

2014•2015
FACULTEIT GENEESKUNDE EN LEVENSWETENSCHAPPEN
*master in de revalidatiewetenschappen en de
kinesitherapie*

Masterproef

"Wandering through the Jordan desert with multiple sclerosis". How hi
king
and outdoor life can recalibrate body awareness and self-identity in people with multiple

Promotor :
dr. Joeri CALSIUS

Copromotor :
Prof. dr. MARIE D'HOOGHE

Minne Van Den Noortgate

*Scriptie ingediend tot het behalen van de graad van master in de revalidatiewetenschappen
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How hiking and outdoor life can recalibrate body awareness and
self-identity in people with multiple sclerosis.

Acknowledgment

I would like to thank Dr. Joeri Calsius for the feedback and advice in the process of writing this thesis. A special thanks to Prof. Dr. Marie D'hooghe for her enthusiasm, sharing her knowledge and giving feedback when needed; the entire team of the MS Petra 2014 project for giving me the opportunity to be part of this extraordinary experience and of course to the participants in this study, whose insights and remarkable wordings made the paper what it is today. I would also like to thank my sister, Sandrijn Van Den Noortgate, for the linguistic revision of the thesis.

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Research context

This master's thesis part two is the continuation of master thesis part one, which was a literature review on body experience and identity of people with multiple sclerosis (MS).

As seen in master thesis part one, written by Minne Van Den Noortgate and Pieter Van Schelvergem, literature on body experience and body perception in people with MS is limited. Studies exploring the effect of physical exercise and physical challenges on the previously mentioned topics are practically non-existent. As this is exactly what will be researched in master's thesis part two, it can provide important insights into this matter.

The research described in master's thesis part two is one part of an observational study on a group of people with MS who participated in the MS Petra 2014 project, a hiking expedition through the Jordan desert. The project was initiated by Paul Van Asch together with the MS Society Flanders.

The study design and recruitment of the participants was part of the existing project, so no part of this was the student's responsibility. The research question was established in master thesis part one by Minne Van Den Noortgate and Pieter Van Schelvergem, together with Dr. Calsius, who is the supervisor of this master thesis. A focus group, led by Dr. Calsius, was used to acquire the data. The preparation of the focus group, which included the choice of topics and questions, was done by Minne Van Den Noortgate under the supervision of Dr. Calsius. Data-processing and -analysis, as well as the writing were done by Minne Van Den Noortgate independently, with feedback from Dr. Calsius.

The format of the journal 'Multiple Sclerosis Journal' was chosen together with Prof. Dr. D'hooghe and Dr. Calsius.

Abstract

Background: Although people with MS benefit from exercise, a more sedentary life seems common among this population. Exercise positively influences body awareness (BA), while chronic illness seems to have an adverse effect.

Objectives: This study explores changes in BA and identity – the so called ‘lived body’- in people with MS after a unique hiking expedition through the Jordan desert in the spring of 2014.

Methods and design: A focus group was organized afterwards with all nine participants. The Interpretative Phenomenological Analysis was used to analyze the data.

Results: Three main themes and six subthemes could be identified. The first main theme ‘Peers and society’ focuses on group dynamics and social stigma. The second theme ‘the lived body’ discusses bodily experiences and self-identity. In the third and last theme, therapeutic effects of the journey and their translation into daily life are explored.

Conclusion: Participating in this unique hiking project had a powerful effect on body awareness and the lived body of the participants with MS. Experiencing life outdoors brought them back to basics, changed their bodily attunement and empowered them in self-belief and social resilience. It was described as an awakening in dealing with MS.

