Parting the Red Sea: Sociotechnical Systems and Lived Experiences of Menopause

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ABSTRACT

Menopause is a major life change affecting roughly half of the population, resulting in physiological, emotional, and social changes. To understand experiences with menopause holistically, we conducted a study of a subreddit forum. The project was informed by feminist social science methodologies, which center knowledge production on women's lived experiences. Our central finding is that the lived experience of menopause is social: menopause is less about bodily experiences by themselves and more about how experiences with the body become meaningful over time in the social context. We find that gendered marginalization shapes diverse social relationships, leading to widespread feelings of alienation and negative transformation — often expressed in semantically dense figurative language. Research and design can accordingly address menopause not only as a women's health concern, but also as a matter of facilitating social support and a social justice issue.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI)**; **Collaborative and social computing**; • **Social and professional topics → Women**; • **Applied computing → Health informatics**.

KEYWORDS

Lived Experience, Menopause, Feminist Research, Women's Health

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1 INTRODUCTION

Menopause signifies the end of a woman's[1] reproductive ability. It is marked by the point at which an individual has gone twelve months without menstruating. Linked to diverse physiological changes, menopause is commonly understood as a personal women's health issue and examined through the lens of clinical medical research. Accordingly, medical therapies have been developed and evaluated, and topics such as the risks of early menopause and the ways that lifestyle factors contribute to symptoms have been examined. Technology research has complemented these approaches, including decision support about treatment options [64, 84] and identifying related and cooccurring symptoms [99]. In HCI, researchers are beginning to examine design requirements for mobile applications that coach women through menopause [91] and support them in managing their health through features such as tracking [57].

As this work progresses, it is important to attend to a body of work outside of HCI and health sciences on menopause that has asserted that menopause doest not fit neatly into the dominant medical paradigms [34, 67] – these include needs and experiences that could not possibly be met by clinicians or a health care system. Further, women's health has an uneasy history with medicine (e.g., exclusion from clinical research and under-diagnosed and treated [87, 96]), making other approaches to this topic necessary.

HCI research has begun to confront tensions between women's health and biomedical approaches: rather than locating the responsibility to care for others or stay healthy entirely on an individual, which neglects social and societal factors affecting health [77], researchers are noting the

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[1] Individuals in this paper are referred to as women, following the language in our data and prior work in HCI on women's health [32]. People not identifying as women also experience menopause, and not all who identify as women experience menopause.

need for collaborative and systemic action to promote health equity [10, 27]. Instead of reducing health to a set of physiological or functional characteristics, researchers are describing how taboos generated by the marginalization of women directly inhibit speech and information seeking [6, 10, 70]. As these perspectives develop, there have been calls to rethink women's health technology [5, 11]. In this paper, we respond to this call and establish the domain of menopause as a fruitful area for research and design for HCI.

To ask how HCI might contribute to wellbeing during menopause, we report on women's experiences of menopause as articulated on Reddit. We use an interpretivist social science methodology, informed by feminist social science and literary hermeneutics, which emphasizes the centrality of women's lived experiences [35, 66, 101]. This is design-oriented research; our intention in conducting the research is not to discover broad truths about menopause and how it intersects with technology use. Rather, in accordance with HCI's predilection for developing accounts of user experiences to drive design [36, 100], our goal is to discover ways to improve women's health experiences as designers.

Past work on menopause has found that menopause is a social and cultural process as much as it is a biological one [30]. Our central finding, which unfolded from accounts produced by and on topics determined by women, extends past work to conclude that *the lived experience of menopause is often social.* That is, menopause is less about how a woman experiences her body by herself and more about how that experience of her body is situated in, and becomes meaningful through, relationships with coworkers, medical professionals, partners, family, internet strangers, and dialogue with herself across decades. These social experiences are positive and negative; shaped by self-discovery, taboos, pride and shame, images of femininity in the media, a need to prove that symptoms are real, sexual conflict, humor, and estrangement. Women speak of experiences where something – sociality – is missing. Mainstream discourse and the institutions that produce them fail to prepare women for the changes they experience. Taboos and bias towards aging and in particular, aging women, "other" and marginalize. As we discuss, women desire experiences with menopause that are social, rather than isolating and strange.

All of this suggests that menopause has profound experiential dimensions, issues of marginalization and social injustice. HCI is well poised to address the social qualities of menopause experience as it becomes increasingly mediated by sociotechnical systems. We argue that HCI should work alongside, but not subordinate itself to, a health research agenda. This research engages with women's lived experiences with menopause to put forth new avenues for design.

2 BACKGROUND AND RELATED WORK

Most people experience menopause in their late forties or early fifties, though for some it is much earlier or later [75]. Menopause is preceded by perimenopause, years when ovaries decrease the production of certain hormones and people begin to experience physiological changes, including changes in menstrual frequency or flow, hot flashes, insomnia, pain during sex, weight gain, and mood changes [1]. Menopause signifies the end of reproductive ability, after which one is post-menopausal.

Sociocultural Perspectives on Menopause

Despite the generalities above, there is no universal menopausal experience. Rather, menopause is shaped by one's sociopolitical context and life history [30]. People of different ethnic and sociocultural contexts experience menopause differently [8, 20]. Other factors that affect experiences include interactions and relationships with others [12, 98], stress, diet, and reproductive history [68], and personal attitudes towards menopause [9, 31].

Menopausal experiences are also shaped by dominant societal attitudes. Menopause is currently treated as a taboo topic [25]. Researchers have charted how ideas about menopause have changed over time, with implications for how people make sense of their own experiences with menopause: from being linked to sin and decay in Victorian times to neurosis in the early 20th century. In the 1960s as synthetic estrogen became available, menopause began to be treated as a disease of estrogen deficiency [67]. Now considered a health issue, menopause was addressed with intervention-oriented approaches, such as HRT (hormone replacement therapy) [34]. At first administered widely, negative effects were found and HRT was recognized as something to be used with caution – at the smallest dose for the shortest time, and not for those with a history of certain conditions [3]. Health informatics research has supported medical approaches, via decision support about treatment options [64, 84] and supporting women in identifying related and cooccurring symptoms [99].

The medicalization of menopause has been critiqued by feminist scholars [29, 79] and discredit women's own experiences with menopause [34]. Further, by reverting what can be seen as natural changes in the body, medical approaches may esteem youthful feminine states, in turn perpetuating ageism and sexism towards women as they age [28]. Instead, some call for menopause to be treated as a natural part of life rather than a disease [34, 67].

