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When chronicity meets cyclicality: The cultivation of embodied knowledge and selfhood by cis-gender women with cystic fibrosis

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Abstract

This article offers the case of cystic fibrosis (CF), a multi-system disease, to illustrate how individuals with chronic illness cultivate and apply embodied knowledge to optimize their well-being. We identified three interrelated processes that occur when disease chronicity and menstrual cyclicality meet: 1) knowledge production with a period-tracking app; 2) application of embodied knowledge to manage life with menstrual-related CF symptoms; 3) cultivation of the body-self as a menstruating woman with CF. These dynamic processes capture how cis-gender women with CF attune to their bodies, navigate their illness, and situate themselves within their lifeworlds. Genetic conditions like CF are apt for studying these processes because adults have managed their disease for decades, with longitudinal experience that often exceeds that of their clinicians. Our evidence elucidates the co-constitutive nature of chronic disease, gendered subjectivity, and

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Institutional Review Board

The pilot study, MENstrual Symptom TRacking to Understand and Assess (women) Living with CF, received an exemption from the University of Washington's Institutional Review Board.

CRedit authorship contribution statement

Sandy Sufian: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Rebecca Mueller:** Writing – original draft, Writing – review & editing. **Elinor Langfelder-Schwind:** Data curation, Formal analysis, Investigation, Writing – review & editing. **Katherine Caldwell:** Data curation, Formal analysis, Methodology, Visualization. **Georgia Brown:** Data curation, Writing – review & editing. **Molly Ruben:** Project administration. **Sheila Mody:** Investigation, Methodology. **Patricia Walker:** Investigation, Writing – review & editing. **Emily Godfrey:** Funding acquisition, Supervision, Writing – review & editing.

biological processes in flux. We explored the menstrual cyclicality of chronic disease symptoms by having 72 participants track their CF symptoms across 4 menstrual cycles on a customized period-tracking app. We performed semi-structured interviews with 20 participants to understand how they interpreted these cyclical CF symptoms. We learned that digital tracking attuned participants to monthly fluctuations in CF symptoms. They applied this knowledge to manage their lives and shape their sense of self. We argue that women with CF produce distinct embodied knowledge during their reproductive years, shaping their illness experience, disease management, overall health, quality of life, and selfhood. The dynamics we describe may reflect broader patterns by which women with other chronic illnesses experience their bodies and understand themselves in the world.

Keywords

Embodiment; Chronic illness; Cystic fibrosis; Women's health; Disability; Digital health

1. Introduction

This article offers the case of cystic fibrosis (CF) to illuminate how individuals with chronic illness cultivate embodied knowledge and apply it to optimize their well-being and nurture self-understanding. It examines a form of embodiment that results when chronicity (chronic disease) and cyclicality (menstrual cycle) meet; that is when chronic disease symptoms (e.g., pulmonary congestion, gastrointestinal symptoms) fluctuate beyond their baseline at points in the menstrual cycle to influence cis-gender women with CF's "being-in-the-world" (DeJarlais & Throop, 2011; Harris, 2021; Merleau-Ponty, 1962).

Embodiment is a relational concept that contextualizes the bodymind and signifies its power to represent and create subjectivity (DeJarlais & Throop, 2011; Price, 2015; Ellingson, 2017); it is the foundation of "self, meaning, culture and society" (Williams & Bendelow, 1998). Used by Price to explore a disability politics of desire and pain, and consistent with scholarly insights about embodiment, the term "bodymind" resists the dualism of body and mind and understands mental and physical processes as affecting one another (Ellingson, 2008; Price, 2015; Williams & Bendelow, 1998). We use bodymind and embodiment to signal the physical, cognitive, affective, and sensory ways of cultivating and applying embodied knowledge and constructing selfhood. We understand embodied knowledge as grounded in "visceral, felt, or enlivened bodily experience," which shapes how individuals see and navigate their worlds (Ellingson, 2008; Harris, 2021). These experiences influence individuals' ever-evolving sense of self, or what Van Wolputte calls the "body-self" (Van Wolputte, 2004).

To explore the phenomenon of cultivating embodied knowledge and constructing selfhood in the case of CF, we asked participants to digitally track their CF symptoms daily across four consecutive menstrual cycles using a customized, period-tracking study app. We then interviewed select participants to explore four questions: 1) what they discovered about any fluctuating CF symptoms in the study's tracking phase, 2) if and how digital tracking helped enable those insights, 3) how they applied this new embodied knowledge to mediate

symptoms and improve their well-being, and 4) how their knowledge shaped interviewees' self-understanding as menstruating women with CF. We argue that women with CF produce critical and distinct forms of embodied knowledge during their reproductive years, shaping their illness experience, disease management, overall health, quality of life, and selfhood. Our findings elucidate the co-constitutive nature of chronic disease, gendered subjectivity, and biological processes in flux. They also demonstrate how digital tracking devices can enhance and solidify embodied knowledge. The dynamics we describe may reflect broader patterns by which individuals with other forms of chronic illness experience their bodies and understand their "being-in-the-world."

CF is a progressive multi-system disease characterized by chronic lung infections and pancreatic enzyme deficiency. Childhood-onset genetic conditions like CF are especially apt for studying the processes of cultivating embodied knowledge and self-meaning because affected adults have managed their disease for decades, with longitudinal experience that often exceeds that of their clinicians. Adults' perceptive corporeal knowledge derives from a lifetime of symptoms like coughing, bloating, and joint pain; hours of daily medical treatments to manage symptoms and resolve periodic lung infections; repeated pulmonary function tests, blood draws, and chest x-rays; and discussions with CF peers and the clinic team about navigating life with the disease.

Historically, CF was a childhood disease, but center-based care and medical advancements gradually shifted the median life expectancy from 5 years in 1954 to 56 years in 2022 (Cystic Fibrosis Foundation, 2022; McBennett et al., 2022). The recent introduction of highly effective therapies called Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) modulators has reduced morbidity and improved survival, transforming CF into a disease where individuals live well into adulthood and females reach milestones like menarche and menopause. Women are currently facing their reproductive years before the medical establishment has developed comprehensive knowledge and proactive strategies to address the disease's interaction with sexual and reproductive health-related issues.

Extant scientific knowledge indicates that at puberty, the mortality rate of females with CF surpasses that of males (Swezey & Ratjen, 2014). The mechanism behind this sex disparity is multi-faceted but primarily involves a cascade where higher estrogen levels exacerbate underlying pulmonary infection by converting *Pseudomonas aeruginosa* (PA) into its more virulent, treatment-resistant form. This cascade then leads to pulmonary decline and mortality (Abid et al., 2017; Chotirmall et al., 2012; Harness-Brumley et al., 2014). Due to this disparity, women with CF fervently desire additional research on the impact of female sex hormones on CF symptoms to facilitate better medical management and social adaptation (CFReSHC, 2018, 2020).

