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Younger Women Living with Chronic Disease: Comparative Challenges, Resiliencies, and Needs in Heart Disease and Breast Cancer

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Abstract

Background: Younger women with chronic disease (<60 years of age), especially women with stereotypically “men’s” heart disease (HD), are understudied. Unique difficulties may occur with HD, which is less commonly associated with women, compared with breast cancer (BC). Similarities may also exist across younger women, as chronic disease is less normative in younger people. Intersections of gender, age, and the specific disease experience require greater attention for improving women’s health. This exploratory qualitative study compared younger women’s experiences of HD or BC.

Methods: Semistructured interviews with 20 women ($n = 10$ per disease) were analyzed using applied thematic analysis.

Results: Amidst building careers, intimate relationships, and families, women felt thwarted by disease-related functional problems. Cognitive-behavioral coping strategies spurred resilience, including integrating the illness experience with self-identity. Barriers arose when medical professionals used representativeness heuristics (*e.g.*, chronic disease occurs in older age). Important experiences in HD included worsened self-image from disability, negative impact of illness invisibility, and persisting isolation from lacking peer availability. Initial medical care reported by women with HD may reflect gender biases (*e.g.*, HD missed in emergency settings and initial diagnostics). New information provided by the younger women includes limited illness-related optimism in women with HD facing age and gender stereotypes, as well as the advantages and disadvantages of peer availability in BC.

Conclusions: Greater public awareness of younger women with chronic disease, alongside structural support and connection with similarly challenged peers, is suggested. As advocacy for BC awareness and action has strengthened over past decades, similar efforts are needed for younger women with HD.

Keywords: younger women, heart disease, breast cancer, gender, stereotype, disparity

Introduction

WOMEN’S HEALTH REMAINS understudied, contributing to disparities in medicine.¹ The voices of younger women with potentially life-threatening diseases need to be elevated, especially for the leading causes of mortality: heart

disease (HD) and breast cancer (BC).^{2,3} While no universal age range defines “younger” women with HD and BC, women amid the “social timing”⁴ of life associated with younger womanhood (*e.g.*, biological motherhood⁵) may be conceptualized as “younger.” A commonly accepted age cutoff for the elderly/geriatric population in HD^{6–8} and

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BC⁹-related studies is <65 years old (y.o.), with precedence of women <60 y.o. being described as “younger.”^{10,11} Prior research also demonstrates that women <60 y.o. at the time of diagnosis may be particularly vulnerable in terms of well-being and mental health compared with older women (≥60 y.o.).^{12,13} Thus, for the purposes of the current article, “younger” refers to women <60 years of age.

In addition to the general stresses of chronic disease (*e.g.*, fear of cancer recurrence¹⁴ or another heart attack¹⁵), disruptions experienced earlier in adulthood (*e.g.*, sexual dysfunction, role impairment)^{16–18} and balancing existing social roles⁴ (*e.g.*, motherhood,⁵ employment) result in younger women’s greater psychosocial needs.¹⁹ In fact, younger women with BC experience worse quality of life (QOL) and depressive symptoms compared with both disease-free younger women and older women with BC.²⁰ Younger women with HD may have similarly pronounced psychological distress^{21–23} in relation to impaired age-normative functions, alongside added hardships from gender-related stereotypes for HD.

Typically perceived as a “man’s disease,” the risk of HD in women is often underestimated by physicians,²⁴ with only 21% of diagnosed women having discussed HD with a physician prediagnosis. Opposing the general population reduction in HD mortality, younger women are experiencing increased HD mortality.²⁵ Contributors to this disparity may include the underrepresentation of women in cardiovascular research, gender bias influencing medical practice²⁶ (*e.g.*, doctor/patient gender match affecting myocardial infarction mortality²⁷), and low public awareness. Forty-five percent of women in a U.S. survey were not aware that HD is the leading cause of women’s mortality, with younger women being least informed.²⁸

By contrast, awareness of BC, the most common cancer in younger women,² has risen substantially in recent decades. The synergistic benefit of advances in medicine and public awareness is reflected in increased five-year survival rates. Yet, because BC is more prevalent in older age,²⁹ with a majority of diagnoses in women above the age of 60,³⁰ age-related stereotypes may influence medical care for younger women. Younger women with HD may similarly face age-related stereotypes, compounded by gender-related stereotypes. However, the challenges, resiliencies, and needs of younger women with chronic disease at their common intersection of younger age yet potentially differing gendered disease expectations are unknown.

Qualitative research has the strength of understanding complexity³¹ in the experience of understudied groups with rich description that quantitative studies can lack. Therefore, the primary research focus of the present study was to explore the converging and diverging experiences of younger women with HD or BC, using semistructured interviews. Another goal was to present more information about the psychosocial needs of younger women with HD, given the dearth of research.

Methods

Procedure and participants

With Institutional Review Board approval, purposive samples of younger women with medically confirmed HD or BC were recruited for the study through phone or email. We

first recruited 10 women with HD who were <60 y.o. at the time of their diagnosis, from a list of women’s HD specialty clinic patients agreeing to be contacted regarding their heart condition for awareness campaigns, education, and future research. The HD clinic providing women-specific care (*e.g.*, screening, counseling, postpartum referrals) is housed within the Cedars-Sinai Medical Center in Los Angeles, a large metropolitan medical center serving a diverse population regarding ethnicity, socioeconomic status (SES), and language. For comparative purposes, women with BC exactly matching the HD sample’s ages at diagnosis were recruited. Women with BC were from the greater Los Angeles subsample of a completed longitudinal study involving 19.3% Latina women and covering a broad SES range.^{32,33} The parent BC study examined depressive risk and resilience factors in the year after a primary diagnosis of invasive BC among women with English literacy; all recruited women were willing to be contacted for future research.

Verbal consent was obtained for conducting phone interviews and audiorecording. Two interviewers trained in semistructured interviewing (professional journalist, clinical psychologist) conducted the phone interviews in English. Questions included “Will you please tell me a little about your [heart disease/breast cancer] history?,” “Did you know much about [heart disease/cancer] in women when you were diagnosed?” For all questions see Supplementary Appendix SA1.

