Giving meaning to illness: An investigation of self-defining memories in patients with relapsing-remitting multiple sclerosis patients

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ABSTRACT

Multiple sclerosis (MS) patients are often unable to adequately fulfill their established roles due to physical disabilities and cognitive changes, making this chronic illness particularly threatening to personal identity. Twenty-five MS patients and 25 healthy controls were asked to recall five self-defining memories (SDM). Overall characteristics of SDM did not differ between patients and controls; MS patients displayed preserved capacity to draw meaning upon past events. Moreover, almost two-thirds of MS patients mentioned at least one illness related SDM and about 25% of patients’ SDM referred to MS. These memories were experienced as more negative and associated with more tension than other SDM but led toward more positive emotion and less negative emotion over time; they were also more central and more integrated to the personal identity. We concluded that self-challenging events due to MS may trigger both cognitive and emotional processes enabling the integration of illness in patients’ self-representations.

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1. Introduction

Multiple sclerosis (MS) is the most frequent chronic neurological condition in young adults. It is characterized by a wide variety of clinical symptoms (physical disability, cognitive impairment, mood disturbances, fatigue and pain) that can have severe psychosocial consequences (e.g. difficulties in carrying out daily living activities, unemployment, increased dependency on the partner, etc.). Relapsing-remitting MS represent the most common form of the disease (85% of the cases) with alternating phases of relapse of symptoms and partial or complete remission, and no disease progression between relapses. As the disease progresses, functional disabilities accumulate. Up to now, no curative treatment is available.

MS diagnosis is typically established in patients aged between 20 and 40 years, i.e. at a time in life when key life choices are made (such as whether to settle down, have children and build up a career) or when family and professional...
responsibilities are at their peak. Thus, this chronic illness induced profound changes in the patient's everyday life and in his/her self-perception. MS challenges the patient's self belonging to the pre-onset of the illness. It may lead to "biographical disruption" (Bury, 1982) and constitute a devastating experience for some patients (Charmaz, 1983), whereas others exhibit capacities to positively integrate the illness into the post-onset sense of self (Boeije, Duijnstee, Gypdonck, & Pool, 2002; Couture, Brassard, & Brault-Labbé, 2014; Irvine, Davidson, Hoy, & Lowe-Strong, 2009; Pakenham, 2008). Better understanding on how illness affects the patient's self would be of great interest to grasp whether the patient is in the process of integrating his/her illness or not. This point seems important with a view towards psychotherapy.

One way of addressing this issue is to study the illness related self-defining memories (SDM, Singer & Moffitt, 1991). SDM are memories of highly significant life events that help to explain who one is as an individual with his/her own characteristics. SDM are vivid, had been thought about many times, are closely linked to other related memories, and revolve around the most central goals and conflicts in an individual's life. These memories must be at least one year old and could have either a positive or negative valence; the critical condition is thought that they originate strong feelings (Blagov & Singer, 2004; Singer, Blagov, Berry, & Oost, 2013). SDMs are thought to ground identity. Importantly, they can only be integrated into a coherent representation of the self if they are associated with "meaning making" (Blagov & Singer, 2004). This cognitive process refers to the ability to learn lessons about past events. It allows individuals to stand back from a past event and to realize how this event has changed the way they see themselves, others or the world. In times of biographical change, an effort for meaning making is necessary to ensure a sense of self-continuity (Habermas & Köber, 2015). At an emotional level, McAdams (2001) described "redemption" sequences, i.e. narratives with change from negative to positive emotion, and "contamination" sequences, i.e. narratives with a shift from positive to negative emotion. Wood and Conway (2006) compared emotions experienced during recall of SDM and emotions that participants felt when the events occurred and described a "benefaction effect" (BE), i.e. more positive emotion over time. Both the process of redemption and the pattern of benefaction play a major role for integrating difficult past events into a coherent life story (Berna et al., 2011a, 2011b; McAdams, 2001; Wood & Conway, 2006).

