

NAI

menopause



Kelda Baljon



Agatha Tutia



Lan Vu

Table of Contents

03 Introduction

05 Background

09 Research Methods

15 Results

43 Design Implications

47 Appendices

Literature Review

Subject Matter Experts

Competitive Assessment

Recruitment

Semi-Structured Interviews (Part 1)

Participatory Workshop

Semi-Structured Interviews (Part 2)

Literature Review

Insights

Archetypes + Personas

Models

Principles

Opportunities

03 *Introduction*



How can we empower each person
as they experience their individual
menopausal journey?*

Executive Summary

Over half of the Earth's population will go through, is going through, or has gone through menopause. Menopause can cause unpredictable periods, hot flashes, insomnia, weight changes, vaginal dryness, anxiety, and other uncomfortable experiences, and these biological changes can last for up to ten years. It occurs at a time of life when many women are experiencing their children moving out of their homes, their parents requiring end-of-life care, changes to their employment or financial situations, and shifts in their romantic relationships. Amidst all these changes, menopause is a frequently stereotyped, sensitive, and taboo topic, which has rendered it relatively under-supported in today's Western society

*empower = educate, support, validate, comfort, give agency, and attitudinal adjustments



05 *Background*

We dug into existing literature, spoke to academic, medical, and social experts in the area, and explored existing products and services to understand our opportunity space.

Literature Review

Over half of the Earth's population will go through, is going through, or has gone through menopause. And as the expectancy of life increases, one in three women will be postmenopausal [13, 17].

Biological Definition

Menopause is the body's permanent cessation of menstruation. It is marked by being 12 months since a woman's last period [4]. It also marks the end of her fertility, and is considered by anthropologists to be the moment that a woman can take on non-reproductive social roles [9]. Menopause naturally occurs in midlife, between the ages of 45-55, but it can also be induced medically [10].

The transition into menopause or perimenopause can occur years before a woman's last period. Irregular periods tend to be the first signs, and perimenopausal changes can also include hot flashes, sleep problems, and lower libido.

Cultural Context

There is limited research on female bodies because of the "taboo" nature of sexuality and reproductive health [1]. In fields like sociology, gender studies, and aging studies, some work has been done to assert that the cultural, generational, and social context wherein menopause occurs can have a big impact on the experience [2, 6, 12, 15]. Research has also uncovered that employment and relationships can produce more stress than menopause [18].

Expectations and Knowledge

Former work has also shown that women lacked knowledge about menopause before experiencing it and that they had more negative expectations of menopause when their expectations were based on what they had heard from other women, whereas their expectations were more positive or neutral when based on their own thoughts [3].

Attitudes

Additionally, attitudes toward menopause vary. There is a distinction between those who see menopause as a medical condition requiring treatment and those who see it as a phase of life to be managed by "natural" means [7]. Most commonly, women see themselves as becoming less of a "woman" due to the loss of femininity that comes with menopause and aging [19]. There are also different coping strategies among menopausal women: those who reactively addressed the issues, those with troubling distress about their discomfort, and those with inventive, positive outlooks [16].

Menopause in HCI

Though menopause has been studied to some extent in the medicine and sociology disciplines, current research is still limited. In the Human-Computer Interaction (HCI) field, there is meager research addressing this phase every woman experiences. Currently, there are only three HCI papers in the Association for Computing Machinery (ACM) Digital Library addressing how design thinking can play a role in menopause. These papers addressed various topics from mobile health intervention systems [8] to participatory design methods [14] to speculative self-tracking technologies [5].



“And as the expectancy of life increases, one in three women will be postmenopausal.”

Subject Matter Expert Interviews

For our primary research, we interviewed five experts from various fields to better understand menopause from different cultural, medical, and support community perspectives. Our goals were to understand three themes that emerged from our literature review: information gaps, non-medical treatments, and support structures.

Our Initial Research Questions

1. What are the knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?
2. What non-medical strategies do people currently use to relieve menopausal symptoms?
3. What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?

Medical Perspective

Dr. Keehn gave us a walkthrough of an appointment where a patient may be experiencing menopausal signals. For general checkups or annuals, if a woman is in her mid-40s then Dr. Keehn may ask her questions about changes to her body to check if she was in perimenopause. However, it is more likely that women would bring up possible signals during either her annual or a “symptom-focused” appointment. In the latter scenario, Dr. Keehn would check for age-related ailments to rule out life-threatening illnesses before confirming that the signals are from menopause. When asked about how women can prepare themselves for menopause, she said that going into “the Change” mentally and physically healthy can help improve the overall experience.

Support Community Perspective

In order to understand where menopausal people are supported or unsupported, we all joined the Menopause Support Group on Facebook which has over 30,000 people and counting. We spoke to the moderator, Gwen Harris, who happened to live in the Seattle area. We wanted to learn about how she manages moderating the group and what challenges she faces. Our interview with Gwen confirmed that menopausal women seek a safe space to share their experiences and to cope with their biological changes. We also observed that moderators may have biases of their own which can influence the direction of the group culture or community.

Research Perspective

Dr. Guthrie provided us with a biostatistical perspective on menopause in the realm of medical research. She talked about the MsFLASH (Menopausal Strategies: Finding Lasting Answers for Symptoms and Health) study and current gaps and challenges in menopause research. She talked about pharma’s influence on what gets researched and placed on the market, rather than research for the sake of knowledge or health. From Dr. Guthrie’s point of view, we learned that menopause research is devalued because it is a quality of life issue and is considered non-life-threatening.

Sociocultural Perspective

Dr. Kenney and Dr. Woods provided a historical and sociocultural perspective on menopause. In Western cultures, menopause is attributed to aging and loss of femininity which can lead to stereotypes and generalizations of menopausal women. This negative lens on menopause can add to the isolation that many women experience as they go through “the Change”.

Many women wish they had better timelines and expectations for menopause, but the path to those resources is not well-paved, and instead there is a lot of confusion and misinformation.

Additionally, the context of the life stage at which menopause occurs in can impact the experience that people go through such as empty nesting, changes in financial situations, or shifts in social responsibilities.

“So many stereotypes, jokes, and insulting tales on what a menopausal woman is like.”

- Dr. Nancy Kenney

Takeaways

Our five expert interviews helped us understand that menopause is a multifaceted phase of life which can occur during a time of societal changes that comes with aging. Additionally, there are a variety of menopausal experiences since signals can be variable in nature and severity. We came away from our expert interviews with knowledge on how to conduct our first round of semi-structured interviews. We needed to be mindful and sensitive of each person’s diverse experience since it can be an uncomfortable topic to discuss.

For detailed expert interview transcripts or notes, please see Appendix A, pg 47.



Katherine Guthrie

Katherine Guthrie
Member, Public Sciences Division,
Fred Hutch



Gwen Harris

Administrator,
Menopause Support Facebook Group



Elan Keehn

Professor
Gender Studies and Psychology
University of Washington



Nancy Kenney

Professor
Gender Studies and Psychology
University of Washington



Nancy Woods

Professor Emerita
School of Nursing
University of Washington

Competitive Analysis

For our competitive assessment, we decided to go broad and examine the market of menopause in order to achieve the following:

1. Understand the services and products offered for menopausal people
2. Target various menopausal symptoms
3. Learn how these services and products are successful
4. Sense where these services and products fall short

Takeaways

Although there are many services and products available in the market to aid menopausal people, these six competitors show the diverse opportunity spaces within menopause that are worth exploring. The competitive assessment helped validate the opportunity spaces we came to later in the project. These opportunity spaces can stand alone or be combined into a more comprehensive experience.

1. Clear Information and Timelines
2. Community and Support
3. Physical Comfort
4. Attitudes

For more in-depth information on our opportunity spaces, see pg 45.

Broad Assessment Table

NAME	FORM	DESCRIPTION	REASON FOR SELECTION	SIGNAL(S) TARGETED	STRENGTHS	PAIN POINTS	TAKEAWAYS
MENOPAUSE CAFE	Discussion Group	Menopause cafes are group directed discussion of menopause with no agenda, objectives or themes. It is a discussion group rather than a support or counseling session.	The menopause cafe in its current state is a technology-free experience where people come together to discuss menopause.	All signals	<ul style="list-style-type: none"> Low cost to attend Empowers people to hold their own menopause cafes Encourages men and kids to attend 	<ul style="list-style-type: none"> New concept that began in 2017 Only in the UK and Canada Guidelines to host seem abstract and unclear Stresses that it's not a support group 	<ul style="list-style-type: none"> Goes beyond the screen Provides a safe space to share menopausal experiences Menopausal cafes are open to all people regardless of gender or age Aims to "change" and helps normalize the experience
MENOPAUSE SUPPORT GROUP	Facebook Group	A private Facebook group where women can share their experiences, ask for advice, seek validation through other women socially.	It's the largest Facebook group for menopause support. We wanted to investigate what people discussed on this platform.	All signals	<ul style="list-style-type: none"> Immediate and active conversation amongst members An avenue to openly discuss private/intimate issues A safe space for women Popularized by a segment Good Morning America did on menopause 	<ul style="list-style-type: none"> Major difficulty in moderating the group Newsfeed loses knowledge due to the large amount of comments Questions are repetitively asked Not a place for medical advice Men and/or transgendered people are not allowed Tension and arguments between members can occur 	<ul style="list-style-type: none"> A very active group for women to vulnerably talk about their issues A supportive community Women want to connect with other women and validate their experiences Potential for it to be a toxic and negative space The group moderator has major influence and power over the direction and culture of the group
GLOW	Mobile App	Glow's menstrual and ovulation calculator helps women learn about their fertility, whether avoiding or attempting pregnancy.	With a larger and similar, though younger, audience - Glow aims to support many of the same spaces we have considered when looking at menopause (community, partner's support, knowledge, tracking).	None	<ul style="list-style-type: none"> An attractive UI Robust set of features, including a period tracker, data analysis, algorithm-driven predictions, and more A huge market share Hugely positive reviews 	<ul style="list-style-type: none"> The community feature is unmoderated and can be hit or miss Glow must support a diverse set of audiences (i.e. pregnancy information, period tracking, etc.) 	<ul style="list-style-type: none"> This app is hugely successful Differs from menopause because it was designed for a person with a goal -- to conceive a child Unmoderated discussions that can be harmful and divisive Attempts to improve the community experience by creating specific groups and spaces for different people with various interests
BBC: THE MENOPAUSE SERIES	Podcast	A week-long series exploring menopause's impact on women's work and relationships, and potential treatments	We wanted to see how a media-based company was broadcasting menopause to the general public	All signals	<ul style="list-style-type: none"> Has a following of 3.9 million following (2013) Audience trust attributed to journalistic expectations Active listener participation Ability to bring conversation to the mass public 	<ul style="list-style-type: none"> Only broadcasted in the United Kingdom Content limited to that one week Mostly videos of audio clips No transcripts provided Load time of pages excessively long No comment sections 	<ul style="list-style-type: none"> Conversation on public radio is normalizing menopause First impression of website looks full of information and resources, but mostly consists of audio clips from the show Content is limited to just the week-long series from January 2018
THE WISDOM OF MENOPAUSE	Nonfiction Book	An in-depth look at the menopausal transition. The book discusses the emotional, mental, and physical changes that menopausal women undergo and how to support the "change".	The "go-to" book on menopause. The Wisdom of Menopause touches on one of our secondary insights about how women are under informed about menopause and seek resources to help them fill this knowledge gap.	All signals	<ul style="list-style-type: none"> Wisdom of menopause has reached millions of readers The book is affordable (approx. \$14 - \$17). Can also be obtained through local libraries or exchanged among friends A plethora of information on the menopausal transition Can be read in a public or private setting 	<ul style="list-style-type: none"> Speaks about menopause from a privileged and Western perspective Contains a wealth of information, it might not apply to all women The amount of information presented can feel overwhelming - the book has 768 pages 	<ul style="list-style-type: none"> The Wisdom of Menopause is accessible for people who want more information about menopause However, menopause can vary greatly from person to person, so not all readers will find the advice helpful or relevant Many Amazon reviewers mentioned the book as a great reference guide to menopause
COOL JAMS	Clothing	Cool-jams Inc. designs moisture wicking pajamas, loungewear, and temperature regulating bedding. This product can be used for hot flashes or other reasons that might cause night sweats.	Out of all the physical products we discovered, it was the most advertised and recommended for people experiencing night sweats. We chose Cool-Jams to explore how a non-tech product fares in the market and how it can make a ease hot flashes.	Hot flashes	<ul style="list-style-type: none"> An average review of 4.3 stars on Amazon Relatively affordable Based on the reviews, it seems like Cool-Jams work well Listed widely in articles providing advice to menopausal people Targets a very specific symptom Creative use of an innovative type of fabric 	<ul style="list-style-type: none"> Pajamas are not attractive Reviewers mention that Cool-Jams don't always fit well Not well-marketed, primarily done through blog endorsements and online retail sites It's not a complete fix to hot flashes, just something to mitigate night sweats 	<ul style="list-style-type: none"> This is a great application of a very particular product -- moisture-wicking fabric It does its part to support people physically, but this is a technology-first product Only a small comfort in the broader experience of menopause

09 *Research Methods*

We spoke to menopausal women through semi-structured interviews and a participatory workshop to better understand their experiences and attitudes.





Recruitment

Our goal for recruitment was intersectionality. We wanted to reach out to people of different socioeconomic statuses, ethnicities, and gender identities to better understand the variety of menopausal experiences.

To recruit menopausal people, we created a landing page (menopause-design-research.webflow.io/) with a link to a screener survey which we advertised on flyers. We placed these flyers in neighborhoods, community centers, and cafes in Beacon Hill, U-District, Capitol Hill, Greenlake, and Wallingford. Although this was a high effort task, we recruited a more diverse range of woman from our flyers. We also contacted church communities and a gender center directly. Additionally, we reached out to our networks in California for remote semi-structured interviews. This helped us in reaching our goal of intersectionality.

For online recruitment, we reached out to groups on Facebook, Reddit, and Meetup; this ranged from Seattle mom groups to knitting clubs. To further facilitate Facebook recruitment, we contacted every member of the 30K+ member Facebook Menopause Support Group who listed themselves as living in Seattle, which was around 50 people. We also posted a Craigslist's ad in the Seattle community portal.

Lastly, our growing community of people who are interested in menopause helped spread the word about our study through their networks which immensely helped us during recruitment.

Research Questions & Semi-Structured Interviews (Part 1)

Initial Research Questions

Through our research questions, we wanted to understand menopausal women's behavioral and attitudinal responses to their biological changes. Additionally, to comprehend how information and support influence each person's behaviors and attitudes towards menopause.

1. How, where, and when do people learn about menopause?
2. What kind of support (or lack thereof) do menopausal people receive from medical professionals?
3. How does menopause affect a person's self-image and identity as a woman, mother, wife, etc?
4. Where are menopausal people supported or unsupported in both their private communities and public life?

First Round of Semi-structured Interviews

In our initial round of semi-structured interviews, we spoke with six women experiencing signals of menopause. We wanted to gain an understanding of their menopausal experiences and how they have impacted their daily lives; from work to relationships to self-image.

To see our interview scripts, see Appendix D, pg 68.

To see our interview transcripts, see P1-P6 in Appendix E, pg 70.

For key insights from our interviews, see Insights, pg 16.



Participatory Workshop

We wanted to harness the collective mindset of menopausal people and empower them to have an honest discussion about their biological changes. In order to accomplish this, we held a participatory design workshop with eight menopausal women. The workshop lasted two and a half hours.

Overview of Activities

Letter to Pre-menopausal self (10 minutes)

For this activity, we asked each woman to write a letter to your premenopausal self.

Goals:

- + To get people to reflect on their menopausal experience
- + To understand what people wish they have known before entering menopause

Open Discussion/Focus Group (45 minutes)

We used the personal letter as a segue into our group conversation about menopause.

Goals:

- + To understand the collective mindset of menopausal people
- + To find out where support structures currently exist for menopausal people and where they don't

Ideation Activity (45 minutes)

For the ideation activity, the participants became the “designer” and created an affinity diagram based on their individual and collective menopausal experience. They organized their experiences with menopause into five categories: Health, Relationships, Who Am I, Public Life, and Other.

Goals:

- + To understand problems menopausal people want solved or addressed
- + To find pain points of the menopausal experience.

We conducted the ideation activity in three parts.

1. Ideation

We asked each woman to take 10 - 15 minutes to generate topics on menopause. This could be their own biological changes or effects of menopause in a broader context.

2. Affinity Diagrams

In small groups, participants wrote and organized the sticky notes into the five categories: Health, Relationships, Who Am I, Public Life, and Other.

3. Sticker Rating

After the affinity diagram, we gave the participants a blue sticker and an orange sticker.

For the blue sticker, the participant placed it on the category impacted her the most or what she would change about menopause.

For the orange sticker, the participant placed it on the category that would benefit all menopausal women if it was solved.

To see where the women placed their stickers, see Appendix H, pg 116.



Updated Research Questions & Semi-Structured Interviews (Part 2)

Overview of Activities

For our second round of semi-structured interviews, we decided between our primary stakeholders, menopausal women, or our secondary stakeholders such as their partners or coworkers. During the workshop, we were surprised during the sticker activity that on an individual level women wanted their signals alleviated while on a collective level they felt that the menopausal community could benefit from more support and treatment. This observation revealed that the defining factor for each woman was not only something unique to her, but also on a larger level of support for herself. We decided that providing support to menopausal women is an important opportunity. This also helped us decide to continue interviewing menopausal women, because we were more interested in her experience rather than that of the pre-menopausal woman, partner, or other related stakeholder.

Through our new research questions, we wanted to understand each menopausal woman's unique behavioral and attitudinal responses to their biological changes. Additionally, we wanted to see how information and support influence each person's behaviors and attitudes towards menopause.

Behavioral

1. How does each person respond to their menopausal symptoms (mentally, emotionally, and physically)?
2. How has information on menopause influenced the actions individuals take in response to their symptoms?

Attitudinal

1. How are a person's attitudes on menopause formed?
2. How does a person's attitude change throughout the experience?
3. How does a person's attitude impact their menopause experience?
4. How can information affect individuals' attitudes on menopause?

Semi-Structured Interviews (Part 2)

For our second round of semi-structured interviews, we examined each woman's main menopausal signals and the steps they took, if any, to alleviate them. We also asked them to reflect on their menopausal experience and what they want future generations of women to know about menopause.

In our first interview, we discovered that we were hearing and learning things we had already heard repeatedly. We altered the script, but continued to feel that we had reached data saturation. By the third interview of our second round, we decided to stop early to focus on data digestion. We decided we needed more time to synthesize the new data along with our data from the first round of interviews and workshop.

To see interview transcripts, see P7-P9 in Appendix E, pg 70.

For key insights from our interviews, see Insights, pg 16.



Transcription & Coding

We dug through our data via manual transcription and coding to better comprehend our data more thoroughly. We decided to each transcribe the interviews we missed so we would all have a better understanding of our data. This became immensely helpful for reaching consensus in every step that followed, from choosing codes to creating personas and identifying design principles.

In order to see emerging themes, we created a matrix of our 85 coding categories. We noticed that non-hormonal treatments or natural remedies were frequently mentioned as well as the value in building a support system.

For full list of codes, see Appendix I, pg 118.

Coding Matrix

CODES	CATEGORY	COUNT	PERCENTAGE	P1	P2	P3	P4	P5	P6	P7	P8	P9	W1	W2	W3	W4	W5	W6	W7	W8
Natural/non-medical/non-hormonal	Solution	14	82.35%	x	x	x	x	x	x	x	x	x		x		x		x	x	x
Value in building support systems	Support	14	82.35%	x	x	x	x	x	x	x	x	x		x	x		x		x	x
Variety of experiences	Differences	12	70.59%	x	x	x	x	x	x	x	x	x		x	x					x
Not a big deal	Perception	12	70.59%	x		x	x	x	x		x	x	x	x		x	x	x		
Extenuating circumstances	Medical	11	64.71%		x	x			x		x	x	x	x		x		x	x	x
Process of periods going away	Menstruation	11	64.71%		x	x	x			x	x	x	x	x	x		x			x
Hot flashes	Physical	11	64.71%			x	x	x	x	x	x	x	x			x			x	x
Broader conversation	Social	11	64.71%		x		x		x		x	x		x	x	x	x	x		x
Night sweats	Physical	11	64.71%	x	x	x		x	x	x	x	x				x		x	x	
Relief from having no periods	Menstruation	10	58.82%	x	x	x	x			x		x	x		x			x		x
Avoidance of HRT	Medical	10	58.82%		x	x	x	x	x	x	x	x		x		x				
Sleep problems	Physical	10	58.82%	x	x	x		x	x	x		x		x		x		x		
No conversation or information from maternal figures	Social	10	58.82%			x	x			x	x	x	x			x	x	x	x	
Positive mindsets	Perception	10	58.82%			x		x	x		x	x	x		x			x	x	x
Experience with Doctor	Medical	9	52.94%	x	x		x		x	x	x			x		x				x
Weight (gain/loss) management	Physical	9	52.94%			x	x	x	x	x	x					x		x		x
Men don't understand MP	Information	9	52.94%	x		x	x			x	x	x			x	x			x	
Should have known beforehand	Information	9	52.94%		x	x			x	x	x	x		x				x	x	
Infertility	Physical	9	52.94%	x	x		x	x	x			x	x					x	x	
Female body	Physical	8	47.06%		x		x					x	x	x			x	x		x
Symptoms get worse	Physical	8	47.06%	x		x				x		x		x		x		x		x
(Good) communication and support w/ partner	Social	8	47.06%	x	x	x		x				x				x		x		x
Conversation or information from maternal figures	Social	8	47.06%	x	x						x	x				x	x	x	x	
(Silent) endurance	Perception	8	47.06%		x	x	x	x				x		x		x		x		

15 *Results*

After fully digesting our data, we generated descriptions of the experience through insights, archetypes, and concept models.



Insights

01 Each experience is *different*.

02 People don't know what to *expect*.

03 Women are *silently enduring* menopause.

04 Body literacy creates *agency*.

04 There is *tension* between instinctual frustration and reflective acceptance.

05 Aging and menopause are deeply *intertwined*.

06 The end of menstruation can be a *relief*.

07 Women tend to prefer *natural* treatments.

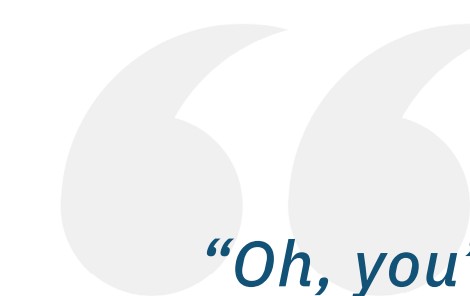
01 Each experience is *different.*

Explanation

Menopause is highly variable between individuals, making it difficult to identify a “typical experience.” Current scientific research is limited, which contributes to the sense that no one knows that is “normal”.

Principles

- + Consider the variety of experiences
- + Be direct and clear
- + Respect agency and empower
- + Be sensitive of taboo



“Oh, you’ll have all these various symptoms that might be generally true but it’s really unique and the severity, the frequency, all those things can be really unique to a person.” - W3



Dark blue dots indicates the participate that contributed to the insight.

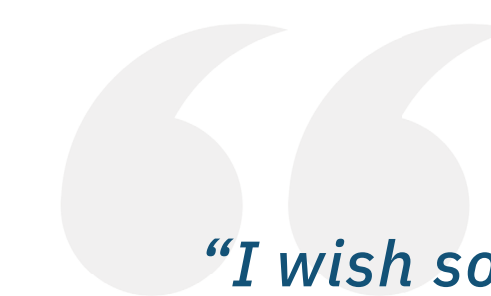
02 People don't know what to *expect*.

Explanation

Since there are no clear expectations of menopause, women often feel uncertain about “the Change,” both before beginning their experience and during it. There is a lack of clarity around menopause timelines and what to expect next. This mismatch between expectations and realities can lead to frustration or isolation.

Principles

- + Consider the variety of experiences
- + Respect agency and empower



“I wish someone (a doctor or any educated person) would have told me what I would (or could) experience later in the menopause state.” - W7

03 Women are *silently* *enduring* menopause.

Explanation

Menopause is a quality of life issue aging women are expected to silently endure, so there is a lack of interest in creating a broader discussion about it. When women do share their experiences with others, they discover relief through acknowledgement, a sense of legitimacy, and information exchange.

Principles

- + Celebrate the change
- + Respect agency and empower
- + Be sensitive of taboo



“So it’s just like what women do we suffer in silence.” - P4

04 Body literacy creates agency.

Explanation

Women can feel a greater sense of control through understanding their body's behaviors, because when they can attribute a biological change to menopause, they can a) seek resources and treatments, and b) manage its effect on their self image and social responsibilities.

Principles

- + Celebrate the change
- + Respect agency and empower
- + Be sensitive of taboo



"I've educated myself about it and I feel like I'm armed a bit more." - P8

05

There is *tension* between instinctual frustration and reflective acceptance.

Explanation

Even when a woman has embraced and accepted menopause as a phase of life, her signals can still be disruptive and lower her quality of life. This can lead to an emotional tension between feeling frustrated about discomfort and feeling accepting of this “natural phase”.

Principles

- + Recognize the natural phase of life
- + Consider the variety of experiences
- + Be direct and clear
- + Respect agency and empower



“I need to work with the menopause, I need to not fight it anymore, I need to embrace it...I’m just not as tough on myself anymore and I need to just try to wait for the next symptom. What’s next?” - P8

06 Aging and menopause are *deeply* intertwined.

Explanation

Many women entering and in menopause don't know what to expect from their menopausal experience because it is variable between individuals and current scientific research is limited.

Principles

- + Consider the variety of experiences
- + Acknowledge aging
- + Be direct and clear
- + Respect agency and empower



“It seems like every couple months, there’s a new thing related to aging in general that is like ‘Oh great, now I gotta do this.’” - P9

07 The end of mensuration can be a *relief.*

Explanation

Menopause can come with a lot of uncomfortable signals, but for many, menstruation was uncomfortable and a hassle, so unless they had still hoped to have children, women were relieved to see menstruation end.

Principles

- + Be direct and clear
- + Respect agency and empower



“We suffered through menstruation and menstruation, for me, was far worse. I’m glad to be done with that!” - P4

08

Women tend to prefer natural treatments.

Explanation

Unless symptoms are severe, most women prefer using non-medical solutions rather than hormone replacement therapy (HRT) because of misconceptions about HRT from the media and word of mouth.



“I’m really kind of anti-wanting to go on hormone replacement just because of the side effects and the cancer risk and all that stuff. If it doesn’t continue to get a little bit better then I would maybe consider it.” - P3



25 *Archetypes & Personas*

Through the creation of personas we discovered archetypal patterns, but also a variety of experiences we wanted to highlight.

Behavioral Archetypes

Throughout our primary research, four distinct behavioral archetypes emerged. To create these archetypes, we collected some of the primary features of our conversations with each of our seventeen participants and looked for important trends and similarities between participants.

Each archetype illustrates the behaviors and attitudes that a set of people have as they experience menopause.



“The Attributer”

(P2, P3, P7, P8, W7)

Summary

Her main source of support and information comes from Facebook. She feels better attributing her signals to menopause, because then she knows it’s her body and not her.

Goals

- + Get partner to believe and understand that she’s going through menopause
- + Receive support and validation
- + Relieve her discomfort without Hormone Replacement Therapy (HRT)
- + Confirm that she’s not going crazy

Pain Points

- + Symptoms are very disruptive and inconsistent
- + Information is hard to find
- + She doesn’t know what she can do to ease signals
- + The doctor was unhelpful during her appointment

Needs

- + Proof of menopause and its effects
- + Reliable information
- + Non-medical solutions
- + A support network



“The Laid-backer”

(P1, P4, P5, W3, W8)

Summary

Since her symptoms are not severe, she thinks menopause is not a big deal. She has a good support system and feels pretty unphased about menopause. Her biggest wish would be to change the stereotypes around menopause such as the cranky old lady.

Goals

- + Live a regular life
- + Not let anything get in the way of her ability to work
- + Earn others’ respect

Pain Points

- + Crazy menopausal lady stereotype
- + Wishes others had an easy transition too

Needs

- + Low-effort solutions to signals
- + Normalcy



“The Explorer”

(P6, P9, W4, W6)

Summary

She is a highly proactive seeker of information who was shocked to discover how little she knew about menopause. When she first realized she was in menopause, she struggled with feeling old because she still views herself as young, but gradually, she learns to embrace it. She is likely to choose the most effective solution based on research rather than instinct.

Goals

- + Be well informed about everything, including her own body
- + Cure her illness
- + Feel comfortable about her age

Pain Points

- + There is a lot of inaccurate information, so she has to find credible sources
- + Symptoms are very disruptive and inconsistent
- + Insecurity about her body and her age

Needs

- + Reliable information
- + Effective relief from discomfort
- + Reasons to feel confident and secure



“The Internalizer”

(W1, W2, W5)

Summary

The Internalizer has significant, disruptive signals, but she keeps her experience to herself. Within her social circles, female health issues are seldom talked about and often viewed negatively. She feels that she would be burdening other people with her problems and that she should just power through it.

Goals

- + To not feel like a burden
- + Continue to live her life as usual
- + Relief from signals

Pain Points

- + Signals are disruptive and inconsistent
- + Isolated
- + Information online is contradictory and hard to understand

Needs

- + Easier access to information about what’s happening to her and what actions she can take
- + Social support

27 *Personas & Individual Journeys*

Based on our primary research, we combined emerging themes to create a persona for each archetype. Our personas show possible behavioral reactions and provide in-depth biological and societal context to generate a deeper understanding of the experience.

Each persona is complemented by an individual journey map of key moments that define their menopausal experience.

These key moments are categorized consecutively from:

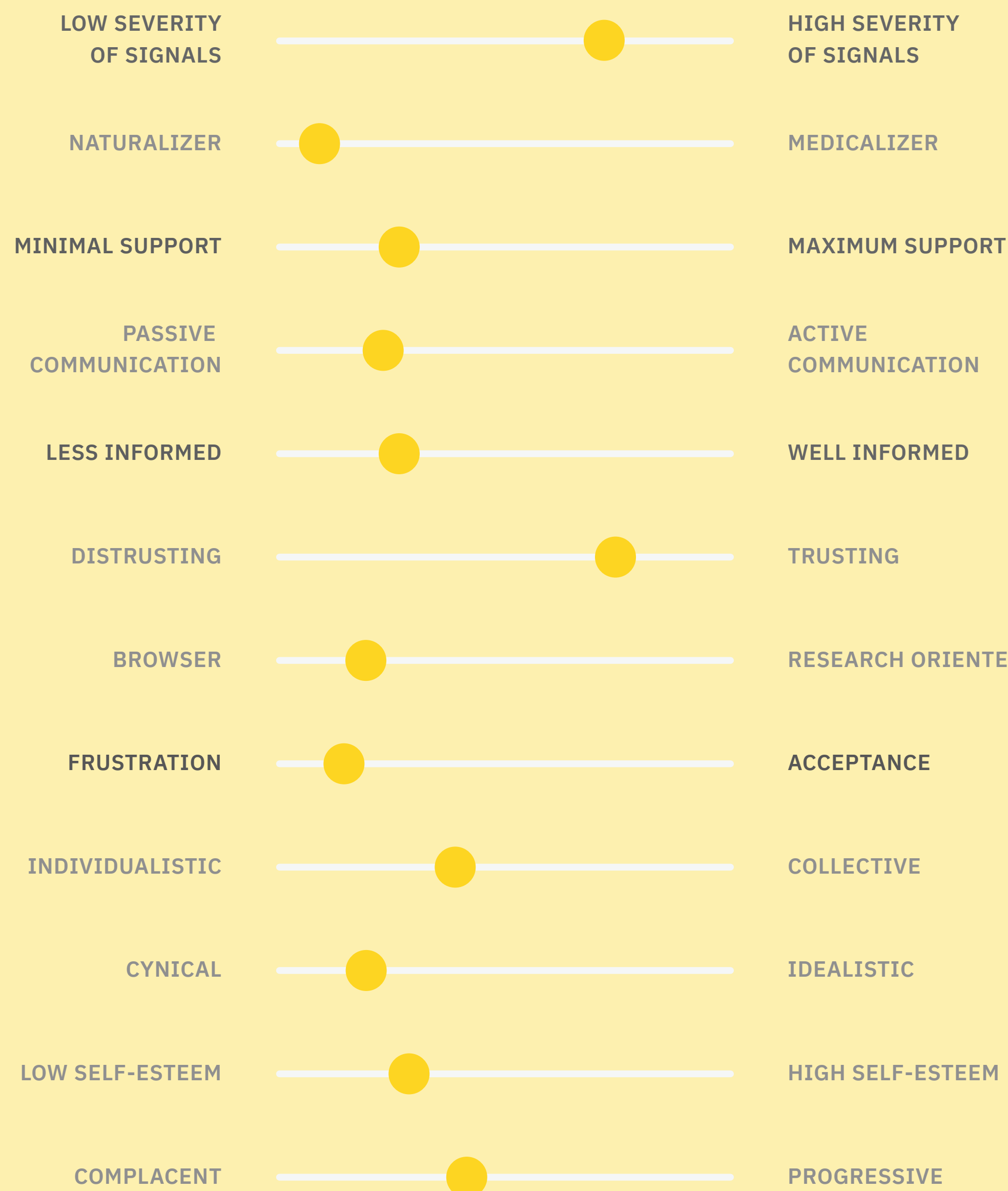
- 1) the realization that she has begun perimenopause
- 2) her signals reaching the peak of disruption or severity
- 3) potential efforts to find information and solutions
- 4) potential efforts to find support and community
- 5) her reflections on her experience.

These specific moments are grouped into larger phases that are further discussed in our models: quality of life changes, validation, and acceptance.



Shruti

“The Attributer”



“You hear from hundreds of other women online going, ‘Does anybody have the same experience?’ You go, ‘Oh thank god! Yes, Yes, Yes, Yes!’” - P3

Background

Shruti is 51, recently married, and has no children. She has been in perimenopause for just over two years, and had her last period 3 months ago. She sees her menopause as an affliction that she has to manage. It has impacted not only her daily life, but also her relationship with her husband, Darius.

Confirmation from Doctor

For the past three months, Shruti noticed that her periods have been irregular which never happens. She has an annual coming up, so she decides to ask her doctor about her periods.

At her doctor’s appointment, the doctor told her that she is in perimenopause. Shruti was taken back, because menopause never crossed her mind. The doctor offered HRT and other medications, but Shruti told the doctor that she wants more of a holistic treatment because she heard HRT can cause cancer. The doctor couldn’t provide any natural alternatives and told her to “power through it”.

Mental Signals

Shruti’s biggest struggle during perimenopause has been her *mood swings* and exacerbated *mental health*. She has struggled with anxiety her whole life and she feels helpless now that it has gotten even worse. She finds herself having extreme emotional responses to things her husband does, like not wiping off the counter. This can be incredibly frustrating, because she knows her response is irrational.

Facebook Support

Shruti joined a Facebook support group to get more information on holistic treatments. While searching for natural treatments, Shruti saw a post about mood swings. She was shocked that over 60 women have commented on it saying that they struggle with it too. Shruti felt relieved and much better about herself. It’s normal to have mood swings when you’re in perimenopause.

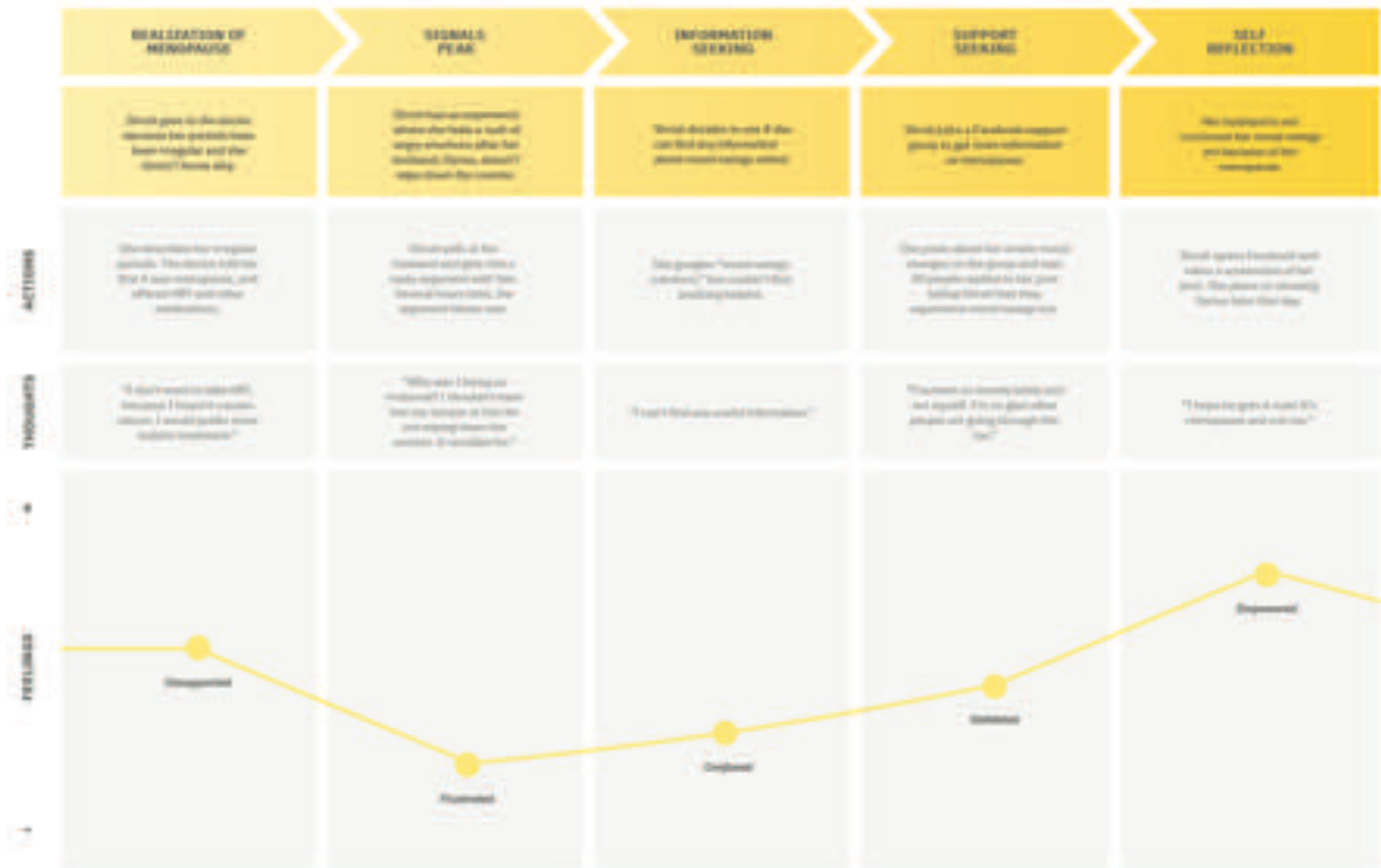
After a mood swing, Shruti talks to Darius, but he doesn’t believe her when she says it’s because of menopause. She shows him the Facebook support group as proof. He relents, but is still frustrated. Since she knows men will never get it, the support she finds on Facebook has made menopause bearable because she can find hundreds of women who have similar experiences to her.

Shruti finds most of her information on blogs and through the Facebook support group. In spite of what she has learned, she still has a lot of questions about menopause and feels rather uncertain and disempowered.

It’s Not Me

Shruti has gradually come to better terms with menopause since attributing the changes she is experiencing to biology. As long as it’s menopause and not her (or her identity) that’s causing these changes, she can come embrace this phase of life.

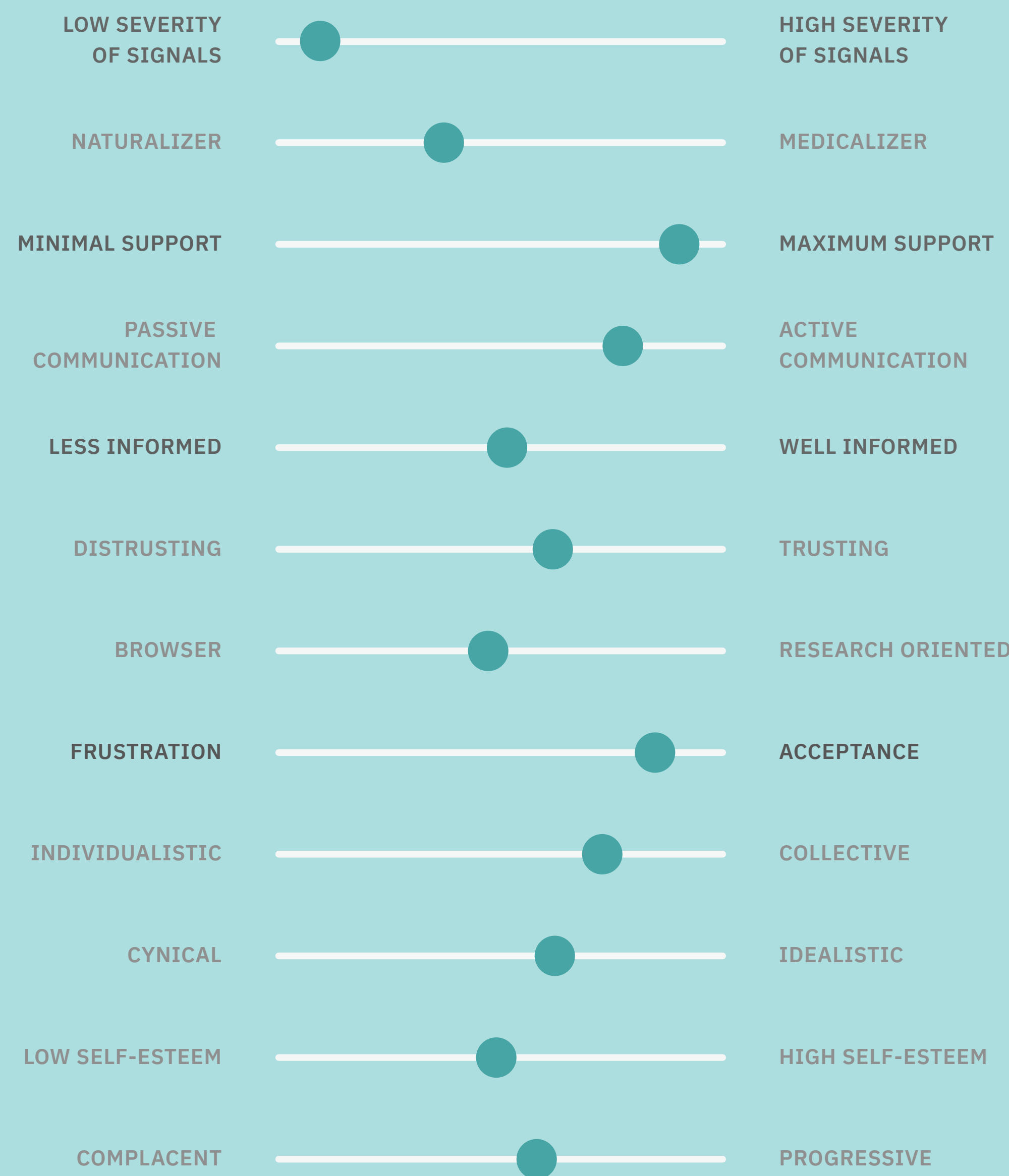
Shruti, "The Attributer"





Taylor

“The Laid-backer”



“It’s not like it’s changed my ability to go to work or deliver things that I’m responsible for.” - P5

Background

Taylor is a 54 year old woman. She has been married for 24 years, and has two kids ages 18 and 21. Taylor has been experiencing irregular periods for almost a year and has had a couple of hot flashes so she is positive that she is in menopause. She’ll check with her doctor next time she sees him.

Confirmation from Doctor

At her annual, Taylor describes her symptoms to the doctor and the doctor runs some diagnostic tests. The doctor tells Taylor that she’s correct and is currently in perimenopause. If her symptoms get worse, Taylor can contact her for treatment.

No Need for Resources

While she was shopping at a bookstore, Taylor comes across “Our Body, Ourselves: Menopause”.

She quickly flips through the pages and puts the book back. So far it has been an easy transition for her, so she hasn’t sought out treatment or more information. Menopause is not a big deal and even though she has annoying hot flashes she can power through it. Plus, it has been a relief not to get periods. Her periods were far worse and now she doesn’t have to worry about getting pregnant.

Occasional Hot Flashes

Taylor has hot flashes that occur about once a month and the very occasional night sweat. When she has a hot flash, she doesn’t sweat, she just feels some heat. At work, if she experiences a hot flash, she silently endures it since the discomfort will

Offering Sympathy

Taylor’s friends and family have always been supportive of her and even more so know that she is going through menopause. It’s nice to have people to talk to.

Recently, Taylor had lunch with her friends and one of them started complaining about the insomnia they been having because of menopause. Though she has the occasional hot flash, Taylor doesn’t really have the kinds of problems her friends have, so she felt lucky and offered her sympathy. She wishes that every woman can have an easy menopausal transition.

Crazy Menopausal Lady

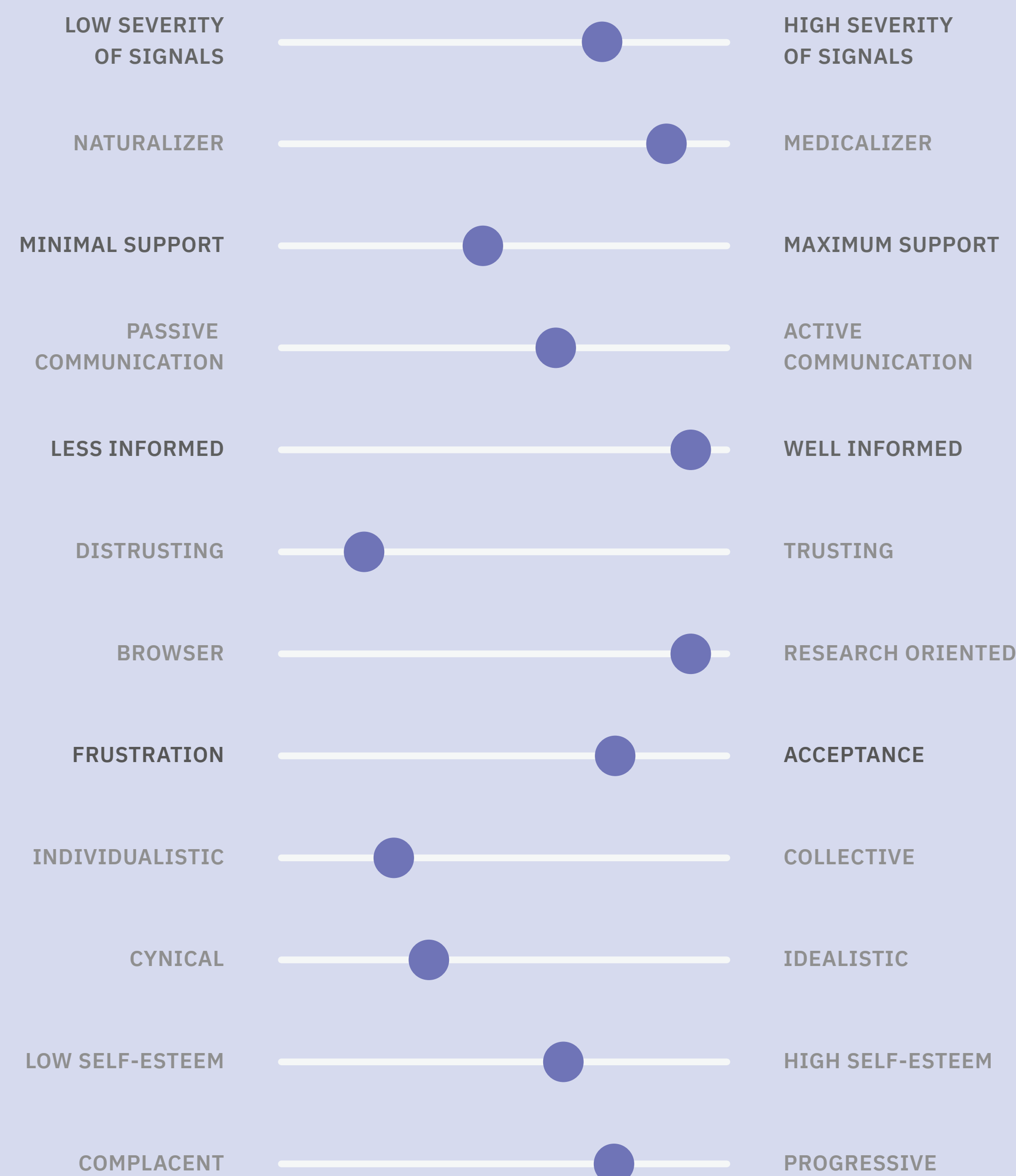
Taylor thinks the only downside to menopause is the negative stereotypes and perceptions of menopausal women. It seems as though most people, especially men, picture a menopausal woman as an old, grumpy, and graceless woman fanning herself. It’s a natural phase that ALL women go through! It shouldn’t be used as a means to justify “bad” or “grumpy” behavior. She wishes there was a broader discussion about menopause that would help mitigate these stereotypes.