Analysis

Interviews were transcribed verbatim by research assistants and checked for accuracy. Interview transcripts were analyzed in NVivo 12 using applied thematic analysis.^{34,35} A primarily inductive analysis method, deriving codes and categories from the data, was appropriate because the goal was to discover similarities and differences in the experiences of younger women with HD or BC, which are not widely examined in the literature. J.H.J.K., B.L.D., E.E.A. familiarized themselves with all the interviews and independently generated initial codes and categories. We created a coding dictionary comprehensively incorporating the data-derived initial codes and categories, and four trained research assistants coded the transcripts. Each transcript was independently coded by at least two coders, and an iterative process was used to resolve coding discrepancies and to revise candidate themes (supervised by J.H.J.K., B.L.D.). The final intercoder reliability exceeded 0.90, indicating excellent agreement.³⁶ Resulting categories and themes were determined by consensus (J.H.J.K., B.L.D., E.E.A., A.L.S.), with the importance of themes determined by contribution to understanding the range of women’s experiences rather than by frequency counts. Although the analysis was primarily inductive, final categories and themes were partly informed by psychological literature and concepts (only when best representing the data), consistent with the background of the analysis team. However, the analysis was not predetermined by psychological theory. Theme saturation was achieved by the sixth interview for both groups, using the CoMeTS procedure.³⁷

Results

Twenty women ($n=10$ per disease) diagnosed before 60 y.o. ($M_{age\ at\ diagnosis}=45.2$, $SD=8.6$, $range=34–58$) participated; we included a woman diagnosed at 58 y.o. in each

group because they shared the common “social timing”⁴ of motherhood with other younger women in the study. The ischemic HD-diagnosed sample ($M_{age\ at\ interview}=52.2$, $SD=9.8$, $range=37-64$) included seven white women, one Black woman, one Latina, and one Asian woman; nine of 10 were mothers. Diagnosed with primary invasive BC (stages I-III), the BC sample ($M_{age\ at\ interview}=52.3$, $SD=10.4$, $range=37-66$) included six white women, three Latinas, and one Asian woman; five of 10 were mothers. The average age at diagnosis for the remaining nine women in each group was 43.8 ($SD=7.7$, $range=34-53$). Time since diagnosis at interview averaged 7.00 years ($SD=4.56$) and 7.10 years ($SD=2.38$) for HD and BC, respectively. Interview duration averaged 34.14 minutes ($SD=8.98$) and 37.30 minutes ($SD=17.17$) for HD and BC, respectively.

Four main themes (Coping and Resilience, Processing Identity, Implications of Social Norms for Chronic Illness, and Personal Account of Illness-related Challenges) demonstrated similarities and differences across women with HD and BC. Qualitative distinctions are described below. Supplementary Appendix SA2 documents the number of women represented in each theme, by chronic disease type.

Theme 1: coping and resilience

All women demonstrated resilience through prior and continued use of active coping strategies (Table 1). A majority of women in both groups described cognitive coping strategies encompassing helpful thoughts or reframing illness. These included: acceptance, gratitude, meaning making, reaffirming values-based priorities, and mentally drawing upon sources of strength (children, spirituality). All women used behavioral coping strategies such as increasing social interactions, problem solving, and self-care.

Although women with HD implemented both cognitive and behavioral coping, women with BC reported a wider variety of cognitive strategies, and no women with HD described present-minded or self-affirming thoughts. Most women with BC described optimistic thinking, such as knowing “*everything was gonna turn out fine*” and from knowing other family members who “*lived to a healthy, ripe old age*.” Women with HD did not describe past or present optimism about disease outcome. Regarding behavioral coping, all women with BC discussed social interaction, and most were involved in giving back to the community or advocating for others with BC. In contrast, few women with HD described such coping. Additionally, no women with HD described involvement in self-development activities such as cultivating new skills/hobbies or pursuing career advancement.

Theme 2: processing identity

Processing personal identity was prominent throughout, with descriptions of illness-related changes in participants’ views of womanhood with regard to youth, normative roles, and goal achievement (Table 2). Comparative processing was common, for example to societally normative roles for healthy younger women such as “*having kids, having careers*,” which may have become compromised. Women also described whether they had integrated the chronic illness into their identity and whether their current self-image had improved, remained constant, or had worsened since diagnosis.

Both groups of women described occupational losses, but only women with HD reported a permanent inability to work. Similarly, women in both groups described interruptions in social roles (*e.g.*, mother, partner); however, women with BC described reduced capacities, whereas women with HD reported complete losses such as being unable to pick up their children, have sex, or give birth. Regarding perceptions of youth, only women with BC described physical changes and accelerated aging as a result of treatment.

Along with permanent occupational or social losses, no women with HD described integrating the illness into personal identity. Rather, women with HD expressed feeling completely engulfed by HD and having lost a part of who they once were. Although two women with HD mentioned an improved or unchanged self-image, the remainder described a compromised self-image. In contrast, no women with BC described feeling engulfed by cancer; instead, most characterized cancer as a small part of personal identity, with self-image being improved or unchanged.

Theme 3: implications of social norms for chronic illness

Women alluded to existing social norms for chronic illness (*e.g.*, expected symptom profiles, recovery timelines) and their implications across multiple domains (*e.g.*, available medical care, self-expectations, family/public support) (Table 3). Both groups described an initial lack of physician concern:

“I had higher than normal cholesterol since I was in my early 20s ... but [no doctor] ever felt it was a big deal ... I had a heart attack, and a double bypass. One artery was 99% blocked. My cardiologist says that, except for one person—who was overweight and smoked—she had never seen a patient who presented [as severe] ... No point in [being] angry about it, but [I’m told] had I been properly tested, even in my 20s, problems would have shown up.” (HD participant S)

“‘Oh I found this lump,’ and the doctor’s like, ‘You’re too young,’ ... then you wait a year, and the situation’s much worse.” (BC participant G)

However, women with HD also presented examples of gender bias in emergency care and with diagnostics:

“The cardiologist in the ER said an angiogram showed my arteries were visually perfect, nothing was going on. That episode eventually was determined to be my first heart attack ... [a women’s cardiologist] diagnosed coronary microvascular disease.” (HD participant Q)

“[A friend with chest pains] went to the [ER], got put in a waiting room. By the time they got to her, she was in a full-fledged heart attack. While she was waiting, a man came in [with heart attack symptoms]. They treated him immediately.” (HD participant S)

Some women also described an initial lack of personal awareness about HD or BC in younger women, which related to being surprised at diagnosis. All women with HD expressed being initially unaware that HD was the leading cause of younger women’s mortality or that women experience different symptoms than men:

“[while] being wheeled away in the ER ... ‘Does your left arm hurt? No? Then it can’t be a heart attack.’ How I thought I had food poisoning and waited all night before coming to the hospital.” (HD participant T)