How MS patients strive to maintain a positive and coherent sense of self in the face of chronic illness has already been explored by means of questionnaires (Pakenham, 2007, 2008) or semi-structured interviews (Boeije et al., 2002; Couture et al., 2014; Irvine et al., 2009) that directly addressed the relationship between self and illness. However, to our knowledge, no study has explored whether and how the illness is present in SDM of patients diagnosed with MS, and how SDM are integrated into the self when they relate or not to the illness.

Our first aim was to compare the characteristics of patients’ SDM with those of healthy subjects. Our second purpose was to focus on patients’ illness-related SDM to better understand how illness affects the patient’s identity. Our assumption is that SDM linked with MS promote more self-reflection and are consequently better integrated into the self than other SDM. Moreover, we examined emotional and self-related factors involved in the integration of illness-related SDM. Lastly, we explored the clinical and neuropsychological correlates of meaning-making.

2. Methods

2.1. Participants

Twenty-five patients with definite MS according to the McDonald criteria (McDonald et al., 2001) were recruited at the Neurology Unit of two French hospitals. They were all treated by natalizumab (Tysabri®). Inclusion criteria were the diagnosis of a relapsing remitting disease course, an Expanded Disability Status Scale (EDSS; Kurtzke, 1983) score ≤ 5 (corresponding to mild functional disability), no recent exacerbation of MS symptoms, an absence of major signs of depression according to the Montgomery and Asberg Depression Rating Scale (Bondolfi et al., 2010; Montgomery & Asberg, 1979; clinical threshold score ≥ 15). We excluded depressed MS patients in order to avoid alteration of SDM characteristics due to depression and not specifically to MS (Harkness, 2011).

Twenty-five healthy controls matched for gender, age and education level also took part to the study. Exclusion criteria for all the participants were poor knowledge of French and documented psychiatric illness, neurological disorder (other than MS for the patients) or any other chronic illness.

Table 1
Demographical and clinical data.

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<tr>
<th></th>
<th>MS patients</th>
<th>Healthy controls</th>
<th>Statistical analysis</th>
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<tbody>
<tr>
<td>N</td>
<td>25</td>
<td>25</td>
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<tr>
<td>Gender (ratio female/male)</td>
<td>19/6</td>
<td>19/6</td>
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<tr>
<td>Mean (SD)</td>
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<tr>
<td>Age (in years)</td>
<td>42.5 (9.3)</td>
<td>40.8 (10.1)</td>
<td>t = 0.61; p = 0.54</td>
</tr>
<tr>
<td>Education level (in years)</td>
<td>13.4 (2.7)</td>
<td>13.7 (2.1)</td>
<td>U = 295.0; p = 0.74</td>
</tr>
<tr>
<td>Duration of MS (in years)</td>
<td>13.9 (8.6)</td>
<td></td>
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<tr>
<td>Age at onset (in years)</td>
<td>28.6 (9.5)</td>
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</table>
Demographic and clinical data are presented in Table 1. Male and female patients did not significantly differ in demographic and clinical variables. All subjects gave prior informed consent and we complied with the APA ethical standards.

2.2. Materials

2.2.1. Neuropsychological assessment

All patients completed a standard neuropsychological examination in order to assess their cognitive status, bearing in mind that general intellectual capacities and language should be preserved to ensure normal grasping of instructions. Likewise, impaired executive functions are often observed in MS and might interfere with meaning making capacities.

Verbal IQ was estimated with the Wechsler Adult Intelligence Scale-III (Wechsler, 1997), short form (Axelrod, Ryan, & Ward, 2001) and premorbid IQ with the French adaptation of the National Adult Reading Test (Mackinnon & Mulligan, 2005). Nonverbal reasoning was assessed with the Advanced Progressive Matrices, Set 1 (Raven, Raven, & Court, 1998). Language was examined by means of a stringent naming test (Déno 100, Kremin, 2002). Verbal anterograde memory was assessed using the Rey Auditory Verbal Learning Test (RAVLT; Rey, 1964). Finally, executive functions were probed with the phonological fluency test (National Hospital, London), Stroop test (Stroop, 1935) and Brixton Spatial Anticipation Test (Burgess & Shallice, 1997).