Women's Health in HCI

Women's health is gaining momentum as an area of research in HCI. Researchers are examining maternal health: before, during, and after pregnancy. Recent work begins to consider menstruation and menopause. Lee et al. conducted focus groups and interviews to identify design considerations for mHealth [57]. Another project envisions an adaptive application to coach people through menopause [91]. Similar to these works, we have found the importance of speaking about menopause with others in one's social circle (which [57] used to motivate a social networking component of their application) as well as a general lack of knowledge of menopause [91]. Our paper situates these findings from past work in the context of marginalization, which we find shapes the experience of menopause in many ways.

Past work on menstruation is also relevant to this topic. Epstein et al. examine how and why people track their menstrual cycles [32]. One reason is to support the interpretation and management of emotions (e.g. recognizing increasing anxiety is due to an upcoming period) [32]. Unlike the often regular and trackable period cycle, menopausal experiences are often unpredictable and unfamiliar in our data, with many individuals asking whether they are normal and how to account for changes they are experiencing. Critical HCI work has used the topic of menstruation to ask broad questions about intimate technology and design. Bardzell et al. [16] analyze the critical design Menstruation Machine [2]to support Research through Design approaches. PeriodShare is a speculative design fiction to provoke critical reflection on self-tracking and intimate technology [88]. This work questions whether new menstruation apps and products neglect important political and cultural dimensions [88].

Women's health HCI research often takes up these sociopolitical dimensions. A CHI workshop on women's health confronted taboo, power, and prejudice [11]. Gui et al. refer to the ways that embodied knowledge and experiences with pregnancy are disregarded by a dominant biomedical view [42]. Examining urinary incontinence, Almeida et al. argue that taboos around women's bodies shape healthcare [5]. These taboos are being confronted explicitly in research on breastfeeding, learning about intimate anatomy, and abortion [6, 10, 70]. Other work recognizes the burden that technologies designed for the individual place on women, and instead investigate systemic or collaborative approaches [10, 27]. In our data, we too find the significance of taboo and a lack of a sense of shared experience. The work in women's health joins a growing body of HCI research calling for an expansion past a solely medical model of health. These works call for other approaches, such as designing for health activism [77], self-care [72], and wellness [41].

Women's Lived Experience

HCI researchers have proposed holistic accounts of user experience (e.g. [100]). Interpretivist and philosophical approaches to experience in HCI, including accounts based on Deweyan pragmatism [80, 100] and Richard Shusterman's somaesthetics [49, 50, 58, 85] foreground experiential qualities including involvement, pleasure, and embodiment [14]. Questions about whose experiences, which experiences, and how experiences shape knowledge production have dominated feminist scholarship. A feminist turn to experience involves "taking real life as the starting point, its subjective concreteness as well as its societal entanglements" [35]. Feminist standpoint theory centers the experiences of a marginal group as a point of departure for research [44, 46]: "women's identity as a distinct and specific social group begins with their 'lived experience' as women." ([66], p.21). This approach is ethically justifiable, but also leads to empirical insights harder to acquire by other means [13].

While feminist scholars have recognized the importance of understanding marginal groups' experiences, many also caution against essentializing these groups [13]. The idea that women share a "common experience" on specific issues is contested because the sociopolitical differences between individuals are so vast [66]. Yet it is possible to distinguish between the idea of experiences shared by women that are innate and unique to women (i.e., the essentialist view) and experiences shared by woman that are situated within social structures and patterns and empirically visible. In other words, to assert that all women, regardless of culture or ethnicity, gain the same kind of unique knowledge as a result of menopause is essentializing. In contrast, it is not essentializing to say that, for example, many women in our study have expressed the feeling that the medical establishment does not take menopause sufficiently seriously.

3 METHODOLOGY

This research analyzes the lived experience of women experiencing menopause. In doing so, it balances a commitment to taking known medical dimensions of menopause seriously with an equal commitment to women's accounts — their words, lived experiences, and the marginalization that they encounter. Some of what we are interested in is not directly observable: the subjective experience of menopause; the ways that sexism, taboos and other forms of structural marginalization shape those experiences. Our methodology pursues our research goals in such a context by blending qualitative empirical methods with feminist and hermeneutic interpretive methods [14, 15].

Approach

After considering a number of publicly available English, US-based forums on menopause, we selected a subreddit forum because of the scale of its threads and number of users. We used the Reddit API with the PRAW Python library to scrape all posts (417 threads with 617 uniquely identified authors, with M=7.66, SD=7.48 comments) from https://www.reddit.com/r/Menopause/. The threads dated from June 2012-March 2018. We began with thematic analysis [22], with all authors separately open-coding and generating themes for the most recent 100 threads. Example codes at this stage included *normalcy*—what are normal experiences of menopause; *transformation*—mental and physical changes that accompany menopause; *institutional marginalization*—issues with doctors; and *personal details*—revealing context about yourself to the subreddit. We then came together for a discussion of the themes. Noting that the dataset was experientially rich and intense, and expressed lived experiences of women, we realized a feminist social science methodology was well suited for this topic.

The resulting interpretivist method pragmatically borrowed from critical discourse analysis, blending close reading (i.e., an emphasis on diction, figurative language, metaphor, etc.) and inductively identifying and categorizing themes, in order to understand women's lived experiences as manifested in these texts [4, 82]. After identifying women's lived experiences as the focus of our analysis, we began to attend to linguistic practices with heightened sensitivity. In particular, we identified intertwined themes on the marginalization of menopause from society at large, employment of figurative language to describe physical and emotional experiences with menopause, and social solidarity as well as conflict (e.g., among other women and partners). With these themes in mind, two authors collectively coded 200 additional threads. We interleaved coding the most recent and oldest threads to ensure that results were not biased to a certain time period; for example, in older posts, social norms may not have been established, but give valuable information about motivations of the subreddit. Newer posts may better reflect contemporary issues and how members have evolved over time. We reached data saturation with the next 39 most recent threads (i.e., a single top-level post followed by 0 or more comments) and the 161 oldest threads. In total, we coded 300 threads and 2065 comments (each thread had an average of M = 6.95, SD= 7.24 comments), approximately 72% of the entire Menopause subreddit corpus. We stopped coding upon reaching data saturation, when further analyses no longer yielded significantly new insights on women's lived experiences with menopause.