TABLE 1. COPING AND RESILIENCE EXAMPLES

	<i>Heart disease</i>	<i>Breast cancer</i>
Cognitive		
Acceptance	<i>"I'm acutely aware that I can't do [daily activities at the same capacity] I did [before], but I'll be OK. I've hit a "reset" button." (HD participant T)</i>	<i>"You are in flux. You have never been one thing, and you will never be one thing. And if you can accept you for you, then a lot of the suffering in your whole life goes away." (BC participant J)</i>
Gratitude	<i>"I'm blessed that the heart attack gave me a chance to step back from a crazy life." (HD participant N)</i>	<i>"I would not be here, being the person I am today. It made me really more appreciative." (BC participant B)</i>
Meaning making	<i>"God has me here for a reason." (HD participant S)</i>	<i>"I think a lot of people probably go down like a fear of dying path, but for me, it was more about: "Oh my gosh, I must be called to do something really amazing, once I recover. I hope I'm going to be up to that." (BC participant C)</i>
Normalization	<i>"As long as I can take care of myself physically, emotionally, spiritually. Your body isn't the only thing." (HD participant L)</i>	<i>"Every time you have to deal with those things [that] sort of build you, you start to learn to just cope ... and know that you can continue on. So, was it just breast cancer? No. I think it's been a number of things over the course of my life." (BC participant A)</i>
Present-minded	N/A	<i>"I should enjoy this moment because bigger things could happen." (BC participant D)</i>
Self-affirmation	N/A	<i>"I have found a lot of positive things in this experience. I feel kind of proud of myself for that." (BC participant G)</i>
Sources of strength	<i>"I live pushing through that pain, trying to be a good example to [my kids] ... [They] drive my will to keep fighting." (HD participant Q)</i>	<i>"When you have cancer, you don't know what's going on in your body. It's kind of out of your hands. [So] I depend more on God now." (BC participant I)</i>
Value-centered	<i>"Life is precious; [we need to] be thoughtful about priorities." (HD participant N)</i>	<i>"I try to deal with life differently, and I had to let go of a lot of superficial stuff and focus on what was really important." (BC participant H)</i>
Positive mindset	<i>"I think, with everything that happens to me, I learn something [that] adds to my bag of tricks! I can grow." (HD participant N)</i>	<i>"I've stayed very positive and knew I was going to do everything in my power to beat everything." (BC participant F)</i>
Behavioral		
Social interaction	<i>"I found WomenHeart [and] got trained to be a speaker. At the training, I met a woman my age. She became a good friend. There's a lot we don't have to say – she gets it." (HD participant S)</i>	<i>"Other women that have gone through it, we chat about it, and there were three of us that were about 3 months apart, and we got together and talked about our experiences and, "What are you doing about this?" and offered hints and things." (BC participant E)</i>
Giving back/advocate	<i>"I'm a spokesperson for [several heart-associated] groups." (HD participant Q)</i>	<i>"I also feel like I've been able to mentor other women to help them understand the relationship between stress and disease so that they don't have to go down the path I went down." (BC participant C)</i>
Problem focus	<i>"I can sweep the kitchen floor, but I can't bend down to pick up. I learned to pick up toys with my toes!" (HD participant K)</i>	<i>"I found a way to keep my hair... which was very helpful, in terms of maintaining my dignity and feeling healthier than I probably was going through it." (BC participant C)</i>
Self-Care	<i>"I was doing yoga and meditating before; now, I do more. I've made other changes ... I pace myself more, rest more." (HD participant L)</i>	<i>"I became more aware and involved with my own self-care." (BC participant C)</i>
Self-development	N/A	<i>"I love to travel. I like to experience new things. I'm learning a new language. I'm trying to. Well, I speak four languages already. I'm thinking about going back. I want to learn some self-massage therapy to ease anxiety in kids." (BC participant B)</i>

HD, heart disease; BC, breast cancer; N/A, not applicable.

TABLE 2. PROCESSING IDENTITY EXAMPLES

	Heart disease	Breast cancer
Interruption by illness		
Goal disruption	<p>“I tried going back to corporate America. I wasn’t well enough, landed in the hospital again, and got fired. They said, ‘if you’re not back at your desk by Tuesday, you’ll be terminated.’” (HD participant S)</p> <p>“I still can’t work ... The first thing [new] people ask is, ‘What do you do?’ And I say, ‘I don’t do anything. I’m disabled.’” (HD participant Q)</p>	<p>“But ultimately, it changed my career path. It kind of screwed up my career. I was about to get a big promotion at work, and then I had to take a bunch of time off work, and then that job was gone.” (BC participant G)</p>
Loss of normative roles	<p>“I’ve been told I can’t have children. It [all] sucks!” (HD participant T)</p> <p>“[It’s] like having my hands tied. Little faces looked up at me, and I couldn’t do anything. I can’t have sex. I can’t do anything!” (HD participant Q)</p>	<p>“It was really hard the second time, because I was trying to care for my kids, and trying not to be a burden on my mom or anyone else ... I needed help. I needed to let people do things for me and for my kids.” (BC participant H)</p>
Loss of physical youth	N/A	<p>“I got really wrinkly, all of a sudden. It really aged me. I couldn’t touch my toes anymore, like I still have my mobility issues where the surgery was. It made me feel old.” (BC participant J)</p>
Illness-self conceptualization		
Acceptance or enrichment	N/A	<p>“It’s part of my life. It’s part of what I am. And I would not be here, being the person I am today.” (BC participant B)</p>
Engulfment	<p>“I don’t know who I am with this. I’m not a whole person ... bottom line is, I’m a different person now.” (HD participant T)</p>	N/A
Compartmentalization	<p>“Life is precious; [we need to] be thoughtful about priorities, I don’t think of myself as a sick person ... I don’t say ‘heart disease.’ If I’ve had heart attacks, does that mean me?” (HD participant N)</p>	<p>“I just feel like I’m just living my life ... I’ll think about it twice a year when I go see my oncologist ... but other than that, I don’t honestly think of myself as a breast cancer survivor... It’s just like, ‘Wow, I’m just living.’” (BC participant C)</p> <p>“Cancer’s just one aspect of my life.” (BC participant J)</p>
Resultant self-image		
Improved	<p>You ask about self-image. Well, to be literal ... I’m more fashionable! Yoga pants and sweatpants are “sick clothes” to me now. (HD participant T)</p>	<p>“After breast cancer, I’m probably more confident ... I realized I had nothing to be insecure about [my appearance] before, having my breast removed or losing all my hair, my eyebrows not growing back ... Things like that [are] very superficial.” (BC participant H)</p> <p>“I’m more outspoken now, compared with years ago. And I believe more in myself, too ... It [gave] me ... more confidence” (BC participant I)</p>
Unchanged (positive meaning)	<p>“No [change in view of myself]! ... I’m still me.” (HD participant M)</p>	<p>“I still feel beautiful and sexy ... That’s who I had always been. And that, cancer didn’t change ... putting makeup for the first time in who knows how long, [4-year-old son] was standing behind me ... and he said to me, ‘Huh! Mama, you look like a princess.’ Even though I did not have hair, and I did not have my eyelashes, and I did not have eyebrows, and I was bloated, I had never felt more beautiful in my life.” (BC participant B)</p>
Worsened	<p>“Yes, I do [think differently about myself]. It makes me sad. I don’t feel as strong as the woman next to me.” (HD participant K)</p>	<p>“[My] ego, I think, was based on how smart I was, or at least how quickly my memory worked, and so I could rely on it. So, when that went during treatment—it’s not come back fully, and that’s tough.” (BC participant J)</p>

N/A, not applicable.