2.2.2. Self-defining memories questionnaire

A French adaptation of the questionnaire initially proposed by Singer and Moffitt (1991) was used (Berna et al., 2011a, 2011b) to elicit the narration of five SDM. This adaptation consisted in the participants having 7 ± 2 days to think of their five most important memories instead of retrieving their memories, immediately as originally done by Singer and Moffitt (1991). As all MS patients were examined at the hospital, the aim of the above mentioned modification was to limit the likelihood of selecting events related to their illness, owing to the context of the examination.

A self-defining memory was defined to the participants as follows: (a) It is at least 1 year old; (b) It is a memory from your life that you remember very clearly and that still feels important to you even as you think about it; (c) It is a memory that helps you to understand who you are as an individual and might be a memory you would tell someone else if you wanted that person to understand you in a basic way; (d) It may be a memory that is positive or negative, or both, in how it makes you feel now. The only important aspect is that it leads to strong feelings; and (e) It is a memory that you have thought about many times. It should be familiar to you like a picture you have studied or a song you have learnt by heart.

2.2.3. Positive And Negative Affective States (PANAS; Watson, Clark, & Tellegen, 1988; French version: Gaudreau, Sanchez, & Blondin, 2006)

This adjective checklist comprises two 10-item subscales of positive (active, alert, attentive, determined, enthusiastic, excited, inspired, interested, proud, and strong) and negative (afraid, ashamed, distressed, guilty, hostile, irritated, jittery, nervous, scared, and upset) affects, the intensity of which is rated by participants on a 5-point Likert scale (with 1 = not at all or very slightly and 5 = extremely). Participants were asked to complete this questionnaire twice for each SDM. First, they had to rate how they felt when the self-defining event occurred, i.e. their “recalled emotions”, and second how they currently felt when remembering the event, i.e. their “current emotions”. Cronbach’s alpha coefficient for the current study was 0.86 for positive affect and it was 0.90 for negative affect for “recalled emotions” and 0.90 for positive affect and 0.89 for negative affect for “current emotions”. These coefficients were comparable with those obtained for both the original (0.89 for positive affect and 0.85 for negative affect) and the French versions (0.90 for positive affect and 0.80 for negative affect).

2.2.4. Centrality of Events Scale (CES), short form

The CES measures how central an event is to a person’s identity and life story, i.e. the extent to which an event forms a reference point for self-understanding, the attribution of meaning to other experiences in a person’s life and the generation of expectations for the future (for examples, item 5: “This event permanently changed my life”, item 7: “This event was a turning point in my life”). Items were rated on a scale of 1 (totally disagree) to 5 (totally agree). The short form is composed by the seven questions with the highest correlations with the sum of the other questions of the 20-item scale and had a Cronbach’s alpha coefficient of 0.88 (Berntsen & Rubin, 2006). Internal consistency for the current sample was excellent (Cronbach’s alpha = 0.90).

2.3. Procedure

After the first session, in which neuropsychological baseline examination was carried out, patients were given one week to find five memories that best fitted the SDM criteria according to the aforementioned description of SDM. Written instructions, mentioning the characteristics of SDM were given to participants. They were instructed to write the title and details of each SDM. The second session took place 7 ± 2 days later. Patients were asked to evoke each SDM out loud and to date it. After their narrative, patients were asked to rate the PANAS twice successively, assessing firstly the intensity of the emotions they had felt at the time of the event (i.e., “recalled emotions”) and secondly their current emotions when remembering the event at hand. Finally, they were asked to rate the CES for each memory. Healthy controls completed the SDM task only.
2.4. Scoring

2.4.1. Self-defining memories

Each SDM was scored for specificity, content, meaning making, redemption/contamination and tension.

