

Wandering Through the Desert with Multiple Sclerosis: How Outdoor Life Recalibrates Body Awareness and Self-Identity

Joeri Calsius^{1*}, Minne Van Den Noortgate¹, Gert Roncada², Paul Van Asch³ and Marie D'hooghe^{4,5}
Hasselt University¹, Independent researcher², Physiotherapy³, Vrije Universiteit Brussel⁴, National Multiple Sclerosis Center⁵
*joeri.calsius@uhasselt.be**

Abstract: *People with multiple sclerosis benefit from exercise, however, they commonly lead a more sedentary lifestyle. Therefore, they may lack the positive effects of activity on body awareness and self-identity. This study explores changes in body awareness and identity in people with multiple sclerosis after a unique hiking expedition through the Jordan desert in the spring of 2014. A qualitative study design was applied, the interpretative phenomenological analysis method was used in a focus group with all nine participants of the expedition. Three main themes and six subthemes were identified to explore this study on a thematic basis. The first main theme 'Peers and society' focused on group dynamics and social stigma. The second theme, the 'Lived body' discussed bodily experiences and self-identity. In the third theme, 'Therapeutic effects' of the journey and their implementation into daily life were explored. The findings suggest that participating in this unique hiking project had a powerful effect on the lived body experience of the participants. Experiencing outdoor life brought them back to basics, changed their bodily attunement and empowered their self-belief and social resilience. Several participants described this experience as an awakening in dealing with multiple sclerosis.*

Keywords: Body awareness; self-identity; lived body; qualitative research; multiple sclerosis; thematic study; body experience; therapeutic; lived experiences; personal control; treatment control; emotional response; expedition

Introduction

Multiple sclerosis is a chronic disease of the central nervous system with a wide range of physical symptoms, including loss of motor skills and sensory functions (Blaney and Lowe-Strong, 2009). Clinical research has provided evidence for beneficial effects of exercise and physical activity on physical parameters such as walking ability, muscle strength and aerobic capacity (Motl and Pilutti, 2012). It has also been demonstrated to influence quality of life and fatigue (Motl and Pilutti, 2012). Despite the proven benefits, people with multiple sclerosis are less likely to be physically active than healthy subjects (Motl, McAuley and Snook, 2005). Common barriers to engage in physical activity are fatigue, illness perceptions

or the idea that exercise might trigger relapse or increase symptoms (Kayes, McPherson, Taylor, Schlüter, & Kolt, 2011; Plow, Resnik and Allen, 2009). On the other hand, social support and encouragement in group seem to have a facilitating effect (Kayes et al., 2011).

The present study describes the experiences of people with multiple sclerosis who participated in a 10-day hiking expedition through the Jordan desert after intense physical preparation. The goal of the expedition to the historical city of Petra was to promote physical activity and social participation in people with multiple sclerosis. This study aims to explore how an extreme challenge, such as a trekking through the Jordan desert, can affect bodily experiences and awareness, in addition to feelings of identity in people with multiple sclerosis. This study was set up using a qualitative design similar to the one used in a previous project, the 2012 expedition to Machu Picchu for people with multiple sclerosis (Calsius et al., 2015). Therefore, given the nature of this problem statement, the purpose of this study was to explore the central theme through the data analysis procedures by using a phenomenological-hermeneutic approach centered on the concept of the lived experience of the participants suffering from multiple sclerosis who participated in the 10 days Petra Jordan desert expedition.

Conceptual framework

The key aspect of body awareness is the ability to tune into the body and experience it as simultaneously being and having a body (Fogel, 2011; Mehling et al., 2009; Mehling et al., 2011). In that way, body awareness transcends the physical body. Husserl distinguished the physical body (Körper) with object-like characteristics from what is called the lived body (Leib), which is intentional and more subject-like (Bullington, 2013). This lived body, defined as our bodily anchoring in the world, refers to the meaningful experience of living in the world through the body (Stanghellini, 2013). In short, it is about how people experience being present in the world they live in and interacting with it, viewed from a bodily perspective.

Mehling (2011) defines body awareness as the subjective, phenomenological aspect of proprioception and interoception that enters conscious awareness and is modifiable by mental processes including attention, interpretation, appraisal, beliefs, memories, conditioning attitude and affect. Chronic suffering or illness is thought to impact the obvious and harmonious experience of having and being a body. The obviousness of being bodily aware tends to disappear and tuning into the body often becomes a problem in chronic illness (Bullington, 2013). Grytten et al., (2005) describes the mechanism of creating a protective capsule around the self as a result of no longer meeting socially acceptable standards and feeling useless. This greatly affects the ability to be bodily aware.

