

# Hawai‘i Journal of Health & Social Welfare

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# Hawai'i Journal of Health & Social Welfare

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# Unmet Reproductive Health Needs of Transgender and Gender Diverse People in Hawai‘i: A Qualitative Needs Assessment

Ghazaleh Moayedhi DO, MPH; Steph Lee DNP; Reni Soon MD, MPH; Cathy Kapua BPA; Maddalyn Sesepasara; Shandhini Raidoo MD, MPH

## Abstract

The purpose of this study was to assess the reproductive health experiences of transgender and gender diverse people in Hawai‘i, identify reproductive health needs that were unmet, and explore opportunities for addressing those needs. This was a qualitative, semi-structured individual interview study. Adults who identified as transgender or gender diverse were interviewed about their experiences accessing reproductive health services, their needs, and their ideas about clinical settings in which to receive reproductive health care services. Interviews were conducted until thematic saturation was reached. Six trans men, 6 trans women, and 4 people who identified as non-binary or genderqueer were interviewed. Negative experiences in health care settings, particularly when seeking reproductive health care services, were common. Participants often had multiple providers and gender-affirming care was often accessed separately from other health care services. Desires for fertility and pregnancy varied widely between participants but were often not addressed at the initiation of gender-affirming care. Finding trans-friendly providers was notably difficult and participants often relied on friends and other members of the transgender community for guidance. Obstetrics and gynecology clinics present a potential opportunity for access to reproductive health services although their gendered environment was concerning for some participants. Transgender and gender diverse people in Hawai‘i have access to some reproductive health services but experience stigma in certain settings. There is a need for ongoing improvement in reproductive health care services in Hawai‘i to improve access for transgender and gender nonconforming people in Hawai‘i.

## Keywords

gender diverse, needs assessment, obstetrics and gynecology, reproductive health, transgender

## Abbreviations

ID = identification  
GP = general practitioner  
LGBT = lesbian, gay, bisexual, transgender  
LGBTQI = lesbian, gay, bisexual, transgender, queer, and intersex  
OB/GYN = obstetrician-gynecologist  
PCP = primary care provider  
TGD = transgender and gender diverse

## Introduction

Transgender and gender diverse (TGD) people experience significant barriers to comprehensive health care and subsequently experience significant adverse health outcomes in the United States.<sup>1-3</sup> Despite increased efforts to educate medical professionals on approaching TGD patients with sensitivity to their lived experience, health care needs, and efforts to improve health insurance coverage for gender-affirming care, there

remain disparities in health care access for TGD people.<sup>4-6</sup> Reproductive health and the implications of gender-affirming hormone therapy and surgical care are particularly important to take into consideration for TGD people who may be considering pregnancy or childbearing in the future.<sup>7</sup>

There are approximately 7800 transgender people in Hawai‘i, making up 0.7% of the population.<sup>8</sup> In 2013, researchers at the University of Hawai‘i at Manoa School of Social Work conducted an in-depth needs assessment of the lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI) communities of Hawai‘i.<sup>9</sup> This study found that the LGBTQI community faced many challenges in receiving health care, including stigma and discrimination in health care settings and inconsistent insurance coverage.<sup>9</sup> TGD people in Hawai‘i reported the lowest rates of perceived wellness, highest rates of being uninsured, the lowest access to a regular primary care provider, and higher rates of discrimination in health care settings compared to other members of the LGBTQI community.<sup>8</sup> Based on their findings, researchers called for additional work to understand and address the specific challenges for TGD people in Hawai‘i. A survey of obstetrician-gynecologists (OB/GYNs) in Hawai‘i indicated that OB/GYNs are comfortable providing sexual and reproductive health services to TGD people but are less familiar with gender-affirming care such as hormone therapy or requirements for gender-affirming surgery.<sup>10</sup> The aim of this study was to identify the unmet reproductive health needs of TGD people living in Hawai‘i through a community-based needs assessment and to understand the potential for reproductive health service provision in obstetrics and gynecology clinics and other clinical settings.

## Materials and Methods

This study was a qualitative reproductive health needs assessment to identify the unmet reproductive health needs of TGD adults living in Hawai‘i using a community-based participatory research approach. Researchers at the University of Hawai‘i John A. Burns School of Medicine partnered with the Kua‘ana Project at the Hawai‘i Health and Harm Reduction Center to design the research instruments, recruit study participants, contextualize results, and disseminate study findings. The Kua‘ana Project is a non-profit organization in Honolulu that provides social services, support, and HIV and hepatitis education and testing for the TGD community of Hawai‘i. The Kua‘ana Project is closely connected to the O‘ahu transgender community and



all of the staff of the Kua‘ana Project identify as transgender. Structured interview questions were developed for TGD people in Hawai‘i aimed at understanding their sources of reproductive health care, insurance coverage, access to gender affirming care, discrimination from reproductive health care providers, fragmentation of health care, parenting intentions, and ideal settings for reproductive health care delivery. The University of Hawai‘i research team developed the interview questions collaboratively based on the reproductive health care subjects to be explored. The interview guides were evaluated internally for clarity, conversational flow, and TGD community relevancy by the Kua‘ana Project team and community partners. Interview guides were modified in an ongoing process to explore emerging themes. Interviews were conducted until thematic saturation was reached.

The University of Hawai‘i research team all identify as people of color, with 3 cis identified people and 1 trans identified person. The Kua‘ana Project team members both identify as trans people of color. Interviewers were from the University of Hawai‘i and included 2 cis identified people and 1 trans identified person; 2 are OB/GYNs and 1 is a nurse. All interviewers have experience and training in qualitative interviewing.

Participants were recruited using fliers and case manager referrals at Kua‘ana Project, online advertising on Craigslist, and referrals from other TGD clinics in O‘ahu.

People were eligible to participate in the study if they identified as transgender, intersex, genderqueer, gender diverse, gender non-binary, or any other TGD identity; were 18 years or older; lived in Hawai‘i; and were willing to complete a demographic survey and 20-30 minute phone interview in English. A trained research assistant screened all potential participants for study eligibility over the phone. If they met inclusion criteria, participants were scheduled for a phone interview with researchers and sent a link to complete the demographic questionnaire online. Demographic characteristics of participants were obtained separately from interviews in order to de-identify interview responses and protect confidentiality of sexual health information. Demographic data were collected and managed using REDCap software (Vanderbilt University, Nashville, TN). Study participation was voluntary. Participants were compensated with a \$25 electronic gift card for their participation.

Informed consent was obtained verbally from participants prior to starting the interview. Interviews were conducted via telephone and audio-recorded with participants’ permission. The interviewers did not have prior clinical or research relationships with the participants. Study participants were recruited and interviews conducted from December 2017 - December 2019 until thematic saturation was reached. Interview recordings were transcribed by study staff. All personal identifying information was removed from the transcripts.

Researchers met regularly during the recruitment phase to evaluate emerging themes and ensure continued clarity of the interview questions. A codebook was created and updated using a grounded theory approach through an iterative process of content analysis throughout the recruitment period. Once thematic saturation was reached, 2 researchers (SR and GM) conducted line-by-line coding of transcripts using Atlas.ti software, version 8.4.4 (Atlas.ti Scientific Software Development GmbH, Berlin, Germany). Discrepancies in coding were discussed and resolved by mutual discussion.

This study was approved by the University of Hawai‘i at Mānoa Institutional Review Board (2017-00309).

## Results

Eighteen TGD people in Hawai‘i were screened for study participation and 16 people completed the semi-structured phone interviews. Seven people identified as trans masculine, 6 people identified as trans feminine, and 3 people identified as non-binary or mixed gender. Participant ages ranged from 20 to 58 years old, with a median age of 30 years old. Most participants lived alone or with a roommate, but 2 participants reported having unstable housing or being houseless. Many respondents had received some form of gender affirming care, most commonly hormonal treatment. All participants answering the demographic survey were located on the island of O‘ahu.

From the interviews 5 major themes were identified: (1) negative experiences in health care settings are common, (2) gender-affirming care is often accessed separately from other health care services, (3) A welcoming health care environment and health care providers who are open to caring for TGD people are important to TGD people, (4) desires for fertility or pregnancy are variable, but often are not addressed at the initiation of gender-affirming care, and (5) obstetrics and gynecology clinics present a potential opportunity for access to reproductive health services for TGD people.

### Theme 1: Negative Experiences in Health Care Settings are Common

Almost all participants reported either having negative experiences in the health care system themselves, witnessing friends or partners have negative health care experiences, or knowledge of TGD community members with negative experiences (**Table 1**). Misgendering was the most common negative experience that participants reported, although experiences ranged from inexperience of providers to outright refusal of care. Misgendering occurred both on an interpersonal level but also at an institutional level.

Participants acknowledged the limitations of the current medical establishment with respect to the binary setup of health care

services for cisgender men or cisgender women, and the assumptions that providers, particularly providers of reproductive health services, often make about sexual partners, behaviors, pregnancy risk, and menstrual experiences.