Taylor, "The Laid-backer"

	REALIZATION OF MESSAGE	REBELLIOUS PHASE	INTRODUCTION TO WORKING	WORKING STRATEGY	FINAL REALIZATION
STATEMENTS	"I'm going to do this job as well as I can."	"I'm not working here because I don't want to."	"I'm a member of the union, and I'm going to work for the union."	"I'm going to do this job as well as I can, but I'm not going to work for the union."	"I'm going to do this job as well as I can, but I'm not going to work for the union."
ACTIONS	Taylor's first action was to do the job as well as he could, but he was not working for the union.	Taylor's second action was to do the job as well as he could, but he was not working for the union.	Taylor's third action was to do the job as well as he could, but he was not working for the union.	Taylor's fourth action was to do the job as well as he could, but he was not working for the union.	Taylor's fifth action was to do the job as well as he could, but he was not working for the union.
REQUIREMENTS	"I'm not going to work for the union."	"I'm not going to work for the union."	"I'm not going to work for the union."	"I'm not going to work for the union."	"I'm not going to work for the union."
PERFORMANCES	High	Low	Medium	High	Low



Carina
“The Explorer”



“So, I was really, really sad when menopause was confirmed...it's kind of facing the fact that I'm getting older, but also thinking wow I'm not that old.” - P9

Background

Carina is highly educated, 46, and single. She had her first hot flash four months ago. She considers herself a knowledge seeker and feels empowered to find answers on her own. Carina feels well-informed about most aspects of her life, but was surprised when she began experiencing unexpected biological changes. Carina wishes she had known more about menopause when she began experiencing the signals.

Physical Signals

Her experience with menopause is highly physical, especially her vaginal dryness and hot flashes. The hot flashes have affected her sleep, and she has brought a fan in to work to keep by her desk.

Additionally, Carina has found it hard to date and be intimate with someone because of her vaginal dryness. She often feels embarrassed and frustrated with what she considers her “illness”.

Hoping to alleviate her signals, Carina researches HRT, using medical and scientific resources as well as her friends, to triangulate the information she finds. After exhaustively researching HRT, she decides to undergo treatment.

The First of her Friends

Although Carina has a good support system, she feels isolated because she is the first among her friends to experience menopause. Most of her friends don't understand the severity of her symptoms and how it impacts her daily life. Since undergoing HRT treatment, Carina gradually embraces this phase of life. She looks forward to sharing her experiences with her friends once they start experiencing menopause.

Am I Old?

For Carina, she reacted emotionally when she first realized she was in menopause. Menopause meant she was old, which was a scary moment for her. As time has passed, she has developed a more positive attitude about aging, because she knows that it's a natural part of a woman's life that can't be changed.

If Men Went Through This

Carina's menopausal experience also makes her occasionally angry, because she knows if men went through it, there would be more research and resources which can lead to better treatment. She hopes that the next generation of woman can change that and come up with solutions to alleviate signals.

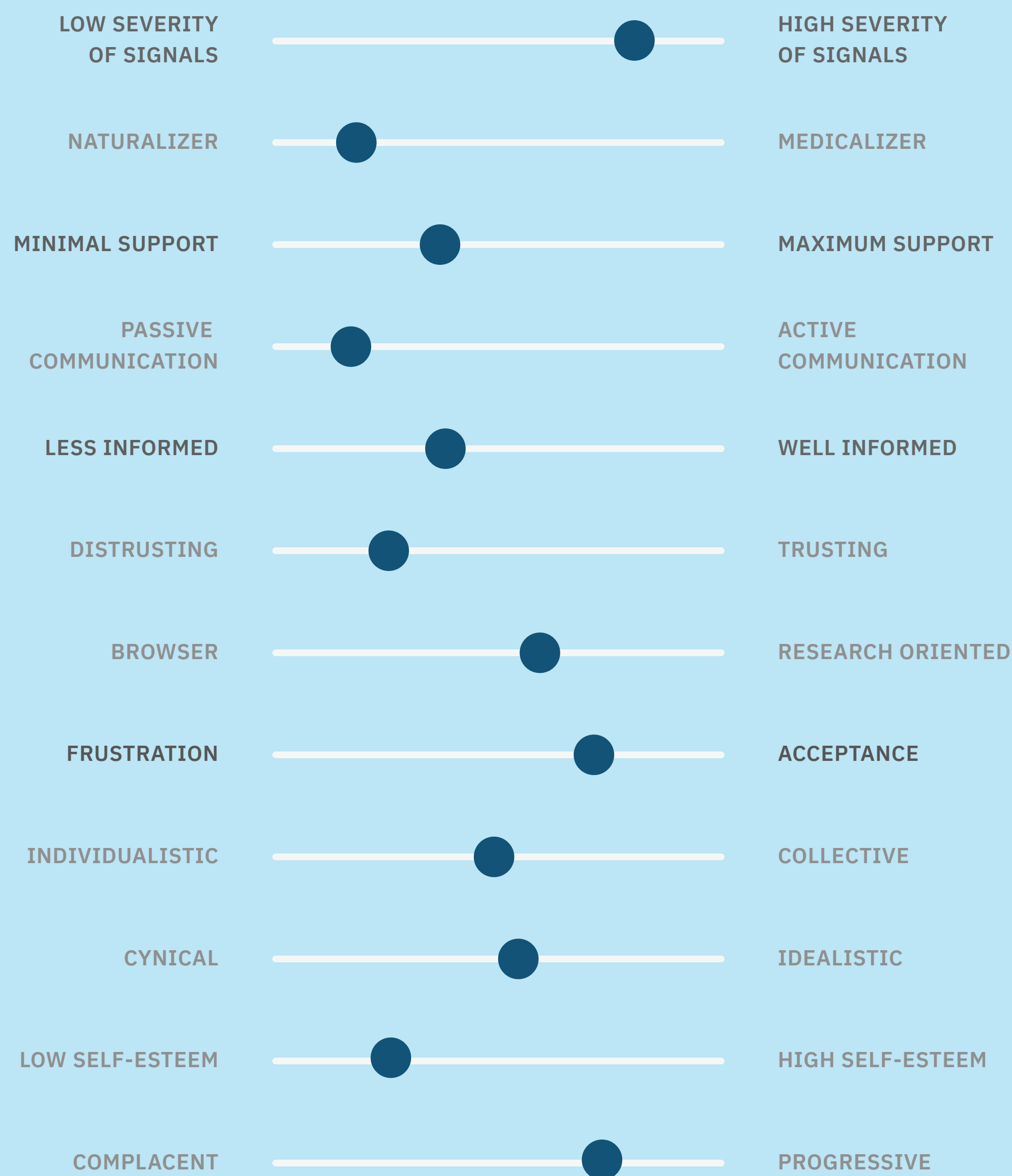
Carina, "The Explorer"





Hoa

“The Internalizer”



“The way periods and menopause have been talked about, especially growing up, it was considered more of a negative. Talked about in a negative way.” - W2

Background

Hoa is 54, married with one teenage daughter. Her life revolves around her family and she feels like she doesn't have enough time for herself.

Connecting the Dots

For the past few months, Hoa has experienced sleeping problems and the occasional night sweat which happens at least twice a week. She doesn't think much of it until she sees a Facebook post from her friend Amy. Amy's post mentions trouble sleeping and problems with night sweats because of menopause. Hoa is slightly taken back because Amy's experience sounds just like hers. She has never really considered menopause as the reason for her sleeping problems. Hoa realizes she must be in perimenopause.

Exhausted

Hoa's insomnia affects her daily life because she has no energy to do her routine tasks. She has tried herbal supplements and nothing has helped. She wants to look for more resources, but doesn't know where to go and the information on the internet can be unreliable and confusing.

Although her sleeping problems are bad, Hoa doesn't think to go to the doctor. She would rather just deal with it. If her insomnia got unbearable, then maybe she would consider going to the doctor.

Doesn't Want to be a Burden

Hoa doesn't talk to her husband because it's not his problem and he wouldn't understand anyway. She feels alone and has thought about reaching out to her closest friend Trang for support, but decides against it because Trang is dealing with her own problems. Hoa doesn't want to be a burden and bother Trang.

She decides to call her mom instead. Maybe she can offer some advice, although Hoa doesn't remember her mom talking about it while growing up. Hoa asks her mom what her menopausal experience was like and her mom laughs, says "oh, it's horrible", and changes the subject.

Hoa tries to bring it up again, but her mom brushes it off. After the phone call, Hoa doesn't know how to process the conversation. Why doesn't her mom talk about? Is it a cultural thing? Hoa really doesn't remember any conversations with her mother about women's health.

Enduring

Although the insomnia has impacted her day-to-day life, Hoa tries to build a wall against feeling too much self pity about menopause. She tries to just cope with it and move on with her life, rather than spending too much time dwelling on it.

Hoa, "The Internalizer"



36 *Collective Persona Journey Map*

Each woman experiences menopause differently. This collective journey map highlights the variety of experiences, showing that some people have mostly neutral or consistent experiences, while others see more dramatic shifts and fluctuations.

Below this collective journey map is a menopause timeline for each of our personas which highlights the diverse lengths of perimenopause, which has a significant impact on each experience.



Shruti



Taylor

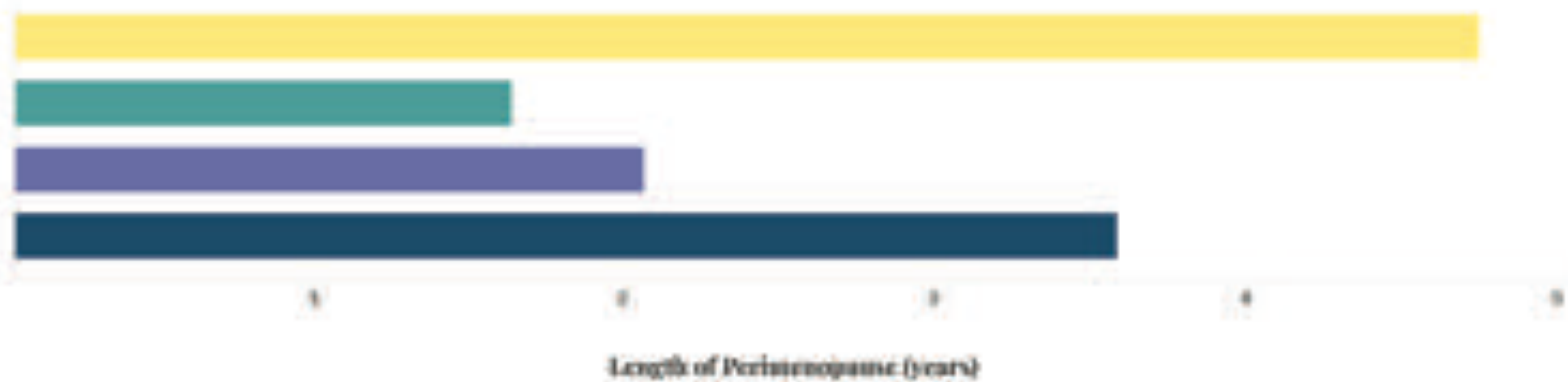


Carina



Hoa

Collective Journey Map



38 *Models*

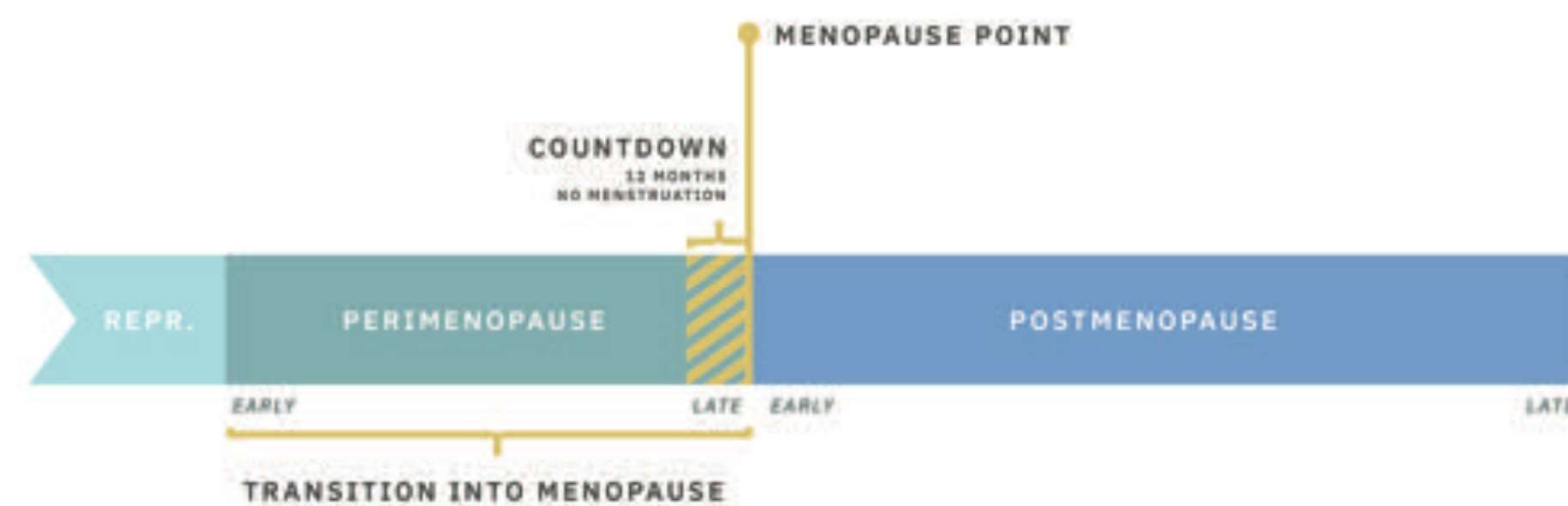
While each menopausal journey varies from woman to woman, there are overarching models that externalize these interactions within the experience.

Menopause Timelines

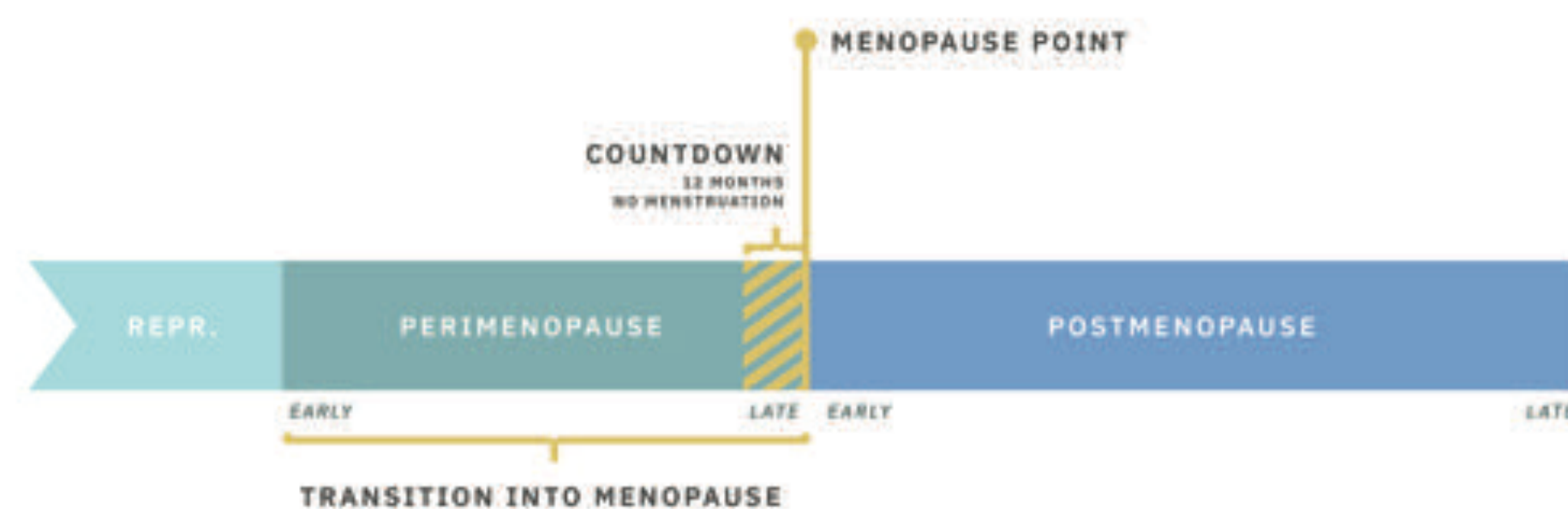
The menopausal experience is divided by the the menopause point, the point at which a woman has not menstruated in 12 months. The transition into menopause is perimenopause and the phase after the menopause point is postmenopause. We have termed the 12 months of no menstruation as “the countdown”.

In addition to the natural transition into menopause, there are various timelines in addition due to early menopause: surgical, treatment-induced, and premature ovarian failure.

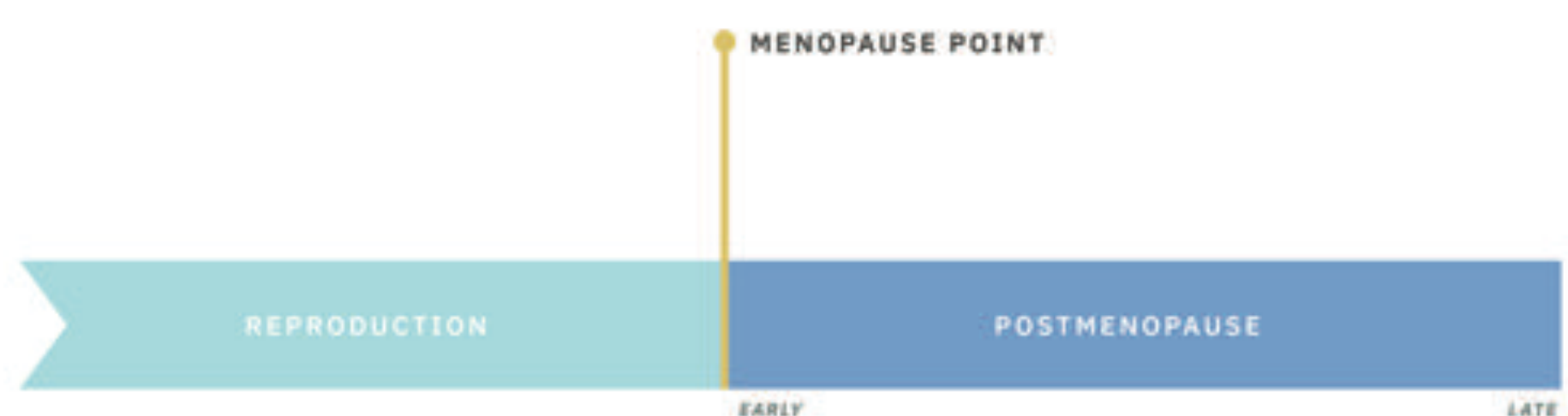
Premature Ovarian Failure (Below Age ~40)



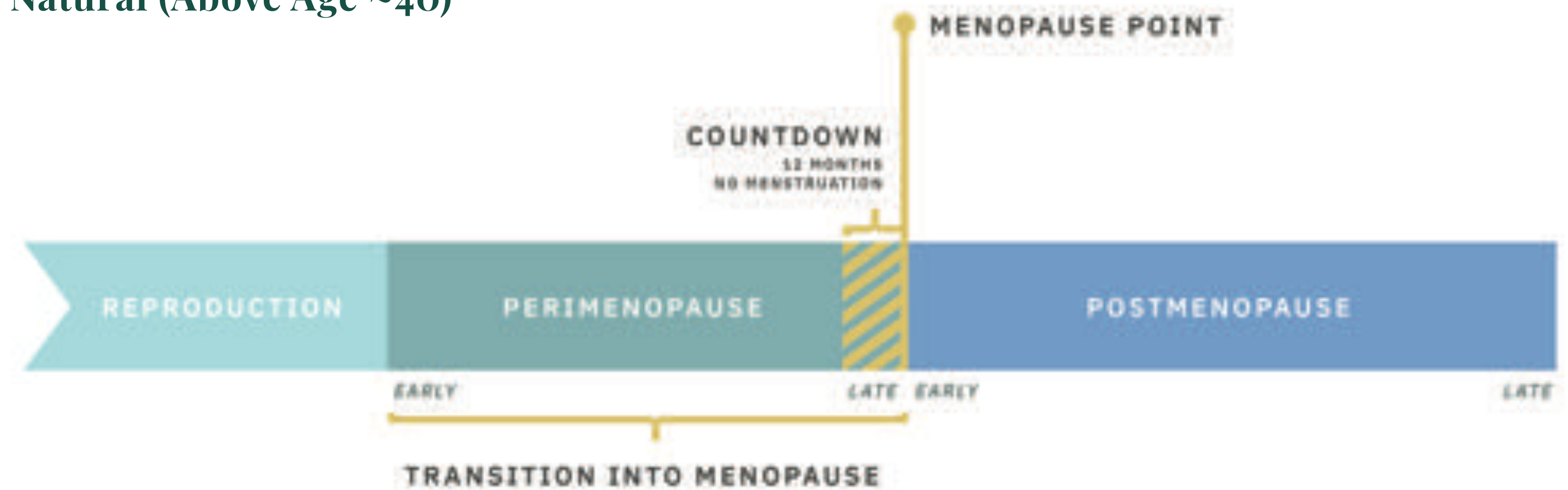
Hysterectomy (Uterus Removed, Ovaries Not Removed)



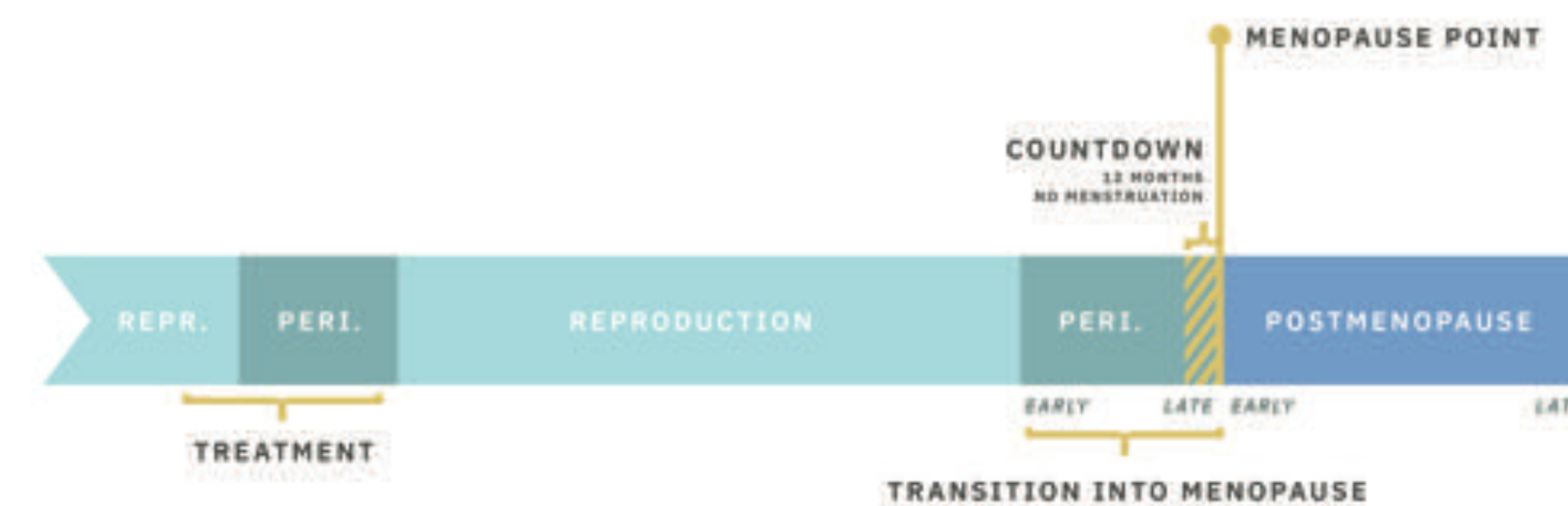
Oophorectomy (Ovaries Removed)



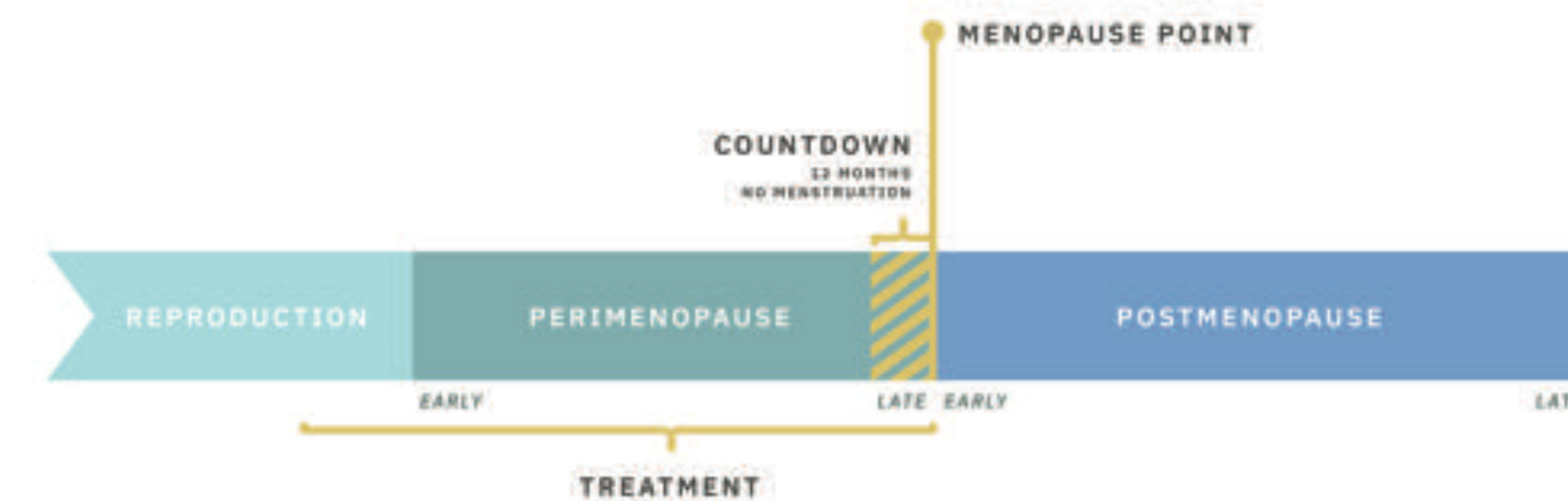
Natural (Above Age ~40)



Chemotherapy (Above Age ~40) and Radiation (Pelvic/Ovarian)

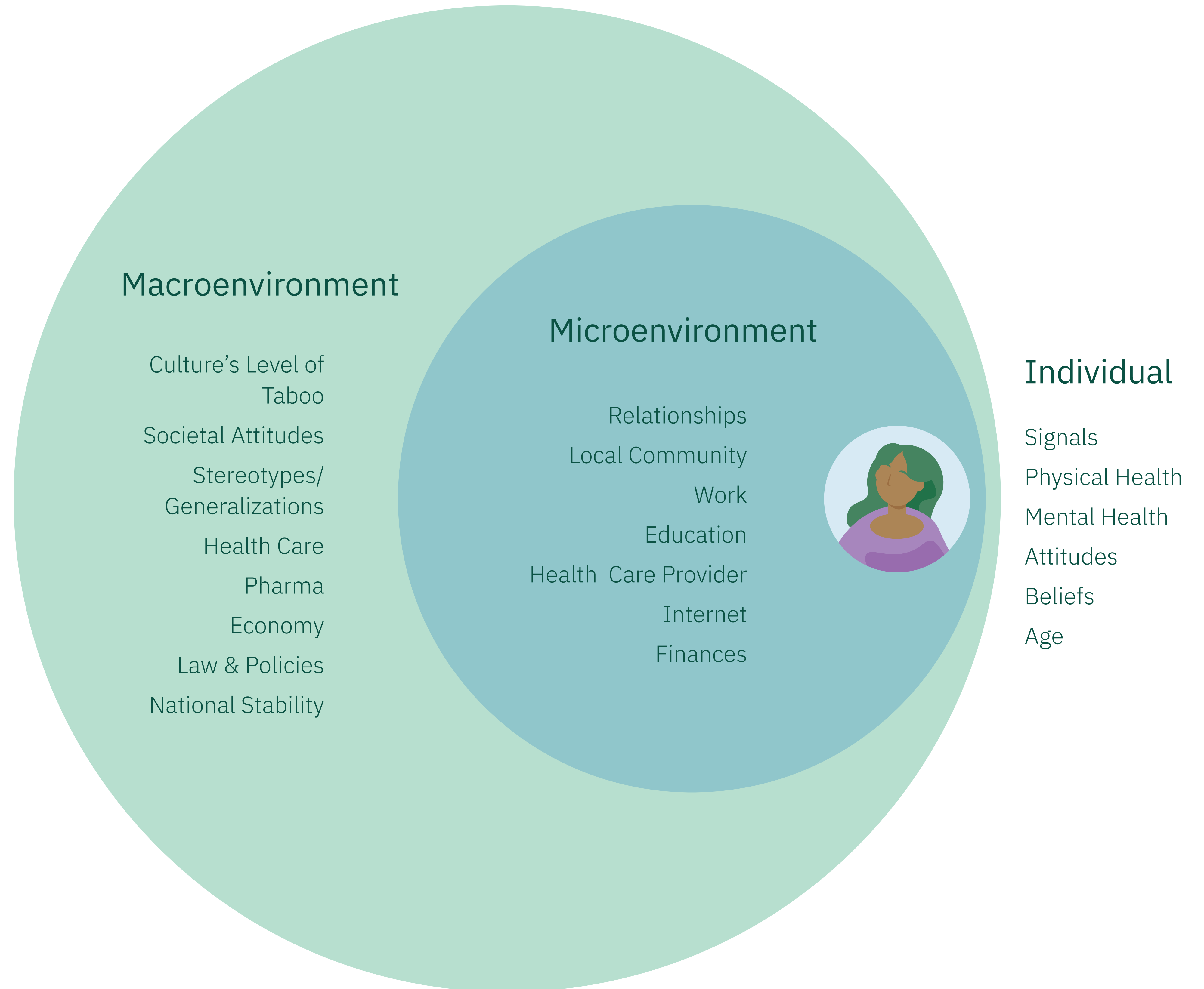


Chemotherapy (Under Age ~40) and Radiation (Other)



Quality of Life

Factors other than the biological response to hormone changes impact the menopausal experience. What is defined within the macro-environment, micro-environment, and individual factors affect her quality of life and how she seeks information and support.

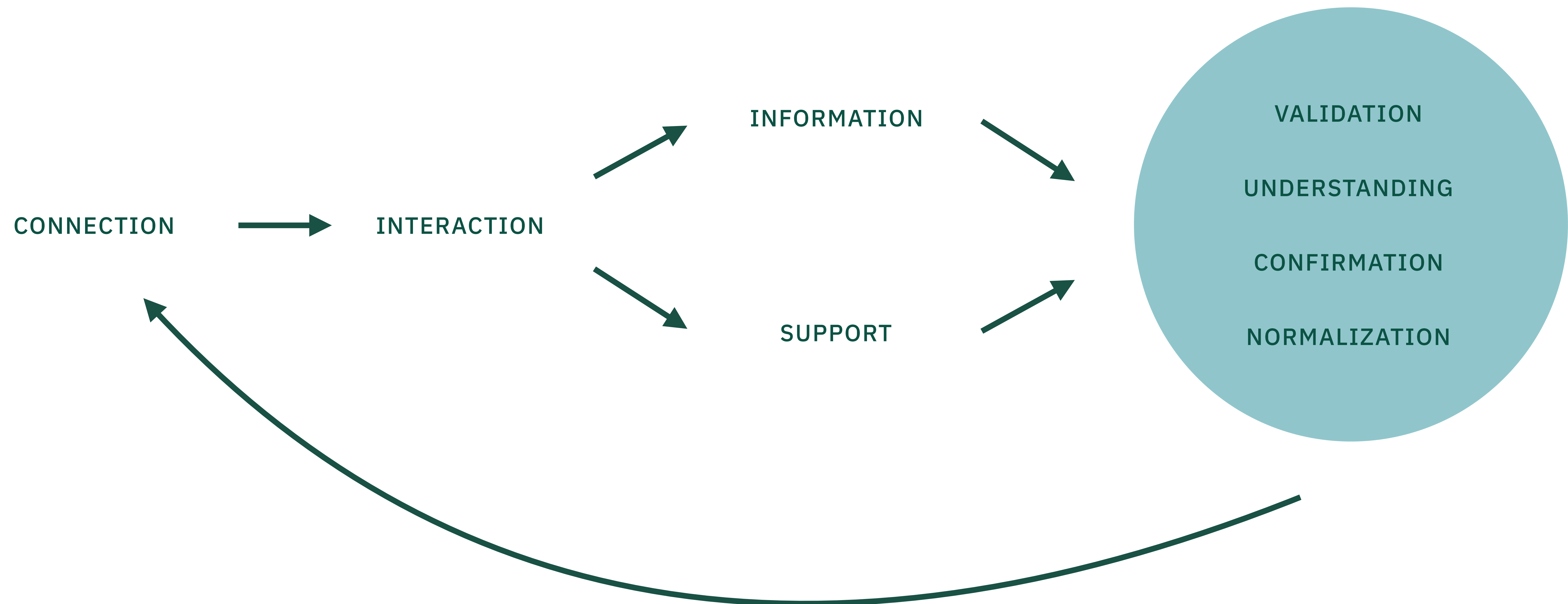


Validation

Through the process of gathering information and receiving support, the menopausal woman's experience is validated.

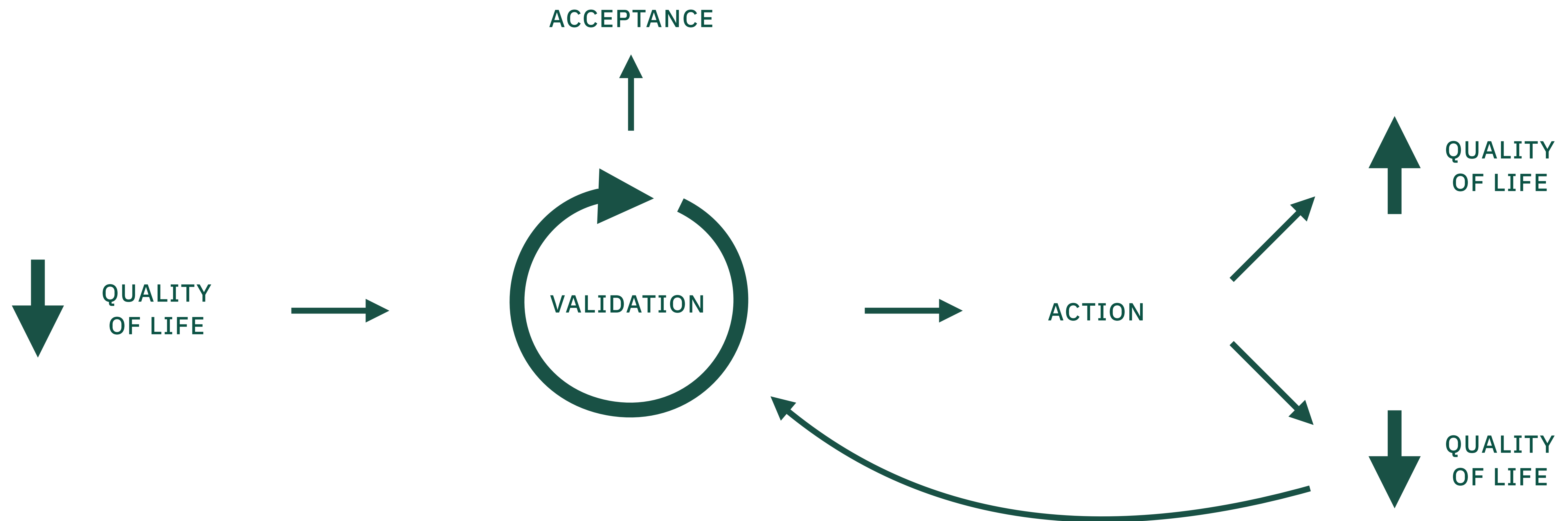
When quality of life is disrupted by a signal, the woman will attempt to seek information or support or both. How she seeks out interactions and the level of success from those interactions contribute to the variety of experiences. The process of validation has been broken down to Connection, Interaction, Information, Support, Validation.

This model also represent aspects in which any of these points leading to validation can fail due to macro, micro and individual factors.



Menopause Experience

Overall, quality of life and validation impacts the menopausal experience in how they individually react to it. When a signal disrupts quality of life, decreasing it, she will attempt to gain information and support through the validation model. This can lead to her taking an action in attempt to alleviate her signal with an action (solution). This can either improve her quality of life or it continues to be a low quality. If quality of life is not improved, this can lead her back to seeking out information and support. It's through these interactions that lead her to her own prescription of acceptance.



4.3 *Design Implications*

Considering what we now know about the menopausal experience, we propose a series of principles and opportunities for a design solution.



Design Principles

01

Celebrate the change.

Although menopause can be an overwhelming time, it is also a time of celebration and self-love. Highlight the highs of menopause, but also acknowledge the lows.

02

Recognize the natural phase of life.

Menopause is not an illness, but a natural phase of life and aging. Use “signal” or “biological changes” instead of “symptoms”.

03

Consider the variety of experiences.

People will have a variety of signals and diverse lengths of perimenopause. Be inclusive and cognizant of intersectionality.

04

Acknowledge aging.

Menopausal people have broader priorities and concerns in their lives. Recognize and empathize with the many social and physical changes that happen in midlife.

05

Be direct and clear.

Menopausal resources contain a lot of ambiguity. Provide information that is accessible and easy to understand.

06

Respect agency and empower.

Menopausal people have the right to manage their own bodies and selves. Respect this agency and help people access it.

07

Be sensitive about the taboo.

Menopause can be a sensitive, uncomfortable, and taboo topic. Be mindful of cultural, geographical, and societal differences.

Design Opportunities

As we move forward, we will begin with ideation to narrow down our opportunity space. Afterwards, we'll do another round of competitive assessment to gauge our narrowed space in order to begin prototyping and testing our concepts. Once we finalize our design direction, we will publish our concept and use this research for the bulk of our publication. We are excited to head into the next phase of our project and produce a design concept that will be emergent of our data.

01

Clear Information and Timelines

People wish they had known more, both before and during menopause, so how can we disseminate information at the appropriate times?

People have trouble finding credible information, so how can we ensure that reliable information is easy to find?

There is limited existing research on menopause, so how can we obtain and utilize more data about menopause to create predictable timelines and body literacy?

02

Recognize the Natural Phase of Life

A support system is invaluable when going through a change of life, so how can we help people build their social circles?

Menopause can be a taboo topic, making it hard to talk about, so how can we open up the conversation?

03

Physical Comfort

Signals are highly disruptive, so how can we reduce their effects with emerging technology like cooling fabrics and sleep therapy?

People have trouble finding appropriate and effective solutions, so how can we clear the path to a personalized treatment plan?

04

Attitudes

Going through menopause can create emotional stress, so how can we make it a positive experience?

Generalizations and stereotypes about menopause are unfair and devalues aging women, so how can we dispel them?

Information and support can create feelings of empowerment and security, so how can we promote those feelings?

References

1. Almeida, Teresa, Rob Comber, and Madeline Balaam. "HCI and Intimate Care as an Agenda for Change in Women's Health." Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems. ACM, 2016.
2. Ballard, Karen D., Diana J. Kuh, and Michael EJ Wadsworth. "The role of the menopause in women's experiences of the 'change of life'." *Sociology of Health & Illness* 23.4 (2001): 397-424.
3. Berterö, Carina. "What do women think about menopause? A qualitative study of women's expectations, apprehensions and knowledge about the climacteric period." *International Nursing Review* 50.2 (2003): 109-118.
4. Gold, Ellen B. "Demographics, environmental influences, and ethnic and international differences in the menopausal experience." *Menopause*. 2000. 189-201.
5. Homewood, Sarah. "Designing for the Changing Body: A Feminist Exploration of Self-Tracking Technologies." Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems. ACM, 2018.
6. Jaspers, Loes, et al. "Health in middle-aged and elderly women: a conceptual framework for healthy menopause." *Maturitas* 81.1 (2015): 93-98.
7. Kaufert, Patricia, et al. "Women and menopause: beliefs, attitudes, and behaviors. The North American Menopause Society 1997 Menopause Survey." *Menopause (New York, NY)* 5.4 (1998): 197-202.
8. Lee, Mirim, et al. "Understanding Women's Needs in Menopause for Development of mHealth." Proceedings of the 2015 Workshop on Pervasive Wireless Healthcare. ACM, 2015.
9. Mead, Margaret. "On Freud's view of female psychology." *Women and analysis* (1974): 95-106.
10. Nachtigall, Lila, and Joan Rattner. Heilman. *Estrogen: A Complete Guide to Menopause and Hormone Replacement Therapy*. Harper Resource, 2000.
11. *Our Bodies, Ourselves: Menopause*. Simon & Schuster, 2006.
12. Pitkin, Joan. "Cultural issues and the menopause." *Menopause International* 16.4 (2010): 156-161.
13. Soules, Michael R., et al. "Executive summary: stages of reproductive aging workshop (STRAW)." *Climacteric* 4.4 (2001): 267-272.
14. Trujillo, Amaury, and Maria Claudia Buzzi. "Participatory User Requirements Elicitation for Personal Menopause App." Proceedings of the 9th Nordic Conference on Human-Computer Interaction. ACM, 2016.
15. Utz, Rebecca L. "Like mother,(not) like daughter: The social construction of menopause and aging." *Journal of Aging Studies* 25.2 (2011): 143-154.
16. Vicki Kafanelis, Betty, et al. "Being in the script of menopause: Mapping the complexities of coping strategies." *Qualitative Health Research* 19.1 (2009): 30-41.
17. Vincent, Grayson K., and Victoria Averil Velkoff. *The next four decades: The older population in the United States: 2010 to 2050*. No. 1138. US Department of Commerce, Economics and Statistics Administration, US Census Bureau, 2010.
18. Woods, Nancy Fugate, et al. "Is the menopausal transition stressful? Observations of perceived stress from the Seattle Midlife Women's Health Study." *Menopause (New York, NY)* 16.1 (2009).
19. Woods, Nancy Fugate, Barry Saver, and Tom Taylor. "Attitudes toward menopause and hormone therapy among women with access to health care." *Menopause (New York, NY)* 5.3 (1998): 178-188.



A *Expert Interviews*

Nancy Kenney

Expert Interview Summary

Name: Nancy Kenney, PhD
Title: Professor in Gender Studies and Psychology
Interview Date: 4/10

Interview Moderator: Kelda
Note Takers/Observers: Aggie and Lan

Background Info

Teaches a course on psychobiology of women and studies female identity, specifically motherhood. Menopause is a subtopic mentioned in the course description.

Interview Objectives and Relevance to Capstone

- Get a psychology/gender studies perspective on menopause (the rest of our experts are more biological).
- We are looking for non medical solutions to our problem statement, which we think she can help guide us toward.
- We also hope to receive further reading and interview recommendations.

Script

Introductions

- MHCI+D program: designing technology around a human-centered problem
- For our capstone we spend a quarter doing research in a problem area - we chose menopause, have read a lot through academic resources, Facebook, popular news sources

Our research questions:

- What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?
- What non-medical strategies do people currently use to relieve menopausal symptoms?
- What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?

Nancy once contributed to a paper about Taiwanese menopausal identity. Also

- does research on egg donors and is currently working on motherhood. Any other relevant experience we are missing?

Question(s) specific to that expert's expertise

- In your research about motherhood, has menopause come up at all? How does menopause affect the experience of motherhood?
- What has the sociocultural arch of menopause been in the US? Can you tell us a little bit about the history of cultural perceptions?
- Where do menopausal people find support today?
- Leave open-ended to start, but can probe with these categories
 - Physical
 - Knowledge
 - Emotionally/culturally
- Where do you think menopausal people need more support?
 - Physical
 - Knowledge
 - Emotionally/culturally
- Review and reflect on our insights (card sort!)
- Are these relatively accurate from your experience?
- Rank these in order of urgency and explain why you ranked them in that way
- Suggestions for further reading & interviewing?

Transcript

Kelda:

MHCI+D program: designing technology around a human-centered problem

Capstone: we spend a quarter doing research in a problem area - we chose menopause. Have read through a lot of academic resources, Facebook, and popular news sources.

Research questions:

What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?

What non-medical strategies do people currently use to relieve menopausal symptoms?

What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?

You once contributed to a paper about Taiwanese menopausal identity. Also does research on egg donors and is currently working on motherhood. Any other relevant experience we are missing?

Nancy:

Just had lunch with Nancy Woods from the school of nursing.

Women's experience with menopause

Perimenopausal and issues related with symptoms

“the menopause guru”

Kelda:

We have an interview scheduled with her next week. In your research about motherhood, has menopause come up at all? How does menopause affect the experience of motherhood?

Nancy:

I haven't actually studied that, but menopause tended to occur at the end of the mother role

Social and psychological discomfort of reaching menopause confounded by empty nest idea

Esp women who have motherhood as a major identity point

In all likelihood you probably didn't want to have kids, but that you can't can be devastating

This changes over time as context changes

Such as adult children moving back more these days

More technology that allows menopausal women to give birth - ethically fair? What does it mean to the child? To the society?

