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Factors influencing health care utilization following a cardiovascular event among Aboriginal people in Central Australia.

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Mémoire présenté à la Faculté des études supérieures en vue de l'obtention du grade du MSc. en Santé Communautaire.

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Faculté des études supérieures

Ce mémoire intitulé:

Factors influencing health care utilization following a cardiovascular event among Aboriginal people in Central Australia.

présenté par:
Stella Artuso

a été évalué par un jury composé des personnes suivantes:

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président-rapporteur

Mark Daniel
directeur de recherche

Margaret Cargo
codirecteur

....
membre du jury

RÉSUMÉ

Les aborigènes australiens souffrent d'un état de santé global plus mauvais comparé à celui de la population australienne en général, surtout en ce qui concerne les maladies cardiovasculaires. Malgré cet écart au niveau de leur état de santé, les aborigènes d'Australie utilisent les services de santé différemment et à des taux beaucoup plus bas. Si on désire améliorer l'utilisation des soins de santé (USS) chez les aborigènes atteints de maladie cardiaque, nous devons essayer de mieux comprendre les facteurs qui restreignent ou facilitent leur emploi. Cette étude qualitative a privilégié l'approche exploratoire en se servant d'entrevues non structurées, de groupes de discussion et d'entrevues semi-structurées chez des participants sélectionnés par choix raisonné : malades cardiaques aborigènes (*n* = 7), participants non cardiaques de la communauté (*n* = 15) et fournisseurs des services de santé et de recherche (*n* = 12). Nous avons identifié les obstacles les plus importants à l'USS au niveau du système de santé. Ils comprenaient les problèmes de communication, les caractéristiques organisationnelles ainsi que la disponibilité et la prestation des services de santé. Au niveau individuel, les facteurs influençant l'USS incluaient le besoin perçu, les expériences passées négatives et la connaissance limitée de leur maladie, alors que le soutien parallèle au niveau interpersonnel servait de facilitateur principal à l'USS. Nos résultats indiquent que les patients aborigènes atteints de maladie cardiaque se heurtent à des obstacles significatifs à l'USS. La conséquence en est une qualité des soins insuffisante et sous-optimale qui augmente le risque de complications cardiaques ultérieures et qui affecte leur niveau de l'USS.*

Mots-clés: services de santé; utilisation; facilitateurs des soins /obstacles aux soins; maladies cardiovasculaires; santé des aborigènes australiens; santé des indigènes.

** Les termes employés pour désigner des personnes sont pris au sens générique; ils ont à la fois valeur d'un féminin et d'un masculin.*

ABSTRACT

Aboriginal Australians suffer from poorer overall health compared to the general Australian population, particularly in terms of cardiovascular disease and prognosis following a cardiac event. Despite such disparities, Aboriginal Australians utilize health care services at much lower rates than the general population. Improving health care utilization (HCU) among Aboriginal cardiac patients requires better understanding the factors that constrain or facilitate use. This qualitative study employed an exploratory approach using two sequential phases – a cultural and contextual adaptation for the interview guide, and a data collection phase – among purposively selected participants including Aboriginal cardiac patients (*n*=7), non-cardiac community participants (*n*=15) and health care and research providers (*n*=12). Compelling barriers to HCU were identified at the health care system level, and included Communication Issues, Organizational Characteristics and Availability and Delivery of Health Services. Individual-level factors influencing HCU included Perceived Need, negative Previous Experiences and Limited Knowledge of Illness, while Alternate Support at the Interpersonal level acted as the primary facilitator to HCU. Aboriginal cardiac patients face significant barriers to HCU, resulting in insufficient and sub-optimal quality of care, significantly risking subsequent cardiovascular events and affecting their level of HCU.

Keywords: health service; utilization; facilitators/barriers to care; cardiovascular disease; Australian Aboriginal health; Indigenous health.

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1. **ACACIA**: The Australian Coronary Prospective Audit
2. **CASPA**: Central Australian Secondary Prevention of Acute Coronary Syndromes
3. **CDEP**: Community Development Employment Projects
4. **CR-CHUM**: Centre de recherche du Centre Hospitalier de l'Université de Montréal
5. **CVD**: Cardiovascular disease
6. **HCU**: Health Care Utilization

DEDICATION

To the people of Mparntwe (Alice Springs), who, despite inconceivable and almost insurmountable odds, remain resilient, courageous and demonstrate great strength of spirit and kindness, you have been an inspiration to me.

To my family and friends for their unconditional love, support, and patience, thank you.

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CHAPTER 1: INTRODUCTION

Chapter 1: Introduction

This chapter provides a brief overview of cardiovascular disease among Aboriginal Australians and how it affects their health outcomes. It is followed by a description of the patterns of and barriers to health care utilization (HCU) among Aboriginal people in Australia and concludes by explaining the need to explore the factors influencing HCU among Aboriginal Australian cardiac patients at individual and contextual levels.

Problem Statement

Cardiovascular Disease Among Aboriginal Australians

Cardiovascular disease (CVD) is the primary cause of early adult mortality among Aboriginal Australians (Paradies & Cunningham, 2002) and is the single greatest contributor to the burden of disease in the Northern Territory of Australia (Zhao, Guthridge, Magnus, & Vos, 2004). Among Aboriginal Australians, age-standardized cardiovascular mortality is twice that of the general population, with age-specific mortality rates between six to eight times that of other Australians aged 25- 64 years old (Walsh, 2001). Compared to other Australians, CVD is three times more prevalent among Aboriginal Australians (Mathur, Moon, & S., 2006). In the Northern Territory, CVD accounted for 19.1% and 15.7% of the disease burden among Aboriginal men and women, respectively (Zhao et al., 2004). Premature mortality resulting from CVD is a major contributor to the 20-year life expectancy gap between Aboriginal Australians and non-Aboriginal Australians, resulting in life expectancy similar to that within low-income countries (Paradies & Cunningham, 2002; Zhao et al., 2004)

Patterns of and Barriers to Health Care Utilization

Utilization of health care services can positively influence health outcomes (Andersen, 1995). Although Aboriginal Australians demonstrate poorer overall health compared to the general population, they utilize health care services differently and at a much lower rate than other Australians (Deeble, Mathers, & al., 1998; McDermott, Plant, & Mooney, 1996; Thomas, Heller, & Hunter, 1998; Walsh, 2001). They predominately use publicly provided services and under-utilize services offered from Commonwealth funding for Pharmaceutical Benefits, Medicare, specialist services and general practitioner consultations (Deeble et al., 1998; Walsh, 2001). Specific to the Northern Territory, Aboriginal patients have higher rates of cancellations, non-attendance at scheduled appointments and premature discharge against hospital staff's advice (Gruen, Weeramanthri, & Bailie, 2002). Even when Aboriginal Australians do utilize health care services, they may experience a wide range of difficulties, particularly when interacting with non-Aboriginal health care professionals. These difficulties include communication issues, lack of cultural awareness among non-Aboriginal staff, racism and loneliness (Andrews, Simmons, Long, & Wilson, 2002; Hayman, Wenitong, Zangger, & Hall, 2006; Wardman, Clement, & Quantz, 2005). Several commentators have suggested that Aboriginal patients often demonstrate limited knowledge of their illness and how to access health care services (Andrews et al., 2002; Wardman et al., 2005; Hayman, Wenitong, Zangger, & Hall, 2006). In the Northern Territory, limited availability of health services, cultural inappropriateness of services provided, poverty and poor overall health service structure negatively affect HCU among Aboriginal Australians (Gruen et al., 2002).

Among cardiac patients, utilization of cardiac management programs has been shown to reduce readmission rates, extend overall survival, improve quality of life, decrease the need for interventional procedures and reduce the incidence of subsequent myocardial infarctions (Aoun & Rosenberg, 2004; Clark et al., 2007; Hare & Bunker, 1999). Despite these benefits, few cardiac services and specialists are available to individuals living in rural and remote areas of Australia (Clark et al., 2007). In areas where cardiac services, such as cardiac rehabilitation programs are available, utilization among Aboriginal Australians remains comparatively low. In a study from rural/remote Queensland, only 6% of eligible Aboriginal cardiac patients engaged in cardiac rehabilitation programs (Shepherd, Battye, & Chalmers, 2003).

The low rate of HCU among Aboriginal cardiac patients is alarming considering the high prevalence of cardiovascular disease, particularly in the Northern Territory. Only two studies have explored the variations in HCU among cardiac patients in this region (Brown, 2006; Maloney, 2005). The Central Australian Secondary Prevention of Acute Coronary Syndromes (CASPA) study (Brown, 2006) aimed to determine the quality of care provided to Aboriginal patients experiencing acute cardiac events in the Northern Territory, and to explore Aboriginal patients understanding of their illness and progression through the health care system. In this study, Aboriginal patients had significantly worse survival following events, and were less likely to travel to tertiary referral centres for specialist investigation and care than non-Aboriginal patients. Reasons offered for this finding included the possibility that Aboriginal cardiac patients might not have been offered the same services as non-Aboriginal patients, and that Aboriginal cardiac patients might have refused specialist investigation. Both explanations would suggest important barriers to HCU and require further investigation. The thesis presented by Maloney (Maloney, 2005) explored Aboriginal and non-Aboriginal cardiac patients' experiences, conceptions of their cardiac event and how these factors influenced delay times. The study addressed the barriers to HCU experienced at the time of the cardiac event, such as lack of transportation, long waiting times and communication problems, but did not explore patient's experiences utilizing health care services following their cardiac event. Both studies reveal structural and communication barriers to HCU at the health system level, however these findings must be reproduced and extended. There is a need to better understand Aboriginal patients' ability to negotiate the health care system, perceived need to seek post-discharge care and cardiac services available to them, as no studies have yet been conducted to address these issues.

Individual and Contextual Level Influencers

To date, studies investigating HCU have predominantly addressed individual level influences, including demographic variables, lifestyle, knowledge, attitudes and beliefs, education and income levels (Phillips, Morrison, Andersen, & Aday, 1998). An individualistic framework places complete responsibility on the individual regarding their decision to use, or refuse, health care services. Exclusive use of an individualistic framework to better understand the variations in HCU obscures the factors that shape the context in which utilization occurs (Phillips et al., 1998). Larger contextual factors, such as availability of health care services, regional poverty, and cost of health care services, are increasingly more important among different ethnic and cultural groups, as HCU is typically lower, despite a greater level of need within such groups (Scheppers, van Dongen, Dekker, Geertzen, & Deeker, 2006). It is necessary to acknowledge that while individuals make their own choices regarding health behaviors (e.g. HCU), they are often influenced by contextual factors that go beyond personal choice. In order to appropriately understand the variations in HCU among Aboriginal Australians, HCU models need to acknowledge and incorporate important historical, political, structural, social, and cultural factors

(Carson, Dunbar, Chenall, & Bailie, 2007; McDermott et al., 1996; Scheppers et al., 2006 ; Trudgen, 2000).

Given the prevalence of CVD and studies suggesting lower levels of HCU among Aboriginal Australians, there is a need to explore the factors influencing HCU following a cardiac event, not only at the level of the individual, but also at larger contextual levels.

CHAPTER 2: LITERATURE REVIEW

Chapter 2: Literature Review

This chapter provides an overview of the available literature regarding HCU with emphasis on ethnic minorities and Aboriginal populations. It then discusses the study's research question, its objectives, and its pertinence and concludes by introducing the conceptual framework used to guide this study.

Literature Review

In our aim to explore the factors influencing HCU following a cardiac event among Aboriginal Australians living in and around Alice Springs, a comprehensive bibliographic research under relevant databases (Medline & Ovid, PubMed, PsycINFO, CINAHL) and keyword searches (health service; utilization; facilitators/barriers to care, cardiovascular disease; Australian Aboriginal health; Indigenous health) was conducted. The next section describes the concept of HCU and the primary factors influencing use among ethnic minorities, Aboriginal populations and cardiac patients.

The Concept of Health Care Utilization

Attempts to understand variations in HCU have been the topic of much scrutiny for well over 35 years (Andersen, 1968), during which time, HCU has been explored among different populations (Blais & Aboubacrine, 1999; Gelberg, Andersen, & Leake, 2000; Wardman, Clement, & Quantz, 2005) and within different contexts (Haddad & Fournier, 1995; Rosenberg & Hanlon, 1996). It has been defined in terms of *access to* health services, and is considered to occur only when this access is realized (Andersen, 1995). HCU is described as an individual behavior, which is a function of one's surrounding environment and societal forces affecting the availability, accessibility and affordability of services (Andersen, 1995). HCU is differentiated between *potential access* of health care services and *realization of access*, Andersen (1995) states that potential access does not equal or guarantee use. However, he does explain that greater *potential access* increases the possibility of utilization. Andersen's views regarding accessibility are shared by others (Donabedian, 1973; Long, 1994). However, the assumption that accessibility equals greater utilization is questionable, as other obstacles have been shown to impede use (Andrews, Simmons, Long, & Wilson, 2002; Rosenberg & Hanlon, 1996; Wardman et al., 2005). Scheppers et al., (2006) describes HCU as not only accessing services, but as the process of utilizing health care services on a regular basis for both the prevention and treatment of illnesses, while Donabedian (1973) refers to HCU as simply satisfying one's *need* to use services.

Authors investigating the variations in HCU have used different indicators to measure utilization. Some consider HCU as a single consultation while others consider the type, frequency, location and purpose of each consultation (Andersen, 1995; Rosenberg & Hanlon, 1996; Scheppers, van Dongen, Dekker, Geertzen, & Deeker, 2006 ; Wardman et al., 2005).

Among the numerous frameworks and models developed to analyse and understand HCU, Andersen's Behavior Model of Health Service Use (Andersen, 1968) is the most commonly used (Blais & Aboubacrine, 1999; Phillips, Morrison, Andersen, & Aday, 1998; Scheppers et al., 2006). This model has undergone constant revision (Andersen, 1995; Andersen & Newman, 1973), critique (Bass & Noelker, 1987; Guendelman, 1991) and has been adapted by other researchers to analyze different contexts of HCU.

The initial model introduced three determinants to HCU, *predisposing factors, enabling factors,* and *need. Predisposing factors* are individual level characteristics with low potential for change e.g. age, sex, and ethnicity. *Enabling factors allow* a behavior to occur, have high potential for change and are strongly associated to HCU e.g. the availability of health personnel and facilities, while *need* is presented as both individuals' perceived need and clinicians' evaluated need to utilize health care services. *Need* has been described to have a low potential for change, however this is questionable, as education has been suggested to alter one's perceived or evaluated need for use (Andersen, 1968).

The model has since evolved (Andersen, 1995; Andersen & Newman, 1973) to include other factors such as *Environment, Health Behavior* and *Health Outcomes.* For example, *Environment* acknowledges the importance the health care system (policy, resources, organization) and external environments (political and/or social situations) have on HCU and subsequently, health outcomes. Contextual characteristics represent the *opportunity structure* available to individuals and are based on the structure, functioning and accessibility of health care services, which is further influenced by the economic status of the environment.

Although Andersen's Behavior Model of Health Service Use (Andersen, 1995) and other health behavior-environment models (Daniel & Green, 1995) address contextual factors influencing HCU, most existing studies predominately focus on individual level factors. Environmental factors, such as the health care system or the community are known to play an important role in utilization but are not well understood and provider-related characteristics, such as physician's gender equally influence utilization but are still largely neglected in the literature (Phillips, K.A., et al. 1998). Litaker (2005) and Phillips (1998) recommend the incorporation of larger, contextual factors to enable appropriate comprehension of the milieu where HCU occurs and thus facilitate effective usage, such as the consideration of the social and economic climate of a region, availability and access to health care services, poverty and racism.

Health Care Utilization Among Ethnic Minorities

Identifying the factors influencing HCU are complex; such influences vary among individuals, their surrounding environment and are subject to constant change over time, as environments and the individuals within them jointly evolve (Scheppers et al., 2006). The specific barriers of HCU linked to ethnic minorities are presented below.

Ethnic minorities have been shown to utilize health care services differently when compared to the general population (Plunkett & Quine, 1996; Scheppers et al., 2006 ; Walsh, 2001), with such utilization occurring at a lower rate despite a greater level of need. Ethnic minorities have been shown to be the least likely group to identify a regular source of health care and those most likely to perceive bias when seeking treatment (Litaker, Koroukian, & Love, 2005). A lower level of utilization among ethnic minorities has been linked to numerous factors, with limited intercultural communication presented as one of the most significant barriers to HCU. Health care provider's poor language skills, communication style and lack of interpreters negatively influence use (Betancourt, Green, & Carrillo, 2000; Plunkett & Quine, 1996). Communication problems affect how patients understand their illness or the treatments given to them. In a study by Betancourt et al. (2000) investigating the challenges in cross-cultural health care, there was evidence of a disjunction between the levels of perceived need to utilize health care services among ethnic minorities compared to the level of need evaluated by their health care provider. Ethnic minorities have also opined that health care providers lack important cultural knowledge; are often unaware of existing cultural differences (Betancourt et al., 2000; Plunkett & Quine, 1996) and may not consider a patient's particular needs (Scheppers et al., 2006).

Further, ethnic minority groups have been shown to perceive the quality of care they receive as low (Scheppers et al., 2006). There may well be differing criteria on which patients and health care providers assess the quality of care given or received. Individuals have been found to assess the quality of services based on interpersonal interactions between the provider and themselves, referred to as health care providers' "responsiveness" (Shengelia B., Tandon A., Adams O., & C.J.L., 2005). Lack of responsiveness or the presence of an impersonal approach among health care providers has been shown to leave patients dissatisfied with the services they receive and as a consequence, to label such services as of poor quality (Shengelia B. et al., 2005). Another factor affecting HCU is a patient's limited knowledge of how to access health care services. A study investigating the difficulties carers from non-English speaking backgrounds experience during HCU listed being unaware of available services and problems accessing health services as primary reasons underlying under-utilization (Plunkett & Quine, 1996). Minority groups may feel intimidated utilizing heath care services and thus refrain from asking questions of health care providers (Khan, N. 1994). Isolation (Devitt & McMasters, 1998), social circumstances (Scheppers et al.2006), poverty and cost of health care (Haddad & Fournier, 1995) also influence HCU.

Ethnic minorities face different barriers to HCU when compared to the general population. They are a highly vulnerable population due to lower levels of education, income, and social status and are often victims of discrimination (Scheppers et al., 2006). Barriers can affect individuals from various ethnic minorities in diverse ways, and therefore cannot necessarily be generalized; however, the literature represents a good overview of potential obstacles ethnic minorities face when attempting to utilize health care services.

Health Care Utilization Among Aboriginal Individuals

The factors influencing HCU among Aboriginal individuals are similar to those influencing ethnic minorities, yet a number of issues specific to Aboriginal individuals are also evident. As for other ethnic minorities, Aboriginal individuals have different utilization patterns, and experience intercultural communication problems, lack of cultural awareness among health care providers, poverty, limited knowledge of their illness and how to access health care services (Devitt & McMasters, 1998; Gruen, Weeramanthri, & Bailie, 2002; Walsh, 2001). The general barriers to HCU among Aboriginal individuals are presented below.

Aboriginal individuals often express concern over the lack of Aboriginal healthcare workers available to them. Aboriginal patients explained that Aboriginal healthcare workers help them feel comfortable in an unfamiliar setting and alleviate communication problems arising between health care providers and themselves (Andrews et al., 2002; Hayman, Wenitong, Zangger, & Hall, 2006; Wardman et al., 2005). The majority of Aboriginal patients (72%) use health services provided by Aboriginal healthcare workers and the same proportion state that traditional ceremonies and activities are integral to their health care process (Wardman et al., 2005).

Although Australia has a publicly funded health care system, poverty is documented as a barrier to HCU among Aboriginal Australians (Gruen et al., 2002; Marrone, 2007). Patients who have to relocate to town or cities to access appropriate care often lack sufficient funds for transportation, accommodation and food (Gruen et al., 2002).

Recent research focuses on the impact of racism on health (Larson, Gillies, Howard, & Coffin, 2007; Paradies, 2006). Interpersonal racism is significantly associated with poor mental and physical health among Aboriginal Australians (Larson et al., 2007). Health care services in Australia are described as institutionally racist for various reasons, including inadequate health care funding for Aboriginal Australians' higher level of need, generally low level of culturally appropriate services, and displaying differences in treatment regimes between white and Aboriginal patients (Henry, Houston, & Mooney, 2004). In a Canadian study by Baker & Daigle (2000), members of the Mi'kmaq First Nation community felt "lessened as a person" when health care professionals insulted them and treated them as "dirt" because of their native status. Patients felt humiliated, embarrassed and hurt by what they perceived as health care professionals discriminatory treatment. Although experiences of interpersonal or institutional racism may evidently deter HCU, there is a current lack of research identifying the effect racism has on HCU among Aboriginal populations.

Living in remote or rural areas also acts as a barrier to HCSU among Aboriginal people as limited health care services and specialists are available (Gruen et al., 2002; Marrone, 2007). This is especially troubling considering that over 70% of Aboriginal Australians live in rural areas (Marrone, 2007). Aboriginal people report feeling isolated and lonely when they have to access health services in town, stating that it is especially difficult to leave behind their family members and community (Devitt & McMasters, 1998). Negative past experiences with HCU, such as staff unfriendliness and miscommunication also affect use (Baker & Daigle, 2000; Walsh, 2001; Wardman et al., 2005). Gruen (2002) reported cultural inappropriateness, poverty and health service structure as barriers to HCU among Aboriginal people living in the Northern Territory.

There are, however, interventions that have been shown to reduce barriers to accessing health care. Across the Top End of the Northern Territory, the establishment of outreach services helped overcome barriers such as distance, communication issues and lack of cultural awareness often experienced by Aboriginal people, increasing HCU by over a four fold (Gruen et al., 2002).

Health Care Utilization Among Cardiac Patients

Western studies examining the factors influencing HCU among cardiac patients have primarily focused within the context of attendance at cardiac rehabilitation programs (Beswick et al., 2004). In the United States, factors hindering use of cardiac rehabilitation programs among rural residents are linked to an individual's *intent* to attend a cardiac rehabilitation program. Intent is usually defined based on clinician's referral and is the most significant factor influencing participation (J. E. Johnson, Weinert, & Richardson, 1998). Having to travel long distances to participate in cardiac rehabilitation services is also found to impede utilization (J. E. Johnson et al., 1998). Other factors, such as being young and having social support also positively influence participation as younger individuals are more frequently referred to cardiac rehabilitation programs than older cardiac patients (J. E. Johnson et al., 1998; N. Johnson, Fisher, Nagle, Inder, & Wiggers, 2004). A study by Beswick et al. (2004) demonstrated that lower participation rates were associated with demographic variables such as older age and gender (females are less likely to participate) and social structure variables such as social deprivation and ethnic minority status.

Conversely, Aboriginal Australians described different factors influencing participation in cardiac rehabilitation programs, including competing priorities, miscommunication, lack of Aboriginal healthcare workers, cultural understanding, and continuity of health services, particularly for individuals living in remote area communities (Hayman et al., 2006). Only 6% of eligible Aboriginal cardiac patients living in remote areas of Queensland utilized cardiac rehabilitation programs. Low participation rates are primarily linked to lack of knowledge of cardiac rehabilitation programs. Other factors, such as low-income and having a large extended family also contribute to this low rate. Purchasing healthy foods required for rehabilitation programs is often expensive and Aboriginal Australians customarily purchase and share their food with their entire family (Shepherd, Battye, & Chalmers, 2003).

Recently, a series of research projects has focused on cardiac disease in Aboriginal people from Central Australia (Brown, 2006; Field & Wakerman, 2002; Maloney, 2005). Maloney's (2005) findings and qualitative work from the CASPA Study (Brown, 2006) are worth noting in regards to understanding the factors influencing patients' decision and ability to use health care services. Maloney (2005) sought to explore to what degree patient previous experiences and conceptions of a heart attack influenced delay times and other markers of interaction with necessary care, with particular reference to differences between non-Aboriginal and Aboriginal clients. Aboriginal clients experienced significant structural and communication barriers when receiving care. Participants' experiences of care within the hospital setting were not universally negative, as important positive elements were displayed throughout. Similarly, some patients were happy to receive tertiary care at referral hospitals despite significant fear and difficulties with communication, yet others were not. The factors influencing one's decision to use health care services are complex, particularly within the context of intercultural communication and health care system interaction.

Preliminary qualitative data from the CASPA Study (Brown, 2006) involving interviews with over 100 patients experiencing acute heart disease has also outlined important structural barriers to care for Aboriginal people, particularly for those in remote area communities. One of the most striking finding is that significantly fewer Aboriginal clients, compared to non-Aboriginal clients living in remote areas, are traveling to tertiary referral centres for specialist investigation and care, even though both services have been associated with improved survival. There are likely to be many reasons for this, such as fear, lack of perceived need to seek care or institutionalized racism; however, most reasons are not yet fully understood.

Many factors influence the appropriate care and treatment of Aboriginal cardiac patients. However, data exploring utilization of appropriate cardiovascular health services among this marginalized population is limited despite this population's disproportionately high morbidity and mortality rates (Walsh, 2001). Understanding the facilitators to HCU has not yet been explored in this context, and available preliminary research around barriers to care must be confirmed, extended and scrutinized.

Research Question, Objectives, and Pertinence

In order to address HCU patterns among Aboriginal cardiac patients, we asked "*What are the factors influencing HCU following a cardiovascular event among Aboriginal people in Central Australia?*" To answer this, we had two objectives: the primary objective was to explore the factors influencing HCU following a cardiac event among Aboriginal Australians living in and around Alice Springs, a regional population hub that draws Aboriginal people in from remote surrounding areas and which also includes a substantial Aboriginal population both within and on the outskirts of the town. As a secondary objective, we sought to explore the inter-relationships existing among the factors influencing HCU and how they may affect subsequent use of health care services.

The overall aim of this study was to better assess Aboriginal patient's needs in relation to cardiac care in order to target and align health care service redevelopment across the Alice Springs region. Obtaining information from Aboriginal peoples' perspective will provide policy makers with information relevant to augmenting the factors facilitating HCU and reducing the systematic barriers confronted by this population, thereby improving health outcomes.

