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Understanding the Meaning of Fatigue at the End of Life: An Ethnoscience Approach

Abstract

Purpose: Fatigue is a devastating state of body and mind associated with distress at the end of life. We report the results of the third in a series of papers outlining a novel approach we have developed for understanding the meaning of fatigue by exploring how this meaning is shaped by beliefs and values. The aims of the study were to examine the perception and experiences of fatigue held by patients attending a hospice in England; identify the behavioural patterns that distinguish fatigue from tiredness and exhaustion; provide conceptual definitions of tiredness, fatigue and exhaustion.

Method: An Ethnoscience design was selected. The sample comprised nine people who attended a hospice between May and December 2009. Inclusion criteria included: at least 18 years of age, experiencing fatigue, able to provide informed consent and resident in the selected city in northern England for 10 years. Data were collected from two consecutive semi-structured interviews for each participant.

Results: We found that tiredness, fatigue and exhaustion are markers of progressive functional decline. Fatigue had two dimensions: 1) *Mental Challenge*, which included: emotional effects, cognitive realisation of decline and mental tenacity and 2) *Physical Challenge*, which included: limitations in leisure activities, limitations in functional roles and re-patterning routines.

Conclusions: This study provides evidence that symptom experience is socially constructed, which has potential implications for the development of effective interventions.

Key words: fatigue, end of life care, cancer, ethnoscience, ethnography, hospice

Introduction

Fatigue is a devastating state of body, mind and existence and is experienced by a multitude of sufferers across the globe for many different reasons. The burden of fatigue is an almost universal experience for those who have cancer (Fisher, 2006; Servaes, Gielissen, Verhagen, Bleijenberg 2007; Rosman, 2009) and conditions requiring palliative care (Rose, Pugh, Lears, Gordon, 1998; Small, Lamb 1999; Kralik, Telford, Price, Koch, 2005), affecting between 76-99% in both these populations (Ream and Richardson, 1996; Curt, 2000; Radbruch, Strasser, Elsner, Gonçalves, Løge, Kassa et al., 2008).

Despite its high prevalence, the nature of fatigue is not well understood and as a result, health care professionals remain perplexed about the best way to treat fatigue. Aside from moderate, aerobic exercise (Edmonds, McGuire, Price, 2004; Rietberg, Brooks, Uitdehaag, Kwakkel, 2004; McNeely, Campbell, Rowe, Klassen, Mackey, Courneya , 2006) and a small group of pharmaceutical stimulants (Peuckmann-Post, Elsner, Krumm, Trottenberg, Radbruch, 2010), options for treatment remain limited (Mitchell, Beck, Hood, Moore, Tanner, 2007; Kirshbaum, 2010).

One of the problems in fatigue management is that researchers and clinicians have difficulty agreeing on what fatigue is. For example, Bartley and Chute (1947), two of the earliest fatigue researchers, described fatigue as an indicator that the body lacked resources to cope with physical demands placed upon it. Years later, Grandjean (1968) proposed a biofeedback process that linked fatigue, consciousness, perception and thinking. Grandjean's work formed a foundation for most recent studies of fatigue. Piper used Grandjean's ideas to develop the Integrated Fatigue Model (1987), which is comprised of four

fatigue manifestations (perception, physiological, biochemical and behavioural) surrounded by 13 types of 'patterns' that influence the perception of fatigue and its clinical manifestation. The Psychobiological-Entropy Hypothesis postulated by Winningham emphasised an approach based upon balancing restorative rest with restorative activity (Nail 1997). Kralik and colleagues (2005) have described fatigue as a 'multi-dimensional and complex phenomenon that affects physical, cognitive, emotional and social functioning' (p378), which concurs with the some literature (Piper, Lindsey, Dodd, 1987; Richardson, 1995; Krupp and Christidoulou, 2001; Ameringer and Smith, 2011). A more recent approach to the management of fatigue in cancer care has been to view and attempt to treat multiple symptoms simultaneously as a cluster (Dodd, Miaskowski and Paul 2001; Barsevick 2007).

