Towards a Holistic Framework of Cancer Related Fatigue: Qualitative Data on the
Experience of Embodiment in Breast Cancer Survivors

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Abstract:

Cancer Related Fatigue (CRF) is one of the most common and detrimental side effects of cancer treatment. Despite its increasing prevalence and severity CRF remains dismissed by the majority of clinicians. One reason for the apparent gap between clinical need and clinical undertaking is the penchant towards reductionist accounts of the disorder: a tendency to discount the interface between the lived experience of sufferers and the multi-dimensional etiology of CRF as it manifests adversely on a day-to-day basis.

We undertook semi-structured interviews with 13 Breast cancer survivors suffering from CRF and then subsequently coded their responses using Team Based Qualitative Analysis. We focused most specifically on shifts in embodied awareness that accompanied our participant's experience of CRF.

Our analysis revealed multiple dimensions of the social and bodily underpinnings of fatigue. Most relevantly we found a consistent change in the reported capacity for awareness of bodily sensations. This shift in awareness appeared to be directly connected to the experience of CRF and a newfound, “respect” for the needs of the body. Furthermore, we found that many of the practices that were described as helpful in alleviating fatigue were oriented around eliciting a sense of embodied awareness, examples being: dance, yoga, and shamanic ritual. This relationship with bodily sensations existed in conjunction with the anxiety and trauma that arose as a result of cancer treatment. Our analysis suggests that the quality of awareness and relationship to bodily experience in CRF is a functionally relevant component of the disorder and should be considered as an experiential target moving forward.

1 Introduction:

1.1 Background

Cancer-related fatigue (CRF) commonly accompanies Cancer and has been defined as “a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (National comprehensive Cancer network). It is now estimated that 39% of individuals will be diagnosed with some form of cancer over the course of their lifetime. (NCI 2013 statistics) For many of these persons, the burden of disease will not end after treatment, but will

continue to manifest as a host of factors that impair quality of life (QOL) and catalyze subsequent pathologies. (Gregory et al 2000, Holley 2000, Kurzock 2001, Schultz et al 2003, Yabroff et al 2004, Mustian et al 2007, Roscoe 2007, Bower 2008, Brown 2009, Salligan 2015, Antoni et al 2016) More so than depression, pain, or nausea, patients rank CRF as the post-treatment symptom that causes the most distress and interference in daily life. (Young and White 2006, Stone and Minton 2008) CRF is reported by patients to be a sudden and debilitating loss of energy that is more severe, more persistent and more incapacitating than any form of pre-cancer fatigue. (Holley 2000, Wu and Mcsweeny 2007, Bower 2014) For many individuals in the throes of CRF, resting, at best, grants only a momentary feeling of relief. (Medysky et al 2017) Given its severity many patients find CRF to be nearly impossible to articulate, making the disorder both detrimental to an affected individual's QOL and difficult to characterize in clinically tractable terms. (Wu and Mcsweeney 2007, Duijts et al 2014) Currently, despite the steadily increasing number of cancer survivors, as well as the exponential growth in Psycho-oncological research, CRF remains largely undiagnosed and undiscussed by clinicians. (Koornstra et al 2014) As one of this study's participants put it, cancer-related fatigue is "a silent cry". (Participant 10)

The commonly cited and oft criticized war metaphors that abound within depictions of cancer underscore the importance of gaining a more holistic embodied understanding of fatigue. Wu et al, in a highly cited paper on the topic of CRF, characterize fatigued cancer survivors as either *fighters*: "Some people exercise their will to master their fatigued body and retain the sense of integrity and the feeling of not being controlled by the illness", or conversely as having a tendency to *surrender*: "Some people

may simply give up control when the body is unable to meet the demands or expectations” (Wu 2007). The underlying assumptions of this war-oriented dichotomy are manifold. Most notable is the notion that one can through enough effort “master” the fatigued body as opposed to “simply giv(ing) up”. Susan Sontag writes in *Illness as Metaphor*, “Theories that diseases are caused by mental states and can be cured by will power are always an index of how much is not understood about a disease.”(Sontag 2001) Through asking participants to describe their bodily experiences of fatigue- how CRF feels and how they react to those feelings- we hoped to rigorously evaluate whether traditional accounts of the subjective dimensions of CRF were consistent with participant’s depictions of living with the disorder. By elucidating trends in the multi- dimensional and highly heterogeneous experience of CRF, our study’s participants provide important insights into what the experiential components of the disorder are. In our team-based qualitative analysis of these interviews, we identify key aspects of the multidimensional experience of CRF and examine the basis for an understanding of these components in shedding light on how future clinical interventions could be tailored to the needs of survivors.