In normal circumstances, the body is constantly present, yet peripheral to our perceptual awareness, which is described as pre-reflective (Carman, 1999; De Haan, 2012). This state of pre-reflectiveness or absence of focused awareness, is what Zeiler (2010) calls bodily disappearance and is seen by Fogel (2011) as neither implicit nor explicit and not necessarily non-verbal. On the other hand, eu-appearance is defined (Zeiler, 2010) when the body is

experienced in the foreground of attention as pleasant and a source of joy. This can be the case in sports, sexuality and sometimes pregnancy. However, in chronic pain or suffering, awareness can be ruptured by the loss of harmony between body, mind and world, resulting in bodily dys-appearance (Zeiler, 2010). The body is experienced as a thing which is broken and needs to be repaired. The body is no longer something a person is, but merely something he/she has. This dysfunctional state of body awareness may also be seen as a cause for depression, feelings of stress, attachment insecurity and chronic physical disease (Fogel, 2011). Based on these phenomenological approaches, body awareness can be seen as a multi-dimensional concept and is characterized by its ability to move from fore- to background and from a negative over a neutral to a positive load.

Besides its effects on body awareness, chronic illness seems to heavily impact how people experience their identity. Loss of identity and feelings of being alienated and detached from what once gave meaning to their lives are common in chronically ill people (Bullington, 2013). In phenomenology, this is easily understood because an individual is conceived as the perspectival origin of his experiences, behavior and thoughts and considered to be the center of self-awareness, object-experience and meaning bestowing (Stanghellini, 2013). The quintessence here is the embodied presence in the world which is coined as the lived body. It also underlies body awareness and is in line with what Gyllensten (2010) calls embodied identity. So, the capacity of being bodily aware is a keystone of self-experience. (Carman, 1999) also pointed out the concept of identity includes a bodily point of reference of being related to and embedded in the world.

By disturbing the ability of being bodily aware, chronic illness disrupts the basic feelings of being an embodied identity, being some-body. By consequence, the ability to experience oneself as an embodied intelligence and to tune into one's body as a source of wisdom, is severely affected in chronically ill people (Bullington, 2013), including people with multiple sclerosis (Price, 1993).

Methodology

This qualitative research is part of the multiple sclerosis Petra project 2014, a hiking expedition through the Jordan desert to the historical city of Petra. The project was initiated and coordinated in collaboration with the multiple sclerosis Society Flanders in order to promote physical activity and participation among people with multiple sclerosis. Candidates for the trip were selected by neurologists and physiotherapists affiliated with the National Multiple Sclerosis center in Melsbroek, Belgium or Fit Up, a physiotherapy and fitness center in Kontich, Belgium. Selected candidates were able to walk independently for at least 500 meters, corresponding to having an Expanded Disability Status Scale score of 4 or less.

The group consisted of six women and three men, aged 27 to 59 years. The participants were highly motivated to exercise and followed a six-month training program before the start of the expedition. The training phase included an exercise test and an individualized training program. The entire observational study period started from the beginning of the training phase and ended six months after completion of the journey. This longitudinal observation

included measurements of physical activity, depression, anxiety, fatigue, quality of life, illness perception and illness progression. Two months after the expedition, a focus group was organized in the National Multiple Sclerosis Center in Melsbroek, Belgium.

Research Method, Tools, Techniques and Research Participants

The goal of this study is to provide a better understanding of possible changes in body awareness and identity after completing a unique journey through the Jordan desert. To acquire data and obtain in-depth information, the research technique of a focus group was used. The 90-minute focus group session was prepared by listing a series of questions on the main topics including the lived experience, body awareness and feelings of identity (appendix 1). All nine participants agreed to attend the focus group which took place at the National Multiple Sclerosis Center in Melsbroek. The session was led by an experienced interviewer, a physical therapist and clinical psychologist.

Data Analysis Procedures

Following the verbatim transcription of the audio recording, data was analyzed using a phenomenological hermeneutic approach, i.e. the Interpretative Phenomenological Analysis (IPA). The first step of this analysis consisted of coding the transcript, to get a better insight in the participant's experience (appendix 2). Every citation considered to be meaningful, according to the participant or the researchers, was given an open code (appendix 3). When similar statements emerged, open codes were grouped in axial codes. After completing the coding process, patterns or subthemes were identified.

The results focused on phenomenological descriptions and meaning-making rather than on causal relations. The researchers stayed as close as possible to the original text and used citations whenever possible. To reduce the risk of blind spots in the analysis, analyst triangulation was used with data being reviewed by multiple observers (two students and one team member who participated in the trek) and analysts (a psychologist, a physical therapist and a neurologist). This multidisciplinary approach helped to ensure perspective triangulation.

Furthermore, a process of peer debriefing was conducted amongst primary caregivers and therapists who were not involved in the research. Existing theoretical preconceptions regarding the interpretation of results in this study were discussed extensively amongst and outside our research group before being molded into a conceptual framework. To ensure anonymity, all subjects involved are described using the term 'participant' and gender reference is neutralized by using only male pronouns.

