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Journal of Medicines Optimisation

Developing a patient-centred approach to get best outcomes and value from medicines

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In this issue:

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AIM OF THE JoMO

Medicines optimisation is a person-centred approach to safe and effective medicines use to ensure that people obtain the best possible outcomes from their medicines. The aim of the JoMO is to contribute to that process and play an influential and key part in shaping better patient care and the role that medicines can play. The JoMO provides a vehicle to enable healthcare professionals to stimulate ideas in colleagues and/or disseminate good practice that others can adapt or develop to suit their local circumstances.

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All material should be sent electronically to the Editor-in-Chief (alex.bower@pharman.co.uk).

Our two 'Developments in Practice' papers refer to optimising the use of medicines in older people. The first considers the consultation process itself and stresses the need for empathy in a clinical setting if pharmacists and other healthcare professionals are to provide safe and effective support about medicines. It is indicated that healthcare practitioners should consider any preconceptions they may have about older people and set aside any ageist stereotyping. The PETAL plan lists key points to consider when undertaking a conversation with an older person who has physical or cognitive challenges. A 'Five As' model is provided as a way of structuring the consultation process.

The second paper looks at a pilot study of a process that involves a Consultant Pharmacist conducting clinical medication reviews with older people who have recently been discharged from hospital – whether they then reside in their own homes or in a care home. The benefit of pharmacists and other health professionals working jointly across the primary and secondary care interface is clear. The outcomes included improvements to optimise the use of medicines at an individual patient care level and a trend towards reduced emergency department attendances and hospital re-admissions. Importantly, the project has led to additional pharmacists being recruited to take the work forward and plans are in place to further extend the scheme.

Many readers of the JOMO will not have direct contact with patients. Many of those who do will not have the time to really find out the difficulties that a patient might be experiencing with

their condition – the focus will be on the medicines aspects alone. The Patient Perspective section is designed to help fill that gap. In this section, patients tell their stories about how they cope in their daily lives and what sort of experiences they have had in their interactions with healthcare professionals. You will find them to be illuminating but may also find them harrowing.

In this edition a patient explains what it is like living with trigeminal neuralgia whilst another outlines their condition of dopa-responsive dystonia. People may not have just one therapeutic condition to cope with and have many challenges – such as taking 12 different medications and up to 59 doses each day. There are many messages in these patient stories – here are just a few:

"There needs to be greater communication and exchange of information between healthcare professionals."

"Adopt an holistic approach, listen to the patient and recognise that just because a person isn't making a fuss their condition is nonetheless distressing."

"Please do not see me simply as 'a patient with a disease or condition that you are treating' but as a complete person with many other conditions that interact with each other."

"I am the same person I was before I needed to use a wheelchair - I can still think and talk for myself."

HYPERLINKS

References and other resource material as appropriate can be accessed directly via hyperlinks in the Journal.

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Improving pharmacy consultations for older people with disabilities

Professor Nina Barnett, *Consultant Pharmacist, Older People, London North West Healthcare NHS Trust, Medicines Use and Safety Division, NHS Specialist Pharmacy Service; Visiting Professor, Institute of Pharmaceutical Science, Kings College London.*

Correspondence to: nina.barnett@nhs.net

Abstract

Title

Improving pharmacy consultations for older people with disabilities.

Author list

Barnett NL

Summary

Older people are members of our society at one end of the age spectrum of the population. They are a group of people at risk of multiple long-term conditions and frailty who value their health, independence and well being. In a recent UK survey it was found that 5 million people of adult state pension age reported a disability. When considering the medicines-related needs of older people, the use of empathy in a clinical setting to provide safe, effective medicine support is at the heart of providing best care within routine pharmacy consultations for older people with disabilities. In order to do this, healthcare practitioners must consider their preconceptions about older people and actively put those that are inappropriate to one side.

Optimal support can be provided through considering the patient's requirements for Patience, Environment, Time, Attention and Language (PETAL). When identifying the issue to address, whether physical or mental, overt or covert, use sensitive and empathic communication. Many patients with disabilities are used to managing their conditions and are often in a good position to suggest solutions to their own issues. Where cognitive challenges exist, do not assume that your patient cannot be part of a conversation; assess how much inclusion they want and, where appropriate and considering consent and capacity, ensure information is passed to the person managing their medicines.

By identifying the needs of the older person in a pharmacy consultation using an individualised approach, healthcare professionals can facilitate an interaction that optimises patient health and well being.

Keywords: (MeSH and non-MeSH): aged (older people), disabled (disability), communication (communication skills), pharmacy, PETAL

Background

Described variously as elderly, senior citizens and aged, older people are members of our society at one end of the spectrum of the population. People widely differ in who they consider to be old and Public Health England¹ state that there is no agreed definition of older people. The World Health Organisation suggests that many westernised countries use age 65 years as a definition for older age,² while the United Nations definition is over 60 years.

Older people are not a separate section of society, but rather a group of people at risk of frailty, multimorbidity and polypharmacy who value their health, independence and well-

being. Chronological age is not synonymous with biological age and old age can also be considered more broadly as the point where chronological age meets with a decline in health, physical or cognitive abilities. This decline often leads to disability, which for the purpose of this article, constitutes a physical or mental (including cognitive) condition which restricts a person's movement, senses or activities. Disability in older people is common. In a recent UK survey it was found that 5 million people of adult state pension age reported a disability.³ Conversations with older people should therefore be founded on the assumption that older people, like everyone else, are responsible for their own health and are able to make decisions about their health-related needs. When considering the

medicines-related needs of older people, the use of empathy in a clinical setting is at the heart of understanding the patient experience within a consultation for older people with disabilities. The provision of safe evidence-based choice of medicines applies equally to all populations.

Making medicines optimisation part of routine pharmacy practice is central to good pharmaceutical care of people with multimorbidity, disabilities and in their older age. The National Service Framework for Older People (NSF)⁴ was the first national document to formally recognise age discrimination and a lack of dignity and equity in healthcare. It provided a 10 year plan to support identification of key issues in a variety of areas of health where older people were being disadvantaged and a system to prevent future discrimination. The Social Care Institute for Excellence in their Dignity in Care guide⁵ continues to support the principles in the NSF for Older People through improving the way health and social care professionals interact with people to maximise dignity and respect. Recent NICE guidance on multimorbidity supports optimising care for adults with multiple long-term conditions using an individualised, person-centred approach based on what is important to the patient in terms of treatment, which includes medicines.⁶ The principles of an approach that take into account multimorbidity are particularly relevant in the care of older people, many of whom will have a number of long-term

conditions to manage. One might therefore suggest that, rather than treating older people as a 'special case', the role of healthcare professionals working with older people should be to identify single or multiple morbidities affecting their health and wellbeing that matter to them and support them to achieve improved management.

What challenges face older people?

