

## Nurses and 'difficult' patients: negotiating non-compliance

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### Nurses and 'difficult' patients: negotiating non-compliance

**Background.** There is a large body of nursing literature on patient non-compliance. While some articles address non-compliance as a patient problem to be resolved by nursing interventions, there is also a growing number that critique this approach. This reflects the discomfort many nurses feel about the practice of labelling patients as non-compliant.

**Aim.** The aim of this discussion paper is to build on the critical nursing literature to offer an alternative to the interventions commonly directed at patients who do not follow health care advice. This alternative approach locates patients within their social context and focuses on those who adapt health care advice to fit with their beliefs, life situation and circumstances. The aim is to encourage nurses to learn about how health care treatments affect patients' *lives*, and not merely their *health*.

**Method.** Specific nursing articles were reviewed to demonstrate the ways in which the concept of compliance is used within the nursing literature. These articles were then used to support an argument that promotes a patient-centred approach to health care.

**Conclusion.** A patient-centred approach involves transferring power and authority away from health care professionals and towards patients. We encourage nurses to take a leadership role by changing the way in which health care is delivered towards a focus on patients' *lives*. Learning about patients' lives may assist nurses to offer health information to patients that is more relevant and, therefore, useful.

**Keywords:** compliance, social model of health, patient-centred care, nursing, clinical decision-making

### Introduction

Patients do not necessarily follow the advice given to them by health care practitioners. This mismatch between what is

prescribed in terms of medication or lifestyle changes and what patients actually do is commonly referred to as non-compliance. Non-compliance is encountered to various degrees in all fields of health care, involving an estimated

38% of patients on short-term treatment; 43% of patients on long-term treatment; and 75% of patients advised to make lifestyle changes in the United States of America (USA) (DiMatteo 1994). In Australia, McElduff *et al.* (2001) calculated that incidence of and mortality related to heart attacks could be reduced by 40% if health promotion targets were met. Such statistics serve to focus attention on the problems associated with non-compliance. Certainly there is a problem; and working out what to do about it has produced a vast literature in the medical, nursing and allied health disciplines.

The aim of this discussion paper is to offer an alternative approach to the interventions commonly directed at patients who do not follow health care advice. Our review of the nursing literature indicates that the promotion of patient compliance is seen as an integral part of high quality nursing care (Marston 1970, O'Brien 1979, Wainwright & Gould 1997). This review also indicates that nursing interventions aimed to improve patient non-compliance derive from specific assumptions about what is causing the problem. This assumption can be summarized as follows:

If health care advice is based on scientific evidence that the treatment will benefit the patient, it is rational to assume that patients will follow this advice.

As a consequence of this assumption, the literature largely interprets non-compliance as a problem located in irrational patient beliefs that contradict scientific evidence, or in patients' lack of knowledge or understanding. The literature describes behaviour modification programmes, better education programmes, and improved therapeutic communication as strategies to reduce non-compliance. As with those developed in other health care disciplines, compliance-enhancing strategies developed by the nursing profession have had little effect (Haynes *et al.* 1996, 2002).

### **An alternative view of non-compliance**

There is a small but growing body of nursing literature arguing that the dominant view of non-compliance fails to take sufficient account of the social context of patients' lives. Within this alternative social view, it cannot be assumed that non-compliance is simply a matter of patients choosing not to follow advice. Instead, it is recognized that choice may be severely constrained by the social circumstances in which patients live their lives. For example, is a female patient who lives in a violent neighbourhood non-compliant if she fails to follow advice to walk around the block each day?

By recognizing the mediating effect of social context, nurses are better able to understand and validate patients'

actions. Instead of continuing to label them as non-compliant, and basing interventions on assumptions of patient irrationality or recalcitrance, this alternative view can provide the basis for understanding the aspects of patients' lives that are contributing to non-compliance. We argue that this alternative approach is neglected in, although not absent from, the nursing literature.

