

“I do not Really Belong out there Anymore.” Sense of Being and Belonging Among People with Medically Unexplained Long-Term Fatigue

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Please quote as:

Lian, O. S., Lorem, G. F.: "I Do Not Really Belong Out There Anymore": Sense of Being and Belonging Among People With Medically Unexplained Long-Term Fatigue". *Qualitative Health Research* 2017, 27(4):474-486. DOI: 10.1177/1049732316629103.

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Abstract

In this article we explore relations between health, being, belonging and place through an interpretive thematic analysis of autobiographic text and photographs about the everyday lives of ten women and men living with medically unexplained long-term fatigue in Norway. While interpreting their place-related illness experiences we ask: how do they experience their being in the world, where do they experience a sense of belonging/not belonging, and why do places become places of belonging/not belonging? The participants describe experiences of 1) being socially detached and alienated, 2) being imprisoned, 3) being spectators who observe the world, and 4) senses of belonging. They describe senses of being and belonging/not belonging as closely attached to physical and symbolic aspects of places in which they reside, and they wistfully reflect on the question of ‘why’. The study illustrates the influence of experienced place – material as well as immaterial – on health and illness.

Introduction

According to Gadamer (1996), the enigma of health is that we are most aware of it – and understand it best – when we have lost it, or when it is endangered, obstructed or compromised. This relates to our usually “absent body” (Leder, 1990). Our body tends to recede or disappear from direct conscious perception, as our attention often dwells on the actions we use our body to perform (Leder, 1990). However, it tends to appear again from its absent position when it no longer functions the way it used to and ought to, as in the case of illness. The same argument goes for being and belonging; it is tacitly experienced, often taken for granted and, therefore, most easily grasped and articulated when our experience of belonging becomes disturbed, tested or lost - because this makes us more aware of it (Bennett, 2015). Experiences of not belonging can also generate knowledge about what belonging means, and how it becomes created, sustained and changed.

Starting from these assumptions, we explore illness-related senses of being and belonging/not belonging expressed by women and men living with medically unexplained long-term fatigue, and diagnosed with Myalgic Encephalomyelitis (ME). Our aim is to gain knowledge about how this condition affects people’s sense of being and belonging/not belonging. Our main research questions are: how do they experience their being in the world, where do they experience a sense of belonging and not belonging, and what is it that makes certain places become places of belonging and not belonging?

We approach these questions empirically through experiential auto-photographic and autobiographical data. Through photographs and words, six women and four men living with ME in Norway describe and explain their illness experiences in relation to those places in which they reside in their everyday lives. Based on an interpretive thematic analysis of these multimodal narratives, we explore their sense of belonging and not belonging (dissonant and harmonious relationships between self and society) in relation to *place-related* illness experiences. While approaching their stories, we draw on a combination of sociological and philosophical perspectives on the relation between health, being, belonging and place.

ME is a medical name for a contested chronic condition characterized by a debilitating long-term fatigue, accompanied by a broad range of symptoms such as malaise, dysregulation of body temperature, increased sensitivity towards sensory impressions, bowel problems, sleep disturbance, cognitive problems, muscle pain, muscle weakness and reduced mobility (Carruthers et al., 2011). Medically, the condition is difficult to identify, explain and cure.

Without observable biomarkers to verify organic disease, ME remains medically unverifiable. This introduces an element of stigma into the lives of those who live with ME (Jason & Richman, 2007). We chose ME as a case for our study because of its symptomatology, its contested nature, and the social stigma it entails.

As often with medically contested conditions (Aronowitz, 1998; Nettleton, 2006; Robson & Lian, 2016), people with ME struggle to obtain acceptance for having an actual disease, and thus permission to be ill. Previous research drawing on interview and survey data indicates that people living with ME often experience stigmatization, emotional distress, social isolation and disbelief (Anderson et al., 2012; Bülow, 2008; Larun & Malterud, 2007; Pini & Soldatic, 2012; Åsbring & Narvanen, 2002). In a quantitative study, as much as 95 % of the respondents reported experiences of alienation (Green, Romei & Natelson, 1999). These experiences are partly related to loss of career, income and social networks (Jelbert, Stedmon & Stephens, 2010; Whitehead, 2006). With this study, we seek to expand this body of knowledge through data-sources never previously utilized in this field of research (as far as we know): auto-photographic and autobiographical data created with minimum researcher influence. Our attention to place-related illness experiences and belonging, our narrative approach and our interdisciplinary design also contributes to the originality of our study.

We start our presentation by exhibiting our theoretical framework and study design. Following these introductory parts we present our empirical data, structured according to four main themes: being detached, being a witness, being imprisoned, and belonging. In our final discussion, we reflect on some wider implications of our study, including those of a methodological kind.

