

# UWHR 2021

 THE UTAH WOMEN'S HEALTH REVIEW



# Masthead

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Volume 2 Number 1 May 2021

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## Letter from the Editor

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Since its official launch in May of 2020, The Utah Women's Health Review has continued to grow in marvelous ways. We are excited to introduce the 2021 issue, which includes thirteen original manuscripts—seven research articles, three commentaries, and three data snapshots. Additionally, we provide a link to the recorded proceedings from the 2021 “Sex, Gender, and Women's Health Across the Lifespan Virtual Symposium” and three reprints from the UU Gender-based Violence Consortium and USU Utah Women and Leadership Project. Original contributions to this issue, outlined below, thoughtfully consider at least one of the 7 Domains of Health —physical, reproductive, social, emotional, occupational, financial, environmental, intellectual, and spiritual health—in addition to shedding light on race and gender health disparities.

### Research Articles:

- Taylor and Hamilton confirm the significant need for improved sexual and reproductive health education for adolescents with cystic fibrosis and the need for standardization in care.
- Elzinga et al. report on how pregnant adolescent women relate to the concepts of planning, wanting, and intending pregnancy differently than pregnant adults, highlighting the need for continued development of tools that more accurately define and reflect the complexity of adolescents' pregnancy experiences.
- Kah et al. share their findings of increased postpartum depression among women experiencing prepregnancy/prenatal physical abuse and partner-related stress among a representative Utah population of 142,963 postpartum women. Their research findings are of significant public health importance as we witnessed rising rates of intimate partner violence during the COVID-19 pandemic. (UWHR NIH PubMed Cited Article: PMID: [35706583](#))
- Powell et al. report on the increased risk of gender-based violence among sexual and minority women at the University of Utah, bringing attention to the need for enhanced efforts to address existing services and resource gaps.
- Seage et al. report that overall, Utah women having prepregnancy and prenatal depression and anxiety have a 67% higher probability of preterm labor. Interesting, being of Hispanic/Latina ethnicity was found to protect against preterm labor for those with prepregnancy and prenatal depression, possible via increased social support, but more research is needed (UWHR NIH PubMed Cited Article: PMID: [35669386](#))
- Pentecost et al. identify the proportion of perinatal women screening positive for depression only, anxiety only, and co-occurring anxiety/depression. One of their key findings was that approximately 1 in 20 would have been missed among those with a positive anxiety screen based on their total Edinburgh Postnatal Depression Scale (EPDS) score alone. Their findings highlight the importance of considering both the EPDS score and the anxiety sub-scale among perinatal to provide more comprehensive and improved mental health care.
- Kelly et al. sought to describe which populations throughout the contiguous US would experience the most dramatic impacts if state-level abortion bans were enacted. Through a sophisticated ecological and spatial analysis, they found that if states enact abortion bans as expected, 46.7% of the country's women will experience an increased distance to abortion care. (Highlighted in the Utah Chronicle, <https://attheu.utah.edu/facultystaff/post-ro-e-millions-will-travel-farther-for-abortion-care/>)

### Data Snapshots:

*Leveraging the Utah Pregnancy Risk Assessment Monitoring System, Utah Department of Health; <https://mihp.utah.gov/pregnancy-and-risk-assessment>: Population-based analyses representative of all postpartum Utah women, including high-risk women, due to sophisticated stratified sampling scheme.*

- Duane et al. used UT-PRAMS data from 2009 to 2015 to (1) provide updated estimates of the prevalence of fertility treatments among women in Utah experiencing a live birth and (2) assess how infertility treatments are associated with women's age and prior live births. They report that approximately 10% of women who ultimately had a live birth sought treatment for infertility during this time frame, with around 5% for women 20–24 years to over 25% for women 40 years or older.
- Shaaban et al. used UT-PRAMS data from 2012 to 2020 to shed light on the social determinants of health, including age, race, insurance type, education, and income, that play a significant role in whether a mother will attend her postpartum checkup. The authors educate us on the importance of postpartum care to prevent pregnancy-related morbidity and mortality. They note that federal legislation and community interventions can help improve postpartum checkup attendance.
- Alsafi et al. used UT-PRAMS data from 2009 to 2019 to report the U-shaped relationship between maternal age and infant mortality and strategies to reduce infant mortality through federal and state education programs. Additionally, the authors educate us on other critical predictive factors for infant mortality, including maternal education, showing a near doubling of infant mortality among women with an 8th-grade education or less compared to women with at least an associate degree or higher.

#### Commentaries:

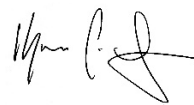
- Ryanna Durrant provided an enlightening commentary on the cognitive health of widows in the US, highlighting how social leisure activities provide a protective role for widows and may serve as a coping strategy to preserve cognitive functioning.
- Lueken et al. gave a powerful message on the multi-generational effect of illiteracy in the lives of Black American women. The authors underscore the need for “efforts to create intellectually stimulating and creative enrichment among young Black students that must include integrating Black, Brown, and Indigenous people's stories and culture into educational spaces....”
- Bradford et al. wrote an essential commentary on the impacts of menopause on cognitive function, with a call to action for continued research on the effects of decreased estrogen levels on cognitive decline and a more individualized approach to ex-

amine the effects of hormone replacement therapy among postmenopausal women.

Our 2022 issue is well underway with an increasing number of submissions and publications. The journal publishes original research or review articles, data snapshots, and commentaries focusing on women's health or sex and gender differences that affect the 7 Domains of Health—physical, social, emotional, intellectual, environmental, financial, and spiritual. The Editorial Board reflects our ONE U for U (1U4U) approach to sex and gender health. By creating and hosting this peer-reviewed journal within Eccles Library Digital Publishing, UWHR can facilitate publication opportunities for established sex and gender health researchers, graduate students, residents, and up-and-coming professionals all over Utah. UWHR's rolling submissions and publication dates allow for a fast turnaround time and a satisfying experience for submitting authors. Using the WordPress platform, we invite ongoing submissions. There are no publication charges. All published articles are covered by a Creative Commons License (CC BY-NC-ND 4.0) and assigned a DOI. UWHR could not succeed without our invaluable peer reviewers and associated editors. Please contact us if you are interested in serving in either of these capacities.

We look forward to receiving and reviewing your submissions this year and beyond!

Sincerely,



Karen Schliep, PhD MSPH  
Utah Women's Health Review  
Editor-in-Chief

# Sex, Gender, and Women's Health Across the Lifespan

## Virtual Symposium 2021

Visit the virtual symposium at <https://uwhr.utah.edu/virtual-symposium-2021/> for video presentations, Q&A, abstracts, and posters.

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<b>Pediatric and Adolescent Gynecology: What You Should Know</b>	Katherine Hayes, MD, University of Utah
<b>HPV and COVID-19 Vaccine Hesitancy Among Young Adults in the Mountain West</b>	Deanna Kepka, PhD, MPH, Huntsman Cancer Institute
<b>Reproductive Years: Contraception-Gender Preferences Over Time</b>	Rebecca Simmons, PhD, MPH, University of Utah
<b>Over the Rainbow: Health Equity for Sexual &amp; Gender Minority Older Adults</b>	Charles P. Hoy-Ellis, PhD, MSW, LCSW, University of Utah
<b>Sex and Gender Differences in Risk of Alzheimer's Disease and Related Dementia</b>	Karen Schliep, PhD, MSPH, University of Utah
<b>Gender, Policy, and Health Across the Lifespan</b>	Claudia Geist, PhD, University of Utah
<b>Refining the Assessment of Placental Somatic Variation</b>	Nathan Blue, MD, University of Utah
<b>Women with Synchronous Uterine and Ovarian Cancers: Misdiagnosed and Mistreated?</b>	Robert Dood, MD, University of Utah
<b>COVID-19 and Pregnancy: What Do We Know Now?</b>	Torri Metz, MD, University of Utah
<b>Sex &amp; Gender Differences with COVID-19</b>	Scott Benson, MD, PhD, MPH, University of Utah
<b>The Impact of COVID-19 on the Mental Health of Diverse Communities</b>	Anu Asnaani, PhD, University of Utah
<b>Perceptions of Gender Inequality Among Academic Authors of Outcomes Research</b>	Monet Luloh, University of Utah
<b>Methamphetamine Rewards and Brain Dopamine May Increase with Housing at Moderate Altitude in Females: Sex-Based Animal Model Studies</b>	Shami Kanekar, PhD, University of Utah
<b>COVID-19 Vaccination Intent Relates to HPV Vaccination Receipt</b>	Kaila Christini, MsPH, Huntsman Cancer Institute
<b>Preventing Structural Gender-based Violence on a University Campus: Advancing the Bystander Concept to Upstander Intervention</b>	Bobby Younce, MSW, University of Utah Diana Powell, MSW, University of Utah
<b>Supporting Midlife Women in the Menopause Transition: MsFLASH and Individualized Menopause Plans</b>	Andrea Z. LaCroix, PhD, University of California San Diego

# Gender-Based Violence Consortium: Visualizing Change, Resisting Violence Symposium **2021**

Visit the virtual symposium at <https://uwvr.utah.edu/gender-based-violence-consortium-visualizing-change-resisting-violence-symposium-april-16-2021/> for video presentations, Q&A, and transcripts.

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## Opening Remarks

Annie Fukushima, University of Utah

## Visions of Social Change

Ananya Chatterjea, Ananya Dance Theatre  
Yolanda Francisco-Nez, Restoring Ancestral Winds  
Liliana Olvera-Arbon, UCASA  
Keith Squires, University of Utah

## Leading Social Change to End Sexual Violence

Elizabeth Kronk Warner, S.J. Quinney College of Law  
Tasha Toy, Dixie State University  
Julie Valentine, Brigham Young University College of Nursing  
Kozue Akibayashi, Doshisha University

## Healing Communities

Amita Swadhin, Mirror Memoirs  
Fuifuilupe Niumeitolu, University of California, Davis  
Caroline Lovell, Women's Wisdom Initiative  
Saundra Shanti, Spiritual Care/Arts in Medicine

## Previously Unsubmitted Sexual Assault Kits: Lessons Learned from Salt Lake County

Heather C. Melton, University of Utah

## The Coordinated Community Response to Non-Fatal Strangulation in Intimate Partner Violence: A Pilot Program

Annie Fukushima, University of Utah  
Veronica Lukasinski, University of Utah  
Kwynn Gonzalez-Pons, University of Utah

## Gender-Based Violence as Structural Violence Among Sexual & Gender Minority Populations: Pilot Data from the University of Utah

Diana Powell, University of Utah  
Bobby Younce, University of Utah  
Lisa H. Gren, University of Utah  
Charles P. Hoy-Ellis, University of Utah  
Caren J. Frost, University of Utah

# Sexual and Reproductive Health Education for Adolescents with Cystic Fibrosis

Courtney S. Taylor & Jennifer L. Hamilton  
/ University of Utah

## Abstract

**Background:** To assess the SRH needs of adolescents with CF and create a SRH education guideline for CF providers.

**Methods:** Adolescents and young adults (AYA) were asked to complete a questionnaire about SRH educational needs. If the AYA was under the age of 18 years, their parent was also asked to participate. Survey data were analyzed using descriptive statistics, the Mann Whitney U test, and content analysis of the qualitative data. An evidence-based SRH education guideline was developed and presented to key stakeholders. CF clinic staff were asked to complete a pre- and a post-intervention survey to assess their perspectives of the guideline and report perceived barriers to SRH education. Surveys were created using recommendations from previous SRH education research and CF content experts.

**Results:** 29 AYA and 17 parents completed the survey. 13 CF staff completed the pre-intervention survey and 8 completed the post-intervention survey. Of the AYA surveyed, 18 (62.1%) were female and 11 (37.9%) were male. 31% (9/29) of AYA reported they had talked with a CF provider about SRH. 47.2% (8/17) of parents reported their child had talked about SRH with a CF provider. Almost all participants reported they want CF-related reproduction included in SRH education. Although not statistically significant, CF clinic staff who reported that they currently include or would include SRH education in their practice increased from 50% to 87.5%.

**Conclusions:** The findings confirm the significant

need for improved SRH education for adolescents with CF and the need for standardization in care. Adolescents in this CF center want SRH education from their CF care team. The lack of statistically significant differences in the results of CF staff could be related to sample size or resistance to practice change.

**Implications:** Future action is needed to address barriers to SRH education and implement an SRH education guideline.

## Introduction

### Problem Description:

Adolescents and young adults (AYA) with cystic fibrosis (CF) encounter similar sexual and reproductive challenges as their healthy counterparts. They also have disease-specific sexual and reproductive health (SRH) concerns.<sup>1</sup> 42% of adolescent girls with CF report being sexually active.<sup>1</sup> Survival rates and overall health are improving for CF, with more individuals living into adulthood.<sup>1-4</sup> This creates a greater need for SRH information for AYA with CF.

### Available Knowledge:

There are no guidelines for SRH education for AYA with CF.<sup>5</sup> The Cystic Fibrosis Foundation has information regarding SRH for individuals with CF, but there are no guidelines for providers.<sup>6</sup> Studies have looked at patient preferences for SRH education.<sup>5, 7, 8</sup>

### Rationale:

The ACE Star Model of Knowledge Transformation was used to conceptualize the implementation. This is a model for knowledge transfer and application in healthcare quality improvement.<sup>9</sup> It includes discovery



research, evidence summary, translation to guideline, practice integration, and evaluation (Figure 1).<sup>10</sup>

Figure 1

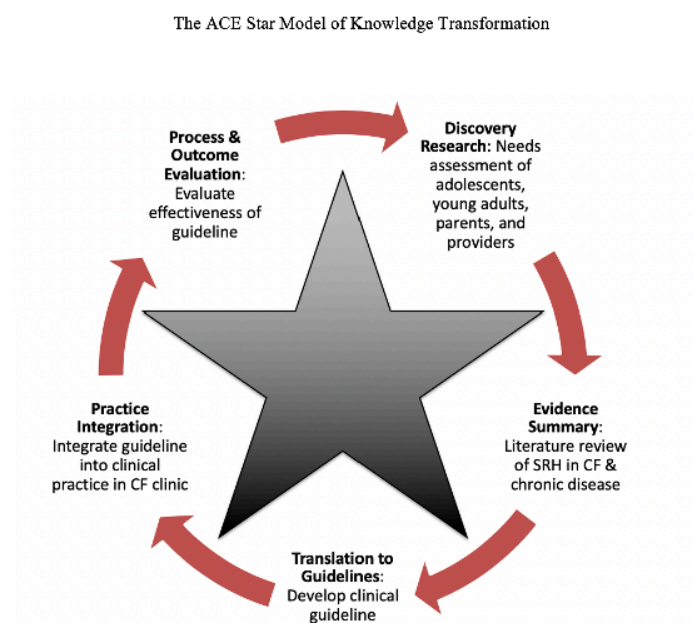


Figure 1: The ACE Star Model of Knowledge Transformation

### Specific Aims:

The purpose of this project was to assess the SRH educational needs of AYA with CF by surveying these individuals, their parents, and the CF care team, and to create an evidence-based SRH education guideline, present it to key stakeholders, and evaluate the CF care team's assessment of the guideline.

## Methods

### Context:

This project was completed at a Cystic Fibrosis Foundation-accredited CF center associated with an academic medical center in the Intermountain West serving five states. The center has an adult and a pediatric clinic; both clinics were involved with this project. The pediatric and adult teams consist of physicians, nurse practitioners, physician assistants, pharmacists, social workers, dietitians, respiratory therapists, registered nurses, and other health team members. Most patients seen in the CF center are White. For this project, only patients aged 14 to 24 years were included. For patients under the age of 18 years, their parents were also asked to participate.

### Intervention:

Surveys were created to assess AYA and parent needs related to SRH education. A survey for CF clinic staff was also created to assess SRH education needs, barriers, and attitudes. For four months, AYA and parents seen in the CF center were asked to participate by completing a paper questionnaire. Additionally, the parent survey was made available online via a link posted on a regional CF social media page. The CF staff survey was emailed to clinic staff to complete.

Based on the results from the needs assessment, a SRH education guideline for CF providers was developed using evidence-based recommendations related to SRH in pediatric chronic disease. The purpose of the guideline was to help clinicians in educating adolescents with CF. While developing the guideline, stakeholders were asked for their input and recommendations.

A report of the results from the needs assessment and the SRH education guideline were prepared and presented to key stakeholders in the CF center. A survey was created to assess the CF care team's perspective on the satisfaction, feasibility, and usability of the SRH education guideline as well as their confidence, attitudes, and perceived barriers to using it. Following the presentation, this survey was sent to the CF clinic staff via email.

### Study of the Intervention:

13 CF clinic staff participated in the pre-intervention survey (pre-survey), and 8 CF staff in the post-intervention survey (post-survey). CF staff were surveyed before and after they were presented with the clinic needs assessment findings and SRH education guideline to compare findings and evaluate the guideline. Pre- and post-surveys were sent via email. This project did not have a comparison group. There were no other quality improvement projects related to SRH education being implemented at the same time in the CF center at this institution.

### Measures:

The surveys used to measure processes and outcomes were created using recommendations from previous research done in SRH education. The surveys were reviewed and piloted by content experts and CF providers for content appropriateness, face validity, and ease of completion. Surveys included closed, open-ended, and Likert scale questions. The AYA and parent survey

included a Likert scale of very satisfied to very dissatisfied to measure participant satisfaction with SRH education they had received and current SRH knowledge. CF staff’s perceived importance of SRH education and topics were measured in the pre-survey using a Likert scale of 1 to 5, with 5 representing very important. Additionally, the CF staff survey included measurements of confidence, comfort, resources, and skills needed to provide SRH education using a Likert scale of strongly agree to strongly disagree. The CF staff post-survey included the same measures and were compared to pre-survey results using the Mann Whitney U test. Pilot data demonstrated that each survey took less than 10 minutes to complete.

The data from paper surveys for AYA and parents were entered electronically into a secure data base for statistical analysis. After entry, the paper survey data was compared carefully to the electronic data to ensure no errors were made. Additionally, the surveys from CF clinic staff that were completed electronically were reviewed for completeness and accuracy.

### Analysis:

Quantitative survey results were analyzed using descriptive statistics, including frequency distributions and summary statistics for central tendency and variability. The Mann Whitney U test was used to evaluate pre- and post-survey data, as data was non-parametric and unpaired. A content analysis was completed for qualitative survey results by carefully reading and coding responses. The coded data were then categorized, organized, and summarized to identify common themes.

### Ethical Considerations:

This study was approved by the University of Utah Institutional Review Board. Participation in the study was completely voluntary, and participants could withdraw at any time. Parental permission, consent, and assent were explained on the survey cover letter, and completion of the survey implied consent. No signatures were obtained. Participants were assured that their survey responses were confidential; furthermore, surveys remained anonymous

## Results

29 AYA 14 to 24 years of age participated in the survey

(Table 1).

Table 1

Demographic Characteristics: Adolescent and Young Adult Survey

Variable	N (%)	M (sd)
Age		18.0 3.0
Gender		
Female	18.0 (62.1%)	
Male	11.0 (37.9%)	
Transgender male		
Transgender female		
Other gender identity		
I'd rather not say		
Ethnicity		
White/Caucasian	28.0 (96.6%)	
Hispanic or Latino	1.0 (3.4%)	
Black or African American		
Native American or American Indian		
Asian		
Pacific Islander		
Eastern Indian		
Multiple races		
Other		
Unknown		
I'd rather not say		
Primary Language		
English	29.0 (100.0%)	
Spanish		
Chinese		
French		
Arabic		
Other		
Health Insurance		
Uninsured		
Private insurance	20.0 (60.9%)	
Medicaid	3.0 (10.3%)	
Medicare		
Other	1.0 (3.4%)	
I don't know	5.0 (17.2%)	

Table 1: Demographic Characteristics: Adolescent and Young Adult Survey

Most participants reported they had received SRH education regarding CF (89.7%), however, only 19.2% reported receiving this education from a healthcare provider. It was reported as being most frequently received at school, from a parent, or the internet. School and a parent were most frequently reported as the most important source of information on SRH. The majority (57.7%) of AYA reported they were satisfied with the SRH education they had received, but only 31% reported they had talked with a CF provider about SRH. Of those who said they had talked with a CF provider regarding SRH, the majority (66.6%) was either very satisfied or satisfied with the education. Puberty and fertility/pregnancy were the most common topics to have been discussed with a CF provider (Figure 2). 55.2% of participants reported that age 13 to 15 would be their preferred age to start discussing SRH. When asked about preferences regarding from whom they would want to receive SRH education, 38% had no preference, 24% preferred a CF provider, 24%

preferred a parent; 48.3% had no gender preference. The majority (65%) of AYA reported that their ideal educational resource would be an online resource. Almost all respondents (96%) reported they would want CF-related reproduction included in SRH education (Figure 3).

In reviewing open-ended survey questions, the AYA who participated repeatedly stated that they want more information regarding SRH or would have wanted

more information as an adolescent (N=16). These responses included statements such as “make it more of a topic during the teenage years,” “talk about it more,” “giving more information,” and “have the discussion early.” Another common theme identified was patient comfort during SRH discussions (N=5). Responses included “make it not sound gross” and “ask them if they feel comfortable talking about it.” Two respondents spoke about privacy, such as “no parents in the room” and “speak about it without parents present.” Family

(N=10), health (N=8), and SRH (N=5) were common themes in responses when participants were asked what they value for their future life. Responses included “a healthy one,” “being sexually healthy,” “being healthy enough to have kids,” “family,” and “I want to have safe sex practices, effective contraception and a family eventually.”

17 parents of CF adolescents participated in the parent survey (Table 2). The majority (58.8%) of parents reported that their child had received SRH education regarding CF. Of those who had received SRH education regarding CF, 90% of parents reported it was from a CF provider, and 70% reported it was from a parent. 41.2% of parents reported their child had not talked about SRH with a CF provider, while 47.1% reported their child had talked to a CF provider about SRH, 50% of parents were either very satisfied or satisfied with the education. The most discussed topic was puberty, followed by fertility/pregnancy (Figure 4). 41.2% of parents reported they would prefer their child receive SRH education from both the parent and a CF care team member, and 35.3% had no preference. Over 40% of parents felt that before age 13 was the most appropriate age for SRH education, and 35% felt age 13 to 15 was the most appropriate. Most parents reported the ideal educational

**Figure 2**  
*Adolescent/Young Adult: SRH Topics Discussed*

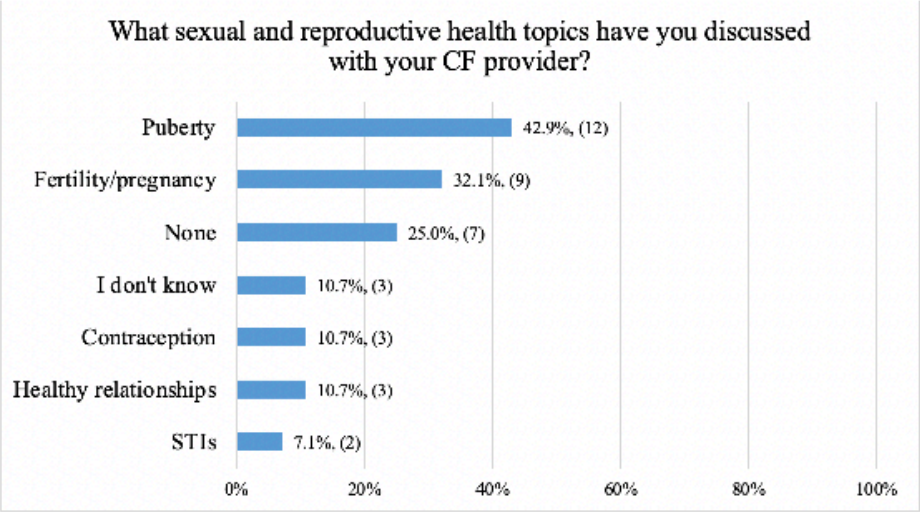


Figure 2: Adolescent/Young Adult Survey- SRH Topics Discussed

**Figure 3**  
*Adolescent/Young Adult: Preferred SRH Topics*

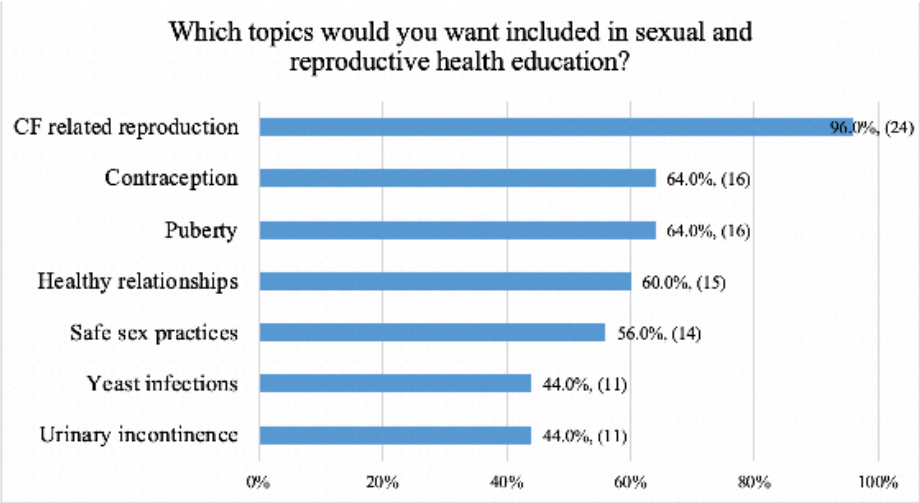


Figure 3: Adolescent/Young Adult Survey- Preferred SRH Topics



**Table 2***Demographic Characteristics: Parent Survey*

Variable	N (%)	M (sd)
Gender		
Female	13.0 (76.5%)	
Male	4.0 (23.5%)	
Transgender male		
Transgender female		
Other gender identity		
I'd rather not say		
Ethnicity		
White/Caucasian	17.0 (100.0%)	
Hispanic or Latino		
Black or African American		
Native American or American Indian		
Asian		
Pacific Islander		
Eastern Indian		
Multiple races		
Other		
Unknown		
I'd rather not say		
Primary Language		
English	17.0 (100.0%)	
Spanish		
Chinese		
French		
Arabic		
Other		
Health Insurance		
Uninsured	2.0 (11.8%)	
Private insurance	15.0 (88.2%)	
Medicaid		
Medicare		
Other		
Child with CF		
Son with CF	7.0 (41.2%)	
Daughter with CF	14.0 (82.4%)	
Age of Child		16.0 2.5

Table 2: Demographic Characteristics- Parent Survey

resource would be a written resource (52.9%). The top three topics that parents want to be included in their child's SRH education were CF-related reproduction, healthy relationships, and puberty.

According to open-ended responses in the parent survey, parents consistently reported the desire for the CF care team to understand the needs of the parent and patient (N=8) such as "don't be nervous about discussing sex and make it a natural discussion when the patient is ready," "listening and allowing time for them to open up, ask questions..." and "find out how much the parents want this discussed with their child." One parent felt that standardization would be helpful. They said, "just making it a routine part of the exam and discussing [it] openly from childhood to adulthood." Other common themes for how to support adolescents with SRH education included resources (N=3) and CF-specific information (N=2). Family (N=6) and knowledge (N=3) were common themes of what parents value for their children's future. Responses included "that she be comfortable and knowledgeable in her own body...have all information and education to be able to make choices that are right for her" and "that she understands what she needs to happen in order to get pregnant

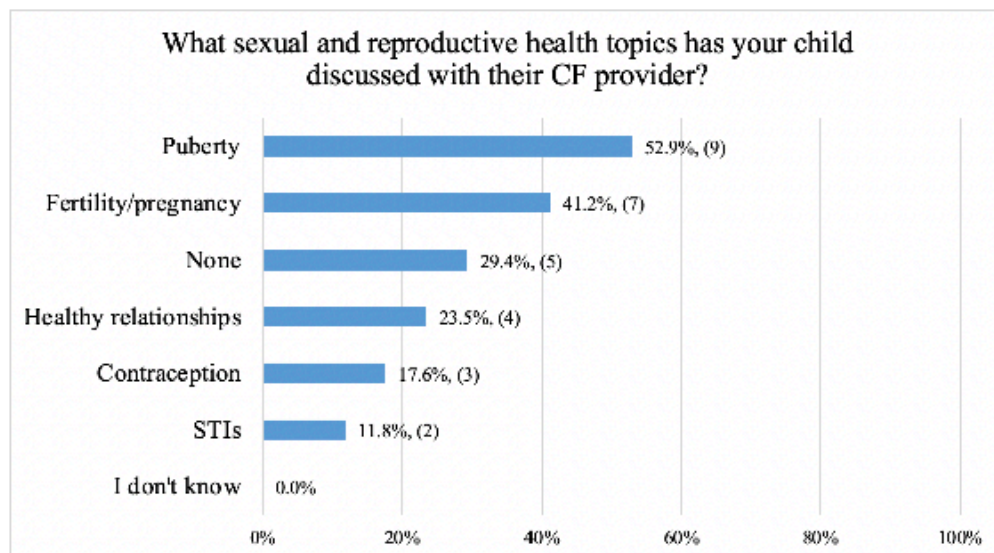
**Figure 4***Parent: SRH Topics Discussed*

Figure 4: Parent - SRH Topics Discussed

and have a safe and healthy pregnancy.”

The CF staff pre-survey was sent via email to 24 participants and left open for a 7-week time frame. A reminder email was sent after 5 weeks. The response rate was 54% (N=13). The largest number of respondents were pediatric CF providers (38.5%). No adult CF providers responded. Half of the respondents reported that they currently include SRH education in their practice. 84.6% of participants felt that the CF provider or team has a role in the discussion or provision of SRH care for adolescents with CF. The large majority (83.3%) felt that the CF provider should be the one to initiate SRH discussions. Of note, 23% reported that multiple team members should be involved in the discussion of SRH issues. The pre-survey results showed that the CF staff’s perceived importance of SRH care averaged 4.3 ( $\pm$  0.75) on a scale of 1 to 5, with 5 representing very important. Additionally, results showed that CF staff’s perceived importance of including urinary incontinence, contraception, and fertility in SRH education averaged 4 or greater using the same scale ( $4 \pm 0.8$ ,  $4.2 \pm 0.9$ ,  $4.3 \pm 0.8$  respectively). There was a wide range of the perceived importance of including puberty, menstruation, and vulvovaginal candidiasis in SRH education with averages of  $3.8 (\pm 1.5)$ ,  $3.8 (\pm 1.4)$ , and  $4 (\pm 1.4)$ , respectively, using the same scale. Table 3 shows the results for all SRH topics.

According to the open-ended responses from CF staff, standardization of SRH education (N=8) and more information (N=11) were consistently reported as ways to improve confidence and comfort with SRH care. Responses included statements such as “a culture

that it is an expected part of adolescent care,” “having aligned goals or standards that all providers and team members in clinic discuss,” “protocols and ownership from all of the CF providers,” and “information, talking points, a standardized way to dismiss family from room.” Identified barriers to providing SRH education included the following common themes: culture (N=4), family concerns (N=7), time (N=2), and provider comfort/confidence (N=7).

The CF staff post-survey was sent via email to 10 participants and left open for 3 weeks. A reminder email was sent after 2 weeks. The response rate was 80% (N=8). The largest number of respondents were pediatric CF providers and pediatric CF nurses. The large majority of respondents reported they plan to include SRH education in their practice (87.5%).

CF staff’s perceived confidence and comfort in providing SRH education averaged 3.75 ( $\pm$  0.6) and 4 ( $\pm$  0.6) in the pre-survey and 3.6 ( $\pm$ 0.9) and 3.5 ( $\pm$  1.0) in the post-survey, respectively, on a scale of strongly agree to strongly disagree. The CF care team’s perception of having the resources and skills to provide SRH education averaged 3.25 ( $\pm$  0.8) and 4 ( $\pm$  0.6) in the pre-survey and 2.9 ( $\pm$ 0.8) and 3.75 ( $\pm$ 0.7) in the post-survey, respectively, using the same scale. There was no statistically significant difference in the CF care team’s self-assessment of their confidence and comfort in providing SRH education and their perception of having the needed resources and skills. Additionally, there was no statistical difference found in the perceived importance of SRH education (Table 4). Although not statistically significant, there was an increase in

**Table 3**  
*CF Staff SRH Topic Importance*

Variable	<i>M</i>	<i>(sd)</i>
Fertility	4.4	0.8
Contraception	4.2	0.9
Healthy personal relationships	4.1	1.1
Sexually transmitted infections (STI)	4.1	1.0
Urinary incontinence	4.1	0.9
Vulvovaginal candidiasis	4.0	1.4
Sexual activity	3.9	1.0
Puberty	3.8	1.5
Menstruation	3.8	1.4

Table 3: CF Staff SRH Topic Importance

participants who reported they would include SRH education in their practice to 87.5%, compared to the 50% who reported they currently include SRH education in their practice in the pre-survey.

Half of the participants in the CF staff post-survey either strongly agreed or agreed with the statements “the proposed SRH guideline is sustainable” and “the proposed SRH guideline is easy to use.” Most participants, 75%, reported they neither agreed nor disagreed with the statement, “I will use the proposed SRH guideline.” Only 37.5% agreed that “the proposed CF SRH guideline can be implemented in the CF clinic.”

In the open-ended responses from CF staff in the post-survey, time (N=5) and resistance from parents (N=3) were consistently reported as barriers and concerns to providing SRH education and using the proposed SRH guideline.

Additionally, the importance of SRH education was described by participants (N=4).

The missing data included one incomplete CF staff pre-survey. The survey was completed online, and 1 participant failed to answer all the questions. Since the survey was anonymous, it was not possible to recover the missing data.

## Discussion

### Summary:

The results demonstrate that adolescents with CF and their parents want information about SRH from their CF care team. Adolescents reported that more information about SRH from their CF care team would help them feel better supported in their SRH decisions and concerns. Although members of the CF care team reported the importance of SRH education, only 50% reported that they currently include it in their practice.

**Table 4**  
*CF Staff Pre-Post Frequency Table*

Variable	<i>N (%)</i>		<i>N (%)</i>	
	<i>Pre-Survey</i>		<i>Post-Survey</i>	
I am confident in my ability to provide SRH education				
Strongly agree	1.0	(8.3%)	1.0	(12.5%)
Agree	7.0	(58.3%)	4.0	(50.0%)
Neither agree nor disagree	4.0	(33.3%)	2.0	(25.0%)
Disagree			1.0	(12.5%)
Strongly disagree				
I am comfortable providing SRH education				
Strongly agree	2.0	(16.7%)	1.0	(12.5%)
Agree	8.0	(66.7%)	4.0	(50.0%)
Neither agree nor disagree	2.0	(16.7%)	1.0	(12.5%)
Disagree			2.0	(25.0%)
Strongly disagree				
I have the resources I need to provide SRH education				
Strongly agree	1.0	(8.3%)		
Agree	3.0	(25.0%)	2.0	(25.0%)
Neither agree nor disagree	6.0	(50.0%)	3.0	(37.5%)
Disagree	2.0	(16.7%)	3.0	(27.5%)
Strongly disagree				
I have the skills I need to provide SRH education				
Strongly agree	2.0	(16.7%)	1.0	(12.5%)
Agree	8.0	(66.7%)	4.0	(50.0%)
Neither agree nor disagree	2.0	(16.7%)	3.0	(37.5%)
Disagree				
Strongly disagree				
How important do you feel SRH care is for your patients?				
5 very important	6.0	(46.2%)	2.0	(25.0%)
4	5.0	(38.5%)	4.0	(50.0%)
3	2.0	(15.4%)	2.0	(25.0%)
2				
1 not at all important				

Prior to this project, the CF center identified a gap in care with no standard SRH education guidelines for CF providers to follow and no data specific to their patients’ SRH needs. Following the presentation of the SRH education guideline, there was no statistically significant difference found in the CF clinic staff’s self-assessment of confidence and comfort in providing SRH education and their access to needed resources and skills. Although not statistically significant, there was an improvement in the percentage of staff that stated they would include SRH education in their practice.