Kelda:

You said with kids moving back, it might be changing? How?

Nancy:

Maternal role doesn't end - family dynamics? This hasn't been well-studied

It's very interesting because these young people have all this supervision and it creates interesting dynamics

Exactly what kinds of problems people are having with menopause...

Emotional issues are tied to physiological symptoms

Hot flashes can be debilitating

During day: feelings of discomfort & social implications (what can I do, how much of my clothing can I strip off in public, who can I tell)

“Working while being a woman is still considered a crime”

If they occur at night: that affects sleep, and people need sleep.

Going without sleep day after day after day...

My twin cousin went through 10 years of repeated hot flashes. I had one. - how menopause can vary dramatically among women.

Not knowing what is going on - unfortunately so many stereotypes & jokes about menopausal women - so everyone approaches menopause with sheer terror

“You go from a woman to an old hag”

Going through menopause is losing your femininity

If I'm no longer feminine, will anyone like me? How can my partner like me if I'm not feminine?

“Feminist” books of the 60s (Forever Feminine) - encouraged hormone therapy to stay young

In addition to loss of femininity, aging is also tied to menopause

Western society - no respect for old people

Menopause is at 50 which isn't actually old in this day and age

Most women don't mind not menstruating

Even young women are using contraceptives to prevent menstruation

It's not MP, it's the physical effects, most of which are actually just aging

Vaginal dryness or lower libido
Don't know how to talk about their partners about sex regardless of age
No experience of communicating what they need and what they want
Passive implications of menstruation before becoming "okay" to talk about
"Double standards"

Kelda:
What has the sociocultural arch of menopause been in the US? Can you tell us a little bit about the history of cultural perceptions?

Nancy:
In th 1900s:
Real fears with a menstruating woman
Shorter lifespan
Common death was childbirth
If you made it to menopause - you survived!
"It's scary how little science knew about women's body"
Dangerous times
Women's mental health during menopause
Belief that women went crazy bc they were losing the one thing that made them a woman
We put them in positions where they couldn't do much harm like raising kids
Started doing good research on mental health
The data never really support the mental health issue
For example, PMS (basket cases) can't trust them with anything (i.e. Hillary Clinton)
Haven't done really good studies on menopause and the mental health issues (and the prevalency thereof and whether those issues are actually connected to those hormonal changes)
Did find increase in depression at midlife, but it seemed like more of an age thing
Everyday woman doesn't try to seperate it. It's easier to blame MP than a crappy life.
Most women aren't well-trained on how their body should be acting
Internet groups are wonderful to share experiences
Wouldn't go to doctor because there might be something wrong with me, and "as long as I'm not told, there's not something wrong with me"
Article for class - multigeneration women
Mothers + daughters, younger have just gone through MP and comparing the two experiences
Younger women: even if they see as just a natural evolution of the body over time, they still want biomedical confirmation
Novel symptoms lead to concerns about our bodies falling apart, so nice to have confirmation that they're not. Plus the modern approach means many women are on contraception so might need test to know.
It's an interesting time -- between times when bodies are unspeakable to times where everything is very natural (which doesn't prevent us from worrying that what I'M experiencing might not be normal).
Everything is fine... IF this is what I think it is, but how do I know that it is what I think it is?

Kelda:
So we've talked a little bit about this, but where do menopausal people find support today from your experience?

Nancy:
Online
These women have been playing with computers for 20 years
For better or for worse
Internet friends are just as good as in person friends and both just as good as what they know

Kelda:
We've been on the FB support group and there's a lot of panic, and it seems overwhelming to me.

Nancy:
Who's going to post here? If you're coasting through life and you're content, you're not joining these groups
There's no moderation of the group. Who's going to stop the panic if it's just a bunch of sort of educated individuals saying what they're experiencing.
If you develop app for people to use, how do you help them understand that yeah you should experience, BUT if it goes too far you should get it looked at... without creating panic.

Kelda:
This kind of addresses my next question - is there anywhere where you think menopausal people need more support?

Nancy:
To know that symptoms are perfectly normal
Know that there is a sex life after menopause
Being depressed is NOT a normal sign of menopause, if you're depressed, it needs to be treated.
Unfortunately a lot of people don't have a social support system
Study after study, the more people you have in your support system the better off you are
If family is just like "ignore her, she's menopausal," that's very isolating

Kelda:
Please review these cards and let us know whether they seem accurate and also rank them in order of importance.

Elan Keehn

Expert Interview Summary

Name: Elan Keehn
Title: Elan Cary Keehn, A.R.N.P., N.D - certified nurse practitioner at the Women’s Health Care Center at UWMC-Roosevelt
Interview Date: 4/12

Interview Moderator: Aggie
Note Takers/Observers: Kelda and Lan

Background Info

- Keehn’s clinical interests include integrative preventative care, nutrition, endocrinology and adolescent care.
- Keehn is a certified nurse practitioner and naturopathic doctor. Her goal in medicine is to provide compassionate, individualized, integrative care, and to bridge allopathic and naturopathic medicine for her patients.
- She strives to help her patients holistically move toward a healthier and happier way of being.

Interview Objectives and Relevance to Capstone

- Get a medical perspective on the menopausal experience
- Participate in a “menopause” walkthrough to get a patient’s perspective

Script

Introductions
MHCI+D program: designing technology around a human-centered problem
For our capstone we spend a quarter doing research in a problem area - we chose menopause, have read a lot through academic resources, Facebook, popular news sources
Can we record?
Our research questions:
What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?
What non-medical strategies do people currently use to relieve menopausal symptoms?
What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?
Can you take us through what a menopausal patient will experience from the waiting room to the medical professional interaction to leaving the clinic?

What are the reasons for scheduling an appointment?
At what point does the Women’s Health Clinic proactively ask questions about menopause? When do you come to this conclusion?
Is perimenopause explained to women at a certain age?
How long do they wait in the lobby, exam room?
How do you tell them about menopause?
What do you tell them the estrogen count check is for?
What resources do you give them?
What are the common myths?
Can you clarify whether or not depression and mental health is linked with menopause?
What can a woman do?

Transcript

AT
If you can take us through what you typically experience with a menopausal patient from the waiting room and kind of described that process along with several different types. Maybe a patient that’s perimenopausal, someone that’s in menopause, and someone who’s post-menopause.

EK
Well, you know, though, to be in the waiting room all of them, they get called back by a medical assistant and then they get their vitals taken and then their reasons for the visit. So I would say for my post-menopausal, menopausal, and perimenopausal patients, I’m either seeing that because they make a specific visit about symptoms are experiencing or it’s their annual and they want to talk about the symptoms, they’re experiencing so we don’t bring people in just to talk with them about menopause.

It’s usually something that they’re either there anyways. And so becomes a discussion or they have questions about it, or they’re experiencing experiencing symptoms that they wonder what’s going on and sometimes they’re related to menopause and sometimes not. But then they schedule an appointment. So then, you know, they come back and they they get their vitals taken they tell the MA what their why they’re here.

AT
What does MA stand for?

EK
MA is a medical assistant. Okay, so they’re the ones that groom the patients they call their names, bring them back into their room, get their vitals, typically they should be updating medications and then finding out why they are why they’re here for the visit, and then they come back to me. Bring me their paperwork and then I go in and conduct the visit.

AT
Okay, so what happens when you meet with them?

EK
It kind of depends why they’re here if it’s kind of a visit that they like what we call a follow up visit or a focused visit. They usually come in and they say, you know, they’re here because they’re hot flashing or their periods are changing or they’ve developed sleep problems and brain fog or you know their moods are changing and and they tend to be kind of in the 45 to 50 ish. Those are more perimenopausal people who come in.

So then I would sit down with them and you know what brings you in today. And then we went talk about their concerns and I would conduct the visit. Otherwise it’s looking like they come in and they’re here for their yearly exam and they say, you know, under their concerns their concerns, maybe any of those symptoms like “I don’t know what’s going on with my periods” or like “I’m starting to have hot flashes” and so we then talk about their symptoms from there.

That kind of what you’re getting it.

AT
Yeah. Um, I was wondering, too, at what point you because my friend mentioned that they do a test to see if they’re in menopause like can you describe that test.

EK
Yeah, and it’s not one that we actually do very often they’re probably thinking of follicle stimulating hormone.

AT
I think so, yeah.

EK
So when someone is postmenopausal their follicle stimulating hormone is elevated and it stays elevated when they are in a perimenopausal state that follicle stimulating hormone can be up and down and up and down. And so by getting one check of it. It’s not going to tell me for sure heading towards menopause. They can’t give me a clue because of its kind of elevated it gives me an idea, but if it’s really significantly elevated then then it means they are.

Now in some women, they can have primary ovarian insufficiency which is kind of like an early menopause day and if there’s a woman that I’m suspect if I’m evaluating her for that I always check the follicle stimulating hormone, and you have to check that with an estradiol because if the estradiol is really elevated that can give you a false reading for the follicle stimulating.

AT
Can you spell Estradiol?

EK
E-s-t-e-r-a-d-i-o-l. And it's basically estrogen, we check estrogen.

Yeah, but then there's that's kind of the perimenopausal symptom. I tend to see them when they are systematic and they want to have a conversation about what's going on. What symptoms they're experiencing and, you know, depending on how bothersome or how impactful symptoms are to their quality of life. We talk about different interventions or recommendations.

Then there's also the postmenopausal women that tend to come in more usually the only reason, they'll come in related to their menopause is: 1) if they need a refill on medications that they're already taking to manage menopausal symptoms or 2) if they start bleeding again after they've been menopausal.

AT
In terms of proactively asking questions about menopause. What age do you start like with women who come in regularly or like once a year, when do you start looking for those symptoms?

EK
You know that's a hard question cuz menopause is so variable, I would say Upper 40s is when I really start to talk about it and I specially talk about it even more if they bring up any kind of symptom that may be related to perimenopause and those are all over the board from fatigue to their menstrual cycles changing not necessarily becoming irregular but maybe they're getting a little shorter maybe they're getting a little heavier maybe they're getting a little lighter maybe some mood fluctuations maybe some change in their skin. Maybe some changes in their, their sleep or their energy levels.

So usually I kind of let them kind of start that conversation because often if you I feel like if you know you want to have a patient, be aware of what menopause can look like, but if you start giving them a list of "oh you're, you can become perimenopausal between this age and this age, and here all the symptoms that you might experience." Patients start focusing on those symptoms and finding them even when they're not an issue.

AT
What, what is the talk, I guess?

EK
The talk?

AT
So do you have it you ever sit down, like when you tell a patient about menopause and if they don't really understand it. What do you tell them?

EK
I try to keep it very simple basically that it's a time in their life or their hormones start to change typically their estrogen levels drop and that it's, you know, this is

something that's not an illness or anything that's problematic and, you know, explain that there are some people who experience no symptoms whereas, you know, there's a variety of other experience uhh other symptoms they can experience usually that the best indicator of what their menopause will look like is talking to an older sister, a mom, or maternal aunt.

And in terms of preventative medicine, we want to make sure their bones stay strong and I kind of talked about their increased risk to osteoporosis

And that's really it, you know. In general, when they have their annual exam, we talk about all the different guidelines and preventative measures that we do, they're not necessarily related to menopause.

AT
There was a question from a prior expert interview talking about aging versus menopause and that sometimes people will lump aging effects with menopause. Whereas, they're not entirely related and I was just wondering, your thoughts about that and how true or or more clarification about that.

EK
Yeah, well, you certainly aging and menopause are two different things. And sometimes they can overlap, though, you know, I think of aging and joint starting to wear out become more painful and unnatural decrease and energy and a change within skin and often maybe a slight rise and in blood pressure and blood sugar and different stuff like that. That tends to be aging. That's not really related to the menopausal piece but then there's some a lot of the menopausal symptoms can also be related to aging changes in sleep habits and patterns. Skin changes to decrease, too, decrease in energy too, so there can be some overlap, but they're also, you know, different things.

AT
Right, in terms of mental health is there more correlation with menopause and mental health so like depression?

EK
Yeah, hormones really play a big role and mood stability and serotonin levels and all these different neurotransmitters that affect our moods and so with the hormonal fluctuations and changes you can get changes in neurotransmitters and and all kinds of changes in mood stability. I would say what I see most frequently is not suddenly a patient is depressed and they've never been depressed, but there's a lot more fluctuations like there's more depressive thoughts. There's more irritability, there's more just a feeling like you don't necessarily have control over your emotions and your moods as maybe you felt like you did previously.

AT
And that's kind of checked into when they're describing with the, the MA. It's like you'll look for depression too.

EK

Yeah the MA does do PHQ2 test -should have added- that which is a simple 2-question test that kind of looks into depression and if there's anything that kind of indicates depression and they get a PHQ9 form, which is a little bit more in depth about depressive thoughts and then when I come into the room I follow up on that.

AT
And are there any I guess like therapists in the area that you would recommend knowing who would like talk more about like menopause.

EK
Yeah, I have a list of referrals. I give to my patients very commonly. I don't have anyone on there that specifically focuses on menopausal time of your life. And we are also getting a psych-nurse practitioner here psychiatrist nurse practitioner, so they'll be able to see all my patients. But again, they're not going to focus specifically on menopause. Yeah,

AT
But they would maybe have some experience

EK
yes oh yeah yeah

AT
Oh, I missed this question. Sorry. So back to that estrogen count so it's usually just to make sure it's taken the...

EK
the follicle stimulator?

AT
The follicle stimulator. So that's like the only one though for the estrogen count.

EK
Right. Usually I order, both at the same time.

AT
Okay. Wait, so the follicle and then there's an estrogen count so they're two separate ones?

EK
There's two separate tests. Follicle stimulating hormone and estradiol. The follicle stimulating hormone is the one I look at a little bit more in terms of diagnosing kind of getting diagnosing menopause, the amount of pause, but I want that estradiol in there because I want to make sure it's on the lower end and not the higher end if it's on the higher end it can really screw up the follicle stimulating count, what I would expect to see and a menopausal patient is the estradiol lowering and the follicle stimulating hormone increasing

AT

That makes for more sense.

LV

Something you mentioned earlier, if you're having a discussion with your menopausal patient, you listed interventions. Can you name some of those interventions?

EK

Yeah. Well, I mean, there's a lot of different ones: always making sure that they're they're eating well, they're getting regular exercise, they know about you know the hot flashes, layering working on sleep hygiene. If it's mood like working on you know therapy piece but then if you're getting into more medications. Some people will use a certain anti depressant like Effexor for hot flashes or gabapentin another medication for hot flashes or then there's for hormone replacement treatment.

And there's a huge list of those if it's just vaginal symptoms. Then I tend to do a localized vaginal estrogen

if it's more systemic symptoms. I am I, I always start with a bio identical FDA approved estradiol patch as possible because patches thought to be less have side effects and there's also an oral estradiol and that you can do and if they have a uterus, you also have to piggyback that with progesterone and then there's different options of progesterone. There's also supplements, there's like black cohosh and maka you know whole bunch of different supplements that you can try if they're wanting more of a holistic approach and I usually will do that in addition to do acupuncture. Acupuncture can be helpful for hot flashes, too.

AT

We're part of the menopause support group on Facebook and there's a lot of talk of CBD oil

EK

Huh!

AT

and I was just wondering what for specific for flash

EK

For hot flashes?

AT

For everything.

EK

I would think CBD oil is definitely for mood flex, well more for well, people can get joint pain and achiness, and I would think of the CBD oil for that. I'm surprised about the other effects.

AT

The amount of times we've seen it pop up, I feel like every day there will be at least one post about it.

EK

Yeah, yeah.

AT

And then there's a lot of women who, quote:

“They can take my estrogen for my dead hands”

EK

Oh, they don't want them to get have their estrogen taken away.

Yeah, and that's always an issue is getting women- counseling women on the you know the risks around estrogen and you know we like to start as close to perimenopausal time as possible. Have it be the shortest amount of time in the shortest and the smallest dose, with the goal of not having them on it for more than five years. But yes, a lot of women, they do not want to let go of their estrogen.

AT

Do you think that comparatively to this center to the different types of women health centers in Seattle. Like, do you think that there are different variations in how menopause is treated.

EK

Yeah, yeah, yeah.

AT

And do you know of a particular clinic in mind that might because that way we can see a different- if we can try to get a scheduled interview?

EK

No, I mean, I would just the only thing I would say is if someone is, you know, doing more like family practice, you know, they may not see as much menopause, so they may not be as used to like counseling women, and the treatments and stuff like that but I can't think of a practice that is very different than what we do.

AT

Yeah, you guys have any other questions in mind?

LV

Yeah what are the myths surrounding menopause, or like urban legends or something that people may come in. And you're like, let's step back a little bit.

EK

So I would say some people come to think that kind of their sex life it's like the death of their sex life which for some women, that's an issue for sure but doesn't mean the death of their sex life.

I would say that's the biggest concern and the biggest myth.

KB

inaudible

EK

i think that there's a lot to be said about going into menopause at a really healthy state already.

There's actually I've seen a fair amount of data on exercise and hot flashes so already going into menopause and and in the kind of the healthiest state you can be so already having good healthy habits. I think often you know some women, there's there's just it's out of their control. But for it for some women, I think that can really make menopause a lot more manageable.

I think what I see a lot is people that are getting ready to like have a baby then like yes this is a time that I'm going to be like the healthiest of my life. I'm gonna try I'm gonna have this baby. And then they have the baby and then as they age you know everything's about children if they have children, of course, not everybody has children, everything's about their children and then suddenly this menopause time is upon them. And I think if they were to also take that as like I'm about to enter menopause, I want to be in the healthiest I could be. I think that would really improved a lot of women's experiences.

AT

Is there anything else that women can do prior to making sure that their menopausal experience so maybe it's not just physically, but mentally,

EK

I think, you know, talking to parents more talking to family members more about their experience around menopause can be helpful because sometimes menopause can be a pretty isolating time for women. It's like they feel like suddenly something that's totally taken control of their bodies and they've lost all control so talking to people that have been through it. And also, you know, the family members. It gives them idea what their menopause might look like.

And I think just I think the communication around it is important being, you know, talking to friends and medical providers and therapists and just not isolating themselves.

AT

So for and like this might be just more the logistics. So how long do you think an entire appointment takes with from like the waiting room to the MA to waiting in the exam room to talking to you to doing estrogen count slash other word I can't pronounce.

EK

Are you talking more of a problem focused visit or an annual?

AT
Probably, the problem focus.

EK
Depending on the complexity anywhere from 15 to 30. We're allotted 20 minutes, but that includes the patient coming back, getting their vitals seen then being done and then walking out the clinic.

AT
And then what would it be before an annual?
EK
We get 40 minutes.

AT
And then everything's pretty much communicated via Ecare afterwards, or sometimes phone call.

EK
Mhmm.

KB
Is there a symptom that people come in with more often or less often, or like a symptom that people don't come in for?

EK
I would say most common symptoms are hot flashes is probably the most common and of course changes in their menstrual cycle.

Patients don't come in for... Joint pain is a big, joint pain and achiness is a big part of menopause, I think, and a lot of people don't come in with just that complaint because because that's one that could also just be an aging thing.

KB
Do you think that there are people who have like really severe mood swings or depression. Don't come in because they don't realize it's related to menopause?

EK
Well, a lot of people come in with mood issues and they and it could be menopausal or could not be menopausal.

I think the most most commonly menopause exacerbates mood issues mental health stuff that's already there.

AT
How long has the like in western medicine been involved with menopause. Like, when did it become more of a health issue because we read some like crazy stuff from the 1800s.

EK
Oh, God, like I have no idea.

AT
Yeah and I guess like we were assuming like around the 1900s because it always it kind of like started more when like women, we're living longer

EK
Yeah that would make sense. Yeah, I don't know

KB
inaudible And she's saying that it's like it has only recently become a more negative thing. That people used to be more relieved by..*inaudible*

EK
Yeah, well I mean now I think part of it is that everyone wants to stay young and it's it is something that can shift of different stage in their life. Some people experience grieving over the loss of their fertility and then there's their menstrual cycles.

LK
Would you attribute this also to why maybe menstruation is something quietly talk about whereas menopause is not a silent topic but it's not as discussed widely.

EK
I would say that the reproduction is why menstruation gets talked about so much more either trying to not reproduce or trying to reproduce, but it could also be that

AT
Are women told to discuss this with their partners, because we mentioned like talking to, like, you're like the women in your life

EK
That that's a good point. Usually I don't say, Oh, you should go home and talk to your husband or your female partner about this but I mean I think it is important to have everyone cuz it's gonna impact impacts them it's going to impact their partner, their family. Everybody.

AT
I will say if I know my mother was in menopause, I would have been a lot more empathetic.

EK
Yeah, yeah. Oh, would you have understood menopause at that age?

AT
Yeah, and that's like the question: how does a mother tell their children?

EK
Yeah, I don't know...

AT
What does that look like.

EK
I don't know if you know, most people are what teenagers when their mom's in menopause Yeah, because I can be like "Screw you, mom, my hormones are all over the place."

LV
Especially with something that we notice, people are getting married later. Currently my mom is going through menopause and like going through all this research, I'm much more empathetic then I'm making sure she's not isolated, I make sure I call her everyday.
EK
But you probably wouldn't have had that approach at 12 or 15.

AT
Yeah, but around then that's when we find out about our period. And so we kind of already become aware of the human body.

EK
But I feel like you're so self absorbed at that point. Everything is all about you. So you don't really care that much what your mom is going through. Yeah.

AT
Or maybe it's like dad or partner and like they're sitting down like "listen your mom's going through change and just like yeah she loves you."

Katherine Guthrie

Expert Interview Summary

Name: Katherine Guthrie
Title: Member, Public Health Science Division, Fred Hutch
Interview Date: April 17, 2018

Interview Moderator: Lan Vu
Note Takers/Observers: Kelda Baljon and Aggie Tutia

Background Info

- Dr. Guthrie is a PI of the Data Coordinating Center for MsFLASH (Menopausal Strategies: Finding Lasting Answers for Symptoms and Health), a network of scientists who design and conduct multiple concurrent clinical trials to identify treatments for alleviating the most bothersome symptoms of the menopausal transition.
- Has written research articles with Nancy Woods

Interview Objectives and Relevance to Capstone

- To understand menopause from a statistical perspective
- To understand the data collected from previous research on menopause and where there are gaps or study limitations

Script

Introductions

MHCI+D program: designing solution around a human-centered problem

Why we are studying menopause

Our research questions:

What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?

What non-medical strategies do people currently use to relieve menopausal symptoms?

What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?

Based on MsFlash and other research you have done, what are some stats that you found interesting?

One article focuses on a patient’s priorities for alleviating menopausal symptom. In the article it mentions differences among race and educational levels. Are there any other demographic or societal factors, you would like to explore further in regards to

menopause?

There can be a range of menopausal symptoms from sleep fatigue to brain fog. In your research, how do you differentiate between aging or menopausal?

In the next 10 or 20 years, what do you envision for the research and/or discourse surrounding menopause?

Suggestions for further reading or who to speak with?

Transcript

We gave Dr. Guthrie an overview of our project and goals for the remainder of the quarter. We also provided information on the experts we have already talked to.

This led us into a discussion about the Facebook Menopause Support Group.

<Showed Dr. Guthrie the Facebook Menopause Support Group>

Katherine Guthrie (KG)

Well interesting...it’s all over the place. Some of this stuff makes me nervous, but I’m not a doctor though.

<KG cringes and laughs as she scrolls through the Facebook group>

Lan Vu (LV)

So, you mentioned that some of the information on the Facebook group makes you nervous. What makes you nervous exactly?

KG

Well I think this is the issue that you’re tapping into and that MsFLASH it tapping into which is that there’s been research, not as much research as in a lot of other fields, but women don’t always seem to know what are good treatments, what works, what’s normal, you know... but I think it does speak to the lack of information and the lack of sort of basic understanding in the culture about what women are going through.

I mean my best example is in the study during our fifth trial, we decided to do something different and we looked at vaginal symptoms, which are very common in postmenopausal women and some things like dryness, itching, irritation, and then issues with sex. You know for the physicians in our group, this was something that was very well understood. This happens. This is very common, but a lot of women who came into the trial had no idea that was a normal thing and that their husbands

thought they were maybe making this up and you know a lot of people were really interested in just having that acknowledgment that this was a common problem and people were trying to figure out what to do about it.

LV

Going off of that, do you have any inklings of why these information gaps exist?

KG

My opinion and this is informed by my work, but just, you know, as a 50 year old woman myself and women in their midlife start to become invisible, you know, women are of most interest to the culture when we’re young - this sounds really negative – but we’re of interest when we’re child-bearing, but once you’re past that point I think, not a lot of attention is paid to women and what we’re going through because we’re not as interesting to men.

LV

For menopause and your research, how do you distinguish between the effects of aging and menopausal symptoms?

KG

Right...that’s a good question and I really don’t know. Our MsFLASH research has focused on symptoms that are very common in women in this age range mostly in their 50s but between the ages of 40 – 60. I don’t know how much of that is aging and how much is you know the exact mechanism of the estrogen changing and some of it is just I think, yeah, I think they’re tied together and it’s hard. It’s hard to say.

LV

Are there any surprising stats that you noticed throughout your research on menopause?

KG

Our fourth study focused on insomnia and really fascinating for all of us. Let me back up for a minute, we had a particular outcome of interest, which was hot flashes in the first three studies. We also collected a whole bunch of other information through a survey. It’s about quality of life. Sleep, sexual function - in our lab study, we looked at urinary incontinence and function. So, we kind of try to gather as much as we can just to understand, you know, sort of all the multiple symptoms and what women are going through. We noticed in the first three studies that all these women who had hot flashes also had trouble sleeping and there’s been some research on it - kind of a like the chicken and egg thing - like people say, well, they’re woken up by their hot flashes, but that’s not necessarily true because there are women who said they’re waking up because of whatever and then they’re having hot flashes because they’re awake. So, that’s why we did that fourth study where we targeted insomnia –

in particular, we were trying to see if the treatment we had, which was cognitive behavior therapy worked. We wanted to know whether that would help with sleep and hot flashes and it turns out it just help sleep and not hot flashes, which was kind of interesting. Women still felt like they had 20 hot flashes, but they were sleeping better so those kinds of things are interesting because they are occurring together and it's hard to tease it apart.

LV
In terms of existing support structure for menopausal woman, what would be a good support system for someone that's going through menopause or thinks they're going through menopause but is unsure.

KG
That's a good question. Don't really know what's out there. You know I worked with OBGYNs, this is their daily life where people coming in and saying I have this symptom. I am part of an organization called NAMS which is North American Medical Society and we presented our results there for three or four years now. It's kind of interesting because I can't get too far into this because I don't want to get catty or anything. But there are serious disagreements between some of us in MsFLASH and NAMS because NAMS as a as an organization tends to support using estrogen, hormone therapy orally, vaginally - you know that estrogen is kind of this holy grail a little bit. In our research, we really pushed back on that. In fact, our latest study, the vaginal study, one of the interventions was vagifam, which is a low dose estrogen pill that is actually a tablet that you put in your vagina. So, that you don't get systemic estrogen so theoretically women with cancer could take it. Although there's issues with that. Our studies show that it didn't help any more than a placebo.

And so, like NAMS as an organization just sent an email blast few weeks ago saying, wait, wait, wait, don't abandon vagifem. It's really important. There's pushback on that. So, so I don't know. So, I feel...I think we get upset as researchers because we feel like what support is there for women to really understand what the options are when there's sort of these camps of people who really want estrogen to be the answer.

LV
Like you said there is a lack of information, but there are also information gaps as well. And so...I guess in the future, where would you like to see those information gaps minimized?

KG
That brings me back to Andrea's project. So, we have this big grant right now. We're in the third or fourth year of this five-year grant and during the first three years we pretty much spent all of our time running vaginal health trials and the second part what we're funded for is a dissemination project.

What is unique about what we do is that it's federally funded. It's not funded by drug companies and are not influenced by what drug companies want us to show. We're trying to find the best questions that need to be answered and to fill those information gaps and try and answer those as best we can, of course, you can only do so much. But it still feels like an uphill battle getting that information out to women and their clinicians. So, I think, you know, the awareness of there being non-hormonal alternatives for hot flashes - there being cognitive behavioral therapy intervention for insomnia is kind of known now in literature to be really helpful for insomnia, but there are not many people practicing it. So, it's like if you say, okay, I want to find a therapist. It's like, there aren't many people doing it. So, there's just there's a disconnect. Where-as you know I also work in cancer and cancer treatment. It's like, okay, it's front page in the New York Times. The next day, and you know, if I have this kind of cancer. I want that drug I read about. It's sort of more direct. Whereas, you know these conditions are not life threatening. There's not a sense of urgency about it. You can live with sleep problems and hot flashes and vaginal dryness. It's a quality of life issue.

I don't think I can clearly define exactly where the gaps are and how they should be filled. That's not my area. Ask me in a few years when I am going through menopause! I have all my colleagues to ask.

LV
When you talked about clinical information that is being dispersed to menopausal woman. What if there is mistrust between women and their doctors where symptoms may be misdiagnosed?

KG
That's a good question. You know I wouldn't be surprised. I think generally people have mistrust around doctors in our country and in our culture around pharmaceutical companies and advertising. I have some distrust around doctors pushing medications that are expensive. Like vagifem is really expensive. Basically, our study was saying you don't really need expensive stuff, you know, use some lube.

I don't know this for sure, so I'm hesitant to say...generally is just that women have always felt that menopause is treated as, like, 'oh, now you're older and getting a little crazy and you're complaining a lot'. So, there's sort of a diminishing of women's experiences and symptoms. So, I think the male dominated medical culture is a part of that.

So, when the women's health initiative started, which was, you know, big clinical trials testing what was called hormonal replacement therapy at that time, but the idea was you replace the estrogen you're losing and then here, you're fine. You're like I am a woman again. It's like a magic pill and there were more people on hormone

therapy than any other medication in this country at that time. It's like millions of people were taking because doctors were just handing out it was like everything that ails you that this make you feel better. It's not necessarily that estrogen is bad or that nobody should take it, but that you know there are other options out there. There should be allowance for questions and discussions of downsides.

LV
How is your experience working or running clinical trials with menopausal woman? Were they open to talking about their symptoms or how menopause impacted their lives.

KG
Yeah, I think...I mean I was not in the clinics, so I was not interacting with women directly, but yeah, I was working with those clinicians all the time. So, hearing their stories and hearing reactions and getting the forms back where we have all these places for people to answer questions. Menopausal women wanted to tell us a lot which was really cool. You know, it's like we have this humongous PDF file. Now, we're kind of sifting through like - are there any patterns there? What's the gist? And some of what I told you is about feeling like their symptoms were not recognized. They seem happy to even be able to talk about it, even if they maybe didn't get relief from the medications we're testing. I'm always amazed with clinical trials, people are very altruistic. I mean they come for their own health, you know, hoping that whatever we're testing is going to help them. But I think people do have a sense of that. It's like this is a big, you know if I can help other women, especially in cancer, knowing that they might benefit that the next person who has this disease.

LV
Did you see any patterns of where there were big misconceptions around menopause?

KG
Yeah, I think...I mean the biggest one is my experience with the vaginal health trial that people just didn't realize how common that is. Does that answer that question?

LV
Yes, it does! That's it for my questions, but I want to open it up to Aggie and Kelda to see if they have any questions.

Kelda Baljon (KB)
I'm interested in the whole NAMS vs. MsFLASH - if you can discuss that further.

KG

You know NAMS is a research organization, but they have funding from pharma for like their conferences and stuff like that. It really changed in my career from when I started, drug companies could come in and here's lunch for you and have a pen... there was like this like influence that was very obvious and direct. Then there were these laws that were like, no, we can't have doctors being influenced. Now it's like when I go into a government meeting and they have like water in the back, there's no coffee and no snacks because it's like that would have been funded by drug companies and now it's like we can't have any of that.

But then again in cancer. There's this encouragement to have public/ private partnerships. So, I find it very frustrating because you need to work with drug companies because they have the drugs. We want to test you know they have the money to support these things, federal government supporting research, but only up to a point.

You're always trying to walk this line as I mean I think of myself as a public researcher, you know, my salaries paid by federal taxpayers - you guys support my research. And so, we have to keep our eye on that, that it's like what's in the public's interest.

The drug companies are motivated by profit. I mean, there's nothing terrible about saying that. I mean that's their goal is to make money. And so, the questions they're asking are different and the methods that they have are different because their whole focus is a different one. And so, it's always trying to have this balance of I'm not necessarily against you know medication - medications have saved my life. I'm sure you know but it's a line we are walking all the time of trying to figure out what's the truth of things? What's the important knowledge? What is good and the bad? That's the reality.

AT

Yeah, but around then that's when we find out about our period. And so we kind of already become aware of the human body.

EK

But I feel like you're so self absorbed at that point. Everything is all about you. So you don't really care that much what your mom is going through. Yeah.

AT

Or maybe it's like dad or partner and like they're sitting down like "listen your mom's going through change and just like yeah she loves you."

Gwen Harris

Expert Interview Summary

Name: Gwen Kibler Harris
Title: FB Menopause Support Group Moderator
Interview Date: 4/16, 3:00pm

Interview Moderator: Aggie
Note Takers/Observers: Lan & Kelda

Background Info

Gwen has moderated the Menopause Support Group, which has grown from 5k members in November to 28k today. She underwent menopause about 5 years ago. She is the CEO of a company that sells products to help women “de-age”.

Interview Objectives and Relevance to Capstone

- Get her perspective on the highs and lows of online support
- Learn more about the history of the Facebook group and trends she has observed regarding our research questions

Script

Introduction
I’m Agatha Tutia, I’ll be interviewing, this is Kelda and Lan, they will be taking notes. Is it alright if we record this interview and take some pictures?
We’re part of the Human-Computer Interaction and Design program at UW, and we’re currently in our thesis project focusing on designing a tech experience around a human-centered problem.
We are researching menopause for our thesis. We have read a lot through academic resources, Facebook, popular news sources, but we wanted to reach out to you to gain more insight.

Throughout the rest of our research, we’ll be asking ourselves these questions which are, and you don’t have to answer them, they’re just to give you a sense of what we’re looking for:

What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?

What non-medical strategies do people currently use to relieve menopausal symptoms?

What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?

And to confirm with you, the Menopause Support group was passed down to you 3 years ago. You have actively moderated and posted in the group. You featured in Good Morning America this past January.

Expert Questions

What was the Facebook group like prior to Good Morning America?

After GMA, what were the major changes to the Facebook group?

What has your experience been moderating the group now?

What are your responsibilities as moderator?

Do you read every post?

Do you respond? Have often?

What are some of the challenges of moderating the group?

Do you ever disagree with something someone posts and what do you do in that case?

Do you control for accuracy of information at all?

Where do you envision this group going in the future? Do you have any goals for the group?

What are the benefits to keeping the group to only women?

How can men be more informed and understanding? How can pre-menopausal women be more informed?

Where do menopausal people find support today?

Are you familiar with any in-person support groups? How do you think that might differ from an online community?

Any support to the physical aspects?

Any support to the educational or awareness aspects?

Any support to the emotional and/or culturally aspects?

Where do you think support is lacking for menopausal people?

As a moderator, what are the most sought advice or information?

Leave open-ended to start, but can probe with these categories

More support to the physical aspects?

Any support to the educational or awareness aspects?

Any support to the emotional and/or culturally aspects?

Before we wrap up, here are a set of cards, and if you could rank in order of urgency and, if you feel desired to, reword them, that would be wonderful.

Are these relatively accurate from your experience?

Why did you ranked them in that way?

Suggestions for further reading & interviewing?

Notes

Kelda:

Grew slowly over 6 years but it’s so quick now

Grew up in Africa where you talk about things more

Here people don’t talk about things as much

I don’t go on the group a lot and spend time reading it, because it’s sad or people are mean

I have eyes and ears out there reporting

Every other week I post what the group is

Considered more admins but decided not to, but those who I might ask (even my friends), they become combative, competitive, I’m on there a lot, I have to moderate it

Women are like cats

I use facebook only for business

Yes huge change since GMA, 150/day, asked facebook to put a max on but it’s not possible

Suicidal thoughts are blocked, needs to be loving

Transgenders experience totally different things

Men posing as women

“our world is perverse”

This is a non-medical group, we say right away “talk to your doctor”

Doctors have tried to grow their practice in there, but not allowed

We become way too progressive if businesses can promote themselves “try to keep it a personal space”

Support should hopefully be a husband or family

Emotions run amok

Technology has taken the personal touch out of community with family and friends

I’ve gotten a lot of requests for conventions and stuff

Putting people together all across the world

It’s been so impressive how much I’ve been able to do all out of my own need

Doctors aren’t supportive at all, big pharma’s pill they want to take

Went to female naturopath closer to my age

Wellness regime I do now came from her, organic apothecary

· Wellness cleansing

So much toxicity in our environment, cancer and everything is coming from toxic environment

Food from new Zealand where they’re not allowed to use those things

Medical doctors are only given about 2 weeks of nutritional training, and nutrition

Used to work in medical background, big pharma and FDA, they are taught to give pills, only country in the world that is like that

CBD oil is great, marijuana is great. I started using it after gallbladder surgery (needed it

due to genetics), had pancreatitis, had trouble digesting food,
Don't sell the actual product

Had total hysterectomy at 31 so I've been going through it forever, but it got much worse 6 years ago
Carrying changes of clothes during day and had to change sheets at night

Advice to women to speak with partners: this will just exacerbate earlier problems, there is no magic. If you're already on edge it won't get better. Emotional outbursts where you feel out of control. Easy escape route for the relationship.

Skin bleeding and scaley

Eyes hurt a lot when she opened them, she was sweating so much that she lost hydration, and her eyelids were getting glued to eyes

Doctor was best friend but didn't know what would happen during menopause

Didn't have that relationship with mother, because grew up in boarding schools. There isn't really local support.

Facebook group for husbands to support each other as husband of menopause. They have to WANT to be educated, but they don't really often seem to want that. Men can google, but they don't.
Haven't talked to my children about menopause.

A lot of emotion that goes into that, it's scary, you don't want to admit that time is going by, and a lot of suffering in silence.

Oldest son married her best girlfriend and is going through menopause now, but never interested in his mother's menopause.

Our society is very much about selfish, self motivation.

Australian/new zealander/European people are more open on the group

The future: getting bigger! Cat fights, suicidal, selling a product all came in today

2 years ago almost closed it down, 90% of what I get is wow this was amazing, thank goodness

Didn't have education, best friend as gyno never said anything, didn't have a mother to talk to about this (or anyone else). But knowing something will take place, that's a big deal. Blindsided, I was scared, just like getting a period without knowing anything about it.

Friend nancy kerner says this has been the best part of her life because she understands herself better

Lan:

Don't go on the group alot - getting so sad (emotional drainage)

Doesn't read the post, post regularly what the purpose is

Has eyes and ears

Feed moves rapidly

Considered other people being admin

Requirements

I know my purpose - combative

Women are like cats

Started to help self

Facebook is only for business

I don't want other admins

11, 000 to 28,000 - 150/day

Noticeable change in the post

Love and support group

Will not tolerate suicidal thoughts - no negative feelings

No transenders

Who knows what crazy things men do - perverse

Active doctors are?

Non-medical group - consult your doctors

No selling in a support group

Become way too progressive

Where do women need more support?

Fortunate to have a husband

Emotions run amok

Family can be a support, but technology has taken away that personal connection

Technology exacerbates people experiencing symptoms

Solution that works for me

Describe your experience with menopause

Doctors are not supportive

Want to give you a pill - big pharma

Ways in which relationship with medical doctor can be improved

Only two weeks of nutritional training

Comes from a medical background

Relationship with partner and menopause

Started menopause at 31

Worst later about 6 years later

Advice to women re: partner

Depends on context of relationship

Support group you can trust

How did you know it was menopause

Perched skin

Losing hydration

Never told her the effects of an induced menopause

Never talked to maternal figures

Raised in boarding school

Survive on my own

Society is selfish

Easiest way is start support group

Support from other men

Another FB for men about menopause

Support from children

I don't think they would care

Who would want to hear about their mother's menopause?

Bc it is something foreign - there's so much emotion involved

You don't want to admit that you're changing

What does "hot flash" means to someone that doesn't get them

Future of menopausal support group

Keeps growings

Couple of years ago - contemplating closing it down bc of negativity

Hit me like a ton of bricks because i didn't have the education (about menopause)

Be kind to yourself bc your body is growing through changes

Menopause has been a great season of her life because it make her understand herself better.

Nancy Woods

Expert Interview Summary

Name: Nancy Woods
Title: Professor Emerita
Interview Date: April 24, 2018

Interview Moderator: Kelda Baljon
Note Takers/Observers: Lan Vu and Aggie Tutia

Background Info

Nancy Woods is Dean Emerita of the University of Washington School of Nursing and Co-Director of the de Tornyay Center for Healthy Aging. She is the “menopause guru” of UW and a prolific publisher of articles, especially relating to the Seattle Midlife Women’s Health Study in the 90s.

Interview Objectives and Relevance to Capstone

- To understand menopause from a research background
- To see if she has seen any trends in menopause knowledge + awareness over the years
- To understand what knowledge exists about menopause uncertainty in midlife women

Script

Introductions
MHCI+D program: designing solution around a human-centered problem
Why we are studying menopause
Our research questions:
What are the current knowledge gaps for people experiencing menopause and what current efforts exist to try to fill those gaps?
What non-medical strategies do people currently use to relieve menopausal symptoms?
What are the emotional support structures for people experiencing menopause and in what ways do they feel unsupported?
Based on our understanding of your research, we saw a few papers relating to knowledge gaps for people experiencing menopause. What do you think are some of the biggest knowledge gaps and why?
Which knowledge gaps might have the worst outcomes for their physical or emotional well-being?

What can medical professionals do to prepare for menopausal patients?
Why aren’t women getting all the knowledge they need from their medical professionals now?
Or from the internet?
Or from their friends?
Are there any current efforts you are aware of to fill those gaps?
What do you think might be an effective strategy for disseminating knowledge?
In much of your literature I noticed a split between women who see menopause as a medical condition needing medical treatment and women who see it as a natural condition requiring natural treatment. How do you see menopause?
Is this split really so black and white?
Is there a way to consider it a little bit of both?
In regards to emotional support, I found in much of your research that depression and stress are not necessarily caused by menopause. Do you think menopause is still an arena in which women need emotional support? Why or why not?
How has the menopausal experience changed in the 20 years since the SMWHS was first conducted?
What have you observed?
What is different about today’s world and the women going through menopause today from those women of the 90s?
How do you think it might continue to evolve when millennials begin experiencing menopause?
Review and reflect on our insights (card sort!)
Are these relatively accurate from your experience?
Rank these in order of urgency and explain why you ranked them in that way
Suggestions for further reading & interviewing?

Notes

Aggie:
1990 followed a cohort of women for 20 years
Still doing data analysis
Late 1980s, one study in the US that talked to women, community, general public
Specialty work care, different population
Initial study, small study 100 women, replicated to 600 in Seattle
Women had very little idea what to expect, what they were concerned, no idea what this would be like
Depression link mother to daughter, no study
Seattle midlife study, participant advisory group
Wanted to know how things would progress for them
When will this be done
How long will this last?
Concerned with bleeding
Keep cards of menstrual studies
Analyze that data when they started skipping

Collaborate around world
Looking at symptoms, would go to see a health care provider and their symptoms not taken seriously
Most women very unhappy from this
What kind of symptoms?
Women can get depressed
From their other symptoms
Subject to depression
What should they expect?
Will they be troublesome or not?
Sleep symptoms, very problematic especially for moms with kids at home and women caring for elderly parents
Look at menopause in the broader context of life
What can they do with their symptoms?
Hormone Therapy
Women’s Initiative: study for HRT preventing heart disease, nobody knew if it prevented heart disease, but HRT required healthy non-smokers
2002, stopped. Women were seen getting hurt (60s)
Estrogen only stopped.
Decision to use HRT or not
New release about the WHI trial
Confusion was not about hormones for symptoms, but should you use for heart disease especially if you were older
50s vs 60s different response
Increase in distrust with HRT, looking for nht
SSRI, for anxiety
Those drugs began trial
Other drugs used for other uses, gabipentin, got rid of hot flashes
Back to saying judiciously use HT low dose
Complementary, alternative medicine, many other therapies
Accupuncture, mind-body, herbal preparations, soy preparations
Women are very interested in other alternatives
EMOTIONAL
Support groups 1990s, 2000s, professional societies prepare people to lead these groups in a support group context
It isn’t what contemporary women want or not
Now social media
Dave Gustas? HRT into a a HIV thing
Social component chat room, women used it, but not a lot
Now, using social media to bring ppl together
Electronic communication
Doing things on the phone
Social support
Information
Emotional
Those two can work together, if somebody is tuned into
AFFECT of support
SOCIAL SCIENCE
The gap is “Is this normal? Am I sick? My menstrual cycle is all messed up, what is hap-

pening.”

Gap. Any type of treatment, it should support their lifestyle. Being able to function and keep it going.

Responsibility of life and body changing

Professional societies that have granted new guidelines, new websites and publications for doctors

The more accurate information in women’s hands and screens

People in healthcare need to listen, they might be more concerned with losing bone

Helping people in general evaluate.

Health literacy, how to read a website and if it’s accurate LOL LIKE FAKE NEWS - LMAO

Medical framework on a conversation may not make sense

Put in broad sense can give a story

There are experiences some cures encourage you to not talk anything about your re-productive organs, difficult for women to bring that up

The solution should unload the stigma!

“Often women are not..”

Less acceptable to say you are depressed in cultures

Study of women, includes different types of the ethnicities. Early focus groups, to get it with the ethnic groups

10 minute visit. Health care is so expensive. Rationed to talk about one thing.

List of questions for women to prepare women for their visit

iPad app: nurses made an app for adolescence to menopause

Discovered: asked about symptoms, can they group them together

Most women have clusters of symptoms

What do you attribute these to?

Draw a picture, which causes which

To take to their doctor to explain their story

A lot of women have too much hw, and offend their doctor

HC professionals to handle that information

Not exactly sure about CBD, but with chemotherapy, it helps to for those to eat and get rid of nauseous

Opiod problem in the country

Some idea what to expect

Provide women with some information, a typical experience looks like this

Shape of the experience, <graphing motion>

Pain symptoms, CBD oil makes sense

It is to be expected, part of the lifespan

Danger of medicalizing this, yes

So sleep deprived that she crashed her car

“Nobody has died from a hot flash”

Emotional support from friends and family

Depends on the individual woman

May not want support

Depression and stress part of a cluster

Relationship problems will increase too

Stress-hot flash relationship

Difference today, more information accessible through online resources (always been books)

Millennials will be receptive to finding information than the baby boomers

Looking at self-monitoring

Lan:

What are some of the biggest knowledge gaps?

Started study in the 1990s - followed a cohort of women in seattle

1980s - one study that has been done that talked to women (gen. public) - specialty health care providers

Initial study done in East Coast

In both studies - “women had little idea of what to expect”

If mother is depressed they would get depressed

Anticipating negative experiences based on other ppl’s experiences

Led to the Seattle midlife study

Wanted to know how things would progress for them

If they started to get irregular cycles - they wanted to know how long will it be done?