2. Methods:

2.1 Participants:

Participants were recruited through posters hung throughout Providence, Rhode Island and word-of-mouth. In order to be eligible for the study participants had to have:

- 1.) Undergone treatment for Breast Cancer
- 2.) Be at least six months out of active treatment.
- 3.) Rate their fatigue at least a 3 out of 10.

- 4.) Be capable of speaking English.
- 5.) Be under eighty years of age.
- 6.) Have not been hospitalized for a psychiatric disorder at any point in the last year.

N=20 people contacted us with interest in the study, of these, n=4 were ineligible because they rated their fatigue as being too low, and n=3 did not show up at the appointed time for the interview. All Participants knowingly signed a consent form that was approved by Brown University Institutional Review Board.

2.2 Interviews:

Following pre-screening, CP met participants (n=13) for a semi structured interview. (Bariball and While 1994) Interviews lasted between 30 and 240 minutes, sometimes over the course of two meetings. Interviews were then transcribed with the use of *Transcribe* software. 26 hours of interviews were collected, transcribed, and codified in total.

2.3 Interview Analysis

In this paper we utilized methods a technique based off of Kathleen Macqueen's team-based qualitative analysis. (Macqueen 1989) Initially CZ, CK, and CP met to decide upon the semi-structured interview questions (see figure 1). Following the collection of the 13 interviews CP, CK, and CZ read through each interview and created three separate codebooks based off of emergent themes. An iterative process followed wherein differences between the codebooks were discussed and resolved (Kerr et al 2011a, Kerr et al 2011b) Based on this codebook CP went through each participant's transcript and

categorized relevant pieces of each interview. This new document was then once again read and discussed by CK and CZ. LC and TK were also consulted about the validity of the codebook after its completion and helped to distill relevant themes. (see figure 2A-2N for excerpts from the codebook and figure 3 for a visual depiction of the emergent model)

Results:

3.1 The General Experience of Fatigue:

Fatigue appeared to exist on two broad temporal scales for our participants. Most viscerally, there were what Participant 10 termed, “energy crashes” (figure 2A) sudden bursts of overwhelming exhaustion that required the immediate cessation of whatever action was at hand. These crashes required forced many of our participants to radically reshape their day-to-day lives in an effort to accommodate these precipitous losses in energy.

In addition to these sudden drop offs there was also a more difficult to define chronic experience of imbalance, or what Participant 4 termed “heaviness”, as if the basic constituents of everyday sensation had been altered. (Figure 2B)

For many of our participants the experience of sudden precipitous energy loss and chronic “heaviness” existed simultaneously, serving at once to shackle attempts to return to a pre-cancer pace of life and dampening those experiences that remained energetically feasible. The source of this two-faced fatigue was often inexpressible for the individuals we spoke with. It existed more generally as a lack, a gap in what was expected of the body

and what was physically possible. As Participant 2 put it, *I don't know, I kind of feel like my life is a little bit less than it used to be.*" (Participant 2)

3.2 Interpersonal and Clinical Influences

Because chronic fatigue experiences appear on the surface to be akin to the fatigue of healthy life, interpersonal relationships can become difficult as those without CRF struggle to understand its additional burden. It is this unknowable and yet apparent ordinariness that serves, in many cases, to prevent the crippling nature of CRF to be meaningfully addressed or articulated by loved ones, medical practitioners, or even the sufferer of CRF themselves. (Figure 2C) In fact, for many of our participants, CRF had never been defined as a possible outcome of their cancer experience. As such, exposure to our study was the first time they learned that chronic energy loss was a normal side effect of cancer treatment instead of an anomalous personal reaction.(Figure 2D) The chronic lack of information on CRF was compounded by cultural views regarding what an appropriate level of energy should be, as well as an articulated or implicit desire on the part of family and medical staff to move past the tumultuous experience of cancer and return to normalcy. As with Participant 1(see figure 2D), this often lead to an experience of guilt and sense of responsibility for the experienced fatigue. (figure 2E) Guilt arose not only as a result of ineffective social and medical support systems, but also as an internalized adherence to what Participant 10 termed the "Protestant work ethic". The language surrounding this ethic often took the form of a moral imperative, as if the experienced lack of energy was a personal decision or as Participant 1 termed it, "character flaw". This ethical dimension in the experience of CRF accentuates the metrics