Theoretical Framework

‘Sense of Belonging’ is a mode of being and acting in the world (Bennett, 2015; Miller, 2003). It designates a human experience of being in a place – physically and/or emotionally – where we feel part of something greater than ourselves. This experience entails a sense of identification with, or attachment to, cultures, people, places and material objects, and an experience of being at ease and in harmony with ourselves and our social, cultural, relational and material contexts (May, 2013). Through these identifications, we (as individuals) become attached to the social and material environment that we inhabit and experience (Casey, 1997; Wood & Waite, 2011). When a sense of belonging relates to other people, it is generated,

changed and sustained by assessing who and what we are, compared to others. Being in a situation where we feel we belong, entails an experience of being included, united, recognized, accepted and understood within a social setting. Belonging involves a sense of being in harmony with “the various physical and social contexts in which our lives are lived out” (Miller, 2002, p. 220), or being ‘at home’ (Antonsich, 2010). On the other hand, a sense of not belonging involves an experience of being alienated (not being in harmony with our environment), i.e. an “unhomelike” being-in-the-world (Gadamer, 1996), or “matter out of place” (Douglas, 1966).

We connect belonging as a mode of being to Heidegger’s concept of Being-in-the-world (Heidegger, 1967). We characterize this as an all-pervasive sense of our existence in – and connection to – the surrounding world. We are always tuned (*Stimmung*) into the world in some way or other. We humans have a general understanding of ourselves, including our own mode of being (*Befindlichkeit*). Our experiences represent an immediate and attuned perception and response towards possibilities and limitations we encounter in our everyday lives; in our environment and in ourselves (Heidegger, 1993). The world that we take for granted in the course of our daily lives is always a “with-world” (*Mitwelt*) – a world shared with others (Heidegger, 1967) and our surrounding environment (*Umwelt*) – the world as perceived by us (Heidegger, 1984). Sense of belonging varies in a range of ways from person to person and from time to time, and there is not a single, normal, constant way of finding ourselves in the world. Serious illness can alter our attunement into the world (Ratcliffe, 2009).

Seen in a sociological perspective, senses of being and belonging are inherently social and cultural phenomena as they are generated through interactions between human beings drawing on cultural norms and values. To experience acceptance and recognition, for instance, means that you recognize that other people or “the culture” give it to you. Although individually perceived, senses of being and belonging are therefore more than just a personal and psychological matter of identity (Antonsich, 2010). The relation between individual and society is mutually constitutive, and people’s sense of belonging is a fundamental element in the connection between a society and its individuals (Bell, 1999; Elias, 1991; May, 2011). A study of people’s sense of belonging is therefore also a study of the interconnectedness between self and social structure more generally.

‘Sense of place’ is a core concept in our theoretical framework. Our bodies are always emplaced, and our individual and social activities always take place somewhere. A place always has an immaterial symbolic dimension (what it signifies), but not necessarily a material dimension (physical attributes) (Casey, 1997; Gieryn, 2000; Morley, 2001). Our ‘sense of place’ is a construct of experience that refers to material or immaterial spaces “invested with meaning” (Domosh & Seager, 2001, p. xxii). Whenever physically located, a place is usually defined as a limited and localized portion of bounded space (geographical location and physicality), demarcated by physical and/or symbolic boundaries (Eyles, 1985; Gesler & Kearns, 2002). Its physical attributes can be described in terms of size, shape, boundaries, objects, artifacts or people occupying its spaces, but it is the *experienced* materiality and the social construction of place that interests us here. Whether physically located or not, all places have a symbolic dimension that entails the ascribed symbolic meaning that we – the interpreters – assign to it, either consciously or less consciously (Andrews, Chen & Myers, 2014, p. 1). What a place signifies is individually interpreted, but our interpretations are infused with cultural norms and values and therefore culturally embedded (Lian, 2007). Whether physically located or not, space becomes a place when it is experienced, identified, named and symbolically constructed as people assign meaning to it. A place is, therefore, a symbol of something, beyond the physical. The symbolic meaning is part of our ‘sense of place’.

Study Design

The study presented in this article is part of a larger, six-year research project aiming to explore the experiences of people with ME through a broad range of data capturing methods, including patient experiences (Lian & Hansen, 2015), illness experiences (Lian & Rapport, 2016), online debates (Lian & Nettleton, 2014) and changing medical constructions (Lian & Bondevik, 2015). A reference group consisting of representatives of patient organizations and doctors is connected to the project to advise the research team. Some of these representatives (namely people with ME) have been involved in planning the project. The first author had a meeting with the representative group and presented the preliminary plans to them. Final decisions on the design were made after these discussions. Their input has been of vital importance, especially in relation to the final wording of the questions raised in the participant brief.

Participants

In April 2014, we invited 15 purposely-selected people living with ME to participate in the study. Because our intention was to receive detailed in-depth information from a small sample, and thereby give priority to depth above width, we expected this number to be sufficient. The candidates were suggested by members of the reference group (those living with ME themselves), based on instructions about inclusion and exclusion criteria, formulated to ensure diversity in age (20-60), gender (equal distribution), health status (very severe degree of ME excluded because they would be unable to manage the task), duration of symptoms (at least six months) and place of residence (rural/urban and north/south). The main inclusion criterion was having a self-reported diagnosis of ME (although it is their bodily condition, not their diagnosis, that is our main concern). Of the 15 invited, 10 agreed to participate (Table 1) and five declined due to ill health. Those who agreed were asked to deliver their data within two months. The sample is diverse in relation to age, gender, health status and geographical location. To protect the identity of our participants, we do not reveal individual information about their health status.

