

The Turbid Crystal Ball: Life Plans Affected by MS

Literature and Patient Narrative Compared

T Das, AA Kaptein, J Haan

Leiden University Medical Centre (LUMC), Leiden, the Netherlands

Abstract

Since multiple sclerosis (MS) has its onset at a young age, it is valuable to know how it affects life plans and future perspectives of patients. Through two narratives, this aspect is discussed in this article. The first is the autobiographical journal: *The Journal of a Disappointed Man* by WNP Barbellion, published in 1920, and the other one is from a contemporary patient. Despite the fact that both narratives are derived from different

centuries, clear similarities have been perceived in the patients' life plans and future perspectives. The narratives show that the life plans of both patients were adjusted due to physical limitations. Additionally, both patients experienced sorrows for losing the ability to perform passionate hobbies during their life. Moreover, a strong sense of uncertainty was expressed in both narratives concerning their future.

KEY WORDS:

MULTIPLE SCLEROSIS, NARRATIVES, LIFE PLANS, MEDICAL HUMANITIES

Introduction

Chronic illness can influence the course of a patient's life in undesired directions. When diagnosed with a lifelong disease at an early age, initial future hopes and dreams may be shattered. Multiple sclerosis (MS) is a disease which predominantly has its onset in young adults and can result in symptoms such as fatigue, sensory loss and coordination problems.¹ However, there is a difference between the biomedical model which describes the 'disease' MS, and the subjectively self-perceived 'illness' due to MS.² Repeatedly, studies have shown how MS patients score significantly lower than healthy controls in their perception of their quality of life.^{3,4} Still, insight into the authentic illness experience can only be given through the narratives of individual patients and is thus equally important, as the medical story, for the doctor to understand and treat the disease.⁵ As MS affects patients at a young age, it is valuable to see through patient narratives how it can affect life plans and future perspectives. Therefore, this article will attempt, through qualitative research, to elucidate this aspect of

living with the disease by analyzing the biographic writings of WNP Barbellion: *The Journal of a Disappointed Man* (1920)⁶ and a case example of a present-day patient who has been interviewed for this purpose. We show that, despite the gap of about a century, both narratives display clear similarities concerning their life plans. Apparently, the impact of MS on the patient's future perspectives has remained the same throughout the ages.

Historical and Contemporary Perspective

Many novels and biographies on MS have been written; Barbellion's *The Journal of a Disappointed Man* (1920) is the first autobiographical journal about the disease.⁶⁻⁸ It is important to emphasize that despite the diagnostic and therapeutic improvements related to MS, this journal can still be a valuable source for understanding the patient's experiences. Barbellion's 20th century journal has been selected for analysis in this article, because it features

excerpts from the author as a 13 year old until 2 years before his death at the age of 27. This way the reader becomes familiar with the author's life before and during the disease directly through his observations in a chronological structure.⁹ Throughout the journal, the reader follows Barbellion's difficult professional career as a naturalist and the development of his illness.

Barbellion's journal has been compared with a contemporary narrative derived from an interview with 'April,' a 52-year-old Dutch woman who has been living with MS for approximately 30 years. To understand life plans and future perspectives, it is interesting to compare two narratives from ambitious patients, as it is our expectation that these persons often think about the future and plan their life in such a way as to fulfill their life goals. A disease like MS prevents or hinders certain goals from being achieved, thus making the limits of the patient's life plans noticeable. April appeared to be suitable for the narrative analysis because of the similarities between her diagnosis history and that of Barbellion, as well as her ambitious personality.

Common Grounds

When comparing the two narratives, three main themes became apparent, and these will be addressed in this paper. First, there is the professional component in the life plans. Second, it appeared that the disease had taken away possibilities from the patients to exercise hobbies or other passions. Third, a feeling of uncertainty about the future was expressed in both narratives.

Professional Life Plan

It is easy to perceive that the narratives of both Barbellion and April stem from ambitious patients. Barbellion already described as a young boy, before any illness was present, how ambitious he was: 'What heaps of things to be done! How short the time to do them in!' (p12). Similarly, April expressed her eagerness to continue working against her doctor's advice, although she had already received her diagnosis of MS. She continued to function as a nurse for several years until it became too exhausting for her. Forced by her illness, she eventually left her professional career, and focused since on an

