

Managing medicines in multimorbidity: a patient perspective

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ABSTRACT

An exploration of the patient experience of managing medicines for multiple long-term conditions from the patient perspective. Difficulties and coping strategies are presented, with some exploration of the ways that clinicians, prescribers and pharmacists help or hinder this experience.

INTRODUCTION

Many people who are chronically ill take medication to manage symptoms or prevent their condition becoming worse. It is to be hoped that these medications do what they are intended to do, but patients may find it bothersome, and side effects are a common feature of many medicines. As such, it is common to hear people complain about taking regular medications. They must remember to take them at the right time, perhaps before food, or after food, or on an empty stomach. They must cope with drowsiness or upset stomachs that come with the medicine. These problems may be complicated by the symptoms of the very condition the medicine is meant to treat.

This is all compounded when a person has multiple long-term conditions and has medicines for each of them. Taking myself as the example, a person may have a medicine that must be taken as soon as possible on waking up, another that must be taken a specified time before each meal, another at noon, another at bed time, others spaced evenly through the day, a range of skin treatments applied at different times and in different circumstances, and twice-daily inhalers. As well as dealing with regular medicines, a person will also have to manage as-needed medications, or anything extra added for short-term problems, and managing medicines is generally not the most complicated situation a person will have to address.

In this article, I will explore some of the difficulties of managing medications with multiple long-term conditions from the patient's point of view. I will also explore some methods that patients use to cope with these difficulties, sometimes with the support of health professionals, including pharmacists, and some that we might hesitate to tell our doctors about.

I will also explore the love/hate relationship between patients and our medicines, and some of the ways the balance can differ between patients.

This is based in part on my own experience, but also on the extensive conversations I have had with other people who live with multiple long-term conditions. These have mostly been younger people, largely under 40, but this is not to the exclusion of

older people. Most of the examples are framed in terms of tablets, but generally apply equally in terms of other oral medications, inhalers and so forth. Issues of inconvenience can become even greater for some forms of treatment, such as topical treatments on large or hard-to-reach areas, or nebulisers.

'THE STEADY STATE'

By using the term 'steady state', I am referring to the fact that everybody faces challenges when they first start a new regimen of medication, even if it is just the simple fact of getting used to taking it. However, if nothing changes, one will sooner or later reach a 'steady state', where the patient muddles along, generally doing okay. Adherence may be better or worse in this state, but generally remains consistent. This does not mean that there are no problems, merely that someone is coping with them as well as they can with a given level of support, and that they feel they are handling it well enough.

In this section, I will outline some of the problems that patients experience and ways we may cope with them—with help from professionals, or from friends and family, or entirely on our own.

Remembering medicines and knowing what you have taken

If all of your medicines are tablets taken once a day, for example, in the morning, then life is pretty simple, however many you are taking. It is not fun taking half a dozen tablets at once, but it is *straightforward*.

However, many medicines are taken more than once a day, and fewer when you want ones you can take all at the same time of day. Once a person has been prescribed medicines for three conditions, it seems to be extremely unlikely that all of them will be once a day. Pain is a feature of a lot of chronic conditions, and medicines for pain tend to be taken several times a day. Many medicines for all sorts of conditions have pharmacokinetic profiles, which mean the medicine is spaced out through the day. Certainly, as patients we must assume that there is a good reason for our medicines to be so inconvenient!

So we find ourselves having to take some medicines when we wake up, and another set (that might be different) mid-morning, another in the afternoon and another at bedtime—for a relatively simple case. We may also be told that taking them too much could lead to organ damage, and forgetting to take them could lead to rebound or withdrawal symptoms; the stakes certainly seem particularly high in cases like anticonvulsants used



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in pain relief, such as gabapentin, where warnings include sudden cessation leading to seizures even in those who have never had them before.

So we certainly want to take our medicines correctly, but it is not unusual for either a medical condition or a side effect to cause some uncertainty as to whether you have taken a medicine. You might set a reminder on your phone, but if you are busy when it goes off, it is easy to dismiss it and forget about it. It is then easy to be uncertain whether you took the medicine or not.