Hot flashes - how long would it last?

Irregular bleeding - is this something i need to be worried about

Questions can be answered but no data

Are there any predictable patterns?

Menstrual diaries

Where were there gaps?

Different symptoms that women had

Biggest complaint was to go to healthcare provider, but their concerns wouldn’t be taken seriously

Women can get depressed for many reasons

With more hormonal changes they can be more susceptible

What should they expect?

Don’t know if the symptoms will be troublesome or not

Many women also care for their elderly parents

“It’s not just menopause”

What is the broader context of life?

A lot of women were concerned about what they should do about their sympt.

Women’s Health Initiative

Study started out trialing HRT for preventing heart disease

In 2002, study was stopped - 2 years later estrogen only trial was stopped

Next project: Decision whether or not to use hormone therapy

Confusion about result of studies

Whether you should use hormones for heart diseases - probably not

Confusion among women of whether to take HRT for hot flashes

Non-hormonal therapy

SSRI - depressive med - started a trial to see if they were effective against hot flashes

Back to staying judiciously

Try to use the lowest dose possible when it comes to hrt

Complementary and alternative medicine

Acupuncture

mind/body therapy

Herbal preparation

Soy preparation

Emotional support

Was an era when women would come together for support group 90s early 2000s

Energy to try to prepare people to lead support groups

Isn’t what contemporary women want or need

Now we have social media and chat rooms

Dave gustus? HIV

Took his architecture and related to menopause

Moderated chatroom

Now get women together using social media - electronic communication

Affective support/information

More emotional support

Social sci lit

Meta data

Current knowledge gaps

“Is this normal?”

Am I sick?

“Am I too young?”

Quest for understanding do I have something going on that I should worry about

Any type of treatment

Social world

Work

Other responsibilities

Treatment for lifestyle

Juggling responsibilities where you may have limited financial resources

All the while you have who am I?

Medical personnel

More accurate information

People in healthcare to listen and don’t make assumptions

Helping people in general evaluate the accuracy of what they see on websites.

Health literacy

Medical framework on a convo they might not understand you

Cultural or Racial differences

Culture encourage for you to not take about something person or about reproductive - hard to bring it up

Unload the statement

Mood symptoms

Less acceptable to say that you’re depressed

Study of women across the nation - 2500 women

Other reasons why best practices don’t happen - “Oh, it’s called the 10 minute visit”

You feel rationed that you only can talk about one thing

Preparing women for their doc visits

From app - asked about symptoms and grouped them together

Clusters of symptoms

What do you attribute these too and are they related to each other

Last part of the app is to draw a picture - they have their own mental model

Cause and effect

Do you mind asking them what they want their data for?

Bring it to their exam

Help explain their story

Uba is informatics prof from UW - tacoma

Health care prof to know how women use information about menopause - triangulation

Menopausal myths

Reaction to fb group

Hand on her face

Concentrating

Made a funny face

Huhhhhh?

“I think moderated or unmoderated - what you don't have with unmoderated you don't have the perspective of a medical personnel, but sometimes women are right”

Social support - shared experiences

No one can guarantee you that your experience can be a b c or d

But you can provide women with information that a typical experience can look like this - what is normal?

Something about the shape of the experience - when you can expect changes in your body

My bias is that a majority of us - it is to be expected - reproductive aging - it's typical - is there a danger of medicalizing it? Yes

There are serious consequences of the symptoms

Women are uncomfortable - treating the symptoms in accepting way

Emotional support - depend on the individual woman

The biggest difference is that information is more accessible to women via online resources

It was more generation - baby boomers -who changed things about childbirth - I think that the millenials will be much more effective at finding information

self -monitoring

Not very good menopause software

B *Recruitment Materials*

Flyers

W UNIVERSITY of WASHINGTON

MHCI +D
human-computer interaction + design

Are you experiencing symptoms of *menopause?*

Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.

You may be eligible to participate in a research study.

- + The study seeks to understand the experience of menopause
- + It does not involve any medication or treatment
- + Qualified participants can receive Amazon gift cards

Please visit bit.ly/studymp to sign up.

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

Menopause research study
bit.ly/studymp

W UNIVERSITY of WASHINGTON

MHCI +D
human-computer interaction + design

Are you experiencing symptoms of *menopause?*

Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.

You may be eligible to participate in a research study.

The study seeks to understand the experience of menopause. It does not involve any medication or treatment. Qualified participants can receive Amazon gift cards.

Visit bit.ly/studymp to sign up.

W UNIVERSITY of WASHINGTON

MHCI +D
human-computer interaction + design

Are you experiencing symptoms of *menopause?*

Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.

You may be eligible to participate in a research study.

The study seeks to understand the experience of menopause. It does not involve any medication or treatment. Qualified participants can receive Amazon gift cards.

Visit bit.ly/studymp to sign up.

W UNIVERSITY of WASHINGTON

MHCI +D
human-computer interaction + design

Are you experiencing symptoms of *menopause?*

Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.

You may be eligible to participate in a research study.

The study seeks to understand the experience of menopause. It does not involve any medication or treatment. Qualified participants can receive Amazon gift cards.

Visit bit.ly/studymp to sign up.

W UNIVERSITY of WASHINGTON

MHCI +D
human-computer interaction + design

Are you experiencing symptoms of *menopause?*

Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.

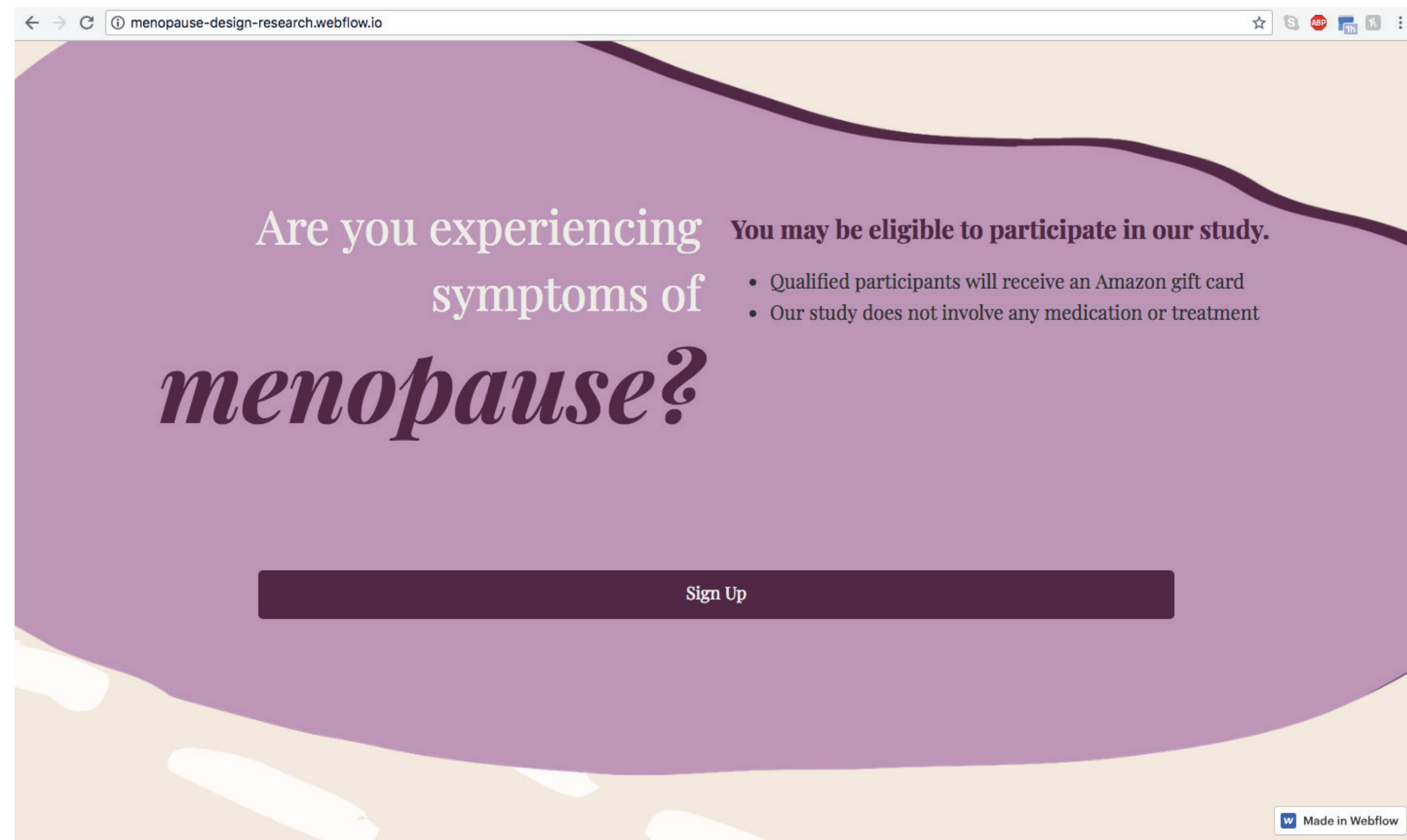
You may be eligible to participate in a research study.

The study seeks to understand the experience of menopause. It does not involve any medication or treatment. Qualified participants can receive Amazon gift cards.

Visit bit.ly/studymp to sign up.

Digital Materials

Landing Page



Facebook Group Post Script

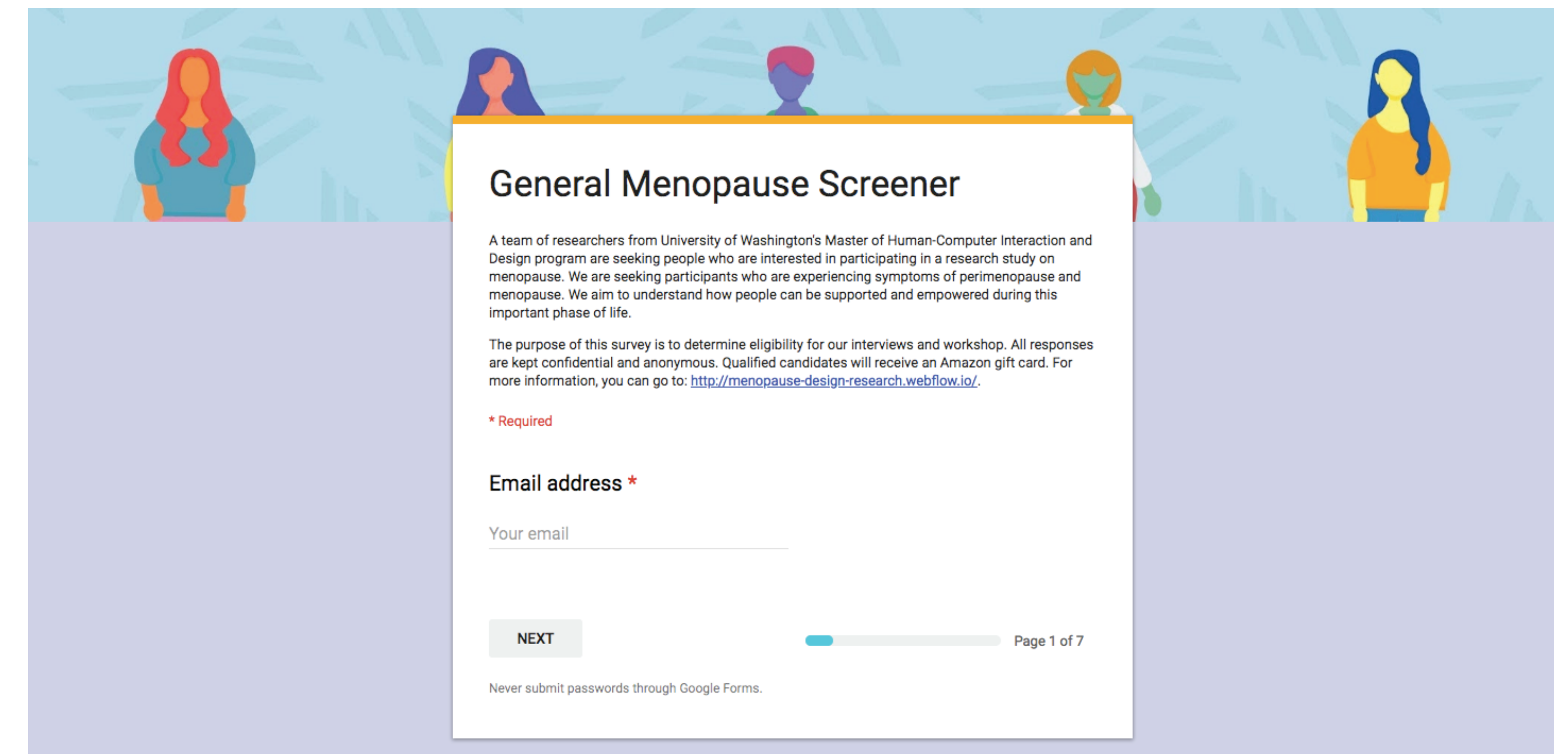
Hi everyone! Is anyone here experiencing symptoms of menopause (or know anyone who might be)? I'm a Master's student at UW doing research about the experience of menopause and we are looking for people to participate in our study. Qualified participants will receive Amazon gift cards. The study will not involve any medication or treatment. If interested, sign up here, and feel free to message me with any questions! <https://goo.gl/forms/RK7MoGIz6QcisLWg1>

Facebook Message Script

Hi [name of potential recruit]! I found you on the [Facebook Group Name] Group. I'm a Master's student at the University of Washington and I'm part of team doing some research on what the experience of menopause is like and what we might be able to do to better support people experiencing menopause. If you'd be interested in talking with us, we'd love to hear from you. We have some Amazon gift cards available too.

Great! Could you fill out this short survey? Then we will email you in the next couple weeks to schedule something!

Screenener



Introduction

A team of researchers from University of Washington's Master of Human-Computer Interaction and Design program are seeking people who are interested in participating in a research study on menopause. We are seeking participants who are experiencing symptoms of perimenopause and menopause. We aim to understand how people can be supported and empowered during this important phase of life.

The purpose of this survey is to determine eligibility for our interviews and workshop. All responses are kept confidential and anonymous. Qualified candidates will receive an Amazon gift card. For more information, you can go to: bit.ly/studypm.

Questions

- Email address
- Where did you hear about this survey?
- Are you experiencing symptoms of menopause and/or perimenopause?
- Common symptoms include hot flashes, mood swings, fatigue, weight gain, osteoporosis, anxiety, loss of libido, vaginal dryness, and trouble sleeping.
- Have you undergone any of these medical procedures? Pick most recent if multiple.
- In which parts of your life has perimenopause/menopause affected you the most? (Check all that apply.)
- What has your experience with perimenopause/menopause been like?
- We're looking for people of various ages. Which of the following categories includes your age?
- What is your first name?
- What is your last name?

- What is the best phone number to contact you?
- What is your zip/postal code?
- When are you typically available?
- Anything else we should know about your availability?
- Are you of Hispanic, Latino, or of Spanish origin?
- How would you describe yourself? (Check all that apply)
- How do you describe your gender identity?

Terminate/End of Survey

Thank you for completing our survey! If selected for the study, you will be contacted by one of our team members. For more information, please visit our website at bit.ly/studymp.

C *Consent Form*

Hi [name of potential recruit]! I found you on the [Facebook Group Name] Group. I'm a Master's student at the University of Washington and I'm part of team doing some research on what the experience of menopause is like and what we might Our study focuses on supporting a culture of people who are more comfortable, informed, and empowered during menopause. We want to learn firsthand from people who are going through menopause and understand their experiences.

My participation in the interview is voluntary. I can choose not to answer any question at any time.

I understand that I will be compensated a \$15 Amazon gift card for my participation. I may withdraw and discontinue participation at any time without penalty. If I feel uncomfortable in any way during the interview, I have the right to leave the study, knowing that my compensation will not be reduced in such an event.

Participation involves answering questions asked by the researchers, and discussing my personal experiences with perimenopause or menopause.

Photos will be taken during both activities. I understand that the researchers will do their best to respect any sensitive information in the communications.

I do NOT consent to photos being taken of me

I consent to photos being taken of me

An audio recording of the interview will be captured.

I do NOT consent to my audio being recorded

I consent to my audio being recorded

Notes will be written about me during the interview. I understand that the researcher will not identify me by name in any reports using information obtained from this interview, and that my confidentiality as a participant in this study will remain secure. Subsequent uses of records and data will be subject to standard data use policies which protect the anonymity of individuals and institutions.

I have read and understand the explanation provided to me. I have had all my questions answered to my satisfaction, and I voluntarily agree to participate in this study.

NAME

SIGNATURE

DATE

D *Semi-Structured Interview Script (A)*

Introduction

Hi, I'm [interviewer] and this is [note-taker] and [photographer]. Thank you so much for meeting with us to discuss your experience with menopause. We're graduate students from the University of Washington studying Human-Computer Interaction and Design.

Our study focuses on supporting a culture of people who are more comfortable, informed, and empowered during menopause. We want to learn firsthand from people who are going through the different phases of menopause and understand their experiences.

For our first phase of the project, we are trying to get a clear understanding of the menopausal experience.

Today, I'll be talking with you, [note-taker] will be taking notes, and [photographer] will be taking some photos and additional notes to help us remember what you've told us. We'll let you review these photos at the end. We'd like to record this interview, is that still alright with you?

Please read this consent form. <Hand consent form> If you agree to the terms outlined, please sign the form and let us know if you have any questions.

Additionally, I just want to reiterate that you may refuse to answer any question or end the interview at any time. If you agreed to an audio or video recording, you may ask that we stop recording at any time. Also, all personal information will be kept anonymous.

Do you have any questions? Thanks again!

Would you like to use the restroom or get a drink/snack before we start?

Questions

- To start us off, can you tell us a little about yourself?
- What's your age?
- What is your highest level of education?
- Are you perimenopausal, menopausal, or postmenopausal?
- Are you working?
- Do you have a partner?
- Do you have children?
-
- Knowledge about Menopause
- If you ask them to tell you about when they "first realized they may be experiencing symptoms of menopause" you may get the answers to some of the follow-up questions below:
 - When did you first think you were experiencing menopause?"
 - What lead you to suspect you were experiencing symptoms?"
 - Is there anything you wish you had known about menopause earlier?
 - Do you feel well-informed about menopause now?

- What do you do when you have questions about menopause or your symptoms?
- Symptoms
- What has your menopausal experience been like so far?
- What methods do you use to alleviate your menopausal symptoms?
 - Any non-medical methods (i.e. take a bath, herbs, exercise, etc)?
- Medical Support
- For your menopausal symptoms, have you seen a medical professional?
 - How has this experience been?
 - Do you believe they have provided you the support needed through menopause?
- Workplace
- How do you fill your days? Do you work out of the home (and how do I answer if I'm self-employed and have a home office?)?
- What is your job(s)?
- What is your schedule like?
- How many people do you closely work with?
- Do they know you are going through menopause?
- Has menopause ever interrupted you from work?
- What would you like changed in the workplace for you?
- Family & Relationships
- Do you have a partner?
- Do you share with your partner about your menopausal symptoms and experiences? Why?
- Can you describe any struggles that have come up in your relationship because of menopause?
- Are you a parent?
 - How many kids do you have?
 - What are their ages?
 - Have you ever discussed menopause with them? Why?
 - How has menopause affected your role as a parent?
- Self Esteem / Identity
- Has your self image been altered during this experience? How?
- Community & Support
- Who do you look to to find social and emotional support?
 - Are they experiencing menopause as well?
- What technologies or references do you currently use in relation to menopause? (i.e. apps, websites, books, etc.)
- Have you ever supported another person experiencing menopausal symptoms?
- In what areas of your life do you feel you have the most and least support?
- What advice would you give me?
- If you could change something about menopause for people who have not yet experienced it, what would you change?
 - Symptom alleviation aside, anything else?
- Is there anything else you'd like to tell us?

E *Semi-Structured Interview Transcripts (B)*

Participant 1

Moderator: Agatha Tutia
Note taker: Kelda Baljon

AT
Can you tell us about yourself?

P1
Grew up in Seattle. In Beacon Hill. Lived in several other places tho and I've been at the university for 20 years. Currently do not live in Seattle, but commute everyday.

AT
Start off with menopause. When did you find out that you were in menopause?

P1
You heard of the lovely term perimenopause? It's kind of of telling you that this is happening. It was about 8 years ago. I noticed really distinctive things happening. I was late on stuff truthfully cause I'm old now. It was about 8 years ago when I went to the doctor and is this the change happening now. She was like oh yes, I see it took awhile. It wasn't a surprise.

AT
So, it's been building up for awhile. Did the doctor tell you what was going on?

P1
She didn't really. I was the one that told her what was happening and she basically confirmed my knowledge of the situation.

AT
So, was there anything you wish you've known before perimenopause and menopause started?

P1
I probably would have like to confirmed that everyone experiences it different. All I had was what my mother has gone through. Of course my grandmother never talked about it because no. And I didn't know anyone elses mom who ever gone through this. So I didn't really know what to expect. Mine is a little bit more subtle than what my mother gone through. It would have been nice to confirm that I wasn't slowing losing my mind and not really in tuned with my body. Even though I was very intune <inaudible>.

AT
Compared to today, do you feel more well informed about mp?

P1
Not really. I feel like there's more information out there. But it's not said in a way that different people can say I am experience this, but not this. So some women get cramps and some never do. That's what I think. Nothing really says that. These things will be different depending on who you are and what your life was like before menopause. Cause lots of information is just information though, but no context given.

AT
What were the major symptoms that you experienced?

P1
The big deal was no periods. Oh that was good! I had bad cramps. Then I noticed my skin changing; not on my face, but like on my chest and arms. It will come in rashes. The memory thing. It's really irritating. To not be able to remember from one hour to the next without having to write down somewhere. "What was I doing a minute ago?" That's a really interesting symptom because sometimes pregnant people get that, it's called pregnancy brain, where they forget things. I knew very well that I was not pregnant. So that was not the issue. So, that really had me that was actually the first thing that led me to go to the doctor. Is this normal, am I having a stroke or something else is going on in there. So, that was a big deal, memory - feeling scattered brain. Didn't like that all and still don't like that. And I do write everything down now i'd never used to do that. Other ladies at work..."it's okay. You'll be fine. Nothing horrible. You're not dying and you're not going crazy.

AT
Were there any methods to help alleviate symptoms like the rash, like if you end up having like an ointment or not really sure how you can help with memory fog.

P1
The fog...the best thing I could do was write some notes, keeps notes so that was helpful. The rash thing wasn't really a rash, just uneven skin, little bumps on the skin. And I found that using like a sugar scrub seem to soothe the skin and take some of the bumps down a bit. Then all of a sudden my acne flared up.

AT
I've read about that and I have bad acne again like this is going to happen to me again.

P1
Mhmm. It can happen again. I looked at mom, she says I can't help you. She had the same issue.

AT
So for the symptoms that you can really couldn't treat on your own like did you have a medical professional to fix or was it mostly on your own?

P1
It was mostly on my own. She didn't offer a lot of help. So I thought well what would I normally do. I'm gonna try a few things. It wasn't disfiguring me in a way. I noticed it more than other people did.

So for the memory thing. When your boss says we've talked about that an hour ago this is when you need to make a change. Fortunately, she's very forgiving.

AT
For the doctor experience, could you talk about anything more anything that frustrated

you or like something good during and after the menopause timeframe.

P1
Well, do you mean was anything good about our interactions.

AT
Just interaction. Like the information she gave you and how that went about.

P1
She didn't really give too much information, except she gave me some sympathy and that was about it because she said that there really wasn't anything she could do, except to say this is happening. If it gets really extreme then we'll talk. But besides nothing much happened.

AT
Do you happen to have a partner?

P1
Yes.

AT
How has the experience with your partner been like?

P1
Well, he thought it was hilarious which didn't go well for him for a while. But he's understanding...to know that it's just a life process that he doesn't have to go through.

So that was that was okay. There wasn't any craziness behind it alone. Yeah.

AT
How did you end up sharing this information with him?

P1
Well when I went to the doctor. The first time she's like yeah...it's the change of life. He said...yeah I told you that. That's what I knew too, but I meant verification from like a professional. He's like I get it. It's okay. It's okay. It happens. So, we're good, we went out for dinner.

AT
So, were there any no struggles with it or was it pretty solid?

P1
It was so it was okay because I haven't had anything extreme happen. I don't have a lot of mood swings or anything like that. The sweat were kind of scary at first because I didn't have the hot flashes during the day, but I would go to bed and once every three weeks nights I would have night sweats. I would throw off all the covers and my cats like what just happened. But besides that there hasn't been anything really extreme, just <inaudible>.

AT
But overall supported?

P1
Yes.

AT
Are you a parent?

P1
No.

AT
Okay. Then we'll skip all those questions because that's an entanglement. All right. Your job experience, you kind of mentioned how like you experience brain fog when you're at work. Can you described like when you were working on at the time and like what your schedule is like.

P1
First really notice the issue of trying to get an event together and for my life, I could not remember the list of names. The way that I got my list of names together and I couldn't keep it straight at first without concentrating on it really hard. And I haven't had that problem before.

AT
For their people who worked around you, like did they knew what you're going through. Or...

P1
I didn't really know at the time. I wasn't really sure I just figured I was losing parts of my brain. So not like me totally not know what I was doing, like that. So I didn't say anything. I just would stay late or come in early and I live very far south so my commute was an hour and a half each way. So I was here a lot into the night. That was an issue.

AT
How would you have liked to workplace to change in your benefit?

P1
I don't think I really wanted to change at all because this isn't really their issue. It's just, it's a life issue. I can go to the boss saying and can we see a way to work with it. I just wanted you to understand that this is what going on. I was going to keep doing my job. I might be a little slow. I'll get it done. Whatever it takes. That's the only kind of understanding I really need. <inaudible>
Yeah because it's just a process. Fortunately for me, there's nothing extreme.

AT
During this experience do you think menopause affected your self image?

P1

Not really. I know a lot of women go, 'Oh my god, it means I'm old now'. Didn't really mean that to me. Okay that process of life has stopped. I didn't want kids anyways, what do I care. Unfortunately I've been watching That's 70 Show. The mom just discovered she's in menopause and she has all these crazy things happen mood swings and all that crap. Okay, you're doing this for the comedy because that's not real life. It's not that big of a deal to me. Some people it will be... to me it just means there's a change in life. it was funny when my mother went through it because hers was more extreme. So, I've been lucky. My sister too.

AT
So you notice any like more positive changes before and after?

P1
Nothing positive really happened it was just the next phase in life. I didn't have to worry about getting pregnant. Didn't really worry about it before and it wasn't really on my radar anyway. So that was the big deal. I needed less sleep <inaudible>, but then I need more sleep again. It's like it was cool for a while and then it came back. Nothing else.

AT
For the social and emotional support, did you feel like you needed that?

P1
It's nice to have women friends to talk to when something amusing would happened like I would have brain fog and go I forgot to write that down. "You were in the meeting, what happened?" Having somebody there for that was good. <inaudible> It was nice in general just to be around other women who would give you support and say <inaudible> was everything okay today, is there anything that you need help with, anything interesting you think you forgot today. Yes, I have friends like that. <inaudible> Like we get to laugh at you now. Fortunately they <inaudible> just deal and they were good, really helpful, I didn't feel alone.

AT
Is there anyone that you've given support to?

P1
I actually haven't had to because like I said <inaudible> for some reason my sisters really confides in me what they went through. "Well, I feel cheated". I really didn't talk to them about it either because again we didn't have a big change. I think one went on HRT. I don't know what the other one did. Oh, because they had surgery. And that's why, but they both went on hormone therapy and didn't really experience any big changes.

AT
Were there any technologies or references that you currently use or is there like any technologies are like sources of references like books, pamphlets that you ever use like to refer to help you with menopause?

P1

No. Skated through it.

KB
Did you ever google anything?

P1
No. It wasn't that dramatic to even want to look anything up. I never did.

AT
Okay, last final question. If you could wave a magic wand and change one thing about menopause, what would it be and this can be for you or for like all women,

P1
I wish that all women had an easy transition because sometimes it's not that easy. The hot flashes <inaudible> because it will come out of nowhere like that. To be a public display and for that to happen to anybody. Mood swings to be ENTERTAINING. I just wish it was easier for women <inaudible>. I was lucky. I was way lucky. I figure it was a good tradeoff for having bad cramps. <inaudible>.

AT
Is there any final thoughts of wisdom, maybe a better question would be like if you're talking to me, and I'm like, I've been experiencing perimenopause like what would you tell me?

P1
Don't stress too hard about it, find women friends and say this is going on and have you had this happened, create a circle of people to support you because you might need it. Don't be afraid to go to the doctor and if you don't get the answer, ask again or find a different doctor Which is what I had to do before the menopause. I had a doctor who told me that cramps do not exist.

AT
That was a female doctor?

P1
Yeah

AT
That makes me sad

P1
Yeah. And now they've discovered cramps do happen. Really?

AT
I believe that is a true statement.

P1
Yes. They are real.

Participant 2

AT

All right. Well, that's all of our questions.

Moderator: Lan Vu

Note taker: Agatha Tutia

P2

Two things. One I think that women don't share as much about menopause as maybe we could and what I found is, I was like what because my periods aren't, like changes cycle isn't the first symptom. That's very minor, other stuff has come up first. I've been like what the hell is going on and it's only when I actually make a point to to ask other women I know my age. They go "Oh yeah, right. And all of this stuff comes out."

That's really different than say my experience with other life where people talk about it, like parenting, maybe when we talk about parenting we lie, but we talk about it. It's not like people talk about getting their first period a lot more and there are still things we might not say but it's spoken of a lot and I think we have a much better idea of what happens and how stuff like that happens and menopause. I think whatever the reason is, but it has been like the last couple of months where I've been like our friend. Oh, you're my age and Oh, let me check in with you and every single person is like, whoa. Yes, I'm you know, experiencing that. And so that's really interesting.

LV

I guess going off with that. How would you describe the first time, like, you kind of realized like, oh, maybe this is what I'm going through?

P2

Well, I would say. The problem is I can't remember. Two years ago I started getting night sweats and I was like what the hell is this and I went to my doctor and I was like 'what gives' and she was like well you have nothing else obviously wrong with you and you are that age. So I would say this is probably it, don't worry about it and I was like okay right and then I totally didn't think of it again until January when somebody on my Facebook feed who I went to high school with made a comment "mark the date I got my first night sweat". And I went, Oh wait, this isn't just a thing happening is the thing happening to women but you know my peers my own age and then I put together that I have other symptoms and oh, that might be and that was kind of revelatory for me when that all fell into place.

LV

I guess when you started finding out about like other people experience the same symptoms. Is there anything you wish you'd known earlier about menopause?

P2

I think the focus ad the discussion that I received was much more on what it does to your period and like there's a lot about hot flashes and I haven't had a daytime hot flash at all. The primary thing I've experience is like emotional sensitivities and moodiness. A lot of people have talked to me about forgetfulness, which I don't think I've been hit all that much. Or maybe it's just obliviousness, hard to say with that kind of symptom.

But I would say that like none of - You know like in Sex and the City has talked about hot flashes, but like, yeah, and everybody talks about HRT and they talk about periods a lot. I don't think I had any awareness of what you're starting to go through perimenopause

and these are like there was nothing like this is what you can expect and when I talked to like my mom because you know we speak to our moms about these things.

My mom was like "I hardly notice" well you know what my mom is bipolar. And when I think back what was going through at this point in her life, she was. She was like, wacky, super emotional, and I think we attributed it to her mental health problems, but it seems completely plausible that it wasn't just that.

Yeah i mean i did IF to have my daughter and there was a huge lesson about how much our hormones affect our psyche and it's really easy for us to sweep it under the rug, be very, very stoic about it and yet I think these are, it's huge, and it's it's not just an inconvenience it can actually be a really different experience

LV

When you have questions about menopause, what do you do and who do you go to?

P2

I've done some online searching where you know so for example when I kind of identified this was a thing.

And I'd say most resources I get for whatever reason has been about how to treat symptoms. My opinion is that medical advice found online is dubious. You don't really know the quality of the source. So then you have to find a certain number and quality of data that all agrees before you do something.

And then like I said I asked my mom, asking people I know who maybe aren't speaking of it. And there's this whole thing like people talk on Facebook. What you talk about on Facebook isn't what you'd talk about in person. What we do online or on Facebook is a public persona.

There are people who go online and let it all out but a lot of us are like oh no this is forever. You say something revealing, and it's just as likely that some stupid ass friend from your past is going to be like I'm now going to take the opportunity to [INAUDIBLE]. I'm very careful, careful that what you say is something that you can

LV

That you still feel supported, that you don't feel attacked, right?

P2

Well, it depends, but I think I definitely edit what I say online and they say the I actually need support thing much more in person or in private messages. I think it might work like I am in the Facebook group for people in perimenopause and I'm sure I can say things there, but they're such a big group and it's so basically anonymous like I could go outside and yell.

LV

How do you feel about that group, like being a part of that group. What made you join that group in the first place?

P2
I was looking for information. It does feel better to know that it isn't just happening to me, that other people experienced different things. What I found pretty quickly in that group was that I wasn't learning anything and I wasn't making, I wasn't feeling super connected. But I think it's because it's so big but also because it's just people are like I'm having this problem what do you all do and it's like the same answers over and over right. There aren't, they aren't really talking about really complex strategies, they're talking about black cohosh, HRT...

LV
CBD?

P2
I've heard, yeah, I've seen that.

I've got another complicating factor which is that I have had some serious GI issues and I had surgery last summer where they took out half my colon.

And my acupuncturist – so I've opted for acupuncture and it's great, I'm having really good results with it. Which is funny, because I don't really believe in alternative medicine. I don't have to believe in it for it to work. I go in, I feel better, I go back, I feel better. The nice thing is it's short-lived enough that if it doesn't work, I'm not going to feel the effects of it like I would if I took a pill every day.

And I haven't actually seen a whole lot of discussion about acupuncture on the groups, which I think is a shame but so I have my acupuncturist is trying to get me to take herbs and I'm like yeah when I swallow this stuff, it doesn't always have the effect that it has on other people because my GI is so out of wack and I've resisted so far and we're sort of okay if the acupuncturist by itself doesn't seem to be covering it at some point, then we'll see but the longer I can hold off on swallowing a thing, the better.

LV
Can you describe what your MP experience has been so far, what symptoms you go through?

P2
I've had night sweats for about two years. And then for about a year and I didn't put this together for a really long time. About a year ago I had an experience where I completely overreacted to something and I was literally like why in the world am I having this extreme emotional response right like I can step back and say that but that didn't actually translate into and I'm not going to have the emotional response, I was like really super upset.

And then there were a couple more things, like meaningful life events, like somebody died, the person who died was a [INAUDIBLE] my child, like why should I cry for two days when [INAUDIBLE] my child. So this was just sort of going on. And I was like, What the hell, and then like I said this person posted something in December or January and I went – light bulb moment - this is what's going on and literally I went, wait a minute, perimenopause Google symptoms. Right. I have these. Okay, this is an avenue of ap-

proach to address this. And then I think it took til Feb to do acupuncture, maybe January, and I've been doing the acupuncture and it's been mostly working. I still get the night sweats a little bit but those don't bother me as much. I would say mood swings have been my dominant symptoms and the thing that therefore I place the most emphasis on addressing.

LV
I know you mentioned acupuncture as like one of the non medical remedies for menopause, is there anything else you used that is non-medical?

P2
No

LV
How about any tech that you used?

P2
No. No. And my cycles aren't, I mean I track my cycles, but not in a really detailed way like there are people who actually do like this is how I feel today and this is how I feel tomorrow and I'm like I'm circling a number of the calendar when I get my period. And my periods did go wacky for a little while, I went down to a three and a half week cycle and I used to be on 3-5 days.

And when I told my acupuncturist this and she was like oh, oh, we have to fix that and literally I was like I should be getting my next few days I'm on a 3.5 week cycle and she was like oh we'll fix that and she did a thing and my cycle went back to like a few days. It was crazy. And my cycle had been on a 3.5 week cycle for four months. And she did the thing and it just fixed it.

How the fuck does that happen? I don't believe in this stuff but what am I going to do? Like, it's happening. And there's an inconvenience factor but I don't really care. I mean, what, 3 days here or there. It's not like – do our periods impact our life, like yeah, but I'm 47. If at this point I can't cope with getting my period, I'd have a bigger problem. So timing of my cycle is not a huge thing, because it's so predictable. I mean if I were doing like some people, bleeding, bleeding, bleeding for months, that might throw me more.

I don't consider myself fertile at this point, mostly because of my experiences with IVF and what we went through to get pregnant and sort of the data that came out of that and so I'm not doing the things that I did when I was younger, where I'm like, oh, I need to know when my period is coming bc I need to know if I'm pregnant. I don't have that, I'm like 99.9% sure you know like technically [INAUDIBLE] I'm not going to be pregnant. So it's - the timing is less important to me than it was before. And I think yeah it's like everybody's like, oh, but you never know as long as you're getting your period you could get pregnant. And yet I don't think that's borne out by the vast majority of women. I think for the vast majority of women our fertility precipitously in our mid thirties, and really fertile people can still get pregnant in their forties but most of us are not really fertile people and we don't. and there comes a point where we are not really getting pregnant even though we're still getting periods which are the genes, and our eggs, [INAUDIBLE].

LV
And then just expanding on your menopausal experience, have you ever sought medical doctors or anything?

P2
The only thing I did was literally I went and I'm like, what the hell are these night sweats and she's like, oh she went through a checklist with me and oh it's perimenopause but other than that I haven't.

I'm not considered technically menopausal, because menopause, they use the word at the very end, where the bulk of the symptoms happen in perimenopause. I haven't skipped a period yet.

LV
I guess when the doctor with the checklist. What was that experience and what was on the checklist?

P2
Have you - she was ruling out illness, okay so she wasn't particularly speaking to me about menopause, she was particularly like have you had any unexplained weight gain - or weight loss – I don't even remember, have you blab la bla. Okay you don't have cancer. Right. What else causes night sweats: cancer, infection, how long it was like, how long has it been going on, heavy weight loss, something else but it was literally like the checklist of are you seriously ill. No. And then if you're not then like this is it. And I think there might have been an opportunity at that moment, I mean, I think I might have said something to her like oh is there anything I need to do. And she's like, no. Right at that moment I probably could have said to her, this is really a problem for me. How do we address it but that's not where I was at. Oh this is weird, and it's waking me up, oh yeah and I'm getting insomnia.

You know like wake up and I can't go back to sleep for like an hour. And I'm fortunate that my lifestyle [INAUDIBLE]. But yeah, I have not actually gone to them and said I'm having these symptoms. How do I fix them? I've gone straight to the acupuncturist. I have these symptoms, what can you do for me? And again she's very focused on the night sweats and I'm like okay whatever, you know. Partly I think it has to do with the healthcare system. And the fact of my insurance will cover acupuncture, but we have to be like working on one diagnosis for a little while and then like find a different symptom and work on that. They won't give me like unlimited sessions for perimenopausal symptoms. It has to be here's a symptom, here's the next symptom, and they kinda like drag it out, but that just has to do with being in healthcare.

LV
Menopause can affect different parts of the life, especially for relationships. So in that context you share with your partner like your MP experiences?

P2
Yeah, he and I have really good communication. There are definitely men who are like “you don't talk to me about girl things” and he's not like he's like, “Sure, you can talk to

me about that, how fascinating is that, that you have different parts and they do these things and I don't have that"

So I would say that because of our relationship because we communicate in a very like just about everything in general in a very open fashion and because there's absolutely nothing having to do with my MP that he could be defensive about, like, why did you wipe down the counter is more stressful conversation.

Yeah, I mean, I don't know how much he's been able to provide insight, you know, and you have to be very careful with the conversations of oh yeah I'm feeling grumpy today, oh yeah you do seem grumpy today. Oh yeah I'm premenstrual, oh yeah I know you were premenstrual. Like no no no. We've been married almost 10 years so he knows but we do speak about it. I am able to share my experience with him, and he's able to generally be sympathetic and engage in my -. I process out loud, instead of processing internally, and he's really great about engaging in processing out loud with me.

LV
So I know you mentioned you had a child in kindergarten? What's your child's name?

P2
Eleanor

LV
I'm guessing she's about 5. And then, how has MP affected your parenting?

P2
I don't know, it's pretty hard to tease out all of the elements of my experience, bc a small child is changing all the time. Right. It might be different if I had a couple of children and therefore my-. You know, I was just a parent to those, but instead I'm a parent with one child and I'm figuring this out and my style is when I'm experiencing something personally challenging like moodiness or being tired or whatever to try and insulate her from that as possible, but because, well I think if she were a teenager she would probably get more of a hit, but because she's little her requirements are still difficult, but straightforward right like when they're little like there's so much of it is physical stuff, like please sit down while you eat and please use utensils and just eat your breakfast. And so that's actually pretty easy to do, no matter what's going on with me and I get the impression, having been a teenager, that when you're dealing with a teenager there's a lot more mental, emotional challenge involved in managing them. But she's so little that I don't think it's impacted her a whole lot. I don't actually think I've been more or less moody with her.

She does a thing – I don't know if this is just parenting, it's probably just parenting. She does a thing where. She and <husband> like to watch costume dramas and they've been watching Amadeus and it has this soprano aria. And they convinced me to put it on her iPad. Her iPad which has no video content, all audiobooks and music. And now, she spends an hour every day singing soprano aria. And there are people who come over and are like it's so lovely what she's doing and I'm like I'm glad you feel that way. It's kind of painful. I don't know if it would be me anyway, that I'm sensitive to sound, or if hormones aggravate.

I had really bad post-partum depression and one of the things I found during that was that, that hormonal swing and that's what I feel like it mostly was, absolutely aggravated my sensitivity to sounds. Does that make me more sensitive to small child in soprano aria, I don't know. The thing is that I don't say to her don't do that, I say to her can you do that in another part of the house? Mama doesn't like it that loud. Instead of like we're both in the kitchen, there's no sound absorption. You can stay here and be quiet or go to another room and be loud.

That's the only thing I think might affect her, because she's so little, and her needs are so straightforward.

LV
Have you ever thought of saying something to her?

P2
She doesn't, she has no concept of mensuration. She's just wrapped her head around gender. Unfortunately, she's really bad impression of childbirth because at one point I watched too many episodes of Call the Midwife with her. The premise is [INAUDIBLE].

Eleanor watched all of this and has decided she is going to marry her best friend who's a girl, Fiona, they're in kindergarten. And Fiona is going to have all the babies. But I think it's completely healthy when you're 6 to be like childbirth looks like no fun I'm not going to do that.

So I don't think that she has a picture – she doesn't know I get periods, I don't hide it, but it's also not like come here little girl let me show you my menstrual pad. When she gets closer to adolescence we will be having more talks about that, but at this point she's just too young to get. She can't tell time. We're still working on how far away is July. My kid is crazy – she has these verbal abilities.

Skipping this

Easy for us as adults to think we can talk to kids about anything and we probably can but there really are certain core concepts like the passage of time and how we track things like what they can actually you know things like age related changes are actually predicated on a concept of an age. Although last night she did say "I'm getting breasts" and I looked at her and I said really?

LV
Speaking about I guess self image – how has menopause affected yours?

P2
The only thing I can think of is. I don't like the mood instability and it doesn't make me feel better. Feeling a little bit. If I had a real corporate career and I feel like being mood swingy, I feel like wait a minute, how come this isn't under my control, you know, and so I think that that's a challenge that makes me feel more ready about myself. I'm super ready to stop having periods and when I've talked to other people, they're like yeah it's great once it all settles down. It's great.

And I'm not experiencing. You know, I think when you're in full blown MP, you start more changes. I don't know I don't know this is where I don't have information, where people on the other side are not reaching back through the curtain to say this is what's coming down the road. People will say this is what I'm doing, but people aren't Oh, yes, people aren't saying oh yeah I'm done with that but here's what it was like for me.

I'm not experiencing changes in my skin or whatever, right now, it's more like wacky roller coaster with no obvious this is the direction we're going, it's just all over the map. So I haven't experienced changes that I can attribute to MP that could make me feel a certain way, but I don't like the mood swings. I really don't like, like this makes me feel crappy about myself. And then it makes me feel better when I'm like this isn't me, this isn't unique to me, it's just a thing.

Like you know you have a baby and you accept physical changes, you get stretch marks and it might be a bummer but it's not a surprise. Right now I'm not experiencing anything like that.

LV
Before I go into the last question. AT, do you have anything? If you had a magic wand and could change one thing and why?

P2
That's difficult because really, there's only one symptom bugging me and if I can make that go away I would. But if I couldn't make that go away I would say, having a predictable timeline, so for example going through adolescence, you know, feels natural to me to compare to getting your period. We're really educated on your body is going to go through, we have sex ed. Your body is going to go through these changes, we can't tell you exactly when, but here's the order of things. Interesting parallel, my daughter can't tell time, but that's why routine is so important, so that she knows A comes before B comes before C. And I feel like with this experience no one can say to me these are the things that are going to happen to you, this is the order, this is roughly how long it will take. They say, could take ten years. Could they be doing testing on me and my hormones and give me a better timeline? I don't even know.

The therapies that we have available to us get very mixed reviews. People are like HRT, great, but maybe not great, maybe dangerous, maybe ew. And so I think there is a lot that could be done to make the whole process better communicated and I would really like if we had a timeline, kind of like with adolescents where you're like you can expect that you're going to get body hair and you're gonna get breasts and at some point you're going to get your period and yeah, this is normal. This is what you can expect. And with menopause it's not communicated and what's communicated is vague, so I would love, other than getting rid of symptoms, I would love to actually, more pertinent to your research. I would love if there was better information that I could apply to myself.

And instead of like, Look, this is happening. It would be like oh this is gonna happen. Because when we do get our periods, people have been talking about it for years. Years! You're like oh and there's a thing. I remember knowing when the first girl in my class got her period you know, whispered, but no one talks about this, I think because nobody

knows what the fuck is going on.

LV

MP is so variable, it's ok to feel out of tune with your body. No one says that.

P2

What if we communicated more, would that change? I don't know, but there's so little data that I don't know. And then we talk about treatments. Most of human existence we haven't had treatments, just like childbirth. We now have things to make childbirth easier, but ultimately you still have to incubate your child and nobody's going to like – I swear when I was going to have birth I was like no one is going to star wars into me and teleport this child out of me, I'm going to have to do this. I was kind of in denial. And I had a really fast childbirth but I was really like wait, no I'm not looking forward to this.

In a way, this is really what I want to do. We should know more about it, because like every woman in some way experiences this. So why we're like half the population. Where's the data. I mean, I guess there are lots of women who die before that happens but not most women.

AT

What advice would you give your daughter when the time came? And what would be a good time

P2

In her thirties. Probably when she starts considering birth. Not to keep it a secret. We can keep it secret and be like I'll tell you now. I wouldn't keep it a secret, but it's just not relevant. What's most important as parents is to feed her data that's relevant. I don't think MP is relevant until you're in your 30s and 40s. Your body changing and mensuration and getting your period and sex and relationships, teenage hormones, which are also super crazy hard, and then we have estrogen and fertility and deciding between career and children. I believe that in giving women control over childbearing, we're having fewer children and growing up as a child has changed. We are no longer in a society where nearly all sexually active women are having a kid – we're not growing up in big families where our mothers are having kids our aunts are having kids.

