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# Women's Experiences of Health-Related Communicative Disenfranchisement

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#### ABSTRACT

Women's inequitable healthcare experiences are epistemic injustices by which women are discredited and harmed in their position as knowers of their health and their bodies. Drawing on the theory of communicative disenfranchisement (TCD), we sought to amplify voices of women experiencing communicative disenfranchisement (CD) and to unify their stories according to theoretical premises, namely, attention to power, material conditions, discourse, identities and relationships, and process. We interviewed 36 women living in the United States whose health issues have not been taken seriously by health care providers, friends, and family – pervasive sources of disenfranchising talk surrounding health. Mapping onto the TCD framework, our findings explicate the process of CD, including the material and immaterial consequences of disenfranchising talk and women's responses to such talk. CD unfolded as a protracted and often circular process of women seeking care but encountering health dismissals and minimalizations, blaming and shaming, normalizing of their pain, and psychologizing. We unpack how disenfranchising talk rendered women *crazy* and *dehumanized* them and inflicted *shame* and *loss*. Women responded to disenfranchising talk with *silence*, and they (re)claimed their *voice* by resisting psychogenic explanations for their problems, critiquing women's healthcare, asserting their needs, and advocating for others. We discuss the implications of this research for theory and praxis.

... When someone tells you you're crazy often enough, like often enough, then you'll, suddenly you'll think that you're crazy ... because everyone's been telling me to ignore things and ignore things. Like, I almost can't even tell what's like, normal.

This reflection from our participant, Kristina (21, Hispanic), is an all too common experience, as women - cisgender and transgender alike - have a long and enduring history of being dismissed when they make their health issues and needs known. Commonly framed as a gender bias in healthcare (Hoffmann & Tarzian, 2001), medical gaslighting (Sebring, 2021), or invalidation (Bontempo, 2022a), women's inequitable experiences in healthcare settings transcend time and space. Prominently, many have written about the discursive history of hysteria - an affliction of white middle- and upper-class women who were considered weak, frail, and nervous (Briggs, 2000)-stretching over thousands of years (e.g., Koerber, 2018; Tasca et al., 2012) and how "the female mind and body repeatedly emerge as foreign, mysterious, or defective versions of the male mind and body" (Koerber, 2018, p. 186). Although no longer classified within the Diagnostic and Statistical Manual of Mental Disorders, hysteria is still deeply embedded in women's healthcare today through the gendered distribution of talk describing women more often than men as being "hysterical" and "hormonal" (Koerber, 2018) and in diagnoses understood as hysteria by a different name, including somatoform disorders and medically unexplained symptoms (Dusenbery, 2018). Beyond the healthcare space, family and friends discredit women (Armentor, 2017). In families, individuals contest women's illnesses, labeling them as "drama queens" and "irrational" (Thompson &

Duerringer, 2020). One Black woman in Pryma's (2017) study said, "Even my sister says I'm acting like a crazy to get a check."

Women's inequitable healthcare experiences are epistemic injustices in which women are discredited and harmed in their position as knowers of their health and bodies (Fricker, 2007; Hintz, 2022a). Such injustices stem from two sources. First, women suffer from hermeneutical injustice (Fricker, 2007) or a knowledge gap (Dusenbery, 2018). Women's health has been historically excluded from medical research, yielding far less knowledge about women's bodies and health compared to men's, limiting the hermeneutical resources available for making sense of women's experiences and addressing their needs (e.g., language, research and physician education about women's health; Fricker, 2007), and putting women's lives at risk. Second, women suffer from testimonial injustice (Fricker, 2007), or a trust gap in healthcare (Dusenbery, 2018). Women's accounts are simply trusted less than men's (Mik-Meyer, 2011; Pryma, 2017). For instance, chest pain prevalence is similar in women and men, yet men are 2.5 times more likely than women to get referred to a cardiologist for care (Clerc Liaudat et al., 2018).

The purposes of this study are two-fold. First, we aim to amplify voices of women experiencing health dismissal. Critical empirical research (e.g., Moore, 2017) such as ours critiques and disrupts the status quo and works to improve conditions for women's health and women's healthcare. Despite increasing scholarly attention to women's inequitable treatment in healthcare settings (e.g., Samulowitz et al., 2018)

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and their everyday experiences of dismissal and invalidation from friends and family (e.g., Bontempo, 2022a; Hintz & Scott, 2021), meaningful change has yet to be realized. Women's stories of being minimized, gaslit, and discredited continue to circulate in the public sphere, including on social media, in the news, and on blogs. Yet, disparate health outcomes for women in such areas as cardiovascular care (Vallabhajosyula et al., 2022) and pain management (Samulowitz et al., 2018) exist and persist globally (Kapilashrami & Hankivsky, 2018), and in the U.S., women of color in particular experience worse health outcomes than their White counterparts (Clayton et al., 2014).

The second purpose of this study is theoretically oriented. Although women identify those in their interpersonal relationships - namely healthcare providers, friends, and family - as common sources of health dismissals, there has been limited theory in interpersonal communication that accounts for power, discourse, and the very real and material consequences of being discredited in everyday life. Drawing on the newly developed theory of communicative disenfranchisement (TCD; Hintz & Wilson, 2021) and interviews with 36 women in the United States - a society dominated by the biomedical model of health care and related discourses of individualism and morality surrounding health - we explicate the process of women's health-related CD over time. We uncover the consequences of disenfranchising talk for women and how women respond to talk that constructs their pain as not real, valid, or worthy of attention and care. In doing so, we demonstrate the heuristic value of TCD as a lens for understanding women's health-related CD and for catalyzing positive social action.

# Women's experiences of health-related communicative disenfranchisement

The theory of communicative disenfranchisement (TCD; Hintz & Wilson, 2021) is a newly-developed critical framework for examining communicative disenfranchisement (CD), the process by which individuals' identities, relationships, and experiences are treated as not "real" or of value. CD is produced and sustained through *disenfranchising talk* that discredits, silences, and/or stereotypes one's identity, relationships, and/or experiences (Hintz & Wilson, 2021). TCD was developed with the expressed purpose of infusing interpersonal communication with critical theory. Such a theoretical addition remedies a lacuna in theorizing, as it is difficult to locate health dismissals among canonical interpersonal processes of disclosure, social support, and uncertainty, as examples. These processes are typically studied from a postpositivist perspective that has contributed greatly to understandings of communication in relationships but has neglected issues of power, history, and material conditions (Moore, 2017). For instance, what would typically be considered unsupportive responses to health disclosures are recast through TCD's conceptual tools as disenfranchising talk that (re)produces (a) persistent discrimination on the basis of gender intersecting with other identities and (b) a lack of knowledge about women's health that results in underdiagnoses, missed diagnosis, and no or delayed care and treatment, thereby putting women's health, well-being, and lives at risk.

