Racism has also been shown to affect physical health through the mechanism of the physiologic stress response, as measured by chronic inflammatory markers, and it also directly links to increased depressive and anxiety symptoms [12]. In a meta-analysis involving 293 studies, racism was associated with poor mental health (depression, anxiety, and psychiatric distress) and poor general health and physical health [13]. One study showed everyday discrimination is associated with higher odds of developing psychiatric experiences (odds ratio [OR] 4.59) and lifetime psychotic experiences (OR 4.27) in a large sample that included Latino, Asian, African American, and Caribbean Black adults [12]. The association between racism and mental health was stronger among Asian Americans than among Blacks [13]. Everyday discrimination experiences among Asian Americans increased the likelihood of being diagnosed with depression (OR 1.72) and anxiety (OR 2.24) disorders within the past 12 months while controlling for confounding variables such as poverty level, acculturation, physical health, family cohesion, and social desirability [14]. Among studies that explore Asian American subgroups, racism is associated with poor mental health in college students, East Asian adults, and South Asian adults [15-17]. Regardless of the range of mental health severity impacts, racism experiences among minoritized groups yield consistent results of harmful psychological and physical health deterioration.

Displays of Individual-Level Racism

Expression or displays of racism can vary in subtlety, from microaggressions to more deadly acts of physical assaults. Racist words can be directly aimed at an individual, which is called direct racism, or at the minority group identified by the individuals, termed indirect or vicarious racism [18]. Those who experience repeated racism may harbor a constant state of fear and heightened awareness called racial discrimination vigilance [11]. The developmental theory of embodiment emphasizes the strong connection between the social environment and how people come to understand the world around them, such that the social structure of domination and privilege can lead to the embodiment of health inequities [19]. This internalization of unjust social premises is an antecedent to conscious and unconscious vigilance, leading to poorer mental and physical health [19]. Due to the COVID-19 pandemic lockdown, more racist attacks were perpetuated online, although face-to-face or in-person racist acts continued to rise as well [18,20-23]. The increased use of social media during and immediately after the lockdown contributed to an increase in online anti-Asian sentiments, as these platforms are venues where people tend to be uninhibited [24]. An analysis of more than 1 million social media hashtags distinguishing the degree of anti-Asian sentiment association with word choice revealed that 50.4% (392,037/777,852) of #ChineseVirus contained anti-Asian sentiments compared to 19.7% (of 495,289) of #COVID-19 [25]. The use of these terms increased dramatically from March 9 to 23, 2020; the degree of increase was statistically different between #ChineseVirus and #COVID-19 [25]. Regardless of the method or intensity of anti-Asian racist expression, data indicate that all types of racism negatively impact Asian American individuals' mental health and well-being. This impact is especially pronounced when racism is perpetrated through social media platforms [25]. Throughout this article, we use "anti-Asian sentiment" to represent the central concept encompassing this broader display of racism, whether subtle or overt.

Racism Experienced by Asian Americans in the Context of the COVID-19 Pandemic

In the last weeks of 2019, COVID-19 emerged in Wuhan, China, eventually leading to a worldwide lockdown in March 2020. COVID-19 is related to an earlier viral strain that caused a smaller-scale pandemic in November 2002 with clinical presentation of severe acute respiratory syndrome. Both phenomena originated in China, fueling the spread of misinformation and anti-Asian sentiments. Studies indicate that anti-Asian sentiments (racist sentiments, including microaggression and unconscious biases) increased significantly during the COVID-19 pandemic [18,20,21,24-27]. Like other racial minorities living in the United States, racism against Asian Americans is not a recent phenomenon; it persists throughout American history, as documented in the Yellow Peril, Japanese internment, and the perpetuation of the model minority sentiment [5,6]. The intensity and wide range of racist displays against Asian Americans, including social media posts [24,28], discriminatory behaviors, and hate incidents, dramatically increased during the COVID-19 pandemic [20,26]. Systematic reviews about Asian American hate or Asian American hate combined with mental health during the COVID-19 pandemic are limited. We are mindful that an accurate assessment of the impact of the COVID-19 pandemic is limited by incomplete and inaccurate reporting of physical and mental health outcomes [29].

We conducted an integrative review to explore mental health problems experienced by Asian Americans during the COVID-19 pandemic. The purpose of this review is to understand how anti-Asian sentiments (prejudice, hatred, or racism) impact mental health (anxiety, depression) among Asian

Americans (Asian immigrants and Asian Americans) living in the United States during the COVID-19 pandemic. Guided by the integrative review procedures, we focused our research investigation on the PICO question, “How do anti-Asian sentiments (prejudice, hatred, or racism) impact mental health (anxiety, depression) among Asian Americans (Asian immigrants and Asian Americans) living in the United States during the COVID-19?”

Methods

Study Design

We followed the integrative review methodology described by Whittemore and Knafl (2005) [30], which includes five general steps: (1) defining the target population and problem, (2) literature search, (3) data evaluation, (4) data analysis, and (5) data presentation. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) were used to guide the reporting of this review.

Search Strategies

From June 2021 to November 2023, the authors, including a librarian with expertise in conducting systematic reviews, searched multiple electronic databases. Searched databases were Embase, PubMed, CINAHL, Cochrane, PsycINFO, and Web of Science. We extensively searched for publications reflecting the impact of the COVID-19 pandemic lockdown officially implemented in March 2020. We included articles published between January 1, 2020, and November 31, 2023, to include the effect of COVID-19 in the initial phase, even before the national announcement of the COVID-19 lockdown mandate.

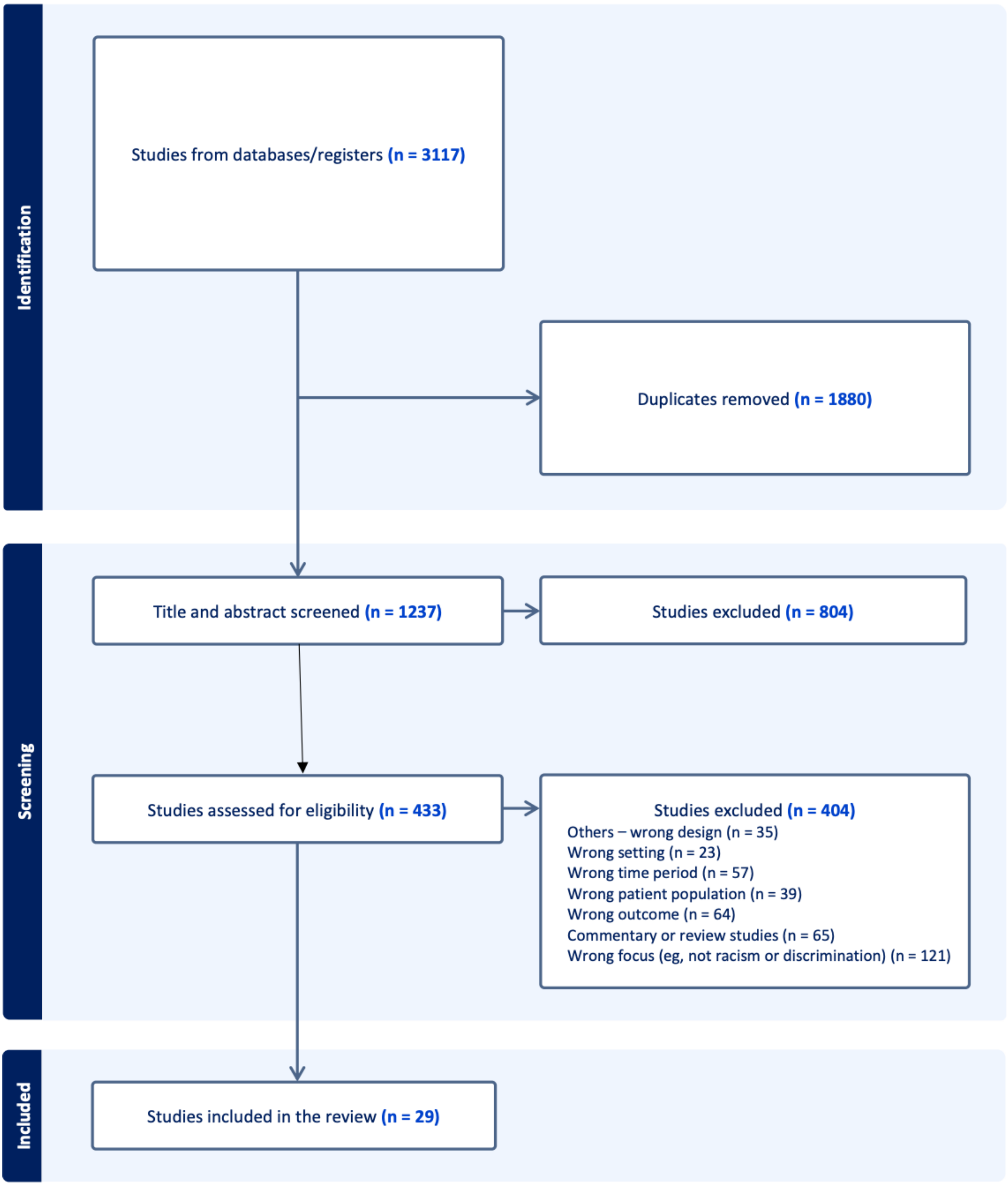
Study Selection and Inclusion and Exclusion Criteria

We searched for peer-reviewed publications of empirical literature reporting about anti-Asian sentiments and mental health and well-being among Asian Americans in the United States during the COVID-19 pandemic. Search terms used in the study were as follows: Asian Americans AND COVID-19, AND mental health–related terms (mental health OR depression OR anxiety), AND terms related to racism (racism OR model minority OR health inequity). An initial search in PubMed and CINAHL helped to identify a complete list of key search terms that accurately described our aim of identifying relevant articles. We then applied these search terms to identify references in related databases. For inclusion in this review, studies must: (1) be published in peer-reviewed research journals; (2) focus on Asian American populations; (3) report on anti-Asian sentiment, individual-level racism, or discrimination; and (4) report on mental health outcomes. We excluded the following: (1) conference abstracts, (2) opinion or discussion reports, (3) systematic reviews, (4) research not published in English, and (5) research not conducted in the United States.

Data Extraction

Figure 1 shows a flow diagram of the study screening process. From the original 3117 citations identified, 1880 duplicates were removed, with 1237 remaining. Two researchers independently reviewed titles and abstracts and agreed to exclude 804 publications because they did not include Asian Americans, were not conducted during the COVID-19 pandemic, did not measure mental health outcomes, or were commentaries. The 433 remaining articles received a full-text review by 2 independent reviewers, with a third reviewer to resolve the disagreements. A total of 404 articles were excluded.

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart: search results and study selection procedures.



Synthesis of Findings

Two authors independently reviewed 29 articles. They coded them into a table format, including details about participants' characteristics, settings, sample size, study designs, aims, statistical methods, and main results. The primary clinical outcomes investigated and reported to be associated with racism in the articles reviewed were depression and anxiety. The same 2 reviewers compared abstracted data and then discussed the data with a third reviewer to achieve consensus.

Results

Quality Appraisal

We used the Joanna Briggs Institute (JBI) guidelines for appraising cross-sectional research to assess the quality of the reports (Table 1). The JBI Critical Appraisal Checklist for Cross-Sectional Studies includes "yes" or "no" confirmation of 8 criteria regarding the overall conduct of the investigations surrounding the scientific rigors about study subjects and settings, standard condition measurement, reliable and valid outcome measurements, appropriate statistical analysis, and description of confounding factors (Table 1).

Table . Quality assessment of studies included in the review (n=29).

	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?
Chae et al, 2021 [11]	Y[a]	Y	Y	Y	Y	Y	Y	Y
Cheah et al, 2020 [22]	Y	Y	Y	Y	N/A[b]	N/A	Y	Y
Cheah et al, 2023 [31]	Y	Y	Y	Y	Y	Y	Y	Y
Dhanani et al, 2022 [32]	Y	Y	Y	Y	Y	Y	Y	Y
Ermis-Demirtas et al, 2022 [33]	Y	Y	Y	Y	Y	Y	Y	Y
Fanta et al, 2023 [5]	Y	Y	Y	Y	Y	Y	Y	Y
Haft and Zhou, 2021 [34]	Y	Y	Y	Y	Y	Y	Y	Y
Huynh VW et al, 2022 [35]	Y	Y	Y	Y	N[c]	N/A	Y	Y
Huynh VW et al, 2022 [35]	Y	Y	Y	Y	N	N/A	Y	Y
Huynh J et al, 2022 [36]	Y	Y	Y	Y	Y	Y	Y	Y
Ikram et al, 2023 [37]	Y	U[d]	Y	Y	N	N/A	Y	Y
Keum and Choi, 2022 [38]	Y	U	Y	Y	Y	Y	Y	Y
Layug et al, 2022 [39]	Y	Y	Y	Y	N	N/A	Y	Y
Lee et al, 2020 [10]	Y	U	Y	Y	N/A	N/A	Y	Y
Li et al, 2023 [40]	Y	Y	Y	Y	Y	Y	Y	Y
Litam and Oh, 2022 [41]	Y	U	Y	Y	Y	Y	Y	Y
Litam et al, 2022 [41]	Y	U	Y	Y	Y	Y	Y	Y
Liu et al, 2020 [42]	Y	Y	Y	Y	Y	Y	Y	Y
Liu et al, 2022 [43]	Y	Y	Y	Y	Y	Y	Y	Y
Lu et al, 2022 [44]	Y	U	Y	Y	N	N/A	Y	Y
McGarity-Palmer et al, 2023 [45]	Y	Y	Y	Y	Y	Y	Y	Y
Oh et al, 2022 [46]	Y	U	Y	Y	N	N/A	Y	Y

	Were the criteria for inclusion in the sample clearly defined?	Were the study subjects and the setting described in detail?	Was the exposure measured in a valid and reliable way?	Were objective, standard criteria used for measurement of the condition?	Were confounding factors identified?	Were strategies to deal with confounding factors stated?	Were the outcomes measured in a valid and reliable way?	Was appropriate statistical analysis used?
Oh et al, 2022 [47]	Y	U	Y	Y	Y	Y	Y	Y
Pan et al, 2020 [48]	Y	Y	Y	Y	Y	Y	Y	Y
Jun et al, 2021 [49]	Y	Y	Y	Y	Y	Y	Y	Y
Wu et al, 2021 [50]	Y	Y	Y	Y	Y	Y	Y	Y
Zhou et al, 2023 [51]	Y	Y	Y	Y	Y	Y	Y	Y

[a] Y: Yes.

[b] N/A: Not applicable.

[c] N: No.

[d] U: Unclear.

Study Characteristics

All 29 studies, with a wide range of sample sizes (from N=64 to N=7813), utilized cross-sectional survey designs conducted during the COVID-19 pandemic starting in March 2020, assessing possible associations between individual-level racism and mental health outcomes (Table 2 and Figure 1). All 29 articles received a score above 7 using the JBI Critical Appraisal tool. Three articles provided mental health outcomes of children as direct recipients of racism, directly or indirectly, through their parents [5,23,31]. These studies measured individual-level racism, focusing on direct racism; four assessed vicarious racism, and one assessed vigilance [3,9,22,23,31,39]. Five studies distinguished between online racism and in-person racism, and one differentiated the victim experience between US-born and foreign-born Asian Americans [22,23,31,33,44,48]. Our synthesis of available data revealed that racism against Asian Americans during the COVID-19 pandemic in the United States impacted the 2 mental health outcomes of depression and anxiety.

Table . Literature review matrix summary.

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
1. Chae et al, 2021 [11]	604 Asian Americans; 844 Blacks in 5 US cities	May 21, 2020, to July 15, 2020	Vicarious racism (7-item Likert); vigilance (4-item Likert)	Depression and anxiety	Racism is associated with depression (Asian Americans: *b*=1.92; Blacks: *b*=1.72); racism is associated with anxiety (Asian Americans: *b*=2.4; Blacks: *b*=1.98); vicarious racism is associated with depression (Asian Americans: *b*=1.54; Blacks: *b*=0.90); vicarious racism is associated with anxiety (Asian Americans: *b*=1.98; Blacks: *b*=1.65)	Limited to 5 US cities
2. Cheah et al, 2020 [22]	543 Chinese Americans and their 230 children	March 14, 2020, to May 31, 2020	Online direct racism; online vicarious racism; in-person direct racism; in-person vicarious racism; health-related Sinophobia; Sinophobia in media	Psychological well-being (Ryff's 18-item); GAD-7[a], Beck Depression	Prevalence of racism: online racism (31.7% adults; 45.7% youths); online vicarious racism (76.8% adults; 76.5% youths); in-person racism (50.9% adults; 50.2% youths); in-person vicarious racism (88.5% adults; 91.9% youths). Psychological well-being was negatively associated with most types of racism. Anxiety and depression were positively associated with all types of racism.	Measured 6 types of racism in Chinese Americans and their children

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
3. Cheah et al, 2023 [31]	529 Chinese American parents and their 225 children (4 - 18 years old)	2020 and 2021	Health-related Sinophobia; media Sinophobia: online direct, online vicarious, in-person direct, in-person vicarious	Psychological well-being (Ryff's 18-item); GAD-7; Beck Depression	Dimensions of racism were more strongly associated with parent anxiety symptoms (interaction effect b values ranging from 0.74 to 1.76; P values ranging from .004 to <0.001) in 2021 than in 2020. Parent online vicarious discrimination was more strongly and positively associated with parent depressive symptoms (interaction effect b=1.03; P<.001). Racism dimensions were more strongly associated with youth anxiety symptoms (interaction effect b ranging from 0.92 to 1.65; P values ranging from .013 to <.001) in 2021 than in 2020.	Demonstrated the increased gravity of the mental health issues with time
4. Dhanani et al, 2022 [32]	Asians and Asian Americans (T1 only: n=401; T1 and T2: n=311)	April 2021	Experienced discrimination (Everyday Discrimination Scale); vicarious discrimination (adapted version of 3-item Vicarious Racism Scale)	PHQ[b]-9	Significant association with increased depression (r=0.31, P<.001), physical health symptoms (r=0.32, P<.001), and increased sleep disturbances (r=0.23, P<.001). Vicarious discrimination related significantly to all outcome variables (depressive symptoms: r=0.25, P<.001; physical health symptoms: r=0.27, P<.001; sleep quality: r=−0.17, P=.003; sleep disturbances: r=0.20, P<.001).	Focused measures of discrimination that occurred during the pandemic

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
5. Ermis-Demirtas, et al, 2022 [33]	114 Asian Americans: Chinese (53.5%), Japanese (24.6%), Korean (8.8%), Vietnamese (7%), Thai (3.5%), Filipino (2.6%)	January to May 2021	COVID-19–related discrimination online; COVID-19–related discrimination offline	PHQ-Adolescents, GAD-7	COVID-19–associated discrimination online and COVID-19–associated discrimination in-person variables accounted for an additional 18% variance in the outcome variable (PHQ-Adolescents; $F_{4,109}$=60.19; P<.001; R^2=.69; adjusted R^2=.68).	It was controlled for childhood trauma.
6. Fanta et al, 2023 [5]	229 East/Southeast Asian parents of a child between 2 and 19 years. Chinese (41%), Taiwanese (27.5%), and Filipino (11.8%).	Not applicable	Discrimination subscale of the General Ethnic Discrimination Scale; COVID-19 Discrimination Fear.	Anxiety and depression subscales of DASS-21[c]	Discrimination predicted higher levels of anxiety (B=.38, P<.001) and depression (B=.23, P<.001). Fear of discrimination was positively associated with anxiety (B=.18, P=.004)	Explored moderating effects of coping styles
7. Haft and Zhou, 2021 [34]	Chinese American college students (134 before and 64 after COVID-19)	Fall semester (September 9, 2019, to December 3, 2019) versus spring semester (February 4, 2020, to March 23, 2020)	Perceived discrimination	Beck Anxiety Inventory; overall media exposure; negative Chinese media exposure	An association between racism and anxiety was found (r=0.36, P<.001). The COVID-19 pandemic moderated the relationship between racism and anxiety. Negative Chinese media exposure mediated the relationship between racism and anxiety.	Measured during the immediate COVID-19 period
8. Huynh J et al, 2022 [36]	176 Asian American young adults and adolescents from 17 Asian ethnicities, mostly: Chinese (35%), Vietnamese (27%), and Filipinx (18%)	May 2021 to March 2022	Anti-Asian violence: experienced and perceptions of safety	PHQ-9	Three-quarters and two-thirds of participants felt less safe and depressed, respectively. Feeling less safe was more pronounced (P<.01) among those who experienced racism and depression.	Youth experience with racism
9. Huynh MP et al, 2024 [6]	3508 Asian Americans: Chinese (19%), Filipino (13.4%), Indian (19.1%), Korean (6.5%), Vietnamese (8.4%), other Asian Americans (15.2%)	January-April 2021	Anti-Asian discrimination; impact of discrimination	PHQ-2, GAD-7	Facing discrimination led to increased odds of psychological distress (OR[d] 2.10, 95% CI 1.61-2.74).	Examined moderating role of social support, stratified by gender

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
10. Huynh VW et al, 2022 [35]	380 self-identified East Asian and Southeast Asian American adults: Chinese (26.3%), Japanese (12.6%), Vietnamese (8.7%), Cambodian (8.4%), Korean (7.1%), Filipino (6.1%), Thai (5.5%), Malaysian (4.2%), Taiwanese (3.9%), Indonesian (3.9%), Hmong (3.7%), Laotian (3.7%), Burmese (3.2%), Singaporean (2.6%)	Not applicable	COVID-19–associated discrimination	CES-D[e], GAD-7	Discrimination was associated with anxiety (*r*=.50, *P*<.01) and depression (*r*=.49, *P*<.01).	Included subdomain of discrimination, and across ethnic identity
11. Ikram et al, 2023 [37]	289 self-identified Asian Indians living in the United States	May 2021 and July 2021	Individual discrimination	Two items: (1) feeling down, depressed, or lonely; and (2) feeling nervous, tense, or worried	Overall, 66% and 46% reported discrimination and poor mental health, respectively. Shapley additive explanations revealed that discrimination is 1 of the 6 predictors of poor mental health.	Use machine learning for data analysis
12. Keum and Choi, 2022 [38]	139 Asian American emerging adults: Chinese (28%), Asian Indian (15%), Filipino (9%), Vietnamese (8%), Japanese (6%), Korean (2%), Thai (2%), Taiwanese (2%), Bangladeshi (1%), Indonesian (1%), Hmong (1%), Laotian (1%), Singaporean (1%), Cambodian (1%), bi/multiethnic (between Asian ethnicities) (9%), others (3%)	June to July 2021	COVID-19 racism	AUDIT[f], PHQ-9	COVID-19 racism predicted alcohol use severity (standardized effect β=.514, 99% bootstrapped CI .314-.713). Furthermore, the mediating analysis showed that racism predicted alcohol use severity through depressive symptoms and drinking to cope motives, accounting for 48% of the variance explained.	Examine mediating effects; small sample size

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
13. Layug et al, 2022 [39]	1147 adults (aged 18 years or above): White (47.86%), Latinex (11.6%), Black (9.5%), Indigenous (0.96%), mixed (2.88%), Asian Americans and Pacific Islanders (26.68%), Chinese, Japanese, Korean, Filipino, Vietnamese, Indian, Pakistani, Bangladeshi, Sri Lankan, Hmong	March 3 to 15, 2021	Online racial discrimination: individual discrimination, and vicarious discrimination	PHQ-9, GAD-7	Individual online perceived discrimination was a significant positive predictor of STS[g] (β=.52, *P*<.001), depression (β=.53, *P*<.001), and anxiety (β=.41, *P*<.001). Vicarious online perceived discrimination was positively associated with STS (β=.39, *P*<.001), depression (β=.39, *P*<.001), and anxiety (β=.33, *P*<.001). Asian Americans reported higher vicarious discrimination than Latinx and White Americans.	Explored moderator effect of racial-ethnic identity
14. Lee et al, 2020 [10]	410 Asian Americans		Impact of COVID-19; racial discrimination; social support (Multidimensional Scale of Perceived Social Support)	BAI[h], CES-D; physical health; sleep health	Asian Americans reported experiencing racism (30%), anxiety (40%), depression (53%), sleep health problems (43%), and physical health problems (15%). Social support had a buffering effect on depression.	Highlighted the buffering effect of social support in the experience of depression
15. Li et al, 2023 [40]	301 Chinese Americans	April 8 - 21, 2021	A perceived double threat, online media, and the community COVID-19 racial discrimination	Anxiety (GAD-7)	231 (76.74%) reported threats due to their Chinese ethnic background. Predictors for anxiety were racial discrimination from the local community (OR 0.47, 95% CI 0.39 - 0.71, *P*<.001), media/online (OR 0.36, 95% CI 0.26 - 0.53, *P*<.001), the perceived threat from the COVID-19 virus (OR 0.33, 95% CI 0.23 - 0.51, *P*<.001) and perceived racism threat from Chinese background related to COVID-19 (OR 0.31, 95% CI 0.21 - 0.49, *P*<.001).	The perceived double threat was explored

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
16. Litam et al, 2022	187 Asian Americans		Everyday discrimination Scale (9 items); multigroup ethnic identity; Coping Strategies Inventory-SF	Satisfaction with Life Scale; CES-D revised; BAI	Racism has a negative association with life satisfaction (*b*=−0.253, *P*<.001), and a positive association with depression (*b*=1.479, *P*<.001). Ethnic identity is a positive moderator of the relationship between racism and depression. Coping strategy is a positive moderator of the relationship between depression and life satisfaction.	Highlighted the moderating effect of ethnic identity in racism and life satisfaction association
17. Li et al, 2023 [41]	246 Filipino Americans (who experienced or witnessed COVID-19 racism)	Not indicated	COVID-19–related racial discrimination (modified Everyday Discrimination Scale)	Anxiety (Beck Anxiety Inventory), depression (CESD-R)[i]	COVID-19–related racial discrimination was significantly negatively related to life satisfaction (β=−.208, *P*<.001) and positively related to depression (β=.505, *P*<.001) and anxiety (β=.496, *P*<.001). Coping strategy moderated the mediated relationship of COVID-19 racial discrimination via depression with life satisfaction.	Focused on those who experienced or witnessed COVID-19 racism
18. Liu Y et al, 2020 [42]	3665 US population	March survey (March 1031, 2020) versus April survey (April 1-28, 2020)	COVID-19–associated discrimination	PHQ-4	Racism increased from March (4%) to April (10%). Non-Hispanic Blacks and Asian Americans experienced increased racism compared to other groups. People who perceived racism reported increased depression (March: OR 0.77; April: OR 1.01)	The total sample included 75% non-Hispanic White

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
19. Liu T et al, 2022 [43]	565 Asian Americans: Chinese (40%), South Asian (18.1%), Southeast Asian (20.1%), Korean (10.4%), Japanese (4.8%), others (6.6%).	June 2020	COVID-19–specific racism and internalized racism	DASS-21 and PHQ-15	Internalized racism moderated the relations between vicarious racism and psychological distress only for those who were 1.5 generations and above. Individuals who reported higher levels of internalized racism (upper 33%) had higher mean scores of both psychological distress, $F_{2,558}$=24.25, P<.001, and somatic symptoms, $F_{2,556}$=6.86, P=.001, when compared to those with low levels of internalized racism (lower 33%). Generational status moderated the relations between vicarious racism and psychological distress (DASS-21) differentially by generation, a test of three-way interactions was significant, ΔR^2=.011, $F_{1,550}$=7.53, P=.006, b=.025, t_{550}=2.74, P=.006.	Examined the complex 3-way interaction among COVID-19–related racism, generation status, and internalized racism

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
20. Liu MA et al, 2022 [52]	289 Asian Americans	Mid-July 2020	Discrimination experiences (frequency and attribution on race)	Social anxiety (Social Interaction Anxiety Scale), depression (Epidemiological Studies–Depression measure), accumulated stress (Social, Attitudinal, Familial, and Environmental Acculturative Stress Scale–Short Form)	Discrimination was significantly and positively related to depressive symptoms (*B*=7.64, *P*<.001) and alcohol use (*B*=7.05, *P*<.001). This relationship fell short of significance for social anxiety symptoms (*B*=1.55, *P*=.051). About half of the overall sample reported experiencing discrimination (51.6%). Collective self-esteem significantly moderated the relationship between attribution to race and social anxiety (*P*=.021), and internalized racism weakened the relationship between discrimination frequency and depression (*P*=.038).	Moderators were explored.
21. Lu et al, 2022 [44]	218 Asian American college students	March 27 to April 17, 2020	Direct online racial discrimination and general vicarious racial discrimination	GAD-7 and PHQ-9	Overall, 58.7% and 88.1% reported direct online and vicarious racial discrimination, respectively. Direct online racial discrimination was significantly related to depression (*r*=.29, *P*=.003) and anxiety (*r*=.25, *P*<.001). Vicarious racial discrimination also showed a significant relation with depression (*r*=.30, *P*<.001) and anxiety (*r*=.46, *P*<.001).	Examined buffering effect of social support depending on the locus of control factor

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
22. McGarity-Palmer et al, 2023 [45]	3478 Asian Americans: Chinese (19%), Filipino (13.4%), Indian (18.5%), Korean (6.4%), Vietnamese (8.4%), Pakistani (2.3%), Japanese (3.4%), Cambodian (4.3%), other (5%), multiethnic (2.2%), multiracial (16.8%)	2021	Coronavirus Racial Bias Scale; discrimination	PHQ-4	In total, 24% of Asian Americans (95% CI 21.6-25.6) reported experiencing discrimination. COVID-19–related collective racism was associated with increased psychological distress, above and beyond sociodemographic factors, and other COVID-19–related stressors (R^2=0.36, 95% CI 0.33-0.38).	Performed subgroup analyses
23. Oh S et al, 2022 [46]	270 Korean Americans	Not applicable	Everyday discrimination	BAI and CESD-R	COVID-19–related racial discrimination had significantly positive correlations with depression and anxiety (*R*=.73 and *R*=.61, respectively). Ethnic identity scores were positively correlated with scores of racial discrimination, anxiety, and depression, ranging in magnitude from *r*=.22 to .39.	Explored potential impacts of ethnic identity and coping strategies
24. Oh and Litam, 2022 [46]	725 Asian Americans and Pacific Islanders: Chinese (24.1%), Filipino (23.4%), Korean (17.2%), Vietnamese (7.9%), Japanese (7.0%), Thai (1.9%), other Asian ethnicities (18.3%)	Not applicable	Everyday discrimination	BAI and CESD-R	The path between experiences of racial discrimination and life satisfaction was mediated by anxiety (*b*=−.086, *SE b*=.022, *t*=−3.843, 95% CI −.131 to −.042) and depression (*b*=−.044, *SE B*=.017, *t*=−2.590, 95% CI −.077 to −.011). Coping strategies attenuated the link between discrimination and anxiety, and discrimination and depression.	Examined the role of coping in the relationship between racial discrimination and 2 mediators (anxiety and depression)

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
25. Pan et al, 2020 [48]	6707 Asian Americans	March 10-31, 2020	COVID-19 stigmatization	PHQ-4	A higher percentage of foreign-born Asian Americans experience racism than US-born Asian Americans (11.2% vs 10.9%). People who experienced COVID-19–related stigmatization reported increased psychological distress (19.9% vs 10.6%). US-born Asian Americans who experienced racism were more likely to exhibit psychological distress than non-Hispanic whites.	Included a larger population and Asian Americans
26. Jun et al, 2021 [49]	254 Asian Americans: Chinese (27.1%), Filipino (13.7%), Korean (10.8%), Vietnamese (10.8%), Japanese (8.7%), other (28.7%)	May 2020	COVID-19 discrimination (occurrence and impact); communication sources about COVID-19	CES-D (20-item)	Both COVID-19 racial discrimination (*b*=4.40, *P*<.001) and previous racial discrimination (*b*=3.05, *P*<.001) were positively associated with depressive symptoms. The negative effects of racism did not vary among different Asian American groups. Not all sources of communication help with depression. Talking with the spouse alleviated depression and interaction on social media depression.	Focused on those 254 who experienced racism

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
27. Wu et al, 2021 [50]	68,218 data points, tracking 7778 individuals over 13 survey waves	March to September 2020	Acute discrimination	PHQ-4	The mental health gap between Asian Americans and whites (gap=0.98, *P*<.000) is greater than the gap between Asian immigrants and whites (gap=0.18, *P*<.000). 11% of Whites, 22% of Asian Americans, and 21% of Asian immigrants encountered discrimination. A 1-unit within-person increase in acute discrimination leads to a within-person increase in mental disorders by 0.066 units (*P*<.001). Racism mainly explains the disproportionate mental health impact of the pandemic on Asian Americans. US-born Asian Americans experience more racism and anxiety than foreign-born Asian Americans.	Larger population and hone in on Asian American experience from a large dataset

Publication	Sample population	Time frame	Racism variables	Mental health outcomes	Main findings	Strengths/significance
28. Zhou et al, 2023 [51]	Three waves of Asian Pacific Islander students across campuses: Fall 2019 (n=3929), Spring 2020 (n=7813), and Fall 2020 (n=4804).	September-December 2019, March-May 2020, September-December 2020	COVID-19–related discrimination	PHQ-9 and GAD-7	In Fall 2020, experiencing COVID-19–related discrimination was associated with 1.90 greater odds of moderate to severe depression (95% CI 1.13 - 3.19; *P*=.016), 2.15 greater odds of severe depression (95% CI 1.29 - 3.58; *P*=.003), 1.72 greater odds of moderate to severe anxiety (95% CI 1.07-2.75; *P*=.024), and 1.77 greater odds of severe anxiety (95% CI 1.04 - 3.01; *P*=.035).	Large sample inclusive of young adult Asian Pacific Islanders

[a] GAD-7: General Anxiety Disorder-7.

[b] PHQ: Patient Health Questionnaire.

[c] DASS-21: Depression and Anxiety Stress Scales.

[d] OR: odds ratio.

[e] CES-D: Center for Epidemiologic Studies Depression Scale.

[f] AUDIT: Alcohol Use Disorders Identification Test.

[g] STS: Secondary Traumatic Stress.

[h] BAI: Beck Anxiety Inventory.

[i] CESD-R: Center for Epidemiologic Studies Depression Scale Revised.