The work described in this paper is built on different conceptualisations of fatigue based in stress theory (Selye, 1950, 1956, 1971; Aistars, 1987; Cameron, 1997; Glauss, 1998), Using this approach, Olson conducted an extensive review of the literature and a series of qualitative studies in populations who experienced fatigue for different reasons, and proposed that fatigue was a behavioural marker for the inability to adapt to stressors associated with advanced chronic disease and treatment (Olson 2007; Olson, Krawchuk, Quddusi, 2007; Olson, Turner, Courneya, Field, Man, Cree, 2008). These stressors reduced the inability to adapt by causing a decline in cognitive functioning, muscle endurance, sleep quality, social interactions, and an increase in emotional reactivity. Olson distinguished between tiredness, fatigue and exhaustion on the basis of changes in these five areas (Olson 2007). For example, individuals with tiredness reported short-term memory loss, while individuals with fatigue reported difficulty concentrating, and individuals with exhaustion reported confusion.

Our team, comprised of researchers from Canada, Italy, Thailand, England and Sweden is interested in the idea that in addition to stressors associated with disease and treatment, the manifestations of fatigue are also influenced by the meanings we attach to fatigue and that these meanings are socially constructed. This idea is supported by the work of Kleinman,

Eisenberg and Good (2006), who argue that the perceptions associated with illness are influenced by social spheres of life such as gender, family, age, ethnicity, race, socioeconomic status, geographical location and occupation. To learn more about the possible variations in the meaning of fatigue, we decided to replicate the work of Olson, Krawchuk, Quddusi, (2007) in Thailand, Italy, England and Sweden. These countries were chosen because social spheres in these countries have been described extensively by others and because individuals with expertise in oncology and qualitative research methods were available in these places. The report of our study in Thailand has been accepted for publication (Pongthavornkamol, Olson, Soparatanapaisrn, Chatchaisucha, Kamkhon, Potaros et al., 2011), and the results of our study in Italy are in review. In this paper we report the results of our study in England.

Aims:

1. To examine the perception and experiences of tiredness, fatigue or exhaustion held by patients attending a hospice in northern England.
2. To identify the behavioural patterns that distinguish fatigue from tiredness and exhaustion.
3. To provide conceptual definitions of tiredness, fatigue and exhaustion.

Methods

Design

We used an ethnoscience design (Sturtevant 1964), for the study in each of the five countries in our project. Frake (1962) notes that this design facilitates the discovery of cognitive structure by examining what people say. Since language is the primary symbol system through which meaning is conveyed, the study of language provides a way to uncover implicit beliefs and values that shape meaning. Ethnoscience provides a systematic approach for studying language, with particular emphasis on the unique relationships among

beliefs and values (French, 1963; D'Andrade 1995). Rather than classifying data into themes or categories, the focus in ethnoscience is on identifying key words and phrases related to a given domain, and then understanding how these words and phrases are related to each other. Patterns in these relationships across participants help to uncover the beliefs and values that shape meaning (Evaneshko and Kay, 1982; Graffigna, Vegni, Barrello, Olson, Bosio, 2011) and are often represented in a hierarchical model such as a taxonomy.

Sample and Setting

The sample for this study comprised nine individuals, consecutively drawn from among those attending a hospice in a northern city in England. Inclusion criteria included: at least 18 years of age; self-reported experience of tiredness, fatigue or exhaustion; considered to be in the palliative stage of an illness (where the patient has active, progressive or advanced disease and the focus of care is quality of life); able to provide informed consent; resident in a selected city in northern England for 10 years and sufficient energy to participate in a half hour recruitment interview and two interviews lasting up to 45 minutes each. Cultural and racial diversity were welcomed with the proviso that all selection criteria were satisfied. Individuals were excluded if they were unable to read and write English. In keeping with standard practice in qualitative studies, the sample size was determined by saturation of analytic categories. Participants were added to the study until all analytic categories were saturated and no new information was obtained.

Ethics

Ethics approval was obtained from a university based Research Ethics Committee and the Clinical Quality Group of the hospice where the data were collected. A follow-up questionnaire was sent to all participants inviting them to provide feedback about the conduct of the study and to add any further thoughts they may have had following the two interviews.