Five interrelated assumptions of TCD inform scholars' interrogation of interactions which "catalyze disempowerment and maintain the status quo" (Hintz & Wilson, 2021, p. 242). First, TCD locates power in discourse, the means by which certain knowledge claims are validated and others are discounted (Hintz & Wilson, 2021). The interrelations between discourse, discursive formations, and episteme produce regimes of truth. The medical community is one such example. Healthcare providers (hereafter "providers") are positioned within the regime of truth to shape and implement the standards by which illnesses are deemed more or less "real," despite patients' claims to embodied experiences (Hintz & Wilson, 2021; Swoboda, 2006). Women are more affected by nonvisible, poorly understood, under-funded, and stigmatized chronic illnesses such as depression, autoimmune diseases, including fibromyalgia, and recently, long COVID (e.g., Angum et al., 2020; Mirin, 2021). These disadvantages are representative of hermeneutical injustices (Fricker, 2007) that are (re)produced in interactions with providers when, for instance, they say that they are "are baffled by [your] disease" or "don't believe in that disease" (Alameda Cuesta et al., 2021, p. 17).

Second, TCD assumes that discourses and material conditions, both of which evolve over time, (re)produce disenfranchising talk. These conditions have histories that also change across time, "shaping and constraining" interaction occurring both in the public sphere (i.e., discourses called upon in talk) and private sphere (i.e., personal history; Hintz & Wilson, 2021, p. 244). For instance, a provider who dismisses their Black female patient's concerns about pain may be drawing upon false beliefs about biological differences across racial groups (Ghoshal et al., 2020; Hoffman et al., 2016), limited knowledge of women's health (Dusenbery, 2018), and biased recommendations for pain treatment (Samulowitz et al., 2018). Dismissal by said provider shapes the patient's views and approaches to future interactions; the patient not only has her health care needs unmet, thereby prolonging her suffering; her experiences being discredited may exacerbate or catalyze emergent (mental) health issues as she navigates anxiety surrounding interactions in healthcare (Swoboda, 2006).

Third, TCD regards communication as constituting reality. Contrary to deterministic principles that conceive of communication as mere information exchange, this perspective views communication as the means by and through which reality is shaped, constrained, and altered. Hence, CD is produced and sustained in interactions - not something that one is (e.g., "disenfranchised populations") but something that happens to and elicits response from individuals. Indeed, individuals subject to disenfranchising talk may "critique, resist, and transform" the status quo in order to empower themselves (Hintz & Wilson, 2021, p. 245). For example, a patient may resist a provider's ascription of psychosocial causes to otherwise medically unexplained symptoms by seeking second opinions (Stortenbeker et al., 2021). Others might interpret this resistance as further evidence of the patient's psychosocial concerns. What unfolds, then, is a sequence of interactions in which power is established and maintained or resisted and transformed. This is also described as the process of (dis) enfranchisement, the fourth assumption of TCD. A process

orientation allows researchers to explore experiences of CD across interactions in seemingly disparate contexts. For instance, researchers might identify a pattern of events in the health stories of individuals with stigmatized identities, including transgender patients (Wagner et al., 2016), Black mothers (Adebayo et al., 2021), and overweight or obese women (Mold & Forbes, 2011). A process view also enables a researcher to draw connections to the consequences (material and immaterial, proximal and distal) in women's lives which precipitate as a result of disenfranchising talk.

Lastly, TCD acknowledges that interactions have multiple meanings, and that attending to a particular task holds meanings about relationships and identities (Hintz & Wilson, 2021). For instance, a doctor doubting the patient's experience indicates their relationship is not built upon trust, and that the provider does not view the patient as a credible reporter of their own health. Furthermore, the patient may not pursue additional treatment, presuming that other providers will reach the same conclusions about their symptoms. Indeed, recent research finds that women with endometriosis report increased depressive symptoms in relation to being invalidated by providers, partly because such invalidation is negatively associated with decreased self-esteem (Bontempo, 2022a).

To employ TCD, Hintz and Wilson (2021) suggest that scholars: first, consider meanings for self and relationship within interactions of disenfranchising talk; second, examine the influence of disenfranchising talk on individuals' views and approaches to future interactions in the same realm; and finally, investigate how these inferences inform individuals' perceptions of the communication, their identities, the relationships being implicated, in addition to the consequences of each. This framework provides a scaffold for amplifying the voices of women experiencing CD and unifying their stories according to theoretical premises, namely, attention to power, material conditions, discourse, identities and relationships, and process. Hence:

**RQ1:** How do interactions in which women's health complaints are dismissed become embedded in a larger overarching process of CD?

**RQ2:** What material and immaterial consequences of disenfranchising talk do women experience?

**RQ3:** How do women respond to disenfranchising talk?

# Methods

As part of a larger study of women's experiences of health dismissal, the three authors and a graduate research assistant conducted semi-structured interviews with 36 women (i.e., female-identifying) residing in the U.S. about "not being taken seriously for their health issues" by health care providers, friends, and family (as stated in the study advertisement). Interviewees were between the ages of 21 and 70 (M = 33.44, SD = 12.63). Most identified as White/Caucasian (n = 28, 77.78%), followed by Black/African American (n = 6, 16.67%), Filipina (n = 1, 2.78%), Hispanic (n = 1, 2.78%), and Middle

Eastern (n = 1, 2.78%). Eight participants (22.22%) reported multiple racial identities. Women reported an average household income of \$73,851 (SD = \$59,322) and possessed an associate's degree or greater. Reproductive health issues were most prevalent (e.g., endometriosis, PCOS; n = 13, 36.11%), followed by mental health concerns (e.g., depression, anxiety; n = 12, 33.33%) and chronic pain (e.g., back, pelvic; n = 6, 16.67%), among a range of other health issues (e.g., supraventricular tachycardia, multiple sclerosis; n = 11, 30.56%). More than two-thirds reported multiple health concerns (n = 26). All 36 women experienced dismissal in the medical context, with 22 also experiencing dismissal in their personal lives with friends and family. Table 1 provides information about participants' demographics and health-related information.

