

1 **Emotions towards magnetic resonance imaging**
2 **in people with multiple sclerosis**

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51 **Abstract:**

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53 *Objectives:* People with multiple sclerosis (pwMS) often have magnetic resonance
54 imaging (MRI) examinations. While MRI can help guide MS management, it may be a
55 source of anxiety for pwMS. We aimed to develop and validate a questionnaire on
56 the “EMotions and Attitudes towards MRI” (MRI-EMA).

57

58 *Material & Methods:* The questionnaire was developed, tested in 2 samples of pwMS
59 and validated in a sample of n=457 pwMS using exploratory (EFA) and confirmatory
60 factor analysis (CFA).

61

62 *Results:* EFA revealed 4 factors underlying the questionnaire: *fear of MRI scan, fear*
63 *of MRI results, feeling of control over the disease and feeling of competence in the*
64 *patient-physician encounter.* CFA confirmed the model fit. Receiving the MRI results,
65 but not undergoing the procedure was associated with anxiety. Seeing MRI results
66 gave participants a feeling of control over the disease. Only 50% felt competent to
67 discuss MRI findings with their physician. Fear of MRI results was especially high
68 and feeling of competence low in participants with a short disease duration and little
69 MRI experience.

70

71 *Conclusion:* PwMS don't feel competent when discussing the role, MRI plays in their
72 care. Receiving MRI results caused anxiety and provides some pwMS with a -
73 perhaps false - feeling of control over the disease. The MRI-EMA constitutes a new
74 tool for the assessments of pwMS' feelings towards MRI, that can be applied in future
75 research and clinical settings.

76 **Introduction:**

77

78 Even though people with multiple sclerosis (pwMS) often have magnetic resonance
79 imaging (MRI)(1), there is little information on their experiences with MRI. MRI plays
80 a key role in the diagnostic process in multiple sclerosis (MS) (2) and is used to
81 monitor disease activity and assess treatment response. (3)

82 Understanding MRI results is complicated by the “clinico-radiological paradox”, which
83 describes the limited association between MRI-visible MS- lesions and clinical
84 outcomes.(4) In the course of the disease, at the level of individual pwMS, the
85 number and configuration of MRI lesions **don't necessarily match actual disability.**
86 **But lesion number and location at disease diagnosis do to some extent serve as**
87 **predictors for conversion from clinically isolated syndrome (CIS) to clinically definite**
88 **MS (CDMS) (5) and for long-term disability status (6,7).**

89 Despite the limitations, as clinical parameters such as EDSS-score are less
90 sensitive to disease activity (8), practitioners rely on MRI when managing MS,
91 especially when assessing treatment response. (1) There is an ongoing debate on
92 the definition of non-response. (9)

93 Still, pwMS state that MRI is of high importance to them.(11)(12) A systematic
94 review on qualitative research concerning MRI experiences including 15 studies with
95 7 to 70 participants and various diseases suggested, that MRI may be a cause of
96 anxiety.(12) No study has focused on pwMS' feelings towards MRI. PwMS may be
97 especially scared of MRI: Up to 15 % of recently diagnosed pwMS fulfill the criteria of
98 posttraumatic stress disorder (PTSD) in coping with diagnostic information. (13)

99 In a survey with n=104 pwMS, participants stated, they felt lost in the MRI
100 scanner.. (10) Patients may also fear, that new lesions have evolved without

101 experiencing any symptoms. To find out to what extent pwMS feel burdened by MRI
102 we developed and validated a questionnaire on the “EMotions and Attitudes of
103 people with MS towards MRI” (MRI-EMA). We aimed to develop a patient-oriented
104 measure, which can be applied as an outcome in e.g. educational studies about MRI
105 in MS.

106 **Material & Methods**

107 The development of the MRI-EMA comprised 5 steps. The first 4 served to refine the
108 items and generate an item set. In the final step, the newly developed questionnaire
109 was administered to a large, representative sample of pwMS in order to evaluate its
110 psychometric properties.

111

112 **Development of an item pool**

113 First, a set of items was developed based on the results of Brand et al. (10) The first
114 draft of the questionnaire “emotions and attitude towards MRI (MRI-EMA)” (MRI-EMA
115 pilot 1) consisted of n=15 items. The items focused on the experience inside the MRI
116 scanner and were rated on 5-step Likert scales (only poles are named specifically,
117 categories between the poles were only numbered; this applies for all Likert scales in
118 this study) or with yes/no-questions.

119

120 **Pilot survey 1**

121 The questionnaire was administered to n=100 consecutive pwMS from the MS day
122 hospital of the University Medical Centre Hamburg-Eppendorf, Germany, right before
123 or after an MRI. It was intended to collect data close to the procedure to have a
124 response with minimized recall bias. The results were analyzed and used to refine
125 the questionnaire.

126

127 **Qualitative study**

128 After analysis of the pilot 1-results, the scale format was changed from a 5- to a 4-
129 step Likert scale to avoid central tendency. Semi-structured interviews were used to
130 identify ambiguity in wording and improve the questionnaire. Six pwMS were asked

131 to read the questions out loud and verbalize their thoughts (think-aloud technique
132 (14)). The interviews were audiotaped and transcribed verbatim. Content validity was
133 assessed using a method described by McCorry et al. (see Supplement 1(15)).

