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Penetrating the Dark Silence

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This study articulates women's lifeworld experience of unexplained and unexpected fatigue. Interpretive phenomenology situated within the perspective of Maurice Merleau-Ponty provides the study framework. Using purposive sampling, the study investigated the unexplained fatigue of 12 women in a southeastern state. Data analysis of interviews revealed a lost voice within the phenomenon of fatigue, providing new insights into this diffuse and dehumanizing experience. Ethical considerations are addressed for recognizing, hearing, and caring for women living with disabling fatigue to extend the goals of Healthy People 2010 by addressing new ethical priorities for quality of life over the next decade. **Key words:** *chronic fatigue*, *ethic of care*, *Merleau-Ponty*, *narrative ethic*, *phenomenology*, *quality of life*, *women's health*

"I am tired so tired. . . . at the end of every day I am in a state of exhaustion.". . . "The fatigue is unrelenting . . . I wake up tired . . . and it just gets worse!" These are the words of women in the research study described here. I have used these same words many times to describe my own feelings, and hear them repeatedly from women for whom I provide care, from those I socialize with, and from those I know in my own family. Coupled with these descriptions of fatigue are complaints from these same women about depression, angst, inability to concentrate, difficulty with sleep, and the overwhelming sense of "being drained." These warning signs reflect the totality of the aspects of personhood (the body, the soul, and the spirit) within the context of significant transformations of quality of life.

This article describes a phenomenological study in which women shared their experiences of chronic and quality of life–altering fatigue. The study is centered on 12 American women's unique experiences with fatigue and their particular understandings of this phenomenon as they attempted to comprehend this troubling and pervasive lived experience. Presented here are the whisperings within the everyday lives of a yet unheard American sisterhood of fatigue, which has important implications for extending the goals of *Healthy People 2010*[1] to address new ethical priorities for quality of life.

States of persistent tiredness and fatigue are ever increasing in the lives of American women.[2] Scholarship of such lived experiences, however, is limited. In order for nurses and others to appreciate the meaning and significance of this experience, a contextual understanding of the impact of unexplained fatigue on quality of life is needed. Without an understanding of these experiences, we, as nurses, will neither seek nor recognize the early warning signals of unexplained fatigue. My intent is to give voice to accounts of women's experience of living within the phenomenon of unexplained fatigue revealing quality of life transformations.

THE ENIGMA OF QUALITY OF LIFE

Quality of life implies a "general sense of happiness and satisfaction with our lives and environment and includes all aspects of life,

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including health, recreation, culture, rights, values, beliefs, aspirations, and the conditions that support a life containing these elements. *Health-related quality of life* reflects a personal sense of physical and mental health and the ability to react to factors in the physical and social environments."[1(p10)] Health-related quality of life, like fatigue, is a complex subjective indicator challenging definition and measurement.

Recognizing that healthy individuals are linked to healthy communities, *Healthy People 2010's* research agenda promotes systematic study of this relationship in each of its 28 focus areas. Inquiry that seeks to give voice to individuals situated within communities affords opportunity for increasing contextual understanding about quality of life as it is lived. Understanding unexplained fatigue as a disability rather than a symptom, this article offers important insights into little known aspects of health-related quality of life in the lives of women who live within its dark regions.

THE PROBLEM OF FATIGUE IN WOMEN

Diseases with symptom clusters including pervasive fatigue that affect women's health are being researched in many disciplines and from many perspectives.[2–4] Evidence indicates that fatigue is debilitating, overwhelming, and pervasive in the lives of women with explainable illness states. Many women across the lifespan in the United States, particularly those at midlife, exhibit signs of energy alterations, fatigue, and chronic fatigue.[2–6] Recently, investigations associated with altered states in vitality, such as tiredness as it relates to quality of life in women and other populations, have begun to appear in the literature.[7–12] These studies have helped expand our focus on women's multiple social roles leading to lifestyle priority conflicts and potential health risks.

