

**“A Journey Hiking Through the Desert”: A Thematic Analysis of Bodily
Awareness and Identity in Patients with Multiple Sclerosis**

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Content:

1. Research Content.....	1
2. Abstract	3
3. Introduction	5
4. Methods	7
4.1 Research Question	7
4.2 Context	7
4.3 Qualitative Research Method	7
4.4 Data Analysis	8
5. Results	9
5.1 MS and Me: Body Experience	9
5.2 MS and Others	13
5.3 The Journey	14
5.4 The Life after the Journey	16
6. Discussion	19
6.1 Principal Findings	19
6.2 Strengths and Weaknesses	19
6.3 Implications for Future Research	19
7. Conclusion	21
8. Reference List	23
9. Appendices	
1. Questionnaires	
2. Thematic Analysis	
3. Coding	
4. Results	

1. Research Context

Multiple sclerosis is one of the most common causes of disability and is accompanied by a wide range of physical symptoms and great emotional and psychological impact (Courts, Buchanan, & Werstlein, 2004). An increasing amount of research is being done in the domain of multiple sclerosis, and is meant to optimize treatment and to better understand the impact of chronic illness.

This master thesis is situated in the Master in Rehabilitation Sciences and Physiotherapy part of the Department of Medicine at the University of Hasselt.

This research is a continuation of master thesis part 1, “ Multiple Sclerosis: The Lived Body”. The first part comprised a literary study on how patients with MS experience their body and how their lives are affected by the illness. Three main themes were discussed: “Getting a Diagnosis”, “ The Impact of MS” and “Living with MS”.

In this second part of the master thesis, the participants undertook a journey through the desert of Jordan. The goal of this research is to explore whether this trip influenced the way the participants see themselves, the way others see them and how they feel about their bodies.

This research was led by Dr. J. Calsius. The research question is developed by the student and approved by the supervisor. The research design and method was premised by Dr. J. Calsius, my promoter. Move to Sport’ and the ‘MS Society of Flanders’ handled the project’s recruitment. Pieter Van Schelvergem and Minne van den Noortgate were in charge of the focus group and the data collection. Following this part, the master thesis was split into two separate parts. The format of the “journal physical therapy” was used.

2. Abstract

Background: Multiple sclerosis is a chronic neurodegenerative disease, with both neurological and physical symptoms. In recent years, there has been an increased interest in the psychological impact of the illness.

Objectives: This research aims to provide a better understanding of the effects of a challenging journey and how people with MS experience their body, how others perceive these patients and how their lives changed after the journey.

Design: This research is designed in accordance with qualitative research.

Methods: After the journey, a 16-days hike throughout the desert, a focus group was planned and the results were analyzed using thematic analysis.

Results: Four main themes were constructed, and divided into 15 subthemes. The first theme was “MS and Me: Body Experience” with five subthemes, “MS and Others” was the second theme and had three subthemes. The third theme was “The Journey” and had three subthemes and the last one was “The Life after the Journey” with four subthemes.

Conclusions: The journey could have a positive effect on bodily awareness and the identity of the participants with MS. They have changed their lifestyle after the journey. Prior to the journey the disease could determine the course of one’s life. They gained more control over their bodies. Therefore an improved bodily awareness is the result. In this way, a new sense of identity is formed and MS has become a part of their lives. The world has a better image about the physical capacities of patients with MS.

3. Introduction

Multiple sclerosis (MS) is a chronic neurodegenerative disease (Kingwell et al., 2013) with a prevalence of about 74 out of every 100,000 people in Belgium (Rosati, 2001). MS can cause pain and many motor symptoms, as well as further difficulties in vision, mood, cognition, speech, upper and lower limb function, bladder and bowel function, sexual function and fatigue and cerebellar symptoms in advanced stages (Benedict et al., 2011; Burke, Hooper, Barlow, & Hatter, 2013; Courts et al., 2004; Esmail, Munro, & Gibson, 2007; Schapiro, van den Noort, & Scheinberg, 1984; Solaro, Tanganelli, & Messmer Uccelli, 2007). It can also lead to depression (Minden et al., 2013) and anxiety (Halligan & Reznikoff, 1985; Korostil & Feinstein, 2007). Research has shown that people with MS are less active than healthy people (Sandroff et al., 2012). As a result, their general health tends to worsen, which decreases the quality of life (Janardhan & Bakshi, 2002). People with MS face reduce bodily awareness and lose their identity because the disease dominates their lives (Kralik, Koch, & Eastwood, 2003; Mozo-Dutton, Simpson, & Boot, 2012; Peterson, Kielhofner, Tham, & von Koch, 2010; Pfaffenberger et al., 2011; Saleh, 2007; Toombs, 1995). Research has shown that when patients with MS exercise on regular basis, they experience fewer complaints about fatigue, have an improved mobility and a better quality of life (McCullagh, Fitzgerald, Murphy, & Cooke, 2008; Motl & Gosney, 2008; Snook & Motl, 2009; Stroud & Minahan, 2009).