occupation which she found more worthwhile: motherhood. Determined to achieve a goal, she pictured that being a mother meant more to her than a professional aspiration: '*For if I could not have children, I could basically do nothing.*'. Despite a temporary worsening of symptoms during her pregnancy, she is currently a proud mother of two children, thereby achieving this major aim in her life. Similarly, Barbellion was forced to realize that his illness would not allow him to live a long life, thereby eliminating his chances to be successful at his chosen profession as a naturalist: '*The haven of successful accomplishment remains as far off as ever. Oh make haste!*' (p105); '*Why can't I either have a first-rate disease or be a first-rate zoologist?*' (p106). In fact, the only way he could become a great scientist and simultaneously a celebrated author, was through a scientific literary study of himself as an MS patient, being the 'pathology specimen'.⁸ Thus, he realized that his journal could be the only key to fame, and thereby his 'fleet to immortality': '*...Am developing a passionate belief in my book and a fever of haste to complete it before the congé définitif.*' (p81). In addition, he expressed his regret about the possibility that his journal, and with that, his entire existence, would remain unnoticed after his death: '*It would be cruel if even after I have paid the last penalty, my efforts and sufferings should continue to remain unknown or disregarded.*' (p255). Apart from achieving literary fame, he also wanted his wife and daughter to have some income through the sales of his journal.^{7,8} Thus, both April and Barbellion expressed a desire to leave something behind of themselves, either through a printed journal, and the associated fame and income, or through progeny. These two unique examples reveal that initial professional plans get diluted because of physical limitations and are replaced by other goals in life.

Losses Experienced

It has previously been described that for an acute disease, plans and activities can temporarily be put on hold, but recommence once the disease period has passed. However, this so-called restitution narrative, does not seem to apply to chronic diseases.⁵ Once the sickness has forced a modification of the patient's life plan, it is likely that

a grieving process will continue to exist over the original life plan.⁵

This aspect was clearly visible in the two narratives, as they indicate that at a certain moment in time, hobbies or passions could not be practised any longer. As an illustration, Barbellion's greatest passion was writing. He expressed his regret about the disease, and the way it slowly appeared to take away his abilities: *'It is a consummate vengeance this inability to write... How amusing that in this agony of isolation such an aggressive egotist as I should have his last means of self-expression cut off. I am being slowly stifled.'* (p303).⁶ Likewise, April mentioned the gradual progression of the disease as it took away her abilities and passions: *'The disease takes away everything of oneself. I am currently facing the maximum of what I can tolerate.'*⁶ During an emotional part of the interview, April recalled her inability to practise horseriding due to her coordination problems; she declared this to be her biggest loss due to the disease, together with no longer being able to take care of her horse. Feelings of guilt prevailed as she said: *'It is simply killing to realize that you can't be there for your horse any longer.'*

On a more positive note, April has developed a coping strategy to lighten the feeling of gradually losing her abilities. Instead of continuously relating to her limitations, she accepted her physical restraints and tries to focus on the activities which she is still able to do: *'When I go walking, I know exactly when to take rests in order to not overburden my body. If I have done too much, I know the following day will be "payday".'* Barbellion, on the other hand, stated that he was content with his misfortune: *'We feel that a calamity by overtaking us has distinguished us from our fellows... A man with a grievance is always happy.'* (p68).⁶ He did think of his illness in a positive way at times: *'It is fortunate I am ill in one way for I need not make my mind up about this war.'* (p181); Paradoxically, despite having MS, he lived relatively longer than his peers who were sent to the front during World War I. Barbellion expressed mixed emotions concerning this fact: *'I feel almost ashamed of myself because I am not yet dead seeing that so many of my full-blooded contemporaries have perished g alloin this war. I am so grateful for beinwed to live so long that nothing that happens to me except death*



Figure 1. Portrait of half-affected face painted by the patient 'April' © 2011

could upset me much.' (p213).⁶ As a last coping strategy, it has been speculated that by the mere act of writing his journal, it gave him an opportunity to express himself and retain his mental strength:⁷ *'These precious journals! Supposing I lost them! It would be the death of my real self and... I should probably commit suicide.'* (p170).⁶

Uncertain Future

Both patients expressed their uncertainty about their future. The disease course of MS is still difficult to predict for individual patients.¹⁰ Prognostically, there is little that can be offered to the patient and studies revealed this to be one of the greatest challenges for the individual.¹¹ Barbellion, for example, expressed that: *'The future has nothing for me.'* (p151).⁶ *'I have never at any time lived with any sense of security.'* (p134). Barbellion was a follower of the egotist intellectual movement of the 20th century, and as a consequence he continuously asserted the importance of his individual being and awareness.^{7,8} This could be the reason that many fragments are about his death: *'As an egotist I hate death because I should cease to be I.'* (p63).⁶ As reflected in his journal, it is obvious that initially he was afraid of death and *'hated it bitterly. But now that my end is near and certain, I consider it less and am content to wait and see.'* (p286).⁶

Similarly, April already expressed her uncertainty about the course of MS to her doctor as well: *'Doctor, the crystal ball in which you look is turbid.'* When discussing her future, she accepted that there is no cure and would rather *'continue slacking like this in this state, than deteriorate any further'*.