Parallel to coding, we engaged in discussion and close reading, informed by feminist social science and literary hermeneutics. Close reading unfolds across iterations of reading. Initially, the analyst seeks to build a *literacy* with the main contents of the texts. This literacy gradually develops into a *sensitivity*. This sensitivity is at once more subjective and more insightful; it characterizes what we become able to perceive. With each iteration, we read fewer passages and in a richer way; connect passages to other passages, theory, images in popular media, and so on; and become more sensitive to use of language, structure, and connotation. A sensitivity helps focus attention and develop criteria with which to curate selections from the whole. We also attended to figurative language (i.e., non-literal language, such as metaphors and hyperbole) to generate powerful insights. In doing so, we drew from linguistic textual analysis as it has been developed to locate patterns among unusual structures of language to enable inferences about psychological meaning [37]. We applied this approach as we coded the second set of 200 codes referred to above. Some of the codes that came out of this process included *recurring metaphors used to make sense of experiences*, such as "stranger in my body," and that of a "journey"; *hyperbole to demonstrate distress*, such as "I am the cause of global warming"; and *vivid imagery to communicate subjective feelings* (e.g. wringing out one's shirt with sweat). We increasingly engaged texts as written, resisting the move to paraphrase them in more literal language, and learned to see affinities across texts based on diction and metaphor (e.g., of blood and heat) rather than imposing what we already knew about menopause onto the text.

Our analysis was also informed by feminist social science as it foregrounds women's experiences a source of knowledge production. The turn to feminism is appropriate to our inquiry in several ways, as well as our selection of Reddit forums as the source of text (as opposed to, for example, interviews). This subreddit serves as a form of consciousness raising that we can learn from, where people discuss and mobilize attention around marginalized and gendered topics [51]. Also, individuals may feel more comfortable talking about stigmatized topics online, as opposed to face-to-face with researchers [18, 63, 74]. The "pseudonymity" afforded by Reddit likely led to more discussion of taboo or uncomfortable topics [93]. We also found benefits from drawing on conversations that referred to past interactions and community norms that built up over time, similar to [56]. Most importantly, conversations were self-initiated or brought up in response to others experiencing menopause, meaning that the analysis centered on what was brought up by women, rather than researchers (i.e., during interviews). This approach differs from past work to understand social dimensions of menopause, which have largely relied on interviews about particular topics. Finally, key to our hermeneutics is our positionality. This research is neither medical research nor cultural studies, though it draws from both. Instead, it situates women's experiences of menopause in a field that designs sociotechnical systems. Even as we sought to discover themes in texts, we were linking them to HCI agendas.

In doing so, we hope to open up new design spaces. Instead of asking, how might Reddit forums better support women experiencing menopause?, we ask: what might it mean for a smart home or smart city to be "smart" about women experiencing menopause? By situating this subreddit's discourse in a dialogue with HCI, we become actors in sense-making. In hermeneutic theory, our "prejudices" both bias us and also form the basis of mutual understanding and empathy that underlies any sense-making at all. We accept both consequences of our methodology.

Ethical Concerns and Limitations

Study procedures were approved by our university institutional review boards. In writing this paper, we considered adopting a "moderate disguise" strategy to obscure quotes to protect the privacy of participants [23]. However, we decided to keep quotes as written because a key component of our methodology is taking words as written; obscuring quotes would run counter to this. Additionally, given that the forum is the only English subreddit on menopause and is fairly small, it would be easy for a reader to trace mildly obscured comments back to individuals.

We selected the subreddit after considering more active forums, all of which happened to be based in the UK. As US-based researchers, it became clear that familiarity with a healthcare system is key to gaining intimacy with accounts of menopause. Consequently, our findings come from a single, US/English online community. The findings are certainly influenced by their source. For example, past research has found that different symptoms, such as hot flashes, are more likely to be experienced in Western contexts (e.g. [38]). People with worse attitudes towards menopause experience more symptoms [9, 31], and some research has found different attitudes towards health-related perceptions of aging in different cultural contexts [59]. Associations between youth and beauty in the US also contextualize the aging appearance-related comments [39]. Future work should examine more diverse perspectives by examining different online platforms to compare experiences and conducting interviews in different sociocultural contexts.

Reddit as a data source has other limitations. We could not tell the ethnic and racial, economic, or regional diversity of forum participants. There may be significant homogeneity to the population—for instance, individuals may share certain characteristics such as high technological literacy. Finally, those that wrote on this forum may share certain characteristics such as intense or very negative experiences with menopause, or those more open to sharing and social connection. Thus, this analysis reflects a particular set of experiences with menopause. Additionally, there are some tensions in choosing Reddit for a feminist approach: including that it can be easy to assume a scientific distance from forum participants and that the site may be frequented by people who have more knowledge and access to resources.

4 FINDINGS

We describe the lived experiences of women going through menopause, as told by women. Though the stage (perimenopause, menopause, post-menopause) is unclear, we refer to "women experiencing menopause." Quotes are denoted by P[post number].

Figurative Descriptions of Experiences

Feminist anthropologist Emily Martin observes contemporary medical discourse's metaphors of the body experiencing menopause as a factory that is failing, regressing, in withdrawal, following inappropriate orders, and in a state of loss [65]. Here, we examine the metaphors and other figurative language that women themselves use. Women describe intense physical and psychological experiences. They use descriptions of transformation and being inhabited to describe the foreign experience of menopause – sometimes with an overwhelming negativity, but sometimes with hope.

When medical discourse is not enough. Many individuals use medical discourse to describe experiences. This often involves quantification (e.g. months since last period), medication and supplement regiments, and the biological mechanisms by which medications and supplements work, as seen in P257's post: *"Antidepressants actually *can* help- there's evidence for several SSRIs reducing vasovagal symptoms. But what REALLY helps is hormonal birth control. (It also helps prevent osteoporosis by maintaining bone-healthy estrogen levels)."* Many women are knowledgeable in medical understandings of menopause. Like past research on online health community, we found that individuals were well versed in medical understandings, and shared both clinical accounts and experiential accounts [42]. In this case, experiential terms appeared where medical or standard discourse was not sufficient. A variety of evocative terms are used to describe experiences, such as unusually heavy periods described as *"flooding."* In particular, "hot flash," a term used in medical research and everyday life, is not sufficient. 'Hot' does not begin to capture the intensity of *"pouring sweat,"* leaving P257 to *"wring out my shirt [from] sweat."* "Flash" implies a fast, temporary state, but individuals draw parallels between interrogation techniques with the months of hot flashes that startle them awake at night. The contrast between medical discourse and the lived experiences is described by P327: *"Honestly, I think the medical establishment has tried too hard to put formal separate names to what's essentially a long, irregular, idiosyncratic process for most women."* Medical labels contain experience through demarcation and diagnosis. This language cannot capture experiences that evade averages or involve a fluidity that defies demarcation. Instead, individuals draw on a rich array of figurative language to describe these experiences.