Data Collection and Analysis

Following ethics approval, hospice staff were informed of the study and its aims and then assisted in the identification of potential participants by handing out study information to individuals who met the inclusion criteria. If individuals indicated to the staff that they were possibly interested in participating in the study, the staff member notified the research team. A member of the research team then met with each potential participant to provide complete and detailed information about the purpose and procedures of the study, answered any questions and obtained written informed consent from those interested in taking part in the study. All data were collected at the hospice between May and December 2009. Basic demographic details such as age, diagnosis and history of illness and treatment were collected from individual case notes prior to the interview. At the interview session an inclusion criteria checklist was completed to ensure eligibility of each participant. The Edmonton Symptom Assessment System (ESAS) (Bruera, Kuehn, Miller, Selmsler, Macmillan, 1991) numeric scale was administered to facilitate the description of the sample. The ESAS consists of severity scales for eight common symptoms (pain, tiredness, nausea, depression, anxiety, appetite, wellbeing and shortness of breath, plus an option of identifying another concern or problem). All symptoms were rated on a scale of 0 - 10, where zero indicated that the problem was not present and 10 indicated the 'worst possible' severity. In addition, participants were asked to rate their current level of fatigue ranging from 1-10 using a separate single item scale, which will be referred to as the Fatigue Scale.

Participants were advised that two interviews would be conducted and that each would last a maximum of 45 minutes. The initial interview began with an open ended question designed to elicit a narrative of his or her fatigue experience e.g. "Please tell me what a typical day is like for you?" As comments pertaining to tiredness, fatigue or exhaustion were made, questions that explored the boundaries of these experiences were asked, for example: "How is the kind of tiredness you have now different to that of the past?" Following the description of their own experience, participants were asked to comment on the attributes of fatigue as

described in the study by Olson (2007): changes in emotional, cognitive and muscle function; control over body processes and decreased social interaction. This was done to determine which areas held personal meaning as evidenced by their responses and anecdotal descriptions. Notes were taken by the interviewer to record key points of interest such as particular word choices and use of language; these were used later on in the interview session for confirmation, elaboration or summation purposes. All interviews were digitally audio recorded and transcribed to facilitate analysis. The first phase of analysis was completed by the principal investigator without the use of computer software. Results were then discussed in team meetings comprised of the leaders of the project for each country using web-based meeting software.

Analysis of the first interview consisted of identifying specific words and phrases that contributed to the conceptual definitions of tiredness, fatigue and exhaustion. First, the audio recording of the interview was played and written notes were made. When the transcript of the interview was available, it was reviewed and phrases that described the experience of fatigue were highlighted and recorded onto index cards (one phrase per card). Cards from each participant were gathered to form a large set, which were taken to the second interviews.

The second interview took place one to two weeks after the first and was based on the card sort technique described by Spradley (1979). Participants were asked to sort the set of the index cards generated from the preceding first interviews into discrete categorical piles and to think aloud as they did this. If they felt that a particular phrase did not concur with their experience or perspective, then the card was discarded from their session. For the first round, individuals could generate as many piles as they wished. In the second round the cards were gathered and re-sorted into no more than three piles; in the last round this was reduced to two. On the back of each card, we noted the pile to which the card was assigned during each of the three sorting exercise. For example, 3/2.1 would refer to participant number three, second sort, first pile. When he or she finished with each round, the

participant was asked to name each pile of cards and identify the similarities and differences between the piles. A comparison of the labels from these three card sorts for each participant was used to construct a table showing how the words and phrases were related to each other. Each table was compared with the tables obtained from the sorts completed by other participants, with the goal of identifying patterns that were common across study participants. These patterns provided the data from which we identified beliefs and values that shaped the meaning of tiredness, fatigue, and exhaustion.

The identification of key words and phrases in this study was facilitated by the use of ethnographic content analysis (ECA) (Altheide, 2004). ECA is a systematic and analytic method for coding and analysing all forms of text and documents; it is concerned with qualitative comparisons of situations, settings, styles, images and nuances (Altheide, 1999). In this approach, precursor themes, concepts and variables can provide a starting point for analysis but then others can be included and integrated as in the process of constant comparative analysis associated with grounded theory methods (Glaser and Strauss, 2009).

