Expanding Personal Informatics: Menstruation and Pregnancy Healthcare Journey For Practising Muslim Women

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ABSTRACT

While HCI research in women's health continues to increase, HCI researchers have yet to conduct work at the intersection of women's health and religious practices. This oversight is particularly troubling given how religious and faith practices influence health and impact individuals' behaviors, including interaction with technology in their everyday lives. In my research, I aim to design women's health technologies that simultaneously support the reproductive and pregnancy journey while considering, being inclusive of, and responsive to their religious goals and values. My dissertation is centered on the female Muslim population in the US. My completed studies focused on understanding how this population tracks its menstrual cycle (the starting phase for the reproductive and pregnancy healthcare journey), engaging with technology for tracking health and religious goals, and how they balance tracking within religious contexts such as Ramadan. These studies unveiled an intricate connection between tracking for health purposes and religious-related reasons, paving the way for my ongoing and future work, which I will discuss in the subsequent sections.

CCS CONCEPTS

• **Human-centered computing → Empirical studies in HCI**.

KEYWORDS

Women's Health, Health Journeys, Islam, Religion, Inclusive Design, Menstruation, Pregnancy

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1 INTRODUCTION AND RESEARCH QUESTIONS

Personal Informatics has long established that individuals have lived experiences, varied goals, and objectives, often supported by tracking. However, Epstein et al. [5] pointed out that a significant portion of the Personal Informatics literature focuses on tracking health-related behaviors, encompassing physical, mental, sleep, and dietary research. Despite the growth and pervasiveness of personal informatics tools in everyday life, there is a noticeable gap in research exploring Personal Informatics at the intersection of religious practices, especially when these practices are interconnected with individuals' health and overall well-being. My research is dedicated to understanding and designing health technologies tailored to a population of women seeking to manage health and faith practices concurrently. The intersection of health, faith, religion, and technology design remains relatively uncharted in HCI research, offering researchers a distinctive chance to create meaningful sociotechnical systems.

Prior research has emphasized the need for researchers and designers to consider how religious aspects impact an individual's daily life [16] when designing new technologies. HCI researchers have advocated for the need to investigate ways of designing to support faith-based populations [22–25]. Researchers interested in considering faith, religion, and spirituality in HCI studies are starting to build this foundation– key exemplars include Islamic HCI and designing for the Muslim world [10, 11, 16, 17], and workshops on faith, religion, and spirituality in HCI that have recently been conducted at CHI 2022 [18], NordiCHI [15] and DIS 2023 [14]. There are 3.45 million Muslims within the United States alone [4], whose faith practices adhere to specified underlying principles and values [16]. Current statistics indicate that Muslims account for 23% of the world's population [4]. The Muslim faith is distinguished by its rituals, beliefs, guidelines, and religious laws, which significantly shape individuals' perceptions and interactions with the world [16]. By understanding this population's unique needs and perspectives, we can better support and design inclusive and responsive technologies to their identity and values.

I developed my understanding using the following frameworks and theoretical underpinnings: The Lived Informatics Model [7], Bardzell's Feminist HCI [2], Friedman's Value Sensitive Design (VSD) Theory [8], and Critical/Reflective Design [19]. The Lived Informatics model posits that individuals have varied tracking goals, providing a more comprehensive insight into their utilization of self-tracking tools and shedding light on unexamined tracking challenges for prospective designers and researchers to address [7]. Value Sensitive Design (VSD) is an approach for identifying and grappling with value-laden design decisions [8]. Reflective design examines how technologies embody and propagate unconscious cultural assumptions [19]. Reflective Design includes analysis, construction, and assessment of novel computing devices that embody alternative possibilities [19]. Embracing this model also opens the prospect of investigating and designing for a culturally rooted population, encompassing religious rituals and communal practices.

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These frameworks and theories prompt an examination and reflective discourse on how technology is conceived, embraced, and utilized—who it is intended for, and which values are ingrained in its design. VSD and Reflective design urge researchers to ponder whose values are affected or impeded by existing designs and the trade-offs inherent in those designs. Feminist HCI [2, 3] introduces pluralism, participation, embodiment, self-disclosure, advocacy, and ecology principles. The advocacy aspect of Feminist HCI encourages researchers and designers to create tools that enhance the lives and well-being of underrepresented populations. Historically, research on women's reproductive and pregnancy healthcare journeys has predominantly focused on women in the global south and the Western world, often overlooking considerations of faith values or religious identities.

