
Resisting medications: moral discourses and performances in illness narratives

Jamie Murdoch, Charlotte Salter, Jane Cross, Jane Smith and Fiona Poland

Faculty of Medicine and Health Sciences, University of East Anglia, Norwich

Abstract Adherence research has been dominated by attitudinal approaches that isolate individual statements made in interviews and then assign a fixed attitude to the individual who made that statement. Despite much sociological research having raised questions about the notion of fixed attitudes, little research has theorised the process by which individual utterances about medicine-taking are produced as a form of resistance to medications within interviews. Using Goffman's concept of performance as a starting point, this article offers an alternative framework for conceptualising adherence presentations when provided in the form of a rhetorical narrative. Through the presentation of case material taken from interviews with participants who had not taken prophylactic asthma medications as prescribed, we develop Goffman's concept of performance to theorise the production of adherence talk in two important ways. First, individual performances can be seen to be shaped by how moral discourses of illness management transfer across contexts. Second, performances are subject to inequalities in the resources interactants have access to. An extended definition of Goffman's concept of performance is thus offered, arguing that the 'meaning' of individual performances is produced by a combination of which moral discourses interactants orientate to and which discourses are used to categorise individuals.

Keywords: communication, medications, narrative, performance, discourse

Introduction

The brown, I mean with, I've had two or three or four different doses of the brown one and I've played about with it for a week, for nine months sort of thing, and I'm adamant that it's not made any difference. It really hasn't. Yeah and I did forget to take it and I did forget to, it was just how and the, this thing about using the two in conjunction. Well, it just, I just never really accepted it (Murdoch 2010: 113).

When people talk about how they manage illness they display a version of their private experience to an audience in a public space. For many, such displays involve negotiating 'appropriate' use of medication – a discursive space where different moralities of illness management may be contested and negotiated. Although much research has used interviews to elicit people's views and experiences of illness and medications as a means of

understanding why people do not 'adhere' to prescribed treatments, less attention has been paid to unpicking the process by which such talk is produced. In this article we examine how discursive contexts shape illness and adherence presentations within research interviews and how we might treat talk about medicine-taking in understanding how individuals manage illness on a daily basis.

The prescribing of standardised medications to patients to achieve and maintain disease control occupies a prominent place in the delivery of modern medical care. However, it is estimated between a third and half of all medicines prescribed for long term conditions are not taken as recommended (Nunes *et al.* 2009). Nearly 200 potential barriers to adherence have been investigated with little success in predicting adherence to prophylactic medications (Vermeire *et al.* 2001).

A large proportion of adherence research since the 1970s has investigated individual patient characteristics as indicators of adherence including beliefs, personality, gender, age, sex, marital status, social class, disability and psychosocial factors (Vermeire *et al.* 2001). Clinical guidelines on medication adherence place beliefs about medications and medicine in general as having the greatest influence on adherence (Nunes *et al.* 2009). Researchers have frequently elicited individuals' beliefs by deploying structured questionnaires (Horne *et al.* 2002), or interviews (Halm *et al.* 2006), to construct a direct relationship between the patient's belief about their disease and treatment with their adherence behaviour. These methods embody an essentially individualistic philosophy about the relationship between talk, social context and individual attitudes, built on the principles of social cognition models (SCMs) (Christensen 2004). The assumption behind SCMs is that the contribution of social context can account for any contingent deviation from the theoretical expectation that an individual attitude will determine medicine-taking. This means that any medicine-taking action which does not logically follow from an individual's attitude is therefore to be explained by modifying contextual variables, such as a newspaper article or a conversation with a friend. The key theoretical link between individual perception and adherence therefore remains intact. Talk within interviews is typically viewed as an accurate articulation of individual attitudes, isolated from the context of production, and similarly functioning to uphold the existence of the fixed individual attitude. By presupposing that individuals have fixed attitudes, the tools and data produced solipsistically substantiate the existence of such attitudes.

A range of literature has created difficulties for attempts to reduce decisions about medication to individual characteristics, examining how people negotiate medicine-taking in competing social spaces, such as in HIV (McCoy 2009), diabetes (Peyrot *et al.* 1987), arthritis (Arluke 1980), and asthma (Adams *et al.* 1997). People may choose not to take medication in order to assert control over their condition (Conrad 1985); because medications are too disruptive to lifestyles (Hunt *et al.* 1989); or as a means of asserting control in patient-provider relationships (Hayes-Bautista 1976).

This work highlights the importance of attending to the influence of relationships on medicine-taking and indicates the role of talk about illness management as a negotiation of these relationships. Examples of how these negotiations shape discussions about medicines have been examined in detail in the patient-provider relationship. Clinicians can be seen to contribute to patients being categorised as 'compliant' (Lutfey 2004) through ongoing interactions; patients have shown divergence in accounts about medicine-use given in and outside surgery (Britten 1996); may have unvoiced agendas in consultations (Barry *et al.* 2000); and may resist treatment decisions (Stivers 2006), and questions about medicine use (Salter 2010). While much of this research has analysed nuanced interactive dynamics of medication resistance, little is known about the process by which resistance to medicine-

taking is constructed in an extended rhetorical narrative. This understanding is needed in a context where researchers deploy the concepts of SCMs as a rationale for decontextualising such talk into sets of isolated attitudinal statements about medications and illness. This article seeks to begin this process by offering a conceptual framework for making sense of face-to-face talk about medications and illness management. Beginning with Goffman's (1959) concept of 'performance' this article theorises how resistance to medicine-taking is constructed when people talk to researchers. Here we examine how viewing such talk as performance may have important implications for conceptualising what is happening when people discuss their illness and medications. We consider why and how patients offer information about illness and medications and also how clinicians may (and perhaps should) interpret and better understand patients through their talk to assist them in making shared treatment decisions.

