

Using public engagement and consultation to inform the development of ageing- and dementia-friendly pharmacies - Innovative Practice

Abstract

This study explored public perceptions about the importance of, and how to create, ageing- and dementia-friendly pharmacists and pharmacies. In September 2016, four focus groups (45 minutes each) were conducted with sixteen participants who represented organisations, groups or forums working with and/or for older people and people with dementia in Greater London. Discussions were recorded via hand-written notes and thematically analysed. Participants confirmed the importance of pharmacists and pharmacies being ageing- and dementia-friendly and described variability in whether this is currently the case. Suggested strategies for improvement included targeting communication, pharmacist leadership and shop layout.

Word count

1,765

Key words

Ageing, dementia, geriatric medicine, medication, pharmacy

Running title

Ageing- and dementia-friendly pharmacy services

Introduction

Consumers, policy makers and researchers world-wide have become increasingly interested in the concept and development of dementia-friendly communities (Alzheimer's Disease

International). A dementia-friendly community is defined by the Alzheimer's Society as *'supportive and inclusive of people affected by dementia'* (Alzheimer's Society) and by Alzheimer's Australia as *'a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value'* (Alzheimer's Australia, 2017). A priority area in creating dementia-friendly communities is access to appropriate healthcare services, to support people with dementia to live at home for as long as possible (Alzheimer's Australia, 2017).

Pharmacies are important places that people with dementia visit (Brorsson, Ohman, Lundberg, & Nygard, 2011). People with dementia are prescribed multiple medications (Schubert et al., 2006) and they consider pharmacists as crucial to their medication management team (While, Duane, Beanland, & Koch, 2012). As a result, pharmacies should be ageing- and dementia-friendly (Bennett, 2015). The Alzheimer's Society (Alzheimer's Society, 2015) and Alzheimer's Australia (Alzheimer's Australia, 2017) have developed toolkits to support businesses in the pursuit of becoming dementia-friendly, with suggestions including: pharmacists should identify specific medication needs of local people with dementia and their carers, to ensure tailored, person-centred pharmacy services; staff should be trained in dementia-appropriate communication; and the pharmacy workplace environment should be assessed for adequate signage, lighting, colour contrast, labelling and quiet areas (Alzheimer's Australia, 2017; Alzheimer's Society, 2015; Stafford, 2015).

This study aimed to explore the perceptions of individuals who represent organisations that work with and/or for older people and people with dementia, regarding the importance of ageing- and dementia-friendly pharmacists and pharmacies, and how they can be created.

Methods

In September 2016, JG-T presented a public seminar at the Age UK London's offices concerning her Australian ageing- and dementia-related research. All individuals on the Age UK London's offices electronic mailing list were invited to attend. These individuals represented at least 500 organisations, ranging from small, local clubs to large forums with over 1000 members, working with and/or for older people and people with dementia in Greater London. The first 20 interested individuals were registered to attend. Immediately after the public seminar, JG-T invited all attendees to participate in a focus group. A study explanatory statement was provided and a signed consent form was required. Seminar attendees were invited to participate in this study as their work roles increased the likelihood that they could knowledgeably contribute to the study.

It was anticipated that all 20 public seminar attendees would participate in the study, leading to a total of four focus groups with five participants each. The total number and size of focus groups was chosen to ensure all relevant issues would be identified without new ideas emerging (Smith, 2002) and that all participants could contribute to discussions (Krueger, 1994; Smith, 2002). Each focus group was moderated by one of four facilitators (including JG-T). This allowed multiple focus groups to be conducted simultaneously, after the public seminar had concluded, at the Age UK London's offices. All facilitators had experience undertaking qualitative research, were appropriately skilled to guide discussions without influencing them and to ensure equal participant contributions, and three of them were pharmacists (Patton, 1990).

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74 To maintain anonymity, and as per the study ethical approval, participant names were not
75 used during discussions, audio-recording was not possible and identifying information could
76 not be recorded. Each facilitator used hand-written notes to record the main focus group
77 discussion points and participants had the opportunity to assist the facilitator in ensuring
78 that their contributions were accurately recorded. This methodology has been
79 recommended in circumstances where audio-recording is not possible (Kitzinger, 1995). This
80 study followed similar, successful methodology where public engagement has informed
81 priorities in health and social care research and practice (Alsaeed et al., 2016; Poland et al.,
82 2014).

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84 An open-ended, semi-structured question guide (McNeill & Chapman, 2005) was developed
85 by JG-T (Table 1) to allow participants to raise new ideas or issues that they believed were
86 important, which focus group facilitators could further explore by asking additional
87 questions (Smith, 2002). Communicative validity was assessed in this study by comparing
88 study findings with existing dementia-friendly community guidelines (Alzheimer's Australia,
89 2017; Alzheimer's Society, 2015; Smith, 2002).

90

91 Table 1. Semi-structured question guide

Number	Question
1	What makes a health care environment/health care professional ageing- or dementia-friendly?
2	How important is it that pharmacies/pharmacists are ageing- and dementia-

	friendly?
3	Do you perceive that pharmacies/pharmacists are ageing- and dementia-friendly currently (and describe how they are or are not)?
4	What are your recommendations to make pharmacies/pharmacists more ageing- and dementia-friendly?
5	How should we be educating our pharmacy students/health care professional students to be more ageing- and dementia-friendly?

92

93 *Ethical approval*

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95 As JG-T was based at Monash University (Australia), ethical approval was obtained from the
 96 Monash University Human Research Ethics Committee (Project Number: 0742). This ethical
 97 approval allowed JG-T to conduct the study in the UK.

