INVESTIGATING MEDICINES-RELATED ROLES AND PROBLEMS EXPERIENCED BY INFORMAL CARERS OF OLDER PATIENTS

By DINESH GUPTA, MSc, MRPharmS, FELICITY SMITH, PhD, MRPharmS and SALLY-ANNE FRANCIS, PhD, MRPharmS

- *AIM — To identify the medicines-related roles and associated problems experienced by informal carers of older care-recipients to inform the development of hospital pharmacy services for the support of these carers.*
- *DESIGN — A descriptive study using semi-structured interviews.*
- *SETTING — 18 informal carers tending to older patients discharged from Oldchurch and Harold Wood Hospitals, Essex.*
- *OUTCOME MEASURES — Carers own descriptions of activities and problems associated with managing medicines for older care-recipients.*
- *RESULTS — The interviews revealed that a wide range of medicines-related activities and responsibilities were undertaken by informal carers. These included ordering and collection of prescriptions, administration of medicines, solving problems and providing advice on medicines. Problems were associated with all these activities. Carers also described their involvement in decision-making, and the impact of the activities on their personal lives. Perceived and unmet needs were identified, including involvement in medication review and information to enable effective management of medicines following discharge.*
- *CONCLUSIONS — Informal carers provide a valuable role in assisting older people with their medicines. However, they require information and advice which hospital pharmacists are in a position to give.*

Mr Gupta is senior directorate pharmacist for women and children's services, Barts and The London NHS Trust, Dr Smith is reader and Dr Francis is lecturer in pharmacy practice at the School of Pharmacy, University of London. Correspondence to Felicity Smith, School of Pharmacy, University of London, Brunswick Square, London WC1N 1AX

The Office for National Statistics has estimated that there are 5.7 million informal carers in Britain.[1] These include family and friends who are not paid for their caring activities. If informal care was to be funded by the Government, it has been estimated that it would cost £33bn annually.[2] The Government's policy document, "A strategy for carers", acknowledges both the contribution of informal carers to health care and the need to provide appropriate support services.[3]

Half of all informal carers care for persons aged 75 years or more.[1] Older people are more likely to suffer from multiple conditions, and are by far the greatest consumers of prescription medicines. Their increased susceptibility to drug-related injury, due to altered pharmacokinetic and pharmacodynamic properties of drugs, is well documented. Age-related impairment of cognition, memory, eyesight, hearing and dexterity have been cited as contributing factors to medication misadventure, which sometimes results in hospital admission.[4] The National Service Framework for Older People has identified the need to maximise the benefits which older people gain from their medicines.[5,6]

Previous research into care-giving has explored the burden placed on carers. However, little attention has been devoted to the roles and specific needs of informal carers in the use of medicines. Researchers have found that carers may have a high level of involvement in the provision of medicines for their elderly care-recipients.[7]

Goldstein and Rivers,[8] in a study of 20 informal carers, found a lack of medicines-related knowledge and an inability to access some of the pharmaceutical and medical services available, resulting in carers experiencing difficulties in fulfilling their medicines provision roles. In the US, a study of informal carers of elderly family members reported that involvement in the management of care-recipients' medicines was related to the stress experienced by carers.[9] In a larger US study, Mallet and King[10] evaluated carers' knowledge of medicines and found that, although carers could identify the purpose of the prescribed medicines in 92 per cent of cases, the side effects were known in only 13 per cent of cases.

A barrier to the provision of support for carers in the community is the lack of opportunity for health professionals to identify carers, and this is compounded by the fact that many people providing assistance to older people do not regard themselves as carers. After discharge from hospital, many people will receive informal care from family and/or friends. This provides an opportunity for identifying the key roles that these carers take on, which can involve assistance with a range of activities in the use of medicines. The aim of this study was to investigate the medicines-related roles and identify associated problems experienced by informal carers of older care-recipients. The findings of the study may be used in developing hospital pharmacy policies to recognise and address the needs of carers, thereby contributing to the Government's strategy of supporting informal carers.

METHOD

For the purposes of the study, informal carers were defined as an adult relative or friend who provided unpaid medicines-related assistance to the care-recipient. This approach was a departure from other studies in which respondents identified themselves as carers. It was recognised that assistance with medicines can be provided by people who do not regard themselves as carers. This group of carers is usually excluded in sampling strategies that rely on self-identification.

