

Resisting medicines: a synthesis of qualitative studies of medicine taking

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Abstract

The study aimed to synthesise qualitative studies of lay experiences of medicine taking. Most studies focused on the experience of those not taking their medicine as prescribed, with few considering those who reject their medicines or accept them uncritically. Most were concerned with medicines for chronic illnesses. The synthesis revealed widespread caution about taking medicines and highlighted the lay practice of testing medicines, mainly for adverse effects. Some concerns about medicines cannot be resolved by lay evaluation, however, including worries about dependence, tolerance and addiction, the potential harm from taking medicines on a long-term basis and the possibility of medicines masking other symptoms. Additionally, in some cases medicines had a significant impact on identity, presenting problems of disclosure and stigma. People were found to accept their medicines either passively or actively, or to reject them. Some were coerced into taking medicines. Active accepters might modify their regimens by taking medicines symptomatically or strategically, or by adjusting doses to minimise unwanted consequences, or to make the regimen more acceptable. Many modifications appeared to reflect a desire to minimise the intake of medicines and this was echoed in some peoples' use of non-pharmacological treatments to either supplant or supplement their medicines. Few discussed regimen changes with their doctors. We conclude that the main reason why people do not take their medicines as prescribed is not because of failings in patients, doctors or systems, but because of concerns about the medicines themselves. On the whole, the findings point to considerable reluctance to take medicine and a preference to take as little as possible. We argue that peoples' resistance to medicine taking needs to be recognised and that the focus should be on developing ways of making medicines safe, as well as identifying and evaluating the treatments that people often choose in preference to medicines.

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Introduction

In 2003, three high-profile reports on medicine taking were published; one from the World Health Organisation (WHO, 2003), second from the government funded Medicines Partnership (Carter, Taylor, Levenson, & for The Medicines Partnership, 2003) and the last from the Kings Fund (Harrison, 2003). Meanwhile, an initiative called 'Ask about Medicines Week' was launched to 'help promote partnership in medicine taking between medicine users, carers and health professionals' (www.askaboutmedicines.org). During 'Ask About Medicines Week' the British Medical Journal dedicated an issue to the theme of 'concordance' (Issue 7419), as did the official journal of the Royal Pharmaceutical Society (Issue 7270 of The Pharmaceutical Journal). What prompted this attention?

The aim of the WHO report was to improve worldwide rates of 'adherence' to long-term treatments for chronic conditions, which at present the authors of the report estimate to be 50%. They claim: 'Poor adherence is the primary reason for suboptimal clinical benefit. It causes medical and psychosocial complications of disease, reduces patients' quality of life and wastes health care resources' (p. 25). Likewise, the Medicines Partnership cites 'a rising drugs bill and the key role of medicines in promoting health' (Carter et al., 2003, p. 2) as the key reasons for improving compliance. Both reports review the literature to identify factors influencing medicine taking. The Medicines Partnership cites demographic factors, issues to do with the medicine itself, 'beliefs' about medicines, concerns about the value or appropriateness of medicines, psychosocial issues, confusion and physical difficulties as influential factors. The WHO report suggests that the following affect medicine taking: social and economic factors, health care team and system-related factors, condition-related factors, therapy-related factors and finally, patient-related factors (among which are included anxieties about the treatment, stress, perceptions that the medicine is not needed or effective and non-acceptance of illness).

The independent Kings Fund report (Harrison, 2003) was written in response to a 'growing recognition' that the interests of those who provide health care do not necessarily coincide with the needs of those who use it. Harrison argues that the current emphasis on pharmaceutical products distracts attention from other approaches to health care such as behavioural therapies, illness prevention, public health interventions and 'alternative therapies'. Furthermore, because research priorities are not determined by consumers, he argues that the needs of major groups have been ignored and important therapeutic areas neglected. 'These circumstances have produced health care systems that are highly drug dependent and that in general cannot see themselves being any different' (Harrison, 2003, p. 18).

Vermeire, Hearnshaw, Van Royen, and Denekens (2001) observe that during three decades of quantitative research into non-compliance, more than 200 variables have been studied, but none can be considered as consistently predictive of compliance. The authors suggest that despite continuing research, there have been few insights since the 1980s. Most of the research has been on the extent and determinants of non-compliance but Vermeire et al. argue that this research has been fragmented, of variable methodological quality and lacking an integrating model or theory. They suggest that the lack of success in this field is due to neglect of patients' perspectives and an absence of qualitative research. Blaxter and Britten's (1996) review of lay beliefs about medicine taking provided an insightful explanation for the behaviour that many professionals find bewildering; they concluded that lay people do not view medicine as something to be taken 'as prescribed' but rather as a resource for use as they see fit. The authors suggest that more qualitative research is needed to shed light on the topic.

Rather than conducting further qualitative studies of medicine taking, the aim of our study was to try and progress the field by synthesising the available qualitative research into lay experiences of medicine taking, using the technique of meta-ethnography.

A brief note on the terminology of medicine taking is first necessary. This has undergone three key changes during the last few decades, that of compliance, adherence and now concordance. Compliance is traditionally assumed to refer to doctors' desire for patients to comply with their instructions about taking medicine. Adherence was subsequently offered as a more neutral expression, but the tone remained prescriptive, so a new model, that of concordance was proposed (Blenkinsopp, Bond, & Britten, 1997). Concordance refers to the anticipated outcome of the consultation between doctors and patients about medicine taking, if both parties can be encouraged to work together as partners. In practice the three terms are often used interchangeably, despite the subtle differences in meaning and perspective.

Methods

We used this definition when searching: 'Papers whose primary focus is patients' views of medicines prescribed and taken for the treatment of a long- or short-term condition (excluding medicines only taken for preventive purposes)'. The study had to use both qualitative methods of data collection and analysis and be published in English. We chose the 10-year period from 1 January 1992 to 31 December 2001 (the study began in Spring 2002) believing that most of the relevant studies would be found within this period. We were aware that a

small number of important early studies would be missed (e.g. Arluke, 1980; Trostle, Allen Hauser, & Susser, 1983; Conrad, 1985) but needed to set limits on what was a potentially large number of available studies.

We searched Medline, Embase, Cinahl using detailed (Table 1) and simple (Table 2) searches, as well as Web of Science, PsychInfo and Zetoc (Table 3). For the handsearches, we asked colleagues and team members to suggest any relevant papers, searched departmental databases of references, checked reference lists of obtained papers and searched the Medicines Partnership website (www.concordance.org). We also handsearched the Arts and Humanities Library and the Medical Library of Bristol University, as well as key sociological, anthropological and practice journals. The searches produced 42 studies (21 electronically, 21 by hand searching). A second researcher (GDW) repeated the electronic search strategy and identified one additional paper. (Late in the course of the synthesis we found a study that we had missed (Erwin & Peters, 1999.) As this was found once the synthesis was well advanced, we did not include it.)

We appraised the papers prior to synthesis using a version of the CASP criteria for quality appraisal (Critical Appraisal Skills Programme (CASP), 1988) that we modified for use as a precursor to the synthesis (available from the corresponding author). Exclusions were made if studies turned out to be insufficiently focused on the topic, or not actually qualitative (sometimes studies collected data using qualitative methods but did not analyse the data qualitatively). Five papers were excluded following appraisal, giving a total of 38 papers to be synthesised.

We used the meta-ethnographic approach developed by Noblit and Hare (1988) and adopted by Britten et al. (2002) and Campbell et al. (2003). We began by organising the studies into groups dealing with the same medicines, then within medicine groups, by date of publication (Table 4). We then translated the findings from the studies into each other within each of the medicine groups. Noblit and Hare (1988) suggest that the process of translating findings into each other goes something like, ‘one case is like another, except that...’. (p. 38) We followed this process systematically, so e.g., paper 1 might have findings X, Y and Z. Paper 2 might have findings x and y (findings similar to findings X and Y in paper 1), finding w (something new that was not in paper 1), but nothing like finding Z from paper 1. This synthesis of papers 1 and 2 would then be compared with paper 3 in the same way, then the synthesis of papers 1, 2 and 3 would be compared with paper 4 and so on until all the studies within each of the groups had been translated into each other. This process of translating the findings into each other is one of ‘reciprocal translation’ (Noblit & Hare, 1988) and is appropriate when the studies are essentially about

similar issues. The process produced a ‘reciprocal translation’ in textual form, for each of the medicine groups. To clarify how the findings related to each other, we developed ‘maps’ of the key findings for each of the groups by drawing the relationships between them. Fig. 1, e.g., shows the ‘map’ produced for proton pump inhibitor medicines.

We determined how the findings related to each other across the medicine groups by comparing the medicine maps with each other and developing a model that was able to encompass the findings from all of the studies in the synthesis. Our model changed slightly as the synthesis progressed, but the final version is shown in Fig. 2. Dowell and Hudson (1997), authors of one of the studies in the synthesis, had previously developed a model of medicine taking that was similar in many ways, but which was unable to ‘hold’, or account for all the findings from the studies in our synthesis. Our model proved to be an invaluable organisational aid during the synthesis process. We then brought together the reciprocal translations by synthesising them. This involved reading and rereading each one (referring to the original papers where necessary) and analysing and interpreting the data thematically, the themes corresponding to the headings given in the synthesis findings below. This produced what Noblit and Hare (1988) describe as a ‘line of argument’ synthesis. At this stage a reconceptualisation of the findings is possible, which is an attempt to produce a concept or concepts that explain all the data if possible, in a fresh way. In our case this was done by the first author and then the concepts were considered, discussed and agreed upon in meetings with all the authors. The whole synthesis process is summarised in Box 1.