This project consisted of a 16-day hike throughout the desert of Jordan, which was meant to promote exercise among patients with MS and also to demonstrate their capabilities to the world. In response to this study, the psychosocial aspects of the patients, such as bodily experience and identity, were taken into account.

Body awareness can be described as “ the subjective, phenomenological aspect of proprioception and interception that enters conscious awareness and is modifiable by mental processes including attention, interpretation, appraisal, beliefs, memories, conditioning attitude and affect” (Mehling et al., 2009, p. 1).

Prior to this study, a five-day hike at high altitude throughout Machu Pichu was organized in the context of a similar research conducted by Calsius et al. (2015). The difference in this study was the length of the journey and the environment. The trip took place in the desert of Jordan and lasted 16 days. This trip was three times longer than the journey in Machu Pichu. Calsius et al. concluded that the journey has had a deep and profound effect on the bodily awareness and identity of the patients (Calsius et al., 2015).

In addition to this research, there is little explored in similar studies. The only studies that have been published so far are on the topic of how a chronic illness affects the body, very rarely do they talk about an intervention that is extremely challenging for its participants. Only in the research of Calsius et al. (2015) and D'hooghe et al. (2014) (Calsius et al., 2015; D'Hooghe M et al., 2014).

The purpose of this study is to identify the effect of the journey on the bodily experience of the participants, to examine how the world perceives them, and finally, to understand the changes in their daily habits after the journey.

4. Methods

4.1 Research Question

The purpose of this study is to examine the effect of the journey throughout the desert on the body experience of patients with MS, how they perceive the world and whether the journey has led to any changes in their daily habits.

4.2 Context

This qualitative research is situated in the 'MS Jordanië 2014' project. This journey was meant to facilitate exercise and physical activity in persons with MS. 'Move to Sport' and the 'MS-society of Flanders' are the organizations behind this project, which promote exercise among patients with chronic diseases. The participants received physical coaching, medical and neurological support because of the intensity, safety, risk on fatigue and heat throughout the journey and preparation (Cath Smith, Hale, Olson, & Schneiders, 2009; Catherine Smith, Olson, Hale, Baxter, & Schneiders, 2011). They were selected by the 'National MS center of Melsbroek'. All the participants had been diagnosed with multiple sclerosis and had an Expanded Disability Scale Score (EDSS) of 4 or lower, a disability scale for quantifying and monitoring the disability level in patients with MS (Cho et al., 2014; Kurtzke, 1983). The patient's motivation was an additional prerequisite because of the training required before the journey and because of the difficult of the journey itself.

Nine participants were selected for this journey, six women and three men between the age of 27 and 59. One of the female participants had to stop in the preparation phase and was replaced by another participant. The journey itself consisted of a 16-day hike, in which the participants slept outside. All the participants signed the informed consent and agreed to participate. Each patient received an individualized training program before the journey, which included professional help to prepare him- or herself. Two months after the journey, they participated in a focus group that was organized at the MS Center in Melsbroek.

4.3 Qualitative Research Method

The aim of this study is to explore the effects of the trip, including the preparation, with a focus on how they experience and perceive their own body. Furthermore, the study aims to examine the influence of others on the identity of MS patients, and how this influence changed the patients' daily lives. In this study, a focus group was utilized because of the number of participants and because of the purpose of the research (Morgan, 1997). By using a focus group, one can describe the different experiences of the journey, and additionally, the interaction between the participants can be of interest (Horsburgh, 2003; Howitt, 2013). The focus group was led by an experienced interviewer, who himself is both a physical therapist and a clinical psychologist. He asked questions, divided into different themes (appendix 1)(Morgan, 1996). The duration of the focus group was one hour and 30 minutes.

