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Issues potentially affecting quality of life arising from long-term medicines use: a qualitative study

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Abstract

Background

Polypharmacy is increasing and managing large number of medicines may create a burden for patients. Many patients have negative views of medicines and their use can adversely affect quality of life. No studies have specifically explored the impact of general long-term medicines use on quality of life.

Objective

To determine the issues which patients taking long-term medicines consider affect their day-to-day lives, including quality of life.

Setting

Four primary care general practices in North West England

Methods

Face-to-face interviews with adults living at home, prescribed four or more regular medicines for at least one year. Interviewees were identified from primary care medical records and purposively selected to ensure different types of medicines use. Interviews were recorded, transcribed and analysed thematically.

Results

Twenty-one interviews were conducted and analysed. Patients used an average of 7.8 medicines, 51% were preventive, 40% for symptom relief and 9% treatment. Eight themes emerged: relationships with health professionals, practicalities, information, efficacy, side effects, attitudes, impact and control. Ability to discuss medicines with health professionals varied and many views were coloured by negative experiences, mainly with doctors. All interviewees had developed routines for using multiple medicines, some requiring considerable effort. Few felt able to exert control over medicines routines specified by health professionals. Over half sought additional information about medicines whereas others avoided this, trusting in doctors to guide their medicines use. Patients recognised their inability to assess efficacy for many medicines, notably those used for prophylaxis. All were concerned about possible side effects and some had poor experiences of discussing concerns with doctors. Medicines led to restrictions on social activities and personal life to the extent that, for some, life can revolve around medicines.

Conclusion

There is a multiplicity and complexity of issues surrounding medicines use, which impact on day-to-day lives for patients with long-term conditions. While most patients adapt to long-term medicines use, others did so at some cost to their quality of life.

- Many aspects of long-term medicines use can potentially affect patients' quality of life, in addition to the conditions for which they are prescribed, and this impact needs to be more widely recognised.
- Health professionals should consider the potential burden of medicines use on any individual when managing long-term conditions.
- A means of quantifying the medicines-related issues which potentially affect patients' quality of life may prove useful.

Introduction

An increasing body of literature recognises that while clinical guidelines and specialist care may result in better disease management, they also create a drive towards prescribing leading to multiple medicines use which is becoming burdensome to patients[1,2]. Increasing medicines use leads to more frequent problems with medicines[3]. Polypharmacy in the elderly can increase cognitive dysfunction through anticholinergic burden[4,5] with adverse effects on social functioning and mood. Many prescribed medicines are used to prolong life or prevent secondary events; in England 14 of the top 20 dispensed drugs in 2010 fell into this category, accounting for 26% of all items dispensed[6]. Patients are expected to take these medicines long-term, with many providing no direct positive feedback in terms of efficacy, but potentially causing adverse effects. Adverse effects are only one aspect of medicine use which could cause difficulties, distress or place a burden on patients. Therefore we suggest that long-term medicines use could potentially adversely affect quality of life and suggest defining this as a modification of Bowling's definition of health-related quality of life: "individual responses to the physical, mental, and social effects of medicines use on daily living that influence the extent to which personal satisfaction with life circumstances can be achieved[7]."

Although there is increasing emphasis on patient-reported outcomes, studies rarely incorporate patient views of using medicines. A systematic review showed many patients hold negative views towards medicines, with some resisting taking medicines because of concerns about harm or dependence[8], but positive views also exist [9]. One patient-led study declared that "many older people's lives are governed by the drug regimes they must follow, they experience varying degrees of difficulty in complying and their quality of life suffers as a result" [10]. Purposeful non-adherence, through adaptation of medicine regimens to personal lifestyle by occasional missed doses, reducing doses or frequency of medicines to minimise adverse effects may benefit some patients[11].

Most qualitative studies exploring the impact of using medicines have involved one group of medicines or patients[8]. Quantitative studies measuring impact have focused on specific aspects of medicines use, such as anticholinergic burden[12], capacity to manage medicines[13] and satisfaction

with medicines[14]. We identified no qualitative studies specifically assessing the impact of using long-term medicines on day-to-day life.