often utilized by cancer survivors to express the experience of fatigue. For many, CRF was defined on the basis of what they could do rather than how they felt.(Figure 2F) This means of structuring the experience of CRF around a sense of productivity rather than internal state places the onus of fatigue on the survivor themselves instead of deleterious physiological factors. This sense of responsibility was at times reflected in the pejorative stance some participants took to the notion of being affected by fatigue at all. (Figure 2G) A sense of responsibility over one's fatigue is of course not only an abstract psychooncological construct. For many of our participants there was simply not enough room in their day-to-day lives for the chronic exhaustion they experienced post treatment. Across participants, this lead to an experience of CRF as something that existed outside the realm of definition as anything in its own right, but rather an extension of prevailing, often untenable, social circumstances. (figure 2H) Though there were, of course, a number of positive exceptions to the social trends we've outlined in this section; generally speaking, the felt experience of CRF was not so much shaped by embedded social relations as it was obscured by them. Often the lack of information patients received coupled with implicit or explicit presumptions on the nature of fatigue lead sufferers to feel guilty and responsible for their lack of energy. Furthermore, the means of describing CRF often reflected this view such that the most relevant metric for CRF was an individual's productivity rather than their internal state.

3.3 Changed Experience of the Body:

_____ The means by which CRF manifested in the felt sense of the body was highly heterogeneous for our participants. For those who felt their fatigue could be linked to a specific body location, CRF was almost always a head centered phenomena. The vast

majority, however, had trouble pinning CRF to an explicit part of the body as one could with muscular weakness or pain. (figure 2I) For these participants, fatigue appeared qualitatively to be akin to a loss of communication across the body, leaving only an overwhelming need to cease activity. This lack of meaningful communication throughout the body was contextualized for participants by the trauma of their cancer experience. For many the “disorientation” (Participant 5) of the fatigued body was fundamentally connected to the violence of being treated for cancer. (figure 2J) Trauma in Breast Cancer Survivors has been increasingly reported in recent years (Cordova et al 2007, Chan et al 2011). The most consistent and tangible way this trauma appeared to manifest for our participants was in their articulated fear of recurrence. Given that the object of anxiety, a tumor, manifests within the body, the interior space becomes a staging ground for the harrowing “assault” of treatment. This affective dimension of post-cancer experience manifests as a shift in the valence of interoceptive and somatic afferents. Because of the constant drive to interrogate sensations as they arose, participants commonly reported a chronic pulled towards a body-centered rumination. (figure 2K) These shifts towards an anxiety-driven monitoring of bodily sensations represents a pathological face of one of the most surprising consistencies that emerged from our Participant’s accounts of CRF. Many of our Participants reported, contrary to our expectations, a much greater awareness of their bodily sensations on a day-to-day basis and a radically changed understanding of what Participant 3 termed, “the mind-body interface”. This increase in embodied awareness appeared to be driven directly by the fatigue itself and an understanding that “honoring the fatigue” (Participant 3) was an effective approach for buffering the “crash” of fatigue and potentially ameliorating symptomology. (figure 2L) The relationship

between the shifts in bodily awareness driven by anxiety and those driven by a desire to “honor fatigue” often coincided dynamically over the course of the day. Many of our Participants described a newly developed metacognitive capacity that allowed them to be aware of bodily signals without necessarily ruminating on their specific characteristics. (figure 2M) Practices that worked to either actively or passively facilitate shifts in non-judgmental embodied awareness were often highlighted by Participants as being particularly helpful tools for moving through the experience of fatigue. The nature of these practices was varied, examples being; visualization meditations (Participants 5 and 3), movement based practices like yoga (Participants 2 and 4), dance (Participant 1), ecstatic Christian prayer (Participant 12), shamanic ritual (Participant 11), and gardening (Participant 7). The shared faculty of all these practices was the apparent foregrounding of the body during an experience without it being an intentional object of focus; the experience of losing oneself in an action. (Figure 2N) Our analysis revealed that one of the most important factors in the experience of CRF was the change in embodied awareness (ie the awareness of bodily signals and the tendency to try to interpret their meaning) that followed cancer treatment. This changed experience of the body was not apparently linked to any specific practice, social climate, or personal belief system but rather arose as a result of learning to “honor the limitation” that followed from living with chronic fatigue. In addition to this apparently beneficial mode of awareness, there was also a more pernicious anxiety-driven shift in sensory cognizance, such that innocuous bodily signals or pain took on a different valence and were thus amplified by attention. This increase in awareness seems contrary to the apparent loss of specificity in interpreting the state of the body during fatigue experiences, what Participant five termed, “wanting to lump”. For