Negative experiences with the health care system contributed to anxieties about future health care experiences and an overall reluctance to seek care within the medical establishment. In particular, having a provider who demonstrated obvious inexperience with transgender bodies or reacted negatively to gender identity disclosure was particularly concerning for participants.

## Theme 2: Gender-affirming Care is Often Accessed Separately from Other Health Care Services

Most participants reported having multiple different providers for various health care needs (Table 2). Participants who were receiving gender-affirming health care services often received these from a provider who was not their primary care provider, resulting in additional appointments and complexity in coordination of care.

Gender-affirming care was particularly difficult to access for people with other medical conditions. Health care providers in other specialties who provided treatment for other medical conditions were often reluctant to discuss gender-affirming therapies and cautioned participants about the risks of gender-affirming hormone therapy in conjunction with the treatment of their chronic medical conditions. Participants expressed difficulty communicating with some of their health care providers about their desire to pursue gender-affirming care.

A few participants received their gender-affirming care and their primary care and preventive services from the same provider or clinic. For those who had this experience, they reported high satisfaction with their health care, particularly with respect to being able to be open with their provider about their gender identity and their health care needs.

Surgical care was notably difficult to access, and participants who had gender-affirming surgeries reported difficulty finding a surgeon who was comfortable with gender-affirming surgeries. Primary care providers had limited knowledge of surgeons in the community, and participants who sought surgical services often relied on word-of-mouth from other TGD people or on internet searches to find surgeons.

Subtheme	Quote
Misgendering	"I'd go for a hospital visit and right away they'd get my pronouns wrong because, all my medical records, even though I legally changed my name and everything and my pronoun marker on my ID, the hospital refuses to change it. Every time I go to the hospital, for anything, it depends on who I get. But if they see it says miss, and I'm obviously presenting as a male, it depends on what they feel like doing that day." – 26-year old trans man
Limitations of binary health systems	"They'll make statements like... they're talking about women and I feel like they're including me in that group when they're talking and I know that that's a little bit more nuanced and more difficult for health care providers to do, but it's kind of like, don't tell me what women's experiences on this thing are 'cause I'm not one of them, I don't know." – 35-year old trans man
Negative experiences with health care providers	"For instance, the last gynecologist that I saw that actually made me decide to put a pause on going to see gynecologists was a doctor... I thought would be friendly but I shared something about my identity and her reaction was so... I don't even know how to describe it, but it made me feel so uncared for and unwanted in that environment that I didn't go back." – 30-year old non-binary person

ID = identification

Subtheme	Quote
Fragmented care	"So I have 3 different providers for all that different stuff because my PCP does not want to handle my hormone treatment because he does not feel capable of handling the hormone treatment, he doesn't want to do gynecology. My gynecologist doesn't feel capable of handling my hormone treatment. And I also because I have a severe clotting disorder, see a specialist for my clotting disorder. And so it's very complicated." – 50-year old trans man
Gender-affirming care and other medical diagnoses	"I was actually asked from my doctor, you know, 'cause my kidneys were doing really bad. He was like, 'Are you eating a lot of fatty food, what's going on?' And he actually said, 'Are you going through hormone therapy?' And I go, 'Maybe.' And he asked me more about it and where am I getting it from and he highly suggests that I don't do it... As stubborn as I am, I'll lose a kidney [laughing] to gain a vagina" – 28-year old trans woman
Integrated care	"Well, my primary care provider is an inclusive LGBT clinic. So, it was very easy for me to disclose [my gender identity], that's the reason why I went there in the first place." – 25-year old trans man
Gender-affirming surgical care	"I had called about 4 or 5 doctors that specialized with breast augmentation and 1 of them actually had told me that he will not accept transgender patients whatsoever. And his reasoning was it was too hard because they still have masculine or male tissue and it would be... much more work than he would want to do to create the pocket, to insert the implant. And the rest were like, "We do, we can, but we don't know how, we can't promise how it's gonna come out, we don't, we've done 1 or 2, we don't really see a lot of transgender clients." And it was just kind of very awkward but for me I like to be upfront with them because I want them to know what they're getting into especially if you're cutting into me." – 30-year old trans woman

PCP = primary care provider. LGBT = lesbian, gay, bisexual, transgender

### Theme 3: A Welcoming Health Care Environment and Health Care Providers Who are Open to Caring for TGD People are Important to TGD People

Although most participants were currently receiving some form of medical care, many noted that their providers had limited knowledge of other TGD-friendly providers to whom participants could be referred for medical, surgical, or specialty care (Table 3). Participants often relied on their friends or other members of the TGD community to find TGD-friendly health care professionals for their other health care needs. Concern about stigma was an important driving factor in trying to identify TGD-friendly providers through community connections.

Providers who were friendly and welcoming were typically viewed very positively by participants, even if they noted that the providers may have limited knowledge in TGD-specific care. Some participants also noted that while the physical clinic surroundings may be important to creating a welcoming environment, that the most important part was being able to access care at all.

Disclosing their gender identity to a provider's office prior to seeking care was a common method for some participants to determine whether the provider they were attempting to see was experienced with caring for TGD people or open to providing care to them. This was particularly important for participants who were already receiving gender-affirming care or who had plans to receive gender-affirming care in the near future.

Despite the many obstacles to finding health care providers or services, many TGD people were hopeful for the future of health care for themselves and their communities. They expressed resiliency and a sense of optimism about the future of TGD health care. Despite facing personal difficulties in seeking care, participants were eager to improve health care and provider education and experience for the future generations of TGD people.

### Theme 4: Desires for Fertility or Pregnancy are Variable, but Often are Not Addressed at the Initiation of Gender-affirming Care

Participants expressed a wide spectrum of desires for fertility, pregnancy, and parenting (Table 4). The desire for fertility or pregnancy was intimately tied to participants' goals for gender-affirming care and the timing of their care, particularly gender-affirming surgeries. Fertility concerns in relation to gender-affirming care were particularly common for transmen, whose decisions around hysterectomy or oophorectomy would definitively impact their future childbearing potential.

Participants perceived that the assumption that people undergoing gender-affirming care were not interested in childbearing was prevalent among health care providers. Moreover, participants also reported that at the initiation of gender-affirming therapy they assumed they would not want to pursue pregnancy or childbearing in the future. The cost of gamete preservation and storage was also a deterrent for participants, many of whom were already incurring significant medical costs for their gender-affirming care.

For some participants, their desire to be pregnant or to be a parent changed over time, with new relationships, or with age. While they may not have considered childbearing or parenting when initiating their gender-affirming care, they uncovered a desire for pregnancy or parenting over time. For participants who had had gender-affirming surgeries that resulted in sterilization, such as hysterectomies or oophorectomies, options for parenting were more limited. Others who were unable to be pregnant or bear children themselves identified numerous creative ways, such as different modes of adoption, to fulfill their desires to parent.

With respect to pregnancy specifically, participants noted that the culture of pregnancy and pregnancy care, which is focused on the cisgender female body and experience, can be alienat-

Table 3. A Welcoming Health Care Environment and Health Care Providers Who Are Open to Caring for Transgender and Gender Diverse (TGD) People Are Important to TGD People – Theme 3	
Subtheme	Quote
Reliance on social networks to find providers	"Okay, you gotta go and find a new primary care doctor. Okay, you don't know which ones are what you call 'LGBT friendly,' you see. You start asking around like, 'Oh have you ever heard if he or she is nice?' It's a gamble, and you know some doctors, they might not treat you too well or they might give you a stink eye look or you can feel the chemistry and stuff like that." – 44-year old transwoman
A provider's attitude is more important than the clinical setting	"I would much rather go to a place that I know is affirmative of who I am, even if it's a little corridor. If I know that's the spot that I go to, to get those same things but the space and people and services are inclusive of me, I'm good. Just give me a room." – 30-year old non-binary person
Gender identity closure prior to appointments is important	"When I called to look for a new OB/GYN I specifically called and asked each OB/GYN's office. I want an OB/GYN who is willing to work with a transgender man who may go through transitioning with bottom surgery. And I will not work with an OB/GYN who will not do that." – 50-year old transman
Hopeful about resources for future generations	"I try to be a good role model for other trans girls. And I mean I see it getting even younger, you know? And the resources they need, the information they need, the components they need that they try to find, it's really hard, you know." – 28-year old transwoman

OB/GYN = obstetrician-gynecologist

ing to TGD people and that these assumptions and narrow definitions contributed to the marginalization of TGD people in pregnancy-related health care. Participants who were considering pregnancy expressed reluctance to receive care through the standard medical establishment due to these concerns.

**Theme 5. Obstetrics and Gynecology Clinics Present a Potential Opportunity for Access to Reproductive Health Services for TGD People**

Participants had received reproductive health services in a variety of places ranging from their primary care providers to specialists such as OB/GYNs to reproductive health clinics (**Table 5**). Experiences with reproductive health services varied. The specific focus on reproductive health services was often viewed as a positive factor in obstetrics and gynecology clinical spaces.