Assessed Domains of Racism

As indicated in the previous section, racism encompasses multiple dimensions and forms of expression that depend broadly on social contexts and many other factors. To provide greater insights into this phenomenon as gleaned from our integrative review, a clear understanding of how the authors described various forms of racism is critical to providing a complete picture of what Asian Americans experienced during the COVID-19 pandemic.

Despite the variability in the measurements used in assessing racism among these 9 articles, the victims experienced racist expressions and acts in identifiable ways. Everyday discrimination is defined as the perception of “being treated with less courtesy and respect” [41,42,50,53]. Beyond lack of courtesy and respect, additional descriptors of racism include “receiving poor services at restaurants or stores” [42,50,53,54]. COVID-19–associated acute discrimination was captured by a shorter version of a questionnaire, including only 4 elements of racism (treated with less courtesy and respect, receiving poorer service, being threatened or harassed, and being subjected to others’ fear of COVID-19) [50]. Some victims reported exposure to more aggression, such as physical attacks or verbal attacks of “go back to your own country” [42,50,53,54]. However, some researchers captured more subtle expressions of racism described, for example, “people assume my English is poor due to my race” or “you are called names or insults” [34,55]. Specifically relevant to mental health, the concept of racial discrimination vigilance is worth considering. It is defined as “physical, behavioral, cognitive, and emotional attentiveness to the environment in anticipation of experiencing racism” due to repeated exposure to racism [11]. More subtle expressions of racism experience are described as vicarious racism, which is “indirectly hearing about or seeing racist acts committed against either a member of one’s racial group (friends or family members) personally or in the news” [11].

Assessed Domains of Mental Health

Depression

All 29 articles consistently reported depression as a primary outcome, establishing a direct link between the experience of racism and depression among Asian Americans during the COVID-19 pandemic [5,6,11,31-34,36-39,41-48,50-58]. The association between racism and depression among Asian Americans during the COVID-19 pandemic is profound, as derived from moderate sample size studies and large probability-based, nationally representative samples (Table 2) [50,55]. Most publications reported statistically significant relationships between racism and depression. Consistent with existing literature, Asian American individuals exposed to racist expressions directed at other Asian American groups (vicarious racism) were more likely to experience depression [11,22,31,36,44,48,55]. Being exposed to racism in all forms (online-direct, online-vicarious, in-person–direct, in-person–vicarious, hate-related Sinophobia [defined as fear or dislike of China], and Sinophobia in media) was significantly associated with depression, validating our understanding that social environments of hatred and stereotypes can influence the psyche and mental health of those experiencing racism [22,36,39,58]. Foreign-born Asian Americans and US-born Asian Americans experienced the highest COVID-19 stigma among eight ethnoracial groups: (1) White only, non-Hispanic; (2) White only, Hispanic; (3) Black only; (4) Asian only, foreign born; (5) Asian only, US-born; (6) Asian of mixed race; (7) non-Asian of mixed race; and (8) Indigenous only [53,59,60]. Focusing specifically on racism related to the COVID-19 pandemic, Asian Americans who experienced COVID-19 stigmatization were significantly more likely to report psychological distress (depressive symptoms) than those who did not [53]. COVID-19 stigmatization refers to describing a characteristic or a group of people in a way that shows strong disapproval related to the COVID-19 pandemic; it is a form of discriminatory expression [53]. In a large population-based study evaluating the mental health impact of the COVID-19 pandemic, US-born Asian Americans disproportionately experienced more significant levels of depression than foreign-born Asian Americans, suggesting that demographics and acculturation may explain differing racism experiences [50].

Anxiety

Researchers used various tools in multiple domains of racism and found that anti-Asian sentiments have statistically significant associations with anxiety [5,6,11,18,22,31,33-35,38-41,43,44,46,47,51,52,55,56]. Cheah et al 22found that Asian Americans who self-reported more significant vicarious racism had more symptoms of anxiety when controlling for sociodemographic characteristics. The strength of this association was higher than that measured among African Americans during the same assessment time frame around the COVID-19 pandemic, possibly suggesting that this social crisis had a more ethnic-specific impact [9]. Similar to the finding on depression, all types of racial discrimination and Sinophobia were associated with anxiety among adult Asian Americans [22]. In a survey study of 410 Asian American participants who experienced racism during the pandemic, increased incidents of discrimination significantly predicted anxiety symptoms, and social support had a buffering effect for anxiety [44]. Of interest is the damaging impact racism had on younger Asian Americans. Among Asian American youths, anxiety symptoms and internalizing problems were associated with all types of racial discrimination and Sinophobia, suggesting detrimental effects of racism experienced either directly or indirectly through their parents' experience [22,31,37]. Cheah et al [22] further highlighted that vulnerable youths may be more impacted by COVID-19–related racism because these youths are exposed not only to direct racism but also to the indirect impact of their parents' victimization experiences, which may translate into increased family stress, a hostile family environment, and negative parenting.

Potential Moderators of Depression and Anxiety

Our analysis identified potential moderating factors influencing the relationship between racism and mental health outcomes of depression and anxiety. The synthesis of the data points to the importance of social support in reducing the impact of racism; Asian Americans who experienced a greater incidence of discrimination with less social support reported significantly more depressive symptoms [6,54,55]. In addition, coping strategies and collective self-esteem moderated the relationship between COVID-19 racial discrimination and depression [41,43,46,52,56]. This relationship between racism and anxiety exists through the mediating effect of harmful Chinese media exposure, which is the exposure a person has to the negative portrayal of Chinese immigrants in the media [29,33]. Examples of negative portrayals of Asian Americans may include roles demonstrative of submissiveness, sexual fetish, perpetual foreigners, and model minority. Negative displays or mentions of Asian Americans in media have been shown to incubate and foster racist sentiments against Asian Americans throughout history, particularly during the COVID-19 pandemic, ultimately having harmful effects.

Considering the historical perspective of racism against Asian Americans in the United States, the COVID-19 pandemic intensified the impact of racism on Asian Americans' mental health, as shown in a moderating effect of the COVID-19 pandemic on the relationship between racism and anxiety [33]. A comparative assessment of social media usage before and after March 16, 2020, indicated that the number of hashtags associated with anti-Asian sentiments (eg, #Chinesevirus) increased significantly. Because of the lockdown mandate, online indirect racism became more common, translating into some challenges for accurately assessing the mental health impact each form of racism may have had on Asian American communities.

Discussion

Principal Findings

Our integrative review synthesis of the relationships between COVID-19–related racism and mental health indicates that there are positive correlations between racism, depression, and anxiety. This study represents a comprehensive, up-to-date integrative review of the impact of COVID-19–related racism on mental health outcomes experienced by Asian Americans living in the United States. We identified 2 significant mental health outcomes, including depression and anxiety. Potential factors such as the portrayal of nonstereotypical roles of Asian Americans, effective framing of news media, and social support may mitigate the impact on mental health outcomes to counteract this difficult-to-avoid exposure [29,33]. Researchers described further investigations of moderating factors such as coping style, ethnic identities, and social support to lay the groundwork for potential mitigation [5,6,43,44,56,61]. Strengthening ethnic identity and coping strategies are possible avenues to empower individuals to lessen the impact of racism on mental health.

Our original intent was also to include the impact of racism in the form of physical assaults or crimes perpetrated against Asian Americans during the COVID-19 pandemic. However, we found few that examined direct links between racism and bodily harm. According to the private organization assessment of hate crimes during the COVID-19 pandemic, physical assaults on Asian Americans and Pacific Islanders increased to 1900 cases in 2020 in the United States, coinciding with the pandemic's peak [62]. Although it is indisputable that hate crimes against Asian Americans dramatically increased during the pandemic, the limited availability of systematically collected data beyond anecdotal reports is possibly due to the lack of a standardized reporting system and the hesitancy of victims to report the crime [63].

While acknowledging that Asian Americans as a group comprise many ethnic origins and languages, this review suggests that Asian Americans experienced the impacts of racism similarly across all ethnic groups. However, it is noteworthy that the experience of racism and its effects on mental health differs between US-born Asian Americans and foreign-born Asian Americans [50,53]. The long-existing view of Asian Americans as "perpetual foreigners" may contribute to the fact that US-born Asians reported a sense of not belonging in either their native countries or the United States. Similarly, the experience of racism differs among generations (first or foreign-born vs second or US-born vs third or US-born) [3,40,43,47].

Although our integrative review revealed that depression and anxiety are significant sequelae of COVID-19–related racism among Asian Americans, some studies identified sleep disturbance as a secondary consequence of racism. Because mental health and sleep are firmly connected, and sleep disturbance can be viewed as a mental health construct (even though it is frequently measured as physiological health), we did not include this outcome as a separate category [58,61,64]. The interconnectedness of these variables emphasizes the overarching influences of racism on mental health that affect both the mind and body.

The impact of COVID-19–related racism on mental health among ethnic minority groups share similarities, yet there are some unique aspects among Asian Americans. Blacks and Latinx Americans also experienced worse depression and anxiety as COVID-19–related racism escalated [11,42,50]. Although all minority groups in the United States have experienced historical and systemic racism, COVID-19–related racism affected Asian Americans or persons who present with Asian phenotypes uniquely because they have been blamed for the origin and the transmission of SARS-CoV-2. Although comparing the deteriorating mental health experienced by Asian Americans and other minority groups is insightful, overemphasis on this difference may prove to be divisive rather than unifying. Further, within Asian American ethnic groups, differences exist in education levels, household incomes, and access to social benefits. Analyzing data as a whole without recognizing these differences may risk ignoring more profound health disparities in some subgroups. Regardless of minority group, a comprehensive approach to addressing racism should include "initiatives to raise awareness levels of the pervasiveness of inequities in health, build empathy and support for addressing inequities, enhance the capacity of individuals and communities to actively participate in intervention efforts and implement large scale efforts to reduce racial prejudice, ideologies, and stereotypes in the larger culture that undergird policy preferences that initiate and sustain inequities" [65]. All 29 articles reviewed here utilized one type of research design, cross-sectional survey study designs, and were conducted during the COVID-19 pandemic in March 2020. Most studies in our review used a small sample size, making it difficult to generalize to the larger population. Although we intended to include all Asian American groups in our original search, most studies included Chinese Americans, and some studies included participants from a single ethnicity, such as Korean, Filipino, and Asian Indians [22,31,34,37,40,41,47,56]. Since we included only studies conducted in the United States, we should avoid generalizing study findings in different geographical and cultural contexts outside the United States. Importantly, Asian Americans are nonmonolithic, with diverse socioeconomic and educational backgrounds, and it is challenging to describe precisely how racism affects each group [29].

Clinical Implications and Future Research

Overview

The act of racism (with its plethora of presentations) has a range of impacts on the victim that span from mental health deterioration, discriminatory effects (employment), and physical crime (physical assault). Our integrative review results address an essential query by summarizing how racist sentiments impact mental health and well-being among Asian Americans living in the United States during the COVID-19 pandemic. This scientific knowledge provides a foundation for further research directions and clinical implications addressing this urgent issue with the following recommendations.

Public Awareness and Individual-Level Education

Following the US Commission on Civil Rights 2023, Statutory Enforcement Report on the Federal Response to Anti-Asian Racism in the United States, there is a need to increase public awareness campaigns and education about all dimensions of racism, systemic racism, the prevalence of racism, and anti-racism initiatives [59]. Given the profound mental health impact of racism, a culturally tailored educational program should be provided to Asian Americans, their family members, and the community. Academic programs may include a clear understanding of the legal right to safety and security, with attention to social justice and equity. These public awareness campaigns and education efforts should positively impact personal and systemic changes with measurable and meaningful outcomes. In raising public awareness about anti-Asian sentiments in America, it is essential to include all types of racism. Evidence shows that subtle displays of racism are more prevalent than the overt type yet they can still potentially be harmful. Biases, left unrecognized and not dealt with, have the potential to fuse into systemic racism. The success of public awareness and education depends on financial support and advocacy for funding to build and sustain these essential initiatives and address the root causes of these acts and words.

Programs to Document Incidents of Racism and Hate Crimes

There is an urgent need to establish programs to empower Asian American community members to recognize racism and report all occurrences of racism. Ponce (2022) indicates that only 6.9% of Asian Americans reported race-based hate, and 62.4% of these reported no exposure to race-based unfair treatment [63]. This report revealed that there is discordance between reporting and actual exposure; Asian Americans were found to experience high psychological distress, forgo necessary medical care, and have personal conflicts and insecurity about safety [62]. Since racist incidents often occur among vulnerable Asian Americans (eg, females, older adults, and young victims), the provision of specific "how-to" tools for recognizing the problem and promptly filing reports is of importance. To create action plans to address racism in the United States, accurate and timely documentation of the incidents is necessary [29,49]. As announced by the Biden administration, a system for reporting hate crimes against Asian Americans was established and funded. However, a barrier to this effort may be a lack of public awareness and education programs to educate vulnerable victims about recognizing and reporting these crimes.

Intervention Programs for Mental Health

Our findings suggest a critical need to design interventions such as culturally responsive trauma-informed treatment to address the mental health needs of victimized Asian Americans. Culturally responsive, trauma-informed intervention includes the recognition that the current anti-Asian sentiment may activate intergenerational trauma, reinforce cultural mistrust, and echo centuries of historical oppression [41]. Counseling approaches and intervention programs aiming to address this traumatic psychological distress within the context of COVID-19–related racism should incorporate relevant contributing factors that may mediate or moderate the effects of racism on mental distress [54]. Culturally sensitive trauma-informed care refers to the capacity for health care professionals to provide trauma-informed assessment and intervention that acknowledges, respects, and integrates patients' and families' cultural values, beliefs, and practices.

We need to advocate for resources supporting intervention programs to address mental health that are culturally relevant and anchored in engaging family- and community-level initiatives [12,66-68]. In exploring the type of social support that may help alleviate mental health (communication method about the COVID-19 pandemic), not all communication sources help alleviate depression among Asian Americans who experienced racism [54]. Talking with a partner/spouse was shown to be the type of communication with the most positive impact on depression, suggesting family- or community-level intervention programs to be the most helpful [54]. More research is needed to understand the moderating impact of social support and ethnic identity as a possible intervention for those who experience racism-related depression.

Conclusions

This integrative review summarizes the gravity of the mental health outcomes of depression and anxiety among Asian Americans associated with a wide range of racism related to the COVID-19 pandemic. Our findings suggest a critical need to design interventions such as culturally responsive trauma-informed treatment to address various Asian American groups' urgent mental health needs. Furthermore, more research is needed to examine the long-term impact of discrimination on mental health in Asian Americans and address the ongoing health inequity in health care practice.

Acknowledgments

Research reported in this publication was supported by the National Institute of Health and the National Center for Advancing Translational Sciences (NCATS) through the Center for Translational Science Institute at the University at Buffalo (number UL1TR001412). The Patricia H and Richard E Garman Behavioral Health Nursing Research Grant also supported this project.

Conflicts of Interest

None declared.

Checklist 1
PRISMA checklist.
[PDF File, 90 KB - apinj_v9i1e63769_app1.pdf]

References

1. National commission to address racism in nursing. Defining Racism. URL: https://www.mnorn.org/uploads/1/4/6/6/146650864/defining-racism-june-2021.pdf [accessed 2021-06-05]
2. Williams DR, Lawrence JA, Davis BA. Racism and health: evidence and needed research. Annu Rev Public Health 2019 Apr 1;40:105-125. [doi: 10.1146/annurev-publhealth-040218-043750] [Medline: 30601726]
3. Cheng AW, Chang J, O'Brien J, Budgazad MS, Tsai J. Model minority stereotype: influence on perceived mental health needs of Asian Americans. J Immigr Minor Health 2017 Jun;19(3):572-581. [doi: 10.1007/s10903-016-0440-0] [Medline: 27246287]
4. Nicholson HL Jr. Associations between major and everyday discrimination and self-rated health among US Asians and Asian Americans. J Racial Ethn Health Disparities 2020 Apr;7(2):262-268. [doi: 10.1007/s40615-019-00654-0] [Medline: 31664673]

5. Fanta A, Kodama Muscente K, Kim SE, Tsai W, Huang CY. Coping, racial discrimination, and psychological distress among Asian American parents. Couns Psychol 2023 Nov;51(8):1066-1095. [doi: 10.1177/00110000231191754]
6. Huynh MP, Yellow Horse AJ, Mai NM, Mantuhac J, Saw A. Discrimination and psychological distress among Asian Americans during COVID-19: gender differences in the moderating role of social support. Am J Orthopsychiatry 2024;94(1):23-32. [doi: 10.1037/ort0000702] [Medline: 37768606]
7. Li Y, Nicholson HL Jr. When 'model minorities' become 'yellow peril'-othering and the racialization of Asian Americans in the COVID-19 pandemic. Sociol Compass 2021 Feb;15(2):e12849. [doi: 10.1111/soc4.12849] [Medline: 33786062]
8. McKnight-Eily LR, Okoro CA, Strine TW, et al. Racial and ethnic disparities in the prevalence of stress and worry, mental health conditions, and increased substance use among adults during the COVID-19 pandemic - United States, April and May 2020. MMWR Morb Mortal Wkly Rep 2021 Feb 5;70(5):162-166. [doi: 10.15585/mmwr.mm7005a3] [Medline: 33539336]
9. Maglalang DD, Peregrina HN, Yoo GJ, Le MN. Centering ethnic studies in health education: lessons from teaching an Asian American community health course. Health Educ Behav 2021 Jun;48(3):371-375. [doi: 10.1177/10901981211009737] [Medline: 34080477]
10. Lee FC, Adams L, Graves SJ, et al. Counties with high COVID-19 incidence and relatively large racial and ethnic minority populations - United States, April 1-December 22, 2020. MMWR Morb Mortal Wkly Rep 2021 Apr 2;70(13):483-489. [doi: 10.15585/mmwr.mm7013e1] [Medline: 33793463]
11. Chae DH, Yip T, Martz CD, et al. Vicarious racism and vigilance during the COVID-19 pandemic: mental health implications among Asian and Black Americans. Public Health Rep 2021;136(4):508-517. [doi: 10.1177/00333549211018675] [Medline: 34034574]
12. Williams DR. Stress and the mental health of populations of color: advancing our understanding of race-related stressors. J Health Soc Behav 2018 Dec;59(4):466-485. [doi: 10.1177/0022146518814251] [Medline: 30484715]
13. Paradies Y, Ben J, Denson N, et al. Racism as a determinant of health: a systematic review and meta-analysis. PLoS One 2015;10(9):e0138511. [doi: 10.1371/journal.pone.0138511] [Medline: 26398658]
14. Gee GC, Spencer M, Chen J, Yip T, Takeuchi DT. The association between self-reported racial discrimination and 12-month DSM-IV mental disorders among Asian Americans nationwide. Soc Sci Med 2007 May;64(10):1984-1996. [doi: 10.1016/j.socscimed.2007.02.013] [Medline: 17374553]
15. Kim PY, Kendall DL, Cheon HS. Racial microaggressions, cultural mistrust, and mental health outcomes among Asian American college students. Am J Orthopsychiatry 2017;87(6):663-670. [doi: 10.1037/ort0000203] [Medline: 27732011]
16. Louie-Poon S, Idrees S, Plesuk T, Hilario C, Scott SD. Racism and the mental health of East Asian diasporas in North America: a scoping review. J Ment Health 2022 May 11:1-16. [doi: 10.1080/09638237.2022.2069715] [Medline: 35543389]
17. Siddiqui SM. Acculturative stress, everyday racism, and mental health among a community sample of South Asians in Texas. Front Public Health 2022;10:954105. [doi: 10.3389/fpubh.2022.954105] [Medline: 36353288]
18. Yu HH. Revisiting the bamboo ceiling: perceptions from Asian Americans on experiencing workplace discrimination. Asian Am J Psychol 2020;11(3):158-167. [doi: 10.1037/aap0000193]
19. Krieger N. Measures of racism, sexism, heterosexism, and gender binarism for health equity research: from structural injustice to embodied harm-an ecosocial analysis. Annu Rev Public Health 2020 Apr 2;41:37-62. [doi: 10.1146/annurev-publhealth-040119-094017] [Medline: 31765272]
20. Dhanani LY, Franz B. Unexpected public health consequences of the COVID-19 pandemic: a national survey examining anti-Asian attitudes in the USA. Int J Public Health 2020 Jul;65(6):747-754. [doi: 10.1007/s00038-020-01440-0] [Medline: 32728852]
21. Zhang M, Gurung A, Anglewicz P, Baniya K, Yun K. Discrimination and stress among Asian refugee populations during the COVID-19 pandemic: evidence from Bhutanese and Burmese refugees in the USA. J Racial Ethn Health Disparities 2022 Apr;9(2):589-597. [doi: 10.1007/s40615-021-00992-y] [Medline: 33651371]
22. Cheah CSL, Wang C, Ren H, Zong X, Cho HS, Xue X. COVID-19 racism and mental health in Chinese American families. Pediatrics 2020 Nov;146(5):e2020021816. [doi: 10.1542/peds.2020-021816] [Medline: 32873719]
23. Tsai JY, Phua J, Pan S, Yang CC. Intergroup contact, COVID-19 news consumption, and the moderating role of digital media trust on prejudice toward Asians in the United States: cross-sectional study. J Med Internet Res 2020 Sep 25;22(9):e22767. [doi: 10.2196/22767] [Medline: 32924948]
24. Nguyen TT, Criss S, Dwivedi P, et al. Exploring U.S. shifts in anti-Asian sentiment with the emergence of COVID-19. Int J Environ Res Public Health 2020 Sep 25;17(19):7032. [doi: 10.3390/ijerph17197032] [Medline: 32993005]
25. Hswen Y, Xu X, Hing A, Hawkins JB, Brownstein JS, Gee GC. Association of “#covid19” versus “#chinesevirus” with anti-Asian sentiments on Twitter: March 9-23, 2020. Am J Public Health 2021 May;111(5):956-964. [doi: 10.2105/AJPH.2021.306154] [Medline: 33734838]
26. Le AB. The health impacts of COVID-19-related racial discrimination of Asian Americans extend into the workplace. Am J Public Health 2021 Apr;111(4):e17-e18. [doi: 10.2105/AJPH.2020.306139] [Medline: 33689443]
27. Cho H, Li W, Cannon J, Lopez R, Song CC. Testing three explanations for stigmatization of people of Asian descent during COVID-19: maladaptive coping, biased media use, or racial prejudice? Ethn Health 2021 Jan;26(1):94-109. [doi: 10.1080/13557858.2020.1830035] [Medline: 33059486]

28. Abidin C, Zeng J. Feeling Asian together: coping with #COVIDRacism on subtle Asian traits. Soc Media Soc 2020 Jul;6(3):2056305120948223. [doi: 10.1177/2056305120948223] [Medline: 34192032]
29. Wang D, Gee GC, Bahiru E, Yang EH, Hsu JJ. Asian-Americans and Pacific Islanders in COVID-19: emerging disparities amid discrimination. J Gen Intern Med 2020 Dec;35(12):3685-3688. [doi: 10.1007/s11606-020-06264-5] [Medline: 33009656]
30. Whittemore R, Knafl K. The integrative review: updated methodology. J Adv Nurs 2005 Dec;52(5):546-553. [doi: 10.1111/j.1365-2648.2005.03621.x] [Medline: 16268861]
31. Cheah CSL, Ren H, Zong X, Wang C. COVID-19 racism and Chinese American families' mental health: a comparison between 2020 and 2021. Int J Environ Res Public Health 2023 Apr 7;20(8):5437. [doi: 10.3390/ijerph20085437] [Medline: 37107719]
32. Dhanani LY, Franz B, Pham CT. Experiencing, anticipating, and witnessing discrimination during the COVID-19 pandemic: implications for health and wellbeing among Asian Americans. Front Public Health 2022;10:949403. [doi: 10.3389/fpubh.2022.949403] [Medline: 36311624]
33. Ermis-Demirtas H, Luo Y, Huang YJ, Gerstein LH, Rami F. The impact of COVID-19-associated discrimination on anxiety and depression symptoms in Asian American adolescents. Int Perspect Psychol 2022 Jul;11(3):153-160. [doi: 10.1027/2157-3891/a000049]
34. Haft SL, Zhou Q. An outbreak of xenophobia: perceived discrimination and anxiety in Chinese American college students before and during the COVID-19 pandemic. Int J Psychol 2021 Aug;56(4):522-531. [doi: 10.1002/ijop.12740] [Medline: 33426695]
35. Huynh VW, Raval VV, Freeman M. Ethnic-racial discrimination towards Asian Americans amidst COVID-19, the so-called "China" virus and associations with mental health. Asian Am J Psychol 2022;13(3):259-269. [doi: 10.1037/aap0000264]
36. Huynh J, Chien J, Nguyen AT, et al. The mental health of Asian American adolescents and young adults amid the rise of anti-Asian racism. Front Public Health 2022;10:958517. [doi: 10.3389/fpubh.2022.958517] [Medline: 36711363]
37. Ikram M, Shaikh NF, Vishwanatha JK, Sambamoorthi U. Leading predictors of COVID-19-related poor mental health in adult Asian Indians: an application of extreme gradient boosting and Shapley additive explanations. Int J Environ Res Public Health 2022 Dec 31;20(1):775. [doi: 10.3390/ijerph20010775] [Medline: 36613095]
38. Keum BT, Choi AY. COVID-19 racism, depressive symptoms, drinking to cope motives, and alcohol use severity among Asian American emerging adults. Emerg Adulthood 2022 Dec;10(6):1591-1601. [doi: 10.1177/21676968221117421] [Medline: 38603255]
39. Layug A, Krishnamurthy S, McKenzie R, Feng B. The impacts of social media use and online racial discrimination on Asian American mental health: cross-sectional survey in the United States during COVID-19. JMIR Form Res 2022 Sep 19;6(9):e38589. [doi: 10.2196/38589] [Medline: 36121698]
40. Li AL, You Y, Wu KL, Shan HB, Kim Y, He QL. The COVID-19 pandemic: a double threat to Chinese Americans' mental health. Int J Ment Health Promot 2023;25(6):783-797. [doi: 10.32604/ijmhp.2023.026956]
41. Litam SDA, Oh S. Ethnic identity and coping strategies as moderators of COVID-19 racial discrimination experiences among Chinese Americans. Counseling Outcome Research and Evaluation 2022 Jul 3;13(2):101-115. [doi: 10.1080/21501378.2020.1814138]
42. Liu Y, Finch BK, Brenneke SG, Thomas K, Le PD. Perceived discrimination and mental distress amid the COVID-19 pandemic: evidence from the Understanding America Study. Am J Prev Med 2020 Oct;59(4):481-492. [doi: 10.1016/j.amepre.2020.06.007] [Medline: 32829968]
43. Liu T, Liu CR, Chang YJ. Asian American mental health amidst COVID-19 anti-Asian racism: internalized racism and generational status as moderators. Asian Am J Psychol 2022;13(4):328-338. [doi: 10.1037/aap0000284]
44. Lu Y, Wang C, Tummala-Narra P, Kim J. Asian Americans' racial discrimination experiences during COVID-19: social support and locus of control as moderators. Asian Am J Psychol 2022;13(3):283-294. [doi: 10.1037/aap0000247]
45. McGarity-Palmer R, Saw A, Tsoh JY, Yellow Horse AJ. Trends in racial discrimination experiences for Asian Americans during the COVID-19 pandemic. J Racial Ethn Health Disparities 2024 Feb;11(1):168-183. [doi: 10.1007/s40615-022-01508-y] [Medline: 36602751]
46. Oh S, Arañez Litam SD, Chang CY. COVID-19 racial discrimination and mental health of Korean Americans: role of ethnic identity and coping strategy. Stigma Health 2022;7(4):461-470. [doi: 10.1037/sah0000407]
47. Oh S, Litam SDA, Tummala-Narra P, Kim J. COVID-19 racial discrimination on mental health and life satisfaction among Asian Americans: examining a moderated mediation model. Asian Am J Psychol 2022;13(3):270-282. [doi: 10.1037/aap0000267]
48. Pan S, Yang CC, Tsai JY, Dong C. Experience of and worry about discrimination, social media use, and depression among Asians in the United States during the COVID-19 pandemic: cross-sectional survey study. J Med Internet Res 2021 Sep 1;23(9):e29024. [doi: 10.2196/29024] [Medline: 34351304]
49. Jun J, Woo B, Kim JK, Kim PD, Zhang N. Asian Americans' communicative responses to COVID-19 discrimination in application of co-cultural theory. Howard Journal of Communications 2021 May 27;32(3):309-327. [doi: 10.1080/10646175.2021.1922103]

50. Wu C, Qian Y, Wilkes R. Anti-Asian discrimination and the Asian-white mental health gap during COVID-19. Ethn Racial Stud 2021 Apr 9;44(5):819-835. [doi: 10.1080/01419870.2020.1851739]
51. Zhou S, Banawa R, Oh H. Stop Asian hate: the mental health impact of racial discrimination among Asian Pacific Islander young and emerging adults during COVID-19. J Affect Disord 2023 Mar 15;325:346-353. [doi: 10.1016/j.jad.2022.12.132] [Medline: 36623563]
52. Liu MA, Prestigiacomo CJ, Karim MFA, Ashburn-Nardo L, Cyders MA. Psychological outcomes and culturally relevant moderators associated with events of discrimination among Asian American adults. Cultur Divers Ethnic Minor Psychol 2024 Apr;30(2):363-373. [doi: 10.1037/cdp0000568] [Medline: 36355695]
53. Pan SW, Shen GC, Liu C, Hsi JH. Coronavirus stigmatization and psychological distress among Asians in the United States. Ethn Health 2021 Jan;26(1):110-125. [doi: 10.1080/13557858.2020.1849570] [Medline: 33307773]
54. Woo B, Jun J. COVID-19 racial discrimination and depressive symptoms among Asians Americans: does communication about the incident matter? J Immigr Minor Health 2022 Feb;24(1):78-85. [doi: 10.1007/s10903-021-01167-x] [Medline: 33677775]
55. Lee S, Waters SF. Asians and Asian Americans’ experiences of racial discrimination during the COVID-19 pandemic: impacts on health outcomes and the buffering role of social support. Stigma Health 2021;6(1):70-78. [doi: 10.1037/sah0000275]
56. Litam SDA, Oh S. Coping strategies as moderators of COVID-19 racial discrimination in Filipino Americans. Asian Am J Psychol 2022;13(1):18-29. [doi: 10.1037/aap0000253]
57. Yu N, Pan S, Yang CC, Tsai JY. Exploring the role of media sources on COVID-19-related discrimination experiences and concerns among Asian people in the United States: cross-sectional survey study. J Med Internet Res 2020 Nov 6;22(11):e21684. [doi: 10.2196/21684] [Medline: 33108307]
58. Dhanani LY, LaPalme ML, Pham CT, Hall TK. The burden of hate: how nonwork discrimination experienced during the COVID-19 pandemic impacts Asian American employees. J Bus Psychol 2023;38(3):621-635. [doi: 10.1007/s10869-022-09848-6] [Medline: 36213150]
59. The federal response to racial disparities in the COVID-19 pandemic. US Commission on Civil Rights. URL: https://www.usccr.gov/files/2023-09/fy-2023-se-report_0.pdf [accessed 2024-11-21]
60. Ruiz NG, Im C, Tian Z. Discrimination experiences shape most Asian Americans’ lives. Pew Research Center. URL: https://www.pewresearch.org/race-and-ethnicity/2023/11/30/discrimination-experiences-shape-most-asian-americans-lives/ [accessed 2024-11-21]
61. Oh H, Ko J, Waldman K. Church-based sleep screenings to detect mental health problems among Korean-Americans. J Immigr Minor Health 2019 Dec;21(6):1440-1443. [doi: 10.1007/s10903-019-00861-1] [Medline: 30694433]
62. Le TK, Cha L, Han HR, Tseng W. Anti-Asian xenophobia and Asian American COVID-19 disparities. Am J Public Health 2020 Sep;110(9):1371-1373. [doi: 10.2105/AJPH.2020.305846] [Medline: 32783714]
63. Ponce NA, Adia AC, Banawa RA, Tan S, Sabado-Liwag MD. Measuring Asian hate: discordant reporting of race-based hate incidents and unfair treatment and association with measures of wellbeing. Front Public Health 2022;10:958857. [doi: 10.3389/fpubh.2022.958857] [Medline: 36299752]
64. Jang Y, Shin J, Cho S, Kim G, Chiriboga DA. The interactive role of chronic medical conditions and sleep disturbance in predicting depressive symptoms among Korean American older adults. Aging Ment Health 2011 Mar;15(2):198-203. [doi: 10.1080/13607860903493366] [Medline: 21140307]
65. Williams DR, Cooper LA. Reducing racial inequities in health: using what we already know to take action. Int J Environ Res Public Health 2019 Feb 19;16(4):606. [doi: 10.3390/ijerph16040606] [Medline: 30791452]
66. Macaraan WER. The notion of Kapwa amid Asian hate. J Public Health (Oxf) 2022 Aug 25;44(3):e421-e422. [doi: 10.1093/pubmed/fdab268] [Medline: 34240214]
67. Ka’ai K, Lee R, Chau V, Xu L. Advancing health equity for Asian Americans, Native Hawaiians, and Pacific Islanders. Health Equity 2022;6(1):399-401. [doi: 10.1089/heq.2022.0075] [Medline: 35801149]
68. National Academies of Sciences, Engineering, and Medicine. COVID-19, Health Equity, and the Asian American, Native Hawaiian, and Pacific Islander Communities: Proceedings of a Workshop—in Brief: The National Academies Press; 2022. [doi: 10.17226/26700]

Abbreviations

JBI: Joanna Briggs Institute
OR: odds ratio
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Edited by H Ahn; submitted 28.06.24; peer-reviewed by F Mata-Greve, T Vo; revised version received 27.11.24; accepted 06.03.25; published 02.04.25.

