



2022

Living with Multiple Sclerosis as a former marathon runner: Impact of attitude and past behaviour on self-care maintenance and perseverance

Michael Stephanou
University of Oxford

Follow this and additional works at: <https://pxjournal.org/journal>

 Part of the [Health Services Administration Commons](#), [Medical Education Commons](#), [Nervous System Diseases Commons](#), [Rehabilitation and Therapy Commons](#), and the [Social and Behavioral Sciences Commons](#)

Recommended Citation

Stephanou M. Living with Multiple Sclerosis as a former marathon runner: Impact of attitude and past behaviour on self-care maintenance and perseverance. *Patient Experience Journal*. 2022; 9(3):12-18. doi: 10.35680/2372-0247.1756.

This Personal Narrative is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

Living with Multiple Sclerosis as a former marathon runner: Impact of attitude and past behaviour on self-care maintenance and perseverance

Cover Page Footnote

This article is associated with the Patient, Family & Community Engagement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PtFamComm

Living with Multiple Sclerosis as a former marathon runner: Impact of attitude and past behaviour on self-care maintenance and perseverance

Michael Stephanou, *University of Oxford, michael.stephanou@gtc.ox.ac.uk*

Abstract

As healthcare professionals, we have a duty to promote the wellbeing of individuals living with chronic diseases and this could be accomplished through the establishment of self-care strategies that are both collaborative and self-directed. Insight into the complex behaviours and backgrounds of individuals who show initiative in dealing with chronic disease could help achieve this by revealing drivers of health-seeking and engaging behaviours. Therefore, by deducing the complex interactions between attitude, past experiences and disease outlook, broader patient welfare could be championed through the implementation of targeted interventions which promote self-care in chronic disease. This article aims to explore these ideas by focusing on the story of a former marathon runner and proactive secondary progressive Multiple Sclerosis sufferer, Mr. Evans, who has taken charge in leading an active and healthy lifestyle to manage his condition. His sense of patience and self-worth are rooted in his attitude and upbringing and are factors which have championed his ongoing wellbeing and understanding of his condition.

Keywords

Multiple Sclerosis, self-care maintenance, past behaviours, motivation, perseverance, disability, self-care, self-education, care continuity, behavioural sciences

Introduction

Self-care behaviours in chronic disease are a crucial tool that can allow individuals to be proactive in coping with their condition and improving their healthcare outcomes. This is especially pertinent in chronic disease where long-term commitment toward healthcare through self-directed, health-promoting actions can improve physical and mental wellbeing.^{1,2} Therefore, supporting individuals in undertaking such actions is an important strategy which could be employed across conditions and healthcare systems. However, problems arise due to the complexity in determining how to elicit such actions, as well as the high agency they require.³ One way to better implement such a strategy is to analyse the lives of individuals who espouse the ethos of self-care and to try determining what drives their behaviour, bearing in mind that it may be subconscious and not the result of intentional behavioural changes. I will aim to reveal some of these concepts through an analysis of a patient called Mr. Evans, who shows tremendous perseverance in managing with multiple sclerosis (MS), by looking at his past experiences and outlook on life in the context of the health-promoting behaviours he displays.

Definition of Self-care Behaviours and Impact on Quality of Life

Self-care maintenance points to actions that are performed to improve and sustain well-being, while self-care management is the process of proactively responding to symptoms when they arise.⁴ These behaviours aim to exert control over disease symptoms and progression, and studies have shown that when they are poorly observed in chronic disease worse healthcare outcomes can follow,⁵ along with a poorer quality of life.⁶ Quality of life is often measured as combination of both subjective and objective perception which accounts for holistic wellbeing, and there is interest in determining how self-care behaviours can be targeted to account for these elements.^{7,8} One study focusing on chronic heart failure management revealed that self-care confidence, functional capacity, knowledge, health literacy and social support are all behaviours which are positively correlated with disease management and wellbeing.⁵

Based on this study Mr. Evans' actions allow him to supplement his quality of life, in the context of secondary progressive MS and his symptoms. He is an informed, well-supported and medically literate individual who is confident in taking ownership of his wellbeing, traits which have served him well in his disease journey. The positive self-care maintenance behaviours that Mr. Evans displays are evident in his everyday life but also reflected in

past behaviours. On a daily basis, Mr. Evans chooses to eat healthily, restrict his alcohol and sugar intake, remain physically active and perform self-directed physiotherapy sessions. He performs these activities to maximise physical wellbeing and uses experience in tailoring activities to what benefits his body. Mr. Evans has displayed agency in all points of his life and once motivation has been established, he is proactive in working towards his goals.