many of our Participants exercises that facilitated a shift in the experience of the body were particularly effective at changing a Participant's outlook on post cancer circumstances and in some cases ameliorating CRF altogether.

Discussion:

In this paper we utilized team-based qualitative analysis to illuminate trends in the subjective experience of CRF. Our analysis revealed that CRF was defined by two broad elements. One was the sudden, overwhelming, exhaustion one Participant termed an “energy crash.” The other was a more subtle, chronic, shift in the experience of the body, such that participants reported simultaneously an increased need to “listen to” and “honor” the body and its sensations, while also reporting tremendous anxiety towards the meaning of sensations as hallmarks of the cancers’ return. In many cases social factors lead participants to dismiss their experiences of fatigue outright, viewing exhaustion as being reflective of personal or psychological weakness instead of a biological phenomena beyond their control. This tendency changed the means by which CRF was experienced by participants and shifted the reference frame of fatigue from a focus on internal state to one based around productivity. For some women, embracing this model of fatigue was effective at helping them to structure a sense of well-being and return to normalcy (Participants 9 and 6). For others, these social factors effectively obscured CRF such that for years following treatment some had no comprehension they were chronically exhausted, only that they were “screwing everything up”(Participant 7). In describing

what exercises were most effective at alleviating CRF, a number of women brought up practices that foregrounded the body without making it the explicit object of focus.

One predominant theme throughout all of the interviews was the recognition that the trauma of cancer and subsequent crash in energy meant that the women in our study were forced to devote cognitive resources to what would otherwise be an unconscious phenomena. As participant 5 put it, “I cannot hold my body up, that’s the language I use.”

The need to chronically maintain an awareness of how bodily resources were being utilized is functionally akin to the rumination that accompanied fear of recurrence. Both factors constantly force a survivor’s awareness back into the body with an associated negative valence. The experience of being in a fatigued body was emotionally charged for many participants who felt guilty and insufficient as a result of their fatigue. As such, the constant pull back to the body as a necessary function of conserving energetic resources was also a constant return to socially subsidized feelings of “feeling like a bum”(participant 10). Likewise, the experience of “constantly tracking” bodily sensations drained cognitive resources and represented a significant source of emotional distress. Chronically being in the body can therefore be seen as both a symptom and a cause of the altered embodied experience of CRF.

In direct response to the constant convergent experience of anxiety and energetic depletion, many participants described being forced to more actively listen to their bodily sensations. As participant 2 stated, *“I think it’s very easy to ignore what your body is telling you, because we get so caught up in our daily activities... it’s not going to tell you like maybe what your mind would tell you.”*

For Participant 2, listening to the body was akin to the cessation of “get(ting) caught up” and allowing otherwise invisible bodily signals to be perceived and to guide actions and behaviors that would be supportive and nourishing, rather than oriented around socially subsidized definitions of productivity. This newfound tendency to “respect their limitation”(Participants 5) or “honor their fatigue”(Participant 3), is perhaps indicative of attempts to engage with bodily sensations that can no longer be overlooked as a function of CRF in a way that is nourishing instead of ruminative.

