



Acceptability of HPV self-collection: A qualitative study of Black women living with type II diabetes and social vulnerability

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ARTICLE INFO

Keywords:

Cervical cancer
cancer screening
HPV self-collection
HPV self-sampling
diabetes
Disparities
Healthcare
Endocrinology
Special Populations

ABSTRACT

Introduction: Human papillomavirus (HPV) causes 99.7% of cervical cancer cases. Cervical cancer is preventable through early detection via HPV testing. However, the number of women screened for cervical cancer has not increased in the last several years. Lower screening rates among women living in high poverty and social vulnerability areas, Black women, and women with chronic co-morbidities (e.g., type 2 diabetes (T2D)) are associated with their higher cervical cancer mortality rates. When screened, Black women are more likely to be diagnosed at later stages and die from cervical cancer. HPV self-collection decreases barriers to cervical cancer screening and can help lessen disparities among underserved women. This study aimed to examine the acceptability of HPV self-collection among Black women with T2D living in socially vulnerable communities.

Methods: Qualitative semi-structured interviews were conducted with 29 Black women with T2D living in communities with high social vulnerability. The Health Belief Model informed the development of the interview guide to gather data on the acceptability of HPV self-collection.

Results: Three main themes aligned with the Health Belief Model were identified: (1) HPV self-collection provides a comfortable alternative to in-clinic HPV testing (perceived benefits); (2) HPV self-collection would result in awareness of current HPV status (health motivation); and (3) Women were concerned about collecting their sample accurately (perceived barriers).

Discussion/Conclusion: Black women with T2D living in communities with high social vulnerability identified multiple benefits of cervical cancer screening through HPV self-collection. Women are concerned about their ability to collect these samples correctly. Our findings call for future studies focusing on increasing self-efficacy and skills to collect HPV samples among Black women with chronic conditions like T2D who reside in underserved communities with high social vulnerability.

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<https://doi.org/10.1016/j.jcte.2024.100331>

Received 1 November 2023; Received in revised form 26 January 2024; Accepted 15 February 2024

Available online 25 February 2024

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Introduction

Cervical cancer is preventable, yet 11,542 women were newly diagnosed and 4,272 women died of the condition in the United States (U.S.) in 2020 [1]. Cervical cancer screening is credited with significantly decreasing mortality from cervical cancer in the U.S. [2]. Screening for cervical cancer can entail a cervical cytology (i.e., examining cervical cells for the presence of pre-cancerous cells collected from a woman's cervix), a human papillomavirus (HPV) test (i.e., detecting the presence of the HPV virus and, if found, determining if the viral strain is of a high-risk HPV subtype), or an age dependent combination of cervical cytology and HPV testing [2–4]. Cervical cancer mortality disparities may be explained by underscreening due to limited access to care and social-cultural factors including fatalistic attitudes, fear, HPV vaccine hesitancy, and limited knowledge and awareness of cervical cancer risk [5–7]. Understanding cervical cancer screening behaviors can be informed by the Health Belief Model (HBM) [8,9]. The HBM-related influences on cervical cancer screening uptake include the impact of cultural beliefs and attitudes in seeking preventive care [9].

Cervical cancer screening plays a crucial role in early detection and prevention of disease. When screening guidelines are followed, it allows for the detection and removal of pre-cancerous lesions and early-stage diagnosis of cervical cancer, improving the chances of successful treatment [10]. However, significant disparities exist in screening rates among different racial and ethnic groups. Data from a nationwide survey conducted among women in 2017 showed that Hispanic and non-Hispanic White women have 2.49 higher odds of receiving cervical cancer screening in the last 5 years compared to Hispanic and non-Hispanic Black women (95 % CI, 1.12–4.54) [11]. Notable, a separate study using 2018 National Health Interview Survey data found no significant differences in the rate of up-to-date screening when comparing Black women (77.8 %) to White women (77.9 %) [12]. In addition, Black women are more likely to be diagnosed with cervical cancer at regional and distant stages compared to White women [13].

Despite the screening disparities, Black women face numerous barriers to accessing cervical cancer screening. These barriers are both similar to barriers in the general population, such as poverty, lack of insurance, lack of transportation, and lack of knowledge about cervical cancer and screening [6,14,15], and unique to their lived experiences as an underserved group. Unique barriers include experiencing health care mistreatment that is associated with racism, fear and mistrust of the health care system, and competing priorities that hinder timely screening [6,15–17].