4.4 Data Analysis

The collected data were analyzed using a thematic analysis, which can be defined as, “a poorly demarcated, rarely acknowledged, yet widely used qualitative analytic method within the psychology” (Braun & Clarke, 2006, p. 77). The data are examined in order to identify several themes that can provide potential answers to the research question. In this case, an inductive method was used, which meant that the content of the data directed the coding and theme development. Furthermore, this study used a realist and a semantic approach. According to Howitt and Cramer (2011) “The central processes of the thematic analysis are transcription, analytic effort and theme identification.”(Howitt, 2013, p. 178)

According to Braun and Clarke (2006), “the process of carrying out a thematic analysis consists of six separate stages, there is a great deal of unbridled going backwards and forwards between the different stages of the analysis”(Howitt, 2013, p. 182). The first step is the familiarization of the data. This step focuses on reading and re-reading the data, in order to gain familiarity to it. The next step involves the generation of open codes that identify the important features of the data. The entire dataset is coded, and afterwards, all the codes are collected. In the third stage, the purpose is to search for themes. The codes that are obtained become collected data in order to identify significant broader patterns of potential themes. In the next step, the themes are reviewed to determine if the themes depict a convincing story behind the data. After this step, the themes are defined and named. The last step is comprised of a written report of the themes (Howitt, 2013). (Appendix 2)

5. Results

The thematic analysis results in four themes, namely 'MS and Me: Body Experience', 'MS and Others', 'The Journey' and 'The Life after the Journey'. All these themes are further divided into subthemes.

4.1 Theme 1: MS and Me: Body Experience

5.1.1 Physical Elements

Before the journey, each participant received a personalized training program, so as to prepare him- or herself for the hike. At time, the participants faced frustration when they needed to train for the journey. These trials occasionally resulted in negative thoughts, as the participants thought that the journey would be tougher than they had expected.

"Lelijk gevloekt tijdens die trainingen en daardoor ging ik misschien ook met een stuk gemengde gevoelens vertrekken."

In the case that participants lived near to each other, they had the opportunity to train together. They encouraged each other because of the fact that they too had MS. Subsequently, the group setting led to peer pressure within the group, and therefore, made them train better.

"Een stuk samen getraind ook omdat we dicht tegen elkaar woonden."

For most of the participants, the journey was physically difficult. It required a lot of energy from their bodies. In this way, the participants' physicality posed a limitation for the journey. Furthermore, the journey was harder than the preparations, as the exact circumstances of the journey could not be simulated.

"Was fysiek niet te onderschatten."

A link was identified between the physical and emotional aspects. The journey was so challenging and difficult that the emotional aspect predominated the physical. All the memories of the past returned as a result of this emotional response.

"Bij Petra is er bij mij de emotie afgelopen van de voorbije tien dagen, de voorbije maanden, de voorbije jaren."

5.1.2 Psychological Elements

Most of the participants exhibited a positive response. Going on a journey throughout the desert is an extraordinary experience. This opportunity increased the motivations of the participants to participate in this project and had an influence on the mentality of the group.

“Iedereen een goede ingesteldheid had en uh, we waren er voor mekaar.”

The journey was an emotional occasion, and for some participants, the emotional aspect had a greater influence than the physical aspect. The emotional trials could lead to either positive or negative impacts. Some participants felt more vulnerable while others felt joy.

“Emotioneel misschien zelfs nog zwaarder dan fysiek.”

Furthermore, there was a boost in their morale, as a result of the fact that they had time to think about their bodily experiences and to identify themselves as a patient with MS. Therefore, a shift in their bodily awareness can occur..

“Energie kwam ineens terug, mentaal ook, wat de rest op dreef bracht.”

The participants were substantially more self-assertive. They were able to understand their bodily requirements and boundaries. In this way, they constructed a new interpretation of their identities, an identity in which they placed themselves in the primary position, rather than the disease.