Attempts at definition, measurement, and symptom relief of fatigue have failed to find the lost voice of women with unexplained fatigue. Contextual perceptual understandings of experiences are required to allow meanings and significance to emerge. This study explored the contextual situations of women living with unexplained fatigue through the following research questions: What is the meaning and significance of fatigue prevalent in the lives of contemporary American women? How do these women visually represent, interpret, and articulate their experience of embodied fatigue? This study was framed with the assumption that each person experiences fatigue contextually and holistically. One lives and feels fatigue holistically, simultaneously experiencing this state within one's soul (mind), spirit, and body.

LITERATURE REVIEW

As previously noted, Healthy *People 2010*[1] places increasing life expectancy and improving quality of life as its first goal. The Institute of Medicine[13] has set forth an agenda for collaborative redesign of healthcare using a population model to study health in order to anticipate needs, decrease waste, and utilize evidence-based decision making while incorporating patient needs, values, and controls. The National Institute of Nursing Research (NINR)[14] in its mission statement speaks of the reduction of risk for disease and disability, as well as promotion of healthy lifestyle and quality of life for those with chronic illness. Its research theme of changing lifestyle behaviors for better well-being emphasizes health promotion for both the well and the ill.

Given this context, it becomes an ethical priority to extend our understanding of what it is to be "well." If there is no explanation for fatigue, is it assumed that the person is "well"? Despite good intentions to ameliorate problems, healthcare professionals, using only objective rationale, may oppress or harm those entrusted to their care "in the name of quality of life."[15] To avoid potential harm in the name of quality of life, we must guard against the usual judgments concerning quality of life

that may not take into consideration its inherently subjective nature and gain a better understanding of unexplained fatigue, how it occurs, and how it is perceived by those who find themselves living within this experience.

Fatigue defined

This research defines fatigue as persisting distress and decreased functional status related to a decrease in energy.[16] Chronic or persistent fatigue results in loss of productivity and reduction in quality of life and is a debilitating symptom that crosses multiple stress-related disorders. The literature contains many studies examining fatigue related to chronic illness. Fatigue has been described as an unpleasant, subjective symptom with multidimensionality, rendering it difficult to define and to measure.[2,17–21] Nurses and others have studied fatigue to learn about the phenomenon, to measure the concept, and to ascertain effective interventions for specific disease management.

Unexplained fatigue in this study refers to a fatigue state, often, though not always chronic, that remains diagnostically invisible using current technologies. This contrasts with *explained* fatigue associated with illnesses such as cancer and autoimmune diseases. These are experienced as *explained* in the sense that diagnostic technologies detect or measure markers explicating the phenomenon within a cause and effect relationship. As several participants noted, this unexplainable aspect was one of the most dehumanizing of their fatigue experience.

Embodiment defined

Cartesian dualism and later logical positivism have had a long-standing influence in presenting opposition to the notion of embracing embodiment in the pursuit of knowledge.[22] Nevertheless, philosophers, theologians, mystics, and scientists have sought the phenomenon of the soul and its connection to the body or its embodiment. In *The Visible and the Invisible,* Merleau-Ponty argues that "science manipulates things and gives up living in them . . . only coming face to face with the real world at rare intervals."[23(p159)] In *Phenomenology of Perception,* Merleau-Ponty says that existence is expressed before thinking and is pre-given, incarnate, and social; that "the world is inseparable from the subject which is nothing other than a project of the world; the subject is inseparable form the world."[24(p491)] In summary, Merleau-Ponty says that we are our bodies and that without them *we* would be impossible. Our perception, our understanding, our identities originate in and are experienced through our bodies. We know our worlds through this vehicle.

The concept of embodiment is most often used in nursing to reflect awareness that is known through our bodies.[25–27] Embodiment here is defined in a manner that reflects the phenomenological views of Merleau-Ponty,[23–24] as how we as humans live in, experience, and find significance in our world through our bodies, especially thorough perception, language, and movement in space and time. The philosophical underpinnings of embodiment are central to this study.