Disparities in cervical cancer mortality are exacerbated by social vulnerability [18]. The social vulnerability index is a census measure that quantifies level of external stressors including household characteristics, socioeconomic status, racial and minority status, and access to reliable transportation that disproportionately threaten communities' ability to address health challenges [19]. Individuals living in areas with high social vulnerability and rural areas have significantly lower cervical cancer screening rates [20]. A significantly higher proportion of racial/ethnic minority populations live in high social vulnerability areas than the White population, resulting in inequities in health outcomes [21]. Disparities faced by the Black population in the context of healthcare access and mistrust is a complex issue deeply rooted in history. Historical events and a legacy of discrimination have sown deep-seated mistrust of the healthcare system [22]. Access to quality healthcare remains a challenge due to limited access to facilities in Black communities, transportation issues, and socioeconomic disparities. Cultural competency gaps in healthcare providers, along with racial bias, can further erode trust [23].

Type 2 diabetes (T2D) is a risk factor that is associated with poor survival for cervical cancer, as highlighted in a systematic review published in 2017 [24]. Black women with T2D have 55 % higher odds of being diagnosed with cervical compared to white women with T2D [18]. Women living with T2D are less likely to receive cervical cancer

screening [25]. In the U.S., the proportion of Black individuals living with T2D is higher (12.1 %) when compared to White individuals (7.4 %) [26]. A 2021 study of women living in the southern U.S. found that women with T2D are significantly less likely to receive HPV testing compared to women without T2D [25]. According to a recent study using statewide clinical data in Florida, Black women living with diabetes have higher odds of being diagnosed with cervical cancer compared to White women living with diabetes [18]. Clinicians have shared that prioritizing the management of chronic medical diseases such as diabetes interferes with cervical cancer screening [27]. As a result, diabetes exacerbates cervical cancer diagnosis for Black women living with T2D.

The intrusive nature of a clinically performed pelvic examination to collect cervical cells for testing is a barrier to screening among Black women [28,29]. The American Cancer Society's most updated guidelines recommend primary HPV screening as the most sensitive test to screen for cervical cancer [2]. Among low-income Black women, emerging studies show that HPV self-collected screening, which allows women to collect samples for screening themselves, is acceptable because it is convenient, decreases anxiety, and is less painful and uncomfortable compared to provider-collected samples [30,31]. Self-collection increases the uptake of screening [32,33].

Management of pre-existing chronic medical diseases may be prioritized over cervical cancer screening in time-limited primary care visits [27]. Given that self-management of T2D entails several aspects of care, including self-monitoring of glucose levels, medication management, and other factors, HPV self-collection may provide an alternative addressing time limitations and underscreening for women with T2D with limited access to care. Despite this, there is a lack of literature on understanding HPV self-collection perceptions of Black women living with T2D and in neighborhoods with high social vulnerability. This study examined the acceptability of HPV self-collection tests among Black women with T2D living in areas with high social vulnerability.

Material and Methods

Participants

We recruited women who received care from a large academic medical center in the Southeastern U.S. and had previously given their consent to be contacted by researchers. Inclusion criteria included women who met the following: 1) identify as Black, 2) between 25 and 65 years of age, 3) have a diagnosis of T2D, 4) no prior diagnosis of cervical cancer or hysterectomy, and 5) live in a census tract area representing the highest two quartiles of social vulnerability scores. We identified women who met the inclusion criteria and invited them to participate in the study. Women were initially contacted once via email and then through one phone call for recruitment. Team members (SB, YM) recruited participants and conducted informed consent over the phone with participants signing consent forms electronically in Research Electronic Data Capture (REDCap). [34] REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources [34,35]. One-on-one interviews lasting between 45 and 60 min were conducted via Zoom by RSM and CC. Interviews were audio recorded and transcribed verbatim for analysis. Survey and interview notes were managed with REDCap. The study was approved by the University of Florida Institutional Review Board (IRB# IRB202101112).