We recruited participants via network sampling through social media and a university-wide e-newsletter. Individuals completed a Qualtrics online form to indicate their interview-(er) preferences. We individually contacted participants to schedule and conduct interviews using Zoom. We offered participants a \$15 Amazon e-gift card for their time. Participants chose their pseudonyms. The interview guide is located in Appendix A. Interviews ranged from 20 to 82 minutes (M = 51, SD = 16.06). Interviews were transcribed by one of the authors or professionally and checked for accuracy by one of the authors.

Our analysis was guided by a phronetic iterative approach (Tracy, 2020); phronetic referring to research that prioritizes practice in context, and iterative referring to the alternation during analysis between emergent readings of the data and ethics readings of existing literature. We employed constructivist grounded theory techniques throughout our data collection analysis (Charmaz, 2014), namely, engaging in simultaneous data collection and analysis, memo-writing, and in vivo coding. Such an approach is aligned with our purposes of exploring the process of CD more inductively and conducting "social justice research projects that address pressing social issues and policies" (Charmaz, 2014, p. 115). During the interview process, all authors drafted memos after each interview, and we met as team to discuss our memos and interpretations several times. These conversations informed subsequent data collection wherein we included, as examples, questions about advocacy and identity. We stopped interviewing when we agreed that our memos and conversations were not reflecting substantially new ideas (i.e., theoretical saturation; Charmaz, 2014). We want to acknowledge our standpoints as women with varying identities, including being mixed race, educated, part of the LGBTQ community, and immigrant. In addition, we have experience being personally dismissed by doctors and have served as advocates for friends and family members. Our standpoints as researchers of these identities and experiences impacts the ways in which we conducted interviews and interpreted the findings.

We engaged in three stages of coding: primary-cycle coding, second-cycle coding, and synthesizing activities (Tracy, 2020). We primary-cycle coded transcripts in a lineby-line manner to generate descriptive codes, "labeling bits of data in close but quick reading" of the data (Clarke & Charmaz, 2019, p. 9). Primary-cycle coding transpired in three cycles. In the first cycle, authors independently coded the same six

Table 1	. Participant	demographics	and health-related	information.
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		Annual				
		household			Marital	
Pseudonym	Age	income	Race	Education	Status	Health Issues
Allison	27	\$0	Black/Latino	Associate's	Married	Cancer
Anne	26	\$44,300	White/Caucasian	PhD	Single	Food allergies; polycystic ovarian syndrome
Bianca	34	\$120,000	White/Caucasian	Bachelor's	Married	Supraventricular tachycardia
Blanche	26	\$0	Black American	Bachelor's	Unknown	Depression
Cat	36	\$100,000	White/Caucasian	Bachelor's	Married	Anxiety/depression, irritable bowel syndrome, suicidal ideation
Catherine	31	\$67,000	White/Caucasian	PhD	NA	Endometriosis
Charlotte	25	\$21,000	White/Caucasian	Master's	Unmarried	Endometriosis, eating disorder, attention deficit hyperactivity disorder, head injury, anxiety
Claire	32	\$110,000	White/Caucasian	Bachelor's	Married	Child birth complications, pelvic floor issues
Elaine	30	\$75,000	White/Caucasian	Master's	Unmarried	BRCA2 gene, pregnancy-related back pain
Ellen	26	\$42,000	Pacific Islander/White/ Caucasian	Bachelor's	Married	Domestic abuse, tumor headaches, endometriosis
Hailey	27	\$67,000	White/Caucasian	Bachelor's	Unmarried	Postural orthostatic tachycardia syndrome, copper toxicity, chronic back pain caused by scoliosis and kyphosis
Норе	70	N/A	White/Caucasian	PhD	Married	Gallbladder issues, esophageal asthma, issues associated with mammogram, broken ankle
Jasmine	35	\$25-30K	Middle Eastern	Master's	Unknown	Episodic depression, panic attacks
Joy	38	\$40-\$5K	White/Caucasian	Master's	Married	Sinus infections, gallbladder issues, fibromyalgia
Karen	53	\$0	White/Caucasian	Associate's	Married	Multiple sclerosis
Katie	22	\$300,000	White/Caucasian	Bachelor's	Single	Mast cell activation syndrome, postural orthostatic tachycardia syndrome, Ehlers Danlos syndrome
Katy	32	N/A	White/Caucasian	JD	Single	Anxiety/depression, obsessive compulsive disorder, vaginal cysts
Kiki	25	\$140,000	Black American	Bachelor's	Single	Mental health concerns
Kristina	21	\$60,000	Hispanic	Bachelor's	Unmarried	Irregular periods
Laura	29	\$40,000	White/Caucasian	Master's	Unmarried	Anxiety/depression, podiatry issues, skin cancer
Lily	24	\$100,000	Black American	Bachelor's	Unmarried	Rashes, allergies
Linda	63	\$30,000	Black/African American	HS	Divorced	Diabetes
Maria	26	\$42,000	White/Pacific Islander	Bachelor's	Married	High blood pressure, preeclampsia
Megan	26	\$120,000	White/Caucasian	Master's	Married	Polycystic ovarian syndrome, endometriosis
Mikayla	22	\$100,000	Filipino	Bachelor's	Unmarried	Dysmenorrhea
Natalie	24	\$57,000	White/Hispanic	Master's	Single	Pneumonia, depression, anxiety
Nicole	32	\$77,000	White/Caucasian	Master's	N/Ă	Endometriosis, seasonal depression
Nikita	60	\$160,000	White/Caucasian, Black/ African American	Master's	Married	Trouble managing weight, high blood pressure (self-managed /resolved)
Quinn	33	\$40,000	White	Bachelor's	Married	Pancreatitis, cysts, appendicitis, basilar migraines, depression, obsessive compulsive disorder, anxiety
Rory	27	\$80,000	White/Caucasian	PhD	Married	Interstitial cystitis, polycystic ovarian syndrome, bladder issues, chronic pelvic and joint pain
Rose	29	\$120,000	White/Caucasian	Master's	Married	Crohn's disease
Rufus	63	\$90,000	Mixed Caucasian	Master's	Unmarried	Spinal injury, traumatic brain injury, depression, anxiety, chronic headaches
Sarah	38	\$140,000	White/Caucasian	Law degree	Unmarried	Anxiety, insomnia, allergic reactions, sleep apnea, seizures of an unknown cause, painful periods
Sara	27	\$10,000	White/Hispanic/Latino	Master's	NA	Ulcerative colitis, polycystic ovarian syndrome
Sasha	25	\$42,000	White/Caucasian	Master's	Married	Fibromyalgia, chronic body pain
Scoob	40	\$118,000	White/Caucasian	Master's	Unmarried	Invitro fertilization complications, sinus surgeries