Examples include Mr. Evans stopping smoking at a young age in order to commit to playing sports at a higher level, but more pertinently surrounding his condition he has shown exceptional commitment to his physical wellbeing, from early on. Mr. Evans has been dedicated to controlling his weight through diet ever since his lack of mobility and decline in physical activity left him feeling hopeless, since he always took his weight for granted as an athlete. In the early days of diagnosis Mr. Evans was also driven to pursue disease modifying therapies which he has stuck with to this day in the hopes that they have been making positive contributions, despite this being unclear. Therefore, Mr. Evans has displayed a huge degree of self-control, self-sacrifice and self-agency in dealing with his MS and studies have for holistic wellbeing and there is interest in determining how self-care behaviours can be targeted to account for these elements.^{7,8} One study focusing on chronic heart failure management revealed that self-care confidence, functional capacity, knowledge, health literacy and social support are all behaviours which are positively correlated with disease management and wellbeing.⁵

Based on this study. Mr. Evans' actions allow him to supplement his quality of life, in the context of secondary progressive MS and his symptoms. He is an informed, well-supported and medically literate individual who is confident in taking ownership of his wellbeing, traits which have served him well in his disease journey. The positive self-care maintenance behaviours that Mr. Evans displays are evident in his everyday life, but also reflected in past behaviours. On a daily basis Mr. Evans chooses to eat healthily, restrict his alcohol and sugar intake, remain physically active and perform self-directed physiotherapy sessions. He performs these activities to maximise physical wellbeing and uses experience in tailoring activities to what benefits his body. Mr. Evans has displayed agency in all points of his life and once motivation has been established, he is proactive in working towards his goals.

Examples include Mr. Evans stopping smoking at a young age in order to commit to playing sports at a higher level, but more pertinently surrounding his condition he has shown exceptional commitment to his physical wellbeing, from early on. Mr. Evans has been dedicated to controlling his weight through diet ever since his lack of mobility and decline in physical activity left him feeling hopeless, since he always took his weight for granted as an athlete. In the

early days of diagnosis Mr. Evans was also driven to pursue disease modifying therapies which he has stuck with to this day in the hopes that they have been making positive contributions, despite this being unclear. Therefore, Mr. Evans has displayed a huge degree of self-control, self-sacrifice and self-agency in dealing with his MS and studies have shown that such behaviours combined will have contributed to an improvement in his quality of his life.^{5,6,9}

Influence of Past Experiences and Attitude on Disease Outlook and Management

It is a well formulated concept that past behaviours and childhood traits can influence decision making and even well-being later in life.^{10,11} In fact, one study expresses the belief that childhood conscientiousness can continue to contribute to physical and emotional wellbeing in adulthood, independent of personality challenges.¹⁰ Another study, based on the self-perception theory, speculates that people who are aware of their past behaviours can use their attitudes towards those actions in guiding repetition of similar behaviours.¹¹ These ideas relate to Mr. Evans' general perspective on life and disease.

Mr. Evans grew up in a depressed post-war Ireland where "there was not much in the way of luxuries," and he believes he experienced true austerity during those times. Upon reflection, he admits that his childhood was isolated but that as a child you "don't know any better." Mr. Evans goes further in attributing this harsh upbringing as a major contributing factor to his lifelong mentality of dealing with whatever is at hand "rather than crying about it." His conviction developed from a young age has allowed him to leave unpleasant instances in the past while avoiding self-pity, as it "achieves nothing but making you miserable." As a result, it would not be egregious to deduce that Mr. Evans' past has helped establish his attitude toward his condition, and in his case long-term self-reliance and determination have generated proactive behaviours and management strategies.

