

Menopause Legacies: Designing to Record and Share Experiences of Menopause Across Generations

SHAAN CHOPRA, University of Washington, USA

LISA ORII, University of Washington, USA

KATHERINE JUAREZ, University of Washington, USA

NUSSARA TIEANKLIN, University of Washington, USA

JAMES FOGARTY, University of Washington, USA

SEAN A. MUNSON, University of Washington, USA

Menopause is often overlooked or medicalized, consequently devaluing individual experiences and failing to support individuals experiencing this life event. Family dynamics, death, and taboo further mean that individuals often miss out on information that could help them contextualize their experiences. We examine participant experiences with menopause and explore designs of digital and non-digital legacies for sharing menopause experiences across generations. We conducted semi-structured interviews and design sessions with 17 participants who experienced or are experiencing menopause. We report participant information needs and sense-making practices, including what personalized information participants wish to pass down and preferred formats for intergenerational sharing. Findings highlight the potential of using storytelling and life-logging to create “holistic” memories of the menopause journey, to support self-reflection, and for using legacies to initiate conversations about marginalized health experiences. We identify future design and research opportunities for the HCI and CSCW communities to support intergenerational sharing of non-medicalized and stigmatized health experiences.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; • **Applied computing** → *Health informatics*.

Additional Key Words and Phrases: menopause; women’s health; digital legacy; information needs; narrative; heirloom; life-logging, sense-making; support; non-medicalized health; personal informatics; design considerations

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1 INTRODUCTION

Menopause signals the end of menstrual cycles, and hence the potential ability to give birth. This phase in the reproductive health journey of a person who menstruates carries similar importance as other life events or health changes, such as menarche, pregnancy, or childbirth. Medical studies have

Authors’ addresses: Shaan Chopra, schopra7@cs.washington.edu, University of Washington, Seattle, Washington, USA; Lisa Orii, lisaorii@cs.washington.edu, University of Washington, Seattle, Washington, USA; Katherine Juarez, kajuarez@cs.washington.edu, University of Washington, Seattle, Washington, USA; Nussara Tieanklin, nussara@cs.washington.edu, University of Washington, Seattle, Washington, USA; James Fogarty, jfogarty@cs.washington.edu, University of Washington, Seattle, Washington, USA; Sean A. Munson, smunson@uw.edu, University of Washington, Seattle, Washington, USA.

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found genetic influences on reproductive health aging and symptomatic menopause experiences (e.g., hot flashes, night sweats) [145]. But as with other experiences of women's health¹, menopause does not fit into dominant medical paradigms. Needs and experiences of women's health are often not fully addressed by the healthcare system [20, 74], with doctors rarely discussing menopause with their patients or even dismissing patient concerns as "normal" [101]. Moreover, a lack of information contributes to uncertainties around bodily changes due to menopause, leaving people unprepared for this phase of their lives [74]. People try to make sense of their personal menopause experiences by learning from the experiences of others, including contextualizing their experiences in family history [74]. However, people remain largely uninformed about menopause due to family dynamics, death of family members, and the associated taboo [74].

Health researchers have raised concerns about evolving medical standards. These standards push for medicalization of menopause, defining all midlife and older people experiencing menopause as "hormonally deficient" and in need of interventions such as Hormone Replacement Therapy (HRT) to maintain health and increase longevity [89]. Although treatments such as HRT can benefit people with troublesome symptoms, medicalization tends to emphasize negative aspects of menopause (e.g., end of fertility, youthfulness, and sexuality) and may increase stigma and apprehension about this natural stage of life [1, 88]. Moreover, HCI and design researchers who studied lived experiences with menopause found "*menopause is less about bodily experiences by themselves and more about how experiences with the body become meaningful over time in the social context*" [74]. To push back on medicalization, design researchers have refused to design self-tracking tools that risk medicalizing a natural process and sustaining negative views of the menopausal transition [61]. They have also created technologies that help celebrate the body during menopause and dismantle oppressive systems [24]. For example, Bardzell and colleagues developed design frames and concepts for new products and services to support varying menopause experiences. These design frames included addressing symptoms as well as supporting non-medical experiences (e.g., supporting self-discovery and self-expression, calling out taboos, supporting sociability in menopause-relevant situations) [12]. In a similar vein, our work centers participant preferences and experiences with the goal of exploring designs for recording and sharing menopause experiences, without necessarily medicalizing the process.

Moreover, we choose to focus on sharing experiences within familial and intergenerational contexts. Families and close ones are often an important source of support during similar life events and transitions (e.g., fertility-related transitions [27, 28]). Potential genetic influence on symptomatic menopause experiences [145] is another reason people might benefit from familial sharing. Our study also responds to a call by HCI researchers to design for intergenerational sharing of menopause experiences [74], envisioning a future where designs support passing down personal health experiences to future generations so that individuals can better understand their family's health and wellbeing history and potentially draw insights into their own experiences.

We leverage concepts from digital legacy literature to create design sketches to support exploration of participant preferences and designs for intergenerational sharing, extending them to the context of menopause. Digital legacies preserve and share digital information about life experience after death [26], and can take many forms (e.g., photos, videos, websites, social media profiles). In the context of health, interventions have sought to improve the well-being of patients [56] by encouraging them to reflect on and share their experiences [34, 45]. However,

¹We use the term women and women's health in this paper to refer to a wide spectrum of people, including cis women, queer women, and gender non-binary individuals, and encapsulate health topics concerning them. Research has found that medicalization has led to neurosis of all women's bodies even though embodied experiences of queer women and gender non-binary people may differ from those of cis women [99]. We also acknowledge the erasure of trans women in women's health literature [69].

these works focus on health conditions and highly medicalized contexts (e.g., cancer), which contrasts with our research context of menopause.

We investigate the following research questions:

- **RQ1:** What are people's experiences around menopause, specifically their sense-making practices, information needs, and any associated challenges?
- **RQ2:** What information about menopause do people want to pass to future generations? What information do they wish they received from earlier generations?
- **RQ3:** With whom and in what forms do people who experience menopause want to pass or receive this information?

To address these questions, we conducted in-depth interviews and design sessions with 17 participants who experienced or are experiencing menopause to: (1) understand their experiences, practices, and information needs, and (2) explore possibilities for designing artifacts or tools to record and share experiences across generations. We drew on the concepts of *narratives*, *heirlooms*, and *life-logging* from digital legacy literature to create design sketches, each depicting ideas for potential digital and non-digital formats for recording and sharing menopause experiences with family members and future generations. These design sketches were introduced as probes during participant sessions, which were conducted in four different languages (English - 12, Spanish - 2, Japanese - 1, Thai - 2) depending on each participant's preferred language for communication.

This paper makes three contributions. First, we provide a detailed account of experiences of menopause that shape participant information needs, sense-making, and communication practices. We also uncover multiple challenges participants describe in preparing for, accepting, and receiving information and support around menopause (e.g., stigma around menopause and its impact on physical, mental, and emotional wellbeing; absence of family members with relevant experiences; issues translating shared recommendations to one's personal context). We highlight multiple participant perspectives, including our interpretations of when participant cultural backgrounds affected their perspectives on sensitivity of specific experiences and communication practices. Second, drawing on past work on digital legacies, we developed sketches of potential ideas to use as probes to prompt participant reactions to different concepts for recording and sharing menopause experiences across generations. Most participants expressed a preference for menopause-specific narratives or a life-logging approach. We found that life-logging and narrative-based storytelling can help in recording legacies that create more holistic "memories" of an individual's menopause journey - going beyond sharing of symptomatic experiences and considering menopause a significant "part" of their lives but not an all-consuming experience. We also identified the potential of personal legacies as conversation initiators and teachable resources that can supplement general menopause awareness. Based on our findings, we engage with HCI and CSCW literature to provide recommendations for creating legacies for stigmatized and gender marginalized health concerns which need not be medicalized. We discuss opportunities for future research on intergenerational information sharing, accounting for concerns around access, privacy, and longevity.

2 RELATED WORK

We begin by situating our work at the intersection of HCI and CSCW literature on women's health and menopause. We also provide some social context around stigma, support, and non-medicalization of menopause, as has been discussed in prior non-HCI work. We then articulate concepts from digital legacy literature and our adaptation of the same to support sharing of menopause experiences across generations without medicalizing the process.

2.1 Women's Health, Menopause, & Its Non-Medicalization

Women's health is a key area of interest for the HCI and CSCW communities. Research has covered a wide range of topics, including menstruation [18, 43, 47, 133–136], menstrual syndromes [22, 144], sexual well-being [11, 38, 66], intimate care [4–6, 125], and maternal health [8, 72, 107, 126, 142]. Researchers have examined information seeking and sense-making practices [22, 49, 109, 133], education and awareness in different cultural contexts (e.g., European adolescents [122], Global South [65, 130, 135]), intimate data collection [43, 48], and related tools and interventions [6, 9, 12, 63, 95]. Different phases of the menstrual and reproductive health journey have been studied, with a significant portion focused on designing for individuals experiencing perimenopause and menopause [12, 24, 61, 74, 76, 137].

Studies with people experiencing menopause have found that they might experience uncertainties regarding body changes that could be due to menopause or pure circumstance [24]. These uncertainties stem from a lack of information, leaving people unprepared to experience this phase of their lives. Uncertainty and lack of education/awareness also impacts information-seeking, sense-making, and communication practices during other phases of menstrual and reproductive health [22, 117, 135], which are often affected by stigma and other restrictions on “holistic engagement” with women's health [71]. Moreover, symptoms similar to those one might experience during menopause (e.g., loss of fertility, changes in physical appearance, impact on emotional well-being) contribute to feelings of uncertainty and stigmatization around menstrual syndromes [22]. The essentialized understanding of the terms “women” and “health” can engender perceptions that stigmatize a natural state of being, such as the view that the menopausal body is undesirable [69]. Although the beliefs and taboos might differ across cultures, emotional instability, physical decline, and reduced quality of life are often at the heart of negative perceptions around menopause [68, 79]. Positive views of menopause are also centered around the end of menstrual bleeding, marking freedom from societal restrictions based on cultural beliefs that menstruation is polluting [113, 119, 120], and allowing for more sexual freedom [81]. Moreover, biological determinism might heighten negative perceptions in the case of queer women and gender non-binary individuals [62], requiring careful management even when using intersectional and inclusive design approaches [7, 60]. Researchers suggest the use of visual methods (e.g., speculative design) as a mode of knowledge generation for stigmatized and gender marginalized health topics [69, 115, 123], as they can help engage with topics that people might not discuss openly to build deeper understanding of the range of concerns [69]. Our work adopts a similar process, using design sketches to evoke participant reactions to different ways of documenting and intergenerational sharing of menopause experiences.

