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Patients with Multiple Sclerosis in Psychotherapy: Processes of Meaning Making and Self Transformation

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Abstract

Background: Recent empirical literature on autoimmune diseases has focused extensively on the implementation and evaluation of psychosocial interventions. Psychotherapy and counselling processes for multiple sclerosis (MS) have gained special attention given the cognitive and behavioral dimensions of the symptoms as well as their unpredictable course. The current study aims to gain a deeper understanding of the meaning making processes for persons with MS (PwMS) who are in psychotherapy treatment.

Method: The sample of this study consisted of ten PwMS who described their experience of the illness and of psychotherapy of choice through semi-structured interviews. Data collection and analysis adhered to Interpretative Phenomenological Analysis guidelines.

Results: The results revealed that PwMS struggled with understanding the initial symptoms, contemplated taking medication, and related symptom development to psychological factors such as depression. Participants were preoccupied with disability representations and questioned the trustworthiness of their bodies. They worked towards integrating the illness into their identity and described how psychotherapy encouraged psychological agency whilst feeling supported and “accepted”.

Conclusions: Psychotherapy contributes to the processes of shaping participants’ life worlds, offering a space to self-organize and reflect within genuine therapeutic relationships.

Keywords

Multiple sclerosis, Psychotherapy, Meaning making, Interpretative phenomenological analysis

Introduction

MS is a central nervous system disease which is characterized by demyelination, inflammation, and neurodegeneration [1]. There are about 2.2 million cases of MS worldwide, while in Greece, 6,861 to 8,649 cases of MS were recorded in 2016 [2]. The progression of the illness exhibits significant individual variation [3] and PwMS present great symptom diversity and complexity, ranging from vision problems, fatigue, spasticity and pain to cognitive dysfunction and mood disorders [4]. Literature has focused extensively on the psychiatric and psychological dimensions of MS [5]. PwMS have a higher prevalence of anxiety and depression than the general population [6] and anxiety is a predictor of de-

pression for this population [5].

The unpredictability of symptom development along with the physical, emotional and cognitive facets of the illness have a significant impact on patients' quality of life, relationships, social status and other significant areas of living [7,8]. PwMS's appraisals of their condition, the healthy behaviors they exhibit, such as physical activity and exercise, quality sleep, a well-balanced diet, keeping positive relationships with their family as well as their sense of independence are amongst the variables related to higher quality of life [9,10]. The prospect of relapse or further deterioration makes coping difficult [8]. Positive affect, optimism, self-efficacy, task-oriented coping strategies and meaning-making processes have been found to foster adjustment to illness [11]. PwMS face the challenge of integrating the disease into their identity [12,13] as they strive to develop a sense of coherence and control over their illness. These processes are positively related to emotional, psychological, and social wellbeing [3,11].

Psychosocial interventions and their efficacy have been the focus of MS literature over the past years. Research focuses on Cognitive Behavioral Therapy (CBT) and other approaches offering short-term and self-administered protocols. The results of such interventions show moderate effects on reduction of depression and [12,14]. CBT facilitates the adjustment process as do stress management interventions [15]. Even though the intervention programs can be demanding and difficult to integrate in their everyday schedule, PwMS express appreciation of the contact with therapists and co-participants in the therapeutic contexts [16,17].

Living with MS places the person in precarious positioning where continuous behavioural and cognitive modifications are required in confronting physical and psychosocial challenges. Restructuring and continuity of their identity, emotions, relationships, self-efficacy have been correlated to better mental health and psychological well-being [3,11,13]. The role of psychotherapy in these processes, enhancing cognitive appraisal and coping requires further investigation [13] through systematic exploratory analysis of diverse perspectives [18]. Focusing on PwMS's accounts of their lived experience of psychotherapy, the present study aims to add to the knowledge of how psychotherapy facilitates PwMS's endeavor to acquire coherence and consolidate a new identity after the diagnosis.

Methods

Context and method

Ten PwMS who were engaged in psychotherapy treatment of their choice provided detailed accounts of their symptoms, diagnosis processes, and initiation of psychotherapy. Data collection and analysis are guided by the Interpretative Phenomenological Analysis framework [19], a method used widely in health psychology

research to capture the experience of illnesses [20,21]. The study was approved by the Psychology Department Committee of Panteion University of Social and Political Sciences.