For many participants, particularly those who identified as transwomen and described themselves as presenting as very feminine, obstetrics and gynecology clinics were viewed as spaces that were affirming of their feminine identity. Issues with use of the wrong name (deadnaming, which is the act of referring to a transgender or gender diverse person by a name they were given in the past but with which they no longer identify) or staff lack of knowledge of a participant’s new name resulted in uncomfortable encounters for participants.

Conversely, those who identified as trans men found obstetrics and gynecology clinic spaces to be exclusionary and expressed concern about scrutiny from staff and other patients, particularly if their appearance was more masculine.

Despite the fact that many viewed obstetrics and gynecology clinics as a necessary entity in the provision of reproductive health services, there were numerous suggestions for ways to improve these clinical spaces to make them more comfortable and more welcoming to TGD people. These ranged from having gender-neutral bathrooms and inclusive signs in waiting rooms, to having clinics specifically stating their openness to caring for both cis and TGD clients.

When asked to describe their ideal clinic in which to receive care, participants most commonly discussed the need for comprehensive care in a single location. Having providers who were experienced with TGD care or who identified as TGD themselves was also important to participants as it indicated that providers may have had their own personal experiences with gender-affirming care. The availability of other services such as mental health care, voice therapy, and referral options for other TGD-friendly providers in the community was also important in an ideal clinic model.

Table 4. Desires for Fertility or Pregnancy Are Variable, but Often Are Not Addressed at the Initiation of Gender-Affirming Care—Theme 4	
Subtheme	Quote
Fertility concerns related to gender-affirming care	"[I discussed fertility] with my OB/GYN, yeah, but that was pre-transition. I didn't even know if I wanted to be pregnant in the future, but I did feel like it was important for me to preserve my uterus health or, you know, reproductive health, so that maybe in the future that, maybe I do decide to bear a child, I wouldn't worry about that in the future because the birth control that helped regulate my periods would help my reproductive health." – 25-year old transman
Stigma and assumptions about parenting and childbearing goals	"I think that because there's a stigma attached to being trans, not many people think that we want to reproduce. So they just push it aside and are kind of like, 'Well if you can't do it the traditional way then that's it.'... And that's like a big thing that prevents trans people from seeing that they can have a family. You know, people are like, 'Well if you get rid of the parts then what's the use?' But... I mean, give them an option." – 26-year old transman
Desires for pregnancy, parenting, and childbearing can change	"I didn't think it was necessary [to discuss future pregnancy with my medical providers] because I didn't think it was something that I would consider and as time goes on, given my relationships, and getting older and trying to figure out what I want to do with my future I'm starting to consider the possibility that I might want to have a child." – 22-year old transman
Gendered language around pregnancy	"There's a lot of conversation that's based around womanhood for pregnancy and childbearing which... is mostly for like cis womanhood or the occasional emphasis on the transman but what I find very irritating is a lot of people don't mention a transwoman. Especially when transwomen have a huge stake in reproductive services. I- I just feel like the industry around pregnancy [is] like another barrier for a lot of trans people to be marginalized." – 21-year old transman



Table 5. Obstetrics and Gynecology Clinics Present a Potential Opportunity for Access to Reproductive Health Services for Transgender and Gender Diverse People – Theme 5	
Subtheme	Quote
Specialized in reproductive health	"There's a feeling of emotional and physical safety that I feel that I really do enjoy about OB/GYN spaces that I am in. I do enjoy that it is a space that is specific to concentrating on my reproductive health. Like I'm there to work on this part of myself and I like that. I value health in my body so much and reproductive organs are so vital and having a space to go think about that and nurture that part of myself." – 30-year old non-binary person
Affirmation of female identity (for trans women)	"I portray myself as a woman and being a transgender woman I feel like I look like a woman but I still have my insecurities... If it's just a clinic for women, like OB/GYNs, of course I would feel totally at home and comfortable going to do my check ups... When I first started [going to an OB/GYN office for care] and I didn't change my name, and they're calling out, 'Michael, Michael?' <sup>a</sup> And I'm getting up and I'm wearing a dress, it's very shameful, and embarrassing. People are looking like, there's a few looking like, 'Oh maybe she called her last name first, Michael.' No but really my name is Michael, you know?" – 28-year old transwoman
Scrutiny from other patients (for trans men)	"I wouldn't want people to be seeing me waiting in the waiting room. They would be looking at me like, 'What is this guy doing here?' because I don't look like a girl. And they're going to be staring at me and most of those ladies take their kids there too and that's really uncomfortable as well. Because the kids are going to be like, 'Mommy, is that a guy or is that a lady?' I know it's not their fault they don't know. Still, it just gets on my nerves." – 36-year old non-binary person
Improvements towards inclusive spaces	"I know that a lot of medical facilities have different kinds of posters on the walls with different information. If there was something there identifying the office as an inclusive space. Maybe put up little flags, flag stickers, stuff like that. Make it known walking in that it was a safe space." – 22-year old transman
Integrated multidisciplinary networks	"For me, the ideal set up would be... where they actually have like a full staff, whether it's a mixture of the OB/GYN, the psych department for mental health, as well as individual specialists, as well as a GP. Like having it all centrally located and then maybe, if they don't then they have a list of names that are connected in the community. Like a connected network of LGBT health care providers that are... comfortable working with LGBT [people]." – 30-year old transwoman

GP = general practitioner

<sup>a</sup> Names have been changed to protect the identity of participants

## Discussion

The participants in the current study had a wide variety of reproductive health experiences with the health care system. Overall, most were able to access some care, although the care they received was sometimes from providers who were not experienced with TGD care, or did not take their gender identity and unique needs into consideration. Some experiences were uncomfortable, particularly in clinical spaces that focused on gender-specific care.

Fertility, pregnancy, and desires for future childbearing were often not addressed as part of reproductive health care for TGD people. TGD people may not be aware of the impact that gender-affirming care, particularly gender-affirming hormone therapy, can have on fertility and desires for pregnancy or parenting may change over time. Major professional organizations recommend that the desire for fertility or gamete preservation be addressed prior to initiating gender-affirming hormone therapy.<sup>11,12</sup> Gamete preservation and storage is also often prohibitively costly and may not be covered by all insurance companies, thus there is an ongoing need for advocacy in this area to ensure access to comprehensive reproductive health services.

Although the American College of Obstetricians and Gynecologists recommends that care for TGD people is within the scope of practice for OB/GYNs, many are inexperienced or not comfortable with providing services to a TGD population.<sup>10,13</sup> In addition, the cisgender female-oriented language, clinical spaces, and assumptions inherent in obstetrics and gynecology

care can be uncomfortable and alienating for TGD people. This was particularly noted to be true for language around pregnancy and pregnant bodies.

These results indicate that there is a need for improved integration of services and improved referral systems within the medical community in Hawai'i so that TGD people can access the care that they need. Gender-affirming surgical care is particularly challenging to access in Hawai'i due to a lack of experienced providers and this was highlighted by multiple participants. Targeted recruitment of providers with experience in gender-affirming surgery or support of training in gender-affirming surgery during general medical education are strategies that can improve access to surgical options in a local setting. Providers' attitudes towards TGD people, particularly in being friendly, welcoming, and respecting names and pronouns, were highly important to participants, and often noted to be more important than providers' experience in TGD health care. Addressing TGD care throughout the process of medical training through workshops, lectures, and direct patient care may lead to more health care providers who are open to providing care for TGD populations in the future.

The major strength of this study is its community-oriented nature. This study was a collaborative effort between community organizations and health care providers who serve the TGD population to establish trust with the community during recruitment, and a variety of different recruitment methods were used. A diverse group of transgender male, transgender female, and non-binary people were interviewed to reflect the spectrum of

gender identity and of people who may present for reproductive health services. People were also asked about their ideal clinic to foster consideration of health care possibilities that may not exist currently within the health care system.

This study is limited by selection bias as participants volunteered to discuss their experience with prior care, and thus selected for people who were comfortable talking about these experiences. All of the participants lived on O‘ahu, the island in the state of Hawai‘i with the highest level of health care services and number of providers. Although there are some gender-affirming services on other islands, the unique geographic barriers in Hawai‘i make it more difficult for people to access care that requires flying to other islands. Participants on other islands in the state may not have the same experience with accessing health care services, including reproductive health services, as those on O‘ahu.

## Conclusions

TGD people in Hawai‘i are able to access some reproductive health services, but do not always receive counseling about fertility and pregnancy prior to gender-affirming hormone therapy. Access to care is often fragmented and people often rely on their community to find TGD-friendly providers. While obstetrics and gynecology clinics are potential places for TGD people to receive reproductive health services, additional work is needed on the part of providers and clinic staff to create inclusive spaces and to provide skilled care for the TGD community.

## Conflict of Interest

None of the authors identify a conflict of interest.