At the end of the synthesis it became apparent that one paper (Pradel, Hartzema, & Bush, 2001) had not contributed to the synthesis. The paper had been borderlined due to a possible insufficient emphasis on the topic. It was therefore excluded. The final number of papers that contributed to the medicines synthesis is therefore 37 (see Box 2).

Findings

Study perspectives

Key features of the studies in this synthesis are summarised in Table 5. Most are concerned with medicines taken on a long-term basis for chronic illnesses. The earlier sociological and anthropological studies emphasised the rationality of lay behaviour, challenging the ideology of compliance that dominated preceding decades. A small number of sociological studies investigated medicine taking in its own right

Table 1
Initial detailed Medline search for medicines synthesis

#	Search history	Results
1	Exp*prescriptions, drug/	1852
2	Pharmaceutical preparations/ad, ae, ct, du [administration and dosage, adverse effects, contraindications, diagnostic use]	1144
3	Drugs, non-prescription/ad, ae, ct, tu [administration and dosage, adverse effects, contraindications, therapeutic use]	376
4	Drug therapy/ae, nu, px, ut [adverse effects, nursing, psychology, utilization]	865
5	Drug utilization/	2620
6	prescrib\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	11,166
7	prescription\$1.mp [mp = title, abstract, cas registry/ec number word, mesh subject heading]	7383
8	non-prescription\$1.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	190
9	over the counter.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	870
10	OTC\$1.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	503
11	dispens\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	2795
12	pharmaceutical\$1.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	10,561
13	drugs\$1.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	14,959
14	medicin\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	37,736
15	medication\$1.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	23,725
16	drug therapy.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	6123
17	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16	215,999
18	Patient compliance/	6509
19	Treatment refusal/	2126
20	Self medication/ae, px, ct, nu [adverse effects, psychology, contraindications, nursing]	132
21	Self administration/ae, px, nu [adverse effects, psychology, nursing]	162
22	complan\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	13,108
23	complying.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	225
24.	adher\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	14,055
25	treatment refusal.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	2144
26	self-administ\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	4750
27	concord\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	5522
28	Attitude to health/	10,643
29	Knowledge, attitudes, practice/	9853
30	Patient acceptance of health care/eh, px [ethnology, psychology]	951
31	Physician–patient relations/	8459
32	Adaptation, psychological/de [drug effects]	43
33	Nonverbal communication/ or communication/ or persuasive communication/ or communication barriers/	8415
34	Health behavior/ or life style/ or stress, psychological/	17,403
35	Self care/ae, px, ut [adverse effects, psychology, utilization]	496
36	Risk taking/	2677
37	Decision making/de [drug effects]	11
38	Decision support techniques/	1906
39	Sick role/	1831
40	Self concept/	4901
41	medicine taking.mp.	22
42	18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41	96,869
43	focus group\$1.mp	2414
44	Interviews/ or interview\$.mp. or Research/	43,854
45	Nursing Methodology Research/mt [Methods]	258
46	patient experience.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	134
47	patients' experiences.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	188
48	patient perception.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	112
49	patients' perceptions.mp. [mp = title, abstract, cas registry/ecnumber word, mesh subject heading]	402

Table 1 (continued)

#	Search history	Results
50	patient perspective.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	79
51	patients' perspectives.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	77
52	ethnograph\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	667
53	content analysis.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	943
54	grounded theory.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	555
55	qualitative.mp. or Health Services Research/ or Research Design/	26,939
56	43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55	70,155
57	qualitative.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	12,358
58	17 and 42 and 56	2105
59	57 and 58	305
60	limit 59–yr = 1997–2001	268

Table 2
Simple Medline search for medicines synthesis^a

#	Search history	Results
1	Patient compliance/ or patient compliance.mp.	7154
2	adherence.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	6563
3	medicin\$.mp.	37,736
4	medication\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	23,725
5	qualitative\$.mp. [mp = title, abstract, cas registry/ec number word, mesh subject heading]	16,190
6	1 or 2	12,812
7	3 or 4	60,560
8	5 and 6 and 7	37
9	Limit 8–yr = 1997–2001	32

^aThe simpler Medline search produced all the useful studies that had been identified in the longer search but nothing additional. We repeated these two searches in Embase and Cinahl. The simple search was just as efficient as the more comprehensive search in Medline and Embase, and more sensitive in Cinahl.

but the absence of compliance as a starting point was rare in the studies. A few studies addressed specific economic questions or professional issues. More of the later studies were practice orientated and aimed to increase adherence. Few considered the experience of those who reject medicine outright, or those who accept it uncritically. The majority of the studies, including the sociological ones, focused on the reasons why people do not take their medicine as prescribed, suggesting that most authors directly or indirectly adopted the medical agenda. The ideology that people should take their medicines as prescribed was predominant.

Synthesis findings

Our findings fall into three parts: (i) the ways people evaluate their medicines and the difficulties they encounter in doing so, (ii) medicines and identity and (iii) the ways people take their medicines.

(i) Lay evaluation of medicines and its difficulties and limits

Trying out the medicine and weighing up the costs and benefits. The most common way of evaluating medicines was to try it out and weigh up the benefits of taking it against the costs of doing so. Although the studies focused less on the benefits it was clear that people did place hope in their medicines, the most common being for relief or control of symptoms. Other hopes were for avoidance of relapse and hospitalisation, for disease progression to slow down or halt, for the prevention of a future illness, or for normality.

Adverse effects: were a key criterion in the evaluation of treatment and worries about these were found in the context of rheumatoid arthritis (Donovan & Blake, 1992), cancer (Ersek, Miller, & Du Pen, 1999) asthma (Adams et al., 1997), digestive disorders (Pollock & Grime, 2000; Boath & Blenkinsopp, 1997), high blood pressure (Johnson, Williams, & Marshall, 1999; Svensson, Kjellgren, Ahlner, & Saljo, 2000) and schizophrenia (Rogers et al., 1998; Usher, 2001). However, the studies

Table 3
Search terms for Zetoc, WoS and PsychInfo databases

Database	Search terms
Zetoc	'prescri*' and 'qualitative'
Web of science	(medicine* or medication* or prescription*) and (compliance or adherence or concordance) and (qualitative or grounded same theory or patient* same interview* or patient* same perception* or patient* same experience* or content same analysis or ethnography).
PsychInfo	(medicine* or medication* or prescription*) and (compliance or adherence or concordance) and (qualitative or (grounded adj theory) or (patient* adj interview*) or (patient* adj perception*) or (patient* adj experience*) or (content adj analysis) or ethnography) and (PO = HUMAN).

Table 4
Organising papers into medicine groups

Medicine group	Papers
Antiretroviral therapy	Siegel and Gorey (1997) Stone et al. (1998) Erlen and Mellors (1999) Halkitis and Kirton (1999) Proctor et al. (1999) Siegel et al. (1999) Siegal et al. (2000) McDonald et al. (2000) Murphy et al. (2000) Johnston Roberts and Mann (2000) Barton Laws et al. (2000)
Anti-hypertensives	Morgan (1996) Van Wissen et al. (1998) Johnson et al. (1999) Svensson et al. (2000)
Psychotropic medicine	Kalijee and Beardsley (1992) North et al. (1995) Barter and Cormack (1996) Rogers et al. (1998) Angermeyer et al. (2001) Usher (2001)
Proton pump inhibitors	Boath and Blenkinsopp (1997) Pollock and Grime (2000)
Asthma medicine	Adams, Pill, and Jones (1997) Prout et al. (1999) Buston and Wood (2000) Walsh et al. (2000)
Miscellaneous medicines	Donovan and Blake. (1992) Dowell et al. (1996) Ersek et al. (1999) Atkin and Ahmad (2000) Smith et al. (2000)
Medicines in general	Roberson (1992) Britten (1996) Dowell and Hudson (1997) Watson et al. (1998) Lumme-Sandt et al. (2000)

on HIV stood out because of their participants' emphasis on the adverse effects of antiretroviral therapy.

All the studies on antiretroviral therapy reported peoples' experiences of the adverse effects of treatment, which included nausea, vomiting, GI distress, kidney stones, insomnia, headaches, rashes, dry skin, diarrhoea, dizziness, numbness, feeling generally lousy, a bad taste in mouth, neuropathy, anaemia, breathing difficulties, fatigue, stiffness, mood swings, visual problems, leg pain, hair loss, liver damage, cancers, blackening of fingertips and nails, loss of appetite, general ill health and sweating. These reactions were unpleasant and challenging in their own right, but because they could be so frequent, severe and unpredictable they also instilled fear and distrust of the medicine. Furthermore, they could have the effect of restricting social activities, affecting friendships, relationships and work, making it difficult to look after families and sometimes necessitating disclosure of the illness (Erlen & Mellors, 1999; Halkitis & Kirton, 1999; Proctor, Tesfa, & Tompkins, 1999; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Johnston Roberts & Mann, 2000; McDonald, Bartos, & Rosenthal (2000); Siegel & Gorey, 1997). Consequently, many people viewed their medicines negatively, especially women (Johnston Roberts & Mann, 2000; Siegel & Gorey, 1997).

Acceptability of regimen: People also evaluated their regimen in terms of whether it fitted in with their daily schedules. All of the studies on HIV except two (Siegel & Gorey, 1997; Siegel, Schrimshaw, & Dean, 1999), described the impact of the regimen in strikingly similar ways. For example, Stone et al.'s participants found the regimen highly demanding because of the need to take the protease inhibitors exactly as prescribed. This meant that people had to radically alter the times they slept and ate, thus life's normal flow was interrupted. Participants described it as becoming '*the central organising principle*' (Stone et al., 1998, p. 589), so overwhelming that they were no longer in control of their lives.