The study was strengthened by the overall number of surveys completed and the fact that multiple groups were surveyed, including AYA, parents, and CF staff. Additionally, there was a wide range of ages surveyed among AYA with CF, from 14 to 24 years.

### Interpretation:

The results support current literature on SRH educa-



-tion for adolescents with CF. In addition, our study found that more than half of AYAs surveyed reported they had not discussed SRH with a CF provider. Frayman and Sawyer reported that young adults receive the majority of their SRH knowledge from their parents<sup>2</sup>; we found that 70% of AYAs surveyed received SRH education from their parents. Our study found that the CF care team feels SRH education is important and that they play a role in discussions around SRH, but only 50% of care team members are currently including it as part of the care they provide. Qualitative results from this study found that CF clinic staff lack confidence and comfort to provide SRH education; Kazmerski et al reported comparable findings.<sup>11</sup>

The impact of the project on people and systems was evident when presenting the proposed SRH education guideline to the CF care team. The guideline was met with resistance: there was general resistance to practice change as well as concerns regarding the difficulties of implementing new activities in a busy specialty clinic, such as lack of time, need for training, and individual comfort level. The proposed SRH education guideline is inexpensive but may be time-intensive to execute. However, based on the results of this study that indicate that adolescents with CF want SRH education, the effort would be worthwhile.

The lack of statistically significant differences in the CF staff results could be related to several factors. Although there was a robust overall survey response, there was a small CF staff sample size with 13 pre-survey and 8 post-survey participants. Additionally, barriers within the clinic, including resistance to practice change, could have contributed to the lack of statistically significant findings.

### **Limitations:**

There are several limitations to the generalizability of the study. Only 1 parent survey was completed online via social media. Efforts were made to adjust for this limitation by allowing more time to complete the survey and a reminder post. The sample was homogenous,

with almost all respondents identifying as White and English speaking, but this is consistent with the ethnic demographics of CF.

The risk of selection bias on results is another identified limitation. More females completed the AYA survey than males (62.1% and 37.9%, respectively). Additionally, there were more parents of daughters with CF than sons with CF (82.4% and 41.2%, respectively). It is possible that females and parents of females were more willing and comfortable to complete the survey and return it. Although CF is not a sex-linked genetic disease, it is also possible that more females were seen in the clinic during the timeframe of the project.

### **Health Implications:**

The findings in this project confirm the significant need for improved SRH education for adolescents with cystic fibrosis and the need for standardization in care. This project provided valuable data to the CF center regarding their own patients' needs and a proposed SRH education guideline based on those needs as well as evidence-based recommendations. The proposed guideline has the potential to improve SRH education for adolescents with CF. The next steps for this project include addressing identified barriers and implementation of the proposed SRH education guideline in this CF center. Given the significant response from adolescent girls and their parents, this may be the first group to target.

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# The Impact of COVID-19 on Utah Women and Work: Health Impacts

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The COVID-19 pandemic of 2020–21 has affected workers across the globe, and women in the workforce have been disproportionately impacted, including those who live in Utah. The pandemic affected every aspect of life, especially physical and mental health. While the fatality rate has been higher for men, the pandemic impacted women's mental health at a higher rate with more women being laid off or furloughed in certain industries (e.g., retail, food services, hospitality), experiencing increased workloads in other sectors (e.g., healthcare, education), absorbing greater unpaid caregiving responsibilities from homeschooling and childcare disruptions, and reporting elevated instances of domestic violence.<sup>1</sup> These impacts have led to increased post-traumatic stress disorder, anxiety, and depression among women.<sup>2</sup>

To better understand these experiences, Utah Women & Leadership Project (UWLP) researchers conducted an extensive, in-depth survey to understand the impact of COVID-19 on Utah women and work. The survey opened for data collection in January 2021 to all Utah women aged 20 and older who were either currently employed or who were unemployed due to the pandemic. The objective was to understand more clearly the experiences of Utah women as they navigated paid work during the pandemic. This comprehensive study collected data on a wide variety of topic areas and included both quantitative and open-ended questions to capture respondents' perceptions and experiences. This brief is the final in a six-part series on the impact of COVID-19 on Utah women and work.<sup>3</sup> In this brief,

we focus on qualitative findings regarding the most oft-mentioned impact of the pandemic: mental and physical health.

## Study Background & Overview

An online survey instrument was administered to a non-probability sample of Utah women representing different settings, backgrounds, and situations (i.e., age, education, race/ethnicity, marital status, socioeconomic status, county/region, job type, sector/industry, hours worked per week, employment status, and workplace situation). A call for respondents was announced through the UWLP monthly newsletter, social media platforms, and website. In addition, the research team members worked closely with nonprofit organizations, chambers of commerce, government agencies, municipalities and counties, women's networks and associations, multicultural groups, businesses, universities, churches, and volunteers who assisted in disseminating the survey to their employees and contacts. Additionally, targeted recruitment efforts were made to include women of all demographics throughout the state, including providing the survey in both English and Spanish (see design information in previous briefs).

Overall, 3,542 Utah women completed the survey, with 2,744 responding to at least one of the four open-ended questions. The demographics and limitations for survey respondents who responded to qualitative items are summarized in Table 1 in a previous brief titled "No. 32: The Impact of COVID-19 on Utah Women and Work: Career Advancement Challenges." Of all qualitative respondents, 30% mentioned a mental health toll and/or felt additional stress during the pandemic. This was by far the most oft-cited sentiment

mentioned in open-ended comments; it was repeated in every one of the four open-ended questions. Of the 2,530 respondents who responded to the open-ended question, “What benefits, if any, have you experienced (or anticipate experiencing) in your job/career because of the COVID-19 pandemic?” 9% mention mental and physical health benefits of the pandemic, mostly due to the time saved working from home that could be spent on more valued activities. On the flip side, of the 2,713 respondents who responded to the open-ended question, “How has the pandemic affected your work experience?” 4% specifically mentioned a toll on their physical health. All responses were coded and analyzed for major themes and subthemes. Select comments are included in the narratives below that exemplify responses within the following four categories: Cause of Mental Health Toll, Effects of Mental Health Toll, Physical Health Toll, and Mental and Physical Health Benefits.

## Causes of Mental Health Toll

Surprisingly, no clear trends emerged in the analysis of qualitative responses that mentioned a mental health toll by demographics such as age, education level, race or ethnicity, marital status, industry, or career stage. While the lack of obvious trends can also be attributed to sample limitations, the qualitative data indicate declined mental health despite demographic and work-force differences.

Additionally, worsening mental health did not discriminate by situations or experiences. The mental health toll of the pandemic emerged in a wide variety of circumstances and situations. For example, those working from home felt a mental health toll, as did those going into the office. Also, the factor of children in the home made a difference: respondents caring for children felt burned out and overwhelmed, while those without children felt isolated and lonely. This section documents respondents’ perspectives of their worsening mental health. Specifically, five primary causes emerged regarding the impacts of the pandemic on mental health: experiencing work pressure, contracting and spreading COVID-19, having children at home, coping with financial instability, and working essential jobs.

**1. Work Pressure:** Of those who described a mental

health decline (N=855), 29.9% cited work-related pressure as the cause. In some cases, respondents working from home felt they had to work more hours and press themselves to prove they were still as productive as they had been when they worked in the office. According to one respondent, “I feel kind of forgotten by my work, especially since I’m actually working much more now, and I don’t feel it’s appreciated. I have been very stressed that I’ll get in trouble for being less productive, and I can’t afford to get fired or anything because my spouse is in a hospitality industry that is struggling to stay afloat. I’ve just been really stressed.” Another respondent felt the same: “I think the major difficulty for me, as someone with no kids and is employed, has been the pressure to turn things around at unrealistic rates to show that you are in fact working from home and the mental health/burnout that is causing.”

Furloughs of colleagues or additional COVID-19 requirements meant more work responsibility was put on respondents, often without extra pay. For example, one woman stated, “I worked at a busy restaurant as a bartender. The day after the shutdown I was the only ‘To Go’ employee. None of us had been trained on it so there was a lot of stress. Ultimately it was also a significant loss of income as people tend to tip less compared to dining experiences. I was making approximately 1/3 of my previous income but working more hours.” Another respondent said, “I am more concerned about my job performance. My mental health is at an all-time low. I worry about everything (family, finances, household responsibilities, ability to eat, etc.) except work, but not being worried about work has me in a continuous cycle of anxiety and worry.” Lastly, a teacher explained, “Due to pressure placed on me from my job, I have seen a significant decline in my mental and physical health. With the added expectations, I am getting burned out, working longer hours, and feeling anxiety and depression creep into my everyday life. As a teacher, I am working every day in person to meet students’ needs but am also being expected to have an online course for students as well. This only adds stress and anxiety to my already overwhelming feelings.”

**2. Contracting and Spreading COVID-19:** Almost a quarter (22%) of respondents were worried about contracting and spreading COVID-19, especially those who were not able to work from home and had coworkers who were not as cautious. One respondent stated, “Work is more mentally and emotionally



draining. I feel like I have to constantly defend my choice to always wear a mask, be cautious, and keep safe social distance between coworkers when that's what we have been told to do." A second Utah woman explained, "Because I have two high-risk family members at home and I am expected to work in close contact with people at work, I am quite worried about contracting the virus and passing it on to my loved ones. I would hate to be the one who 'killed' my spouse and daughter. This has caused a lot of stress and anxiety for me." Another respondent said, "My husband's work has affected my mental health greatly. I had to go on more antidepressants and couldn't cope with the kids and stress because we couldn't go anywhere or see anyone. The worst part is feeling alone in taking it seriously in Utah, which reduced the places we could go even more because we couldn't trust others to wear masks or distance or anything." And a final respondent explained, "Depression increased due to lack of human interaction, but anxiety increased when going into the office as people didn't always take social distancing and masks seriously."

**3. Children at Home:** Some respondents who had children at home (12.6%) often felt the work pressures mentioned above in addition to added home responsibilities as they navigated homeschooling and COVID-19 precautions. This mother explained, "It's been so much harder. I've had to watch my three-year-old kid from home while I work, and I have a job that I'm in meetings most of the day. I work in a male-dominated industry, so I feel they don't understand when they hear the craziness in the background. My work-life balance has disintegrated since working from home, and I'm on call now for projects 24-7. My emotional wellbeing has taken a huge hit as we dealt with my husband's furlough, postponement of school for my daughter, and my burnout. It's been rough." Another mother stated, "The childcare and household responsibilities fell disproportionately on me, while my partner basically went 'back to business as usual' and I was left in the dust trying to balance full-time work and full-time childcare. My mental and physical health took a steep decline. Fortunately, my work has been flexible enough to allow this, but the burnout is very real, and I feel like I am paying a higher price than my partner in this pandemic." And this working mother shared her experience: "I have a child with profound special needs and trying to homeschool her was extremely difficult. She almost ended up losing her ability

to walk, regressed on all her goals like communication and toileting, got super depressed, and more. My husband was never sent home from his workplace during COVID, so he went to work every day, and the responsibility of the house and homeschooling fell on me as I was trying to work from home. It felt like I could never get a full day of work in unless I worked late at night. Even now it's midnight and I am taking this survey because I didn't have uninterrupted time today to do it."

**4. Financial Instability:** Some respondents (11.6%) felt increased financial strain and pressure to secure financial stability as they were not able to secure the same hours as before the pandemic, experienced a furlough, lost business, or saw their spouse lose their employment. This business owner explained, "I'm saddened and extremely worried about the next month, and the next. I'm getting very little sleep because of worry and working long hours trying to do so much of it myself. We're exhausted and scared we will be shut down again. Our small business won't survive another shutdown." Another respondent described her particular situation, "As a single woman, I have not experienced some of the stresses many women have in balancing home schooling or a partner working from home at the same time. That being said, I am the primary support system for my elderly parents and have had to shoulder some of the financial burden because my mother was furloughed from her job. This additional support I must give them has put me in a constantly stressful situation regarding finances."

**5. Essential Workers:** A mental health toll was also reported by those on the front lines of the pandemic (essential workers), such as healthcare workers, educators, and grocery store workers, to name a few (6.4%). One healthcare worker stated, "I've got quite a few patients with risk factors. It's stressful thinking that if I unknowingly passed COVID along to them, someone could potentially die from it. So, my personal life has changed dramatically. I basically only interact in person with my husband and daughter. Sometimes, I feel quite isolated. Throughout the course of my workday, although I'm taking precautions, I feel vulnerable to becoming infected. It's stressful. Every patient comes in with an increased level of stress and anxiety due to the pandemic, so I'm interacting with stressed, anxious people all day."

A teacher also explained, "My administration seems to



think the precautions are ‘over the top’ when they are actually barely meeting the minimum. We’re scared, overwhelmed, and feeling totally burned out. We have to keep track of virtual, in-person, and quarantined students. It feels like we’re doing multiple jobs at once. This is my 8th year of teaching and the first year that I hate my job. We are constantly bullied by the public to ‘do our job or shut up.’ Our fears are laughed at. I feel totally invalidated and undervalued.” Another teacher agreed, “The social out lash against teachers and the disregard for our family’s wellbeing makes me depressed. I wish our state was handling this better, and I wish that we were being compensated for all the additional responsibilities. I have never felt more expendable, disrespected, and have never considered leaving my job more.”

And this respondent said, “I’m in frontline retail grocery sales, and this year has been so stressful and exhausting. I’m grateful to have job security, but my mental and emotional health has suffered greatly during the last year. I’m a single parent trying to juggle enormous pressure at work to maintain sales numbers and take care of my family and home responsibilities. I’m working 60, sometimes more hours a week, worrying about getting sick, and they just keep pushing us for more.”

## Effects of Mental Health Toll

The effects of mental health decline were often described by study participants as actual diagnoses, including stress, general mental health decline, anxiety, guilt and failure, burnout, fatigue, depression, and loneliness. Respondents also described indirect effects such as their work suffering, the inability to focus or be productive, feeling overwhelmed, and feeling like a failure in all areas of their lives. Five effects of the mental health impacts of the pandemic emerged as primary themes: stress, unspecified mental health toll, anxiety, burnout or fatigue, and isolation or loneliness.

**1. Stress:** Of respondents who felt a mental health toll from the pandemic (N=855), 51.1% specifically mentioned increased stress. One respondent remarked, “I’m a childcare provider, and I feel like I’m putting my life and other peoples’ lives at risk daily. We are constantly bleaching things and trying to avoid being coughed on just in case. Children have been brought into our facility while infected with COVID-19.

Things are very tough and stressful every day.” Another explained, “I am more tired now than I have ever been because of the mental and physical stress of wondering if this could be the day I catch COVID-19 and die.” Another study participant stated, “I feel stress about the safety of the work environment, the change in workload and requirements, and an increase in amount of work that needs to be done at home.” And a final woman said, “I am stressed every time I go to work because nobody is wearing masks, sanitizing, and washing, and nobody within the company enforces it.”

**2. Unspecified Mental Health Toll:** Another 20.8% mentioned a general negative impact to their mental health without a specific classification. One respondent stated, “I feel like I’ve been exposed to a trauma repeatedly over the last 10 months, and my typical coping mechanisms are drastically reduced. I’m the type of person who really needs something out on the horizon to look forward to in order to keep my mental health in a good place. With those things ripped away and no timeline for knowing when they will come back, keeping a positive outlook or good mental health has been a huge struggle.” And one mother remarked, “I have worked harder than ever before. I am the primary breadwinner for the family and, while my job was never at risk, I felt driven to perform to ensure it remained stable. The tone while my children were at home was really awful. I was unable to balance the demands of an executive role with the demand of schooling my children (8 and 15 years old). That experience alone will require counseling for all of us.”

**3. Anxiety:** For 17.5% of respondents, the pandemic caused increased anxiety. One respondent said, “I have a very stressful job and now I’m stressed out about the pandemic and the world in general. I’m not sleeping well. I have constant anxiety. It’s nearly impossible to focus at times. I’m certainly not as productive as before, and that causes additional stress. I’ve started looking for a different job; something with fewer deadlines and less stress.” Another respondent explained, “I have had difficulties concentrating because of generalized anxiety due to the changing nature of my work and the fact that I know people that are ill and could be dying.” Another respondent noted, “The impact of the pandemic on working parents cannot be understated. We have faced responsibility for teaching and caring for our children 24/7, all while trying to work full-time in a new and unfamiliar environment of 100% telework.

Those of us in the ‘sandwich generation’ also had to take on responsibility for our parents during this time, including things like grocery shopping and mental health support. Many of us also had the misfortune of having children and/or parents test positive for COVID or have to spend time in quarantine due to exposure. The level of worry and anxiety impacted every aspect of life.”

**4. Burnout and Fatigue:** Burnout and fatigue were felt by 14.9% of respondents who reported a mental health toll. As covered in this and previous briefs, additional responsibility at work and at home took its toll on Utah women. One respondent explained, “Every female faculty member on this campus whom I’ve spoken to in the last 10 months is burned out. We are literally on fire with burnout. Most of the advice we get is to ‘just do what the male faculty members are doing because look how much they are getting accomplished during COVID!’ There is no relief to the pressure. I can’t do more, be more, earn more . . . there isn’t anything left! The free mental health services are not available until June 2021.” One healthcare worker stated, “I’m working long hours, being on call, planning and preparing for surges, and dealing with demands of projects, timelines, and a reduction in force. This year has been extremely challenging for me. My mental health was the worst it’s been in years. I required medication to help me deal with things. I felt like I was juggling 20 balls in the air and at any time they would all fall. I did not see an end in sight.” Lastly, one woman stated, “I’m tired. I’m sad.”

**5. Isolation and Loneliness:** Social distancing and remote work had a negative effect on 12.3% of respondents who reported loneliness and feelings of isolation. This respondent explained, “I have to work very long hours all by myself, which is very lonely and depressing. Therefore, my mental health has declined greatly. It is hard to be alone all day and then not be able to gather with friends at home on top of that. Loneliness has been the biggest side effect of COVID-19 for me.” Another participant stated, “In this rural area, there is not a lot to do, and our complete social interaction comes from school and work. I grew up in a bigger city, and it was extremely hard to move to this rural area and then to be sent home in isolation to teach. It was hard mentally.” One woman explained, “I have a really hard time feeling like I’m doing well or progressing. I’m essentially alone for the entire workday

and, with the pandemic, I’ve been alone most of the time anyway. If I’m having a really bad mental day, then those conditions make it brutal. I can’t just talk to someone in passing if I’m feeling down; I must make a bigger effort. So, by the time I talk to someone, it’s usually because I’m at a boiling point and can’t handle whatever I’m feeling.” Lastly, one respondent explained, “Having zero onsite and face-to-face time has been difficult for me. I did not realize how much socializing I gained from work, nor how important it was to my happiness, energy, and mental health.”

## Physical Health Toll

Only 114 respondents (4% of the sample) mentioned a physical health toll from the COVID-19 pandemic. These physical health declines included both direct effects such as contracting the virus and indirect effects like less movement and exercise and physical problems that manifested from the stress of their experience. Three themes emerged regarding the physical health impact of the pandemic: unspecified toll, COVID-19 sufferers, and indirect impacts.

**1. Unspecified Toll:** Of the 114 women who reported a physical health toll, 33.3% did not offer specifics but mentioned a general toll (often alongside a mental toll). For example, one respondent shared, “I feel my mental health, physical health, and motivation has greatly decreased.” Another respondent said, “The impact of a spouse losing their job is catastrophic. The loss has a major impact on me financially, physically, emotionally, socially.”

**2. COVID-19 Sufferers:** Direct physical health impacts were felt by 23.7% of those who reported a physical health toll. These largely included those who contracted the virus and any ongoing effects stemming from the illness. A respondent in healthcare explained, “I got very ill with extreme fatigue and heart problems, which nobody seems to have any help for.” A teacher weighed in with her experience, “One of the most frustrating things about this was I did get COVID. My quarantine time was difficult because I still had to keep my classes going with online work even though I felt horrible. I remember answering real-time questions for students while taking vomit breaks.” One childcare provider stated, “As of today, I shut down my family childcare program due to testing positive for COVID-19 yesterday. I am extremely worried that

parents, who put trust in me, will enroll their children somewhere else. I am also very worried about the health of the children that were under my care and got exposed to COVID-19 through me.” A final respondent commented, “I was unable to work for 6 weeks due to having COVID and being a long-hauler. The headaches, brain fog, and complete exhaustion prevented me from doing anything. I’m 10 weeks out and still have exhaustion. I can’t run or walk for extended periods of time.”

**3. Indirect Impacts:** Another 19.3% reported indirect physical health impacts stemming from their pandemic experience, such as those caused from stress or working from home. For instance, one respondent stated, “The expectation to just step up and do more work for less pay, even though others were furloughed or laid off, has been demoralizing and has led to stomach ulcers, bad sleep, burnout, and likely a job change.” Another woman explained, “The amount of stress outside of work (politics, increased stress and difficulty in safe grocery shopping, scarcity, etc.) has also impacted my stress tolerance levels, which contributed to the burnout brought on by work. I have developed major stress-related digestive problems as well as muscular injuries since the start of the pandemic.” One respondent said, “At work, I had a nice desk, keyboard tray, and a chair that prevented me from developing issues with my right arm, shoulder, and my right leg. Since working from home, these have come back and have been significant.” Finally, one respondent stated, “Health-wise it has been a struggle because I have migraines. Moving into the virtual world means more time staring at a computer screen and more migraines.”

Some 13% of these respondents described less movement and activity due to working from home. For example, one respondent explained, “I have put on some weight and believe it is mostly due to not needing to move as much. Everything is electronic and right at my fingertips, so I don’t walk to the print room or file room or to meetings. Our 30 min/3 day a week exercise time at work was taken away because of the pandemic. For some strange reason, we have no exercise program available with telework, and I probably need it more now than ever before.”

## Mental and Physical Health Benefits

Of the 2,530 respondents who responded to the

open-ended question, “What benefits, if any, have you experienced (or anticipate experiencing) in your job/ career because of the COVID-19 pandemic?” 43.5% mentioned the ability to work from home and/or more flexibility in their schedules. A large proportion of those respondents said the increased flexibility and remote work improved their physical and/or mental health. Of the 9% (N=218) of respondents who mentioned mental and physical benefits of the pandemic, 56.9% attributed the benefits to working from home and flexibility.

Respondents felt they were better able to focus and could be more productive working from home. They appreciated the time saved from having no commute, which helped them better fit in time for valued activities, relationships, and exercise. For example, one respondent stated, “I work 100% from home now. I love it! My mental and physical health is better. Less stress, better eating habits, calmer. I’m saving money by not driving and buying clothes for work. My overall quality of life has improved dramatically. I have more quality time with loved ones. I can’t say enough about the positive impact on my life personally.” Summarizing the feelings of many respondents, one woman said, “The freedom of working from home has been huge. I didn’t realize how much stress was involved in physically being at the office. I feel I’ve been better able to care for myself and my household by physically being in my home more often.” Two related themes emerged from the participants’ responses: mental health benefits and physical health benefits.

**1. Mental Health Benefits:** Respondents felt that the ability to work from home, and the flexibility it afforded, helped improve their overall mental health. Reduced stress levels and anxiety, more quality time spent with family and pets, and improved work-life balance were specifically mentioned by respondents as benefits. One respondent explained, “I feel less stress and anxiety induced by in-office work, workplace drama, and commuting.” Another stated, “It’s helped me work more efficiently and produce better work. Since I’m working from home, I’m fighting less anxiety, which allows me to be a better worker.”

One mother in our study said, “This has been a great opportunity to open the line of communication with our kids about mental health, taking care of both our mental and physical health, and taking care of family



relationships.” Another mother stated, “The increased flexibility has been amazing! I feel much more able to take care of my children’s needs and much less stressed about their daily schedules.”

Notably, 10.1% of respondents who felt a mental or physical health benefit described their employers’ increased focus and prioritization of employees’ physical and mental health. One participant explained that there was “more understanding of mental health needs” from her employer, and a deeper “understanding of balancing work/family life.” Another respondent shared, “My workplace has emphasized personal care and taking time for the things that help me recover, process, and feel happy as priorities.” Finally, one woman explained that employers had “really stepped up emotional and mental support,” while others made sure that their employees had access to the needed resources to improve their mental health.

**2. Physical Health Benefits:** In addition to the flexibility of working from home, many Utah women listed “no commute to and from work” as another major benefit. They explained that they were able to spend more time sleeping and exercising, preparing healthier meals, and practicing better overall self-care. For example, one respondent felt that the simplified lifestyle “increased time for exercise and self-improvement.” While working from home, one woman shared, “I can read and respond to emails on my home treadmill and not worry that I won’t be changed and presentable again precisely within a one-hour allotted lunch break. The pandemic has improved my work life.” Another shared, “I’ve been eating healthier since moving home because I’m able to cook things on my lunch break instead of having to go get something from a fast-food place.” A final participant explained, “It has allowed me to work from home, which, in turn, allowed me to get more sleep. It was a whole domino effect from there. I was able to get more sleep, which helped me eat better, which gave me more energy, which led to exercising more, which led to an overall healthier me.”

Some respondents referenced cleaner work environments as a benefit of changes due to the pandemic. One respondent shared that she hoped that her employer would “continue to clean/sanitize” and have employees stay home if they were feeling sick. Another listed “increased sanitization and cleanliness in my workspace and jobsite overall,” as a benefit. For re-

spondents who worked in industries that received early access to the vaccine, several mentioned receiving the vaccine as a major physical health benefit.

## Conclusions and Recommendations

This research brief sheds light on the health effects of COVID-19 on working women. Because of the health risks of COVID-19 and the safety precautions implemented to decrease risk, women either lost their job, were sent home to work, or risked their health by interacting with coworkers and/or the public. For those who experienced remote work, some enjoyed the extra time for family, activities, and exercise. More often, however, women felt mental declines from either the additional responsibility of both working at home and taking care of their family or feeling isolated and lonely. Utah women working with the public felt anxiety about contracting and spreading the virus and, in some cases, felt a lack of support from the community regarding health risks. While some experienced decreased physical health from contracting the virus, others faced physical problems that manifested from the stress of their experience.

There are important actions that can support the mental and physical health of Utah women in the workforce. First, all women, especially women of color and those with low household income levels, need better access to mental health care to heal and thrive. Employers can ensure adequate mental health coverage in insurance options and foster an atmosphere that acknowledges and supports mentally healthy activities and lives. Legislators can support mental health coverage amendments, mental health days for students and employees, and overdose and suicide prevention programs.

Second, flexible and remote work options benefit many women and families, evidenced by those who said it led to a healthier work/life balance, increased productivity, and provided more time for relationships, preferred activities, and exercise. Employers can continue to offer a work-from-home option for applicable positions or, if the position requires an office presence, allow for flexibility in work hours. Research has shown that empathetic and supportive policies attract and retain employees, along with increasing employees’ psychological safety, organizational commitment, and productivity.<sup>4</sup> Utah state and local governments can

implement policies that support Utah women in terms of childcare, flexible work arrangements, and family leave policies.

The pandemic has impacted nearly every aspect of Utah women's lives, which, for most, includes their physical and mental health. Ensuring that women can thrive mentally and physically is important moving forward. As Utah leaders and residents better understand the challenges that Utah women have faced related to COVID-19, a more equitable recovery can be crafted.

This will, in turn, strengthen our businesses, families, communities, and the state as a whole.

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# Fertility Treatment in Utah: A Pooled Analysis of 2009–2015 Utah Pregnancy Risk Assessment Monitoring System (PRAMS) Data

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## Background

Infertility is a common chronic condition affecting 8% to 12% of couples in the United States and worldwide.<sup>1–3</sup> Infertility is unique because it is usually experienced by a couple and not an individual. Since the underlying causes of infertility are most commonly (in approximately 50% of cases) due to a combination of male and female factors, it is often necessary to treat both people.<sup>1,4</sup>

Infertility is defined as the inability of a couple to conceive after having regular sexual relations without using contraception for 12 months or more in a woman younger than 35 years and for at least 6 months in a woman aged 35 or older.<sup>5</sup> Primary infertility is defined as the “inability to achieve a spontaneous clinical pregnancy,” whereas secondary infertility is defined as “the inability to achieve a spontaneous clinical pregnancy following a previous spontaneous pregnancy.”<sup>6</sup> Infertility rates may be rising due to trends in delaying pregnancy, since advanced reproductive age increases the risk for infertility.<sup>7</sup> Women typically experience peak fecundability in their mid-20s, with a gradual but significant decline in fecundability beginning at age 32, followed by a more rapid decrease beginning at age 37.<sup>8</sup> Men begin to experience an increased probability of sterility beginning in their late 30s, with rates accelerating after age 40.<sup>7</sup>

Infertility treatment in Utah is of particular interest, because the state has a strong pronatalist culture and one of the highest birth rates in the US.<sup>9–12</sup> The main objectives of this data snapshot are (1) to provide updated estimates of the prevalence of fertility treatments among women in Utah experiencing a live birth and

(2) to assess how treatments for infertility are associated with women’s age and prior live births.<sup>12</sup>

## Methods

To investigate fertility treatment in Utah, we used 2009–2015 data for women aged 20 to 40+ years from the Utah Pregnancy Risk Assessment Monitoring System (PRAMS) via the IBIS-PH interactive query system. PRAMS is an ongoing population-based surveillance system funded and conducted by the Centers for Disease Control and Prevention (CDC) in collaboration with state health departments, which samples mothers who have given birth to a live infant.<sup>13</sup> In Utah, PRAMS is maintained by the Utah Department of Health’s Reproductive Health Program. Approximately 200 Utah mothers randomly selected from birth certificate data are sampled every month to participate in UT-PRAMS. UT-PRAMS uses a stratified sampling system based on maternal education and infant weight to capture smaller but higher at-risk populations.<sup>14</sup> Weighted response rates for 2009–2015 were between 67% and 81%, above CDC-required minimum response rates.

The outcome of interest was birth to couples that had received fertility treatment, defined as the index birth. Couples without a prior pregnancy who received fertility treatments were classified as experiencing primary infertility; women with 1–4 previous live births who received fertility treatments were classified as experiencing secondary infertility.<sup>6</sup> This was assessed via the question, “Did you take any fertility drugs or receive any medical procedures from a doctor, nurse, or other health care worker to help you get pregnant with your new baby?” The response to this question was binary

(yes/no). Age was categorized into 5 groups: 20-24, 25-29, 30-34, 35-39, and 40+ years. Parity was dichotomized into those without a prior live birth (indicator of primary infertility) and those with 1-4 prior live births (indicator of secondary infertility). Mothers with 5 or more live births were excluded from the current study due to very small numbers and relatively larger standard errors. Weighted prevalence and 95% confidence intervals (CI) are reported. IBIS-PH interactive query system for UT-PRAMS data takes into account the weighted stratified sampling per CDC protocol.<sup>15</sup>

Results

A total of 10,396 women, with a yearly range from 1,367 to 1,666, participated in UT-PRAMS from 2009 to 2015. Most women (83.0%) were younger than 35 years, with 14.0% aged 35-39 and only 3.0% aged 40 and older. The overall proportion of infertility treatment among study participants was 10.6% (95% CI: 9.3, 11.1).

The prevalence of infertility treatment among women with live births is higher among older women (Figure 1). It ranges from less than 5.0% at 20-24 years to over 25.0% at age 40 years or older.

Table 1 illustrates the prevalence of infertility treatment among women in different age groups based on whether they had experienced a previous live birth or not, which may serve as an indicator for secondary or primary infertility, respectively. Rates of infertility treatment increase with age, especially among women who have never experienced a live birth previously and therefore may suffer from primary infertility. For women aged 20-24 years, there is minimal difference between women with a previous live birth compared to women without a previous live birth: 3.7% (95% CI 2.3, 6.1) and 5.2% (95% CI 3.7, 7.2), respectively.

Table 1. Weighted Prevalence of Infertility Treatment by Age and Parity, Utah PRAMS 2009-2015

Age Group	Number of Previous Live Births	Infertility Treatment (%)	95% Confidence Interval
Overall		10.2	9.3, 11.1
20-24 years	1-4	3.7	2.3, 6.1
	none	5.2	3.7, 7.2
25-29 years	1-4	5.9	4.8, 7.3
	none	16.4	13.3, 19.9
30-34 years	1-4	10.5	8.8, 12.6
	None	25.8	20.3, 32.3
35-39 years	1-4	15.3	11.6, 19.9
	none	24.6	15.1, 37.3
40+ years	1-4	18.9	9.0, 35.3
	none	65.6	33.7, 87.7

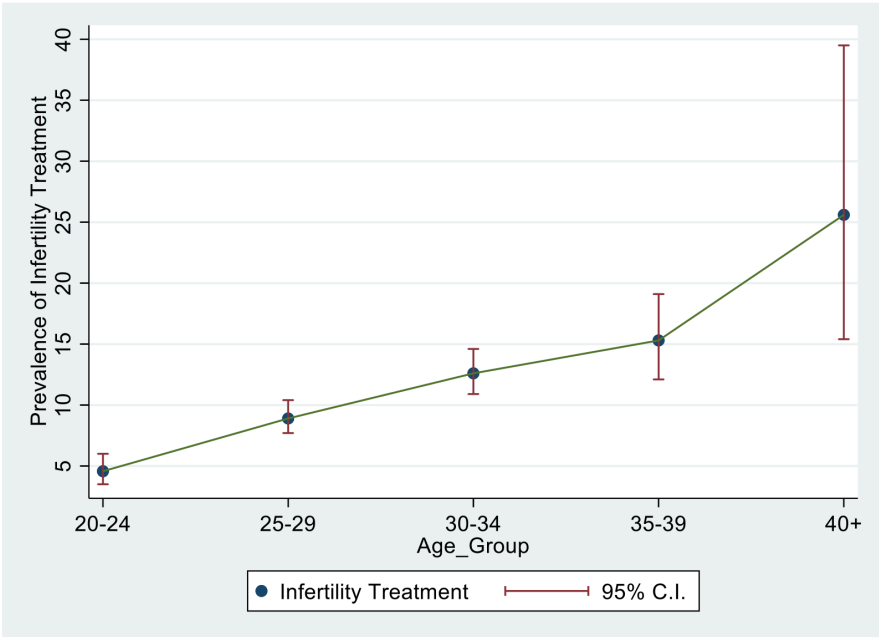


Figure 1. Weighted Prevalence of Infertility Treatment in Utah (PRAMS 2009-2015) by Age Group



In the 25-29 and the 30-34 year age groups, the percentage of participants without any previous live birth who received infertility treatments was 2.5 times higher than participants with previous live births. In women aged 35-39 years, the percentage of women without a prior live birth who received infertility treatment was about the same as for women aged 30-34 years, but there was a higher percentage of women with probable secondary infertility who received infertility treatment. Finally, for women aged 40 years and older, the prevalence of fertility treatment is 18.9% (95% CI 9.0, 35.3) for women with prior live birth, and 65.6% (95% CI 33.7, 87.7) for women without prior live birth, albeit with wide confidence intervals.

## Discussion

This data snapshot of Utah during 2009-2015 revealed that about 10% of women who ultimately had a live birth sought treatment for infertility. Given that the PRAMS database samples only women who successfully experience a live birth, the actual percentage of women who sought treatment for infertility is likely much higher. Although not directly comparable, data from the National Survey for Family Growth (NSFG), conducted during 2002-2015, shows that the percentage of all married women aged 15-44 years who received infertility services was consistently around 12.0%. Additionally, in the NSFG studies, the percentage of women aged 15-44 years with primary infertility who have ever received any infertility service ranged from 6.5% to 7.1%, which was approximately the same proportion of women with secondary infertility.<sup>14</sup> In contrast, among Utah women aged 25 years or older, those who had not previously had a live birth were more than twice as likely to receive infertility treatments as compared to those with presumably secondary infertility: 16.4% to 65.6% versus 5.9% to 18.9%, respectively.