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# The Memory Assessment Scale: A Population-based Cognitive Impairment Screening Instrument

William T. Tsushima PhD; Justin R. Abe; Andrea M. Siu MPH

## Abstract

This study re-examined the Memory Assessment Scale (MAS), a brief memory test developed in Hawai‘i in 1987, to assess whether it remains a valid and reliable cognitive impairment screening tool in Hawai‘i. Patients suspected of having neurocognitive dysfunction were divided into 2 groups (those with and without mild cognitive impairment) based on their results on a battery of neuropsychological tests. No differences in MAS scores were found between patients with and without mild cognitive impairment. Further research with the MAS comparing patients with mild cognitive disorder to healthy controls is indicated to further examine the efficacy of this population-based test.

## Keywords

memory assessment, population-based, brief screening test, mild cognitive disorder

## Abbreviations

AUC = area under the curve  
GMI = General Memory Index  
IMI = Immediate Memory Index  
MAS = Memory Assessment Scale  
MMSE = Mini-Mental State Examination  
ROC = receiver operating characteristic  
WMS III = Wechsler Memory Scale III

## Introduction

The most widely applied screening instrument for the assessment of cognitive dysfunction is the Mini-Mental State Examination (MMSE),<sup>1</sup> but a meta-analysis concluded that MMSE has limited ability to differentiate between mild cognitive impairment and healthy controls.<sup>2</sup> Further, a systematic review of brief cognitive screening instruments recommended that clinicians should not consider 1 screening instrument, like the MMSE, be used in every setting.<sup>3</sup> Instead, the reviewers cited the importance of population-based validation of screening tests, with data consisting of pertinent reference values that can serve to evaluate how well a person performs compared with a relevant population. The reviewers reported an unfortunate lack of instruments that are validated in a population-based cohort.

In Hawai‘i, where the multi-ethnic diversity in the population is particularly unique in the United States, the need for a relevant population-based cognitive screening instrument is especially important. According to the 2021 US Census Bureau American Community survey, Hawai‘i’s population is approximately 37.5% Asian, 23.7% White, 10.6% Native Hawaiian and other

Pacific Islander, 1.9% Black, 0.3% American Indian and Alaska Native, 1.6% “some other race,” and 24.4% “two or more races.”<sup>4</sup> While the total population in Hawai‘i has increased significantly since the 1980s, from about 964 691 to 1 453 498 in 2021, the ethnicity mix is approximately the same.

The only known cognitive screening tool developed in Hawai‘i is the Memory Assessment Scale (MAS) that was introduced in a study in the 1980s.<sup>5</sup> The results of the research that examined the efficacy of the MAS with neurological patients revealed an internal consistency reliability coefficient of 0.94 and an accuracy rate of 83% in identifying memory impairment in patients diagnosed with a neurocognitive disorder. The correlation between the MAS and the Luria Nebraska Neuropsychological Battery Intermediate Memory Scale was 0.63 ( $P < .01$ ). The assessment of memory as with the MAS is critical because memory impairment is the first and most severely affected cognitive domain in dementia,<sup>6</sup> and is generally considered the best predictor of cognitive decline.<sup>7</sup>

Since the original study, the MAS has not been investigated empirically. The purpose of the present research was to re-examine the efficacy of the MAS in Hawai‘i. With the growing population of the elderly, this research was driven by the desire to assess a brief memory test instrument that can identify individuals who are at risk for developing dementia, because memory deficits have been found to be early indicators of subsequent cognitive decline in older individuals. A review of over 40 brief memory tests developed to identify patients with mild cognitive impairment raised questions about the high risk of bias of many of the existing tests due to the unblinded evaluations comparing patients from memory clinics with diagnosed cognitive deficits to patients assumed to have no cognitive disorder.<sup>8</sup> The present study avoided the bias of past studies that compared patients with known cognitive deficits versus healthy normals, by examining only participants with questionable neurocognitive dysfunction.

## Methods

### Participants

The study involved archival review of 114 patients (78 men, 36 women) who underwent comprehensive neuropsychological examination at Straub Medical Center due to questionable neurocognitive conditions. Many of the participants suffered mild traumatic head injury at work, in a motor vehicle accident, or at home. Other conditions included stroke, seizure, electrocu-

tion, near-drowning, depression, and IV epinephrine overdose. The average age of the patients was 44.1 years (SD=15.8; Range 18-81). The average educational level was 14.0 years (SD=2.5). The average duration between onset of injury and date of testing was 33.1 months (SD=29.7).

To assess the efficacy of the MAS, 2 groups of patients were formed based on their performances on the Halstead-Reitan Neuropsychological Test Battery<sup>9</sup>: a Mild Cognitive Disorder group ( $n=53$ ) that consisted of patients who exhibited significant cognitive impairment in their test results, and a No Cognitive Disorder group ( $n = 61$ ) that consisted of patients who had no cognitive impairment according to their test results. The MAS scores of the 2 patient groups were compared. The demographic characteristics of the participants are presented in **Table 1**. Data pertaining to the head injury conditions can be seen in **Table 2**.

This archival study, with data acquired at Straub Clinic, was evaluated by the Hawai'i Pacific Health Research Institute and was determined to be exempt from Institutional Review Board review.

## Measures

The MAS is a 33-item questionnaire comprised of items from standard memory scales and psychiatric interview schedules.<sup>5</sup> See **Table 3**. It is administered by a technician and can be completed in less than 10 minutes. The MAS has been used as a simple introductory tool for the patients and was not considered in the interpretation of the neuropsychological test battery results. In addition to the MAS, the patients were also administered the Wechsler Memory Scale-3rd Edition (WMS-III),<sup>10</sup> as part of a comprehensive neuropsychological examination. WMS-III is

Table 1. Memory Assessment Scale Study Participant Demographic Information				
	Mild Cognitive Disorder (n=53) Number (%)	No Cognitive Disorder (n=61) Number (%)	Test statistic	P-value
<b>Sex</b>				
female	17 (47%)	19 (53%)	0.0113	.92 <sup>a</sup>
male	36 (46%)	42 (54%)		
	<b>Mean (SD)</b>	<b>Mean (SD)</b>		
<b>Age (years)</b>	44.4 (17.5)	43.9 (14.3)	0.105	.92 <sup>b</sup>
<b>Education (years)</b>	14.1 (2.8)	13.9 (2.3)	-0.218	.83 <sup>b</sup>
<b>Time from injury to evaluation (months)</b>	30.3 (28.2)	35.3 (30.9)	1.254	.21 <sup>b</sup>
<b>Positive neurodiagnostic test<sup>c</sup></b>	15 (28.3%)	15 (24.6%)		

<sup>a</sup> Chi-square test

<sup>b</sup> Mann-Whitney U test

<sup>c</sup> Halstead-Reitan Neuropsychological Test Battery

Table 2. Types and Frequencies of Head Injuries and Illnesses	
	N = 114
<b>Motor Vehicle Accident</b>	61
<b>Fall</b>	14
<b>Other</b> (head injury, head trauma on boat, head trauma by airplane turbulence, struck on head, hit by beam, by rock, by sledgehammer, by elevator door; electrocution, near drowning, intravenous epinephrine overdose)	11
<b>Illness</b> (dementia, stroke, seizure, multiple sclerosis, neurological disorder, AIDS, depression)	10
<b>Assault/Fight</b>	6
<b>Head Injury at Home</b>	7
<b>Explosion</b> (military, civilian)	3
<b>Unknown</b>	2



Table 3. Memory Assessment Scale Instrument<sup>5</sup>

Memory Assessment Scale	
Examiner's Questions	Patient's Response
My name is _____	
I am a psychologist (psychology technician)	
Please tell me your full name	
_____	1. Unable to give full name.
When were you born? (What year, month, day?)	2. Unable to give year.
_____	3. Unable to give month.
How old are you? _____	4. Unable to give the day.
What is your address?	5. Gives incorrect age.
_____	
What is your zip code? _____	6. Unable to give address.
What is your telephone number? _____	7. Unable to give zip code.
What is your social security number? _____	8. Unable to give phone number.
What kind of work do (did) you do? _____	9. Unable to give social security number.
Where were you born? _____	10. Unable to identify job.
What was your mother's maiden name? _____	11. Unable to identify birth place.
What year is this? _____	12. Unable to give mother's maiden name.
What month is this? _____	13. Unable to give the year.
What day is this? _____	14. Unable to give the month.
What day of the week is it? _____	15. Unable to give the day.
What did you have for breakfast? _____	16. Unable to give the day of the week.
_____	
What did you have for dinner last night? _____	17. Unable to identify breakfast.
_____	
What did you do yesterday afternoon? _____	18. Unable to identify dinner.
_____	
What city or town are we in? _____	19. Unable to say what was done yesterday.
What kind of place is this? _____	20. Unable to name city.
(An office, hospital, store?)	21. Unable to recognize nature of place.
Who is the President of the United States? _____	22. Unable to name President.
Who was the previous President (before present President?)	
_____	23. Unable to name previous President.
Who is the Governor of (patient's home state)? _____	24. Unable to name Governor.
Who is the Mayor of (patient's home town)? _____	25. Unable to name Mayor.
What is the name of your doctor (or person who referred patient for assessment)? _____	26. Unable to name referring person.
What is (s)he doing for you? _____	
_____	27. Unable to indicate what referring person is doing.
Why are you here today (purpose of visit)? _____	
_____	28. Unable to give purpose of visit.
Did I ask you about your weight? _____	29. Believes that weight was asked.
Did I ask you about the kind of work you do? _____	30. Forgot that job was asked.
Did I ask you about your father? _____	31. Believes that question about father was asked.
What is my name? _____	32. Forgot interviewer's name.
What is my job title? _____	33. Forgot job title.
Patient's Name _____	Date _____
	MAS Score (Total errors) _____

a widely used, individually administered measure of memory for immediate and delayed recall, and is a standard component of neuropsychological testing. From the WMS-III, 2 scores, the Immediate Memory Index (IMI) and the General Memory Index (GMI), were utilized in this study.