McDonald, Bartos, and Rosenthal (2000) found that the drug regimen had a long-term impact on social relationships, employment and studying, not just daily

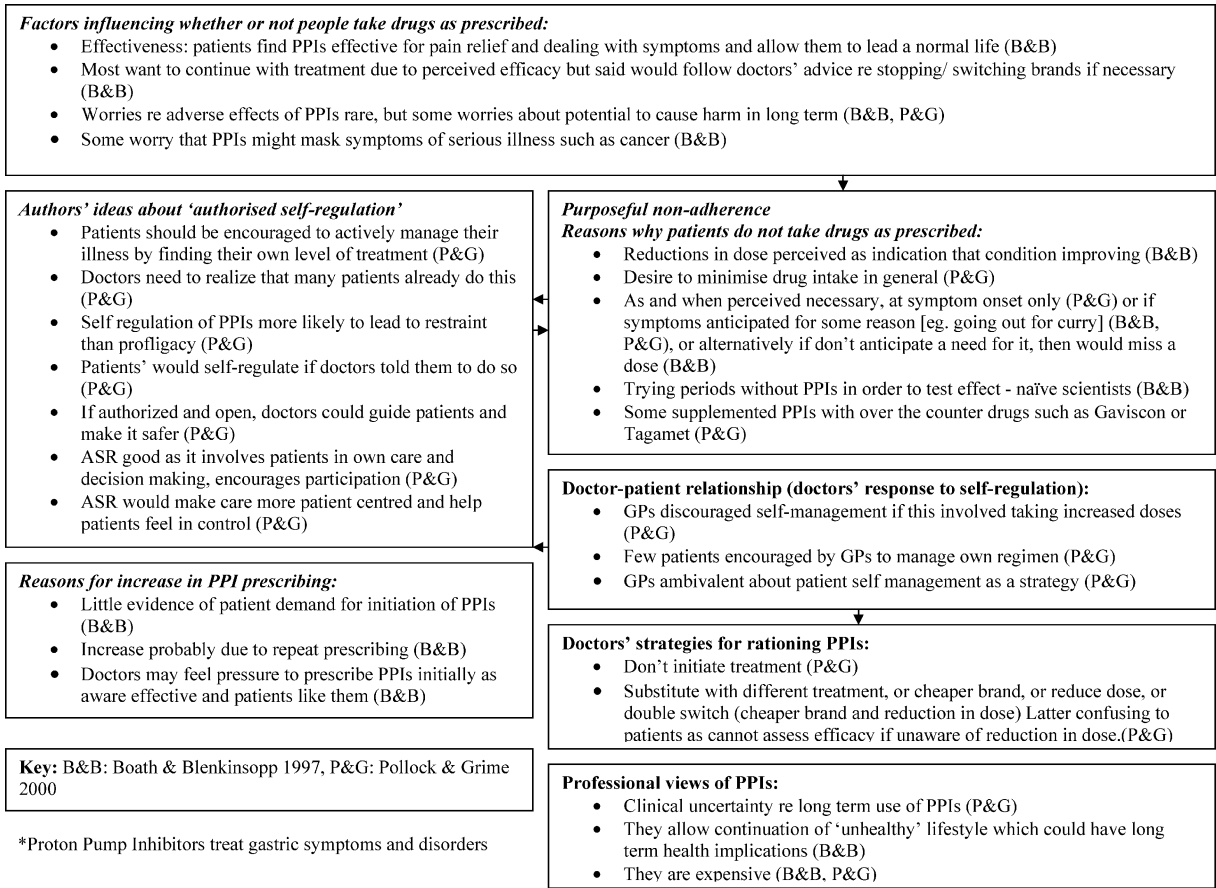


Fig. 1. Proton pump inhibitor* studies (Map).

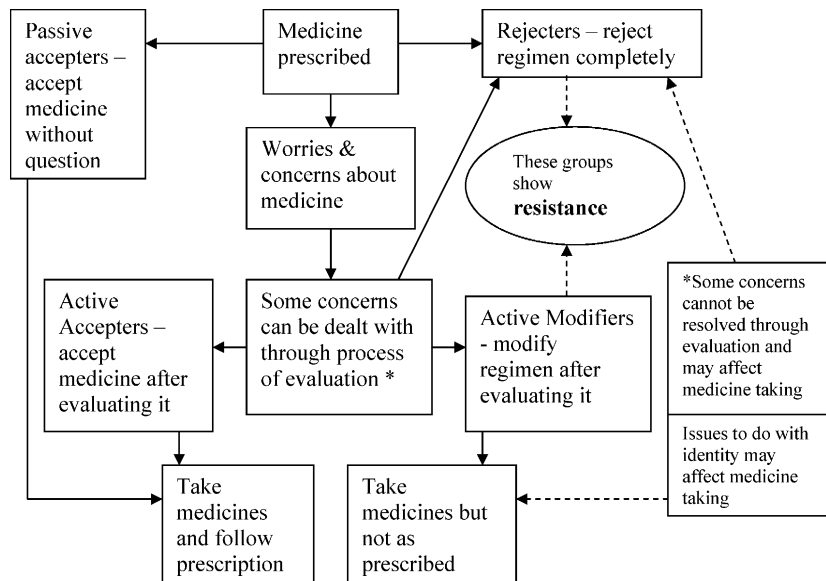


Fig. 2. Model of medicine taking.

Box 1

Stages of the synthesis

1. Topic selection
2. Searching for the studies
3. Reading and appraising the studies, including initial extraction of main findings/concepts
4. Organising studies into medicine groups
5. Translating studies into each other *within* medicine groups; produces a raw textual synthesis for each medicine group (reciprocal translations)
6. Determining how findings relate to each other *within* medicine groups; produces 'medicine maps'
7. Determining how studies are related *across* the medicine groups; produces overall model of medicine taking
8. Synthesising translations *across* the medicine groups; produces an overall textual synthesis of medicine taking ('lines of argument' synthesis) and enables further conceptual development

Box 2

Process of exclusions

Total papers produced by searches	43 (21 handsearching, 22 electronically)
Total papers appraised	43
Papers excluded following appraisal	5
Papers initially included in synthesis	38
Papers excluded during synthesis	1
Total papers finally synthesised	37

routines. The authors found that men fitted the social world around their medical regimen whereas for women the social world took priority and impinged on the regimen. Women were more concerned about the impact of the regimen on relationships while men were concerned about its impact on themselves. The women also resisted the demands of the regimen more than men and worried less about not taking the drugs as prescribed. Johnston Roberts and Mann (2000) additionally report that their women only sample found the regimen exceptionally difficult to follow because it competed with their care-giving roles and relationships.

The frequency of doses and number of pills were also found to be problematic (Halkitis & Kirton, 1999; Proctor et al., 1999; Johnston Roberts, & Mann, 2000; Barton Laws, Wilson, Bowser, & Kerr, 2000) as was the taste, smell, size and shape of the pills themselves (Johnston Roberts, & Mann, 2000; Barton Laws et al., 2000). None of the other regimens had such an impact as antiretroviral therapy, although the study on children with thalassaemia major suggests that chelation therapy was experienced as profoundly disruptive (Atkin & Ahmad, 2000). Nearly all of the sample cited the use of

the pump (that delivered the treatment) as the most difficult and hated aspect of their illness. Older children especially hated it because it disrupted their social life and marked them out as different. For this reason, some decided not to pursue the treatment.

Weighing and balancing: In the case of HIV, the undesirable effects of treatment could be so bad that some people had to question whether it was worth continuing with it (Barton Laws et al., 2000; McDonald et al. (2000); Siegel & Gorey, 1997; Siegel et al., 1999; Proctor et al., 1999). McDonald et al. (2000) note that the overwhelming impact of adverse effects affects peoples' evaluations of antiretroviral therapy because it is difficult to appreciate the potential benefits when experiencing such unpleasant symptoms. Some of the women in Siegel and Gorey's (1997) study felt that despite the possible benefits of AZT, the effects were too debilitating to make it worthwhile; others felt that 'alternative' treatments were better for quality of life. In Siegel et al.'s (1999) study some of the participants described the medicine as more threatening to their well-being than the disease for which they took it. Similarly, Proctor et al. (1999) found that some of their