A self-assessment scale of disability (Calsius et al., 2015) and the brief version of the Illness Perception Questionnaire (IPQ) were assessed over a 12-month period and are currently being processed within the broader quantitative context of our research group. The brief IPQ assesses the beliefs that individuals construct about their disease (Broadbent, Petrie, Main and Weinman, 2006) with five items on cognitive illness representations, two items on

emotional representations and one item on illness comprehensibility. The scale has a good test-retest reliability and concurrent validity with relevant measures. Results will be analyzed descriptively considering the small sample size.

Results

The qualitative analysis of the central research problems relating to the participant's identity and body experience led to three main themes in which six subthemes were identified (appendix 2), derived from axial codes based on open coding of the transcript (appendix 3). In presenting the results we choose to integrate the quotes of the participants –marked in italics- throughout the description of the results instead of isolating them. Every theme is also introduced by a typical quote.

Peers and society

The first main theme is “Peers and society”, which looks at group experience on one hand, and the perception of society and outsiders on the other hand.

Group experience

“I remember my first hike, none of us got on a camel because we had trained so hard...so a ride on these animals was really no option...for none of us. Everybody agreed on that.”

Group experience was one of the main topics discussed by the participants. In particular, the feeling of being understood by peers, which was expressed as

“the others just knew, you did not have to explain” and “they understand you”.

The fact that they shared having multiple sclerosis was seen as an important connection and part of their bonding. Some even said that

“this group would normally not fit together”

This was because of the differences in age and ability. Participants also pointed out how they felt empowered by the group:

“but because we needed each other and went for the same goal we actually made a group together”.

One of the participants was afraid of heights and never would have climbed a mountain. However, as the group wanted to take a picture on top of the mountain, he felt stimulated and gently pushed to do it anyway. Group experience was perceived as positive, even though participants agreed that it was not always easy because of their differing functional abilities. One participant felt “left behind at the start”, because of the high pace of the group.

Nonetheless, at the end of the journey, they all felt like they completed the journey “at their own pace, with their own strength”.

Society and outsiders

“My intention is to show the world that we, multiple sclerosis patients, can still do a lot. It might not be as easy, but...we do matter. Despite our illness, we can still achieve many things and yes, we still get energy out of doing things till the very end.”

The feeling of being together with peers during the journey provided a marked contrast to their situation at home. The participants verbalized this condition as “being alone in the world” and “being criticized because you’re not supposed to be able to do this”. The experience of a social stigma became apparent through statements such as

“you seem to need a wheelchair to be considered as multiple sclerosis patient” or “do you really have to be incapable of everything to be accepted?”

One participant described how difficult it was to explain what it means to have multiple sclerosis and how difficult it is for the environment to understand why working may be impossible but finishing the journey was not. The expression “we are the people” indicated the absence of social stigma amongst peers. Instead of being outsiders in everyday life,

“it was normal to all of us, we all had the same little medical kit and that was the only time we talked about multiple sclerosis”.

However, the group did not want to be promoted as an “multiple sclerosis group”. Participants rather tried to show the world what they were capable of and wanted to be spokespersons for the multiple sclerosis community. “We matter” was in fact the first statement made, accurately describing the general feeling of the group. This was confirmed by another participant as

“we can still do something, it might not be as easy as for others but... we still matter”.

It was important for them to show that “despite the illness you can still achieve a lot”.

The lived body

In the second main theme, the core topic of “the lived body” is discussed, divided into the primarily bodily experiences on the one hand and identity on the other.

Body experience and body awareness

“A growth process...the whole journey was one profound awakening.”

Here, the main topic was how participants got to know their limitations and how they dealt with them. This resulted in a substantial heterogeneity of answers. One participant stated that “running up against your absolute limits” was more confronting than “exceeding your own limitations”. For another participant, running into physical limits was not at all the main experience. For this participant, the impact of the physical experience was negligible. A third participant explained how pushing his limits during this trip, caused his body to blow the whistle on him. This experience helped him to know his body better. This was confirmed by another participant who said

“my psychologist always says, to know your limits, you first have to reach them, and that’s how it is”.

While the first person did not accept his limitations before or after the journey, the latter said he did learn to accept them. He said that the journey taught him to keep pushing his limits, but also to accept them. In other words, becoming more aware of physical limits resulted for some participants in finding peace with their ill body, which is a key component of healthy body awareness. The acceptance of those limits was also expressed as “being in control”. The group did not unanimously agree on whether or not they gained more control over their body because of the expedition. While some, especially the younger participants, did not have a feeling of control whatsoever, others did feel more in charge of their body. This was expressed as “gaining control over your fatigue, by staying physically active” and modified by the statement that he “did not control the exacerbations”. The participants who did not feel in charge of their body and illness, also described that they did not own their body. In these cases, the body was more often described as an object, in contrast to the participants who felt in charge of their body and explicitly denied these statements. Nevertheless, they all agreed that this trust could disappear with new symptoms or exacerbations. So trust, to them, is related to knowing their body and the feeling of control over it.