In my dissertation, I focus on practicing Muslim women in the West who remain a minority- a choice driven by the expectation that they would have greater trust in a researcher who shares a similar background. These individuals primarily identify as women, practicing a faith, living in the West, possessing health and faith-related goals, and seeking to prioritize their health, well-being, and faith simultaneously. Liang et al. [12] mentions that *"over 30 years of HCI research showed how HCI scholars have historically neglected users who might have multiple marginalized identities"*. This argument is similar to Friedman's tripartite VSD model [8] that encourages conceptual investigation, where questions such as – *who are the stakeholders? What values do these stakeholders possess? And who has the final say in technology design for a particular group of people?*– are posed. My dissertation aims to fill a gap and contribute to scholarship by considering an underexplored population in our design of technologies for women's health. In our pursuit of genuine human-centered design, primarily when catering to marginalized users with diverse identities, it is crucial not to overlook aspects like faith/religion and values (such as the choice to adhere to a particular faith/religion) that profoundly influence the daily lives of many within these populations. My research questions are as follows:

- **Research Question 1: On Values in Technology for Pregnancy Healthcare Journey.**
  What is the existing research in human values? What values are considered, prioritized and designed for in Menstruation and Pregnancy Healthcare Research in HCI?
- **Research Question 2: On Technology for Menstrual Tracking.**
  How do practicing Muslim women in the US track their menstrual cycle? How do they engage with existing menstrual tracking applications? What challenges do they encounter?
- **Research Question 3: On Tracking Health and Religious Goals Simultaneously**
  What health-tracking technologies simultaneously support interlinked health and faith goals? For example, simultaneously tracking menstruation and missed fasting resulting from menstruation or other health challenges?
- **Research Question 4: Designing for a Culturally Inclusive Menstruation Journey that Considers Health & Religious Goals.**
  How could we design culturally inclusive and responsive personal informatics tools to support Muslim women's holistic goals better?

2 COMPLETED WORK

My dissertation comprises a four-part research investigation to answer the research questions above. Three parts have been successfully concluded. Studies 2 and 3 have been accepted to CHI 2024 [10, 11]. The final part is being designed, proposed, and iterated upon. Being part of the CHI Doctoral Consortium would allow me to present my work, receive valuable feedback, and enhance my ongoing research. In the subsequent sections, I discuss the completed studies and their contributions.

2.1 Study 1: Investigating Values in Menstruation and Pregnancy Healthcare Journey Research

Addressing Research Question 1: In this research, I conducted an extensive literature review of HCI papers centered on the publications of pregnancy healthcare journeys from 2012 to 2022. I carefully categorized each paper based on the respective phases of the pregnancy journey, which included menstruation, fertility, pregnancy, and lactation/post-partum. Additionally, I extensively researched the study of human values, value-centered design, and critiques associated with this approach. I harnessed the concept of human values to guide my analysis of the HCI pregnancy journey papers. Subsequently, I qualitatively analyzed the values presently considered, researched, integrated, or hindered within pregnancy healthcare research literature. This analysis allowed me to uncover the opportunities and gaps in existing research, creating a valuable opening to contribute to the unexplored intersection of women's health, personal informatics, and religious practices. My research and dissertation are firmly situated within these interdisciplinary fields. It is worth noting that this study served as a pivotal component of my qualification exams at Indiana University, with guidance from my research advisor and the participation of three committee members. The outcomes of this study were also presented at the WISH (Workgroup on Interactive Systems in Healthcare) Symposium during CHI 2023. WISH @CHI 2023 allowed me the opportunity to receive constructive feedback and refine my work as I continued my dissertation writing. This work will be submitted to TOCHI in the coming months for review.

Contributions: Leveraging VSD's Methodology of Conceptual Investigation, this study contributes to mapping, identifying, and analyzing the human values currently considered in HCI research. Drawing upon Schwartz's Model of Human Values, the study unveils potential gaps and opportunities for researchers to explore the intersection of values and the pregnancy healthcare journey.