To identify informal carers, older hospital inpatients being discharged to their own homes (or to the home of a family member or friend) were randomly selected and invited to participate in a brief recruitment interview. The number of older patients discharged in the previous month from medical, surgical, oncology and care of the elderly directorates of Oldchurch and Harold Wood Hospitals in Essex, England, was obtained. This was used as a guide to find the proportion of older patients dis-

charged from each of these directorates. A similar proportion of current older inpatients were then sampled. Wards were visited in a random order determined by the use of a computer-generated random number sequence and on any given ward, the names of patients eligible for inclusion were randomly selected. Patients were eligible for inclusion if they were aged 65 years or over and were taking one or more prescribed drugs. The purpose of the recruitment interview was to identify older people (that is, care-recipients) who received assistance in the management of medicines from informal carers, before admission.

Care-recipients were asked for permission to contact the informal carers. The informal carers were then invited to participate in a semi-structured interview at the hospital. The interview schedule comprised mainly open questions about the daily assistance that was provided with medicines. Details of specific activities and responsibilities (for example, ordering or collecting prescriptions from the surgery or pharmacy, help with opening containers, administration, advising on use of medicines), carers' roles in medication review, and any problems they had experienced, were recorded. The carers were also asked for views on their role in managing medicines and its perceived impact on their lives. The written consent of both care-recipients and carers was obtained before the interviews. Procedures and instruments were approved by the local research ethics committee.

The interviews were audio-taped and transcribed verbatim. The data were analysed using an approach in which the responses from all carers to each question were grouped. This enabled a description of the types of activities undertaken by the carers, as well as the identification of issues and concerns from the perspectives of the carers using a grounded approach. Such an approach refers to the use of grounded theory in the analysis of the data. Grounded theory is the process of generating hypotheses and concepts from the data during the course of research.[11]

Results

Of the 78 patients randomly selected for the recruitment interview, 53 consented and 42 interviews were successfully conducted. As for the remaining 11 patients, two were unavailable for interview on at least three visits to their bedside and nine had difficulties due to cognitive impairment, speech problems, deafness, or a poor command of the three languages spoken by the interviewer, that is, English, Punjabi and Hindi.

Out of the 42 patients who undertook the recruitment interview, an informal carer involved in managing medicines was identified in 34 cases and permission to contact the carer was obtained from 27 patients. However, interviews could only be conducted with 18 carers because, in five cases, the carers declined and in the other four cases, establishing contact with the carers was not possible. All interviews were conducted in English and lasted approximately 30 minutes.

Characteristics of the sample The age range of the 18 care-recipients was 65–86 years (mean, 74 years), with equal numbers of men and women. Of these, 11 were from medical wards, three from surgical wards, two from care of the elderly wards and two from oncology wards. Care-recipients were each taking between two and eight prescribed medicines (mean, 4.2).

The age range of carers interviewed was 28–75 years (mean, 53 years). The sample included 14 women (10 daughters and four wives) and four men (son, brother, grandson, friend). Only eight of the care-recipients lived regularly with their carers, four lived with their carers every now and then, and six did not live with their carers. The duration of caring was between two and 31 years (median, 4 years).

Medicines-related activities of carers A number of medicines-related activities undertaken by the carers was identified.

Ordering and collecting prescriptions All 18 carers were involved to varying extents with ordering prescriptions from the surgery and collecting medicines from the pharmacy. Of these, 14 reported being responsible for monitoring the supplies of medicines. The remaining four carers were informed by their care-recipients when medicine supplies ran low.

Fourteen carers stated that they always visited the same pharmacy. An advantage of returning to the same pharmacy was illustrated by one carer whose care-recipient was blind and used bottle size and shape as a means of identifying his medicines:

"I ask [pharmacy staff] to put them, like in different bottles…different bottles, so as he'd know which tablets is in which bottles.…He only takes about three or four different tablets and the pharmacist keeps a record of what size bottles he used before and he always sticks to the same ones so [C-R] knows what's in what." (C16)

Administration of medicines The extent of carers' involvement with the administration of medicines was highly variable. Different levels of involvement could be characterised according to the actual and perceived needs of the care-recipients.

At one level, assistance was provided to enable the care-recipients to have access to their medicines and take doses at the appropriate times. For example, carers loosened child-resistant caps, requested ordinary screw tops when collecting medicines from the pharmacy and refilled Dosette (monitored dosage) boxes once a week. Carers also described removing medicines from their containers and leaving them with the care-recipients. This sometimes involved carers removing all the doses for one day at the same time, or removing each dose at the time it was needed. This means that carers would have to make themselves available several times a day.

At another level, carers described giving a dose or observing the care-recipient to ensure that the medicine had been taken. For example, one carer described how she assists her care-recipient with inhaled doses. She activates the aerosol inhaler device for her care-recipient in addition to supervising the administration of all other medicines.