Please cite as:
Von Visger T, Lyons A, Zhou Y, Wardlaw K, Park E, Chang YP
COVID-19–Related Racism and Mental Health Among Asian Americans: Integrative Review
Asian Pac Isl Nurs J 2025;9:e63769
URL: https://apinj.jmir.org/2025/1/e63769
doi:10.2196/63769

Original Paper

Evaluating the Quality, Content Accuracy, and User Suitability of mHealth Prenatal Care Apps for Expectant Mothers: Critical Assessment Study

Fateme Asadollahi[1], MSc; Samira Ebrahimzadeh Zagami[2], PhD; Saeid Eslami[3], PhD; Robab Latifnejad Roudsari[4], PhD

[1]Department of Midwifery, Student Research Committee, Mashhad University of Medical Sciences, Mashhad, Iran
[2]Nursing and Midwifery Care Research Center, Mashhad University of Medical Sciences, Mashhad, Iran
[3]Department of Medical Informatics, School of Medicine, Mashhad University of Medical Sciences, Mashhad, Iran
[4]Department of Midwifery, School of Nursing and Midwifery, Mashhad University of Medical Sciences, Mashhad, Iran

Corresponding Author:
Robab Latifnejad Roudsari, PhD
Department of Midwifery
School of Nursing and Midwifery
Mashhad University of Medical Sciences
Qarashi Building, Central Office of the University
Daneshgah Street
Mashhad, 91388-13944
Iran
Phone: 98 9370400607
Email: rlatifnejad@yahoo.com

Abstract

Background: The proliferation of health apps in the digital health landscape has created significant opportunities for health promotion, particularly during pregnancy. However, despite the widespread distribution and popularity of pregnancy mobile apps, there are limited data on their quality and content.

Objective: This study aimed to evaluate the quality, content accuracy, and suitability of the most popular and freely available Persian mobile health (mHealth) apps for prenatal care in expectant mothers.

Methods: Through a systematic search, a total of 199 apps were screened from available app stores using the search term “pregnancy app” until July 2023. Inclusion criteria were apps in the Farsi language, freely available, downloaded more than 10,000 times, and designed for pregnant women. Ultimately, 9 apps met these criteria. These apps were downloaded onto mobile phones and assessed by 2 independent reviewers using the Mobile App Rating Scale (MARS), the Coverage and Depth of Information Checklist, and the Suitability Assessment of Materials (SAM). Statistical analyses explored relationships between app quality metrics and user ratings.

Results: The 9 apps evaluated had an average MARS score of 3.55 (SD 0.61) out of 5. Aesthetics (mean 4.02, SD 0.45) and Functionality (mean 4.11, SD 0.36) scored the highest, followed by Engagement (mean 3.29, SD 0.53) and Information (mean 3.09, SD 0.48). User star ratings did not strongly correlate with MARS scores (r=0.38, P>.05). Regarding health information coverage, 6 out of 9 (66.7%) apps were rated as poor, and 3 (33.3%) as adequate. For SAM, 4 (44.4%) apps were rated as superior and 5 (55.6%) as adequate. No app received a poor score.

Conclusions: The study underscores the need for improved standards in pregnancy app development to enhance educational efficacy and user satisfaction. Health care providers should recommend high-quality pregnancy apps with appropriate content to ensure effective health promotion. These findings contribute to understanding the current landscape of pregnancy apps and highlight areas for future research and regulatory attention.

Trial Registration: PROSPERO CRD42023461605; https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=461605

(Asian Pac Isl Nurs J 2025;9:e66852) doi:10.2196/66852

KEYWORDS

pregnancy; prenatal care; mobile health apps; mHealth; women's health; health care providers; quality assessment; content evaluation; suitability assessment; digital health; smartphones; eHealth; telehealth; telemedicine; health promotion; technology; functionality; systematic search

Introduction

eHealth represents an innovative approach within the health care sector, using information and communication technology to enhance access to health care services and improve their quality [1]. eHealth encompasses various digital technologies, including telemedicine, mobile health (mHealth) apps (MHAs), electronic health records, and health information systems. These technologies aim to bridge the gap between health care providers and patients by enabling remote access to health care services, improving communication, and enhancing the overall quality of care [2].

MHAs are an integral part of the broader digital health ecosystem, including wearable technologies, virtual reality, telemedicine, and eHealth. These apps significantly enhance the accessibility and delivery of health services, especially with the increasing demand for smartphones and other digital devices driven by rapid technological advancements [3]. These apps empower individuals to participate in symptom control and identification, receive treatment, and obtain personal feedback and motivational support [2,4,5]. Pregnancy apps, in particular, have become popular resources for expectant mothers, offering functionalities ranging from fetal development tracking to health tips and educational content [6,7]. However, the reliability of health recommendations provided by pregnancy apps remains a significant concern. For instance, a study found that 89.7% of Chinese mobile apps for pregnancy and postpartum care did not provide safety statements or supporting evidence, and 68% of US apps similarly lacked evidence-based content [8]. Also, a systematic review of sexual and reproductive health apps revealed that, while a variety of apps exist, only a few meet high-quality design standards or demonstrate effectiveness in real-life settings [9]. These findings emphasize the critical need for research into the usability and evidence-based development of MHAs, particularly those targeting pregnancy care.

It is crucial for these apps to provide accurate and reliable evidence-based content that considers the cultural and linguistic needs of the target audience, including information on cultural practices and traditions related to pregnancy and childbirth [10].

While the quantity and user acceptance of Iranian pregnancy apps have grown significantly, the credibility of the information within these apps remains invalidated. A study conducted in Iran found that only 1.3% of pregnancy-related mobile apps were developed with the participation of obstetricians, and only 5% used reliable information resources [11]. This lack of professional input may affect the accuracy and reliability of the information these apps provide.

Despite the proliferation of pregnancy apps, there is a notable lack of research evaluating Persian-language apps. Existing studies on digital health tools in Persian often overlook the unique challenges faced by expectant mothers, such as the need for culturally relevant information and user-friendly interfaces that accommodate varying levels of comprehension and accessibility requirements specific to their needs [12]. Furthermore, data on the effectiveness of these apps in delivering evidence-based health information and supporting positive health outcomes is scarce [11].

The aim of this study is to assess MHAs for Iranian pregnant women by evaluating them across three key aspects: (1) quality assessment; (2) content accuracy via assessing coverage and depth of information, which assesses how thoroughly the app addresses relevant health topics, including work and rest practices during pregnancy, nutrition education, stress management, interpersonal relationships, and pregnancy care instructions, with significant implications for maternal health and well-being; and (3) user suitability of materials, which examines the quality of the app's content to ensure it is accurate, reliable, and user-friendly. Specifically, this study seeks to answer the following questions:

1. What apps are available?

2. What is the quality of these apps, as measured by the Mobile App Rating Scale (MARS)?

3. How comprehensive is the content provided by these apps?

4. How suitable are these apps for expectant mothers based on their design and cultural relevance?

Methods

Study Design and Protocol Registration

This study used a systematic approach to identify, select, and evaluate Persian-language pregnancy apps available up to July 2023. The methodology was designed to ensure a rigorous and transparent evaluation process. A detailed protocol for the review was developed and registered with the International Prospective Register of Systematic Reviews (PROSPERO; ID CRD42023461605).

Search Strategy and Inclusion Criteria

The app search was conducted between June 1, 2023, and July 31, 2023, focusing on major platforms commonly used by Persian-language app users. Searches were performed on Google Play Store, Cafebazaar App Store, Myket Market, Kandoo, Iran Apps, Avval Market, and Pars Hub. To enhance comprehensiveness, an internet-based search via Google was also conducted as a supplementary measure to identify apps not listed on these platforms.

Given the dynamic nature of search results on the Google Play Store, the search was conducted manually to ensure relevance. The Apple App Store is not officially accessible in Iran due to regional restrictions. However, using a virtual private network is legal in Iran, and Iranian users frequently use virtual private networks to connect to the store and download apps. Apps were identified by sequentially navigating through search results. We screened all results until no new eligible apps were identified, which required reviewing up to 10 pages per platform. No web crawler was used, but search results were manually exported by recording app details (eg, name, description, and download count) directly into a predesigned data extraction form.

The search was conducted using a combination of Persian keywords related to pregnancy and their English equivalents. Search terms included were "pregnancy," "prenatal care," "motherhood," "pregnant," and "mother and baby." Apps were considered eligible if they met the following criteria: the app must be in Persian, freely available, with or without in-app purchases, compatible with the Android operating system, having more than 10,000 downloads, designed for pregnant women, provided information on at least one of the following topics: work and rest practices during pregnancy, nutrition education, stress management, interpersonal relationships, or pregnancy care instructions.

Apps were excluded from the analysis if they met any of the following criteria: inaccessibility due to dead or broken links, duplication, design as e-books, news sources, magazines, podcasts, blogs, games, or gaming-related content. In addition, apps were excluded if their primary function was monitoring or timing without providing educational content, or if they required paid subscriptions or included freemium content that limited access to essential features.

Screening Process and Data Extraction

In order to determine eligibility, two independent reviewers (FA and SEZ) screened the titles, images, and descriptions of the identified apps during the search. In cases of disagreement, a third senior reviewer (RLR) was consulted to reach a consensus.

Data from eligible apps were extracted systematically by two reviewers (FA and SEZ) who were trained to ensure consistency and accuracy.

Eligible apps were downloaded and tested on a Xiaomi Mi Mix 3 device running Android 12. Extracted data included app name, version, developer, cost, in-app purchases, user rating, number of ratings, and last update date.

App Features and Quality Assessment

Using 3 primary assessment tools, 2 reviewers with expertise in midwifery and reproductive health independently evaluated the apps.

The MARS

MARS evaluates app quality across 4 dimensions including (1) engagement to assess fun, interest, adaptability, interactivity, and target group relevance; (2) functionality to examine performance, usability, navigation, and gestural design; (3) aesthetics to evaluate layout, graphics, and visual appeal; and (4) information quality to review the accuracy, goals, credibility based on the evidence and quality, and quantity of information, including visual information.

Apps were rated using a 5-point scale (1=inadequate to 5=excellent). A mean score was calculated to determine overall quality. Disagreements were resolved by involving a third assessor.

The validity of the Persian (Farsi) version of the MARS questionnaire, translated and culturally adapted from the original scale, was rigorously assessed and confirmed through various psychometric measures. The fit indices demonstrated strong construct validity for each dimension (root-mean-square error of approximation [RMSEA]=0.074, Tucker-Lewis index [TLI]=0.922, comparative fit index [CFI]=0.940, and standardized root-mean-square residual [SRMR]=0.059). Reliability was reported as good to excellent across domains, with Omega coefficients ranging from 0.79 to 0.93, indicating high internal consistency. Furthermore, the instrument exhibited strong interrater reliability, with an intraclass correlation coefficient of 0.82, demonstrating a high level of objectivity [13].

Coverage and Depth of Information Checklist

This researcher-developed tool assessed educational content based on guidelines by Iran's Ministry of Health [14], which are provided in Multimedia Appendix 1. The checklist used in this study was developed and validated to ensure its reliability and suitability for evaluating MHAs designed for Iranian pregnant women. The development process began with an extensive review of the literature, expert consultations, and adherence to relevant maternal health guidelines to identify key topics and items for inclusion. These topics covered essential domains such as pregnancy care, stress management, nutrition education, and exercise practices during pregnancy. Coverage was scored as follows: correct and sufficient (2 points), partially correct or insufficient (1 point), and incorrect or not addressed (0 points). The total score categorized app content as Superior (41-46 points, 90%-100%), Adequate (23-40 points, 50%-89%), or Poor or Low (<23 points, ≤49%). The resulting checklist was structured with clear, measurable items to evaluate the quality, coverage, and depth of information provided by the apps.

To ensure the checklist was a reliable and effective evaluation tool, it underwent a pilot testing phase. A sample of 5 MHAs was selected for this pilot, chosen to represent a variety of features and content typically found in apps targeting pregnant women. Two independent reviewers with reproductive health specialists having experience in the evaluation of health apps assessed the apps using the checklist. This process served two primary purposes: to evaluate the internal consistency of the checklist items and to measure interrater reliability.

The checklist showed strong internal consistency (Cronbach α=0.85) and substantial interrater reliability (Cohen κ=0.80), confirming its alignment and consistency in measuring information coverage and quality. Minor ambiguities identified during pilot testing were revised, resulting in a robust and validated tool used to evaluate the MHAs comprehensively (Multimedia Appendix 2).

Suitability Assessment of Materials

The authors conducted a suitability assessment of patient education material using the Suitability Assessment of Materials (SAM) tool. Each item was rated as superior (2 points), adequate (1 point), or not suitable (0 points). The SAM consists of 22 items grouped under four categories: literacy demand, layout and type, learning stimulation and motivation, and cultural appropriateness. Apps featuring content that lacked cultural alignment, such as multimedia showcasing non-Iranian contexts or dietary advice incompatible with local practices, were found to be less effective in addressing user needs. In contrast, apps that included culturally tailored recommendations, such as adherence to Islamic dietary guidelines or the use of culturally familiar imagery, were more favorably received. Scores were categorized as follows: 0%-39% (not suitable), 40%-69% (adequate), and 70%-100% (superior).

A study assessing SAM's interrater reliability for written stroke education materials showed that most individual SAM items had high interrater reliability, with 17 out of 22 items achieving substantial, almost perfect, or perfect weighted κ values (≥0.60), with a total agreement of 96% [15].

Data Analysis

Data analysis was conducted based on the extracted data from the included apps. The extracted data were first tabulated across all studies, and then the collected data were analyzed using IBM SPSS Statistics (version 25.0). Descriptive statistics, including mean and SD, were calculated for the app ratings from the MARS, Coverage and Depth of Information Checklist, and SAM. This analysis provided a comprehensive overview of app quality, content coverage, and suitability. The research team adhered to ethical principles, including honesty and trustworthiness, in data analysis and when presenting the study's findings. To protect the rights of the app developers, the names of the apps were identified by codes in this systematic evaluation.

Ethical Considerations

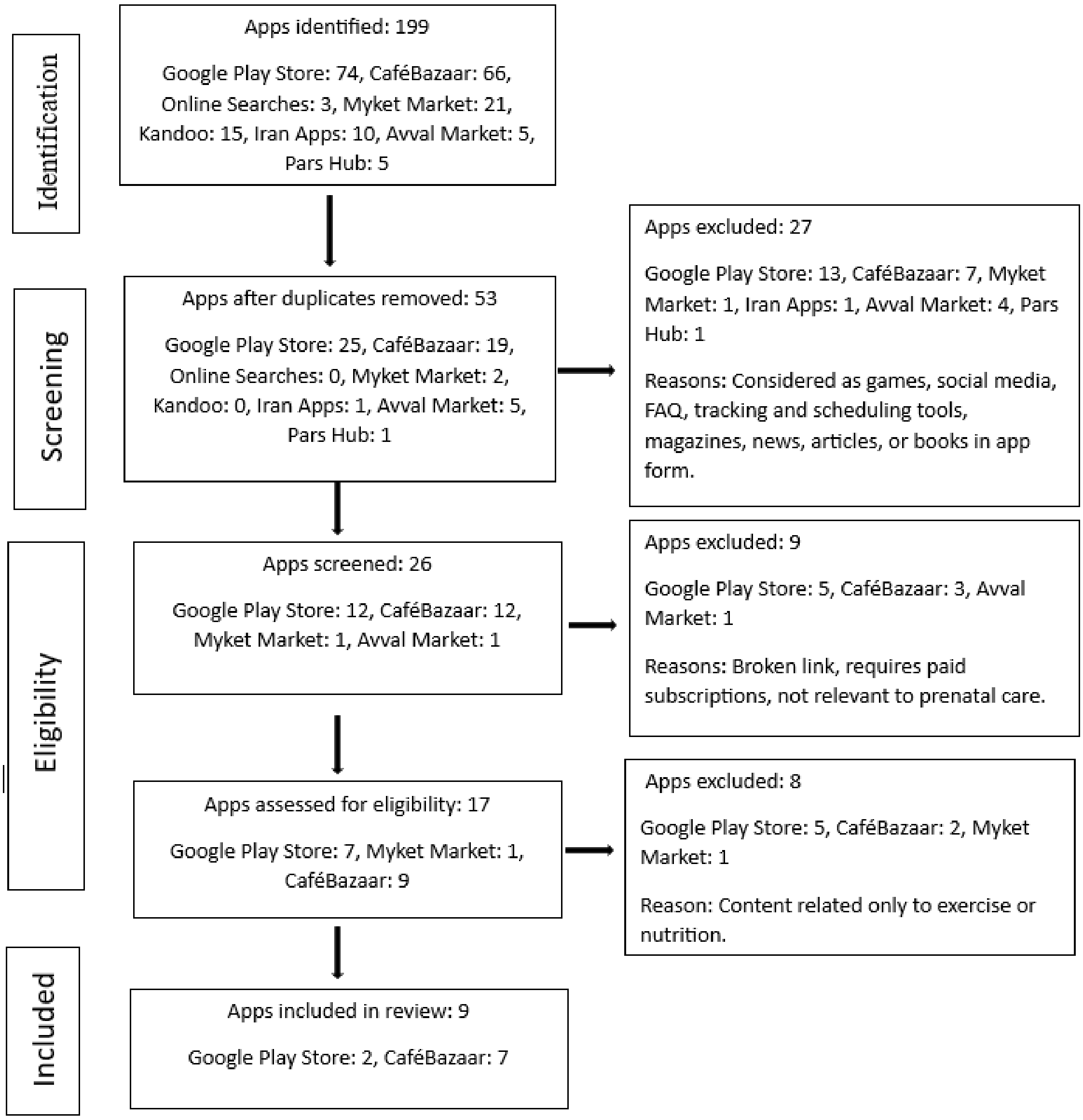
The research study was approved by the Research Ethics Committees of Mashhad University of Medical Sciences, Mashhad, Iran (IR.MUMS.REC.1400.179). Since the study involved the assessment of publicly available MHAs, no personal data or identifiable participant information were collected. The apps evaluated are commercially available and publicly accessible, ensuring user privacy and confidentiality. No compensation was provided or required for this study as it involved the assessment of publicly available MHAs and not the participation of individuals.

Results

App Selection Process

The app selection process for this study is outlined in Figure 1. A comprehensive search identified 199 pregnancy-related apps from multiple sources, including internet-based databases, major app stores, and local markets, using the keywords "Pregnancy," "Pregnant," "Pregnancy care," and "Prenatal care." During the initial screening, 146 duplicate entries were removed. For apps found on multiple platforms, the version from the platform with the higher download count was retained for evaluation, ensuring only one version of each app was included. This process left 53 unique apps for further evaluation. These apps were screened for relevance to pregnancy and availability in the Persian language. During this screening process, 27 apps were excluded because they either did not focus on pregnancy or were not available in Persian, leaving 26 apps for further review. The remaining 26 apps were then assessed against the study's predefined inclusion criteria, which considered factors such as app functionality, comprehensiveness of content, and language suitability. In this phase, 9 apps were excluded for failing to meet these criteria. This left 17 apps for a detailed eligibility assessment, during which 8 additional apps were excluded for not fully aligning with the requirements. Ultimately, 9 apps (2 apps were available on the Google Play Store, and 7 apps were available on CaféBazaar) met all criteria and were selected for a comprehensive evaluation regarding their quality, content, and suitability for Persian-speaking pregnant women.

Figure 1. Flow diagram for apps' selection.



Description of the Selected Apps

Of the 9 apps reviewed, 2 were sourced from Google Play and 7 from CaféBazaar. All selected apps were freely available for download. These apps were commercially developed and lacked affiliations with government agencies, academic institutions, or clinical trials. None had associated scientific publications.

A total of 2 apps had substantial user bases with more than 500,000 downloads each, while 3 apps had more modest download numbers of over 10,000. User ratings ranged from 2.9 to 4.7 stars, with most apps (7 out of 9) receiving ratings of 4.2 or higher. We considered the star ratings that appeared on the platform where the app had the highest number of downloads. In these platforms, the star rating system ranges from 1 star (the lowest rating) to 5 stars (the highest rating).

In total, 5 apps required in-app purchases for full functionality. Notable features across the apps included personal profile creation (6 apps), multilingual support (1 app), and offline functionality (2 apps). Only 2 apps provided transparency about their development and scientific teams. Table 1 summarizes these characteristics. Multimedia Appendix 3 provides the original ratings for all included apps.

Table 1. Summary of app characteristics.

App Code[a]	Downloads	Star rating	In-app purchases	Offline functionality	Language	User interaction	Scientific team
APP N1	>500,000	4.5	Yes	No	Persian	Yes	Yes
APP N2	>500,000	4.7	Yes	No	Persian	Yes	No
APP N3	>10,000	4.2	No	Yes	Persian	No	No
APP N4	>10,000	4.3	Yes	No	Persian	Yes	No
APP N5	>10,000	4.7	Yes	No	Persian	Yes	No
APP N6	>50,000	4.7	No	Yes	Persian	No	No
APP N7	>100,000	2.9	No	No	Persian	Yes	No
APP N8	>100,000	4.5	Yes	No	Persian	Yes	Yes
APP N9	>50,000	4.5	No	No	Persian or English	Yes	No

[a] APP N refers to the app code number (eg, APP N1 refers to app code number 1).

App Quality Assessment

The MARS tool evaluation revealed varying quality levels across the 9 apps. The scores ranged from 2.1 to 3.75 out of 5, with most apps (7 out of 9) scoring above 3. Reviewer-specific scores are presented in Multimedia Appendix 3.

Looking at the subscales, Aesthetics and Functionality emerged as the strongest domains, with median scores of 4. Engagement showed moderate performance, with a median score of 3, while Information quality was generally lower, with a median score of 2.8.

APP N4 demonstrated the strongest performance in three domains (Engagement: 4.2, Functionality: 5, Aesthetics: 4.6), while APP N8 led in Information quality (3.5). The lowest-performing app across most domains was APP N3, as shown in Table 2.

Relationship between app features examining the data qualitatively reveals several patterns. First, apps with higher MARS scores (above 3.5) generally received better user ratings, with most having ratings of 4.5 stars or higher. However, this trend was not consistent for all apps. For instance, APP N2 received high user ratings (4.7 stars) despite having a relatively low score in the information quality domain (2.8).

Second, the two most downloaded apps, with more than 500,000 downloads each, shared specific features. These included in-app purchases, user interaction capabilities, and regular content updates. Nevertheless, a higher number of downloads did not necessarily correlate with higher MARS scores, suggesting that download numbers alone are not a reliable indicator of app quality.

Finally, apps developed by teams with scientific expertise (2 out of 9) tended to score higher in the information quality domain, with scores exceeding 3.2. Conversely, apps with offline functionality (2 out of 9) tended to have lower overall MARS scores compared with apps with internet-based functionality, suggesting that offline accessibility may be associated with compromises in other quality domains such as engagement or information quality.

Table 2. MARS scores for antenatal apps.

App code[a]	Overall MARS score	Engagement	Functionality	Aesthetics	Information
APP N4	3.75	4.2	5	4.6	2.2
APP N2	3.62	3.6	4.1	4	2.8
APP N9	3.62	3.8	4.1	4.1	2.8
APP N1	3.57	3.4	3.8	3.9	3.2
APP N8	3.55	3.6	3.8	4	3.5
APP N5	3.35	3.5	4.2	3.9	1.8
APP N7	3.1	2.9	2.5	3.2	3.5
APP N6	2.27	1.7	2.5	2	2.6
APP N3	2.1	1.6	3	1.3	2

[a] APP N refers to the app code number (eg, APP N1 refers to app code number 1).

Coverage and Depth of Information

Most apps provided relatively poor coverage and depth of health information. Table 3 summarizes the completeness of the content.

None of the apps addressed all the essential training subjects recommended by the Deputy Minister of Health. A total of 6 apps were rated as poor for coverage and depth of health information and 3 apps were rated as adequate. Topics such as sexual health, oral health, immunization, substance avoidance, stress management, and prenatal classes were either poorly covered or entirely neglected. Furthermore, none of the apps provided references for the educational content, raising concerns about the accuracy and reliability of the information.

Table 3. Coverage and depth of information in apps.

App code[a]	Overall coverage rating	Key topics covered	Missing topics
APP N1	Adequate	Pregnancy changes, fetal growth, physical activity	Sexual health, immunization, stress management
APP N2	Adequate	Nutrition, common complaints, warning signs	Oral health, prenatal classes, substance use
APP N3	Poor	Pregnancy changes, physical activity	Comprehensive information on health subtopics
APP N4	Adequate	Fetal growth, physical activity, nutrition	Sexual health, immunization, substance use
APP N5	Poor	Common complaints, warning signs	Oral health, prenatal classes, stress management
APP N6	Poor	Basic pregnancy changes	Comprehensive coverage on health subtopics
APP N7	Poor	Common complaints	Sexual health, immunization, substance use
APP N8	Adequate	Physical activity, nutrition, common complaints	Sexual health, prenatal classes, stress management
APP N9	Adequate	Pregnancy changes, fetal growth, physical activity	Oral health, immunization, substance use

[a] APP N refers to the app code number (eg, APP N1 refers to app code number 1).

Suitability of Information

The SAM assessment revealed varying levels of content suitability across apps. A total of 4 apps achieved superior ratings (>70%), while 5 were rated as adequate (40%-70%) as shown in Table 4.

In terms of Literacy and Layout, high-performing apps (SAM>70%) consistently showed strong literacy demand scores, with layout quality typically aligning with overall suitability ratings. Learning stimulation emerged as the most challenging domain, being consistently the lowest-scoring area across all apps. Even apps with superior overall performance demonstrated significant room for improvement in user engagement strategies.

Cultural appropriateness presented a particularly interesting dimension, with scores ranging widely from 35% to 95%. Notably, apps with superior overall ratings typically exhibited more refined cultural adaptation, suggesting a strong correlation between cultural sensitivity and overall app quality. Apps with culturally misaligned content, such as multimedia depicting non-Iranian contexts or dietary advice unsuitable for local practices, were noted as less effective in meeting user needs. Conversely, apps incorporating culturally aligned recommendations, such as content adhering to Islamic dietary laws or featuring culturally relevant imagery, were better received.

Diving deeper into the quality patterns, apps with superior SAM ratings (>70%) shared several common characteristics. These apps distinguished themselves through comprehensive content organization, clear visual hierarchies, consistent cultural adaptation, and robust interactive elements. This suggests that successful pregnancy apps go beyond mere information delivery, focusing on user experience and cultural relevance.

Conversely, most apps revealed consistent areas requiring improvement. These included enhancing learning stimulation features, developing original educational media, ensuring cultural consistency, and providing authoritative reference citations. These gaps highlight the potential for future app development in the pregnancy support digital ecosystem, pointing to opportunities for creating more engaging, culturally sensitive, and scientifically grounded mHealth resources.

Table 4. SAM scores for suitability of app information.

App code[a]	Total score (%)	Literacy demand (%)	Layout and type (%)	Learning stimulation and motivation (%)	Cultural appropriateness (%)
APP N1	81.25% (Superior)	90% (Superior)	85% (Superior)	55% (Adequate)	95% (Superior)
APP N2	75% (Superior)	88% (Superior)	82% (Superior)	50% (Adequate)	80% (Superior)
APP N3	42% (Adequate)	48% (Adequate)	30% (Not suitable)	30% (Not suitable)	60% (Adequate)
APP N4	84.25% (Superior)	92% (Superior)	90% (Superior)	75% (Superior)	80% (Superior)
APP N5	70% (Superior)	85% (Superior)	70% (Superior)	65% (Adequate)	60% (Adequate)
APP N6	44 % (Adequate)	40% (Adequate)	35% (Not suitable)	25% (Not suitable)	35% (Not suitable)
APP N7	48.75 % (Adequate)	75% (Superior)	50% (Adequate)	30% (Not suitable)	40% (Adequate)
APP N8	67.5 % (Adequate)	75% (Superior)	80% (Superior)	50% (Adequate)	65% (Adequate)
APP N9	68.75 % (Adequate)	80% (Superior)	75% (Superior)	55% (Adequate)	65% (Adequate)

[a] APP N refers to the app code number (eg, APP N1 refers to app code number 1).

Discussion

Principal Findings

This study evaluated the quality, content accuracy, and user suitability of 9 popular Persian MHAs designed for prenatal care, using standardized assessment tools. The findings revealed that while the apps generally performed well in aesthetics and functionality, they showed notable deficiencies in information quality and coverage. Only a third of the apps achieved adequate health information standards, and none excelled in this category. Despite moderate user ratings, the results highlight significant gaps in the educational and informational content of these apps, underscoring the need for improved standards in app development to better serve expectant mothers.

App Availability and Characteristics

Based on the results, no apps were found with any background of scientific documents or being based on the evidence, including the results of the clinical trials. All reviewed apps lacked transparency regarding affiliations and were set up to be commercial rather than as an intervention to change health behavior. All included apps were mostly commercial and were not designed by university academics or research staff. In line with the results of our study, Musgrave et al [16] also indicated that, in their review study of pregnancy apps available in Australia, the affiliations and sources of funding information indicated that all apps were commercially developed and the scientific reviewer teams were not introduced. As a result, this is one of the weaknesses of apps because in order to increase their reliability, the scientific staff or resources for training must be specified [17]. This finding is particularly concerning given the critical role of accurate and comprehensive health information in antenatal care. The qualitative study on mothers' views on mHealth in self-care for pregnancy identified the need for reliable and trustworthy information in pregnancy apps [12]. Pregnant women were found to be interested in using apps for self-care, but they required reliable and accurate information to make informed decisions about their health [12]. Research highlights the importance of reliable content in health apps. They report that only 5% of the examined apps used reliable information resources, which is a significant concern given the importance of accurate information for pregnant women [11].

In our study, of the 6 apps scoring highest for quality, only 2, APP N7 and APP N9, did not contain in-app purchases. This finding aligns with another review article investigating nutrition-based pregnancy apps, which reported that highly rated MARS apps often required in-app purchases and could not be operated without internet access [18]. Concurrently, recent data suggest that only 5%-10% of app users are willing to pay for in-app purchases [19]. Furthermore, in our study, most applications could not be used without internet access, with only 2 apps offering plain textual information available offline. Similarly, the study by Musgrave et al [16] identified the lack of access to app content without an internet connection as a limitation of mHealth.

App Quality Assessment

The MARS tool revealed a nuanced quality landscape. With an average score of 3.55 out of 5, the apps demonstrated moderate quality. Aesthetics and Functionality emerged as the strongest domains, while Information quality consistently scored lower. The high user ratings and significant download numbers of apps such as APP N4 and APP N1 reflect their popularity and perceived utility among users. These apps scored well in terms of user engagement, functionality, and aesthetics, as evidenced by their high MARS scores. This aligns with the general trend observed in health app evaluations where engaging, visually appealing, and easy-to-use apps tend to garner higher user satisfaction [20]. For instance, APP N4 excelled in the engagement and functionality domains with scores of 4.2 and 5, respectively. This suggests that users value interactive and well-designed interfaces that enhance their overall experience. This finding is consistent with studies noting that apps with high engagement features often receive favorable user feedback and higher ratings, even if their informational content is not comprehensive [21].

However, despite their high user ratings, these apps often fall short of delivering thorough educational content. This discrepancy between user satisfaction and content quality highlights a critical issue in the design and development of health apps [22]. Users may prioritize user experience and accessibility over the depth and accuracy of information, which can lead to gaps in the provision of comprehensive health education [23].

Content Comprehensiveness

Our study found significant deficiencies in the coverage and depth of information provided by most apps. Despite their high engagement scores, many apps scored poorly in the information domain of MARS and lacked comprehensive coverage of essential pregnancy-related topics. For example, none of the apps covered all the crucial educational topics outlined by the Deputy Minister of Health, and several key areas, such as sexual health and prenatal classes, were consistently neglected. Also, the lack of verifiable sources for the educational content in the reviewed apps further exacerbates this issue, as it raises questions about the accuracy and credibility of the information disseminated to users.

While some apps offered a higher percentage of educational content coverage needed for pregnancy, they were inadequate or neglectful in more than half of the apps on topics such as sexual health, immunization, stress management, and introducing prenatal classes. This observation aligns with findings from another review, which reported that only 16 (31.4%) apps contained information on appropriate pregnancy weight gain as defined by the Institute of Medicine guidelines [18].In addition, a previous study by Tinius et al [24] on apps related to physical activity during pregnancy found that none of the included apps incorporated goal-setting in alignment with the American College of Sports Medicine (ACSM) and American College of Obstetricians and Gynecologists (ACOG) guidelines. The most frequently covered topics in the apps were changes during pregnancy, fetal growth, physical activity, nutrition, common complaints, and warning signs, consistent with other reviews [25]. Overall, reviewers noted that nearly half of all apps were poor or inadequate for recommending to others.

Suitability and Cultural Relevance

The evaluation of the apps using the SAM tool revealed mixed results regarding the suitability of health information. While 4 out of 9 apps (APP N1, APP N2, APP N4, and APP N5) were rated as superior in terms of suitability, the majority were merely adequate, and none were found to be unsuitable. This suggests that while some apps do meet the basic requirements for suitable health information materials, there is substantial room for improvement.

Notably, APP N1 and APP N4 received the highest scores in the SAM evaluation, reflecting their superior suitability for the intended audience. These apps likely benefited from their engaging and user-friendly design, which aligns with findings from previous studies indicating that well-designed health information materials are more likely to be effective [12].

Although many apps were evaluated as good to excellent on the SAM score across dimensions such as literacy demand, layout, and type, they received lower scores in the areas of graphics and illustrations and learning stimulation motivation. Similarly, a review of apps for infant feeding reported that 42% of the apps were rated as superior, 54% as adequate, and 3% as unsuitable [26]. However, Cheng et al [26] noted lower scores for readability and cultural appropriateness, which contrasts with our results. Our study determined that most programs were culturally appropriate for Iranian users. This discrepancy may be attributed to the fact that many of the apps in the study by Cheng et al [26] were developed outside of Australia, specifically in America, the United Kingdom, and the European Union, where cultural differences are expected. In contrast, the apps examined in our study were all designed by Iranian teams, which likely contributed to their relative cultural appropriateness.

A unique strength was the cultural appropriateness of these Iranian-developed apps. Unlike international apps that may struggle with cultural adaptation, these apps demonstrated a strong understanding of local user needs. However, areas for improvement included original educational media and interactive elements. These insights underscore the need for app developers to focus on comprehensive design and cultural considerations to enhance both the quality and user experience of pregnancy apps [27].

The study reveals a critical gap between app popularity and quality. High download numbers and user ratings do not guarantee comprehensive or reliable health information. This underscores the urgent need for rigorous content development standards, transparent scientific affiliations, comprehensive educational coverage, and enhanced user engagement strategies.