While most participants described their challenges to be both physical and mental, one person stated to be pushed by physical limits only. This participant said “emotions are important, because emotions are nerves and multiple sclerosis is also nerves, so I do see the link”. This link between illness and physical or emotional challenges was expressed explicitly by another participant. This person had an exacerbation right after the journey and noted that the people around him thought it was caused by the physical challenge. The participant did not believe this to be true. He said that he “often gets exacerbations after an emotional experience”. He also noticed that with this exacerbation, it was easier for him to “snap out of it”. He said it took less time to “get over it, both physically and mentally”, thanks to the lessons learned during the journey.

Identity

“Before the trip I had the feeling that if I looked at life as a game, the fun was over. And now, now I walk through life like I’m living in extra time. Really, it’s playing extra time.”

The trip was described as “an emotional rollercoaster”, an “awakening” including a drastic change in how participants felt about themselves and their illness. It was also described as “finding yourself again” and “realizing that you are not that person with multiple sclerosis, you are you, creative, full of ideas, and you also have multiple sclerosis”. One participant expressed the feeling of “having walked through multiple sclerosis” and experienced a sudden change in identity. The way participants looked at life in general seemed to have changed as well. It was stated by one of them as follows. Life looked like a game before the trip, “the fun was over”, whereas afterwards he felt like he was “*living in extra-time*”. Realizing what they were able to do and what life still had to offer resulted in quotes such as:

“On top of Aaron’s mountain, I realized, I can take the world” or “I have multiple sclerosis and I still did all this”.

Pushing their limits and opening themselves up to a new realm of possibilities was experienced as deeply empowering. Taking on more challenges in the future, was a goal expressed by most of the participants, as was changing their attitude towards life.

“Enjoy the things you really want to do and don’t feel like you have to live up to other people’s expectations” and “do the things you want to do, take action, don’t postpone” were some of the newly constructed life mantras.

Therapeutic implications

Therapeutic implications constitute the last theme. This theme explores possible therapeutic elements of the trek and how these were experienced. The overall lived experience of the trip is discussed as a part of this theme as well.

Therapeutic elements

“During the trip I had found a kind of peace that I wanted here too but I didn’t manage to get it into my daily life back here. It was my therapist who beautifully said to me that I was still trying to live the rhythm of the desert, only it is almost impossible to realize this at home.”

The journey itself contained some therapeutic elements that had a direct or indirect effect on the participants. Most often described was the ‘back to basics’ experience of sleeping outside, close to nature. All participants agreed that following the rhythm of sunrise to sunset —the rhythm of the desert”—had a beneficial effect on their energy level or *élan vital*. Living a more basic life, without artificial needs was perceived as revitalizing. *Uncomplicated food without added sugars and living without a television that keeps you awake longer than necessary* are just some examples. Merely experiencing *the complete silence*, the fact that “*fewer stimuli were fired*” at them and they were “not obliged to do things” made them feel much more energetic and at ease. The basic outdoor lifestyle of the trip seemed to greatly benefit their bodily attunement. When they were asked how they would implement this lifestyle at home, most participants hesitated whether or not this could be done. One

participant mentioned the risk of “*becoming isolated in society*” and others agreed by adding “*there were no other people there, it was just us*”. They believed that it worked out much better in this context than it would do in daily life. Nevertheless, some participants, inspired by the outdoor experience, already made some practical changes in their lives. One participant removed added sugars from his diet, while another took up a course on mindfulness, trying to grasp the peaceful rhythm he experienced in Jordan. Once back in Belgium, the group organized a gathering in the Ardennes to create a similar experience by sleeping outside again, close to nature.

The lived experience

“In Jordan, I had a lot of time to think, I actually found peace there and because I had a very hectic period before I left, I promised myself never to take up that crazy rhythm ever again. This was the right thing to do, I just felt it”

The group spontaneously reflected on how they experienced the trip once they were back at home. Some participants commented that they did not fully realize what they had achieved, until taking up their daily life once again. Only when “falling back into the old routine”, all of them realized how groundbreaking the experience had been. One participant described “a feeling of decompression”. Everybody agreed that the journey did not feel like therapy even though the journey had a therapeutic effect. Participants were less unanimous on whether this effect could be translated into therapy. Actively trying to recreate the experience in therapy, “would put yourself in a different position”. Another participant added that when you

“deliberately search for this experience as a form of therapy, you make yourself vulnerable”.

The need to focus on themselves as a person rather than a patient seemed to appear once again.

Illness progression and illness perceptions

One participant experienced relapses during the training phase which resulted in increased gait problems due to spasticity and the decision not to participate to the journey. Eight out of the nine selected participants at baseline completed the journey and observational period. Four of them reported exactly the same disability level at the end of the 12-month period when compared to baseline. Three participants indicated an improvement and one participant found her condition to be deteriorated after experiencing a relapse in the second half of the study period.