Importantly, when participants described practices that were helpful in dealing with their fatigue, they often used language oriented around a departure from an explicit awareness of bodily sensations: activities which “carr(y) you away within (them)”(Participant 1) helped Participants to feel more energized and tap into a deeper level of embodied understanding. It is possible that beyond the direct physiological benefits of something like yoga or dance there is also a shift in the quality of embodied awareness carried by a practitioner throughout their day. If this is the case these assorted practices can be seen as behavioral interventions designed to change the tendency to meaningfully tap into the signals that arise from the body rather than simply physical exercises. Indeed recent evidence from a number of sources support this notion. (Mustian et al 2007, Bower et al 2012 Thomas et al 2014)

What emerges from this analysis is a view that the difference between ruminative and nourishing awareness of the body in cancer survivors is a matter of what heuristic is applied to the experience of fatigue. When an internal sensation, can be meaningfully understood as fatigue it can lead to a set of nourishing actions that are squarely in line with the needs of the body. Alternatively if an individual interacts with embodied

sensations on the basis of an embedded cognitive framework (fear of recurrence or a sense of guilt/responsibility) then the fatigue or pain that arises from the body is characterized differently and an individual continues to be “caught up” in the experience without changing their bodily state.

Conclusion:

In this manuscript we laid out a model of CRF based on the changed nature of embodied awareness following treatment. This model is generative in that it identifies new experiential targets that may be important in designing interventions moving forward. The notion that the quality of embodied awareness present in fatigued cancer survivors is an important aspect of the disorder is a novel means of articulating chronic fatigue and its relevant shifts in day-to-day experience. Future studies should apply neurophenomenological techniques to more accurately assess whether and how the quality of embodied awareness present in survivors meaningfully influences the experience of fatigue over dynamic time scales.

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Figure 1:Figure 1)

Semi Structured Interview Questions

1	Though we've gone over the consent form, before we begin do you have any questions?
2	Will you tell me the broad outline of your cancer experience starting with your diagnosis?

3	Is there anything specific about your Fatigue you'd like to share with me at this time?
4	Do you talk about fatigue differently depending on who you're discussing it with? If so, how would you describe it with a friend? Concerned family member? Clinician?
5	Is there a specific part of your body that you feel your fatigue affects more than others? If so what part? - What are the qualities of fatigue in that body part? Are these qualities different from fatigue you might feel elsewhere?
6	Does your fatigue ever move throughout your body?
7	Do you ever experience whole body fatigue? If so, is the quality of this fatigue different from singular body part fatigue? In what ways are they

	different?
8	Does the quality of your fatigue change depending on your environment?
9	How largely does fatigue factor into your planning for the day, if at all?
10	How many times a day, on average, would you say you need to rest? What does rest entail?
11	Do you think others understand this need?

12	Do you think fatigue has changed the way you function? If so, how?
13	When you feel fatigued what actions do you take?
14	Have you found anything that is particularly effective in decreasing your fatigue? if so what is it?
15	Is your current level of fatigue comparable to what you experienced pre treatment? If not how is it different?
16	Is the day-to-day level of fatigue you feel comparable to anything you experienced prior to treatment

17

When during the day is your fatigue the worst? Why do you think that's the case?

Figure 2:

2A	<p><i>“(Fatigue) comes out of nowhere. It is prolonged....it's a crash. It's an energy crash. It hits you upside the head. You can't necessarily foresee... you try to hedge it. You try to measure what you do. Which is debilitating in itself. But you have to look at life a different way. And it's different now because now I have to think about energy.” (Participant 10)</i></p> <p><i>“The fatigue will come over like a fog coming in on a Mountain Top. I've seen it happen. Come in and all of a sudden the snow drops. It comes in like a wall and then boom it hits. And you just have to lie down.” (Participant 12)</i></p>
	<p><i>“So I'm in a rut and that's how I feel about everything, my mind is in a rut, my body's in a rut... I don't feel comfortable</i></p>

2B	<p><i>in my own skin anymore, and I just have no energy, it's a lose lose situation."</i></p> <p><i>(Participant 8)</i></p> <p><i>"It's just a heavy feeling it feels like my body is heavy. I have to push it through the day, through the atmosphere, like the atmosphere is heavy." (Participant 4)</i></p> <p><i>"It just feels like my whole body is tired, like the way that I'd describe it is that I cannot hold my own body up."</i></p> <p><i>(Participant 5)</i></p>
2C	<p><i>"I just I can't get my things done, I can't, and you know I'm exhausted at work... it's really hard for people to understand that if you have no energy and you can't focus and your day is lost. You know, how can you convey that to someone...? That can be very devastating." (Participant 7)</i></p> <p><i>"They dismiss (cancer related fatigue),</i></p>