INSERT TABLE 1 ABOUT HERE

Data

Our data consists of first-person accounts of place-related illness experiences. We asked the participants to tell us – through photographs and words – about their illness experiences in relation to those places in which they reside in their everyday lives by addressing the following two questions: “If places, where you reside in your everyday lives, make a difference: 1) in which environments do you experience your illness as *least* taxing, and 2) in which environments do you experience your illness as *most* taxing?” We emphasized ‘everyday life’ because it entails “the essence of who we are and our location in the world” (Pink, 2012, p. 143). We formulated the questions as broadly as possible to encourage the participants to give us holistic illness experiences (recognizing that people rarely compartmentalize their life into physical, mental and social components), and to limit researcher influence. Because we are dealing with experiences that are usually taken for granted, and therefore most easily reached in a more indirect way, we deliberately avoided asking them directly about being and belonging. We asked each participant for an autobiographical story, created by a combination of text (maximum two pages) and photographs (maximum ten). Through their irrefutability, photographs complement the texts in that they serve to “re-anchor the subject in the physical world, insist on the verifiable

presence of an embodied and solid individual ... an integrated, authorial self, located in a body, place, and time” (Rugg, 1997, p. 2). The texts were translated from Norwegian into English (except one that was submitted in English). In order not to lose the finer detail and nuance through translation, and to ensure linguistic conformity and consistency, the first author continuously checked the translated texts against the original Norwegian texts. Using “photography placed in conjunction with auto-biographical texts” (Rugg, 1997, p. 2) means that we benefit from the complementarity of two different lines of data.

Analysis

In stage one, the first author identified some main themes that run through all datasets, and classified extracts from the ten datasets that might belong to these themes. The themes were drawn inductively from the data, not from theoretical considerations or previous research (bearing in mind that prior knowledge always affect our interpretations). Based on this preliminary classification of themes, both authors collaborated in the analysis of the data (first individually and then together in face-to-face discussions). While doing so, we conducted an interpretive thematic analysis of the data, first on a participant-by-participant basis (to respect the uniqueness of each story), and then as a combined dataset. The interrogative pronouns “how”, “where” and “what” were key words in our analysis. To ensure trustworthiness of our interpretations, we discussed and compared alternative interpretations before settling on a classification of four main emerging themes. We then grouped extracts from texts and images together according to these four themes, and we searched for, identified and discussed patterns of divergence and convergence across the themes. In the final stage of the process, we interpreted the data in relation to both sociological and philosophical theories and perspectives. Our theoretical framework was constructed *after* finalizing a thorough analysis of the data, to preserve our inductive approach.

Photographs and texts exist in an integrated and mutually enhancing relationship and each of them extend our understanding of the other (Berger, 2013; Drew & Guillemin, 2014; Rapport, Doel & Elwyn, 2007; Rugg, 1997). All our participants explicitly related their text to their photographs. We therefore treat each participant’s contribution as *one* story, presented through textual and visual means, and assess the texts with the accompanying photographs in mind. While interpreting their stories we try to grasp both explicit and implicit messages.

Drawing out meaning from photographs is particularly difficult because photographs are ambiguous and “weak” in intentionality (Berger, 2013). Decoding visual messages simply means “I have decided that seeing this is worth seeing” (Berger, 2013, p. 18). Why the participants found it worth seeing, we do not know. Still, as interpreters we relate what we see to ourselves and ascribe meaning to it – and thereby extend the frozen moment beyond itself – by lending it a past and a future (Berger, 2013, p. 64). However, we do not explicitly comment on the photographs, but leave it to the reader to reflect upon.

Ethics

The Norwegian Data Protection Official provided ethical approval for this study in April 2014 (id. 38160). This approval covers all aspects of the study, including the information pack whereby we informed the candidates that their participation was voluntary and that they could withdraw from the study at any time. In addition, we gave details about how to protect their anonymity, store the data and publish the results. All participants contacted the project manager (first author) via phone or email to ask questions about the study before deciding whether they wanted to participate or not (mainly questions concerning the main purpose of the study, and some practical issues). All conversations ended with them confirming their participation by signing a written consent form.

Sense of Being and Belonging

After comparing their stories, certain patterns emerged across all ten datasets. We identified four dominating (partly overlapping) themes: being detached, being a spectator, being imprisoned (three aspects related to not belonging) and belonging.

Being Detached From Life “Out There”

“... I’ve learnt over the years that coming into a context where I seldom get to join, and thinking that this will be a break from my illness, is not very realistic. The focus on my illness and my limitations is seldom more overwhelming than when I meet people I have not seen for a while. The visit (yes, because I do not really belong out there anymore...) demands that I am both physically and mentally prepared to face my limitations in the door.”