### **Overview of the nursing literature**

According to a literature search using the CINAHL database with 'patient compliance' as a key word, 969 journal articles have been published on this topic between 1980 and 2002. Murphy and Canales (2001) divide the nursing literature on non-compliance into three distinct categories: acceptance, rationalization and evaluative. The first category contains a large body of literature that accepts non-compliance as a patient problem to be resolved by nursing interventions. As such, this often focuses on specific illnesses (e.g. asthma, rheumatoid arthritis, renal failure, heart disease, mental illness) or groups of patients (e.g. children, older people). The second category – rationalization – offers a critique of the term non-compliance but continues to use it because of its importance as a health care issue. The third, much smaller body of literature – evaluative – expresses concern about the term compliance and evaluates it from various perspectives.

For the purposes of building a critical argument, key articles were selected from each of Murphy and Canales' (2001) categories. A critical review of this literature was then used to support an alternative patient-centred approach which takes into account patients' social context.

### **Non-compliance as problem-to-be-resolved**

For the most part, the nursing literature reinforces the medical view that non-compliance is a 'substantial problem' with 'devastating consequences' for society (Marston 1970, Baer 1986) specifically costly relapses and re-hospitalizations (Lund & Frank 1991). Compliance is not only assumed to be in patients' best interests, but is also equated with a 'social good'. Marston (1970) and Mulaik (1992) regard the benefits of following the prescribed treatments as 'obvious', believing that the people who suffer most from failure to follow health care advice are patients themselves. Although these arguments are based on a range of implicit assumptions, they are frequently used in the literature to justify nursing's commitment to ensuring patient compliance.

To identify non-compliant patients, 'objective' measurements are more common than patient self-reporting. The most

common methods are pill counts and laboratory results (e.g. urine and blood tests). Labelling patients as non-compliant was formalized when the North American Nursing Diagnosis Association (NANDA) recognized non-compliance as a legitimate nursing diagnosis. According to Kyngas *et al.* (2000), this nursing diagnosis was devised in response to discomfort with the paternalistic definition of non-compliance prescribed by Haynes (1979). NANDA's definition of non-compliance is non-adherence to a therapeutic recommendation following an informed decision and expressed intention to attain therapeutic goals (NANDA 1995). It locates non-compliance within the category of 'choosing', defining it as a person's informed decision not to adhere to a therapeutic recommendation (Wright 1998). The criteria for the diagnosis are:

- direct observation of non-compliance,
- statements by client or significant others describing non-compliance, and
- objective tests revealing non-compliance (NANDA 1995).

The NANDA's nursing diagnosis created a 'compliant/non-compliant' dichotomy, with the 'non-compliant' diagnosis often being recorded in patients' records. According to NANDA (1995), high risk populations include those who have begun new and/or complex treatment regimens. The aetiological factors include patients' values; cultural and spiritual factors; knowledge or skill deficit; perceived therapeutic ineffectiveness; denial of illness; and family pattern disruption. Apart from family pattern disruption, there is no acknowledgement in NANDA's aetiological factors of social circumstances.

Another approach to identifying non-compliance is that which focuses on identifying barriers to change (McSweeney 1993). This approach relies heavily on psychometric instruments to quantify 'compliance behaviour' or tendencies to non-compliance, including the Miller Attitude Scale, Perceived Beliefs of Others Scale, Health Intentions Scale, Health Behaviour Scale and Compliance Behaviour Scale (Miller *et al.* 1990).

Using a combination of these approaches, nursing researchers have identified a range of over 200 variables that are argued to account for patients' non-compliance (Cameron 1996). These factors include gender, race, religion, marital status, socio-economic status and education. However, the results from this empirical research are contradictory. While some nursing research indicates a correlation between compliance behaviour and certain variables (O'Brien 1979, Miller *et al.* 1990), other research reports little or no such correlation (Ryan & Falco 1985, Cameron 1996). This inability to make predictions about compliance behaviour led Cameron (1996, p. 248) to use a more universal approach in which 'every patient is a potential defaulter'.