Mr. Evans' coping mechanisms are rooted in his strong-willed attitude and have aided in sustaining his quality of life⁶. As can be deduced from previous quotes, Mr. Evans subscribes to the emotional philosophy of being kind to oneself by not lamenting on the past and by avoiding damaging thoughts. He says the best advice he ever received after his diagnosis was to "focus on what you can do, not what you can't" and this spoke to the resilient side of his mindset which he developed growing up. Mr. Evans has also used humour to come to terms with certain situations, for example in cases where women in society would "tsk-tsk" him for appearing drunk during the day, due to his unstable gait secondary to cerebellar ataxia, he laughed off the situation and thought "so what if I am." His established self-esteem, avoidance of emotional

sabotage and general proactivity have acted as effective coping strategies and endorsed his ongoing wellbeing.^{12,13}

Acceptance and Resilience as Encouraging Markers in Chronic Disease

Mr. Evans' attitude, as shaped by his past, has also allowed him to confront the ramifications of his condition and somewhat come to terms with the implications on his life. Acceptance has been suggested as a crucial component for adjustment to disability,^{14,15} but Mr. Evans' situation is even more complex as not only has he had to deal with the loss of ability but also the knowledge that his condition could unexpectedly worsen at any point.¹⁶

Nonetheless, Mr. Evans' general approach to life guided his journey of acceptance in what researchers have shown is a constructive manner.¹⁷ After his diagnosis, he underwent a set of "value changes"¹⁸ while not letting his condition define him but rather seeing it as one of the characteristics which can be used to describe him.¹⁶ This concept is extremely pertinent when we consider that before his diagnosis Mr. Evans was a marathon runner who derived great joy and purpose from extensive physical activity. He admits that the adjustment from athlete to chronic disease sufferer with impaired mobility was difficult early on, but now he is able to look back on his previous athletic feats fondly and without regret. He remains active on a daily basis indulging in his passions for Do-it-yourself (DIY) renovations, swimming (when possible) and alternating between taking long walks and using a static bicycle. Therefore, Mr. Evans' determination has allowed him to strive towards maximising his wellbeing within the confines of his condition.¹⁶ This is relevant since studies have shown that acceptance can be related to greater self-esteem, as well as increased motivation and engagement in daily activities.¹⁹

Mr. Evans' outlook on his condition and coping strategies also reveal an internal locus of control (LOC) in which he truly believes that his own actions have the power to influence the environment around him.²⁰ Patients who exhibit an internal LOC are more likely to be motivated to seek health-related information and comply with treatments, which have shown to be beneficial traits in the management of MS.¹ One can go further in saying that Mr. Evans displays resilience, since he has favourably adapted in response to the immense hardships he has faced.^{21,22} Research into MS patients has shown that emotional coping strategies which aim to avoid stress along with disease acceptance that helps bypass negative illness perception can contribute to self-efficacy and the establishment of a symbiotic state of resilience and improved quality of life.^{23,24} Mr. Evans displays all these characteristics and is an example of how self-care maintenance can serve to benefit chronic disease sufferers.

Considerations of Self-care Behaviours

Further research has highlighted additional qualities which can assist in the self-management of chronic debilitating conditions, many of which Mr. Evans displays of his own accord. In a population of chronic pain sufferers, two prevailing themes mediating persistence emerged and were focusing on social activities and keeping occupied²⁵. In keeping occupied, individuals in the study stated the need to "keep going" by doing as much as possible and learning to be positive, rather than feeling sorry for themselves.^{25,26} This relates directly to Mr. Evans' philosophy whereby he tries not to make things hard on himself by focusing on the past, but rather seeks to maximise his daily productivity and wellbeing.

Participants also expressed an affinity for social interaction as this allowed them to externalise their focus and distract themselves, helping them strive toward a more "meaningful life."^{25,27} While Mr. Evans restricts his social interactions to his partner and close family, he finds solace in his DIY home renovations and relishes the process of seeing his projects come together. This relates to the findings that self-directed purposeful activities can act as vectors for keeping productive and engaged.²⁸ Nonetheless, characteristics of disease progression which are often uncontrollable can impact on quality of life in MS, with worse symptoms,²⁹ poor emotional coping strategies,³⁰ social isolation³¹ and financial problems³² leading to a decline in quality. Even though Mr. Evans displays some of these risk factors such as fatigue,³³ bladder dysfunction³⁴ and limited social interaction,³¹ these have been counteracted by the numerous protective behaviours he exhibits which have helped augment his quality of life.³⁵ From a financial point of view, he states that he is "very fortunate" to be financially stable and that this allowed him to retire when his work was becoming overwhelming. However, he does state that the fact that his MS diagnosis was made late (over 4 years after the first presentation of symptoms) was frustrating because he only got access to additional financial compensation at this later time. Moreover, although not exceedingly socially engaged, Mr. Evans has constructed a strong support network which he relies on and which is an important facilitator of improved mental health in chronic disease.^{36,37} Limited social interaction does not seem to impact his wellbeing negatively, and throughout the COVID-19 lockdown, he has coped in the face of prolonged isolation with great belief in the societal beneficence of these restrictions. The immense self-motivation Mr. Evans displays gives him purpose and allows him to persevere in spite of his condition, while also displaying the formidable benefits self-care maintenance behaviours can provide.