“Ik ga minder dingen doen, minder uh dingen doen die ik ook niet wil doen en meer aan mezelf denken, dingen doen die ik zelf wil doen en ik wil tot rust komen. “

5.1.3 Positive Interaction with the MS Body

In some cases, a good bodily awareness can result in greater control over the body. Bodily awareness can lead MS patients to know exactly what they can and cannot do, and furthermore, to experience their own boundaries. Figuratively, they could gain more control over the disease and could determine the course of their own lives.

“Je moet u leven daar niet door laten doen.”

The journey has led to the patients having less fear, and since their bodies were able to handle an extreme challenge, they felt as if they could do everything. Moreover, travelling in a group comprised entirely of MS patients could have led to less anxiety because of the fact that they exchanged experiences.

“Door met jullie in die woestijn te zitten en heel veel te praten met jullie en jullie verhalen over MS te horen, heb ik veel minder schrik.”

When a patient has adequate control over their body and has no anxiety, confidence in their body is nearby. Although this statement is not generalizable for all patients with MS. An amelioration of trust is common when the group accomplishes a journey throughout the desert. This can change really expeditiously, for example, when the body does not function the way that it must.

"Als je u goed voelt en ge hebt niks die dag dan denkt ge: "Het zit goed. Het gaat oké. Maar als je dan de dag nadien ne mindere dag hebt of ineens ne opstoot of zo."

The journey could have led to more confidence in the own body and a better bodily experience. The participants learn to live with the disease.

"Ik leer er mee omgaan en ik wil wel grenzen verleggen."

5.1.4 Negative Interaction with the MS Body

At times, it is difficult to be confronted with the body's restrictions. The participants, however, were also confronted with the restrictions of their personalities, which became evident after the journey was completed. The mind is sent astray, it thinks all is perfect and that it will be easy to accomplish the journey, but the body's restrictions can become a limited factor.

"Dus dat ik iedere keer weer verder wil gaan en daardoor word ik wel ne keer teruggeroepen."

This can serve as a setback, since the patient may expect that it will be a perfect journey because of the long preparation. A setback like this can also happen after the journey, when an exacerbation is presented quickly afterwards.

"Een stuk een teleurstelling van een opstoot te krijgen."

In this situation, the patient's feeling that they have no control over their body could become stronger. The disease could decide the course of action, and therefore, some bodily awareness could be lost. This can also occur after years of having the disease.

"Geen gevoel dat ik controle heb."

Patients may consequently have an anxious feeling, since they do not know what could happen over the course of a day. The journey itself was unpredictable, similar to the social contact between the participants.

"Ik vond dat altijd heel angstaanjagend dat van dag op dag kon gedaan zijn."

If all this happens in the course of one's life, it is normal that one's trust in the body or the disease can be questioned. A person may doubt their bodily awareness, which can lead to a vicious circle of negative thoughts.

"Ik zal mijn ziekte nooit vertrouwen!"

5.1.5 How to deal with my Body

When a person has a chronic disease such as MS, it is difficult to accept the impairment in the early stages. The person experiences disbelief and denial. Finally, after a period of acceptance, the disease further impairs the person and life continues. The person can become more familiar with their body and their bodily experience can improve.

“Kon bij neerleggen, van het is oké dat ik het heb en ik ga er verder mee moeten maar het is wel oké en ik kan dees nog.”

In some cases, however, the person does not accept the disease. They live with it, but not accept it.

“Ik ben iemand die het nooit gaat aanvaarden.”

MS has many faces, and can change daily. The difficult part of the disease is that a person with MS does not know if it is going to be a good or a bad day. This influences their bodily awareness because of its fluctuating character. These people must live from day to day.

“Dat is ook moeilijk van MS, de ene dag kun je zo goed zijn en de andere dag erop kun je o zo slecht zijn. Da je denkt van hoe is dees mogelijk. “

5.2 Theme 2: MS and Others

5.2.1 The Influence of the Camera Crew

During the trip, a television program's camera crew followed the participants. One of the candidates told the story of her life with MS and how she deals with it. Within the group, however, there were mixed feelings about the presence of this crew. For some of the participants, their presence was a positive experience since the world received a better impression of MS. The crew mostly stayed in the background.

"Ik vind dat die mensen zich heel, zich zeker niet opgedrongen hebben als cameramensen, dat die eigenlijk met de groep vrij... zich aangesloten en meegedaan hebben op een vrij spontane manier. Ik moet zeggen dat vanaf de tweede dag ik daar geen enkele last meer heb van gehad."

