



# Tale of Two Courthouses: A Critique of the Underlying Assumptions in Chronic Disease Self-Management for Aboriginal People

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## REVIEW

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## Abstract

This article reviews the assumptions that underpin the commonly implemented Chronic Disease Self-Management models. Namely that there are a clear set of instructions for patients to comply with, that all health care providers agree with; and that the health care provider and the patient agree with the chronic disease self-management plan that was developed as part of a consultation. These assumptions are evaluated for their validity in the remote health care context, particularly for Aboriginal people. These assumptions have been found to lack validity in this context, therefore an alternative model to enhance chronic disease care is proposed.

### Introduction

Chronic Disease Self Management (CDSM) has been adopted whole heartedly as an effective tool in the fight against chronic diseases across Australia. It has been supported by policy makers and clinicians and a couple of models have been favored overwhelmingly. There has been little criticism in the literature of the appropriateness of adopting these models across all community groups. We have been exploring the opportunities of increasing self management for remote Aboriginal people particularly in the Pilbara region of Western Australia and propose that there may need to be a new model.

### Insights from the Old Cossack Courthouse

Cossack Courthouse is not unlike any other early colonial building; thick stone walls made from local rock, the furniture, heavy dark brown wood consisting of three lines of benches, two docks and the raised platform for the judge's bench. The white-washed walls are covered with pictures of the town's history; cabinets full of artefacts from the past. The white-wash reinforcing the point that there is not a single picture, nor story of the Aboriginal people who lived there, attended

the courthouse, or worked in the town. Yet we know from other records they were dragged through in chains, to be processed, punished, and pushed aside. It is easy to sit at the judge's bench, the former comfort of the seat clear despite the wear and tear of the years and look down on the court. Today sitting at the bench, it is easy to feel the authority this seat, this platform gives, lifting oneself up above the common people of the court. It is easy to see the world through the colonial judge's eyes and values, and the need to remove the encumbrances, the Ngarluma/Yinijibarndi people, to progress wealth acquisition and colonial power.

What is harder is to sit on the rows of benches in the body of the court, or enter the dock, and touch the experience of the Aboriginal people who were forced through here, often in chains. The alien experience that few non-indigenous Australians can relate to. That is the past, the legacy we have been given by our forbears, a legacy lost in this museum of social history, as it is now referred to on the placard outside.

### The Burden of Chronic Disease

Many believe past colonial practices of racial denigration, the classification of Aboriginal people as fauna, the forced migration, the separation of Aboriginal children from their families; the simple but effective abuse of human rights has resulted in the chasm that separates white Australian quality and quantity of life from that experienced by Aboriginal people. The figures are well known, the latest Overcoming Indigenous Disadvantage Key Indicators 2009 [1] reminds us that that the difference in life expectancy at birth is currently 11.5 years for men and 9.7 years for women; infant and child mortality is 2-4 times the rate for Aboriginal children. Rates for hospitalisations from chronic disease are 6.4 times higher than for non-Aboriginal people, and Aboriginal people are 45.8 times more likely than non-Aboriginal people to be hospitalised for injury, poisoning and other external causes. Even more concerning is that report's overview which states. "Across virtually all indicators in this report, there are wide gaps in outcomes.... However, many indicators show that outcome are not improving, or are even deteriorating" (p 12).

There is a great deal of mortality and morbidity caused by acute illnesses, accident and injuries, with a large number of people committing suicide. However, the major burden to health and cost to health care is that resulting from chronic disease. In 2004-05, 77% of Australians had at least one longterm condition, and 80% of those aged 65 years and over had three or more long-term conditions [2]. The recent National Health and Hospitals Reform Commission report found that around 70% of our health



care budget is consumed by chronic conditions that are potentially preventable (such as cancer, cardiovascular disease, mental disorders and diabetes), and that 10% of hospital stays could have been avoided if better care had been provided earlier [3].