The WISH @ CHI 2023 Submission: *Conceptual Investigation of Values in Pregnancy Healthcare Journey Research* [PDF || Poster]

2.2 Study 2: Menstrual Tracking in Muslim Women in the US

Addressing Research Question 2: My follow-up study addressed the research gap gleaned from Study 1 above. Epstein et al. [6] underscored the need for additional studies involving individuals from various cultural, faith, and ethnic backgrounds, areas not thoroughly explored in their research. One of the significant challenges when investigating individuals from these diverse cultural, faith, and ethnic backgrounds, especially within marginalized communities, revolves around gaining access to the community and cultivating the participants' trust in the researcher. My colleagues and I undertook the task of examining menstrual tracking in Muslim women in the US (a population that is a minority within a heterogeneous society). We used survey and semi-structured interview methods. In the Phase I survey, we engaged with 134 participants; in the Phase II semi-structured interview, we engaged with 20 participants; in the Phase III survey, we engaged with 77 participants. Our primary aim was to extend prior research work while addressing the gap identified in Study 1 by exploring the experiences of faith-based Muslim women, shedding light on how they interact with menstrual tracking applications. The study also highlighted the challenges and limitations Muslim women face when using period-tracking apps. We identified substantial disparities between the features of existing tracking applications and the specific needs and values of faith-based Muslim women. As an outcome of this study, we derived valuable insights that offer design implications and recommendations for shaping future period-tracking apps that are inclusive of Muslim women's unique requirements and principles. One finding of this research was the pivotal role of faith in motivating menstrual tracking among Muslim women. They used tracking for health purposes and to fulfill religious obligations such as fasting, which they would need to make up later due to their menstruation. While conducting this research, it informed participation and engagement with the following:

- The CHI 2022 workshop on 'Faith, Religion and Spirituality at CHI' where I presented the submission titled: *Reflections on Considerations For Research Within Muslim Women Population* Accessible Links: PDF
- The co-authored newspaper article: *"No, submitting junk data to period tracking apps won't protect reproductive privacy"* by Siek, Ibrahim & Hayes [20].

Upon conducting Phase I and II of the study, a significant shift in the political landscape regarding reproductive health was marked by the overturning of Roe v. Wade. This necessitated the validation of my research findings within a post-Roe v. Wade context to ascertain whether the population I had studied continued to utilize and interact with menstrual tracking applications. In response to this change, I initiated a third Phase III survey involving 77 participants to investigate their experiences and responses to questions about Roe v. Wade and the usage of menstrual tracking applications.

The findings from Study 2 are published here ([11]). The findings from this study have sparked my subsequent research study, particularly in exploring this population's experiences with a specific religious obligation - *Ramadan* and fasting, an aspect highlighted by several participants.

Contributions: Empirical understanding of Muslim women's menstrual tracking practices and engagement with technology. I offer design considerations for designing tracking applications inclusive of Muslim women's religious values and needs.

2.3 Study 3: Tracking For Health and Religious Goals – A Diary Study in Ramadan

Addressing Research Question 3: In Study 3, my colleagues and I employed a combination of surveys, diary studies, and semi-structured interviews to gain insights into the impact of faith practices on tracking behaviors in Muslim women, with a specific focus on the context of Ramadan, a month during which Muslims globally fast from dawn to sunset. This research aimed to identify tracking requirements that pertain to both health and faith aspects among Muslim women, building upon the design recommendations established in Study 2. Throughout Ramadan in 2023, from mid-March to mid-April, we closely collaborated with our participants through a diary study. This diary study explored their tracking needs, considering both health-related and religious perspectives, with particular attention to how they manage disruptions to their religious practices caused by menstruation. The diary study method was imperative within the study's context, as the participants were fasting from dawn to sunset. However, we faced a significant challenge in recruiting participants who could consistently participate throughout the study. In total, we engaged with 9 participants in our month-long diary study. It became evident that mothers of toddlers encountered difficulties actively participating in the study and managing their religious commitments during the month, along with the various demands of their daily lives.