Framework for measures

The Health Belief Model [8,9] informed a semi-structured interview

guide to gather data on cultural beliefs and attitudes regarding cervical cancer and preventive screening procedures. Participants were asked about their perceived benefits and barriers of HPV self-collection after a description of self-selection tests was provided. We asked participants about factors that would influence their decision to self-collect their sample for testing, information they would need to collect their own sample, their self-efficacy, perceived advantages and disadvantages, and whether they prefer self-collection or a test performed by their clinicians (Supplement 1).

Analysis

Interviews of 29 participants were professionally transcribed verbatim. Descriptive statistics were conducted via SPSS, while qualitative data were coded manually. Initial coding involved using the interview guide to code transcripts by categories corresponding to the interview guide. Interviews were coded independently by five researchers (RSM, KS, SB, SO, and AR). Codes pertinent to HPV self-collection were selected for this manuscript. Thematic analysis using a data-driven approach was then applied to analyze the HPV self-collection transcripts [36]. Transcripts were re-read, and codes were generated using line-by-line coding. The codes were then used to form a codebook, which the five researchers used to code transcripts. The researchers met to resolve conflicts and generate or modify codes. After the initial round of coding, codes were organized into groups and named to conceptualize themes. The main codes and themes highlighted in this manuscript were selected based on frequency of occurrence.

Results

A total of 29 participants participated in this study, the majority (n = 20, 69 %) were above the age of 45 years, (n = 11, 38 %) had completed some college or more, (n = 13, 45 %) were married, and more than half

Table 1
Demographic characteristics of participants.

Characteristic	Total (n = 29)	Percent of Total
Age (years)		
25 – 39	8	27.5 %
40 – 49	6	20.6 %
50 – 59	7	24.1 %
60 – 69	8	27.6 %
Education		
Left school and did not get a high school diploma or GED	3	10.3 %
High school diploma	5	17.2 %
Some college classes	9	31.0 %
2-year or 3-year college degree (associate degree)	2	6.9 %
4-year college degree	7	24.1 %
Master's degree	3	10.3 %
Marital Status		
Never been married	8	27.6 %
Married	13	44.8 %
Widowed	3	10.3 %
Separated	1	3.4 %
Divorced	4	13.8 %
Access to Health Insurance		
Insured	29	100 %
*Health Insurance Type		
Medicaid	17	58.6 %
Medicare	5	17.2 %
Private Insurance	8	27.6 %

*One participant was enrolled in both Medicaid and Medicare.

(n = 17, 59 %) had Medicaid insurance (See Table 1). Five participants shared that they would not be willing to do an HPV self-collection test, (n = 4) had at least some college education or more, (n = 3) were married, (n = 3) had Medicaid insurance, and all participants were over the age of 50 years.

The three main themes identified aligned with the Health Belief Model: (1) HPV self-collection provides a comfortable alternative to in-clinic HPV testing (perceived benefits); (2) HPV self-collection would result in awareness of current HPV status (health motivation); and (3) Women were concerned about collecting their sample accurately (perceived barriers) (See Table 2).

THEME 1: PERCEIVED BENEFITS - HPV SELF-COLLECTION PROVIDES a COMFORTABLE ALTERNATIVE WAY TO IN-CLINIC HPV TESTING

With clinician collected samples from the cervix via a pelvic exam, women reported fear of pain from the screening procedure as a barrier to cervical cancer screening. Participants shared that HPV self-collection would allow them to collect the sample in the comfort and privacy of their homes while reducing fear of experiencing pain from collecting the sample. One participant shared:

“I think it will be easier, because I’m in the comfort of my own home. So, I won’t mind, like I won’t be afraid to take it.” (Participant 13).

Another patient shared that HPV self-collection would be less painful as they can control the sample collection from their bodies.

“But even other women who do the Pap smear are very rough, and like I said, I have a small cervix, and you can be rough with everybody. So, I can do it, and I know what I can take and what I can handle than having somebody else do it. That makes me more comfortable.” (Participant, 08).

Patients shared that HPV self-collection would provide them with the opportunity to collect samples in a comfortable setting without having to deal with time constraints at the doctors’ offices; one patient shared:

“You could do it in the privacy of your own home. You might not feel as uncomfortable or rushed because the doctor sometimes they’re backed up, or they’re running behind ... they have so many other patients.” (Participant 07).