1.1. Literature review

Scholarship on adult CF embodiment and its relationship to lived experiences is limited (Willis et al., 2001). Noted exceptions include two dissertations that examine how people with CF negotiate chronic disease, risk, technology, and identity (Maynard, 2003; Mueller, 2021). Due to this lacuna, we drew from a broad range of literature to analyze our findings, including work on phenomenology and the body, disability and impairment, and digital

tracking and health. These bodies of work help us discern how women with CF observe, experience, and make meaning of disease-specific, cyclical symptom patterns, and how this knowledge shapes behavior and selfhood.¹

Critical Phenomenology, Cultural Phenomenology, and the Body.—Social science literature on embodied knowledge and embodiment draws from Merleau-Ponty's notion that the body is the basis of human subjectivity and being-in-the-world (Crossley, 1995; Merleau-Ponty, 1962). Critical and cultural phenomenologists have built upon the work of Merleau-Ponty and others to consider how embodied experiences are imbricated in social, cultural, political, and material conditions. Crossley calls this approach a carnal sociology of the body where the social is embodied, and the body is social (Crossley, 1995).

Along with Merleau-Ponty, philosopher Drew Leder's idea of the absent body is highlighted in critical phenomenology scholars' work. Leder posits that embodied experience for the abled body is an experience of the world where the physical body recedes into the background or becomes absent (Leder, 1990). Conversely, Leder contends that when a person's body has a dysfunction, she becomes intensely aware of her body, and the world recedes. These moments are what Leder calls dys-appearances. The concept of dys-appearances helps contextualize the keen bodily awareness often observed in chronic illnesses like CF (Leder, 1990).

Sociologists' recent scholarship on the sensorial and affective nature of bodily awareness foregrounds the role of sociality in producing and transmitting embodied knowledge. Their insights are also central to our analysis (Ellingson, 2008; Robertson, 2020; Underman, 2022). Equally influential is Ellingson's call to use participants' and researchers' sensorial and affective accounts to consider the embodied nature of knowledge production (Ellingson, 2006, 2017). Given that our main interviewer/PI also has CF, we understood our interviews to be sites of intercorporeal and intersubjective engagement.

Anthropologists have also brought phenomenological concepts and methods to bear by examining numerous ethnographic cases (Csordas, 2005/2008; DeJarlais & Throop, 2011; Van Wolputte, 2004; Weiss, 1999). We utilized Csordas' groundbreaking edited volume, *Embodiment and Experience*, which calls for centering the body in theories of culture, particularly by examining the idea of "being-in-the-world" in cultural conceptions of lived experience (Csordas, 2005). We also relied on Kleinman's classic anthropological work on chronic illness narratives to consider how "illness becomes embodied in a particular life trajectory, envired in a concrete lifeworld" (Kleinman, 2020). Comparing chronically ill individuals to interpreters, diarists, and cartographers, Kleinman emphasizes the longitudinal cognitive and affective processes by which individuals decipher patterns in their illness trajectory. The chronically ill engage in a persistent re-examination that affords "the opportunity for considerable self-knowledge" that can enhance treatment as the patient's explanatory model of chronic illness may guide modifications in behavior.

¹An extensive literature review is beyond the capacity of this essay. We have accessed a much larger body of work in preparation for this article. We have highlighted the works that inform our analysis directly here.

This social science scholarship helped us map the concrete ways women with CF read their bodies (Crossley, 2007; Parton et al., 2016; Wilde, 2003; Williams & Bendelow, 1998), including how they “notice” small bodily changes, and how they adapt their routines and surroundings to accommodate such change. We also explore how women with CF define their embodied experiences in relation to, and as against, others as a way of understanding themselves. To examine how women defined embodied knowledge in relation to others, work on the phenomenology of impairment and disability was particularly instructive.

The Phenomenology of Impairment and Disability.—Scholars of impairment posit that the impaired body is a site of meaning, a knowledge source, and the basis of experience (Hughes & Paterson, 1997). The body exists within social structures and is “imbued with meaning through sensory experience, language, relationships, and interactions” (Charmaz, 2019). Social scientists who study impairment and chronic disease have explored the experiences of impairment, including the bio-social and corporeal impacts of impairments upon people’s functioning, how people living with illness adapt to their unstable bodies, how they process stigma and exclusion, and how they reconcile themselves to illness to attain a sense of wholeness (Charmaz, 1995/2006/2019; Scambler & Scambler, 2010; Thomas, 2012/2012). We use these insights to interrogate the effects of the menstrual cycle on CF symptoms, the processes by which women with CF navigate their bodies in flux, and how they situate themselves within and beyond the CF community to construct their subjectivity. While our analysis maps onto this literature, it also departs from previous research, which has mainly focused on acquiring a chronic illness. In contrast, our work examines a genetic condition in early childhood. Impairment fluctuations occur here because of the intersection of CF and the menstrual cycle. Adaptations to routines are a response to this cyclicity, and the construction of embodied selfhood is not a process of reconciliation but of reexamination.

We also draw from the work of scholars of critical disability studies who emphasize that disability is experienced in and through the body and reject the strict distinction between impairment and disability. These scholars emphasize that disability is neither inherently pathological nor a fixed identity but rather a category that materializes through social relations; it is a dynamic, negotiated experience (Hartblay, 2020; Hughes & Paterson, 1997). Critical disability studies scholars center the experiences of disabled people and, therefore, are attentive to the phenomenology of disability (Toombs, 1995). As such, most contemporary scholars (Hughes & Paterson, 1997; Clare, 2013, 2017; Goodley, 2013; Price, 2015) see disability as an embodied, situated, and social experience that is “constituted out of an ever-changing flow of relations among bodies, practices, institutions, experienced personally and socially constructed” (Lewiecki-Wilson & Cellio, 2011). Many of these scholars have also shown how disability, like race and gender, is inextricably tied to the production of social difference (Dickel, 2022).

Disability sociologist Tobin Siebers’ work has been particularly influential in pushing the critical realist turn in disability studies, a move that has challenged the impairment/disability divide that social model of disability proponents traditionally espoused (Goodley, 2013; Rembis, 2019). Drawing from feminist work on situated knowledge (Haraway, 1988; Harding, 1986), Siebers’ theory of complex embodiment highlights the “effects of disabling

environments on people's lived experiences" and the physical, emotional, affective, and social impairment effects in disabled people's lives (Siebers, 2016). He, and subsequently others, see disability as productive; they argue that precisely because disability is an oppressed social location, it generates unique perspectives, embodiments, and experiences outside the ideology of ability. It can thus offer valuable knowledge about myriad forms of human variation (Siebers, 2016; Weiss, 2015). The ways scholars of impairment and disability think about the body and lived experiences are instructive for interrogating how women with CF's bodies are sites of meaning about difference and variation; prediction, control, and expectation; and gender and women's futures.