Table 5
Features of the 37 studies synthesised

Source paper (<i>n</i> = 37)	Country setting	Participants (female)	Sample origins	Group	Data collection
Donovan and Blake (1992)	UK	54 (39) people	Hospitals	Miscellaneous (inflammatory arthropathy/osteo-arthritis/minor rheumatology complaints)	Semi-structured interviews, before and after recorded consultation with doctor
Kalijee and Beardsley (1992)	USA	70 people	Rural mental health clinic	Psychotropic medicine	Observation of meetings, group sessions, in depth interviews
Roberson (1992)	USA	23 (14) black adults aged 19–77, varied education; 18 hypertension, 8 arthritis, 5 diabetes, 1 asthma, 1 hepatitis, 1 erythema multiforme	Southern rural African American community population	Medicines in general	Unstructured interviews
North et al. (1995)	New Zealand	22 Europeans (11) aged from 34 to 82	One group from the community and one from self-help group	Psychotropic medicine	In depth interviews
Barter and Cormack (1996)	UK	11 (10) aged 60–90. Also sample of 20 (12) elderly people ‘randomly’ sampled on street, not on benzodiazepines	Community (those in receipt of benzodiazepines for at least a year)	Psychotropic medicine	Semi-structured interviews
Britten (1996)	UK	30 (11) aged 20–70, 27 white, 2 black and 1 middle eastern	Two London GP practices: poor area (9 patients), affluent (21)	Medicines in general	Semi-structured interviews
Dowell et al. (1996)	UK	17 people	Urban Scottish general practice	Miscellaneous (rapid prescribing changes)	In depth interviews, twice over 6 months
Morgan (1996)	UK	60 (30): 30 white, 30 African Caribbean (30) all aged at least 35	15 general practices in London Borough of Lambeth	Antihypertensive medicine	Semi-structured interviews
Adams, Pill, and Jones (1997)	UK	30: 14 women (10 w/c, 4 m/c) and 16 men (8 w/c and 8 m/c). Aged 19–57	Single GP practice in S. Wales (former mining) town	Asthma medicine	In depth interviews
Boath and Blenkinsopp (1997)	UK	20 (11) aged 28–68, 15 married, 10 working, 1 unemployed, 1 housewife, 4 unable to work and 4 retired	One fund-holding group medical practice	Proton pump inhibitors	Semi-structured interviews
Dowell and Hudson (1997)	UK	44 (24), 23 aged over 65, 12 living alone	2 samples, both from GP registers	Medicines in general	In depth interviews
Siegel and Gorey (1997)	USA	71 women, 42% black, 17% white, 40% Puerto Rican. Mean age 34.9 years. 37% working. 82% were parents. Median	HIV organisations, including hospitals and community organisations	Antiretroviral medicine	Unstructured interviews

Table 5 (continued)

Source paper (<i>n</i> = 37)	Country setting	Participants (female)	Sample origins	Group	Data collection
Rogers et al. (1998)	UK	household income low (\$12500 pa) 34 (12) aged 18–56, varied social class	Voluntary groups, MIND centres/outpatient centres, inpatients	Psychotropic medicine	In depth interviews
Stone et al. (1998)	USA	56 (28), 50% white, 29% black, 21% Latino, mean age 37, varied education	5 hospital and community centres in Boston and Providence	Antiretroviral medicine	Focus groups
Van Wissen et al. (1998)	New Zealand	19 (15), 2 Maori, 17 European. Age range 41–67, mean age 54	Register of people previously involved in hypertension research	Antihypertensive medicine	In depth interviews
Watson et al. (1998)	Australia	37 women aged 59–83 living independently in the community	Two community pharmacies	Medicines in general	Semi-structured interviews
Erlen and Mellors (1999)	USA	6 (2), 5 'on disability' 1 employed, 3 white, 3 black, all high school educated	University trial unit/community AIDS ministry/private practice	Antiretroviral medicine	Semi-structured interviews
Ersek et al. (1999)	USA	21 (18), mean age 60 (42–79), mostly white, educated, married	Larger longitudinal study (not known where patients from)	Miscellaneous (cancer)	Semi-structured interviews
Halkitis and Kirton (1999)	USA	37, 22% female, mean age 42. Men: 24% heterosexual, 76% bisexual or gay. Women: majority heterosexual, 38% black, 24% Latino, 35% white	Attendants of large city AIDS service organisation	Antiretroviral medicine	Focus groups
Johnson et al. (1999)	USA	21 (17), aged 65–92, Caucasian, retired	Local emergency centres and physicians' offices	Antihypertensive medicine	Semi-structured interviews
Proctor et al. (1999)	USA	39: 27 men age 30–69, 12 women age 29–60. 9 white, 16 black, 4 Hispanic. 10 gay men, 9 heterosexual men, 9 heterosexual women, 11 injecting drug users	Five NY institutions providing AIDS services: 3 state, 1 federal and 1 private	Antiretroviral medicine	Focus groups
Prout et al. (1999)	UK	9 families: 5 middle class, 4 working class, incl. 4 girls, 5 boys aged 10–12	Larger EU-Biomed project. Asthma clinics in 2 GP practices in towns in Midlands	Asthma medicine	Repeated interviews, some open-ended some using check list
Siegel et al. (1999)	USA	78 (20), age 50–68, 41% black, 19% Puerto Ricans, 40% non-Hispanic white. Majority single, most living alone. 51% heterosexual, 42% gay. Varied	Community based health and social organisations, support groups, advocacy groups and drug treatment centres in New York City	Antiretroviral medicine	Questionnaires and semi-structured interviews

Atkin and Ahmad (2000)	UK	education, low income (only 18% on \$20,000 > pa) 25 children: 12 boys, 13 girls, average age 13.9. 22 Pakistani Muslim, 1 Bangladeshi Muslim, 1 Iranian Muslim, 1 Indian Hindu. (15 school, 7 college, 2 unemployed, 1 university)	Health professionals' records, eg paediatricians/specialist haemoglobinopathy workers in 6 localities in Midlands/Northern England	Miscellaneous (thalassaemia major)	In-depth interviews, twice over 6 months
Barton Laws et al. (2000)	USA	25 (8) aged 27–57, 9 white, 3 black, 12 Latina, 1 Portuguese	AIDS groups in Massachusetts and Boston, word of mouth	Antiretroviral medicine	Semi-structured interviews
Buston and Wood (2000)	UK	49 (29), mean age 15.6. Mean age of diagnosis 4.9. 35 at school, 7 in further education, 5 unemployed and 2 employed	Hospital asthma clinics in Greater Glasgow	Asthma medicine	Semi-structured interviews
Lumme-Sandt et al. (2000)	Finland	No information, except originally 448 people aged 90 > . 250 interviewed. Data from 151 interviews referring to medication	All people over 90 living in the city of Tampere in Southern Finland	Medicines in general	Narrative/biographical interviews
McDonald et al. (2000)	Australia	76 (13) aged 25–62. 52 gay men, 2 women and 6 men bisexual, 11 women and 5 men heterosexual. 84% of interviewees currently using antiretroviral medicine	Larger HIV Futures Study of people with AIDS/HIV in Australia. AIDS organisations/ mailing lists, hospitals, doctors' surgeries, adverts	Antiretroviral medicine	Semi-structured interviews
Murphy et al. (2000)	USA	39, aged 33–54, 69% male. 44% black, 39% white, 6% other/ mixed race, 6% Latino. (16% graduate college degrees, 24% undergraduate college degrees, 32% some college, 19% high school, 8% less than a high school education)	HIV clinic and advertisement in an AIDS publication	Antiretroviral medicine	Focus groups
Johnston Roberts and Mann (2000)	USA	20 women aged 25–54. 50% Hispanic, 35% black, 15% white. Varied education. Two thirds with 1 > children.	Los Angeles HIV/AIDS clinic	Antiretroviral medicine	Participants kept a journal
Siegal et al. (2000)	USA	49 (9) HIV+ adults aged 50–67, in NY City metropolitan area. 45% black, 51% white, 4% Latino. 51% heterosexual, 18% bisexual, 31% gay/lesbian. Education varied, 86% unemployed. 63% live alone	Community-based health and social organisations, HIV support groups and HIV advocacy organisations in NY City	Antiretroviral medicine	Semi-structured interviews
Smith et al. (2000)	UK	No information on participants	Relevant national and local voluntary organisations	Miscellaneous (arthritis/ respiratory disease/mental health)	Focus groups

Table 5 (continued)

Source paper (n = 37)	Country setting	Participants (female)	Sample origins	Group	Data collection
Svensson et al. (2000)	Sweden	33 (15, mean age 58 (range 35–83), mean duration of hypertension 10 years (range 1–30)	Rural GP centre and specialist hypertension unit in major hospital, both in Southern Sweden	Antihypertensive medicine	Semi-structured interviews
Walsh et al. (2000)	UK	35 people, no other information given	One general practice	Asthma medicine	In depth interviews
Pollock and Grime (2000)	UK	82 (43, aged 28–83, 88% > 45, 77% economically inactive, mainly w/c	General practices in North Staffordshire Health Authority	Proton pump inhibitors	Semi-structured interviews
Angermeyer et al. (2001)	Germany	80, 60% male. Third aged < 30; third 30–40; third 40 >. 74% single; 37.5% live alone, 20% with parents, 17.5% partners	Four hospitals	Psychotropic medicine	Semi-structured interviews
Usher (2001)	Australia	10, mostly male, being treated for schizophrenia and taking neuroleptic medication. No other info	Consumer groups/advertising in relevant newsletters	Psychotropic medicine	Two in depth interviews each

participants chose quality of life with HIV in preference to the treatment.

Roberson (1992) found that some of her participants similarly concluded that their regimens (for a variety of illnesses) were too disruptive to continue with. Both studies of neuroleptic medicine for schizophrenia (Rogers et al., 1998; Usher, 2001) found that there were high gains associated with taking the medicine in terms of reduced symptoms, improved ability to deal with symptoms and reduced risk of relapse, but also high costs in terms of physical and psychological adverse effects and the stigma and discrimination associated with taking neuroleptics. The process of weighing costs against benefits was also found with benzodiazepines (North, Davis, & Powell, 1995), clozapine (Angermeyer, Loffler, Muller, Schulze, & Priebe, 2001) and treatment for rheumatoid arthritis (Donovan & Blake, 1992).

Stopping the medicine and seeing what happens. Siegel et al. (1999), referring to patients as 'naïve scientists', suggest that people formulate hypotheses about medicines causing effects then test these hypotheses by altering the dose or stopping the medicine in order to observe the effects. This seems to have been a popular method with several types of medicine; antiretroviral therapy (Siegel et al., 2000), Proton Pump Inhibitors, or PPIs (Boath & Blenkinsopp, 1997), antihypertensive medicine (Johnson et al., 1999), inhalers (Buston & Wood, 2000) and NSAIDs (Donovan & Blake, 1992). While several of these studies implicitly refer to this type of test, none outlines it in any great detail.