Participants and data collection

For recruitment, the first author visited a university neurological outpatient clinic, followed social media groups and communicated with therapists known for working with PwMS. An information leaflet and the consent form were provided to stakeholders. Eligibility criteria included being 18 years of age and above, with the diagnosis of MS and involved in psychotherapy in a context of their choice during the time of data collection. Ten PwMS agreed to participate who were primarily female (n = 9) and their ages ranged from 31 to 63. They were all Greek, five of them were married, two widowed and three were single. Eight participants engaged in individual psychotherapy and two in group psychotherapy in integrative, cognitive behavioral, psychodynamic and systemic frameworks. The interviews were scheduled at convenient times and places for the participants. Eight participants were ambulatory without walking aids and two used a wheelchair. The interview questions were open-ended in order to promote reflection on their lived experiences as they appear in Table 1. Interviews lasted from 32 to 46 minutes. All interviews were conducted by the first author, they were audio recorded and transcribed verbatim. All participants read and signed the written consent form before recording, ensuring they agreed to the confidentiality, anonymity as well as to their right to withdraw from the project Table 1.

Analysis

The analysis followed the case-by-case path as indicated by the guidelines for IPA [19]. Each case was analyzed in detail before moving to the next. A long list of

Table 1: Interview questions.

Please describe your Multiple Sclerosis.
When did it start?
How has it evolved?
How do you think about it?
How do you feel about it?
How has it influenced your everyday life?
How has it influenced your relationships?
Please describe your psychotherapeutic process?
When did it start?
How has it evolved?
How do you think about it?
How do you feel about it?
How has it influenced you? Your perceptions of self?
How has it influenced your everyday life?
How has it influenced your relationships?

Table 2: Summary of results.

Superordinate Themes	Themes
The label	Appearing and disappearing: A phantom-like ailment Reacting to and conceptualizing the diagnosis Attributing MS symptoms to psychological factors
Relationship with the body: Images of disability	The wretched world of the disabled: Activism and criticism The wounded body: Distorting and eluding the senses Coming to terms with symptoms: A path from de-realization and depersonalization to integration
The external and internal world of reconciliation	Relationships with professionals, significant others and society Reflecting on MS remedies: The use of psychotherapy Self-transformation: Focusing on the present and looking beyond

themes and superordinate themes, written in detailed, explicit manner, was recorded for each case. The relationships and associations between them were then recorded separately, creating images and diagrams to delineate how data from each case related to each other. At this stage, deeper interpretations of the results with regards to the meaning participants gave to each theme were recorded. The analysis was discussed with the research auditor after each stage, describing reflections, and themes based on researchers' understandings. The team of researchers then discussed the results. Discrepancies were integrated into the analysis, all suggested themes were recorded and the team went 'back and forth', revisiting the transcripts checking for accuracy.

Results

Three superordinate themes were generated representing the reflexive and complicated process of meaning-making by the participants. Participants strived to conceptualize the initial symptoms and their inconsistency until the MS label was provided. Their bodies and the way they interpreted their lifeworlds encompassed representations of disability. They also explicated the internal and external factors which facilitated the process of reconciliation with the illness. The results are summarized in [Table 2](#).

The label

Appearing and disappearing symptoms: A phantom-like ailment: Initially participants experienced locomotor and vision problems, numbness, and fatigue, of varying intensity and duration. They were initially confused as the symptoms were "coming and going." Doctors and significant others struggled to conceptualize symptoms and labeled them as "random findings," "poliomyelitis," "optic neuritis," "fatigue," "psychological problems," and "burn out". The absence or inconsistent presence of an explaining framework for the symptoms left participants "abandoned" and helpless: "I could not get out of bed, my hands and feet were numb, I was losing my sight slowly until I lost it completely and no doctor could help me, it was very difficult for a long

time." When they were symptom - free, participants felt MS had forgotten about them and "let them be" but eventually MS "found them" especially when they felt most vulnerable, to "report its presence." Participants used metaphors to describe the experience of the first symptoms: "as if I was run over by a truck" and "as if I had weights on my legs." One participant described depression as one of MS's initial symptoms and felt like he was "hitting a wall."