### Chronic Disease Self-Management

One of the dominant approaches being advocated for reducing the impact of chronic disease, both to the individual and health care system is Chronic Disease Self-Management (CDSM). This is best evidenced by the current Federal Government approving the allocation of a total of \$13.1 million to 82 organizations to deliver specific chronic disease self-management and lifestyle risk modification programs in communities and regions throughout Australia. However, the concepts of CDSM are derived from health care in the dominant western cultures, and there appears to be little critical appraisal of its appropriateness for Aboriginal people, in particular those living in and remote communities. The Department of Health and Ageing when launching the National Chronic Disease Self-Management Initiative states "Effective self-management is based on a partnership between the person with the disease, their families and health professionals, in which they are encouraged to play an active role in monitoring and managing symptoms and signs of illness, managing the impacts of illness on their lifestyle, emotions and interpersonal relationships, and adhering to treatment regimens" [4]. This view of self-management and the role of CDSM are also articulated by the Flinders Human Behaviour & Health Research Unit. They argue that self-management "involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimens." Further it is proposed that The Flinders Model is "underpinned by cognitive behavioural therapy (CBT) principles, offers a generic approach to chronic condition self-management that can be applied to a wide range of health conditions" [5]. From this stand point a "good" self-manager is someone who:

1. Has knowledge of their condition
2. Follows a treatment plan (care plan) agreed with their health professionals
3. Actively shares in decision making with health professionals
4. Monitors and manages signs and symptoms of their condition
5. Manages the impact of the condition on their physical, emotional and social life
6. Adopts lifestyles that promote health.

### Challenging the Assumptions of CDSM

So the question is how appropriate is this model of CDSM for remote health care. The first point to consider is the authoritarian nature of this model. When examining the descriptions presented on CDSM we find two sets of contradictory descriptions being used. On the one hand we see terms such as "partnership", "agreed" and "patient-centred". Yet this is contradicted by the pre-determine approach that Flinders advocates. Further, self-management

is described in terms of "adhering to treatment regimes", and in the six principles and descriptions we find the term "adopt a lifestyle that promotes health". The message being that if you do not follow the "agreed" plan, you are a "bad" self-manager. Thus the concept of CDSM is embedded within the concept of adherence. The World Health Organisation defines this as "the extent to which a person's behaviour taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider"[6]. This definition, as well as the definition for similar terms used in the literature, such as compliance and concordance is based upon a clear set of assumptions:

1. There are a clear set of instructions to comply or adhere to
2. The health care professionals agree on what a person should be trying to do
3. There is agreement about what decisions have been made

Unfortunately, none of these assumptions stand up to scrutiny in the health care context. The recommendations for many chronic conditions are not clear, just consider the dietary recommendations for diabetes, with the different instructions concerning fat, carbohydrate, fibre, protein intake, along with glycemic index, regularity of food intake, and matching food intake to medication. That is without considering whether different health care professionals that an individual will see (nurse educator, dietician educator, doctor, podiatrist, practice nurse) will give the same recommendations to follow. A recent paper highlighted that even when working in relatively small teams, in this case paediatric diabetes care teams, there is substantial disagreement between professionals in the same team about basic information such as targets for glucose control [7]. There is also a substantial evidence base documenting that health care professionals and patients do not even agree on the presenting problem for a consultation [8] or the treatment decisions made in a consultation [9]. The discrepancy between the individual's recall and the health professional's is often blamed on the patient not paying attention to the health care professional. However, more recent studies indicate that health care professional's recall of the consultation is as inaccurate as the person with the condition. For example, one study demonstrated that 2/3 of treatment recommendations that a health care professional reported giving/making during a consultation, were not actually given in the consultation [10]. It should be noted that this study in diabetes care was completed in an outpatient clinic where the professional and patient were predominantly from the same culture and had the same first language. Thus the assumptions that underpin the ideas of adherence and compliance are theoretical and empirically invalid in the context of chronic disease [11, 12]. Although there are token gestures made in the literature by those advocating CDSM based approaches, their continued slippage into the language of adherence, compliance and judgement about those who don't act on the information and advice they are given indicates the



true authoritarian nature of the commonly advocated models of CDSM.