Being Possessed and Transformed. Figurative language is consistently used to describe how menopausal strangeness and change is experienced: by being inhabited, and transformed. Individuals describe how they had *"woke up in a stranger's body"* (P113), a *"beast inside me... both physically and mentally,"* (P131) or feel their *"body being hijacked by an alien"* (P101). P87 describes similar sentiments for other life phases, mainstreamed via film:

> *"My son wants to be a screenwriter and I told him there's a market for a movie that metaphorically depicts menopause, in the way that The Exorcist depicted female puberty, Alien/s depicted pregnancy and childbirth, and David Cronenberg depicts all manner of...reproductive horror" (P87).*

The metaphor of menopause as a kind of possession gives a sense of its experiential power. It also has connotations of impurity, in that the self is now a hybrid of two things, "me" and an inhabiting alien. That being possessed lends itself to the horror genre is a topic we return to below.

Women also describe experiences as transformations. A once *"chill easy going"* (P310) demeanor is no more: *"I've always been sweet natured, now, I am a raging bitch, a person who once loved sex and now can't be bothered and [is] dreadfully unhappy... want my sweet demeanored, laid back me again"* (P408). This is particularly disturbing, given that individuals have *"spen[t] 20-30 years building up"* (P21) a personality, only to find it transform. Changes are often discussed in relation to how they impact others, such as spouses and coworkers. With physical transformation, individuals speak of how life-long approaches to dieting no longer work, and despite immense effort, they are *"becoming one of those people I always swore I wouldn't become - round and matronly"* (P104). Both inherited and willed super-attributes are seen as destroyed by menopause, with some avoiding antidepressants and other treatments to avoid weight gain.

In contrast to the often-negative descriptions of being possessed and transformed, a journey metaphor communicated more positive experiences and even hope. Getting through the worst of perimenopause is to *"come through the other side"* (P351). P351 describes herself as in the midst of this journey: *"[I'm] Starting to feel like this is going to truly be a wonderful part of my life, like starting over in a good way; like graduating or something."* Similar hope is offered to others: *"It's temporary, so don't worry too much... I'm nearly 3 years post-menopausal, and at this point I'm actually feeling much more stable and mellow than I've ever felt. It gets better, I promise"* (P134). The journey metaphor emphasizes the long timescale of menopause: individuals live several decades before experiencing menopause, perimenopause can last nearly a decade, and people may live post-menopause for half a century or more. Thus, the experience of menopause cannot be considered in isolation; rather, it must be understood in context of the experience of womanhood across the lifespan. In addition to a sense of stability, other positives are described as the reward for *"graduating"* menopause, including the end of: cramps/back pain; worries about staining beloved underwear; the need for birth control; unwanted pregnancies; ruminating about what others think; as well as better relationships with significant others. Several describe an improved comfort with speaking their minds: P2 tells a story that took place at a restaurant where, *"Thanks to the glory of menopause I instead became a She-Hulk... I went straight up to the couple, told them in no uncertain terms that they'd ruined our lunch."* Here, being inhabited is not uncomfortable, but welcome. This is consistent with research that has found in contrast to medical discourse, women can have mixed or positive experiences with menopause [29, 79].

Both transformation and being inhabited are effective ways of conveying not only the emotive experience of menopause in non-medical terms, but perhaps, more importantly, how this experience is foreign when compared to what they have known about their bodies and emotions. Indeed, past research has considered the importance of imagery and metaphors of menopause, and how they "reflect and perpetuate gender images and cultural anxiety about aging, femininity, and sexuality" [34]. These metaphors express how women feel out of control, frustrated, and disgusted with changes they experience. At the same time, we see some (though a minority) of metaphors express positive, rejuvenate emotions. What makes this experience impactful is that the experience is wholly alien to them during perimenopause – once some time has passed, they sometimes emerge in what they describe as an improved state.

Marginalization

The experience of menopause takes place against a backdrop of marginalization which includes institutional experiences (in particular with the medical establishment), silencing and concealing, and the shame and stigma faced by aging women.

Institutional Experiences. Individuals speak of negative experiences with medical institutions. They discuss difficulty finding medical professionals with expertise on menopause: *"After going through pages and pages of on-line statements about their practices from local ob/gybs I found one (ONE!) mention of menopause. (This doctor had attended a seminar on it)"* (P370). One can imagine a design approach that makes information about specialists more accessible to individuals such as P370. However, this approach would not help her, as more than an information access issue, she is affected by the *"very few resources, or even apparently much interest from the medical community, just a sort of blithe indifference about normal questions and concerns" (P370).* The lack of attention and information in mainstream media, healthcare, and medical research is met with shock given how menopause is a *"normal stage of adult life"* (P370) experienced by *"half the human population"* (P272). This is consistent, though, with the way that women's health is marginalized across the life span [40]. Individuals discuss how their experiences with menopause as a woman's health concern stood in sharp contrast to the ways that men's needs were taken seriously, citing examples such as Viagra for erectile dysfunction. P293 said:

> "It's so sad that there's no support at all for women…If men went through this there'd be an entire industry dedicated to it, and special resorts in really cold places where they could go to be more comfy. Instead we sleep on beach towels, dust ourselves with powder, take some NSAIDS, and get on with it."

This disparity is attributed to *"our bullshit men-first-with-the good-shit medical culture"* (P310). Women recognize that the marginalization of women's health, and menopause in particular, has to do with patriarchal attitudes.

Even when women can find health care professionals, they must convince doctors of the existence or severity of their experiences. P311 writes, *"No one believed me. My 'doctor' said, 'You're being hysterical.'"* Even upon finding a center specializing in menopause, she still found the doctors to be "*skeptical,*" though at her insistence they eventually prescribed her medication for regulating hormones and sleep. Women experiencing menopause *"decade[s] before expectations"* (P326) have a particularly difficult time making a case to doctors. Needing to convince disbelieving doctors has been found in studies of people living with rare diseases [62], but is surprising for something so common.