2.4.1.1. Specificity. Each SDM was coded as nonspecific (0) or specific (1). A SDM was rated as specific if it described an event that happened at a particular place and time and lasted less than a day. Non-specific memories included repeated and/or extended events.

2.4.1.2. Content. Content is the principal theme emphasized in the narrative. It was distinguished in seven categories (as described by Thorne & McLean, 2001): 1. Life-threatening events (narratives that refer to deaths, accidents, injuries, sexual or physical assaults to oneself or another person), 2. Recreation/exploration (narratives centered on hobbies, parties, traveling, holidays or sporting activities), 3. Relationships (include first love, interpersonal conflict, separation, reconciliation), 4. Achievement (either one’s own or one’s group/family effortful attempts at mastery or accomplishment with regard to physical, material, social, or spiritual goals, irrespective of the outcome, for example passing or failing an exam, learning to drive), 5. Guilt/shame (guilt about lying or hurting someone), 6. Drug/alcohol/tobacco use (first experience of smoking or taking drugs, or getting very drunk), and 7. “Event not classifiable” (included any narrative that did not fit well into the above categories).

2.4.1.3. Integrative meaning. An integrative SDM is one in which the participant makes explicitly meaning out of an event. Meaning making was considered to be present when participants took a step back from narrative events and descriptions to make an additional statement about the significance or meaning of the memory. For example, "I got some problems of sensitivity in my feet, and my general practitioner advised me to undergo an MRI. So I did it. The resident, who carried out the examination, callously informed me that there were spots, in my brain. The neurologist explained afterwards that they were plaques of demyelination seen in MS. I was devastated, it was a turning point. Since that precise moment I have changed my way of seeing things, my vision of the future is changed. I live with the sword of Damocles...".

A non-integrative SDM contained only the event description (Singer & Blagov, 2000). Each SDM was coded for the absence (0) or presence (1) of meaning making.

2.4.1.4. Tension. Each SDM was also coded for the presence (1) or absence (0) of tension. Tension was defined as an explicit reference to discomfort, disagreement, or unease during the narration of the event (Thorne, McLean, & Lawrence, 2004).

2.4.1.5. Redemption/contamination. A SDM was coded as “redemption” if the narrative included a negative event (e.g., a life threatening illness) followed by specific positive consequences (e.g. seeing oneself as a stronger person because of the illness experience) and as “contamination” if a positive event goes suddenly bad (McAdams, Reynolds, Lewis, Patten, & Bowman, 2001).

2.4.1.6. Illness-related SDM (only for patients). Each narrative was coded as being related to MS or not. Illness-related SDM either explicitly evoke MS or suggest a direct link with the disease without mentioning MS (for example visual difficulties that prevent a patient from driving or inability to continue horse riding due to pain). Thus, they could refer to MS diagnosis or others aspects of the disease (first attack, functional disabilities or treatment), but also to “benefit finding” (Mohr et al., 1999)/“victories over the illness” (Charmaz, 1983; for example obtaining a degree or a job, getting married or becoming mother despite MS).

Two independent raters coded responses for each SDM. The agreement between the two raters was very good (Kappa coefficient was >0.80 for all SDM measures). When the two ratings differed, the final rating was made following discussions between the two raters.

2.4.2. Benefaction effect

For each SDM, we compared “recalled” and “current” emotions scores (PANAS) and calculated a “benefaction effect” score by adding up the absolute values for the increase in positive emotions and reduction in negative emotions between the time the event occurred and the time of remembering (see, Wood & Conway, 2006). Thus, we applied the following formula: \[ \text{BE} = (\text{score of positive “current emotions”} - \text{score of positive “recalled emotions”}) - (\text{score of negative “current emotions”} - \text{score of negative “recalled emotions”}). \]

