Managing medications for individuals living with a dementia: Evaluating a web-based information resource for informal carers

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Managing medications for individuals living with a dementia: Evaluating a web-based information resource for informal carers

Abstract

Aims: The purpose of the study was to evaluate the usefulness of the "Managing Medicines for People with Dementia" (www.dementiameds.com) website for informal carers.

Background: The management of medications for individuals living with a dementia by informal carers is a neglected area of care. We know that informal carers find it difficult accessing reliable and comprehensive information about medications. We also know that the Internet is a contemporary and growing medium through which consumers access health information. This study was unique in that it brought these two elements together through an interdisciplinary study about the usefulness of a new website providing information on medication management.

Methods: Data collection consisted of focus groups with informal carers of individuals living with a dementia. Data were analysed through content analysis.

Findings: Four themes were generated from the data to explain the evaluation of the website by informal carers: (1) Suitability of the website; (2) Presentation of the website; (3) Unexpected benefits of the website content; (4) Future enhancements for website. Participants overwhelmingly agreed the content of the website filled a gap in information needs about medication management for individuals living with a dementia.

Implications for practice: This qualitative evaluation demonstrated the value of the website as a resource for informal carers of individuals living with a dementia. The resource could also be used by community nurses and other healthcare practitioners to help informal carers better manage the medication regimes of individuals living with a dementia. The resource has the potential to reduce complications associated with mismanagement of medications and contribute to new policies for implementing safe medication practices.

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Conflict of Interest Statement

The author(s) declare no conflict of interest.

KEY WORDS

Dementia, medication adherence, caregivers, medical informatics, health education, internet

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INTRODUCTION

Worldwide, 46.8 million people have dementia and this number is expected to increase to 131.5 million by 2050 (Prince et al., 2015). Dementia is a syndrome characterized by deterioration in memory, thinking, behaviour and the ability to perform everyday activities (Alzheimer's Australia, 2017). With this cognitive decline, people living with dementia often require support from formal and informal carers in managing their day-to-day activities. This may involve assistance with their healthcare, including support with their medication management needs.

Regardless of this support, people living with dementia are at greater risk of experiencing medication mismanagement because of the decline in their cognitive capacity(Mitchell, Harvey, Brodaty, Draper, & Close, 2015). There is evidence to suggest that medication management for individuals living with dementia is an area which needs to be improved, and in particular when these patients transition from home to hospital or nursing homes (Deeks, Cooper, Draper, Kurrle, & Gibson, 2016). Registered nurses (RNs) are amongst the formal carers whose responsibility it is to ensure that older people avoid experiencing medication mismanagement by having a good understanding about the safe and effective use of their medicines. However,informal carers, such as family members with no formal healthcare training, are often responsible for supporting the medication management needs of older people living at home, including those living with dementia (Gillespie, Mullan, & Harrison, 2013). Informal carers report finding medication management stressful, complex and difficult, primarily because they perceive that they lack sufficient knowledge and training to take on this role (Gillespie, Mullan, et al., 2013). Further, according to the evidence, informal carers report safety concerns, such as ignorance about the potential dangers of crushing medications and medication errors resulting from unsupervised use by their care recipients (Gillespie, Harrison, & Mullan, 2013; Maidment & MacFarlane, 2009). .

The risk of medication mismanagement is further exacerbated in older people (≥ 65 years) requiring multiple medications to treat their multiple co-morbidities (Garfinkel & Mangin, 2010). This combination of co-morbidities and polypharmacy, (when five or more medications are prescribed (Scott IA, Hilmer SN, Reeve E, & et al, 2015)) places them at increased risk of medication mismanagement (Poblador-Plou et al., 2014). These in turn can increase the distress and concern among carers, and in particular the informal caregivers, managing medications for these people living in their own homes (Fox et al., 2013).