In this quote, a woman describes her encounters with people she has not seen for a while as difficult (although stated somewhat indirectly) because she then has to face her limitations “in the door”. This metaphorical statement refers to an experience of seeing oneself from the

outside, either as in a mirror or as other people do. She also describes how she experiences her position in the world more generally: “The visit (yes, because I don’t really belong out there anymore...)” By linking ‘visiting’ and ‘belonging’ she portrays herself and her place in the world as a visitor. By adding the word “anymore”, she indicates that she once used to belong. She describes a similar experience in another part of her text:

“It’s so lovely having a window facing the road, the lawns, the children playing, the cars, the cats, the seagulls, and everything that moves. The window marks distance in a way, as I am up here, and everyone else is down there.” (Photograph 1. Kitchen window, in attachment.)

This woman metaphorically describes a total of eight “windows facing the world”, and she describes how these windows serve as «channels» between herself and the outside world:

“... I want to preserve the possibilities I have, the leeway I have to spare, as much as possible, and not the least what I can call the windows in my being: The different channels where I am allowed to experience and receive light and life from outside to enrich my life.”

Through the window-channels she receives light and life from a world that is “outside” her own.

Several other participants express similar experiences, as in this poem by a woman:

“The body inhibits, a plane vomits sound, who are the people in it? The little life I live, the waiting, the frames, the clammy claw ... happy children’s voices far away, a train, a car – it all happens in another place, a reminder of what I cannot take part in, be a part of. Trapped in the green, but excluded from. Life.”

In this poem, she describes her experiences of being in the house she lives in. In a few lines, she describes why: her “little life”, “the waiting”, and the vomiting noise from a plane that reminds her of all the strangers inside it that she does not know (“who are they?”), and who belong to another place – a place where she is not, and cannot, be a part of because she is “trapped” and “excluded”, which indicates an involuntary situation of exclusion and detachment. However, naming the sound of the plane as “vomit” introduces doubt: is “another place” a place she wants to be or not? The quote is from one of her two poems. In the second poem, she repeats her experiences of not belonging:

“Noise of an engine far away infiltrates the silence, tells about another life, a time I am no longer a part of. By the birds warning, the sound breaks, breaches through and in. Insists.”

A man expresses a similar experience in relation to a harbor:

“The harbor isn’t far away. Here, positive emotions do not surface so easily. I think it is because I am reminded of how it used to be to work and to travel. Now I do neither, and I have not done so for many years. I assume the positive emotions are absent because I am missing something. I miss working, and I miss traveling. I miss participating in life, as I did when I was healthy. Nevertheless, I have gone there a few times to look at life.”

Life is something he looks at from an outsider’s position, without participating. He describes his being in the world as a spectator and observer, almost like a visiting foreigner.

“Participating in life” is something he misses.

Other participants express the negative sides of their social detachment from society in similar ways:

“Perhaps because it is so rare, it feels like a big experience when I get to go out – an experience of participating in a larger context.”

Again, being a participant in life is a rare experience.

A man shares his thoughts about how his social isolation becomes more bearable by reading a letter from his grandmother:

“Her words make me happy and less isolated in this bedroom. I shut out the treacherous mental picture that pops out of the usually empty mailbox and instead focus on the beautiful letter next to me.”

The empty mailbox signifies his social isolation.

Participating “in a larger context” or “in life” is something they are excluded and detached from because of the physical and social limitations imposed on them by their illness:

“There are some places I would like to go to because I want to meet new people with the same interests as I have, but because of the limitations from the illness it becomes hard to fit in.”

This woman also recalls the things she used to do, that her illness now prevents her from doing:

“Behind the shiny wardrobe-doors, dresses, nice clothes and jewelry are hanging in anticipation of festivities that, unfortunately, gleam with its absence. The worst thing is the shoes at the bottom of the closet. They remind me of everything that I can no longer participate in, of meeting-places that are no longer available.”

By giving her shoes, clothes and jewelry a symbolic meaning, they become reminders of her social detachment and alienation. She also relates her social detachment to not having a job. She describes how she gets (or creates?) an experience of “going to work”, although she does not:

“Every day when I walk the five steps from the terrace-door over to the writing pavilion, I feel that I go to work.”

The participants often describe their social network as limited to close relatives, and perhaps a few close friends. Or not even that. A man blames himself for being unable to socialize, and this gives him a guilty conscience:

“I don’t even have the energy to tell my friends I can’t join them. Again. I don’t have the energy to call my parents and say that I need them. I feel like a bad father. A bad husband. A nuisance for everyone involved in my life.”

The anaphoric formulation of his message – a bad father, a bad husband and a nuisance for everyone else – serves to intensify his message. His experience of being a burden to others can be triggered for instance by hearing sounds from other places in the house whilst in bed:

“I have to eat my breakfast in bed, silently crying for myself when I hear the noises of the family. Why can’t I just be “normal”?”

Being unable to eat breakfast with his wife and daughter because he has to stay in bed creates a distance between himself and his family. He does not want to accept this situation, and he asks: “Why can’t I just be normal?” One of the women seems to accept her social detachment as “a fact of life”:

“That’s just how it is... I’ve come to accept that I don’t associate with as many as I used to do.”