transcripts, simultaneously writing memos and referencing sensitizing concepts and descriptions (e.g., epistemic injustice; Fricker, 2007; power/knowledge, discourse, disenfranchising talk; Hintz & Wilson, 2021). In cycles two and three of primary-cycle coding, we independently coded different sets of data and continued memo-writing. We met after each round of coding, sharing memos, forwarding interpretations, and making constant comparisons among and between data. We sought to preserve participant language (i.e., *in vivo* codes) and use gerunds as much as possible to preserve action (Charmaz, 2014), yielding the following common primary-cycle codes: "in my head," "worsening health," "switching doctors," "knowing my body," "don't be afraid say/ask," "self-managing," and "receiving a diagnosis."

We then began second-cycle coding to synthesize, condense, and hierarchically-organize significant and frequent primary-cycle codes into more explanatory codes. For instance, we discussed how our primary-cycle codes, conversations, and existing literature coalesced around the notion of a "journey," which participants referenced often and explicitly and we understood as the process of CD. In addition, we noted how women's stories were imbued with emotion, struggle, and for some, trauma and abuse. Women described how disenfranchising talk eroded their trust in others and their trust in themselves. Some of our second-cycle codes included "getting nowhere," "having enough," "going crazy," and "grieving."

Finally, we engaged in synthesizing activities (Tracy, 2020), including outline development of the theoretical relationships between second-cycle codes and negative case analysis. Our outline analysis was guided by our research questions. First, we constructed a plotline of CD with second cycle codes (e.g., "journey") and identified factors that made stories dissimilar, for example, the role of health insurance, identity markers, and family. This plotline forms the basis of our narrative in the findings (RQ1). We also combined and condensed secondcycle codes to illustrate how disenfranchising talk operated to render women *crazy* and *dehumanized* them and inflicted *shame* and *loss* (RQ2). For instance, "crazy," was an *in vivo*  code that we conceptualized through coding, memo-writing, and discussions as women being told their pain is "all in their head" (i.e., "you are crazy" as disenfranchising talk) and women's reality being destabilized over time (i.e., "going crazy" as a consequence of CD).

Finally, we integrated second-cycle codes centered on women's responses to disenfranchising talk; many women responded with *silence* and some contested doctors' conclusions, asserted their needs, and advocated for themselves and others, (re)claiming their *voice* (RQ3). Negative case analysis included interpreting the significance of enfranchising talk, such as when doctors listened to women, said they believed and understood women, and acted to find answers and provide treatment. These cases are woven throughout the findings to contrast the devastating consequences of disenfranchising talk. We shared our findings with all women in the study, as each gave consent to be contacted for member checking (Charmaz, 2014). Nine responded and provided feedback. All validated our findings, and several expanded on their stories and provided health updates, which we folded into our findings.

### **Findings**

We asked how interactions in which women's health complaints are dismissed become embedded in a larger overarching process of CD (RQ1); what material and immaterial consequences of disenfranchising talk do women experience (RQ2); and how do women respond to disenfranchising talk (RQ3). Corresponding to each research question and mapping onto the TCD framework, our findings explicate the process of CD, the material and immaterial consequences of disenfranchising talk, and women's responses to such talk.

### Communicative disenfranchisement as a process (RQ1)

CD unfolded as a sustained and often circular process of seeking care and experiencing disenfranchising talk (Alameda Cuesta et al., 2021). As the following accounts illustrate, that talk was preceded by discursive, material, and historical conditions; unfolded across time; was associated with material and immaterial consequences; and shaped how women responded and drew inferences about future interactions surrounding their health (Hintz & Wilson, 2021). Women's stories often began by engaging the medical system for care upon experiencing symptoms that alarmed, induced pain, or seemed out of the ordinary. Many women in this study were adolescents at the time their "journey" started (Scott et al., 2022; Soucie et al., 2021), and they noted how easy or difficult it was to access care from the outset, largely owing to parental support and material conditions including insurance and access to transportation. Women who lacked any combination of these resources as youth were free to pursue healthcare when they became adults and moved. Mikayla was unable to seek care for what she later knew to be dysmenorrhea because her "family, despite the fact that they are in healthcare field, didn't take [her] concerns seriously." Her parents are "conservative" and surmised they would believe she was having sex if she were to obtain contraceptives to manage her pain, demonstrating overlapping discourses of promiscuity and women's pain as normal. For

Mikayla, "really college was like the door opening for me, so I could take control of my health." Conversely, some women shared how parents could be allies of women's health, accompanying them to medical appointments and providing everyday support and validation (i.e., enfranchising talk).

When women engaged healthcare, they encountered providers who invalidated their concerns, which manifested as various forms of disenfranchising talk, including dismissals and minimalizations, blaming and shaming, normalizing of their pain, and psychologizing (Bontempo, 2022b). Of note is how many women said they did not recognize that they were being dismissed at the time it happened. After all, as they shared, they were young, had parents who advocated for them, implicitly trusted their doctors, and "didn't really know [their] body like [they] do now" (Linda). Natalie shared how it was this study that made her realize doctors had dismissed her: "I never put two and two together. That is why I kind of don't love going to the doctor." Natalie's reflection underscores (a) how disenfranchising talk is viewed as stemming from legitimate sources (e.g., doctors) and for legitimate purposes, thereby becoming culturally legitimated and ubiquitous; and (b) how research can be transformative for participants by revealing and addressing their needs and motivations for participating (Hintz, 2022b).