PHILOSOPHICAL UNDERPINNINGS

Phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation. Phenomenological methods are valuable for bringing to the fore the experiences and perceptions of individuals, and therefore at challenging structural or normative assumptions. Adding an interpretive dimension to phenomenological research, such as hermeneutics, enables it to be used as the basis for practical theory and allows it to inform, support, or challenge policy and action.[25,26,28–32]

Phenomenology has been viewed by nurses as particularly relevant to nursing inquiry.[5,9,22,25,28,33–36] The orientation to real-life occurrence and to persons in relationship with others (embodiment, holism,

and the lifeworld), and with the goal to understand the meaning of experience (self-interpretation and intentionality), is important for nurses, whose practice engages people with their experiences of health and illness.[22,25,29,35,36]

Merleau-Ponty

Merleau-Ponty's phenomenology, like Husserl's, is to return to the "things themselves" but not as eidetic (vivid but unreal) transcendental essences. Merleau-Ponty believed that essences give clues about the human condition. These essences are experienced in what he calls a *lifeworld* where he strove to build up "an authentic, multidimensional description of the *Lebenswelt* [Husserl's lifeworld of every day living]: one that would take us directly into the realm of our lived-experience and one that would not neglect any of its meaningful ontological features."[37(p45)]

These essences are known to us as we participate in this world as embodied beings. Merleau-Ponty did not believe that to know and understand we must remove ourselves. Instead, he argues that by reflecting on experiences with the lifeworld, rich understandings and interpretations unfold about human beings, from persons who are embodied, historical, and temporal. Meanings are central to his epistemology and ontology.

Merleau-Ponty uses dialectic reasoning to avoid the traps of "either/or" reductionism, believing that human existence cannot be adequately examined from a set of presumptions that include a dualism of mind and body (subject and object). Merleau-Ponty says that we cannot see without being seen. We are both subject and object and the union of these notions is both visible and invisible. As human persons, we are indivisible body-subject. In *The Structure of Behavior,* he opines ". . . Man is not a rational animal. The appearance of reason and mind does not leave intact a sphere of self-enclosed instincts in man . . . ."[37(p7)] Fatigue is known in the soul (mind, will, and emotions) and yet there is so much more to the meanings of this experience. Embodied fatigue allows the person to recognize his own body as object, and a disabled object at that.

The centrality of the body-subject inextricably links this study to Merleau-Ponty. His position holds that our body (body-subject) is the provider of meanings that we bear throughout our lives.[37–39] This idea indicates that we are "not an abstract, absolute consciousness, but in some way inserted into the world of space and time, and, according to Merleau-Ponty, it is our embodiment that realizes this insertion."[40(p6)] He holds that we, in our embodied states, are recreated as we experience our lifeworld.[23,24]

METHODS

This study employed 2 qualitative methods: interpretive phenomenology[39] and visual interpretation.[41] Only the interpretive phenomenology findings are presented here. Twelve American women across the lifespan were asked to describe an experience of fatigue versus tiredness. Study selection criteria included women experiencing unexplained fatigue (including, but not limited to, syndromes such as chronic fatigue and fibromyalgia) and excluded women experiencing fatigue states resulting from diagnostically identifiable or measurable disease, that is, cancer, Lupus, etc. Thus, embodied fatigue was studied as a disability and not a symptom. It is the disabling nature of unexplained fatigue that transformed the women's quality of life.

After approval by the Human Subjects Review Board and informed consent, a purposive, snowball sample was obtained by networking with healthcare colleagues, community contacts, and others within a local region in a state in the southeastern United States. Face-to-face unstructured interviews were conducted with each participant. An interview guide using prompts to elicit day-to-day experience was employed. Participants were queried about a time that "stood out" or one that they would "never forget" because it reminded them of what it meant to

discover a fatigue that differed from any tiredness they had ever known. They were asked to begin by telling about a time in their everyday life when they recognized this fatigue for the first time and what it had been like to live their lives since that initial recognition. Nonverbal (ie, body postures, gestures, facial expressions, etc.) data were noted by the researcher using observation field notes.