Although we do not know the proportion of infertility treatment that did not result in live birth, it is well established that with other factors being equal, infertility treatment is more likely to be successful among couples with secondary infertility.<sup>15</sup> Further, in the prior UT-PRAMS study mentioned above, seeking early infertility treatment was more common among women with at least one prior live birth.<sup>9</sup> Therefore, if there is a bias in our ascertainment of fertility treat-

ment, it would tend to inflate the prevalence of fertility treatment among those with secondary infertility. This strengthens our finding that women with primary infertility were much more likely to seek infertility treatment than women with secondary infertility (9%-15% absolute difference between ages 25-39, and over 45% in women aged 40-44 years). This may reflect the predominant religious culture in Utah that stresses the importance of having children.<sup>9</sup> The cultural emphasis might be a relatively stronger motivation for having the first versus subsequent children. This may be similar to some societies where children are highly valued for social, cultural, and economic reasons.<sup>16</sup> In such social settings, women experiencing infertility may experience emotional distress.<sup>17, 18</sup>

At the intersection of the 7 domains of health, infertility has a considerable bearing on almost all of them, and especially in the areas of physical, social, and emotional health. There is evidence that the psychological effects of infertility are similar to that of cancer and heart diseases.<sup>18</sup> Infertility or subfertility indicate the presence of other underlying physical illnesses in either women (e.g., ovulatory dysfunction, hormonal abnormalities) or men (e.g., oligospermia, infection).<sup>19</sup> Furthermore, infertility itself may be a risk factor for early mortality in both women and men.<sup>20-21</sup>

Since infertility is a relatively common chronic condition that can significantly impact a person's health and well-being, efforts for prevention and early identification are important. It may be beneficial for individuals to develop a greater awareness of their reproductive capacity, including how to determine whether they may be fertile or not. Women can learn to chart external signs or biomarkers that reflect internal hormonal changes that result in ovulation, which is essential for female fertility.<sup>22</sup> By using fertility awareness-based methods (FABMs), women can also monitor their health and work with physicians trained in restorative reproductive medical (RRM) approaches to identify and treat potential underlying causes of infertility.<sup>23-25</sup> Men may also benefit by learning about the factors that affect their fertility and the steps they can take to improve their reproductive health. Finally, clinicians should counsel patients about their reproductive life plans by discussing patients' goals. The reproductive life plan encourages women and men to reflect on their reproductive intentions in the context of their personal values and life goals.<sup>26</sup>



Limitations of our study of infertility treatment in Utah come from the use of the PRAMS database. First, the dataset only includes women who experienced a live birth. Because women without a live birth are not included in the PRAMS database, the actual percentage of Utah women seeking infertility treatment is higher, as fertility treatment does not guarantee live birth. Second, receiving fertility treatment does not necessarily always indicate that infertility was present. Studies with earlier UT-PRAMS datasets (2004-2008) found that 5.0% of women received infertility treatment even though they did not meet the formal definition for infertility, i.e., had been trying to conceive for less than 6-12 months.<sup>10</sup> For these 2 reasons, our find

ings of the prevalence of fertility treatment by age and parity cannot be directly translated into an estimate of the prevalence of primary or secondary infertility. Nevertheless, they do provide important insight into the patterns of the use of infertility treatment in Utah.

## Acknowledgements

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# Exploring the Dimensions of Adolescent Pregnancy Intendedness, Wantedness, and Planning

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## Synopsis

**Study question:** How do pregnant adolescent women perceive and understand the pregnancy classification terms “planned,” “wanted,” and “unintended” used by the National Survey of Family Growth?

**What is already known:** The clinical relevance of measuring intended and unintended pregnancy in the National Survey of Family Growth (NSFG) is unclear, particularly to the adolescent population. While modernized measurements are available, more investigation is needed on how pregnant adolescent women conceptualize and relate to their pregnancies.

**What this study adds:** Pregnant adolescent women relate to the concepts of planning and wanting pregnancy as distinct and different concepts, while they do not relate to the terms intended or unintended pregnancy. The classifications used by NSFG may therefore not accurately capture the lived experience for adolescent women. This may cause pregnant adolescent women to inadvertently misclassify their pregnancies, thereby obscuring appropriate targets for intervention.

## Abstract

**Objective:** To clarify how pregnant adolescent women relate to terms and concepts used by the National Survey of Family Growth (NSFG) regarding unintended pregnancies, specifically the classification terms of “planned,” “wanted,” and “intended” pregnancies. NSFG is a tool designed to measure pregnancy intendedness in order to inform health and social service programs.

**Methods:** We conducted in-depth interviews with 28 pregnant adolescent women. Interviews explored how each woman understood the classification terms used in the NSFG (intendedness, wantedness, and planned) and conceptualized her pregnancy.

**Results:** Most pregnant adolescent women designated their pregnancy as unintended and unplanned. While most women had a clear ideal for a planned and wanted pregnancy and did not currently experience these ideals, many still considered their pregnancy to be wanted. Partner and family support were associated with the wantedness of a pregnancy by the woman. Women experienced confusion about the term “intended” and offered varying interpretations thereof.

**Conclusions:** The NSFG classifications do not accurately capture the lived experience for pregnant adolescent women, who may consequently misclassify their pregnancy.

**Implications:** Findings support the continued development of tools that more accurately define and reflect the complexity of adolescents’ pregnancy experiences and provide more relevant classifications, such as pregnancy acceptability, for public health and clinical practice.

## Introduction

Unintended pregnancies are more likely than intended pregnancies to result in low birth weight, pre-term birth, elective abortion, maternal depression, and child abuse and neglect.<sup>1,2</sup> Due to these poor outcomes, researchers and government agencies have attempted to measure unintended pregnancies in the United States

for decades. The National Survey of Family Growth (NSFG), a cross-sectional survey, is a major avenue for collecting these data.<sup>3</sup> In this survey, which is completed by women aged 15-49, pregnancies are classified as “intended” if the woman reports she got pregnant at a time of her choice or later, “mistimed” if the woman reports she wanted a pregnancy in the future but not at that particular time, or “unwanted” if the woman reports she never wanted any more children.<sup>4</sup> Both unwanted and mistimed pregnancies are classified as “unintended.”

The validity of the data gathered from the NSFG has been called into question.<sup>1,5,6</sup> Researchers argue that the cross-sectional, dichotomized nature of classifying pregnancies into two distinct categories—intended or unintended—misrepresents the complexity of the situation for many women.<sup>5,7-13</sup> As a result, many pregnancies may be misclassified by the measurement, which may then obscure the appropriate targets for intervention to reduce associated negative outcomes.<sup>7,9,10,14-16</sup>

We conducted the current study to explore how pregnant adolescents perceive and understand the pregnancy classification terms from the NSFG. In this phenomenological, cross-sectional qualitative study, we explored pregnant adolescent women’s perceptions to generate hypotheses about the dimensions and determinants of adolescent pregnancy intendedness. Ultimately, we wish this study to contribute to more meaningful measurement and improved prevention and outcome interventions.

## Methods

### Sampling and Recruitment

Women were eligible for the study if they were (a) pregnant, (b) younger than 18 years, and (c) able to speak English. We used purposive sampling to ensure we enrolled women of varying ethnicities (Hispanic and non-Hispanic) and who made various decisions about their pregnancies (completing the pregnancy and either keeping the baby or adopting the baby out, having an abortion). We recruited women from several clinics in Salt Lake City, Utah: a university-affiliated teenage-mother program, a woman’s clinic, and a local adoption agency. Women were approached in the clinics and invited to participate in the study. An initial questionnaire screened for eligibility. Eligible women

were asked to sign an informed consent document. For women who consented, interviews took place that same day, in a private room in the clinic of recruitment. All research activities were approved by the University of Utah’s Institutional Review Board.

### Data Collection

We conducted 28 one-on-one interviews with pregnant women younger than 18 years. The interviews began with the standard questions used by the NSFG for pregnancy intendedness and then proceeded into open-ended questions (Table 1).

**Table 1:**  
Comparison of the NSFG questions and the semistructured interview guide

NSFG Questions*	Questions from Interview Guide*
What birth control methods were you using at the time you became pregnant?	<ul style="list-style-type: none"> <li>• In your opinion, what are some reasons women get pregnant when they aren’t planning to?</li> </ul>
Before you became pregnant, had you stopped using all methods of birth control?	<ul style="list-style-type: none"> <li>• In your opinion, what are some reasons that men get women pregnant when the men aren’t planning to?</li> </ul>
How much time was there between when you stopped using all methods of birth control and when you got pregnant?	
Was the reason you had stopped using all methods of birth control because you yourself wanted to become pregnant?	
Right before you became pregnant, did you yourself want to have a(nother) baby at any time in the future?	<ul style="list-style-type: none"> <li>• In your opinion, is this a (wanted/unwanted) pregnancy? Why?</li> </ul>
So, would you say you became pregnant too soon, at about the right time, or later than you wanted?	<ul style="list-style-type: none"> <li>• Did you expect this pregnancy?</li> <li>• In your opinion, is this a (planned/unplanned) pregnancy?</li> </ul>
How much sooner than you wanted did you become pregnant?	<ul style="list-style-type: none"> <li>Why?</li> </ul>
Right before this pregnancy, did you want to have a(nother) baby with that partner?	<ul style="list-style-type: none"> <li>• What is your partner’s attitude about this pregnancy?</li> </ul>
Right before you became pregnant, did the father want you to have a(nother) baby at any time in the future?	<ul style="list-style-type: none"> <li>• Did you and your partner discuss the possibility of you getting pregnant before it happened?</li> </ul>
So, would you say you became pregnant sooner than he wanted, at about the right time, or later than he wanted?	<ul style="list-style-type: none"> <li>• What kind of support are you getting from others about the pregnancy?</li> <li>• What role do you think men play in preventing pregnancy?</li> <li>• What role do you think men play in planning pregnancy?</li> </ul>



Please choose from a scale from one to ten. On this scale, a one means that you were very unhappy to be pregnant and a ten means that you were very happy to be pregnant. Tell me which number best describes how you felt when you found out you were pregnant.	<ul style="list-style-type: none"> <li>• What was your reaction when you first found out you were pregnant?</li> <li>• How do you feel about this pregnancy?</li> </ul>
Please choose from a scale from zero to ten. On this scale a zero means trying hard not to get pregnant, and a ten means trying hard to get pregnant. If you had to rate how much you were trying to get pregnant or avoid pregnancy right before you got pregnant this time, how would you rate yourself?	
Please choose from a scale from zero to ten. On this scale, zero means you wanted to avoid a pregnancy and a ten means you wanted to get pregnant. If you had to rate how much you wanted or didn't want a pregnancy right before you got pregnant this time, how would you rate yourself?	

\*The NSFG questions are given in the order they were asked in the NSFG and in this study; however, the order of the questions was different. The first question in the semi-structured interview was "How do you feel about this pregnancy?" See Appendix for interview guide.

Women were not told into which category they were classified by the NSFG questions. Interviews were conducted in Salt Lake City and surrounding suburbs from February 1996 to July 2003. Each interview was completed by a single interviewer (R.F. or D.H.). Both interviewers received training and feedback from senior study investigators, who included two psychologists and a family physician. All interviews utilized the same interview guide based on our previous research.<sup>10</sup> This guide followed a semi-structured outline of points to cover and possible follow-up questions to address each point (see Appendix). The opening question for the semi-structured component of all interviews was "How do you feel about this pregnancy?", with a follow-up question of "Why?" Each participant was asked if her pregnancy was planned, wanted, and intended, with follow-up questions of "Why?" The interviewer probed further to fully explore why the women answered the way they did and how they defined each NSFG term: intended, unintended, wanted, unwanted, planned, unplanned (Table 2). Participants were additionally asked what circumstances would make the pregnancy the opposite of what they answered (e.g., if their pregnancy was wanted, what would make it unwanted?). After each interview, basic demographic information was obtained. Interviews lasted between

30-45 minutes each and were transcribed verbatim. These transcripts were compared to the audio tape by the interviewer and corrected as needed. No compensation was provided to the participants.

**Table 2: Themes, Formulated Meanings and Subthemes**

Theme <i>Formulated Meaning</i>	Subthemes
<p>Intendedness</p> <p><i>Intendedness centers on preconception circumstances (i.e., sexual actions and consequences, and participant prepared/unpreparedness for pregnancy)</i></p>	<ul style="list-style-type: none"> <li>• Pregnancy was unintended due to young age, accidental nature, or lack of planning.</li> <li>• Participants had varying meanings of the term intended, including accepting consequences of sexual choices, planning ahead, or accepting God's will.</li> <li>• Participants experienced uncertainty about the meaning of intendedness.</li> </ul>
<p>Planning</p> <p><i>Planning is very similar to intendedness, and centers on preconception circumstances (i.e., participant age, finances and relationship with partner)</i></p>	<ul style="list-style-type: none"> <li>• Pregnancy was unplanned due to problems with obtaining or using birth control, not preparing for pregnancy before conception.</li> <li>• Pregnancy was mistimed due to young age and unrealized desired achievements.</li> <li>• Participants had a clear ideal for a planned pregnancy including financial security, preconception planning with partner, and being older; their own situation did not reflect the ideal.</li> </ul>
<p>Wantedness</p> <p><i>Wantedness is distinct from intendedness or planning and centers on post-conception (i.e., how participants feel about the pregnancy, how their family and partner respond and largely determines whether they will continue the pregnancy)</i></p>	<ul style="list-style-type: none"> <li>• Wantedness was distinct from planned, intended and mistimed: unplanned, unintended pregnancies can be wanted or unwanted, and wantedness can change throughout a pregnancy.</li> <li>• Family and partner support were very influential in wantedness; a supportive family and partner promoted wantedness and an unsupportive family and partner promoted unwantedness.</li> <li>• Participants had a clear ideal for a wanted pregnancy including having a supportive partner and family, being financially stable, graduating from school, and being older.</li> <li>• Some pregnancies were wanted despite not having the ideal circumstances.</li> </ul>
<p>Initial feelings about pregnancy</p> <p><i>Initial feelings relate to the participant's feelings upon finding out she is pregnant (i.e., her own reaction and those of her family and partner)</i></p>	<ul style="list-style-type: none"> <li>• Initial feelings about pregnancy were shock and fear.</li> <li>• Adolescents experienced apprehension and fear about telling family and others about the pregnancy.</li> </ul>

## Analysis

Our analysis followed a phenomenological analytic approach, as outlined by Moustakas<sup>17</sup> and Creswell and Poth.<sup>18</sup> The primary coder (D.E.) read the transcripts several times; memos with initial impressions and possible broader meanings were recorded. From each transcript, significant phrases that reflected how each woman conceptualized her pregnancy were identified. These significant statements were then organized into larger themes or clusters. A codebook was created to represent the common lived experience for women in this study. This codebook included both deductive codes based on the NSFG terms and inductive codes based solely on the themes that emerged from the transcripts.

Validation of this initial work was achieved through a second round of coding by more experienced researchers (J.S., L.G., and C.F.). Each read two complete transcripts, totaling 21% of the data. Multiple team meetings were conducted to discuss any discrepancies in the codebook and reach consensus.

## Results

### Sample Description

Twenty-eight women participated in the interviews; 65% identified as White Non-Hispanic (n=18) and 35% identified as White and Hispanic (n=10), with no other minorities represented. The average age was 15.9 years, with ages ranging from 14 to 17 years. All participants had less than a high school education. Participants were not asked about gender identity or expression. All stages of pregnancy gestational age were represented, ranging from 6 to 34.5 weeks. Five participants were choosing to abort the pregnancy (18%), 2 were choosing adoption after birth (7%), and 21 were planning to keep the baby after birth (75%).

### Themes

#### *Intendedness*

Overwhelmingly, participants classified their pregnancy as unintended. (We include their statements below, with participants' ages in parentheses.) When asked why, most women cited being too young, for instance: "Cause I'm too young, I think, to be having a child at this age" (17y). Participants also classified pregnancies as unintended when they perceived it as a mistake or accident, e.g.: "It was unintended. I didn't mean to get

pregnant. I mean, it was a mistake in the first place, but now I've made the mistake, I'm gonna undo it" (16y). A lack of planning or trying for a pregnancy was another reason for classifying pregnancy as unintended. A representative response: "I wasn't planning on getting pregnant even though you could say we were asking for it because we weren't using birth control or anything, so we weren't planning it" (17y).

Participants offered varying meanings of the word intended. First, several participants expressed the idea that just having sex makes a pregnancy intended because the woman knows the consequences. One participant stated: "Well, because I knew what I was doing and so I knew that if I had sex, I would have a possible chance to get pregnant" (15y). A second interpretation of intended was that planned pregnancies were intended and accidental pregnancies were unintended. Intended was "wanting to have it and we planned it" and unintended was "that you didn't want to have it, probably it was just an accident" (17y).

A third definition came from a 16-year-old participant. She believed that pregnancy was divinely intended or unintended, and stated:

I think if God intended you to have a child, then you're intended to have it, then you should, and then you should be the one to take care of it. I think if you're intended to have kids then you're gonna have 'em or there's something that's gonna stop that.

When asked what would make their pregnancy intended, many participants were unsure of what this term meant, with one bluntly stating: "I don't know what that means" (16y). Several asked clarifying questions, such as: "What does intended mean—planned or unplanned?" (16y) or "What does that mean? Intended, like did we want it to happen?" (15y).

#### *Planning*

Most participants identified their pregnancy as unplanned. Many participants identified problems using birth control as the reason for the unplanned pregnancy—including birth control failure, not using birth control correctly, or not using birth control at all. Several women blamed condom failure, including a 15-year-old woman who became pregnant after her first sexual intercourse: "obviously it broke because that happened." Inconsistent birth control usage was

also named as a reason for an unplanned pregnancy. Several women stated that they just did not use birth control, resulting in an unplanned pregnancy: “But again, I knew the consequences and I knew about condoms. I knew about pills and everything, and I didn’t do it” (15y).

Participants also referred to a lack of preconception planning and preparedness with their partner or family as a reason for their unplanned pregnancy. One woman specified, “When you plan for it, you actually sit down and, well, this much money will go to the baby and try to like figure finances and stuff like that, but we didn’t do that. So, it was unplanned” (16y).

Almost universally, these adolescent women characterized their pregnancy as mistimed and expressed a desire to be older before pregnancy. One woman articulated: “I am going to be a senior in high school, and I don’t have any money. I have goals where I am going to be a big thing when I grow up and you know. You can’t have a baby and do all the stuff at the same time” (17y).

Nearly all participants expressed an unambiguous view of what an ideal planned pregnancy involves: being older, being financially secure, and planning with their partner beforehand. For most women, their actual situation was the opposite of their ideal. Many participants were facing very difficult financial situations: living with their parents and struggling to become financially independent with little education and little opportunity. When asked what she would do to plan a pregnancy, one woman expressed: “I’d make sure I was ready. Like financially and everything like that. I want to get an apartment before I have another kid” (15y).

#### *Wantedness*

The terms of wanted/unwanted pregnancy seemed to invoke a deeper emotional reaction and more nuanced feelings than the terms intended/unintended and planned/unplanned did. Responses around wantedness often moved away from the choices and circumstance surrounding conception and toward the ongoing pregnancy and birth. While nearly all participants described their pregnancy as unplanned, mistimed, and unintended, many still declared their pregnancy wanted. For instance, one participant replied: “I’ve just always wanted kids; so, to me, even if it came at bad timing and I wasn’t married or anything, it would still be wanted” (16y).

Wantedness could change throughout a pregnancy. Many adolescent women expressed initial unwantedness but, over the course of the pregnancy, came to want the pregnancy: “It’s not unwanted. Well, it was at first, but now, no” (16y).

Family and partner support were very influential for nearly all women. Participants expressed how much they needed and desired family support throughout their pregnancy, whether they were planning an abortion, adopting out, or keeping the baby: “I couldn’t ask for a better mother... she came home and we talked about it... and we both know it’s not right to abort a baby, but under the circumstances, there was really nothing we could do. I kind of relaxed when she told me it was alright to do” (15y).

Family support significantly affected wantedness. A family supportive of the woman and her pregnancy was associated with a wanted pregnancy, and a family unsupportive of the pregnancy was associated with an unwanted pregnancy: “I never planned it and I guess it’s more wanted now than unwanted because of all the support that his family is giving me and my sister and him, but I’ll still need more support from my family longer” (17y). Conversely, when asked what would make her pregnancy unwanted, one participant stated, “not having any support of people around me” (16y).

Partner support also affected whether a pregnancy was wanted. One participant expressed initial unwantedness, “but when I talked to him [the partner] about it, and he’s like, you know, don’t worry about it, I’m going to help you take care of it” (17y), she expressed deep wantedness and planned to keep the baby after birth. Conversely, when asked what would make their pregnancy wanted, one participant stated, “if my partner wasn’t such an asshole” (17y).

Our interviewers probed deeply into what exemplifies their ideal wanted pregnancy. The answers were similar across all clinics and pregnancy choices: having a supportive partner and family, being financially stable, graduating from school, and being older.

#### *Initial Feelings About Pregnancy*

All but two participants expressed negative, surprised, or shocked feelings when finding out about the pregnancy. One woman expressed her initial reaction as “shocked. Very shocked. I didn’t expect it” (17y).



Nearly all women expressed fear about their families' reactions to the pregnancy, with one woman stating:

I was scared that maybe my mom, she didn't want me to keep the baby, and she wanted me to get an abortion and I wouldn't. I said no and she threatened me with lots of things and that was scary. I thought I would lose my mom through the whole thing because she was so upset. (16y)

Participants were also fearful of how their families' perception of them would change and of losing their support. For example, one participant expressed: "Your parents think that you are a good kid. And all of a sudden, she is bad now, because look at what she did" (17y).

## Discussion

We found that most adolescent pregnancies are unintended and unplanned but not necessarily unwanted. When discussing intendedness and planning, women focused on preconception circumstances; when discussing wantedness, women centered on support from others and their own feelings after conception. This finding is consistent with the conclusion of Gomez and colleagues that unplanned and unexpected pregnancies can sometimes still be welcomed.<sup>8</sup> It is also consistent with our prior work that found a similar distinction between planning and wanting among adult women.<sup>10</sup>

The NSFG includes the following question: "Right before you became pregnant, did you yourself want to have a(nother) baby at any time in the future?"<sup>4</sup> For most pregnant adolescent women, the answer is yes, but not currently. This response means the pregnancy will be classified as mistimed, and therefore also unintended. This classification fails to account for any differences in wantedness, which for most women in our sample was decided after conception. Important factors that help determine pregnancy outcomes—i.e., maternal acceptance of pregnancy, ceasing risky behaviors, and seeking prenatal care—are obscured in the overall classification of mistimed. Our findings are consistent with growing evidence that pregnancy acceptability might be an improved construct to better capture true lived experiences.<sup>11,12,19,20</sup> Measuring pregnancy acceptability may classify adolescent pregnancies into more clinically relevant groups, distinct in varying levels of wantedness and resulting pregnancy

actions, and provide a clearer picture of adolescent pregnancy and targets for intervention, both before and after conception.

Our study suggests that pregnant adolescent women use widely varying interpretations of the word intended regarding pregnancy. Several women thought simply having sex—with its resulting consequences—created an intended pregnancy. Others thought intended pregnancies were planned before conception. Yet others believed pregnancy was divinely intended. Additionally, many women were very confused about the meaning of this term and could not provide a definite response to questions regarding intendedness. Although the word pair intended/unintended is used in the NSFG classifications, intended is not a term that seems clear to pregnant adolescent women.

Our findings highlight a chasm between the reality of pregnant adolescent women and their idealized views of a planned pregnancy. Most of our participants had goals around additional education, career development, stable relationships, and adequate finances; however, none of them experienced these ideals at the time of pregnancy and were facing situations of inadequate support and little opportunity. Other researchers suggest that preventing teenage pregnancy is a multifaceted, complex issue that involves more than just sexual education.<sup>21,22</sup> Instead, it requires a collaborative conversation, a social determinants of health approach, and an examination of the root causes of teenage pregnancy.<sup>22</sup> Rather than focusing purely on individual behavior change, a broader view is needed to improve the social, economic, and built environment pregnant adolescents inhabit. Our findings support these approaches.

## Limitations

Our study faced several limitations. First, our sample was less diverse than the US population. However, our sample included both Hispanic and Non-Hispanic pregnant women younger than 18 years who represented the full spectrum of plans for pregnancy (keep, abort, or adopt). Second, our data were collected in the years 1996-2003. While some circumstances surrounding adolescent pregnancy have changed (i.e., more readily available contraceptives and a declining unintended pregnancy rate), current research suggests that very little has changed for the fundamental dynamics of planning or wanting a pregnancy.<sup>23</sup> Our work adds

to the limited availability of data in this field. Additionally, the core NSFG questions remain the same, and our results are consistent with research published recently, suggesting our data are relevant and reflect an ongoing need for this line of research.<sup>6</sup> Third, as with the NSFG, our data are from a cross-sectional assessment of our participants' views, and we do not have longitudinal assessments over time. However, several of our participants described significant shifts in their attitudes that had occurred prior to the interview.

## Health Implications

Our results confirm that adolescent pregnancy is frequently fraught with social difficulties: initial apprehension, fear of others' reactions, and difficult economic, living, and educational circumstances. Considering these difficulties, adolescent pregnancy prevention efforts should continue to be a major goal of health and social programs across the country. However, coupled with comprehensive sexual education and access to family planning, a more engaged conversation is needed: one that helps adolescent women envision a path toward their own ideals for future pregnancies, give them opportunity to succeed on this path, and help them see how current behavior affects their future.

In addressing the issues of adolescent pregnancy, the NSFG classification of mistimed (a subcategory of unintended) does not capture the range of lived experiences for many pregnant adolescent women or identify potential target factors for achieving better outcomes. Aiken and colleagues hypothesize that women who judge their pregnancies to be acceptable—independent of planning and intention—will have more positive outcomes.<sup>19</sup> We recommend employing instruments that incorporate questions about pregnancy desire, post-conception wantedness, and/or acceptability. More relevant measures will enable researchers and practitioners to reach the ultimate goal behind pregnancy measurement: (1) improved pregnancy out-

comes for mothers and children and (2) enhanced reproductive agency and empowerment for women.

## Implications for Practice

Our study adds to the existing evidence supporting the development of more robust and relevant concepts of pregnancy for adolescents, such as pregnancy acceptability. However, further inquiry is needed into designing and validating instruments for pregnancy acceptability and related concepts. Moving forward, we believe qualitative data is needed to understand the determinants of pregnancy acceptability.

In addressing adolescent pregnancy clinically or in public health, we confirm that different adolescent women may have very different attitudes and behaviors during pregnancy, ultimately affecting outcomes for both the mother and the baby. Assessing the gap between the adolescents' ideal and actual circumstances may provide insight for the individual adolescent pregnancy. Finally, partner and family support are extremely influential for pregnancy outcomes for adolescent women. Understanding and assessing partner support and pregnancy wantedness may provide effective avenues for intervention.

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## Disclosure of Potential Conflicts of Interest

None reported.

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## Appendix

### Interview Guide

#### CURRENT PREGNANCY

- How do you feel about this pregnancy?
- Did you expect this pregnancy?
- What was your reaction when you first found out you were pregnant?
- Did you and your partner discuss the possibility of you getting pregnant before it happened?
- [When you first started having sex? What did you do? What did you talk about?]
- [At the time you had sex that led to this pregnancy, were you thinking that you might get pregnant?]
- What is your partner's attitude about this pregnancy?
- What kind of support are you getting from others about the pregnancy?
- [Explore: financial, material, emotional, social, moral]
- In what ways is your life changing with this pregnancy?
- In your opinion, is this a (planned/unplanned) pregnancy? Why?

- [What would have to be different in your life to make this an (unplanned/planned) pregnancy? What does unplanned/planned mean to you?]
- In your opinion, is this a (wanted/unwanted) pregnancy? Why?
- [What would have to be different in your life to make this an (unwanted/wanted) pregnancy? What does wanted/unwanted mean to you?]

#### GENERAL ATTITUDES

- In your opinion, what are some reasons women get pregnant when they aren't planning to?
- In your opinion, what are some reasons that men get women pregnant when the men aren't planning to?
- If a woman has an unexpected pregnancy, do you think she should continue the pregnancy or not?
- What role do you think men play in preventing pregnancy?
- What role do you think men play in planning pregnancy?
- Are there any other comments you would like to make on these issues?



# Association Between Pre-pregnancy and Pregnancy Physical Abuse, Partner-related Stress, and Post-partum Depression: Findings from the Utah Pregnancy Risk Assessment and Monitoring System (UT-PRAMS), 2016-2018

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## Introduction

Negative consequences of post-partum depression (PPD) are significant, for both birthing parents and their offspring.<sup>1-6</sup> Morbidity and mortality associated with PPD are deserving of increased scrutiny overall and especially in Utah, the nation's youngest state (median age 30.5 years)<sup>7</sup> and fourth-most fertile state, with a fertility rate of 68.4 births per 1,000 women aged 15 through 44 years.<sup>8</sup> National prevalence of PPD among postpartum women is 12.5 percent<sup>9</sup>; in Utah, the PPD prevalence is 15.3 percent among mothers.

Several factors known to contribute to risk for PPD are pronounced in Utah.<sup>10</sup> The state ranks last in the nation for pay parity between men and women.<sup>11</sup> A growing body of research demonstrates that socioeconomic factors, including lack of pay parity, may collectively have multiplicative synergistic impact on adverse health outcomes, including depression and addiction.<sup>12-15</sup> Significantly, an estimated 36.9 percent of Utah women have been victims of domestic violence, compared to the national average of approximately 25 percent, and Utah is rated the 17th-worst state in the nation for domestic violence.<sup>7</sup>

The 2-fold purpose of this study was to examine (1) the association between physical abuse (pre-pregnancy and prenatal) and PPD and (2) the impact of stressful life events on the risk of PPD.<sup>16,17</sup> A better understanding of the predictors of PPD may be instrumental in designing and implementing interventions that have the potential to decrease the incidence of PPD and its adverse impacts.

## Methods

### Sample Description

This cross-sectional study<sup>18</sup> was conducted among women who participated in the Utah Pregnancy Risk Assessment Monitory System (UT-PRAMS) survey between January 1, 2016, and December 31, 2018, recalling pre-pregnancy, prenatal, and early postpartum events and exposures. PRAMS is a surveillance program of the US Centers for Disease Control and Prevention (CDC) that gathers data across the nation (most states and territories as well as tribal and local health departments) and provides geographic-specific data critical in accomplishing its primary goal of reducing infant mortality, which is a common worldwide measure of overall national health.<sup>19</sup> Since its inception in 1987, PRAMS has been utilized as a useful data source in ascertaining the changing risks and health outcomes associated with pregnancy for women and children. In addition to measuring pregnancy health, data is collected on socioeconomic status, life experiences, and quality of life, with the additional goals of mitigating risks and adverse health outcomes for women and children.

To address health risks and outcomes that are most pertinent to their unique populations, states and territories maintain a measure of control over stratifying data collection. UT-PRAMS oversamples women of lower education levels and infant birth weight to purposely capture data on a known high-risk population.<sup>20</sup> Approximately 200 women are contacted each month and asked to complete the survey. Those contacted are randomly selected within each stratum.

## Primary Exposure, Physical Abuse

The primary exposure of interest was physical abuse experienced before and during pregnancy. Participants were asked the following questions: (1) “In the 12 months before you got pregnant with your new baby, did any of the following people push, hit, slap, kick, choke, or physically hurt you in any other way?”, with options being “husband or partner,” “ex-husband or ex-partner,” and “someone else.” Participants were instructed “for each person to check ‘No’ if they did not hurt you during this time or ‘Yes’ if they did.” (2) A similar question was asked for the period of pregnancy, switching the first part of the question to “During your most recent pregnancy.”

## Secondary Exposure, Life Stress

The secondary exposure of interest for this study was life stress. The Phase 8 PRAMS questionnaire includes 13 questions regarding specific stressful events in the 12-month period prior to the birth of the child. The stressful events listed are (in order asked):

- (1) A close family member was very sick and had to go into the hospital;
- (2) I got separated or divorced from my husband or partner;
- (3) I moved to a new address;
- (4) I was homeless or had to sleep outside, in a car, or in a shelter;
- (5) My husband or partner lost his job;
- (6) I lost my job even though I wanted to go on working;
- (7) My husband, partner, or I had a cut in work hours or pay;
- (8) I was apart from my husband or partner due to military deployment or extended work related travel;
- (9) I argued with my husband or partner more than usual;
- (10) My husband or partner said he didn’t want me to be pregnant;
- (11) I had problems paying the rent, mortgage, or other bills;
- (12) My husband, partner, or I went to jail;
- (13) Someone very close to me had a problem with drinking or drugs;
- (14) Someone very close to me died.

A dichotomous variable (yes/no) was used for each event, and the events were categorized into 1 of 4 groups: partner-related stress (questions 2, 7, 8, 9),

traumatic stress (questions 4, 11, 12), financial stress (questions 5, 6, 7, 10) and emotional stress (question 1). Question 3 (move to new address) was not included in our analysis given that the outcome could be either a positive or negative experience.<sup>21</sup>

## Primary Outcome: Postpartum Depression

The primary outcome measure of interest for this study was PPD, which was determined by having answered “always” or “often” to either of the following 2 UT-PRAMS questions that captured postpartum depressed mood and anhedonia: (1) “Since your new baby was born, how often have you felt down, depressed, or hopeless?”, and (2) “Since your new baby was born, how often have you had little interest or little pleasure in doing things you usually enjoyed?”

## Covariates

Covariates considered as potential confounding factors known to impact risk of abuse, life stress, and PPD included maternal age (continuous), race (White/non-White), ethnicity (Hispanic/non-Hispanic), marital status (married/not married), income level ( $\leq \$30,000$ ,  $\$30,000-\$55,000$ ,  $\geq \$55,000$ ), parity (continuous), history of preterm birth (yes/no), tobacco or alcohol consumption in past 2 years (yes/no), and depression before or during index pregnancy (yes/no). Lower educational attainment has also been shown to be more common among women who experience PPD,<sup>22-24</sup> and the differences between the overall population of Utah women and the study participants are shown in Figure 1. Accounting for some missing data, 58 individuals surveyed in this data sample were under the age of 18 years and too young to have achieved education levels measured here.

## Statistical Analysis

Sociodemographic and health history characteristics among women with and without PPD were compared using the chi-square test for categorical and t test for continuous variables, considering the complex sampling design. To test the association between physical abuse, life stressors, and PPD, unadjusted and adjusted robust Poisson distribution models were used to estimate unadjusted and adjusted prevalence ratios (PR) and 95% confidence intervals (CI). Adjusted models considered maternal age, race/ethnicity, education, income, marital status, prior preterm births, parity, depression before and during pregnancy, and tobacco

or alcohol use in last 2 years. An additional adjustment for pre-pregnancy and prenatal partner-related, traumatic, financial, and emotional stress was done for the final model looking at physical abuse and PPD. Similarly, an additional adjustment for pre-pregnancy and prenatal physical abuse was done for the final model looking at stressful life events and PPD. Data analysis was generated using SAS software version 9.4 (SAS Institute, Inc., Cary, NC) and Stata Software 14.2 (StataCorp, LLC, College Station, TX).