However, it is important to consider how excessive agency and resiliency could potentially lead to worse healthcare outcomes. This idea is presented in the scenario when Mr. Evans was offered mitoxantrone treatment early on in his diagnosis. Mitoxantrone is a chemotherapy which aims to improve MS symptoms, but causes several severe side effects, and at the time it was being proposed it had questionable efficacy. Despite these concerns, Mr. Evans was extremely in favour of the treatment and stated that he felt he had no other viable options and that his doctor's in-depth explanations were "overplayed" because "any side effects would be better" than the current circumstance. While this speaks to the desperation he felt at the time, it does seem as though his strong-willed character did not allow him to fully consider the potential risks of treatment. In addition, the exceptional agency Mr. Evans displays can come into conflict with scientific recommendations. His continued self-directed commitment to disease modifying therapies, none of which are recommended by National Institute for Health and Care Excellence (NICE) guidelines and despite his doctors echoing this sentiment, reveal the concern that excessive, unsupervised agency could be detrimental, especially in the current climate of rampant medical misinformation on social media.

Future Implications of this Research and Reflections on the Current Healthcare System

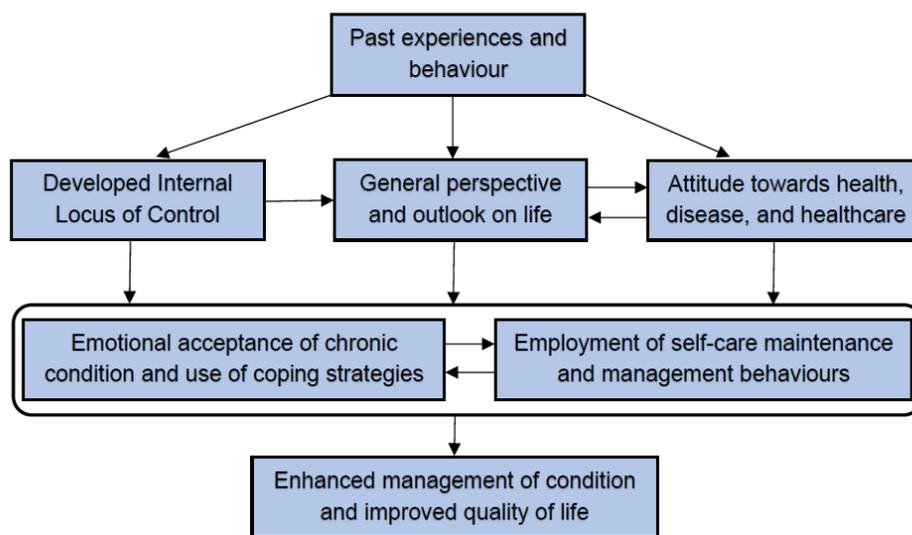
Mr. Evans' scenario speaks to the idea that in chronic disease more can be achieved with what individuals do for themselves, rather than what is done for them.³⁸ By understanding what drives the motivation of individuals such as Mr. Evans and by determining from where their positive health promoting actions are derived, policy-based

health behaviour change can be directed toward chronic disease sufferers.⁹ While it is difficult to infer a causal relationship between attitude, past experiences and health-seeking behaviours it is evident that all these factors interlink to influence wellbeing (Figure 1).