Now we're having children, esp my daughter, where there is literally no other child on our block. We're growing up, where adults aren't as experienced with child-raising as they were when we had younger siblings and were growing up in bigger families where [INAUDIBLE] and i think this all comes down to the birth control and there's this change in society and i would love to go back and do grad school and study that, but i'm probably not gonna.

41:49

AT

Talks about when mp education should happen - we feel like our generation is getting later and later - it should align with when kids become adolescents

P2

But that depends when you have your kids, right. I had, <husband> was my second hus-

band and that was not a relationship [INAUDIBLE]. <husband> kind of talked me into breathing (?). So i did the thing that's going to become more and more common with people who can where I had a whole career and i stopped working just before i turned 40. Will i even re-enter the workforce, i don't know. I mean it's great. I made enough money to pay off my mortgage. That means when we had our child we had a level of financial security that people in their 20s don't have. And everybody's like, Oh, but at 40 you're so mature and i'm like yeah but my child is a crappy sleeper and i guarantee you i didn't have the physical stamina in my 40s that i had in my 30s.

So I think, but I think more and more we're going to see women choosing to have a full career, maybe using IVF, maybe not, it turns out the magical age for using IVF is 37. According to the guy who did my IVF. That at 37 the decrease in fertility becomes much sharper and after 37, unless you had children previously, the chances of you getting children are sharply curtailed. At the age that i had eleanor when i was 40, of all the rounds of IVF that they did in my clinic, the success rate was 15%. This is not told to women, that we can freeze our eggs, but this is not guaranteed.

When you see celebrities and they're having children, like janet jackson at 50, chances are those are not their eggs and they are lying. Absolutely people are lying. Those are not their eggs, no way. And it's easy to get pregnant at 50 if they're not your egg. But the benefits, in my opinion, and this is totally not your research, of IVF extending - does it a little bit, but it's actually not nearly the success rate is not nearly what we'd like to think because we see [INAUDIBLE], because we see the success and we do not see all the failures and the people who go into massive debt because nobody wants to talk about their sob story but anyway so i think there is this change of society and i think that, you know, MP is the combination of that, but infertility happens way before menopause does.

Anyway i would probably share my experience with her, this is what my experience was, this is what i found to be successful or not successful and kind of after that and i kind of after that. For all I know she's like, Mom. I don't want to talk to about that.

Irrelevant story about vaginal issues

Yes, I would share with her my experience. What does she do with that? Hard to say. But i wouldn't, the thing that I would unfortunately share with her which isn't directly related to menopause is here are the trade offs in terms of career versus child, my mom had me at 23 and my brother at 33 and I watched that and I thought actually having a kid in your 20s is a much better experience than having a kid in your 30s. It's not obvious, but you know, my mom just took me everywhere, and she didn't know financial security. Whereas she had my brother at 33 and I think that hit was much more acute, much more like oh i have to make these sacrifices, oh i have to stop what i'm doing.

So i think my focus my daughter will be much more like let's talk about making this decision and how can I, not having kids anymore, support you in having a broad array of options, rather than have a child and suck it up, take a hit to your career, or wait. I mean <husband> worries all the time about being 60 at her high school graduation.

Lol my dad was 60 at my HS grad and 68 at my brother's -K

Well, he doesn't know, his mom had him at 21.

AT and LV talking about parents, P2 talking about parenting older, financial security.

We can be as intellectual as we want, but childbearing, and menopause, and periods - we are animals. Childbirth is an amazingly animalistic experience. It's not an intellectual thing. It's like your body is doing a thing. I mean, like, really it's such a physical experience.

51:23

I think childbearing is a very physical experience, unless you get a nanny. My friend is a single mom with two kids, she works at amazon and she got 4 nannies.

Parenting choices discussion

AT + LV (~54:30)

About talking to mom about stuff

P2

Different people roll with insomnia better or worse. I would probably be much worse, except that when I was working I was always on call, so i was a kind of infrastructure and so I became very accustomed to being woken up in the middle of the night and then my daughter slept so badly so actually this insomnia is nothing compared to the hell of 3 years of what she did like that was horrible. And this is like okay i wake up and then she goes to school and i take a nap.

LV

Gift cards

P2

Yeah, actually most of the people in Seattle i know are like Eleanor's classmates parents who, for the most part are about 10 years younger than i am because most people don't have kids at 40.

I really, the experience of IVF really brought home to me how much our hormones affect our brains like I really not taken that into consideration and then I had this really intense hormonal experience and I was like wow they inject me with the thing and my brain does this and are you kidding me? It was quite eye-opening for me and yeah really so yeah so I'm happy. I mean, I'm happy to pass it on. Where did I see your thing oh no you reached out to me.

Participant 3

Moderator: Lan Vu
Note Taker: Kelda Baljon

LV

yeah. So before we get started, I think kind of want to give you kind of an overview of the study and I'm here with my teammate Kelda right now and Kelda will be taking notes on our conversation and everything. anytime of this study, you can refuse to answer any questions. And you can stop the audio recording at any time as well. Please let me know what you're comfortable with and we're more than happy to oblige for that. So, as you know, we're doing our study on menopause and we kind of look at menopause under lens of women empowerment, because we wanted to do something to help empower women and then we start to look at 10 of women's health and realize that we know that all women go through menopause, but didn't realize how little we know of this subject.

Um, so to start us off. Can you tell us a little bit about yourself?

6:12

P3

I am 51. I am the mother of a 21 year old daughter. married. I'm married. I just recently was laid off and now I'm going back to work. Trying to get my foot back in the work pool which is difficult this time, especially with going through menopause.

I guess that's about the main thing is I'm not sure what else you'd like to now, feel free to ask me anything.

LV

That sounds perfect. Thank you so much. And then, when did you find out that you were in menopause.

6:56

P3

Alright. The symptoms started when I was about 49 and they've gotten increasingly worse and within the last year. So it started, where I lost my period. I've never been officially tested yet but I haven't had my period in 2-3 years. Symptoms make it clear that yes I am in menopause. So the next time I go to the doctor, I'll just have them y'know triple confirm it or however you want to put that. So I started about 49.

7:37

LV

How did you think that you're going through menopause. What was that experience like?

P3

Well at first, it wasn't that big of a deal or it was actually kind of a relief to not be getting my period anymore. You know, a lot of women say how great to not have the monthly curse.

8:00

it didn't bother me at first because I didn't have any symptoms, other than the lack of my period. And as time went on, then the symptoms started to happen. And they started

to accumulate and yeah the last year's been.. Not fun.

8:19

LV

when you experience kind of menstruation kind of stop did it all start all at one. So it was a gradually decrease of your periods.

P3

For me, it stopped right away and some of it could be. I haven't been to the doctor in like four years for my physical and I do have thyroid issues. And so I don't know if that contributed to it but regardless of that if it did or not. Now I know that I'm officially in menopause because I'm getting all the other symptoms.

8:55

LV

Is there anything you wish you had known about menopause earlier before you started filling

9:03

P3

yeah I wish I'd known all of this. That's why when I found that you guys found me through that Facebook support group, menopause support group. And when I found out it was like, "I am not going crazy" you know because it's yeah, you feel like you're going nuts.

9:23

LV

yeah. And it sounds like it just happens unexpectedly as well.

P3

Yeah.

LV

and then going on that note, do you feel well informed about menopause now.

9:40

P3

Yeah. Yeah, I do. I feel well informed just because I am living the experience and again due to that support group. It's been confirmed. But it's like okay this is normal. Okay, this is another symptom that's normal. You know, because we all start to freak out like Oh my god. about what's going on with my body, but then when you you know hear from hundreds of other women going, "Does anybody have the same experience?" You go, "oh thank god. Yes, yes, yes, yes." So that's been very, very helpful.

10:17

LV

Yeah, I know, something that we noticed like shared experience is really, really important as well.

P3
So huge

10:24
LV
So when did you when you do have questions about any of your symptoms are about your menopause experience. How do you go about finding answers to those?

10:36
P3
Well, my best friend is a couple years older than me. And so she went through menopause before I did and she didn't have the symptoms quite as extreme as I did. She had a different version of symptoms that she and I have been able to. She's been a good source of advice for me and like I'll bring up the symptom did you have this while you were going through menopause and she would laugh and say, "Yeah, but I didn't want to tell you I thought if I told you that you would start imagining that you have that symptom" you know and and again serious with the biggest support right now is that support group on Facebook as crazy as that sounds.

LV
Yeah, I definitely can see that. So what has your experience been like so far what kind of symptoms are you experiencing?

11:29
P3
Severe... severe... hot flashes followed by immediately by cold flashes, which I didn't even know that existed until I started having. I've always had anxiety and panic my whole life, but it has catapulted. I mean I can't even begin to tell you it's just out of control. I would say sleep I actually sleep better now and I don't know why. When I first went into menopause. I wasn't sleeping as well.

And now for some reason I seem to be I mean I don't sleep fantastically but I am sleeping a lot better. It's mainly the physical and the mental symptoms. The hot flashes and and the anxiety.

12:22
LV
When you mention you have severe hot flashes. How often do they occur?

12:28
P3
It varies from day to day so i can go a few days and have maybe two or three but then like the other night I think it was Saturday night I literally I felt like I went to bed and I felt like I was having a hot flash the entire evening my whole sleep. I didn't even sleep. I was just drenched in sweat. I couldn't cool off.

12:57
Even if I put a fan on me and it was, the minute it would subside then I would get a cold flash and then I think "okay I'm over. It's over." And then two seconds later, the hot flash

would kick in again.
So it really varies.

13:34
LV
What was your question there any treatments both like medical or non treatments to leave your symptoms

13:48
P3
I just recently started, only 2 weeks ago on CBD oil. I started on that and on the days that I've been trying to take a few drops in the morning and a few drops at night and it could be placebo. I'm not quite sure, but I do notice that when I take my that my hot flashes name to be lessening and that's the one thing that they talked about on the support group and a lot of women you know and I'm sure you know the research, kind of, I mean CBD is great for many, many malities out there and and so I think that I'm seeing success with that.

But I'm you know I'm still not perfect but I noticed that even today in this hot weather. I think I had one hot flash today.

14:50
LV
I know that you mentioned earlier in the conversation that you haven't confirmed with a doctor. I'm about your menopausal symptoms that sounds like you are going through menopause. Have you considered going to a doctor for any of your symptoms?

15:09
P3
kind of no because I'm really kind of anti wanting to go on hormone replacement just because of the side effects and the cancer risk and all that stuff. If it doesn't continue to get a little bit better than I would maybe consider it. I'm much more of a natural person. And so I think I would consider maybe bio identical hormones or some sort of progesterone cream or something like that, but for right now I'm doing this CBD Oil and I'm just I'm just seeing how this is going to work for me.

15:51
LV
That's great to hear and I know a lot of women to feel the same way about that and menopause is such a variable experience and it can impact different aspects of your life. So we're going to kind of touch into different parts. So, in regards to family and relationships. Do you share with your partner your menopausal experiences and why or why not?

16:19
P3
I do to a certain point, especially when I am overloaded with heat and I'm sweating because you know sometimes I literally will have to get up and walk away from a group situation because I have to go outside and get fresh air and I tend to be kind of a private

person. Anyhow, and I know I fully understand that men don't get it, and never will.

16:48
So I don't like to stand around and act like I'm complaining, so I'm pretty good at just kind of keeping it to myself and then just talking to my female friends who who know exactly what what's going on. Man, I've talked to my daughter a bit about that because that's one thing that my mom never did she really completely ignored that whole subject and now she's no longer with us. And I'm trying to make sure that even though my daughter's only 20, that maybe when she's 50 she'll remember this.

17:26
LV
Yeah, and that's a great segue into our next session. When you speak with your daughter about menopause. What is this discussion like and how is her to the top

P3
Again, she's only 20, so she's still trying to figure out her period. She's having a lot of period issues. I think this is something that kinda, I mean she knows one days it's gonna happen. You know it's 30 years ahead of you. So, you know, I'll just tell her you know "sorry roll down the window. Having a hot flash."

So we kind of almost make a joke out of it. But then I will tell her you know I just want you to be aware that these are potential symptoms, because I wish I had known this so that I wouldn't have been so caught off guard. And I think she hears me that I think just because of her age and stage of her life. I think a lot of it kind of goes in one ear and out the other.

18:25
LV
Has menopause in any way affected your role as a parent

P3
18:37
I don't think it has. She's 20. Been an empty nester The timing was kind of funky, you know, I started as soon as she left the house. It was kind of a double whammy for me and I kind of decided to be a hands off, let her be independent kind of parent when she went off to college, I would have done that regardless.

As a parent, I don't think it has.

19:11
LV
and then kind of going into another context workplace. I know that you just started a job, do you mind describing what your job is and what your schedule is like?

P3
I am doing temping for through the UW right now. The UW temping program. I just started my new gig there and it will be very only 6 weeks. It's going to be from 8 to 3. Part-time job.

And then from there, I'm just going to have keep looking for work and what else I can pick up from them.

LV
If you did experience a hot flash or anything or any menopausal symptoms. How do you react and do your coworkers know or do you tell your co workers?

P3
20:12
in the job that I recently got laid off from, I was really close to them, I worked with a dad and a son. And I was very close to both of them and they all kind of got to know the drill. Because it would be one minute my coat was on, the next minute my coat was off. One minute on, one minute it was off because I'd be hot and I'd be freezing then I was hot. And I told them way early on. I'm a pretty upfront person, so I just told them upfront, "you have to deal with that I'm going through menopause" and they were like, "Oh, okay."

20:54
Now that I've started this DVD though I'm now working the office. I'm working in the UW, kind of dungeon kind of room with no windows or anything and I was worried. The first day I showed up because I thought this means I'm gonna just be sitting here with hot flashes all day and I haven't had one yet since I've been at work.

I don't know if it's the CBD or I don't I just don't know.

But I did tell my supervisor because i well i had kind of a hot flash the other day and she was showing me around and I I could feel my face is turning really bright red and I said, "I know we barely know each other and this is too much information, but I'm going through menopause so this happens from time to time.

21:48
LV
What was her reaction to that?

P3
She just kinda grinned. And she's in here 30s and she just kind of smiled and she said, "I heard that's not very fun" and I said no it isn't.

some people sail through it because I have another friend who went through menopause and she said now I had no issues. I'm like, screw you. She said, I used to get hot flashes occasionally, but now my period just stopped and a couple of hot flashes here and there. And that was the end of it.

22:26
LV
Yeah, that's something that we found through our study that's amazing is how menopause can vary so much among different people. Everyone has a unique experience in a way.

22:37
P3
Yeah, well I have my best friend that I was telling you about it has already gone through it.

She went through a horrific time and she keeps telling me, "I know you're going through a bad time but be thankful that you didn't have what I did", because she had extraordinarily heavy bleeding and by fibroids and she had to go have surgery and it was like really really bad. And so I mean yeah i've i've heard all different kinds of stories. It's kind of funny. And then the other thing when you're asking about symptoms and is that I have lost essentially all of my muscle mass and I've lost a ton of weight because because my anxiety is so bad and my anxiety sits in my stomach.

And so everything makes me feel nauseous and and if I do want to eat something. It's always clean food, you know like, I'll eat a cucumber dipped in Ranch, well, that has no calories. So while I'm eating healthy. I'm very I mean I just know that I'm not healthy because you know I've dropped so much weight and I have no fat left in my body which is so funny, I've spent my whole life trying to lose weight and now I'm desperately trying to gain it. and so that was another reassuring thing about the Facebook group was a bunch of women on there with said the same thing cuz you know a lot of people complain about the weight gain and then there's a subsection of us that are like we we wish that we could eat because we I do miss eating you know

I've developed a lot of food aversions that's that's a strange thing that's happened in menopause

24:37
LV
Now, that's interesting to know because like you mentioned, we'd notice a lot of people have mentioning weight gain, but we don't see that many people mentioning like there can be weight loss as well. So it's a good thing that you mentioned that.

P3
Yeah. I was so relieved. I really thought there was something more wrong with me. But yeah, there's so far there's been about 20 women on this support group that are like yeah, I have lost every muscle and I have to force myself just to drink a protein smoothie and it's like yep I hear your sister. I'm the same way.

25:14
LV
Along in that subject with like self esteem and identity. How has your image been altered during menopause.

P3
This is a strange answer other than feeling miserable a lot of the time, I actually feel more confident and sure of myself and I don't know if that's because of my age or is it correlated to the hormonal stuff going on or does that make sense?

LV

That does make sense.

P3
Yeah.

LV
And then I know that you mentioned that you had a hot flash today. Do you mind if it was at work..

P3
No, that was yesterday.

LV
Cuz you mentioned like it's hot outside but I only had one hot flash I believe what was the context.

P3
Yeah, and I think that was it. And it wasn't even that bad. I think I was just sitting at my desk and I could kind of feel my temperature rising and then I just took off my jacket and then I was fine and I drank a lot of water and and that was kind of I haven't had one since. That was probably 10 this morning.

LV
Something that you mentioned throughout the conversation was how great the Facebook community has been. Is there anywhere else, or is there anyone or any place that you go to to find social emotional support?

27:00
P3
My best friend and I think that's about it because she's the only person personally that I know that you know that has gone through it and really understands because she had a kind of a bad go too. like my other friend that went through menopause blew right through it. I can't talk to her about it because she can't relate to it. You know, I used to try and talk to her about it now. And she goes, "No, I have no issue." It's like, Okay, well then I'm done complaining to you.

27:38
LV
in your opinion, are there any and cons to the Facebook

P3
Pros are obviously the support and knowing that you're not alone in this.

The cons would be from what I have gathered on there is that a lot of people are trying to sell, well, not a lot, but it's making some people upset. They are trying to sell like multi level marketing products for menopause. So they kind of use it as more of an advertising place to make money if that makes sense.

And so a lot of the women get upset about that and then every once in awhile you get

Participant 4

somebody who’s in a really bad mood and decides to post really nasty stuff.

But for the most part I have found it really, really helpful.

28:43

LV

Um, we’re all actually in them in a plus support group as well. And it’s amazing the amount of posts people people put every single day too

P3

Yeah.

LV

And then what kind of technologies or references do you currently use in relation to menopause. For example, any apps website books devices, etc.

P3

Well, I did the CBD oil and then I have Christiane Northrup’s book. Wisdom of Menopause.

And then in terms of apps. It’s more. I mean, I suppose it’s a little bit menopause related but I’ve just recently downloaded, which I have all fallen through listening to on but on some meditation apps to kind of help with the anxiety because I have a couple friends who are really into that and they said that really can you know has helped them and and then I’m trying to up my exercise program, but it’s kind of tough when I don’t have a whole lot of energy

LV

that’s understandable and then our last question is if you had a magic wand and can change one thing about menopause, what would it be and why?

30:16

P3

It would be getting my weight- my appetite back. So I could put on a healthier amount of weight and look healthier

LV

And then I guess outside of symptoms. Is there anything else that you wish was different about your menopausal experience

P3

Um, everything. Yeah right there. Yeah, no, the anxiety, the anxiety and the hot flashes are. The hot flashes I can almost deal with the anxiety is just paralyzing No, I wish that yeah

It’s bad enough to have anxiety your life, but to have it just amplify times a 1000 is just bleghh, it’s just not fun.

LV

and then is there anything else you would like to tell us?

K

If you could give advice to somebody who was like just having their first symptoms or, like, you know, had not yet had any symptoms. What would you tell them?

P3

Definitely get a support group because you honestly think that you’re crazy. That really is the number one. Yeah, at least for me.

Moderator: Aggie Tutia

Note taker: Kelda Baljon

AT

Hi, I’m Lan’s friend slash teammate for the project.

P4

Yeah, yeah. Let me get out of the noise here.

AT

Okay, yeah just let me know when you’re ready, and then we can like get started. Okay, perfect. Well, just to guess start us off. We’re part of the master of human computer interaction in design program we’re in our exploratory research phase of getting a better understanding of menopause and how women are and people are experiencing it. So this is just an interview, just like a general conversation and really excited to get started. So can you start us off with telling us a little bit about yourself. Also my teammate Kelda is also here.

P4

Okay, I’m <redacted>. I’m full Latina. My parents are from Ecuador. I’m probably on the tail end of menopause. I’m not right in the middle of it, but I think I’m over the first of that stuff. I’m a professional. <inaudible> pretty well. I don’t fit into any of the Latina stereotypes that people have around here. I’ve been in IT and make pretty good money.

AT

Yeah. Can you tell us your age, so we can have that down.

P4

I’m in the late 40s and probably closer to 50s. My background I was born in the south. I went to college. My parents are immigrants from Ecuador. I was born in New Orleans. Yeah, it’s a great place. Born in New Orleans, raised in the deep south, went to graduate school at Berkeley. Got married and have two kids who are at Berkeley. One of them is graduating and they are making more money than what I do now.

AT

That’s great! Well, it seems like we can start talking about your kids because that’s just a good natural path, were they in college when you started experiencing menopause or were they in high school.

P4

They were in college.

AT

Yeah, we’re they like living with you like can you talk about that experience of like if they ever notice or if you ever talked to them about it?

P4

They’re in college and not living with me. I’ve probably talk to them about it. But prob-

ably as young adults they don't really care <inaudible> This problem is a long way off. They also probably do listen to some of that because they know genetically that something that happens to me might happen to them, but not necessarily. They are showing some differences in how things are...I mean they have bad menstrual cramps and I had menstrual cramps...but they also have acne and I didn't have acne. So they kind of see that there could be some differences, but they just don't really care and i don't think anyone saw any crazy moods. The only thing is that I have a hot flash and that's crazy and they just ignore.

AT
Well, I think, yeah, it's interesting because I didn't know about menopause that much until we started researching about it and I started bringing it up with my mom and I asked her, like, oh, like did you experience menopause and she's, she laughed at me and she was just like, Yeah, I did like like that like I had a cold house and then I realized like she kept the house cold during the winters because of her hot flashes and I never understood why so I was always frustrated with her. I feel like an open...less frustrated when she told me.

P4
Yeah, I think it wasn't on the radar for any...my husband and I have different temperatures. So it just like what women do we suffer in silence. I talked to my doctor about it because hot flashes are really a pain in the ass and she if it bother you that much she can put me on estrogen and I was like nah not that bad. I will just suffer through it. We suffered through menstruation and menstruation for me was far worse. I'm glad to be done with that. With menstruation. I'm glad to be done with that. Very happy. Menopause only last for a year or two. It gets less and less.

AT
Did you notice any symptoms before the actual, like before the no period

P4
You get less periods before the hot flashes start I thought. The only thing that bothers me are the hot flashes...those are the direct symptoms of menopause. But I don't know if that's aging or a part the hormonal changes that happen after menopause. You gain weight. It's really hard to maintain and I never really thought about weight that much until now. And now it's like I don't eat anything and I still gain weight. So it's tough getting old and you also become...the thing about getting older that may or may not do with menopause. You know you become invisible. It's different for most women. I mean I think for my mother it was hard because she was a great beauty and age is not kind to people. Well I never had great beauty so it wasn't a big deal. I think menopause is a symptom of a larger problem of aging women. I don't know if there's a difference between POC and white women. They might have access to drugs to make them feel better and things to make them look pretty. When you're a POC.. like I went to a thing yesterday where there was a whole bunch of women my age and selling oil and they said, 'oh, your skin is so great!' They said, 'brown, don't brown'. So, menopause is a symptom of a larger issue of women aging.

AT

Right. So what was the first kind of realization that came up and like I think I'm experiencing perimenopause or like I think something's happening to my body.

P4
Losing your menstruation would the biggest thing. That's a weird thing. I think you know you're not going to have more kids. You made that decision in your 30s and 40s that you're not going to have kids. You also want your own life again because kids take so much of your life away. But you know I love my kids. So I think when you don't get your period anymore that is kind of a big deal. You realize that I cannot have kids anymore. That's it! You're body has made the decision for you vs. you making that decision. I think that's a bigger deal than most women let on. Thank god, I don't have to carry tampons around. God, I don't have to worry about leakage. Thank, god I don't have to worry about cramps. So there's elation, but emotionally your body is saying that you cannot have kids anymore and the third child is not going to happen. You are old. So that was probably a big deal emotionally whereas the symptoms of menopause are just annoying. They are just annoying versus that idea that, 'wow, that's it!'

AT
Do you wish that anyone had told you more about menopause or specifically about this. I guess the transition. In like what exactly would you want someone to tell you.

P4
Well, my mother I don't even know if she went through menopause. I assumed she did. She didn't talk to me about that. It's pretty typical not of just her generation, but she comes from a third world country they don't talk about menopause. I didn't have any grandparents around or aunts. I didn't know anything, but at a young age, I didn't have the that kind of relationship with my mom. She didn't talk about sex, so um at a young age, I was a self-learner, I was self-taught.

As I got older, I was reading and hanging out with my peers that are older than me and talking to them. So I kind of knew what was going on not in a structured way and I keep my ears open. When I read an article on Facebook, Facebook knows your age and articles would pop up that were relevant to me that were relevant to me so I kind of knew, but no one can really prepare you for it. No one can tell you what it is like to be a college student until you become a college student. You kind of know, but until you're in it. Then you're like, 'oh!' This is a little different for me based on my SES, color of my skin, gender, sexual preferences. It's gonna be a little bit different. So I kind of know. Also, women who have children also have they know that there are hormonal shifts in your body, especially if they are sudden...not even mothers because strange things can happen to them during puberty. So we kind of know that our body is going to fuck us up and make us uncomfortable.

When you finish pregnancy you have nine months of these hormonal changes and it all reverts back. So you get a weird kind of hot flash. So as women you're kind of use to our body doing this to us. Men don't have this problem. So I don't think I have any surprises. I was prepared as anyone could be and living in this age where we get so much information. I don't know how my mom was prepared. She certainly didn't want to prepare me for anything because it was taboo. But I don't think it was taboo anymore. I am talking to you.

AT
I am also not a man talking to you.

P4
Yeah, men don't quite get it. My husband didn't quite get it. Men don't get much.

AT
Is there anything that you've shared with your partner about menopause and your experiences?

P4
Yeah, I did, but you know. He's a kind guy, but he's a white guy. I don't think there's any difference between white or POC men. It's just one of those weird things that women do, it's not gonna kill her so I'm not that concerned. As long as it didn't look like something like my health was failing. Like women have weird menstrual pain and they just forget about it. It can't be <inaudible>, but your period. I don't think it was as debilitating as menstruation is in some ways because like you're going camping and you have to carry pads, you have to think about this it was always in the back of your mind when you're planning your trip where menopause you don't. Oh you get a hot flash and usually happens at the worst time like in a meeting and you get a 'woosh' sheen of sweat all over you and then it goes away and then you're cold because you have this sweat that is cooling your body down, but you're not hot anymore.

So it's uncomfortable when it happens and sometimes at the peak of menopause it happens everyday, all the time. Like your periods you know that it's going to go away and deal with it next month. In my case you're thinking, okay - maybe I have to deal with this for six months and I don't know if it will go away. So it's not a life threatening thing. It's more of it's really really annoying, but you don't have to plan your life around it. You don't have to plan your vacations around it. I don't know anyone that has had it so bad that they...

AT
Yeah no one has died from menopause.

P4
Yeah...it's more of just an annoying thing. I don't remember feeling any grumpiness. That's something you have to ask my husband, but I don't know. I think I was more grumpy with cramps. But I can't speak to other POCs who might have limited information. My mom didn't prepared me for this and if she did maybe I didn't listen. I don't think my kids listen.

AT
In the cases where like you would you say like you could go to your husband if you wanted to, or did you seek support elsewhere?

P4
I could go to my husband, but he wouldn't take me too seriously. I did talk to my doctor, I have really good health insurance and do choose female doctors and not male doc-

tors. I feel like they don't take anything seriously and so when I talk to my doctor about menopause, she's been through it because she's older. She said, 'my advice is to power through it'. But if it's really bothering me I go to a doctor. A female doctor. I don't go to male doctors and most in every incident i had a problem I think they took me seriously enough because they are doctors and took the hippocratic oath, but they are not sympathetic. And I think it's good to have doctor that is older. To have been through it and say when you...like what they do when you're pregnant. That it would end. It ends before death.

AT
Can you describe one doctor visit and what that was like?

P4
I only have one doctor visit a year and it wasn't specific to that. It was just my annual that I do. You know you go for your annual test there. I knew I was going to my annual and can discuss anything I want with her.

AT
Okay so you kind of had like questions beforehand, or like you were a little bit prepared to talk to her about your menopause.

P4
Yeah it was something that I wanted to bring up. These hot flashes were a pain in the ass. I thought she would give me home remedies or and she just said you got to power through it. There's not much you can do unless you take certain medications and I wasn't comfortable taking medication. Well you know I'll power through it. It just varies you know.

AT
You were talking about you got a hot flash during work. Can you talk about how it like hot flashes affect you more in work or talk about or your coworkers.

P4
I don't know if they noticed. It's just like all of a sudden you take off your sweater. I'm in the Bay Area so you know you're layered already. You suddenly get really really hot. It does break what you're doing at that moment. If I am working at my desk, it's not that big of a deal. I just throw off my sweater. But you're in the meeting you can't concentrate anymore for that period of time. It usually doesn't last that long and people don't really notice it. I do sweat more than most people. So I don't know if it was visual. Like I said you're old you're invisible anyways and no ones really watching you. It's probably disruptive as getting a bad cramp in a meeting. Like, 'ouch!' and it breaks your concentrate and you wait for the cramp to subside. It's probably a similar disruption, but it's not painful, but it's annoying because you're really hot then you're freezing so you have to put your sweater back on cause you have this sweat on you that cools. It's just annoying. I noticed some people or more vocal about it then other. There's a women in my office and she's like, 'oh, I just had a hot flash'. Well everyone knows because you just told them. Whereas, I would just sit there and I'm quiet. I don't think it's that noticeable.

AT

What would you like change in the workplace to if there was anything. It doesn't have to be a huge thing and like are changing this like the social classes or just something like some small changes that you think would be more like helpful for you if you were going through hot flashes or other symptoms.

P4
Yeah...when it's general we do have these hormonal shifts that happen once a month to a long periods to a year. It's a bigger issue with children in this case in every women you can never have kids and go through menopause. I don't see it as an issue of singularity. It's a part of a bigger issue of women's health in the office for...I think it's a great equalizer too because it is issues with all races and sexual preferences of all women do it. I was just reading an article today about how a women report that the meanest people in the office are other women. It just seems that it's not just sexual harassment and we're being mean to each other. It's important that we should all work together and recognize. I think when you're young you don't recognize when a woman is uncomfortable or bitchy. You forget that once a month you feel like crap. You know some people have it worse than others and you forget that too. Misogyny comes from other women. I think it's all part of a bigger thing. We just need recognize to each other that we're all going through phases and one phase is not more important than the other.

AT
Okay, so kind of just changing the culture of women in the workplace to being more positive would be the best.

P4
That would be great, but that's a big big big thing. I don't think...yeah I don't know. Maybe it's <inaudible> syndrome. It's a bigger social issue that women are competing with other women over jobs and not mean high jobs...

AT
Do you think it's the same for like outside the workplace too? Like is it easier to be supported outside with other women?

P4
No, I don't think it's just the workplace. I think...so I belong to an all women's book club and they might be more supportive of those kid of hormonal issues. I think the bigger issue that they don't think of are issues on societal level. But at the same time the people you choose outside of your work are your friends. <inaudible> at work they're not sympathetic, but more competitive. Women outside can be bitchy too, but you can walk away and you can't do that at work.

AT
Right...yeah so you mentioned the book club. Are there other places where you go for social emotional support.

P4
I would have to say online because I think I'm more pigeonholed in the real world. I have my book club and people around my age. I have other interest that are not age related or body related. I don't think menstruation or going through menopause or even

age or anything obvious like sexual preference or being married or my immigration status which I have and I know I'm privilege in that way. I don't think that should be my only defining thing. I have a big interest in art and graphic art and this has a very young population and some ways male dominated because I didn't grow up with these things. So online I get that kind of support, but far as body...you know body issues or hormonal issues I don't get that online other than reading. I don't need...I'm one of those people who don't need a lot of help or support because I'm self-taught, self-raised so...as long as I can get some kind of information as long as my doctors says, 'yeah, i'm fine.' Then I'm fine. I'm not very typical so...my sister's bipolar so she might say something different.

AT
Would you say like you're more likely to just like Google information like on the spot like oh I think this is happening. So I'll just Google.

P4
Yeah, exactly. I think I probably did that. I want to see how long menopause lasts. So those kinds of questions. It's so much easier because online you get probably a random sample, but if I asked a coworker they would say, 'it lasted ten years for me' and I would be damn and not knowing that she was an outlier.

AT
Do you remember any of the things you searched?

P4
Probably how long it last? How many hot flashes a day? I didn't get all the other symptoms so I would look online and I think I'm doing better. I don't get vaginal dryness, crankiness, no...I'm always cranky. So, I remember being comfortable by the fact that I didn't have that, but hot flashes, but I started earlier than most people...so I was like uhh is that good? But they have a range and stuff and I am a data person by nature so having the data is comforting rather than someone saying...<inaudible>

AT
Do you happen to use a Fitbit or some sort of like smart watch.

P4: I had a FitBit. Now I have an Apple Watch! It's funny because I went to this party last night and it beeped.. my blood pressure...it's usually low, but it was saying that it was high. Why am I nervous? So I live a very quantify life because of these things and maybe it's too much information I have, but I kind of like it. And I know I was getting anxious because I didn't want to be in a meeting. So...cause my blood pressure tends to be very low so it's 120 it tells me everything. I like living a quantitative life and I know a lot of people don't like knowing more. I was more anxious before the internet. Cause now I can get information on anything.

AT
Okay. Well, is there any other technology or <inaudible> you us to to learn more about menopause?

P4: No just the internet. Besides my doctor and as long...my bloodwork you know. She

did my blood work and everything was fine. There's was a weird hormonal thing happening and she did put that on my notes. They actually give you a diagnosis and that diagnosis seems very important to them whether you are post, pre, or in the midst of it they want to know. The doctor said everything is okay and the internet was not scaring me. People ignore me anyways because I'm old. Then I'm okay. I mean I worry about other things.

AT
Are there any areas in your life where you feel like you have a lot of support versus like no or little support?

P4
Good question. I think my issues are not not normal. I think the issues of being a woman...an older woman just so many issues that I feel for my daughters, you know they are going to go through all of this. There's a lot of things about being a young woman that can be problems and it just exacerbated as you get older, I think...I made a life for myself where I can take care of myself and if I need the support I know where to get it because I've always been very independent, but there are larger issues that bothered me more control over big political issues like <inaudible>, our president, stuff like that so people disturb me. I don't feel I have enough support around me to talk about it even the woke guys. I think the larger, political, social issues give me more anxiety and the little things like my health, my body...I have a bit more control over. I think women, especially POC women, as we age it gets really hard and I can't describe how hard it's going to be for all you girls. Our place in society is based on how we look that...you will age and you might age better than other people, but you will age and the way people see you as an intellectual, as a professional, is so much based on looks that menopause doesn't mean an end to certain hormones that make you look younger. So those things are out of our control and those are hard.

AT
Can you talk about also just like the more positive things where you are supported in?

P4
Oh there's a lot of positive things as you're getting older and when you're in menopause because there's freedom of not caring about your looks so much. I remember as a kid... why does she look like that? Why doesn't she take care of herself? You don't give a shit anymore. There's a freedom in that. There's freedom when your kids are older and they don't need you as much anymore. I mean they still need you, believe me...they call, it's not a crazy intensive love as when they are little. I have a lot of freedom, but that depends on the individual. I know so many women my age and they don't want to retire because they don't know what to do, BUT I can't wait to retire I have so many things to do. I have the income to do what I want, buy what I want, it's great having money and finally at an older age...I've been working since I was 14 and I have finally somewhat of an income...I just don't give a shit what guys think about me anymore and that's wonderfully freeing, wonderfully freeing to not be dating or even my friend who is 70 who doesn't want a man and doesn't need a man and that's wonderful! I see younger women competing and being bitchy towards each other for jobs or men and I just above all of that. I don't give a shit and it's great! You know, I don't care, I don't care. My job is stable enough I don't need to be competing with anyone. I have a good marriage which

is a miracle, but even if something happens to him I would search for another guy and I am fine...like I said I wasn't a great beauty so losing my looks wasn't that big of a deal because it wasn't my identity. What was hard for me was my identity was working out and running and you can't do that much when you're older and I've replaced that with many things with other things that identified with. It's great! I see twenty year olds? No not at all. I envy having a 20 year old body that can run, but don't envy going into that world where women are bitchy to each other and where you have to compete with white men which is such a hard thing to do because they don't believe that they are competing.

AT
Well if it helps my ex boyfriend felt like he was competing...so the pressure is on.

P4
Yeah...he doesn't see the wall that you have to go through. He just walks through and you have to climb the wall because people are looking at your beauty more than his. They see you as the stereotypes, the ethnicity is. Whether they are woke or not. It is what we are taught our entire lives. It's so amazing that they think they are not seeing you that way. So...you have a brick wall...a woman, your ethnicity, your age, when you're fat or pretty or whatever. It's a wall they don't have to go through. So white men!

AT
I think in the next couple generations. It's gonna be I mean there's already a cultural reckoning.

P4
I hope so, I look at my daughters and good thing I raised them in Berkeley. Their boyfriends - they both know how to talk to them and educate them - they both are dating white guys. I see my daughters and they don't care. The younger generation of women are so much better than my generation in so many ways. So there is hope. The older women who broke barriers they can't enjoy the fruits of their labor. The suffererates... they did so much so that we can vote and we took it for granted. So everything has to be looked at in a historical perspective. They can't enjoy it, but they are doing it for future generations.

AT
Going back to menopause...so you were kind of talking about how your daughters. You like you kind of mentioned to menopause to them at like what age do you think you would like you would have a sit down conversation with them about menopause and like if you were like...

P4
I can have sit-down conversations with my daughters on pretty much anything like sex because I felt when they are toddlers I made it a part of our conversations so it wouldn't be a such a big taboo thing. Like their menstruation. It's not a big thing. It's nature. Everyone women goes through it. I didn't have sit downs like this is what your body is doing because you're like a woman I didn't do that because it makes it sounds so weird versus something that...I knew about menstruation, but I didn't know anything about menopause so I didn't have a sit down conversation about it. I just make them know

that it just happens you know...at this age you have menstruations. Instead of sitting down, I am talking about it as it is happen. Emotionally, I think they just watch me. It's not like I have a hot flash and they go what is it like mom? It wasn't like sitting down talking about being a women...it feels hokey. Same thing about sex. I didn't say your dad has a ding-a-ling, your dad has a penis or I have a whatever. We just used real words. It's a part of life. I don't have to sit-down and talk to them unless you now even with finance. They know to put things in your 401K. I think we kind of glamorizing this whole thing makes it like we have to be almost ashamed of it when we shouldn't be. It is what it is, you know. So, I don't think anything is really age-appropriate. It's not a bad thing. So why do they have to hear about it when they are 17 or a magic number, kids are so emotional different anyways. It's not some big deal that you can't talk about it. I mean I think they're okay.

AT
Okay, so final question if you could change one thing about menopause or people have not experienced it. What would you change?

P4
I would change the kind of... cause I know women who go through menopause in their 30s due to infertility problems and stuff. I kind of wish I can change the stereotype of this crazy lady, grumpy. The same reason I would like the stereotype of PMS to go away. It's an excuse or crutch that men go, 'oh,we can't talk to her because she's on her period', 'oh, we can't talk to her because she's PMSing', 'oh, we can't talk to her because she's going through menopause'. The whole stereotype of crazy when you know when cave women are able to survive with this weird hormonal system that we're on. It's the same thing with the <inaudible> talk with my kids. It's natural...same thing with menopause we all do it differently. I had a completely different one then someone else did. So they go "oh this crazy lady is going through menopause, it must be why she's angry.' No he's angry because you're being a dick to her. Of course she's angry! It just drives me crazy you know. Or even women uses it to justify bad behavior. Nope...you're just being a dick. You're being a bitch. So it's just the stereotype that bothers me alot.

AT
Yeah that's that's a great answer. Yeah. Is there anything else you'd like to share with us. Any final words of wisdom or anything.

Participant 5

Moderator: Kelda Baljon
Note taker: Lan Vu

0:43
KB
Can you tell us a little bit about yourself?

P5
Sure. I'm 53, married, lived in Seattle for 20 plus years, I work in technology for Nordstrom, no kids, enjoy hiking, exercising lifestyle as it goes.

KB
So when did you find out you were in menopause?

P5
So when I was looking at the sign up thing. It was like either you're in or you're in perimenopause I don't have an official diagnosis, one way or the other but given my age and symptoms. It's the assumption I'm in somewhere in the..

KB
When did you know that? When did you figure that was starting?

P5
It probably started a year ago.

KB
What led you to suspect you were experiencing menopause?

P5
Having hot flashes mostly, sleep disruptions at night

KB
Is there anything you wish you had known about menopausal earlier?

P5
Not really. There's clearly a lot of information online so it's easy to find that. And I have friends who've already gone through menopause. I've heard some of it from them. I didn't feel like there wasn't anything I didn't know.

KB
Wasn't too surprising?

P5
No

KB
What do you when you have questions about menopause?

P5

Mostly I look online or talk to my friends.

KB
So what has the experience been like so far? You've said trouble sleeping and hot flashes, and it's been going on for about a year. Has that been what you're expected?

P5
Pretty much. I expected the standard things you hear about. I haven't really noticed any really other things. I guess the only other thing is it's much harder to lose weight is the other thing I've noticed. So what I was used to like be able to do a certain thing and eat a certain way. I had to adjust calorie consumption.

KB
What methods do you use to alleviate your symptoms? What do you do to ease sleep?

P5
I don't take anything so I don't take supplements or different things. I'm not on hormone replacement things. I do have an IUD for a different issue so i get progesterone from that. But I don't know that it's impacting my sleep one way because I still have them. So really when I get hot, I just go somewhere that cooler, or take off the covers, but I really don't do anything.

KB
What kinds of places to you go that are cooler?

P5
If I'm up or I'm at work or something, I'll go outside and walk around for a few minutes or I have a fan at my desk so I might turn that on. That kind of stuff. And at night, it's mostly like taking over the covers. Or I might get up and get some water, move around a little sometimes seems to help.

KB
Do you keep water by your bed a lot?

P5
No, I usually get up.

KB
Are you trying to lose weight? Are you doing anything special for that?

P5
The gym I go at has like training programs on a regular basis. So I did one in January. It's kind of like *inaudible* But right now, no, I'm not actively training to lose weight, I'm just actively trying to not gain weight.

KB
I guess is that more pronounced than in the past.

P5

yeah. Yeah, definitely. I definitely can't consume the same calories, even though I exercise approximately the same way.

KB
And then the trouble sleeping is that all around hot flashes?
P5
Yeah, it's pretty much hot flashes. Once you get hot, then you get unsettled, hard to get back to sleep again

KB
For your menopausal symptoms, have you seen a medical professional?

P5
I haven't for my menopause symptoms. I'm due to go back to see my gynecologist for my other issues that I have uterine bleeding so I'm due to go back to see her. So I'll probably ask her about it when I go. But I haven't sought out treatment for it, it's obviously not that bad.

KB
You work here. What is your schedule like? 9 to 5?

P5
Yeah, it's pretty much 9 to 5.

KB
How has menopause kinda roll in your workplace?

P5
I don't think it has had anything significant.. It doesn't ever. just sometimes it's embarrassing if you're sitting in a meeting and all of sudden, you get a hot flash and you're fanning yourself, or you get up, that sort of stuff, but it's not like it's changed my ability to go to work or deliver things that I'm responsible for.

KB
Do your coworkers know you're going through menopause or when you're having a hot flash?

P5
I don't know. I mean we haven't ever discussed it openly, but I would guess they figured it out. Because I have my fan on or cuz I'm like taking off my sweater. I would assume they figured it out.

Actually one of my coworkers, we have talked about it. But the others, we have not most recently had that conversation.

KB
How old are you coworkers?

P5

They range from 29 to about mid-40s.

KB
Have you talked to your manager about it at all?

P5
No

KB
Would you like anything in the workplace changed?

P5
I think pretty much the things that I need I've been able to do right now so I can't think of anything in the office necessarily need to be different. A fan is pretty much, mostly solves the problem. That's pretty easy implemented.

KB
Do you ever wish you could talk about it more openly?

P5
I guess I never really thought about that. Not really, I guess I'm relatively a private person at work so I don't share a lot of other things going on, necessarily. So for me, if it's not impacting my ability to do my work. I don't necessarily see why I need to talk about it.

KB
Do you share with your partner your menopausal experience?

P5
Oh, yes. He hear about it.

KB
Why do you talk to him about it?

P5
More like I'm griping about it's hot, fanning myself because I'm warm. And sometimes like if I get up at night like I'm hot, I'll wake him up. Sorry, but it's hot so I need to get up. It's more of that kind of thing but not like, I mean we talk about it actually more so as a kind of joking kind of thing.

Since my symptoms aren't particularly bad.

KB
Has there been any struggles like any moments he doesn't understand what is going on?

P5
He gets it from like, I don't know if he understands what it actually is like, but I think he gets that this is an uncontrollable thing happening to you like you can't control when you will have a hot flash or whatever your symptom is.

I think he gets. It's sort of annoying and it can make you kinda grumpy. I don't really want to be like having this right now. So it could be irritating but I think he gets that. I just don't think he necessarily gets what it's like to have your hormones doing *inaudible*

KB
What about your self image? Do you think your self image has been altered? Your identity? What you think about yourself?

P5
Nope. I don't think so. I don't think it's really impacted me positively or negatively.

KB
As far as you not having children, does it affect your relationship with not having children? Menopause you can no longer have children. Did you feel anything when that happened or was that something you were always comfortable with?

P5
Yeah, it was my choice not to have children. To some degree, it's like okay well, less things to worry about kind of a thing. So yeah, I didn't feel a change in that it was like it was a final done.

KB
Who do you got to find social or emotional support?

P5
Definitely, my husband from that perspective. And then I have a good group of friends who are very supportive. That if I wanted advice about something, that is who I would go to. Advice or suggestions that is where I would go to.

KP
Is your group of friends, people who already been through menopause already?

P5
Yeah, a couple of my friends have already been through menopause. One of them had to have a hysterectomy. They've kind of been through and then another friend who's around my age is kind of going through it. They've had experiences. Each one has had different symptoms and have done things differently based on their symptoms. So it's a good mix of what people have been taking: so hormones, the over-the-counter stuff, what people find effective.

KB
Have you considered taking hormones yourself?

P5
I don't find it bad enough to warrant that. Unless it were to get a lot worse, I would maybe go that route.

KB
What would it have to take?

P5
I mean it would have to be impacting my day to day abilities to go through life. If I started feeling depressed or more irritable or really unable to sleep because like when I sweat it wakes me up all the time. I don't have like insomnia where I like stay awake all night long. I wake up and then I can go back to sleep so you have to be something like that where it's really impacting, my life and my ability to work, or to be a good partner or friend.

KB
Do you ever talk to your mother about this?