In addressing how healthcare professionals can support older people towards better health, the first challenge to consider is the healthcare professional's preconceptions about older people. Ageist stereotypes are inaccurate and unhelpful.^{7,8} Healthcare professionals need to identify personal prejudices and actively put these to one side, as well as challenging ageist language and assumptions in others.

It is helpful to consider how to approach an older person who comes into the pharmacy. Think about how to greet them and ask how they'd like to be addressed. This will vary according to local and cultural norms and how familiar the patient is to you. If you don't know the patient, it is best to use their formal title as, in the UK, use of a first name without invitation can be considered over-familiar. When you address an older person, remember that they can be doctors, professors, ministers of religion or lords, not just Mr, Mrs, Ms or Miss! If the patient

1. **PATIENCE, EMPATHY and COMPASSION.** Get yourself in the right frame of mind, which may mean taking a quiet moment to focus on the patient. Remember, they may need more time than other consultations. If you are really engaged with the patient they may feel safe to disclose something that you find upsetting. While it's easy to sympathise, your job is to be **empathic**. This means you keep your experiences out of the conversation but focus on how they are feeling and how you can help them optimise their health.

For example, think how you would you feel if you had mild dementia and wanted to be part of a conversation about your health but found the healthcare professional ignoring you and only speaking to your spouse or carer?

2. **ENVIRONMENT:** Ask your patient what they need to be comfortable so they are in the best possible situation to engage in conversation. If your patient has a hearing or cognitive impairment, or your environment is noisy, try to find somewhere quieter, speak slowly and clearly and ask if the volume of your voice is appropriate, being mindful of confidentiality. Think about how your environment works for someone with poor mobility. It is also helpful if you sit face-to-face and keep eye contact during the conversation.
3. **TIME:** You may need more time to speak to older patients especially those with speech difficulty, cognitive impairment or slow mobility. For example, think about how can you accommodate someone who walks more slowly to maintain dignity? Some older patients may just need more time to focus on what they want to say. Make sure you allow time for a patient to ask you questions. If you don't have the time, consider whether you should be having the conversation at all at that time and whether or not it would be better to reschedule.
4. **ATTENTION:** Pay full attention to the patient and be conscious of avoiding distractions for you and for them. Ask open questions and wait for the answer. Don't let your thoughts, questions, assumptions and biases cloud what the person is saying. Use clarifying questions if you are unsure of the point they are making. It's easy to assume that a person with disabilities has nothing to offer. How would you feel if that was you? You can learn something from everyone you speak to.
5. **LANGUAGE:** Where appropriate, use simple language, simple words and short sentences to help maintain focus for the conversation. Offer patients the opportunity to make a note of key points and, where memory or comprehension appears or is expressed as a challenge, ask the patient what would help; for example a picture, diagrams or words. How do you manage language impairment? If you had difficulty speaking after a stroke and people ignored you in conversation or kept completing your sentences rather than waiting for you to get the sentence out, how would you feel?

Box 1: The PETAL plan - key points to consider when undertaking a conversation with an older person who has physical or cognitive challenges ©Nina Barnett 2016

arrives with a carer, it is usually appropriate to speak to the patient directly first, unless you are told to the contrary. If unsure, don't assume; ask, as each situation will be different.

While supporting people who have physical or cognitive challenges will inevitably take more time, it is up to the healthcare professional to identify when this is required, tell others that they are about to engage in a longer conversation and take the time to support the patient. If the patient feels they are being rushed to complete a conversation, it will reduce the effectiveness of the conversation for both parties and potentially reduce future opportunities for interaction and support. When considering what specific support healthcare professionals can offer, it is useful to consider both physical and cognitive challenges.

Physical challenges

Identifying the physical issue, whether overt or covert, is key to optimising communication. If you identify an issue, ask the patient what help they would like in optimising the conversation for them. If they haven't specified a problem but you think it's there, try a 'would it be helpful' question and add your suggestion. Most people will know what they need from you to support their involvement in a conversation. Think about what you already know and what you need to learn. For example, what do you know about people who have hearing or sight loss? What does 'blind' mean to you? Did you know that registered blind doesn't mean the patient can't see anything?

How do you manage language impairment? If you had difficulty speaking after a stroke and people ignored you in conversation or kept completing your sentences for you, rather than waiting for you to get the sentence out, how would you feel?⁹

Cognitive challenges

It is easy to assume that there is an 'all or nothing' conversation when people have cognitive challenges, but the reality is that most people are somewhere in-between. Think about what you know about dementia, delirium, learning disabilities and what you are assuming. For example, how confident are you to have a conversation with someone who has dementia? Have you

ever done this? What do you need to learn to do this effectively? There are a number of resources available to support you in improving your skills in communicating with people who have dementia.^{10,11,12}

PETAL

There are various ways to assist healthcare professionals in optimising communication with older people who may face physical or cognitive challenges to communication. A number of resources provide excellent guidance.^{8,13,14} The list in Box 1, known as the PETAL plan, provides a summary of things to consider.

General tips

Remember that one size won't fit all so you will need to tailor your conversations to individual needs. Be active in your effort to ensure patient dignity at all times, including avoiding being patronising or condescending in your interaction with older people. If a sensitive topic comes up show empathy; be professional and reassuring to encourage disclosure. If you are concerned that the patient has not understood or retained the information discussed in the conversation, ask the patient. While assessment of capacity is beyond the scope of this article, if you are concerned about someone's ability to understand or retain information, you may wish to follow this up with the patient's medical practitioner.

Structuring a consultation

The information above is helpful in considering how to tailor the content of medicines-related conversations with older people who have physical and mental health challenges. Healthcare professionals may find it useful to use a structure for these conversations. The following process, known as the 'Five As', provides a framework for short, focussed consultations with older people (see Box 2). Based on the GROW model of coaching¹⁵ it provides an asking, rather than telling, approach¹⁶ and promotes effective engagement with patients, supporting the integration of empathy within clinical consultations, the importance of which has been recognised as often

1. **ASK** the patient what they want from the consultation. Identify their issue and DON'T ASSUME you know what they want. Give them your full attention as you listen to their answers.
2. **ACKNOWLEDGE** the patient's situation to demonstrate you have taken their issue on board. DONT JUDGE THEM, even if they express views or opinions you don't agree with.
3. **ADDRESS** the issues they bring up honestly and be clear about what you can do to help even if you can't do what they want. Identify potential problems and discuss how to manage them. When working towards solutions, it is helpful to ask the patient what ideas they have and then offer your suggestions/signposting/support. You might include health promotion opportunities here.
4. **ACCEPT** the patient's decision. If they have made a decision you don't agree with, make sure they have understood the risk/benefits but be careful not to judge them. This 'leaves the door open' for future conversations.
5. **AGREE ACTIONS.** Ask the patient to tell you what they are going to do, how they will put that in place and reiterate what you have agreed to do. Agree a specific follow-up plan, how this will be communicated to other relevant healthcare professionals and what to do if problems arise before the scheduled follow-up.

