

Renal Myth Busters: Indigenous People are the Least Compliant with Treatment

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Abstract

This is the first in a series of papers aiming to debunk or demystify common myths in renal practice through an exploration of current evidence. Definitions and construction of myths are initially discussed. The notion that indigenous Australians are less compliant than other patient groups is explored. Using a story from practice the veracity of this 'renal myth' is examined. Evidence presented suggests that the idea of compliance has a number of difficulties, and that there is scant evidence of a racial base for compliant behaviours.

Introduction

This is the first in a series of short papers looking at some commonly held myths in renal practice. During the dinner at the last RSA conference in Melbourne discussion arose about a number of common 'myths' that delegates believed were pervasive but were untrue and led to poor patient support. Our goal in this series is to debunk or demystify these myths through an exploration of current evidence. This first paper will begin with a short exploration of myths, and how they are constructed. A story from practice will follow to illustrate a commonly held belief about compliance in racial and ethnic groups. We will subsequently explore the veracity of this 'renal myth'.

What is a myth?

A myth is defined by the Oxford Dictionary as "a widely held (untrue or discredited popular) story or belief;

a misconception; a misrepresentation of the truth; an exaggerated or idealized conception of a person, institution, etc.". The key point here is the *veracity*, or *truth*, of the story or belief. Bell (2003) in his exploration of national identity, suggested that myths are not neutral nor simply evolving over time; rather they are stories that simplify and selectively tell the story of the past experience. He argued that myths are constructed and shaped, either through deliberate intentional manipulation or unintentionally. Whether intentional or not, the end effects of myths are to create single truths that reduce complexity and hide exceptions to that 'truth'. Myths in this way are simplistic and present a version of reality that represents one (rather than multiple) ways of seeing the world.

Simplistic does not denote a value rating of good or bad. Myths function in several ways. They provide a way of relating the lessons learned in experience and also

Key Words

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provide a sense of continuity with the way others have worked and practiced. Myths therefore teach us about aspects of life. Smith (2002) identified three paradoxical (or contradictory) qualities of myths. First, myths are both truthful and fantasy. Secondly, they are generalised but specific. The third and possibly most significant paradox for this discussion is that myths arise from knowledge gained in experience and interpretation of that experience. Interpretations can be selective and are influenced by our values. It is important to remember that myths are not errors, because they have elements of the real within them (Cohen 1969).

The noted nursing scholar, Peggy Chinn (1985) argued for nurses to critically analyse myths and separate what is invention from verifiable information. This analysis needs to also ascertain whose interests are served in the maintenance of the myth. This series of articles will pursue Chinn's call for analysis of myths.

Our story

Indigenous people are often referred to as non compliant – is race a factor? A story from practice was the place to begin to explore if this is a myth. We have used

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pseudonyms and altered minor aspects to protect the identity of the patients.

Two male patients in a renal unit, both were in their mid forties; one was a Scottish immigrant and the other an indigenous Australian. Both men were of similar weight, although Adam was shorter and more muscular, compared to Ben who was thin and tall. Both had a diagnosis of IgA nephropathy and had been on the dialysis program for less than 2 years.

Adam was a very fit, strong man who had a wife and three young children. He dialysed in a satellite centre three times a week after work. He took phosphate binders as prescribed and, except for an occasional splurge of home grown tomatoes, controlled his diet very well. Even though he came to dialyse after work, he always took and recorded his own vital statistics, set up his machine and prepared himself for dialysis except for cannulating his fistula. He smelled of sweat, but not unpleasantly. After some time Adam received a transplant.

Ben was different to Adam. He refused to do any of the preparatory tasks commonly asked of patients. He would comment, "What are you nurses paid for if I do it?" He rarely refilled prescriptions, seemingly happy to wait until his increasing hypertension and elevated phosphate levels were recognised by staff who subsequently organised more routine medication for him. His monthly blood results were usually sub-optimal. He lived alone and had no telephone. His clothes and skin never appeared clean except over his fistula prior to cannulation (at the staff's insistence). There was a permanent stale, musty smell we associated with his presence. Ben regularly missed dialysis sessions, but became irate when the police were called

to see if he was still alive. He voiced concern that his "neighbours must think I am a criminal." Ben died alone in his flat close to the 2nd anniversary of him commencing dialysis. He was found by police, when he had not attended dialysis for a week.

No, Adam was not Scottish, but an aboriginal man who managed to live effectively with his renal disease. Race in this case seems to contradict the common myth that indigenous people are non compliant.

Published evidence

There is little evidence to support the notion that race or ethnicity is a factor in non compliance (or adherence) to recommended treatments. Before exploring this evidence, we need to clarify the meaning of compliance. The following section is drawn from the author's previous work (Wellard & Beddoes 2005).

Compliance

Compliance has been variously defined, but infers patient submission to medical and/or health professional advice in relation treatment (Vermeire et al. 2001). It is estimated that compliance rates in chronic illness vary from 80% (Kyngäs et al. 2000) to 50% (Cameron & Gregor, 1987, Turk & Rudy, 1991), depending on how compliance is defined and measured (Hailey & Moss 2000). Non compliance has been noted as having severe consequences, including exacerbation and progression of disability (Turk & Rudy, 1991). A failure to follow treatment regimens can result in patients needing emergency treatments, and hospitalisation to re-establish a stable condition (Lamping & Campbell, 1990). Consequently, non compliance creates an additional economic burden on the health care system (Vermeire et al. 2001).