Reacting to and conceptualizing the diagnosis: Diagnosis eventually came as "a bolt from the blue – lightning in a clear blue sky". Two participants lost a great deal of weight in a short period of time and described an intense, shock reaction comprised of grief and guilt "[a nutritionist told me] it was my fault I had MS because of my diet and what I ate and this had such an impact on me that I lost 20 kilos in two months." However, six participants felt "relief" at the time of diagnosis, because they initially thought they had a severe psychological disorder or cancer. As one of them said, "you do not die from that [MS]" and that there could be "worse" illnesses than MS. All participants mentioned that MS "came into their lives to change them" giving a different meaning to their lives and relationships. Appraisals of MS were usually associated with the absence of active symptoms. When participants did not experience the intensity, severity, and strong functional impact of the relapses, "they were OK", they felt that they could evaluate MS in a more positive way. As two participants described, "for me it was a gift, but I am saying this because I am well, I don't know what I would say if I had residual symptoms", "it opens new paths, different paths, but under the condition that one is well." As they endeavored to incorporate the new label in their lives, when symptoms were not present, and they could live as if they never received the diagnosis.

Attributing MS symptoms to psychological variables: Participants concluded that MS presented itself as a counterblow to depression, stress, loss and anxiety. They followed this line of thinking regarding understanding the causes of MS. The illness for them came

as a retaliation, “*reaction*”, or “*reply*” to their lifestyle up until that point. Two participants understood MS as something punitive: “*my body punished me, I was doing something wrong.*” Five participants discussed the connection of MS with motherhood and how the symptoms escalated after their pregnancies. Participants mainly associated the onset of symptoms with grief. Such associations included: “*I had one strong relapse in 2012; my mother had died and psychologically I was really bad*” and “*I had stopped working in 2010 and I was really sad, I was staying indoors and perhaps that is how I got it [MS].*” Participants described MS as a “*psychological disease*” and insisted that “*it is not biological.*” All participants reflected on how disease progression was closely related to their psychic world: “*if you think of what I have been through, I should be in a wheelchair.*”

Relationship with the body: Images of disability

My body and the “wretched world of the disabled”:

Participants’ representations of MS included wheelchairs, lack of locomotor activity, as well as significant cognitive deficits. These representations were generated by contact with PwMS and information from various sources such as books and web pages. Images equated MS with disability; “*once someone had told me, but I was misinformed, that the person hardens [becomes like a rock – sclerosis] from the inside towards outside.*” Participants were disquieted and disconcerted in contemplating the contested disability world: “*I was registered at the Association [for PwMS] and they started sending me their journal every three months and I read it but I started crying because I was seeing the symptoms saying ‘oh no, this is how I will become.’*” Concomitantly, they struggled to accept and identify themselves as disabled people, or potentially disabled people, reflecting on whether they belonged to this group or not. For one of the non-ambulatory participants disability gave her an identity and purpose “*I consider myself disabled, not ill.*” Another participant discussed her experience working with people with disability as “*a wretched world.*” Nevertheless, even for those who could stand and walk, “*a wheelchair is always hanging over our heads*” as an intruding thought and constant reminder of their disability.

The wounded body: Distorting and eluding the senses: Even when the symptoms were not active, the self-image of participants was bound to a wounded body that was untrustworthy, “*I cannot go to the super market on my own. I am too slow placing things in the bag. I do not have the flexibility to move, to do anything.*” MS distorted their senses and perception of the world: “*I was bending my neck and it felt as if electric current went through my body. Imagine, I was in a restaurant and I thought that the waiter was throwing oil on my back and I told him ‘hey, what are you doing,’ and there was no one behind me.*” One of the participants described how she felt her body was in a panic state

constantly and did not tune in with her mind: “*I have this insecurity that my body doesn’t cooperate with me 100%, and always in the back of my head I feel I need to protect myself and others when I hold something hot or a knife.*” They illustrated the sense of apprehensiveness as if, “*holding a half-full glass in your hand all the time, at some point you get tired.*” All participants described their efforts to maintain control of their bodies by being attuned to bodily sensations and understanding them, “*I have reached a point where I can understand whether a symptom is related to MS or when it is something different*” even though two of them gradually reached the point that they could not take care of themselves and eventually, “*other people decide for me now.*”

Coming to terms with symptoms: A path from de-realization and depersonalization to integration:

When participants experienced the symptoms of MS, they experienced a kind of ‘depersonalization and derealization’ process “*I did not have ‘sclerosis’ in my mind and no one else did, it was a disease that went away and I was fine.*” Intense relapses prevented participants from integrating MS as part of their lives: “*as if it wasn’t me [when she could not walk]; I remember all these, and I think it wasn’t me, that they [symptoms] don’t exist [...]*”, “*I had symptoms of numbness but I attributed them to how tired I was.*” For eight participants it was important to continue with their everyday activities and pursue goals under the condition that MS would not become a barrier: “*I am trying to forget it [MS] so that I undertake what I can accomplish, it’s not that I deny it or I undermine it, or I don’t want to have any connection to it, or that I am afraid of it, I am not afraid, but yes, I am trying to forget it as much as I can.*” One participant described the experience of coming to terms with MS after the end of the first session with the psychotherapist: “*when I came out of the psychologist’s office I saw the whole world from a strange point of view, even the light that was coming from the sky, I just stared at it, and I realized that something changed in my life.*” As participants sought some semblance of normality in dealing with their chronic illness, they focused their efforts on reconciling with the symptoms: “*you do your best with what you have*”, “*I know MS will not go away and I will always have it with me.*”

The external and the internal world of reconciliation

Relationships with health professionals, significant others and society:

Intimate relationships of care and support were very important for the participants of this study: “*I do not want them to see me as another patient [professionals] [...] [with the neurologist] we have become best friends.*” For three participants, the relationship with their psychotherapist was unique and resembled the characteristics of personal relationships: “*with my psychotherapist, beyond the therapeutic relationship, we have come closer, I don’t know why, maybe*

she saw something in me, and we have become friends.” They explicitly discussed their relationships with their parents, partners and families as important in the process of living with the illness. Three participants discussed their mothers’ reactions to the diagnosis: “my mother, years after the diagnosis, told me during a fight that she knew about what I had from the beginning, that she was pretending and did not tell me anything about it [...] instead of supporting me when she found out, she avoided it.” They detailed their family’s difficulties in accepting the diagnosis: “I feel I need to help them accept, that, in this family there are not five of us, there are ten of us [MS as the 6th member]”, “[as symptoms deteriorated] my daughter told me ‘I want my old mum back’, and that was devastating.” Work relationships were another important area that was greatly impacted by MS. Two participants had been forced to leave their workplace due to the MS diagnosis and experienced redundancy as, “disgraceful; I should not have left like that, I feel evicted.”

Reflecting on MS remedies: The use of psychotherapy: Participants engaged in a context of non-medical interventions like the psychosocial support offered in psychotherapy “this is the gift of MS for me, to have one day a week for myself [the day of psychotherapy session] because if I did not have the illness, I would never have done it.” They found that they needed to confront the ‘attacking’ nature of the disease and put things in order: “I need to curtail my autoimmune illness; I understand that something happens with me and my defense system attacks my body.” They explored their conceptualization of the illness “a big part that I said I want to work on was the subject of ‘why did this happen to me?’.” In this context, psychotherapy was considered important as it encouraged psychological agency and praxis, provided techniques for pain relief, improving relationships and creatively confronting everyday challenges. Therefore, even though psychotherapy could not “undo” MS, participants found the relational space to work on everyday problems and solutions. They believed that psychotherapy had a positive effect on their MS “I am 100% sure that only psychotherapy helps me, there is no point taking the medication” and concluded: “Of course, there is no question, it [psychotherapy] has a positive effect; and I wonder if I had started it when I found out about MS how things would be, maybe my life would be different [...] I would have dealt with it [MS] better.” Two participants described the processes in group psychotherapy, the relationships that were developed, the fact that the members felt like “family.” They felt appreciated and “accepted” and engaged with others by “sharing in an open way.” These processes helped them “move to the other side” that is accepting the diagnosis and the limitations it imposed.

