

Experiences of using long-term medicines: the Living with Medicines Questionnaire

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Why we did this study

Medicines are the most common way in which diseases are treated. Approximately half the UK population use at least one regular medicine. Many people use a lot of medicines. Most people cope with the effort of collecting prescriptions and having them dispensed at a pharmacy, then sorting out which ones to take when. But some find this difficult. People may develop unwanted effects from medicines, and sometimes these can impact on their everyday lives in many different ways. Sometimes people may feel the medicines they are using aren't working as well as they would like.

What we wanted to find out

We wanted to try and measure the experiences people have using long-term medicines, which may have a negative impact on their lives.

What we did

We have developed a questionnaire, called the Living with Medicines Questionnaire (LMQ). This was put together using information from interviews with patients who were using long-term medicines and we have done a lot of testing with this questionnaire. It has 41 statements with which people are asked to agree or disagree and which add up to give a total score. The statements cover eight different aspects of using medicines:

- Relationships with health professionals
- Practical difficulties with using medicines
- Costs of medicines
- Concerns about medicines
- Side effects
- Interferences with day-to-day life
- Perceptions of effectiveness
- Control over using medicines

The questionnaire also has a scale which asks people to rate how much of a burden they feel using their medicines is from 0 to 10 and we asked people to tell us something about their experiences.

Who we asked

We asked patients aged 18 years or over who were taking at least one regular prescription medicine to complete this questionnaire. We asked patients who were in general practice waiting rooms, hospital clinic waiting rooms and community pharmacies.

We gave out 1306 questionnaires and 422 were returned. Just over half were from women – (53%). The age of respondents ranged from 18 to 92 but 40% were aged 65 years or above. 334 people had fully completed the questionnaire.

What we found out

- The number of regular medicines they were using ranged from 1 to 26
- 13% were using 10 or more different medicines
- 11% had to use a medicine at least three times a day
- 14% needed help with using medicines
- 33% paid for prescriptions

We looked at each of the eight aspects of using long-term medicines in turn.

Relationships with health professionals

Most people had good relationships with health professionals, but 33% didn't feel they had enough information about their medicines.

One lady aged 71, who used two medicines wrote: *"I feel that my doctor does not review or explain why he has prescribed the particular drugs."*

Practical difficulties with using medicines

16% had difficulties getting their prescriptions and having them dispensed, while 19% had to put a lot of planning and thought into using their medicines. 9% did not think it was easy to keep to their medicine routine and 10% were not comfortable with the times they should take their medicines. These difficulties were not just in older people or those using a lot of medicines.

One lady aged 47 who uses one medicine wrote: *"GP management insist all prescriptions are requested in person at the surgery, the opening times are incompatible with my working hours."*

Costs of medicines

It was clear that not everyone who needed medicines received free prescriptions and not everyone could afford the fees. One lady aged 54 who used five medicines had retired early through ill health yet was not eligible for free prescriptions, while a 21-year-old had seven different medicines and felt it was a *"nightmare having to pay ridiculous amounts"* for them.

Concerns about medicines

More than half the respondents (58%) were concerned about the long-term effects of medicines and 36% were concerned about potential interactions between their medicines. 34% didn't feel they had enough information about their medicines and 38% would like more say in the brands of medicines.

Side effects

20% of people felt that side effects were bothersome and interfered with day-to-day life and affected their quality of life.

Interference with day-to-day life

Many people felt that medicines interfered with social and leisure activities, social relationships and sexual relationships, particularly younger people. For example, one 34-year-old man felt that having to carry all his equipment for injecting insulin to treat diabetes 'advertised' his condition. A 28-year-old lady considered that having to take tablets in public made her feel shameful. An 18-year-old said her medicines made her tired and dizzy so she could not go out a lot. Overall 27% agreed that their life revolved around using medicines.

Perceptions of effectiveness

The majority of people felt their medicines were working and were grateful for them. But over a quarter felt their medicines did not live up to their expectations. One lady, who was 63 years old and used 16 medicines wrote that her medicines: *“have no effect on the amount of pain I am in, which makes my life revolve around pain and depression.”*

Control over using medicines

More than half of the respondents said they could not change the dose or the time of their medicines and didn't have enough say in choosing their medicines, instead feeling obliged to stick to the regime prescribed by their doctor. One said it was *“difficult to get the GP to alter dose or change medication”*, while another said *“I am not given choices on medicines and treatments.”*

Perceived burden of using medicines

Although many people had concerns or difficulties, most did not feel that using long-term medicines was a 'burden'. However the total score on the questionnaire was clearly related to the feeling of burden.

What this means

- Some people clearly have difficulties with or are not entirely happy with using the long-term medicines prescribed for them. It may be that patients who returned the questionnaire may have been less satisfied than those who didn't. Nonetheless, health professionals need to be aware of the many different problems which people do experience.
- Everyone who is prescribed a medicine makes a decision about whether or not to use it. Our study suggests that there are quite a lot of people who feel they do not always have much choice or who have to put considerable effort into using medicines, which don't always work and cause side effects.
- Doctors, nurses and pharmacists should listen more to patients and ask them about their experiences with using long-term medicines. If patients are unhappy they may be less likely to use the medicines prescribed for them and get benefit from medicines.

How you can use this research

If you use long-term medicines, think about the eight areas included in our questionnaire and consider whether you have any problems or concerns in any of these areas. You could take away a copy of the questionnaire and fill it in, which may help you to identify the issues you are unhappy about, so you can discuss these with your doctor or pharmacist next time you see them. They may be able to give you advice or suggest changes so you have a better experience with medicines.

You should expect your doctor or pharmacist to ask how you are getting on with your medicines. If they don't, why not take the initiative and tell them.

You should have your medicines reviewed at least once a year. If this isn't happening, you can ask for a review.