	<p><i>I'm tired of telling them, so I just go for my annual physicals now, and I don't even bother to complain, because they just treat me like it's nothing...part of me thinks that maybe the Doctors are right."</i></p> <p>(Participant 8)</p>
2D	<p><i>"When I saw the little, you know the flyer, I think there's a part that makes me say, Oh this is a thing? I mean I sort of think of it as a character flaw (laughs) Whereas if other people are experiencing it too... I think it makes me feel like less guilty about it somehow."</i> (Participant 1)</p>
2E	<p><i>"I just feel like I feel so lazy, I can't get up, I'm not getting anything done. You just feel like a bum... The Protestant work ethic. You just keep going. And with this, you can't, you just can't. (Participant 10)</i></p>
2F	<p><i>"For years, I didn't know that I was exhausted. I just knew I could only work 25 hours a week or I'd be screaming at</i></p>

	<p><i>my kids, I'd be screwing everything up, you know it's only over time that I came to realize -- so it's-- it's a very hard thing to pin down." (Participant 7)</i></p>
2G	<p><i>"I think it's a lot of mind over matter. I mean does everyone else complain about how exhausted they are and they can't do anything? Put their big girl pants on. Man up!" (Participant 9)</i></p> <p><i>"People use things like cancer as, um, an excuse not to do something, alright... they'll let that stop them from doing something with their lives... Cancer is not going to hold me back." (Participant 6)</i></p>
2H	<p><i>"Coupled or tripled on top of financial issues, now you've got nothing, all these bills to pay, your husband just left you because you're not a woman anymore. Your kids are upset. They don't know how to deal. So they're acting out or acting in. Everyone is a disaster and there is no net to catch this... I've got a special needs</i></p>

	<p><i>son that goes back and forth between the states, I'm trying to drive him. puking my guts up, I can't go to work... So fatigue.</i></p> <p><i>Yeah. Yep. Definitely. Definitely”</i></p> <p>(Participant 12)</p>
2I	<p><i>“From the neck down my body just wants to like-- lump.” (Participant 5)</i></p> <p><i>I think it's more of a sensation. I don't think it's from my body or my mind per se, it's just I get, I get to the point where it's like, maybe I tried to stay up. And sometimes it works and sometimes it doesn't... I don't know maybe it could be like one of those you know the internal clock? Maybe I have to reset my internal clock. (Participant 6)</i></p> <p><i>“I think it starts inside me. Not so much my legs or arms. Torso and head. It's something that almost, like the energy, seizes. Just gone...There's just nothing</i></p>

	<p><i>left. I say the same thing over and over and that's all I can come up with. There's just nothing left. (Participant 10)</i></p>
2J	<p><i>"I think on some fundamental level my body has no idea what f*****g happened to it, it was just existing and trying to be nice, and then all of a sudden comes the poison and the cutting, ya know, cutting parts of me out and the medication and I think my body, sort of at a pseudo existential level is completely disoriented and my bits... my bits have no idea what's going on, you know, and I haven't even recovered. (Participant 5)</i></p>
	<p><i>"I sit and my knees hurt or my legs hurt, and I say, 'uh oh I hope it's not cancer', you know it's just the constant level-- like there's a low level of anxiety all the time that I think contributes, and it makes you much more aware of what's going on inside your body." (Participant 3)</i></p>

<p>2K</p>	<p><i>“If I touch my armpit those little muscle nodules, I'll be like Oh yeah, that's cancer yeah all the time. If I touch my tummy, I'll be like ooh yeah, if I don't know what I'm touching, I feel like little bumps, okay that's cancer. I'm constantly convinced that I have brain cancer because I am dropping things.” (Participant 5)</i></p>
	<p><i>“I think fatigue is real and I think when it happens it's part of your mind-body mechanism. And it's good to honor fatigue when you can... I think it's part of respecting your body and not always being so focused on what's going on in your mind. Just stopping, like stopping thinking about when it happens and just like tune in to what's happening in your body, and I've been able to do that more since I've had my breast cancer. I don't know maybe you need to go through a life changing event like that to become more</i></p>