Strengths and Limitations

The study had several strengths. It used a comprehensive evaluation framework using 2 independent reviewers, which enhanced the reliability of the assessments. Concentrating on Persian MHAs for prenatal care, the study filled a significant gap in the literature and highlighted areas for improvement, particularly regarding the coverage and depth of health information. However, our study had several limitations. The evaluation was restricted to apps available on Android Play stores available in Iran, potentially excluding other resources on different platforms or less accessible databases. In addition, a key limitation is the rapidly evolving MHA market. Some apps included in this review may no longer be available, and new apps may have emerged since the data collection, which could affect the relevance of our findings. Our study also did not explore the long-term user engagement or the impact of these apps on user health outcomes, which could provide deeper insights into their effectiveness.

Implications of Findings

The implications of these findings are significant for both app developers and health care providers. High user engagement and aesthetic appeal are crucial for attracting users, but the ultimate value of antenatal apps lies in their ability to deliver reliable, comprehensive health education. Given the increasing reliance on digital tools for health information, ensuring that apps provide accurate, well-rounded educational content is essential. Our study underscores the need for more rigorous standards and oversight in the development and evaluation of health apps to ensure they meet the informational and usability needs of their users. For health care providers, these results suggest caution when recommending apps to expectant mothers. Providers should consider not only the popularity and user ratings of an app but also its content quality and the credibility of the information it provides.

Future Research Directions

Future research should expand the scope to include a wider range of platforms and perhaps a broader geographic scope to capture a more comprehensive view of available antenatal apps. Further studies should also look into the longitudinal impact of these apps on maternal health outcomes and user behavior. In addition, exploring user feedback and integrating it into apps' evaluation could provide a more nuanced understanding of app performance and areas for improvement. Given the rapid evolution of digital health tools, continuous monitoring and evaluation are necessary to keep up with emerging trends and ensure that these tools remain relevant and useful for their intended audiences.

Conclusion

A systematic evaluation of MHAs for prenatal care in Iran revealed a critical need for stricter quality control. While numerous pregnancy apps exist, many lack the quality and comprehensive content mandated by the Ministry of Health. Furthermore, the accuracy of educational content is questionable due to the absence of reliable references or involvement of health care professionals. This research highlights the importance of evaluating app quality and suitability for user navigation while also emphasizing the need to assess the use of behavioral change techniques like goal setting and self-monitoring. By identifying these gaps and deficiencies, researchers can recommend improvements and integrate evidence-based strategies to enhance the effectiveness of pregnancy apps in promoting healthy behaviors and ultimately improving maternal and infant health outcomes.

Acknowledgments

We are grateful to Mashhad University of Medical Sciences, Mashhad, Iran for funding fieldwork during this study under grant number (IR.MUMS.REC.1400.179). This study is part of the doctoral thesis of the first author (FA), funded by the Vice Chancellor for Research, Mashhad University of Medical Sciences, Mashhad, Iran.

All authors declared that they had insufficient or no funding to support open access publication of this manuscript, including from affiliated organizations or institutions, funding agencies, or other organizations. JMIR Publications provided APF support for the publication of this article.

Data Availability

All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors' Contributions

FA and RLR contributed to conceptualization and methodology. FA and SEZ performed data curation. FA conducted formal analysis. RLR performed project administration and supervision. FA assisted with writing-original draft. FA, RLR, and SEZ contributed to investigation and writing-review and editing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Clinical Standards and Guidelines by Iran's Ministry of Health.
[PDF File (Adobe PDF File), 751 KB - apinj_v9i1e66852_app1.pdf]

Multimedia Appendix 2
Checklist for Evaluating Mobile Health Applications for Pregnant Women.
[DOCX File , 17 KB - apinj_v9i1e66852_app2.docx]

Multimedia Appendix 3
Original ratings for mobile health app evaluation.
[DOCX File , 27 KB - apinj_v9i1e66852_app3.docx]

References

1. Senbekov M, Saliev T, Bukeyeva Z, Almabayeva A, Zhanaliyeva M, Aitenova N, et al. The recent progress and applications of digital technologies in healthcare: a review. Int J Telemed Appl 2020;2020:8830200. [doi: 10.1155/2020/8830200] [Medline: 33343657]

2. Tabatabaei SM, Ghaedi R, Khonsaraki EA, Talebi A. Application of mobile health to improve self-care among pregnant women: a literature review. J Med Physiol 2021;5(1):1 [FREE Full text]
3. Eşiyok A, Divanoğlu SU, Çelik R. Digitalization in healthcare-mobile health (M-Health) applications. Journal of ASU FEAS 2023:15-174. [doi: 10.52791/aksarayiibd.1241287]
4. Gandapur Y, Kianoush S, Kelli HM, Misra S, Urrea B, Blaha MJ, et al. The role of mHealth for improving medication adherence in patients with cardiovascular disease: a systematic review. Eur Heart J Qual Care Clin Outcomes 2016;2(4):237-244 [FREE Full text] [doi: 10.1093/ehjqcco/qcw018] [Medline: 29474713]
5. Short CE, Finlay A, Sanders I, Maher C. Development and pilot evaluation of a clinic-based mHealth app referral service to support adult cancer survivors increase their participation in physical activity using publicly available mobile apps. BMC Health Serv Res 2018;18(1):27 [FREE Full text] [doi: 10.1186/s12913-017-2818-7] [Medline: 29338722]
6. Selvakanmani S, Manasvini G, Pavithra S. BABYBLOOM – Nurturing pregnancy and parenthood with personalized care. 2023 Presented at: International Conference on Research Methodologies in Knowledge Management, Artificial Intelligence and Telecommunication Engineering (RMKMATE). 2023; November 01-02, 2023; Chennai, India. [doi: 10.1109/rmkmate59243.2023.10368844]
7. Zhu C, Zeng R, Zhang W, Evans R, He R. Pregnancy-related information seeking and sharing in the social media era among expectant mothers: qualitative study. J Med Internet Res 2019;21(12):e13694 [FREE Full text] [doi: 10.2196/13694] [Medline: 31799939]
8. Yu H, He J, Li K, Qi W, Lin J, Szumilewicz A. Quality assessment of pre- and postnatal nutrition and exercise mobile applications in the United States and China. Front Nutr 2023;9:942331 [FREE Full text] [doi: 10.3389/fnut.2022.942331] [Medline: 36698473]
9. Muehlmann M, Tomczyk S. Mobile apps for sexual and reproductive health education: a systematic review and quality assessment. Curr Sex Health Rep 2023;15(2):77-99 [FREE Full text] [doi: 10.1007/s11930-023-00359-w]
10. Haq ZU, Naeem A, Zaeem D, Sohail M, Pervaiz NUA. Development of a digital platform to promote mother and child health in underserved areas of a lower-middle-income country: mixed methods formative study. JMIRx Med 2024;5:e48213 [FREE Full text] [doi: 10.2196/48213] [Medline: 39087559]
11. Shirvanian-Dehkordi M, Zare-Farashbandi F, Samouei R, Nouri R. Mobile health applications for pregnancy in Iran: current state investigation. J Educ Health Promot 2022;11:338 [FREE Full text] [doi: 10.4103/jehp.jehp_1126_21] [Medline: 36567998]
12. Pouriayevali B, Ehteshami A, Kohan S, Saghaeiannejad Isfahani S. Mothers' views on mobile health in self-care for pregnancy: a step towards mobile application development. J Educ Health Promot 2023;12:308 [FREE Full text] [doi: 10.4103/jehp.jehp_534_22] [Medline: 38023089]
13. Barzegari S, Sharifi Kia A, Bardus M, Stoyanov SR, GhaziSaeedi M, Rafizadeh M. The persian version of the mobile application rating scale (MARS-Fa): translation and validation study. JMIR Form Res 2022;6(12):e42225 [FREE Full text] [doi: 10.2196/42225] [Medline: 36469402]
14. Ministry of Health and Medical Education of Iran. Ministry of Health and Medical Education of Iran. (2024). Clinical standards and guidelines. Retrieved from Clinical Standards and Guidelines (behdasht.gov.ir). URL: https://irangov.ir/ministry-of-health-and-medical-education [accessed 2025-01-11]
15. Hoffmann T, Ladner Y. Assessing the suitability of written stroke materials: an evaluation of the interrater reliability of the suitability assessment of materials (SAM) checklist. Top Stroke Rehabil 2012;19(5):417-422 [FREE Full text] [doi: 10.1310/tsr1905-417] [Medline: 22982829]
16. Musgrave LM, Kizirian NV, Homer CSE, Gordon A. Mobile phone apps in Australia for improving pregnancy outcomes: systematic search on app stores. JMIR Mhealth Uhealth 2020;8(11):e22340 [FREE Full text] [doi: 10.2196/22340] [Medline: 33196454]
17. Atukunda EC, Siedner MJ, Obua C, Musiimenta A, Ware NC, Mugisha S, et al. Evaluating the feasibility, acceptability, and preliminary efficacy of supportMoms-uganda, an mHealth-based Patient-Centered Social Support Intervention to Improve the use of maternity services among pregnant women in rural southwestern uganda: randomized controlled trial. JMIR Form Res 2023;7:e36619 [FREE Full text] [doi: 10.2196/36619] [Medline: 36862461]
18. Brown HM, Bucher T, Collins CE, Rollo ME. A review of pregnancy iPhone apps assessing their quality, inclusion of behaviour change techniques, and nutrition information. Matern Child Nutr 2019;15(3):e12768 [FREE Full text] [doi: 10.1111/mcn.12768] [Medline: 30569549]
19. Imam S, Frank A. To pay or not to pay: understanding mobile game app users' unwillingness to pay for in-app purchases. Journal of Research in Interactive Marketing 2022;16:633-647 [FREE Full text] [doi: 10.1108/JRIM-02-2021-0053]
20. Mustafa AS, Ali N, Dhillon JS, Alkawsi G, Baashar Y. User engagement and abandonment of mHealth: a cross-sectional survey. Healthcare (Basel) 2022;10(2):221 [FREE Full text] [doi: 10.3390/healthcare10020221] [Medline: 35206837]
21. Wilks CR, Chu C, Sim D, Lovell J, Gutierrez P, Joiner T, et al. User engagement and usability of suicide prevention apps: systematic search in app stores and content analysis. JMIR Form Res 2021;5(7):e27018 [FREE Full text] [doi: 10.2196/27018] [Medline: 34259163]

22. Shamsujjoha M, Grundy J, Li L, Khalajzadeh H, Lu Q. Human-centric issues in eHealth app development and usage: a preliminary assessment. 2021 Presented at: IEEE International Conference on Software Analysis, Evolution and Reengineering (SANER); March 09-12, 2021; Honolulu, HI. [doi: 10.1109/saner50967.2021.00055]
23. Nelson LA, Pennings JS, Sommer EC, Popescu F, Barkin SL. A 3-Item measure of digital health care literacy: development and validation study. JMIR Form Res 2022;6(4):e36043 [FREE Full text] [doi: 10.2196/36043] [Medline: 35486413]
24. Tinius RA, Polston M, Bradshaw H, Ashley P, Greene A, Parker AN. An assessment of mobile applications designed to address physical activity during pregnancy and postpartum. Int J Exerc Sci 2021;14(7):382-399. [doi: 10.70252/aqig9215]
25. Muñoz-Mancisidor A, Martin-Payo R, Gonzalez-Mendez X, Fernández-Álvarez MDM. Content, behavior change techniques, and quality of pregnancy apps in Spain: systematic search on app stores. JMIR Mhealth Uhealth 2021;9(11):e27995 [FREE Full text] [doi: 10.2196/27995] [Medline: 34787587]
26. Cheng H, Tutt A, Llewellyn C, Size D, Jones J, Taki S, et al. Content and quality of infant feeding smartphone apps: five-year update on a systematic search and evaluation. JMIR Mhealth Uhealth 2020;8(5):e17300 [FREE Full text] [doi: 10.2196/17300] [Medline: 32459187]
27. Bilal AM, Pagoni K, Iliadis SI, Papadopoulos FC, Skalkidou A, Öster C. Exploring user experiences of the mom2B mHealth research app during the perinatal period: qualitative study. JMIR Form Res 2024;8:e53508 [FREE Full text] [doi: 10.2196/53508] [Medline: 39115893]

Abbreviations

ACOG: American College of Obstetricians and Gynecologists
ACSM: American College of Sports Medicine
CFI: comparative fit index
MARS: Mobile App Rating Scale
MHA: mobile health app
mHealth: mobile health
PROSPERO: International Prospective Register of Systematic Reviews
RMSEA: root-mean-square error of approximation
SAM: Suitability Assessment of Materials
SRMR: standardized root-mean-square residual
TLI: Tucker-Lewis index

Edited by A Mavragani; submitted 24.09.24; peer-reviewed by M Muehlmann; comments to author 13.11.24; revised version received 03.12.24; accepted 25.12.24; published 13.02.25.

Please cite as:
Asadollahi F, Ebrahimzadeh Zagami S, Eslami S, Latifnejad Roudsari R
Evaluating the Quality, Content Accuracy, and User Suitability of mHealth Prenatal Care Apps for Expectant Mothers: Critical Assessment Study
Asian Pac Isl Nurs J 2025;9:e66852
URL: https://apinj.jmir.org/2025/1/e66852
doi:10.2196/66852
PMID:

Pediatric Sleep Quality and Parental Stress in Neuromuscular Disorders: Descriptive Analytical Study

Sajjad Khaksar[1]; Mehdi Jafari-Oori[2]; Forogh Sarhangi[2]; Malihe Sadat Moayed[2]

[1]Student Research Committee, Baqiyatallah University of Medical Sciences, Tehran, Iran

[2]Nursing Care Research Center, Clinical Sciences Institute, Nursing Faculty, Baqiyatallah University of Medical Sciences, Vanak Square, Tehran, Iran

Corresponding Author:
Malihe Sadat Moayed
Nursing Care Research Center, Clinical Sciences Institute, Nursing Faculty, Baqiyatallah University of Medical Sciences, Vanak Square, Tehran, Iran

Abstract

Background: Neuromuscular disorders (NMDs) constitute a heterogeneous group of disorders that affect motor neurons, neuromuscular junctions, and muscle fibers, resulting in symptoms such as muscle weakness, fatigue, and reduced mobility. These conditions significantly affect patients’ quality of life and impose a substantial burden on caregivers. Spinal muscular atrophy (SMA) is a relatively common NMD in children that presents in various types with varying degrees of severity.

Objective: This study aimed to evaluate the sleep quality of children with NMDs, particularly SMA types 1, 2, and 3 and assess the stress levels experienced by their parents.

Methods: A descriptive analytical study was conducted from February to October 2023, in selected hospitals and dystrophy associations in Tehran and Isfahan, Iran. A total of 207 children aged 1 - 14 years with various NMDs were included in the study. Data were collected using a web-based questionnaire with 3 parts: demographic information, the Children’s Sleep Habits Questionnaire to assess children’s sleep, and the Stress Response Inventory to measure parental stress. Statistical analyses were performed using SPSS version 22, with an α level of .05.

Results: Significant differences in sleep quality were found among SMA types, with mean scores of 74.76 (SD 7.48) for SMA type 1, 76.4 (SD 7.29) for SMA type 2, 72.88 (SD 6.73) for SMA type 3, and 75.87 (SD 5.74) for other NMDs (P=.02). A correlation was found between sleep and length of hospital stay (r=0.234, P<.001)and between sleep and the child’s sex (r=−0.140, P=.04). Parental stress scores averaged 95.73 (SD 32.12). There was not a statistically significant difference in parental stress scores among the 4 groups (P=.78). This suggests that parental stress levels were similar across different NMD groups.

Conclusions: Sleep disorders are prevalent among children with NMDs, especially SMA. Parents experience high levels of stress that can affect the care they provide. Therefore, interventions to improve children’s sleep and address parental stress are crucial. Regular screening, counseling, and tailored support are recommended to enhance the well-being of children with NMDs and their families.

(Asian Pac Isl Nurs J 2025;9:e56667) doi:10.2196/56667

KEYWORDS

spinal muscular atrophy; neuromuscular disorders; sleep quality; pediatrics; parental stress; children; parents; muscular atrophy; muscular disorders

Introduction

Neuromuscular disorders (NMDs) are a diverse group of disorders that affect motor neurons, neuromuscular junctions, and muscle fibers, resulting in various disease onsets, presentations, and prognoses. Examples of NMDs include spinal muscular atrophy (SMA), Charcot-Marie-Tooth disease, congenital myasthenia gravis, and Duchenne muscular dystrophy [1,2]. Children with NMDs can also develop central nervous system disorders such as cerebral palsy and spinal cord injury [3]. Common symptoms of NMDs include muscle weakness, fatigue, reduced mobility, and decreased physical performance. Additionally, these patients may experience orthopedic, cardiac, infectious, and respiratory problems, which can negatively impact their quality of life [4].

The global prevalence of neuromuscular diseases, as estimated through a systematic reviews of studies, ranges from 16 per 10,000 to 25.1 per 100,000 individuals and affects people of all ages [5]. The most common autosomal recessive disorder in children with NMDs is SMA, and it affects approximately 1 in 10,000 individuals and has a carrier frequency of 1 in 50 in certain populations [4]. Despite this, there have been no comprehensive epidemiological studies conducted on children with NMDs, particularly SMA, in Iran. Only one study in Iran identified Duchenne muscular dystrophy as the most prevalent NMD, with no comprehensive data available on SMA or other NMDs [6].

Many NMDs, including SMA, cause progressive muscle weakness that affects the respiratory system, leading to reduced upper airway function, impaired coughing and secretion clearance, and weakened chest wall support [7]. As a result, children with NMDs, particularly SMA, are at high risk for upper airway obstruction, pulmonary aspiration, frequent respiratory infections, sleep-disordered breathing (SDB), hypoventilation, and respiratory failure [8,9].

SDB is a prevalent complication in children with advanced NMDs [10]. It occurs intermittently due to partial or complete upper airway obstruction, leading to disrupted sleep patterns and ventilation [11]. The prevalence of SDB in healthy children is approximately 1%, while up to 70% of children with NMDs experience it [12]. The common issues faced by these children include sleep disturbance, drowsiness, night sweats, nausea, morning headaches, fatigue, and poor academic performance. Therefore, effective management of SDB is crucial to reduce complications and enhance the quality of life for children with NMDs [13,14]. According to research, sleep disorders in children can result in sleep problems for their parents. When children struggle to fall asleep, their parents also have difficulty sleeping, which can cause stress and lead to missed workdays [15]. In a recent study, the mental health of parents of a child with a NMD was assessed using the Psychological Adaptation Scale questionnaire, which revealed high levels of mental health problems among parents [16].

Stress and anxiety among parents and caregivers can also have negative effects on children, potentially leading to a lack of support from mothers. Confusion in parental behavior, particularly from mothers, can be harmful to their children [17]. Furthermore, research has indicated that changes in a mother's psychological functioning, such as increased stress and anxiety, can influence her perception of her child's sleep problems [18]. Despite numerous studies highlighting the association between parental stress and sleep quality in children with NMDs, comprehensive research specifically focusing on a large cohort of patients with SMA remains limited. Globally, existing studies have primarily concentrated on genetic, laboratory, and epidemiological aspects with small sample sizes and a restricted focus on a few NMDs [6,12,19].

This study aimed to bridge this knowledge gap by examining various aspects of sleep in Iranian children with NMDs, with a particular emphasis on SMA. Using child-specific sleep assessment tools, this study sought to identify the correlation between sleep disturbances and parental stress in this population. The findings of this study can increase our understanding of the sleep experiences of children with NMDs and their parents' stress levels. Eventually, these findings can be used to formulate approaches that enhance the well-being of such children and minimize emotional strain on parents in various cultural environments.

Methods

Study Design and Participants

This descriptive analytical study was conducted as part of a larger study in selected hospitals in Tehran and Isfahan, as well as the dystrophy association of these centers, from February to October 2023, in Iran. The study included a sample of 207 children diagnosed with a NMD, with inclusion criteria of having any muscular dystrophy with an unknown cause and being between preschool and school age (1 to 14 years old). The exclusion criterion was an incomplete questionnaire.

Data Collection

A cross-sectional web-based survey was conducted using the SurveyHeart platform [20] to collect data from caregivers of children with NMDs. Participants were recruited through convenience sampling at selected hospitals and centers in Tehran and Isfahan, Iran. To optimize participation, caregivers were informed about the aims of the study and the significance of sleep for children with NMDs. Data were gathered using a 3-part web-based questionnaire. The initial section captured the demographic information using closed-ended questions. Subsequently, children's sleep habits and parental stress levels were assessed using the Children's Sleep Habits Questionnaire (CSHQ) and the Stress Response Inventory (SRI), respectively, and both used Likert scale items.

Web-Based Questionnaire

Demographic Characteristics

The demographic data examined in this study included the child's sex and age, number and length of hospitalizations, use of specific medications for treatment, parents' educational levels, parents' job, recruitment organization (military or civilian), and number of children in the family.

Children's Sleep Habits Assessment

The CSHQ, which was reviewed and designed by Owens et al [21], was created to assess the sleep habits of 623 preschool- and school-aged children. They showed that the CSHQ was an effective tool for evaluating sleep quality in children. The questionnaire consisted of 35 statements rated on a 3-choice Likert scale across 8 categories: sleep resistance, sleep anxiety, parasomnia, breathing disorders during sleep, waking up at night, sleepiness during the day, sleep duration, and sleep onset delay. Statements 1, 2, 9, 10, and 28 were scored in reverse order. The total score ranged from 33 to 99, with a higher score indicating poorer sleep quality (score ≥41) [21]. In a previous study, the homogeneity of the questionnaire was determined to have a Cronbach α of 0.8 [22]. The validity of the children's sleep habits questionnaire was assessed based on content validity, and its internal consistency has been found to be 0.82 [15]. In another study, the Cronbach α was 0.816 [23].

Parental Stress Assessment

To assess parental stress levels, the SRI scale developed by Koh et al [24] was used. This questionnaire was designed to explore the emotional, physical, cognitive, and behavioral aspects of stress responses. It was a self-reported measure, requiring participants to indicate the extent to which they experience each symptom on a 5-point Likert scale ranging from “not at all” (0 points) to “completely” (4 points). The stress response questionnaire consisted of 39 items and 7 subscales: tension (6 items), aggression (4 items), somatization (3 items), anger (6 items), depression (8 items), fatigue (5 items), and frustration (7 items). The following points were assigned to calculate the score for each tension subscale: 16 for aggression, 12 for somatization, 24 for anger, 32 for depression, 20 for fatigue, and 28 for frustration. The minimum and maximum scores were 0 and 156, respectively. The reliability of the SRI tool was examined, resulting in a Cronbach α of 0.97, with a 3-week interval between assessments [24]. The validity of the Persian version of the SRI tool in Iran was confirmed, with an α coefficient of 0.963. Validity was further assessed through factor analysis using the principal parts method and Varimax rotation [25]. In the present study, the Cronbach α for this tool was 0.941.

Ethical Considerations

This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. The study protocol was approved by the Ethics Committee of the Baqiyatullah University of Medical Sciences (code IR. BMSU. BAQ. REC.1401.129). Written informed consent was obtained from the guardian or legal guardian of each child participant. Participants (or their legal representatives) had the right to withdraw from the study at any time without any consequences. All data collected during this study was anonymized to ensure participant privacy.

Statistical Analysis

For statistical analyses, mean tests with SDs and nonparametric tests (Spearman, Kendall τb, and Kruskal-Wallis) were used to measure qualitative and quantitative variables and determine their relationship with the types of dystrophy, respectively. All analyses were considered statistically significant at an α level of .05. The statistical data were analyzed using SPSS version 22 (IBM Corp).

Results

Demographic Characteristics

This study aimed to investigate the demographic and clinical characteristics of children with NMDs. Of the 207 children enrolled, 50 (24.2%) had SMA type 1, 95 (45.9%) had SMA type 2, 54 (26.1%) had SMA type 3, and only 8 (3.9%) had other NMDs. Specifically, 4 children had Duchenne muscular dystrophy and 4 children had Becker muscular dystrophy. Regarding sex, 114 participants (55.1%) were boys and 93 (44.9%) were girls. Those with SMA type 1 included 20 boys (9.7%) and 30 girls (14.5%). The children with SMA type 2 group included 50 boys (24.2%) and 45 girls (21.7%), and those with SMA type 3 included 36 boys (17.4%) and 18 girls (8.7%). Additionally, for children with other NMDs, there were 8 boys (3.9%). The mean age of the children was 7.14 (SD 4.41) years. Additionally, out of 207 families, 49 (23.7%) were military, while 158 (76.3%) were civilians (Tables 1 and 2).

Furthermore, we examined the clinical characteristics of these children. Children with SMA type 1 had the longest average length of hospitilization and the highest average number of hospitalizations among the 4 groups. There were significant differences in both the length of stay and number of hospitalizations among the 4 NMD groups (*P*<.001). Conversely, no significant correlations were found between the other demographic variables and the different NMD groups, suggesting that the length of hospital stay varied significantly (Table 2). Additionally, this study assessed the use of specific medications to treat these children. Of the children enrolled in the study, 70% (35/50) with SMA type 1, 63% (60/95) with SMA type 2 (63%), 52% (28/54) with SMA type 3, and 50% (4/8) with other NMDs received disease-specific treatment.

Table . Demographic characteristics of the study participants (n=207).

Characteristics	SMA[a] type 1	SMA type 2	SMA type 3	Other NMD[b]	Total
NMD of the child, n (%)	50 (24.2)	95 (45.9)	54 (26.1)	8 (3.9)	207 (100)
Father's education, n (%)					
Less than a diploma	18 (8.7)	16 (7.7)	19 (9.2)	0 (0)	53 (25.6)
Diploma	16 (7.7)	31 (15)	17 (8.2)	6 (2.9)	70 (33.8)
Bachelor's degree	12 (5.8)	26 (12.6)	13 (6.3)	2 (1)	53 (25.6)
Graduate	4 (1.9)	18 (8.7)	5 (2.4)	0 (0)	27 (13)
No answer	0 (0)	4 (1.9)	0 (0)	0 (0)	4 (1.9)
Mother's education, n (%)					
Less than a diploma	12 (5.8)	24 (11.6)	22 (10.6)	0 (0)	58 (28)
Diploma	26 (12.6)	33 (15.9)	24 (11.6)	2 (1)	85 (41.1)
Bachelor's degree	10 (4.8)	29 (14)	8 (3.9)	4 (1.9)	51 (24.6)
Graduate	2 (1)	9 (4.3)	0 (0)	2 (1)	13 (6.3)
Father's job, n (%)					
Recruitment	14 (6.8)	30 (14.5)	24 (11.6)	4 (1.9)	72 (34.8)
Part-time	21 (10.1)	38 (18.4)	14 (6.8)	4 (1.9)	77 (37.2)
Home	0 (0)	2 (1)	0 (0)	0 (0)	2 (1)
Unemployed	13 (6.3)	10 (4.8)	15 (7.2)	0 (0)	38 (18.4)
Vacation	2 (1)	15 (7.2)	1 (0.5)	0 (0)	18 (8.7)
Mother's job, n (%)					
Recruitment	2 (1)	20 (9.7)	5 (2.4)	2 (1)	29 (14)
Part-time	0 (0)	10 (4.8)	2 (1)	0 (0)	12 (5.8)
Home	44 (21.2)	57 (27.5)	43 (20.8)	6 (2.9)	150 (72.5)
Unemployed	2 (1)	0 (0)	0 (0)	0 (0)	2 (1)
Vacation	2 (1)	6 (2.9)	4 (1.9)	0 (0)	12 (5.8)
Recruitment organization, n (%)					
Military	11 (5.3)	23 (11.1)	13 (6.3)	2 (1)	49 (23.7)
Civilian	39 (18.8)	71 (34.3)	41 (19.8)	6 (2.9)	158 (75.8)
Number of children in the family, n (%)					
1	17 (8.2)	44 (21.2)	17 (8.2)	4 (1.9)	82 (39.6)
2	21 (10.1)	34 (16.4)	22 (10.6)	4 (1.9)	81 (39.1)
3	12 (5.8)	15 (7.2)	13 (6.3)	0 (0)	40 (19.3)
4	0 (0)	2 (1)	2 (1)	0 (0)	4 (1.9)

[a] SMA: spinal muscular atrophy.

[b] NMD: neuromuscular disorder.

Table . Demographic characteristics of the study participants.

Variable	SMA[a] type 1, mean (SD)	SMA type 2, mean (SD)	SMA type 3, mean (SD)	Other NMD[b], mean (SD)	*P* value[c]
Sleep score[d]	74.76 (7.48)	76.40 (7.29)	72.88 (6.73)	75.87 (5.74)	.03
Parental stress score[e]	94.72 (28.83)	98.81 (30.76)	94.89 (33.69)	91.25 (45.03)	.78
Length of stay (days)	1.76 (0.71)	1.03 (0.19)	1.58 (0.69)	1 (0.00)	<.001
Number of hospitalizations	2.16 (0.87)	1.55 (0.83)	2.09 (0.87)	1 (0.00)	<.001
Age of the child (years)	4.32 (3.65)	9.75 (4.86)	6.25 (4.62)	8.25 (4.62)	.02

[a] SMA: spinal muscular atrophy.

[b] NMD: neuromuscular disorder.

[c] Kruskal-Wallis test.

[d] Total sleep score: mean 74.37, SD 7.14.

[e] Total stress score: mean 95.73, SD 32.12.

Sleep Habits of Children

The mean sleep score for each group was 74.76 (SD 7.48) for SMA type 1, 76.4 (SD 7.29) for SMA type 2, 72.88 (SD 6.73) for SMA type 3, and 75.87 (SD 5.74) for other NMDs. There was a statistically significant difference in the sleep scores among the 4 groups (*P*=.02). This indicated that at least 1 group had a significantly different mean sleep score than the other groups (Table 2). Pediatric sleep was influenced by various demographic variables, some of which had significant correlations while others did not. A significant positive correlation was observed between sleep score and the length of hospital stay (*r*=0.234, *P*<.001), suggesting that longer hospital stays were associated with a decrease in the quality of pediatric sleep. Furthermore, a significant negative correlation was found between sleep and sex (*r*=−0.140, *P*=.04), suggesting that sex differences affected pediatric sleep patterns. However, the correlations between sleep and NMD (*r*=0.121, *P*=.08) and the father's education (*r*=−0.119, *P*=.08) were weak and nonsignificant. Similarly, the correlation between sleep and the number of children (*r*=.025, *P*=.72) was very weak and nonsignificant, indicating little to no association (Table 3).

Table . Correlation analysis between pediatric sleep, parental stress, and demographic variables.

Variable	NMD[a]	Length of stay	Parental stress	Father education	Sex	Child number
Pediatric sleep						
r[b]	0.121	0.234	0.454	–0.119	–0.140	0.025
P value	.08	<.001	.53	.08	.04	.72
Parental stress						
r	0.231	–0.049	—	–0.061	–0.017	0.032
P value	.46	.48	—	.38	.80	.65

[a] NMD: neuromuscular disorder.

[b] Spearman rank correlation coefficient.

Parental Stress

The parents of children with SMA type 2 reported the highest mean stress score of 98.81 (SD 30.76), followed by the parents of children with SMA type 3 (mean 94.89, SD 33.69), SMA type 1 (mean 94.72, SD 28.83), and other NMDs (mean 91.25, SD 45.03). There was not a statistically significant difference in parental stress scores among the 4 groups (*P*=.78). This suggests that parental stress levels were similar across the different NMD groups (Table 2). No significant correlations were found between parental stress and the demographic variables examined (Table 3).

Discussion

Principal Findings

This study found that children with NMDs, especially those with SMA, had significantly lower sleep quality according to the CSHQ. Frequent sleep disturbances in children with NMDs can significantly increase the overall disease burden for patients and their caregivers [26]. As a result, parents of children with NMDs can experience high levels of stress. However, sleep disorders in people with NMDs, especially in children with SMA, have not been well studied. Therefore, it is necessary to evaluate sleep in patients with NMDs [27,28]. Our study is the first to examine a large group of children with NMDs, particularly SMA, in Iran. One notable difference between our study and others [29-33] was the number of patients with SMA. In this study, we assessed the sleep of 199 children with SMA using the CSHQ. The results of our study, demonstrating reduced sleep quality in children with SMA, align with those of Chiang et al [33], who reported significantly lower mean sleep scores in this population compared to healthy controls [34]. These findings are consistent with those of a study on children with SMA type 1 [35], a study of 85 children with SMA type 1 and 2 in Italy [29], a study on 31 children with SMA type 1, 2, and 3 [30], and a study on children with myotonic dystrophy [36].

Furthermore, the results of our study showed that the mean score of sleep disorders in children with SMA type 2 was higher than that of other types of NMDs, although there was not a statistically significant relationship between individual and family factors. However, in contrast to the study by Pera et al [29], sleep disorders were reported more frequently in children with SMA type 2 compared to other children. Additionally, Chacko et al [30] reported fewer sleep disorders in children with SMA type 3. This discrepancy may be attributed to sample size, as the studies done by Chacko et al [30] and Pera et al [29] included only 9 and 13 children with SMA type 3, respectively. Another difference between our study and the aforementioned studies was the use of a sleep assessment tool. Chacko et al [30] used polysomnography, whereas Pera et al [29] used the Sleep Disturbance Scale for Children. However, further research and evaluation are necessary to gain a better understanding of the sleep disorders in children with NMDs.

Sleep problems are common in childhood and adolescence and are related to various factors, such as learning, memory, and emotional and behavioral problems [37-39]. This study aimed to investigate the individual and family factors that influence children’s sleep. The study examined the child’s age, the number and duration of hospitalizations, the parents’ education and occupation, their employing organization, and the number of children in the family. In this study, no significant relationship was found between parents’ education and their children’s sleep. However, a study on children with NMDs found that higher levels of parental education and income were associated with a reduced care burden for parents. This, in turn, led to improved sleep quality and a better overall quality of life for their children [40]. Furthermore, a study conducted on healthy children showed that children whose parents had a university education were more prone to experiencing sleep issues than children whose parents did not graduate from high school [41].

The child’s age was taken into consideration when studying childcare outcomes. This is because as a child with a NMD ages, parents’ caregiving responsibilities become more challenging due to the progression of the disease. For example, a study conducted in Brazil examined 31 caregivers of children with Duchenne and found that older boys were more likely to be better understood by their caregivers in terms of their needs and care [42].