Women speak about doctors not taking their symptoms seriously. Doctors, however, pay attention to what can be measured numerically, even when this does not match experiences: *"My first endocrinologist… had no idea how terrible hot flashes are. 'The bloodwork was okay, so I can't change anything.' Um, the BLOODWORK can kiss my ass! I AM THE CAUSE OF GLOBAL WARMING"* (P341). Research has noted how the medicalization of menopause can lead doctors to inadvertently "dismiss certain symptoms as they highlight others" ([83] in [30]). Researchers have investigated ways to support doctors in empathizing with patients (e.g. [78]) and sharing understandings of patient care priorities [60]. In some cases, healthcare professionals are neglecting experiences that can be addressed in a medical context. However, due to the medicalization of menopause, people may be seeking relief from health care professionals for symptoms that do not have treatments, and will pass with time. This may be trivial from a medical perspective, but is a fruitful avenue for HCI to approach from the perspectives of self-care, the lived experience, or community building.

Intersections with class also exist. Though traditional doctors specializing in menopause are hard to find, *"...plenty of doctors with 'luxurious East Side townhouse suites'… mix custom bio-identical estrogen and hormone 'prescriptions' in-house. They never accept insurance..."* (P370). Insurance factors into what people can afford and use, including prescriptions given to them by health care professionals: some women speak about not being able to afford basic treatments while others consider options less medically necessary (e.g. for hair growth) *"spendy"* (P325) but worth it .

Societal Attitudes Towards Women, Aging, and the Body. Individuals describe physical changes they experience in menopause, such as a feeling that their skin is becoming papery and differences in the distribution of weight on their bodies, as well as changes from aging more broadly, such as grey hair and wrinkles. These changes are often described as negative, with references to *"fading looks"* (P330) and acknowledgements that the societal value of women is tied to a youthful, thin appearance. P295 said, *"...the thought of being genetically past my sell by date is...hard. in a culture that is relentlessly obsessed with youth, I feel like my worth, as a human, is rapidly draining away."* Some push back on these cultural valuations of women, arguing that women can be beautiful at any age, or their value extends beyond beauty: P294 writes *"As nice as a tight ass is, youthful beauty belongs to the young; we have better things to offer the world."* Individuals also note how women's health topics experienced at younger ages received far more attention:

> "I mean, we're taught about periods, birth control and/or abstinence, making sure we go to the gynecologist regularly for PAP Smears so we get checked out to be sure all is alright, STD's, AIDS, the birthing process, and PMS. What no one is taught about much, if at all, is perimenopause or menopause… " (P264).

Recent HCI work describes how older people use blogs to reconcile individual experiences of ageism and formulate ways of pushing back on ageist views [56]: individuals here use Reddit to respond to similar ageist and gendered views.

Women work to conceal unpredictable appearances of menopause symptoms. They take precautions, using both a tampon and a pad in anticipation of a "flooding" period. Menstrual products are not always enough, as P399 writes: *"Last two were so heavy it felt like a cough or sudden movement i bleed true my pads which i did a few times. At work I had to sit on a plastic bag so not to stain my chair good thing I'm in a private office."* Hiding is difficult in public spaces, and the workplace is one site where visible signs of menopause do not seem to be appropriate [81]. They describe shame at the idea of being seen by others during these times, and some (somewhat jokingly) refer to secluding themselves, such as not leaving the house in order to avoid being seen flushing. Though the unpredictability of these periods or flushing is new, hiding things associated with one's body is not: women often hide signs of menstruation their whole life, down to the *"secret stash of lady product in my purse"* (P316). Past HCI research has found that embarrassment and the feeling that certain parts must stay hidden impact women's health and self-care [5, 6].

Intimate Experiences. One place where women cannot hide menopause is in their homes and bedrooms. Many women refer to husbands that remain supportive despite mood swings or changes in libido: *"My husband is handling it pretty well. He's very supportive, which makes it not so horrible for me"* (P349). The impact of menopause is described as substantial on male spouses, requiring them to be heroes to withstand this phase: P374 refers to her *"poor Husband-Man-the-Brave."* This type of praise for supportive husbands has been found in past research on menopause, which describes how this positive discourse indicates that men are acting out of the norm for their gender [30].

Yet, women describe conforming to dominant norms of heterosexuality. Vaginal dryness associated with menopause gets in the way of intercourse, and individuals described the need to engage in more foreplay, to *"involve lubricants or just suffer through the pain that sometimes happens"* (P104). These preparations are further described by P104 as *"tak[ing] all the sexiness and spontaneity out of things."* Being ready for sex at any time, without the need to "warm up" is seen as the ideal state. P103 writes: *"So we tried about a million lubes and ended up with KY Liquibeads. They seem to work fairly well… less pain for me but still some enjoyment for hubby."* In this case, a situation that works *"fairly well"* involves minimized pain for P103 and maximized pleasure for her husband: no mention is made of her own pleasure. Past research has also found women describe "enduring" sex despite pain from vaginal dryness because of the centering of male pleasure and vaginal intercourse [97].

Some women write of husbands who do not take seriously that their experiences are associated with menopause. These husbands think women are "blaming it" (e.g. lack of libido) on menopause. A number of posts include husbands writing into the forum to ask for help dealing with their wives who were experiencing menopause. Some confirm women's claims that husbands think that menopause is an excuse or that women are not taking responsibility to overcome these symptoms:

> "My wife went through this 'wonderful' change, and we no longer have sex. I'm very unhappy about it. The symptoms have gone away, but her sex drive is completely gone...She is using this as an excuse, and I have read it does effect her sex drive, but it can come back, but not on it's own" (P103).

Others describe how their wives transform before their eyes from supportive and easygoing to raging and irrational: *"I'm just a suffering husband… confronted with the horrible reality that is menopause. Sure, I know all the women suffer. And, I realize that most, if not all, women, have zero ability to control the caustic nature of their being once menopause takes hold..."* (P310). P310 then reassures readers that he will not leave his wife: he will stand by as her caustic, out-of-control transformation brings him suffering.