Analytic rigor

Analytic rigor was addressed using the five verification strategies outline by Morse, Barrett, Mayan, Olson and Spiers (2002): methodological coherence, sampling adequacy, simultaneous data collection and analysis, theoretical thinking and theoretical development. Methodological coherence was maintained by carefully choosing the best design to address the research questions at the outset of the study and then monitoring the data as the study unfolded to ensure that this initial decision was still appropriate. Sampling adequacy was addressed by carefully selecting participants who had the ability to address the research topics and by ensuring that all data were saturated. Third, data were collected and analysed concurrently. This iterative relationship between data collection and data analysis meant that knowledge obtained early in the study could be used to inform subsequent interviews. Theoretical thinking, the fourth component of verification, requires that emerging theoretical

ideas must be confirmed in both data already collected and in the new data. This step goes hand-in-hand with concurrent data collection and analysis. In our study, theoretical thinking took place primarily during our web-based team meetings. As new features were identified, the principal investigator provided team members with textual references from the interview under discussion, as well as similar references from earlier interviews. This discussion helped us to develop questions for future interviews with new participants.

Findings

The sample

Nine participants (Table 1) contributed to the study. Six were female and three were male. The average age was 56 years ranging from 48 to 71 years. Eight participants had metastatic cancer and one had a neurological illness. Two participants died during the study. The first person died soon after the second interview and his data was fully incorporated into the dataset. The second person died in the interval between interview one and two. In this second case the interview was fully transcribed to aid in the overall interpretation of the study, even though a second interview was not available. Quotations from these two participants were integrated into the analysis and report.

When asked to rate their level of fatigue according to the single item scale, seven out of the nine participants reported a score over five. One woman (participant number 3) recorded a score of one. When asked by the researcher to confirm her answer, she replied that she has had to live with extreme tiredness for over 22 years due to caring for her husband and had to deny its existence in order to get on and cope with her daily responsibilities; this explains her response to the scale. Several individuals reported other symptoms such as pain, poor appetite, shortness of breath, depression and anxiety.

[Table 1 here please]

The fatigue taxonomy

The overarching feature of fatigue in this study viewed a continuum ranging from tiredness to exhaustion as a progressive decline in physical function. One participant said:

I don't know how to explain it. I feel like I want to do things, I want to stay awake longer but it just beats me...I know if I did that I would be shattered. If I stayed awake and did something, it would make me feel worse and I would have to sleep for longer. And I think it is part of the cancer that's making me feel like that, and it is getting worse. [pt4]

I can't walk far at all now, and I am getting much slower, which is so frustrating! It irritates me. There are things that I want to do, like get out on my motorbike, which makes me feel a lot better, but I am on a limited timescale now. I don't know how long I will be able to continue...I try to build myself up, but I know that there is not much that I can do that will really help now. [pt7]

The final version of the taxonomy displays two segregates, six sub segregates and numerous explanatory elements (Table 2).

[Table 2 near here please]

The Mental Challenge

The Mental Challenge was observed through expressions of emotional and cognitive adaptations and were characterised by the self-realisation that disease was progressing and that the end of life was approaching. Participants reported that the physical effects of fatigue encroached upon their ability to conduct their lives, and that they were aware of their declining health. Participants were aware that they were not going to recover from their illness but did not express defeat or hopelessness. Rather, they were determined to continue to do as much as possible. This decision was deliberate and focused. Three sub-

segregates represent the core components of *The Mental Challenge*: 1) *emotional effects* 2) *cognitive realisation of decline* and 3) *mental tenacity*. Within each sub-segregate, elements, consisting of actual words and phrases, often expressed by the participants, were used to substantiate and elucidate the meaning of each sub-segregate.

Emotional effects denotes the emotional responses experienced as a result of the fatigue. The aspects of emotion that were prominent were worry, frustration, annoyance and fear. Participants said things like: 'I worry all the time, about the future. That puts a strain on me' [pt9] and 'I want to do more'...I can't do what I want [pt6].' Participants linked changes in their physical bodies and their ability to think clearly and included changes in this dimension. One participant noted, 'my body is a mess...I have chaotic thoughts, like a crazy mixed up kid [pt2].' Fear was an important part of the emotional dimension. One participant said, 'no matter how positive you are, you cannot take the fear away [pt1].' It is clear that fatigue is much more than a physical symptom of weakened muscle that restricts endurance. Here we have an indication of its wide ranging impact on emotion and view of self. For the most part, participants spoke rather calmly about their emotions. There were no outbursts of tears or anger, but at times a struggle to maintain composure was observed as they spoke about their distressing circumstances. Verbal language was the vehicle used to describe what they were feeling and their observations.