2.5. Statistical analyses

The data were analyzed for normal distribution with the Shapiro-Wilk test and for homogeneity of variance with the Levene test. Subsequently, data were compared between groups using independent t-tests unless the normality and homoscedasticity assumptions were not met, in which case we applied Mann-Whitney U test. Categories of content were
compared between groups using Chi-square tests. In order to analyze the characteristics of memories across groups, a multilevel statistical analysis was used, which is particularly relevant for autobiographical memory studies because it allows memories to be treated as the statistical unit while taking into account the intra-subject variance and the fact that memories are not independent in a given individual (Wright, 1998). The multilevel model assigned memories to level 1 and participants to level 2, and the analyses were performed using the MLwiN software, version 2.10. Whenever significant interactions were observed, post hoc analyses were performed separately in each group. The relationships between percentage of memories associated with integrative meaning and cognitive scores were analyzed by means of the Spearman’s correlation tests depending on the distribution and the homogeneity of variance of the data.

3. Results

3.1. Neuropsychological assessment

Mean scores for the MS patient group are summarized in Table 2. None of our patients presented with general intellectual capacity impairment. By considering the criterion of 2 standard deviations below the normative mean to determine impairment, none of our patients was impaired on the Stroop test, the Rey Auditory Verbal Learning Test for total mean number of words and only one patient was impaired on the delayed recall score. Naming capacities on visual confrontation were preserved in all patients. On the contrary, six of them performed below the cut-off in phonological verbal fluency, revealing impaired abilities to retrieve information from semantic memory. Men and women did not significantly differ in performance on cognitive tests.

3.2. Characteristics of SDM in MS patients vs. healthy controls

They are presented in Table 3. No significant difference was observed between the two groups for any of the studied variables (p > 0.05 in all cases).

Secondary analyses were conducted in order to examine further how emotional (benefaction effect, BE) and self-related (centrality of events, CES) factors of memories varied according to the presence or absence of integrative meaning in memories. Both BE and CES scores were subjected to separated analyses of variance (ANOVA) with group (patients vs. controls) and meaning making (present vs. absent) as predictor variables. These analyses revealed that the BE score was significantly higher in events associated with meaning making (p < 0.001) and that this difference was more pronounced in patients in comparison with controls as shown by a significant interaction between meaning making and group factors (p = 0.02). The CES score was also significantly higher in events associated with meaning making (p = 0.03) but did not differ across groups and the interaction was not significant (all ps > 0.10).

<table>
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<td>Neuropsychological baseline examination scores for the MS patient group.</td>
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All mean scores were the normal range (in comparison with the normative data of each test: 5th percentile or cut-off depending on the test).

<sup>a</sup> Wechsler Adult Intelligence Scale-III, (Wechsler, 1997); short form, (Axelrod, Ryan & Ward, 2001).
<sup>b</sup> F-NART, French National Adult Reading Test; (Mackinnon and Mulligan, 2005).
<sup>c</sup> Advanced Progressive Matrices, Set 1; (Raven, Raven & Court, 1998).
<sup>d</sup> Rey Auditory Verbal Learning Test; (Rey, 1964).
<sup>e</sup> Kremin (2002).
<sup>f</sup> National Hospital, London.
<sup>g</sup> Stroop (1935).
<sup>h</sup> Burgess and Shallice (1997).
3.3. Characteristics of MS-related SDM vs. other SDM in the patient group

Sixteen out of 25 patients (64%) mentioned at least one SDM related to their illness. Interestingly enough, only 1 out of 6 male patients (16.7%) reported MS-related SDM, whereas 15 out of 19 (78.9%) female patients evoked illness-related memories (Yates Chi-2 = 1.10, p = 0.29). Further, 25.6% of the patients’ SDM (32/125) were categorized as related to their illness. Regarding patients’ illness-related SDM, 31.2% (10/32) referred to the MS diagnosis, 34.4% (11/32) referred to other aspects of the disease and 34.4% (11/32) referred to “victories over the illness”. None of our patients reported more than 3 SDM related to MS.