While comparing their stories we see that although they are richly varied, most of them present – in one way or another – an experience of being socially detached, excluded and alienated from the rest of the world because of their illness. In an experiential sense they describe themselves as being removed from people in the world “out there”, or being strangers or visitors that does not belong to the place they inhabit. In an experiential sense, they are “matter out of place”.

Being Imprisoned

“In prison with bad conscience ... I want to give them so much, but I am bound in chains.” (Photograph 2. In prison with bad conscience, see attachment.)

In this extract, a man combines two metaphors – “prison and “Bound in chains” – to describe an experience of a lack of freedom.

Experiences of imprisonment are described by several other participants:

“The lock-house imprisons me; the illness has put chains on my feet.”

This quote is from a poem where a woman writes about the house she lives in, which she calls “*slusehuset*”. The Norwegian word she uses is her making. Translated into English it would be “the lock-house” or “the lock-chamber” (as in a sluice). Combining these two words connotes a house whose purpose is to lock something in – in this case: water. Used in conjunction with “imprisons me” and “chains on my feet”, she signals an experience of being trapped and deadlocked. She also briefly describes how she manages to survive her involuntary confinement and restricted freedom:

“And in the middle of it all, a pile of books that constantly remains just as high, a distraction, a kind of escape, a place to survive, a breathing space.”

Describing her books as “breathing space” and “a place to survive” suggests that there are other places in her house with less breathing space, in other words: suffocating places.

The woman who describes eight “windows in my being” portrays her life with ME as being confined to “a life within four narrow walls”, a view she elaborates in detail:

“With ME, the wide and soft borders shrink to something that can be described as a room with four walls. Borders can no longer be trained and stretched. They have fixed walls. They can perhaps be moved a bit over several years, but for the moment they mark the merciless limits of my life. If I try to stretch the borders, I risk losing some of the little freedom to act that I have, at least for some time. Within this four-wall room is my life.” (Photograph 3. This is my life, see attachment.)

This woman describes being in the world metaphorically as being confined to ‘a room’ (in singular form) with limited space and freedom. Its inflexible narrow space marks “the merciless limits” of her life. A man uses a similar but even stronger metaphor for a lack of freedom:

“Having “my own cave” is absolutely necessary.”

Most participants describe experiences of living a restricted life in an involuntary solitary confinement, and some of them describe this as a being of mere existence (quotes from both genders):

“I hadn’t prioritized what was important for me for so long. I had not been out of the house for two weeks – I deserved it! I want to live, not just exist!”

“*The window facing inwards*: I try to make peace with my body’s need for a rest from impressions and movements and just existing, winning over boredom and the concerns.”

Accounts of restricted freedom are often accompanied by descriptions of a longing for freedom (quotes from both genders):

“I want to go out! I want to feel the wind, show my daughter the world outside, enjoy the nature ... But if I do not, what is life for?.”

“I got an electric wheelchair a few years ago ... [it] gives a wonderful feeling of freedom! I get a small taste of the freedom others have when they travel around in the world.”

“My mother has a cabin in the mountains ... I can only go for short strolls around the cabin walls, but I read a lot of maps and look at possible hikes that I may be able to manage one day. Being here brings me peace and the experience of being on a mountain hike.”

Most participants are confined to their home, which often means their houses and gardens. Being at home is necessary because they are unable to move around, and because of their inability to tolerate strong sensory impressions (quotes from both genders):

“Outside there is the noise of cars on the road, the temperature is more changeable (a little too warm in the sun, and suddenly too cold when it becomes cloudy or windy), and I can’t lie as comfortably and relaxed as I can on the sofa or the bed.”

“Occasionally I can go out in the garden. It happens perhaps once or twice a year. Then I sit and watch the flowers, and I take the opportunity to take some photographs that I can look at later. If I can manage, I talk to my neighbor.”

A man reflects on the point about it all:

“Every effort of trying to live only brings me closer to wanting it all to end. How could I possibly think it would be worth it?.”

Comparing the data related to this theme reveals a consistent pattern: an experience of imprisonment. When they describe their home and their world they use words like “prison”, “cave” and “bound in chains”. They describe this entrapment and lack of freedom with ambiguity, as it is a prison and a protective shelter at the same time. The participants express a strong longing for the freedom they once enjoyed. Now, they mourn its absence. An underlying theme, however, is that of accepting their fate. Between the lines, we sense a hope (but not an expectation) for a better future. Some participants question the meaning of life itself.

Being a Spectator

“The television is my window to the world.... I feel privileged when I, through the screen, get to learn about other people, about their life experiences, cultures and customs ... With TV, radio, Wi-Fi and books I follow the world outside.”

“This sofa corner is also my window to the world. TV has much to offer, and a computer with an Internet connection is something you get dependent on when you do not get out a lot.”

Most participants describe their being in the world as spectators. The word “window” – often succeeded by “to the world” – is a commonly used in these descriptions. These windows are mainly information- and communication technology and glass-windows (quotes from both genders):

“... I can sit/lie for several hours just enjoying the living-room and the view from the couch, and follow the daylights wandering through the window panes and see the shadows that move.”