134

135 Pilot survey 2

136 Before administration to a representative validation sample, the revised 18-item
137 instrument was tested on n=104 consecutive pwMS visiting the MS day hospital
138 (MRI-EMA pilot 2 questionnaire).

139

140 Online validation study

141 After minor wording revisions the questionnaire was presented as an 18-item online
142 survey to pwMS (MRI-EMA validation questionnaire) via the website of the German
143 MS self-help society (<http://dmsg.de>) for 1 month. The results were used to calculate
144 an exploratory (EFA) and confirmatory factor analysis (CFA). To increase
145 homogeneity of the sample, only patients with clinically definite MS (CDMS) were
146 included in the validation process.

147

148 **Statistics**

149 Descriptive statistics

150 Descriptive statistics and *t*-tests were calculated using SPSS version 24.0.

151

152 Exploratory factor analysis (EFA)

153 To perform the EFA and CFA on two separate sub-samples, the validation sample
154 was randomly split into 2 stratified halves. Stratification criteria were *level of*

155 *disability, time since diagnosis and number of MRIs.* These criteria were suspected to
156 be confounded with attitude and emotions regarding MRI.

157

158 *Determining sampling adequacy*

159 The EFA was calculated using SPSS version 24.0. Kaiser-Meyer-Olkin Measure
160 (KMO) of sampling adequacy, a measure for the variance in the variables caused by
161 underlying factors, was assessed. High values (approaching 1.0) are an indicator that
162 the data is suitable for a factor analysis. Bartlett's test of sphericity shows whether
163 the variables are unrelated; if they were, searching an underlying structure would be
164 futile. Values of <0.05 allow execution of a factor analysis.

165

166 *Model selection and factor extraction*

167 Identification of the ideal number of factors was determined using the Bayesian-
168 Information-Criterion (BIC) (Software: MPlus Version 7, Muthen&Muthen, Los
169 Angeles, USA) and comparing models using 1 to 5 factors. (16) EFA (principal axis
170 factoring) using a VARIMAX-rotation was conducted and a stepwise exclusion of the
171 items with the lowest communalities after extraction was performed. Communalities
172 of >0.6 in the rotated factor solution was set as the criterion for stopping the
173 backward stepwise exclusion. (See Supplement 2.) To ensure replicability, items with
174 a factor loading of <0.6 were excluded from the questionnaire. After the factors were
175 identified, the values of the Likert scales of the single items were combined and
176 divided by the number of included items.

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180 Confirmatory factor analysis

181 To test the construct validity of the 4-factor-solution, a CFA was calculated using R
182 software version 3.2.1 with the LAVAAN package (maximum-likelihood method). To
183 assess goodness of fit, χ^2 , degrees of freedom, comparative fit index (CFI), tucker-
184 lewis-index (TLI) and root mean square error of approximation (RMSEA) were
185 calculated. Values of >0.95 for CFI and TLI as well as <0.05 for RMSEA were
186 deemed indicators of a good fit; >0.9 (CFI and TLI) and <0.08 (RMSEA) were
187 considered acceptable.(17)

188

189 Analysis of covariance

190 An analysis of covariance using stepwise exclusion was performed in SPSS 24.0 to
191 identify the predictive value of the sociodemographic variables.

192

193 **Inclusion criteria and informed consent**

194 The study has been approved by the ethics committee of the Hamburg Chamber of
195 physicians (number PV5722). Participation was voluntary. Participants in all sub-
196 studies met the inclusion criteria, if they were older than 18 years and diagnosed with
197 CDMS or were suspected of having MS based on the participants' own assertion.
198 Written consent was obtained personally for the MRI-EMA pilot 1 and 2 questionnaire
199 and online for the web-based survey. Participants did not receive a financial
200 reimbursement.

201

202 **Results**

203

204 **Cohorts**

205 The pilot 1 cohort comprised $n = 100$. The pilot 2 questionnaire was tested in 6
206 pwMS (4 with CDMS, 2 with suspected MS) in semi-structured interviews (18), before
207 being rolled out to a cohort of $n = 104$. Within the online validation study, $n = 753$
208 started and $n = 498$ participants finished the MRI-EMA validation questionnaire
209 (finishing rate: 66 %). After all participants with suspected MS or more than 5 percent
210 missing answers had been excluded, $n=457$ participants remained. The validation
211 cohort was randomly split into 2 stratified subgroups. No differences in the
212 demographic variables were observed between the 2 groups (all p -values > 0.005 ,
213 $mean = 0.42$, standard deviation (SD) = 0.29) (For demographic data see Table 1.)

214

215 **Questionnaire results**

216 Pilot survey 1

217 The questionnaires obtained close to the scanning (exact time point, i.e. pre- or post-
218 scan, not recorded) revealed that less than 10% rated MRI scanning as “very
219 unpleasant”, almost 80% thought, their MRI was “very helpful” for their MS-follow-up.
220 About 20% reported they were worried about receiving their MRI results (see
221 Supplement 3.) Four questions concerning the MRI procedure were rephrased, 8
222 questions addressing the MRI findings and 3 questions about the patient-physician-
223 communication were added, leading to the MRI-EMA pilot 2 questionnaire with $n=18$
224 items..