Based on this discussion and the existing literature, self-care maintenance behaviours appear to display extreme potency in chronic disease management. As a result, a greater emphasis on assisting patients in undertaking self-directed actions can be suggested as a healthcare approach. However, studies which relate self-care maintenance behaviours to quality of life in MS can be scrutinised and more standardised research needs to be done in this field. Many of these studies are limited to small sample sizes which lack ethnic and socioeconomic diversity, and confounding variables are often not well defined which makes it difficult to yield generalisable information.^{1,16} Thereafter, from a design point of view most studies are cross-sectional rather than longitudinal and the questionnaires they employ are often variable and lack external validation which complicates the process of interpreting them and making comparisons between them.^{1,16}

Nonetheless, it has been proposed that behaviour change models should move toward a multi-disciplinary process which meaningfully involves stakeholders and allows them to undertake joint ownership of initiatives, rather than relying on a paternalistic, academically- dominated approach.³⁹ Novel interventions could therefore focus on expanding health literacy, social support and disease knowledge in chronic disease sufferers, in the hopes of

Figure 1. Interlinking factors which influence Mr. Evans' disease management



improving self-care confidence and maintenance in these individuals⁵ (Table 1).

Psychological wellbeing is also extremely important to consider in MS sufferers, as part of a biopsychosocial approach to treatment.⁴⁰ Emotional healthcare interventions which promote listening to patients' experiences rather than making premature clinically-derived recommendations could help facilitate patients coming to terms with their condition.⁴¹ By tailoring healthcare interventions based on the knowledge of effective perseverance and coping strategies, self-care maintenance behaviours and an improved quality of life can be promoted in long-term disease sufferers^{5,6} (Table 1). As a result, targeted treatment approaches which involve disease acceptance, social involvement and collaboration on healthcare initiatives could increase confidence and resilience in chronic disease sufferers.

In the context of Mr. Evans' story, there are notable scenarios in which the current healthcare system fails the chronic disease sufferers it intends to treat and therefore needs to be improved upon. A prominent lack of communication in the early stages of disease presentation

and identification may exist and this diminishes the trust patients have in the healthcare system. This was what Mr. Evans encountered with the first neurologist undertaking his care, whereby he felt the doctor was not being "open and honest" with him. He believes that this may have delayed his diagnosis and therefore delayed immediate steroid treatment, thus missing an opportunity to stunt his disease progression. As a result, he took it upon himself to seek a second consultant. Moreover, a lack of resources resulting in delayed treatment timing is disappointing and often times demeaning to patients. Mr. Evans receives Botox injections into his bladder to help control his urinary incontinence successfully, but often must wait long past the appropriate date before a repeat appointment. This regularly leads to long spans of leaking and loss of bladder of control, which is degrading. Furthermore, established healthcare counselling on disease modifying treatments that may fall outside of the scope of traditional healthcare recommendations, should be implemented. This could help avoid unrecommended usage of medication in a more tactful manner which respects patient autonomy, while circumventing condescension from healthcare workers which Mr. Evans has experienced in the form of comments such as "you are wasting your

Table 1. Self-care behaviours in chronic disease, their positive effects on disease management and potential strategies which can be used to promote them. Mr. Evans displays all these actions.

Health-promoting quality or action	Benefit to condition	How action could be promoted
(1) Medical Literacy and understanding of condition	(1.1) Recognition of physical symptoms and disturbances - can guide health seeking actions (1.2) Can also contribute to disease acceptance	(1.1.1) Healthcare engagement and communication (especially in early stages of diagnosis) (1.2.1) Provision of accessible, understandable information through counselling or leaflets
(2) Healthy eating and physical activity	(2.1) Promotion of physical wellbeing and symptom control	(2.1.1) Information provision (2.1.2) Subsidising diet and gym plans to try establish accessibility and motivation
(3) Keeping busy with meaningful activity	(3.1) Coping with condition and giving a sense of purpose	(3.1.1) Assisting individuals in undergoing "value changes" during the coping process by listening to their experiences and identifying new potential hobbies
(4) Support system in place	(4.1) Emotional coping and perseverance	(4.1.1) Organising social support groups or even support calls during lockdown

money.” By addressing these injustices and healthcare gaps, a more fortified approach toward self-care maintenance promotion can be achieved.

Conclusion

There are a multitude of actions, termed self-care maintenance behaviours, which can play an active role in improving quality of life and perseverance in chronic disease sufferers. Examples such as emotional coping strategies and healthcare engagement are very much self-directed tools, and there is interest in determining how they emerge and how they can be implemented in healthcare because of their beneficial outcomes. Mr. Evans exhibits a host of these behaviours, and they have helped him manage with his MS progression over the past 20 years. By attempting to unravel the complex origins of these behaviours (Figure 1), more synergistic behaviour change approaches can be established which give confidence to patients and champion their progressive wellbeing.

