Patients’ acceptance and adherence of their medication: results from a European multi-disease study with online patient community

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Background
- Management of most chronic conditions requires the patient to take long-term treatments.
- Lack of adherence and persistence are major barriers to treatment efficacy.
- Patients’ behaviour and attitude toward their treatment are hypothesised to result from a complex evaluation of the benefits and the costs of their treatment.
- Measuring patients’ acceptance of their medication can help better understand and predict patient’s behaviour towards treatment.
- The ACCEPT® Questionnaire assesses both the level of treatment acceptance and its determinants.
- The MMAS-8® Questionnaire assesses the level of adherence to treatment.

Objectives
- This study aimed at:
  - Evaluating the level of acceptance and adherence for various chronic diseases in real life using a patient online community in 5 languages.

Methods
- Study design:
  - An observational, cross-sectional study conducted through the French, English, German, Spanish and Italian Carenity platforms between October 2015 and February 2016.
  - The Carenity platform is a European online patient community created in 2011 in which both patients and their relatives, concerned by a chronic disease, can share their experience, find basic tools for health follow-up and contribute to medical research.
  - Patients included were adults suffering from any chronic disease and currently receiving treatment for this disease.

Assessments
- All patients connecting to the Carenity platform were invited to complete an online questionnaire including:
  - Questions on demographics, chronic disease and medication.
  - The ACCEPT® Questionnaire assesses the level of treatment acceptance.
  - The MMAS-8® Questionnaire assesses the level of adherence to treatment.
- The level of acceptance was assessed using a 6-item questionnaire, including 5 multi-item dimensions (“Medication Inconvenience”, “Long-term Treatment”, “Regimen Constraints”, “Side Effects”, “Effectiveness”), and one single-item acceptance dimension (“Numerous Medications”).
- One “General Acceptance” multi-item dimension.
- The answers on all items assessing the patients’ level of treatment are based on a three-level assessment: “I don’t find this easy to accept”; “I find this easy to accept”; “No” for patients not bothered by the subject addressed in the item.
- The answer choice on the “general acceptance” items is Likert’s.
- Scores range from 0 to 100 for multi-item dimensions with higher score indicating greater acceptance. The single item dimension score is kept as the original 3-point response scale common to all items (1 = poor adherence; 2 = moderate adherence; 3 = high adherence).
- The Morisky Medication Adherence Scale (MMAS-8®):
  - 8-item scale with a score ranging from 0 to 8 with the following interpretation: 0 to <6 (low adherence), 6 to <8 (moderate adherence) and 8 (high adherence).

Statistical analysis
- Descriptive statistics were used to describe the patient population and the ACCEPT® and MMAS-8® scores.
- Pearson correlations between the Acceptance/General dimension and MMAS-8® scores were calculated.
- Diseases with at least 100 patients were analysed individually, while other diseases were all grouped together.

Results
- Patient population:
  - 7,089 patients participated to the study, but 4 were excluded from the analysis sample because of age (n=3) or absence of responder (n=1).
  - Among the 7,089 patients included in the analysis, 4,646 connected to the French Platform, 1,290 to the English, 585 to the Italian, 387 to the Spanish and 181 to the German (Table 1).
  - Respondents, aged between 18 and 90 years, were mostly female (68.4%).
  - More than 360 chronic diseases were represented, among which 16 including more than 100 patients (Figure 1).

Table 1: Description of the patient population (N=7,089)

<table>
<thead>
<tr>
<th>Age (Years)</th>
<th>German (N=181)</th>
<th>English (N=1,290)</th>
<th>French (N=4,646)</th>
<th>Spanish (N=387)</th>
<th>Italian (N=585)</th>
<th>Total (N=7,089)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>55.8 (11.4)</td>
<td>51.3 (12.8)</td>
<td>54.0 (12.9)</td>
<td>47.1 (11.7)</td>
<td>52.3 (12.2)</td>
<td>53.0 (12.8)</td>
</tr>
<tr>
<td>Median (Q1 - Q3)</td>
<td>56.49 (44.94)</td>
<td>53.44 (61.55)</td>
<td>55.65 (64.44)</td>
<td>48.41 (50.53)</td>
<td>52.45 (60.54)</td>
<td>54.65 (60.54)</td>
</tr>
<tr>
<td>Min - Max</td>
<td>21 - 92</td>
<td>18 - 98</td>
<td>18 - 98</td>
<td>18 - 96</td>
<td>19 - 81</td>
<td>18 - 90</td>
</tr>
<tr>
<td>Gender (%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>51.4</td>
<td>25.6</td>
<td>32.3</td>
<td>19.1</td>
<td>40.3</td>
<td>31.6</td>
</tr>
<tr>
<td>Female</td>
<td>48.6</td>
<td>74.2</td>
<td>67.7</td>
<td>80.9</td>
<td>59.7</td>
<td>68.4</td>
</tr>
</tbody>
</table>

Figure 1: Patient disposition
- Across diseases, great variations in mean Acceptance/General score were observed, from 34.2 (fibromyalgia) to 65.8 (type 1 diabetes).
- Within each chronic disease, there were patients reporting the highest possible (100) and the lowest possible (0) Acceptance/General score (Figure 2). A high proportion (27.7%) of respondents suffering from fibromyalgia reported the lowest acceptance score (0). On the other side, a high proportion of patients suffering from type 1 diabetes and COPD reported the highest level of treatment acceptance (82.1% and 25.2%, respectively).
- Most differences (20-30 points) were observed for most dimensions between the disease with the lowest mean score and the disease with the highest mean score. This difference was larger for the Acceptance/Side effects with more than 40-point differences between the disease with the lowest mean score (breast cancer, 37.0) and the disease with the highest mean score (type 1 diabetes, 77.8) (Table 2).