Goffman's concept of performance

Goffman addressed the problem of how individuals go about establishing and maintaining their individual appearance within everyday life. Goffman argued for face-to-face interactions to be treated as a domain of analysis in their own right, so providing a means to compare different kinds of face-to-face interactions as a form of social order, situated in time and space. He argued that people project social roles in staged performances and he used this theatrical metaphor to explain a wide range of interactions. Goffman's unique dramatisation of everyday face-to-face encounters directed attention to the intricate and contingent functions of impression management and problems people often have in conveying their intended version of themselves and their role within specific face-to-face interactional dynamics. Goffman defined performance as:

All the activity of a given participant on a given occasion which serves to influence in any way any of the other participants (1959: 26).

Goffman situated the performance of roles in a moral context, socially binding the performer and the co-participants by a sense of shared moral obligation to accept and treat the performance as 'real'. What people 'ought' (Goffman 1959: 24) to see in a performance is therefore key to the ongoing interaction. Goffman offered a framework for seeing performances as situated within a particular interactional order which has links with Bourdieu's later concept of 'habitus' to explain socially recognisable behaviour. However in Goffman's (1983: 11) later work, he argued for a relationship between social structure and individual expression which, rather than being unidirectional and deterministic, constituted a 'loose coupling'. From this stance interactional displays do not reproduce exact copies of idealised normative behaviour but produce loosely recognisable versions of culturally understood behaviour appropriate for specific social roles. In such cases the performance the 'audience' sees should be interpreted in relation to those culturally-understood social roles being activated within the interaction taking place. Individual utterances may therefore be similarly understood as manifesting a loose coupling between cultural discourse and the idiosyncrasies of particular interactions.

Drawing on Goffman's framework of interactional behaviour we can talk about medicine-taking as a performance which will be situated spatially, historically and morally, enabling examination of its functions within an interactional dynamic with particular pertinence for understanding peoples' actual medicine-taking.

Talk about health and illness as social and moral action

Seeing health and illness talk as social and moral action has been highlighted in a range of disease specific literature such as AIDS and drug use (Hassin 1994); chronic pain (Werner *et al.* 2004); and treatment decisions for cancer (Bishop and Yardley 2004). People may make choices about taking medicines to avoid stigma and maintain social relationships (Conrad 1985); and may spontaneously avoid disclosing illness within interactions to keep illness understated in a relationship (Charmaz 1991). Radley (1993) argued illness experience entails an individual, not just meeting specific physical requirements to participate in society, but also arranging details of their lives to avoid stigmatisation. Health-related actions and their presentation therefore need to be legitimised, if the individual is to avoid moral condemnation (Broom and Whittaker 2004) and to achieve a status that does not separate them from cultural conceptions of a 'normal' health status.

Goffman's notion of performance is reflected in studies demonstrating performance of illness in everyday life (Bury 1988, Faircloth 1999), and has been used to understand how people provide illness narratives in clinical settings, referred to by Mattingly (2004: 73–94) as 'healing dramas'. Riessman (2003a, 2003b) used the theories of Bourdieu and Goffman to examine two contrasting performances of masculinity, situating these accounts within an interactional context in which the social structures of gender, class and disability could be seen to structure, and be reinvented in, accounts of the body and social space.

The objective of the study in this article was to examine the discursive construction of asthma management, for people previously reporting they had not taken asthma prophylactic medication as prescribed. Individual culpability for causes and display of asthma, have been shown as linked and circulated in a variety of linguistic contexts through history (Murdoch 2010). How people construct talk about prophylactic medicine-taking as a moral concern is particularly pertinent because such talk is frequently used by researchers and clinicians to assess and improve how people 'adhere' to medications over a long period of time.

Methods

This study was carried out as the qualitative component of a large randomised controlled trial, ELEVATE (Price *et al.* 2011). ELEVATE compared clinical and cost effectiveness of different asthma medications and showed that for some people with asthma, a prophylactic medicine (leukotriene receptor antagonist) may be as effective as usual inhaled steroids. The qualitative component was to elicit the experiences and perspectives of participants, prescribed prophylactic medications as part of ELEVATE, and to examine the production of talk about their condition and medications.

Participants and setting

Twenty-six out of a total 306 participants were recruited for the qualitative study. ELEVATE participants had been prescribed a prophylactic asthma medication – either an inhaled steroid or a tablet prophylaxis – and were clinically assessed as having inadequate asthma control and quality of life, measured by a combination of breathing tests and questionnaires. The focus of this sub-study was on those participants with a record of 'previous non-adherence' as opposed to newly prescribed. Fifty-four ELEVATE participants were identified as potentially 'non-adherent' to the prophylactic medications based on analysis of

prescription records and their self-reported non-adherence to previously prescribed inhaled steroids. Twenty-four of these 54 participants agreed to be interviewed. We recruited two further participants who had not taken asthma prophylactic medications before entering the study.

All participants were white British, lived in Norfolk, Suffolk and Cambridgeshire and spoke English as a first language. The range of participant demographic characteristics closely matched the broader sample in the main trial in terms of: age (between 17 and 80 years, average 49 years (main trial = 46 years); gender (13 (50%) were women; main trial = 51%); and time since diagnosis (between 1 and 40 years, average 12 years; main trial = 13 years). Participants for the qualitative study also offered diversity in terms of occupation, reported as: farmer, farm manager, school pupil, retired general practitioner, social services employee, telephone engineer, health visitor, caterer, housewife, cleaner, car showroom manager, retired, trainee school teacher, and pub landlord.

Ethical considerations

ELEVATE was approved by the Eastern Multi Centre Research ethics committee and local ethics and research governance committees. Participants were invited to take part in the qualitative component concurrently with ELEVATE during 2004–2005. When contacting participants the researcher informed them the aim was to understand their views and decisions about asthma and medications, as well as views of health and illness in general. Signed informed consent was given by each participant.