Social and familial context is also important for grounding menopause experiences. Researchers have discussed menopause as *less about bodily experiences by themselves and more about how experiences with the body become meaningful over time in the social context* [74]. Women often try to make sense of their personal menopause experiences by learning from the experiences of other women, including contextualizing their experiences in family history [74]. Moreover, families and close ones are often an important source of support during life events, such as menopause and other fertility-related transitions [27, 28], and family dynamics are key in shaping individual perceptions and experiences. For example, in some cultures, middle age women have historically been expected to prioritize familial responsibilities (e.g., care-taking of elderly relatives) [78] over their menopausal transition. Women also experience barriers to accessing family history and support, due to reasons such as family dynamics, death, and taboo. Past research on menstrual health [22, 49, 133] also recognized comparing experiences with others, including experiences shared online (e.g., on Reddit [22, 74]), to be a key part of individual sense-making practices.

Researchers have thus called for design to support recording and sharing menopause experiences and related health information with other women, friends, providers, and future generations [74]. Feminist scholarship has created design frames documenting varying menopause experiences and developed concepts that support individual sense-making as well as sociability in menopause-related situations (e.g., “meno-hotels” that provide care and address all needs for individuals experiencing menopause) [12]. However, the concepts focus mainly on contemporaneous experience sharing around menopause [12], that is, recording experiences for sharing with future generations is still an open design research problem. Our work responds to this call by understanding menopause-related information individuals wish to pass to future generations and within families, and potential ways to record and share.

Lastly, medicalization of menopause is a growing concern, especially as practices in various cultures are often based on non-medicalized views (e.g., not seeking treatment [120], use of alternate therapies [80, 121]). To resist medicalization, HCI researchers have responded by creating technology that celebrates the body during menopause and works to dismantle oppressive systems [24]. Personalized applications that support tracking symptoms intend to help women understand the “eventual consequences” on their health [131, 132], but these interventions risk affirming negative connotations and view natural changes as problems that must be fixed. Researchers have thus also refused to design self-tracking tools that risk medicalizing menopause [61]. Although our research refrains from medicalizing menopause experiences, we do introduce journaling and health tracking in our design sessions. Our findings intersect with the medical system as participants report on interactions with medical providers, including challenges in information-seeking and communication. However, resisting medicalization does not necessarily mean not engaging with medical providers, but dismantling an oppressive system and ensuring women’s experiences are not disregarded [24]. Thus, we focus on information sharing and support-seeking, viewing menopause as a part of the reproductive health journey, not necessarily fitting within dominant medical and diagnostic paradigms.

2.2 Digital Legacies & Documenting Health Journeys

A digital legacy is a collection of digital information available about a person following their death [143]. Researchers have created systems to address challenges introduced by non-material digital legacies (e.g., data ownership [82, 112]). HCI and CSCW research has examined passing on of legacies and post-mortem access in the context of social media [15, 103, 110], such as the curation of digital memorials [15, 16, 92]. In such literature, access to digital legacies has been a main consideration, with a focus on the concerns about who can access what data and when [37]. Our work engages more broadly with different digital and non-digital formats for creating and sharing legacies (e.g., journals, video logs, voice recordings, social media) to explore information people would like to share with future generations and any corresponding reservations.

Digital legacies are often studied with consideration for the value of physical objects, such as heirlooms, that are traditionally used for collecting and passing down memories. Physical objects can encourage reminiscence [55, 70] and represent relationships and experiences [55]. Researchers have also leveraged existing practices with physical objects to design technologies that allow digital collection and archival of records and memories [32, 70, 104, 108], incorporating the benefits of physical objects. For example, Banks et al. [10] examine “technology heirlooms”, digital artifacts that maintain a physical form (e.g., a hard drive) and are passed on from a previous owner to leave an impression of that owner. However, studies have also found a tension in the creation and management of digital legacies while maintaining the familiarity of transmission of physical objects [55]. In contrast, leaving behind the constraints of physical forms allows digital legacies to store a lifetime’s worth of information and experiences [29, 53]. Low-cost, abundant digital

storage can support life-logging, the capturing of daily life in varying detail and for different purposes [57]. Capturing such mundane activities can allow legacy creators to reconnect with family through sharing personal experiences, reflecting on personal development, and augmenting memories [21, 29, 36, 127, 128].

Although digital legacies do not face the same preservation issues as physical objects, they bring other challenges. Older adults who are not familiar with legacy-creating technologies may feel excluded when creating and inheriting digital legacies, while acknowledging that the younger generations are not only more familiar with technologies but also more confident in their technical abilities [127]. Moreover, digital legacies could complicate inheritance processes [3, 59, 84, 110] as there is a lack of established approaches to post-mortem digital information management [91, 93], including challenges around honoring the deceased's wishes [37]. There is also little research on what people might want to curate from the abundant information captured using life-logging. In our study, life-logging emerged as a way to create legacies that do not focus only on menopause but instead treat it as a part of people's lives. Our discussion further engages with principles of archival science [94] to understand what people wish to share and in what capacity, specifically appraisal (i.e., what to keep), sensitivity review (i.e., what cannot be disclosed), and access (i.e., who has permission to view records).

In health contexts, digital legacies have been used to document experiences and to facilitate informational and emotional support. Creating health video logs can help individuals process their own physical and emotional accomplishments and struggles while also offering tangible strategies, encouragement, and inspiration to viewers with similar health conditions [64, 77]. Audiovisual narratives have also been examined for feasibility and acceptability among patients with advanced cancer [35]. For example, women who survived gynecological cancer recorded audiovisual narratives that were shared with cancer survivors, finding that the process of recording supported reflection on their own experiences and also informed survivors of later experiences after treatment [46]. In such a way, storytelling and narration-based interventions can serve many purposes for survivors, such as providing a sense of closure [35] and empowering people with similar experiences [25, 31]. By focusing on the experiences of storytellers, storytelling can also help shift away from medicalization and a perception of an individual as a "victim of disease" [50]. Moreover, researchers have created theoretical frameworks for sense-making in chronic illness using self-monitoring data [83]. In the context of stigmatized health, documenting health journeys has the potential to facilitate reflective sense-making as individuals interact with multiple versions of themselves (i.e., their past and present selves) [67]. Our work similarly aims to highlight individual experiences as opposed to medical understanding of menopause, and we therefore create a design space which focuses on documenting and sharing of personal experiences. We also examine preferred formats for recording and intergenerational sharing of menopause legacies, structuring our sessions such that individuals reflect on their information needs and challenges in receiving support, while creating legacies they felt would be valuable for future generations to contextualize their experiences.

3 METHODS

Our IRB-approved study took place from February to June 2022. Our goal was to understand participant experiences with menopause, specifically their information seeking and sharing practices, and to engage them in thinking about/designing artifacts for recording and sharing experiences with future generations. We conducted sessions with 17 participants, each consisting of a semi-structured interview with a design component.

Table 1. Self-reported demographic details of study participants.

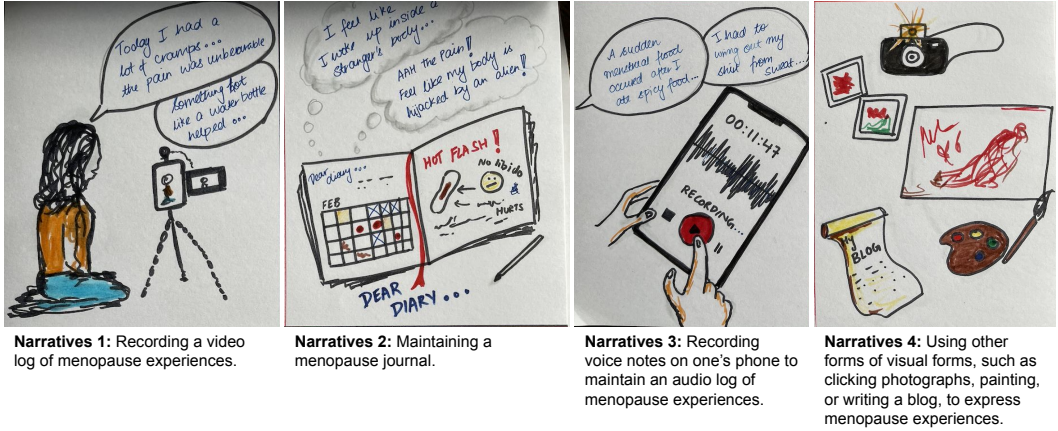
P#	Gender	Current Age	Age of Starting Menopause	Length of Menopause Experience	Self-Reported, Open-Ended Nationality/Race	Language Used for Study
P1	Cis-Woman	49	44	4 years	Indian	English
P2	Cis-Woman	56	50	6 months	Japanese	English
P3	Cis-Woman	54	40	10 years	Salvadoran	Spanish
P4	Cis-Woman	47	41	7 years & ongoing	African American	English
P5	Cis-Woman	60	39	1-2 years	Thai	Thai
P6	Cis-Woman	50	46	1 year	Indian	English
P7	Cis-Woman	62	55	6 years	American	English
P8	Cis-Woman	72	55	16 years	African American	English
P9	Cis-Woman	72	48	16 years	African American	English
P10	Cis-Woman	62	48	7 years	African American	English
P11	Cis-Woman	66	50	3 years	American	English
P12	Cis-Woman	68	40	8 years	Thai	Thai
P13	Cis-Woman	49	48	2 years & ongoing	Japanese	English/Japanese
P14	Cis-Woman	43	32	6 years	African American	English
P15	Cis-Woman	60	48	4 years	African American	English
P16	Cis-Woman	55	49	6 years	African American	English
P18	Cis-Woman	52	51	1 year & ongoing	Mexican	Spanish

3.1 Participant Recruitment

Participants were recruited using a combination of snowball [58] and purposive [129] sampling, using social media platforms (e.g., Twitter, Facebook, Reddit), a medical research participant pool associated with our university, and our personal networks. Ten participants were recruited using social media by posting on menopause and women’s health-specific groups and pages and the medical research participant pool, while eight were from our personal networks (4 first-hand connections, 4 second-hand connections). Recruitment text can be found in supplementary materials. Because menopause is a personal and potentially sensitive experience, not everyone is willing to share their experiences with others. By posting in relevant spaces, we aimed to recruit people who had experiences of menopause and were already interested in intergenerational sharing of those experiences. Thus, all potential participants were required to complete a screening survey to ensure eligibility: (1) are currently experiencing or have experienced menopause and (2) are interested in sharing their experiences with future generations. Because our research group is multicultural and multilingual (i.e., with members fluent in English, Hindi, Japanese, Spanish, and/or Thai), we did not restrict to only US nationals and English-speaking participants. Although this afforded the opportunity to include perspectives anchored in different cultures, we did not seek to systematically make cultural comparisons in this study.

After recruiting 18 participants, we conducted one-on-one sessions with 17 in their preferred language (1 participant dropped out due to scheduling issues). Table 1 details self-reported participant demographics and the language used for study sessions. Participants were compensated with a \$20 (or equivalent) gift-card.