Nursing research is facing the same problems as medical research by using medical and psychological paradigms to measure, categorize and predict patients' behaviour with the aim of changing it. The problem for both medical and nursing research is that few, if any, effective interventions have emerged from this work (Haynes *et al.* 2002). However, in the case of nurses there is the possibility of playing an instrumental role in changing health-related behaviour through forming a 'therapeutic relationship' with patients. These 'therapeutic relationships' aim to convince patients to follow the prescribed treatment (Lund & Frank 1991). At the extreme end of this approach we even find references in the literature to 'fear communication' as an effective way to improve compliance (Cameron 1996). Cameron (1996) also suggests that it is reasonable for nurses to take a 'compliance-orientated history' as an extension of the usual nursing and medical history.

### Nursing critique of non-compliance research

Although a great deal of nursing literature refers to non-compliance as a problem to be identified, measured and resolved, there is a growing literature across all health care disciplines that critiques non-compliance (Stanitis & Ryan 1982, Edel 1985, Ryan & Falco 1985, Trostle 1988, Watson 1990, Wright & Levac 1992, Wuest 1993, Lundin 1995, Sherman 1996, Rapley 1997, Wainwright & Gould 1997, Playle & Keeley 1998, Wright 1998, Murphy & Canales 2001). A consistent theme in this critique is lack of acknowledgment of the range of factors that may influence patients' decision-making. This critical literature notes a lack of analysis of the complete range of responses associated with adjustment to illness (Rapley 1997), and Murphy and Canales (2001) have highlighted issues of control and power that are associated with the term compliance.

In this critical literature, it is suggested that the nursing diagnosis of non-compliance is strongly subjective. Although NANDA uses a collection of objective and subjective data from which to draw a diagnosis, it has been suggested that this labelling is predominantly based on nurses' opinions of patients' behaviour. This means that compliance is an ambiguous theoretical construct (Betts & Crotty 1988), and questions have been raised about what exactly nurses are responding to when they diagnose a patient as non-compliant (Ryan & Falco 1985).

There is little doubt that such patients are stigmatized when they are described as being recalcitrant, bad, willful, deviant, recidivist, manipulative, failures, cheats and rule-breakers, among other epithets (Playle & Keeley 1998). Thus, patients who fail to conform to the therapeutic regime are

labelled, and once the term 'non-complier' (with its various negative connotations) is ascribed, it sticks (Wright 1998), denying legitimacy to actions that differ from professional prescription.

Playle and Keeley (1998) argue that non-compliance can be seen as behaviour that challenges professionally-held beliefs, expectations and norms. While on the surface the research on compliance appears to be concerned with improving health care, it also involves issues of professional control and entrenched beliefs about nurse-patient relationships. Non-compliance can, therefore, be seen as a label used by professionals to maintain power and control over patients: it is ascribed by nurses *onto* patients.

A move away from simply labelling patients as non-compliant is evident in the critical nursing literature on compliance. Betts and Crotty (1988), for example, suggest that nurses could intervene more effectively if researchers explored the process by which individuals become compliant, rather than simply labelling them as compliant or non-compliant. Nevertheless, there continues to be a focus on interventions to promote compliance. Another move involves the term 'compliance' being replaced by a new language of 'adherence' (Lutfey & Wishner 1999), 'therapeutic alliance' (Madden 1990), 'mutuality' (Henson 1997), or 'patient participation' (Cahill 1998). Despite this new language, understanding what is best for patients' *lives* is rarely addressed in the literature. For example, when a person does not follow professional advice, their actions are rarely validated. Although 'patient participation' and 'self-management' movements are developing in which patients are assuming more responsibility for the prevention, detection and treatment of health problems (Cahill 1998), they are still expected to behave in accordance with recommendations made by health care experts. Although the language has changed, the fundamental assumptions underpinning these new movements remain the same, and in some respects they may be merely another way to facilitate patient compliance with prescribed treatments.