Reeling from dismissal, women often disengaged from healthcare while simultaneously questioning themselves and trying to self-manage their symptoms. Isolated, women wondered if their symptoms were real, worthy of attention and care, and whether receiving this kind of treatment from providers was normal. Women attributed being discredited to their intersectional identities, namely: gender and age, race, socioeconomic status, insurance status, and education. Nicole shared, "So I think, like, as a white woman, sometimes I feel like they want to handle me with like kid gloves, like, [mocking voice] "Oh! Well, your pain. Oh!" Linda attributed a physician's over-prescribing to Linda's race: "I think that was tied to me being a Black woman." Kristina articulated the irony of receiving better care when she was younger, on Medicaid, and had to drive over an hour for care. Now she has private insurance but is receiving worse care: "It was just really sad to see that those people that were like crossing their arms and like turning their heads away from you are the same people that open up their arms when you have like a, you know, a well-known name, like insurance." As women considered whether others were right to dismiss their health concerns, they continued experiencing chronic symptoms, which they had no choice but to manage with no or over the counter medications or to "grin and bear it" (Charlotte; Scott et al., 2022). Some women had to conceal their pain because of others' disbelief, fearing shame and blame. This was especially the case for reproductive health issues associated with embarrassment and mental health issues with stigma.

Women typically reengaged the medical system after being initially dismissed. Some were motivated by the injustices they had experienced, determined to find a diagnosis, receive treatment, and contest what they were told was "normal." For instance, Kristina said, "I, like, personally know, like, myself . . . no, like, there's definitely something that's not right. And no one's, like, listening to what I'm saying." Women described CD processes intersecting with lifespan processes (Poole, 2013) and their youth and development as one reason they were susceptible to CD. They grew confidence in themselves and their knowledge of their bodies as they aged. Jasmine reflected on her childhood experiences with mental illness: "I didn't know. I didn't have the language to describe what I was going through because I was a kid."

Some women hesitated to reengage but were in crisis and needed immediate care. When women reengaged, most became more discerning in their healthcare provider choices (Alameda Cuesta et al., 2021), specifically seeking female providers. Karen said, "I'm gonna say, it's the female doctors that I have that are compassionate. They listened to me. They validate me. They see me." Women were particularly disappointed when female physicians were dismissive. Linda reasoned, "You would think the female doctors would understand better than the male doctor would, but it was the male doctor who listened to me and heard me." Some women sought alternative medicine because "they give you more time" (Sasha). Although women described "growing distress" (Nicole) and simultaneously being "tired" (Hailey) by their experiences in healthcare, some continued to see the same providers, largely due to material conditions as barriers to seeing other providers; for instance, they did not live close to healthcare facilities, specialists, or providers who accepted their insurance.

Eventually, most women were validated to some extent and consequently received treatment for and relief from their symptoms. Yet, all women described continually occupying liminal spaces, unsure of what their health issues mean, how to live with them, and whether they would be believed in the future. Typically, women saw several new physicians before finding those who listened, validated women's concerns, searched for answers, shared decision making, and followed up (i.e., enfranchising talk). As legitimated knowledge claims, diagnoses not only rendered women's symptoms and concerns as "real" within a medical frame, but also gave women linguistic and knowledge "resources," as Catherine called them. As such, she was "much more in control" of her health with a diagnosis and "more empowered" to ask for a second opinion. For most women, however, dismissal was a persistent feature of their chronic illnesses. As Joy reflected:

I have about eight or nine specialists now. And I've gone through over 100 tests, diagnostic tests, in the last year. So, I dealt with a lot of people ... and you know what? It's not just this past year that defines my frustrations in the moments where there's dismissiveness. It's really, you know, like a lifetime right, it's never just the one moment.

Joy's story, like many, resembled a chaos narrative (Frank, 2013) with a plot that "imagines life never getting better" (p. 97). Women were on a "merry go round of pills" (Cat), "trapped in this cycle of medication" (Charlotte), and experienced "endless cycles" (Katie) and "vicious cycles" (Karen) of engaging and being dismissed. Defeated and disempowered, women described their great efforts to self-manage their symptoms, live with pain, and visit doctor after doctor, still "getting nowhere" (Nikita). In sum, CD is an isolating, painful, and humiliating process sustained by disenfranchising talk from physicians (primarily), family, and friends, that often interacts with material conditions such as insurance and transportation.

# Material and immaterial consequences of disenfranchising talk (RQ2)

In addition to emplotting the process of CD, we unpack how disenfranchising talk operated to render women *crazy, dehumanized* them, and inflicted *shame* and *loss*. Reflecting TCD's core assumptions, these consequences are both material and immaterial harms (Hintz, 2022a) that shape women's identities and relationships.

# Crazy

Women's sense of reality was eroded over time (i.e., "going crazy"), as healthcare providers – but also family and friends – minimized, dismissed, or called into question women's health complaints and concerns (i.e., invalidated; Bontempo, 2022b). Commonly, doctors told women that without an organic or justifiable cause for their symptoms, their physical pain was psychosomatic— "all in your head" (Megan) and either made up or caused by stress and mental health issues (see also Hintz, 2022a; Krebs & Schoenbauer, 2020; Wright, 2019). Catherine described the effects of dismissals over time:

Whenever I go to the doctor now, like, my heart rate and blood pressure are really high, every time. And it's, like, it's— "I'm sorry, I'm anxious because for 10 years I was just told you know, 'You're too stressed. You're too stressed.""

As Catherine's experience suggests, women often experienced a paradox: going to the doctor for medical needs worsened their overall health, both in the short- and long-term. Disenfranchising medical interactions, in combination with having their concerns go unaddressed, caused and exacerbated mental health issues to which their symptoms were initially attributed, sustaining the disenfranchisement (Birk, 2013). Karen narrated how, after living for years with a multiple sclerosis (MS) diagnosis that became contested among her doctors, she can predict how medical encounters will unfold, as "They love, love, love, love to go to the hysterical woman:"

There's a pattern where they get – I call it getting the cart before the horse. You know, they, they, "Oh, you've got depression, anxiety, and that's why all this is happening." And I'm like, but I wouldn't have depression and anxiety if I felt okay, if these things weren't happening. Um, I'm typically very active and social and doing all these things.

In sum, disenfranchising talk drew upon discourses that constructed women as "crazy" and psychiatrically unstable, encouraging women not to trust themselves and instead believe that they need to "suck it up" and that their pain is "normal" (Scott et al., 2022), despite their severe, consistent, and worsening health issues. Women also described attempting to reconcile the medical "gaslighting" (Laura) they experienced with the truth they knew of their bodies.