For others, however, the crew had a negative and artificial effect. Sometimes, the real experience of the journey was lost because some things had to be done over again. Therefore, the participants could not enjoy the environment and the fact that they were doing something extraordinary. Their connection with the journey was lost and for a couple of participants the camera crew ruined the trip.

"Ik heb dat Petra-gevoel niet gehad omdat we ne keer door die kloof moesten en dan terug moesten komen voor de camera."

5.2.2 The Togetherness of a Group MS Patients

To travel in a group in which all the persons have MS could have created a positive effect. Nobody looks down upon any of the other travellers because everyone is facing the same impairment. In this case, a connection arose between the participants. Moreover, the participants were able to accept what others said or the things that occurred, since everyone there had the common experience of living with MS.

"Dat zorgt er wel voor dat je in groep andere dingen doet en andere dingen aanvaardt."

The participants were able to tell the others about their experiences, and furthermore, could discuss the experiences of their body to one another, since they were all familiar with the same feelings.

"Wat ge misschien thuis niet gemakkelijk kunt zeggen omdat iemand zonder MS dat niet kan verstaan of niet kan bevatten. "

When someone had a problem or delayed the group, the group was able to help the needy participant. This dynamic demonstrated an advantage to travelling in a group in which everyone faces the same impairment. They cared for each other and certainly accomplished this journey as one group. Furthermore, each participant helped the others to the finish line.

"Dan krijgt ge een duwtje in de rug van de ene of andere van komaan. "

It is of interest how fast a group can be formed. Prior to the journey and preparation, no participant was familiar with any of the others. They came from different regions and there was an age difference within the group. MS had brought them together. A connection was made between the different identities. The group became stronger and stronger towards the end of the journey.

"In het begin waren we niet enorm samen."

5.2.3 How does the World look at MS

The world has a specific image of patients with MS: people with MS cannot do something that is physically difficult. Sometimes, people with MS are associated with wheelchairs. They are not taken seriously when they plan to do something, because they think that they cannot handle it. This can be very frustrating for these patients. It is possible they lose a piece of their identity, 'being the patient' instead of 'living with the disease'.

"MS is rolstoel, die kunnen niet te veel doen."

As a result, patients with MS can become isolated from society. Other people do not know what it means to have a chronic disease, how it feels and how to cope with it. For a patient with MS, this could be a difficult issue. It can be difficult to talk about the illness with someone who does not have it. Therefore, people with MS can sometimes feel alone in the world, which can cause frustrations.

"Heel hard alleen op de wereld zijn op die moment van dees snapt nu niemand."

5.3 Theme 3: The Journey

5.3.1 Personal Experiences about the Journey

All the candidates were positive about the journey. They thought it was the perfect place on earth, and that perhaps it was heaven. It was a place where they came to rest and became focused on their own body. The desert presented a loneliness and silence that doesn't exist in Belgium. They had time to think and to re-evaluate their bodies. At home they were stuck in the daily routine and this was absent throughout the journey.

"Je zit in de molen en wij zijn effkes uit die molen geweest vind ik."

The journey was an extraordinary experience for everybody. It was something that only a few had ever dreamed about, and a feat that they thought would be impossible to finish. To complete this journey, despite their disease, will be unforgettable for many. When they had to tell their experiences to healthy persons, it was difficult. This difficulty is normal, because often, there is lack of empathy.

"Je kan dat ook niet vertellen aan iemand"

The project was named 'MS Petra', though for a lot of participants Petra was not the peak of the journey. It was perhaps the toughest moment since it was the end of a long trip. In their opinion, the real peak was the Aaron-Berg.

"En eigenlijk heel bizar, het project heet Petra ze hadden het beter Aaron-berg genoemd."

The Aaron-berg is difficult and mysterious, especially for a person with MS. The connection of one's mind and body is so close, not only on a physical level, but also on an emotional level. When they reached the peak of the mountain, a new interpretation of the identity was created. The identity of "being a patient with MS" has switched in "having MS"

"K had me daar ook niet aan verwacht maar die Aaron-berg vond ik 100 keer moeilijker, zowel fysiek als emotioneel. "

The journey was perhaps too long, since after 16 days, it is possible that one's connection to their body is reduced. Fatigue can occur, which therefore can decrease the participants' level of motivation.