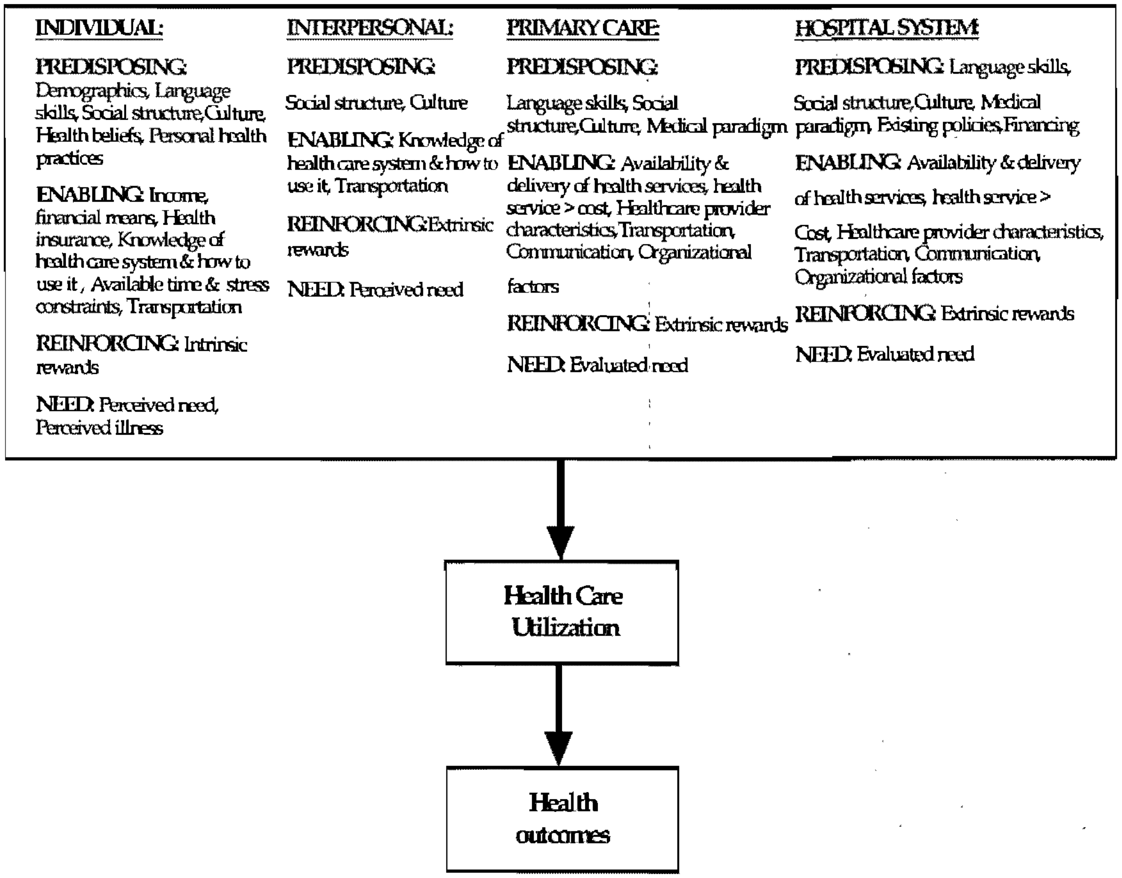
Conceptual Framework

Pre-existing frameworks and models used to explain HCU (Andersen, 1995; Green & Kreuter, 1991; Scheppers et al., 2006) were used to develop an *a priori* conceptual framework (Figure 1, p. 16).

Population characteristics, *predisposing, enabling,* and *need* described by Andersen (1995) and *reinforcing factors* proposed by Green & Kreuter (1991) were combined and resulted in four general conceptual themes presumed to potentially influence HCU through impacts on individual, collective and organizational behaviors (Andersen, 1995; Daniel & Green, 1995). For the purposes of this study, *predisposing factors* are defined as any factor that motivates and/or explains an individual's decision to utilize health care services based on their preferences or related experiences. This utilization behavior stems from demographic and social structure influences operating at ecological levels (Andersen, 1995) and individual level "knowledge, attitudes, beliefs, values and perceptions" (Daniel & Green, 1995). *Enabling factors* are elements or situations that allow utilization behavior to occur. *Reinforcing factors* act as a "reward" following HCU to encourage and/or support the continuation of this behavior. The "reward" or incentive may be intrinsic, such as personal gratification or extrinsic, such as receiving praise from clinicians following a cardiac check up. Finally, *need* is described as an individual's perceived need to use heath care services based on their perceived illness and/or clinician's (physician, nurse, or health care professional) evaluation of their illness.

Figure 1 (p.16) shows how our four conceptual themes have been categorized into four levels of social organization - *Individual, Interpersonal, Primary Care* and *Hospital System*, these distinctions adapted from Scheppers et al. (2006). The *Individual* level refers to patient level characteristics, such as health beliefs and attitudes, language skills and/or previous experiences with health care services. The *Interpersonal* level refers to the support system surrounding individuals, which may influence HCU, such as family support received during a patient's medical consultation. Finally, factors at the *Primary Care* and *Hospital System* levels refer to elements influencing utilization in regards to the health care system itself, such as communication issues, the cultural awareness of staff, organizational factors and availability and delivery of health services. The potential influences of HCU are listed according to their relevant level of social organization and conceptual theme. Use of health care services is viewed as a function of these factors, influencing an individual's decision and ability to use health care services. HCU then impacts on individuals' health outcomes. The factors influencing HCU may be exclusive to one level or may act as precursors to, or as barriers or facilitators at another level, creating inter-relationships between the levels.

FIGURE 1 Factors Influencing HCU Among Ethnic Minorities: an *a priori* Conceptual Framework



INDIVIDUAL:	INTERPERSONAL:	PRIMARY CARE:	HOSPITAL SYSTEM:
PREDISPOSING: Demographics, Language skills, Social structure, Culture, Health beliefs, Personal health practices ENABLING: Income, financial means, Health insurance, Knowledge of health care system & how to use it, Available time & stress constraints, Transportation REINFORCING: Intrinsic rewards NEED: Perceived need, Perceived illness	PREDISPOSING: Social structure, Culture ENABLING: Knowledge of health care system & how to use it, Transportation REINFORCING: Extrinsic rewards NEED: Perceived need	PREDISPOSING: Language skills, Social structure, Culture, Medical paradigm ENABLING: Availability & delivery of health services, health service > cost, Healthcare provider characteristics, Transportation, Communication, Organizational factors REINFORCING: Extrinsic rewards NEED: Evaluated need	PREDISPOSING: Language skills, Social structure, Culture, Medical paradigm, Existing policies, Financing ENABLING: Availability & delivery of health services, health service > Cost, Healthcare provider characteristics, Transportation, Communication, Organizational factors REINFORCING: Extrinsic rewards NEED: Evaluated need

*Adapted from Andersen (1995), Green and Kreuter (1991), and Scheppers et al. (2006).

CHAPTER 3: METHODOLOGY

Chapter 3: Methodology

This chapter is divided into three sections. The first section describes the research strategy used, the research setting, and the study's participants. The second section explains the data collection methods, nature of the data, confidentiality and data security measures, and ethical considerations that applied throughout the study. The third section describes the analytical method used, data preparation and management, and concludes with the transcription and coding process utilized.

The Study

Research Strategy and Rationale

This exploratory study used qualitative methodology to identify the factors influencing HCU following a cardiovascular event among Aboriginal Australians living in and around Alice Springs. Qualitative research is known for its "interpretative, naturalistic approach" (Denzin & Lincoln, 2000). It studies participants in their natural settings to obtain an in-depth understanding or interpretation of the phenomenon under question. Little is known about the conditions and factors that constrain or facilitate HCU in hard to reach populations like Aboriginal Australians. For this reason, an exploratory qualitative approach was taken that was culturally respectful and congruent with Indigenous knowledge and traditions (Battiste, 2000; Castellano, 2000). The use of focus groups and semi-structured interviews based on an illness narrative was ideal in this setting because oral communication is considered the most culturally accepted form of communication (Donovan, 1997). The use of interviews gives this marginalized population a "voice" by allowing them to share rich and detailed accounts of their experiences. Further, interviews are flexible, interactive and generative as participants are encouraged to freely discuss their experiences and introduce new ideas or experiences. Since few studies have addressed the factors influencing HCU following a cardiovascular event among Aboriginal Australians, the inductive nature of qualitative research enabled us to explore these factors rather than impose a priori hypotheses (Ritchie & Lewis, 2004).

Research Setting

On-site data collection and initial analysis was conducted in Alice Springs, Central Australia from September to December 2006. The research was based at the Central Australia branch of Menzies School of Health Research. Cross-cultural verification was conducted on-site, following data transcription to ensure cultural understanding and avoid misinterpretations. Comprehensive analysis and write-up of the results was conducted in Montréal, Québec from January to November 2007 at the Axe santé des populations, Centre de recherche du Centre Hospitalier de l'Université de Montréal -Hôtel-Dieu (CR-CHUM). The data were interpreted through ongoing feedback between the author, Dr. Alex Brown in Alice Springs (field site supervisor for the research) and my supervisory committee in Montréal. The section below describes the principal geographical and population characteristics of the research setting.

Context. Central Australia, the Southern region of the Northern Territory, is home to 50,000 persons spread sparsely across a region of over 1,000,000 km^2. This study was conducted in Alice Springs as well as in two remote area communities and six town camps located within a 200 km distance from Alice Springs. Located in Central Australia, Alice Springs is the traditional country of the Arrernte people and is located in the McDonnell Ranges. The region is remote and distant from the many urban centres predominately located along the Australian coastlines. Alice Springs contains an estimated population of 28,000 in an area of 149 km^2 with Aboriginal Australians representing 17% of this population. In Central Australia, the majority of Aboriginal Australians reside in remote area communities located hundreds of km from town, while others live along the fringes of town in town camps or in the town of Alice Springs itself. While the 2001 census reported 973 individuals residing in the 19 existing town camps, recent research found that town camps serviced as many as 3,000 Aboriginal people living in, or passing through town camps (Northern Territory Government, 2006). Living conditions vary from one remote area community or town camp to the next, with homes ranging from newly constructed dwellings with running water and electricity to make shift tin sheds with no available amenities. In 2005, the estimated household size in town camps was between 8.5 to 12.6 individuals with 20% of individuals living in a house with 10 or more people. Limited available housing has led to the current high levels of overcrowding and homelessness (Northern Territory Government, 2006).

Population characteristics. Over a dozen traditional Aboriginal languages exist in Central Australia. The traditional local language in the Alice Springs region is Central Arrernte. Eighty-five to 90% of Aboriginal Australians living in town camps and remote area communities reported speaking at least one local language at home. In contrast, virtually no non-Aboriginal persons spoke any local languages at home (Sanders, 2004).

The population structure of Aboriginal Australians is markedly different than that of the remaining Australian population; they have a significantly younger demographic profile with a relatively small proportion over the age of 65. Northern Territory residents make up the youngest population when compared to the rest of Australia. One quarter of this population is under 14 years of age, almost half of whom are Aboriginal (Australian Bureau of Statistics, 2001a; Sanders, 2004).

In some remote area communities only half of the school-age children attend school and illiteracy rates are as high as 93% (McMullen, 2006). Of those who attend school as children, even fewer continue with education. In 1998 only 32% of Aboriginal students continued to Year 12 compared to 73% for non-Aboriginal students (Australian Bureau of Statistics, 2001b). In Alice Springs, only a minority of Aboriginal Australians over the age of 15 stayed on in school, and just 3-4% completed grade 11 or 12. Aboriginal students have also been reported as entering high school with an average literacy level of third graders (Smith, 2001). This is alarming, considering that a literacy level of at least Grade seven is considered the standard throughout Australia (Northern Territory Department of Education (NTDE), 1999).

Nationally, Aboriginal Australians are far more likely to be unemployed compared to non-Aboriginal Australians. In Alice Springs, 75% of Aboriginal Australians living in remote area communities and 85% of Aboriginal Australians living on town camps are unemployed compared to 24% of non-Aboriginal Australians living in town. Of the 15-25% of Aboriginal Australians who are employed most work for the Community Development Employment Projects (CDEP) scheme; a "work-for-the-dole" type of employment offered specifically to Aboriginal Australians. The primary sources of income for individuals living in town camps or remote area communities are from Commonwealth government income support payments (social security payments or CDEP).

Overall, Aboriginal Australians living in town camps around Alice Springs are similar to those living in remote area communities; both groups are more likely to speak an

Indigenous language at home, have lower levels of schooling and have higher unemployment rates than their non-Aboriginal counterparts (Sanders, 2004).

Lifestyle and health. Although Aboriginal Australians maintain many aspects of their traditional lifestyle such as language, grieving ceremonies and use of Ngangkaris[1], Western lifestyles are increasingly being adopted, especially among the younger generations. In Alice Springs, fast food restaurants are located on virtually every street corner, thereby substituting healthy traditional foods with high calorie, high nutrient density foods. This is dietary shift is accompanied by a transition to an inactive, sedentary lifestyle. The adoption of the Western lifestyle following colonization has yielded significant health problems among Aboriginal Australians, particularly chronic illnesses such as cardiovascular disease, renal disease, diabetes and obesity (Daniel M, Rowley K.G., McDermott R., & K., 2002; Daniel M, Rowley K.G., McDermott R., Mylvaganam A., & K., 1999; Davis, McAullay, Davis, & Bruce, 2007).

Available health care services. Health care services available to Aboriginal people vary across Alice Springs, town camps and remote area communities and are described below.

In Alice Springs, Primary Health Care includes privately and public funded services. A private system exists within the town of Alice Springs, whereby general practitioners offer fee for service medical consultations. The public system, funded by the Northern Territory government or federal government, is the principle service mode for Aboriginal clients within Alice Springs and remote area communities. These services are free at the point of service to the individual. The principal primary health care service for Aboriginal clients within Alice Springs is a local community-controlled Aboriginal Medical Service (Central Australian Aboriginal Congress). It is located in the town and offers free primary care services to Aboriginal people.

Alice Springs Hospital is the only hospital in the region, with 164 beds catering primarily to acute care patients and an eight-bed intensive care unit. It has no specific cardiac care unit, and on-site cardiology or interventional cardiology facilities are not available. Cardiac patients requiring investigation are transferred, via the Royal Flying

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[1] Ngangkaris: Aboriginal traditional doctors

Doctor Service or commercial airline, some 1,500 km to tertiary hospitals in Adelaide, South Australia.

In Alice Springs, minimal in-hospital cardiac rehabilitation occurs. Similarly, minimal cardiac rehabilitation is available to Aboriginal or non-Aboriginal patients after discharge. Cardiac specialists visit once every three months, barely addressing the level of need. Very few Aboriginal Australians living in Alice Springs have access to cardiac rehabilitation services following discharge while *no* Aboriginal Australians living in remote area communities have access to any form of cardiac rehabilitation.

None of the town camps have local medical services. Individuals requiring medical attention have to seek health care services available in town. In these cases, potential barriers to HCU frequently arise, such as no transportation and/or the lack of financial means to access transportation.

Most, but *not all* remote area communities have access to community health clinics staffed by at least one nurse, Aboriginal healthcare workers, and a primary care doctor visiting on weekly or fortnightly rotations. Health care specialists visit much less frequently, annually or biannually. Individuals requiring more than basic primary health care services often have to relocate into town, leaving their family and community behind, and from Alice Springs they may then need to be transferred to Adelaide, South Australia.

Study Participants

As the present study's primary focus was to understand the factors affecting HCU following a cardiovascular event experienced by Aboriginal Australians living in and around Alice Springs we included, as study participants, Aboriginal cardiac patients, key informants from the health care and research sectors, and non-cardiac community participants. Participants were selected purposively, based on their knowledge and experiences, their willingness to share their stories, and availability to participate in the study (Spradley, 1979).

All participants were required to be at least 18 years old and live in or within 200 km of Alice Springs. Aboriginal participants were required to identify themselves as

Aboriginal and be accepted as such within their community (C. B. Phillips, Patel, & Cabaron, 1993). The rationale for the inclusion of each group of participants and the sampling strategies are detailed below.

Aboriginal cardiac patients. Aboriginal cardiac patients (*n*=7) who had a cardiovascular event between December 2005 and June 2006 were eligible to participate in the semi-structured interviews.

The Australian acute coronary prospective audit (ACACIA)[2] study provided a cohort of 23 potential Aboriginal cardiac participants. The list of participants was made available by Dr. Alex Brown. The ACACIA cohort list allowed our research team to directly contact potential cardiac participants living in town camps, Alice Springs and remote area communities. Eleven of the 23 potential cardiac participants satisfied the eligibility criteria. Five agreed to participate in the study and six were unable to be located. Given our interest in interviewing cardiac patients, we were able to recruit two additional cardiac participants through participants' family members who satisfied the above mentioned eligibility criteria. A researcher involved in the ACACIA study and I interviewed seven Aboriginal cardiac participants.

Key health care and research participants. To be eligible to participate in the study, key health care and research participants (*n*=12) had to be actively involved in Aboriginal research specifically, and to have had previous health care work experience(s) with Aboriginal Australians from Central Australia. All six participants eligible for the unstructured interviews agreed to participate. For the health care professional focus group, 10 individuals satisfied the eligibility criteria; however, one was on leave, one was unable to attend and two were "no shows". In total, six health care professionals participated in the focus group, comprising of an Aboriginal healthcare worker, two Aboriginal liaison officers[3], a cardiac researcher, a nurse and a physician.

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[2] Ethics approval to contact ACACIA participants for future studies had been obtained from the *Central Australian Human Research Ethics Committee* (See Appendix E).

[3] Aboriginal liaison officers: are government-funded interpreters, typically employed at clinics and hospitals. They assist Aboriginal patients with appointments, hospitalization and transfers. They also provide emotional, cultural and social support and often liaise on behalf on patients and their family.

Non-cardiac community participants. Because of the difficulty accessing Aboriginal cardiac patients we purposively sampled non-cardiac community participants with the capacity to offer insights on use or non-use of cardiac services following a coronary event. These participants were selected based on their previous experience supporting family members who had suffered a cardiac event and their experiences utilizing health care services for reasons other than cardiac related problems. Of the 15 non-cardiac Aboriginal community participants interviewed, 13 participated in the focus group discussions and two participated in semi-structured interviews. The 13 participants were divided into three focus groups, two female (n=6, n=4 respectively) and one male (n=3). Two non-cardiac community participants were interviewed individually as it was inconvenient for them to meet on the scheduled focus group dates. In total, 34 individuals participated in the study with the majority identifying themselves as Aboriginal. The total number and characteristics of the participants are summarized in Table I (p.25).

Table I Participants' Characteristics

Participant's Role	Data Collection Type	*n*	Participant Characteristics			
			Gender	Origin	Age Range	Residence
1. Aboriginal cardiac patients	Semi-structured Interviews	7	3 M 4 F	7 I.	42-65	1T 4TC 2RAC
2. Key health care care & research participants	Unstructured Interviews	6	4 M 2 F	2 I. 4 N.I.	30-56	5T 1RAC
	Focus Group-Health care Professionals	6	3 M 3 M	3 I. 3 N.I.	36-49	4T 1T 1RAC
3. Non- cardiac community participants	Focus Group-Female (01)	6	6 F	6 I.	24-66	3T 3TC
	Focus Group-Female (02)	4	4 F	4 I.	28-66	4TC
	Focus Group-Male	3	3 M	3 I.	30-65	2T 1RAC
	Semi-structured Interviews	2	1M 1F	2 I.	*	1T 1TC
Total		34	13 M 21 F	27 I. 7 N.I.		16 T 13 TC 5 RAC

Note. M = male; F = female; I = Ingenious; NI = non-Ingenious; T = town; TC = town camp; RAC = remote area community, * Missing information, to be resolved prior to publication.

Data Collection

Data collection was done in two sequential phases. In phase one, the interview guides for the focus groups and semi-structured interviews were developed and then used to guide data collection in phase two. Unstructured interviews provided contextual and cultural background information, while focus groups and semi-structured interviews gave participants a "voice" and allowed for a deeper level of understanding regarding the factors influencing HCU among Aboriginal cardiac patients. The details of each phase are described below.

Phase 1: Cultural and Contextual Adaptation for the Interview Guide

Unstructured interviews were conducted with key "informants" (participants) from the health care and research sectors involved in mainstream and Aboriginal specific service provision in remote areas. These interviews provided cultural and contextual background information to inform the development of the interview guide used during the focus groups and semi-structured interviews. I went through this process to familiarize myself with the range of contextual factors critical to understanding the social, health research and health service issues specific to Central Australia, as well as the cross-cultural protocols and ethical conduct of research in Aboriginal communities. This process also helped me gain insight on the health status of Aboriginal people living in and around Alice Springs.

The unstructured interviews (*n*=6) lasted between 45 to 60 minutes and were conducted in English. Translators were not requested, as all interviewees were proficient in English. Participants' responses were noted manually during the interviews and expanded upon and typed in a word processing file following the interviews.

Following completion of all unstructured interviews, the research team (Dr. Alex Brown, a local researcher and myself) participated in a debriefing session to discuss the main ideas raised by the participants and present in the literature. Information from both sources was combined to create a list of potential factors influencing HCU across four levels of social organisation - Individual, Interpersonal, Primary Care and Hospital System, and the four conceptual themes - *predisposing*, *enabling*, *reinforcing factors* and *need*. Through this process we identified factors deductively (from the literature) and inductively (from the unstructured interviews) to develop an illness narrative.

The illness narrative represented a starting point for the focus group and semi-structured interviews. It was developed to stimulate discussion in a story-telling format in accordance with the strong oral culture of Aboriginal Australians (Klappenroth, 2004). The narrative recreated an Aboriginal cardiac patient's "typical" past experience when utilizing health care services and described the potential factors influencing HCU from the time of the patient's cardiac event to six months afterwards.

Phase 2: Data Collection

This phase involved conducting focus groups and collecting semi-structured interview data. Observational notes and journal entries were also recorded throughout the course of the study, providing both contextual and methodological background information.

Focus groups. The purpose of the focus groups was for non-cardiac community informants and health care professionals to discuss and describe, in their *own words,* the factors influencing HCU. A total of four focus groups were conducted and included two female focus groups (*n*=6, *n*=4 respectively), one male focus group (*n*=3) and one health care professional focus group (*n*=6).

The first female focus group and the male focus group were conducted at a local community-controlled Aboriginal organization. The health care professional focus group was held at a local Aboriginal research centre and the second female focus group was conducted at the participants' town camp.

Focus groups comprising solely of Aboriginal community informants were separated according to gender for cultural reasons and to ensure cultural safety and respect for participants. Among Aboriginal Australians, health related issues are best discussed between individuals of the same gender; hence "women's business" and "men's business" are not discussed with individuals of the opposite sex. The health care professional's focus group, which comprised of both Aboriginal and non-Aboriginal participants, was the only focus group not separated by gender as the Aboriginal participants stated they felt comfortable discussing such issues with members of the opposite sex.

Focus groups were conducted in a less structured approach (Gubrium & Holstien, 2002), meaning that the illness narrative was used as a starting point for discussion and allowed for flexibility and change in the narrative. For the most part, the illness narrative was used only about half way before the discussion took on a life of its own and participants began discussing their own issues or past experiences in relation to HCU. During this time, the illness narrative (See Appendix A) was used as a "check list" to assure that participants had addressed the relevant issues while acknowledging any new information they presented. The illness narrative identified domains, such as transportation, social support, recognizing the signs and symptoms of a heart attack, clinicians' treatment of patients and perceived need to use health care services.

I facilitated three of the four focus groups while Dr. Alex Brown facilitated the Health Care Providers focus group. An Aboriginal mediator was used to assist in communication between the participants and me during the two female focus groups as the eldest participants displayed limited English language skills and I had no local language skills. All focus groups were conducted in English and lasted between 60 to 120 minutes. They were audio taped and later transcribed, with the exception of the second female focus group, due to a digital recorder malfunction. In this instance, I read the illness narrative to the participants while a remote area nurse noted their responses. The notes were later transcribed.

Semi-structured interviews. The purpose of the semi-structured interviews was to attain a deeper level of understanding regarding the factors influencing HCU from an Aboriginal cardiac patient's perspective and to allow cardiac patients to discuss and describe their experiences in their own words.

The interview guide integrated issues highlighted during the focus groups with elements from the illness narrative, while allowing participants to add and describe their own experiences. The interview guide contained open-ended questions relating to the four broad domains identified in phase one. Each interview commenced with general questions to initiate discussion (Penrod, 2003), such as: "*The day you had your heart problem - how did your body feel?*" and led to more specific questions "*When people go to Adelaide, sometimes they have to go alone. How did you go to Adelaide?* (See Appendix B).

In total, nine individual semi-structured interviews were conducted. Seven of the interviews were conducted with Aboriginal cardiac patients and two were conducted with non-cardiac community informants. All but one semi-structured interview was conducted at the participants' homes, the exception being one non-cardiac community informant, who was interviewed at a local Aboriginal research centre for reasons of convenience

All semi-structured interviews were conducted in English; however, in two cases family members were present to assist participants who spoke limited English. Interviews lasted between 45-60 minutes, were audio taped and later transcribed.

Observation notes. Observation notes were used as a secondary source of information to provide contextual and background information regarding the study's setting and participant's responses. I took observation notes during the focus groups and semi-structured interviews. These were used to describe the context of each session and document information that could not be attained solely from the audio taped data e.g. description of the setting, participants' non-verbal gestures and participants' responses to the questions (level of enthusiasm, anxiety, calmness etc.). Observations made during each session were titled and dated in a journal logbook for easy and quick return to the data.

Journal notes. Journal notes were used to record personal reflections, thoughts and concerns, as well document research progress. Journal entries contained detailed information regarding scheduled appointments, recruitment process, debriefing sessions, methods and procedures for data collection and analysis and difficulties encountered during the study. Notes were typed, dated and separated by week in a word processing file and used as a reference and memory aid during data analysis.

