Supporting family carers of older people in community pharmacy: a review of guidelines and qualitative study

Principal investigator: Felicity Smith; **Lead researcher**: Liz Jamieson; **Review team**: Richard O'Neill, Jill Craigie, Sarah Edwards; **Other collaborators**: Ashok Soni, Nina Barnett, Asha Katwa, Sharleen Rudolf

EXECUTIVE SUMMARY – February 2016

Background:

The number of older people in the UK is rising with an increasing reliance on familial and social support. The number of unpaid carers for the sick, disabled and increasingly elderly in England and Wales is 6.5 million and this number is predicted to rise to 9 million by 2037. *This project focused on unpaid carers who are mainly family carers.* There is a growing recognition from the Government of the valuable role that these carers play and the Government's first National Strategy for Carers focused on 3 components: *information* for carers; *support* for carers and *care* for carers. The national carers' strategy, *Carers at the heart of 21st century families and communities* (Department of Health, 2008 pg. 16), stated that "by 2018 carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role". The NHS (2014) *Five Year Forward View* recognises that, with an ageing population, increased long-term conditions, and limited funding, carers have a crucial role to play in the future of the NHS.

Previous studies have identified the wide range of medicines-related activities that carers undertake. Carers may provide support with any stage of the medication management process. Community pharmacies are typically based in geographically accessible locations and, unlike GPs and other health professionals, are usually available for consultation without appointment, so many opportunities exist for pharmacists to interact with carers. The UK Government is committed to expanding the role of pharmacists to become more patient-centred, promoting the development of services to support medicines optimisation. Currently community pharmacists do not have access to patient notes or key information about a patient's overall healthcare. The expanding role, and commitment to patient care for pharmacists, has resulted in increased independent responsibility and accountability due to increased expectations of the patient, with a resultant exposure to ethical and moral issues. Little is understood regarding how health professionals interpret or apply their codes of ethics in observing their duty of care to patients, including respecting their autonomy, whilst attending to the needs of carers to enable them to be effective in their roles and moral and legal tensions can arise. From both a pharmacist's and carer's perspective, the pharmacist's role in providing advice and guidance for carers, including the context of the need for confidentiality and liaison with other providers, is unclear.

Research question, Aims, Objectives and Methods:

Research question: In the context of current legal and ethical frameworks how can pharmacy services more effectively meet the medicines-related needs of carers?

Aim: to improve understanding of the current and potential role of pharmacy services in supporting carers of older people.

Objectives:

1. To review and analyse current legal and ethical guidelines in England and Wales that underpin the practice of pharmacists when supporting older people with carers,
2. To determine perspectives of pharmacists and selected health/social care professionals on interpretation of legal and ethical guidelines in terms of supporting carers,
3. To obtain carers' understanding and experience of the role of pharmacy and other services in assisting them in medication-related activities,

4. To suggest ways in which the ethical and legal responsibilities of pharmacists in relation to carers could be clarified for both carers and pharmacists,
5. To inform policy and guidelines on the role of pharmacists in supporting carers, including identifying gaps in both.

Methods: The study comprised two stages. Stage 1 was a review and analysis of legal and ethical documents and guidelines relevant to the practice of pharmacists when supporting carers of older people, some of whom will lack mental capacity, in the use of their medicines (objective 1). It incorporated a review of the literature, including published research, identifying interpretations and application in pharmacy and other settings regarding support for carers who assist older people with medicines. Stage 2 (objectives 2 and 3) was a qualitative research study with carers, pharmacists and other health and social care professionals, in which data were collected in semi-structured, face-to-face, 1:1 interviews. Qualitative analytical procedures were employed. Findings from the two stages were combined to achieve objectives 4 and 5.

Key findings:

This study has identified that pharmacists, more so than other healthcare professionals, need guidance on how to support carers; in particular as community pharmacists often see the carer alone (unlike other healthcare professionals) and they commonly work in isolation without a multi-disciplinary team with whom to discuss dilemmas;

- Community pharmacies do not have formal procedures for identifying carers or access to any systems maintained by other healthcare professionals;
- Pharmacies may employ locum staff and healthcare assistants who may interact with carers;
- Carers may use several pharmacies;
- Patients may have multiple carers, ranging from family members to paid carers, complex care networks present further difficulties for pharmacists;
- A hospital pharmacist, unlike a community pharmacist, may see patients and carers together, facilitating the triangle of care.

No consistent definition of 'carer'

Our study has shown that people who help others with medicines do not always see themselves as carers and pharmacists are not always aware of who might help a patient with their medicines. Various definitions of carer are in use. Potentially anyone can assume the role of carer and often the role is shared between family members and/or paid carers. Carers take time to identify themselves as such and the spectrum of care provided by a carer can be very wide which may make identification of a carer, or self-recognition as a carer, very difficult.

Lack of protocols to identify carers

Our study found that identification protocols for carers were often not in place in healthcare systems. The review found more guidance for GP surgeries than pharmacies in terms of identifying and recording carer status and similar approaches may be effective in community pharmacy.

Recording of carer status

Some medical centres have 'is carer' added to their medical records as a read code which makes carers eligible for support and allows them to be sign-posted to services. Pharmacists admitted that they did not have a systematic method of recording carer status, although at times this was noted on the PMR. Carers are often well known to local pharmacists. Interview findings indicated that this relationship is

valued and provides a framework for pharmacy support. Assuming confidentiality would be assured, most carers were in favour of the pharmacist having access to a summary care record.