The scores for the item consequences, referring to the perceived effects and outcomes of illness and the item identity, a measure of the signs and symptoms perceived by the person to be part of the disease, transiently decreased before the journey. The item emotional response, assessing emotional representations, scored low but showed a similar tendency. Scores for

the items *personal control* and *treatment control* were higher with a trend to become somewhat lower during the second half of the observation period.

Illness beliefs were compared between participants with age < 30 and participants with age > 45 based on their mean values for each item, assessed at 5 consecutive time points (table 1). Somewhat different patterns were found for personal control, understanding and treatment control.

Table 1: Illness beliefs between participants

Items Brief IPQ	Participants with age < 30 (n = 3)	Participants with age > 45 (n= 5)
Consequences (mean±SD)*	3,13 ± 1,25	4,00 ± 2,47
Timeline (mean±SD)*	10,00 ± 0	9,60 ± 0,91
Personal control (mean±SD)*	4,33 ± 2,74	6,48 ± 2,06
Treatment control (mean±SD)*	9,27 ± 1,16	7,32 ± 1,57
Identity (mean±SD)*	3,33 ± 1,40	4,16 ± 2,29
Concern (mean±SD)*	3,80 ± 1,74	3,04 ± 2,09
Understanding (mean±SD)*	6,40 ± 1,45	8,28 ± 0,89
Emotional response (mean±SD)*	3,87 ± 2,29	2,84 ± 2,36

*mean values ± SD of assessments at 5 time points

Discussion

The present data show a powerful effect of this hiking expedition on the participants' body awareness and identity. To a larger extent this seemed to be linked to the outdoor lifestyle and back-to-basics experience as a group. In general, all participants declared to have learned how to attune in a more sensitive way to their body and to have gained an improved overall feeling of well-being.

However, when asked about implementing these benefits in daily life after the trip, the group did not agree. Some participants mentioned that the journey led to a regained bodily control and empowerment. Touching their limits during the expedition helped them to get reacquainted with their body and to accept limitations. In addition, to maintain this positive experience after the trip, they had taken specific actions. These participants suddenly realized that they were no longer defined by their illness, as in 'being a patient with multiple sclerosis', but that they were merely people 'having multiple sclerosis'. This was experienced and described as an awakening.

Other participants did not feel in charge of their body. They expressed a much more distant relation to their body, which they mainly experienced as an object. They indicated not having

been influenced by high expectations of others and family but were not able to maintain the improved bodily attunement. Strikingly, younger participants expressed more difficulties accepting their bodily limits and multiple sclerosis in general, whereas older participants appeared to succeed more frequently in consolidating the obtained benefits related to self-management and bodily attunement, suggesting an age-related effect.

While the median values of cognitive and emotional representations of illness, as assessed with the Brief IPQ, suggested no major changes over time, fluctuations existed with a temporary reduction in the perceived adverse consequences, the signs and symptoms perceived to be part of multiple sclerosis (identity) and the expression of concerns, just before the journey. We have reported similar findings in a previous study with a shorter follow-up period (D'Hooghe M et al., 2014). Nevertheless, there is a substantial variability between individuals. Even though the small number of participants did not allow us to make firm statements, we also find age-related effects when observing illness beliefs. Higher scores for *personal control* and *understanding* are seen in the participants age > 45 when compared with scores in the younger participants. Higher personal control is thought to reflect an internal locus of control beliefs and has been associated with self-efficacy (Broadbent et al., 2006), self-management and improved health outcomes.

On the other hand, higher treatment control scores were found in the younger when compared with the older participants which suggests an external locus of beliefs. Because these beliefs are thought to be important for determining an individual's response, interventions addressing these illness cognitions may potentially improve health-related outcomes.

Even though the beneficial effects of the expedition were recognized as therapeutic, the entire group was reluctant to label the expedition a form of therapy. This label would have stressed their illness and identity as patients, while now it felt more like a spontaneous challenge. They expressed how their focus shifted from multiple sclerosis symptoms and illness to a narrative of personal growth.

The entire group also agreed on the positive effect of being amongst peers. Being around and sharing with other people with multiple sclerosis was described as a calming and empowering experience. The illness itself was a non-topic during the trip. Being mainstream for a while allowed them to feel at ease. This resilience contrasted with how they felt back home. The constant need to account for their actions and to explain themselves, made them think and feel like a patient bringing the focus back to their ill body.

When reviewing existing literature, similar statements can be found, though often in a different context. With regard to the back-to-basics experience, Olson et al., (2010) described how participants longed for stillness and silence. Being able to listen to their inner self and their bodies without having to focus on illness and limitations was also valued as a new way of exploring meaning-bestowing and identity. What is described as knowing your limitations in the present study, is mentioned as an important aspect of adaptation and coping or a constant learning process in other studies as well (Malcomson, Lowe-Strong and Dunwoody, 2008; Peterson, Kielhofner, Tham and von Koch, 2009).