Dowell and Hudson (1997) suggest that the lay testing of medicines may be either an explicit or a subconscious act and that it is more likely if the medicine is to be taken long-term. It seems that some people stop taking their medicine and notice ill effects, convincing them that they need to continue with the medicine. Others notice no benefit from taking their medicines, so stop taking them, and if this goes well, may decide to stop the medicine completely. Donovan and Blake (1992) found that many people with rheumatoid arthritis conducted a process of testing before deciding whether to take the medicine as prescribed. Four of 41 people in their sample taking NSAIDs eventually reduced their doses and six gave up altogether. Donovan and Blake note that some people did not give the drugs sufficient time to work, but were unaware of this.

Observing others, obtaining information. One study, of women's experiences of, and attitudes towards, taking AZT found that some relied on observations of how others fared on AZT before deciding whether to take it. Siegel and Gorey's (1997) participants felt that AZT was experimental and consequently they placed more faith in their observations than in their doctors' advice.

Both Dowell and Hudson (1997) and Donovan and Blake (1992) note that people consult a variety of sources and do not rely solely on their doctors' advice about taking medicines. Some of Roberson's (1992) sample used 'root' doctors as well as informal networks, while Watson, Mitchell, Decrespigny, Grbich, and Biggins (1998) participants sought information from several sources as well as their GPs. Erlen and Mellors (1999) found that information was obtained from support groups, peers, books and the internet when deciding whether to accept medicines.

Objective and subjective indicators. Blood pressure monitoring seems to have been widely used as a means of evaluating the efficacy of antihypertensive medicines (Roberson, 1992; Morgan, 1996; Van Wissen, Litchfield, & Maling, 1998; Johnson et al., 1999). In the context of antiretroviral therapy, however, people seemed less influenced by objective indicators of efficacy, in this case laboratory results such as T-cell counts. Some felt that although their T-cell count had increased or their viral load had dropped as a result of the treatment, subjectively they felt worse (McDonald et al., 2000; Siegel et al., 1999; Stone et al., 1998). A sense of health or symptom alleviation, therefore, seemed to carry more weight for people with HIV.

Gender differences in evaluating medicines. Women were more skeptical about the scientific basis of drugs for HIV, arguing that trials had not been conducted with women, so its effectiveness in women was unknown (Siegel & Gorey, 1997; McDonald et al. (2000); Johnston Roberts & Mann, 2000). Some of the women in Siegel and Gorey's study suggested that doctors were ill informed about the drug yet failed to acknowledge the limits of their knowledge. Stone et al. (1998) point out that, unlike gay men or injecting drug users, women do not belong to the social networks that people with HIV form. They suggest that because of this, women may be less informed about the drugs and therefore more negative about them.

Difficulties with evaluating medicines. A small number of studies noted a few people had difficulty distinguishing the effects of the medicine from the effects of their illness. Morgan (1996) found this in the case of hypertension, while in the case of HIV, Siegel et al. (1999) suggest that patients wrongly interpreted the symptoms of the disease as the undesirable effects of treatment and therefore rejected the treatment mistakenly. Whether or not this is the case is hard to say, but it does highlight the difficulty people face when evaluating their medicines. As noted above, people taking antiretroviral therapy found it confusing if objective indicators indicated improvement but they did not feel any better, or felt worse.

Dowell and Hudson (1997) note that the method of evaluation depends on the person's understanding of the medicine's function, thus analgesics with a short-term, symptomatic effect may be easily assessed. With preventive medicine the evaluative process is difficult because of the lack of immediate symptoms to use as indicators of efficacy. Although health professionals can evaluate medicine in terms of its long-term and preventive effect, lay people can really only evaluate it in terms of its immediate impact on their lives. In the case of antihypertensives, because people are not easily able to assess its impact, some may be uncertain about whether the medicine is necessary, i.e. whether they actually have hypertension. This uncertainty was found in all four studies of hypertension (Morgan, 1996; Svensson et al., 2000; Johnson et al., 1999; van Wissen et al., 1998).

Occasionally, people might have difficulty evaluating their medicine due to a lack of information. In one case, where doctors were substituting patients' usual brand of PPIs for a cheaper brand (Pollock & Grime, 2000), they 'double-switched' by reducing the dose at the same time as changing the brand. The authors note that this was confusing to patients because, being unaware of the dose reduction, they were unable to accurately assess the efficacy of the new drug, with the result that many rejected it as less effective.

Worries about medicines that lay testing and evaluation cannot resolve. While many of the concerns people have can be resolved through lay evaluation of medicines, some are less easily resolved and may linger, affecting decisions about medicine taking. It was widely noted that people dislike depending upon medicines (Roberson, 1992; Adams et al., 1997; Ersek et al., 1999; Morgan, 1996; Angermeyer et al., 2001; North et al., 1995; Barter & Cormack, 1996; Donovan & Blake, 1992). Both Donovan and Blake (1992) and Ersek et al. (1999) note that fear of dependency was a reason why some did not take their medicines. These authors also found that fears about tolerance were an issue, resulting in people taking less than their prescribed doses. Some of Morgan's (1996) participants feared that if they took their antihypertensive medicine as prescribed they might become unable to manage without the drugs, or become addicted to them. Fears about addiction were also found in the context of psychotropic medicines (Angermeyer et al., 2001; North et al., 1995). Worries about taking medicines long term were an issue with hypertensives (Morgan, 1996) and PPIs (Boath & Blenkinsopp, 1997; Pollock & Grime, 2000). Pollock and Grime note that those who were worried about the long-term effects of taking PPIs were more likely to modify their regimen to achieve the lowest possible dose. Two of Boath and Blenkinsopp's (1997) participants were also concerned about the potential of PPIs to mask more serious

symptoms. This was also found by Ersek et al. (1999). All of these concerns could result in people reducing their doses.

(ii) *Medicine and identity*

Non-acceptance. Dowell and Hudson (1997) argue that since taking medicine is equated with having an illness, if people do not accept their illness they are unlikely to accept its treatment. Acceptance was a strong theme in the asthma studies. Adams et al. (1997) reported that some people with asthma denied that they had asthma, or distanced themselves from their asthma (despite their asthma being just as severe as those who accepted their asthma). These people tended to downplay its significance, claiming either that they did not have asthma at all or that it was only slight or 'not real' asthma. They viewed their asthma as acute rather than chronic and did not take the preventative asthma medicine as this entailed acceptance of the asthma identity and the chronicity of the condition. However they did take the reliever medicine 'just in case they demonstrated symptoms in social/public situations'. (Adams et al., 1997, p. 192) As such, they both used relievers and avoided preventers for the purpose of maintaining normality.

Prout, Hayes, and Gelder (1999) and Buston and Wood (2000) also found a tendency to downplay the severity of asthma. In Prout et al.'s study, families did not define childhood asthma as a serious illness, preferring to stress the ordinariness of children instead. As with some of Adams et al.'s sample, Prout et al. found that some of their families doubted their children actually had asthma. The authors argue that inhalers helped maintain this sense of ordinariness. Walsh, Hagan, and Gamsu (2000) identified three categories of people who did not take their asthma medicine as prescribed; those in denial, avoidance and depression. Those in denial did not want to see themselves as having a chronic illness, wanted to manage the asthma on their own and took reduced doses of medicine. Those in avoidance felt that medicine did not help, so they did not attend clinics and neglected their regimens. These two categories have similarities with those in Adams et al.'s study who denied or distanced themselves from the asthma, but Walsh et al.'s third category, of those in depression, do not find their counterpart in any of the other asthma studies.

Barton Laws et al. (2000) suggest that acceptance of being HIV positive is crucial in determining whether or not people take their drugs as prescribed, while Usher (2001) observes the equivalent situation in the context of neuroleptic medicine. Medicines can also be an unwelcome reminder of illness as four of the HIV studies found (Erlen & Mellors, 1999; Halkitis & Kirton, 1999; Johnston Roberts, & Mann, 2000; Proctor et al., 1999) and Ersek et al.'s (1999) study on cancer.

Disclosure and stigma. Many people with HIV were fearful of disclosing their illness to others (Stone et al., 1998; Halkitis & Kirton, 1999; Johnston Roberts, & Mann, 2000; Siegel, Schrimshaw, & Raveis, 2000; Murphy et al., 2000). Rather than take the medicine in public and risk disclosing their HIV status, people might postpone or forego their medicine. One of the women in Johnston Roberts and Mann's study had not disclosed her HIV status to her children so even found it hard to take her pills at home. Barton Laws et al. (2000) found that some people did not initiate treatment due to worry that the regimen would identify them as having HIV.

Rogers et al. (1998) and Usher (2001) both reported that neuroleptic medicine was stigmatising because it could mark out a person as having schizophrenia, while Smith, Francis, and Rowley (2000) found that those with mental health problems reported feeling stigmatised and labelled by their medicine. North et al. (1995) note that some people reported feeling ashamed of using benzodiazepines. Finally, Atkin and Ahmad (2000) found that for children with thalassaemia major, one of the most hated aspects of their treatment was that it marked them out as different from their peers.