"Het was genoeg die 15 dagen denk ik, voor mij, misschien voor een aantal mensen ook. Het was niet teveel maar het was genoeg."

5.3.2 Therapeutic Effect

The mission of the journey was to show other people that despite their symptoms, people with MS can complete a physical challenge. The trip can also be seen as a therapy, in the same way a rehabilitation program can. The journey can be a therapy that can make the body discover its boundaries, in which the participants were able to improve their bodily awareness. For a couple of the participants, the journey had a therapeutic effect, as the purpose of the journey was specifically to promote exercising.

"Eigenlijk voor als voorgesteld van we gaan opnieuw bewegen, we promoten bewegen en dat dat toevallig uitgedraaid is als een enorme, ja voor ons allemaal, wel een therapie denk ik."

Others did not experience a therapeutic effect. For them, it was a trip with peers that shared their disease rather than a therapy. For these participants, the journey was spontaneous. Nobody had told them the journey was a therapeutic intervention. Therefore, they did not view the journey as an intervention, but more as a way to show the world what people with MS are capable of.

" Ook niet als therapie bedoeld werd."

5.3.3 Rediscovery Body

One of the advantages of the journey was the rediscovery of the body; the participants had to rely on their bodies. Furthermore, the setting of the journey played an important role because of the provocative character. When they accomplished this journey, they became more confident and stronger. Moreover, they explored their own boundaries.

"10 keer zo sterk sta als ervoor. "

5.4 Theme 4: The Life after the Journey

5.4.1 Back to Basic

Since no comforts or technology was present throughout the journey, the participants had to rely on nature. In a way, they went back in time, woke up when the sun came up and went to sleep when the sun went down. They followed the rhythm of the nature, which felt good for most of the participants. They felt more in control of their bodies, which could have been therapeutic for them.

"Om ten laatste 9 uur lagen wij terug in ons bed, maar voor mij was dat een perfect ritme."

It is excluded to have the same circumstances here in Belgium and this was a disappointment for a lot of the participants.

"Ge leeft nog altijd volgens het ritme van de woestijn, alleen kunt ge dat hier niet."

The lack of technology served as an advantage throughout the journey, such as television, cell phones, computers, etc. All these devices control life and lead people not to listen to their own bodies. Along the journey, it was back to basics. When the sun went down, it was time for the participants to sleep. If the participants had had a television, they would have watched it instead of going to sleep. They would wake up grouchy in the morning and their connection to their bodies would disappear. This applies to all people.

"Je kunt met veel weniger content zijn vind ik, uiteindelijk hebt ge ne hoop kunstmatige behoeften, die ge niet nodig hebt uiteindelijk."

5.4.2 A new Future

A great benefit of this trip was that afterwards, the participants took the initiative to search for solutions to provide themselves with the same experience they had on the journey, in order to better their bodily experience. The journey served as an awakening for the participants, so that they did not view MS as simply in a wheelchair. It is possible they received a new identity from this trip and started their lives anew.

"Dit nodig had om weer te beseffen van inderdaad ik ben niet zomaar die vrouw met MS."

It is important to take challenges in life. These challenges do not always have to be a journey, but can also be painting, hiking in groups, or of course, mindfulness.

"Die uitdaging neem ik aan en ik ga ervoor."

It is also important to change the food and drinks that one consumes. The absence of sugar in the food during the journey gave a great feeling to some of the participants. They had more energy and a better experience with their bodies.

"Ik ben thuis gekomen en ik heb gezegd van ok, opnieuw geen suiker meer, want ik voel me veel energiever zonder suiker."

5.4.3 Return in Trusted Environment

It is difficult to come home to a trusted environment after staying in such conditions. Along the journey, the participants harmonized their bodies and minds. They never felt so good and they stayed in kindly company. Over the course of the 16 days, they perhaps forgot they had MS. Approaching the end and returning home created difficulties in adaption.

“Daar ter plaatse besepte je dat niet, achteraf als je terug valt in uw routine. “

One big mistake was that they kept living rushed lives, though their situations at home were too complex and too hard to handle. Their bodies had become accustomed to the rhythm of the desert, and were not prepared for the situation at home. Additionally, the people at home are not prepared for their return. This reunion could be overwhelming and trigger the body in a negative way. A solution to this issue could be to take one's time after the return, allowing the body to adapt to the trusted situation

” Ik heb toch wel een dag of drie nodig gehad om met de voetjes terug op de grond te komen.”