P5
My mom had a hysterectomy when she was like 45, so she didn't go through menopause. She was on hormones and she kind of went through a different version of it, we've never really talked about it.

KB
Do you remember when that was?

P5
I was in my 20s.

KB
What technology or references do you currently use in relation to menopause? We talked a little about how you would google stuff. Do you use any apps or books or websites?

P5
Not really.

KB
Like physical products?

P5
Not really. I suppose just trying to find reputable websites that have information, but that's just about it.

KB
So tell me a little bit about that. Has there been anything you looked up before?

P5
I think I looked up like hot flash stuff. Treatments for hot flashes. Definitely I've like over the counter and prescription type things so I've found good either good.. Usually I'll look at the Mayo Clinic or somebody that's actually affiliated hospital type place versus somebody's personal blog.

KB

What about a discussion board or message thread?

P5
Yeah, I haven't really done that for this.

KB
Have you ever supported another person experiencing menopause?

P5
Definitely my friends that have been through it. I've been there when they were talking about how they felt and issues they were having. I've been there for my friends.

KB
Have you had to provide that many advice?

P5
Not really.

KB
In what areas of your life, do you feel the most and least supported? Where you feel the less support?

P5
I guess if I have to say something, probably work because I don't think there's really any accommodations for women going through menopause in a work environment. Just grin and bear it and you'll get through it kind of a thing. There's really is no-anything they really do. I feel like I get support at home socially so. If I have to come up with something, it'd probably be work. And the most is at home.

KB
If I were about to go through menopause, what advice would you give me?

P5
You could go online or talk to your friends, you hear a lot of horror stories so don't assume the worst. And you should kind of let yourself experience it some to figure out what's the right course of action for you because you're going through it doesn't mean you have to be on hormones, doesn't mean you shouldn't be on hormones. You kind of need to figure it out for yourself and there's lots of different people that can talk to you and there's lots of different options because I have some friends who are very supplement, for-supplements and some friends for hormones.

I'd seen both sides of it and some of them try both. And so, you know, it's kind of like you need to self experiment and not go in with what one person says.

KB
If you could change something about menopause for people who have not yet experienced, what would you change? Like anything?

P5
Maybe. Maybe. That sometimes it's sort of joked about. People may make wisecracks about it. It is actually a medical condition and it is difficult, especially how it's impacting you and everyone is different I think sometimes it's treated a little too lightly.

Like before I was in menopause, I remember, I did this myself, you would be like somewhere and you'd be like "Oh, I think I'm having a hot flash now" and kinda joke about it. But also, i think it's like treated not as with much like respect and recognition that it is a big part of a person's life. And it's a big change.

LV
If you were in a supervisor role, how would treat an employee in menopause?

P5
I used to manage people. I don't manage people any more right now. My management style would have been to just say "hey you know I notice in meeting sometimes, you look a little flushed. If there's anything I can do to support you. You know, it's like I don't know what, you don't need to tell me what's going on. I'm just here like if you need something, let me know. Happy to try and work through things with you" just to show like acknowledge you see a person going through something whatever it is you have to do the same for anybody who was showing like somebody shows up a little vacant. Like hey you know, I kinda tell something is going on, if you need something let me know, if you want to talk about it, I'm here to talk about it. Great.

I would just kinda put it out there but not assume what they're just gonna put out. I'm there if they want to talk about it, and if they don't, that's fine too.

Just what can I do to help you out if needed.

KB
Yes. Is there anything else you'd like to tell us about menopause?

P5
Eh, not really, I mean I think for me the biggest thing that I just from my own personal experience is that it's dramatically different for everyone that I talk to. So there's not one size fits all.

So I imagine you're experiencing that as you're talking to people.

Yeah, there's a lot of different people and you know, it's hard to know what makes it different, and whether it's your body or your mental stage or combination of the two. And I know some people I know who have experienced it earlier, I think. I do think you know the question around like having kids go in line with I can't go back. For me, it wasn't an issue, but I do think that would be an interesting subject. For a lot of women, it would probably be a big deal. A much bigger deal than it is for me.

It's not the same pattern for everyone.

Participant 6

Moderator: Agatha Tutia
Note Taker: Lan Vu

LV
recording at any time us. Yeah, so it's more like kind of like organic conversation about menopause and does feel free to share whatever you want. Yeah,

AT
yeah. So to start us off. Can you just tell us a little bit about yourself like your age where you went to school. What stage of experience, etc cetera

P6
I am 15 years living in Orange County. I am a 42 year old woman. Just turned 42 last Saturday, the 21st. My menopause is actually medically induced I guess you could call it. Initially... I am a cancer patient. I'm a cancer survivor, 10 years, and went through chemotherapy treatments to help manage my cancer and during chemotherapy, I went through menopause, because the treatment affects your ovaries and your hormones and so because of the treatment I went through menopause and was in menopausal stage for approximately a year and went through the typical experience that a menopausal woman goes through when there's a lack of estrogen through the body.

After - and I'll explain more what that means here in a minute - But after I finished treatment and was physically stable and I did a lot of holistic protocols to help my body to heal itself after treatment. And so, about six to eight months after my chemotherapy like my last treatment like my periods came back and my body started to basically normalize itself with the help of nutrition supplements and all that.

Fast forward, because of my previous cancer history and because of my genetics, I carry the cancer gene, the BRCA1 cancer gene.

Because of that gene my risk for gynecologic cancers, ovarian specifically, was tremendously high I was actually more than 75th percentile of getting gynecological cancer. And so the recommendation when I was first diagnosed and throughout my entire 10 years of cancer treatment was for me to have a hysterectomy at age 40. Otherwise my risk factor would be that much higher. So, in my mind, I knew that I needed to make the decision on whether or not I wanted to have the hysterectomy and the recommendation was to have full hysterectomy, not just U hysterectomy where they remove the ovaries.

So when I turned 40 I did a consult with my gynecologic oncologist and decided to move forward with the hysterectomy, even though I didn't have any children and was hoping to have children. So that was one of the most difficult decisions I've ever had to make during this entire journey was to move forward with the hysterectomy so I had my hysterectomy in July. What year was that, 2017. I'm sorry, July 2016.

Then, day 2, after my surgery was when I felt my, I re-experienced my menopause symptoms again. Like I was recovering from surgery and had like my night sweats and hot flashes and all of that. So, and since then I've been experiencing menopausal symptoms since my hysterectomy.

Because of my cancer risk, I cannot take hormone replacement therapy, or hormone replacement at all. I'm not taking any replacement hormones at all. So I try to manage my side effects, or the menopausal symptoms with nutrition and with supplements.

So I would have to say the worst part of being a menopausal woman is for me, insomnia. I have a hard time sleeping and staying asleep. That affects me significantly, like, you know, how productive I am and my energy levels and things like that. Memory.

I'm doing everything that I possibly can right now, to try to help that like by taking my [INAUDIBLE], 5H2P and melatonin and all these different things that I take to help me with insomnia.

I do suffer from hot flashes all day long. I'm always hot. I run hot all the time. I'm sweating all the time. Kinda gross. Everybody knows at my office and I have a fan in my face all the time, I sleep with the fan on. I actually had to put an air conditioning unit in my bedroom and keep it like an icebox so that I'm able to sleep. Changing my sheets all the time. Like everything is sweaty and gross all the time, but now it's part of my normal day to day stuff. I don't really pay that much attention to it anymore.

Night sweats are not that bad anymore. Although I'm hot, I'm not like, like in the past, I would have either like cold sweats or you could see like the entire shape of my body in the sheets in terms of wetness. It's kind of gross. But that's subsided. I still get hot at night, but I'm not like sweaty hot at night.

I never really experienced mood swings. And I had a question about that, I had a concern about mood swings, during my consult for my hysterectomy. I had a question to my- I asked the question to my gynecological oncologist about moods because you know I just didn't want to be a rager. You know, you hear about it all the time. Right. But that was my concern. And when I asked the doctor about that he's quite funny, and like he's like well are you typically like that? And I'm like no, I'm actually pretty mild-tempered, I don't really get mad and, you know, I'm not like that. I'm not an angry person at all. And he said, Well, no, it's really whatever temperament you have, it's really enhanced when you go into menopause. If you're not a temperamental person, he's like I don't anticipate that you're gonna be an angry rager after menopause.

So I'm thankful that he was right. I haven't experienced any of that. Although it's hard for me to determine whether, like I am an emotional person, like everything is like, makes me cry and you know just like... but I don't know if that, I think that's more something that's kind of surfaced since I had cancer and you know things make me more emotional now but I don't think that it's gotten worse or improving. I don't think it's gotten worse since menopause. I am already an emotional person. So.

What else. Insomnia is the worst and second to that are the hot flashes. I change color like you can tell I'm having a hot flash when I'm having it. My chest starts to change color, my face, and even like the way that I sweat. I'm not really like a beads, you know how people have like the beaded sweat on their foreheads and like their upper lip? I never used to sweat like that, like even when I work out, I'm not that kind of sweater. Now I am.

AT
yeah so like, what have you been using to like specifically what products. Have you been using to help you through the hot sweats and night and hot flashes because you kind of mentioned like a fan and like the AC unit, but like just wanna make sure we have everything of like what you're doing

P6
I mean I always have to have the air on somewhere like, that's just like, that helps me the most. I think keeping things super super chilled helps me, even just to sleep better I'm able to sleep better when I have A/C running all night and like the room is freezing cold.

The concern was that my, even... There are natural holistic supplements that basically trick your body into thinking it's estrogen, so there's like black cohosh and some of the other supplements out there that are recommended for menopausal women that still have this similar effect that estrogen would in a woman's body. So I try not to take anything that'll mirror estrogen in my body so that I lessen my risk of recurring cancer. Now I realize not all patients, not all menopausal women have that concern, like I do. So I know that for others there's the supplements like the black cohosh and some of the other thing like St. John's wort, I don't remember them all now, but I know that those do work for some people but that's never been something that I ever wanted to test because I knew that I wanted to maintain my estrogen levels low.

AT
for the consult with your doctor was there a time or I guess when you're conversing did he explained to you like you're going to experience men a pause.

P6
Yes.

AT
And there there's like another time to like what's a chemotherapy like was that discussed as well

P6 (10:08)
Yeah, so, there is this medicine called Lupron that basically put your ovaries to sleep and like protects them when you're going through a chemotherapy treatment or cancer treatment. And that preserves your eggs and you're able to still preserve your reproductive organs during treatment. However, for me, but it takes like a month to prepare your body to take Lupron, which delays your treatment about a month or maybe longer because of your cycle, right, so unfortunately for me, I found out that I had cancer, but it was advanced stage cancer. So I had stage 3, but they didn't know until it was stage four and had already spread elsewhere in my body. And because my mother also had cancer, my sister had cancer, I had a high risk cancer family, I didn't have time for Lupron. The recommendation was for me to move forward with chemotherapy right away, control the cancer and if it had spread, you know, to improve the likelihood of saving myself, I didn't have time for Lupron.

So I moved forward with chemotherapy without the Lupron and that's why I went through menopause. So I know also during those conversations and talking about how I didn't really have an option for Lupron or that wasn't a recommendation then I was also told about, you know, what to expect when you go through chemo, that you know your body may respond and you may stop your periods and you know all these things may happen.

Because cancer, chemotherapy, kills cells, even healthy cells and cells that duplicate and multiply and, you know, so it affects your eggs and everything. So I knew that going into it.

AT (11:58)
All right. So like for both cases, you were well informed prior to. Did you so your main symptoms were what has been like the hot sweats and the - the hot flashes and night sweats and the insomnia right?

P6
Insomnia is the worst, and then hot flashes is the second. The night sweats don't really happen a whole lot anymore.

AT
For the workplace. Can you talk about more because you, you mentioned like you have a fan at work, but how do you feel like you're supported in the workplace. Like, do your coworkers know.

P6
I'm an open book. Everybody knows my story and knows, you know, what's happened and what surgery I had and I tell everybody everything. So I do feel supported in that area, I talk about it sometimes with some people, they know when I'm having hot flashes. Or if, you could tell just by looking at me when I'm having a hot flash, you know people are super cute and they start fanning me off. My boss, for example, has a fan in his office too, so anytime we have a meeting he'll like turn it on for me. Yeah, very sweet.

AT
Yeah, that sounds that sounds. Yeah. Would you, that's awesome and within the home. Do you have a partner.?

P6
I was in a relationship for 17 years, that has ended since. So I had a partner when I went through the first initial menopause, and then was dating during this last time, during my hysterectomy, all of that. So you know in terms of, like, I know that there were, there are symptoms like vaginal dryness, things like that that are a concern for women when they're looking into possibly going into menopause. Like I had to make a decision to. And that hasn't been an issue for me whatsoever, which is surprising, because everybody talks about it and that is not an issue for me at all. Like I don't experience any kind of vaginal dryness, pain, or anything like that during intercourse at all.

AT

That's like super nice

P6
It is, yeah, because that's unheard of.

AT
Yeah that's definitely something that women are very aware of entering MP.

P6
In fact, I haven't even really noticed a difference in my libido. Like I think it's still [IN-AUDIBLE]. I mean, I don't know if it's just because I'm always like, I'm not like crazy highly sex[?], but I'm not, that's just part of being a woman. I don't shy away from it.

AT
Yeah, yeah. So for with your self image like do you think that you've changed like how like you've matured, or if you like. Were there any like personal struggles with like how you looked in the world because sometimes with just in society today like menopause typically is associated with aging and I know like you experience menopause and like a very like like not the not like the normal way so I how do you try to compare like do you compare that to aging or like do you just not

P6
No I don't, only because I had to do what I had to do to save my life. That's kind of like, you know, pick your battles.

Like because it is due to cancer and because for me aging is a blessing and an honor like now I'm like okay like that that is not everybody gets age and it's a blessing and I'm just lucky to even be alive and be able to age. So I want to age, I want to get turned into this old lady and be around, you know. So for me, I don't necessarily associate menopause with aging and think of aging as a bad thing.

One thing I have noticed, though, that I've gained weight. It does make you gain weight. Or at least in my case and in my best friend, she and I are both cancer survivors and went through the same surgery, same chemo, same everything, so she I both gained basically same amount of weight. I've gained about 15 pounds since my surgery.

But right after my surgery after my surgery I had a pedestrian accident and I have broken a leg and [INAUDIBLE] so I was pretty sedentary for a while, but I think that they both kind of are the reason why I gained the weight. And now I started working out again doing all these things and changed my diet some. So I'm back to my original weight that I was before surgery. I'm kind of curious like you know how much of it has to do with me being sedentary versus it truly being because of MP. I'm not quite sure. I do carry my weight differently, too. So I noticed weight gain specifically like in the lower tummy area below the belly button, like pelvis area. All my weight has gone like there. And I noticed like my thighs as well and I never like I've always had like, thick legs. Everybody's always told me I had volleyball legs, they're like sports legs, but now they're like flabby like. I'm like what the heck man, why are my legs to flabby? It's not like I changed anything.

AT
They're power legs. Yeah. Um, so, like, Are there any other areas in your life that you feel support or you feel like there's no not that much support in your transition.

P6
Because I am a seeker of resources, I haven't noticed the deficit, or that I haven't had enough resource. And it may have to do also with the line of work that I'm in and the kind of person I am anyway, like I'm always out to seek out resources to learn. I'm a learner, like I need to know everything there is to know about everything going on with me.

I don't feel like there was a gap in understanding or information. Mostly because I sought it out, but also because I have the most amazing doctor helping me through this[?].

AT
Right, right.

LV
and then on that know when you were first experience like hot flashes night process or even insomnia. Where did you go to get like more advice on maybe how to ease the symptoms.

P6
Most of it was already in word-of-mouth conversations I've already had. There is a website that my friend directed me to... something like Menopause and Symptoms or something like that. Something sisters. I forget now.

AT
Hysterectomy sisters?

P6
Hystersisters! That was a really good online resource. Other than that I haven't done a lot of online research, like I haven't searched, because I already knew everything. I did talk a lot to my brother, he's a nutritionist, so he helped me a lot as well and told me like which, what to take for insomnia. Now I'm incorporating like keto [INAUDIBLE] diet, so it's helping in many many areas, I'm noticing my sleep is a lot better too. I'm really watching my sugar.

AT
So more of a natural diet?

P6
More of a natural diet, but also a diet where I'm maintaining my sugar level, super duper low, not only for cancer purposes, but also just for insulin gain, weight gain, energy, inflammation, all those things that every person should be worried about. So, now that I've incorporated that diet into my lifestyle, I noticed that I'm more of an even keel. Like I'm just, I'm [INAUDIBLE]. And I'm losing the weight, and I have higher energy, so there's a lot of benefits that come with that kind of lifestyle, too, that diet change.

AT (21:10)

Yeah, just having an overall like good outlook on life in your health is important. Yeah. Yeah. Are there any like recipe books that you look to or like I know you mentioned your brother and like he diets like does any books or apps or references for

P6

You know which app I do follow? Or like the holistic protocols that I do follow. There's this doctor, he's actually [INAUDIBLE] holistic doctor, which I know a lot of people are really iffy on that kind of protocols that anyway. His name is Dr. Berg, he has an online app, videos, recipes, a podcast, recorded audio files, things like that. Downloadable docs that give you information on supplements and recipes and recommendations it's just, he's really good. I watch a lot a lot of his videos.

AT

What makes makes it so appealing?

P6

Because it makes sense for- everything that he talks about for me, like makes sense and things that I've tried that he's recommended have worked for me.

AT

Okay, so,

P6

And because my brother being a nutritionist and my brother recommends him and they pretty much follow the same types of protocols for supplements and like eating habits and things like that, that I trust, you know. Like my trust level is higher.

LV

Yeah, there's like credibility to exactly yeah yes. so if you were if I was going through menopause, or I haven't gone through menopause. Yeah. And you were to give me some advice, what would it

P6 (23: 03)

I think, a couple things. One, having these honest conversations with your doctor but not always expecting your doctor to tell you everything you need to know, but to come with the questions is key.

Also, there's great value in finding that support system, that buddy that has gone through what you've gone through or is going to be going through, or like for me, my best friend through this entire journey, not just menopause but cancer alone was one of the best gifts that i've ever had, because I could talk to her about things that I couldn't talk to anyone else about. And we just kind of commiserate together. It's kind of funny now, you know we talk about our hot flashes and stuff like that, sometimes it's like we're losing our [INAUDIBLE] because we haven't slept well. Just having that one person like holy crap I didn't sleep well last night, I should lay down right now. You know, like things like that to help lighten up lighten your load a bit because you're not in it alone.

LV

not scare me. I think a friend or support system through anything in life like so, any bigger oh yeah, yeah cuz sometimes you just need to

P6

Yeah! And that just lightens your load right there, being able to share it with somebody.

But one thing I do want to share is that, not the MP symptoms themselves, for me like the biggest thing that like hurts my heart the most is the inability to have children, because I wanted them and didn't get to have them. Like my whole 30s were dedicated surviving cancer, so I wasn't able to focus on building my family. So when the time came to make the decision, I had to make the decision or be a walking ticking time bomb and I couldn't do that to my family or to myself, so I made the choice, you know.

So that to me. I think, you know, I had second thoughts, all the way up the night before my surgery where my best friend's like well you don't have to have surgery tomorrow if you don't want to, and I'm like no, I have to do it. If I don't do it now I'm never gonna do it. So I'm just going to go do it. So, you know, just examining, you know, your why, you know, if it's a decision you have to make, or knowing that you know your body is on a clock I think is important.

AT

Yeah,

P6

And I think it's important for women to also understand the risks of delaying having their baby. I don't know that that's talked about enough. I know that more and more older women are having babies and I don't know the data behind how healthy the babies are or the moms are, like, I don't know. Probably more information readily available on that would be helpful, but at an early age, you know, I would have wanted you know that information in my late 20s/30s.

LV

I'm not sure if this is too personal questions so feel free to not answer if you don't want to that when we're researching menopause. A lot of time the notion of motherhood came up and I guess through the whole process with cancer and menopause has your notion of motherhood changed at all.

P6

In terms of how I feel about it? Or like-

LV

Feel about it like things like I guess things that you know now, like you said that you wish you known sooner your 20s or 30s. I guess in regards to motherhood.

P6

Well, I think one like the amount of appreciation I have for moms, because I lost my

mom so young. Like for me, ---- well it's hard to answer like I'm an independent person and I've always been like a planner and I always wanted to make sure that I had my stuff in line and ready. I can stand on my own two feet before I can move forward, make a decision to have a family, like there aren't any accidents in my world in terms of family. Although it could have happened, but thankfully it didn't. Even now I say that, thankfully it didn't, because I wouldn't have been able to, you know, I wouldn't have been ready.

I don't think that my views of motherhood has changed because of what I've gone through. I think that it's enhanced because of what I've gone through. And I kind of wish I would have done things a little bit more differently. I think had I known then in my 20s, like late 20s/30s, early 30s, even before cancer. If I had known before cancer that I would have to make the decision on having the surgery, which caused my menopause, the hysterectomy, then I would have made other choices differently in regards to the relationships that I had and things that I was putting up with and, you know, things that really ultimately impacted my family structure and, you know, just I wouldn't have - long story short, I would have broken up with the person that I was with for seventeen years sooner had I known, you know, because I knew that that wasn't the right person for me and I don't even know how I hung in there that long. Obviously I don't give up on people very easily, but I think that I would have made choices differently that could have affected the ability of me having a family.

LV

it's I think a lot of the choices that we make. We don't really think of it in the present, how we look at back hi site, in a way, and yeah and i re examine but then you know it's kind of like what we take from it and kind of moving forward with that and that's what like just from our conversation. What I appreciate about you openly discussing what you went through. It's not only insightful, but it's also like inspiring, in a way. So yeah, we appreciate that.

AT

Yes, I'm about to cry a little, like it's it's raw it's honest. Yeah.

LV

So yeah, out of our discussions that we have this round of interviews. This has been the most like insightful and like I said, inspiring conversation so like I really, really appreciate. We really appreciate <redacted>.

P6

thank you very much, hopefully this is helpful.

LV

I know it's really great and I think you definitely give us a different perspective, I think a lot of times there's so many different stereotypes about menopausal woman that a lot of people don't realize that is such a multi dimensional phase of a woman's life. and got

P6

And yeah, I think it affects them in such a personal way, like for me, honestly, now, like,

Participant 7

even though I've gone through and I've had like a double mastectomy and reconstruction and I have scars everywhere and they had to use my back muscles and skin to rebuild my breasts, and I have scars on my back, then I had surgery and then an accident... so I've had a lot. I have a lot of scars.

And knowing now that I can't have them and a lot of people, women, associate motherhood, or their ability or even their sexual organs like they relate that back to womanhood. And that's what makes them a woman are their breast and their ovaries and things like that. And for me it's like No, like I still feel like a woman, I still feel incredibly sexy. I still, like, I'm good.

I think it has a lot to do with mindset too and, you know, just empowering yourself and having faith, like I'm a faith, like I have the love of the Lord, and I believe in the Lord. So it's like for me it's like okay, there are a lot more things that make me me beyond my ovaries and beyond my breast, so.

LV
You can see us were snapping right now. On that note, this was really really great and thank ya know. Thanks again for taking your time to speak with us also thank Joe and she's amazing. And I'm glad she works in such a great environment with the people like you.

P6
Thank you. I love her to pieces. I can't wait to work with her even more. She's gonna help me on a project that I'm working with cancer patients so that's exciting.

LV
Now I'm all actually be at long beach in visiting her. So if I see you in June. I would be great.

Moderator: Agatha Tutia
Note Taker: Kelda Baljon

KB
I'm Kelda. I've been the one emailing you.

AT
And I'm Aggie. Nice to meet you.

P7
I don't really know, but you guys are doing a study or...something

KB
Yeah, so basically we're trying to learn more about the menopausal experience.

P7
Yeah.

KB
So I'm gonna take notes and she will tell you everything.

AT
So I'm going to be interviewing you and here is the consent form, it goes over audio recording.

P7
You can do it. You can do whatever you want. So, I can sign.

AT
So, if there are any questions that I ask you and you feel uncomfortable or you want to leave then that is perfectly fine. So we're going to start off with some warm-up questions. Can you tell me your name and age.

P7
My name is <redacted> and I am 54 and 55 on July 3rd.

AT
What is your highest level of education?

P7
I have a Masters in Public Health.

AT
Are you working?

P7
Yes, I am full-time. I am a technical writer. So, I don't know if you're familiar with <inaudible> exercise equipment they make <inaudible>. I make directions <inaudible>.

AT
Do you have a partner?

P7
For 19 years. Good times.

AT
Children?

P7
No. <inaudible> later in life.

AT
So would you describe yourself perimenopause, menopause, or post-menopause?

P7
<inaudible>. Well I haven't had it for one and a half years, but I get hot flashes...so I think it's post.

AT
Yeah...so menopause is 12 months...

P7
Is that...<inaudible>.

AT
No, you're perfect. Can you give me three to four adjectives that describe yourself.

P7
Passionate, resourceful, charitable, and knowledge-seeking

AT
Can you give me a list of what changes you've experienced <inaudible> menopause?

P7
Oh yeah. Weight gain. Moodiness, just mood swings. You know I kind of gotten weaker. You know muscle mass which is why I work out more to just make sure I get my strength. A little bit of forgetfulness, not like Alzheimer's. My friends were like me too, you know that thing and it was like something obvious. I don't have Alzheimer's yet.

AT
So...yeah for weight gain, can you describe how it has impacted your day-to-day life?

P7
Oh yeah...it sucks! It decreases my self-image, my personal self-image. I was never really thin, but I was about 20 lbs lighter than I am now. My clothes fit better. I felt better about how I looked. <inaudible> It's harder to lose weight. <inaudible>. It's just harder.

AT

So what have you been...well I know what you been doing because in your response you said you work out...

P7
I work out. I eat lower carbs. Not like keto, but I try to eat lower carbs. Diet changes. Working out. Those are probably the things that I do.

AT
How did you come up with working out or dieting? What made you want to do those things?

P7
I started thinking oh my god I'm getting old and I better do something with myself. Try to maintain my health...I mean I was always been a nerd and reader, not super out-doorsy but when I see people who aren't very active I don't want to be like that. My cousins are 64, 69 they're <inaudible> and I look up to them as role models.

AT
Yeah...for the mood swings. How do you respond to those?

P7
Oh, I have fights with my husband where I can't describe why I am upset. <inaudible>. He's rationale and ask what are you upset about. I DON'T KNOW. I actually have a counselor or psychiatrist that I can talk to every six or seven weeks because I don't...just someone I can talk to try to handle myself handle myself because it's not Steve's fault <inaudible>. The focus of what we talked about has changed over the years. So yeah... and I also talk to my friends. I also talk to my cousins. So, I have a lot of friends who are going to go through the same thing so we just talk about it.

AT
How has the hot flashes impacted your life?

P7
<inaudible>. They are embarrassing. You get really red, but it's just...at night I lose my sleep because it's so hot and I have to tell my husband to turn the heater off, but it's actually pretty cold to a normal person. <inaudible>. Yesterday, I went to the opera and I tried to dress pretty, it wasn't cotton <inaudible>. It's uncomfortable, but you know what though I don't want to go get drugs for it because I don't want to get cancer from it. I'm just like...I feel like it's not the end of the world <inaudible>.

AT
Has there been any ways that you relieve hot flashes?

P7
<inaudible>Oh, yeah I sleep sometimes with an ice pack on chest or I tell my husband to put ice pack on back. <inaudible>. Someone described it to me once before I had it and it's like a furnace inside of you. You know what I mean. Your body is making you heat so put an ice pack on it. It doesn't bother me.

AT
For the ice pack, I just need ice for my body?

P7
I mean I was just so hot and I couldn't sleep and I'm like I can't sleep. So a lot of times I put an ice pack on my chest, on my back <inaudible>. It works. It helps.

AT
For forgetfulness, it's not too much right? It goes a little bit.

P7
Right it doesn't impair my ability to do work or...I just noticed that it's something that has gone on gradually and I wonder if I need to go to a neurologist because <inaudible>, but I'm like no it is normal.

AT
Is there anything you do to help your memory?

P7
You know what it is? It's more of a word-finding deficit. You can't find words. It's not like I forget where my keys are. It's more like that 'thing' that goes on the stove. Like pan... yeah a pan. <inaudible>. Something stupid like that. It is always something stupid like that.

AT
Has any of these symptoms significantly changed throughout...like you're weight gain has improved since the beginning.

P7
No. It's gotten worse. I hired a dietician so you know help me through it, help me with my diet <inaudible> so, no things are still kind of the same. I mean the moods have gotten better since I recognize that when I am having one. <inaudible>.

AT
and then hot flashes?

P7
They're...they're...sometimes I wonder if they are diet related. Sometimes I eat less carbs I get <inaudible>, but I can't really tell.

AT
So how often would you say you have hot flashes?

P7
10-20 hot flashes a day, closer to 10.

AT
Has they always been <inaudible>?

P7
No they started of slower and they kind of reach the pinnacle I hope. It hasn't gotten worse for a while now, but first I was <inaudible>.

KB
Well we learned a lot!

P7
My mom had a hysterectomy when she was pretty young and she didn't really go through menopause and my sister is adopted so I don't know <inaudible>.

AT
So when you were first experiencing, how did you first know that you were experiencing menopause?

P7
My periods start to be irregular and they always been like clockwork. Super <inaudible> all of a sudden, I'd be like, 'I'm not pregnant!'. You know it started to be more erratic and then it starts to...

AT
Yeah, can you describe more in detail the first few months? Like some of the key things that happen?

P7
I knew <inaudible> that was the thrill of that because like I was <inaudible> it wasn't a lot of hot flashes...yeah it was very gradual, but yeah it was gradual then I started getting hot flashes, but like once a month and it was really hot...it took awhile.

AT
Now that you're like past it...at least for the first few months, is that anything you wish you have known about menopause? Like biologically?

P7
I'm still, I still don't know what the deal is with drugs. There's a woman, oh I got estrogen or estroban for free, and I don't know <inaudible> cancerous, is it just a joke? Something that is not proven? You know I didn't know what the real risk were because <inaudible> really <inaudible>, but the moodiness I wish I was aware of that sooner because my husband and I had a couple of fights and what not. You know and we are pretty compatible and I would just so mad about something stupid, but I know it was tied into that. It came on and <inaudible> I wish I was more aware. Doctor never really talked to me about it. It was like, 'oh, your periods are gone?'. 'If it gets bad then let me know'. Basically, <inaudible>...okay <inaudible>.

AT
What was your doctor...was that the only experience you had with your doctor about menopause? <P7 nods head> Yeah...okay! That sounds wonderful....

P7
Years ago, I read *Our Bodies, Ourselves*. When my mom was going through it and she was getting older at first...my dad was a gynecologist and mom nurse and I actually have an undergraduate degree in occupational therapy, so I worked in hospitals and I understood all of that...but so I try to self educate myself because I'm responsible. My doctor <inaudible>.

AT
So what was your perception of menopause before you began experiencing it. So, did you have any mindset of it?

P7
I just thought...you know that some people get hot flashes and some people get fat. I didn't really think about the moods, mood swings. Yeah I did not.

AT
Why did you have those expectations about the hot flashes and people getting fat?

P7
I had a friend who had a concert at her house and she was fanning herself. I just knew that once you go through menopause <inaudible> it's impossible the mood swings like, 'okay!'.

AT
Had that align with your expectations?

P7
I mean I really feel like...I mean my body is getting weaker. If I don't do something my muscle mass keeps decreasing um and you know it is hard to lose weight...I mean I know I can do it...the moods I didn't know about.

AT
Did you wish you had a different set of expectations?

P7
I wish I known more about the mood swings. I wish I known more before I got it. Plus, a lot of my friends are five or 10 years younger than me, so I was like the first. I had a few friends who are older, but you know <inaudible>. One of my friends was always fanning herself, but I you know I couldn't ask her, 'what's it like?'. I guess I haven't yet.

AT
So going into menopause, what was your attitude? A lit bit different from expectations.

P7
Right...it was like i was like yeah! Periods are going to stop! Didn't know libido would drop, but...

AT

Why were you so excited about the periods?

P7
It's really irritating. I wasn't having kids and I was like <inaudible>.

AT
So what do you think was like the pros and cons of menstruation vs. menopause?

P7
If you don't want kids or anything. Well you didn't have to deal with that every month...you know. So, yeah...I love that part of it...that part I am very happy with. The cramps...

AT
<inaudible>

P7
Honestly, that part was awesome! It helps balance that a lot. So out of all the badness that was pretty awesome.

AT
Yeah, do you think that having certain expectations ahead of time influences your menopausal experience?

P7
I don't know if they say...it could I mean I don't think it can make you have more hot flashes than you have... you know. I think that it might have been better prepared maybe if I had more information. If my expectations...if I have known, you know like moodiness you now. So of those things and maybe I could have addressed quicker. It took awhile to kind of recognize that this was part of it.

AT
And how has your attitude change throughout your experience?

P7
I've adjusted to hot flashes, and I've worked through some of the moodiness issues so I can identify it and you know manage it better.

AT
Yeah, you were like no more periods! So, I guess it was like the think aloud. What were you thinking...you thought process throughout menopause?

P7
I'm losing it <laughter>. Getting old! One of the things that went through my mind was that I was getting old. I'm closer to death. Yeah that is the one thing that went through my mind. And with oldness it is really interesting. My mother has said this when you're getting old you get invisible, right? I know I'm not that old, but you become invisible because you're not young, you're not hip, you're not what marketing is go for...you know it's like politics or like...all of a sudden I'm like <inaudible> like why do these people want this. When I was young...and then my husband and I are like <inaudible>. I mean when

you get old you get stuck in your ways.

AT
Do you know how with aging and menopause, do you associate them together? Separately?

P7
I thought it was just like...there's middle age and there's old age. I honestly like to think that I'm in middle age, but with menopause I was like, 'oh, crap!'. I know I'm not, but it just dawned on me that I'm switching from middle age to old. Like I start feeling like the kids at work are really young and different work ethics, but it's because work is different now. My job...they can lay me off at any point. You know what I mean? Whereas my dad's and mom's job early in their <inaudible>. So with the young people that I work with, they're like, well, there's no expectation of that's, so I'm not going to give to them my blood, sweat, tears job and I am going to do a good job enough. Where I'm like, I'm gonna work 10 hours a day because that's what I was prompted to do.

AT
Alright...taking a step back to the biological, what do you do when you have questions about your symptoms?

P7
I look it up on the internet which is not a good place to do it because you get so much crap. But I will look it up and I have also looked at *Our Bodies, Ourselves*.

AT
Can you describe a time when you had a question about menopause and what you did to find the answer?

P7
Yeah, I'm still not sure like I have a question was, like, 'how long does this hot flashes last?' One of the questions I have and I've looked it up...I've heard they can last 10 years which totally flipped me out. I still don't know if that's true, I don't have an answer. I'm like, 'holy shit, 10 years!' Things like that, 'how long does it last?' Yeah...I did look up word-finding deficits and people with dementia because my mother had dementia. I looked it up to see...okay I don't have dementia...what is the definition of dementia? What is this? Like what is this, you don't even know what it is. It's cup. I forget the name like cup. That's okay, but if I forget what it's used for <inaudible>.

AT
Yeah. How informed do you feel now about menopause?

P7
Not fully. There's still more. I'm not fully...yeah there's still stuff I don't know. There's still stuff I don't know and then they say everyone is different. Well that's... if everyone's experience is different then how can you tell?

AT
Is there anything else you would like to share? Anything that kind of touches on what we

talked about today?

P7
Definitely knocked my libido down which we didn't talk about. I mean it's harder, but it definitely affected that which is interesting. That's something I didn't know about.

KB
Have you found any solutions for it? I don't know if you want to tell us about your sex life, but...

AT
Tell us so we're prepared

P7
No, I mean we actually talked about it and I'm like this is okay and how do we both feel if the romance that's less than it has been. This is what i am going through, you know. Coming to a middle ground where we both felt comfortable. He's a sweet guy, a really good guy.

AT
Has your relationship been the same since?

P7
I mean we argued for awhile. <inaudible> real fights. Not a lot, but everyone has arguments. It was just you know. He said, I don't know how to tell you this but you're acting like a bitch. I mean he didn't called me a bitch, but he basically said you're acting like a bitch. He's really so mild mannered never say that it was kind of a wake up call to me like whoa this is really affecting and I don't want to ruin this relationship and I love him so I need to, you know, figure this out.

AT
Were there any preparation for him?

P7
No.

AT
So he didn't know you were going through menopause?

P7
Well, no, no. Cuz I didn't realize that first either, but I did and then the hot flashes came constantly. Now he's cold because I want everything icy. I don't think he'd had a lot of experience at all.

AT
Do you think if he had known before he could have...

P7
Oh yeah! <inaudible>

AT
I feel like it should have been a wedding gift..hey hey guys here you go...in a couple of years.

P7
He's really sweet, but you know...men don't understand any of this. I think there's a part of me where he's like don't really want to know. You know I don't want to hear about this. But if I have to say <inaudible> too bad you didn't listen.

AT
Do you have any questions?

KB
You were talking a little bit about the like two sides of thinking about menopause like I don't have to think about my periods anymore and thinking about like menopause, potentially, meaning that you're like you're older, do you think there's been any shift between the positive and the negative thoughts like from the beginning to now?

P7
You know what? I've kind of embrace the older. I don't consider myself old, but the older. I kind of embraced it in that...you know what I just live my life more. I don't care anymore. I just do what I want. Not hurtful or anything. You know what I mean...like there's no fear. I just say everything. I notice there's another woman at work who's going through menopause too and we actually we were in a meeting the other day and she was like, 'I have another career-limiting comment today.' I noticed that if people speak their minds...you know the thing I noticed? I noticed this is real was...I started evaluating thinking to myself, how many years do I have left? You know the 18 summers it's the campaign where you have only 18 summers with your kids and then they graduate and move on. I don't know it's one of those commercials.

You know my mom got dementia at 70 and my dad died at 70. So I'm like we're like 15 years, hopefully more and then I started thinking you know what if it's too short to like be friends with high maintenance people who are a pain in the ass and don't have anything. I'm like, 'oh well... she's been my friend forever, but you know what I don't really like her and I started going through kind of reevaluating my friendships, you know, evaluating how I spent my time and it's actually been really good. I make new friends, but I've also weeded out the people that were really high maintenance and didn't have anything. <inaudible>. I'm just saying, you know, just kind of taking more time for the people that are that I really like.

AT
It's not like a physical transition, but a character transition. Like what kind of life do you want to lead?

P7
Yeah...it's like, I'm already thinking about retirement cause I would like to retire early. It's like what do I want...so I started to kind of playing with that. I never would have done that four years ago...so yeah.

AT
Go you, <redacted>!!

KB
Do you think the first times you were experiencing the changes to your body triggering these thoughts? Or you think it's correlating to aging?

P7
You know I think...I would have thought myself as older and so when that started I was like, 'oh, crap!' I know that people can start menopause in their 40s and that very different experience. I was at the right age for...like 50s.

Participant 8

Moderator: Lan Vu
Note Taker: Agatha Tutia

LV
Hi. This is LV and Aggie calling from the University of Washington menopause study.

P8
Hi, how are you.

LV
I'm good. How has your week been?

P8
Busy, but good.

LV
That's good. As long as this is a good busy then.

P8
Yeah, exactly.

LV
Okay, so thank you for submitting your consent form. So I'm going to go over what we're going to ask you to some personal questions about your menopausal experience. Anytime you can ask us to stop the audio recording and if you feel uncomfortable with any of the questions. You don't have to answer. So feel free to tell us like if you want to pass, but we want it to be more of a informal discussion and so I will be kind of moderating the discussion Aggie will chime in and then she'll be taking notes as well on it but um for me to ask his questions as well. It's like a two way conversation.

P8
Great. Great.

LV
All right, to get us started. Let's, Can you tell me your age and your highest level education?

P8
44 I'll be 45 next month. Undergrad, just undergrad, not grad school.

LV
great. Thank you. And what college. Did you go

P8
[INAUDIBLE]

LV
okay still West Coast. Yeah. Are you currently working, and if so, what are you doing.

P8
Yes, I am. So I just did a crazy thing and I worked at McKinsey and Company for 17 years in external communications and just about a month ago I left to go to a medical technology startup. It's crazy, very, very, very different and I'm doing marketing and I'm doing a lot marketing HR pretty much trying to get all of their structure and infrastructure in play along with marketing so.

LV
Oh, wow. Well, congrats on the move, and out of curiosity. How's the culture shifts different

P8
Well you know what this medical technology company is trying- What we do is we bring the hospital to someone's home but you get a whole hospital. If you need to go to the hospital for heart failure or COB. Other things where it can be managed and you can be stable, we get w treat you in your house. So it's a very loving environment, not that McKinsey wasn't. It can be a huge you know consulting firm. I think the difference in culture is because it is so big. There's a lot of bureaucracy and there's a lot of things that the process is very takes time. Like for example, I was talking to the CFO or the CEO. The other day, and I'm like, I don't like the word HR, let's call it employee experience, he's like ok. I remember trying to get our directory changed, it took three months for them to approve adding our short numbers right so we have like internal voice numbers what what do you need it need to prove that like what. a great company and obviously worked for 17 years but it's just going from something that infrastructure and it takes so much level of approval get anything done actually having a very big voice and the possibility to help shape the company and hopefully it will big.

LV
You know I definitely relate to you. And I think that's why I left my previous job, the bureaucracy and now we're going to something. It sounds like you're going to that area as well. More like human centered.

Yeah, and that's what like we hope to do in this study, it's put like menopause, not just like as a medical condition or not even an illness but view it more as like a human centered issue. So yeah, so we're excited this awesome.

P8
Yeah, scary.

LV
Do you have a partner currently and any children.

P8
Yes, I've been married for five years with my husband and we do not have children by choice.

LV
Right, right. Thank you for sharing that. And then for your menopausal experience. Are you currently pre menopausal- perimenopausal or the menopausal stage

P8 (5:34)
I'm in full-blown menopause. Counting the months!

LV
How long has been since you've been full blown menopause?

P8
I'm glad that you guys are doing this and I hope what you're what you're doing does help to, you know, normalize this and make people realize that they're not going crazy. I think I'm pretty young for MP. I don't have a baseline my sister had issues and went through MP very early too when she was 40 and my mom had a hysterectomy in her 20s so she went into medically induced Mp so I don't have anyone to look at my grandma had a kid when he was 42. So we didn't talk about it like I knew I would tease my mom sometimes when she would say she's having a hot flash. I think that's the only symptom that people really like talk about and you know can articulate because it's the clear physical symptom like you really do.

And let me tell you girls. It sucks. you will not be looking forward to this. I mean, I was just it is funny we're talking today because last night I was I couldn't sleep at all. I was so so sweaty. It's horrible.

But there are a ton of other symptoms and they're just not things that I ever even thought about and I didn't attribute them to going through MP because a) I thought I was too young and B, you know, you know, things like forgetting things like I forget things and it's so like cliché but that happens in your life, what is going on like why did I come in this room like that stuff happens. And when you're not really associating that with what is their true real medical thing that's happening to you. Sometimes you think you're weird. like why is this happening and right, you know, am I starting to go into, you know, early onset dementia, like it's a weird feeling and so I decided to do more, you know, I finally went to the doctor I go to my doctor a lot.

That sounds weird, but I do actually go to the doctor when I'm not feeling well and she finally said let's just test you so I've been tested a few times the to see my hormone levels and that's when you know they- So I've been in full menopause since September 2017 and as you guys probably know you know you have to be without a period for a full year then be considered out of it. So I'm just praying that doesn't happen and I don't start to cross over.

LV (7:59)
no, um, it's interesting that you mentioned but hot I mean hot flashes kind of define the menopausal experience. I mentioned there's can be so many different other things as well. So before we jump into like more information about your menopause Can you give us three three to four adjectives that describe yourself

P8
I'm pretty outspoken quite opinionated. I'm also pretty kind I am very empathetic so. And I'm incredibly an extrovert like I'm extremely social and, you know, the whole Myers Briggs really fits me, I would say that. And loud, I'm also loud, talk a lot.

LV

That's great. So going back to your menopausal experience what information. Did you know about menopause before it started

P8

again, not much. I mean, I feel like I read a lot and I do feel like I know my body pretty well I it's like I've always played sports and and I'm a runner still. So, and I do feel like I'm pretty in tune my body, but I didn't really know. Like I said, we didn't talk about it, it's not anything you really learned about in school right unless, right, like you guys are doing, but like my mom never talked about it. Cuz she wasn't experiencing. She was so young when she went through any of her symptoms and you know I talked to my sister when and actually this is a this is an indication of my family, it should be, because every time something does go wrong, like I had ulcers, and my doctor was like. Does your mom have that I'm like I don't know let me call or something and she's like yeah I had that.

If we just talked more about things like this. I think I would have been more prepared. I didn't and I still spend time looking back going, Wow, this makes more sense like now I can see why I might have acted this way in this situation, or I can see you know why I you know there is a minor bit of like depre-, but it's like you know you just feel off like a low grade fever and you can just feel weird and there's no other explanation that then you can look online or at the symptoms and say there other people are feeling this too or, you know, this could be. Since it's not anything. It's not tangible, the hot flashes are tangible, me forgetting where my keys are are not in me, you know, getting snappy with my husband for no reason. And having like a major mood swing for no reason at all. You can't say, you know, oh! Menopause!

When you're in the middle of it you're just like this is real, it's happening. And that doesn't happen to me a lot, I don't like, I don't have the drastic changes a lot, but I can't, I used to get pretty angry for nothing. And I, I've kind of grown out of that. Or maybe I've learned to cope with that but I mean it could be MP but it might not be but I don't know and I don't know any no one I don't know anyone who could say definitively yes that's exactly why you act that way. So again it messes with your head because you know you're trying to not be a dick. But you can't stop yourself sometime and you can't figure out why.

LV (11:38)

Yeah, no, and we hear that a lot as well and then before you started going through menopause. Did you have like what were your perceptions of it before hand if you had any at all

P8

I just really thought I would be a lot older like I think of it when I think of it. I just think I also really look young and I'm pretty immature at times. I don't think and I know everybody says this, but I don't think you ever feel the age you are, I think you alw-. I don't feel like I'm even 45. It's freaking me out. I just think of little like older ladies, like women, you know, and then you see all these women and I know when women get pregnant really late in life. And I know, I realize that there's probably a lot of

medical help with that like IVF, things like that. But I mean, I just don't see me being someone that should be in menopause, though, even when I started to have symptoms like I, for probably three years I'd have sporadic periods. And I used to be like clockwork. I started my first period when I was 12 and I was clockwork never ever ever missed a period and was always 26 days, like always and then it started going away and you know at the time, we knew we didn't want kids, but you know, and I was on the pill and I'm like every month. I'm like, oh my god. Maybe I'm pregnant you know, to the point where I had my husband get a vasectomy, because I didn't, you know, it was really stressful. If you don't particularly, I love children. I just don't want my own and that would have been a horrible thing to be faced with. So, you know,

That's the other thing I mean, just like so that I still did not think, even though I started having weird periods and the hot flashes, I still didn't think I was in MP. It took until last year when I finally went, I think I'm in, I said to my husband. And that's when I started going and getting tested.