3.2 Preparing the Design Sketches



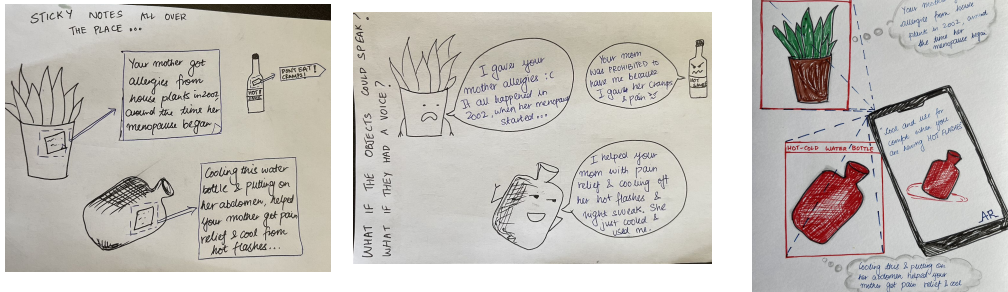
Narratives 1: Recording a video log of menopause experiences.

Narratives 2: Maintaining a menopause journal.

Narratives 3: Recording voice notes on one's phone to maintain an audio log of menopause experiences.

Narratives 4: Using other forms of visual forms, such as clicking photographs, painting, or writing a blog, to express menopause experiences.

Fig. 1. Design sketches created for the *narratives* concept. The individual consciously records their menopause-specific experiences to share with others. These sketches show the use of audio, video, written, or other visual formats for recording and sharing personal narratives about menopause.



Heirlooms 1: Putting sticky notes on household things - that hold some value or memory relevant to one's experiences with menopause - for family members to read.

Heirlooms 2: Each object has a recorded audio message attached to it - almost like objects are talking to an individual, telling them experiences of their previous generations.

Heirlooms 3: AR technology to record and see "virtual sticky notes" associated with specific objects. The individual points their phone at different objects and the value/memory associated with each object pops up on their phone screen.

Fig. 2. Design sketches created for the *heirlooms* concept. The individual records their experiences by associating values with objects in the physical world. These sketches show recorded experiences attached to physical objects (e.g., a plant, a water bottle) that future generations can access to learn about menopause experiences of previous generations.

Informed by prior work on menopause in HCI and digital legacies, we identified 3 different concepts for maintaining and sharing legacies and appropriated them to the context of menopause: narratives, heirlooms, and life-logging. We tried to include some core ideas we saw in digital legacies literature (Section 2.2). We made 4 sketches for narratives (Figure 1) and 3 sketches for each of heirlooms (Figure 2) and life-logging (Figure 3), highlighting ways in which the legacy of a person's menopause experiences could be maintained and shared with family members and future generations. After conducting sessions with 8 participants (P1-P6, P9, P12), we added a

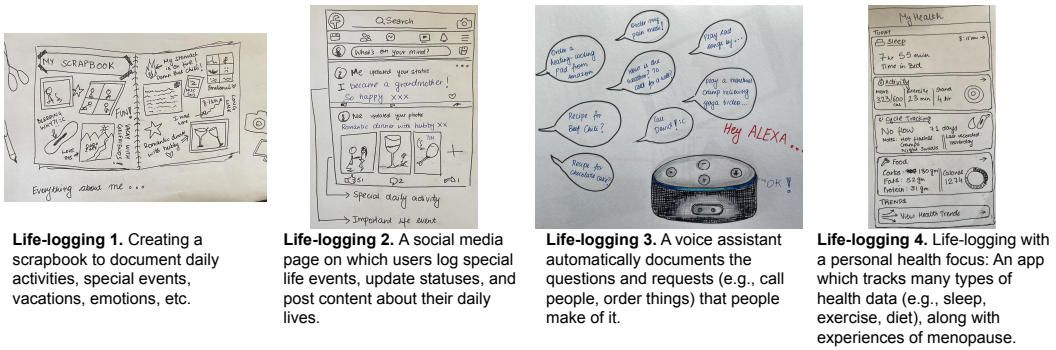


Fig. 3. Design sketches created for the *life-logging* concept. The individual’s everyday activities are recorded to maintain a continuous account of their experiences during menopause. These are not necessarily menopause-related experiences. These sketches show the use of a scrapbook, social media, voice assistant, and general health tracking app for going beyond symptomatic experiences to record everything one felt and did during menopause.

fourth sketch for life-logging (see Figure 3 Life-logging 4) to support probing about elements of digital health tracking and datafication that had saliently emerged in initial sessions. To support different levels of comfort with technology, we created sketches of both digital and non-digital ideas for each concept, so that digital characteristics of sketches would not hinder participants from understanding and relating to each concept. We also included quotes (e.g., “my body is hijacked by an alien”) and terminology (e.g., menstrual flood) from HCI menopause literature [12, 74] in the sketches to build on previous work and make concepts more relevant to the context of our study. Figures 1, 2, and 3 describe each concept and the different sketches made for each concept. We used these sketches as probes during each study session.

3.3 Study Procedure

All sessions were conducted via Zoom (an audio/video teleconference platform). Two researchers were involved in each English session: one conducted the session while the other took notes. Non-English sessions (Spanish, Thai, Japanese) were conducted alone by research team members who were native speakers of that language. They also made notes about the session in English and shared with the research team. Each session lasted 1 to 1.5 hours. We began by describing the goal of the study and obtaining informed consent, including permission to record audio and video.

Each session was split into three phases: pre-design, design, and post-design. The goal of our sessions and design activity was to develop an in-depth understanding of (i) how participants would want to create their own menopause legacies, (ii) what information they would want to include, and (iii) how/with whom they would want to share their legacies. Each session was structured such that participants could also reflect on what they found useful for understanding and managing their menopause, including information or support they wished they had, while thinking about different ways of recording/sharing their experiences. Because legacy creation might be an unfamiliar space for participants, we used design sketches as probes to facilitate the process, aligning with recommendations to use probes for encouraging participation in design tasks that go beyond traditional expertise [85].

In the pre-design phase, we conducted a semi-structured interview to understand participant menopause experiences and how they obtained information about menopause. We inquired about their personal experiences (e.g., “When did you experience menopause?”, “How long did it last?”),

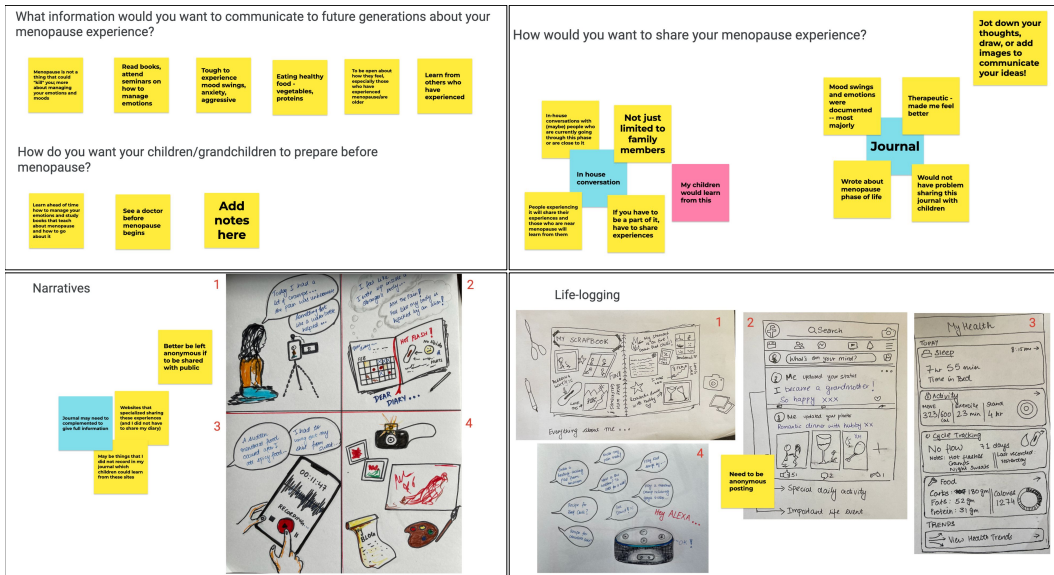


Fig. 4. Sample of annotated Jamboard slides from P15’s design session. The top images show slides used to facilitate brainstorming about information to share with future generations and how to share. These slides came before we introduced the design sketches as probes. The bottom images show slides with the *narratives* and *life-logging* ideas and P15’s annotations on them.

including what information they received or wished to have received prior to starting menopause (e.g., “Did you have any information or guidance before starting menopause?”, “How did this information prepare you for your menopause experience?”, “What more information do you wish you knew before starting menopause?”).

In the design phase, we used Google Jamboard² to facilitate co-design and brainstorming. Participants could use the Jamboard slides as their canvas to write, annotate, and/or sketch their ideas. However, because many participants were hesitant to sketch and/or not comfortable using Jamboard, those participants verbally conveyed their ideas to the researchers, who shared their screen and annotated the Jamboard as the participant spoke, so the participant could give feedback to make sure the board reflected their ideas. Figure 4 shows sample Jamboard slides annotated during P15’s session. Participants were encouraged to brainstorm ways they would like to record and share their menopause experiences with family members and future generations. Participants were first given several minutes to consider how to communicate their learnings and experiences, then we used the design sketches to probe their ideas and design process. For each of the three concepts (narratives, heirlooms, life-logging), we asked about the participant’s initial thoughts, effectiveness of the concepts for communicating their menopause experiences with future generations, and whether they would like to incorporate any of the ideas proposed in the sketches into their lives. We further probed on how participants would like to use some of these artifacts or the information they documented (e.g., to share with others, to self-reflect) and the participant’s desired limits on sharing (e.g., with whom they would want to share, in how much detail). However, though planned as co-design, we found that participants were more comfortable reacting to the design space we presented. While some participants suggested some modifications to the design sketches presented

²<https://jamboard.google.com/>

(e.g., P4 modified Narratives 2 to be a chapterbook that could be passed down generations and every menopause-experiencing family member could contribute to it) and one proposed a new concept (P2 proposed a questionnaire that allows people to enter their experiences and compare with others), conversations primarily focused on reactions to different points in the design space represented by the design sketches. After interacting with the sketches, we concluded the design phase by encouraging participants to return to their initial brainstorming to add or make any changes (e.g., to notes, designs, thoughts) based on the discussions we had in the design phase. The outcomes of this design activity are summarized in Table 2.

In the post-design phase, we asked participants to reflect on the design activity and share their thoughts and feedback.