### Statistical Analyses

The data were analyzed using parametric and non-parametric statistics to compare the 2 groups with regard to age, sex, education, and duration between onset of injury and date of examination. The reliability of the MAS was examined for inter-item consistency with the Kuder-Richardson Formula 20 test. Logistic regression evaluated the ability of MAS to predict Mild Cognitive Disorder patients when adjusting for IQ and memory scores. Spearman's rank correlation coefficients were obtained to assess the relationship between the MAS with IMI and with GMI.

Receiver operating characteristic (ROC) curves and area under the curve (AUC) examined the diagnostic performance of the MAS, IMI, and GMI in identifying Mild Cognitive Disorder patients. Using varied cut-off scores for the MAS and known Cognitive Disorder status, the sensitivity and specificity levels of the MAS were determined. Lastly, univariate item analysis (Fisher's Exact) was conducted for questions that were consistent across respondents (based on the previous Kuder-Richardson Formula 20 test) to identify MAS test items that were able to differentiate between Mild Cognitive Disorder and No Cognitive Disorder patients. Stata IC 15.0 software was used for all statistical analyses (StataCorp, College Station, TX). Findings were considered statistically significant at  $P < .05$ .

### Hypotheses

Based on the results of the prior study of the MAS, it was hypothesized that the MAS scores of patients in the Mild Cognitive Disorder group would be significantly lower than patients in the No Cognitive Disorder group. Significant correlations between the MAS with the IMI and with the GMI would be found.

## Results

**Table 4** presents the memory test scores of the Mild Cognitive Disorder and No Cognitive Disorder groups. Differences between the 2 groups in age, sex, education, and duration between injury and testing date were not statistically significant. The inter-item consistency results, with a Kuder-Richardson coefficient of 0.81, supported the homogeneity and reliability of the test items in the MAS. The logistic regression yielded an odds ratio of 0.88 (95% CI [0.77, 1.01]), which indicated that the MAS score was not predictive of Mild Cognitive Disorder. The Spearman correlation coefficient between the MAS and the GMI was 0.36, and between MAS and the IMI was 0.32. The correlations were low but statistically significant ( $P < .001$ ).

The ROC curves and AUC analyses indicated that MAS (0.58), IMI (0.58), and GMI (0.62) were not able to identify Mild Cognitive Disorder patients the majority of the time. In comparison, the GMI (0.62) was more likely to identify Mild Cognitive Disorder patients when compared to MAS and IMI. **Figure 1** presents the ROC curves for the MAS, IMI, and GMI, compared to the diagonal line that represents a random ability to identify Mild Cognitive Disorder patients.

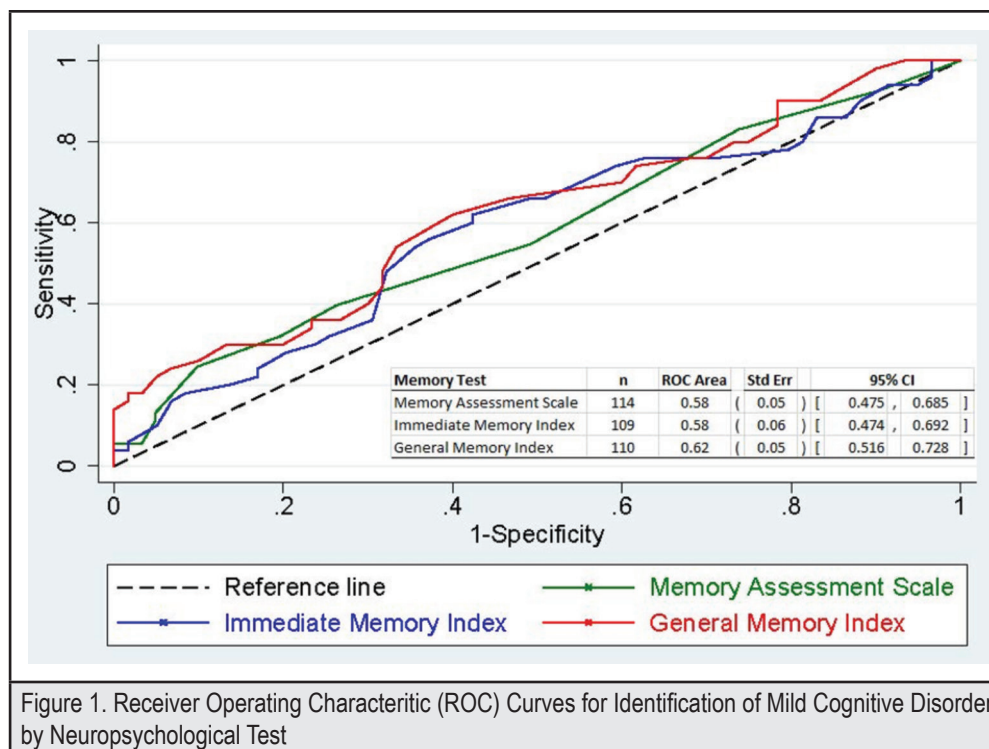
Using a cut-off score of 32, the sensitivity level of the MAS was 83% and its specificity was 26%. With a cut-off score of 31, the MAS sensitivity was 54.7%, while specificity was 50.8%. A cut-off score of 30 resulted in a MAS sensitivity of 39.6% and a specificity of 73.8%. Item analysis, using Fisher's Exact Test, found 5 MAS items that significantly differentiated the Mild Cognitive Disorder and No Cognitive Disorder groups. They were questions No. 6, "What is your address?" ( $P = .04$ ), No. 14, "What month is this?" ( $P = .02$ ), No. 22, "Who is the President of the United States?" ( $P = .02$ ) No. 30, "Did I ask you about the kind of work you do?" ( $P = .037$ ), and No. 32, "What is my name?" ( $P = .038$ ).

Table 4. Memory Test Scores of Two Cognitive Disorder Groups				
	Mild Cognitive Disorder (n=53) Number (%)	No Cognitive Disorder (n=61) Number (%)	Test statistic	P-value
<b>Memory Test Scores</b>				
MAS	28.8 (4.4)	30.1 (2.3)	1.491	.14 <sup>a</sup>
IMI	87.6 (17.9)	92.5 (16.7)	1.4677	.15 <sup>b</sup>
GMI	87.5 (18.8)	95.8 (16.7)	2.4752	.01 <sup>b</sup>

Tests: MAS=Memory Assessment Scaled, IMI=Immediate Memory Index, and GMI=General Memory Index

<sup>a</sup> Mann-Whitney U test

<sup>b</sup> Two-sample t-test



## Discussion

The aim of this study was to re-examine the Hawai‘i-based MAS that was shown in 1987 to be effective in identifying patients diagnosed with a neurocognitive disorder.<sup>5</sup> Unlike the previous MAS study in which the MAS scores of cognitively impaired patients were significantly lower than the patients without cognitive impairment, the present investigation found no significant difference in MAS scores between the Mild Cognitive Disorder and No Cognitive Disorder patients. An apparent reason for the disparate findings was that the cognitively impaired participants in the earlier study were comprised of more severely impaired patients, all of whom evidenced abnormal findings in a neurological examination as well as in a neurodiagnostic test, as compared to the patients without cognitive impairment who had negative neurological examinations and neurodiagnostic test results. In the present study, only 28.3% of the Mild Cognitive Disorder patients and 24.6% of the No Cognitive Disorder patients had a positive neurodiagnostic test result. In short, the neurological conditions of the 2 current groups of participants in this research may not have been substantially different from each other, thus obtaining relatively similar MAS memory scores.