Digitized Embodiment.—Lastly, our study is in conversation with scholarship on digitized embodiment and sensory knowing. This literature informed our analysis of how our study's digital tracking intervention shaped how women cultivated embodied knowledge. Critical digital health studies scholars have long explored how people produce notions of selfhood and embodiment through their interactions with digital technologies, or what Deborah Lupton calls digital assemblages (Lupton, 2014, 2017). Lupton and her colleagues, Maslen and Harris, have argued that as an "extra somatic resource" (Latour, 2004), digital technologies engage the senses to contribute to individuals' heightened awareness of, and new knowledge about, the materiality, sociality, and temporality of their bodies (Harris, 2021; Lupton, 2017; Maslen, 2017). This scholarship, along with newer work, has focused on how sensory knowing through digital tracking has enabled women to confirm the efficacy of existing strategies or tailor new, more effective ones to maximize their self-efficacy and quality of life (Algera, 2022; Del Busso et al., 2022; Lupton & Maslen, 2018, 2019a, 2019b). Given the widespread availability of digital devices and the feasibility of tailoring apps to specific patient populations (Adam, Bond, Burton, de Bruin, & Murchie, 2020; Cummings et al., 2011; Ponder et al., 2020), the CF-menstrual tracking case provides further evidence about how people with chronic or genetic diseases cultivate embodied knowledge through digital tracking. Our work highlights how even with a genetic disease where bodily awareness is already quite astute, tracking symptoms can still enhance and solidify embodied knowledge. Our study also uniquely examines a digital intervention where participants track *two phenomena simultaneously* and produce knowledge about the intersection of CF symptoms and the menstrual cycle.

2. Methods

The pilot study, MENstrual Symptom Tracking to Understand and Assess (women) Living with CF (aka MENSTRUAL), involved two remote, sequential phases: a digital tracking phase and an interview phase. In the first phase, participants digitally tracked their menstrual-related CF symptoms and their severity for four consecutive months. We decided to use digital tracking instead of paper because digital tools are commonly utilized in health self-tracking, including for CF self-management (Davis et al., 2022; Del Busso et al., 2022; Lupton, 2017; Vagg et al., 2021). The research team chose the period tracker smartphone app Kindara for its willingness to customize its HIPAA-compliant app for our specific research purposes. The app's study version was pre-populated with 22 CF pulmonary, sinus, gastrointestinal, and rheumatological symptoms. Some symptoms were

already in the standard app but were redefined with CF-specific definitions in the study symptom dictionary (Table 1 in italics). The study app also included 19 menstrual and “other” symptoms. These were part of the standard app and did not require redefinition.

Participants could add symptoms in the notes section of the app. Though not shared with the research team, they could use other app sections to input additional personal tracking information (e.g., spotting, sex information, custom symptoms). At the study orientation, the research coordinator showed participants how to use the app (for iPhone and Android users). She instructed them to set up daily reminders track symptoms on their phones. She also sent participants an electronic version of the instructions.

In the second phase of the study, we interviewed a subset of participants about what they learned about their symptom patterns during the tracking phase. We used constructivist grounded theory to understand how women produced embodied knowledge through tracking, how they applied it to manage menstrual-CF symptoms in their daily lives, and how they constructed a sense of embodied selfhood from those interactions (Charmaz, 2014).

2.1. Recruitment and participants

We recruited eligible women via social media and email announcements on patient listservs. Our inclusion criteria included English-speaking, regularly menstruating cis-gender women with CF, including those on hormonal contraceptives with a monthly withdrawal bleed, aged 18–45 years (Godfrey et al., 2020b), and residing in the United States. We limited the inclusion criteria to cis-gender women since we wanted to understand physiological processes alongside social roles. Participants self-identified their gender identity. We excluded women on continuous contraception, planning a pregnancy, or who were pregnant, and those on the transplant list or who were post-transplant.

Since this study coincided with the widespread use of CFTR modulator therapy in the CF population, we required a stable dose of modulators (duration of 3 months) before enrollment, given that modulators are very effective and often reduce disease symptoms. Eighty-nine percent of participants who enrolled were on CFTR modulator therapy.

We asked participants to indicate their interest in being interviewed during study enrollment. We used purposive sampling by age to identify invited interviewees. Participants gave their consent to track symptoms via an online consent form but gave verbal consent for the interview.

Interviewees composed a subset of a larger sample of 72 women who completed digital tracking. Out of the six age ranges in which we classified the participants (18–21; 22–25; 26–29; 30–35; 36–40; 41–45), the interviewee group included: 3 of 4 invited participants (18–21 group); 1 of 7 invited (22–25 group); 5 of 6 invited (26–29 group); 4 of 9 invited (30–35 group); 5 of 16 invited (36–40 group); 2 of 4 invited (41–45 group). Reflecting CF patient demographics in the US, most participants were white and represented multiple geographical locations.

2.2. Interviews

Before starting the study, we piloted the interview questions with ten women with CF. The interview questions reflected the following domains: the effects of digitally tracking menstrual-related CF symptoms on awareness of cyclical patterns; symptoms' impacts upon participants' health and daily obligations; interventions to alleviate symptoms; and insights into being a menstruating woman with a chronic illness.

Two team members conducted the semi-structured, video-conference interviews with 20 women with CF after they finished the study's first phase. We followed Ellingson's recommendation of "doing embodiment" by embracing the main interviewer's (first author; co-PI; disability studies researcher; woman with CF) embodied subjectivity and engaging in embodied reflexivity (Ellingson, 2006/2017; Rice, 2009). Due to her own experience, the first author became committed to studying if and how other women experienced exacerbated, cyclical CF symptoms. This approach helped shape the interviewee's engagement (Charmaz, 2014; Ellingson, 2006). The second interviewer, a women's health physician, conducts research on issues of contraception within the CF female population and is familiar with this population. The team's coder, a woman with CF, used her experiential expertise to create the first set of codes. Each interview lasted between 45 and 90 min. We audio-recorded and transcribed the interview via a HIPAA-compliant video conference application. Transcripts were de-identified; pseudonyms with demographic descriptors are attributed to each quotation in the Results section. After the study's second phase, transcript cleaning, open-coding, and memo-taking were performed.