TABLE 3. IMPLICATIONS OF SOCIAL NORMS FOR CHRONIC ILLNESS EXAMPLES

	<i>Heart disease</i>	<i>Breast cancer</i>
Awareness/expectations		
Doctors not concerned (due to gender or age)	<p>“I was ... fit, a 25-year vegetarian ... On a tread mill [in male cardiologist’s office] I got the sharp chest pain again. I was so glad because I thought, ‘Now he’ll see what’s going on’. He said, ‘It couldn’t be your heart’ and [sent me] to a gastroenterologist. I spent the next year having every possible part of my body checked ... At the end of the year, I couldn’t walk from the house to the car without blinding chest pain. The last doctor said it was anxiety and prescribed antidepressants. [On my own] I went to a [women’s cardiology clinic] ... [cardiologist] found three blocked arteries, including one 98% blocked. She did an immediate triple bypass and saved my life.” (HD participant R)</p>	<p>“[My doctor said] ‘it doesn’t really look like anything. Do you want to wait 6 months to just do a follow-up?’ and I was like, ‘Well I’d rather just get this out of my mind.’ And he’s like, ‘Well you know biopsy’s painful, and I don’t know if your insurance will cover it.’ I was like, ‘Well I’d really like to do that. Can we look into it?’” (BC participant J)</p>
Lack of/limited personal awareness	<p>“The night before [the heart attack], I swam a mile, and noticed I had little stamina. The next day, I was sort of uncomfortable, but I went to work. I felt a little nauseated... I went to bed, but soon woke up restless and uncomfortable ... The second night, I was nauseated again ... I went back to sleep and woke up fine...when I finally went to the ER late that afternoon, my troponin was 15, showing I’d had a heart attack ... My heart attack symptoms were typical of women, but I didn’t know that ... They did a grand rounds on me ... because they wanted medical students to know that [some women] ... present with no risk and often no [typically male] symptoms.” (HD participant O)</p>	<p>“And I thought breast cancer was for people who had more breast than I do, and I would joke about, when I would get mammograms that, ‘Oh, this is crazy. I should just have a chest x-ray since I’m very small-breasted.” (BC participant D)</p>
Public/family unaware	<p>“Why don’t women know about it? Still? What’s our brand? We don’t have a brand. All those pink ribbons. The [level of] heart disease awareness versus breast cancer awareness, we’re not even in there. It isn’t better... What can we do? Women aren’t afraid of heart disease, but they see pink ribbons everywhere.” (HD participant Q)</p>	<p>“[Coworkers] couldn’t understand why—because in the past, usually, cancer is related to like older people.” (BC participant I)</p>
Sharing about illness		
Circumstantial	<p>“Occasionally, I’ll reveal it if I think it would be helpful [to the person I’m talking with.] Otherwise, I don’t share.” (HD participant O)</p>	<p>“I don’t really like to bring it up that much either ... It depends on the situation. I’m not hiding it, but it’s not something I always tell everybody.” (BC participant G)</p>
Openly/consistently	<p>“I don’t feel I have to hide it. Might as well get it off my chest. Since I’m not getting much support around here, why not get it [somewhere else?] I talk [to people] in the waiting room.” (HD participant P)</p>	<p>“For me, being an advocate, talking about it openly, the same way I talk about my divorce, or my car, or my job, or my dog, is a real part of my life. Just instead of hiding it.” (BC participant J)</p>

(continued)

TABLE 3. (CONTINUED)

	Heart disease	Breast cancer
Peer availability consequence		
Comparisons (re-experiencing, self-minimizing, guilt, worry)	N/A	<p>“I hear of another family friend get it. And then I worry about them, and then they ask me questions, so then, I re-live those moments, and I’m like, ‘Oh yeah that did kind of suck.’” (BC participant D)</p> <p>“And not a lot of people on this journey ended up my way—or even less sick than I was—that are no longer here. And I am still here ... I experienced a sort of survivor’s guilt because I had some friends who died.” (BC participant B)</p> <p>“It’s really scary to see people who were doing fine, and then a couple months later, they’re gone. And so, you’re like, ‘that can happen to me, it can happen to anyone.’” (BC participant C)</p>
Isolation	<p>“Right off, I felt isolated. Alone. I knew no other woman who’s had a heart attack. I knew two men ... I was alone in the experience.” (HD participant O)</p>	N/A
Inadequate support		
No change in family behavior	<p>“The family ... my husband and the extended family, not my children. I feel so hurt over this ... They think I’m making excuses [to avoid working]. Even a heart attack didn’t convince them!” (HD participant K)</p>	N/A
Fleeting support	N/A	<p>“When I was first diagnosed, it was like, a lot of support, a lot of worry, and then now, I think that has gone away. And yeah, I don’t know ... but now, it’s kind of going back to the status quo.” (BC participant G)</p> <p>“I think everyone was really happy to get back to normal as quickly as possible. And that made them more comfortable, which, I don’t think is the happiest thing, but that’s how people are, right? They just don’t want to deal with it, so as quickly as you could look normal and act normal and be normal, the more they can not think about, not only your mortality but their own.” (BC participant J)</p>
Negative health provider interactions	<p>“My discomfort with doctors is, they don’t have enough time.” (HD participant N)</p> <p>“The meds, especially, bother me. Before, I wouldn’t even take Tylenol! In the hospital, I asked a nurse, ‘How long will I be on this?’ She looked at me incredulously and said, ‘Forever!’ That was the first time I cried.” (HD participant L)</p>	<p>“I just feel rushed ... I usually kind of come in with a list of questions, just like rattle them off real quick. She gives me her quick answers, and it’s not like she’s pushing me off, but I do feel like, ‘Okay, like, I’m low priority to her probably. I’m five years out. My cancer wasn’t crazy aggressive.’ ... maybe I’m imagining it, but, kind of annoyed, like if you ask too many questions and really want answers ... it’s like, ‘I have way more important cancer patients to get to than you.’ And I mean, she’s not saying that, but it’s just like, ‘I’m below level here. I don’t want to waste her time.’” (BC participant G)</p>