Keywords

Multiple sclerosis, body awareness, body experience, lived body, lived experience, identity, phenomenological analysis

Introduction

Multiple sclerosis (MS) is a chronic disease of the central nervous system with a wide range of physical symptoms, including loss of motor and sensory functions.¹ Research has shown that exercise and physical activity have a beneficial effect on physical parameters such as walking ability, muscle strength and aerobic capacity.² There is also evidence that there demonstrating an effect on factors such as fatigue and quality of life.² Despite the proven benefits, people with MS are less likely to be physically active than healthy subjects.³ Fatigue and not believing in the benefits of exercise are common barriers for people with MS to engage in physical activity.^{4,5} On the other hand, social support, encouragement and having the opportunity to exercise with others seem to have a facilitating effect.⁵ The present study describes the lived experience of people with MS who participated in a 16-day hiking expedition through the Jordan desert. The goal of the expedition to the historical city of Petra was to promote physical activity in this population by providing a unique group experience, outside the regular training environment. In 2012 a similar project took place, the MS Machu Picchu 2012 project. A study with the same set-up as the present one was completed after completion of a climbing expedition to Machu Picchu.⁶ The present study was executed independently, but the results will be compared to identify similarities and irregularities.

In this study, we aim to explore how an extreme physical and possibly mental challenge, which is the trek through the Jordan desert, can affect body awareness, body experience and the identity of people with MS. The topics in this qualitative research are explored using a phenomenological hermeneutic approach to provide a conceptual framework as well as to analyze the data.

To provide a better understanding of the importance of body experience and body awareness in chronic illness, a theoretical framework is needed. Body experience can be defined as a “conscious experience of the body and attitude towards the body as a whole”.⁷ The body as a whole is not limited to the physical body alone. Husserl differentiated the physical body (Körper), which has object-like characteristics and the “lived body” (Leib), which is intentional and more subject-like.⁸ The lived body is defined as an intelligent body, it is what makes interaction with others and the world possible. By definition, the lived body is central to the experience of the self, the world and others. The lived body is a central concept in phenomenological research and crucial to the concept of body awareness. In normal circumstances, the body is constantly perceived, yet it is peripheral in our perceptual awareness.⁹ When the body is experienced as something negative, as is often the case in illness or pain, it becomes the focal point of the attention.¹⁰ Body awareness can thus move from fore- to background and from a negative over a neutral, to a positive load. Both body experience and body awareness are dynamic and multi-dimensional concepts, prone to change with chronic illness. Identity is, both as a consequence of the latter statement and by itself, another aspect of a person that can be affected by chronic illness. When chronic illness negatively affects the self, this can result in a loss of positive self-images and a loss of self-identity.¹¹ The dynamic character of body awareness and identity as well as the interaction between them, the experience of the surrounding world and the experience of others, reaffirms the importance of researching these topics in chronic illness.

Methods

Context

This qualitative research was part of the MS Petra project 2014, a hiking expedition through the Jordan desert to the historical city of Petra. The project was initiated by Paul Van Asch, together with the MS Society Flanders in order to bring attention to the importance of physical activity and participation for people with MS. Candidates for the trip were selected by different neurologists and physiotherapists, affiliated with the National MS center in Melsbroek, Belgium or Fit Up, a physiotherapy and fitness center in Kontich, Belgium. To be selected, the candidates had to be highly motivated and have an EDSS score no higher than 4, meaning they only have a mild disability and are able to walk independently. The selected group consisted of six women and four men, aged 27 to 59 years old. The participants were enrolled in 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 project ran over a twelve month period, starting from the beginning of the training phase and ending 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 end of the expedition, a focus group was organized in the National MS Center in Melsbroek, Belgium.

Qualitative research method

The goal of this study is to provide a better understanding of possible changes in body awareness, body experience and identity after completing a unique journey through the Jordan desert. Together with a previous study by Calsius et al (2015), this study attempts to provide insight into MS patients' lived experience of a possibly life-changing physical challenge. To provide in-depth information, a focus group was used for data-acquisition. Because the journey itself was a group experience, a focus group was the preferred option over individual interviews. This way the group dynamic and interaction could also be observed and discussed. All nine participants agreed to attend the focus group that took place in the National MS Center in Melsbroek. The one-hour focus group was led by an experienced interviewer, who is a physical therapist and clinical psychologist. Beforehand, a series of questions about the main topics was compiled; the lived experience, body experience and identity (table 1). The focus group itself was audiotaped and transcribed verbatim afterwards. To analyze the data, a phenomenological hermeneutic approach, i.e. the Interpretative Phenomenological Analysis (IPA), was used.