All verbal data were transcribed verbatim. The first step of analysis was description and interpretation ensued as data analysis progressed.[33,42,43] Each woman's narrative was read, re-read, listened to, and spoken aloud during transcription (using voice recognition software) and descriptive notes were made. Analysis proceeded by coding recurring key words and phrases to identify essences that led to themes and an overarching pattern. A research team consisting of 2 PhD nurse educators, 2 PhD philosophers, and myself, all of whom had prior expertise in phenomenological inquiry and analysis, reviewed the data. Each team member read and summarized selected transcripts and offered individual insights into data analysis, which I merged into a final interpretive summary document that reflected essences of the phenomenon. I endeavored at all times to present the authentic voice from each participant. This document was mailed to each participant as part of a member check.

FINDINGS

All participants were Caucasian with various types of Christian faith backgrounds and identified a heterosexual orientation. Ages ranged from 25 to 72 years and the women resided in rural, small town, and suburban settings. The addition of the illustrative drawing and its self-interpretation during the interview was optional. Nine of the 12 women illustrated their stories of fatigue; as noted earlier, visual data are not included in this report.

The essences and patterns presented here provide insight into the dark world of chronic, unexplained fatigue. *Transformation* was identified as the overarching pattern and the connection that united each woman's narrative. No longer able to maintain any semblance of their former lives, each woman provided evidence that she had been changed, with a new status quo, not one that she chose, but rather one she learned to accept in her exertion to survive. This transformation exemplified 5 essences defined as "invariant structures without which the object or event would 'cease to exit as itself.'"[43(p310)] The 5 essences are Persistent Doing, The Overwhelming Weight of Exhaustion, Not Understanding, Bondages, and Expectation.

Persistent Doing. The women in this study were "doers." Each one speaks to us of their lives before fatigue overcame and redefined their living. Their lives were full of tasks; goals; and lists: laundry, dishes, children, dinner, husbands, and boyfriends, not to mention careers and extended family responsibilities; a litany of the mundane kept them running. They were not lazy women. Instead, they *never* stopped. Even in the throes of fatigue, these women persisted in their "doing" as they sought to find a way back to the "doing" of their former lives.

The women tell us that they would keep going no matter what. They pushed their bodies and continued to push despite lack of sleep, physical pain, and misery:

> . . . . So, it's push, push, push all my life I've had to push myself because I didn't feel good. . . . But I try . . .

> . . . Just, gosh, you know when you are just pushing, pushing your body so hard and your body is yelling at you and you are still pushing . . . you say I'm sorry but I have to get this done. You know, I am not going to bed until 11 o'clock because I can't get it all done before 11 o'clock.

> . . . it was just hectic you know it was like you hit the ground running, you get up at six o'clock put a load of laundry in and get the kids up and get breakfast, throw the lunches in the lunch bags and out the door. And teach all day, you know, I tried to. . . I would work through my lunches so I wouldn't bring any paperwork home. So there were really no breaks all day, you know when the kids were in music or something like that I worked on paperwork.

So I wouldn't have to bring anything home, and, and also with the super mom thing. I also wanted to be super teacher, you know, I wanted to be the best teacher in the whole school . . .

Life energy seems lost yet threads of subjective vitality come into view from time to time:

. . .and then I'll get up and do a little "jiggy" for a while, and then I'll collapse and then sometimes I'll get a piggyback ride, and I'll just kind of dance on someone's back, and then, ah—my favorite was the on-the-ground Macarena. I just did the hand movements. . .

And so I sometimes have a little burst of energy or all of a sudden I feel like, "Hey!". . .to my husband, "Let's stay up and watch a movie together or something. And do something fun because this day has been horrible; I've been dragging all day. . ."

The body is doing, yet the region of the soul drives the action. The will to "do" is stuck in an "ON" position and these women never slowed down long enough to even consider that they *could* decide to stop.

The Overwhelming Weight of Exhaustion. The women's stories (and illustrations) were replete with heaviness, pressures, and feelings of being overwhelmed. Collapse, sleep disruption, and tiredness without recovery permeate their lifeworld. This aspect of fatigue brought inactivity, guilt, and deep depression. Isolated and silenced by others' unbelief that anyone could be *this* tired; the women tell us that they no longer feel valuable. Overcome by a giant, pounding, relentless tidal wave of fatigue, their exhaustion seems insurmountable:

. . . just feeling so overwhelmed. I guess that's the word I would use, it's just there. . . And feeling a lot of pressure. . . (Tearful) it was very painful. Because I became suicidal and. . . , didn't feel like I was worth anything.

