

# A qualitative study exploring medication management in people with dementia living in the community and the potential role of the community pharmacist

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## Executive summary

### Background

The number of people living with dementia is increasing rapidly. Dementia increases the likelihood of risk factors, such as comorbidity and polypharmacy, for adverse drug reactions; the presence of cognitive impairment also increases the risk of medication errors. With increasing cognitive impairment, medication management shifts from the responsibility of the person with dementia to formal (paid) or informal (family) carers. Informal carers may not feel equipped for such a role which they can find burdensome and stressful, worsening the quality of life of the carer and person with dementia. Community pharmacists may be able to support informal carers with medication management and the need for further research exploring this potential role has been identified. This project aimed to explore the perspectives of the key stakeholders to understand the key challenges associated with medication management and how community pharmacists can support PwD living in the community with medication management.

### Method

This report used a qualitative approach with data triangulation from three studies (a meta-synthesis, qualitative framework analysis and an Interpretative Phenomenological Analysis) to provide a valid and reliable understanding of the objective of this report from different perspectives. The meta-synthesis was conducted in order to explore (and appraise) published literature investigating medication management in PwD living at home; the effect managing the medication of care-recipients has on informal carers of PwD and the role healthcare professionals have in supporting PwD and their informal carers manage medication.

Participants for the qualitative research were recruited from the Alzheimer's society, Dementia UK, local GP surgeries and local dementia support groups (including a support group for people with

dementia in the black and minority ethnic [BME] community in Yorkshire). Snowballing (when participants are asked to identify other potential participants) was also used. Data was analysed using framework analysis to explore the experiences and perspectives of PwD, informal carers and HSCP (including pharmacists) in regards to medication management in PwD and the role of community pharmacists in supporting PwD to manage their medication. Additionally, Interpretative Phenomenological Analysis (IPA) of the experiences of eight informal carers living with someone with dementia was conducted to understand how informal carers make sense of their individuality and their lived experiences of dementia, medication management and relationships with healthcare professionals.

## **Results**

Thirty-two participants (11 informal carers; 5 PwD; 16 HSCP [4 GPs, 5 nurses, 3 paid carers, 4 community pharmacists]) were recruited. These results focus on the framework analysis. Three key themes were identified:

1. Informal carers and PwD described the key challenges experienced by PwD and their informal carers in relation to medication management. The caring role commonly included responsibility for medication management which created both practical problems and an emotional burden. Informal carers reported that, the characteristics of dementia increased the challenge associated with managing medication. Informal carers found the process complex particularly if they were managing their own medication as well. This burden was worsened by any difficulty in obtaining appropriate support from HSCP and if the PwD was taking a complex regimen.
2. Informal carers, PwD and HSCP shared valuable perspectives about the process of medication management in PwD dwelling in the community. The process could be improved by co-ordinated and on-going support from HSCP with clear communication about medication. This support should focus on the informal carer. Medication reviews, particularly when conducted in the home environment, could have a potentially positive impact on medication management.
3. Pharmacists were thought to be underutilised, and informal carers and HSCP identified how community pharmacists could support medication management to a greater extent. Pharmacists needed to promote their services and work within a multi-disciplinary environment with full access to medical records. There was also a need for named pharmacists specially trained in dementia care and for pharmacists to work outside the pharmacy; for example conduct medication reviews in the person's own home.

## **Discussion**

Medication management in PwD in the community is frequently very complex and needs to be improved. As dementia develops medication management becomes the responsibility of informal carers, who frequently have little or no experience or knowledge. Informal carers found this role

challenging particularly when the person lacks an understanding of the need for medication. This challenge was compounded by, at times, limited support from HSCP.

There was general agreement that PwD living in the community would benefit from more active support from community pharmacists. This support should include education delivered within the pharmacy and more practical aspects such as going into people's houses to help them organise the medication and develop strategies to avoid medication errors. Barriers to an expanded role included the difficulty accessing pharmacy services partly due to the current funding model. Community pharmacists would also need full access to appropriate medical records and work within a multi-disciplinary framework.

### **Implications for practice and policy**

HSCP need to have a clear understanding of the potential challenges that PwD and their informal carers face every day in relation to medication management; these challenges may often be hidden behind the front door. Pharmacists should focus on developing their role outside the physical environment of their community pharmacy. Policy should focus on supporting informal carers of PwD with medication management and enable community pharmacists to fulfil such a role. Research policy should reflect the need for further research.

### **Research Implications**

Future research needs to build a robust base of evidence on community pharmacy and how services from community pharmacy can be improved in terms of quality and patient-centered approach. From this enhanced evidence-base a complex intervention should be developed in line with Medical Research Council (MRC) guidelines. Further research is also needed on the challenges faced by people from BME communities.

### **Conclusion**

Medication management for PwD living in the community appears to be a complex process with informal carers playing a key role. Community pharmacists could improve the process by providing further support to informal carers.