<p>2L</p>	<p><i>honorable towards your whole self really, not just the mind but the body as well, they're both interconnected as far as I'm concerned, it's all one."</i> (Participant 3)</p> <p><i>"I think too often we ignore what our bodies are telling us. Whether it's being in pain, or being hot, or cold, or you have a headache. I think we tend to brush it away when our bodies are really like these super friends that we have... and we don't give them enough respect that they deserve... when I listen to my body it's usually a good idea."</i> (Participant 2)</p>
<p>2M</p>	<p><i>"So I spent a lot of time driving myself crazy by trying to categorize the symptoms- label their intensity, figure out what caused them, come up with a treatment plan, but when they're subclinical I can't do it... and sometimes</i></p>

	<p><i>I get to this loop where I'm trying to like interpret my symptoms but I have to be like no I don't have enough data, all I can do is honor the limitation I feel right now.” (5)</i></p>
2N	<p><i>If I garden I lose track of all time. So that’s really what puts me in a --, everyone says oh you should go to church and I'm like this is church for me.</i></p> <p><i>(Participant 7)</i></p> <p><i>it’s one of those odd things where like I’ve been taking dance classes and stuff, and I may go to it feeling fatigued, but actually doing the dance stuff, and more so then running, you know, because there’s something that sort of carries you away within it, you sort of surrender to it as opposed to running which is so repetitive. And you know, I like, it’ll alleviate it while I’m there, I’ll be like wow I was so tired when I came in but</i></p>

*I'm getting kind of energized from this
and I'll feel good for a while afterwards.*

(Participant 1)

*"My personal.. I like to call it my toolbox.
The tool that I'm using with this crisis in
my life is actually music and meditative
music. and worship. prayer worship in
music and praise... That I find helps to
bring me to another level where I can
move forward and feel better. (12)*

Figure 3:

A Multi-Dimensional Model of Fatigue as An Embodied Experience

Sense of fundamental inadequacy

the worst part about (fatigue) was laying on the couch, seeing it was a nightmare, knowing I had work to do, but I couldn't go out and do it... That was the worst part. Thinking that I was being a bum. (Participant 10)

Ongoing Anxiety

I just know I always felt really guilty and ashamed because I realized I could not work more than 25 hours a week and do my kids, I just couldn't, I would just fall apart. And even now when I get really tired, before when I used to get really tired I used to just scream at my kids and stuff like that, but now when I get really tired I just, I cry because I can't think. (Participant 7)

Psychosocial Factors

"I think fatigue in general is sort of... it umm, it feels embarrassing, I don't know if it's our culture, or my particular upbringing that you know... productivity and stamina and energy and a certain kind of energy is encouraged." (Participant 1)

New Sense of Identity

so I feel pushed into middle age without having had kids and that's very painful... it is about power in our society, like to walk into a place and people will treat you a certain way because of how you look, and having lost that, there are a lot of identity pieces there. (Participant 5)

Trauma of Cancer and the process of treatment

"Yeah it kinda feels like... your body has been assaulted pretty much. it's not even just the chemotherapy or just the surgery... Constant assault. Constant physical assault." (Participant 13)

Debilitating and Chronic Lack of Energy

"The fatigue will come over like a fog coming in on a Mountain Top. I've seen it happen. Come in and all of a sudden the snow drops. It comes in like a wall and then boom it hits. And you just have to lie down... It's a horror show because you know you're going to wake up and get punched in the face again with fatigue. You can't control it. Can't." (Participant 12)

Changed Valence of Somatic Afferents

"I don't ignore (bodily sensations) anymore. I used to be like, 'that's fine', Now I feel like I'm constantly tracking what hurts where, and how long it's been hurting for and do I have to be worried about this one, or not." (Participant 3)

Functional Necessity of monitoring Energy Levels

I think about (energy) now. Never had to think about it before. If you were sick, then you'd be tired so you'd go to sleep. If you get a solid sleep then you woke up and you felt better. This isn't the way it is, so it's a whole new way of dealing with how you conduct your life. (Participant 10)

Change in Quality of Interoceptive Awareness

I feel differently, it feels differently, I feel I have more of an acute awareness of what's going on in my body and how it feels, and I kind of walk this thin line between being aware of it and trying not to be too pulled into it all the time. (Participant 4)

New Sense of Mind Body Interface

"I think too often we ignore what our bodies are telling us. Whether it being in pain, or being hot, or cold, or you have a headache. I think we tend to brush it away when our bodies are really like these super friends that we have... and we don't give them enough respect that they deserve... when I listen to my body it's usually a good idea." (Participant 2)