This study therefore aimed to explore patients' views of using long-term medicines on their day-to-day lives, to facilitate developing a tool to measure the impact and burden of using medicines, which could affect quality of life.

Objective

To determine the medicine-related issues which patients taking long-term medicines consider affect their day-to-day lives.

Method

A series of face-to-face semi-structured interviews were undertaken with adult patients regularly prescribed four or more medicines. Approval was obtained from both NHS (Ref: 08/H1016/71) and University Research Ethics Committees and Sefton Primary Care Trust (PCT).

Setting and inclusion criteria

Participants were recruited from four general medical practices in North West England covering varying levels of deprivation. Inclusion criteria were: adults, living at home taking at least four medicines for chronic medical conditions for at least one year. Exclusion criteria were: patients under 18 years of age, physical, mental or cognitive impairment reducing ability to be interviewed, any patient whom their GP felt was unsuitable due to current physical, mental or personal circumstances.

Recruitment

Practice-based pharmacists identified patients fulfilling inclusion criteria from medical records. After stratification by age and sex, a random sample were invited to participate by letter, with an information leaflet and eligibility form, requesting contact details and prescribed medicines currently used, plus freepost envelope. Medicines details were used to purposively sample thirty potential

participants from among those agreeing to interview, to maximise variation in medicines and formulations.

Interviews

The interview guide (Box 1), developed by the research team utilising medicine-related problems from the literature and professional expertise, was piloted with three individuals using long-term medicines. This assessed the guide's ability to enable and encourage respondents to explore the issues they felt were relevant to using medicines, particularly those potentially reducing or enhancing the quality of their day-to-day lives, while allowing views to be raised on topics not covered.

<<INSERT BOX 1>>

Semi-structured interviews lasting approximately 45 minutes were conducted by a psychologist, audio-recorded with permission and transcribed. Thematic analysis was carried out using an inductive approach[15]; themes were identified separately and agreed by two researchers, then both analysed and coded all transcripts independently. Interviews continued until data saturation was reached.

Results and Discussion

A total of 131 patients agreed to participate in the study, with 105 agreeing to interview. Of the 30 invited for interview, 22 agreed. Saturation of themes was reached after analysis of 21 interviews. To confirm this, a further interview was conducted and analysed but no further issues emerged. The remaining respondents and those not agreeing to interview were invited to participate in later stages of the study[16]. The 21 interviewees comprised 11 males and 10 females, age range approximately 20 to over 80, using 163 prescribed medicines, range 4 to 17, average 7.8 per patient. Medicines used were categorised using the British National Formulary[17] and formulation (Table 1).

Table 1 Medicines used by the 21 interviewees

Therapeutic category of medicines*	Number of medicines
Gastro-intestinal system	20
Cardio-vascular system	53
Respiratory system	11
Central nervous system	17
Endocrine system	16
Obstetrics, gynaecology and urinary tract disorders	5
Nutrition and blood	16
Musculo-skeletal and joint problems	11
Drugs acting on the eye	4
Drugs acting on the skin	10
Formulations	Number of medicines
Oral solid dose	126 (including one chewable tablet)
Oral liquid	6
Inhalers	7
Eye drops	4
Topical skin	10
Suppositories	3
Injection	5
Sublingual spray	2
Primary purpose	
Symptomatic relief	65 (39.9%)
Prophylaxis	84 (51.5%)
Treatment	14 (8.6%)

* categorised by BNF chapter

Eight major themes emerged from the interviews: relationships with health professionals, practicalities, information, efficacy, side effects, attitudes, impact and control.

1. Relationships with health professionals

Although not included in the interview guide, all patients raised this issue, indicating an inextricable perceived link between medicines and relationships with those who prescribe and provide them.

These relationships are fundamental to how many patients perceive and use medicines, impacting on other aspects, as described later. Perceptions concerning health professionals' attitudes towards participants and their medicines differed dramatically. Five accepted decisions, placing unquestioning trust in doctors, while expressing a feeling of powerlessness in the relationships[8], but two felt a need to question or challenge recommendations.