Another result of this study was the difference among various groups of patients with NMDs in terms of sleep examination, age, duration, and number of hospitalizations. The results of Chacko et al [30] also corroborate our findings in a sleep study of children with SMA types 1, 2, and 3. They demonstrated that sleep quality was lower in children with SMA type 1 than those with SMA type 2 and SMA type 3 [30]. The length of stay and number of hospitalizations varied among children with different types of SMA and NMDs in general. The findings of Lin et al [43] also support the results of this study. In terms of hospitalization, Chan et al [44] revealed that patients with SMA type 1 had more than 10 visits per year, patients with SMA type 2 had 8 - 23 visits, and patients with SMA type 3 had 12 - 28 visits annually. Regarding hospital stays, the average stay length for patients with SMA type 2 was longer than patients with SMA type 3 but shorter than patients with SMA type 1. The results from Chan et al [44] also confirmed the difference in the duration and number of hospitalizations among these children. Additionally, there was a significant relationship between the duration of hospitalization and sleep in children. When children are hospitalized, they tend to sleep less and have lower quality sleep [42]. A study also found that children admitted to general pediatric and intensive care units slept an average of 2 hours less than they did at home before hospitalization, according to their parents’ reports [42]. It is important to note that admitting a child to a hospital is a stressful experience that can increase parental anxiety.

Parents of a child with a chronic disease often experience significant stress that impacts various aspects of their lives [45]. This study aimed to investigate the stress levels of parents of children NMDs by using 7 subscales: tension, aggression, somatization, anger, depression, fatigue, and frustration. The results indicated that parents of children with NMDs experience varying levels of stress, with parents of children with SMA type 2 experiencing higher levels. This aligns with a study that found no significant difference in stress levels among parents of children with NMDs such as Williams syndrome, Down syndrome, and autism spectrum disorder [46]. This study also stated that the similarity in parental stress levels across different NMD groups suggests that the specific type of disorder may not be the main cause of stress [46]. Additionally, a study reported that parents of children with NMDs experienced high levels of stress, with no significant difference between mothers and fathers [47]. Another study examined emotional distress symptoms among mothers of sons with Duchenne and Becker muscular dystrophy, comparing them to a control group of women matched for sex and age. The study found that these mothers reported a lower quality of life and more emotional distress, depression, stress, and clinical anxiety symptoms compared to the women in the control group [48]. Given the consistent reports of higher stress levels among parents of children with NMD, it is crucial to focus on implementing adaptive strategies for families and parents. Screening and intervention measures for families of children with NMDs are essential steps to support these families. NMD associations that provide assistance to these patients should consider implementing measures to screen and support parents of these families. It would also be beneficial to identify centers that offer mental health services and refer families based on their health insurance coverage.

In addition, we expected to observe a significant correlation between children’s sleep and parents’ stress levels. However, this relationship was not statistically significant, despite several studies indicating a connection between children's sleep and parents' stress [18,49,50]. Perhaps this difference can be attributed to the numerous and diverse factors that impact the sleep of children with NMDs and the stress experienced by their parents. Additionally, the intermittent nature of medication administration, frequently resulting from drug supply constraints, can further compromise the sleep quality in this patient population.

Another study aimed to assess the level of stress experienced by parents of children who were hospitalized. The study included 352 parents whose children were hospitalized, and it was found that these parents generally experienced mild-to-moderate levels of stress. Interestingly, the study also revealed that parents who reported lower stress levels tended to feel more satisfied. This study identified several factors that predicted higher levels of stress among parents. These factors included having a low level of education, having a child hospitalized for more than 14 days, and having a child who had visited the hospital frequently in the past [51]. These findings can be generalized to other children with neurodevelopmental disorders because parents of such children often experience higher levels of stress, due to the frequent hospitalizations that their children require. As the duration of their child's hospitalization increases, parents are more likely to report higher levels of stress.

This study, along with others that emphasize sleep disturbances in children with NMDs and the stress experienced by their parents, highlight the urgent need for comprehensive interventions. In this context, studies by Bedi et al [52] and Mellies et al [53] demonstrated that noninvasive ventilation normalizes nocturnal gas exchange and improves diurnal gas exchange, respiratory disturbance index, arousals from sleep, nocturnal heart rate, sleep architecture, and overall quality of life in children with NMDs by reducing symptoms and enhancing daily functioning. However, adherence to noninvasive ventilation, especially in rapid eye movement–related SDB, remains unclear. For instance, nocturnal bilevel positive airway pressure treatment has been shown to help individuals with limb-girdle muscular dystrophies return to their usual daily activities [54]. In addition to noninvasive ventilation, other interventions such as pharmacological treatments, behavioral strategies, and sleep health literacy are also important [55-57]. Implementing these interventions can be challenging; however, they are crucial for improving sleep quality and overall health. It is essential to understand which patients are at a higher risk of developing sleep dysfunction and should be actively monitored. Moreover, more rigorously designed studies are needed to evaluate the long-term benefits and cost-effectiveness of various sleep interventions for children with NMD.

Limitations

One limitation of this study was its methodology. The findings reported here were correlational, not causal, and they do not imply causality. Data were collected using self-reported web-based questionnaires. The extensive sample size necessitated the use of this method; however, it limited control over response conditions, thereby introducing potential biases and reducing the reliability of the findings. Our current methodology does not thoroughly evaluate various factors, such as environmental, psychological, physiological, and social influences on sleep quality. Future research should employ a multidimensional approach, incorporating objective sleep measurements and detailed clinical evaluations to gain a more comprehensive understanding of the sleep disorders in this population.

Conclusions

The results of our study indicate that sleep disorders, particularly SMA, are common in children with NMD. Furthermore, our examination of parental stress levels revealed a high level of stress among these parents, which can affect the quality of care for their children. Therefore, interventions should be implemented to improve the sleep of these children. Additionally, due to the high level of stress experienced by parents, it is necessary to implement measures for screening, identification, and referral for counseling. These families should be regularly evaluated and supported, and interventions should be tailored based on the intensity of their stress.

Acknowledgments

Thanks to the guidance and advice from the Clinical Research Development Unit of Baqiyatallah Hospital. The authors would like to express their gratitude to all the parents and children who participated in this study. We appreciate your contribution. All authors declared that they had insufficient funding to support open access publication of this manuscript, including from affiliated organizations or institutions, funding agencies, or other organizations. JMIR Publications provided article processing fee support for the publication of this article.

During the preparation of this work, the authors used Gemini (Google AI) for translation and style correction to enhance grammar and clarity. They carefully reviewed and edited all content to ensure accuracy and coherence. The authors hold the final responsibility for the content.

Conflicts of Interest

None declared.

References

1. Mary P, Servais L, Vialle R. Neuromuscular diseases: diagnosis and management. Orthop Traumatol Surg Res 2018 Feb;104(1S):S89-S95. [doi: 10.1016/j.otsr.2017.04.019] [Medline: 29196274]
2. Obradović D. “Neuromuscular Disorders” Noninvasive Mechanical Ventilation and Neuropsychiatric Disorders: Essential Practical Approaches: Springer; 2023:167-172. [doi: 10.1007/978-3-031-27968-3]
3. Michel C, Collins C. Pediatric neuromuscular disorders. Pediatr Clin North Am 2020 Feb;67(1):45-57. [doi: 10.1016/j.pcl.2019.09.002] [Medline: 31779836]
4. Rathore G, Kang PB. Pediatric neuromuscular diseases. Pediatr Neurol 2023 Dec;149:1-14. [doi: 10.1016/j.pediatrneurol.2023.08.034] [Medline: 37757659]
5. Sanmaneechai O, Thongsing A, Likasitwattanakula S, Netsuwan T. Pediatric neuromuscular diseases prevalence in Siriraj Hospital, Thailand’s largest tertiary referral hospital. SMJ 2020;72(2):125-131. [doi: 10.33192/Smj.2020.17]
6. Tehrani KHN, Hajiloo M, Asadollahi E, Lagini FP. Prevalence of muscular dystrophy in patients with muscular disorders in Tehran, Iran. Eur J Transl Myol 2018 Apr 24;28(2):7380. [doi: 10.4081/ejtm.2018.7385] [Medline: 29991987]
7. Voulgaris A, Antoniadou M, Agrafiotis M, Steiropoulos P. Respiratory involvement in patients with neuromuscular diseases: a narrative review. Pulm Med 2019;2019:2734054. [doi: 10.1155/2019/2734054] [Medline: 31949952]
8. Rose L, McKim D, Leasa D, et al. Respiratory health service utilization of children with neuromuscular disease. Pediatr Pulmonol 2018 Oct;53(10):1378-1386. [doi: 10.1002/ppul.24145] [Medline: 30129703]
9. Fauroux B, Griffon L, Amaddeo A, et al. Respiratory management of children with spinal muscular atrophy (SMA). Arch Pediatr 2020 Dec;27(7S):7S29-7S34. [doi: 10.1016/S0929-693X(20)30274-8] [Medline: 33357594]
10. Qin Y, Yan-Min B, Xin-Guo L, et al. Clinical features of sleep-disordered breathing in children with neuromuscular disease. Chin J Contemp Pediatr 2021;23(2). [doi: 10.7499/j.issn.1008-8830.2011030]
11. Gipson K, Lu M, Kinane TB. Sleep-disordered breathing in children. Pediatr Rev 2019 Jan;40(1):3-13. [doi: 10.1542/pir.2018-0142] [Medline: 30600274]
12. Chidambaram AG, Jhawar S, McDonald CM, Nandalike K. Sleep disordered breathing in children with neuromuscular disease. Children (Basel) 2023 Oct 11;10(10):1675. [doi: 10.3390/children10101675] [Medline: 37892338]
13. El-baroudy N, El Falaki M, Afify O, et al. Assessment of respiratory function and sleep disorders in children with myopathy. Sri Lanka J Child Health 2021;50(2):215. [doi: 10.4038/sljch.v50i2.9558]
14. Rosen CL. Sleep-disordered breathing (SDB) in pediatric populations. In: Essentials of Sleep Medicine: A Practical Approach to Patients with Sleep Complaints: Springer; 2022:215-250. [doi: 10.1007/978-3-030-93739-3]
15. Ozgoli G, Sheikhan Z, Soleimani F, et al. A study of effectivefactors on sleep disorders in 4-6years old children in Tehran city, Iran. Qom Univ Med Sci J 2015;9(5):50-60. [doi: 10.61186/psj.19.3.41]
16. Ortega J, Vázquez N, Flores C, Amayra I. Mental health and psychological adaptation on parents of children with neuromuscular diseases. Child Health Care 2022 Jan 2;51(1):62-78. [doi: 10.1080/02739615.2021.1961581]
17. Daneshvar Ameri Z, Taghavi Larijani T, Kazem Nejad A, et al. The effectiveness of partners’ learning method on anxiety and stress in mothers of children with cystic fibrosis. IJN 2017;30(108):23-32. [doi: 10.29252/ijn.30.108.23]
18. Khaksar S, Kalhor F. Maternal stress and sleep of hospitalized children: the effects of a using video call intervention to improve family-centered care. J Pediatr Nurs 2022;9(1):65-75. [doi: 10.22034/JPEN.9.1.65]
19. Savad S, Ashrafi MR, Samadaian N, et al. A comprehensive overview of SMN and NAIP copy numbers in Iranian SMA patients. Sci Rep 2023 Feb 24;13(1):3202. [doi: 10.1038/s41598-023-30449-7] [Medline: 36828874]
20. SurveyHeart. URL: https://surveyheart.com/ [accessed 2025-01-03]
21. Owens JA, Spirito A, McGuinn M. The Children’s Sleep Habits Questionnaire (CSHQ): psychometric properties of a survey instrument for school-aged children. Sleep 2000 Dec 15;23(8):1043-1051. [Medline: 11145319]
22. Wang G, Xu G, Liu Z, Lu N, Ma R, Zhang E. Sleep patterns and sleep disturbances among Chinese school-aged children: prevalence and associated factors. Sleep Med 2013 Jan;14(1):45-52. [doi: 10.1016/j.sleep.2012.09.022] [Medline: 23218539]
23. Ahmed MM, Younis NM, Abdulsalam RR. Assessment of changes in sleep habits in elementary students during covid_19 lockdown. Int J Med Toxicol Leg Med 2022 Jan;25(1and2):76-80. [doi: 10.5958/0974-4614.2022.00018.3]
24. Koh KB, Park JK, Kim CH, Cho S. Development of the stress response inventory and its application in clinical practice. Psychosom Med 2001;63(4):668-678. [doi: 10.1097/00006842-200107000-00020] [Medline: 11485121]
25. Khaksar S, Maroufi M, Kalhor F. Reducing maternal stress in pediatric hospitalization during the COVID-19 pandemic by improving family-centered care with bedside telehealth: a pilot randomized clinical trial. Iran J Psychiatry 2022 Oct;17(4):361-368. [doi: 10.18502/ijps.v17i4.10684] [Medline: 36817806]
26. Boentert MJC, Neuroscience T. Sleep disorders in neuromuscular diseases: a narrative review. Clin Transl Neurosci 2023;7(3):23. [doi: 10.3390/ctn7030023]
27. Albdewi MA, Liistro G, El Tahry R. Sleep-disordered breathing in patients with neuromuscular disease. Sleep Breath 2018 May;22(2):277-286. [doi: 10.1007/s11325-017-1538-x] [Medline: 28702830]
28. Arens R, Muzumdar H. Sleep, sleep disordered breathing, and nocturnal hypoventilation in children with neuromuscular diseases. Paediatr Respir Rev 2010 Mar;11(1):24-30. [doi: 10.1016/j.prrv.2009.10.003] [Medline: 20113988]
29. Pera MC, Romeo DM, Graziano A, et al. Sleep disorders in spinal muscular atrophy. Sleep Med 2017 Feb;30:160-163. [doi: 10.1016/j.sleep.2016.11.012] [Medline: 28215241]

30. Chacko A, Sly PD, Gauld L. Polysomnography findings in pediatric spinal muscular atrophy types 1-3. Sleep Med 2020 Apr;68:124-130. [doi: 10.1016/j.sleep.2019.12.004] [Medline: 32035302]
31. Verrillo E, Pavone M, Bruni O, et al. Sleep architecture in children with spinal muscular atrophy type 2. Sleep Med 2016 Apr;20:1-4. [doi: 10.1016/j.sleep.2015.12.015] [Medline: 27318218]
32. Bertrán K, Sans Capdevila O, Nascimiento A, Ortez C, Natera D, Iranzo de Riquer A. Sleep breathing disorders in pediatric patients with spinal muscular atrophy 2. Sleep Med 2022 Jan;89:85-89. [doi: 10.1016/j.sleep.2021.11.006] [Medline: 34923450]
33. Chiang J, Xiao L, Nigro E, et al. Sleep disordered breathing in infants identified through newborn screening with spinal muscular atrophy. Sleep Med 2023 Nov;111:161-169. [doi: 10.1016/j.sleep.2023.09.019] [Medline: 37778092]
34. Bonuck KA, Goodlin-Jones BL, Schechter C, Owens J. Modified Children’s Sleep Habits Questionnaire for behavioral sleep problems: a validation study. Sleep Health 2017 Jun;3(3):136-141. [doi: 10.1016/j.sleh.2017.03.009] [Medline: 28526249]
35. Ryan MM. The use of invasive ventilation is appropriate in children with genetically proven spinal muscular atrophy type 1: the motion against. Paediatr Respir Rev 2008 Mar;9(1):51-54. [doi: 10.1016/j.prrv.2007.10.002] [Medline: 18280980]
36. Romigi A, Franco V, Placidi F, et al. Comparative sleep disturbances in myotonic dystrophy types 1 and 2. Curr Neurol Neurosci Rep 2018 Oct 31;18(12):102. [doi: 10.1007/s11910-018-0903-x] [Medline: 30382420]
37. Lewien C, Genuneit J, Meigen C, Kiess W, Poulain T. Sleep-related difficulties in healthy children and adolescents. BMC Pediatr 2021 Feb 16;21(1):82. [doi: 10.1186/s12887-021-02529-y] [Medline: 33593333]
38. Cortese S, Wang F, Angriman M, Masi G, Bruni O. Sleep disorders in children and adolescents with autism spectrum disorder: diagnosis, epidemiology, and management. CNS Drugs 2020 Apr;34(4):415-423. [doi: 10.1007/s40263-020-00710-y] [Medline: 32112261]
39. Chen X, Ke ZL, Chen Y, Lin X. The prevalence of sleep problems among children in mainland China: a meta-analysis and systemic-analysis. Sleep Med 2021 Jul;83:248-255. [doi: 10.1016/j.sleep.2021.04.014] [Medline: 34049044]
40. Travlos V, Patman S, Downs J, Hince D, Wilson AC. Parent carer quality of life and night-time attendance in non-ambulant youth with neuromuscular disorders. Dev Neurorehabil 2021 Oct;24(7):456-465. [doi: 10.1080/17518423.2021.1908440] [Medline: 33944675]
41. Assari S. Parental education and children’s sleep problems: minorities’ diminished returns. Int J Epidemiol Res 2021 Mar 30;8(1):31-39. [doi: 10.34172/ijer.2021.06]
42. Stremler R, Micsinszki S, Adams S, Parshuram C, Pullenayegum E, Weiss SK. Objective sleep characteristics and factors associated with sleep duration and waking during pediatric hospitalization. JAMA Netw Open 2021 Apr 1;4(4):e213924. [doi: 10.1001/jamanetworkopen.2021.3924] [Medline: 33792731]
43. Lin CW, Kalb SJ, Yeh WS. Delay in diagnosis of spinal muscular atrophy: a systematic literature review. Pediatr Neurol 2015 Oct;53(4):293-300. [doi: 10.1016/j.pediatrneurol.2015.06.002] [Medline: 26260993]
44. Chan SHS, Wong CKH, Wu T, et al. Significant healthcare burden and life cost of spinal muscular atrophy: real-world data. Eur J Health Econ 2023 Nov;24(8):1373-1382. [doi: 10.1007/s10198-022-01548-5] [Medline: 36403177]
45. Cohn LN, Pechlivanoglou P, Lee Y, et al. Health outcomes of parents of children with chronic illness: a systematic review and meta-analysis. J Pediatr 2020 Mar;218:166-177. [doi: 10.1016/j.jpeds.2019.10.068] [Medline: 31916997]
46. Ashworth M, Palikara O, Van Herwegen J. Comparing parental stress of children with neurodevelopmental disorders: the case of Williams syndrome, Down syndrome and autism spectrum disorders. Res Intellect Disabil 2019 Sep;32(5):1047-1057. [doi: 10.1111/jar.12594]
47. Mah JK, Thannhauser JE, Kolski H, Dewey D. Parental stress and quality of life in children with neuromuscular disease. Pediatr Neurol 2008 Aug;39(2):102-107. [doi: 10.1016/j.pediatrneurol.2008.04.011] [Medline: 18639753]
48. Jackson JL, Korth CX, Leslie CE, et al. Health-related quality of life and emotional distress among mothers of sons with muscular dystrophy as compared to sex- and age group-matched controls. J Child Neurol 2021 Mar;36(3):177-185. [doi: 10.1177/0883073820962927] [Medline: 33034535]
49. McQuillan ME, Bates JE, Staples AD, Deater-Deckard K. Maternal stress, sleep, and parenting. J Fam Psychol 2019 Apr;33(3):349-359. [doi: 10.1037/fam0000516] [Medline: 30762410]
50. Martin CA, Papadopoulos N, Chellew T, Rinehart NJ, Sciberras E. Associations between parenting stress, parent mental health and child sleep problems for children with ADHD and ASD: systematic review. Res Dev Disabil 2019 Oct;93:103463. [doi: 10.1016/j.ridd.2019.103463] [Medline: 31446370]
51. Tsironi S, Koulierakis G. Factors associated with parents’ levels of stress in pediatric wards. J Child Health Care 2018 Jun;22(2):175-185. [doi: 10.1177/1367493517749327] [Medline: 29277106]
52. Bedi P, Hasbun G, Castro-Codesal M. 570 comparing NIV adherence in early versus advanced stage sleep disordered breathing for children with neuromuscular disease. Sleep 2021 May 3;44:A225-A225. [doi: 10.1093/sleep/zsab072.568]
53. Mellies U, Ragette R, Dohna Schwake C, Boehm H, Voit T, Teschler H. Long-term noninvasive ventilation in children and adolescents with neuromuscular disorders. Eur Respir J 2003 Oct;22(4):631-636. [doi: 10.1183/09031936.03.00044303a] [Medline: 14582916]
54. Angelini CI, Ansevin C, Siciliano G. The role of sleep in neuromuscular disorders. Front Neurol 2023;14:1195302. [doi: 10.3389/fneur.2023.1195302] [Medline: 37456652]

55. Thetford J, Chang M, Eng K. 1156 “NIV Nap” to improve PAP acceptability and hypoventilation in neuromuscular disease. Sleep 2024 Apr 20;47(Supplement_1):A495-A495. [doi: 10.1093/sleep/zsae067.01156]
56. Sankri-Tarbichi AG. Respiratory and sleep disorders in chronic neuromuscular disease, an update and therapeutic approach. Clin Res Pulm 2013 Aug. [doi: 10.47739/2333-6625/1007]
57. Yoshizaki A, Mohri I, Yamamoto T, et al. An interactive smartphone app, Nenne Navi, for improving children’s sleep: pilot usability study. JMIR Pediatr Parent 2020 Dec 1;3(2):e22102. [doi: 10.2196/22102] [Medline: 33122163]

Abbreviations

CSHQ: Children’s Sleep Habits Questionnaire
NMD: neuromuscular disorder
SDB: sleep-disordered breathing
SMA: spinal muscular atrophy
SRI: Stress Response Inventory

Edited by H Ahn; submitted 23.01.24; peer-reviewed by A Hassan, L Willem, M Tanriverdi; revised version received 21.09.24; accepted 23.09.24; published 28.01.25.

Please cite as:
Khaksar S, Jafari-Oori M, Sarhangi F, Moayed MS
Pediatric Sleep Quality and Parental Stress in Neuromuscular Disorders: Descriptive Analytical Study
Asian Pac Isl Nurs J 2025;9:e56667
URL: https://apinj.jmir.org/2025/1/e56667
doi:10.2196/56667

Original Paper

Disparities in Clinical and Experimental Pain Between Non-Hispanic White and Asian American Individuals With Knee Osteoarthritis and the Role of Pain Catastrophizing: Pilot Study in Florida

Chiyoung Lee[1,2], PhD, RN; C. Kent Kwoh[2,3], MD; Juyoung Park[1], PhD, MSW; Lindsey Park[1], BS; Hyochol Ahn[1], PhD, APRN, ANP-BC

[1]College of Nursing, University of Arizona, Tucson, AZ, United States
[2]The University of Arizona Arthritis Center, Tucson, AZ, United States
[3]Division of Rheumatology, College of Medicine, University of Arizona, Tucson, AZ, United States

Corresponding Author:
Chiyoung Lee, PhD, RN
College of Nursing
University of Arizona
1305 N Martin Avenue
Tucson, AZ, 85721
United States
Phone: 1 5206266154
Email: clee33@arizona.edu

Abstract

Background: Although a few studies have delineated the disparities in knee osteoarthritis (KOA) pain between non-Hispanic White and Asian American individuals, a significant research gap persists in elucidating the mechanisms underlying these differences.

Objective: This pilot study aims to examine psychological factors, specifically pain catastrophizing and negative affect, as potential explanatory mechanisms for these dissimilarities.

Methods: A cross-sectional design was used. Forty community-dwelling participants aged 50-70 years with self-reported KOA pain, including 20 non-Hispanic White and 20 Asian American individuals, were recruited in North Central Florida. Clinical KOA pain intensity was assessed using the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) and the 4 subscales of the Short-Form McGill Pain Questionnaire-2. Quantitative sensory testing was conducted to measure experimental sensitivity to heat- and mechanically induced pain, including heat pain, pressure pain threshold, and punctate mechanical pain, as well as inhibitory pain processes through conditioned pain modulation. Pain catastrophizing was evaluated using the Coping Strategies Questionnaire-Revised Pain Catastrophizing subscale, while negative affect was assessed using the Positive and Negative Affect Schedule. Bayesian mediation analyses were used to examine both direct and indirect effects (mediation) between variables.

Results: Asian American individuals exhibited higher pain catastrophizing scores than non-Hispanic White individuals. Pain catastrophizing, at high levels, contributed to WOMAC and Short-Form McGill Pain Questionnaire-2, which measured clinical pain. Race had no direct effects on these pain scores but exerted significant indirect effects via pain catastrophizing (WOMAC pain: 0.96, 95% CI 0.03-2.16; continuous pain: 0.84, 95% CI 0.18-1.70; intermittent pain: 0.78, 95% CI 0.03-1.71; neuropathic pain: 0.43, 95% CI 0.03-0.95; and affective pain: 1.05, 95% CI 0.24-1.99); thus, pain catastrophizing likely fully mediated the relationship between race and these pain measures. While Asian American individuals reported greater experimental pain sensitivity (heat pain, pressure pain threshold, and punctate mechanical pain) than non-Hispanic White individuals, these racial effects were not mediated by pain catastrophizing. Asian American individuals reported higher negative affect scores compared with non-Hispanic White individuals; however, negative affect did not mediate the relationship between race and any pain measures.

Conclusions: The results demonstrate the contribution of pain catastrophizing to clinical pain in Asian American individuals with KOA and identify it as a potential mechanism underlying group differences in KOA pain between non-Hispanic White and Asian American individuals. However, caution is warranted due to the exploratory nature of this study and the treatment of Asian

American individuals as a monolithic sample. Hence, future replication with larger and more diverse samples is necessary. Additionally, the lack of mediation effects of pain catastrophizing in the relationship between race and experimental pain suggests the need to explore other factors, such as biological, genetic, social, and environmental influences. Moreover, further research is essential to clarify the role of negative affect.

(Asian Pac Isl Nurs J 2025;9:e64415) doi:10.2196/64415

KEYWORDS

Asian American; non-Hispanic White; osteoarthritis; pain; pain catastrophizing

Introduction

Background

Symptomatic knee osteoarthritis (KOA), characterized by pain, disability, and diminished quality of life, is a prevalent joint disorder in middle-aged and older adults [1]. Traditional perspectives have primarily linked KOA pain to structural joint changes; however, the weak correlation between radiographic findings and clinical symptoms suggests that structural abnormalities alone do not comprehensively account for the pain experienced by sufferers [2-5]. This indicates that additional factors, including psychosocial influences, may significantly impact the severity and perception of OA-related pain [6].

The prevalence of symptomatic KOA is projected to increase in racially and ethnically marginalized groups [7]. Although significant disparities in clinical and experimental pain have been reported across racial and ethnic groups with KOA, relevant studies have predominantly compared non-Hispanic White with African American individuals [8]. Asian American individuals, a rapidly growing minority, have been underrepresented in pain research despite emerging evidence indicating that they experience greater KOA-related pain than non-Hispanic White individuals [9], challenging cultural stereotypes of stoicism. To date, no studies have delineated the mechanisms underlying the differences between non-Hispanic White and Asian American individuals.

The biopsychosocial model of pain recognizes the importance of various psychological factors in pain [10]. One such factor, pain catastrophizing—cognitive and affective pain appraisal characterized by the tendency to address and magnify the threat value of painful stimuli and feel helpless owing to pain—is reportedly significantly correlated with increased knee pain severity in both clinical and experimental settings [11-13]. Notably, Asian American individuals have been reported to exhibit higher levels of pain catastrophizing, possibly influenced by acculturative stress and cultural practices affecting pain perception and response [14]. The greater use of pain catastrophizing among racial and ethnic minorities can also be attributed to health disparities resulting from structural and systemic barriers to adequate pain treatment and biased health care interactions [15,16], possibly promoting negative perceptions regarding pain management and the belief that their pain cannot be controlled and is likely to worsen. Considering the association between higher levels of pain catastrophizing and increased KOA pain, pain catastrophizing plausibly mediates the racial disparities observed in KOA pain between non-Hispanic White and Asian American individuals.

In addition to specific pain-related factors, broader elements, such as depression and negative affect, influence knee pain experiences, and this prevails in situations involving clinical and experimentally induced pain [17-19]. Ahn et al [20] found higher levels of depression to occur in Asian American individuals with self-reported KOA pain compared with those in age- and sex-matched non-Hispanic White individuals, and such variations in depression evidently mediated racial group differences in clinical and experimental pain. Negative affect, a general predisposition to experiencing aversive mood states, has been associated with racial discrimination and psychological distress among Asian American individuals [21]. Daily microaggressions contribute to higher levels of mental health symptoms and negative affect among Asian American individuals [22-24] and specific Asian American groups [25]. To date, the role of negative affect in racial disparities in KOA pain between non-Hispanic White and Asian American individuals has not yet been investigated.

Objectives

This pilot study aims to investigate psychological factors, specifically pain catastrophizing and negative affect, as potential explanatory mechanisms underlying group differences in KOA pain between non-Hispanic White and Asian American individuals. Elucidating these mechanisms may inform the development of targeted interventions that improve KOA pain management in the understudied Asian American population and help address pain disparities across racial groups.

Methods

Study Participants

This cross-sectional analysis used baseline data from the randomized controlled trial registered at ClinicalTrials.gov (NCT02512393) to examine the efficacy of transcranial direct current stimulation on KOA pain. Detailed selection criteria and enrollment procedures have been documented previously [26]. In summary, at baseline, 40 participants with KOA pain (20 non-Hispanic White and 20 Asian American individuals) were recruited in North Central Florida between September 2015 and August 2016 through local advertisements. Participants were eligible if they were aged 50-70 years, had self-reported unilateral or bilateral KOA pain as per American College of Rheumatology criteria, could speak and read English, and were willing and able to provide written informed consent before enrollment. In our sample of Asian American individuals, detailed information on subgroup ethnicities, languages, cultural backgrounds, and demographic characteristics was not gathered during data collection and is therefore unavailable in this study.

Exclusion criteria ensured participants did not have concurrent medical conditions that could confound osteoarthritis-related outcomes or coexisting diseases that could impede protocol completion, including (1) prosthetic knee replacement or nonarthroscopic surgery on the affected knee; (2) serious medical illness, such as uncontrolled hypertension, heart failure, or recent history of acute myocardial infarction; (3) peripheral neuropathy; (4) systemic rheumatic disorders, such as rheumatoid arthritis, systemic lupus erythematosus, and fibromyalgia; (5) alcohol or substance abuse; (6) cognitive impairment (ie, Mini-Mental Status Examination score≤23); (7) history of brain surgery, tumor, seizure, stroke, or intracranial metal implantation; (8) pregnancy or lactation; and (9) hospitalization for psychiatric illness within the past year.

Measurement

The collected basic characteristics included age, sex, BMI (kg/m²), Kellgren-Lawrence radiographic grade, employment status, marital status, educational attainment, and household income.

Clinical KOA Pain

The Western Ontario and McMaster Universities Osteoarthritis Index Pain Subscale.

Average knee pain for the past 48 hours was measured by the pain subscale of the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC), which consisted of 5 items on a 0-4 Likert scale measuring the pain severity during walking, climbing stairs, sleeping, resting, and standing [27]. The participants' responses to each pain question were summed up to derive an aggregated score for pain intensity (range: 0-20). The subscales in WOMAC demonstrate reliability and validity in evaluating patients with KOA [28,29].

Short Form McGill Pain Questionnaire-2

The Short Form McGill Pain Questionnaire-2 (SF-MPQ-2) has been validated and widely used to assess the multidimensional qualities of pain [30]. It consists of 4 subscales, including continuous pain (6 items: throbbing pain, cramping pain, gnawing pain, aching pain, heavy pain, and tender), intermittent pain (6 items: shooting pain, stabbing pain, splitting pain, electric-shock pain, and piercing), neuropathic pain (6 items: hot-burning pain, cold-freezing pain, pain caused by light touch, itching, tingling or pins and needles, and numbness), and affective description of pain (4 items: tiring-exhausting, sickening, fearful, and punishing-cruel). Each subscale score was computed as the average of answered items, with higher scores indicating greater pain intensity.

Quantitative Sensory Testing

A multimodal Quantitative Sensory Testing (QST) battery was used to assess pain sensitivity using precisely controlled protocols that elicit pain with thermal and mechanical stimuli, as well as inhibitory pain processes. This includes heat pain (ie, threshold and tolerance), pressure pain threshold (PPT), punctate mechanical pain (PMP), and conditioned pain modulation (CPM). The sequence of heat and mechanical testing was randomized and counterbalanced, while CPM was always administered last to minimize any potential carryover effects. The same researcher performed QST on each participant throughout the study, and all participants were provided with standardized recorded instructions to prevent bias during data collection and to enhance the reliability of the results.

Thermal Testing Procedures

All thermal stimuli were delivered using a computer-controlled TSA-II NeuroSensory Analyzer (Medoc Ltd) to measure heat pain thresholds and heat pain tolerances on both the index knee and the ipsilateral ventral forearm using an ascending method of limits. At each body site, the thermode position was moved between trials to prevent sensitization or habituation of cutaneous receptors. Starting from a baseline of 32 °C, the thermode temperature increased at a rate of 0.5 °C per second until participants responded by pressing a button on a handheld device. Participants were instructed to press the button when heat first becomes painful to assess the heat pain threshold, and when they could no longer tolerate the heat pain to assess heat pain tolerance. Three trials of heat pain threshold were conducted at the first test site, followed by 3 trials of heat pain tolerance were conducted. Then, 3 trials each at the second test site were conducted, with a 5-minute rest period between sites. The average of the 3 trials was calculated for each individual, providing overall heat pain threshold and tolerance temperatures for analysis.

Mechanical Testing Procedures

Mechanical pain response was measured via 2 approaches. First, PPT was assessed by applying blunt mechanical pressure to deep tissues (ie, muscle and joint) via a handheld digital pressure algometer (Wagner). Increasing pressure was applied at a constant rate of 0.3 kgf/cm^2 per second to measure the PPT at 4 sites—the medial and lateral aspects of the index knee, ipsilateral quadriceps, and trapezius. The order of testing sites was counterbalanced and randomized. For assessing PPT, participants were instructed to inform the experimenter when the sensation "first becomes painful" occurred, and the pressure was recorded. The results of the 3 trials at each body site were averaged for each site, and then these PPTs at 4 sites were averaged to derive an overall measure of PPT. Second, PMP stimuli evaluated cutaneous mechanical sensitivity on both the index patella and the back of the ipsilateral hand. We used calibrated nylon monofilament that delivered a target force of 300 g to obtain verbal ratings of the pain intensity on a scale of 0 (no pain sensation) to 100 (the most intense pain sensation imaginable) following 10 contacts at the rate of 1 contact per second. An overall score for each site was computed by averaging across 2 trials.