The study design

Face-to-face interviews were undertaken with 26 participants to examine how they described their asthma and explained their medicine-taking. Mason's (2002: 68–74) guide to structuring qualitative interviews was used to construct an interview schedule and a series of 'topic cards' to guide the discussion. These included: 'biography of asthma', 'treatments', 'relationships and asthma' and 'risk and severity', helping the interviewer elicit a mixture of narratives and 'attitudes' from interviewees. Interviews lasted approximately one hour, ranging from 30 minutes to 105 minutes.

Analysis

In the initial analysis, audio tapes of all interviews were listened to, to identify the different ways participants justified their medicine-taking, and five different 'accounting styles' were then assigned to participants' explanations. However, when we examined the interview transcripts we discovered that participants' explanations varied to such an extent that our initial categorisations could be seen to gloss over this complexity. To resolve these problems we therefore analysed transcripts, using concepts drawn from discursive psychology (DP) (Potter and Wetherell 1987), and linguistic ethnography (Rampton *et al.* 2004), to identify how the 26 participants constructed versions of their asthma management and medicine-taking, potentially using a range of rhetorical devices to legitimate their actions. A key aspect of DP analysis is not only how speakers present themselves and versions of events but also how they can be seen to undermine competing, less desirable, alternative interpretations. Transcripts were therefore analysed to identify all instances of participants orientating to competing versions of illness management and how these versions varied throughout the interview. Evidencing these devices enables insight into how people may not simply report information about their beliefs about illness or medication but instead orientate to issues of blame and accountability activated within the interactions taking place.

Findings

Twenty three of the 26 participants interviewed employed a range of rhetorical devices to justify their medicine-taking, while three participants offered little justification for their behaviours. Participants' justifications could be seen to activate multiple moral discourses of illness management which were used in different ways to perform different interactional tasks. By identifying what is different and shared in these interactional sequences we were able to examine the relationship between discourses of morality and individual utterances. Demonstrating the moral structuring of participants' talk in this way highlights how talk about asthma management can be theorised as performance rather than an accurate articulation of an individual's attitudes about health, illness or medication. However, our aim was not to organise our data into a complete set of ways in which participants justified medicine-taking. While many participants provided similar explanations for not taking the medications, within our discursive analytical framework, assigning a single thematic category to each participant would have been both illogical and not possible, as participants could be seen to deploy diverse, and sometimes contradictory, explanations within the same interview. Rather, we aimed to identify how participants' talk was produced.

Our level of analysis in this study was therefore language, not individuals, and our means of generalising findings the manifestation and circulation of language in different social spaces. Birdwhistell (Varenne and McDermott 1998) provides a useful analogy to illustrate such an approach. Individuals, viewed as threads of a rope, are discrete, discontinuous objects, which also contribute to the twisted continuity of the rope, so that statements about individual threads (attitudes, experiences, expectations) can also be viewed as statements which demonstrate how threads and rope are linked (social structure, power, connectivity of language). In our study, if different participants with distinct ways of talking about medicine-taking could be seen to orientate to similar moral discourses of illness management this could provide the threads linking individual utterances to the rope of social structure; what Goffman referred to as 'loose coupling'.

The five extracts presented here have been selected as representing distinct ways in which participants justified their medicine-taking. Our focus on these few cases permits readers to develop a sense of the complexity of adherence presentation in the context of research interviews, enabling an alternative conceptual framework to be offered to that held within the SCM philosophy. Despite displaying different versions of asthma management, these participants can be seen to display distinct similarities in the moral discourses of medicine-taking they deployed and activated within those interactions. The cases presented here are therefore not intended to be viewed as the set of ways in which the participants in our study talked about medicine-taking, but instead offer a diverse set of cases whose use might help in finding a perspective from which to examine the structuring of talk about medicine-taking.

Minimising asthma and symptom control in an everyday context

A commonly-identified explanation for not taking asthma medications involves people minimising the impact of asthma on everyday life (Protudjer *et al.* 2009). Such explanations were also common with many of this study's participants and Extract 1 presents such an example. However, when viewing this talk as a rhetorical performance, we can see potential implications of this strategy in everyday settings. Martin, a 56-year-old farm manager, diagnosed with asthma in his 40s, deploys a strong stylistic assertion to minimise his condition in the opening line.

Extract 1: Martin

-
- | | |
|------------|---|
| 1. Martin: | So I have it has been. But I stress it is not a debilitating problem insofar as my |
| 2. | y'know my work is concerned or my you know my life is concerned. Um I |
| 3. | don't play football I do occasionally bouts of strenuous work um but it's |
| 4. | managed and I'm very fortunate in that you know I can choose (in the middle |
| 5. | of something?) what what I do at work rather than um you know being in a |
| 6. | managerial position I mean I don't wanna y'know er brag but you do have a |
| 7. | little bit of flexibility um and if there's you know y'know there's somebody |
| 8. | else available who will move the grain lorry up and you know I would do his |
| 9. | job while he did while he did that and if it's unavoidable well I I'll do you |
| 10. | know put a mask on and move the lorry myself which is it's not an <u>issue</u> as far |
| 11. | as I'm concerned you know the guy um you know I can certainly ask |
| 12. | somebody else can you just move down while I take over from you everybody |
| 13. | knows that the reason I'm doing it I'm not frightened of work but they just I |
| 14. | can manage it in that way um so I suppose you could say well actually you are |
| 15. | changing your lifestyle but not to that degree. |
-

