

Patients' problems with new medication for chronic conditions

N Barber, J Parsons, S Clifford, R Darracott, R Horne

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See end of article for authors' affiliations

Correspondence to: Professor N Barber, Department of Practice and Policy, The School of Pharmacy, 29/39 Brunswick Square, London WC1N 1AX; nick.barber@ulsop.ac.uk

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Objectives: To assess patients' adherence to new medication for a chronic condition (and whether non-adherence was intentional), patients' problems with their medication, and their further information needs.

Methods: A longitudinal survey with data collection at 10 days and 4 weeks was performed on 258 patients recruited from 23 community pharmacies in south east England. Patients were eligible to participate if they were starting a new chronic medication and were either 75 years or older or had one of the following chronic conditions: stroke, coronary heart disease, asthma, diabetes, and rheumatoid arthritis. At each time point a semi-structured telephone interview was conducted and a postal questionnaire was sent.

Main outcome measures: Self-reported adherence, causes of non-adherence, problems with medication, information needs.

Results: Sixty seven (30%) of 226 patients still taking their medication at 10 days and 43 of 171 (25%) still taking their medication at 4 weeks were non-adherent. At 10 days 55% of the non-adherence was unintentional and the remainder was intentional; these proportions were similar at 4 weeks. 138 of 208 (66%) participants still taking their new medication at 10 days reported at least one problem with it. 137 of 226 patients (61%) expressed a substantial and sustained need for further information at 10 days and 88 of 171 (51%) at 4 weeks. Several patients who were adherent or reported no problems at 10 days were non-adherent or had problems at 4 weeks.

Conclusions: A significant proportion of patients newly started on a chronic medication quickly become non-adherent, often intentionally so. Many have problems with their medication and information needs. Patients need more support when starting on new medication for a chronic condition and new services may be required to provide this.

Non-adherence to medication is a significant problem for patients with a chronic condition, with 30–50% of patients not taking their medication as prescribed.¹ The implications of this non-adherence are far reaching and, in addition to the obvious health costs to patients, the cost of non-adherence in the USA has been estimated to reach \$100 billion annually.² The reduction of non-adherence is thought likely to have a greater effect on health than further improvements to traditional biomedical treatment.³

The literature contains many explanations of why patients do not adhere to treatment,^{4,5} but there are lacunae in our knowledge. We do not know when non-adherence to a new medication for a chronic condition starts. Furthermore, non-adherence is often classified according to patient intent as intentional and unintentional, but we do not know the proportion of non-adherers in each category. Unintentional non-adherence occurs when the patient wishes to adhere but is prevented in some way—perhaps they forget or are unable to take the medication because the dose form is inappropriate. Intentional non-adherence is related to issues of motivation and how people perceive their medicine. With a greater understanding of when and why non-adherence occurs, we may be able to intervene effectively before it becomes established.

A recent discussion of the literature on adherence to treatment for chronic conditions argued for more research on the identification of pragmatic reasons for missing doses, and emphasised the necessity of this information for the development of interventions that focus on these reasons.⁶ Studies that adopt this approach are scarce; it was recently noted that most of the literature on adherence to treatment

has been theoretical and empirical research accounts for less than one tenth of the published literature.⁷

The aim of this study was to explore patients' problems with new medication for chronic conditions. The objectives were to:

- assess how soon after being prescribed a new medication for a chronic condition the non-adherence starts, and whether this is an intentional act;
- explore the extent and type of medication related problems experienced by patients;
- assess the further information needs that patients have regarding their medication.

METHODS

Study participants

Patients presenting a prescription in one of 23 community pharmacies in south east England were recruited opportunistically between March 1999 and February 2000. They were eligible for inclusion in the study if they were picking up a new medication for a chronic condition and were aged 75 years or older or had one or more of the following chronic conditions: stroke, coronary heart disease, asthma, diabetes, and rheumatoid arthritis. These conditions were chosen because they are specific priorities for the NHS. Exclusion criteria were the inability to understand spoken English, no telephone, or aged under 18 years. The pharmacists who were recruiting patients received training beforehand.

Written informed consent was obtained from all participants and the study was approved by the Northern

multicentre research ethics committee and local research ethics committees.

Measurement tools

Patients received a telephone interview from a researcher 10 days after recruitment; those who responded received another at 4 weeks. A semi-structured telephone interview, which had been piloted and revised, was used to obtain information to meet the study objectives. We asked patients about their adherence, problems, and "issues" with their medication and their information needs. Open ended questions were used and patients' responses were recorded verbatim where possible. A postal questionnaire was sent immediately after each interview to establish demographic information and health status using the question on general health from the SF36 questionnaire.⁸

Measurement of adherence

Patients' self-reports about their non-adherence were chosen since those who report non-adherence tell the truth⁹ and this method detects problematic levels of non-adherence.¹⁰ Non-adherence was determined from the question:

"People often miss taking doses of their medicines for a whole range of reasons. Thinking first of the medicine that you started taking when you started on this study (that is,), when was the last time you missed taking a dose of this medicine?"