Conditioned Pain Modulation

Ten minutes after assessing the thermal or mechanical pain, the CPM was evaluated. CPM reflects the endogenous pain inhibitory pathway (ie, descending pain inhibition) also known as the "pain inhibits pain" paradox [31]. CPM was assessed by determining the change in PPT on the trapezius, immediately following the immersion of the contralateral hand up to the wrist in the cold-water bath (12 °C) for 1 minute. The initial preimmersion PPT measurement was conducted just before placing the hand in the water. Thirty seconds after hand immersion, participants were asked to rate the cold pain intensity (0-100) from the immersed hand followed by the second PPT measurement, and were informed to keep their hand in the water bath for as long as tolerable up to 1 minute. After the removal of the hand, the final PPT measurement was taken. This temperature was chosen based on prior experience with middle-aged and older adults with KOA, where 12 °C was found to produce moderate yet tolerable pain for most participants. Water was continually circulated and maintained at a constant temperature by a refrigeration unit (Neslab). An increase in PPT following cold water immersion demonstrated pain inhibition.

Pain Catastrophizing

The Coping Strategies Questionnaire-Revised measures the use of strategies for coping with pain by assessing 6 domains—distraction, catastrophizing, ignoring pain sensations, distancing from pain, coping self-statements, and praying. Participants rate how often they use specific strategies on a 7-point Likert scale from 0=never to 6=always, with higher scores indicating greater usage for each domain. This study used the 6-item catastrophizing subscale, with scores calculated as the mean of the responses. The reliability and validity of the Coping Strategies Questionnaire-Revised subscales have previously been shown to be acceptable [32,33].

Negative Affect

The Positive and Negative Affect Schedule includes 20 items that evaluate the frequency of both pleasant and unpleasant emotions individuals experience [31]. The inventory is divided into 2 subscales, each with 10 items for positive and negative emotions. Negative affect is calculated from the sum of 10 items (afraid, ashamed, distressed, guilty, hostile, irritable, jittery, nervous, scared, and upset), rated on a 5-point scale from 1=very slightly or not at all to 5=extremely. A lower total negative score indicates less negative affect (range: 10-50). The Positive and Negative Affect Schedule has been validated and demonstrates reliability, with an α coefficient range of .84 to .87 for negative affect [34].

Statistical Analyses

Descriptive statistics were used to characterize the study participants. Chi-square or Fisher exact test for categorical variables and the 2-tailed *t* test for continuous variables were used to compare participant characteristics between the groups. Composite measures for QST were created by calculating *z* scores for the heat pain threshold and tolerance at the arm and knee; PPT at the medial and lateral aspects of the index knee, ipsilateral quadriceps, and trapezius; and PMP at the index patella and hand. The *z* scores for each pain measure were subsequently averaged across the body sites to yield overall heat pain threshold, heat pain tolerance, PPT, and PMP values for the analyses.

Separate path analytical models were estimated to assess the indirect effects (mediation) of ethnicity (coded 0 for non-Hispanic White and 1 for Asian American individuals) via pain catastrophizing or negative affect on each clinical and experimental pain measure. The path models facilitated the examination of both direct and indirect effects. Model fit, path coefficient estimates, and 95% highest posterior density CIs (“credibility” in Bayesian terms) for parameter estimates were generated using the Bayesian estimation method in Mplus (version 8.8; Muthén & Muthén). Bayesian estimation is advantageous in that it precludes the necessity of the normality assumption in the sampling distribution of estimates and potentially provides more accurate parameters in small-sample cases [35]. Model fit was evaluated using the criteria and methods recommended by Muthén and Asparouhov [36]. Where 95% CIs did not overlap with zero, the effect was considered significant.

Ethical Considerations

The institutional review board (IRB) of the University of Arizona (UA) considers investigators engaged in research if they (1) interact with participants for research purposes, (2) have access to identifying study information, (3) obtain informed consent from research participants, or (4) the UA directly receives part of federal funds for the study (ie, UA is the prime awardee). If none of the earlier are true, then the researchers would not need IRB approval. Thus, this secondary analysis of deidentified data from an existing randomized controlled trial does not need any IRB approval. The original study (NCT04016272) received appropriate ethical approval, and written informed consent was obtained.

Results

Table 1 presents the characteristics of the participants by race. The groups differed in terms of age (*P*=.001), BMI (*P*=.001), and Kellgren-Lawrence radiographic grade (*P*=.01). The mean age of non-Hispanic White individuals was 65.1 (SD 7.05) years, whereas the mean age of Asian American individuals was 54.8 (SD 7.36) years. The BMI for non-Hispanic White and Asian American individuals was 28.0 (SD 3.12) kg/m² and 25.0 kg/m² (SD 3.41) kg/m², respectively. Out of 20 Asian American individuals, most (n=11, 55%) were classified as grade 0. In contrast, grades 3 and 4 were predominant among non-Hispanic White individuals, with 7 out of 20 (35%) participants falling into these categories. Additionally, grade 2 was more common among non-Hispanic White individuals (8/20, 40%) compared with Asian American individuals (2/20, 10%). There were no significant differences between the groups in sex proportion, employment status, marital status, educational attainment, and household income.

Table 1. Basic characteristics of the participants (N=40)a.

Characteristic	Non-Hispanic White (n=20)	Asian American (n=20)	*P* value
Age (years), mean (SD)	65.1 (7.05)	54.8 (7.36)	*.001*
Sex, n (%)	8 (40)	13 (65)	.21
Male	12 (60)	7 (35)	
Female	8 (40)	13 (65)	
BMI (kg/m^2), mean (SD)	28.0 (3.12)	25.0 (3.41)	*.001*
Kellgren-Lawrence radiographic grade, n (%)			*.010* [b]
0	2 (10)	11 (55)	
1	3 (15)	5 (25)	
2	8 (40)	2 (10)	
3	6 (30)	2 (10)	
4	1 (5)	0 (0)	
Employment status, n (%)			.28
Yes	9 (47)	12 (71)	
No	10 (53)	5 (29)	
Marital status, n (%)			.13[b]
Married or partnered	13 (65)	18 (90)	
Nonmarried or unpartnered	7 (35)	2 (10)	
Educational attainment, n (%)			.50
2-year college degree or less	8 (40)	5 (25)	
4-year college degree of higher	12 (60)	15 (75)	
Household income (US $), n (%)			.52
More than 50,000	11 (58)	8 (42)	
50,000 or less	8 (42)	11 (58)	

[a] Significant results are indicated in italics.

[b] Fischer exact test.

Descriptive statistics for variables used in the path models are presented in Table 2. Figure 1 shows the mediation path (race → mediator → pain). Fit for each of the models was acceptable, with all 95% CIs for the difference between observed and replicated chi-square values encompassing 0, all posterior predictive values >.45, and convergence of posterior parameter trace plots. Tables 3 and 4 provide results of the path analysis, including direct and indirect effects and the 95% highest posterior density CIs for each of the pain measure models.

Table 2. Descriptive statistics for pain-related outcomes, pain catastrophizing, and negative affect among non-Hispanic White and Asian American individuals (N=40).

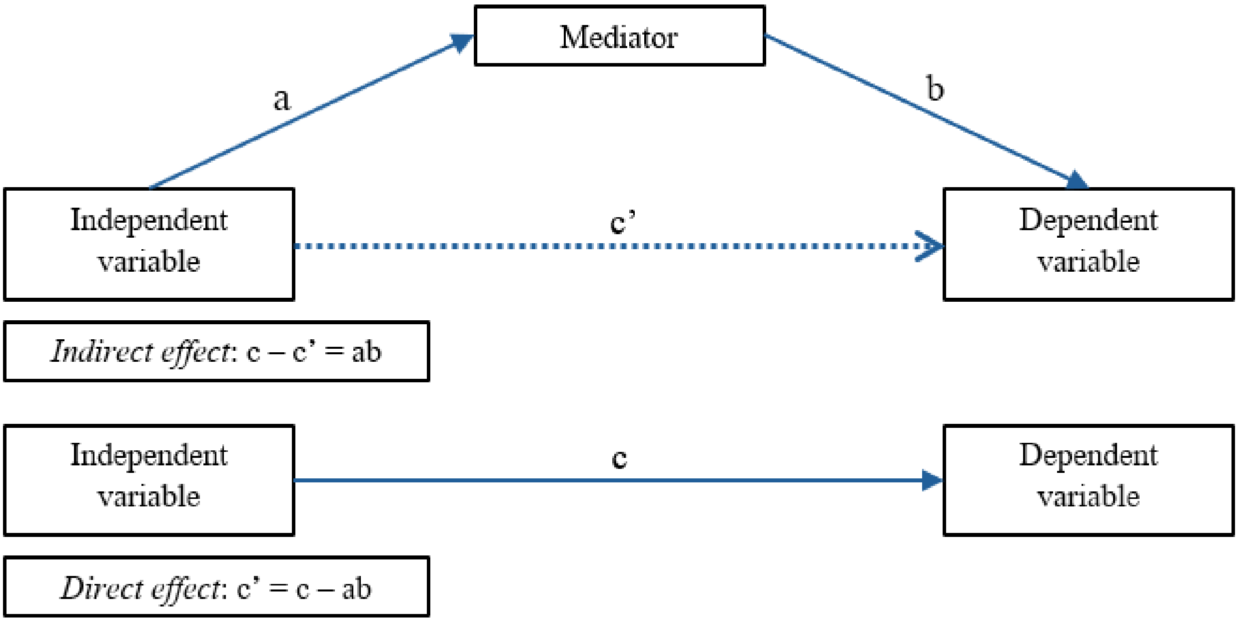
Pain measures	Non-Hispanic White (n=20)	Asian American (n=20)
WOMAC[a] pain (range: 0-20), mean (SD)	4.90 (2.55)	4.40 (2.67)
SF-MPQ-2[b] continuous pain (range: 0-10), mean (SD)	1.78 (1.94)	1.98 (1.37)
SF-MPQ-2 intermittent pain (range: 0-10), mean (SD)	1.28 (2.19)	1.47 (1.83)
SF-MPQ-2 neuropathic pain (range: 0-10), mean (SD)	0.67 (0.93)	1.07 (1.24)
SF-MPQ-2 affective pain (range: 0-10), mean (SD)	0.79 (1.83)	1.46 (1.66)
Heat pain threshold[c], mean (SD)	0.49 (0.82)	–0.49 (0.74)
Heat pain tolerance[c], mean (SD)	0.51 (0.76)	–0.51 (0.73)
Pressure pain threshold[c], mean (SD)	0.45 (0.86)	–0.45 (0.61)
Punctate mechanical pain[c], mean (SD)	–0.62 (0.56)	0.62 (0.76)
Conditioned pain modulation, mean (SD)	1.29 (1.14)	1.16 (0.71)
Pain catastrophizing (range: 0-6), mean (SD)	0.31 (0.74)	1.33 (1.25)
Negative affect (range: 10-50), mean (SD)	14.00 (4.29)	20.15 (9.02)

[a] WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.

[b] SF-MPQ-2: Short-Form McGill Pain Questionnaire-2.

[c] Average *z* score.

Figure 1. Mediation path model. For clinical pain measures, we measured WOMAC pain and SF-MPQ-2 pain. To produce composite QST measures, average z scores were computed for heat pain threshold and heat pain tolerance measurements at the arm and knee; PPT measurements at the medial and lateral aspect of the index knee, ipsilateral quadriceps, and trapezius; and PMP measurements at the patella and hand. a = direct effect of race on the mediator; b = direct effect of the mediator on pain measures after controlling for race; ab = indirect effect of race on pain measures operating through the mediator; c' = direct effect of race on pain measures after controlling for the mediator; c = total effect of race on pain measures without accounting for the mediator. Due to the small sample size, we analyzed each mediating effect (ie, pain catastrophizing and negative affect) separately. PMP: punctate mechanical pain; PPT: pressure pain threshold; QST: quantitative sensory testing; SF-MPQ-2: Short-Form McGill Pain Questionnaire-2; WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.



In each model (Table 3), the direct effect of race on pain catastrophizing (Figure 1; a = direct effect of race on the mediator) indicated that Asian American individuals had significantly higher pain catastrophizing scores than non-Hispanic White individuals (mean difference 1.03; 95% CI 0.29-1.70). Additionally, as shown in Table 4, in each model, the direct effect of race on negative affect indicated that Asian American individuals yielded significantly higher negative affect scores than non-Hispanic White individuals (mean difference 6.15; 95% CI 1.11-10.80).

Table 3. Estimated direct and indirect effects with 95% CI (N=40; pain catastrophizing as a mediator)[a,b].

Pain outcomes (R^2)	Direct effects		Indirect effect, ab (95% CI)
	c' (95% CI)	b (95% CI)	
WOMAC[c] pain (0.179)	–1.53 (–3.39 to 0.25)	1.00 (0.21-1.81)	0.96 (0.03-2.16)
SF-MPQ-2[d] continuous pain (0.283)	–0.67 (–1.78 to 0.40)	0.85 (0.38-1.34)	0.84 (0.18-1.70)
SF-MPQ-2 intermittent pain (0.187)	–0.64 (–2.07-0.73)	0.81 (0.20-1.43)	0.78 (0.03-1.71)
SF-MPQ-2 neuropathic pain (0.215)	–0.06 (–0.83 to 0.67)	0.45 (0.12-0.78)	0.43 (0.03-0.95)
SF-MPQ-2 affective pain (0.410)	–0.41 (–1.47 to 0.60)	1.06 (0.61-1.52)	1.05 (0.24-1.99)
Heat pain threshold[e] (0.284)	–1.07 (–1.67 to –0.50)	0.08 (–0.17 to 0.34)	0.07 (–0.20 to 0.39)
Heat pain tolerance[e] (0.304)	–0.94 (–1.52 to –0.39)	–0.07 (–0.32 to 0.18)	–0.06 (–0.38 to 0.19)
Pressure pain threshold[e] (0.259)	–0.96 (–1.54 to –0.41)	0.06 (–0.19 to 0.31)	0.05 (–0.23 to 0.34)
Punctate mechanical pain[e] (0.462)	1.09 (0.58-1.57)	0.15 (–0.07 to 0.37)	0.14 (–0.09 to 0.43)
Conditioned pain modulation (0.168)	–0.49 (–1.70 to 0.16)	0.36 (0.07-0.65)	0.34 (0.00-0.79)

[a] Significant results are indicated in italics.

[b] c' = direct effect of race on pain measures after controlling for pain catastrophizing; b = direct effect of pain catastrophizing on pain measures after controlling for race; ab = indirect effect of race on pain measures operating through pain catastrophizing.

[c] WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.

[d] SF-MPQ-2: Short-Form McGill Pain Questionnaire-2.

[e] Average *z* score.

Table 4. Estimated direct and indirect effects with 95% CI (N=40; negative affect as a mediator)[a,b].

Pain outcomes (R^2)	Direct effects		Indirect effect, ab (95% CI)
	c' (95% CI)	b (95% CI)	
WOMAC[c] pain (0.091)	–1.05 (–2.92 to 0.83)	0.09 (–0.03 to 0.22)	0.50 (–0.23 to 1.59)
SF-MPQ-2[d] continuous pain (0.094)	–0.17 (–1.36 to 1.04)	0.06 (–0.02 to 0.14)	0.34 (–0.13 to 1.04)
SF-MPQ-2 intermittent pain (0.155)	–0.45 (–1.83 to 0.95)	0.11 (0.02-0.20)	0.59 (–0.04 to 1.48)
SF-MPQ-2 neuropathic pain (0.186)	0.04 (–0.70 to 0.80)	0.06 (0.01-0.11)	0.34 (–0.03 to 0.80)
SF-MPQ-2 affective pain (0.108)	0.32 (–0.93 to 1.59)	0.06 (–0.02 to 0.14)	0.32 (–0.17 to 1.04)
Heat pain threshold[e] (0.274)	–1.01 (–1.58 to –0.43)	0.00 (–0.03 to 0.04)	0.02 (–0.25 to 0.27)
Heat pain tolerance[e] (0.297)	–1.01 (–1.56 to –0.45)	–0.00 (–0.04 to 0.04)	–0.00 (–0.25 to 0.26)
Pressure pain threshold[e] (0.255)	–0.94 (–1.49 to –0.38)	0.01 (–0.03 to 0.04)	0.03 (–0.22 to 0.29)
Punctate mechanical pain[e] (0.453)	1.13 (0.65-1.62)	0.02 (–0.01 to 0.05)	0.09 (–0.10 to 0.36)
Conditioned pain modulation (0.039)	–0.15 (–0.85 to 0.56)	0.01 (–0.04 to 0.05)	0.02 (–0.31 to 0.33)

[a] Significant results are indicated in italics.

[b] c' = direct effect of race on pain measures after controlling for pain catastrophizing; b = direct effect of pain catastrophizing on pain measures after controlling for race; ab = indirect effect of race on pain measures operating through pain catastrophizing.

[c] WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index.

[d] SF-MPQ-2: Short-Form McGill Pain Questionnaire-2.

[e] Average *z* score.

Direct Effect of Race on Pain Measures After Controlling Pain Catastrophizing

The direct effect of race on the heat pain threshold (c'=–1.07), heat pain tolerance (c'=–0.94), and PPT (c'=–0.96) indicated that Asian American individuals had lower mean scores on these experimental pain measures than non-Hispanic White individuals after controlling for pain catastrophizing. The direct effect of race on PMP (c'=1.09) indicated that Asian American individuals generated higher mean scores on this pain measure than non-Hispanic White individuals after controlling for pain catastrophizing. After controlling for pain catastrophizing, Asian

American and non-Hispanic White participants yielded similar mean scores for clinical pain measures.

Direct and Indirect Effect of Pain Catastrophizing on Pain Measures

Pain catastrophizing exhibited positive direct effects, while race exerted positive indirect effects through pain catastrophizing on WOMAC (b=1.00, ab=0.96), SF-MPQ-2 continuous (b=0.85, ab=0.84), SF-MPQ-2 intermittent (b=0.81, ab=0.78), SF-MPQ-2 neuropathic (b=0.45, ab=0.43), and SF-MPQ-2 affective (b=1.06, ab=1.05) pain. These results indicate that participants with higher pain catastrophizing scores tend to have higher values on these pain measures after controlling for race. Considering that race had no direct effects on these pain scores but exerted indirect effects via pain catastrophizing, the effects of race were likely fully mediated through pain catastrophizing for these measures. After controlling race, we did not identify any direct effects of pain catastrophizing on the heat pain threshold, heat pain tolerance, PPT, and PMP. Surprisingly, pain catastrophizing exhibited positive direct effects on CPM (b=0.36).

Direct Effect of Race on Pain Measures After Controlling for Negative Affect

Based on the direct effect of race on the heat pain threshold (c’=–1.01), heat pain tolerance (c’=–1.01), and PPT (c’=–0.91), Asian American individuals yielded lower mean scores on these experimental pain sensitivity measures than non-Hispanic White individuals after controlling for negative affect. The direct effect of race on PMP (c’= 1.13) indicated that Asian American individuals had higher mean scores on this pain measure than non-Hispanic White individuals after controlling for negative affect. Race had no direct effect on CPM. After controlling for negative affect, Asian American and non-Hispanic White participants were found to have similar mean scores for all clinical pain measures.

Direct and Indirect Effects of Negative Affect on Pain Measures

We exclusively detected direct effects of negative affect on SF-MPQ-2 intermittent (b=0.11) and SF-MPQ-2 neuropathic (b=0.06) pain after controlling for race. Race exerted no indirect effects on pain measures via negative affect in any of the path models.

Discussion

Principal Findings

This study investigated whether variations in pain catastrophizing and negative affect explain group differences in clinical and experimental pain between non-Hispanic White and Asian American individuals with KOA. Our main finding suggests that Asian American individuals show higher levels of pain catastrophizing than non-Hispanic White individuals and that it plays a relevant role in greater clinical pain in Asian American individuals. The results additionally indicate that participants with higher pain catastrophizing scores tended to have higher WOMAC- and SF-MPQ-2-measured clinical pain. Furthermore, Asian American individuals exhibited greater sensitivity to experimental pain compared with non-Hispanic White individuals; however, this difference was not due to pain catastrophizing. Asian American individuals also reported experiencing more negative affect than non-Hispanic White individuals, yet this did not seemingly influence the relationship between race and any pain measures.

Comparison With Prior Work

Disparities in pain catastrophizing based on race and ethnicity have been documented in individuals with KOA [13,37-39] and various other pain-related medical conditions [40-43]; notably, individuals who self-identify as minorities, including Black and Hispanic or Latinx groups, are reported to engage in pain catastrophizing as a pain coping strategy more frequently than their non-Hispanic White peers. Increasing evidence also suggests that catastrophizing is a significant mediator of race differences in clinical pain. A recent study by Fullwood et al [39] found that pain catastrophizing mediated the relationship between race (Black vs non-Hispanic White individuals) and WOMAC pain in adults with KOA. Similar findings were reported in the study by Lane et al [43] on individuals with chronic spinal pain receiving physical therapy and the study by Fabian et al [44] in healthy pain-free samples. Our study expands on previous investigations by identifying pain catastrophizing as a significant contributor to group differences in clinical pain between non-Hispanic White and Asian American individuals.

Extensive prior research has demonstrated that pain catastrophizing is associated with undesirable pain outcomes, including more frequent pain experiences or greater pain intensity [11-13]. However, our finding that Asian American individuals have higher clinical pain scores with increasing levels of pain catastrophizing represents a novel contribution to the field. The exact reasons underlying the significantly higher pain catastrophizing scores among Asian American individuals compared with non-Hispanic White individuals remain unclear. A possible explanation is the relationship between accultural stress and pain catastrophizing in Asian American individuals. Ahn et al [14] suggest that chronic stress contributes to increased pain perception, potentially owing to its physical impact from chronically high levels of sympathetic activation and subsequent physiologic exhaustion; this, in turn, may reduce one’s ability to cope with the added stress of pain [45]. They further note that a major source of chronic stress for immigrants could be the process of acculturation [46,47]. In addition, higher pain catastrophizing scores among Asian American individuals could be attributed to a cultural emphasis on pain-related stoicism in Asian communities, which may discourage openly expressing chronic pain to avoid burdening others [48,49]. This cultural disposition causes Asian American individuals to suffer silently, thus amplifying their mental agony. Furthermore, Asian cultural communication styles often prioritize indirectness and subtlety, which can result in less effective communication with health care providers from different cultural backgrounds regarding pain experiences [50]. This communication gap may hinder effective pain management and perpetuate a cycle of unexpressed and poorly managed KOA pain, thereby contributing to higher levels of pain catastrophizing compared to non-Hispanic White individuals. Furthermore, immigrants’ experiences with the health care system and the challenges they encounter in accessing adequate pain treatment may lead to poorer pain outcomes. This may foster negative thinking about their pain and may leave Asian American patients feeling that their pain is unmanageable and will inevitably worsen.

Asian American individuals reported greater experimental pain sensitivity (heat pain, PPT, and PMP) than non-Hispanic White individuals, replicating previous findings on middle-aged and older adults with KOA [9] and similar reports on younger Asian American individuals [51]. Furthermore, heightened sensitivity occurred at both the affected knee and unaffected body sites, suggesting increased central sensitization. However, pain catastrophizing could not explain the racial group differences in any measures of experimental pain in this study. This contradicts previous studies wherein pain catastrophizing was found to influence racial group differences in QST measures among nonclinical samples [52-55] and patients with chronic low back pain [41]. Several explanations can be proposed for such findings. First, Meints et al [55] found that racial group differences in cold pain tolerance (non-Hispanic White vs African American individuals) were mediated by the rumination component of pain catastrophizing but not by the magnification or helplessness components, examining the mediatory effects of different pain catastrophizing components may yield varied results. Second, other critical factors, such as biological, genetic, social, and environmental mechanisms, may also influence the observed differences. For instance, Rowell et al [51] found that differences in endogenous pain regulatory mechanisms, such as mean arterial pressure and heart rate, potentially play a role in the differences in experimental pain sensitivity between young non-Hispanic White and Asian American individuals. Based on earlier evidence, genetic links to pain phenotypes differ according to racial or ethnic group, potentially generating dissimilarities in pain sensation. For example, pain sensitivity has been associated with variations in the catechol-O-methyltransferase [56] and μ-opioid receptor genes [57]. Moreover, frequency differences in the alleles of pain-related gene polymorphisms may contribute to racial and ethnic disparities in pain responses [58]. Furthermore, studies have suggested a role for nutritional supplement status [59], lower sociodemographic resources [60], and racial discrimination [61] in accounting for individual or racial and ethnic differences in experimental pain sensitivity—all of which potentially contributed to the observed differences but require further evaluation in the future.

Asian American individuals had significantly higher negative affect scores than non-Hispanic White individuals. Although higher negative affect scores were strongly correlated with both intermittent and neuropathic pain (measured using the SF-MPQ-2), negative affect did not seem to influence the relationship between race and any pain measures. Various negative affect-related constructs are important to pain; nevertheless, they differ in specificity and are conceptually distinct; some constructs are general, such as anxiety, depression, and negative affect, whereas others are more specifically pain-related, such as fear of pain, pain anxiety, and pain catastrophizing [62]. Overall, our preliminary findings suggest that pain-specific variables (ie, pain catastrophizing) should be prioritized over general negative affect to minimize pain disparities between non-Hispanic White and Asian American individuals. However, further studies involving larger sample sizes are necessary to confirm our findings. In fact, a study by Ahn et al [9], which established that higher depression levels in Asian American than in non-Hispanic White individuals explained racial group differences in clinical and experimental pain, included 50 participants per group. Additionally, we could not account for covariates, such as sex, age, and pain-related medication, owing to the small sample sizes in the path models, which might have affected the results.

Strengths and Limitations

Our study is the first to highlight the crucial role of pain catastrophizing in explaining disparities in clinical KOA pain between non-Hispanic White and Asian American individuals, contributing to the growing body of literature on racial group differences in pain among individuals with KOA and its associated psychological conditions. Further, the study's strength was upheld by its comprehensive examination of pain in Asian American individuals using a wide range of pain measures, focusing on a population that has received limited attention in studies assessing and managing KOA pain.

This study has certain limitations. First, the findings may not be generalizable as they are based on a convenience sample from a specific region. Moreover, the Asian American participants in the study were limited to English speakers. These limitations introduce challenges in interpreting the findings, underscoring the need for samples from other regions and a more diverse group of Asian American individuals for cross-validation. Second, as previously mentioned, a key limitation of this study is the lack of information about potential commonalities or differences within our broadly categorized, monolithic Asian American sample. Therefore, caution is warranted when interpreting our conclusions. Furthermore, although we use the term "Asian American" when referring to the prior works, we acknowledge the significant heterogeneity within this population, including the diverse countries of origin of participants in individual studies and the considerable variation across "Asian American" cohorts in different studies. Thus, our discussion on racial and ethnic differences should be carefully interpreted. Third, this pilot study had a small sample size. Consequently, statistical analyses were constrained, and data outliers were more likely to skew the results, highlighting the need for a larger sample size. Furthermore, the combination of the small sample size and the lack of subgroup information on the Asian American sample limited the study's capacity to be specifically designed or sufficiently powered to explore variations within smaller subgroups of Asian American individuals. Fourth, the cross-sectional design hindered our ability to discern the directionality of the relationships between variables. Indeed, evidence suggests that pain catastrophizing may not be a characterological trait but a complex phenomenon that can both affect and be affected by pain [39]. Kim et al [48] argue that as clinical pain scores increase, a sense of helplessness or an inability to control chronic knee pain may develop, contributing to higher levels of pain catastrophizing in Asian American individuals. These important relationships warrant further investigation in future studies. Furthermore, previous studies have evaluated pain catastrophizing over a longitudinal period to better understand its influence on pain over time in adults with KOA [39]. Similar studies should also be conducted in Asian American samples. Finally, we acknowledge that the term "pain catastrophizing" can considered pejorative and stigmatizing, conflicting with patient-centered care approaches [63]. Labeling patients in this manner potentially leads to blame and stereotyping, adversely affecting decision-making and care quality. Recent analyses have proposed that "pain-related worrying" and "pain-related distress" may better capture the essence of what is measured by pain-catastrophizing items [64].

Future Directions

This pilot study's findings provide a crucial foundation for future research and clinical practice. Considering the limited sample size, we analyzed each mediatory effect separately. Future studies including larger samples may use more sophisticated models to concurrently examine a broader range of factors, thereby more comprehensively elucidating the mechanisms underlying racial disparities in pain between non-Hispanic White and Asian American individuals; in addition to pain catastrophizing and negative affect, as previously discussed, future research should investigate biological, genetic, and other psychological variables essential to understanding chronic KOA pain and evaluate them as explanatory mechanisms to develop more tailored interventions.

Additionally, it is important to acknowledge that the lumping of Asian American groups together in the current study is problematic, as it obscures the tremendous diversity and complexity within and across these groups. This approach may have excluded individuals with varying levels of pain catastrophizing and negative affect or overlooked how acculturative stress and cultural practices—factors that can vary greatly between Asian American subgroups—may influence pain perception and response. Therefore, future studies should account for the demographic and social construction of the Asian American category and its implications in KOA pain research to ensure nuanced and culturally informed analyses.

Finally, our findings underscore the need to systematically assess and treat pain catastrophizing in Asian American individuals in health care settings to ensure effective pain management. Interventions targeting this maladaptive cognitive style among Asian American individuals may help mitigate racial disparities in clinical pain. In particular, the interventions should be culturally sensitive and tailored by further scrutinizing the factors influencing pain catastrophizing in Asian American individuals. If acculturative stress influences pain catastrophizing, then therapy for pain catastrophizing (eg, cognitive behavioral therapy) could be enhanced by focusing on culturally sensitive stress management techniques. In addition, a better understanding of differences in pain experiences based on race, sociocultural background, and experiences with the health care system—such as Asian communities facing structural and systemic barriers that influence pain—may help reduce disparities in pain management.

Conclusions

This pilot study examined psychological factors, specifically pain catastrophizing and negative affect, as potential explanatory mechanisms behind racial group differences in clinical and experimental pain between non-Hispanic White and Asian American individuals with KOA pain. Apparently, pain catastrophizing is essential to addressing racial disparities in clinical KOA pain; however, further research is warranted to verify our findings and elucidate unresolved mechanisms.

Acknowledgments

This study was supported by the NIH/NINR Grant R15NR018050. The original study is registered at www.clinicaltrials.gov (NCT04016272). The authors attest that there was no use of generative artificial intelligence technology in the generation of text, figures, or other informational content of this manuscript.

Data Availability

The datasets generated during and/or analyzed during this study are available from the corresponding author on reasonable request.

Authors' Contributions

CL and CKK were responsible for the conception or design of the work. LP and HA contributed to the acquisition of the data. CL and CKK were involved in the analysis and interpretation of the data, as well as drafting the work. JP and HA revised the manuscript critically for important intellectual content. All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Conflicts of Interest

HA is the Editor-in-Chief of Asian/Pacific Island Nursing.