These problems are relatively straightforward to solve in principle, with compliance aids. Whether we fill them ourselves, they are filled by a carer or by our pharmacy, they have the marvellous characteristic of being able to immediately tell whether we have taken the tablet or not. When combined with reminders from phones, computers or specialist devices, this allows us a fairly reliable way to take our medicine when we should take it, and in the worst case it allows us to know exactly what we forgot. However, the reliability of this strategy rather depends on how complicated your medication schedule is.

Coordinating medicines

The difficulties in remembering to take medicines, and avoid unintentional overdoses, are compounded when you have more complicated instructions to follow. My most complex medication schedule was when I had to take three different medicines first thing in the morning, another 20 min before each meal, another that I could not eat for an hour after taking, two that I needed to take with or after food, one as close as reasonably possible to noon, one at some point in the afternoon and two at bedtime. Not to mention several possible ‘as-needed’ tablets, twice daily and ‘as-needed’ inhalers, and twice-daily skin treatments. I resorted to two full sets of four-a-day dosette boxes and still had to keep track of some things separately. Even then, it was a rare day that I took everything exactly as I was supposed to.

That was a relatively short-lived case as one of the sets of tablets was a course of antibiotics. It has, however, occurred more than once, and I am told of cases that are more complex and continue on an ongoing basis. As our medications are often added to our regimens one at a time, prescribers rarely seem to think about how they all add up, and dispensing pharmacists rarely seem to take an active interest even when they are dispensing a laundry list of medication all at once. Yet we, as patients, tend to assume that the professionals we are dealing with know what they are doing and rarely mention our difficulties unless we are outright asked if we have difficulty managing our medicines or it reaches the point where we feel truly desperate.

Having a carer supporting the management of medicines can be a huge benefit, whether they be a family member or a paid assistant, but that is not available to everyone. Unfortunately, this is an area where I am afraid I am not aware of any miraculous, straightforward ways to cope with the problem.

Side effects

Side effects are part and parcel of medications. While there is the occasional treatment with little or no adverse effects, most come with patient information leaflets with a bewildering array of possible effects. Even if patients do not suffer most of the side effects of a given medication, taking many medicines makes it far less likely that they will avoid unpleasant reactions—particularly when you consider the possibility of interactions. It took some time, in my own case, for the symptoms of serotonin toxicity to be recognised. It was a mild case, to be sure, and I

would hope in a more dangerous case it would be noticed sooner, but I was in and out of various doctors’ offices with strange symptoms for weeks before anyone put it together. I understand that there are several categories of medication that can have cumulative effects in that way, and clinicians are not always good at informing patients of risks or telling that what to watch out for. Do not even get me started on grapefruit.

Sometimes, the attempt to manage side effects leads to taking additional medications, which may or may not be prescribed. A patient may increase their use of an as-needed medicine or may add an over-the-counter medicine. We may even take an additional medicine for its side effect rather than its usual purpose, such as taking over-the-counter opioids for their effect on digestion rather than to relieve pain. And we can be quite slow to admit that we do these things for fear we will be told to stop without being given an effective alternative.

On the subject of over-the-counter medications, though, patients who have many prescribed medicines may also be reluctant to take any over-the-counter medications that they have not previously been told are okay. This is because we will be asked if we take any other medicines, and we say ‘yes’. We will be asked what, we will start to reel off the list and be told to wait while someone fetches the pharmacist. Sometimes, the pharmacist will disappear off in back to look things up, come back in 10 min and then give us the go-ahead or not. It can even be quite clear that the pharmacy staff resent this imposition, though pharmacists occasionally appear to relish the break from routine. Some patients appreciate the importance of these checks, some do not, but it is terribly disheartening for us either way. Often, we are not sure if it is worth the hassle—including the hassle for the pharmacist—so we decide that we can do without the decongestant, antihistamine or medicine for an upset stomach.

ADDING MEDICINES

However precarious and stressful it might be, the ‘steady state’ is at least relatively stable. However, it is inevitable that, sooner or later, something will be changed, short or long term. A medicine might be removed as no longer needed but the greater impact is found in adding or changing medicines, and the experience of people with multiple chronic illnesses seems to focus on adding medicines. This is particularly relevant to side effects and interactions with the simple reminder that these things get a lot more chaotic as medicines are added.