Confidentiality and Security of Data

To ensure confidentiality, participants' names were de-identified using personal identification codes. Hospital and/or clinics' names were replaced by either [hospital] or [clinic]. All original data related to the study will be securely retained for five years at the Centre de recherche du Centre Hospitalier de l'Université de Montréal -Hôtel-Dieu with copies retained under similarly secure conditions at the Menzies School of Health Research in Alice Springs. All data has been stored in locked file cabinets within locked storage rooms with restricted entry conditions. All electronic information is kept in a password protected, confidential manner and will be destroyed after the elapsed time period.

Ethical Considerations

Approval was obtained from two separate Human Research Ethics Committees: the *Comites d'evaluation scientific et d'éthique de la recherché* in Montréal, Québec (See Appendix C) and the *Central Australian Human Research Ethics Committee* in Alice Springs, Central Australia (See Appendix D).

The *Central Australian Human Research Committee* accepted the research study, but specified that the information sheet presented to participants needed to be expressed clearly and plainly to participants. Consequently, the Informed Consent Form was written in simple terms and all information was expressed orally with the presence of an interpreter when required, to ensure adequate understanding and clarity of the issues addressed.

The Aboriginal cardiac participants contacted for this study were previous participants from the ACACIA study. Ethics approval to contact ACACIA participants for future studies had been obtained from the *Central Australian Human Research Ethics Committee* (See Appendix E).

During our first meeting with potential participants it was explained to them that their participation in the study was entirely voluntary; they were not required to answer all questions if they did not wish to do so; and they were free to withdraw from the study at any time without justification.

Given the cross-cultural context of this study, some knowledge regarding Aboriginal culture, appropriate research and interpersonal skills were required. As I had no previous work experience with Aboriginal people from Central Australia and minimal previous field research experience, I prepared myself by reading the relevant literature, familiarizing myself with the codes of research ethics and discussing relevant issues with Drs. Mark Daniel and Margaret Cargo, who have extensive experience working with Indigenous populations in Canada and Australia. In the field, Dr. Alex Brown, an Indigenous physician who has spent the last seven years developing and understanding the appropriate cultural protocols and ethical conduct for working with Australian Aboriginal people, supported me. Given the potential for miscommunication and cultural difference between the interviewees and myself, I was always accompanied by an appropriate person (e.g. experienced researcher, Aboriginal mediator, or experienced interviewers).

Specific cultural protocols such as sitting along side participants instead of sitting opposite them, avoiding direct eye contact and direct questioning were explained to me and followed during my encounters with participants. As a female, I asked specific permission to interview male participants, in my attempt to respect their decision to discuss “men’s business” with me. None of the male participants expressed any objections to my interviewing them; this may have been because a male accompanied me the majority of the time.

Data Analysis

This section begins with a brief description of the analysis method used. It is followed by an explanation of how the data were prepared and managed, a detailed description of the transcription and coding process and procedures used for validating and crosschecking information.

Analytic Method

The thematic conceptual matrix (TCM) proposed by Miles and Huberman (1994) was used to guide data analysis. A TCM is an ordered type of within-case display, which can be used to visually display data as a matrix or a network from a single "case". For this study, the TMC was used to display information on the factors influencing HCU in a small group of Aboriginal Australians living in and around Alice Springs. The factors discussed by the participants were separated into 4 columns representing the levels of social organization: *Individual, Interpersonal, Primary Care* and *Hospital System*, while the rows of the matrix represented 4 conceptual themes: *predisposing, enabling, reinforcing factors* and *need.* The levels of social organization listed in the columns were adapted from Scheppers et al., 2006 while the higher-order themes listed in the rows of the matrix were theoretically derived from Andersen's Behavior Model of Health Service Use (1995) and Green & Kreuter's health behaviour-environment model (1991). A mixed coding method, which combined deductively and inductively derived codes, was used to code the data. The codes were then listed in the matrix according to their level of influence and associated themes to visually display the data.

Data Preparation and Management

Establishing an efficient data preparation and data management system is essential to assure quick and easy document retrieval (Miles & Huberman, 1994), record the progress of, and facilitate data analysis (Tesch, 1990).

All data was typed and saved in separate Word files and managed in ATLAS/ti (ATLAS.ti, 2004) a qualitative software program. Transcribed texts were then imported into ATLAS/ti and saved as primary documents. ATLAS/ti enabled the management of these primary documents, sorting the codes into different categories and assessing their relationships. The network view provided a visual representation of the linkages between codes, aiding in the conceptualization of inter-relationships. Memo manager allowed easy access to all the comments made during the analysis process. Descriptive memos were used to define and describe codes, interpretative memos contained the questions I posed, my general thoughts and realizations reached during the coding and analysis process and methodological memos traced the steps and modifications made during the analysis process. All data related to the research study (primary documents, quotations, codes, memos, and networks) were saved as one hermeneutic unit (the analytic unit which contains everything relevant to a particular project).

Transcription

In total, 13 primary documents, each pertaining to a participant case, were analysed for this study. These documents contained key observations derived from the observation notes added at the time of transcription. Focus groups (*n*=4) and semi-structured interviews (*n*=9) were recorded using a digital recorder; a hand-held tape recorder was used as back up. Initially, each recording was listened to in its entirety to develop general impressions of the content. I then re-listened to the recordings and transcribed the primary documents verbatim. Transcription details include all non-verbal contexts and observations derived from observation notes, which incorporate emotional content, body language, long pauses, and background noises. A standard notation system was developed and used throughout the transcription process to ensure all non-verbal content was consistently recorded (Darlington & Scoot, 2002). Verbatim transcription of the digital recordings guaranteed that all audio data was available for analysis. The fact that I was the only person transcribing the documents further ensured that the transcriptions were handled in a consistent manner.

Procedural validity of the transcripts. Cross-cultural verification following transcription was used to counteract potential misinterpretations and augment cross-cultural understanding. This was done with consenting participants, clarifying the conceptual meanings behind the English terms used and vague passages. Although all data were collected in English, the conceptual meanings behind some words or phrases had to be verified. For example, use of the word "shame" by many Aboriginal participants had a different meaning when compared to the "western" or English use of the word (Trudgen, 2000). Comments were noted alongside the uncertain statements to clarify their intended meaning while the original statements remained unchanged. Transcription accuracy and reliability was evaluated by re-listening to the recordings while re-reading the transcripts (Darlington & Scoot, 2002). Overall, the transcripts were deemed accurate after minor adjustments were made (e.g., notes on conceptual meanings and spelling of communities' or individual's names).

Coding

Data analysis for this study involved two phases. In the first phase, the focus groups and individual interviews were coded according to a mixed coding approach, incorporating 32 theoretically derived codes from the conceptual framework (Figure 1, p.16). In the second phase, codes were quantified to derive a rough indication of the potential importance of the factors influencing HCU outside of the qualitative data alone.

Phase 1: mixed coding. The initial step of coding consisted of reviewing the conceptual framework to ensure familiarity with the categories guiding the analysis (Van Der Maren, 1996). Initially, this was done on a daily basis, until I was comfortable with the framework. Prior to analyzing the transcripts, each transcript was read twice and a summary was prepared to identify the main ideas (Creswell, 2003; Tesch, 1990).

Data analysis started by coding the two focus groups done with Indigenous women. An *idea* - the segment of text to be coded - was selected as the unit of analysis and was kept constant throughout the coding process to allow for accurate counter-coding and verification. Each unit was assigned a word or short expression or "code" (Tesch, 1990). As transcripts were analysed, deductive codes from the conceptual framework were assigned to each text unit. When text units were identified for which there were no deductive codes, new codes were developed. Thus, coding proceeded through the assignment of text units to either pre-existing deductive codes or new inductive codes.

As I was building the TCM, I was careful to compare and contrast codes with each other and to group them according to their respective similarities and differences. The codes "fear" and "competing priorities", for example, appear in the matrix under the deductive codes of *"individual"* and *"predisposing"* while the codes "no transportation" and "no telephone" are found under *"individual"* and *"enabling"* while "fixed" is found under *"individual"* and *"need"*. In making these distinctions in the coding, it was important to revisit the coding definitions upon which the conceptual framework was based. Using the network views in ATLAS/ti, which allowed me to see the codes visually and in relation to their families, facilitated building the matrix. It is important to note, however, that some codes operated at multiple levels and were assigned their respective levels as suggested by the data. One of the most complicated examples concerns the code "ORG poor quality of care" which operated both at the *"primary care"* level and the *"hospital system"* level under *"enabling"* and *"need"*.

In coding the data, relationships between categories were identified with the aid of the network view in ATLAS/ti. Specific types of relationships included: "a consequence of", "because of", "is associated with", and "is part of". Specifying these relationships points to hypotheses that may be worthy of testing in future studies. The categories were linked by directional arrows, creating a hierarchical flow chart display aiding in the conceptualization of the interrelationships existing between the conceptual themes and their levels of social organisation.

Data were coded, compared and contrasted for all 13 transcripts. Analysis proceeded more slowly at the beginning and progressed more quickly as I became familiar with the conceptual framework. During the coding process, patterns became evident as similarities and differences between codes arose. Similar patterns were depicted among the participants' experiences utilizing health care services. For example, all participants spoke about miscommunication arising between the clinicians and themselves and their lack of understanding regarding their illness, medical procedures and prescribed medications. Other issues were not so uniformly represented, such as participants' discussion of the transportation services available at the Hospital System level.

Procedural validity of the coded data. The validity of the coded data was verified using the following techniques. First, the use of a mixed coding method meant a constant return to the conceptual framework and research question whenever a new code emerged in order to verify its relevance (Van Der Maren, 1996). For example, participants' experiences presented new codes such as "racism", "mistrust", and "fear"; barriers not previously considered in the conceptual framework, but relevant to the research question.

Second, a lexicon, a precise document explaining the coding rules and definitions, was developed. It aided in attaining conceptual validity, coding consistency and intra-coder reliability, later assessed by personally counter-coding the transcripts. Coding was standardized, meaning that the same codes were attributed in a systematic manner to the same comprehensible units (Van Der Maren, 1996). Third, the coded data were then verified through counter-coding, a process where the analyst refers back to the transcripts and "blindly" codes with the aid of the lexicon. Six of the 13 primary documents were randomly selected and counter-coded resulting in an intra-rater reliability of 84% (Miles & Huberman, 1994; Van Der Maren, 1996). Counter-coding enabled me to re-define the codes where problems of conceptual validity occurred, make necessary adjustments and thereby increase the conceptual validity of the data.

Phase 2: data transformation. In the next phase of the data analysis process, the qualitative codes were quantified to visually represent the magnitude of the factors influencing HCU and to derive a rough indication of the potential importance of the factors influencing HCU outside of the qualitative data.

Two specific strategies were used to quantify the data for this purpose. First, the use of counting enabled me to "see" the data by looking at the distributions of the codes, categories and themes. Second, a frequency graph was exported from ATLAS/ti to Excel so that column graphs could be generated. Through a time consuming process, codes were assigned to each individual focus group participant. It was then possible to determine how many people in any focus group mentioned each code. The codes were calculated for all participants in the following manner: each code mentioned by each participant was counted as one, regardless of how many times a participant mentioned that code, e.g. a participant mentioned the code "fixed" three times, the code "fixed" was counted as one for that participant. The totaled codes were then regrouped into their categories and summed to provide a column graph at each level of social organization.

Opportunistic member checking was conducted following the analysis of the transcribed data. Member checking was used to verify the results with agreeing participants by providing them with a summary of the key findings (Creswell, 2003, Donovan, & Spark, 1997). Participants strongly agreed with the results, stating they were congruent to their own and/or significant others' experiences with the health care system.

CHAPTER 4: RESULTS

Chapter 4: Results

This chapter describes the results based on the analysis of the transcribed data generated from the focus groups and semi-structured interviews and from the deductive codes provided in the conceptual framework (Figure 1, p.16). The results are listed according to their levels of social organization: *Individual, Interpersonal, Primary Care* and *Hospital System* and their magnitude of importance. Results are supported through the use of quotations, a standard practice of qualitative research. The chapter concludes with a framework that explains the factors influencing HCU among Aboriginal Australians living in and around Alice Springs.

The results described in the next section apply to both the *Primary Care* and *Hospital System* level influencers; results exclusive to just one level are indicated as such.

Primary Care and Hospital System Level Influencers

The most predominant barriers to HCU for Aboriginal Australians in this study were issues classified as enabling factors, such as Communication Issues, Organizational Characteristics, Availability and Delivery of Health Services, Racism and Lack of Cultural Awareness. Other factors affecting HCU were the predisposing factor Western Biomedical Model and the reinforcing factor Lack of Health Care System Support/Ownership.

Communication Issues

Miscommunication was the most influential factor hindering participants' decision to utilize health care services. Participants discussed Communication Issues arising at various levels and the impact of poor communication on the process and outcomes of care. These are described below.

Limited communication between the health care system and the patient. A major issue was miscommunication that frequently occurred between clinicians and patients, either when the clinician explained the necessary information to the patients but did so in an inappropriate manner, or when the clinician simply did not provide the necessary information to patients.

In the first situation, clinicians explained the nature of patients' illnesses, cardiac procedures and medications, but often did so in ways that were confusing to patients. One nurse acknowledged this miscommunication problem: "I don't think the majority of the time when I explain things to people they understand at all what I'm telling them."

Many participants complained of clinicians' use of complicated medical jargon and their inability to speak local languages. They explained the need for information to be relayed in their own language to ensure accurate understanding of their illness and the medical concepts and terms used. However, local language skills were not a prerequisite for staff prior to their employment at the health care services. The majority of clinicians had no local language skills.

Participants explained that they desired information be communicated to them clearly and expressed frustration at not being able to comprehend clinicians' explanations:

> Well, sometimes I can't understand them, they talking that type of language they learnt in medical school, you can't, you don't know that! I tried to look up a few words in the dictionary; it's not there, IT'S JUST NOT THERE, I mean you gotta look up in doctor or medical books.

In the second situation, clinicians simply did not explain relevant information or details about patients' condition, cardiac procedures or prescribed medications. Participants felt that clinicians were intentionally withholding important information by not explaining what was wrong with them: " I just say, 'What's wrong with me?' and [clinicians] tell me 'Oh, nothing wrong here, you all right, go home, go home tomorrow', just like that." Clinicians' lack of explanations affected patients' trust in them and the health care system.

Inadequate explanations regarding patient's illness left patients uncertain about their health status.

> Well, (long pause), I went to see doctors in hospital and at the [clinic] here… and they always tell me I got a weak heart and sometimes other doctors tell me I got a BIG heart, I don't know which one to believe, you know?

Participants explained that they were often afraid and/or anxious to undergo necessary cardiac procedures because clinicians did not tell them what to expect. One patient described the fear and confusion she felt during an angiogram procedure as a result of this:

> When I got down there [hospital], umm, they shaved my groin but they never done the test through the groin. They done the test, they put the tube through here (pointing to her wrist and then her elbow) and I didn't know what to do… I was full naked on a big operating bed, just with a blanket over me and a plastic over my arm…and I was thinking, if they want to do something with my arm, then why am I full naked? I must be gonna die, that's what I was thinking, I might die!

Communication Issues, negative Previous Experiences and Fear affected patients' future HCU.

In addition to not understanding their illness or cardiac procedures, clinician's poor explanations also affected patients' understandings of their prescribed medications. Medications were handed to patients with a written indication of use or they were briefly explained without assuring proper patient comprehension. This meant that patients were sent home without a clear understanding of how or when to take their medications:

> I take my tablets, don't know what tablets they give me, the nurse just got tablets for me from pharmacy and sent me home. They supposed to be giving you tablets and you know, telling you what to do when you get back home and all that, but nothing.

Many cardiac patients did not know why they were taking their medication "I got a few tablets there, some of them I don't know why I am taking it for." Further, most patients did not understand the need to continue chronic disease medications over the long term: "They get that medicine [first batch] and when they finish that, 'Oh, I'm alright'. They don't realize that they are on tablets for life."

Inappropriate clinician explanations meant patients were unable to fully benefit from their prescribed medications because they were not used correctly or were not adhered to. Patients did not understand the need to continue their medications, which affected their future decision to utilise health care services.

Participants linked limited communication between clinicians and patients to the majority of *Individual* level barriers they experienced. Limited clinician-patient communication resulted in negative Previous Experiences among patients thereby affecting their level trust in the health care system and augmented their Fears. It also affected patient's Knowledge of Illness and their Perceived Need to use health services.

Limited communication within the health care system. It was not uncommon for clinics or hospitals to be unaware of patients' medical histories, their recent cardiac interventions and/or prescribed medications because the health care systems were not effectively communicating these issues. "There was a town person who went down [to Adelaide] the other day and I'm sure [the clinic] doesn't know anything about them, I'm positive."

The lack of communication between the health care systems often meant that many patients were transferred to Adelaide for cardiac interventions only to return to Alice Springs and receive no follow-up care. Health care professionals explained that acquiring knowledge of a patient's recent cardiac admission was "rare" and often "a big bonus". If clinicians had the privilege of knowing this information, their next task required them to "chase up" the treating hospital for patients' discharge summary or test results. One participant described her experience working as a health care professional in remote area communities.

> I've been sitting, as a visiting DMO [district medical officer], in [remote area community] and classic example, I get this discharge summary faxed to me dated from an admission six weeks ago with a patient who's been down, had a cardiac procedure and has got all his medications changed at procedure. Is he back in the community? He's obviously only had, if he's lucky, two weeks worth of medication given to him...so chances are he's in the community, had no follow-up, and he hasn't had enough medications or check-up because we haven't even known he's gone down to Adelaide. That's NOT uncommon, in fact, that's sadly, probably the norm.

Based on participants' accounts it was unclear who was responsible for transferring such information. As a result, responsibility was shifted from one person to the next without the required information communicated between the two treating hospitals or clinic.

> The cardiology team down in Adelaide often say "follow up by the cardiologist or by the medical team in [in Alice Springs]", and it never quite gets communicated for whatever reason, and so suddenly you find six months later that this patient has not been seen by anybody or has been seen by you and you're still waiting for that follow-up.

One participant discussed the dire implications miscommunication had on patient's health outcomes when patients were left abandoned at the airport following their hospital admission; the heath care systems did not inform each other of the patients' arrival to the airport and therefore transportation was not arranged.

> It's a classic example of people who died up north for those same things as communication, people going back out bush [remote area communities]. Old men being left on the side of an air strip somewhere. People have physically died from that lack of communication.

Communication issues occurring between the health care systems were linked to the organizational factors occurring at the *Primary care* and *Hospital System* levels. Poor communication meant medical files were often incomplete and test results were difficult to obtain. Clinicians were often unaware of their patients' health status and therefore did not effectuate the necessary follow-up care.

Limited communication between the health system and the patient's family. Family members were usually not involved in patients' treatment because of the limited communication that arose between the health systems and the patient's family. Participants stated that family members were typically not present during consultation or contacted when a patient was admitted, transferred to or discharged from a hospital. "When someone is going to Adelaide, I [nurse] don't consciously think, 'Oh, does all his family know that he's going to Adelaide?' That is something we don't, I don't do. It's something I actually haven't even thought of." As a result, many family members were unaware of the patient's cardiac illness, the required medical procedures or follow-up care. An Aboriginal liaison officer stated: "I went back and I talked to the household families and they were all 'Hey, we didn't know she was going to have [an operation]...that's new, we never hear it.'"

Limited communication occurring between the health care systems and the patients' family acted as a barrier to HCU because the fundamental role that Aboriginal families play in patient care was not recognized. Health care professionals attributed the difficulties of contacting family members, particularly those from remote area communities, to staff's heavy workload, high staff turnover, limited telephone accessibility in remote area communities, difficulty contacting local staff after-hours and reaching family members due to high levels of mobility[1].

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[1] A common characteristic if Indigenous Australians is frequent intra-regional migration. Over one quarter of Indigenous Australians reported a change of residence in 2001.

The communication issues addressed earlier between clinicians and patients meant full consent of cardiac procedures were often compromised. The need for both patient and family consent was required in this context, as family members often took on the role of interpreters to compensate for the health care systems failing communication methods.

> We are alternating the communication, meaning the consent is not there. It's actually, medically...legally, it's dicey, because its not informed consent! Informed consent here [in Alice Springs] involves full consent of the patient as well as the family, it really does.

Family members are more than just interpreters; they provide guidance, social support, they are decision makers and communicators between hospital and family around the region. They play an integral role in patient care, however their exclusion during consultations and informed consent affected their ability to support patients.

Aboriginal liaison officers. Health care services have tried to alleviate the communication gap between clinicians and patients by providing patients with Aboriginal liaison officers. "There is no understanding between the doctor and the patient. If an interpreter was there, they could interpret what the doctor is saying."

Aboriginal liaison officers provided an alternative to clinician-patient communication problems by translating and explaining medical terminology and procedures to patients in their own language, sometimes at their own home. The presence of Aboriginal liaison officers helped reduce the fears and anxieties often associated with a foreign hospital environment.

Although Aboriginal liaison officers played a crucial role in improving clinician-patient communication issues, these needs were barely being met. Participants complained that they were rarely available and provided inflexible hours at both the Primary Care and Hospital System level. They stated the need for Aboriginal liaison officers after-hours and on the weekends. Aboriginal liaison officers acknowledged their limited availability and explained that the health care system needed to do more to address their demand.

All cardiac patients interviewed confided that Aboriginal liaison officers were not present at the time of their hospital admission thereby compromising what they understood about their cardiac event: “Especially that emergency department too, hey? There is not one interpreter there…and [patient] can’t understand, they’re just nodding their head.”

Finally, many participants discussed the absence of standard guidelines to determine if, or when a patient required an Aboriginal liaison officer. The decision to seek an Aboriginal liaison officer’s services was left to the discretion of the attending clinician, meaning that the use of liaison services relied heavily on the clinicians’ own cultural awareness and understanding of patients needs. “ [Nurse] You can’t have an interpreter there all the time. It’s only for important things like when, you know, you are going to chop someone’s foot off that you need to have an interpreter.”

Disregard for appropriate clinician-patient communication compromised patient’s understanding of their cardiac illness, cardiac procedures and future health decisions. In order for Aboriginal liaison officers to fill the tremendous communication gap between clinicians and patients, the health care system needs to support them by recognizing their importance and increasing their availability.

Organizational Characteristics

Organizational problems posed considerable barriers to HCU for Aboriginal people. Long Waiting Times and Inflexible Hours of care were the basic organizational characteristics impeding use. Meanwhile, other factors such as Poor Intake Procedures and Poor Continuity of Care were linked to Communication Issues and also contributed to the difficulties faced by Aboriginal cardiac patients trying to utilize health care services.

Waiting times and inflexible hours. Many participants complained of the long waiting times and inflexible hours often associated with seeing a clinician.

> What you find is that Aboriginal people get up and walk out. They’ll wait maybe five or six hours and then say, “Ah stuff this, I’m going” because that doctor is not going to see them and so they walk out without even being seen by doctors.

Long waiting times often was the reason behind some participants’ complete refusal to use health care services: “That’s the reason they don’t want to go to [clinic], too long waiting…" Inflexible hours limited the services available to patients at the clinic and in the emergency department, further deterring HCU.

Poor intake procedures. Poor Intake Procedures occurred exclusively at the Hospital System level. Participants experienced problems with their admissions to hospitals following their transfer because appointments were often not scheduled, accommodation was not booked and, in some instances, the receiving hospital had no idea why patients were there: "To get down there [Adelaide] and to find out you wasn't even booked in and they don't even know why you're down there for."

Poor continuity of care. Virtually all patients experienced Poor Continuity of Care following their discharge from the hospital. The health care system's poor organizational management contributed to the lack of continued care and included such issues as a) Incomplete Medical Files, b) Difficulty or Inability to Obtain Test Results and c) Poor Follow-Up Care.

a) Incomplete medical files: Patients' discharge summaries following a hospital transfer were often incomplete or missing. Ideally, they are completed within 72 hours of a patient's discharge. The original copy is placed in the patient's medical records, one copy is given to the patient and a second copy is given to the referring agency. Most participants stated that they never received a letter upon hospital discharge and health care professionals complained that they either never received a patient's discharge summary or, if it was received, it was often incomplete or received weeks, even months later.

> I think you are looking at 60% of discharges are not done. Or else if they are done they are done to a degree that they are of no use, they've put two lines going " they are in for this…" that's it.

Consequently, clinicians were unaware of previous treatment and diagnosis resulting in uncertainty in treating their patients, affecting their follow-up care.

b) *Difficulty or inability to obtain test results:* Similarly, participants experienced great difficulty or were unable to attain their test results. This left patients questioning their health status and delayed their necessary treatments.

> The problem is I have to look at the patient's results. They may have found something. They may have found nothing. If they didn't find anything they need to tell [the patient]. If they found something, they need to tell her too. Otherwise [the patient] is going around "Do I have a heart problem? Haven't I got a heart problem?"

Failure to receive test results led some participants to consider their cardiac interventions a "waste of time". These negative experiences affected patients' trust in the health care system and left them hesitant to use health care services in the future.

c) Poor follow-up care: As part of a secondary prevention program, cardiac patients require a minimum of one follow-up appointment every 6 months. However, following participants' cardiac interventions, participants seemed to fall in a "black hole". None of the seven cardiac patients interviewed received any follow-up appointments with cardiac specialists or even a general practitioner. Patients' discharge summaries and test results were not communicated back to the required hospital and clinic. Consequently, clinicians and patients were unaware of their health status or any need for follow-up care. The health care system did not initiate any form of secondary prevention methods necessary to assure patients' overall survival, better quality of life or minimize risks of future cardiac interventions. Cardiac patients were basically treated for their event and then sent home.

Poor organizational factors were linked to Communication Issues arising within the health care system, affecting patients' ability to receive on going cardiac care.

Availability & Delivery of Health Services

Availability and delivery of health services had an important influence on HCU. Factors such as Limited Escort Eligibility, Lack of Health Care Services/Specialists, Limited Transportation and Lack of/Inappropriate Cardiac Education acted as barriers to HCU.

Limited escort eligibility. This barrier occurred exclusively at the Hospital System level. Escorts were family members or kin who could accompany patients while they were transferred to, or from, a hospital. They helped patients negotiate health care services, translated and explained medical terminology, and most importantly provided social support. However, limited escort eligibility often impeded family engagement within the health care system and impacted on the quality and outcomes of care.