3. Results

We identified three interrelated processes that occur when chronicity and cyclicity meet: 1) women cultivate embodied knowledge with digital tracking; 2) they apply that embodied knowledge to manage life while having menstrual-related CF symptoms; and 3) they cultivate embodied selfhood as menstruating women with CF. These processes are iterative and dynamic. They capture how women with CF navigate their illness, identity, and lifeworlds.

3.1. Knowledge cultivation with a cycle-tracking app

By digitally tracking menstrual-related CF symptoms, women developed a distinct type of embodied knowledge that linked CF symptoms with the menstrual cycle. Women with CF already have a keen sense of their body and their relationship to it. Living with a chronic disease from birth, they are constantly aware of their body's fragility, its unpredictability, and its impact on their daily lives. As Stacy, a woman in her mid-forties, explained, if she did not have CF, "I would not know my body as intimately as I do." But tracking made women even more attuned to their bodyminds, to the cyclical nature of their CF symptoms, and to the type and timing of CF symptoms that occurred during the menstrual cycle.

Discerning cyclical patterns by digitally tracking symptoms helped participants develop embodied knowledge through "physiological biofeedback"; the app data cultivated an awareness about symptoms, timing, and severity, which prompted women to engage in

sensemaking. (Algera, 2022; Maslen, 2017). This biofeedback loop was iterative; as new inputs further refined awareness, women's knowledge about the CF-menstrual link became more solidified and defined. By monitoring their CF symptoms daily over four months, women engaged in sensory and cognitive work that alerted them to when, as Evelyn, a woman in her early 20s, remarked, "there's something to be concerned about." The length and consistency of tracking contributed to the feedback loop (Algera, 2022). For instance, Claire, a woman in her early 40s, acknowledged that knowing was not innate but learned (Harris, 2021), stating she needed to track "consistently to actually see any kind of pattern."

Digital tracking sharpened women with CF's corporeal awareness and sensory knowing (Algera, 2022; Del Busso et al., 2022; Hamper, 2020; Lupton, 2017; Lupton & Maslen, 2018, 2019a; Maslen & Harris, 2021) by concretizing the link between CF and menstruation. Women produced knowledge about this link by engaging daily with the app's interactive technology, creating personalized data, noticing patterns, and learning about themselves. Talia, a woman in her late 20s, remarked, "I looked forward to it [tracking] because I could see the information about myself." She became excited about tracking, stating, "I never wanted to miss [a day] so I could correlate any signs or symptoms." The positive value interviewees assigned to such knowledge and to monitoring their bodies operates within a context where CF patients are regularly asked by their doctors to monitor their symptoms, usually by organ system. Parents and CF doctors taught interviewees this orientation to their bodies when they were children. As they grew into adulthood, interviewees honed this skill, practicing "reading signs" to keep themselves healthy and alive (Harris, 2021).

The "interrelations between the tool [app] and the body" involved in tracking actively co-created women's knowledge about the CF-menstruation link (Algera, 2022; Harris, 2021; Maslen, 2017; Maslen & Harris, 2021). It did so through mechanisms similar to that which Harris and Maslen observed in their study on "digital-sensory learning" among caregivers and physicians (Maslen & Harris, 2021), including 1) noticing changes from and returning to their baseline (with CF); 2) searching for signs and symptoms; and 3) digitally archiving symptoms in an app. Interviewees became aware of minute symptom changes, particularly when CF symptoms worsened or returned to baseline at specific points in the menstrual cycle. Interviewees like Claire highlighted when symptoms returned to baseline: "And then after my period ended, I was good for a little while and clear and calm, and all my symptoms disappeared." Sarah, a woman in her late 30s, concurred, "Mine get back to baseline ... the normal baseline of bloating that comes with CF, you know, Trikafta®."

Sarah was not alone in pointing out CFTR modulators' profound effects on CF symptomology. The latest drug formulation of CFTR modulators, Elexacaftor/Tezacaftor/Ivacaftor or ETI, became available to most Americans with CF six months before enrolling in our study. Capturing this unique moment in women's narratives underscored the contingent nature of embodied knowledge (Weiss, 2015). Many spoke at length about how ETI has changed the profile of which menstrual-related CF symptoms are most prominent and most severe. They stated that ETI has alleviated the pulmonary issues they experienced before and during menses prior to the advent of this medicine (Despotes & Donaldson, 2022). ETI has also eased cyclical CF symptoms like catamenial hemoptysis, fatigue, and

coughing. “My congestion during my period definitely isn’t like what it used to be,” remarked Lucy, a single woman in her early twenties. It is “definitely night and day,” Sophie, a woman in her late 30s, observed. Instead of pulmonary issues, participants on ETI now describe gastrointestinal issues as the most prominent among all reported menstrual-related CF symptoms. ETI has also caused a change in menstrual bleeding patterns and cycle length and has thinned women’s cervical mucus. Despite these changes, sex disparities in health outcomes persist in the modulator era. A recent study showed CF lung exacerbations have been reduced more in males than females on ETI (Wang et al., 2023).

The app’s digital interface allowed women to register their bodies’ shifting physiological processes and make sense of them as cyclical (Maslen, 2017). Some interviewees felt that the ability to view the app’s calendar and symptoms simultaneously enabled them to cognitively integrate menstrual-related CF symptom patterns. Others discerned patterns through the app’s statistical or graphing functions. Olivia, a woman in her early 20s, for example, stated,

.... looking at all the statistics and cycles, it was eye-opening to see because [this is how] I feel in my head. I know how I feel but seeing it on the app was a nice visual thing to be: ‘This is what my symptoms are, and this is what I should look for in the future.’

She added that by looking at the app’s statistics function, she could see that her more severe CF digestion issues were cyclical. “I had constipation, bloating, diarrhea, gassiness pretty much every time I had my period, which was very interesting to me.” Many interviewees observed similar menstrual fluctuations. A sensitivity to cyclical symptom patterns enabled interviewees to recognize that, around the time of menses, they had an increased susceptibility to lung infections, a decreased therapeutic response to pancreatic enzymes (medicines used to help nutrient absorption), and were more likely to be hospitalized (Scambler & Scambler, 2010). Claire noted: “... anything that was going to go wrong happened right before I started [my period]”. Some participants noticed a connection between worsened CF symptoms and specific times during the menstrual cycle even before the study. Rachel, an interviewee in her early 30s, commented, “I know that I’ve noticed it [the CF-menstrual link], and I know a lot of my female CF friends have also noticed it.” Tracking confirmed this prior knowledge.