It thus appears that she prefers to endure the current state of the disease, because it simultaneously gives her a sense of certainty. Progression of the disease would be very hard for her to accept, since she has a strong feeling that she has already given up so much of herself due to the disease: *'If such a state may ever arise, I would ultimately desire euthanasia instead'*. Similarly, Barbellion stated the same desire a century ago: *'I wish I possessed the wherewithal to end it at my will. It would be well to be able to control this: the time, the place, and the manner of one's exit.'* (p286).⁶

A great deal of uncertainty might be due to the progressiveness and suddenness of the disease. April stated: *'It simply happens to you. I never drank alcohol or smoked, I used to live a healthy and active life, so why me?... All of a sudden, I was blind.'* Likewise, Barbellion wished that *'life were an art and not a lottery.'* (p266),⁶ thereby illustrating the acuteness of his misfortune.

Conclusions in Context

The most important results are that, at least for these two patients, initial professional life plans of MS patients appear to be diluted and adjusted due to progression of the disease. Additionally, both patients expressed disappointment about the progressive course of the disease, which took away their abilities to perform their original passions in life. Third, the future appeared uncertain for them due to the unpredictability of the disease. Living with such uncertainty can be difficult for patients, but it seems that sooner or later, a certain acceptance of the disease keeps them mentally stable.

In the past, there have been qualitative studies on the losses that are experienced by MS patients. These findings appeared to be similarly detectable in the physical and social component,^{12,13} as described by Barbellion and April. However, there have not been extensive studies yet on the life plans of MS patients.¹⁴ Although this study has only looked at two narratives, it confirms the importance of relating classic narratives with current-day patients, because many similarities between them prevail. On the whole, it could be a useful practice for practitioners to relate memorable literary narratives to narratives of their patients.¹⁴ Practitioners could improve their understanding and in that way inspire and support patients.

Acknowledgements

We would like to sincerely thank the anonymous patient 'April' for her time and effort to share her medical life story with us.

Conflict of Interest

No conflicts of interest were declared in relation to this article.

Address for Correspondence

Tridib Das

Leiden University Medical Centre (LUMC)

Medical Psychology LUMC

Postzone J9, PO Box 9600, 2300 RC

Leiden, the Netherlands

Tel: +31 6 4963 4144

E-mail: t.das@umail.leidenuniv.nl

Received: 10 August 2010

Accepted: 1 September 2010

References

1. Compston A, McDonald IR, Noseworthy J, Lassmann H, Miller DH, Smith KJ et al. *McAlpine's Multiple Sclerosis*, 4th ed. New York: Churchill Livingstone, 2003; pp199, 200.
2. Robinson I. Personal narratives, social careers and medical courses: analyzing life trajectories in autobiographies of people with multiple sclerosis. *Soc Sci Med* 1990;**30**:1173-1186.
3. Putzki N, Fischer J, Gottwald K, Reifschneider G, Ries S, Siever A et al. Quality of life in 1000 patients with early relapsing-remitting multiple sclerosis. *Eur J Neurol* 2009;**16**:713-720.
4. Miller A, Dishon S. Health-related quality of life in multiple sclerosis: The impact of disability, gender and employment status. *Qual Life Res* 2006;**15**:259-271.
5. Brody H. *Stories of Sickness*, 2nd ed. New York: Oxford University Press, 2003; pp10, 59, 72-73, 106-107.
6. Barbellion WNP (pseudonym for Bruce Frederick Cummings). *The Journal of a Disappointed Man*. London: Chatto and Windus, 1920.
7. Arts K. Living in the grave. In: *Tante krijgt een zenuwtoeval* Haan J (ed). Overveen: Belvédère Publishing, 2006; pp15-26.
8. Swiderski RM. *Multiple Sclerosis Through History and Human Life*. Jefferson, NC: McFarland & Company Inc., 1998; pp105-116.
9. Williams G. The genesis of chronic illness: narrative reconstruction. *Social Health Illness* 1984;**6**:175-200.
10. Sayao AL, Devonshire V, Tremlett H. Longitudinal follow-up of 'benign' multiple sclerosis at 20 years. *Neurology* 2007;**68**:496-500.
11. Malcolmson KS, Lowe-Strong AS, Dunwoody L. What can we learn from the personal insights of individuals living and coping with multiple sclerosis? *Disabil Rehabil* 2008;**30**:662-674.
12. Edmonds P, Vivat B, Burman R, Silber E, Higginson IJ. Loss and change: experiences of people severely affected by multiple sclerosis. *Palliat Med* 2007;**21**:101-107.
13. Hakim EA, Bakheit AM, Bryant TN, Roberts MW, McIntosh-Michaelis SA, Spackman AJ et al. The social impact of multiple sclerosis—a study of 305 patients and their relatives. *Disabil Rehabil* 2000;**22**:288-293.
14. ter Meulen BC, Haan J, Meulenbergh F. Narrative neurology: Access to the patient's experiences. *Ned Tijdschr Geneesk* 2009;**153**:A304.