Cognitive realisation of decline refers to statements about changes to their daily lives that constantly reminded participants of their illness, functional difficulties and increasing disability. These included references to the burden of physical symptoms and the impact of medical interventions. The elements included here were identified in context as disease, pain, pain medication, radiotherapy, chemotherapy, change in appetite and change in diet. One participant said, 'deep down I know I am not fine...some days, the fire will not light [pt7].' Another added, 'I don't want to go out... I have just lost the motivation. [pt9]' Participants were very aware of the changes they were experiencing. One participant noted, 'when I looked in the mirror, it wasn't me at all [pt8].' Another participant recounted, 'my

mind plays tricks on me [pt2].’ Participants recounted what they had been through in terms of their disease, treatment and struggles, while moving swiftly onto the awareness that their condition was worsening. If their spine was crumbling because of cancer metastases, the pain, decreased movement and possibility of spinal collapse was going to increase; they knew it and they spoke about their realisation honestly. Hence, the phrases above are potentially quite profound as they reveal the exceptional ability of humanity to analyse and then elucidate perceptions of ‘coping’ with the approaching end of life.

Mental tenacity was the term used to convey a sense of perseverance and persistence of not succumbing to illness observed in the majority of participants. One participant noted, ‘I am always pushing *to do*, [pt1]’ and a second participant, in response to the perception that her family was taking over her affairs, said, ‘I want others to recognise what I can do [pt6].’ Participants were aware of their limits and were determined to do as much as possible. For example, one participant said, ‘I know my limits, but keep at it [pt2].’

There was a definite sense of fortitude and purpose observed in the participants’ approach to life. They were adamant that they wanted to contribute to the study, knew where they preferred to sit, persevered with the card sort exercise and expressed politely but directly, when they had had enough. Despite their levels of fatigue and other distressing symptoms, there was hardly any expression of helplessness or complacency. Moreover, it was evident that participants wanted to do as much as they possibly could, while they were able.

Problems arose when those close to them (e.g. family members) were viewed as being too protective. Persistence, stubbornness, obstinacy and tenacity are human characteristics that in some circumstances can be critical to survival. However, in this population *mental tenacity* referred to the drive to be active and not give in to illness unless there was no other option. As oppose to the *cognitive realisation of decline*, this aspect of the fatigue experience was about recognising what they could do, identifying barriers that stood in their way and then making a plan of action for how to proceed.

The Physical Challenge

In addition to the more cognitive, mental and emotional expressions of the influence of fatigue emanating from the sample, prominence was given to the physical burden. It was noteworthy that a substantial number of descriptions within the narrative were specifically about functional limitations and subsequent adjustments. The narrative included details of how specific roles and capabilities were affected and altered by increasing levels of fatigue. The sub-segregates that expound this area are: 1) *limitations of leisure activities* 2) *limitations of functional roles* and 3) *re-patterning of daily routines*.

The *limitations of leisure activities* was associated with negative statements about how participants' lives had changed gradually as a result of fatigue and were often expressed as 'I cannot...' The elements delineated here consisted of common types of leisure activities: *physical* (gardening, walking), *passive* (watching TV or reading and not falling asleep), *social* (meeting friends and family) and *expansive* (travel, acquiring knowledge, surfing the web). Interactions with people who were helpful, therapeutic and considered fun to be with, were differentiated from the more general task of keeping up with many friends and acquaintances. For most leisure activities it seemed that participants wanted to continue to do as much as they could manage, but there were definite limitations.

Similarly, the context of *limitations of functional roles*, categorised as: self-care, family and work, originated from negative statements surrounding functional obligations and responsibilities. Most of the interviewees included at least one story about how they could not do what they could have done, just a few months ago. Examples were provided about food shopping, housework, helping others, inviting people over for dinner parties and walking the dog. Functional decline was observed most frequently in the loss of the ability to bear weight on their legs and muscle weakness rather than a problem to do with memory or cognitive, organisational ability. One participant referred to the loss of mobility and flexibility

and a 'constant battle with gravity' [pt6]; she could get down on the floor easily enough, but getting back was the real challenge for her.