References

1. Bragazzi, NL. The Gap in the Current Research on the Link between Health Locus of Control and Multiple Sclerosis: Lessons and Insights from a Systematic Review. *Multiple Sclerosis International* 2013;972471: 8 pages
2. Black R, & Dorstyn, D. A biopsychosocial model of resilience for multiple sclerosis. *Journal of Health Psychology* 2015;20(11): 1434-1444
3. Public Library of Science. Interventions requiring less individual agency should be prioritized to fight obesity. *ScienceDaily*. 2016 Retrieved from: www.sciencedaily.com/releases/2016/04/160405161134.htm [Accessed: 10th February 2021]
4. Al-Sutari MM, & Ahmad MM. Effect of educational program on self-care behaviors and health outcome among patients with heart failure: an experimental study. *International Journal of Evidence-Based Healthcare* 2017;15(4): 178-185
5. Zou H, Chen Y, Fang W, Zhang Y. & Fan X. Identification of factors associated with self-care behaviors using the COM-B model in patients with chronic heart failure. *European Journal of Cardiovascular Nursing* 2017;16(6): 530-53
6. Gil-González I, Martín-Rodríguez A, Conrad R, & Pérez-San-Gregorio MÁ. Quality of life in adults with multiple sclerosis: a systematic review. *BMJ open* 2020;10(11): e041249. doi: 10.1136/bmjopen-2020-041249
7. Lauer G. Concepts of quality of life in mental health care. In: Priebe S., Oliver, J. P. J., Kaiser, W., editors. *Quality of Life and Mental Health Care*. Philadelphia, PA: Wrightson Biomedical (1999) p: 19–34
8. Megari K. Quality of Life in Chronic Disease Patients. *Health Psychology Research* 2013;1(3): e27 doi:10.4081/hpr.2013.e27
9. Allegrante JP, Wells MT, & Peterson JC. Interventions to Support Behavioral Self-Management of Chronic Diseases. *Annual Review of Public Health* 2019;40: 127–146
10. Hampson SE. Mechanisms by Which Childhood Personality Traits Influence Adult Well-being. *Current Directions in Psychological Science* 2008;17(4): 264–268
11. Albarracín D, & Wyer RS, Jr. The cognitive impact of past behavior: influences on beliefs, attitudes, and future behavioral decisions. *Journal of Personality and Social Psychology* 2000;79(1): 5–22
12. Strober LB. Quality of life and psychological well-being in the early stages of multiple sclerosis (MS): Importance of adopting a biopsychosocial model. *Disability and Health Journal* 2018;11(4): 555–561
13. Hernández-Ledesma AL, Rodríguez-Méndez AJ, Gallardo-Vidal LS, Trejo-Cruz G, García-Solís P, & Dávila-Esquivel FJ. Coping strategies and quality of life in Mexican multiple sclerosis patients: Physical, psychological and social factors relationship. *Multiple Sclerosis Related Disorders* 2018;25: 122-127
14. Li L, & Moore D. Acceptance of disability and its correlates. *Journal of Social Psychology* 1998;138: 13–25
15. Linkowski DC. A scale to measure acceptance of disability. *Rehabilitation Counseling Bulletin* 1971;14: 236–244
16. Stuifbergen A, Becker H, Blozis S, & Beal C. Conceptualization and development of the Acceptance of Chronic Health Conditions Scale. *Issues in Mental Health Nursing* 2008;29(2): 101-114
17. Antonak RF, & Livneh H. Psychosocial adaptation to disability and its investigation among persons with multiple sclerosis. *Social Science and Medicine* 1995;408: 1099–1108
18. Dembo T, Leviton GL, & Wright BA. Adjustment to misfortune—a problem of social- psychological rehabilitation. *Artificial Limbs* 1956;3: 4–62
19. Viane I, Crobez G, Eccleston C, Devulder J, & De Corte W. Acceptance of the unpleasant reality of chronic pain: Effects upon attention to pain and engagement with daily activities. *Pain* 2004;112: 282–288
20. Rotter JB. Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs* 1966;33(1): 300-303
21. Craig A. Resilience in people with physical disabilities. In P. Kennedy (Ed.) *The Oxford Handbook of Rehabilitation Psychology*. 2012. Oxford University Press: p: 474–491
22. Rutter M. Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *The British Journal of Psychiatry* 1985;147: 598-611
23. Gajofatto A, Donisi V, Busch IM, Gobbin F, Butturini E, Calabrese M. et al. Biopsychosocial