Upon analysis, we found that participants' perspectives on overall well-being needed to encompass their faith and religious experiences. We also unveiled the specific health and religious goals our participants carried out, the diverse tools they utilized to achieve these objectives, and the challenges and conflicts they encountered in their interactions with these tools. Study 3 is now finished and published at CHI 2024 (See [10]). Following the conclusion of Studies 1 through 3, I am scheduled to propose my final set of studies in November 2023. I intend to leverage the unique opportunities at the CHI 2024 Doctoral Consortium to shape and enrich my study design. I plan to seek potential collaborators and explore networking opportunities around the intersection of Personal Health Informatics, women's health, and underexplored populations.

Contributions: This research enhances the understanding of how users engage with tracking technologies in intricate, real-life, and religious contexts, particularly among underrepresented groups such as menstruating Muslims. It offers insights into the unique needs of Muslim women seeking to balance their overall well-being, especially in the context of Ramadan. It also offers perspectives on considering religious wellness in addressing the wellness needs of these communities through technology.

2.4 Study 4: Co-Designing For The Menstruation Journey Using ARC

Addressing Research Question 4: Leveraging the unique strengths of Asynchronous Remote Communities (ARC), my colleagues and I aim to design collaboratively with participants for their ideal menstruation journey experience. We aim to conduct a two-month ARC study with at least 15 participants. Participants will be involved in entry surveys, weekly co-design activities in private online groups, and final interviews and surveys. ARC study allows researchers and participants to co-design prototypes of technology, and in particular, this method could also allow researchers to utilize the speculative design approach [1, 9] to imagine and speculate on futuristic technology for their health journey [13]. Given this project's formative stage, the CHI Doctoral Consortium's timing is perfectly aligned, offering the opportunity to gather crucial feedback on our ARC-based design, refine our design activities, identify potential collaborators, and explore intriguing open-ended questions and directions of the study.

2.5 Future Work: The Pregnancy Journey

Potential future direction for this work could focus on the next stage of the reproductive health journey, e.g., fertility and pregnancy phases, post-partum phases, etc., in the lives of Muslim women. The study could explore the intersection of faith and religious goals within pregnancy and fertility to understand the individual needs, obstacles, and support systems women encounter as they navigate the transition from menstruation to fertility and, subsequently, during pregnancy. Building on existing pregnancy literature, we propose the following directions by engaging with Muslim women to: (1) explore how Muslim women navigate cultural, religious, and personal expectations surrounding fertility and pregnancy, uncovering any potential conflicts or unique considerations specific to their faith, (2) investigate the full spectrum of their pregnancy healthcare journey, including prenatal practices, social support systems, and anticipations for motherhood and beyond, (3) the negotiation of religious duties and healthcare decisions that pregnant Muslim women undertake, identifying potential challenges and strategies for navigating this complex space, (4) Explore how technology can potentially serve as a bridge between their religious needs and health goals during both the fertility and pregnancy journey.

3 OVERALL CONTRIBUTIONS OF MY DISSERTATION

To exemplify my contributions, I draw upon Wobbrock et al.'s [21] framework for HCI contributions, which encompasses seven categories: 1) Empirical, 2) Artifact, 3) Methodological, 4) Theoretical, 5) Dataset, 6) Survey, and 7) Opinion. My individual studies' contributions primarily fall within the empirical category; a secondary contribution type is a dataset; both contribution types offer insights into how individuals engage with systems and enrich our understanding of human behavior [21], particularly behaviors that include religious goals and practices. My overall contribution combined offers an opinion-type contribution by exploring the dynamic relationship between religious and health goals, particularly emphasizing the menstrual and pregnancy phases within traditionally underexplored communities, such as Muslim women residing in Western societies. Refer to Table 1 for a summary of the contributions of dissertation work to the field of HCI. I hope that my dissertation work serves as the foundation for future research endeavors, which could involve collaborative design initiatives aimed at providing tailored support for menstruation and pregnancy in line with the needs of practicing Muslim women. Ultimately, my research underscores the importance of expanding Personal Informatics to accommodate the development of health technologies sensitive to religious practices and values, offering insights for creating technological solutions that can address the unique challenges and requirements of Muslim women of faith and potentially other women of faith.

4 EXPECTED NEXT STEPS AND CHALLENGES

My anticipated next steps involve the planning and design of my fourth study. However, I have lingering questions as I design the final studies in my dissertation. For my next steps, I intend to submit Study 1 to TOCHI for review, design, and iterate on the ARC Study. As I present at CHI 2024, I plan on taking the feedback and critique gained into developing and refining Study 4. Later this year, I will begin the ARC Study and submit the findings at the next CHI or CSCW. I also plan on commencing my dissertation writing at the end of the year to defend my dissertation and graduate in May 2025. I would also like to collaborate with more researchers on Personal Health Informatics and Women's Health.