“My writing-pavilion has five windows high up on the wall. No-one can look in, but the windows let in much light and give me a panoramic view of the sky. I feel so privileged!”

“Sometimes when I have enough energy, I sit and look out of the little window in the living room. I look at the life beyond my shielded existence ... The window in my living room has become a nice vantage point.” (Photograph 4. Life passes by, see attachment.)

For the latter participant, life “beyond” is something he can witness from his “shielded existence”, as a spectator observing life through a window.

Another window to the world “out there” is a balcony:

“Just outside the wall lies the «Hundred Acre Wood». In the summer when there are leaves on the trees, you can stand in the middle of this little forest, and not see anything other than trees. I do not go there very often. However, I can see it from my balcony, and I know it is there.”

She appreciates being able to see the wood, and knowing it is there, even though it is rarely reachable.

Yet again we find a consistent pattern: across all data sets, the participants describe themselves as being spectators who witness and observe the world outside their own. They often conduct these observations through glass-windows and communication technologies. They express their role as spectators both with of sadness and gratitude: they are grateful for their ability to conduct these observations.

Belonging

“The water turns, catches the sun in flakes, throws the dust up to me.
The birds twitter, call, tell me that I am alive, that I belong, that all is mine ...

I do not want to part, I want to be in the silver, in silence, in the green shining. In the sun that wakes me earlier than I want to get up, and yet calls me out of

warm sleeping clothes. In the cold air around bare feet on its way out in the grass, to the privy with a view, a small red hut in high grass.

It is here I want to be, live, sleep, long, write, eat. It is here life gets through to me without me needing to stretch out for it. It just fills me while I stand – completely quiet, or sit on my couch, listening, feeling, love.

Everything that is named ME is far away; thoughts do not let it in. Here I am just me.

In a world where ME does not exist, borders float outwards, allow me more breath, body assembles, becomes whole again.

Alive.” (Photograph 5. Where I become whole, see attachment.)

This woman describes a place where she experiences a sense of belonging: her rural cottage home. In this place, life gets through to her in such a way that “ME does not exist”, and she is ‘just me’. Only two women describe a place where ME does not exist. For the other one, this place is by her sewing machine:

“In my bedroom I have a sewing cabinet. My sewing machine is there, ready to use. I do not even have to lift it out, if I can’t bear to. I can just open the door, put the plug in, and voila! I am full of dreams of things I wish to create. I cannot bear it all, but some of it. Moreover, there is an enjoyment in being allowed to be engaged with (knitting-) needles, yarn and colorful fabrics. Here I am actually free from everything called an illness.”

By the sewing machine, she is able to place her attention on what she is doing in such a way that her body – and all its shortcomings – disappears from her direct conscious perception for a limited period of time.

Other participants express a sense of belonging related to significant others:

“I have a few friends that I see on a regular basis. Along with the family, they are so updated on my health situation, that it doesn’t have to be a topic very often, and yet I feel like they understand me and my limitations as well as possible. These are precious relations.”

For this woman, significant others are “precious relations” because they understand her and her limitations, which probably means that she does not have to explain or justify her actions all the time. A man expresses similar experiences:

“All those who regularly come to this house are familiar with my situation and know my circumstances. This means I do not need to explain that there are things I cannot manage, I do not need to take energy from reserves that shouldn’t be touched in order to appear healthier than I am, and I am not embarrassed to ask for help from personal assistants or others.”

To be “understood” is important for them. Families (and sometimes a few close friends) are important not only because of their understanding and acceptance, but also because of their mere presence. A man describes it like this:

“I get up and kiss my daughter and we play and laugh. Her smile makes me forget the first feeling of “not another day again” and I am reminded why I keep going.”

In addition to significant others, most participants express a sense of belonging in relation to natural landscapes (quotes from both genders):

“...we sit in the grass and see the spring birds returning, putting a smile on my face. I can almost remember how I felt on trips like this before I got ill. I smile. Who can possibly be luckier than me in the whole world?”

“When the weather allows (meaning that it does not rain, snow or is too cold) I take a ride in the electric wheelchair.... I can sense the feeling of happiness when I scorch along the paths and feel the wind blowing in my hair.”

When they write about natural landscapes they emphasize the tranquility, the beauty and the bird song, but more as a longing than as a reality because their illness usually prevents them from going there, or enjoying it the way they used to. One woman has arranged her garden in a way that brings nature to her home:

“As soon as I wake up, I place myself outside with coffee and breakfast. The bird-song is life affirming. The green color from the field and the trees around seem overwhelmingly beautiful to me. In the flowerbed, I have planted lavender, roses, clematis, bell-bushes, myrtle, lobelia and marguerites. It gives me great joy to watch

the plants grow vigorous under loving care. I sense that I accomplish something and become part of something beautiful.”

She relates her experience of becoming “part of something beautiful” to what she can see, hear and smell whilst in her garden:

“I sit/lie on the outdoor couch for a few hours in sun and shade, looking at the landscape towards the farm in the horizon, receiving bird-song and flower-scents, and sensing gratitude towards life.”