. . . I wanted to kill myself [speaking very softly, long pause] I couldn't see any future. I couldn't see anything, you know, I had parents who had no idea what I was going through. I had kids that were so frustrated by that point that I might as well have been dead.

I'm just so, I'm a level of weak that I can't even understand. I'm a level of sick that I can't even fathom, but I can't sleep, and it's Hell, it's just Hell.

Sartre theorizes that emotions are gestalts that move the will to action.[44] The heavy weights of fatigue experienced by the women in this study seem to have paralyzed and defeated the will. Mentally, a profound, dense fog weighs down the lifeworld of these women:

My brain feels like lead. . . . I guess that's a better way to put it. My brain just stops functioning, and it was like . . . I couldn't concentrate. . . . very confused, things that were normal to me before were just, like an obviously easy task, would become very difficult. So I guess my brain would be . . . I feel like my brain was [cryptic laugh] attacking me.

Even with all of this profound exhaustion, a strand of vitality would sometimes pop out of the lifeworld:

. . . and then sometimes I'll have a little burst of energy, like from noon to five it's like I'm pretty tired and then from five to seven or five to eight I'll be OK. . . . I kind of use and take advantage of these little spurts of energy. . . .

But the spurt of vitality was fleeting. One woman observed:

I guess it just takes so long to build up the energy, you know?

The overwhelming weight of exhaustion reflected a dark and anguished region of the lifeworld of fatigue.

Not Understanding. These women voiced being misunderstood, not knowing what or why, and perpetual uncertainty surrounding the lifeworld of fatigue. Even with the great wall of exhaustion described above, the fear of not knowing what caused the fatigue in the first place left them dazed. Fear, anxiety, and despair often resulted as they searched to understand within themselves what they were certain that no one else understood. The maps they used to navigate the territory of their lives before fatigue were no longer useful. Not knowing where they were, they were desperate for understanding. They needed to

have others understand that something *real* had happened to them; that they were *not* making this up. They had lost their voice to connect this experience outwardly to others and also within themselves:

I went to tons of doctors, my first doctor's just "yeah, you're really stressed out, it's just a stress breakdown, oh you're just depressed, here's some Zoloft . . . and he didn't understand [crying] that I wasn't just tired and I wasn't just mental or emotional or out of it . . . my limbs didn't work anymore, like I could willpower with everything within me and I could not lift my own arm. And don't tell me that it's just a stress breakdown! And so he referred me to other doctors . . .

That's what we get so tired of hearing. It's got to be in her head, there is nothing the matter with her, she looks fine. You know, she looks like she always looks. It's invisible, and nobody sees it. Nobody knows, nobody understands, nobody, nobody. They just don't understand they have no idea that you can wake up in the morning and know that there is just no way in the world that you're going to get out of that bed, you know.

. . . I don't feel like anyone to this day ever understood what I went through. It's just kind of hard . . . I don't know, because if I had something like cancer that people could understand, I think they would've been more compassionate. But I just kept saying I'm tired. I don't feel good, but nothing really looks wrong on the outside. . .but my husband still. . . he would think I was lazy. He would come home and say, "Why didn't you do that load of wash?" or whatever. And I just felt like I could not dredge up the energy to pick up a wash basket and carry it downstairs . . .

Not knowing what they were experiencing or why is complicated further by the transient threads of vitality that appeared without notice or understanding. The energy of life appeared with cycles known only to itself. One participant describes this puzzling phenomenon:

And I just I get up usually like I said about six, take my medicine, and go lie down and sometimes sleep till noon. And then by evening about, you know about suppertime I'll start feeling somewhat better, and a little more normal. Now why that is, I don't know.

Sartre's idea that an emotional gestalt will move individuals to action seems valid here.[45] These women seemed tortured with "not knowing." They seemed to be searching relentlessly to discover what had happened to them and why it happened to them in particular. They were overcome with despair because fatigue was unintelligible; invisible to the diagnostics and to others, but visible in their embodied lives. It had left its mark and seemed to have radically transformed their voice and their sense of human worth.