Another participant shared that the HPV self-collection test would be

Table 2
Thematic findings of perceived benefits, health motivation, and perceived barriers to HPV self-collection.

Themes	Key Findings	Example Quotes
Perceived Benefits of HPV Self-collection (Participant 13)	Participants found HPV self-collection in the comfort of their homes to be less fear-inducing, less painful, and less embarrassing compared to clinician-collected samples. Participants valued the convenience and privacy of self-collection.	<i>“I think it will be easier because I’m in the comfort of my own home. So, I won’t mind, like I won’t be afraid to take it.”</i>
HPV self-collection Health Motivation	Participants were motivated to self-collect their samples due to a desire to stay informed about their current health status, even in the absence of pain or symptoms. Participants emphasized the importance of early detection and prevention.	<i>“The advantages is I’m getting screened, which can potentially save my life or stop me from having other complications because I don’t know whether that leads to other problems. So, the advantage of it is to take it and to make sure nothing else is going on.”</i> (Participant 15)
Perceived Barriers to self-collection	The most salient barrier to self-collection at home was collecting the sample accurately.	<i>“I feel like for some reason, I may not do it right, and I could get the wrong diagnosis. I’d for a trained professional to do it so I can definitely be able to rely on what they find..”</i> (Participant 15)

less embarrassing compared to the pelvic exam. As evident by this statement, the relative age and identity of the doctor performing the test can be a factor in perceived discomfort in the procedure:

“No, listen, ... might not care, but I’m not using my vagina to have somebody physically look and do the test right there, you get a little bit of embarrassment. You know you have to do it, because it’s for your health, but that don’t stop you from being embarrassed, because when after I had my Pap smear, I came home and I said to my girls, “That was a baby who did that.” He’s a doctor. He’s a qualified doctor. Yes, I would let him do it. But to me, he can’t be older, maybe I have grandchildren his age. Do you know what I mean?” (Participant 21).

In summary, HPV self-collection offers a promising alternative to address concerns about the fear and discomfort associated with pelvic exams, allowing individuals to take control of their own sample collection.

THEME 2: HEALTH MOTIVATION – HPV SELF-COLLECTION WOULD RESULT AWARENESS OF CURRENT HPV STATUS

Participants shared that they would be motivated to take the HPV self-collection test because they would want to know their current health status. One participant shared that taking the test would be preventative:

“not that I am feeling pain and symptoms, it would be a precaution.” (Participant 16).

Another added that current health concerns were a motivator to get the screening;

“Because again I’ve had like recurrent yeast infection and BV, [Bacterial vaginosis] so just to make sure we’re good.” (Participant 10).

Another participant added that a doctor’s recommendation to complete the test would influence them to take the test:

“My general health and what my doctor knows about my general health or whatever, can influence me either way, can sway me either way. Like I said, I feel like that’s the role we need to take, then I will go that way. The advantages is I’m getting screened, which can potentially save my life or stop me from having other complications, because I don’t know whether that leads to other problems. So, the advantage of it is to take it and to make sure nothing else is going on.” (Participant, 15).

Although participants shared that the HPV self-collection test would inform them about their current health, most shared concerns and fear of a cancer diagnosis. One shared that taking the test would induce anxiety about the test results:

“I feel I have enough things to deal with. And taking that test will make me one start wandering/worrying? Do I have this or don’t I have it [CANCER]?” (Participant, 18).

In conclusion, while participants expressed strong motivation to stay informed about their current health status through HPV self-collection, it is important to acknowledge the need to improve education around the interpretation of HPV self-collection results and follow-up.

THEME 3. PERCEIVED BARRIERS: WOMEN WERE CONCERNED ABOUT COLLECTING THEIR SAMPLE ACCURATELY

When asked about barriers to performing the test at home, almost all participants shared that they do not anticipate any barriers that would preclude them from conducting HPV self-collection at home. Participants shared that they would be able to self-collect their samples in the privacy of their homes as long as they receive the tests and do not experience any shipping problems. One participant shared:

“I probably would do the self-sampling [COLLECTION] as long as I have no problem shipping for it.” (Participant 11).

Another participant shared that self-collection may be more affordable compared to in-clinic testing:

“I imagine the cost would be cheaper because when you go to the doctor, sometimes you get lab fees, or if you if you’re admitted to the hospital, you think you’re paying one bill, you have lab fees, you got specialist fees.”