Analysing the rhetorical work in this extract shows Martin deploying several devices to provide evidence for his claim that his asthma was not debilitating and he was responsibly managing his condition. He illustrates his control of his asthma by detailing a common scenario at work; a flexible situation that was agreed and understood by his colleagues and was afforded by his managerial position. Along with a list of other activities where his asthma was being 'managed', Martin provided a catalogue of evidence to support the case that 'it is not a debilitating problem' (line 1). However, as a consequence of scripting a typical work scenario to demonstrate this position, Martin could be seen to negotiate a number of positions or 'footings' (Goffman 1981), activated by using this scripting device and which threatened an alternative interpretation of his behaviour. This is evidenced in the interactional repair work Martin displays. First he orientates to a potential interpretation that suggests that the adaptive strategies he uses at work show someone struggling to cope with work activities, 'it's not an issue as far as I'm concerned' (lines 10–11), then that he was exploiting his employees, 'everybody knows that the reason I'm doing it' (lines 12–13), and that he was lazy or workshy, 'I'm not frightened of work but they just' (line 13). We can see Martin was simultaneously attempting to construct different versions of his self which included 'responsible person with asthma', 'person with health problem that is not an illness', 'conscientious worker', and 'good manager'. Finally, Martin's assertion that his lifestyle had not changed 'to that degree' offers further evidence of a key issue at stake in this discussion of asthma prevention. Whether his lifestyle had changed was not a question put to him. So it seems reasonable to infer that he was responding to the framing of this interactional sequence within competing moral discourses of appropriate and responsible illness management, while also responding to different moral discourses from his everyday life, defining what it means to be a good manager and a hard worker.

Martin's presentation of a 'responsible person with asthma' does not appear to fit neatly with Martin's 'responsible manager' discourse, appearing to potentially risk positioning himself as a manager who exploits members of his workforce for his own ends. This is a rhetorical *cul de sac* for Martin, as he becomes reliant on the listener to provide any discursive space for this tension to pass without confrontation. Martin could be seen to orientate to and actively manage this tension thereby validating the importance of these different moral frameworks within the interaction taking place. This insight into the moral dimensions of Martin's talk demonstrates that an approach which reduces Martin's talk to

an attitudinal statement, that he viewed his asthma as ‘not debilitating’, would miss important insights into how Martin’s asthma management is influenced by what asthma and illness mean as activities, set alongside other socially-situated activities in his working environment. Martin’s decisions appear to be influenced at least as much, by his preoccupation with being seen as a good manager; a good worker; and as someone who does not have an illness; alongside simply taking a view of his asthma as not being serious enough to warrant regular prophylactic treatment.

Deploying a sick-role discourse to blame healthcare

In contrast to explanations such as those seen in Martin’s extracts, several participants justified their medicine-taking by blaming clinicians or healthcare generally. The next extracts are taken from an interview with Irene (pseudonym), a 63-year-old retired woman with a complicated medical history, diagnosed with asthma 15 years previously, who explained why she had not attended her local surgery. Irene was prescribed asthma prophylactic tablets and argued that she stopped because she thought they made little difference. The following two extracts were chosen to typify a pattern whereby Irene situated her health problems within the context of an untrustworthy, uncaring medical profession, yet presented through rhetorical devices which served to rationalise her criticisms.

Extract 2: Irene

-
- | | |
|-----------|--|
| 1. Jamie: | What don’t you like about the tablets? |
| 2. Irene: | I think you keep filling your body up with all these tablets and you know, I |
| 3. | don’t know I just feel that, is that causing my problem, you see with my |
| 4. | problem my stomach problem I just, I (??) with my stomach, em, I feel |
| 5. | everything I eat I get pain in here I ain’t been to the doctors with it yet. Sort of |
| 6. | there like, I don’t know if I got an ulcer or what and I, I think tablets you |
| 7. | know, I don’t know it might be me, I ain’t really a big fan of tablets. |
| 8. | You see but I have been taking them for years coproximol and I’m saying |
| 9. | years, no they’re now telling you that they’re bad. They going to take them off |
| 10. | the shelf, don’t know if you saw the article? |
-

Here, Irene expresses a general concern about tablets which serve to contextualise the decisions about the asthma tablet. She does this by deploying a metaphor, ‘fill up’, to directly challenge the value of taking an aggregated category ‘tablets’. The idea of the body as a container which can be filled up stresses the argument that adherence means her body cannot keep any more tablets in, spilling over with medication. She blends the mitigating phrases ‘I don’t know I just feel that’ and ‘I don’t know it might be me’ with a personal narrative of her long experience with tablets and stomach problems to present her criticism of tablets. The sense of apprehension emphasised with a lack of cohesion in the sentence ‘I just, I (??) with my stomach, em, I feel everything I eat I get pain...’ suggests an uncertainty in presenting this position, yet her arguments are supported and therefore normalised with reference to a press article as evidence ‘they’re now telling you that they’re bad’. By using the collective term ‘they’ to refer to science and medicine, Irene might be justifying not taking the asthma tablet by associating it with and undermining the solidity of medical knowledge regarding another tablet. Her behaviour can thus be accepted as reasonable because if medical knowledge about medications changes then it cannot be trusted, raising questions for taking them. Her earlier statement that she ‘just sort of left it’, can now be understood as acceptable and frees her

from blame. As this interaction continued, Irene's position on medications was set within dissatisfaction with healthcare more generally and similar rhetorical devices were used to account for her nonattendance at her local surgery.