Patients were defined as non-adherent if they had missed any doses in the previous 7 days; this was followed up by probes for an account of the reason. We chose this definition as it has been suggested that low adherence is indicated if one or more doses are missed.¹⁰ Furthermore, theories of human error suggest that all deviations from correct action are of interest.¹¹ The reason given for non-adherence was categorised as either intentional or unintentional by two of the researchers separately (SC and NB); any discrepancies were resolved by discussion. We also distinguished between partial and complete non-adherence. Partial non-adherence was defined as missing one or more doses of medication and complete non-adherence as completely stopping the medication without consulting the GP.

Analysis of data

Qualitative data from the open ended questions were coded by researchers (JP, SC) and validated by a pharmacist (NB); any mismatches were discussed and agreed upon. SPSS version 10 was used to store all the data and to analyse the quantitative data.

RESULTS

A total of 258 patients were recruited from 23 community pharmacies, of which 239 were interviewed at 10 days and 197 at 4 weeks (fig 1). The characteristics of the patients are shown in table 1.

Adherence

Of the 239 patients interviewed at 10 days, 13 had stopped taking the medication on medical advice. Table 2 shows the extent of non-adherence at 10 days and 4 weeks. Of the 226 remaining, 67 patients (30%) were non-adherent to their new medication. There were 26 cases of non-adherence to other prescribed medication, eight of which were patients who were also non-adherent to their new medication; the remaining 18 had been completely adherent to the new medication. Overall, 85 patients (38%) were non-adherent to at least one of their prescribed medications. At 4 weeks 197 patients were interviewed, 26 of whom had stopped their new medication on medical advice. Of the 171 remaining, 43 (25%) were non-adherent to their new medication; 19 of

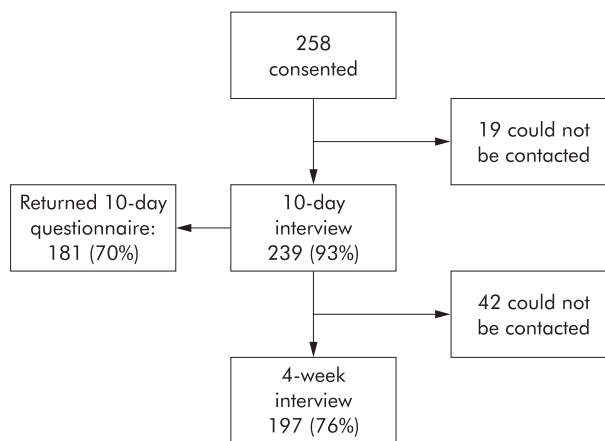


Figure 1 Flow of participants through the study. All percentages are derived from the number of patients who consented to participate in the study.

Table 1 Demographic details of the study sample

Demographic details	
F:M	124:115
Median (range) age (years)*	67 (18–89)
Age ≥75 years	41 (23%)
Employment status*	
Retired	127 (70%)
Employed	38 (21%)
Unemployed	16 (9%)
Self-reported health status*	
Excellent	4 (2%)
Very good	22 (12%)
Good	79 (44%)
Fair	63 (35%)
Poor	11 (6%)
Uncertain	2 (1%)
Self-reported condition	
Cardiovascular	136 (57%)
Asthma	24 (10%)
Arthritis	19 (8%)
Diabetes	17 (7%)
Bronchial	14 (6%)
Stroke	7 (3%)
Other	22 (9%)

All information was obtained from the first telephone interview (n = 239) unless marked * which was obtained from the first postal questionnaire (n = 181).

these had also been non-adherent at 10 days and 24 had previously been adherent.

The proportion of intentional to unintentional non-adherers was similar at 10 days (45% v 55%) and 4 weeks (44% v 56%). None of the unintentional adherers had completely stopped taking their medication but, of the

Table 2 Adherence to new medication

	Still taking medication at 10 days (n = 226/239)	Still taking medication at 4 weeks (n = 171/197)
Adherent	159 (70%)	128 (75%)
Non-adherent	67 (30%)	43 (25%)
Partial non-adherence	49	26
Complete non-adherence	18	17

intentional non-adherers, 18/30 (60%) had completely stopped taking their medication at 10 days and 17/19 (89%) at 4 weeks.