Another woman finds comfort in her faith in God; “the window facing upwards”:

“I am not sure if the Bible counts as a ‘place’, but for me it is the window facing upwards. The challenges are the same, and sometimes a bit too much. But the belief that my little room with four walls after all rests on a safe and solid ground with someone so much greater than me, gives me a precious light over a life facing a future with many questions. It has quietly softened some uneasiness throughout the years ...”By Jesus, I am always acknowledged. However life may turn out in this world: Always loved, and never forgotten!”

The stories of the participants are dominated by a sense of not belonging. When they express a sense of belonging somewhere or to something, this belonging relates to God, natural landscapes and finding meaning in creative activities, and to significant others that understand their situation (which means that they do not have to face the stigma usually entailed in their illness). While being in a place – experientially – where they sense belonging, they are able to experience happiness and gratitude towards life, and reminded why they “keep going”. Places where they experience a sense of belonging they describe as a kind of “emotional refuge” (Fields, 2011).

Discussion

The participants in this study describe how their illness has altered their “being-in-the-world”. Although each story is unique, they are remarkably similar. The predominant storyline is about a lack of belonging, and how their lives (all of it, not merely limited parts of it) have become permeated by their illness. They relate their current life with ME to both past experiences and future potentiality (what life could become without ME), and they thoughtfully reflect on all three time-dimension in terms of situations being within ‘potential, ‘restorable’ or ‘actual’ reach (Schutz & Luckmann, 1973). While comparing their current

situation to their previous life, they describe something that resembles a fundamental collapse (the commonly used concept 'disruption' is too weak a word for it). Some participants express hope to "be well again", but always with uncertainty and sometimes with doubt. Most of them seem to have accepted their fate, and explain how they "reinvent" their lives to adjust to the unchosen "limits of their lives". All participants mourn their inability to fulfill their needs and wants and their social roles in the way that they once used to and would like to, and they worry about the future. Their texts and their photographs are mutually supportive and complement each other. We believe that the process of shooting, looking at and selecting photographs have promoted self-reflection, and thereby contributed to the textual results.

The stories of the participants are predominantly about the limitations that their illness imposes on their lives, especially how their illness affects their everyday life and alienates them from themselves, from the world outside and from an ordinary (homelike) life. They describe their social detachment as an imprisonment, and they describe how they from their detached position observe and witness the "other" world "out there" through various channels (glass windows, balconies, gardens and communication technology mainly). In various ways, most of them express gripping experiences of how they exist without living.

The participants relate the negative consequences of their illness partly to its symptomatology (lack of energy, immobility and inability to tolerate strong sensory impressions), and partly to the social stigma it entails. This stigma is fused by medical constructions of this ailment (Jason & Richman, 2007; Lian & Bondevik, 2015). The cornerstone of the modern biomedical cosmology is technologically generated findings provided by laboratory procedures and mechanical and electronic devices (Jewson, 1976). Based on this way of knowing, conditions that are difficult to identify, localize, explain and cure with the aid of biomedical knowledge and technology become medically incomprehensible (because they are un-observable by the human eye). Thereby, they "escape the reality principle by apparently existing only in terms of subjective experience" (Cohn, 1999, p. 195). In the absence of organic pathology identified by biomarkers and scientific explanations, doctors often turn to psychogenic explanations. In our culture, where we perceive less physical as less "real", this introduces an element of stigma into the lives of those who live with medically unverified conditions.

Although experiences of social detachment, alienation, self-blame and lack of societal understanding dominate their texts, most of them express experiences of being part of – and

in harmony with – something greater than themselves. Their sense of belonging relates to God, creative activities, significant others and natural landscapes. These findings are in line with previous research: natural landscapes have been described as ‘therapeutic landscapes’ affording healing powers (Gesler, 1992), and leisure-based art-making can offer “restorative experiences” (Reynolds & Vivat, 2010).

All participants describe their sense of being and belonging/not belonging as closely connected to the material and immaterial aspects of places in which they reside in their everyday life (without separating the two). While some places nurture a sense of belonging, other places exhibit disharmony and a lack of connectedness with place that nurture an experience of being “matter out of place” (Douglas, 1966). Thoughtfully, they reflect on the ways in which physical and symbolic aspects of places they inhabit shape opportunities and constraints that influence their health, the way they perceive their health problems, the social consequences of being ill, and their abilities to engage in everyday life and fulfill their social roles. They also thoughtfully reflect on the symbolic meaning of artifacts (such as a mailbox, a dress, a piece of jewelry, a letter and a book) and sounds (such as bird-song, a plane-engine and “noises of the family”). Through these reflections, they demonstrate how they attach meaning to the things they are surrounded by in a way that transcends mere appearance, usefulness or physicality (Harman, 2013).