# Dehumanized

Disenfranchising talk disconnected and estranged women from their bodies. Like the women in Hernández and Dean's (2020) study, women we talked to did not feel as if they owned their bodies, let alone knew their bodies (i.e., alienation). This was evidenced by two observations we made of the data. First, we discussed how our coding reflected less "doing" by women and more passive "being" (e.g., "being unsure"), "feeling" ("feeling awkward"), and "having" (e.g., "having abnormal bloodwork") things done, consistent with the TCD assumption that CD is something that happens to women (Hintz & Wilson, 2021). Laura described her involvement in her care with increasing distance throughout the interview, exemplified by reflections such as, "I like to, you know, be involved in my own health decisions, too," implying contrast between what Laura would like to do and what she does and is able to do.

Second, women referred to their bodies as abject sites (Hernández & Dean, 2020), foreign and strange (e.g., "I'm kind of one of those weird people that has, like, a mix of stuff;" Cat), as well as sites of violence. For the former, Bianca described being "hook[ed] up to all the monitors," and Cat said they "made [her] into a zombie." They also described a violent relationship with healthcare, characterizing interactions in which they considered "[going] in there, guns blazing" (Karen), and doctors were "just kind of throwing narcotics at me" (Scoob) and "shoot[ing] like chemicals into my head for no reason" and "shooting in the dark" (Bianca). Overall, women narrated being dehumanized and treated inhumanely. Mikayla poignantly said, "I think when I first started experiencing the pain and not being able to get treatment, I really did think of myself as less as a human being, because I couldn't get the treatment I needed ... "

Jasmine had panic attacks and episodic depression since she was a young child, but her family only agreed to her seeing a psychiatrist because her academics were being impacted, and her status as a gifted child was a "defining characteristics for girls" in Egypt. At home, her family "did beat me and they did lock me inside the house and all of that" to force her to focus on her studies. And, the psychiatrist she hoped would help her only furthered the CD. His notes were "very dehumanizing," and he brokered "promises" of "freedoms" between she and her parents if she would "work on things" to "prove that I'm responsible." Jasmine's story is a complex and traumatic example of how women in this study had neither agency nor ownership over their bodies and their healthcare choices as a result of disenfranchising talk.

# Shame

Women were shamed for their health issues, which were construed as products of poor self-management and a personal failure to be doctorable - to present problems in ways that are worthy of medical care and attention (Heritage & Robinson, 2006). More specifically, women described being the target of humiliating remarks about their bodies and confronting weight stigma. Ellen recalled how one doctor said her problems were "because I was fat ... [I] ended up in a, an extreme weight loss program at [healthcare center]. Lost 60 pounds. Didn't help my headache." Even when women gained or lost the prescribed weight, complex health issues persisted. Women were worse for the wear, both in terms of the shame they were subjected to and the ways in which that shame influenced their care. Anne's doctor wanted Anne to keep restricting calories, yet Anne was "miserable and tired and lethargic all the time." Scoob said, "My

reproductive journey was delayed for nearly four years because it was blamed on my weight." Material consequences of body shaming included delayed diagnoses and treatments.

Women were also shamed for mental health issues. Bianca described several interactions in which her anxiety was made to blame: "And she's like, you're fine. It's just in your head. It's just anxiety." Women were told their health issues were "just" anxiety, stress, and depression, which simultaneously stigmatized women and delegitimized their physical pain. Jasmine, who was diagnosed with severe episodic depression and panic attacks, explained how cultural values held by her providers and family in Egypt inflicted shame and blame for her health issues:

... if they're very religious, they would interpret you struggling mentally with like being far away from God, or they're not following God's righteous path or something. So, all of this makes you not want to share it, which is the opposite of what you should be doing.

Rather than questioning why care for and knowledge about women's health is inadequate, disenfranchising talk operated to lead women to wonder: what is wrong with *me*? Blanche explained the impact of being dismissed when she was having a mental health crisis: "Like, I was wondering what's wrong with me, that someone can tell me like that. I was thinking about this." In many ways, shame served as the embodiment of dismissal for women; shame was being blamed both for their health issues and for being treated poorly.

#### Loss

Women grieved their bodies and whole years of their lives due to poor quality of life and health as a result of CD. Many spent years seeking a diagnosis for common women's health issues. Through her experience, Catherine learned: "... on average for my condition with endometriosis it [takes], on average, 10 years for a woman to receive a diagnosis." Women missed opportunities and experiences in different life domains, particularly in their youth. For instance, Quinn was pulled from school in order to treat her chronic pain. She explained:

I just like disappeared. You know I – from school, and I always say that it took three months before my best friend called me. Just like, you just kind of go away ... I even look at that now and look at their friends, like my group of friends had stayed a group of friends and I just like, you know, watch[ed] it from afar.

Women made all sorts of sacrifices, suffering from health issues that had seemingly obvious conclusions, while depleting many of their personal and emotional resources. Rose described the cost of prioritizing her health: "There was like six months where I paid for [a] very expensive acupuncturist that I honestly could not really afford. Like, I went into debt to go to this dude, because it's not covered by insurance." Women feared losing good healthcare. About her aging physician, Nikita said: "I feel bad that he's older than me because he's going to retire before I die. I'm sad about that. I don't know how I'm going to find somebody who ... cares about me as much as he did." Losing a good doctor was not only a relational loss and an inconvenience; it engendered feelings of vulnerability to be subjected to CD. Women made difficult decisions with whole futures at stake. One of the consequences of disenfranchising talk for women is that it closed off access to care that women need for family planning, in turn causing anticipated grief and loss. Catherine described thinking not just of herself but a future partner in healthcare interactions:

I'm alone. I'm in these rooms alone advocating for myself, but I'm also making decisions for this hypothetical person that I have no idea who they are and what they're going to you know and so that's been – I definitely feel like alone in the room.

Allison had breast cancer and was never informed that infertility was a potential side effect of medication she was prescribed. She explained how potential infertility was stressful to her and her mother, who is from Kenya, where "they take [fertility] so seriously that you might find someone is not married because they are infertile." For Catherine and Allison, disenfranchising talk made it difficult to be hopeful about partners and children, as women incurred not only current losses, but also future ones.

# Responding to disenfranchising talk (RQ3)

TCD asserts that CD is not only something that happens to women, but also something to which they may respond. Representing opposing replies to disenfranchising talk, women answered with *silence* on the one hand and (re)claimed their *voice* on the other.