Development of the Managing Medicines for People with Dementia Website

Based on evidence systematic review of the literature (Gillespie, Mullan, et al., 2013) and the findings of an Australian qualitative study highlighting the concerns of informal carers' about managing medications for people living with dementia (Gillespie, Harrison, et al., 2013), the "Managing Medicines for People with Dementia" website (www.dementiameds.com) was developed (Gillespie RJ, Mullan JR, & Harrison L, 2013). The website includes information about how to safely manage medications, as well as additional resources aimed to reduce informal carers' concerns. The website provides information in both written and audio form, available in English, Macedonian and Italian (two significant ethnic groups in Australia). This allows site visitors access to the information, irrespective of their reading ability. Providing this

information via the internet was deemed appropriate because many informal carers are computer literate and access the internet for health related information (Zickuhr, 2011; (Burns, Jones, Iverson, & Caputi, 2012). Furthermore, to help ensure that the information on the website was reliable and credible, the guiding principles of the 'Health On the Net Code of Conduct' (The Health on the Net Foundation, 2017) was complied with. In addition, the Health Summit Working Group Criteria (Thakurdesai, Kole, & Pareek, 2004) was used to provide clear criteria which could be used to evaluate the website.

This paper reports on one aspect of a larger evaluation study, and focuses on evaluation feedback received from informal carers who spoke English as their first language.

Aim

To evaluate the usefulness of the "Managing Medicines for People with Dementia" (www.dementiameds.com) website for informal carers who spoke English as their first language.

METHOD

In this qualitative descriptive study (Thorne, 2016), evaluation of the user's experience and response to using the website took place through focus groups. Focus groups allow participants to consider their views in relation to the views of others (Patton, 2002). Using focus groups enabled the investigation of individual points of view, whilst benefiting from the outcomes of group discussions, as participants also engaged with the responses of other participants. In addition, the focus groups enabled the researchers to capture a range of opinions and insights from across the groups, as well as within (Krueger & Casey, 2000). Focus groups also served as an efficient way to generate data from a larger group of participants than would be possible with one-to-one interviews alone.

The Consolidated Criteria for Reporting Qualitative studies (COREQ) guidelines shaped the reporting of the study design and data analysis. Ethical approval was obtained through the local university's Human Research Ethics Committee.

Sample and setting

The eligibility criteria for inclusion in this study were informal carers (family members, friends and/ or neighbours) of people living with dementia who spoke English as their first language. A convenience sample was recruited of people who had experience with caring for a family member or friend living with dementia.

To recruit participants for the study, the researchers approached local contacts in healthcare and social services, including informal carer support groups and special interest groups run by older people. Promotional activities included posting information flyers in local community facilities (e.g. libraries), nursing homes and community care service facilities. In addition, participants in each focus group were asked to refer suitable participants for future groups.

Data collection

Three focus groups were conducted in regional New South Wales, Australia. The focus groups, which lasted between 60-90 minutes, occurred in a private home in a retirement village, a community hall and a nursing home.

Table 1: Focus Group Composition

Group	Location	Participants
1	RACF meeting room	5 (4 female 1 male)
2	Private home in Lifestyle village	8 all female
3	Community Centre Room	3 female

Prompt questions were developed based on the online evaluation survey used to gain feedback from users of the "Managing Medicines for People with Dementia" website (www.dementiameds.com). The prompt questions were refined after each focus group to ensure that the data generated answered the research questions. These prompts served to guide and encourage discussion among the focus group participants (Table 1).

Table 2: Focus group prompt questions

1. **What is the main message of the content in this resource?**
2. **Do you think the content is relevant to your situation as a carer, relative or friend of a person with dementia?**
3. **What is useful about this resource for helping a carer to look after medicines of a person with dementia?**
4. **What do you particularly like about the resource? What did you particularly dislike about the resource?**
5. **What types of people do you think would read the material in this resource?**
6. **What is easy to read and understandable about the content? What is difficult to read and understand in the content?**
7. **What are your views about the way the content is presented in this resource? e.g. colour choices.**
8. **What are your views about the accessibility of the resource and the content? In particular considering the target audience who are carers of a person with dementia.**
9. **Can you comment on the style of the resource? e.g. the graphics and images.**
10. **How would you judge whether the content is reliable or believable?**
11. **In what ways could the resource be improved?**