References

1. He Y, Li Z, Alexander PG, Ocasio-Nieves BD, Yocum L, Lin H, et al. Pathogenesis of osteoarthritis: risk factors, regulatory pathways in chondrocytes, and experimental models. Biology 2020;9(8):194 [FREE Full text] [doi: 10.3390/biology9080194] [Medline: 32751156]

2. Bedson J, Croft PR. The discordance between clinical and radiographic knee osteoarthritis: a systematic search and summary of the literature. BMC Musculoskelet Disord 2008;9:116 [FREE Full text] [doi: 10.1186/1471-2474-9-116] [Medline: 18764949]
3. Caneiro JP, O'Sullivan PB, Roos EM, Smith AJ, Choong P, Dowsey M, et al. Three steps to changing the narrative about knee osteoarthritis care: a call to action. Br J Sports Med 2020;54(5):256-258. [doi: 10.1136/bjsports-2019-101328] [Medline: 31484634]
4. de Oliveira Vargas E Silva NC, Dos Anjos RL, Santana MMC, Battistella LR, Marcon Alfieri F. Discordance between radiographic findings, pain, and superficial temperature in knee osteoarthritis. Reumatologia 2020;58(6):375-380 [FREE Full text] [doi: 10.5114/reum.2020.102002] [Medline: 33456080]
5. Son KM, Hong JI, Kim D, Jang D, Crema MD, Kim HA. Absence of pain in subjects with advanced radiographic knee osteoarthritis. BMC Musculoskelet Disord 2020;21(1):640 [FREE Full text] [doi: 10.1186/s12891-020-03647-x] [Medline: 32993609]
6. Hunt MA, Birmingham TB, Skarakis-Doyle E, Vandervoort AA. Towards a biopsychosocial framework of osteoarthritis of the knee. Disabil Rehabil 2008;30(1):54-61. [doi: 10.1080/09638280701189960] [Medline: 17852218]
7. Deshpande BR, Katz JN, Solomon DH, Yelin EH, Hunter DJ, Messier SP, et al. Number of persons with symptomatic knee osteoarthritis in the US: impact of race and ethnicity, age, sex, and obesity. Arthritis Care Res 2016;68(12):1743-1750 [FREE Full text] [doi: 10.1002/acr.22897] [Medline: 27014966]
8. Vaughn IA, Terry EL, Bartley EJ, Schaefer N, Fillingim RB. Racial-ethnic differences in osteoarthritis pain and disability: a meta-analysis. J Pain 2019;20(6):629-644 [FREE Full text] [doi: 10.1016/j.jpain.2018.11.012] [Medline: 30543951]
9. Ahn H, Weaver M, Lyon D, Kim J, Choi E, Staud R, et al. Differences in clinical pain and experimental pain sensitivity between Asian Americans and Whites with knee osteoarthritis. Clin J Pain 2017;33(2):174-180 [FREE Full text] [doi: 10.1097/AJP.0000000000000378] [Medline: 28060784]
10. Bevers K, Watts L, Kishino N, Gatchel R. The biopsychosocial model of the assessment, prevention, and treatment of chronic pain. US Neurol 2016;12(2):98-104. [doi: 10.17925/USN.2016.12.02.98]
11. Campbell CM, Buenaver LF, Finan P, Bounds SC, Redding M, McCauley L, et al. Sleep, pain catastrophizing, and central sensitization in knee osteoarthritis patients with and without insomnia. Arthritis Care Res 2015;67(10):1387-1396 [FREE Full text] [doi: 10.1002/acr.22609] [Medline: 26041510]
12. Somers TJ, Keefe FJ, Pells JJ, Dixon KE, Waters SJ, Riordan PA, et al. Pain catastrophizing and pain-related fear in osteoarthritis patients: relationships to pain and disability. J Pain Symptom Manage 2009;37(5):863-872 [FREE Full text] [doi: 10.1016/j.jpainsymman.2008.05.009] [Medline: 19041218]
13. Terry EL, Fullwood MD, Booker SQ, Cardoso JS, Sibille KT, Glover TL, et al. Everyday discrimination in adults with knee pain: the role of perceived stress and pain catastrophizing. J Pain Res 2020;13:883-895 [FREE Full text] [doi: 10.2147/JPR.S235632] [Medline: 32431537]
14. Ahn H, Jackson N, An K, Fillingim RB, Miao H, Lee M, et al. Relationship between acculturative stress and pain catastrophizing in Korean Americans. J Immigr Minor Health 2021;23(4):741-746. [doi: 10.1007/s10903-020-01083-6] [Medline: 32915374]
15. Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. J Pain 2009;10(12):1187-1204 [FREE Full text] [doi: 10.1016/j.jpain.2009.10.002] [Medline: 19944378]
16. Luong MN, Cleveland RJ, Nyrop KA, Callahan LF. Social determinants and osteoarthritis outcomes. Aging health 2012;8(4):413-437 [FREE Full text] [doi: 10.2217/ahe.12.43] [Medline: 23243459]
17. Finan PH, Quartana PJ, Smith MT. Positive and negative affect dimensions in chronic knee osteoarthritis: effects on clinical and laboratory pain. Psychosom Med 2013;75(5):463-470 [FREE Full text] [doi: 10.1097/PSY.0b013e31828ef1d6] [Medline: 23697467]
18. Johnson AJ, Laffitte Nodarse C, Peraza JA, Valdes-Hernandez PA, Montesino-Goicolea S, Huo Z, et al. Psychological profiles in adults with knee OA-related pain: a replication study. Ther Adv Musculoskelet Dis 2021;13:1759720X211059614 [FREE Full text] [doi: 10.1177/1759720X211059614] [Medline: 34900003]
19. Speed TJ, Richards JM, Finan PH, Smith MT. Sex moderates the effects of positive and negative affect on clinical pain in patients with knee osteoarthritis. Scand J Pain 2017;16:66-73 [FREE Full text] [doi: 10.1016/j.sjpain.2017.03.005] [Medline: 28850415]
20. Ahn H, Weaver M, Lyon D, Choi E, Fillingim RB. Depression and pain in Asian and White Americans with knee osteoarthritis. J Pain 2017;18(10):1229-1236 [FREE Full text] [doi: 10.1016/j.jpain.2017.05.007] [Medline: 28619697]
21. Tang D. Experiences of Racial Discrimination and Emotion Dynamics Among African Americans and Asian Americans [dissertation]. Washington, DC: American University; 2024.
22. Ong AD, Burrow AL, Fuller-Rowell TE, Ja NM, Sue DW. Racial microaggressions and daily well-being among Asian Americans. J Couns Psychol 2013;60(2):188-199. [doi: 10.1037/a0031736] [Medline: 23421777]
23. Nadal KL, Wong Y, Sriken J, Griffin K, Fujii-Doe W. Racial microaggressions and Asian Americans: an exploratory study on within-group differences and mental health. Asian Am J Psychol 2015;6(2):136-144. [doi: 10.1037/a0038058]
24. Lin LT. Hate is a Virus:? Relations Among Racial Microaggressions, Acculturation, Collective Self-Esteem, and Psychological Distress in Asian Americans During COVID-19 [dissertation]. Buffalo, NY: State University of New York; 2023.

25. Nadal KLY, Corpus G, Hufana A. The forgotten Asian Americans: Filipino Americans’ experiences with racial microaggressions and trauma. Asian Am J Psychol 2022;13(1):51-61. [doi: 10.1037/aap0000261]
26. Ahn H, Woods AJ, Kunik ME, Bhattacharjee A, Chen Z, Choi E, et al. Efficacy of transcranial direct current stimulation over primary motor cortex (anode) and contralateral supraorbital area (cathode) on clinical pain severity and mobility performance in persons with knee osteoarthritis: An experimenter- and participant-blinded, randomized, sham-controlled pilot clinical study. Brain Stimul 2017;10(5):902-909 [FREE Full text] [doi: 10.1016/j.brs.2017.05.007]
27. Bellamy N, Buchanan WW, Goldsmith CH, Campbell J, Stitt LW. Validation study of WOMAC: a health status instrument for measuring clinically important patient relevant outcomes to antirheumatic drug therapy in patients with osteoarthritis of the hip or knee. J Rheumatol 1988;15(12):1833-1840. [Medline: 3068365]
28. Bellamy N, Buchanan WW. A preliminary evaluation of the dimensionality and clinical importance of pain and disability in osteoarthritis of the hip and knee. Clin Rheumatol 1986;5(2):231-241. [doi: 10.1007/BF02032362] [Medline: 3731718]
29. Roos EM, Klässbo M, Lohmander LS. WOMAC osteoarthritis index. Reliability, validity, and responsiveness in patients with arthroscopically assessed osteoarthritis. Western Ontario and MacMaster Universities. Scand J Rheumatol 1999;28(4):210-215. [doi: 10.1080/03009749950155562] [Medline: 10503556]
30. Dworkin R, Turk D, Revicki D, Harding G, Coyne K, Peirce-Sandner S, et al. Development and initial validation of an expanded and revised version of the Short-Form McGill Pain Questionnaire (SF-MPQ-2). Pain 2009;144(1-2):35-42. [doi: 10.1016/j.pain.2009.02.007] [Medline: 19356853]
31. Yarnitsky D, Arendt-Nielsen L, Bouhassira D, Edwards RR, Fillingim RB, Granot M, et al. Recommendations on terminology and practice of psychophysical DNIC testing. Eur J Pain 2010;14(4):339. [doi: 10.1016/j.ejpain.2010.02.004] [Medline: 20227310]
32. Jensen MP, Keefe FJ, Lefebvre JC, Romano JM, Turner JA. One- and two-item measures of pain beliefs and coping strategies. Pain 2003;104(3):453-469. [doi: 10.1016/S0304-3959(03)00076-9] [Medline: 12927618]
33. Rosenstiel AK, Keefe FJ. The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. Pain 1983;17(1):33-44. [doi: 10.1016/0304-3959(83)90125-2] [Medline: 6226916]
34. Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: the PANAS scales. J Pers Soc Psychol 1988;54(6):1063-1070. [doi: 10.1037//0022-3514.54.6.1063] [Medline: 3397865]
35. Wang L, Preacher KJ. Moderated mediation analysis using Bayesian methods. Struct Equ Model 2014;22(2):249-263. [doi: 10.1080/10705511.2014.935256]
36. Muthén B, Asparouhov T. Bayesian structural equation modeling: a more flexible representation of substantive theory. Psychol Methods 2012;17(3):313-335. [doi: 10.1037/a0026802] [Medline: 22962886]
37. Nemati D, Quintero D, Best TM, Kaushal N. Investigating the association between knee osteoarthritis symptoms with pain catastrophizing domains between Hispanics and non-Hispanic Whites. Rheumatol Int 2024;44(11):2539-2546. [doi: 10.1007/s00296-023-05396-1] [Medline: 37597058]
38. Quintero D, Jose J, Kholodovsky E, Jahn J, Travis L, Costello IJ. Ethnicity and knee osteoarthritis: a comparative analysis of pain, function, and pain catastrophizing between South Florida Hispanic and non-Hispanic adults. Res Square 2024 [FREE Full text] [doi: 10.21203/rs.3.rs-4400220/v1]
39. Fullwood D, Gomez RN, Huo Z, Cardoso JS, Bartley EJ, Booker SQ, et al. A mediation appraisal of catastrophizing, pain-related outcomes, and race in adults with knee osteoarthritis. J Pain 2021;22(11):1452-1466 [FREE Full text] [doi: 10.1016/j.jpain.2021.04.018] [Medline: 34033964]
40. Meints SM, Miller MM, Hirsh AT. Differences in pain coping between Black and White Americans: a meta-analysis. J Pain 2016;17(6):642-653 [FREE Full text] [doi: 10.1016/j.jpain.2015.12.017] [Medline: 26804583]
41. Meints SM, Wang V, Edwards RR. Sex and race differences in pain sensitization among patients with chronic low back pain. J Pain 2018;19(12):1461-1470 [FREE Full text] [doi: 10.1016/j.jpain.2018.07.001] [Medline: 30025944]
42. Leung L. Pain catastrophizing: an updated review. Indian J Psychol Med 2012;34(3):204-217 [FREE Full text] [doi: 10.4103/0253-7176.106012] [Medline: 23441031]
43. Lane E, Barnes C, Fritz J. Differences in pain experience among different racial and ethnic groups. Phys Ther 2024;104(10):pzae001. [doi: 10.1093/ptj/pzae001] [Medline: 38181396]
44. Fabian LA, McGuire L, Goodin BR, Edwards RR. Ethnicity, catastrophizing, and qualities of the pain experience. Pain Med 2011;12(2):314-321 [FREE Full text] [doi: 10.1111/j.1526-4637.2010.01015.x] [Medline: 21143756]
45. Edwards CL, Fillingim RB, Keefe F. Race, ethnicity and pain. Pain 2001;94(2):133-137. [doi: 10.1016/S0304-3959(01)00408-0] [Medline: 11690726]
46. Schwartz SJ, Unger JB, Zamboanga BL, Szapocznik J. Rethinking the concept of acculturation: implications for theory and research. Am Psychol 2010;65(4):237-351 [FREE Full text] [doi: 10.1037/a0019330] [Medline: 20455618]
47. Jang Y, Kim G, Chiriboga D, Kallimanis B. A bidimensional model of acculturation for Korean American older adults. J Aging Stud 2007;21(3):267-275 [FREE Full text] [doi: 10.1016/j.jaging.2006.10.004] [Medline: 18670580]
48. Kim HJ, Park H, Juon H. The mediating role of pain catastrophizing on the association between depression and pain severity and interference among elderly Asian immigrants with chronic pain. J Pain Res 2021;14:737-745 [FREE Full text] [doi: 10.2147/JPR.S304440] [Medline: 33737831]

49. Kawi J, Reyes AT, Arenas RA. Exploring pain management among Asian immigrants with chronic pain: self-management and resilience. J Immigr Minor Health 2019;21(5):1123-1136. [doi: 10.1007/s10903-018-0820-8] [Medline: 30182206]
50. Wang JHY, Adams IF, Pasick RJ, Gomez SL, Allen L, Ma GX, et al. Perceptions, expectations, and attitudes about communication with physicians among Chinese American and non-Hispanic White women with early stage breast cancer. Support Care Cancer 2013;21(12):3315-3325 [FREE Full text] [doi: 10.1007/s00520-013-1902-8] [Medline: 23903797]
51. Rowell LN, Mechlin B, Ji E, Addamo M, Girdler SS. Asians differ from non-Hispanic Whites in experimental pain sensitivity. Eur J Pain 2011;15(7):764-771 [FREE Full text] [doi: 10.1016/j.ejpain.2010.11.016] [Medline: 21561793]
52. Kim HJ, Greenspan JD, Ohrbach R, Fillingim RB, Maixner W, Renn CL, et al. Racial/ethnic differences in experimental pain sensitivity and associated factors—cardiovascular responsiveness and psychological status. PLoS One 2019;14(4):e0215534 [FREE Full text] [doi: 10.1371/journal.pone.0215534] [Medline: 30998733]
53. Forsythe LP, Thorn B, Day M, Shelby G. Race and sex differences in primary appraisals, catastrophizing, and experimental pain outcomes. J Pain 2011;12(5):563-572 [FREE Full text] [doi: 10.1016/j.jpain.2010.11.003] [Medline: 21277836]
54. Meints SM, Hirsh AT. In Vivo praying and catastrophizing mediate the race differences in experimental pain sensitivity. J Pain 2015;16(5):491-497 [FREE Full text] [doi: 10.1016/j.jpain.2015.02.005] [Medline: 25725173]
55. Meints SM, Stout M, Abplanalp S, Hirsh AT. Pain-related rumination, but not magnification or helplessness, mediates race and sex differences in experimental pain. J Pain 2017;18(3):332-339 [FREE Full text] [doi: 10.1016/j.jpain.2016.11.005] [Medline: 27908838]
56. Vetterlein A, Monzel M, Reuter M. Are catechol-O-methyltransferase gene polymorphisms genetic markers for pain sensitivity after all?—A review and meta-analysis. Neurosci Biobehav Rev 2023;148:105112. [doi: 10.1016/j.neubiorev.2023.105112] [Medline: 36842714]
57. Fillingim RB, Kaplan L, Staud R, Ness TJ, Glover TL, Campbell CM, et al. The A118G single nucleotide polymorphism of the mu-opioid receptor gene (OPRM1) is associated with pressure pain sensitivity in humans. J Pain 2005;6(3):159-167 [FREE Full text] [doi: 10.1016/j.jpain.2004.11.008] [Medline: 15772909]
58. Hastie B, Riley J, Kaplan L, Herrera D, Campbell C, Virtusio K, et al. Ethnicity interacts with the OPRM1 gene in experimental pain sensitivity. Pain 2012;153(8):1610-1619. [doi: 10.1016/j.pain.2012.03.022] [Medline: 22717102]
59. Glover TL, Goodin BR, Horgas AL, Kindler LL, King CD, Sibille KT, et al. Vitamin D, race, and experimental pain sensitivity in older adults with knee osteoarthritis. Arthritis Rheum 2012;64(12):3926-3935 [FREE Full text] [doi: 10.1002/art.37687] [Medline: 23135697]
60. Sibille K, King C, Garrett T, Glover T, Zhang H, Chen H, et al. Omega-6: Omega-3 PUFA ratio, pain, functioning, and distress in adults with knee pain. Clin J Pain 2018;34(2):182-189 [FREE Full text] [doi: 10.1097/AJP.0000000000000517] [Medline: 28542024]
61. Goodin BR, Pham QT, Glover TL, Sotolongo A, King CD, Sibille KT, et al. Perceived racial discrimination, but not mistrust of medical researchers, predicts the heat pain tolerance of African Americans with symptomatic knee osteoarthritis. Health Psychol 2013;32(11):1117-1126 [FREE Full text] [doi: 10.1037/a0031592] [Medline: 24219416]
62. Mounce C, Keogh E, Eccleston C. A principal components analysis of negative affect-related constructs relevant to pain: evidence for a three component structure. J Pain 2010;11(8):710-717 [FREE Full text] [doi: 10.1016/j.jpain.2009.10.014] [Medline: 20015698]
63. O'Brien J. Calls to rename "pain catastrophizing" backed by international patient-researcher partnership. International Association for the Study of Pain. 2020. URL: https://www.iasp-pain.org/publications/pain-research-forum/prf-news/150718-calls-rename-pain-catastrophizing-backed-international-patient-researcher-partnership/ [accessed 2024-07-01]
64. Crombez G, De Paepe AL, Veirman E, Eccleston C, Verleysen G, Van Ryckeghem DML. Let's talk about pain catastrophizing measures: an item content analysis. PeerJ 2020;8:e8643 [FREE Full text] [doi: 10.7717/peerj.8643] [Medline: 32181053]

Abbreviations

CPM: conditioned pain modulation
IRB: institutional review board
KOA: knee osteoarthritis
PMP: punctate mechanical pain
PPT: pressure pain threshold
QST: quantitative sensory testing
SF-MPQ-2: Short-form-McGill Pain Questionnaire-2
UA: University of Arizona
WOMAC: Western Ontario and McMaster Universities Osteoarthritis Index

Edited by T Leung; submitted 16.07.24; peer-reviewed by H Park, A Mukherjea; comments to author 13.09.24; revised version received 31.12.24; accepted 20.01.25; published 25.02.25.

Please cite as:
Lee C, Kwoh CK, Park J, Park L, Ahn H
Disparities in Clinical and Experimental Pain Between Non-Hispanic White and Asian American Individuals With Knee Osteoarthritis and the Role of Pain Catastrophizing: Pilot Study in Florida
Asian Pac Isl Nurs J 2025;9:e64415
URL: https://apinj.jmir.org/2025/1/e64415
doi:10.2196/64415
PMID:

Original Paper

A Culturally Tailored Artificial Intelligence Chatbot (K-Bot) to Promote Human Papillomavirus Vaccination Among Korean Americans: Development and Usability Study

Minjin Kim[1,2], RN, PhD; Ellie Kim[3], BS, BA; Hyeongsuk Lee[4], RN, PhD; Meihua Piao[5], RN, PhD; Brittany Rosen[3,6], CHES, MEd, PhD; Jeroan J Allison[2], MD, MS; Adrian H Zai[7], MD, MPH, PhD; Hoa L Nguyen[8], MD, MS, PhD; Dong-Soo Shin[9], PhD; Jessica A Kahn[10], MD, MPH

[1]College of Nursing, University of Cincinnati, Cincinnati, OH, United States
[2]Department of Population and Quantitative Health Sciences, University of Massachusetts Chan Medical School, Worcester, MA, United States
[3]College of Medicine, University of Cincinnati, Cincinnati, OH, United States
[4]Research Institute of AI and Nursing Science, College of Nursing, Gachon University, Incheon, Republic of Korea
[5]School of Nursing, Chinese Academy of Medical Sciences, Chinese Academy of Medical Sciences & Peking Union Medical College, Beijing, China
[6]Division of Adolescent and Transition Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, United States
[7]Department of Population and Quantitative Health Sciences, Division of Health Informatics and Implementation Science, University of Massachusetts Chan Medical School, Worcester, MA, United States
[8]Department of Population and Quantitative Health Sciences, Division of Epidemiology, University of Massachusetts Chan Medical School, Worcester, MA, United States
[9]School of Nursing, Hallym University, Chuncheon, Republic of Korea
[10]Department of Pediatrics, Albert Einstein College of Medicine, Bronx, NY, United States

Corresponding Author:
Minjin Kim, RN, PhD
College of Nursing
University of Cincinnati
3110 Vine St
PO Box 210038
Cincinnati, OH, 45221-0038
United States
Phone: 1 7202095559
Email: kim3m4@ucmail.uc.edu

Abstract

Background: Human papillomavirus (HPV) is the most common sexually transmitted infection (STI) worldwide and is associated with various cancers, including cervical and oropharyngeal cancers. Despite the availability of effective vaccines, significant disparities in HPV vaccination rates persist, particularly among racial and ethnic minorities, such as Korean Americans. Cultural stigma, language barriers, and limited access to tailored health information contribute to these disparities.

Objective: This study aimed to develop and evaluate the usability of K-Bot, an artificial intelligence (AI)–powered, culturally tailored, bilingual (Korean and English) chatbot designed to provide culturally sensitive health information about HPV vaccination to Korean immigrants and Korean Americans.

Methods: K-Bot was developed using CloudTuring and Google Dialogflow. Its dialogues were created using Centers for Disease Control and Prevention (CDC) evidence-based HPV information and tailored to the Korean American population based on findings from previous studies. The evaluation and refinement process for K-Bot was organized into 3 phases: (1) expert evaluation by a multidisciplinary panel, (2) usability testing, and (3) iterative refinement based on feedback. An online survey collected demographics, HPV awareness, and vaccination status before 6 focus groups (N=21) sessions using semistructured questions guided by Peter Morville’s usability framework. Quantitative data were analyzed descriptively, and thematic analysis assessed usability, cultural relevance, and content clarity across 6 dimensions: desirability, accessibility, findability, credibility, usability, and usefulness.

Results: Participants had a mean age of 23.7 (SD 4.7) years, with most being female (n=12, 57.1%), second-generation individuals (n=13, 61.9%), and single (n=20, 95.2%). HPV awareness was high (n=19, 90.5%), vaccine knowledge was also high (n=18, 81.8%), but only 11 (52.4%) participants were vaccinated. Feedback-driven refinements addressed usability challenges, including simplifying navigation and adding visual elements. Participants described K-Bot as a promising tool for promoting HPV vaccination among Korean and Korean American users, citing its bilingual functionality and culturally tailored content as key strengths. Evidence-based information was valued, but participants recommended visuals to improve engagement and reduce cognitive load. Accessibility concerns included broken links, and participants proposed enhancements, such as animations, demographic-specific resources, and interactive features, to improve usability and engagement further.

Conclusions: Usability testing of K-Bot revealed its potential as a culturally tailored, bilingual tool for promoting HPV vaccination among Korean immigrants and Korean Americans. Participants valued its evidence-based information, cultural relevance, and bilingual functionality but recommended improvements, such as enhanced navigation, visual elements, and interactive features, to boost engagement and usability. These findings support the potential of AI-driven tools to improve health care access by addressing key barriers to care. Further research is needed to evaluate their broader impact and optimize their design and implementation for individuals with diverse health care needs.

(Asian Pac Isl Nurs J 2025;9:e71865) doi:10.2196/71865

KEYWORDS

human papillomavirus; HPV vaccination; artificial intelligence; AI; chatbot intervention; Korean Americans; usability testing; culturally tailored intervention

Introduction

Human papillomavirus (HPV) is the most common sexually transmitted infection (STI) worldwide, with the highest prevalence observed among young adults [1]. Persistent HPV infection can lead to various cancers, including cervical cancer, which remains a leading cause of cancer-related deaths among women aged 20-39 years [2]. Additionally, HPV is associated with oropharyngeal cancers, which are increasingly prevalent among men and tend to develop at younger ages compared to other HPV-related cancers [3].

To combat the burden of HPV-related diseases, the US Advisory Committee on Immunization Practices (ACIP) recommends routine HPV vaccination for adolescents aged 11-12 years, with catch-up vaccination for individuals aged 13-26 years who have not completed the vaccine series [4]. Recently, the 9-valent vaccine was approved in the United States for use in adults aged 27-45 years [5]. Korean Americans are at a relatively high risk for HPV-related cancers, yet they exhibit significant disparities in HPV vaccination rates [6,7]. Notably, Korean American women demonstrate a particularly low intention to receive the HPV vaccine, with only 34.6% expressing a willingness to get the vaccine in prior studies [8]. Our previous research further indicates that only 32% of participants aged 27-45 years have received the HPV vaccine at least once, with differences by sex (females: 35.3%; males: 12.5%) [9]. Korean Americans face several critical barriers to HPV vaccination, including cultural stigma surrounding STIs, language barriers, and al ack of culturally tailored health information. These challenges are compounded by limited knowledge and awareness of HPV and the benefits of vaccination, contributing to persistently low vaccination uptake, which contributes to lower vaccination rates [8-12]. In addition to this knowledge gap, several factors influence HPV vaccination intentions among Koreans and Korean Americans. These include parental recommendations for the HPV vaccine, the perceived benefits and severity of HPV infection, a history of cervical cancer, beliefs about cervical cancer screening for daughters, experiences with sexual activity, and sociodemographic factors (eg, occupation, education, and income) [7,8]. To address these challenges, culturally tailored interventions are essential to improve HPV vaccination uptake within this population, especially for communities that may encounter cultural and linguistic challenges in accessing health care information. For example, prior efforts have included culturally relevant health information that has demonstrated promise in increasing awareness and promoting vaccination by addressing cultural stigmas and misconceptions [9,13,14]. However, many of these approaches rely on traditional methods of information dissemination, which may lack the interactivity and personalization needed to address individual barriers effectively.

KakaoTalk is the most popular mobile messaging app in South Korea. It has become an integral part of daily communication and workplace interaction, offering various features beyond basic text messaging [10]. KakaoTalk has also been used in health research, demonstrating its potential as a platform for delivering health interventions. Studies have explored its role in supporting Korean American family caregivers [11] and promoting health interventions to Korean Americans with limited English proficiency [8], including efforts to promote HPV vaccination [12]. Additionally, KakaoTalk serves as a digital communal space for middle-aged Korean women [15], demonstrating its broad accessibility and significance across diverse Korean populations, from teenagers to older adults, both in South Korea and among Korean Americans.

Artificial intelligence (AI) chatbots have emerged as innovative tools for delivering personalized, leveraging advanced capabilities to address barriers in health communication [16]. Unlike static interventions, such as printed materials or one-size-fits-all campaigns, AI chatbots offer interactive, real-time engagement, making them particularly effective in addressing nuanced health behaviors and misconceptions [16]. The effectiveness of chatbot-based interventions in promoting behavior change is well supported in the literature. For instance, multiple studies have reported high levels of engagement, usability, and satisfaction with chatbot interventions targeting adolescents and adults [16-18]. Recent studies have explored innovative approaches to promote HPV vaccination, particularly among adolescents and young adults. Digital health interventions, including chatbots, have shown promise in improving knowledge and vaccination intentions [19-21]. Particularly, a study conducted in South Korea developed an eHealth communication intervention using a KakaoTalk chatbot, which shows promising usability scores among experts and adolescent girls [20].

Although existing studies demonstrate the potential of chatbots to influence health behaviors through interactive and personalized engagement, there remains a significant gap in culturally tailored chatbot interventions specifically designed for HPV prevention and cancer risk reduction. Despite the growing evidence base, no studies have focused on developing a chatbot that addresses the unique cultural and linguistic barriers faced by specific populations, such as Korean immigrants and Korean Americans.

To address these gaps, we aimed to develop K-Bot, an AI chatbot designed to deliver culturally tailored, bilingual (English and Korean) health information, specifically targeting Korean immigrants and Korean Americans—groups with unique cultural and linguistic barriers to HPV vaccination [8]. This study also aimed to evaluate the usability of K-Bot to assess how easily and effectively the tool can be used as a culturally sensitive, AI-powered chatbot providing real-time health information about HPV vaccination.

Methods

Study Design

The development and usability evaluation of K-Bot followed a structured, iterative process comprising 3 phases: chatbot development, expert evaluation, and usability testing. Evaluations were conducted with both a multidisciplinary expert panel and user groups to ensure the chatbot's clinical relevance, cultural sensitivity, and practical usability.

Ethical Considerations

All study procedures were approved by the Institutional Review Board (IRB) of the University of Cincinnati (IRB protocol 2022-0347). All study procedures were conducted following institutional guidelines and ethical standards for research involving human participants. Informed consent was obtained from all participants prior to their participation.

Chatbot Development

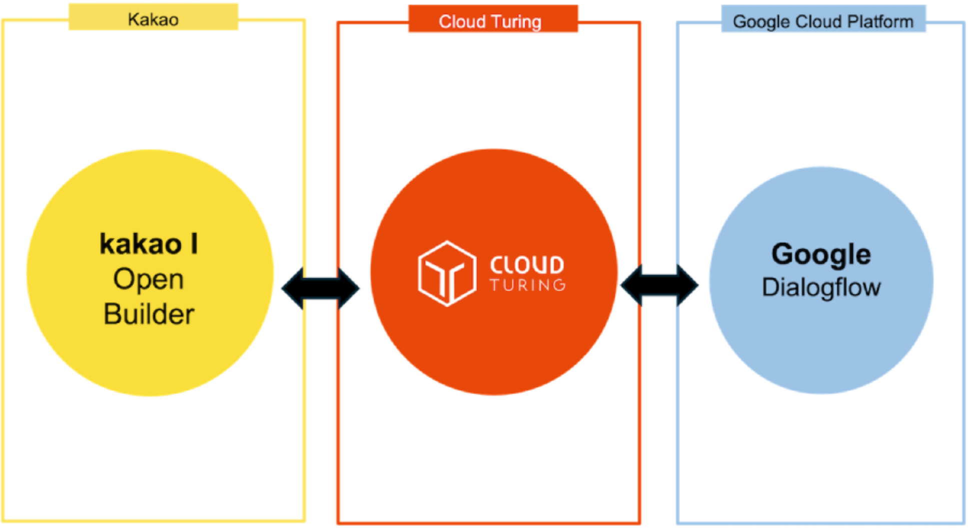
The development of the K-Bot chatbot was based on a structured and systematic process leveraging both advanced technology platforms and cultural tailoring to address HPV vaccination disparities among Korean Americans.

Platform Selection and Chatbot Design

K-Bot's development required a multidisciplinary team, including AI developers from South Korea who were integral to the implementation of the AI chatbot and its deployment on relevant platforms. The team also included experienced health researchers in designing and evaluating chatbots from South Korea, 2 health care professionals based in the United States and 2 Korean community representatives, who provided insights to ensure cultural relevance. This diverse team brought together expertise in AI, health care, and cultural adaptation to ensure the chatbot's relevance and effectiveness across both Korean and Korean American populations.

The chatbot was built using CloudTuring [22], a platform offering AI-driven solutions for advanced natural language understanding, and Google Dialogflow [23], a widely used conversational AI framework that enables natural language processing (NLP), intent recognition, and context-aware responses. The chatbot was integrated with the existing management system, allowing for continuous updates and improvement through the Kakao Chatbot Manager and Cloud Turing platforms (Figure 1).

Figure 1. K-Bot architecture and integration with the existing management system.

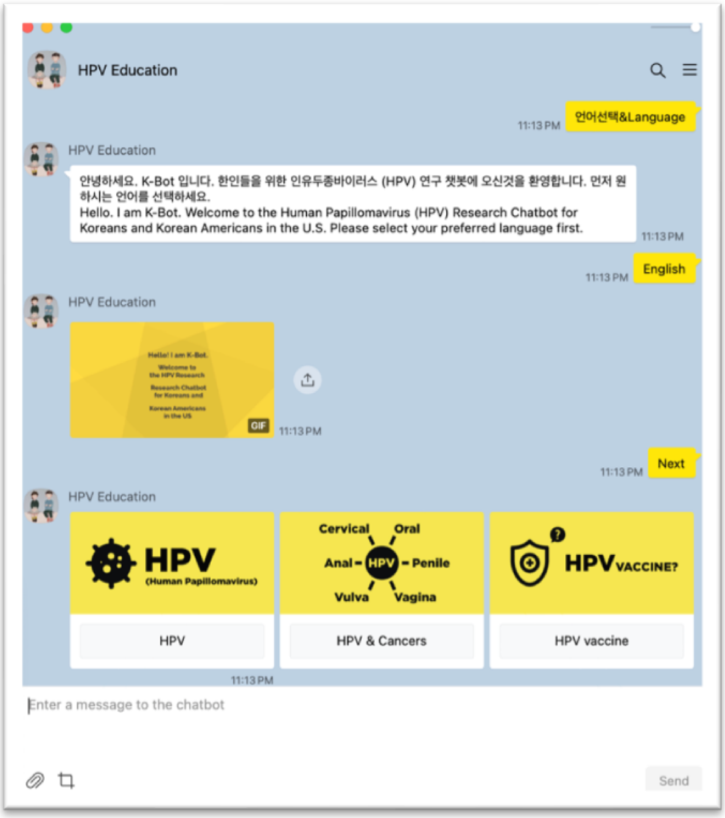


These tools facilitated bilingual interactions in English and Korean, supporting accurate communication and seamless user engagement. Deployment was carried out on the KakaoTalk messaging app (Figure 2), which is widely used by Koreans for communication [24], and a Wix-based website, requiring secure hosting and compliance with privacy standards. The development process spanned 5 months, with iterative refinements made based on expert and user feedback.

The chatbot's dialogues were designed based on evidence-based guidelines from the Centers for Disease Control and Prevention (CDC) and tailored to the Korean American population using findings from previous studies [12,25,26].

The chatbot was structured using a hierarchical organization of major, medium, and minor classifications, which guided the users toward their desired information. Each interaction was categorized under major topics (eg, HPV vaccine), followed by medium-level subcategories (eg, vaccine safety and side effects), and further segmented into minor classifications (eg, detailed explanations of side effects). This modular structure ensured logical navigation and efficient access to information, which is critical for users seeking health-related information.

Figure 2. K-Bot interface within the KakaoTalk app. HPV: human papillomavirus.



11:13 PM 언어선택&Language

HPV Education

안녕하세요. K-Bot 입니다. 한인들을 위한 인유두종바이러스 (HPV) 연구 챗봇에 오신것을 환영합니다. 먼저 원하시는 언어를 선택하세요.
Hello. I am K-Bot. Welcome to the Human Papillomavirus (HPV) Research Chatbot for Koreans and Korean Americans in the U.S. Please select your preferred language first. 11:13 PM

11:13 PM English

HPV Education

Hello! I am K-Bot.
Welcome to the HPV Research
Research Chatbot for Koreans and
Korean Americans in the US
GIF 11:13 PM

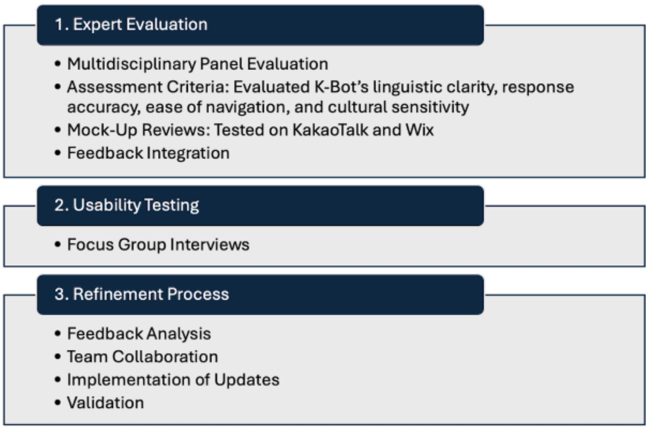
11:13 PM Next

HPV Education

Structured Evaluation and Refinement Process

The evaluation and refinement of K-Bot followed 3 distinct phases: (1) expert evaluation, (2) usability testing, and (3) refinement (Figure 3).

Figure 3. Evaluation and refinement process of K-Bot.



1. Expert Evaluation
- Multidisciplinary Panel Evaluation
- Assessment Criteria: Evaluated K-Bot's linguistic clarity, response accuracy, ease of navigation, and cultural sensitivity
- Mock-Up Reviews: Tested on KakaoTalk and Wix
- Feedback Integration

2. Usability Testing
- Focus Group Interviews

3. Refinement Process
- Feedback Analysis
- Team Collaboration
- Implementation of Updates
- Validation

Expert Evaluation

A multidisciplinary panel conducted a comprehensive evaluation of K-Bot, leveraging expertise in health care, cultural studies, AI, and community engagement. The panel included a clinician specializing in HPV prevention, researchers with extensive knowledge of Korean culture and its influence on health behaviors, an AI specialist experienced in chatbot development, and students in health-related fields representing Korean community perspectives. This diverse composition enabled a holistic assessment, ensuring the chatbot's clinical relevance, cultural sensitivity, technical functionality, and alignment with community needs.