The part that may be less obvious to professionals is the upset new medicines can cause to a patient’s carefully worked out and settled strategies for coping with treatments. As alluded to above, this can be a relatively small change, the addition of a medicine with a slightly different dose pattern or requirements, such as taking with food or on an empty stomach, and a fairly simple, settled pattern can be thrown out of equilibrium.

This is not merely a matter of slotting something else in or using an extra dosette box. People become able to manage their routine not simply by coming up with coping strategies, but by habit. Not only do the coping strategies have to be adapted, but habit is thrown off. This not only makes it difficult to cope with the new medicine, but also makes it harder to cope with the medicines that had been a reasonably comfortable routine.

A LOVE-HATE RELATIONSHIP

The relationship between chronically ill people and their medication is frequently one of a balance of love and hate. Some people tend towards one end of that spectrum than the other, but it is unusual to find a chronically ill patient, especially one

with multiple chronic conditions, whose attitude towards their medication is one of complete happiness or displeasure.

When we can tell that a medication is actually working, we may be prepared to tolerate a lot. We may resent having to take tablets five times a day, but would not trade it for the world. We may feel terribly burdened by the side effects of a drug, resent feeling sleepy, or confused, or keyed-up, or nauseous—but would not even consider trading those effects to have the original symptoms back. A patient may bemoan how awkward it is to spend time and enlist the help of a family member to apply skin treatments several times a day, but still infinitely prefer that situation over the original complaint.

On the other hand, we may feel that a medicine we take is not worth it. We do not feel it is giving us a worthwhile benefit for the side effects or even the effort of taking the treatment. However, we do not raise this with our doctors as we do not wish them to think we are resisting treatment. Some patients will just silently stop taking a medicine, but keep having the prescriptions filled regularly to keep their doctor from knowing. Others may simply be inconsistent in their adherence, taking their inhaler ‘when they remember’, or only two out of three doses of tablets most days. Patients may be more forthcoming about this to a professional with no direct connection to the prescriber, but may assume that anything they say to a pharmacist could be reported back to the doctor in any case.

The simple, if unhelpful, point to take from this is that you cannot make assumptions when you see that a patient is being prescribed a laundry list of medications. The patient may find them no burden at all or may find them a terrible burden; even in the latter case, however, they may very much prefer taking them to not taking them. They may even not be taking them properly, which may produce unexpected results if they spend time in a controlled environment where their medication use is actively encouraged, such as an inpatient setting. This is likely all true for those taking a smaller number of medications, but my experience suggests that these sorts of complications are more likely to arise in cases where there are multiple medications, especially where they produce a complicated medicine regimen.

If you can advise a patient on many medicines that there are some they could stop taking to no ill effect, or that two or three

medicines could be replaced with one to do the work of several, a positive response is much more likely. A patient who is reasonably stable may still be reluctant to want things changed, but they are less likely to feel that someone wants to take away their medicine if there is a clear benefit to stopping medicines. Any changes in prescriptions must be discussed with the patient in an open way, considering risks and benefits both pharmacologically and in relation to the person’s life and condition. There must be an option of stopping for a short time, monitoring and reviewing in case the medicine needs to be restarted or replaced. In this way, deprescribing is a collaborative, positive process for both patient and prescriber.

CONCLUSION

Managing medicines is a major challenge of life with multiple chronic illnesses. It can be a considerable burden, but it would be a mistake to assume that people in this position will be eager to give up any of their medications. As always, patients’ preferences vary, and the ability to cope with disruption also varies. However, patients with multiple long-term conditions may particularly benefit from support and sympathetic approaches in prescribing, dispensing, medicine reviews and even over-the-counter enquiries and purchases.

Deprescribing is a particularly sensitive area, which patients may respond to with enthusiasm, but may also view with suspicion—or even distrust. Being familiar with a patient’s goals and preferences before starting the conversation, then finding out how the patient feels about their medications, will allow more effective collaboration with the patient. This collaboration is important to produce an effective result and maintain a relationship of trust with the patient.

Supportive health professionals, who listen to us and treat us as individuals, are invaluable to people with complicated medical lives. We encounter them far too infrequently. My hope is that clinicians will pay more attention to the complications found in patients’ lives and that this will improve outcomes for all of us.

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