Lack of policy guidance for pharmacists in relation to carers

Our study found that policy guidance is vague and does not address the range of ethical issues that supporting carers can present to pharmacists. The legislation makes reference to a need for information and support for carers but our review found a lack of policy guidance on how to involve carers, especially for pharmacists, and particularly when there might be conflicting responsibilities to patient and carer. GPhC guidance (2012) recommends that pharmacists exercise their professional judgment and make decisions about disclosing information on a "case-by-case basis", without further direction. Hence there is a gap between the complexities of the 'triangle of care' and policy guidance. Guidance indicates that patients should come first, for example, a joint statement by the GPhC and RPS *Using standards and guidance to ensure patient centred professionalism in the delivery of care* (2014) states that patient-centred care should be at the heart of everything that pharmacists and pharmacy teams do. It was unclear how this responsibility to patients is to be reconciled with the pharmacist's responsibility to, and putative rights of, carers, when the two conflict. The literature found that, in the absence of guidance, pharmacists draw on more general rules. If pharmacists use a common sense approach rather than the Code of Ethics, then different pharmacists, faced with the same situation, may respond to an ethical dilemma in a different way.

Obtaining service user consent by pharmacists

Policy guidance does not cover how pharmacists should obtain or record consent. The interview data showed that consent was not being obtained routinely from patients to share information with carers in community practice. However, everyday pharmacy practice may not be conducive to the consent process as the pharmacist may not see the actual patient.

Knowledge of guidance

Most healthcare professionals, including pharmacists, said they were only vaguely or quite familiar with their professional guidance. Pharmacists will call a colleague for advice rather than refer to guidance.

Training in ethics and knowledge

Our review found that pharmacists are not very familiar with ethics, with most not having had any training since their degree. Patient confidentiality, consent and capacity were not well understood. Most pharmacists support people who help others with medicines ad hoc and information is provided in the patients' best interests. A review of the literature regarding empirical ethics research in pharmacy highlighted the paucity of studies in regard to community pharmacy (Cooper et al., 2007). None focused on the needs of carers. The increasing patient focus of future practice raises the question as to whether teaching in pharmacy law and ethics has developed to equip pharmacists for the accountabilities now expected in health care practice (Wingfield et al. 2003). Support for carers presents an additional dimension.

Lack of awareness of the role of pharmacy services / pharmacist

Our study found that there is a general lack of awareness among patients and carers of the expanded role of pharmacy services. Carers therefore may not be aware of the information and support that could be provided, which places an onus on the pharmacist to be proactive in offering advice.

Recommendations:

1. Who is a carer?
• A definition is required that works for pharmacy services, so a starting point might be to identify "a person who assists someone else with their medicines in any way". This broad definition will include both those who self-identify as carers and others who provide more limited assistance, but who, along with the people they care for, may also benefit from information and support.
Further research could be undertaken to assess the application of this definition for pharmacy services and carers.
2. Identification of carers
• A pharmacy agreed method of identifying carers is required and one suggested method might be to formulate triage questions. Possible triggers could be new prescription items, which could indicate a new diagnosis, or a patient running out of medicines. Carers are more likely to come forward if a description of what is meant by the term is given and some help is offered. • Pharmacies to collaborate with GP practices, where systems and approaches to identify carers are also being developed. This could be at CCG level.
Further research could test this triage question.
3. Raising awareness of how pharmacy teams could help those who help others with medicines
• Self-identification of people who help with medicines could be supported by local and national campaigns and voluntary organisations using posters/advertising, e.g. via the library, local council website, social media: *'do you help someone with their medicines?' If so, your pharmacy could.....* • Pharmacists could be more proactive in offering advice and services. Carers or people who help with medicines could be involved more explicitly – e.g. in MURs or NMS.
4. Pharmacists' obtaining patient consent to share information
• Pharmacists need guidance on how to obtain consent when the patient is not present.
Further research is needed to develop feasible methods and a suitable tool to obtain consent.
5. IT systems and recording of carer status
• Community and hospital pharmacy system suppliers could add a field for carers which would include one which recognises any carer with medicines responsibility. This could also be recorded on the e-discharge and paper discharge forms. The system could also record consent information and be regularly updated. • This information needs to be shared with healthcare professionals in primary and secondary care.
Further research could consider how this information can be recorded, maintained and accessed by community pharmacists
6. Supporting pharmacy teams to develop their role in terms of carer support
Policy guidance • Our work suggests that pharmacists would benefit from guidance as part of a revised code of ethics as to how they could support people who help with medicines on an informal basis and this would include identification of such people, recording their details, the ethics of working with them to support patients and recognition of them as an expert partner in patient care. Stakeholders could inform guidance which could be endorsed by carers' organisations. • General Pharmaceutical Council could include the pharmacist/pharmacy working with relevant carers within their assessment tools.
Work with the RPS and GPhC to develop guidance and professional standards.
Training • Bespoke training programmes for pharmacists could be developed to upskill the workforce drawing on components from other courses that are available and adding in components which are not covered. Subjects could include consent, confidentiality, information sharing and capacity (cognitive functioning, dementia). • Training could be online, face to face, or a CPPE workshop, using case studies or scenarios. • Develop peer mentoring and support groups to embed and strengthen pharmacy role.
Further research could consider how pharmacist prescriber training may inform a model.