Extract 3: Irene

-
- | | |
|-----------|---|
| 1. Jamie: | So you've been, how many times have you been back in to the |
| 2. | surgery in the last year for your asthma? |
| 3. Irene: | I'm a, you see this is the thing I should see an asthma nurse but thing is |
| 4. | the only time my asthma's <u>ever</u> mentioned down that surgery is if I had, like |
| 5. | when I had bronchitis, ' <i>ooh, you got asthma eh, take more inhaler</i> ' you know, |
| 6. | ' <i>do more inhaler</i> ' but apart from that there's no em, request to see the asthma |
| 7. | nurse or anything like that and as far as I'll be honest with you I do find in |
| 8. | today's world and I'm not alone we got one of the best surgeries I think down |
| 9. | there, I really do but, they still like say you went down with a complaint |
| 10. | and you got two or three other things on your mind, they don't want to hear, |
| 11. | you got to make another appointment all the time. For the specialised thing, |
| 12. | whatever you want and invariably I think they don't really you know, want to |
| 13. | know really to be honest. |
-

Here the interviewer's (Jamie's) question appeared to represent a face-threatening act which Irene could be seen to orientate towards. The issue appeared to be potential criticism that she was not taking responsibility for her asthma because she had not attended the surgery as she should. This is evidenced with the use of the modal verb 'should' (line 3). However, this was merely a preface to direct criticism of the quality of care that she received, namely that the surgery did not take enough interest in her asthma, 'the only time my asthma's ever mentioned down that surgery' and that 'they don't really you know, want to know really to be honest' (lines 12–13). Here Irene constructed a very clear picture of herself – as a patient with concerns she wanted to discuss, and 'that surgery' – as dismissive of these concerns, lacking interest in her individual circumstances. These versions were not merely described, but were authenticated using a range of rhetorical devices. First, she provided a specific example of a typical response to her expressions of concern, adopting the voice of doctors and nurses in an ironic tone '*ooh, you got asthma eh, take more inhaler*' you know, 'do more inhaler' (line 6). This was followed by a normalisation device positioning her uncaring surgery as pervasive of the NHS more generally and representative of an uncaring world. Moreover she used the evidence of allies 'I do find in today's world, and I'm not alone' (lines 7–8). This served to rationalise her stance by erasing any notion that this view was radical or irrational. She added weight to her argument by twice revealing she was confiding in the interviewer – 'I'll be honest with you ... to be honest'. This represents a truth claim which has been thought through and which she has amassed evidence to support. Irene also set these criticisms within a mitigating phrase which served to position her criticisms as reasonable, 'we got one of the best surgeries I think down there, I really do' (lines 8–9).

These extracts were indicative of how Irene could be seen to manage issues of blame and accountability for her decisions and views about medications and healthcare generally. Thus a moral discourse of illness management and health behaviour appeared to be activated within the interaction in allocating blame for her symptoms and decisions about medicine-taking. We are left in no doubt that Irene made a particular connection between the provision of health and a particular moral expectation. Further,

she set up a moral connection between those who provide healthcare, how that care should be delivered, and the motivations and characteristics of those doing the caring.

It may be interpreted, drawing on Parsonian theory (1951), that Irene was deploying a ‘sick-role’ discourse where the sick person is exempted from normal social responsibilities, not blamed for being sick, expected to seek competent help in the form of a doctor and to comply with a prescribed regimen. Irene’s explanation was not a precise version of Parsons’ concept but drew on this model of the doctor-patient relationship to construct a version which tackled the particular issues at stake within the interaction. These appeared to orientate around whether Irene was justified in not attending her surgery more frequently and not taking prophylactic asthma medication. Irene’s version of the sick-role included criteria for a competent physician – somebody who attends to the patient’s individual circumstances, ‘the specialised thing’ (line 11) and proactive in managing the patient’s asthma (lines 6–7). In deploying a visual metaphor of the individual passively filling up and spilling over with tablets (Extract 2, line 2), Irene also activated a culturally-available conceptualisation of the sick individual with a range of unspecified symptoms and vague causes which the tablets were producing rather than solving. Irene’s rhetoric rested on arguing that doctors, nurses and the institution of medicine had not met the conditions of competent physician and reliable treatment regimen. In this sense, the institution of medicine can be said to have violated the sick-role contract that Irene had set up. Thus Irene was able to justify not only her non-attendance but also her decision to not take the asthma tablet and position this as virtuous and preventive rather than causative of illness.

Deploying a sick-role discourse for self blame

Irene explained her health problems by directing blame towards the dangers of medications and uncertainty in medical knowledge as well as directly questioning the motivations of clinicians themselves. By contrast, Stephen, aged 31, self-employed with asthma since childhood, was the only participant of the 26 interviewed who repeatedly blamed himself for his asthma problems.

Stephen was asked how he saw the future in terms of his asthma and to reflect on his experiences with doctors and nurses. Here we demonstrate how Stephen directly positioned himself as a bad patient within a moral framework of a sick-role discourse.

Extract 4: Stephen

-
- | | |
|-------------|---|
| 1. Stephen: | I don’t have any complaints over my treatment of doctors or |
| 2. | asthma nurses over the last few years. I think basically they’ve been |
| 3. | banging their head against a brick wall with me over the years. |
-

Stephen used a common metaphor, banging one’s head against a brick wall, to describe doctors’ and nurses’ actions. This positioned clinicians as persistent, well-intentioned and importantly active in doing the ‘banging’. In contrast, Stephen constructed himself as the wall – a fixed, immovable object. Having ‘no complaints’, set this metaphor within a moral discourse of roles and responsibilities which clinicians fulfilled. Like Irene, Stephen deployed a discourse which set up a sick-role contract between him and clinicians. How Stephen positioned himself within this moral contract, however, is interesting and in Extract 5, in contrast to Irene, it was Stephen who violated the sick-role contract.

Extract 5: Stephen

-
- | | |
|-------------|---|
| 1. Stephen: | I'm just sort of glad to be part of this study and in a way feel guilty on <u>my</u> part |
| 2. | over the years of not being very helpful or cooperative or whatever hhh and I |
| 3. | just think well if I've got a chance to be part of one of 700 people in the |
| 4. | country that are doing this to try and battle against asthma then I'll do |
| 5. | anything that I can to, to try and help really. And if you know, it's opened up a |
| 6. | <u>big</u> can of worms and it's brought everything to <u>my</u> mind and it's quite |
| 7. | <u>upsetting</u> you know at times, <u>talking</u> about how you feel and how it |
| 8. | makes you feel <u>psychologically</u> as well. |
-

Stephen not only admitted guilt but displayed remorse for his behaviour and offered a commitment to become a better person given a chance. These notions of guilt, cooperation and having chances, reproduced a rehabilitation discourse set within dominant medical discourses of remission (Frank 1995), and also cultural probationary discourse of criminals (Proeve *et al.* 1999). Stephen's justification of non-adherence involved constructing himself at a crossroads in his life. Within his talk, Stephen could be seen morally to be taking the right road at this crossroads. While his previous behaviour was positioned as uncooperative and a violation of a sick-role contract, the commitment to change functioned interactively to present himself as on a different road, to be a purposeful and rehabilitated patient.