“I just take what the doctor said and I believe them, they’ve got tremendous power, doctors haven’t they?” (2)

“I know when it’s not working and when it’s not working I will actually go into me doctor and say ‘look this is not working, can we up the dosage or can we try this can we try that.’ ” (7)

Eight participants described negative experiences and dissatisfaction with these relationships, citing some unacceptable aspects of consultation style, including not listening to legitimate views.

“sometimes you feel as if you’re getting fobbed off... [with] medications which you last tried ten years ago which didn’t work ten years ago why are they going to work now? And you think well, this is just, ‘I’ve given you something, go away and come back in six months’.” (5)

Few felt able to discuss concerns about medicines with health professionals; one described deliberately selecting an approachable individual. Five raised barriers such as lack of time, language and lack of experience.

“Consultants have a language of their own and I think you need an interpreter most of the time to understand precisely what they’re saying.” (3)

Many studies have explored the doctor-patient relationship and the impact of communication styles on patient satisfaction, adherence to therapy, understanding and health outcomes[18-20]. Our findings suggest that despite teaching and guidance about the need to adapt consultation skills to individual patients’ needs and increased patient involvement in decision-making[11], some patients are still justifiably dissatisfied.

Four patients expressed dissatisfaction about lack of continuity of care and failure to transfer information about medicines.

“he said ‘oh carry on putting the drops in’ then I saw the student who said ‘carry on putting the drops in’, so two people had said without picking up that I was allergic to it.” (6)

Continuity of care incorporates three aspects: informational, management and relationship continuity[21], and may be positively associated with patient satisfaction[22,23]. Its lack is associated with higher morbidity[24], while failure to share or transfer information about medicines leads to both polypharmacy and other problems, such as the potential for adverse effects illustrated here, with its attendant impact on quality of life[25].

Ten interviewees discussed pharmacists and their staff, most positively, citing helpfulness in supply and ability to explain about medicines, although one felt pharmacies’ busyness made them unsuitable places to discuss medicines. Busyness has previously been identified as a barrier to uptake of pharmacy services[26,27].

“I don’t really like dealing with the pharmacy because when you go over there, there’s loads of people in there... but I don’t mind dealing with the doctors.” (8)

These positive experiences may derive from the view that pharmacists are ‘experts on medicines’ and more easily approached than doctors, as no appointment is needed[28,29].

2. Practicalities of using medicines

Interviewees who used them praised prescription collection and delivery services. Nine interviewees however were unhappy with the effort required to obtain both prescriptions from surgeries and medicines from pharmacies, including failure to synchronise repeat quantities requiring unnecessarily frequent prescriptions, insufficient medicines supplies and concern about running out.

“when I get to the end of my prescription I worry in case I don’t get my prescription in so that I don’t run out. I mean I really would worry, you know.” (6)

Although all participants had developed routines for using medicines, which had become automatic or ‘second nature’ – “*you think nothing of it*”- interviews revealed the extent of the physical and organisational effort required by some patients in using medicines. This was particularly evident for complex routines, such as varying daily doses or once weekly dosing, and when medicines changed. The impact of changes in daily routine sometimes resulted in medicines not being used.

”I don’t like these (compliance aid] because sometimes my fingers don’t lift the thing up... I don’t have long nails you see...The number of times I’ve dropped one in the bathroom, been hunting all over.” (2)

”.. two one day, three the next, I write myself a little card, Monday, Tues...I take the back of the pack and I put September one, two, three, right down to fifteen, then I start another page, sixteen and so on. And then I do another one for October so just in case I throw that box away. Otherwise I wouldn’t remember how many I’d had the day before if I didn’t write it down.” (2)

Practical problems such as difficulties in opening packaging, identifying medicines due to manufacturer changes and the need to develop strategies for remembering to take medicines, are common[9,30]. Several studies demonstrate that regime complexity is in itself problematic[8]. One study found on average five issues with potential to impact adversely on medicines taking among older people[31]. A variety of services enabling pharmacists to support medicines use exist in many countries[32-35]. These services should consider the patient’s experience of using medicines[11], but in reality often expound the predominant beliefs about medicines’ benefits, essentially attempting to increase adherence rather than question medicines’ impact or reduce burden.