(continued)

TABLE 3. (CONTINUED)

	<i>Heart disease</i>	<i>Breast cancer</i>
Invalidation/ minimization	<i>“I told an employer my situation and it back-fired. Now I’m more careful.”</i> (HD participant T)	<i>“I still remember calling into the nurses ... that I didn’t feel good and my nose is bleeding, and this and that and they would just not have as much compassion ... and say, ‘You know, honey? You’re going through chemo.’ Uh, yeah, thank you, I do realize that. But it’s like when you’re in that place—sometimes you just want someone to say, ‘Why don’t you try this?’ Or just—I don’t know. I guess I was searching for some sort of support.”</i> (BC participant H) <i>“[She] kind of threw the cancer thing in my face, and it really hurt. She was like, ‘You know what? You have to figure out your career. You have to figure out your life. I had cancer too, and I was able to keep working afterward,’ and blah blah blah. And that really hurt.”</i> (BC participant G)
Lack of formal support	<i>“I was sent home with binders full of information, but nobody prepared me for the emotional roller coaster I was about to get on ... Nothing about depression or the psychological side.”</i> (HD participant S)	N/A

N/A, not applicable.

After diagnosis, both groups of women found psychological support through their primary medical specialist, family, and friends, but reported inadequate or absent support during the illness experience and in survivorship. Some women described occasionally feeling unimportant and rushed at doctors’ visits. Interactions with doctors were important, particularly the appropriate balance of responding empathically and not overemphasizing the severity of the illness. A continued overemphasis on disease by family and friends was viewed as unhelpful, as was communicating that “everything is done” and “back to normal.” For two women with HD, family reacted with disbelief regarding their disease or symptoms, and family members’ unchanged attitudes discouraged their coping efforts.

Notably, only women with HD did not mention formal support (i.e., staff psychologists or connection to other younger women with HD). Women with HD wished for their own community, which they were not sure was available.

“How I would love a community [of supportive women] ... It would change my life!” (HD participant K)

“I don’t know where to go ... All these [support groups for cancer]! Where’s our support group, I want to know! ... I’d like to talk to other women who’ve had a heart attack.” (HD participant P)

Consequently, only women with HD described persistent isolation due to not knowing other younger women with HD.

“I’m alone in this. Very alone. I need a connection ... make sure we’re not left out of the conversation. I have another 35–40 years on this earth and I’d like to have friends who can help me understand how to live them ... We’re not all old!” (HD participant T)

The need for different types of formal support, such as childcare or tailored cardiac rehabilitation, was also evident.

“I’m not going to cardiac rehab. We’re raising our three grandchildren – I can’t afford it.” (HD participant P)

“I eat well, exercise, am not overweight, and don’t need to manage my cholesterol! [Cardiac rehab] was useless for me. I was discounted.” (HD participant O)

In contrast, women with BC knew of and formed supportive relationships with other younger women with BC, but peer availability also prompted making comparisons and triggered negative thoughts and feelings (e.g., re-experiencing, survivor’s guilt, worry about mortality).

Despite differing levels of public awareness, availability of younger women-specific structural support or peer availability, the two groups similarly felt greater awareness was warranted, and they shared their experience with others when appropriate.

Theme 4: personal account of illness-related challenges

Women also provided accounts of HD- or BC-related challenges, apart from their identity or societal norms about chronic illness (Table 4). These comprised reflections about the illness trajectory and symptoms, including functional limitations, control perceptions, the disease’s impact on others (e.g., young children), and the visibility/invisibility of illness.

Broadly, all women reported increased demands on daily living compared with prediagnosis. Both groups described symptoms of pain, depression, anxiety, fear, uncertainty, and loneliness. For example, women expressed generalized feelings of uncertainty and concerns related to disease progression. However, women with HD described low daily QOL due to functional disability, emotional suffering, complex medical regimens, and they viewed pain as

TABLE 4. PERSONAL ACCOUNT OF ILLNESS-RELATED CHALLENGES EXAMPLES

	<i>Heart disease</i>	<i>Breast cancer</i>
Control		
Gaining control by making choices	<i>“The doctor wants me on meds, but I’ve taken myself off everything but aspirin. And, I switched to [named cardiologist] so I could talk to a woman specialist.”</i> (HD participant O)	<i>“I made the personal decision to not have radiation.”</i> (BC participant A) <i>“I shaved my head. I did not lose my hair ... I know that I would have lost my hair which is why I shaved it.”</i> (BC participant D)
Perceiving little control	<i>“Even with medications forcing [blood] vessels to dilate, I had a stroke 3 months ago. It was bad. It upsets me that I can’t really do much to control this disease.”</i> (HD participant Q)	<i>“You cannot know everything, like where the cancer comes from, or things like that, so that’s something out of your control ... Because you never know what’s going to happen. You never know if the thing that we do will work.”</i> (BC participant I)
Impact on others		
Negative	<i>“Yes. It’s especially affected my [younger child]. If I don’t feel good, [the child] is afraid and is always checking me out. The older [child] is less so, but [the fear] is there.”</i> (HD participant R)	<i>“My husband ... it bummed him out ... He just wanted to pretend it didn’t happen. His drinking picked up ... My existence for at least a year just caused people around me to have to deal with a crisis, or at least something in their life changed, and who they are really showed up with how they responded to it.”</i> (BC participant J)
Positive	N/A	<i>“My son and daughter have both over the years written me cards ... I think just viewing my strength and resilience probably helps them. It reflects that in them, that they see it in themselves, too. And I think it’s helped them when they’ve had some tough times in their own lives. They’ve referred to my example like basically, ‘If you can do it, I can do it,’ that kind of thing.”</i> (BC participant C)
Negative sequelae		
Increased demands in daily life	<i>“The doctor who told me about the tachycardia said, ‘if you were my daughter, I’d tell you to get really tuned in to your body, and then, avoid those things that start it.’ That’s what I did. After a while, I could tell what I could and couldn’t do. I couldn’t bend over to pick something off the floor. That, often, would start it, but once, it happened when I kissed my [child] goodnight. I couldn’t drink out of a straw and walk at the same time ... A shower couldn’t be too hot or too cold ... My life is extremely monitored.”</i> (HD participant K) <i>“I’m not a pill-taker, and now I have to take four or five pills a day just to stay alive.”</i> (HD participant P)	<i>“I cannot wait until the last day. Literally, every time I go to the doctor, I’m like, ‘Can I quit now? The tamoxifen?’ It reminds me daily, ‘Oh, I went through breast cancer.’ So, I can’t wait for the day where it’s my last pill ... I am constantly worried that’s going to lead to uterine cancer.”</i> (BC participant D) <i>“Just sometimes, bone pain still exists. I don’t know if it ever goes away. I’m into six years, and you still have things in the back of your mind. Bone pain, you just deal with it. You just do what you [have to] do.”</i> (BC participant F) <i>“I still get scans every 6 months, and I still go in once a month for my Lupron, and still feels very much a part of my life.”</i> (BC participant G)
Pain	<i>“Pain scares me [more now,] because I’m afraid of having another heart attack ... Normal people could handle the stress of [uncomfortable interpersonal interactions], but I get chest pain.”</i> (HD participant K)	<i>“Well, with radiation, that’s pretty painful. My skin reacted pretty poorly to that. And then I had lingering chest pain and rib pain from radiation that lasted probably a couple years. And I still get pain, and I tell the doctors, you know, it’s... from radiation, from surgeries, it’s just kind of lingers. But I mean, no. It’s nothing terrible at this point. And I also get pain—I don’t know if this is related to your question, but I have a lot of stuff. I have a lot of side effects from the hormone therapy. That’s a whole other story. There’s all sorts of bone and joint pain and just feeling like an old person.”</i> (BC participant G)