Similar to Irene, Stephen drew on traditional ideas of the doctor-patient relationship and constructed versions of himself, doctors and nurses in explaining his non-adherence to medications. However, unlike Irene, Stephen undertook little rhetorical work to discredit potential alternative interpretations of his actions. This may be because he blamed himself for his non-adherence and positioned his explanation within broader discourses of remission, rehabilitation and remorse. Blaming oneself and not doctors could be seen as a submissive and compliant position within traditional doctor-patient conceptualisations. This discursive action does not challenge a powerful institutionalised set of roles and relationships but instead reproduces a widely understood discursive object, the 'bad patient' within this common discourse. In addition, in British society an explanation of self-blame and remorse is typically viewed as 'honest' when activated within rehabilitation discourse. There was therefore little need for Stephen to provide supporting evidence for the version being constructed. Alternatively, Stephen may have attempted to save 'face' by criticising himself, enabling him to 'own' any judgement of his behaviour, rather than potentially having it directed at him through the ongoing discussion. Stephen's 'owning' of the criticism may therefore have limited the need for Stephen to justify his asthma management any further.

This contrast between how Stephen and Irene deployed these discourses provides an important point of triangulation between the justifications, strengthening the interpretation that moral discourses were structuring participants' talk. The construction of the 'bad patient' within Stephen's sick-role discourse (requiring little rhetorical work and supporting evidence), and the 'bad doctor' within Irene's account (requiring a lot of rhetorical work and supporting evidence), highlighted the moral value attributed to being a compliant patient within a medical discourse regarding clinical advice and prescription instructions. The contrast between the interviews of Irene and Stephen thus provides further evidence that a moral discourse of illness management was activated within participants' talk which included traditional notions of compliance to doctors' instructions.

Study limitations

Being asked to provide a long narrative about one's asthma was an unusual occurrence for many participants in this study. The interviews, while well defined from an academic perspective, may have had vague boundaries and definitions for participants. Thus it is conceivable that those who justified their medicine-taking may have responded to particular interactional conditions activated within individual interviews. These encouraged an individualising discourse within research which had recruited participants based on their asthma being categorised as inadequately controlled and those patients being potentially blameworthy for that inadequate control. For many participants, being interviewed about their decisions was likely to activate issues of blame and accountability. This raised uncertainties for the authors regarding how far claims about the role of morality in talk could extend beyond these circumstances to other types of interaction about medicine-taking. Such uncertainties posed a requirement to identify data that could be considered 'new' and this evidence has been discussed elsewhere (Murdoch *et al.* 2010).

Discussion

This study identifies difficulties in interpreting talk about medicine-taking as accurately representing an individual's management, attitudes or beliefs about illness. A process of analysis which isolates talk into sets of de-contextualised statements risks categorising that talk in ways which mask its function within the interaction of its production. Alternatively, by viewing such talk as continuously constructed performances, loosely structured by moral discourses, we can then see reported individual statements working interdependently in constructing presentations of self and behaviour. These 'presentations of self', crucially, may orientate to different concerns and may be more about how people wish to be understood according to different moral issues activated within those interactions. This point has been made by Williams (1993), who argued that terms such as 'adaptation', 'adjustment', 'coping', when applied to how people live with chronic illness, are based on a world of contingency. These are categorisations of actions according to potential adverse outcomes, for example, an asthma attack. Williams argued that these categorisations fail to account for peoples' talk about their illness not orientating to these contingencies. People with chronic illness, he argues, are not trying to display an optimum management strategy, rather how they wish to be understood according to differing moral dimensions that inform their lives. The discursive psychological analysis of the face-to-face interviews conducted in this study highlights Williams' point, with speakers seen to deploy complex rhetorical devices to construct particular versions of self and behaviour and to undermine less desirable alternatives.

The complexity identified in participants' talk reveals the intricate dimensions of impression management that Goffman referred to and also the dynamic relationship between individual utterance and social structure. Participants activated culturally understood discourses, by presenting their versions of their asthma management as plausible to meet the interactional tasks of ensuring their performances functioned effectively. The same moral discourses of illness management were seen in very different explanations, suggesting their circulation to different social spaces for different interactional functions. However, analysis showed that participants did not deploy replicas of these discourses but actively constructed their own versions to meet specific interactional demands on them to justify their medicine-taking. This loose coupling between social discourse and talk indicated how notions of morality, illness management and medicine-taking may circulate a wide range of social spaces

which structure talk in interactions about medicine-taking and which may be used creatively to meet a range of interactional concerns.

Although Goffman examined what was unique and shared between face-to-face encounters, in this study, identifying evidence of the circulation of discourse extended the boundaries of Goffman's conceptualisation of performance beyond the immediate interactional context. Participants could be seen to orientate simultaneously both to medical and also to other cultural discourses of illness management, indicating performances not bounded by the face-to-face interaction but orientating to discourses pertinent to their everyday lives. Talk about medicine-taking is therefore organised not just by the ongoing interaction (as often argued in conversation analysis of clinical interactions) but is structured by discourse that circulates across social spaces. In clinical interactions these discourses may be visible or invisible within the talk taking place, while in this analysis of narrative become more explicit in the speaker's rhetorical construction of their illness management.