Box 2: FIVE As structure for short pharmacy consultations ©Nina Barnett 2016

underplayed.¹⁷ This is also a useful set of questions for the practitioner to ask themselves as a self-reflection exercise to learn from previous challenging consultations. This model relates to the health coaching approach as described in the Centre for Pharmacy Postgraduate Education (CPPE) consultations for pharmacy practice guide¹⁸ and readers may find it useful to refer to the medicines-related questions outlined in the 'Four Es' model for use within the structure below.

The benefit to using these tips in the conversation is that you are addressing what is most important to the patient. If you have something you feel you need to talk about, ask them what they want to talk about and then tell them what you'd like to cover. Talk about their issues first and agree a way forward for these issues. If you agree with the patient about the focus of the conversation at the start but the conversation veers off track, you can then politely remind the person about what they said they wanted to talk about and ask if there is any more about that required. If not, the conversation will end and, if more is needed, it will get back on track. Remember to be honest. If you don't know the answer to a question, ask when they need the answer by and agree to get back to them. Most people don't need the answer right away.

You can also use the 'Five As' as a self-reflection tool to identify elements of consultations that you feel went well or analyse consultations that you would do differently next time.

Points for practice

- An individualised, non judgemental approach to older people with physical and/or mental challenges is essential.
- Listen to what your patient wants from you and involve them in finding solutions to their medicines related issues.
- Consider how to use PETAL to support better consultations.
- Structure your consultation to make the most of the time you have with your patient using the 'Five As' model. Use the 'Four Es' to help you with questions.
- Use your experiences as a way to identify and address your learning needs.

Conclusion

Older people are fellow members of our society who may have multiple comorbidities with physical and cognitive challenges to communication. The role of the healthcare professional in a pharmacy setting is to identify what the older person needs from a pharmacy consultation and, using an individualised approach, facilitate an interaction that optimises patient health and well-being.

Declaration of interests

Professor Barnett has nothing to disclose.

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ROME PAD (Review Of Medicines for Elderly Patients After Discharge): A pilot study in domiciliary and care home settings

Sally Bower, *Head of Medicines Optimisation, Leeds West Clinical Commissioning Group*; Heather Smith, *Consultant Pharmacist - Older People/Interfaces of Care, Leeds Teaching Hospitals NHS Trust*.

Correspondence to: sallybower@nhs.net

Abstract

Title

ROME PAD (Review Of Medicines for Elderly Patients After Discharge): A pilot study in domiciliary and care home settings.

Author list

Bower SK, Smith H

Introduction

There is a need to improve the follow-up of medicines-related care in high-risk older people post-discharge. The extent to which this can be done by holistic, patient-centred, clinical medication reviews post-discharge has been assessed in a pilot study. The benefits in terms of patient experience, medicines rationalisation, reduction in emergency department attendances and re-admissions to hospital have been identified.

Method

Hospital-based clinical pharmacists identified older people who were at high risk of medicines-related problems post-discharge. A Consultant Pharmacist conducted 36 clinical medication reviews in domiciliary settings (26 patients) and care home settings (10 patients) using a patient-centred and holistic approach involving multi-disciplinary and multi-agency working.

Results

The quality of care and patient safety was improved. On average, 2.5 medications were stopped, 0.4 medicines were started and 5 pharmacist contributions to patient care were made for every patient reviewed. GP acceptance of recommendations was good and 92% of recommendations were actioned. Although numbers are small, data for 28 patients followed up for 6 months post-review showed a trend towards reduced emergency department attendances and hospital re-admissions and a neutral effect on GP contacts. Patient experience feedback was good. The focus of the project was on improving quality of care and medicines safety but, nevertheless, a cost saving of £212 per patient, on medicines alone, was achieved.

Conclusion

The project demonstrated an increase in the quality of care and the safety of medicines use for high-risk older people post-discharge. The evidence obtained suggests that the provision of clinical medication reviews post-discharge should be further developed.

Keywords: medicines optimisation, polypharmacy, patient questionnaire, clinical medication review.

Introduction

Risks post-discharge

The risks that may occur when hospital inpatients are transferred to primary care and the risks for new residents in care homes have previously been reported.^{1,2}

A large study found that medicines were the cause of 6.5% of hospital admissions³ but this percentage may be higher in older people.⁴

Despite the improvement in timely, electronic transfer of

information over recent years and national guidance,⁵ transferring people between care settings continues to pose risks to patient safety, quality and continuity of care. A recent national audit report on medicines-related communication when patients move between care settings indicates that there is room for improvement in terms of the information provided about medicine changes supplied by hospitals and the pathways and processes to deal with discharge information in primary care.⁶

The audit, which was based on 1,454 patients prescribed over 10,000 medicines, showed the following:

- on average, each patient was taking 6.9 medicines
- allergy status was only fully documented in 76% of cases
- 79% of patients had at least one new medicine started but the reason for initiation was only stated in 50% of cases
- 27% of patients had at least one medicine stopped as an inpatient but the reason for stopping the medicine was only documented in 57% of cases
- 23% of patients had the dose of at least one medicine changed
- apparent unintentional omissions of pre-admission medicines were noted in 33% of patients
- intentional changes were not actioned on the GP system within 7 days of discharge for 13% of patients
- medicines reconciliation in primary care was mainly completed by the GP, Clinical Commissioning Group or practice pharmacist or the practice receptionist
- at least one change was incorrectly actioned in 6% of patients post-discharge.⁶

Previous work

Leeds Teaching Hospitals NHS Trust (LTHT) has reported on work to improve medicines information and support for older people at the time of discharge and post-discharge. This showed an improvement in the quality of care and medicines safety for patients and an apparent reduction in re-admissions to hospital.^{7,8,9}

Leeds West Clinical Commissioning Group (LWCCG) has shown in their 'Care Homes And Medicines Optimisation Implementation Service' (CHAMMOIS) that patient-centred, holistic clinical medication reviews (CMRs) can improve the quality of care, medicines safety and reduce medicine costs for care home residents.¹⁰

Aims

Our primary aim was to build on the previous transfer of care and care homes work to improve the quality of care and the safety of medicines for older people living in **both** domiciliary and care home settings following discharge from hospital through:

- the identification of patients at high risk of medicines-related problems post-discharge by clinical pharmacists in secondary care
- the delivery of post-discharge, holistic, patient-centred Level 3 CMRs.^{11,12} Medication review has been defined as 'a structured, critical examination of a patient's medicines with the objective of reaching an agreement with the patient about treatment, optimising the impact of medicines, minimising the number of medication-related problems and reducing waste'.¹¹
- a focus on the management of problematic polypharmacy^{13,14,15,16}
- the process of minimising medicines (deprescribing).^{12,16}

ROMEPAID was a proof-of-concept project to determine if timely, holistic, patient-centred CMRs for high-risk older people post-discharge improved quality of care, medication safety and

readmission rates, resulting in a reduction in medicines-related attendances to the emergency department and/or hospital.