5.4.4 Back in the Trap

As a result of the difference between the journey and home, there can be a risk of isolation in the family. It takes time for the participants to adapt to their old situation, and therefore, they may be emotionally absent for the first few days after the journey.

“Ik was totaal geen lid van mijn gezin en ik denk dat de kinderen mij tegen de dinsdag ongeveer terug als hun moeder gezien hebben.”

When the adaptation is complete, the participants risk doing too much in a short time. They still feel good and have no complaints. They could think that they can handle the world, but could have forgotten that they have MS. When this happens, the chance to collapse is great.

“Mijn fout is ook geweest om meteen weer beginnen te werken ook.”

6. Discussion

6.1 Principal Findings

The results suggest that the journey has had a positive impact on bodily experience and the identity of the patients with MS. Despite the modern technologies for physical rehabilitation, there are a few agents to improve psychosocial status. This journey was not meant to be considered therapy, but was more of a project to promote exercise. After studying the results, we can suggest that a journey like this can be a therapy on the psychosocial domain. Participating in a challenging hike, can be physically or emotionally difficult for the patient with MS. To complete this kind of journey in a peer-group, can positively affect the motivation of the participants and can also improve their interactions. The journey itself improved the bodily experience and thereby having MS becomes normal instead of being a patient with MS. Hereby, the participants gain back control over their own lives. Hiking in unfamiliar surroundings, far away from all the modern technology in utter silence, would be a good setting to get a better connection with one's body. Going back to basics could be seen as an alternative therapy to improve bodily awareness and increase interception. The participants will do things in a different way than they did before the journey. They have more respect for their body and will gain more control over their lives, rather than the disease controlling. In this way, a new interpretation of identity is formed and MS has become a part of their lives. Similar results were found in the research of Calsius (Calsius et al., 2015).

6.2 Strengths and Weaknesses

Qualitative research is a suitable method to provide better insight in the experiences and opinions of the participants. In order to gather a lot of data, a focus group is recommended. According to Howitt D. (2013), an optimal focus group consists of six to ten participants (Howitt, 2013; Morgan, 1997). The fact that an experienced interviewer conducted the interview led to good control and desired data (Morgan, 1996). Furthermore, a thematic analysis provided a systematic overview of the results.

One of the weaknesses of this study was that there was no focus group in the preparation of the journey. This fact caused an unclear image of the evolution throughout the project. Since the researcher was not a part of the experience, he was not able to fully relate with the participants. Furthermore, The inexperience of the researcher could have led to a misinterpretation of data. Finally, the reproducibility of the entire MS population is not clear because of the small sample size used in this study.

6.3 Implications for Further Research

Previous research used different settings, such as an altitude hike or a journey throughout the desert. Perhaps it would also be interesting to see if the same results could be reached throughout a hike in a trusted environment.

7. Conclusion

The journey had a positive effect on bodily awareness and the identity of the participants with MS. They have changed their lifestyle after the journey, and they considered their bodies to be more important. Prior to the journey the disease could determine the course of one's life. Because the participants had explored their boundaries throughout this journey, they gained more control of their bodies. Therefore an improved bodily awareness is the result. In this way, a new sense of identity is formed and MS has become a part of their lives. The world has a better image about the physical capacities of patients with MS, and as a result, some stereotypes about MS have been countered.

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9. Appendices

Appendix 1: Sample questions

- Hoe was het om op fysiek vlak geconfronteerd te worden met je lichaam?
- Hebben jullie in Petra een soort van identiteitswissel doorgemaakt?
- Hoe is het vertrouwen in je lichaam geëvolueerd na deze reis?
- Zijn er dingen in het dagelijkse leven die jullie gaan veranderen in de toekomst?
- Hoe voelde het om gevolgd te worden door een camera ploeg?

Appendix 2: Thematic Analysis

Table 1 Phases of thematic analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Table copied out: Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*(3), 77-101.