Additionally, participants' versions of illness management were subject to the resources available to them and those which they felt relevant within the interaction taking place. This highlights the potential for performances to be judged differently, depending upon with whom, about what, and where the interaction is taking place. From a medical perspective, that commonly deploys a discourse of adherence in framing patients with asthma, it is possible to argue that Martin's and Irene's explanation of their asthma management should be interpreted very differently. Martin may be seen as much more 'fully engaged' with his asthma, using various self-monitoring strategies which therefore justified his not taking prophylactic medication. In contrast, Irene may be judged to have 'incorrect' or 'irrational' beliefs. However, as Martin and Irene can each be seen orienting to very different moral concerns, we have no way of knowing whether Martin is actually more engaged with his asthma. Thus, rather than individuals' attitudes towards medication and illness being elicited and categorised within interactions about illness management, it is an individual's linguistic performance that may be categorised by the researcher, doctor, nurse, according to the criteria set up within that interaction.

Performing different social roles, in key interactional contexts, can enable access to particular types of outcomes regarding the clinical management of symptoms or enabling participation in activities within everyday settings such as work. Understanding how talk about medicine-taking operates as a performance therefore provides insight into interactional processes by which people living with chronic illness might come to be categorised, the relevance of these categorisations and their consequences for treatment decisions. Within clinical discourses of illness management, patients may become designated as 'good patients', 'bad patients', 'responsible', 'irresponsible', as having 'accurate understanding' or 'incorrect beliefs', as 'compliant' or 'non-compliant'. Such discourse-related categorisations may be based on clinical judgements of the effectiveness of their talk within an interaction according to particular criteria of disease control and associated recommendations for appropriate management. Peoples' performance of that talk may affect how they are assigned within that framework and consequently to the treatment decisions reached by clinicians ultimately resulting in patients potentially being prescribed unwanted medications.

If conceptualisations of patients' talk require its re-location within a performative context, so too do notions of 'evidence' and of patient and clinical 'expertise' in reaching treatment decisions. Such evidence, provided by the patient, instead of focusing only on their talk as a means of assessing the accuracy of patient's beliefs, could also be read as indicating the dilemmas and issues at stake when negotiating competing moral concerns. The need to facilitate discussion of patient's concerns about medications has already been highlighted in research that has shown the difficulties patients experience in articulating such concerns

(Barry *et al.* 2000). Taking this stance, the clinician's role as expert would therefore be less about advising patients on what they 'should' be doing but rather offering a treatment that meets the patient's concerns and needs. This is not to say that patients become 'empowered decision-makers' or that clinical consultations should be an arena where decisions are necessarily shared. Despite ideological shifts towards conceptualising consultations as being 'patient-centred', some patients actively defer to medical expertise in reaching treatment decisions (Pilnick and Dingwall 2011). Rather, discussions about illness management could be repositioned so that decisions are more fully informed by issues pertinent to patients in everyday life. Thus patient expertise does not lie in providing the treatment solution, but in their experience of issues affecting their participation in everyday activities.

Address for correspondence: Jamie Murdoch, School of Nursing Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich Research Park, Norwich, NR4 7TJ
e-mail: jamie.murdoch@uea.ac.uk

Acknowledgements

We thank all participants, whose contributions have been essential to this study; David Price, Ian Harvey, Stan Musgrave, Annie Blyth and Carole Bull of the ELEVATE research team; the Suffolk and Norfolk Research and Development Consortium for supporting this study; the Health Technology Assessment for allowing it to take place; and Simon Horton and Paul Chilton who participated on the supervisory panel for this study.

References

- Adams, S., Pill, R. and Jones, A. (1997) Medication, chronic illness and identity: The perspective of people with asthma, *Social Science and Medicine*, 45, 2, 189–201.
- Arluke, A (1980) Judging drugs: Patients' conceptions of therapeutic efficacy in the treatment of arthritis, *Human Organisation*, 39, 1, 84–6.
- Barry, C.A., Bradley, C.P., Britten, N., Stevenson, F.A. and Barber, N. (2000) Patients' unvoiced agendas in general practice consultations: qualitative study, *British Medical Journal*, 320, 7244, 1246–50.
- Bishop, F.L. and Yardley, L. (2004) Constructing agency in treatment decisions: Negotiating responsibility in cancer, *Health (London)*, 8, 4, 465–82.
- Britten, N. (1996) Lay views of drugs and medicines: Orthodox and unorthodox accounts. In Williams, S.J. and Calnan, M. (eds.) *Modern Medicine. Lay Perspectives and Experiences*. London: UCL Press.
- Broom, D. and Whittaker, A. (2004) Controlling diabetes, controlling diabetics: Moral Language in the Management of Diabetes Type 2, *Social Science and Medicine*, 58, 11, 2371–82.
- Bury, M. (1988) Meanings at risk: The experience of arthritis. In Anderson, R. and Bury, M. (eds.) *Living with Chronic Illness: The Experience of Patients and Their Families*. London: Unwin Hyman.
- Charmaz, K. (1991) *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.
- Christensen, A.J. (2004) *Patient Adherence to Medical Treatment Regimens: Bridging the Gap between Behavioral Science and Medicine*. New Haven, CT: Yale University Press.
- Conrad, P. (1985) The meaning of medications: another look at compliance, *Social Science and Medicine*, 20, 1, 29–37.