This article outlines the project and the outcomes achieved over a 12 month period commencing in February 2015.

Method

Staffing

A Consultant Pharmacist (i.e. one of the authors) was seconded by LWCCG for one year on a 0.4WTE basis.

An initial role involved establishing the project and obtaining access to SystmOne and EMIS systems in GP practices.

Patients were identified for review by clinical pharmacists in LTHT and these patients were then referred to the Consultant Pharmacist-Older People/Interfaces of Care. The Consultant Pharmacist then provided face-to-face, patient-centred CMRs for highly complex, older people living in either care home or domiciliary settings.

The review of GP records prior to visits initially took about 1.5 hours but this became less as familiarity was gained with SystmOne and EMIS. Travel to/from the domiciliary or care home setting care ranged from 20 minutes to 1 hour. Visits at the domiciliary or care home setting took 20 minutes to 1 hour with the latter reducing to about 30 minutes as more experience was gained. Follow-up, including the time to record the consultation on the GP system, ranged from 30 minutes to 1 hour depending on the number of issues that needed to be resolved.

Once the project was established, the Consultant Pharmacist then trained medicine optimisation pharmacists to undertake the role and supported them whilst they obtained the necessary experience by providing advice when sought and reviewing their recommendations post-CMR where appropriate. During this phase, the Consultant Pharmacist undertook case-finding at LTHT of suitable patients for the project and encouraged clinical teams to refer appropriate patients.

Priority areas

Medicines optimisation was focussed on the following five areas:

- personalised and holistic reviews
- specific high-risk medicines
- medicines minimisation (deprescribing) by discontinuing less beneficial or unwanted medicines
- appropriate monitoring.

Standard Operating Procedure (SOP)

A SOP was developed to ensure consistency of service provision and recording.

Domiciliary visits

Patients/informal carers were contacted in advance to explain that the purpose of the visit was to discuss their medication following their recent discharge from hospital. They were informed that the visiting pharmacist would have a clear identification badge to confirm who they were.

Patients had the option to decline a visit. This was taken up by two patients - one had Intermediate Care Team members going in four times a day after a fracture and did not want an additional person coming in although she was happy to talk on the phone. The other patient who declined a visit was profoundly deaf and also had cognitive impairment.

Visits were conducted in accordance with the LWCCG lone worker policy, which includes making contact with a 'buddy' before and after a visit to maintain the personal safety of the visiting pharmacist.

Some patients had key safes, which is usually highlighted on GP records, in which case it was necessary to obtain the access code prior to the visit.

Some of the most vulnerable patients had Community Matrons (CMs) who were helpful in terms of getting consent from the patient for the visit. The CM also provided reassurance for the patient during the visit, actioned agreed changes afterwards and provided any follow-up/monitoring required e.g. reviewing pain control, inhaler technique, rechecking blood pressure (BP).

Process

The judgement of clinical pharmacists at LTH was used to identify older people who were at high risk of medicines-related problems post-discharge. The reasons for referral related to polypharmacy, potentially inappropriate medicines and/or medicines support needs (adherence issues).

A systematic approach for the CMR was adopted based on that previously adopted in LWCCG for care home residents in the CHAMOIS project. This approach involved:

- review of GP practice patient medical records
- requesting appropriate monitoring, observations or tests
- measurement of BP, heart rate and/or postural BP where appropriate
- for patients in care homes, visiting the care home, viewing records and talking to the carer
- for patients in care homes, reconciling medicines administration record (MAR) charts with current repeat medicines on the GP system
- talking with residents and engaging with family members
- establishing a list of medicines, doses and frequencies that the older person is actually taking for older people living in their own homes
- liaising with other healthcare team members and non-medical prescribers
- recording findings in GP practice records
- making recommendations to GPs for medicine changes, monitoring tests and care planning
- liaising with other healthcare professionals involved with the older person's care where appropriate
- communicating the agreed medicine changes, monitoring criteria and personalised care plan to the older person or their informal carer
- liaising with the community pharmacist where appropriate to ensure safe management of medicines and continuity of care

- following up patients to ensure that the care plan had been implemented, was acceptable to the older person and was producing the intended outcomes.

Where the patient had a CM, a number of joint visits were conducted by the Consultant Pharmacist and Medicines Optimisation Pharmacists with the CMs. This improved communication of medicine changes and follow-up and enabled changes to be made in a timely manner. Informal feedback suggested that the CMs found the pharmacist reviews helpful and informative and that they believed the reviews resulted in improved patient outcomes e.g. reduction in adverse drug reactions or medicines-related re-admissions.

Patients were left with a card containing the name and contact details of the visiting pharmacist in case they had any questions after the visit.

Data collection

A data collection tool was developed to collect data and outcomes. This recorded details about the patient, medicines taken, recommendations made and whether or not these were accepted, follow-up and cost information.

Multi-disciplinary and multi-agency approach

Appropriate links were already well established with elderly care consultants and clinical pharmacists at the acute and mental health trusts. The Consultant Pharmacist also had previously established links with CMs in Leeds and community technicians from Leeds Community Healthcare Trust. These technicians provide telephone and domiciliary medicines support for patients across Leeds as well as training staff who support medicines administration in domiciliary settings.

In view of the need to improve the quality of holistic patient-centred care and facilitate care coordination,^{17,18,19} links had already been made with specialist teams and the multi-disciplinary neighbourhood teams during the pharmacist-led work in care homes in LWCCG. These links were strengthened further during the project and the Consultant Pharmacist liaised with a wide range of teams involved in the care of older people during the course of the CMRs e.g. anticoagulation clinic, arrhythmia team, mental health team, Parkinson's disease (PD) team and community continence, heart failure and diabetes services.

Patient experience

Patient experience questionnaires were given to patients who had received a clinical review by the Consultant Pharmacist and who were able to complete the questionnaire. 14 questionnaires were completed.

All patients felt that information was given in a way they could understand and that they received all the information they wanted. 6 patients felt the CMR helped a lot, 7 patients felt it had helped to some extent and 1 patient was unsure.

All patients rated the Consultant Pharmacist highly for politeness, bedside manner and knowledge of medicines.

Outcomes

Over a 12 month period between February 2015 and February 2016, 36 post-discharge CMRs were completed by the Consultant Pharmacist. A total of 26 were in a domiciliary setting and 10 in a care home.

