Health Literacy in Special Populations; Implications for Practice and Policy

Dr Laura J Sahm
Senior Lecturer in Clinical Pharmacy, UCC.
Overview

• Learning Objectives
• Background
• Aims
• Methods
• Results
• Conclusion
• Future recommendations
Learning Objectives

• At the end of this talk you should be able to:

• Define special populations as it refers to health literacy
• Give details on the prevalence of limited health literacy as it applies to the (i) obstetric and (ii) clozapine patient population
• Detail the problems which can arise if this trend continues
• Give practical examples of how this can be improved in your practice
Health Literacy definition

“the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions”.
Prevalence in Ireland

• At a minimum, 1 in 7 Irish adults have limited health literacy, which may affect their ability to promote, protect, and manage health.
Health literacy and beliefs about medicines in an obstetric population at Cork University Maternity Hospital (CUMH)

• **Aim:**
  
  • To assess the impact of demographic factors on both health literacy and medication beliefs and to determine the relationship between health literacy and beliefs about medicines
Study 1: Obstetric patients

Methods

• Permission for this study was granted by the Clinical Research Ethics Committee (CREC), University College Cork.

• Data were collected by interviewer-assisted survey at the ante-natal unit of Cork University Maternity Hospital between the 4\textsuperscript{th} and 24\textsuperscript{th} January 2012.
Study 1: Obstetric patients

Methods

- Pregnant females attending the antenatal unit of Cork University Maternity Hospital (CUMH), Ireland were approached and asked whether they would like to participate in the study.

- Inclusion criteria:
  - aged 18 years or over,
  - spoke fluent English and
  - did not have any visual or hearing impairments.

The demographics collected included; age, ethnicity and education level. Education levels have been classified as follows: Secondary (ages 12-19 years), Tertiary (Certificate or Diploma; Degree; postgraduate qualification).
Study 1: Obstetric patients

Methods

- Survey was in three parts;
- a demographic section; age, ethnicity, profession and level and age leaving education
- a health literacy assessment which comprised six statements regarding health literacy and a Rapid Estimate of Adult Literacy in Medicine (REALM) which categorises patients based on their performance in a sixty-six word test with a score of 60 or less indicating marginal health literacy and a score of 61-66 indicating adequate health literacy and
- a ‘Belief about medicines Questionnaire’ (BMQ).
Study 1: Obstetric patients

Methods

• The BMQ consists of two parts; general and specific. In this instance the general BMQ was used which consists of eight statements divided into two categories: General Harm and General Overuse.

• Participants responses were recorded on a five point Likert scale where 1= Strongly Agree, 2= Agree, 3= Don’t Know, 4= Disagree, 5= Strongly Disagree, thus, the lower the score the greater the belief in the statement.
Data analysis

- Data analyses were conducted using Stata/MP version 11.0 (StataCorp, College Station, Texas, United States).
- Chi-square analysis was performed to examine associations between age and level of education on health literacy, as defined by REALM categorisation.
Results Study 1:

• Of 404 females;
• 15.3% (n=62) displayed limited health literacy.
• Age and health literacy were significantly associated with one another, as were health literacy and level at which participants completed formal education.
• More than 1 in 7 had limited health literacy; these women may benefit from educational initiatives.
• Limited health literacy is associated with a more negative perception of medicines in this cohort.
## Study 1: Obstetric patients
### Demographics

<table>
<thead>
<tr>
<th>Age</th>
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<tbody>
<tr>
<td>18-25</td>
<td>58</td>
</tr>
<tr>
<td>26-30</td>
<td>101</td>
</tr>
<tr>
<td>31-35</td>
<td>159</td>
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<tr>
<td>36-40</td>
<td>77</td>
</tr>
<tr>
<td>&gt;40</td>
<td>9</td>
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<table>
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<tr>
<th>Ethnicity</th>
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<td>White-Irish</td>
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<tr>
<td>White- Other</td>
<td>53</td>
</tr>
<tr>
<td>Asian-Irish</td>
<td>1</td>
</tr>
<tr>
<td>Asian-Other</td>
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<table>
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<tr>
<td>Junior Certificate</td>
<td>34</td>
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<tr>
<td>Leaving Certificate</td>
<td>78</td>
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<tr>
<td>Post Leaving Certificate</td>
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</tr>
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<td>Degree</td>
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<td>Postgraduate</td>
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<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Professional</td>
<td>66</td>
</tr>
<tr>
<td>Managerial/Technical</td>
<td>90</td>
</tr>
<tr>
<td>Semi-Skilled</td>
<td>89</td>
</tr>
<tr>
<td>Skilled Manual</td>
<td>31</td>
</tr>
<tr>
<td>Non-Skilled</td>
<td>17</td>
</tr>
<tr>
<td>Health Professional</td>
<td>16</td>
</tr>
<tr>
<td>Student</td>
<td>9</td>
</tr>
<tr>
<td>Housewife/Homemaker</td>
<td>53</td>
</tr>
<tr>
<td>Unemployed</td>
<td>33</td>
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</table>