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226

227

228 Qualitative study

229 While some participants expressed high anxiety triggered by discussing MRI findings
230 during the semi-structured interviews, others described it as “*interesting*”, and stated
231 their “*relief*” after seeing “*what [was] happening*”. Several believed, that their MRI
232 results were a strong predictor for future activity: “*Nothing is more significant than an*
233 *MRI, nothing can show me more clearly the activity of my MS.*” (See Supplement 4.)
234 Analysis of the transcribed interviews revealed 18 issues with 8 questions (see
235 Supplement 1). One question was dropped, as 5 participants didn’t understand it, 2
236 questions were merged.

237

238 Pilot survey 2

239 About 60 % of participants were not afraid of the MRI scan, but one third was scared
240 of the MRI results. Over 40% of participants felt eased by “knowing what was going
241 on” and one third expressed a sense of control over the disease as a result of MRI.
242 Just 40 % of participants believed they were competent enough to discuss their
243 results with their doctor. To almost 60 % of participants, MRI was of great
244 importance.

245

246 **Validation study**

247 Exploratory factor analysis (EFA)

248 The data was suitable for EFA according to a KMO value of 0.667 and a statistically
249 significant Bartlett's Test of Sphericity ($p < 0.005$). The lowest BIC was observed for
250 a 4-factor-model. As depicted in Table 2, 10 items were retained that had factor
251 loadings >0.6 .

252 The factors were labeled *fear of MRI scan* (2 items; explained variance: 15 %), *fear*
253 *of MRI results* (3 items; explained variance: 17 %), *feeling of control over the disease*
254 (3 items; explained variance: 19.15 %) and *feeling of competence in the patient-*
255 *physician encounter*" (2 items; explained variance: 9.63 %).

256

257 Confirmatory factor analysis (CFA)

258 Construct validity of the final, 10-item MRI-EMA questionnaire was confirmed using
259 CFA. χ^2 was not significant ($\chi^2 = 356.40$; degrees of freedom = 29; $p = 0.184$)
260 indicating a good model fit. The other fit indices indicated a satisfying fit with CFI and
261 TLI >0.95 (CFI= 0.991, TLI= 0.986) and RMSEA <0.05 (RMSEA= 0.032).

262

263 Questionnaire findings

264 The factor *fear of MRI scan* comprises 2 statements concerning the MRI procedure
265 (see Table 3). On average, participants scored a value of 1.8 ($SD \pm 0.88$). Only 20%
266 of participants indicated, that they were afraid of the MRI scan (Likert rating of 3/4).
267 The factor *fear of MRI results* comprises 3 items about negative feelings when
268 receiving the MRI results. On average, participants scored a value of 2.5 ($SD \pm 0.95$).
269 For example, 55% gave a Likert rating of 3 or 4, when asked, whether they'd been
270 afraid of their last MRI findings. The factor *feeling of control over the disease* refers to
271 the fact, that patients seem to think, that their MRI results show them "what is going"
272 and comprises 3 items. On average participants scored a value of 2.7 ($SD \pm 0.89$).
273 Fifty-eight percent stated, that the MRI provided them with a feeling of control over
274 the disease (Likert rating of 3/4). The factor *feeling of competence* consists of 2 items
275 and addresses, if pwMS feel competent to talk about their MRI findings during the
276 patient-physician encounter. On average participants scored a value of 2.6 ($SD =$

277 ± 0.92). Fifty-four percent indicated not to feel competent to discuss results with their
278 physicians (Likert rating of 3/4) (see Table 4).

279

280 Determinants of emotions towards MRI

281 Comparing participants with a short disease duration (≤ 5 years, $n = 239$) vs. a long
282 disease duration (> 5 years, $n = 218$) revealed no difference in *fear of MRI scan* (\leq
283 $5y$: 1.8, SD 0.86 vs. $> 5y$: 1.8, SD 0.92) or *feeling of control over the disease* ($\leq 5y$:
284 2.7, SD 0.86 vs. $> 5y$: 2.6, SD 0.92). But a significant difference ($p < 0.005$) was seen
285 in *fear of MRI results* and *feeling of competence*: participants with a shorter disease
286 duration were significantly more anxious of their MRI results ($\leq 5y$: 2.7, SD 0.91 vs. $>$
287 $5y$: 2.3, SD 0.94) and felt less competent ($\leq 5y$: 2.5, SD 0.9 vs. $> 5y$: 2.7, SD 0.92)
288 (see Figure 1, upper panel).

289 The same pattern was found in participants with few, i.e. < 5 ($n = 139$), vs. many, i.e. \geq
290 5 , previous MRIs ($n = 318$). While no difference was observed concerning *fear of*
291 *MRI scan* (< 5 MRIs: 1.8, SD 0.86 vs. ≥ 5 MRIs: 1.8, SD 0.9) and *feeling of control*
292 *over the disease* (< 5 MRIs: 2.6, SD 0.84 vs. ≥ 5 MRIs: 2.7, SD 0.91), participants
293 with less MRIs felt more anxious about their MRI results (< 5 MRIs: 2.7, SD 0.97 vs. \geq
294 5 MRIs: 2.4 SD 0.92) and less competent (< 5 MRIs: 2.4, SD 0.92 vs. ≥ 5 MRIs: 2.7,
295 SD 0.92) (see Figure 1, lower panel).