The outcomes were:

- 91 medicines were stopped (2.5 medicines/patient on average)
- 14 medicines were started (0.4 medicines/patient) e.g. bone protection for patients at high risk of fracture
- BP and heart rate (HR) was checked for 10 patients
- 185 recommendations were made to GPs and 171 (92%) were accepted and actioned
- A total of 189 contributions were made (5.25/patient on average) including medicine changes, rationalisation of medicines e.g. to fit in with daily routines or reduce the number of times medicines were taken each day, referrals to other healthcare professionals such as a patient with PD who had been newly moved to a care home but had been lost to follow-up by the PD team, provision of education and advice for older people, informal carers or the wider healthcare team
- GP acceptance of recommendations was good and 92% of recommendations were actioned
- 28 patients were followed up for 6 months after their CMR (others were lost to follow-up as they had moved area or died). For these 28 patients, the number of admissions, Emergency Department (ED) attendances and GP contacts before and after the CMR is shown in Table 1. Figures for a year prior to review were included to show that the 6 month position was fairly typical and highlights that the patients referred were high-risk patients with a high usage of services.
- 5 patients required post-review follow-up of lying and

Admissions	
Admissions 1 year prior to review	87
Admissions 6 months prior to review	61
Admissions 6 months post review	31
Emergency Department (ED) Attendances	
ED attendances 1 year prior to review	126
ED attendances 6 months prior to review	77
ED attendances 6 months post review	56
GP Contacts	
GP contacts 1 year prior to review	413
GP contacts 6 months prior to review	231
GP contacts 6 months post review	219

Table 1: Number of attendances before and after CMR

standing BP and/or HR and 1 patient required rechecking of their urea and electrolytes.

Medicines stopped related to potentially inappropriate medicines such as benzodiazepines as published by O'Mahony et al in the STOPP criteria,²⁰ unnecessary medicines e.g. proton pump inhibitors originally prescribed for gastroprotection versus antiplatelets where the patient was no longer taking the antiplatelet and medicines where the patient had made an informed decision to stop taking or using e.g. analgesics, calcium supplements and laxatives.

Medicines started consisted of bone protection for patients at high risk of fracture and gastroprotection versus long-term antiplatelets.

Referrals

7 older people (19%) required an additional referral, 2 patients required referral to their GP, 1 patient complained of chest pain and 1 patient expressed a desire to harm themselves during the pharmacist visit. Other referrals included referral to Audiology, PD specialist nurse, Psychiatry, Leeds Eating & Drinking Service and the Respiratory Clinic.

Patient safety

3 medicine-related errors, e.g. inaccurate doses on medicines reconciliation post-discharge in the community, were reported into the local medicines risk team.

Costs

Total cost savings for the 36 CMRs was £7,624. This was despite additional costs incurred on medicines that were started. An average net cost saving of £212 per CMR was achieved.

Case studies

Patient Story 1

PS1 is an 86 year old man who lives alone. He has a cardiac pacemaker and a past history of Type 2 Diabetes Mellitus, Chronic Obstructive Pulmonary Disease (COPD), chronic kidney disease, ischaemic heart disease, myocardial infarction x 2, benign prostatic hyperplasia and urinary tract infections (UTIs). He was referred due to concerns about adherence particularly with his inhalers. PS1 did not have symptoms from his COPD despite not using his Seretide inhaler and had no recent exacerbations or admissions secondary to COPD so the Seretide inhaler was discontinued. PS1 had a compliance aid but tamsulosin and ferrous sulphate were not in the compliance aid and PS1 was forgetting to take these so these were added to the compliance aid (a recent ferritin level was low). PS1 was taking trimethoprim and amoxicillin as rotating prophylactic antibiotics to prevent UTIs. He had not had a UTI recently and recent urine cultures obtained in secondary care showed that organisms present were resistant to both trimethoprim and amoxicillin. After discussions with Microbiology, the antibiotics were stopped. Omeprazole was reduced from 20mg bd to 20mg od as there was no indication for the high dose but PS1 was taking aspirin regularly. PS1 had several items on repeat that he wasn't taking or using (Movicol, E45 cream and piroxicam gel) so these were removed from his repeat prescription list on the GP system.

Patient Story 2

PS2 is a 79 year old lady who had recently been admitted to hospital with hyperglycaemia. PS2 lives alone and has Alzheimer's Disease. She was taking a total of 16 medicines, was struggling to manage her medicines and had difficulty swallowing larger tablets. She was seen at home by the Consultant Pharmacist during a joint visit with her community matron. PS2 wanted to reduce the number of tablets she took every day and following discussion with PS2 and the CM, folic acid and ferrous sulphate were stopped (recent haematinic results were well in range). Thiamine was stopped as PS2 no longer drinks alcohol. Amitriptyline was reduced with a view to reducing gradually over several weeks before stopping due to potential adverse cardiac effects and risk of falls. The community diabetic team reviewed PS2 the following day and stopped her oral hypoglycaemics and started insulin which is being administered by district nurses.

Patient Story 3

PS3 is an 85 year old gentleman living in a residential home. He was recently admitted to hospital with a urinary tract infection, fall and acute kidney injury. He has a past medical history of dementia, chronic kidney disease stage 3, hypertension, stroke, atrial fibrillation, fractured neck of femur and left ventricular systolic dysfunction. The Consultant Pharmacist visited PS3 at the residential home and discussed his medicines with him. The following changes were made with PS3's agreement. Ferritin level was normal so ferrous fumarate was stopped. PS3 was not requiring Laxido prn so this was stopped. PS3 was taking citalopram 20mg od and mirtazapine 15mg nocte. The doses were cross-tapered to reduce then stop citalopram and increase mirtazapine to 30mg nocte as he had prolonged QT on his ECG and postural hypotension in hospital. PS3's mood was quite low at the time as his son had moved away from the local area recently. Aspirin was stopped as not indicated but PS3 had a history of previous ischaemic stroke so clopidogrel was started. Anticoagulation was not started due to the high risk of falls. Lansoprazole 15mg daily was added for gastroprotection. PS3 was also taking atorvastatin 10mg at night. This was stopped as the dose was low and was unlikely to result in long-term benefit. PS3 was taking Fortisip 125ml tds and Calogen Extra 40ml bd but his appetite was good, he was eating well and his weight had increased significantly over the past month. A referral to the Eating & Drinking Service was made as PS3 should be able to stop some nutritional supplements.

Discussion

The current service has resulted in improved partnerships, pathways and workstreams for older people post-discharge from hospital.

The number of patients was too small to show a causative effect on ED attendances and re-admissions to hospital but there was a trend towards reductions in both these aspects in the 6 months post-CMR compared to the 6 months pre-CMR (27% in ED attendances and 49% for re-admissions for the small number of patients who were followed up). There was no corresponding increase in GP attendances after the CMRs, which was reassuring for GP colleagues who may have been concerned about an increase in workload resulting from

medicines minimisation activities.