The evaluation process systematically assessed K-Bot's responses, navigation, and cultural appropriateness using predefined criteria. These criteria included linguistic clarity, response accuracy, ease of navigation, and the cultural framing of sensitive topics, such as HPV vaccination. The usability evaluation framework incorporated principles from the International Organization for Standardization (ISO) 9241-11 standards, emphasizing efficiency, effectiveness, and user satisfaction to ensure comprehensive assessment [27]. The chatbot's response design followed a structured methodology that incorporated synonyms, key phrases, and importance ratings on a scale of 1-5, with 5 indicating the highest priority for delivering critical information. Experts rated responses based on their relevance, clarity, and alignment with the cultural and informational needs of the target audience, ensuring the chatbot provided accurate and contextually appropriate replies.

The research team conducted mock-up reviews to evaluate the chatbot before usability testing. One review used the English version, and the other used the Korean version of the chatbot. Additionally, the team tested the chatbot on 2 different platforms: KakaoTalk and Wix. These sessions focused on identifying areas for improvement, such as simplifying technical terms, integrating culturally relevant idioms, and enhancing navigation flow to optimize the user experience before moving forward with usability testing involving participants.

Iterative improvements based on the research team's feedback were incorporated into the chatbot's design, prioritizing culturally sensitive topics and user-relevant queries. Linguistic clarity was enhanced by simplifying technical terms and integrating culturally relevant idioms to increase accessibility. These revisions were discussed and validated during research team meetings, confirming improvements in usability, cultural sensitivity, and alignment with the needs of Korean immigrants and Korean American users.

Usability Testing

Recruitment and Eligibility

Participants were recruited using a combination of the researchers' networks, a community-engaged approach, and social media platforms guided by the previous successful recruitment [6]. Recruitment efforts were centered around the research theme, "Let's Talk About HPV," which was designed to engage participants and emphasize the importance of learning about HPV and its vaccine. Potential participants who expressed interest in the study were contacted within 1 week by research personnel to confirm their eligibility. Eligibility criteria included (1) individuals aged 18-45 years, (2) possession of a mobile phone or a computer with internet access, (3) residence in the United States, and (4) fluency in English or Korean. Upon confirming eligibility, research personnel scheduled an interview and provided participants with a password-protected Zoom link via email.

Usability Testing Procedures

Usability testing was conducted between May and June 2022, involving 21 Korean American participants who were divided into 6 focus groups, with each group consisting of 2-5 individuals. The variation in group size allowed us to accommodate participants' availability and facilitate in-depth discussions. Data saturation was monitored by the facilitators throughout the sessions. Each focus group session lasted approximately 60-90 minutes. Only audio recordings were used for data analysis, ensuring that participants' identities remained confidential. Participants were encouraged to use pseudonyms instead of real names to promote anonymity. The primary objective of this study was to gather feedback on the K-Bot rather than to explore participants' awareness and attitudes toward HPV prevention. Therefore, the sensitive nature of HPV-related questions was minimal. Participants were informed about the purpose of the study, the voluntary nature of participation, and their right to withdraw at any time without consequence.

Each usability testing session followed a structured protocol to ensure consistency and comprehensive data collection:

- Introduction: Participants were introduced to the study, its objectives, and the importance of their feedback in improving the chatbot's functionality and cultural relevance. The project's development history, including initial focus on Korean college women and subsequent expansion to a broader age range, including both men and women, was explained.
- Consent and survey: After reviewing the study information sheet and agreeing to participate, participants were provided with an online survey. This survey collected information about their sociodemographic characteristics, awareness of HPV, the HPV vaccine, and their vaccination status.
- Preinteraction discussion: Prior to interacting with K-Bot, participants were asked questions regarding their familiarity with HPV-related topics and any previous experience with chatbots. Specifically, we discussed whether they had heard of HPV or its vaccine and whether they believe they had received adequate information about the topic.
- Chatbot interaction: After completing the survey, participants received a link via email to interact with K-Bot. They were reminded that the chatbot was available in both English and Korean languages. At this stage of development, the K-bot experience consisted of 2 parts: a 32 question-and-answer (Q&A)–style survey, followed by the interactive chatbot. Participants were encouraged to document any errors, navigation challenges, or suggestions for improvement during their interaction. Additionally, K-Bot provided links to external resources, such as CDC

PDF files, to test its interoperability and ensure seamless access to supplementary health information.
- Postinteraction feedback: We asked participants questions guided by Peter Morville's honeycomb model [27], as shown in Table 1. Participants were asked about usability, ease of navigation, adequacy of information, reliability of chatbot responses, and integration with external resources. They also provided suggestions for improvement. After the interview, participants received a US $20 Amazon gift card as compensation for their time and input.

Table 1. Semistructured interview questions with Morville's usability framework.

Usability dimension	Definition	Corresponding interview questions
Usability	Ensures the system is easy to use and navigate	• How was your experience with K-Bot? Did you find it easy? • Were the buttons and navigation clear and easy to understand?
Usefulness	Determines whether the system provides valuable and relevant content	• Was there enough information provided by the chatbot?
Credibility	Evaluates the reliability and trustworthiness of the system's responses	• Were the responses from the chatbot reliable?
Findability	Assesses the ease of accessing information within the system	• Was it interoperable with external sources? • Were the PDF files for the CDCa resource pages loading and adequate?
Desirability	Examines the appeal and attractiveness of the system design	• What did you think about the overall design of the chatbot? • Did you find the chatbot visually appealing and engaging?
Accessibility	Ensures the system is available and usable for a diverse audience	• Was there any information you wish was included in the chatbot?
General feedback	Captures any additional participant input for further refinement	• Any additional comments?

Data Collection and Analysis

An online survey that takes 5-10 minutes was conducted prior to qualitative interviews to gather insights into participants' demographics (eg, age, sex, cultural identification, generational status, educational attainment, marital status, employment status, and annual household income), HPV awareness, and vaccination status. Quantitative data were analyzed using descriptive statistics with SPSS version 28 (IBM Corp). All focus group sessions were recorded using Zoom, and audio recordings were captured via Audacity [28] as backup. Transcriptions were manually prepared and saved in Microsoft Excel, with anonymized participant IDs to maintain confidentiality. We monitored the duration of participants' interactions with K-Bot, which typically lasted about 10-15 minutes. All data were stored securely on password-protected drives.

Qualitative data were manually analyzed using a systematic thematic analysis to identify recurring patterns in feedback. The analysis followed Braun and Clarke's 6-phase framework: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report [29]. Transcripts were independently coded, guided by 2 researchers using Morville's usability framework, covering aspects such as usefulness, usability, findability, credibility, accessibility, desirability, and value. Coding discrepancies were resolved through discussion to ensure a systematic approach.

Refinement

The refinement process was structured to systematically integrate insights from usability testing into iterative improvements into the chatbot's design and functionality. Feedback collected during usability sessions was reviewed and categorized into thematic areas, including navigation, content clarity, and technical performance.

- Feedback analysis: All participant suggestions, navigation issues, and identified gaps were documented and categorized. For example, repeated difficulties with navigating back to previous sections were flagged as high-priority issues.
- Team collaboration: Key findings were shared with the chatbot development team during research team meetings. Actionable items were prioritized based on their potential impact on user experience and alignment with study objectives.
- Implementation of updates: Adjustments were implemented through CloudTuring. Navigation was improved by adding clearer button labels and a dedicated Help section to guide users. The content was expanded to include additional HPV-related information that participants indicated as missing. Machine learning algorithms were updated to improve response accuracy and ensure that the chatbot delivered contextually relevant answers.
- Validation: Updates were tested internally by the research team to ensure that changes effectively addressed the

identified issues, contributing to the dependability and confirmability of the intervention's iterative development.

Results

Quantitative Findings

Sociocultural Demographic Characteristics

As presented in Table 2, participants had a mean age of 23.67 (SD 4.66) years. The majority were female (12/21, 57.1%), second-generation individuals (13/21, 61.9%), and single (20/21, 95.2%).

Table 2. Demographic characteristics of focus group participants (N=21).

Characteristics	Value
Age (years; range 18-37), mean (SD)	23.67 (4.66)
Sex, n (%)	
Female	12 (57.1)
Male	9 (42.9)
Cultural identification, n (%)	
Completely or more Korean than American	6 (28.5)
Equally Korean and American	9 (42.9)
More American than Korean	6 (28.6)
Generational status, n (%)	
First generation (born outside the United States)	8 (38.1)
Second generation (born in the United States)	13 (61.9)
Education, n (%)	
High school degree or equivalent	6 (28.6)
Some college, no degree	3 (14.3)
Bachelor's degree	9 (42.9)
Master's degree	3 (14.3)
Marital status, n (%)	
Single (never married)	20 (95.2)
Married or in a domestic partnership	1 (4.8)
Current employment status, n (%)	
Full time (≥40 hours)	9 (42.9)
Part time (≤39 hours)	2 (9.5)
Student	10 (47.6)
Annual household income (US $), n (%)	
<50,000	8 (38.1)
50,000-99,999	8 (38.1)
≥100,000	5 (23.8)

Awareness of HPV and HPV Vaccination

As presented in Table 3, most participants had heard of HPV (19/21, 90.5%) and the HPV vaccine (18/21, 81.8%). Half (11/21, 52.4%) of them had received the HPV vaccine, with 7 (63.6%) of the 11 participants completing all 3 doses.

Table 3. HPV[a] awareness and vaccination status of focus group participants by sex (N=21).

Characteristics	Female (n=12) frequency, n (%)	Male (n=9) frequency, n (%)
Heard of HPV before this study		
Yes	11 (91.7)	8 (88.9)
No	1 (8.3)	1 (11.1)
Heard of HPV vaccine or Gardasil before this study		
Yes	11 (91.7)	7 (77.8)
No	1 (8.3)	2 (22.2)
Received the HPV vaccine		
Yes	7 (58.3)	4 (44.4)
No	0	3 (33.3)
Do not know	5 (41.7)	2 (22.2)
Number of HPV vaccine doses received (n=11)		
1	0	1 (25.0)
2	2 (28.6)	1 (25.0)
3	5 (71.4)	2 (50.0)

[a]HPV: human papillomavirus.

Qualitative Findings and Refinement

Based on the preinteraction discussion and postinteraction feedback, participants highlighted the importance of K-Bot's bilingual functionality, expressing appreciation for its ability to deliver information in both English and Korean. Many found the information about HPV and the HPV vaccine to be helpful, with some sharing that they learned new details they were previously unaware of. Some participants who had completed middle and high school in Korea had never heard of HPV and its vaccine. Some participants also shared they came in with the preconception that the vaccine was primarily for women's health. However, after interacting with the chatbot, 1 (4.8%) female participant stated, "I feel like I would want my spouse, or partner, to have it." One male participant mentioned that he thought he would not be affected by HPV, but the interactions with K-Bot "put it into perspective that maybe I'm also prone to it." This positive change in sentiment toward the HPV vaccine was shared by other male participants in the focus groups.

The usability of the K-Bot intervention was evaluated through focus group interviews guided by Morville's usability framework:

- Usability: Focus group participants found that the Q&A format at the beginning of the interaction was time-consuming as some "stopped reading the info after answering the question" and found it "cumbersome." The Q&A section was removed and consolidated into the interactive portion. However, participants found the chatbot's button-based Q&A format simple and intuitive, with 1 (4.8%) participant mentioning it was like a "very guided Q&A session." Several requested more detailed information about complex topics, such as stress and HPV. To address this, expandable sections were introduced into the interactive K-Bot, allowing users to delve deeper into specific topics, while maintaining the simplicity of the button-based structure.
- Usefulness: External links to resources were valued for their credibility, but broken links were noted as a barrier to usability. All external links were repaired, and additional resources, including directories of health care providers, were added to ensure comprehensive support. Tailored resources were also developed to meet the needs of specific demographics, particularly first-generation Korean Americans. For instance, 1 (4.8%) participant voiced that "it would be helpful if you add the term [for HPV] that is used more generally in Korea" since they may not recognize the term "human papilloma virus" or "HPV."
- Credibility: The credibility of the chatbot was bolstered by its evidence-based content and integration with trusted sources, such as the CDC. However, participants emphasized the importance of culturally relevant information tailored to Korean Americans, especially for those more familiar with Korean resources. Automatic PDF file downloads were replaced with direct links to reputable sources as participants did not like "surprise downloads crowding the phone." This change ensured easier access, while maintaining trust, especially with concerns about the possibility of users not "trusting the information on the K-Bot." Additionally, culturally sensitive content and terms were refined to resonate with the target demographic.
- Findability: Participants appreciated the structured menus but reported difficulties navigating the menu items at the medium and minor classifications. For instance, 1 (4.8%) participant remarked, "I kept forgetting what I read versus what I did not read, because there were so many subcategories." To resolve this, the final menu options were simplified through consolidation of similar topics, and a search function was added to help users quickly locate relevant information. Visual cues, such as highlighted

buttons and GIFs, were also incorporated to guide users more effectively through the content.

- Desirability: To increase desirability, participants suggested incorporating visual elements to improve engagement and support users with varying health literacy. In response, GIFs and images were added to the chatbot interface. One participant commented, "The menu items were clear but could use more explanations for people who are not familiar with medical terms." Additional descriptions were added to clarify technical terms, and a "Back" button was introduced to enable users to revisit previously accessed information, enhancing overall navigation.
- Accessibility: Although participants found the chatbot intuitive, some noted challenges with language switching and navigation at the end of interactions. For example, 1 (4.8%) participant shared, "It was not immediately clear how to switch languages at the beginning." To address this, clearer instructions for language switching were integrated during onboarding, and the navigation flow was streamlined to ensure smooth transitions, particularly during extended interactions. Button formats were also standardized for greater usability.

Feedback from participants provided valuable insights into their interaction with the chatbot and informed specific refinements to enhance its effectiveness (Table 4). Key refinements were implemented based on usability testing to address the needs of Korean immigrants and Korean American users and optimize the intervention for promoting HPV vaccination.

Table 4. Findings from semistructured interviews and refinements.

Usability dimension	Findings	How the findings were addressed
Usability	• The button-based navigation was intuitive. • Participants suggested adding a "Back" button. • Some users were confused by the language selection.	• A "Back" button was introduced to enable participants to revisit previously accessed information. • Language-switching instructions were made clearer and added as part of the onboarding.
Usefulness	• Participants valued information about HPV[a] transmission and vaccination. • External links (eg, CDC[b] fact sheets) were credible and useful. • Suggestions included using visuals to reduce cognitive load.	• Animated GIFs were integrated to complement text-heavy content. • External links were checked, repaired, and updated. • Resources were tailored to specific demographics, especially first-generation Korean Americans.
Credibility	• Evidence-based content and links to trusted sources enhanced credibility. • Feedback emphasized culturally sensitive language and early trust building.	• Automatic PDF file downloads were replaced with direct links to trusted sources, such as the CDC. • Culturally relevant terms and tailored content for Korean Americans were refined. • An introductory message established credibility and outlined the chatbot's purpose.
Findability	• Menus were structured and effective but sometimes overwhelming. • A simplified navigation structure was recommended.	• The final menu options were simplified, and a search function was added to help users quickly locate relevant information. • Visual cues, such as highlighted buttons and GIFs, were incorporated to improve findability and guide users effectively.
Desirability	• Clear icons and buttons were appreciated. • Suggestions were made for animations and introduction videos to enhance engagement.	• Visual elements, including GIFs and images, were introduced to engage users. • Animations and a 2-minute introduction video were included to enhance user appeal.
Accessibility	• Bilingual support in English and Korean was well received. • Broken links hindered accessibility; regular updates were suggested.	• An email address for the bilingual researcher was added to allow participants to report any issues with broken links or accessibility.
General feedback	• Suggestions for demographic-specific content, clearer instructions, and interactive features were provided. • Misconceptions about the HPV vaccine being unnecessary for men were corrected. • Participants realized the importance of vaccinating at a young age.	• Demographic-specific resources and culturally sensitive information were added. • A brief instruction page and visual cues were included to guide users through the chatbot. • The culturally tailored K-Bot fostered a more open and informed dialogue, centered around increasing the awareness and understanding of HPV.

[a] HPV: human papillomavirus.

[b] CDC: Centers for Disease Control and Prevention.

Discussion

Principal Findings

This study examined the development and usability evaluation of K-Bot, an AI chatbot created to provide bilingual, culturally sensitive health information about HPV vaccination for Korean immigrants and Korean Americans. The study assessed the chatbot's usability in delivering accurate health information and identified both strengths and areas for refinement, contributing to the optimization of chatbot-based health interventions aimed at promoting behavior change and informing the development of more targeted and effective strategies in future implementation trials.

This study found that although participants exhibited high awareness of HPV and its vaccine, actual vaccine uptake remained low, particularly among male participants. Participants reported that K-Bot addressed this disparity by providing inclusive education, which is critical for promoting vaccine uptake among all individuals. Participants identified K-Bot's bilingual functionality and culturally tailored content as significant strengths, with the dual-language option allowing access to health information in both English and Korean. This finding highlights the necessity of linguistic inclusivity in digital health tools to engage diverse populations effectively. However, the usability evaluation revealed areas for improvement, including navigation complexity, challenges with language selection, and limited visual engagement. Although this study incorporated GIFs and images to improve visual engagement and support users with varying levels of health literacy, these enhancements alone may be insufficient to address the broader and more nuanced challenges faced by diverse user populations. Addressing these limitations through iterative design refinements and leveraging emerging technologies, such as multimodal conversational systems, could further optimize K-Bot's usability and impact on health behavior change.

Comparison With Prior Work

The findings of this study align with the existing literature, indicating that HPV vaccination is often perceived as primarily relevant to women, particularly within the Korean community [12,25,30]. Previous research has shown that cultural perceptions and public health messaging in Korea have historically targeted females, contributing to persistent disparities in vaccination rates by sex [31]. This misconception can be traced back to Korea's initial HPV vaccination program, which was launched in 2016, focusing exclusively on adolescent girls before expanding to include boys in 2024 [32]. This focus on vaccinating only specific groups likely influenced public attitudes among Koreans and Korean Americans, as immigrant health behaviors are often shaped by practices from their country of origin [12,25]. This exclusion of boys may have perpetuated misconceptions in Korean American communities, furthering barriers to vaccine uptake, particularly where familial and community norms strongly influence health decisions, [33]. Similar findings in previous studies suggest that these culturally ingrained beliefs can create significant barriers to HPV vaccination among males, necessitating targeted educational intervention [12]. Addressing these challenges requires inclusive education tailored to Korean Americans, which highlights the importance of HPV vaccination for all individuals in preventing disease and reducing transmission. Participants shared that the chatbot helped correct the belief that HPV vaccination is exclusively for women, a misconception that has been widely documented in the literature as a significant barrier to male vaccination [34]. Culturally tailored digital interventions, such as K-Bot, have the potential to play a critical role in addressing these challenges.

K-Bot's culturally tailored approach aligns with a growing body of research advocating for the use of culturally sensitive design elements. Studies have shown that culturally sensitive design elements, such as language adaptability, empathy, and humor, enhance user trust, engagement, and the overall efficacy of digital health interventions [35]. By integrating a culturally sensitive design, K-bot exemplifies the potential of AI-driven technologies to mitigate health care disparities by improving access to accurate, culturally relevant health information. The study also adds to the emerging evidence on the existing literature focusing on culturally tailored digital interventions in mitigating barriers to HPV vaccination. Although the domain of culturally adapted chatbots remains underexplored, this study reinforces the critical need for such interventions to address cultural stigmas and misconceptions surrounding HPV. The existing literature highlights the critical need for culturally sensitive interventions, especially given the deeply rooted cultural stigmas and misconceptions surrounding STIs in many Asian American communities [36,37]. These stigmas often act as significant deterrents, discouraging open discussions about HPV vaccination, particularly among Asian immigrant populations where cultural norms may further limit access to accurate health information [37]. By directly addressing these cultural and linguistic barriers, K-Bot represents an important advancement in leveraging AI-driven tools to deliver tailored health information and promote equitable access to preventative care.

Strengths and Limitations

This study's strengths lie in its rigorous, iterative design process, combining expert evaluation with participatory user feedback to optimize K-Bot's functionality. Integrating user feedback into iterative refinements follows the best practices in participatory design for digital health interventions [37], emphasizing the importance of collaborative frameworks in enhancing usability and user satisfaction.

This study has several limitations that should be considered when interpreting the findings. First, the limited sample size reduces the generalizability of the results, as the insights gained may not fully represent the broader population. Second, although K-Bot's culturally tailored design was well received by this specific group, its applicability to other Asian American subgroups or culturally diverse populations remains uncertain. Lastly, the study primarily relied on self-reported data, introducing potential biases, such as social desirability and recall bias, which may affect the accuracy of the findings.

Future Research Directions

The findings underscore K-Bot's potential as both a stand-alone intervention and an integrated tool within health care systems to address HPV vaccination disparities. Future research should focus on evaluating its feasibility and efficacy through rigorous trials, with particular attention to its scalability across diverse health care settings. Longitudinal studies are essential to assess K-Bot's sustained impact on vaccination uptake and behavior change. Expanding K-Bot to other Asian American subgroups would enhance its adaptability and engagement, addressing the heterogeneity within these populations. K-Bot's reliance on NLP, while effective in delivering structured and evidence-based information, presents limitations in managing open-ended queries. K-Bot was developed prior to the emergence of generative AI technologies, such as Chat Generative Pretrained Transformer (ChatGPT). The recent literature examining the application of ChatGPT in nursing education, practice, and research highlights several advantages of generative AI [38]. These capabilities suggest significant potential for enhancing K-Bot's functionality by enabling more dynamic, context-sensitive, and user-centered interactions. However, as noted in the literature, ethical considerations, such as minimizing misinformation and ensuring cultural sensitivity, must be prioritized to safeguard the intervention's credibility and trustworthiness [38]. Although K-Bot's reliance on NLP ensures accurate, evidence-based responses, its limited ability to manage open-ended queries highlights a need for integrating advanced AI technologies to better meet user needs. Additionally, usability feedback from this study may differ among various age groups, with younger users potentially being more tech-savvy than older adults. Future iterations of K-Bot could explore tailoring its interface and functionality to accommodate different subgroups, such as adolescents and parents, to enhance user engagement and satisfaction.

Conclusion

In conclusion, K-Bot exemplifies an innovative, culturally sensitive approach to addressing HPV vaccination disparities among Korean Americans. By delivering personalized, bilingual health information, K-Bot has successfully demonstrated its potential to overcome barriers related to language, stigma, and misinformation. Although the study's findings are encouraging, they are based on a smaller sample size, and further research is needed to validate these results across a broader and more diverse population. Refinement of the chatbot's usability and potential customization for different age groups and cultural contexts could enhance its effectiveness. The positive reception of K-Bot suggests it could be a scalable tool for public health interventions. Exploring the application of AI-driven chatbots in other populations remains a promising avenue for addressing health inequities and promoting equitable health care access.

Acknowledgments

We thank Dreamyoungs for its contribution to the development of the intervention. We also extend our gratitude to our research participants for their invaluable feedback during the usability testing phase.

This work was funded by the University of Cincinnati's Office of the Vice President for Research and supported by the National Institutes of Health/National Institute of Nursing Research (NIH/NINR K23 grant K23NR02034).

Data Availability

Data are presented in the main manuscript.

Conflicts of Interest

None declared.

References

1. Kombe Kombe AJ, Li B, Zahid A, Mengist HM, Bounda G, Zhou Y, et al. Epidemiology and burden of human papillomavirus and related diseases, molecular pathogenesis, and vaccine evaluation. Front Public Health 2020 Jan 20;8:552028 [FREE Full text] [doi: 10.3389/fpubh.2020.552028] [Medline: 33553082]
2. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2018. CA Cancer J Clin 2018 Jan;68(1):7-30 [FREE Full text] [doi: 10.3322/caac.21442] [Medline: 29313949]
3. Liao C, Francoeur AA, Kapp DS, Caesar MAP, Huh WK, Chan JK. Trends in human papillomavirus–associated cancers, demographic characteristics, and vaccinations in the US, 2001-2017. JAMA Netw Open 2022 Mar 01;5(3):e222530 [FREE Full text] [doi: 10.1001/jamanetworkopen.2022.2530] [Medline: 35294540]
4. Meites E, Szilagyi PG, Chesson HW, Unger ER, Romero JR, Markowitz LE. Human papillomavirus vaccination for adults: updated recommendations of the Advisory Committee on Immunization Practices. MMWR Morb Mortal Wkly Rep 2019 Aug 16;68(32):698-702 [FREE Full text] [doi: 10.15585/mmwr.mm6832a3] [Medline: 31415491]
5. FDA approves expanded use of Gardasil 9 to include individuals 27 through 45 years old. US Food and Drug Administration. 2018 Oct 05. URL: https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm622715.htm [accessed 2025-06-07]
6. Kim M, Lee H, Kiang P, Aronowitz T, Sheldon LK, Shi L, et al. A storytelling intervention in a mobile, web-based platform: a pilot randomized controlled trial to evaluate the preliminary effectiveness to promote human papillomavirus vaccination

in in Korean American college women. Health Educ Behav 2020 Apr 20;47(2):258-263 [FREE Full text] [doi: 10.1177/1090198119894589] [Medline: 31958991]
7. Jo S, Han S, Walters CA. Factors associated with the HPV vaccination among Korean Americans and Koreans: a systematic review. Int J Environ Res Public Health 2021 Dec 21;19(1):51 [FREE Full text] [doi: 10.3390/ijerph19010051] [Medline: 35010311]
8. Hong YA, Yee S, Bagchi P, Juon H, Kim SC, Le D. Social media-based intervention to promote HBV screening and liver cancer prevention among Korean Americans: results of a pilot study. Digit Health 2022;8:20552076221076257 [FREE Full text] [doi: 10.1177/20552076221076257] [Medline: 35140979]
9. Niccolai LM, Hansen CE. Practice- and community-based interventions to increase human papillomavirus vaccine coverage: a systematic review. JAMA Pediatr 2015 Jul;169(7):686-692 [FREE Full text] [doi: 10.1001/jamapediatrics.2015.0310] [Medline: 26010507]
10. Tinmaz H, Lee JH. General and instructional perceptions of South Korean messenger: 'KakaoTalk'. IJLC 2020;12(2):143. [doi: 10.1504/ijlc.2020.106715]
11. Lee K, Seo C, Shuffler J, Miyawaki C, Grill J, Shin H. Examining physical and social environments of Korean American family caregivers of persons living with dementia. Innov Aging 2021;17(5 Suppl 1):908. [doi: 10.1093/geroni/igab046.2959]
12. Kim M, Güler A, Kim D, Lee RC. A qualitative study of ethnic Korean women and men's experiences of HPV and HPV vaccination in the United States. Ethn Health 2024 Feb 16;29(2):179-198. [doi: 10.1080/13557858.2023.2279933] [Medline: 37970802]
13. Rani U, Darabaner E, Seserman M, Bednarczyk RA, Shaw J. Public education interventions and uptake of human papillomavirus vaccine: a systematic review. J Public Health Manag Pract 2022;28(1):E307-E315. [doi: 10.1097/PHH.0000000000001253] [Medline: 33208719]
14. Zhang X, Tang L. Cultural adaptation in HPV vaccine intervention among racial and ethical minority population: a systematic literature review. Health Educ Res 2022 Jan 27;36(5):479-493. [doi: 10.1093/her/cyab034] [Medline: 34542147]
15. Moon J. The digital wash place: mobile messaging apps as new communal spaces for Korean 'smart Ajummas'. In: Cabañes JVA, Uy-Tioco CS, editors. Mobile Media and Social Intimacies in Asia. Dordrecht: Springer Netherlands; 2020:63-76.
16. Aggarwal A, Tam CC, Wu D, Li X, Qiao S. Artificial intelligence–based chatbots for promoting health behavioral changes: systematic review. J Med Internet Res 2023 Feb 24;25:e40789 [FREE Full text] [doi: 10.2196/40789] [Medline: 36826990]
17. Gabrielli S, Rizzi S, Carbone S, Donisi V. A chatbot-based coaching intervention for adolescents to promote life skills: pilot study. JMIR Hum Factors 2020 Feb 14;7(1):e16762 [FREE Full text] [doi: 10.2196/16762] [Medline: 32130128]
18. Piao M, Kim J, Ryu H, Lee H. Development and usability evaluation of a healthy lifestyle coaching chatbot using a habit formation model. Healthc Inform Res 2020 Oct;26(4):255-264 [FREE Full text] [doi: 10.4258/hir.2020.26.4.255] [Medline: 33190459]
19. Choi J, Tamí-Maury I, Cuccaro P, Kim S, Markham C. Digital health interventions to improve adolescent HPV vaccination: a systematic review. Vaccines (Basel) 2023 Jan 22;11(2):249 [FREE Full text] [doi: 10.3390/vaccines11020249] [Medline: 36851127]
20. Kim Y, Lee H, Park J, Kim Y, Kim DH, Lee Y. eHealth communication intervention to promote human papillomavirus vaccination among middle-school girls: development and usability study. JMIR Form Res 2024 Oct 28;8:e59087 [FREE Full text] [doi: 10.2196/59087] [Medline: 39466304]
21. Tao C, Li Y, Li J, Li M, Yu E, Amith M, et al. VaxBot-HPV: a GPT-based chatbot for answering HPV vaccine-related questions. Res Sq Preprint posted online 2024. [doi: 10.21203/rs.3.rs-4876692/v1] [FREE Full text] [doi: 10.21203/rs.3.rs-4876692/v1] [Medline: 39315262]
22. From customer response to marketing, customer service automation with chatbots. CloudTuring. URL: https://www.cloudturing.com [accessed 2025-03-07]
23. The new way to cloud starts here. Google Cloud. URL: https://cloud.google.com [accessed 2025-03-07]
24. Build with Kakao developers. Kakao Corp. URL: https://developers.kakao.com [accessed 2025-03-07]
25. Kim M. Barriers to HPV vaccination among Korean men in the United States. CJON 2022 Jun 1;26(3):324-327. [doi: 10.1188/22.cjon.324-327]
26. Kim M, Lee H, Kiang P, Kim D. Human papillomavirus: a qualitative study of Korean American female college students' attitudes toward vaccination. Clin J Oncol Nurs 2017 Oct 01;21(5):E239-E247. [doi: 10.1188/17.CJON.E239-E247] [Medline: 28945722]
27. ISO 9241-11: ergonomics of human-system interaction. Part 11: usability: definitions and concepts. ISO. 2018. URL: https://tinyurl.com/bdcp6zzs [accessed 2025-03-07]
28. Audacity is the world's most popular audio editing and recording app. Audacity. URL: https://www.audacityteam.org [accessed 2025-03-07]
29. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
30. Kim M, Lee H, Kiang P, Aronowitz T, Sheldon LK, Shi L, et al. HPV vaccination and Korean American college women: cultural factors, knowledge, and attitudes in cervical cancer prevention. J Community Health 2019 Aug 12;44(4):646-655 [FREE Full text] [doi: 10.1007/s10900-019-00634-9] [Medline: 30863974]

31. Kim J, Jung M. Associations between media use and health information-seeking behavior on vaccinations in South Korea. BMC Public Health 2017 Sep 11;17(1):700 [FREE Full text] [doi: 10.1186/s12889-017-4721-x] [Medline: 28893212]
32. Vaccination information. National Immunization Program. Korea Disease Control and Prevention Agency. URL: https://nip.kdca.go.kr/irhp/infm/goVcntInfo.do?menuCd=132&menuLv=1 [accessed 2025-03-07]
33. Hong SJ. Gendered cultural identities: the influences of family and privacy boundaries, subjective norms, and stigma beliefs on family health history communication. Health Commun 2018 Aug 25;33(8):927-938. [doi: 10.1080/10410236.2017.1322480] [Medline: 28541817]
34. Dibble KE, Maksut JL, Siembida EJ, Hutchison M, Bellizzi KM. A systematic literature review of HPV vaccination barriers among adolescent and young adult males. J Adolesc Young Adult Oncol 2019 Oct 01;8(5):495-511 [FREE Full text] [doi: 10.1089/jayao.2019.0004] [Medline: 31090474]
35. Zhai C, Wibowo S. A systematic review on cross-culture, humor and empathy dimensions in conversational chatbots: the case of second language acquisition. Heliyon 2022 Dec;8(12):e12056. [doi: 10.1016/j.heliyon.2022.e12056]
36. Kim B, Aronowitz T. Invisible minority: HIV prevention health policy for the Asian American population. Policy Polit Nurs Pract 2019 Feb 16;20(1):41-49. [doi: 10.1177/1527154419828843] [Medline: 30774026]
37. Sen S, Nguyen HD, Kim SY, Aguilar J. HIV knowledge, risk behavior, stigma, and their impact on HIV testing among Asian American and Pacific Islanders: a review of literature. Soc Work Public Health 2017 Jan 02;32(1):11-29. [doi: 10.1080/19371918.2016.1173612] [Medline: 27410387]
38. Zhou Y, Li S, Tang X, He Y, Ma H, Wang A, et al. Using ChatGPT in nursing: scoping review of current opinions. JMIR Med Educ 2024 Nov 19;10:e54297-e54297 [FREE Full text] [doi: 10.2196/54297] [Medline: 39622702]

Abbreviations

ACIP: Advisory Committee on Immunization Practices
AI: artificial intelligence
CDC: Centers for Disease Control and Prevention
ChatGPT: Chat Generative Pretrained Transformer
HPV: human papillomavirus
NLP: natural language processing
Q&A: question-and-answer
STI: sexually transmitted infection

Edited by T Leung; submitted 29.01.25; peer-reviewed by I Sokale, H Ryu; comments to author 25.02.25; revised version received 03.03.25; accepted 04.03.25; published 07.04.25.

Please cite as:
Kim M, Kim E, Lee H, Piao M, Rosen B, Allison JJ, Zai AH, Nguyen HL, Shin DS, Kahn JA
A Culturally Tailored Artificial Intelligence Chatbot (K-Bot) to Promote Human Papillomavirus Vaccination Among Korean Americans: Development and Usability Study
Asian Pac Isl Nurs J 2025;9:e71865
URL: https://apinj.jmir.org/2025/1/e71865
doi:10.2196/71865
PMID:

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org