296

297 Four analyses of covariance were performed to examine, to what extent the
298 sociodemographic variables predicted the 4 different factors. Across the 4 factors, a
299 maximum of 2 variables was included in the models. Across all models, between 2 to

300 8 % of the variance in the factor values was explained. i.e. the predictive value of the
301 sociodemographic variables was small (1 to 5%) to moderate (6 to 14%). (19) The
302 variables with the greatest predictive value were age and disease duration with 7.8%
303 explained variance for the factor *fear of MRI results* and the number of previous MRIs
304 with 6.6 % explained variance for the factor *feeling of competence*. Unstandardized
305 beta-coefficients, p-values and explained variance for each model are reported in
306 Supplement 5.

307

308 **Discussion**

309 Despite the frequent use of MRI in the management of MS, little is known about
310 pwMS' perception of MRI. To assess how pwMS feel about MRI, we developed and
311 validated the 10-item "emotions and attitude towards MRI questionnaire" (MRI-EMA).
312 Validation was performed using EFA and CFA. EFA revealed 4 underlying factors
313 (*fear of MRI scan, fear of MRI results, feeling of control and feeling of competence in*
314 *medical encounters*); CFA revealed a good model fit. The major finding based on the
315 scale was that most pwMS do not fear MRI per se, but are anxious about the results
316 and unsure about their interpretation.

317 The few studies that have investigated patients' perceptions of MRI in MS (10) or
318 other conditions (12) have shown anxiety associated with the MRI scanning
319 procedure. In this study pwMS were anxious about their MRI results, but not the
320 scan, (see Figure 2.). One explanation is pwMS' concern about silent disease activity
321 being revealed by the MRI, which may trigger anxiety about future disease
322 progression. A moderately high value of the factor *feeling of control* suggested that
323 the MRI results gave participants a feeling of control over their MS (see Figure 2). In
324 reality, correlations between MRI activity and clinical disease activity and prognosis

325 are modest at best. (4,7) In clinical practice diagnostic tests are usually applied
326 based on the idea of control (20), but possible practical consequences are often not
327 discussed. And knowing “what is going on”, is not necessarily helpful when
328 interpretation of changes on a scan is difficult.

329 Patients scored a moderately high value on the factor *feeling of competence during*
330 *the patient-physician encounter* (see Figure 2). In previous studies, pwMS correctly
331 answered 60% of MS- (21) and MRI-specific knowledge questions. (10) Therefore,
332 subjective and objective competence may differ. Additionally the high value might be
333 explained by the fact that 60 % of the participants agreed with the first of the 2 items
334 in this factor, which asks, whether one is able to help decide, if an MRI examination
335 makes sense. However, when asked about their feeling of competence in this
336 discussion, more than 50 percent of patients stated that they did not feel competent.

337

338 Patients' expectations of MRI scanning seem to change with growing MRI
339 experience. Participants with a disease duration of ≤ 5 years as well as < 5 previous
340 MRIs felt significantly more anxious about their MRI results, and less competent to
341 discuss them, in comparison to participants with a longer disease duration and more
342 previous MRIs. This group of patients might especially benefit from specific MRI
343 education. In the analysis of covariance, while disease duration and number of
344 previous MRIs had a significant influence on the factors *fear of MRI results* and
345 *feeling of competence*, respectively, the effect was only moderate. This doesn't
346 contradict the findings of the group comparisons as these contrasted very early
347 disease (< 5 years) vs. a wide range of longer disease durations. Continuously, the
348 disease duration might only have a significant, however small impact.

349

350 Patient education has been shown to decrease anxiety before medical procedures,
351 e.g. in the perioperative setting. (22) In a qualitative study on MRI experiences of
352 n=10 participants with different diseases including MS, patients reported that being
353 informed about the MRI procedure decreased anxiety during the scan. (23) We
354 propose, that increasing MRI knowledge using a patient education program might
355 decrease anxiety concerning MRI results and increase feeling of competence in
356 pwMS. In a previous survey (10) 90 % of n = 104 pwMS were interested in an MRI-
357 specific education program; a 2-hour group-based MRI education program on this
358 was highly appreciated and resulted in a substantial knowledge increase. ^[12] We are
359 currently developing a web-based education tool, with which we hope to not only
360 increase MRI-specific knowledge, but to decrease negative emotions towards MRI,
361 assessed using the MRI-EMA, and boost pwMS' confidence discussing their MRI
362 results in MS in patient-physician encounters.

363

364 **Limitations**

365 Recruiting participants online may have introduced a selection bias towards more
366 informed or technologically aware pwMS. We only validated the questionnaire in
367 people with CDMS.

368

369 **Conclusion**

370 The MRI-EMA is a novel, patient-oriented outcome instrument assessing the
371 emotions and attitude of pwMS towards MRI. PwMS were less stressed by the MRI
372 scan itself than the results. MRI results gave pwMS a possibly false feeling of control
373 over their MS. Fifty percent did not feel competent to discuss their results with their

374 physicians. Anxiety was greater and feeling of competence lower in pwMS with few
375 previous MRIs or short disease duration.