Participants described two problems when trying to obtain an escort, first, minimal resources were available and, second, the escort systems' guidelines were not adapted to meet Aboriginal people's needs.

In the first instance, patients living in remote area communities who required medical attention were flown to Alice Springs via the Royal Flying Doctor Service (RFDS) or patients requiring cardiac interventions were transferred to Adelaide via either the RFDS or a commercial airline, depending on the severity of their condition. However, there were few RFD planes available in Central Australia and limited room on them further restrained escort eligibility. There were only four places available on a typical RFDS plane (2 seats, 2 stretchers); therefore the ability for a patient to bring an escort with them depended on how many patients had to be transferred on that day and the patients' condition. If a patient was in critical condition, both a doctor and a nurse were required on board, reducing the number of seats available to escorts:

> Medical ring you up and say "I got six people that need to go to Adelaide tomorrow!" and you're like, "Well, that's lovely, I have ONE plane that has the potential to go down to Adelaide. So, unless you have a life-threatening thing that needs to go this second, there is no room.

High demands and limited resources meant patients often had to fly alone. Many participants, however, were afraid to fly alone and some told stories of family members refusing to get on the plane, compromising the medical attention they required: "Obviously [refusing an escort] doesn't help the patient who is already scared of what's going on and is already saying, 'No, I don't want to go because I'm not having an escort' they then say no."

In the second instance, the escort system set strict guidelines for escort eligibility that were not adapted to meet Aboriginal peoples needs living in Central Australia. The guidelines were limited to underage patients or those with special needs, neglecting important language barriers and fear commonly experienced by Aboriginal patients.

Limited Escort Eligibility negatively influenced the proportion of patients who agreed to be transferred to Alice Springs or Adelaide for cardiac care:

> That's why, you know that stuff when family members can go with them, it's really important, otherwise you wouldn't get half of what you get now and you probably don't even get most people NOW! You know, with that family member, more likely that they'll go.

Strict escort guidelines set up in the Northern Territory did not address Aboriginal patient's needs, compromised family support and resulted in patient's refusal to utilize health care services.

Lack of health care services/specialists. Despite the high levels of morbidity and mortality experienced by Aboriginal people living in and around Alice Springs, limited health care services were made available to them. The lack of a cardiac unit and minimal cardiac specialists in remote areas and in town acted as a significant barrier, impeding HCU. Absence of cardiac services affected cardiac patients' continuity of care, augmenting their risks for subsequent cardiac events.

Participants spoke of having to relocate from their communities into town so they could access the appropriate health care services: "Not much places up north, ain't a clinic. It's about a two and half-hour drive from Elliot to Tennant Creek, that's the nearest hospital."

This meant participants had to leave their family and community behind to seek treatment in town. Participants described situations of patients refusing treatment so that they could return to their families, jeopardizing their own health because the health systems were not addressing their needs.

> One day she [patient] didn't come in and they were like " go check on that woman, we haven't seen her for a couple of weeks." So, we went to see her and she was sitting down in that house [in town]. She didn't want to get treated anymore; she'd given up on life. She gave up because she couldn't get back to country[2], she lost all hope, she lost herself, who she was, and she had no family visiting her. She was isolated from everything and in the end she passed away.

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[2] Country: home land

This situation was not uncommon. Many participants told stories of patients refusing health care services because they felt isolated, family members were not included in their care, and they could not afford the cost of living in town.

Limited transportation services. A significant proportion of Aboriginal people living in town camps or remote area communities did not have access to transportation. Although the health care system provides transportation, the majority of participants described it as highly inadequate and unreliable, and stated that it impacted their ability to attend medical appointments: "Yah, sometimes [bus service] say they're coming and they don't. They say they are coming on a certain day and then they don't come."

At the Hospital System level, patients transferred from Alice Springs to Adelaide requiring transportation had mixed responses. Some patients said the liaison team provided them with transportation, while others recounted stories of family members left stranded at the airport with no means of transportation from the airport to the hospital. Virtually all patients returning home via commercial airline from Adelaide said that there was no transportation service waiting for them when they arrived at the Alice Springs airport.

Limited transportation services reinforced individuals' negative Previous Experiences and impacted on their future HCU.

Lack of/inappropriate cardiac education. An important part of the post discharge management of cardiac disease is enrolment in a cardiac rehabilitation program where emphasis is on secondary prevention and health education. However, cardiac patients described receiving minimal or no cardiac education. In the rare event that patients received some form of cardiac education they received it during highly inappropriate times, such as in the Intensive Care Unit.

Cardiac education held in such circumstances was far from ideal as patients had just suffered a cardiac event, were frightened and in an unfamiliar environment. Health care professionals stressed the need for post-discharge cardiac services:

> There is enough research out there to say what you're told when you are in the Intensive Care Unit or the Coronary Care Unit, you don't even

> remember 10%...because you're so frightened, and everyone is frightened, no matter what color you are. So, it's as though you need something to be reinforced when you come back and cardiac rehabilitation is what needs to happen.

Some participants described their cardiac education as watching an angiogram video, which was "very westernised in its own approach." None of the cardiac patients interviewed attended any form of cardiac rehabilitation following their event. One clinician described the virtually nonexistent cardiac rehabilitation in Alice Springs as "disgusting", as it was an inconceivable notion not to have cardiac education when Aboriginal people have the highest rates of cardiovascular illness. "I think at the moment there is 15 hours of cardiac education a week, for the whole of Alice Springs. So that's 200 events a year, 15 hours." Limited information was available for cardiac patients to understand their illness, their medication and required lifestyle changes to prevent subsequent cardiac events. This affected individuals' Knowledge of Illness and their Perceived Need to utilize health care services.

Limited resources and the health care system's failure to acknowledge or deliver appropriate services and care to Aboriginal patients was demonstrated by Limited Escort Eligibility, Lack of Cardiac Services and Transportation and Limited/Inappropriate Cardiac Education, thereby affecting HCU.

Lack of Cultural Awareness

Lack of cultural training among non-Aboriginal clinicians and the failure of health care systems to recognize gender appropriate care acted as barriers to HCU. Non-Aboriginal clinicians received minimal or no cultural training prior to, or while delivering health care services in and around Alice Springs. A one-day, Aboriginal Cultural Awareness Program (A-CAP) was offered to hospital staff after 3 months of employment. "You go to A-CAP 1 as part of your orientation...which is one day, and that's it, that will be ALL of you're cultural orientation."

Remoteness, limited resources, understaffed health care services, and immense workload lead to high staff turnover. High staff turnover and limited available cultural awareness programs meant that it was not uncommon for hospital staff to have never attended the cultural awareness program while working at the hospital. As a result, clinicians were seen by participants to Lack Cultural Awareness, which compromised communication with patients and thus their ability to provide appropriate care. This was particularly alarming in a hospital setting where 85% of the patients were Aboriginal.

Another factor influencing HCU was the failure of health care systems to recognize and deal with gender appropriate care. Within Aboriginal Australian culture, gender is highly regarded when seeking health care services. Commonly referred to as "women's" and "men's business", female patients discuss their health issues and are seen by female clinicians and vice versa for males.

> If a male wants a male, well, then a male doctor gotta see that person. You know, that's what I see all the time. When that old lady talking language, I hear her, I just tell that doctor, "She don't want to see you she want to see a female doctor."

However, limited numbers of clinicians in remote area communities and limited hospital staff meant gender appropriate care was often not attained. Participants' decision to use health care services when a clinician of the opposite sex was present varied among participants, regardless of their age or sex. Some participants did not mind being treated by someone of the opposite sex; others sought treatment but felt shame[3] and unease doing so, while other participants delayed treatment until a clinician of the same sex was on duty or their symptoms became extremely severe. "I was really shame for a man doctor to do it. Cause out bush [remote area community], a long time ago, they used to just have women doing it, no men around. And yah, they feel really, really shamed men doing it."

The health care systems' failure to provide cultural awareness programs and gender appropriate care was linked to individuals' negative Previous Experiences.

Racism

A major factor negatively influencing HCU was racism. Almost all Aboriginal participants felt they were not offered the same health care services or treatment options as

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[3] Shame: from the Indigenous perspective, shame includes feelings of embarrassment. It is also used when someone feels they are being treated in a condescending manner.

white patients and that clinicians were purposely not explaining their condition or listening to their concerns. Aboriginal participants expressed strong concerns regarding treatment by clinicians. They stated a perception that clinicians were not interested in their health outcomes and did not want to treat them.

> It's "You do it this way", "This is the best treatment for you" and a white person will come in with the same thing and it's "You got this choice and you got this choice, what do you want to do?"

Some health care professionals agreed with Aboriginal participants, stating:

> We certainly use [interpreter services] well enough if it's a European that comes [to hospital]. A German speaking person, or you know, an Italian speaking person, we automatically go get that [interpreter services] straight away or find someone to do it. But if we want a Pitjantjatjara, or an Alyawarr speaking person, you know, we can use the interpreter speaking services, but we don't.

Furthermore, Aboriginal participants felt that their treatment was affected by widely held stereotypes about Aboriginal individuals: "People think that ALL Aboriginal people drink [alcohol], that's why we get treated the same way, as the drunks in town."

Ambulance drivers' resistance to pick up patients living in town camps depict one way that racism affected Aboriginal individuals' HCU: "There is a lot of stigma from the health service providers about entering into town camps, especially at nighttime."

Participants described instances when ambulance drivers delayed or simply refused to pick up patients living on town camps with a "bad reputation." "As soon as you say, 'I need an ambulance at [town camp]', they say 'What?' especially if it's really serious, if they hear it's at [town camp], then it might be a different story..."

Ambulance driver's resistance represented just one of the significant barriers Aboriginal people had to struggle with on a daily basis in order to utilize the health care services they were entitled to:

> You think "Well, what's the cause of that death rate, why Aboriginal people dying so young?" And the reason why they are dying so young is, if you're born black in this country, from the day you're born to the day you die, you struggle. Everyone look at your color of your skin and they treat you different. And that's the big problem, why a lot of men dying of heart

> disease, kidney disease, diabetes, all these diseases at an early age because their life is just such a struggle…you hear it all the time, and, it's RACISIM.

Constant discrimination experienced by Aboriginal patients led to feelings of disempowerment and loss. "We [Aboriginal people] got no hope…it's a white town now, white community."

Racism affected individuals' trust in clinicians, reinforced negative Past Experiences and affected HCU: "Yah, a lot of those doctors and nurses don't care, you know. Why do Aboriginal people keep on going back when they are sick, broken or what ever? [Clinicians] won't explain it properly."

Western Biomedical Model

The health care system's emphasis on the Western Biomedical Model negatively influenced HCU by Aboriginal peoples. Participants described the health care system as complex, confusing and foreign to them and they were often unaware of how to negotiate it. They could not relate to the lack of relationship between clinicians and themselves and as a result felt uncomfortable utilizing health care services.

Participants described the difficulties they encountered in negotiating the hospital system in Alice Springs and particularly in Adelaide They had trouble finding their accommodation and scheduled appointments. Intake procedures, transfers, meetings with cardiac specialists and enquiring about follow-up appointments were all unfamiliar to them. Participants felt intimidated and confused when accessing health care services. "We went to the resident wing, and he left me there. I had to sign in and then I had to go into the hospital the next day to find out where my tests were and I was lost."

Further, participants stressed the importance for clinicians to build relationships with their patients in order for them to feel comfortable and trust them: "You need to develop a relationship, make it about PEOPLE, gain trust." Clinicians believed that the high staff turn over was one of the reasons for the lack of relationship occurring between clinicians and patients.

> We know that there is such a BIG turn around of nurses, and particularity doctors. A lot of the clients have no idea who the doctors are. Even at [clinic], there are a few people that have been there for quite a long time.

Lack of Health System Support/ownership

A few participants reported that the health care system did not acknowledge the context in which Aboriginal people lived and thus, did not support their needs. The system was described as "top-down," with Aboriginal people uninvolved in the development and implementation of the health care services delivered to them. One participant in particular explained the importance of Aboriginal involvement in health care services:

> Give people the power to be able to say, "Well, we want this" and then resource those ideas. Putting the money behind what the people themselves are saying, not listening to white fella, who don't know nothing about Aboriginal people.

It was stressed that to have effective and functional health care services Aboriginal people must feel a sense of ownership

> First and foremost, it's gotta be clear that Aboriginal people have got to have ownership in programs that are delivered to them. Once they have ownership, they WILL participate, they will be involved, and they will come for services.

Outcome: Poor Quality of Care

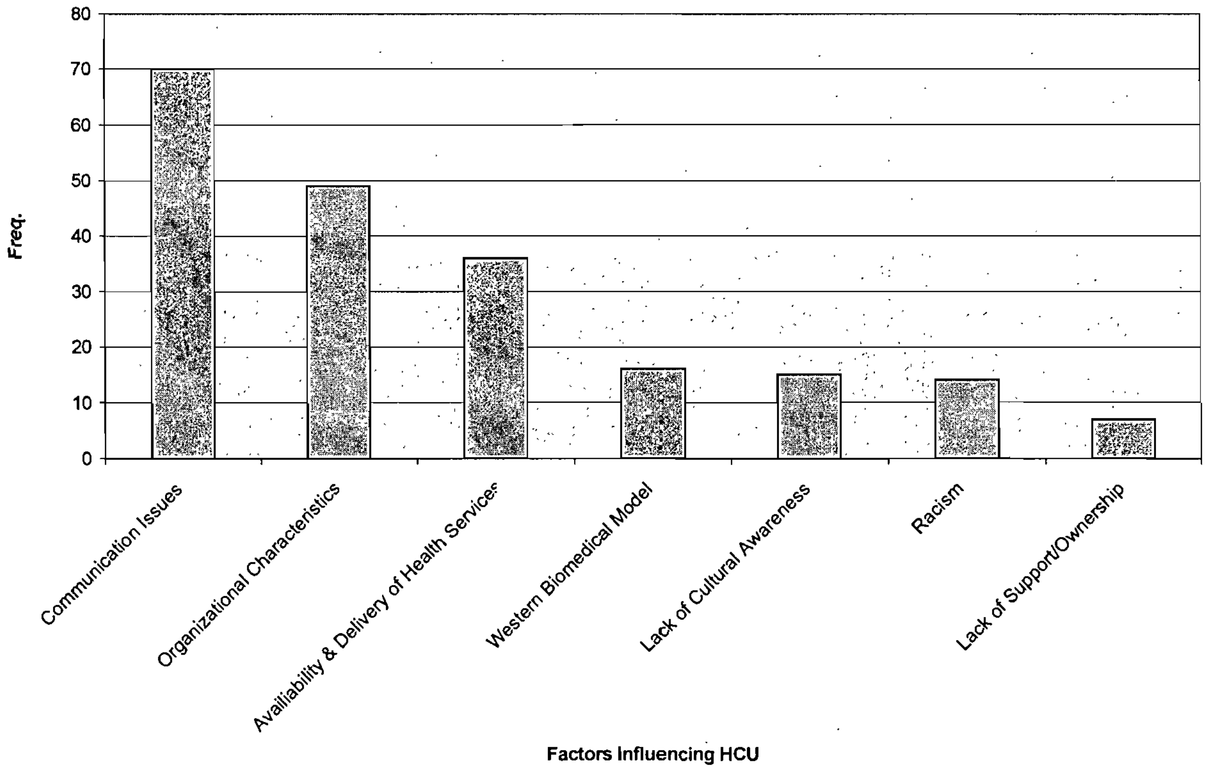
The communication and structural barriers presented at the Primary Care and Hospital System levels resulted in patients receiving insufficient and poor quality of care. Communication Issues arising between clinicians, patients and family members affected individual's Perceived Need to utilize health care services, Knowledge of Illness and contributed to their negative Previous Experiences and Mistrust in the health care system. Poor Organizational Characteristics were linked to Communication Issues and resulted in Poor Continuity of Care as patients experienced great Difficulties in Obtaining Test Results and receiving Follow-Up Care. Limited Availability and Delivery of Health Services meant that family support was often compromised and patients had to relocate into town to access required health services. Inappropriate Cardiac Education affected patients' Knowledge of Illness and their Perceived Need to utilize health care services. The Western Biomedical Model made it difficult for patients to negotiate the health care system. Lack of Cultural Awareness and Racism demonstrated the system's failure to acknowledge and respect Aboriginal patient's needs and beliefs. These factors reinforced negative Previous Experiences and reduced the level of trust individuals had in the health care system. Lack of health care system support further contributed to the poor quality of care received by patients, they were not involved in the development of services and as a consequence, services offered to them were not adapted to their needs.

Many participants described the typical scenario of the care being received as: clinicians quickly assessing them, giving them Panadol[4] and then sending them home. "Doctor just checks you over, you can be sick as a dog and they might just give you Panadol." One participant described how this poor quality of care led to her brother's death:

> My brother had a heart attack when he was only 25. We took him to [clinic] and one of the doctors at [clinic] only gave him Panadol and sent him home instead of getting checked out properly, instead of sending him to the big hospital. He went home and he passed away.

The frequencies of factors influencing HCU at the *Primary Care* level are presented in Figure 2 (p.55). The top three influencers in descending order were: Communication Issues, Organizational Characteristics and Availability & Delivery of Health Services.

FIGURE 2 Primary Care Level Influencers



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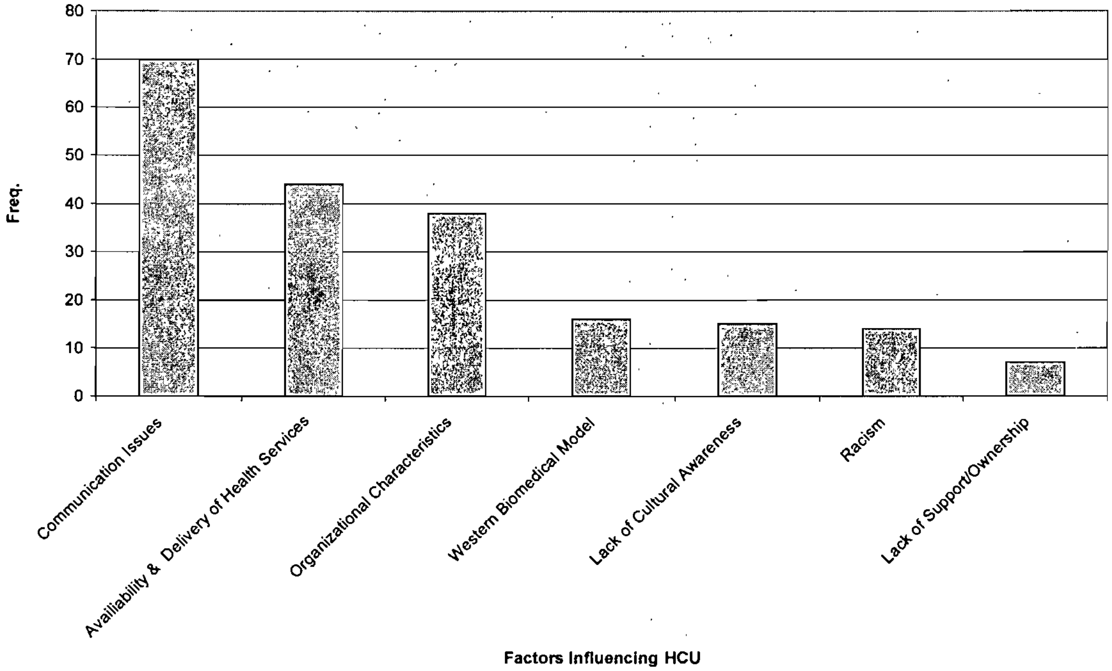
[4] Panadol: paracetamol

Frequencies of the *Hospital System* level influencers are presented in Figure 3 (p.56), in this case, the top three influencers, in descending order were: Communication Issues, Availability & Delivery of Health Services and Organizational Characteristics.

FIGURE 3 Hospital System Level Influencers



Individual Level Influencers

HCU at the Individual level was primarily influenced by one's Perceived Need to utilize health care services (need), negative Previous Experiences (predisposing factor) and Limited Knowledge of Illness (enabling factor). Other predisposing factors, such as Fear, Competing Priorities, Mistrust, and Avoidance Relationships also affected HCU. Lack of enabling factor, Basic Needs, hindered individuals ability to access health care services and predisposing factor, Ability to Negotiate the Health Care System, did not facilitate HCU.

Perceived Need

The vast majority of participants believed they did not need to seek health care services following their cardiac procedures. This was due to many factors, including Lack of Cardiac Education and Communication Issues between clinicians and patients, clinicians and patients' family members and within the health care system itself. Consequently, one of the most prominent factors discussed among participants was the idea of being "fixed" or cured following a cardiac intervention. Limited understanding of their illness and cardiac procedures affected patients' decision to obtain follow-up care. Many patients believed that the cardiac procedures cured them and they no longer needed to seek health care services or take their prescribed medication. The idea of being "fixed" affected HCU and compromised patients' health outcomes.

> They opened for my blockage, oh, what, maybe a half an hour, fifteen minutes? They took photo of me first, you know, that blockage, and then when they opened them, those blockages, they took those pictures after. And then they showed me before and after. Before, it was all blocked and after, it was all clear.

One participant referred to his angioplasty procedure as "magic" and disclosed that he had not gone for a follow-up appointment since his cardiac event 7 months prior to our interview. The idea of being "fixed" following cardiac procedure(s) was further reinforced by many participants no longer experiencing symptoms related to their cardiac illness: "We [liaison officers] get a lot of that from our clients: 'Naw, we alright', 'Hey, you gotta go to follow-up, check up', 'Naw, I feel good now.'"

Some participants even refused to seek further treatment or follow-up care because they believed they were "fixed" or cured.

> Soon as [patients] come back to Alice Springs some of them follow-up, and some of them don't cause they think that's it, that trip down to Adelaide actually fixed them up. They think, "I don't need to, the proper doctors was there."

Participants did not differentiate between "looking fit" or feeling good and being healthy. Most participants believed that if an individual looked good they were healthy. Consequently, participants expressed confusion when a family member or some one close to them became suddenly ill or passed on.

> We had a bloke working out at one of the communities, fit, healthy bloke, skinny, no fat, nothing. He was working at [remote area community] for a construction company and the apprentice went around to wake him up and he was dead on the floor.

Because many participants did not feel the need to use health care services, some decided to leave the hospital prior to being discharged. Participants either took their own leave (TOL), which meant they left the hospital without notifying the hospital staff or they left the hospital by signing themselves out against hospital staff's recommendations. Although health care providers interpreted this behaviour as being uncooperative or refusing treatment, patients left the hospital because they felt they were "fixed". Other reasons for leaving were because of fear, loneliness, missing their family, their country and due to family obligations

Previous Experiences

Previous experiences were either positive or negative and included personal and significant others' past experiences. Most participants had negative Previous Experiences and linked them factors occurring at the health care system level, such as Communication Issues, Racism, Organizational Characteristics, Lack of Cultural Awareness, and Limited Availability and Delivery of Health Services. Negative Previous Experiences reinforced and impacted on other *Individual* level barriers such as Fear and Mistrust.

Aboriginal Australians' strong oral culture acted as a means of transmitting knowledge about previous experiences with health care services. Participant's explained how their own or significant others' negative previous experiences influenced their HSU decisions in the future. Participants' knowledge about family and community members who had died after seeking health care services was the greatest deterrent to HCU This led them to infer causal associations between HCU and death. "That's the story I always hear, you know, 'You going to Adelaide? They gonna put you in a coffin' that's what I hear all the time."

The disproportionately higher levels of cardiovascular illness among Aboriginal Australians and delay in seeking treatment may explain the high mortality rates associated with utilizing health care services: "The patients who are the SICKEST often end up going down to Adelaide and so, therefore, of-course there is going to be a high proportion that suddenly dies."

Participants' negative Previous Experiences and the possibility of not returning to their country was rationale enough for individuals to completely refuse health care services and thus treatment.

Yet negative experiences were not ubiquitous among Aboriginal patients. Positive previous experiences facilitated HCU. Participants explained that having another Aboriginal person recount their previous experiences acted as an important motivator to utilization and educated future patients. It also acted as a form of alternate support for patients having to negotiate the health care system.

> This young fella [Aboriginal male], he wasn't having anything to do with us [nurses] because we were all female and we wanted to teach him about [his] angiogram. And this old lady [Aboriginal female], she's sitting there telling him what they are going to do to him in [hospital]. And it was really good, he listened to her...so, at least it was coming from someone who had been down there, that's been through it all.

Mistrust

Participants' perceptions of clinicians and the health care system were far from ideal and greatly influenced HCU. Mistrust was a consequence of Communication Issues, Racism, lack of clinician-patient relationships and Lack of Cultural Awareness at the health system level and negative Previous Experiences at the *Individual* Level. Miscommunication between clinicians and patients affected patients' understanding of their illness and health status. This meant that participants often misinterpreted the reason why patients passed on and attributed their higher levels of morbidity and mortality to clinicians' mistreatment of Aboriginal patients: "Cause a lot of Aborigine people passing away you know, and they think that doctors are doing something to them." Another patient stated: "They might get sick of it, you know, the job, and give [Aboriginal patients] a needle to go away."

Consequently, participants' decision to seek care was associated with the level of trust and respect patients had for the clinician. Instances where clinicians demonstrated appropriate care and developed relationships based on mutual respect and trust facilitated HCU.

Fear

Fear also influenced HCU and was a consequence of Communication Issues, Racism, Limited Escort Eligibility, the Western Biomedical Model and negative Previous Experiences.

The vast majority of Aboriginal participants described negotiating the health care system, travel, medical procedures and feeling isolated as frightening experiences, particularly when they were alone. "It's scary when... you don't have any family down there [hospital], or don't know anybody."

Staff's inability to speak local languages further enhanced patient's feelings of fear, as they were being spoken to in a language they did not understand regarding important issues, such as their illness and cardiac procedures. Poor intercultural communication led them to misinterpret, or not fully comprehend, what was being explained or what they should expect. "She gets frightened cause she doesn't know what the doctor is talking about, you know. She might have to have an operation and she don't know."

As a result, patients often delayed their treatments, took their own leave (TOL) or refused health care services. " To tell you the truth; I'd be frightened to go there. If a doctor tells me 'You gotta have a big operation' I'd be frightened, I'd say NO!"