Self-transformation: focusing on the present and looking beyond: Participants outlined processes of changes and transformations moving the “I am healthy”

threshold to a different point after the diagnosis. All participants focused on the present, accepting their diagnosis and subsequently, enhancing their capacity for resilience. As they explained: “I want to live now, I want to live the present, I want to live my life; I am not waiting. I do not want to wait for something to happen, for me to live well. I want to live well now.” Participants strived to integrate MS into their identity, attributing positive meaning to the illness. They needed to view it as a “gift”, as a situation that gave “purpose in their life”, as an “awakening”, “a warning sign”, a motive for self-care and initiation of psychotherapy. They participated in MS support groups, events, offered advice to newly diagnosed PwMS and facilitated non-discrimination activities: “there are people who tell me not to go there because it takes me back [to MS] [...] or it saddens me or I do not want to be like them, but I do not accept this, I go there and I interact with friends.”, “however, then I turned it into a positive thing [disability]; when I started occupying myself with Facebook with a group called...” As they concluded, “I am lucky this disease came to my life, I understand myself better and I enjoy my everyday life.” Even though participants endeavored the ever-changing and unpredictable nature of the illness, they viewed MS as a “necessary evil” that had to happen: “maybe it happened for that reason; it is hateful, but OK, maybe it happened so that I can re-assess some things... how to go on living.” Viewing themselves as persons with MS and accepting the limitations as well as the opportunities for change that the diagnosis raised, appeared to be a significant reconciliation process.

Discussion

For the participants in this study MS initiated a journey of reflection with feelings ranging from confusion and anxiety to relief and reconciliation. They tacitly, yet unwillingly, assumed that their bodies had become malfunctioning equipment, emplacing them, currently and in the future, within the disability world. Decisions along the way, especially seeking psychotherapeutic treatment that was “right” or “worked” for them, helped in “moving” and accepting their strengths and challenges. The relationship with the therapist and process of reconciliation with the diagnosis as it was facilitated in psychotherapy were highlighted in by the participants. These findings are congruent with other results of Gottberg, et al. [17].

In the present study disability was conceptualized as “a wretched world”. This coincides with previous research findings in which PwMS felt they joined the “cripple club” as they tried to integrate the diagnosis into their lives [22]. PwMS have described how their body is untrustworthy, perceiving it as something separate from their self and eventually coming to terms with it via self-awareness and mindfulness [23,24]. As participants described, MS became a separate entity with which they interacted in their endeavor to incorporate

it into their self-image. The perception of PwMS's selves and their self-efficacy appear important in the management of the symptoms whereas the level of disability does not influence that process [25,26]. Participants in this study talked about a change as to how they perceived their health. Similar to our findings, PwMS have reported that they incorporate a "new normal" in the meaning they attribute to their health status [27].

Feelings of depression, losses they incurred and emotional turmoil are associated for participants to the symptoms' appearance, agreeing with previous research findings [18]. MS was conceptualized as a psychological disease and participants reflected on cognitive and emotional means of coping with the symptoms. The sense of coherence, understanding of the illness and positive appraisal are important in reducing negative affect towards integrating the illness into their identity [11,28]. Participants in this study used psychotherapy as a means to embrace their strengths and the challenges they faced, explain and accept their illness that was no longer a phantom or foreign entity wreaking havoc in their bodies. The absence of relapses enhanced the process of positive evaluation of the disease according to the results of this study. Psychotherapy processes enhance positive emotions and benefit finding which are essential factors towards reduction of depression symptoms, acceptance and effective coping [3,13,29].

Limitations and suggestions for further research

The present qualitative study describes the experience of ten persons with MS, and the results cannot be generalized to the population of MS patients. Moreover, the PwMS who agreed to participate reflected on processes of positive appraisal and adjustment; however, it is acknowledged that this is one perspective of the experience of the illness and more data should be collected in order to acquire diverse views. Despite limitations, the study offers an account of the participants' pathways from diagnosis to reconciliation. More exploratory research is needed in order to investigate possible associations between psychological factors and onset of MS symptoms. Moreover, the benefits of retaining employment and active social roles must be further explored.

Conclusions and Implications for practice

The reconciliation processes allowed participants in our study to incorporate meaningful activities such as psychotherapy into their lives. The results support the conclusion that attributing meaning to the illness is integral to acquiring agency. Psychosocial interventions enhancing coherence, self-efficacy, and re-defining the self are important in the process of adjustment [22]. Even though CBT is the framework suggested in the literature, therapists must be specially trained as to how to adapt interventions to the characteristics of PwMS. Given the results of this study, meaning-making process-

es and re-evaluation of life seem significant for PwMS. Thus, experiential and phenomenological interventions can individualize therapy and enhance outcomes.

Disclosures

The Authors declare that there is no conflict of interest.

All authors have contributed to the article.

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