Appendix 3: Coding

Subthemes	Open codes
13 Dagelijkse routine	<p>“je gaat s ‘avonds om 5 uur bijvoorbeeld naar huis en dan ga je terug voor uw tv zitten”, “je gaat uw gras afdoen en is gedaan en morgenvroeg om 8 uur beginnen we opnieuw,”; “Daar ter plaatse besepte je dat niet, achteraf als je terug valt in uw routine “; “we moesten wel met onze voeten stillekesaan op de grond komen “;”Ik heb de fout begaan alhoewel ja het was vastgelegd de uitnodiging voor Petra is na het plannen van een ski-reis gekomen, dus die ski reis lag vast en die vertrok de dag na het landen uit Petra.“; ”nu we gaan we ne keer kijken wat er nog allemaal op ons to do lijstje staat”; ” soms van als ik tv aan kijken ben, dat ik zo denk van: “Voorwa? Kruip in mijn bed.”; ” Wat zit ik hier nu eigenlijk nutteloos naar die tv te staren. En dat ik eigenlijk gewoon kan gaan slapen. En ik voel me morgen 10 keren beter.”</p>
14 Back to basic	<p>“back to basic gevoel”; “terug naar basic”;” En tv was er niet”;” om terug buiten te slapen “;”Ik denk ook dat je dat aan iedereen kunt aanraden en niet alleen aan MS-patiënten. In het algemeen aan iedereen.“; “je kunt met veel weniger content zijn vind ik, uiteindelijk hebt ge ne hoop kunstmatige behoeften, die ge niet nodig hebt uiteindelijk.“</p>
15 Persoonlijke verschillen	<p>“heel gespreide leeftijdsgroep “; “De leeftijd”; “We zijn misschien zelfs verschillend van karakter “;”“We zijn ook allemaal van verschillende regio’s”</p>
16 Openbaring	<p>““ ik heb MS”. “Ik heb dit of ik heb dat”; “nooit geprofileerd als MS groep”;” Ik ben open gebloeid “</p>
17 De ziekte	<p>“MS heeft veel gezichten “;”mijn uitvallen ga ik niet onder mijn controle hebben, die heeft mijn fugalomotoke onder controle”</p>
18 Ervaring	<p>“je kunt dat vertellen door een fotootje te tonen ma je kunt niet zeggen wat da was.”; “Je kan dat ook niet vertellen aan iemand”; “Je kan dat ook niet verklaren en dat hoeft ook niet.”; “De gesprekken dat wij gedaan hebben, de kampvuren dat wij gedaan hebben”;” We hebben Jordanië écht beleefd. “;”Ik vond dat een raar moment, Petra. “;”Een dubbelgevoel he. Opluchting en zo van oh het zit er al op”;” dat je achter u gekeken hebt en kijk, da is gebeurd en”; “er is gene moment dat ik ‘s ochtends opsta en dat Petra niet door mijn hoofd is gegaan “; “Als ik daar nu aan terug denk dan zou ik al terug kunnen wenen van wat wij daar allemaal hebben gedaan. “. “in Jordanië heel veel tijd om te denken, ik ben daar tot rust gekomen eigenlijk”; “ik vind dat heel moeilijk om dat te verwoorden.”;” we moeten dat niet in woorden altijd zeggen maar we hebben dat in daden bewezen ,”</p>

Appendix 4 results

Categories	Main themes	Sub themes	Initial codes
MS: the disease	Me and MS: body awareness	Physical elements	1, 4, 28
		Psychological elements	12, 19, 22, 29, 30, 38, 40
		Positive interaction with the MS-body	24, 31, 34, 51, 54, 55
		Negative interaction with the MS-body	5, 6, 26, 32, 35, 50
		How to do deal with my body?	8, 9, 17, 52
	Ms and others	The influence of the camera crew	46, 47, 48, 49
		The togetherness of a group MS patients	2, 3, 15, 21, 25
How does the world look at MS		27, 43	
The challenge	The journey	Personal experiences of the journey	11, 18, 20, 23, 36
		Therapeutic effect of the journey	44, 45
		Rediscovery body	16, 53
	The live after the journey	Back-to-basic	14, 42, 56
		A new future	7, 10, 33, 57
		Return in a trusted environment	13, 37
		Back in the trap	39,41

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Richting: **master in de revalidatiewetenschappen en de kinesitherapie-revalidatiewetenschappen en kinesitherapie bij inwendige aandoeningen**

Jaar: **2015**

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