- model of resilience in young adults with multiple sclerosis (BPS-ARMS): an observational study protocol exploring psychological reactions early after diagnosis. *BMJ Open* 2019;9(8): e030469. doi: 10.1136/bmjopen-2019-030469
24. Wilski M, & Tasiemski T. Health-related quality of life in multiple sclerosis: Role of cognitive appraisals of self, illness and treatment. *Quality of Life Research* 2016;25(7): 1761- 1770
 25. Sofaer-Bennett B, Holloway I, Moore A, Lamberty J, Thorp T, & O'dwyer J. Perseverance by older people in their management of chronic pain: a qualitative study. *Pain Medicine* 2007;8(3): 271-280
 26. Wagnild G, & Young HM. Resilience among older women. *Journal of Nursing Scholarship* 1990;22(4): 252-255
 27. Fairley P. Mind over matter, Chapter 2. *The Conquest of Pain*. London: Michael Joseph; 1978:55-86
 28. Clark P, & Bowling A. Quality of everyday life in long stay institutions for the elderly. An observational study of long stay hospital and nursing home care. *Social Science & Medicine* 1990;30(11): 1201-1210
 29. Nickel S, von dem Knesebeck O, & Kofahl C. Self-assessments and determinants of HRQoL in a German MS population. *Acta Neurologica Scandinavia* 2018;137(2): 174–180
 30. Phillips LH, Henry JD, Nouzova E, Cooper C, Radlak B, & Summers F. Difficulties with emotion regulation in multiple sclerosis: links to executive function, mood, and quality of life. *Journal of Clinical and Experimental Neuropsychology* 2014;36(8): 831–842
 31. Mikula P, Nagyova I, Krokavcova M, Vitkova M, Rosenberger J, Szilasiova J. et al. Social participation and health-related quality of life in people with multiple sclerosis. *Disability and Health Journal* 2015;8(1): 29–34
 32. Cichy KE, Li J, RuMr.ill PD, Bishop M, & Roessler R. Non-vocational health-related correlates of quality of life for older adults living with multiple sclerosis. *Journal of Rehabilitation* 2016;82: 36–44
 33. Leonavicius R. Among multiple sclerosis and fatigue. *Neurology, Psychiatry and Brain Research* 2016;22(3-4): 141–145
 34. Khalaf KM, Coyne KS, Globe DR, Malone DC, Armstrong EP, Patel V. et al. The impact of lower urinary tract symptoms on health - related quality of life among patients with multiple sclerosis. *Neurourology and Urodynamics* 2016;35(1): 48–54
 35. Kumpfer KL. Factors and processes contributing to resilience: The resilience framework. In: Glantz MD and Johnson JL. (eds) *Resilience and Development: Positive Life Adaptations*. New York: Kluwer Academia/Plenum Publishers 1999:180-224
 36. Tough H, Siegrist J, & Fekete C. Social relationships, mental health and wellbeing in physical disability: a systematic review. *BMC Public Health* 2017;17(1): 414
 37. Costa DC, Sá MJ, & Calheiros JM. Social support network and quality of life in multiple sclerosis patients. *Arquivos de Neuro-Psiquiatria* 2017;75: 267–271
 38. Jensen MP, Nielson WR, & Kerns, RD Toward the development of a motivational model of pain self-management. *The Journal of Pain* Nov 2003;4(9): 477-492
 39. Araújo-Soares V, Hankonen N, Presseau J, Rodrigues A, & Snichotta FF. Developing Behavior Change Interventions for Self-Management in Chronic Illness: An Integrative Overview. *European Psychologist* 2019;24(1): 7–25
 40. José Sá M. Psychological aspects of multiple sclerosis. *Clinical Neurology and Neurosurgery* 2008;110(9): 868-877
 41. Telford K, Kralik D, & Koch T. Acceptance and denial: Implications for people adapting to chronic illness: Literature review. *Journal of Advanced Nursing* 2006;55: 457–464