Interviewees’ digital sensory work helped them understand *why* they have worsened symptoms; it highlighted a cause (e.g., time in the cycle and corresponding hormonal fluctuations) and effect. Rachel noted that before tracking, she would notice mood swings, congestion, or gastrointestinal symptoms as separate symptoms with no root cause. Tracking “helped put them [symptoms] all togetheras a whole ... it framed everything into this nice little picture All of this makes so much sense now.” Hazel acknowledged that the connection between CF symptoms and the menstrual cycle was not something she had “given much credit to before,” while Claire conceded that before tracking, she thought the link was “just in my head.” Before tracking, she noticed that her pulmonary function test results dropped around her period, but she didn’t think about her other symptoms. Tracking was the first time, “Where I actively put them together.”

Despite having an already acute sense of their bodies due to having a chronic disease, many interviewees admitted that because of their familiarity with CF symptoms, they had not realized the degree to which menstrual-related CF symptoms were affecting them until they began tracking for this study. Evelyn stated, “What’s really been interesting about this study is that I’m noticing patterns more than I thought I would.” When asked if she would have noticed a pattern before tracking, Claire remarked, “I would have just said, oh, what’s the weather today? I wouldn’t have thought twice had I not been steadily tracking.” Talia added that she appreciated the app because “it helped answer more questions about myself than I thought I knew. I don’t think I gave enough credit before [tracking] to the menstrual cycle.” She noted that using the app helped her think more about how her mind begins to see patterns. She recommended tracking as “a very valuable tool for women with cystic fibrosis.”

3.2. Applying embodied knowledge to manage life with menstrual-related CF symptoms

Interviewees used the astute embodied knowledge they gained from tracking to tailor disease management strategies to mitigate their symptoms’ impairment effects and improve their lives (Manderson & Smith-Morris, 2010; Mueller, 2022). As Amelia, a woman in her late 20’s, stated, “I think it [tracking symptoms] makes you think about it [menstrual-related CF symptoms] more. If you have the same symptom three days in a row, maybe you should do something about it.” Indeed, attuning to cyclical CF symptom patterns helped women articulate how their actions and feelings impact how their body feels. Most participants commented that their exacerbated symptoms hinder their ability to contribute to family, work, and self-care responsibilities. Such understanding empowered women to devise targeted strategies to manage their menstrual-related CF symptoms to improve their lives (Algera, 2022; Charmaz, 1995; Del Busso et al., 2022; Harris, 2021).

3.2.1. Bodily control and pushing through—Discussing the link between CF symptoms and the menstrual cycle prompted women to describe their illness experiences, the fluidity and fragility of their bodies, and their desire for more bodily control. They used the language of ‘pushing through’ to signal a sense of regaining control and performing resilience. Interviewees wanted to gain better control over the physical, emotional, and relational aspects of their cyclical symptoms (Parton et al., 2016). The desire to possess bodily control was women’s way of stabilizing a body in flux with its uncertainty and ambiguity (DeJarlais & Throop, 2011). They believed that having bodily control would drastically improve their quality of life (QOL) (Heggdal, 2013, 2021); in fact, they used such control as a measure of their QOL.

Interviewees appreciated tracking because it enabled them to know which menstrual-related CF symptoms to expect and their timing, even if this information could not eliminate symptoms. Once interviewees could predict the timing of menstrual-related CF symptoms through digital tracking, they could adjust their lives accordingly. This knowledge offered a way to affix illness, create calm, lessen anxiety, and increase self-efficacy and self-esteem (Kelly & Field, 1996).

The desire for control reflected the capriciousness of women's bodyminds and performed affective work in cultivating embodied knowledge (Parton et al., 2016; Robertson, 2020). Interviewees reported they dreaded getting their periods because it heralded intensified CF symptoms and portended an unstable body. Olivia described being on "high alert" during her period. She constantly self-surveilled her body, feeling anxious she might miss something.

Others mentioned the impairment effects of typical menstrual symptoms on QOL. Women recognized, for instance, that menstrual symptoms compounded the effects of CF symptoms. Talia relayed: "[They are] one extra thing on top of cystic fibrosis when you add your menstrual cycle on top of it, it takes it to that next level" The additional fatigue accompanying a period could weaken the body, causing CF pulmonary and sinus infections to fester. Olivia relayed, "My body has to put in a lot of work to get my period because there's so much going on in my system between my lungs and everything ... "

Despite the need for bodily control, some interviewees were determined to adapt to the vicissitudes of chronic illness since they could not control having a genetic disease (Charmaz, 1995). They worked instead to control what they could, like their environment, attention to symptoms, or treatment strategies. But frequently, they felt their body betrayed them, particularly when worsened menstrual-related CF symptoms arose; they internalized worsened symptoms as personal failure (Willis et al., 2001). Rachel described how canceling plans during her period led her to "talk horribly to herself."

As a result, many women defined "doing well" as when symptoms were non-apparent to others (Charmaz & Rosenfeld, 2006). Melanie, a woman in her mid-20s, however, understood that having invisible symptoms could be a "blessing and a curse" because "looking healthy" does not translate into non-existent symptoms. Melanie worried that if others think she is doing well, they may not recognize her continued needs.

While many interviewees focused on what they can control, others, like Rebecca, a woman in her mid-thirties, deal with what they cannot by "pushing through." Pushing through, akin to the trope of disability overcoming (Rembis, 2013), counters participants' self-perception of being "unproductive," a "failure," "not beautiful," or "abnormal" (Clare, 2001, 2013; Johannesson et al., 1998). Participants invoked individualistic notions like normality, productivity, rest, femininity, futures, and stress when they spoke of pushing through (Maynard, 2003).

Interviewees "push through" to demonstrate resilience and perseverance. This discourse functions as a logic of QOL deriving from interviewees' socialization in the CF community, where long-term, daily self-management and grit are revered (Muther et al., 2018; Toprak et al., 2019). Pushing through is also consistent with scholarly discussions about QOL and CF, which primarily focus on coping, depression/anxiety, and body image (Bray et al., 2009; Gee et al., 2003; Quittner et al., 2005, 2014). Pushing through conforms to American cultural health, wellness, and illness norms. For women like Missy, an interviewee in her late 30s, pushing through allows her to feel "human." She wants to fulfill her obligations, even on the day(s) when her bodymind is distressed due to more severe, menstrual-related

CF symptoms. Interviewees acknowledged that pushing through during these times could do more harm than embracing self-care and rest.

Menstrual-related CF symptoms that infringe upon participants' professional (work, school) and personal lives (family, dating, self-care) challenge women's attempts to push through and exert bodily control. They may have to miss desired activities, raising fears about a less active social life. Ava, a woman in her early 30s, described times when her cyclical sinus congestion and migraines were so severe that she canceled plans. But she still 'pushed through' by continuing to work:

... I do have to cancel plans and stay in bed with a heating pad on the couch or in the bathtub. I have worked from a bathtub before Wow, yeah, I guess it just has become normal.