The final sub-segregate grouping, *restructuring of daily routines*, comprised accounts of how participants were actively engaged in adapting and re-patterning their lives to better manage fatigue and other sequelae of illness. This group of elements revealed largely practical solutions to the limitations of both leisure activities and functional roles. Elements included: *delegation and asking for help, scheduling and planning, making life easier and giving oneself more time*. Examples included scheduling plenty of time to get ready to go out, taking taxis, opting for guided bus tours, using a shopping basket as a strategy to buy less [less to carry] and agreeing to do the cooking, which was viewed as being enjoyable, but leaving the clearing and washing-up to others.

The taxonomy comparing the domains of Tiredness, Fatigue and Exhaustion

The findings from this study were compared to the definitions of tiredness, fatigue and exhaustion in the Edmonton Fatigue Framework (EEF) (Olson 2007). This analytic step resulted in fuller, richer and clinically relevant definitions (Table 3). The word *domain* is being used here to refer to a discrete construct, zone or state of energy depletion i.e. *Tiredness, Fatigue or Exhaustion*.

[Table 3 should appear near here please]

The Taxonomy of Tiredness, Fatigue and Exhaustion shows the progression of the adaptive response. *Tiredness* was described as an inconvenience that had a slight impact on mental, emotional and functional aspects of daily activity; the effects were variable and manageable.

I can recharge quite quickly...I can overextend and knacker myself [pt9])

The domain of *Fatigue* however, was associated with an increasing awareness of hardship and necessary limitations. There was evidence in the transcripts to indicate that routine

daily activities had become more difficult and adjustment to depleted energy adaptation required serious consideration and planning. The emotional, cognitive and mental aspects (the sub-segregates) included expressions of neutral acceptance and active re-patterning of how things were done, but also quite intense illustrations of struggling to perform functional and social roles, as well as constant worry and frustration. For example:

*I used to put all my energy into trying to stay awake – now I just go to sleep
[pt8]*

I am not able to control when I fall asleep. I just nod off...sometimes I won't realise that I have gone to sleep until X [partner] has woken me up [pt3]

Generally if I pace myself, I am okay...but I do have to plan, that's essential. If someone drops in [for a visit] I panic a bit. I know I will pay for it. [pt9]

Evidence of decline into the third domain of *Exhaustion* was suggested at some points in the interviews and was supported more substantially through analysis of transcripts and consideration of the ESAS and Fatigue Score. Two of participants passed away during the data collection phase and thus the data here are not as complete as they might otherwise be. According to the data from this sample, *Exhaustion* was characterised by inability and disinterest in planning, re-patterning and devising ways to attend to functional and social aspects of life. For example:

It is odd, but even laughing makes it [exhaustion] worse [pt5]

I don't have a social life, just try to get through the day [pt8]

*On bad days, sometimes it is just too much effort to get up to get some water
[pt5]*

People in this state do not have many reserves and the participants characterised this by simply attending to immediate challenges and requirements.

Discussion

In this study an ethnoscience approach was used to examine the first-hand experiences of fatigue amongst individuals attending a hospice. All but one of these individuals had advanced cancer. On a basic level, the findings indicated that the words used to describe fatigue reflect a broad spectrum of expected behaviours and adaptive responses. However, following further, more intensive analysis, the existence of an internal cognitive, emotional and physical struggle emerged that appeared to reflect a determination to adapt to declining health. The most striking observation from the overwhelming majority of interviews was the emphasis placed on *what could not be done* rather than actual descriptions of physical or mental decline. Participants seemed to define their fatigue in terms of their functional ability to carry out a task or activity and then reflected upon their mental and emotional adaptations. The taxonomies reflected these two sides of functional decline.

The anthropological, sociological, historical and political literature was searched in an attempt to define, describe or explain the values and beliefs of the English people and thereby anchor our observations within the context of national identity. The importance and role of functional ability was not revealed or suggested despite the wide diversity of research methodologies and comparisons with other nationalities. However, some notion of national characteristics was expressed by a modern politician who provides an insider's perception of shared values and behaviours; it includes: valuing individual freedom, a quirky and subversive sense of humour, angered at injustice, hardworking (i.e. Protestant work ethic), engaged with the world and the suffering of others and being better understood through literature than any other art (Gove 2007). There are some similarities between this description and the descriptions provided by study participants. Our participants valued their freedom and their independence, were tenacious in their approach to facing daily tasks and were reluctant, sometimes angered, when illness affected their capabilities.