If the purpose of the screening test is to identify individuals who may have a cognitive disorder, to be followed by a safe and more specific test for definitive diagnosis, or by a low-cost, low-risk intervention, a lower MAS cut score that increases diagnostic sensitivity but with a corresponding decrease in specificity may be desirable.<sup>11</sup> In that case, an MAS cut-score

of 32 that results in a sensitivity of 83% and specificity of 26% would be preferable. On the other hand, if the objective is to identify patients with a brain disorder who would then need a costly or invasive next step, such as positron emission tomography scanning or lumbar puncture, it may be better to maximize specificity to minimize unnecessary major procedures in patients incorrectly classified as having cognitive disorder. In that situation, an MAS cut-off score of 30 would result in a sensitivity level of 39.6% and specificity of 73.8%. Ultimately, the clinician using the MAS needs to select the cut-scores optimized for their purpose. Users of screening tests should strike a balance between sensitivity and specificity to rule in or out the participants with cognitive disorder.<sup>12</sup>

In this study, the diagnostic performance of MAS was limited in identifying Mild Cognitive Disorder patients, with an AUC of 58%. Reviewers of screening tests for cognitive impairment concluded that brief instruments, like the MMSE or MAS, suffer from their brevity and limited coverage of abilities. Thus, while a brief 10-minute test fits well within a time-constrained medical visit, a comprehensive assessment of skills would require 4 to 6 hours of administration time to retain stronger psychometric qualities.<sup>13</sup> Additional disadvantages of the more informative comprehensive cognitive testing is that it requires a battery of testing equipment and trained staff that are not compatible with a standard clinical visit, as well as entailing further costs.

The value of a population-based psychometric instrument, like the MAS, cannot be overstated. Population-based tests that

are validated with persons who closely resemble the group to which an individual belongs provide the best comparisons that maximize the accurate diagnosis of brain-impaired persons.<sup>14</sup> With revisions, the MAS, as a population-based memory scale, has the potential to be a valuable asset for clinicians in Hawai‘i seeking a screening test to assist in the detection of patients with mild memory impairment. The data from this study can be used to improve the accuracy of the MAS with item analyses, preserving test items that are effective in differentiating those with and without cognitive disorder, and to conduct a follow-up study with individuals 60 years and older.

## Limitations

Several limitations of this research are noted. The relatively small sample sizes of the 2 groups could have lowered the statistical power of the analyses, contributing to the null findings. The smaller sample limited the ability to reveal differences, and this is particularly relevant in this research because the majority of Mild Cognitive Disorder patients had mild neuropsychological impairment. A comparison with a larger sample size could have enhanced the diagnostic capacity of the MAS in identifying memory deficits in mild cognitive impairment. This retrospective study did not systematically require neurodiagnostic tests that would be valuable in understanding those with memory difficulties. The reliability of the MAS was evaluated with an inter-item consistency measure, whereas a preferred test-retest reliability measure was not possible with a single test administration. Additional MAS research with a larger sample of patients exhibiting varied severity of cognitive dysfunction should be considered to further assess the efficacy of this screening test in Hawai‘i. A study that compares the MAS scores of patients with mild cognitive disorder with healthy controls would be especially beneficial.

## Conclusions

The present study found a significant correlation between the MAS and the WMS-III, a widely used memory test. However, no differences in MAS scores were found between patients with and without mild cognitive disorder. Revision of the MAS may be needed for it to be utilized as a population-based cognitive screening instrument.

## Conflict of Interest

None of the authors identify a conflict of interest.

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# Leukocytoclastic Vasculitis Localized to the Uterine Cervix

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## Abstract

Patients with gynecologic vasculitis should be evaluated for systemic disease as prognosis and treatment can vary depending on systemic involvement versus isolated disease. Leukocytoclastic vasculitis is a rare, immune-mediated small-vessel vasculitis. Leukocytoclastic vasculitis of the uterine cervix with systemic involvement has not previously been reported. A 25-year-old female with abnormal cervical cancer screening presented for colposcopy. Biopsies were notable for dysplasia and concurrent leukocytoclastic vasculitis. The patient later recalled a recurrent rash of her lower extremities, suspicious for systemic disease. Patients with gynecologic vasculitis should be evaluated for systemic involvement because prognosis and treatment differ from that of isolated disease. Additionally, leukocytoclastic vasculitis of the uterine cervix may be associated with both hormonal contraception and infections such as human papillomavirus, and any resulting cervical dysplasia should be monitored for progression and treated accordingly.

## Keywords

vasculitis, leukocytoclastic, cervix, colposcopy

## Abbreviations

CIN 1-3 = cervical intraepithelial neoplasia 1-3  
GynV = gynecologic vasculitis  
HPV = human papilloma virus  
LCV = leukocytoclastic vasculitis  
LGSIL = low grade squamous intraepithelial lesion  
PAN = polyarteritis nodosa

## Introduction

The term vasculitis refers to a heterogeneous group of conditions of vessel wall inflammation, which can be further differentiated by vessel size and histologic features. Leukocytoclastic vasculitis (LCV) is more specific, referring to a hypersensitivity vasculitis that is confined to small vessels and is characterized by neutrophilic inflammation in post-capillary venules.<sup>1</sup> Additional histopathologic features of LCV include endothelial swelling, fibrinoid necrosis, and erythrocyte extravasation. Leukocytoclastic vasculitis typically manifests with isolated cutaneous findings, usually as palpable purpura, macules, papules and/or bullae.<sup>2</sup> However, other organ systems may be involved, such as the kidneys, heart, gastrointestinal tract, lungs, and central nervous system. In some instances, LCV can be the predominant vasculitis seen in systemic diseases such as rheumatoid vasculitis and sarcoidosis.<sup>3</sup> Triggers for LCV include infections, medications, vaccines, malignancies, and autoimmune diseases, but an estimated 50 percent of LCV cases are idiopathic.<sup>3-5</sup> Prognosis is generally good and self-limiting, yet some studies have reported decreased overall survival rates in patients with LCV.<sup>3-5</sup>

Gynecologic vasculitis (GynV) refers to any inflammatory vascular condition within the female reproductive tract.<sup>6</sup> Although rare, it has been well documented. GynV is typically an incidental finding on surgical specimens and most often confined to a single organ.<sup>6,7</sup> Few cases of necrotizing vasculitis of the uterine cervix have been reported. More specifically, LCV of the uterine cervix has not been published in the medical literature.<sup>9</sup> We present a case of LCV of the uterine cervix identified by colposcopic biopsy after abnormal cervical cancer screening in a patient with recurrent, self-limiting lower extremity skin changes.

## Case

A 25-year-old nulliparous female presented to the gynecology clinic for colposcopy after cervical cancer screening resulted as a low grade squamous intraepithelial lesion (LGSIL). Human papilloma virus (HPV) testing was not completed. She was otherwise healthy and had no complaints. The patient was using an etonogestrel/ethinyl estradiol vaginal ring continuously for contraception.

The colposcopy was notable for a friable nulliparous cervix with abnormal contour. After application of acetic acid, acetowhite epithelium and punctation were noted at the 4, 8, and 11 o'clock positions with multiple small vessels visualized throughout the cervix. Biopsies at each location were taken, and endocervical curettage was performed.

The final pathology demonstrated cervical intraepithelial neoplasia grade 1 (CIN1) in all 3 cervical biopsy specimens along with microglandular hyperplasia consistent with exogenous hormone administration. Uniquely, each of the biopsies also showed atypical vascular changes characterized by fibrin thrombi, vessel wall destruction and cellular debris with many extravasated red blood cells (**Figure 1**), diagnostic for LCV. Endocervical curettage was negative for dysplasia and vasculitis.

The patient was referred to the rheumatology clinic for further evaluation. There, she revealed experiencing intermittent lower extremity skin changes, which were self-limiting and recurred sporadically. She was asymptomatic at the time of this clinical evaluation. Basic blood counts, metabolic panel, c-reactive protein (CRP) and erythrocyte sedimentation rate (ESR), hepatitis, human immunodeficiency virus (HIV), and autoimmune serologies such as antineutrophil cytoplasmic antibodies, antinuclear antibodies, anti-cyclic citrullinated peptide (CCP) antibodies, serum complements, rheumatoid factor, were then obtained and unremarkable. The patient was suspected to have