3. Information about medicines

More than half the participants felt they needed information to allay their concerns, beyond that provided directly by health professionals, which they obtained by various means, including books, patient information leaflets (PILs) and the internet.

“I’d like to know what I’m taking them for and what it does and what if I don’t take them and what happens and long-time problems that can occur taking them. You know, cause you’re forever hearing them on tele aren’t you” (4)

“If I don’t know, I’ll buy a book, then I’ll read up on it” (18)

Conversely, four participants either did not want to know about their medicines or would never seek further information. One was uncertain about the usefulness of PILs and three considered that information caused or worsened rather than allayed concerns, meaning further reassurance and clarification from a health professional was needed.

“some people read this (leaflet) and think ‘my God I could have that, could have this’ ... So I’m conscious of that, you know, and I have asked at length, exactly what’s in this...plus exactly what does it do?” (20)

Much research suggests that most patients want information about their prescribed medicines [8,11,30]. Several studies suggest that while most patients read PILs, particularly the section on side effects, health professionals often fail to recognise or respond to this desire[10,36,37], with the potential for patients to become dissatisfied. GPs’ perceptions about what information patients want is a major influencing factor on consultation behaviour[38], with potential to influence relationships.

4. Efficacy

For many medicines, interviewees were clear about perceived efficacy, but also recognised that prophylactic medicines provided no tangible evidence of benefit.

“If it was a pain killer you can assess it...there’s no visible signs (with antihypertensives)” (15)

With medicines prescribed for symptomatic relief, as opposed to specific treatment or presumptive diagnosis, efficacy is detectable and patients can assess it by reducing or stopping them and observing symptoms[8,39].

“I know the alternative would be hell because I’ve tried without them” (1)

The overall proportion of symptomatic medicines such as analgesics in overall prescribing is decreasing, while prophylactic medicines are increasing[7]. Over 50% of all medicines being used by the interviewees were essentially prophylactic, with only approximately 40% potentially providing some positive feedback by way of symptom relief (Table 1).

Three patients believed that medicines may counteract each other when taken together, so deliberately spaced doses throughout the day. Another’s trust in their prescriber extended to the assumption that co-prescribed medicines were unlikely to interact. For one patient, medicines’ efficacy was judged to be related to the haste with which they were prescribed.

“So the medicine didn’t help me and it did really affect my quality of life taking those, because of the way I was feeling. And I thought you know ... sometimes they try and put you on tablets too quickly. You don’t get that discussion time to say ‘well can we discuss the side effects of these tablets?’ ” (9)

The view that doctors prescribe medicines too quickly has been found to result from perceptions of patient’s desire for a prescription during consultation[40,41]. This contrasts with actual patient views showing a general aversion to using medicines and some resistance to doing so[8].

5. Adverse effects

Three participants accepted that side effects were inevitable and were prepared to tolerate them to obtain benefits from medicines. Three others had discontinued some medicines, viewing the side effects as unjustifiable, worse than the problem the medicine was treating. Other studies have shown similar views, concerning medicines for HIV, schizophrenia and rheumatoid arthritis[8].

“I curse them and they’ve made me so uncomfortable, all the side effects.” (15)

In addition to actual experiences of side effects, one participant imagined experiencing all those listed in the PIL, while another expressed concern about when side effects would occur, both in the immediate and longer term.

“I think if you had those side effects, your quality of life would be very affected. And I mean by that it’s not just having stomach upsets, it’s actually the anxiety (of) when are they going to hit me?” (9)

Two participants found difficulty in discussing potential side effects with health professionals.