Figure 2: Acceptance/General score for each disease

Box = interquartile (Q3-Q1); + = mean; — median; upper and lower bars = observed max – min values. Boxplots are ranked based on mean Acceptance/General score.

Table 2: Description of ACCEPT® dimensions mean scores: unmet needs and achievements

<table>
<thead>
<tr>
<th>Determinants</th>
<th>Three diseases with worst level of acceptance in the dimension (Mean SD)</th>
<th>Three diseases with best level of acceptance in the dimension (Mean SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance/ Medication Inconvenience Dimension</td>
<td>Type 1 diabetes 60.2 (29.1)</td>
<td>Hypothyroidism 95.5 (13.4)</td>
</tr>
<tr>
<td></td>
<td>Ankylosing spondylitis 72.6 (25.1)</td>
<td>Arterial hypertension 92.4 (13.1)</td>
</tr>
<tr>
<td></td>
<td>Rheumatoid arthritis 77.4 (28.4)</td>
<td>Breast cancer 91.4 (15.4)</td>
</tr>
<tr>
<td>Acceptance/ Long-term Treatment Dimension</td>
<td>Bipolar disorder 47.1 (24.2)</td>
<td>Multiple sclerosis 60.8 (22.8)</td>
</tr>
<tr>
<td></td>
<td>Parkinson 48.4 (24.3)</td>
<td>COPD 59.0 (22.2)</td>
</tr>
<tr>
<td>Acceptance/ Regimen Constraints Dimension</td>
<td>Type 1 diabetes 50.5 (23.2)</td>
<td>Type 2 diabetes 58.1 (21.4)</td>
</tr>
<tr>
<td>Acceptance/ Numerous Medication Item*</td>
<td>Fibromyalgia 1.79 (0.84)</td>
<td>Multiple sclerosis 2.35 (0.79)</td>
</tr>
<tr>
<td></td>
<td>Parkinson 1.87 (0.92)</td>
<td>Arterial hypertension 2.33 (0.77)</td>
</tr>
<tr>
<td>Acceptance/ Side Effects Dimension</td>
<td>Breast cancer 2.91 (2.32)</td>
<td>Arterial hypertension 3.06 (2.33)</td>
</tr>
<tr>
<td></td>
<td>Ankylosing spondylitis 4.61 (3.38)</td>
<td>COPD 7.83 (3.0)</td>
</tr>
<tr>
<td>Acceptance/ Effectiveness Dimension</td>
<td>Rheumatoid arthritis 4.75 (3.45)</td>
<td>Hypothyroidism 77.7 (30.4)</td>
</tr>
<tr>
<td></td>
<td>Breast cancer 14.95 (5.29)</td>
<td>Asthma 76.4 (32.7)</td>
</tr>
</tbody>
</table>

*Single-item score, ranges from 1-3 SD: Standard deviation

Level of adherence
- For each disease, there were patients reporting the highest adherence score of 8 on the MMAS-8. The lowest adherence level was not reported for all of these diseases (Figure 3).
- None of the diseases was observed to have a high mean adherence score (mean Adherence score <65 for all diseases, indicating low to moderate adherence).

Figure 3: Adherence score for each disease

Box = interquartile (Q3-Q1); + = mean; — median; upper and lower bars = observed max – min values. Boxplots are ranked based on mean MMAS-8® adherence score.

Link between general acceptance and adherence
- According to Pearson correlation coefficient, general acceptance and adherence are significantly correlated (0.27 in the global population, p<0.0001).
- From one language to another, this link can be different (from 0.17 for German-speaking population to 0.30 for Italian-speaking population).
- While most of the diseases showing the highest levels of general acceptance also show the highest levels of adherence (arterial hypertension, COPD, hypothyroidism, diabetes), some interesting contrasts are found (e.g. asthma, with high level of treatment acceptance and low level of adherence, or breast cancer, with low level of acceptance and high level of adherence).
- This link was also studied for each disease and showed some important differences. The only two diseases for which the null hypothesis is not rejected are hypothyroidism and COPD (correlation=0.016, p=0.87; correlation=0.14, p=0.09, respectively).
- For the other diseases, the correlation coefficient goes from 0.17 (ankylosing spondylitis) to 0.39 (epilepsy).

Conclusion
- Acceptance and adherence are two different but related constructs. While adherence assesses behaviour towards treatment, acceptance explains and partially predicts behaviour. This relationship is complex and varies across diseases.
- The results from our study may highlight unmet needs across a large variety of chronic diseases, and for each disease, the treatment attributes that are a concern for patients and where therapeutic innovation is needed.

References
4. For more information, please contact: Elodie de Borck, edeborck@mapigroup.com, www.mapigroup.com