Results

As the body is the key connection to the world we live in, it is a fundamental aspect of our identity. Several topics relating to the participant's identity and body experience are discussed in the results of the data-analysis. The findings are presented in three themes and six subthemes, constructed from axial codes based on open coding of the transcript (table 2, table 3). The first main theme is "Peers and society", which looks at the group experience on the one hand, and the perception of society and outsiders on the other hand. 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. "Therapeutic implications" constitute the last theme. This theme explores possible therapeutic elements of the trek and how the therapeutic aspect was experienced. The overall lived experience of the trip is discussed as a part of this theme as well.

Peers and society

The group experience

The 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're able to empathize with you more". That they were all MS patients was seen as an important connection, it was "part of their bonding". Some even said that "this group would not normally click" because of the differences in age and ability, but that they "needed each other". One participant said "there we were we, not the person with MS, because we were surrounded by people who constantly work with people with MS, while all of us had MS. Everyone knew that it was there, how it felt and what you could expect. MS was never a disturbing presence". They also pointed out the empowering effect that the group had on them. One of the participants said he was afraid of heights and would never climb a mountain, but because the group wanted to make a picture on top of the mountain, he climbed it anyway. He said that this "was the push to do it anyway" and that he "never would have done this alone". Although the group experience was perceived as positive, it was not always easy from the start. The participants had different abilities and one woman said she felt "left behind at the start", because she could not keep up the pace. But at the end of the journey, they all felt like they got to complete the journey "at their own pace, with their own strength".

Society and outsiders

The feeling of being together with peers provided a stark contrast to their situation at home. The participants specifically verbalized this 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 an MS patient, do you really have to be unable to do anything to be accepted?". One woman described how people could not understand why she could not work anymore, but did manage to finish this journey. The absence of social stigma amongst peers was expressed as "we were the people". Instead of being outsiders in

everyday life, “it was all normal there, we all had the same little medical kit and that was the only time we talked about MS”. The group agreed on not promoting themselves as an “MS group”, but trying to show the world what they were capable of and being a spokesperson for the MS community. “We matter” was in fact the first statement made and it accurately describes the general feeling of the group. It was later on 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 “you don’t have to be inferior to anybody else”, that “despite the illness you can still achieve a lot”.

The lived body

Body experience and body awareness

The experience of getting to know their limitations and how they handled this was the main topic discussed. One man stated that “running up against his absolute limits” was more confronting to him than “exceeding his own limitations” was. On the other hand, one woman stated that running into those physical limits was not at all her main experience; she didn’t find the impact of the physical experience to be that big. A third participant explained how pushing her limits during this trip caused her body to blow the whistle on her. She stated that she got to know her body better because of this. This was confirmed by another woman 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 her limitations before or after the journey, the latter said she did learn to accept them. She said that the journey taught her to always keep pushing her limits, but to also accept them, whatever they may one day be. In other words, becoming more aware of their physical limits, for some, resulted in finding peace with their ill body, which is a key component of healthy body awareness. This accepting (or not) of those limits, was also verbalized as “being in charge” (or not). The group did not unanimously agree on whether or not they gained more control over their body, because of the expedition. While some, especially younger participants, did not have a feeling of control whatsoever, some of the 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 she “did not control her exacerbations”, they were “controlled by this little device”. The ones that did not feel in charge of their body and thus their illness, were the same people that described not trusting their body and vice versa. It was expressed as “knowing you can wake up in the morning and you know, legs done, this was it” and “still touching your legs every morning, just to make sure everything’s okay”. These statements were explicitly denied by the ones that did feel in charge. In the statements on not trusting the body and the illness, the body is described as an object and talked about in the third person. They did all agree on that trust, if it was there, collapsed with new symptoms or an exacerbation. So trust, to them, is related to knowing their body and the feeling of control over it.

While most participants described the limitations and boundaries they experienced to be both physical and mental or emotional, one man stated that only physical limits were pushed in his case. In his statement he said “emotions are important, because emotions are nerves and MS is also nerves, so I do see the link”, however he “did not find the experience to be all too emotional”. The link he

described, between the illness, the physical and the emotional, was expressed explicitly by another participant who had an exacerbation right after the journey. She noted that people thought it was caused by the physical challenge. She did not believe this to be true; she stated that she “often gets exacerbations after an emotional experience”. She also noticed that with this exacerbation, it was easier for her to “get out of it”, she said it took less time to “get over it, both physically and mentally”, thanks to the lessons learned during the journey.