(Participant 7).

When participants were probed further and asked whether they would prefer to self-collect their sample or get tested at the doctor’s office, almost half of the participants shared that they would prefer to conduct their own HPV self-collection, while the other half shared that they preferred that a doctor conduct the HPV sample collection. Participants who preferred HPV self-collection over getting tested at the doctor’s office shared that privacy and convenience were the main benefits of choosing self-collection;

“Get my own (HPV-SELF COLLECTION), do my own. (BECAUSE) ... The discomfort of getting a Pap smear at the doctor’s office.” (Participant 08).

Participants who preferred getting their HPV testing at the doctor’s office shared that they were concerned about being unable to collect their samples accurately. Participants shared that they prefer the test to be conducted at the clinic because a healthcare provider will do it; therefore, they would be more confident about the accuracy of the results.

“I feel like for some reason, I may not do it right, and I could get the wrong diagnosis. I’d for a trained professional to do it so I can definitely be able to rely on what they find. No, I just don’t trust doing it myself, although, I probably could, but I’d wait for a trained professional because they would know what to do in there and get what they’re looking for. I wouldn’t know what I’m looking for, I wouldn’t know what to do.” (Participant 15).

Another participant added that having a physician collect the sample would prevent having to retake the test:

“Because I don’t think I’m going to do it right. Or have it walk deep enough for, long enough. So, they know how to do it versus me trying to do it myself... So, I would rather it’d be done correctly, than you have to do it over. Like me not doing it correctly myself and do the whole process over again.” (Participant 13).

In-clinic exams were also preferred because doctors could test for other health concerns. One participant shared:

“If I had to pick one or the other, I would do the Pap smear because we can do everything, just not the HPV. We could do all other tests, so I rather Pap smear.” (Participant 10).

One participant shared that a doctor recommending the test and acknowledging that patients could perform the test would motivate them to take their self-sample:

“Only thing I think that can motivate me to remotely do it by myself is the doctor say this is something that is done in home, this is something that don’t need to be done in a clinic. And then, I guess I will have no choice but to do it at home, but that’s the only reason”. (Participant 15).

Participants also shared that having video instructions on collecting the sample would be helpful:

“I think so [HAVING INSTRUCTIONS], especially if they had a video or something. I mean, I YouTube everything nowadays ... but like mini video, and they can use one of those little models or something. I think that will be helpful.” (Participant 7).

Another participant added:

“I mean, I refer I’d be like a small little video, where you can log on and be able to look at a video and not just read a piece of paper [FOR INSTRUCTIONS].” (Participant 13).

Participants generally expressed a willingness to perform HPV self-collection at home, citing privacy, cost-effectiveness, and convenience as key motivators. However, a significant portion also voiced concerns about accurately collecting samples on their own, preferring in-clinic testing for the assurance of professional accuracy and the opportunity to address other health concerns. Incorporating video instructions for self-collection could potentially address some of these barriers and enhance the feasibility of HPV self-collection at home.

Discussion

Our study aimed to identify the acceptability of HPV self-collection tests among Black women living with T2D and social vulnerability.

Our study found that although our sample of Black women living with T2D and social vulnerability found mail-based HPV self-collection tests acceptable, the women were concerned about whether they would be able to collect a sample correctly and yield accurate results. Although most women found the tests acceptable, they reported that they would prefer to have their HPV testing conducted by a physician. Overall, our study adds to the emerging literature reporting that Black women with social vulnerability generally find HPV self-collection tests to be acceptable [30,31,37–39].

The preferences of Black women with T2D living in socially vulnerable communities are consistent with the literature showing that approximately half of women with social vulnerability find HPV self-collection tests acceptable [40]. A systematic review and meta-analysis reported a pooled estimate of 59 % for preference for HPV self-collected screening compared to a clinical test [40]. When examined by race, Black women are less likely to prefer the HPV self-test compared to White women; for example, in North Carolina, 45 % of Black women compared to 61 % of white women preferred the HPV self-test compared to the pap test [38]. Given that self-management of T2D entails several aspects of care, including self-monitoring of glucose levels, medication management, and other factors, we expected unanimous acceptability of the HPV self-collection test among our sample. The mode of engagement with HPV self-collection does affect acceptability; with high acceptability, 100 % of participants supporting clinic-based delivery and return [41], compared to 82 % for home mail delivery and return [30].