Hazel, a woman in her late 30s, and Ava mentioned that menstrual-related CF symptoms are "debilitating" and make exercising difficult. For Lisa, a woman in her mid-30s, worsened, cyclical CF symptoms cause depression. Though mood changes during menstruation are common for many non-CF women, navigating multiple health issues and medications compounds women with CF's stress. So, when asked what parts of one's QOL would improve if menstrual-related CF symptoms could be alleviated, Rachel stated:

... everything would be. Like astronomically better: mental health, physical health, my relationship, my family literally everything

3.2.2. Strategies—When their bodyminds become distressed, women with CF apply their embodied knowledge to exert agency over their lives. The types of symptoms identified in tracking influenced their strategies for self-management and revealed how resourceful women were in using their knowledge. Strategies take various creative forms: mitigating symptoms, introducing self-care, changing schedules and routines, and managing their environments. Women create strategies that are inherently flexible to accommodate their bodyminds but are also boundary-setting to optimize functioning when cyclical CF symptoms worsen.

Strategies to Mitigate Symptoms.: Many interviewees tried to alleviate menstrual-related CF symptoms by increasing the frequency of nebulizer treatments, bronchodilators, and airway clearance. They hydrate, take stool softeners or peppermint pills, use a humidifier, a heating pad, or hot/cold compresses, do extra nasal rinses, or see a chiropractor or naturopath. Some schedule their CF clinic visit to coincide with the end of their period when they feel better so their pulmonary function test results are at their best. Others arrange a standing order at an infusion center to receive outpatient IV antibiotics when menstrual-related CF symptoms worsen. Evelyn increases the dose of pancreatic enzymes to help absorb nutrients at meals because they "don't work" during her period, a practice confirmed by many other interviewees. Missy increases pancreatic enzymes three days before the start of her period to prevent intensified CF-gastrointestinal symptoms.

Women with CF also prioritize food choices to mitigate symptoms. They identify triggers and make a variety of dietary shifts from what Sarah, a woman in her late 30s, calls

“eating clean” to eating fewer greasy foods, adjusting dairy intake, consuming more fiber, or reducing artificial sweeteners and processed foods.

Strategies of Self-Care.: Women also incorporate diverse types of self-care practices to relieve exacerbated symptoms. They take short walks or long baths, alter their workout routines, nap, get massages, use essential oils, read, and spend time with animals. Hazel meditates to “not push the physical symptom away but just sit with it.” To address emotional fragility during menses, interviewees engage a therapist, journal, or do breathing exercises, visualization, and mindfulness. All these strategies reflect and produce embodied knowledge.

Strategies to Adjust Schedules.: Interviewees preemptively treat symptoms or proactively make scheduling changes to their routines to address physically and emotionally unstable times; if they do not, disruptions to their routines occur. These disruptions cause women to temporarily relinquish their roles as caregivers, spouses, friends, parents, or sisters, significantly affecting their quality of life. Olivia and Missy said fulfilling role expectations, keeping relationships balanced, and maintaining routines are essential to their well-being because they do not want to “take advantage” of situations or burden others (Goodley, 2013; Toombs, 1995).

Still, women are careful about how they expend energy when symptoms flare. They take breaks or rest during affected days and avoid making plans right before and during their period. They weigh activities’ costs and benefits and decide when they can “push through” and when they need to shift plans. Knowing the expected timing of their menstrual-related CF symptoms helps them institute these adjustments.

Strategies to Manage Environments.: Interviewees leverage their embodied knowledge to strategically manage their environments. They do so to recapture a sense of equilibrium or to transform “misfitting” into “fitting” (Garland-Thomson, 2011). For example, some interviewees keep extra water on hand or tote extra pancreatic enzymes. Others work from home to manage fatigue and menstrual-related CF-gastrointestinal symptoms.

Sources of Strategies.: Self-management strategies come from various sources: experience, trial and error, readings, physician recommendations, and social networks, including the CF community. CF websites, Facebook groups, Instagram, and Discord are some sites where women share strategies to relieve symptoms and rebalance their lives. Interviewees use online platforms to swap ideas about easing menstrual-related CF symptoms and experiences, thereby establishing “repositories of embodied knowledge that complement biomedical conventions of managing CF” symptoms during the menstrual cycle (Mueller, 2021). Drawing from these repositories helps cultivate community bonds. Sophie, for instance, said that CF peers “get it” in ways those without CF cannot. She believes women with CF are “in it together”; that is, they recognize a female-specific illness experience about CF-specific menstrual experiences. These common experiences help women engage in collective forms of care and form close bonds (Price, 2015; Underman, 2022).

3.3. Cultivating the body-self as a menstruating woman with CF

Cultivating and applying their embodied knowledge about the link between disease chronicity and menstrual cyclicality prompted women to reflect on the multiple, interlocking bodily experiences that constitute what Van Wolputte calls the “body-self,” an embodied subjectivity that is always becoming (Van Wolputte, 2004). Women articulated this dynamic form of embodiment by emplacing themselves within and beyond their biosocial community (Rabinow, 1996; Van Wolputte, 2004; DeJarlais & Throop, 2011; Harris, 2021).

Gender and disease form central components of women with CF’s body-self. (Clare, 2013, 2017; Nowakowski, 2019; Willis et al., 2001; Weiss, 1999). Interviewees’ perspectives about how these identities interrelate or overlap were heterogeneous, ranging from integrated to alternating to separate. For Stephanie, her CF and gendered identity are co-constitutive:

I think that having to deal with CF and everything else that comes with growing up as an adult female, has helped me accept CF ... [and] accept having CF as a female.

For Sophie, menstruating women with CF “have a unique understanding of being a woman.” To her, this perspective creates solidarity with her female CF peers because they all feel, “Oh great, here’s another added pile of crap added to my list of crap.” Olivia, on the other hand, gives alternating priority between her identity as a person with a chronic illness and as a woman, revealing the self-presentation challenges chronic illness can pose. Olivia’s words also point to the “identity trade-offs” people with chronic illness make as they weigh their situations (Charmaz, 1995; Kelly & Field, 1996):

I never want my CF to over-define me and limit me in any way, but I think that sometimes I do combine them [being a woman and having CF] ... I don’t always prioritize them equally. I feel that some days, CF defines me, and then other days, I try to push CF into a corner and be a regular woman who doesn’t have all these problems going on in the background.