Identity

The trip was often described as “an emotional rollercoaster”. Some of them described the journey as an “awakening”, a drastic change in how they felt about themselves and their illness. It was described as “finding yourself again” and “realizing you are not that woman with MS, you are you, creative, full of ideas, and you also have MS”. One man expressed the feeling of “having walked through MS”, followed by stating that “leaving MS behind is overrating it”, but he did experience a sudden change in identity. The way they look at life in general seemed to have changed too, a feeling of “living in extra-time” was expressed, while before, the same man stated that if he looked at life like a game, “the fun was over”. A generalized realization of their and abilities and the possibilities that life still has to offer also occurred during the trip. “On top of Aaron’s mountain, I realized, I can take on ‘a’ world”, one man stated. “I have MS and I did all this” was how another participant described the realization. They experienced knowing how much they were able to achieve as empowering. Taking up more challenges in the future was a goal set by most of them, as was changing their attitude in life. “Enjoy the things you really want to do and don’t let expectations by others lead you” and “do the things you want to do, take action, don’t postpone” were some of the newly constructed life mantra’s.

Therapeutic implications

Therapeutic elements

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 they had by sleeping outside, close to nature. They all agreed that following this rhythm of sunrise to sunset, “the rhythm of the desert”, had a beneficial effect on how they experienced their energy or élan vital. Living a more basic life, without “artificial needs” was perceived as revitalizing too. “Uncomplicated food without added sugars” and “living without a television that keeps you awake longer than necessary” are just some examples. Not only the practical things, but merely “the complete silence”, the fact that “fewer stimuli were fired” at them and they were “not obliged to do as much” made them feel much more energetic and at ease. The basic, outdoors lifestyle thus seemed to benefit their bodily attunement greatly. When they were asked how they would implement this lifestyle in their daily lives, most participants hesitated whether or not this could be an option. When one participant pointed out the risk of being “isolated in society”, others agreed by adding “there were no people there, it was us and that was it”. They believed that when it was just them together with this vast silence, it worked out much better than it would in daily life. Nevertheless, some participants already made some practical changes in their

lives inspired by the trip. One woman removed added sugars from her diet, while another picked up a course of mindfulness, trying to grasp the peaceful rhythm she experienced in Jordan. The group also organized a weekend together in the Ardennes, Belgium, to create a similar experience by sleeping outside again, close to nature.

The lived experience

Something that was not directly asked, but that the group did spontaneously comment on, was how they experienced the trip itself and how they experienced coming back afterwards. It was commented by a number of people, that they did not fully really realize what they had achieved or being there, until they were back. They all agreed that they only realized how groundbreaking the experience was, when they “fell back into their old routine”. It was defined as “a feeling of decompression” by one participant. Another important aspect was how to them, the journey did not feel like therapy. They all agreed on the statement that it had a “therapeutic effect”, but the reactions got more on the defensive side when they were asked if this could be translated into therapy. None of them felt as if the journey was meant to be a form of therapy, it was “spontaneous and it grew on you spontaneously” and if you would “actively try to find the same experience in therapy, you would put yourself in a different position”. A second participant added that when you “actively search for this in the form of therapy, you make yourself vulnerable”. The need to focus on themselves as a person, rather than a patient is once again apparent in the statements above.

Discussion

The present data shows that the hiking expedition had a powerful effect on the participant's body awareness and identity. The outdoors-lifestyle and back-to-basics experience had a great beneficial effect on their bodily attunement. The group agreed on that they got to know their body better because of the journey and that they experienced an improved feeling of general well-being. How the perceived benefits were transferred to daily life can be narrated in two stories.

One side of the story is that of the people who learned to trust their bodies more. In their story it becomes apparent that the positive effects of the journey lead to regaining control over their body and a feeling of empowerment. They mentioned taking specific actions after the trip to maintain the positive bodily experiences they had during the trip. Reaching their limits during the expedition helped them to get them reacquainted with their bodies again and in some cases, accept that body with its limitations. These people experienced the awakening and the sudden realization that they were not defined by the illness, but that it was just a part of who they were.