Generations, Time, Other Women

This forum allows heterogenous experiences – in contrast to dominant, medicalized views of menopause – to be shared and then normalized with a virtual sisterhood across time and space.

A Virtual Sisterhood. A solely medical approach perpetuates negative cultural attitudes towards menopause by framing it as a disease [92]. In contrast, some redditors discuss menopause as a *"natural process that women have been going through for centuries"* (P307). They relate to women across centuries, but also those just decades older. In particular, older women are described by some as defying stereotypes of being sex-less or unattractive: *"I see some of these older women settled into menopause and notice how vital and sexy they appear, how they seem to know themselves and care little about what other people think, and it makes me look forward to that time in my life"* (P306) In these cases, individuals are not looking to older women for information. Rather, they identify in others ways of living with menopause that challenge convention.

In addition to those who had gone through menopause before them, individuals consider those who will follow:

> "...all my friends are younger than me, and since I'm only 38, I get to machete through this jungle first while they laugh at me from the already-cleared trail :p" (P103)
>
> "In my wide circle of women friends, I'm pretty much the oldest so I have been telling about my experience to anyone who would listen because, I swear to fuck, the only thing I'd heard about from my elder women was hot flashes. and that really didn't happen to me at all" (P129)

Women link across time and space to form a sort of networked sisterhood: P129 writes that this subreddit, *"is good for our sharing and for younger women coming into peri/meno and wanting a community to check in with."* The forum is a way to support individuals from these imagined future generations, who consequently become active participants [7, 19].

Often, sociality is set against the backdrop of marginalization: women experience peri/menopause together as *"sisters-in-adversity"* (P264). Discussing a shared difficulty avoiding weight gain, P343 writes, *"Here's to us sister, I raise my carbohydrate free vodka water to yours."* The forum functions as an exceptionally welcoming space, unlike many other online spaces for women [47, 71]. Individuals who do not fit the norm are reassured when they express doubts about whether they are welcome, such as those experiencing perimenopause at a young age (naturally or due to hysterectomies). Researchers as well as family members such as husbands and children are likewise welcomed. Again, this welcoming and open space takes place with an awareness that this would not and could not happen in many settings: *"there has just been this veil of secrecy around women's health for a long time. It really isn't very many generations ago that women didn't talk about *any* female health issue because it 'wasn't proper'"* (P257).

A Place for Heterogenous Experiences. Many individuals end their posts seeking out affirmations that their experiences are normal. In particular, women speak of only having heard of hot flashes, but not experiences such as changes in libido, vaginal dryness, mood swings. In response, they are often assured that these experiences are normal (and often, had been experienced by the replier). Finding others with similar experiences is a key motivation for joining and even starting the forum: *"I actually created this subreddit when I was in the midst of it in hopes of finding other women who might be going through the same thing, because my friends seemed to be sailing through it and my doctor wasn't that sympathetic at first"* (P70). P70 notes that her experience was more difficult than her peers and not taken seriously by her doctor. The subreddit serves, in different ways, to provide solidarity to women whose experiences do not fit within the popular mold of menopause as relatively unproblematic. Though there is a dominant narrative of menopause, including the age it takes place and the symptoms it entails, the enormity of the variance in experience is apparent from the thread: including the symptoms, the age of onset, the duration, and whether it is experienced as physical and/or mental. This lack of knowledge of the different ways individuals might experience menopause reflects the way menopause – something experienced by so many individuals – is marginalized in medical and popular discourse. As a result, P121 writes, *"we really are forced to cast about to others."*

The subreddit can be thought of as a form of "consciousness raising" in which taboo speech is encouraged between marginalized individuals, who begin to understand how their experiences are not isolated [51] and, importantly, document these experiences [90]. Women tell stories of their menopausal experiences, which include but also go beyond physiological experiences with menopause to injustices that lead to the marginalization of their common experience.

Making Sense of Personal Experiences through Connections with Others. As has been described in HCI health informatics work, individuals look to experiences of others with similar health experiences to understand what their own trajectories might look like [26, 33, 52]. P399 uses someone's menstrual history to draw a parallel to herself: *"I'm also 51 and looks like you started [having periods] around 12 too plus I'm having a lot of the same."* Unlike previous work, family history is seen as immensely important in menopause. First, the prevalence of cancer in one's family tree has implications for treatment (i.e., the riskiness of Hormone Replacement Therapy). Second, the age of menopause onset and symptom type and severity of family members help individuals, as P408 writes, *"give me some insight into my own [course]."* As important as this awareness is, women struggle to piece together this information. Not uncommon is missing information for a number of reasons, including family dynamics, death, and the taboo nature of the topic: *"I don't know when or if my mom went through menopause, she passed away a few years ago and was only 54. I didn't get to talk to her much the last few years of her life and she never talked about anything like this"* (P121). As important as others' experiences were, individuals discuss how they are still, as P54 said, *"on my own course with it."* Another post explains this further: *"I've learned that every woman has a different experience, length and affect when going through menopause"* (P408). These individualized experiences, though, are contextualized through the histories of others.

5 DISCUSSION

Past work has found that menopause is a social and cultural process as much as it is a biological one [30]. Expanding on this past work by interpreting women's lived experiences on Reddit, we call attention to the specific ways in which menopause is social. We argue that physiological experiences with menopause become meaningful in the shifting relations between the experiencing self and the social world — a social world in which women's experiences are marginalized. In short, menopause is meaningful not because of physiological symptoms that an individual woman privately feels, but rather because her bodily change is enacted in the social world; that is, it is intersubjectively experienced [55].

Reimagining Menopause Research in HCI

This paper, in engaging deeply with women's lived experiences, is not best suited for resulting in a list of concrete design discussions, but rather as envisioning a new way to approach design in this space in ways that involve but do not exclusively lie in the medical domain. Our findings can be used to interrogate and envision extant and future sociotechnical systems. The discussion that follows borrows from the metaphor "blood language," referring to the distinctive use of language by women to communicate menopause experiences.

Blood Language. One approach in health informatics research is to analyze text on forums and online communities authored by people with particular health-related conditions. Through this approach, researchers have gained insight into the lived experience in a broad array of contexts. We were struck by the richness of the experiential language used in our data, including figurative language (i.e., non-literal language, such as metaphor, metonymy, hyberbole, synechdoche, euphemism) and rapid pragmatic shifts (e.g., from medical vocabulary to slang in a sentence). This use of language makes it possible to express complex experiences; for example, a poster might use medical vocabulary to speak with precision, and switch to metaphor to express how it feels to live through those experiences.