### Chronic Disease Self-Management in the Context of Aboriginal Health

When advocating CDSM we need to consider the person's ability to adopt a lifestyle that promotes health. Inherent in the CDSM model is that it is possible and within the control of the individual to adopt these lifestyle behaviours. However, the model fails to consider the availability and cost of the foods that would be needed to follow current dietary recommendations. In a study of income and living costs on the Anangu Pitjantjatjara Lands it was estimated that a household on Community Development Employment Program income, marginally more than unemployment benefit, would have to spend between 79% and 85% of their income to meet their basic needs for food and other necessities [13]. A reduction of 40% in store prices would be required to make basic food and hygiene items affordable on current income levels. Consequently, most people cannot afford to eat or feed their children every day. Each fortnight, families have between one and three 'Mai Wiya' (no food) days when families have only tea and damper [13]. The Northern Territory market basket survey estimates that families in remote locations would have to spend 35% of their income to buy basic healthy food [14]. By contrast, the Australian Household Expenditure survey showed that for the average Australian household about 18% of weekly expenditure (not income) was spent on food [15]. Availability of basic foods decreases with remoteness, with 12% of the basic basket items missing in very remote stores [16]. Some have postulated that it is actually not possible for people in remote communities to afford the contents of a healthy eating plan, even if it were available. If this is the case for the basics of diet, consider the likelihood of availability of the health care needs of the individual. For instance optimal care for type 2 diabetes requires regular review of diabetes metabolic markers, HbA1c, Cholesterol, blood pressure, and subsequent titration or change in medication to achieve these targets. To achieve optimal control of type 2 diabetes (glucose, blood pressure and lipids) and management of complications may mean individuals may need to be on up to 9 different medications to optimally control their blood pressure, lipids and glucose levels [17].

We also have the need to consider the culture of people living in remote communities, and how the CDSM models override this, for example where western dietary recommendations are in conflict with Aboriginal beliefs and traditions (e.g conflict between dietary restrictions and western recommendations for consumption of red meat during pregnancy, which is to some people taboo). The CDSM principles blame the individual for not adopting the appropriate lifestyle. Some people practice grieving rights and complete sorry business. The food and activity choices during these times are not within the remit of the individual to choose. Again the CDSM models do not account for these practices, and label the person as a "bad" self-manager.

A further problem for CDSM and the Flinders Model is that it is underpinned by cognitive behavioural therapy (CBT)

principles. CBT shares many things in common with most of the interpersonal psychological therapies such as, using behavioural re-inforcements, stress management and relaxation techniques, as well as encouraging physical and social activity. However, the one component that makes CBT distinct from other interpersonal therapies is the emphasis that the individual's thought content is wrong, and that if you change the content of people's thoughts, then their behaviour will change, resulting in improved psychological and physical health [18]. This approach has been shown to have great value for certain conditions where incorrect or distorted cognitions or thoughts are the root cause of the condition. However, where this is not the case then CBT has very limited effectiveness, as highlighted by a recent meta-analysis of CBT and relaxation for the treatment of anxiety disorders. For specific phobia based anxiety, where there are clear cognitive distortions, CBT is more effective than relaxation. However, for Generalised Anxiety Disorder, where there are frequently such inaccurate distortions, CBT is NO more effective than relaxation therapy alone [19]. CBT is only a valid approach when the thoughts that are driving people's behaviour are actually wrong. In the context of remote health many of the "maladaptive thoughts", as they would be labelled by therapists, are commonly accurate reflections of the situation in which people and communities find themselves. One study reports that over 20% of Aboriginal Australians have been exposed to 7-14 major life stress events (death, incarceration, violence and severe hardship) in the previous 12 months [20]. So to engage a theoretical approach that would require the invalidation of the anticipation of negative appraisals of the future would seem wholly inappropriate. Further, the impact of these stressors on individual's susceptibility to mental health problems, such as depression and subsequent chronic disease are well documented in the medical literature [21, 22]. Yet the CDSM model just labels these as barriers to be overcome by the individual, and failure to do so means you are not a "good" self-manager.