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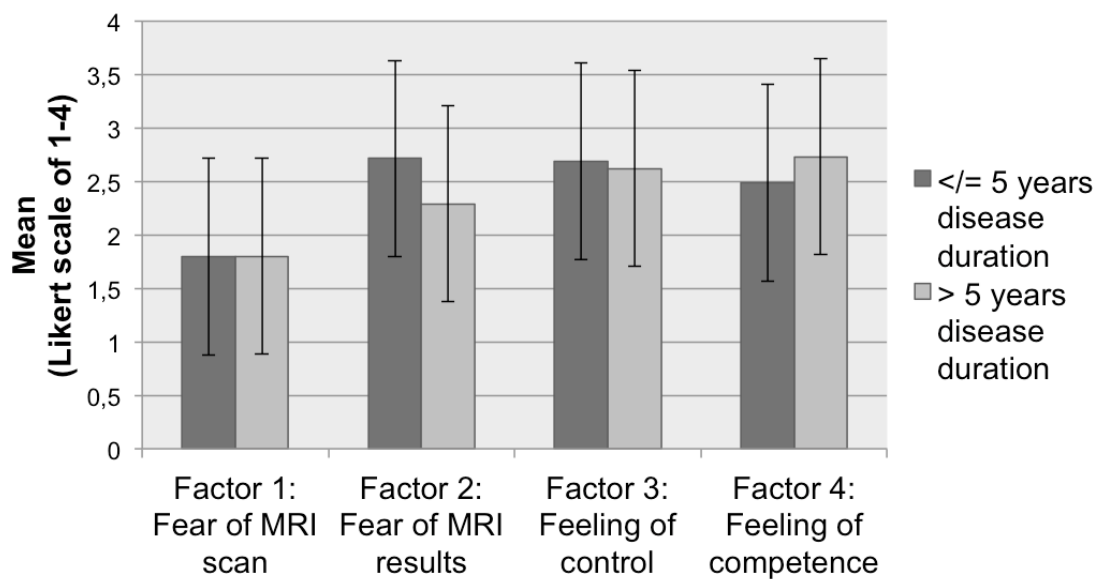
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Figure 1: Emotional differences in pwMS with a short disease duration and little MRI experience

Upper panel: Differences concerning the factor values of pwMS with a disease duration of less vs. more than 5 years. Depicted are mean values and standard deviation.

Lower panel: Differences concerning the factor values of pwMS with less vs. more than 5 previous MRIs. Depicted are mean values and standard deviation.



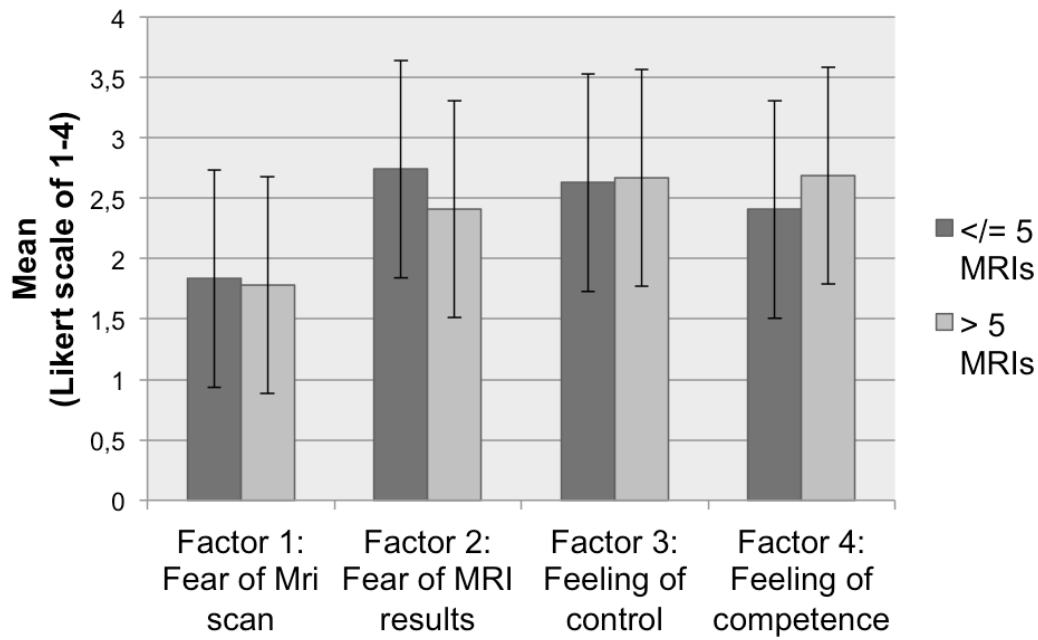
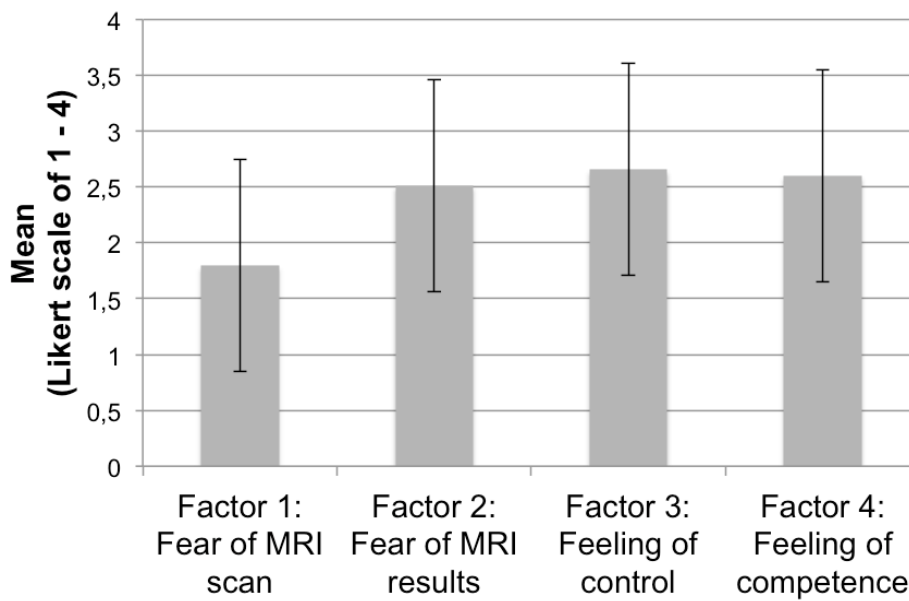