We saw many stories where an unexpected menstrual "flood" occurred. If this was privately experienced, the speaker might emphasize the discomfort of wetness or the hassle of having to clean clothing, yet such narratives were uncommon. More typically, the story was of embarrassment or shame: that is, the feeling that this event might have had witnesses who would negatively judge her. Here we turn to film theorist Tarja Laine, who explains that shame

> "directly reveals the intersubjective foundations of individual existence, as shame is simultaneously [...] a way of seeing oneself from the standpoint of others, and a sensed inability to take control of one's identity and organize a response. [...] shame operates motivationally; with the imagined look of the Other" ([55], p. 19)

Here, too, it is worth attending to the diction: "flood" is a hyperbolic description of menstrual flow. We believe that hyperbolic language is used not only to communicate that the objective quantity of the flow was high (as opposed to spotting), but also to communicate the subjective experience of it — a kind of natural disaster, a situation with sufficient urgency and threat that it cannot be ignored or pushed off.

We have shown that language about menopause is often not limited to literal, objective symptom characterizations, but rather intersubjectively felt and directed utterances. Attending to the figurativeness of language increasingly became a methodological tactic we used to sympathetically engage women's lived experiences. In health informatics, researchers have pursued technical approaches to analyze large bodies of text, such as natural language processing, topic modeling, and sentiment analysis. Critiques have arisen that common techniques neglect features such as slang and community nomenclature [76]. Here, we emphasize the importance of retaining experiential language in its own right, in addition to translating it into medical terminology. Sociotechnical systems should be expressive enough to support the experiential language of menopause.

Blood Geography. Our data suggests that menopause has a geography, as it is experienced differently in different spaces. Diminished libido and vaginal dryness might not register as experiences in the workplace, but in the bedroom, can be traumatic. Because geography is linked to intersubjectivity, this result is not surprising, and not all locations foreground conflict. In places where people are alone, such as bathrooms or private offices, menopausal experiences are relatively benign. One individual described a flooding occurrence with relief: *"good thing I'm in a private office."* And, significantly for HCI, sociotechnical platforms such as Reddit are part of the menopausal geography, places where women can find sympathetic fellow travelers. Yet the comfort that these private/socially limited spaces afford is positive because they facilitate a women's compliance with social mores to hide matters of female hygiene. Again, we see that societal taboos and patriarchal structures do not merely color experiences; they are the very condition of possibility of those experiences.

Prior research has emphasized distinctions between space and place [45] and how spaces are subjectively experienced and socially interpreted. Recent research investigates ways that people (e.g. during gender transition [43] and veterans [86]) experience online spaces as stressful or unsafe (as well as supportive). There is no question that many places are experienced as hostile by women experiencing menopause. Places make women feel shame, alienated, even monstrous. A societal pressure to hide signs of menopause creates a demand for privacy with obvious spatial implications. Debates about public breastfeeding are a visible testament to this, even though breastfeeding (in contrast to menopause) is often viewed as positive [10]. An implication for areas including CSCW, ubiquitous computing, IoT, and smart cities is whether their innovations reinforce the hostility of these places, or if they contribute to computationally rich places in which menopause is unremarkable: a re-menopausing of space. For example, if we focus on HCI for menopause only in the context of the clinic, one can easily imagine a future where menopause stays hidden in private spaces, reproducing today's taboos into the future. Alternatively, we can imagine additional spaces where menopause might exist. This work is already beginning with smart homes and IoT: with design concepts that regulate lighting [48] and home temperature [53] based on menstrual cycles and menopause. What else might be produced from design that does not keep menopause behind closed doors?

Blood Monsters. In the beginning of the novella, *The Metamorphosis*, Gregor Samsa wakes up as a giant insect [54]. He struggles to understand his new body. He imagines how his family and workplace will react and even addresses his situation to his reader, saying, "I cannot make you understand. I cannot make anyone understand what is happening inside me. I cannot even explain it to myself." He has changed, and all of his social relationships will need to change as well. More profoundly, though, he does not understand who he now is, so he lacks a basis on which to build new intersubjective relations. Consequently, he fails to build positive social relations (his relatives feel disgusted, though obligated to care for him); at the end of the novella he dies in isolation.

People commonly assume that individuals identify with their bodies and have one body over a lifetime. But metaphors of transformation are abundant in our data, and for many, the transformation is into an incomprehensible being. Their descriptions of being transformed in to beasts or hulks and being hijacked by aliens suggest more than entering into a new life phase: they suggest a combination of unknowability and also impurity (the woman is partly herself and partly this new non-human entity). Not coincidentally, unknowability and impurity stand at the core of all horror fiction [24]. That many women express themselves in a horror genre indicates that menopause can be terrifying. Not all narratives are so dramatic, but there are other subtle ways that women are rendered unknowable and impure. A partners' inability to understand implies an underlying inscrutability. A doctors' inability to believe suggests that the woman is no longer a normal human. Many of the women in the subreddit describe an experience followed by a question about whether this is normal. We all need to feel human in our own bodies, but sometimes do not. This is no attitude that we can turn on or off, but the outcome of social labor – something design research can understand and support. HCI researchers use technologies for bodily transformation, and often align with hegemonic goals: losing weight, getting fit, being a better lover. Researchers can approach design not only in terms of society-level goals (e.g., caloric goals), but also to account for and even address intersubjective body experiences, including shame, alienation, feeling comfortable in one's skin, or accommodating bodily transformation. Interestingly, seeking reassurance that one is "normal" can be found across the spectrum of health informatics research: with cancer [61], pregnancy [42], and rare diseases [62]. We suggest the quest for normalcy arises when there is unknowability, and in particular where marginalization exists. Here, we see questions for health informaticists and design researchers to pursue: what would it take for menopause to be knowable at the level of lived experience, where women do not feel like monsters with superpowers and dirty secrets, where all geographies respect the dignity of women as they are, where women are taken seriously when expressing everyday human suffering, and where their preferences are just as legitimate as those of the people around them?

Blood Sisters. So far, one of the few positive responses to the preceding questions are informal sisterhoods of support. Traditionally, these include family relations: mother-daughter, sister-sister, or close friends, especially where taboos about menstruation and menopause make it an improper topic. As we have seen, sociotechnical systems such as Reddit open up the circle into a national or global networked sisterhood. Though one might anticipate a day when these circles expand to include other genders, our data suggests that it has not yet come.