Talia stated, “I always put more of cystic fibrosis with who I am as an individual, not necessarily being a woman. But the hardships I’ve had to go through have made me a stronger woman.” Claire differentiated her gender identity and her CF identity in constructing her body-self:

... I’ve always separated the two from each other. I have my CF and all that goes with it, and then I have my womanhood and all that goes with it; if they happen to overlap, okay, but I never connected them.

The emergence of CFTR modulators has also contributed to women’s rethinking of their body-self. Indeed, these medications have not only modulated CFTR pathways but also women’s biographies. ETI’s revolution in CF care has led to women’s reappraisal of expectations about their bodies, opportunities, and relationships; with improved prognosis, interviewees have developed new conceptions of their bodyminds as healthier and more functional (Mueller, 2023). Most interviewees on modulators have shifted from experiencing uncertain futures to establishing plans and habits for those with more stable lives. Olivia, for instance, told of the radical impact modulators have had on her life:

I'm able to have the privilege to go to college and do my [medical] treatments and studyand I try to reevaluate and refocus on the things that I do have instead of what I don't have or wish I had.

Some participants, like Jennifer, a woman in her late 20s, even feel like they “don't even have cystic fibrosis anymore.”

Given women's longer life expectancy resulting from effective clinical and drug management, menstruation has come to signal larger issues like pregnancy and fertility. Recognizing that menstruation gives women the biological possibility of having children, interviewees emphasized their family-building expectations. Hazel spoke about decision-making relating to pregnancy and motherhood, emphasizing that “a menstruating woman is being a mom and your choice of whether to go down that path, and it is our choice” Ava talked about the limits of her body in the past and how she was told she would not be able to have kids, leaving her to ponder surrogacy. Olivia linked her ambivalence about having children with the still uncertain future that she recognizes is part of having CF:

... when a lot of conversations come up about death and dying or pregnancies and starting families, I have to view it in a different way than everyone else. To this day, I don't know if I'll be able to have kids. I don't know what my future looks like, and I feel it's really made me appreciate just being in the moment.

3.3.1. Women with CF's body-self as intersubjective and intercorporeal—

Like others with chronic illnesses, interviewees made meaning of their body-self by describing their intersubjective and intercorporeal engagements (Csordas, 2008; Weiss, 1999). Comparisons with others reinforced the key features of identity and embodiment, including intersubjectivity, relationality, sociality, and the constant awareness of one's body (DeJarlais & Throop, 2011; Price, 2015; Siebers, 2016). They enabled women to uniquely situate and distinguish themselves as reproductive-aged women with a chronic disease (Dickel, 2022; Ellingson, 2017; Willis et al., 2001), to define their priorities, elevate the value of health in their lives, and delineate where they fit within their lifeworlds.

One of the ways women discussed their distinct experiences of being a woman with CF was to make contrasts with others in the CF community. Rachel, for instance, highlighted the extra symptomatic burden of menstrual-related CF symptoms, stating, “Guys [with CF] don't have to go through this.”

Comparisons about Normality, Body Image, and Beauty.: Interviewees used the language of normality/abnormality, chronicity, and difference when narrating comparisons, signaling their perceptual entanglements with a highly valued, abled world. These entanglements, in turn, reveal the power of ablenormativity, where “the cultural dominance of a pathology paradigm that assigns values of health, normality, worth, and functionality to normatively abled bodies” is activated and embedded in women's narratives (Brown, 2018). For instance, Stacy articulated how her worsened menstrual-related CF symptoms challenge her self-identity as a “normal person.” Like Olivia, she brackets out CF symptoms and routine disruptions from her self-understanding to maintain a self-image of being “basically healthy.” In so doing, she separates her impaired body from her self-concept to “allay

disquieting fears” about herself and her bodymind (Charmaz, 1995; Parton et al., 2016). When she compared herself to her daughter, for instance, Stacy also highlighted the value of health. She stated, “.... I look at my daughter, who is the epitome of health [and] I literally did not know it was possible for somebody to be this healthy, but evidently, you can be.”

Situating themselves within ableist environments, women described experiences of ‘felt stigma’ and exclusion, reflecting social science insights about the reciprocity between the body and social representation as a critical dynamic in constructing embodied selfhood (Charmaz, 2019; Dickel, 2022; Thomas, 2010; Weiss, 1999). These experiences substantiate Weiss’ idea that intercorporeal encounters with cultures of ableism or sexism can influence individuals’ self-image (Weiss, 1999/2015). Some interviewees saw their status as women with CF as being on par with the second-class status of being disabled in society; they acknowledged the need to navigate society’s notions about the femininity of disabled women (Fausto-Sterling, 2000) and how the “irrevocable difference” between disabled bodies and ableism can “sink beneath our skin” (Clare, 2001; Weiss, 1999).

Discussions about menstruation and gendered subjectivity also cued comments about body image and cultural notions of beauty, often society’s proxy for being healthy. Many women highlighted feeling inadequate compared to American standards of beauty and femininity. These sentiments echo the findings of other studies of women with CF and women with cancer (Johannesson et al., 1998; Parton et al., 2016). Claudia, a woman in her late 30s, for instance, focused on how she did not fit within cultural notions of a feminine body, saying:

.... I don’t have a womanly figure at all. I have this little boy figure, but I have these skinny legs and arms that’s always bothered me I don’t look like some of my peers.

Women defined their unique positionality and priorities by comparing their body image with others, including other women with CF. They elevated the value of health in their lives as a counterweight to feeling inadequate and to articulate a more positive self-image. Olivia stated:

.... I try to tell myself that despite what I think I should look like or what I think I should be, that’s not me. I have this chronic illness I have cystic fibrosis. It redefines things ... I would love to have the hips that all women have and the breasts. But, at the end of the day, so long as my lungs are happy ... I’m not going to be what everyone else is going to be, so I try to make my own definitions, my [own] forms of beauty.

Sophie commented on the issue of body image among women with CF but then couched the issue with regard to her health status and longevity:

There’s a lot of insecurity about our bodies working properly. Yet, on the opposite side, I feel so lucky and amazed that my body is as strong and healthy as it is, considering what I have personally gone through. It still shocks me to think that I’m 37.

Comparisons about Monitoring the Body: Interviewees pointed out that differences in menstrual experiences between abled women and those with CF stemmed from the presence or absence of the body; that is, as Leder has explained, the condition of noticing [presence] or not noticing the body [absence] and being hindered or unhindered, respectively, in routines. For women with CF, whose bodies are always present due to the chronicity of their disease, it is difficult to imagine and relate to “healthy” women’s regular inattention to their menstrual cycle. Olivia observed that she is constantly aware of her menstrual cycle, even though her friends are surprised when their periods start. She attributes this “hyper-awareness” to the comfort gleaned from “knowing what’s going on with my body” and the fear of being “out of control.”