The researcher, who also served as the facilitator of the focus groups, recorded focus group discussions on a digital voice recorder and transcribed them verbatim. Participant identification was anonymized with each individual assigned an identification code. The participant

information sheet included the "Managing Medicines for People with Dementia" (www.dementiameds.com) website address, which participants were asked to view prior to the focus group. At commencement of each focus group, participants were asked whether they had viewed the website and all but one reported that they had done so. During the focus groups, iPads and laptops with "wifi" connection were provided to the participants, who were asked to work in pairs on a single device. The participants were asked to scroll through the website pages as they made their contribution to the focus group discussion..

Data analysis

Data analysis commenced immediately following the transcription of the digital recordings. The transcribed data were analysed thematically as it provides an accessible and flexible approach to analyse qualitative data (Silverman, 2006). Using a line-by-line constant comparative method to code the data and generate themes on the transcripts (Corbin & Strauss, 2008) provided an initial explanation of the perceptions and views of the participants regarding the website. Lines of data which reflected common views and perceptions about the website were grouped together using codes created by the researchers. The lead author led stage one of the analysis. Next, authors 2 and 3 undertook a verification activity to ensure the preliminary set of themes generated by the lead author explained the evaluation of the website by the participants. The themes from the data analysis were inductively derived and used to authentically reflect what participants said during the focus groups. As this was a small-scale study with limited resources there was no capacity to invite the participants to check the transcribed data or review the themes generated to explain the findings.

Data collection ceased once the initial data analysis failed to generate any new themes, thus indicating data saturation (Silverman, 2006). This occurred after analysis of the transcript from the third focus group.

A more in-depth data analysis then continued with a focus on developing a deeper understanding about the perceptions and views of the participants. Sets of codes were further grouped together using themes to provide more explanations about the meaning of the views and perceptions about the website. The final themes generated from the first stage of the analysis were arrived at through discussion between the three researchers completing the coding activities (Corbin & Strauss, 2008). The researchers then used an iterative process to discuss discrepancies between codes, until consensus was reached.

Reflexivity

In qualitative research it is important to consider the potential personal bias of the researcher for or against the topic under investigation. In this study, the researcher undertaking this stage of the evaluation of the 'Managing Medicines for People with Dementia' (www.dementiameds.com) website was not part of the original team who developed it. This meant that the analysis was, potentially, undertaken more objectively than might have been possible if a member of the original team who developed the website lead the analysis of this stage. The researcher (author one) spoke English as her first language, which was the same as the participants undertaking this part of the research. Therefore, there was less chance of cultural misunderstandings between the researcher and participants. Also, the researcher was a registered nurse working as a manager in a nursing home. The participants were family carers and again this reduced the risk of over-identification with the participant group because the

researcher's main client group are older people (Shaw, 2016). These considerations are important but their mitigating impact must not be exaggerated or ignored. Even when researchers are reflexive, bias can occur, and this needs to be acknowledged when interpreting the rigor of qualitative findings (Shaw, 2016).

RESULTS

Participants
The three focus groups comprised a total of 16 participants and took place in the community in urban and regional locations in NSW, Australia. All participants were informal carers of people living with dementia. Most were family members; spouses (n=3) and children (n=7), and the remainder were friends (n=6). All were over 45 years, most between 60 and 75 years (94%); all but one was female (94%). All participants were born in Australia and spoke English at home. During the focus groups, all participants demonstrated an ability to access information from the "Managing Medicines for People with Dementia" (www.dementiameds.com) website.

Themes
Four themes generated from the qualitative analysis: (1) Suitability of the website; (2) Presentation of the website; (3) Unexpected benefits of the website content; and (4) Future enhancements for website.