Characteristics of illness-related SDM vs. other SDM in the patient group are presented in Table 4. Percentages of meaning making, tension, negative events and CES were significantly higher in illness-related SDM than in other SDM (p < 0.05 in all cases), but no difference was observed for BE.

Further ANOVAs compared both BE and CES scores according to the presence of meaning making and to the presence of illness content. These analyses confirmed that the BE score was significantly higher in memories associated with meaning making (p = 0.014) but the interaction between illness and meaning making factor was not significant (p > 0.09). The CES score was higher in memories associated with meaning making and those related to the illness but these differences were marginally significant (p = 0.053 and p = 0.066, respectively). The interaction between meaning making and illness factors was significant (p < 0.001) and explained by a particularly high CES score of memories related to the illness that were associated with meaning making in comparison with other memories (all ps < 0.001).

| Table 4 | Characteristics of the patients’ self-defining memories (SDM) related or not to the illness. |
|---------------------------------|---------------------------------|---------------------------------|
| Illness-related SDM (n = 32) | Other SDM (n = 93) | Statistical analysis |
| Self defining memories | | |
| Specific event | 68.8% | 75.0% | ns |
| Presence of integrative meaning | 43.8% | 15.2% | p < 0.05 |
| Presence of tension | 78.1% | 34.8% | p < 0.05 |
| Negative events | 59.4% | 37.0% | p < 0.05 |
| Redemption in negative events | 0% | 5.5% | ns |
| Contamination in positive events | 15.4% | 11.5% | ns |
| PANAS | | | |
| Recalled emotion (positive and negative) | 55.0 (12.6) | 52.3 (15.1) | ns |
| Current emotion (positive and negative) | 44.3 (12.6) | 42.2 (14.5) | ns |
| Centrality (CES) | 3.9 (1.1) | 3.3 (1.1) | p < 0.05 |

PANAS: Positive And Negative Affective States; CES: centrality event scale.
3.4. Correlation analyses

Correlation analyses carried out in the patient group showed a significant relation between phonological verbal fluency scores and percentage of memories with integrative meaning (r = 0.43, p = 0.04). No other significant correlation was found between percentage of integrative meaning and cognitive scores or clinical variables (duration of MS, age at onset).

4. Discussion

This study is the first to address the issue of SDM in non-depressed patients with relapsing remitting MS (and to our knowledge, the first to investigate SDM in a chronic somatic illness population) and to examine the emotional and self-related factors involved in the integration of SDM related to illness in MS patients.

4.1. Characteristics of SDM in MS patients vs. healthy controls

Our results highlighted that overall characteristics of SDM did not differ between patients and controls.

Although autobiographical memory impairment had been demonstrated in relapsing-remitting MS patients using tasks that do not explicitly investigate memories highly relevant to personal identity (Ernst, Blanc, De Seze, & Manning, 2015; Ernst et al., 2013, 2014), our patients reported as many specific SDM as the healthy controls. The suggestion that AM impairment in MS patients is likely caused by a deficit of retrieval strategies rather than loss of personal recollections is coherent with our findings. Indeed, access to SDM might be facilitated due to frequent retrievals, as SDM involve essential themes and concerns for the self. An alternative interpretation is that the task of SDM does not require memories to be specific; it assesses the spontaneous tendency to retrieve specific events rather than the ability to retrieve specific events. Our results are in line with previous findings in other clinical conditions like schizophrenia. In fact, several studies (Berna et al., 2011a, 2011b; Raffard et al., 2009: Raffard et al., 2010) did not find less specific SDM in patients with schizophrenia although these patients have more difficulty retrieving specific episodes of their past (see Berna et al., 2016 for a meta-analysis).

Our results showed that SDM content did not significantly differ between the two groups. Not surprisingly, contrary to what has been observed in patients with schizophrenia (Raffard et al., 2009) or autism spectrum disorders (ASD; Crane, Goddard, & Pring, 2010), MS patients did not report fewer memories about past achievements than healthy controls. It is also worth noting here that MS does not seem to prevent patients from experiencing successful events as defining their self.