Many examples illustrate the movement between the levels of involvement according to the perceived needs of care-recipients. For example, one carer left out medicines for her care-recipient when he was well, but supervised their administration when he was

unwell:

"When he is better than he is now, I don't have to watch him but if, you know, when he's really poorly, then I do watch because, as you saw today, he's very trembly and one could drop on the floor, and if he doesn't tell me, well then, I don't know if he hasn't took it, do I?" (C8)

In another case, the carer described different levels of supervision according to their beliefs regarding the relative importance of different drugs. For example, one carer described her role in administering two particular medicines, believing them to be the most important components of the care-recipient's regimen, but allowed the care-recipient to administer the remaining medicines:

"But certain ones, I make sure he takes. He has to, you know, like his aspirin tablet and his Losec tablet. I have to make sure he takes them, but his pain-killers, I just leave there you know and he takes them." (C6)

Analysis of carers' descriptions of the assistance they provided with the administration of medicines revealed that this was not confined to practical elements but also entailed judgement and decision-making on behalf of the care-recipient.

Problems with medicines experienced by carers In all, 15 carers described one or more problems that they had experienced with their care-recipient's medicines. The other three carers reported no problems. Non-compliance with medicines by the care-recipient was central to many of the problems reported by carers. This included both intentional non-compliance, for example, refusal by the care-recipient to take medicines, and inability to comply, which was generally due to mental or physical impairment. Other problems described by carers include incorrect entries on the prescription which led to incorrect supplies, side effects of drugs, allergic reactions, drug interactions or contraindications, and drugs perceived to be ineffective.

A lack of review of prescribed medicines by GPs and hospital doctors at outpatient clinics, and uncertainty as to whether a drug was still required, were also expressed. The following reasons were identified from the transcripts that had influenced carers to seek a review:

- Lack of effectiveness of medicines, as perceived by the carer (five reports)
- Emergence of side effects, as perceived by the carer (two reports)
- Concern over whether the drug was still required (two reports)
- Search for a more suitable dosage form (one report)
- Symptoms getting worse on current medication, as perceived by the carer (one report)

These responses demonstrate the extent to which carers assumed responsibility for ensuring the safe and effective use of medicines and provide an indication of the information and support that could be required.

One carer described how she activates the aerosol inhaler device for her care-recipient in addition to supervising the administration of all other medicines

Carers were asked about their awareness of changes made to their care-recipients' medicines. Nine carers reported that they were generally not informed of any changes, four stated that they usually learnt of changes by asking their care-recipient, another four found out for themselves and one carer reported that he had no knowledge of his care-recipient's medicines; his role was limited to fetching and carrying the prescriptions and medicines to and from the surgery and pharmacy. The remaining carers claimed that they were generally notified of changes made to their care-recipient's treatment, although they reported that this only occurred because they accompanied their care-recipients to all consultations. The carers acknowledged that, in their absence, this mode of communication broke down. Three carers reported these problems in association with hospital admission, one of whom saying:

"I'm not normally notified until it's time to go home and then I seem to have different tablets that I have to give him." (C17)

One carer expressed the view that if on occasions she was overlooked, then she accepted that the onus was on her to find out about any changes.

Advice, decision-making and responsibility for medicines Ten carers described advising their care-recipients about their medicines. Advice included reminders to take medicines, reinforcement of labelling directions, emphasising the importance of complying with drug regimens, encouraging the care-recipients to take "when required" doses at appropriate times and recommending an increase in dosage to respond to symptoms.

Three carers lived with a dying or cognitively impaired care-recipient and described assuming total responsibility for the management of medicines which was integrated with the provision of other aspects of personal care, such as assistance with activities of daily living. This involved evaluating the care-recipient's therapy requirements for symptom control, including administering doses according to what the carer believed to be appropriate, recording and reporting clinically relevant information, and making decisions about when to refer. This indicated a shift of responsibility and decision-making for medicines to the carer:

"My mum has no control over her drugs at all. She's given them…I give them to her whenever she needs them…in between times, if I feel that she needs something extra, then I will give it…obviously not drug drugs, but like paracetamol, anti-sickness, Kwells and things like that. I mean I don't increase her MST or morphine or anything like that, I wouldn't do that. But if…I feel that she needs that increased, then I will get on to somebody and have that sorted out." (C7)

Descriptions of advice-giving sometimes exposed different views between carers and care-recipients which is a potential source of conflict that could result in a consequent loss of autonomy for medicines by the care-recipient. One carer reported remonstrating with her care-recipient over his tendency to take too many tablets.