The observed age-related effect with regard to self-management and bodily attunement sustained in daily life in this study is in line with the findings reported by Wilski and Tasiemski (2015). In their study of correlates of self-management in people with multiple sclerosis, self-management, as measured with the multiple sclerosis Self-Management Scale, improved with age. Scores correlated strongly with self-efficacy and appeared to be higher in women and in highly educated people. Improved self-management was described as related to less disability, better quality of life and treatment outcomes.

The positive effects of feeling accepted when being around peers is described in multiple studies on people with multiple sclerosis (Malcomson et al., 2008; Olsson et al., 2010; Olsson, Skar and Soderberg, 2011). The awkward experience of being constantly looked at, as experienced by the participants back home, was also mentioned in study of the Machu Picchu Project (Calsius et al., 2015) as “the other’s gaze”. It is described as a conscious awareness of yourself and your body caused by the feeling of being looked at by others (De Haan, 2012). Although their illness made them feel much more visible and looked at, this increased awareness evaporated while being among people who either had multiple sclerosis or understood how it felt to have multiple sclerosis. This felt stigma is also confirmed by several studies (Mozo-Dutton, Simpson and Boot, 2012; Toombs, 1995; Vickers, 2010).

An important and unique aspect of the hiking trip was the back-to-basics experience. All participants acknowledged the positive effect of living close to nature, suggesting a healing quality of acquiring a more natural lifestyle. Which factor or combination of factors contributed to the experienced healing effect is not clear from the findings in this present study. Potential elements are dietary factors, a daylight-based rhythm, sleeping in nature, social support and an environment which poses no social obligations. Even though there is an increasing evidence for environmental factors to be involved in the course of multiple sclerosis (Amato et al., 2017), the exact role of lifestyle factors remains to be elucidated. Therefore, they are generally not implemented in primary care and therapy (Grant & Riise, 2016).

The overall experience of this trip through the Jordan desert could be summarized as resulting in both individual and group effects. The individual effects were related to learning to know their body more profoundly, experiencing it in a positive way as a result of living a more basic life close to nature and being challenged physically. This led to a more positive and befriending attitude towards their body, a change in lifestyle and increased self-belief and social resilience. For some, it was easier to retain these benefits in their daily lives than it was for others. On a group level, being distracted from focusing on multiple sclerosis and its disabilities as they were surrounded and accepted by peers, helped participants to feel more at ease and accepted as a person. All participants described in lesser or greater detail how these beneficial feelings were the result of an improved bodily contact and awareness. Being bodily attuned in a more conscious and sound way allowed them to feel more complete and ensured them of their body as a trustworthy informant and partner.

The focus group was conducted and analyzed according to common guidelines and no inconsistencies were found in the data. Our findings comply with those in the literature, improving the validity and trustworthiness of the presented results. Since the research themes and context were similar to a previous expedition with people with multiple sclerosis (Calsius et al., 2015), it created the opportunity to compare and interpret the present findings as possibly innovative and sound.

However, there are limitations to this present study. First, a focus group prior to the trip could have helped to define the pre-existing state of body awareness of the participants and register the actual changes in a more profound way. Second, some participants might not have felt comfortable to talk about certain aspects in group. So, additional individual interviews could have contributed to our understanding of some of the statements and interactions. Third, we started the analysis from a specific phenomenological paradigm to obtain proper answers to the central research question. It is possible that the use of a specific conceptual framework resulted in a somewhat one-sided interpretation of the results. Fourth, the participants followed a six-month training program before the start of the expedition. Currently there is insufficient indication of possible influences of a preparatory training program on the results. Lastly, the findings were compared to the findings of a previous very similar research to improve generalizability. It should be kept in mind that the study population in both studies was small and selected, with mild to moderate disability at most. It cannot be ensured that the findings would also apply to people with more severe multiple sclerosis.

Additional research on this topic is required to provide more conclusive results. In this study, the participants described a positive personal growth experience. Future research could investigate the possibility of sustaining this experience over time. Additional research on factors that could influence the effect on body awareness and identity can provide valuable information as well. These factors could include disease severity and dominant symptoms.

Conclusion

Participating in this unique hiking project had a powerful effect on body awareness and the lived body experience of the participants with multiple sclerosis. Experiencing outdoor life brought them back to basics, changed their bodily attunement and empowered their self-belief and social resilience. Shifting the focus from symptoms and illness to personal growth, influenced this experience considerably. For some, this ability to tune into their body and experience themselves in a more resilient way endured while others had more difficulties to maintain these benefits in daily life. The overall experience of this hiking trip was described as an awakening in living with multiple sclerosis.

Disclosure statement

The authors declare there was no potential conflict of interest.

Funding

There was no funding for this study.