<table>
<thead>
<tr>
<th>Literacy</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-case (REALM score 61-66)</td>
<td>342</td>
</tr>
<tr>
<td>Case (REALM score 61&gt;)</td>
<td>62</td>
</tr>
</tbody>
</table>
Figure 1: Age vs. REALM scores
Study 1: Health literacy results

- Degree and postgraduate students were significantly more health literate than other groups (p<0.05).
- Those aged between 31-35 and 36-40 were also significantly more health literate (p<0.05).
- Professionals, managerial/technical and health professionals had significantly higher REALM scores.
### Study 1: Obstetric patients

**Results**: BMQ as a function of HL

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Don’t Know</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most medicines are addictive</td>
<td></td>
<td>2.50</td>
<td>3.404</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Natural remedies are safer than medicines</td>
<td></td>
<td>2.597</td>
<td>3.170</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicines do more harm than good</td>
<td></td>
<td></td>
<td>3.702</td>
<td>3.097</td>
<td></td>
</tr>
<tr>
<td>All medicines are poisons</td>
<td></td>
<td></td>
<td>3.977</td>
<td>3.548</td>
<td></td>
</tr>
<tr>
<td>Doctors place too much trust in medicines</td>
<td></td>
<td>2.88</td>
<td>3.32</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Those with adequate HL**
- **Those with limited HL**
Beliefs about medicines; age, education and occupation

• BMQ scores showed that the >40 years group and the 31-35 group were significantly more positive about certain statements.

• Post leaving cert, degree and postgraduate groups had significantly more positive views about medicines than secondary, junior and leaving cert groups.

• Healthcare professionals were significantly more positive about medicines than other groups.
Further reading:

Journal of Health Communication
International Perspectives

ISSN: 1081-0730 (Print) 1087-0415 (Online) Journal homepage: http://www.tandfonline.com/loi/uhcm20

Associations Between Health Literacy and Beliefs About Medicines in an Irish Obstetric Population

Lydia Duggan, Suzanne McCarthy, Laura M. Curtis, Michael S. Wolf, Caroline Noone, John R. Higgins, Susan O'Shea & Laura J. Sahm
Study 2: Clozapine patients

Background

• Schizophrenia is often a severe and disabling disorder. It begins with a disruption in cognition and emotion and patients eventually experience positive or negative symptoms or both.

• Positive symptoms include hallucinations and delusions, negative symptoms include avolition, alogia, apathy, and poor or non-existent social functioning.
• Imagine suddenly developing an illness in which you are **bombarded with voices** from forces you cannot see, and stripped of your ability to understand what is real and what is not. You discover that you cannot trust your senses, your mind plays tricks on you and your family or friends seem part of a **conspiracy** to harm you. Unless properly treated, these psychotic experiences may destroy your **hopes and ambitions**, make other people recoil from you and ultimately **cut your life short**
Study 2: Clozapine patients
Burden of schizophrenia

- Lifetime risk 1%
- Typically manifests in 20s: slightly more common in men than women
- Course of the illness is highly variable
- 25% full recovery
- 75% will experience a relapse:
  - 50% partial recovery
  - 25% chronic illness
- Recovery:
  - ‘Being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms’
- 10% die by suicide
Study 2: Clozapine patients
Introduction to clozapine

- First ‘Atypical’ antipsychotic
- Hospital only initiation monitoring and supply
- Treatment resistant schizophrenia (at least two other agents tried at optimal dose for an adequate duration)
- Dose titration starting at 12.5mg daily. Average dose 450mg daily
- Missed dose: >2 days requires re-titration
- Plasma levels can be useful
- Caffeine increases and smoking decreases clozapine levels
- Hypersalivation, constipation, fever, seizures
- Agranulocytosis
  - Weekly blood samples for 18 weeks, fortnightly up to 52 weeks, monthly thereafter
  - Registration with a monitoring service
Study 2: Clozapine patients
Aims and objectives

• The main aim of this study was to improve knowledge amongst schizophrenic patients on clozapine through a pharmacist intervention.

• Objectives:
  • Design a user-friendly PIL on clozapine, which has a higher FRES and a lower FKGL than the company-produced PIL.
  • Design and pilot a questionnaire which assesses patient knowledge of clozapine.
  • Using the questionnaire conduct a baseline audit of current level of knowledge regarding clozapine.
  • Provide patients with both verbal and written information on clozapine.
  • Using the REALM screening tool, assess patient’s health literacy.
  • Using the same questionnaire, re-audit the patients after a specified time interval to determine whether pharmacists’ intervention has improved their knowledge of clozapine.
  • With the results from the REALM, evaluate the link between health literacy and patients understanding of clozapine.
Study 2: Clozapine clinic

- Patients, over 18 years,
- attending the Clozapine Clinic of a Cork urban teaching hospital,
- based upon clinician guidance regarding their suitability.