Furthermore, patients were not impaired in their ability to give a meaning to their SDM. Meaning-making plays a fundamental role in the construction of the self, in that it enables a person to update his/her self-concept with newly acquired information (Singer, 2004). It is generally predictive of psychological health, optimal adjustment, well-being and personal growth (Singer & Conway, 2011; Singer et al., 2013). The ability of meaning making was also impaired in patients with schizophrenia (Berna et al., 2011a, 2011b; Raffard et al., 2009; Raffard et al., 2010) or with autism spectrum disorder (Crane et al., 2010), two conditions also characterized by dramatic alteration of self. Interestingly and in line with the results found by Berna et al. (2011a), a significant positive correlation between meaning making capacities and some measure of executive functions was observed suggesting that metacognitive capacities (as those involved during meaning making) partially relate on more basic executive function. One may thus hypothesize that MS patients characterized by impaired executive functioning may have more difficulty drawing meaning upon their SDM, but as executive functions of the patients included in our sample were relatively preserved, further studies with patients suffering from more severe cognitive impairment may be conducted to confirm our assumption.

Turning to the emotional level, MS patients did not evoke more SDM associated with tension or negative events than controls. They did not differ from controls in term of redemptive or contaminative memories. It should be noticed that we excluded depressed MS patients as SDM of currently depressed people were more likely to contain contamination sequences and demonstrate negative affect (Harkness, 2011). No difference was observed for emotions intensity or benefaction effect score between groups; both patients and controls feel more positive emotion about the event now, compared with how they recall feeling at the time. Moreover, events recalled by the patients did not differ from those of healthy controls in terms of centrality.

Further analysis revealed that BE score was higher in events associated with meaning making especially in the MS group, suggesting that meaning making was associated with positive emotional integration of the event. This point is worth mentioning as recent studies have challenged the view that “meaning making is always good” by showing that meaning making associated with negative life events may also support negative enduring self-view with deleterious consequences for the self (Waters, Shallcross, & Fivush, 2013). Hence, learning a lesson from a past experience leads people to feel a more positive emotion about the event now, compared with how they recall feeling at the time of its occurrence. Events associated with meaning making were also more central.

4.2. Characteristics of MS-related SDM vs. other SDM in the patient group

Probably, the most interesting finding of the present study, is that MS patients’ identity is strongly influenced by their illness. Indeed, almost two-thirds MS patients recalled at least one illness-related SDM and about one third of all patients’
SDM referred to MS. However, we observed that only one man (out of six) evoked illness-related SDM. It seems possible that men did not report MS related SDM because they were avoiding the memory in order to minimize any distress associated with recalling it. Although men and women did not significantly differ in demographical, clinical and cognitive variables, our male sample was very small (this is not surprising as MS is two to three times more common in women than in men) and consequently our results have to be interpreted cautiously. Nevertheless, some studies reported that men differ from women in how they experience MS (Casetta et al., 2009; Upton & Taylor, 2015). Despite severe physical impairment, women suffering from MS appeared to maintain psychological and mental well-being to a greater extent than men (Casetta et al., 2009). Having MS often means that the individual must take on a dependent and passive role (Boeije et al., 2002; Shevil & Finlayson, 2006). For men, this can be especially difficult since it is inconsistent with the independent role they generally occupy (Casetta et al., 2009). Other studies also showed that men are more likely than women to cope with stress by denying the problem or avoiding it. However, in the case of personal health stressors, there is no strategy that men used more than women (Tamres, Janicki, & Helgeson, 2002).

Our study also showed that none of our MS patients evoked more than 3 illness-related SDM. Leventhal, Idler, and Leventhal (1999) argue that, in the context of a chronic illness, psychological health is associated with the ability to retain (or perhaps develop) aspects of the self that are not illness related. Bogart (2015) reported that integration of one’s disability into the self was associated with lower psychological distress in patients with MS.