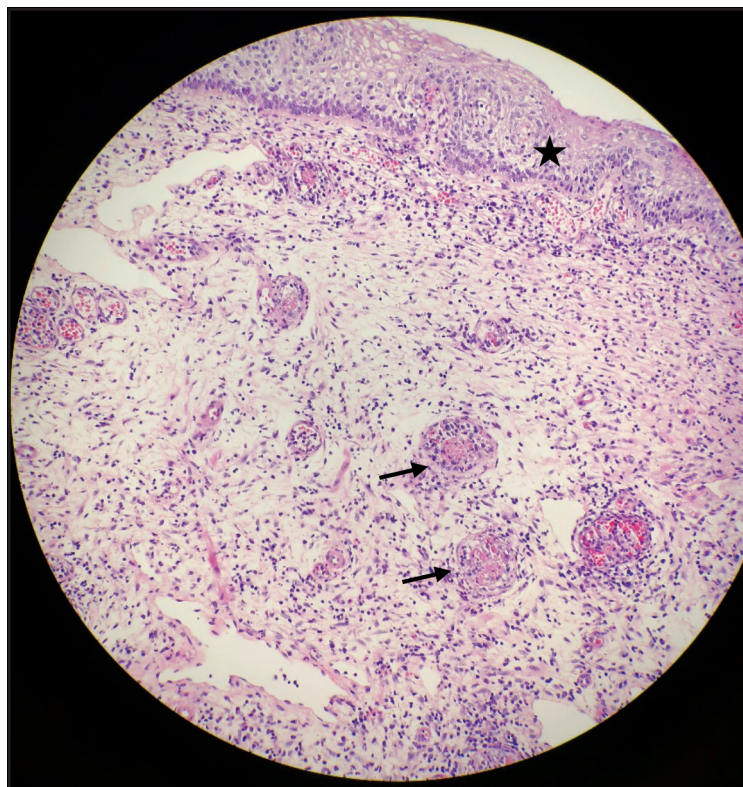


Figure 1. Initial colposcopy biopsy with fibrin thrombi, vessel wall destruction and neutrophilic cellular debris with many extravasated erythrocytes consistent with leukocytoclastic vasculitis (LCV, black arrows). Cervical intraepithelial neoplasia 1 (CIN1) shown (black star)

systemic LCV with skin and cervical manifestations. She was provided with a prednisone taper for future LCV skin recurrences and instructed to return to the gynecology clinic in 12 months to repeat the cervical cancer screening.

One year later, the patient's cervical Pap smear and HPV co-testing were significant for LGSIL and high-risk HPV positive status (HPV 16, 18, and 45 negative). The repeat colposcopy demonstrated acetowhite epithelium, punctation, and small vessels were again visualized at the 4, 8, and 11 o'clock positions; biopsies along with an endocervical curettage were obtained. The pathology was notable for CIN3 in the four o'clock specimen, and CIN1 was found within the 8 and 11 o'clock specimens and endocervical curettages. Additionally, LCV was again seen in the 11 o'clock specimen, and nonspecific vascular changes were present in the 4 and 8 o'clock specimens. The patient then underwent an uncomplicated loop electrosurgical excision procedure where high-grade cervical dysplasia and LCV were confirmed. The margins of the specimen were positive for high grade dysplasia and close observation was recommended. Throughout this time the patient denied further lower extremity skin lesions and had not used the prednisone taper. Prior to her next cervical cancer screening, the patient was lost to follow up after relocating out of the state.

## Discussion

This case presents an opportunity to consider the evaluation of LCV and other GynV either found incidentally or in conjunction with systemic symptoms. This diagnosis presents important considerations including the etiology of the vasculitis, evaluation and treatment, and associated morbidity and mortality. Patients with GynV are most commonly asymptomatic; however, some may experience abnormal vaginal bleeding or present with pelvic masses.<sup>6</sup> When diagnosed with LCV or other GynV, evaluation for systemic disease is recommended.<sup>3,6</sup> A comprehensive work up includes erythrocyte sedimentation rate, complete blood count, basic metabolic panel, hepatitis panel, HIV testing, antistreptolysin titer, chest x-ray, antineutrophil cytoplasmic antibodies, antinuclear antibody, rheumatoid factor, serum complement, and serum or urine electrophoresis tests. If patient is not up to date, cervical cancer screening should be considered.<sup>4,6</sup> Management includes removal of triggers such as the discontinuation of offending drug agents and treatment of diagnosed infections. Mild vasculitis cases are managed with supportive measures, but severe or chronic cases may require steroid administration.<sup>4</sup>

The prognosis of both LCV and other GynV is favorable. Naturally, as GynV is usually diagnosed after surgical resection of the affected organ, when confined to a single organ the GynV mortality rate is low.<sup>6</sup> A 2016 retrospective analysis of 112 patients with LCV showed a 5-year survival rate of 75.6 percent, and of the 27 total deaths that occurred during the study period, only 2 were attributed to LCV. In this study, age over 65 years was associated with decreased survival.<sup>3</sup> Another study of 84 patients reported a 5-year survival rate of 85 percent compared to 95 percent of the control population, with none of the 15 deaths directly related to LCV.<sup>5</sup> In most cases, LCV is not the direct cause of mortality, instead it is an associated finding of infections, medications, and malignancies.

Overall, LCV is rare. A 2014 population study found an incidence rate of 0.0045 percent for biopsy-proven LCV.<sup>5</sup> Vasculitis of any histology found within the female genital tract is also uncommon, with studies demonstrating an incidence of 0.04-0.15 percent of surgical specimens.<sup>6,7</sup> In a case series, isolated necrotizing vasculitis similar to polyarteritis nodosa (PAN-type) was isolated from the uterine cervix in 66 percent of 88 cases reviewed.<sup>8</sup> While small-vessel necrotizing GynV has previously been observed, this case is unique in that LCV of the uterine cervix has not been specifically documented.

In most LCV cases, the etiology is idiopathic. However, triggers for LCV are known and diverse. They include infections such as streptococcal upper respiratory tract infections, viral hepatitis, and mycobacteria.<sup>3-5</sup> Regarding GynV, LCV may also be associated with sexually transmitted infections such as chlamydia, gonorrhea, HIV, syphilis, and HPV.<sup>4</sup> The occurrence of GynV in the presence of HPV-related cervical dysplasia has previously been reported. One case reported chronic cervicitis as well as necrotizing granulomatous vasculitis after cervical conization.<sup>9</sup> Sixteen cases of polyarteritis nodosa (PAN)-like necrotizing vasculitis were related to intraepithelial cervical neoplasia in another case series.<sup>10</sup> Interestingly, all reported cases of vasculitis have been diagnosed on specimens obtained from cervical excisional procedures or hysterectomies and not simply colposcopic biopsies.<sup>7-12</sup> Although more research is needed, this may suggest an association between GynV, cervical dysplasia, and high-risk strains of HPV.

Other causes of LCV include drug reactions to many common medications including antibiotics, nonsteroidal anti-inflammatory drugs, antiepileptics, beta-blockers, immunosuppressants, diuretics, chemotherapy agents, diabetic medications, and antidepressants.<sup>3-5</sup> Although the mechanism of action is unclear, a 2015 case report identified a patient with the diagnosis of cervical vasculitis onset approximately 5 weeks after medroxyprogesterone contraceptive injection suggesting progesterone immunomodulation as a trigger for the condition.<sup>13</sup> This patient had been continuously using an etonogestrel/ethinyl estradiol vaginal ring for over 1 year suggesting possible progesterone-mediated vascular changes may be a factor in this case.

The occurrence of GynV with systemic involvement is less clear. One study looked to classify 163 patients with GynV, and of those 31 percent had systemic symptoms or signs of other organ system involvement. Systemic disease in these patients involved mostly musculoskeletal, pulmonary, or renal systems. Most patients complained of constitutional and musculoskeletal symptoms such as headache, polymyalgia rheumatica, and arthritis.

In conclusion, this case brings to light evidence that LCV can be found in the uterine cervix, and the importance of evaluating patient with isolated findings of LCV for systemic disease. The recommended workup is presented, as well as a review of causes, triggers, and prognosis. While many cases of LCV and other GynV are asymptomatic and self-limited, further evaluation should be considered, treatable conditions should be addressed, and patients monitored for the development of systemic disease. Although studies are limited, current evidence show decreased survivability in the setting of isolated and systemic LCV diagnosis, and patients should be aware of possible outcomes. Additionally, this case points to a possible correlation between both hormonal contraception and HPV infection with cervical LCV, although more research is needed to explore these associations.

*The views expressed in this abstract/manuscript are those of the author(s) and do not reflect the official policy or position of the Department of the Army, Department of Defense, or the US Government.*

## Conflict of Interest

None of the authors identify a conflict of interest.

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# INSIGHTS IN PUBLIC HEALTH

## The Health and Social Impacts of the Maui Wildfires: Post-Disaster Care from a Sociocultural Lens

Ryan Holliday PhD; Lauren S. Krishnamurti PhD; Shiloh E. Jordan PhD; Marissa A. Sia PsyD; Lisa A. Brenner PhD; Lindsey L. Monteith PhD

Insights in Public Health is a recurring column from the public health community and is coordinated by HJH&SW Contributing Editor Mapuana Antonio DrPH from the Office of Public Health Studies in the Thompson School of Social Work & Public Health at the University of Hawai'i at Mānoa and Contributing Editor Nichole J. Fukuda MS from the Hawai'i Department of Health.

### Background

The wildfires on the island of Maui resulted in over 100 deaths, rendering it among the deadliest wildfires in US history.<sup>1</sup> The potential impacts of the Maui wildfires on those residing on the island encompass loss of housing and employment in the context of financial difficulties; exacerbated mental health symptoms and suicide risk; and permanent loss of important cultural sites. Existing health and social service disparities may further exacerbate the wildfires' impact and recovery. Each of these domains is discussed further below.