(continued)

TABLE 4. (CONTINUED)

	<i>Heart disease</i>	<i>Breast cancer</i>
Depression	<i>“The depression [I have] is from not being normal. I question why I’m here. Why me? The suffering hasn’t let up at all.”</i> (HD participant Q)	<i>“I mean, I did have depression. I mean, I’m here now obviously. I had all this. Moments... I mean, it’s either that, or you fall into a really dark... kind of depression.”</i> (BC participant B)
Generalized fear and uncertainty	<i>“[Now], I live with a certain amount of fear and anxiety. Definitely.”</i> (HD participant R)	<i>“You definitely think about the future and how it’s going to impact you.”</i> (BC participant A)
Fear of illness progression	<i>“I do [have fears.] I’m aware it could happen again. I live with the concept of ‘will it hurt?’”</i> (HD participant T) <i>“I’m afraid of dying and leaving my children – I’m not ready to die! I’m afraid I’ll have [another] heart attack. I really try to embrace the positive but the fear [continues] on a regular basis, especially when I feel my heart go ‘blip.’”</i> (HD participant L)	<i>“They can’t tell you these things. They say, ‘Oh yeah. You’re cured.’ But then when it came back again, that really scared me, and I was like, ‘Well, now what?’ Well, now there’s no safety I feel like. If it comes back next year, then what?”</i> (BC participant H)
Loneliness	<i>“I don’t talk to many friends because I’m off work ... It’s very stressful and lonely. I’d like to talk to other women who’ve had a heart attack.”</i> (HD participant P)	<i>“You feel that nobody else understands what’s going on with you, with your body, and with everything you’ve gone through.”</i> (BC participant B)
Illness visibility		
Invisible	<i>“No [support] at all [from my family] ... There’s nothing they can see. I look OK. [You] can’t tell from looking at me that I’m sick ... [I would like] tips on how to deal with family when they think there’s nothing wrong, because [this] doesn’t show! ... patients’ families should go to a support group or class to learn their impact [on the patient], how ... to give loving support.”</i> (HD participant K)	<i>“especially with the Penguin Cold Cap I didn’t lose my hair, so the outside world didn’t really see a difference in how I looked. And that was helpful cause I didn’t have to go into those conversations in line at the market.”</i> (BC participant C)
Visible	N/A	<i>“The way people treated me because I didn’t have hair, and I didn’t have eyelashes or eyebrows, and people not making eye contact with me, not wanting to help me. For the first time, I realized what it was like for somebody who perhaps had a disability or didn’t look like the way society expected them to look ... bad swelling, my legs looked like tree trunks, and all you could see were little bones for my toes.”</i> (BC participant J)

unpredictable and potentially life-threatening. Although daily living for women with BC also involved additional medications, their altered QOL primarily involved symptom management (worrisome thoughts about cancer recurrence, memory decline, residual pain) and fear, which was buffered, for some, by being in remission.

The nature of symptoms and treatment procedures also related to women’s sense of control. Both groups described instances of very little control. Women with HD perceived little control over when they might experience a heart attack, heart-related symptoms, and symptom interference with daily life. Women with BC perceived little control over the causes of cancer, treatment outcomes, or survival. In terms of gaining control, two women with HD and a majority of women with BC described making choices and being proactive with physicians to obtain the care they preferred. The

women with HD described switching to a “woman specialist” or reducing medications. Women with BC described choosing a mastectomy over lumpectomy (or vice versa), preemptively shaving head hair and freezing eggs before chemotherapy, or foregoing radiation/surgery. Although women with BC recalled many opportunities to make treatment choices, the accompanying sense of control could feel overwhelming due to uncertain outcomes.

The experience of women with HD and BC differed in two additional ways: the disease’s impact on others and its visibility. Women with BC felt that the illness had both negative and positive impact on others, whereas all women with HD reported only negative impact on others. For women with BC, positive consequences included instilling resilience and thankfulness in children, family members’ increased gratitude for life and one another, and increased respect from

family members. HD survivors' negative consequences included family members' increased worry and fear for the women's health and survival, financial and psychological hardships for partners, younger children not understanding chronic illness, and added responsibilities for family members.

Women in the HD sample described their disease as largely invisible, which had negative consequences. Women explained that family members continued to worry about their health or responded with disbelief because they "look normal" without visible indicators of illness. In comparison, women with BC described disease-related changes that were both visible (hair loss, reduced skin elasticity, changed or missing breast tissue, body scars, aged appearance) and invisible (e.g., cessation of menstruation, hot flashes). For women with BC, the visibility of cancer (losing hair, changed or missing breast tissue, body scars, aged appearance) was most challenging when social or intimate relationships were disrupted, and self-esteem was compromised. For one woman with BC, however, physical visibility of BC created opportunities to start a dialog with her family. Unlike women with HD, women with BC described ways to achieve invisibility or look "the same" through clothing and breast reconstruction positively or as a signal of recovery.