1. Suitability of the website
This theme relates to the suitability (or lack thereof) of the website content for the target audience: carers of people living with dementia. Participants, overwhelmingly, expressed that the website contained important and relevant information and felt that it was suitable for most informal carers. There was an emphasis on the suitability of the website for people seeking information "*early*" in the dementia experience.

Participants generally considered the website a valuable resource which they could use themselves. There was, however, a variation in opinion about the range of people who would benefit from the website. For example, it was suggested that someone in the early stages of dementia would find the website useful to assist with maintaining their independence. One participant provided a specific example of how she thought a relative in the early stages of dementia may want to use it.

> *"I had a conversation with a cousin the other day who knows he is in the very early stages of, he knows he is forgetting things and is getting confused and he is computer literate and really intelligent, so someone like him."*
>
> (friend, Gp2 P5)

The following participant provided a summary of the suitability of the website for a diverse audience.

> *"Yeah 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."*
>
> (child, Gp2 P6)

One participant believed the general practitioner had a responsibility to give helpful advice about medication management, but that this often does not occur. The participant felt that the website encouraged informal carers to ask for more information from general practitioners.

Several aspects of the content were seen as very useful and generated much discussion among the participants. For example, provision of advice on obtaining a medication review from a pharmacist and information on over-the-counter medicines.

> *"Depending on how complicated the number of medicines ... the information about getting a review with the chemist is quite useful."*
>
> (spouse, Gp2 P2)

Participants suggested that the website contained important information about various devices which could be used to assist with the safe and timely administration of medications. There was discussion and critique on medication aids and their usefulness or otherwise. Several participants noted aids they intended to follow up.

> *"So to me that is information I thought gee that is something I can follow up, yeh the blue phone, the automatic carousel dispenser, I had no idea and I liked the fact that at the end it gives information that you can actually follow up on any of those um aids and equipment you are interested in."*
>
> (child, Gp3 P2)

2. Presentation of the website

Theme two relates to the presentation and format of the website. Participants reported obtaining information easily from the website. During the focus groups, the participants browsed the website and made a range of comments. They viewed the language and wording of the website for the most part to be clear, succinct and appropriate.

> *"I think it's* [the website is] *logical ...* [and] *well set out. How the doctor can help you and how the pharmacist can help you and what the medicines, um what to look for and be aware of with the blister packs,* [was] *helpful."*
>
> (friend, Gp1 P5)

Several participants commended that the font size, contrast and the use of "plain English" on the website aided their reading and understanding. Participants remarked on and discussed the audio format of the available information. The general consensus was that the feature was a helpful inclusion.

> *"I found that it was really good plain English, and because you know I have always been aware of vision problems, ... audio is just fantastic, a big tick in my eyes."*
>
> (friend, Gp3 P3)

Although participants commented that the language used on the website was straight forward and clear, a number took exception to several terms used. For example, one participant noted the over use of the term "family member" and the participants agreed that informal carers were not only "family members".

> "And my other dislike … is the fact that "family members" the phrase was used, I didn't actually count but there were 29 pages and probably 2 or 3 different times on each page. I just thought that was a bit of overkill."
>
> (friend, Gp1 P5)

Participants further criticized the lack of gender, age and cultural diversity visually represented on the website. They believed that the photos in the website needed to more clearly reflect the diversity of people living with dementia, as well as the different informal carer relationships.

The website's usability and navigation were also discussed. All participants had experience in accessing websites, although some were more adept than others. For example, several participants found the inability to scroll continuously down the page to be inconvenient.

Other participants expressed the opposite view; one stated that although they were not proficient at using websites, they did not encounter any navigational problems.

> "I am not computer friendly enough … but I looked at it and I was quite happy to progress. I found my way around it."
>
> (spouse, Gp1 P2)

3. Unexpected benefits of the website

Theme three relates to information about and links to other services. The website provided an opportunity for participants to gather information beyond the primary purpose of the website, medication management. In particular, they discussed the usefulness of specific information on other support services, which did not directly relate to safe medication management.