Problems caused by medicines

At the 10 day interview 208 patients were still taking their new medication (of the 239, 13 had stopped on medical advice and 18 were completely non-adherent). Of these 208, 138 (66%) reported at least one problem or issue with their new medication. In total, 241 problems/issues were reported and were coded into one of three categories: side effects ($n = 121$, 50%), concerns about the medication ($n = 103$, 43%), and difficulties with the practical aspects of taking the medication ($n = 17$, 7%). Examples are shown in table 3.

Of the 138 patients reporting a problem/issue at 10 days, 56 (41%) reported at 4 weeks that their problem had been resolved but 31 (22%) reported that they were still experiencing a problem; data were unavailable for 51 (37%). Thirty six patients (26%) reported new problems emerging at 4 weeks; 12 of these had not reported a problem at 10 days. Most of the problems were related to side effects ($n = 23$, 64%), eight (22%) were concerns about the medication, and five (14%) were related to practical aspects of medication taking.

Information needs

There was a substantial and sustained need for further information expressed in the interview. At 10 days 137 of the 226 patients still taking their medication (61%) said they had further information needs, as had 88 of 171 (51%) of those still taking their medication at 4 weeks. These needs were consistent at both time points with about half wanting more information on their medication ($n = 59$ (43%) at 10 days; $n = 46$ (52%) at 4 weeks) and over a quarter wanting information on their condition ($n = 38$ (28%) at 10 days; $n = 26$ (30%) at 4 weeks).

Of the three areas of concern (non-adherence, problems, and information needs), only 37 (16%) of the 226 patients still taking their medicine at 10 days said they were adherent, problem free, and had received sufficient information. One area of concern was present in 86 (38%) of cases, two areas in 65 (29%), and three areas in 38 (17%). Of the 67 non-adherent patients, 38 (57%) additionally said they had problems and information needs. A greater proportion of intentional non-adherers declared problems with medicines (26/30, 87%) than unintentional non-adherers (22/37, 59%, $p = 0.016$, Fisher's exact test) at 10 days.

DISCUSSION

Patients who started a new medication for a chronic condition experienced considerable problems. About one third did not take their new medication as prescribed, almost

half of these deliberately so. The incidence of non-adherence was greater with new than with existing medication. Patients frequently encountered problems and had substantial unmet needs for information and support. While some problems were resolved, many were not and new ones were reported.

This rapid emergence of non-adherence and the related plethora of problems have not previously been recognised, nor has the fact that, although some problems are solved, new ones emerge in the first month. Why is this the case? Two factors seem likely. The first is that the current prescribing and dispensing processes are of limited effectiveness. The second is that patients have needs that can only emerge once they have experienced taking a medication.

There is an extensive literature that chronicles the inadequacies of the current processes. Doctors give little information about medication in their consultation and often make inappropriate judgements about the expectations of their patients.¹² The style of communication used by doctors for patients with chronic conditions is one that concentrates on the condition rather than the whole person, which results in less satisfaction and more non-adherence.¹³ Even when patients are given information, they often misunderstand what their doctor says and fail to recall much of the information they are given.¹⁴ Pharmacists have the potential to rectify many of these problems when dispensing medication but often do not; 58–90% of patients report never or rarely receiving unsolicited advice from a pharmacist.^{15 16}

Even when information about a medicine is given to a patient, it is not specific to that patient but describes a population response to the medication. However, once the patient experiences the medication they get some knowledge of what it does to them and new questions will arise. Patients will form beliefs about the necessity of the medication and formulate concerns about the consequences of its use—factors which have been shown to influence adherence.¹⁷ They will want to know whether it is working or not and, if they feel different in some unpleasant way, whether the medication caused it or not. It is at this point, when patients need new questions and concerns to be resolved, that they are failed by existing medical services. Given their information gap, they consult with friends and relatives and try to reason their way out using their existing beliefs about their condition, their medications, and the way they work. This process can involve false beliefs or an imbalance of correct beliefs about the medication, all of which may encourage inappropriate non-adherence.

The main limitations of this study are the serendipitous nature of recruitment and the use of self-reports of non-adherence. The opportunistic sampling, while geographically widespread, may not be representative of the population as a whole. The use of self-reported non-adherence may under-report the true incidence of non-adherence; if this is the case, the results provide even greater cause for concern.

The findings of this study could be used to contribute to improving the quality of patient care. It seems there is a role for a new service to support and advise patients in their early days of medication taking and to change prescribing decisions if necessary. The NHS has ambitious new plans for pharmacists¹⁸ that include management of repeat prescribing and wider prescribing powers. It may be that, in collaboration with prescribers, new pharmacy services can be developed to meet this substantial need.