## Results

### Sample Characteristics

A total of 4,101 women, representing 142,963 Utah women who delivered during that time frame, completed the UT-PRAMS survey between 2016 and 2018. Among the respondents, 72.7 percent were White, 15.0 percent White-Hispanic, 5.3 percent non-White-Hispanic, and 7.0 percent non-White, non-Hispanic. Over 77 percent of study subjects were married, 20.2 percent never married, and 2.3 percent divorced or widowed. The mean age was 28.4 years (range, 15-44 years), with approximately 22 percent living at very low income levels of \$20,000 or less per year, and the highest education level of almost half of the participants (46.8%) was a high school diploma. While the World Population Review reports that nearly 37 percent of Utah women experience abuse in their lifetimes,<sup>7</sup> only 5 percent of respondents in this study reported pre-pregnancy and/or prenatal abuse. Women with PPD compared to women without PPD were inclined to be younger, unmarried,

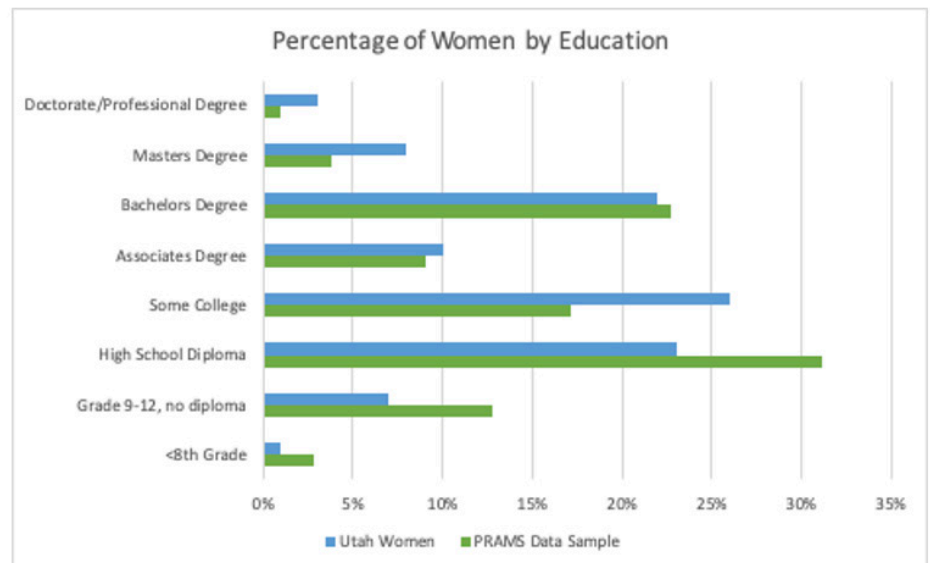


Figure 1: Percentage of total sample by degree attainment compared to overall Utah statistics regarding educational achievement, including trend lines.

**Table 1: Characteristics of women in the UT-PRAMS survey 2016-2018 by postpartum depression (PPD) (n=4,101, representing population of 142,963 women)**

Characteristics	PPD 16%	No PPD 84%
Age (in years) mean ± SE	27.9 ± 0.3	28.9 ± 0.1
Maternal race		
White	91%	91%
Non-White	9%	9%
Maternal ethnicity		
Hispanic	85%	84%
Non-Hispanic	15%	16%
Marital status		
Married	73%	84%
Not married	27%	16%
Education level		
<9th grade	1%	
9-12th grade	6%	2%
High school	19%	9%
Some college	22%	22%
Associate degree	12%	12%
College degree or above	39%	38%
Income level		
\$0-\$28,000	36%	25%
\$28,001-\$57,000	30%	30%
\$57,001+	35%	44%
Parity (mean ± SE)	1.5 ± 0.1	1.4 ± 0.1
History of preterm birth	6%	5%
Smoke >1 cigarette in last 2 Y=years	19%	9%
Alcohol in last 2 years	41%	32%
Depression before pregnancy	35%	14%
Depression during pregnancy	43%	13%
Before or during pregnancy: any physical abuse	12%	3%
Partner-related life stress (12 months prior to birth)	42%	22%
Traumatic stress (12 months prior to birth)	24%	10%
Financial stress (12 months prior to birth)	57%	45%
Emotional stress (12 months prior to birth)	34%	27%

Descriptive characteristics of women in UT-PRAMS by PPD; with/without calculated by *t*-test or chi-square where applicable, with consideration of the stratified random sampling. n (%) unless otherwise noted.

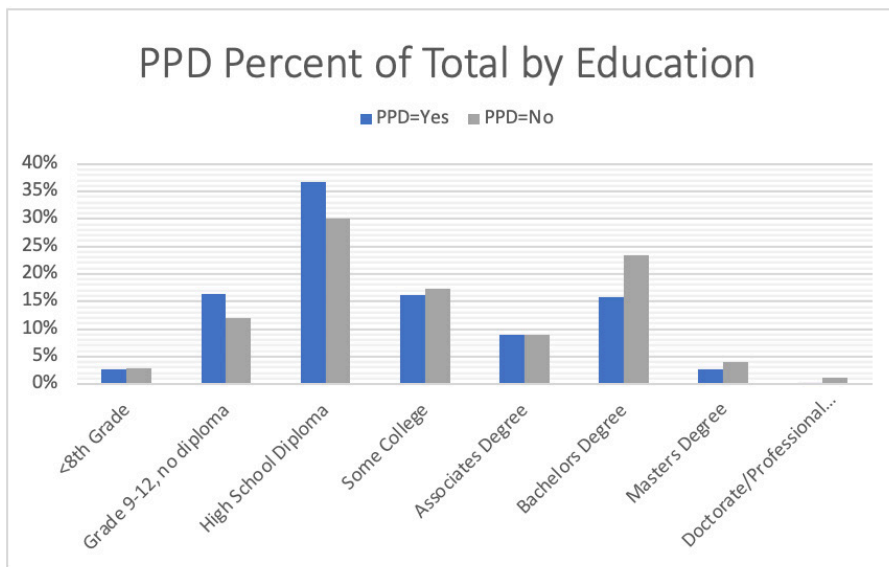


Figure 2: Educational attainment of study participants

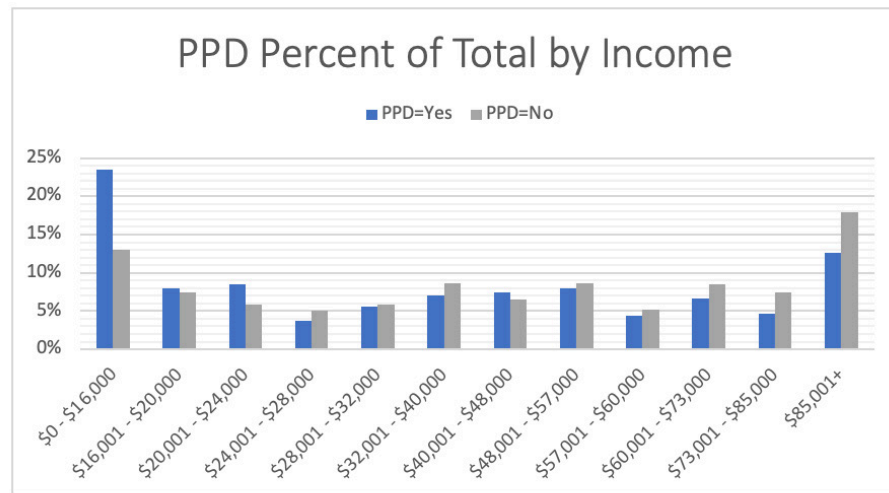


Figure 3: Income level of study participants

Table 2: Physical abuse and partner-related stress and association with postpartum depression

	Unadjusted RR PR (95% CI)	Model 1 aPR (95% CI)	Model 2 aPR (95% CI)
<b>History of Physical Abuse</b>			
Yes	3.06 (2.43, 3.85)	1.74 (1.32, 2.29)	1.56 (1.19, 2.07)
No	Reference	Reference	Reference
<b>Partner-Related Stress</b>			
Yes	2.12 (1.77, 2.53)	1.47 (1.20, 1.80)	1.32 (1.07, 1.65)
No	Reference	Reference	Reference
<b>Traumatic Stress</b>			
Yes	2.35 (1.93, 2.84)	1.42 (1.12, 1.79)	1.22 (0.94, 1.57)
No	Reference	Reference	Reference
<b>Financial Stress</b>			
Yes	1.53 (1.28, 1.84)	1.18 (0.97, 1.43)	1.09 (0.89, 1.34)
No	Reference	Reference	Reference
<b>Emotional Stress</b>			
Yes	1.29 (1.07, 1.56)	1.08 (0.88, 1.32)	1.04 (0.85, 1.28)
No	Reference	Reference	Reference

Model 1 adjusted for maternal age, race/ethnicity, education, income, marital status, prior preterm births, parity, depression before and during pregnancy, and smoking or alcohol in last two years.

Model 2 adjusted for Model 1 plus other abuse or stress-related factors listed in Table 2.

and more likely to consume alcohol, smoke, and have a history of depression and life stress (Table 1). They also leaned toward lower education and income levels (Figures 2 and 3).

### Physical Abuse and Postpartum Depression

Four percent of women reported abuse, with 3 percent reporting abuse during pregnancy (1% by husband or partner, 1% by ex-husband or ex-partner, and 1% by someone else) and 4 percent reporting abuse before pregnancy (1% by husband or partner, 2% by ex-husband or ex-partner, and 1% by someone else). Twelve percent of women with any abuse prior to or during pregnancy experienced PPD compared to 3% of women who did not report abuse (Table 1). In the unadjusted analyses, women who experienced any physical abuse had a 3.06 higher PR (95% CI, 2.43, 3.85) of having PPD compared to women who did not (Table 2). After adjusting for maternal age, race/ethnicity, education, income, marital status, prior preterm births, parity, depression before and during pregnancy, and smoking or alcohol consumption in the last two years, the aPR was 1.74 (95% CI, 1.32, 2.29). Further adjustment for partner-related, traumatic, financial, and emotional stress did not appreciably alter findings (aPR 1.56; 95% CI, 1.19, 2.07) (Table 2).

### Life Stressors and Postpartum Depression

Among the total sample, 25 percent of women reported partner-related stress (42% with PPD and 22% without PPD), 12 percent traumatic stress (24% with PPD and 10% without PPD), 47 percent financial stress (57% with PPD and 45% without PPD), and 28 percent emotional



stress (34% with PPD and 27% without PPD) (Table 1). In the unadjusted analyses, women who experienced any partner-related, traumatic, financial, or emotional stress had a 2.12 higher PR (95% CI, 1.77, 2.53), 2.35 higher PR (95% CI, 1.93, 2.84), 1.53 higher PR (95% CI, 1.28, 1.84), and 1.29 higher PR (95% CI: 1.07, 1.56) of having PPD, respectively, than women who did not (Table 2). Adjustment for potential confounders including other stressors and physical abuse attenuated the results. However, women who reported partner-related stress, compared to those who did not, still showed a 32 percent higher prevalence of PPD (95% CI, 7%-65%) (Table 2).

## Discussion

Findings from this study revealed that women who were exposed to pre-pregnancy and prenatal abuse were at a 1.6 higher probability for PPD after considering numerous confounding factors such as life stressors in the year before birth. The results also suggested that exposure to life stressors, notably partner-related stress, is associated with a 1.3 higher probability of PPD after similar adjustment. Age, educational attainment, income, and marital status, among other elements, are known demographic factors that may reliably predict PPD risk. Screening of these demographic indicators in conjunction with careful exploration of exposure to partner-related abuse and experienced stress may provide opportunities for PPD prevention and mitigation interventions.

The findings from the UT-PRAMS data are validated by other studies in both low-income and high-income countries.<sup>25-29</sup> For example, a study by Desmarais et al. conducted in Western Canada looking at intimate partner abuse before and during pregnancy showed that 84 percent with postpartum mental health problems reported abuse before pregnancy, and 70 percent experienced abuse during pregnancy.<sup>30</sup> Similarly, Tsai et al. employed secondary data analysis among women during pregnancy and postpartum in South Africa; the study reported a significant association between intimate partner violence and depression during pregnancy and postpartum.<sup>31</sup> Additionally, this study found both independent and adjusted significant associations between physical abuse and PPD. In a study conducted in France, Gaillard and colleagues corroborated these findings with physical abuse and depression during

pregnancy having significant associations with PPD.<sup>32</sup> Although the present study utilized a cross-sectional study design, other studies using different methods arrived at similar findings and conclusions. Rogathi et al., in a prospective cohort study of postpartum depression among women who experienced intimate partner violence, showed that the odds of having postpartum depression increased by more than 3 times compared to women who did not.<sup>33</sup> Similar to the present study, younger women were inclined to develop more PPD than older women.<sup>33</sup>

The effects of physical abuse, coupled with other social health factors, can be long-lasting. A study of physical, sexual, and social health factors with associated trajectories of maternal depressive symptoms in pregnant women showed that 32.7 percent of women manifested subclinical depressive symptoms with 9 percent showing persistent symptoms of depression up to 4 years postpartum.<sup>34</sup>

The present study also found that partner-related stress, such as arguments, was a significant predictor of PPD. This is consistent with findings from other studies.<sup>35</sup> A Japanese study by Miura et al. revealed that verbal and physical abuse during pregnancy was significantly associated with PPD even after adjusting for potential confounders (OR=7.05, 95% CI, 2.23-10.55).<sup>35</sup> The findings from Muira and colleagues are important for this present study because similar questions and responses were used in determining the occurrence of physical abuse. These similar results established the co-existence of physical and verbal abuse from intimate partners. Thus, establishing the history of exposure to physical violence and verbal abuse serves as an important measure in determining association. In a study conducted in Ohio, Das et al. concluded that a documented history of exposure to depression during pregnancy is significant in identifying mothers who are at higher risk of anxiety and stress. Furthermore, stressful life events determined by using the Life Events Questionnaire (LEQ) to measure the degree of life stress have been found to be significantly associated with the prevalence of PPD.<sup>27</sup> Thus, these factors should be screened in combination with depression.<sup>36</sup>

## Limitations

Our study has limitations. First, the outcome of

interest, PPD, lacks an official medical diagnosis and is dependent on participant responses to survey data. While screening questions mimic validated clinical screening tools,<sup>37</sup> they may not always correctly classify the actual condition of PPD. Second, an important demographic factor for which this data set differs from the overall Utah population is race and ethnicity. The dataset contains the following racial breakdown: 72.7 percent White, 6.9 percent non-White, non-Hispanic, and 20.3 percent Hispanic (higher than the national average). Thus, findings from this study will be generalizable for White and, to some extent, Hispanic women but no other minority groups prevalent in Utah.

## Conclusion

It may be of value to explore the relative impact of specific factors associated with adverse outcomes, as this data may help inform decisions about use of finite resources in mitigating and preventing harm. Our study found that exposure to abuse before and during pregnancy, in addition to partner-related stress, were significant predictors of PPD. Further examination may be warranted to explore the interplay between partner-related physical abuse, life stressors, and perceived stress on risk of PPD, as women may suffer similar negative life events but appraise the impact or severity differently.

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# Utah Girls, Young Women, and Physical Activity

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## Setting the Stage

The benefits of physical activity are well documented and improve all aspects of health and overall well-being.<sup>1</sup> Globally, on average, 37.1% of women are insufficiently physically active while only 23.4% of men are<sup>2</sup>; this trend is also found in Utah, where 19.4% of women are insufficiently physically active while only 17.6% of men are.<sup>3</sup> While women often live longer than men, they are frequently in worse health.<sup>4</sup> Physical inactivity contributes to the development and severity of chronic diseases including cardiovascular disease, diabetes, and hypertension.<sup>5</sup> In addition to affecting physical health, physical inactivity is also associated with poor mental health. Physical activity can contribute to positive self-image and improved confidence, which is critical for meaningful community participation as well as developing interpersonal relationships.

The Utah Women & Leadership Project (UWLP) seeks to better understand the status, experiences, and challenges of Utah women in order to strengthen the impact of women and girls.<sup>6</sup> This snapshot summarizes research regarding physical activity levels, access, and barriers for girls (ages 7–11) and young women (ages 12–17) to help decision makers understand that instilling physically active habits early can improve the health and wellbeing of Utah women for the rest of their lives. This research snapshot reviews three key areas:

- 1) Gender physical activity levels and the importance of physical activity;

- 2) Gender physical activity factors; and
- 3) Recommendations to increase physical activity of Utah girls and young women.

## Guidelines & Comparison

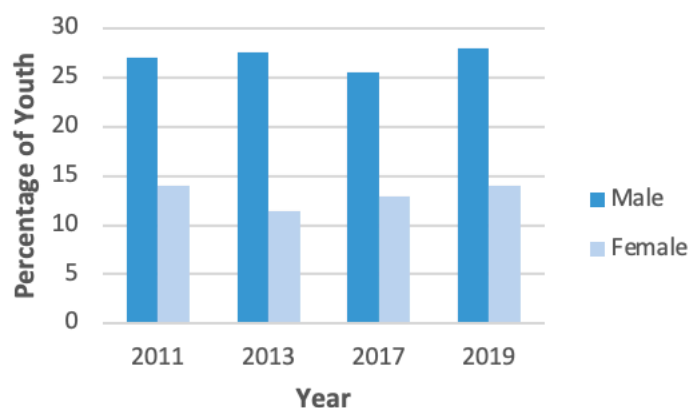
### National Recommendations

The majority of Americans do not meet the physical activity guidelines recommended for their age. It is advised that children and adolescents, ages 6 to 17, get 60 minutes or more of moderate-to-vigorous physical activity each day. For adults, at least 150–300 minutes of moderate intensity or 75 minutes of vigorous intensity aerobic physical activity per week, or a combination of both, is recommended.<sup>7</sup> In terms of steps, the daily recommended average for adolescents and adults is 10,000, and for girls it is 11,500.<sup>8</sup> However, due to a number of barriers (see “Specific Gender Barriers” section), women and girls are not meeting the guidelines at disproportionately high rates compared to men and boys.

### Utah Comparison

In Utah, 28% of boys meet the recommended physical activity levels set by the state, compared to only 14% of girls (see Figure 1).<sup>9</sup> These numbers have been consistent over the past ten years, meaning half as many girls and young women are regularly getting recommended physical activity as compared to boys and young men. An analysis of the American College Health Association's National College Health Assessment III data found that female college students were significantly less likely to meet physical activity guidelines compared to male college students.<sup>10</sup> Research has found that women of various ages report facing more barriers to physical activity than men.<sup>11</sup>

**Figure 1: Recommended Physical Activity by Sex, Utah Youth Grades 9–12, 2011, 2013, 2017, and 2019<sup>12</sup>**



## Specific Gender Barriers

### Lack of Options

A major barrier for girls and young women mentioned in the literature in terms of participating in fitness activities is the lack of options for physical activity that they prefer.<sup>13</sup> Most physical education classes consist primarily of competitive sports, which young women identified as their least favored activity. Women, young and old, show preferences for yoga, walking, biking, and dancing. The scarcity of what they see as viable options, in combination with the lack of discussions with girls and young women on their preferred choice for physical activity, leads to lower rates of participation. When girls and young women are offered different options for physical activity, studies show there are increased levels of autonomy, self-determination, and participation.<sup>14</sup> Studies also suggest that accounting for preferences when developing physical education curricula and after-school physical activity programs can increase participation among young women.<sup>15</sup>

Men prefer different types of physical activity than women. Unsurprisingly, men prefer strength training, and women tend to prefer moderate intensity cardiovascular activities.<sup>16</sup> One study found that when given a list of common exercises to perform, male teens and young adults chose strength training exercises and females chose low-impact cardiovascular activities.<sup>17</sup> Interestingly, the benefits of physical activity differ for men and women depending on what types of exercise they participate in. One research team found that women who participate in regular, low-impact activities report higher levels of self-esteem and quality of life compared to women who participate in regular, high-intensity activities.<sup>18</sup> These researchers found that the opposite is true for males,

which suggests the need for a gender-tailored approach to engaging young adults in physical activity.

### Gender Roles and Perceptions

Societal gender roles are strongly associated with young women's lack of participation in physical activity. Children, youth, and young adults have differing views on the functionality of their bodies based on their biological sex.<sup>19</sup> Notably, young women experience negative social feedback after participating in a school physical education class if they are not able to shower or change clothes because of how they appear to others, especially to boys.<sup>20</sup> Teen women prioritize conforming to socially accepted ideals of beauty, which include being small, slight, and soft. This may come from the perceived lack of social capital for women participating in physical activity beyond maintaining feminine attractiveness.<sup>21</sup>

Positive body image is correlated with increased levels of physical activity,<sup>22</sup> yet Utah women have low rates of body acceptance, which may be a factor in correlated low rates of physical activity. A 2017 UWLP report<sup>23</sup> revealed the high rates of cosmetic surgery per capita in Salt Lake City in past years, which trumped that of Los Angeles and was second only to Miami. This report documented the problem that follows from society assessing a woman's success based on her attractiveness, which reduces a woman's identity and potential to the shape of her body and increases sexual objectification.

Another study found that the benefits of physical activity, including reduced levels of stress, were lost if the motivating factor to exercise was weight loss or body toning.<sup>24</sup> More specifically, it found that motivating reasons to exercise predicted quality of life outcomes for women over actual exercise. This is concerning as research has found that conforming to societal ideas of attractiveness, including thinness, is, again, young women's main motivator to participate in physical activity. Encouraging girls and women of all ages to participate for reasons beyond maintaining or achieving attractiveness has been

shown to increase their motivation to be physically active.

### **Lack of Social Support**

Social support from friends was noted as a key factor to girls and young women engaging in physical activity, yet many noted that social support from friends, parents, and teachers to participate was lacking. Girls and young women report less enjoyment in physical activity and less confidence in their abilities as they get older, which may stem from consistent lack of societal encouragement to be physically active, as well as societal pressure to not be competitive or strong.<sup>25</sup> The lack of social support also appears in the inadequate facilities and gym attire provided for young women.<sup>26</sup> Young women report inadequate changing and showering facilities, a lack of time for showering, and inappropriate gym attire (such as short skirts) as reasons they do not participate in physical education.<sup>27</sup> Feeling self-conscious about their physical appearance while wearing exercise or fitness clothing is another barrier to participation in physical activity that teen women face.<sup>28</sup>

### **Additional Barriers for Women of Color**

Several research studies have reported a variety of additional barriers related to physical activity for girls and women of color.<sup>29</sup> For example, one Utah study found that, culturally, Pacific Islanders felt it was unacceptable for women to be in the sun and sweat, which could reduce women's physical activity. In addition, research by the Women's Sports Foundation found that the drop-out rate for urban girls of color doubles that of suburban white girls, largely due to increased poverty resulting in a lack of resources.<sup>30</sup> Several studies identified hair health among young African American women as a barrier to physical activity.<sup>31</sup> One team of qualitative researchers found that perspiration on hair and hair style maintenance, image, and social comparisons, along with the lack of solutions to overcome hair-related issues, were all barriers to physical activity for the women of color interviewed.<sup>32</sup> Participants of the study also mentioned how the monetary and time burdens of fixing and maintaining hair styles further contributed to the issue.

### **Moving Forward**

Since the passage of Title IX in 1972 mandated that federally funded educational institutions must provide

women equal opportunity in sports, the number of women participating in sports went from one in 27 girls to today's two in five girls participating.<sup>33</sup> While large strides have been made in women's sports, gaps still exist. According to The National Federation of State High School Associations, in 2018–2019, boys across the nation had 1.13 million more sports opportunities than girls.<sup>34</sup> In Utah alone, close to 39,000 boys participate in sports compared to just over 28,000 girls. A nearly 1:1 male-to-female population ratio in Utah leaves almost 11,000 more opportunities for boys to participate in sports than girls.<sup>35</sup> About 87% of the National Collegiate Athletic Association (NCAA) schools still provide disproportionately more opportunities to men.<sup>36</sup>

While there are many programs in Utah and the nation that promote physical activity, few have the specific goal of increasing physical activity levels of girls and young women. Although the problem is recognized, solutions have been slow to be adopted. Research has suggested the following recommendations to address and resolve these problems:

**First**, parents and guardians should encourage physical activity for girls and young women. Fewer things have greater impact on a girl's long-term physical activity levels than her parent's own physical activity and their enthusiastic encouragement. Findings from the LOOK Longitudinal Study revealed that lower participation in physical activity among girls was associated with weaker influences at the school and family levels.<sup>37</sup> These findings suggest that a girl's lack of involvement in physical activity has roots in sociocultural norms and can be changed with education. Another study reviewed 180 nine-year-old girls and their parents to examine parenting strategies that led to long-term increases in their daughter's physical activity levels.<sup>38</sup> It was found that logistic support (e.g., registering their daughters for sports teams and facilitating transportation to sports events) and explicit modeling (such as the parents themselves participating in physical activity) led to increases in physical activity among the girls studied. The study also reported that having just one physically active parent can have a positive impact on a girl's long-term participation in physical activity and overall health.

**Second**, the most basic way to ensure that girls and



women have physical activity options that are favorable to them is by asking what they enjoy doing and then tailoring physical activity options accordingly as preferences may vary by age group, particularly in school physical education classes. Studies<sup>39</sup> have reported that girls and women are more likely to be physically active when they enjoy what they are doing and have opportunities to participate with friends and peers as well.

**Third**, promote gender inclusivity in all types of sports. Researchers<sup>40</sup> have found that gendered trends in sports limit teens' potential by pressuring young men to participate in competitive sports while discouraging girls and young women from doing the same. Encouraging children to explore sports and physical activities that interest them, rather than the ones that girls typically play, can lead to increased interest and engagement.

**Finally**, improving the visibility of women's athletics can improve girls' and young women's interest in sports, and it can increase societal interest as well. Ensuring that women athletes have access to adequate and equitable facilities, preventative care, media coverage,<sup>41</sup> sponsorship, and funding can increase the credibility of women's sports. In turn, the fanbase and social support will increase, resulting in expanded opportunities. An important byproduct will be the encouragement young women show for each other as they pursue athletics and, in the long term, a physically active life.

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## Conclusion

The benefits of physical activity are clear, yet thousands of Utah girls and women are participating at significantly lower levels than boys and men. With only 28% of boys and 14% of girls meeting the recommended physical activity levels set by the state, change is needed for all.<sup>42</sup> Exploring the barriers associated with the lower levels of participation, specifically for females, has laid the groundwork for the recommendations for change offered in this snapshot. The way forward requires parental involvement and role-modeling, asking girls and women what they want to do and then providing support for those activities (even if the choices are historically associated with the male gender), and making women's athletic pursuits and events equally visible for everyone. Finding ways to increase the physical activity of girls and women will improve their overall health and wellbeing, which, in turn, will impact the health and wellbeing of Utah families, communities, and the state as a whole.

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# The Cognitive Health of Widows in the United States

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## Problem Statement

In the United States, more than 900,000 older adults are widowed each year.<sup>1</sup> Losing a spouse is considered one of the most stressful life events,<sup>2,3</sup> one that is predominantly experienced by older women.<sup>4-6</sup> About 30% of women aged 60 to 74 years are widowed,<sup>5</sup> and over 40% of women aged 65 years and older are widowed compared to only 13% of men aged 65 and older.<sup>6</sup> Women typically live another 15 years after the loss of their spouse<sup>5</sup> and face aging-related challenges without their life companion.<sup>2</sup>

The loss of a spouse can be a very isolating experience,<sup>4,7</sup> leaving the surviving partner to grieve not only the death of a loved one but also the loss of their planned life as a couple.<sup>7</sup> Since women tend to outlive male partners, this primarily affects widows. The transition to widowhood entails the process of grieving and the need to adjust to a new livelihood<sup>2</sup> as well as challenges related to loneliness. This significantly stressful life event can also negatively affect social connections, life satisfaction, and mental health.<sup>7</sup> Through the increased stress and changes, spousal loss also affects the cognitive health of older adults.<sup>3</sup>

## Status of Literature

Several studies have confirmed that older widows experience poorer cognition and accelerated decline in their cognitive function.<sup>8-10, 1, 11-13</sup> Assessing cognitive health is a complicated process,<sup>4</sup> but various explanations exist.

First of all, the loss of a spouse can be detrimental for

the brain because it may result in dysregulation of the hypothalamic-pituitary-adrenal axis.<sup>3</sup> Secondly, this loss commonly increases depressive symptoms and may cause major depressive disorder.<sup>14,12,3</sup> Lastly, spousal loss usually means the loss of one of the most important social contacts—a critical source of daily cognitive stimulation—which may accelerate cognitive decline.<sup>2,3,13</sup>

Cognitive interventions may target those who have been recently widowed.<sup>1</sup> As widowed women navigate through the process of rebuilding their social world, social leisure activities (SLA) may help maintain cognition and better adjust to life during widowhood.<sup>2,7</sup> SLA can be defined as important determinants of health and well-being for older adults that encompass a variety of activities and shared experiences.<sup>7,15</sup> These activities can be physical or cognitive, such as attending a church, group, or organization meeting; visiting with friends or family members; participating in a fitness class; sharing interests with a group; going out for dinner or shopping; or walking and hiking outdoors.<sup>15</sup>

Social leisure can play an integral role in the coping process for widowed women by allowing them to find distraction, new paths forward, and social groups where they can discover and build a sense of community. In one study, leisure provided widowed women with a safe space to explore the adjustment to widowhood and learn from other women who have already been living this lifestyle. This sense of understanding and peer-mentorship created hope for recently widowed women that their loss may not be painful forever and that they could live a meaningful and pleasurable life.<sup>7</sup>

## Call to Action

The growing large number of older widows suffering from cognitive decline poses a heavy burden currently not met by sufficient attention and policy interventions.<sup>13</sup> It is crucial to find ways for widows to maintain cognitive functioning.<sup>2</sup>

SLA provide a protective role for widowed women and may serve as a coping strategy to preserve cognitive

functioning.<sup>2</sup> Given the research and findings, interventions at community and policy levels that encourage social involvement and engagement in cognitive activities for older widowed women should be favorably supported.<sup>2,7</sup> Social workers, program directors, and other community leaders should be engaged in efforts that promote, advocate, and implement these types of community-based programs for widowed women.<sup>7</sup>

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# What Role Does Hispanic/Latina Ethnicity Play in the Relationship Between Maternal Mental Health and Preterm Birth?

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## Abstract

**Objective:** To investigate the association of prepregnancy and prenatal depression and/or anxiety on preterm birth (PTB), while also exploring Hispanic/Latina ethnicity as a potential effect modifier.

**Methods:** Study population included respondents of UT-PRAMS (2016–2019). Associations between prepregnancy and prenatal depression and/or anxiety and PTB were evaluated using Poisson regression models accounting for stratified survey sampling.

**Results:** Women with prepregnancy and prenatal depression and anxiety, compared to those without, had a 67 percent (95% CI: 19%, 134%) higher probability of experiencing PTB, after controlling for relevant socio-demographic, lifestyle, and reproductive history factors. Impact of depression on PTB was slightly higher than impact of anxiety. Hispanic/Latina ethnicity was found to protect against PTB for those with prepregnancy and prenatal depression alone (aPR: 0.53, 95% CI: 0.24, 1.21) or both depression and anxiety (aPR: 0.51, 95% CI: 0.18, 1.40) compared to being non-Hispanic/Latina (aPR: 1.79, 95% CI: 1.25, 2.55 for depression alone; aPR: 1.62, 95% CI: 1.18, 2.21 for depression and anxiety).

**Conclusions:** Overall, Utah women reporting prepregnancy and prenatal depression and anxiety were more likely to have a PTB. Being of Hispanic/Latina ethnicity was found to mitigate the risk of PTB among women with depression and anxiety.

**Implications:** Prepregnancy and prenatal mental health screenings and treatment are key to lessening

the impacts of depression and anxiety on both mother and infant. Hispanic/Latina ethnicity may be protective against PTB among women experiencing mental distress. Whether this is through increased social support or through a different mechanism should be explored in future research.

## Introduction

In 2019, the national preterm birth (PTB) rate rose for the fifth year in a row, affecting approximately 10 percent of infants and causing growing concern among medical and public health officials.<sup>2</sup> PTB poses several risks to an infant including immature lungs, difficulty regulating body temperature, poor feeding, and slow weight gain.<sup>3</sup> Maternal depression and anxiety have been directly linked to PTB, with long-term effects on both mother and baby.<sup>4–7</sup> This is especially relevant since depression is the most common psychiatric disorder in the US and highest among women, with anxiety not far behind.<sup>9</sup> A recent study reported that women with both mental health disorders were found to have a higher rate of PTB than those with only depression, only anxiety, or without either disorder.<sup>10</sup> An extensive body of prior literature has established that a history of prepregnancy depression and anxiety is a strong risk factor for prenatal depression<sup>11–17</sup> and that prepregnancy and prenatal depression and anxiety are highly comorbid.<sup>18,19</sup> For that reason, this study explores the potential cumulative impact of prepregnancy and prenatal depression and anxiety (PPDA) on the likelihood of PTB in Utah. Ethnicity is also highly associated with the risk of PTB,<sup>20</sup> and this study will look at what effect Hispanic/Latina ethnicity, which makes up the second-largest ethnic group in Utah, may have on risk for PTB.



## Methods

### Study Population:

This is a cross-sectional study design using data from the Utah Pregnancy Risk Assessment Monitoring System (UT-PRAMS) survey, Phase 8 (January 1, 2016, through December 31, 2019). The Centers for Disease Control (CDC) developed the standardized data collection methodology used for the national-level PRAMS survey and continues to provide oversight for the survey's methodology and protocol.<sup>21-23</sup> PRAMS is a mixed-mode surveillance system (mail and telephone) that uses birth certificate information as its population-based sampling frame. One key aspect of PRAMS is the stratified systematic sampling, which oversamples on features related to high-risk women such as mothers of low-birthweight infants, living in high-risk geographic areas, and belonging to racial/ethnic minority groups.<sup>21</sup>

UT-PRAMS Phase 8 drew stratified (by maternal education and infant birthweight) samples of approximately 200 new mothers (2–6 months after delivery of a live birth) every month.<sup>24</sup> New mothers were contacted via mailed questionnaire (available in English and Spanish) multiple times and telephone follow-up. An informed consent document was included with each survey packet explaining the participants' rights. Consent is implied if the survey is completed. The total sample of Utah mothers completing the PRAMS Phase 8 questionnaire was 5814, reflecting an estimated population of 188,700 women. The sample comprises 16.2 percent Hispanic/Latinas and 10.9 percent non-White, making it representative of Utah's race/ethnicity make-up consisting of Hispanic/Latinas (14.4%), Blacks or African Americans (1.5%), American Indians or Alaskan Natives (1.6%), Asians (2.7%), Native Hawaiians or Pacific Islanders (1.1%), or those of two or more races (2.2%).<sup>25</sup> The expected national PRAMS response rate is 60%, with Utah exceeding this goal at 65% (2016), 66% (2017), 62% (2018), and 69.5% (2019).

Mothers' responses were linked to extracted birth certificate data items, including pregnancy complications for index birth. The PRAMS weighting process produces an analysis weight considering the stratified sampling along with nonresponse and noncoverage components. The analysis weight of the PRAMS data can be interpreted as the number of women like herself in the population that each respondent represents. This

study and the use of PRAMS data (de-identified) have been acknowledged by the University of Utah Institutional Review Board as nonhuman subject research.

### Outcome:

The primary outcome of interest was whether or not a woman experienced PTB, defined as a live birth before 37 weeks into the pregnancy.<sup>2</sup> The obstetric estimation of gestation, which uses ultrasonography within the first two trimesters to determine gestational age and the estimated delivery date, is added to the birth certificate within 24–48 hours of the birth.<sup>26,27</sup> However, it is important to note that the obstetric estimation of gestation may vary by up to 10–14 days.<sup>28</sup>

### Exposure:

The PRAMS questionnaire asks women whether they had experienced depression or anxiety (each requiring yes/no answers) during the 3 months before the most recent pregnancy (prepregnancy) or during the most recent pregnancy (prenatal). We created a combined impact variable to include women who had both depression and anxiety in the 3 months prior to conception and during pregnancy (PPDA). This combined impact variable was chosen due to the common comorbidity of these 2 disorders in women (both pre-pregnant and prenatal) as well as the possibility that the combination for a sustained period of time may result in a cumulative impact increasing the risk for PTB.

### Covariates:

Confounding factors believed to influence both depression and anxiety as well as PTB were determined based on prior literature. Demographic and lifestyle factors included race/ethnicity, maternal age, marital status, maternal education, total household income, and body mass index (BMI). Additionally, smoking, drinking, and prior history of high blood pressure and diabetes as well as reproductive history were also considered as potential confounding factors.<sup>7,20,29-32</sup> Given prior theories on the role that maternal race/ethnicity may play in mental health-adverse birth outcome associations,<sup>33</sup> we additionally tested whether Hispanic/Latina ethnicity may modify the association between prepregnancy and prenatal depression and/or anxiety and PTB.

### Statistical Analysis:

Participant characteristics were reported by the exposure of interest (ie, PPDA) and took into account PRAMS’ weighted analysis formatting.<sup>19</sup> All variables were dichotomous or categorical and reported as weighted percentages.