Bondages. Living in the lifeworld of fatigue was experienced as being trapped in an unknown, painful, and unseen place. The women relayed to us images of vicious cycles from which they could not break out. These took the form of addiction, pain, depression, anxiety, immobility, and isolation. It is here that the women endured a dehumanization, merging all the aspects of their fatigue into a bondage or imprisonment. Prisoners, however, generally know why they have been incarcerated and how long their sentence will run. These women did not. Their bonds were concealed and their prisons were their own bodies. They sought a way out and found that no one was listening. Looking for a protector to rally around and champions to release them, they became disillusioned. They perceived such confining isolation:

I felt like I was in a deep dark hole and I couldn't get out.

. . . it's like fatigue with lack of sleep that's to me like a spiraling, that's what they are talking about this picture; they have pictures with spirals that you can't get out of, like, almost like the hamster on the wheel. And for me I'm running fast. I know I was talking to . . . my boyfriend. He said, you have a choked jet with lead feet on it? I said no, I'm running fast just trying to get out. I'm just trying to get out, you know.

It is a dark place right now. It is. And I'm, and really I'm trying but there are times when it gets really rough and . . . I don't let the emotion out. I don't think I do . . . It did happen a long time ago, somebody said, you are like a trash can with a lid that's going to blow off . . .

There were times when life itself became confinement. The women in this study portrayed a lifeworld of fatigue as a relentless nightmare, a great lake of fire, from which they found no escape.

Empty, empty.. . . it's kind of like you're an outsider looking at everyone else. You're alone.

. . . . I was a total nervous wreck. I could not even sit down and have dinner. I was so jittery, I would fix dinner, put it on the table, I'd have to get up. I couldn't even sit down to eat. It was just like I was in fast-forward constantly. And I stayed in a constant exhausted state because of that.

The bondage of fatigue confined these women; they were silenced, as they perceived no human value. Their lost voices cried in isolating silence. They could no longer "do" and no one really heard or understood. The transformative essences merged.

Expectation. Surprisingly, hope, anticipation, and expectancy arises out of these stories like the phoenix out of the ashes. Several women expressed the belief that all things happened for a reason even if we never realize the reason. This essence embodies the hopeful, seeking of prospects; an unlikely, albeit genuine, aspect of living with chronic, unexplained fatigue. It resonates with the phenomenological concept of the opening of new horizons:

. . . . I mean, I hope that there is . . . I want other people to know that there is hope even when you're feeling hopeless.

. . . I had to change my lifestyle, but I don't think it [fatigue] took the joy out. But I think that's because I've always had the Lord and no matter what the trials and the "tribs" that come your way, you still experience the joy of the Lord. He gives us the strength that we need. . . . I would think about the Lord and how He allows these trials in our lives and following Him and not get all stressed but just allow the fatigue to "just be." Because of the Lord and because of the strength that He gives me, I've become a fighter and a warrior, and I overcome, I overcome.

And I haven't gone back to church. I mean, I have tried going back to the church that I went to before, but it's kind of like this is not where I want to be so. I need to work . . . I feel like I need to work on that. Reconnect . . . reconnect with. . . . with the spiritual side.

Many of these women spontaneously delved into their particular faith backgrounds as they talked about this part of their lifeworld. Each woman *wanted* to believe that the trials of her fatigue would be worth it, even in the face of evidence seemingly to the contrary. This hope, however, was not clear-cut or well defined. It took them inward to places that are often left untraveled.