Evelyn described her persistent, present body as well:

You’re constantly aware of things. You know your body better because of it. I can see how people who don’t have as many issues as me may not be able to tell exactly what’s wrong with their body until they see a pattern.

When describing a conversation where she asked her abled daughter about menstruation, Stacy said:

I’ll ask her to get a feel for what’s going on [and] help her know her body, and she says, ‘I don’t know.’ I’m sitting there going, ‘What do you mean? How can you not know? This is what happens to you every day or every month; how do you not know?’ But she does not have to. She has no reason to pay attention because it all just works.

4. Discussion

The case of reproductive-aged women with CF grounds theoretical discussions of embodied knowledge and embodied selfhood with an empirical example of women with chronic illness (Crossley, 2007). It helps scholars understand how women with long-term illnesses, particularly those fewer common conditions that start in childhood, experience and make sense of the intersections between disease chronicity and menstrual cyclicality. It shows how women with CF think about and navigate their bodyminds and illness experiences, actively making decisions to help ameliorate or accommodate symptoms.

Our findings help scholars learn about how women attune to their bodyminds through digital tracking, how they create strategies for self-management through embodied practices to optimize their well-being, and how they make meaning about themselves as menstruating women with chronic disease within the context of their lifeworlds. Like Maslen’s characterization of diagnostic sensemaking, these processes are recursive: when the technique and tool that facilitates embodied knowledge changes, so does the process of knowledge cultivation and the corresponding sensory and material practices it prompts. Accordingly, the application of a tracking tool helps (re)define women’s self-identity and self-relation as menstruating women with chronic illness (Maslen, 2017; Maslen & Harris, 2021). When new strategies are adopted to alleviate symptoms and disruptions to life, interviewees physically and emotionally *feel* something different, again looping back to remake meaning about their being-in-the-world (Turner & Rojek, 2001).

Moreover, as social norms and the cultural, technological, and medical environments in which women with CF live transform, so will their embodied experiences and subjectivity. Such historical exigency is exceptionally salient in the age of CFTR modulators. Drastic changes in women's experiences prompted by modulators have, and will, radically realign women's knowledge and self-understanding about the possibilities and limits of their bodyminds, relationships, and horizons. Whereas much literature on chronic illness chronicles the embodied experience of symptom onset and the different phases of curable, progressive, or intermittent illness (Kleinman, 2020, Charmaz 2020), our study provides insights into the embodied processes by which individuals with lifelong progressive illness adapt to disease-modifying therapies that stabilize disease.

Asking women to digitally track chronic disease symptoms along the menstrual cycle allowed women to cultivate embodied knowledge about the intersection of two phenomena that are often studied as distinct. Our findings mirror many scholarly observations about how digital health trackers and their features co-shape people's knowledge and engage the senses. But the production of the type of embodied knowledge we present here—one that emphasizes overlap and intersection—needs to be studied more. Many discussions of digital tracking focus on people who do not live with chronic diseases. Moreover, analyses of embodied knowledge of people with chronic disease tend to examine those who *acquire* diseases rather than those who have had them since birth. Studying a group of women who are already quite attuned to their bodies (given life with a genetic disease from birth) revealed an even more heightened attunement with tracking. As such, our work shows that tracking can strengthen bodily awareness in already-attuned people and prompt those with chronic illness to develop carefully designed strategies to accommodate further bodily changes. Though it is debatable whether persistent dysfunctions can produce a complete fading of the world for people with chronic disease, we see that the dysappearances produced by cyclical CF symptoms can create even greater awareness of women's bodyminds. Our analysis reveals that women unwittingly use Leder's "absent body" idea to differentiate their embodiment from others.

In our case, women's awareness is very specific as it centers on the type, timing, and severity of cyclical disease symptoms. Such specificity provides women with new information that suggests the reason for the fluctuations. Acquiring this knowledge has positive, affective effects that empower women to predict their symptom patterns, adjust their lives, and rethink their self-understanding. Like Kleinman's "archivists researching a disorganized file of past experiences," our participants developed explanatory models of cyclic fluctuation, which guided behavior modifications to restore agency and improve their quality of life.

5. Conclusion

This study detailed how menstruating women with CF cultivate embodied knowledge about the cyclical patterns of their CF symptoms. This knowledge shapes how they manage their disease, optimize their health and well-being, and make sense of themselves within the contexts of their worlds. Embodied experiences involving other chronic illnesses could mirror the processes we describe in our results.

Generating knowledge about how women with chronic illnesses cultivate embodied knowledge can also improve clinical care. It can help educate physicians who may otherwise doubt women's symptoms due to a lack of scientific evidence. Such skepticism can produce invalidated selves (Charmaz, 2000). Hazel summed up the need this way:

I feel that it's important as a menstruating woman to ... let someone on my CF team know that I've experienced a certain increase in certain symptoms around my menstrual cycle, not because I need anything from them [but for them to be] aware and educated about what other women who are seeing them and who may be starting menstruation or, are already menstruating, may [also] be experiencing ...

In an era where more people with CF are living longer, making processes like the cultivation of embodied knowledge and selfhood legible for medical professionals is a crucial step toward training them how to provide quality care.

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Table 1

Symptoms in Study App

CF symptoms	
Pulmonary symptoms	asthma (wheezing; <i>shortness of breath</i>) <i>coughing</i> hemoptysis (coughing up blood) sputum/mucus production (coughing up mucus) painful breathing pleurisy (sharp pain with inhalation)
Sinus symptoms	<i>headache</i> sinus headache (pain in one or both temples or on the forehead) <i>runny/stuffy nose</i> (defined for study as congestion blocking air; postnasal drip; blowing out more mucus)
Gastrointestinal symptoms	malabsorption (gastrointestinal pain, gas and/or <i>bloating</i> , greasy stools, and/or <i>diarrhea, constipation</i>) <i>bloating</i> <i>bowel movement pain</i> <i>gassy</i> GERD (reflux; heartburn) <i>indigestion</i> <i>nausea</i> stomachache <i>vomiting</i>
Joint symptoms	<i>arthritis</i> (<i>joint pain</i> or tenderness; joint redness; joint stiffness) <i>muscle pain</i> or tenderness
Menstrual and other symptoms	
Menstrual symptoms	abdominal cramps ('menstrual cramps' in the standard app was changed to abdomina cramps in the study app) acne breast pain fatigue mood changes trouble sleeping
Other	dizziness fever food cravings hot flashes itching lower back pain night sweats numbness painful sex painful urination pelvic pain sore throat watery eyes

* Symptoms in italics are part of the standard app but were used in the study app as CF symptoms with specific definitions.