“I mean when I mentioned it at the hospital it was like brushed off if I’m honest. It wasn’t like ...it might be you know a side effect, all medications have side effects, yeah it’s understandable, do you want to sit down and talk and we’ll identify which medication is causing the problems.” (9)

Doctor dismissal of patients’ perspectives on adverse effects has been found previously[40,42,43], although many patients can identify adverse effects[44]. Adverse effects are relatively common[36,45,46], can seriously affect quality of life, reduce willingness to use medicines[9,11] and have the potential, if not identified, to result in yet further prescribing to alleviate them, the ‘prescribing cascade’[47].

6. Attitudes towards medicines

Six participants felt that medicines were necessary to relieve symptoms or prolong life and were grateful for these benefits, while at the same time wishing they did not need medicines.

“they definitely do (disrupt your life) because one thing you do know is you’ll never have a normal day again, you know when you get up and you don’t have to think about taking medicines or doing the injections... I’m getting fed up with taking these now. I wish I could just throw them all in the bin.” (9)

Seven however showed more negative attitudes, using words such as ‘hate’ or ‘curse’ them; one was ‘embarrassed’ by taking medicines to the extent that she would ‘rather put up with the problem than take the medicine’, while one showed the potential of such an attitude on future medicines use.

“I don’t like taking them. If it’s another one they’re going to give me, I’m pretty reluctant then to have any more” (14)

Acceptance of medicines is associated with acceptance of illness, shown in various conditions, including asthma, HIV, schizophrenia and cancer[8]. Such acceptance varies between individuals and within individuals depending on the particular medicine[8,9]. Whether or not a patient views a medicine as positive can be influenced by worries about possible adverse effects, dependence and long term harm[8,41], all of which were voiced by participants. In particular three expressed concerns about long-term medicines use, both in terms of their potential for dependency and the need to accept theoretical long-term benefits of prophylaxis against future problems.

“are they doing anything for me? they must be doing something good but I don’t know. I’m still transfixed over the situation of not having any symptoms, maybe they’re keeping the symptoms at bay.” (14)

Concerns about dependence and tolerance may lead to regime changes, including ‘drug holidays’[8].

7. Impact of taking medicines on everyday life

Six participants described disruptive effects of medicines on both routine everyday activities, such as meal times, going to bed and sex life, and non-routine activities such as holidays or outings, beyond any impact of medical conditions.

“I’ve been dragged out of a few pubs before today, you know, because I’ve been in the toilets with me needle and the bouncers have been to the door and dragged me out thinking I’m injecting heroin or something and you don’t even get to explain ‘I’m a diabetic.’ ” (4)

Adverse impacts on social activities has been shown previously involving friendships, relationships and work, while the perceived need to take medicines exactly as prescribed can also interrupt daily life[8,30]. Our participants suggested that having to take medicines routinely could in itself be disruptive. While most perceived this as manageable, it required a good knowledge of medicines’ indications, how they worked and how changes in routine affected efficacy. Not all adaptations to accommodate medicines use were based on sound knowledge, leading to potentially unnecessary changes in routine or avoidance of activities. For example, in the following quotation, lifestyle disruption occurred to accommodate the perceived importance of administration time.

“if I’m going out in the evening... I can ... take the more vital ones earlier on in the day so they get into my system... sometimes it may mean that I have to stay up a little while longer than I would normally do to take things like statins or the ACE inhibitors you know, because they tend to have to be taken late at night” (3)

Health professionals, often guided by manufacturers’ recommendations, frequently emphasise the importance of regular and continuous medicine use, including specific advice about timing. The evidence for such emphasis is variable and the impact of occasional small variations in timing on efficacy probably minimal, but could be significant for patients’ quality of life.

8. Control over using medicines.

Most participants felt they had control over some of their medicines in terms of timing, doses and whether to use them at all. Indeed, one patient had stopped all his cardiovascular prophylactic medicines against advice because of adverse effects he considered unacceptable.

‘I think that, the way I feel has been improved. I may not live any longer but it’s just, I feel better.’
(13)

“to a large extent that particular drug I’m in charge of... take them as I want, nothing to do with the doctor.” (17)

One was convinced of differences in both side effects and efficacy between branded and generic products, but had little control over the choice of product.