To explore the associations between prepregnancy and prenatal depression and/or anxiety and PTB, we used Poisson regression models with a robust error variance. The models, accounting for PRAMS’ use of stratified sampling, generated adjusted prevalence ratios (PR) and 95% confidence intervals (CI).<sup>34,35</sup> The referent group was women without PPDA. Mothers who did not have data for key exposure variables were removed from the analysis population. Effect modification by Hispanic/Latina ethnicity was conducted via a stratified analysis and on a multiplicative scale using the Wald test. Stata 15.1 was used for the analysis.

Results

After excluding missing values from key exposure variables (depression before/during pregnancy and anxiety before/during pregnancy), 4166 women (72%) were included in the primary analyses, reflecting an estimated population of 136,090 women (Figure 1).

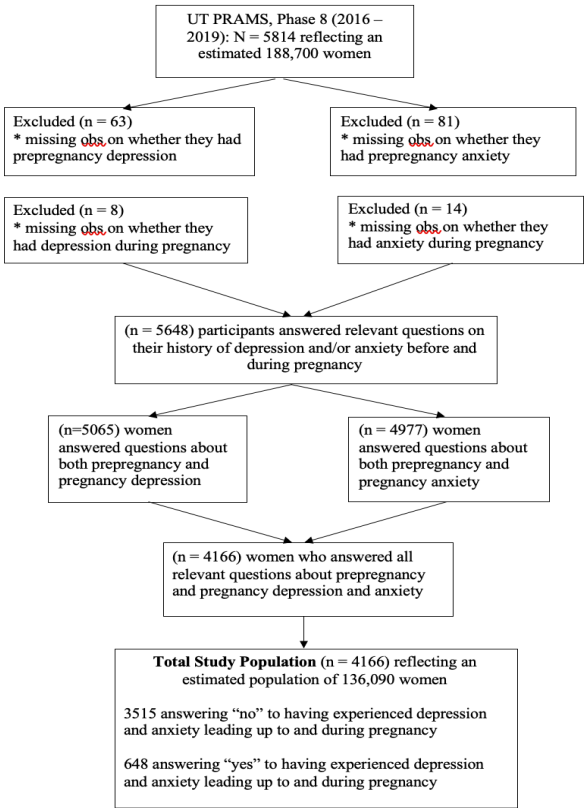
Among this study population, 13 percent had PPDA while 87 percent did not (Table 1). White non-Hispanic/Latina women were more likely to report PPDA (16%) compared to white Hispanic/Latina women (11%).

Table 1. Sociodemographic characteristics, clinical, and reproductive history of study participants with and without prepregnancy and prenatal depression and/or anxiety (n = 4166)\*

		With Prepregnancy and Prenatal Depression & Anxiety (13%)	Without Prepregnancy and Prenatal Depression & Anxiety (87%)
Characteristics	Total		
	%**	%**	%**
Demographic information			
Age (Categorical)			
	<= 18 years	1.4	3.9
	19-24 years	22.2	35.8
	25-30 years	39.5	35.5
	31-35 years	24.9	17.1
	36-40 years	10.5	7.7
	41+ years	1.5	0
Marital Status			
	Single or other	16.7	29.4
	Married	83.3	70.6
Race: White			
	No	10.9	6.9
	Yes	89.1	93.1
Ethnicity: Hispanic/Latina			
	No	83.8	88.6
	Yes	16.2	11.4
Education Level			
	<= 8th grade	1.5	0.7
	9-12 grade	6.2	12.4
	HS grad/GED	19.4	28.8
	Some college, no degree	21.5	27.7
	Associate degree	12.3	10.8
	Bachelor's degree	31.2	16.7
	Master's degree	6.1	2.8
	Doctoral degree	1.8	0.1
Household Income			
	<= \$20,000/year	0	0
	\$20,001-\$57,000/year	46.4	58.3
	\$57,001-\$85,000/year	26.7	24.7
	\$85,001+/year	26.9	17.0
Lifestyle factors			
History of smoking within last 2 years			
	No	91.5	73.6
	Yes	8.5	26.4
History of alcohol use within last 2 years			
	No	67.6	51.5
	Yes	32.4	48.4
BMI			
	Underweight (< 19.8)	10.7	10.3
	Normal (19.8-26)	50.8	41.1
	Overweight (> 26-29)	13.5	14.6
	Obese (> 29)	25	34
Potential Comorbidities			
Diabetes			
	No	99.6	99.6
	Yes	0.4	0.4
High blood pressure			
	No	98.8	98
	Yes	1.2	2
Reproductive History			
Previous preterm births			
	No	95.0	93.0
	Yes	5.0	7.0
Number of previous live births			
	None	34.8	37.9
	1-3	56.7	55.6
	4-7	8.2	6.5
	8+	0.3	0
Plurality (previous births)			
	Single	98.1	98.7
	Twins	1.8	1.3
	3+	0.1	0

\* n = 4166, reflecting an estimated population of 136,090 women  
\*\* Weighted percentages used unless otherwise specified

Figure 1. Study Participant Flow Chart



The median age was 28 years (mean age 28.8, SE 8.7).

The median age was 28 years (mean age 28.8, SE 8.7). The majority of women were White (89.1%), non-Hispanic/Latina (83.8%), married (83.3%), had at least some college (72.9%), and did not smoke (91.5%) or drink alcohol (67.6%) within 2 years before pregnancy. A high percentage did not have the common comorbidities of diabetes (99.6%) or high blood pressure (98.8%) within 2 years prior to pregnancy. Household income ranged from \$20,001 to \$57,000 for 46.4 percent of the population and was above \$57,001 for the remaining participants (Table 1).

Almost a third of mothers in this study gave birth for the first time (34.8%) while the others had experienced 1–3 (56.7%), 4–7 (8.2%), and 8+ (0.3%) previous live births, respectively. Of those with previous live births, 98.1% delivered a single child, 1.8% delivered twins, and 0.1% delivered multiples. Of women with a previous live birth 5% of women reported previous PTB. The prepregnancy BMI categories for participants was underweight (10.7%), normal weight (50.8%), overweight (13.5%), and obese (25%). Women with PPDA, compared to those without, were more likely to have a history of smoking and/or drinking alcohol within the past 2 years, to be obese, have high blood pressure, a history of PTB, and/or given birth to multiples.

**Association Between Depression and/or Anxiety and Preterm Birth:** In the unadjusted analysis we found

that women reporting PPDA, compared to those without, were 1.55 (95% CI, 1.22, 1.99) times more likely to experience PTB. Those with depression alone were 1.48 (95% CI, 1.18, 1.85) times more likely to experience PTB, and those with anxiety alone were 1.44 (95% CI, 1.17, 1.78) times more likely (Table 2).

After adjusting for maternal race, age, household income, marital status, and education level, women with PPDA, compared to those without, were 1.67 (95% CI, 1.19, 2.34) more likely to have PTB. Those with depression were 1.54 (95% CI, 1.15, 2.07) times more likely to experience PTB, while those with anxiety were 1.51 (95% CI, 1.16, 1.96) times more likely (Table 2).

After additional adjustment for previous preterm births, number of previous live born, recurrent diabetes and/or high blood pressure, BMI, and smoking and drinking within the previous 2 years, those with PPDA were 1.59 (95% CI, 1.05, 2.40) more likely to have PTB, while those with depression were 1.56 (95% CI, 1.08, 2.24) more likely to experience PTB and those with anxiety 1.31 (95% CI, 0.95, 1.78) more likely (Table 2). Stratification by Hispanic/Latina ethnicity showed effect modification for prepregnancy and prenatal depression and PTB in both the parsimoniously adjusted model and fully adjusted model (Wald P for both=0.04) (Table 3).

**Table 2. Weighted Percentages and Unadjusted Prevalence Ratios and Confidence Intervals of Women with Prepregnancy and Prenatal Depression and/or Anxiety and Preterm birth**

Pregpregnancy and prenatal mental health factors	Total		Experienced Preterm birth	Did not experience a preterm birth	Unadjusted Prevalence Ratio	Model 1**	Model 2***
	%		%	%	PR (95% CI)	aPR (95%CI)	aPR (95%CI)
<b>Depression and anxiety</b>							
Yes	13		19	12	1.55 (1.22, 1.98)	1.67 (1.19, 2.34)	1.59 (1.05, 2.40)
<b>Depression only</b>							
Yes	14		20	13	1.48 (1.18, 1.85)	1.54 (1.15, 2.07)	1.56 (1.08, 2.24)
<b>Anxiety only</b>							
Yes	21		28	20	1.44 (1.17, 1.78)	1.51 (1.16, 1.96)	1.31 (0.95, 1.78)

\*Weighted percentages used unless otherwise specified

\*\* Model 1 was adjusted by maternal race, age, household income, marital status, and education level.

\*\*\* Model 2 was further adjusted by previous preterm births, number of previous live born, recurrent diabetes and/or high blood pressure, BMI, and smoking and drinking within the previous two years.

**Table 3. Relationship Between Prepregnancy and Prenatal Depression and Anxiety and Preterm Birth, stratified by Hispanic/Latina**

Ethnicity

Hispanic/Latina	Preterm birth versus no preterm birth		
	Unadjusted PR (95% CI)	Model 1* aPR (95% CI)	Model 2** aPR (95% CI)
Depression and anxiety	0.78 (0.41, 1.47)	0.51 (0.18, 1.40)	0.54 (0.14, 2.04)
Depression only	0.69 (0.39, 1.22)	0.53 (0.24, 1.21)	0.40 (0.13, 1.24)
Anxiety only	1.47 (0.81, 2.69)	1.98 (0.93, 4.26)	2.00 (0.72, 5.64)
Non-Hispanic/Latina	Preterm birth versus no preterm birth		
	Unadjusted PR (95% CI)	Model 1* aPR (95% CI)	Model 2** aPR (95% CI)
Depression and anxiety	1.73 (1.33, 2.25)	1.79 (1.25, 2.55)	1.70 (1.1, 2.63)
Depression only	1.64 (1.28, 2.08)	1.62 (1.18, 2.21)	1.66 (1.14, 2.42)
Anxiety only	1.47 (1.18, 1.85)	1.48 (1.12, 1.97)	1.25 (0.89, 1.75)
Adjusted Wald Test for Hispanic/Latina Ethnicity			
	Unadjusted	Model 1*	Model 2**
Depression and anxiety	$p = 0.02$	$p = 0.06$	$p = 0.10$
Depression only	$p = 0.01$	$p = 0.04$	$p = 0.04$
Anxiety only	$p = 0.03$	$p = 0.06$	$p = 0.64$

\* Model 1 was adjusted by maternal race, age, household income, marital status, and education level.

\*\* Model 2 was further adjusted by previous preterm births, number of previous live born, recurrent diabetes and/or high blood pressure, BMI, and smoking and drinking within the previous two years.

## Discussion

After accounting for relevant sociodemographic, lifestyle, and reproductive history factors, women with prepregnancy and prenatal depression and anxiety, compared to those without, had a 67 percent higher probability of experiencing PTB. Women experiencing depression but not anxiety had a 56 percent higher probability of experiencing PTB, and those with anxiety but not depression were 51 percent more likely to have PTB. Our findings indicate that among the entire study population, the cumulative effect of depression and anxiety has a greater potential impact on PTB risk than either alone. Effect modification by Hispanic/Latina ethnicity was found to act as a protective factor against PTB for those with prepregnancy and prenatal depression and anxiety as well as those with depression only.<sup>36</sup>

**Strengths of the Study:** The use of PRAMS data allows for a population-based analysis that is representative of all women in Utah, including at-risk women, due to its systematic stratified sampling scheme. Our ability to capture self-reported depression and anxiety data before and during pregnancy and to link these data to

birth records for PTB assessment is novel, especially since questions on maternal depression and anxiety were added to the UT-PRAMS survey only in 2016.<sup>37</sup> The UT-PRAMS questionnaire and linked birth records also allow us to take into account multiple important confounding factors including sociodemographic, lifestyle, health, and reproductive history.

**Limitations of the Data:** This study faces the limitation of selection bias by only focusing on mothers who had a live birth.<sup>38,39</sup> The precision and accuracy of obstetric estimation of gestation, which can vary up to 14 days, may potentially lead to misclassification bias. Missing data for the outcome, key exposures, and covariates could lead to selection bias. Recall bias may also be a factor, as the questionnaire asks women at 2–6 months postpartum on experiences they had before and during pregnancy. Social desirability bias may also be a factor as not all mothers may wish to report on their smoking, drinking, or drug use due to the stigma associated with them. Additionally, the PRAMS questionnaire asks women to confirm that they experienced anxiety and/or depression before and during pregnancy without regard to standardized testing and clinical diagnoses.<sup>40</sup> This may result in the data over-



-estimating the prevalence of diagnosed depression and anxiety or underestimating based on poor screening.<sup>41</sup> The severity of the mental disorder(s) is also not addressed. During PRAMS Phase 8, 43.8% of women were screened for depression during the 12 months before pregnancy, compared with 68.9% during prenatal care visits, and 85.9% during postpartum health care visits. This study did not explore the impact of stress and abuse factors on PTB among UT-PRAMS participants. The intensity of alcohol consumption and tobacco use are not provided in the data, which may directly impact the potential association between health behavior and the risk of PTB; these questions should be included in future questionnaires. The impact of prepregnancy and prenatal depression and/or anxiety on postpartum depression would also benefit from additional study.<sup>2, 42</sup> Finally, we were not able to explore how race may modify the association between maternal depression and/or anxiety and PTB due to only having access to dichotomous race variable (White vs non-White). Given the high rate of PTB among Black women, more research is needed on potential factors that can explain this disparity.<sup>33</sup>

**Interpretation:** The findings of an association between prepregnancy and prenatal depression and anxiety and PTB is in harmony with a large body of prior research.<sup>2, 7, 25, 34-45</sup> It is notable that many studies look at depression and anxiety separately instead of as ongoing comorbidities, and this has led to varying results in the literature.<sup>2,17,27</sup> Adhikhari, et al, found that when depression and anxiety coexist, the symptoms are likely to be more severe and pose a higher risk of PTB.<sup>7</sup> Similar to our findings, both maternal smoking and alcohol consumption can increase the risk of PTB.<sup>46-50</sup> Unlike other studies,<sup>24,29</sup> however, our study did not find that age played a significant role in predicting PTB among women with prepregnancy and prenatal depression and anxiety. This may be because only 13.4% of this sample fell in the high-risk categories of under 18 or over 35 years of age. Liu, et al, reported that prepregnancy obesity is associated with PTB in the general population, which is similar to this study's findings of a mild association between obesity (BMI >29) and PTB.

The finding of Hispanic/Latina ethnicity as a protective factor against PTB is also in line with existing literature.<sup>26, 27, 46</sup> Future research should delve further into reasons that Hispanic/Latina ethnicity may be protective, including through increased social support, as has

been hypothesized.<sup>26, 27, 46</sup>

## Health Implications

Pregnancy is a particularly vulnerable time for mothers, and the cumulative impact of prepregnancy and prenatal depression and anxiety can affect maternal mood and increase the likelihood of PTB and impaired fetal development. This, in turn, can lead to long-lasting psychological and neurological effects for the child.<sup>32</sup> Additional research with a larger, more diverse group is needed to further test the overall associations between a mother's age, race, ethnicity, and prepregnancy and prenatal depression and anxiety, and PTB.<sup>52,53</sup> Mental health screening during prepregnancy, prenatal, and postpartum visits is imperative to develop appropriate mitigation measures.<sup>54</sup>

## Conclusion

By looking at the existence of both depression and anxiety from prepregnancy to birth, the prevalence and cumulative impact of these mental disorders and their association with experiencing PTB can be better understood. This study highlights a positive association, which translates into a higher risk for PTB among women who experience the cumulative impact of prepregnancy and prenatal depression and anxiety, compared to those with only one disorder or none at all. The finding of an effect modification by Hispanic/Latina ethnicity emphasizes the impact of, most likely, social factors associated with maternal ethnicity and the risk of PTB.

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# Disparities in Distance to Abortion Care Under Reversal of Roe v. Wade

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## Abstract

**Background:** With federal abortion protections under threat, it is important to consider how abortion care access will change in certain places and populations if abortion laws revert to states. Abortion policy and access have strong spatial patterns in the US. State-level bans could severely reduce access in vast regions, worsening access in areas with already poor access. This may exacerbate disparities and lead to large-scale impacts on reproductive health. Beyond describing where abortion care may change, we sought to describe which populations could experience the most dramatic impacts if state-level bans are enacted.

**Methods:** We conducted an ecological and spatial analysis of abortion facilities and county-level populations in the contiguous United States (CONUS). Outcomes were Euclidean distance to abortion care, as well as change in distance after policy changes.

**Findings:** If states enact abortion bans as expected, 46.7% of the country's women would see an increase in distance to abortion care. Currently, more than half (62.6%) of all U.S. women live within 10 miles of an abortion clinic, but if state-level abortion bans go into effect, only 40.2% of women would live that close. The median distance would increase from 38.9 miles to 113.5 miles. In particular, women in the Deep South, Midwest, and Intermountain West could have to travel much farther for care. State-level bans may disproportionately impact women of color, those living in poverty, and people with less education.

**Interpretation:** The impacts of state-level abortion bans will span across racial, ethnic, and socioeconomic demographics, but the effects will be felt disproportionately

tionately by Black, Hispanic/Latinx, and impoverished women and those with less education. The changes have potential to exacerbate disparities in maternal healthcare outcomes at a large scale.

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## Introduction

As abortion-restricting legislation has been enacted at the state level, spatial disparities in abortion care access have grown<sup>1</sup>—and with the Supreme Court's expected majority ruling to strike down Roe v. Wade, access to abortion care will likely become substantially worse in large regions of the country.

In the decades since the Roe v. Wade decision, abortion has been the target of numerous legal restrictions.<sup>2</sup> By mid-year, 2021 was already the most prolific year for abortion legislation, with 21 state governments enacting restrictive abortion laws.<sup>3</sup> In the most extreme case, the Texas legislature prohibited abortion beyond six weeks of gestation with Senate Bill 8 (SB 8), effectively banning most abortions; healthcare providers estimated that 85 to 90% of patients seeking an abortion in Texas were beyond the six-week mark.<sup>4</sup>

On December 1, 2021, the Supreme Court heard arguments in the case of Dobbs v. Jackson Women's Health Organization, in which the state of Mississippi has asked the court to reverse all prior abortion decisions. This would remove federal protections of the right to abortion before fetal viability, allowing states to establish laws that could restrict abortion completely. While a formal decision is not expected until June 2022, the majority of justices are in favor of reversing or weakening Roe v. Wade.<sup>5,6</sup>

When abortion access is restricted, women seeking an abortion experience more stress, incur more out-of-pocket expenses, and must travel farther to obtain care.<sup>7</sup> Restricting access to abortion services is also associated with adverse maternal and infant health outcomes.<sup>7-9</sup> When restrictive legislation was enacted at the state-level in Texas, women of color were disproportionately affected. Average abortion rates progressively decreased as distance to clinics increased, but women of color were less likely to successfully obtain an abortion than White women.<sup>10</sup> While disparities in abortion care have previously been documented, the scale and degree of impact on sociodemographic groups with state bans has not been investigated in a published study.<sup>11</sup> Herein we quantify how distance to abortion care is expected to change in the US without *Roe v. Wade*.

## Methods

A list of 1,045 abortion clinics was obtained from the Advancing New Standards in Reproductive Health (ANSIRH) group's Abortion Facilities Database. ANSIRH is based at the University of California San Francisco (UCSF), and the database is updated periodically. Clinics that have closed (N = 238) or do not provide abortion services (N = 294) were excluded, leaving a total of 739 clinics for analysis.

County-level characteristics were obtained for women aged 15–49 in 3,108 counties in the contiguous US, and these attributes were applied to the county population-weighted centroids. We examined differences in expected increase in distance to care by race (Black, White, American Indian, Asian, Pacific Islander, Multiple Races), ethnicity (Hispanic or Latinx, not Hispanic or Latinx), educational attainment (some high school, high school diploma, some college, college degree), poverty, and rurality. Racial and ethnic composition and population estimates for 2019 were obtained from the US Census Bureau (USCB).<sup>12</sup> Poverty, education, and rurality measures were obtained from the USDA Economic Rural Development Society (ERDS), which were based on the 2020 Census and 2015–2019 American Community Survey (ACS).<sup>13,14</sup> Of note, ACS measures of educational attainment only describe individuals aged 25 or older.

almost certainly ban abortion if *Roe v. Wade* were overturned or weakened, and five additional states would be likely to ban abortion without federal protections in place.<sup>15</sup> These include most Southern states (Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, Oklahoma, South Carolina, Tennessee, Texas, West Virginia), areas of the Midwest (Indiana, Iowa, Michigan, Missouri, Nebraska, North Dakota, Ohio, South Dakota, Wisconsin) and parts of the West (Arizona, Idaho, Montana, Utah, Wyoming).<sup>15</sup>

Change in distance to abortion clinics was our primary outcome, with a secondary outcome of the amount of change in distance. Using ArcGIS Pro software from the Environmental Systems Research Institute (ESRI), Euclidean distance to the nearest abortion clinic was calculated in miles for all county centroids.<sup>16,17</sup> Clinics in states likely to ban abortion were then removed, and the Euclidean distance was re-calculated. If distance to abortion care increased, that county population was considered to be affected by potential abortion bans. These geographic measures were merged with sociodemographic variables, and the resulting data were analyzed further in R statistical software. Counties were grouped by expected increase in distance to abortion care (no change, ≤50 miles, ≤100 miles, ≤150 miles, ≤300 miles, ≤400 miles, and >400 miles). Distance increments were chosen for interpretability and visualization, with larger increments at greater distances.

## Results

More than half (62.6%) of all U.S. women currently live within 10 miles of an abortion clinic, but if state-level abortion bans go into effect, only 39.0 percent of women would live that close. Most counties (N = 1694, 62.0%) would experience an increase in distance to abortion clinics. The median distance to the nearest clinic is currently 38.9 miles, but with bans the typical distance would increase almost three-fold (median: 113.0 miles).

With state-level abortion bans, about 50 million women aged 15–49 (59.5% of this population) would live in counties without a clinic — 1.7-times more than present. As Figure 1 shows, wide swathes of the country would have to travel hundreds of miles for care,

Twenty-one states have legislation in place that would



including most of the South, portions of the Midwest, and throughout the Intermountain West. Figure 2 illustrates where the change would have the most pronounced impact, with county populations experiencing the greatest change in distance to care. In the top map of Figure 2, dark red areas represent counties with an increase of greater than 100-fold. These are primarily urban counties containing abortion clinics, and populations in these areas would experience the most dramatic impacts. For instance, a typical person in

Miami-Dade County, Florida currently needs to travel less than a mile for care—but that distance would increase by 426 miles. The lower map in Figure 2 shows this change in distance in terms of miles. Distance to care would increase by hundreds of miles for the Deep South, with no bordering states providing care. Table 1 shows county-level sociodemographic characteristics by expected change in distance (no change,  $\leq 50$  mi,  $\leq 100$  mi,  $\leq 150$  mi,  $\leq 300$  mi,  $\leq 400$  mi,  $>400$  mi).

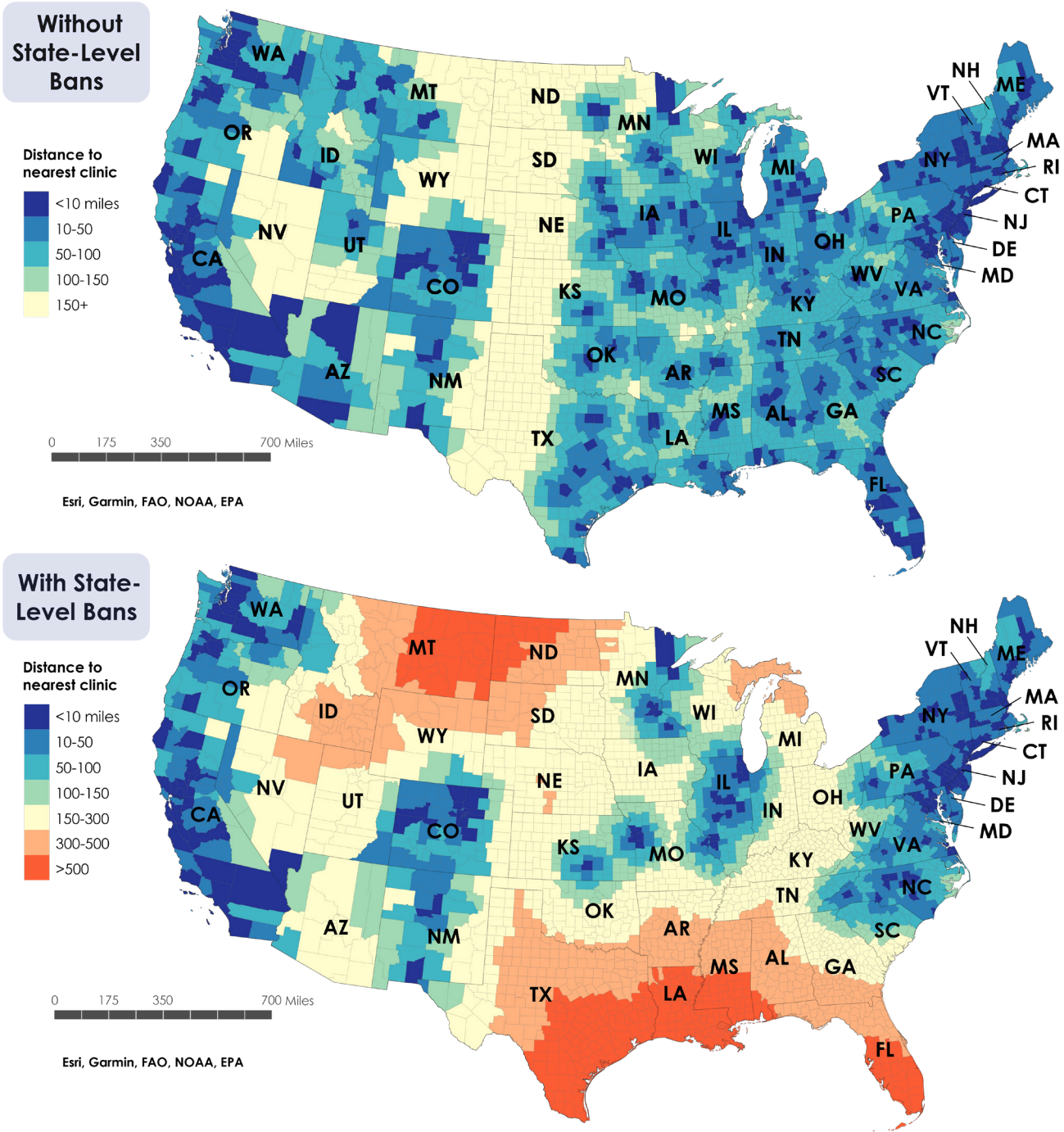


Figure 1. Euclidean distance to abortion providers from contiguous US county populations.

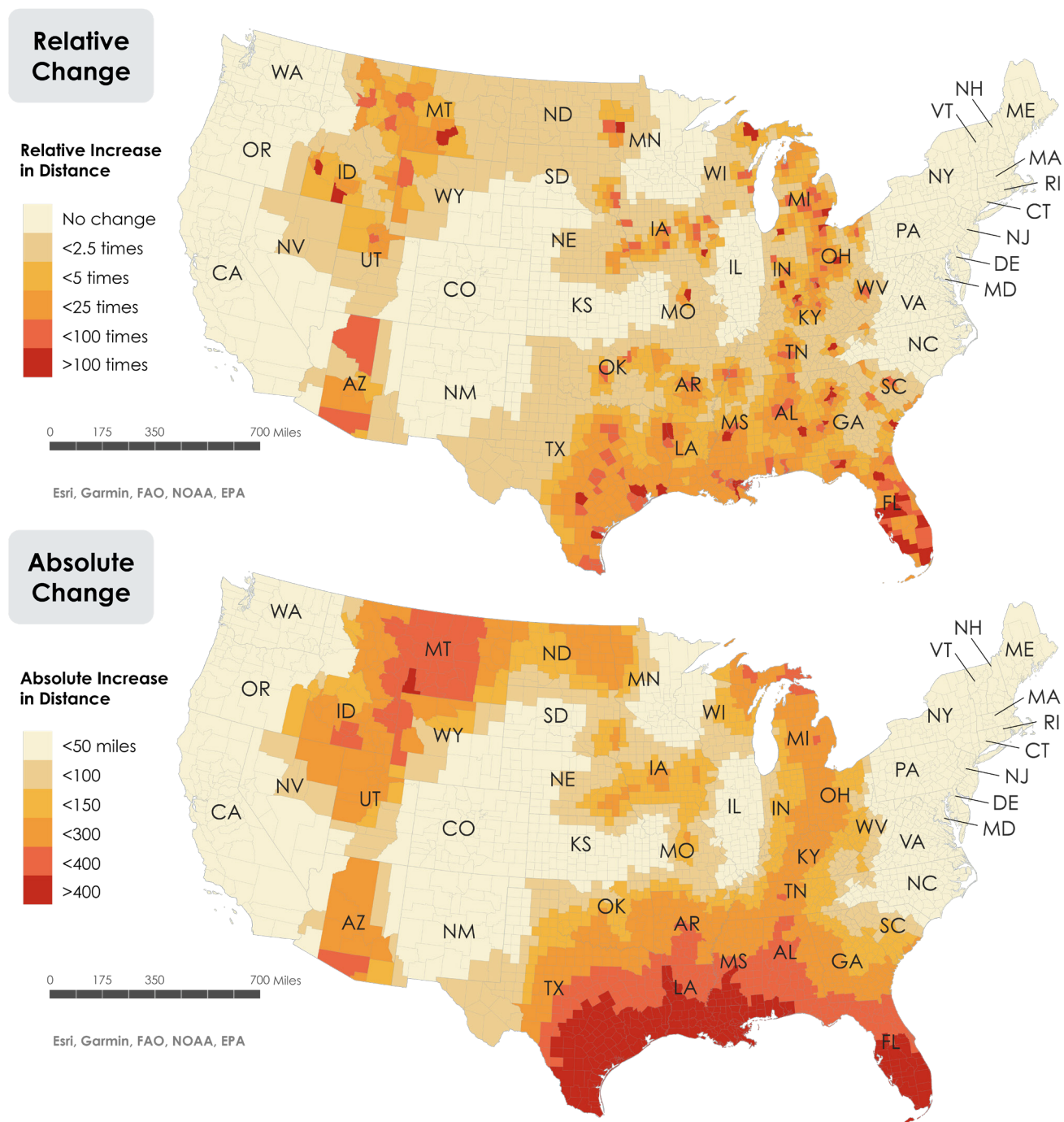


Figure 2. Relative and absolute change in distance to abortion care.

Both rural and urban areas will be impacted if state-level bans are implemented. About 66% of rural counties (N = 680) and 60% of urban counties (N = 1,014) will be affected. Of the 46 counties that will see an increase of more than 400 miles, 89.1% are also urban. As shown in Figure 2, the relative change in distance to care would increase most dramatically in urban areas, where most clinics are currently located.<sup>11</sup> More than 36 million women in urban areas will be impacted to some degree. Relatively small changes (increases of less than 50 miles) will be experienced by

more rural areas (56.9%), because most clinics are further from rural populations. Across all groups, 68.7% of women of reproductive age in rural populations would see an increase in distance required to reach an abortion clinic.

Economic measures tend to change as distance to care increases. The most affluent group, with the highest median household income at \$60,724, will experience no change in distance to care. Poverty levels (11.1%) are also lowest in this group and highest (14.0%) in the

	Expected Increase in Distance to Abortion Care						
	No Change	<50	<100	<150	<300	<400	>400
Number of Counties	1136	406	466	370	567	141	46
Rural Counties (%)	409 (36.0%)	241 (56.9%)	212 (45.5%)	153 (43.0%)	268 (47.3%)	35 (24.8%)	5 (10.9%)
Number of Reproductive Age Women	44,850,229	4,021,339	6,241,226	5,404,185	13,809,405	5,027,921	4,981,167
Median Household Income	\$60,724	\$52,229	\$53,317	\$53,394	\$51,862	\$53,338	\$56,322
Percent in Poverty	11.1	14.0	12.8	12.5	12.8	12.9	14.9
Some High School (%)	8.0	8.7	7.7	7.4	7.5	8.1	10.9
High School Diploma (%)	17.1	21.9	21.5	20.0	17.9	18.9	17.3
Some College (%)	19.0	20.6	20.1	19.5	20.4	19.9	18.0
College Degree (%)	24.0	16.3	17.6	18.9	19.8	19.9	19.3
Race and Ethnicity							
Black (%)	12.0	9.5	12.1	15.2	16.7	16.5	18.5
White (%)	75.2	85.3	81.6	77.4	76.0	77.3	74.3
American Indian or Alaska Native (%)	1.3	1.4	1.2	1.8	1.3	0.7	0.8
Asian (%)	8.2	1.7	2.6	2.8	3.5	3.1	4.6
Native Hawaiian or Other Pacific Islander (%)	0.3	0.1	0.1	0.2	0.2	0.1	0.1
Two or More Races (%)	3.0	2.0	2.4	2.7	2.4	2.2	1.8
Hispanic/Latinx (%)	20.1	13.2	7.1	7.9	13.8	21.9	45.0

**Table 1. County-Level Demographic Characteristics by Change in Distance**

next group, which will experience the smallest impacts (change of  $\leq 50$  mi). In unaffected areas, a college degree is the most common educational attainment (24%). In places with relatively minor impacts (change of  $\leq 50$  mi), a high school diploma is more common than a college degree (21.9% vs. 16.3%). Areas with the biggest impacts (change of  $>400$  miles) also have the highest proportion of people without a high school diploma at 10.9% and the highest poverty rate (14.9%).

Proportions of Asian people and those of two or more races were highest in areas with no change. In these counties, 12.0% of people are Black. By contrast, counties with the biggest expected impacts are 18.5% Black. This group also has the lowest proportion of White people at 74.3%, although 45.0% of the people in these areas are also Hispanic or Latinx. This area, visualized in the absolute change map of Figure 2, consists of

most of the coast of the Gulf of Mexico, encompassing large regions of Texas and Florida, most of Louisiana, and areas of Mississippi and Alabama. It also includes one county in Montana.

About 45 million women of reproductive age (53.5%) will experience no change in distance to abortion care. Roughly 16 million (19.3%) may have to travel up to 150 miles further than they do currently. Combined, 24 million women (29.3%) will see an increase in travel distance greater than 150 miles to obtain care.

It is important to note that, while the degree and relative amount of impact varies across demographic groups, all sociodemographic groups would, on average, see an increase in distance to abortion care on average.



## Discussion

Millions of women would be affected by state-level abortion restrictions, and racial, ethnic, and socioeconomic disparities in distance to care would be exacerbated. These results represent the worse-case scenario, assuming *Roe v. Wade* is overturned all 26 states restrict abortion to the point that all clinics close. However, because 12 states (including Utah) have “trigger” bans<sup>3</sup>—set to take effect immediately if *Roe v. Wade* is overturned—some of these impacts are guaranteed to take effect, if the Supreme Court rules in favor of Mississippi.

While distance to abortion care will increase dramatically in some areas, access will be more difficult for some than others. Women with resources enabling them to travel will likely be more successful in obtaining an abortion. However, our results show that distance to abortion care would increase the most for counties whose populations are already the most disadvantaged. This could exacerbate existing healthcare disparities, both geospatial and sociodemographic.<sup>19</sup>

Across all distance to care, there will be urban and rural populations. Rural areas, which already have disparate access to healthcare, will be positioned even further from abortion care. Some urban areas, despite having concentrated populations and greater demand for health services, would become deserts for abortion care, as shown in Figure 1. Salt Lake City, Utah, for example, has the nearest abortion clinic to some parts of Wyoming, Idaho, and Nevada. Without it, even Salt Lake City residents would need to travel hundreds of miles to reach the nearest clinic, in Colorado. Changes like this could create a complex issue of managing reproductive care for a variety of geographically diverse populations, and meeting this need will likely require a multi-pronged approach.