> "I also like the fact that they actually mentioned (ahm) DBMAS [Dementia Behaviour Management Service] and I thought that was really good."
>
> (child, Gp3 P2)

The following extract further demonstrates that participants considered the additional information provided in the website useful.

> "I found it really all useful if I went to look to see what else is around, actually there is not much and so on sites like the Alzheimer's Association they might have some of those medicines and might have some of those tools, resources that you can get there um they didn't have much you know, as comprehensive information as you have on that website."
>
> (child, Gp 2 P6)

One participant, an informal carer and full time worker initially expressed that she was a busy person who had knowledge about medications. However, after viewing the website and some of the links, prior to the commencement of the focus group, she suggested that she found some good information for herself and that others with less knowledge than herself, would also benefit from the information available on the website.

Another participant, an informal carer to non-English speaking parents, commented that the website content was useful because she did not know that access to the national interpreter service could be gained via a General Practitioner free of charge and commented.

> *"I also thought that having the phone number for the telephone interpreting service was terrific …I will be asking the doctor when I go with mum and dad next time is to ask them if they are registered…"*
>
> (child, Gp3 P2)

4. Future enhancements for website

When invited to make recommendations about how the website could be improved, several participants suggested that it would be helpful for the website to generate a medication record that informal carers could complete prior to attending a healthcare appointment. This was further supported by discussions about the need to improve communication around medication management between healthcare providers.

> *"A sort of summary sheet … that you could have the name of the drug … the GP surgery can produce a list but it doesn't have those important reminders like what the most common side effect is, or they mustn't or must take it before or after a meals and those sorts of things."*
>
> (spouse, Gp2 P6)

Participants in all groups engaged in discussions on the topic of younger onset dementia and on the wide range of experiences among informal carers and people living with dementia. Their feeling was that addressing these issues would enhance future iterations of the website.

> *"We always assume that you're in your 80s or 90s to have dementia … more and more younger people seem to be getting it* [dementia]*. So I feel that slanting a picture like that is assuming that you have to be old to get dementia."*
>
> (spouse, Gp1 P1)

Several participants highlighted that going forward, the website needs to be maintained and kept up-to-date. The participants floated ideas on how this could be done. One suggestion proposed to enhance the accessibility of the information on the website was to develop an "App".

> *"I was wondering about an app because so many people are on their smart phones everywhere they go, I was wondering whether this would be useful as an app in some way for the phone?"*
>
> (friend, Gp3 P3)

DISCUSSION

The development of the "Managing Medicines for People with Dementia" website occurred in response to findings in the literature and from previous research which identified the information and support needs around medication management of informal carers of people living with dementia (Gillespie, Harrison, et al., 2013; Gillespie, Mullan, et al., 2013). Managing medication regimes can be a complex task which can result in stress for older adults, people living with dementia and their informal carers (Francis, Smith, Gray, & Denham, 2006; Kaasalainen et al., 2011; Reinhard, Levine, & Samis, 2012). The experiences shared by participants in this study reflected the potential complexity of this task.

This paper reports on an evaluation of the "Managing Medicines for People with Dementia" website by informal carers who spoke English as their first language through the use of focus groups. The themes identified during these discussions were: the suitability of the website, the presentation of the website, the unexpected benefits of the information provided and suggestions for future enhancements of the website.

Theme 1: Suitability of the website

Participants believed that the website was a suitable medium to provide medication support which was relevant for both people living with the early stages of dementia and their carers. The authors were unable to identify evaluations of any other online medication-related resources. However, since older adults are much more likely to be internet users than they were fifteen years ago (an increase from 14% to 67%) (Anderson & Perrin, 2017), and because older people with complex chronic conditions have been shown to use smart phone apps to support medication management (Mira et al., 2014), it could be suggested that online resources are appropriate for this audience.

Theme 2: Presentation

The findings from our study demonstrate that informal carers found the content and structure of the website both useful and usable. Previous studies have indicated that the provision of online health information to consumers can provide: awareness of educational materials, easy access to such materials, improve the quality of interactions with healthcare providers and improve health outcomes (Win, Hassan, Bonney, & Iverson, 2015).