The study focused on improving the quality and safety of patient care but it also reduced prescribing costs by an average of £212 per CMR by ensuring that:

- medicines prescribed are clinically indicated with optimal dosing
- medicines (and diseases) are appropriately monitored to ensure they are effective and not causing harm including avoidance of falls and falls-related injury
- the views of older people and/or their carers are taken into account so that older people are only prescribed medicines that they are willing to take and that formulations and timing schedules are acceptable to them
- preventative medicine is used where appropriate
- medicines are ordered in appropriate quantities each month to minimise waste
- the medicines used offer the best value for money.

Overall, integration between pharmacy teams from different organisations and different sectors has been improved during the project. For example, links have been strengthened with the Intermediate Tier Technician Team from Leeds Community Healthcare Trust.

Pharmacists in LWCCG have integrated into the neighbourhood teams and have developed closer working relationships with the healthcare professionals within these teams e.g. community matrons. Direct referrals from the teams for CMRs have also increased.

ROMEPADE developments

During the pilot study, 4WTE Grade 8a pharmacists were recruited to provide holistic CMRs for patients with long-term conditions cared for by groups of GP practices.

LWCCG clinical pharmacists received further training in polypharmacy, CMRs and consultation skills and the Consultant Pharmacist completed a number of joint patient visits/CMRs with these pharmacists.

Patients were then referred to the LWCCG pharmacists rather than the Consultant Pharmacist for CMR.

Peer review sessions for the medicines optimisation pharmacists to review cases were also delivered during the project. This involved pharmacists reviewing the pre-CMR GP records of older people who had participated in CMR consultations with the Consultant Pharmacist. The Consultant Pharmacist then facilitated workshops where the pharmacists discussed how they would approach the consultation and the medicines optimisation options for each patient could be further explored.

Patient Information leaflets (PILs) are available in some local polypharmacy documents to help prepare people for a CMR. These were not used in the pilot study but will be considered in the future to develop the service.

To ensure that they maintained best practice and as part of the quality assurance system, the pharmacists also participated in regular local and regional peer review meetings. Later in the project, the pharmacists discussed cases that they had reviewed themselves with the group, to highlight areas of good practice and any contentious issues, problems or alternative options that may not have been fully considered. Regional meetings included peer support meetings facilitated by the Consultant Pharmacist and an experienced care home and practice pharmacist, which are held quarterly for pharmacists working in domiciliary and care home settings in the North of England.

This paper only reports outcomes from the CMRs conducted by the Consultant Pharmacist but it is noted that the other pharmacists conducted 48 CMRs during the project period.

The future for the ROMEPAD project

In the future, the medicines optimisation pharmacists in primary care could triage referrals and re-direct these to community pharmacy and/or the intermediate tier technician team where appropriate.

During the pilot study, all referrals were received and passed on to the relevant teams by the Consultant Pharmacist. A generic e-mail has now been set up at LTHT to accept referrals and clerical staff forward these referrals to the relevant CCG generic e-mail address. This should improve the efficiency and timeliness of referrals. Other healthcare professionals, e.g. medical staff, are now also able to refer patients who would benefit from a CMR on to primary care.

Work is also on-going within Leeds Teaching Hospitals NHS Trust to implement an electronic referral system from secondary care to community pharmacists.

Discussions have taken place with the Heads of Medicines Optimisation at Leeds North and Leeds South & East CCGs. Referrals for CMRs are now being received from secondary care across Leeds and this has become mainstreamed and is now 'business as usual'.

Conclusion

The pilot study has demonstrated an increase in the quality of care and the safety of medicines use for older people through holistic, patient-centred medication reviews. The evidence obtained in the pilot study suggests that the approach to provide CMRs post discharge merits further development in the interests of improving patient care.

Declaration of interests

The authors have nothing to disclose.

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Patient Perspectives

The process of medicines optimisation places patients at the heart of the process. It seems only right, then, to seek the views of patients about their experiences with medicines, their medical condition in general and their contacts with health professionals. Understanding what it is really like for a patient to live with a particular clinical condition will hopefully assist healthcare professionals to become more effective with their interactions and communications with patients and improve the healthcare services provided.

This has been done by providing patients identified through healthcare contacts with a template of questions to be completed anonymously by the patient on the basis that no individual be named or identifiable from the content. What some people have to cope with and the way they do it will amaze you.

Trigeminal neuralgia

Abstract

A patient's experience of living with Trigeminal Neuralgia is outlined. The way contacts with healthcare professionals could have been better are described. The medicines that are being taken, the elements of service provision that have been found to be most helpful and the steps needed to improve the ongoing management of the condition are identified. Key messages for healthcare professionals that have arisen from the patient experience are indicated.

Keywords: medical condition, medicines, dentist, pain, carbamazepine.

About your medical condition

What is the medical condition that is most important to you and is being presented here?

Trigeminal neuralgia

Can you please explain the problems you experience with this medical condition?

Frequent and recurring spikes of severe pain in both upper and lower left jaw brought on by eating, draught, pressure, etc. There are brief periods of respite but, at its worst, it results in a dread of eating, cleaning teeth, going out or engaging in social activity. This leads to tension and makes the condition worse.

It can be both depressing and debilitating, especially when sleep is disturbed and it is difficult to find a pillow that gives support while being soft enough to cradle the affected area - memory foam is far too hard.

It affects confidence as it is impossible to hide the effect of a spike of excruciating pain and this means that social interaction is avoided.

Can you please say how the medical condition was first diagnosed?

The dentist instructed me to seek pain relief from my GP.

Can you please say when the medical condition was first diagnosed?

April 2016.

If you look back, what would you have liked to have been different in terms of contact with health professionals, etc?

With hindsight, I should have been more assertive in demanding attention for the condition. I raised my problems with my dentist at the time at virtually every visit, thinking it must be a dental issue. He merely kept asking which tooth was causing the problem, which was impossible to answer as it was the whole area. Some advice from him about pain control would have been beneficial. I had numerous X-rays which failed to show any problem and, because I do have periods of respite from it, thought it had perhaps settled down and followed his advice to

use Sensodyne toothpaste and take a pain killer. No mention of neuralgia was ever made and I was given the impression that I just had sensitive teeth. There was no indication given that it could be a medical, rather than a dental, condition.

When the paracetamol failed to provide any relief I consulted the pharmacist who suggested a different type of painkiller but at that time I had no diagnosis so I was seeking help for sensitive teeth.

With a change of dentist came a recognition that this was something that needed to be pursued as he informed me that there was treatment specifically for this condition, which I had not been told before. I followed his advice to see my GP but was just told to take paracetamol.

A particularly acute and lengthy bout forced me to seek advice from a different GP who prescribed a treatment regime and informed me of the nature of the condition, the long-term outlook and alternative forms of treatment if the prescribed course was not effective or didn't suit me. I now understand how the current treatment can be modified and feel able to consult the GP as and when needed. This GP took time to explain the condition and the alternative forms of treatment, the fact that it is one that can be managed but not cured and how we can work together to reach a point where I am happy with the outcome. This results in a very different and positive attitude towards the problem.