> ...Family friend, grew up with us, he had to go down to [hospital]. It was life or death for him, [but] he kept putting it off, he was very frightened. He was a very educated, highly educated bloke. By the time he ended up going down there [hospital], he ended up dying on the operating table.

Competing Priorities

HCU was also influenced by competing priorities, which included current social issues in Alice Springs, family obligations associated with Aboriginal culture and obligations to attend grieving ceremonies.

Participants explained how individuals often prioritized other issues occurring in their surrounding environment over their own health. Participants discussed Grog[7] in particular: "They are not coming quick to hospital. They don't see the doctor. They just sit down and drink, and all that, you know."

Family obligations, such as taking care of family members, were another competing priority that acted as a barrier to HCU. Significant importance was placed on looking after elders and children regardless of the potential health consequences that neglecting one's health may have implied. Many women were worried about leaving their children or grandchildren alone while they are away in the hospital.

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[7] Grog: alcohol

> We try again to explain, you know, "You gotta think about yourself sometimes, ...you're really sick, you gotta go [to the hospital]." And a lot of response, a lot of families, I get "who's gonna look after them [children] when I go?"

Obligations to attend grieving rituals or sorry camp[7] also affected HCU. It was not the cultural requirement to attend sorry camp that acted as a barrier, rather it was the high frequency in which deaths, and thus sorry camps occurred. One participant, for example, was away in remote area communities for two months attending successive sorry camps.

Avoidance Relationships

Avoidance relationships also influenced HCU. They are part of an intricate arrangement within the Aboriginal kinship system that guide individuals' social and intimate interactions. These relationships assign a set of rules regarding whom individuals are permitted to be in the presence of and whom they must avoid. They are applied either continuously such as in the relationship between a mother-in-law and her son-in-law in Central Australia, or may be applied occasionally, such as during ceremonial activities, or can be quite formal in that two individuals may be allowed to be in the same room together, but they must follow certain rules such as avoiding eye contact and/or they must sit sideways from each other (Franks & Curr, 1996).

> Yah, I [Aboriginal healthcare worker] can't talk if he's my relation. He can't tell me, but if he's somebody else, then yes, he can tell me all the story of how he's feeling and I'll explain it to the doctor there. If he's my cousin or something, he can't tell me nothing.

Participants explained that avoidance relationships might deter a patient from seeking care when they were in a direct avoidance relationship with the attending Aboriginal clinician or liaison officer. They spoke of patients waiting until there was another clinician available before they sought health care services.

Limited Knowledge of Illness

The level of knowledge one had regarding their illness, its causes, disease management and potential complications greatly influenced HCU. Participants displayed limited knowledge relating to both their illness and the signs and symptoms associated with

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[7] Sorry camp: grieving ceremony

a heart attack: " Well, I get a little bit weak and palpitation, like I can't breathe properly, yah, I don't know why I am like that."

Participants wanted to acquire more information about their condition however, faulty communication between clinicians and patients and non-existent cardiac education programs meant that patients were often left uninformed.

> Well, I didn't know what was wrong with me. I thought that they might find out what was wrong with me in [hospital], but they just said, "You'll be fine, you'll live a long time". That's not much, you know. I want to know what's wrong with me, inside my body, you know.

The majority of cardiac patients interviewed stated that they had no idea they were having a heart attack at the time of their event. Participants' inability to identify the signs and symptoms of a cardiac event was associated with the fact that their symptoms did not always correspond to what they considered to be "typical", such as having "squeezing pain in the chest" or "chest really tight". Their knowledge revolved around chest pain, but did not include other potential signs and symptoms. Participants described their symptoms as being dull, with no sharp pains in the chest area, "like I'm throwing up inside, and no [chest] pain, no aches..." Although most participants knew of at least one member in their family or community that suffered a cardiac event, this did not ensure their knowledge of the signs and symptoms of cardiovascular disease.

Communication issues between clinicians, patients, family members and lack of cardiac education affected individual's Knowledge of Illness and ability to identify the signs and symptoms of a cardiac event. This affected patients' Perceived Need to utilize health care services both at the time of their event and following discharge.

Basic Needs

Owning a telephone or vehicle was considered a basic need to access HCU. Few participants possessed either one. Many participants worried about having to rely on family members or walk long distances in emergency situations. Relying on family proved problematic at night when family members were less available. Acquiring transportation for medical emergencies was a greater concern for participants in remote area communities. Ambulance services were not readily available for individuals living outside of a 20 km radius from town. This significantly increased a patient's reliance on family or community members. Participants recounted stories of individuals they knew who passed away prior to reaching the hospital because they didn't have access to a telephone or vehicle: "...then she died, that old woman died right there...I brought her where she want to go [hospital], but nothing, she died in the car, right there, that old woman I picked up along the way."

Limited Ability to Negotiate the Health Care System

The majority of participants discussed the difficulties they, or their significant others encountered while utilizing the health care system. However, cardiac participants who were competent to negotiate the system, and who spoke fluent English and requested their own follow-up care, still experienced great difficulties attaining their test results, making appointments with specialists and attaining information necessary to understand their illness. As a result, HCU did not improve despite their ability to negotiate the system.

> She said that she has to make all of her own appointments and chase [clinic] to get what she wants... she calls them when its time for them to fill up her pill box. She said they should do their job.

One cardiac patient described her experience chasing up test results following an angiogram procedure and explained that she still had no response after three months. In the meantime, she was unaware of her health status, what medication, if any, she should take and what possible interventions should be taking place.

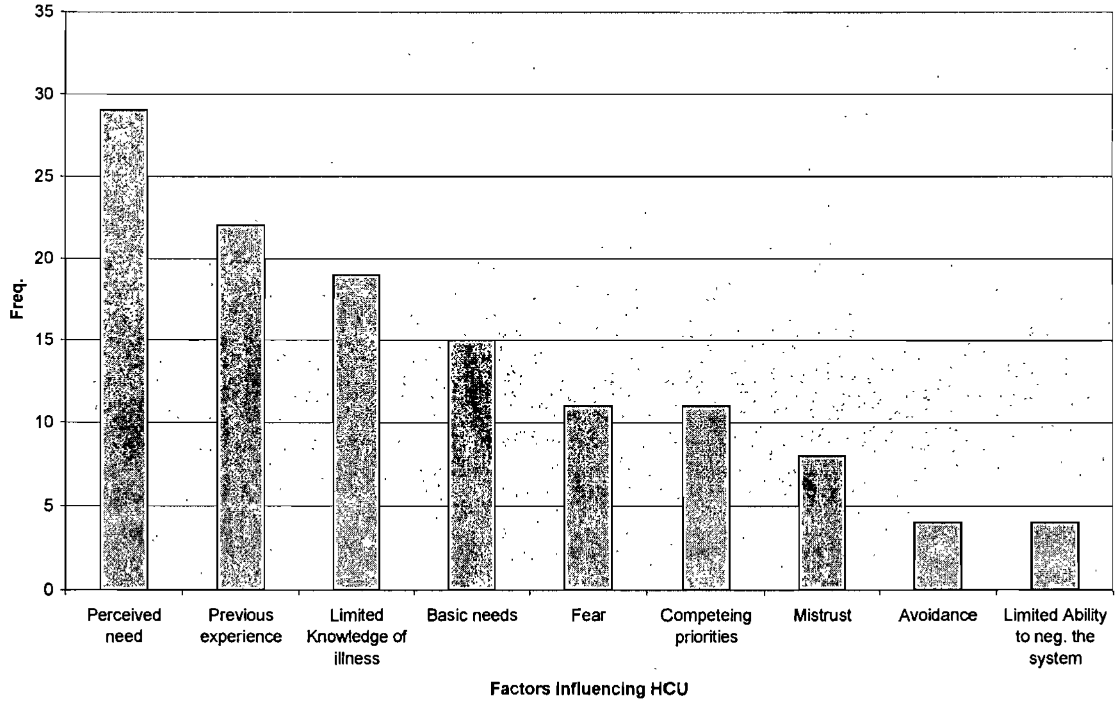
> No, there was no appointment made for me to go back hospital. I don't even know what my results was. I went to [clinic] and told one of them doctors over there and he was following it up for me...this was a few months ago now.

Unfortunately, this was not uncommon, many participants expressed concern regarding their inability to receive test results and obtain follow-up care despite being proactive.

Most of the Individual level factors influencing HCU were a consequence of the barriers experienced at the *Primary Care* and *Hospital System* levels. Perceived need and Limited Knowledge of Illness were a result of Limited Cardiac Education and Communication Issues. Racism, Organizational Characteristics, Communication Issues, Lack of Cultural Awareness and Limited Availability & Delivery of Health Services were found to reinforce negative Previous Experiences. Fear and Mistrust were consequences of Communication Issues and Racism. Fear was also linked to Limited Escort Eligibility and the Western Biomedical Model, while Mistrust was linked to Lack of Cultural Awareness and lack of clinician-patient relationships.

Evaluating frequencies of occurrence indicated that Perceived Need, Previous Experience and limited knowledge of illness were the strongest influencers of HCU at the Individual level (Figure 4, p.64).

FIGURE 4 Individual Level Influencers



Interpersonal Level Influencers

Alternate Support

Because of the various communication and structural barriers to HCU patients often relied on family members, friends or other patients for alternate support. They helped patients negotiate health care services by acting as interpreters, explaining medical procedures and keeping them company during hospital transfers and admission. However, due to Limited Escort Eligibility and the health care systems failure to include family members in patients care, Alternate Support was sometimes compromised. When patients did have access to Alternate Support, it acted as the primary facilitator to HCU.

Family members ensured that there was at least one person present to accompany a patient during their hospital stay. When family members were allowed to do so, they would sleep at the hospital; otherwise, they would return the following morning.

> There's usually two members of the family that would go [to the hospital]. One would go right away and the other would follow probably later on in the week. They are there to support them [patients] and to be acting as a translator for them.

Participants told stories of family members who paid for their own transportation and accommodation in Adelaide when they were ineligible to accompany patients under the escort system. Although a financial strain for many Aboriginal families, kin felt that their presence was important. "YES! That's important [having family with you]. When we went back to Adelaide, my son, family, they flew out on [commercial airline] and come back here [Alice Springs] by train."

Cardiac patients who had previously utilized health care services and who, therefore, had some knowledge of how to negotiate the health care system, also acted as an Alternate Support. They described helping other patients in the hospital by bringing them to their appointments, making sure their accommodation was booked and explaining to patients where they had to go and what they had to do while they were in the hospital.

> When I got down there, I slept at residence wing because I knew where to go now. There were some other people from out bush and they didn't know where to go, so I said "Just follow me, I've been here before.

Alternate support played a fundamental role in increasing patients' HCU, a factor that the health care system must acknowledge if it is to improve utilization among Aboriginal patients: "A lot of people don't want to come unless they got family members."

The next section describes the framework developed to explain the factors influencing HCU. The framework presented in Figure 5 (p.66) is based on the study's results following the analysis of the transcribed data generated from the focus groups and semi-structured interviews and from the deductive codes provided in the conceptual framework (Figure 1, p.16).

Framework and Summary

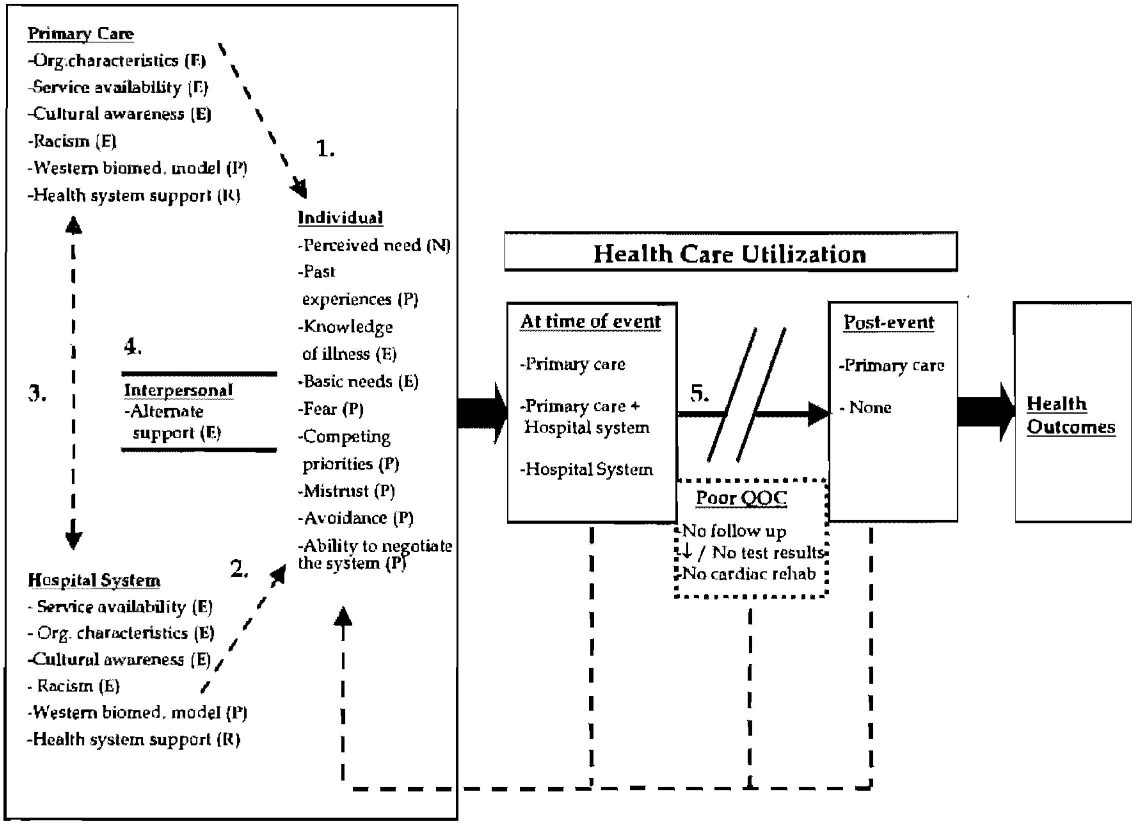
The first box displays how the levels of social organization: *Individual, Interpersonal, Primary Care* and *Hospital System*, influenced HCU and subsequently health outcomes. They are identified according to their groups of influence: *Predisposing* **(P)**, *Enabling* **(E)**, *Reinforcing* **(R)** and *Need* **(N)**. Lack of enabling factors predominately influenced HCU at the *Primary Care* and *Hospital System* level, predisposing factors influenced *Individual level* factors, while the enabling factor, Alternate Support, facilitated HCU at the *Interpersonal* level. The health care system presented the strongest barriers and significantly influenced *Individual* level factors, and thus HCU. Communication Issues were the most significant barrier to HCU and are thus represented by the dashed arrows: **1**, **2** and **3.** Number **4** represents how Alternate Support links the health care system and the individual, facilitating HCU. HCU is a function of all these factors, acting either separately, or in combination.

HCU is shown in the "At time of event" and "Post-event" boxes. At the time of their cardiac event, participants described using *Primary Care* and *Hospital System* services or using either one exclusively. Post-event, some participants described utilizing solely *Primary Care* services, mainly to refill their monthly prescriptions, while other participants described not utilizing any health care services at all.

The barriers experienced by individuals at the *Primary Care* and *Hospital System* levels following their cardiac event resulted in patients' receiving *Poor Quality of Care (QOC)*. The slashed arrow, **5** represents the lack of continuity of care following their cardiac event. Patients did not receive follow-up care, had difficulty or did not receive their test results and no participants received any form of cardiac rehabilitation. These factors compromised patients' future HCU and impacted on health outcomes.

Feedback loops represent how HCU affected individual's subsequent decisions to use health care services.

FIGURE 5 Factors Influencing Health Care Utilization following a Cardiovascular Event Among Aboriginal Australians in Central Australia.



Legend:

– – – – →	Communication Issues
—//—→	Breakdown in continuity of care
QOC	Quality of Care
(P)	Predisposing
(E)	Enabling
(R)	Reinforcing
(N)	Need

CHAPTER 5: JOURNAL ARTICLE:

Factors Influencing Health Care Utilization Following a Cardiovascular Event Among Aboriginal People in Central Australia.

***Journal to be submitted to:** Medical Care Research and Review

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Factors Influencing Health Care Utilization Following a Cardiovascular Event Among Aboriginal People in Central Australia.

Cardiovascular disease (CVD) is the primary cause of early adult mortality among Aboriginal Australians (Paradies & Cunningham, 2002) and is the single greatest contributor to the burden of disease in the Northern Territory of Australia (Zhao, Guthridge, Magnus, & Vos, 2004). Among Aboriginal Australians, age-standardised cardiovascular mortality is twice that of the general Australian population, with age-specific mortality rates between six to eight times that of other Australians aged 25-64 years (Walsh, 2001). Compared to other Australians, CVD is three times more prevalent among Aboriginal Australians (Mathur, Moon, & S., 2006). In the Northern Territory, CVD accounted for 19.1% and 15.7% of the disease burden among Aboriginal men and women, respectively (Zhao et al., 2004). The premature mortality resulting from CVD is a major contributor to the 20-year life expectancy gap between Aboriginal Australians and non-Aboriginal Australians.

Despite disparities in health status, Aboriginal Australians utilize health care services differently and at much lower rates (Deeble, Mathers, & al., 1998; McDermott, Plant, & Mooney, 1996; Walsh, 2001). Specific to the Northern Territory, Aboriginal patients have higher rates of cancellations, non-attendance at scheduled appointments and premature discharge against hospital staff's advice (Gruen, Weeramanthri, & Bailie, 2002). Even when Aboriginal Australians do utilize health care services, they may experience a wide range of difficulties, particularly when interacting with non-Aboriginal clinicians, including communication problems, lack of cultural awareness, racism and loneliness (Andrews, Simmons, Long, & Wilson, 2002; Hayman, Wenitong, Zangger, & Hall, 2006; Wardman, Clement, & Quantz, 2005). Specifically, few cardiac services and specialists are available in rural and remote areas of Australia (Clark et al., 2007) and HCU among Aboriginal Australians in need of cardiac management programs is low (Shepherd, Battye, & Chalmers, 2003), even though evidence has linked use of these programs to significant health benefits (Aoun & Rosenberg, 2004; Clark et al., 2007; Hare & Bunker, 1999).

To date, studies investigating HCU have predominately addressed individual level factors including demographic variables, education and income levels (K. A. Phillips, Morrison, Andersen, & Aday, 1998). An individual-oriented framework places primary responsibility on the individual regarding their decision to use, or refuse, health care services and obscures the factors that shape the context in which utilization occurs (K. A. Phillips et al., 1998). Larger contextual factors, such as availability of health care services, regional poverty, and cost of health care services, are increasingly more important among different ethnic and cultural groups, as HCU is typically lower, despite their greater level of need within such groups (Scheppers, van Dongen, Dekker, Geertzen, & Deeker, 2006). In this article we explore both individual and contextual level factors influencing HCU among Aboriginal cardiac patients in Central Australia.

New Contribution

One way to improve HCU among Aboriginal Australians is to better understand the factors that influence this behavior. Data exploring utilization of appropriate cardiovascular health services among this marginalized population is limited despite their disproportionately high morbidity and mortality rates (Walsh, 2001). Recently, a series of research studies have focused on cardiac disease in Aboriginal people from Central Australia (Brown, 2006; Field & Wakerman, 2002; Maloney, 2005). Only two have explored the variations in HCU among cardiac patients in this region (Brown, 2006; Maloney, 2005). Both studies reveal structural and communication problems at the health care system level as barriers to HCU. Our study explores these, and other potential barriers at various levels, including individual, interpersonal and health care system levels. Research concerning HCU among Aboriginal cardiac patients has failed to explore patients' experiences following their event (Maloney, 2005). We addressed this issue by exploring patients' experiences with the health care system 6 to 12 months post-discharge. Finally, this study contributes to the literature a culturally sensitive HCU framework that is adapted to the needs of Aboriginal Australians living in Central Australia. This framework identifies a comprehensive list of factors influencing HCU among Aboriginal Australians and describes the relationships between these factors to account for variations in HCU.

The overall aim of this study was to better assess Aboriginal patient's needs in relation to cardiac care in order to target and align health care service redevelopment across Alice Springs, Central Australia.

Conceptual Framework

Factors presumed to affect HCU at different levels of influence, informed by Anderson's Behavior Model of Health Services Use (Andersen, 1995); Scheppers et al., 2006 and Green and Kreuter's (1991) health behavior-environment model were adapted to build an *a priori* conceptual framework for ethnic minorities (Figure 1). We combined population characteristics: *Predisposing, Enabling,* and Need (Andersen, 1995) and *Reinforcing* factors (Green & Kreuter, 1991) examined within and across four levels of social organization -*Individual, Interpersonal, Primary Care* and Hospital System, adapted from Scheppers et al. (2006). Table I defines terms used in the conceptual framework.

Method

Little is known about the factors that influence HCU in hard-to-reach populations such as Aboriginal Australians. To understand these factors we elected to survey cardiac patients as well as community members and health service providers using an exploratory qualitative approach that was culturally respectful and congruent with Indigenous knowledge and traditions (Battiste, 2000; Castellano, 2000). This study was nested within a larger, nationwide study- the Australia Acute Coronary Prospective Audit (ACACIA).

Study Setting

The study setting, Alice Springs, located in Central Australia, is the traditional country of the Arrernte people. Altogether, Aboriginal Australians represent 17% of the estimated 28,000 people, with the majority residing in remote area communities (Northern Territory Government, 2006). Aboriginal people also live both in and around Alice Springs in town camps. In town, primary health care services include privately- and public-funded services, with Aboriginal clients principally utilizing the public system. Alice Springs Hospital is the only regional hospital and has no specific cardiac care unit. Patients requiring cardiac investigation are routinely transferred 1500 km to tertiary hospitals in Adelaide, South Australia. Most remote area communities have access to clinics, but town camps have no local medical services. Specialists visit remote area communities annually or biannually, but no cardiac rehabilitation is available; individuals requiring more than basic health care must relocate to town, where minimal in-hospital and post-discharge cardiac rehabilitation is provided.

Recruitment and Eligibility

Three groups of participants were recruited from September to December 2006: 1) *Aboriginal cardiac patients* (*n*=7); 2) *non-cardiac community participants* (*n*=15) and 3) *health care and research providers* (*n*=12). Participants were selected purposively, based on their knowledge and experiences, willingness to share their stories, and availability to participate (Spradley, 1979). Eligibility criteria for this study required all participants to be 18 years or older and living in or within 200 km of Alice Springs. In addition, Aboriginal participants had to self-identify as Aboriginal (C. B. Phillips, Patel, & Cabaron, 1993). *Aboriginal cardiac patients* were recruited through the Australia Acute Coronary Prospective Audit (ACACIA) and through participants' family members. To be eligible to participate, they needed to have experienced a cardiovascular event between December 2005 and June 2006. *Non-cardiac community participants* were selected based on their experiences supporting family members with cardiac illness and with HCU for non-cardiac health problems. *Key health care and research participants* required experience in Aboriginal-specific research and health care work with Aboriginal Australians from Central Australia. Table 2 summarizes participants' characteristics.

Data Collection

Data collection was conducted in two sequential phases. Procedures included unstructured interviews, focus groups and semi-structured interviews. In phase one, the interview guides for the focus groups and semi-structured interviews were developed and then used to guide data collection in phase two.

Phase 1 involved unstructured 45-60 minute interviews (*n*=6) undertaken with participants to provide the necessary cultural and contextual background to guide the development of interview guides. Translators were not requested, as all interviewees were proficient in English. Following debriefing, the research team (primary author, A.B. and a local researcher) identified factors inductively (from the unstructured interviews) and deductively (from the literature). This information informed the development of an illness narrative style interview guide designed to stimulate discussion in a story-telling format.

This approach is consistent with the oral culture of Aboriginal Australians (Klappenroth, 2004).

In phase 2, we conducted 60-120 minute focus groups and 45-60 minute semi-structured interviews, also in English. We audiotaped and later transcribed these sessions.

The purpose of the focus groups was for non-cardiac community informants and health care professionals to discuss and describe, in their *own words,* the factors influencing HCU. A total of four focus groups were conducted and included two female focus groups (*n*=6, *n*=4 respectively), one male focus group (*n*=3) and one health care professional focus group (*n*=6). We separated Aboriginal focus group participants according to gender to ensure cultural safety and respect for participants. Either the primary author or A.B. facilitated the focus groups. An Aboriginal mediator was used to assist in communication between the participants and the primary author during the two female focus groups.

Semi-structured interviews aimed to attain a deeper level of understanding of the factors influencing HCU primarily from the perspective of Aboriginal cardiac patients. Seven of the nine interviews were conducted with Aboriginal cardiac patients and two were conducted with non-cardiac community informants. In two cases family members were present to assist participants who spoke limited English. The primary author and a local research team member conducted the interviews.

Two institutional ethics committees, the Central Australian Human Research Ethics Committee in Alice Springs, Central Australia and the Comites d'evaluation scientific et d'éthique de la recherché in Montréal, Québec approved the study. Information pertaining to the study and consent was expressed orally to participants, with the presence of an interpreter when required. Appropriate cultural protocols and ethical conduct were followed (Franks & Curr, 1996).

Data Analysis

A thematic conceptual matrix (TCM) (Miles & Huberman, 1994) and a mixed coding method that combined deductively- and inductively-derived codes guided data analysis. A TCM is an ordered type of within-case display, which can be used to visually display data as a matrix or a network from a single "case". For this study, the TMC was used to display information on the factors influencing HCU in a small group of Aboriginal Australians living in and around Alice Springs. The factors discussed by the participants were separated into 4 columns representing the levels of social organization: *Individual, Interpersonal, Primary Care* and *Hospital System*, while the rows of the matrix were divided into: *Predisposing, Enabling, Reinforcing* and *Need.* The codes were then listed in the matrix according to their level of influence and associated themes to visually display the data. All primary documents were transcribed verbatim. Following transcription, we employed cross-cultural verification to counteract potential misinterpretations and augment cross-cultural understanding with consenting participants. An *idea* was selected as the unit of analysis. Data was managed using Atlas-ti qualitative software (ATLAS.ti, 2004). Counter-coding was used to verify the coded data and resulted in an intra-rater reliability of 84% (Van der Maren, 1996). To derive a rough indication of the potential importance of the factors influencing HCU outside of the qualitative data alone, we quantified codes based on their frequency of occurrence. Opportunistic member checking was conducted following the analysis of the transcribed data. Member checking was used to verify the results with agreeing participants by providing them with a summary of the key findings (Creswell, 2003, Donovan, & Spark, 1997).