“they say these days that there is no difference between specific and generic medications. Now I can tell them categorically that there is....if they have to continue prescribing generic medications for you, they need to accept that they are different, they’re produced in a different way.” (3)

Generic prescribing is encouraged internationally and England has the highest rate in the world, with many patients likely to experience an imposed switch to generic medicines or even a therapeutic switch[48]. Patients may be unhappy with such switches, yet studies suggest that few challenge them[49,50]. Attitudes to generic medicines are potentially influenced by personal experiences and education and while patients may have misconceptions about generics[51], differing excipients contribute to variations in adverse effect profiles.

Two participants considered that their lives were controlled by their need for medicines. Many others feared varying their doctor’s instructions, stating that medicines use was not in their control and that they were powerless to change it.

“I’m in control to the extent that I have to be a slave to them... I’d be afraid to sort of do without them.” (1)

“your life revolves around tablets, everything else has to fit around them” (15)

This is similar to previous perceptions that for some patients medicines represent a “treadmill” which controls their lives[10]. While some patients want more involvement in making decisions regarding medicines, this is not universal[52,53]. However empowerment through greater understanding may enable patients to gain the desired degree of control over their medicines use which some seem to lack.

Strengths and Limitations

The study involved patients purposively selected from a large sample of all ages who agreed to participate, although willing participants may have wished to raise issues. Selection from a large sample ensured a wide range of drug and formulation use, whereas most previous work has focused on specific conditions or groups of medicines. Interviews were conducted in patients' own homes, thus did not exclude the housebound or those with disabilities, and allowed individuals to fully describe their experiences. The number interviewed was small, but two authors were involved in analysis and agreed that saturation of themes was reached. The study's origin in a School of Pharmacy may have contributed to positive views being expressed of pharmacists and their services and staff.

General Discussion

The study findings lend weight to the argument that managing chronic disease creates a burden for patients[1,9,30], in this case, coping with polypharmacy. They are in line with other published studies indicating that patients have both positive and negative views towards long-term medicines and that coping with medicines is one potentially burdensome aspect of medical treatment[9,30]. The themes emerging from the data relate well to those from such studies. Key differences are also evident, however, as a result of specifically seeking issues in the interviews about the impact of medicines use on day-to-day activities, feelings of control over medicines use and time spent in developing and keeping to routines.

The positive views expressed throughout, for example, concerning good relationships with health professionals, clear benefits of the medicines themselves and ease of keeping to routine are all likely to impact positively on how patients view the impact of their medicines on overall quality of life. On the other hand, negative views relating to adverse effects, the extensive commitment to managing medicines on a day-to-day basis, lack of control over their use and impact on social life are likely to have negative effects on peoples' day-to-day lives, including quality of life. While clearly of lesser impact than conditions for which medicines are used, it is increasingly important to be aware of how medicines can and do affect individuals and to be able to measure these impacts.

These findings offer salutary lessons for practitioners, both those who prescribe ever increasing numbers of medicines and those purporting to help patients cope with their medicines burden. The tendency to prescribe too quickly, failure to explore or take account of patients' views or to give credence to their concerns and to provide the sort of information they want and need to minimise the disruption that medicines can have on everyday life must be addressed if we are genuinely considering the patient perspective. As polypharmacy increases, increasing effort is needed by all health professionals to ensure that the burden of medicines is not too great for any individual to cope with.

Conclusion

Our study shows the multiplicity and complexity of issues surrounding long-term medicines use which impact on day-to-day lives for patients of all ages with long-term conditions. While most patients adapt to long-term medicines use, others did so at some cost to their quality of life.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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Box 1 Topic guide for interviews

Can you tell me about or show me your medicines?	How do you actually get your medicines?
How do you use your medicines?	How do your medicines fit in with your life?
How important do you feel your medicines are to you?	How you know if your medicines are OK for you?
Is there anything you don't like about your medicines?	Do you have any worries about your medicines?
Do you feel you know enough about your medicines?	Would you change anything about your medicines if you could?