The other side of the story is that of the participants that did not feel in charge in any way. They were the most reluctant to incorporate elements of the journey into their lives at home. A much more distant relation to their body was expressed; they described their body as an object. So although all of them confirmed that not being distracted by other's expectations or excessive amounts of stimuli made them more aware of their own body, their own needs and their own wishes, not everybody could maintain this feeling after returning.

The entire group was reluctant of naming the expedition a form of therapy, but they did confirm its therapeutic effects. Defining the journey as therapy put the focus back on the illness, which was something they did not feel the need for. Actively looking for the same experience as therapy was seen as putting themselves in a vulnerable position, as opposed to merely challenging themselves to complete this journey and experiencing the therapeutic effects spontaneously. To experience the benefits, the focus must not be on reducing symptoms or the illness itself, but more on personal needs and personal growth. The entire group did agree on the effect of being amongst peers. Being around peers and experiencing this together was seen as a positive, calming and empowering experience. The illness itself was a non-topic during the trip. Being the norm instead of the exception allowed them to feel at ease with themselves and their illness. This contrasted greatly with how they felt back home. A stigma surrounding MS was experienced and they constantly felt the need to explain and account for their actions. Having to explain themselves, because of their illness, made them feel more like a patient and put the focus on their illness and their ill body. This can be described as the effect of "the other's gaze". De Haan describes it as the feeling of being consciously aware of yourself and your body caused by the feeling of being looked at.¹² Being different, because of their illness, made them feel much more visible and looked at. This increased awareness of the ill body was eliminated by being around people who either had MS or understood how it felt to have MS.

The overall experience can be summarized as having both individual effects and group effects. The individual effects were caused by getting to know their own body better, experiencing their body in a positive way as a result of living a more basic life close to nature and challenging their body physically. This resulted in a more positive attitude towards the body and the illness, 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. The group effect can be explained by not focusing on the illness itself by being surrounded by peers. This diminished the increased awareness of the ill body that they experienced in daily life. It led to a feeling of being more at ease with and more accepting towards their body with its disabilities and the illness itself. A normalized body awareness and thus a better bodily attunement caused them to not define themselves solely as patients anymore.

A focus group prior to the trip could have helped to define the actual changes in a more profound way and define the pre-existing state of body awareness of the participants. Secondly, some participants might not feel comfortable talking about certain aspects in group, so additional individual interviews could be conducted in a similar study in the future. We also started the analysis from a specific paradigm to properly answer the research question, and even though we did stray away from the original topics, there is still the possibility that the use of this specific framework made for a somewhat one-sided interpretation of the results. Using different ways of both qualitative and maybe even quantitative measures could reduce this risk. Lastly, the findings were compared to the findings of a previous very similar research to improve generalizability. It should be kept in mind that both studies used a small sample of people with MS, who only had a mild disability. It cannot be ensured that the findings would also apply to people with more a severe disability.

Additional research on this topic is required to provide more conclusive results. Future research could investigate the underlying factors to the differences in the effect on body awareness and identity. It could also study other, easier to achieve experiences that might provide similar benefits.

Conclusion

Participating in this unique hiking project had a powerful effect on body awareness and the lived body of the participants with MS. Experiencing life outdoors brought them back to basics, changed their bodily attunement and empowered them in self-belief and social resilience. It was described as an awakening in dealing with MS.

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Appendices

Table 1: focus group questions

<i>Main question</i>	<i>Sub questions</i>
How did you experience this trip?	What was it like to do this as a group? What were the pros and cons?
	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?
	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 (source of strength, source of frustration?)
	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? Why?	

Table 2: IPA results

<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	

Table 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

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Ik/wij verlenen het wereldwijde auteursrecht voor de ingediende eindverhandeling:

"Wandering through the Jordan desert with multiple sclerosis". How hiking and outdoor life can recalibrate body awareness and self-identity in people with multiple sclerosis.

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

Jaar: **2015**

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