PENETRATING THE DARK SILENCE

Foxfire, a phenomenon that Mark Twain used in *Huckleberry Finn* when Tom Sawyer and Huck are scheming to dig a tunnel under the cabin where Jim is imprisoned, may be a useful analogy. Tom and Huck talk about their need for light, yet realizing that a lantern would be too bright and expose them. Tom advises Huck, "What we must have is a lot of them rotten chunks that's called foxfire, and just makes a soft kind of glow when you lay them in a dark place."[45(pxxi)] Foxfire defined by a dictionary is "an eerie phosphorescent light; a luminescence produced by decaying wood."[45(pxxii)]

Foxfire is a natural phenomenon that occurs in untamed forests. It can be seen only if there is a certain amount of darkness. "At night, foxfire looks like a jewel, but the next day it's just rotten wood. . . . On moonlit nights you can hardly see foxfire there's too much light. . . Foxfire could be everywhere and you'd think it was moonlight scattered about. It takes a real pitch black night to see it."[45(pxxii)]

It is reasonable to assume that when one sees foxfire, what one is seeing is the demise or fading away of the energy of the decaying wood. It has a mystical quality not unlike the fatigue that was uncovered in this study. Is it feasible that to truly see or understand embodied fatigue there must also be a certain kind of darkness? The women of this study speak of darkness, a dark night in their souls. Theirs are

tales of loneliness, misunderstandings, pain, and fear. Remembering to value this darkness may help in our ability to recognize the fatigue that hides when the light of science shines upon it. It, like foxfire, may be invisible under this intense scrutiny, yet is real.

It is therefore crucial to bear in mind that in order for fatigue to be visible, we must proceed with caution. Scholarly examination often seeks to shed light into otherwise dark places, as this inquiry intended to do. Yet, a strong, focused light may obscure the very knowing that we seek. This presentation of findings allows fatigue to illuminate itself as we listen to the women who live and have lived within its dark places. We are called to discover the voices that have been silenced; we are called to care for and see, even in this dark region, the need for "doing,"the overwhelming weight of exhaustion, the pain of not understanding, the sense of bondage, and the hope of expectation experienced by these women. It is only after we have seen and believed, that we can penetrate the dark silence of unexplained fatigue.

CONCLUDING POSSIBILITIES

Embodied fatigue is unintelligible; no one understands or can see it. Nevertheless, it is *real* experientially. Findings from this study hint at the complexity of understanding the quality of life of women experiencing unexplained fatigue. Yet, it is here, in the examination of this lost voice, that we discover the intricacies of embodied fatigue and the need to expose the darkness of the phenomenon in order to avoid harm in the name of quality of life. Out of the dark, painful, and oft times poignant world these women inhabit, the 5 essences converge to form a pattern of transformation of quality of life—a quality of life that is reshaped from that which existed prior to the experience of embodied fatigue.

The quality of each life has been broken, bearing the wounds of chronic fatigue. The lifeworld accounts from these participants are tales of *wounded storytellers*, a concept arising from the work of sociologist and postmodern ethicist Arthur Frank.[46] His work informs us that individuals with chronic illness have different bodily experiences and means of communication than those who have lived without persistent chronic conditions. He argues that when a person suffering from illness tells his or her story, the person ceases to be passive as a victim of illness or recipient of care. By seeing the ill person in this manner, one is able to discover an action possible for those who otherwise have been set apart, on a shelf, so to speak.

Frank uses his project of recounting the narratives of those wounded by illness to offer ethical insights into the darkness of being ill outside of *patienthood*:

> Clinical ethics is concerned primarily with professional and institutional ethical responsibilities to patients. But with the increasing proportions of chronic and degenerative diseases, more ill people spend more of their time not being patients; what I call the "remission society" grows. The ethical questions for members of the remission society are not adjudications of health care conflicts but *how to live a good life while being ill*. . . . The core ethical questions concern what the ill person should want for herself and others. As ethical questions, desires become responsibilities: what is *good* to want for oneself and others?[46(p156)]

The narrative ethic described by Frank is not an effort to replace other forms of medical ethics. It is rather an effort to point out a crucial but ancillary role in "leading physicians to recognize the moral dimension in *every* medical encounter."[46(p156)] Frank argues that narrative ethics has a unique arena, and that is illness outside of *patienthood.* He is interested in persons and the relations that occur between ill persons and those who seek to provide their care. Frank tells his readers that he is not concerned with presenting "thick description of cases" but rather with a concern "with ill people's self stories as moral acts and with care as the moral action of responding to those self-stories. . . narrative teaches that being human is the perpetual finding out of what is good and virtuous. . .".[46(p157)] The women of this study have been wounded in ways that

have caused them to wonder if there is any value in their very humanness. This is most certainly not "good" in the moral sense.