References

- Amato, M. P., Derfuss, T., Hemmer, B., Liblau, R., Montalban, X., Soelberg Sorensen, P., . . . Group, E. F. W. (2017). Environmental modifiable risk factors for multiple sclerosis: Report from the 2016ECTRIMS focused workshop. *Multiple Sclerosis*, 1352458516686847. doi:10.1177/1352458516686847
- Blaney, B. E., & Lowe-Strong, A. (2009). The impact of fatigue on communication in multiple sclerosis. The insider's perspective. *Disability and Rehabilitation*, 31(3), 170-180. doi:10.1080/09638280701869629
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60(6), 631-637. doi:https://doi.org/10.1016/j.jpsychores.2005.10.020
- Bullington, J. (2013). *The Expression of the Psychosomatic Body from a Phenomenological Perspective*. Dordrecht: Springer.
- Calsius, J., Courtois, I., Feys, P., Van Asch, P., De Bie, J., & D'Hooghe, M. (2015). "How to conquer a mountain with multiple sclerosis". How a climbing expedition to Machu Picchu affects the way people with multiple sclerosis experience their body and identity: a phenomenological analysis. *Disability and Rehabilitation*, 1-7. doi:10.3109/09638288.2015.1027003
- Carman, T. (1999). The Body in Husserl and Merleau-Ponty. *Philosophical Topics*, 27(2), 205-226.
- D'Hooghe M, B., Feys, P., Deltour, S., Van de Putte, I., De Meue, J., Kos, D., . . . Van Asch, P. (2014). Impact of a 5-day expedition to machu picchu on persons with multiple sclerosis. *Multiple Sclerosis International*, 2014, 761210. doi:10.1155/2014/761210
- De Haan, S. (2012). The phenomenology of body experience. In D. Denys (Ed.), *Handbook Psychiatry and Philosophy* (pp. 214-227). Utrecht: De Tijdstroom.
- Fogel, A. (2011). Embodied Awareness: Neither Implicit nor Explicit, and Not Necessarily Nonverbal. *Child Development Perspectives*, 5(3), 183-186. doi:10.1111/j.1750-8606.2011.00177.x
- Grant, W. B., & Riise, T. (2016). Multiple sclerosis. *Neurology*, 86(14), 1275.
- Grytten, N., & Måseide, P. (2005). 'What is expressed is not always what is felt': coping with stigma and the embodiment of perceived illegitimacy of multiple sclerosis. *Chronic Illness*, 1(3), 231-243. doi:10.1177/17423953050010030601
- Gyllensten, A. L., Skär, L., Miller, M., & Gard, G. (2010). Embodied identity—A deeper understanding of body awareness. *Physiotherapy Theory and Practice*, 26(7), 439-446. doi:10.3109/09593980903422956
- Kayes, N. M., McPherson, K. M., Taylor, D., Schlüter, P. J., & Kolt, G. S. (2011). Facilitators and barriers to engagement in physical activity for people with multiple sclerosis: a qualitative investigation. *Disability and Rehabilitation*, 33(8), 625-642. doi:10.3109/09638288.2010.505992

- Malcomson, K. S., Lowe-Strong, A. S., & Dunwoody, L. (2008). What can we learn from the personal insights of individuals living and coping with Multiple Sclerosis? *Disability and Rehabilitation*, *30*(9), 662-674. doi:10.1080/09638280701400730
- Mehling, W. E., Gopisetty, V., Daubenmier, J., Price, C. J., Hecht, F. M., & Stewart, A. (2009). Body Awareness: Construct and Self-Report Measures. *PLoS One*, *4*(5), e5614. doi:10.1371/journal.pone.0005614
- Mehling, W. E., Wrubel, J., Daubenmier, J. J., Price, C. J., Kerr, C. E., Silow, T., . . . Stewart, A. L. (2011). Body Awareness: a phenomenological inquiry into the common ground of mind-body therapies. *Philosophy, Ethics, and Humanities in Medicine*, *6*(1), 6. doi:10.1186/1747-5341-6-6
- Motl, R. W., McAuley, E., & Snook, E. M. (2005). Physical activity and multiple sclerosis: a meta-analysis. *Multiple Sclerosis Journal*, *11*(4), 459-463. doi:10.1191/1352458505ms1188oa
- Motl, R. W., & Pilutti, L. A. (2012). The benefits of exercise training in multiple sclerosis. *Nature Reviews Neurology*, *8*, 487. doi:10.1038/nrneuro.2012.136
- Mozo-Dutton, L., Simpson, J., & Boot, J. (2012). MS and me: exploring the impact of multiple sclerosis on perceptions of self. *Disability and Rehabilitation*, *34*(14), 1208-1217. doi:10.3109/09638288.2011.638032
- Olsson, M., Skar, L., & Soderberg, S. (2010). Meanings of feeling well for women with multiple sclerosis. *Qualitative Health Research*, *20*(9), 1254-1261. doi:10.1177/1049732310371103
- Olsson, M., Skar, L., & Soderberg, S. (2011). Meanings of being received and met by others as experienced by women with MS. *International Journal of Qualitative Studies on Health and Well-being*, *6*(1). doi:10.3402/qhw.v6i1.5769
- Peterson, E. W., Kielhofner, G., Tham, K., & von Koch, L. (2009). Falls Self-Efficacy among Adults with Multiple Sclerosis: A Phenomenological Study. *OTJR: Occupation, Participation and Health*, *30*(4), 148-157. doi:10.3928/15394492-20091123-02
- Plow, M. A., Resnik, L., & Allen, S. M. (2009). Exploring physical activity behaviour of persons with multiple sclerosis: a qualitative pilot study. *Disability and Rehabilitation*, *31*(20), 1652-1665. doi:10.1080/09638280902738375
- Price, M. J. (1993). Exploration of body listening: health and physical self-awareness in chronic illness. *Advances in Nursing Science*, *15*(4), 37-52.
- Stanghellini, G. (2013). Embodiment and schizophrenia. *World Psychiatry*, *8*(1), 56-59. doi:10.1002/j.2051-5545.2009.tb00212.x
- Toombs, S. K. (1995). The Lived Experience of Disability. *Human Studies*, *18*(1), 9-23.
- Vickers, M. H. (2010). Illness onset as status passage for people with multiple sclerosis (MS). *Journal of Health and Human Services Administration*, *33*(2), 193-227.
- Wilski, M., & Tasiemski, T. (2015). Illness perception, treatment beliefs, self-esteem, and self-efficacy as correlates of self-management in multiple sclerosis. *Acta Neurologica Scandinavica*, *133*(5), 338-345. doi:10.1111/ane.12465
- Zeiler, K. (2010). A phenomenological analysis of bodily self-awareness in the

