User Centred Evaluation of the Managing Medicines for People with Dementia Website

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Managing Medicines for People with Dementia

Please choose a language to continue...

English
Italian (Italiano)
Macedonian (македонски)

www.dementiameds.com
BACKGROUND

• One in three people will be diagnosed with a dementia
• Most will be cared for in family homes

• **AIMS**: to support medication management amongst people living with a dementia and their carers, with a focus on those from CALD backgrounds
PROJECT TIMELINE

SESIAHS Multicultural Health Grant 2011/12

RG’s MPH 2012/13
- Italian site developed
- Publications

Global Challenges Funding 2015
- Macedonian site developed, evaluated and refined

Future
- Collaborate with Aston University, UK
STAGE 1 - METHODS

• **Stage 1:** Identifying issues described by ethnic minority informal caregivers as they manage medication.

• Three focus groups and seven individual interviews using semi structured interview guide.

• Italian, Greek, Macedonian, Portuguese, Croatian and Dutch adult family caregivers
STAGE 1: Major Themes

- Medication management is a source of stress and may be a point of conflict for family caregivers.
- Family support of this caregiving role is considered to be extremely important.
- Family caregivers believe that they would benefit from external information and support regarding medication management.
STAGE 1: Conclusions

• One way to help combat this stress and conflict is to provide all family caregivers good quality, timely information and resources from reputable sources which include healthcare professionals, support groups and trustworthy internet sources.

• Information presented in easy to understand English and translated into community languages, as well as being made available in other formats, such as visual presentations will increase the accessibility and usefulness of resources.
Stage 2:

- Search for dementia specific medication management information resource.
- Development of a multilingual dementia specific medication management information resource.

Stage 3:

- Pilot testing and evaluation of resource.
STAGE 2: Developing an information resource

- Initial evaluation found: no comprehensive dementia specific medication management information resource is available.
- Development of content for the new resource was guided by:
  - findings from qualitative study
  - information from stake-holders
  - Other key considerations: literacy level and readability, health literacy, cultural relevance, accessibility
Stage 2: Information resource

Key messages

• Undertake regular medication reviews
  – reduce regime complexity where possible.

• Regular use of blister packaged medications
  – regularly checked for safe usage

• Always enquire about whether or not medications can be crushed and/or mixed with food
STAGE 2: Information resource

Key messages 2

• Go to reputable sources of information about medication e.g. GP, pharmacist, nurse

• Use interpreter services when and if possible

• Attend caregiver support groups for ongoing information and support
STAGE 2: Information Resource development & evaluation

- An initial website with English and Italian versions was developed and pilot tested.

STAGE 3

- The results of this study informed the second iteration of the website (www.dementiameds.com)
- Macedonian version of the materials
- Managed using a content management system.
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www.dementiameds.com
EVALUATION SURVEY

• Survey Monkey – 26 items
  – Perceived Health Web Site Usability Questionnaire (PHWSUQ) for older adults – satisfaction, ease of use & usefulness
  – Health literacy levels (measured using Chew's three screening questions)
• Google Analytics
• Evaluation survey live June – September 2015
SUMMATIVE USER TESTING

- Users were asked to complete five tasks
- Think-Aloud method
FOCUS GROUPS & INTERVIEWS

- English – 3 focus groups (n=16)
- Italian speaking caregivers – 1 focus group (n=6)
- Macedonian speaking caregivers 9 interviews

- Suitability, presentation, understandability, accessibility and credibility of content
- Suggest improvements and additions
- Suitability of in-language versions
QUALITY & SUITABILITY OF INFORMATION & EVALUATION OF READABILITY

• **Suitability Assessment of Materials** assessed six areas: content, literacy demand, graphics, layout and type, learning stimulation and motivation and cultural appropriateness.

• **Health-Related Web Site Evaluation Form** has 36 questions, covering: content, accuracy, author, currency, audience, navigation, external links and structure.

• **Health on the Net** eight principles: authority, complementary, confidentiality, attribution, justification, transparency, financial disclosure and advertising.

• **Readability** Flesch Kincaid, Gunning Fog, Simple Measure of Gobbledygook (SMOG), Dale-Chall, Italian Read-IT Dylan Text Tools and the Italian Translated Readability Analyser.
GOOGLE ANALYTICS

• 12,616 page views across 3,117 sessions.
• Approximately 10% were return visitors (n=302).
• Average visitor viewed 4.05 pages and stayed for 2.13 mins.
• Most site visitors came from Australia (n=1,155; 37.05%)
• Visitors also from
  – USA (n=622; 20%)
  – China (n=124; 4%)
  – Japan (n=66; 2%)
  – South Korea (n=52; 2%)
• The majority used a desktop computer (94%; n=2,928) and internet browser Chrome (67%; n=2,082).
Demographics