#### Silence

Women responded with silence when they were yelled at, scolded, and punished for becoming upset; indeed, disenfranchising talk functions to silence women and sustain CD (Hintz, 2022a). Cat recalled a particularly humiliating experience during an anorectal manometry wherein she was crying and a doctor was "yelling," "It's not that bad ... You need to calm down." Silence also happened over time, the result of erosion of women's trust in others and in themselves. Sarah said, "I quit telling doctors that I'd be out of breath, because like they acted like I was crazy," and because "I felt like I got scolded for like telling them, like, how I'm feeling." Katy explained how her reality that she "can't really get anyone to take me seriously" had diminished her ability "not only to advocate for myself, but almost to even articulate what's going on." Despite being certain of herself and her body, she blamed herself: "I don't really feel like I've done a great job advocating for myself."

Consequently, women minimized their health issues in conversations and avoided talking about their health altogether. They made inferences about future interactions and forecasted that talking about their health issues would inflict further harms, and that engaging others about their health was futile because nothing would come of it. As Sarah explained: Even while condemning the harm that was done to them, Sarah and others described a kind of chilling effect (Roloff & Cloven, 1990) wherein they could not challenge or express complaints to providers for fear of retribution or further harm. Linda described submitting; she now just listens to the doctors talk. She does not "talk back to them and, you know, be rude or disrespectful because they can give me something that can really make me worse." Some women stopped seeking healthcare altogether, choosing to live with pain and health uncertainty rather than endure persistent dismissal. Karen explained how having her MS diagnosis contested and not getting care for over a decade compounded existing barriers. She lives in a small town with limited access to specialists. Although there is an MS clinic at a nearby academic medical center, "I don't have any trust. Why would I go and subject myself to all that, um, to have somebody sit there and go, 'I don't think so.'?" In sum, silence was more than a reaction to disenfranchising talk; silence was also the cumulative effect of neglect, invalidation, and punishment.

# Voice

Women (re)claimed their *voice*—and their bodies – by resisting psychogenic explanations for their problems, critiquing women's healthcare, asserting their needs, and advocating for others (see also Hintz, 2022a). For themselves, many women needed to heal from years of dismissal that made them question their experiences – a process of learning to trust themselves and that they, as Nicole said, are "worth good care" and "are not just a clinical textbook definition of anything." Rose described needing to claim her illness identity so that others would not minimize or dismiss her health issues. She reflected, "I had to kind of be willing to own my illness, so that other people would take me seriously ... I think I almost had to like maximize my disease for other people to stop minimizing it."

Women talked about standing up for themselves and "fighting" to be heard. In particular, Hailey contested the idea that looking healthy and being healthy are one in the same, a discourse drawn upon in disenfranchising talk she was subjected to. She shared, "That's why I try to like talk about what I'm going through, because I want people to understand." Critiquing how others normalized her pain, Claire shared, "There's a difference between something being common and something being okay." Rufus advocated for herself in conversations with providers, communicating expectations for personalized care:

I think I want to set a tone from the very beginning. It's not that I'm a pain in the ass, it's a, "Hey, I want you to know as a healthcare provider. I take my health seriously, so I may ask you additional questions or I'll question a diagnosis or something."

Many women emphasized how and why their health issues were unique. Ellen resisted providers' attempts to discount her pain by making comparisons to others: "Still, it's like 'Okay like, I'm sorry, they're in a lot of pain, too, but that doesn't mean I'm not or that all pain is even for different people." She championed to be seen as an individual with needs that may or may not be consistent with others' experiences of similar issues.

A lot of times like I don't even tell people what's going on ... I just don't feel like they're going to care. Or, like I've been scolded in the past about things. Like I saw this one allergist that said, "Well, rashes aren't allergic reactions. They're just side effects or medications. You should stop saying that it's an allergic reaction."

Women also advocated for themselves and others by critiquing healthcare and sharing stories and information with other women. Hope, who navigated esophageal and gallbladder issues, challenged providers and hospital administration: "I do not want it happening to another patient, I mean – you know, that's the most I can do is not have it happen to another patient and bring up the awareness." Elaine described: "I took some action to do what was in my power to, you know, find out if I had cancer at that time. And I think I would, you know, continue to do what I could be an advocate within like the BRCA Facebook pages and support groups."

In summary, experiences of health dismissal were reified by an ongoing process of CD sustained through disenfranchising talk. Such talk constructed women as crazy, unreliable narrators of their health and made them mistrust themselves. It also dehumanized women and alienated them from their bodies as well as inflicted shame and loss. Women responded with silence, forced to forsake healthcare, cover or downplay their symptoms, and self-manage uncontrolled pain, illustrating the profound effects of CD on women and their health and wellbeing across their lifespan. Most described exercising agency and voice by resisting characterizations of their suffering as "normal" and seeking better conditions for themselves and other women. Together, our findings reflect and affirm a core assumption of TCD that CD is something that both happens to women and to which they must respond (Hintz & Wilson, 2021).

### Discussion

The first purpose of this study was to amplify voices of women experiencing health-related CD, as women's disparate health experiences and health outcomes endure (e.g., funding for women's health, exploration of sex/gender differences in medical research; Dusenbery, 2018), and women - particularly women with intersecting marginalized identities - are literally dying due to CD. The second purpose of this study was to apply the newly-developed theory of communicative disenfranchisement (TCD; Hintz & Wilson, 2021). As an interpersonal communication theory that is critically-oriented, TCD helped us remain rooted in issues of power, discourse, material conditions, process, and the constitutive nature of communication. We show how, when women's health issues and concerns are dismissed in their relationships with providers and friends and family, women experience erasure (Birk, 2013). When women are silenced and cannot voice their health concerns, they and their health issues cannot be acknowledged. That which is not acknowledged does not exist. In this study we found that disenfranchising talk operated to normalize women's pain, condone the harms done to them, and permit neglecting women's health issues.

To our knowledge, this study is one of the first to apply TCD and demonstrates the validity and heuristic value of TCD as a framework for critiquing the status of women's health care and forwarding avenues for positive change (see also Hintz, 2022a). In particular, this analysis draws connections between communication, public sphere ongoings, and negative material and immaterial consequences in women's lives, an important contribution to the literature which remains largely steeped in the sociopsychological metadiscourse (Craig, 1999). Such understandings of the problems are prompts to action and inform practice (Lincoln & Lynham, 2011), with the findings of this study pointing to several practical implications for the provision of care and support for women experiencing health issues. Following Hintz and Scott's (2021) guidance, we draw on our findings to forward both first-order (interactions that constitute CD) and second-order (underlying conditions that make CD possible) changes.