Note that our view of good practice is not that adherence is always right. We are taking non-adherence as a marker that there is a problem in the process of prescribing and the experience of using medicines. It is likely that these findings have significance beyond UK practice as the incidence of non-adherence is similar worldwide.^{1 4 5}

Table 3 Examples of problems caused by medicines

Nature of problem	Examples
Side effects	Numbness, oral thrush, nausea, vomiting, giddiness Stopped taking new medicine because of side effects
Concerns	Not keen – don't believe in taking pills Worried about taking new medicine, for example because of previous side effects, allergy, potential interactions
Practical aspects	Tablets difficult to swallow Hard to remember complicated regime Have to take half a tablet and hard to break accurately

Key messages

- The current literature does not adequately explain when and why non-adherence to new medication for a chronic condition begins.
- Patients newly started on a medication for a chronic condition have a substantial unmet need for information and support 10 days after prescribing.
- Approximately one third of patients were non-adherent, often intentionally so.
- The results provide support for a new service tailored to the individual needs of patients.

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Authors' affiliations

N Barber, J Parsons, S Clifford, Department of Practice and Policy, The School of Pharmacy, London, UK

R Darracott, Professional Services Manager, Moss Pharmacy, Fern House, 53–55 High Street, Feltham, Middlesex, UK

R Horne, Professor of Psychology in Health Care, University of Brighton, Sussex, UK

J Parsons is now at the Vera Institute of Justice, New York, USA and R Darracott is now Director of Corporate and Strategic Development, Royal Pharmaceutical Society of Great Britain.

REFERENCES

- 1 **Horne R**. Adherence to medication: a review of the existing literature. In: Myers LB, Midence K, eds. *Adherence to treatment in medical conditions*. Amsterdam: Harwood Academic Press, 1998.
- 2 **Lewis A**. Noncompliance: a \$100 billion problem. *Remington Report* 1997;5:14–5.
- 3 **Haynes RB**, Montague P, Oliver T, *et al*. Interventions for helping patients to follow prescriptions for medications (Cochrane Review). In: *The Cochrane Library*, Issue 4. Oxford: Update Software, 2001.
- 4 **Dunbar-Jacob J**, Erlen JA, Schlenk EA, *et al*. Adherence in chronic disease. *Ann Rev Nurs Res* 2000;18:48–90.
- 5 **Meichenbaum D**, Turk DC. *Facilitating treatment adherence*. New York: Plenum Press, 1987.
- 6 **Dunbar-Jacob J**, Mortimer-Stephens MK. Treatment adherence in chronic disease. *J Clin Epidemiol* 2001;54:s57–s60.
- 7 **DiMatteo MR**. Future directions in research on consumer-provider communication and adherence to cancer prevention and treatment. *Patient Educ Counselling* 2003;50:23–6.
- 8 **Ware JE**, Sherbourne CD. The MOS 36 item short form health survey (SF-36): conceptual framework and item selection. *Med Care* 1992;30:473.
- 9 **Haynes RB**, Taylor DW, Sackett DL, *et al*. Can simple clinical measures detect patient non-compliance? *Hypertension* 1980;2:757–64.
- 10 **Haynes RB**, McDonald HP, Garg AX. Helping patients follow prescribed treatment. *JAMA* 2002;288:2880–3.
- 11 **Barber N**. Should we consider non-compliance a medical error? *Qual Saf Health Care* 2002;11:81–4.
- 12 **Barry CA**, Bradley C, Britten N, *et al*. Patients' unvoiced agendas in general practice consultations: qualitative study. *BMJ* 2000;320:1246–50.
- 13 **Barry CA**, Stevenson FA, Britten N, *et al*. Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Soc Sci Med* 2001;53:487–505.
- 14 **Ley P**. Improving communication, satisfaction and compliance. In: Marcer D, ed. *Communicating with patients*. London: Chapman and Hall, 1988.
- 15 **Livingstone CR**, Pugh ALG, Winn S, *et al*. Developing community pharmacy services wanted by local people: information and advice about prescription medicines. *Int J Pharmacy Pract* 1996;4:94–102.
- 16 **Morrow N**, Hargie O, Woodman C. Consumer perceptions of and attitudes to the advice-giving role of community pharmacists. *Pharm J* 1993;251:25–7.
- 17 **Horne R**, Weinman J. Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *J Psychosom Res* 1999;47:555–67.
- 18 **Department of Health**. *Pharmacy in the future*. London, Department of Health, 2000 (available at www.doh.gov.uk/pharmacyfuture/index.htm).