- Demographics such as gender, age, employment and smoking status, were gathered from all participants.
- The total daily clozapine dose, duration of clozapine treatment, and information regarding the clozapine DVD was also noted.
Data analysis

- The statistical package for the Social sciences (SPSS) Version 15 (SPSS, Chicago, Ill.) was used for data analysis. M. Sahm PhD assisted with statistical analysis and interpretation.

- Descriptive statistics include frequencies, percentages and mean values. Means are reported with standard deviation (SD) where appropriate. Bivariate analyses were conducted to determine any statistically significant relationships between varying parameters e.g. Age versus dose of clozapine. Pearson’s correlation coefficient is reported for parametric data and Spearman’s rho is used to describe correlations with non-parametric data.

- Correlations were significant at the 0.05 level unless otherwise specified. Paired samples T-test is used to describe the correlation between the scores obtained at first and second interviews.
Study 2: Clozapine patients
Flow diagram showing study population

Total
n = 70

Clinically unsuitable
n=14

Refused
n=2

Pilot n=5

1st Interview
n=49

Lost to follow-up*
n=5

2nd Interview
n=44
Study 2: Clozapine patients
Results

• Forty patients (65% male, 95% unemployed and 70% smokers)

• Average age 38.0 years (SD) (SD 11.2) completed the REALM.

• The average score was 60.6 (±8.7).

• Twenty-nine patients (72.5%) were found to have “adequate” health literacy with the remaining eleven patients (27.5%) found to have either “marginal” or “low” health literacy.
Study 2: Clozapine patients
Results of the Flesch-Kincaid readability score for PILs

<table>
<thead>
<tr>
<th></th>
<th>FRES*</th>
<th>FKGL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Company-designed PIL</td>
<td>49.7</td>
<td>10.3**</td>
</tr>
<tr>
<td>Pharmacist-designed PIL</td>
<td>62.0</td>
<td>8.1***</td>
</tr>
</tbody>
</table>

*The higher the score, the easier the document is to understand.
**A FKGL of 10.3 equates to an approximate reading age of 15 years.
***A FKGL of 8.1 equates to an approximate reading age of 13 years.
Study 2: Clozapine patients
Total scores for patients for first and second interviews

<table>
<thead>
<tr>
<th></th>
<th>Average</th>
<th>Max</th>
<th>Min</th>
<th>Standard deviation</th>
<th>Standard Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total score 1&lt;sup&gt;st&lt;/sup&gt; interview (out of 13)</td>
<td>8.16</td>
<td>13</td>
<td>3</td>
<td>2.59</td>
<td>0.39</td>
</tr>
<tr>
<td>Total score 2&lt;sup&gt;nd&lt;/sup&gt; interview (out of 13)</td>
<td>9.57</td>
<td>13</td>
<td>2</td>
<td>2.73</td>
<td>0.41</td>
</tr>
</tbody>
</table>

Correlation and significance of the improvement in scores between the first and second interviews

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Correlation</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pair 1 Score of 1&lt;sup&gt;st&lt;/sup&gt;&amp;2&lt;sup&gt;nd&lt;/sup&gt; interview*</td>
<td>44</td>
<td>0.694</td>
<td>0.000**</td>
</tr>
</tbody>
</table>

** p< 0.001

* Score 1<sup>st</sup> = Score in first interview;
Score 2<sup>nd</sup> = Score in second interview
Study 2: Clozapine patients
Adherence to therapy

• Non-adherence is high in schizophrenia
  – Ten days post discharge: Up to 25% partially non-adherent
  – 1 year: 50% non-adherent
  – 2 years: 75% non-adherent
• Increases risk of relapse

• Strategies to improve adherence
• Information before prescribing and discuss (name, how it works, likely benefits and side effects, how long to continue it)
• Shared decision making
• Explore concerns at each contact
• Specific to schizophrenia, good social and family support
• Explore aspirations for the future and how medication could help
• Explore positive and negative aspects about taking medication and past experiences
• Systematically monitor effectiveness and side-effects
• Manage adverse effects when they occur
• Overcome practical issues
Study 2: Clozapine patients
Conclusions

• Only 72.5% of the population would have been expected to be able to read the company-produced PIL.
• This compares to 95% of the group, which would have been expected to be able to read the pharmacist-designed PIL.
Implications for policy and practice

• These studies raise questions regarding the
  (i) assumptions which healthcare professionals may make with regard to their pregnant patients and their positive / negative beliefs about medicines
  (ii) accessibility of patient leaflet information to a vulnerable group within society.
  (iii) More than a quarter of this clozapine population was found to have marginal or low health literacy. Patient information should be matched to the health literacy level of the target population.
Further reading:

Perspectives in Public Health
http://rsh.sagepub.com/

Health literacy and the Clozapine patient
Susan Brosnan, Elizabeth Barron and LJ Sahm
Perspectives in Public Health 2012 132: 39
DOI: 10.1177/1757913911431038

The online version of this article can be found at:
http://rsh.sagepub.com/content/132/1/39

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