The second objective of the study was to identify behaviours that distinguish *tiredness*, *fatigue* and *exhaustion*. This was a crucial aspect of the study because this is the knowledge that is intended to be used to inform pragmatic and concrete interventions for clinical practice. By characterising each state of energy depletion, we hoped that health care practitioners would be better able to offer and devise appropriate interventions and advice. For example, individuals who report tiredness may find it easy to manage with no additional intervention from health care providers; fatigue, on the other hand, may require considerable input given the reduced functional ability. This input may range from modifications of the living environment to facilitate independence to emotional support given the distress associated with functional change. The development of interventions to support individuals experiencing exhaustion require much more study, but our findings suggest the importance of minimising stimuli so that the individual is able to focus their energy internally.

Our findings resonate to a certain extent with findings of others (Piper, Lindsey, Dodd, 1987; Richardson, 1995; Krupp and Christidou, 2001; Kralik, Telford, Price et al. 2005; Ameringer and Smith, 2011), however none of these studies offered relational dimensions between the themes or segregates nor mention tiredness or exhaustion as part of the conceptualisation. The ethnoscience approach was instrumental to advancing the conceptualisation of the progressive continuum of fatigue through utilising taxonomical displays where relationships between different levels (domains, segregates, sub-segregates) were featured.

The drive to re-pattern routine daily activities in order to adapt to decreasing amounts of energy was an important part of our findings not seen in our studies in Canada (Olson 2007; Olson, Turner, Courneya, Field, Man, Cree, 2008) or Thailand (Pongthavornkamol, Olson, Soparatanapaisrn, Chatchaisucha, Kamkhon, Potaros et al., 2011). This finding shows one of the subtle but important differences in the meaning of fatigue in our three countries. A second interesting difference is that the participants in England did not mention or reflect upon a loss of cognitive capacity; they denied noticing any loss of concentration, memory or

intellectual ability. Instead, interviews were filled with accounts of chaotic thinking and the acknowledgement of physical decline and advancing disease, details of how they were trying hard, exhibiting the *mental tenacity* to re-pattern their lives and the many negative implications related to *limitations on leisure* and *functional roles*. The expressed emphasis on functional limitations was interpreted as an indicator of declining health, which in a palliative care population, signifies the approach of the end of life.

Conducting research in a hospice setting requires ongoing and careful attention to the comfort of participants owing to their advanced stage of illness. For this reason, all interviews were carried out in the hospice and at a time specified by the study participant. At no point during any of the interviews had any participant become emotionally upset, but one could imagine that this might happen given the topics covered in the interview. However, two participants died during the data collection stage of the study and this was distressing for the investigator, particularly when listening and reading through their contributions. This is an important element of qualitative research in areas such as advanced illness. Our study team was spread out around the world and so it was difficult to support each other. For this reason we recommend that researchers in multi-site teams ensure that there are at least two team members at site who can debrief regularly during the data collection process.

The findings reported here are derived from a small sample, but the data were rich with detailed description. The findings thus may be considered to comprise a relatively complete account of the experience of study participants. A detailed description of these individuals is provided so that readers can determine the extent to which the findings of our study may be relevant in their settings.

It is acknowledged that the study was open to all people within the palliative care sector, yet participants with cancer far outnumbered those with non-malignant conditions by a ratio of 8 to 9. Therefore, it is likely that the findings have not captured the full range of experiences and perspective of the intended population.

Conclusions

From a wider, sociological perspective, this study provides support for the idea that the meanings attached to symptoms are socially constructed. While the differences in findings from the three countries (Canada, Thailand and England) reported thus far may be considered subtle, they raise the important issue of thinking about how the differences in meaning could be built into interventions in ways that are appropriate to one's social context. The participants in this study were proud of their tenacity and the ways in which they were solving their functional challenges. They were distressed by situations in which their abilities were not recognized or accommodated. Participants in this study seemed to want to play an active role in ongoing daily activity and did not perceive any cognitive limitations in doing so. In the next phase of this work we will compare the accounts of tiredness, fatigue, and exhaustion in each of the countries in our project and discuss the implications of similarities and differences for the development of interventions.