(iii) *Ways people take their medicines*

A small number of studies categorised the various ways in which people take their medicines (Figs. 3 and 4). However, none of these included a category of medicine taking that came up exclusively in the studies on mental illness, that of 'imposed compliance'. This term was coined by Usher (2001) to describe the result of the pressure to take medicine that is exerted by relatives or health professionals. Writing in the context of neuroleptic medicine for schizophrenia, she suggests that some people only take their medicines because they feel powerless to do otherwise. Some of Usher's participants reported that friends and relatives surveyed them for signs of illness and if they felt it necessary, exerted pressure on them to take their medicine. Rogers et al. (1998) also found that some of their participants had experienced relatives or friends strongly encouraging or forcing them to take their neuroleptic medicines. Some had experienced coercion from health professionals when in the past they had not taken their medicine. An extreme form of imposed compliance is the administering of medicine by injection (Kaljee & Beardsley, 1992). Less apparent is the pressure to take medicine that is imposed by society. Rogers et al. (1998) suggest that people on neuroleptic medicine perceive the existence of an unwritten social contract; take the medicine in order to be tolerated by the community. Smith et al. (2000) also reported that some people with mental illness felt that medicine was used to control them and make them acceptable to society.

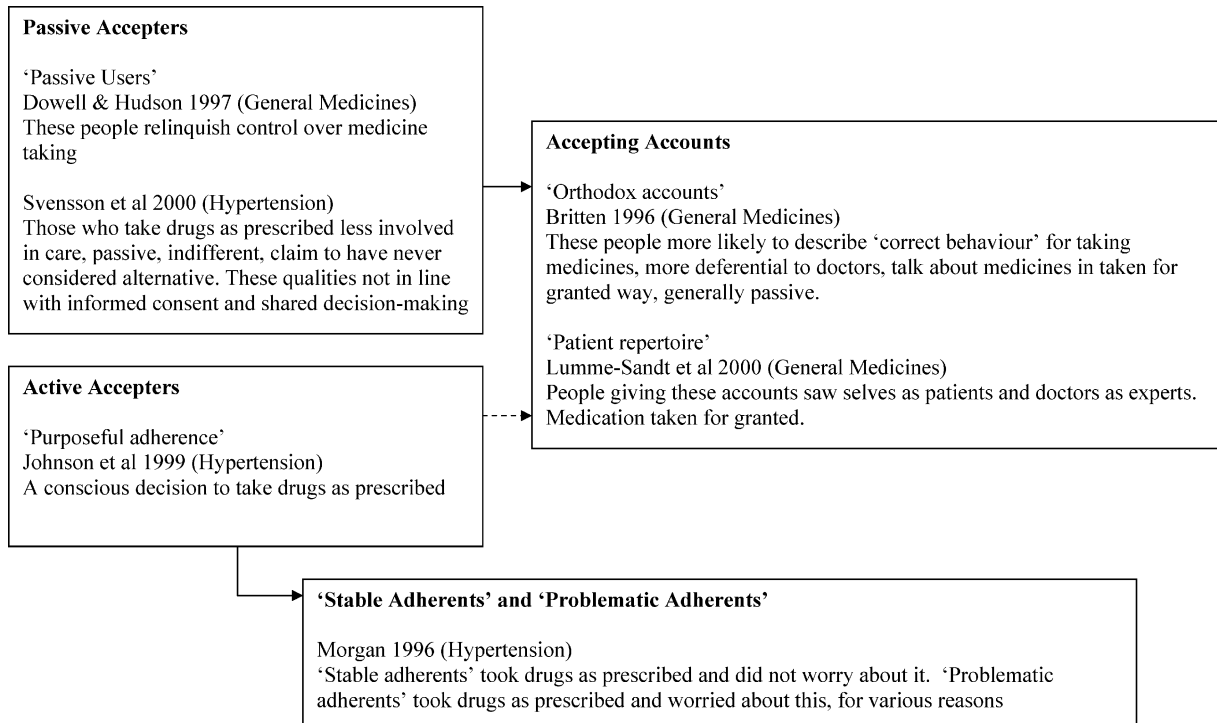


Fig. 3. Categories of those who do take their medicine as prescribed.

Ways of modifying the regimen

Motivation to minimise intake. Roberson (1992), Watson et al. (1998) and Dowell and Hudson (1997) all note that people are motivated to minimise their intake of medicines. Donovan and Blake (1992) found that more than four fifths of their sample spontaneously expressed their dislike of having to take drugs. Even people taking PPIs and benzodiazepines—medicines commonly regarded as being overused by patients—were found to minimise their intake (Pollock & Grime, 2000; Boath & Blenkinsopp, 1997; North et al., 1995). Most of the strategies people use to modify their regimens reflect a desire to minimise medicine intake.

To decrease adverse effects and addiction: Many people adjusted their antiretroviral regimens to try and realise some therapeutic gain while minimising adverse effects (Siegel & Gorey, 1997; Siegel et al., 1999; Erlen & Mellors, 1999; Siegel et al., 2000). This might involve reducing the dose, skipping doses or taking tablets separately rather than all at once. Some people specifically referred to ‘drug holidays’ as a way to stop the build of toxicity and to cleanse their bodies (Erlen & Mellors, 1999; Barton Laws et al., 2000; Stone et al., 1998). This could mean going without medicine for periods ranging from a week to a month or more and was also found with antihypertensives (Morgan, 1996).

North et al. (1995) report that many people tried to restrict their use of benzodiazepines in order to avoid addiction. In the context of rheumatoid arthritis Donovan and Blake (1992) note that the strategy of reducing doses meant that people often had to put up with considerable amounts of pain and discomfort as a result.

To make the regimen more acceptable: Some of Siegel et al.’s (1999) participants amended their antiretroviral regimen to fit in with their daily schedule, arguing that complete adherence was not necessary for therapeutic gain. Similarly, some of those in Siegel et al.’ (2000) study were not worried about straying from their regimen, suggesting that the optimum regimen was unknown anyway. They argued that flexibility with the regimen allowed life to continue without too much disruption and that strict adherence was not attainable. Barton Laws et al.’s (2000) findings confirm this. In the case of chelation therapy for thalassaemia major, Atkin and Ahmad (2000) report that some children would use the infusion pump less frequently than prescribed, or would disconnect the needle at night because the regimen was too intrusive.

For financial reasons: Some of Roberson’s (1992) sample reduced doses because they could not afford the prescribed amounts. Financial difficulties that impacted

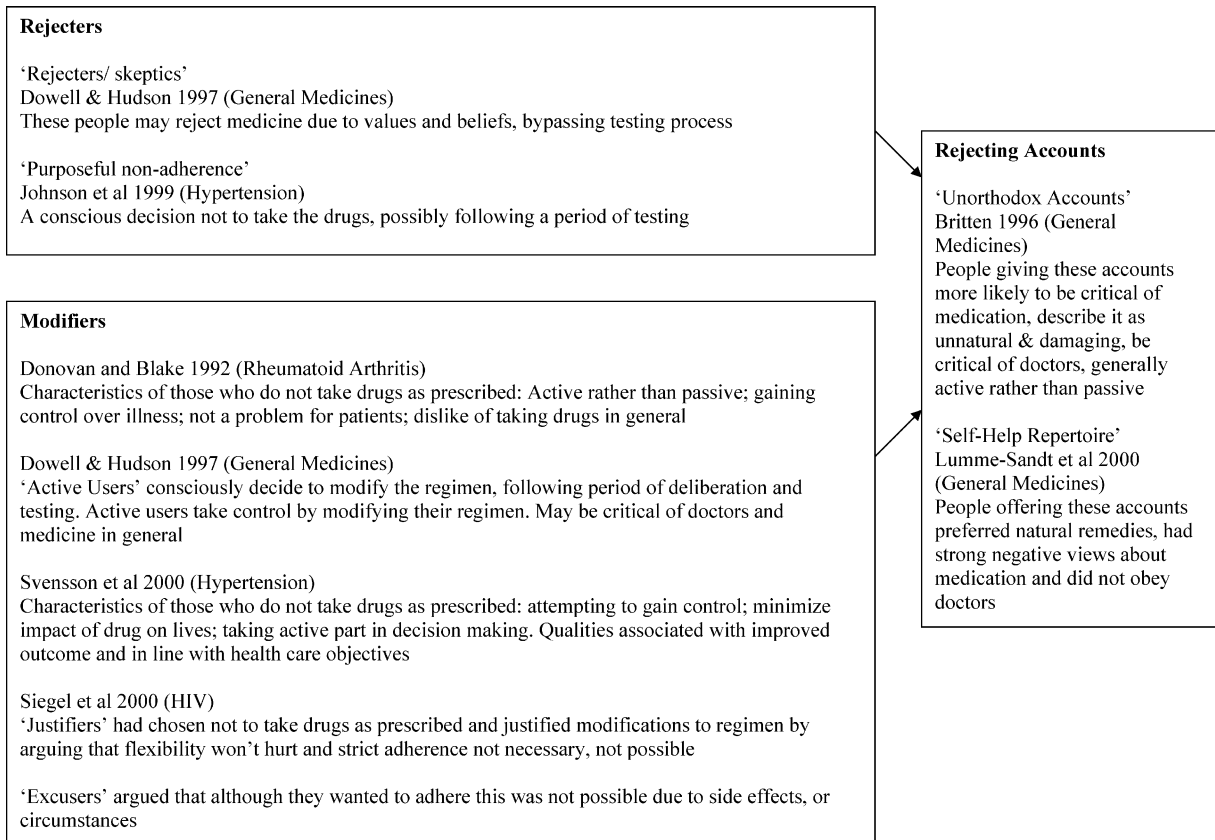


Fig. 4. Categories of those who do not take their medicine as prescribed.

on medicine taking were also reported by Ersek et al. (1999), Barton Laws et al. (2000) and Siegel et al. (2000).

