Patients’ views on adherence to treatment in schizophrenia

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Aims and development of the survey
The 2012 GAMIAN-Europe survey

- GAMIAN-Europe, a patient-driven pan-European organisation, represents the interests of persons affected by mental illness and provides:
  - Advocacy
  - Information and education
  - Combating stigma, discrimination and exclusion
  - Patients’ rights
  - Cooperation, partnerships and capacity building
  - Promoting self help and community care

GAMIAN, Global Alliance of Mental Illness Advocacy Networks

GAMIAN/ P. Arteel, personal communication
GAMIAN-Europe endeavors to capture patient views through surveys sent out through the network member associations.

Translated survey packs posted online on the GAMIAN website, Facebook, Twitter and LinkedIn pages.

- Stigma (2006 and 2010)
- Physical and mental health (2011)
- Adherence to treatment (2012)
- Mental Health and workplace (2013)
The need to understand the patients’ perspective of adherence (2)

- There are a range of patient-, treatment-, environment- and physician-related factors that contribute to partial and/or non-adherence to medication in patients with schizophrenia.¹⁻³
- Understanding poor adherence from a patient perspective may help to identify ways to address adherence more effectively

Aims of the survey

In 2012 GAMIAN-Europe conducted a survey on adherence to treatment amongst patients with schizophrenia.

The survey results are intended to be circulated amongst National and EU policymakers.

- With the aim of improved integration of mental and physical healthcare for patients living with mental health disorders.

This project was financially supported by an educational grant from Janssen Pharmaceutica NV.

GAMIAN/ P. Arteel, personal communication.
The survey was compiled by a steering committee of patient representatives and academics:

**Who?**
- Patients

**How many?**
- 403

**Where?**
- 18 countries (GAMIAN website)*

**When?**
- April – July 2012

**Poster presented at:**
- ECNP (October 2012)

Questions were designed to assess patients’ experiences of:
- Medication
- Psychotherapy/counselling
- Psychoeducation
- Self-help initiatives

*The survey could also be downloaded and completed copies returned by post

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria; GAMIAN/ P. Arteel, personal communication
Adherence to treatment is more than adherence to medication.

- Antipsychotic medication is widely recommended as first-line treatment in patients experiencing their first episode psychosis.

- Multi-model care as adjuncts to medication to help alleviate symptoms and improve adherence, functioning and QoL.

- Delivery of targeted information to increase the knowledge and understanding of the illness and treatment.

- Self-help groups offer a voice with the time to listen to patients’ concerns, their side effects and their self doubt.

- Four cornerstones to treatment:
  - Medication
  - Psychoeducation
  - Psychotherapy/counselling
  - Self-help

QoL, quality of life

GAMIAN/ P. Arteel, personal communication
Background of respondents
Patient survey: the demographics

403 responses from 18 countries

Demographics
- 63% of respondents were male
- 64% were aged 31–50 years

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47% of respondents had been hospitalized five times or more

<table>
<thead>
<tr>
<th>Times hospitalized</th>
<th>Patients, %</th>
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<tbody>
<tr>
<td>Never</td>
<td>7</td>
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<tr>
<td>1</td>
<td>16</td>
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<td>2–4</td>
<td>31</td>
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<tr>
<td>5–10</td>
<td>26</td>
</tr>
<tr>
<td>&gt;10</td>
<td>21</td>
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</tbody>
</table>

Number of hospitalizations

Fewer patients from WEU (38%) than EEU (47%) were hospitalized five times or more

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria; GAMIAN/ P. Arteel, personal communication

WEU, Western European Union; EEU, Eastern European Union
Most respondents believe it is important to take treatment as prescribed

Responses varied according to treatment type, with strongest agreement on the importance of medication.

Q/ I think it is important to always attend treatment exactly as prescribed by the doctor

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria
Many patients did not consider themselves well informed about treatment options

- 50% of respondents thought themselves to be well informed about possible treatment options
- 37% did not consider themselves well informed

Q/ Were you well informed on possible treatment options?

WEU, Western European Union; EEU, Eastern European Union; EU, European Union
Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria; GAMIAN/ P. Arteel, personal communication
Fewer than 4% of patients receive the ‘best package of care’ as considered by GAMIAN-Europe

- 92% of respondents reported receiving antipsychotic medication
- 40% of respondents received medication along with psychosocial therapy
- 48% of respondents received antipsychotic medication alone

WEU, Western European Union; EEU, Eastern European Union; EU, European Union

No respondents reported receiving psychoeducation/self help; psychotherapy/self help; psychotherapy/psychoeducation; psychoeducation

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Reasons for not currently taking medication or having stopped medication

The most commonly specified reason for medication non-adherence was side effects (31%) 

Although 42% of patients selected other unspecified reasons

- Side effects: 31.3%
- Lack of belief/trust/respect for effect of treatment: 18.1%
- Financial reasons: 7.6%
- Dislike of treatment: 12.5%
- Lack of effectiveness: 13.2%
- Stigma: 16.7%
- Other: 42.4%

Patients could select more than one option
Reasons for not attending or having stopped getting psychotherapy

Dislike of treatment was the most commonly specified reason for not attending or having stopped psychotherapy.

Although 29.8% of patients selected other unspecified reasons.

Patients could select more than one option.

Reasons for not attending psychoeducation

- I do not want to be informed: 30.3%
- Financial reasons: 22.9%
- Information not useful: 18.2%
- Stigma: 32.0%
- Other: 2.6%

Of patients not involved in psychoeducation embarrassment to disclose their illness and not wanting to be informed were the most commonly specified reason for not attending or having stopped psychoeducation.

*Patients not involved in a psychoeducational programme
†Information not useful for me; it was not adapted to my skills

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria

Patients could select more than one option
Reasons for not attending self help*

- Did not know self help groups existed: 23.7%
- No local groups: 15.8%
- Lack of belief/trust/respect for effect of treatment: 19.1%
- Financial reasons: 6.6%
- Did not want to meet other mental health patients: 16.2%
- Lack of effectiveness: 17.0%
- Stigma: 16.2%
- Other: 26.6%

*A considerable proportion of patients were not aware of self help groups

Although 27% did not attend for other, unspecified reasons

*Patients who did not attend meetings of a self help group

Patients could select more than one option

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria
Role of patient organization
Members of patient associations tend to have more positive attitudes towards treatment.

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Financial impact on adherence to treatment
Patients believe that financial barriers effect their attendance to treatment

Patients financial constraints impacted psychotherapy and psychoeducation the most. These constraints were greatest in Eastern European countries.

Q/ Is there a financial barrier to attend treatment: for financial reasons (it’s too expensive, I cannot afford it)?

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria
Conclusions

Summary of key findings
Conclusions (1)

Adherence to treatment covers more aspects than antipsychotic medication alone, however:

- Few respondents received medication in combination with other therapies
- Many patients were not well informed about treatment options

Families play an important role in the lives of patients with schizophrenia

- Patient care and treatment adherence are shared responsibilities

Many patients face financial barriers to accessing all forms of treatment

- There is an additional pressure of the financial crisis, particularly in Eastern European countries

Gauci et al. Poster presented at ECNP, 13–17 October 2012, Vienna, Austria
Conclusions (2)

Patient associations have an important and often underestimated role in managing schizophrenia

- They can help engage patients in treatment and encourage adherence

Members of patient organizations surveyed

- Had a better understanding of treatment choices available
- Were more positive towards treatment
- Were more likely to receive optimal care in line with current treatment guidelines

Thank you

http://www.gamian.eu