LV

I mean you aid that you can have associated menopause with aging. Do you know why you kind of had those expectations or why you perceive menopause with aging

P8 (13:46)

I think it probably had a lot to do with TV, I mean it is not something that's portrayed in younger people like in media or, you know, TV, movies, things like that. I mean not that that's like, you know, the Menopause Show like it's not in any of that, you know. I think my mind just goes it's the older people. And so I was really I was really sad when it was confirmed. I'm like, and I, you know, again, it's kind of facing the fact that I'm getting older, but also thinking wow I'm not that old to be doing this and you know even when I told my mom. She's like, no, you're not in menopause. There's no way you're too young, and I'm like yeah I am so trust me.

Yes, I think that probably had to do with books and movies and TV, no other reason. I don't remember I'm trying to think I really don't remember like having conversations with any women throughout my life and then saying you know menopause, although it's funny, you know, three weeks ago I was -- my company based in Boston so I travel a lot and I was talking to my colleagues and they both like yes and they start telling me all the stuff that they're on and I'm like, oh my god, but they're also older they're in their mid 50s. So these women are still experiencing full, you know, they're probably postmenopausal but they still experiencing these symptoms. So I think that might be the other thing, too, is that now, do i have to do this for 15 years? Like last month I spotted a little bit and I almost started crying because I'm like now I start over, and how long's this going to take?

LV

and then you touched on this briefly. But what was your personal attitude going into menopause.

P8

Again, I don't think I'm as old as I am anyway, so I don't I don't think it. For a moment. You just have like that midlife crisis moment for me at least, I mean it's not some-

thing I dwell on, it's not something I mean I dwell on it when I can't sleep and drown in the sweat but I don't think about it you know a lot, but I do keep it in my head so when something does trigger if I do forget something or you know. And forgetfulness, which for me is hard because I really have a pretty almost photographic memory and so you know when I'm in a meeting and I'm like, what did they just say, like that's that's messing with my life right I mean that's not me forgetting my keys I can always find that, but no potentially, you know, am I now sounding like I don't know what I'm talking about? Do I not sound like I'm smart enough to be in the room with these people, you know that that those kind of thought getting your head. And it's not as if I can be in a meeting and say sorry guys I'm in menopause I you know I'm in MP, that explains it! Nor would I want to use it as an excuse, but it is a real thing. And it really does happen and we really do go through this

LV

Like you said, it affects different parts of your life as well so kind of taking a step back, when and how did you first know that you were experiencing menopause and kind of talk us through those moments and kind of describe the first few months or any stories that you have,

P8

Again, to be completely honest, I didn't, maybe I was in denial but I also have - this is going to come as a shock. Yes. I also have ADHD. So I move really quickly I talk really fast and I'm on meds that would make me sweat. So, so my doctor prescribes another med to try to kind of counterbalance that counteract that. So I think when I initially started going through that, I you know, A) just ignore the fact that it was getting periods or I didn't ignore but I didn't attribute it to, you know, potentially being on my way to MP, but I kind of could excuse the way the other things too. Right, so I could just so I I honestly think when I was probably in that phase for three or four years and then I finally you know hadn't had a period, you know, for a long time at all probably six months and I was feeling weird. I mean, I've gained weight which is not fun and I exercise a lot and I haven't changed my eating habits. So, so I'm trying to figure out, you know what, so you know, that's what I just wanted to know and that's when I started to get the blood tests, just to confirm, but I don't really think I gave it much thought aside from am I pregnant every month. Even though my husband had a vasectomy.

LV

yeah I can just be a variable experience and as you said like it can be sweat can be attributed to different things as well so you can believe not have a clear answer anything like that.

And so going I'm going to go into each of your symptoms and I kind of wrote them down as you were talking so one of those symptoms that you mentioned is having brain fog or forgetfulness. And so I guess what goes on in your mind when you're experiencing forgetfulness whether at home or in the workplace.

P8

Yeah so it's weird, so here's a good example, so last week I was in Boston for work and I was online buying something and I forgot my zip code. I could not for the life of me remember my zip code. And I'm like, what the hell. And I had to you know kind of sit

there for a minute. And again, I don't I didn't think to myself to say this because of menopause, I don't personally do that, but you know, but that's what it is. And I know my zip code. I know my address. Can you imagine like not knowing? And so if it's a weird feeling like one day I forgot how to spell a very simple word, you know, and I'm like what is happening. And so, you know, I'm I kind of have a self deprecating sense of humor and so I'm fine making fun of myself and that's kind of how maybe a coping mech-, I don't know, but that's just what I do, I'm like oh my gosh I'm losing my mind I can't remember how to spell a word!

But you know it is it's, it can be a scary feeling, especially if you know if you do stop and think about it for a minute and you know what if what if it. I mean I can just imagine thinking that it could be something else and kind of spiraling into this. Oh my god. What's wrong with me and all that stuff but you kind of have to laugh it off, but it's not a fun feeling and especially when it like I said if it affects your work. I'm just now at this company for two months and I don't want to, you know, not seem confident but you know it's like take copious notes. I used to not have to do that. Right. I mean, I used to be able to pretty much bank everything that people told me, and now I do have to refer to my notes and that's been quite an adjustment. So you find ways around things right. You just have to figure out how to cope with them.

LV
that you cope by with forgetfulness by taking notes and referring back to, you know, are there else you used to help you remember things

P8
Find my phone app. My husband laughs that we need to have, it has to be even more precise because I know my phone's in the house. We need to actually have it say okay you know you left it in the fridge for something like that so um yeah i mean I do that, I do make lists now. I'm such a not a list person.

I'm again Myers Briggs [inaudible]. I'm not a P I'm not a J. If you know what that means. So like thinking I have to be stuck under structure and things like that. So I don't I used to not like to take [INAUDIBLE] with but now I have to you know it's even simple things like there's another example forgetfulness. I do travel a lot for work and I have to actually make a checklist now of what I'm going to take in terms of clothing, because I kid you not, I've gotten to another city and forgotten pants. I've gotten to another city and having two like not the right pairs of shoes for no reason. I just I get I guess I see a squirrel. I don't know, but I get sidetracked and then I forget to finish

I guess another way that you know. And again, this isn't every day. I'm not going into some crazy, you know, it but just be preventative because you never know when it's going to hit you. The zip code thing really just threw me for a loop. I could not believe it that I. I've lived here a long time

LV
then you said that last night you experienced an episode of hot flashes so can you kind of take us through that and like, how was like what goes on your mind when like last night when you experience a hot flash

P8
Well it's horrible because it for me it's typically at night. Right. I mean, it's usually when I'm sleeping and so you just can't sleep so you're sweating like crazy. You take the covers off, then you're freezing because you're wet, and then it's this horrible cycle that you get in where you can't you can't fix it and you can't sleep and what can you do like my doctor prescribed you probably want to know what the medicine she gave me. I'm on some medicine. They're supposed to help with this, it's an anti-psychotic I think, but it's used off label. Um, gabapentin. Anyway it's it goes to help with hot flashes and it has but last night did not help at all. So yeah it's just a horrible. Like then you just want to get up, because you can't sleep. But then, you know, it also happens you know when it happened in another situation, like during the day and you're like, I'm sorry, sorry I'm sweating on you.

You just don't want to be you know when that happens. And I'm like, you know, now that we're talking about it, I know it was because I was having a real hot flash. I was leading this group of consultants on a Boeing tour and we were on the bus and I literally it was summer I remember but we were in a shuttle taking us to Boeing and I was sweating through my shirt like you could see and I'm just like this is so embarrassing, I'm completely wet and my shirt's thin enough that everyone can see but then you have other coping mechanism. You know, you start wearing patterns, you don't wear solid colors like you don't you make sure you have a jacket or something just so if you do have, you know patterns don't show if you get sweaty through them. You can't wear a light pink shirt, otherwise, you know, you're a mess.

LV
And how often would you describe having either night sweats or hot flashes.

P8 (24:49)
I have the night sweats probably three days a week at least, sometimes more. Hot flashes, during the day it's not as bad. I think that and again I don't know if this is why. I might be making excuses, they think that they can be triggered sometimes by if I'm in a stressful situation. But then again, I don't know, it might just be the anxiety, but it's very similar to the night sweats because it's not just not just like oh my gosh my armpits or my hands are sweating or your whole body. I don't know the last time, when you're not exercising your stomach got sweaty but it's a weird thing.

LV
and then I guess since you first started experience menopausal symptoms in September has the hot flashes night sweats change throughout the for example like their severity or the frequency or anything along those lines.

P8
It's completely random. To be clear, I was officially diagnosed September 2017, I've been experiencing this for like five years.

It's random I wish that that's the only thing that sucks man cuz you can't say oh it's Tuesday, I'm going to have a hot flash tonight like or you know, or I have to go into this client meeting. I'm going to have a hot flash. It could be as innocuous as Oh, I'm gon-

na meet my friend for breakfast and that's when it happens like there's no sense or rhyme or reason at least in my experience.

I don't know I tried to think through it because again the night stuff is horrible and just think did I eat something weird, is my pattern different, am I out of, you know, my normal routine, you know, so just trying to put a finger on why they are triggered or if it is just completely random. I've no idea but I can't figure it out. If you guys get that question answered, please let me know.

LV
you gained weight during menopause similar to the last two symptoms like what goes like what were you thinking when you first noticed like weight gain even though like you haven't changed your exercise routine or your eating habits

P8
Yeah, so for me, I's just thinking, I mean I realize that women. There's no [INAUDIBLE] once they hit and you know bone density, I know those things happening with with this and I've always been really conscious of my weight. So like I said, I run I work almost 8 miles. I run a lot. I also go to like boot camp. I mean, I'm doing all the things that I think I should do to maintain a healthy weight and I'm still not i'm not let's let's be clear. I am in no way overweight. I'm not.

But you know when you pull on the pants that you've been wearing for the last you know five years when they're snug and for me its weight gain around my middle which is even worse, like I wouldn't mind having a bigger butt, that's like in now. But no, no I gain weight it's in my stomach and so you know it's uncomfortable and you know you're trying to think of everything you can do to stop it. You know, I don't I don't have the answer to that yet either. And I also am trying to find balance and not, you know, turn into those running 40 miles a week...

I have to figure out, and I guess the other thing, like, you know, you start to mourn that-you're like okay well this is just my life now like I can't I'm not 30 anymore. I can't just go on a you know power cleanse and you know lose 10 lbs in a week. I mean, you can't. I think this is now where my life is and I'm going to have to come to terms with it and that's okay. I mean, maybe that's the good thing about knowing what it's from and you're really not having any say over it.

I've gained 10 pounds which is like one. I was 127 and I'm almost 140 now. Not giving up the fight, girls!

LV (29:01)
so I know that you have different coping mechanisms for each of the symptoms have you sought out information or like alternatives to kind of alleviate any of these

P8
Yeah so I do some exploring. I've talked to quite a few people, not quite a few, but like you guys found me from that Facebook MP page, I joined it. It's kind of annoying. To be honest. Like I haven't gone and looked at it in a while, I don't know, man.

Anyway, there's a lot of good information there. But then there's a lot of weeding through like oh this is me, I'm 56, I'm going through MP. I'm like, I don't need to go through 45,000 people pictures or selfies of themselves to know that we all have this so that's, that's me, it's, it's an annoying site for me, you know.

I've talked to several people, my doctor's tried to talk to me about hormone replacement. I don't want to do that. I don't I don't know if I need it. So you know I've read all the things but I haven't really jumped into anything yet. Maybe I'm just still in denial. I don't think it's as bad as some people have it and I know it's really really terrible for a lot of women I just, I'm not sure I'm quite there yet but I'm open to whatever would make it better. But the hormone replacement thing scares me and so I mean I don't want to do that.

LV (30:29)

Can you explain why like HRT or the hormone treatment scares you, you know,

P8

My mom went on it for a while and isn't it just not- again this is very naive of me I shouldn't say it scares me when I don't really know enough about it, but I've just heard that it can be dangerous. And that was years and years ago and I'm sure it's evolved and gotten better. But, you know, as someone who has to take medicine every day anyway for a ADHD and now this medicine that's supposed to not make me sweat at night. I really don't want this, I would like to not be on 60 pills by the time I'm 60. I don't even know if it's in pill form, I don't know, I've heard there's a patch right, I think I'd have to have much worse symptoms before I would try to go that route.

LV

yeah and i mean you touched on a thing that we found throughout our research with that there is a variety of information and you have to guess yourself whether it's credible or not. So I can definitely see where you're coming from for that. And then for our next set of questions they're kind of more of reflective questions. And so I wanted to ask you.

P8

Before you do, there's one other symptom that's actually a really really really really big one that I should have touched on. Sex drive. It's clearly been - I don't know why - I, you know I haven't been married that long, but I certainly am not, you know, and it could affect my marriage. I mean, we're we're really happy now and he's very understanding, but I just can't sometimes and and so that that has a huge, you know really could affect your marriage if I don't want to have sex ever.

LV

um if you don't mind, sharing more about sex drive do you mean like lower libido or vaginal dryness or a combination of both.

P8

Both.

LV

And then for this. When did you start kind of experience like lower drive and like vaginal dryness,

P8

A couple of years, maybe a year, it hasn't been a really long time. But it's noticeable like it's not just I ate a huge meal I don't want to have you know it's not like that. It's this almost, I can't and and it takes. Yeah, it's definitely um, And I full on 100% attribute that to MP. 100%

LV

do you do anything to kind of like relieve the symptoms in a way for example lubrication or anything along those lines

P8

This is funny, my doctor was talking me through all that and, answer to your question, yes. But my doctor is a wonderful woman and she's like there's something you can use and some people really like to use coconut oil because it tastes good and I'm like wait, what? How'd you know? Like that's a whole other part of sex. But yes, we do use that, and we have to, I couldn't otherwise, it's that painful for me. And it never used to be, so that's a big one.

LV

thanks for sharing that, honestly we want an honest conversation that's really you brought it up because so many different parts of our lives and I and reproductive health and section of the taboo topic. It should be more widely discuss yeah

P8

It's hard probably for a lot of men and I think probably my husband's come around, but you know they don't get it. It's not again. You can't you don't understand it. People start thinking or you know they're not attracted to me anymore or saying, you know, maybe they want to be with someone and like the insecurity it causes in relationships can really be you know it can be really terrible and yeah so I mean if you don't have a really great strong open communication policy and if your partner's not really understanding, you know what if they thought you were lying. I mean, that's if that were the case, you're in a terrible relationship and you should get divorced anyway, but I could see someone you know initially thinking it's just insecurity but it's [INAUDIBLE] relationship and that's never good.

LV

Yeah, no, it definitely changes relationship dynamics and we're really glad that you brought that up till yep I don't think that's partly. we're both okay

There's this amazing woman. I am just like obsessed with her. She's in her 70s and she like was the first one to talk about at the workshop.

And so going into kind of the more reflective portion of our interview did the reality of a pause align with your expectations.

P8

Yeah, so I came in with very low expectations so no they don't align with my expectations. I did not think that this would happen to me, which is ridiculous because it happens to everyone you know every woman. Why I would have some hall pass, I don't know, but it's not something that I thought about that much.

So along your reflective lines. I really do wish I would have come in, especially in this you know first year or so being able to look at it and saying, you know what, this is probably what this is, I can get help I can get some definitive answers I can you know spend more time figuring out systems, I can put the coping mechanisms in place that I think I'm going to need to use and start doing that early rather than just thinking I'm going absolutely crazy but because nobody talks about it and no one.. And even like people are just like I told one of my good friends who she's almost 50 and she's not in MP at all. And she's my best friend and I'm like Lisa I'm in menopause. And she's like, No, you're not. I'm like, Yes, I am, and she's like No you're not.

And I'm like okay now you're just adding to my paranoia, you know, and so I said look, I went and I had testing. I have I can show you my hormone levels. I know that those tests can be skewed a bit based on when you get a test, but I had more than one done and I'm off the charts in menopause according to them, plus the other symptoms. So anyway, you know why women, you know.

(37:32)

[INAUDIBLE], she's lovely. But she's like, No, you're not. Because in her mind I bet she doesn't want to think about her going into it. You know, if we just talked about all of this more and that's my reflection and I wish I would have, you know, would have been armed with more information and been able to immediately say, you know oh this is what's happening. This is where it's going, this is your time, you know, with any other illness or anything like if you're going to get the flu, you're like I'm getting the flu. And you know exactly what that is. Because you either had it or people talk about it or you're seeing the symptoms or things like that.

Just having a better understanding of what I was about to go through would have been immensely helpful and so yeah.

LV

Have your attitudes or menopause change throughout the experience, who I know you confirm that you're in menopause September 2017 and you been experience often on for like five years has How has your attitude changed throughout the whole entire experience so far

P8

I'm not as hard on myself. So I think that I wish that more people would go through the testing because, you know, and again, it can be as controversial as people want to say but for me I like being able to look at something and saying yes this is now what, you know, I'm not as hard on myself anymore since September, like when I do forget something I can laugh at it more and and like the zip code thing, it did freak me out. And I'm like, holy shit this was the funniest thing and I'm like what if I get lost, I'm going to have to pin my address on the inside of my shirt, you know, those sorts of

things.

So I just I'm much more forgiving of myself and I also feel like when I feel like I'm going to snap like if my husband doesn't put a dish in the dishwasher for the 50,000th time I can sense that it's gonna happen. And then I just have to continuously remind me to not you know get moody and not get snappy angry for things that don't matter. So I think maybe that is the whole divine intervention, if you believe in that sort of thing, that you know you do sort of soften your, at least for me, I've softened my attitude. I've always been extremely hard on myself. I'm very type A, I'm very- I'm a perfectionist. So I don't know I just kinda let things go, because now things aren't in my control anymore, I used to be able to control everything in my life. Like especially like the waking thing. I can always cont-, it doesn't seem like I can right now and maybe I will never be able to again. But I am you know not as hard on myself because of, you know, because of menopause because I know that there's something happening inside me that I can't help. And so I need to work with it. I need to work with the MP, I need to not fight it anymore, I need to embrace it. I need to, like, cover it in a little blanket, and try to work my way through, but I think that's the real thing is I'm just not as tough on myself anymore and I need to I just try to wait for the next symptom. What's next?

LV
I mean your perception of menopause towards the in the beginning when you initially started kind of focuses on aging, but now since having experienced menopause. What is your perception of the context, like in the broader context of life

P8
Yeah, I mean it still goes back to aging. It is another chapter. I know I'm not old, 45 is not old. I tease my mom all the time that she needs to prepare to live to 105 because we come from cornbread stock that live a long time despite health and eating habits.

So I know I'm gonna live a long time, but it also, you know, this is a strange one for me and I like I said, we did make choice, but now knowing that I can't, like if I wanted to. It is a change of your li-. I'm changing I'm going into that next chapter, you know, I don't know, that's kind of how I see it now I feel like I wish there was more, like we said, and I feel really bad for people who are go into it in their 30s like I can't.

Again, it is what it is. There's nothing we can do about it, there's band-aids we can put on symptoms. And I hope that, you know, those continue to evolve and get better and women actually use them. And me too.

But there's nothing there's nothing we can do. I mean, I wish to God, I could put a spell and make men have it. Even for a day you know, I mean, like the pharmaceutical industry would change because they would focus on that like nobody's business, but you know.

LV
No our body goes through so much though. Yeah, I can definitely relate to that. I know you touched on, you know, did the reality menopause align with your expectation how you wish you had like you were more informed about it before all began. So looking

back on your experience now how informed the Phil about the menopause expands

P8
I feel like I've self educated myself, you know, I guess that's redundant. I've educated myself about it and I feel like I'm armed a bit more.

I think that you can get into the vortex too. Like you can Web MD the hell out of yourself and then you turn into, you know, this hypochondriac, so I don't spend a lot of time, but when something unusual does happen to me. Like I said, I do know my body very well. I just do and so you know if I have a rough week running like that happens too for me like I run a lot and I run fast. And then there can be weeks where I cannot and, you know, the first two days when that happens I think, ok, that's it, my running days are over. I apparently lost all lung strength and leg strength and you know when things happen like that. I immediately do run and try to be like could this be and that's the first thing I do is see if there's some weird, random symptom that I'm experiencing, but then you know, it comes right back and I'm fine. So I don't know but I do look through the lens of everything that could happen to me, could you know or is happening, could be housed or you know couched in menopause and I do look through that lens when I'm thinking of the things that happen to me in my mind and my body

LV
yeah you in a way reframe your experience through the lens of menopause and so for our kind of before we go into conclusion question I kind of want to see if any are diligent note taker has any questions for that because I know we went through a lot. I want to make sure that we got everything yeah I'm curious if you could talk a bit about

AGGIE
how you communicate with your husband about menopause.

P8
Yeah. So here's the thing, like I also don't like to make excuses. You know like I don't want to be that person like oh, it's because I'm in menopause. So, you know, I try to just remind him and actually ask for his help, you know, if I am being a certain way, because sometimes you don't see it, you're in the moment and you know if I'm being particularly crabby for no reason. We're very close and we're very happy. So if I'm snappy and stuff, I want him to call me out and I've asked him to do that, so I can check myself, right, to say okay let's rebalance.

And you know the sex part is hard, I feel bad for him, you know. It's even the libido thing that's probably the hardest and I get that. And he's very patient and kind. C'mon, he's a guy. And he's seven years younger than me. You know.

It's hard for him, so, it's hard to talk to him about, because I don't have an answer, like I don't know why, I don't know why, I can't say why, and so there's no conversation starter there. It's just I'm sorry, I can't, this is how I feel. It's almost sometime repulsive, which is so sad, because there's no reason for that to be that way. So that's the hardest part of things, but the other stuff, you know, my husband is the funniest person I know. So I mean like, falling down crack up funny and so, he can turn anything into, you know, making me laugh. And I don't know. To be honest, I think it would be, I

could see someone who didn't have good support or who was alone, you know, kind of getting into somewhat of a depression and you know you do need someone to talk to you and I do try to, you know, probably. As we talked on the phone forever, I talk a lot. As you can tell, you know, I probably over-explain, you know, he's probably like, Okay, too much information. I'm good.

I try to keep him in the loop of how I'm feeling and what's happening in that moment, I think that, like I was saying about the whole night sweats when I was trying to, when I try to over-analyze and think, Oh, did I eat something weird and I mean, I do that too with mood and things. I'm like, what happened and you know honestly exercise is a huge, is a great thing. I mean, we all know the benefits of exercise. It's a great thing, it's a clearing of your head, it has a meditation aspect of it for me, running. I think I probably, he'd probably leave me if I didn't have that. Because I think I would just be so crazy [INAUDIBLE].

So you know he'll remind me to run or say have you done this today, you know, we just have to stay in, you know, constant communication, but you know there's days where I just want to cry and I do cry and you know him being a guy wants to fix everything and wants to make it better. And there's nothing he can do. And it's hard for him to think that there's nothing he can do to fix it, there's not, there's nothing he can do. And that's okay. And that's the thing that guys need to also learn. I'm sure you guys have experienced, you know, we don't always need fixing. We just need to get through feeling how we feel in that moment and then we'll be fine. Just let me cry. If it makes him feel better. I put on it a sad movie, so he thinks that's what I'm crying about but it has nothing to do with that and I'm not even really watching the movie but, you know, anything to make everyone feel better and more comfortable.

LV
and a <redacted> we enjoy over sharing, so don't worry about that. And then you briefly touched on this. I'm just curious if you had unlimited money and resources in the world. What would he create to improve them and have has hooks.

P8
I think I touched on it, I think if guys experienced any of this, there'd be a ton more research. I think more than anything that the human experience is so important and I really do feel like, you know, the first time I went to that message board on Facebook, even though drives me crazy now but when I first went, I'm like, holy shit I am not alone in this. And I think that educating people and not having it be such a taboo thing that's what I would want to do because, again, we can't, unless the pharmaceutical company does this, you know, huge push and tries to create drugs that can make all of this go away, we're all going to go through it and we all have to figure it out and we all have to be as mentally prepared as you can be. So talking to younger people about it and getting people... and that's just girls, guys too, like I don't think Charlie even knew menopause was before this whole thing started. I mean his mom, I'm sure he knew that things got different, but women don't, especially the older generation, women don't talk about. If she was having a bad day, she wouldn't have said you know what's happening to me. No, you have kids to raise, you're doing, you're working, you're just trying to get through your day, you're not going to stop and pause and take your, you

know, 12 year old son, to the side and say, let me tell you why this was happening, let me tell you how I'm feeling. And at that age, they're not going to care anyway. But if we start having a conversation so that people can know what's going on and actually be able to mentally associate you know what is coming. If I had all the money in the world. I would do that.

I would also probably get a summer house in Alaska where it's cold, and not be so hot. It is good, though, because guys always say that girls, you know, like the heat too high, and I'm the opposite. My husband's like 65 degrees, my God, and I'm like I don't care, put on a onesie, I'm not turning the heat up. I'm going to sleep through the night, so you need to suck it up.

But yeah, I mean, I don't think there's anything I could do it. Regardless of the amount of money, so you know, I think I said earlier that I am empathetic. I don't want other people to feel like they're losing their minds and that's what I think that should be done and hopefully what you guys are doing with this study will help. I mean, you're not doing it for no reason.

AGGIE
yeah I have a follow up question in terms of so like again you have a limited money and resources, what would you create to improve YOUR experience.

P8
Yeah, I don't I don't think money would do anything. Buy air conditioners. I mean, you know, clearly, that's my biggest symptom is or, you know, I could get a handler. I could get an entourage and they could carry on my stuff for me.

I don't think that money is the answer. I think it's all in your head. I think that, you know, getting in the right headspace and I don't think money can help with that. I don't see there being an answer. And so I think getting through it knowing it's gonna happen. And, you know, turning the boat right into the wave, like that's what you gotta do.

AGGIE
Okay, let me reframe the question just a little bit. So you have a magic wand. Okay, so this is like money without like it's like you have your iron man like you're super smart like you're you have like all this tech you're you're in the startup world like what would you create to make you like a cooler superhero of menopause, or like what would like make your life better with technology or like that's not available right now

P8
I don't know I mean I think I think for me, I just like to know I like to...

I like concrete evidence I would like if there was some technology I could create, it would be something that would tell me what I'm feeling, you know, your hormones are surging or they're dipping. Like this is why it's happening, because again, when you're in the moment you don't know and it could just be... you could say well I'm just pissed off today, well no, maybe it has something to do with this.

For me at least, I would want to be able to see that. I would love to be able to show my

husband, This is why I don't feel like having sex this week. Yeah, girls [INAUDIBLE].

You know saying like, Look, this is what's happening inside of my body. I like tangible things and I would like to be able to attribute it to something. I mean, you know, it's like the whole thing when people were talking about mental illness and they say well you know if you broke your leg, you go to the doctor. It should be clear you broke your leg, but you know when you have issues going on in your head nobody can see it, so they don't really believe it. That's how it feels to me.

Like last night when I was sleeping. But what if it's another medical condition, like now am I just continue to go through thinking it's menopause and then one day find out I have abnormal sweat glands syndrome. I don't know but you know just having some sort of way to figure it out and know what's going on versus trying to square everything in your own head. I don't know if that's the answer you're looking for, but that's the only thing I can think to do.

LV (54:20)
I mean it's interesting how you mentioned like this realization of the internal body because I mean too soon part body litters tease it's limited in the sense that, like you said, we only can look at the physical but what about the internal body literally and everything like that. That's your like the answer that you put it's great for your experience and I think it's a theme for a lot of other woman as well so snaps to you.

That's what we do.

Well, I'm happy to do this. It is cathartic to talk about this sort of stuff. It feels good to know other people are trying save the world, one MP page at a time.

AGGIE
a movement, we're writing the men upon well

P8
That's some self protection right there, you're arming yourself with what you're gonna need in 25, hopefully 30 years.

AGGIE
like talking about this with like my other friends. They're like, why, don't you know like this is gonna happen like this could happen, like your vaginas is going to dry up and

P8
Don't forget, it's all about the coconut oil.

AGGIE
you can moisturize your hair and your vagina!

LV
before we let you go, is there anything else you would like to share with us anything

P8

I think we got it all. I think I'm glad I remembered the whole thing libido thing, and again if I get my period in the next six months, I will literally punch through a wall. I'm looking forward to getting to the other side and slowing down on all these symptoms.

LV
definitely. And thank you for being so candid today open. I'll follow up with you via email. Give me your \$15 amazon gift card and oh no no it's like it's part of the process, no worries about that. It's already attached to an email. Yeah, it's not. even though you're on that startup money doesn't hurt. It was ... blog post is we're trying to document for kind of design process and everything we're currently in the research phase right now, but we'll go to the design phase next quarter and then we'll present to the public and August. So listen, everyone that participated more information.

Participant 9

Moderator: Kelda Baljon
Note Taker: Lan Vu

KB
So what's your highest level of education?

P9
PhD

KB
And are you working?

P9
Yeah

KB
And what do you do?

P9
I am.. I'll call it science translation as Washington Sea Grant. Ocean acidification primarily.

KB
Okay well that's cool! Do you have a partner?

P9
Yeah.

KB
Are you married?

P9
Yeah.

KB
And children?

P9
Yeah, 17 and 13.

KB
And can you give me three to four adjectives that describe yourself?

P9
I feel like formerly energetic. Kinda losing my energy, curious. Easily excited about new ideas. shiny is like a big distraction for me. New ideas are like that's what all go for rather than my annual reporting for example.
Yeah physically pretty fit like a bike commuter and probably have some bearing on your study.

KB
What stage of menopause are you in?

P9
I wish I could tell you. I haven't had period in awhile. I kind of lose track, it it's probably been six months. I don't think I've hit the official benchmark. Yeah. And before that they were just like, totally unpredictable usually much more spaced apart than they used to be. But I would never have any idea and I think when I filled out your initial survey, I had not started hormone therapy so some time in the last month during four weeks I started oral estrogen, progesterone because I signed for my annual visit with my gynecologist. And last year she offered these to me and I said, No, I'm fine. And this year it's been like yeah.

KB
Alright we'll talk more about that in a minute, we'll start with before menopause. So what information did you know about menopause before it started.

P9
I'm so surprised how little I knew. you know you read books when you're a teenager about puberty and get all that and there are no- who's that author Judy Blume. There probably but I have not read "Judy Blume" books for menopause to like prepare you for that experience.

So I was really surprised by all the other physical changes that happened, besides just, you know, stopping having your periods and when I was talking to my mom like, "when did you have menopause. You know, how many months did it last. And she's like, "Months?" she's like, "it can be like a decade" I was horrified. That's really bad news.

Hot flashes were kind of funny because I'm thinking that's what they were talking about. Man. It really is powerful and disruptive.

KB
So what do you think you like, what did you know going into it? Like you knew hot flashes were apart of it.

P9
Yeah, that's about it.

KB
What was your kind of overall perception of menopause before experiencing it?

P9
All I was thinking, it'd be nice not to have periods anymore.

KB
Why do you think you expected it just to be periods going away?

P9

Probably because I had not been interested enough to like investigate at all. I've never seen any like social marketing, but that's really not the right term, you know just social education. You know, it's sort of, hush hush as menstruation is in general. I imagine only more so because, you know, the young women who are leading the "let's just stop making this a thing" kind of movement about having periods. Those women aren't going to be having menopause for some time. I really doubt my generation is going to do anything about it.

KB
So what do you think your personal attitude was going into menopause?

P9
I'm pretty blase [unimpressed or indifferent to something because one has experienced or seen it so often before]. I've always not phased by various physical changes, you know, either like medical issues that have come up or the sort of gradual, you know right here, wrinkle and like yeah

I wasn't planning on mitigating it. I was just gonna ride through it. Yeah.

KB
So let's talk about the transition: when and how did you first know that you were first beginning to experience menopause?

P9
Because I have a regular once a year exam with a nurse practitioner at Seattle OBGYN so I've been seeing her for, you know, 15 years or so it always comes up once a year. So she would ask like what are you experiencing and I would certainly tell her, so I knew that, Oh, this must be menopause.

And that's one of the misunderstandings. I thought menopause with the process of, sort of, you know, ending the fertile period or whatever of your life. I didn't know it was officially after- perimenopause was a new term for me once we started discussing it a couple of years ago, but I would say when perimenopause symptoms started. That's...

What was the question?

KB
When did you know?

P9
Oh, yeah. It was simply because my periods were getting super erratic. yeah and just for me personally I very allergic to a lot of environmental antigens and I have to get myself desensitization shots and I realized that it would be really bad for me to give those injections to myself if I was about to have my period. I didn't understand why there is a hormonal basis it turns out, but I would just notice that I would have systemic reactions to shots that normally would only raise a mild welt, and so that is when I really started trying to pay attention to "When am I gonna get my period?" because I couldn't predict it and it seemed like nine times out of 10 I gave myself the shot, but then I got my period then I'd have to take 15 Benadryl or something. Yeah, so that is probably what

caused me to really notice, otherwise I would have just like not paid attention.

KB
When you kind of had that moment of realizing that you're probably starting what what were you feeling?

P9
I was already feeling old. I've been feeling really old for several years. Yes, like, "Oh, this is just one more thing."

KB
Can you kind of describe a little more of those first few months, like, do you have a story, you can share about those first few?

P9
No because it wouldn't. No, I wouldn't recall when that was. I have a pretty sort of bad temporal memory and my story would probably be related to the allergy shots.

KB
Did the other things besides your erratic period start in those first few months.

P9
No, no. Yeah, probably for at least a year, maybe more. It was sort of just like just the periods and the hot flashes really didn't start until- it's probably been somewhere between six months and at the same time, you know, the other symptom that you don't really learn about until you start to realize it's happening to you. And so you learn a bit about it is like vaginal dryness switches. That's as, you know, I wouldn't say disruptive as hot flashes.

KB
Are those your two main symptoms would you say?

P9
Not sure you can blame... yeah emotionally, I don't feel it.

yeah i don't i mean there been times earlier in my life. But I think we're not connected to any perimenopausal symptoms, where I felt much more like on edge and you know some of the other symptoms that people say sometimes happen during menopause. And I hope end when you're officially in menopause. Yeah, those are not really getting to me.

KB
We're going to talk through hot flashes and vaginal dryness a little bit. So for each symptom. So what goes on in your mind when you experience a hot flash?

P9
Like in the beginning or now that I'm used to them or both?

KB

Both

P9
In the beginning it was just sort of, you know, kind of surprising and sort of interesting in the way that being pregnant is interesting, your body sometimes just does what it wants to do and it's on its own agenda. And again beginning I thought well this is weird, but it'll soon be over. But later as I started to settle in and I realized it was kind of becoming a regular part of my life. It was you know what could serve-- What are coping strategies. I'm usually freezing cold when I go to bed 10 months of the year I have a hot water bottle down by my feet and lots of blankets on and so sometime after I've gone to sleep and I'm warm, all of a sudden- I have more layers than most people perhaps so just figuring out how to like sleep so that I can quickly cool off and not really wake up.

I think I sort of had gotten there and my nighttime symptoms are worse in than my daytime. Nighttime hot flashes were appeared more regularly, daytime ones were sort of like one month, I have them and another couple of months, I wouldn't.

Those were harder because usually you're at work or dressed and you really have to get stripped down fast. It happens you know i mean you can't even think I'll set this up because it's only gonna last a minute. Yeah, you're just got to cool off and this jacket has a zipper that gets stuck and by the time, I've gotten it off, I'm fine.

I don't have like sweat through so that is not like apparent to other people that this has happened and you know so far. Thank goodness for that. It's uncomfortable.

The nighttime ones I felt like I was sort of able to deal with. I wasn't really waking up that much. Not fully awake, so I could go back to sleep. So by the time last month that I decided to start the estrogen, progesterone it really was because of the vaginal dryness symptoms in more than the other, but now that I'm sleeping better. I'm like, Oh, I remember when I sleep as much, it's better.

KB
So with sleeping. You went to bed layered you kind of describe what you did in order to make it easier to sleep a little better?

P9
I would just fling all the covers off and not wear flannel pajamas. I'll wear lighter pajamas or, just a T shirt or something like that. Yeah, my husband loves to sleep with the windows up and most of the year. I usually hate that, that's why I have the hot water bottle but that helps

KB
What kind of led you to that strategy was it just word of mouth?

P9
Flinging your clothes off? Instinctively.

And my sister in law said oh yeah I remember one year I bought like 20 tank tops. Yes, like my base layer was always a tank top. I was just prepared to take off everything but

the tank top.

KB
Did you kind of adopt that strategy?

P9
I would like to, I just haven't gotten around to shopping.

KB
For the daytime hot flashes. Is there anything specific you started doing to try to..

P9
No, I mean other than starting the progesterone. No, I do have a couple of tanks. And they really don't-like those can disappear for a couple months and then they'll just come back and be really intense for a while

KB
So you don't know whether to dress for them?

P9
I mean you can always have a tank top on you.

KB
So you kind of described how the symptoms change. So you didn't have that much at the beginning and then you started to have them and now they're getting better again for them?

P9
The hot flashes?

KB
Yes.

P9
They are but that's what the therapy is supposed to do.

KB
That makes sense.

So we can talk about vaginal dryness. What goes on in your mind what that happens?

P9
It's sort of practical like you know my old lube wasn't working, you know, and actually my nurse practitioner, a month ago, she said, try coconut oil so I'm trying out coconut oil.

The other thing that goes through my mind is my husband doesn't really know this is happening you know he's quite adaptable, you know, and he would be concerned and stuff but he wouldn't be aware and so you know on the increasingly rare occasions when you're like actually having sex with your husband. That's not the exact moment you real-

ly want to have a long discussion about vaginal dryness. This isn't as much fun as it used to be. Yeah. And, you know, sometimes I bleed

But, you know, I'll talk to him about it other times.

KB
What do you do to relieve that change? You said coconut oil. Is there anything else?

P9
It helps not to have a three minute encounter. If you warm up a little bit and naturally you are a little more lubricated.

I also have always been kind of prone to yeast infections and I didn't like to try not to resort to the over the counter antifungal stuff if I could. So for quite some time again as the recommendation from my gynecologist making little boric acid capsules, you can get boric acid at the drug store and little dissolvable things, you fill them yourself. And if I am diligent about after sex, getting up and inserting public capsules then things are generally better.

I think the start of the you know the trauma of dryer sex probably just exacerbates the whole situation so like trying to balance pH, which is probably also changing as the hormones change or at least make it whatever the pH for boric acid is. That helps. But that's sort of a hard practice.

KB
So that helps with it?

P9
It helps avoid yeast infection, which already sort of you know compound an already sort of painful situation.

KB
Does this affect your day to day life with your life.

P9
No, he's probably tired of hearing me sounds kind of negative about getting older. Yeah, I'm sure he doesn't want to be married to someone who thinks of themselves as you know spent.

I guess, in that sense, it would make our relationship a little bit less fun and more tired.

But day to day, no, we still do the same things, with picking up the kids, scheduling, that sortof thing.

We've been married for 25 years.

KB
So has the vaginal dryness symptom, has it changed throughout the last period of time that you've been experiencing it?

P9
I would say it's probably gotten worse over the- it's probably been about four years maybe five since my periods started to be less predictable. So yeah, it's definitely gotten worse over that period of time. I didn't really- I don't think I really was noticing it as a compromising situation until about last 18 months.

KB
Do you think your emotional reaction has also changed over the last five years to the vaginal dryness?

P9
I don't think so... Oh, this sucks? No, I think I'm just kind of practical.

I do think there are probably solutions and I'm trying them.

KB
What do you do when you have a question about menopause or the changes in your body?

P9
Online, first. I don't really do like girl talk with my mom. She is still alive. I can mention it to her. She can certainly be sympathetic if I'm having a hot flash when she's around because she lives in the Seattle area. I haven't discussed vaginal dryness with her.

So the probably the internet first and then my OBGYN.

KB
Can you kind of describe a time when you had a question about menopause and what you did to find the answer?

P9
In the past, I had already been on the hormones for therapy for a couple weeks. It was time for me to have my shots. I was just about to do it and then I thought, Wait a minute. I have no idea like what normal,-you know, back when you're in your 20s and 30s- what the normal certain hormone fluctuation is. I should check and see if these hormones that I'm now supplementing are naturally high right before your period because if that's the case, then I'm never safe to have shots. So I looked online and found out that yes in fact both of those hormones peak and then they start to go down and you have your period.

And so then I called Seattle OBGYN and I said, "Hey, you know, I might have this problem, we didn't discuss it when I was in you know how to manage these two treatment regimes. And is it okay for me to like, you know, I only have to do this every 12 weeks. Can I go off the hormones for a week and have a shot and then go back on?"

And they called back pretty quickly and they said you know that's not really. I didn't know how quickly the hormones cleared out of your system. Your take them every 24 hours, but I didn't know. Could I just like create a little safe window by stopping for a

few days and they said that's not really healthy and in truth the supplement- the level that you're on is lower than what your natural hormone level would have been when you were menstruating right and so try it. Have your epi-pen right by it and just see how things go. So I did and it was closer to this systemic reaction. Wasn't so bad. Like if it's confined to the area where I give myself my shots. If it affects my breathing and I start to itch everywhere then that's would be something I would have to work on further, but so far so good.

KB
So kind of reflecting, did the reality of menopause was align with your expectations and what was different?

P9
No.

KB
We kind of covered this question

P9
I was not thinking about it too much. And when I learned that it it was potentially a decades long process was.. disappointed.

KB
Do you wish you had different expectations?

P9
yeah i mean i think it would have been great to have learned about this. I don't think I would have paid any attention you know in junior high/high school when you're having your officially state sanctioned sex ed yes. It would have been like completely irrelevant. Yeah, so I'm not sure what would be...

you know what a good time of life to sort of inject this information into people is when they're pregnant and you're just a sponge for "Oh this is all so cool, look at what my body can do." That would be really good time to include some information on perimenopause and menopause

Increasingly you know in our society, in our demographic where people are having children quite late in life. So they're much closer to perimenopause when they're pregnant for the first time.

So at that point, you're really realizing for the first time that your body can massively change. A lot of it you can't do anything about you will never be the same again. There's no going back to prepartum basically and you're kind of accepting that you're in a good mental space to like look down the road and say "okay I can anticipate this." and this sort of like mentally prepare.

KB
How do you think knowing more before the experience would have helped you?

P9

I didn't decide to try hormone therapy. I said no for like the two previous annual visits to my doctor because I didn't think-again I thought I can just weather this. What made me change my mind was two months ago I read a distilled science article and science news, the publication. It takes peer reviewed articles, but then someone writes short summaries. It's very approachable. I can read physics articles in that magazine physics and I don't know physics.

So I read an article in that about the results from really large study about hormone therapy and the surprising results that they've gotten initially caused to cancel the whole study which was that it led to increased rates of certain I don't remember what that heart disease, maybe cancer bad things. And this article was looking back on that. Several years later and really saying you know the media skewed the story, one way and with more careful assessment of the data which had been done at the time. It just didn't make news was that it really depends on what age you are like the risk was definitely elevated for older women, older than me taking hormone therapy, but for the age group where it was primarily being given to address perimenopause and menopause symptoms, the risk was only slightly elevated and the gains probably outweigh the risks there. So when I'm 65 or 70. I may not want to be on but now it's probably an overall positive until I read that and then I set up my next appointment. I'm going to talk about this.

And so if I had more information much sooner, I would have probably *inaudible* under that article or even the initial study more informed earlier and maybe been okay with going on hormone therapy earlier. That was in the article, and because they include sort of anecdotal evidence. A lot of women said, "Oh, now that I get this. I'm trying this. I should have done it earlier."

I'm kind of a science-y person. I have access to that information. I'm not intimidated by you know even even pure, you know, the original format let alone distilled for the public format. I think a lot of women don't read science news, they read whatever the newspaper

KB

We talk to a lot of yeah

inaudible

P9

So that would be really something to address. This is true of everything, the media, almost everything. Right, right. So that's not a problem you're gonna fix. Something to really help people be more objective, to be able to make objective decisions would be great.

KB

Your attitudes on menopause changed. So you kinda said in the beginning, you had a blase attitude towards those types of things, have those attitudes changed.

P9

Yeah, I think this one is more like I'm willing to include it in the category of health and

medical issues that I can imagine. Like wrinkles, grey hair, not managing that, but the list goes on and on. It seems like every couple months. There's a new thing related to aging in general that I like oh great, now I gotta do this.

Probably taking, watching my calcium, it's gonna be the next thing I really don't want to add another one. Resize I'm not very convinced about the best way to deliver calcium. If I were to try and drink enough dairy..*inaudible* I can't do that. Supplements aren't the best way to deliver a lot of necessary things your body's used to. So I haven't really spent the time to figure out what's a good solution yet.

KB

Would you say your attitudes on menopause have become more positive or negative or neither?

P9

Slightly positive, you know, they're not negative anymore. I'm past denial. I'm in acceptance. I'm in acceptance. Slightly positive because I feel like I'm taking steps and I'm hoping that they will address the issues that bother me. It's definitely easy to talk about with my peer group. There's plenty of women who are about the same stage. Everybody wants to, "Oh yeah, that happens to me too." Things like this. And I saw this taped to a telephone pole, oh yeah, this is me, I can respond to it. Feeling more proactive definitely helps things.

KB

How informed do you feel about menopause now?

P9

Better. I haven't read a book on it, unlikely to. I'm sure there are other symptoms. Either I'm not going to experience or haven't yet and I'm not feretting those out right now. I'm still sort of like I'll deal with it when it comes.

KB

Final question: if you had a magic wand, what would you create to improve the menopausal experience?

P9

I would make it shorter.

KB

Shorter?

P9

Yeah, definitely. like one to two years. And I say that, not knowing what is on the other end. I mean, maybe like the new status quo on the other end will be even more whatever and unpleasant. And I'll look back and I'll say, gee, that wasn't so bad while I was going through menopause, perimenopause.

So what am I in for?

KB

Uh, I don't know.

LV

Well, what I learned for in my research is so variable. Some women have it for a few years another one for decades like you mentioned there's no like typical one experience.

KB

That's been our big thing lately, everyone experiences it so differently. How can we manage that?

P9

I'm sure there probably is already like- a people of New York style blog out there were women just like write up their individual experiences and you can just go read as many as you want until you're saturated.

But I think that would be useful.

And hey, this is very telling. This would be the symptom that I forgot to tell you about and that's the forgetfulness. That could be tied to lots of things, but I have heard that post-menopausal women also have- they can't just remember things. It starts with pregnancy. Also, and it's called mom brain and you never really get your brain back and part of that is that you're just more distracted by people who will not sit patiently and wait until you're ready to hear them. I went to a talk recently on campus about the aging brain, woman from the psychology department, medical researcher. Everything, not necessarily driven by menopause was - actually, it starts to decline much earlier. They're already on the downhill slope. You may have noticed. At around 50 and even the slope increases so that sucks.

Yeah, but you know there are ways to manage that one is to never be away your iCal. Find coping strategies and also just sort of let people around you know like you're like, yep. This is the new me I know I just said snake when I meant elephant. I mean you know what I was talking about.

LV

If we were perimenopausal what would you say?

P9

Don't fight it, don't resent it. It's like death, you know, you're not going to avoid it.

I've heard. I've never myself said things like this, but I've heard other women who are, you know, on the far side of it and saying, I embrace my crone-ness. At the time when I was much younger, I was like, "Who would want to?"