Thus, the CDSM model is basically saying to the people in remote communities, here is the information; here is what you need to do, now get on and do it. This places responsibility on the individual and ignores the wider social and physical context that individuals in remote communities find themselves. It fails to acknowledge the impact of the wider social determinants of health and places the responsibility for improving health solely on the individual. This may be a valid approach in metropolitan areas and possibly rural areas but for remote health care the CDSM agenda just feels like another Cossack Courthouse ignoring the values, history and choices available to Aboriginal people. However, it is worth noting that Greenhalgh recently summarised several myths around the evidence base for CDSM [23]. She noted that few studies actually report any improvements in disease outcomes; that there is no evidence to support the assertion of reduced health care utilisation or health care costs; there is evidence that these are in fact increased following CDSM programs.





There is little evidence to suggest the CDSM models are effective outside the carefully selected groups of patients included in the research trials. Greenhalgh also proposes that there is evidence of publication bias in the CDSM literatures, noting only positive trials are being published [24]; and the self-management education literature continues to suffer from the lack of psychological equivalent placebos for the control groups [25] who are commonly randomised to receive no additional chronic disease care, support or advice.

### An Alternative from the Old Courthouse Art Gallery

In a town further to the North, it is a warm night; the trees are softly lit with warm colours on the small lawn in front of the Old Courthouse Art Gallery. The murmur of the crowd slowly stills as the speaker asks for their attention. Following a welcome to country by a Kariyarra elder and introductions, the artists from a new local Aboriginal art group move forward to the welcome and acknowledge the interest in their work. Inside, the white wash is here also, but no longer a covering of old, rather a backdrop to the new, and its role to emphasise and draw the eye to the vibrant Aboriginal art work on display. The bookshelves also promote Aboriginal work, culture, values and traditions. So here in this courthouse we see reconciliation. Here we see the gallery, staffed by western professionals, working to promote the local community's work and way of seeing the world. The art is representational, but not an obvious representation to the casual non-Aboriginal observer. This work shows how the local artists see, feel and experience their world. This is very different from many of the western audience. In this courthouse we see how the dominant culture is acknowledging and valuing the Aboriginal community.

Reconsidering chronic disease care for remote Aboriginal people requires a new set of assumptions. This means supporting Aboriginal communities and people to identify their own priorities. Supporting the community to create the solutions they would like to explore, and working with them to secure the resources to implement their solutions. This means valuing and promoting the strengths of the Aboriginal community, culture and people. These are key features of community development models. Community development implies an awareness of exploitation and oppression. Community organising is based primarily on the conviction that people are capable of finding solutions to their own problems. This in no way negates the often indispensable role of experts, but it means that experts can best contribute by supporting initiatives decided on collectively by people who have joined together to address their community's needs. Community development means "working with communities and assisting communities in finding plausible solutions to the problems they have identified" [26, p.7]. Aboriginal people in Australia have participated in community development for thousands of years, yet they have been forced to adapt to a non-Indigenous community development model for several decades [26]. This approach shares many similarities with those who advocate a whole systems approach, also known as social ecology [23] which advocates looking beyond the interaction between the educator (lay or professional) and the person with the illness, to take in the wider social and physical context in which the individual lives. The whole system and

community development approaches support the creation of environments physical, emotional, spiritual and social that address the multi level determinants of health, rather than placing the blame and responsibility on the individual alone [27].

To make a difference in closing the gap in life expectancy between non-Aboriginal and Aboriginal people, we would like to propose that there is a move away from Chronic Disease Self-Management in remote health care, and switch to supporting Community Developed Models of Chronic Disease Care (CDM-CDC).

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#### PEER REVIEW

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#### CONFLICTS OF INTEREST

The authors declare that they have no competing interests