3.4 Data Analysis

All recordings were transcribed in the language in which the session was conducted. We did not translate the non-English sessions for analysis, so as to preserve language nuances and cultural references. We analyzed all collected data (i.e., transcripts of audio recordings, session notes, annotated Google Jamboards) using reflexive thematic analysis [14]. The first and second author started by coding two English sessions individually and comparing their analysis to develop a rough outline of the coding scheme. The first author then open coded data from each English session and began constructing initial themes based on patterns in the data (e.g., “Absence of female family members or those with relevant experiences”, “Impact of lack of open conversations on receiving information/support”, “Unsure how to use information shared by family/friends”). Conceptually similar codes were grouped into higher-level themes that were used to structure the findings (e.g., “Challenges in communicating about and receiving menopause-related support from friends and family members”). The first author performed this process iteratively, using a combination of open and axial coding [118], while discussing with the other authors as the coding developed (specifically the second author). Although codebooks are not part of reflexive thematic analysis, we did document codes and initial themes to facilitate coordination across researchers. This coding scheme was then used by the second, third, and fourth authors to analyze the non-English sessions for which they were each a native speaker. The authors came together frequently to discuss codes and themes, to continue developing a shared understanding, and to resolve disagreements. All authors remained in constant touch with the data through the collection and analysis stages, providing regular feedback to each other.

3.5 Limitations & Ethical Considerations

Due to COVID-19 restrictions, we designed the study such that all sessions were conducted remotely, using Zoom and Google Jamboard to collaborate and brainstorm. As noted, participants did not engage with the Jamboard as much as we had hoped and were more comfortable reacting to the design space we presented. We therefore updated our protocol, giving participants an option to verbally convey their ideas while the researcher shared their screen and annotated the Jamboard. We thus adapted and improvised our design activity [75] to fit the constraints of an online environment and participant levels of comfort with the technology. Such practices are common in design research with children [140, 141] and older adults [116], as co-design facilitation is often unbalanced, with participants requiring assistance in using and designing with different platforms, and preferring to talk through their ideas and react to the design space.

Four of the six authors, although currently based in the US, are of non-US origin and have different native languages (Hindi, Japanese, Spanish, Thai). Participant demographics (specifically language and culture) correspond to our backgrounds, the need to share a language with participants, and our recruiting from our personal networks (among other sources). Although recruiting

via personal networks afforded some convenience, personal familiarity also provided additional context supporting in-depth and nuanced understanding of participant experiences. Moreover, because the study was conducted over Zoom, we had flexibility to engage with participants with different self-reported nationalities/race, affording us the opportunity to include different cultural perspectives around cultural stigmas, views on non-medicalization, and familial support around women's reproductive and sexual health.

To maintain the privacy of participants, we quote only relevant excerpts from sessions and remove any personally identifiable information. As noted, analysis was performed in each participant's original language. To support English language readers, we use translated versions of the quotes and provide the original quotes in supplementary materials. Although native language speakers translated the non-English quotes, the translations might not be completely accurate, possibly losing cultural significance of words and references.

Although some of our findings are informed by the cultural backgrounds of participants (e.g., social stigma around menopause and mental health, use of natural remedies like Ashwagandha³), our research focuses only on the experiences and possibilities for designing tools to enable intergenerational sharing. We also acknowledge genetic influences of menopause may differ across racial and ethnic groups [145]. Participant age and how long ago they experienced menopause also affected how much they remembered the experience. Participants had different levels of digital literacy and comfort with technology which significantly shaped their design decisions (e.g., preferences for digital versus non-digital formats) and potentially participation in the design activity and using Jamboard. Finally, we focused on and recruited for experiences and needs of those who wish to share, so our results do not reflect views of those who have no interest in sharing.

4 FINDINGS

4.1 Participant Experiences & Current Sense-Making Practices

Participants described their experiences of menopause, focusing on their practices of management and sense-making as well as challenges faced in preparing for, accepting, and relieving symptoms.

4.1.1 Identifying Menopause Symptoms & "Not-Normal" Bodily Experiences. Participants reported different symptoms that helped them identify menopause onset or whether they were still experiencing it (because menopause can last several years). These included physical/bodily symptoms (e.g., irregular menstrual flow, hot flashes, difficulty sleeping, skin irritation, weight gain) as well as symptoms that directly impacted their sexual experiences (e.g., vaginal dryness, pain during sex, decreased sexual drive). Participants also discussed effects on their mental and emotional wellbeing, leading to mood swings, anxiety, depression, and reduced patience.

In some cases, participants were uncertain about what was considered a "normal" experience of menopause. This included being unsure whether specific experiences were due to menopause or other health complexities and underlying conditions, such as arthritis (P6) or infections (P7). For example, P1 had previous gynecological issues and could not exactly "pinpoint" when her menopause started. She was undergoing treatment and had a Mirena intrauterine contraceptive device (IUD) placed: "I mean, the changes in my uterus were not like, they were not like the normal menopausal changes."

4.1.2 Challenges in Preparing for Menopause. Nine participants explicitly noted having felt unprepared and wished they had known more about different symptoms before they experienced

³Ashwagandha is a supplement derived from a herb used in Ayurveda (a form of non-western medicine) which may help alleviate menopause symptoms such as hot flashes and urinary symptoms [138]

menopause. This lack of knowledge and foresight led some participants (P3, P7, P9, P14, P15, P18) to not prepare before menopause started.

All I knew about menopause was that when a woman gets to, let's say, the age of 50 or so, she experiences menopause. I was surprised I had it at the age of 40... not like I was too young or something but I wasn't expecting it early... So I didn't need the knowledge I had and the experience I had was quite different from the knowledge I had of it [menopause]... I didn't see it coming. So I didn't quite pay attention to having enough knowledge about it. (P9)

Menopause often came “unexpectedly” (P15), as a “shock” (P7), or “out of nowhere” (P7). P14 and P18 noted that despite having close family members (e.g., sister, mother) who went through menopause, they did not receive information about it and were not prepared. P18 attributed this to: “*people back then were too private and reserved. They didn't even talk to you about menopause... no one prepared me for the first day of my period or menopause*” (translated from Spanish). This could also be connected to P18's upbringing within a *machismo* culture where women are often reserved and private as a means to maintain a good image in society. P13, on the other hand, more directly attributed “*the need to hide it, not hide it but... not be open about menopause*” (translated from Japanese) to the Japanese culture of keeping things hidden and out of the public eye. This can further be because menopausal transition is not given much significance in Japanese culture as it is often seen as a natural part of aging, not a condition which indicates physical decline or emotional instability, and women are often expected to prioritize other familial responsibilities at that age [78].

Although previous literature has cautioned against medicalization of menopause—especially situations in which the medical situation pushes people toward certain ways of navigating menopause—participants emphasized wanting support from clinicians and medical systems to facilitate understanding their experiences and options for navigating them. Seven participants who felt ill-prepared also consulted a doctor to help identify and understand symptoms and potential treatments. Doctors were generally helpful in letting patients know they were “*approaching menopause*” (P7) and advising exercises, being on a diet, “*supplement(ing) to make up for depleting calcium resources*” (P1, P6). However, participants (P1, P3, P8, P15) complained about not receiving sufficient and “*explicit information*” about symptoms as well as relief methods and treatments (e.g., medications, HRT, dietary recommendations) before starting menopause. Evolving understanding of menopause treatments, such as HRT, might have led doctors to be unaware of or uncertain about some treatments and thus not recommend them [40].

Lack of awareness of mental and emotional health impacts of menopause also contributed to unpreparedness:

I wasn't aware of the fact that it [menopause] would affect my emotions... maybe I would have prepared better for... Maybe lift up my spirits. (P14)

The combined stigma around menopause and mental health made participants feel “*restricted to go and ask anybody [about menopause] because... I [P9] felt overwhelmed, depressed and irritated... and shame talking to someone about it*” (P9), leading to lack of information, support, and therefore a lack of preparation. Past HCI work on menopause has shown that stigma often stifles conversations, hence inducing isolating experiences [12, 74]. Through that lens, participants' unpreparedness might be further amplified by conversational stigma around mental health, along with the stigma of menopause itself.

4.1.3 Assessing & Making Sense of Bodily Experiences. Participants shared different ways in which they learned, assessed, and made sense of their experiences.

Six participants described reading books and looking up information online when they were already experiencing different symptoms. P4 “*just Googled some stuff and realized what was going on*” (i.e., that she had started menopause). In contrast, P1 correlated information provided by her gynecologist to information from online resources, validating the information and her experiences of menopause with a Mirena IUD.

Participants also noted speaking with various female family members (e.g., mothers, aunts, sisters) and friends to make sense of menopause and to compare their experiences:

I heard a lot of scary stories about hot flashes. So many of my friends couldn't work, go to work, or get on trains or go in front of people because of the hot flashes. So I was very scared of that... It would be very difficult if I could not speak to people because I'm doing a consulting job. So it was very scary, but it didn't happen to me luckily. (P2)

Although many participants experienced similar symptoms to family members (e.g., P7's mother got itchiness and rashes on her body while approaching menopause, similar to P7's experience), other participants could not relate to the experiences of family members. However, even when they had dissimilarities in specific experiences, participants received other guidance and recommendations from family and friends. These included recommendations for when to visit a doctor, diet plans, self-care routines, as well as reassurance that things would be fine.

Participants also shared that expressing oneself by talking to someone (i.e., those who could relate to or had knowledge of menopause) helped relieve stress and helped “*with a lot of other issues*” (P4), such as improving mental well-being and relationships with family members.

Participants also consulted with medical providers to make sense of their experiences. Although a few shared positive interactions with doctors, others raised concerns such as normalization of their menopause-related issues. In some cases, this seemed aimed at making participants comfortable with their experience: “*My doctor told me I shouldn't panic because it is a normal thing that happens to every lady at that age*” (P7). In others, participants felt their concerns were “*brushed away*” (P9) by doctors, making them feel further stigmatized in talking about menopause and negatively affecting sense-making.

Lastly, some participants reported paying close attention to their body as a way to understand and assess the effects of menopause. For example, P4 shared how she made sense of her experiences by paying attention to changes in her body and subsequently searching for relevant information online:

like to know your body and pay attention to your body because the stuff that you see on Google or what somebody would tell you that can be good for their body, but everybody doesn't do the same thing. So if you kind of pay attention to ... just little things kind of like 'I know that I'm not a person that gets hot/sweaty...' So that was like... a red flag to me like this, I normally don't get this hot. So let me Google and find out what's going on... that's what I would just say pay attention to, to your body and know your body, like what's going on with your body... (P4)

Although P4's doctor wanted to put her on oestrogen (as a part of HRT), she “*did more research on different medicines*” to understand what would work for her body and decided to instead take vitamins and Ashwagandha gummies because oestrogen would have “*too many side effects.*” P15 also chose not to follow recommendations for HRT because of the possibility of complications (e.g., indigestion, headaches, leg cramps, swelling in the body) arising from the treatment.