When I had a prescription for carbamazepine the pharmacist explained what it was for, how to take it and was (and is) happy to answer any questions.

I should have pursued this more energetically but as frequent X-rays didn't identify any problem I accepted the advice that it was sensitivity and followed the regime suggested until it reached the point where it was becoming unbearable.

The pharmacist I use couldn't have been more helpful but didn't have sufficient information to make a difference. Many people don't like to feel they are wasting the doctor's time and if told something tend to accept and put up with it. This must be difficult for health workers to identify but if someone raises the same issues time and again then it should be investigated.

The most profound change for me has been a dentist and GP who recognised this wasn't some minor issue, who shared their knowledge, involved me in the process and made it clear I wasn't wasting their time.

I do not suffer as severely with this as some people. I think this was part of the problem as the periods of respite give the illusion that the problem has gone, which of course it hasn't. Now, through talking to the GP, I understand that the treatment regime should continue during the periods of respite as it will recur.

About your medicines

Please list the medicines you taking for your medical condition.

- Carbamazepine (low dose of 100mg night and morning to be monitored and increased until pain level controlled).
- Ibuprofen.

Have you had any particularly bad experiences with regard to your medicines? If so, please explain and indicate how this could be avoided in future.

Restless nights and disorientation in the day. If the dosage needs to be increased but the side effects continue then referral to a specialist for alternative medication will be needed.

Have you had any particularly good experiences with regard to your medicines? If so, please explain.

Although the pain isn't controlled, the severe spike doesn't reach the same excruciating level as previously. This provides hope that the condition can be controlled.

About the services you received

What have you found to be most helpful to you in terms of the services you have received?

A dentist and a GP who listened, recognised the problem, provided information, provided medication and continued to monitor progress. This, in turn, enables control to be taken of the condition with confidence that professional support is on hand.

To what extent have the health professionals you have come in contact with appreciated what it was like from your position as a patient?

Initially not at all. However, there is now a willingness to listen and provide help to return to normal life.

To what extent was the information you were given about your medical condition sufficient for you?

The GP discussed the condition at length, gave printed information and is monitoring closely so any concerns can be addressed on a regular basis.

To what extent did the health professionals you came in contact with communicate effectively with you?

Initially not at all, now very effectively.

What have been the best experiences you have had with the services you have received?

Professionals who listen, appreciate the devastating effect this condition has and encourage consultation with them.

About other medical conditions

Do you have other medical conditions and how do they make life problematic for you?

Torn ligament right knee: limitations to mobility.

Carpal tunnel syndrome: pins and needles sensation in hands and forearms, burning sensation in fingers.

About going forward

What would you like to happen at this stage that would make living with your condition easier for you?

Getting the pain management right and having a period of respite.

If you could give a brief message to healthcare professionals, what would it be?

Adopt an holistic approach, listen to the patient and recognise that just because a person isn't making a fuss their condition is nonetheless distressing.

Please add any other comments or observations that would be helpful to health professionals who are responsible for providing services for you.

There needs to be greater communication and exchange of information between healthcare professionals.

What are the three most important things that health professionals should learn from your experiences?

- 1) Missed and delayed diagnosis leads to a reluctance to seek further help.
- 2) An opportunity should be afforded to patients to be proactive in their treatment - but they are not professionals and need advice and guidance.
- 3) Listen to patients.

Declaration of interests

In the spirit of being open and transparent, would you please disclose any payments, interests or activities that could be perceived as influencing what you have written.

A fee was offered by Pharmacy Management to complete this questionnaire within a defined timescale. I have no other interests to declare.

KEY LEARNING POINTS FOR HEALTH PROFESSIONALS IDENTIFIED AT THE EDITING/PEER REVIEW STAGES

- The importance of listening to the salient points made by the patient and recording in the notes.
- Taking a 'whole person' approach to understanding and solving the problem.
- Realising that a health situation can change quite rapidly and the changes therefore need to be identified and considered.

Dopa-responsive dystonia/Early-onset Parkinsonism

Abstract

A patient's experience of living with Dopa-responsive Dystonia/Early-onset Parkinsonism is outlined. The way contacts with healthcare professionals could have been better are described. The medicines that are being taken, the elements of service provision that have been found to be most helpful and the steps needed to improve the ongoing management of the condition are identified. Key messages for healthcare professionals that have arisen from the patient experience are indicated.

Keywords: medical condition, medicines, pain, spasms

About your medical condition

What is the medical condition that is most important to you and is being presented here?

Dopa-responsive dystonia/Early-onset Parkinsonism.

Can you please explain the problems you experience with this medical condition?

My problems began with pain and posturing of my left foot and leg. Over time this has progressed to muscle spasms in both feet, legs and trunk – it can be almost everywhere throughout my body. My body becomes fixed and I experience extreme pain. This can happen at any time of the day or night. The pain worsens with movement although I generally have more attacks at night, which causes me to wake up frequently. Daily, I am very tired and very slow. I usually feel better in the mornings than the afternoons - evening times I am extremely tired and unable to function so well. I walk around the house and can take a few steps with crutches. Out of the house I use a wheelchair. More recently, I am unable to sit up for any length of time.

Can you please say how the medical condition was first diagnosed?

At age eleven I started attending high school. I became much more active and played lots of sports. My left leg and foot became much more painful and twisted. I began to have major problems with participating with sports and eventually even walking. The problems were investigated. I saw many types of doctors of varying specialities. Eventually, I was seen by a neurologist and admitted to a specialist hospital. After many tests and at age 17 years, I was diagnosed with Dystonia. Later, I was seen by a movement disorder specialist doctor and was further diagnosed with Early-onset Parkinsonism.

Can you please say when the medical condition was first diagnosed?

1985.

If you look back, what would you have liked to have been different in terms of contact with health professionals, etc?

- Faster diagnosis.
- Greater understanding of the condition by healthcare professionals.

About your medicines

Please list the medicines you taking for your medical condition.

- Lansoprazole 30mg gastro-resistant capsules
Take one every day
- Bisacodyl 5mg gastro-resistant tablets
Take one to two at night
- Miragbegron 50mg modified-release tablets
Take one every day
- Nitrofurantoin 50mg tablets
Take one at night
- Gabapentin 300mg capsules
Three to be taken four times a day
- Tramadol 50mg capsules
Take two every 4-6 hours
- Domperidone 10mg tablets
Take two three times a day

- Celecoxib 200mg capsules
One or two to be taken every day
- Sinemet CR 50mg/200mg tablets
One to be taken five times a day
- Baclofen 10mg tablets
Take 3 in the morning, 2 at lunch time, 2 at tea time and 3 at bed time
- Dantrolene 25mg capsules
Take two tablets three times daily
- Lorazepam 1mg tablets
Take half a tablet when required

Medication is clearly a time consuming, ever changing, constant in my life. I have a wonderful partner who keeps us constantly on top of things; not least in having to collect prescriptions on a constant basis!