- 70 site users
- Majority aged between 45 – 64 yrs (n=49, 77%)
- Majority female (n=54, 84%)
- Highly educated (n=62, 97% - tertiary studies)
- All from Australia
- Respondents were mainly service providers

Internet Use

- Use of Internet for >5yrs (n=61, 97%)
- Very comfortable using Internet (n=46, 73%)
- Online for >15 hrs/week (n=38, 60%)
Trustworthy (n=61, 94%)
A fifth spoke a language other than English at home (n=12, 19%)
Useful to people from your cultural background (n=62, 97%)
### SURVEY MONKEY – Perceived Health Website Usability Questionnaire

<table>
<thead>
<tr>
<th>Range</th>
<th>Mean (SD)</th>
<th>Mean Converted*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfaction</td>
<td>5 – 35</td>
<td>27.3 (7.1)</td>
</tr>
<tr>
<td>Ease of Use</td>
<td>3 – 21</td>
<td>16.1 (3.7)</td>
</tr>
<tr>
<td>Usefulness</td>
<td>3 – 21</td>
<td>15.9 (4.7)</td>
</tr>
<tr>
<td>Mean</td>
<td>11 - 77</td>
<td>59.2 (13.42)</td>
</tr>
</tbody>
</table>

* Mean value/highest possible score x 100 = total percentage

USER TESTING

- Sample of 10 - to detect 85% of usability problems
- Aged 26 - 79 years; mean age 51.8 years
- Four were male (40%)
- Participants were informal carers of people diagnosed with a dementia
- They all spoke English at home
- The majority were born in Australia (90%)
- Nine participants had used the internet for 5+ years
- Over half reported using the internet >10-15 hrs/week (60%).
USER TESTING

• Task 1 - required the language settings on the website to be changed; successfully completed by 60%
• Task 2 - required participants to locate the site map, and navigate to a specific page; completed by 90%
• Task 3 - required participants to find a contact number; completed by 20%
• Task 4 - locate where to subscribe for email updates; completed by 10%
• Task 5 – ‘name one benefit of the Blister Pack medicine system?’; 50% completion rate.
Numerous variables affected task completion time, including the presence of children, phones ringing, and the telling of personal stories.

Participants who reported >10 hrs of internet use/week were more successful.

Use of dedicated software confused some participants.

The research was undertaken using computers and laptops with which the participants were not familiar.
FOCUS GROUPS & INTERVIEWS

Data from the interviews and focus groups were combined and analysed.

- Participants found the site content to be useful and comprehensive. They felt that people in the early stages of dementia could use the site to maintain independence.

“Look, it’s great, I think that it will be useful for the older generation, and especially the Macedonian community…” (Macedonian language interviewee #2; son)

“There are possibly two scenarios, there is the person still living independently that is trying to manage it themselves (um) but then you get the scenario where the person is basically being looked after full-time…” (English language focus group; daughter, Gp 2 P6)
FOCUS GROUPS & INTERVIEWS

Use images showing greater diversity with regards to gender, age and cultural differences.

“People seem to be getting younger and younger developing it [dementia]… So I feel that slanting a picture like that is assuming that you have to be old to get dementia…” (English language focus group; spouse, Gp1 P1)
Participants from English speaking backgrounds found the content clear and acceptable but mixed responses to the Italian and Macedonian text and audio information.

“The Italian was hard with the long words.” (Italian focus group, daughter)

“Just what I said before the way is written and formatted, maybe a little bit clearer, more dot points, and I think a lot less jargon.” (Macedonian language interviewee #4; daughter-in-law)
QUALITY & SUITABILITY OF INFORMATION & EVALUATION OF READABILITY

• The site was found to be very reliable and provide superior materials.
• Some minor issues in site design were identified including missing items: date the website was created, date the page was updated, contact information and some missing developers credentials.
• Readability ranged from grade six to college level.
• Medical terms, such as ‘Alzheimer’s’, will have affected the readability scores.
• Audio versions of the information are available in each language.
Multiple methodologies provided robust site testing identified the majority of usability issues.

Convenience samples were frequently used, which normally limits generalisability - the number of different evaluations will have picked up the majority of issues.

Ideally, these methods would have been employed sequentially - their use reflects research in a real world setting.
CONCLUSIONS

• The results of the evaluation used to inform final design changes to the website.

What next?
• Translate information into other languages frequently spoken in Australia.
• Ideally the site will be promoted by national bodies such as Alzheimer's Australia.
Questions?
CONTACT INFORMATION

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The Team
Judy Mullan, Lindsey Harrison, Robyn Gillespie, Khin Than Win, Amanda Baker & Victoria Traynor.

The Students

Gillespie, R.J., Harrison, L., & Mullan, J. 2013 *Medication management concerns of ethnic minority family caregivers of people living with dementia.* Dementia 0(0) 1-16 Advanced Online Publication DOI: 10.1177/1471301213488900

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