Corroborating information from different sources helped these participants better understand their bodies, validate their experiences, and choose treatments that work for them. Moreover, P13 described experiencing a “*change of consciousness*” (translated from Japanese) towards her body after experiencing menopause. Heightened awareness of changes in her body motivated P13 to

pursue more regular physical examinations as compared to before menopause, change her approach to management, and take better care of her body.

4.1.4 Relieving Menopause Symptoms & Challenges with Acceptance. Participants shared multiple ways they relieved their symptoms. These included **medical ways** (e.g., painkillers to relieve symptoms such as headaches (P6), non-western medications and supplements such as Ashwagandha gummies for improving sleep (P4) and traditional Chinese herbal medicine (P13)), **non-medical ways and lifestyle practices** (e.g., regular exercise and yoga, increasing vegetable and protein intake, increasing water intake, following a self-care routine, applying cold water pads to comfort from hot flashes), and **distracting oneself** or “*shifting my focus away from menopause and towards things I enjoy in my daily life*” (P13, translated from Japanese). Some recommendations were shared by family members who experienced similar symptoms. For example, P14’s sister shared her self-care routine, recommended regular exercises (e.g., yoga, long walks in the morning), and suggested P14 track her activity. Other recommendations were either shared by doctors (e.g., HRT, dietary changes, “*start exercises*” (P7), watch water intake) or learned by participants through reading online resources, watching videos, or experimenting with their health (e.g., changing and assessing diet).

However, symptom relief methods participants could use were affected by their environment, especially in public or work settings or when symptoms “*came at the wrong time*” (P11). While at home, P4 could “*just take my clothes off*” and “*wait for the [hot flash] wave to die down,*” these were not options at work. She resorted to milder measures such as drinking water and stepping outside for air.

Some participants also described their struggles with “*accepting*” the effects of menopause, including menopause’s impact on their physical appearance, mental well-being, and care-seeking behavior. For example, P7 struggled to embrace the change in her physical appearance:

The body changes... There were a lot of body changes like I started having saggy breasts and it got me worried... I think that affected me emotionally because you know... we love our physical looks a lot... So I was worried about that... it got me down. (P7)

Similarly, P11 noted feeling “*unnecessarily upset about little things*” during moments of discomfort. P16 struggled to accept her changing body image and self-identity: “*I had this feeling that I was actually losing my body.*” P9 described downplaying her symptoms to avoid seeking care, hoping things would “*normalize*” on their own and that menopause would “*go away*” without actively doing something, but also that she felt “*constrained*” due to menopause.

4.2 Information Needs & Communication Challenges

Participants wished they had known information to support preparedness, about symptomatic details and management techniques, and about menopause experiences of their family members. They also described barriers to seeking that information and support from family members and earlier generations.

4.2.1 Types of Information Needs. Participants shared what they wish they knew before starting or while experiencing menopause. This included general awareness and information to support preparedness (e.g., early Calcium and Vitamin D supplementation to maintain bone health (P1, P6), tactics to manage emotional changes (P15)). Three participants (P1, P11, P14) felt information about different resources to consult (e.g., books, videos, talk shows) would also have been useful. Others reported wanting more details about different bodily changes and symptoms (e.g., change in size of menses, mood swings, pain), medicines, potential treatments and supplementation, as well as the impact these could have on their daily lives. As in Section 4.1.2, participants shared that such

information would have helped them feel more prepared. Eight participants would have liked to have known more about experiences of their family members as they felt those may have informed or been similar to their own (e.g., due to genetics, similar living environment). They noted that it would have been good to know about “red flags” (P4) to watch for as well as general family health history or genetics that could influence menopause.

4.2.2 Challenges in Receiving Information & Support from Earlier Generations, Family Members, & Friends. Participants reported challenges in communicating about menopause and receiving information and support from friends and family. A common obstacle was the absence (or lack) of female family members or those with relevant/similar experiences, including absences due to death. Three participants (P1, P11, P15) lost family members and could not communicate with them about menopause: “I lost my mom at a very tender age. So she wasn’t there to answer any of these questions.” (P11). P1’s late mother lacked the experience of menopause as she had a hysterectomy—a surgical procedure to remove the womb—in her 40s and P1 noted having “not many ladies in my house” she could talk to. Although participants also turned to their female or menopause-experiencing close friends for information and support, lack of similarity in experiences was another challenge. Other types of “absences” included family members not being able to remember their experiences due to old age and lack of close relationships or regular communication with distant cousins or family.

While other participants had access to family members who could share, they reported barriers to open conversations which prevented them from accessing the support these family members could offer. Although participants noted many benefits of open communication (e.g., building an understanding among the family about personal experiences, helping individuals better accept and manage their menopause), participants described hesitating due stigma and the fear of conversations becoming “gossip” (P3, P18). For example, P16 did not talk with her spouse about menopause and “avoided him” when experiencing symptoms such as severe cramps, sharing: “I was somehow maybe scared or shy to talk to anyone about what was happening to me.” P2 also expressed hesitation in speaking with her immediate family members (husband, daughter, son) because she felt her symptoms were not “that severe.” However, P2 felt comfortable speaking with friends or acquaintances to gain information and make sense of her experiences. For P3, the fear of gossip prevented her from initiating conversations about menopause with her coworkers or friends. Since P3 had a tough experience with menopause (e.g., depression, which is also taboo in Hispanic culture), she did not want to take any chances by sharing her sensitive experiences with others. P18 attributed the lack of information sharing to “lack of communication, lack of everything in general because that topic [menopause] isn’t spoken about much” (translated from Spanish), potentially indicating that speaking about menopause was considered taboo within her community. Similarly, P5 spoke to the potential conversational stigma around menopause in her community, noting that people (e.g., P5’s neighbors) might be willing to share their experiences “but we’ll have to ask, if we don’t ask, they would not just tell” (translated from Thai).

In other cases, participants did not anticipate that the information and support they could receive from family members or friends would be useful or relevant, and so they did not pursue such conversations. P13 did not talk about menopause to her family (e.g., with her husband) because she was unsure how useful the conversation would be. At the same time, P13 recognized the importance of having open conversations about menstruation with her daughter, whose experiences significantly differed from her own, and this encouraged P13 to potentially talk about menopause with her children in the future:

My daughter has horrible menstrual cramps, even though I have no problems. Since I had never gone through that kind of trouble myself, I can’t relate to my daughter’s experience of taking birth control pills for cramps or her pain. When my daughter experiences menopause,

I don't know if I will still be alive, but I hope to understand together the body, which with menopause, is especially linked to the mind. It's not something that you can do away with medicine, but more to do with...how to carry your mind...That's why I really felt that it would be nice to be able to take various approaches. (P13, translated from Japanese)

Participants also struggled to see connections between their personal experiences and some recommendations:

Then she [my mom] recommended medicine for me, which of course, I didn't take as my mom's quite old. And she believes in this traditional stuff. So I don't take that... she talked about me doing exercise. And at that time, I didn't see any reason for exercising. I didn't see how that connected to menopause. I guess... She didn't have a good knowledge of what to be done about. But she was the only one I talked to about it. (P9)

This mismatch between information shared by others versus the support needed or wanted by an individual can be due to differences in experiences of the participants as compared to their family members and friends. Alternatively, participants may want more in-the-moment support but receive more reflective or anticipatory support. Past work has shown that people's support needs may differ from the support others offer, and so they do not always perceive support offered as support [87]. Consequently, P9's experience with not understanding her mother's recommendations may not have reflected a lack of support, but instead a mismatch between what support she wanted or was prepared to hear and what her mother thought she might need. Moreover, participants may not explicitly know their information and support needs, but instead might uncover those needs as part of later discussing and reflecting on their experiences.

4.3 Preferences for What, When, & How to Share

Participants described different information they wanted to share with family members and future generations, their preferred means for sharing, and thoughts on when and how to share. Table 2 summarizes participant preferences for formats of documentation & sharing and the menopause legacies they designed after engaging with the design sketches. Participants also shared preferences around supporting self-reflection, facilitating comparison, and creating menopause-specific versus life-logging artifacts.

4.3.1 Types of Information to Share & Value of Personalized Narratives. Some participants highlighted the need for general menopause education, in the form of classes (P3, P9), informative charts and educational materials (P1, P9, P10), and online support groups/information means (e.g., Facebook pages and social media influencers (P7)). They expressed the need for more awareness about menopause and its impact on mental, physical, and emotional health.

Most participants wanted to share their experiences and advise their children on how to prepare and make sense of menopause. This included sharing intimate details about their symptoms and how to identify potential triggers (e.g., spicy food triggering hot flashes), and what worked for them (e.g., medications and supplementation, lifestyle practices, specific pain-relief yoga poses). For example, P4 wanted to share details about vitamin supplements and “*natural ways to handle symptoms*” so that “*they [her children] won't have to search for it.*” She felt this was important because one's symptoms might be different from those listed online and wanted to “*write down about this [the Ashwagandha supplement] that helped me so maybe it might help you [her children].*”

Participants also wanted to give pre-menopause advice so their children and future generations could prepare to support their health and other needs. This included advice on consulting doctors regularly after a certain age, early supplementation (during 30s and 40s) to maintain bone health and other nutrient levels (which are impacted after child-bearing and during menopause), and also how to have conversations about menopause with partners and family members. Participants further

Table 2. An overview of (1) methods participants used to record their menopause experiences before participating in our study, (2) menopause legacies participants designed or expressed preference for during the study for recording and sharing their experiences.