Despite a range of critical analyses in the nursing literature, little has changed in terms of actual nursing practice – except perhaps to make nurses more aware of the problematic nature of their work. Diwan *et al.* (1997) suggest that some nurses cope with their unease by using vagueness when delivering health and lifestyle advice, and highlight some of the difficulties for nurses, including balancing a range of factors such as giving advice that they regard as important with not appearing to interfere in the way people live; representing expert knowledge whilst respecting patients' expertise; communicating risks without causing undue anxiety; and encouraging personal responsibility whilst acknow-

ledging patients' limited ability to effect change in social conditions.

However, there is an alternative way of proceeding that capitalizes on the discomfort that Diwan *et al.* (1997) suggests that nurses experience. This alternative patient-centred approach is embedded within a social model of health.

## A social model of health

When nursing researchers label patients as non-compliant, the causative factors that are identified tend to be individual attributes or behaviours. These factors appear to be much more amenable to intervention than do the social factors (economic, environmental and cultural) that have long been identified as determining health status. It is true that this focus is often well-justified: a bacterial infection cured by an antibiotic or surgery to set a broken limb are clear examples. There are, however, situations where this reductionist method produces interventions that fail to address what is a complex problem. We argue that non-compliance is one such case.

In the social model of health, health and illness are features of the complex and interactive system commonly referred to as 'life'. The model recognizes the importance of social factors in shaping health behaviour and outcomes. Included here is behaviour that is referred to as non-compliance. If we are to understand why patients do not comply with health care prescriptions, we need to acknowledge that this behaviour is related to the way in which social context enables or constrains a person's capacity to adopt a recommended treatment regime.

Good holistic nursing practice means that nurses must recognize the social factors that constrain people's capacity to change. When patients are consistently non-compliant, an approach based on the recognition of social constraints can provide a more in-depth understanding of how treatments affect their lives. This approach recognizes that it is not realistic to expect all patients to comply with all health care recommendations. When patients do not follow recommendations, there is an opportunity for relationships to develop in which nurses are more respectful of those who reject or adapt this advice. Like Lannon (1997), we argue that knowing patients and their particular circumstances is critical and will allow nurses to work in ways that will enhance genuine partnerships and may even reduce resistance to health care advice.

By acknowledging the potential constraints of the social context, nurses will be less inclined to label patients as non-compliers and better placed to work with them. There is a

potential role for nurses to show leadership in changing the way health care is delivered. As we learn more about patients' lives, they will become better positioned to interact in ways that are meaningful to them. This will also enable nurses to bring information about patients' lives into the process of health-care decision-making. This in turn will allow health-related information to be packaged in a way that is relevant, and therefore more useful, to patients.

By moving to a social paradigm for understanding patients' decisions, nurses can broaden the types of explanations, and therefore the types of solutions, they have for 'therapeutic adherence' (Lutfey & Wishner 1999). This move will allow for more dynamic relationships between nurses and patients, relationships in which the latter are regarded as experts about their own lives.

The patient-centred model is an alternative approach, but we argue that it does not go far enough. Without fundamental changes to the power structures that are reflected in traditional models of the ownership and control of health care knowledge, this approach is likely either to be met with resistance or to be counter productive (Parry & Pill 1994). Parry and Pill (1994) argue that there are risks in taking social context into account. Changes to models of communication in consultations imply changes in the ownership and control of health care knowledge. This is likely to be met with resistance both from practitioners and patients, for different reasons: from practitioners because it represents a loss of control, ownership and authority, and from patients because it does not seem 'normal' – it upsets traditional roles. For patients, there is also the risk that such knowledge may provide an increase in the areas available for surveillance by health professionals. Patients may resist communicating more about themselves and their social context unless they are sure that such information will not be 'used against them', and would need to be very sure that the power balance had shifted before they took on a different role.

If the underlying assumption about why nurses should use this kind of communication is to encourage patients to follow health care recommendations, Parry and Pill (1994) warning is justified. If, on the other hand, this type of communication gives patients' expertise credibility and validity, nurses can incorporate aspects of patients' experience into the framework of treatment.