Figure 2: Mean values of the factors: Emotions and attitude of pwMS towards the MRI

Depicted are the mean values and standard deviation of the 4 factors identified in the factor analysis.



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Table 1: Demographic data of the 3 cohorts of the MRI-EMA development.

Demographic data is depicted for the pilot 1, pilot 2 and validation cohort. (SD = standard deviation)

Pilot 1 cohort N=100 (SD)	Pilot 2 cohort N=107 (SD)	Validation cohort	
		Exploratory sample N=229 (SD)	Confirmatory sample N=228 (SD)

Women (%)	68	71	71.6	70.6
Age (years)	41.9 (±12.6)	39.5 (±12.9)	43.2 (±10.5)	42.3 (±11.0)
CDMS* yes/suspected (%)	70/14	70/n.d.**.	100/0	100/0
Disease course (%)				
Primary Manifestation	n.d.	20.6	0	2.1
RRMS	n.d.	50.5	78.6	80.2
SPMS	n.d.	7.5	9.6	8.3
PPMS	n.d.	5.6	5.2	3.1
Unclear	n.d.	13.1	0.66	6.1
Time since diagnosis (years)	7 (± 9.0)	6 (±7.4)	7.9 (±-7.9)	7.5 (±7.6)
Level of disability (1 – 9)	n.d.	n.d.	3.0 (±1.6)	3.1 (±1.9)
Education (%)				
High school degree	n.d.	57.0	72.5	61.8
Secondary degree	n.d.	30.8	24.5	30.3
No degree/ primary degree	n.d.	12.1	3.1	7.9
Number of received MRIs***	5 to 10	< 5	5 to 10	5 to 10

*CDMS: clinically definite multiple sclerosis; ** n.d. = not determined; *** Categories: <5, 5 to 10, >10 MRIs

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Table 2: Factor loadings of the MRI-EMA validation questionnaire.

Factor loadings for the final 10 items of the MRI-EMA validation questionnaire generated by means of factor analysis using varimax rotation. Significant factor loadings, i.e. >0.6, are printed in bold.

	Factor 1: Fear of MRI scan	Factor 2: Fear of MRI results	Factor 3: Feeling of control	Factor 4: Feeling of competence
1. The MRI examination calms me, because the findings indicate what's going on.	-0.11	-0.04	0.65	0.05
2. The findings of the MRI examination provide me with a feeling of control over my illness.	-0.01	-0.06	0.88	0.08
3. With the findings of my MRI examination I feel less helpless with regard to my illness.	-0.01	0.03	0.80	0.08
4. I was quite preoccupied with the possible findings of my last MRI examination <i>before</i> I even knew them.	0.09	0.78	0.05	-0.05
5. I was quite preoccupied with the findings of my last MRI examination <i>after</i> I knew them.	0.09	0.71	-0.17	-0.06
6. I was afraid of the possible findings of my last MRI examination.	0.20	0.72	0.05	-0.04
7. I am afraid of the MRI examination.	0.91	0.23	-0.08	-0.02
8. I feel helpless during the MRI examination.	0.75	0.14	-0.14	-0.18
9. I feel competent to discuss the findings of my MRI with my physician.	-0.08	-0.06	0.10	0.70
10. I am able to help decide whether an MRI examination makes sense.	-0.07	-0.04	0.03	0.65
Explained variance (in %):	<i>14.77</i>	<i>17.00</i>	<i>19.15</i>	<i>9.63</i>

Table 3: Mean values of 4 factors describing attitudes towards MRI

Factor values were obtained by combining the values of the included items (X out of 4) and dividing by the number of items. Mean values and their standard deviation (SD) are depicted in the table below.