P#	Before the design session: What, if anything, participants already used or were using to RECORD their experiences.	After the design session: What they designed/expressed HIGHEST preference for RECORDING & SHARING their experiences.
P1		Life-logging on a social media platform or on an app.
P2	Used Google calendar for tracking period cycles.	Questionnaire that allows people to enter their experiences and compare one's own experiences. to others.
P3		Have conversations in person and share audio recordings.
P4		Menopause-specific chapter book which can be passed down generations and every menopause experiencing family member (e.g., daughter) can contribute.
P5		Menopause-specific diary.
P6		"Scrapbook or diary of my life" where one can channelize their thoughts.
P7		App to record/track activities one must engage in during menopause. App to help "distract" from menopause experiences.
P8		Diary only about menopause, recording incidents & experiences in detail.
P9		Record voice notes about menopause experiences & store on the cloud.
P10		Diary only about menopause experiences, written only by self.
P11	Maintained a journal about her life.	Life-logging in a journal, add sticky notes about menopause experiences to journal; share entire journal with children before they start menopause. Sticky notes about menopause experiences on wall.
P12		Menopause-specific diary for recording information-related to symptoms or other related menopause experiences.
P13	Maintained a diary recording incidents (including menopause-related incidents), emotions felt based on incidents, interpretations of those emotions, and reflections on how they should have reacted.	If living with family, share menopause experiences in conversational format only.
P14	"Scribbled" something about menopause-related cramps and stuck it to her bedside wall; one time incident.	Diary just for menopause. Recording in audio or video format about menopause experiences.
P15	Maintained a journal focused on tracking her emotions (e.g., mood swings, anxiety); included menopause-related tracking such as level of pain and emotional stability during that time.	Journal for tracking emotions (including menopause related emotional stability & pain levels).
P16	Maintained a diary specifically for her menopause experiences.	Menopause-specific diary with an addition of "diagrams" or pictures that relate to her menopause experiences.
P18		Audio recordings to share after she has finished menopause.

shared ways in which their children and future generations could identify symptoms and make sense of their experiences. Although consulting doctors was one, participants also recommended reading information and research papers/blogs online (P1, P14), reading books (P15), and talking to older people/friends/other women who experienced menopause (P3, P4, P14, P15, P16). Lastly, almost all participants wanted to give their children general advice, encompassing symptom details and sense-making practices, encouraging them to see menopause as “*not a big deal*” (P2) and just a “*phase of life*” (P1). P7 summarized this by detailing information she wanted to share:

I would love to write/share about what the fuss [around menopause] is all about. What to expect and what not to expect... How your body reacts to it, how your body changes, things to eat, things to do, how to exercise daily, the type of exercise you should engage in... How to talk to people about it [menopause]... fun things to do... [how] to distract yourself with things that you find interesting. (P7)

4.3.2 Preferences: Non-Digital vs. Digital Formats. Upon probing for concrete ways of documenting and sharing menopause experiences with children and future generations, participants expressed preferences for a variety of non-digital (e.g., diaries/journals) and digital formats (e.g., digital calendar, voice recordings, social media blogging, phone apps for tracking). Table 2 describes each participant’s preferred formats and designed legacy.

Physical written formats, such as journals and diaries, were a popular preference, with 8 participants sharing their fondness for writing and journaling as a form of self-expression and reflection: a “*good release*” (P1), “*easier and better*” (P4). Most participants wanted to be the only person to write in such a journal (“*Because it’s my experience. It’s like my channel.*” (P11)).

However, P4 ideated on how she could turn a journal into a “*chapter book*” in which menopause-experiencing individuals of different generations of her family could each contribute a chapter:

It [my journal] can be my chapter in the book... there is some room for my daughter to put her experiences in it and pass it on to her daughter and so on... I will pass it on so that it can be a family thing that goes from generations... because everybody is different and what helps them could help somebody else... or couldn’t help them. . . so yeah it would be like I’ll be chapter one, my daughter is chapter two... (P4)

This could become an ever-growing physical family artifact that could be passed down across generations, supporting addition of chapters by each menopause-experiencing family member and providing recipients a greater repository of relevant experiences to contextualize their own menopause journey. However, P4 also discussed practical concerns in maintaining such a written artifact. These included a lack of time or willingness to contribute among potential contributors, which past works have also recognized as challenges to creating digital (or physical) legacy [127].

Participants described benefits of digital documentation formats. These included the ease of documentation and data entry (e.g., speaking to record a voice note or instruct a voice assistant), storage in “*the Cloud*” (P9, P11), replaying recordings and accessing digital records when needed, and passing down records with low likelihood of misplacement (e.g., “*it is much easier to just share a social media handle with my children*” (P1)). Participants raised concerns about longevity of physical artifacts, which they believed digital formats could solve:

It would be nice to be able to record a video about my menopause experience if I know how. But writing a diary is definitely something that I am capable of... I know for sure that I can write a diary [about my experiences], but how invincible would that be? How long will it last? If it is in a video format, it would last longer. (P5, translated from Thai)

Another potential benefit of digital formats was the ease of entering information into standardized formats (e.g., calendars, tracking questionnaires). For example, P2 wanted to use a “questionnaire” to track her menopause experiences, with her responses exportable to software such as Google Sheets:

If there is a questionnaire like, ‘what is the level of your menopause experience?’ For example - hot flashes, chills, or mood changes, weight gain/losses or something like that, we can answer those questions on a 1-to-5 scale... that would be helpful because it’s more standard and you can compare those symptoms between people... people can just answer the questions subjectively, so that will be helpful... maybe a Google Sheet thing will be good... (P2)

Although manually entering information in digital formats (e.g., Google Sheets, a tracking app) might be technically tedious, P2 felt “collect(ing) information for myself, my sister, aunt, and mother” and “put(ting) that information from several people in one place” could also facilitate easier comparison of experiences, as contrasted to if experiences were recorded in disconnected, physical formats (e.g., physical calendars or diaries).

Participants also described benefits of using existing social media (e.g., Facebook, WhatsApp) for recording and sharing, as their children already used these platforms and they would be more “acceptable” than physical diaries (P1).

Voice recordings (Narratives 3 in Figure 1) were of particular interest to P18, as she felt she could transparently and easily share her toughest experiences in spoken language. This preference could also be attributed to a norm among the Latin American diaspora to use voice notes for communication and passing down memories [30]. P3, who has a similar cultural background, was also intrigued by the voice memos, although she wondered how appealing it would have been for her to record her menopause experiences as she had chosen to keep those with herself given the sensitivity of the topic.

Some participants (e.g., P5, P11) were less familiar with technology and social media, and so they anticipated some digital formats would be challenging to use. For example, P5 was interested in using a voice assistant for life-logging (Life-logging 3 in Figure 3) and the AR-based heirloom idea (Heirlooms 3 in Figure 2), but had limited experience with technology and felt she lacked the capability/would not practically be able to use any of the proposed digital ideas. Past work has recognized challenges related to the digital divide, resulting in people wanting to use technology but feeling incapable to do so [127]. From that perspective, despite multiple participants noting the benefits of digital formats, not everyone might feel capable of or comfortable with using them. We further reflect on limitations of digital formats in the discussion.

4.3.3 Preferences: When & How to Share. Participants also discussed considerations for when and how they could share their documented artifacts and experiences. Eleven participants emphasized the importance of having a face-to-face conversation with their children and grandchildren. For example, P1 wanted to have a “mature discussion” in a “relaxed environment in a very casual way.” Similarly, P14 wanted to sit with her two daughters during a Christmas holiday (a time when her family came together). Participants also wanted to share their documented artifacts (e.g., journals, social media) while having face-to-face conversations. For example, P4 wanted to hand her journal to her daughter/grandchildren and have them initially go through it while having a conversation, using the journal to initiate that conversation.

However, of the six participants who were recording or had recorded some of their menopause experiences before this study (column 2 of Table 2), none had shared the diaries or calendars they had created with children or family members. P2, who had used a Google calendar to track her period cycles during menopause, said “it did not even occur to me to be open about this [menopause] to

the next generation”, attributing it to her culture wherein it is uncommon to be open about sensitive health topics such as menopause.

Age was another key consideration for deciding when to share experiences and artifacts with children. Participants wanted their children to be of “*appropriate age*” (P15) or in their 40s (i.e., nearing menopause) when they had these conversations and were given the artifacts. There is thus commonly an implicit gap between when participants might record the information (i.e., most likely while experiencing menopause) and when they would want to share it.

4.3.4 Self-Reflection & Boundaries of Sharing. Some participants also saw menopause artifacts and the process of recording their experiences as a means to support self-reflection on their menopause journey and emotional experiences. For example, participants stated they would like to “*go back [to their recorded menopause legacy] and reflect on it*” (P8), “*look back on it [my journal]*” (P11). P9 said that along with sharing her experiences in the form of voice notes with her children and grandchildren, she could also listen to them “*from time to time.*” Additionally, two participants (P7, P15) felt that journals and social media were a “*good tool to express [themselves]*” and deal with their emotions.

However, formats to support self-reflection could differ from formats in which participants wanted to share their experiences with others. For example, P1, P4, and P13 would have preferred to maintain a hand-written diary or journal, but felt certain digital formats (e.g., video logging, voice recordings, social media) would be more “*acceptable*” (P1) to their children and future generations:

Vlogging [video logging] is a good idea because future generations are not into reading/picking diaries and books. Though writing a diary has always been a good relief for me. (P1)

In prior work, older adults were less familiar with legacy-creating technologies but often anticipated that younger generations were more comfortable with these formats [127]. We see similar thinking in P1’s preference for video logs over a written diary, as a way to create documentation in a format she felt future generations would be more likely to access and use.

Moreover, because menopause was a personal topic, participants did not always feel a need to share everything they recorded and were selective about who should access what information. For example, P16 said she “*will share everything [about menopause]*” but “*would not like to share about the sex aspects.*” This calls into question whether P16 just preferred not to share about the “*sex aspects*” or felt it was not something they wanted to hear. She would “*want to delete pages*” from her menopause diary before giving it to her children. Similarly, P4 wanted to be selective about who got access to her menopause journal as “*certain things that happen [during menopause] I wouldn’t like to tell everybody that.*” Some participants did not like the idea of using social media to share their menopause experiences because it was not “*very private.*” For example, P6 would not want to just “*blog [about] my life,*” even if it was for sharing “*positively about menopause with future generations,*” highlighting a preference for selectively sharing experiences among more private circles.

In contrast, six participants said they would like to be “*very open*” (P9, P11) about their experiences with their children, grandchildren, and even non-family members, maintaining “*no secrecy*” (P9) and having no problem with people reading “*all that I have written in my journal*” (P11). P10 was open to sharing some of her experiences with anyone who could benefit (e.g., her children, neighbors, friends) but did not want to share about the emotions of fear and worry she experienced during menopause. Prior work on stigmatized health has shown that people are often selective about what information to share publicly [17, 106]. Based on that, P10 might want to be more private about the emotional and mental health aspects of menopause. Alternatively, she might not want to perpetuate feelings of fear and worry to others.

4.3.5 Making It “Menopause-Specific” vs. Menopause as a Part of Life-Logging. Participants were divided on whether they wanted to create a menopause-specific artifact versus a life-logging artifact that contains menopause-specific information along with other daily life information.

Seven participants were more inclined to create a menopause-specific artifact, such as a journal or chapter book. P4 was particular on documenting her menopause experiences in “*something separate*” because she did not want to “*mix [information about menopause] with everything else.*” Similarly, P9 expressed interest in the narrative sketches (Figure 1) because she wanted to “*keep restricted to talking about menopause.*”

Four participants expressed their preference for the life-logging approach. Consistent among these was a feeling that “*menopause is only a part of my life... It will be good if I can record my life experiences, what I cherished in my life, to share with the next generations*” (P2). Although recording menopause experiences was considered important, these participants did not want to talk only about menopause. They liked life-logging wherein they could record everything going on in their lives during their menopause phase, not just symptomatic experiences. For example, P1 liked the social media page idea (Life-logging 2 in Figure 3) as she could record all her life experiences (e.g., important events, fun activities, random outings) and share the “*whole package*” with her children. She also ideated how the social media page could be adapted to include a separate tab or section to document experiences during menopause so that people could filter by it, potentially reducing the difficulty of engaging with entries relevant to a specific topic within a life-log. The ability to integrate recording, tracking, and sharing of menopause experiences into current practices (e.g., writing, sharing voice notes) and interfaces (e.g., Google Calendar, social media) also helped participants not consider menopause an isolated experience or the only thing influencing their lives.