Results

Table 3 provides a condensed version of the factors influencing HCU among Aboriginal Australians living in and around Alice Springs. Our results are based on the analysis of the transcribed data generated from the focus groups and semi-structured interviews and from the deductive codes provided in the conceptual framework (Figure 1). The following text provides a detailed account of the factors influencing HCU, listed according to their magnitude of importance.

Primary Care and Hospital System Level Influencers

The most predominant barriers to HCU for Aboriginal Australians in this study were issues classified as enabling factors, such as Communication Issues, Organizational Characteristics, Availability and Delivery of Health Services, Racism and Lack of Cultural Awareness. Other factors affecting HCU were the predisposing factor Western Biomedical Model and the reinforcing factor Lack of Health Care System Support/Ownership.

Communication Issues

Virtually every participant discussed communication problems either between clinicians and patients, clinicians and family members or within the health care system itself. These issues are described below.

Limited communication between the health care system and patients. Most participants described language barriers between clinicians and patients as a barrier to HCU. Clinicians explained the nature of patients' illnesses, cardiac procedures and medications, but often did so in ways that were confusing to patients. Participants explained that they desired information be communicated to them clearly and expressed frustration at not being able to comprehend clinicians' explanations:

> Well, sometimes I can't understand them, they talking that type of language they learnt in medical school, you can't, you don't know that! I tried to look up a few words in the dictionary; it's not there, IT'S JUST NOT THERE [emphasis added], I mean, you gotta look up in doctor or medical books.

In other instances, clinicians did not explain relevant information or details about the medical procedures to their patients, leading to feelings of Fear and Mistrust:

> When I got down [to the hospital], umm, they shaved my groin but they never done the test through the groin. They done the test, they put the tube through here (pointing to her wrist and then her elbow). I didn't know what to do… I was full naked on a big operating bed…and I was thinking, if they want to do something with my arm, then why am I full naked? I must be gonna die, that's what I was thinking, I might die!

Inadequate explanations also affected patients' ability to manage their disease. In many cases, this affected patients' understanding of their prescribed medications. A clinician explained how this altered patients' adherence to their medications: "They get that medicine [first batch] and when they finish that, 'Oh, I'm alright'. They don't realize that they are on tablets for life." Patients did not understand the need to continue their medications, which affected HCU in the future.

Limited communication between the health care system and the patient's family. Participants stated that family members usually were not present during consultations or contacted when a patient was admitted, transferred to, or discharged from a hospital. As one nurse explained, "When someone is going to Adelaide, I don't consciously think, 'Oh, does all his family know that he's going to Adelaide?' That is something we don't, I don't do." Clinicians attributed this to heavy workload and high staff turnover, limited telephone accessibility in remote area communities, difficulty contacting staff after hours and high mobility[i] of Aboriginal patients. Aboriginal participants explained the benefits of family involvement:

> The benefits go back to the family because the family understand what this illness is, the patient understands what this illness is and if the husband can't understand English, the wife will interpret or cousin will interpret or daughter might interpret... and so, everybody can get that one picture of what the doctor talking about.

Limited communication within the health care system. In many instances communication between the regional hospital and clinics, hospitals in Adelaide and remote area clinics was compromised. As a result, patients' medical records were not transferred to clinics and hospitals. Acquiring patients' medical records was described as "rare" and often "a big bonus" by clinicians. As a result, patients who received cardiac care in Adelaide often returned to Alice Springs and received no follow-up care.

Unavailability of Aboriginal Liaison Officers. Aboriginal liaison officers, government-funded interpreters, represented one solution to clinician-patient language barriers and helped reduce patients' fears and anxieties. Despite Aboriginal liaison officers' crucial roles, they were rarely available. Converging storylines from liaison officers, health care professionals and patients suggested that they required greater resource support from the health care system to increase their availability. Many participants also described the absence of standard guidelines to determine if, or when, a patient required a liaison officer as a barrier to HCU: " [Nurse] You can't have an interpreter there all the time. It's only for important things like when, you know, you are going to chop someone's foot off that you need to have an interpreter."

Communication Issues were linked to the majority of Individual level barriers described by participants, such as patients' Limited Knowledge of Illness, Perceived Need, Mistrust, negative Previous Experiences and Fear.

Organizational Characteristics

Long Wait Times and Inflexible Hours were commonly observed to impede HCU. Meanwhile, other factors such as Poor Intake Procedures and Poor Continuity of Care were linked to Communication Issues and also contributed to the difficulties faced by Aboriginal cardiac patients trying to utilize health care services. We discuss each of these factors below.

Wait times and inflexible hours. Long wait times and inflexible hours limited available services and often deterred HCU.

> What you find is that Aboriginal people get up and walk out. They'll wait maybe five or six hours and then say, "Ah stuff this, I'm going" because that doctor is not going to see them and so they walk out without even being seen by doctors.

Poor intake procedures. This barrier occurred exclusively at the Hospital System level. Participants experienced problems with scheduling appointments, accommodation and, in some instances receiving hospitals did not have patients on record. "[You] get down [to Adelaide]...to find out you wasn't even booked in and they don't even know why you're down there for."

Poor continuity of care. All seven cardiac patients experienced poor continuity of care following their hospital discharge. The health care system's poor organizational management contributed to the lack of continued care and included such issues as a) incomplete medical files, b) difficulty or inability to obtain test results and c) poor follow-up care.

a) Incomplete medical files: Many clinicians complained they never received patient's discharge summaries. If they were received, they were often incomplete and received weeks following patients' discharge. Consequently, clinicians were unaware of previous treatment and diagnosis resulting in uncertainty in treating their patients, affecting their follow-up care. Incomplete medical files were linked to Limited communication within the health care system.

b) Difficulty or inability to obtain test results: Similarly, participants experienced great difficulty or were unable to attain test results. This left patients questioning their health status and delayed necessary treatments.

> The problem is I have to look at the patient's results. They may have found something. They may have found nothing. If they didn't find anything they need to tell [the patient]. If they found something, they need to tell her too. Otherwise [the patient] is going around "Do I have a heart problem? Haven't I got a heart problem?"

Failure to receive test results led some participants to consider their cardiac interventions a "waste of time". These negative experiences affected patients' trust in the health care system and left them hesitant to use health care services in the future.

c) Poor follow-up care: As part of a secondary prevention program, cardiac patients require a minimum of one follow-up appointment every 6 months. However, following participants' cardiac interventions, participants seemed to fall in a "black hole". None of the seven cardiac patients interviewed received any follow-up appointments with cardiac specialists or even a general practitioner.

Poor organizational characteristics were linked to Communication Issues arising within the health care system, affecting patients' ability to receive on going cardiac care.

Availability & Delivery of Health Services

Factors such as Limited Escort Eligibility, Lack of Health Care Services/Specialists, Limited Transportation and Lack of/Inappropriate Cardiac Education acted as barriers to HCU.

Limited escort eligibility. Limited Escort Eligibility refers exclusively to the Hospital System level. Escorts were family members or kin who accompanied patients when transferring to or leaving a hospital. Their involvement improved the likelihood that patients would agree to be transferred to tertiary hospitals: "...When family members can go with them, it's really important, otherwise you wouldn't get half of what you get now..." However, resource constraints and restrictive escort policies often impeded escort eligibility to accompany patients.

> Medical ring you up and say "I got six people that need to go to Adelaide tomorrow!" and you're like, "Well, that's lovely, I have ONE [emphasis added] plane that has the potential to go down to Adelaide. So, unless you have a life-threatening thing that needs to go this second, there is no room."

In addition, escort policies were not adapted to meet Aboriginal people's needs; they were limited to underage patients or those with special needs, neglecting important language barriers and fear commonly experienced by Aboriginal patients.

Lack of health care services/specialists. Lack of a cardiac unit and minimal cardiac specialists acted as significant barriers to HCU. While some participants spoke about patients relocating so they could access the appropriate services, others described cases in which patients refused treatment so that they could return to their community and family:

> One day [patient] didn't come in ... So, we went to see her and she was sitting down in that house [in town]. She didn't want to get treated anymore; she'd given up on life. She gave up because she couldn't get back to country[ii], she lost all hope, she lost herself, who she was, and she had no family visiting her. She was isolated from everything and in the end she passed away.

This situation was not uncommon. Many participants told stories of patients refusing health care services because family members were not included in their care, they felt isolated and they could not afford the cost of living in town.

Limited transportation. A significant proportion of Aboriginal people living in town camps or remote area communities did not have access to transportation. Although the health care system provides transportation, the majority of participants described it as highly inadequate and unreliable, and stated that it impacted their ability to attend medical appointments. At the Hospital System level, virtually all patients returning home commercially from Adelaide said that there was no transportation service waiting for them when they arrived at the Alice Springs airport. Limited transportation services reinforced individuals' negative previous experiences and impacted on their future HCU.

Lack of/inappropriate cardiac education. All cardiac patients described receiving minimal or no cardiac education. When it was provided, it often occurred during inappropriate times, such as while patients were in the Intensive Care Unit. One clinician described the virtually non-existent cardiac rehabilitation in Alice Springs as "disgusting" as it was inconceivable not to have cardiac education when Aboriginal people have the highest rates of cardiovascular illness. Lack of cardiac education affected individuals' Knowledge of Illness and their Perceived Need to utilize health care services.

Lack of Cultural Awareness

The vast majority of clinicians explained that non-Aboriginal clinicians received minimal or no cultural training relevant to their delivery of health care services. The lack of cultural awareness compromised communication with patients and clinicians' capacities to provide appropriate care. This resulted in negative experiences with clinicians and affected patients' decisions to use health care services.

The health care system's failure to recognize the need for gender-appropriate care was another factor that influenced HCU. Within Aboriginal Australian culture, gender is highly regarded when seeking health care services. Commonly referred to as "women's" and "men's business", female patients discuss their health issues and are seen by female clinicians and vice versa. Participants revealed mixed feelings about the lack of availability of gender-appropriate care: some did not mind, others felt shame[iii] and others delayed treatment until a clinician of the same sex was available or their symptoms became extremely severe. "I was really shame for a man doctor to do it. Cause out bush [remote area communities], a long time ago, they used to just have women doing it, no men around."

The health care systems' failure to provide cultural awareness programs and gender appropriate care was linked to individuals' negative Previous Experiences.

Racism

Almost all Aboriginal participants described feeling as if they were not offered the same health care services or treatment options as white patients.

> It's "You do it this way", "This is the best treatment for you" and a white person will come in with the same thing and it's "You got this choice and you got this choice, what do you want to do?"

Many participants also perceived that clinicians did not listen to or ignored their concerns: "I complain about a lot of things, but I don't think [clinicians] want to help us. They would rather see us all dying, that's what they want to do." Furthermore, Aboriginal patients felt that their treatment was affected by widely held stereotypes about Aboriginal individuals: "People think that ALL Aboriginal people drink, that's why we get treated the same way, as the drunks in town."

Ambulance drivers' resistance to pick up patients living in town camps or remote area communities depict one way that racism affected Aboriginal individuals' HCU: "As soon as you say, 'I need an ambulance at [town camp]' they say 'What?' especially if it's really serious, if they hear it's at [town camp], then it might be a different story..."

Constant discrimination led to feelings of disempowerment and loss. "We [Aboriginal people] got no hope...it's a white town now, white community." Racism affected individuals' trust in clinicians, reinforced negative Past Experiences and affected future HCU.

Western Biomedical Model

The health care system's emphasis on the Western Biomedical Model negatively influenced HCU by Aboriginal peoples. Participants described the health care system as complex and confusing, leaving patients feeling overwhelmed and unaware of how to negotiate it. Further, patients could not relate to the lack of relationship between clinicians and themselves and as a result, felt uncomfortable utilizing health care services: "You need to develop a relationship, make it about PEOPLE, gain trust."

Lack of Health System Support/Ownership

A few participants reported that the health care system did not acknowledge the context in which Aboriginal people lived and thus, did not support their needs. The system was described as "top-down," with Aboriginal people uninvolved in the development and implementation of the health care services delivered to them. One participant in particular explained the importance of Aboriginal involvement:

> Giving people the power to be able to say, "Well, we want this" and then resource those ideas. Putting the money behind what the people themselves are saying, not listening to white fella, who don't know nothing about Aboriginal people.

Outcome: Poor Quality of Care

The communication and structural barriers presented at the Primary Care and Hospital System levels resulted in patients receiving insufficient and poor quality of care. Communication Issues arising between clinicians, patients and family members affected individual's Perceived Need to utilize health care services, Knowledge of Illness and contributed to their negative Previous Experiences and Mistrust in the health care system. Poor Organizational Characteristics were linked to Communication Issues and resulted in Poor Continuity of Care as patients experienced great difficulties in obtaining test results and receiving follow-up care. Limited availability and delivery of health care services meant that family support was often compromised and patients had to relocate into town to access required health services. Inappropriate cardiac education affected patients' Knowledge of Illness and their Perceived Need to utilize health care services while the Western Biomedical Model made it difficult for patients to negotiate the health care system. Lack of Cultural Awareness and Racism demonstrated the system's failure to acknowledge and respect Aboriginal patient's needs and beliefs. These barriers reinforced negative Previous Experiences and reduced the level of trust individuals had in the health care system. Lack of Health Care System Support further contributed to the poor quality of care received by patients, Aboriginal people were not involved in the development of services and as a consequence, services offered to them were not adapted to their needs.

Individual Level Influencers

HCU at the Individual level was influenced by three main factors: Perceived Need to utilize health care services (Need), negative Previous Experiences (Predisposing factor) and Limited Knowledge of Illness (Enabling factor). Other predisposing factors, such as Fear, Competing Priorities, Mistrust, and Avoidance Relationships also affected HCU. Lack of the enabling factor, Basic Needs, hindered individuals' ability to access health care services and the predisposing factor, Ability to Negotiate the Health Care System, did not facilitate HCU.

Perceived Need

Poor clinician-patient communication and limited cardiac education was linked to patients' misunderstandings about their illness, and subsequently, care seeking behavior. Many participants did not differentiate between "looking fit" or feeling good and being healthy. A Aboriginal liaison officer illustrated this point:" We get a lot of that from our clients 'Naw, we alright.' 'Hey, you gotta go to follow-up, check up.' 'Naw, I feel good now.'" Almost all cardiac participants believed they were "fixed" once they received treatment from specialists.

> Soon as [patients] come back to Alice Springs some of them follow-up, and some of them don't cause they think that trip down to Adelaide actually fixed them up. They think, "I don't need to, the proper doctors was there."

Previous Experiences

Most participants described their experiences as negative and linked them multiple factors represented as Communication Issues, Organizational Characteristics, Racism and Lack of Cultural Awareness. Aboriginal Australians' oral culture acted as a means for transmitting previous experiences with health care services to others. Participants' knowledge of family and community members who died after seeking health care services was a strong deterrent; many even inferred a causal association between HCU and death, particularly when patients were transferred to Adelaide: "That's the story I always hear, you know, 'you going to Adelaide? They gonna put you in a coffin' that's what I hear all the time."

Negative Previous Experiences also acted to reinforce other Individual level barriers, such as Fear and Mistrust. In contrast, having Aboriginal persons recount their positive experiences facilitated HCU and educated future patients. It also acted as a form of alternate support for patients having to negotiate the health care system.

> This young fella [Aboriginal male], he wasn't having anything to do with us [nurses] because we were all female and we wanted to teach him about [his] angiogram. And this old lady [Aboriginal female], she's sitting there telling him what they are going to do to him in [hospital]. And it was really good, he listened to her...so, at least it was coming from someone who had been down there, that's been through it all.

Mistrust

Participants' perceptions of clinicians and the health care system were far from ideal and greatly influenced HCU. Mistrust was described as a consequence of Communication Issues, Racism and Lack of Cultural Awareness at the health care system level and negative Previous Experiences at the Individual level. Many participants ascribed Aboriginal individual's morbidity and mortality to clinicians' mistreatment of patients: "Cause a lot of Aborigine people passing away you know, and they think that doctors are doing something to them."

Fear

The vast majority of Aboriginal participants described negotiating the health care system, travel, medical procedures and staff's inability to speak local languages as frightening experiences, particularly when they were alone. "She gets frightened cause she doesn't know what the doctor is talking about, you know. She might have to have an operation and she don't know." As a result, Aboriginal patients often delayed treatment, left hospitals early or refused health care services.

Competing Priorities

HCU was also influenced by competing priorities, which included current social issues in Alice Springs, family obligations associated with Aboriginal culture and obligations to attend grieving ceremonies. Participants explained how individuals often prioritized other issues occurring in their surrounding environment over their own health. Participants discussed Grog[iv] in particular: "They are not coming quick to hospital. They don't see the doctor. They just sit down and drink, and all that, you know." Participants also placed family and community affairs ahead of their own individual health. Many women worried about leaving their children and/or grandchildren to go to the hospital:

> We try again to explain, you know, "You gotta think about your self sometimes, ...you're really sick, you gotta go [to the hospital]." And a lot of response, a lot of families, I get "who's gonna look after them [children] when I go?"

The frequency in which grieving ceremonies occurred also acted as a barrier to HCU.

Avoidance Relationships

Avoidance relationships are part of an intricate arrangement within the Aboriginal kinship system that guide individuals' social and intimate interactions. These relationships assign a set of rules regarding whom individuals are permitted to be in the presence of and whom they must avoid (Franks & Curr, 1996). Avoidance relationships deterred some patients from seeking care when they were in a direct avoidance with the attending Aboriginal clinician or liaison officer. Participants spoke of waiting until another clinician was available before seeking health care services.

Limited Knowledge of Illness

Participants displayed limited knowledge of cardiovascular disease and its signs and symptoms: " Well, I get a little bit weak and palpitations, like I can't breathe properly, yah, I don't know why I am like that." None of the cardiac patients interviewed were aware they were having a heart attack at the time of their event. Communication Issues within the health care system and with patients and Lack of Cardiac Education stymied participants who wanted to acquire more information about their condition. This affected patients' Perceived Need to utilize health care services both at the time of their event and following discharge.

> Well, I didn't know what was wrong with me. I thought that they might find out what was wrong with me in [hospital], but they just said, "You'll be fine, you'll live a long time". That's not much, you know.

Basic Needs

Owning a telephone or vehicle was considered a basic need to access HCU. Few participants possessed either one. Many participants worried about having to rely on family members or walk long distances in emergency situations. They recounted stories of individuals who passed away prior to reaching the hospital because they lacked these basic needs.

Limited Ability to Negotiate the Health Care System

Cardiac patients who were able to negotiate the system, spoke fluent English and requested follow-up care still experienced great difficulties during HCU:

> She said that she has to make all of her own appointments and chase [clinic] to get what she wants… she calls them when its time for them to fill up her pill box. She said they should do their job.

Most of the Individual level factors influencing HCU were a consequence of the barriers experienced at the Primary Care and Hospital System levels. Perceived Need and Limited Knowledge of Illness was a result of Limited Cardiac Education and Communication Issues. Racism, Organizational Characteristics, Communication Issues, Lack of Cultural Awareness and Limited Availability and Delivery of Health Services were found to reinforce negative previous experiences. Fear and Mistrust were consequences of Communication Issues and Racism. Fear was also linked to limited escort eligibility and the Western Biomedical Model, while Mistrust was linked to Lack of Cultural Awareness and lack of clinician-patient relationships.

Interpersonal Level Influencers

Alternate Support

Because of the various communication and structural barriers to HCU patients often relied on family members, friends or other patients for Alternate Support. They helped patients negotiate the health care system, acted as interpreters, explained medical procedures and provided social support. Family members ensured that there was at least one person present to accompany a patient during their hospital stay. When family members were allowed to do so, they would sleep at the hospital; otherwise, they would return the following morning.

> There's usually two members of the family that would go [to the hospital]. One would go right away and the other would follow probably later on in the week. They are there to support them [patients] and to be acting as a translator for them.

However, due to systemic barriers, this facilitator was often compromised. Almost all participants described the need to include family members in patient's care.

Framework and Summary

We developed a culturally sensitive framework that outlines the factors influencing HCU following a cardiac event among Aboriginal Australians in Central Australia (Figure

2). Lack of enabling factors predominately influenced HCU at the Primary Care and Hospital System levels, while predisposing factors primarily influenced Individual level factors. Communication Issues were the most significant barrier to HCU and are thus represented by dashed arrows: 1, 2 and 3. Number 4 represents how the presence of enabling factor, Alternate Support, links the health care system and the individual and thus facilitates utilization. HCU is a function of all these factors, acting either separately, or in combination. HCU is shown in the "At time of event" and "Post-event" boxes. The slashed arrow, 5, displays the poor *Quality of Care (QOC)* patients received following utilization. Feedback loops represent how HCU affected individuals' subsequent decisions to use health care services and its impact on health outcomes.

Discussion

This study makes five contributions to advancing the understanding of factors that influence HCU following a cardiovascular event among Aboriginal people in Central Australia. Each contribution is discussed followed by the study's limitations and concludes with suggested implications for interventions in support of improved HCU and long-term outcomes for Aboriginal patients suffering a cardiac event.

The first contribution resides in development of a culturally sensitive framework that articulates the factors presumed to affect health care utilisation among Aboriginal Australians living in Central Australia at different levels of influence. Our *a priori* application of pre-existing HCU frameworks proved useful in guiding our methodology, data analysis and disseminating our results. However, classical health services utilization frameworks developed for mainstream populations do not always address important factors influencing HCU among socially marginalized populations, such as Aboriginal Australians, if our experience offers any potential for generalizing. For instance, Scheppers et al.'s (2006) adapted version of Andersen's model (Andersen, 1995) does not address racism as a barrier to HCU among ethnic minorities, even though it is noted that such populations are often victims of discrimination and segregation (Scheppers et al., 2006). Institutional racism in the Australian health care system has previously been documented (Henry, Houston, & Mooney, 2004) and our findings demonstrate that patients or stories of significant others who experienced racism are less likely to use health care services in the future. Similarly, issues such as negative Previous Experiences, Mistrust, Fear and

Competing Priorities are not included in other HCU frameworks. In the present analysis, these factors represented important barriers among Aboriginal Australians and need to be considered when trying to improve HCU. Participants described Communication Issues at various levels as the most important factor influencing HCU. Andersen (1995) does not address communication problems as a potential barrier to HCU and although Scheppers et al. (2006) listed Communication Issues at the patient and provider level, the important role family members play in facilitating clinician-patient communication and the health system's need to provide appropriate services to ensure and support intercultural communication is not dealt with by Scheppers et al. (2006) treatment of influences.

The second contribution demonstrates the prominence of Communication Issues in influencing HCU. Although the literature highlights critical issues in communication between the health care system and Aboriginal Australians (Gruen et al., 2002; Lowell, 2001; Trudgen, 2000), no previous studies pinpoint the levels at which these problems arise or note their impact on utilization. Communication Issues at and between the Primary Care and Hospital System levels significantly affect HCU and increase other barriers at these levels, such as Poor Continuity of Care. Communication Issues further contributed to the barriers arising at the Individual level, such as Perceived Need and Mistrust and resulted in reliance on family members at the Interpersonal level.

Communication at all levels of social interaction is essential for effective HCU, as without it a disjunction occurs between individuals and the system built to support their health care needs. Our findings demonstrate that Aboriginal cardiac patients in Alice Springs usually are not involved in their treatments, have a poor understanding of their illness and are uncomfortable with the rigid and impersonal clinician-patient interactions that dominate their experiences. Linguistic barriers and different worldviews further strain clinician-patient interactions and, in turn, reinforce severely compromised communication. The divide was so significant that some patients completely refused to use health care services, even in the face of death.

Third, our findings reveal the important role structural barriers have on HCU at the Primary Care and Hospital System levels. These are consistent with previously reported HCU barriers experienced by Aboriginal populations internationally, such as lack of interpreter services, racism and cultural inappropriateness (Baker & Daigle, 2000; Gruen et al., 2002; Wardman et al., 2005). Our findings support previous research identifying poverty as a barrier to HCU (Gruen et al., 2002; Haddad & Fournier, 1995; Scheppers et al., 2006). Lacking the financial means to own a telephone or a form of transportation directly impacted on how and when Aboriginal cardiac patients used health care services. Lack of these basic needs meant appropriate care was needlessly delayed. Lack of cardiac services and specialists available in and around Alice Springs is disturbing considering the burden of CVD in this region. In-hospital cardiac services are highly inadequate and do not meet the magnitude of need while post-discharge services are virtually non-existent, resulting in an insurmountable barrier to HCU for cardiac patients. This finding is consistent with recent literature describing the inequitable distribution of cardiac management programs in rural and remote areas of Australia, (Clark et al., 2007). More specifically, these structural barriers were similar to those reported in a recent study conducted among Aboriginal and non-Aboriginal cardiac patients living in Central Australia (Maloney, 2005). Our results however, present *predominantly* negative accounts of HCU, whereas Maloney (2005) describes both positive *and* negative accounts. This discrepancy may have arisen because non-Aboriginal participants did not experience the same barriers as most Aboriginal participants (e.g. lack of gender appropriate care, communication problems and geographical remoteness).

It is imperative to acknowledge that the majority of these structural barriers point to *limited* or *absent* enabling factors, such as *lack* of cultural awareness or *lack* of cardiac education. Enabling factors have been described as having a greater potential for change (Andersen, 1995). Their presence allows an action, in this case HCU, to occur. Focus should therefore be placed on assuring their presence to potentially improve HCU and effect change at the Individual level. This interpretation is consistent with health promotion strategies that emphasize changing environments to enable greater support for individuals from the systems with which individuals interact (Green & Kreuter, 1991).