Using medicine symptomatically: Morgan (1996) found that some of her African Caribbean respondents used their anti-hypertensive drugs in the same way as they used their herbal remedies, i.e. symptomatically. Some people described feelings of weakness or tiredness, eye problems, dizziness or hotness and perceived these as indications that their blood pressure was elevated, in which case they might take their medicine. Roberson (1992) and Johnson et al. (1999) found that some people checked their blood pressure and decided upon dosage accordingly. In Donovan and Blake's study (1992) some people with rheumatoid arthritis altered their doses according to the symptoms they experienced, as did some people on psychotropic medicine (Kaljee & Beardsley, 1992; Rogers et al.'s, 1998; Angermeyer et al., 2001).

Using medicine strategically: A few of Morgan's (1996) respondents reported that they would not take their antihypertensive medicine if they intended to drink alcohol, for fear that the interaction would have severe consequences. Rogers et al. (1998) also found that

several people adjusted their doses of neuroleptic medicine when they wanted to go for a drink, with most stopping their medicine on the day they drank alcohol. Boath and Blenkinsopp (1997) and Pollock and Grime (2000) found that some people took PPIs as and when they thought it necessary, either at symptom onset, or by relating the dosage to their proposed diet.

Replacing or supplementing medicines with non-pharmacological treatments: Most of Roberson's (1992) sample took home remedies in addition to their prescribed medicines. Vinegar, Epsom salts, lemon and garlic were taken for hypertension, 'Ben-Gay' and copper wire or bracelets were used for arthritis, horehound tea or buttermilk for diabetes and rabbit tobacco tea and pine top for asthma. A few people sought advice from 'root doctors'. Several of Ersek et al.'s (1999) participants used non-pharmacologic methods to reduce pain and also to reduce their use of analgesics. About half of the people in Donovan and Blake's (1992) study used some sort of 'alternative' remedy either instead of or as well as their medicine, including kelp, cod liver oil, feverfew, dietary changes and homeopathy.

Morgan (1996) found that over half of the African Caribbean people in her study took herbal remedies. Respondents reported taking Cerasee and ‘Constitution Bitters’, a drink containing a blend of seven herbs. The African Caribbean women boiled grapefruit skins with garlic and drank the water to reduce blood pressure. Morgan notes that these herbal remedies were taken either in addition to, or instead of, prescribed medicines. She observes that people regarded these medicines as potentially less harmful and powerful than prescribed drugs because they were seen as ‘natural’. Those who worried about the potentially harmful effects of prescribed drugs might take a break from them and use natural remedies for a period instead. Lumme-Sandt, Hervonen, and Jylha (2000) note that their respondents who talked spontaneously about traditional remedies seemed to use the latter as their primary medicine, while others used both medical drugs and traditional remedies alongside each other.

Doctor–patient communication about regimen modifications. Some of Roberson’s (1992) respondents reported being scolded by their doctors if they made their own decisions about health care. Instead of confronting these doctors, however, patients would change to another doctor. Britten (1996) also suggested that people who gave ‘unorthodox accounts’ did not mention their beliefs to doctors, thus appearing ‘orthodox’ while in the surgery. Once outside the surgery, however, they regained control by modifying or rejecting their prescription. Rogers et al. (1998) observed that people with schizophrenia who modified their regimens were unlikely to reveal this to health professionals due to previous experience of coercion, or awareness of their powerless position.

Pollock and Grime (2000), recommend that patients should be encouraged to find their own level of treatment, since their tendency is to under- rather than over-medicate anyway. Furthermore, they argue that more patients would ‘self-regulate’ if doctors helped them to do so and that if the practice were authorised and open it would be safer than at present, as well as helping people feel in control. They suggest that doctors need to recognise that many patients self-regulate already. Similarly, Dowell and Hudson (1997) suggest that since there is a powerful drive to minimise use of medicines and since patients will continue to test and modify their medicines, doctors may as well assist them in doing so. Svensson et al. (2000) reach similar conclusions with regard to anti-hypertensive medicine. They argue that ‘non-adherence’ is sound behaviour and only dangerous if not communicated to health professionals. They suggest that it should be encouraged because it allows patients to take control and make decisions, characteristics associated with good clinical practice.

Discussion of findings

It is important to remember that our sample of studies represented only a small range of medicines, taken mainly for chronic illnesses. Furthermore, the illness most frequently represented in the studies was HIV, which provided relatively extreme experiences of medicine taking. A person’s experience of medicines is likely to differ according to the medicine in question and the nature of the illness for which it is taken. For example, it is possible that those classified in some of the studies as ‘rejecters’ might become ‘accepters’ if they were given a different medicine, or vice versa. Equally, it is important to remember that in some cases the consequences of not taking medicines as prescribed can be serious, or fatal.

Lay evaluation

The significance of the lay evaluation of medicines lies not simply in the fact that it occurs, but in the reasons why it occurs. The urge to evaluate suggests widespread caution about taking medicines as well as distrust in the information given about medicines. It may also reflect an intuitive understanding that population set doses may not be appropriate for individuals. Recently the worldwide vice president of GlaxoSmithKline acknowledged that most prescription medicines do not work on most people who take them (Independent, 8 December 2003, see also Smith, 2003). Lay people, in testing their medicines, are attempting to determine whether there are any adverse effects, whether the medicine works for them and if so, to establish the most suitable dose for themselves (in much the same way as ‘N of 1’ trials are conducted. For example, see Johannessen, Petersen, Kristensen, & Fosstvedt, 1991).

Adverse drug reactions

The literature on adverse drug reactions (ADRs) suggests that people are right to be cautious about taking medicines. Heath (2003) points out that more people are admitted to hospital for ADRs than for problems relating to ‘non-compliance’. A meta-analysis of studies in the US found the incidence of fatal ADRs (excluding those due to prescribing errors) to be between the fourth and sixth leading cause of death (Lazarou, Pomeranz, & Corey, 1998) while in England and Wales the Audit Commission estimated that just under 11% of hospitalised patients suffer an ADR, with mortality following ADRs showing a marked upward trend (Eaton, 2002). Yet the very real risks involved in taking medicine are either ignored or treated dismissively in the literature. For example, the WHO report states, ‘Concerns about medicine typically arise from *beliefs about adverse effects* and disruption of lifestyle and from more *abstract worries* about the long-term effects and

dependence' (p. 44, italics added). Lay reports of the adverse effects of medicines are consistently dismissed, despite the fact that the current Yellow Card system, which relies on doctors voluntarily reporting ADRs, has been estimated to capture only 1% of actual ADRs (Medawar, Herxheimer, Bell, & Jofre, 2002; Medawar & Herxheimer, 2003/2004). 'Medication errors' caused by poor prescribing, poor dispensing, and poor labelling are also a significant problem (Department of Health (DoH), 2004).

Concordance

As noted earlier, some authors suggested that doctors need to accept that patients modify their regimens and that the way forward is to encourage authorised self-regulation. This is similar to Donovan and Blake's earlier call for 'active and co-operative relationships between patients and doctors' (1992) and to the newer concept of concordance, the aim of which is to involve patients in making decisions about their medicines, to ensure that they have enough information for doing this, and to support them with any problems they might have. Thus doctors might help patients with their testing and their modifications, providing feedback and guidance. 'Crucially, concordance advocates a sharing of power in the professional–patient interaction' (Weiss & Britten, 2003, p. 493).

The concordance approach could work in cases where doctors can help patients determine appropriate individual doses, provide information on adverse effects and how to deal with them as well as the information necessary to conduct their evaluations safely and effectively. However, concordance depends upon doctors and patients sharing information honestly. Unfortunately, Cox, Stevenson, Britten, & Dunder (2002) found that doctors emphasise the benefits of treatment rather than discussing its possible harms or risks, despite patients regarding these topics as essential. Equally, as noted earlier, people are unlikely to be honest about how they take their medicines for fear of being scolded. Socially excluded patient groups, such as those with poor mental health or HIV, are even less likely to achieve 'concordance' with their doctors, possibly because they are less normative in their attitudes or because they feel disempowered due to their membership of marginalised groups. This is not to suggest that health professionals should give up trying to deal with patients' concerns, but to make the point that the power imbalance inherent in the doctor–patient relationship will not easily be resolved by concordance.

It has also been suggested that concordance is simply another way of encouraging people to take their medicine, except that this time the coercion is concealed (Heath, 2003). This is an important consideration.

Nevertheless, while doctors may be in control during the consultation, the medical profession is oddly powerless once the person has left the surgery. Lay people have always exercised their power to reject prescriptions or modify their regimens. Undoubtedly they will continue to exercise this power, as this is 'normal' behaviour for them.

Relationship between health and medicine taking

Arguably, the ideologies of compliance, adherence and concordance, because they revolve around the axis of pharmaceutical medicine, distract attention away from non-pharmaceutical approaches to health. Heath (2003) makes the point that the rhetoric of both concordance and compliance uncritically endorses medicine taking. The most profound and hidden assumptions in the medicine-taking debate are, firstly that taking medicine is beneficial, and secondly that it is the only possible response to ill health. In fairness, the original conceptualisation of concordance, as set out in the RPSGB report acknowledged that taking medicine was not always the best thing to do and that: 'Almost all medicines have the capacity to harm as well as to do good' (1997, p. 21).