Five participants discussed the importance of using technology and the process of life-logging to distract and relax themselves from emotionally taxing experiences. For example, P3 noted that technologies such as Facebook were “*the only thing that distracted me*” from painful experiences “*when menopause was hitting me the hardest*” (translated from Spanish). Similarly, P15 felt journaling about her life in general helped her “*pour out the content of my heart*” and “*control*” her emotions, as she was getting “*overwhelmed by anxiety, or depression, or whatever it was*” due to menopause.

Lastly, participants wanted their children to cherish their life-logged journals and social media handles as “*memories*” (P9, P11, P14) and things that “*deepen understanding of your family*” (P2), wanting the process of going through those artifacts to be “*enjoyable*” (P2) and non-strenuous. Thus, for some participants, it was important to not treat menopause as an all-consuming, medicalized experience but as a part of their everyday lives.

5 DISCUSSION

We discuss future research and design directions for creating legacies to record and intergenerationally share experiences of menopause and other stigmatized health contexts that need not be medicalized. We also highlight the value of and challenges around leveraging personal narratives and storytelling using life-logging to create holistic memories.

5.1 Understanding Stigma, Unhealthy Comparisons, & Translation Issues

This section discusses barriers to information receiving and sharing: impacts of stigma, unhealthy comparisons, and information translation issues. It highlights tensions between medicalization versus normalization and draws on literature on gender marginalized health [24, 61, 74] to build on the view of menopause as a social justice matter. As past work [12, 24] and participants describe cultural dimension of their menopause, we emphasize that future work developing digital legacies for menopause might need to tailor and adapt for different cultures and norms. Cultural norms and

practices shaped many barriers that participants encountered to menopause preparedness, such as being reserved/private about sensitive experiences (P18) and keeping things out of the public eye (P13), and future work should more systematically explore differences and similarities in design opportunities across cultures.

5.1.1 The Double Stigma of Menopause & Mental Health. Stigma is a significant barrier to communication that could support menopause preparedness (section 4.1.2) and acceptance (section 4.1.4), including receiving informational and emotional support from previous generations (section 4.2.2). Previous research on menopause in HCI [12, 74] and our findings present that stigma often stifles conversations about menopause, thus depriving individuals of intergenerational information sharing and inducing isolating experiences. Moreover, normalization of menopause experiences, being “*brushed away*” (P9) by doctors, and self-normalization to avoid seeking care (e.g., P9 avoided going to the doctor by downplaying her symptoms and hoping they would “*go away*”) all created further conversational stigma. Lack of open conversations can then further increase stigma, deny information that could support individual sense-making, and undermine preparedness. Participants also reported negative effects on their mental health and emotional wellbeing, and that they were unaware of these impacts until they experienced them. Women have double the rates of depression during peri- and post-menopause [2]. We believe mental health impacts of menopause (including struggles with accepting changes in physical appearance and body image) intertwine with cultural stigmas around menopause and women’s health [74] to cause double stigma and to create multiple barriers around preparedness, acceptance, and information receiving. Thus, designers must consider mental health impacts when creating technology or non-digital artifacts for recording and sharing of menopause legacies. Because stigma around menopause and mental health are intertwined, future research should explore how to design to be sensitive to this interdependence and potentially break the vicious cycle if one starts to worsen the other.

It is also important to navigate tensions between stigmatization due to normalization versus medicalization of experiences [61]. As seen in our findings, participants wanted clinicians to listen to their experiences and provide more “*explicit information*” (P1) and details about treatments such as HRT (section 4.1.2). Although participants wanted information, they neither wanted clinicians to dismiss their experiences as normal (and thus to be handled as a natural process) nor to push them toward medical treatments (imposing a medical framing on what participants saw as a natural process [1]). Thus, we reiterate that resisting medicalization does not mean refraining from engaging with medical systems or treatments altogether, nor normalizing health experiences, but instead ensuring that women’s personal experiences are given as much importance as they desire and are not sidelined just because they do not fit within dominant medical paradigms or because they carry stigma associated with bodily changes and mental health impacts.

5.1.2 Risks of Sharing & Translation Issues. Section 4.1.3 describes how participants learned, assessed, and made sense of their experiences. Comparing with others (friends, family members, co-workers) emerged as a common sense-making approach. However, there might be a risk that comparing with experiences of others or with information found online may lead individuals to feel their experiences should be the same, or that the same treatments should work, despite menopause experiences varying greatly [39, 114]. Paying close attention to one’s own body and its needs (e.g., P4) and corroborating information from different sources (e.g., P4, P15) can help diminish this risk.

Moreover, given potential genetic influences on menopause [145], family members might be better comparisons than online resources or comparison groups (e.g., on Reddit). However, we also anticipate that comparison with family members or previous generations could have

negative consequences. For example, older generations who were themselves failed by the medical system [139] or by norms of their generation or community [97] could pass along biased and outdated ideas that harm future generations. Additional harm could be caused to queer women and gender non-binary individuals who experience menopause whose needs are far from addressed by current medical systems [54] and run the risk of further stigmatization [24]. Thus, there might be risk in sharing menopause legacies as they could encourage unhealthy comparisons and perpetuate harmful views, especially given the gender and age-based marginalization people going through menopause still experience. Further research is required to design legacies that facilitate healthy sense-making by not forcing comparisons with other's experiences when not required and reduce the risk of perpetuating harm, especially to those more vulnerable (e.g., non-binary individuals, communities more affected by cultural stigmas around menopause and women's health).

As described in section 4.2.2, there can be mismatches between the support and advice shared by previous generations and the needs of recipients. For example, P9 was unsure how certain recommendations made by her mother applied to her (e.g., "traditional" medicines, exercise). Although P9 may have refused her mother's recommendations because of the medicines being "*traditional stuff*," we also see a dilemma between *my family might be more like me* in some regards, but *less like me* in others. Only talking about what one did for their context of menopause might not be enough. Future generations might also need to think about how they might use or adapt information provided by others/previous generations for their own contexts. Further, such a translation issue might occur more around health topics such as menopause (i.e., which do not fit neatly into dominant medical paradigms and effects of which are enigmatic) as compared to conditions that better fit within dominant medical paradigms (e.g., diabetes, hypertension) or topics concerning "healthy" individuals (e.g., menstruation absent reproductive health issues).

Legacy recorders could go beyond sharing just symptomatic experiences to detail how they managed and made sense of their menopause and made decisions about their health. Such advice can facilitate self-assessment and encourage people to engage more with their bodies [24] to contextualize their experiences, rather than overly relying on other people or online resources. It could also be beneficial as one might not be able to directly use information shared by family members without learning through self-experimentation what works best for them.

Moreover, there is not always alignment between the support future generations want (perceived support) versus the information shared by previous generations (received support) [87]. When discussing sharing information, participants talked about documenting experiences, whether details of everyday life captured in a life-log or journal, or a more synthesized reflection. However, when they talked about wanting support, it was often about answering a particular question or receiving emotional support in the moment. Moreover, media preferences and technology change with time, and people may prefer to access information in formats that did not even exist when it was recorded. This challenge of translating both the medium and the format in which people prefer to record information to those in which future generations hope to access it, while ensuring alignment between perceived and received support, will be an important topic for future HCI and CSCW research.

5.2 Creating Holistic Memories of the Menopause Journey

In section 4.3, we reported on different types of information participants would like to share about menopause with their future generations and formats in which they would like to do so. Participants were particularly interested in narrative-based storytelling and life-logging for documenting and sharing their experiences. This section draws on past research on women's health and health-related storytelling and discusses implications for designing legacies that create a holistic picture of and

individual's life during menopause, facilitate self-reflection along with sharing learnings without necessarily focusing only on unpleasant or negative aspects, and facilitate sensitive conversations.

5.2.1 Life-Logging & Storytelling. Although menopause entailed unpleasant physical and emotional experiences (e.g., hot flashes, mood swings), participants wanted to share general advice encompassing symptomatic details and words of encouragement with their children and future generations. Life-logging emerged as a popular approach for recording and sharing experiences beyond specific physical or emotional experiences. Participants showed interest in life-logging design sketches (Figure 3), resonating with the feeling that menopause is just part of one's journey and not an isolated experience or the only thing influencing their life. Similarly, past literature confirms the ability of storytelling to change the perception that an individual is a "victim of a disease" [50], focusing on empowering people with similar experiences [25, 31] by discussing health management strategies and providing encouragement [46, 64, 77].

Storytelling has been used in communicating about stigmatized health experiences (e.g., abortion [13, 90], HIV [124], gynecological cancer [46]) and in mental health recovery [33, 35, 102], suggesting its potential in navigating communication barriers created by the double stigma of menopause and mental health. Although the sketches we introduced as probes depict different storytelling formats (e.g., voice notes, journal, scrapbook), future research can more concretely explore using life-logging as part of going beyond sharing of just medical experiences in storytelling about sensitive health topics. This could include considerations around using life-logging as a way to distract from menopause experiences by focusing on other parts of their lives (e.g., as with P3 using social media to distract herself).

Participants also viewed life-logs as artifacts that could deepen understanding of one's family (Section 4.3.5), helping create "memories" for children to cherish about their previous generations (P9, P11, P14). We imagine life-logged data can be leveraged to create more holistic memories pertaining to menopause years, not focusing just on symptomatic experiences. Future work can examine the kinds of identities individuals wish to create for themselves using their life-logged data and how future generations receive these life-logs.

However, there are concerns around the information recorded in life-logs. First, some information collected by life-logs might just be irrelevant noise (e.g., voice assistants capturing background noise or irrelevant information as they are used for mundane tasks such as turning on the lights). Past work on life-logging has highlighted similar concerns around noise from intentional and unintentional logging of irrelevant events [53]. A second concern is the difficulty of engaging with a particular topic (e.g., menopause), as separating out and interacting with relevant memories might be hard. More participants were inclined towards a menopause-specific legacy (e.g., journal for menopause experiences) due to the ease of keeping menopause information "separate" (P1, P4). Although a life-log may contain details of interest on a variety of topics, that same variety may present barriers for future generations seeking to use it to learn about any specific topic (e.g., shared menopause experiences). Further research is needed to explore how to remove or filter "noise" from life-logs and to examine the extent of information that should be included in a menopause life-log (i.e., appraisal of what to keep [94]) so as to create a cherishable, holistic memory of an individual and their menopause journey while also being useful for future generations.