Fourth, research concerning HCU among Aboriginal cardiac patients has failed to explore patients' experiences following their event (Maloney, 2005). Our findings reveal a severe breakdown in cardiac patients' continuity of care following discharge. Various communication and structural barriers, such as Communication Issues within the health care system affected patients' ability to receive test results, follow-up care and cardiac rehabilitation services. A disconnect between the Primary Care and Hospital System services meant that most cardiac patients failed to receive essential health care services. The health care system needs to improve the provision of services required for the appropriate management of cardiac illnesses. Future research and action in this area is warranted.

Finally, our findings point to the important role that family members play in Aboriginal cardiac patients' care. Family members acted as cardiac patients' alternate support system by intervening in areas where the health care system systematically failed. They provide guidance, social support, experiential wisdom, education, transportation and improved communication.

Despite the numerous roles family members played in patient care, their role as interpreters is the most commonly addressed and accepted as standard practice in Alice Springs. The health care system's expectation that family members should accurately interpret complicated medical terminology without previous training is both unethical and unrealistic and is likely to have led to and continue to lead to significant levels of misinterpretation, some of these being extreme and ultimately life-threatening (Territory Health Services, 1997) as well as general communication breakdown (Lowell, 2001). Over reliance on family members sidesteps the health care system's responsibility to provide Aboriginal Australians with the services they require (Pollack & McCarthy, 1984). While family involvement is essential in Aboriginal patient's care, family members should not be expected to replace health care services. Family member involvement should be viewed in a comprehensive manner, by including them in consultations, hospital admissions and transfers, while acquiring informed consent and following discharge when important lifestyle modifications, regular follow-up care and adherence to medication are required.

Limitations

The study's limitations arise primarily from the restricted time available for field research, and population characteristics (e.g. high mobility), as discussed below.

Limited time available in the field affected the primary authors' ability to develop trust and build strong relationships with participants. This may have affected the amount and type of information participants disclosed.

Sampling problems arose among Aboriginal cardiac patients. We anticipated recruiting at least 13-15 Aboriginal cardiac patients. However, due to time limitations and the high mobility of Aboriginal people, it was extremely difficult to attain this objective. As a result, we had a small cardiac patient sample size (n=7) and did not reach saturation relative to our research question.

Further, the experiences of cardiac patients who died prior to arriving to a clinic or hospital are not included in this study. Future research should focus on acquiring these stories, in a culturally sensitive manner, from family members or kin of the deceased. These individuals may have suffered significant barriers to HCU, which may or may not be similar to those who have survived their cardiac event. This group may provide additional information that can serve to improve HCU among Aboriginal Australians.

All individual and group interviews were conducted in English, with the use of Aboriginal mediators or family members when necessary, as participants demonstrated strong spoken English language skills. Regardless of the high level of linguistic knowledge shared between the participants and the primary author, inevitable cultural and language divides should be acknowledged when interpreting the results, e.g. differences in the conceptual meaning of English terms used or differing worldviews.

Implication for Interventions

To facilitate HCU among Aboriginal Australians in Alice Springs, policy makers, mainstream health bureaucracies and institutions must address the communication and structural barriers operating at the health care system level. Attending to these factors may then lead to improvements at the Individual level and reduce patient reliance at the Interpersonal level. Suggested actions are listed in Table 4 and are briefly described below.

As a short-term objective, emergency telephones will greatly reduce time delays often associated with trying to contact emergency personnel. Currently, ambulance services are not available in remote area communities, and although efforts to change this are required; the provision of telephone services could be effected quickly, and this at the very least, would allow individuals to contact other potential means of transportation.

Long-term objectives suggest a fundamental change within the health care system to improve communication issues occurring at a variety of levels. It has long been recognized that improving intercultural communication is associated with better health outcomes, decreased health disparities and increased health care access (Shapiro, Desiree, Gutierrez, & Zhuang, 2006). Outreach services integrated in town camps and remote area communities have the potential to improve communication on all levels and facilitate informed consent. Also, adequate outreach may prevent dislocation from family, reduce the need for transportation and educate affected family members. Aboriginal healthcare workers can help patients feel more comfortable, improve communalization, and increase patients' knowledge of their illness. Specific to Alice Springs, cultural awareness programs must inform and sensitize clinicians so they can acknowledge and address the presence of avoidance relationships, family obligations, patient's social circumstances and the need for gender appropriate care. In the present study, the health care system failed to acknowledge the context in which Aboriginal people lived and thus, provided services that did not support their needs. Community involvement will ensure that health services meet the health needs of the community, community members' feel culturally safe in the services delivered to them, and that communication and shared knowledge of cardiovascular health and CVD is improved.

Conclusion

Aboriginal Australians living in and around Alice Springs face significant barriers to HCU at multiple levels (Figure 2). Communication issues and structural barriers at the health system level impact on Aboriginal Australians' ability and/or decision to utilize health cares services. These barriers, in turn, negatively affect the factors influencing use at the Individual level. Family members play an intermediate role of linking the health care system to individuals, and act as patients' primary gateway to negotiating the health care system. Due to these barriers, Aboriginal cardiac patients receive sub-optimal quality of care, significantly risking subsequent cardiovascular events and affecting their level of HCU. If we are to improve HCU among Aboriginal cardiac patients, we must listen to their stories and experiences and adapt our health care services to meet their needs.

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[i] A common characteristic if Indigenous Australians is frequent intra-regional migration. Over one quarter of Indigenous Australians reported a change of residence in 2001.

[ii] Country: home land

[iii] Shame: from the Indigenous perspective, shame includes feelings of embarrassment. It is also used when someone feels they are being treated in a condescending manner.

[iv] Grog: alcohol

TABLE I Description of Terms Used in Conceptual Framework

Predisposing factors	Any factor that motivates and/or explains an individual's decision to utilize health care services based on their preferences or related experiences.	Adapted from Andersen (1995)
Enabling factors	Elements or situations that allow utilization behavior to occur	Adapted from Andersen (1995)
Need	An individual's perceived need to use heath care services based on their perception of their illness	Adapted from Andersen (1995)
Reinforcing factors	Act as a "reward" following the use of health care services to encourage and/or support the continuation of this behavior. Can be intrinsic or extrinsic.	Adapted from Green & Kreuter (1991)
Individual level	Refers to patient level characteristics, such as health beliefs and attitudes.	Adapted from Scheppers et al. (2006)
Interpersonal level	Refers to the support system surrounding individuals, which may influence HCU, such as family support received during a patient's medical consultation.	Adapted from Scheppers et al. (2006)
Primary Care & Hospital System	Refers to elements influencing utilization in regards to the health care system itself, such as communication issues and the cultural awareness of staff	Adapted from Scheppers et al. (2006)

Table II Participants' Characteristics

Participant's Role	Data Collection Type	*n*	Participant Characteristics			
			Gender	Origin	Age Range	Residence
1. Aboriginal cardiac patients	Semi-structured Interviews	7	3 M 4 F	7 I.	42-65	1T 4TC 2RAC
2. Key health care care & research participants	Unstructured Interviews	6	4 M 2 F	2 I. 4 N.I.	30-56	5T 1RAC
	Focus Group-Health care Professionals	6	3 M 3 M	3 I. 3 N.I.	36-49	4T 1T 1RAC
3. Non- cardiac community participants	Focus Group-Female (01)	6	6 F	6 I.	24-66	3T 3TC
	Focus Group-Female (02)	4	4 F	4 I.	28-66	4TC
	Focus Group-Male	3	3 M	3 I.	30-65	2T 1RAC
	Semi-structured Interviews	2	1M 1F	2 I.	*	1T 1TC
Total		34	13 M 21 F	27 I. 7 N.I.		16 T 13 TC 5 RAC

Note. M = male; F = female; I = Ingenious; NI = non-Ingenious; T = town; TC = town camp; RAC = remote area community, * Missing information, to be resolved prior to publication.

TABLE III Summary of Results

Primary Care and Hospital System Level Influencers

Communication Issues (-)
-Limited communication between the health care system and patients,
-Limited communication between the health care system and family,
-Unavailability of Aboriginal liaison officers,
-Limited communication within the health care system.

Organizational Characteristics (-)
-Wait times and Inflexible hours
-Poor Intake Procedures*
-Poor Continuity of Care: a) incomplete medical files, b) difficulty/inability to obtain test results and c) poor follow up care.

Availability & Delivery of Health Services (-)
-Limited Escort Eligibility*
-Lack of Health Care Services/Specialists
-Limited Transportation
-Lack of/inappropriate cardiac education

Lack of Cultural Awareness (-)
Racism (-)
Western Biomedical Model (-)
Lack of Health System Support/Ownership (-)

Individual Level Influencers

Perceived Need (-)
Previous Experiences (-) (+)
Mistrust (-)
Fear (-)
Competing Priorities (-)
Avoidance Relationships (-)
Limited Knowledge of Illness (-)
Basic Needs (-)
Limited Ability to Negotiate the Health Care System (-)

Interpersonal Level Influencers

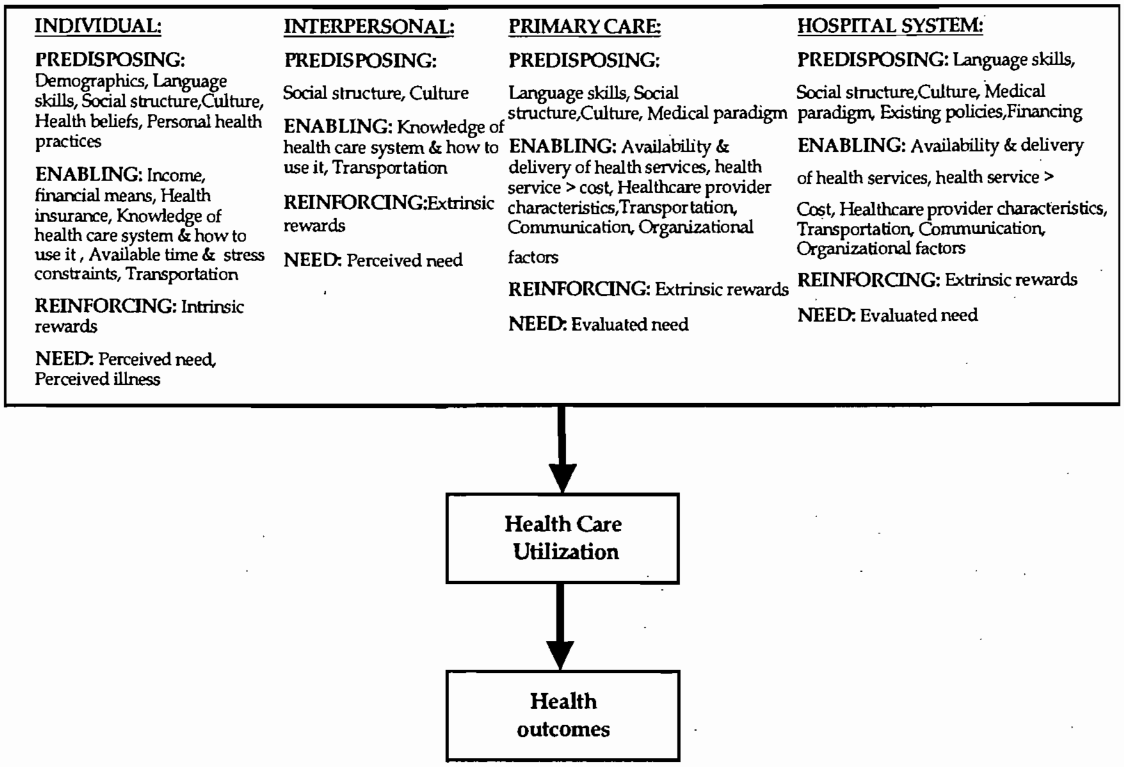
Alternate Support (+)

Note. * Refers exclusively to the Hospital System level; (+) Facilitator to HCU; (-) Barrier to HCU.

TABLE IV Implications for Interventions

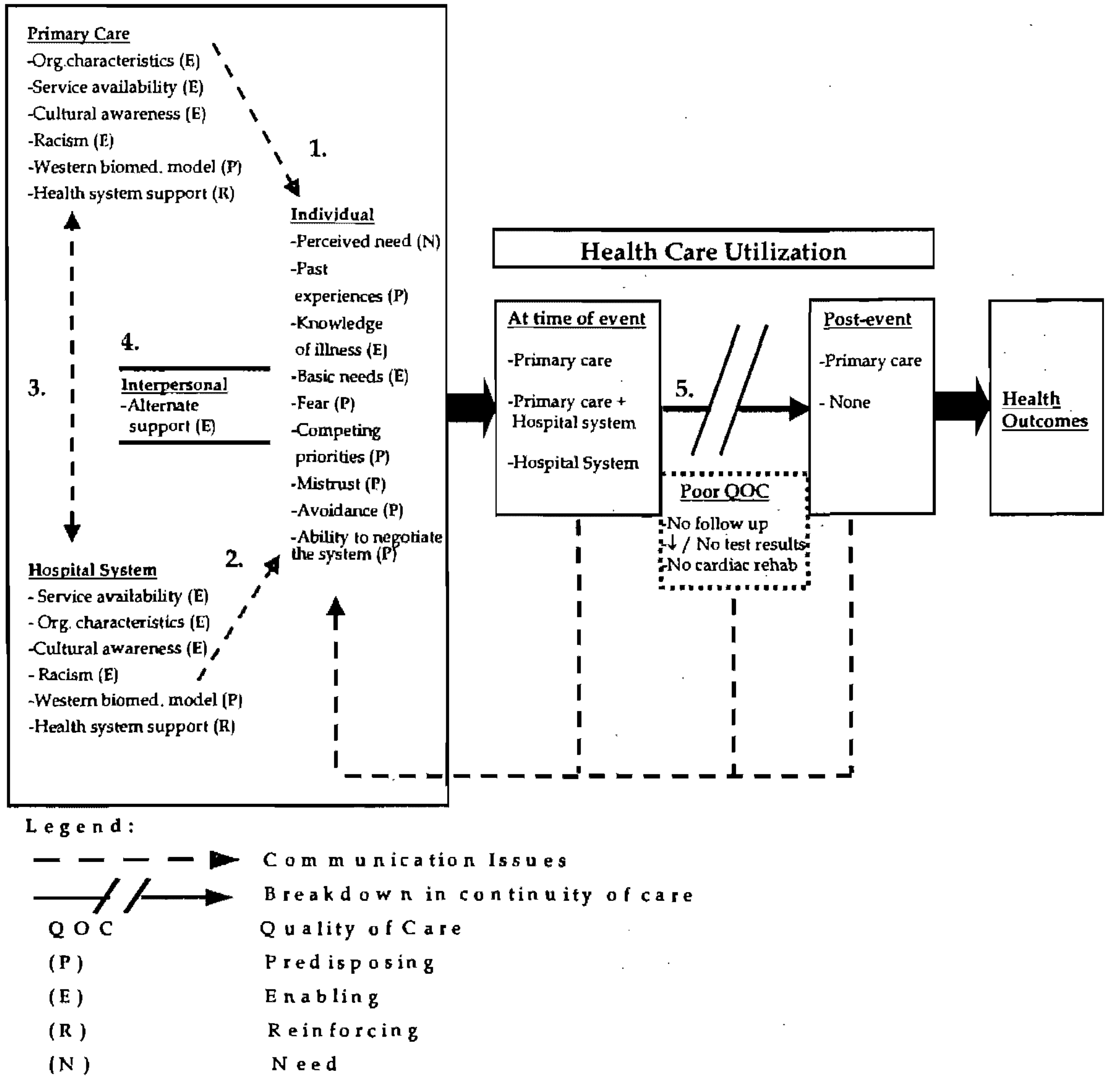
Implications:	Suggested Actions:
Telephone and Transportation *(Short-term)*	-Install functional, no-cost emergency telephones in town camps and remote area communities, -Primary Care level: ensure reliable transportation services for individuals requiring transport into town, -Hospital System level: set up transportation services to allow patient pick-up at Alice Springs Airport.
Intercultural Communication *(Long-term)*	-Specialized medical training for interpreters, -Greater access and availability of trained interpreters, -Development of standard guidelines that enable clinicians to evaluate patients' level of comprehension and need for an interpreter, -Compulsory intercultural communication programs, conducted prior to, and during non-Aboriginal clinicians' employment with the health care system, -A coordinator at the Hospital System level who is responsible to ensure the flow of communication between Alice Springs hospital, Adelaide, clinics in town, community clinics and family members, -Educational resources to promote patient understanding of their illness, treatment options, cardiac procedures, prescribed medications an their need for continued care in ways that are meaningful to Aboriginal concepts of physiology and disease (e.g. in a holistic manner, use of visual props) (Hayman et al., 2006).
Outreach Services *(Long-term)*	-Cardiac awareness and rehabilitation programs conducted by Aboriginal health care workers in local language(s), targeting patients & family members, -Regular cardiac specialist visits to ensure follow-up, -Regular screening and testing for chronic illnesses.
Cultural Awareness Program *(Long-term)*	-Cultural awareness programs of adequate intensity and duration, consistent with need and frequency of contact with Aboriginal people in remote and rural Australia, conducted prior to, and during, clinician's employment with the health care system where contact with Aboriginal people can be reasonably expected, -Cultural awareness programs that incorporate cultural knowledge, humility and safety (Papps & Ramsden, 1996; Shapiro et al., 2006).
Community Involvement *(Long-term)*	-Involve community members in the planning, implementation, participation and evaluation of health care services and cardiac awareness/rehabilitation programs, -Aboriginal individual involvement in health services as health professionals, health care workers, liaison officers, community leaders, social workers, health researchers, etc. Development of true and equal partnerships between health care services (Primary Care and Hospital Services) and local Aboriginal Community Controlled Health Services (Hayman et al., 2006).

FIGURE 1 Factors Influencing HCU Among Ethnic Minorities: an *a priori* Conceptual Framework.



*Adapted from Andersen (1995), Green and Kreuter (1991), and Scheppers et al. (2006).

FIGURE 2 Factors influencing health care utilization following a cardiovascular event among Aboriginal Australians in Central Australia.



CHAPTER 6: DISCUSSION

Chapter 6: Discussion

This study makes five contributions to advancing the understanding of factors that influence HCU following a cardiovascular event among Aboriginal people in Central Australia. Each contribution is discussed followed by suggested implications for interventions in support of improved HCU and long-term outcomes for Aboriginal patients suffering a cardiac event. The chapter concludes with a description of the study's limitations and strengths.

The first contribution is the development of a culturally sensitive HCU framework that is adapted to the needs of Aboriginal Australians living in Central Australia. Our *a priori* application of pre-existing HCU frameworks (Figure 1, p.16) proved useful in guiding our methodology, data analysis and disseminating our results. However, these frameworks do not address important factors influencing HCU among socially marginalized populations, such as Aboriginal Australians, if our experience offers any potential for generalizing. For instance, Scheppers et al.'s (2006) adapted version of Andersen's model (Andersen, 1995) does not address racism as a barrier to HCU among ethnic minorities, even though it is noted that such populations are often victims of discrimination and segregation (Scheppers, van Dongen, Dekker, Geertzen, & Deeker, 2006). Institutional racism in the Australian health care system has previously been documented (Henry, Houston, & Mooney, 2004) and our findings demonstrate that patients or stories of significant others who experienced racism are less likely to use health care services in the future. Similarly, issues such as negative Previous Experiences, Mistrust, Fear and Competing Priorities are not included in other HCU frameworks. In the present analysis, these factors represented important barriers among Aboriginal Australians and need to be considered when trying to improve HCU. Participants described Communication Issues at various levels as the most important factor influencing HCU. Andersen (1995) does not address communication problems as a potential barrier to HCU and although Scheppers et al. (2006) lists Communication Issues at the patient and provider level, the important role family members play in facilitating clinician-patient communication and the health system's need to provide appropriate services to ensure and support intercultural communication is not dealt with by Scheppers et al. (2006) treatment of influences.

To our knowledge there is no existing framework that addresses HCU among Aboriginal Australians. Andersen's model uses a Westernized approach to understanding HCU and does not consider barriers such as Lack of Cultural Awareness, gender appropriate care and health care system support, Limited Escort Eligibility and need for family involvement. The framework (Figure 5, p.67) not only provides a comprehensive list of the factors influencing HCU among Aboriginal Australians, it also describes the relationships between these factors to account for the variations in HCU.

The second contribution demonstrates the prominence of Communication Issues in influencing HCU. Although previous literature has highlighted critical issues in communication between the health care system and Aboriginal Australians (Gruen, Weeramanthri, & Bailie, 2002; Lowell, 2001; Trudgen, 2000), no previous studies pinpoint the levels at which these problems arise or note their impact on utilization. Communication Issues at and between the *Primary Care* and *Hospital System* levels significantly affected HCU and negatively affected other factors occurring at these levels, e.g. Organizational Characteristics, such as Incomplete Medical Files or Poor Follow-Up Care, which were influenced by limited communication within the health care system. Communication Issues further contributed to the barriers arising at the *Individual level* by impacting on individuals' level of Perceived Need and Knowledge of Illness, these serving as important drivers of HCU. In addition, poor communication contributed significantly to narratives of negative Previous Experiences, which in turn led to Mistrust within health care settings and patient and family Fear. As a consequence, Aboriginal patients frequently sought to enlist the direct support and guidance of appropriate family members, in an attempt to better negotiate what were predominantly confusing and foreign institutional systems.

Communication at all levels of social interaction is essential for HCU, without it, a disjunction occurs between individuals and the system built to support their health care needs and requirements. Our findings demonstrate that Aboriginal cardiac patients in Alice Springs are usually not involved in their treatments, have a poor understanding of their illness and are uncomfortable with the rigid and impersonal clinician-patient interactions that dominate their experiences. Linguistic barriers and different worldviews further strain clinician-patient interactions and, in turn, reinforce severely compromised communication. The divide was so significant that some patients completely refused to use health care services at all, even in the face of death. There can be no greater indicator of a failing health care system than when individuals choose death over utilization.

Third, our findings reveal the important role structural barriers have on HCU at the *Primary Care* and *Hospital System* levels. These are consistent with previously reported HCU barriers experienced by Aboriginal populations internationally, such as lack of interpreter services, racism and cultural inappropriateness (Baker & Daigle, 2000; Gruen et al., 2002; Wardman, Clement, & Quantz, 2005). Our findings support previous research identifying poverty as a barrier to HCU (Gruen et al., 2002; Haddad & Fournier, 1995; Scheppers et al., 2006). Not having the financial means to own a telephone or a form of transportation directly impacted on how and when Aboriginal cardiac patients used health care services. Lack of these basic needs meant appropriate care was needlessly delayed. The lack of cardiac services and specialists available to patients living in and around Alice Springs is disturbing considering the burden of CVD in this region. In-hospital cardiac services are highly inadequate and do not meet the magnitude of need while post-discharge services, such as cardiac education and rehabilitation, are virtually non-existent, resulting in an insurmountable barriers to HCU for cardiac patients. This finding is consistent with recent literature describing the inequitable distribution of cardiac management programs in rural and remote areas of Australia, stating that no cardiac management programs exist in the Northern Territory or Tasmania directly impacting on cardiac patients ability to receive appropriate evidence-based care (Clark et al., 2007). More specifically, these structural barriers were similar to those reported in a recent study conducted among Aboriginal and non-Aboriginal cardiac patients living in Central Australia (Maloney, 2005). Our results, however, present *predominantly* negative accounts of HCU, whereas Maloney (2005) describes both positive *and* negative accounts. This discrepancy may have arisen because non-Aboriginal participants did not experience the same barriers as most Aboriginal participants did (e.g. lack of gender appropriate care, communication problems and geographical remoteness).

The impact of structural barriers to HCU remained apparent even when patients experienced few communication problems and were able to negotiate the health care system, or when patients experienced few Individual level barriers such as understanding the need to utilize health care services or not being afraid to use them, and still experienced difficulties utilizing health care services.

It is imperative to acknowledge that the majority of these structural barriers are *limited* or *absent* enabling factors, such as *lack* of cultural awareness or *lack* of cardiac education. Enabling factors have been described as having a greater potential for change. Their presence allows an action, in this case HCU, to occur. Focus should therefore be placed on assuring their presence to potentially improve HCU and effect change at the Individual level. This interpretation is consistent with health promotion strategies that emphasize changing environments to enable improved interactions between individuals and the systems with which they interact (Green & Kreuter, 1991).

Forth, research concerning HCU among Aboriginal cardiac patients has failed to explore patients' experiences following their event (Maloney, 2005), even though access to secondary prevention strategies have unprecedented health benefits (Aoun & Rosenberg, 2004; Clark et al., 2007; Hare & Bunker, 1999). Our findings reveal a severe breakdown in cardiac patients' continuity of care following discharge. Various communication and structural barriers, such as Communication Issues within the health care system, Organizational Characteristics and Availability and Delivery of Health Services affected patients' ability to receive test results, follow-up care and cardiac rehabilitation services. A disconnect between the *Primary Care* and *Hospital System* services meant that most cardiac patients failed to receive essential health care services. The health care system needs to improve the provision of services required for the appropriate management of cardiac illnesses. Future research and action in this area is warranted.

Finally, our findings point to the important role family members play in Aboriginal cardiac patients' care. As the primary facilitator, family member presence must be prioritized in efforts to improve HSU among Aboriginal Australians. Family members acted as cardiac patients' alternate support system by intervening in areas where the health care system systematically failed. They provided guidance, social support, experiential wisdom, education, transportation and improved communication.

Despite the numerous roles family members played in patient care, their role as interpreters is the most commonly addressed and has been accepted as standard practice in Alice Springs. The health care system's expectation that family members should accurately interpret complicated medical terminology without previous training is both unethical and unrealistic and is likely to have led to, and continue to lead to, significant levels of misinterpretation, some of these being extreme and ultimately life-threatening (Territory Health Services, 1997) as well as general communication breakdown (Lowell, 2001). Over reliance on family members sidesteps the health care system's responsibility to provide Aboriginal Australians with the services they require (Pollack & McCarthy, 1984).

Discrepancies were evident in considering what defined care for Aboriginal Australians versus clinicians representing the health care system. To a considerable extent, medical practitioners enact medical care in the context of the health care system. It is unclear whether, generally speaking, they would accept such responsibility as extending outside of the immediate context in which medical care is enacted. Aboriginal Australians see care as extending beyond the medical care practice context to include the factors that enable them to follow through on follow up recommendations. A remarkable number of these factors could be dealt with via improved intercultural communication channels.