### Impacts

#### Housing, Employment, and Finances

Maui's infrastructure has been devastated by the destruction of local housing and businesses, raising concerns about homelessness and unemployment; specifically, 6000 individuals were estimated to be homeless because of the wildfires.<sup>2</sup> Concerningly, rates of homelessness were already high in Maui, an island which lacks the infrastructure to house thousands of displaced residents.<sup>3</sup>

Further, the costs of the wildfires are estimated to be in the billions of dollars, largely based on property damage, lost output, and decreased tourism.<sup>4</sup> Tourism is the largest sector of Maui's economy, accounting for approximately 40% of the island's gross domestic product. This has adversely impacted the island's economy, as well as access to employment among residents, for whom tourism accounts for 51% of jobs.<sup>5</sup> Finally, the State of Hawai'i, including Maui, has the highest cost of living in the US, coupled with wages far below the national average; consequently, these losses in Maui are likely to result in significant economic repercussions among residents for years to come.<sup>6</sup>

### Mental Health

Countless individuals may also experience lasting psychological injuries from the Maui wildfires. The mental health sequelae of widespread disasters, including wildfires, upon individuals residing in impacted communities has been well-documented.<sup>7</sup> Survivors commonly report experiencing post-disaster symptoms of posttraumatic stress disorder (PTSD), depression, and anxiety.<sup>8</sup> Beyond the initial impact, the wildfires may necessitate longer-term health care needs for survivors. Those who subsequently develop PTSD or depression may require access to evidence-based psychotherapy and pharmacotherapy. Yet barriers to health care access and engagement, including inter-island distance, rurality, and a lower availability of providers relative to demand in Hawai'i, pre-dated the wildfires.<sup>9</sup> For example, approximately 20% of Hawai'i residents with a psychiatric condition report unmet treatment needs.<sup>10</sup> Concerningly, mental health practitioners are limited, with a 22% shortage in psychiatrists across the Hawaiian islands, as indicated by an estimated shortage of 43.4 full-time psychiatrists in 2020.<sup>10</sup>

Although these aforementioned factors were likely exacerbated by the wildfires, additional barriers have arisen which may impact health care access and engagement. For example, the number of individuals likely to need counseling to process this traumatic event is anticipated to burden an already overtaxed behavioral health care system.<sup>11</sup> Moreover, contextual factors, such as loss of transportation following the wildfires, may further hamper use of mental health services.<sup>12</sup>

### Suicide Risk

Readiness to address the potential for increased suicide risk among those affected by the Maui wildfires is also essential. In Hawai'i, suicide is one of the leading causes of preventable death: 979 Hawai'i residents died by suicide from 2017 to 2021.<sup>13</sup>

Though post-disaster suicide risk may not increase immediately, risk appears to increase long-term.<sup>14</sup> One study found that the largest increase in county-level suicide rates following natural disasters occurred 2 years later.<sup>15</sup> Therefore, it is essential to not only address the potential for increased suicide risk in the immediate aftermath of the wildfires, but also elevated risk over a longer period. This may be facilitated by considering specific groups that may be at particularly elevated risk for suicide following natural disasters, such as those bereaved, injured, or whose family have been injured; those with pre-existing or newly onset mental health conditions (eg, PTSD, depression); and those experiencing economic instability and loss of social support.<sup>16</sup> Supporting survivors in coping with loss and injury, accessing evidence-based mental health care, and obtaining economic and social support are therefore likely integral to post-disaster suicide prevention. Addressing mental health and psychosocial sequelae which drive both short-term and longer-term suicide risk is also essential.

## Culture

In addition to economic and mental health consequences, collectively understanding and acknowledging the full extent of cultural losses in the wake of the wildfires is also essential. In particular, the sociocultural and community impacts, particularly for Native Hawaiians, should be considered. The town of Lahaina suffered immense damage to its historic sites and irreplaceable cultural artifacts. Many of these structures dated back over a century and represented histories pre-dating statehood. Lahaina is a symbol of King Kamehameha's unification of the Hawaiian Islands, serving as the inaugural capital of the Hawaiian Kingdom and historically housing Hawaiian royalty.<sup>17</sup> Lahaina is also considered sacred to Native Hawaiians due to its deep-rooted connection to the land (*‘āina*) – encompassing physical land, sustenance, and spiritual ties to ancestral land.<sup>18</sup> The enduring history of land and culture loss experienced by Native Hawaiians, including annexation and colonialization, may further compound grief in the wake of the wildfires.

## Regional Factors: Social Isolation, Rurality, and Service Limitations

Importantly, factors in the Pacific Island region (eg, rurality, difficulty accessing care on other islands) may further exacerbate the psychosocial impacts of the wildfires and accompanying devastation. Unlike some regions of the continental United States (CONUS), some areas within Pacific Island regions lack access to specialty health care and social services, which are necessary following large-scale disasters. Hawai‘i has 6 verified trauma centers, none of which are located on Maui.<sup>19</sup> Despite federal (eg, Department of Defense, Federal Emergency Management Agency) and State of Hawai‘i Department of Health on-site crisis response efforts, the devastation in Maui resulted in severe injuries (eg, third-degree burns, severe traumatic brain injuries) requiring transportation of those injured to the island

of O‘ahu.<sup>20</sup> Temporary relocation or separation from family or communities may disrupt individuals' ability to obtain essential social support during acute distress. Notably, social isolation following natural disasters and traumatic events is associated with more pernicious mental health outcomes, whereas social support is critical to coping with the immediate aftermath of natural disasters and in preventing post-disaster mental health sequelae.<sup>21</sup>

## Addressing These Multi-Faceted Impacts

Advancements in technology and telehealth offer modern opportunities to aid Maui residents in the wake of this disaster. Remote or virtual care may be pragmatic and beneficial as infrastructure is rebuilt. However, programs aimed at enhancing digital literacy and access to reliable internet may need to precede virtual care. High-quality telehealth psychotherapy services are also offered across Hawai‘i and CONUS. A seminal study initially conducted in Hawai‘i demonstrated non-inferiority for telehealth in treating PTSD, relative to in-person therapy.<sup>22</sup> Telehealth approaches may increase access to empirically-supported care and follow-up appointments, and thus may aid those impacted by access issues (eg, rurality; transportation and employment challenges) post-disaster. Telehealth can also promote access to health care for displaced individuals who are seeking housing in the wake of this natural disaster. Survivors experiencing distress can additionally contact crisis hotlines, such as the 988 Suicide and Crisis Lifeline, which offer risk assessment and can provide brief empirically-supported interventions (eg, Safety Planning for suicide prevention). Additionally, crisis hotlines can connect callers to local services (eg, emergency services, hospitalization) in real time, as appropriate.

Others outside of Maui can also consider ways to help, including recognition of the vital cultural knowledge needed to maximize the effectiveness of relief and recovery efforts. As culturally-sensitive interventions are optimal to increase the effectiveness of interventions, consideration of cultural factors is essential when addressing the potential impacts previously discussed.<sup>23</sup> The demographics of Lahaina include individuals identifying as Asian, Native Hawaiian, Pacific Islander, multi-racial, and White.<sup>24</sup> Given the under-inclusion of Native Hawaiians and Pacific Islanders in health research, those impacted by the disaster may be underrepresented in existing literature.<sup>25,26</sup> Services focused on solely increasing resources, without cultural context (historical and current), are not likely to meet true needs. Providers are encouraged to use a framework of cultural humility, enabling treatment that strengthens individual residents of Maui and meets the needs of the community.<sup>27</sup> This also helps to ensure true investment in the Maui community, rather than a more temporary, fleeting approach to community mental health. In addition, to optimize patient-centered, culturally-sensitive care, tailoring care for individuals in this community may include integrating family and spiritual leaders into treatment, as well as community-based initiatives to de-stigmatize access

and engagement in mental health services. Social services must also consider contextual and cultural factors. In a region where extended families often live together, housing models should consider broader family configurations for transitional housing and emergency shelters.<sup>28</sup> Vocational rehabilitation approaches should address job loss, with childcare and transportation concerns in mind; remote work opportunities and flexible schedules may also be valuable.

## Summary

While the immediate effects of the Maui wildfires are well-documented, the impact on individuals, families, communities, and all of Hawai'i is likely to endure. Though complete understanding of the long-term impacts of these wildfires will take time, existing health and social service infrastructure, particularly beyond Maui, can be used to aid survivors and community members. Further, additional health, social, and research endeavors are necessary to fully understand and adapt care for impacted Maui residents. In particular, empirical examination to understand the extent of traumatic sequelae among survivors, including impact on mental health, suicide risk, and psychosocial functioning (eg, ability to maintain employment in the context of psychiatric symptoms), is critical. Development and evaluation of programming to increase health and social services to displaced residents, as well as to prevent long-term adverse outcomes (eg, trauma symptomology, heightened suicide risk), is likely also a necessary and important next step.

## Conflict of Interest

None of the authors identify a conflict of interest.

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