Conflict of Interest Statement

None declared.

Acknowledgments

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Table 1: Participant Characteristics

ID	Gender	Age (years)	Diagnosis	Fatigue Score ^a	ESAS ^b	Researcher's Impression
1	female	71	Metastatic breast cancer	6	Pain, tiredness, drowsiness, appetite, shortness of breath	Pushes self all the time to accomplish physical, cognitive and functional tasks
2	male	49	Inoperable throat cancer	10	Pain, tiredness, nausea, appetite, wellbeing, shortness of breath	Has noticed a definite decline in physical, cognitive and functional abilities. (passed away shortly after 2 nd interview)
3	female	59	Inoperable metastatic breast cancer	1	anxiety	Cares for her quadriplegic husband and has not slept for more than two hours at a time for the past 22 years. Highly stressed, noticeable loss of concentration
4	female	48	Metastatic breast cancer	7	Pain, tiredness, anxiety	Struggling to cope and worried about her future; aware that she is not 'fine'
5	male	55	Systemic multi-system atrophy	9	Pain, tiredness, depression, anxiety, appetite, wellbeing, shortness of breath, diarrhoea	Chronic condition is advancing and he is trying hard to retain his dignity and social roles (i.e. grandfather)
6	female	70	Metastatic cancer of the pancreas	8	Tiredness, drowsiness, appetite	Giving in to fatigue despite a very strong will. [died a week after 1 st interview]
7	male	52	Metastatic throat cancer	7	Appetite, nausea, constipation	Very aware of advancing disease and fatigue, has nightmares
8	female	51	Metastatic oesophageal cancer, breast cancer, COPD, osteoporosis and diabetes	8	Tiredness, depression, drowsiness, appetite, shortness of breath	She wants to get on with things quickly because she know that she will soon tire.
9	female	50	Metastatic breast cancer	3	Pain, tiredness, anxiety, drowsiness, wellbeing	Trying very hard to be well but disease is progressing and hard to stay motivated

^a Fatigue Score (0 =no fatigue to 10 = worst ever fatigue)

^b Symptoms for which severity scored 5 or higher

Table 2: The Taxonomy of Fatigue: Declining Function

Segregates					
The Mental Challenge (emotional and cognitive adaptations)			The Physical Challenge (physical and social adaptations)		
Sub-segregates					
Emotional effects	Cognitive realisation of decline	Mental tenacity	Limitations in leisure activities	Limitations in functional roles	Re-patterning routines
Elements					
Worry	Acceptance	Persistence	Physical	Self-care	Delegation and asking for help
Frustration	Avoidance	Perseverance	Passive	Family	Scheduling and planning
Annoyance	Awareness of changes	Determination	Social	Work	Making life easier
			Expansive		Giving self more time

Table 3: Taxonomy Comparing Tiredness, Fatigue and Exhaustion

[note to Editor: intended to be in colour]

SEGREGATES	SUB SEGREGATES	DOMAINS		
		Tiredness	Fatigue	Exhaustion
The Mental Challenge	Emotional effect of decline	Mood is variable, dependent on type and level of activity	Characterized by annoyance, frustration, worry	Sense of giving in (to sleep, to health)
	Cognitive realisation of decline	Attributable to an identifiable cause	Day to day struggle (but still benefitting from palliative treatments and medications)	Noticeable decline
	Mental tenacity	Able to plan and complete activities	Realise that sometimes they cannot push themselves – there is not enough energy to complete task	Little indication of ‘pushing self’ and wanting to do more
The Physical Challenge	Limitations in leisure activity	Able to continue activity	Continues activity with imposed limitations energy to complete task ‘Can’t do what I want to do’	Does not consider doing activity (unless has large amount of support)
	Limitations in functional roles	Able to continue activity	Continues activity with imposed limitations	Does not consider doing activity (unless has large amount of support)
	Re-patterning routines	Able to adjust lifestyle	Plans and re-patterns lifestyle but sometimes gets ‘caught out’ cannot finish what was planned)	Does not attempt to re-pattern gives in to sleep

		Can describe a “pattern of liveliness to exhaustion”
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