Factor	Value (mean)	Standard deviation (SD)
Fear of MRI scan	1.8	±0.88
Fear of MRI results	2.5	±0.95
Feeling of control over the disease	2.7	±0.89
Feeling of competence during the patient-physician encounter	2.6	±0.92

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Table 4: Results of the MRI-EMA validation study.

Results of the MRI-EMA questionnaire (in %) administered online to n=457 participants. Items that were eliminated after factor analysis are highlighted in grey. (Poles: 1= I don't agree at all, 4= I completely agree; steps in between were numbered only).

Factor	1	2	3	4
Fear of MRI scan	52	28	14	6
I feel helpless during the MRI examination.	50	26	14	10
Fear of MRI results	21	23	26	30
I was afraid of the possible findings of my last MRI examination.	26	24	25	25
I was quite preoccupied with the possible findings of my last MRI examination before I even knew them.	28	25	25	22
I was quite preoccupied with the findings of my last MRI examination after I knew them.	10	18	30	42
Feeling of control	21	21	31	27
The MRI examination calms me, because the findings indicate what's going on.	29	29	26	16
The findings of the MRI examination provide me with a feeling of control over my illness.	15	20	33	32
With the findings of my MRI examination I feel less helpless with regard to my illness.	26	28	27	19
Feeling of competence	8	16	25	51
I am able to help decide whether an MRI examination makes sense.				
I feel competent to discuss the findings of my MRI with my physician.				
Finally				
I have the possibility to discuss my MRI findings with a				

omitted items	doctor.				
	I feel relieved after the MRI examination.	18	21	32	29
	I always have similar feelings during an MRI examination.	8	11	35	46
	The result of my last MRI examination is/was of great importance to me.	7	12	27	54
	I feel more ill, if an MRI result shows new lesions.	29	29	27	15
	I believe that the findings of my MRI examination correspond to my symptoms.	12	25	38	25
	With the findings of my MRI examination, I can estimate how much I will be affected by my illness in the future.	42	31	19	8
	It is important to me, that my neurologist/radiologist and I look at my MRI results together and that he/she explains them to me.”	78	16	4	2

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Development and validation of a questionnaire on the emotions and attitude (MRI-EMA) towards MRI in people with multiple sclerosis

Supplement material

Supplement 1: Content validity analysis of the MRI-EMA pilot 2 questionnaire

Comprehension and content validity of the MRI-EMA pilot 2 version was tested via think-alouds and open questions in semi-structured qualitative interviews with n=4 participants with clinically definite MS and n=2 suspected of MS. Participants were asked to complete the questionnaire, reading the questions out loud and verbalizing their thoughts. Then participants were asked 6 additional questions for more detailed information, criticism and suggestions to the questionnaire. The interviews were audiotaped and transcribed verbatim. In a first step, the statements were examined and assigned to superordinate categories according to their content (e.g. fear of MRI results or shared decision making). In a second step, comprehension and problems with the questionnaire were assessed by categorizing all text passages into six possible categories, taken from a coding framework of a former think- aloud study^[17]:

1. All text passages indicating that there were no problems experienced with this item.
2. All text passages where participants express the opinion that the item is not appropriate to their circumstances.

3. All text passages indicating that the participants do not fully understand the content of the item.
4. All text passages where participants repeat the question more than one time as a result of difficulty in understanding the item.
5. All text passages where participants make suggestions to the questionnaire.
6. All text passages where participants criticize the questionnaire.

The number of problems was calculated for each question. Problems were discussed and the questionnaire was revised.

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Supplement 2: Communalities of the exploratory factor analysis

The communalities describe the proportion of each variable's variance that can be explained by the factors.

	Initial	Extraction
1. I am afraid of the MRI examination.	.591	.888
2. I feel helpless during the MRI examination.	.568	.632
3. I was quite preoccupied with the possible findings of my last MRI examination <i>before</i> I even knew them.	.431	.613
4. I was quite preoccupied with the findings of my last MRI examination <i>after</i> I knew them.	.420	.542
5. I was afraid of the possible findings of my last MRI examination.	.435	.557
6. The MRI examination calms me, because the findings indicate what's going on.	.374	.439
7. The findings of the MRI examination provide me with a feeling of control over my illness.	.593	.786
8. With the findings of my MRI examination I feel less helpless with regard to my illness.	.555	.659
9. I feel competent to discuss the findings of my MRI with my physician.	.258	.502
10. I am able to help decide whether an MRI examination makes sense.	.234	.434

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Supplement 3: Results of the MRI-EMA pilot 1 cohort

Results of the MRI-EMA pilot 1 (in %) administered to n=100 participants right before

or after receiving an MRI. (Poles were named explicitly, steps in between were numbered only.)