Given the magnitude of state-level bans, we expect to see a variety of large-scale impacts from state-level bans, particularly if these policies do not increase contraceptive access. Unfortunately, some women will likely be desperate enough to resort to unsafe methods for terminating their pregnancy.<sup>8</sup> Poor access to abortion care is associated with poor maternal and infant health, and many groups may experience increases in these impacts.<sup>9</sup> With millions more women living farther from care, the clinics that remain open will likely

experience higher patient volume. After restrictions were imposed in Texas in 2020, the number of out-of-state abortions increased by more than 600%.<sup>20</sup>

In some ways, the Supreme Court’s decision could set women’s health back decades—however, America today is not the same as pre-*Roe* America. Women can easily learn about their options online. They can find providers, connect with advocates, and learn about the dangers of attempting to end their pregnancy without a medical professional. As always with the internet, misinformation will likely spread as well.

## Limitations

Because we used areal units, this study is subject to ecological bias. The ability to obtain an abortion likely varies within counties, and beyond this, people with financial means can travel farther distances for care. Furthermore, the demographic composition of counties does not perfectly reflect the populations seeking an abortion.

We used Euclidean distance to approximate travel distance. Calculating Euclidean distance with population-weighted centroids tends to underestimate driving distance to healthcare facilities in both rural and urban areas.<sup>19</sup> However, not all women have access to a vehicle, and in regions where women may need to travel hundreds of miles for care, those with financial means may choose to travel by airplane. Because Euclidean distance performs equally well for rural and urban areas and does not assume mode of travel, we preferred this method.

Medication abortions are becoming more widely available, although these may be targeted by state-level policies, as well. These may be sought online, preventing travel, but it will be difficult to predict the scale of medication abortions, particularly when obtained illegally.

The disparities described here only reflect the disparities in distance to care—but this will likely compound with other disparities. As this study was conducted at the county level, we were not able to parse out the intersectionality of these issues, although it is worthy of further investigation.



## Conclusion

Millions of women will be impacted if Roe v. Wade is overturned or weakened. State-level abortion bans may exacerbate racial, ethnic, and socioeconomic disparities. Healthcare professionals and patient advocates should prepare to address these disparities and provide for patients as abortion care dynamics evolve.

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### *Data Sharing*

County-level data and a data dictionary will be made available to others upon publication (brenna.kelly@hsc.utah.edu). In accordance with ANSIRH's Abortion Facilities Database Confidentiality Agreement, facility data and identifying information cannot be disclosed.

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# The Impacts of Menopause on Cognitive Function

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## Problem Statement

An estimated 1.3 million women will enter menopause each year in the US.<sup>1</sup> While menopause is commonly viewed as affecting only reproductive health, studies have shown that the reduction of estrogen significantly impacts cognitive functioning as well.<sup>2,3</sup> A decline in cognitive functioning may begin as forgetfulness, then progress to cognitive impairment and eventually lead to dementia. Alzheimer's Disease (AD) is the most common cause of dementia and kills 1 in 3 older adults annually.<sup>4</sup> Women make up two-thirds of AD and dementia diagnoses, yet there is no information from either the Centers for Disease Control<sup>5</sup> or the Alzheimer's Association<sup>4</sup> that is specific to women and estrogen. This shows that more research needs to be done to examine the connection between estrogen and cognition to determine potential prevention and treatment for dementia in aging women.

## Status of Literature

Every woman goes through menopause, either through the natural aging process or the surgical removal of the ovaries. The most common symptoms of menopause are hot flashes, changes in mood and appetite, sleeping difficulties, lower libido, decreased concentration, and issues with cognition and memory.<sup>6</sup> Some of these symptoms are cloaked in stigma, while hot flashes and reduced sex drive are widely, and stereotypically, discussed in the popular media, drawing attention away from the important neurological symptoms.<sup>7</sup> Both brain and ovaries are part of the neuroendocrine system, and estrogen produced by the ovaries is critical for providing energy to the brain.<sup>8</sup> Conde et al.<sup>9</sup> found

that a decline in cognitive performance was a prevailing complaint among menopausal women.

Menopause also has a documented impact on women's brain functioning, especially in relation to memory. The majority of women report memory decline, especially short-term memory loss, to be a major symptom of menopause.<sup>10</sup> Studies have also shown menopause to cause a reduction in processing speed and verbal memory.<sup>10</sup> Additionally, in a neuroimaging comparison to age-similar men, menopausal women showed changes in brain structure such as volume reduction in certain areas and hypometabolism of glucose.<sup>11</sup>

Depression and anxiety are also common symptoms due to the decrease in estrogen. Estrogen loss is correlated with diminished synapse formation in the basal forebrain and hippocampus and reduced cholinergic and serotonergic brain functions, which impacts cognition and mood.<sup>3</sup> Depression and anxiety can also affect cognition, as Devere explains,<sup>12</sup> indicating there may be more to consider when diagnosing and treating cognitive impairment. Because menopause has so many associated symptoms, it can be difficult to discern whether a patient's mental health symptoms are a result of menopause or have a different etiology.<sup>10</sup> It is crucial that healthcare providers understand the scope of menopausal symptoms and how they might interact with mental health.

Unfortunately, mental health symptoms, issues with working memory and verbal memory, and slower cognition are not the only obstacles facing menopausal women. The impact of reduced estrogen on the brain can put women at a higher risk of developing AD.<sup>6</sup> Menopausal women display similar neurological

changes as those with AD, including reduced gray matter in the parietal and temporal regions and brain underactivity as indicated by glucose tracers.<sup>6</sup>

## Call to Action

Studies have shown that estrogen influences cognitive function across several regions of the brain, namely those involved with information retrieval and memory, and evidence proves that menopause and AD are linked.<sup>12</sup> This is an under researched topic, and one that is critical to the well-being of women. While some literature about cognitive decline in menopause

contains controversy over the treatment of dementia, it is still a valid research area<sup>2</sup> that further highlights the importance of recognizing the effects of decreased estrogen levels on cognitive decline. It is important for neurologists to take menopause as well as perimenopause into consideration when evaluating memory decline among women. Lastly, because there is the potential for contradiction in study results due to studying women with a variety of genetic factors for dementia, further research needs to take a more individualized approach to examine the effects of hormone replacement therapy among postmenopausal women. This is an issue that, if addressed, can have a life-changing impact on women's well-being and longevity.

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# Utah Statewide Needs Assessment: Domestic Violence, Sexual Violence and Human Trafficking – 2022 Report

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## Key Terms

- Scholar Sarah Deer illuminates how the Colonial legal system has failed Native communities due to patriarchy and oppressive structures that condone violence, perpetuating the oppression of marginalized communities.
- Domestic violence is the willful intimidation, physical assault, battery, sexual assault, and/or other abusive behavior as part of a systematic pattern of power and control perpetrated by one intimate partner against another. It includes physical violence, sexual violence, psychological violence, and emotional abuse. The frequency and severity of domestic violence can vary dramatically; however, the one constant component of domestic violence is one partner's consistent efforts to maintain power and control over the other (NCADV n.d.)
- Severe forms of human trafficking are: Sex Trafficking – The recruitment, harboring, transportation, provision, obtaining, patronizing, or soliciting of a person for the purpose of a commercial sex act which is induced by force, fraud, or coercion, or in which the person induced to perform such act has not attained 18 years of age; or Labor Trafficking: The recruitment, harboring, transportation, provision or obtaining of a person for labor or services, through the use of force, fraud or coercion, for the purpose of subjection to involuntary servitude, peonage, debt bondage or slavery (USA 2020).
- Indigenous people are Native people's to a land.

Indigenous may also include other Native peoples from other contexts who have settled on other lands.

- LGBTQIA+ is a term to refer to people who are Lesbian, Gay, Bisexual, Transgender, Intersex, Asexual, Queer and other sexually and gender diverse communities.
- Native American / Alaskan Native comprises of the indigenous peoples of the North American continent, commonly referred to as the United States, and also in other contexts as Turtle Island.
- People of Color is a complex term to refer to racial and ethnic minoritized communities such as Asian American, Black, African American, Hispanic, Latino/a/x, Pacific Islander, and Mixed Race or multi-racial people.
- Sexual violence is an all-encompassing, non-legal term that refers to crimes like sexual assault, rape, and sexual abuse (RAINN 2022).

## Introduction

The purpose of the Utah State Wide Needs Assessment is to understand the extent to which resources are available to address domestic violence/intimate partner violence, human trafficking, and sexual violence in Utah:

- Services available to assist survivors and victims of domestic violence/intimate partner violence, human trafficking, and sexual assault in Utah, particularly in underserved communities (including outreach, direct services, housing, prevention, and culturally relevant services).
- Estimation of the types and extent of survivor needs, including in underserved communities.

- Assess for the presence and extent of gaps pertaining to geographic location (rural and urban), service type, and accessibility, including underserved communities.

The study addresses the needs of survivors of domestic violence (DV), sexual violence (SV), and human trafficking (HT) in Utah. The study takes place in Utah which has a population of 3.3 million people, and is growing rapidly in size and diversity. 14.4% of the state are Hispanic/Latino, 2.7% are Asian, 2.6% are two or more races, 1.6% are American Indian/Alaskan Native, 1.5% are Black/African American, and 1.1% are Native Hawaiian or Pacific Islander.

There is a need to respond to violence in the state of Utah. The overall perception of domestic violence, sexual violence and human trafficking in Utah are that conditions have worsened, the physical violence has become even more deadly. While participants of this study described a growth in local response, they illuminated how silence and the culture of Utah continues to create challenges for survivors.

Data from the Utah Department of Health has shown that one in four adult homicides are domestic violence-related, and that 1 in 10 males or 2 in 11 females will experience interpersonal violence. In 2018, a report from the Utah Department of Health showed that intimate partner violence (IPV) affected 18.1% of adult females and 10% of adult men (Utah Department of Health 2018). And 37% of transgender people will experience domestic violence in their lifetime (Peitzmeier et al., 2020). The same report indicated that less than 15% of Utahns who experienced IPV sought help for it. And between 2018 and 2019, there were 72 cases of strangulation identified related to domestic violence in Salt Lake City alone (Fukushima et al., 2020). Homicide is more likely for victims who experience strangulation by 750%.

Across the state of Utah, domestic violence organizations conduct a Lethality Assessment Program (LAP). Between 2016 and June 2021, 24,202 LAP screenings were conducted. It was found during the last two years of LAP screenings that 3,653 cases faced high danger (Utah Domestic Violence Coalition 2022).

Similar data shows that rape is the only violent crime in Utah with a rate higher than the national average.

Research conducted by Dr. Melton illuminates that 40% of CODIS (Combined DNA Index System) hits are serial offenders. RAINN conveys that 1 in 6 women experiences sexual violence in her lifetime (n.d.).

Human trafficking is under-reported and more difficult to identify. In 2020, there were also 182 victims of human trafficking identified in the state from the National Human Trafficking Hotline (n.d.) and 1,413 cases 2017 to 2020.

Although victims of domestic violence, sexual violence, and human trafficking experience these forms of abuse specifically, they oftentimes may intersect in the form of polyvictimization where a survivor may experience multiple forms of abuse in their lifetime.

This report reflects the tip of the iceberg. There is limited data on domestic violence, sexual violence and human trafficking in Utah and how minoritized populations are impacted by violence. Additionally, there is a lack of comprehensive studies on American Indian and Alaskan Native communities, and much of the data represents national studies. Therefore, this study represents what Sonia Salari refers to as the iceberg effect of maltreatment, where what is known is the tip of the iceberg and there is so much unknown, and many survivors who experience violence that goes under-reported.

*The “culture leads to victim-blaming quite honestly. I think that survivors oftentimes feel a lot of self-blame, which then can go into feelings of shame, which really we know mental health-wise, what those feelings of shame affect people so negatively... [Utah] culture also is less likely to believe survivors when they come forward... when we look back historically at rape laws or domestic violence laws, they stem back to times when women were seen as property; and because they were seen as property, that led to those first rape laws really being that they had to actively resist... we still see that bleeding through in our culture” – Nurse*

*“So, what has happened over these last three decades has absolutely changed how we do things. The problem is we still have so much violence. It hasn’t ended... We need to make sure that what we do is effective. Because frankly we can do harm.” – Lawyer*

## Methods

Previous statewide needs assessments focused on domestic violence service providers and human trafficking noted similar areas necessary to improving

response within Utah. Gezinski (2017) recommended specific steps to be taken within each section (funding, education, legal services, community, continued research), including outcome measurement and conducting a statewide assessment every 3-5 years. Fukushima et. al. (2018) recommended long-term comprehensive service provisions, coordinated community response, increased outreach to identify vulnerable populations, survivor leadership, as well as facilitating local education and awareness efforts. After multiple conversations with local organizations – the Utah Domestic Violence Coalition, the Utah Coalition Against Sexual Assault, Restoring Ancestral Winds, and DCFS, it was established that a state-wide needs assessment be conducted under the leadership of the Principal Investigator (Dr. Fukushima) and the Gender-Based Violence Consortium. A needs assessment is defined by Peterson and Alexander (2001) as “the role of needs assessment is to identify and also address needs.” It is a “tool for determining valid and useful problems.” Overall, a needs assessment is a “collection of data bearing on the need for services, products, or information.” The research team will conduct a mixed methods study to further understand the needs for service provision surrounding domestic violence, human trafficking and sexual assault. The Utah State-wide Needs Assessment employs mixed methods which triangulates qualitative and quantitative data collection. The methodology for this study involves survey distribution (N=293), followed by focus groups and/or interviews (N=41) with experts of domestic violence, sexual assault, and/or human trafficking. Data collection occurred between July and December 2021. Recruitment occurred after IRB approvals (IRB\_00141188) online via social media and emails. Focus groups and emails were conducted remotely utilizing Zoom. Data collection occurred between July 2021 until May 2022.

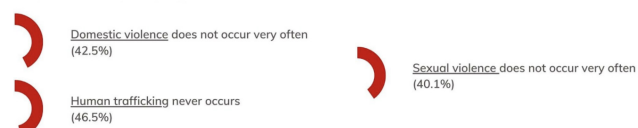
## Participants

293 individuals participated in the online survey and 41 individuals participated in focus groups and interviews. Participants were professionals with a wealth of experience working on domestic violence, sexual violence or human trafficking with an average year of experience for survey participants being 9.5 years and 11 years for interviewees and focus group participants. Expertise by types of violence varied with

the highest of expertise in domestic violence (n=216), sexual violence (n=165), and child abuse (n=124). Of the 283 participants who disclosed their range of professional identities, the highest representation was with advocates (20%), mental health providers (18%), administrator/executive director/director (14%), and medical providers (8%), with participants identifying in smaller numbers as prevention and education (5%), victim service provider (5%), case manager/supervisor/manager (4%), housing provider (4%), receptionist/secretary (2%), researcher/analyst (2%), volunteer (2%), child welfare (1%), legal provider/lawyer (1%), outreach (1%), law enforcement (1%), social service provider (1%), and less than 1%: religious leaders and media/marketing. Survey participants were 89% female identifying with smaller participation from male and gender-nonconforming participants, 82% heterosexual with 19% identifying as Lesbian, Gay, Bisexual, Asexual or Queer, with diverse racial participation with Asian and Hispanic / Latino slightly lower than the Utah population, and White over-represented, with other racial minorities in parity with Utah population. Survey Participants were able diverse with 17% identifying with living with a disability. Interviewees and focus group participants were predominantly women (95%), and heterosexual (80%), with smaller participation from men (5%) and Lesbian, Gay, Bisexual or Queer (20%), and were closer to parity with Utah racial demographics, with larger participation from Alaskan Native/American Indian (5%). Participants were also geographically diverse. Although a large number were from Salt Lake County, participants also joined from southern, northern and eastern Utah. Additionally, 47 participants identified as survivors.

## Community Perceptions

Misperceptions about domestic violence, sexual violence and human trafficking persist. Nearly 4 in 10 of the surveyed participants believe that the community believes that: domestic violence and sexual violence do not occur very often and that trafficking never occurs. Regardless of the perception that violence is not occurring very often or at all, there is a need to raise awareness about violence in Utah.





## Marginalized Communities

In order to be effective at responding to violence, it is essential that governmental and nongovernmental responders address the response for the most marginalized in communities. There are a variety of marginalized communities, where this study brings to the fore specific communities and people:

- American Indian / Alaskan Native communities
- Communities of Color: Black, Latinx/a/o/Hispanic, Asian, and Pacific Islander
- Immigrant communities
- LGBTQIA+ (Lesbian, Gay, Bisexual, Transgender, Intersex, Asexual) communities
- Communities living with a disability

### *American Indian / Alaskan Native*

There are 8 federally recognized tribes in Utah: Confederated Tribes of the Goshute Reservation, Navajo Nation, Northwestern Band of Shoshone Nation, Paiute Indian Tribe of Utah, San Juan Southern Paiute, Skull Valley Band of Goshute, Ute Mountain Ute Tribe, Ute Indian Tribe. Restoring Ancestral Winds is a tribal coalition that addresses stalking, domestic, sexual, dating, and family violence. RAW collaborates with UDVC and UCASA, Rape Recovery Center, as well as providers funded by DCFS work to support survivors of domestic violence, sexual violence, and human trafficking. Also, RAW has partnerships with the Strong Hearts Native Helpline and the National Indigenous Women's Resource Center. In 2021, Gentle Ironhaw Shelter opened in Blanding to house domestic violence survivors.

Domestic violence is deadly for Native people where four out of 5 Native women and girls are affected by violence with homicide rates 10 times the national average. And 1 in 3 Native women are raped in their lifetime. Utah is the 10th most dangerous place for Native peoples, with the highest numbers of missing and murdered indigenous women, girls and two-spirit cases (Lucchesi and Echo-Hawk 2018). Additionally, there is a need to address non-Native violence against Native people, where 80% of abusers are non-Native people.

There has been an increase in partnerships between Utah governmental representatives and Native leaders. In 2020, a Missing and Murdered Indigenous Women task force was created, with representatives

of Restoring Ancestral Winds. While there is a wealth of expertise, knowledge and desire to support Native communities, the AI/AN are truly under-resourced financially, where in the diverse tribes, there may be only one officer to investigate a region or one advocate to support survivors.

Although there are 574 federally recognized tribes, the diverse native communities continue to experience homogenization. Additionally, the rurality of tribal communities, means that survivors oftentimes traverse long-distances to have their needs met, distances that they do not have resources to travel or it may impact the ability for the survivor to engage with services if they are also parenting. For Native survivors accessing services, there is a need to increase education and awareness of serving diverse cultures. Participants described Native survivors experiencing re-traumatization when accessing resources with governmental and non-governmental agencies. Culture is incredibly important when responding to the needs of Native survivors. One interviewee described how justice responses to Native survivors might sometimes include advice, recommendations or processes that go against Native beliefs. There is a need to provide culturally aware services that work in collaboration with funding Tribal communities to provide the expertise and services. The Urban Indian Health Center was lauded as a model. Many Native leaders would like to support non-Native organizations, however, they are under-resourced in people and time to lend their expertise to other organizations. Therefore, there needs to be two-fold forms of resourcing occurring for Native communities: 1) increasing funds to Native organizations and 2) diversifying recruitment in organizations to actively recruit Native experts. Additionally, federal funds have been utilized to support traditional ceremonial forms of healing as a means to foster culturally aware responses to violence – this is highly recommended that such resourcing is supported.

Recognizing that there are different mechanisms of reporting of violence, this impacts what is known about Native communities. Some tribal communities report to SANE nurses, where information and reporting is centralized with Public Health Services. Or others are working with American Indian Health Services. Some data surrounding violence against American Indians and Alaskan Natives focuses on domestic violence, excluding sexual violence. Additionally, Indian

nation is fluid and broad, which means that Native communities may be accessing non-native services.

The justice system is not very compatible with ... the Diné or Navajo culture, so that's frustrating for them and it feels like they are re-victimized by that process pretty often. I think that there's a decent amount of implicit bias and/or racism that that community faces with law enforcement and there's a lot of work to be done there. So, even that willingness to work with law enforcement is really traumatizing whether you're a victim or not... There's a lot of trauma regarding children being taken from their homes, placed into schools, but also through DCFS. – Administrator, Nonprofit

"(American Indian and Alaskan Native survivors) want to be able to stay on the Nation within their surroundings that are familiar. But unfortunately, you know, those opportunities exist outside of the reservation and will often put [Native communities] in a more vulnerable situation... In the state of Utah ... where MMIW in Salt Lake City is also noted as running in the Top 10 city of 71 cities... It's far too risky to... for a Native woman to take her children into an urban setting, and risk her life, and her children's life as she is seeking out those opportunities without the support of her relatives" – Administrator, Nonprofit

As an agency, we are actively working upon fostering that relationship with our tribal community. And we know we have failed in some places—we know it—and it is something that we have become very aware of... And especially with the Gabby Petito case, we're like, "Wait a minute. That is a tragedy that happened, but what about all these other people that are from our community that we didn't even know that they were missing? Why don't we know that?" – Advocate

## Communities of Color

### Black, Latinx/a/o/Hispanic, Asian, and Pacific Islander

**Table: Sexual Violence & Domestic Violence Racial Comparison**

Race / Ethnicity	% of Utah Population	Rape/Sexual Assault in lifetime	Domestic Violence in lifetime
White	86%	18%	34%
Two or More Races	3.04%	24%	50%
Asian	2.32%	7%	25%
Black/African American	1.19%	19%	40%
Native American	1.09%	34%	84%
Native Hawaiian/Pacific Islander	.89%	7%	68%
Hispanic/Latinx	15.1%	25%	34%

Sources: API-GBV, Blackburn Center, Rosay 2016, VeryWellMind, Stockman et al., 2015.

Utah is increasing in diversity with a population increase between 2010 and 2020 of 17.4% (Clair 2020). Although Utah is growing in diversity, an ongoing concern is how to support the racially and ethnically diverse communities that experience domestic violence, sexual violence and human trafficking. Although organizations such as Comunidades Unidas, Pik2AR, Utah Coalition Against Sexual Assault Spanish language-line, Asian Association of Utah, and coalition members support survivors regardless of race, there is a need to address race and ethnicity in Utah. Color-blind racism is the norm in Utah, where people do not "see race." However, "We cannot un-will ourselves to un-see something that we've already seen." Race is a powerful social identity, where diverse and culturally aware responses to violence are much needed in the state. Survivors are hesitant to access services due to the perception of resources being for "whites" or unable to accommodate diverse communities. Additionally, there is a need to provide specialized services and groups for diverse communities to grapple with how there are layers of oppression that they experience due to violence, when seeking out services/resources, and when attempting to leave or heal from violence or abuse. As data shows, communities of color are being impacted by domestic violence and sexual violence at a greater rate than their white counterparts. Communities of color are a central factor that impacts who is more likely to experience being trafficking where communities of color are disproportionately represented in sexual economies, and in effect vulnerable to trafficking (Butler 2015; Fukushima 2019). This does not make communities of color more violent, but rather, highlights the ongoing impacts of structural violence and decades-old discriminatory policies, like redlining, on communities of color that also exacerbate conditions of abuse.

I've talked with a few people who have identified as indigenous, African American... various identities that they're like "I just don't feel comfortable accessing these whitewashed services. And I'm not going to, because it's just not safe for me." – Advocate

We need more spaces with women of color conversations being silenced and it being okay for it to be silenced so that they can feel safe... it's another layer of oppression, they're coming out of abuse, they've been oppressed. They're fleeing. And the [responders] in the space where they're fleeing [to]... don't get what they're dealing with... All these layers of oppression that intersect with each other... – Government worker

The Pacific Islanders, there are [85,000] in Utah. It's the largest community outside of the Pacific Islands. They struggle, I think it's fair to say. I don't want to speak for them, but those are some communities that come to mind. – Administrator, nonprofit

*"We have seen more folks that are refugee status or identify as refugee... that community... also needing much more support... And also a cultural response to what their experience of that, not only sexual violence, but all the things that contribute to like how they're feeling right now with all the trauma they've endured and witnessed too." – Clinical Director "The need... it's about funding. I would love to be able to have a bilingual therapist; I would love to be able to have support groups in Spanish and be able to just really, again, following with that trauma-informed care be able to provide our clients, no matter where they come from, the best services and the most informed services." – Advocate*

Utah refers to itself as a "welcoming," conveying that there are efforts in support New Americans who welcome. 9% of the Utah population is immigrant (American Immigration Council 2020). Immigrant communities include US diasporas who are also indigenous (for example, Native people whose peoples are not traced to the Utah region), refugees, asylum seekers and migrant laborers. The top national origins in Utah are Mexican, Indian, Venezuelan, Peruvian, and Canadian. 140,517 people in Utah lived with at least one undocumented family member. And 1 in 9 Utah workers are immigrant. Immigrants are found laboring in a range of industries, with higher representation in building and grounds maintenance, construction/extraction, farming/fishing/forestry, production, and food preparation and serving. These industries are also the same industries where trafficking is more likely to occur. The Violence Against Women Act and Trafficking Victims Protection Act include protections for immigrant survivors of violence, where they are able to access services and immigration relief. However, despite the resources available to immigrant communities, they continue to face a range of barriers including: staying in abusive conditions due to fear of law enforcement, lack of multi-lingual services, and an absence of culturally responsive resources to newcomers who experience violence. Although UCASA and COLAVI (Colavi: La Coalición Latina En Contra De La Violencia Intrafamiliar) provide support in Spanish, Spanish is just one of the many languages preferred by people from Latin America, and even a second language for people whose preferred language are Zapotec, Mixteco, Quechua, Guarani, among the many languages spoken in Latin America, which it is estimated that 560 indigenous languages are spoken in Latin America (Existe Ayuda, n.d.). Language access and immigration relief are central to supporting immigrant survivors of violence.

Over 1 in 2 of the surveyed believe survivors fear calling the crisis-line due to their legal status and over a third found crisis-line insufficient due to there being no interpreter/translation provided. Fear due to their legal status is also a barrier for immigrant survivors accessing housing, when seeking legal services, and when reporting crimes to law enforcement. Nearly half of the participants also believe that survivors do not seek out medical services due to fear about their legal status. And 1 in 2 believe that survivors are unable to have their immigration needs.

### LGBTQIA+

*"We actually don't see a lot of trans folks in our center from what my experience would have seen, and I think that's like an area that we're trying to focus on as well, it's like how can we better train ourselves and create a space for survivors that are trans[gender] to be able to feel comfortable enough to receive services from us and if not, who can we refer to that would be a better fit?" – Therapist "Homeless youth that we're dealing with that are transgender and LGBTQIA they feel more marginalized in the community... There aren't safe spaces for them... It's not safe, it's more trauma... In jail, prison, and in detention facilities they're not affirmative. We're not training spaces where harmed LGBTQIA show up to be affirmative. So, it's just another place where there's more trauma and more abuse and more vulnerability. I just had a transgender female come out of the male side of the prison. And she was supposed to complete an inpatient program on the men's side of the prison where she was being sexually harassed, almost assaulted by other prisoners and being shamed by the officers... Where are the safe spaces for an LGBTQIA child of color that's fleeing a home where they reject him or her and then they show up at a space where they can be trafficked?" – Government worker*

Lesbian, Gay, Bisexual, Transgender, Intersex, Queer survivors of violence experience a range of violence that are higher rates than their heterosexual counterparts. While it is estimated that 35% heterosexual women will experience rape, physical violence or stalking by an intimate partner in their lifetime, for gay men it is 26%, for lesbian it is 44%, and 61% for bisexual women (NISVS 2010). And while it is estimated that 1 in 5 women experience sexual violence in a lifetime (CDC 2021), the rates for transgender people is nearly 1 in 2 (HRC Foundation 2021).

Similar to communities of color, LGBTIQ survivors of violence continue to feel that there are not enough safe spaces for them. And that overall, LGBTIQ+ community members continue to have lower rates of help-seeking due to a range of concerns with being "outed" or experiencing discrimination (NCAVP 2016; Barker 2022). Particular areas of need and barriers for LGBTIQ+ is with accessing housing and healthcare (Belknap et al., 2009).

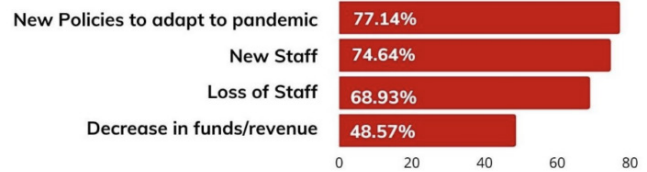


## Disability

6.8% of Utahns live with a disability, and 11% of those living with a disability are uninsured. There are a range of challenges that are faced in addition to experiencing violence. Participants described how it was difficult to put people into boxes that are required for disability services. It is common for domestic abusers to threaten the safety of animals to compel survivors to stay in abusive conditions. Although HB175 expands protective order protections for animals, there exist a range of disabilities that impact survivors of violence beyond emotional animal assisted services. People living with a disability have a higher prevalence of abuse, and are three times more likely to be sexually assaulted compared to peers without a disability (NCADV 2018b) with other studies conveying that people living with a disability are 7 times more likely to experience sexual assault (Shapiro 2018). And 40% greater chance of experiencing intimate partner violence. A review of 54 cases in Florida found that 28% of human trafficking involved individuals with intellectual disabilities (Nichols and Heil 2022).

*"There's so little awareness about the [number] of women with disabilities who are assaulted... I think when people think of disabilities, they may think of someone in a wheelchair with a severe cognitive disability. But we're talking about women with autism, brain injuries, and men, they're in the jails. They are the people on the streets as well. So, just recognizing that disability spans across all of our areas and we all are kind of responsible for making sure that awareness is out there." – Government worker*

### The top 4 changes experienced in the last year:



## Barriers



## Services & Response

### Change

There are 21 organizations that provide services to survivors of sexual violence and 26 organizations to survivors of domestic violence. Oftentimes these organizations are providing services for multiple types of abuse. And human trafficking responses is coordinated through the Utah Trafficking in Persons Task Force. During the past year, 83% of the participants described how their organizations experienced change, with the most change with regards to adapting to the global pandemic, new staff, loss of staff, and decrease in funds/revenue.



Survivors in Utah face a range of barriers, that impact their ability to access services. In particular, they fear their abuser, do not want their abuser to get into "trouble", lack knowledge about resources, lack financial resources to leave, or are unable to leave due to child care for children.

Survivors in Utah face a range of barriers, that impact their ability to access services. In particular, they fear their abuser, do not want their abuser to get into "trouble", lack knowledge about resources, lack financial resources to leave, or are unable to leave due to child care for children.

There are not enough resources to survivors. Over 4 in 10 of respondents do not believe there are enough to support survivors of domestic violence. Over half of respondents do not believe there are enough resources

to support survivors human trafficking. And nearly 4 in 10 of respondents do not believe there are enough resources to support survivors of sexual violence.

Despite the wealth of knowledge and years of expertise, 1 in 2 of respondents thought about leaving their organizations because of feeling overwhelmed or overworked, desires to earn more money or receive better benefits, lack of support from leadership, the organization's culture, or trauma from their work.

Nearly 1 in 2 of the participants have thought about leaving their organizations.



"There is very high turnover and I think that's because burnout is so severe. I think everyone is experiencing secondary trauma because there is just so much on your plate at all times. And I think we can all relate to that." -- Victim Advocate

"We are well supported in the take wellness time and time off and flexing schedules... At the end of the day there's two of us... It's difficult... Everybody's doing four jobs and it's true, all of our offices are very lean and we have very minimal staff... it means that everyone is doing lots of different roles and that's difficult." -- Advocate

"I think there's a very strong argument to be made that if we want to provide our clients with the best services, we then need to really invest in our staff. Because it's very difficult for a client who has made a relationship with, say, a case manager or a therapist, and then a month later, they find out, okay, they have to start over again with somebody else. So, it really does affect the services and the quality of the services that we can provide to our clients." -- Program coordinator

## Needs

The top five needs for survivors of domestic violence, sexual violence and human trafficking: housing, financial support, emotional support, mental health, and family support.



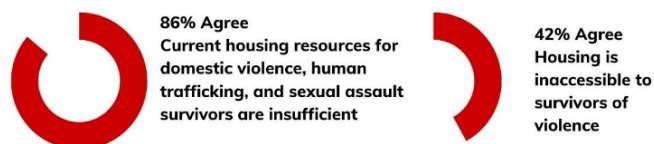
5 Top needs for survivors of violence:

- Housing
- Financial support
- Emotional support
- Mental health
- Family support

## Crisis Line

Survivors of sexual violence, domestic violence and human trafficking need to know where to call to reach out for help. The top reasons why survivors call a crisis-line is because they are seeking safety, they need emotional support, or assistance with urgent needs such as housing, medical, and other needs. Current challenges faced by crisis-line services are that survivors are unaware of the crisis-line, survivors fear calling due to their legal status, the crisis-line needs more staff support, survivors are denied services/support due to eligibility requirements, or there was no interpreter/translation provided.

## Housing



A majority of the participants believe that housing for survivors of sexual violence, domestic violence and human trafficking are insufficient. And 4 in 10 believe that housing is inaccessible. The top five barriers survivors face when accessing housing is that there are either not enough beds or housing options. Housing options are unaffordable to survivors. In the past year



housing in Utah increased by 3.8%. For survivors of violence the inability to afford housing may impact their ability to leave abusive conditions or heal from the violence they experienced. The limited options for housing in Utah and restrictions with funding also means that survivors may be considered ineligible for housing. Survivors may also be unaware of housing services. And for immigrant survivors, although Utah is welcoming to migrant community, those whose traffickers or abusers used their legal status to compel them to stay in abusive conditions means that survivors are also afraid of authorities due to their legal status.

Utah's strong owner rights have led victims who are renters and call law enforcement for safety, to experience consequences – landlord evictions for “disturbing the peace.” In addition to being uprooted from their homes, survivors who are forced to evict under these circumstances face a range of additional barriers of not receiving their deposit back for breaking the lease (Peterson et al., 2021).

### Transportation

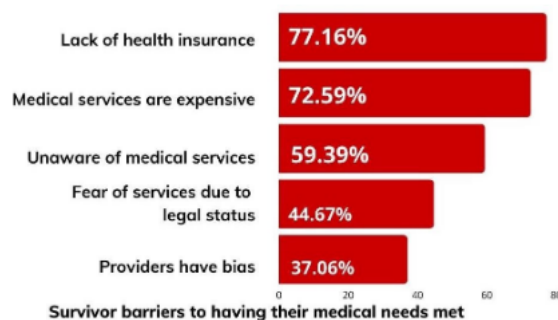
Transportation came up regularly during the interviews and focus groups. Participants described how lack of transportation or the inability to travel long distances to services, impacts survivors. Although there are resources in all parts of Utah, for survivors in rural settings finding their way to services is not always easy, and may add further stress.

"Transportation is an issue. We can ... try to secure shelter for somebody ... But there are very, very limited options. When it comes to transportation, getting somebody to a place. And, that's a huge barrier that comes up." -- Victim advocate

### Medical

Medical services are essential and a basic need from physical to mental health needs. Survivors of IPV accrue higher costs compared to non-survivors due

to immediate aftermath of violence as well as long-term issues (McLean and Bocinski 2017). The lifetime costs for survivors of rape is estimated \$122,461 per victim (Peterson et al., 2017). Trafficking survivors are accessing healthcare while being trafficked, with 68.3% being seen at the emergency room (Lederer and Wetzel 2014). In the aggregate, respondents of this study top five reasons survivors of violence sought out medical services due to needing urgent care, substance use treatment, primary care, care for another family member, or to receive reproductive services. While there are many medical needs, survivors continue to face barriers due to their lack of health insurance, the costs associated with medical care, they are unaware of medical services, fear service providers due to their legal status, and experience bias or discrimination from medical providers.



### Justice & Law



#### Top 5 legal needs

1. Protective order/restraining order
2. Custody of Child
3. Divorce
4. Legal needs related to domestic violence
5. Prosecution of abuser



#### Top 5 barriers reporting to law enforcement

1. Fearful of LE because of legal status
2. Maltreatment from LE
3. Bias/Discrimination from LE
4. Denied Support
5. Racial profiling

Domestic violence is a misdemeanor and law enforcement are required by law to use reasonable means to protect victims and prevent further violence (Utah Code sections 77-36-2.1 & 2.2). The top five reasons that survivors reach out to law enforcement are for safety/protection, filing a complaint, aiding in an investigation, criminal system related issues, or probation. For sexual violence survivors, only 1 in 10 of sexual assault cases end in a conviction with people of color three times as likely to be charged in contrast to a

white perpetrator (Jacobs 2021). Survivors face a range of barriers when reporting to law enforcement including being fearful of law enforcement due to their legal status, experiencing maltreatment from law enforcement, bias and discrimination from law enforcement, being denied support, and racial profiling.