- Faircloth, C.A. (1999) Revisiting thematisation in the narrative study of epilepsy, *Sociology of Health & Illness*, 21, 2, 209–27.
- Frank, A. W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago, IL: The University of Chicago Press.
- Goffman, E. (1959) *The Presentation of Self in Everyday Life*. Garden City, NY: Doubleday.
- Goffman, E. (1981) *Footing*. In *Forms of Talk*. Oxford: Blackwell.
- Goffman, E. (1983) The interaction order: American Sociological Association, 1982 presidential Address, *American Sociological Review*, 48, 1, 1–17.
- Halm, E.A., Mora, P. and Leventhal, H. (2006) No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma, *Chest*, 129, 3, 573–80.
- Hassin, J. (1994) Living a responsible life: The impact of AIDS on the social identity of intravenous drug users, *Social Science and Medicine*, 39, 3, 391–400.
- Hayes-Bautista, D.E. (1976) Modifying the treatment: Patient compliance, patient control and medical care, *Social Science and Medicine*, 10, 2, 233–8.
- Horne, R. and Weinman, J. (2002) Self regulation and self management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication, *Psychology and Health*, 17, 1, 17–32.
- Hunt, L.M., Jordan, B., Irwin, S. and Browner, C.H. (1989) Compliance and the patient's perspective: Controlling symptoms in everyday life, *Culture Medicine and Psychiatry*, 13, 3, 315–34.
- Lutfey, K.E. (2004) Assessment, objectivity and interaction: The case of patient compliance with medical treatment regimens, *Social Psychology Quarterly*, 67, 4, 343–68.
- Mason, J. (2002) *Qualitative Researching* 2nd edn. London: Sage.
- Mattingly, C. (2004) Performance narratives in the clinical world. In Hurwitz, B., Greenhalgh, T. and Skultans, V. (Eds.) *Narrative Research in Health and Illness*. Malden, MA: Blackwell.
- McCoy, L. (2009) Time, self and the medication day: A closer look at the everyday work of 'adherence', *Sociology of Health & Illness*, 31, 1, 128–46.
- Murdoch, J. (2010) The Discursive Construction of Prophylactic Medicine Taking for People with Asthma: Interactional Issues and Moral Discourses. School of Allied Health Professions: University of East Anglia.
- Murdoch, J., Poland, F. and Salter, C. (2010) Interactional contexts in a data-sharing focus group, *Qualitative Health Research*, 20, 5, 582–94.
- Nunes, V., Neilson, J., O'Flynn, N., Calvert, N., Kuntze, S., Smithson, H., *et al.* (2009) *Clinical guidelines and evidence review for medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence*. London: National Collaborating Centre for Primary Care and Royal College of General Practitioners.
- Parsons, T. (1951) Illness and the role of the physician: A sociological perspective, *American Journal of Orthopsychiatry*, 21, 3, 452–60.
- Peyrot, M., McMurry, J.F. and Hedges, R. (1987) Living with diabetes: The role of personal and professional knowledge in symptom and regimen management, *Research in the Sociology of Health Care*, 6, 1, 107–46.
- Pilnick, A. and Dingwall, R. (2011) On the remarkable persistence of asymmetry in doctor/patient interaction: A critical review, *Social Science and Medicine*, 72, 8, 1374–82.
- Potter, J. and Wetherell, M. (1987) *Discourse and Social Psychology: Beyond Attitudes and Behaviour*. London: Sage.
- Pound, P., Britten, N., Morgan, M., Yardley, L., Pope, C., Daker-White, G., *et al.* (2005) Resisting medicines: A synthesis of qualitative studies of medicine-taking [review of adherence literature], *Social Science and Medicine*, 61, 1, 133–55.
- Price, D., Musgrave, S.D., Shepstone, L., Hillyer, E.V., Sims, E.J., Gilbert, R.F., *et al.* (2011) Leukotriene antagonists as first-line or add-on asthma-controller therapy, *The New England Journal of Medicine*, 364, 18, 1695–707.
- Proeve, M.J., Smith, D.I. and Niblo, D.M. (1999) Mitigation without definition: Remorse in the criminal justice system, *Australian and New Zealand Journal of Criminology*, 32, 1, 16–26.

- Protudjer, J.L.P., Kozyrskyj, A.L., Becker, A.B. and Marchessault, G. (2009) Normalization strategies of children with asthma, *Qualitative Health Research*, 19, 1, 94–104.
- Radley, A. (1993) The role of metaphor in adjustment to chronic illness. In Radley, A. (ed.) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. London: Routledge.
- Rampton, B.K., Tusting, K., Maybin, J., Barwell, R., Creese, A. and Lytra, V. (2004) UK linguistic ethnography: A discussion paper. UK Linguistic Ethnography Forum. Available at <http://www.ling-ethnog.org.uk> date last accessed 6 May 2012.
- Riessman, C.K. (2003a) Analysis of personal narratives. In Holstein, J.A. and Gubrium, J.F. (eds.) *Inside Interviewing: New Lenses, New Concerns*. Thousand Oaks, CA: Sage.
- Riessman, C.K. (2003b) Performing identities in illness narrative: Masculinity and multiple sclerosis, *Qualitative Research*, 3, 1, 5–34.
- Salter, C. (2010) Compliance and concordance during domiciliary medication review involving pharmacists and older people, *Sociology of Health & Illness*, 32, 1, 21–36.
- Stivers, T. (2006) Treatment decisions: Negotiations between doctors and patients in acute care encounters. In Heritage, J. and Maynard, D.W. (eds.) *Communication in Medical Care: Interaction between Primary Care Physicians and Patients*. Cambridge: Cambridge University Press.
- Varenne, H. and McDermott, R. (1998) Successful failure. Available at http://varenne.tc.columbia.edu/hv/sf/p_11_13.html date last consulted 13 March 2012.
- Vermeire, E., Hearnshaw, H., Van Royen, P. and Denekens, J. (2001) Patient adherence to treatment: Three decades of research. A comprehensive review, *Journal of clinical pharmacy and therapeutics*, 26, 5, 331–42.
- Werner, A., Isaksen, L.W. and Malterud, K. (2004) ‘I am not the kind of woman who complains of everything’: Illness stories on self and shame in women with chronic pain, *Social Science and Medicine*, 59, 5, 1035–45.
- Williams, G. (1993) Chronic illness and the pursuit of virtue in everyday life. In Radley, A. (ed.) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. London: Routledge.