While family involvement is an essential element in Aboriginal patient's care, family members should not be expected to replace health care services. Family member involvement should be viewed in a comprehensive manner, including them in consultations, hospital admissions and transfers, while acquiring informed consent and following discharge when important lifestyle modifications, regular follow-up care and adherence to medication are required.

Implications for Interventions

To facilitate HCU among Aboriginal Australians in Alice Springs, policy makers, mainstream health bureaucracies and institutions must address the communication and structural barriers operating at the health care system. Addressing these factors may then lead to improvements at the Individual level and reduce patient reliance at the Interpersonal level. Based on the study's findings, the following actions are suggested: as a short-term objective, there is a need to provide telephone and transportation services in town camps and remote area communities. As long-term goals, there are complementary needs to develop programs to ensure and strengthen intercultural communication, develop outreach services, develop compulsory cultural awareness programs for all non-Aboriginal health staff working with Aboriginal patients and increase community involvement in health services targeted to Aboriginal Australians.

Telephone and Transportation Services (Short-term)

Functional, no-cost emergency telephones must be installed in town camps and remote area communities. This will greatly reduce time delays often associated with trying to contact emergency personnel for individuals without access to a telephone. Currently, ambulance services are not available in remote area communities, and although efforts to change this are required; the provision of telephone services could be effectuated quickly, and this at the very least, would allow individuals to contact other potential means of transportation (e.g. Royal Flying Doctor Service, or family members).

The health care system needs to provide more resources support at the *Primary Care* level to ensure available and reliable transportation services for individuals requiring transport into town for reasons such as attending medical appointments and renewing/refilling their monthly prescriptions.

At the *Hospital System* level, transportation services need to be set up to allow patient pick-up at Alice Springs Airport following their return from Adelaide. Many patients are often left abandoned at the airport following their transfer with no means of returning to their home, be it in town, town camp or remote area community.

Intercultural Communication (Long-term)

Fundamental change is required within the health care system to improve communication issues occurring at a variety of levels. Although trained interpreters are essential to improving clinician-patient communication, they are but a partial solution. Intercultural communication programs and educational resources are also required. We suggest:

- The use of trained interpreters with specialized medical training,

- Greater access to trained interpreters, with greater availability after hours and in hospital Emergency Departments and Intensive Care Units,
- The development of standardized guidelines that enable clinicians to evaluate patients' comprehension and their need for an interpreter,
- Compulsory intercultural communication programs to all non-Aboriginal clinicians, conducted prior to, and during their employment with the health care system. The program will address linguistic barriers as well as cultural differences. Linguistic barriers include elements, such as clinicians' communication style and avoidance of complicated medical jargon, while cultural differences address the different conceptual meanings behind certain words and phrases, an understanding different worldviews, and how these may affect one's interpretation of their illness (Papps & Ramsden, 1996; Trudgen, 2000),
- Communication within the health care system also needs to be addressed; a coordinator at the Hospital System level is needed who would be responsible to ensure the flow of communication between Alice Springs hospital, Adelaide, clinics in town, community clinics and family members,
- There is a lack of shared understanding about cardiovascular function and CVD between clinicians and patients, which compromises effective communication. This situation compromises the extent to which patients understand their illness and the information explained to them. The development of educational resources is suggested to promote patient understanding of their illness, treatment options, cardiac procedures, prescribed medications an their need for continued care (Cass et al., 2002),
- Educational resources should be expressed in ways that are meaningful to Aboriginal concepts of physiology and disease. For example, educational resources should address cardiac illness in a holistic manner rather than addressing individual body parts (Cass et al., 2002). The use of visual props should also be incorporated.

With reference to the key problem of inadequate communication, it has long been recognized that improving intercultural communication is associated with better health outcomes, decreased health disparities and increased health care access (Shapiro, Desiree, Gutierrez, & Zhuang, 2006).

Outreach Services (Long-term)

It is evident that the current health care system does not meet Aboriginal people's needs. To overcome the communication and structural barriers to HCU faced by Aboriginal Australians, outreach services need to be integrated into town camps and remote area communities. Such services might include:

- Primary prevention: cardiac awareness programs conducted by Aboriginal healthcare workers in local language(s),
- Secondary prevention: cardiac rehabilitation programs conducted by Aboriginal healthcare workers in local language(s), targeting both patients and affected family members,
- Regular cardiac specialist visits to ensure patient follow-up,
- Regular screening and testing for chronic illnesses,

Outreach services have the potential to improve communication issues on all levels and facilitate improved informed consent. Also, adequate outreach may prevent dislocation from family, reduce the need for transportation and educate affected family members. Aboriginal healthcare workers conducting programs in local languages can help patients feel more comfortable, improve communalization, and increase patients' knowledge of their illness. Regular visits will help develop relationships, build trust and mutual respect and assure patient follow-up. It will reduce the pressures and immense workload experienced by health care services in town and long waiting times. One study demonstrated that specialized outreach services overcame barriers to HCU in remote Australia (Gruen et al., 2002).

Cultural Awareness Programs (Long-term)

The lack of cultural training programs available to non-Aboriginal clinicians working in Central Australia is disturbing. Aboriginal Australians represent 30% of the Northern Territory, and yet no compulsory cultural awareness programs are required prior to clinicians' employment in the health care system. Those that are required during practice are woefully inadequate and inconsistent with the magnitude of the needs underpinning this legislated requirement. Clinicians' limited cultural knowledge affects how they communicate with patients and how much they understand the context in which patients live. This can influence the nature of interactions, the experience and judgments made by

Aboriginal patients, the decisions made by clinical staff and thus perceptions of the quality of care received. Importantly, these experiences frame the interactions between Aboriginal patients and the system beyond the level of the individual, transmitted through narrative across kin and generations. These stories, as do much of the oral history of trauma and disparity experienced by Indigenous peoples, influence the type, nature, expectations and judgment of the health care interaction, and thus influence choices to seek care, the likelihood that an individual will receive care, and assessments of the quality of care received.

Clinicians must understand and address the context in which health behaviors and decisions occur. Specific to Alice Springs, clinicians must acknowledge and address the presence of avoidance relationships, the need for gender appropriate care, family obligations and patient's social circumstances when attempting to build and establish relationships and articulate appropriate health management programs.

There is an urgent need for all non-Aboriginal health staff working with Aboriginal patients to engage in cultural awareness programs. We suggest structural changes to ensure:

- Cultural awareness programs of adequate intensity and duration, consistent with need and frequency of contact with Aboriginal people in remote and rural Australia, are conducted prior to, and during, clinician's employment with the health care system where contact with Aboriginal people can be reasonably expected,
- Clinicians provide the optimal quality of care to their patients; cultural training programs will incorporate cultural knowledge, humility and safety. *Cultural knowledge* will inform clinicians of Aboriginal culture so they can better understand patients' beliefs and values and thus be aware of, and address, their needs. *Cultural humility* acknowledges that one can never be fully competent in another culture, and that humility is a life long process which requires constant self-refection and awareness of one's own biases towards individual differences (Shapiro et al., 2006). *Cultural safety* requires clinicians to analyse their own culture and the ways it may impact on their health care practices and patient treatment. Further, patients, not clinicians, determine to what degree they feel safe with the health care services they

receive, placing patients in a position of empowerment (Papps & Ramsden, 1996; Shapiro et al., 2006).

Understanding patients' beliefs, values and cultural background will help reduce biases and stereotypes clinicians often carry when working in an intercultural context, and thus reduce the level of racism patients encounter when utilizing the health care system (Johnson, Somnath, Arbelaez, Beach, & Cooper, 2004). Clinicians, who are open minded and flexible to individual differences, when those individuals are reasonably similar to them, have the potential to improve clinician-Aboriginal patient relationships, treat their patients fairly, and appropriately attend to their needs. By respecting differences and avoiding cultural imposition (Bacote-Campinha, 2003) patients can feel welcomed, understood and have positive experiences with the health care system, increasing future HCU.

Community Involvement (Long-term)

"Let the community control the services, not the services control the people."

In the present study, the health care system failed to acknowledge the context in which Aboriginal people lived and thus, provided services that did not support their needs. Health care services were designed, implemented and delivered to Aboriginal people without consulting or involving Aboriginal communities. A myriad of barriers to HCU exist because Aboriginal people do not have an equal voice and role in the health care services delivered to them. Lack of Cultural Awareness, poor clinician-patient communication, lack of relationships between clinicians and patients and Racism are all consequences of Aboriginal individuals' exclusion from the health care system. In order to reduce the level of Mistrust, Fear and negative Previous Experiences Aboriginal Australians associate with the current health care system, and encourage empowerment and ownership in health care services among Aboriginal people, we suggest:

- Community involvement in the planning, implementation, participation and evaluation of health care services and cardiac awareness/rehabilitation programs,
- Encouragement of community control in all areas of health care, so that the services are aligned to the specific health needs of the community,
- Aboriginal individual involvement in health services as health professionals, healthcare workers, liaison officers, community leaders, social workers, health researchers, etc.

- Development of true and equal partnerships between mainstream health care services (Primary Care and Hospital Services) and local Aboriginal Community Controlled Health Services (Hayman, Wenitong, Zangger, & Hall, 2006),
- Delivery of cardiac services that are congruent with Aboriginal needs by consulting and involving local communities in the planning and development of these services (e.g. ensure that family members are involved in patient care, have Aboriginal healthcare workers educating cardiac patients as well as family and community members use of visual props, etc.).

Community involvement will ensure that health services meet the health needs of the community, that community members' feel culturally safe in the services delivered to them, and that they will improve communication and shared knowledge of cardiovascular health and CVD. Having Aboriginal people involved in health care services will encourage Aboriginal patients to engage, participate and use health care services. Partnerships with mainstream health services will increase access to health resources, support sustainability and continuity of care (Hayman et al., 2006).

Community involvement should not negate the government's responsibility to provide appropriate health care services entitled to all individuals and should provide necessary funding required support Aboriginal health care needs (Wilson, 2001).

In order to attain effective community involvement and develop true and equal partnership mainstream health services need to trust, respect and listen to Aboriginal communities' needs.

Limitations

The study's limitations were predominantly due to the restricted time available in the field and population characteristics (e.g. high mobility) and are discussed below.

Researcher's Relationship to the Context

Limited time available in the field, from September to December 2006, affected my ability to develop trust and build strong relationships with participants. This may have affected the amount, and type of information participants disclosed.

Sampling Problems

In order to address the research question, I anticipated recruiting at least 13-15 Aboriginal cardiac patients. However, due to my short time in the field and the high mobility of Aboriginal people, I experienced great difficulty and only recruited seven cardiac participants. As a result, I did not reach saturation relative to my research question.

Further, the experiences of cardiac patients who died prior to arriving to a clinic or hospital are not included in this study. Future research should focus on acquiring these stories, in a culturally sensitive manner, from family members or kin of the deceased. These individuals may have suffered significant barriers to HCU, which may or may not be similar to those who have survived their cardiac event. This group may provide additional information that can serve to improve HCU among Aboriginal Australians.

Methodology

Initially, it was projected that focus groups would be completed prior to the semi-structured interviews so that the themes emerging from the analysis of focus groups could inform semi-structured interviews. This would have allowed me to address the themes presented by the non-cardiac community informants in greater depth with the Aboriginal cardiac patients. However, due to limited available time for fieldwork, this was not possible. I had to work my schedule around participants' availabilities, as I may not have had another opportunity to meet with them. This meant that the focus group discussions and semi-structured interviews were conducted concomitantly.

Language

All individual and group interviews were conducted in English, with the use of Aboriginal mediators or family members when necessary, as participants demonstrated strong spoken English language skills. Regardless of the high level of linguistic knowledge shared between the participants and myself, inevitable cultural and language divides should be acknowledged when interpreting the results, e.g. differences in the conceptual meaning of English terms used or differing worldviews.

Study's Strengths

Methodology

Miles & Huberman's (1994) *Standards for the Quality of Conclusions* were used to augment the "goodness" of the study's findings and can be judged by the following five criteria: *objectivity/confirmability; reliability/dependability/auditability; internal validity/ credibility/authenticity; external validity/transferability/fittingness* and *utilisation/ application/action orientation.*

Objectivity/confirmability. This is attained when data from the study originates from the field and conclusions are grounded in the experiences and stories shared by the participants' rather than based on the preconceived notions of the researcher(s). A detailed description of the methods undertaken throughout the study with consistent use of journal notes and memos created in ATLAS/ti, allows readers to evaluate the procedural decisions taken during data collection and analysis phases and the conclusions drawn. Data sources from this study will be retained for five years and are available for verification by external reviewers (if deemed necessary). All data has been made retraceable to its original sources. Interpretations and conclusions can be verified through the analysis of both original transcripts and transformed data. The use of ATLAS/ti provides an easy and accessible means to verify the data.

Reliability/dependability/auditability. Data were collected, transcribed and analysed in a consistent and stable manner. Use of the deductive theoretical framework provided a structure for organizing information, yet allowed for emergence of new themes presented by the participants. Focus groups and semi-structured interviews used illness narratives and interview guides to explore participants' experience(s) with the health care system congruent to the study's research question. I transcribed all interviews (focus groups and semi-structured interviews) using a standard notation system (Darlington & Scoot, 2002), to ensure they were handled in the same manner. A lexicon was used to code data, resulting in an intra-rater reliability of 84% and a thematic conceptual matrix (TCM) was used to guide data analysis. The findings of this study display parallelism across the three sample populations. Despite different reasons for HCU, Aboriginal cardiac patients, key informants, and non-cardiac community participants experienced or described similar barriers to HCU.

Internal validity/credibility/authenticity. Results from this study were supported by participants' quotations, allowing readers to judge for themselves the authenticity of the findings. As well, the conclusions drawn from this study were presented to, and reviewed by Aboriginal and non-Aboriginal health researchers from Darwin, Northern Territory at the CR-CHUM-Hôtel-Dieu on July 20th 2007. The study's results "rang true" to the health researchers, in that, the findings were congruent to what they have witnessed among Aboriginal Australians living in Darwin. Coded data were "well linked" to the conceptual themes derived from pre-existing theoretical frameworks (Andersen, 1995; Green & Kreuter, 1991; Scheppers et al., 2006). The use of various qualitative methods (unstructured interviews, focus groups and semi-structured interviews) and different sample populations led to converging conclusions, thereby enhancing the validity of the findings. Finally, the findings were verified and deemed accurate through the use of member checking with agreeing participants.

External validity/transferability/fittingness. Findings may transfer to Aboriginal communities where the characteristics of the population, availability of health care services and the social and cultural contexts are similar to those of this study. A detailed description of Alice Springs, participants' characteristics, their lifestyle, living conditions, and available primary care and hospital services enable the reader to evaluate the transferability of the results to other studies.

Utilisation/application/action orientation. Obtaining information from Aboriginal people's perspectives provides Aboriginal community-controlled organizations with findings that are familiar and relevant to them, which can be used to develop or maintain appropriate health care services within their communities. Policy makers can use these findings to enhance their understanding of the factors influencing HCU among Aboriginal Australians, so that policy changes and health care interventions are more effective, culturally meaningful and aligned to meet the needs of Aboriginal Australians.

Conclusion

Aboriginal Australians living in and around Alice Springs face significant barriers to HCU at multiple levels. Communication and structural barriers at the *Primary Care* and *Hospital System* levels significantly influence Aboriginal Australians' ability and/or decision to utilize health cares services following a cardiovascular event. These barriers, in turn, negatively affect the factors influencing use at the Individual level. Family members play an intermediate role of linking the health care system to individuals, and act as patients' primary gateway to negotiating the health care system. Due to these barriers, Aboriginal cardiac patients receive sub-optimal quality of care, significantly risking subsequent cardiovascular events and affecting their level of HCU. If we are to effect any improvement in HCU among Aboriginal cardiac patients, we must listen to their stories and experiences and adapt our health care services to meet their needs.

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APPENDIX A

Illness Narrative for Male Focus Group

Jim is a 42-year-old man, living in a small town camp. The closest health care facility is about five km away, and he has no car for transport. He is married, has three children and is also taking care of his brother's children. He has been working on CDEP for the last two years, and enjoys it. He has been healthy all his life, but was diagnosed with diabetes two years ago.

A couple months ago, Jim was sitting around with his mates, having a few drinks after a big feed. He starts getting a funny feeling in his upper stomach. Jim thinks it may be indigestion so he ignores it. By the end of the night, the pain is getting worse and his mates notice that he is having trouble breathing. They suggest that maybe he should get some help. Jim refuses, but soon starts to experience more trouble breathing and the funny feeling in his stomach is now painful; he finally decides to get some help.

Are you able to tell me:

Where would you bring Jim? Why?
i.e. Congress, Alice Springs Hospital, Ngangkari

How would Jim get there? Why?
i.e. ambulance, someone's car, taxi...

Who should accompany him? Why?

Jim is now at Alice Springs Hospital. The doctor has just told him he has had a heart attack. He is shocked and confused by this; he did not think he was having a heart attack! His eldest son has accompanied him; he speaks English very well. Jim is very happy having his son with him as he explains to him what the doctors are saying and is keeping him company while he waits for test results. While they are waiting, a group of six doctors enter the room. They approach a white patient lying in the bed next to Jim. They spend a lot of time with this patient, asking him many questions and writing down some notes. They then approach the edge of Jim's bed; they do not address him or his son. Instead, they begin to discuss his condition among themselves, write down some notes and then walk away. Jim and his son are both very upset. This makes Jim feel like he is not important enough to be greeted or explained his own condition.

Are you able to tell me:

How would you recognise a person who is having a heart attack?

Do you think Jim was treated differently because he is Aboriginal?

Finally, after waiting nearly six hours, a nurse tells them that Jim will have to be flown down to the Royal Adelaide Hospital for an angioplasty. Unfortunately, there is not enough room for his son on the plane, so Jim will have to fly alone. Jim is frightened, his uncle died at Adelaide Hospital, he doesn't want to go! The attending nurse does not understand why Jim is making such a big fuss about flying down to Adelaide alone, so she simply shrugs off his concerns.

Are you able to tell me:

If Jim was part of your family and he asked you what he should do, what would you tell him?

How should the nurse of handled Jim's worries?

Jim decides to go to Royal Adelaide Hospital, despite his worry and has his angioplasty. A male doctor quickly explained what an angioplasty was to him, but he had a hard time understanding the words he used. He didn't ask any questions because he felt shame.

What are the major communication problems for people accessing health care?

After his angioplasty Jim feels fine; he doesn't feel like he has had a heart attack at all. He is lonely and misses his family, and is worried about his job and other things that have been happening at home. He feels like he is wasting his time at the hospital.

Do you think people leave the hospital or do not go to the hospital because of worry for family?

Before leaving Royal Adelaide Hospital, the nurse gives him medications, which he is told to take for two weeks. When he leaves the hospital, he is not given any paperwork and is sent straight home. Jim is happy to be back with his family and is feeling much healthier now. He feels that the angioplasty has "cured" him. 2 weeks have past and he has finished all his medications. He is relieved because he can now go back to his regular life.
What should the nurse have told Jim before he left?

Is Jim right? Is he "fixed" because he feels better?

During this time, he gets a visit from family from out bush. He tells them what has happened and they are worried for him. His older cousin tells him that he is supposed to be taking his medication forever and must visit the doctor every three to six months. Jim thinks doesn't need to do these things because he is "fixed".

How important is family in making sure people get care or take their medications?

What might be stopping Jim from wanting to go back to the doctor or taking his medications?

BREAK TIME!

Recap: Go over all the points the participants have mentioned

What should we do to make the system better?

APPENDIX B

Semi-Structured Interview Guide

1. The day you had your heart problem- how did your body feel? Did you know you were having a heart attack?
2. What happened next? (Where did you go, how, who did you call?)
3. What made you decide to go to the Hospital/Congress?
4. What causes heart attacks? What caused your heart attack?
5. What were you told about your heart problem?
6. Did you understand what they told you about your heart problem? Did you ask questions?
7. Do you think you were treated differently because you are Aboriginal?
8. Did they explain what was going to happen to you in Adelaide before going there? What did they tell you?
9. When people go to Adelaide, sometimes they have to go alone. How did you go to Adelaide?
10. What made you decide to go to Adelaide?
11. What happened to you when you were there?
12. Before leaving the hospital in Adelaide, did anyone explain what you needed to do next? (Medication, follow-up appointments)
13. Are you happy you went down to Adelaide? Can you tell me what they did to make your time there pleasant?
14. How do you feel now?

**What should we do to make the hospitals work better? Make it easier for Aboriginal people to use the hospital or clinic?

APPENDIX C

CHUM

CENTRE DE RECHERCHE
Comités d'évaluation scientifique et d'éthique de la recherche
Édifice Cooper
3981, boulevard St-Laurent, Mezz 2
Montréal (Québec) H2W 1Y5

Téléphone : [information retirée / information withdrawn]
Télécopieur : [information retirée / information withdrawn]
Courriel : [information retirée / information withdrawn]

Le 14 juillet 2006

Mme Stella Artuso
Clinique St-Urbain
3875, rue St-Urbain [information retirée / information withdrawn]
Montréal (Québec)
H2W 1V1

Objet : ***ND06.061 – Approbation accélérée initiale***

Facteurs influençant l'utilisation des services de santé chez les Aborigènes du centre de l'Australie ayant subi une complication cardiovasculaire

Madame,

J'ai pris connaissance des documents reçus en date du 05 juillet 2006 concernant le projet en rubrique en vue d'une approbation accélérée :

- *Formulaire de présentation – Formulaire A – Annexe 2.1*
- *Formulaire de renseignements supplémentaires – Annexe 2.2*
- *Résumé d'un protocole de recherche*
- *Renseignements et formulaire de consentement – Version 03 juillet 2006*
- *Information and consent form – Version July 03, 2006*
- *Protocole – Version 26 juin 2006*

En vertu des pouvoirs qui me sont délégués par le Comité d'éthique de la recherche du CHUM pour procéder à une évaluation accélérée, il me fait plaisir de vous informer que j'approuve votre projet puisqu'il s'agit d'un projet se situant sous le seuil de risque minimal. Je vous retourne donc sous pli une copie du formulaire portant l'estampille d'approbation du comité. Seul ce formulaire devra être utilisé pour signature par les sujets. Il serait cependant important qu'il soit revu, et modifié au besoin, par un comité d'éthique de la recherche local.

La présente constitue l'approbation finale du comité suite à une procédure d'évaluation accélérée. Elle est ***valide pour un an à compter du 14 juillet 2006,*** *date de l'approbation initiale. Je vous rappelle que toute modification au protocole et/ou au formulaire de consentement en cours d'étude, doit être soumise pour approbation du comité d'éthique.*

Le comité suit les règles de constitution et de fonctionnement de l'Énoncé de Politique des trois Conseils et des Bonnes pratiques cliniques de la CIH.

Vous souhaitant la meilleure des chances dans la poursuite de vos travaux, je vous prie d'accepter, Docteur, mes salutations distinguées.

[information retirée / information withdrawn]

Brigitte St-Pierre, conseillère en éthique
Vice-présidente
Comité d'éthique de la recherche
Équipe Hôpital Notre-Dame du CHUM

BSTP/go
P. j.

APPENDIX D

CENTRAL AUSTRALIAN
HUMAN RESEARCH ETHICS COMMITTEE
PO BOX 4066
ALICE SPRINGS NT 0871

31 October 2006

Dr Alex Brown
Menzies School of Health Research
PO Box 40660
ALICE SPRINGS NT 0871

Dear Alex

Re: 'Factors influencing health service utilisation following a cardiovasular event among Aboriginal people in Central Australian'

The Committee has approved this project with the following comments:

- The information sheet needs to be communicated clearly and plainly to participants.
- We expect that the focus groups questions will be further developed.

The committee requires that you submit a progress report every six months, and a final report on completion of the project.

Good luck with your project.

Yours sincerely

[information retirée / information withdrawn]

Dr John Wakerman
Chair
Central Australian Human Research Ethics Committee

APPENDIX E

FILE COPY

CENTRAL AUSTRALIAN
HUMAN RESEARCH ETHICS COMMITTEE
PO BOX 721
ALICE SPRINGS NT 0871

Dr Alex Brown
Senior Research Fellow
Menzies School of Health Research
Centre for Remote Health
PO Box 4066
Alice Springs NT 0871

Dear Dr Brown

The CAHREC has considered your application for approval for the research project entitled **"Australian acute coronary prospective audit".**

The committee decided to grant approval for your project to proceed.

The committee requires that you submit a progress report every six months, and a final report on completion of the project.

Good luck with your project.

Yours sincerely

[information retirée / information withdrawn]

Dr John Wakerman
Chair
Central Australian Human Research Ethics Committee

17 January 2006

RESEARCH ETHICS COMMITTEE APPROVAL FORM

The Central Australian Human Research Ethics Committee – Alice Springs, Northern Territory
(Name of Ethics Committee)

voted at its meeting on 24 NovemBER 2005 to give FINAL APPROVAL
(Date of Meeting)

for the Sanofi-Synthelabo, a member of the sanofi-aventis Group, sponsored trial to be conducted by
(Sponsor)

Dr Alex Brown *(Principal Investigator)*	at	Menzies School of Health Research *(Site Where Trial Will Be Conducted)*

The following documents were reviewed and approved:

Protocol Title:
Australian Acute Coronary Syndromes Perspective Audit - ACACIA

Protocol Number: PM_L_0051	Final Version: 1	Dated: 05 July 2005
Protocol Amendment	Number/Version: ________	Date: ____________
Protocol Amendment	Number/Version: ________	Date: ____________
Patient Information Sheet	Version: 1	Date: 04 August 2005
Consent Form	Version: 1	Date: 04 August 2005
Next of Kin Consent Form		Date: 30/10/05
Investigator's Brochure	N/A	

Other: (please describe eg. Advertisement; Investigator's Brochure)
The HREC acknowledges that registered nurses or the study co-ordinator for this study can obtain consent from participants.

This HREC is constituted and functions in accordance with the National Statement on Ethical Conduct in Research Involving Humans (1999)

[information retirée / information withdrawn]	[information retirée / information withdrawn]	30.1.06.
Name IEC Chairperson/Designee	Signature	Date