5 MY DOCTORAL TRAINING AT INDIANA UNIVERSITY BLOOMINGTON

I am a fourth-year Ph.D. student at Indiana University, based in Bloomington, where I am enrolled in the Informatics program, specifically focusing on the Health track. Additionally, I hold a minor in Human-Computer Interaction (HCI) and a Master of Public Health. I am fortunate to be under the mentorship of Dr. James Clawson. The typical duration for Ph.D. programs at Indiana University is five years when pursued full-time, involving three major milestones: qualification exams, proposal presentation, and dissertation defense. Participation in the CHI 2024 Doctoral Consortium would be a unique experience for me. In 2023, I applied for the CSCW doctoral consortium, but my application was not successful, primarily because I had not reached the proposal stage of my Ph.D. program. However, by the time the CHI 2024 Doctoral Consortium takes place, I will have made substantial progress beyond my proposal. This timeline aligns seamlessly with my plan to utilize the Doctoral Consortium as I prepare for the final phases of my research studies. I am confident that I am an exceptionally well-suited candidate to derive immense value from the CHI Doctoral Consortium. Since my rejection from the CSCW doctoral consortium, I have achieved the following milestones:

- I've successfully completed three out of the four phases of my research investigation.
- Two of the finished phases have been accepted [10, 11] and will be presented at CHI 2024.
- I've proactively seized opportunities to share and receive feedback on my research by delivering workshop presentations at prestigious conferences.

Table 1: Summary of Research Questions and Contributions to the Field of HCI

Study No.	Research Questions	Contribution	Contribution Type	Status
1	What are values currently being designed for in pregnancy healthcare journey research?	By drawing upon Schwartz's Model of Human Values, the study unveils potential gaps and opportunities for researchers to explore in the intersection of values and pregnancy healthcare journey	Empirical	Complete Presented at WISH @CHI 2023 (Publication coming soon)
2	How do Muslim Women in the US track their menstrual cycle and engage with menstrual applications?	Understanding of Muslim women's menstrual tracking practices and design considerations for designing tracking applications inclusive of Muslim women's religious values	Empirical	Complete See publication [11]
3	What are the tracking experiences of Muslim Women within a religious context (e.g., Ramadan)?	Understanding of user engagement with tracking technologies in complex, everyday contexts among underrepresented groups (i.e., menstruating Muslims), offering potential inspiration for empowering communities' wellness needs through technology	Empirical	Complete See publication [10]
4	*How could we better design culturally inclusive and responsive personal informatics tools to support Muslim women's holistic goals?*	*Prototypes and/or futuristic speculative design of menstrual tracking technology for Muslim women*	Empirical	*Still PlanningStudy*
Overall	Combining RQ1, RQ2, RQ3, and RQ4	Convey and encourage the HCI community to broaden the scope of Personal Informatics by incorporating a more comprehensive approach to individuals' overall well-being, including their religious values.	Opinion	Incomplete To be completed for Dissertation Defense (2025)

- Currently, I am in the process of drafting the final phase of my project.

These accomplishments demonstrate my dedication and progress in my academic journey. I am eager to further enhance my research through the valuable opportunities the CHI Doctoral Consortium can provide.

6 BENEFIT STATEMENT

I am currently in my fourth year as a Ph.D. Student in Health Informatics and Human-Computer Interaction (Ph.D. minor) at Indiana University Bloomington. I am applying to be considered for the 2024 CHI Doctoral Consortium so I can develop my research further, share my completed and ongoing research with my peers and established researchers, and gain more feedback for my ongoing and planned studies. Participating in the CHI Doctoral Consortium will be beneficial in the following ways

- Enable me to gain critique and feedback, particularly on the relationships between women's health, faith, and values. In return for participating in the CSCW 2023 Doctoral Consortium, I hope to both engage and provide actionable feedback and support for my peers' research work.
- Helping me tackle the open questions and challenges regarding Study 4. Participating in the Doctoral Consortium would also open my work up to the broader HCI community.

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