We have a wonderful GP, with electronic communications for all prescription needs. Any queries are dealt with the same day with a telephone consultation. New and repeat requests are sent electronically from the GP to the pharmacy, and are ready for collection in good time.

Each day my medication is set out in a '1 Week Pill Chest', which has seven removable containers - one for each day. Each is split in to four sections: breakfast, lunchtime, teatime and bedtime. It is not filled by the pharmacy - it is done here at home. Most of the tablets are divided in to breakfast, lunch, dinner and bedtime sections. For the other, additional, tablets I have a reminder set on my phone.

Most of the time I don't really require any additional help as my body 'knows' when it is medication time. This of course falls apart if I am unwell - when this happens I always have someone around to help me take the correct medication at the correct times.

Have you had any particularly bad experiences with regard to your medicines? If so, please explain and indicate how this could be avoided in future.

- Tiredness
This can be overcome by pacing myself throughout the day e.g. I wake up early at 6.00am to take medication. I then need to have an hour or so resting whilst the medication begins to work and the side effects wear off.
- Constipation and sickness
Although these may seem like routine everyday problems, they have a major effect on my day to day life. These are managed by my GP.
- Assumptions by healthcare professionals that new problems are side effects of recent medication changes when in fact they are due to new un-related conditions. I have been prescribed new medication by hospital consultants but, when home and taking the new medication, I have suffered sickness, headaches, and diarrhoea. These have been attributed to the new medication's side effects by healthcare professionals when the new symptoms were actually due to a bug contracted whilst in hospital, or a urinary tract infection (UTI), and nothing to do with the side effects of the new medication. This could be overcome by the GP having greater awareness of any unusual medication that is prescribed, doctors being mindful that other 'routine' illnesses can occur alongside a long-standing and more complicated condition and being under the direct supervision of the hospital consultant until the new medication is settled.

Have you had any particularly good experiences with regard to your medicines? If so, please explain.

- Sinemet tablets made a huge improvement to my day-to-day life. I experienced less pain and much fewer spasms. I would say that this drug has changed my life.
- Nitrofurantoin has reduced the number and frequency of UTIs. This is a significant improvement.
- Pain medication is always helpful.

About the services you received

What have you found to be most helpful to you in terms of the services you have received?

All of the services I have received have been helpful. I am very thankful for the care that I receive. Most helpful have been:

- specialist knowledge and diagnosis of a Consultant Neurologist and a Movement Disorder Specialist Professor.
- continued and constant help, support and understanding by the GP Practice.

- a prompt and accurate service from the local pharmacy. Often, because of contact with multiple doctors and departments, drugs may be issued that are contraindicated. The Pharmacist is often the most important person to notice this and avoid problems arising.
- the provision of an electric wheelchair by Wheelchair Services has been helpful in allowing me to leave the house in a safe and comfortable way.

To what extent have the health professionals you have come in contact with appreciated what it was like from your position as a patient?

This has been varied and patchy. In specialist hospitals and departments, consultant knowledge and awareness has been good. When in contact with other healthcare professionals, however, understanding has been poor, such as:

- nurses and healthcare assistants have NO understanding
- physiotherapists have very little understanding
- GP understanding is varied. One GP said that he knew nothing about the condition and told me to look it up on the internet. Another GP told me they have no understanding of the condition and I need to discuss everything (even something as routine as a cold) with my specialist consultant. They did not appreciate what it is like for me at all. Other GPs have a good understanding and try to appreciate what it is like from my position.

To what extent was the information you were given about your medical condition sufficient for you?

At first, the information I was given was poor. At the time of diagnosis I was told how to spell the condition, but nothing about what it would mean to me. I was directed to The Dystonia Society for further information. Later, specialist consultants have provided me with good information.

What have been the best experiences you have had with the services you have received?

- Specialist Consultants.
- Care given by GPs after such poor experiences with earlier GP Practices.
- Pharmacy services.

About other medical conditions

Do you have just one medical condition that make life problematic for you? If 'No', please list the other medical conditions and explain the main problems you experience with each one:

Medical condition	Main problem experienced
Oesophageal spasm	Thoracic pain
T5 spinal cord hernia due to arachnoid cyst	Thoracic pain
Transverse myelitis	Weakness and numbness in lower limbs
Degenerative spine disease	Thoracic and Lumbar pain
Neuro-inflammatory disease	Thoracic pain

About going forward

What would you like to happen at this stage that would make living with your condition easier for you?

- Pain reduction
- A reduction in the number and severity of spasms
- Be able to walk around outside
- Reduced tiredness.

All of these I would like to happen but I realise it is unlikely that they will be achievable - but you did ask the question!

If you could give a brief message to healthcare professionals, what would it be?

Thank you for taking care of me.

Please add any other comments or observations that would be helpful to health professionals who are responsible for providing services for you.

Please do not see me simply as 'a patient with a disease or condition that you are treating' but as a complete person with many other conditions that interact with each other.

Also, see me as a person - not simply as a medical condition.

What are the three most important things that health professionals should learn from your experiences?

- 1) Raise awareness of Dopa-responsive dystonia and other Early-onset Parkinsonism conditions.
- 2) Patients have other conditions as well as the one they are treating.
- 3) I am the same person I was before I needed to use a wheelchair - I can still think and talk for myself.

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KEY LEARNING POINTS FOR HEALTH PROFESSIONALS IDENTIFIED AT THE EDITING/PEER REVIEW STAGES

- Having lived with a debilitating long-term condition, we should remember that some patients are experts in monitoring and managing their condition. The implication of this is that we should ask the patient what works or does not work before offering advice.
- An important part of living with a debilitating, long-term condition is the burden of appointments and visits to pharmacies to collect medicines. The attendance at clinic appointments or at pharmacies for the collection of prescriptions or advice should be supported and made as easy as possible e.g. scheduling of supply of all medicines at the same time, better communication between primary and secondary care. Patients who do not have another person in the household to help them manage their medicines may be particularly at risk of drug-related misadventure.
- If we are privileged enough to have a patient with a rare, debilitating long-term conditions present to us, we should start by getting to know the person rather than the patient with a disease and a list of medicines. We should then read up on and learn about their disease in a way that leads to the patient receiving better drug related advice from us.



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Constructive comment to further understanding and debate about a topic is encouraged and welcomed.

Guidance on submitting correspondence appears at the front of the journal.

Please submit your correspondence to the Correspondence Editor:
(correspondence@jmedopt.com)

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There is a JoMO LinkedIn Group. It is a closed group but everyone who requests the JoMO will be permitted to join. Readers are encouraged to comment upon and discuss items about medicines optimisation.

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Readers are encouraged to follow Pharmacy Management on @pharman to use our dedicated Twitter hashtag (#jmedopt) to draw attention to and debate topical issues having to do with medicines optimisation.

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