Impact of medicines-related roles Managing the medicines of care-recipients was viewed as a small but integral part of the caring role, and as such contributed to the burden associated with caring:

"There is a series of things which…he's needed doing that are your basic ordinary…wash, dress, toilet, pills, you know. It's just a series of things to get done." (C9)

Carers provided examples of how they had to adjust their lives to accommodate their caring role. For example, one carer had to work unsocial hours so as to be available to accompany her father to his outpatient clinic appointments. Other carers also described having to take time off work to tend to their care-recipient.

Specific requirements of managing medicines could interfere with activities and aspirations of the carer. One carer described how district nurses could be contacted to give her mother's evening doses of intravenous antibiotics in the event of her not being present to do this herself (a task for which she had received training). But since the nurses were not trained in intravenous administration, these doses were given intramuscularly:

"I always feel a bit guilty, sort of, because I

know it's painful for her [to receive the dose intramuscularly], so, I mean, I still do go out quite a bit…her evening dose is usually about 11 o'clock, so I just aim to get back by then." (C17)

These findings reveal how attempting to provide practical assistance with medicines interfered with carers' lives. However, practical roles were often supplemented by advice-giving and shared responsibility which could also contribute to the emotional burden of caring.

Discussion

Little research has been published regarding the roles and problems of informal carers in assisting people with their medicines. Although this was a small study, it enabled the documentation of carers' perspectives of the help they provide to their older care-recipients in the management of medicines, the problems they experience and their requirements for information and support. The age distribution of the carers in this sample did not differ significantly from national data which found that the age of most carers is between 45 and 64 years.[3] Similarly, high proportions of carers were caring for a relative.

All carers assisted in the ordering and collection of prescription medicines, and in most cases, took responsibility for managing this process. To be effective in these activities, carers have to be informed about the products required and the timing of subsequent prescriptions. During a hospital stay, changes to prescribed medicines can be expected. It was clear from these interviews that carers were not routinely informed of changes to their care-recipient's medication.

In the administration of drugs, the carers varied in the extent of their involvement. This sample demonstrated the range of administration activities including managing different dosage forms. Changes in the health of the care-recipient also resulted in variation in the intensity of assistance required at different times. Thus, the advice and information to carers should be specific to the drug needs of their care-recipient (for example, inhaler technique), as well as awareness that the level or type of involvement could change at different times. Difficulties in complying with prescribed directions were common. The source of these problems were varied but they included practical problems in administration, comprehension of dose directions, as well as concern regarding the effects of drugs. In addressing the needs of carers, it is important that all these issues are discussed.

The extent of involvement with the administration of medicines had implications for carers in terms of the time and commitment required. The carers in this sample also provided examples of how these roles affected their personal lives. These issues should also be acknowledged in advice regarding, and reviewing of, the care-recipient's medicines.

Hospital pharmacy services for older people can provide a valuable contribution to the Government's strategies to improve medicines-related services and support for informal carers and older people

Carers reported making assessments of, and decisions regarding, the care-recipient's need for their medicines. Thus, in providing assistance with the administration of medicines, what may appear as a straightforward set of tasks is actually a complex role that involves clinical judgements, assumption of varying degrees of responsibility for clinical outcome and communication with health professionals.

Descriptions of examples of intentional non-compliance revealed the potential for differences between carers and care-recipients regarding medication. The perspectives of the carer and care-recipient may be important in determining subsequent effectiveness of therapy. The needs and wishes of both carers and care-recipients should be taken into account in developing services to support carers in their medicines-related roles. This may require systematic involvement of both the care-recipient and carer.

This study also highlighted the partnerships between carers and care-recipients in managing medicines, including areas of potential conflict. It is important that the rights to, and needs for, information, support and care of both the carer and care-recipient are respected by health professionals and that the health services support this partnership in the management of patients' medicines.

To be effective in their medicines-related activities, carers require information and advice relevant to the needs and wishes of the care-recipients as well as their own roles and circumstances. This study identified a wide range of medicines-related activities that carers can be involved in, and the associated problems. It also exposed the lack of a dependable system for providing information and support for carers concerning medicines. In the hospital setting, pharmacists have the opportunity to identify informal carers and support them in a number of ways. For example, hospital pharmacists can involve carers in medication review by explaining the reasons for stopping or changing drugs. Pharmacists in hospitals can also serve as a source of advice and information regarding medicines, and they can liaise with community pharmacists about changes to drug therapy after discharge from hospital. By meeting needs such as these, hospital pharmacy services for older people can provide a valuable contribution to the Government's strategies to improve medicines-related services and support for informal carers and older people.

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