Discussion

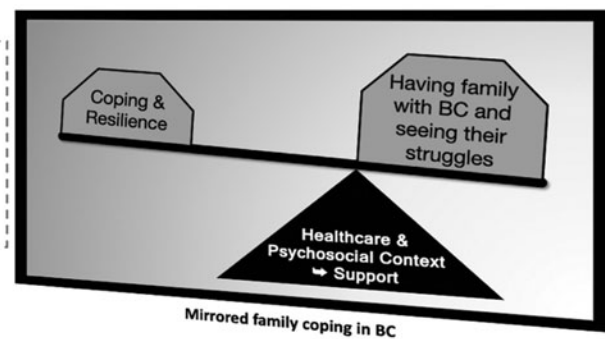
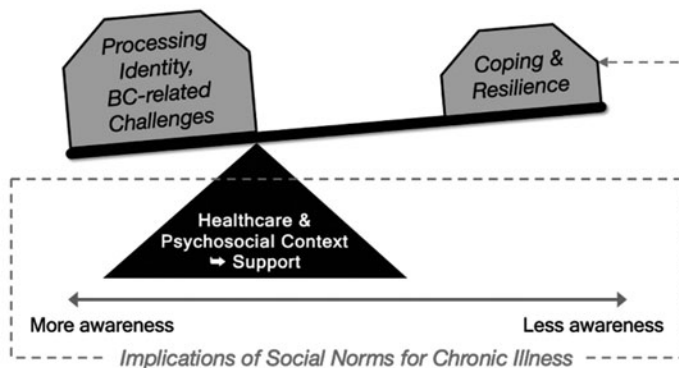
Findings highlight the potential cascading influences of age and gender stereotypes regarding chronic illness on younger women. Younger women with HD and BC had

similarities as "atypical" younger women, per societal expectations, including experiencing barriers to diagnosis and high-quality medical care. Limited public knowledge may increase difficulties in important life domains such as intimate relationships, occupational advancement, and child rearing, which were threatened by the onset of HD or cancer. Women counteracted the heavy demands of chronic illness and self-identity renegotiation with approach-oriented coping and interpersonal support. Figure 1 depicts this balancing act on a lever with illness demands "load" force on the left and individual coping "efforts" force on the right, with the degree of difficulty determined by where the fulcrum (balancing point) is positioned.

Associated with age stereotypes of chronic disease (i.e., illness occurring in older age), the lever may remain tipped toward illness demands for both groups of women; but notably, the lever may be more tipped toward demands for younger women with HD due to additional gender biases (low societal awareness) and their largely invisible disease. The medical and psychosocial demands on younger women with HD may outweigh their resources, especially if tangible support is absent. This potentially greater imbalance for women with HD vs. BC may be mirrored in familial coping, captured by the groups' differing accounts of how the disease influenced their families.

Additionally, both groups' descriptions brought forth added or diverging information from previous literature (Table 5), particularly with implications for women with HD. First, contrary to previous studies⁶ of women with HD,

Breast Cancer



Heart Disease

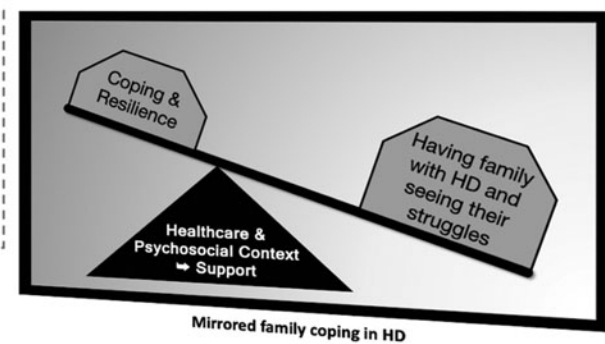
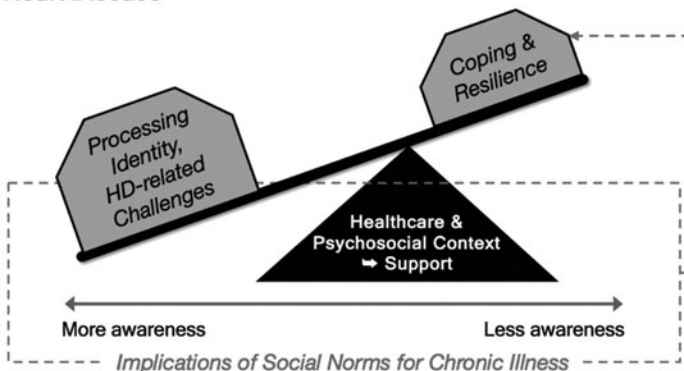


FIG. 1. Balancing demands and resources for young women with chronic disease.
Note. Themes are italicized.

TABLE 5. SUMMARY OF INFORMATION PROVIDED BY YOUNGER WOMEN WITH CHRONIC DISEASE

<i>Supporting previous literature</i>	<i>Added or diverging information on younger women</i>
<p>Chronic Disease</p> <ul style="list-style-type: none"> ● Identity negotiation ● Active coping ● Increased psychological and physical symptom burden (<i>e.g.</i>, depression, pain) ● Prevalent fear of recurrence ● Ambivalence about being a “survivor” <p>Women with Chronic Disease</p> <ul style="list-style-type: none"> ● Using a variety of coping strategies <p>Younger Women with Chronic Disease</p> <ul style="list-style-type: none"> ● Barriers to earlier diagnoses related to representativeness heuristics (age stereotype) ● Distinct psychosocial needs compared with older women with chronic illness ● Loss of normative roles (<i>e.g.</i>, impaired in continuing parental tasks as before) <p>Younger Women with Heart Disease</p> <ul style="list-style-type: none"> ● HD risk underestimated ● Inadequate support ● Disbelief from family members²⁷ <p>Younger Women with Breast Cancer</p> <ul style="list-style-type: none"> ● Distress due to disease/treatment-related menopause and infertility ● Negatives of illness visibility 	<p>Younger Women with Heart Disease vs. Breast Cancer</p> <ul style="list-style-type: none"> ● <u>Illness identity</u>: <ul style="list-style-type: none"> ○ Engulfment (HD) vs. Acceptance/Enrichment (BC) ○ Compartmentalization present in both HD and BC ● <u>Degree of disability</u>: <ul style="list-style-type: none"> ○ Permanent inability to work inside or outside the home (HD) vs. Changes in work environment or skills used (BC) ● <u>Differential effects of illness invisibility</u>: <ul style="list-style-type: none"> ○ Lacking family/social support (HD) vs. Can signify recovery (BC) ● <u>Impact of disease on family</u>: <ul style="list-style-type: none"> ○ Primarily negative psychologically and interpersonally (HD) vs. Primarily positive psychologically and interpersonally (BC) <p>Younger Women with Heart Disease</p> <ul style="list-style-type: none"> ● Limited optimism ● Potential consequences of both age and gender stereotypes <p>Younger Women with Breast Cancer</p> <ul style="list-style-type: none"> ● <u>Duality of peer availability</u>: benefitting from social support while also experiencing internal comparison, self-minimization, survival guilt ● <u>Duality of treatment decision making</u>: opportunities to gain a sense of control but also feeling overwhelmed by many options and uncertain outcome ● <u>Positives of illness visibility</u>: creating opportunities for dialogue, giving/receiving support