In addition to enforcement, survivors of violence have a range of legal needs. This includes protective orders, restraining orders, custody of a child, divorce, legal needs related to domestic violence and prosecution of their abuser. After reporting to law enforcement, legal needs continue to be unfulfilled because they are expensive, survivors are unaware of services, there is a need for more providers/staff, fear of services due to their legal status, and survivors were denied support/services. Filing protective orders can be a lengthy process for survivors. And abusers violate protective orders (Gillis 2021), and take advantage of the system by finding ways to block survivors from receiving protection or representation. 1 in 2 of the participants believe that survivors are unable to have their immigration needs met. Overall, survivors of violence have varying perceptions of justice – for many of the interviewees participants described the need for more education as justice and transformative forms of justice that do not rely on the criminal legal system that is intended to be healing for all with accountability (Mingus 2022). A transformative justice question is by focusing response on: what do survivors and people who have caused harm need?

Campus Response

Universities and educational environments are an important site of prevention. However, current challenges have emerged on campuses despite Title IX resources and processes. These challenges have included:

- Inability to support students after the student transfers from another institution
- Difficulty of victim confidentiality; conflicts with mandated reporting
- Polyvictimization (i.e., stalking, domestic violence, sexual assault intersecting)
- Difficulties reporting
- Desire for institutional accountability
- International students are not entitled to the same support/benefits

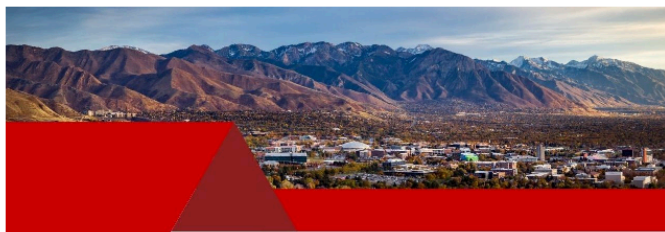
Although it appears that some institutions are on the decline with rape or fondling reporting, it is unclear if rape and other forms of assault are on the decline or if victims are not reporting. Additionally number of incidents is not indicative of campus severity – it only illuminates that reporting is occurring.

Campus programming in university settings during domestic violence awareness month (October) and sexual violence awareness month (April) has increased discussions about violence and in effect, campus reporting.



Table: Sexual Violence & Domestic Violence Racial Comparison

U of U	2018	2019	2020
Rape	19	30	31
Fondling	35	25	20
SUU	2018	2019	2020
Rape	4	7	6
Fondling	5	0	0
Weber	2018	2019	2020
Rape	19	12	4
Fondling	0	1	0
BYU	2018	2019	2020
Rape	--	--	14
Fondling	--	--	57
Utah Tech	2018	2019	2020
Rape	6	1	--
Fondling	2	0	--



"It really starts with society, right? So, up until this point, society has had a very victim-blaming point of view, especially with sexual assault, 'What was she wearing?', 'What was she doing?' 'What was she drinking?'

When it really comes down to people just shouldn't sexually assault other people, no matter what, right?

....

Everybody has had this belief ... whether you choose to take it is up to you, right? But when everybody around you believes that, it's hard...

So, then our police officers and our emergency room staff, and our EMS, and everybody else--our prosecutors and our detectives--maybe have that innate belief, that core belief that... 'they did something to have this inflicted on them.'

And so, it really comes down to ... education"

- Advocate

Violence prevention in the state of Utah encompasses a state-wide conference on domestic violence (organized by the Utah Domestic Violence Coalition in September or October (in collaboration with Utah Association of Domestic Violence Treatment), annual state-wide conference on sexual violence during the month of March (organized by UCASA), and an annual symposium on human trafficking organized by the University of Utah and the Utah Trafficking in Persons Task Force (in January). During the month of October DVAM (Domestic Violence Awareness Month) activities are ongoing throughout the month. Additionally, Sexual Assault Awareness Month has led to a robust amount of activities including most recently Denim Day at the Capitol Hill on April 27, 2022. And in 2021, Stop the Violence Utah was created to foster a state-wide campaign (<https://stoptheviolenceutah.org/>). State-wide coalitions, local nonprofits, academic institutions, continue to invest time and energy into organizing educational content on domestic violence, sexual violence and human trafficking. However, these endeavors are under resourced and education in primary education limited.

Primary education on domestic violence continues to put onerous on victims to affirmatively refuse, instead of teaching consent (Villarreal and Evelyn 2021). The primary need to foster more education and prevention is to fund these endeavors, support education and prevention in rural settings, provide more resources to organizations to staff prevention and education, foster relationships between community and organizations, and continue to make opportunities visible.

The priority areas for violence prevention in the state of Utah, based on needs:

- Increase funding to prevention efforts
- Increase awareness in rural communities
- Increase campaigns targeted at increasing survivor awareness
- Increase ins staff/providers dedicated to prevention and education efforts
- Build community partnerships to foster trust between organizations and the community's served.

## Recommendations

### Recommendation 1: increase monetary resources to respond to marginalized communities

Alaskan Native/American Indian, People of Color, LGBTQIA, immigrant, and people living with disabilities continue to experience being under-deserved. In order to support dynamic communities, have complex cultural, social, and linguistic needs, organizations need more resources to house, provide programming, offer culturally relevant services, and hire multilingual staff.

### Recommendation 2: Systematic data collection & centralized information sharing

Currently there is no centralized mechanism for data collection to track survivor needs overtime. Additionally, while there are coalitions that collect some information and reporting is required for DCFS funded entities, the public sharing of data to inform communities on progress and resourcing survivors is much needed. Resourcing the coalitions to hire staff to manage data and to share across coalitions in de-identified way will help not only support survivors, but also assist the various collectives in moving forward with a

response that is data driven.

### **Recommendation 3: Culturally aware responses and trauma-informed response**

There is a need to foster culturally aware and trauma-informed services and response. There are multiple promising models that it would benefit the state to invest in to respond to domestic violence, sexual violence and human trafficking. These models include: trauma-informed systems, housing first, human rights, theory driven responses (i.e., feminist multicultural / critical race theory / indigenous epistemologies), and community coalition and partnerships. What came through in the interviews and surveys is the need for translation and the strength of culturally responsive services.

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*Read the full report here.*

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# Gender-Based Violence as Structural Violence Among Sexual & Gender Minority Populations: Pilot Data from the University of Utah

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## Abstract

**Objectives:** To examine gender-based violence (GBV) against sexual and gender minority (SGM) women at the University of Utah as structural violence. A better understanding of GBV within SGM populations can improve prevention efforts and intervention, and advance further research.

**Methods:** This study utilized quantitative methods of data collection in the form a survey.

**Results:** This pilot study found that among University of Utah women responding to the survey (N = 211), bisexual women (n = 53) reported experiencing GBV at disproportionately higher rates than their heterosexual counterparts (n = 116) in the past 12 months (n = 14 [27%], n = 17 [15%] respectively). The most highly reported type of GBV were unwelcome sexual advances, gestures, comments, or jokes (n = 35 [71%], n = 52 [47%]), followed by being shown or sent explicit photos or videos (n = 15 [31%], n = 15 [13%]) among bisexual and heterosexual students, respectively.

**Conclusions:** SGM women are at greater risk of experiencing GBV, as they are subject to additional factors characteristic of their marginalization. These factors interact at individual, interpersonal, and structural levels, influencing key health outcomes among SGM women.

**Health Implications:** Approaching GBV against SGM women as an issue of structural violence can facilitate a more comprehensive understanding and enhance efforts to address gaps in existing services and resources. In doing so, the emotional, physical, and social

wellbeing of these marginalized populations can be improved.

## Introduction

Estimates indicate that 1 in 3 women worldwide will experience gender-based violence (GBV) in her lifetime.<sup>1</sup> Among women attending college, 26 percent of undergraduate and 10 percent of graduate students are targets of sexual assault and/or rape.<sup>2</sup> Heteronormativity is implicit in this statistic in the historically and current view that heterosexuality is assumptive for both agents and targets of GBV. GBV is “violence directed at an individual based on his or her biological sex or gender identity. It includes physical, sexual, verbal, emotional, and psychological abuse, threats, coercion, and economic or educational deprivation, whether occurring in public or private life.”<sup>3</sup> Women are more likely targets for GBV than men. In support of the idea that GBV as currently constructed is heteronormative, emerging data suggest that sexual and gender minority (SGM) women (e.g., bisexual, transgender, lesbian women) are at greater risk of experiencing GBV compared to their heterosexual counterparts. Some research has indicated that SGM women overall are 3.7 times more likely than heterosexual women to experience GBV.<sup>4</sup> Other research suggests that bisexual women are 1.8 to 2.6 times more likely to experience GBV than heterosexual women.<sup>5</sup> SGM women are also more likely to be targets of GBV by both women and men agents.<sup>5</sup> In this pilot mixed-methods study, we examined the incidence and experience of GBV for SGM women at the University of Utah (UU), the state’s flagship public institution.



Methods

This pilot project used quantitative data collection in the form of a survey open to university community members. The UU’s Institutional Review Board (IRB) approved the project. We present here a preliminary consideration of our findings.

Data Collection: Quantitative

The project began with the development of a quantitative data collection tool in REDCap, a research electronic data capture software, and took approximately 10 minutes to complete.<sup>6</sup> The survey was composed of 52 questions based on the Draft Instrument for MeasuringCampus Climate Related to Sexual Assault developed by the US Department of Justice<sup>7</sup> as well as on Utah’s Behavioral Risk Factor Surveillance System (UT-BRFSS).<sup>8</sup> Survey questions included items assessing sexual violence, eg, “In the past 12 months, has anyone HAD SEX with you or ATTEMPTED to have sex with you after you said or showed that you didn’t want them to or without your consent? (yes/no),” and intimate partner violence, eg, “During the past 12 months did an intimate partner push, hit, slap, kick, choke, or physically hurt you in any other way? (yes/no).”

Once the survey was constructed, we recruited participants from the UU from September to December 2020. We announced the study in a regular newsletter for medical and health students, staff, and faculty. We also distributed the survey link to colleagues in our professional networks at the UU and posted flyers at several campus locations. Due to the pandemic, the university was largely operating remotely at this time. Because student life was disrupted during this phase of the study, data collection was negatively impacted. The total number of survey respondents was 211.

Analysis

Descriptive and frequency data from the survey are included here to capture perceptions about GBV in a higher education setting from respondents who identify as women on a university campus.

Results

Table. 1 Top 3 Reported Types of Unwanted Sexual Contact

Last 12 Months	Bisexual		Heterosexual		Other Identities	
	n	%	n	%	n	%
1. Sexual advances, comments, jokes	35	71	52	47	9	53
2. Shown/sent sexual pictures, photos, or videos	15	31	15	13	1	6
3. Pressured to have sexual contact after saying no	9	18	12	11	2	13
Since Beginning of the Year 2020	Bisexual		Heterosexual		Other Identities	
	n	%	n	%	n	%
1. Sexual advances, comments, jokes	34	76	42	44	9	56
2. Shown/sent sexual pictures, photos, or videos	15	33	13	14	1	6
3. Flashed/exposed themselves to you	4	9	4	4	1	6

Note: “Other Identities” refers to participants who identified as lesbian/gay, pansexual, or another sexual orientation not listed.

Table 1 shows descriptive statistics for the top 3 reported types of GBV experienced by heterosexual and bisexual women in the last 12 months, with the start date falling between September and December 2019, depending on when the survey was completed in 2020. The top 3 reported types of unwanted sexual misconduct were (1) unwanted sexual advances, comments, and/or jokes, (2) shown/sent unwanted sexual pictures, photos, or videos, and (3) sexual contact after saying “no.” It is worth noting participants reported experiencing the same top 2 forms of GBV since the beginning of 2020. The third-most frequently reported type of GBV experienced since the beginning of 2020 was being “flashed or exposed themselves to you without your consent,” which was different than findings for the last 12 months. The change in the third-most reported type of unwanted sexual violence from being pressured to having sex to being flashed by others may give insight into how the COVID-19 pandemic impacted unwanted sexual contact.

Strengths & Limitations

The study is limited by its small sample size, for which there are several reasons. The study took place after the COVID-19 pandemic had begun, which made it difficult to recruit participants. The volatile topic of the study may also have contributed to lower participation. These factors possibly contributed to a sample size that

was not as robust as planned.

Responses to the survey gave us preliminary information about how SGM women experience GBV in a university setting. This data provides useful information for future studies. Additionally, we now have a better idea of how to recruit participants for our next study to allow for a larger sampling. Further exploration might examine how the COVID-19 pandemic has contributed to sexual and gender minority women’s experiences of gender-based violence. Qualitative methods of data collection may also yield substantial insights into these experiences.

Table 2. Sample Characteristics of Participants (N = 211)

Variable	n	%
<b>Sexual Orientation</b>		
Heterosexual	116	55
Bisexual	53	25.1
Gay/Lesbian	7	3.3
Pansexual	3	1.4
Not listed	7	3.3
Missing	25	11.8
<b>Race</b>		
American Indian or Alaskan Native	5	2.4
Asian	7	3.3
Black or African American	5	2.4
Native Hawaiian or Pacific Islander	1	.5
White	171	81
Something else not listed	6	2.8
Missing	16	7.6
<b>Biological Sex</b>		
Female	169	80.1
Male	16	7.6
Missing	26	12.3
<b>Gender Identity</b>		
Woman	169	80.1
Man	15	7.1
Another identity	2	.9
Missing	25	11.8

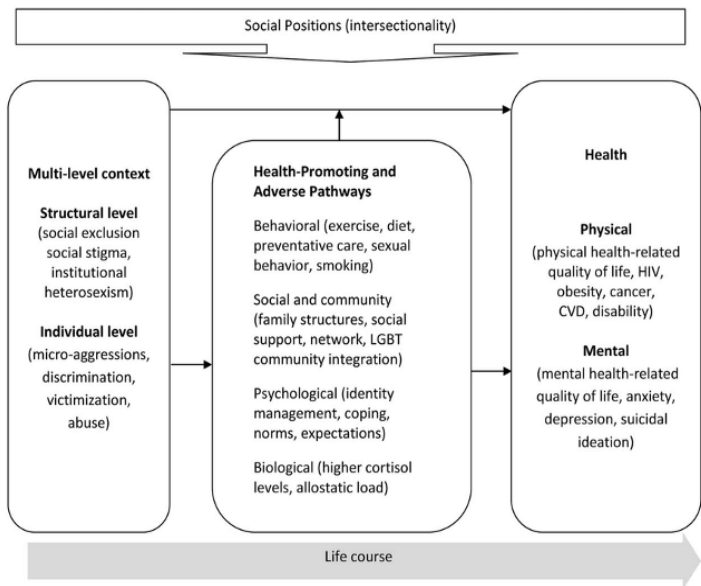
Discussion

Sample characteristics for the 211 participants who completed the survey are shown in Table 2. Only 19 percent identified as non-White, while just under 20 percent identified as non-female assigned at birth, with the same percentage identifying their gender identity as women. Due to the small number of participants identifying as gay/lesbian or pansexual (5%), our survey findings primarily provide insight into how heterosexual and bisexual White women experience GBV at the UU. Participants who identified as lesbian/gay, pansexual, or another sexual orientation not listed

in our survey were combined into “other identities” in Table 2.

Although it is easier to identify GBV at the individual level, GBV is an example of structural violence. In the effort to promote health equity for SGM populations, it is crucial to explore GBV against SGM women within the context of structural violence. Structural violence is defined as a “form of violence wherein some social structure or social institution may harm people by preventing them from meeting their basic needs.”<sup>9</sup> The Health Equity Promotion Model (HEPM) (see Figure 1)<sup>10</sup> provides a useful framework for understanding how GBV structural and individual factors interact to influence key mental and physical health outcomes among SGM women.

Figure 1.



Reflecting the existing literature,<sup>11</sup> our findings suggest that rates of GBV among bisexual women in Utah are higher than in heterosexual, cisgender populations. While heterosexual and cisgender women face many of the same risk factors for experiencing GBV, SGM women are subject to additional factors characteristic of their marginalization, such as discrimination, identity concealment, and social stigma.<sup>10, 11</sup> These stressors manifest and interact at structural levels, such as heterosexism, and individual and interpersonal levels, including targeting because of one’s non-heterosexual and/or non-cisgender identities. Such a cascade contributes to the greater likelihood that SGM women experience GBV and feel discouraged from seeking assistance.<sup>12</sup>

We typically examine GBV through a heteronormative perspective, depicting (heterosexual) men as perpetrators and (heterosexual) women as victims. Heteronormative assumptions about GBV are sustained at the structural level through institutional heterosexism.<sup>12</sup> Other structural elements manifest in the form of widespread social conditions and attitudes, such as stigma, exclusion, and erasure of SGM identities.<sup>12</sup>

Even if an individual knows cognitively that anyone can perpetrate or experience GBV regardless of their gender or sexual orientation, the occurrence of such can be difficult to identify if GBV is only recognized and validated in heterosexual, cisgender relationships. The lack of awareness regarding GBV against SGM populations is an ongoing, structural issue in terms of both the relevant literature and within the larger cultural consciousness. This results in GBV against SGM going both unnoticed and unaddressed, thereby further perpetuating the myth that it does not exist and simultaneously worsening its effects.

Positioning GBV against SGM women as an issue of structural violence invites opportunities for greater mobilization. Considering the various structural elements that contribute to GBV allows for exploration and acceptance of one's personal responsibility for a societal issue. It also draws attention to shifting gender norms, the need for education about GBV in SGM populations, and the empowerment of girls and women across the lifespan. In this way, every person can take part in changing the environment to prevent GBV.

## Health Implications

GBV manifests structurally via individual, social, and political attitudes and conditions. For example, legal definitions of GBV, discrimination from service providers, and a dearth of LGBTQ+ specific resources result in fewer avenues for justice for SGM women.<sup>5</sup> Current states' legal definitions about domestic violence—a form of GBV—that exclude same-sex couples impede victim/survivor ability to pursue legal remedies.<sup>5</sup> When GBV occurs in same-gender relationships and the individuals involved are of similar stature, police tend to assume equivalent power dynamics in the relationship, and all too often they arrest both parties, known as dual arrest.<sup>13</sup> When the GBV incident involves physical violence, the dual arrest paradigm may

preclude the actual target being able to access protections available through statute, while the GBV agent may use the dual arrest to attempt to convince the GBV target that they are also culpable for the violence. Such a dynamic may support and propagate a continuing cycle of GBV in SGM relationships.

One reason bisexual women may be at greater risk for GBV, and less likely to reach out subsequent to being targeted, is fear of disclosing their sexual orientation. Long-term concealment of sexual orientation has been linked to increased risk for depression and chronic health conditions.<sup>14</sup> GBV is associated with a myriad of poor physical and mental health outcomes, including depression, post traumatic stress disorder, chronic illness, and sleep disorders.<sup>15, 16</sup> This links to 2 of the 7 domains of health: mental and physical health.<sup>17</sup> The intersection of these 2 dynamics (identity concealment, poorer mental and physical health) may in part explain the disparately high rates of GBV that bisexual women experience. The top 2 reported types of GBV experienced at the college level by both bisexual and heterosexual participants were unwelcome sexual advances, gestures, comments, or jokes, and receiving unwanted sexual pictures, photos, or videos. This finding indicates that bisexual and heterosexual women in college may experience similar, specific types of GBV, and it highlights an opportunity for universities to develop resources aimed at addressing them. It is critical to keep the ubiquity of the experience in mind when developing resources and support on university campuses, as repeated university-wide announcements about specific incidences of GBV can contribute to secondary trauma. While inadvertent, such messaging can act to perpetuate GBV at an institutional level.

It is also important to consider the lack of resources and avenues for justice for those who experience technological forms of GBV. This absence is significant, as technological forms of GBV (such as the sharing of explicit photos without consent) can have severe, lasting consequences for the affected individual, especially SGM.<sup>18</sup> The victim-survivor may suffer great impacts to their psychological and emotional wellbeing; such impacts may be compounded if assistance for GBV does not recognize or competently address violence enacted through digital means. Certain types of technological GBV have impeded the victim-survivor's ability to maintain employment, thereby affecting their financial health and stability.<sup>11</sup>

Continued research is necessary to gain a better understanding of GBV against SGM women as an issue of structural violence. Identifying other structural elements contributing to GBV can enhance efforts to

address gaps in existing services and provide more comprehensive, competent resources for SGM populations.

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# Opportunities in Mixed Method Health Literacy Research Among Hispanic Women in Utah

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## Problem Statement

National and local news cycles often highlight health-related disparities of the Hispanic community. Underlying many of the reports is the important concept and impact of health literacy. Health literacy becomes important for caregivers and/or patients when faced with a situation that requires the ability to find, understand, and use health information and services. Health literacy among Hispanic women is particularly important to highlight because of the lack of available data and impact Low Health Literacy (LHL) can have on individuals and family units. Due to limited research literature regarding the Hispanic women population in Utah, information regarding health literacy needs and barriers is most likely inferred from larger studies or not available on open-source research systems. This commentary is meant to describe a problem while also promoting open-sourced mixed method research as a solution. Additionally, it is important to highlight the need for multidisciplinary collaboration in pursuance of innovative solutions to address the health literacy needs of Hispanic women in Utah.

## Status of Literature

There is a known fluctuation of health literacy among individuals who are able to read well and are comfortable using numbers.<sup>1,2</sup> Within the United States, researchers estimate limited English language proficiency among the Spanish speaking population, anywhere between 30– 51%<sup>3</sup>, Utah specific numbers are not conclusive at this time. Difficulties arise in situations where the caregiver and/or patient is not familiar with medical terms, how their body works, is unable

to interpret statistics, and evaluate risks and benefits of treatment.<sup>1</sup> Additionally, when faced with a with a serious diagnosis or illness, individuals with LHL may feel scared or confused during their healthcare experience.<sup>1</sup> LHL puts Hispanic immigrants at a higher risk for low or no access to healthcare and healthcare services.<sup>4,5</sup> Researchers believe this is due to a number of number of possible barriers such as low education levels, low English proficiency and/ or non-citizenship status which leaves Hispanic patients to assume they are ineligible for U.S. healthcare services, fear stigma, or deportation.<sup>5</sup> Researchers also postulate LHL leads to difficulties interpreting spoken or written information<sup>6</sup> which instigates outcomes such as high rates of return emergency room visits<sup>6,7</sup>, low medication adherence<sup>8</sup>, and misunderstanding of health insurance<sup>9</sup>.

Specifically within the Hispanic women community, researchers are concerned with LHL in association with chronic diseases such as cardiovascular disease and diabetes<sup>7,10</sup>. Past research suggests U.S. born Hispanic women are less likely to access mental health services, due to a persistent stigma in relation to mental health services and lack of health information understanding.<sup>11</sup> Similar reports exist for other medical services.<sup>4</sup> Utah-specific evaluation of LHL, health outcomes and women is available, but remains difficult to find via open-source search engines, data banks and journals.

## Call to Action

Promoting health literacy among Hispanic women may seem difficult, but interventions such as community-based health education programs have proven

effective in the past.<sup>4,5</sup> Utah-based research is needed in order to understand where and what health literacy interventions could be used to increase health literacy rates among Utah Hispanic women. Currently there is limited open-sourced information available regarding health literacy among Hispanic women in Utah. Researchers concur that in order to improve health literacy among Hispanics further research is needed to better identify and explain health literacy gaps.<sup>4,5,7,10,12</sup> Mixed method research is potentially a solution.<sup>5,10</sup> Specifically, after a systematic review of 77 Hispanic population-related studies the following topics were recommended as areas of possible mixed method research opportunities: 1. The influence of acculturation on migrant health ; 2. The role of informal (e.g., family) vs. formal (e.g. promotoras) social support in

facilitating health care access; 3. The “Hispanic mortality paradox”; 4. Traditional healing and medicine among Hispanic immigrants.<sup>5</sup>

Along with academic research efforts to improve health literacy among Hispanic women, efforts within community structures and systems are also needed. The Center for Disease Control and Prevention promotes a multidisciplinary and collaborative approach known as “Health in All Policies” in order to integrate and articulate health considerations into policymaking decisions.<sup>13</sup> Health researchers investigating Hispanic health literacy also ask for consideration of comprehensive health and immigration reforms that respect the human right of Hispanic immigrants to gain access to health care.<sup>5</sup>

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# Anxiety Symptoms and Severity among Perinatal Women Screened for Depression with the Edinburgh Postnatal Depression Scale

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## Abstract

**Objectives:** Describe the prevalence of anxiety among perinatal women screened with the Edinburgh Postnatal Depression Scale (EPDS) and identify the proportion of women screening positive for depression only, anxiety only, and co-occurring anxiety/depression.

**Methods:** Routine screening for depression was offered to all clients at 5 rural Utah public health department clinics. The online EPDS screening was completed electronically at the clinic or on a smartphone or computer. The 3-question subscale within the EPDS provided a preliminary screen for anxiety.

**Results:** A total of 2008 completed the EPDS. The EPDS anxiety sub-scale had good reliability ( $\alpha = 0.841$ ). A total of 761 women screened positive on the EPDS scale (37.6%) and 516 screened positive on the anxiety sub-scale (25.7%). Among those with a positive EPDS score, 494 had co-occurring anxiety symptoms (64.9%), and 267 had depression symptoms alone (35.1%). Among those with a positive screen on the anxiety subscale, 22 had a negative overall EPDS score (4.3%). The difference in the proportion of Latinx women screening positive for anxiety  $n = 72$  (21.0%) compared with non-Latinx women  $n = 411$  (26.7%) was statistically significant.

**Conclusions:** Most women who screen positive on the EPDS also screen positive on the anxiety sub-scale. Among those with a positive anxiety screen, approximately 1 in 20 would have been missed based on their total EPDS score.

**Implications:** To provide more comprehensive perina-

tal mental health screening and subsequent care, it is helpful to consider the total EPDS score as well as the anxiety sub-scale.

## Introduction

Perinatal anxiety (PA) is a common feature of perinatal mood disorders and often co-occurs with perinatal depression, with 1 in 5 of women experiencing anxiety during pregnancy or postpartum.<sup>1</sup> Perinatal depression (PD) is one of the most common complications of pregnancy, occurring in approximately 1 in 7 pregnant women and in approximately 1 in 5 postpartum women. PD and anxiety are highly comorbid.<sup>2</sup> High rates of anxiety disorders among women with depression during the perinatal period have been documented.<sup>2-5</sup>

Screening perinatal women for depression is increasingly common, while a concurrent focus on identifying anxiety is less common. This is likely due to a lack of screening tools specific to perinatal anxiety (PA), despite the importance.<sup>1</sup> The Edinburgh Postnatal Depression Scale (EPDS) is a well-validated and widely-used screening tool for depression during the perinatal period.<sup>6</sup> The EPDS contains a 3-question anxiety subscale called EPDS-3A. Despite its availability and use, providers rarely evaluate the EPDS anxiety sub-scale scores independently due to limited studies, as well as mixed results of the validity of EPDS-3A in detecting perinatal anxiety.<sup>7</sup> However, identifying women with perinatal anxiety alone or co-occurring with perinatal depression is important in order to provide optimal care, as evidence-based approaches to treating women with anxiety and those with

co-occurring depression/anxiety can differ from the approaches for addressing depression alone, including pharmacological treatment.<sup>8,9</sup> Anxiety and depression are not identical emotional states, with anxiety being more associated with a future orientation and depression being more associated with past orientation.<sup>10</sup> Thus, a more precise understanding of perinatal women's mental health status will facilitate optimal care. The purpose of this study is to describe the prevalence of anxiety among perinatal Utah women screened with the EPDS and to identify the proportion of women screening positive for depression only, anxiety only, and co-occurring anxiety and depression.

Methods

Routine screening for perinatal depression was offered to all pregnant and postpartum individuals receiving services (e.g., immunizations, WIC- Women, Infants, and Children food supplement program certification) at public health clinics in five rural public health districts in Utah, including Central, Southeast, Southwest, San Juan, and Tooele. This study was approved by the Institutional Review Board at the University of Utah (IRB\_00071041) and funded by the Utah Department of Health. The EPDS screenings were primarily completed during WIC certification clinic visits via an electronic tablet and the REDCap data management system survey tool. The EPDS survey was also available via a survey link, to be completed later at a time more convenient for clients. Women took the English-language survey at the public health clinic or used the survey link provided by the clinic to complete the survey later on their own device.

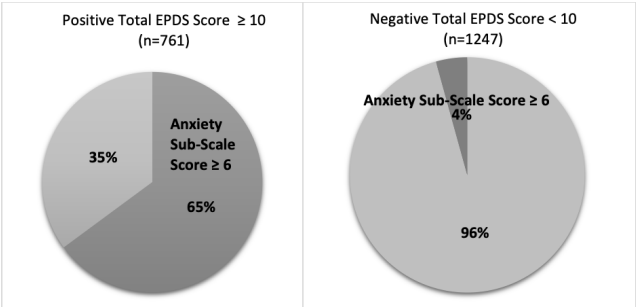
In addition to the EPDS screening tool, the REDCap survey included demographic questions, e.g., the individual's age, gestational age or postpartum weeks, ethnicity, language preference, insurance type, location of clinic, and race. Each item of the EPDS was rated on a 0 (No, never; No, not at all) to 3 (Yes, most of the time; very often; quite a lot) rating scale. A cutoff value of 11 on the EPDS has a sensitivity of 0.81 (0.75, 0.87 95% CI) and specificity of 0.88 (0.85, 0.91) to detect perinatal depression.<sup>11</sup> However, for this study, a cutoff value of 9 on the EPDS was selected to capture the greatest number of women with perinatal depression and anxiety, inclusive of mild symptomatology.<sup>11</sup>

The anxiety subscale (EPDS-3A) analyzes a latent construct found in responses to 3 questions in the EPDS instrument. The EPDS-3A sum of responses ranges from 0 to 9 with a cut off score of 6 suggesting symptoms of anxiety, and is unique from overall EPDS scores among childbearing women.<sup>12</sup> Factor analysis of the EPDS suggests potential value as a multi-dimensional tool, with three items forming a subscale measure for symptoms of anxiety: including *I have blamed myself unnecessarily when things went wrong, I have been anxious or worried for no good reason, I have felt scared or panicky for no good reason.*<sup>13</sup> The EPDS takes less than 5 minutes to complete.

Results

A total of 2,008 women completed the EPDS screening between 2018-2020 and had complete data on the anxiety sub-scale (9 women had missing data on the subscale and were excluded from analysis). The population demographics are shown in Table 1. The EPDS total scale had excellent reliability ( $\alpha = 0.915$ ) while the anxiety sub-scale had good reliability ( $\alpha = 0.836$ ). Of the 2,008 women screened, 37.9% of women (N=761) screened positive for perinatal depression and 25.7% (N=516) screened positive on the EPDS anxiety sub-scale. Among the women who scored positive on the overall EPDS scale, 64.9% also scored positive on the EPDS anxiety sub-scale (see Figure 1). A total of 267 scored positive on EPDS overall but negative on the EPDS anxiety sub-scale (35.1%). Also, a total of 22 individuals scored positive on the EPDS anxiety sub-scale (4.3%) despite having a total EPDS of less than 10 (see Figure 1).

Figure 1: Edinburgh Postnatal Depression Scale (EPDS) Overall Scores and Proportion with Positive Anxiety Subscale



Out of 2008 women screened, 761 (37.9%) screened positive (≥ 10) on the EPDS tool. Among all individuals who scored positive on the EPDS tool, 65% also scored positive on the anxiety sub-scale (≥ 6). Among the 1247 individuals who screened negative on the EPDS, 49 (4%) screened positive on the anxiety subscale. In other words, 4% of women with anxiety alone would be missed if the only consideration is the total score of the EPDS.

We were also interested in evaluating any association between screening scores and ethnicity. Of the women that answered the ethnicity question (n=1,885), a lower proportion of Latinx women screened positive for EPDS overall (32.9%) compared with non-Latinx women (38.8%),  $\chi^2(1) = 4.157, p = 0.04$ . Similarly, the proportions of women screening positive for anxiety overall was lower among Latinx women (21.0%) compared with non-Latinx women (26.7%),  $\chi^2(1) = 4.721, p = 0.03$ .

Table 1 Demographics Table

Demographic Table		N =	
		2008	%
Age	Mean+-SD	26.3±5.9	
	Median (min, max)	26 [14, 57]	
Missing		58	
Age	Less than 24	856	42.6
	25 - 34	879	43.8
	35 - 44	210	10.5
	45 or older	5	0.2
	Missing	58	2.9
Pregnancy Status	Pregnant	594	29.6
	Postpartum	1033	51.4
Marital Status	Missing	381	19
	Single	673	33.5
	Married	927	46.2
	Living with Partner	334	16.6
	Divorced	55	2.7
Insurance type	Widowed	6	0.3
	Missing	13	0.6
	None	269	13.4
	Medicaid	1232	61.4
	Private/Group	370	18.4
Race	Other	123	6.1
	Missing	14	0.7
	American Indian or Alaskan Native	265	13.2
	Asian	12	0.6
	Black or African American	19	0.9
	Native Hawaiian or Other Pacific Islander	28	1.4
	White	1474	73.4
	From multiple races	50	2.5
	Prefer not to answer	15	0.7
	Missing	92	4.6
	Unknown	53	2.6

Discussion

More than 1 in 3 women in the study screened positive for perinatal depression based on their overall EPDS score, and more than 1 in 4 had a positive screen on the EPDS anxiety sub-scale. Approximately two-thirds of women with a positive overall screen also had a positive anxiety sub-scale. Use of the EPDS 3A as well as the Hospital Anxiety and Depression Scale (HADS-A) to identify women with anxiety during late pregnancy,

and at 2 to 4 months postpartum, demonstrates that 28% of new mothers exhibit anxiety symptoms.<sup>16</sup> This is comparable to the prevalence of anxiety symptoms found in our study.

Among all women who screened positive on the anxiety sub-scale in the current study, approximately 4% would have been missed based on their total EPDS score (<9), indicating no symptoms of depression. This result is aligned with the work of Lautarescu et al., (2022) who found that between 1.9% to 3.38% of women with perinatal anxiety symptoms may have been missed because their total EPDS screen was negative (<13).<sup>15</sup> Another study found that the EPDS 3A identified an additional 2.5% of anxiety cases that would not have been detected using the total EPDS score alone.<sup>7</sup>

Studies suggest effectiveness in using the EPDS for detecting anxiety using the sub-scale. Smith-Nielsen et al. (2021) found that an EPDS 3A of over five was optimal for identifying anxiety (sensitivity: 70.9; specificity: 92.2; AUC: 0.926).<sup>7</sup> The authors concluded that the EPDS anxiety subscale may be a time-efficient screening tool for perinatal anxiety and can be used to identify both anxiety and depression.<sup>7</sup> Loyal et al. (2020) reported that the EPDS 3A has good internal consistency which is greater than or equal to 0.70. Furthermore, it was reported that the overall EPDS score was more strongly associated with the 3A anxiety scores than with the HADS-A anxiety scores, although the study concludes that further studies are needed to evaluate its validity during pregnancy. To assess validity of a 4-item EPDS anxiety subscale by comparing it to the Spielberger State-Trait Anxiety Inventory (STAI-6), van der Zee-van den Berg et al. (2019) included items 3,4,5, and 10 of the EPDS instrument, and reached a conclusion that the 4-item subscale does not provide adequate screening for anxiety compared to the STAI-6 in a community sample of postpartum women. They also concluded that the 4-item subscale may not allow discrimination between depression and anxiety compared to the STAI-6.<sup>17</sup> This finding is in alignment with our findings that the majority of women with symptoms of depression also had anxiety symptoms, while a small number were experiencing only anxiety symptoms without depression.