Feminist scholars are said to be instrumental in an ongoing discourse concerning the idea of care in the context of moral thought.[47,48] Caring is contextual. In his reflections on caring related to ethics and embodiment, Hamington notes, "Care is an approach to morality that is basic to human existence—so basic, I will argue, that our bodies are built for care—and therefore can be woven into traditional theories [of ethics]. Care is a way of being-in-the-world that the habits and behaviors of our bodies facilitate. Care consists of practices that can be developed or allowed to atrophy."[47(p2)] It seems, that for these fatigued women, caring habits are highly developed with respect to others and have been allowed to atrophy in terms of themselves.

Feminists such as Carol Gilligan and Nell Noddings have been credited by Hamington for providing the foundation for a moral theory upon which caring ethics can be situated.[47] In *Moral Boundaries* Tronto offers a critical perspective on care linked to prevailing moral theory and to feminine ethics.[48] Tronto argues that overarching issues, which she has named "moral boundaries", frame modern conceptualizations of moral thought and therefore ethics. She suggests redrawing moral boundaries through "a care ethic" that does not exclude ideas that do not fit with the existing world view of morality. Her thesis is that women and their views of morality (caring in particular) have been marginalized, in large part, because of these boundaries.

As we look at ethical considerations of quality of life extending past Healthy People 2010, the experience of embodied fatigue calls out for recognition in order to prevent harm. This is a group of women that might be found anywhere living in 21st-century America. Fatigue is endemic. Healthy fatigue—tired after a hard day—builds and restores us. Unhealthy or imbalanced fatigue, instead of restoring us, leaves us exhausted, imprisoned, misconstrued, and wholly transformed.

So what can we do? We can find these women. We can put into place approaches to scholarship that will help to penetrate the dark silence that surrounds their quality of life. These women who have formed their own Sisterhood are invisible to our healthcare system where we could and should connect with them. Shining the scientific light of diagnostics on this phenomenon is similar to shining the light on Foxfire. The disability is not visible in the light. These women are told they are "fine" but they are not. Three women in my study talked to me about wanting to end their lives. One woman whispered, "I wanted to kill myself . . . I couldn't see any future. I couldn't see anything, you know, I had parents who had no idea what I was going through. I had kids that were so frustrated by that point that I might as well have been dead."

Consider the "lost voice" arising from the women of this sisterhood. This loss is not even recognized, let alone understood. One woman in my study found this bumper sticker–like postmodern slogan, so apropos, "I am woman, I am invincible, I am tired!" This, it seems, is support for social, cultural, and ethical issues that reach into human care practices in ways that have yet to be determined. As nurses, we cannot aid these women if we are not aware of them and unable to hear them. Nurses are encouraged to find ways to listen and respond to those enduring chronic, complex, and often unseen experiences such as fatigue and to embrace our call to care and comfort. Together we can envision new possibilities related to recognizing, hearing, and caring for persons who may either be unknown or marginalized within current North American nursing practice settings.

Clinical nurses, educators, and scholars, choosing to advocate for themselves and for others in the embodied context of caring relationships, are here offered another frontier to explore. The mutuality of this need is inherent in our social mandate as a profession—and perhaps in our disciplinary survival—as we move into the new millennium.

As I have presented my research in a variety of settings, nurses who have heard these stories have articulated that they suddenly realized they had been trying to measure a phenomenon that was not measurable. They have reflected on the new understandings the voices of fatigued women have yielded. Frank's narrative ethic urges us to consider quality of life initiatives for those who, like these women, live lives outside of "patienthood."[46] Tronto's moral boundaries[48] and the feminist ethic of care[47] may provide avenues for nursing to explore new ways to penetrate the dark silence surrounding those outside of patienthood—extending *Healthy People 2010's*[1] goal of improving quality of life for these lost voices. They wait, calling to us: "If someone reads this ... *one* person and just ... understands me ... then that's all I want."

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