Three themes that are aligned with the theoretical constructs of the health belief model explain the perception of HPV self-collection among our participants. First, the perceived benefit of HPV self-collection is comfort, which includes collecting a sample from the cervix with less pain compared to a pelvic exam. Our findings align with previous literature showing that Black women are receptive to the HPV self-collection tests and find the tests more comfortable than in-clinic pap tests [39]. Another perceived benefit was the ability to collect the sample in the privacy and convenience of one's home. Both the comfort benefits of less pain and privacy have been reported in previous literature, including a systematic review summarizing factors that influence the acceptability of self-collection [40]. Black women have described that self-collection can prevent embarrassment from the invasive process of retrieving a sample from the cervix. Specifically, women report that a provider inserting a cold device into the vagina can be uncomfortable and embarrassing; therefore, self-collection may provide a more comfortable alternative [39].

Second, the health motivation construct supports being informed about one's health status as a perceived benefit and motivator that would inspire women to engage in HPV self-collection. Our study's findings align with studies showing that women are interested in learning about their health status and view the HPV self-collection tests as an avenue to care for their health by knowing their health status [39].

Lastly, concerns about taking the test correctly and producing an accurate sample were a shared barrier to HPV self-collection. Women were concerned that their samples may not be as accurate as those collected by a health provider, which aligns with previous studies reporting that women view doctor exams as more accurate [39]. A study of low-income women in North Carolina found that 20 % of women believed that the pap test protects women more than self-collection tests, while 7 % believed that self-collection tests were more protective than pap tests [38]. Although women in the study significantly believed that the pap test was more protective, there was no significant difference in their level of reported trust to give accurate results between the two screening tests, therefore conflicting with our qualitative findings [38]. Concerns over the sampling accuracy are important to note because anxiety over the results of cervical cancer screening is well documented as a barrier to screening. Fatalistic beliefs over positive results preclude some women from seeking cervical cancer screening. Significantly more women have reported being afraid of HPV self-collection positive test results compared to pap test results [38].

Our study has some limitations. Our study results can only be generalized to Black women with social vulnerability, T2D, and who are engaged in care. All our participants were recruited from one academic medical center, and our patients had all previously consented to be contacted for research purposes; therefore, our sampling may also result in findings that can only be applied to this specific population. Studies show that sexual behavior, e.g. having opposite sex partners, the number of sexual partners, or history of sexually transmitted infection (STIs), increases uptake of cervical cancer screening [42]. We did not collect data on number of sexual partners or history of STIs from our participants. However, one study shows that the number of sexual partners did not influence the perception of risk or screening for cervical cancer among Black women [43]. Lastly, participants did not get to see or test the actual HPV self-collection devices and responded to questions based on how the self-collection process was described to them.

Despite the limitations, our study has several strengths. First, to our knowledge, this is the first research to focus on HPV self-collection preferences among Black women with social vulnerability and T2D. Cervical cancer mortality is disproportionately higher among Black women and women with high social vulnerability [18]. Moreover, diabetes is associated with poor prognosis for cervical cancer [24]. Therefore, our findings and using a precision public health approach will inform future targeted interventions to improve early detection of cervical cancer among Black women.

Conclusion

Our study's findings support research that HPV self-collection is a promising avenue for increasing cervical cancer screening among vulnerable women. Although Black women with social vulnerability and T2D identified benefits of HPV self-collection, they were concerned about their ability to collect their sample correctly. Our findings call for future implementation science studies focusing on improving HPV self-collection self-efficacy among vulnerable women.

Research reported in this publication was supported by the University of Florida Clinical and Translational Science Institute, which is supported in part by the NIH National Center for Advancing Translational Sciences under award number UL1 TR001427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Funding

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgments

This study would not be possible without the participation of patients at UF Health who agreed to participate in this study. Research reported in this publication was supported by the University of Florida Clinical and Translational Science Institute, which is supported in part by the National Institutes of Health (NIH) National Center for Advancing Translational Sciences under award number UL1 TR001427. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jcte.2024.100331>.

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