The sisterhood facilitates re-intersubjectivization of menopausal women. If shame is the intersubjective emotion that isolates by taking an individual's identity out of her hands, the sisterhood can build bonds with an identity the woman herself controls. Within the sisterhood, and its limited geographies, it is acceptable to talk about spotting and floods, sexual problems, disconnections with doctors and colleagues, and experiences of self-alienation. She is typical in her accounts; neither inscrutable nor impure. Consciousness raising, where individuals develop vocabularies to identify and address shared oppression, have been vital catalysts for activism [51]. In feminist movements, this has resulted in concrete, influential, and distributed forms of activism such as *Our Bodies, Ourselves* that protested the medical profession's paternalistic view of women and empowered women through shared, codified experience [40]. The sisterhood creates spaces and relations that can reverse the isolation and help alleviate experiences of estrangement and dehumanization. Supporting not only such sisterhoods, but more importantly the mechanisms by which people help others counter feelings of estrangement and dehumanization, is a fruitful avenue of research for HCI.

The Intersection of Health and Menopause

Menopause is deeply impacted by marginalization, including by research and medical institutions. Relatedly, while referred to as a women's health issue, menopause includes elements that reach beyond concerns typically located in the domains of health and medicine, such as experiences with ageism and sexism. For these reasons, menopause is a challenging domain for health HCI researchers. We engage with current discussions on this topic below.

Tracking and Menopause. Researchers are beginning to examine tracking for people experiencing menopause [57, 91]; here we apply findings of this paper to demonstrate how our work can engage with current trends in women's health technologies. First, understanding that menopause involves marginalization in the clinic, we might be cautious in how we use tracking to support dialogue with health care providers. We see that when women's experiences do not align with what is known in the literature or a provider's practice–for example, experiencing negative feelings but lacking indicative test results–these factors may continue to be neglected [62], regardless of whether they are tracked and presented to the provider. Quantifying women's health, therefore, may further marginalize dimensions of individuals' experiences that cannot be counted or do not register with current medical practices. Additionally, some aspects of menopause do not actually have a medical response or medical treatments are not desired (e.g., due to family history of cancer). And the clinic may not be the best place to address, for example, feeling ashamed of one's body or fear of one's husband leaving them. Instead, we suggest that recording experiences accompanying menopause may help women, especially by supporting them in sharing with others–potentially providers, but also fellow women, friends, and future generationss–as well as in capturing these experiences for themselves. We provide three considerations:

Capturing experiences in addition to quantitative data. Applications should support the capture of diverse experiences in menopause. This paper indicates the importance of blood language (see section 5) – the ways that women use words and phrases to express their experiences. Women should be able to customize the terms that they use to describe their experiences (e.g., flood, spotting) and there should be space for rich textual descriptions.

Including context. As indicated in *blood geography* under section 5, menopause is deeply shaped by where it takes place. Epstein et al. found that one reason individuals track menstrual cycles is to interpret and manage their emotional states (e.g. recognizing increasing anxiety is due to an upcoming period and adjust anxiety medication) [32]. How women interpret and manage situations with menopause are different in different places (e.g., at the workplace vs. at home). Individuals should have the ability to track locations as well as the experience itself as a way to support sensemaking and reflection.

Leveraging sociality. We see two opportunities for social interactions in the design of applications for menopause, both stemming from concepts in *blood sisters*. First, we can support women in sharing their data with one another, similar to how individuals currently use the subreddit. Having access to others' experiences can help people obtain and share social support and help people answer the common question "am I normal?" Second, researchers might support the creation of records that can be shared across generations. Women in our data wished to know details about how their family members, who were now deceased, had experienced menopause as a way to understand their own experiences. As a starting point, we can draw on researchers who think of objects as holding social history [95] and draw from and contribute to researchers examining tracking over the long term [69]. We can design for the layering of reflections and experiences of generations of women through notions of heirloom objects [21, 73], which call for the design of technologies amenable to being passed on and valued over several lifetimes. How would women wish to receive information about their relatives' experiences with menopause? For example, given the impact of life history on menopause, they might search for those with similar traits.

Tensions in HCI and Women's Health. In taking a feminist social science approach, we discuss problematic aspects that arise related to healthcare and how gender intersects with the healthcare experience, but only touch on socio-economic dimensions of medicine. Low socio-economic status and racial and ethnic minority groups face disproportionate barriers to health in the US [89]. As we continue to innovate in the area of menopause, we must keep in mind that tying health experiences to costly technology can increase health inequity [94]. As HCI and design research enters domains traditionally covered by health research, tensions emerge that are not easily grappled with [17]. Examining the ways that people describe their lived experiences, including attention to their language, may be a useful approach for other areas where tension exists between a population and medical/research institutions, such as HIV and health disparity research.

As problematic as interactions with healthcare institutions can be, we cannot reject a biomedical view of women's bodies for many reasons, including that these views are important to many of the women in our data. This was seen in instances including sharing information from physicians, attempts to understand how symptoms might be relieved, and discussions of medical risks associated with different therapies. The question, then, becomes how we might work productively with/in healthcare institutions and cultures. Such a collaboration faces challenges, as the epistemologies of medicine and design research have evolved separately and for separate purposes, exhibit different forms of rigor, and evaluate success in different ways. Even so, they are challenges worth facing, so that design researchers and health informaticians might identify shared goals and ways forward.

6 CONCLUSION

This research draws on feminist social science methodologies to understand the lived experiences of women going through menopause. We find that women's experiences with menopause are impacted by, but also far exceed, issues that we traditionally associate with medicine. Hot flashes, sweating, and irregular menstruation are both physiological symptoms and felt as natural disasters. Hormonal changes prompt questions about the benefits and risks of HRT and are also the beginnings of a screenplay for a new Alien movie. An inconsiderate restaurant patron transforms a woman into a hulk. Physiological symptoms are not the only part of women's discourse; they are not even the most important part of it. Experiences of isolation, conflict, shame, transformation, and hilarity suggest that menopause is a social experience situated in meaningful spaces and places. Social technologies are part of menopause's geography. We present opportunities to help answer questions such as: What future geographies will sociotechnical systems create? What is HCI's role to ensure that those systems welcome, rather than isolate, the women who will inhabit them?

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