MRI in MS survey – insights into access, understanding and interest by people with MS

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Disclosures

LC, EV, AD, DS and WV are employees of icometrix
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Introduction

• MRI scans have become the main tool to monitor disease progression and treatment effect in MS

• While studies showed more than 2/3 of patients aim to play an active role in their disease management [1] some strong MRI-related knowledge gaps have been reported [2]

• In order to help MS patients to be more active in their disease management, more studies need to investigate the MRI-related knowledge, attitudes, information needs and experiences of MS patients

Methodology

• We launched a worldwide survey which was answered by 876 people with MS (PwMS), predominantly located in the US and Canada (91.4%)
  • 80.0% Female
  • Age:

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>25 to 34</td>
<td>4.8%</td>
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<tr>
<td>35 to 44</td>
<td>11.7%</td>
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<tr>
<td>45 to 54</td>
<td>27.2%</td>
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<tr>
<td>55 to 64</td>
<td>34.1%</td>
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<tr>
<td>65 to 74</td>
<td>19.4%</td>
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<tr>
<td>75 to 84</td>
<td>2.8%</td>
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• Survey consisted of questions concerning MRI access, viewing, knowledge and information needs

* We did not include answers such as ‘Not Sure / Prefer not to say’ into the analyses
* One subject aged under 24 participated in the survey
Results – MR scan frequency

- Only 0.6% \((n = 5)\) of PwMS have never had an MRI performed for the purpose of diagnosing or treating.

- Only 54.9% \((n = 474)\) undergo an MRI scan every year or more frequently

How often do you get an MRI for your MS, on average?

- More frequent than six months (0.9%)
- About every six months (8.8%)
- About every year (45.1%)
- About every two years (25.9%)
- Less often than every two years (19.2%)
Results – MR image access

- Almost 27% (26.9%, n = 228) of patients have never received an electronic version of their MRI from their clinic or radiology lab.

  Have you ever received an electronic MRI, and how?

  - Received it after requesting (46.1%)
  - Got if from participating in a study (3.2%)
  - Received it without me asking (23.9%)
  - Never received an electronic version of my MRI (26.9%)

- Of those patients that received an electronic version of their MRI, 79.9% (n = 560) got it on a CD-Disk, 15.6% (n = 109) through their clinic’s patient portal, 4.0% (n = 28) through a direct download into their computer or other device and 0.6% (n = 4) on a USB-drive.
Results – MR image viewing and knowledge

• Of PwMS that received an electronic version of their MRI
  • 70.5% \((n = 431)\) looked at their MR images on their own
  • Of those people, only 13.3% \((n = 57)\) claimed to completely understand their MR images:

  How well did you understand the images in your MRI?
  
  Not at all (9.1%)
  Not very much (23.5%)
  Somewhat (54.1%)
  Completely (13.3%)
Results – MR image viewing

- 70.2% ($n = 99$) of the PwMS that have access to an electronic MRI but have not looked at it on their own, would like to do so.

- Reasons for not viewing the electronic MR images on their own were ($n=225$):
  - Not knowing how to interpret the images (46.1%)
  - Not having the software application to view them (33.9%)
  - Not knowing how to view the images (32.8%)
  - Not being able to load the images (12.2%)
Results – information needs

• 98.2% (n = 836) of PwMS are interested in knowing about changes between their MRIs

• 94.7% (n = 767) of PwMS wanted to know if their MRI scan was performed according to clinical MS guidelines

• 96.6% (n = 714) of PwMS would be willing to share their MRIs with researchers
Conclusion

• Only a small proportion of PwMS reported complete understanding of MR images, illustrating the importance of MRI education

• In order to support PwMS to look at their MRI scans on their own, education plays a crucial role but clear instructions and easy access are also important

• Almost all PwMS expressed interest in knowing whether a scan was performed according to guidelines, and whether any changes were present compared to their previous MRI scan