It is clear that perinatal women suffer from both anxiety and depression, and identifying women with each condition, as well as those with co-occurring anxiety

and depression, will help providers tailor care, interventions, and guidance to meet each individual's unique needs. Perinatal anxiety and depression are often treated with similar interventions, such as selective serotonin reuptake inhibitors and cognitive behavioral therapy, but women may need different resources and reassurance if they are experiencing both conditions, or experiencing anxiety alone.<sup>18</sup>

Our findings that non-Latinx women have higher rates of positive overall EPDS screens and anxiety sub-scale screens than Latinx women is aligned with the study of de la Rosa et al. (2021) reporting Latinx women were significantly less likely to report an EPDS score of 10 or above (8.6%) than non-Latinx women (20.5%).<sup>19</sup> Hartley et al., (2014) recommend using the total EPDS score and EPDS-3A to identify PD and PA in Latinx women but also recommend further validation studies.<sup>20</sup> In contrast, Liu & Tronic (2012) found that Latinx women experience higher levels of postpartum depressive symptoms than non-Hispanic white women.<sup>21</sup> Some studies suggest that stigma and social acceptability, as well as low rates of seeking care, are contributors to the differences in the documented diagnosis of depression among Latinx women, despite of the number of reliable screenings to detect PD.<sup>23</sup> Further studies are required to assess the meaning of lower score of EPDS in Latinx women compared to non-Latinx women. Our screening questions were only in English, which means findings may not be generalizable to Latinx women who do not speak English.

The strengths of our study include a large sample size and use of the EPDS, a widely used screening tool in healthcare settings. Limitations of the study include lack of an anxiety-specific comparison tool administered alongside the EPDS 3A subscale, such as the GAD-7. Additionally, study findings may not be generalizable to all perinatal women, as individuals completing the screening were all rural residents who

were visiting public health clinics that largely provide services to an underserved population. Future research comparing the EPDS-3A to other validated, reliable anxiety scales such as the GAD-7 is warranted. Furthermore, future studies could include evaluation of differences between Latinx and non-Latinx childbearing women, to better understand discrepancies.

## Health Implications

Consideration of the total EPDS score as well as scores on the anxiety sub-scale (or screening for both anxiety and depression with two separate scales) is important in providing more comprehensive perinatal mental health screening and care with appropriate guidance and resources. There is a high occurrence of PD and PA, and the EPDS is an efficient tool to screen and treat both anxiety and depression. However, future studies are required to assess validity of EPDS-3A compared to other anxiety scales. Utilizing the EPDS-3A can be a first step to identify the risk of perinatal anxiety and to initiate discussion about further screening or treatments of the symptoms. While more research will be required, the EPDS-3A sub-scale may be an efficient way to screen patients for anxiety at the same time as screening for depression, using only one screening tool.

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# The Hand that Rocks the Cradle Cannot Read this Title:

## The Multi-Generational Effect of Illiteracy in the Lives of Black American Women

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### Problem Statement

In this commentary we will discuss the multi-generational effects of illiteracy for Black women and their children in the US, including financial and health literacy, intellectual challenges, social costs across generations, and the elements of discrimination that negatively impact their ability to access help and find success. In the US in 2020, the female literacy rate was 53.7 percent, which was 21.6 percent lower than the male literacy rate of 75.3 percent. When women with limited education, which is tied to illiteracy, become mothers, their children tend to experience lower levels of cognitive and socio-emotional functioning and academic achievement. They experience less success, both in school and later as adults in the workforce.<sup>1</sup>

The National Assessment of Educational Progress (NAEP) reported 85 percent of Black students in eighth grade lack proficiency in mathematics and reading skills.<sup>2</sup> The ability to read and write affects every single aspect of our lives, from the way we work to the food we eat:

*Illiteracy has a far-reaching impact on women who are not proficient in the areas of prose literacy (the ability to read instruction materials, brochures, news stories), document literacy (the ability to read and comprehend job applications, maps, payroll forms, schedules), and quantitative literacy (the ability to balance a check-book, figure out a tip, determine interest rate). (4)<sup>3</sup>*

We will show the aspects of discrimination that hinder women from achieving literacy, and how reading and writing are used to create a foundation for living a creative, independent, and critically aware life.<sup>4</sup>

### Status of Literature

Created in 1972, Title IX states that “no person in the United States shall, on the basis of sex, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any education program or activity receiving Federal financial assistance.”<sup>5</sup> Title IX was meant to enact systemic change in the intellectual and creative aspects of young women’s education but sadly it has not achieved what it was created to do. This failure continues to impact generations, particularly among Black women.

The tie between illiteracy and lack of financial independence for Black women reveals complex social problems in the profiles of incarcerated Black women. These are likely to be young, low-literate, poorly skilled, and undereducated single mothers, who are unprepared for employment that pays a living wage. Often, they are survivors of physical and sexual abuse, have substance abuse problems, possess multiple physical and mental health problems, and are convicted primarily of drug-related charges.<sup>3</sup>

The literature highlights that Black women who do not achieve the foundational literacy skills through our public educational system in their youth have less opportunity for intellectual advancement, creating a vulnerable multi-generational situation for women when they become mothers and cannot help their own children to learn to read and write.<sup>6</sup> Children of adults with low literacy will likely (72%) have even lower literacy skills.<sup>7</sup> Education journalist Natalie Wexler emphasized that “Literacy needs its own focus because reading is the gatekeeper to functioning and succeeding academically, professionally, and civically.

It underlies access to virtually all knowledge.”<sup>2</sup>

## Call to Action

The US educational systems must effectively educate its citizens and respond to the aftermath of systemic racist and sexist policy in educational institutions, which have resulted in a dis-investment in Black women’s education. Illiteracy can cost the US nearly \$225 billion in workforce productivity loss and results in expenses for federal and state welfare programs.<sup>8</sup> Transformative measures must be implemented in policy to cascade changes.

Dual-generation strategies draw from findings that the wellbeing of parents is vital to their child’s socio-emotional and cognitive intelligence.<sup>9</sup> “The three key components are 1) high-quality early childhood education, 2) job training for mothers that leads to a credential for high-wage/high-demand jobs and 3) family/peer support services” (4).<sup>1</sup>

Many existing programs such as Head Start, a federal program that promotes school readiness of children from low-income families, the Workforce Investment

Act, and the Higher Education Act “could be blended with state and local funding to create new dual-generational programs” (16).<sup>1</sup> An example of this includes Community Action Project (CAP) Tulsa’s Career Advance program, where parents of children in Head Start are recruited for post-secondary education and workforce training.<sup>9</sup> In urban communities, places such as public libraries, resource centers, healthcare clinics, churches, and employment centers could all promote or create resources for low-education women and their developing children. For example, the national Jeremiah Program operates out of 7 urban locations and provides early childhood education for children and life-skills training to single mothers.<sup>9</sup>

Positive educational experiences act as protective factors for young women and girls of color growing up in adverse or oppressive environments. Efforts to create intellectually stimulating and creative enrichment among young Black students must include integrating Black, Brown, and Indigenous people’s stories, and culture into educational spaces, as well as exploring alternate forms of expression and thought processing through poetry, spoken word, art, story, theater, dance, film, etc.<sup>4</sup>

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# Postpartum Checkups in Utah: An Analysis of 2012-2020 Utah Pregnancy Risk Assessment Monitoring System (PRAMS) Data

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## Background

Approximately 700 women die each year from pregnancy-related complications in the United States. About one in three maternal deaths happen between one week and one year postpartum. Most of these deaths are preventable, and closing the gaps in access to quality care can help.<sup>1</sup> Postpartum healthcare occurs during the first six weeks after childbirth and examines various aspects of maternal health, including physical, mental, and emotional.<sup>2</sup> Many women experience various physical discomforts, including increased rates of fatigue,<sup>3</sup> increased backaches and headaches,<sup>4</sup> sleep disorders, and bowel disorders.<sup>3</sup> Becoming a mother can sometimes provoke mental and emotional distress, often becoming too severe and resulting in postpartum depression.<sup>5</sup> The lack of postpartum follow-up can sometimes leave many diseases undiagnosed, often leading to postpartum death. Postpartum death can also occur due to severe bleeding, high blood pressure, infection, and cardiomyopathy.

Postpartum visits allow healthcare providers to screen for maternal emotional health, facilitate breastfeeding, monitor the newborn's growth and overall health, counsel women about family planning, and refer mother and baby to additional services.<sup>6</sup> These visits become critical in maintaining maternal and neonatal health. This review aims to assess the prevalence of postpartum care and identify the demographics of the women who miss their postpartum checkups in Utah.

## Methods

We used 2012-2020 data for women for the Utah Pregnancy Risk Assessment Monitoring System (PRAMS)

via the IBIS-PH interactive query system to investigate postpartum care in Utah. PRAMS is an ongoing, population-based surveillance project coordinated by the Centers for Disease Control and Prevention (CDC). Utah is one of 47 states that collect PRAMS data annually with the intent to monitor maternal and child health indicators. Each month, approximately 200 new mothers are randomly selected for participation using Utah birth certificates. Data is collected by following a protocol developed by the CDC that utilizes mail and telephone questionnaires, and approximately 60% of randomly-selected new mothers respond to the surveys. The responses are weighted to represent all women who have live births in Utah.<sup>7</sup>

Missed postpartum appointments served as the outcome of interest. This outcome was assessed via the question, "Since your new baby was born, have you had a postpartum checkup for yourself?" The response to this question was binary (yes/no). The demographics available to us through the PRAMS data were age, race, education, income, previous live births, marital status, ethnicity, and insurance status. Age was separated into 7 different categories: 0-17, 18-19, 20-24, 25-29, 30-34, 35-39, 40+). Parity was divided into three categories: no prior live births, 1-4 prior live births, and 5+ live births. Race was dichotomized into White and non-White participants, and education was divided into less than high school, high school, some college, or college graduate. Prevalence of missed checkups and 95% confidence intervals were reported. The data reported through IBIS-PH considered weighted stratified sampling used by PRAMS.

## Results

12,814 women, with a yearly range of 1,232 to 1,698, participated in UT-PRAMS from 2012 to 2020. Out of these women, in 2020, 11.14% (CI 9.4 -13.16%) of women did not attend their postpartum checkups. The rate of women without a postpartum check had declined steadily from 10.22% in 2014 to 7.97% in 2019. The 2020 rate of 11.14% is the highest recorded (Table 1).

Figure 1 shows the prevalence of not receiving postpartum care among non-White women in Utah is much higher than White women. It ranges from 9.65% in 2016 (CI 5.1% - 15.4%) to 21.19% in 2014 (16.11% - 27.35) of women identifying as non-White not receiving postpartum care. In 2020, 9.78% of White mothers

(CI 8.0 - 11.9%) did not have a postpartum checkup compared to 19.04% of non-White mothers (CI 13.52 - 26.14%).

Women who did not receive postpartum care tended to have lower education levels (Figure 3). Between 2012 and 2020, women with less than a high school education contributed to 51.6% of those who did not receive postpartum care. In 2020, 34.03% of mothers with less than high school education, 13.8% with high school education, 10.92% with some college, and 5.55% with college degrees did not have a postpartum visit. Table 2 shows the prevalence of missed postpartum checkups based on the demographics provided by IBIS-PH.

Year	Postpartum checkup (2009 and later)	Confidence Bounds - Lower Limit	Confidence Bounds - Upper Limit	Number of Responses	Relative Standard Error (Coefficient of Variation %)
2012	10.64	9.04	12.49	222	8.25
2013	9.01	7.52	10.76	179	9.13
2014	10.22	8.6	12.11	173	8.73
2015	9.93	8.28	11.88	180	9.23
2016	9.71	8.07	11.63	158	9.33
2017	8.79	7.19	10.69	154	10.11
2018	8.62	7.03	10.53	137	10.3
2019	7.97	6.47	9.79	141	10.56
2020	11.14	9.4	13.16	170	8.59
Overall	9.57	9.01	10.16	1,514	3.06

Table 1: Rate of Insufficient Postpartum Care (From 2012) by Year

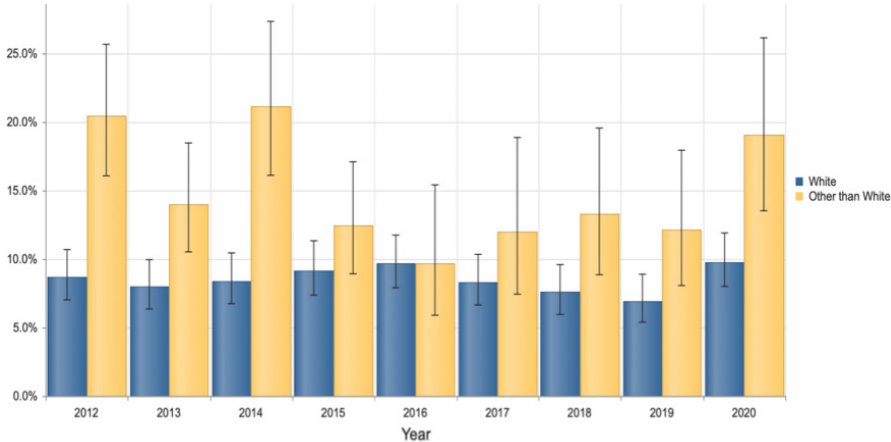


Figure 1: Rate of Insufficient Postpartum Care (From 2012) by Race and Year

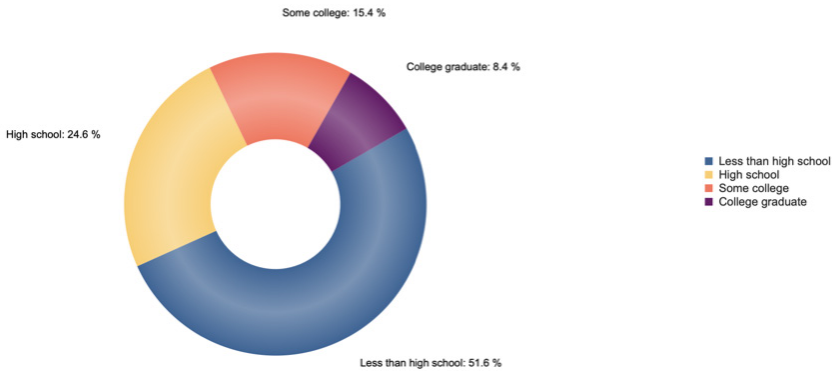


Figure 2: Education Distribution Amongst Women Not Receiving Postpartum Care (From 2012)

Table 2. Demographics of Postpartum Care Users in Utah (PRAMS 2012 and later)

Characteristic	Not Receiving Postpartum Care	95% CI
Age		
0-17	16.15	11.07- 22.96
18-19	19.12	15.52-23.33
20-24	11.19	9.94-12.59
25-29	8.49	7.57-9.51
30-34	9.08	8.01-10.29
35-39	8.08	6.69-9.73
40+	10.52	7.2-15.12
Race		
White	8.51	7.92-9.15
Other than White	15.21	13.6- 16.96
Education		
Less than high school	27.13	25.01-29.36
High school	12.92	11.77-14.17
Some college	8.1	7.04-9.3
College graduate	4.42	3.67-5.3
Income		
<100% FPL	17.87	16.29-19.56
101-138% FPL	13.66	11.63-15.97
139-185% FPL	9.79	8.18-11.67
>185% FPL	5.65	5.03 - 6.34
Number of Previous Live Births		
1-4	10.64	9.89-11.44
5 or more	14.4	11.12-18.45
None	7.07	6.27-7.96
Marital Status		
Married	7.7	7.12- 8.33
Unmarried	18.33	16.74- 20.04
Hispanic Status		
Non-Hispanic	7.89	7.28- 8.53
Hispanic	18.76	17.14-20.51
Insurance		
No insurance	20.51	18.69-22.45
Medicaid	16.05	13.89-18.46
Private	6.48	5.89-7.13
Other Insurance	7.57	5.4-10.52

## Conclusion

The data snapshot of Utah PRAMS from 2012-2020 reveals increases in postpartum care for multiple demographic categories between 2012 and 2019 until a decrease in 2020. In general, women who did not receive postpartum care were younger, less educated, unmarried, underinsured, lower-income, and have more children than women who receive postpartum care. This review examined the demographics of women who were more

likely to miss a postpartum checkup. Determining these demographics can help target future interventions to increase postpartum care. The social determinants of health, such as age, race, insurance type, education, and income, play a significant role in whether a woman will attend her postpartum checkup, as previous studies have shown.<sup>8,9</sup> Postpartum care touches on all seven health domains while emphasizing physical, social, and emotional health.

Women under 20 years old were less likely to attend postpartum checkups, as shown in our data snapshot and other studies.<sup>10</sup> Wilcox et al. suggests that rates of postpartum depression are higher among adolescents.<sup>8</sup> Still, because these women are more likely to miss their checkups, providers are less likely to identify and treat the symptoms. Others mention that postpartum depression does not occur immediately after discharge, so rapid screening becomes ineffective and long-term postpartum care is necessary.<sup>11</sup> Sober et al. examined adolescent pregnancies and found that two-thirds of the teens felt they became pregnant ‘too soon.’<sup>12</sup> Creating programs emphasizing family planning and contraceptive usage can help delay unwanted childbearing in adolescents.

Barriers to postpartum-care access play a role in postpartum checkup appearances. Women with Medicaid or without insurance, and those who live below the federal poverty level, are less likely to attend postpartum checkups. Currently, Utah Medicaid participants only have up to 60 days of postpartum coverage, which would not be sufficient to be able to diagnose and treat particular mental, physical, or emotional distresses.<sup>13</sup> Our findings correspond with national data on other states that have not approved Medicaid expansion. These individuals are less likely to gain access to a provider, or paying for a checkup may be a low priority.<sup>14</sup> Mothers may prioritize purchasing essentials for their infants instead of postpartum healthcare. States with Medicaid expansion had increased usage of postpartum services, such as



preventive, contraceptive, and mental health services.<sup>15</sup>  
<sup>16</sup> Policy changes that include more women covered by governmental healthcare assistance can help increase postpartum checkup attendance.

### *Policy Implementations and Interventions*

Federal legislation serves as the primary catalyst for improved maternal health outcomes, including postpartum checkup attendance.<sup>17</sup> One legislative change would be to include state Medicaid coverage of birth center deliveries, as only 30 state Medicaid programs cover these costs.<sup>18, 19</sup> Strengthening these birth centers can improve access to maternal care for low-income women and ease the burden on hospital systems. Changing economic incentives, such as lowering the reimbursement for unnecessary cesarean sections and increasing midwives' compensation, can also improve maternal health outcomes. Financial adjustments can also include increasing coverage for home births and lactation consultants.<sup>20, 21</sup>

Community interventions play an equally important function in improving postpartum checkup attendance. Establishing bilingual partners and doula programs have improved postpartum care rates and the quality of care.<sup>22, 23</sup> These programs target minority, low-income groups to receive quality care. Other interventions include providing postpartum care information packets and lists of community resources to pregnant women; studies conducted by the Centers for Medicare and Medicaid Services found that 100 percent of women who received these packets attended their postpartum care appointments.<sup>23</sup> Some women do not attend postpartum appointments due to further barriers, such as lack of transportation. To combat

these barriers, healthcare teams could make home visits to screen for postpartum depression, educate the mothers, and conduct a postpartum assessment.<sup>23, 24</sup>

### *Limitations*

The standardized approach of PRAMS' data comparison across multiple states and years increases the breadth and depth of the data collected. Information is collected on demographics, preconception, pregnancy, and postpartum on health-related behaviors, attitudes, and outcomes. However, limitations of our study also arise from the data collected through PRAMS. PRAMS data are self-reported and may be subject to social desirability and recall biases. Additionally, some of the variables are limited in the data they report. For example, parity is only defined as no live births, 1-4 live births, or 5+ live births. PRAMS also lacks information about pregnancy complications and delivery type, which may play a significant role in care. There are other factors that PRAMS does not address, like available transportation to the doctor and distance to a healthcare facility.

### *Conclusion*

In this data snapshot, sociodemographic factors were highly associated with missing a postpartum checkup. Because these checkups help examine women's mental and physical health, interventions focused on improving attendance of postpartum checkups can substantially increase the health of new mothers and neonates. Finding new ways to create accessible and affordable healthcare can also increase the attendance of these appointments. Interventions that educate the public, especially underserved populations, about the necessities of postpartum care could also improve attendance.

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# An Overview Analysis of Infant Mortality in Utah:

## A Comprehensive Analysis of 2009–2019 Utah Pregnancy Risk Assessment Monitoring System (PRAMS) Data

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### Background

Although the infant mortality rate in the US appeared stagnant in the early 2000s, there has been a steady decrease in the overall rate since the 1990s.<sup>1</sup> Compared to the national trend, infant mortality in Utah has not shown a striking decrease within the same time frame but has maintained a relatively steady slope downward.<sup>2-3</sup> It has been determined that the leading causes of infant mortality in Utah are preterm birth, birth defects, sudden unexpected infant death (SUID), and medical conditions an infant may have that predisposes them to a shortened lifespan.<sup>2</sup>

Infant mortality is defined as the number of deaths in children under one year of age per 1000 live births in the same year, which has been regarded as a highly sensitive measure of population health.<sup>4</sup> Preterm birth is the delivery of a baby before 37 weeks of gestation has been completed and has various sub categorizations, such as very preterm (28–32 weeks) and extremely preterm (<28 weeks).<sup>5</sup> Due to uncertainty in precisely estimating gestation time, some countries categorize a preterm infant by birth weight of less than 2500g.<sup>5</sup> One of the leading causes of infant mortality is birth defects. It is a term used for conditions of malformations, disruptions, or deformations that may be due to physical or biochemical abnormalities.<sup>6</sup>

The seven domains of health are all interconnected with infant mortality rates, but environmental, intellectual, and financial health are of particular relevance when analyzing the causes and stressors of infant mortality. Factors related to environmental health, such as the mother's working environment and the presence of industrial pollution, can have a direct negative effect on the health of a fetus that can contribute to infant

mortality.<sup>7</sup> While intellectual health includes more than formal education, studies have found an association between low maternal education levels and an increased risk of infant mortality.<sup>8</sup> Socio-economic status, or financial health, can have a significant effect on the overall health and well-being of the parent and infant. A study conducted in Nepal found that regions mainly composed of poor and middle-class individuals experienced higher infant mortality rates than the wealthier areas of the country.<sup>9</sup> These three domains of health can all contribute to a lack of access to resources and support that may impact the likelihood of infant mortality.

Infant mortality rate can be an important indicator of population health when comparing the health status of countries or regions with the passage of time or at a single point in time. This information can also assist in guiding the allocation of health services and resources. For instance, Utah Pregnancy Risk Assessment Monitoring System (PRAMS) data indicate that parity, age, and education have notable effects on rates of infant mortality.<sup>2</sup> Analyzing this information will allow for reflection on the current systems that are in place that may put certain populations at a disadvantage and make adjustments to better support them. While old and young age and lower education are well known risk factors for infant mortality,<sup>8</sup> whether parity directly contributes to increased risk of infant mortality in Utah or is simply confounded by older age has yet to be explored. The main objectives of this data snapshot are to analyze the recent infant mortality trends in Utah and how they compare to national data. Additionally, we set out to evaluate the independent relationship between maternal parity and infant mortality in Utah, taking into account maternal age.

Methods

The data utilized for this analysis of infant mortality in Utah was collected from the years 2009 to 2019 for infants who died before their first birthday from Utah PRAMS via the Indicator-Based Information System for Public Health (IBIS-PH). PRAMS collects data directly from birth parents of live infants to provide estimates of various maternal and infant health indicators.<sup>10</sup> Forty-six states, including additional US territories and local municipalities, participate in the surveys through funding and collaboration between the Centers for Disease Control and Prevention (CDC) and local health departments.<sup>11</sup> The Utah Department of Health (UDOH) Reproductive Health Program manages the Utah division of PRAMS. Utah PRAMS conducts an annual survey to gain insights into maternal experiences before, during, and after pregnancy. The survey is administered based on a sampling system that randomly selects approximately 200 new mothers from Utah birth certificates two to four months after delivery.<sup>12</sup> The data is stratified by birth weight and maternal education to highlight underrepresented groups.<sup>13</sup>

The outcome of interest was infants who died before their first birthday (under 365 days).

Data collected by Utah PRAMS was a pooled analysis spanning 10 years and included surveying maternal parity, age, and education levels. Response options to education level question included 8th grade or less;

9th–12th grade no diploma; high school graduate or GED completed; some college credit, but no degree; associate degree (e.g. AA, AS); bachelor’s degree (e.g. BA, AB, BS); master’s degree (MA, MS, MEng, Med, MSW, MBA); doctorate (e.g. PhD, EdD) or professional degree (e.g. MD, DDS, DVM, LLB, JD); none; or unknown. Deaths per 1,000 live births and 95% confidence intervals (CI) were reported for each education level. In our analyses assessing the relationship between parity and infant mortality, we accounted for confounding by maternal age via stratification.

Data and Results

Between 2009 to 2019, Utah PRAMS collected information on 554,557 live births to Utah resident mothers regardless of where they occurred within Utah.<sup>14</sup> Since the information related to live births in the Utah PRAMS database is collected from the birth and death certificates of the infants, it is difficult to gauge the number of women represented by the number of live births. Therefore, one woman might account for more than one live birth from 2009 to 2019. Of those live births, 2,834 resulted in infant deaths at 364 days or less.<sup>14</sup> The study consisted of approximately 31.9% of women between the ages of 35 to 44, 33.4% of women between the ages of 20–34, and 34.8% of women between the ages of 15–19.<sup>14</sup> The overall infant mortality rate in Utah from 2009 to 2019 was 5.2 infant deaths per 1,000 live births which was 0.66 fewer infant deaths per 1,000 live births than the US average (Table 1).

Table 1. Infant Mortality: Deaths Under 1 year of Age Per 1,000 Live Births, Utah and USA (2009-2019)

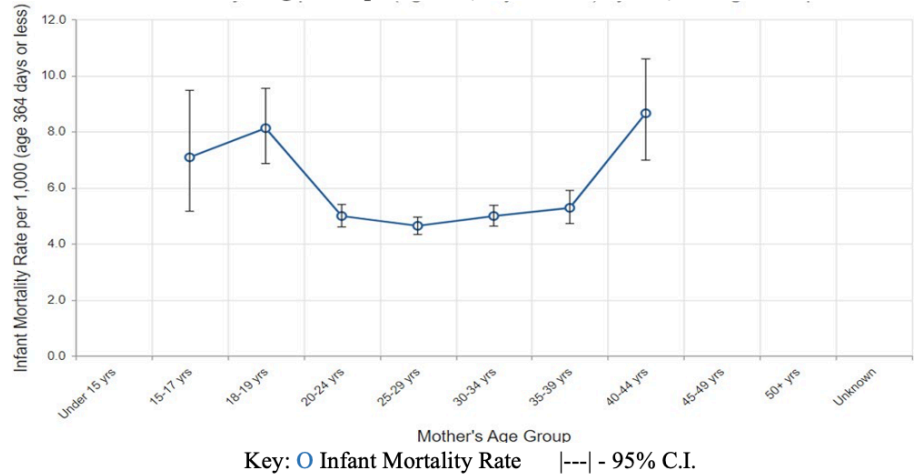
Year	Utah	USA
2009	5.3	6.4
2010	4.8	6.2
2011	5.5	6
2012	4.8	6
2013	5.2	6
2014	4.9	5.8
2015	5.1	5.9
2016	5.4	5.9
2017	5.8	5.8
2018	5.4	5.7
2019	5.3	5.6
Average	5.2	5.9



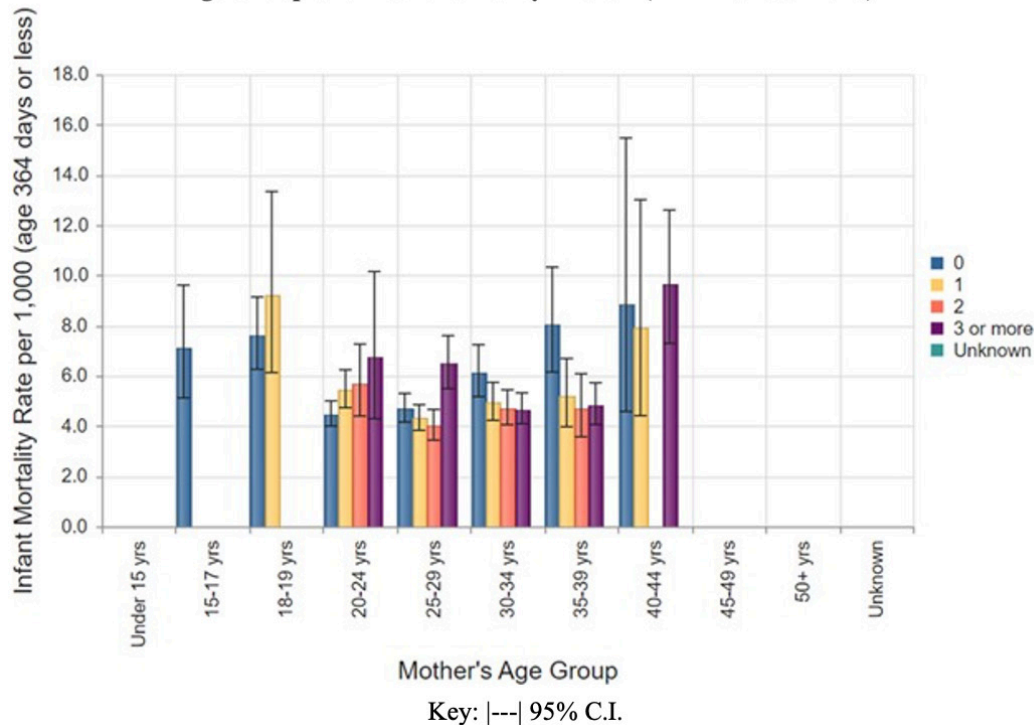
Despite a lower average infant mortality rate in Utah compared to the USA, higher infant mortality rates were prevalent among women aged 15–17, 18–19, and 40–44 years old in Utah (Figure 1). Mothers between the ages of 20–39 years old had an infant mortality rate of around 5 deaths per 1,000 live births. The infant mortality rate tends to be higher around critical moments of reproductive development in a woman’s life, such as puberty around the ages of 15–19 and the beginning stages of menopause which is around 40–44 years of age.<sup>15</sup> These two phases demarcate the beginning and the end of the female reproductive life cycle.<sup>15</sup>

In the maternal age stratified analyses assessing relationship between parity and infant mortality (Figure 2), maternal age appears to be driving the relationship with a similar U-shaped relationship as seen in Figure 1. While 3+ parity showed the highest probability for infant mortality among women ages 25–29 and 40–44 years, nulliparous women had the highest probability of infant mortality among women ages 30–34 and 35–39 years. However, overlapping 95% CIs throughout the many comparisons indicate any direct association between parity and infant mortality is null.

**Figure 1. Infant Mortality Rate per 1,000 Live Births (Age 364 days or less) by Mother’s Age Group in Utah (PRAMS 2009-2019)**



**Figure 2. Infant Mortality Rate per 1,000 Live Births (Age 364 days or less) by Mother’s Age Group and Mother’s Parity in Utah (PRAMS 2009-2019)**



In addition to age, there appeared to be a correlation between maternal education level and infant mortality rate. Women who reported only completing the 8th grade were twice as likely to experience an infant loss compared to those who held doctorates or professional degrees (Table 2). However, there was a steady

decline in the probability of experiencing infant loss as each degree level increased. Mothers in the unknown category were the most susceptible group to experience infant loss, surpassing those who reported an education of 8th grade or less by an additional 4 deaths per 1,000 children (Table 2).

**Table 2.** Infant Mortality Rate Per 1,000 Live Births Compared to Mother's Education in Utah (2009-2019)

Mother's Education (2009 and after)	Infant Mortality Rate per 1,000 (age 364 days or less)	95% CI Lower Limit	95% CI Upper Limit	Relative Standard Error (Coefficient of Variation %)
8th Grade or Less	7.43	5.86	9.28	11.4
9th-12th Grade, No Diploma	6.39	5.67	7.17	5.88
High School Graduate or GED Completed	6.16	5.7	6.65	3.91
Some College Credit but No Degree	4.82	4.47	5.19	3.82
Associate Degree	4.31	3.82	4.86	6.05
Bachelor's Degree	4.04	3.72	4.39	4.2
Master's Degree	3.78	3.07	4.6	10.05
Doctorate or Professional Degree	3.64	2.33	5.42	20.41
None	**	**	**	**
Unknown	11.92	10.16	13.89	7.83
<b>Overall</b>	<b>5.11</b>	<b>4.92</b>	<b>5.3</b>	<b>1.88</b>

### Discussion

The data analyzed in this snapshot of infant mortality between the years 2009–2019 in Utah has illustrated that women in the age groups 15–17, 18–19, and 40–44 years old experienced 3 more infant deaths per 1000 live births than 20–24, 25–19, 30–34, and 35–39-year-olds, on average. It should be noted that parity and infant mortality are confounded by age. Women aged 40–44 were identified as the most at-risk group for infant mortality. It is also essential to identify other high-risk groups, such as women who did not receive an education past the 8th grade and those in the 17–19 age group. Since Utah IBIS and PRAMS collected data on all live births in the state, the data analyzed gives the most accurate rates for Utah at the time.

Extreme maternal ages were notably associated with an increased risk of infant mortality. Biological maturation, sociodemographic factors like education, and economic factors play a role in adverse outcomes of adolescent and advanced maternal age pregnancies.<sup>16-18</sup> These effects include an increased likelihood of infant mortality and adverse pregnancy and infant health outcomes.<sup>16-18</sup> The negative impacts of advanced maternal age are also partly due to the link between increasing maternal age and a higher prevalence of pre-existing health conditions that may cause pregnancy complications, such as hypertension, obesity, placenta previa, gestational diabetes, etc.<sup>19</sup> When considering interventions for these age groups, various biological and societal factors of each patient must be addressed to meet their needs.

As mentioned previously, a strength of PRAMS is its capacity to collect data that allows for a population-based analysis of all live births in Utah. However, the limitations of this analysis of infant mortality in Utah are linked to the limitations of the PRAMS database. Data from individuals who did not experience a live birth are not included in the PRAMS database. While infant mortality does not include stillbirths, comparing data on stillbirths and their possible causes to causes of infant mortality could have the potential to reduce the risk of both outcomes. Parity measures birth after at least 20 weeks of gestation in the US.<sup>20</sup> If spontaneous or elective abortions occurred, data on that information was not collected by PRAMS to be factored into data on parity. The data regarding education was self-reported, so there could have been misreporting or a lack of reporting (Table 2).

Since there is a range of causes for infant mortality, a variety of prevention efforts would be necessary to decrease infant mortality rates. There is a strong association between infant mortality and maternal education.<sup>21</sup> Therefore, education would be a powerful tool for both patients and healthcare providers to improve maternal and neonatal outcomes. The Utah Women and Newborn Quality Collaborative (UWNQC) aims

to meet that goal by using “evidence-based practice guidelines and quality improvement processes.”<sup>22</sup> The target populations for decreasing infant mortality based on the data analyzed from Utah PRAMS would be at the two ends of the U-shaped relationship between maternal age and infant mortality. This includes women between the ages of 15–17, 18–19, and 40–44. Utah offers a federally funded Personal Responsibility Education Program (PREP) that provides adolescents information on various pregnancy prevention interventions. Older women can seek advice at family planning clinics and programs to prevent pregnancies. The UDOH Maternal and Infant Health Program (UDOH-MIHP) also provides family planning services through the Mother to Baby Utah program. Prenatal counseling can be a useful tool to reduce infant mortality among pregnancies that are at risk for adverse health effects due to advanced maternal age. Genetic counseling could be further recommended to identify biomarkers that may increase the risk of infant mortality. The UDOH-MIHP is reviewing data compiled from public health programs to identify risks throughout the stages of pregnancy and develop corresponding programs to address those issues.<sup>2</sup> Continued efforts on all fronts are crucial to reducing infant mortality in Utah as well as other populations.

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