experience of pain and pleasure: on dys-appearance and eu-appearance. *Medicine, Health Care and Philosophy*, 13(4), 333-342. doi:10.1007/s11019-010-9237-4

Paper Received November 2, 2018; Accepted January 22, 2019; Published May 2, 2019

Appendix

Appendix 1: focus group questions: example

<i>Main question</i>	<i>Possible Sub questions</i>
How did you experience this trip?	What was it like to do this as a group?
	What did this trip mean to you? What's the thing you'll remember the most? What did you learn from it?
	Did you expect the hiking to be more or less challenging than it eventually was? Could you describe how you felt during the hiking
	Did you think the preparation for the journey was sufficient or too much? Was the preparation emotionally and mentally sufficient?
What effect did the journey had on you and your body?	How did you experience your body during the trip? What did your body tell you?
	Did you sometimes feel it was too much for your body to handle? If yes, how did you deal with this?
	Did the experience of your body change after completion of the trip?

Does this experience influence daily life?	Do you feel like you're being approached differently by your family or friends?
	Do you experience challenges in daily life differently?
Would you participate in a journey of sorts again or would you recommend others to do the same?	In what manner will you tell about your experiences to others? How do you look back on it?

Appendix 2: IPA results: fragment

<i>Theme</i>	<i>Subtheme</i>	<i>Axial code</i>	<i>Open code</i>
Others	Group experience	Understanding by fellow members	8a, 17
		Support by fellow members	8, 8b, 11, 12b, 16, 35
		Empowerment by fellow members	9, 12a, 12b
	Society and others	Not being understood by others	14, 15, 46, 58, 82
		Stereotypes	42, 50a, 50b
		Being a part of society	57, 58, 62, 68
		Showing people MS	3, 2a, 2b
The lived body	Body awareness and bodily experiences	Physical effects of the journey	38, 46, 53, 54, 79
		Limitations and pushing them	18a, 18b, 21, 22, 31, 34
		Trust and distrust in the body and the self	20, 23, 24, 56, 74a, 75
		Physical-emotional link	44, 47

		Being in charge (or not)	51, 53, 54, 55
		Accepting	29a, 29b, 29c, 52
	Identity and emotions	Seeing their possibilities	1a, 1b, 4, 5, 19, 30, 39, 45
		Personal effects of the journey	48, 49, 59, 60, 60a, 60b, 61, 78, 81, 83, 86
		Emotional effects of the journey	6, 7, 28a, 28b, 28c, 41, 79, 80
		Awakening	16, 25, 26, 27, 43a, 43b, 43c, 76, 77
Therapeutic implications	Therapeutic elements	Back to basic	33, 33a, 33b, 33c, 61, 62, 63, 64, 65, 67
		Translating the experience	66, 67, 69, 72, 84, 85, 86
		Taking challenges	32
	Lived experience	Inability to explain	37
		Awareness of the moment	40
		Awareness of the therapeutic effect	70, 70a, 70b, 71, 71a, 73

Appendix 3: Open coding and corresponding citations: fragment

<i>Open code</i>	<i>Citations</i>
18a	Exceed your limitations; I exceeded my limitation
21	Running into your absolute limits

8b	We needed each other
8a	You sense each other better; we were in this together; they can sense you better
57	Feeling alone in this world

Paper Received November 2, 2018; Accepted January 22, 2019; Published May 2, 2019