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99 *Data analysis*

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101 Data were analysed using a thematic approach, which involved familiarisation with the raw
 102 data, identification of key themes as they emerged, defining and naming themes, formation
 103 of an initial coding frame, and indexation of the data to that coding frame (Pope, Ziebland,
 104 & Mays, 2000). The coding frame was discussed among all four focus group facilitators to
 105 ensure the validity and credibility of data analysis and to clarify discrepancies.

106

107 **Results**

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Four focus groups, of approximately 45 minute duration, were conducted with a total of 16 participants (only 16 of the 20 public seminar registrants actually attended the public seminar). The seven male and nine female participants were representatives of organisations, groups or forums working with and/or for older people and people with dementia in Greater London. Participant work roles ranged from positions of leadership to lay members and volunteers. Many participants were aged older than 55 years and used their and their members' personal experiences to inform discussions. According to the ethical approval of the study, specific participant characteristics were not recorded. Identified themes are presented below in italics.

The importance of ageing- and dementia-friendly pharmacists and pharmacies.

Participants explained that as the population is ageing and the number of people with dementia is increasing, there is an increase in healthcare being provided in the community setting, and pharmacies are community-based healthcare destinations that are accessible to older people and people with dementia. However, they explained that there does not appear to be a satisfactory ageing- and dementia-friendly standard being adhered to by pharmacists and pharmacies. Participants mentioned that it could be more difficult for pharmacies to be ageing- and dementia-friendly if they were part of large organisations, compared to smaller, independent pharmacies, where staff could be more familiar with the community they serviced.

Strategies to improve how ageing- and dementia-friendly pharmacists are.

Participants suggested that when communicating, pharmacists should: allow people with dementia adequate time to communicate without feeling rushed; use eye contact; be calm, patient and respectful; physically approach patients from behind pharmacy barriers; and consider writing important information down for the patient where necessary. Participants suggested that pharmacists could ask general practitioners to help them identify patients with dementia, so that a dementia register could be developed and more individualised services provided. However, pharmacists would need to be aware of the risk of stereotyping or labelling people with dementia. It was suggested that pharmacists could also adopt a leadership role in providing ageing- and dementia-friendly services and encourage other pharmacists to also take on this role. When referring to healthcare professionals in general, participants suggested that they should adopt a positive ageing- and dementia-friendly attitude and that dementia-friendly terminology should be used when communicating about dementia (e.g. 'living', compared to 'suffering' from dementia).

Strategies to improve how ageing- and dementia-friendly pharmacies are.

Participants recommended that: pharmacies are easily identifiable and accessible if they are located within large shops; signage should be clear and limited in number; there should be seating, a private consultation room and a hearing loop system; door mats should not be black; and a clear and concise list of what pharmacies do or do not do should be present, as well as information regarding where older people can access healthcare services. It was recommended that pharmacies adopt ageing- and dementia-friendly standards, which are developed in conjunction with people with dementia and their carers. Additionally, pharmacies should be regularly assessed for dementia-friendliness (e.g. using mystery

shoppers) and provided with a dementia-friendly rating or clear signage that identifies them as dementia-friendly.

Strategies to improve how ageing- and dementia-friendly healthcare professional students are.

Participants recommended that students should undertake work experience in different settings (care homes, hospitals, pharmacies, dementia cafes, memory clinics, day care centres) where they may encounter older people and people with dementia. Additionally, students could be asked to explore the experiences they've had with their grandparents or become friends with older people. Participants explained that the ageing- and dementia-friendly theme should be incorporated throughout all years of the educational program, it should be compulsory for students to attend ageing- and dementia-related topics, and relevant topics could be taught by older people and people with dementia. Participants felt that students should understand that older people and people with dementia differ in terms of their characteristics and needs and that ageing does not always lead to cognitive impairment or dementia.

Conclusion

This study has provided important insight into public perception of the importance of developing community pharmacies as dementia-friendly environments. Participant suggestions of how to develop dementia-friendly pharmacies were similar to those in Alzheimer's Society and Alzheimer's Australia guidelines (Alzheimer's Australia, 2017;

Alzheimer's Society, 2015) including, clear signage, considering the input of people with dementia when designing dementia-friendly environments, and using dementia appropriate language (Swaffer, 2014). With regards to the suggestion of a dementia register, increasing pharmacist awareness of patients with dementia may instead be addressed by the current National Health Service (NHS) initiative to allow community pharmacists to view Summary Care Records (SCR) (NHS Digital, 2017a, 2017b). These patient-specific electronic records are created from general practitioner medical records, must contain certain patient information (e.g. current medications), and may contain other information if the patient wishes (e.g. chronic medical conditions, such as dementia) (NHS Digital, 2017a, 2017b). Pharmacists can view SCR if they are involved in the patient's care and have their consent (NHS Digital, 2017a, 2017b). Pharmacist-accessible SCR could address potential issues associated with developing a pharmacy-based dementia register, such as not having a regular pharmacist to whom details of the person with dementia could be sent, the need for a general practitioner to obtain consent before disclosing medical details about a specific patient, and the difficulties associated with establishing comprehensive data protection policies and practices. In terms of policy, practice and research implications: the Alzheimer's Society and Alzheimer's Australia should collaborate with pharmacy organisations like the Royal Pharmaceutical Society of Great Britain and Pharmaceutical Society of Australia, to determine how best to support the implementation of available guidelines (Alzheimer's Australia, 2017; Alzheimer's Society, 2015); pharmacists should explore local logistical, organisational, financial and personal barriers and facilitators to guideline implementation; and future research should comprehensively explore whether ageing- and dementia-friendly strategies are currently being implemented into pharmacies.

205 **Declaration of Conflicting Interests**

206 None Declared

207 **Supplementary Materials**

208 Data available upon request

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