There are positives to every stage of your life. So, you know, if you can look at it as a sign that you're- that's new, interesting stuff. Great.

LV

Explains our program and topic.

P9

Yeah, it's interesting because the baby boomers who tend to drive a lot of social thought they're way past this and they didn't make this one one of their priorities.

forgot something-pause

Oh, well, you know, it'd be interesting to look like you know biologically speaking a woman is as valuable as long as she's reproductive, right? And that has all kinds of social ramifications. Look at Hollywood actresses, blah, blah, blah. So, you know, you're probably unless you're having medical support, not even having babies. as you approach perimenopause, menopause. So you're probably already like past your valuable, biologically speaking, stage. But I think maybe one of the reasons people will say this about women's health care in general doesn't get nearly the attention that male issues get because you know they're in charge, have been in charge. So this is another layer to that. Not only are we women, and we're not getting- and this issue isn't as important. We're becoming less important women from a lot of perspectives and so it's even less likely to get attention. So again, highlighting the ways in which women become more valuable because menopause could help shift attitudes which raises you know, there's lots of human and animal examples where post reproductive females are super valuable because they've done it. They've seen it, they can help out, they've got the wisdom and the time to be more productive members of society, but nobody makes me feel like that.

KB

I think that's called the grandmother hypothesis, we read about that

LV

You brought up about becoming this invisible as you age and that's something that's been brought up multiple times as well. So there's this social, cultural perspective as well as under Western lense. That's been interesting, too.

P9

Yeah, and you know women are asking to be less visible as sexual objects.

LV

The male gaze

P9

Well, that goes away. You don't really miss that unless it was a filler of your self-esteem. So the flip side, maybe maybe sort of the #metoo that says "hey look at us in a different way" will help benefit old women too.

Thank you so much.

Thanks for sitting outside. I'm sure we're all freezing.

E
Workshop Info

Agenda

Arrivals (1:20 pm - 1:40 pm)

Introductions (1:40 pm - 2:00 pm)

Letter to Your Premenopausal Self (2 pm - 2:10 pm) - Lan

Open Conversation/Focus Group (2:10 pm - 2:55 pm) - Aggie

Break (2:55 - 3:10)

Ideation Activity (3:10 - 3:55) (Kelda)

Closing/Buffer time (Lan)

About Us

The Master of Human-Computer Interaction + Design (MHCI+D) Program

- This is a one-year interdisciplinary program under the Design, Information, Human-Centered Design and Engineering, and Computer Science Schools. We are taught how to use research and engineering methods to influence what we design via today and tomorrow’s technology.

The Team

- Agatha Tutia, Kelda Baljon, and Lan Vu are three Master candidates dedicated to incorporating an empathetic design mindset in our work.

About Our Project

Purpose of Thesis

As part of our program, we must complete a team thesis. Working as a team for 19 weeks, we are expected to interview experts and our target audience, conduct research studies, think of solutions, test out ideas, and finally, present a final design concept of our solution.

Our end goal is not to create a to-market product, but to come up with a design solution that can contribute to further discussion, research, and product development within academia and industry.

Why Menopause?

“We want to support a culture of people who are more informed, comfortable, and empowered during the phases of menopause.”

Initially, we aimed to focus on women empowerment, especially in women’s health. After further research, we decided to pursue menopause because despite it being a phase that all women go through, it is often a underserved topic.

Currently, we are in the research phase of our project and plan to narrow down further into a particular area of menopause that we can solve for. We will begin brainstorming for ideas once our research phase has ended in June. Follow our progress at <https://medium.com/designing-for-menopause>.

Final Presentation

We will be presenting our concept on Thursday, August 16th at the Seattle Central Public Library. Details will be forthcoming.

G Workshop Transcript

4:50

W1

I'm W1, I live downtown and my time is pretty much my own. One thing I like about menopause is less inconvenience and one thing I don't like

For me, it sort of happened suddenly, one doctors checkup. I was still ovulating and the next I was menopausal so that really happened very fast.

5:31

W2

I'm W2, I actually live in --, not a very nice city. What I do during the day, well I'm a Mom, and a interpreter. I just came from work. I just participate <and that was long?> at the high school with the immigrants and refugees, yes with the Seattle Police Department and I - it hit me so fast menopause. I thought it was gradual and I thought it's like the average age is 52 and I'm only 48 and I am shocked and there's nothing I like about it. cuz I wasn't prepared and I did not realize how much it is affecting me so.

6:32

LV

Thank you for sharing.

6:38

W3

I'm W3, and I live in Bellevue. I'm taking some time off and I need to return to work eventually <laughter>. So right now I cycle a lot because it's cycling training season right now and um. Uh, so menopause. So I think I am in the middle of you know where my periods are trickling, and they kind of stopped and then they decided to come back really really really slow rate.

So I what I like and don't like well actually I don't like that. It's not that I don't like. It's just I'm not sure when it's going to come back if it's going to come back. So it's a little bit unpredictable and

then what I like, oh, what I don't like as I feel like my body's changing, it may be related to age or hormones changing. So I'm not as strong or as fit as I used to be and I love to be active, so that that bothers me.

7:46

W4

I'm W4, by day I host a morning news program for public radio station in downtown Everett, and I live in the South Rivervale Creek area

I don't, I'm perimenopausal right now. I don't like anything about it. In the past three and a half years I gained 50 pounds. I have a new medical symptom, I feel like every month. Right now, wearing a halter monitor because I've been having chest pains and heart palpitations, and I was hospitalized. It's just every time you turn. And the worst thing about it is every time you go to the doctor, or the OB GYN they tell you all your tests are normal. So you never really get an answer for anything, you are just kind of left

to suffer through it for however long that process takes. So right now there's absolutely nothing I enjoy about it. I kind of feel lost, like I don't even know who I am these days.

8:45

W5

I'm W5 I I just moved last week to Capitol Hill. I was previously living in Wedgewood. I'm currently taking some time off, but I've done work in transportation, environment energy, like program manager. And I have a lot of similarities to W3 in terms of the light and less of the flow, that's been going on for a few years. Some months I don't have period.

I'm not sure I would say that there's anything I don't like yet because I haven't had any extreme, really extreme, things that I heard about. So I consider myself fortunate thus far.

But I want to learn more about it, and it's great to be with a group of women who talk about something that isn't talked about very much. I'm very grateful to be here.

9:58

W6

I'm W6. I think I'm the <lone dame> (something meaning the oldest lady) of this group. <laughter>. I'll be 70 in December. I was kind of thrown into menopause in 1999. I had a hysterectomy for massive bleeding and I had to have things for some pathological reason I no longer remember the name of but none of my, my parents, my mother, my grandmother, great aunt, my aunts, my sisters, none of us went into menopause normally. Everybody had hysterectomies for one reason or another.

All medical, sound medical reasons but still a hysterectomy so I didn't know at all what to expect. After my surgery, They put me on HRT - hormone replacement therapy - and that, that went on for about six years and then they discovered that there were a lot of problems with those drugs and so they said I should wean myself off from it and it took about six weeks and I was about 10 days from the end of that period when the hot flashes started.

And I had been free of them in 12 years. and they're mostly at night I have never had night sweats. So I didn't have to wake up and change the sheets, like I heard some women do but but it's still generally around three in the morning wakes me up with them. It takes anywhere from two to five minutes to cool off most of the time. So my sleep is probably the biggest impacted problem.

11:49

The good thing for me was always to be through with the mess. I didn't have children. I could have children, and it was like, Oh, why do I have to go through this every month and I had, I had also rather severe PMS that spiked just before ovulation and just before menses. So that was very difficult for me emotionally. They did not take my ovaries when they did my hysterectomy so I still continued to have the PMS fluctuation but that has pretty much gone away now. So I'm kind of done with that.

12:31

So I would say the only thing that I'm still unhappy about are these hot flashes at night and, I don't know, some people said they never go away. Oh, I forgot to mention that I am retired. I used to describe myself as an artist with a day job now I'm an artist without a day job. I try to spend as much time in my studio as I can.

13:03

W7

My name is W7 --, that's a Finnish name. And I live in Everett, South Everett, that's close to you or by the mall, sadly closing, all the places in Everett close.

Let's see my average day, I'm on a LOA - a leave of absence - from <Walden> University online. I'm doing a Masters of Public Health, which I love. I already have a book idea and even found a publisher, through Facebook. I have to say how amazing Facebook is because even through Facebook I found this group, and even through Facebook I am gaining support for menopause through closed groups which I highly recommend.

13:50

So leading into - I can't really say there's anything I don't like about menopause, because I'm trying to use my mind and say you know this is a stage of life and I'm stronger than this and I'll find an answer. Because I've had, I'm a classified a disabled veteran. So I've had to use a lot of hormones over the years, prednisone, to be able to breathe. So I've also had a closed group for that. The reason I say what I say is because I've had to use my mind for a lot of things and overcome so many obstacles that I feel that there's nothing in my way, <the weight of life that will get in> my way that I'll find an answer for this point if I can only be able to think. That means that I have to keep my memory, you know, very intact to avoid Alzheimer's and dementia, because like my grandma had that I don't want that. So that would be like really bad but menopause I feel is just a stage of, you know, I can overcome this. And I know that I have all the confidence in the world that I'm gaining. I don't care that I gained 20 pounds, because I know it's menopause, it's not me. And you know you just find a way to love who you are because you have support and people in your life, you know boyfriends, girlfriends moms, dads, whatever. So, you know, but I'm like all of you. I want to say that I don't like it. I don't like that I can't have children. But you know what, this is a phase and I'm excited to face the next phase of my life. I'm excited as I'm getting older, because I don't want to be a kid again. I don't want to be just born. I'm already becoming somebody better. So I see it as very exciting, but it's also very exciting hearing everybody to say what you're saying. I think I covered what I liked and I don't like, kind of mish-mashed them.

15:29

LV

thank you for sharing. quick introduction of yourself.

15:45

W8

Hmmmm, hahaha. I was in traffic and, you know, let's see. My name is W8 and I would say I started experiencing symptoms when I was about 40 and I'm 50 now, and that was, you know, hot flashes. I went to a naturopathic doctor and tried to get different kinds of estrogen treatment that could help and it was a nightmare. And then it just

stopped and five years of nothing. Oh, it's over. Now it's kind of back again. And I'd say what I don't mind about it now is that less periods, less time, and money spent all the products

and what else about that probably just knowing that that phase of my life is nearing the close. Awesome. Totally over it.

The bad side, I would say is, you know, I started, I started my period I was 11 and from 11 to 15 I had severe cramping, to the point where I was put on birth control at 14 and I still had severe cramping, I was out of school a lot because it was I had tons of X rays done. They thought something was wrong. So yeah, guess what I get the end the book end which is it's happening all over again so extreme cramping extreme, but no blood, like, okay, fine. You know, I'd rather have blood.

But anyway. Luckily, medical marijuana is now legal and so I've actually found something that can go directly to the source because there's been so many studies done on cannabis and treating different types of symptoms for cramping so yay so about once every six months, I just have to check out and have the tincture that helps for the cramps. So, so that's probably the worst part. I have children. So I've benefited from the time that I didn't have my cycle. I guess that's it.

Focus Group Transcript:

Aggie: Now that we all read each other's letter and got a sense of where each person is coming from. Is there anything else you wish you had known before the symptoms began? Now that you heard from other people and maybe some things popped up.

W1

It's validating to hear that other people didn't have family members to talk to. It wasn't a divider for my mother and myself. She had cervical cancer and a hysterectomy at 27. So, when I was 13, that would drive me up the wall faster than when she said "ARE YOU ON YOUR PERIOD?!". Not a positive interaction.

Aggie: Right...I think a lot of people mentioned the relationship with their mother and how that info wasn't passed on. For future mother and daughter relationships. What other ways can this be improved. Let's brainstorm.

W6

I would hope that's improve. I know that my nieces and great nieces more communitive than my mother was with us. I'm the oldest of 8 children, the first 5 and last one was a girl, and this was not talked about. This was not discussed and the same kind of thing, "Oh! It sounds like you're on your period!"

I can imagine because scientific studies show that women in the same household, prisons, convents, other situations – their cycles tend to match up after a while. I probably never realized this in boarding school/high school, but can you imagine 100 girls having their periods at the same time every month? Well...the nuns were probably having theirs at the same time too. *laughter* Maddening, but no openly talks about it. I hope now that younger women, younger mothers will bring this up. I, myself kinda of develop the

more spiritual aspects of it, but even if you don't go in that direction just to understand that this is all part of being a female.

With my kids we talked about it openly here are the facts and here's all the other stuff. They don't like it when I talk about it, but I don't care. Plain and simple. Because that's what my mother did. She gave the facts textbooks and everything else was a little more difficult to get out of her, but so far it's going well. I got a 14 year old and a 12 year old.

W4

My mom didn't talk about it, but now I ask her questions she is an open book. When I was having symptoms my GYN said...well you're so young, but my mom was 35 so it was really not when you look at family history. Same - I have two 16 years old girls and we are cycling with each other about one week apart. So we have those open conversations especially with my husband, for him to understand what my symptoms are and how they impact our marriage, and it's not just me saying I don't wanna have sex I just have no desire to do it. I'm tired. He needs to know as well. It's important to have these open conversations because it's not a shameful thing

W2

I think it's a culture thing, because even among female friends and I remember one year we got a call from my younger sister that our mom who lives in ca was dying. No one knows what was going on. They said she's bleeding and it turns out that the doc put her on HRT. Because she lacks English and she didn't understand that was one of the side effects. She was bleeding out of the blue after not having a period. She thought she was dying and went to the ER. My sis and I started bawling on that phone that mom is dying. Mom is in the ER and my sister said she is bleeding and dying. And that was it never discussed again. She went home. That's it. I'm fine and that's was it.

For me going through this right now I have no one to talk to. Because we don't talk about this in conversation and I feel like I'm going crazy. I have no one to talk to other than online like learning on my own. Did approach primary health care provider and she said she can put me on HRT but I already approach health in a holistic way - I don't want to take a unnatural thing I just want to take herbs or something. I will also do a better job.

I have a daughter who is also sixteen and I will do a better job of discussing these things. I remember taking her to classes and learning about periods together to have an honest discussion and when the time comes she won't be alone like I am. I approach my friends and all they say is its' very crazy and that's it - end of conversation. It's a cultural thing and no one talks about it. I approach them and it's not something they want to share so I have to back off. Am I the only one that is going crazy?

40:45

W4

I think men are often grossed out by periods and all those things and it's a woman's problem so they don't want to deal with it. We're kind of embarrassed to talk about it with them, especially in the workplace. Right. So there are men who don't even understand what we women are going through. You know, all the emotional things and the cramps and all those kinds of things. And yeah, so I think that's a huge part of it. And

then I think they're kind of dismissive to like well you know some people say well you know Eve gave Adam just totally write it off as like something like whatever you know and it's not whenever like.

W6

I think with my husband. It's caused him to come out about how he's changing. We're the same age. So we're all aging, you know, the alternative is what death? And so it's interesting you know and I talked about how my body's changing. Yeah, I noticed there's some and so you know you share a story. Someone tend to talk about themselves. And so that's what ends up happening. And so I do think there's a sense of empathy there and more aging which no menopause is a phase of aging. So there you know some correlation that's been helpful. And then we can spend on that for a little while and then come to some kind of all right we're both there. It's fine.

This is kind of interesting because that's the other part of this for me is hot flashes and I have been experiencing that vaginal dryness for the last 15 years and this is a is a difficult topic because when we were younger. We were very sexually active and then I think through a combination of my husband works very long hours and travels a lot. There's a lot of timed stress in our life. And so it's got down to. Okay. It's Saturday morning we have 15 minutes, except that we don't go anymore it takes more time. I'm be very open here but he's having some difficulty himself with a little bit of erectile dysfunction could be blood pressure medication or something.

But of course, does he go to the doctor and find out...NO. So I kind of keep prodding I kept pulling back and I experiment with different lubricants and trying to figure out what we're and of course I'll tell you now. It all takes preparation and time. You just don't roll over and go anymore. you know, I had to take care of things. Get ready.

And so it has changed our relationship a fair amount, although I have to say that it hasn't... that it is difficult in some ways because of what we went through with the PMS, and I'm telling you I am really a champion at PMS, I had a very difficult time. In fact, I was in one of the early PMS study at UW. Oh my gosh, that's what I'm learning about PMS in the early 80s and I was coming here for six weeks study program. So, but because we went through that and made managed to get through it.

We built a lot of communication and developed a lot of relationship around those difficulties and we're able to kind of develop some strategies. So now our communication is strong enough that we're moving into a new phase of difficulties, as it were. And, um, and it's okay you learn that intimacy is not only about activity. There's other things that make your relationship and strengthen your relationship. It's a little hard, you know, is it's kind of a grieving separating process, but more emotional than I thought, but we'll get through it to throw away 45 years of marriage because you can't have sex anymore on a Saturday morning.

Aggie: Yeah. Any other experiences with partners?

W7

Sure. Well, I'm separated from my husband. Are we live apart and we're both you know

someone professionals out there, I guess and I started noticing that women are cutting hair at this age. So I'm looking around going, Okay, who's wearing what and how are you wearing it - your hair is long and it's up your hair is long. It's down but it's back and it's pulled back your hair is long and you've left it like me long. Your long, up, long, short.

You're older and it's just how it is and so most, so a few of us have it down that most of us are still long at this age. Oh, interesting. I'm 52 - by the way, and so let's see my husband's five years older. So he's 57. So when he started having problems with his prostate, because that's what happened to him. I started sweating all the time like super hot hot flashes around the neck like at my night sweats, big time like I'm drenched what I get up every morning. It's like I showered in my sweat. Okay, so I wash my more often. Of course, I think. So this is ok but I've already worked out because I already sweat it out. So, you know, sweating is like working out you sweat out your toxins. So it's good to sweat every day. I from the Finnish culture and our culture is we sweat like the Indians do have a sweat lodge of the sauna I don't have a sauna. So now I do it my bed.

So I'm like on the menopausal close groups going well what are other people doing because they're sweating so it says that they have their fan going. I have my little fan in my separated apartment. He lives in a house. I live in an apartment. And it's twirling. I could cool myself down. you know I'm getting to the point where okay maybe we can still live together one day, but right now it's about HIPAA filtration for my breathing which affected my health. So I left. And so we've been married only four years. So it's still relatively new. So we both married late, so we're we married where we're like already starting to have issues. So, and I didn't have children, either.

And so I still want to foster mom and 52 years of age I ready to be a foster mom. So I don't even know the future if I can be with my husband. So kudos to all the ladies. I guess I don't know if there's any of you that are single but you know I've been single most of my life, having to pay my own way doing everything and I just took a retail job at a Lane Bryant and just got myself to where almost my husband is financially, just like that.

You know it's just been an interesting ride every which way for me, but I would say the sweating is extreme, the nightsweats and, you know, you look around what are women wearing and you look like capris are great because you get more air you know right more breathability. Cotton is great because like also more breathability and I go around buying more cotton shirts or the polyester because one time I nearly passed out at a fair wearing polyester because my fabric wasn't breathing. Never in my 20s did I ever do that. So hopefully, here's a few ideas I can remember, you know, in general to succeed. During this phase because it really is. I think about how are we going to make it through and what can we do and how can we help one another other and focus groups can focus on menopause but also helping other women and give good advice and hopefully I can help.

Aggie: Thank you. Okay, so we kind of went a little bit off for, like, I want to return to I guess the relationships we have with our friends and our families. We touched base on like partners and our mothers, but just let's focus in on friends now. How have our friends contributed to our journey and how have they not contributed to our journey.

W7

I was just going to say something about that earlier, I would say the negative for me is that because I had asthma all my years from age 19 I had asthma and the veterans because I was in the army. Actually I pass through and did everything I had to do so I wasn't that bad but I had a lot infections. I was on presidone but could you say what the question was...menopausal moment...

Aggie: How have your friends supported you?

W7

thank you because I was getting there but I always go off somewhere else and chat too much. I'm a chatter. So basically the in my life just discounted me and thought that I was something else. So since my mom did have the severity of nights sweats or the night sweats so bad. Same with my Aunt... both of them recently actually said, Well, is it something else because I didn't have that or is it is it some other health issue that you need to tell the doctor about it. No, I know it is not because I know it's very normal. So I wouldn't classify myself office disabled. I would classify myself is very able and even more so than some people and even more so than the people sometimes I have put me down negatively. So I rise to the occasion and I have had to all my life. I'm glad that goes out for a long bike ride for 10 miles to be more fit, I do. I've told my mom to you still have 20- 25 pounds to lose because that will really help your diabetes. That'll be me! First out there and the first opinionated one. It puts the toe in my mouth that gets in trouble. But it's worth it because if you don't step up for yourself and defend then who's going to.

Aggie: W7, W7. That's not the answer to the question, so we're going to...

W7: That's my negative stuff I have to get out.

Paola: would anybody else like to share maybe some of...

W3

Yeah so I have a friend. She's like a year older than me and we only get together like twice a year for each other's birthday but she's a very, very close friend and it's like connecting instantly every time we see each other, but she went through some symptoms and she actually would share them with me and every time I see her, she would go so when you near there, you know, because I so I think with her lead just feeling so natural talking about that sharing her own experience and her ability to ask me. It's made it easier for me to also check in with her life.

So okay... did you experience this, you know, the next time I see her. And then also to do that with other girlfriends too and I've had a pretty positive response from women. Once I asked you know I'll say something about what's going on with me, they they seem to be really happy to share what they've come through.

Paola: Yes, W5. Not to put you on the spot, but we'd love to hear everybody's experience and input. So if you wouldn't mind sharing your experience of partnerships, or with friends.

W5

Sure. My experience with my friends is generally people my friendships, people will talk about it but it won't necessarily bring it up unless it's like something that just happened or an experience that they just had.

I myself haven't really brought it up. So I'm thinking and listening and hearing about the stories. I'm thinking, well, maybe I maybe I should be the one to bring up the topic more often with friends around my age, a lot of my friends seem to have had more trouble though more serious things. So, and I haven't had the level of challenges that they have had. So part of me thinks, maybe I shouldn't bring it up because if I talk about it with someone who is going through some really challenging. I mean place like this is different. So I'm just wondering, oh, how can I, how can I be a good friend, or how can I talk about things.

I mean a place like this is different. it hasn't really been basically it hasn't been talked about.

W3

just to share that with you too. So in my that relationship with the friend I was talking about. It's that and in the context of our relationship has always been. It's her time to get away from her kids and it's my time.

So there's nobody else we're usually going for a run and going out somewhere afterwards to eat. So it's just like there's no you know family around. There's no other distraction. It's very, very much. Since we only see each other twice a year. It's like catch up on all our challenges or personal challenges and so it's a very good context, I guess, and an easy context just shares.

W8

Now I have a similar friend, we see each other about once a year. She lives in Barcelona and so her experience is very different culturally because naturopathic doctors and men and Western medical MDS are about the same level in terms of their practice so she can see naturopathic doctors, so we always have talked about everything everything that's going on, physically, mentally, emotionally, and it's been very easy but comparing our experiences from one country to the next and that's really interesting.

51:40

Paola: What are some of the differences?

W8

The biggest thing is that it's it's just facts on her side. And it's not a closed topic, it's every minute all the women in her life talk about it if some comes up. It's just on the table. The man just have to deal with it. You know, there's no and you know she she lives up with a Catalan family and her husband is Catalan and extremely Catalan you know very male dominating. She's like, well, this is me you've signed on, you know, and she has two step daughters who are now 16 and 19 and so they've always and that was part of the deal is that she brought that openness to their lives about their bodies and about their cycle, etc.

So I think that's part of it is that he sees the benefits. He's like, I know nothing. Can you help here and so she she's helped with that part.

So probably is her personal experience and but I'm I guess I'm making the leap between the cultural differences because that's what I'm saying. It's not like an American has just been living in Spain as an American she's been there for 30 years she really is living as a Catalanian

Paola: W1 would you like to share anything?

W1
All my girlfriends are not experiencing this, and so i feel alone in it and my mother has a hystero my when she is 27. My grandma has always called it the curse, so it's something I had to figure it out by myself.

Paola: How do you find support?

W1
I go to a therapist for other issues and I haven't really sought out support.

Paola: Thank you for sharing. I also go to counseling so I can relate personal issues and separation issues, but I also have a closed group - estroven (sp?) -

W7 (?): Where did I first spot it...either grocery outlet or Winco that it was at Walmart so Walmart. It was quite a bit more like more than \$5 for it, but you have to do at least 60 days. It says, Are they the ingredients are the packaging it says you have to do at least two months worth, which is 60 days and it has soy isoflavones. Did I say it right. I'm not sure but that's the was in the ingredients and supposed to help and it helps you to sleep. Also because it's kind of makes you sort of peaceful and there's different types of the packaging. What is like for more sleep or what is more for mood. So this is a second one I've tried for 60 days. So yeah, I feel some help. I still wet around the back a lot but it's helped us bed early on as well.

W6
I used that as well...it was about 2006 there was about and it was helpful.

Paola: What are other methods that you have found that help relieve symptoms and kind of help ease

W7: Don't drink as much coffee anymore. Just go for the decaf. Three, three to four to five cups a day and it's way too much give you a heart attack. You just can't handle this much of a naturopath said that you have to build the stomach Flora so you could do enzymes so 75 70% of your stomach is is where your immunity is so if you're performing well here you'll perform well overall, and processing, everything will be much easier when everything's at peak.

So it's added enzymes so told me that I can't hardly eat anything anymore. And I'm I'm

doing some of that, but it's so strict. It's like so extreme I still kind of do my own thing a little bit but basically not much you can eat if you go to a naturopath

Paola: Has this been the experience for everybody else?

W4
well for me going through my GYN and they actually had me go the natural route and get like a progesterone cream from like the natural store which didn't help me at all and then just kind of being at wit's end going to the GYN and said, well go try the natural route. So I went to a naturopath and we tried all kinds of different supplements that didn't help with any symptoms and then she put me on a natural progesterone that that I guess it's peanut based and that really threw my emotions into a tailspin I found that I was super depressed and agitated. So I got to wean myself off of that.

And now for the depression symptoms that I felt I started taking St. John's Wort and I have found that that's helped immensely. I had to I guess the recommended dosage was three a day, but I got major headaches with that so I cut back to what a day and I still find that it helps with those symptoms but nothing has helped with the weight gain I've tried.

Before all the symptoms started I was like in great shape, exercise like 6-7 days a week diet was on point then just started gaining weight and would even go even more hardcore with exercise and dieting and the weight just kept creeping on so I still haven't found out how to deal with that symptom.

And as far as the night sweats and hot flashes are tried magnesium, but it has an effect on my stomach. So I don't even know what to do with that my husband doesn't even sleep in the room with me anymore. I have the windows open and the fan going away 24/7.

So yeah, the one thing is with the with the depression and mood swings St. John's wort has help?

W5
Oh, I just rewind a little bit. Just to add on to what I said before, I the person I talked to the most about all this stuff in my personal things is my sister who is younger and she's eight and a half years younger than I am. And so I tell her when I started experiencing things.

A few years ago I just started talking to her as I've done in my life and just she's the one I've talked to the most and then she's you know she would remember. Oh, what did our mom say about this thing because our mom died in 2012. So even though I haven't talked to my friends as much with my sister who, with whom i've been talking about these things. She has a good memory too.

1:02:28

W7
I've tried as black cohosh and black currant oil and black currant oil you can do two a

day it's relatively inexpensive at like Vitamin Shop or Vitamin world. black cohosh can cause liver problems. So I only do it every other day because I didn't want to hurt my liver is medications also can hurt your liver because everything processes through your liver and a lot of processing. So you want to keep your liver healthy. Also drink water to the point where you're pee clear water, so you're flushing out your kidneys. So they're pure and clean every day, just like you would working out three or four times a week or walk or whatever. And so that helps your health as well. I've tried to live that all my life that you just, you know, pee out your impurities and sweat out your concerns and doing stuff like that. And maybe that's a way that I haven't got cancer or that's a way that you know don't eat packaged foods because they cause cancer, especially in this society.

These days where everything's packaged but you know my grandma had cancer, like on my dad side and everything so there's just for me. There's so much to watch out for. I'm almost paranoid even even eating half the things that are out there these days. It's kind of scary.

W8
I want to bring us back on something that W4 said. You said that you worked out like a lot and you're still experiencing the same symptoms, regardless of your exercise. It's interesting. I thought that was what was working for me.

W4
I can't even tell you how many times my thyroid has been tested. So I've had that done three times as a matter of fact, just this last week I had it tested again. And it's...

W8
Interesting.

Someone
That's might be what's working for you

Paola: yeah and that's exactly right. I mean, it's. That's why we want to hear everybody's experience because you know one thing may work for you and other members may not work for you that works for somebody else. So definitely, if you want to share W1. What are some of the methods that worked for you.

W1
it was really like I was 45 and I was still ovulating and I was 46 and still ovulating.

My significant other died and I neglected my health for a while and then I was not ovulating because I had breast cancer.

Paola: I'm sorry.

W1
So it was like BOOM. Yeah. Everything hits all at once and then the apartment had bed bugs.

Paola: So stress probably was a factor. How are you doing about that.

W1

I take a lot of l... I live with my roommates so I deal with my personal summers when that happens.

W6

I brought back the art of fans. Number of years ago and I just like stop worrying about what people might think about me but especially in church and theaters and large events. I just carry a little folding fan, get them everywhere. I'm some nice ones and people started giving them to me as gifts when they realized they use them, but I just you know and and most of the hot flashes I found for me because I didn't have the night sweats along with them, usually last just a few minutes, so I could just put the fan a little bit. It's a lot nicer than a theater than slapping the program back and forth which causes a racket. And I had one woman one time say to me bring that over here for a little bit.

Paola: That's wonderful! Bringing it back as an accessory.

1:06:34

W7

The other thing is they're buying those cute fans at the dollar store that look beautiful, but only just put on the wall. You can hang with by the other wall anytime and grab it, but one lady on the close group I wish I knew these names, but these are great women but one lady said I think yesterday or today that she has one of every purse or she has a wood one or hers is from Spain, whatever it is. The fans are really popular for women to you know get a part if you just go back and forth on paper

W6

but not the battery powered when those, those are rude. I've seen women making noise and so in any kind I was at a funeral and a woman pull one of those. everybody has their own solutions, but sometimes in public life that impacts.

Aggie: Has there been a time when you experience a hot flash or a symptom..not a symptom there should be a better word for it because it isn't a disease where you experience a moment where you're like outside of the home and you're all of a sudden it's like I can't believe this is happening right now:

W8

I got a major story. I'll make it fast. So I was working at Facebook last year, you know, everyone around me is like 30 years younger and all going to work and I'm all ready and I felt I felt kind of sick in the morning, but it wasn't really sure. And I, my mother passed when I was when she was just turned 60 so I don't really get all the info on what happened with her in menopause, so I wasn't sure what to expect and then suddenly I felt this gush, and I had massive hemorrhaging and I didn't have any cramps. If I had had cramps, I would have just walked into the ER, but I didn't. And as I kind of just felt God I look and I had massive hemorrhaging all my - I was bloody from my waist almost all the way down to my knees, I was just soaked everywhere and I was coming off the bus. So I took off my jacket, wrapped around my waist and I walked across the street and took a bus the next way and waited for the stores to open downtown. It was like eight in the

morning and I just went and I went directly to - I knew this woman. I'm pretty sure the department in Nordstrom where I could go and I said I need black pants and black underwear and I need them right now and I need a tampon and I just looked at her and I just told her exactly what - and she went "OK" and she went and got it. And i went into the bathroom and I took everything off and threw them in the trash and changed and then went to work and I was fine. So it was just like are we cleaning house here is this it. Am I done because I want to be done like is that the end of the blood?

1:09:20

W1

Excuse me, something like that happened to me. I was in a volunteer position. I would carpool and with the person who work there and I was a volunteer. Luckily she could she could take me home but it ended up that I had uterine <Appalachian> so well. Don't have that anymore.

1:09:38

W8

At least that's out.

1:09:41

W6

Well, that's what precipitated my hysterectomy is 24 hours of constant heavy bleeding like that and a lot of pain and I was so scared and I finally went to the emergency room and they called my doctor and said okay so when will we do the hysterectomy and it was a matter of, you know, I was in ER in 24 hours or in the OR in 24 hours. So it was it was a very quick. I didn't have time to think about any ramifications or any considerations, but it was it was fine just change - you know, your life can just change so fast. I think women experience that so much more than men. Men have accidents, but women's bodies just suddenly I don't know, just get crazy at times. So things can really change.

1:10:44

W4

With the hot flashes I there are times when I'm just having a conversation and I can feel the sweat like dripping down my breasts or like down my back. It's just like it's just and you feel, it's like kind of like an electricity, just like a hotness that I feel it's just like the weirdest thing and I like I need to get cool air right now, and that's what I'm being in my head as I'm having this conversation with them. I cannot even focus on I'm just feeling the sweat dripping for just like no apparent reason. Yeah, I have a collection of [fans] now.

1:11:17

W7

Same here like I'll just go I'll be somewhere but just I'll just say to somebody, I'll turn "I'm having a heat stroke". And they'll say are you, you know, an older woman, she'll say, Oh, I know what you're talking about. You make a friend. And I do it all the time, standing somewhere in public places it's crazy so yeah

1:11:36

W3

Actually "heat stroke" is a good, kind of, kind of a milder term.

1:11:42

W7

Actually I like her term too, kind of a personal summer.

1:11:48

W3

So guys can kind of get it but not - I think there's something a little bit weird about saying you know I'm in menopause or something like that.

1:11:59

W7

My husband says that I'm so moody. I'm up and down and all over the place and I just say it's hormones so you wouldn't understand.

1:12:07

W8

But I think the side humor is key to it, like, you know, keeping a sense of humor about it.

1:12:14

W3

Yeah acknowledging it but also keeping a little lighter.

1:12:16

LV

This discussion has been really, really great. I want to make sure that everyone gets their break too. So we can definitely continue the discussions, but... How about let's take a 10 minute break. So feel free to get more refresh

1:12:31

me questions. What are the assets and then restrooms.

1:12:37

Thank you.

1:12:55

W7

Who here are having by minor heat, heat strokes

1:13:21

lovely

1:13:42

W7

These are like ideas. Ideas

1:13:48

to do right now, but

1:13:52
mostly for like anything that resonated with you with your menopausal experience stuff falls under these categories.

1:14:41
W6
It's vital

1:18:24
starting school.

W2
What is called when you can't recall things? You know what it is but you just can't remember watch and watch. I watch Jeopardy and I'm able to watch, and I know the answer, but I can not say it, it used to be like boom. And suddenly, I can't, I can't remember anymore., I get really upset, because I can't remember. I don't know how many times I had to walk around the parking lot looking for my car. I don't know where it is. One time it took me almost like half an hour. I can't remember where I park my car. So I take a picture of my car, and I have to make sure I know where I'm coming back. It's so bad, I don't know if something's wrong with it. Brain fog! That's what it is.

1:20:15
W4
So are you still in process or are you done?

1:20:22
W2
I'm not done, I'm just starting. It just hit me boom like this. It was not like, you know, your period tapers off or something or you know gets light or something. It's just overnight. Because, one thing, a lot of people complain about their period. But one thing is factious(??) company for me and I don't have a lot difficulty... it was very consistent for me. I know exactly what day it was coming and what day it's not. If I had a little cramp I could handle it and it's fine. It's a routine thing for me, like a balance. I keep a diary. Suddenly, like boom it's gone. It was not like tapering off.

1:21:20
W4
How long has it been?

1:21:22
W2
A year now and it was overnight. I keep losing hair.

1:21:39
Before I was very on the go and now I'm like I get my kids from school, force myself to cook dinner.

1:21:49

W2
I because I pride myself on being so active and so strong and then it's like, even if I have to work harder, I'm fine. Now I have to take much more effort and I have to like take caffeine, like a boost or a drink. I have to take that. And then at night I can't fall asleep. That's why I'm going crazy.

1:22:13
W4
Yeah, I toss and turn at night. I can't even tell you the last time I had a good night's sleep.

1:22:25
W2
Yeah! I can't. Just now I have to drink two glasses of wine before bed to go to sleep.

W7
Did it help you?

1:22:42
W2
Yeah, it helped but then the next day I feel tired. I'm not going to take any sleep medication, I'm not going to go there. I tried that route, I got nightmares, man. Yeah. Sleep medication. One of the side effects? Nightmares. Oh my god. The doctor said stop immediately don't take any more. Yeah, serious insomnia.

1:23:18
W4
I did try over the counter <CD?> but then I stopped because that can be habit-forming. I was like I don't want to have to rely on that.

1:23:23
W2
The OBGYN only offer HRT. That's all they offer.

1:23:28
W4
Right. Yeah. I don't want to do that.

1:23:33
W7
They have the estroven weight management.

1:23:35
W4
I tried that. It didn't work.

1:23:38
W7
I saw that at Costco.

1:23:41
W7
It works, a little. You know, it's more than a little at least for me. I really like the one that's anti-stress.

1:24:00
W4
I tried the magnesium but I got bad stomach cramps. So I was just talking to my primary again when I went in for a follow-up for the heart stuff. Well, actually the cardiologist. With the palpitations. She was saying ... could cause palpitations down the line. She was saying magnesium and I said I got cramps and she said you can change dosage.

1:24:37
W2
I got my thyroid checked because I'm so tired. And hair loss, that's why I kept my hair short. It used to be down here.

1:24:44
W7
I have the thinning hair too.

W4
I have it really bad, too

1:24:53
W2
I'm greying.

1:25:01
Biuten is supposed to help, you know the supplement. It's supposed to help Hair, Skin and Nails.

1:25:06
W7
I haven't either. I'm not getting any health coming(?) I'm gonna take it anymore. I get just as many in the sink every day, literally, if I put my hair in a ponytail. I have to pull this part forward a little bit because I'm always bald right here. Yeah. What is it that we can do to get... I'm going to try that little rejuvenator thing. maybe try a little later, where you have to press into there...

1:25:33
W4
I made my own elixir with some flower sage, essential oil and peppermint and some other one. So I just kind of rub it in here.

1:25:40
W6
My husband didn't like the smell of it. So I use it in the mornings.

1:25:52

W7

Well if it works for you it shouldn't be about the smell.

1:26:26

W6

Well, no

inaudible

Post-it Notes Activity Transcript

Kelda

Okay, so can you guys talk why you put the stickers where you did? Let's start with orange.

W4

I put mine on weight gain for me that's just been a really huge issue for me. You know someone who never had any weight issues and then to all of a sudden not be able to fit anything in my closet and it never gets better. It gets worse. So even in like a couple weeks time my weight will go up like five to seven pounds.

And then to be constantly told well there's nothing wrong with you, like not being used. So for me, that's a huge thing. It's an image thing for me I don't necessarily care what other people think. But I care what I think about myself, you know, and the fact that I was so frustrated. One day I just went within an arm and grabbed everything out of my closet and threw it into a bin and I have like maybe four things that I wear and I just recycled back so I'm like, I'm not going to go shopping for all of these big like I'm just not going to do that, you know, it's just kind of been a battle for me. So for me that's a big thing.

and with the blue line I put it on the medical community and their knowledge about this like I feel like they don't listen honestly when I go to my GYN and it's more like well you just have to deal with it and they just dismiss it so I feel there's like a lack of empathy, there's maybe a lack of understanding about these issues. I feel like if it wasn't you know this was a men's issues they would like find ways to treat it. You know what I mean. And so I feel like we just get the shaft.

W5

I had a similar perception on the blue sticker for cultural side of things, because the way it's been talked about, especially growing up, it was considered more of a negative. Talked more in a negative way. Things should be talked about differently or in a positive way or to acknowledge things that may be challenging, but it's part of being a woman, part of growing up getting older. cultural side can change.

If it were men or men's issue. It was told there have been studies for decades of studies to back whatever they would need, but for women, it's not been something given enough attention to.

Kelda: How about you W6?

W6

All right. Well, I did put my orange sticker on the physical issues the vaginal dryness. I've enjoyed sex over the years. I'm not ready to give that up entirely right so between my husband and I, and and both of us having a little different problems that are related the same way. I keep working on finding some way to change that. And some of it is stress, stress causes stress, you know, that's kind of a critical factor for me right now I can live with the hot flashes I get along with that, and most of the other things have dissipated over time, but that's a big one still for me.

And on my blue one, I think variety of treatments available is more the idea that again like other people have been saying to get this out there to make it more open something that we can discuss openly, especially as women, but also to help men understand this is just a phase of life that we're going through just the way things are, a better understanding.

Kelda: What about you (W7)

W7

The orange I put hot flashes because mine are really really really extreme especially because hormonal, also because it's like a voice, "Do I smell yet?" and "What natural-based perfume can I use or cologne or essential oil which is how I think, a lot of natural things. But I also feel like I'm laundering more so I'm trying to buy sensitive products for laundering better, like ethic products at Target or naturally-based for the environment stuff.

So for me, specifically that standard and every time I drink coffee I just had some right now, like, you know, super super hot flash like it's continuous it's not just one to another. Another study I said I asked the lady how many hot flashes would you consider having menopause like how do you count them? we talked about it. She said you really need to have at least ten and I told her, Well, I probably have at least 15. At first, I counted them, it's like gotta be at least between 10 and 15. she says you have to have 10 to get into the study and she took me to study. So this was another thing that I did and I found it also on Facebook.

The sweats is like for me but back it's like okay I'm doing laundry like two times more than I ever did. And I think that when I lose weight, it will be less but that's the hope I have in my mind trying to get overcome it and get power over it, the body. and the blue sticker. I put variety of treatments available.

(W7 corrects W6 in that she actually put her sticker to honoring the body in all its aspects, not the variety of treatments).

I liked that, too. Standing there, I couldn't decide and but I did actually put it our treatments available because I thought, well, you know, even if it's naturally-based could be considered a treatment cuz there is something for it, but without support. We can't do it either. So it's not just one thing, but we need so many things. we really need the bal-

ance. Because balance is like bliss is like harmony and that means we're operating better.

W8

For the blue. I put support because and I was thinking like this. I was thinking, everything from people you know support groups to society accepting this is part of life for humans. So, except it if we didn't have women we wouldn't have humans and this is part of human life. So there you go.

So support and all the aspects and orange I put spirituality, because I think that when I started going through menopause is a very intense period of my life. My both my parents were sick and passed within six months of each other and I cared for them and I learned a lot about that and I became more spiritually focused. I always was. But I keep it more so and so the spiritual part of it for me is just the acceptance. Now this is we're created this way, we didn't have really a whole lot of choice and where we are born or when we were born or any of that. And so, that to me all leads to the big picture, which is the spiritual aspect.

W2

I put down for fatigue (orange sticker) because I feel tired. And it's affecting me the most because I'm losing my hair and all these symptoms that I'm having, insomnia and I have hot flash at night and I don't sleep. I'm exhausted all of the time. I'm mentally exhausted a lot. And I put the blue one on the internet, information and more people have access to that and that will help a lot of people what's going on and make it more acceptable and is a more holistic woman power woman natural process of life.

W3

I put my orange dot on physical and it's just more, I think it's actually self image. and I love to be very active and so I can see it's already it's impacting that area and I'm not training up to be.

For the blue one, I put on internet and social media, but it's actually. some other people put support and its really intermittent, that's like a medium for support, whether it's a Facebook group or just knowledge out there and I would agree with the acceptance by the general community that it's just like you know teenagers go through their phase. This is just it's just it's a natural process that people might experience different things but it's a natural thing.

Shouldn't be a hushed thing or thought of negatively.

Kelda: What have you learned from this afternoon, you guys learned anything new?

W2

So I hope there's more of this so that you said more open and more supportive group. HoV

W6

sounds a little weird to say but I moved beyond a lot of the issues the younger women. And so in a way, it's affirming for me as well. It's a phase, and let me tell, it's a phase,

but it does pass on. Yeah, you know I've got a couple issues that I'm still working on, and if we do this again in a year, a year and a half, I'll probably have other issues. (laughter) Give me a call.

W4

I will say that I learned that there are phases to it. So what I'm going through now feels like the world is going to end, but that there is some light at the end of the tunnel.

W8

The perspective is the biggest thing, you know, we're so wrapped up in our own little worlds that it's so easy to forget that there are other perspectives on this issue you know i mean i think you know other topics but it didn't really occur to me on a regular basis that I know people have different symptoms and experience in differently, but a lot of it is how you perceive those symptoms and how you perceive yourself in that situation. That's something I learned today.

W3

I learned that, yeah, there's so many different unique experiences. I was talking to someone that earlier that menopause, people say, oh, you'll have all these various symptoms really that might be generally true but it's really unique and the severity, the frequency, all those things can be really unique to a person and I just wanted to thank you gals for doing this. Yes, I don't know that I've ever shared and I actually didn't share everything but it was very easy to share here with other other women. Something that's usually not talked about.

H *Workshop Sticker Placement*

	WHAT'S IMPORTANT TO ME	WHAT'S IMPORTANT FOR EVERYONE
W1	N/A	N/A
W2	Fatigue	Internet: Access to information, broader conversation
W3	Physical/self image	Internet and Social Media
W4	Excessive Weight Gain	Medical Community still knows little about women's health
W5	Spirituality	Cultural experiences/broader convo
W6	Vaginal Dryness	Honoring the body/Better broader convo
W7	Hot Flashes	Variety of Treatments: balance of treatment and support
W8	Spirituality, acceptance of big picture	Support

I Qualitative Codes

Differences

Cultural differences
Variety of experiences

Gender

Generalizations and stereotypes
Gender Roles

Information

Credible sources
Info through Facebook
Info through word of mouth
Men don't understand MP
More Informed now
Searching for menopause information online
Should have known beforehand
Validation of signals from peers
Self confirmation of symptoms
What's wrong with me?
Distinguishing menopause from other
Uncertainty/Unclear Information now
Info from literature
Informed about Menopause

Medical

Avoidance of HRT
Avoiding doctor
Doctor confirmed
Go to doctor
Prepare for the doctor
Extenuating circumstances
Experience with Doctor

Menstruation

Relief from having no periods
Process of periods going away

Mental

Exacerbated mental health
Mood swings
No mood swings

Perception

(Silent) endurance
Negative perceptions on aging
Not a big deal
IS a big deal
Positive mindsets
Quality of life
Desiring a pleasant biological transition
Attributing biological changes to MP
Feelings of isolation
Lack/mismatch of expectations
Positive Aging
Self Image

Physical

Brain fog/Forgetfulness
No forgetfulness
Hot flashes
No hot flashes
Infertility
Night sweats
sex not affected
Sex life (vaginal + libido)
Skin
Sleep problems
Symptoms get better
Symptoms get worse
Weight (gain/loss) management
Female body
Uncertainty about what body is doing (now)
Other bio changes

Social

Limited to No communication w/partner
(Good) communication and support w/ partner
Humor to converse
No conversation or information from maternal figures
Conversation or information from maternal figures
Not talking to shield others
Broader conversation
MP irrelevant to daughter
Public life affected
Talk to daughter openly
Affects relationship

Solution

Natural/non-medical/non-hormonal
Variety of treatments
HRT
Want data & timelines
Self Exploration

Support

Value in building support systems
FB cons
FB support
Non-supportive friends
No support

Work

Helpful Boss
Affecting work
Not affecting work
Open @ work
Other women @ work