Furthermore, although illness-related memories were more linked with negative affect and associated with more tension than other SDM, they were also more integrated to the self and associated with a higher score of centrality. One may first interpret this result in line with the view of chronic illness as representing a “biographical disruption” in the life of patients (Bury, 1982). Charmaz (1983) has also reported the destructive effects of illness on identity. However, our findings also highlight that self-challenging events due to the illness trigger both cognitive and emotional processes enabling beneficial integration of illness into patients’ self-representation and identity. They were consistent with those of others authors who claimed that MS can be integrate in the patients’ self (Boeije et al., 2002; Couture et al., 2014; Irvine et al., 2009; Pakenham, 2008). They also supported the idea of “biographical reinforcement”, i.e. that some aspects of identity may be reinforced post-diagnosis (Carricaburu & Pierret, 1995). Indeed, some patients evoked memories related to their favorite activities that they are proud to continue despite illness. Thus, not all illness-related SDM were negative. For example, a patient recalled her wedding and all the support she received from her family to organise it while she was hospitalized the week before.

We showed that MS patients learn from past illness-related experiences and integrate these new meanings into the self structure, creating integrative memories. Thorne et al. (2004) reported that meaning making more often emerged when the memories contained a reference to a stressful event. Indeed, it is adaptive to reflect more thoroughly on stressful than non-stressful events. We suggest that MS promote reflection. This could explain the difference in degree of integration between illness-related SDM and other SDM. In addition, careful processing of stressful events can potentially lessen the tension associated with recall of the event. This could explain the absence of difference in BE between SDM related to the illness and other SDM.

4.3. Limitations

A limitation of our work is that our sample may not be representative of the whole MS population as we included only non-depressed relapsing-remitting MS patients without severe cognitive impairment. As previous studies have shown that executive deficits may partially account for impaired meaning making capacities in other clinical conditions (see Allé et al., 2015; Berna et al., 2011b), the absence of difference with healthy controls observed in our patients with MS may reflect the fact that those patients had relatively preserved executive functioning, which is in contrast with previous data found in other studies. Therefore, we cannot completely rule out that patients with more advanced stages of relapsing-remitting forms or progressive forms of MS characterized by more severe impaired executive functioning may encounter greater difficulty drawing lesson upon and integrating past self-significant events related to their illness.

Finally, as we did not include measures of psychological distress or wellbeing, the assumption that meaning making was associated with better wellbeing (Singer & Conway, 2011; Singer et al., 2013) cannot be firmly established.

5. Conclusions and clinical implications

Diagnosis of MS represents a major turning point in the life of a person. Moreover, MS can challenge personal identity in impinging established life roles and goals (Irvine et al., 2009). Patients had to adapt to their new condition (Dennison, Yardley, Devereux, & Moss-Morris, 2010). Personal identity implies a dynamic perspective in which it is continuously formed and transformed according to life experiences. Restructuring patients’ identity has been demonstrated to be a key aspect for the psychosocial adjustment of MS (Irvine et al., 2009). Due to their preserved ability to extract meaning from their illness-related memories, MS patients are able to integrate chronic illness in their current identity and maintain self continuity, and successfully adapt to MS. Recently, a group-based cognitive behavioral therapy program was developed for patients with MS which focuses on helping them to redefine their identities and goals according to their disabilities, and consequently reduced depression and foster psychological well-being (Graziano, Calandri, Borghi, & Bonino, 2014). Such interventions, together
with interventions targeting the kind of meaning associated with self-defining memories (Singer, 2005) should represent a new direction for clinical practice. Finally, future research should tackle gender differences in coping with MS and focus on progressive form of MS to confirm the findings in our relapsing-remitting MS group. It would also be worthwhile conducting a further study involving a comparison group made up of patients suffering from a chronic physical or mental illness (for example, epilepsy or schizophrenia) in order to compare the impact of MS on subjective identity with that of another chronic illness and determine what may be specific to MS with regard to other illnesses.

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References