Participants had a range of views about the suitability of the content for the target audience.
Aspects which the participants considered of particular importance were the website content, the visual aids and illustrations available on the website and the audio format and navigation attributes. Participants found the website content to be reliable for the target audience. This is contrary to other studies where concerns about the reliability of the information provided on health websites have been found (Burns et al., 2012). The audio function of the website also received praise and general approval. Participants found that they could navigate their way around the website with a suggestion from some that the scrolling function be replaced by "click on the arrow" function. Navigation is important as ease of navigation and accessibility of websites are vital to the appeal of internet information (Cline & Haynes, 2001)

Theme 3: Unexpected benefits:

Although the primary focus of the website was to support safe medication management, the researchers were surprised at the positive impact that the links to other resources, such as support service website addresses, had on participants. Similarly, the section dealing with the

various medication administration aids, which was considered well illustrated, triggered positive feedback from the study participants. The study participants also valued the fact that the website encourages users/visitors to seek out face-to-face interactions with healthcare providers to further assist with their information needs. This suggests that the participants valued a multi-modal website that provided not only health education but also acted as a portal to other resources.

Theme 4: Future enhancements
Several participants remarked on the lack of images/illustrations on website. Participants commented that "people" were missing and consequently the diversity of people, both ethnically and age wise, affected by dementia was not visually represented. Based on this feedback, the website will be updated to increase the appeal and relevance of the website for the diverse range of people affected by dementia. Interestingly, in terms of age, this finding aligns with previous research which has shown that older adults do not see themselves as old and prefer to view pictures of younger-old people online (Mazur & Lee, 2003). However, it is hard to know whether in this instance this was the sole motivating factor or whether the need to acknowledge younger-onset dementia was also a driver behind the comments.

While health websites might not be able to replace the role of healthcare providers in providing information, websites have the potential to reinforce information provided by healthcare providers. Websites also allow people to go back and review information as many times as they wish, at a time which is convenient to themselves. A further benefit of providing information through websites is that it is relatively cheap and easy to update, as compared to updating paper-based resources. It is important, therefore, that the website be promoted through other avenues, such as dementia websites and newsletters, with a view to reaching even more informal carers who would benefit from visiting the site. The website has the potential to be used by RNs worldwide. However, prior to this occurring, it would be advantageous to explore the views and opinions of RNs, working in various settings, on website.

The researchers struggled to recruit participants to the focus groups, with recruitment taking more than six months. This was despite recruitment being spread over a 100km region, and the use of a range of promotional strategies which included advertising posters displayed in libraries, healthcare and aged care services and shopping centres. Perhaps one of the main reasons for these recruitment difficulties was that the study occurred over the Christmas break, which coincides with summer in the Southern hemisphere.

Strengths and Limitations
This study evaluated the "Managing Medicines for People with Dementia" website from the perspective of informal carers of people living with dementia. The findings suggest that even though the participants valued the website, they have provided useful suggestions which could help to further improve the website. In addition, the findings highlight that the website could be used to support healthcare providers, including RNs, in educating informal carers about how to manage medications for people living with dementia. Further, this study is one component of a larger evaluation program which included feedback from informal carers from Italian and Macedonian backgrounds.

Only one participant was male, suggesting that further evaluation with male carers might be necessary. As RNs are often the first point of contact for in-home care, it is suggested that their views on the website be sought.

CONCLUSIONS

This qualitative study evaluated the "Managing Medicines for People with Dementia" (www.dementiameds.com) website from the perspective of informal carers of people living with dementia who spoke English as their first language. Participants agreed that the content of the website filled a gap in information needs about medication management for people living with dementia, and also made suggestions on how the website could be enhanced. The website is a contemporary, internationally relevant resource which could be used by health care practitioners, such as RNs, to help educate informal carers on how to safely manage medications for people living with dementia.

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