As a first-order change, providers must validate women's experiences as real, valid, and worthy of attention and care. Women deserve to be treated with dignity – as experts of their bodies and individuals with needs, values, and ideas who can make decisions about their own health. As power/knowledge in TCD, providers should be reminded of the multiple meanings and significance of language to produce truth claims, particularly language surrounding the use of "normal" and the delivery of a diagnosis (Ballard et al., 2006). For women in this study, being told that what they were experiencing was "normal" and nothing to worry about was not reassuring, even if intended as such. Instead, being told everything was "normal" increased uncertainty and fueled anxiety because women did not *feel* normal (Kroenke, 2013).

Whereas diagnoses are typically considered "bad news," for women in this study, being diagnosed not only validated their concerns, but also provided a frame for reality (Jutel & Nettleton, 2011), granting them credibility and their bodies admission to the sick role and providing access to care and support that affected their physical well-being. However, diagnostic labels are themselves imbued with social meaning that can be harmful, such as somatoform disorders and medically unexplained symptoms that are modern code for "hysteria" (Dusenbery, 2018). Hence, we caution that diagnoses should not be considered desired end states or resolutions to problems encountered in health care, as problem persists and new problems emerge upon being diagnosed. For diagnosis that explicitly or implicitly suggest mental illness, providers must take the utmost care to validate women's physical symptoms (Newton et al., 2013). Mental illness cannot be scapegoated for a lack of provider knowledge or effort to explore other diagnostic possibilities. When a diagnosis is elusive, providers can point to limited medical knowledge rather than place responsibility on women (Werner & Malterud, 2005).

As a second-order change, underlying conditions that made CD possible must improve. Women need to be better represented in science, medicine, and research. Research on women's health and healthcare has to be funded and addressed with urgency. That research must include women and represent the diversity of women's voices and experiences; even after policies were put into place to include women in clinical research, women were excluded from participating due to "inconsistent application" and "poor communication" (National Institutes of Health, n.d.). Such research then needs to be put in the hands of women so they can receive the education women in this study wanted and needed but did not have. Doctors did not always educate women in our study during consultations, and some families were avoidant of health topics, leaving women without knowledge or language to talk about their embodied experiences for much of their lives

(i.e., disempowered). To the extent that relationships shape CD in healthcare, family and friends can be crucial allies to women. Most women in this study described parents and sometimes siblings as healthcare advocates when women were underage. As young adults, many women still called upon parents to help seek second opinions, navigate insurance, and stand up for women with unhelpful providers. As adults, most women described other women with shared experiences as a source of understanding, support, and advocacy as well.

This study's contributions should be considered alongside its primary limitation in that, as an initial application of TCD, we took a broad approach to the kinds of health issues and intersectional identities included in the study. The sample was mostly White, educated, and middle class on average. Future research should recruit a more diverse sample or assume an intersectional lens from the outset. The latter approach could better represent TCD's assumption that CD's discursive and material dimensions are rooted in histories. For example, studies may explore CD experienced by women of color with contested illnesses such as fibromyalgia, chronic fatigue syndrome, or long-haul COVID and by drawing on feminist disability theories (e.g., Bailey & Mobley, 2019).

### Conclusion

Our findings explicated the process of CD, with most women's stories reflecting a "journey" of discursive struggle characterized by persistent attacks on women's word and on their bodies – primarily within healthcare – as they sought legitimacy, grieved what they had lost, and recovered from the harms and trauma they experienced. Within CD, disenfranchising talk was connected to multi-faceted consequences that implicated women's identities, their health, and their relationships, often stripping women of their dignity, autonomy, and will to continue battling for attention and care. We forward a number of calls to actions to improve health care for women and the material conditions that make CD possible and acceptable.

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# Appendix A

#### **Interview Guide**

Your health story

- (1) First, tell me a little bit about your health issues and your journey with them . . .
  - a. How did they start?
  - b. Where are you now?

# Your experiences of dismissal

- (1) [Dismissal]:
  - a. We're interested in women's experiences of not being taken seriously for their health issues – times your health issues have been dismissed, downplayed, etc.
    - i. Can you share interactions in which you were not taken seriously for your health issues by:
      - 1 Family? Friends? Health care providers?
    - ii. For each relationship type:
      - 1 How did this experience make you feel?
      - 2 How did you respond to the person?
      - 3 Why do you think others have not taken your health issues seriously?
        - a Do you feel the person's dismissal is tied to who you are?
        - b Your relationship?
        - c The type of health issues you have?
      - 4 Have interactions with the person changed over time? Have they become more or less supportive?
- (2) [Identity Implications]:
  - a. How have these experiences of dismissal affected how you think and feel about yourself?

- b. How have these experiences of dismissal affected how you think and feel about your health issues?
- (3) [Conversations Implications]:
  - a. For those who have not taken your health issues seriously, what if any differences do you see in the conversations about your health more broadly:
    - i. With family? With friends? With physicians?
  - ii. Things you avoid talking about? Things you're more willing to talk about?
  - b. What is the most supportive or helpful conversation you have had?
- c. What is the least supportive or helpful conversation you have had?(4) [Relational Implications]
  - a. How have these conversations had an impact on your relationship-(s) with:
    - i. With family? With friends? With physicians?
- (5) [Advocacy and Support]: Not being taken seriously for health issues sounds really difficult and I appreciate you sharing your experiences with me. It is a lot of work to take care of your health needs.
  - a. Do you consider yourself an advocate for your health issues?
  - b. In what ways do you advocate for your health needs?
  - c. Do others advocate with/for you?
  - d. Where do you find support when others do not take your health issues seriously?
  - e. What do you think should be done to help women be taken more seriously for their health issues?
- (6) [Advice/Closing]: To conclude the central portion of the interview, we would like your advice.
  - a. What advice would you have for women in your position faced with health issues others do not take seriously?
  - b. What advice would you have for anyone to whom a woman discloses their health issues? (family, friends, medical providers)
- (7) [Other comments]: Our goal is to give voice to women such as yourself when it comes to health and being taken seriously. Is there anything else you feel I should know that will help us with this goal?