Physiological and biochemical tests are frequently used to measure compliance (Fielding & Duff 1999). Treatments are designed to maintain ideal biochemical and physical levels. Therefore the degree of compliance is assessed by the proximity of a patient's levels to these predetermined levels. However, variations in these levels may not always indicate 'non compliance'. Changes in the illness state and variability in the treatment may contribute to fluctuations from the expected (Lamping & Campbell, 1990). In the case of unstable diabetes, whilst frequently attributed to poor compliance, Tanenberg (2001) reported that insulin resistance accounted for many reported cases of non compliance in people with diabetes.

Current definitions of compliance infer a relationship of authority and power of one individual (health professionals) over another (the patient) (Kontz 1989; Vermeire et al. 2001). Compliance needs to be redefined to incorporate the patients' right to choose not to adopt treatment regimens. However, in arguing for collaborative relationships yet retaining the language of compliance, there remains a failure to relinquish control by health care workers. The continued use of patient centred language and the use of interventions targeted at changing patient behaviour suggest the continued desire to facilitate adherence to treatment within a framework where health professionals adopt a father like influence (paternalistic) (Fielding & Duff 1999; Kontz, 1989; Vermeire et al. 2001). Kelly and May (1982) found that health workers labelled non complaint patients as 'bad patients'. This seems to remain a consequence of perceived non-compliance in current practice.

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Thorne (1990) identified two explanations patients give for non compliance with treatments. First, non compliance is a mechanism of self protection that comes from distrust in the quality of the decisions made by medical and health care workers about their treatment. Second, the need to maintain relationships with health care personnel prohibits total withdrawal, so non compliance serves as a strategy to exercise some control over the relationship.

Non compliance in ESRD

The research related to non compliance in ESRD is extensive, and some studies do suggest ethnicity is associated with compliance. However, a number dismiss any racial or ethnic connection. Many factors influence these contradictory findings, but the major factor is inconsistent definition and measurement (Rosner 2006), making comparison and interpretation of findings challenging.

Loghman-Adham's (2003) review of the literature related to medication compliance in the context of dialysis provides a useful starting point. He summarised the range of linked to compliance as including: patient perceptions of the benefits of treatment, quality of patient-professional communication, socioeconomic background, level of motivation, age and available family and social support. His review found a number of USA studies identified high rates of non-compliance amongst blacks, however these rates of non compliance have been correlated with lower socioeconomic status where some racial groups are over represented.

Social support has been clearly linked with compliance in haemodialysis patients, where people with high levels of family support demonstrating lower

interdialytic weight gains and better biochemical profiles than those with limited family support (Patel et al. 2005). Similarly, differences in coping and adaptation noted between white and blacks diminish when the influence of education is taken into the analysis (Greco, Brickman and Routh 1996). People with lower levels of education may be at higher risk of depression and non compliant behaviours. Kutner, Zhang and Brogan (2005) found limited evidence of a racial association with compliance, but did note that longevity of treatment seemed to produce more non compliance in blacks.

Compliance in Australian Indigenous people

There have been a number of studies and reports exploring compliance as it related to health outcomes for Indigenous Australians, which have been popularised as issues of poor adoption of medical treatment advice and unhealthy behaviours of individuals. Kim Humphery and Tarun Weeramanthri (2001) detail the scope of this work in their book. They suggest that there are a number of issues in delivering Western health care to indigenous populations. Cross cultural problems do arise where people frequently perceive the interventions they are asked to adopt are at odds with their Indigenous health beliefs (McConnel 2003, Hamrosi, Taylor & Aslani 2006). The absence of effective communication between health providers, patients, families and their communities have been identified as influencing compliance with treatment regimens in rural and remote Aborigines (Humphery & Weeramanthri 2001).

Socioeconomic status has also been clearly linked to compliance in Australian Indigenous people. Murray (2003) reported that access barriers were substantial for Aboriginal people

including poverty and geographical distances to services. English literacy amongst Australian indigenous people is generally poor, associated with limited access to appropriate literacy education and living in amongst others who speak 2-4 other languages (Kral & Swab 2003, Every & Young 2002). Racist attitudes of hospital staff and difficulty in communications with limited access to interpreters and /or Aboriginal Liaison Officers have been discussed as barriers for Aboriginal people (Humphery & Weeramanthri 2001). These barriers are not limited to those in rural and remote environments but are equally an issue in urban centres.

Our conclusion

Compliance is not a matter of race or ethnicity. It depends on an individual's response to their diagnosis, their education and life circumstances down to the individual patient personality, on whether he or she will comply with some or all of the dialysis team's recommendations for their treatment regimen.

Race and ethnicity are one factor in an individual's response to medical treatment regimens. There is no magic solution to resolving non compliance, but a move away from paternalistic stereotyping to negotiated aims and goals of treatment may be one way for us to support improved outcomes for Indigenous people.

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