However, the reports by the WHO (2003) and the Medicines Partnership (Carter et al., 2003) both claim that greater adherence will lead to better health. Yet a systematic review of interventions to increase adherence to medicines found that successful interventions (of which there were nineteen out of thirty nine) did not lead to large improvements in adherence or treatment outcomes (McDonald, Garg, & Haynes, 2002; McDonald, Lefebvre, Antes, & Galandi, 2002). Furthermore, a study on the use of NSAIDs found that an adaptable approach that involved varying the dose according to the presence of symptoms was less likely to result in hospital admission for upper gastrointestinal bleeding than was rigid compliance to prescribed doses (Wynne & Long, 1996; Herxheimer, 1998).

While the bulk of the medicine-taking literature uncritically assumes that pharmaceutical drugs and Western medicine are the only response to ill health, those people who reject their prescriptions outright, clearly think otherwise. Presumably so too did the 1 in 3 Americans in 1990 who reported using at least one 'unconventional therapy' in the previous year, and who spent almost \$13.7 billion on alternative health treatments in the same year (Eisenberg et al., 1993). It is estimated that approximately half the general population in developed countries uses complementary and alternative medicine, or CAM (Ernst, 2000). Harrison (2003) argues that user support for CAMs '...indicates in the clearest possible way that a significant number of people do not like conventional medicine or that it has failed them in particular ways' (p. 36).

Sociology and medicine

The sociological studies in this synthesis barely touched the assumptions that taking medicine is beneficial and is the only possible response to ill health. As such, sociologists have to a large extent adopted the medical agenda. Only a few studies considered those who rejected medicine (Britten, 1996; Dowell & Hudson, 1997; Lumme-Sandt et al., 2000), despite the fact that this group probably has the most to tell us about the reasons for the widespread reluctance to take medicine. Nevertheless, the early sociological and anthropological studies in this synthesis (Donovan & Blake, 1992; Roberson, 1992; Kaljee & Beardsley, 1992; Morgan, 1996; Adams et al., 1997; Rogers et al., 1998) demonstrated that people have understandable and logical reasons for not taking their medicine as prescribed and challenged the assumptions inherent in the ideology of compliance. As such they undoubtedly influenced medical culture to the extent that the term ‘compliance’ is no longer considered appropriate.

The value of syntheses

Our synthesis revealed that only a minority of the studies referenced each other, even when papers were about the same medicines (Table 6). This suggests that research in this field at least, is not an evolving process whereby new studies build on earlier ones and where research is only conducted after the relevant literature has been reviewed and important questions identified. Rather, among the later studies, there appeared to be little regard for earlier relevant studies and, certainly within the HIV literature, a tendency for studies to replicate each other.

Syntheses are able to provide a weight of evidence about particular issues. In our synthesis, e.g., only one of the studies (Dowell & Hudson, 1997) dealt with the lay evaluation of medicines in any detail, yet when synthesised, the studies revealed much data on this topic, substantially more than any individual study produced alone. Our synthesis also produced a weight of evidence about peoples’ concerns with the safety of their medicine that has not been found elsewhere. Single studies reporting worries about medicines are not taken to be sufficient evidence, yet when studies are brought together the weight of evidence is hard to ignore.

The studies in the synthesis involved a diverse group of medicines, were conducted in several different countries, with disparate samples and methods and for varying readerships. Nevertheless, it was possible to systematically draw these studies together and come to new conclusions. By systematically relating findings from different studies to each other it is possible to establish new relationships between concepts and arrive at a fresh understanding of the issues. The result of the re-ordering, re-linking and re-analysis of material that a synthesis

entails represents what Noblit and Hare (1988) call a ‘lines of argument’ synthesis and what Britten et al. (2002) refer to as ‘third-order’ concepts. At this stage further conceptual development is possible. Two such concepts that resulted from our synthesis are now presented.

Bringing medicine into the medicine-taking debate

In our view, one of the key conclusions produced by this synthesis is that the main reason why people do not take their medicines as prescribed is because of concerns about the medicines themselves. On the whole, the findings suggest that there is considerable reluctance to take medicine and a preference to minimise medicine intake. This is in contrast to earlier theories that attributed ‘non-compliance’ to failings in patients, or current theories that attribute it to failures of the ‘system’ or health professionals. Although medicines are obviously at the centre of the medicine taking debate, and although lay people have repeatedly demonstrated their wariness of medicines, their worries have tended to be marginalised, or, as noted earlier, treated as ‘beliefs about medicines’, despite the well-documented existence of ADRs.

It is difficult to imagine how or why this most obvious factor has been overlooked but it may be due to the dominance of the cultural belief in the benefit of pharmaceutical medicines. Or perhaps it was dismissed because of the view that patients, doctors and systems are easier to modify than medicines themselves. It may be because most of the research has ignored the lay perspective and has failed to involve consumers, resulting in a mismatch between the priorities of researchers and those of patients (Chalmers, 1995; Tallon, Chard, & Dieppe, 2000). However, sociologists are also responsible because we have tended to focus on ‘perceptions’ of medicines or the ‘meanings’ people attach to medicines. This tendency has significant consequences. It makes the person, rather than the medicine, the focus of attention, in much the same way as the WHO (2003) report (as noted in the introduction to this synthesis) considers anxieties about medicines to be ‘patient-related’, rather than ‘therapy-related’, factors. The result of this is that attempts are made to modify patient behaviour, or the doctor–patient consultation, rather than question the appropriateness of the medicine. Thus, because peoples’ accounts are not taken at face value, the more mundane issues about the physical reality of medicines and the effects they have on peoples’ bodies and minds are obscured and patients’ priorities and concerns are neglected.

Resisting medicines

We feel that many lay peoples’ response to medicine is best captured by the concept of resistance. In part this is

Table 6
Citations

Medicine	Author citing	Author cited
HIV	Siegel and Gorey (1997)	None
	Stone et al. (1998)	None
	Erlen and Mellors (1999)	None
	Halkitis and Kirton (1999)	None
	Proctor et al. (1999)	None
	Siegel et al. (1999)	Siegel and Gorey (1997)
	Siegal et al. (2000)	Siegel and Gorey (1997); Siegel et al. (1999)
	McDonald et al. (2000)	None
	Murphy et al. (2000)	None
	Johnston Roberts and Mann (2000)	None
Barton Laws et al. (2000)	Stone et al. (1998)	
Anti-hypertensives	Morgan (1996)	Donovan and Blake (1992)
	Van Wissen et al. (1998)	Roberson (1992)
	Johnson et al. (1999)	Dowell and Hudson (1997); Van Wissen et al. (1998)
	Svensson et al. (2000)	None
Psychotropic medicines	Kalijee and Beardsley (1992)	None
	North et al. (1995)	None
	Barter and Cormack (1996)	None
	Rogers et al. (1998)	None
	Angermeyer et al. (2001)	None
Usher (2001)	None	
PPIs	Boath and Blenkinsopp (1997)	Dowell et al. (1996)
	Pollock and Grime (2000)	Boath and Blenkinsopp (1997); Donovan and Blake (1992)
Asthma medicine	Adams et al. (1997)	Donovan and Blake 1992; Morgan 1996
	Prout et al. (1999)	Adams et al. (1997)
	Buston and Wood (2000)	None
	Walsh et al. (2000)	Adams et al. (1997); Donovan and Blake (1992)
Miscellaneous medicines	Donovan and Blake (1992)	None
	Dowell et al. (1996)	None
	Ersek et al. (1999)	None
	Atkin and Ahmad (2000)	Prout et al. (1999)
	Smith et al. (2000)	None
Medicines in general	Roberson (1992)	None
	Britten (1996)	Donovan and Blake (1992)
	Dowell and Hudson (1997)	None
	Watson et al. (1998)	None
	Lumme-Sandt et al. (2000)	Donovan and Blake (1992), Britten (1996), Adams et al. (1997)

because the term encapsulates the ways in which people take medicines at the same time as attempting to minimise their intake. However, the majority of people represented in this synthesis were not just unwilling or reluctant to take their medicines, nor simply cautious. The strategies they adopted to manage their medicine taking indicate varying degrees of resistance to the prescription they were given and if the term sounds strong, it should be remembered that the huge literature on 'non-compliance' only exists because so many people have continued to resist taking

medicines in the face of sustained advice, interventions and admonishments.

The term resistance also captures lay peoples' active engagement with their medicines, as well as the ingenuity and energy they bring to dealing with them. Additionally, it carries the suggestion of something hidden, which is accurate, since most people conceal from their doctors the modifications they make to their regimens. The term resistance is usually employed in relation to the exercise of power, or coercion. As such, it entails acknowledging that the traditional approach to medicine taking has

been, and in varying degrees continues to be, coercive. In this context it should be noted that the noun 'medicine' refers both to the pharmacological substance as well as to the profession that prescribes it.

Policy and practice implications

There is a need to accept that people are unlikely to stop resisting their medicines. Doctors could assist people in their lay evaluations of medicines by providing the necessary information, feedback and support and by prescribing safely. However, doctors will need training and support to do this effectively. The policy emphasis needs to be less on attempting to modify peoples' behaviour and more on developing safer medicines. This huge undertaking involves questioning the present methods used to develop and test medicines (Horrobin, 2003) and ensuring that more attention is paid to safety at the licensing stage, possibly by having a probationary period. Additionally, safer ways need to be found of administering medicines, and of monitoring their effectiveness and acceptability to individual patients. Effective ways of identifying ADRs in all patients need to be developed and implemented. Furthermore, in recognition of the fact that many people prefer not to take medicines, funds should be allocated, firstly to determine what sort of treatments patients prefer, and secondly, to evaluate the safety, efficacy and cost effectiveness of those preferred treatments.

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