The social model of health is, therefore, not enough on its own. In addition, we need a paradigm shift that transfers some degree of power and authority to patients. We need to recognize that they have the expertise to make rational decisions about the way in which treatment recommendations impact on their own lives. Without this paradigm shift,

the aim of asking patients about their social context remains merely a mechanism to change their behaviour (i.e. improve compliance), and popular phrases such as 'development of shared meanings' and 'a more egalitarian relationship' are merely rhetoric.

Patient empowerment is not a new concept to nursing (Price 1986, Gibson 1991, Malin & Teasdale 1991, May 1995), yet the operationalization of such an ideology is far from straightforward (Wright 1995, Elliott & Turrell 1996, Turrell 1996). There is as yet no clear consensus for defining and evaluating a patient-empowered service provided by nurses. Elliott and Turrell (1996) caution against reducing patient empowerment to rigid guidelines and practices that could very well become 'a new dogma which slowly blinkers and entrenches nurses' (p. 46). Instead, they encourage nurses to embrace the challenges and tensions that exist in trying to empower patients. Such tensions may include creating information overload when ensuring informed consent, accepting patients' health choices that are counter to the medical model, and accepting those patients who exercise their right to not partake in decisions regarding their illness management (Elliott & Turrell 1996).

The framework that is being recommended here requires listening to patients, and being able to convey their rationality to other health care practitioners. Patients do not need (re)education or coercion, but acceptance. Nurses have the opportunity to take a leadership role in supporting this new assumption that social context helps to explain patients' behaviour as rational.

## Conclusion

To date, the predominant aim of nursing research on compliance has been to find new ways for nurses to encourage patients to follow doctors' recommendations. There is a risk here that nurses may be complicit in undertaking work that doctors themselves are not prepared to do. Although one section of the nursing literature critiques understandings of compliance, it fails to give clear directions for the future. As such, it fails to recognize opportunities for change.

For many years, nursing research aimed to find better ways of making patients comply with treatments. NANDA encouraged the process of labelling patients by making non-compliance a nursing diagnosis, although the assumptions on which this nursing diagnosis are based have been critiqued (Wright 1998). While more recent nursing literature has moved away from labelling, there continues to be a focus on interventions that promote compliance.

### What is already known about this topic

- Patient non-compliance is a persistent concern for nursing practice.
- Most research on compliance focuses on ways for nurses to encourage patients to follow health care recommendations.
- Current interventions do not effectively enhance compliance.

### What this paper adds

- Nurses can play an important role in providing a broader approach to compliance.
- Patients' social contexts mediate their ability to comply with health care recommendations.
- Nurses integrating an understanding of patient contexts with current nursing practice will result in more effective interventions.

It has been suggested that there needs to be a theory of compliance that matches the holistic, philosophical basis that nursing espouses (Burckhardt 1986). Alternatively, it has been suggested that the term 'compliance' may become obsolete because of its negative and authoritative connotations, eventually being replaced with 'adherence' or 'negotiation' (McCord 1986). Yet, rather than merely changing labels, it is our view that a reconceptualization of patients' actions is required, based on an understanding of patients' actions in the contexts of their lives. In particular, nurses must acknowledge the importance of patients' self-knowledge.

Nurses have an opportunity to take a leadership role in the health care team by learning about how treatments affect patients' lives, not merely their health. Removing notions of compliance and non-compliance will allow nurses to take a leadership role in bringing knowledge of patients' lives into the health care decision-making process. Nurses have the opportunity to change the way health care is delivered by giving due consideration to the social context in which patients live, work and play. However, we caution that nurses may embrace the social paradigm at their peril if the same assumptions that underpin the biomedical model continue to be adopted within a new framework.

The paradigm shift that has been proposed in this article is for a patient-centred model in which communication between patient and nurse needs to change to give greater importance to the patient point of view. This new model not only shifts power and authority towards patients, but implies an advocacy role for nursing. It requires that nurses listen to

patients and accept them as experts in their own lives and their health choices, and then convey the rationality of patient decision-making to other health care practitioners. As patient advocates, nurses need to abdicate complete monopoly over the knowledge base and incorporate aspects of patients' life experiences into the health care arena. In particular, they must acknowledge the importance of patients' self-knowledge.

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