younger women with HD did not report optimism regarding illness outcomes. As found across the four themes, hardships limiting normative younger womanhood, such as social isolation and a permanent inability to work, may add to a limited positive (optimistic) future orientation. Moreover, in the Processing Identity theme, younger women with HD described a predominantly engulfed identity³⁸ (*i.e.*, the disease dominating identity), which requires clinical attention given its association with more hospitalizations³⁹ and poor psychological and physical functioning⁴⁰ in adults with chronic disease. In contrast, most younger women with BC reported optimism and described acceptance or enrichment identities³⁸ (*i.e.*, the disease being part of *or* bringing positive change to identity, respectively), which are linked to positive adjustment.⁴⁰ The difference in future orientation and self-identity between the two groups may, in part, be due to the nature of the diseases and associated treatments. Undoubtedly, as evidenced in the Societal Norms for Chronic Illness and the Illness-related Challenges themes, the combination of illness invisibility, added gender stereotypes, and low societal awareness may contribute to a less supportive psychosocial context (moving the lever’s fulcrum to the right and increasing difficulty for balancing illness demands; Fig. 1). A potential result could be lowered optimism (*i.e.*, reduced coping and resilience to balance illness demands as in Fig. 1) or hindered processing of self-identity.

Findings suggest some ways to balance illness demands, specifically for women with HD, supporting recent recommendations for psychological care.⁴¹ First, women with HD may benefit from expanding their coping to include cognitive behavioral techniques, such as acceptance, present-mindedness, and value-centered action,^{42,43} given the rela-

tive absence of such strategies in the Coping and Resilience theme compared with women with BC. Second, findings from the Coping and Resilience and Implications of Social Norms themes suggest that additional supportive resources may enhance self-identity (*e.g.*, self-development opportunities; alternative pathways to goals⁴⁴/roles), by leveraging personal strengths,⁴⁴ and reduce barriers for attending support groups or rehabilitation (*e.g.*, considering childcare needs⁴⁵). These resources in addition to structured consultations (*e.g.*, managing social roles,⁴⁶ fertility concerns^{47,48}) and psychological processing (*e.g.*, coping with thoughts about symptoms,⁴⁶ illness-self conceptualization,^{40,49} as described in the Processing Identity theme, may help increase positive self-image, which predicts future QOL, and circumvent less-effective coping strategies.⁵⁰ Given women’s reported needs for sustained social support in the Implications of Social Norms theme, and with social support being predictive of HD-related outcomes for women,⁵¹ involving supportive partners, family, and friends in ongoing care and providing ways to connect with other younger women with similar HD problems (*e.g.*, formal support groups⁴⁶) may also yield benefit.

Remediation strategies to increase public and professional awareness of HD in younger women (*e.g.*, that nonobstructive plaque predicts mortality in women but not men⁵²), may help shift the fulcrum to ameliorate the challenges of HD. Continued efforts are needed to make HD “real” through education and training on risks/symptoms of HD to counter stereotypes, and through investing in more research.²⁸ As is the case for standardized clinical procedures, the dearth of scientific evidence for younger women⁵³ remains a barrier to implementing and integrating high-quality psychosocial care into practice. Steps to increase knowledge

on younger women may include more funding opportunities, the intentional research inclusion of younger women, and the representation of younger women on local, regional, and global advisory boards informing health care provision quality and policies. Qualitative and mixed-methods research will bolster efforts by uncovering specific needs in underserved populations as well as documenting quality-of-life benefits that may not initially result in cost-related outcomes such as health care visits.

To our knowledge, this exploratory study is the first to compare the experiences of younger women with HD or BC. In addition to supporting extant evidence about younger women with chronic disease, new information suggests directions for women with HD. It is important to keep in mind that the findings are limited to women served in similar clinical settings and with similar demographics. Both samples of women were recruited from clinics serving a large metropolitan area with heterogeneous ethnicity, SES, and language; however, it is still possible that women's experiences may differ due to sample characteristics. A limitation of the study is the retrospective perspectives of women recalling their experiences seven years postdiagnosis. What women shared may be a result of having processed their illness experience over time. It is notable, however, that even with the passage of time, feelings of psychological distress and loneliness for women with HD remained. Our study also interviewed a small number of women, though we arrived at theme saturation and six interviews can be sufficient with purposive samples⁵⁴ for describing commonalities in experience. Other limitations of the sampling were not including women with metastatic BC, and not having sufficient racial/ethnic diversity to probe additional nuances for younger women with HD or BC. We hope this study will spur additional research to examine broader intersections of chronic disease experiences for younger women, to achieve equity in care for all women.²⁸

Conclusion

Overall, continuing to increase awareness of HD and cancer in younger women is needed, alongside bolstered structural support. In line with advances in advocacy over past decades, younger women with BC describe some support through medical professionals and online organizations. However, awareness and resources for younger women with HD may be slim, potentially contributing to poor self-image, persistent isolation, and hardships that might be circumvented with greater efforts for advocacy, training, research, and clinical services. Intervention at multiple levels (individual, family, medical/scientific organizations, societal) may ease women's efforts to balance illness-related demands by enhancing coping, resiliencies, and creating positive psychosocial and medical contexts that fill supportive needs.

Author Contributions

C.N.B.M. and I.S.P. conceived the study, and C.N.B.M., I.S.P., A.L.S., E.E.A. contributed to the study design. I.S.P. and J.H.J.K. collected the data. J.H.J.K., B.L.D., and a trained coding team supervised by J.H.J.K. and B.L.D. analyzed the data. J.H.J.K., B.L.D., E.E.A., and A.L.S. contributed to the interpretation of the results. J.H.J.K. and B.L.D. co-wrote the first draft and all authors contributed to revisions.

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Supplementary Material

Supplementary Appendix A1
Supplementary Appendix A2

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