Regarding the narrative form of their stories, some are factual and some are poetic. The poetic ones are written as poems, diaries or memoirs. All participants mainly use first person singular as speaker reference, like ‘I’ and ‘my’ in their texts. This makes it clear to the reader that they “speak” from their own perspective, and it makes their stories personal and authentic. From time to time, the participants describe their experiences metaphorically: regaining energy is “charging a battery”, home is a “cave” or a prison where they “almost hibernate”. Sometimes they describe their experiences indirectly: the man who feels “less isolated” when he reads a letter from his grandmother does not explicitly mention an experience of being isolated. Similarly the woman who covers her sofa-bed with a blanket to make it appear less like a bed does not explicitly say that she wants to hide traces of her illness (but that is probably how most of us would interpret her statement). Through this indirect communication they do not need to spell out intimate thoughts that might be difficult to share with strangers.

Although the participants were given a short brief with only two questions to address, all of them provided rich and thoughtful texts about a broad range of illness experiences. The detailed, well-written and honest stories that the participants provided along with text-related photographs is the main strength of our study. The photographs are valuable in that they allow us to ‘visit’ places that are part of their daily life in a non-intrusive manner. We believe that the low level of researcher influence (participant brief short and widely formulated), the involvement of people with ME in the planning process (which enabled us to ask the participants questions that they found relevant) and the heterogeneity of participants (stretching from a young man with a wife and a newborn baby, to an older woman living on her own) serves to strengthen the study. On the other hand, the low number of participants might have limited our study. Despite the heterogeneity of the group, their stories are remarkably similar, but we cannot be sure that our sample size has been optimal. The sample size also limits our possibilities to explore diverging experiences across age, gender and place of residence, which would have been interesting (although no such patterns are indicated in our material). Despite these limitations, we do think that the results reveal at least some universal experiences of living with medically contested chronic conditions. Finally, our data collection method does not allow us to ask participants to elaborate their stories, or follow up their statements with new questions. This might increase the chance of over-interpreting their stories. In an attempt to minimize this risk, we strive to keep the voice of the participants at the forefront and stay close to their stories in all parts of the process.

Wider Implications

Studying illness experiences among people with first-hand knowledge about contested chronic conditions illuminates how actual implications of such conditions are the result not only of the feeble body, but also culturally and medically contingent ways of perceiving health and illness. The less biomedical knowledge we have, the larger the room for cultural influence becomes (Lian & Bondevik, 2015). Medical constructions of illnesses are powerful, and they can serve to either remove or enforce stigma and blame. If we overlook the limits of medical knowledge and technology and confuse “not medically verified” with “nonexistent”, stigma is enforced. If we accept the limits of medical knowledge and technology and let the voice of the patients be heard, understood and acknowledged, stigma is removed. In order to do so, we need to accept that illness-as-experienced and theoretical accounts of it are two different kinds of knowledge that both need to be taken into account in our understanding of

illness. Acknowledging the experiential dimension of illness is of vital importance for health care workers who seek to adapt their professional help to the needs of these patients, especially in the case of chronic conditions for which there is no known medical cure and the role of the health care professional is limited mainly to helping the patient to learn how to live with a long-term ailment.

Without being asked, the participants in this study relate their illness experiences to existential questions about the meaning of life (“what is life for”, and “How could I possibly think it would be worth it?”), the character of their existence (“the merciless limits of my life”), what it means to be “normal” and live a “normal” life (“if I was going to return to a normal life”), and how to endure and accept suffering as an integral part of their lives (“the belief that my little room with four walls after all rests on a safe and solid ground with someone so much greater than me”). Through these accounts, the participants redirect our attention towards fundamental questions about the human condition. Most of all, their stories illustrate how being chronically ill is an existential situation and a particular way of being in the world as a human being (Von Weizsäcker, 1986). Their stories thereby become a testimony to how experiences of living with a debilitating chronic illness raise existential questions, which each of them address not only to themselves but also – indirectly – to those who listen to their stories.

Acknowledgements

We would like to thank the participants of this study for their generosity, Anette Gilje and Frances Rapport for participating in planning the study, and the anonymous referees for useful comments to the first draft of our article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and or publication of this article: The Norwegian Research Council, Research Program of Health and Care Sciences (grant no. 212978/H10).

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Bios

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Attachment

Table 1. Participants

Participant	Woman1	Woman2	Woman3	Woman4	Woman5	Woman6	Man1	Man2	Man3	Man4	Range
Age	40-50	20-30	40-50	50-60	50-60	30-40	30-40	20-30	40-50	40-50	26-58
Urban residence	Yes	Yes	Yes	Yes	No	Yes	No	Yes	No	Yes	-
Word-count	1570 ^a	1300 ^b	1650 ^a	1100 ^b	1180 ^b	540 ^a	1420 ^c	680 ^a	1200 ^a	1360 ^b	540-1650
Number of photos	10 color	8 color	9 color	10 color	10 color	5 color	9 color	2 color	7 b/w	9 color	2-10

^a Translated by first author

^b Translated by professional

^c Originally in English

Photographs (all photographs are copyright protected)

Photograph 1. Kitchen window



Photograph 2. In prison with bad conscience



Photograph 3. This is my life



Photograph 4. Life passes by



Photograph 5. Where I become whole