5.2.2 Supporting Self-Reflection along with Sharing. Although our design sessions focused on documenting and sharing experiences for the benefit of future generations, we found that participants also saw legacies as a means to reflect on their own menopause journey. The process of recording helped some participants (e.g., P7, P15) express, interpret, and reflect on their experiences and related emotions (e.g., P13). People commonly describe their life in the form of stories to reflect on their experiences [111], both privately and socially. For example,

although people with PCOS used digital spaces such as Reddit to communicate with other people with PCOS for validating and making sense of their experiences, their descriptions included self-reflections about diagnosis journeys, management processes, and health decisions [22]. Expressing experiences thus became a form of self-reflection and further supported the sense-making process, which we also found to be an essential part of participant menopause journeys (section 4.3.4). Similarly, Epstein et al. designed a tool to support sharing data-backed stories of fitness accomplishments and do-it-yourself projects to get support, advice, or feedback, but found that participants primarily used it for their own self-reflection and reminiscence [41]. Thus, it is often difficult to differentiate when describing experiences is a form of documenting experiences for oneself versus for others [41, 44]. This is not necessarily bad, as storytelling becomes a means to support both self-reflection and sharing. Hence, we see potential for self-reflection and sense-making in menopause legacies, via designs to support building a better understanding of one's own experiences, processing related emotions, and consequently navigating other aspects of life while experiencing menopause. Further research is needed to find balance of synergies in creating menopause legacies that support self-reflection for individuals documenting their experiences and support future generations in learning from shared experiences and contextualizing their own experiences.

5.2.3 Legacies as Conversation Initiators & Teachable Resources. In section 4.3.3, participants emphasized the value of conversations for sharing their experiences and wanted to share their menopause legacies while having a face-to-face conversation. Although age of the inheritor was a key consideration for deciding when to share, this finding is in contrast to past research where digital legacies are often passed on after an individual has died [15, 103, 110]. Our research thus uncovers the potential of menopause legacies as initiators for sensitive conversations about reproductive health changes. Past HCI and CSCW research has used physical and digital design artifacts (e.g., comic books, storyboards, educative videos) to facilitate communication and conversations about sensitive health topics (e.g., menstrual health [133], HIV [124]). Additionally, design research popularly uses probes, such as cultural probes [52] or design probes (e.g., [134], our design sketches) for initiating conversations and personal storytelling. A promising future research direction could be to leverage menopause legacies as probes and explore their role in navigating stigma and facilitating open conversations about gendered marginalized health among relevant family members.

In section 4.3.1, participants also discussed the need for general menopause education (e.g., in forms similar to sex-education classes) to increase awareness of physical, mental, and emotional impacts of menopause. Our study did not focus on artifacts or materials for general education, but we imagine that menopause legacies can also act as teachable resources that supplement general awareness with personal narratives of family members whose experiences might directly relate to one's own (e.g., due to similar health histories [74]). Moreover, participants expressed interest in sharing advice on sense-making because experiences of individuals may differ despite similar genetics. Future work can draw on design considerations proposed in work on women's health education (e.g., "cultivating curiosity" to interact with one's own body [6, 19], sensitizing those who cannot experience menstruation [133] or PCOS [22]), appropriating such approaches for sharing personalized experiences as a source of menopause education. Lastly, differences in menopause symptoms [145], communication practices, and experience of stigma may arise due to people's varying ethnic and cultural backgrounds (e.g., P3 experienced stigma talking about menopause and its mental health impact in her community, fearing it may become gossip). Thus, researchers, designers, and people who may be in a position to provide menopause advice must account for cultural and socioeconomic dimensions in legacies, in personalized education materials, and in facilitating communication related to sensitive health topics.

5.3 Considerations for Intergenerational Sharing of Non-Medicalized Sensitive Data

In section 4.3, we described types of information participants would like to share about menopause and components they found important for digital and non-digital legacies to embody. This section discusses considerations for designing menopause legacies, drawing upon existing literature on digital legacies and using principles of archival science: appraisal (i.e., what to keep), sensitivity review (i.e., what cannot be disclosed), and access (i.e., who has permission to view records) [94]. We provide future research directions for examining and incorporating these considerations in designing legacies for sensitive yet non-medicalized health experiences.

5.3.1 Intentional Exclusion on Content & Privacy Perspectives. In section 4.3.4, we reported on participant boundaries for sharing. Participants did not always feel a need to share everything they recorded, considered menopause a very personal topic, and would be selective about who got access to what information. As in section 5.2, granular access control can be challenging, especially for legacies that are built through life-logging. Personal and sensitive experiences documented in such legacies can be difficult to share even with family members. For example, although participants recognized benefits of documenting difficult or stigmatized experiences during menopause, they would choose to remove certain “sex aspects” (P16) and mental health impacts (P10) from their journals before sharing with family members. This calls into question the difference between *what one prefers to share* versus *what is appropriate for sharing*, a challenge also highlighted by Nissenbaum’s conceptualization of privacy as contextual integrity [100] and discussed in past CSCW research in stigmatized health [73, 133], patient-clinician sharing [23], and sharing about well-being or fitness [42, 96, 98]. The idea of *too much information* (TMI) or inappropriate information can present barriers to sharing—when the sharer anticipates the audience may not want to hear the information—and to accessing the information—if the recipient anticipates they would be accessing information they do not want to know. Misunderstandings about the sharer’s reasons for distributing the information can also result (e.g., someone asking for support gets interpreted as humble bragging [42]). With digital legacies, where sharing and access may be separated by significant periods of time, these challenges may be even harder to navigate. Future research should examine how such misunderstandings might play out across time in legacies and identify design approaches for mitigating them. Although people may want to refrain from sharing sensitive information about sexual and mental health, knowing those details can be beneficial for future generations to contextualize their menopause experiences and reduce self-stigmatization. It is also possible that someone wants to share such sensitive information but their future generations do not want to receive it. Participants wanted to share their legacies while still alive, and past research has found that comfort levels with sharing may change during a person’s lifetime due to changes in health, familiarity with technology, and technological innovations [105]. Future work could therefore explore sharing sensitive health experiences using a need-to-know approach, which could thus adapt to changing privacy perspectives.

Future research should also consider how legacy creators can regulate access to their legacies. Although access permissions are relatively easy to control in digital legacies (e.g., access to specific digital recordings such as social media posts and video logs can be changed without affecting other parts of the legacy), legacy creators and recipients should be informed about how to manage their privacy preferences especially since menopause can be a sensitive topic and not everyone is familiar or comfortable with digital formats. In light of commercial Female-oriented technologies (FemTech), researchers have raised concerns regarding collection of intimate data (e.g., How are the data used? Who has access to it?) and discussed the importance of user rights for protecting their integrity and preserving their data [86]. Although legacies are intended to stay within families and close circles of the legacy creator, future research should also examine minimal safeguards

that could be instilled in digital legacies to protect the integrity of those sharing their experiences and safely preserve their collected data. Moreover, granting differential access to content is not as straightforward for physical artifacts because the particular content that legacy creators may prefer not to share is embedded within the entire artifact. One approach may be to remove pages with content that is not to be shared (P16). Still, future considerations of physical legacies should explore how to exclude certain content from the shared artifact without damaging or affecting other parts.

5.3.2 Planning for Post-Mortem Data Access. Incremental sharing could also be effective for minimizing the mismanagement of post-mortem access. Although our participants assumed they would share their legacies with their families when alive, unexpected death can drastically change how a digital legacy is passed down. Recipients may be left managing copious data without guidance [59]. Legacy creators should plan to ensure their privacy wishes are met [59], such as by appointing a “*data steward*” [110] (e.g., a daughter or niece to whom the creator intends to transfer the legacy). Conversations between a legacy creator and data steward, or documentations of a legacy creator’s privacy wishes, could allow recipients to properly manage post-mortem access. However, even if a data steward is successfully identified, they may not have the technical ability to manage the data [51]. The lack of capacity for digital legacy systems to facilitate multi-user logins could further pose a barrier to smooth data ownership transmission [3, 59]. Abrupt situations, such as sudden death of the legacy creator, could also deprive the data steward of opportunities to clarify privacy expectations, leading to tensions between what the data steward believes best honors the memory of the deceased and what the deceased legacy creator intended to pass down [37]. These challenges raise the open questions of to whom, to what extent, how, and when to pass down a digital legacy.

5.3.3 Considering Longevity & Additive Nature of Legacies. Participants anticipated that physical and written artifacts (e.g., diaries, journals, chapter books) would be valuable for legacy creation and self-expression. Further, P4 suggested converting her journal into a chapter book that could become an ever-growing, additive family artifact. Such an artifact could provide recipients with experiences of different family members from earlier generations, potentially making comparisons less unhealthy (section 5.1.2). Recipients could see if experiences of family members differed from each other and build a better understanding of how they should contextualize their own experiences with respect to previous generations.

However, invincibility and longevity are imperative for an artifact to manifest a legacy and be passed down generations. In section 4.3.2, P5 raised concerns about the longevity and permanence of physical legacies, as physical artifacts could become inaccessible to future generations (e.g., considering a physical diary versus a video log which could “*last longer*”). Due to a physical artifact’s short life span, new physical artifacts may need to replace those that are exhausted. One way to overcome this impermanence is to digitize the legacy after its creation (e.g., taking pictures of each page of a journal). Digitization of non-digital artifacts could also help address the mismatch between participants preferring written formats to record their experiences but feeling their children would be more receptive to digital formats (e.g., video logs, a social media page). However, digitization could invoke further complex decisions about preservation and disposal of physical artifacts. Digitization also risks data loss due to technical failures or may lack the capacity to accommodate sporadic use and access. Researchers have explored alternative ways of digitization, such as leveraging existing physical objects (e.g., old-fashioned radios) to design embodied digital mementos (e.g., sonic mementos of family holidays) that allow for digital collection and archival of records and memories [32, 108]. Yet, future research should continue to explore how longevity of non-digital legacies (and physically-embodied digital legacies) can be enhanced to ensure permanence and preservation of information across generations.

6 CONCLUSION

We presented results of a design study to envision how to document and share personal menopause experiences across generations. Participants described wanting cross-generational sharing of menopause experiences to support preparation, acceptance, and communication. However, such experiences were often unavailable due to absent family members or stigma. Participants indicated they would have valued receiving personalized narratives from menopause-experiencing family members, and that recording this information could have supported their own sense-making and self-assessment. We also noted the value of life-logging as a way to view menopause as a part of one's life rather than an isolated experience. Designers might leverage personal narratives and storytelling using life-logged data to create legacies that depict holistic memories of the menopause journey. Such menopause legacies could support self-reflection along with sharing and could facilitate sensitive conversations among family members. However, legacies will also need to address challenges of data access, non-static privacy perspectives, and longevity. Although this research focuses on menopause, we anticipate these considerations can inform designs that support intergenerational sharing of other stigmatized and gender marginalized health experiences which need not be medicalized.

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