	1 - Very unpleasant	2	3	4	5 - Easily endurable	No answer
1. How do you experience the procedure of the MRI examination in general?	3	6	12	21	56	2
2. How do you experience the administration of the contrast agent?	4	3	11	20	57	5
3. How do you experience the narrowness in the MRI?	6	7	13	18	53	3
4. How do you experience the noise in the MRI?	8	12	16	29	32	3
5. How do you experience the length of time of the examination?	5	12	15	23	34	11
	1- Not helpful at all	2	3	4	5- very helpful	
6. Do you think the MRI examination helps you to estimate the evolution of the MS- disease?	1	2	10	22	56	9
	1- very worried	2	3	4	5- not at all worried	
7. Thinking of the potential results I am...	10	7	40	17	19	7
	1- no knowledge at all	2	3	4	5- very much knowledge	
8. How do you estimate your own knowledge on the importance of MRI in MS?	2	8	24	44	16	6
	1- not important	2	3	4	5- very important	
9. Would you like to understand the written report?	2	2	8	14	67	7
10. Would you like to understand the MRI images?	4	1	17	22	48	8
	1- no not at all	2	3	4	5- yes, extensively	
11. Have you been informed about the possible results before the examination?	10	9	21	23	31	6
12. Did you inform yourself about the methods of MRI?	16	13	14	28	21	8
	yes		no	I do not mind		

13. Is it important to you to learn of the preliminary results right after the examination?	60	21	13	6
14. Do you generally want to receive a written report?	79	2	13	6
15. Do you receive a written report?	50	31	-	19

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Note: Only the poles of the Likert scales were named explicitly.

Supplement 4: Results of the content validity analysis

Superordinate topics identified during the think alouds with n=6 participants about the MRI-EMA pilot 2 questionnaire and exemplary quotations.

MRI scan	Anxiety	To me, the examination itself is not bad at all, but afterwards, the results, is certainly something that I am afraid of.
	To be at the mercy	I do not feel exposed at all. I do it for myself, this is what keeps me going, what gives me answers.
	Perception throughout time	During the first MRI scan [...] I had a different feeling than now, because now I know how it feels, I know that I am safe and that I can press the stop button when necessary. [...]
	Feeling relieved	I am relieved because something is getting done, because I get answers. It is especially helpful if nothing new is appearing or no new inflammation is seen. First and foremost, by actively doing something and caring about me [...], it relieves me to see what is happening.
MRI results	Anxiety	Of course, I'm afraid, I am always [...] afraid.
		I'm not afraid [...]The results interest me, whether it is something positive. And I just hope that it is not negative.

	To be at the mercy	They give me [...] a result of what is happening, but I still feel like I am at the mercy of the disease.
		[...] Actually the disease does what it wants and I can't do anything against it.
	Relevance	Nothing is more significant than an MRI, nothing can show me more clearly the activity of my MS, thus MRI results are of huge importance to me, actually the most important, because with it I can see, how active it is.
	Sense of control	I really have a certain control with the MRI results, because there, the activity of the disease is becoming the most visible.
Okay, [with the scan] I know what is going on, but I can't influence the disease itself.		
Understanding MRI	MRI Knowledge	[...] I think regular MRI scans make sense, just to have regular checks. Especially in the case of relapses, in order to estimate what is active.
		It is best to perform an MRI together with a CT scan.
Doctor-patient communication	Looking at images with doctor	No one has ever looked at the MRI images with me. And of course this makes me insecure [...].
		I was irritated that the doctor in the hospital has neither talked to me nor showed me the images of my brain. [...] It would have been important to me to have seen the

		pictures earlier.
	Decision making	[...] In the end I would probably leave the decision to the doctor [...] But in situations, where it seems important to me to perform an MRI, I would ask the doctors to do so.

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Supplement 5: Explained variance of the sociodemographic variables predicting the factor values

An analysis of covariance using backward exclusion was used to calculate the unstandardized beta coefficients and explained variance of the sociodemographic factors predicting the 4 factors (*fear of MRI scan*, *fear of MRI results*, *feeling of control*, *feeling of competence*). Depicted are the beta coefficients (center) and the partial eta² for each model (bottom row).

Sociodemographic variables	Factor 1: Fear of MRI scan <i>mean (SD)</i>	Factor 2: Fear of MRI results <i>mean (SD)</i>	Factor 3: Feeling of control over the disease <i>mean (SD)</i>	Factor 4: Feeling of competence <i>mean (SD)</i>
Sex Women Men	1.9* (±0.1) 1.6* (±0.15)	excluded	excluded	excluded
Level of disability	excluded	excluded	excluded	excluded
Number of previous MRIs < 5 MRI 5 to 10 MRIs >10 MRIs	excluded	excluded	excluded	2.4* (±0.23) 2.57* (±0.21) 2.93* (±0.17)

Magnetic resonance imaging in multiple sclerosis

Disease course Primary manifestation RRMS SPMS PPMS Unclear	excluded	excluded	2.7* (± 0.84) 2.7* ($\pm 0,33$) 2.3* (± 0.42) 3.1* (± 0.51) 2.4* (± 0.32)	excluded
Level of education	excluded	excluded	excluded	excluded
	<i>change in mean per year (SD)</i>	<i>change in mean per year (SD)</i>	<i>change in mean per year (SD)</i>	<i>change in mean per year (SD)</i>
Age	excluded	- 0.02/year* (± 0.08)	excluded	excluded
Disease duration	excluded	- 0.03/year* (± 0.012)	excluded	excluded
Explained variance in % (partial eta²)	2.1	7.8	2.7	6.6

* p-value <0.00

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